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## Foreword to 2nd edition

The Muscular Dystrophy Campaign is pleased to be able to publish the second edition of the Adaptations Manual. Although written for those affected by muscular dystrophy and allied conditions and professionals working with them, feedback has indicated that it is useful to other disabled people.

This second edition retains the format of the first, but details have been updated and in some cases chapters have been rewritten. Since the first edition, the UK and devolved Governments have amended the grant funding systems for adaptations and equipment. Scotland's system is in the process of changing and in England, Northern Ireland and Wales greater flexibility has been given to Local Authorities, but although this will influence the way adaptations are funded, it should not affect the adaptations that people are able to receive across the country (see Chapter 12). Other chapters in the manual that have significantly changed are Chapters 5, 8, 9, 10, 11i, 13a and 18.

Chapter 13b is a questionnaire, which asks about your experience of adapting your home. Please photocopy and complete this and return it to us – you will be providing the Muscular Dystrophy Campaign with useful evidence of the problems faced by people with muscular dystrophy, and on the effectiveness of different solutions.

Much of this second edition is now available on the MDC website at [www.muscular-dystrophy.org](http://www.muscular-dystrophy.org). The Muscular Dystrophy Campaign also publishes factsheets, including some about equipment and adaptations in addition to those listed in Chapter 5. These are available from our information service or can be printed from our website.

As ever, legislation, techniques and products change and evolve. The Muscular Dystrophy Campaign would welcome being advised of any changes, omissions or errors; please contact our National Occupational Therapy Advisor at our Head Office.

The importance of Occupational Therapy in enabling people with muscular dystrophy to live independent lives, should not be underestimated.



Christine Cryne  
Chief Executive  
Muscular Dystrophy Campaign

## Foreword to 1st edition

It was over 39 years ago, in October 1961, that I began work on the research programme that was to lead in November 1963 to the publication by the Royal Institute of British Architects of the first edition of my *“Designing for the Disabled”*. The concern that had prompted the venture was that architects needed to be informed about how to design houses convenient for wheelchair users to live in. It was a topic which, at the time, had barely been explored in Britain; to find out more, I went first to learn from occupational therapists in Sweden and Denmark about the innovative ideas they were developing for homes for housewives who used wheelchairs, in particular about how kitchens and bathrooms could be planned and equipped so that they could be managed independently.

At that time, the professional work undertaken by occupational therapists in Britain was increasingly focused on programmes aimed at helping disabled people manage in their own homes, on tackling daily living tasks. From 1971 – when local authority social services departments came to be established – the opportunities open to them expanded. Philippa Harpin was among those who led the way. Trained at the London School of Occupational Therapy, she practised first in Bradford, before working with children with cerebral palsy in a residential school in Cumberland, followed by work in a rehabilitation centre for elderly people in Northumberland. Philippa was then appointed as National Occupational Therapy Advisor to the Muscular Dystrophy Campaign and has worked tirelessly with adults, parents and children with muscular dystrophy and allied conditions. She has become an acknowledged authority in that field and, while contributing articles to numerous professional journals, lecturing and presenting papers with great enthusiasm, wrote *“With a Little Help”* – a book about equipment for people with muscular dystrophy. Research has included the projects *“Why do some, but not all, boys with muscular dystrophy need attention in the night?”* (gaining a Diploma in Social Research) and *“A focus on attitudes and counselling skills, and their role during the milestones and experiences in the lives of a boy with Duchenne muscular dystrophy and his family”* (for a Diploma in Counselling skills). She then set herself the demanding task of writing this book and urging it through to publication.

This book – the fruit of Philippa’s unique knowledge of her field and long experience in it – tells how families and individuals faced by the challenges that come with muscular dystrophy can be helped to make day-to-day life at home more convenient, more easily manageable and more rewarding. It is a book of practical information, advice and guidance, which will be widely welcomed and which I am pleased to commend.

Selwyn Goldsmith  
April 2000

## Preface

Why has this manual been written and for whom? Disabled people and their families often feel that they have been left on their own to find out all they need to know, before embarking on adaptations – and the main impetus for the manual has been to try to redress this problem. Also, we know from a housing adaptations survey carried out several years ago, that families feel that community staff do not always have the experience necessary to understand the specialist needs of people with muscular dystrophy and allied neuromuscular conditions; it has to be acknowledged that many of these disabilities are rare. So the manual is for disabled people, their families and carers, occupational therapists and other professionals including architectural designers, who are involved in advising. Writing for a diverse group with different perspectives is difficult and the emphasis varies according to the information discussed.

The purpose of successful adaptations is to provide accessibility into and around the house and garden, so that if a wheelchair is used there is sufficient circulation space for the most appropriate model, to provide the most suitable equipment and facilities and to safeguard the privacy and dignity of the users, making life easier for both them and their carers. The ultimate goal is to try to help disabled people to maintain or regain as much independence as possible, and thereby to improve the quality of life for everyone concerned.

The aim of the manual has been to bring together all the strands of the decision-making involved in achieving the most satisfactory outcome, while at the same time obtaining the best value for money. This is not easy – as anyone disabled will tell you. Some people know exactly what they need; others are seeking advice. When the disability is progressive, as in most types of muscular dystrophy and allied neuromuscular conditions, the future may be uncertain and the people concerned may not be aware of what they are likely to need or of the solutions that are available. This manual seeks to provide all the necessary information and, where possible, to offer alternatives, so that disabled people and their families can be involved in the choices.

I am also fully aware of the financial constraints. Nevertheless, I hope that the content of this manual will demonstrate and justify the needs, to try to eliminate much of the controversy that, unhappily, many people feel is involved before they are able to have what they need.

Some of the information, although updated, will be familiar to readers because it has been made available and has been well tried and tested. Gathered over the 25 years that I worked for the Muscular Dystrophy Campaign, it is the result of one-to-one work with disabled people and their families. I hope that I listened carefully and I am indebted to you all. I have learnt, too, from all the occupational therapists and workers with other professional backgrounds, including the Muscular Dystrophy Family Care Officers, social workers, healthcare staff, architects, designers, researchers, grant officers and other funding agencies, and I thank them for their help. It was good to work with so many people who have the best interests of disabled people at heart. I hope the outcome is useful to all those who are involved in the important and rewarding work of all aspects of adaptations and ‘new-build’ schemes – now and in the future.

*Philippa Harpin*

# The Adaptations Process

*A guide to the stages involved, with the precise order varying according to the procedures of individual Local Authorities*

1. **Contact with Social Services/Social Work Department**  
to request a visit from the community occupational therapist (OT).
2. **Meeting to discuss with occupational therapist (community and/or paediatric)**  
needs and alternative schemes (lift vs extension etc.) in relation to the disability. Where possible, enlist the help of a Muscular Dystrophy Family Care Officer (FCO) or the National OT Advisor.
3. **Assessment of equipment.**
4. **Preliminary appointment of architectural designer.**
5. **Decisions made in relation to adapting or re-housing,**  
and also about equipment, with the help of the architectural designer, if possible.
6. **Estimation of preliminary costs.**
7. **Exploration of funding**  
with Improvement Grant (Scotland) or informal Disabled Facilities Grant (DFG) 'Test of Resources' by grants officer as a means of assessing the ability of the disabled person or the family to contribute to the costs of the adaptation, and the contribution that they are likely to have to make.
8. **Review of decision to adapt, re-house or 'new-build'**  
in the light of available funding, and approximate costs.
9.
  - a. **Formal appointment of architectural designer.**
  - b. **Meeting to discuss details of architectural brief and equipment**  
with architectural designer, OT, FCO and, possibly, grants officer.
10. **Submission by OT of recommendations on disability needs**  
to Grants Department.
11. **Initial sketches drawn by architectural designer**  
who has informal discussions with the area planning officer, where appropriate.
12. **Meeting of family, architectural designer, OT, FCO and, possibly, grants officer to:**
  - a) choose draft layout;
  - b) clarify which items will be grant eligible;
  - c) discuss architectural services to be provided. The choice is between:
    - i. drawing of plans, submission for Planning and Building Regulations Approval and writing up detailed specifications only; or preferably
    - ii. overall responsibility, as above, but also including submission of scheme for a grant, administration of the building contract and inspection of the building work.
13. **Preparation of plan by architectural designer;**  
if agreed by family and OT, submission for Planning Approval and for Building Regulations Approval.

- 14. Drawing up of specifications (including specialist equipment)**  
by the architectural designer on receipt of Planning Approval (usually 4–8 weeks after submission). May submit for Building Regulations Approval at this stage.
- 15. Receipt of Building Regulations Approval.**
- 16. Checking of specifications**  
at meeting of disabled person and/or the family, with the architectural designer, OT and FCO.
- 17. Establishment of responsibility for inspections of work**  
(in addition to Local Authority building inspectors) is essential if the architectural designer is unable or has not been allowed to provide the full service: will inspections be provided by technical services through the Grants Department, and what responsibility will be taken by the community/paediatric OT, disabled person and/or the family?
- 18. Sending out of plan and specifications for builders' estimates or formal tenders**  
depending on the scale of the building works.
- 19. Completion of final 'Test of Resources'.**
- 20. Receipt of tenders from builders,**  
evaluation by the architectural designer, and submission (with additional paperwork) to the Grants Department.
- 21. Selection of contractor.**
- 22. Approval of grant;**  
notification to the disabled person or the family of their contribution (if any).
- 23. START of WORK.**
- 24. Work regularly inspected;**  
disabled person or the family knows whom to contact if any problems arise.
- 25. Checking of finished work against plan**  
by everyone involved *before* the builder receives final payment.

# Be Your Own Keyworker

## *Suggestions for a DIY approach to the adaptations process for disabled people and/or their family and carers*

This manual is intended to make the process of adaptations easier for disabled people and their families and carers. It is primarily for everyone with muscular dystrophy or an allied neuromuscular condition and the wide range of professionals trying to help them. However, it is hoped that the manual will be useful to a much wider audience.

Although some disabled people may prefer to take a less active part in the process, there are many of you for whom there is no better solution than being your own keyworker. No one will care more than you about the adaptations and decisions made to achieve the optimum result. This manual should help you from the outset to understand the whole process. Although time-consuming, it will put you in control of the stages to be worked through, from the first referral to the Social Services Department and the assessment procedure, to the completion of the building work. However, the whole process of adaptations can be very stressful and you must ask for help at each stage if you need it – and particularly if you feel bogged down by it all.

## Use the following 10-point plan

### 1. File correspondence

Keep all correspondence together. Many families experience reluctance on the part of advisors to put anything on paper. Therefore, always ask for important decisions to be put in writing and press for a written reply to any query. Copies of all communications keep the file up to date and make it easier to back-track if, for example, your trusted occupational therapist (OT) leaves and no-one else seems to know what is going on.

### 2. Record contact details

Record the name, address and telephone number of everyone involved. It is also useful to know on which days and hours they are at work, and when it is best to contact them (particularly as many OTs work part-time). A form is included for you to photocopy and use to record this information. File it with your correspondence.

### 3. Accurate diary recording

In the same way, photocopy the sample diary page or draw up your own. Make enough copies, punched to fit your file, to ensure that they are readily available. Use the diary as a simple means of recording the date and time that each telephone call is made or received, and every meeting held, in relation to the adaptations. Make an accurate record of the conversation and ask for an explanation of anything you do not understand. Ensure that you are given a time-scale (even if only approximate) for the completion of each stage and what happens next. This enables you to monitor the progress and check that the work is followed through by the appropriate person. If you are unhappy with the progress of the scheme, then your record of the dates of all the calls and meetings puts you in a strong position if you need to make a complaint.

### 4. Chase up outcomes

While acknowledging that all workers are trying to keep up with very heavy workloads, keep track of these time-scales. If they are not met, make contact to find out what is happening. Most workers will welcome a timely reminder.

### 5. Muscular Dystrophy Adaptations & Building Design Network

Where possible, use this scheme to find a designer who has attended a workshop about people with neuromuscular conditions, and has experience of planning for their disabilities and needs.

### 6. Want vs needs

The word 'want' always creates a negative response from workers in statutory services and should be replaced with the word 'need'. This is probably because of the wording in the Disabled Facilities Grant guidelines which states "... distinguish between what are desirable and possibly legitimate aspirations of the disabled person, and what is actually needed and for which grant support is fully justified".<sup>1</sup>

## 7. Outcome of the assessment

Always aim for the best but, if necessary be prepared to compromise on the less important items, if these can be funded with an additional grant (but no contribution) and included at a later date. The priority is space, as this is difficult to add on in the future.

## 8. Funding

Many schemes break down from the outset because of the emphasis placed on funding issues. Therefore, the needs assessment becomes overlooked. If you have to fund your own adaptations, the Local Authority still has a responsibility to provide advice. You must contact the community OT and ask for assistance.

The priority is to establish what is needed and only then to consider the funding problems. It may sound negative to talk about funding as a problem, but it is necessary to be aware that there are few schemes where it is not a problem. The majority of people experience similar difficulties.

## 9. Complete the adaptations questionnaire

It is important, for future schemes, that the Muscular Dystrophy Campaign learns from your experience. We would, therefore, be very grateful if you would complete the questionnaire included in Chapter 13, whether or not you have used the Muscular Dystrophy Adaptations & Building Design Network. This will enable us to monitor the standard of adaptations and plan services to families.

## 10. Pass on your experience

If you are able to master the process, your experience will be invaluable to others. This is the value of belonging to a Muscular Dystrophy Branch, as it enables disabled people and their families to benefit from the support of learning from each other.

## Reference

- 1 *Circular 17/96 Private Sector Renewal: A Strategic Approach, Annex I.* HMSO, 1996, pg. 198.

# Keyworker

## Adaptations Scheme: Contact Names & Addresses

*(Sample pages for photocopying)*

Name: ..... Date of Birth: .....

Address: .....

Postcode: .....

Telephone No. (Home): ..... (Work): ..... Fax No: .....

Name	Role	Address inc. postcode	Tel no.	Fax no.	Best time to contact
	G.P.				
	Consultant				
	Muscular Dystrophy Family Care Officer				
	Muscular Dystrophy National OT Advisor	Muscular Dystrophy Campaign 7-11 Prescottt Place London SW4 6BS info@muscular-dystrophy.org www.muscular-dystrophy.org	Tel: 020 7720 8055	Fax: 020 7498 0670	

## Adaptations Scheme: Contact Names & Addresses

Name	Role	Address inc. postcode	Tel no.	Fax no.	Best time to contact
	Social worker				
	Physiotherapist				
	Paediatric OT				
	Community OT				
	Grants officer				
	Architectural designer				

## Adaptations Scheme: Contact Names & Addresses

Name	Role	Address inc. postcode	Tel no.	Fax no.	Best time to contact

# Assessment of Need

## for children & adults with muscular dystrophy & allied neuromuscular conditions

### *A discussion of the main issues involved in a housing and equipment assessment*

This chapter spans most of the sections in this manual and should be used in conjunction with them.

⇒ The purpose of the assessment	1
⇒ Who should be involved?	2
⇒ Starting the assessment process	4
⇒ Should the assessment cover the short-term or the long-term needs?	5
⇒ Catering for the difficulties in the assessment	6
⇒ The outcome options	12

## The purpose of the assessment

The overall aim of an assessment is to:

- provide greater independence for you or your disabled child to enable you to achieve your full potential;
- help to overcome the mobility difficulties;
- identify the present and future needs to ensure that, as far as possible, the same facilities are provided as those enjoyed by non-disabled people;
- ease the role of the carer/s.

The effect of suitable housing and appropriate facilities should not be underestimated. To quote one parent from the research project *Homes unfit for children: housing disabled children and their families*:

*"If you get your home right you can cope. This house is like a cocoon. It doesn't matter what is coming to us now. How can you make a tough decision in a house that's not a home? Within 24 hours of being in this house it was like WOW! She was a different child. Her confidence increased overnight. I can't describe to you the difference in Debbie".<sup>1</sup>*

## Who should be involved?

There are several groups of people who need to be involved in the assessment:

- ⇒ the disabled child or adult and the family or carers;
- ⇒ the hospital, school or paediatric OT, and/or;
- ⇒ the community OT;
- ⇒ a Muscular Dystrophy Family Care Officer (FCO)/National OT Advisor;
- ⇒ a designer from the Muscular Dystrophy Adaptations & Building Design Network;
- ⇒ a grants officer.

### The disabled child or adult and the family or carers

In addition to adults, it is important that any teenagers or younger children who are interested are involved in every stage and that no meetings take place without them. When contentious issues are to be discussed, it is sometimes suggested that meetings are held away from the home to exclude the family: this is a practice that should not be encouraged, unless the applicant, or the family, chooses not to be present.

### The hospital, school or paediatric OT

The involvement of an OT, other than the community OT, will depend upon whether the person attends a hospital. In the case of children, staff working in a Child Development Centre, the Social Services Children's and Family Disability Team, or school may also know them. The best possible professional practice is for Health Trust/paediatric OTs and community OTs to work together; in many areas liaison is excellent. A paediatric OT is likely to have worked with the individual child and to know both the child and the parents. This, together with insight into the needs of children and knowledge of children's equipment, will result in a first-class assessment to pass on to the community OT, who arranges for this information to be included in the adaptation scheme.

### The community OT

Frequently, OTs working in the community are placed in a difficult position, when they are asked to assess the needs and to worry about the budgets at the same time. However, the OT role is very clearly that of an advocate and the prime function is to assess the need. This is set out in the *Code of Ethics and Professional Conduct for OTs* which states:

***“Services should be client centred and needs led”.***

*“When relevant and appropriate, occupational therapists should negotiate and act on behalf of the clients in relation to upholding and promoting the autonomy of the individual”.*

... *“Occupational therapists have a duty to take reasonable care for clients whom they accept for treatment/intervention.*

*Every client should have a clearly recorded assessment of need and objectives of treatment/intervention.*

*Occupational therapists should always record unmet needs.*

*Failure to do so would be considered professionally unacceptable”.*

... *“Occupational therapists should state and substantiate their views to employers about resource and service deficiencies which may have implications for clients and carers”.*<sup>2</sup>

The community OT is, in fact, the key person in the assessment process because, although others can make recommendations, unless the community OT agrees that the need exists, the work will not be covered by a grant.

### **A Muscular Dystrophy Family Care Officer (FCO)/National OT Advisor**

The Muscular Dystrophy Campaign employs FCOs, with either a social work or healthcare background, to work with families with muscular dystrophy or an allied neuromuscular condition. Their knowledge of the disabilities and their experience of the wide range of problems encountered is a useful resource, not only for the disabled person and the family but also for the other professionals working with them. In addition, the National OT Advisor is available to help, when necessary. Their contact details are included in the address list in Chapter 18.

OTs and other professionals working with disabled people have a very broad knowledge of disability, but cannot be expected to be experts in relation to every type of physical disability, or to know the most relevant solutions to difficulties associated with each medical condition. Competent professionals recognise this and are always keen to ask for the advice of a specialist worker who has greater experience in a particular field. Several years ago, during a housing survey among families with muscular dystrophy and allied neuromuscular conditions, many of the respondents expressed the following opinions:

*"The Local Authority - even if willing - works with too wide a range of disabilities to know specialist answers".*

*"A specialist in muscular dystrophy knows the needs in the future, not what others appear to see when assessing".*

### **A designer from the Muscular Dystrophy Adaptations & Building Design Network**

Using an architectural designer with specialist knowledge of planning housing and facilities for people with muscular dystrophy and allied neuromuscular conditions will be invaluable; this innovative service is discussed in detail in Chapter 13.

### **A grants officer**

Local authorities (LAs) adopt different procedures, but if grants officers are going to question the OT's assessment, it is helpful for them to attend one of the initial meetings. It is more constructive to be aware from the outset, rather than at a later date, of any item that will not be covered by the grant. In addition, if grants officers are present when Disability Needs forms are completed (see Chapter 10), they will have a greater understanding of the needs, which will be essential to help to justify the cost of these expensive schemes. Although many Social Services Departments will have a similar form, it will not highlight the details specific to neuromuscular conditions.

## Starting the assessment process

The aim is to plan ahead, so that the adaptations are completed by the time that they are needed. Therefore, the timing is influenced not only by the physical disability – and in many cases by its progression – but also by the length of the adaptations process. The start of the assessment process is, therefore, influenced by the following:

- ⇒ the expected time-scale and delay;
- ⇒ the timing of adaptations for children;
- ⇒ the timing of adaptations for adults.

### The expected time-scale and delay

This is considered first because it is usually a surprise to people anticipating the need for adaptations, to know how long the process takes. In most areas it would not be pessimistic to anticipate that the time from the first referral to the Social Services Department to completion of the building work is likely to be 2 years. This time-scale will be a problem to any family where there has been a delay in diagnosis or where re-housing has been delayed.

After the lengthy procedure of planning the scheme, there is frequently a delay between the submission of the paperwork for the grant (the plans, estimates for the building work and equipment, formal grant application, etc.) and grant approval. This is usually because the Grants Department is waiting for more money to become available in the next financial year and the delay cannot be prevented. This underlines the importance of starting the adaptation process in good time before the improved facilities are needed.

### The timing of adaptations for children

The emphasis is on trying, with sensitivity, to help anyone who is having difficulty facing the need for adaptations and for the facilities which will be essential in the long term, and (for children still able to walk) to carry these out in preparation for the time when, for example, climbing the stairs becomes impossible. Because of the lengthy process involved in adaptations it will be appropriate for most families with a boy with Duchenne muscular dystrophy (DMD) to start the process when he is 6. For those children who have never been able to walk, the adaptations must be planned and completed before the child uses a wheelchair or is too heavy to be carried up and down the stairs.

### The timing of adaptations for adults

The initial problem for many adults with a neuromuscular condition who are able to walk, is the increasing difficulty in getting up from a seated position; however, fortunately, there are several excellent pieces of equipment available to help (see Chapter 8b *Seat to Standing*). The correct time to start planning adaptations is when this equipment is needed, so that the work is completed before a wheelchair is essential for at least part of the day.

## Should the assessment cover the short-term or the long-term needs?

In assessing the needs, there are two conflicting views as to whether the adaptations should be carried out:

- ⇒ piecemeal, to solve the problems as they occur;
- ⇒ for both the short term and long term.

### Piecemeal adaptations

Adaptations should never be carried out at an earlier stage than you or your family feel is necessary, and, on a few occasions, someone disabled or their family may feel that staged adaptations are the best course of action. However, if this is because you are having difficulty looking into the future and facing the problems in advance, it will be more constructive for you to be given time and sensitive help. This will give you the opportunity to come to terms with any fears and to delay the start of the adaptations until the process has been worked through and you feel more able to plan for the future.

There are many disadvantages to piecemeal adaptations and, if possible, these should be avoided, for the following reasons:

- they involve you in intermittent upheaval;
- they accentuate any physical deterioration resulting in the need for constant psychological adjustment;
- they are likely to increase the cost in providing the necessary facilities;
- they may preclude better solutions in the future, because the initial work is not compatible structurally with the long-term plans and needs.

### Adaptations for both the short term and long term

Research has shown that, for parents of a boy with DMD, the way in which the diagnosis is given and the help and support that the family receives at that time and in the subsequent months, influences their acceptance and their ability to cope.<sup>3</sup> However, no two people are the same and reactions will vary. The core service of the Muscular Dystrophy Campaign Family Care Officers recognises the importance of giving priority to newly diagnosed families. All families need time to adjust before having to face adaptations and the need to consider the long-term solutions. This is particularly difficult when there is a delay in diagnosis, as you may then have to start adaptations before you are ready psychologically.

## Catering for the difficulties in the assessment

The main emphasis is to establish the present and future housing and equipment needs, which will depend on the following:

- ⇒ understanding the condition and the progression of the disability, with reference to the medical and social model;
- ⇒ identification of the needs;
- ⇒ demonstration and trial of the most appropriate equipment;
- ⇒ suitability of the present housing;
- ⇒ availability of funding and grants.

### Understanding the condition and the progression of the disability

At this stage in the discussion of the assessment of needs it is necessary to itemise the effects of neuromuscular conditions, because a knowledge and understanding of the problems experienced justifies the need, and therefore the funding, of sophisticated adaptations and equipment. The aim is not to give credence to the medical model of disability; the Muscular Dystrophy Campaign is committed to the social model of disability discussed on the next page.

### The medical model of disability

It is important to establish the medical condition because the severity of the disability, the rate of progression and the possible need of a wheelchair will influence the decisions. Factsheets are available from the Muscular Dystrophy Campaign covering most types of muscular dystrophy and allied neuromuscular conditions (see Chapter 5). However, most of these conditions have several factors in common, which affect the assessment of need.

- **Most (but not all) are progressive** and the deterioration can be both physically and emotionally demanding.
- **They are selective muscle wasting conditions** (muscular dystrophies) **or conditions in which the nerve impulses fail to reach the muscles** (spinal muscular atrophy), resulting in severe muscle weakness in the legs, arms, neck and the trunk.
- **Many people either find it difficult or impossible to walk** and the wheelchair used is usually powered, because of the inability to propel a wheelchair owing to arm weakness.
- **If walking is possible, the emphasis is usually placed on the need to continue walking** for as long as possible and, when this becomes difficult, to use a standing frame daily, for as long as practical and for as many years as can be tolerated. The importance of erect posture is to delay hip and knee contractures in order to maintain the ability to lie flat and to extend the legs. Also – and even more important – this encourages a lordosis (which is a forward curvature of the spine), in order to delay a scoliosis or side curvature. This standing routine has important implications for adaptations, as it involves the need to provide work surfaces to encourage standing and the simultaneous opportunity for purposeful activities, and also the space to store a standing frame.

- **The effect of the arm weakness is particularly debilitating** and is not always fully understood. Very few people with a neuromuscular condition can raise their arms above shoulder height and, as the condition progresses, they are unable to lift their arms off the wheelchair armrests and rely on creeping with their fingers, or moving their arm by grasping clothing or a finger with teeth. This means that the height of the work surfaces needs to be very precise, so that hand function can be maximised.
- **The trunk weakness results in lack of balance** and stability making support necessary when sitting in a chair or a bath.
- **Some disabilities are stereotyped, (although the rate of deterioration is variable),** which means that adaptations can be planned for the future.
- **The muscle weakness results in sudden, extreme and abnormal tiredness,** to the extent that many adults initially use a wheelchair for part of the day only – either for specific activities or when too tired to walk. This means that the height of surfaces needs to be suitable for both standing and sitting and, because of the arm weakness, the adjustment has to be operated electrically.

### The social model of disability

As long ago as 1976, disabled people themselves have been using the so-called ‘social model of disability’ to define themselves and their own experiences. The Union of the Physically Impaired Against Segregation in that year gave the following definition:

*"In our view it is society which disables physically impaired people. Disability is something imposed on top of our impairments by the way we are unnecessarily isolated and excluded from full participation in society. Disabled people are therefore an oppressed group in society".<sup>4</sup>*

The social model today is taken to include people with all impairments – physical, intellectual and sensory – and those with mental health problems. By placing the emphasis on the barriers to disabled people’s participation in society, it provides a cure to the ‘problem’ of disability – removal of those barriers. Although it does not avoid mention of the symptoms or functional limitations linked to impairments, it does not locate disabled people’s problems entirely in their own bodies. Thus, the social model is in distinction to an individual or medical model of disability.

There is no written statement regarding agreed terminology adopted by the disability movement. However, it is generally considered that ‘disabled people’ is preferred to ‘people with a disability’ because this fits in with the social model, i.e. people are just people until they are disabled by a barrier or policy. This is supported in the writing of this manual, as the aim is to build an environment within the home that eliminates barriers and allows the maximum degree of independence in the use of the facilities.

This philosophy is shared by Selwyn Goldsmith, the architect who for many years has set the disability architectural standards. In the preface of his latest book he writes:

*"The disabled' is an ambiguous term. It can mean, as it usually does, people with disabilities, those who have something wrong with them that a physician can describe. That is the medical model. Or it can mean people, whether or not they be 'medically' disabled, who are in some other way disabled – who are financially disabled, for example or socially disabled, or architecturally disabled. It is architecturally disabled people with whom this book is concerned, those who when using or attempting to use buildings can find themselves confronted by impediments which prevent them from doing so, or allow them to do so only with difficulty and inconvenience. They are disabled because the architect who designed the building did not anticipate their needs, or did not care about them".<sup>5</sup>*

Perhaps this manual will go some way to put things right in the homes of people with neuromuscular conditions.

## Identification of the needs

A *Disability Needs Assessment Form* (Chapter 10) has been compiled and piloted for several months, in preparation for the publication of this manual. The aim has been to make the assessment process as easy and thorough as possible, while at the same time identifying the choices to be made – (e.g. lift vs extension and bath vs shower), the equipment to be assessed, housing specifications to be considered – and recording the initial funding issues. In addition, these are all discussed in greater detail in this manual, as follows:

Chapter 6	<i>Lift vs Extension;</i>
Chapter 7	<i>Bath vs Shower;</i>
Chapter 8a	<i>Equipment for Adaptations;</i>
Chapter 11	<i>Justification for Funding;</i>
Chapter 12	<i>Funding of Adaptations/Understanding the Grant Systems/VAT;</i>
Chapter 15	<i>Adaptation Specifications: Access/Bathroom/Bedroom/Electrics/Heating/Storage;</i>
Chapter 16	<i>Kitchens.</i>

## Demonstration and trial of the most appropriate equipment

Chapter 8a itemises the equipment that should be assessed and the order in which decisions should be made. In *every* case, it is essential that the equipment is assessed in conjunction with an OT who knows the family circumstances and whose responsibility it will be to both establish the need and justify the expense. There are three ways in which this can be carried out:

- ⇒ a visit to a Disabled Living Centre;
- ⇒ assessment in the home;
- ⇒ visiting another house where a similar adaptation has been carried out.

## A visit to a Disabled Living Centre

This may be an enlightening occasion for an adult who has not received much practical help, but for parents the visit should be handled with great sensitivity and approached with a positive attitude. The aim is to counteract the disabling features of the condition and to increase the independence (and, therefore, the happiness) of the child. It should also be emphasised that the early and appropriate timing in assessing equipment will prevent delay and the subsequent frustrations in having to cope without adequate facilities. A child is likely to enjoy the visit: trying out the high-tech equipment and flying through the air in a hoist can be an interesting experience, provided that it is introduced in a positive and enjoyable way.

## Assessment in the home

If an item of equipment is not held in the nearest Disabled Living Centre or if a Centre is difficult to visit, most firms will carry out a home demonstration. In addition, a specialist service has been arranged by *Daily Care* (see Chapter 18 *Addresses*) who will visit your house and bring most of the adaptations equipment on one visit. This will be much easier than having different firms demonstrating individual items. Alternatively, the firms may be able to let you know if the equipment has been installed in the area and arrangements can be made for the assessment. This may be particularly important where a realistic trial is not possible unless the equipment is plumbed into a water supply, e.g. a shower toilet.

## Visiting another house where a similar adaptation has been carried out

In many cases, this is a supportive way to carry out the assessment. This may be particularly true if the adults have the same difficulties or if the children are close in age. The Muscular Dystrophy FCO or community OT may be able to make the arrangements, and this is likely to be the most satisfactory way of assessing equipment.

## Suitability of the present housing

A number of factors are involved, as follows:

- ⇒ access and suitability of the garden and the area surrounding the house;
- ⇒ suitability of the existing facilities or the adaptability of the house;
- ⇒ the importance of space;
- ⇒ recommended size of rooms;
- ⇒ the use of existing rooms;
- ⇒ the need for a disabled child with a neuromuscular condition to have a separate bedroom.

Other issues will be involved if moving is considered, and these are included in the discussion on the outcome options (see page 12).

## Access and suitability of the garden and the area surrounding the house

The importance of access into the garden and a suitable paved area is discussed in Chapter 15 *Adaptation Specifications*. The area surrounding the existing house is not usually of great importance, because a powered wheelchair can climb a gradient of 1 in 4 and any road is unlikely to be as steep (although this is frequently a problem with private drives). Although a sloping site should be avoided when selecting a new house, this feature in the existing house need not be the sole reason for a family move.

## Suitability of the existing facilities or the adaptability of the house

- The aim is to ensure that there are en-suite facilities with a bedroom and bathroom large enough for the person (and partner) and for the essential furniture and fittings, in addition to adequate circulation space for a wheelchair. See Chapter 11 for details of the space requirements.
- Are these facilities currently available either on the ground floor or upstairs? If upstairs,
  - Can a through-floor lift be installed (i.e. is there a suitable position on the ground floor with a suitable position directly above – either on the landing or in the bedroom) or are the stairs suitable for a wheelchair-platform lift?
  - If a through-floor lift is proposed up to a bedroom, is the room large enough for both the lift and for the fittings that are needed in the room?
  - If not, is the garden suitable for a large-enough extension?

## The importance of space

This should not be underestimated and frequently is the reason for adaptations needing to be reconsidered within 5 years of completion. It is important to justify the need for space to either of the following:

- a grants officer, to ensure that the proposed extension is large enough when there is concern about the cost;
- a planning officer or Planning Committee who are anxious to reduce the size of an extension.

This information has been presented in Chapter 11a *The Long-Term Housing Needs, including the Importance of Space*, and Chapter 11b *Space Requirements*, to enable them to be photocopied, and submitted with other information to justify the need for space.

## Recommended size of rooms

Questions are frequently asked about the optimum size of the rooms. These are difficult to answer without details of access, the shape of the rooms, the number and size of windows and (if an extension is to be built) how this will dovetail with the existing house. It is more constructive for the architectural designer to be given an accurate brief early in the process; when the essential features and space dimensions have been considered. These will determine the size of the rooms.

## The use of existing rooms

There may be several issues to be discussed on the number and use of existing rooms, which may include the need to retain the following:

- ⇒ a dining room;
- ⇒ a room for a temple or a room to be used for prayer;
- ⇒ a spare room for a carer.

## The need to retain a dining room

Grants officers are responsible for seeing that the grant is spent appropriately. In this respect, they may suggest that a dining room is used to provide a ground-floor bedroom. However, this is not practical for someone with a neuromuscular condition. It is essential to have wheelchair access under a dining-room table in order to have a surface large enough to support the forearms and to provide adequate space for the dinner plate, side plate and mug; the use of a wheelchair tray is not adequate for meals.

For many families, quality family time is achieved when sharing a meal around a table and, for active families, this may be the only opportunity to talk and listen to each other. Many disabled people do not have the same opportunities as others to go out in the evenings. The ability to entertain friends at home may be an important factor to prevent isolation, and to provide a break from caring for someone who is severely disabled. Some families may need the dining room for business entertaining.

Where a dining room adjoins the sitting room, creating a throughroom may increase the wheelchair circulation space and provide a family room. In the same way, a kitchen and dining room may be opened up to create a kitchen/diner and thereby improve access, increase circulation space, or borrow natural light where a window has been lost due to the building of an extension.

### **The need to retain a room as a temple or a room to be used for prayer**

This need is the easiest to establish as race relations and racial tolerance are recognised as important and clearly understood. It is also important to respect the Asian tradition of having separate sitting rooms for men and women.

### **The need to retain a spare room for a carer**

One of the great distresses to anyone disabled and their partner (or parents) is that their private lives become exposed when they ask for help from a statutory service. It can be difficult to explain the need to retain a spare room. Many disabled people can be very restless at night and, for a partner who has to work the following day, it is often essential to retain a room in which they can periodically get a less disturbed night. This may be particularly important when either is ill or recovering from an operation.

It may also be necessary to accommodate a carer, on a temporary or permanent basis – or friends who stay overnight to help. To have extensive adaptations carried out that would not be adequate in the future and would involve either restarting the adaptation process or involve re-housing, is shortsighted and will prove more expensive in the long term.

A bed-sit is invaluable if a carer is needed for a teenager or young adult living at home with parents; problems can arise if the carer has to share the living area with the rest of the family, who subsequently lose their privacy, resulting in the build-up of family tensions.

### **The need for a disabled child with a neuromuscular condition to have a separate bedroom**

Many children need attention in the night and it is unfair to constantly disturb another child sharing the room, who will then be tired at school the next day. Where a family has two affected children, if the parents get up to see one child and the other is disturbed, the parents will never get back to bed. Giving attention to both children at the same time does not always reduce the number of times it will be necessary to get up; repositioning is to increase comfort when necessary, rather than to turn the disabled child routinely to prevent pressure sores. An age gap – and therefore a difference in bedtimes – may also make it unsatisfactory for two children to share a room.

### **Availability of funding and grants**

These are considered in Chapter 12 *Funding of Adaptations*.

## The outcome options

Having assessed the needs, and considered the suitability of the present house – and depending upon the financial circumstances – a decision will need to be made between the following:

- ⇒ adapting the house;
- ⇒ moving.

### Adapting the house

Before adapting a house, it is wise for the grant applicant, or their family, to give serious thought to the proposals. If there are any doubts, re-housing – or house-hunting, if you own your own house – should be considered. It is essential, where it is decided to go ahead with the adaptations, to be certain that all the alternatives were carefully examined for reassurance that the right decision was made. It is also important that, if you have any misgivings during the adaptation process, you should voice these doubts and be prepared to reconsider the alternative options. If this is difficult, it may help to enlist the support of a Muscular Dystrophy Family Care Officer.

Architectural services are grant eligible. However, a Disabled Facilities Grant (DFG) or an Improvement Grant will not be approved unless the adaptations are carried out. If the adaptations do not go ahead, it will be necessary to pay the architectural designer for the work completed without a grant to cover the cost.

### Dissatisfaction with the proposed adaptation plan

In owner-occupied houses it is important to remember that the house belongs to the grant applicant or the family: you are the people who have to cope with the disability in the home and the grant is payable to you. Details of the grant are included in Chapter 12 *Understanding the Grant Systems*, but if the plans are not what you or your family feel that you need, it is important that your concerns are voiced. This is equally important in rented property. If there is disagreement on the best options and a position of stalemate is reached, discuss with the grants officer about drawing up alternative plans. Provided that the two sets of plans are equally suitable from the disability point of view, they can be priced separately, the grant paid on the cheaper scheme and you could be given the opportunity to pay the difference and build your preferred plan.

### Moving

There are a number of issues to be considered:

- ⇒ social and family factors;
- ⇒ long-term housing needs;
- ⇒ housing pitfalls to avoid;
- ⇒ suitability of the proposed house, if necessary with adaptations;
- ⇒ re-housing to a rented property;
- ⇒ advice before accepting a re-housing offer;
- ⇒ mortgages for disabled people;
- ⇒ buying or renting a bungalow;
- ⇒ building a new home.

## Social and family factors

The importance will vary according to the priorities of each individual family:

- Is the timing right psychologically for everyone concerned?
- Will the move involve losing the support of neighbours, friends and relations?
- Is there an appropriate school for the disabled child, within reasonable distance?
- Will the move affect the rest of the family, including the education of siblings?
- The needs of siblings are discussed in the publication *Hey, I'm Here Too*.<sup>6</sup>
- What are the local facilities?
- What effect, if any, will a move have on the jobs or careers of the family?

Following a move to a suitable house that needs adaptations, a grant application can be made in the normal way.

*N.B. Because bungalows offer ground-floor accommodation, there may be difficulties in justifying the need for adaptations. See further advice on page 16.*

## Long-term housing needs

When making a re-housing application, it is important to be clear about the housing needs, as this information will be essential to send to the lettings officer of the Housing Department or to the allocation or development officer of a Housing Association.

Separate pages have been prepared on the long-term housing needs and the need for space, and are included in Chapter 11. They can be photocopied to include with applications.

## Housing pitfalls to avoid

### Houses built into a hillside

The expense of excavating the site and building retaining walls will reduce the amount of funding available to provide the access and facilities needed.

### Houses with insufficient space for an extension at sides or rear

It would be unusual to gain planning consent for an extension other than a porch on to the front of the house, unless it is not in front of the building line.

### Where an extension would be too narrow without building up to the boundary or impacting on neighbours

Look to see if a precedent has been set by extensions to other houses in the road.

## Suitability of the proposed house, if necessary with adaptations

Ask for advice before making the final decision on whether to accept a lease or to buy a particular house, to ensure that, if it needs to be adapted, it is suitable. There are some houses that are either impossible to adapt or that would prove so expensive as to be impractical. Seek this advice from someone that you can trust and who will be considering your best interests – and the best person to help you will be an architect/designer with relevant experience, a Muscular Dystrophy Family Care Officer or an OT.

The dilemma for some LA personnel looking at a house before purchase, may be that their responsibility is to look for the cheapest way to adapt it. If the house is suitable for a lift, there may be the temptation, in the case of a disabled child, to dictate how the bedrooms should be allocated, suggesting that the child uses the double room intended for the parents. Where there is a dining room, it may be insisted that this is used as a bedroom, making it more difficult later to argue the case for retaining a room for meals.

## Re-housing to a rented property

If you rent your home you may choose to remain in rented property or you may have no alternative. You will have to apply to be re-housed in a more suitable council house or a Housing Association or privately-owned property. However, if you are a council tenant and would consider buying a house, you should enquire if the LA operates an incentive scheme which provides capital to help families to move out of the rented sector.

## Advice before accepting a re-housing offer

The following must be discussed:

- ⇒ the suitability of the house;
- ⇒ availability of grants;
- ⇒ the willingness of the Housing Department, Housing Association or private landlord to adapt the property, if necessary;
- ⇒ rent;
- ⇒ security of tenure.

### The suitability of the house

See page 9.

### Availability of grants

This issue is discussed in Chapter 12 *Funding*.

### The willingness of the Housing Department, Housing Association or private landlord to adapt the property, if necessary

This should be discussed with the community OT and a commitment received in writing from the appropriate department, before accepting the property. If the adaptations cannot be carried out before moving into the house, the commitment should also include a time-scale for the work to begin – and the arrangements for alternative accommodation, if it proves impossible to remain in the house with builders on site.

### Rent

Housing Association property can be expensive to rent and, if you are not receiving housing benefit, it may be wise to discuss the proposed rent before being re-housed or before a house is purpose built.

### Security of tenure

There may be a number of issues, including security of tenure, which will be relevant to rented property irrespective of who owns the house. These should be checked out with care, with legal advice if necessary. A solicitor can be contacted at a Citizens Advice Bureau or at the nearest Disability Law Centre – both of which will be listed in the telephone directory – or by contacting the Disability Law Service (see Chapter 18 *Addresses*).

If the property has been specifically built or adapted for a disabled person, or is to be adapted for them, the partner or family should find out what the future position would be if the person dies:

- Will you be allowed to remain in the house or be asked to move?
- If you have to move, how long will you be allowed to stay after the bereavement (as it is difficult to cope with a move while the grieving is very acute)?
- If the house belongs to a Housing Association, will you be offered another of their properties or will you have to go on to the council housing waiting list?
- Will you be allowed to wait until you have been offered a house that you like – in an area in which you want to live – or will you be expected to accept the first offer?

### Mortgages for disabled people

Do not assume that disability and possibly a shortened life expectancy make it impossible to get a mortgage. Seek advice from building societies or independent financial or mortgage advisors.

### Buying or renting a bungalow

A bungalow can be the ultimate solution for anyone unable to climb stairs or using a wheelchair. However, before thinking of moving to a bungalow the following should be considered:

- ⇒ advantages of a bungalow;
- ⇒ disadvantages of a bungalow;
- ⇒ the need to justify adaptations;
- ⇒ advice before purchase.

#### Advantages of a bungalow

- ***Instant access to every room in the home***

Clearly, this is the main reason for choosing a bungalow, and is achieved with none of the disadvantages of a lift. The advantages of single-floor accommodation are:

- if a child needs attention in the night, the parents do not have to go downstairs;
- disabled parents who are unable to climb stairs, will be able to go into their children's bedrooms;
- it is feasible for anyone unable to climb stairs to assume the responsibility for supervision of the maintenance and cleaning of the house.

#### Disadvantages of a bungalow

These are as follows:

- ⇒ cost;
- ⇒ noise;
- ⇒ situation;
- ⇒ difficulty in justifying adaptations.

- **Cost**  
The cost of a bungalow is much greater than the equivalent floor area in a house and, as a result, you may have to buy a bungalow smaller than ideal and/or increase your mortgage. The size of the mortgage is not taken into account in the ‘Test of Resources’; the means test of the Disabled Facilities Grant (DFG). These additional outgoings may make it impossible to pay your assessed contribution.
- **Noise**  
There is no ceiling to deaden the sound of your children’s music!
- **Situation**  
If the bungalow is sited among other bungalows, you are likely to be surrounded by older people who may be less tolerant of children and their noise.
- **Difficulty in justifying adaptations**  
When considering buying or renting a bungalow you must be aware of the problems you may subsequently experience in obtaining a grant for adaptations, as the bedroom and bathroom are already on the ground floor. It is easier to justify an extension for a disabled person who has an upstairs bedroom and who cannot climb stairs or who uses a wheelchair. It may also be difficult to convince the landlord of a rented bungalow that adaptations are essential.

The DFG legislation includes a number of facilities for which grant is mandatory and in the context of this discussion the following are relevant:

*“facilitating access by the disabled occupant to:*

- *and from the dwelling or the building in which the dwelling or, as the case may be, flat is situated;*
- *a room used or usable as the principal family room;*
- *or providing for the disabled occupant, a room used or usable for sleeping;*
- *or providing for the disabled occupant, a room in which there is a lavatory, or facilitating the use by the disabled occupant of such a facility;*
- *or providing for the disabled occupant, a room in which there is a bath or shower (or both), or facilitating the use by the disabled occupant of such a facility;*
- *or providing for the disabled occupant, a room in which there is a wash hand basin or facilitating the use by the disabled occupant of such a facility”;*<sup>7</sup>...

In a bungalow the ‘disabled occupant’, will have access to *a room for sleeping and a room in which there is a lavatory, bath, shower or washhand basin* and may be denied a grant to provide a bedroom and bathroom which are both *large enough and adjacent* for provision of en-suite rooms. If you or your family try to help yourselves by moving into a more suitable home and use up your savings in the process, it is an injustice if you are then denied a grant. If necessary, this must be challenged. Had you remained in your previous house you would have been given (depending upon need and the means test) a DFG (England, Wales and Northern Ireland) or Improvement Grant (Scotland) with the possibility of a top-up grant or loan to provide an accessible and en-suite bedroom and bathroom. See Chapter 12 *Funding of Adaptations*.

## The need to justify adaptations

- **The need for en-suite facilities**

It is recommended that everyone with a neuromuscular condition, who needs a wheelchair or will need one in the future, should have en-suite facilities. This enables them to be undressed on their bed and be taken to the bathroom (possibly on an extended track of the ceiling hoist) within the warmth and privacy of the two rooms.

The provision of en-suite facilities *is* a real need and, if the bathroom or bedroom is too small to allow sufficient space for the additional door, necessary equipment and the circulation space for a wheelchair, then an extension *is* needed.

## Advice before purchase

When considering moving to a bungalow, it may be wise to involve the Muscular Dystrophy FCO and subsequently to check the position with the community OT, who can be contacted through the local Social Services Department. The alternative is to seek other advice – or be prepared to fight the case after purchase.

## Building a new home

Replacement grants are available in Northern Ireland and these are discussed in Chapter 12 *Funding*. In the past, in the rest of the UK, although it may sound illogical, if you decided to build, there were no Housing Department Grants unless you moved in first and then asked for adaptations – and in some areas this may still be the situation. However, the Social Services Department will usually provide a ceiling hoist and may consider helping with essential fittings such as a lift, shower toilet, specialist bath and washbasin.

With the introduction of amendments to the grants system in 2003, depending upon the LA's policy, discretionary grants/loans may be available to help with the purchase of a more suitable house and this might extend to the provision of purpose-built facilities within a proposed 'new-build' house. It would be wise to approach the community OT or grants officer as early as possible, to discuss the options of both financial help and/or the provision of equipment.

## References

- 1 Oldham, Christine, Beresford Bryony. *Homes unfit for children: Housing disabled children and their families*. Policy Press in conjunction with the Joseph Rowntree Foundation, 1998.
2. *Code of Ethics and Professional Conduct for Occupational Therapists*. College of Occupational Therapists, 2000, pg. 5-6.
3. Green, Josephine M, Murton, Frances B. *Duchenne muscular dystrophy: The experiences of 158 families*. Centre for Family Research, University of Cambridge, 1993.
4. Oliver, Mike. *Understanding Disability: From Theory to Practice*. Macmillan Press, 1996.
5. Goldsmith, Selwyn. *Designing for the Disabled*. Architectural Press, 1997.
- 6 Siegel, Irwin M. *Hey, I'm Here Too!* Muscular Dystrophy Campaign, 1998.
- 7 *The Housing Grants, Construction and Regeneration Act 1996, Chapter 53*. HMSO, pg. 13-14.

# Muscular Dystrophy & Allied Neuromuscular Conditions

## Introduction

Factsheets on a range of neuromuscular conditions, and on some disability issues, are available from the Muscular Dystrophy Campaign. These are constantly reviewed and updated. A full set can be found on and printed off from the organisation's website: [www.muscular-dystrophy.org](http://www.muscular-dystrophy.org)

Alternatively, photocopy the page, indicate the factsheet required  and return to:

Information Service  
Muscular Dystrophy Campaign  
7–11 Prescott Place  
London SW4 6BS  
tel: 020 7720 8055  
fax: 020 7498 0670  
e-mail: [info@muscular-dystrophy.org](mailto:info@muscular-dystrophy.org)

- Alternative Therapies
- Annual Review
- Anaesthetics
- Becker muscular dystrophy
- Booklist on the muscular dystrophies and neuromuscular disorders
- Carrier detection tests and prenatal diagnosis
- Children with muscular dystrophy in mainstream schools

### **Congenital Myopathies**

- Central core myopathy
- Congenital fibre type disproportion myopathy
- Minicore (multicore) myopathy
- Myotubular or centronuclear myopathy
- Nemaline myopathy
- Congenital muscular dystrophy
- Congenital myotonic dystrophy
- Duchenne muscular dystrophy
- Duchenne muscular dystrophy: the older child
- Education
- Emery-Dreifuss muscular dystrophy
- Facioscapulohumeral muscular dystrophy (FSH)
- Facts about muscular dystrophy
- Gastrostomy

- Heart check
- Hereditary Motor and Sensory Neuropathies - HMSN (Charcot-Marie-Tooth disease)
- Holiday factsheet
- Hospital card
- Inclusion Body Myositis
- Inheritance and the muscular dystrophies
- JPT Annual Review
- Joining the Campaign
- Juvenile Dermatomyositis
- Limb-Girdle muscular dystrophy
- Manifesting carriers
- Muscle biopsies
- Making breathing easier
- Metabolic disorders that cause pain and/or weakness on exercise
- Mitochondrial myopathies
- McArdle's disease
- Myasthenia Gravis
- Myositis Ossificans Progressiva
- The Myotonias
- Myotonic dystrophy
- Ocular myopathies
- Periodic paralyses
- Personal relationships and sexuality
- Polymyositis and Dermatomyositis
- Pregnancy and reproduction in muscle disorders
- Student pack
- Surgical correction of spinal deformity
- Target MD
- Transport factsheet
- Weight control in patients with muscular dystrophy
- Would it help to talk? (Emotional needs)

## Support Groups

Support Groups are run by and for people with neuromuscular conditions, and their families and friends - and those listed below have very close links with the Muscular Dystrophy Campaign. They offer a variety of services such as a newsletter, providing information and emotional support - and putting individuals and families in touch with each other.

### Association for Glycogen Storage Disease

9 Lindop Road  
Hale  
Altrincham  
Cheshire  
WA15 9DZ  
tel: 0161 980 7303 (after 6pm)  
e-mail: [info@agsd.org.uk](mailto:info@agsd.org.uk)  
contact: Mrs Ann Phillips  
web: [www.agsd.org.uk](http://www.agsd.org.uk)  
*Glycogen Storage diseases including:  
Von Gierke's disease, Pompe's disease  
Andersen's disease, McArdle's disease*

### CLIMB Children Living with Inherited Metabolic Diseases

Climb Building  
176 Nantwich Road  
Crewe  
CW2 6BG  
tel: 0800 652 3181  
e-mail: [info@climb.org.uk](mailto:info@climb.org.uk)  
contact: Mrs Lesley Greene  
web: [www.climb.org.uk](http://www.climb.org.uk)  
*Includes Mitochondrial Myopathy*

### CMT United Kingdom

PO Box 5089  
Christchurch  
BH23 2WJ  
tel: 0870 7744 314  
e-mail: [secretary@cmt.org.uk](mailto:secretary@cmt.org.uk)  
contact: Karen Butcher  
web: [www.cmt.org.uk](http://www.cmt.org.uk)  
*Hereditary Motor and Sensory Neuropathy,  
also known as Peroneal muscular atrophy and  
Charcot-Marie-Tooth disease*

### Congenital Muscular Dystrophy Support Group

21 Morrison Drive  
Pitcorthie  
Dunfermline  
Fife  
KY11 5DJ  
tel: 01383 736 084

### Duchenne Family Support Group

37a Highbury New Park  
Islington  
London  
N5 2EN  
tel: 0870 241 1857  
e-mail: [dfsg@duchenne.demon.co.uk](mailto:dfsg@duchenne.demon.co.uk)  
helpline: 0870 606 1604  
contact: Rosemary Matthews  
web: [www.dfsg.org.uk](http://www.dfsg.org.uk)  
*Duchenne muscular dystrophy*

### FSH-MD Support Group

8 Caldecote Gardens  
Bushey Heath  
Herts  
WD23 4GP  
tel: 020 8950 7500  
fax: 020 8950 7300  
e-mail: [fshgroup@hotmail.com](mailto:fshgroup@hotmail.com)  
contact: Mr Norman Jonas  
web: [www.fsh-group.org](http://www.fsh-group.org)  
*Facioscapulohumeral muscular dystrophy*

### **Guillain-Barre Syndrome Support Group**

Lincolnshire County Council  
Council Offices  
Eastgate  
Sleaford  
Lincs  
NG34 7EB  
tel: 01529 304 615  
helpline: 0800 374 803  
e-mail: admin@gbs.org.uk  
contact: Mrs Glenys Sanders  
web: www.gbs.org.uk

### **The Jennifer Trust for Spinal Muscular Atrophy**

Elta House  
Birmingham Road  
Stratford upon Avon  
Warwickshire  
CV37 0AQ  
tel: 0870 774 3651  
helpline: 0800 975 3100  
(Mon-Fri 9-5)  
fax: 0870 774 3652  
e-mail: jennifer@jtsma.org.uk  
contact: Mrs Anita Macaulay  
web: www.jtsma.org.uk  
*Severe SMA (Werdnig-Hoffman disease)*  
*Intermediate SMA*  
*Mild SMA (Kugelberg-Welander disease)*  
*Adult SMA*

### **Mitochondrial Myopathies**

3 Home Farm Cottages  
Yearby  
Nr Redcar  
Cleveland  
TS11 8HQ  
tel: 01642 480 973  
email: mitolinks@aol.com  
contact: Vic/June Wood  
*Mitochondrial myopathies*

### **Myasthenia Gravis Association**

Central Office  
Keynes House  
Chester Park  
Alfreton Road  
Derby  
DE21 4AS  
tel: 01332 290 219  
helpline: 0800 919 922  
e-mail: mg@mgauk.org.uk  
web: www.mgauk.org  
*Myasthenia Gravis, Lambert-Eaton*  
*Myasthenia, syndrome and Congenital*  
*Myasthenia*

### **Myositis Support Group**

146 Newtown Road  
Woolston  
Southampton  
SO19 9HR  
tel: 02380 449 708  
Mon-Fri 9am-3pm  
e-mail: enquiries@myositis.org.uk  
contact: Mr & Mrs Oakley  
web: www.myositis.org.uk  
*Dermatomyositis and Polymyositis*  
*Juvenile Dermatomyositis*  
*Inclusion Body Myositis*

### **Myotonic Dystrophy Support Group**

35a Carlton Hill  
Carlton  
Nottingham  
NG4 1BG  
tel: (Answerphone) 0115 987 0080  
fax: 0115 987 6462  
e-mail: mdsg@tesco.net  
contact: Mrs Margaret Bowler  
web: www.mdsguk.org  
*Myotonic dystrophy (also known as*  
*Steinert's disease and Dystrophia Myotonica)*  
*Congenital myotonic dystrophy*

# Lift vs Extension

## for children & adults with muscular dystrophy & allied neuromuscular conditions

*The factors to be considered by a disabled person and/or their family to help make a well-informed choice*

To be used in conjunction with:

Chapter 8a	<i>Equipment for Adaptations;</i>
Chapter 11	<i>Justification for Funding;</i>
Chapter 14	<i>Scales &amp; Templates;</i>
Chapter 15	<i>Adaptation Specifications;</i>
Chapter 18	<i>Addresses: Manufacturers/Suppliers/Sources of Advice.</i>

The main issue involved in the choice is an assessment of the best use of space. The decision is about which option either uses up the least space or gives access to the most space and the opportunity to provide the best facilities, within both the house and garden.

A lift is usually the first option to be considered, particularly if a grant application is being made, as grants officers prefer to approve adaptations that are within the structure of the house. However, where both a lift and an extension are possible structurally, the final decision must depend upon which option will be the most appropriate for the disabled person and the carers, bearing in mind the long-term effects of the particular disability.

Guidance is presented under the following headings:

	⇨ Lift	2
	⇨ Ground-floor extension	5
⇨ Making the choice between a lift & a ground-floor extension		6
	⇨ Summary	9

## Lift

The issues to be considered are:

- ⇒ types of lifts available;
- ⇒ is a lift appropriate?
- ⇒ choice of model.

### Types of lifts available

These are as follows:

- ⇒ stairlift with a platform for a standing passenger;
- ⇒ stairlift with an integral chair;
- ⇒ stairlift with a platform for a wheelchair;
- ⇒ vertical through-floor lift.

#### Stairlift with a platform for a standing passenger

Unless there are unusual circumstances or a lift is needed for only a short period, this type is not recommended for the safety of anyone with muscular dystrophy.

#### Stairlift with an integral chair

Many adults prefer this type of lift; however, unless such lifts are used as a 'stop-gap' solution, they are not suitable for anyone with muscular dystrophy. This is because of the difficulty in transferring on and off the seat, the problems of both balancing and carrying objects, and, if/when a wheelchair is necessary, the need for a second wheelchair upstairs.

#### Stairlift with a platform for a wheelchair

Although these lifts do not take up valuable space in a house, there has to be a large enough area, both at the base of the flight of stairs and at the top, to accommodate the platform. In addition, there must be sufficient space to enable the user to manoeuvre the wheelchair with ease, on and off the platform. These lifts also take up the full width of the stairs and therefore prevent anyone else using the stairs at the same time.

#### Vertical through-floor lift

These models are usually open and not enclosed in the same way as a public service lift. Initially, even if a wheelchair is not needed, this type of lift will be invaluable as a means of going between the two floors and carrying small items such as toys and washing. If necessary, a wall-mounted seat can be fitted prior to the use of a wheelchair in the future. However, this may be contraindicated because of the difficulty of standing up from the seat unless it is high enough to be used as a 'perching' seat.

Forward planning is essential to ensure that, where possible, the lift will be suitable for the size of any wheelchair that may be used in the future, and for the combined weight of the chair (which could be **140kg**) and the occupant.

## Is a lift appropriate?

The following questions need to be answered:

- ⇒ Is the house large enough for the loss of space taken up by the lift and access to the lift to be unimportant?
- ⇒ Is there a suitable position for the lift on the ground floor and directly above on the first floor – or are the stairs suitable for a wheelchair-platform lift?
- ⇒ Are the first-floor facilities suitable in space and layout for a wheelchair?

### Is the house large enough for the loss of space taken up by the lift and access to the lift to be unimportant?

Most houses lack space and are unsuitable for the installation of a lift. The space needed for a lift is considerable, because of the area needed for both the lift and access to the lift. The recommended size is likely to be approximately **1500mm** in length and **1000mm** in width for the lift – and an area of the same size in order to approach the lift in a wheelchair and open the door.

### Is there a suitable position for the lift on the ground floor and directly above on the first floor – or are the stairs suitable for a wheelchair-platform lift?

Does the layout of the rooms allow for a double bedroom, large enough for the essential fittings and a lift, to have en-suite facilities? Boys with Duchenne muscular dystrophy and other children and adults with neuromuscular conditions are often undressed on their bed and then they transfer into the bathroom either on a mobile bath or shower chair, or on an extended track of the ceiling hoist. The latter option is usually chosen when a shower toilet and/or bath with an integral seat is installed. Adjoining rooms enable this procedure to be carried out within the warmth and privacy of the two rooms – and respects the dignity of the disabled person.

### Are the first-floor facilities suitable in space and layout for a wheelchair?

There is no point in installing a lift if either the bathroom or bedroom is too small. It is important to be aware of the space needed in the future as the need for additional equipment and the size of the wheelchair increases.

#### Bathroom

There must be sufficient space for the following:

- **A suitable bath or shower**

Where possible, the choice of equipment must be made on the basis of need and not space, and the choice will be between:

- an *Arjo* Sovereign bath with space to cover the arc of the seat;
- Mermaid Ranger with a pillar at the side or end of the bath, with space to cover the arc of the seat;
- ASM Multi-System;
- level-access shower.

- **Vanity washbasin**
    - 1050-1200mm in width and a front-to-back depth of 675-695mm.
    - 1000mm in front of the basin to allow sufficient space for a wheelchair to approach squarely.
  - **Toilet**
    - 900mm at the exposed side of the toilet for positioning a wheelchair for sideways transfer.
    - 500mm from the centre of the pan to the wall or nearest obstruction. This allows space for wall-mounted rails and for a chair to be superimposed over the pan, if either are needed.
  - **Additional door**
    - 926mm width door to provide direct access to the bedroom.
- The circulation of a powered wheelchair**
- 1700mm turning circle or the space to carry out a 3-point turn.

## Bedroom

There must be a suitable position for the lift (if it cannot be accommodated on the landing) and yet enough space for the essential items, as follows:

- **Wall space for an electric bed**
  - Length: 2155mm.
  - Width: 2160mm for a double bed, and either 1080 or 1220mm for a single bed. It is always wise to allow for the wider single bed because this option will then be possible in the future - or will allow a single bed to be pulled away from the wall to enable a carer to work from both sides of the bed.
  - Side: 1800mm to enable the ceiling hoist over the bed to be used for transferring from one wheelchair to another, or from wheelchair to easy chair or Mermaid Ranger/shower chair.
- **Standard storage facilities**
  - Wardrobe and chest of drawers.
- **L-shaped working surface**
  - A minimum length of 1800mm x 1200mm.
- **Door**
  - 926mm width door to provide direct access to the bathroom.
- **The circulation of a powered wheelchair**
  - 1700mm turning circle.

## Choice of model

The factors to consider are as follows:

- ⇒ whether the lift has to be suitable for a wheelchair;
- ⇒ the space available for the most appropriate model;
- ⇒ the size of lift and weight limitations;
- ⇒ the availability of electronic doors and the sensitivity of the switches;
- ⇒ the position of the controls;
- ⇒ choice of lift.

## Whether the lift has to be suitable for a wheelchair

For most people with a neuromuscular condition, it is vital to have a wheelchair model of lift installed, if a wheelchair is needed now or is likely to be needed in the future. This will avoid incurring the additional and considerable expense of changing the lift at a later date, usually to a vertical through-floor lift.

## The space available for the most appropriate model

The approximate space has been discussed, but it is important to find the most suitable model of lift and to check the dimensions.

## The size of lift and weight limitations

These may be crucial, particularly for adults, and children as they get older and use more sophisticated, larger and heavier wheelchairs. Care must be taken to ensure that the lift that is installed will not limit the choice of wheelchair in the future. The recommended size is approximately **1000mm** in width and **1500mm** in length (which may be a 'special' car size in the wheelchair model).

## The availability of electronic doors and the sensitivity of the switches

The lift must have electronic doors and accessible, sensitive controls to ensure that it can be operated independently, particularly in the long term when the disability may have increased.

## The position of the controls

The position of the controls and their accessibility, on the ground floor, first floor and in the lift is very important. The height of the switches and the space at either side will be crucial, and these measurements are discussed under *electrical fittings* in Chapter 15 *Adaptation Specifications*.

## Choice of lift

A number of firms manufacture or supply lifts, and individual Local Authorities tend to prefer to use one firm only, as this makes servicing and repairs more straightforward, although if the lift has been bought with a housing grant, maintenance may be the responsibility of the applicant. Two firms have frequently supplied lifts to people with neuromuscular conditions and, when exploring the options, these firms may be a good place to start. However, this does not mean that other lifts are not satisfactory, provided that they are the recommended size, travel the required height and are available with suitably-positioned, touch-sensitive controls.

Harmony wheelchair lift: *Terry Group Ltd*  
VM31/VM51 or VM36/VM56 vertical lifts: *Wessex Medical Equipment Co Ltd*

## Ground-floor extension

The questions to be answered are:

- ⇨ Is there sufficient space in the garden?
- ⇨ Can the extension be accessed from the hall or family area and (ideally) not through the kitchen?
- ⇨ Can the extension be used to provide wheelchair access into and out of the house?
- ⇨ Can the extension be used to provide wheelchair access between the house and garden?

### **Is there sufficient space in the garden?**

Is the garden large enough for a bedroom/bathroom extension of adequate size, preferably retaining access down the side of the house? One of the problems may be in getting planning permission, but many Planning Departments will look more favourably and 'bend' their rules where disabled facilities are needed. See Chapter 11 *Space Requirements*, Chapter 14 *Scales & Templates* and details in Chapter 15 *Adaptation Specifications*.

### **Can the extension be accessed from the hall or family area and (ideally) not through the kitchen?**

If the kitchen is a narrow galley kitchen, can this be widened to make access safer?

### **Can the extension be used to provide wheelchair access into and out of the house?**

In some situations, where a ramp is not possible at either the front or back door, or where a second fire exit is needed, wheelchair access to the house can be provided into the person's bedroom via French windows or a glazed door with an adjacent window. It is essential to ensure that the doors have a level-access threshold.

*N.B.* It is important to have a fire exit from the bedroom, if the kitchen (which is often the seat of the fire) lies between the extension and the rest of the house.

### **Can the extension be used to provide wheelchair access between the house and garden?**

An external door from the bedroom is also needed in adaptations where there is no other alternative wheelchair access into the garden or patio at the back of the house. However, because access to the garden is a discretionary item in the Grant, the need may have to be fully justified.

## **Making the choice between a lift and a ground-floor extension**

If the house is equally suitable for *either* a lift *or* extension the following should be considered:

### **Lift – Advantages**

These are as follows:

- ⇒ provided that the doors are wide enough, every room in the house is accessible to the disabled person;
- ⇒ the opportunity for disabled children with particular problems to sleep near their parents;
- ⇒ the carer does not need to go downstairs if the child or adult needs attention in the night.

## **Provided that the doors are wide enough, every room in the house is accessible to the disabled person**

This is likely to be essential to parents who want to be able to get into their children's bedrooms and want to maintain responsibility for the housekeeping and maintenance of the first-floor rooms. In addition, it ensures that the wheelchair user is not excluded from the different areas of family life; this may be important psychologically.

## **The opportunity for disabled children with particular problems to sleep near their parents**

This may be important to families who have a timid, anxious child or a very severely disabled toddler who needs constant attention in the night.

## **The carer does not need to go downstairs if the child or adult needs attention in the night**

This may be particularly important when either the carer is not well or the disabled person is ill and may need even more help than usual.

## **Lift – Disadvantages**

The factors to consider are as follows:

- ⇒ the space needed;
- ⇒ a person with a neuromuscular condition may not be independent in the use of a lift;
- ⇒ the possible need to use the lift to access a toilet;
- ⇒ if the disabled person is in the bedroom or bathroom and needs help, the carer has to go upstairs;
- ⇒ a lift may isolate a young person;
- ⇒ lift maintenance is expensive.

## **The space needed**

A lift takes up valuable space in a home; it is not a thing of beauty; and, although it is expensive, it is unlikely to add to the value of a house.

## **A person with a neuromuscular condition may not be independent in the use of a lift**

Having to be helped places an additional burden upon the carers; if the user is independent, the procedure in using the lift will take time. Consequently, the lift may be used only a few times during the day.

## **The possible need to use the lift to access a toilet**

Unless there is an existing wheelchair-accessible toilet (with a ceiling hoist, if needed) on the ground floor, or the space and funding to provide one, the user would have to go upstairs in the lift each time the toilet was needed.

## **If the disabled person is in the bedroom or bathroom and needs help, the carer has to go upstairs**

This may occur many times each day, and possibly at inconvenient times (e.g. while the carer is cooking a meal).

## **A lift may isolate a young person**

Teenagers often choose to spend many hours in their bedrooms and, because of the length of time taken to use the lift, (compared with the time for direct access from the family living areas into an extension), this may tend to isolate them from family activities.

## **Lift maintenance is expensive**

Maintenance of equipment provided with a grant is usually the responsibility of the applicant and this may be expensive. Social Services sometimes provide this help and this should be checked when decisions are being made.

## **Extension – Advantages**

These are as follows:

- ⇒ provides the facility of a purpose-built bed-sit;
- ⇒ allows a teenager to move freely and quickly between the family areas and their bedroom;
- ⇒ provides the convenience of a ceiling hoist on the ground floor;
- ⇒ enlarges a home;
- ⇒ provides purpose-built facilities;
- ⇒ provides a ground-floor, wheelchair-accessible toilet.

### **Provides the facility of a purpose-built bed-sit**

This is likely to be important to a teenager and, with the installation of double-swing doors, allows independent and instant access to and from the room, in a powered wheelchair.

### **Allows a teenager to move freely and quickly between the family areas and their bedroom**

This provides independence and freedom that should not be underrated. Anyone with a teenage child will confirm that often teenagers prefer the privacy of their own rooms and tend to spend much of their free time amongst their possessions. A ground-floor room provides this privacy without the tendency to become isolated.

### **Provides the convenience of a ceiling hoist on the ground floor**

Allows a ceiling hoist, installed over a bed, to be used to transfer a person from one wheelchair to another during the day, without having to go upstairs. In addition, it enables a child's easy chair with castors, which is used in the family sitting room, to be wheeled into the bedroom, in order to use the hoist for lifting in and out of the chair.

### **Enlarges a home**

An extension provides an additional facility that will add to the value of the house.

### **Provides purpose-built facilities**

A purpose-built extension is likely to provide better facilities than adaptation of existing rooms.

## Provides a ground-floor, wheelchair-accessible toilet

This will be very important in a house where there may not be an existing suitable toilet. Also, as the user will always be on the same floor as the toilet, it will be quicker to access.

### Extension – Disadvantages

These are as follows:

- ⇒ reduces the size of the garden;
- ⇒ if the child or adult needs attention in the night the carer has to go downstairs;
- ⇒ not suitable for a timid child.

### Reduces the size of the garden

Limiting the garden may be a disappointment to keen gardeners and unless the garden is large, will restrict the space for siblings to play.

### If the child or adult needs attention in the night the carer has to go downstairs

This may be a frequent problem, particularly during times of illness and chest infections.

### Not suitable for a timid child

In spite of the provision of intercoms, a timid child may not like sleeping downstairs alone and may feel anxious and isolated from the rest of the family. As a result, one or both parents may end up bringing their bed downstairs to be near their child.

### Summary

The ideal solution is a large house where there is an activities room on the ground floor and sufficient space for a lift, without having a detrimental effect on the circulation of a wheelchair. However, the majority of people live in houses in which there is insufficient space for a lift and the retrospective experience of many families is that (unless there are special circumstances) an extension is a more suitable choice for most – but not all – children. This is because it increases the wheelchair circulation space in the house and will enable children to move quickly and easily between the family areas and their hobbies in their bedroom. With the same value of hindsight, a lift is essential for adults who want to retain access to their children's bedrooms, or for housekeeping and maintenance of the rooms on the first floor.

In deciding between a lift and an extension, as can be seen, there are advantages and disadvantages to both options. The issue is one in which many people feel the need to defend their choice. The problem is that opinions will vary, not only between different families but within the same family, as the importance of the advantages and disadvantages will vary from week to week and from year to year, depending upon the individual situation or problem experienced at any particular time. The aim of this chapter is to provide information based on these factors, so that where both options are possible, each family can make the most informed choice.

# Bath vs Shower

## for children & adults with muscular dystrophy & allied neuromuscular conditions

*A guide to help disabled children, adults and their families  
make a well-informed choice*

To be used in conjunction with:

- Chapter 8a     *Equipment for Adaptations;*
- Chapter 9     *Hoisting;*
- Chapter 18    *Addresses: Manufacturers/Suppliers/Sources of Advice.*

### Factors influencing the choice

- ⇒ Outcome of the equipment assessment 2
  - ⇒ Available space 2
- ⇒ Whether the bathroom is for the exclusive use of the disabled person 2
  - ⇒ Bath – Advantages 2
  - ⇒ Bath – Disadvantages 3
  - ⇒ Level-access shower – Advantages 4
- ⇒ Level-access shower – Disadvantages 5
  - ⇒ Personal preference 5
  - ⇒ Long-term solutions 5

## Outcome of the equipment assessment

The assessment of both showering and bathing equipment is the key to the choices available. The following criteria need to be considered:

- the optimum shower/toilet chair and the person's ability to use the shower independently;
- a comparison of the ease of showering with that of bathing for both the disabled person and the carer;
- the most suitable method for getting in and out of the bath independently or with help;
- the need to provide support in the bath;
- the need to provide support on the toilet, and, if a shower toilet is needed, to ensure the support provides the optimum washing and drying facility;
- the optimum method of transfer between the bedroom and bathroom.

These issues are discussed in greater detail in Chapter 8a *Equipment for Adaptations*.

## Available space

The space within the existing bathroom should not be the main criterion unless there is no opportunity to enlarge the room. Ideally, an alternative bathroom for the exclusive use of the disabled person should be provided, if necessary by building an extension.

## Whether the bathroom is for the exclusive use of the disabled person

Where possible, facilities should be for the exclusive use of the disabled person. They are likely to be slow in the bathroom, making it impractical for sharing with others. Also, much of the equipment is specialised and not ideal for the rest of the family. It is important that the needs of all the family are considered.

## Bath - Advantages

- Bathtime for a young family can be an important playtime and social occasion to be shared with other members of the family.
- Deep water provides buoyancy and freedom of movement. This is a great advantage to anyone with no voluntary movement in their limbs. It can be the most important reason for choosing a bath for a boy with Duchenne muscular dystrophy (DMD). A bath is relaxing and soothing and can help with sleep if taken before going to bed.
- A whirlpool bath can be fitted, or a standard bath can be used with a spa bath mat and separate motor; these facilities may provide great pleasure and increased relaxation to someone who has little or no movement in their limbs. It is unlikely that this would be grant aided with a Disabled Facilities Grant or an Improvement Grant, but can be purchased privately or might be funded by a Charitable Trust.
- A bath provides the opportunity to soak, which may be important for anyone who uses a wheelchair and gets hot and sticky around the bottom, particularly in the summer. It also makes it easier for feet to be soaked.

- People with neuromuscular conditions tend to feel the cold because of their immobility and muscle wasting; immersion in hot water helps them to keep warm while bathing.
- A bath can be supplied with a chair to provide support. This equipment should be provided in advance of urgent need, to help the user to feel confident in the bath.
- Anyone who leans forwards or sideways because of spinal curvature may lack balance and feel safer in a bath than in a shower.
- Equipment is available to lift someone safely in and out of the bath and avoid dangers of lifting manually. The choice is between a Mermaid Ranger (MD model) or ASM Multi-System, or a ceiling hoist, used in conjunction with an integral seat which swings in and out of the bath and is raised and lowered electrically. In addition to children, this type of bath is a solution for adults who can transfer independently. See Chapters 8a and 8b.
- If knee contractures are likely to be a problem, the *Arjo* Sovereign baths, which provide support under the knees, are available.
- Carers are able to remain dry when helping to wash the bather.
- Carers can take their own weight on the bath rim and eliminate the need to lean forwards without support that causes back strain.
- To protect the carer's back, baths can be installed raised up from the floor or a height-adjustable model used, e.g. *Arjo* Sovereign or *Kingkraft* Easibath Hi-Lift.
- A bath can (and should) be fitted with an over-bath shower or integral showerhead providing some of the additional advantages of a shower, particularly for hair washing. At a later stage, if the person has knee contractures that make it impossible to extend the legs forwards to lower the Mermaid Ranger seat to the bottom of the bath, the bath seat can be raised and the shower used to wash the top half of the body. Alternatively, an *Arjo* Sovereign bath should be considered or, if reclining is not satisfactory, one of the other bath models with an integral seat.

## Bath - Disadvantages

- From quite an early age, children may need help to get in and out of the bath. Parents who are not ready to accept the need for specialised equipment will take a risk with their backs by continuing to lift. It is difficult to observe good lifting techniques (i.e. keeping the back straight and the knees bent) when lifting out of a bath. However, simple bathing equipment with a seat, which is lowered and raised using battery power, is likely to help at this stage and is discussed in Chapter 8a.
- A bath takes up more space than most level-access showers, and equipment such as a Mermaid Ranger can take up valuable circulation space in a smaller bathroom. The alternative of a ceiling hoist may be satisfactory for a minority of adults, but will not provide enough support for others or for a boy with DMD, unless used with a bath with an integral seat.

- If the person develops very severe knee and hip contractures and/or a spinal curvature, it may be difficult to sit in a comfortable and well-supported position on any other bath seat. The seat may have to be used higher in the water because the legs cannot be extended forwards and this means that more water is needed in the bath.
- A Mermaid Ranger (MD model) can be used to lift into and out of the bath. Although the chassis can be raised **32mm** to superimpose the seat over a shower toilet, the washing and drying action will not be as effective as it would be when sitting directly on the toilet seat. For this reason it is *not* recommended that a Mermaid Ranger and shower toilet are used together.
- Baths are considered to be less hygienic than a shower, particularly by many Asian people, and also use more water.
- Although some larger adults and older boys with DMD support themselves with the side of the bath, others may find a standard bath too constricting and need a corner bath with the installation of a ceiling hoist extending from the bedroom. However, in these cases, support in the bath must be considered and a Mermaid Ranger may be satisfactory.

## Level-access shower - Advantages

- Takes up less space than a bath, which is important where there is no alternative to using a small existing room.
- When sited adjacent to the toilet pan, the level-access area, provided it is truly level, can also be the transfer space needed at the side of the pan for positioning a wheelchair.
- When not in use, the shower area increases the circulation space in the bathroom.
- A shower may help maintain independence where the user is able to walk or propel a shower chair, but is unable to get in and out of a bath without help. This can be the most important reason for choosing a shower for those expecting to remain independent in the foreseeable future. Assessment of an electrical height-adjustable shower seat is recommended for anyone able to walk, but having difficulty getting up from the seat (see Chapter 8b).
- Showering is likely to be quicker than having a bath.
- Showers are considered more hygienic than baths, and more economical as they use much less water.
- When showering a child, you can get in with them and create a 'fun' time.
- People of some faiths, including Hindus, Muslims and Sikhs, wash in running water.

## Level-access shower - Disadvantages

- Leaning over a waist-high shower screen can be difficult for a helper and reaching down to wash the bather's feet is impossible. The alternative may be a waist-high rail with a short shower curtain, but this will not keep water within the shower area as satisfactorily.
- People with neuromuscular conditions often complain of feeling cold in a shower, particularly if they are not independent and are unable to move under the spray.
- It is impossible to have a good soak and it is more difficult for a carer to wash the bottom of a bather who is sitting in a shower chair.
- Some older boys with DMD dislike the pressure of the water on their body.
- Some adults with muscular dystrophy may be able to wash independently in a bath, but unless the height of the shower seat can be adjusted electrically, they have difficulty in washing their feet in a shower.
- Some types of floor construction can make a level-access shower impossible and/or expensive to install.

## Personal preference

It is important that the individual person or the family make the choice, having had the opportunity to discuss all the issues involved.

## Long-term solutions

The difficulty with many neuromuscular conditions is that their progressive nature makes it not always possible to choose one method of bathing suitable in the long term. The ideal answer would be a bathroom large enough to accommodate both a bath *and* a level-access shower area. Although Housing Associations who provide purpose-built accommodation may choose this option, grants officers and community OTs may not agree that the space needed for dual installation is justifiable. However, it is worth noting that the "*purposes for which an application for a Disabled Facilities Grant must be approved*" include "*a room in which there is a bath or shower (or both)*". See Chapter 12 *Funding*. An alternative is to ensure that the space allocated for the shower is sufficient to accommodate a bath in the future, and vice versa. Thus the option can be changed with an additional grant that is justified on the grounds of changing needs. Conversely, the practicality of installing a bath over a floor area prepared for a shower can be considered. If a shower is needed in the future, the only cost involved is that of removing the bath and either tiling the floor or installing a shower tray.

Readers will be aware of the difficulties of offering advice without knowing the personal preferences and circumstances of everyone involved. Feedback on any of the above would therefore be appreciated.

# Equipment for Adaptations

## for children & adults with muscular dystrophy & allied neuromuscular conditions

### *A guide to the equipment to be considered when planning adaptations*

To be used in conjunction with:

- Chapter 4      *Assessment of Need;*
- Chapter 10    *Disability Needs Assessment Form/Architect Brief;*
- Chapter 11    *Justification for Funding;*
- Chapter 12    *Funding/Understanding the Grant Systems/VAT;*
- Chapter 15    *Adaptation Specifications;*
- Chapter 18    *Addresses: Manufacturers/Suppliers/Sources of Advice.*

## Introduction

When planning adaptations for people with a neuromuscular condition, a number of items of specialist equipment should be considered. All the equipment in this manual has been included because it influences decisions relating to the adaptations, it needs to be plumbed in or installed, or it involves the provision of adequate space. In every case, the alternatives must be assessed before the final brief is given to the architectural designer.

The discussion is included under the following headings:

- ⇒ Providing access into the house & to the first floor 2
  - ⇒ Equipment in the bathroom 5
  - ⇒ Equipment in the bedroom 22
- ⇒ Justification of funding of equipment 24
  - ⇒ Equipment in the kitchen 25
    - ⇒ Ordering equipment 25
    - ⇒ Environmental controls 26
- ⇒ Providers & funding of equipment, adaptations & services 28

## Providing access into the house and to the first floor

A number of items of equipment may have to be considered, as follows:

- ⇒ short-rise lift;
- ⇒ Steplift;
- ⇒ portable ramps;
- ⇒ automatic door opener;
- ⇒ lift.

### Short-rise lift

This type of lift may be needed where there is a very steep approach to a house (particularly from the pavement) and there is insufficient space for a ramp. A number of firms produce short-rise lifts that overcome heights of up to **1000mm** and their specifications in relation to the cost should be compared. One suggestion is given below.

*The Ultimate Lifting Platform LP1000: Wessex Medical Equipment Ltd*

### Steplift

There are situations where it is impossible to build a ramp of the correct gradient, either because there is insufficient space or because the garden is too steep. In these instances, access to the house can be provided by installing a Steplift and the model discussed has been well tried and tested over a number of years. This consists of a platform (with safety rails and a folding front ramp) which rises hydraulically, with the standard model overcoming any height up to a maximum of **1000mm**. Bridging options for up to 3 treads are available, if necessary.

The platform, which is **1400 x 800mm**, is large enough for most wheelchairs and has a lifting capacity of **250kg**. However, the size of the platform can be increased by special order. A number of safety features are included and the unit is suitable for outdoor use, with in-built protection for the electrical unit and against corrosion.

*Terry Group Ltd*

### Portable ramps

In the context of an adaptations manual, the purpose of including portable ramps is to overcome difficult access into a house, usually as a temporary measure until adaptations have been completed or suitable housing has been found. However, there are also houses fronting straight on to the pavement where there is insufficient space for a ramp, short-rise lift or Steplift.

Portable ramps have improved considerably in recent years as they are manufactured in lightweight aluminium or fibreglass, which makes them easy to handle and fold either into one-half or one-third of their length. The choice is between channel ramps of between **150** and **250mm** width and full-width ramps. Channel ramps are usually easier to carry and store; however, if the disabled person needs to be pushed up the ramps and the carer is small, it can cause great strain on the carer's lower back because of the height involved. A wide ramp, where the carer walks up the ramp, makes this manoeuvre easier; however, this has to be offset against the fact that the ramps are more cumbersome and difficult to handle.

Various sizes are available and the length needed will depend upon the height of the steps to be bridged; as a rough guide this is likely to be a gradient of between **1 in 4** and **1 in 8**. However, the maximum and recommended heights and weights that are suitable for each ramp must be discussed with the manufacturer or supplier. There are many suppliers of ramps and the following are two suggestions:

*Portaramp/Division of Trident Industrial Ltd  
Thorworld Industries Ltd*

## Automatic door opener

The inability to open either the front or back door is very limiting to anyone wanting independence and can result in a disabled person becoming housebound. There is little value in being supplied with an indoor/outdoor powered wheelchair to increase independence if you then have to ask for help to open the door to get out of the house. In the past, supply of an automatic door opener has been limited to a disabled person living alone; however, now that disability needs are better recognised, these should be considered to increase the independence of *all* disabled people, including children, and particularly those who are old enough to be left in the house on their own.

Although automatic doors are widely used in commercial situations, the choice of domestic models is limited. However, there are a number of features and options that need to be discussed and considered either before or at the time of the assessment/choice of model, as follows:

<b>Comparative chart of features of automatic door openers</b>			
	Abloy from <i>RSL Steeper Ltd</i>	Spectra from <i>Southern Care Systems Ltd</i>	R.F. Door opener from <i>Ridley Electronics Ltd</i>
Door can be opened and closed manually when the opener is not activated electrically.	✓	✓	✓
'Finger protection' is installed along the hinged side of the door (as recommended by British Standard guidelines where doors are opened automatically and manually).	✓ as standard	✓ as optional extra	✓ as optional extra
Model suitable for standard opening and/or sliding doors.	standard only	standard only	standard & sliding
Model suitable for wood, aluminium & uPVC doors. (The latter usually supplied with multi-point locking, which may have to be opened manually in the morning and door closed with single lock.)	✓ including multi-point locking	✓ depending on locking system	✓ depending on locking system
Wide range of handset options.	✓	✓	✓
Operated by choice of push-button, infrared or radio controls.	✓	✓	✓
Speed of opening is automatically set, but time delay before closure can be altered to suit individual needs.	✓	✓	✓
Ability to detect a temporary obstacle & stop.	✓	✓	✓
Ability to distinguish between a temporary obstacle & the resistance of weather-proofing seal on the door frame.	✓	✓	✓

<b>Comparative chart of features of automatic door openers (cont.)</b>			
	Abloy from <i>RSL Steeper Ltd</i>	Spectra from <i>Southern Care Systems Ltd</i>	R.F. Door opener from <i>Ridley Electronics Ltd</i>
Weather-proofing seal compresses for the first half-second of the opening cycle to take pressure off the electric latch release, to enhance reliable operation.	✗	✓ as standard	✓ as optional extra
Advice available to choose optimum position for 13amp fused-spur, power source.	✓	✓	✓
Battery back-up for use in a power cut & as safety feature in the event of fire.	✓	✓ as standard	✓ as optional extra
Can be linked to door intercom & environmental control.	✓	✓	✓

If this equipment is not essential at the time that the adaptations are carried out, and if funding is tight, the fused spur should be installed to avoid affecting the decorations in the future, with the installation delayed until necessary, and then funded either through a subsequent housing grant or with help from a voluntary charity.

## Lift

A number of factors need to be considered when a lift is being chosen, and these have been included in Chapter 6 *Lift vs Extension*.

A telephone in the lift in case of lift breakdown may give a greater feeling of security for people using a lift when alone in the house. Phones may be an integral part of the lift, although mobile and cordless phones may make this safety feature more straightforward.

The model chosen must be large enough for any wheelchair likely to be needed in the future and able to take the weight of the chair and occupant. For this reason, the 'special' car size or the largest wheelchair lift are recommended, but there may be situations where the most appropriate position for the lift is too small and alternative options may need to be considered.

## Vertical wheelchair lifts

A number of firms manufacture or supply lifts, and individual Local Authorities (LAs) tend to prefer to use one firm only, as this makes servicing and repairs more straightforward, although maintenance of the lift is usually the responsibility of the grant applicant. Two firms have frequently supplied lifts to people with neuromuscular conditions and, when exploring the options, these firms may be a good place to start. However, this does not mean that other lifts are not satisfactory, provided they are the recommended size (see Chapter 6 *Lift vs Extension*).

Harmony wheelchair lifts: *Terry Group Ltd*  
VM31/VM51 or VM36/VM56 vertical lifts: *Wessex Medical Equipment Co Ltd*

## Equipment in the bathroom

Decisions to be made in relation to the choice of bathroom equipment are as follows:

- ⇒ bath vs shower;
- ⇒ level-access shower;
- ⇒ bath with an over-bath shower;
- ⇒ the need for a changing table;
- ⇒ body dryers;
- ⇒ the most suitable toilet;
- ⇒ essential washbasin features;
- ⇒ flooring.

### Bath vs shower

The first decision to be made is whether a bath with an over-bath shower, or a level-access shower, is the more appropriate. Personal choice will be very important; however, from a disability point of view, as a very rough guide, if you are independent in a shower but not in a bath, a shower is likely to be the better solution. With this exception, most people with a muscle problem feel that a bath is more satisfactory as it provides the opportunity to relax tired and aching muscles, and the depth of the water provides buoyancy to limbs which might otherwise have difficulty in moving.

A helper usually finds it is less of a strain on their back to assist with washing, by kneeling at the side of a bath and taking their weight on the bath rim, rather than leaning over a shower screen or trying to keep dry behind a shower curtain. It is also very difficult to wash a dependent person's feet and the lower part of their body in a shower, without getting into the shower with them.

A separate chapter is included in the manual itemising the issues that need to be considered. This should be read and discussed, and the relevant equipment demonstrated and assessed, before a decision is made.

### Level-access shower

The issues to be considered are:

- ⇒ standing or sitting use;
- ⇒ wall-mounted rails;
- ⇒ wall-mounted seat or a mobile shower chair;
- ⇒ most appropriate type of shower base.

### Standing or sitting use

Many people opt for a shower because they can walk; and having a shower while standing is easier than getting into a bath. For anyone likely to be able to continue standing, this may be the best solution; however, for many people with a neuromuscular condition, standing may not be very safe, and using a wall-mounted seat or shower chair should be considered. However, if the shower is to be used standing, the use of rails and their positioning will be important.

## Wall-mounted rails

Rails can be wall mounted or floor mounted; the former are recommended as they do not obstruct the circulation areas. Most people with a neuromuscular condition have insufficient arm strength either to pull with their arms or to push down, to help themselves to stand up; consequently, rails will have very limited value and are more often considered to be in the way. However, in a shower area they may be useful if positioned for an elbow to rest on when hair washing and to provide support, particularly around a room for someone unsteady on their feet. Because rails might be considered unsightly in a living area, furniture or even the wall will be used for support; however, in the bathroom, rails will be more appropriate, particularly if the user has bare feet and safety would otherwise be jeopardised.

The appearance of rails in this situation has improved enormously in recent years and two possible ranges have been included in this manual. If rails are needed, their height and position will be critical to each individual and should be assessed carefully.

Neaco Support System: *Go Independent*

Multi System with hand rail or support arms and wall-mounted rails: *Pressalit Care Ltd*

## Wall-mounted seat or a mobile shower chair

This information covers:

- ⇒ the factors to be considered;
- ⇒ electric, height-adjustable, wall-mounted shower seat;
- ⇒ mobile toilet/shower chair/cradle.

### The factors to be considered

The decision will be influenced by the ability to walk, the ability to stand up from a chair and whether the person has sufficient arm strength to propel a shower chair. The difficulty of a wall-mounted seat is that, if it is installed at the correct height for standing up, it will be too high to get down to wash the feet; however, if a shower chair is used, how does the user stand up from the chair? These difficulties are shared by many adults, resulting in the need for height adjustability.

### Electric, height-adjustable, wall-mounted shower seat

The answer is an electrical height-adjustable seat which rises sufficiently for the user to stand up and yet can be lowered near enough to the floor to allow the bather to sit with their feet firmly supported on the floor and their forearms supported on their thighs, and also enables the bather to be able to get down to wash their feet. The seat should have a supportive backrest and arms that project beyond the front of the seat to provide support when standing. See Chapter 8b '*Seat to Standing*', page 6.

SC.EL: *Astor-Bannerman (Medical) Ltd*

Multi System shower seat and support arms: *Pressalit Care Ltd*

### Mobile toilet/shower chairs/cradle

The choice is between:

- ⇒ Aquability/Freeway, toilet/shower chairs;
- ⇒ Sutton Shower Cradle.

- **Aquability/Freeway, toilet/shower chairs**

These are the two models that are particularly recommended as they are modular chairs that are available in alternative frame sizes, and have a detachable front arm and choice of backrest, footrest and seat. They can be supplied with straight and splayed side arms, to either increase the seat width or provide trunk support. When the assessment is carried out, the chair should be built up around the person to ensure that the correct support is achieved. If necessary, the frame and armrests can be manufactured to a specific height and made-to-measure models are available.

Aquability: *ASM (Accessories) Ltd*  
Freeway: *Westholme Ltd*

- **Sutton Shower Cradle**

This is recommended for anyone who needs more trunk support than is provided with either the Aquability or Freeway chairs and is supplied in three standard sizes with the option of a seat aperture. It may be necessary to alter the specifications of this chair to suit the individual user and made-to-measure models are available.

*ASM (Accessories) Ltd*

### Most appropriate type of shower base

The choice depends on:

- if the shower is to be used independently;
- if the shower area is adjacent to the toilet and needs to be used for positioning a wheelchair for sideways transfers on to the pan;
- the need for help from a carer.

The choice is between:

- ⇒ Neatdek;
- ⇒ shower trays;
- ⇒ sloping tiled floor.

#### Neatdek

In the first two situations the priority is not only to have a wheelchair-accessible shower but also for the floor of the shower to be absolutely level. The conventional tiled floor that slopes to a drain outlet is not recommended, because any gradient is difficult for anyone with a neuromuscular condition either to walk up or to propel a shower chair up – and it will be essential for the floor to be level so that the wheels of the wheelchair are stable to ensure safety while transferring. The answer is to install a Neatdek, which is an attractive and truly level-access shower grille. One of its advantages is that the water drains across the whole shower area and the grille can be supplied in a variety of sizes, depending on whether the floor is concrete or wood. The largest size is a replacement for a bath, which is a good recommendation if a bath is needed in the future. The grille is usually nylon coated in a choice of white, beige or red. The Neatdek is supplied with a lever to lift up the grille for cleaning and the Cambridge model which is now available for concrete floors is manufactured in four parts to make this easier.

*Go Independent*

## Shower trays

It is recommended that the largest shower tray that is possible in the space available is used and if a bath is likely to be needed in the future, a bath-replacement tray should be installed. If the proposed shower is for an existing room, site surveys can be arranged.

A number of trays are available from different firms and several ranges of level-access trays that are widely used, and are very satisfactory, are recommended.

Level-entry trays (a range of 39 different sizes below and above floor level): *Autumn Mobility Ltd*  
Impey Level-Dec: *Creative Healthcare Ltd*  
Dove, ESL and Chiltern Invadex ranges: *Go Independent*

## Sloping floor

If the shower is to be used with help, a sloping floor will be satisfactory, provided that it is laid properly and water drains away satisfactorily. Unfortunately, experience shows that this work needs to be supervised to ensure that the gradient is introduced competently without being extreme (thereby creating difficulty in pushing the shower chair) and to ensure that the water is contained within the shower area.

## Bath with an over-bath shower

The main factor in choosing a bath instead of a shower is to enable bathers to relax their muscles in the warm water while keeping warm and enjoying the buoyancy. When an assessment is carried out, it is important to clarify the issues in relation to bathing that are important for people with neuromuscular conditions and also to be familiar with the alternative equipment to provide the solutions.

In addition, there are three interdependent issues to be considered in relation to the use of a bath and movement between the bedroom and bathroom. These are:

- safety for the bather in the water;
- eliminating manual lifting in and out of the bath;
- ease of transfer between the bedroom and bathroom, for both the disabled person and the carers.

These priority issues need to be considered in relation to the other factors that influence the choice between a bath and a shower, and these are listed below in the order in which they should be discussed. It is then necessary to consider:

- the length of time for which this solution is likely to be satisfactory;
- the effect of the choice of equipment on the rest of the family.

Therefore, when carrying out the assessment, the following issues need to be resolved:

- ⇒ the support in the bath, needed now or in the future to ensure safety;
- ⇒ the ability to move limbs and enjoy the buoyancy of the water;
- ⇒ ease of washing or being washed;
- ⇒ how to get in/out of the bath (preferably independently), and how the alternative equipment to provide support influences the process;
- ⇒ the method of transfer between the bedroom and bathroom;
- ⇒ whether the method chosen is likely to be a short-term or long-term solution;
- ⇒ whether the facilities are exclusively for the use of the disabled person or to be shared.

## The support in the bath, needed now or in the future to ensure safety

This is the crucial decision to be made, as safety is obviously the first priority. The inability to support yourself, with the result that you feel that you are going to float forwards, is very distressing. Bathtime is a useful playtime for a child; if a method is to be found for a child to be left to play safely without constant supervision, the parents must have complete confidence in the equipment. Unless the bather gains support from the side of the bath, a supportive seat will be necessary, with arms to lean on to provide trunk control.

The choice of equipment to provide the correct support is limited and there are seven alternatives, as follows:

- ⇒ vacuum support cushions;
- ⇒ *Kingkraft* Easibath Hi-Lift;
- ⇒ *Kingkraft* Contour;
- ⇒ Oxford Mermaid Ranger;
- ⇒ *ASM* Multi-System;
- ⇒ *Arjo* Sovereign;
- ⇒ *Arjo* Solo bath (or similar model).

### Vacuum support cushions

These systems consist of waterproof-covered shaped cushions filled with beads which, when the air is extracted, become rigid enough to provide support. A number of shapes are available and they can be used in conjunction with a ceiling hoist. Although useful for small, floppy children in an Easibath (see below), this option is not usually recommended for people with neuromuscular conditions in a standard bath as there are problems in providing enough support and yet allowing access to wash and sufficient freedom of movement to enjoy the buoyancy of limbs in the water. In addition, many bathers want the hoist sling removing in the bath, with the subsequent difficulties for the carer to reposition the sling while leaning over the bath with a rotated spine. This is a difficult manoeuvre as it is impossible to maintain the advice to bend the knees and keep the back straight, when reaching into the bottom of the bath.

Support cushions: *Kingkraft Ltd*

### *Kingkraft* Easibath Hi-Lift

This model is particularly suitable for small, floppy children because it combines a supportive bath with a shower platform and a changing table – and there is the opportunity to have a spa facility. Although the bath depth is standard, the length (up to **1970mm**) or width (up to **970mm**) can be made to fit the space available.

The unique fold-down side of the bath is level with the seat height of a standard wheelchair, which will help with transferring a child, if initially, a ceiling hoist is not used. The manual or powered height adjustability allows individual carers to work at the optimum level for their back. The shape and design of the cushioned, internal supports can be made to measure and redesigned when necessary.

The option of twin wastes is recommended to allow the water to drain quickly so that the child can be dried and dressed without feeling cold.

Advice with plumbing and electrical specifications is offered.

*Kingkraft Ltd*

### **Kingkraft Contour**

This model provides the same facilities as the Easibath, but is deeper and the internal space is larger, without increasing the overall length or width. Aesthetically it may be preferred to the Easibath.

*Kingkraft Ltd*

### **Sunrise Medical Mermaid Ranger**

This bath hoist consists of a pillar installed at either the end or (more usually) the side of the bath, to which the seat is attached, prior to winding a handle and lifting the seat into the bath. Winding this handle at the top of the pillar is strenuous and particularly difficult for small carers (and especially for those mothers of boys with Duchenne muscular dystrophy (DMD) who are manifesting carriers). Therefore, it is very pleasing that the Ranger is available with an electric motor, which can be bought as an 'add on' unit for existing models. In the future, it is recommended that it is always supplied with this motor.

The advantage of the seat is that it is comparable to a toilet seat, which usually makes it comfortable, particularly as it should always be supplied with a padded seat and backrest. If additional padding is needed, a *Sumed* bath or commode cushion can be superimposed. If the seat aperture is too large for small children, the size can be reduced with a *Mothercare* Softee Trainer seat, placed under the padded seat.

*Sumed International (UK) Ltd*

*Mothercare Ltd*

The Mermaid Ranger footrest has always been height adjustable if the MD model was ordered, but this is now available as standard. However, if an existing unit is supplied from the Social Services stock, it must be checked that the footrest is suitable.

The Mermaid Ranger hoist is supplied with a chassis that is invaluable as a means of moving between the bedroom and bathroom and to provide support over a toilet. However, the Mermaid Ranger is not recommended if a shower toilet is to be used initially or in the future. This is because if it is superimposed over a shower toilet, the chassis has to be raised **32mm**, with the subsequent compromise of the washing and drying action which is discussed on page 17. A ceiling hoist used with the shower toilet is more satisfactory, as the user sits directly on the seat. It then becomes necessary for a supportive frame to be used, (see also page 17).

Bathers who subsequently develop knee contractures, which prevent their legs from being extended forwards, will be more comfortable with the seat raised up from the bottom of the bath. However, the disadvantage is that the depth of water covering the bather will be reduced. It will then be necessary to install a shower unit over the bath which will be useful also for hairwashing, and essential for anyone who needs to shower rather than use a bath, for religious reasons. Ideally there should be space at the end of the bath to enable a helper to reach a shower, wall-mounted at the side of the bath - with the bonus of being able to move freely behind the bather.

This equipment was first recommended about 10 years ago and although it has proved invaluable for many boys with DMD in the early stages, it is not often a long-term solution. With the passage of time, some larger boys have found it too constricting and others have found that it does not provide the support that is needed. In the latter case there is the advantage that, with the supply of a new mast arm, the Mermaid Ranger can be exchanged for the *ASM* Multi-System.

One of the advantages of this equipment is that it can be used with a standard bath and a Jacuzzi bath mat (see next page). For anyone who lacks trunk stability, the need for a supportive seat is important, as the spa bubbles may affect the bather's ability to balance.

*ASM (Accessories) Ltd*

*Daily Care Ltd*

- **Ozomatic Hydrotherapy Unit (Jacuzzi bath mat)**

Many people with muscular dystrophy have gained a great deal of enjoyment and pleasure from these mats (or a spa built into an *Arjo* Sovereign bath). Although they have no proven medical benefit for anyone with a neuromuscular condition, the effects of the buoyancy and stimulation caused by the pressure from the bubbles may help muscle relaxation. It is important to stress that, initially, the unit must be used on a low setting, for less than five minutes, so that the bather can assess the effect on their body before building up the pressure and the time span used. The firm is offering a substantial discount to anyone with muscular dystrophy and will demonstrate the unit in the home.

*Scan Mobility Ltd*

### **ASM Multi-System**

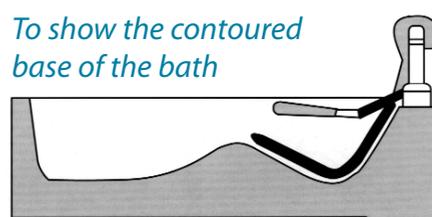
This seat offers excellent support and is very suitable for smaller children who cannot sit upright in a bath and for teenagers who have been using the Mermaid Ranger but have subsequently lost weight and it no longer provides the support needed. The ASM Multi-System can be placed in the bath using the same mast as the Mermaid Ranger (with a replacement arm) or alternatively using straps to attach it to a ceiling hoist. In either case the cradle will need to be used in conjunction with a mobile chassis either to move between the bathroom and bedroom or to support the cradle while a hoist sling is used to lift the child or young person on to the bed. The cradle is available in three sizes, but where necessary can be made to measure. The frame allows the seating angle to be changed so that, in a more upright position, with an aperture in the mesh, it can be used to provide support on the toilet.

*ASM (Accessories) Ltd*

### **Arjo Sovereign bath**

Many bathers prefer to recline, in which case the *Arjo* Sovereign baths are ideal and there are many features that make these baths particularly suitable for people with neuromuscular conditions, as follows:

- the baths have an integral seat which lowers into the bath and raises out of the bath electrically;
- the arms of the seat provide good support particularly as they extend in front of the bather;
- because the seat reclines as it lowers into the bath, the resting position takes full advantage of the depth of the water;
- the seat incorporates an excellent head support which is necessary for anyone who has had a spinal fusion, or has difficulty in controlling their head;
- the base of the bath has a raised central contour which provides support to anyone with knee contractures and prevents the bather from floating forward;
- in the past there has been the option of electrical rotation of the seat, which is recommended for people with a neuromuscular condition because it will provide an opportunity to increase independence and where necessary, make it easier for the carer to lift the legs over the bath rim. In future models, hopefully, this facility might be available again;
- when the bath is used in conjunction with a ceiling hoist and as the seat swings out of the bath above the rim, the seat is at the correct height for the carer to remove, or reposition the ceiling hoist sling.



There is the choice of three models, as follows:

- **Sovereign Standard:** The standard model in which the bath rests on the floor with a rim height of **610mm**. This model enables the carer to kneel at the side of the bath and support their trunk against the bath and their arms on the rim.
- **Sovereign Fixed Height:** The bath is raised up on small legs so that the bath rim is at a height of **840mm**, making this model a better choice for any carers who are unable to kneel at the side of the bath.
- **Sovereign Hi-Lo:** This model moves up and down electrically from rim height **615 - 960mm**, so that the bath is at the correct height to prevent the need for the carers to stoop and for bathers to transfer in and out of the bath. The additional cost will be justified in a multi-use situation where there will be the varied needs of each individual and their carers to consider.

Justification for the funding of these baths is included in Chapter 11c.

*Arjo Ltd*

### **Arjo Solo bath (or similar model)**

A number of firms manufacture baths that have integral seats that swing into and out of the bath (some with powered rotation) and can be raised and lowered electrically into the bath. The seat should pivot from the corner of the bath, so that it projects as far as possible from the side of the bath to ease the process of transfer; the bath should be a model that has the maximum range of seat-height adjustment. This may be essential for achieving the height needed to stand up; eventually, the minimum height may be of equal importance to ensure that a sliding downhill transfer can be achieved from a wheelchair that may not have a height-adjustable seat.

With the exception of the *Arjo* Sovereign, all these baths have a seat that supports the bather in an upright position; for many adults this may be the ideal sitting position to enable them to lean forward to wash.

*Arjo Ltd*

Having established which equipment will ensure safety, it then needs to be considered in relation to the other important issues listed on page 8.

### **The ability to move limbs and enjoy the buoyancy of the water**

Buoyancy is particularly important to anyone with restricted movement of the limbs and can be therapeutic to aching arms and legs to help to relax the muscles and relieve cramp; this feeling of well-being can be enhanced by a whirlpool or spa facility. Many boys with DMD find it easier to do their physiotherapy exercises and stretches after a long soak in a bath. However, the buoyancy will be restricted by the use of a hoist sling and it is therefore important for the bather to be well supported so that the sling can be removed (preferably before the bather gets into the bath) or loosened while in the bath. The spa facility can be built into the bath, as in the *Arjo* Sovereign bath, or supplied with the use of a jacuzzi bath mat with a separate motor. This alternative has been discussed on the previous page.

### **Ease of washing or being washed**

The sitting position of an adult can be crucial; some people need to sit upright to gain full function in their arms; others who are not able to be independent may find it easier to be washed when reclining. This makes the choice of bath important, and is discussed above and on the previous page, in relation to the *Arjo* baths. It is not satisfactory to leave a ceiling hoist sling in position, as this will make it difficult to gain access to wash.

## How to get in/out of the bath (preferably independently), and how the alternative equipment to provide support influences the process

The options are as follows:

- ⇒ using portable equipment;
- ⇒ using installed equipment to increase independence;
- ⇒ using equipment to help the carer.

### Using portable equipment

If the bather does not need support in the bath, is it possible to get in and out of a standard bath independently, or will simple portable bathing equipment be adequate to make this possible? Such equipment consists of bath seats that can be raised and lowered between the bottom of the bath and the bath rim. The choice is not covered in this manual, as it does not affect the provision of an adaptation; however, it may be a useful ‘stop-gap’ solution while waiting for adaptations to be carried out.

### Using installed equipment to increase independence

If help is needed to get in and out of the bath, can independence be restored or maintained with the use of a specialist bath? It is always important to try to provide equipment that the disabled person can use independently, at least initially and, if possible, that will also be suitable for use with a carer in the longer term.

Of the equipment included, the specialist baths will be ideal for increasing independence in getting in and out of the bath for both children and adults who are still able to walk. An *Arjo* Sovereign bath (see page 11) may appear to be unnecessarily sophisticated for a boy with DMD who can still walk and the suggestion may be made to delay the supply. In fact, the reverse is true, as this bath will maintain his independence in getting in and out until he is unable to walk with bare feet, but even at this stage it will make it easier for his parents to help him.

### Using equipment to help the carer

If help is needed, how will the carer lift the bather out of the bath without involving lifting manually? This must be with either a ceiling hoist or a bath seat like the Mermaid Ranger that lowers on to a chassis. If a ceiling hoist is used in conjunction with an integral seat, as in the *Arjo* baths, the sling is much easier to position as helpers can work at the correct height for their backs.

## The method of transfer between the bedroom and bathroom

The choice is between the following:

- ⇒ using a wheelchair;
- ⇒ using wheeled bathing equipment;
- ⇒ on an extended track of a ceiling hoist.

### Using a wheelchair

This is not a satisfactory option, apart from when the toilet is needed, and there is insufficient time to hoist the person on to the pan – or when using the washbasin. Two separate tracks in the bedroom and bathroom, using the wheelchair in between, is not a recommended option – raising and lowering the bather from the wheelchair is time consuming and necessitates readjusting the person’s sitting position each time.

## Using wheeled bathing equipment

There are two options:

- a shower chair, self-propelled or pushed by a carer (this has already been discussed on page 6 in relation to a level-access shower);
- a bath seat on a wheeled chassis, e.g. a Mermaid Ranger or an *ASM Multi-System* which were discussed on pages 10 and 11.

## On an extended track of a ceiling hoist

This option is discussed in Chapter 9 *Hoisting*. It is particularly satisfactory when used with a bath with an integral seat (e.g. an *Arjo Sovereign* or an *Arjo Solo* bath, or another similar model), which makes the process of putting on the sling and taking it off very straightforward for the carer. It allows the carer to work at the right height for their back and keeps the sling dry, as it is taken off before the bather enters the bath. A ceiling hoist eliminates the need for a bulky mobile hoist that may be a problem to store (particularly when a bathroom is used by the rest of the family).

## Whether the method chosen is likely to be a short-term or long-term solution

The aim should be to provide a long-term solution and in 90% of cases this will be possible; however, as many of the conditions discussed in this manual are progressive, a solution at an initial stage may not always be appropriate several years later. The progression of the disability in most neuromuscular conditions is stereotyped, but the finer details – such as the degree of knee contractures, the weight gain or loss and the shape of the spine, and therefore the ability to balance – will not be known and may influence the future success of equipment. Nevertheless, this is no excuse for not trying to achieve the ultimate solution; but rather a justification for possible failure!

## Whether the facilities are exclusively for the disabled person or to be shared

The aim should be to provide en-suite facilities, as discussed fully in Chapter 4 *Assessment of Need*. However, whether the disabled person has exclusive use of a bathroom may influence the choice of equipment. Where en-suite facilities are to be provided, unless the existing bathroom is to be used, the facilities are usually for the exclusive use of the disabled person, as partners and the rest of the family can use the house bathroom. However, in bungalows, or when a lift has been installed in a house and therefore the disabled person has access to the bathroom, it is often felt to be adequate for the disabled person to have to travel across the hall or landing to go to the bathroom. Alternatively the en-suite facilities may be provided by installing an additional door between a bedroom and bathroom and retaining the existing door from the hall or landing, so that the bathroom can still be used by the rest of the household. Neither is ideal or recommended, because of the lack of privacy, the length of time that the disabled person is likely to take in the bathroom and because the equipment provided may not be suitable for the rest of the family.

If a lift is installed, ideally there should be a wheelchair-accessible toilet on the ground floor, because it is a real hassle for a disabled person to have to use the lift each time; a ground-floor toilet has the additional advantage of being available for the rest of the family and partially overcoming the difficulties ensuing from the length of time taken in the bathroom by the disabled person. The exclusive use of en-suite facilities for a disabled person in a house where a lift has been installed is rare, as few houses are large enough for two bathrooms on the first floor; however, this may be a compromise that is necessary where the choice is for a lift, rather than a ground-floor extension. See Chapter 6 *Lift vs Extension*.

## The need for a changing table

There are a few houses in which it is structurally impossible to provide en-suite facilities because the rooms cannot be reorganised internally and because there is insufficient space in the garden to build an extension. In these unusual circumstances only, an alternative may be to provide a changing table within the bathroom, on which the disabled person can be undressed prior to bathing - and subsequently dried and dressed.

The most satisfactory type of changing table has the following features:

- ⇒ height adjustment;
- ⇒ an adjustable, elevating backrest.

### Height adjustment

This simulates an electric bed with a high/low facility to allow the surface to be placed at the optimum height for carers in order to protect their backs.

### An adjustable, elevating backrest

This will allow the disabled person to be supported in the most comfortable sitting position when this is easier for dressing.

### Recommended models

There are a number of options, including the following models:

- CT120/CT150 Child's changing table
- CT190 Adult-sized changing and showering table.  
These models are powered and have a height adjustability of **800mm**. The adult model travels from **150 - 950mm** and the child's can be mounted at the most suitable height for the carer. Both are wall mounted with the adult model gaining additional support from the floor.

*Astor-Bannerman (Medical) Ltd*

- Linido hinged showerstretcher. The stretcher is hinged on the wall and lowers on to folding floor supports. The mild steel frame can be supplied coloured at no extra cost and special modifications are available.

*Otto Bock UK Ltd*

- Shower bench. This can be powered or installed on the Multi System (see Chapter 17 *Multi-use Facilities*).

*Scanflex Ltd*

*Southern Care Systems Ltd*

*Pressalit Care Ltd*

## Body dryers

Many people who have been towel dried by a carer following bathing never feel completely dry, and would prefer the privacy of drying themselves. An additional advantage of the dryer is that it doubles up as a booster heater for the bathroom.

### Apres Shower Body Dryer/heater

The advantage of the Apres Shower Body Dryer is that its height and length ensure that the warm air reaches every part of the body. The dryer is controlled by an air-pressure switch that can be mounted in the optimum position for the user, which is likely to be at a height and position similar to that of a light switch (see Chapter 14 *Scales and Templates*).

*Apres Shower Dryers Ltd*

*Go Independent*

*Total Hygiene Ltd*

## The most suitable toilet

In making decisions in relation to the most suitable pan, the choice will be influenced by the age and size of the user, their ability to balance and their ability to clean themselves. There are three solutions:

- ⇒ infant toilet;
- ⇒ low-level cistern with a long flush pipe;
- ⇒ shower toilet.

### Infant toilet

Usually, the only situation in which infant toilets are fitted is in schools where children of a particular age will be using the pan. However, many young children would find a smaller pan at home a great help, both in balancing and in getting on and off the pan. Installation will depend upon three factors:

- whether the child is using the same bathroom as the rest of the family;
- the success of the alternative of a toilet-trainer seat (e.g. Softee Trainer) to reduce the size of the seat hole on a standard pan and a Step Stool (both from *Mothercare Ltd*);
- whether a superimposed chair or frame is a better and longer-term solution for a child who is likely to have difficulty in balancing.

### Low-level cistern with a long flush pipe

This type of pan has an inlet pipe between the cistern and the pan and is not close-coupled. The importance of the inlet pipe is that the pan can be installed sufficiently far forwards from the cistern to allow a chair to be superimposed over the pan, with the chair seat correctly lined up with the bowl underneath (see Chapter 15 *Adaptation Specifications*).

*Twyford Ltd*

### Shower toilet

There are a number of issues to be considered in relation to this specialised equipment:

- ⇒ the purpose of the shower toilet;
- ⇒ use with a superimposed toilet chair;
- ⇒ MD toilet frame;
- ⇒ use with a ceiling hoist;
- ⇒ justifying the cost;
- ⇒ choice of models;
- ⇒ comparative chart.

### The purpose of the shower toilet

Shower toilets were previously known as a combined WC and bidet. Their function is to wash and then dry the user's bottom to eliminate the need for toilet paper. They are essential equipment for anyone unable to reach to clean themselves.

### Use with a superimposed toilet chair

In the past these toilets have been used by people with neuromuscular conditions, with a superimposed Mermaid Ranger (or a special toilet chair made to be used in conjunction with this equipment); however, neither option is recommended because it is important that the user's bottom forms a seal with the seat, to ensure a satisfactory washing and drying action. Obviously, when the user is sitting on a chair over the top of the pan, the water and hot air have to travel further and their action and, therefore, effectiveness, are compromised. The better solution is to use the toilet with a ceiling hoist and for the disabled person to use a special frame for support (see below).

### MD toilet frame

This height-adjustable frame was designed for use with the Clos-o-Mat (see below) and a ceiling hoist, enabling the user's bottom to form a seal on the toilet seat to allow the most effective washing and drying action; a superimposed chair will be a poor compromise. The frame has a mesh backrest, a height-adjustable footrest and armrests; and where necessary, it can be made to measure. The frame must be floor-fixed for stability.

*Daily Care Ltd*

### Use with a ceiling hoist

To ensure flexibility in the user's seating position, the ceiling hoist track should run from front to back over the pan, rather than from side to side. This is important to ensure that the water washes the correct parts.

### Justifying the cost

Privacy on the toilet is very important and, as this need is widely understood, there is not usually a problem in justifying the cost; however, for the occasions where this is necessary, see Chapters 11d and 11e.

### Choice of models

There are two models to consider:

- **Clos-o-Mat**

A decision will have to be made whether a plinth (available in **25, 50, 75** and **100mm** heights) will be required; this will be influenced by the user's leg length (because of the need to place their feet on the floor) and the optimum height for transfers.

**N.B.** *The optional super-sensitive switch must be supplied.*

*Total Hygiene Ltd*

- **Geberit**

This unit offers a wide range of adjustable rocker and infrared switches. As with the Clos-o-Mat, it can be supplied with a cushion seat and douche washing to suit male or female users.

*ESL Healthcare Ltd*

The chart on the following page is included to help with the choice.

<b>Comparative chart of shower toilet features</b>	
<b>Geberit: ESL Healthcare</b>	<b>Clos-o-Mat: Total Hygiene</b>
<b>Floor or wall mounted?</b>	
In a domestic situation, units are normally floor mounted; but, in a residential setting, it is easier to keep the floor clean if they are wall mounted.	Usually floor mounted; if wall-mounted units are to be installed, wall construction must be checked.
<b>What height are the pans?</b>	
Optimum height will be important for tall users, for side transfer from wheelchairs and to reduce gap between a superimposed chair and the pan.	
Floor mounted: <b>430mm</b> plus choice of 16 measurements, up to additional <b>110mm</b> height Wall mounted: from minimum height of <b>345mm</b> to height required. Mounted on wall frame: <b>415 - 615mm</b>	<b>400mm</b> (top of pan) plus <b>25, 50, 75</b> or <b>100mm</b> plinths, placed under floor-mounted pan
<b>Overall dimensions: height x width x depth</b>	
<b>910mm x 460mm x 710mm</b>	<b>820mm x 500mm x 710mm</b>
<b>Can a chair be superimposed?</b>	
Height and width of pan will need to be checked carefully. Assisted and self-propelling Westholme Freeway and Chiltern Invadex chairs are manufactured for use over both units. If the seat size is too wide, this can be reduced, if necessary, using side and backpads.	
<b>Are these bidets satisfactory when used with a superimposed chair?</b>	
Use of a chair is a compromise, as the water has further to travel and (more important) the warm air escapes. When a user sits directly on the seat (see <i>Daily Care MD</i> toilet frame, on previous page) their bottom forms a seal, which contains both the water and the warm air. It is important that the disabled person's bottom is properly dried to prevent sores.	
<b>Does the shower toilet need to be modified for use with the superimposed chair?</b>	
Would be supplied with a remote control.	When commissioned, the seat switch (normally activated when the user is sitting directly on to the seat) is wired out.
<b>What height should the unit be when used with a superimposed chair?</b>	
If a superimposed chair (not a frame) is essential, both shower toilets should be raised so that the seat of the chair fits as closely as possible to the top of the bowl.	
Pan height can be set to individual requirements	<b>50mm</b> is the recommended plinth to raise pan to height of <b>450mm</b>
<b>Can the unit's settings be adjusted to suit user requirements?</b>	
Water spray intensity and the drying temperature can be adjusted to ensure optimum effectiveness and comfort. This may be particularly important when used with a superimposed chair.	Douche temperature and pressure can be adjusted by the Clos-o-Mat engineer.
<b>Is the water pressure significant?</b>	
Works on water pressure and if this is low, the problem would be identified at site survey and installation of booster pump would be advised.	Integral pump ensures that external water pressure does not affect the use of the shower toilet.

<b>Comparative chart of shower toilet features (cont.)</b>	
<b>How is the water heated?</b>	
A heat exchanger warms the water prior to use.	Stores sufficient warm water for each wash.
<b>How are the functions operated?</b>	
There is a choice of 3 remote-control switch handsets to activate the washing, drying and flushing cycles.	The operating lever should be depressed for 20-25 seconds so all the warm water is used, and to ensure maximum time of drying air. Flushing is simultaneous with douche wash, which is important for infection control, particularly for multi-use.
<b>Is an odour extractor available?</b>	
Pressure on the seat activates the odour extractor.	Optional extra.
<b>Country of manufacture</b>	
Switzerland	UK
In Europe, shower toilets are personal hygiene/luxury bathroom products not used exclusively by disabled people.	
<b>Colours</b>	
White is standard, but if a colour is required, the manufacturers can be contacted.	White is standard, but coloured pans (manufactured abroad) are an optional extra N.B. Continental colours differ from British.
<b>Who commissions the installation?</b>	
Standard commissioning service is not provided. It is important to check that the installer is fully trained and has been on the firm's course. All ESL surveyors have been trained to commission.	It is important to check that unit has been fitted correctly, conforms to water/electricity regulations, is suitable for client - and that switches or isolator switches are fitted. Total Hygiene's own service engineers commission all installations, irrespective of who has carried out the work.
<b>Guarantees/Maintenance contract</b>	
12 months, with a maintenance contract (after guarantee expires) of up to 5 years.	
Cost: £80 per annum + parts and includes service.	Cost: £100 parts and labour per annum and includes service.
It may be wise to have this included in the grant, unless Social Services Dept. agree to pay for maintenance.	
<b>Available from:</b>	
Imported by <i>ESL Healthcare Ltd.</i>	May be purchased direct from <i>Total Hygiene Ltd</i> or from one of their local distributors.
Contact the firms above to request on-site demonstration	

## Essential washbasin features

A number of features are needed to make a washbasin suitable for a person with a neuromuscular condition. The ideal basin for anyone with severe weakness in their arms, and who is not able to lean forward and then regain their position in the wheelchair, did not exist until the two models discussed in the chart below were specifically designed.

<b>Comparative chart of height-adjustable washbasin features</b>	
<b>ABW4/ABW4SP:</b> <i>Astor-Bannerman (Medical) Ltd</i>	<b>Spectra:</b> <i>Southern Care Systems Ltd</i>
<b>Width along front edge</b>	
Any width <b>750 - 1200mm</b> . Surface can be cut to any shape, if necessary; size and shape do not affect cost.	Two widths <b>700mm or 1050mm</b> ; size does not affect cost.
<b>Front-to-back measurement</b>	
<b>675mm</b> from front edge to wall is standard, but can be made any measurement.	<b>645mm</b> (standard) or <b>695mm</b> (to order). Latter recommended to allow for length of chair under basin - from front edge to housing containing mechanism.
<b>Front profile thickness</b>	
<b>13mm</b>	<b>19mm</b>
<b>Are there any other special features to the bowl and surface?</b>	
The basin is shaped to allow wheelchair access.	
Surface recessed for soap on right-hand side (optional left).	Surface recessed to allow splashes to drain back into bowl.
<b>What material is used for the basin and surrounding surface?</b>	
Corian, a solid, 'marble-like' material, which is non-scratch and easy-to-clean.	One-piece epoxy moulding with glossy, scratch-resistant finish.
<b>Colours available</b>	
12 standard colours for surface, with further range of 80 colours for which there is additional charge; bowl white.	Choice of 4 colours; bowl same colour as surround.
<b>Vertical travel</b>	
<b>450mm</b> with minimum and maximum heights depending on wall-fixing height.	<b>400mm</b>
<b>Is there a safety device to prevent the basin lowering too far and crushing the user's knees?</b>	
Yes	Yes
<b>How are the functions operated (i.e. height-adjustability, tap &amp; plug control)?</b>	
Handset with touch-sensitive switches (standard) or infrared controls for any function. Option of custom-designed handset to operate any/all functions. Controls can be fixed to basin surface with additional option of touch-free tap control.	

<b>Comparative chart of height-adjustable washbasins (cont.)</b>	
<b>ABW4/ABW4SP: Astor-Bannerman (Medical) Ltd</b>	<b>Spectra: Southern Care Systems Ltd</b>
<b>Does it matter if the control handset falls in the water?</b>	
No, handset and switches are waterproof.	
<b>Does the basin have electrical safety protection?</b>	
Yes. Because the basin is supplied at mains voltage and transformed within the appliance, an RCD (residual current device) is built-in. In the event of an electrical fault, this device isolates the mains supply, so that the power switches off immediately.	Yes. The transformer is mounted remotely and therefore the appliance is entirely mains free.
<b>Does the basin have a battery back up?</b>	
Yes, it will continue working for up to 24 hours after a power cut.	No
<b>Is there a choice of taps?</b>	
Yes. Basins are supplied with lever (150mm) taps, operated manually - or on ABW4SP, also controlled with touch-sensitive switch on handset. Further option is touch-free, infrared tap system, which if likely to be needed in the future, would be more cost effective to fit initially.	Yes. Full electronic control of water is standard using touch-sensitive switches or infrared controls. Choice of manually-operated lever taps (single or two) supplied to order, positioned as required.
<b>Is the water temperature thermostatically controlled?</b>	
Not normally needed, but can be included as an option when required	Yes, as standard.
<b>Is the basin supplied with a touch-controlled, pop-up plug?</b>	
ABW4: No. ABW4SP: Yes	Yes, as standard.
<b>Does the unit include a shaver socket?</b>	
Yes, on right-hand side, with advantage that socket rises with basin.	No, shaver socket has to be positioned on adjacent wall.
<b>Does the unit include a mirror?</b>	
Rectangular mirror (standard).	Circular mirror.
<b>Is the mirror supplied with a light?</b>	
ABW4: No. ABW4SP: Yes. Strip light is fitted over mirror, switched on and off from handset.	Yes, low voltage halogen spotlights each side and above mirror, operated by switch on handset.
<b>If light is left on inadvertently, is there a timer to switch it off automatically?</b>	
Yes, after 15 minutes.	Yes, after 10 minutes.
<b>Can the basin be fitted in front of a window?</b>	
No, electronics are fitted behind mirror, which cannot be removed.	Yes, basin can be supplied without mirror and light, with price reduced.

<b>Comparative chart of height-adjustable washbasins (cont.)</b>	
<b>ABW4/ABW4SP:</b> <i>Astor-Bannerman (Medical) Ltd</i>	<b>Spectra:</b> <i>Southern Care Systems Ltd</i>
<b>Can the basin be supplied in modular units?</b>	
If height adjustability is not needed initially, basin, integral surface, mirror and standard taps can be supplied, mounted on wall brackets and include option of flexible plumbing. At a later stage, a handset, which includes, touch-sensitive/infrared control of height adjustability, taps and pop-up plug - or entirely touch-free control of taps - can be added, when necessary.	Special handset including infrared controls may be added later.
N.B. If features are likely to be needed in the future, modular supply is not cost effective.	
<b>Is the flexible plumbing supplied with the basin?</b>	
Yes. If basin is initially installed at a fixed height, it is prudent to install flexible plumbing so that this does not need to be changed later.	Yes, concealed behind an <b>80mm</b> - deep cover under basin. This will reduce space for chair length from user's chest to tip of footrests and must be reflected in the front-to-back surface measurement.
<b>Are there any special fitting arrangements?</b>	
Supplier is able to carry out installation. However, fitting is straightforward and specialist flexible plumbing can be supplied in advance to builder, if required. Unit may need commissioning if installed by local, inexperienced contractor.	2-stage fitting process, Wall frame containing fixed plumbing is usually sent to site to enable contractor to complete all plumbing in advance of basin delivery. Basin is then fixed to wall and plumbing plugs into this frame. Manufacturer or network of agents can carry out this part of installation – or both stages, when there are no contractors on site.

### Justifying the cost

See Chapters 11f and 11g.

### Flooring

This is discussed in Chapter 15 *Adaptation Specifications*.

## Equipment in the bedroom

The following need to be included:

- ⇒ electric bed;
- ⇒ ceiling hoist;
- ⇒ work/equipment surface;
- ⇒ intercom.

## Electric bed

The need, the essential features required and the recommended models are covered in Chapter 8c *Electric Beds*.

## Ceiling hoist

The need for a ceiling hoist, the features to be considered, the most appropriate type of slings and all other aspects of hoisting are included in Chapter 9 *Hoisting*.

## Work/equipment surface

All the details of this recommended surface are included in Chapter 15 *Adaptation Specifications*. However, here it is appropriate to discuss:

- ⇒ medical importance;
- ⇒ choice of brackets.

### Medical importance

Modern management of DMD and other forms of muscular dystrophy is to aim to maintain walking and standing for as long as possible, sometimes with the use of long leg calipers and standing frames. It is unrealistic to expect children to stand in a frame without an activity in front of them; therefore, it is necessary to provide them with surfaces that are suitable for use from a wheelchair and with a standing frame, in order that they may use a computer, music centre, etc.

**N.B.** *The importance of this surface from the point of view of a child's medical management and happiness in the future cannot be stressed strongly enough. In addition, now that so many of the GCSE exams include project work, adequate working space is essential. An easily-accessible surface will enable children to slide their forearms on the surface to gain the maximum benefit from their hand function. See Chapter 11 *Justification for the Need & Funding of Working Surfaces*.*

### Choice of brackets

The difference in the two recommended types of adjustable brackets should be mentioned:

#### Independence Range

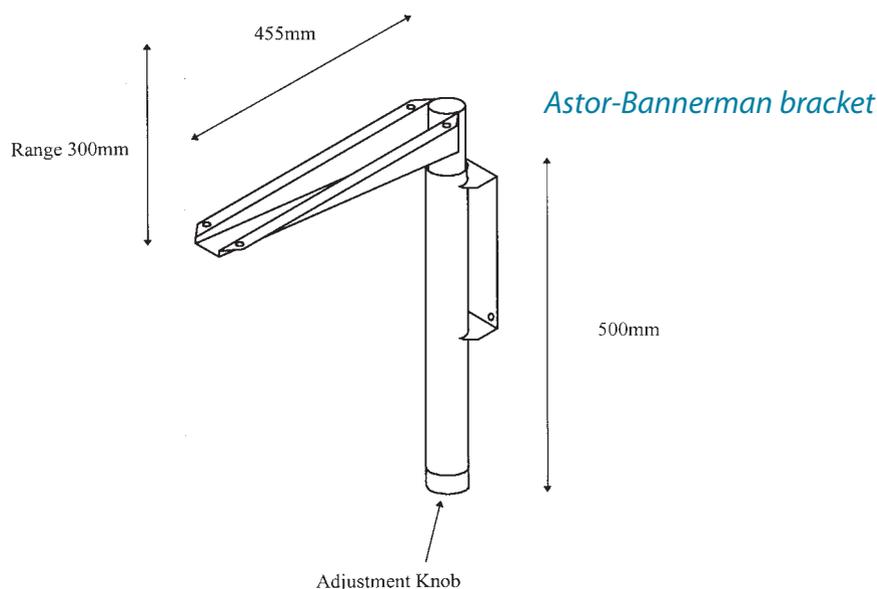
These are the less expensive and have been used over a number of years with great satisfaction. The firm will supply the wall rail, brackets and a four-drawer unit, of which the top drawer is a pull-out surface. Shallow drawers are essential to limit the weight and allow the user, at least initially, to open the drawers independently. It is advisable to buy the **40mm** (not **30mm**) worktop from the local DIY store, so that the design and colour is easier to choose and also to reduce the carriage costs. However, it may be more satisfactory for some families to have the worktops supplied cut to size and ready to install. The wall rail allows the height to be altered in 10 stages of **20mm**.

*Huntleigh Renray Ltd*

## Adjustable brackets

The advantage of these brackets is that the height of the surface can be altered by turning the screw at the bottom of the bracket without removing the surface or anything on it, and the adjustment is infinite and not predetermined.

*Astor-Bannerman (Medical) Ltd*



## Intercom

Parents usually feel more reassured if there is an intercom between the child's room and their bedroom and the sitting room, so that they know that they will hear when the child calls. Initially, it is usually adequate to use unsophisticated units that plug into a **13amp** socket, until the disabled child qualifies for an NHS environmental control, which incorporates a series of intercoms between rooms and to an external door.

*Ridley Electronics Ltd*

## Justification of funding of equipment

The expense of all the bathroom and bedroom equipment included in this manual can be fully justified, which is very important when a grant application is made. For this reason, the value and need of each of the more expensive items are discussed and included in Chapter 11 *Justification for Funding*.

## Equipment in the kitchen

### Height-Right trolley

For many years there has been a need for a powered height-adjustable trolley, and this model was designed for people with neuromuscular conditions. The table has innumerable uses for anyone with difficulty in bending and lifting, or who becomes tired when standing for any length of time. It could also (partially) eliminate the need for height-adjustable kitchen units. The main purpose is to provide a height-adjustable surface controlled from any position and this adjustability can be very important where different heights are needed for different activities. The trolley is invaluable in the kitchen, where it can be used to prepare food (a casserole for example) and then the surface can be raised to the same height as that of any of the oven shelves and the dish safely slid into the oven. Even more important, the hot dish can be removed from the oven without any risk.

This simple unit provides much more versatility than any fixed unit. The difference between its minimum and maximum height (**600** and **1000mm**) is far greater than that of any available height-adjustable but fixed unit. Because it is not fixed in one place and runs on castors, it can be used in any room.

The trolley is both functional and visually pleasing. The **600 x 480mm** wipe-clean top, in heat-proof Corian, an easy-to-clean, non-scratch, marble-like material has been designed to blend well into a home. The trolley is mounted on four castors, which make it relatively easy to move in spite of the weight of the batteries housed in the base which aid stability, together with the fact that the castors can be locked with ease using the control switch. The charging point at the side of this switch uses a small charger similar to that used for a mobile phone.

When the user is unable to stand and needs a wheelchair all the time, the height-adjustability of this trolley is still invaluable.

*Thomas Gideon Design*

### Sit-Easi height-adjustable ironing board

The board is housed in a slimline wall-mounted cupboard and the gas spring provides controlled downward and assisted upward movement. The height can be altered for use either standing or sitting and the cantilevered supports do not obstruct wheelchair access.

*Panilet Tables*

## Ordering equipment

Some specialist items are made to order to incorporate optional features. Lead times may vary during holiday or busy periods. Orders should be placed in advance, with a required date of delivery.

## Environmental controls

The following questions are frequently asked about environmental controls and their supply:

- ⇒ What are environmental controls?
- ⇒ Who pays for the system?
- ⇒ What systems are supplied?
- ⇒ Who is eligible?
- ⇒ Who can refer someone for an environmental control?
- ⇒ Which system would be best?
- ⇒ Who is the assessor?
- ⇒ How long will it take to supply the equipment?
- ⇒ Will anyone demonstrate the equipment following installation?
- ⇒ Who should be contacted if the equipment needs repair?
- ⇒ Can additional equipment be linked to the control at a later date?
- ⇒ Removal of equipment.

### What are environmental controls?

Environmental control systems are designed to provide independence to severely disabled people, by enabling them to operate domestic appliances and equipment by remote control from a display panel. Examples are:

- an alarm;
- intercoms to an external door and to as many rooms as necessary;
- an unlocking system linked to either the front or back door used with an intercom so that the user can ascertain who is at the door before allowing them into the house; and
- use of a loudspeaking telephone, which is supplied with the system and which has the capacity to store numerous numbers.

Accessories are available to enable other domestic appliances, such as lights, heaters, radios, television, beds and curtains, to be operated. Many disabled people may prefer to control some of their appliances, such as their television, with an existing standard remote control. This may apply also to an automatic door opener and an electric bed.

### Who pays for the system?

The Department of Health supplies the systems free of charge, where the disabled person conforms to the eligibility criteria. However, other than alarms and intercoms, accessories are not included in the contract and justification will need to be made to the Social Services Department. Examples would be a curtain control and (in exceptional circumstances) an automatic door opener.

### What systems are supplied?

Although the contracting arrangements are reviewed from time to time, the present contracts for systems funded by the department are with three suppliers:

- *Possum Controls Ltd* who supply the Companion, Freeway and Compact – of which the Companion is likely to be the most suitable for people with neuromuscular conditions;
- *RSL Steeper Ltd* who supply the Fox, Personna, and Lynx (with speech) – of which the Fox will be ideal.
- *SRS Technology Ltd* who supply the SRS100.

## Relevant features

These are as follows:

- units operated by infrared or radio signals, allowing use from anywhere in the house and garden and away from home;
- selection of functions is achieved with the use of a scanning light on the small portable display panel, and the scan speed and an audible tone can be adjusted.
- the selection can be voice announced for anyone with a visual impairment, or who has difficulty in seeing the display when in bed;
- if the standard switch is not suitable, a variety of alternative switches can be plugged into the control panel;
- the Companion and SRS100 can be interfaced with a computer.

## Who is eligible?

Usually disabled people with a neuromuscular condition can be considered for the equipment if they:

- are sufficiently disabled to need the equipment;
- require the independence that the system provides;
- are sufficiently motivated to use it.

The age at which a boy with DMD, or any child, should be referred will depend upon the level of disability and the need, and this should be discussed with the Family Care Officer (FCO) or occupational therapist (OT). However, unfortunately the supply is budget limited and different areas use different criteria, which if necessary can be challenged.

## Who can refer someone for an environmental control?

Usually anyone, but the arrangements will vary from one area to another. If the need has to be justified it is usually a help to discuss the supply with the FCO or OT. Referral is to the co-ordinator in the relevant area, who is responsible for the local administrative arrangements for supply and installation. The address of the co-ordinator can be obtained through the Social Services Department.

## Which system would be best?

*Possum Controls*, *RSL Steeper* and *SRS Technology* will send out information and videos, which are also available from the Muscular Dystrophy Campaign's National OT Advisor. If, as a result, one particular system appears to be the most appropriate, this should be discussed with the medical assessor.

## Who is the assessor?

The assessor will be a medical consultant in the area who has been appointed to do this work and will make home visits to:

- ascertain eligibility;
- help with the choice of system;
- ensure that other cheaper systems would not suffice.

Following this assessment, a report will be sent to the co-ordinator.

## How long will it take to supply the equipment?

There are a number of stages to be followed:

- medical assessment;
- case conference, organised by the co-ordinator and held in the user's home, when a representative of the firm will discuss with the user, the carer and any other health or Social Services staff who are involved, the specific items to be supplied and details of their installation. The equipment will be demonstrated, technical questions answered and installation arrangements discussed;
- installation of electrical sockets or joinery work, if required. This will be the responsibility of Social Services under the *Chronically Sick and Disabled Person's Act* – and it would be wise to ensure that an OT or social worker from the department is present at the case conference, to be delegated the task of making the necessary arrangements;
- installation of the environmental control.

## Will anyone demonstrate the equipment following installation?

Yes, the supplier will demonstrate the equipment and ensure that the user is confident in its use. If an OT is present, they would expect to be available to help if any problems arise in using the equipment in the future, and to provide a follow-up and review, if and when necessary.

## Who should be contacted if the equipment needs repair?

A telephone helpline is available to report problems or to ask for advice on the use of the equipment. In the event of difficulty contacting the firm, the co-ordinator should be notified.

## Can additional equipment be linked to the control at a later date?

Yes. The co-ordinator should be contacted, to make any necessary arrangements. However, if additional equipment is to be provided privately, the firm can be contacted directly.

## Removal of equipment

If the equipment is no longer required, the co-ordinator will arrange for it to be removed by the contractor.

## Providers and funding of equipment, adaptations and services

See Chapter 12 *Funding of Adaptations*.

# ‘Seat to Standing’

## for adults with muscular dystrophy & allied neuromuscular conditions who have difficulty standing up from a seated position

To be used in conjunction with:

Chapter 4	<i>Assessment of Need;</i>
Chapter 10	<i>Disability Needs Assessment Form/Architectural Brief;</i>
Chapter 12	<i>Funding/Understanding the Grant Systems/VAT;</i>
Chapter 15	<i>Adaptation Specifications;</i>
Chapter 17	<i>Multi-use Facilities;</i>
Chapter 18	<i>Addresses: Manufacturers/Suppliers/Sources of Advice.</i>

Many adults with muscular dystrophy and allied neuromuscular conditions are able to walk, but find it increasingly difficult to stand up from a sitting position and need the help of specialist equipment. This chapter includes information in clearly identified stages:

⇒ The method of standing up	2
⇒ Choice of equipment & the importance of assessment	2
⇒ Shared features of the recommended equipment	2
⇒ Timing of the supply of the equipment & its funding	3
⇒ Specialist equipment recommended	3
⇒ The link with adaptations	8

## The method of standing up

This is usually achieved in one of two ways:

- positioning the legs in a wide stance with the knee joint locked and the legs straight; leaning forward on to a stable surface such as a table; bringing the feet closer together and then either climbing up the furniture or pressing on the thighs in order to extend the back and to balance;
- twisting sideways; leaning heavily on one arm; pushing the legs out to the rear so that the knee joint is straight, and levering the body up using furniture as support.

## Choice of equipment and the importance of assessment

Most people with neuromuscular conditions find that equipment that throws them forward with their knees flexed is inappropriate, because it is then impossible to straighten the knees to stand up. Fortunately, there are several pieces of equipment that have proved to be useful. In most cases, the equipment was either developed to help people with neuromuscular conditions or has been modified as a result of feedback from users.

It must be stressed that the equipment should be assessed prior to ordering, and it is essential that, if statutory funding is to be sought, the person responsible for arranging the funding is at the assessment.

## Shared features of the recommended equipment

These are as follows:

- a seat which rises horizontally on which the user can inch forward without being thrown forward, although a minor push at the last stage in the process of standing up can be helpful to some disabled people;
- a seat which, depending on the user's height rises to a sufficient height (usually between **790** and **870mm**) to enable users to lower themselves to their feet with the knees braced back;
- armrests which rise up with the seat to provide stability and something to hold on to at the side of the thighs while the user is standing and slowly extending the back to achieve balance;
- no protrusion at the base of the equipment to get in the way of the feet;
- designed to provide the help required while being aesthetically acceptable and not looking like 'disability' equipment.

## Timing of the supply of the equipment and its funding

Most people with a neuromuscular condition choose to struggle to stand up for many years because they feel that this physical activity keeps their muscles active. This decision is a personal one, but it may be more productive to accept the use of equipment at an early stage in order to conserve energy for more worthwhile activities. In addition, one of the difficulties of initially using this equipment is the need to alter the method of standing up. Therefore, it is important to consider these items when standing up is just beginning to get difficult, because it is easier to adapt when less disabled. Early supply will save the frustration of struggling, particularly if there is a delay while funding for the equipment is sorted out. It is likely that several of the items mentioned will be required and, if the need is staggered or identified by forward planning, this may help Social Services to budget the funding. Also, if the equipment will be needed for several years, it is more likely to be funded than items that will be needed for a short time only.

## Specialist equipment recommended

This is needed to overcome the difficulties experienced in standing up from the following:

- ⇒ easy chair;
- ⇒ office chair;
- ⇒ toilet;
- ⇒ shower;
- ⇒ bath;
- ⇒ bed;
- ⇒ car;
- ⇒ raising from the floor, following a fall;
- ⇒ wheelchair.

### Easy chair

#### Regent 2745

This chair is particularly suitable because the seat rises horizontally (or at an angle) to a height of between **620** and **740mm**. Two motors enable the backrest and legrest to be controlled independently of each other so that the most suitable position can be adopted, i.e. sitting with the legs either down or raised, or lying down. The design has been upgraded to extend the arms forward to provide more support when standing and to make the chair much more comfortable than the previous model. The chair is upholstered in a choice of velour, but there is also the option of the users supplying their own material.

*Ortho-Kinetics (UK) Ltd*

## Devon Recliner

This chair has a number of interesting features. The actions to raise and lower the legs, backrest and seat height operate independently of each other and the seat has the option of rising horizontally or at an angle. The armrests can be raised out of the way, which is invaluable for sideways transfers if standing up becomes difficult. As the chair has the option of a rotational base, it allows the user to turn the chair round which may be useful when reaching items and allows the optimum positioning of a wheelchair. The chair is attractive and is available in a choice of leather or fabric upholstery; detachable seat and backrest cushions allow the use of loose covers. Two sizes are available.

*Bakare Beds Ltd*

## Made-to-measure, powered self-lift chairs

The option of a model, individually made to order, provides the opportunity to obtain a child's riser chair – and to cater for the individual needs of adults, which will include both tall and large users. However, it must be noted that the minimum seat height is **360mm** (to allow space under the chair for the motor) and prior to a referral for a small child, it must be assessed whether this height allows them to sit squarely with their feet on the floor. The use of a footstool may obstruct standing up from the chair - or require a helper to move and reposition the stool.

The chair has a seat-height adjustability of **405mm**, which means that a tall user, who, for example, needs the seat height at **560mm** to maintain a good postural seated position, can then raise the chair to the maximum seat height of **965mm**, from which to stand. There is the option of the seat rising horizontally, at an angle - or to the required height horizontally, completing the action with a tilt.

Seat widths range from **460-740mm**, the weight limit is **222kg** and it should be possible to incorporate all the features needed by a user with a neuromuscular condition.

*Gordon Medical & Rehabilitation Services Ltd*

## Office chair

### eMove powered chair

This electric, self-lift office chair, combined with powered mobility, was designed for people with muscular dystrophy. The seat rises horizontally with the option of a powered seat tilt (if needed, to give the final push) and the armrests and footplate rise with the seat to provide stability to the user. The minimum to maximum seat height is **520-730mm**, but this can be modified. The seat and backrest are fully adjustable and are available in various sizes with an optional headrest. The firm specialises in postural seating, and using their POSE (Personal Office Seating Evaluation) system, can ensure the user sits correctly by tailoring the upholstery to individual requirements.

The chair has a tight turning circle and narrow width, which helps access in limited spaces. There is the option of 5 speeds, with an easy-to-operate joystick control for direction and seat adjustments. 'Swing back' armrests allow sideways transfer from a wheelchair. The weight limit is **120kg**.

If a disabled person in employment needs the chair to help carry out their work, an assessment should be arranged in conjunction with the disablement employment advisor, who can be contacted through the local Job Centre. This support is essential for funding by the Department for Work and Pensions - and it may be prudent to accept the firm’s offer of a two-week trial.

*Advance Seating Designs*

## Toilet

### Porta Toilet Riser

This electric toilet raiser, which is used superimposed over a standard toilet pan, has been developed from two previous models and its features have been designed for people with neuromuscular conditions. The seat rises horizontally and the range of height adjustability from **450 – 810mm** is excellent. If front transfer is used (which is unlikely for people with a neuromuscular condition) the front bar may restrict this manoeuvre.

The Porta Riser has been modified from **240V** mains power and now uses the Linak Jumbo battery system which is fixed to the bathroom wall, when the riser is bolted to the bathroom floor – and installation is therefore very straightforward.

Unfortunately the alternative wider model for use over a Clos-o-Mat is no longer available.

*Huntleigh Healthcare Ltd*

### Ginnerup Toilet Lift

There are many adults with a neuromuscular condition who initially need help to stand up from a standard toilet and in the future will need to use a shower toilet, see Chapter 8a, *Equipment for Adaptations*. Powered toilet lifts are expensive and ideally a unit should be used that will be suitable for both the short and long term. The Muscular Dystrophy Campaign has worked hard to interest a manufacturer in producing a powered toilet lift which can be used with either a Clos-o-Mat or Geberit shower toilet and finally this has been achieved. The unit has **395mm** of height adjustment with the seat rising to a height of **890mm**; in its lowered position there is **95mm** from the top of the seat to the rim of the pan. The sensitive switches are positioned on the side of the end of the arms, which raise to allow sideways transfer when standing up from the toilet is no longer possible - but height adjustability is needed to allow the transfer to be carried out ‘downhill’. The overall width is **650mm** and the front-to-back depth **660mm**.

*Moderna Contracts Ltd*

## Shower

### Electric height-adjustable shower seat

Many adults with neuromuscular conditions have difficulty standing safely in a shower, but if they sit down on a shower seat or chair, they are unable to stand up independently. The answer is to use an electrical height-adjustable seat which rises sufficiently for the user to stand up and yet can be lowered near enough to the floor to allow bathers to sit with their feet firmly supported on the floor and enables them to be able to get down to wash their feet. The seat should have a supportive backrest and arms that project beyond the front of the seat to provide support when standing.

## SC.EL Shower chair

This model was designed for people with muscular dystrophy. It is powered and can be lowered to within **100mm** of the floor with a range of **800mm** of height adjustment. The maximum height that can be achieved will be influenced by the height at which it is installed. The seat can be supplied with armrests that can be raised independently and which are the recommended length to provide sufficient support when standing.

*Astor-Bannerman (Medical) Ltd*

## Multi System and support arms

The powered seat can be installed at either **150 or 250mm** from the floor with **620mm** of height adjustment. This equipment is discussed in detail in Chapter 17 *Multi-use Facilities*.

*Pressalit Care Ltd*

## Bath

### Specialist baths with integral electric seats: *Arjo Solo* and *Arjo Sovereign* baths

A number of firms manufacture baths that have integral seats that swing in and out of the bath and can be raised and lowered electrically into the bath. The seat should pivot from the corner of the bath so that it projects as far as possible from the side of the bath to ease the process of transfer, and should have the maximum range of height adjustment. This may be essential for achieving the height needed to stand up, and eventually the minimum height may be equally important to ensure that a sliding 'downhill' transfer can be achieved from a wheelchair that may not have a height-adjustable seat.

With one exception, all these baths have a seat that supports the bather in an upright position; for many adults this may be the ideal sitting position to facilitate leaning forward to wash; a suggested model is the *Arjo Solo*. However, many bathers prefer to recline, in which case the *Arjo Sovereign* baths are ideal. Further details of these baths are included in Chapter 8a *Equipment for Adaptations*.

*Arjo Ltd*

## Bed

### Electric beds

The most important feature of these beds, in relation to helping users to get to their feet, is that they are height adjustable. At a later stage they also have the additional advantage that their minimum height enables the user to move 'downhill' from most wheelchair models to transfer into bed, and to raise the height of the bed above the wheelchair seat height to get out of bed. However, it is important to compare the minimum and maximum heights of the bed with the seat height of the wheelchair. In addition, the bed chosen must have the other features needed by people with a neuromuscular condition. It will be important to consult Chapter 8c *Electric Beds*, which includes a comparative chart showing all the relevant measurements.

The need for an electric double bed will have space implications in the bedroom and may further substantiate the need for adaptations.

Princess 5000: *Action Assist Ltd*

Homecare bed: *Ashworth Trading*

Volker 3080PH: *Bakare Beds Ltd*

Baltic: *Centromed Ltd*

Super Baltimore: *Huntleigh Healthcare Ltd*

Guldmann Flexus 2: *Moderna Contracts Ltd*

Scanbed 750 - Standard, Short and Extra Low: *Scan Mobility Ltd*

Bed in Bed: *Theraposture Ltd*

## Car

### Seat Raise to Standing

The seat platform (which can be made to measure) is positioned at the side of the car seat and is lowered to a horizontal position when the car door is opened. The driver or passenger swivels round and slides on to the seat with their feet out of the car. The seat platform is then raised electrically, operated from a control button either on the end of a lead or fixed in a convenient position in the car. The unit lifts anyone weighing up to **150kg** and the standard seat rises **450mm** to a height to allow the user to stand. The seat is then folded up and the door closed.

When equipment is assessed the potential user needs to decide:

- the optimum seat size;
- the height needed from which to stand.

Modifications are readily available and the only limitations are those imposed by the size of the car. **2000mm** of height adjustment, for example, is available to access a motor home.

When the car is changed, the unit can be transferred with minimal fitting costs.

*KC Mobility Services Ltd*

### Raising from the floor, following a fall

It is inevitable that anyone with muscular dystrophy who is having difficulty walking will, on occasions, fall down; eventually, climbing up the furniture to get up from the floor will be impossible. A portable unit that lies flat on the floor and rises up to a height from which the person can be helped to stand up, will then be needed.

The alternative is to rise to a suitable height to transfer (preferably ‘downhill’) to a wheelchair that has an elevating seat or to a standard wheelchair used to move to another surface within the house. This may be on to one of the items of powered equipment discussed in this chapter, which rises to a height from which the disabled person can stand.

There is a choice of three items of equipment, as follows:

- ⇒ MK2 Elevator Recovery System;
- ⇒ Mangar Elk;
- ⇒ Mangar Booster.

### MK2 Elevator Recovery System (ERS)

The ERS consists of a comfortable, padded, easy-to-clean seat and backrest with head and neck support, on a wheeled frame to be used by a helper. The unit is placed on its side behind the user’s back as they lie on their side in the recovery position. The trunk, lap and thigh, colour-coded straps are passed under and over the disabled person and buckled. The person and the frame are then rolled until they are lying on their back on the seat and backrest. As the switch is operated, the user is raised upwards and forwards to a fully-supported, semi-standing position with the seat height at **515mm**. The equipment is very stable and is suitable for use both indoors and outdoors. It is powered by a rechargeable battery, with a battery-charge indicator - and has a lifting capacity of **160kg**. The ERS is compact and easy to use in confined spaces – and when not in use, folds for storage.

*Cane & Able Ltd*

## Mangar Elk

This unit consists of four compartments approximately **500mm** square, inflated by a small battery-operated compressor, which will lift up to **320kg** to a height of **565mm**. The Elk and compressor are convenient to carry, and to store when not in use. The advantage of the Elk is that when deflated it is flat on the ground, which makes it easier for anyone unable to push on their arms, to raise their bottom into the correct position. Because the unit does not have a backrest, armrests or safety straps and may lack stability, it is not designed for independent use by anyone with a neuromuscular condition and will require the assistance of at least one helper.

*Mangar International Ltd*

## Mangar Booster

This unit is similar to the Elk, but may be used independently. To provide greater stability on surfaces such as carpeted floors, the suction feet are placed firmly on a 'stability' board. The Booster is available in standard or 'extra' lift models, which rise to a height of **500** or **700mm**; the weight limit is **130kg** (or **160kg** as a special order). The unit is supplied with side flaps to help ease up the user's bottom from the floor, with the option of non-slip flaps. The backrest is supplied as standard, but the optional armrests may be essential to increase stability when the unit is inflating and to help when standing.

Unlike the Elk, the minimum height of the Booster is **100mm**. This increased floor-to-seat height may make it more difficult for the users to raise themselves up on to the cushion – or to be lifted on by a helper.

*Mangar International Ltd*

## Wheelchair

### Wheelchairs with height-adjustable seats

Many adults will be able to stand and take weight on their feet for several years after walking becomes impossible. The equipment discussed in this chapter will continue to help them to get to their feet, and a wheelchair will then be needed to travel between the various items of equipment. The wheelchair must have an elevating seat to enable standing and transfer on to the equipment (and vice versa). When standing becomes impossible and a sideways transfer to and from a wheelchair is necessary, the maximum and minimum height adjustment will be crucial to allow these transfers to be carried out moving 'downhill'. Some of these wheelchairs are included in Chapter 8d *Wheelchairs*.

## The link with adaptations

When this equipment is first needed, many adults make alterations to their homes that they feel are adequate at the time, but prove to be inappropriate as soon as a wheelchair is needed. It is often particularly difficult for anyone with a progressive condition to plan ahead for the use of a wheelchair, but experience has shown that in the interim period this will increase independence and in the longer term will be cost effective.

# Electric Beds

## for children & adults with muscular dystrophy & allied neuromuscular conditions

*A guide to help the disabled person, their family or carers and the healthcare professionals advising in the choice of an appropriate bed*

To be used in conjunction with:

- Chapter 14     *Scales & Templates;*
- Chapter 18     *Addresses: Manufacturers/Suppliers/Sources of Advice.*

## Introduction

Experience has shown that electric beds are invaluable for boys with Duchenne muscular dystrophy (DMD) and children and adults with all types of muscular dystrophy, spinal muscular atrophy (SMA) and allied neuromuscular conditions. In making a choice there are a number of questions to be answered:

- ⇒ Why are electric beds needed? 2
- ⇒ When is the right time to supply a bed? 4
  - ⇒ What features are needed & why? 4
  - ⇒ Can the bed turn the user over? 11
- ⇒ How can a bed be assessed & who should attend the assessment? 11
  - ⇒ Does the bed comply with safety standards? 11
- ⇒ What service & support is offered for breakdown & maintenance? 12
- ⇒ Who should supply the funding & maintain the bed, specialist mattress & turning unit? 12
  - ⇒ Which models are the most appropriate for people with neuromuscular conditions? 12
  - ⇒ What are the specifications of the recommended beds? 13

## Why are electric beds needed?

Electric beds have eight main uses. These are to:

- ⇒ alter the height of the bed to help the user to get in and out;
- ⇒ complement the use of a ceiling hoist, when getting out of bed;
- ⇒ change the user's position in bed;
- ⇒ help the user to sit up from lying down (and vice versa) and to sleep in the most comfortable position;
- ⇒ provide support behind the back and under the knees;
- ⇒ help postural drainage;
- ⇒ allow the carers to work at the optimum height to protect their backs;
- ⇒ provide a height-adjustable surface on which to carry out physiotherapy exercises.

### Alter the height of the bed to help the user to get in and out

This is a helpful feature for the following:

- ⇒ people able to walk or stand to transfer;
- ⇒ wheelchair users.

### People able to walk or stand to transfer

Many people with muscular dystrophy need a bed that can be positioned low enough to allow them to 'flop' into the centre. This is important because when in bed it is very difficult for them to move across the bed. It is also important for some users, that the bed lowers sufficiently to enable them to lift their legs up on to the mattress. The bed must also be capable of rising to a sufficient height to help them to stand up from the edge of the mattress by dropping on to their feet with their legs fully extended. This height adjustment is essential, because unless their knees are fully extended and braced they will collapse to the floor. Equipment that pushes them forwards to take weight on their feet with their knees bent makes it impossible for them to brace back their knees.

### Wheelchair users

Because people with a neuromuscular condition usually have severe arm weakness, they are unable to push down on their arms to raise their bottom to transfer sideways. A sliding board will help the process, particularly if it is used 'downhill', and the height adjustability will make this possible. The minimum height of the bed will be crucial and should be checked in relation to the seat height of the wheelchair.

### Complement the use of a ceiling hoist, when getting out of bed

It is easier to position the ceiling hoist sling and to attach the straps to the hoist when the person is sitting in the electric bed with their back supported. An electric bed and a ceiling hoist, used in conjunction with a shower chair, Mermaid Ranger (see Chapter 8a *Equipment for Adaptations*) or an extended track into the bathroom (see Chapter 9 *Hoisting*) eliminate all manual lifting within the home.

## Change the user's position in bed

Anyone who sleeps on their back can use the bed to sit up independently during the night. If they are able to alter the angle of their shoulders and move their legs, they can then lie down again in a different position. In this way, cramp can be relieved, or a trapped arm or ear released, for example, thus eliminating the need to call for attention. As many parents and/or carers have to get up during the night to help their child (sometimes as often as ten times), the provision of an electric bed is likely to ease the situation and the strain on the family. This is important because, in spite of broken nights, they still have to cope the following day.

For an adult living alone, an electric bed may be the only way of maintaining independence; for many adults it is the only means of their partner or carer getting a less-disturbed night's rest. It may be necessary to use the bed in conjunction with a turning unit (details are included on page 11) or to consider one of the models that tilt laterally.

## Help the user to sit up from lying down (and vice versa) and to sleep in the most comfortable position

An electric bed allows the user to sit up in the morning without help; however, for most people with a neuromuscular condition, it is crucial that the backrest rises almost to a right-angle to allow them to sit erect and to lean forward. Conversely, the backrest allows the person to change from sitting to lying down – or to sleep at any angle in between, which may be important if they have a chest infection.

Ideally, when the backrest is raised, it should not pivot from a *fixed* point; its base should move backwards to compensate for the thickness of the mattress and prevent a ridge forming on the surface. This retains the same space on the sitting platform and prevents the possible need to raise the thigh section to prevent the user from slipping down the bed. It also avoids stomach compression and maintains comfort while sitting.

## Provide support behind the back and under the knees

The backrest provides support when sitting, and because the footrest can be lowered, a comfortable sitting position can be achieved. This means that going to bed early to read or watch TV does not result in the constant need to call for help to be moved. The angle of the knee bend must be capable of achieving almost a right-angle, not only to provide the correct support behind the knees for anyone with knee contractures but also to continue to make it possible for their legs to be extended forwards.

## Help postural drainage

Many children with either DMD or SMA, and some adults, need postural drainage when they have a chest infection. In the past, it has been recommended that the bed action should include the Trendelenburg position of head down and feet up so that, if the person is very thin and it is difficult to clap their chest, this position could be used to drain the chest. However, although as yet there is no Directive issued in the UK, European Standards are now being introduced in Scandinavia, which stipulate that the Trendelenburg position should not be used without 24-hour medical supervision. The alternative suggestion is that the person receives approval from their medical advisors, to be placed in this position in their own home; it is recommended that individuals and their families discuss the advisability of this with their GP or hospital consultant. In addition, it could be discussed whether the knee bend in the mattress platform can be used to achieve a satisfactory position.

## Allow the carers to work at the optimum height to protect their backs

The ability to raise and lower the bed to the optimum height for the carers when they are dressing the person in bed, and also for positioning a hoist sling, is likely to be an invaluable feature, particularly if the carers are of different heights.

## Provide a height-adjustable surface to carry out physiotherapy exercises

The same principles apply as outlined in the preceding paragraph.

## When is the right time to supply a bed?

The supply of an electric bed is justified when the child or adult is finding it difficult to sit up in bed and/or has difficulty in standing up from the edge of the bed. Provision should not be delayed until either activity is impossible and a helper finds the person too heavy to pull up into a sitting position; nor should it be delayed until regular attention is needed in the night. There is evidence to show that, as far as possible, it is important in the case of children to prevent a pattern of broken nights developing, and this can be achieved by allowing the child to maintain movement in bed with the help of an electric bed. Once a child has established the need to call parents in the night in order to change position, it is hard to break the pattern.

## What features are needed and why?

In the choice of beds, the needs of people with neuromuscular conditions are specific and are related to the following:

- ⇒ bed width;
- ⇒ design of the mattress platform;
- ⇒ switch sensitivity;
- ⇒ number of motors;
- ⇒ angles of the bed that can be achieved;
- ⇒ height adjustment and the method used;
- ⇒ minimum and maximum height;
- ⇒ provision of bed and grab rails;
- ⇒ choice of mattress;
- ⇒ provision of a back-up battery;
- ⇒ stability (including braked castors), robustness and proven reliability;
- ⇒ link to an environmental control;
- ⇒ appearance of the bed.

### Bed width

The overall dimensions of the bed are larger than those of standard beds and should be checked carefully when adaptations are planned. In this case it would be prudent to allow sufficient space for the largest model in the width of bed required. Three widths are available:

- ⇒ single;
- ⇒ wide single;
- ⇒ double.

## Single

**1007mm** is the standard width, which is adequate for most people.

## Wide single

Some adults who 'flop' into bed need a bed width of **1220mm**, or even a double bed - for their use alone. This may also be the appropriate size for larger teenagers and adults, particularly if they have three sleeping positions and cannot be lifted back into the centre of the bed each time. Some manufacturers will make beds to order, so the size can be specified, if necessary, but this may add to the cost.

## Double

A number of firms widely advertise their beds, particularly double beds, in newspapers and magazines; most of these beds are suitable for people who are not disabled, but who want to be able to sit up in bed with their back supported. However, many of these beds do not have the features that are needed by people with neuromuscular conditions.

The decisions relating to double beds (for use by two people) are complicated because of the wish to reconcile the emotional/physical needs of sleeping with a partner with the practical difficulties of a disability, which in the context of this Adaptations Manual are likely to be progressive. This is particularly complex because the priorities will change as the disability increases, but because beds are expensive, it will be prudent to consider the long-term needs. However, although it is important to refer to page 2 in order to relate the uses of these beds with the features of the recommended models, which are included in the charts starting on page 14, only the people concerned know what compromises they are prepared to make.

Only one manufacturer supplies a double bed that has all the recommended features for people with neuromuscular conditions. A single (or wide single) electric bed can be placed adjacent to a standard divan or a purpose-made divan of the same length as the electric bed, to create a 'double bed'. If an existing bed is used, the firm will measure the bed and provide an insert to lengthen the bed. The beds are joined together using steel brackets at the head and foot and have a pine surround with a double headboard and footboard.

The beds can be made up separately with individual fitted bottom sheets and used with a king-size duvet over both beds. Between the beds there will be a gap of approximately **100mm**, but this can be filled in with a mattress insert which is supplied with the bed. This allows independent sleeping positions, and the couple may feel that, although separate mattresses are used, this is an acceptable compromise for a double bed. The alternative is a bed where, if one person sits up, they both sit up; this also increases the cost.

Depending on the width of both the electric bed and the divan, this bed will be at least **2000mm** square and this may significantly reduce the wheelchair circulation space; the implications in relation to the size of the room need to be considered carefully. When adaptations are carried out it is important that the size of the bedroom should be planned around the eventual use of a large bed, even though an electric bed may not be needed immediately. This is not only important for a couple living together, but also for a disabled person, living on their own, who is likely to have a relationship in the future.

## Design of the mattress platform

Three factors are important:

- ⇒ the number of sections;
- ⇒ size;
- ⇒ ease of transporting.

## The number of sections

Beds are supplied with either three or four sections. A four-sectioned mattress platform is essential because it incorporates a small platform, which remains horizontal. The person sits on this platform and it prevents them from becoming wedged between two of the sections when their knees are raised. Even more important, it prevents them from slipping down the bed when their legs are lowered – because getting back up the bed independently is likely to be impossible and having to lift someone up the bed is a difficult manoeuvre for the carer.

These difficulties are also prevented by a backrest which, when raised, does not pivot from a fixed point. This should move backwards, preventing the lower body from becoming jammed against the knee break, which would cause pressure on the lower stomach and pelvic area.



*To show the mattress platform sections and their relationship in size*

## Size

The leg sections in the mattress platforms are more or less the same length in most of the models, which is a problem when a small child is using a bed. However, some models have a smaller hip-to-knee section to cater for the needs of these children; it should be checked whether this section can be enlarged when the child grows. Conversely, very tall people can have an extension on to the end of the platform, or a model which can be manufactured longer (see charts on pages 14-20).

## Ease of transporting

Most, if not all electric beds divide into two parts – the wheel-base and the mattress platform. However, in order to reduce the weight that has to be carried when the bed is installed, it may also be important that the *platform* divides into two parts (although it is vital that this is not at the expense of the other recommended features). This additional feature is essential when the bed has to be carried up to the first floor or when the user is planning to move the bed from one venue to another.

## Switch sensitivity

It is essential that beds for anyone with a neuromuscular condition have super-sensitive switches. The importance of the switch cannot be stressed sufficiently, bearing in mind the muscle-wasting effect of muscular dystrophy and the need to control the bed independently. Most controls are supplied with a tight spiral cord, which can be stretched to reduce the tension that would otherwise cause it to spring out of reach.

## Number of motors

The number of motors influences both the actions of the bed and the ability to alter the bed height. There are four choices:

- ⇨ one-motor bed;
- ⇨ head raising unit;
- ⇨ three-motor bed;
- ⇨ four-motor bed.

## One-motor bed

For many years, this was the only type of bed readily available at a reasonable cost. As the switch is operated, the head and foot of the bed move simultaneously to place the person in a supported position. Unfortunately, this type of bed has three major disadvantages:

- for people who are able to extend their legs, the automatic bending of the knees encourages knee contractures;
- it is impossible to alter the position of the legs in relation to the back, in order to adopt the most comfortable position possible;
- the height of the bed cannot be altered.

## Head-raising unit

Inexpensive units are available to place under the mattress to raise the head of the bed only. Usually, these are unsatisfactory as a *permanent* solution for anyone with a neuromuscular condition, because sitting up with the legs straight places a strain on the back of the knee, particularly if there is any degree of contracture. Also, the person tends to get pushed down the bed and, without the strength to push down on the arms, is unable to move back up again. However, because these units are portable, they may be useful to provide limited help when away from home, or as a temporary measure while waiting for a bed to be supplied. In addition, some couples may prefer a bed elevator on their double or king-size bed to provide support to sit up, even though this equipment lacks the functions of a four-motor electric bed.

If the unit raises the head and at the same time flexes the hips and knees slightly, so that the user is sitting in a hollow, they may become unbalanced. As with all equipment, it is necessary for an assessment to be carried out.

*Centromed Ltd*

*Marcon Lifting Systems (Turnblade Ltd)*

## Three-motor beds

Two motors provide the ability to change the position of the legs and back independently of each other and the third allows the height of the bed to be adjusted independently. However, alternative positions for the user's legs cannot be achieved by this means, and manual operation does not provide the independence needed.

## Four-motor beds

These are the recommended models for people with muscular dystrophy and SMA, and have the invaluable advantage of two motors to alternate the leg actions, to provide support behind the knees when knee contractures are present, and to raise the person's legs if necessary to reduce oedema. The third motor raises the head of the bed and the fourth alters the height.

A number of beds are promoted as four-motor beds, but two of these motors are used to alter the height. As a result, although the user is able to control the knee break, the foot section can only be operated manually by the carer.

## Angles of the bed that can be achieved

The angles of the bed are critical (see pages 16 – 18). The backrest must rise to an angle of at least **70°** because anything less would make it difficult to lean forward. The knee break must be able to achieve approximately **90°** to ensure the bed is suitable for anyone with severe knee contractures. In addition, the leg section of the bed must be capable of lowering, ideally electrically, to allow the option of a comfortable sitting position to be adopted.

## Height adjustment and the method used

The base of the frame affects the method of altering the height of the bed, as follows:

- ⇒ fixed height;
- ⇒ hydraulic;
- ⇒ electric.

### Fixed height

Fixed-height beds are not recommended, as height adjustment is essential. Some Local Authorities are refusing to provide home care if the bed is not height adjustable.

### Hydraulic

Altering the height of a bed with a hydraulic footpump demands a certain amount of physical effort on the part of the carer and has been known to cause foot injuries. The financial saving is not considered worthwhile in relation to the additional physical stress. It also denies independence to anyone able to stand or walk.

### Electric

Electric beds are operated effortlessly and can be adjusted independently by the person using the bed.

## Minimum and maximum height

The mattress platform of the recommended models have a height-adjustment range of between **345 – 560mm**. It may be important to offer a choice in the range of height that is possible, because the ability to achieve the minimum height is usually at the expense of the maximum height. The exception is the 750 Extra Low model from *Scan Mobility Ltd*. With its 'low-built lift', the mattress platform can be lowered to **240mm**, but because the height range is **560mm**, the maximum height is not compromised. On some models this variation can be organised with the insertion of spacers in the sleeves where the castors are attached; these spacers are removed to enable the bed height to be as low as possible and added to increase the maximum height. In addition, the depth of the mattress can alter the height of the bed, and the firmness of the edge of the mattress may influence the person's ability to stand up from the bed.

### Minimum height

The minimum height may be crucial for sideways transfer from a wheelchair, particularly as movement is easier 'downhill' - and for anyone who has difficulty lifting their legs into bed. A low height may be important for a small child (e.g. with SMA) who, with the help of an electric bed, can get out of bed independently. However, in this case, the base of a bed table or mobile hoist may not fit under the bed.

### Maximum height

The maximum height will be essential to increase the clearance under the bed if either a bed table or a mobile hoist is used, or to allow a tall carer to work at a comfortable height. Furthermore, it may be needed to provide the vital additional millimetres necessary for adults using the height of the bed to get into a standing position.

## Provision of bed and grab rails

There are two types of rails:

- ⇒ side bed rails;
- ⇒ grab rails.

### Side bed rails

Rails may be considered essential to ensure safety and to provide a feeling of security, bearing in mind the maximum height of the bed. However, if a bed is positioned against a wall, only one rail will be necessary (unless it serves as a grab rail to help the user to turn over or move in bed). The rails should be easy for the helpers to lower and raise without pinching their fingers.

The effect of rails on side transfers for adults must be considered carefully to ensure that the rail does not increase the gap between the chair and the mattress and jeopardise the disabled person's independence getting into bed. It must be assessed whether the rail can be removed and whether help will be needed.

The possible danger of either a child under the age of 12, or a small adult, trapping their head or body in the gap between rails should be prevented with the supply of net or padded covers. Where the bed has moving parts - as in adjustable beds - additional vigilance is needed. When bed rails are used with an air mattress or mattress overlay, the height of the rail must be sufficient to prevent the person rolling over the top. When the bed and/or specialist mattress is assessed, a 'Risk Assessment' must be carried out on the suitability of the bed rail for the individual user. See section on safety on page 11.

### Grab rails

Grab rails are usually approximately **500mm** long and stand **50mm** proud of the bed frame. It should be possible to clamp them in any position on the frame and they may be a help to adults when getting into bed, or moving in bed. Overhead grab poles will not be suitable because of the difficulty anyone with a neuromuscular condition has in reaching upwards.

## Choice of mattress

There is a choice of three types of mattress:

- ⇒ interior sprung;
- ⇒ foam;
- ⇒ specialist mattresses and mattress overlays.

### Interior sprung

An interior-sprung mattress is likely to be the most comfortable. These mattresses are sprung across the width of the bed, so that they bend where necessary. However, a ridge is sometimes caused where the mattress bends, particularly on beds where the backrest pivots from a fixed point (i.e. there is no backward movement of the backrest when elevating) see chart on page 16 - and a mattress overlay may be needed to overcome the consequent discomfort.

### Foam

There is a tendency for foam mattresses to cause sweating and sometimes the user (particularly if they are overweight) can feel the mattress platform underneath. A **150mm** depth of mattress is needed by anyone weighing over **82kg**, but a **100mm** depth should be adequate for everyone else. The bed supplier may also offer the option of a specialist foam mattress.

## Specialist mattresses and mattress overlays

A survey was carried out with the help of a number of disabled children and adults, to try to find out which are the best types of mattress or mattress overlays to ensure:

- comfort in the night;
- to restrict the number of times that they need to be turned or moved.

Thirteen mattresses or overlays were assessed by each participant in the trial over at least 2 weeks in any one month, and questionnaires were completed. The result was that most disabled children and adults find specialist mattresses helpful, but that there was no statistical evidence that any type was more valuable than another. Therefore, it is important to assess the alternatives and where necessary to ask for an extended trial over a couple of weeks.

As previously mentioned, the depth of the mattress and its firmness will influence the ability to stand up from the edge of the bed. Also, it may be important to balance the need for comfort in bed with the need for a firm surface to allow as much movement as possible.

## Provision of back-up battery

Because the electrical features are essential, these beds must have the benefit of fully rechargeable batteries that provide between 48 and 72 hours of normal use in the event of mains power failure.

## Stability (including braked castors), robustness and proven reliability

Some disabled people spend more time in bed than others and the bed must be robust to reflect this additional use, particularly when the user is heavy. The bed must be able to withstand the 'snatch weight' involved when adults sit down suddenly and heavily as they get into bed. The frame must have braked castors to ensure safety and stability, and it is vital that the model chosen is stable at its maximum height.

When a bed is an important part of the coping strategy for a disabled person (or for their carers), reliability and trouble-free use are essential. This is discussed again in relation to the alternative models now available.

## Link to an environmental control

Identification of the recommended beds that can be linked to the Possum, RSL Steeper and SRS Technology environmental controls are included in the chart on page 18. This will be necessary only when a user is unable to operate the touch-sensitive hand controls or reach for the handset.

## Appearance of the bed

Although appearance comes last in the list (because funding personnel may not feel this is an important feature) individuals and families would place much more emphasis on the need for the bed to look attractive. Disability equipment should no longer be clinical in appearance. Most of the beds have attractive wooden headboards, and a valance can be used, where necessary, to hide the frame and mechanism of the bed.

## Can the bed turn the user over?

### Kineticare Tilting Bed System

Although some of the recommended beds will not turn the occupant over, the Kineticare Tilting Bed System is available. This consists of a power unit with a sub-mattress (i.e. an inflatable bag, which is positioned under the existing mattress on the bed). Using low air pressure, the pump slowly inflates one side of the sub-mattress while the other deflates and the unit can be programmed to turn the person every half-hour, hour or 2 hours. Although the unit is unlikely to be satisfactory unless *the users sleep on their back*, it has been shown to reduce the pressure on the body. Work continues to produce a pump with a remote-control, touch-sensitive switch that can be operated independently by the person in bed - and this should be available soon. The Muscular Dystrophy Campaign has a unit that can be lent on an extended trial to anyone for whom the demonstration has proved successful. Contact *Daily Care Ltd*.

*Marcon (Turnblade Ltd)*

### Lateral tilt on powered beds

Two of the beds included in the chart on page 14 will tilt the user from side to side and assessment is recommended. Unfortunately, the lateral tilt is at the expense of other features and therefore, prioritising the actions required - coupled with the need to compromise - may be necessary when choosing the most satisfactory bed.

Princess 5000: *Action Assist Ltd*  
Baltic: *Centromed Ltd*

### Limitation of the lateral-tilting facility on both powered beds and the Kineticare System

It is important to appreciate that although a tilting action will relieve pressure and may improve comfort, it will not reposition limbs. When turned on their side, some adults will have sufficient movement to be able to do this independently, but it is likely to be a residual problem for boys with DMD.

## How can a bed be assessed and who should attend the assessment?

Both the child and his parents, or the adult, must assess the value of a bed, either at the nearest Disabled Living Centre or by asking the firm to arrange a home demonstration. It is essential that this is co-ordinated with the Muscular Dystrophy Campaign Family Care Officer, the occupational therapist or any other advisor who is making an application for funding. Where appropriate, it will be essential to liaise with the district nurse or health visitor attached to the GP practice, because a bed is usually considered to be community nursing equipment and their opinion may be asked for by the budget holder. If the district nurse or health visitor knows the family and was present at the assessment, they will be in a good position to support the application, although supply may not be either straightforward or guaranteed.

## Does the bed comply with safety standards?

All products must be 'CE marked' to meet the requirements of the Medical Devices Directive and where possible, the guidelines of the British Standard EN 1970:2000, "*Adjustable Beds for Disabled Persons*"<sup>1</sup> should be followed. This includes standards for beds that are intended for use by people over 12 years old. Unfortunately, this report is very expensive, but extracts in relation to rails are reproduced in the Medical Devices Agency booklet "*Bed Safety Equipment*"<sup>2</sup>. As yet there are no UK published standards for beds for younger children, but readers should be aware of the booklet "*Advice on the Safe Use of Bed Rails*"<sup>3</sup>.

## What service and support is offered for breakdown and maintenance?

It is important that service arrangements can be made with the supplier and that there is an efficient procedure for repairing beds when necessary. This should be checked at the time of the assessment.

## Who should supply the funding and maintain the bed, specialist mattress and turning unit?

From experience, electric beds have proved so invaluable to boys with DMD and to children and adults with other neuromuscular conditions that, following a thorough assessment, there should not be any difficulty in justifying the need.

Electric beds, specialist mattresses and other accessories are usually considered to be nursing equipment, in which case the supply is the responsibility of the Health Authority. The professional advisor should make an application to the community physician or paediatrician, senior nursing officer or Trust manager. In other areas, beds are considered to be equipment to increase independence and are supplied by Social Services, or in some cases by joint Social Services/Health Authority Home Loan stores.

Unfortunately, there are areas where neither the Health Authority nor Social Services Department have accepted the responsibility for supplying beds and mattresses; applicants should therefore be warned that either a successful outcome cannot be guaranteed or that there might be a delay prior to supply, if finance is a problem towards the end of the financial year. Conversely, there may be money in the budget that will be forfeited if it is not spent, and is, therefore, unexpectedly available to pay for a bed.

In desperation, disabled people, their parents or advisors resort to writing to charities and voluntary groups to fund beds. Often, because of the urgency, this is the only course of action. Unfortunately, private funding usually places the responsibility for maintaining the bed on the user or the family, although some Social Services Departments may agree to provide a maintenance contract. In these circumstances, ownership of the bed is forfeited, but this may be a price worth paying in order to be free of any ongoing costs.

However, the provision of beds and accessories should be seen as the responsibility of statutory services. Where possible, the appropriate department or personnel should be informed of future needs spanning several years, so that the cost can be built into long-term budgets.

## Which models are the most appropriate for people with neuromuscular conditions?

There would appear to be a large market for electric beds because the number of additional models becoming available is increasing rapidly. However, many of these beds are termed 'community beds' because they are easier to transport and install in a private house, but they are likely to lack the robustness and stability of the well-tried and tested models - and do not offer the required features. Disabled people are 'heavy' users of beds and reliability over a number of years is essential, so the additional cost, which is marginal in relative terms is a price worth paying.

The range of beds available has been assessed extensively by boys with DMD, by children and adults with other neuromuscular conditions, and by their professional advisors. The most satisfactory models, bearing in mind the essential features that have been discussed in this chapter, are included in the chart on the next page.

## What are the specifications of the recommended beds?

The chart on the next page itemises the relevant features of each bed in relation to the needs of children and adults with muscular dystrophy and allied neuromuscular conditions. If other beds are to be considered, the specifications must be comparable.

A spare column has been included in the chart, so that it can be photocopied and sent to the appropriate firm to record the details of their bed. This will allow the disabled person to make an informed choice.

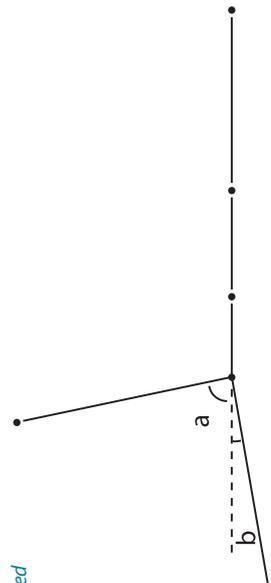
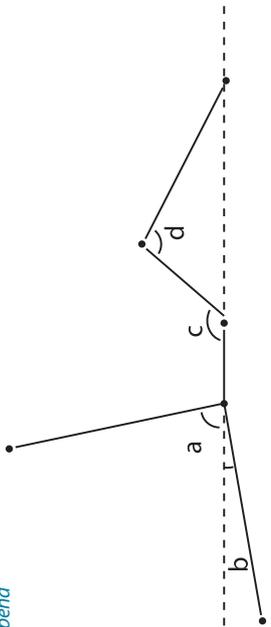
## Comparative chart of electric bed features of recommended models

Model & name of manufacturer/supplier	Guldmann Flexus 2 <i>Moderna Contracts Ltd</i>	Scan 750 <i>Scan Mobility Ltd</i>	Super Baltimore <i>Huntleigh Healthcare Ltd</i>	3080PH Volker <i>BaKare Beds Ltd</i>	Baltic <i>Centromed Ltd</i>	Princess 5000 <i>Action Assist Ltd</i>	Bed in Bed <i>Theraposture Ltd</i>	Homecare bed <i>Ashworth Trading</i>
<b>Specifications of recommended beds</b>	<b>PRINCIPAL REASONS for RECOMMENDATION</b>							
	Used for many years by people with MD & allied conditions, who have experienced robustness & reliability of the beds				Tilt user laterally, to aid independence or reduce frequency of manual turning (do not reposition user)			
	All actions & facilities needed by people with MD & allied neuromuscular conditions are included - see information below		Aesthetically popular & all sizes available, but independent leg control is restricted. Important to check sections 3, 5 & 6 on chart		Some actions & facilities needed by people with MD & allied neuromuscular conditions are not available - & priorities will need to be established. (Please check columns carefully)			
	Complete range of sizes including children's							
Single	✓	✓	✓	✓	✓	✓	✓	✓
Wide single	X	✓	X	✓ 2 sizes	✓	✓	✓	✓
Double	X	✓	X	X	✓	X	✓	✓
Head and foot board	Beech	Beechwood	Wood panelled	Many options	Several options	Beechwood	Several options	Several options
	<b>MATTRESS PLATFORM</b>							
Four-section	✓	✓	✓	✓	✓	✓	✓	✓
Child's four-section platform	X	✓ on 710 (thigh section 150mm shorter)	X	✓	✓	✓	seperate child's model available	can be made to suit individual child
Breaks into how many sections to transport?	2	3	4	3	4	7	2	2
	<b>OVERALL SIZE</b>							
Width	1007mm	1010mm	1135mm	1000mm	915mm	1010mm	900 or 1000mm	stdn.1030mm
Wide single	X	1220mm	X	1100 & 1300mm	1040mm	1161mm to order	various	any
Double	X	2160mm	2100mm	2100mm	1220mm	✓ adjoining to order	1800 or 2000mm	to order
Length	2110mm	2120mm	2185mm	2110mm	2115mm	2200mm	2050mm	2140mm
Extension	200mm	150mm	X	200mm	X	X	200mm	any to order

Comparative chart of electric bed features of recommended models (continued)

Specifications of recommended beds (continued)	Guldmann Flexus 2 Moderna Contracts Ltd	Scan 750 Scan Mobility Ltd	Super Baltimore Huntleigh Healthcare Ltd	3080PH Volker Bakare Beds Ltd	Baltic Centromed Ltd	Princess 5000 Action Assist Ltd	Bed in Bed Theraposture Ltd	Homecare bed Ashworth Trading
<b>RAILS</b>								
Side Rails	✓	✓	✓	✓	✓	✓	✓	✓
Description	Wood	Collapsible wooden	Drop-down metal	Wooden fold away	Drop-down metal	Metal with wood laminate	Various	Collapsible wooden
Rail gaps less than 60mm	70mm	120mm	✓	✓	✓	110mm	Can be less than 60mm	120mm
Or covering supplied	Covering available	Net or padding available	Covering not necessary	Padding available	Padded sides	Padding available	Padding available	Padding available
Grab rails	✓	✓	✓	860mm (head) 590mm (foot)	✓	Top & middle section of side rail	✓	✓
Length	390mm	230mm	530mm	220mm	220mm	With side rail raised, top rail: 257mm middle: 172mm	various to order	top section of side rail
Height above mattress platform (mattress depth must be deducted to measure clearance)	280mm 250mm	90 or 200mm	185mm	Various to order	390mm	With side rail raised, top rail: 257mm middle: 172mm	Various to order	300mm

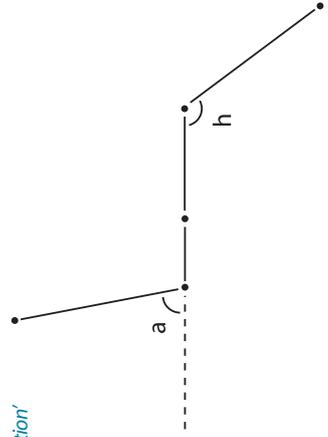
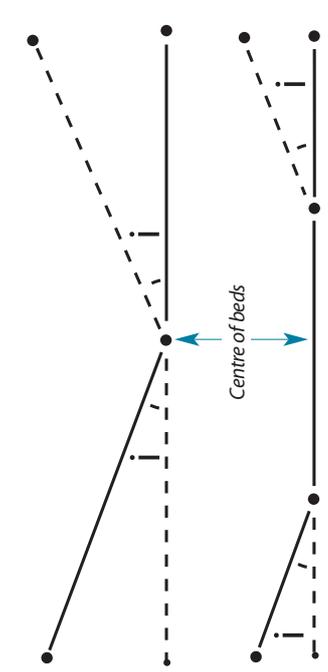
## Comparative chart of electric bed features of recommended models (continued)

Specifications of recommended beds (continued)	Guldmann Flexus 2 Moderna Contracts Ltd	Scan 750 Scan Mobility Ltd	Super Baltimore Huntleigh Healthcare Ltd	3080PH Volker BaKare Beds Ltd	Baltic Centromed Ltd	Princess 5000 Action Assist Ltd	Bed in Bed Theraposture Ltd	Homecare bed Ashworth Trading
<b>CASTORS</b>								
Braked castors	4	4	2	4	4	4	4	4
Central locking	✓	✓	X	✓ on handset	X	Dual locking	✓	X
<b>CONTROL</b>								
Number of motors	4	4	4	4	6	4	3 or 4	4
<b>1. Electric control: raise backrest</b>	✓	✓	✓	✓	✓	✓	✓	✓
<p>1. Raise backrest with legs extended</p>  <p>2. Raise backrest/bend hip &amp; knees</p> 								
a) Angle of backrest when elevated	76°	75°	80°	75°	70°	75°	75°	70°
b) Angle of backrest/lowered beyond horizontal ie. head lower than body	Horizontal only, but Trendelenburg option available	Horizontal only, but Trendelenburg option available	10°	14° Trendelenburg option, but not user controlled for safety	Horizontal only, but Trendelenburg option available	Trendelenburg standard for user control. Lockout facility for carer control only	Horizontal only, but Trendelenburg option available	Trendelenburg option available
Backward movement of backrest when elevating	✓	✓	X (See page 9)	✓	✓	X	✓	X
<b>2. Electric control: raise backrest/bend hip &amp; knees</b>	✓	✓	✓	✓	✓	✓	✓	✓
c) Angle at hip bend	104°	130°	120°	105°	140°	105°	105°	130°
d) Angle at knee bend		100°	90°	118°	105°	132°	95°	120°

Comparative chart of electric bed features of recommended models (continued)

Specifications of recommended beds (continued)	Guldmann Flexus 2 Moderna Contracts Ltd	Scan 750 Scan Mobility Ltd	Super Baltimore Huntleigh Healthcare Ltd	3080PH Volker BaKare Beds Ltd	Baltic Centromed Ltd	Princess 5000 Action Assist Ltd	Bed in Bed Theraposture Ltd	Homecare bed Ashworth Trading
<b>CONTROL</b>								
<b>3. Electric control: raise legs with head &amp; trunk flat</b>	✓	✓	✓	X by manual leg ratchet only (i.e. operated by a helper)	✓	X	✓	X
e) Angle at hip bend with knees straight	160°	160°	168°	135°	140°	N/A	135°	N/A
<b>4. Electric control: bend hip &amp; knees with head &amp; trunk flat</b>	✓	✓	✓	✓	✓	X	✓	X
f) Angle at hip bend	135°	130°	100°	135°	140°	N/A	135°	N/A
g) Angle at knee bend	100°	100°	90°	95°	95°	N/A	95°	N/A
<b>5. Electric control: bend hip &amp; knee &amp; raise feet above head with head &amp; trunk flat</b>	✓	✓	✓	X by manual leg ratchet only (i.e. operated by a helper)	✓	X	✓	✓
f) Angle at hip bend	135°	130°	100°	135°	140°	N/A	135°	135°
h) Angle at knee bend with lower leg parallel to bed platform	135°	130°	100°	125°	140°	N/A	125° (manually operated)	160°

Comparative chart of electric bed features of recommended models (continued)

Specifications of recommended beds (continued)	Guldmann Flexus 2 Moderna Contracts Ltd	Scan 750 Scan Mobility Ltd	Super Baltimore Huntleigh Healthcare Ltd	3080PH Volker BaKare Beds Ltd	Baltic Centromed Ltd	Princess 5000 Action Assist Ltd	Bed in Bed Theraposture Ltd	Homecare bed Ashworth Trading
<b>CONTROL (continued)</b>								
<b>6. Electric control: raise back &amp; lower legs to place user into 'armchair position'</b>	✓	✓	✓	✓ by tilting bed forwards only (may not be suitable for smaller child)	✓	✓ by tilting bed forwards only (may not be suitable for smaller child)	✓ (need to decide if prepared to compromise)	✓ (need to decide if prepared to compromise)
 <p>6. 'Armchair position'</p>								
 <p>8. Profile across width of bed</p>								
a) Angle of raised backrest	76°	75°	80°	89°	70°	70°	N/A	N/A
h) Angle at knee bend with lower leg below the horizontal platform	161°	148°	156°	166°	70°	132°	N/A	N/A
<b>7. Electric control: height adjustment</b>	✓	✓	✓	✓	✓	✓	✓	✓
Minimum height top of platform to floor	360mm	360mm also 230mm	332mm (415mm with adaptors)	355 or 395mm	305mm	350mm	375mm (200mm with adaptors)	400mm
Maximum height top of platform to floor	820mm	810mm	692mm (775mm with adaptors)	700 or 795mm	780mm	800mm	800mm	800mm
Sensitive switch control	✓	✓	Order MD control	✓	✓	✓	✓	✓
Possum, RSL Steeper, SRS compatible	✓	✓	✓	✓	✓	✓	✓	✓
Control on lead or fixed	Lead standard/fixed special	Lead	Lead	Lead standard/fixed optional	Lead standard	Fixed (either side)	Lead standard/fixed optional	Lead
Back-up battery (std/optnl)	✓	✓ optional	✓ standard	✓ standard	✓ 24-42 hours	✓ standard	✓ optional	To lower only
<b>8. Electric control: side tilt</b>	✓	✓	✓	✓	✓	✓	✓	✓
i) Angle of right/left turn	N/A	N/A	N/A	N/A	35°	Programmed 8° user op 30° 1 1/2 hrs user operation overrides automatic turning	N/A	N/A
Automatic turn settings	N/A	N/A	N/A	N/A	1/2 hr, 1, 2 or 4 hourly	N/A	N/A	N/A

Comparative chart of electric bed features of recommended models (continued)

Specifications of recommended beds (continued)	Guldmann Flexus 2 Moderna Contracts Ltd	Scan 750 Scan Mobility Ltd	Super Baltimore Huntleigh Healthcare Ltd	3080PH Volker Bakare Beds Ltd	Baltic Centromed Ltd	Princess 5000 Action Assist Ltd	Bed in Bed Theraposture Ltd	Homecare bed Ashworth Trading
<b>MATTRESS</b>								
<b>Spring-interior mattress</b>	✓	✓	✓	✓		✓ to order	✓	✓
Width x length	900 x 1960mm	850 x 2000mm	940 x 1990mm			900 x 2032mm		
Single	X	1200 x 2000mm	X			1040 x 2032mm	Size & firmness to order	Size & firmness to order
Wide single	X	2000 x 2000mm	X	Any size or depth to order	N/A	X		
Double	130mm (others to order)	200mm	200mm			172mm (others to order)	To order	To order
<b>Foam mattress</b>	✓	✓	✓	✓	✓	✓	✓	✓
Width x length	900 x 1960mm	850 x 2000mm	920 x 1960mm	Any size to order	Any size to order	890 x 2032mm	Any size to order	Any size to order
Depth	100mm (others to order)	150mm	125mm			172mm (others to order)		
<b>Specialist mattress</b>	✓	✓	Vaperm	✓	✓	✓	✓	✓
<b>OPTIONAL ACCESSORIES</b>								
Extension piece	✓	✓ built in	X	✓	✓ made to measure	✓ to order	✓	✓
High base adaptors	✓	X not necessary	✓	✓	✓	X	✓	X not necessary
Side rail net covers	✓	✓	X	X	X	✓	✓	✓
Side rail padded covers	✓	✓	not necessary	✓	✓	✓	✓	✓
Grab rails	✓	✓	✓	✓	✓	✓	✓	✓
Mattress retaining straps	✓	✓	✓	X not necessary	✓	✓	✓	✓
Overbed table	✓	✓	X	✓	X	✓	✓	✓
<b>SAFETY STANDARDS</b>								
Does bed conform to safety standards? See page 11	✓	✓	✓	✓	✓	✓	✓	✓

## References

1. BS EN 1970: 2000, *Adjustable Beds for Disabled Persons*. British Standards Institute, 2001.

**Available from:**

BSI Customer Services, 389 Chiswick High Road, London. W4 4AL.  
Tel: 020 8996 9001.

2. Skeet, Julia et al, *Bed Safety Equipment: an Evaluation*. Medical Devices Agency, Department of Health, 2002.
3. Device Bulletin, *Advice on the Safe Use of Bed Rails*. Medical Devices Agency, Department of Health, 2001. Ref. MDA DB2001(04).

**MDA publications** are available free to health and social care providers, on written request from:

**England:** Medical Devices Agency, Business Services, 9th Floor, Hannibal House, Elephant & Castle, London. SE1 6TQ. tel: 020 7972 8360. fax: 020 7972 8124. e-mail: bs@medical-devices.gov.uk

web: [www.medical-devices.gov.uk](http://www.medical-devices.gov.uk) - provides a full list of Disability Evaluation Reports. Technical enquiries e-mail: andy.marsden@doh.gsi.gov.uk

**Northern Ireland:** Dept. Health & Social Services, Defect & Investigation Unit, Health Estates, Stoney Road, Dundonald, Belfast. BT16 1US. tel: 028 9052 3714.

**Scotland:** Scottish Health Care Supplies, Common Services Agency, Trinity Park House, South Trinity Road, Edinburgh. EH5 3SH. tel: 0131 552 6255 ext. 2350.

**Wales:** National Assembly for Wales, HS4, CP2, Cathays Park, Cardiff. CF10 3NQ. tel: 029 2082 3278.

# Wheelchairs

## for children & adults with muscular dystrophy & allied neuromuscular conditions

*A guide to the issues involved in the assessment, choice and manufacture of wheelchairs and the provision of suitable wheelchair access to a house*

To be used in conjunction with:

Chapter 18     *Addresses: Manufacturers/Suppliers/Sources of Advice.*

The information is written for:

- **people with muscular dystrophy** and allied conditions and their carers;
- **therapists and other professionals** who do not have experience in wheelchair and seating assessments;
- **Wheelchair Services staff** who are experts in wheelchair assessment, but may have limited experience in the provision of indoor/outdoor powered wheelchairs and/or the specific needs of people within this disability group;
- **specialist staff of voluntary disability organisations** who may have particular expertise in advising people with specific disabilities and whom Wheelchair Services are encouraged to use or consult, in accordance with section 15 of the *NHS guidelines, HSG(96)34, Powered indoor/outdoor wheelchairs for severely disabled people (May 1996)*. See Appendix 2;
- **wheelchair manufacturers**, in order to highlight the features that need to be considered;
- **architectural designers** who want to understand more about the mobility equipment around which they are adapting the environment.

Guidance is presented under the following headings:

- ⇒ What is a good seating position? 2
- ⇒ The need for specialist seating systems 5
- ⇒ Range of specifications & wheelchair features 7
  - ⇒ Specialist types of chairs needed 13
    - ⇒ Architectural planning issues 15
- ⇒ Appendix 1. Wheelchair standards & guidelines 17
  - ⇒ Appendix 2. Which chair & why? 20

## What is a good seating position?

There are three aims, and prioritising these will depend upon the individual person. The importance of each is likely to vary according to such factors as time of day or the need to carry out an activity. These aims are to:

- ⇒ achieve a good postural position;
- ⇒ maintain functional ability;
- ⇒ ensure comfort.

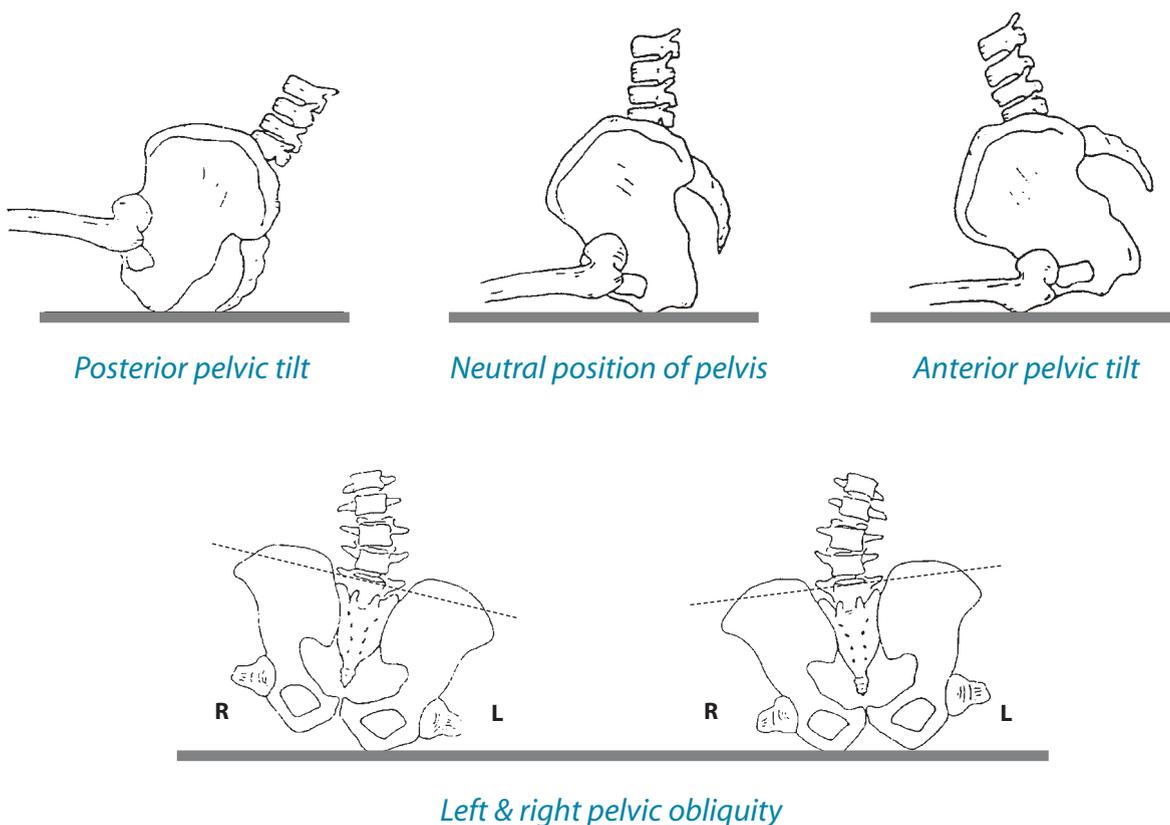
### Achieve a good postural position

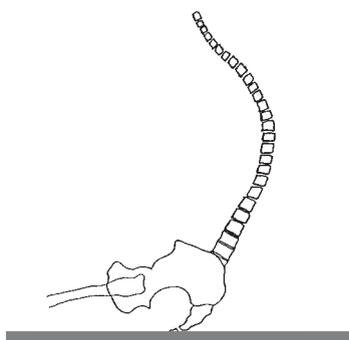
A good postural position may minimise or delay the development and severity of deformity and/or provide support and trunk control. In a progressive disability there is an ongoing need to review the seating position and advice should be sought from the person who carried out the wheelchair assessment. There are two aspects to a good postural position:

- ⇒ maintenance of the correct position of the pelvic girdle;
- ⇒ correct support for the whole body.

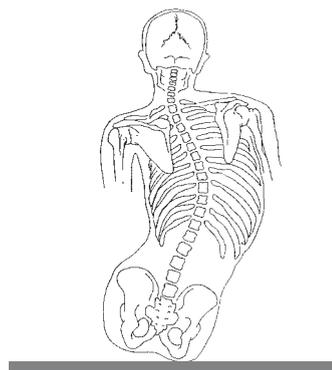
### Maintenance of the correct position of the pelvic girdle

The pelvic girdle must remain in the upright, neutral position, without either a posterior tilt that results in 'sacral sitting' or an anterior tilt that throws the spine forwards, (although a degree of anterior tilt can be helpful and accepted as balanced posture). The iliac crests must be level, with no pelvic obliquity either to the left or right with associated scoliosis (side curvature of the spine) and no rotation of the pelvis.





'Sacral sitting' – showing the accentuated spinal curvature



Pelvic obliquity with associated spinal deformity

Line drawings reproduced with kind permission of Gerald Simonds Healthcare Ltd

## Correct support for the whole body

This depends upon the correct size of chair (see Appendix 1: *Wheelchair Standards & Guidelines*) in relation to the following features:

- ⇒ seat width;
- ⇒ seat depth;
- ⇒ seat surface;
- ⇒ seat height in relation to the footrests;
- ⇒ position and angle of the footrests;
- ⇒ armrest height;
- ⇒ backrest height/angle;
- ⇒ headrest;
- ⇒ position of the wheels on a self-propelled wheelchair or the joystick control of a powered wheelchair.

In contrast to the other chapters in the manual, imperial measurements have been used as this is normal practice for wheelchairs in the UK.

### Seat width

This must be wide enough for comfort and yet a 'neat' enough fit to ensure that the pelvis is stabilised. This ensures that the armrests are near enough to the person to eliminate leaning sideways to gain support from the armpads (which must also be at the correct height) and (unless the chair is powered) that the propelling wheels are as close to the body as possible.

**N.B.** *If side pads are used to reduce the width of the seat, the armpads of the armrests should be extended inwards over the side pads.* This ensures that the person's elbows and forearms are supported without the need to lean sideways.

### Seat depth

The seat depth is crucial to ensure that the spine is supported, while at the same time maintaining the pelvis in a neutral position. With the hips at the back of the chair there must be **1" – 2"** between the front of the seat upholstery and the back of the knee (which is at an angle of **90°**).

### **Seat surface**

The surface must be firm enough to provide support for the pelvis to keep it level. Good support should be identified initially as it influences comfort.

### **Seat height in relation to the footrests**

The user's thighs must remain parallel to the floor with the ankle joint at a right-angle. This is particularly important to prevent plantar flexion (pointing the foot), which will result in long-term foot deformities and make it very difficult or impossible to wear shoes.

### **Position and angle of the footrests**

Unless reclining in order to relax, most people with neuromuscular conditions need to sit upright to enable them to use their limited ability to reach forward and to maintain head control. To provide stability and to maintain this position, the knee joint should be kept at a right-angle. Therefore, the footrests should be parallel to the floor or tipped marginally backwards, ensuring that the ankle joint is also kept at a right-angle. However, when a wheelchair has large front wheels, the footrest hanger has to be angled to avoid obstruction; the footrests nevertheless, can be tipped up to achieve the 90° angle at the ankle joint. Although the angle at the knee joint will have to be increased, this should be kept to a minimum.

### **Armrest height**

The armrests should be at the correct height to ensure that the user's arms are well supported with the shoulders level and not hunched. When the elbows are at the back of the armrests, the elbow joint should be at a right-angle.

### **Backrest height/angle**

The backrest should extend to just below the shoulders for a powered chair, and 2" below the axilla for a self-propelled chair. The backrest angle may be critical to ensure balance and maximum arm function, for example for eating meals. There should be a lumbar pad to ensure good support of the spine and to encourage spinal extension.

### **Headrest**

A headrest should be supplied for anyone with poor head control. In addition, it is essential for anyone travelling in a wheelchair in a van or minibus to use a head support to guard against whiplash injury. A backrest extension may not lie close enough to the back of the person's head and an adjustable headrest, possibly shaped with side wings, may be preferred.

### **Position of the wheels on a self-propelled wheelchair or the joystick control of a powered wheelchair**

The position must be considered carefully to ensure that the person is able to maintain an upright position and does not need to lean either towards or away from the wheels or control, to gain the correct leverage.

## Maintain functional ability

This relates to:

- ⇒ the ability to lean forward;
- ⇒ height-adjustable seats.

### Ability to lean forward

The postural support provided by a seating system must not prevent the ability to lean forward, or reduce function in any way.

### Height-adjustable seats

The importance of this feature is discussed later, in the context of the special features needed by some adults with neuromuscular conditions.

## Ensure comfort

In addition to postural support and cushions, there are two issues involved in providing comfort in a wheelchair:

- ⇒ the ability to change the seating position;
- ⇒ cost.

### The ability to change the seating position

Backache and pain associated with deformity make it essential to be able to alter the pressure on the body, and therefore chairs need:

- reclining backrests;
- seats with 'seat and backrest tilt-in-space' that tilt back from the horizontal;
- legrests that can be raised and lowered independently of each other.

These three functions should be available with the option of being controlled electrically, to allow users complete independence to move within their chairs.

### Cost

Wheelchairs are used by most people with neuromuscular conditions for all or part of the day. Although comfort is, therefore, of great importance, often this is compromised because of lack of funds to buy the most comfortable chair.

It is hoped that the scheme to provide indoor/outdoor powered chairs, with assessment related to individual needs, will ensure that chairs with these important features can be obtained.

## The need for specialist seating systems

The following must be considered:

- ⇒ the features of a good seating system;
- ⇒ commercial systems;
- ⇒ adaptable seating systems;
- ⇒ prophylactic provision;
- ⇒ supply/review.

## The features of a good seating system

These relate to the following:

- ⇒ seat/cushion;
- ⇒ backrest/head support;
- ⇒ foot support.

### Seat/cushion

It is important that:

- there is a firm base under the upholstery or cushion to keep the pelvis level;
- the cushion should be capable of being modified, if necessary, to compensate for a pelvic tilt, and other postural problems;
- the cushion is shaped or deep enough to prevent pressure under the ischial tuberosities and subsequent, associated 'sacral sitting' (posterior pelvic tilt);
- the type of cushion provides comfort and pressure relief, but not at the expense of stability;
- the cushion has not 'bottomed out' either because it was not set up correctly or because of a breakdown in the cushion material;
- side pads of varying size can be inserted, if necessary, in powered chairs to keep the knees together (but not rubbing on each other). These prevent or control abduction (moving out) and rotation of the thighs, which in turn causes inversion of the feet.

### Backrest/head support

From a very early age, children with neuromuscular conditions, particularly boys with Duchenne muscular dystrophy (DMD) tend to lean on one elbow. This posture should be discouraged with the use of side pads, positioned symmetrically on the backrest, to encourage and remind them to sit erect or to relax in a supportive position. If at a later stage the spine develops a lateral curve, the position of the pads can be altered to provide support where it is needed and to help to control the curve.

- A system that includes a lumbar support is needed to encourage extension of the spine and a forward curvature of the lumbar region (lordosis), as this discourages a sideways curvature (scoliosis).
- Many boys with DMD need to sit upright to balance their head – and others use their forearms on a tray for support.
- An effective backrest and head support is essential following spinal surgery.

### Foot support

This is highlighted because of the influence it has on balance, and to draw attention to the specific neuromuscular need to prevent plantar flexion ('foot drop') and equinovarus deformity (rolling out of the feet).

## Commercial systems

There are a number of commercially available modular cushions and seating systems (e.g. Jay, Roho and Vicair) and some Wheelchair Services have developed their own. The advantage of a commercial system is that usually it can be built according to the needs of the user and assessed before purchase. Purpose-built systems cannot be assessed until manufactured and cannot always be adapted so readily.

## Adaptable seating systems

Adaptability is recommended because of the progressive nature of many of the conditions (particularly for a boy with DMD), as it is often difficult for him to accept a change of seating at a later stage.

## Prophylactic provision

When a child first needs a wheelchair – or at least a powered chair – greater attention should be given to a good seating system as a prophylactic measure, because at this age there is no rejection on the part of the child.

## Supply/review

In addition to a quick response in supply, a regular review is needed to ensure that the system is being used to its best advantage and to re-assess in relation to any postural changes. This review should be carried out by Wheelchair Services if the seating was supplied by them – or by the person who carried out the previous assessment.

Specialist seating is not provided as frequently as it should be, because there has often been a struggle to find the funding to buy the chair and additional money is not available. Also, Wheelchair Services may wait until poor posture has developed before prescribing specialised seating – as the funding of preventative measures may not be seen as a priority.

## Range of specifications and wheelchair features

Most of the features are relevant to anyone using a wheelchair, but those that are particular (although not exclusive) to people with neuromuscular conditions are highlighted in the text with an asterisk\*.

The importance of the following are discussed:

- ⇒ seat size;
- ⇒ powered seat/backrest adjustability;
- ⇒ upholstery;
- ⇒ shoulder/head support;
- ⇒ frame;
- ⇒ armrests;
- ⇒ armpads;
- ⇒ leg/footrests;
- ⇒ kerb climber;
- ⇒ control;
- ⇒ battery;
- ⇒ tray;
- ⇒ price.

## Seat size

### ■ **Range of seat width**

The sizes offered should extend from **10"** for the smallest child to **24"** for the largest adult.

### ■ **\*Adjustable seat width**

Although this feature appears to be difficult to incorporate into wheelchair design, it ensures that a chair fits correctly both in the summer when thin clothes are worn and during the winter when extra clothing is needed. Additional width to the chair also helps when a hoist sling is positioned – and allows for growth.

### ■ **\*Adjustable seat depth**

This is necessary to provide good support to the spine to discourage a posterior pelvic tilt and ‘sacral sitting’ – and to allow for growth. Although the use of a back support/cushion may help to stabilise the back, the consequential reduction in the seat depth may be contraindicated in relation to such factors as the armrest length and the position of the control. Also, it is important to ensure support is maintained under the whole length of the femora.

### ■ **Seat height**

The height is important to accommodate the leg length and to provide the optimum level for transfers in and out of the chair. In addition, for those who travel in their wheelchairs, the seat height must allow sufficient headroom to enter vehicles.

## Powered seat/backrest adjustability

### ■ **\*Seat height elevating to approximately 34"**

This should be an optional module to allow adults with muscular dystrophy to stand up from the chair or to reach objects at a height. The importance of this feature is discussed in greater detail on page 14.

### ■ **\*Powered seat and backrest tilt-in-space**

This facility is essential for a wheelchair user who has severe arm weakness and cannot press down with their arms to raise their bottom and relieve the pressure - and will help in the management of pain. It also allows anyone with hip contractures (which prevent them from reclining) to lie back with their head supported. The position is recommended for boys in the later stages of DMD, including after spinal surgery - and to prevent flexion contractures of the neck in anyone unable to hold up their head.

### ■ **\*Powered backrest recline**

In addition to providing the facility to relax, this will reduce the risk of increasing hip contractures and in conjunction with the seat-tilt facility, will ease the insertion of a male or female urinal. See also elevating legrests on page 11.

## Upholstery

### ■ **Choice of firm, but comfortable upholstery**

This is for both seat and backrest, to provide stability, or there should be the option of a hard base for use with a seating system.

## ■ **An attractive appearance and choice of colour**

Aesthetic features are important. This helps both children and adults to accept the chairs and aids the great psychological adjustment that is needed in deteriorating conditions, not only for the child and adult, but also for their relatives and carers.

## ■ **\*Seat belt supplied as standard**

This is essential to ensure safety from the time that the chair is delivered.

## **Shoulder/head support**

### ■ **Choice of height of backrest extension**

A high backrest is more often required to cover the needs of tall people and provide shoulder, rather than head, support.

### ■ **\*Optional adjustable headrest**

Ideally, the headrest should have height, forward/backward and sideways adjustment, in addition to optional wings. This type of headrest is essential to prevent whiplash injury, in anyone who travels in a wheelchair in a vehicle. A headrest extension which follows the angle of the backrest may be too far back to make contact with the person's head. This is particularly true when the person either sits bolt upright or has a forward curvature of the spine.

## **Frame**

### ■ **Easy to fold or dismantle into small pieces**

The chair, either in its entirety, or as separate parts should be light enough to lift into a car with ease.

### ■ **Backrest folds in half**

This will allow carers to lift the person back into the chair, while the base of the spine remains supported. This feature is not always needed, but may be essential where a backrest has been raised – or a backrest extension supplied – to allow for the user's height. It may be an essential feature where a chair is transported in the boot of a car.

### ■ **Choice of chromium-plated or coloured**

Aesthetically, this may be as important to a young person as the colour of the upholstery.

### ■ **Suitable for the attachment of an appropriate seating system**

Ideally, without the need to modify either the frame or the seating system.

### ■ **Provides fixing points**

These are essential for clamping a wheelchair into a vehicle. It is usually more satisfactory if the points are part of the frame, rather than accessories bolted or welded on to the chair.

### ■ **Suitable seat height to allow the headroom needed to access vehicles**

It may be difficult or impossible for the disabled person to bend the head forward to enter the van. Also, it is essential that the user has a headrest extension or head support when travelling in a wheelchair and it is easier if this can be in position before the chair is in the van.

### ■ **Easy-to-grip and height-adjustable pushing handles**

These are for the use of a carer when the gears are disengaged.

## ■ **Sturdy, durable and tamper-proof**

The frame has to withstand heavy use and this should be reflected in the manufacture.

## Armrests

### ■ **\*Height-adjustable within 6" range**

This is particularly important following spinal surgery when the person is sitting more upright in the wheelchair.

### ■ **\*In/out adjustability**

See adjustable seat width, page 8.

### ■ **Supplied with side panels**

These will protect the user from draughts, help with balancing and contain essential items (such as a wallet) within the chair.

### ■ **Easy to remove**

Armrests that are difficult to remove cause a great deal of frustration.

## Armpads

### ■ **\*Width: choice of standard – or wide (possibly with side flange)**

The latter option will prevent the user's arm from falling off the armpad, which is particularly important for those unable to lift their arms on to the pad again, independently.

### ■ **\*Length: standard or extra-long**

It is important to provide full-length support which extends under the wrists, in order to control the joystick.

### ■ **\*Optional support behind the elbow**

This may be important to a minority of disabled people, to prevent their arms from slipping backwards when maintenance of pressure is needed to power the chair up a pavement kerb.

## Leg/footrests

### ■ **\*Standard flip-up**

It is important for the footrests to be moved out of the way to allow access for a carer and/or to enable the disabled person to stand up from the chair.

### ■ **\*Height-adjustability within 6" range**

This is essential to allow various depths of cushions to be used and to enable adjustment of the footrest for the individual leg lengths – and at the same time to ensure that the user's thighs are horizontal.

### ■ **\*Forward/backward adjustability**

This is not a standard feature, although some wheelchairs are available with a choice of footrests. However, trunk stability depends on optimum contact of the feet on the footrest. Therefore it is important to ensure that each ankle is maintained either at a right-angle or at the most suitable angle to allow for any existing foot deformities.

- **\*Adjustable angle to footrest**

As above, this is necessary to maintain the ankle joint at a right-angle or to allow for plantar flexion foot deformities.

- **\*Powered elevating leg/footrest**

This is essential if the backrest reclines and the person has hip contractures. For maximum user independence, the legrests should operate electrically and independently of each other.

- **\*Electrically retractable footrests**

This is a sophisticated feature that at present is available by special modification only. However, it is a facility that is often needed because bending down to lift up or swing the footrests to the side may be impossible – yet essential – to allow a person access within restricted spaces and/or to stand up from the chair.

- **Optional heel and calf straps**

These may help to keep the feet on the footrest. However, there are occasions when the straps should be removed to allow the optimum position of the feet to be maintained.

## Kerb climber

- **Advice on the kerb height that the chair will climb comfortably**

The chair's performance needs to be suitable for the surroundings in which it is to be used. Therefore, it is essential that a demonstration and assessment, with good supervision, is carried out at the user's home. Kerb climbers may be difficult to use if the user's balance is poor.

- **Large kerb-climbing wheels – or a choice of central or side climbers**

It is unlikely that a choice will be available for any particular model of wheelchair, but many users find that, if the wheels do not climb the kerbs, the choice between central or side climbers will depend upon their line of vision.

## Control

- **\*Choice of side or centre control – or the opportunity to fit the alternative – if the condition deteriorates**

This may be important when considering the user's optimum seating position. However, it must be balanced against their independence in moving their wheelchair and their ability to gain access under a surface without help to remove or reposition the control, or the tray on which the control is fitted. A central tray control is likely to cause problems in school as it restricts the space for books and laptop computers. Individual assessment is crucial.

- **\*Ability to swing/slide the control out of the way**

An essential feature to gain access under desks, tables and working surfaces.

- **\*Forward/backward and in/out adjustability**

This will ensure that the disabled person does not have to lean either towards or away from the control to gain optimum leverage.

- **\*Height-adjustability that is independent of the armrest height**

This is a feature that should be available, but is usually a modification. It is needed for the same reasons as above.

- **\*Sensitive control**  
Many people with neuromuscular conditions have severe weakness in their arms and hands, and therefore the sensitivity of the control is important.
- **\*Sensitive on/off switch/speed controls that are accessible**  
These should be on the top surface of the control unit, near the joystick. Controls on a sloping raised console may be difficult to reach.
- **Battery charge indicator**  
Essential for 'peace of mind', particularly when undertaking long journeys.
- **'High tech' shape of remote-control box**  
The value of a 'smart' wheelchair, particularly to young people, cannot be over-stated.
- **\*Optional, small remote-control box**  
This should be available set flush into a tray with no projection below. This option may be necessary for users who need to lean on a tray.
- **\*Optional lap-held switches for the control box**  
These may be necessary for people who need to keep their hands positioned in their lap.

## Battery

- **Easy to lift off**  
A battery which is heavy and difficult to lift off will make it more difficult to fold the chair.
- **Choice of wet or dry battery**  
This choice will be necessary to cater for the conflicting priorities of superior performance versus ease of maintenance.
- **Charging point must be accessible**  
Ease of reaching the charging point will be very important to anyone living on their own who needs to charge the battery independently.
- **Battery range adequate**  
This will, of course, depend on the distances likely to be travelled; it may be useful to have a battery charging point in their vehicle.
- **Option of more powerful (24V) battery**

## Tray

- **\*Standard/rectangular or with 'cut out' front**  
To ensure optimum support for the user's arms.
- **\*Optional availability in perspex**  
To allow the user to see the kerb climber, when positioning the chair at the edge of the kerb.
- **High tech**  
Not 'tea tray' type. Vital for 'street cred'.

## ■ Option of lift-off tray or tray which swings, to store at the side of the chair

The latter may be a practical feature to ensure that the tray is easy to remove and readily available when needed; however, it will increase the chair width.

## ■ \*Forward/backward adjustability

The severe muscle weakness in the arms of many people with neuromuscular conditions makes it important that any working surface is placed in the optimum position to ensure maximum hand function; different activities may require different positions. Also, it may be useful for the tray to be moved marginally forwards for a helper to gain access, or to allow for the thickness of outdoor clothes.

## Price

### ■ Good value for money and as competitive as possible

Unless a chair is tailored to suit an individual client, it may be possible to obtain a significant discount by shopping around - or negotiating with the supplier.

### ■ Inexpensive spare parts that are readily available

This is essential for those totally dependent on their chairs and will ensure a 48-hour standard service or a 24-hour emergency repair service – in accordance with *Section 17* of the guidelines, *HSG(96)34* (likely to change in 2004) which states that NHS maintenance contracts should cover modification, repair and maintenance services, including emergency call-outs.

## Specialist types of chairs needed

There are two types of specialist chairs that are particularly relevant to people with neuromuscular conditions:

- ⇒ active-user/lightweight, self-propelled wheelchairs;
- ⇒ wheelchairs with height-adjustable seats.

### Active-user/lightweight, self-propelled wheelchairs

It will be necessary to:

- ⇒ justify the need;
- ⇒ decide when to supply and the features needed.

### Justify the need

- Active-user wheelchairs have become associated with sport and consequently their *value for people with muscle weakness is not always fully appreciated*. In fact, the advantages gained by disabled athletes are shared by people with restricted power in their arms.
- There is no doubt that all active-user wheelchairs are *easier to propel* than the standard range of chairs supplied by Wheelchair Services in the past, which were designed for stability. Active-user chairs are *more manoeuvrable* owing to their larger wheels and through adjustment of the wheels to the best position for each user. The advantageous camber of the wheels and the lightweight materials from which the chairs are made, are also beneficial.
- In addition to greater ease in propelling and manoeuvring (which enables those

with muscular dystrophy to travel faster), because less strength is needed, they will be *able to sustain the effort for much longer*.

- The supply of an active-user wheelchair may *delay the need for a powered wheelchair* and provides additional grounds to justify its selection.
- A further justification can be made by comparing the time taken, both on a straight run and when manoeuvring around obstacles, between a lightweight wheelchair and a 'standard' NHS chair – and recording the difference in functional ability, which is likely to be significant.
- A lightweight active-user wheelchair will be *easier* for parents and carers to *push up and down kerbs and to lift and stow into a car*. However, it is important to consider whether a folding frame will fit better than a box frame into a small car.
- A sleek, well-designed chair does wonders for a young person's *image and self esteem*, both of which are particularly important considerations.
- The *appearance* of an active-user wheelchair makes the first wheelchair more acceptable to both a child and his parents, and to an adult who is struggling to remain independent – which is very important psychologically.

## Decide when to supply and the features needed

- For children with spinal muscular atrophy (SMA) Type II, a lightweight chair should be supplied from an early age – often before the child is 2 years old.
- There is a critical period when an active-user wheelchair is ideal for boys with DMD. They are usually *still able to walk*, with or without callipers, *but need a wheelchair* when in the school playground, playing outside with friends or shopping. The key aim is to create independent movement, giving *exercise to arms and providing an active way of playing safely*.
- At the initial time of supply, children or adults may not need armrests, but the *seat canvas must provide a firm base. The backrest should extend to just below shoulder height*, which may mean using a small backrest extension.
- Consideration should be given to the likelihood that *increasing support* in the chair will be needed in the future and to the advisability of choosing a model that can have an *extended backrest and armrests* fitted later.
- Some active-user wheelchairs have a fixed sports-bar footrest, but this is a hazard for a user who is able to stand up from the chair. It is also likely to be in the way when the user is being assisted in/out by a carer. In most cases, standard footrests which flip up are more suitable.

## Wheelchairs with height-adjustable seats

These chairs are particularly important to two groups of people:

- ⇒ children with spinal muscular atrophy;
- ⇒ adults with muscular dystrophy.

### Children with spinal muscular atrophy

#### Seat elevation from floor level to wheelchair seat height or higher

This makes a chair very versatile for *pre-school play activities*, and for all children who need the opportunity to *'explore'* in their wheelchair, or to reach different heights.

## Adults with muscular dystrophy

### Help to stand up

Chairs with elevating seats are *essential* for those adults with neuromuscular conditions who cannot stand up from a chair but who *are able to walk or to take the weight on their feet to transfer*. In the latter case, the chair might be the vital link between the powered stand-up/recliner easy chair, powered toilet riser and height-adjustable electric bed.

### Maintain independence

This chair is often the only means by which disabled people can retain the independence *to live on their own*.

### Increase reach

The seat elevation will allow the user to reach up to a higher level, which is an invaluable facility *where muscle weakness limits arm function*.

### Reduce need for adaptations in the home

The opportunity to reach surfaces of different heights may reduce the need for major adaptations, particularly *in the kitchen*.

## Architectural planning issues

### The size and turning circle of a wheelchair

- **Manoeuvring a self-propelled wheelchair in tight spaces usually requires more upper-arm strength than anyone with a neuromuscular condition is likely to possess**

Where possible, a full turning circle will be needed for both self-propelled wheelchairs and for powered chairs. However, there may be situations where the footplates of the chair can turn under a surface, e.g. in a bedroom where there are wheelchair-accessible working surfaces, or in a bathroom where there is an inset basin in a large wall-mounted vanity top.

- **Although the sizes of wheelchairs vary, it is important that there is sufficient space for any model that may be used in the future**

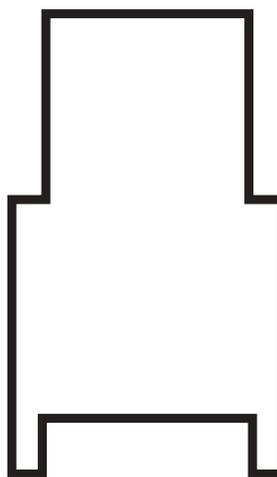
Wheelchairs have become more sophisticated in recent years with an increasing number of chairs being imported from Europe and particularly the Scandinavian countries. Many of these chairs are larger than the standard chairs widely used in the UK. It is important that no options are excluded in the future because of a lack of space. The size of the template reflects the trend towards larger chairs.

### Wheelchair templates

Length: 1250mm Width: 750mm



Scale 1:50



Scale 1:20

## Access into a house

### ■ Ramp gradient

A gradient of **1:20** is recommended for a self-propelled wheelchair, but **1:15** is adequate for a powered wheelchair. If there is insufficient space for a ramp, a short-rise lift or Steplift is an alternative.

### ■ The platform at the top of the ramp

This must extend forwards **1200mm** from the face of the door to allow the wheelchair to be positioned on a level surface and, if necessary, turned through **90°** before moving down the slope.

### ■ Ramp surface

This must be non-slip and have a side upstand of approximately **100mm** for safety.

### ■ A compression threshold

This has a gently curved metal threshold incorporating a central rubber projection that is depressed by a wheelchair and is very satisfactory for both manual and powered chairs. Raised threshold sills (including steel – uPVC weather bars) will prevent access in a powered wheelchair, as the front castors cannot rise over a vertical obstruction.

### ■ The need for wide doors

The width of the doors is influenced by narrow hallways and difficult access problems for a wheelchair, but in most houses a clear opening (i.e. from the face of the door to the door jamb the other side) of between **850** and **900mm** will be satisfactory. If new building is involved, **926mm** doors are recommended.

### ■ Double-swing doors (either single leaf or double leaf)

These are recommended internally to enable a person to open the door independently with the weight of the powered wheelchair. The bottom of the door should be protected with kicking plates.

### ■ Environmental control

The NHS provides environmental controls (see Chapter 8a *Equipment for Adaptations*) to increase independence and these units, in addition to less sophisticated equipment from Social Services, enable a person with arm weakness to *unlock* the door. However the control will not *open* the door, unless linked to an automatic door opener

### ■ Automatic door opener

The importance of an automatic door opener for those who cannot lift their arms and are unable to reach is becoming increasingly appreciated and provision for this should be made by the time that children are using a powered chair without parental supervision. If adaptations are carried out at a very early age, it is prudent to install the fused spur outlet in preparation for installation of the opener, when required.

## Charging a powered wheelchair

### ■ Care of batteries

It is important to follow the manufacturer's instructions for the care of batteries and for the charge to be topped-up regularly. When the battery has completed the charging cycle and the charger is switched off at the mains, it is essential to unplug the charger from the chair to avoid draining the battery.

### ■ A room in which ‘wet batteries’ are to be charged should have good ventilation

For additional safety, a window can be opened when charging is taking place.

### ■ Designated area for charging chairs

It is useful to install a shelf for the charger, adjacent to the **13amp** socket, to eliminate the need to bend down, (see Chapter 14 *Scales & Templates*).

### ■ A shed in which to charge the batteries is not necessary

The only time that special provision needs to be made is where a number of wheelchairs are being charged in the same room, for example in some homes for those who are elderly or disabled. In these cases, it is recommended that the room should be force ventilated, if possible with the ventilation equipment interlocked with the chargers. However, if gel batteries are used, this provision would not be necessary.

### ■ Gel batteries

The performance of gel batteries has improved greatly in the last few years and to avoid the problem of leaving windows open during the winter, it is recommended that this type of battery should be used. Not only does the use of a gel battery avoid the production of significant quantities of hydrogen, but also they have the advantage of no maintenance.

### ■ The need for storage space

Adequate space is very important for the storage of wheelchairs which, although not acknowledged in the *Disabled Facilities Grant* legislation, cannot be stressed strongly enough. Both the Scottish and Bradford eligibility criteria (mentioned in the guidelines, *HSG(96)34*), refer to the need for adequate storage space. Many people with a neuromuscular condition have three wheelchairs:

- a transit chair or self-propelled model;
- an indoor powered chair;
- either an indoor/outdoor or an outdoor powered model.

## Appendix 1: Wheelchair standards and guidelines

There are four standards or guidelines that are relevant to wheelchair users, in the context of this publication, as follows:

- ⇒ Medical Devices Regulations 2002 – *CE Marking*;
- ⇒ Medical Devices Agency. *Guidance on the Safe Transportation of Wheelchairs*;
- ⇒ Measurement of seating and wheelchair dimensions;
- ⇒ *BS 8300:2001 The Design of Buildings and their Approaches to Meet the Needs of Disabled People – Code of Practice*.

### Medical Devices Regulations 2002 - CE Marking

The purpose of CE marking is to introduce uniform and statutory-based controls to regulate the safety and marketing of products throughout the European Community. The European Directive on medical devices, which includes CE marking, is brought into UK legislation under the Medical Devices Regulations. These were updated in 2002 and are aimed at manufacturers who must meet the ‘Essential Requirements’ of the Regulations, including risk analysis and risk management. CE marking means that the manufacturer claims that the product satisfies the ‘Essential Requirements’ for it to be considered safe and fit for the intended purpose.

For wheelchairs, the manufacturers do not need to seek approval of their products by a third party before they are placed on the market, but the Medical Devices Agency (MDA) monitors all aspects of the Regulations as the ‘Competent Authority’ in the UK.

Therapists must ensure that they have read the manufacturers information on a product as a part of their thorough and competent assessment of an individual’s needs. It is the responsibility of the therapist, or client, to complete an adverse incident report on the MDA website or by contacting the MDA (see below) if:

- the manufacturers information is found to be inadequate or inaccurate;
- the equipment fails to perform as stated;
- there is an injury caused by the use of the equipment;
- you think that there may be the potential for an injury to be caused.

The main aim of occupational therapy and rehabilitation is to minimise both the effects and the risks of disability and the risks associated with the use of wheeled mobility or seating equipment while attempting to maximise the individual’s potential. The client must be involved in every stage of the assessment and (where necessary, with advice) enabled to take responsibility for the decision making.

Where modifications are carried out or products are custom made, the responsibility to complete a thorough individual risk assessment lies with the prescriber and will need to take into account the manufacturers information.

### **Medical Devices Agency. *Guidance on the Safe Transportation of Wheelchairs***

Manufacturers should provide information on the transportability of their products within their pre-sales and user information. Most wheelchair manufacturers arrange for their new wheelchairs to be crash tested to give them basic details that they then use to support their transportability statements. Although the results of testing are important, in the event of an accident, there are many other factors that may be (equally or more) significant. These include:

- the speed at which the vehicle is travelling;
- the importance of not sitting sideways or at an angle to the direction of travel;
- the posture and symmetry of the user seated in the wheelchair;
- the appropriateness of the fixing points on both the chair and the vehicle floor.

Hence, the results of crash testing are not the primary information that a user or transport provider needs. The manufacturer should state whether their wheelchair could be transported occupied in a vehicle, or as a piece of luggage. They should give information on any specific procedures or additional equipment that may be required.

It will be important for readers to be aware of the two points of fixture when travelling in a wheelchair in a vehicle. These are as follows:

- an appropriate form of ‘tie-down’ to hold the chair in the vehicle. (N.B. There are many different types on the market now, but you should remember that clamps are generally only suitable for non-powered wheelchairs);

- a separate strap that goes across the upper body of the person in the chair and also across their lap, which is fixed to the vehicle structure. The upper part should be secured to a structure above the shoulder height. The lower ends of the lap belt should be fixed to the vehicle floor. The disabled person (or their carer, if necessary) must take every form of precaution and weigh up the advantages of travel in relation to the risks involved in any mode of transport.

**N.B.** The majority of pelvic straps (with a plastic buckle) secured to the wheelchair or seating are not normally suitable to be used as an occupant restraint in a vehicle. Also, many modern, large, low-floor buses have a designated space for wheelchair users with a padded back support that removes the need for separate straps or 'tie-downs'.

As part of their overall function, the MDA provides advice and guidance to users, carers, healthcare professionals and manufacturers etc. on all safety-related aspects of wheelchairs and seating. Please see the bibliography below. Bulletins are free to health and social care providers.

### Measurement of seating and wheelchair dimensions

For several years there was an attempt to standardise the measurement of seating and wheelchair dimensions. Although this was not taken up by the vast majority of UK wheelchair manufacturers, it is important to consider seat sizes, when assessing a wheelchair and before ordering. In the UK, imperial measurements are usually used for wheelchairs and most manufacturers base their sizes on the size of the seat base or seat canvas. However, users should allow for:

- any additional width between the edge of the seat and the armrests:
- any extra length, from the front of the seat to the front of the backrest, if there is a gap at the rear of the seat and/or any sag in the backrest.

### BS 8300:2001 The Design of Buildings and their Approaches to Meet the Needs of Disabled People – Code of Practice

This covers many items that will be of interest to wheelchair users and to those who are designing buildings and/or who are involved in access issues - and is recommended reading. However, the document is very expensive and the alternative to purchase would be to obtain a copy through your library - or to visit a library that includes British Standards information in the reference section.

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#### Available from:

Wheeled Mobility & Seating Centre, 241, Bristol Avenue, Bispham, Blackpool. FY2 0BR.  
Tel: 01253 596 000. Fax: 01253 596 177. E-mail: mb-mdav@doh.gsi.gov.uk  
Web: www.medical-devices.gov.uk

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Department for Transport, Mobility & Inclusion Unit, Great Minster House, 76, Marsham Street, London. SW1P 4DR

Tel: 020 7944 4923. Fax: 020 7944 6102. E-mail: [miu@dft.gsi.gov.uk](mailto:miu@dft.gsi.gov.uk)

Web: [www.mobility-unit.dft.gov.uk](http://www.mobility-unit.dft.gov.uk)

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Stationary Office Ltd (formally called HMSO)

The Stationary Office bookshops or accredited agents - or

The Stationary Office Ltd, PO Box 29, Norwich NR3 1G.

Tel: 0870 600 5522. Fax: 0870 600 5533. Textphone: 0870 240 3701.

E-mail: [book.orders@tso.co.uk](mailto:book.orders@tso.co.uk). Web: [www.tso.co.uk](http://www.tso.co.uk)

BS 8300:2001, *The design of buildings and their approaches to meet the needs of disabled people – Code of Practice*.

**Available from:**

BSI Customer Services, 389 Chiswick High Road, London W4 4AL. Tel: 020 8996 9001.

## Appendix 2: Which chair and why?

This covers:

- ⇒ NHS provision;
- ⇒ NHS voucher scheme for lightweight/active user chairs;
- ⇒ NHS voucher scheme for indoor/outdoor powered chairs;
- ⇒ Wheelchair choice.

### NHS provision

This section is particularly important in view of the NHS guidelines concerning the provision of wheelchairs. The information included is as follows:

- ⇒ details of the scheme;
- ⇒ referral for NHS wheelchairs;
- ⇒ assessment.

## Details of the scheme

These are discussed in this chapter in relation to the two broad groups of chairs mentioned overleaf. Copies of the guidelines are available from:

Department of Health  
PO Box 410  
Wetherby LS23 7LN  
tel: 01937 840 250  
fax: 01937 845 381

The NHS Department to contact, if necessary, is:

NHS Community Care Branch  
Room 330  
Wellington House  
London, SE1 8UG  
tel: 020 7972 4119 (Pauline Thomas)

However, it is worth noting that in accordance with section 29 of the above guidelines, *"Anyone who is dissatisfied with the service provided under the new arrangements should use the normal NHS complaints procedure"*.

## Referral for NHS wheelchairs

The procedure varies between different areas: although, in most cases, a referral from a physiotherapist or an occupational therapist is accepted, in others the GP must make the referral. The local Wheelchair Services will know which is applicable; the telephone number can be obtained from the GP or local Social Services Department.

## Assessment

These procedures also vary. Accredited therapists usually assess for basic chairs, whereas an appointment can be made with Wheelchair Services for non-standard or more complex needs. Anyone with postural problems may be referred to a specialist team, in which case it might be a help to be accompanied by an MDC Family Care Officer, a therapist or another professional who is familiar with the wheelchair user's needs.

## NHS Voucher Scheme for lightweight/active user chairs

Guidance for the scheme was issued to Health Authorities, NHS Trusts and Wheelchair Service Managers by the NHS Executive in December 1996 (*Wheelchair voucher scheme, HSG(96)53*). The guidance stated that the scheme's primary purpose was to *"give wheelchair users more choice"*, although, at present, with the exception of a few areas, this extends to self-propelled chairs only. All Wheelchair Services were expected to be operating the scheme or to have firm plans for doing so in 1999. The Muscular Dystrophy Campaign is keen to see the benefits of the scheme extended to all users of electrically powered indoor/outdoor chairs (EPIOCs) as soon as possible.

**N.B.** Section 10 of Health Service guidelines, *Wheelchair Voucher Scheme (HSG(96)53)*, states that *"It is not intended that vouchers should, to begin with, be issued for powered wheelchairs"*. This should, however, be revised locally once the voucher scheme has become established.

The scheme offers three options, the second and third of which are designed to enhance the choice of the individual user:

1. **To accept the wheelchair prescribed**, as at present.
2. **The Partnership Option**, where the users contribute to the cost of a more expensive wheelchair of their choice from a range selected by the local Wheelchair Service. The NHS will own the chair and be responsible for its maintenance and repair.
3. **The Independent Option**, where users contribute to the cost of a more expensive wheelchair of their choice, which they then own and are responsible for maintaining.

The Wheelchair Service may include chairs from the range on the next page which can also be considered by a disabled person buying their own chair with (or without) a wheelchair voucher.

## NHS Voucher Scheme for indoor/outdoor powered chairs

As previously stated, the voucher scheme is not available for powered wheelchairs in all areas; however, it is hoped that this type of chair will be included by all Wheelchair Services in the near future. In the meantime, the choice of chairs provided is left to each Health Trust/Wheelchair Services. It is hoped that some of the chairs included on the following pages will be supplied in their range to meet the needs of the individual person and the very specific needs of people with neuromuscular conditions – and to provide the very important element of choice. The Muscular Dystrophy Campaign would be happy to discuss with Wheelchair Services, options for chair ownership and maintenance of more expensive models. It is recommended that the advantages of the person waiving ownership are considered if the chair is maintained free of charge.

### Wheelchair choice

This includes both types of wheelchairs:

- ⇒ lightweight/active user chairs;
- ⇒ indoor/outdoor power chairs.

### Lightweight/active user chairs

The chairs offered by a Wheelchair Service may include chairs within the range below. All these models are prescription chairs with a choice of modules built around the individual users and their own specific needs. It is important that the assessment includes the input of the trained personnel from the different firms, where appropriate, in conjunction with Wheelchair Services.

- **Cyclone range** from *Cyclone Mobility & Fitness Ltd*
- **Handivipp** from *Dan Medica Ltd*
- **Etac and Cirrus ranges** from *Gerald Simonds Healthcare Ltd*
- **Kuschall, Action and REA Comfort ranges** from *Invacare Ltd*
- **Marshall Mark IV** from *Marshall Sports Chairs Ltd*
- **RGK range** from *RGK Wheelchairs*
- **Quickie range** from *Sunrise Medical Ltd*

## Indoor/outdoor powered chairs

It is impossible to mention every chair that may be the most suitable for any particular individual. However, there are a number of chairs that are used regularly for *children and adults with neuromuscular conditions, and the recurring main reasons for their choice are listed.*

### Lox

- Excellent introduction to powered mobility for younger children with SMA;
- excellent appearance;
- three sizes of seat – infant to average size of 5-year-old;
- particularly suitable for young children because seat elevation makes it versatile for pre-school play activities, early mobility and independence;
- quick release into modular pieces for ease of transportation.

*Gerald Simonds Healthcare Ltd*

### Skwirrel

- Well-trying-and-tested chair for children with SMA;
- excellent features including seat-height adjustability;
- available with special switch-control option;
- three sizes of fully adjustable supportive seating;
- seating interchangeable with other systems;
- allows full extension of the child's legs in the 'floor-level' model;
- size needs to be assessed in user's surroundings;
- excellent appearance with 'fun' qualities; friends can travel at the rear of the chair;
- often used in conjunction with the Newton Badger Cub;
- video available.

*DCS Joncare Ltd*

### Skwirrel Maks

- Same pedigree as Skwirrel;
- for larger children, up to approx **10 stone (65kg)**;
- various powered options e.g. height-adjustable backrest/adjustable tilt-in-space seat and backrest, electric-adjustable leg/footrest;
- can fit alternative seating systems;
- special switch-control option;
- Maks can also be 'created' by upgrading the Skwirrel, when child grows;
- video available.

*DCS Joncare Ltd*

### Bobcat DX

- A suitable choice for small children with SMA;
- 'fun' mobility equipment which is aesthetically pleasing;
- height-adjustable seat from floor level;
- various options of supportive special seating and interchangeable standing frame;
- adaptable for growth;
- special switch-control options.

*Smile Rehab Ltd*

## **Kid Power**

- Multi-adaptable design to achieve a good seating position and allow the chair to be altered as the child grows;
- based on the Vitesse range, but with colourful choices for the frame and upholstery;
- suitable to accommodate most seating systems;
- wide range of control options;
- optional powered backrest recline, and seat and backrest tilt-in-space.

*Lomax Mobility Ltd*

## **Vitesse III**

- 'No-nonsense,' well-established chair;
- easy to fold for transportation;
- also available in heavy-duty options – dependent upon the weight of the user.

*Lomax Mobility Ltd*

## **Vitesse 2000/Vitesse 2000 Recliner**

- As above, but also available in a model with an electric reclining backrest.

*Lomax Mobility Ltd*

## **ABC Therapy chair**

- Age range approx. 2-15 years;
- front- or mid-wheel drive for indoor use;
- small turning circle and manoeuvrability;
- two seat sizes with adjustable seat depth and backrest height;
- powered seat raise, and seat and backrest tilt-in-space;
- supportive seating system and tray option;
- special control options.

*Rainbow Rehab*

## **Wizard**

- Front-wheel drive for indoor/outdoor use;
- powered seat raise, seat and backrest tilt-in-space and backrest recline;
- two seat sizes with adjustable seat depth and backrest height;
- supportive seating system and tray option;
- low seat height;
- special control options;
- appealing and fun to drive.

*Rainbow Rehab*

## **Compact**

- Front-wheel drive for indoor/outdoor use;
- low seat height with powered seat raise;
- postural seating options;
- comfort seat with powered seat raise;
- optional seat and backrest tilt-in-space, backrest recline and elevating legrests.

*Rainbow Rehab*

### Miniflex

- Specifically designed for indoor use (limited outdoor);
- manoeuvrable and compact;
- powered seat raise;
- optional powered seat and backrest tilt-in-space and backrest recline;
- optional Comfort seat.

*Rainbow Rehab*

### Flexmobil

- Specifically designed for indoor use (limited outdoor);
- mid-wheel drive for minimum turning circle and manoeuvrability;
- powered seat raise;
- optional Comfort seat with optional powered, seat and backrest tilt-in-space and backrest recline.

*Rainbow Rehab*

### Spectra Plus/Harrier Plus

- Multi-adaptable, which is ideal for achieving a good seating position and allows the chair to be altered as a child grows;
- ability to alter the seat width and depth, features which are available infrequently;
- good upholstery, which provides a firm base;
- wide range of colours;
- easy to dismantle, which makes chair easy to transport;
- frame construction suitable to accommodate other types of special seating;
- good range of accessories;
- optional electric backrest adjustment.

*Invacare Ltd*

### Cruiser 4E

- Front-wheel drive option, which is highly manoeuvrable indoors;
- fitting of specialised seating systems recommended;
- easy to fold for transportation;
- electric backrest adjustment and elevating legrest option.

*Invacare Ltd*

### Storm 3

- Popular with young people because of the high-tech styling;
- various options available, e.g. electric seat and backrest tilt-in-space, electric adjustable backrest, electric elevating legrests;
- optional powered elevating seat (rises up and forwards);
- easy-to-fit modular seating systems;
- wide range of controls;
- up to 6mph option.

*Invacare Ltd*

## **Twister**

- Option of front- or rear-wheel drive for indoor/outdoor use;
- front-wheel drive exceptionally manoeuvrable in confined spaces;
- silent-running motor and range of user-friendly controls;
- powered options include seat elevation, reclining backrest, seat and backrest tilt-in-space, and elevating legrests;
- armrest fully adjustable forward, backward and in/out;
- choice of four seating systems;
- optional clamping bracket.

*Invacare Ltd*

## **Newton Vixen Cub**

- Normally considered to be an indoor chair, but can be used on a good, even, outdoor surface;
- well-trying-and-tested chair, particularly suitable for small children;
- compact chair with narrow turning circle which makes it excellent for indoor use and in confined spaces;
- replacement seating on existing base as child grows;
- also available in outdoor, long-base model;
- usually readily available from Wheelchair Services.

*Newton Products Ltd*

## **Newton Tilt-in-Space Vixen**

- Indoor chair with excellent manoeuvrability;
- can be supplied with basic upholstery or frame only, to accommodate variety of specialist seating systems;
- powered seat and backrest tilt-in-space;
- available through some Wheelchair Services or funded privately.

*Newton Products Ltd*

## **Powertec 40**

- Indoor/outdoor chair;
- custom-built, specified using F45 form;
- wide range of seat sizes and backrests;
- easy-to-transport, folding frame;
- equally suitable for children and adults.

*Sunrise Medical Ltd*

## **Quickie F45**

- Indoor/outdoor chair;
- multi-adaptable which is ideal for achieving a good seating position and allows the chair to be altered as a child grows;
- range of backrests;
- manual or electric backrest recline;
- easy-to-transport, foldable frame.

*Sunrise Medical Ltd*

## Powertec 50s

- Indoor/outdoor chair;
- a trendy, heavy-duty, robust chair able to travel over any terrain and with a good battery range;
- range of backrests and seating;
- manual or electric backrest adjustment;
- manual or electric seat and backrest tilt-in-space;
- colour range appealing to young people;
- easy to transport.

*Sunrise Medical Ltd*

## Quickie F55

- Indoor/outdoor chair;
- 14" - 20" seat width;
- stylish, robust, rigid powerchair with suspension;
- range of backrests and seating;
- manual or electric backrest adjustment (retrofit);
- manual and power seating options (retrofit);
- optional **300mm** seat elevation;
- various speed settings available;
- maximum **21 stone (132kg)** user weight;
- exciting frame colour range.

*Sunrise Medical Ltd*

## Quickie F16

- A quality lightweight clip-on power pack for use on Quickie 2, Quickie 2 Millennium and Quickie RXS manual wheelchairs;
- versatile, but in power mode may not perform as well as a standard electric wheelchair;
- good colour range.

*Sunrise Medical Ltd*

## Jazzy

- Seat frame allows seat growth from **14" x 14" - 20" x 20"** and use of variety of seating frames;
- mid-wheel drive for increased manoeuvrability;
- option of powered seat raise or powered seat tilt;
- on-board charger;
- multiple control options using variety of switches with interface to environmental controls etc. using the Omni Plus.

*Pride Mobility Products Ltd*

## **Mangar Freestyle**

- Seat-height adjustability, which is vital for adults who can walk or stand to transfer, but have difficulty standing up from a chair and reaching;
- small turning circle;
- retractable hand control;
- range of seating options including specialist support seating;
- seat-size modification (or replacement) from small child up to adult;
- manual or electric backrest adjustment;
- leg support adjustment;
- optional 'tie-down' points;
- individual choice of colours for upholstery.

*Mangar International Ltd*

## **Booster Calypso**

- Fun mobility prior to need of indoor/outdoor wheelchair;
- seat position adjustable;
- for access, seat swivels and arm lifts up without altering position of tiller;
- angle of tiller adjustable to maintain support for arms on armrests;
- anti-tip wheels, but not recommended for gradients of more than **10%**;
- with battery removed, chassis divides for transportation;
- mechanically simple;
- three- or four-wheeled versions.

*Movingpeople.net*

## **Booster Beetle**

- Front-wheel drive indoor/outdoor chair with excellent manoeuvrability;
- adjustable alternative made-to-measure seating options with forward adjustment of armrest;
- powered backrest, seat-height adjustability, seat and backrest tilt-in-space;
- powered elevating legrest with powered length adjustability.

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## **Booster Puma**

- Robust rear-wheel drive for indoor/outdoor use with excellent comfort suspension for rough terrain;
- separate seat chassis allows infinitely-variable seat width and depth to accommodate growth;
- other features as Booster Beetle;
- range of controls to suit user;
- particularly suitable for bigger/heavier user up to **19 stone (120kg)**;
- speeds up to **6.5mph**.

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## **Adaptachair**

- Rear-wheel drive, indoor/outdoor chair built to individual needs;
- Recaro seat with adjustable lumbar support;
- powered seat height adjustability, fully-reclining backrest and optional elevating footrests;
- adjustable armrest tilt (but not height);
- minimum seat height suitable for driving and restricted vehicle headroom;
- optional swing-away controller and tray.



# Hoisting

## for children & adults with muscular dystrophy & allied neuromuscular conditions

To be used in conjunction with:

- Chapter 8a     *Equipment for Adaptations;*
- Chapter 10    *Disability Needs Assessment Form/Architectural Brief;*
- Chapter 17    *Multi-use Facilities;*
- Chapter 18    *Addresses: Manufacturers/Suppliers/Sources of Advice.*

Hoisting is a straightforward procedure, but a number of issues need to be considered:

- ⇒ Why use a hoist? The EEC Directive    2
- ⇒ Mobile hoist vs fixed ceiling track (or gantry) hoist    6
  - ⇒ Mobile hoist    7
  - ⇒ Fixed ceiling track hoist    10
  - ⇒ Hoist assessment & slings    20

## Why use a hoist? The EEC Directive

The legislation is considered under the following headings:

- ⇒ lifting: new rules protecting carers;
- ⇒ the employer's obligations;
- ⇒ risk assessment;
- ⇒ individual risk factors;
- ⇒ implications for people with neuromuscular conditions and their helpers;
- ⇒ the professional assessment.

### Lifting: new rules protecting carers

On 29 May 1990, the EEC brought out a Directive (90/269/EEC) "*on the minimum health and safety requirements for the manual handling of loads where there is a risk particularly of back injury to workers... Member States shall bring into force the law, regulations and administrative provisions needed to comply with this Directive not later than 31 December 1992*".

This was followed by:

- Manual Handling Operations Regulations of 1992, introduced on 1 January 1993. "*The effect of this legislation is to prevent accidents and may be relevant to compensation for the injured lifter*";<sup>1</sup>
- Royal College of Nursing *Code of Practice for the Handling of Patients, 1993*. This stated: "*No nurse should take the full weight of any patient, under ideal conditions, weighing more than 30 kilos (approx. 5 stones)*". For two nurses the weight is "*50 kilos (8 stones) with the weight shared between them. Note: Two nurses cannot necessarily lift twice the weight lifted by one nurse*".<sup>1</sup>
- RCN revised *Code of Practice for the Handling of Patients* in April 1996. The RCN at the same time launched a safer patient-handling policy with the aim of eliminating hazardous manual handling in all but exceptional life-threatening situations. The revised code says: "*Manual handling may continue provided that it does not involve lifting most or all of a patient's weight*".<sup>1</sup>

As a result, the importance of hoists and the availability of manual handling equipment have escalated. The latter, however, is not discussed here as such equipment does not influence the adaptations.

The details of the EEC Directive are presented as published so that the implications can be seen in context. To highlight the relevance to people with neuromuscular conditions and their helpers, *comments are placed in brackets and marked with an asterisk*.\*

These comments are related to:

- the specific physical problems of many people with neuromuscular conditions which make handling difficult;
- the importance of avoiding hazardous lifting situations;
- the need for the supply of specialised equipment such as a hoist, and a bed with a height-adjustable mechanism.

## The employer's obligations

These can be summarised under three headings:

- ⇒ general provision;
- ⇒ organisation of the workstation;
- ⇒ information and training of workers.

### General provision

*"... to avoid the need for manual handling of loads by workers. Where this cannot be avoided the employer shall take the appropriate organisational measures ... or provide workers with such means in order to reduce the risk involved in the manual handling of such loads having regard to the Risk Assessment".*<sup>1</sup> \*(This strengthens the need for the supply of a fixed ceiling track hoist.)

### Organisation of the workstation

*"Where the need for manual lifting cannot be avoided, to organise workstations in such a way as to make handling as safe as possible"*<sup>1</sup> \*(by supplying a bed with a height-adjustable mechanism, to make it easier for the disabled person to get in and out of bed and/or to place the bed at the optimum height for the carers when attending to the disabled person in the bed) *"and to assess"* \*(with a comprehensive OT assessment) *"in advance if possible, the health and safety conditions of the work involved"*.<sup>1</sup>

### Information and training of workers

*"Workers must receive information on the weight of loads and proper training on how to handle loads correctly"*.<sup>1</sup> \*(Definition of loads includes people.)

### Risk assessment

From 1 January 1993, UK Regulations state that a Risk Assessment must be undertaken and it is the employer's responsibility to see that this happens. The EC Directive and the UK Regulations acknowledge that there are many factors, divided under four headings, to be taken into account when assessing the risks involved, as follows:

- ⇒ characteristics of the load;
- ⇒ physical effort required;
- ⇒ characteristics of the working environment;
- ⇒ requirements of the activity.

## Characteristics of the load

The manual handling of a load may present a risk, particularly of back injury if it is:

- *"too heavy or too large"* \*(guidelines on weights are contained in the Regulations and the weights are lighter than those of the College of Nursing mentioned on page 2);
- *"unwieldy or difficult to grasp"*, \*(people with neuromuscular conditions are often very floppy);
- *"unstable"* \* (lack trunk control) *"or has contents likely to shift"*;
- *"positioned in manner requiring to be held or manipulated at a distance from the trunk, or with a bending or twisting of the trunk"* \*(lifting out of a bath or transferring manually from one chair to another – or bed to chair);
- *"likely, because of its contours and/or consistency, to result in injury to workers, particularly in the event of a collision"*.<sup>1</sup>

## Physical effort required

A physical effort may present a risk, particularly of back injury if it is:

- *"too strenuous"*;
- *only achieved by twisting movement of the trunk"* \*(leaning over a bath to position a ceiling hoist sling);
- *"likely to result in a sudden movement of the load"*;
- *made with body in an unstable posture"*<sup>1</sup> \*(carrying a child upstairs).

## Characteristics of the working environment

These are unacceptable where:

- *"there is not enough room"* \*(substantiates the need for space in the bedroom and bathroom – see Chapter 15 *Adaptation Specifications* and Chapter 11 *Space Requirements*) *"in particular vertically, to carry out the activity"*;
- *the floor is uneven, thus presenting tripping hazards, or is slippery"* \*(the need for suitable floor covering in the bathroom) *"in relation to the worker's footwear"*;
- *the place of work or the working environment prevents the handling of loads at a safe height or with good posture by the worker"* \*(the need for a height-adjustable bed – see Chapter 8c);
- *"there are variations in the level of the floor or the working surface, requiring the load to be manipulated on different levels"* \*(carrying upstairs);
- *"the floor or foot rest is unstable"*;
- *the temperature, humidity or ventilation is unsuitable"*.<sup>1</sup>

## Requirements of the activity

The activity may present a risk particularly of back injury if it entails one or more of the following requirements:

- *"over-frequent or over-prolonged physical effort involving, in particular, the spine"*;
- *an insufficient bodily rest or recovery period"*;
- *excessive lifting, lowering or carrying distances"* \*(carrying a child upstairs – which substantiates the need for a lift or ground-floor extension);
- *"a rate of work imposed by a process which cannot be altered by the worker"*.<sup>1</sup>

## Individual risk factors

The worker may be at risk if he/she:

- *“is physically unsuited to carry out the task in question;*
- *is wearing unsuitable clothing, footwear or other personal effects;*
- *does not have adequate or appropriate knowledge or training”.<sup>1</sup> \*(Highlights the importance of being taught risk-free transfers instead of manual lifts, e.g. use of hoists, transfer sliding boards, etc.)*

## Implications for people with neuromuscular conditions and their helpers

It must be noted that responsibility lies with the employer and the carer working in the home, school, hospital, etc. In the last few years there has been greater involvement of disabled people in the use of paid carers, as disabled people have received financial grants from the Independent Living Fund. This has increased with the *Community Care (Direct Payments) Act 1997* which allows Local Authorities to make direct cash payments to individuals instead of providing Community Care services that they are assessed as needing. Therefore, it is important to understand the employer/employee relationship. Where the employer is the disabled person or their family, they will have the same responsibilities for the health and safety of the carer as any other employer. A disabled person should ask their Social Services for advice and consider employing carers through an agency. The employee has a duty to make full and proper use of any equipment or system provided by the employer in compliance with the regulations.

If a family or individual does not have the appropriate equipment for use at home they should contact Social Services and ask for a moving and handling assessment. At school, the responsibility would lie with the Education Authority to supply any equipment necessary. The arrangements must focus on the individual needs and a care plan should indicate the chosen method for handling/transferring the person. The professional assessment carried out by a physiotherapist, occupational therapist or nurse who is likely to be employed as a manual handling advisor, must be written down and used as a basis for action and the supply of equipment.

## The professional assessment

The format could be as follows:

- ⇒ purpose of handling task;
- ⇒ disabled person’s data;
- ⇒ environment;
- ⇒ selection of technique(s)/equipment;
- ⇒ needs of paid or family carers;
- ⇒ action.

## Purpose of handling task

- Provide details of the situations in which lifting is necessary and the need to avoid manual lifting.

## Disabled person's data

- Weight, height, shape;
- physical disability and diagnosis, if appropriate;
- ability to assist;
- onset of fatigue;
- clothing \*(*slippery surface of a spinal brace*).

## Environment

- Furniture;
- equipment;
- space.

## Selection of technique(s)/equipment

- Mechanical;
- electrical;
- assistance needed.

## Needs of paid or family carers

### Action

- Care plan;
- re-assessment date.

Once it has been decided that a hoist is essential, two decisions have to be made:

- Is a mobile or a fixed ceiling track hoist a more appropriate method of hoisting?
- Which particular model is the most suitable?

These options are considered below, in turn.

## Mobile hoist vs fixed ceiling track (or gantry) hoist

Essentially, this choice is usually very straightforward, as follows:

- Ceiling hoists run on a ceiling track and transfers can be made under the track only. If all the necessary transfers can be made within the bedroom and bathroom (if an extended track is provided), then a ceiling hoist is likely to be the best option.
- Unless an extended track is feasible, mobile hoists are essential if transfers need to be made in other rooms on the same floor. If transfers are needed on two floors, a ceiling hoist and a mobile hoist are likely to be the best solution.
- A ceiling hoist on a gantry (floor-standing metal frame) may be the best solution when a disabled person requires an overhead hoist temporarily, such as when a house move is pending or another address is visited regularly.
- If a hoist is needed for use out of the house and in the bedroom and/or bathroom, the best solution may be to have two hoists (i.e. a ceiling hoist in the house and a mobile hoist stored in the van or car).

However, there are a number of additional factors that may influence the choice between a mobile or ceiling hoist and these are discussed in relation to the advantages and disadvantages of each type.

## Mobile hoist

The following will be considered:

- ⇒ advantages;
- ⇒ features to be considered and possible disadvantages;
- ⇒ recommended models.

### Advantages

There are three main advantages.

#### ■ The hoist can be used in different rooms

Typically, this would be in a bedroom, to lift in/out of bed, and a sitting room, to lift in/out of an easy chair, or in a school, for use in different classrooms, gym, etc. The main advantage of a mobile hoist is the ability to use the hoist in different rooms that are not adjacent.

#### ■ The hoist is suitable for lifting up from the floor anywhere in the house or garden

For a person who falls regularly and depends on a carer to lift them, a mobile hoist may be invaluable. Assessment of this manoeuvre is essential, as some models are easier to use and more suitable than others in this situation. Alternative equipment for getting up from the floor should also be assessed, (see Chapter 8b ‘*Seat to Standing*’). However, for an adult who falls frequently over a period of several years and needs to be lifted in/out of a bath etc., there may be justification for the supply of both a mobile and ceiling hoist, until safety is ensured by the continuous use of a wheelchair.

#### ■ The hoist can be transported for use away from home

The ability to transport a mobile hoist in a car or van makes it ideal for lifting in other situations and suitable for holiday use. Ensure that the model chosen either breaks down into component parts, or folds and can be wheeled into a suitable vehicle.

### Features to be considered and possible disadvantages

#### ■ Does the boom of the mobile hoist travel through an arc when raised?

Unfortunately, this drags the disabled person forwards and increases the tendency to swing.

#### ■ When moving in the hoist, is there a tendency to swing?

Although it is not recommended that a mobile hoist is used to transport a disabled person from one room to another, sometimes it needs to be pushed/pulled within a room. On these occasions, with the exception of the two recommended models that do not use sling straps, the disabled person tends to swing. This will be difficult for anyone who lacks trunk control and they will feel vulnerable, particularly if unable to hold on to the spreader bar to steady themselves.

#### ■ Does the base of the hoist fit under or around the furniture (e.g. bed or chair), from which the disabled person needs to be hoisted?

If the furniture is too low, can it be raised satisfactorily. If it is too wide to be straddled, is it possible to position one leg of the hoist base under the furniture? If the base of a mobile hoist does not fit under the bed or around the chair, it may be difficult to lower the disabled person into the precise position required.

■ **Is the hoist compact enough to be manoeuvred easily in the areas in which it needs to be used?**

A mobile hoist may be difficult to manoeuvre and this may be impossible in a small room, through narrow doorways or tight turns. It can also be difficult to push a hoist on carpet.

■ **Does the hoist have the required lifting range?**

A mobile hoist may have an extensive lifting range (e.g. from floor to bed), but a limited maximum height to which it can lift. As a result, if the person is to be transferred on to a high surface, the length of the sling straps has to be restricted and the disabled person may feel that their head is likely to bump on the spreader bar.

■ **Where will the hoist be stored when not in use?**

A mobile hoist has to be stored and is yet another piece of equipment cluttering up a house and reducing the vital circulation space required by a wheelchair user.

■ **In a mobile hoist, a disabled person is totally dependent.**

A carer is needed not only to put on the sling but also to push the hoist.

■ **Does the sling provide adequate head support if required?**

Because of the limited distance between the average seat height and the spreader bar of a mobile hoist, disabled people may feel that their head is vulnerable in a sling that is large enough to provide head support, because it is too near the spreader bar.

■ **Is a manual model adequate, or would an electrical model be more satisfactory?**

Operating a manual hoist at the same time as lowering a severely disabled person into a chair may be difficult if the helper has to lift the back of the sling, (because pushing on their knees causes pain) to position the person correctly into the back of the chair. The effort involved, and the height of the operating handle in relation to the height of the main carer, must be assessed. Electric hoists are strongly recommended and are usually considered essential for regular/daily use.

## Recommended models

Many different models of mobile hoists are available, but the models that satisfy all the possible criteria are as follows:

- ⇒ *Arjo Trixie and Arjo Lisa;*
- ⇒ *Liko Golvo 7000ES/7007ES.*

### **Arjo Trixie and Arjo Lisa**

These hoists have several very important features:

- a 'wishbone' spreader that enables fine tuning of the sitting position and therefore of the head control of the disabled person in the sling – and allows this position to be altered instantly. This is an important feature for anybody with a neuromuscular condition. In addition to providing a comfortable sitting position, it also enables the person to be tipped forwards to ensure that their bottom is positioned at the back of the seat before being lowered;
- the sling is attached directly to the spreader bar without the use of straps, thereby reducing the tendency for the disabled person to swing in the sling when the hoist is moved;

- the hoists are suitable for lifting children working on the floor in physiotherapy sessions or adults who have fallen;
- the hoists are powered and therefore are easier and quicker to use, although diligence is needed to keep the battery charged and ready for use;
- the *Arjo Trixie* is easy to fold, push on its wheels and transport;
- the *Arjo Lisa* can be taken apart to transport;
- there is an excellent range of slings in polyester nylon or mesh, in seven sizes. The four-point standard body sling, with additional padding, is recommended for people with a neuromuscular condition. The Arjo representative can be consulted where necessary, if there is no suitable sling in the standard range.

As a result, these hoists are highly recommended for school use for boys with Duchenne muscular dystrophy and children with other neuromuscular conditions, and are equally suitable for adults with all types of MD. It is important to ensure that these models are always assessed when choosing the most suitable mobile hoist.

*Arjo Ltd*

### **Liko Golvo 7000ES/7007ES**

The model numbers relate to the domestic/multi-use hoists respectively. The latter model is slightly larger and will lift higher.

The particular advantages of these hoists are as follows:

- they have a belt-driven column that lifts in the same way as a ceiling hoist, but on a portable frame;
- the legs of the base are powered to move out parallel to each other (all other hoists move out in a 'V' shape) which makes them more stable when being pushed and creates a wider safer working area on the floor. This is particularly useful for:
  - lifting from the floor;
  - straddling furniture;
- it allows the hoists to be used as an aid for standing to transfer or for walking practice.
 

*N.B. In this situation the equipment must be carefully assessed by a physiotherapist experienced in the treatment of people with a neuromuscular condition, with additional advice from the hospital clinic team, and is likely to be contraindicated and unsuitable following spinal surgery.*
- there is an extensive range of slings in three fabrics and five sizes. The range includes a standing/walking vest with leg harness and walking pants, which can be used also with the *Liko 240/242* ceiling hoist.

*Liko (UK) Ltd*

## Fixed ceiling track hoist

The following will be considered:

- ⇒ advantages;
- ⇒ disadvantages;
- ⇒ essential features;
- ⇒ short track vs extended track;
- ⇒ achieving the correct position of the track over the equipment and transfer spaces;
- ⇒ use of a swing kit/room-to-room system;
- ⇒ correct position of the track over the bed;
- ⇒ correct position of the track over the toilet;
- ⇒ recommended position of 13amp fused spur;
- ⇒ the timing of the installation of the hoist;
- ⇒ recommended models.

### Advantages

- The spreader bar rises vertically and the disabled person is not dragged forwards.
- The tendency to swing is limited.
- Use of the hoist does not depend upon the width or height of the furniture or equipment from which the disabled person needs to be hoisted.
- A ceiling hoist, correctly installed, can lift from any equipment under the track, but the spreader bar must have a **360°** swivel.
- Use of a ceiling hoist is not dependent upon manoeuvring through narrow doorways or tight turns.
- It would be unusual for a ceiling hoist to have an inadequate lifting range. The height that a ceiling hoist can lift is limited only by the height of the ceiling and the size of the track and motor.
- A ceiling hoist does not need to be stored.
- A ceiling hoist is unobtrusive (particularly if the track is fitted wall to wall) and takes up no space.
- The hoist can be used independently or with minimal help from a carer. Although help may be needed to position the sling, if a ceiling hoist has suitable touch-sensitive switches, it can be operated by a severely disabled person, and this independence, in a heavily dependent life, is important to most people.
- A ceiling hoist is very safe for a carer to use, without the risk of a back injury.
- The sling will provide adequate head support (if this is required).
- In a ceiling hoist there will be adequate distance between the spreader bar and the floor or the seat and bed height, to ensure that any length of sling can be used without the user's head being vulnerable because it is too near the spreader bar.
- In purpose-built accommodation, the layout can be designed to allow access to all the necessary areas in the house.
- If a disabled person tends to fall in a particular room, a room-covering system will be suitable to pick up from any position.

### Disadvantages

- Unless it is a portable model that can be lifted off the track, a fixed ceiling track hoist cannot be used in two rooms unless they are linked with a track.
- With the exception of en-suite rooms, it may be cumbersome to install a ceiling track to include every room in which a hoist is needed.
- The hoist cannot be used for lifting up from the floor anywhere in the house or garden.
- Unless a disabled person is able to crawl to a position under a ceiling hoist (either a single track or room-covering system) a mobile hoist will be more suitable.

## Essential features

The essential features of ceiling hoists for people with muscular dystrophy and other allied neuromuscular conditions (see also page 18) relate to the following:

- ⇒ sensitive switches;
- ⇒ length of switch cord;
- ⇒ type of switch cord;
- ⇒ swivel spreader bar;
- ⇒ twin or triple sling hooks at each end of the spreader bar;
- ⇒ suitable slings;
- ⇒ emergency lowering device;
- ⇒ rechargeable battery.

### Sensitive switches

As someone with muscular dystrophy becomes increasingly disabled, their dependence on others becomes more acute. Therefore, it is essential to increase independence as much as possible. A ceiling hoist with touch-sensitive switches can be controlled by everyone with any neuromuscular condition. When assessing the suitability of a switch, however, it is important to consider the long-term hand function. Pull cords are never suitable, as it is necessary to be able to raise the arm to pull down the cord; in addition, rocker-switches, although often considered easy to operate, are never as sensitive as push-buttons and, therefore, are not suitable.

### Length of switch cord

This must extend so that the centre of the switch panel is **500mm** from the floor. This enables those users who are unable to lift up their arms, to position the control in their lap, with their arms resting on their thighs.

### Type of switch cord

A switch panel on a straight cord is recommended for anyone with limited strength in their hands and arms, as restraining a curly cord will be impossible. It is then essential to ensure that the cord is not damaged by being trapped or excessively pulled – and that it is the recommended length (see above) to allow the control to be held on the user's lap - eliminating the need to reach upwards.

### Swivel spreader bar

If the spreader bar swivels through **360°** it is not as important to position the wheelchair so that the front and back are parallel with the length of track and, if necessary, they can be at an angle to the track. The swivel feature is vital where a track extends from the bedroom into the bathroom (over the toilet and bath) to assist lowering the disabled person into the correct position.

### Twin or triple sling hooks at each end of the spreader bar

Twin hooks enable the back and leg sections of the sling to be hung on to separate hooks to provide front-to-back depth in the sling and prevent the user from feeling 'bunched up'. Also, if a strap is twisted, it can be repositioned without affecting the other straps. Triple hooks, if available, provide an additional hook on which to hang the strap attached to the head support, but some slings are designed and tailored to support themselves with stiffeners, and/or foam padding.

## Suitable slings

(These are discussed on pages 20-23.)

## Emergency lowering device

It is important that the hoist incorporates a method of being lowered in the event of a power cut. This may be manually or battery operated, or both.

## Rechargeable battery

If the track is to be extended into the bathroom, (either at the time of installation or possibly in the future), it will be necessary to supply a model with a rechargeable battery, rather than a hoist with an extending cord.

## Short track vs extended track

The following will need to be considered:

- ⇒ for use in en-suite facilities;
- ⇒ the choice for initial installation;
- ⇒ factors affecting the choice.

## For use in en-suite facilities

It is essential that people with neuromuscular conditions should have en-suite facilities so that, if necessary, they can be dressed/undressed on their bed and transferred to and from the bathroom within the warmth and privacy of the two rooms, and so that a ceiling hoist track over the bed can extend into the bathroom.

In designing for a person with a deteriorating neuromuscular condition, it is not always possible to anticipate the long-term needs or (particularly in the case of an adult) to reconcile these with the short-term needs. Therefore, if the option of an extended track is not adopted initially, the plans should still be drawn with the fittings sited in the optimum position for an extended track, in case this proves to be the most suitable method of transfer in the future.

## The choice for initial installation

There are two options, as follows:

### **Over the bed and across the bedroom (preferably wall to wall) for use with a mobile bath or shower chair (with the possibility of installing a ceiling turntable with an extended track in the future).**

The track should extend from the wall beside the bed and be long enough to cover the bed width plus adjacent floor area needed for two wheelchairs i.e. plus **1800mm** in order to use the hoist for lifting in and out of bed and from one chair to another. Unless the room is very wide, the track is more unobtrusive if it extends wall to wall and provides the opportunity to charge the hoist in the bedroom, but not over the bed (see pages 16-17);

### **Over the bed (preferably wall to wall) plus an extended track into the bathroom.**

## Factors affecting the choice

- Is a shower or a bath the most appropriate facility? See Chapter 7 *Bath vs Shower*.
- If a shower is chosen, is it used with a shower chair that will transfer the user between the bedroom and bathroom?
- If a bath is chosen, how much support is needed, now or in the future, as this will influence the choice of equipment?
- What is the most appropriate method of lifting in/out of the bath, in view of the equipment chosen to support the disabled person in the bath.
- Is a shower toilet recommended? This is significant, because the washing and (particularly) the drying action is more effective if the disabled person sits directly on the seat and not on a superimposed mobile bath or shower chair. This means that, ideally, a ceiling hoist will be installed (front to back) over the shower toilet.
- The decisions above will dictate whether a mobile hoist chassis or an extended track is used to transfer between the bedroom and bathroom (except where a ASM Multi-System In-Bath Cradle is used, as the cradle can be transferred between the rooms, on either a mobile chassis or a ceiling hoist).

The issues involved in the choice of equipment are discussed in greater detail in Chapter 8a *Equipment for Adaptations*.

## Achieving the correct position of the track over the equipment and transfer spaces

There are four options: curved tracking; ceiling turntables, switched track or a room-covering system, to ensure that the ceiling hoist is able to pick up from the essential positions in a room. The choice would normally be made in two stages, as follows:

- ⇒ curved tracking vs electrically-operated ceiling turntable or switched track;
- ⇒ electrically-operated ceiling turntable or switched track vs room-covering system.

### Curved tracking vs electrically-operated ceiling turntable or switched track

In the past, the position of the bed and the fittings in the bathroom were dictated by the limitations of the track, which could change direction only via a curved section. The advent of powered ceiling turntables allows the track to change direction at any pre-set angle. This is likely to be important in order to install the fittings in the most satisfactory position in the bathroom and to allow those who initially had a ceiling hoist over the bed only (to be used with a Mermaid Ranger or shower chair), at a later date to extend the tracking to the bathroom. Turntables can be operated manually with a pull-cord, or electrically. Anyone with a neuromuscular condition is unlikely to have sufficient arm strength to operate a manual turntable and the cords hanging down are irritating. An electrically-operated turntable will therefore be essential.

Curved tracking is an additional cost and it would be unusual to need less than two or three curved sections in any installation covering the bed, toilet and bath. Therefore, although it is more expensive to install one or two ceiling turntables, the cost can be off-set against the cost of two or three curved sections; however, if the positions of the bed and the bathroom fittings are compromised by trying to accommodate curved tracking, the difference in cost is fully justified.

The architectural designer is advised to send the drawings to the hoist supplier, who will recommend the most satisfactory route for the track from over the bed to the fittings in the bathroom that will/may be used with the ceiling hoist. It will then be possible to ensure the ceiling is prepared for the fitting of the track when/if needed.

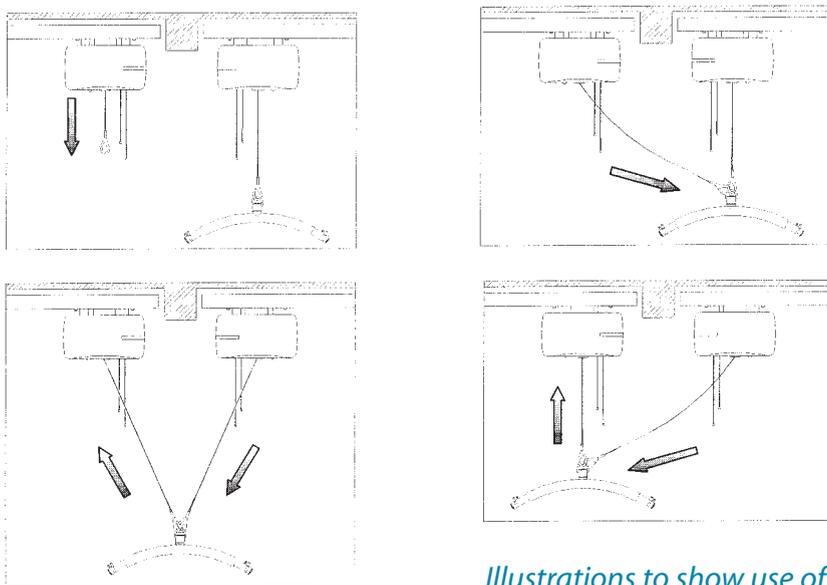
## Ceiling turntable or switched track vs room-covering system

A room-covering system (sometimes called an H or X-Y system), consists of two primary rails installed on two opposite walls in the room, with a traverse rail which straddles the primary rails and runs at right-angles between them. The advantage of this system over a ceiling turntable is that it allows the user to be lifted by the hoist from *any* point in the room, instead of under the fixed track only, which may be particularly essential where a room is being used by several disabled people, such as a hospital ward. In a situation where a hoist is needed in an adjacent room, the hoist can be linked either to a single track or to another room-covering system. The traversing action can be either manual or powered; however, as with a fixed ceiling hoist track, a powered model is recommended to increase the independence of the user.

For multiple occupancy of a bedroom and the shared use of a bathroom, it is recommended that a room-covering system is installed in both the bedroom and bathroom. Where the rooms are adjacent, the track should be extended between both rooms.

## Use of 'Swing Kit'/track-to-track/door-transfer system

Sometimes a supporting lintel is above the door. To avoid the expense and structural difficulty of removing a supporting beam to enable a track to be installed between the two rooms, a 'Swing Kit' can be used to allow the hoist to be extended between the rooms without having to lower the user down into a wheelchair in the adjoining doorway. The hoists in both rooms are taken on their tracks to each side of the wall over the door opening and, by sharing a spreader bar, the person is transferred smoothly between the two hoists as shown below. For the availability of this feature with the recommended models, see the chart on page 19.



*Illustrations to show use of 'Swing Kit'*

*Drawings reproduced with kind permission of Guldman*

## Correct position of the track over the bed

The track should be positioned at right-angles to the length of the bed, parallel to the wall behind the bed headboard, so that the centre of this track to the wall is **1020mm**. This measurement is well tried and tested in relation to an electric bed, so that the disabled person is subsequently lowered on to the small horizontal platform in the bed and will not need to be lifted either up or down the bed, which are difficult manoeuvres for a carer. If the track is parallel to the length of the bed, the disabled person's toes are liable to catch on the bedding, causing great pain. For people with a neuromuscular condition, their feet are particularly vulnerable, as they may be plantar flexed (pointed) in a fixed position.

## Correct position of the track over the toilet

When a disabled person is sitting on the toilet seat it is important that they are positioned correctly in relation to the back support of the cistern; the position is particularly critical for the optimum washing and drying action of a shower toilet. In the case of a child who is growing, or if the disabled person's posture is likely to change in the future, a certain amount of adjustability will be essential – and this can be maintained if the track passes front to back over the toilet. The only contraindication to the track being installed front to back over the pan is if it will be essential to use the hoist to transfer from a wheelchair positioned at the side of the pan. Although a space at the side of the toilet is always recommended (see Chapter 15 *Adaptation Specifications*) if an extended track is used, the wheelchair can be positioned elsewhere in the bathroom under the track, in order to transfer using the hoist.

## Correct position of the track over the Arjo Sovereign bath

It is easier to position the disabled person symmetrically if the track passes front to back over the seat when swung **out** of the bath. This centre line must be **1330mm** from the tap end of the bath and **370mm** from the end of the bath, with **700mm** between the edge of the seat (opposite the tap end of the bath) and the adjacent wall. **N.B** This allows a carer to move around the seat.

## Recommended position of 13amp fused spur

This will depend on the length of track and the option not to charge the hoist over the bed, as follows:

- ⇒ a straight track where an extended track will not be needed in the future;
- ⇒ an extended track;
- ⇒ charging the hoist in the en-suite bedroom, but not over the bed.

### **A straight track where an extended track will not be needed in the future**

The spur power point should be installed at the end over the bed, if it is to be used totally independently by the disabled person (which is unlikely if they have a neuromuscular condition) - or ideally - on the wall opposite the bed.

### **An extended track**

The spur can be installed in one of three positions, as follows:

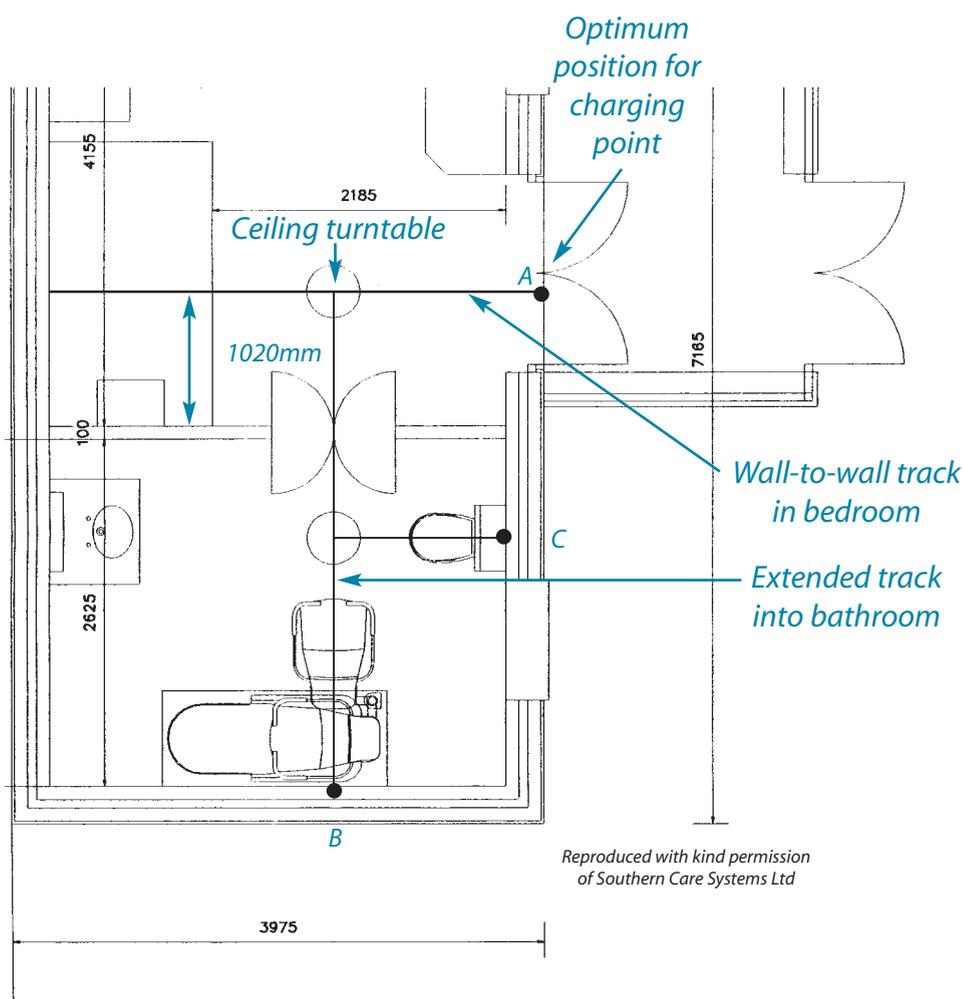
- **(as above) at the end over the bed**, if it is to be used totally independently by the disabled person (which is unlikely if they have a neuromuscular condition);

- **at the other end, in the bathroom,** if a carer will be available to 'fetch' the hoist, when needed; or ideally
- **on the wall opposite the bed.** The hoist will be used at the end of the day to lift the disabled person *into* bed, and then charged overnight. The first use in the morning will be to lift *out* of bed when, in many cases, the toilet may be needed urgently. To avoid the need for the carer to have to fetch the hoist first thing in the morning (and to have to take it into the bathroom last thing at night) it will be more convenient to charge the hoist in the bedroom (and more satisfactory to charge it away from the bed, particularly as the hoist may emit a low-frequency hum when charging).

### Charging the hoist in the en-suite facilities, but not over the bed

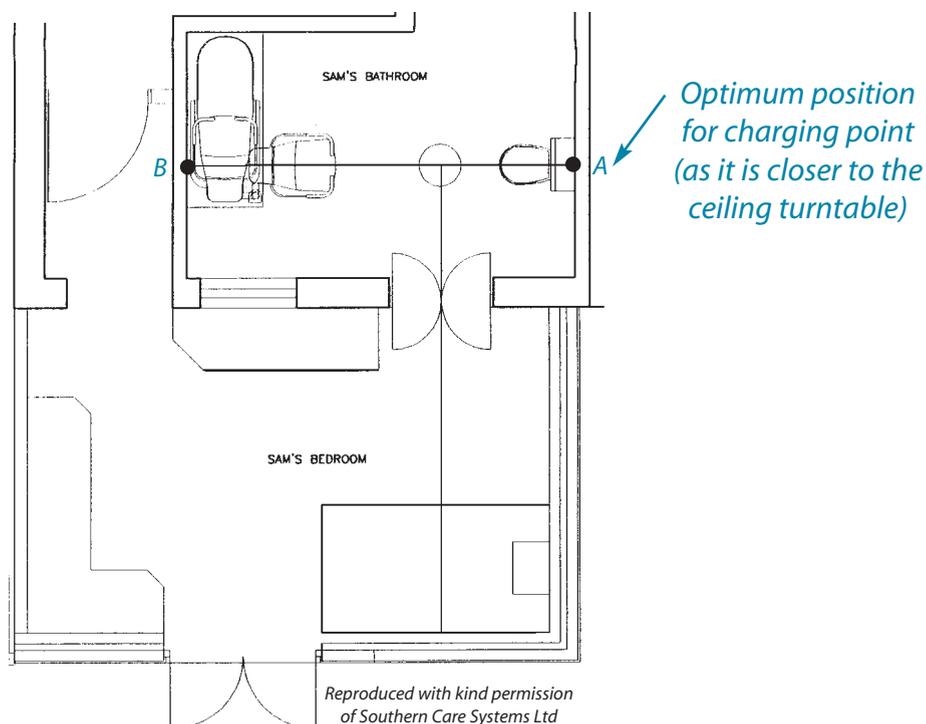
If the bed is positioned at a right-angle to the bathroom door, this can be achieved with a straight track installed from the wall beside the bed to the opposite wall where the charging point is positioned. Therefore, instead of a curved track at the side of the bed, a ceiling turntable is installed to line up with the centre of the bathroom door.

The advantage of a straight track over a curve is that it makes it easier to align chairs correctly when preparing for transfers; furthermore, positioning a bed in this way allows the recommended space for transfers at the side of the bed (i.e. **1800mm**) to double up as the circulation space around the bathroom door.



*Ideal layout for a single bed where circulation space is a greater priority than access to both sides of the bed, showing alternative positions ● A, B or C for the charging points*

## Charging the hoist in the en-suite facilities, but not over the bed



To show alternative charging point positions ● A or B, when the length of the bed is parallel to the face of the bathroom door

Access to both sides of the bed is essential for a double bed, but usually, is not recommended for a single bed, unless the room is very large – for the following reasons:

- to allow as much wheelchair circulation space as possible in the bedroom;
- because of the need to reach a wall light switch when in bed – see Chapter 15 *Adaptation Specifications (electrics)* for positioning of a wall-mounted switch (and the alternative remote-control switch);
- an adjacent wall provides a feeling of security to the person when in bed.

However, because it may be necessary for a carer to have access to both sides of the bed, it is recommended that there is sufficient space (approximately **1000mm**) on the exposed side of the bed, to allow the bed to be pulled away from the wall. It is important to ensure that the bed will not then obstruct the door to the bathroom.

## The timing of the installation of the hoist

If the hoist is not needed at the time when the adaptations are carried out, it is wise to ensure that the ceiling joists are suitable and to install the electrical supply, so that the decorations do not have to be spoilt in the future.

## Recommended models

Provided that the hoist model incorporates all the essential features, (see page 11 and the comparative chart below) the choice will depend on the following:

- whether a room-covering track is the best solution (see page 14);
- the need for a turntable (which should be electric) switched track or room-covering system;
- if Local Authorities prefer to deal with one particular company (often in their own area);
- competitive pricing and reliability.

There are a number of hoist models which have been well tried and tested with people with neuromuscular conditions and are included in the chart below. All ceiling hoists have an electric motor, to raise and lower the disabled person in the sling, and it is a mandatory requirement under lifting regulations that there is an emergency lowering device. However, these are the only features that are common to all models, irrespective of whether they use a single track or a room-covering system. It is important to note that not all the recommended features for people with neuromuscular conditions are available with every model - and it will be essential to consider the options carefully.

If other models not included in the chart are being considered, the format provides the opportunity for the firm to clarify the availability of the recommended features. A spare column has been included so that the chart can be photocopied for this purpose – and when completed – this will enable readers to make an informed choice.

Comparative chart of ceiling hoist features of recommended models							
Hoist model See also pages 11-17	<b>Bravo:</b> <i>Arjo Ltd</i>	<b>Wispa 200/300 Series:</b> <i>Chiltern Invadex Ltd</i>	<b>240/242:</b> <i>Liko Ltd</i>	<b>Guldmann Dan-Hoist:</b> <i>Moderna Contracts Ltd</i>	<b>Spectra:</b> <i>Southern Care Systems Ltd</i>	<b>Transactive:</b> <i>Westholme Ltd</i>	
Slow start (gradual acceleration from rest) is standard for lifting & traversing actions	✓	✓	✓	✓	✓	✓	
Powered movement along single track (with use of curved sections, if necessary)	✓	✓	✓	✓	✓	✓	
Electric ceiling turntable	✓	✓	✗ manual only	✓	✓	✗ manual only	
90° turns standard, but can be built to any angle	✓	✓	N/A	✓	✓	14 outlets on turntable	
Switched track	✓	✗	✓ manual & electric	✓ manual, electric or infrared	✗ turntable performs same function	✗	

Comparative chart of ceiling hoist features of recommended models (cont.)							
Hoist model See also pages 11-17	<b>Bravo:</b> <i>Arjo Ltd</i>	<b>Wispa 200/300</b> <b>Series:</b> <i>Chiltern Invadex Ltd</i>	<b>240/242:</b> <i>Liko Ltd</i>	<b>Guldmann</b> <b>Dan-Hoist:</b> <i>Moderna Contracts Ltd</i>	<b>Spectra:</b> <i>Southern Care Systems Ltd</i>	<b>Transactive:</b> <i>Westholme Ltd</i>	
Powered by curly cord direct from mains transformer	Most firms have discontinued this feature, which is only included here to highlight that it is not recommended for people with neuromuscular conditions						
Continuous powered contact within track	✓	✗	✗	✓	✗	✗	
Battery charged at end of track	✓	✓	✓	✓	✓	✓	
Infrared system available	✓	✓	✓	✓	✓	✓	
Option of emergency raising of disabled person in event of power failure (lowering is mandatory)	✓	✓ until battery runs down	✓ 242 model	✗ will not lift if insufficient charge to complete transfers	✓ until battery runs down	✓ Transactive Plus - up to <b>252Kg (42 stone)</b>	
Swing Kit/Track-to-Track/Door-Transfer system through doorway where adjustment to door header is impossible	✓ called Swing Kit	✗	✓ called 242R2R	✓ called Swing Kit	✓ called Door Transfer	✓ called Transpoint Track-to-Track	
Sensitive push-button (not rocker) switches	✓	✓	✓	✓	✓	✓	
Centre of switch handset to floor can be specified at <b>500mm</b>	✓	✓	✓	✓	✓	✓	
Spreader bar swivels through <b>360°</b>	✓	✓	✓	✓	✓	✓	
How many sling hooks are standard at each end of spreader bar?	Choice of 2, 3 or 4	2	1	2	2	3	
If not supplied as standard, can 3 sling hooks be supplied to order?	✓	✓	✓ with sling side bars	✓ with alternative spreader bar	✓	Standard	

Comparative chart of ceiling hoist features of recommended models (cont.)							
Hoist model See also pages 11-17	<b>Bravo:</b> <i>Arjo Ltd</i>	<b>Wispa 200/300 Series:</b> <i>Chiltern Invadex Ltd</i>	<b>240/242:</b> <i>Liko Ltd</i>	<b>Guldmann Dan-Hoist:</b> <i>Moderna Contracts Ltd</i>	<b>Spectra:</b> <i>Southern Care Systems Ltd</i>	<b>Transactive:</b> <i>Westholme Ltd</i>	
Room-covering system (able to link to single track in adjacent room)	✓ called Bravo room-covering hoist	✓ called X-Y system	✓ called H system	✓ called room-covering system	✓ called X-Y system	✓ called H system	
Is the movement along the track powered or dependent upon a helper i.e. manual?	Manual or powered	Manual or powered	Manual or powered	Manual or powered	Manual or powered	Manual or powered	
Name of sling most suitable for users with MD See next page	MAA 4000 Range	Full support sling	Original high back	Basic high	Spectra MD sling	Westholme MD sling W205	

## Hoist assessment and slings

A number of issues need to be considered:

- ⇒ factors influencing the success of hoisting;
- ⇒ type of sling;
- ⇒ modified or special, 'one-off' slings;
- ⇒ compatibility of slings and hoists;
- ⇒ sling material;
- ⇒ positioning the sling.

### Factors influencing the success of hoisting

In addition to the quality of the initial hoist demonstration, the assessment of the correct type and size of sling, and the most satisfactory method of positioning the sling, are likely to influence both the disabled person's and the carer's acceptance that hoisting is a feasible and practical alternative to manual lifting. The support that the sling provides (particularly if head support is needed) and its comfort in use, will be crucial, particularly in providing confidence to the disabled person.

The timing of the introduction of hoisting is important in the case of children. A hoist should be introduced at an early age while it is a fun experience, so that they become familiar with the process of hoisting at a time when they are less disabled.

## Type of sling

The issues to be covered are as follows:

- ⇒ MD sling;
- ⇒ toileting sling;
- ⇒ toileting sling used to help stand up.

### MD sling

Although most firms have designed a one-piece hammock sling specifically for people with muscular dystrophy, individual assessment is essential and continuous feedback is appreciated and comments welcomed. The sling (see page 20) will have the following features:

- support extending from the base of the spine to the shoulder (or crown of the head, if head support is needed);
- tailoring to reduce the excess material and provide the correct support;
- padding, or stiffeners positioned in slots (so that they can be removed to ease laundering) to hold the sling erect;
- padded leg pieces;
- a method of holding the leg pieces flat against each other vertically, so that the straps – and not the leg pieces themselves – are crossed over.

The difficulty of a supportive sling of this type is that although the sling is satisfactory when used on the toilet, it is not easy to lower the person's clothing. For this reason many people are anxious to use a toileting sling.

### Toileting sling

Toileting slings are available from hoist suppliers and, although the exact design will vary, essentially they are slings with:

- one band behind the back, passing under the armpits and joined to two additional flaps which are fastened at the front of the chest;
- a second band under the thighs;
- the two bands joined together at the side by a piece of the sling material.

The use of this type of sling depends on the back support remaining in the correct position, either because it is held down by the user's arms or because it fastens tightly at the front of the chest. For most people with a neuromuscular condition, the pressure under the arms is too great for the shoulder girdle and they cannot tolerate the compression of the chest with a tight sling. As a result, the sling fastening has to be loosened and the person then jackknives out of the back of the sling. However, there are a minority of people who can tolerate this type of sling; when there is uncertainty, the sling should be assessed.

## Toileting sling used to help stand up

There is the additional option of using the *Liko* vest-like support which has multi-adjustable and flexible cross-straps, in conjunction with the Golvo 7000ES/7007ES models (discussed on page 9) or the Sabina/Sabina Comfort hoist (increased choice of sling options), which have height-adjustable knee blocks to provide front support to help the user to stand.

**N.B.** *This equipment must be carefully assessed by a physiotherapist experienced in the treatment of people with a neuromuscular condition, with additional advice from the hospital clinic team, and is likely to be contraindicated and unsuitable following spinal surgery.*

*Liko (UK) Ltd*

## Modified or special, 'one-off' slings

There will be occasions when a standard sling will need to be modified or a specialist sling designed; usually, the firm supplying the hoist will arrange for this to be carried out. However, if this is not possible, most other hoist manufacturers or suppliers provide a specialist sling design and manufacturing service, which is also available from *Silvalea*. This firm supply a comprehensive catalogue providing details of their service and a measurement chart. A total of 800 designs are available and any replacement sling can be made; this would be an invaluable service to a disabled person using a 'much-loved', but discontinued sling.

*Silvalea Ltd*

## Compatibility of slings and hoists

In the past, the recommendation was that slings should not be used with hoists from different manufacturers. However, it is now generally accepted that slings are interchangeable if the hoist and sling are correctly assessed, inspected and maintained separately, and the hoist hardware is identical, i.e. there is a compatible fitting method (rings, hooks etc.) on both the sling and hoist. Nevertheless, the position regarding compatibility must be checked with each firm – both the hoist and the sling suppliers. To ensure complete peace of mind to the disabled user, the therapist and the carers, *Silvalea* and most other firms have taken out public/products liability insurance cover.

## Sling material

Slings are made in a wide range of materials, but for people with a neuromuscular condition, who will require additional firm padding, the choice is usually polyester nylon for general use and a net sling for bathing; however, in both cases the sling assessment should establish which material the users (the disabled person and the helper) find the most suitable. It is usual for at least two slings to be provided (particularly where a sling is used both in the bedroom and bathroom) to allow a wet or damp sling to dry, and so that slings can be washed one at a time.

## Positioning the sling

Slings are designed so that they are positioned symmetrically behind the disabled person's back; by pulling on the inner curve of the sling they are eased an inch or so under the bottom. The leg pieces are brought forward on each side, ensuring that they are not twisted, and are then taken under the legs in one of two ways:

**Under both thighs to form a bucket seat**

This method is likely to be suitable for smaller disabled people only, as most users in this position will feel too restricted in the sling.

**Under each thigh separately and then brought up between the legs**

This is the recommended method for most disabled people with a neuromuscular condition, but because their selective muscle wasting results in an outward rotation of the thighs, it is important to bring the legs together and support the thighs in a comfortable position. It may be essential to provide an MD sling and that the *straps of the leg pieces of the sling are crossed between the legs* and hooked on to the *opposite* end of the spreader bar to prevent the sling from 'rucking up', moving towards the groin and causing discomfort.

**Reference**

1. Fletcher, B., Holmes, D., Tarling C., Tracy M., *The Guide to the Handling of Patients*. National Back Pain Association, 1997.

# Disability Needs Assessment Form/ Architectural Brief

Date: 

*This assessment form has been designed to:*

- *identify options relating to the needs of each individual;*
- *provide a time-saving method of recording the decisions made;*
- *provide an architectural brief for the drawing of the plans;*
- *consider the funding options;*
- *act as a check-list to ensure all details have been included.*

Not every section will be relevant to every neuromuscular condition or to both adults and children. The form should be used in conjunction with the following:

Chapter 6	<i>Lift vs Extension;</i>
Chapter 7	<i>Bath vs Shower;</i>
Chapter 8	<i>Equipment for Adaptations;</i>
Chapter 9	<i>Hoisting;</i>
Chapter 11	<i>Justification for Funding;</i>
Chapter 15	<i>Adaptation Specifications;</i>
Chapter 16	<i>Kitchens;</i>
Chapter 18	<i>Addresses: Manufacturers/Suppliers/Sources of Advice.</i>

**Name:** ..... **D o B:** .....

**Address:** .....

.....

**Postcode:** ..... **Tel No:** .....

- The user should tick the boxes of items to be included in the adaptations scheme. After the joint visit of everyone concerned, the action plan on page 14 should be completed.

## Housing

- Owner occupied
- Local Authority
- Housing Association
- Privately rented

## Lift vs Extension

- Lift with en-suite bedroom/bathroom
- Ground-floor extension with en-suite bedroom/bathroom

## Access

- Kerb dropped
- Hard standing for car/wheelchair transfers **Width: 3200 – 3600mm**  
**Length: 5200 – 5800mm**
- Carport **Clearance height: 2800mm**
- Garage
- Access around house /path **Minimum width: 900mm**
- Patio/paved area in garden

## Steps/ramps

- Shallow steps **Height and depth to be assessed**
- Ramp gradient for walking **1:20**
- Hand rail (not needed by wheelchair users)
- Ramp gradient (with side safety flange) for powered chair **1:15**
- Ramp **Width: 1200mm**
- Platform at top to extend forwards from door: **1200mm**
- Surface: non-slip
- Steplift
- Portable ramp

## Threshold

- Duraflex RX100 flexible threshold  
*Wintun Ltd*

## Automatic door opener

- Wheelchair-accessible door – installed with the scheme
- Fused spur for future installation  
*Ridley Electronics Ltd*  
*RSL Steeper Ltd*  
*Southern Care Systems Ltd*

## Doors

### Width

- Existing doors. **Clear opening (i.e. door face to door jamb): 850 – 900mm**
- New doors: **926mm leaf**

### Type

- Bedroom: single leaf, double swing
- Bathroom: double leaf, double swing
- Other rooms: .....
- French windows from bedroom

### Door weight

- To be suitable for use with *Liobex* spring, double-action (**100mm**) hinges  
*D & E Architectural Hardware Ltd*

### 'Kick' plates

- Yeoman Shield door-protection plates**
  - 400mm:** (from bottom of door to top of plate) to avoid damage from wheelchair side 'kerb climbers'. Fitted on both sides of bedroom and bathroom doors
  - 800mm:** (from bottom of door to top of plate) to include mark left by wheelchair armrest and/or tray. Fitted on both sides of bedroom and bathroom doors
  - Door fully faced  
*Harrison Thompson & Co Ltd*

## Circulation/size of rooms

- The rooms must be large enough to allow use of electric wheelchair  
**Max width of average chair: 750mm**  
**Max length: 1250mm**  
**Turning circle: 1700mm**

## Dining room

- Needed by disabled person

## Carer

- Retain room for carer (particularly important for a disabled adult)

## Bathroom

- En suite
- Bath with shower over
- Floor-level shower

## Bath

- Acrylic 1700
- New Luna steel 1700 (optional slip-resistant surface and handgrips)  
*Twyford Ltd*

- Sunrise Medical Mermaid Ranger (MD model)**

*ASM (Accessories) Ltd*

*Daily Care Ltd*

- ASM Multi-System**

- Base transporter
- Transfer by static hoist
- Transfer by ceiling hoist

*ASM (Accessories) Ltd*

- Arjo Sovereign baths**

**Length: 1670mm**

**Width: 715mm**

**Space at side of bath for seat (min.): 675mm**

- Standard
- Fixed height
- Hi-Lo
- Left-hand entry
- Right-hand entry

- Air spa (usually funded privately)

- Arjo Solo (or alternative) with non-reclining seat  
*Arjo Ltd*

- Arjo Sovereign tap option** (all include a shower)

- Thermostatic water-control panel
- Bath mounted
- Wall mounted
- Meynell TBS – as above, but thermostatically controlled so that water temperature will not exceed **41°C** (shower) **44°C** (bath)  
*Arjo Ltd*

- Mixer bath taps with integral extended shower hose

To be positioned  
as shown on  
order form

- Kingkraft Easibath Hi-Lift**

- Kingkraft Contour bath**  
*Kingkraft Ltd*

## Level-access shower

- Tiled sloped floor
- Shower tray  
*Autumn Mobility Ltd*  
*Go Independent*

- Impey Level-Dec  
*Creative Healthcare Ltd*
- Neatdek
- Screen  
*Go Independent*
- Support rail and curtain  
*Pressalit Care Ltd*
- Apres Shower Body Dryer  
*Apres Shower Dryers Ltd*  
*Go Independent*  
*Total Hygiene Ltd*

### Shower seat/chair

- Electric height-adjustable wall-mounted seat  
*Astor-Bannerman (Medical) Ltd*  
*Pressalit Care Ltd*
- Aquability or Freeway toilet/shower chair**
  - As above, self propelled  
*ASM Accessories Ltd*  
*Westholme Ltd*
  - Sutton shower cradle  
*ASM Accessories Ltd*

### Toilet

- Classic: Low-level cistern with long flush pipe (**NB: not alternative close-coupled model**)  
*Twyford Ltd*

### Position

- Centre of pan to nearest obstruction on side wall  
(including floor level pipes): **500-600mm**
- Front of cistern to front of bowl: **600mm**
- Exposed side of pan: **900 – 1500mm**

### Shower toilet

- Clos-o-Mat**
    - Super-sensitive switch
    - No plinth
    - 25mm** plinth
    - 50mm** plinth
    - 75mm** plinth
    - Douche arm
    - Standard drain connector
    - Macerator (allow **200mm** behind unit)  
*Total Hygiene Ltd*
- } **To be specified by architect**

## Shower toilet *(continued)*

- Colani toilet seat
- Ergosit toilet seat
- Dania toilet seat
- Softsit toilet seat  
*Total Hygiene Ltd*  
*Pressalit Care Ltd*
- Softee Trainer  
*Mothercare Ltd*
- MD Frame  
*Daily Care Ltd*
- Geberit**
  - Wall hung
  - Floor standing  
*ESL Healthcare Ltd*

## Washbasin

- ABW4/ABW4SP with integral splashback mirror (cannot be positioned in front of window)  
**Front-to-back depth: 675mm**  
**Any width: 700-1200mm**  
**Other width (min 800mm)** .....
- Astor-Bannerman (Medical) Ltd*
- Spectra  
**Front-to-back depth: 645mm (standard) or recommended 695mm (to order)**  
**Two widths: 700mm or recommended 1050mm**  
*Southern Care Systems Ltd*
- Fixed height
- Standard manual-control taps only
- Push-button control taps
- Electronic-control taps
- Automatic over-mirror light  
*Astor-Bannerman (Medical) Ltd*  
*Southern Care Systems Ltd*

## Flooring

- Non-slip ceramic tiles
- Altro Safety flooring
- Nairn Surestep tiles
- Marley Safetred Dimension
- Marley Safetred Aqua
- Other .....

## Bedroom

### Size to accommodate:

- Door to en-suite bathroom
- French windows/glazed door with adjacent window
- Bed
- Storage units
- Adjustable-height L-shaped workstation

### Bed

#### Size

- Length: **2155mm**
- Width: **1080mm**
- Width: **1220mm**
- Width: **2160mm**
- Space at foot of bed: **700mm**
- Space at side of bed: **1800mm**

#### Position

- Adjacent to wall (for single bed unless room very large) with space to pull bed away from wall without obstructing doorway
- Access on both sides (essential for double bed)
- Disabled person sleeps on left/right side (from foot of bed)
- Space nearest to bathroom: **1800mm**
- Space other side: **1000mm**

#### Storage units

- Wardrobe: **1000 x 600mm**
- Chest of drawers: **1000 x 500mm**
- Check size of existing wardrobe/drawers

### Adjustable-height L-shaped workstation

- In bedroom and/or
- On ground floor (if lift installed)
- Wheelchair-accessible surface**
  - Length: **1800 x 1200mm**
  - Depth: **600mm**
  - Position: **ideally in front of window**
- Standing surface**
  - 600 x 600mm**  
*Huntleigh Renray Ltd*
  - 800 x 600mm**  
*Astor-Bannerman (Medical) Ltd*
  - Drawer unit and pull-out surface under

## Suppliers

- 40mm surface:**
  - MFI/DIY Store*
  - Astor-Bannerman (Medical) Ltd*
  - Huntleigh Renray Ltd*
- Wall rail and brackets/Drawer unit
  - Huntleigh Renray Ltd*
- Screw brackets
  - Astor-Bannerman (Medical) Ltd*
- Drawer unit
  - Independence Kitchens*
  - MFI/DIY Store*

## Ceiling hoist

- Bedroom**
  - Electric controls
  - Infrared controls
  - Over bed, wall to wall, parallel to wall behind bed headboard – centre of track to wall behind headboard: **1020mm**
  - Electric 'push-button'/infrared ceiling turntable/switched track
  - Extended track into bathroom
  - Electric 'push-button'/infrared room-covering track
  - Single track extending to electric room-covering track in bathroom
- Bathroom**
  - Electric ceiling turntable
  - Track to extend front to back over centre of toilet
  - Track to extend front to back over centre of bath seat (out of bath)  
**1330mm** from the tap/head end of the bath and **370mm** from the foot of the bath with approx. **600mm** between end of bath and adjacent wall
  - Room-covering track

## Installation

- Architectural designer's plan to be sent to hoist supplier to check exact position of bathroom/bedroom fittings in relation to ceiling track
- Hoist installed when extension completed
- Ceiling prepared and hoist installed when needed

## Funding of ceiling hoist

- Preparation of ceiling/fused spur included in grant application
- Hoist supplied and installed by Social Services
- Preparation of ceiling etc. and hoist included in grant application

## Hoist suppliers

- Bravo: *Arjo Ltd*
- Wispa 200/300 Series: *Chiltern Invadex Ltd*
- 240/242: *Liko Ltd*
- Guldmann Dan Hoist: *N & C Building Products Ltd/Moderna Contracts Ltd*
- Spectra: *Southern Care Systems Ltd*
- Transactive: *Westholme Ltd*
- Other .....

## Slings

- 2 x universal/MD slings
- Without head support
- With head support

## Sitting room

### Easy chair

- Powered stand-up/recliner  
*Bakare Beds Ltd*  
*Gordon Medical & Rehabilitation Services Ltd*  
*Ortho-Kinetics (UK) Ltd*
- Number of single chairs
- Three-seater settee
- Two-seater settee

## Dining room

- Size of table .....

## Kitchen

### Wheelchair access to:

- Sink/drainer
- Taps/spout
- Preparation surface
- Surface for microwave  
or combination oven/microwave
- Side-opening split-level oven: **gas**
- Side-opening split-level oven: **electric**
- Split-level hob: **gas**
- Split-level hob: **electric**
- Power points
- Height-adjustable unit including sink/drainer, preparation surface,  
split-level hob and surface for microwave  
*Astor-Bannerman (Medical) Ltd*  
*Independence Kitchens*  
*N & C Building Products Ltd/Phlexicare Division*  
*Pressalit Care Ltd*

} might be  
considered for an  
interested child

- Standard cooker
- Height-adjustable trolley  
*Thomas Gideon Design*

## Floor surfaces

- Bathroom .....
- Bedroom .....
- Kitchen .....
- Hall .....
- Other areas .....

## Storage/charging area for:

- Two powered wheelchairs (unfolded)
- Transit chair (folded)
- Akron tilt table  
**Length: 1900mm**  
**Width: 560mm**  
*Huntleigh Healthcare Ltd*
- Standing frame  
(Shelf for charger/see next page)

## Light switches

### Type

- Tenby Clipper range  
*Legrande Electric Ltd*
- Touch-sensitive Superswitch
- Remote-control Superswitch  
*Ridley Electronics Ltd*

### Position/height

- All switches in en-suite bedroom except by bed  
**Height – bottom of switch to finished floor level (FFL): 700mm**  
**Space on wall free of obstruction, both sides of switch: 600mm**

### Bathroom

- Wall-mounted switch outside bathroom

## Bedroom (3-way switches)

- Outside room
- Single bed/wall mounted  
**Height – to clear bedding (bottom of switch to FFL): 760mm**  
**From wall behind bed headboard: 1020mm**
- Double bed: pull-cord
- Double bed: remote control
- In an accessible position for use from wheelchair
- Over work surface: spotlights (remote control)  
*Ridley Electronics Ltd*

## Sockets

### Bedroom

- Double bed/adjacent bed head (marginally under bed) skirting board level:  
2 x twin sockets
- Single bed/foot of bed (marginally under), skirting board level:  
1 x twin socket
- Single bed/adjacent bed head (**bottom of switch to FFL): 760mm**  
1 x twin socket
- Above shelf by bed  
1 x twin
- Additional socket for use with vacuum (**bottom of switch to FFL): 700mm**
- Over work surface/wheelchair (**bottom of switch to FFL): 1100mm**  
2 x twin socket (not in corner)
- Over work surface/standing (**bottom of switch to FFL): 1300mm**  
1 x twin socket
- Sloped boxes on work surfaces  
3 x twin socket
- TV
- TV aerial
- Phone socket

### Bathroom

- Shaver point at side of washbasin
- Integral with *Astor-Bannerman* washbasin

### Sitting room

- Powered easy chair

### Charging of wheelchairs

- Twin socket above shelf
- Shelf (to accommodate charger at convenient height)  
**Height from FFL: 850mm**  
**Width: 500mm**  
**Depth: 300mm**

**Fused spurs** for use with the following:

- Specialist bath
- Height-adjustable washbasin
- Shower toilet
- Wall-mounted bathroom heater or body dryer
- Ceiling hoist (preferably in bedroom, but **not** over bed)
- Automatic door opener
- Curtain control

**Position:** determined in conjunction with suppliers

## Heating

### Bedroom

- Temperature: **21° – 24°C**

### Bathroom

- Temperature: **21° – 24°C**
  - Additional wall-mounted fan heater
  - Apres Shower Body Dryer (alternative to a wall-mounted heater)  
*Apres Shower Ltd*  
*Go Independent*  
*Total Hygiene Ltd*

## Smoke alarm

- Wired into mains + battery backup (recommended)
- Battery model (to be installed by family)

## Fire escape

- To be considered for ground-floor extensions positioned near or beyond kitchen

## Intercom

- Internal intercom transmitter/receiver used with **13amp** sockets
- Door intercom/lock system

## Environmental control

- Intercom with environmental control
  - To be referred for provision/installation in scheme
  - To be considered in the future
    - Steeper Fox  
*RSL Steeper Ltd*
    - Possum Companion  
*Possum Controls Ltd*
    - SRS100  
*SRS Technology Ltd*

## Funding

### Housing grant

- Local Authority Housing Revenue
- Housing Association resources
- Improvement Grant application made
- DFG informal application made

£  **DFG/Improvement Grant contribution (informal assessment)**

- Discretionary assistance
- Grant
- Loan (to be considered for top-up)

### Application to be made to Housing/Social Services/Social Work Dept. for:

- Help with contribution and/or
- Top-up over maximum grant

£  **Housing/Social Services/Social Work Dept. assistance agreed**

### Application to Family Fund (under 16 years)

- To match Housing/Social Services/Social Work Dept. discretionary assistance (Joint salary current limit of under £21,500 (Scotland) £23,000 (rest of UK) - April 2003)
- Special case to Family Fund to match Housing/Social Services/Social Work Dept. Discretionary assistance: joint salary is over £21,500 (Scotland); £23,000 (rest of UK)

£  **First guess/estimate of building work cost**

Specialist equipment to be assessed	Price guide (£)	Cost of equipment in scheme (£)
<input type="checkbox"/> Sovereign bath	3,500 - 5,200	
<input type="checkbox"/> Easibath Hi-Lift/Contour	4,400 - 7,000	
<input type="checkbox"/> Electric Mermaid Ranger	2,400	
<input type="checkbox"/> Bath cradle/electric mast/transporter	2,000	
<input type="checkbox"/> Shower tray + screen	800	
<input type="checkbox"/> Height-adjustable shower seat inc. arms	1,400 - 1,515	
<input type="checkbox"/> Shower chair/cradle	300 - 1,700	
<input type="checkbox"/> Body Dryer	435	
<input type="checkbox"/> Height-adjustable washbasin	1,600 - 2,050	
<input type="checkbox"/> Shower toilet	2,150	
<input type="checkbox"/> Ceiling hoist/extended track/electric turntable/two slings	2,800	
<input type="checkbox"/> Automatic door opener	1,000	
<b>Total cost of equipment needed:</b>		£ <input style="width: 100px;" type="text"/>

- Grant covers 5-year warranty/service contract on all equipment

## Action plan

	Action to be taken	By whom
<b>1</b>		
<b>2</b>		
<b>3</b>		
<b>4</b>		
<b>5</b>		
<b>6</b>		
<b>7</b>		
<b>8</b>		
<b>9</b>		
<b>10</b>		

# Justification for Needs and/or Funding of facilities or equipment for children & adults with muscular dystrophy & allied neuromuscular conditions

The following are included:

## **a. The Long-Term Housing Needs, including the Importance of Space**

for boys with Duchenne muscular dystrophy (DMD) & for children & adults with other types of muscular dystrophy & allied neuromuscular conditions.

## **b. Space Requirements**

for boys with Duchenne muscular dystrophy (DMD) & for children & adults with other types of muscular dystrophy & allied neuromuscular conditions.

## **c. Justification for Need & Funding of an *Arjo Sovereign Bath***

for boys with Duchenne muscular dystrophy (DMD) & children & adults with other types of muscular dystrophy & allied neuromuscular conditions.

## **d. Justification for the Need & Funding of a Shower Toilet**

for children & teenagers with muscular dystrophy & allied neuromuscular conditions.

## **e. Justification for the Need & Funding of a Shower Toilet**

for adults with muscular dystrophy & allied neuromuscular conditions.

## **f. Justification for the Need & Funding of an *Astor-Bannerman ABW4/SP* or *Southern Care Systems Spectra Electrical Height-Adjustable Washbasin***

for boys with Duchenne muscular dystrophy (DMD) & children with other types of muscular dystrophy & allied neuromuscular conditions.

## **g. Justification for the Need & Funding of an *Astor-Bannerman ABW4/SP* or *Southern Care Systems Spectra Electrical Height-Adjustable Washbasin***

for adults with muscular dystrophy & allied neuromuscular conditions.

## **h. Justification for the Need & Funding of Working Surfaces**

for boys with Duchenne muscular dystrophy (DMD) & children with other types of muscular dystrophy & allied neuromuscular conditions.

## **i. Justification for the Need & Funding of a satisfactory Central Heating System**

for children & adults with all types of muscular dystrophy & allied neuromuscular conditions.

## **j. VAT form**

Philippa Harpin's work as National Occupational Therapy Advisor for the Muscular Dystrophy Campaign brought her into regular contact with countless children and adults with muscular dystrophy and all the allied neuromuscular conditions. She heard first-hand of their difficulties and has worked closely with them and their professional advisors to find acceptable solutions to their problems. This experience, coupled with the priceless benefit of hindsight, was invaluable in building up knowledge of the facilities and equipment needed.

In conjunction with colleagues, Philippa was able to assess the equipment that is readily available and, where necessary, worked with manufacturers to design more appropriate equipment. The outcome was an ability to recommend a range of very successful and specific equipment. Inevitably, this equipment is sophisticated because many people with these disabilities have to cope with the difficulties of severe arm weakness, in addition to the inability to walk.

The role of National Occupational Therapy Advisor for the Muscular Dystrophy Campaign is not only to help disabled people and their families, but also to provide information and support to occupational therapists (OTs) and other healthcare professionals. Most OTs are working with people with a wide range of disabilities and, although they have a wider breadth of knowledge, they appreciate guidance on the specific needs of people with muscular dystrophy and the allied conditions. As a result, Chapter 8a *Equipment for Adaptations* includes information on relevant equipment and this section is confined to providing separate leaflets to provide justification for its funding and supply. A VAT exemption form is included for photocopying for the convenience of all readers.

It is hoped that OTs will use these leaflets in any way they wish - either by photocopying them to submit with requests for funding, quoting the source, if they feel it may help - or by copying any part of the information into individual letters. If there is any other equipment that should be covered in a leaflet in this way, please let me know, as the range of leaflets can be increased, as necessary.

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# The Long-Term Housing Needs, including the Importance of Space for boys with Duchenne muscular dystrophy (DMD) & for children & adults with other types of muscular dystrophy & allied neuromuscular conditions

Detailed specifications are available when adaptations are needed, but the following provides an outline of needs when re-housing is being considered.

## Garden

### Paved area

A level, dry area accessible from the house is needed for use with a powered wheelchair.

### Access around the house

If there is a path around the house, this must be a minimum width of **900mm**, clear of all obstructions such as drains, rainwater pipes and soil pipes.

### Hard-standing area for a car

Preferably there should be a hard-standing area for a car, accessible from the house and with adjacent space for wheelchair transfers.

## Access to house

### Level or with ramp

A **1:15** ramp with safety flange and platform extending **1200mm** forwards from the door, and a wheelchair-accessible compression threshold are necessary.

### Automatic door opener

This may be essential for adults and also should be considered for older children.

## Internal doors

### Width

All internal doors should have a *clear* opening of between **850** and **900mm**.

### Type

Doors with a double-swing through **180°** (with 'kick' door-protection plates) enable opening by the weight of the wheelchair.

## Bedroom

### Double room

This is needed to provide adequate space for the circulation of a powered wheelchair and sufficient wall space to accommodate:

- an electric bed **1080mm** or **1220mm** in width and **2155mm** in length or a double bed **2155mm** square;
- standard storage units;
- L-shaped working surfaces of minimum size **1800 x 1200mm**;
- a space of **1800mm** at the side of the bed, to allow a ceiling hoist installed over the bed, to be used for wheelchair transfers;
- doorway to bathroom to provide en-suite facilities.

## Bathroom

### Toilet

Standard-height pan, low-level cistern with long flush pipe (not close-coupled model) or shower toilet. Centre of pan to adjacent side wall **500mm**. Minimum space of **900mm** on the other side for positioning a wheelchair and/or providing space for reversing a wheelchair for a three-point turn.

### Washbasin

Inset model of approximately **1050-1200mm** width and **675-695mm** front-to-back, preferably height-adjustable. Provision of lever or electronic taps.

### Bath

**1700mm** with a shower unit at the end of the bath. Circulation space of **840mm** at the side of the bath for a bath seat on a floor-mounted pillar – or for an integral bath seat which swings out of the bath, plus **700mm** for the movement of a carer.

### Shower

Level-access shower tray with provision of a freestanding or wall-mounted half-height screen or rail with shower curtain.

## Electrics/storage/heating

### Switches

Large rocker-type, three-way light switches installed at recommended heights and positions.

### Wheelchair storage area

With twin **13amp** socket for charging chairs.

### Heating

Above-average temperatures (i.e. **21° – 24°C**) in both the bedroom and bathroom, with supplementary booster heater in the bathroom. Thermostats on radiators.

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## Justification for Need & Funding of an *Arjo Sovereign* bath for boys with Duchenne muscular dystrophy (DMD) & for children & adults with other types of muscular dystrophy & allied neuromuscular conditions

There are many reasons why a bath may be chosen in preference to a shower for a person with a neuromuscular condition and Chapter 7 *Bath vs Shower* is available to help with this choice. The ability to soak in warm water relaxes muscles and also bathers are able to enjoy the movement of their limbs in the water, both of which are likely to be important for anyone with severe muscle weakness. Although this buoyancy has undeniable value, it is important that the disabled person, who lacks trunk control, is well supported and feels safe.

The carer's role should also be considered, particularly in relation to the ease of using equipment for lifting in and out of the bath and in helping the disabled person to wash.

In justifying the expense of the *Arjo Sovereign* bath it is important to consider:

- ⇒ difficulties involved in using a standard bath with a ceiling hoist;
- ⇒ use of the *Arjo Sovereign* bath to overcome these problems.

### Difficulties involved in using a standard bath with a ceiling hoist

These are as follows:

- movement of limbs is not possible with a sling in position;
- the sling material makes it difficult to reach all parts of the body for washing;
- taking the sling off when using the bath may make it difficult for the disabled person to balance;
- leaning over the rim of the bath with a rotated spine to take off/reposition the sling will cause back strain for the helper;
- the sling is padded and when raised, there will be a gush of water and a dripping wet sling.

## Use of the Arjo Sovereign bath to overcome these problems

The procedure and value is as follows:

- the user is hoisted on to the chair using a ceiling hoist (with an extended track from the en-suite bedroom);
- the sling is removed while it is still dry, at a height that is suitable for the carer, and is replaced at this optimum height;
- the chair is rotated and lowered electrically into the bath independently, by the disabled person who may need help to lift their legs over the rim, but who at all times remains safe, confident and well supported;
- the arms of the chair are within easy reach and extend in front of the user to provide front support when in the bath, and yet retract and can be removed, if necessary;
- there is an excellent headrest to provide head support, which will be particularly important to boys with DMD and any other user who has undergone spinal fusion;
- as the seat glides gently forwards, it reclines as it reaches the base of the bath (a supported reclined position is difficult to achieve with other bathing equipment for a disabled person); this also enables the depth of the water to be used to its best advantage;
- the knee support within the bath is ideal for anyone who has knee contractures or is likely to have difficulty in fully extending their legs; the support behind the thighs prevents the user from floating forwards in the water.

### Models

There is a choice of three models, depending upon the height of bath needed:

#### **Sovereign Standard - 610mm (24")**

This may be the ideal model for families wanting the bathroom to look as normal as possible. This is a satisfactory choice if the bather can stand up from the seat and if the carers do not have any difficulty kneeling at the side of the bath.

#### **Sovereign Fixed Height - 840mm (33")**

This is suitable where a bath is needed at a higher level, in order to protect the back of a carer who cannot kneel on the floor at the side of the bath – or to help a bather stand up from a higher seat.

#### **Sovereign Hi-Lo - 615-960mm (24 1/2" - 38")**

This is a sophisticated solution where the bath height can be altered instantly to provide flexibility to protect the backs of carers of different heights.

*Arjo Ltd*

*National Occupational Therapy Advisor/Muscular Dystrophy Campaign  
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# Justification for Need & Funding of a Shower Toilet

## for children & teenagers with muscular dystrophy & allied neuromuscular conditions

This equipment, which is a combined toilet & bidet, is essential for anyone unable to use toilet paper because of difficulty in reaching: it provides the alternative of washing and drying the bottom after a bowel motion, and is also used by disabled girls to ensure cleanliness, particularly during the menstrual cycle.

It is not often necessary to have to justify the supply of a shower toilet, because most people responsible for making decisions in relation to funding can identify with the need to maintain privacy on the toilet. Disabled people have to contend with a great loss of dignity, but to have to ask anyone to wipe their bottom for them is totally unacceptable – and is particularly inappropriate because of the possible accusations of sexual abuse if the disabled person is a teenager and the carer is an adult.

The use of this equipment must be assessed prior to supply. Although a demonstration can be arranged by asking the firm to bring a unit to the house, the most satisfactory way of ensuring that the equipment will be satisfactory, is to contact the firm and find out where there is a unit plumbed in and ready to use.

Clos-o-Mat: *Total Hygiene Ltd*  
Geberit: *ESL Healthcare Ltd*

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# Justification for Need & Funding of a Shower Toilet

## for adults with muscular dystrophy & allied neuromuscular conditions

This equipment, which is a combined toilet & bidet, is essential for anyone unable to use toilet paper because of difficulty in reaching: it provides the alternative of washing and drying the bottom after a bowel motion, and is also used by disabled women to ensure cleanliness, particularly during the menstrual cycle.

It is not often necessary to have to justify the supply of a shower toilet, because most people responsible for making decisions in relation to funding can identify with the need to maintain privacy on the toilet. Disabled people have to contend with a great loss of dignity, but to have to ask anyone to wipe their bottom for them is totally unacceptable – particularly if the disabled person is an adult.

The use of this equipment must be assessed prior to supply. Although a demonstration can be arranged by asking the firm to bring a unit to the house, the most satisfactory way of ensuring that the equipment will be satisfactory, is to contact the firm and find out where there is a unit plumbed in and ready to use.

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# Justification for the Need & Funding of an *Astor-Bannerman ABW4/SP* or *Southern Care Systems Spectra Electrical* **Height-Adjustable Washbasin** for boys with Duchenne muscular dystrophy (DMD) & for children with other types of muscular dystrophy & allied neuromuscular conditions

One of the greatest problems for anyone with muscular dystrophy or an allied neuromuscular condition is not only that they cannot walk but also that they have severe muscle weakness in their arms, although usually they retain reasonable hand function. As a result, they cannot lift their arms and have to rely on either creeping with their fingers or sliding their forearms along a surface, often aided by forward and backward movement of the trunk. If an arm falls off the wheelchair armpad, they are often dependent upon asking someone to lift the arm back up again, and this lack of arm function is very debilitating.

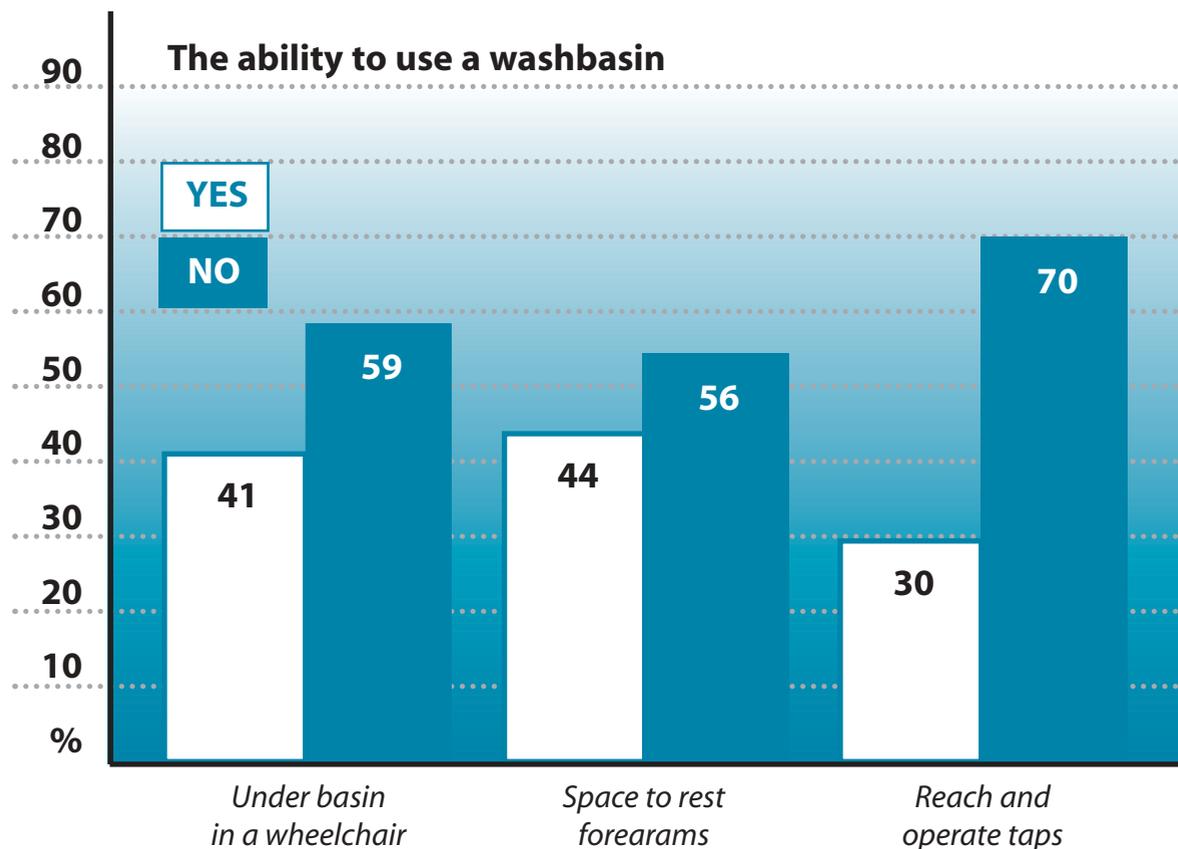
For several years the only solution was a fixed-height washbasin. This was often set into a melamine surface and used with ordinary lever taps. Although detailed notes were provided, builders found it difficult to install correctly, with the result that the work often had to be carried out twice. This was expensive, time consuming and very unsatisfactory. Finally this type of basin was withdrawn, although initially there was no satisfactory alternative.

Modern inset basins are not successful as they are raised up from the melamine surface and impede the sliding process. A fixed-height basin is not satisfactory because it is impossible to find one single height that is suitable on every occasion for both short- and long-term use.

## There is the need for height adjustment because:

- more than one wheelchair will be used and the wheelchair models will change over the years;
- cushions of different depths will be used;
- the wheelchair armrests will need to be raised after a more erect posture is achieved following spinal surgery;
- the optimum height for sliding arms on to the surface and into the water is too low for face washing and teeth cleaning. For a boy with DMD this will mean that, when he leans forward to rinse his mouth after brushing his teeth, he will have to ask someone to push on his shoulders to get him back into his wheelchair.

In a recent research project looking at the quality of adaptations for children and adults with neuromuscular conditions, some of the statistics were unacceptable, as the graph on the next page illustrates. This reflects the difficulties that were experienced in relation to conventional fixed-height washbasins. The fact that almost **60%** of disabled users did not have a wheelchair-accessible basin and **70%** could not reach the taps was a clear indication that a better solution was needed.



### The aim was to produce the following:

- a basin of the correct profile with the bottle trap against the wall – both of which will allow knee access when in a wheelchair;
- a basin which is large enough front-to-back to allow the user to get close up to the front edge without the wheelchair footrests hitting the wall below the basin and preventing this close access;
- a front edge without a fascia, which would obstruct the wheelchair armrests and/or the joystick control of a powered wheelchair;
- a surface less than **15mm** thick, which allows the user to 'creep' with their fingers, to raise their hands and forearms to the front or side of the basin;
- an area at the side of the basin which is large enough to provide forearm support, and the storage of toiletries and a towel within reach;
- a surround to the basin that is shiny and smooth to help users to slide their arms to reach forward;
- a basin set below the surface, without a raised edge, so that sliding arms into the water is not impeded;
- the shape of the basin ensures that the water is close to the user and it is not necessary to lean forwards, which may then make it difficult to sit back upright against the wheelchair backrest;
- tap controls which require no hand strength or pressure to operate and do not involve the need to reach;
- a basin low enough to enable the user to reach into it to wash, but at the same time set into a surface which can be raised high enough to allow their hands to be at the same level as their mouth for cleaning teeth, or their head for combing hair;
- a surface that behaves as a mobile arm support;
- flexible waste and water pipes to allow electric height-adjustability, if needed;
- the option of a mirror (with light) which rises with the basin.

The ability to achieve independence while washing is a very basic and essential need. The design criteria necessitated expensive materials, electronic taps and electric height-adjustability with a safety cut-out to ensure that the surface senses an obstruction below.

There are two models that meet the necessary criteria, as follows:

ABW4/ABW4SP from *Astor-Bannerman (Medical) Ltd*;

Spectra from *Southern Care Systems Ltd*.

A comparative chart to help with the choice is available in Chapter 8a of the Muscular Dystrophy Adaptation Manual. This is a valuable opportunity to try to redress the unacceptable statistics relating to washbasins and independence for a group of severely disabled children.

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# Justification for the Need & Funding of an *Astor-Bannerman ABW4/SP* or *Southern Care Systems Spectra Electrical Height-Adjustable Washbasin*

## for adults with muscular dystrophy & allied neuromuscular conditions

One of the greatest problems for anyone with muscular dystrophy or an allied neuromuscular condition is not only that they cannot walk but also that they have severe muscle weakness in their arms, although usually they retain reasonable hand function. As a result, they cannot lift their arms and have to rely on either creeping with their fingers or sliding their forearms along a surface, often aided by forward and backward movement of the trunk. If an arm falls off the wheelchair armpad, they are often dependent upon asking someone to lift the arm back up again, and this lack of arm function is very debilitating.

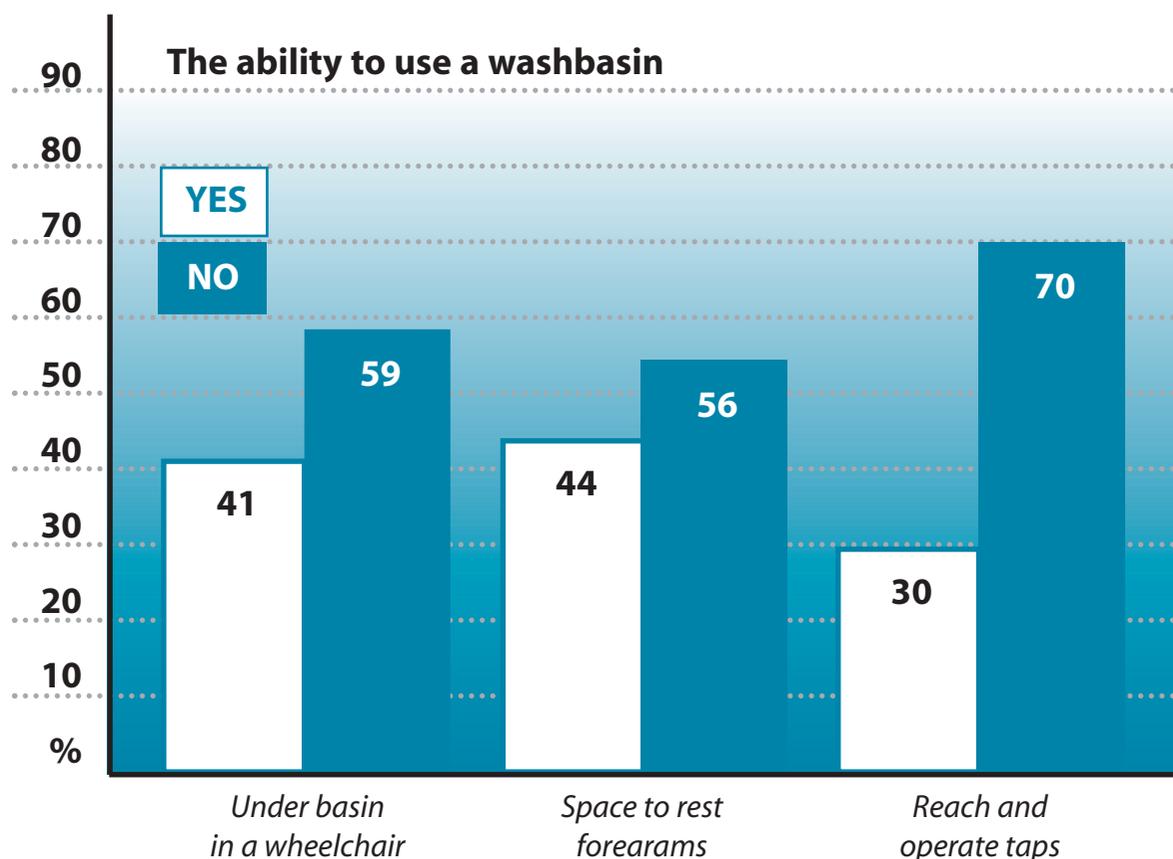
For several years the only solution was a fixed-height washbasin. This was often set into a melamine surface and used with ordinary lever taps. Although detailed notes were provided, builders found it difficult to install correctly, with the result that the work often had to be carried out twice. This was expensive, time consuming and very unsatisfactory. Finally this type of basin was withdrawn, although initially there was no satisfactory alternative.

Modern inset basins are not successful as they are raised up from the melamine surface and impede the sliding process. A fixed-height basin is not satisfactory because it is impossible to find one single height that is suitable on every occasion for both short- and long-term use.

### There is the need for height adjustment because:

- initially the basin may be used when standing and with a wheelchair;
- more than one wheelchair will be used and the wheelchair models will change over the years;
- cushions of different depths will be used;
- the wheelchair armrests will need to be raised after a more erect posture is achieved following spinal surgery;
- the optimum height for sliding arms on to the surface and into the water is too low for face washing and teeth cleaning.

In a recent research project looking at the quality of adaptations for people with neuromuscular conditions, some of the statistics were unacceptable, as the graph on the next page illustrates. This reflects the difficulties that were experienced in relation to conventional fixed-height washbasins. The fact that almost **60%** of disabled users did not have a wheelchair-accessible basin and **70%** could not reach the taps was a clear indication that a better solution was needed.



### The aim was to produce the following:

- a basin of the correct profile with the bottle trap against the wall – both of which will allow knee access when in a wheelchair;
- a basin which is large enough front-to-back to allow the user to get close up to the front edge without the wheelchair footrests hitting the wall below the basin and preventing this close access;
- a front edge without a fascia, which would obstruct the wheelchair armrests and/or the joystick control of a powered wheelchair;
- a surface less than **15mm** thick, which allows the user to 'creep' with their fingers, to raise their hands and forearms to the front or side of the basin;
- an area at the side of the basin which is large enough to provide forearm support, and the storage of toiletries and a towel within reach;
- a surround to the basin that is shiny and smooth to help users to slide their arms to reach forward;
- a basin set below the surface, without a raised edge, so that sliding arms into the water is not impeded;
- the shape of the basin ensures that the water is close to the user and it is not necessary to lean forwards, which may then make it difficult to sit back upright against the wheelchair backrest;
- tap controls which require no hand strength or pressure to operate and do not involve the need to reach;
- a basin low enough to enable the user to reach into it to wash, but at the same time set into a surface which can be raised high enough to allow their hands to be at the same level as their mouth for cleaning teeth, or their head for combing hair;
- a surface that behaves as a mobile arm support;
- flexible waste and water pipes to allow electric height-adjustability, if needed;
- the option of a mirror (with light) which rises with the basin.

The ability to achieve independence while washing is a very basic and essential need. The design criteria necessitated expensive materials, electronic taps and electric height-adjustability with a safety cut-out to ensure that the surface senses an obstruction below.

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# Justification for the Need & Funding of Working Surfaces

## for boys with Duchenne muscular dystrophy (DMD) - & for children with other types of muscular dystrophy & allied neuromuscular conditions

The average age at which a boy with DMD becomes unable to walk is 9½ years. However, long-established physiotherapy research at the Hammersmith Hospital has shown that keeping boys on their feet for as long as possible encourages a lordosis (a forward curvature of the spine at the lumbar region), which can delay a scoliosis, a lateral curvature that often involves rotation. Other physiotherapists working in muscular dystrophy clinics and muscle centres around the UK have proved that good physiotherapy management can keep a boy with DMD standing well beyond his teens. The methods used with varying success are long-leg calipers, swivel walkers (which also serve as standing frames) and standing frames.

For years, boys with DMD have been asked to stand in classrooms to do their work, but this was not being carried through at home because of a lack of incentive – or, at best, children were asked to stand to have their meals and watch TV. This was not productive and, for a number of years, staff working for the Muscular Dystrophy Campaign have recommended the installation of height-adjustable working surfaces in bedrooms. These should have a **600mm** square (or **800 x 600mm**) section at standing height with the rest of the surface for use in a wheelchair. Under the standing surface, a drawer unit with drawers on rollers is installed so that these can be opened easily. The top ‘drawer’ is a pull-out surface, to provide a work area to the side of the user sitting at the surface and thereby increasing the area for reference books etc.

Boys with DMD are unable to raise their arms to reach; wheelchair access right under the working surface allows them to slide their arms and maximise their reasonable hand function. In addition, architectural designers are asked to plan for the sitting surface to be L-shaped, so that a computer keyboard can be placed across the right-angle, with the monitor in the corner and the adjacent surfaces used to support the boy’s forearms.

Without this well thought-out provision of working surfaces, boys in wheelchairs were confined to using a wheelchair tray or table, both of which proved too small and limited their independence. Now the boys can come and go from their activities as they wish and the importance of these surfaces to their happiness cannot be stressed strongly enough. Many boys in the past had no purposeful activity in the home, other than watching TV. They are often artistic and creative, making excellent models, which require space and the ability to support their forearms. Now that GCSE examinations include project work, adequate working space is essential. In addition, the importance of computer literacy cannot be ignored, as many children develop an interest in the subject at a young age and are able to follow it through to further education and employment.

## Justification for the Funding for Working Surfaces

Following the appreciation of the importance of working surfaces, there have not been any applications for an adaptation where the space required for a minimum-sized unit of **1200 x 1800mm**, has been denied. Although the space is allowed – with the added bonus of increasing the circulation space in the bedroom – the provision of the surface and drawer unit by the housing grants have to be justified.

The surfaces have to be installed on height-adjustable brackets so that the height can be altered as the boy grows or when he changes his wheelchair (or uses a cushion) and the wheelchair armrest height and joystick control are raised. A fixed height for the surfaces has proved to be a disaster for boys undergoing spinal fusion, as their wheelchair armrests had to be raised to support their increased back height and after the trauma involved in the operation, they returned home to find they could no longer gain access to their hobbies.

‘Cheap’ adjustable brackets have in the past proved to be unsatisfactory as the surfaces began to ‘bow’ and then needed vertical supports to take the weight. This restricted accessibility in a wheelchair and did not allow a boy to turn under the surface and thereby limited the wheelchair circulation in his bedroom.

The brackets and drawer units recommended are available from:

*Astor-Bannerman (Medical) Ltd  
Huntleigh Renray Ltd*

Most boys’ rooms are in ground-floor extensions with doors swinging through **180°**, so that they have independent and speedy access between their bedroom and the family areas. Others have a lift with electronic doors which enables them to go to their rooms independently. This allows them to use their rooms in the same way as a non-disabled teenager – for homework, interests, to entertain their friends and for privacy. The majority of families would say that the provision of suitable housing and ideal facilities has been the single most important factor in helping them to cope.

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# Justification for the Need & Funding of a satisfactory Central Heating System

## for boys with Duchenne muscular dystrophy & children & adults with other types of muscular dystrophy & allied neuromuscular conditions

Muscles are the main source of heat production and maintenance of body temperature. Therefore, the severe muscle wasting in neuromuscular conditions, coupled with the inevitable reduction or lack of mobility, means that it is essential to provide a higher-than-average level of heating, i.e. 21° – 24°C in both the bedroom and bathroom. This is particularly important in the bathroom, especially where it has more than one external wall. Without adequate heating the bathroom will not be used.

It is important to stress that most children with muscular dystrophy feel the cold from a very young age. As they get older, and their muscle wasting increases and their mobility decreases, the problem becomes more severe. This difficulty is shared by people of all ages with similar muscle conditions.

The installation of a new central heating system or the extension of an existing system, if necessary with an upgraded boiler, can be grant funded where there is medical need. This need should be confirmed by the disabled person's hospital consultant. The cost of installing radiators in rooms that are either inaccessible to the disabled person or not used by them, will not be covered by the grant.

### It is also important to stress that the type of heating system chosen must be:

- instantly controllable and therefore, capable of being boosted when necessary;
- able to provide a constant temperature;
- suitable to be left on, when the disabled person is out of the house.

Storage heaters are not adequate because the temperature must remain constant over any 24-hour period. Also, individual radiant electric heaters are not suitable, because many people would hesitate to leave them unattended - and in no circumstances should the disabled person have to return to an unheated house.

In addition to central heating and a radiant heater in the sitting room, it will be necessary to provide a booster heater in the bathroom. This is needed to increase the temperature during a particularly cold spell in the winter - prior to bathing - and to use when the central heating system is turned off in the summer.

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# Goods and Services for disabled persons: eligibility declaration by an individual

(Reproduced from VAT Notice 701/7)

I (full name)

of (address)

declare that I am chronically sick or disabled by reason of:  
(give a full and specific description of your condition)

and that I am receiving from:  
(name and address of supplier)

\* the following goods which are being supplied to me for domestic or my personal use:  
(description of goods)

\* the following services to adapt goods to suit my condition:  
(description of services and goods)

\* the following services of installation, repair or maintenance of goods:  
(description of services and goods)

\* the following alterations to my private residence:  
(description of alteration see VAT Notices 701/7 paragraph 19)

\* the services of monitoring a personal alarm call system

\* the services of leasing a motor vehicle

and I claim relief from value added tax under Group 14 of Schedule 5 of the Value Added Tax Act 1983.

Signature

Date

\* Delete words not applicable

## NOTE TO SUPPLIER

You must keep this declaration for production to your VAT office. The production of this certificate does not automatically authorise the zero-rating of the supply. You must also ensure that the goods and services you are supplying qualify for zero-rating.

## NOTE TO CUSTOMER

If you are in any doubt as to whether you are eligible to receive goods or services zero-rated for VAT you should consult your local VAT Office before signing the declaration.

**Warning:** Section 39.2. of the VAT Act 1983 provides for severe penalties for anyone who makes use of a document which they know to be false for the purposes of obtaining VAT relief.

# Funding of Adaptations & Equipment

## Understanding the Grants System/VAT

*A discussion on the various sources of funding and the legislation involved in accessing grants following the assessment of need by both the disabled person and their family and the professional workers who are advising*

To be used in conjunction with:

Chapter 4	<i>Assessment of Need;</i>
Chapter 8	<i>Equipment (all sections);</i>
Chapter 10	<i>Disability Needs Assessment Form/Architectural Brief;</i>
Chapter 11	<i>Housing Needs/Space Requirements/Justification for Funding;</i>
Chapter 15	<i>Adaptation Specifications;</i>
Chapter 18	<i>Addresses: Manufacturers/Suppliers/Sources of Advice.</i>

The information is covered in the following sections:

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## The aim of adaptations

This chapter discusses the financial help available. There is no better way to introduce the subject than to quote from DOE *Circular 10/90 House Adaptations for People with Disabilities* which was published when the Disabled Facilities Grant (DFG) was first introduced. This stated “*It is fundamental to the Government’s policy of promoting effective care for people in their own homes and communities that disabled people should, as far as possible, be able to enjoy similar minimum housing standards to those enjoyed by able-bodied people*”.<sup>1</sup> This is a sound basis from which to approach the process of adaptations because we are all familiar with the basic facilities that most people enjoy in daily life. Clearly, disabled people have the right, within the limits of their disability and not the environment in which they live, to have these same facilities available, and the process of adaptations and the funding is to ensure that this is achieved and, equally important, to provide help for the carers.

## Key Principles

The front page itemises the chapters that should be used in conjunction with this funding information. However, in the document, *Delivering Adaptations: Responding to the Need for Adaptation – An Overview*, issued in February 2003 by the Office of the Deputy Prime Minister, some ‘Key Principles’ were laid out. These reiterate much of the information that has been provided in this Adaptations Manual in relation to the key worker, the assessment and the need for choice, but even more important they share the same positive approach. The funding of adaptations is frequently considered within a pessimistic and negative frame of mind. In view of this, quoting from this excellent document, strengthens the arguments considerably because it is published by the Government that is in office at the present time. For the purpose of this manual, the significant words and phrases have been highlighted in bold text.

- “*The purpose of adaptation is to modify disabling environments in order to restore or enable **independent living, privacy, confidence and dignity** for individuals and their families. It is therefore not primarily a matter of building work, the provision of equipment or otherwise modifying a dwelling, but providing an **individualised solution** to the problems of a person experiencing a disabling environment. This approach is often referred to as reflecting the ‘social model’ of disability, in contrast to a ‘medical model’ that focuses upon functional deficits in individuals. Whatever name is adopted to describe it this approach is the only sound foundation for work in this area*”.
- ... “*A particular objective is to ensure that **constraints on independent living are not imposed** on disabled people by virtue of the construction, layout and design of their homes.*
- *Thus the starting point and continuing focus of those seeking to provide an adaptations service should be **the needs experienced and identified by the disabled person** ... The process that delivers an adaptation should be one of **partnership in which the person experiencing the disabling environment is the key partner**. The appropriateness and acceptability of the adaptation outcome should be measured by the extent to which it meets the needs identified by that disabled person sensitively, efficiently and cost effectively. The process should be transparent, equitable and offer **informed choice to the consumer** on both outcome and methods of delivery at all stages.*

- **Quality and choice** should be the shared and corporate goals of all partners in the delivery of an adaptations service.”<sup>2</sup> ...

Finally and most relevant to this chapter:

- *“The pursuit of Best Value is the corporate responsibility of all partners, not only in terms of the most effective use of public funds, but in the provision of a timely service that is both acceptable to and enables the disabled person to achieve their objectives. **Best value will not always be achieved by choosing the cheapest option which may not fully satisfy the present or anticipated needs of the disabled person and thus become wasted expenditure.** Local authorities will therefore need to make appropriate provision to use their discretionary spending powers (particularly those contained in the Regulatory Reform (Housing Assistance) (England and Wales) Order 2002), to top up their budget allocated to meet mandatory duties.*
- *... Legislation in relation to the delivery of adaptations is complex. It includes, for example, statutory requirements (the Chronically Sick and Disabled Persons Act 1970 as amended) to assess needs and to arrange for appropriate assistance to be provided. There are also statutory requirements in relation to disabled persons’ entitlements and the appropriate adaptation to be delivered to meet a particular need, particularly with regard to the right to a Disabled Facilities Grant. A first class adaptations service must take into account and fully reflect all these legislative requirements.”<sup>2</sup>*

## How is funding obtained?

The main issues in securing grants and alternative funding for adaptations and equipment are as follows:

- insight and knowledge of the problems and the quality of the assessment. See Chapter 4 *Assessment of Need* and Chapter 10 *Disability Needs Assessment Form*;
- the experience of working with people with neuromuscular conditions and knowledge of which alternative solutions have worked for other people with identical difficulties. See Chapter 4 *Assessment of Need*, Chapter 8 *Equipment (all sections)*, Chapter 15 *Adaptation Specifications*, Chapter 16 *Kitchens*;
- knowledge of the statutory sources of funding and an understanding of the legislation in relation to grants – and the legal responsibilities of the different agencies involved – in order to access this funding effectively. These issues, in relation to adaptations, are the focus of this chapter and depend on the ownership and situation of the house;
- awareness of any additional funding that may be available.

All the factors provide occupational therapists (OTs) and other healthcare and professional workers with the information required to be able to justify the need and the funding of the equipment or facility that is being recommended; it enables them to support and advise the grant applicant and, where appropriate, to act as an advocate.

## Housing categories

Ownership of housing affects the source of funding for adaptations, and housing can be divided into four categories, as follows:

- ⇒ owner-occupied housing;
- ⇒ Local Authority (LA) housing;
- ⇒ Housing Association (also known as Registered Social Landlord) property;
- ⇒ privately-rented property.

The arrangements made for each category of housing depend on the procedures used in the part of the UK in which the house is situated - and, in particular, on the policies of the LA. The provision of grants and statutory funding – and the legislation that is in force – varies considerably between England and Wales, Northern Ireland and Scotland and they will be discussed separately.

## England and Wales

### Owner-occupied housing

Adaptations are provided through the Disabled Facilities Grant (DFG), Social Services Department and the Department of Health.

### Local Authority (LA) housing

Council houses are usually adapted with funds from the Housing Revenue Account and most LAs have a separate budget for adaptations in their own property. Some LAs advise (or insist) that the tenant applies for a DFG and this is always the tenant's 'right'. However, although the guidance is that *"if the local authority decide to undertake the works from their own resources they should be carried out on the same terms as if a DFG has been awarded"*<sup>3</sup> this is not always the case.

*"The quality of the planned adaptations service should not vary between housing sectors".* Tenants must ensure that they are not discriminated against because they are not owner occupiers. *"DFG is available to all eligible tenants and home owners"* (but this will be means tested and it will not be to the tenant's advantage if they have sufficient income to be assessed to pay a contribution). ... *"and if the local authority has a landlord role it has a responsibility to provide a high class service to its own tenants"*.<sup>2</sup>

### Housing Association property

The funding situations are complex and varied throughout the UK, but existing and potential tenants need to consider the following:

- ⇒ sources of adaptation funding/statutory obligations;
- ⇒ a perfect solution?
- ⇒ 'new-build' programmes;
- ⇒ joint-equity (shared-ownership) schemes;
- ⇒ the need for forward planning.

## Sources of adaptation funding/statutory obligations

All RSL tenants have the right to apply for a DFG. Most of the larger RSLs have a budget for adaptations and should be consulted as soon as possible to determine the position and to ask for permission to carry out the works. They may also be able to offer the alternative solution of purpose-built, specialist housing. *“Where the local authority believes that Registered Social Landlords (RSLs) should make a contribution to the costs of adaptations in their own properties this should be negotiated and established through formal agreement. Whilst there is no specific obligation on the landlord to fund such work, and the Housing Corporation” (England) “has no statutory duty to subsidise the costs involved, it may be considered good practice for a responsible social landlord to respond to the needs of their disabled tenants. Good practice for RSLs in identifying need, liaising with statutory authorities and carrying out works of adaptation is set out in guidance from the Housing Corporation”.* In Wales, the Housing Corporation function is performed by the Assembly. In addition, adaptations to Housing Association properties in Wales are also funded out of a Physical Adaptations Grant through the Social Housing Grant system.

*“In the case of stock transfers from local authorities to housing associations, the new RSL tenants will remain eligible to apply to the housing authority for a DFG, and they will be assessed for needs on the same basis as private owners and tenants. As part of their contractual negotiations, the authority and the new landlord should therefore agree how the management of the needs of the disabled tenants will be addressed and reflect this in clear public and management guidance.*

*It is not lawful for persons in any tenure to be obstructed in making an application for assistance through a DFG”.*<sup>2</sup>

*“The majority of the (adaptation) work has been in response to tenants’ needs from the Housing Associations’ own resources, and the potential of using the DFG from the Housing Department with additional help from Social Services Departments (both of which have a duty and responsibility for the provision of adaptations) is not always fully explored”.*<sup>4</sup>

## Landlord (not LA) or tenant application

If an application is made for a DFG it is important to clarify whether the landlord or the tenant will be the applicant - and it would be wise to discuss the alternatives with the grants officer. It is also crucial to discuss who will be responsible for repairs and maintenance of the equipment (see page 25).

## A perfect solution?

One major Housing Association in England with a great commitment to housing disabled people has adopted a funding policy which states that all adaptations up to £1,500, and half the cost in excess of that figure, are financed from their own resources. The remainder is funded either through the Grants System or Social Services – or jointly. This seems the perfect solution, particularly if the adaptation is for a child who is eligible for help from The Family Fund.

## **‘New-build’ programmes**

Housing Associations in Wales are governed by ‘Lifetime Homes Standards’ for ‘new-build’ properties – and in England, as a large part of Housing Corporation investment is in building new homes, over the years, Housing Associations have been a significant source of first-rate housing for purpose-built homes for particular families. Frequently this has been for disabled tenants living in areas where the LA did not have a suitable house in which to re-house either existing tenants, or sometimes for those currently living in their own property who were unable to afford to increase their mortgage sufficiently to buy a more suitable house.

## **Joint-equity (shared-ownership) schemes**

There have been successful outcomes of joint-equity, ‘new-build’ schemes between Housing Associations and disabled people, which is an excellent solution for owner occupiers who are anxious to retain their housing investment, but unable to increase their mortgage.

## **The need for forward planning**

The situation for tenants can be very frustrating because their needs are the same as those of disabled people living in owner-occupied housing, but the access to funding is more complex. It is impossible to provide definitive advice without knowing the local circumstances. However, if tenants are aware of the local arrangements and the possibilities for funding, these can be explored individually. The main point is that Housing Associations need to build the cost of adaptations or the possibility of ‘new build’ into their budget programmes and applications should be submitted as far in advance as possible. For many people with neuromuscular conditions, future needs can and should be anticipated and a document relating to the long-term housing needs can be found in Chapter 11.

## **Privately-rented property**

Tenants apply for grants in the same way as applicants in owner-occupied housing – but the landlord will need to give permission for any adaptation (minor or major) – and private landlords are not always as accommodating as social landlords. As part of the application, the tenant and the owner of the property will be required to complete and submit certificates relating to the adaptations and conditions concerning their future occupancy of the property (which in the current legislation is for 5 years). In relation to this issue, it is important to check that the landlord does not plan to raise the rent significantly. There may be circumstances where it is an advantage for the landlord to make the application on behalf of the tenant and the grants officer will be able to advise.

## **Disabled Facilities Grant (DFG) and Social Services funding**

Frequently asked questions (and concerns expressed) are listed to explain the funding of adaptations with a DFG or discretionary assistance:

- ⇒ What is the DFG and where will I find the relevant legislation?
- ⇒ Why was the system changed?
- ⇒ What are the purposes for which a mandatory grant must be given?

- ⇒ Do people who live in a mobile home or a houseboat qualify for a grant?
- ⇒ What Disabled Facilities Grants are available and what is the maximum payable?
- ⇒ What discretionary assistance might be available?
- ⇒ Is the mandatory grant means tested?
- ⇒ At what age are young disabled people assessed in their own right?
- ⇒ We are advised to postpone our adaptations until our daughter qualifies in her own right for a grant, but we don't want endless delays. What should we do?
- ⇒ How is the financial assessment carried out?
- ⇒ What do we do if our income this year is not representative of our usual income?
- ⇒ What does it mean when we are told that our contribution is £5,000?
- ⇒ Is our contribution deducted from the total cost of the scheme or from the maximum grant?
- ⇒ What do we do if we cannot afford our assessed contribution for a DFG?
- ⇒ I understand that LAs are being allowed greater flexibility in setting their policies, but how do we know what these are?
- ⇒ If a loan is offered what are the terms likely to be?
- ⇒ Do the Social Services Department have a responsibility to help us financially?
- ⇒ What happens in the case of joint-custody arrangements, where adaptations are needed in two houses?
- ⇒ Are foster parents allowed to apply for a DFG?
- ⇒ We have been told that we won't qualify for a grant, but should we still apply?
- ⇒ What support can we expect if we don't qualify for a grant?
- ⇒ We have two sons with Duchenne muscular dystrophy. Will we get two grants to adapt the house?
- ⇒ Our Grants Department don't seem to have experience of many large adaptations.
- ⇒ Is the Grants Department allowed to say that they have run out of money and there will be no more grants available for the rest of the year?
- ⇒ Can we apply for a grant after we have started the work?
- ⇒ My community OT is very concerned about budgets and does not appear to want the MD Campaign involved in the adaptations.
- ⇒ Who pays the architectural designer and what costs will be included?
- ⇒ We are not receiving financial help with the full cost of our adaptation. To reduce the cost we would like my brother who is a builder to do the work. Is this allowed?
- ⇒ We don't feel that we are getting the help we need, but we don't know what service we can expect.
- ⇒ Equipment will be provided and installed using a DFG. If we no longer need it who does it belong to - and who pays for servicing and repairs?

## What is the DFG and where will I find the relevant legislation ?

England and Wales share the same legislation in relation to DFGs although the funding arrangements differ (see page 10). In July 1990, the DFG replaced the Home Improvement Grant as part of the *1989 Local Government Housing Act*. Subsequently there have been several changes to the DFG, the most significant being:

- in December 1996, *The Housing Grants, Construction and Regeneration Act 1996*, which was accompanied in England by *Circular 17/96, Private Sector Renewal: A Strategic Approach* and in Wales by *Annex 1 of Welsh Office Circular 59/96*;
- in July 2002, the *Regulatory Reform (Housing Assistance) (England and Wales) Order 2002* (referred to in the text as *Order 2002*). The guidance circular in England is *Housing Renewal Guidance (Consultative Document)* and in Wales *Assembly Government Circular 20/02 Housing Renewal Guidance*, which largely replicates *Circular 59/96* (above) in terms of the guidance covering DFGs. *"The Assembly Government will be reviewing the administration of Disabled Facilities Grants in due course. This guidance will be revised in the light of that review".<sup>5</sup>*

The procedure when legislation is changed, is that primary documents are published with details of the amendments to both the grants system and statutory regulations, and these are followed by guidance circulars. The circulars (above) issued by England and Wales are similar, but to avoid confusion readers should refer to the appropriate guidance circular, particularly as these may be revised independently.

The sections of *Circular 17/96* that have particular relevance to the DFG are:

- *Introduction*;
- *Chapter 7: Strategies into Practice – community care and special needs*;
- *Annex I: Disabled Facilities Grant*;
- *Annex JI: Financial Matters*;
- *Annex J2: Calculation of Grant*.<sup>6</sup>

## Why was the system changed?

The DFG was introduced because *"some people needing essential adaptations have been unable to get help with the costs of carrying them out, whilst in other cases, grants have been given to people who could afford to finance the adaptation works without grant"*.<sup>1</sup> The impetus was to give help to the people most in need financially, on a sliding scale, and to **achieve consistency** across the country. To a certain extent this was achieved, but there will always be some LAs who are more sensitive to the needs of disabled people, who interpret the legislation more generously, or have more realistic budgets. Now, with the recent introduction of discretionary assistance, the pendulum has swung the other way to allow LAs more autonomy, flexibility and choice in the way they decide to help. The needs of disabled people have not changed and it is essential to ensure that the introduction of greater flexibility results in greater benefit for disabled people, as the changes were never intended to be a cost-cutting exercise.

The DFG legislation and the relevant subsequent changes will be explained in this chapter. It is important that disabled people are aware that the legislation is very clear about the different purposes for which a mandatory grant can be given, and the help that should be provided.

### What are the purposes for which a mandatory grant must be given?

Section 23 of the *Housing Grants, Construction and Regeneration Act 1996* states that:

- (1) *"The purposes for which an application for a disabled facilities grant must be approved, subject to the provisions of this Chapter, are the following:*
- (a) *facilitating access by the disabled occupant to and from the dwelling or the building in which the dwelling or, as the case may be, flat is situated;*
  - (b) *making the dwelling or building safe for the disabled occupant and other persons residing with him;*
  - (c) *facilitating access by the disabled occupant to a room used or usable as the principal family room;*
  - (d) *facilitating access by the disabled occupant to, or providing for the disabled occupant, a room used or usable for sleeping;*
  - (e) *facilitating access by the disabled occupant to, or providing for the disabled occupant, a room in which there is a lavatory, or facilitating the use by the disabled occupant of such a facility;*
  - (f) *facilitating access by the disabled occupant to, or providing for the disabled occupant, a room in which there is a bath or shower (or both), or facilitating the use by the disabled occupant of such a facility;*
  - (g) *facilitating access by the disabled occupant to, or providing for the disabled occupant, a room in which there is a washhand basin, or facilitating the use by the disabled occupant of such a facility;*
  - (h) *facilitating the preparation and cooking of food by the disabled occupant;*
  - (i) *improving any heating system in the dwelling to meet the needs of the disabled occupant or, if there is no existing heating system in the dwelling or any such system is unsuitable for use by the disabled occupant, providing a heating system suitable to meet his needs;*
  - (j) *facilitating the use by the disabled occupant of a source of power, light or heat by altering the position of one or more means of access to or control of that source or by providing additional means of control;*
  - (k) *facilitating access and movement by the disabled occupant around the dwelling in order to enable him to care for a person who is normally resident in the dwelling and is in need of such care;*
  - (l) *such other purposes as may be specified by order of the Secretary of State".<sup>7</sup>*

### Do people who live in a mobile home or a houseboat qualify for a grant?

As from July 2002, mandatory DFG eligibility was extended in relation to owners' and tenants' applications, to include *"the applicant (who) is an occupier (alone or jointly with others) of a qualifying houseboat or qualifying park home"*.<sup>8</sup>

## What Disabled Facilities Grants are available and what is the maximum payable?

Previously there were two types of DFGs, mandatory and discretionary, but *Order 2002* removed the power to give discretionary DFG. Now the two options are:

- ⇒ mandatory grant;
- ⇒ discretionary assistance.

### Mandatory grant

This is the only type of DFG available, and the difference between England and Wales is in the funding arrangements.

- **England.** The maximum limit for a mandatory DFG is **£25,000**. *“60% of whatever an authority spends on DFGs during the year”* is claimed from Central Government and although it is *“not cash limited”*<sup>11</sup> it is ring fenced and cannot be used for any other purpose. The remaining **40%**, funded by LAs is likely to be cash limited - i.e. the sum is allocated for the DFG budget for each financial year - and when the money runs out, schemes will have to be delayed to the next financial year.
- **Wales.** The maximum limit for a mandatory DFG is **£30,000**. However, the way the Capital funding is allocated is different in that almost all the funding to LAs is ‘unhypothecated’ (not ring-fenced) and it is for LAs to determine how much of their resources are used for DFGs, in the light of their local priorities. The guidance from the National Assembly is that DFGs must be a priority, but this flexibility in setting budgets should make it easier for the LA to respond to these needs and any subsequent financial pressures, without the delays caused by a backlog of schemes to be funded. Viewed optimistically - this must be to the benefit of applicants.

### Discretionary assistance

*“As the mandatory DFG will not be adequate to deal with all likely requests for assistance it is very important for an authority to include in its published policy what form of additional help it will offer in relation to adaptations for disabled people”.*<sup>9</sup>

Order 2002 *“places no limit on the amount of discretionary assistance that can be given for adaptations”.*<sup>3</sup> ... *“in accordance with its published policy”* (either from the Housing or Social Services Departments) ... *“paid in addition, or as an alternative to mandatory DFG”.*<sup>3</sup> Provision may depend on the result of the ‘*Test of Resources*’ or an LA means test, but one of the aims of introducing flexibility, is to try to help applicants who would not have received financial assistance previously. However, LAs are unlikely to help anyone whom they assess as being able to afford to pay for adaptations privately.

### What discretionary assistance might be available?

This could be given:

- “in any form e.g. grant, loan (see page 17 for details of loans);
- “for a wide range of purposes.

*“The Government accepts that loans will not be suitable for all those in need of assistance, and the Order is not intended to bring about the wholesale replacement of grants with loans”.*<sup>3</sup>

An authority can also provide”:

- ⇒ small-scale adaptations;
- ⇒ top-up to mandatory DFGs;
- ⇒ help to move to a more suitable property.

### **Small-scale adaptations**

This will be *“to either fulfil needs not covered by mandatory DFGs or, by avoiding the procedural complexities of mandatory DFGs, to deliver a much quicker remedy for urgent adaptations;*

### **Top-up to mandatory DFGs:**

- *because the works are particularly expensive or where the applicant, for whatever reason, cannot afford their required contribution; or*
- *where there are some works required that are not eligible for mandatory grant, for example:*
  - *works to provide more satisfactory internal arrangements for a disabled occupant where the works are not of a mandatory nature and where they would be of direct benefit to the disabled occupant rather than other members of the household. Such works might include extending or enlarging a dwelling, which is already suitable for the disabled occupant in all other respects.*
  - *works to provide access to a garden adjacent to a property where the disabled person is unable to gain such access from the dwelling through existing door or pathways. Authorities may wish to give discretionary assistance in such cases or may consider there is sufficient merit in including the works within mandatory grant ... as access for the disabled person to and from the dwelling.*
  - *the provision of a safe play area for a disabled child or where certain works of adaptation are required to provide for a disabled occupant to receive specialised care or medical treatment in their own home for which the disabled person is responsible for meeting the cost of works.*
  - *adapting or providing a room to be used for a disabled person who is housebound but nevertheless is able to work from home.*
- *To provide a complete solution to the needs of the disabled person”.<sup>3</sup>*

### **Help to move to a more suitable property**

This will be considered *“where it is more cost effective than adapting the current home of a disabled person to make it suitable for his or her present and future needs, even though the new property may need some adaptation.*

- *Rehousing options include trying to identify and offer suitable accommodation in the social rented sector. LAs should however bear in mind that for many disabled people the location of their home is a key consideration – often they have an established support system of friends, family and local organisations that, understandably, they will wish to maintain.*

- All rehousing options need to be carefully considered and discussed with the disabled person and others concerned ... There are also a number of national sources of advice for older people and people with disabilities on housing options"<sup>3</sup> (e.g. Muscular Dystrophy Campaign).

## Is the mandatory grant means tested?

Yes. The means test is called the 'Test of Resources' (TOR). "In the case of applications for DFGs, only the means of a disabled person for whose benefit the grant would be given and of the disabled person's spouse or partner (or parents in the case of a minor) will be tested"<sup>6</sup> (Annex J1 amendment). See page 14 for details of 'young people'.

It is important to understand the terminology:

- the 'applicant' is the person who has an interest in the house (i.e. the owner);
- the 'relevant person' is the person who is means tested;
- in many cases the applicant and the 'relevant person' (or persons) will be the same.

Most grants officers will carry out an informal 'TOR' at an early stage, prior to application so that you have an indication of your likely contribution.

## The aim of the means test (see also explanatory diagrams on the next page)

The means test is designed to calculate how much the 'relevant person' is deemed to be able to contribute towards the cost of an adaptation, having regard to the personal circumstances. This is carried out by:

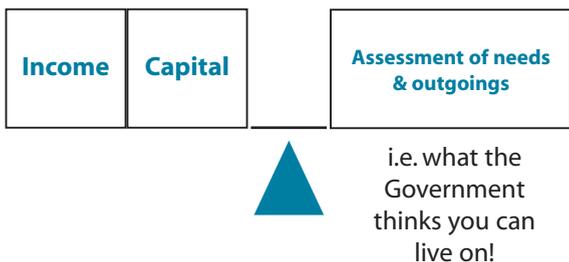
- calculating the 'applicable amount' (the assessment of needs and outgoings) by adding together the allowances and premiums that a person is entitled to. The outcome is the weekly sum of money that the government assumes is needed by that person (and if relevant, the family);
- the 'applicable amount' is then compared with the *actual earnings and other income received – and any capital owned*. Initially, when the DFG was introduced "the savings of each relevant person were completely disregarded up to £5,000"<sup>1</sup> - and this was subsequently amended to £6,000.
- this income and capital when added together is the 'financial resources';
- where the 'financial resources' exceed the 'applicable amount', the applicant is said to have 'disposable income', and therefore will have to make a financial contribution towards the cost of the adaptation;
- the size of the contribution, which in the legislation is called the 'affordable loan', (i.e. the sum which the relevant person is *supposed* to be able to afford to borrow and repay on the basis of income), will rise as the amount of 'disposable income' increases;
- the 'affordable loan' is calculated in set financial bands and, as the 'disposable income' rises into a higher band, the financial contribution rises (disproportionately). This explains why, when two salaries or wages are included in the calculations, the money earned by the second person (who is likely to be in part-time work to help ease financial pressures at the same time as being available to look after a disabled child) may cause a steep rise in the contribution;
- because the *actual* outgoings of the family are not considered (particularly where the applicant has a large mortgage) this may result in the family being asked to pay a contribution that they cannot afford;

- where the income of the 'relevant person' is less than the 'applicable amount', or they are in receipt of Income Support, there will be no contribution to pay.

**No contribution to pay**

i.e. enough to live on and no more

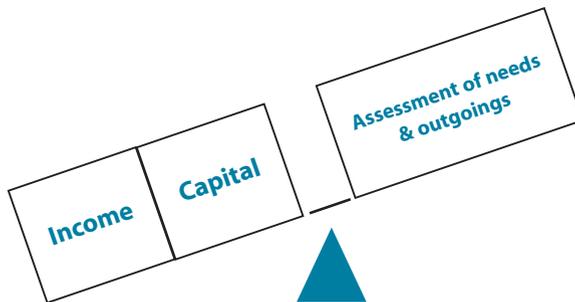
**Financial resources** - equal - **Applicable amount**



**Contribution to pay**

i.e. more money to live on than needed!

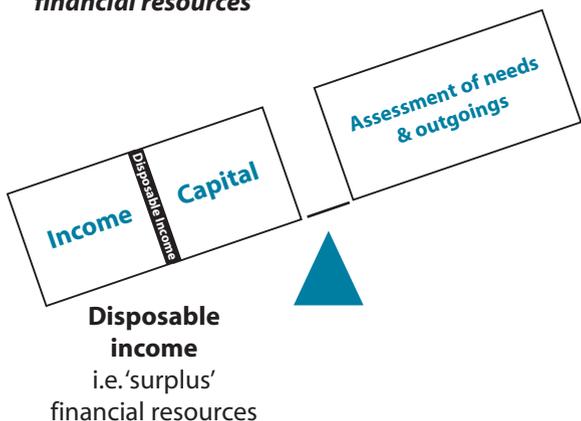
**Relevant person's financial resources** - exceed - **Applicable amount**



**'Disposable income'**

i.e. money left over that is not needed to live on and is available to contribute to the adaptations

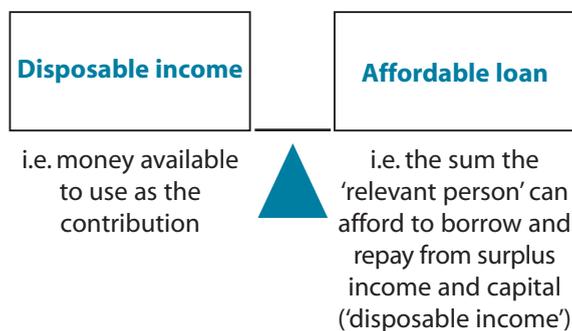
**Relevant person's financial resources** - exceed - **Applicable amount**



**Size of contribution**

i.e. 'affordable loan' increases with size of 'disposable income'

**Surplus financial resources** - equal - **Size of loan able to service**



In practice, it would be unusual to meet an officer, either within the Grants Section (responsible for applying the means test) or the Social Services Department (responsible for assessing and providing for the needs of disabled people and their families), who does not consider that the statutory 'TOR' (other than for people on Income Support) is a very harsh and unfair means test. For this reason, although circumstances will vary between LAs, many Social Services Departments have a procedure for applying their own means test, which takes into account the individual, actual 'outgoings'. See section "What do we do if we cannot afford our assessed contribution for a DFG?" on page 16.

There is a very strong campaign – *Homes Fit for Children*\* – to persuade the Government that, where adaptations for children are involved, the means test should be applied to the child and not to the parents. This is a logical step, as the means test is applied to all young people at 19 or in some cases, at 16 (see below). Failure to do this means that many families with a child who is severely disabled and needs adaptations from an early age are penalised financially, compared with a family with a less-disabled child who is able to wait for adaptations until qualifying in his/her own right. However, with the introduction of the Regulatory Reform Order, the opportunity for greater flexibility will enable LAs to assist those who need additional help following the ‘TOR’.

\* For further details and up-to-date information, please contact the MDC National OT Advisor.

### **At what age are young disabled people assessed in their own right?**

The legislation defines who is the ‘relevant person’ when the means test is applied – i.e. at what age does a young person cease to be a minor (see page 12) - and on whose income (or incomes, where two parents or partners are working) the calculation for the contribution will be based. In April 1997, the definition of the relevant person was amended... *"Where the disabled occupant is under 19 and over 16, is not in full-time non-advanced education (i.e. school), or receives Income Support, he will no longer be treated as a young person and would therefore automatically become the relevant person instead of his parents. In these cases it is the disabled occupant under 19 and not the parents who would be subject to the ‘TOR’ – the means test"*.<sup>10</sup> This means that the disabled person will be classed as the ‘relevant person’ and will be means tested in his/her own right to establish the contribution that will have to be made. However, for anyone on Income Support, no means test will be applied and there would be no contribution to make. If in doubt, please contact your grants officer for advice.

### **We are advised to postpone our adaptations until our daughter qualifies in her own right for a grant, but we don’t want endless delays. What should we do?**

If the adaptations are not needed immediately, there is no reason why plans should not be drawn and submitted for planning permission - followed by an appropriate delay in obtaining builder’s estimates and making the formal grant application. Advice should be sought from the architect and grants officer as to how long these last two processes will take and the time-scales related to the date of eligibility.

### **How is the financial assessment carried out?**

A fairly involved application form is provided, which asks for comprehensive details of income (including welfare benefits) and earnings for the 12 months prior to the application, together with details of any capital. If completion of the form, or any of the questions are difficult, the grants officer can be asked for help. When processing the application, the Grants Department will need to see confirmation of all income, earnings and capital. Where relevant, proof of Income Support will need to be shown, in which case no assessment is carried out.

## What do we do if our income this year is not representative of our usual income?

This situation can arise if the applicant has been working an unusual amount of overtime during the assessment period. Although LAs cannot anticipate future income, provision for a shortened period of assessment to be carried out is covered in the legislation, as follows: *"Whilst there will be many cases where it is appropriate to calculate average weekly earnings by reference to earnings over the previous 52 weeks, authorities should not adopt this method as a hard and fast rule. Where there has been a significant change in a relevant person's circumstances during the previous 52 weeks, authorities should determine average weekly income by reference only to that period, up to the date of the application, which most accurately reflects his or her current situation. For example, the average weekly income of a relevant person currently in stable employment should not be diluted by including any previous periods of unemployment. Similarly, where a relevant person has recently been made redundant, it may not be appropriate to include periods of employment in the assessment of income"*.<sup>6</sup>

## What does it mean when we are told that our contribution is £5,000?

Although contributions can vary between nil and infinity - depending upon the relevant person's financial circumstances – the result of your means test assessment is that you can afford (see page 12) to borrow £5,000 (your *affordable loan*). This does not mean that you are expected to have the money in an account waiting to pay for adaptations! Your contribution is the same, irrespective of the cost of the work or the grant payable and is not reflected as a percentage of either sum.

## Is our contribution deducted from the total cost of the scheme or from the maximum grant?

In the past, the legal department dealing with DFGs, ruled that the contribution was deducted from the cost of the scheme. However, this has changed, and a section on *"Guidance on Existing Legislation ... seeks to clarify the interaction between the maximum limit for mandatory DFGs and the contribution of the grant recipient"*.

*"A local authority has to notify an applicant of certain matters, as follows":*

- *"determine which works are eligible for DFG"*. Any improvements can be included in the work schedule, but if not essential to the disabled person, will not be grant eligible;
- *"determine the expense of carrying out the eligible works"*. The LA examines the contractor's estimate and if the sum is unreasonable, may render part of the cost ineligible for a grant. This is unusual and is normally solved with a discussion between the grants department and the contractor;
- *"determine the cost of ancillary services and charges associated with the works"*. This will include the charges of the 'in-house' Home Improvement Agency or of your own architectural designer (possibly chosen from the Muscular Dystrophy Adaptations & Building Design Network). If it is not practical for your designer to inspect the work, the LA may take on this responsibility, for which they are entitled to be paid, but the cost of administering the grant is a service that must be provided free of charge (see pages 23-24);

- “determine the amount of grant to be paid, ‘taking into account all the relevant provisions of this chapter’”. The Department for Transport, Local Government and the Regions view is that “the amount of grant referred to ... is the amount of DFG which the authority is prepared to pay **before** taking account of the applicant’s resources. That amount will include a further amount in excess of the maximum permitted” <sup>11</sup> (and in the circular the legal interpretation is explained, but is too lengthy to include here). However, “the amount of grant determined by the authority is reduced by the client’s contribution. The effect ... may be illustrated by the following examples.” <sup>11</sup>

	Example A	Example B
(a) Cost of works	<b>£30,000</b>	<b>£30,000</b>
(b) Amount of grant LA prepared to pay	<b>£30,000</b>	<b>£25,000</b>
(c) Client’s contribution (as a result of ‘Test of Resources’)	<b>£10,000</b>	<b>£10,000</b>
(d) Grant payable by LA	<b>£20,000</b>	<b>£15,000</b>

So the LA works out how much it is prepared to pay and then reduces this by the amount of the assessed contribution.

### What do we do if we cannot afford our assessed contribution for a DFG?

“A local housing authority does not have a duty to assist an applicant for DFG in meeting any share of the costs which the applicant is assessed to be responsible for under the test of resources. The housing authority may however, refer cases of hardship to the social service authority or to a joint panel that allocates funding on behalf of the social service authority. It may also consider using its discretionary powers of assistance under housing legislation”. <sup>9</sup> However, many Social Services Departments are likely to ask applicants to provide proof that they cannot afford their contribution (or to pay for the top-up costs of the scheme) and will ask you to apply to your building society for an increase in your mortgage - and /or to your bank for a loan. They may wait to see if these sources of finance are available before considering discretionary assistance. However, you should voice your fears if you feel that borrowing any sum of money is irresponsible because it means you will be over-committed financially and risk becoming in arrears with your mortgage payments with the subsequent danger of losing your house and the facilities provided by the DFG. Ideally, your concern should be substantiated by financial figures - and it would be useful to prepare a calculation of your monthly income and expenses. The outcome is likely to be that the Social Services Department will carry out their own means test, which will take outgoings (such as mortgage) into account.

### I understand that LAs are being allowed greater flexibility in setting their policies, but how do we know what these are?

The flexibility for adaptations is limited to discretionary assistance only and does not include mandatory DFGs. “The Order requires that, prior to using any powers to provide assistance ... a local authority must first have:

- adopted a policy which includes details on the provision of that assistance;
- given public notice of the adoption of the policy;
- ensured that a copy of the full policy document is available for inspection free of charge at all reasonable times at their principal office; and
- ensured that a document containing a summary of the policy can be obtained by post.

*Authorities must also avoid fettering (restraining) their discretion to provide assistance. They may legitimately turn down an application for assistance that falls outside their policy, but cannot do so without there being a mechanism in place to determine such cases. The mechanism should ensure that exceptional cases that fall outside policy are individually considered on a sound and informed basis and approved where appropriate”.<sup>3</sup>*

LAs should have an appeals procedure, if an applicant is dissatisfied with the outcome of their application. Applicants can also complain to their local councillor or MP – or ultimately to the Local Government Ombudsman - although this can be a lengthy process.

### **If a loan is offered what are the terms likely to be?**

You will need to enquire because policies will vary between different LAs, and are likely to depend upon your financial situation. However, *“The Order contains important protections relating to the giving of assistance, whether it is given as a grant, loan or another form of help. It requires that:*

- *authorities set out in writing the terms and conditions under which assistance is being given;*
- *before giving any assistance the authority must be satisfied that the person has received appropriate advice or information about the extent and nature of any obligation (financial or otherwise) that they will be taking on; and*
- *before making a loan, or requiring repayment of a loan or grant, the authority must have regard to the person’s ability to afford to make a contribution or repayment”<sup>3</sup> (probably by applying their own means test). “If they are not in such a position then assistance by some other means, such as a grant, would be necessary.”*
- *...“There is a wide range of options available for local authorities to consider ... whilst developing their policy”.*
- *The principal categories of loan products which could be made available are:*
  - *interest bearing repayment loans – conventional loans either secured or unsecured with interest charged either at the current market rate or at a preferential rate and repayable in regular instalments over a period of time. Such loans are likely to be best suited to those with a regular income which would enable them to make the required repayments.*
  - *interest-only loans – conventional loans, usually secured against the value of an asset where the borrower only pays the interest charge on the amount borrowed in regular instalments. Repayment may vary as interest rates go up or down. The capital is repaid usually on the sale of the asset. Again, this sort of loan is likely to be best suited to those able to meet regular interest repayments, and, where the loan is secured against the property where there is adequate remaining equity in it.*
  - *zero-interest or equity-release loans – a conventional loan registered as a charge against the value of the asset on which no interest is levied. The capital is repaid usually on the sale of the asset”.<sup>3</sup> This type of loan may be best suited to those unable to make regular loan repayments, but who have substantial remaining equity in their home.*

... In deciding which is the right financial product for any particular circumstance, local authorities will need to make a careful assessment of the financial position of the applicant. In the case of equity release products they will also need to make an assessment of the current and possible future value of the property and other actual and potential charges on it".<sup>3</sup> This option may be limited to older applicants (usually over 60) with little or no mortgage - and possibly with the addition of other restrictions.

### **"Income Support for loan interest payments**

People who qualify for Income Support/income based Jobseekers Allowance/Pension Credit may also get help to pay the interest on a loan taken out for specific types of home repairs and improvements. There is a waiting period for persons under 60. This help cannot be confirmed until the loan has been taken out but the Department of Work and Pensions is willing to send out letters of comfort to both the loan recipients and any lender explaining what help is available. Any loan must be used for these purposes within six months of receipt or such further period as may be reasonable in the particular circumstances of the case, in order not to affect any benefits which might otherwise be payable to the person on receiving the loan".<sup>12</sup>

## **Do the Social Services Department have a responsibility to help us financially?**

The situation is as follows:

- ⇒ the role of the Social Services Department to assist with adaptations;
- ⇒ the role of the *Children Act 1989* in establishing the Social Services Department's responsibility to help with the funding of adaptations for children;
- ⇒ The *Quality Protects Programme*;
- ⇒ The *Children First Programme*.

### **The role of the Social Services Department to assist with adaptations**

The legislation is very clear about this responsibility, as follows:

"Social Services authorities' responsibilities under section 2 of the *Chronically Sick and Disabled Persons Act 1970 (CS&DP Act)* to make arrangements for home adaptations are not affected by the grants legislation. Where an application for DFG has been made, those authorities may be called upon to meet this duty in two ways:  
(a) where the assessed needs of a disabled person exceeds the scope for provision by the housing authority under section 23 of the 1996 Act; and  
(b) where an applicant for DFG has difficulty in meeting his assessed contribution determined by the means test and seeks financial assistance from the authority."  
In such cases, where the Social Services authority determine that the need has been established, it remains their duty to assist even where the local housing authority either refuse or are unable to approve an application".<sup>6</sup>

"It is for housing authorities and Social Services authorities between them to decide how particular adaptations should be funded either through the *CS&DP Act* or through a DFG".<sup>6</sup>

## The role of the *Children Act 1989* in establishing the Social Services Department's responsibility to help with the funding of adaptations for children

This Act which covers England and Wales was intended to emphasise the corporate nature of LA responsibility for children in their area. Part III of the Act concerns "*Local Authority support for children and families*" and at section 17, it specifies a general duty "*to safeguard and promote the welfare of children within the area who are in need,*" listing disabled children specifically as a group of children in need, at subsection 10. Authorities are required to keep a register of disabled children, publish information, minimise the effect on disabled children of their disabilities and give them the opportunity to lead lives that are as normal as possible, promoting "*the upbringing of such children by their families*"<sup>13</sup> (section 17.1b). Some Social Services Departments have used their powers under section 17 to help fund adaptations for children, but many have not. It is reasonable to say that the overwhelming priority to Social Services of child protection issues has led to a failure to implement adequately the provisions of the *Children Act* as they relate to disabled children and their siblings.

### The Quality Protects Programme

This is a Government initiative started in November 1998 (*Circular LAC(98)28*) which covers England only and reinforces the *Children Act*. It requires LAs to make a 3-year action plan in regard to children's services (*Quality Protects Management Action Plan or 'MAP'*) and sets out eight objectives that will be monitored. Objective 6 concerns "*children with specific social needs arising out of disability or a health condition*" and says that authorities must ensure their assessed needs are adequately met and reviewed. A sub-objective is "*to arrive at a complete picture of the numbers and circumstances of disabled children by sharing information held by Social Services Departments, Health and Education Authorities*".<sup>14</sup> This last provision will make a significant difference to the policy framework for disabled children, especially if information on the housing needs of these children is collected.

As part of *Quality Protects*, the Secretary of State sent a letter to all Local Authority councillors reminding them of the responsibilities under the *Children Act*; it is, therefore, a programme of which they are likely to be particularly aware.

### The Children First Programme

This is a similar initiative which covers Wales.<sup>15</sup>

## What happens in the case of joint custody arrangements, where adaptations are needed in two houses?

"Where a disabled child has parents who are separated and the child lives for part of the time with both parents, arrangements may need to be made to provide for adaptations at both locations. Mandatory DFG is only available at the address which is the main residence of the disabled occupant, as determined by the local authority".<sup>9</sup>

## Are foster parents allowed to apply for a DFG?

*“The Social Services Department is responsible for assessing the child’s needs and providing appropriate services to meet those needs, which include services to meet needs arising from disability. Foster carers are eligible for DFGs on behalf of a foster child but provision may depend on the type and length of placement. The Social Services Department should establish local agreements and protocols with housing and health partners to ensure that the welfare of children and young people in foster care is actively promoted”.<sup>9</sup>*

## We have been told that we won’t qualify for a grant, but should we still apply?

You will only be told that you won’t qualify for a grant, if your contribution is more than the maximum limit - or the cost of the eligible works (whichever is the lower) - or more than the sum which the LA is prepared to pay. However, it is important to appreciate that this will be an estimate only; final assessments are carried out when the Grants Department receive all the paperwork, including such items as the builders’ estimates.

There are three important issues involved:

- ⇒ the need to know your contribution;
- ⇒ the advantage in following an application through to completion;
- ⇒ alternative options to consider.

### The need to know your contribution

This is important for the following reasons:

- to consider whether this financial assessment might be affected by any circumstances that could change before the final assessment is carried out;
- there may be ways that the LA can give discretionary assistance and this possibility should be explored;
- it may help to decide whether to follow an application through to completion.

### The advantage in following an application through to completion

You should still apply and not be put off by the form filling and bureaucracy (as this will be cut to a minimum if you are unlikely to get any financial help). No one can predict what the future holds; if your circumstances change and you have to move house, or if more sophisticated facilities are needed as the disability progresses, you may need to apply for a further grant. In this case, your contribution to the approved work in your first application would be deducted from your assessed contribution on any subsequent application made within a period of 10 years for an owner applicant and 5 years as a tenant.

This advice is supported by the legislation: *“Authorities should explain to applicants the merits of pursuing an application through to completion even where it is clear the assessed contribution exceeds the cost of the present works and therefore the outcome will be that a ‘nil grant’ is approved. In such cases, the current contribution will be reduced by an amount equivalent to the approved cost of works, not the assessed contribution which may have been greater. Where a local authority intends to approve a grant in such cases they should ensure that the works for which the original application was submitted were completed to a satisfactory standard”.<sup>3</sup>*

## Alternative options to consider

If you are not able to afford the total cost of the proposed plan and the disability is progressive, it may be practical to carry out the work in two stages – and for this to be reflected in the design. Initially the work would be for the short term and subsequently when you need the full scheme, you could apply for a second grant - in which case your contribution would be amended as described above. An alternative would be to complete the building work to overcome the priority, which is likely to be the difficulty climbing stairs - by providing ground-floor facilities or a lift. This would be followed by the application for a second grant when the disability has increased and the specialised equipment is needed.

## What support can we expect if we don't qualify for a grant?

*“Support to those who self-fund.*

*Some people assessed as in need demonstrate a willingness and ability to self-fund” (N.B. This answer is a quotation, and is not substantiated by experience, which has shown that the willingness to self-fund is unusual as most people, whatever their financial circumstances, ‘live up to their income’) “or otherwise fall outside the housing grant system. In such cases, they should receive a copy of the assessment and recommendations for appropriate service response and be assisted in translating these into a specification. They should also be offered technical advice on the selection and engagement of contractors (with access to a list of competent builders, see also page 24) and equipment suppliers. And “this may extend to offering access to contract rates for the purchase of equipment such as lifts or hoists”.<sup>2</sup> ... “This might involve referral to a disabled living centre or Home Improvement Agency ... or to other professionals whose help might be useful”<sup>9</sup> (See Chapter 13 Muscular Dystrophy Adaptations & Building Design Network.).*

## We have two sons with Duchenne muscular dystrophy. Will we get two grants to adapt the house?

Because of the genetic inheritance of many of the muscular dystrophies, the housing adaptation research that was carried out several years ago by the Muscular Dystrophy Campaign, found that **10%** of the adaptations were necessary for two disabled members of the same family. Unfortunately, only one mandatory grant is payable at a time, but if you are eligible for a grant you are likely to be given discretionary assistance. If funding is difficult, and the progression of the disability is variable (as in some of the adult conditions) it may be possible to carry out the work in two stages and the issues involved have been discussed above.

## Our Grants Department don't seem to have experience of many large adaptations

Most of the adaptations needed by people with muscular dystrophy and allied conditions involve either a ground-floor bedroom and bathroom extension - or a lift and adaptations to the bathroom. However, across all disabilities, these extensive adaptations costing over the grant limit are the exception. Although the following statistics may be becoming out of date as adaptations improve and building costs rise, research carried out in 1996 with 39 LAs in England and Wales, found that *“in total 235 grants over £20,000 (England) or £24,000 (Wales) were given in this five-year period by these 39 authorities. Just under one third of the authorities gave none at all in five years and the mean was six or just over one per year. If this is considered in terms of numbers of grants over £20,000 per 100,000 population, the average for one year was 0.8”*.<sup>16</sup>

It is worth noting that “Best value will not always be achieved by choosing the cheapest option which may not fully satisfy the present or anticipated needs of the disabled person and thus become wasted expenditure”.<sup>2</sup>

The *Good Practice System Review Checklist* published by central government, asks the question “Is there a written policy in dealing with complex or very expensive adaptations?”.<sup>17</sup> Ask if this is available - and if not, perhaps your scheme could be used as the basis of providing a policy.

## Is the Grants Department allowed to say that they have run out of money and there will be no grants available for the rest of the year?

A Grants Department must notify “an applicant as soon as reasonably practicable and not later than 6 months after the date of the application, whether the DFG application is approved or refused. However ... the local authority may approve an application for mandatory grant on the basis that the grant, or part of the grant, will not be paid before a date specified in the notification of their decision. The date so specified must not be later than 12 months after the date of the application.”<sup>3</sup> It would be unusual for a scheme to be delayed longer than 6 months. LAs are discouraged from deferring payment “where it would cause hardship or suffering to an applicant whose adaptation needs have been assessed as urgent”.<sup>3</sup>

“There should be a corporate responsibility, binding on all partners, to ensure that the adaptation is delivered sensitively, is fit for the purpose identified by the end user and within a time-frame that is made explicit at the outset. Sections 34 and 35 of the Housing Grants, Construction and Regeneration Act 1996, already make relevant stipulations, but the principle should cover the whole process, from initial enquiry to completion of the case, not simply the element concerned with the grant approval”.<sup>2</sup>

## Can we apply for a grant after we have started the work?

Where there is extreme urgency, there are some LAs that may make special ‘without prejudice’ arrangements for the work to start before approval. It is important to note that this is following (rather than before) discussion with the LA - and the work starts without prejudicing the processing of the subsequent grant application and is at the risk of the applicant. Normally the situation is that you can apply, but it would be very unusual for a grant to be given and the best advice is to avoid placing yourself in this position and **to ensure that a grant is approved before starting the building work**. The restrictions on grant for works already begun is as follows:

- “(1) Subject as follows, a local housing authority shall not approve an application for a grant if the relevant works have been begun before the application is approved.
- (2) Where the relevant works have been begun but have not been completed, the authority may approve the application for a grant if they are satisfied that there were good reasons for beginning the works before the application was approved.
- (3) Where an authority decides to approve an application in accordance with subsection (2), they may, with the consent of the applicant, treat the application as varied so that the relevant works do not include any that are completed. But in determining for the purposes of the application the physical condition of the dwelling, common parts of house or other building concerned, they shall consider the condition of the premises at the date of the application.
- (4) Subject as follows, a local housing authority shall not approve an application for a grant if the relevant works have been completed”.<sup>7</sup>

## My community OT is very concerned about budgets and does not appear to want the MD Campaign involved in the adaptations

Sometimes, there is fear that specialists ‘will raise the expectations’ of the disabled person or their family. This is understandable because therapists are put in the unenviable position of having to assess needs and worry about budgets at the same time. However, it can never be justified that a disabled person is denied information and good practice must involve options and choice. Perhaps your OT is not aware that you (or your child) are likely to have specific needs. OTs have a wide range of knowledge and experience, but cannot be expected to know all the answers - and this is recognised by experienced OTs, who are always pleased to work with specialists such as the Family Care Officers of the MD Campaign. Throughout all the government publications issued recently, co-operative working is both recommended and encouraged, as follows:

*“Specialist organisations that have expertise in meeting the needs of disabled people with particular diagnoses can be helpful in ensuring that the needs and wishes of the disabled person and carers are fully taken into account and reflected in the process of adaptation”. (However, 17/96 distinguishes between what is desirable and what is actually needed in determining what is grant eligible.) “Staff should be encouraged to contact and work with such specialists and to make use of their particular knowledge to produce really effective adaptations”.<sup>9</sup>*

### Who pays the architectural designer and what costs will be included?

A decision will have been made to either appoint your own architectural designer or to use the services of a local agency, which may be operated by the LA. In both cases, the costs charged, which are usually a percentage of the cost of the scheme, are deducted from the grant. There is no statutory scale of fees that LAs must follow; although guidelines are issued, an authority can decide what is reasonable in the light of the work undertaken. However, a LA cannot charge for carrying out their statutory duties.

In this manual, details have been included of the *Muscular Dystrophy Adaptations & Building Design Network* and the advantages of using an architectural designer who understands the needs of people with a neuromuscular condition (see Chapter 13a). In this case, the designer who is helping to plan the adaptations will indicate the range of services that can be given and the relevant costs. It will then be necessary to ensure that there is no duplication of services, by checking whether the LA is making any additional charges.

LAs are not allowed to charge for administering the scheme, and guidance is issued as follows:

#### *“Fees and charges*

*Within their policies, local authorities should also state what preliminary or ancillary fees and charges associated with the provision of assistance will be paid as part of that assistance. This might include fees charged by in-house grant agency services, private architects and surveyors or home improvement agencies, and could include either in-house or out-sourced loan administration costs.*

*... clearly only reasonable and necessary fees and charges should be eligible for assistance ... but without compromising the quality of service provided to the customer".* <sup>3</sup> (which is particularly important in relation to the extensive adaptations discussed in this manual).

It is essential to assess whether you are getting the 'best value for money', as all charges will be deducted from the grant and ultimately affect the cost of the scheme and the amount of additional 'top-up' funding needed.

The timing of the payment is usually discussed between the designer and the grants officer. The only difficulty arises, if the scheme is abandoned for any reason, as the architectural designer will still have to be paid.

### **We are not receiving financial help with the full cost of our adaptation. To reduce the cost we would like my brother who is a builder to do the work. Is this allowed?**

It would be wise to discuss this issue at the beginning of the planning stage and when the initial 'Test of Resources' is carried out by the Grants Department, to see what their policy is so that no delay is caused. Although it is rare for DFGs, it is possible for grants to be given for DIY applications (where either the applicant or a relative carries out the work) but only the cost of materials can be claimed as grant-eligible costs. *"Consideration needs to be given to how to deal with estimates and invoices for assisted work from applicants or members of their family. Allowing such assisted work to be undertaken carries a higher risk of collusion and fraud. Authorities need to consider whether they do not allow this at all, allow it but only pay the cost of the materials, or do allow it. In the latter case, they need to satisfy themselves that the system is not being abused".* <sup>3</sup>

It is important to note that after the LA have approved the contractor's estimate, that the contractor cannot be changed without permission from the LA.

Guidance on contractor selection is included in the advisory documents, as follows:

*"Access to a list of builders approved by the LA for carrying out adaptation works should be open to all contractors who meet a published set of criteria. These may include; production of appropriate insurance, production of evidence of financial standing and evidence of competence in carrying out building work of the categories involved in adaptations. This evidence should be by production of references and provision of access to past work that may be inspected by officers".* <sup>9</sup>

*"Where the disabled person decides to use a contractor that is not on the LA approved list they should be provided with the list of criteria used to vet contractors for admission to the approved list and advised to apply these same tests to their chosen contractor. Their application should not be treated in any way less favourably than if they had used a contractor from the approved list".* <sup>9</sup>

Most LAs do not have an approved list of builders and are not required to have one. However, they may have a list of builders who carry out grant work – and the list normally carries a disclaimer.

## **We don't feel that we are getting the help we need, but we don't know what service we can expect**

If you find the time to read this manual I hope that you will be in a better position to know the answer to your question. Also, three excellent booklets (see references 2, 9 and 16) were published in February 2003 by the Office of the Deputy Prime Minister. Clearly, these were written by a team who understand the needs of disabled people, the ways that LAs should be responding - and provide markers against which you can judge the service you are receiving.

The introduction to *“Delivering Adaptations: Good Practice System Review Checklist”* states *“It will also be helpful to service users and their advocates in shaping their expectations of the service they receive”*.<sup>17</sup>

It is necessary to distinguish between legislation (which is mandatory) and guidelines. However, although these three new documents have no legislative standing, they highlight ‘best practice’ and as such describe the practice and attitudes carried out and adopted by the ‘best’ and most enlightened councils. In the event of the involvement of an ombudsman, it is likely that reference will be made to these guidelines. At the time of printing this manual, the Desk Guide is a consultation document, but the only criticism appears to be that the time scales recommended for adaptations are aspirational. In this respect it is important to appreciate that planning major work to your home is a lengthy procedure and because time is needed ‘to get it right’, the best advice is to plan ahead, to be as patient as possible – and to read Chapter 3 in this manual.

Parts of these publications have been quoted in this chapter, but if you are the key worker in your scheme or if your key worker or advocate has not had the opportunity to read them, please see the references at the end of this chapter.

## **Equipment will be provided and installed using a DFG. If we no longer need it who does it belong to - and who pays for servicing & repairs?**

Equipment provided with a DFG usually belongs to the DFG applicant, but this is not ideal if you have to pay for maintenance, which can be expensive and it may be worth considering maintenance insurance. However, some LAs allow the inclusion of 5-year warranties for lifts and other equipment in the grant-eligible costs, but because this is a discretionary power, it is not used by all authorities.

LAs are allowed to impose conditions that *“specialised equipment such as a stairlift ... may be recovered where it is no longer required. In practice social services are best placed to recover the equipment so that it can be re-assigned to another person”*.<sup>3</sup>

If conditions are imposed, check if this means that the equipment will be serviced and repaired by the LA during the years it is being used, as this would be a very satisfactory arrangement. These issues should be discussed at the time that the adaptation is being planned – and it would be wise to ask who pays for the cost of removing the equipment and carrying out any consequential remedial work to the house. Any conditions must be confirmed in writing.

Further guidance is given on servicing, repairs and extended warranties, as follows:

*“Some items installed as part of an adaptation, such as stair and through-floor lifts and ceiling hoists” (and specialist baths and washbasins) “will need regular servicing and provision made for repair in cases of failure. It is good practice for these arrangements, covering the likely service life of the equipment, to be secured by the LA at the time of installation. The cost of securing services by way of extended guarantee or service contract, when met by a single payment on commissioning, should be included in the calculation of any grant payable”.<sup>9</sup>*

An additional issue is highlighted in the ‘Good Practice Checklist’ for LAs, *“i.e. Do we understand where responsibility will lie when the initial agreement has expired and have we made this plain to the disabled person and carers?”*<sup>17</sup>

## Northern Ireland

The DFG was introduced in 1992 in the *Housing Order, Northern Ireland*, and broadly this mirrored the English legislation, with the exception that a Replacement Grant is available. This may be available when the following conditions apply:

- *“where a disabled person is living in unfit property and the extent of the unfitness is so great that replacement is the most viable option;*
- *where the person has a tie to the land or has lived in the house for 2 years prior to the application;*
- *where the Housing Executive is unable to provide suitable rehousing. Advice should be obtained from the local Housing Executive Grants Office”*<sup>18</sup>

Subsequently, changes to the DFG in England and Wales, the most recent being in December 1996 with the introduction of the *Housing Grants, Construction and Regeneration Act 1996, Chapter 53*, were not introduced in Northern Ireland pending the devolution of power. However, the arrangements for housing in Northern Ireland, in both the public and private sector are set out in the following circular.

## “Circular HSSE (DMHU) 6/98 Care in the community: housing people with disabilities

### Introduction

1. *The purpose of this guidance is to advise Health and Social Services Boards and Trusts of the current arrangements for providing specialist housing and housing adaptations for people with disabilities. It has been prepared in co-operation with the Northern Ireland Housing Executive (NIHE) and sets out the respective roles of that organisation and those of Boards and Trusts in relation to housing issues. It brings together all extant HSS Executive guidance on housing and cancels obsolete guidance.*
2. *This guidance sets out each organisation’s statutory responsibilities under relevant Health and Social Services and Housing legislation.*
3. *In addition, the guidance endorses the need for mutual understanding and co-operation between all agencies involved in housing issues, particularly in relation to any constraints within which they may be operating. A joint HSS Executive/DOE letter underscoring this message was issued on 24 June 1996 to Boards, Trusts and NIHE Offices.*

### **Statutory Responsibilities of the Health and Social Services Boards/Trusts**

4. *The Health and Personal Social Services (Northern Ireland) Order 1972 (the Order), Article 15, and the Functions of Health and Social Services Boards (No1) Direction (Northern Ireland) 1973, paragraph 3, empower Boards to provide equipment and appliances to help people who are disabled with daily living and to assist with the provision of adaptations to private houses so as to increase activity and mobility of such persons living at home.*
5. *The Chronically Sick and Disabled Persons (Northern Ireland) Act 1978 defines disability and provides for the provision of social welfare services including assistance for a disabled person in arranging for the carrying out of any works of adaptation in his home or the provision of any additional facilities designed to secure his greater safety, comfort or convenience.*
6. *The Disabled Persons (Northern Ireland) Act 1989 provides for the assessment of the needs of a disabled person to determine whether these call for the provision of any services in accordance with section 2 of the Chronically Sick and Disabled Persons (Northern Ireland) Act 1978.*
7. *Health and Social Services Boards' statutory obligations have been delegated to Health and Social Services Trusts by Article 3 of the Health and Personal Social Services (Northern Ireland) Order 1994.*

### **Statutory responsibilities of Northern Ireland Housing Executive**

8. *Section 3 of the Chronically Sick and Disabled Persons (Northern Ireland) Act 1978 requires the Northern Ireland Housing Executive to consider the special needs of chronically sick and disabled persons when planning for the provision of further accommodation. The Act also states that proposals for the provision of new housing shall specify those provided to meet the special needs of chronically sick and disabled persons.*
9. *Article 52 of the Housing (Northern Ireland) Order 1992 empowers the Northern Ireland Housing Executive to pay Disabled Facilities Grants to enable privately owned property to be adapted to meet the needs of people with a disability.*

### **Consultations between NIHE and Boards/Trusts on housing needs**

10. *Under Article 67 of the Health and Personal Social Services (Northern Ireland) Order 1972, Boards and the NIHE are required to co-operate 'in order to secure and advance the health and social welfare of the people of Northern Ireland'. Health and Social Services Boards, Trusts, Housing Associations and NIHE should liaise on a regular basis in order to plan for current and future housing needs.*

### **General information**

11. *The NIHE's responsibilities for housing matters relating to disabled people living in the community are set out in its comprehensive booklet "Housing Services for People with Disabilities". For clients, information on the housing adaptation process is contained in booklets relating to private or public sector housing, also issued by NIHE. See references 19 and 20.*

## **Housing Executive Dwellings**

12. *The Northern Ireland Housing Executive provides specialist housing for people with disabilities including wheelchair and mobility housing. The majority of its housing is accessible to ambulant people with a disability. Future new build social housing is moving towards lifetime home standards. NIHE also undertakes, on advice from occupational therapists, adaptations to its property occupied by people with a disability.*

## **Housing Associations**

13. *It is the policy of the Department of the Environment for Northern Ireland that Housing Associations should concentrate mainly on the provision of housing for special groups including elderly people and people with a disability. Such provision embraces both new building and the rehabilitation of existing dwellings. Housing Associations complement Housing Executive programmes and it is important that there is close liaison between Housing Associations, the Housing Executive and Boards and Trusts in assessing need and agreeing schemes, and providing adaptations to their properties.*

## **Adaptations to Private Housing**

14. *The Northern Ireland Housing Executive's grants offices are responsible for processing applications for Disabled Facilities Grants and Minor Works Grants. Any adaptation must be recommended by an occupational therapist and Disabled Facilities Grant is available to owner occupiers, landlords and tenants (excluding Housing Executive tenants) to assist with the cost of the adaptation. Mandatory Disabled Facilities Grant (DFG) has a ceiling of £20,000 and is means tested i.e. the applicant may be required to meet all or part of the cost of the adaptation work.*

15. *In the private sector grants are not available for stair or vertical lifts. An HSS Trust may install a stair or vertical lift or motorised overhead hoist in private housing and in such cases the apparatus remains the property of the Trust with consequent responsibilities for inspection, maintenance, insurance and removal when no longer required.*

16. *Trusts are responsible for the assessment, provision and maintenance of portable equipment to assist daily living. Such equipment must be returned to the Trust when it is no longer required.*

## **Top-up payments**

17. *Where the cost of the work exceeds the limit of the mandatory DFG, an individual may apply to the NIHE for further financial assistance through discretionary DFG. Pending the commencement of the proposed Housing (NI) Order 1999, NIHE may provide such assistance on an extra-statutory basis. **From the date of this circular, Boards and Trusts will no longer have responsibility for financial assistance in such cases.***

**N.B. The provisions of the proposed Housing (NI) Order 1999 relating to the provision of discretionary DFG will NOT apply to subsidising an applicant with all or part of the contribution which the means test determines he/she should make towards the cost of adaptations.**

18. *In cases where, as a result of the DFG means test, an applicant is assessed by NIHE to be able to contribute to the cost of the adaptation but alleges that he/she cannot make the contribution, Boards and Trusts may in **exceptional** circumstances*

consider financial assistance where they have established there is a need. It is for Boards and Trusts to determine the level of assistance appropriate in each case. Boards and Trusts must ensure that in such cases the client **cannot** make his/her contribution rather than **will not** make it. **There is no obligation on Boards and Trusts to meet all or any such requests.**

19. Where a Board or Trust considers that financial assistance is appropriate this should be made by way of payment to the contractor employed by the client to undertake the adaptation work. A condition of Disabled Facilities Grant (DFG) is that work in excess of £5,000 (excluding VAT) must be undertaken by a 'warranted builder' acceptable to NIHE.

### **Model Service Agreement for Housing Adaptations for People with Disabilities**

20. The Housing Adaptations Joint Forum, which is chaired by the HSS Executive and made up of representatives from Boards, Trusts and NIHE, prepared a Model Service Agreement which sets out the respective responsibilities of Health and Social Services Boards and Trusts and NIHE for adaptations to the homes of people with physical disabilities, learning disabilities and mental health problems.

21. The Model Agreement embodies relevant targets but acknowledges that the level of co-operation is subject to prevailing financial constraints. It may be modified, if necessary, with the agreement of all signatories, to suit local conditions.

22. The intention is to ensure consistency of approach throughout Northern Ireland to occupational therapy housing adaptation assessments and subsequent recommendations to NIHE and quality assure Trusts' actions in relation to housing adaptations.

23. The Model Agreement was issued to Boards and Trusts on 27 January 1997.

### **Charters**

24. Charters relevant to housing for people with disabilities are:

- Charter Standards for Community services
- Tenants Charter

### **Cancellation of previous circulars**

25. Previous HSS guidance on housing for people with a disability was set out in circular letters:

HSS (OS5A) 2/76 Housing for Physically Handicapped Persons.

HSS (OS5A) 3/77 Housing for Physically Handicapped Persons:  
House Renovation Grants.

HSS (OS5A) 4/76 Housing for Physically Handicapped Persons:  
House Renovation Grants.

HSS (PH) 3/79 Housing for Physically Handicapped Persons:  
Housing Renovation Grants".<sup>18</sup>

## Scotland: Improvement and Repairs Grant

Scotland retained Housing Improvement Grants when the rest of the UK adopted the DFG, but the grant system has been subject to a number of changes, which came into effect on 1 October 2003.

Questions and details relating to the legislation are as follows:

- ⇒ In what act is the legislation included?
- ⇒ Are guidance notes provided?
- ⇒ To whom are grants available and what are the arrangements for tenants?
- ⇒ Main conditions of eligibility for an Improvement or Repairs Grant.
- ⇒ What are the purposes for which a grant will be given?
- ⇒ Is there a maximum limit on the costs eligible for grant?
- ⇒ Amount of grant.
- ⇒ Minimum percentage grants.
- ⇒ Is the grant means tested?
- ⇒ Who will be assessed?
- ⇒ How will income be assessed?
- ⇒ How will we know if we are going to be eligible for a grant or how much help we will receive?
- ⇒ Procedure for an application.
- ⇒ Subsequent grant applications.

### In what act is the legislation included?

The powers in the *Housing (Scotland) Act 1987, Chapter 26, Part XIII*, to give grants have been amended by the implementation of the provisions in *Part 6* of the *Housing (Scotland) Act 2001*.<sup>21</sup> Some of the detailed arrangements are contained in 'regulations' found in various *Scottish Statutory Instruments*.<sup>22</sup>

### Are guidance notes provided?

Information for applicants and guidance for LAs on the operation of the new grants system are available, as follows:

- ⇒ applicant's guide;
- ⇒ Local Authorities' guide;
- ⇒ grant calculator.

### Applicant's guide

A booklet '*Housing Grants*' can be obtained, either from LAs or from the Scottish Executive Development Department, Housing Division 2, Victoria Quay, Edinburgh, EH6 6QQ. The information in the guide is also available on the Scottish Executive website ([www.scotland.gov.uk](http://www.scotland.gov.uk)) under the headings Topics, Communities, Housing, Private Housing Sector, then select 'Assistance to repair and improve houses'.

### Local Authorities' guide

Guidance on the changes has been issued to LAs and is also available on the website.

### Grant calculator

It is proposed that the website, above, will provide a calculator that will let enquirers have an indication of the level of grant, which they might expect to receive.

## To whom are grants available and what are the arrangements for tenants?

These are as follows:

- ⇒ disabled occupant of private property;
- ⇒ Housing Association tenants;
- ⇒ Local Authority tenants.

### Disabled occupant of private property

A disabled occupant can apply for a grant for adaptations to meet their needs, even if they are neither the owner nor the tenancy holder of the property. The house, however, has to be their only or main residence, or should be expected to be so, within a reasonable period after the work has been completed.

Applicants should be aware of conditions applying to a grant (see below). Where a grant application is made by someone other than the owner, then the owner's consent to the application must be obtained.

### Housing Association tenants

There are around 200 active Housing Associations in Scotland, but they vary in size from those who have a small number of properties within a limited area, to those with substantial numbers and who operate throughout Scotland. After the Social Work Department has made the assessment for an adaptation, the Housing Association should arrange to have the work carried out for its tenants. Housing Associations are expected to include the cost of adaptations in their budgets, in the same way as other necessary maintenance. LAs are still legally responsible for funding, although in practice Housing Associations normally fund this work.

### Local Authority tenants

Grants are not available for LA property but, as with all tenants, the LA is responsible for adaptations when the Social Work Department has recommended an adaptation.

## Main conditions of eligibility for an Improvement or Repairs Grant

There are two sets of conditions:

- ⇒ age of house;
- ⇒ other grant conditions.

### Age of house

If the house was built or converted less than 10 years ago, the applicant would not normally be eligible for a grant unless the Scottish Ministers agree to an LA's request for permission – but this does not apply to a grant for a disabled person.

To avoid confusion, it is worth mentioning that the Council Tax Band restriction on grant applications has been discontinued, but this ruling also, did not apply to grants for disabled people. See '*Scottish Statutory Instruments*'.<sup>22</sup>

## Other grant conditions

These conditions apply to all grants for a 5-year period, beginning when the house becomes fit for occupation after completion of the work, as follows:

- *"the house must be used as a private dwelling;*
- *if the house is occupied by the owner or a member of his family, then it must be their only or main residence;*
- *the house must be kept in a good state of repair.*

*If the house is sold during the period, the grant does not need to be repaid, but the conditions will apply to the new owner of the house for the remainder of the period."*<sup>21</sup>

If the new owner breaches the conditions, it is the new owner who has to repay, not the recipient of the grant.

## What are the purposes for which a grant will be given?

There are two main categories:

- ⇒ disability needs;
- ⇒ general improvements (including provision of standard amenities) or repairs to a house.

### Disability needs

In relation to disability, grants can be used for *"the doing of works required for making (a house) suitable for (the) accommodation, welfare or employment"*<sup>21</sup> of a disabled occupant. This is a very wide description and, the *"relevant types of work"* (in the context of this manual) *are*:

- *to provide a purpose-built extension;*
- *make access easier;*
- *make adaptations to the kitchen;*
- *to provide improvements that benefit a disabled person's welfare or employment;*
- *professional fees, planning permission and building warrant."*<sup>21</sup>

In each case the LA will want to be satisfied that the works are both essential and appropriate. This is usually achieved following an assessment by an OT or another appropriate healthcare professional. In relation to grants for adaptations for a disabled person, it is for LAs to decide whether to approve the grant application. However, an LA that refuses to allocate funds for such grants may be in breach of their legal obligation under the *CS&DP Act*.

### General improvements or repairs to a house

In addition to the needs of disabled people, grants can also be available for three further categories, as follows:

- ⇒ works to ensure that a house meets the tolerable standard;
- ⇒ the provision of standard amenities;
- ⇒ other work beyond the basic tolerable standard.

## Works to ensure that a house meets the tolerable standard

This is as follows:

- *“It is structurally stable;*
- *It is free from rising or penetrating damp;*
- *It has satisfactory access to all external doors and outbuildings;*
- *It has satisfactory:*
  - *lighting;*
  - *heating;*
  - *ventilation;*
  - *drinking water supply;*
  - *cooking facilities;*
  - *drainage for rainwater and from kitchen and bathroom fittings.”*<sup>23</sup>

## The provision of standard amenities

These are as follows:

- *“a fixed bath or shower;*
- *a wash-hand basin;*
- *a sink;*
- *all with a hot and cold water supply;*
- *a toilet.”*<sup>23</sup>

## Other work beyond the basic tolerable standard

*“Councils may also give grants for the following types of work:*

- *Replacing unsafe selectrical wiring;*
- *Installing mains-powered smoke detectors;*
- *Providing adequate heating or insulation;*
- *Replacing lead water pipes;*
- *Reducing exposure to radon gas;*
- *In a building in common ownership (such as a block of flats),*
  - *Installing a fire-retardant door at the entrance to each house;*
  - *Installing a main-door entry-phone system;*
- *Converting another type of building to housing, joining two or more houses into one, or dividing one into two or more houses.”*<sup>23</sup>

Where work involves the general repair or improvement of a house and is unrelated to the needs of a disabled occupant, then any application for a grant should be made by the owner(s) or, in certain circumstances, the tenant. A tenant can apply for a grant provided that the work has been the tenant’s responsibility under his lease for at least 2 years before the date of the application. (This requirement does not apply in the case of works needed for a disabled person.)

## Is there a maximum limit on the costs eligible for grant?

LAs can give grants for eligible work that costs up to £20,000. There are circumstances where they can request consent from the Scottish Executive to base a grant on a higher figure. LAs however are not required to apply for an increase. Some LAs may set their own limit lower than the statutory maximum, in order to spread the available funding further. However, this is rarely applied to adaptations.

## Amount of grant

The 'applicable' income, which is identified as a result of the financial assessment discussed on the next page, is compared with a table, which relates income to percentage grant. The amount awarded is that percentage of the approved cost of works.

## Minimum percentage grants

The grant system now provides for 'minimum percentage grants', where a set minimum level of grant will be payable. The circumstances in which these grants are payable are set out in regulations and include:

- making a house suitable for the accommodation, welfare or employment of a disabled person who lives, or plans to live, in the house;
- situations where the LA must provide grant, that is where they have served a notice or order requiring works to be carried out or where a standard amenity is required;
- works to bring a house up to the tolerable standard.

The minimum percentage grant has been set at **50%** and applicants will receive grant at this level, unless the applicants' income entitles them to receive grant at a higher level.

## Is the grant means tested?

Yes. There are separate 'tests of resources' for occupiers (including all disabled occupiers) and for landlords.

## Who will be assessed?

This depends on the two categories of grant, based on the purposes for which the grant is given, (already discussed) as follows:

- ⇒ disability needs;
- ⇒ general improvements or repair of the house.

### Disability needs

Where grant is sought for works needed for a disabled occupant, it is the income of the disabled person and their partner that is taken into account. If the disabled person is below the age of 16, then the application should be made by whoever receives their child benefit or, if no benefit is received, whoever has prime responsibility for the disabled child. The income of that person and their partner will be taken into account.

### General improvements or repair of the house

In these cases, the income of the owner and all joint-owners, or tenants, and their partner(s) is taken into account.

## How will income be assessed?

This will be as follows:

- *“Assessment is based on income from earnings, savings and investments, occupational/private pensions and any rental income.*
- *All income from welfare benefits and equivalent tax credits will be excluded from the assessment.*
- *Applicants in receipt of Income support or Income-based Jobseekers Allowance will be passported to 100% grant. 100% grant will also be available to those who are assessed as having no income apart from benefits.*
- *All mortgage payments (interest and capital) or rent payments not covered by Housing Benefit will be deducted from the assessed income.*
- *An allowance will be deducted for each child under 16, or under 21 in full-time education.*
- *An allowance will be deducted if either the applicant or their partner is disabled”.*<sup>23</sup>

## How will we know if we are going to be eligible for a grant or how much help we will receive?

LAs have been supplied with computer software for the calculation of grant. As already mentioned, it is proposed that this software will be made available on the Scottish Executive website to enable applicants and advisory organisations to obtain an estimate of grant eligibility.

## Procedure for an application

- The local council will provide an application form. There are separate application forms for adaptations, for repairs and for general improvements/standard amenities
- you will be told what paperwork is required, including the number of estimates that must be submitted;
- there is no time limit for the application to be considered, but you will be informed of the outcome in writing and, if the application is refused, you will be given the reasons;
- plans are subject to the usual Planning and Building Warrant Approval;
- the building work must not start before grant approval has been received;
- following approval, the council may make a condition that the work is completed by a certain date (this will be at least 12 months after approval); however, if the grant is paid in instalments, the 12 months start again from the date of the first instalment; the council can extend this period, on request;
- staged payments may be made during the building process, and the final payment must be made within a month of the completion of the work, provided that the work has been carried out to a satisfactory standard.

## Subsequent grant applications

There are restrictions on subsequent awards of grants; however, there are no restrictions on subsequent grants for adaptations. This recognises that some people's conditions can change and need further adaptations or facilities. (Section 242).<sup>24</sup>

## The Scottish Executive

*(Previously the Scottish Office)*

The Scottish Executive do not give grants themselves, but can give permission to LAs to increase approved expenditure limits. The upper limit on what approved expenditure to pay a grant is decided by the LA, who may or may not have a policy on maximum amounts.

## Social Work Department (Scotland)

Social Work Departments can give financial assistance for adapting houses to meet the needs of disabled occupants; each authority will have their own policies on how housing grant and social work funding interact. Requests are usually considered by special committees and as this may be a lengthy procedure, forward planning is recommended.

They may also assist by providing aids and equipment not covered by the grant. Many Social Work Departments are working on reduced budgets and, in some cases, rely on agents (such as Care and Repair) to help applicants find funding from other sources, such as charities.

## Department of Health/Health Board

Health funding should be considered for:

- ⇒ adaptations;
- ⇒ equipment.

### Adaptations

Finance for adaptations from health sources is more likely to be used to discharge a child from hospital following an extended stay (in many cases from birth), rather than the rare cases where the alternative to adaptations would be a permanent stay in hospital. In reality, other than for surgical procedures (following a fracture and for respiratory and heart problems), few people with neuromuscular conditions are admitted to hospital; this is important, as prolonged bed rest, where possible, should be avoided to prevent acceleration of the muscle wasting.

Funding should be sought for needs that can clearly be argued to be medical; one such example might be for the building of an extension to provide the space needed for dialysis equipment.

### Equipment

For people with a neuromuscular condition the items (other than wheelchairs and surgical appliances) for which health funding is most frequently used is the provision of environmental controls, electric beds and standing frames. In future, requests should be increased for more sophisticated equipment (such as tilting frames for getting users on to their feet to stand, without involving two helpers). The grounds to substantiate this need should be argued within the lifting and handling regulations. Other needs that are clearly health based are the provision of standing surfaces (see Chapter 11), but there is no evidence to show that these have ever been provided from this source.

## The Family Fund

The Family Fund is an independent organisation, funded by the national governments of England, Northern Ireland, Scotland and Wales.

The following should be considered:

- ⇒ the Family Fund's guidelines;
- ⇒ eligibility for application;
- ⇒ procedure when an application is to be made;
- ⇒ basis on which the Family Fund considers providing financial help;
- ⇒ help the Family Fund will consider giving towards an adaptation scheme;
- ⇒ the basis on which a grant of over £10,000 will be given;
- ⇒ other undertakings required – to be signed when a grant or loan is provided;
- ⇒ help for both owner occupiers and tenants;
- ⇒ when the Family Fund should be approached for help;
- ⇒ details the Family Fund will need.

### The Family Fund's guidelines

The purpose of the Family Fund is to ease the stress on families who are caring for a severely disabled child. All grants are *discretionary* and, although decisions are made with as much flexibility as possible to cater for individual needs and circumstances, there are three main criteria, as follows:

- ⇒ the child must be severely disabled;
- ⇒ the child must be under 16 at the time of the application;
- ⇒ the parents must be on a low income (see below).

#### **The child must be severely disabled**

The level of disability is assessed by a Family Fund visitor, who is their representative in the area. The Family Fund may need confirmation of the diagnosis, and this can be supplied through an existing letter in the possession of the family, or by supplying the name and address of the GP, medical consultant or school.

#### **The child must be under 16 at the time of the application**

It is important that the application is made before the young person is 16. Where adaptations are being planned, but the costs will not be known for some time, it is important that referral is made before the young person's 16th birthday. The Family Fund is responsive to individual needs and is aware of the length of time taken by adaptations.

#### **The parents must be on a low income**

Although the income level in April 2003 is £21,500 (Scotland) and £23,000 (rest of UK) with savings of under £8,000, these figures are reviewed annually in April. However, the Fund appreciates that adaptation costs can be excessive, and applications should still be made where the income of the family exceeds these limits, as these will be considered sympathetically.

## Eligibility for a grant

This is reflected by the name of the Fund. The impetus behind the work is to help families, and most of the requests will be received direct from families. However, where adaptations are concerned, it may be a help to the family if supporting information is provided by a professional involved in the adaptation.

## Procedure when an application is to be made

- Referral is made to the Family Fund.
- If the referral is from (or on behalf of) a family that has not previously applied for help, the Family Fund's visitor in the area in which the child lives will arrange to visit the family, discuss their needs and help them to complete the financial form.
- Where families are not known to the Family Fund, it is wise to establish eligibility for help when adaptation funding is first being discussed.
- If the family is known to the Family Fund, and eligibility has been established, the application will be processed immediately. An applicant can usually expect to receive a reply within 4 – 6 weeks.

## Basis on which the Family Fund considers providing financial help

The Family Fund will help only by matching one of the following:

- ⇒ a grant or non-repayable loan;
- ⇒ other discretionary assistance.

### A grant or non-repayable loan

This would be from the Social Services Department under the *Chronically Sick and Disabled Person's Act (CS&DP Act) 1970* or the *Children Act 1989, Part III, Section 17/Children (Scotland) Act 1995, Part II, Section 22 and 23*.

### Other discretionary assistance

Discretionary assistance from the LA Housing Department is given in addition to the maximum mandatory DFG (or in Scotland the LA can be given permission by the Scottish Executive to increase approved expenditure limits). The DFG and Improvement Grant legislation make it very clear that the LAs have a duty to help families in need with the funding of adaptations under the *CS&DP Act*, and in each case it is for the individual authority to decide which department will provide the funds.

The Family Fund will complement the help given only by those LAs that are accepting their legal responsibilities; this is because, if the Family Fund helped families unconditionally, LAs would leave the Family Fund to pick up the bill in every case, and this is not their remit. The Family Fund is anxious that LAs should not perceive the Fund as a way of cutting costs.

## Help the Family Fund will consider giving towards an adaptations scheme

Help from the Family Fund is discretionary; however, with certain conditions, they can consider providing a grant towards:

- part of the 'top up' – i.e. the balance needed after the payment of the family's contribution and the mandatory grant (DFG) or Improvement Grant, to enable the work to go ahead;
- the family's contribution if they are not able to afford this;
- a small grant towards the cost of decorating and/or furnishing the bedroom/bathroom involved in the adaptation: this might be floor covering, curtains and blinds for these two rooms and floor covering to other parts of the house involved in the building work, but does not include specialist beds;
- in some circumstances, help with the cost of height-adjustable work surfaces in the child's bedroom could be included within the category of support for recreational activities. The educational value for homework use, and the therapeutic value of a standing surface, are considered by the Family Fund to be the responsibility of the Education Department and Health Trust respectively and therefore, would not be within their remit.

## The basis on which a grant of over £10,000 will be supplied

The basis of such a grant can vary, depending upon the needs and circumstances, but the terms will be drawn up by solicitors. It may include a charge against the property over a period of 10 years, with the repayment sum reducing on a sliding scale over this period. This could mean that the money would have to be repaid, only if the house was sold during the first 10 years (unless the parents were in a negative equity situation). The family would not be liable to repay the money if the child died (but the family did not move house) within this time.

## Other undertakings required – to be signed when a grant or loan is provided

The family will be asked to sign a form of undertaking that the money will be used for the purposes for which it was given. All receipts must be retained, if necessary to be seen by the Fund's auditors.

## Help for both owner occupiers and tenants

Although the Family Fund will help tenants, there is a budget limit applied to matched funding in rented property. This is applied as follows:

- if a DFG or Improvement Grant (Scotland) is used to fund the adaptations, the Family Fund will consider matching any 'top-up' needed towards the total cost of the scheme/or the family's contribution, or
- the Family Fund can help, but only towards the balance over and above the sum equal to the maximum grant paid with a DFG (£25,000 in England and N. Ireland and £30,000 in Wales) or Improvement Grant (a percentage of £20,000 in Scotland).

## When the Family Fund should be approached for help

The Family Fund should usually be approached when the details outlined below are known; however, in practice, many grants officers will not proceed with planning unless it is realistic for the scheme to go ahead. They will not waste department staff time and are concerned that the family will have to pay the cost of the architectural plans if the adaptations are not carried out and therefore the grant is not paid. In this case, it is wise to contact the Grants Manager at the Family Fund to receive a provisional offer to complement the help from the Social Services Department. However, a final offer is not likely to be made until all the financial figures are known.

## Details the Family Fund will need

Before the Family Fund will confirm the grant they will give, the Grants Manager will require details of the following:

- the parent's or parents' jobs and wages/salaries;
- information on the work that is to be carried out;
- evidence that the Social Services Department consider the work essential because of the child's disability;
- total cost of the work (i.e. builder's estimate plus professional fees for architectural plans and building supervision);
- the amount of DFG (England, Wales and Northern Ireland) or Improvement Grant (Scotland);
- the family's contribution as a result of the 'TOR', the means test of the DFG, or Improvement Grant;
- the proposed financial assistance from the LA Housing or Social Services Departments (England, Wales and Northern Ireland) or the Social Work Department (Scotland) – and the form of this assistance, which could be:
  - a grant towards the total cost of the scheme or a grant to cover the cost of *adaptation equipment* provided at the time that the building work is carried out – to be provided under the *CS&DP Act*;
  - a non-repayable loan;
  - a charge against the property. In this case the Family Fund will look at the LA's terms and conditions and discuss on an individual basis. If an LA loan is to be given, it is important to clarify under what terms it is to be given. The Family Fund will give help under the same terms only and they will want clarification of whether this is reduced on a sliding scale and, if so, over how many years.

This information will need to be confirmed by an employee of the Social Services Department and, to save time, the request for help to the Family Fund can be accompanied by either a letter or a document outlining the terms of the help, or the name and address of the most appropriate person for the Family Fund to contact; this may be the OT or social worker involved or a team leader within the department.

## References

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2. \*Department of Health, *Delivering Adaptations: Responding to the Need for Adaptation – An Overview*. Office of the Deputy Prime Minister, 2003, p. 2-3, 3, 6, 11, 3. (Ref. 02HC00917/3)
3. *Housing Renewal Guidance (consultative document)*. Office of the Deputy Prime Minister, 2002, p. 41, 41, 49, 20, 50, 20, 13, 14, 14, 47, 48, 27-28, 37, 25, 56. (Ref. 02HC00310.)
4. Appleton, Nigel and Leather, Philip, *The Housing Corporation Programme for the Funding of Adaptations*. The Housing Corporation, 1998.
5. National Assembly for Wales, *Reform of Housing Private Sector Renewal Arrangements, Assembly Government Circular 20/02: Housing Renewal Guidance*, 2002, p. 47.
6. Department of the Environment, *Circular 17/96 Private Sector Renewal: A Strategic Approach, Vol. 1/2 & 2/2*. The Stationery Office, 1996.
  - *Introduction*: p. ii;
  - *Chapter 7: Strategies into Practice – community care and special needs*, p. 46-49;
  - *Annex I: Disabled Facilities Grant*, p. 191, 192;
  - *Annex J1: Financial Matters, 203-207 (replaced by pages 8-11 in Circular 03/2002, Housing Grants, Construction and Regeneration Act 1996: Part I, Amendments to the Renovation Grant System – see reference 11 below;*
  - *Annex J2: Calculation of Grant*, p. 208-217.
7. Department of the Environment, *Housing Grants, Construction and Regeneration Act 1996, Chapter 53*. The Stationery Office, 1996, p. 13-14, 15, 17.
8. *The Regulatory Reform (Housing Assistance) (England and Wales) Order 2002*. The Stationery Office Ltd, p 9. (Ref. SI 2002/1860, ISBN 0-11-042523-5).
9. \*Department of Health, *Delivering Adaptations – Desk Guide*, A Consultation Paper. Office of the Deputy Prime Minister, 2003, p. 13, 11, 29, 29, 33, 30, 40, 41, 44. (Ref. 02HC00917/1).
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12. *Circular 05/2003 Housing Renewal*. Office of Deputy Prime Minister, 2003, p. 21.
13. Great Britain, Department of Health. *Children Act 1989*. London, HMSO, 1989.
14. Department of Health *Circular LAC (98) 28. The Quality Protects Programme: Transforming Children's Services*. Wetherby, Department of Health, 1998.
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17. \*Department of Health, *Delivering Adaptations: Good Practice System Review Checklist*. Office of the Deputy Prime Minister, 2003, p. 2, 1, 7. (Ref. 02HC00917/2)
18. *Circular HSSE (DMHU) 6/98 Care in the Community: Housing People with Disabilities*. Northern Ireland Office, 1996.

19. Northern Ireland, *Adapting Your Own Home. A Guide for Major Adaptations in Public Sector Housing*. Housing Executive, 2002.
20. Northern Ireland, *Adapting Your Own Home. A Guide for Major Adaptations in Private Sector Housing*. Housing Executive, 2002.
21. Section 236 of the *Housing (Scotland) Act 1987*, as amended by section 96 of the *Housing (Scotland) Act 2001*.
22. Scottish Statutory Instruments:
  - 2003 No. 314: *The Improvement and Repairs Grant (Prescribed Valuation Band) (Scotland) Order*, 2003.
  - 2003 No. 420: *The Housing Grants (Application Forms) (Scotland) Regulations*, 2003.
  - 2003 No. 434: *The Housing (Scotland) Act 2001 (Commencement No.7, Transitional Provisions and Savings) Order*, 2003.
  - 2003 No. 461: *The Housing Grants (Assessment of Contributions) (Scotland) Regulations*, 2003.
  - 2003 No. 462: *The Housing Grants (Minimum Percentage Grant) (Scotland) Regulations*, 2003.
23. Section 86 of the *Housing (Scotland) Act 1987*, as amended by section 102 of the *Housing (Scotland) Act 2001*; section 244 and Schedule 18 of the *Housing (Scotland) Act 1987*, as amended or repealed by paragraphs 27 and 42 of Schedule 10 to the *Housing (Scotland) Act 2001*.
24. *Housing Scotland Act 1987*. HMSO, 1987, sections 96-105.
25. VAT Notice 701/7/94 *VAT Reliefs for People with Disabilities*. HM Customs and Excise, 1994.

(\* Free publications which are particularly recommended.)

## Where do I get the referenced publications?

### Stationary Office Ltd (formally called HMSO)

The Stationary Office bookshops or accredited agents - or  
 The Stationary Office Ltd, PO Box 29, Norwich NR3 1G  
 tel: 0870 600 5522 fax: 0870 600 5533 text: 0870 240 3701  
 e-mail: book.orders@tso.co.uk web: www.tso.co.uk

### \*Dept. for Transport, the Planning Inspectorate, and the Office of the Deputy Prime Minister

(covering fire safety, housing, local government, neighbourhood renewal, planning and urban policy)  
 Publications centre, PO Box 236, Wetherby, West Yorkshire. LS23 7NB  
 tel: 0870 1226 236 fax: 0870 1226 237 text: 0870 120 7405  
 e-mail: odpm@twoten.press.net or dft@twoten.press.net  
 web (for the Office of the Deputy Prime Minister): www.odpm.gov.uk

### The Housing Corporation Corporate Services

Maple House, 149 Tottenham Court Road, London W1T 7BN  
 tel: 020 7393 2000 fax: 020 7393 2111  
 e-mail: enquiries@housingcorp.gsx.gov.uk web: www.housingcorp.gov.uk

### National Assembly for Wales

Housing Directorate, Cathays Park, Cardiff. CF10 3NQ  
 tel: 029 2082 5111 fax: 029 2082 6989  
 e-mail: housingintranet@wales.gsi.gov.uk web: www.wales.gov.uk

### The Policy Press

University of Bristol, Rodney Lodge, Grange Road, Clifton, Bristol. BS8 4EA  
 tel: 0117 973 8797 fax: 0117 973 7308 e-mail: tpp@bris.ac.uk

### Northern Ireland Housing Executive

Housing and Regeneration, The Housing Centre, 2, Adelaide Street, Belfast. BT2 8PB  
 tel: 028 9024 0588 fax: 028 9031 8358  
 e-mail: information@nihe.gov.uk web: www.nihe.gov.uk

### Scottish Executive

Development Department, Housing Division 2, Victoria Quay, Edinburgh. EH6 6QQ  
 tel: 0131 244 5574 fax: 0131 244 0948  
 e-mail: Kelvin.McBryde@scotland.gsi.gov.uk web: www.scotland.gov.uk

## Voluntary trusts and charities

- ⇒ information needed;
- ⇒ sources of funding.

### Information needed

A number of trusts and voluntary groups will help with a grant towards equipment although most will not help with financing adaptations. Some will accept letters of request direct from individuals and families and others require applications from a professional acting on their behalf. Most will want to know the following:

- confirmation that the applicant falls within their eligibility guidelines;
- financial situation of the applicant;
- reasons why a statutory source is not paying for the adaptations or equipment;
- details of the needs;
- if the request is for equipment, that it has been assessed and the reasons for the choice;
- the cost, where possible including an estimate.

### Sources of funding

There are four categories:

- ⇒ employers and trade unions;
- ⇒ local charities in the area in which the person lives;
- ⇒ national charities;
- ⇒ disability groups.

### Employers and trade unions

This is usually the most successful source of grants, as employers have a loyalty to their existing or former employees. Trade unions may also be prepared to help, particularly if they have a benevolent fund.

### Local charities in the area in which the person lives

The contact names and addresses of local voluntary groups can usually be obtained from the public library and the Citizens Advice Bureau.

### National charities

Most national charities have strict guidelines. These are published in a number of directories, most of which are included in the *FunderFinder People in Need (PIN)* computer programme. This software provides a quick and easy way of finding which charitable trusts (both national and local) might help and covers both individuals in need and others seeking funding for education and training.

### The information to be entered into the computer

Users enter information about themselves (or whoever needs money) to create a search profile. The programme will need to be told a number of details, such as:

- the age, gender and marital status of the person;
- where the person currently lives;
- what the person wants money for (e.g. equipment).

### **The following information can also be added**

This relates to criteria specified by grant-making trusts, as follows:

- other associations people have with an area, such as where they were born;
- current or former jobs;
- membership of a religious group;
- disability problems;
- whether they have served in the armed services;
- membership of certain clubs;
- nationality;
- other characteristics (e.g. housebound, single parent, expectant mother).

### **After the information has been entered**

The search profile is matched against data about charitable trusts coded in PIN. Funders that do not fit are excluded, and results are displayed in alphabetical order. The user can then scan policy information to decide which trusts look promising and these can be selected for printing or saving on to disk. The names and addresses of trusts can be saved in a database file, which can be used in a mail merge.

### **The printout**

The printout will give the name of the trust, its Charity Commission reference number (if it is a registered charity), information about its policy and how applications should be made, its address and telephone number, and a source of further information (such as a directory reference).

Armed with the printout, it must be remembered that most funders get many more requests for support than they are able to help. Because the quality of the application is what counts, be prepared to spend time in getting the application right and, where necessary, enlist the help of a professional who understands the needs and would be prepared either to lend support to the application or to apply on your behalf.

*FunderFinder Ltd*

## Disability groups

There are two sources of funding for people with muscular dystrophy and allied neuromuscular conditions.

- ⇒ the Joseph Patrick Trust (JPT);
- ⇒ the Jennifer Trust for Spinal Muscular Atrophy (JT SMA).

### The Joseph Patrick Trust (JPT)

JPT is the Equipment Fund of the Muscular Dystrophy Campaign of Great Britain and Northern Ireland.

Prior to making an application, the following information will be useful:

- ⇒ eligibility for applications;
- ⇒ what applications can be made;
- ⇒ discretionary powers;
- ⇒ how applications can be made.

- **Eligibility for applications**

*“Applications will only be accepted from, or on behalf of, people with neuromuscular conditions and if their application falls within the guidelines that follow. The value of any grants given will depend on an assessment of all the relevant information made available to the Grants Panel and the resources available.*

- Applications will not normally be considered for items of equipment where there is a duty on the statutory authorities to provide them.
- Grants will not be made for equipment that has already been purchased.
- JPT does not give grants for the full cost of the equipment requested. Only partial awards can be made and the major part of the cost will have to be found elsewhere.
- It is the responsibility of those receiving grants to make arrangements for the insurance, maintenance and repair of the equipment obtained.

- **What applications can be made for**

- **Adaptations to vehicles**

*Grants may be considered for the adaptation of new or used vehicles, but will not be made towards the purchase or lease of vehicles, vehicle deposits, or for the maintenance or repair of vehicles.*

- **Wheelchairs**

*Grants may be made towards the cost of an indoor/outdoor powered wheelchair or other wheelchairs not provided by statutory authorities. Grants will not be made towards wheelchair repairs, insurance, or for items such as batteries, tyres, etc.*

- **Specialised/therapeutic equipment**

*Grants may be made towards the purchase of specialised/therapeutic items (e.g. adjustable beds, riser/recliner armchairs, standing frames, tilt tables, etc.). Assistance towards the cost of computers, other electronic equipment and assistive devices will also be considered.*

- **Discretionary powers**

*The Grants Panel has discretionary powers to make grants to help alleviate distress in exceptional circumstances.*

*Grants will not be made towards the costs of structural building works, or for household furniture or domestic appliances.*

*N.B. Grants are held open for a period of 12 months, after which time they will lapse and a new application will then be required.*

- **How applications can be made**

*All applicants must complete the specific JPT application form and submit appropriate professional assessments (see below) and official estimates/quotations of the costs of the equipment for which assistance is being requested.*

*Professional assessments, confirming the need for and the suitability of the equipment for which assistance is being requested, will be required in all cases. The assessment may be undertaken by FCOs or other appropriate professionals such as occupational therapists, physiotherapists, social workers or nurses. Ideally, the assessments should be sent in at the same time as the application form. However, if people applying have not been able to arrange for an assessment, this should be stated on the application form. In those circumstances, JPT will advise, after consultation with the FCO, on how matters will be progressed. Exceptionally, it may be necessary to obtain more than one assessment or to seek further information.”*

Joseph Patrick Trust  
Registered Charity Number: 2943475

## **The Jennifer Trust for Spinal Muscular Atrophy**

### **Criteria for Equipment Fund Applications**

1. *“The Panel will consider applications on behalf of any person with Spinal Muscular Atrophy – a statement confirming the condition is required. Applications cannot be made for other unrelated conditions.*
2. *All equipment remains the property of the Jennifer Trust and must be returned when no longer required.*
3. *The fund will assist with maintenance and repair costs up to a reasonable level.*
4. *Payments will not be made in retrospect, and applications must be agreed before purchase can be made.*
5. *The Panel will not consider grant applications towards the cost of motor vehicles or vehicle adaptations.*
6. *Persons applying for assistance with funding for electric wheelchairs must apply to their local wheelchair centre first as the Department of Health now provides outdoor powered wheelchairs. This applies to England and Scotland only. Applications will still be considered from Northern Ireland and Wales.*
7. *An up-to-date quotation for the equipment must be enclosed.*
8. *Supporting assessment by a relevant professional must be enclosed.*
9. *An application form must be completed in full.”*

The Jennifer Trust for Spinal Muscular Atrophy  
Registered Charity Number: 327669

## Providers and funding of adaptations, equipment and services

Equipment/Service required	Who should I approach?	Who funds it?	Is it means tested?	Who will assess the need?	Who will pay for insurance & maintenance costs?
<b>Housing</b> Adaptations, Housing Grant	Social Services Dept. occupational therapist (OT)	Grants Dept., Social Services Dept.	Yes – Improvement Grant (Scotland) Yes – Disabled Facilities Grant (rest of UK)	Hospital, paediatric or Social Services Dept. OT	Usually client (equipment funded with the grant) or sometimes provider
<b>Equipment</b> Bath & toilet equipment, electric recliner chairs, trolleys, etc	Hospital or Social Services Dept. OT	Social Services Dept., client	Not usually	Social Services Dept. OT	Provider
<b>Environmental controls</b>	Hospital or Social Services Dept. OT	Local Health Trust/ Board	No	Approved local medical consultant	Provider
<b>Beds</b>	GP, OT, district nurse, health visitor, social worker	Local Health Trust/ Board Occasionally Social Services Dept./GP Practice	Not usually	Provider	Provider
<b>Specialist mattresses</b>	GP, district nurse, health visitor, OT	Local Health Trust/ Board/GP Practice	No	Tissue viability nurse district nurse/ health visitor	Provider
<b>Mobility</b> Manual & indoor-outdoor powered wheelchairs	GP, or hospital consultant, physiotherapist (physio) or OT	NHS chairs through Wheelchair Services	No	Wheelchair Services therapists or accredited therapists	Provider
Chairs outside NHS range & trikes	Physio or OT	Child: Whizz Kidz, Variety Club, Joseph Patrick Trust (JPT) voluntary charities Adult: JPT, voluntary charities	No, but applicant's income & expenditure may be taken into account	Child: Whizz Kidz, therapist, paediatric OT/physio Adult: OT or physio	Client

Equipment/ Service required	Who should I approach?	Who funds it?	Is it means tested?	Who will assess the need?	Who will pay for insurance & maintenance costs?
<b>Vehicles</b> Cars, vans	Motability if client in receipt of higher mobility rate of DLA	Client, in conjunction with Motability if client in receipt of higher mobility rate of DLA & a grant is needed towards deposit	No, but if a grant is needed the applicant's income may be taken into account	Mobility Centres	Client - Hire Purchase Scheme, Motability – Lease Scheme
<b>Vehicle adaptations</b>	Motability	Passenger/driver – Motability Equipment Fund. Disabled person driving from a wheelchair – Motability Driver's Fund	No, but the applicant's income may be taken into account	Mobility Centres Motability	Client
<b>Medical</b> Standing frames respiratory equipment, corsets, shoes	Consultant, physio	Appliance budget holder	No, but there may be a charge	Consultant, physio	Provider (equipment, but not clothing)
<b>IT</b> Computers – school	Special needs teacher, OT	Education Dept.	No	IT tutor, Ability Net, Ace Centres, Communication Aid Centres	Provider
Computers – home	JPT, AIDIS Trust	Part JPT with referral to AIDIS Trust for balance	No	As above or AIDIS Trust	Client
<b>Access to education</b>	Social worker	City, Borough or County Education Dept.	No	Special educational needs officer	Provider
<b>Community Care</b>	Social worker, Community Care Services at Social Services Dept	Social Services, local Health Trust/Board, Independent Living Fund	In some cases, or there may be a charge	Care manager appointed by Social Services Dept.	Provider, or client who arranges own carers not employed by an agency

**N.B.** All services and equipment depend upon an assessment of need, taking into account budget constraints. In some cases, such as the provision of beds (unless there is proof that the supply will ease nursing services) there may be no one in your area who has accepted the responsibility of funding. In all cases, a request should be made to the statutory services, where necessary with the help of the Muscular Dystrophy Campaign Family Care Officer. In situations where the need is urgent, joint funding between a statutory service and the voluntary sector may be used.

## VAT

The discussion covers the following:

- ⇒ equipment;
- ⇒ building alterations;
- ⇒ VAT-exemption form.

### Equipment

#### Why some goods and services are zero-rated and others are not

*"When VAT was introduced in the United Kingdom in 1973, it was agreed that disabled people should not have to bear the additional burden of the tax when they had to buy certain items designed solely for their use, or when requiring adaptations to standard equipment in order for them to be able to use it.*

*Although the range of goods and services which may be zero-rated is now greater than it was in 1973, the basic principle still underlines the current VAT relief. The relief is not intended, therefore, to mean that supplies of all goods and services to disabled people should be zero-rated. Many goods which are of benefit to people with particular disabilities, may not qualify for relief because they are designed for wider use. Nor does the relief mean that eligible goods and services can be supplied VAT free to people who are not disabled. In short, both the goods or services and the recipient have to qualify before zero-rating can be applied".* <sup>25</sup>

#### Who can obtain goods and services VAT free

*"The law provides VAT relief for certain specialised goods needed by people who are chronically sick or disabled".* <sup>25</sup> Details can be taken from the booklet obtainable from Customs and Excise listed in the telephone director, or via their website:

[www.hmce.gov.uk/forms/notices/701-07.htm](http://www.hmce.gov.uk/forms/notices/701-07.htm)

### Building alterations

#### Works zero-rated for VAT purposes

*"The supply of the following works will be zero-rated for VAT where they are carried out to a person's private residence:*

- (a) *the construction of ramps or widening of doorways or passages for the purpose of facilitating the disabled person's entry to or movement within the building, including any preparatory work or making good;*
- (b) *the installation of a lift for the purpose of facilitating the movement of the disabled person between floors of the building. Repair and maintenance are also zero-rated;*
- (c) *the providing, extending or adapting of a bathroom, washroom or lavatory where such provision, extension or adaptation is necessary by reason of the disabled person's condition. In addition, other work essential to the provision of these facilities can be zero-rated.*

*In order for this supply of goods or services to qualify for zero-rating the supplier or contractor must obtain an eligibility declaration from the disabled person".* <sup>6</sup> (Annex I)

### VAT-exemption form

A sample form which can be photocopied is enclosed in Chapter 11.

# Muscular Dystrophy Adaptations & Building Design Network

*An innovative service set up as a resource for adults and children with muscular dystrophy & allied neuromuscular conditions & the professionals who are advising on adaptations*

All chapters of this manual will be used in conjunction with the expertise of the architectural designers

The scheme has been based on three issues with the information included as follows:

	⇒ The need	1
	⇒ How can a first-class adaptations service be provided?	2
⇒ The most effective method of training the people who will be designing the adaptation scheme		2
⇒ Map illustrating the location of the architectural designers		3
⇒ Addresses of the Network architectural designers:		
	England Wales & Scotland	4
	Northern Ireland	13

## The need

Several years ago, a survey was carried out to find out if people with muscular dystrophy or an allied neuromuscular condition were receiving the help they needed with adaptations – and to seek their opinion on whether the Muscular Dystrophy Campaign should be setting up a specialist housing service. We had 440 replies and 92% of the respondents felt it was necessary to set up a specialist Muscular Dystrophy Housing Service, because Local Authority staff were not always aware of the needs of people with a neuromuscular condition.

Some of the statistics thrown up by the survey were disappointing:

- Nearly 60% of people with muscular dystrophy or an allied neuromuscular condition had a washbasin that was not wheelchair accessible.
- 56% had no space around the basin on which to rest their forearms.
- 70% could not reach and operate their taps.
- 50% could negotiate the threshold in their wheelchair and open and close their front or back door independently. However, if you related these figures to people who use a powered wheelchair – and are more disabled – the figures dropped to 10%. Only 1 in 10 of the people in our survey who use a powered wheelchair were able to go freely in and out of their house without help.

Significant numbers felt that the adaptation was too small, that they should have had en-suite facilities or they had made the wrong decisions. Clearly, there was an urgent need to improve the standard of adaptations.

## How can a first-class adaptations service be provided?

The three key people in any adaptation scheme are:

- **the disabled person and their family**, who know to a large extent what they need, but would like advice, particularly in relation to the grants system;
- **the community OT**, who may not have any previous experience of the needs of people with a neuromuscular condition and whose role is to assess these and justify the decisions to a manager who may be more concerned with the budget implications;
- **the architectural designer**, who will have the best interests of the client at heart, but although experienced in designing for disabled people, may not be aware of the specialist needs required by those with muscular dystrophy or an allied neuromuscular condition.

## The most effective method of training the people who will be designing the adaptation scheme

It is not feasible to ensure that every community OT who is dealing with an adaptation for someone with a neuromuscular condition is fully aware of the needs and has received postgraduate training in this field, as there are too many OTs involved.

A second approach seemed to be to set up a network of specialist architects, architectural technicians and surveyors, and this has been achieved. They have all attended a workshop on the needs of people with neuromuscular conditions and each participant has indicated the geographical area that it is feasible to cover. A map and tables with this information is attached and this Network will be a useful resource for families, OT's and other professionals.

Members have been asked to work with the community OT and the Muscular Dystrophy Family Care Officer in their area – and where necessary, to liaise with the National Occupational Therapy Advisor. In this way, specialist architectural help will be provided, the outcome will be monitored with a questionnaire, which is included with this chapter and can be photocopied – and we hope that the standard of adaptations is improving.

# Muscular Dystrophy Adaptations & Building Design Network



To show office base of architectural designers  
(Location shown is a rough guide only)

N.B. Although not reflected by the position of the office bases, readers must be reassured that there is no area in the UK that is not covered by at least one architectural designer.

## Addresses of the Network architectural designers: England, Wales & Scotland

County & unitary authorities	Town/city	Name	Company/Address	Area
Argyll	Ardrishaig	Iain Strickland	<i>McKenzie, Strickland Associates.</i> 23 Bank Street Aberfeldy Perthshire PH15 2BB tel: 01546 603 283 fax: 01887 829 588 e-mail: info@msa-architects.com info@accessiblesolutions.org.uk	
Bedfordshire	Luton	Keith Atkinson	<i>Newspace Designs</i> Unit 1 Portland Industrial Units Kingsway Luton LU4 8HA tel/fax: 01582 405 315 e-mail: newspacedesigns@aol.com	Home Counties Milton Keynes, Northants, London.
Bedfordshire	Dunstable	Kevin Todd	<i>KJM Todd Associates</i> <i>Architectural &amp; Development</i> <i>Consultants</i> Staple House Eleanors Cross Dunstable Beds LU6 1SU tel: 01582 476 404 fax: 01582 475 308 e-mail: kevin todd@kjmtodd.co.uk	Bedfordshire– 1 hour radius Central London to Leicester, Oxford across to Cambridge. Would consider projects in this 50–mile radius.
Birmingham	Sutton Coldfield	Peter Brown	<i>SA Spence Ltd</i> Clanrickarde House 11 Four Oaks Road Sutton Coldfield B74 2XP tel: 0121 323 5255 fax: 0121 323 5266	Stoke-on-Trent, Nottingham, Derby, Leicester, Wolverhampton, Birmingham, Coventry, Worcester, Kidderminster.
Bristol	Bristol	Matthew Deering	<i>Matthew W Deering RIBA</i> <i>Chartered Architect</i> Bramford House 23 Westfield Park Redland Bristol BS6 6LT tel: 0117 973 3776 fax: 0117 973 3782	South West England, South Wales.
Bristol,	Bristol	David Anderson	<i>Mildred, Howells &amp; Co</i> <i>Chartered Quantity Surveyors</i> Royal Colonnade 14 Great George Street Bristol BS1 5RH tel: 0117 929 2894 fax: 0117 925 4356 e-mail: bristol@mildredhowells.co.uk	Bristol, Swansea, Saltash, Gloucestershire. Somerset, Devon, Cornwall.

County & unitary authorities	Town/city	Name	Company/Address	Area
Cambridgeshire	March, Cambridge	Ken Elener	<i>K.L. Elener Architectural Design</i> 9 The Greys, March Cambridge PE15 9HN tel: 01354 656 854 fax: 01354 659 323 e-mail: ken@elener52.freeserve.co.uk	Cambridgeshire into Lincolnshire (South Holland DC), Norfolk.
Cambridgeshire	Cambridge	David Pleasance	<i>Cambridge City Council Housing Services</i> Hobson House 44 St Andrews Street Cambridge CB2 3AS tel: 01223 457 944 fax: 01223 457 959 e-mail: david.pleasance@cambridge.gov.uk	Cambridgeshire.
Cornwall	Liskeard	Anthony Waldren	<i>Caradon Care &amp; Repair</i> 4 Pondbridge House Pondbridge Hill Liskeard PL14 3AB tel: 01579 340 073 fax: 01579 340 806 e-mail: carerepair.caradon@hanover.org.uk	(a) Caradon District Council area for works via Caradon Care & Repair (b) Devon, Cornwall for private works
Cumbria	Carlisle	Stephen Buttler	<i>S Buttler Chartered Architect</i> 9 Howard Place Carlisle Cumbria CA1 1HR tel/fax: 01228 546 487 e-mail: sb@buttler.fsbusiness.co.uk web: www.selfbuild-cumbria.co.uk	SW Scotland W Northumbria, Kendal, Whitehaven, North Cumbria, Dumfries, Haltwhistle, Moffat.
Cumbria	Kendal	Peter Boyd	<i>Mellor Architects</i> 125 Highgate Kendal Cumbria LA9 4EN tel: 01539 727 402 fax: 01539 730 181	Offices in Preston & Kendal cover general area of Cumbria, Lancs, Merseyside, Grtr Manchester, Cheshire.
Derbyshire	Matlock	Austin Cockayne	<i>Derbyshire County Council</i> County Property Department Chatsworth Hall Chesterfield Road Matlock Derbyshire DE4 3FW tel: 01629 580 000 ext. 6283 fax: 01629 585 114 web: www.derbyshire.gov.uk	Anywhere within County of Derbyshire
Dumbartonshire	Dumbarton	Archie Richmond	<i>Richmond Architects</i> Scottish Maritime Museum Building Castle Terrace Dumbarton G82 1QS tel/fax: 01389 765 578 e-mail: ricmondarchitects@compuserve.com	Dumbartonshire, Argyll, Bute, Stirling. Will consider other areas where special need arises.

County & unitary authorities	Town/city	Name	Company/Address	Area
Edinburgh	City	Ian Appleton	<i>The Appleton Partnership Architects</i> Forth Gallery, Forth Street Edinburgh EH1 3JX tel:0131 557 8151 fax:0131 557 8145	Edinburgh & East Scotland.
Edinburgh	City	Heather Chapple	<i>Smith Scott Mullan Associates Chartered Architects</i> 378 Leith Walk Edinburgh EH7 4PF tel:0131 555 1414 fax:0131 555 1448 e-mail:h.chapple@smith-scott-mullan.co.uk web:www.smith-scott-mullan.co.uk	Edinburgh & Lothians.
Edinburgh	City	Katy Divers	<i>City of Edinburgh Council Building Design Services</i> Wellington Court 10 Waterloo Place Edinburgh EH1 3BH tel:0131 469 4028 e-mail:catherine.divers@educ.edin.gov.uk	Edinburgh (education & Local Authority property)
Edinburgh	City	Richard Pollock	<i>Burnett Pollock Associates</i> 17b Graham Street Edinburgh EH6 5QN tel:0131 555 3338 fax:0131 555 4446 e-mail:mail@burnettpollock.co.uk	Edinburgh City, East, Mid & West Lothian, Fife, Scottish Borders, Falkirk, Stirling.
Edinburgh	City	Douglas Read	<i>Dignan Read Dewar Architects</i> 3 Tolbooth Wynd Leith Edinburgh EH6 6DN tel:0131 554 4434 fax:0131 553 4608 e-mail:info@dignanreaddewar.co.uk	Edinburgh City, East, Mid, West, Lothian.
Essex	Chelmsford	Sean Taylor	<i>Sean Taylor Associates</i> Shentalls House Private Road Galleywood Chelmsford Essex CM2 8TH tel/fax 01245 287 144 e-mail:seantaylor40@hotmail.com	Essex & East London.

County & unitary authorities	Town/city	Name	Company/Address	Area
Flintshire	Flint	Dewi Ingman	<i>Flintshire County Council</i> County Offices P.O. Box 4 Flint CH6 5WS tel: 01352 703 430 fax: 01352 703 307	Flintshire area.
Glasgow	Rutherglen	Jim Stamper	ST2 Architects 40 Burnside Road Rutherglen Glasgow G73 4RS tel: 0141 631 4221 fax: 0141 634 1196 e-mail: j-a.stamper@lineone.net	Glasgow.
Gloucestershire	Cheltenham	Oliver Wright	<i>Architectural &amp; Building Consultancy</i> 2 Alma Road Hatherley Cheltenham GL51 3LS tel/fax: 01242 232 900	Gloucestershire, Herefordshire, Worcestershire, Wiltshire, Gwent Oxfordshire.
Gloucestershire	Cirencester	John Marsh	<i>Chartered Building Surveyors</i> The Rookery Rookery Lane Chedworth Glos. GL54 4AJ tel: 01285 720 512 fax: 01285 720 161 e-mail: john@marsh-surveyors.co.uk	East Gloucestershire, North Wiltshire, West Oxfordshire.
Hampshire	Southampton	John Dryden-Brownlee	DB Associates <i>Chartered Architects</i> South Hill Droxford Southampton Hants. SO32 3PE tel: 01489 877 286	Hampshire West Sussex.
Hertfordshire	Cheshunt	Richard Eaton	<i>Eaton Strevens Associates</i> <i>Chartered Surveyors</i> 129 Crossbrook Street Cheshunt Herts EN8 8LY tel: 01992 639 782/637 510 fax: 01992 640 364 e-mail: eatonstrevens@btclick.com	Phone to discuss services within 50 mile radius. Consultation & feasibility service available.
Hertfordshire	St Albans	Anthony Grimwade	<i>Penton, Smart &amp; Grimwade</i> 113 Victoria Street St Albans Herts AL1 3TY tel: 01727 840 911 fax: 01727 844 148 e-mail: pentonsmart+grimwade@psg.demon.co.uk	Hertfordshire.

County & unitary authorities	Town/city	Name	Company/Address	Area
Kent	West Malling	Lesley Wheal	<i>The Home Improvement Agency</i> Gibson Building Gibson Drive Kings Hill, West Malling Kent ME19 4LZ tel: 01732 844 522 direct line: 01732 876 152 fax: 01732 841 421 e-mail: envhlthhsg.service@tmbsc.gov.uk	Tonbridge & Malling Borough Council area.
Lancashire	Nelson	Mike Bennett	<i>Bennett &amp; Brown Ltd Architects &amp; Surveyors</i> Epworth House 35 Carr Road Nelson, Lancs BB9 7JS tel: 01282 618 111 fax: 01282 602 711	Lancashire from Carnforth to Preston to Settle, Manchester, Bolton Bradford - Leeds.
Lancashire	Preston	Peter Boyd	<i>Mellor Architects</i> 12 Eastway Business Village Olivers Place Preston PR2 9WT tel: 01772 797 788 fax: 01772 797 780	Offices in Preston & Kendal, cover Cumbria, Lancs, Merseyside, Gtr Manchester, Cheshire.
Lancashire	Leigh	Francis Haigh	<i>Survey and Design Ltd</i> 28 Railway Road Leigh Lancs WN7 4AU tel: 01942 673 136 fax: 01942 607 054	North West, Cheshire, Merseyside, Gtr Manchester.
Lancashire	Preston	Ian Standige	<i>Heyes + Company Architects &amp; Designers</i> The Root House Clifton Fields Preston PR4 0XE tel: 01772 639 550 fax: 01772 639 555 e-mail: prestonoffice@heyesarchitects.co.uk	North - Carlisle West - Fylde, Coast to Blackpool East - Leeds inc. M65 South - Manchester inc. M62 - Bolton & Oldham.
Leicestershire	Market Harborough	Tony Rodgers	<i>B + R Partnership Chartered Architects</i> 1 Millers Yard Roman Way Market Harborough Leics LE16 7PW tel: 01858 464 986 fax: 01858 434 235 e-mail: design@brp-architects.com web: www.brp-architects.com	Leics & Rutland.
Liverpool	City	Ian Standige	<i>Heyes + Company Architects &amp; Designers</i> Mariner's House 304 Queens Dock Commercial Centre Norfolk Street Liverpool L1 0BG tel: 0151 330 4191/4192 fax: 0151 330 4193 e-mail: livoffice@heyesarchitects.co.uk	North - S'port, Wigan, St Helens East - Gtr Manchester South - N Wales, Mold, Chester Wrexham, Crewe, Macclesfield, Stoke, N'castle-u-Lyme.

County & unitary authorities	Town/city	Name	Company/Address	Area
London	Richmond	Derek Begent	<i>Pillow Associates</i> 29 Howsman Road London SW13 9AW tel: 020 8748 7829 fax: 020 8741 8986 pillowassociates@aol.com	London, Middx, Surrey, Hants, Sussex, Isle of Wight.
London	City	Simon Koupparis	<i>Koupparis Associates</i> 95 Kentish Town Road London NW1 8NY tel: 020 7267 6874 mb: 0795 380 674 fax: 020 7485 6739	London, Middx Surrey within M25.
London	City	Maurice Taylor	<i>Maurice Taylor Architect</i> The Studio 9 Highbury Terrace Mews London N5 1UT tel/fax: 020 7704 0261	London area.
Middlesex	Ruislip	Rumi Adi Hakim	<i>Architectural Consultant</i> 9 Lindem Close Ruislip Middlesex HA4 8TN tel: 01895 625 283	Middx, NW to SW of London, surrounding counties.
Norfolk	Thetford	John Atkins	<i>John Atkins - Architect</i> 64 Melford Bridge Road Thetford Norfolk IP24 2HG tel: 01842 765 382 mb: 07870 625 465 fax: 01842 765 387 e-mail: john@jaaarchitect.demon.co.uk	Norfolk, Suffolk, Essex, Cambs.
Norfolk	Dereham	David Cutting	<i>David A Cutting</i> <i>Building Surveyors Ltd</i> Longacre, 70 Market Street, Shipdham Norfolk IP25 7LZ tel: 01362 821 000 fax: 01362 821 308 email: dacutting@hotmail.com	Norfolk, N. Suffolk, E. Cambs. S. Lincs.
Norfolk	Attleborough	Terry Hickman Smith	<i>T &amp; B Hickman Smith</i> <i>Architects</i> Willow Farm, Fen Street Attleborough Norfolk NR17 1AS tel: 01953 452 099 fax: 01953 452 826 e-mail: hickmansmith@paston.co.uk	Norfolk, Suffolk, N. Essex Cambs.
Norfolk	Norwich	John Norfolk	<i>Alan Norfolk Architectural</i> "The Firs" 34 Margaret Rd New Costessey Norwich NR5 0AU tel: 01603 745 063 (Day) tel: 01603 743 621 (Evening) web: www.anabuildingdesign.co.uk	Norfolk & Suffolk.

County & unitary authorities	Town/city	Name	Company/Address	Area
North Yorkshire	Whitby	Neil Duffield	<i>B.C.&amp;T Consultants Architectural Technologists &amp; Building Surveyors</i> Arundel Howe Byland Road Whitby North Yorkshire YO21 1JH tel: 01947 604 871 fax: 01947 600 010 e-mail: general@bct-consultants.co.uk web: www.bct-consultants.co.uk	N Yorkshire & Cleveland.
Northamptonshire	Brixworth	Leslie Sims	<i>Myles &amp; Sims - Architects</i> 3 Kennel Terrace Brixworth Northampton NN6 9DL tel: 01604 880 294 fax: 01604 881 667	Northants, Leics, Cambs, Beds, & Bucks.
Northumberland	Stocksfield	Peter Ashworth	<i>Peter Ashworth Architect</i> Feathers Cottage Hedley on the Hill Stocksfield Northumberland NE43 7SW tel/fax: 01661 842 466	Northumberland, SE Scotland, Tyneside, NW Durham, E Cumbria.
Northumberland	Wylam	Peter Goff	<i>Orchard Goff Associates</i> Station House, Wylam Northumberland NE41 8HR tel/fax: 01661 852 159	Northumberland, Co. Durham, Tyne & Wear.
Northumberland	Berwick upon Tweed	Donald Chapman	<i>Donald Chapman Architect</i> East Wing, Paxton Hse Paxton Berwick upon Tweed Northumberland TD15 1SZ tel: 01289 386 238	Scottish Borders & North Northumberland.
Nottinghamshire	Mansfield	Anthony Jackson or Darren Binney	<i>Jackson Design Associates</i> Suite 15 Bruns Business Centre Samuel Bruns Way Mansfield Notts NG18 2AH tel: 01623 422 425 fax: 01623 636 766 e-mail: mail@jacksondesign.co.uk	50 mile radius of Mansfield. Notts, Derbyshire, N Leics, West Lincs, S Yorks.

County & unitary authorities	Town/city	Name	Company/Address	Area
North Somerset	Nailsea	Andrew Harrold	North Somerset Care & Repair 21 Somerset Square Nailsea Bristol BS48 1RQ tel: 01275 858 518 fax: 01275 858 559 e-mail: carerepair.northsomerset@hanover.org.uk	North Somerset District only.
Nottinghamshire	Nottingham	Hannah Minton	<i>Barrington J. Minton</i> <i>Chartered Architects</i> <i>Planning &amp; Management</i> <i>Consultants</i> Guncroft Lodge Nottingham Road Lowdham Notts NG14 7AP tel: 0115 966 3672/3 fax: 0115 966 4611	Notts, Leics, W. Lincs, E. Derbys. Further afield if necessary.
Renfrewshire	Paisley	Ian Hickey	<i>Hickey &amp; Hickey</i> <i>Architecture</i> 16 Oakshaw St. East Paisley PA1 2DD tel: 0141 887 7585 fax: 0141 889 0703 e-mail: info@hickeyarch.co.uk	Glasgow & surrounding conurbation. S & Mid Argyll inc. Dunoon, Lochgoilhead, Campbeltown, Oban.
Stockport	Davenport	Alan Hurst	<i>Alan James Hurst</i> <i>Chartered Architect</i> Heaviley House 8 Kennerley Road Davenport Stockport SK2 6EY tel: 0161 456 1203 e-mail: alan.hurst@btclick.com	Manchester & Stockport area (within 20 mile radius).
Suffolk	Ipswich	David Lewis	<i>David S. G. Lewis</i> <i>Chartered Architect</i> 23 Stevenson Road Ipswich Suffolk IP1 2EY tel/fax: 01473 254 619	Suffolk & N Essex.
Suffolk	Sudbury	Stephen Thorpe	Threshold Architects 72 Friar Street Sudbury Suffolk CO10 2AJ tel: 01787 881 661 fax: 01787 882 221 e-mail: homesolvesuffolk@aol.com web: www.homesolve.org.uk	East Anglia, but may cover further up Eastern England, Greater London, Kent & Sussex.

County & unitary authorities	Town/city	Name	Company/Address	Area
Surrey	Woking	Stuart Hicks Rodney Cookson	<i>Stuart Hicks Design Services</i> "Woodrising" St Johns Hill Road St Johns, Woking Surrey GU21 7RW tel: 01483 772 917	25 mile radius of Woking.
Surrey	Mitcham	Andy Hicks	<i>Hicks Design Associates</i> 16 Fowler Road Mitcham Surrey CR4 2LQ tel: 020 8640 7970 fax: 020 8781 1282	S London & home counties to S, SE & SW.
Tyne & Wear	North Tyneside	Ken Swinburne or Jonathan Boggan	<i>Ken Swinburne Associates</i> 23 Commissioners Wharf Royal Quays North Shields North Tyneside NE29 6DN tel/fax: 0191 296 6367 mb 07808 624 932	Northumberland, Co. Durham Tyne & Wear.
Worcestershire	Kidderminster	Andrew Plank	<i>Andrew Plank</i> <i>Chartered Architect</i> 10 Sanderling Court Kidderminster Worcs DY10 4TS tel/fax: 01562 829 523	Worcs & S. Shropshire West Midlands conurbation.

## Addresses of the Network architectural designers: Northern Ireland

County & unitary authorities	Town/city	Name	Company/Address	Area
Co. Antrim	Ballymoney	James Morrison	<i>Hunter Associates</i> 8 Charlotte Street Ballymoney Co. Antrim BT53 6AY tel: 028 2766 3535 fax: 028 2766 7155	Northern Ireland, particularly Co. Antrim & Londonderry.
Co. Antrim	Belfast	Edwin Clarke	<i>VB Evans &amp; Co</i> 19 College Gardens Belfast BT9 6BP tel: 028 9038 1211 fax: 028 9066 1353 e-mail: office@vbevans.com	Northern Ireland.
Co. Antrim	Belfast	Ronnie Little	<i>Roy Kirk Associates</i> 39 Wellington Park Belfast BT9 6DN tel: 028 9066 4428 fax: 028 9066 6984 e-mail: admin@roykirk.co.uk	Northern Ireland & Republic.
Co. Antrim	Belfast	Alastair Macnab	<i>Alastair Macnab</i> <i>Chartered Architect</i> 20 Ferguson Drive Belfast BT4 2AZ tel/fax: 028 9065 7260	Northern Ireland.
Co. Antrim	Belfast	Jim Morrison	<i>Jim Morrison Architects</i> 31 Cricklewood Park Belfast BT9 5GW tel: 028 9066 0017 fax: 028 9020 1710 e-mail: design@hunterassoc.club24.co.uk	Greater Belfast, North Down & South Antrim.
Co. Antrim	Newtownabbey	William Watt	<i>Whittaker &amp; Watt Architects</i> 379 Antrim Road Newtownabbey BT36 5EB tel: 028 9084 1029 fax: 028 9084 3365	Northern Ireland (particularly Greater Belfast, Co. Antrim & Co. Down).
Co. Down	Groomsport	Eve Wilson	<i>Sinclair Wilson Architects</i> Old Coastguard Station Coastguard Lane Ortock Co. Down BT19 6LR tel: 028 9188 2669 fax: 028 9188 2703 e-mail: sinclairwilson@utvinternet.com	Greater Belfast, Co. Down & Bangor Area, Co. Antrim.

County & unitary authorities	Town/city	Name	Company/Address	Area
Co. Down	Dromore	Jonathan Middleton	<i>Jonathan Middleton Architectural Technologist</i> 15 Sunmount Park Dromore Co. Down BT25 1BA tel: 0779 977 8951 e-mail: jmiddle855@aol.com	Co. Down, Co. Antrim, & Greater Belfast.
Co. Down	Belfast	Thomas Barr	<i>Thomas J Barr Chartered Building Surveyor</i> 39 South Parade Belfast Northern Ireland BT7 2GL tel: 028 9020 8308 fax: 028 9020 8308	Greater Belfast.
Co. Down	Belfast	Jonathan Park	<i>Cyril Sweett Ltd</i> Hawarden House 163 Upper Newtownards Road Belfast BT4 3HZ tel: 028 9065 1090 fax: 028 9067 1617 e-mail: jpark@cyrilsweett.co.uk web: www.cyrilsweett.co.uk	Northern Ireland, Republic of Ireland & UK.
Co. Down	Belfast	Janice Houston	<i>Cosarc Design Group</i> The Gas Office 4 Cromack Quay Belfast BT7 2JD tel: 028 9082 8400 fax: 028 9024 1182 e-mail: mail@cosarc-design.co.uk	Northern Ireland, Republic of Ireland & UK.
Co. Fermanagh	Irvinestown	Eamonn Monaghan	<i>Keys &amp; Monaghan Architects</i> 7 Mill Street Irvinestown Co. Fermanagh BT94 1GR tel: 028 6862 8088 fax: 028 6862 8505	Tyrone & Fermanagh (other areas considered).
Co. Fermanagh	Enniskillen	Glen Morrison	<i>GMS Designs</i> Twain Gables 2 Lackaboy View Enniskillen BT74 4DY tel/fax: 028 6632 5206 mb: 07736 930 379	Fermanagh, Tyrone, Donegal, Lietrim.
Co. Londonderry	Coleraine	Michael Rogers	<i>Michael Rogers &amp; Co. Architects Ltd</i> Studio 2 Old Distillery Court Coleraine Co. Londonderry BT52 1LN tel: 01265 329 090 fax: 01265 329 191 e-mail: mra@mcm.com	Northern Ireland - North of Belfast.
Co. Londonderry	Derry	Michael Heverin	<i>Michael J Heverin Chartered Architect</i> 56 Hatmore Park Derry BT48 0AY tel: 028 7126 1118	Derry & North West Ireland.

# Muscular Dystrophy Adaptations & Building Design Network Questionnaire

Section A	<i>Individual details</i>
Section B	<i>Work carried out/outcome</i>
Section C	<i>Time taken</i>
Section D	<i>Building work</i>
Section E	<i>Assessment of needs/plans</i>
Section F	<i>Support</i>
Section G	<i>Facilities/equipment review</i>
Section H	<i>Future involvement of MD Campaign</i>

## Section A. Individual details

(Please draw a circle around your answer, or where necessary, answers)

### A1. Name of neuromuscular condition

- Becker MD
- Congenital MD
- Duchenne MD
- Facioscapulohumeral MD
- HMSN/CMT
- Limb girdle MD
- Myotonic dystrophy
- Spinal muscular atrophy
- Other (please specify) .....

### A2. Age group of disabled person/people

- Under 5
- 5 – 10
- 10 – 19
- 20 – 30
- 30 – 50
- 50 & over

### A3. Were the needs of more than one disabled person involved?

Yes / No

**If YES, please give details** .....

.....

.....

**A4. Mobility: are you**

- Able to walk?
- Self-propelled wheelchair user, indoor/outdoor?
- Powered wheelchair user, indoor/outdoor?
- Other .....

**A5. Who owns your house?**

- Local Authority
- Privately owned
- Housing Association
- Private landlord

**A6. What type of house is it?**

- Bungalow
- Terraced house
- Semi-detached house
- Detached house
- Flat/Maisonette
- Mobile home
- Listed building

**A7. Was your house purpose-built for your disability?**

- Yes / No

**Section B. Work carried out/outcome**

**B1. What was the approximate date when the building work was completed? .....**

**B2. What work was carried out?**

- Ramp - front
- Ramp - back
- Lift
- Ground-floor bathroom
- Ground-floor bedroom & bathroom
- Other .....
- .....
- .....
- .....

**B3. How satisfied are you with the outcome?**

- Extremely satisfied
- Very satisfied
- Fairly satisfied
- Not very satisfied
- Not at all satisfied

**B4. Would you make all the same decisions if you could start again?**

Yes / No

**If NO, what would you change?** .....

.....

**B5. Will you need further adaptations in the future?**

Yes / No

Don't know

**Section C. Time taken****C1. How long did it take from the time you first asked Social Services for adaptations – to completion of the work?**

Under 6 months

6 months – 1 year

1 – 2 years

If over 2 years, please specify number of years .....

**If over 2 years were there any special reasons for the delay?**

.....

**C2. Was the work completed by the time you needed the special facilities?**

Yes / No

**If NO, how long did you have to manage with inadequate facilities?**

Under 6 months

6 months – 1 year

1 – 2 years

If over 2 years please specify number of years .....

## Section D. Building work

**D1. How did you choose your builder?** .....

**Did you get enough help with the choice?**

Yes / No

**D2. How satisfied were you with the way your builder went about the work?**

Not at all satisfied

Not very satisfied

Fairly satisfied

Very satisfied

Extremely satisfied

**If not satisfied, did you feel able to complain?**

Yes / No

**D3. How carefully did the builder follow the plans?**

Extremely carefully

Very carefully

Fairly carefully

Not very carefully

Not at all carefully

**Please describe any mistakes** .....

.....  
.....  
.....

**D4. Who did you feel was responsible for making sure the builder did a good job?** .....

**D5. Was the building work supervised by an architectural designer**

Yes / No

**If YES, how helpful was this?**

Extremely helpful

Very helpful

Fairly helpful

Not very helpful

Not at all helpful

**If NO, do you think it would have helped you?**

Yes / No

## Section E. Assessment of needs/plans

### E1. How well do you feel your needs were assessed?

- Not at all well
- Not very well
- Fairly well
- Very well
- Extremely well

**By whom?** (please specify) .....

### E2. Was an occupational therapist (OT) involved?

Yes / No

### E3. Did waiting for an OT assessment cause a significant delay?

Yes / No

### E4. To what extent do you feel your Social Services OT understood the special problems of MD or your type of disability?

- Extremely well
- Very well
- Fairly well
- Not very well
- Not at all well

### E5. Do you feel that your opinion was:-

#### a. asked for?

Yes / No

#### b. listened to?

Yes / No

**By whom?** (Please specify) .....

### E6. Were you allowed to have everything you felt you needed?

Yes / No

**If NO, please give details** .....

.....

### E7. Who drew the plans? .....

### E8. What did the plans cost?

£ .....

Don't know

## Section F. Support

### F1. How clearly was the Grants system explained to you?

- Not at all clearly
- Not very clearly
- Fairly clearly
- Very clearly
- Extremely clearly

**By whom?** (Please specify) .....

### F2. How well were you kept in touch with what was going on?

- Extremely well
- Very well
- Fairly well
- Not very well
- Not at all well

**By whom?** (Please specify) .....

### F3. What type of grant did you receive and how much?

- (Home) Improvement Grant £
- Disabled Facilities Grant £
- Social Services £
- Family Fund Trust £
- Other Charity/Trust £
- Loan (Please state terms) £ Terms: .....
- None. We had to pay £
- In addition to Grant we had to pay £

### F4. How good was the service you received from the staff involved?

	Excellent	Very good	Good	Fair	Poor	Not involved
<b>Architectural designer</b>						
<b>Builder</b>						
<b>Social Services community OT</b>						
<b>Hospital/clinic OT</b>						
<b>Local Authority grants officer</b>						
<b>Family Care Officer/MDC</b>						
<b>National OT Advisor/MDC</b>						
<b>Other</b> (Please specify below)						

**F5. Did you find the process of adaptations was emotionally difficult?**

Yes / No

**Please give an idea of the stress**

- Extremely stressful
- Very stressful
- Fairly stressful
- Not very stressful
- Not at all stressful

**F6. Did you have any professional to turn to for support?**

Yes / No

**If YES, who?**

- Family Care Officer/MDC
- Grants officer
- Health visitor
- Housing officer
- MD Branch Welfare Officer
- National OT Advisor/MDC
- Occupational therapist Social Services
- Occupational therapist hospital/clinic
- Physiotherapist
- Social worker
- Teacher
- Other, (please specify)

**In what way were they able to help?** .....

.....

.....

**F7. Would you have appreciated more help and advice from the MD Campaign and in what way? (Please be honest)**

.....

.....

.....

## Section G. Facilities/equipment review

### G1. Lift

(If you have a lift, please continue by circling the type of lift and what you think of it).

No lift  (Please continue with G2)

**a) Type of lift**

Seat at side of stairs	Excellent	Very good	Good	Fair	Poor
Wheelchair platform up stairs	Excellent	Very good	Good	Fair	Poor
Through-floor lift	Excellent	Very good	Good	Fair	Poor
Other (please specify below)	Excellent	Very good	Good	Fair	Poor

.....

**b) Can you use the lift entirely independently?** Yes / No

**c) If NO, why not?** .....

.....

.....

### G2. Doors

**a) Can you open and close your bedroom & bathroom doors independently?**  
Yes / No

**b) What type of doors are they?**

Standard  
Double swing  
Sliding  
Other (please specify) .....

**c) Can you open and close either your front or back door independently?**  
Yes / No

**d) Do you have an automatic door opener?**  
Yes / No

**e) Are any thresholds a problem?**  
**If YES, at which door?** .....

**G3. Bathroom**

a) **Is your bathroom big enough for use with a wheelchair**  
(even if you don't use one)?  
Yes / No

b) **Is there space for a wheelchair at the side of the toilet?**  
Yes / No

c) **Do you use a toilet chair over the toilet?**  
Yes / No

**If YES, do you know the make or can you describe the chair?**

.....  
 .....

**How satisfactory is it?**

- Not at all satisfactory
- Not very satisfactory
- Fairly satisfactory
- Very satisfactory
- Extremely satisfactory

d) **Do you have a Clos-o-mat shower toilet?**  
Yes / No

e) **Do you have Geberit shower toilet?**  
Yes / No

**What do you think of it?**

Poor                      Fair                      Good                      Very good                      Excellent

**Any other comments?** .....

.....

**G4. Bathing** - (Please circle your answer).

a) **How do you get in and out of the bath?** .....

I don't have a bath / I have a shower  
 I can't use a bath or shower without help

**Please rate your equipment below**

**Mermaid Ranger (with separate chassis)**

Poor                      Fair                      Good                      Very good                      Excellent

**Arjo Sovereign (formerly Parker Series 300 bath)**

Poor                      Fair                      Good                      Very good                      Excellent

**Other** (Please specify) .....

Poor                      Fair                      Good                      Very good                      Excellent

**Any other comments?** .....

.....

- b) Shower**  
**Do you have a shower?**  
 Yes / No  
**Please circle type of shower**  
 Shower over bath  
 Tiled floor-level shower  
 Shower tray - Type? .....

- c) Type of shower chair** (please describe) .....
- What do you think of it?**  
 Poor                      Fair                      Good                      Very good                      Excellent

**G5. Washbasin**

- a) What type of washbasin do you use?**  
 .....

- b) If you use a wheelchair can you get right under the basin without adjusting the footrests?**  
 Yes / No

- c) Do you have space to rest your forearms?**  
 Yes / No

- d) Can you reach and operate the taps?**  
 Yes / No

- e) What type of taps?**  
 Standard  
 Lever  
 Electronic
- What do you think of them?**  
 Poor                      Fair                      Good                      Very good                      Excellent

- d) Can you reach your toothbrush, towel etc. without help?**  
 Yes / No

**G6. Bedroom**

- a) Is your bedroom en suite with bathroom?**  
 Yes / No

- b) Do you have space for tables or surfaces for computer/stereo/ hobbies etc?**  
 Yes / No

- c) Do you use a ceiling hoist over bed?**  
 Yes / No

**d) With extended track from bed to bath?**

Yes / No

**e) Portable hoist**

Yes / No

**Please specify model** .....**What do you think of your hoist?**

Poor                      Fair                      Good                      Very good                      Excellent

**Any other comments?**

.....

**f) Do you have an electric bed?**

Yes / No

**Please specify model** .....**What do you think if it?**

Poor                      Fair                      Good                      Very good                      Excellent

**Any other comments?**

.....

**G7. Kitchen****a) To get an idea of size, is it big enough to use from a wheelchair?**

Yes / No

**b) If necessary, is there a surface that could be made suitable for use from a wheelchair?**

Yes / No

**G8. Light switches****a) If you use a wheelchair can you reach the switches?**

Yes / No

**If NO, which ones can't you reach?** .....**b) Can you turn the light on/off when in bed?**

Yes / No

**G9. Heating****a) What type of central heating do you have?**

None                      Gas                      Oil                      Electric                      Solid Fuel

**b) Is your bedroom warm enough?**

Yes / No

**c) Is your bathroom warm enough?**

Yes / No

## Section H. Involvement of MD Campaign

**H1. Is your architectural designer a member of the Muscular Dystrophy Adaptations & Building Design Network?**

Yes / No

Don't know

**Please give name** .....

.....

**H2. Do you feel it has been a good idea to have a specialist MD architectural designer to give advice & help with all the stages involved in adaptations?**

Yes / No

Don't know

**If answer is yes or no please could you give your reasons**

.....

.....

**Name and address of disabled person**

(This can be omitted if you prefer)

.....

.....

.....

**Postcode** .....

**Tel:** .....

***THANK YOU FOR YOUR HELP - Your answers will be invaluable and strictly confidential***

Please return this questionnaire to:

*National Occupational Therapy Advisor/Muscular Dystrophy Campaign*

*7-11 Prescott Place*

*London SW4 6BS*

*tel: 020 7720 8055*

*fax: 020 7498 0670*

# Scales & Templates

## Planning & Building Regulations Approval

To be used in conjunction with:

- Chapter 6 *Lift vs Extension;*
- Chapter 8 *Equipment;*
- Chapter 15 *Adaptation Specifications;*
- Chapter 16 *Kitchens.*

The following information is included:

⇒ Metric measurements	1
⇒ Measurement conversion	1
⇒ Scales	2
⇒ Muscular Dystrophy template	2
⇒ Muscular Dystrophy overlay sheets	2
⇒ Sizes	2
⇒ Items included in template & overlay sheets	6
⇒ Measurement conversion table	12
⇒ Planning & Building Regulations	13

### Metric measurements

A generation gap exists between those who continue to use imperial measurements and others who were educated using the metric system or have managed to master the change to the new system. Architectural drawings and plans are conventionally shown in millimetres. Therefore (except in Chapter 8d *Wheelchairs*) this manual has used metric scales exclusively and anyone working with plans should take this opportunity to become familiar with the system – **1000mm** in each metre.

### Measurement conversion

However, for anyone who finds this difficult, a conversion table is included on page 12. For instant easy-to-convert measurements, it is useful to remember that:

<b>25mm = 1"</b>
<b>100mm = 4"</b>
<b>600mm = 2'</b> and, in assessing the size of rooms,
<b>1000mm = 39" i.e. 3'3".</b> Therefore a room <b>4000 x 4000mm</b> is <b>13' x 13'</b> .

## Scales

Most plans are drawn to a scale of **1:50** and therefore this scale has been chosen for the template. On occasions, the bedroom and bathroom layouts may be enlarged to a scale of **1:20**. (In this case, to make scaled shapes to represent the fittings, these can be photocopied from the architectural designer's plans and glued on to card – or a transparent material can be superimposed and the outlines traced.) For convenience, both scales are printed on the edge of the template.

## Muscular Dystrophy template to illustrate the size of the equipment and furniture

### ▶ **Templates (please note the symbol used)**

These are useful tools, which overcome the need to understand and relate to measurements. Use the Perspex template in this manual to draw the size and shape of fittings and furniture directly on to the plans (in pencil so that you can change your mind) or make scaled shapes from a thick plastic. To ensure as much accuracy as possible, the shapes should be outlined with the fine point of a pencil, held at **45°** against the plastic edge of the template. Plastic has an advantage over card, in that it is transparent and allows you to alter the position of fittings and at the same time see the changes in relation to the original drawing. **N.B.** *The template refers to Renray David Baker and to the Parker Series 300 bath. In this edition of the Adaptations Manual, these should read as Huntleigh Renray and as the Arjo Sovereign bath.*

## Muscular Dystrophy overlay sheets – to check the space needed

### ◻ **Overlay sheets (please note the symbol used)**

These sheets should be placed over the fittings on the plans to check whether the correct space has been allowed. The sheet can be pierced to enable a pencil mark to be drawn on the plans to mark the boundary of the space needed. As above, the overlay refers to *Parker Series 300 bath* – please read this as *Arjo bath*.

**N.B.** *When plans have been either photocopied or faxed, it is important to check whether the scale has been affected by using a scale rule against any of the measurements.*

## Sizes

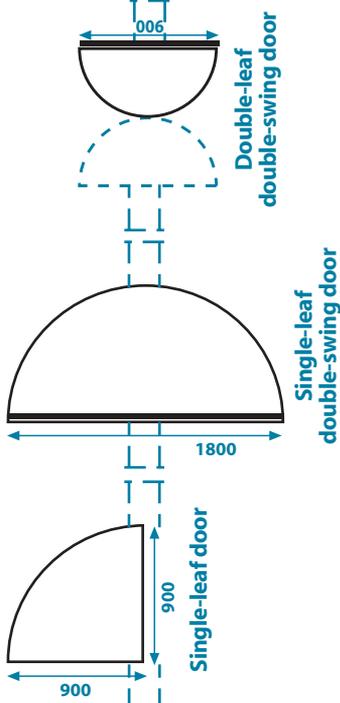
The templates have been drawn to scale and care has been taken to reproduce the sizes of the specific items of equipment as accurately as possible. However, the dimensions will need to be checked against the dimensions of the actual items, particularly where the template and the size represent a range of items (e.g. the sitting room and dining room furniture). In these cases, the size of modern furniture was carefully researched.

Also, it must be stressed that in time, the size of fixtures may change and that the purpose of templates is to act as a guide only. They will be helpful when considering options and making decisions about the position of the fittings and the best use of space, but are no substitute for the professional services of a designer experienced in these types of schemes.

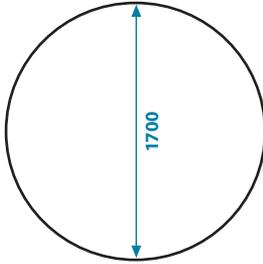
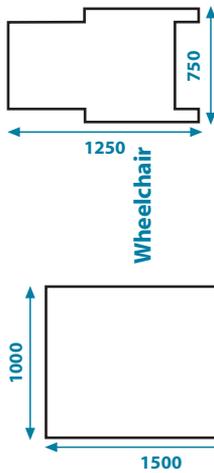
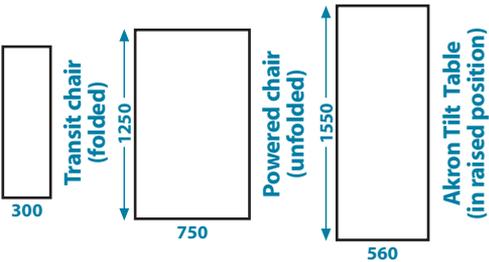
Templates are unlikely to be used by the architectural designer, who will draw the items either by hand with a scale rule (many would say the proper way!) or with the help of a computer programme. The designer will take responsibility for the accuracy of the scale of the drawings or measurements shown on the plans of the adaptation or 'new-build' scheme.

# TEMPLATE

## DOORS SWINGS



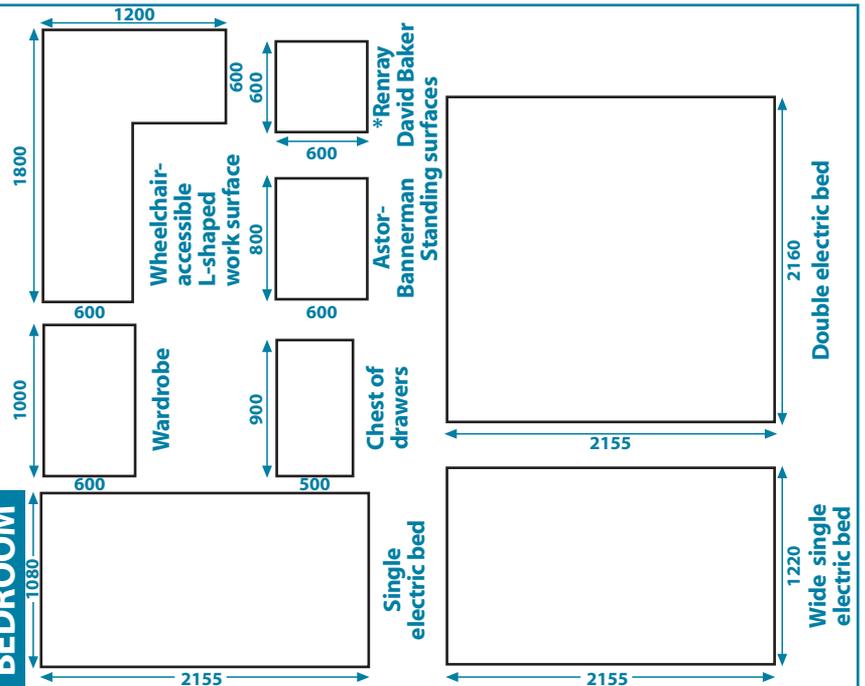
## EQUIPMENT STORAGE



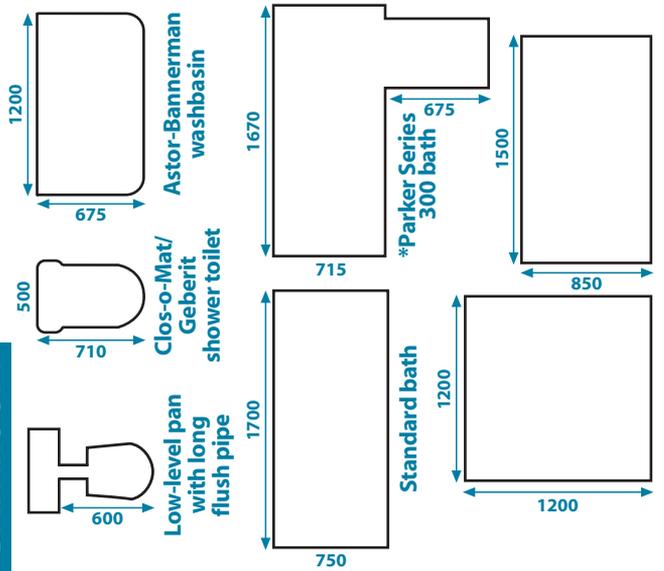
## Muscular Dystrophy Campaign

7-11 Prescottt Place  
London SW4 6BS  
tel: 020 7720 8055  
fax: 020 7498 0670  
e-mail: info@muscular-dystrophy.org  
www.muscular-dystrophy.org

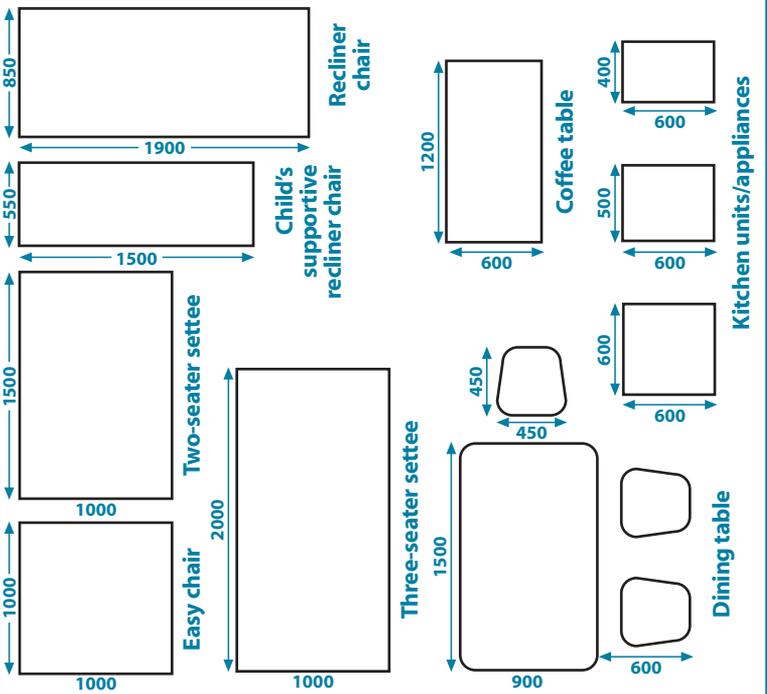
## BEDROOM



## BATHROOM



## FURNITURE

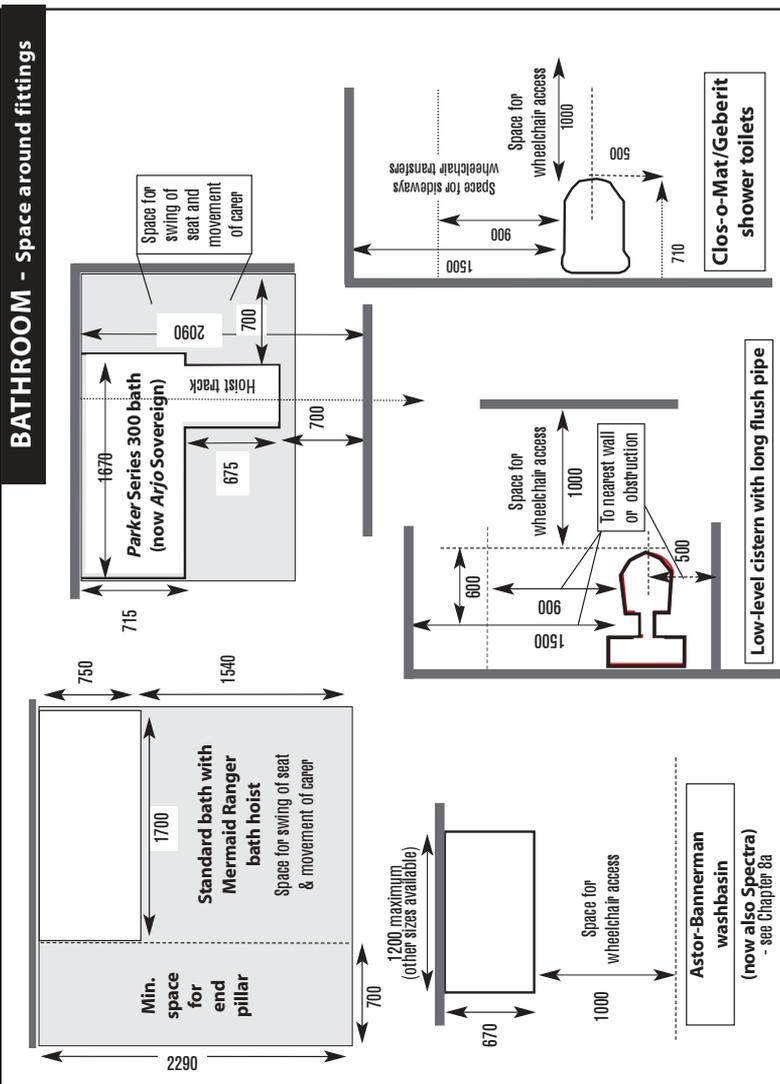


\* See pg. 2

SCALE 1:50

# OVERLAY SHEET

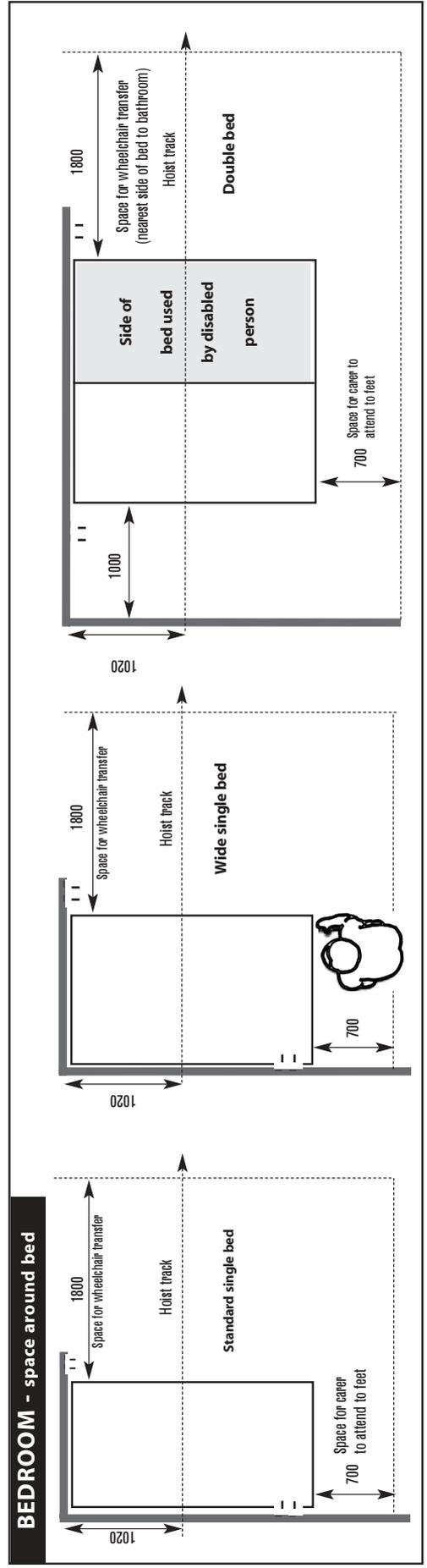
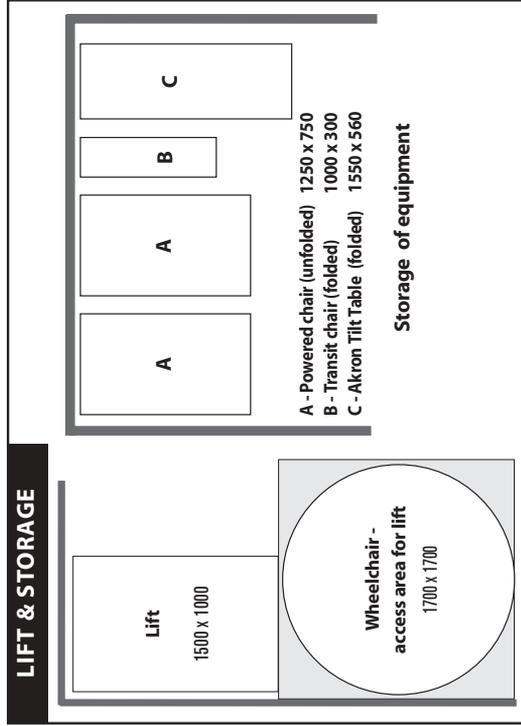
Produced by The Marketing Company - Phone : 0115 931 4586



SCALE - 1:50

7 - 11 Prescott Place  
London, SW4 6BS  
tel : 020 7720 8055  
fax : 020 7498 0670  
e-mail : info@muscular-dystrophy.org  
www.muscular-dystrophy.org

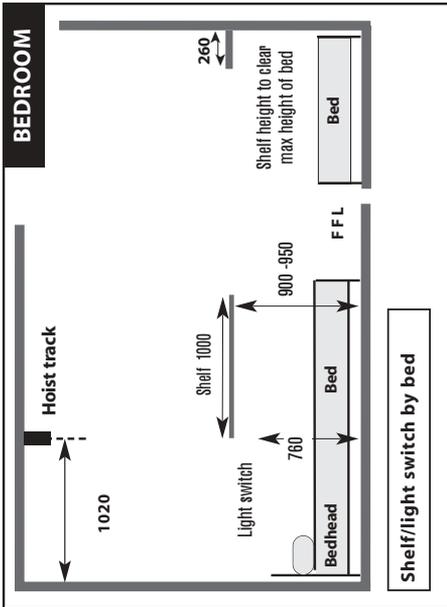
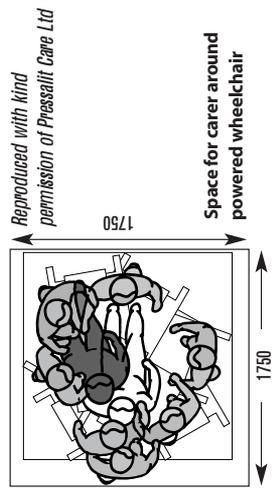
**Muscular Dystrophy Campaign**



# OVERLAY SHEET

**N.B.**

All shapes are based on approximate sizes and should not be used for specific dimensions on design drawings. Drawings can vary by +0% - 2% from sizes quoted.

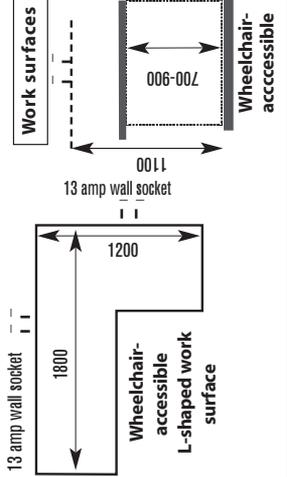
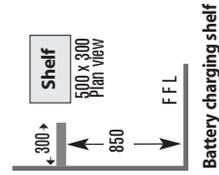
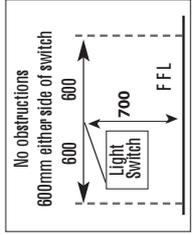


**SCALE - 1:50**

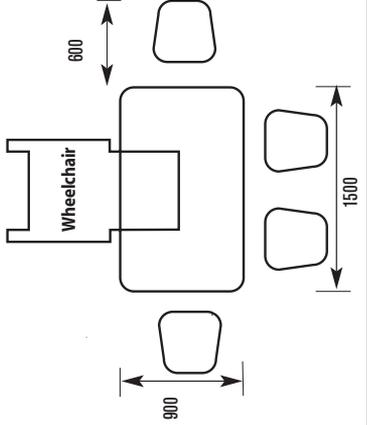
7-11 Prescott Place  
London SW4 6BS  
tel : 020 7720 8055  
fax : 020 7498 0670  
e-mail : info@muscular-dystrophy.org  
www.muscular-dystrophy.org

**Muscular Dystrophy Campaign**

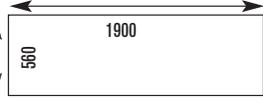
**ELECTRICS**



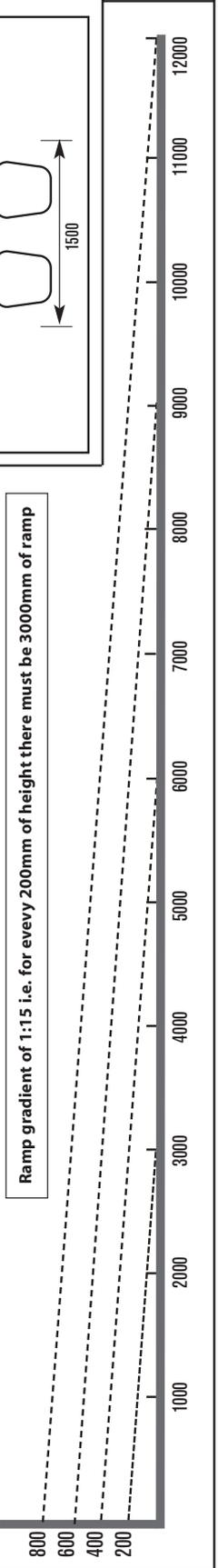
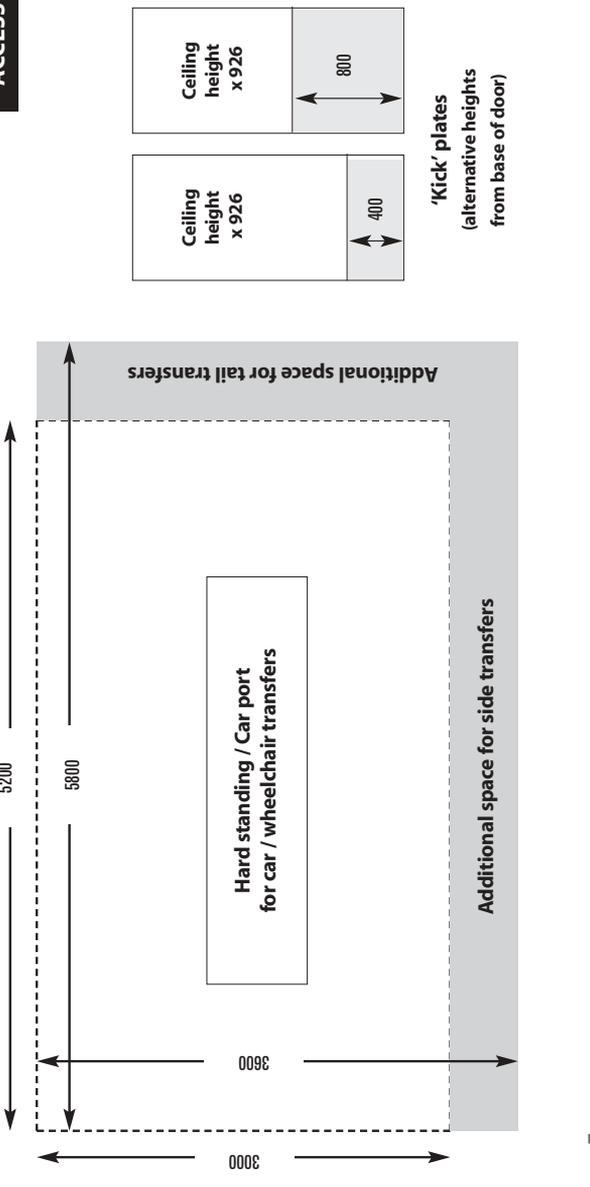
**DINING TABLE & CHAIRS**



**PLINTH**



**ACCESS**



## Items included in template and overlay sheets

It is important in this manual to include a discussion in relation to the size of items which are reproduced in the template **D** and/or overlay sheets **□** as follows:

### Wheelchairs and issues involving their size

#### **D** Size of powered chair

Length: 1250mm

Width: 750mm

#### **□** Space for carers around wheelchair (and hoist)

*(Reproduced with kind permission of Pressalit Care Ltd.)*

##### **1750 x 1750mm**

The size of wheelchair included in the template has been considered carefully. Many children and adults with neuromuscular conditions use a wheelchair, or will need one in the future, and adaptations are always planned with this in mind. The wheelchairs are, almost without exception, powered and the range of chairs available is widening all the time. More chairs are being imported from abroad and particularly from the Scandinavian countries. These chairs and similar British models, have the sophisticated features that are needed (e.g. powered reclining backrests, tilt-in-space seats and elevating legrests). The size of the template is therefore larger than is frequently used in this country, but it is important that no disabled person is placed in the position that they cannot have the most suitable chair in the future, because the size was not taken into account in the planning. The architect employed by *Pressalit Care* in Denmark has considerable experience and of the three templates included in their catalogue, the template used in this manual is the middle size.

#### **D** Wheelchair turning circle

##### **1700mm**

The choice of turning circle is usually either **1500** or **1700mm** and as it relates to the size of the wheelchair it is important to plan for the larger size. This also includes planning for children. There is often the feeling that facilities for young children can be smaller; in fact, the reverse is the case – apart from the fact that it is essential to plan for the future. Young children need space for playing and their wheelchairs frequently have a long base and need as much space as (or more than) an adult chair. However, there are two situations where it may not always be realistic to plan for a turning circle in the room.

##### ■ **Bathroom**

In the bathroom, the alternative will be to use the transfer space at the side of the toilet to reverse the wheelchair while carrying out a three-point turn.

##### ■ **Galley kitchen**

When the kitchen has been adapted, the chair can be turned under the wheelchair-accessible units.

## ▶ Wheelchair through-floor lift (approx. size)

Length: **1500mm**

Width: **1000mm**

The choice of lift must not exclude the largest (see template) and heaviest wheelchairs available (**140kg** + weight of user) without the need to remove or swing away the footrests (which may be impossible for someone with a neuromuscular condition). Therefore, the size of lift included in the template is one of the largest available.

## ☐ Access to lift

**1700mm** turning circle. The area on both floors that must be left free of furniture for turning the wheelchair is approximately the same as the size of the lift.

## Equipment storage

▶ Size of powered wheelchair: **1250 x 750mm**

▶ Transit wheelchair (folded): **1000 x 300mm**

▶ Akron Tilt Table or alternative standing frame: **1550 x 560mm**

Many people who depend upon their wheelchair for all their mobility, have a spare chair for use when their main chair needs repair. Therefore, the storage space must be adequate for:

☐ Two powered wheelchairs (unfolded): **1250 x 750mm each**

☐ Transit wheelchair (folded): **1000 x 300mm**

☐ Akron Tilt Table or standing frame: **1550 x 560mm**

## Shelf in charging area for wheelchair charger

☐ Length: **500mm**

Depth: **300mm**

Bottom of shelf to finished floor level (FFL): **850mm**

## Access

### ☐ Hard standing/car port/wheelchair transfers to/from vehicle

Width: **3600mm** for side transfers

Length: **5800mm** for tail transfers

### ☐ Calculating the length of ramps

In the UK (apart from Northern Ireland) the ramp gradients recommended by Building Regulations changed from **1:12** to **1:15** in 1999. This means that for every **25mm** of step height you need **375mm** of ramp to create a **1:15** gradient (i.e. the step height is multiplied by 15). Conversely, for convenience of calculation a **1000mm** length of ramp will be needed for every **66mm** of step height (or **3000mm** for a height of **200mm**); a ruler recording the latter measurements is included on the overlay sheet.

In Northern Ireland, the gradient is influenced by the length of the ramp i.e.

- under **5m** - **1:12**;
- over **5m** - **1:15**.

## Door sizes and swings

### Existing doors with straight access

Clear opening: **850 – 900mm**

### New building

- Single leaf, standard doors – clear opening: **900mm**
- Single-leaf, double-swing door – clear opening: **900mm**
- Double-leaf, double-swing doors – clear opening: **900mm**

### 'Kick' plates – door-protection panels

- To avoid damage from wheelchair 'kerb climbers': **400mm**
- To cover also the mark left by the wheelchair armrests and/or tray: **800mm**

## Bedroom

**Bed** (approx. size as this depends upon model)

### Need for wide single bed

If a child is likely to be large when he is a young adult, planning should anticipate the need for a wide single bed.

### Need for double bed

Young adults who are having adaptations carried out may wish to plan for the use of a double bed to share with a future partner.

- Single: **1080 x 2155mm**
- Wide single: **1220 x 2155mm**
- Double: **2160 x 2155mm**

### Space around beds

It is important to identify which side of the bed the disabled person prefers to get in and out – or in a double bed which side the person sleeps, as the architectural designer will need to plan the position of the bed with the appropriate side nearer to the bathroom.

- Side of bed (single or double) nearest to bathroom for wheelchair transfers: **1800mm**
- Exposed side of single bed (if head of bed is near a doorway) – to enable bed to be pulled away from the wall for a carer to gain access - without obstructing the doorway: **1000m**
- Space at other side of double bed: **1000m**
- Foot of bed for carer to attend to feet: **700mm**

### Akron Tilt Table (or equivalent equipment)

- Storage space: **1550 x 560mm**
- Adjacent to bed for ceiling hoist transfers, and wheeled to the front of the standing surface: **1900 x 560mm**

- Shelf by bed**  
 Length: **1000mm**. To extend from position of track (i.e. **1020mm** from wall behind bed headboard) to end of bed in front of footboard.  
 Depth: **260mm**  
 Height: under-surface to clear maximum height of bed \***900 – 950mm**

**N.B.** \*The optimum measurement must be checked against the individual model of bed.

- Ceiling hoist over bed**  
 Centre of track to wall behind bed headboard: **1020mm**

- Wardrobe**  
 Width: **1000mm**  
 Front to back: **600mm**

- Chest of drawers**  
 Width: **900mm**  
 Front to back: **500mm**

- L-shaped wheelchair-accessible work surface**  
 L-shape min. length: **1800 x 1200mm**  
 Front to back: **600mm**

- Height range – top of surface to FFL: **700 – 900mm (or 1000mm if the Astor-Bannerman brackets are used)**

**Standing work surface**

- Using *Astor-Bannerman* brackets  
 Width: **800mm**  
 Front to back: **600mm**
- Height range – bottom of surface to FFL: **900 – 1200mm**

- Using *Huntleigh Renray* brackets  
 Width: **600mm**  
 Front to back: **600mm**
- Height range – bottom of surface to FFL: **900 – 1100mm**

**Bathroom**

- Standard bath for use with Mermaid Ranger**  
 Length: **1700mm**  
 Width: **700mm** } exact size depends on bath model
- Space at side for swing of seat: **840mm**  
 Space in front of seat for movement of carer: **700mm** } **1540mm**
- Space for end pillar or movement of carer: **700mm**

- Arjo Sovereign bath**  
 Length: **1670mm**  
 Width: **715mm** } exact size depends on need for end and side panels
- Space at side for swing of integral bath seat: **675mm**

- Space at side for swing of integral bath seat: **675mm**  
Space in front of seat for movement of carer: **700mm** } **1375mm**
- Space at end of bath (side of seat to wall): **700mm**

### **Neatdek (or alternative) shower bases**

(approx. size depending on floor construction)

- ▮ Square min: **1000 x 1000mm**
- ▮ Oblong: **1500 x 850mm**
- ▮ Bath replacement tray (see standard bath for approximate size): **1700 x 750mm**

### ▮ **Height-adjustable washbasin**

Maximum width: **1200mm**

Front to back: **675mm** (at level of wheelchair footrest)

- In front of basin for wheelchair access: ideally **1500mm**, min. **1000mm**

### ▮ **Toilet** (low-level pan with long flush pipe)

- Front to back: minimum of **700mm** to allow wheelchair to be positioned at the side.  
Front of cistern to front of bowl: **600mm**

### ▮ **Shower toilet**

- Front to back: **710mm**  
Width: **500mm**

### ▮ **Toilet and Shower toilet**

- Centre of toilet pan to wall or (nearest obstruction): min. **500mm**
- Exposed side of toilet pan (for sideways wheelchair transfers): min. **900mm**; ideally **1500mm** so that the wheelchair can be angled, if this makes transfer easier.

## **Sitting room and dining room furniture** (approx. size)

### ▮ **Single easy chair**

Width: **1000mm**

Depth: **1000mm**

### ▮ **Two-seater settee**

Width: **1500mm**

Depth: **1000mm**

### ▮ **Three-seater settee**

Width: **2000mm**

Depth: **1000mm**

### **Specialist chairs**

- ▮ Child's supportive easy chair (*Symmetrikit* or similar): **1500 x 550mm**
- ▮ Adult recliner chair – *Ortho-Kinetics*, *BaKare* or *Gordon Medical & Rehab Services*: **1900 x 850mm** (approx.)

**D Coffee table** (approx. size)

Length: **1200mm**

Width: **600mm**

**Dining table with chairs**

**D** Table for six: **1500 x 900mm**

**D** Chairs around table with space to sit down – additional length *and* width: **1200mm**

Table for five – four chairs and a wheelchair: **1500 x 900mm**

Additional space for single chair: **600mm**

Additional space for wheelchair to reverse and turn: **1700mm**

**Kitchen**

**Kitchen units**

**D** Kitchen units standard width: **600mm**

**D** Kitchen units width: **500mm**

**D** Kitchen units width: **400mm**

**D** Depth of all sizes: **600mm**

**D Kitchen appliances** i.e. washers, dishwashers

Width: **600mm**

Depth: **600mm**

**Position and height of light switches**

**All (except by bed)**

Height – bottom of switch to finished floor level (FFL): **700mm**

Space on both sides of switch (to avoid obstruction for wheelchair access adjacent to wall): **600mm**

**By bed**

Height – bottom of switch to FFL: **760mm**

Position: under track (i.e. **1020mm** from the wall behind the bed headboard).

**Position and height of power points**

**By bed**

Head of bed – bottom of plate to FFL: **760mm**

Foot of bed – at skirting board level and marginally under **2155mm** length to ensure that power cords are not a hazard and yet the switch can be reached.

**Over L-shaped work surface**

**Wheelchair-accessible surface:** adjustable between **700 – 900mm (or 1000)** and socket must clear maximum height.

Height – bottom of plate to FFL: **1100mm**

**Standing surface:** adjustable between approx. **900 – 1100mm (or 1200)** and socket must clear maximum height.

Bottom of plate to FFL: **1300mm**

**Sockets:** positioned centrally to length of surface.

## Position of fused spur outlets

Arjo Sovereign bath  
 Body dryer  
 Washbasin  
 Shower toilet  
 Wall-mounted bathroom heater  
 Ceiling hoist  
 Automatic door opener  
 Curtain control

**N.B.** None of the above items is included on the template or overlay sheets. To be checked with individual suppliers.

## Measurement conversion table: metric and imperial measures

The central figures represent either of the two adjacent columns.

Example: 1 centimetre = 0.394 inch and 1 inch = 2.540 centimetres.

### Length

Centimetres		Inches	Metres	Yards	
2.540	<b>1</b>	0.394	0.914	<b>1</b>	1.094
5.080	<b>2</b>	0.787	1.829	<b>2</b>	2.187
7.620	<b>3</b>	1.181	2.743	<b>3</b>	3.281
10.160	<b>4</b>	1.575	3.658	<b>4</b>	4.374
12.700	<b>5</b>	1.969	4.572	<b>5</b>	5.468
15.240	<b>6</b>	2.362	5.486	<b>6</b>	6.562
17.780	<b>7</b>	2.756	6.401	<b>7</b>	7.655
20.320	<b>8</b>	3.150	7.315	<b>8</b>	8.749
22.860	<b>9</b>	3.543	8.230	<b>9</b>	9.843
25.400	<b>10</b>	3.937	9.144	<b>10</b>	10.936
27.940	<b>11</b>	4.331			
30.480	<b>12</b>	4.724			

### Weight

Kilograms		Pounds
0.113	$\frac{1}{4}$	0.551
0.227	$\frac{1}{2}$	1.102
0.454	<b>1</b>	2.205
0.907	<b>2</b>	4.409
1.361	<b>3</b>	6.614
1.814	<b>4</b>	8.819
2.268	<b>5</b>	11.023
2.722	<b>6</b>	13.228
3.175	<b>7</b>	15.432
3.629	<b>8</b>	17.637
4.082	<b>9</b>	19.842
4.536	<b>10</b>	22.046

### Temperature

°C	°F
0	32
5	41
10	50
15	59
20	68
30	86
40	104
50	122
60	140
70	158
80	176
90	194
100	212

°C =  $\frac{5}{9}$  (°F - 32)  
 °F = ( $\frac{9}{5}$  °C) + 32

# Planning & Building Regulations

Arrangements differ within the UK, which will be discussed as follows:

- ⇒ England and Wales;<sup>1</sup>
- ⇒ Scotland;<sup>2</sup>
- ⇒ Northern Ireland.<sup>3</sup>

## England and Wales

The information is divided into the following three sections:

- ⇒ preface;
- ⇒ Planning Consent (Approval);
- ⇒ Building Regulations.

### Preface

Building legislation is under frequent review and these notes should be viewed as a guide only. The architectural designer should be aware of the current situation and be able to advise on systems, procedures and responsibilities.

The best advice is to keep records; any Approval documents may be needed when the property is sold.

### Planning Consent (Approval)

A number of issues are involved, as follows:

- ⇒ the need for Planning Consent (Approval);
- ⇒ contact with neighbours;
- ⇒ the planning application;
- ⇒ application support;
- ⇒ fees;
- ⇒ consultation process;
- ⇒ Approval refusal.

### The need for Planning Consent (Approval)

If it is proposed to build an extension, it is likely that Planning and/or listed building/conservation area Consent (if appropriate) will be required from the Local Authority (LA).

The following are common examples of extension features/proposals that require Planning Consent:

- more than 4 metres high (measured to the ridge if a pitched roof is proposed);
- within 1 metre of a boundary;
- of such a size as to cause a visual impact on the neighbours or the local environment.

## Contact with neighbours

Before commissioning a designer to prepare drawings, it is wise to discuss the proposals with neighbours to assess their reaction. They will be consulted by the LA when the formal application is made and it is usually more effective to contact them informally and note any concerns. Any adverse comments should be made known to the architectural designer who may then be able to avoid any confrontation.

**N.B.** *If the plans are likely to be a contentious issue, it is wise to gain the support of the local councillor (and MP) **before** they have given their allegiance to an objecting neighbour.*

## The planning application

There are two requirements to the application, as follows:

- ⇒ information;
- ⇒ drawings.

### Information

The following will be required:

- full contact details of yourself and your agent (your designer);
- details of the extension (size, use and location);
- details of materials proposed (type, texture and colour);
- details of any trees that will be felled and their location;
- details of proposed foul- and surface-water drainage;
- details of access to the property, both vehicular and pedestrian;
- a declaration that you own (or propose to acquire) the property, or that you have notified the owner.

### Drawings

The following will be required:

- plans, sections and elevations of your proposals (scale 1:100 or 1:50);
- a location plan showing your property in relation to others (scale 1:1250).

Generally, four copies of all documents are required to deposit with the LA.

## Application support

Extensions to domestic properties for people with neuromuscular conditions are often larger than normally encountered by planning officers and applications frequently take longer and require sympathetic negotiation – usually with the assistance of your occupational therapist (OT) – to gain approval.

Your designer will be wise to show the proposed drawings informally to the planning officer to find out if there are likely to be any problems in relation to approval. If concerns are expressed, it is prudent (when the scheme is submitted formally) for the application to be accompanied by letters of strong support from:

- the community OT to confirm that the Social Services Department is actively involved and the needs have been assessed;
- a representative from the Muscular Dystrophy Campaign, stressing the specialist needs for the particular scheme and why other alternatives (usually smaller) would not be satisfactory;
- an explanatory letter from the architectural designer giving reasons why the scheme cannot be altered.

At the same time, contact with the local councillor for the area and other councillors on the Planning Committee (possibly with help from the MP) can help enormously to ensure approval on the grounds of disability, without setting a precedent. It is much easier (and more likely to be successful) to support an application than to try to reverse a decision following refusal.

## Fees

LAs levy fees for assessing Planning Applications and Building Regulations Approval, but these should be waived if it can be clearly demonstrated that the scheme is wholly for the use of a disabled person. Where only part of the plan is for disability needs, the Building Regulation fees may be reduced, but not waived.

## Consultation process

The LA planning officer will assess the information and the impact your proposals will have on neighbouring properties and the visual impact on the area. They will notify your neighbours that you have made a formal application and will give them the opportunity to make an objection to the proposals. Objections will be heard only on planning grounds, such as the proximity to adjacent properties or the size of extension in proportion to the existing house or bungalow. Should the planning officer consider that amendments are necessary, you will be contacted and given the opportunity to change your submission.

## Approval refusal

Once the consultation process has been undertaken, the LA will formally approve or refuse your application. If the application is refused on what you consider to be unreasonable grounds, you have the opportunity to appeal to the Secretary of State for the Environment, but this may be a lengthy process.

## Building Regulations

There are a number of factors to be considered:

- ⇨ whether Building Regulations Approval is needed;
- ⇨ methods of obtaining Building Regulations Approval;
- ⇨ Building Regulations of particular relevance to adaptations;
- ⇨ The *Party Wall Act 1996*.<sup>4</sup>

## Whether Building Regulations Approval is needed

If the proposal is to build an extension or carry out internal adaptations, it is likely that Building Regulations Approval will be required. Building Regulations relate to the structure of buildings, insulation and energy efficiency, connections to the drainage system, access arrangements and the safe use of materials.

The following list, although not exhaustive, gives examples of work that will require Building Regulation Approval:

- construction of extensions;
- removal of internal walls, or other internal structural work;
- installation of additional bathroom facilities;
- alterations or extension to existing drainage systems;

- widening of internal door openings;
- installation of access ramps;
- installation of internal or external vertical lifts.

## Methods of obtaining Building Regulations Approval

There are two methods, as follows:

- ⇒ Full Plans Submission;
- ⇒ Building Notice.

### Full Plans Submission

This method of gaining Building Regulation Approval is self-explanatory and is based on the submission of detailed construction drawings of your proposals, showing construction methods and descriptions of materials used. The drawings are examined by the LA building control officers and any amendments necessary are made prior to construction. The construction must then be carried out strictly in accordance with the approved drawings, with periodic inspections by building control officers to ensure that there is adherence to the approved scheme.

### Building Notice

A Building Notice is a less bureaucratic method of achieving Building Regulations Approval for use where smaller, simpler schemes are being undertaken. By this method the LA is notified formally that work is about to commence, and the building control officers conduct periodic inspections to ensure that construction is being carried out in accordance with the Building Regulations. When using a Building Notice, it is essential to commission an experienced and competent building contractor, and to have the work inspected by your architectural designer to prevent rectification work being necessary, following inspection by the Building Control.

*N.B. Building Regulations Approval does not constitute approval under planning legislation.*

## Building Regulations of particular relevance to adaptations

The designer will be familiar with all the Building Regulations, but there are regulations that may be of particular interest to families and OTs, as follows:

- ⇒ ramped access;
- ⇒ natural ventilation;
- ⇒ daylight;
- ⇒ ventilated lobbies.

### Ramped access

When planning the construction and siting of a ramp, the Building Regulations stipulate that the ramp should have the following features:

- a surface that reduces the risk of slipping;
- flights with surface widths of at least **1200mm** and with unobstructed widths of at least **1000mm**;
- a gradient of not more than **1 in 15**. This regulation was introduced in 1999;
- top and bottom landings, with lengths of not less than **1200mm** each and, if necessary, intermediate landings, with lengths of not less than **1500mm** each, in all cases clear of any door swing;
- a raised kerb at least **100mm** high on any open side of a flight or a landing;
- a continuous suitable handrail on each side of flights and landings, if the length of the ramp exceeds **2000mm**.

### Natural ventilation

When an extension or alterations to existing rooms within a house are planned, the Building Regulations stipulate that:

- **'habitable' rooms** (living rooms and bedrooms, but not kitchen or bathroom) will have rapid ventilation (e.g. opening windows) of **1/20th** of the floor area of the room and background ventilation (through trickle vents in windows of **8000sq mm**;
- **kitchens** need not have an opening window, but must have background ventilation of **4000sq mm** and a mechanical ventilation unit providing extraction at the rate of **30 litres/sec** adjacent to a hob or **60 litres/sec** elsewhere;
- **bathrooms** do not have to have a window that opens, but must have background ventilation of **4000sq mm** and a mechanical ventilation unit providing extraction at the rate of **15 litres/sec** – or passive stack ventilation.

### Daylight

Habitable rooms must have windows with a glazed area equivalent to  $\frac{1}{5}$ <sup>th</sup> of the floor area of the room.

### Ventilated lobbies

The Building Regulations requirement that there should be a ventilated lobby between a kitchen and a bathroom has now been revoked. However, if possible, it is good building practice to provide a lobby.

## The Party Wall Act 1996

If you intend to carry out building work which involves:

- work on an existing wall or structure shared with another property;
- building a free-standing wall or a wall of a building up to or astride the boundary with a neighbouring property;
- excavating near a neighbouring building,

you must establish whether the work falls within the Act, and if it does, arrange for the notification of all affected neighbours and obtain formal consent for the work.

At least 2 months before the planned starting date for work to the party wall, you must serve formal notice, in writing, about what you intend to do. There is no official form for serving notice under the Act, but your notice must include the following details:

- your own name and address;
- the building address (if different from above);
- a clear statement that your notice is a notice under the provisions of the Act;
- full details of what you propose to do including copies of drawings (if appropriate);
- information about when you propose to start the work.

Your neighbour is required to give you formal consent to the work, in writing. This consent should be kept safely with your property deeds. If your neighbour does not give you formal consent, then you are considered to be *'in dispute'* and a third-party surveyor, termed in the Act an *'agreed surveyor'*, is appointed to draw up an *'award'* which allows the work to proceed (or not).

This is a document that:

- sets out the work that will be carried out;
- says when and how the work will be carried out (e.g. not at weekends if the building is a domestic property);
- records the condition of the neighbouring property before the works proceed (so that any damage can be properly attributed and 'made good');
- allows access for the surveyors to inspect the work in progress, to make sure it is in accordance with the award.

Either side has 14 days to appeal to the County Court against an award. Once the award is agreed, it should be lodged with your property deeds.

The fees of the third-party surveyor are to be paid for by the person who wants the work to be carried out, and obviously, the third-party surveyor should not be the person who originally drew up the scheme.

In all cases, as with seeking Planning Consent, it is better to discuss your plans in detail and far enough in advance to enable any problems to be identified before the scheme becomes detailed and expense is incurred.

## Scotland

The information is divided into three sections, as follows:

- ⇒ preface;
- ⇒ Planning Consent (Approval);
- ⇒ Building Warrant.

### Preface

As for England and Wales.

### Planning Consent (Approval)

A number of issues are involved, as follows:

- ⇒ the need for Planning Consent (Approval);
- ⇒ contact with neighbours;
- ⇒ the planning application;
- ⇒ application support, fees and consultation process;
- ⇒ Approval refusal.

### The need for Planning Consent (Approval)

As for England and Wales.

### Contact with neighbours

As for England and Wales.

### The planning application

The information and drawings required vary slightly from one LA to another, but will generally be as for England and Wales with the additional requirement of a *formal* notification of adjoining owners, and occupiers of properties to the rear, side and opposite your house.

**N.B.** *This procedure varies between LAs and should be checked to see if registered mail is required.*

### Application support, fees and consultation process

As for England and Wales, with support from the Social Work Department. The Planning Department will also consult the local Community Council, Transport Department and Historic Scotland (if the building or area is listed).

### Approval Refusal

As for England and Wales, but an appeal would be made to the Scottish Executive.

## Building Warrant

There are a number of factors to be considered:

- ⇒ whether a Building Warrant is needed;
- ⇒ method of obtaining a Building Warrant;
- ⇒ the parts of the Building Warrant that are of particular relevance to adaptations;
- ⇒ The *Party Wall Act 1996*.

### Whether a Building Warrant is needed

As for Building Regulations (England and Wales).

If it is thought that a Building Warrant is not required, obtain a letter from the LA confirming this, and keep it in a safe place, as it may be needed when the property is sold.

### Method of obtaining a Building Warrant

As for England and Wales, but Building Notice procedures are not used in Scotland.

### The parts of the Building Warrant that are of particular relevance to adaptations

The architectural designer will be familiar with all the Building Warrant requirements, but some regulations that may be of particular interest to families and OTs, are as follows:

- ⇒ ramped access;
- ⇒ natural ventilation;
- ⇒ daylight;
- ⇒ ventilated lobbies.

#### Ramped access

The regulations are the same as for England and Wales, with the exception of the following:

- a continuous suitable handrail on the open side of flights and landings, if the drop exceeds **600mm**.

#### Natural ventilation

As for England and Wales, except that when an extension or alterations to existing rooms within a house are planned, the Building Warrant stipulates that:

- 'habitable rooms' (living rooms and bedrooms, but not kitchen or bathroom) will have rapid ventilation (e.g. opening windows) of  $\frac{1}{30}$ <sup>th</sup> of the floor area of the room and background ventilation, through trickle vents in windows, of **8000sq mm**.

#### Daylight

As for England and Wales.

#### Ventilated lobbies

As for England and Wales.

## The Party Wall Act 1996

This Act is only just coming into force in Scotland. Full details are not yet understood, but are likely to be similar to those for England and Wales.

In general, Scotland is in a period of change as the policies of the devolved Parliament come into force. Any notes are likely to be out of date very quickly and therefore the current situation needs checking with the architectural designer.

## Northern Ireland

*The Building Regulations (Northern Ireland) 2000 Part R – Access and facilities for disabled people* applied to all ‘non-domestic’ buildings – and from April 2001 included domestic property.

## References

1. *The Building Regulations 1991*. HMSO, 1991. (Also subsequent amendments.)
2. *The Building Standards (Scotland) Regulations*, 1990. HMSO, 1990. (Also subsequent amendments.)
3. *The Building Regulations (Northern Ireland) 1994 Part R – Access and facilities for disabled people*.
4. *The Party Wall Act 1996*. The Stationery Office, 1996.

# Adaptation Specifications

## for children & adults with muscular dystrophy & allied neuromuscular conditions

### *A guide to the architectural specifications to be considered*

To be used in conjunction with:

Chapter 4	<i>Assessment of Need;</i>
Chapter 8a	<i>Equipment for Adaptations;</i>
Chapter 9	<i>Hoisting;</i>
Chapter 10	<i>Disability Needs Assessment Form/Architectural Brief;</i>
Chapter 14	<i>Scales &amp; Templates/Planning &amp; Building Regulations;</i>
Chapter 18	<i>Addresses: Manufacturers/Suppliers/Sources of Advice.</i>

The following are the issues to be considered:

⇒ Introduction	2
⇒ Lift vs extension	2
⇒ Access	2
⇒ Recommended size of rooms	10
⇒ Use of existing rooms	10
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## Introduction

It is important when planning adaptations for a boy with Duchenne muscular dystrophy (DMD) or for a child or adult with other allied neuromuscular conditions, to understand the disability and to appreciate the long-term physical limitations, as these influence the decisions made and the need for both space and special features. The essential factor to consider is that they will use a wheelchair (usually powered which is less manoeuvrable than a self-propelled wheelchair and therefore requires additional space) and that although they will retain functional use of their hands, the grip and strength will be considerably reduced. Also they will not be able to reach or raise their arms and are likely to lack balance when sitting.

Most of the information in this chapter is relevant to both children and adults, irrespective of the disability, but some items may apply to *either* children *or* adults.

## Lift vs extension

The key issue is to decide the best way to provide wheelchair-accessible, en-suite bedroom and bathroom facilities. This may involve making a choice between a lift and ground-floor extension; a separate chapter, *Lift vs Extension*, has been prepared to help with this decision.

### Lift

The most suitable position on both the ground floor and the first floor will be from the hall to the landing above. However, in many houses it is more likely that sufficient space will be available only from the sitting room or dining room to one of the bedrooms. If this is the case, it must be ensured that this is not at the expense of sufficient space in the room for both the necessary facilities and the circulation of a wheelchair. Allow for a large-enough lift (for a future large, heavy powered wheelchair) and adequate space to access the lift. See Chapter 14 *Scales and Templates*, page 7.

## Access

The issues to be considered are:

- ⇒ the pavement crossing;
- ⇒ the safety of car/wheelchair transfers;
- ⇒ access and movement around the perimeter of the house and patio/paved area;
- ⇒ independent access in and out of the house;
- ⇒ independent access through internal doors.

### Pavement crossing

A dropped kerb will be required for wheelchair use. Application should be made to the Highways Department of the Local Authority. If a charge is made, the grants officer should be approached to see if this cost could be included in the Disabled Facilities Grant (DFG) or Improvement Grant. See Chapter 12 *Funding*.

## The safety of car/wheelchair transfers

The choice is between the following:

- ⇒ hard-standing area;
- ⇒ carport;
- ⇒ garage.

### Hard-standing area

A hard-standing area adjacent to the house is essential to allow the manoeuvre of transferring between wheelchair and a car to be carried out in safety.

- **Width: 3200 – 3600mm** for a wheelchair to be positioned at the side of the car.
- **Length:** Approximately **5200mm** to enable a wheelchair to pass around the back of the car to access the house or garden, with an additional **600mm** for tail transfers from a van using a ramp or hydraulic platform.

### Carport

Ideally, but not always possible, the hard standing should be under cover.

- **Height:** In addition to the length and width, as above, height should be considered if a large van is used. This should have a clearance of **2800mm**, but could be lower for a smaller vehicle.

### Garage

In a 'new build' scheme, the ultimate provision is an integral garage, with a level-access door to the house. The garage should be wide enough for side and/or tail van-to-wheelchair transfers and should incorporate a storage area.

## Access and movement around the perimeter of the house and patio/paved area

### Around perimeter of house

Where possible, it is advisable to maintain external access down at least one side of the house for the wheelchair user, in addition to transfer of lawn mowers, ladders, dustbins etc. from the back to the front of the house. This should be a minimum of **900mm** wide, measured from the drainpipes or the outside edge of the drains and not from the house wall.

### Patio/paved area

A paved area in the garden is essential for the use of an electric wheelchair, particularly when the lawns are wet and muddy. Ideally, French windows or a glazed door from the sitting room or a ground-floor bedroom extension should open out on to this area, which can be used to create an attractive feature to the house with potted plants or raised beds.

An additional bonus may be that container gardening will provide a suitable hobby for someone in a wheelchair who is interested in gardening. Anyone with arm weakness needs to work at the correct height, with the length of the wheelchair parallel to the raised bed or ceramic pot. Lightweight tools are easier to use if the bed is lower than the wheelchair armrests, but if the soil is too low the tools need to be long and become unwieldy. An ideal height will be approximately **600mm**.

## Independent access in and out of the house

This may involve the following:

- ⇒ adaptation of existing steps;
- ⇒ provision of ramp;
- ⇒ installation of short-rise lift/Steplift;
- ⇒ provision of portable ramps;
- ⇒ ensuring that external door(s) are suitable.

### Adaptation of existing steps

If the disabled person is able to walk and is unlikely to need a wheelchair in the immediate future, it may be helpful to create shallow steps, and the height and depth will need to be assessed. If the person walks *and* uses a wheelchair, complementary provision of steps and a ramp will be necessary.

### Hand rails for steps

The height will be critical for anyone with limited arm strength and this will depend upon the user's height. The standard height range of **900 – 1000mm**, with an outside rail diameter of **50mm**, should be assessed individually.

### Provision of ramp

The features in relation to ramps are as follows:

- ⇒ gradient;
- ⇒ hand rails;
- ⇒ safety flange;
- ⇒ platform;
- ⇒ surface.

### Gradient

A gradient of **1:15** is satisfactory, as most people with a neuromuscular condition who use a wheelchair will have insufficient strength to propel a wheelchair up any slope and are likely to be using a powered chair.

However, if the person is able to walk, in common with many people with a neuromuscular condition, they may find it difficult to walk up a ramp.

A gradient of **1:15** may be too steep and **1:20** may be easier, but this must be assessed before a decision is made because the alternative of shallow steps may be preferable.

### Hand rails

Hand rails are useful for people who are able to walk, but are not needed by powered wheelchair users. However, they may be essential to satisfy Building Regulations where the length of the ramp is over **2000mm**.

### Safety flange

For wheelchair users, a side upstand of **100mm** is essential for safety on the open sides of ramps or landings. An earth-filled cavity at the top of the wall, with trailing plants, makes attractive camouflage for a high ramp.

### Platform

A level area at the top of the ramp must extend forwards **1200mm** from the face of the door to allow the wheelchair to be positioned safely on a level surface while the door is opened or closed. The measurement is critical to allow the chair to move beyond the leaf of the open door and, if necessary, to provide sufficient space to turn the chair through **90°**, before moving down the slope. The ramp should be **1200mm** wide.

### Surface

For safety in icy conditions, the surface must be non-slip. This should be achieved without the surface being so rough that the person is shaken in their wheelchair. The ease of cleaning may also be a factor to be considered.

### Installation of short-rise lift/Steplift

In some situations, there is insufficient space for the length of ramp needed to provide the correct gradient. In these cases a short-rise lift or *Terry* Steplift may be the solution and they consist of a powered platform, which rises vertically. These lifts can be used to overcome a steep access from the pavement to the level of the accessible door, or to provide access into the house where there are a number of steps. It is important to ensure that the maximum lifting capacity of the model chosen, is adequate for the combined weight of the user and any heavy powered wheelchair (which could weigh **140kg**) that may be used in the future.

### Provision of portable ramps

These are not a satisfactory solution on a long-term basis, as they will not provide independence; however, they may solve an immediate problem of access in and out of a house, particularly to a terraced house which fronts directly on to the pavement. Ramp design has improved greatly in the last few years and semi-permanent ramps can be made to measure; portable ramps are easy to fold and are available in lightweight material which is comfortable to handle and easy to lift and place in position (see Chapter 8a *Equipment for Adaptations*, page 2).

### Ensuring that external door(s) are suitable

The issues to be checked are the:

- ⇨ width;
- ⇨ threshold;
- ⇨ French windows vs sliding patio doors;
- ⇨ need for a fire escape;
- ⇨ need for an automatic door opener.

### Width

Although ideally, doors should have a clear opening of **900mm**, external doors do not always need to be widened if access through them is straight and does not involve a tight turn.

### Threshold

Raised threshold sills (including steel weather bars) will prevent access in a powered wheelchair, as the front castors will not rise over a vertical obstruction. This is particularly true of uPVC doors, which have become very popular.

- **Wintun RX100** is a compression threshold, where the gently curved metal threshold incorporates a central rubber projection that is depressed by a wheelchair, and is very satisfactory for both manual and powered chairs.

*Wintun Ltd*

- **A uPVC door** can be installed with a level access by sinking the frame into concrete to maintain its integrity and strength, but without a vertical seal at the base it may not be guaranteed weatherproof. It may be possible for this to be overcome by the installation of an open porch.

### **French window vs sliding patio doors**

It is usually easier to provide level access with a glazed door (with adjacent window) than with sliding patio doors. Conventionally, French windows open outwards, particularly where space within the room is limited; however, the prevailing winds, the method of fastening the door/s when open and the need for an automatic door opener should be considered.

### **Need for a fire escape**

It will be essential to provide French windows or a glazed door (with adjacent window) in a ground-floor bedroom if escaping from a fire would otherwise involve passing the kitchen, which is often the seat of the fire.

### **Need for an automatic door opener**

There are two types of automatic door openers, infra-red and radio-controlled which operate on both conventional-opening doors and sliding doors. However, many are produced for commercial use and are particularly expensive and the models available for a domestic situation are limited. The models and the need are discussed in Chapter 8a *Equipment for Adaptations*.

For security, uPVC doors are fitted with multi-point locking. However, facilities are available for an automatic door opener to incorporate a self-relocking lock.

*Ridley Electronics Ltd*

*RSL Steeper Ltd*

*Southern Care Systems Ltd*

## **Independent access through internal doors**

The issues to be considered are:

- ⇒ width of the clear opening;
- ⇒ type of door.

### **Width of the clear opening**

Narrow hallways and difficult access problems will influence the need for wide doors. However, in most cases where the existing access does not involve a 90° turn, a clear opening (i.e. from the face of the door to the door jamb the other side) of between **850 – 900mm** will be satisfactory. If new building is planned, **926mm** doors are recommended. This will involve either using blank doors cut to size, having doors made to measure, or widening standard doors.

## Type of door

There are three types:

- ⇒ conventional-opening doors;
- ⇒ double-swing doors;
- ⇒ sliding doors.

### Conventional-opening doors

If the person is unable to reach with their arms, although standard doors can be closed with the weight of a wheelchair, opening the door will be difficult or impossible; leaving doors open limits privacy. Eventually, the only way that people with a neuromuscular condition will be able to open doors independently is by using double-swing doors or an automatic door opener.

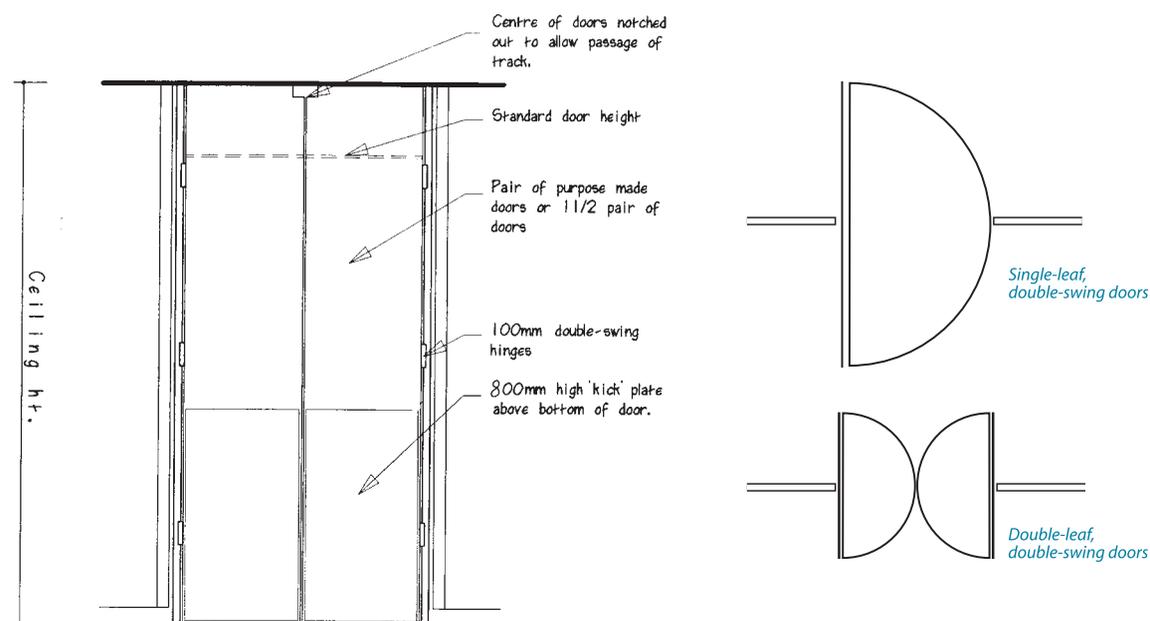
### Double-swing doors

These move through  $180^\circ$  pushed with the footrests of the wheelchair. In relation to these doors, a number of decisions must be made:

- ⇒ choice between single-leaf or double-leaf doors;
- ⇒ which doors to alter;
- ⇒ door material and hinges;
- ⇒ safety issues;
- ⇒ the need for door-protection 'kick' plates.

#### • Choice between single-leaf and double-leaf doors

- **Single leaf.** Usually the first choice for a bedroom, as a single door will provide greater privacy and draught exclusion; however, there may be circumstances where one leaf swinging either into or out of the room takes up too much space.
- **Double leaf.** An alternative to be used where an extended ceiling track has to pass through the opening between a bedroom and bathroom, for example, or where space is limited and it would be an advantage for the size of the door leaf to be reduced.



- **Which doors to alter**

Parents of a disabled child may decide it is adequate to install swing doors on the child's bedroom and bathroom only, but often adults who use a wheelchair choose to have all their doors altered.

- **Door material and hinges**

- **Material.** The weight of the door is crucial to ensure that it is not too heavy to be pushed by a wheelchair and a ply-faced (for painting) flush, internal door with door-protection plates is recommended – for use with the hinges below.

- **Hinges. Liobex 100mm double-action spring hinges** are recommended. It is important that the weight of the door is suitable for this size, because if the door is too heavy and **150mm** hinges are needed, it may be impossible for the door to be opened with a wheelchair.

To install Liobex hinges correctly it is necessary to have or fix a plant down on the hanging frame. Ideally the width of the plant should be the same dimension as the thickness of the door. The thickness of the plant should be sufficient to allow the hinge cylinders to rotate freely after the lipped face has been morticed in. The other lipped face should be morticed into the door, ensuring that both cylinders are free to rotate and that standard door/plant clearance is maintained.

The capstan should be fitted at the top on the plant, and at the bottom on the door. This configuration will ensure optimum efficiency and minimum wear.

Normal installation should be **250mm** from the top and bottom of the door, but because the doors are ceiling height a third hinge should be fitted. Take care to ensure the centre line of the hinges is aligned.

Normal operation of the hinge is achieved by tightening both capstans on each hinge and inserting the pins provided. Normally the top hinges will not require more than three holes, and the bottom hinge two holes. It is important that the capstans are not overtightened. Liobex hinges are lubricated before despatch, but should be lubricated regularly to maintain trouble-free operation.

*D & E Architectural Hardware Ltd*



*Liobex  
100mm hinges*

- **Double-action pivot set hinges** allow the door to swing through **180°** and are easy to push, but because they are not spring loaded the door does not close automatically. For this reason, they may be a better choice for adults who are still able to walk, but are unsteady on their feet.

However, if they are in a wheelchair and there is insufficient space to get the chair behind the door to close it with the footrests, they would need to be able to reach with their arms.

*D & E Architectural Hardware Ltd*

- **Safety issues**
  - **Viewing panel.** Although in the past it was considered to be a wise precaution to install a glass panel, with hindsight these are not felt to be necessary as the person's movements can be anticipated by the sound of the chair motor – and a glass panel has the disadvantage of reducing privacy.
  - **Vulnerable children and adults.** If adaptations are carried out while the child or adult is still able to walk and they are unsteady on their feet or are likely to be unsteady in the future, swing doors will be a potential hazard. At this stage the door can be wedged open; however, care must be taken if there are younger children either living in the home or visiting regularly.

- **The need for door-protection 'kick' plates**

These are not always considered necessary on all doors and some may prefer the alternative of repainting their doors regularly. However, 'kick' plates are recommended to protect the door where it is opened by the weight of a wheelchair. They should be fitted at the bottom of the doors, on both sides.

- **Size/height.** The height from the bottom of the door to the top of the plate should be either **400mm** to avoid damage from the side 'kerb climbers' on the wheelchair, or **800mm**, to cover also the mark left by the wheelchair armrests and/or tray.
- **Material.** Yeoman Shield textured door-protection plates are manufactured in impact-resistant uPVC, and are easily fixed using double-sided adhesive tape. 34 colours are available and will be more acceptable than metal plates, which may have dangerous sharp edges and which tend to look institutional. (In the past, Perspex was recommended, but it has proved unsatisfactory as it cracks. The additional disadvantage of Perspex is that it preserves the colour of the paint and as the colour of the exposed part of the door changes, the result is a two-tone door.)

*Harrison Thompson & Co Ltd*

### **Sliding doors/need for automatic door opener**

There are situations where there is insufficient space to install double-swing doors and architectural designers want to use sliding doors. Considerable arm strength, and the ability to reach when using a wheelchair, are needed to open a sliding door and this type of door therefore, is unsuitable for anyone with a neuromuscular condition unless fitted with an automatic door opener. However, it must be ensured that the runners do not impede wheelchair access and are compatible with ceiling track hoists. The weight of the door may affect the soundproofing.

*Ridley Electronics Ltd*

## Recommended size of rooms

Questions are frequently asked in relation to the optimum size of the rooms. These are difficult to answer without knowing the ease of access to the rooms, the shape of the rooms, the number and size of windows, and how an extension (if one is to be built), will dovetail on to the existing house. Instead, it is more constructive for the architectural designer to be given an accurate brief early in the process; when the essential features and space dimensions have been considered, these will determine the size of the rooms, (see Chapter 14 *Scales & Templates*). The size of the bathroom and the bedroom are discussed in the relevant sections in this chapter.

## Use of existing rooms

In planning adaptations, the suggestion is often made that an existing room should be used to provide new facilities for the disabled person. The rooms frequently targeted are the dining room, spare bedroom and temple or prayer room. The viability will depend on the present use and need for the room - and reference should be made to the discussion in Chapter 4 *Assessment of Need*.

## Bathroom

The following will need to be discussed:

- ⇒ en-suite facilities;
- ⇒ bathroom size;
- ⇒ bath;
- ⇒ level-access shower;
- ⇒ toilet;
- ⇒ rails;
- ⇒ washbasin;
- ⇒ flooring;
- ⇒ colour scheme.

### En-suite facilities

The bathroom must be en suite with the bedroom to allow the option of using an extended track either immediately or in the future. Also, it enables the person to transfer within the privacy and warmth of the two rooms. Severe disability can result in great loss of dignity and it is important that this is prevented.

### Bathroom size

This will depend on the following:

- the fittings necessary;
- space needed around the fittings;
- space needed by carers;
- the circulation of the wheelchair.

These issues are included in Chapter 14 *Scales & Templates*.

The bathroom is considered before the bedroom, because in the bathroom, five major decisions must be made *before* the architect receives his brief:

- choice between a bath (with a shower over) and a level-access shower (the factors to be considered are in Chapter 7 *Bath vs Shower*);
- the degree of support needed in the bath or shower;
- the appropriate method of getting in and out of the bath or shower, either independently or with help;
- transfer between the bedroom and bathroom;
- the possible need for an extended track from the bathroom to over the bed, either in the short or long term, because of existing or anticipated difficulty, getting in and out of bed.

The assessment and options available are discussed in Chapter 4 *Assessment of Need* and Chapter 8a *Equipment for Adaptations*.

## Bath

There are two issues to be considered:

- ⇒ the bathing options;
- ⇒ the need for a shower over the bath.

### Bathing options

There are three recommended bathing alternatives to a shower, which should be considered before a decision is made.

- ⇒ Bath with a *Sunrise Medical Mermaid Ranger* or an *ASM Multi-System*;
- ⇒ *Arjo Sovereign/Solo* baths;
- ⇒ *Kingkraft Easibath Hi-Lift/Contour* bath.

### Bath with a *Sunrise Medical Mermaid Ranger* or an *ASM Multi-System*;

Both are used with a mast mounted at the side (or end) of a standard bath in conjunction with a mobile chassis; however, in the case of the Multi-System, there is the alternative of using it with a ceiling hoist.

The following will need to be considered in relation to the choice of bath.

- **Acrylic vs steel**  
Acrylic baths retain the heat better than metal baths and are warmer to the touch. However, the quality is important because if the acrylic is too thin it will crack and will not be resistant enough to withstand an occasional knock. Choice is important and families may prefer a steel bath.
- **Shape of bath**  
The back of the bath must not be excessively sloped as this obstructs the bath seat and means that the Mermaid Ranger mast will need to be installed nearer to the taps, thereby reducing the space in front of the seat and restricting the leg room.
- **Length**  
It is essential that the bath is a **1700mm** model to allow sufficient length for the Mermaid Ranger seat with the bather's legs extended – or the Multi-System.

- **Hand grips**  
Many helpers find hand grips useful, although they may obstruct bath seats that straddle the rim of the bath.
- **Recommended models**
  - **Steel:** *Twyfords* New Luna (with optional slip-resistant surface and hand grips).
  - **Acrylic:** any model where the shape is as above.

### **Arjo Sovereign/Solo baths**

These specialist baths are used with an extended track between the bedroom and bathroom. The baths and the tap options are discussed in Chapter 8a *Equipment for Adaptations*.

*Arjo Ltd*

### **Kingkraft Easibath Hi-Lift/Contour bath**

These baths should be considered for a small, totally-dependent child. See Chapter 8a *Equipment for Adaptations*.

*Kingkraft Ltd*

## **The need for a shower over the bath**

All the alternatives should include a shower over the bath (or with an extended hose from the taps) and the need is discussed in Chapter 8a *Equipment for Adaptations*.

### **Used with Mermaid Ranger**

The shower should be wall-mounted at the *end* of the bath *opposite* the taps because this is easy for a carer to reach. If there is a space to enable a helper to move around the end of the bath to control the shower or lift off the shower head which is wall-mounted at the *side* of the bath, this will be equally satisfactory if the shower head is hand held and not used fixed to the wall. The alternative of having to lean across the width of the bath will be difficult for a helper and it will be impossible to contain the spray of water when the shower is used in the conventional way by others standing in the bath.

### **Used with Arjo Sovereign/Solo baths**

The entire *Arjo* tap options for the Sovereign and Solo baths incorporate a shower. Alternatively, the baths can be used with a wall-mounted shower – or mixer bath taps with an integral shower head on a long hose. However, the last option will not be thermostatically controlled.

### **Used with Kingkraft Easibath Hi-Lift/Contour bath**

These baths incorporate a shower.

## **Level-access shower**

There are a number of options to be considered:

- ⇒ sloped floor;
- ⇒ tray;
- ⇒ Neatdek;
- ⇒ shower screen or curtain;
- ⇒ shower seat/chair;
- ⇒ shower rails.

## Sloped floor

A slope to a corner drain is usually thought to contain the water more satisfactorily than a slope to a central drain. The gradient must be minimal to allow a disabled person with arm weakness to propel the shower chair up the slope and it is essential to ensure that the contractor is competent to lay the floor satisfactorily.

## Tray

A shower must have level access (without a deep tray), although shallow trays designed to be used in conjunction with shower chairs are satisfactory provided that the access is level. These may be essential in an upstairs installation where there is limited floor depth, or may be recommended where it is vital to contain the water within a very confined area. If the shower area is to be surrounded by carpet it may be advisable to install a single course of tiles around the shower tray. Shower trays are discussed in more detail in Chapter 8a *Equipment for Adaptations*.

*Autumn Mobility Ltd  
Creative Healthcare Ltd  
Go Independent*

## Neatdek

The Neatdek is particularly recommended because it has the advantage over a sloped tiled floor and most shower trays, in that it is absolutely level, making it easier to use a self-propelled shower chair, and provides a stable surface for a wheelchair positioned in the shower area. This will be particularly important if the shower area is adjacent to the toilet and doubles up as the transfer space at the side of the pan.

*Go Independent*

## Shower screen or curtain

The difficulty in retaining water within the shower area and for a carer to stay dry, can be overcome by the use of half-height shower doors, either standard or made to measure, and either portable or wall mounted. However, these are more suitable for anyone who is independent in the shower, as it can be difficult for a helper to lean over the top of the screen. Where a helper is involved, a drop-down rail that incorporates a shower curtain may allow them to get closer to the person needing help to wash.

*Autumn Mobility Ltd  
Go Independent  
Pressalit Care Ltd*

## Shower seat/chair

The recommended models are discussed in Chapter 8a *Equipment for Adaptations*.

## Shower rails

Shower rails can be either:

- ⇒ fixed height;
- ⇒ variable height.

## Fixed height

These are suitable when the disability needs are not progressive and easily identified or where help is not always at hand to adjust the equipment. A continuous hand rail will help anyone who is unsteady on their feet to walk safely from the shower or around the bathroom.

## Variable height

These are more suitable when the height of the rail will need to be changed in the future.

## Toilet

There is a need to consider:

- ⇒ position;
- ⇒ type.

## Position

Centre of the pan to the nearest obstruction (including floor-level pipes) at the wall side should be **500mm**.

**N.B.** *A side-entry soil pipe may obstruct a superimposed chair used for support.*

There must be a minimum of **900mm** on the exposed side of the toilet, to allow space for wheelchair transfers. If the user transfers with the wheelchair at an angle of **45°** to the pan, **1500mm** will be preferable to accommodate the length of the chair and allow space for manoeuvring into position. This space will also allow the wheelchair to be reversed to turn to go out of the room.

## Type

The choice is between:

- ⇒ close-coupled toilet;
- ⇒ low-level pan with long flush pipe;
- ⇒ shower toilet.

### Close-coupled toilet

The pan must not be close-coupled, as this will not allow a Mermaid Ranger on its chassis – or some models of shower chair depending on their size and shape, to be aligned directly over the pan with the lid and seat raised.

### Low-level pan with long flush pipe

This type of pan which has a standard-height pedestal is essential for use with a superimposed Mermaid Ranger or toilet/shower chair because the flush pipe can be lengthened to ensure that the seat of the chair lines up correctly with the pan below. The measurement between the front of the cistern and the front of the bowl must be **600mm**.

The most suitable method of ensuring that the flush pipe is the correct length is to ask the Mermaid Ranger supplier to have a chair in the house when the plumber is ready to install the pan.

*Twyford Classic (or equivalent)*

### Shower toilet

This is equipment previously known as a combined toilet and wash/dry bidet. It should be used with a ceiling hoist rather than a superimposed Mermaid Ranger or shower chair, as the user's bottom forms a seal on the seat and the washing and drying action is more satisfactory than if there is a gap. To ensure flexibility in the seating position of the user, the ceiling hoist track should run front-to-back over the pan, rather than from side-to-side, unless a side transfer is used.

- **Clos-o-Mat**

A decision will have to be made whether a plinth (available in **25, 50, 75** and **100mm** heights) will be required; a super-sensitive switch must be supplied.

*Total Hygiene Ltd*

- **Geberit**

This is an alternative model and further details are included in Chapter 8a *Equipment for Adaptations*.

*ESL Healthcare Ltd*

## Rails

For rails to be useful for anyone with arm weakness they must be at the correct height, in the optimum position, and capable of being raised out of the way when access is needed. Also, they must extend beyond the front of the pan, so that when rising, users have their hands in front of them. The ideal solution is the *Pressalit* support arms on horizontal and vertical brackets, so that their position at the side of the user and their height can be adjusted as necessary.

## Washbasin

- ⇒ recommended models;
- ⇒ taps;
- ⇒ electric shaver point.

### Recommended models

There are two recommended washbasins, both of which were designed for people with muscular dystrophy:

- ABW4/ABW4SP from *Astor-Bannerman (Medical) Ltd*. N.B. The mirror makes it unsuitable to position these washbasins in front of a window.
- Spectra from *Southern Care Systems Ltd*.

See further details and comparative chart in Chapter 8a *Equipment for Adaptations*.

## Taps

### **Astor-Bannerman / Southern Care Systems**

There is a choice between:

- manually-operated taps;
- touch-sensitive switches on a handset; or
- infrared controls installed within reach, on the basin surface in the optimum position for the user. See Chapter 8a, page 20.

### **Lever taps only**

These are recommended for a family bathroom if the parents do not want electronic taps installed. It is important that the tap chosen has a lever of at least **150mm** and is a low tap so that the user does not need to reach up. The tap length is unlikely to be sufficient to allow hands to be washed under the outlet by anyone unable to reach, and these taps will not be suitable for independent use by a boy with DMD. Two taps are likely to be more satisfactory than a single tap in the centre of the basin, as this may be in the way if the user leans forward.

## Electric shaver point

It is essential for a shaver socket to be accessible to the washbasin to enable convenient recharging of an electric toothbrush and to allow the use of a mains electric shaver. See Chapter 8a *Equipment for Adaptations*, page 21.

## Flooring

This is discussed on page 22.

## Colour scheme

Work carried out within the grants system will include a sum to cover a basic range of tiles. It is important that the applicant or their family should be given the opportunity to choose the colour scheme for the fittings and wall tiles and, where necessary, to pay the balance between the cost of the basic range and their preferred range.

## Bedroom

The issues to be considered are:

- ⇒ en-suite facilities;
- ⇒ bedroom size;
- ⇒ ceiling hoist.

## En-suite facilities

It is important that the bedroom is en suite with the bathroom to allow the option of being undressed on the bed and transferred with the ceiling hoist over the bed to either:

- a shower chair, Mermaid Ranger or ASM Multi-System, (the choice is discussed in Chapter 8a *Equipment for Adaptations*) and wheeled into the bathroom in privacy and within the warmth of the two rooms – or
- the bath and/or toilet on an extended track. See Chapter 9 *Hoisting*.

## Bedroom size

It is difficult to be precise about the recommended minimum size of a bedroom. In addition to the shape of the room, access, the number and size of the windows and doors, this will be affected by the specialist needs. The most satisfactory solution is to ensure that the architectural designer is aware of the equipment and space required, and will subsequently design a room of appropriate size.

The detailed space implications are related to the following:

- ⇒ circulation space for a powered wheelchair;
- ⇒ French Windows;
- ⇒ door to bathroom;
- ⇒ bed;
- ⇒ standard storage units;
- ⇒ work/equipment surface.

## Circulation space for a powered wheelchair

The maximum width of the average chair is **750mm**, the length, **1250mm**, and the diameter of the full turning circle should be **1700mm**.

## French Windows

French windows or an external glazed door may be needed to provide access into the house, access to and from the garden or as a fire escape. This may be essential where an extension is built near to the kitchen, which is likely to be the seat of the fire.

## Door to bathroom

This must be large, for a clear opening of **900mm** to be suitable for the use of a wheelchair – and an extended track to the ceiling hoist, installed either immediately or in the future.

## Bed

This is likely to be a specialist bed and the following will need to be considered:

- ⇒ type;
- ⇒ size;
- ⇒ position;
- ⇒ space around the bed.

## Type

An electric bed is likely to be needed when the person can no longer stand up from the edge of the bed or sit up independently. See Chapter 8c *Electric Beds*.

## Size

- **Length:** All the recommended models are approximately **2155mm** in length
- **Width:**
  - Single: **1080mm**
  - Wide single: **1220mm**
  - Double: **2160mm**

## Position

- A bed with the headboard in the centre of a wall will provide access on both sides (which is essential for a double bed for two people) but will restrict the wheelchair circulation in the bedroom.
- A single bed adjacent to a wall has the added advantage that the person can reach a wall-mounted light switch (see page 24 for installation position). A pull switch is likely to be both difficult to reach and to pull with sufficient strength to switch it on or off. However, there should be sufficient space at the side of the bed, to allow the bed to be pulled **1000mm** away from the wall, if/when access is needed for a carer on both sides.
- Ideally, the bed should be positioned so that the occupant can look out of the window when sitting up in bed.

### Space around the bed

- **Side of bed for disabled user: 1800mm**, which is sufficient space for two adjacent wheelchairs to be positioned in order to use a ceiling hoist to transfer from one to another. It must be ensured that if the head of the bed is near to the bathroom door, that there is **1000mm** between the edge of the bed and the door frame to allow access on both sides of the bed (as discussed on previous page) without obstructing the doorway.
- **Side of double bed for partner:** Minimum of **1000mm**.
- **Foot of bed: 700mm** for a carer to move with ease and to be able to attend to the person's feet.

### Standard storage units

**Wardrobe:** Min. 1000 x 600mm

**Chest of drawers:** 900 x 500mm

### Work/equipment surface

The following need to be considered:

- ⇒ medical importance;
- ⇒ layout;
- ⇒ drawers;
- ⇒ shape;
- ⇒ depth;
- ⇒ length;
- ⇒ height adjustment;
- ⇒ position;
- ⇒ typical layout.

### Medical importance

The need will be of greater concern to the OT than the architectural designer and therefore this has been covered in Chapter 8a *Equipment for Adaptations*. See also Chapter 11h *Justification of Working Surfaces*.

### Layout

If standing is possible, there should be two separate surfaces for use either when in a wheelchair or when standing. Ideally, these should be adjacent so that if the 'standing' surface is no longer needed, it can be lowered (provided that this is not hampered by the height of the drawer unit), to lengthen the wheelchair-accessible surface.

### Drawers

It is also essential to supply a storage unit, to be positioned under the standing surface. The recommended unit is made up of three drawers below a 'pull-out' surface, and these may be suitable for independent use because the drawers glide on runners. The pull-out shelf is useful for reference books when working at the adjacent surface.

### Shape

For the lower surface, the aim should be to provide an L-shape so that, when the child or adult cannot lift up their arms, the computer keyboard can be placed across the right-angle with the adjacent surfaces used to support their forearms. The monitor can then be placed in the corner using the otherwise inaccessible surface and allowing sufficient space between the keyboard and screen.

## Depth

The front-to-back measurement of the surface must be **600mm** to allow sufficient depth underneath for the length of the wheelchair, including footrests.

## Length

The length will be determined by the space available, but ideally should be a minimum of: **1800 x 1200mm** for the L-shaped sitting surface and (depending upon the brackets used), either **600 or 800mm** for the standing surface.

## Height adjustment

A height-adjustable system is important to allow the person to work at the optimum height and which can be altered when sitting in different wheelchairs or (in the case of children) with growth.

Decisions will need to be made in relation to the following:

- ⇒ height;
- ⇒ brackets.

- **Height**

The brackets should be positioned on the wall to allow the surface to be adjusted for:

- **wheelchair access: 700 – 900mm;**
- **standing: 900 – 1100mm.**

- **Brackets**

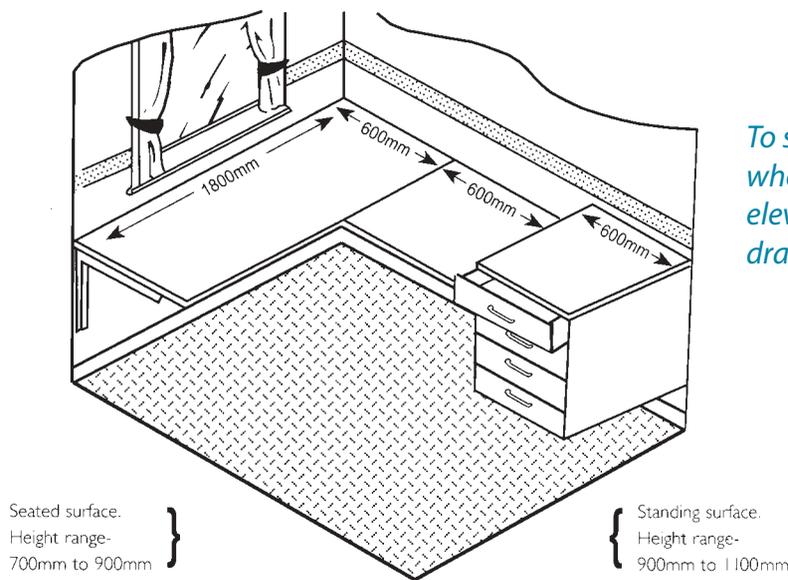
There are two options:

- **Huntleigh Renray.** These units are recommended as the wall rail and brackets are strong and well constructed and allow the height to be altered in 10 stages of **20mm**. The brackets fit behind the drawer unit. The firm will supply the complete package including a drawer unit and a melamine worktop, and in many schemes this may be easier to organise. Alternatively, **40mm** worktop can be bought locally to avoid carriage costs. As the child grows, if the height needs to be adjusted by more than **190mm**, the bracket position can be raised.
- **Astor-Bannerman.** This firm supplies brackets that allow infinite adjustment within the limit of **300mm**. Because they fit at the side (not behind) the drawers, and are **100mm** wide, an additional **200mm** width must be added to the length of the superimposed worktop.
  - A drawer unit can be obtained from: *Independence Kitchens* or *MFI/DIY* stores.
  - a **40mm** surface can be obtained from: *MFI/DIY* stores (at the same time as the drawer unit); or with the brackets direct from *Astor-Bannerman*.

## Position

Ideally, the lower surface should be positioned in front of a window and in this case, if necessary, the maximum height of the surface can be lowered to **800mm** from the top of the surface to the floor.

## Typical layout



To show layout of L-shaped wheelchair-accessible surface and elevated standing surface with drawer unit

*The illustration is reproduced with kind permission of Huntleigh Renray Ltd. See also their leaflet concerning a sample order, which is included in the equipment literature.*

## Ceiling hoist

See also Chapter 9 *Hoisting* which discusses:

- the need for hoisting;
- the essential features required for people with neuromuscular conditions;
- the justification of the additional expense of a ceiling hoist rather than a mobile hoist;
- the factors to be considered when choosing between a wall-to-wall track in the bedroom only or with an extended track into the bathroom.

If a hoist is not needed immediately but is likely to be needed in the future, it will be necessary for the designer to be aware of the need to increase the loading on the joists supporting the track. The extent of the preparatory work will depend on the position of the track in relation to the joists and it would be prudent for any necessary work to be included in the plans (although the hoist may not be installed for several years). The supplying firm will be happy to advise about the optimum layout of the track, the joists and the electrical supply.

When the adaptations are planned the following must also be considered:

- ⇒ track;
- ⇒ position of used spur outlet;
- ⇒ model of hoist.

## Track

### Position

The track should be positioned parallel to the wall behind the bed headboard so that the centre of the track to the wall is **1020mm**.

### Length

There are two options:

- ⇒ wall to wall across the bed;
- ⇒ wall to wall across the bed with the track extended into the bathroom.

The factors to consider in making the choice are covered in greater detail in Chapter 9 *Hoisting*, in addition to the need for an electric turntable or electric switched track.

- **Wall to wall across the bed**

The track should extend from the wall beside the bed for the minimum length needed to cover the floor area required for two wheelchairs, in order for the hoist to be used for transfers i.e. **1800mm**. However, ideally the track should extend wall to wall to ensure it is less obtrusive and to allow the hoist to be charged in the bedroom, but not over the bed. Exceptionally, there may be a situation where this is impossible because there is a door opposite the bed and insufficient space above the door for the hoist.

- **Wall to wall across the bed with the track extended into the bathroom**

This should pass front to back over the bath seat (swung out of the bath) and the toilet – particularly for use with a shower toilet to allow adjustment of the user's position on the seat.

### Position of fused spur outlet

This power socket should be installed on the wall at ceiling height at one end of the length of track that is not above the bed position. If a hoist is not needed immediately, it is still wise to install the outlet so that the decorations do not have to be spoilt in the future. A rechargeable-battery hoist model is recommended, as there is no dangling cord between the electrical supply and hoist motor and is suitable for an extended track – either installed initially or in the future. Anyone with acute hearing may be kept awake by the buzzing sound of the hoist as it charges. If the hoist is charged in the bedroom, it is advisable to install a pull-cord or accessible switch to enable the carer to turn off the hoist or alternatively to charge the hoist during the day.

### Model of hoist

Six models are recommended as they have sensitive light-touch controls and the slings are particularly suitable for people with neuromuscular conditions – in addition, the spreader bars are available (either as standard or as a special order) with three sling hooks on the end, and with a **360°** swivel.

See Chapter 9 *Hoisting* for details of electric turntables/switched tracks, room-covering hoists and recommended models.

## Floor surfaces and coverings

The following should be considered:

- ⇒ shower/bathroom;
- ⇒ bedroom;
- ⇒ other areas;
- ⇒ coconut matting/outside tap.

### Shower/bathroom

Among the alternative floor surfaces are non-slip ceramic tiles, *Altro* safety flooring, *Nairn* Surestep tiles, *Marley* Safetred Aqua and Dimension – and other types that might be recommended by the architectural designer. The disabled person or the parents usually appreciate being asked to make the choice.

Where the bather is able to walk but is unsteady, the surface may be crucial. Although this must be non-slip, the surface must not be too abrasive as the texture grips the sole of the shoe and makes it very difficult to lift the foot. In addition, the alternatives must be practical to clean; a conventional *Altro* surface, which is used in so many installations, might be considered to have too much ‘grit’ in the surface - and raised projections should be avoided, as these harbour dirt around the edges.

### Bedroom

As in the bathroom, the surface must be suitable for people who are able to walk, but have difficulty lifting their feet and/or for those in wheelchairs. The choice is likely to be carpet and it will be important that the pile is not so thick that it will be resistant to the wheelchair. *Flotex* is a very hard-wearing carpet and has been used with success for many years and this has to be balanced against its utilitarian appearance.

*Bonar Floors Ltd*

### Other areas

A compromise might be hardwood (or laminated) floors, which are very suitable for a wheelchair although the surface might be damaged by grit on the chair wheels. However, these may not be suitable for anyone with any degree of difficulty in walking; if this type of flooring is used, to ensure safety it will be important that it is neither polished nor covered by rugs.

### Coconut matting/outside tap

A tap outside the house, in a convenient position for attaching a hose to wash the muddy wheels of a chair, is a thoughtful provision. This can be complemented with a large well with a generous area of wall-to-wall coconut matting immediately inside the wheelchair-accessible door, in order to dry the wheels before entering the house. The depth of the well must precisely match the depth of the matting, to ensure that the rim of the well does not impede wheelchair access. If in the future the matting becomes worn or flattened, it can be raised; one suggestion is to use a layer of carpet underneath. Although the matting is heavy to lift and shake, it can be vacuumed. It is now available in colours.

## Electrical fittings

These cover the following:

- ⇒ light switches;
- ⇒ power points;
- ⇒ smoke alarm.

### Light switches

There are four issues to consider:

- ⇒ height;
- ⇒ space at either side of the switch;
- ⇒ position in the bathroom/bedroom;
- ⇒ type.

### Height

Anyone with a neuromuscular condition is unlikely to be able to raise their arms; the height of the sockets and light switches must therefore be lower than the height usually recommended for wheelchair use.

The ideal height of **700mm** from the bottom of the switch to the finished floor level (FFL) is influenced by the height of the wheelchair armpads. At this height the hand and forearm can be moved sideways and horizontally to touch the switch, while the elbow remains supported on the wheelchair armpad.

### Space at either side of the switch

The limited arm movement and inability to reach makes it necessary to approach the switch with the wheelchair parallel and close to the wall. Therefore, there must not be any obstruction **600mm** on either side of the switch.

### Position in the bathroom/bedroom

#### Bathroom light

A wall-mounted switch outside the bathroom is recommended because it is easier to use than a pull cord. Also, it enables the person to go into a pre-lit room, as it is difficult to manoeuvre into the room and turn on the switch simultaneously.

#### Bedroom lights

Three-way switches are needed:

- ⇒ outside bedroom;
- ⇒ by the bed;
- ⇒ in an accessible position.

- **Outside bedroom**

As above, a switch outside the room will be ideal, in addition to two switches in the bedroom.

- **By the bed**

This is to be used when in bed. Position precisely to ensure that the switch is accessible when the person sits up using an electric bed, as they will not be able to reach behind the backrest of the bed as it rises vertically.

- **Position:** 1020mm from the wall behind the bed headboard i.e. directly under the hoist track.
- **Height:** 760mm from the base of the switch to the finished floor level. This recommended height is higher than other switches in order to clear the mattress and bedding when the electric bed is at its minimum height. The light switch is essential because a lamp on a bedside table would not be suitable for independent use because of the inability to reach. See power points by bed (page 26).

- **In an accessible position**

When the natural light fades, for anyone in their bedroom it is important to be able to switch on a light without having to go out of the room. As it will be impossible to reach the light switch at the side of the bed, a switch must be positioned in an accessible position. If the bedroom has an external door, the optimum position might be at the side of this door, to be used also when coming in from the garden.

## Type

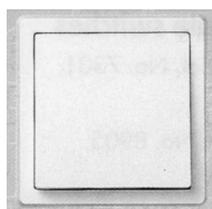
The pressure required to operate switches is important. Standard switches and pull cords are likely to be too difficult to use, as they require too much finger strength or downward arm pressure, respectively. However, there are several alternative solutions, as follows:

- ⇒ Clipper switches;
- ⇒ touch-sensitive switches;
- ⇒ remote-control switches.

### Clipper switches

In these large rocker-type switches the whole front plate moves to operate the switch and requires less pressure than a standard switch.

*Legrand Electric Ltd*



*Tenby Clipper  
light switch*

### Touch-sensitive switches

These are dimmer switches which are operated by contact with some part of the body; although it is necessary to maintain the contact with the switch to dim the light, one light touch only is needed to turn the switch on and off.

Intelliswitch: Argos  
Superswitch: electrical retailers

### Remote-control switches

This type of switch is marginally more expensive, but is recommended for anyone unable to move their arms, as previously discussed, or where there is no suitable accessible position for a switch.

Superswitch: electrical retailers

## Power points

The following will be needed:

- ⇒ **13amp** sockets;
- ⇒ TV power point and aerial;
- ⇒ phone socket;
- ⇒ wheelchair-charging socket;
- ⇒ electric shaver point;
- ⇒ fused spur outlets.

### 13amp sockets

The issues to be considered are:

- ⇒ type;
- ⇒ number needed;
- ⇒ position/height.

### Type

Switched sockets should be installed, because some users will be able to turn them off either by reaching with their fingers or with the use of a 'reaching stick'. Over the bedroom work surfaces and kitchen units, an alternative to installation on the wall is to use sloped socket boxes positioned on the worktop.

### Number needed

- **General use**

As a person with a neuromuscular condition will depend heavily on electrical equipment (such as an electric bed) there is the need to include more than the average number of sockets.

- **Use with an environmental control**

A number of additional sockets will be needed for use with the accessories linked to the environmental control. It is practical to install these when the adaptation is being carried out, but the exact position is not always known. The feasibility and forward planning should be discussed with the representative when the meeting is held to assess the facilities and the client's needs.

Possum Controls Ltd  
RSL Steeper Ltd  
SRS Technology Ltd

## Position/height

- **By bed**

1 x twin socket at a height of **700mm** for use with items positioned on a bedside cabinet (e.g. clock or table lamp) or above a wall-mounted shelf at the side of the bed, see Chapter 14 *Scales & Templates*. The bottom of the shelf must clear the maximum height of the bed. The items can be reached from the shelf only when the bed is at its maximum height.

- **Foot of bed**

1 x twin socket at skirting-board level. If this socket is placed marginally under the foot of the bed, it will ensure that the electrical cords from the powered bed will remain out of sight and avoid a potential hazard.

*N.B. The length of the bed is longer than standard (i.e. 2155mm).*

- **Over work surfaces.** If the surfaces are height adjustable, it will be necessary to install either:

- sloped sockets boxes on the surfaces;
- wall-mounted sockets to clear the maximum height. Allowing for inflexibility of the cord immediately below the plug, the height is:
  - 2 x twin sockets above the sitting surface – bottom of socket to FFL: **1100mm**.
  - 1 x twin socket above the standing surface – bottom of socket to FFL: **1300mm**.

## TV power point and aerial

Most young people want a TV in their bedroom and the position is usually chosen so that they can watch from the bed.

## Phone socket

This may be important for use with an environmental control, both when in bed and when sitting at the work surface.

## Wheelchair-charging socket

### Position

Wet batteries give off fumes, although this is not a problem with dry batteries. As no one can be certain which type of battery will be used in the future, it should be planned to charge the chair outside the bedroom. There must be a designated area for charging the wheelchairs, with the provision of an adjacent electrical socket and background ventilation; this must not be in a cupboard where there is insufficient circulation of air.

### Shelf for charger

It is convenient to provide a shelf below the charging socket on which to stand the charger in order to avoid stooping and the need to lift the charger when vacuuming or cleaning the floor.

- **Width: 500mm**
- **Depth: 300mm**
- **Height: 850mm** to enable a wheelchair to be positioned underneath.

See wheelchair and equipment storage on page 29.

## Electric shaver point

This should be installed adjacent to the washbasin for the convenience of recharging an electric toothbrush and the use of a mains electric shaver.

*N.B. The Astor-Bannerman washbasin has an integral shaver point.*

## Fused spur outlets

These will be needed for the following equipment:

- ceiling hoist. This power socket should be installed on the wall at ceiling height at one end of the length of track, preferably in the bedroom but not above the bed. If a hoist is not needed immediately it is still wise to install the outlet so that the decorations do not have to be spoilt in the future. A rechargeable battery model is recommended, as there is no dangling cord between the electrical supply and hoist motor, and is suitable for an extended track installed either initially or in the future.
- electrical height-adjustable washbasin;
- shower toilet;
- wall-mounted bathroom heater/*Apres Shower Dryer*;
- electrical height-adjustable shower seat;
- specialist bath;
- automatic door openers;
- electric shower. A dedicated circuit from the consumer unit (to a fused spur outlet) will be needed.

**N.B.** *In each case, individual firms should be consulted regarding the optimum position.*

The installation of all equipment needing an electrical supply should be in accordance with the current edition of the Institute of Electrical Engineers (IEE) regulations.

## Smoke alarm

Although it is a requirement of Building Regulations that a smoke alarm is wired into the electrical system in all new buildings, this does not include extensions. However, many Grants Departments now require that they are fitted and are included in the grant schedule. This is a wise precaution in a house with a ground-floor extension – in view of the fact that house fires usually break out downstairs and the child's parent/s will probably be sleeping upstairs. A mains alarm eliminates the responsibility of seeing that the battery is replaced regularly.

## Heating

The factors to be considered are:

- ⇒ temperature;
- ⇒ type of heating;
- ⇒ heating controls;
- ⇒ justification for funding.

## Temperature

Muscles are the main source of heat production and maintenance of body temperature; cold muscles do not work as well as warm muscles. Therefore, the severe muscle wasting of neuromuscular conditions, coupled with the inevitable lack of mobility, means that it is essential to provide a higher-than-average level of heating (i.e.  $21^{\circ}$  –  $24^{\circ}$  C) in both the bedroom and bathroom. This is particularly important in the bathroom, especially where it has more than one outside wall.

## Type of heating

The choice is between one or more of the following:

- ⇒ radiant heater;
- ⇒ central heating;
- ⇒ booster heater/bathroom;
- ⇒ body dryers;
- ⇒ bathroom towel rail.

### Radiant heater

Most people find it warmer and more comforting to sit by a source of radiant heat, but as these normally would not be left on when everyone is out of the house, they should be supplementary to a satisfactory form of central heating.

### Central heating

The source of heat must be constant and controllable. It is important that when the disabled person arrives home, the house is pre-heated to the correct temperature; therefore, the house must have central heating rather than relying on radiant heaters only. Night-storage heaters are not adequate because the heat cannot be controlled or boosted when necessary.

### Booster heater/bathroom

In addition to central-heating radiators, it will be necessary to install a wall-mounted fan heater in the bathroom. This is important to allow the instant heat to boost the temperature prior to bathing in the winter, or to be used when the central heating is turned off in the summer.

*Dimplex*

### Apres Shower Body Dryer

This can be used as an alternative to the above, with the additional bonus of drying the body independently after bathing or showering.

*Apres Shower Dryers Ltd  
Go Independent  
Total Hygiene Ltd*

### Bathroom towel rail

This is a comforting 'luxury' that can be installed in combination with the central-heating radiator, or separately as an additional source of heat.

## Heating controls

These must be positioned where they will be accessible and at the correct height if it is necessary for the user to be able to control the system. See siting of electrical light switches on pages 23 – 24.

### Justification for funding (see Chapter 11i)

Grant eligibility is based on medical need only. The validity of the discussion regarding the temperature in the house should be confirmed with the hospital medical consultant if the need has to be established for the central heating boiler and radiators to be grant eligible. It would not be expected that the grant would cover radiators needed in rooms that are not used by the disabled person.

## Intercoms

It will be necessary to install an intercom in the bedroom of a child or adult to call their parents or carers.

There are two types:

- ⇒ models which plug into a **13amp** socket;
- ⇒ intercoms linked into an environmental control.

### Models which plug into a 13amp socket

These are more convenient than transmitters and receivers linked with a cord, as they can be moved from one room to another.

### Intercoms linked into an environmental control

If an extension is being built for a teenager or adult, it may be appropriate to consider the need for an environmental control so that adequate additional twin switchless **13amp** sockets can be installed when the building work is carried out.

Intercoms are provided within the facilities included in these systems, which are supplied through the National Health Service and are discussed in Chapter 8a *Equipment for Adaptations*.

## Wheelchair and equipment storage

Many people who need a powered wheelchair have two chairs and a transit chair, in addition to such items as standing frames; if the family either does not have a garage, or the garage is too small, storage can be a nightmare. Therefore, it is necessary to make suitable provision, particularly where previous storage areas have been used to provide new accommodation in the adaptations. See Chapter 14 *Scales & Templates*. The area designated for the storage of the wheelchairs may be the appropriate place to charge the chairs.

## Ingredients of a first-rate adaptations scheme

Successful completion of a scheme will depend on a number of important factors as follows:

- ⇒ a competent assessment;
- ⇒ involvement of the disabled person and/or the family or carer;
- ⇒ the architectural brief;
- ⇒ an experienced architectural designer;
- ⇒ the architectural service provided;
- ⇒ choice of builder;
- ⇒ inspection of building work.

## A competent assessment

This must reflect the specific needs of the disabled person and their carer/s. See Chapter 4 *Assessment of Need*.

## Involvement of the disabled person and/or the family or carer

Where necessary, explanation of the plans and good communication/liaison between everyone concerned will ensure that the people for whom the adaptation is being carried out will feel that they have received the help needed.

## The architectural brief

A comprehensive and accurate architectural brief is vital. Please use Chapter 10 *Disability Needs Assessment Form* in conjunction with this adaptation information because it has been designed to:

- identify the options relating to the individual needs;
- provide a time-saving method of recording the decisions made;
- provide an architectural brief for the drawing of the plans;
- consider the funding options;
- act as a check-list to ensure that all the details have been included.

## An experienced architectural designer

It is important that the architectural designer understands the needs of people with a neuromuscular condition and that they have access to this manual. Choosing a designer from the *Muscular Dystrophy Adaptations & Building Design Network* will be a good start because they are aware of the specific needs, but it does not mean that other designers will not be equally competent.

## The architectural service provided

Excellent plans can be drawn, which may fail to produce the perfect end result because they are not carried out as intended. The best outcome will be achieved if the architectural service includes the inspection of the building work and seeing the scheme through to completion. Grants should cover this work, and applicants should be aware of the level of service to be provided.

## Choice of builder

Builders are usually chosen because they have submitted the lowest tender; however, one or two problems may arise:

- lack of understanding of the disability needs and no experience of adaptations;
- making inappropriate suggestions and changes;
- lack of continuity on site;
- lack of respect for the family and property when on site;
- ignorance of how to leave the site safe.

Now that the *Muscular Dystrophy Adaptations & Building Design Network* has been set up, each architectural designer will be able to give advice about choosing the right builder.

## Inspection of building work

In spite of the care taken by architectural designers to include all details in the plans or job specifications, builders do not always appreciate the need to interpret all these instructions precisely. It is vital, therefore, in addition to inspection of the work by the designer, that the grant applicant and/or their carers, appreciate the reasons for each recommendation so that, where necessary, they know that the architectural designer must be alerted if they feel that mistakes are being made.

It is advisable (but not always possible) for the OT to visit regularly while the builder is working. It is essential that the disabled person or the family keep their OT or Muscular Dystrophy Family Care Officer in touch with the progress, so that the installation of fittings from the disability point of view is checked before the builder leaves the site.

# Kitchens

## for children & adults with muscular dystrophy & allied neuromuscular conditions

*A guide to the factors to be considered by the disabled person, the community OT and the architectural designer when kitchen adaptations are being planned*

To be used in conjunction with:

Chapter 8a	<i>Equipment for Adaptations;</i>
Chapter 10	<i>Disability Needs Assessment Form/Architectural Brief;</i>
Chapter 14	<i>Scales &amp; Templates;</i>
Chapter 18	<i>Addresses: Manufacturers/Suppliers/Sources of Advice.</i>

There are many factors that need to be considered:

⇒ Designing for people with neuromuscular conditions	2
⇒ Design criteria	2
⇒ What is the ideal size of kitchen?	4
⇒ Layout of kitchen units & appliances	5
⇒ Units & worktop height adjustability	6
⇒ Sink	7
⇒ Surfaces	9
⇒ Worktops	9
⇒ Ovens, accessories & hobs	10
⇒ Kitchen goods	11
⇒ Storage	12
⇒ Laundry	14
⇒ Electrics	14
⇒ Suppliers of specialist kitchens/services	15

## Design criteria

When planning a new kitchen, or adapting an existing kitchen, the design must fit the specific needs of the disabled person to ensure that their ability to use the kitchen is enhanced. This can be achieved if the following issues are considered:

- ⇒ the individual person's knowledge of their own capabilities and coping strategies, in relation to their disability;
- ⇒ an understanding of the particular effects of the condition;
- ⇒ personal choice;
- ⇒ design-planning skills.

### The individual person's knowledge of their own capabilities and coping strategies, in relation to their disability

This is really important to ensure their safety in using the kitchen. Talking to the individual and others who will use the kitchen – and *listening* – is the best start. Find out which is their stronger side and how they prefer to carry out activities.

### An understanding of the particular effects of the condition

This must reflect both the short-term and long-term needs.

### Personal choice

The user has to live with the outcome and must be involved in the selection of units and the appliances to be included in the layout.

### Design-planning skills

Experience of kitchen design and knowledge of the products available will be invaluable.

## Designing for people with neuromuscular conditions

It is essential to appreciate that people with neuromuscular conditions usually encounter three major problems that should be taken into account in the design. These are:

- ⇒ arm weakness;
- ⇒ leg weakness;
- ⇒ the progressive nature of the disability.

### Arm weakness

This will result in:

- ⇒ lack of strength, particularly for lifting;
- ⇒ difficulty in reaching;
- ⇒ the need to support forearms;
- ⇒ weak handgrip and function.

## Lack of strength, particularly for lifting

necessitating:

- *a continuous surface* on which to slide the pans;
- *careful positioning of the taps* which allows pans to be filled on the surface, eliminating the need to hold them under a tap or lift them out of the sink;
- *shallow drawers* that cannot be overloaded and therefore will be lighter to pull out.

## Difficulty in reaching

necessitating:

- kitchen equipment positioned at the *right height* and within reach;
- drawers and cupboards with *pull-out shelves and baskets* in which items can be located easily.

## The need to support forearms

on a surface when working with hands; this may be coupled with the need to sit down.

## Weak handgrip and function

can be overcome with specialised kitchen equipment.

## Leg weakness

This can be overcome by using a wheelchair or, if the person is able to stand, with the use of a 'perching stool', which will be particularly helpful if standing up from a lower seat height is difficult. Wheelchair-accessible units will be open underneath, or have cupboards with a recess to accommodate the footplates of the chair.

## Progressive nature of the disability

It will be essential to consider the short-term and long-term effects of the neuromuscular condition in order to incorporate all the features needed over a period of years, so that future adaptations are not necessary – or are possible with minimum intervention. This may include installing height-adjustable surfaces, needed as follows:

- ⇒ for use when standing and sitting;
- ⇒ for use with wheelchairs of different seat heights;
- ⇒ for use with powered chairs with different heights of joystick control;
- ⇒ to allow the surfaces to be changed to the optimum height for different activities;
- ⇒ to provide flexibility between the needs of the disabled person and anyone else who uses the kitchen.

## For use when standing and sitting

A muscle-wasting condition can mean that for several years a wheelchair is used for part of the day only – when someone is tired – or when carrying out an activity that is easier from a wheelchair. Therefore, some people will use the kitchen sometimes when standing and on other occasions from a chair. In this situation, it is impossible to find one optimum height for the surfaces.

## For use with wheelchairs of different seat heights

Most people with a neuromuscular condition have more than one wheelchair and as these chairs will have different seat heights or may be used with or without cushions, the height of the kitchen surfaces must reflect these differences.

### **For use with powered chairs with different heights of joystick control**

When a new wheelchair is used, which is likely to be an updated model, it is essential for the surfaces to be altered easily.

### **To allow the surfaces to be changed to the optimum height for different activities**

For anyone with arm weakness, to be able to maximise their hand and arm function, there will be an ideal height at which they need to work, and this will depend on the particular activity.

### **To provide flexibility between the needs of the disabled person and anyone else who uses the kitchen**

Carers' backs are placed under continual strain, and working at the wrong height in the kitchen will add to this problem. Even within the grant legislation, there is reference to the needs of carers.

## **What is the ideal size of kitchen?**

There is no definitive answer, as this depends upon the number of units to be included. If the whole kitchen is to be used by anyone in a wheelchair (now or in the future), it has to be much larger than usual because:

- ⇒ the sink and working surfaces need leg space underneath;
- ⇒ storage units need to be at an accessible level;
- ⇒ stacking units such as a fridge/freezer or a conventional combined oven and hob are unsuitable;
- ⇒ there will have to be space for a table and possibly a powered rising chair;
- ⇒ there must be sufficient space for wheelchair circulation.

### **The sink and working surfaces need leg space underneath**

This means that storage units will need to be separate, taking up additional space, although it is useful to have a cutlery drawer under the drainer or near the sink.

### **Storage units need to be at an accessible level**

### **Stacking units such as a fridge/freezer or a conventional combined oven and hob are unsuitable**

This is because of the difficulty in reaching, and they will have to be installed separately so that each piece of equipment is at the optimum height.

### **There will have to be space for a table and possibly a powered rising chair**

If the person cannot carry meals into another room or use a trolley, it will be essential for the kitchen to be large enough for a table. If the disabled person is able to walk, but has the additional problem of not being able to stand up from a chair, there must be a powered rising chair in the kitchen.

## There must be sufficient space for wheelchair circulation

A wheelchair may be **750mm** wide and **1250mm** long, but it is not necessary to provide a complete turning circle in the centre of the kitchen if the chair can be turned underneath the open units. This may be important in a galley kitchen where the open units can be placed at the end of the kitchen or opposite the sink, so that the chair can turn round in this area without the alternative of restricting the number of units installed.

## Layout of kitchen units and appliances

The following factors are important when planning the layout:

- ⇒ ensure that the oven, hob and sink are on the same run;
- ⇒ allow a minimum width of **900mm** under the sink, hob and preparation area, and next to the oven;
- ⇒ design the oven housing next to the leg space for the hob;
- ⇒ ensure that there is a space on either side of the hob so that pan handles can be positioned sideways;
- ⇒ be clear about the units and fittings that will be needed;
- ⇒ plan for the circulation of a wheelchair.

### Ensure that the oven, hob and sink are on the same run

This allows the disabled person to slide items such as pans, plates and kettles along the worktops, when carrying them from one side of the kitchen to the other is impossible.

### Allow a minimum width of 900mm under the sink, hob and preparation area, and next to the oven

**900mm** is required to give room for the front castors on the wheelchair to turn, as the person will rarely go into the space squarely.

### Design the oven housing next to the leg space for the hob

Where space is limited, the same area of leg space can be used for either unit.

### Ensure that there is a space on either side of the hob so that pan handles can be positioned sideways

This is a safety precaution so that handles are not left projecting forwards from the surface.

### Be clear about the units and fittings that will be needed

The wall space should be divided into **600mm** squares, which is the size of standard kitchen appliances and cupboards, although cupboards can be **500mm** or **400mm** wide. Use the templates to help with the planning. See Chapter 14 *Scales & Templates*.

### Plan for the circulation of a wheelchair

An L-shaped or U-shaped kitchen is ideal, however, if there is no alternative to a galley kitchen, the continuous wheelchair-accessible surface should be on one side, with the kitchen appliances (e.g. fridge and storage units) on the other.

## Units and worktop height adjustability

Units and worktops can be flexible, with surfaces that are raised for someone standing and lowered to accommodate a wheelchair user. Wall cupboards can be moved up to leave surfaces free. Although they can also be moved down, even at a lower height than usual, it is unlikely that anyone with severe arm weakness will be able to reach into them. However, if reaching is possible, restricting the depth will limit the storage space available and a better option may be for all the items needed regularly to be housed at the front of the cupboard or shelf.

Decisions to make about heights when designing a kitchen will include:

- ⇒ Who will use the kitchen?
- ⇒ Is there an optimum height?
- ⇒ Is it adequate for the disabled person to use only a limited part of the kitchen?
- ⇒ Do some (or all) of the kitchen units need to be height-adjustable?
- ⇒ Can there be a combination of fixed units with manual height-adjustable brackets and/or electrically height-adjustable sections?
- ⇒ Would an electrically height-adjustable trolley be an alternative solution?
- ⇒ Which method of height adjustability is the most suitable?

### Who will use the kitchen?

Will this be just the disabled person or others as well?

### Is there an optimum height?

If the kitchen has to be shared, is there a height for the surfaces that will be satisfactory for the disabled person and others in the household – or does the kitchen need to be height adjustable?

### Is it adequate for the disabled person to use only a limited part of the kitchen?

For disabled children who are interested in cooking, but who are unlikely to use the whole kitchen, it may be adequate to provide a suitable surface for the preparation of simple snacks and for positioning a microwave oven.

### Do some (or all) of the kitchen units need to be height-adjustable?

Consider each unit or appliance in relation to the optimum height - and the feasibility of grouping together those that need to be height adjustable.

### Can there be a combination of fixed units with manual height-adjustable brackets and/or electrically height-adjustable sections?

### Would an electrically height-adjustable trolley be an alternative solution?

Do the oven and the surfaces need to be height adjustable or is this innovative equipment a cheaper and more effective solution? See Chapter 8a *Equipment for Adaptations*.

*Thomas Gideon Design*

## Which method of height adjustability is the most suitable?

- ⇒ Infrequent bracket adjustment;
- ⇒ manual adjustment;
- ⇒ electrical adjustment.

### Infrequent bracket adjustment

A few manufacturers make units that can be hung on the wall, at any height. This enables them to be re-hung, at a later date, to suit the changed needs of an individual or family. An experienced fitter will need to change the height of the units and worktops, so this will not give flexibility for the user or users on a day-to-day basis. If you anticipate making height adjustments in this way, avoid tiling down to the worktop. A far better system is to use laminate panels (perhaps in the same colour as the worktop). The brackets to hang the units and worktops can be fixed to the panels, avoiding the need for re-tiling. You can also run all the services behind the panels and avoid re-plastering.

The choice of bracket will depend upon the importance of the ease of adjustment. This may be a bracket under the surface fixed to the wall rail with wing nuts; to adjust the surface height, the wing nuts are removed and the brackets are moved up or down on the wall rail, with the possibility of 10 adjustments of **20mm**.

*Huntleigh Renray Ltd*

The alternative is a bracket that is infinitely adjustable within a range of **300mm** by rotating the nut at the base. These brackets are supplied to fit any type of kitchen.

*Astor-Bannerman (Medical) Ltd*

### Manual adjustment

This involves winding a handle to move the surfaces, or flicking a switch and lifting or lowering the worktop on a counterweight system, making it unsuitable for independent use by most people with a neuromuscular condition. The only advantage is to enable other people who need to use the kitchen to alter the height, but then they would have to remember to re-adjust the units to the correct height after use.

### Electrical adjustment

This method is essential when it is necessary for the height adjustment to be carried out by anyone with arm weakness, in order to provide the independence that the manual system is unlikely to give. A small device with a button is used to raise and lower worktops and kitchen units. This is ideal for moving surfaces and units in a small kitchen, to give the user greater access and storage space and to facilitate use by several people with different needs. Any electrical system must have a safety device to deactivate the power when it detects pressure, for example a finger that might be crushed; this removes the possibility of injuries. When fitting electrical worktops, it is better to fit them against a laminate panel rather than a tiled surface.

## Sink

There are a number of issues in relation to the sink that need to be considered with care:

- ⇒ sink depth;
- ⇒ plumbing;
- ⇒ taps;
- ⇒ left-side or right-side draining board?

## Sink depth

When deciding on the height of surfaces, begin with the sink as this can cause the most problems. Because wheelchair users need to be able to get their legs underneath, the depth of the sink is critical, particularly as many people will need to get armrests and the joystick of a powered chair underneath. Standard depth bowls (**175mm**) are too deep; they will restrict access by making the worktop too high and also make it difficult for someone who needs to rest on their forearms to reach to the bottom. A bowl depth of **125mm** is ideal and is deep enough to allow washing a saucepan, for example. Other users can increase the depth by using a washing-up bowl in the sink.

## Plumbing

Also consider the position of the plumbing. This can hinder leg access and should be placed as near to the wall as possible.

## Taps

The factors to be considered are:

- ⇒ advantage of a swivel-mixer nozzle;
- ⇒ height of the nozzle;
- ⇒ forward projection of the nozzle;
- ⇒ length of the lever;
- ⇒ height of the taps.

### Advantage of a swivel-mixer nozzle

If lever taps with a swivel-mixer nozzle are installed on the surface at the side of the sink (instead of behind the sink), they can be used to fill the sink with water and also swivelled to fill a pan positioned on the surface. This eliminates the need to hold the pan under the tap or lift it up from the bottom of the sink, both of which will be either difficult or impossible.

### Height of the nozzle

This will influence the depth of cooking pan or kettle that can be used.

### Forward projection of the nozzle

This will be crucial for reaching the jet of water in the sink for such procedures as preparing vegetables and washing hands.

### Length of the lever

In order to limit the need to reach, the levers should be at least **150mm**.

### Height of the taps

The taps should be low to prevent the need to reach upwards. Alternatively, remote-control taps can be installed either on the front fascia, ensuring that they do not obstruct access to the sink, or on the surface in the optimum position for the user to reach. Taps on the surface will be easier for anyone relying on sliding their arms and for whom it is difficult to take an arm off the surface to operate the taps or to lift it back again.

## Left-side or right-side draining board?

In this choice, many people are influenced by which is the stronger side of their body. However, they should also consider the need to position a tap on the surface adjacent to the sink, and the ability to slide the pans to the hob without the need to pass over the sink.

## Surfaces

Because of the need to slide the pans, there should be a continuous surface between the sink and oven with sufficient space for the following in between:

- ⇨ food-preparation surface;
- ⇨ surface for microwave;
- ⇨ hob.

### Food-preparation surface

The main area should be between the sink and hob, with a small surface between the hob and oven.

### Surface for microwave

It is likely to be necessary to position the microwave on a surface to enable users to stabilise their forearms to open the oven, and to provide a surface on which to lift/slide the items from the oven.

### Hob

There must be a space on either side of the hob to ensure that pan handles can be positioned sideways and not left projecting forwards from the surface.

## Worktops

The best type of worktop has a ‘waterfall’ edge (a lip running along the front). Some manufacturers put a raised Corian edge around a laminate worktop. This gives the advantage of colour contrast, an aid to anyone with a visual impairment. A waterfall edge reduces the risk of scalds and water spillage by **70%**. It is particularly useful for washing up, as it prevents water spilling into the lap. With moveable worktops, it is advisable to have a waterfall edge around all four edges or fluids will run off the sides. For a disabled person, cleaning a surface will be easier than cleaning a floor, apart from the fact that a wet floor is a hazard to anyone walking, particularly if they lack balance. *However, it must be assessed whether this edge makes it uncomfortable or difficult to support your arms while sliding items around the surface.*

**N.B.** *Do not use a metal sealing joint for worktop joints; this acts as a barrier to sliding items across the surface.*

## Ovens, accessories and hobs

The following will need to be discussed:

- ⇒ types of ovens;
- ⇒ oven height and position;
- ⇒ accessories for use with the oven;
- ⇒ split-level hobs.

### Types of ovens

#### Microwave

It is likely to be necessary to position the microwave on a surface (instead of a housing unit) to enable users to stabilise their forearms to open the oven. The added advantage is that this provides a surface in front, large enough to lift or slide items from the oven and then, if necessary, to slide them around the surfaces to the sink.

#### Combined microwave/convection

This provides the advantages of both methods of cooking and saves space. However, these ovens are smaller than standard ones and will restrict what can be cooked.

#### Ovens with a pull-down door

These are very dangerous. When in use, the interior surface of the door can reach in excess of **250°C**. It also is a barrier for a wheelchair user trying to reach into the oven and puts the user's arm at full stretch, reducing what can be lifted. For someone with limited strength or poor balance, these factors can make pull-down door ovens a potentially lethal hazard. The hinges of pull-down doors are not designed to take the weight of large items, such as casseroles; eventually, they will give way.

#### Convection ovens with the choice of left- or right-side opening door

This is likely to be a better solution, as the door will allow access to the oven without obstructing a wheelchair user. These ovens should come with anti-tip shelves, which can be pulled out the full distance. Each shelf should have its own drip tray. With this system, users do not need to lift a cooking dish out to check or stir the contents; they can simply and safely slide it out. Ovens with side-opening doors and pull-out shelves that lock when full out are available from *Atag*.

#### Floor-standing ovens

These are not suitable for wheelchair users and should be considered only as an additional oven for family cooking if the disabled person is never going to use the oven. However, there may still be the need to install a split-level hob.

### Oven height and position

Most accidents in the kitchen involve the oven. Ensuring that it is at the right height, by setting it in an oven housing unit can reduce the risks. It should be sited at the end of the continuous surface, so that it does not interrupt the ability to slide pans.

## Accessories for use with the oven

### Pull-out surface below the oven

This provides the opportunity for the cook to lean on the forearms when opening the oven door.

### Electric height-adjustable trolley

If it is necessary to move items from one area to another, or to slide food either from a surface or any oven shelf and move it to another part of the kitchen, an electric height-adjustable trolley is recommended. This equipment is discussed in detail in Chapter 8a *Equipment for Adaptations*.

## Split-level hobs

The choice of hobs is as follows:

- ⇒ gas/electric;
- ⇒ ceramic;
- ⇒ induction.

### Gas/electric

The choice between a gas or electric hob is a personal matter, but electric hobs are usually more suitable for sliding pans than gas hobs and may be easier to clean. They also avoid the hazard of a naked flame.

### Ceramic

Although ceramic hobs have the advantage of a level surface, the glass may make it difficult to control the pan when stirring. This can be overcome by the use of a hob guard, which keeps the pan in place. The position of the controls should be assessed carefully; they need to be within easy reach without impeding the ability to slide the pans on and off the hob.

### Induction

Although generally more expensive, these hobs can be an excellent option for anyone disabled. The hob heats by making a connection with a pan – which therefore must be metal rather than enamelled. The surface remains cool and, as soon as the connection is broken, the hob is switched off.

## Kitchen goods

These include:

- ⇒ fridge;
- ⇒ freezer;
- ⇒ combined fridge/freezer;
- ⇒ dishwasher.

## Fridge

A floor-standing, pull-out fridge is best. The door pulls out and so does each individual shelf. Alternately, if the user wants a standard built-in fridge, their range of reach should be assessed and the fridge installed into the housing unit so that they can reach what they consider to be the most important shelves in the fridge.

## Freezer

There is no such thing as a pull-out freezer, as defrosting would start as soon as it was opened. Freezers in the past were considered luxury items; in fact this is usually an essential appliance for anyone who may not be able to shop regularly and may have meals prepared and frozen for them, ready to cook. The same considerations that apply to standard built-in fridges are relevant.

## Combined fridge/freezer

It is unlikely that a combination unit would be satisfactory because of the limited reaching range of a person with a neuromuscular condition.

## Dishwasher

This appliance may not be necessary because it may be easier to wash up in a sink than to bend down or reach to load and empty a dishwasher. However, it may be a very useful item for a helper.

## Storage

The following should be considered:

- ⇒ types of kitchen units;
- ⇒ wall-mounted cupboards;
- ⇒ corner base unit with a carousel shelf;
- ⇒ cupboard with pull-out shelves;
- ⇒ drawer unit with three pull-out baskets;
- ⇒ drawer unit with pull-out surface over three pull-out baskets;
- ⇒ pull-out surface with bowl holes;
- ⇒ portable storage trolley unit.

## Types of kitchen units

Most manufacturers only make standard-sized units; however, a few will make units and doors of any height, width or depth. This makes designing a suitable kitchen much easier. When designing a kitchen for a wheelchair user or someone with mobility difficulties, avoid cupboards with standard shelves as these are a hazard. Even for someone with good upper-body strength, reaching down and into the back of a base unit is virtually impossible. This is why as many units as possible, whether they are base or tall units, should be pull-outs. All drawers must be fitted with fully extendible, metal ball-bearing runners.

Drawers are easier to use than hinged doors with pull-out shelves or baskets because opening the door is an additional manoeuvre. Another advantage is that a drawer handle will be easier to reach than the front of a pull-out shelf. There is a huge range of internal systems for units.

### Wall-mounted cupboards

Fixed wall units tend to be inaccessible and, although they can be fixed lower, they will still be beyond the reach of anyone with a neuromuscular condition. Alternatively, electrically-operated units can be used. If wall units are beyond the reach of the disabled person, although it may not be possible to dispense with the storage space they provide, it will be necessary to provide alternative storage space at a lower level.

When the doors of wall cupboards are open they should not protrude beyond the worktop line, as this can be a hazard. For a **500mm** unit, two **250mm** doors will avoid this problem. Storage units with pull-out baskets will enable someone with limited reach to bring items forward out of the unit and near enough to lift; however, this does require some arm strength.

### Corner base unit with a carousel shelf

These are ideal if fitted with foldaway doors to make the best use of a corner and otherwise inaccessible storage space. They also take the weight of the worktop, which will usually have leg space at either side.

### Cupboard with pull-out shelves

Storage units with pull-out shelves or baskets will enable someone with limited reach to bring the items forwards out of the unit and near enough to lift. However, a cupboard may not be as convenient as a drawer unit because two manoeuvres are needed – i.e. to open the door and to pull out the shelf.

### Drawer unit with three pull-out baskets

Drawers have to be deep enough to store tall items. However, the number of items stored will influence the weight of the drawer and therefore the user's ability to pull it open. Three graduated, but shallow drawers will be more satisfactory than two.

### Drawer unit with pull-out surface over three pull-out baskets

This will provide an additional surface that might be useful in a small kitchen.

### Pull-out surface with bowl holes

This is an alternative to a plain surface and may be helpful to stabilise a bowl, at the same time providing a surface on which to lean.

### Portable storage trolley unit

This may be useful to provide additional storage, with the opportunity of maintaining wheelchair access under the units when the trolley is not positioned under the surface.

## Laundry

Is there a utility room or does the laundry equipment have to be accommodated in the kitchen? The equipment needed will be:

- ⇒ washing machine and tumble drier (or combined machine);
- ⇒ ironing board.

### Washing machine and tumble drier (or combined machine)

These should be positioned at a suitable height for the user, if necessary, by installing them in a housing unit. Unless the tumble drier uses a condenser, it should be sited against an external wall to vent the steam out of the house.

### Ironing board

Many disabled people find that ironing boards (and often an iron) are too heavy to lift and a helper may do their ironing. However, ironing boards that are wall-mounted may be useful. See Chapter 8a *Equipment for Adaptations*.

*Panilet Tables*

## Electrics

- ⇒ 13amp sockets;
- ⇒ light switches.

### 13amp sockets

The position of power sockets must be considered carefully because of the difficulty of reaching. Sockets to be used with the equipment on the worktop will be easier to reach if they are fitted on to an angled plinth, as an alternative to installation in the wall.

### Light switches

The height and position of switches has been discussed in Chapter 15 *Adaptation Specifications*.

## Suppliers of specialist kitchens/services

There are a number of suppliers of specialist kitchens, accessories and appliances. A visit to a Disabled Living Centre will provide the opportunity to assess the huge range of items available. The address of your nearest centre is available from the Disabled Living Centres Council. See Chapter 18 *Addresses*.

Although the list below is not exhaustive, it gives suggestions of firms to contact. Their details can be found in Chapter 18 *Addresses*.

### ***Astor-Bannerman (Medical) Ltd***

Electric worktops.  
Height-adjustable brackets.

### ***Design Matters KBB Ltd***

Professional design and assessment service by UK's only wheelchair-using kitchen designer is offered to architects, other designers, Housing Associations etc. *Design Matters* will also supply and fit purpose-made kitchens, including the *Access Matters* range, tailored to the individual, *Atag* appliances, *Hafele* and *Hettich* drawer parts, metalwork, runners and carousels. In addition, the firm provides a design consultancy service on a negotiated fee basis.

### ***Independence Kitchens***

Manufacturers of wall-hung kitchen furniture.

### ***N & C Building Products Ltd/Phlexicare Division***

Kitchens – fixed and height adjustable.

### ***Panilet Tables***

Ironing boards and tables.

### ***Huntleigh Renray Ltd***

Kitchens – fixed and height adjustable.

### ***Scanflex Ltd***

Kitchens – fixed and height adjustable.

### ***Thomas Gideon Design***

Electric height-adjustable trolleys.

# Multi-Use Toilet, Bathroom & Bedroom Facilities

in schools, hospitals, residential care homes, hospices, holiday centres & hotels

*This information is written as a useful resource for those who are planning to either refit existing facilities or design a new building*

To be used in conjunction with:

Chapter 8a	<i>Equipment for Adaptations;</i>
Chapter 8b	<i>Electric Beds;</i>
Chapter 9	<i>Hoisting;</i>
Chapter 14	<i>Scales &amp; Templates;</i>
Chapter 15	<i>Adaptation Specifications;</i>
Chapter 18	<i>Addresses: Manufacturers/Suppliers/Sources of Advice.</i>

The following are the issues to be considered:

	⇒ Design criteria	2
	⇒ Choice of products	3
	⇒ School bathroom/toilet facilities	14
	⇒ Hospital & holiday centres' bathroom/toilet facilities	17
⇒ Care home, hospice & hospital assisted bathroom/toilet facilities		17
⇒ En-suite facilities in care homes, hospices, hospitals & hotels		18
	⇒ En-suite/bedroom transfer	19
	⇒ Bedroom	21
	⇒ Drawing of plans	22
	⇒ Check-list	23

## Design criteria

In all the situations listed on the previous page, a number of important criteria, when designing the layout of the fittings and choosing the equipment, may be influenced by funding or space limitations. The fittings and equipment must be:

- ⇒ suitable for people with a wide range of physical disability and needs;
- ⇒ suitable for the needs of the carers;
- ⇒ able to withstand regular and heavy use;
- ⇒ attractive;
- ⇒ good value for money.

### Suitable for people with a wide range of physical disability and needs

The aim is to provide as much independence as possible. It is important, depending upon the space available, that alternatives are provided and that they are as flexible as possible with regard to the positioning and height of the fittings. It will be essential to plan for three disability groups:

- people who are disabled, but able to walk;
- wheelchair users who can transfer out of their chairs independently or with minimal help;
- wheelchair users with arm weakness and who cannot transfer out of their chairs and need to be hoisted.

### Building categories and users' ability levels

The type of building and the client group using it will have a great influence on the criteria for design. It is worth considering whether the bathrooms will be used independently, dependently or both in the same room. The following table offers some typical scenarios:

	Independent	Dependent	Both
Schools			✓
Care Homes	en suite	✓	
Hospitals	en suite	✓	✓
Hospices	en suite	✓	
Holiday Centres	en suite		✓
Hotels	en suite		

### Suitable for the needs of the carers

The importance of protecting the carers' backs has been fully recognised since the introduction of EC rules, and this is discussed in Chapter 9 *Hoisting*.

## Able to withstand regular and heavy use

This means that the facilities must be robust and suitable for the heaviest and most disabled people. Unfortunately, members of the general public do not always respect the property of others and the quality of the fittings must reflect the ability to withstand some abuse.

## Attractive

All the equipment recommended must be both attractive and easy to clean.

## Good value for money

The cheapest equipment is not always the best buy; the items included in this chapter have been assessed over a number of years and have proved more economical in the long term.

## Choice of products

The questions asked are:

- ⇒ How can the facilities be flexible enough to suit a wide range of disabled people?
- ⇒ What type of toilet will be the most appropriate?
- ⇒ Is the choice of toilet seat important?
- ⇒ Will support rails be useful?
- ⇒ How can the toilet paper be left within reach?
- ⇒ What space is needed around the fittings?
- ⇒ Which model of washbasin and taps will be the most satisfactory?
- ⇒ Would a changing bench be helpful?
- ⇒ What type and model of hoist should be used?
- ⇒ Will a bath (with over-bath shower) or a level-access shower (or both) be needed?
- ⇒ What type of bath will be needed?
- ⇒ What type of level-access shower will be needed?
- ⇒ What type of shower screen will confine the water?
- ⇒ What type of shower valve?
- ⇒ What type of shower seating should be used?
- ⇒ What type of flooring will be the most satisfactory?
- ⇒ Will colour contrast help?

## How can the facilities be flexible enough to suit a wide range of disabled people?

### **Pressalit Multi System**

This is the recommended solution. It consists of an aluminium horizontal wall track (the Multi track), which is fixed around the room with the top of the track **850mm** from the floor. Individual height-adjustable bracket fittings are then hung on the track.

The advantage is that both the position of the fittings and their height are instantly adjustable. This is invaluable to ensure maximum independence for each individual in relation both to the space needed for transfers and to provision of leverage to stand up. The only permanent fixture in a school toilet is the toilet pan; therefore, when making decisions regarding the positioning of the fittings, this should be the first item to be considered. In residential situations, if a bath is included in the design, this will also be a fixture.

## What type of toilet will be the most appropriate?

The choice is between the following:

- ⇒ close-coupled toilet;
- ⇒ low-level cistern with long flush pipe;
- ⇒ back-to-the-wall/wall-mounted pan with a concealed cistern;
- ⇒ shower toilet.

### Close-coupled toilet

This type may not be satisfactory when used with a superimposed shower/toilet or bath chair. This is because the front-to-back measurement between the front of the cistern and the front of the pan may not be sufficient to allow the seat aperture of the chair to line up accurately with the pan below.

### Low-level cistern with long flush pipe

For these reasons, unless a shower toilet is installed, a low-level cistern and a pan with an inlet that can be lengthened is recommended to allow **600mm** between the front of the cistern and the front of the pan.

### Back-to-the-wall/wall-mounted pan with a concealed cistern

This option is expensive unless a new building is planned. The advantage of this type of installation is that the toilet is practical to keep clean, which in hospital and residential use is particularly important. With this installation it will be essential to install a backrest.

The following recommendations should be considered:

- any toilet pan chosen should project at least **700mm** forwards from the wall;
- there should be **600mm** from the front of the cistern to the front of the pan;
- the optimum pan height is difficult to determine because this will depend on whether the user needs to superimpose a chair over the pan, needs to transfer sideways with or without help, or needs a certain height in order to stand up. As the height of the pan can be raised with a toilet raiser, but cannot be reduced, the height chosen for multi-use must be the minimum height, which is **400mm**;
- the cistern should be relatively narrow so that it does not obstruct side support arms;
- a spatulate cistern flush lever promotes independence;
- a back support hung on the Multi track should be provided when using a concealed cistern because, when the pan is set forwards, the cistern and lid cannot be used for support.

*N & C Building Products Ltd/Phlexicare Division*

### Shower toilet

This toilet was previously termed a combined WC/bidet. It is the recommended solution because it allows the user the privacy of cleansing independently if unable to reach to use lavatory paper. In multi-use, if the bidet action is not needed, the pan can be used as a standard pan. Further details are included in Chapter 8a *Equipment for Adaptations*, with a comparative chart of the alternative models.

Clos-o-Mat: *Total Hygiene Ltd*  
Geberit: *ESL Healthcare Ltd*

## Is the choice of toilet seat important?

Yes, as seats need to be *comfortable* because a disabled person may take a long time on the toilet, *supportive* if there is a problem in balancing, and *flat and wider* if the person is able to transfer independently.

The following need to be considered:

- ⇒ padded seats;
- ⇒ *Pressalit* seats;
- ⇒ use with shower toilet;
- ⇒ raised toilet seat;
- ⇒ hinges.

### Padded seats

Although comfortable, padded seats are not recommended for multiple use because they can be torn and are more difficult to keep clean.

### *Pressalit* seats

The following are all suitable for any of the recommended toilets.

#### Colani

The surface is curved and, because the user sits in a hollow, it is supportive and helps balancing, which will be important for anyone lacking trunk control. The size of the hole is smaller than average, which makes this seat particularly suitable for children from approximately the age of 6. However, it is not suitable for anyone who is able to transfer, but is unable to push down on their arms to lever themselves out of the hollow.

#### Ergosit

This seat is recommended for anyone able to transfer, but who needs a wider surface with a good grip for hand support.

#### Dania

If changing the seats is not practical, this model is a compromise solution that will suit most people. The lid is shaped and, when raised, acts as a back support. It can also be supplied with an open front, which is small enough to prevent the person's thighs from becoming wedged.

### Use with shower toilet

All these non-raised seats are modified by *Total Hygiene* and supplied with their Clos-o-Mat – one of the shower toilets available.

### Raised toilet seat

All the above seats are available raised **50mm**, and the Dania has the additional options of a height of **100mm** and an open front. These should be available to help anyone who can stand up only from a higher position. The pan would not then be suitable for use with a superimposed chair; in a multi-use situation, the raised seat would be removed when not needed.

## Hinges

Public-use hinges B84, which have a through rod, are recommended. The fact that these are also available in an anti-theft version B85 is a recommendation for the quality of the seat! The durability of these seats is the product of the strength of the hinges and the provision of stability buffers, which are mounted at the front and protect the hinges from becoming loose. This is important for anyone who cannot lower themselves gently on to the pan and the seat has to be capable of withstanding a 'snatch' weight.

*Pressalit Care Ltd*

## Will support rails be useful?

The usefulness of rails will depend upon the individual person, and also on being at the optimum height and in the correct position for each user, as follows:

- ⇒ fixed height;
- ⇒ variable height only;
- ⇒ vertically and laterally adjustable;
- ⇒ frontal crossbar.

## Fixed height

Fixed-height support arms are used where the needs of individuals are static/stable and easily identified, or where help is not always at hand to adjust the equipment. In a multi-use situation this type of rail does not provide the flexibility that is needed. (A continuous handrail may help anyone who is unsteady on their feet to walk around the room.)

## Variable height only

These are adequate when it is known that height requirements will vary, but the position of the rails will not need to be changed. If at any time the rails are not required, they can be removed temporarily and relocated or stored.

## Vertically and laterally adjustable

When the needs are unknown or variable, both the height and position of the support arms can be altered to suit each individual as closely as possible. The room can be used equally well by an independent person or someone who needs help, and also in a way that suits the carer.

These products are recommended for multiple-use situations. With the Multi track, the rails can be adjusted to be as near to the user as necessary, and to project **100mm** in front of the toilet pan to provide support when standing up. The height of the rail can be adjusted within a range of **250mm**. An additional advantage of these rails is that they are particularly easy to raise and lower, which will be important for someone with limited muscle power.

## Frontal crossbar

Many children need a support in front of them, and the crossbar from *Pressalit* is quick and easy to fix between two support arms – and to remove. An alternative option, when the toilet is in a corner, is to use an additional support arm on the Multi track on the adjacent wall, so that it lowers in front of the person in the most comfortable position, which can be altered as necessary.

## How can the toilet paper be left within reach?

The arm should include a toilet-roll holder to enable the paper to be within the reach of most users. This should be supplied even with a shower toilet, as the latter may not be used on every occasion as a bidet and drier.

## What space is needed around the fittings?

This is discussed in detail in Chapter 14 *Scales and Templates* and the overlay sheet can be used to check the measurements.

## Transfer space at the side of the toilet

Ideally, this should be **1500mm** with a minimum of **900mm** and, where there is sufficient space, this should be the same on each side of the pan. However, if this is not possible, the distance from the centre of the pan to the nearest obstruction on the adjacent wall on one side should be a minimum of **500-600mm**.

The option to move a basin sideways can create space on both sides of the toilet to achieve left- or right-handed transfers and for people with good arm function, independent washing before transfer away from the toilet.

## Space in front of the basin

This should be a minimum of **1000mm** (or, ideally, **1500mm**) in order that the basin can be approached squarely in a wheelchair.

## Which model of washbasin and taps will be the most satisfactory?

The following should be considered:

- ⇒ height;
- ⇒ method of height adjustment;
- ⇒ Multi System lateral basin movement;
- ⇒ size;
- ⇒ recommended model;
- ⇒ taps;
- ⇒ Multi System accessories;
- ⇒ position of a mirror.

## Height

All wheelchairs have varying heights of armrests and, in the case of powered wheelchairs, the height of the joystick control will vary. Therefore, the basin must be height adjustable to allow wheelchair access to every model of chair. A fixed height, set at the maximum level likely to be needed is not a solution because if it is too high, people with a neuromuscular condition would be unable to lift their arms on to the top of the basin.

## Method of height adjustment

A choice of three mechanisms is available:

- ⇒ electric;
- ⇒ counterbalanced;
- ⇒ manual.

### Electric

If independence is a priority, this instant adjustability is essential for anyone unable to lift their arms or with limited upper body strength.

**450mm** adjustment: *Astor-Bannerman (Medical) Ltd*

**300mm** adjustment: *Pressalit Ltd*

**400mm** adjustment: *Southern Care Systems Ltd*

### Counterbalanced

This has a built-in gas cylinder, which counterbalances the weight of the basin and allows the height to be adjusted with ease by most disabled people unless their arms are particularly weak. This may be difficult for anyone with a neuromuscular condition, but in the settings being discussed there will be a helper available to alter the basin height prior to use. The basin mounting has **300mm** of adjustment, e.g. from **667** to **967mm**.

*Pressalit Ltd*

### Manual

This system may be adequate for people who need infrequent adjustment of the basin; however, if the height needs to be adjusted regularly for more than one person, a counterbalanced or electric system would be more appropriate.

*Pressalit Ltd*

## Multi System lateral basin movement

The above three mechanisms can also be supplied with sideways movement (with a limit of **680mm** for the electrical and counterbalanced systems and up to **1800** for the manual system).

*Pressalit Ltd*

### Size

Ideally, the basin should be approximately **1200mm** in width to allow sufficient space to leave toiletries within reach, and **670mm** front-to-back to enable the user to get right up to the front of the basin without the wheelchair footrests touching the wall behind the basin. A bolt-mounted shallow basin would be suitable for the above adjustable-height systems.

### Recommended model

There are two alternatives, the ABW4 or Beaumonde, both of which can be fixed to the Multi track using special connecting brackets to link the basin mounting to the vanity unit or basin. (The basin should be fitted with flexible hosing so that the position can be adjusted as necessary.)

ABW4: *Astor-Bannerman (Medical) Ltd*

Beaumonde: *N & C Building Products Ltd/Phlexicare Division*

### Taps

The taps should be low and have **150mm** levers to make them easier to reach. The ABW4 can be supplied with very satisfactory lever taps. The alternatives for use with the Beaumonde basin are Novalever basin pillar taps, which are available from the same supplier as the basin. Mixer taps centrally placed are not advisable as the user may find them to be an obstruction when leaning forwards over the basin.

*Astor-Bannerman (Medical) Ltd*

*N & C Building Products Ltd/Phlexicare Division*

## Multi System accessories

A wide range of useful items are available to add to the convenience of the Multi System. In addition to the toilet-roll holders already discussed, these include soap dishes, towel rails, shelves and baskets.

*Pressalit Care Ltd*

## Position of a mirror

A large mirror should be fixed to the wall straddling the area where the washbasin will be positioned. This should extend from **50mm** above the Multi track (i.e. **900mm** from the floor) to a height of **2000mm**.

## Would a changing bench be helpful?

Yes, if there is sufficient space. Ideally, this should be powered, as height adjustment will ensure that it is at the optimum height for the carer and will assist with transfers to and from a wheelchair. It will be helpful if it has an elevating backrest to enable the disabled person to be supported sitting up, or in such situations as being dressed and while the hoist sling is put on.

For a fixed-height model for multi-use, the *Pressalit* shower bench is recommended because it can be used on the Multi track. Unfortunately, it does not have a backrest, but the firm are considering this modification. Alternative powered models with a backrest are available from:

*Astor-Bannerman (Medical) Ltd*

*Otto Bock UK Ltd*

*Scanflex Ltd*

*Southern Care Systems Ltd*

## What type and model of hoist should be used?

The choice is between a ceiling or mobile hoist and the points to be considered, together with suggested recommended models, are discussed in Chapter 9 *Hoisting*. In a school, a hoist may be needed in a number of rooms, in which case a mobile hoist is the best solution. However, if a hoist is needed in the toilet only, a ceiling hoist is likely to be the best option; this is because it does not require physical effort to manoeuvre and does not take up any space in the room. A room-covering system is likely to be the most satisfactory choice.

See comparative chart in Chapter 9 *Hoisting*.

## Will a bath (with over-bath shower) or a level-access shower (or both) be needed?

Where the emphasis is on multi-use, ideally there should be provision for both a separate bath and a shower. The bath should have an integral shower or a wall-mounted shower; the need and positioning are discussed in Chapter 15 *Adaptation Specifications*.

## What type of bath will be needed?

The height of the bath must be adjustable to allow the carers to work at the correct height for their backs. Many institutional baths of this type are available; however, in the context of this manual, where the emphasis is on independence, the *Arjo* Sovereign Hi-Lo should be considered.

*Arjo Ltd*

## Arjo Sovereign bath with shower

As there will be a hoist in the bathroom, this range of baths is ideal as they are particularly practical for carers and yet do not look institutional. Because of the need to protect the carers' backs, the model recommended is the Hi-Lo, which is height adjustable. This bath is described in detail in Chapter 8a *Equipment for Adaptations*.

Arjo Ltd

## What type of level-access shower will be needed?

The items to be considered are:

- ⇒ size;
- ⇒ flooring or tray.

### Size

The size and shape of a level-access shower will be influenced by the size and shape of the room and will be either square or oblong. The recommended sizes are approximately **1000 x 1000mm** or **1500 x 900mm**. If an oblong tray is chosen, the **900mm** depth is recommended because, if the tray is used with a screen, a smaller tray would not allow sufficient space in the shower.

### Flooring or tray

The shower must be a level-access installation and the choice is between a floor laid with a gentle gradient (ideally to a corner drain), a conventional shower tray, Impey Level Dec or a Neatdek - which has the advantage of being the only truly level shower base. For communal use, a wet-floor area is usually the most practical, where possible restricting the gradient to a minimum to help anyone with severe arm weakness who has difficulty propelling up a slope. It is important that the floor is laid by experienced builders, as confining the water without residual puddles will depend upon the correct gradient.

Impey Level-Dec: *Creative Healthcare Ltd*

Other trays: *Autumn Mobility Ltd*

Neatdek: *Go Independent*

Underfloor heating eliminates the need for a radiator and ensures that the floor surface dries quickly.

## What type of shower screen will confine the water?

The choice is between:

- ⇒ portable or wall-fixed screens;
- ⇒ shower curtains – full or half height.

### Portable or wall-fixed screens

These are recommended for use when the disabled person is independent and has no difficulty in positioning or closing the screens, as they confine the water very satisfactorily. Air-assisted models will be easier to open and close. However, where the disabled person depends on help, screens may make it difficult for a carer to lean over the top.

*Autumn Mobility Ltd*

*Go Independent*

## Shower curtains – full and/or half height

If help is needed, half-height curtains fixed below support arms are likely to be the best choice as the carers can position their feet under the curtain, making it easier for them to lean forward. Obviously, the arms are load bearing, with the bonus that they can be leant on by the carers. However, they may also be easier than a shower screen for some disabled people to position independently. It is recommended that the curtains are weighted.

*Pressalit Care Ltd*

In addition, half-height curtains can be used with full curtains, which cover an area of approximately **1500 x 900mm**. The support arm (with half-height curtain) is lowered between the user's wheelchair and the full-length curtain, in order to keep the chair dry and yet to allow the disabled person to transfer and dress in privacy.

*Pressalit Care Ltd*

## What type of shower valve?

The shower valve should be lever operated and with thermostatic control. The valve may be fixed in position or the *Pressalit* Multi shower valve bracket can make movement of the valve possible. Movement allows the valve to be used, for example, for hair washing at the basin, as well as in the shower. The handing of an independent shower can be changed from left to right by moving the valve. The recommended valve is the *Damixa* Thermostatic Shower Mixer.

*N&C Building Products Ltd/Phlexicare Division*

An alternative shower is the *Triton* Millenium with a push-button control. Any shower used must meet EU standards and this must be checked.

## Shower-head holder

This can be mounted on to a *Pressalit* vertical grab rail and a **1000mm** length is recommended for use when either in a chair or standing. The advantage is that the grab rail is stronger than the standard rail installed and can be used as a means of support. If a greater range of positions and heights is needed, two rails can be used.

## What type of shower seating should be used?

- ⇒ wall-mounted shower seat;
- ⇒ self-propelled shower chair;
- ⇒ shower bench.

## Wall-mounted shower seat

The following must be considered:

- ⇒ optional backrest and folding armrests;
- ⇒ height-adjustable support arm;
- ⇒ type of seat;
- ⇒ location of seat;
- ⇒ height adjustability of shower seat.

### **Optional backrest and folding arms**

A backrest will be essential, but should be supplied without the optional standard folding armrests, which will not be long enough for anyone who needs the support to extend in front of their thighs to help them to balance when standing up.

### **Height-adjustable support arm**

As an alternative, the extra projection of the **850mm** support arm would be beneficial; one of these could be slid along the Multi track from the side of the toilet to the optimum position in the shower.

*Pressalit Care Ltd*

### **Type of seat**

The choice is between a padded slip-resistant seat with a ribbed surface for drainage, or a seat with an aperture. The advantage of an aperture is that it provides access for washing and the shape may help stability. The seat depth (front to back) is important to ensure that it is not so narrow that balancing is difficult. An open gap front is not usually recommended for multi-use because, if the users legs are 'windswept', the support will be inadequate and the legs will fall into the gap.

### **Location of seat**

The Multi track allows the seat to be slid towards the wall, so that the disabled person can reach the water controls to be able to use them independently, or away from the wall, so that there is space for a carer on either side to help with washing, repositioning a sling, etc. Alternatively, the seat can be easily relocated to the adjacent wall to provide the option of left- or right-handed use, which may be important for some independent transfers where the user is stronger on one side of the body than the other. This may also be important in a rehabilitation unit where a particular side of the body needs strengthening.

*Pressalit Care Ltd*

### **Height-adjustability of shower seat**

- **Manual adjustment**

If the bather is able to stand up from a seat, but the seat must be at the correct height, the *Pressalit* seat should be used with the Multi track and support arms. The height can be adjusted before the bather enters the shower; this height flexibility makes the shower suitable for the majority of users.

*Pressalit Care Ltd*

- **Electrical adjustment**

Many adults find it difficult to stand safely in a shower; however, if they sit on a shower seat or chair they are unable to stand up independently. The answer is to use an electric height-adjustable seat which rises sufficiently for the user to stand up and yet can be lowered near enough to the floor to allow the bather to sit with feet firmly supported on the floor and with the ability to get down to wash their feet. The seat should have a supportive backrest, and arms that project beyond the front of the seat to provide support when standing.

*Astor-Bannerman (Medical) Ltd*

*Pressalit Care Ltd*

## Self-propelled shower chair

To limit the equipment that needs to be stored when not in use, it may be satisfactory to offer this type of mobile shower chair only. This may be adequate because it can be used both independently by a person able to propel, and also with the help of a carer by others who have restricted arm strength. The priority will be to ensure that the model chosen is supportive and flexible enough in its design to be suitable for people with a wide range of needs. Many shower chairs are available, but the models recommended are modular – with interchangeable seats, armrests and footrest – and, therefore, can be altered to suit the user.

Aquability range: *ASM Accessories Ltd*  
Freeway: *Westholme*

Alternatively, anyone able to propel a wheelchair and transfer independently may find it easier to transfer to and from the more stable wall-mounted shower seat.

## Shower bench

In some cases it is easier to shower a disabled person (particularly a child) who is lying on a shower bench. This will be particularly valuable if the bathroom is not adjacent to the bedroom or ward, as it provides the opportunity to dry and dress the person without transferring to their bed. The bench can be installed at a fixed height (usually **850mm** from the floor) or, ideally, supplied electrically height adjustable, to protect the carers' backs and allow them to work at the optimum height. The alternative is to dry the person on the bed, using waterproof sheeting or a towel to keep the bedding dry; this might be the preferred option in en-suite facilities.

It is likely to be easier to dress someone and to position the ceiling hoist sling when they are sitting up with their back supported; in future, *Pressalit* will be considering the incorporation of a backrest into the bench. The advantage of the *Pressalit* fixed-height bench is that it can be used with the Multi track. Several firms supply benches of this type.

*Astor-Bannerman (Medical) Ltd*  
*Otto Bock Healthcare Plc*  
*Pressalit Care Ltd*  
*Scanflex Ltd*  
*Southern Care Systems Ltd*

## What type of flooring will be the most satisfactory?

### Shower/bathroom

Disabled people who are able to walk, but are unsteady, may depend on a suitable floor surface. Although this must be non-slip, the surface must not be too abrasive as the texture grips the sole of the shoe and makes it very difficult to lift the foot. Non-slip ceramic tiles, *Nairn* Surestep tiles, *Altro* Safety flooring, *Marley* Safetred Aqua/Dimension are surfaces to consider. The alternatives must be practical to clean; surfaces with excessive grit (which are resistant to cleaning) and with bobbles (which harbour dirt around the projections) should be avoided. Laying the floor is a skilled job and employment of a specialist-flooring contractor is advisable.

### Bedroom

As in the bathroom, the surface must be suitable for people who are able to walk, but have difficulty lifting their feet, and/or for those in wheelchairs. If carpet is chosen it will be important that the pile is not so thick that it will be resistant to the wheelchair. Flotex is a very hard-wearing carpet and has been used with success for many years; this has to be balanced against its utilitarian appearance.

*Bonar Floors Ltd*

## Will colour contrast help?

Partially-sighted people will benefit greatly from strong colour contrast. As most flooring, wall materials and sanitaryware are light coloured, a dark blue or red can give excellent colour contrast for the vinyl seating and padded armrests. Supportive products made of matt or non-gloss materials will be less reflective and therefore easier to see. Colours can also have a psychological benefit in making the bathroom more fun to be in and less institutional.

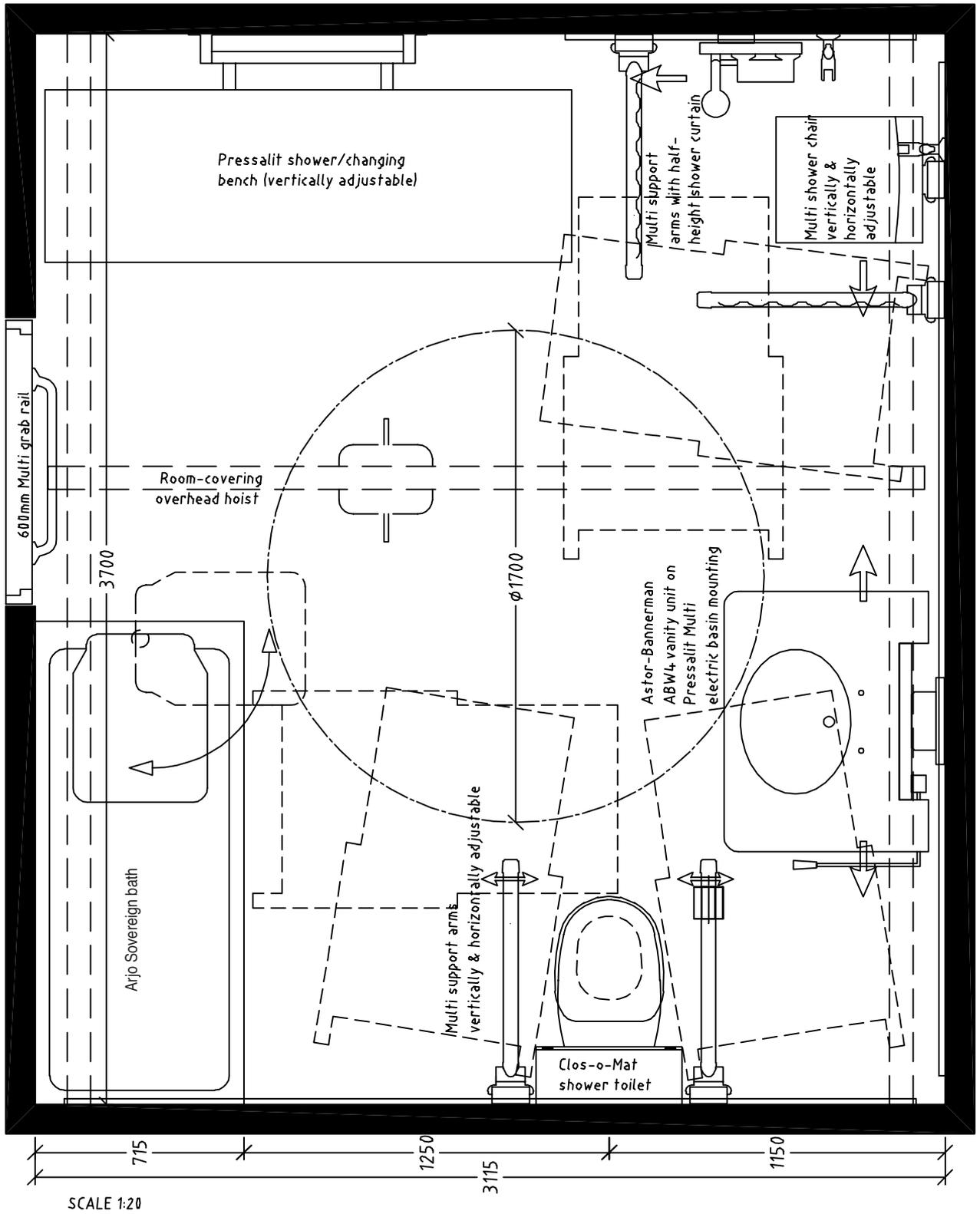
## School bathroom/toilet facilities

The Muscular Dystrophy Campaign is frequently asked to make recommendations when disabled bathroom, toilet and medical facilities in mainstream and 'special needs' schools are planned. Invariably, the facilities are needed for a specific child, but the advice would be, where possible, to design a room that is suitable for all disabled people, irrespective of the disability. This will be cost effective to ensure that it will be appropriate for anyone attending or visiting the school in the future, and essential as more schools are designated as community schools.

### School bathroom facilities

The layout on the next page is an example of appropriate facilities for a school. The following features have been incorporated;

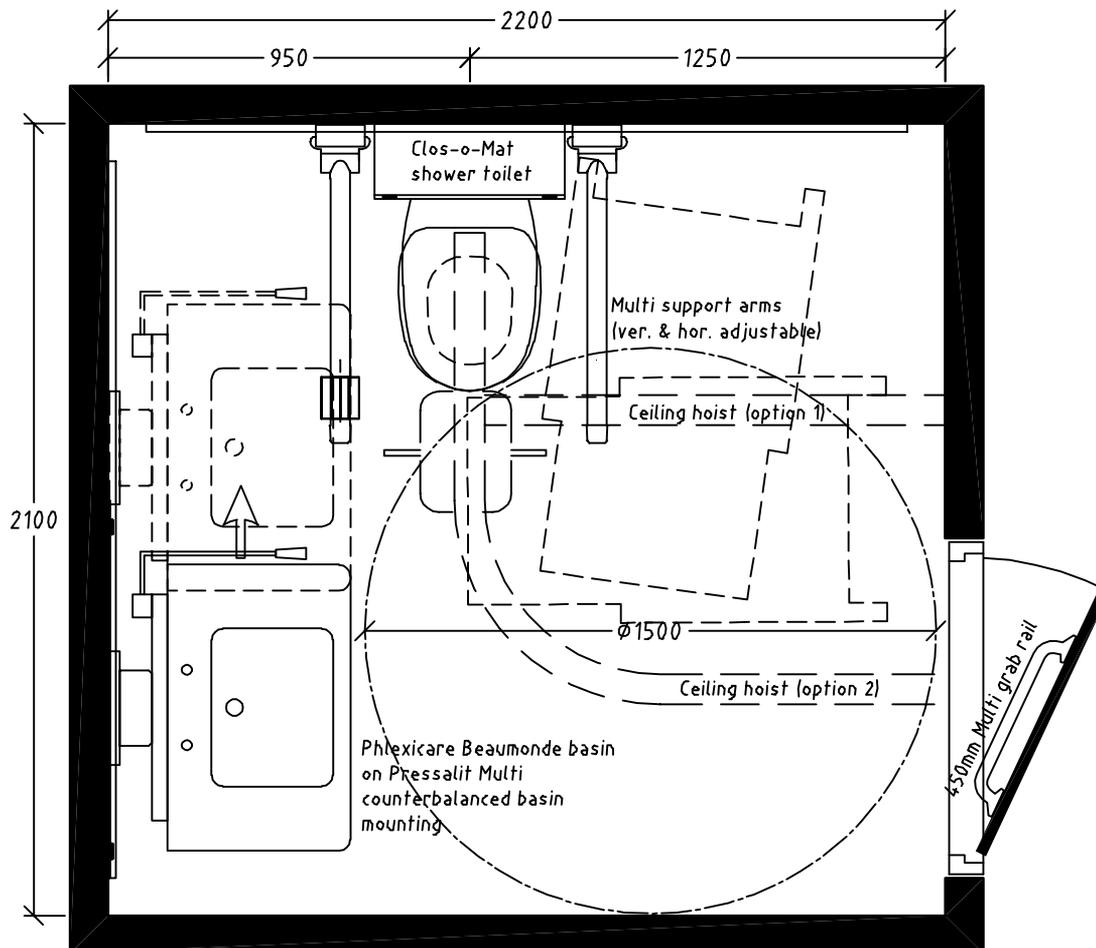
- space on both sides of the toilet for wheelchair and carer access;
- sideways basin movement to within reach of the toilet;
- movement of supportive products to adapt to individual needs;
- turning circle of **1700mm** within the room to allow complete turning of a large mobile hoist or wheelchair;
- shower chair has space away from the corner for assisted showering and can be used in the corner independently left or right handed;
- height-adjustable bath (*Arjo Sovereign Hi-Lo*);
- *Pressalit Care* shower/changing bench.



School bathroom facilities with room size 3700 x 3115mm

## School toilet facilities

The toilet and basin features discussed on page 14 also apply to the toilet facilities, but a room of over **6m<sup>2</sup>** is not always available. The layout below shows a toilet and basin combination in just over **4m<sup>2</sup>**.



*School toilet and basin in a small room*

## Hospital and holiday centres' bathroom/toilet facilities

These are two more building types in which assisted and independent bathing and toileting are likely to be required in the same room. The bathroom and toilet planning discussed in the school facilities are, therefore, equally relevant in these buildings.

It is important that hospital wards and bathrooms in neurological units are appropriately designed and include specialist fittings and equipment. Generally, the facilities offered to disabled people when they are in hospital are inappropriate and, as a result, an admission to hospital can be a very traumatic experience for a severely disabled person. Lack of the correct equipment coupled with an enforced period of immobility, can cause a deterioration in muscle power and mobility and this situation must be avoided.

Residential homes and hospices have a better track record of imaginative planning, and the number of holiday centres anxious to include first-rate facilities for wheelchair users is increasing. An additional bonus would be upgrading selected bedrooms in hotels, which frequently offer disabled facilities that demonstrate a lack of understanding of what is needed.

## Care home, hospice and hospital assisted bathroom/toilet facilities

In care homes, hospices and hospitals, there is likely to be provision for dependent/assisted bathing with en-suite facilities provided for independent use. The layout described on page 14 and illustrated on page 15 provides space for wheelchairs and carers:

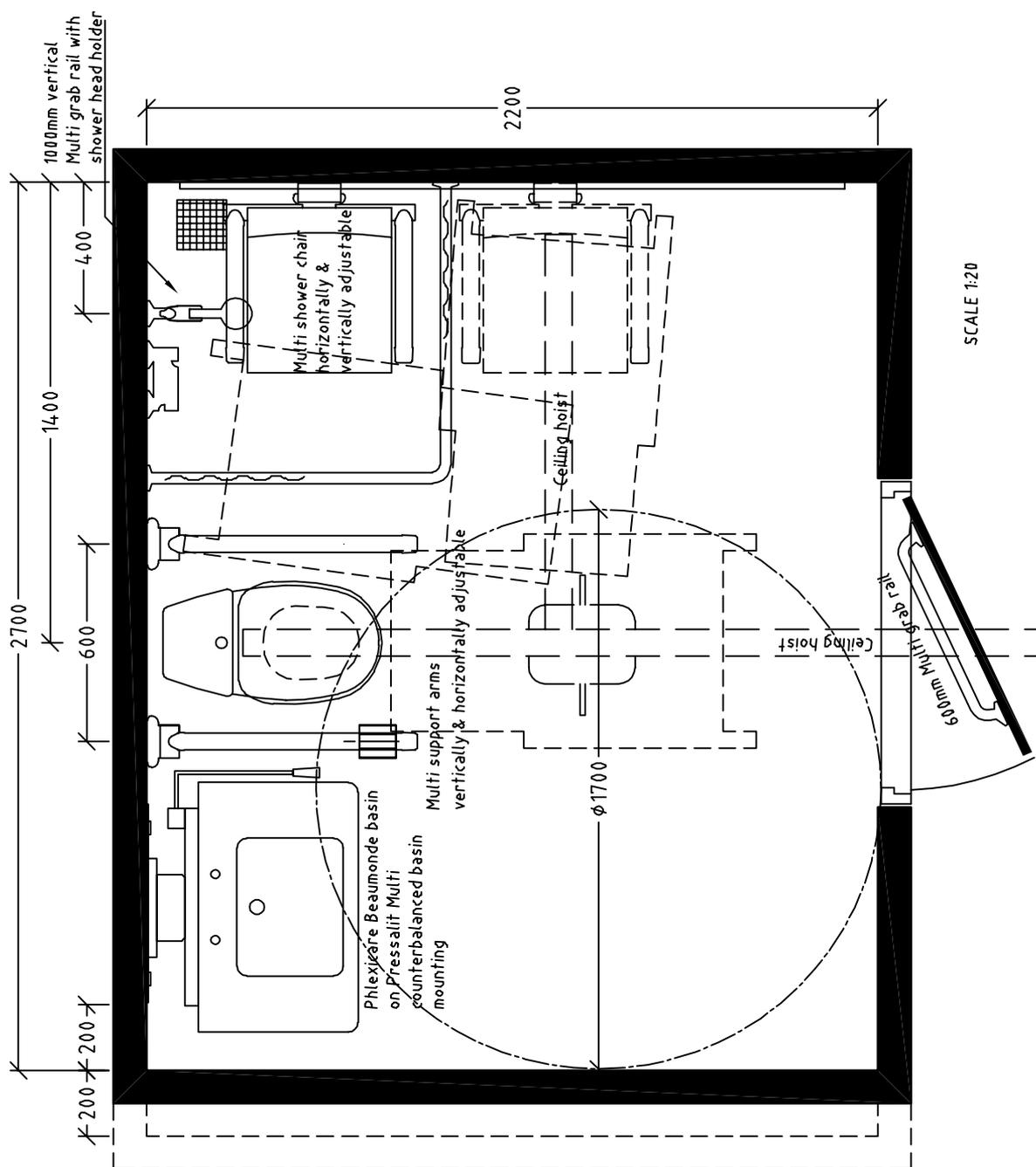
- on both sides of the toilet;
- on both sides of the basin;
- on both sides of the shower seat, and one side and the end of the shower/changing bench.

Each supportive product is height adjustable to meet individual needs and to help the carers' moving and handling procedures.

## En-suite facilities in care homes, hospices, hospitals and hotels

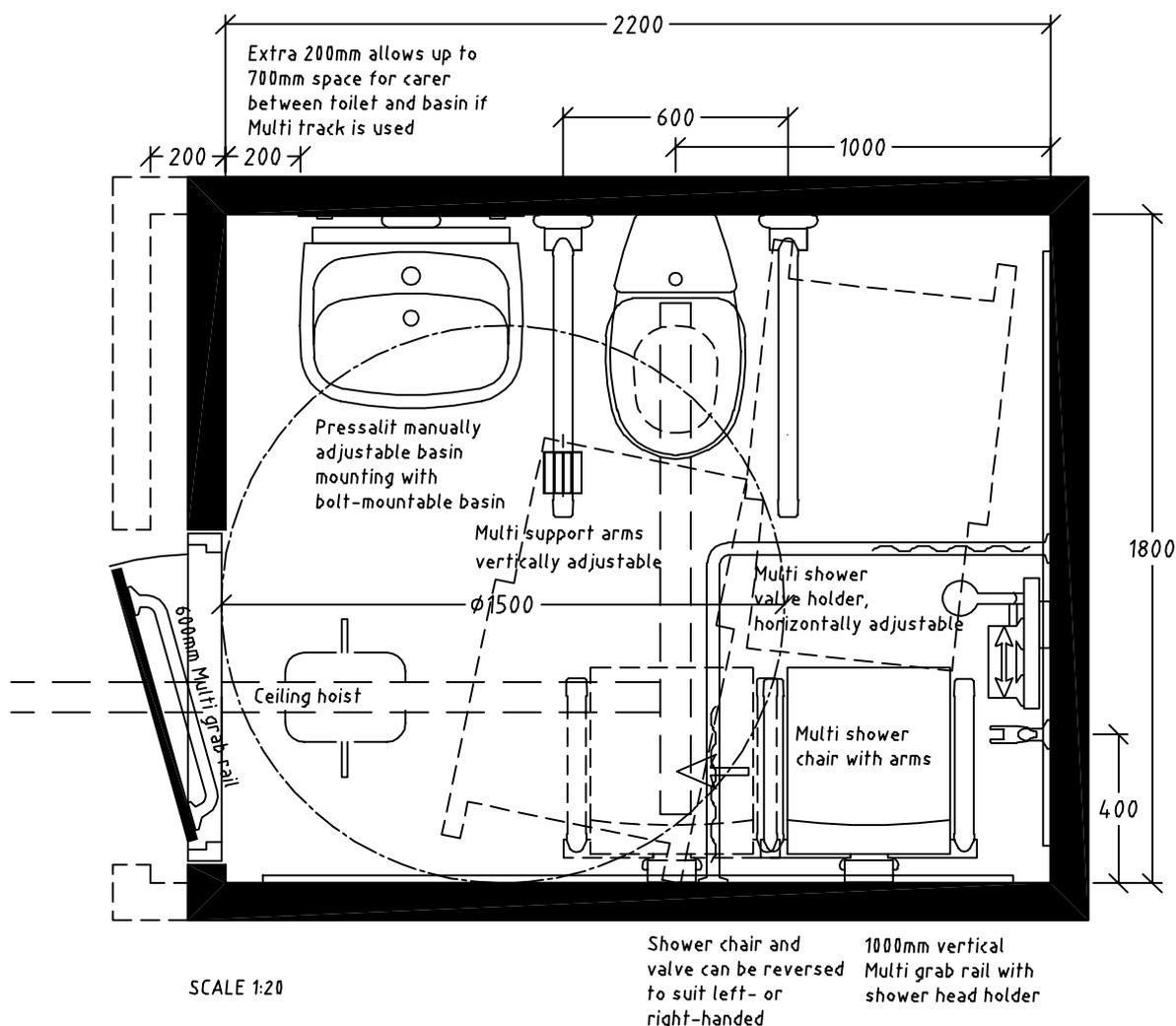
If nearly **6m<sup>2</sup>** of space is available, the layout below would be ideal. It provides:

- space on one side of the toilet and shower for wheelchair transfer (it may be necessary to provide a mix of left- and right-handed layouts);
- height adjustment of supportive products to suit changing needs;
- turning circle of **1700mm** and space for a three-point turn for a large powered chair.



*En-suite facilities with the dotted line above showing the room enlarged by **200mm**. This will allow up to **700mm** space for a carer between the toilet and basin, if the multi-track is used.*

Another room layout is provided on this page. This demonstrates how a facility can be designed in a space of less than 4m<sup>2</sup> for independent use. However, the space limitations would make it difficult for a carer to be of any real help.



### Alternative layout for a small existing en-suite bathroom

## En-suite/bedroom transfer

The bathroom and bedroom must be en suite so that a person can move within the warmth and privacy of the two rooms and can be dressed on the bed following bathing.

Factors to be considered regarding the two rooms are, for example, where and how to transfer from one position to another – bed to shower, hoist to wheelchair, wheelchair to shower chair. Attention should be paid to the placement and type of door, the size of the doorway and floor level differences (if any). For a ceiling hoist, differences in the ceiling height are equally important. See Chapters 8a *Equipment for Adaptations*, 9 *Hoisting*, and 15 *Adaptation Specifications*.

## The method of transfer between the bedroom and bathroom

- ⇒ walking;
- ⇒ using a wheelchair, self-propelled or powered;
- ⇒ propelling or pushed on a shower chair;
- ⇒ using an extended track of a ceiling hoist;
- ⇒ use of room-to-room systems.

### Walking

The floor surface must be non-slip, but must not provide any resistance to the soles of shoes, as this makes it difficult to lift the feet. The surface should be easy to keep clean.

### Using a wheelchair, self-propelled or powered

The significance of the chair lies in its size and the turning space that it needs. Most self-propelled wheelchairs use a **1500mm** turning circle, but a powered chair needs **1700mm**, and this should be the measurement that is used when calculating the required circulation space. As has already been discussed, in many bathrooms it is unrealistic to have a room that is large enough to include a turning circle; the transfer space at the side of the toilet pan can be used for a three-point turn in which to reverse the chair to go out of the room.

Where a wheelchair is used in the bathroom and the person can transfer independently, it is important that the floor is level at the side of the pan to ensure that the wheels are stable.

### Propelling or pushed on a shower chair

### Using an extended track of a ceiling hoist

A ceiling hoist will be a better choice than a mobile hoist because the former is unobtrusive and easier to use; the type of ceiling hoist will depend on whether the rooms are:

- ⇒ en suite;
- ⇒ multiple occupancy of bedroom and shared use of bathroom.

### En suite

This can have a single track passing over the bed and extended into the bathroom usually with a switched track or ceiling turntable (preferably electric) in the bathroom and depending on the layout, also in the bedroom. With practice, users become very adept at using electric switched track or engaging electric ceiling turntables prior to rotation.

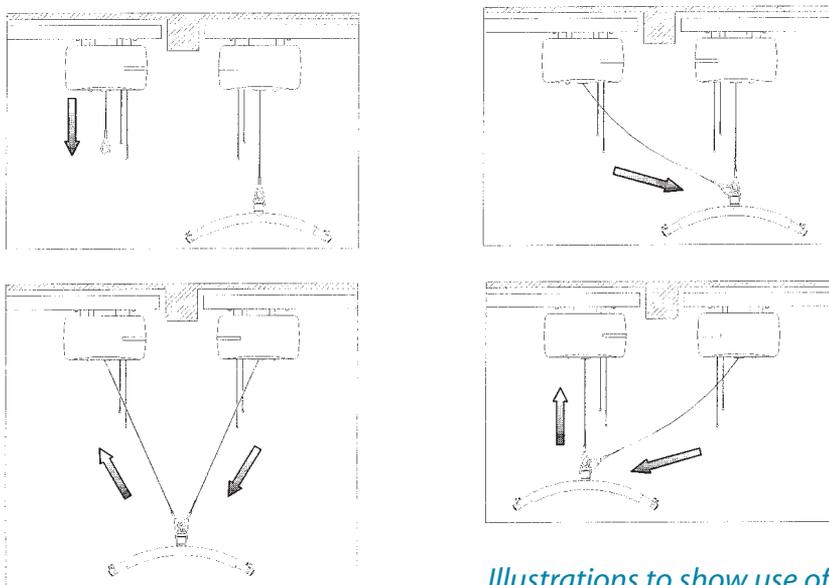
### Multiple occupancy of bedroom and shared use of bathroom

Two room-covering systems (sometimes called X-Y, or H-systems), installed in both the bedroom and bathroom, are recommended because these allow the pick-up point to be anywhere within the rooms. This will be invaluable when a number of people are using the rooms. Where the rooms are adjacent, the track should be extended between both rooms. If experience shows that the hoist is needed in both rooms at the same time, an additional hoist can be provided at a later date.

A comparative chart of recommended models is included in Chapter 9 *Hoisting*.

## Use of room-to-room systems

There will be occasions where the wall above the door is a supporting lintel; to avoid the expense and structural difficulties of inserting a supporting beam to enable a track to be installed between the two rooms, the solution is to use a 'swing kit' to allow the hoist to be used in both rooms without having to lower the user down into a wheelchair between the rooms. The hoists in both rooms are taken on their tracks to each side of the wall over the door opening and by sharing a spreader bar the person is transferred smoothly between two hoists. See diagrams below.



*Illustrations to show use of 'Swing Kit'*

*Drawings reproduced with kind permission of Guldmann*

## Bedroom

Factors to be considered are:

- ⇒ the recommended size of rooms and circulation needed;
- ⇒ the optimum type of flooring;
- ⇒ the recommended bed.

### The recommended size of rooms and circulation needed

Questions are frequently asked in relation to the optimum size of the rooms. These are difficult to answer without knowing the details of the access to the rooms, the shape of the rooms, the number and size of windows and (if an extension is proposed) how this will dovetail on to the existing building. Instead, it is more constructive for the architectural designer to be given an accurate brief early in the planning process; when the essential features and space dimensions have been considered, these will determine the size of the rooms.

An increasing number of the wheelchairs being used are becoming more sophisticated and, as the design features improve, so the size increases. As a result, the turning circle used in planning should be **1700mm**. However, as previously discussed, this may be unrealistic in the bathroom; the transfer space at the side of the toilet can, therefore, be used to reverse the wheelchair, to carry out a three-point turn.

## The optimum type of flooring

As in the bathroom, the surface must be suitable for people who are able to walk, but who have difficulty in lifting their feet and for those in wheelchairs. The choice will depend upon the ease of cleaning and whether this takes priority over the creation of an attractive environment. A compromise between linoleum and carpets might be hardwood floors, but these must not be polished and, for safety reasons must not be covered by rugs.

## The recommended bed

### Electric bed

An electric bed is invaluable and this should be both the correct width and height.

#### Width

There is a choice between a single (with either a child or adult platform), a wide single or a double bed. If more than one electric bed is to be provided, it is recommended that there should be an equal number of single and wide single models, with the use of double beds where appropriate. Many disabled people prefer a large bed, even when sleeping on their own; however, if they depend on carers, a double bed may make it difficult to reach them when they are lying in the centre.

#### Height

It is important that the height is electrically adjustable to help the user to get in and out of bed at the optimum height and to alter the height to suit the nurses/carers working at the bedside (this is an important feature to protect carers' backs). The minimum height may be critical to anyone who needs to transfer sideways to get in and out of bed and who finds it easier to transfer 'downhill'.

Further details of the features and range of recommended beds are included in Chapter 8c *Electric Beds*.

## Drawing of plans

### Involvement of an occupational therapist

This will be essential in order to consider the alternatives discussed in this chapter. However, if the facilities are to be truly multi-use, the assessment of the needs of any individual child or adult will not be relevant, other than as a means of checking that the provision has been designed to embrace all types and severity of disability.

### Free design service from *Pressalit Care Ltd*

This service will be invaluable to anyone making recommendations and to architectural designers who will be responsible for drawing up the plans. The firm supplies an excellent video, which illustrates the products and the features that are discussed in this chapter. For anyone needing advice, contacting the firm may be the best way to start.

*Pressalit Care Ltd*, Riverside Business Park, Leeds Road, Ilkley, West Yorkshire LS29 8JZ  
tel: 01943 607 651 fax: 01943 607 214 e-mail: uk@pressalitcare.com web: www.pressalitcare.com

### Appointment of an architectural designer

See Chapter 13 for details of the innovative service, *Muscular Dystrophy Adaptations & Building Design Network*.

## Check-list

This check-list has been included to:

- identify the options;
- provide a time-saving method of recording the decisions made;
- provide an architectural brief for the drawing up of the plans;
- consider the funding options;
- ensure that all the details have been included.

*The user should tick the boxes of the items to be included*

### Facilities

- En suite with ceiling hoist
- Separate rooms/transfer with chair

### Doors and accessories

- Clear opening: **900mm/1000mm**
- Inward/outward/swing/sliding
- Position of door handle

### Turning circle allowed

- Manual wheelchair: **1500mm**
- Electric wheelchair: **1700mm**

### Measurement around toilet

- Exposed side: **900 – 1500mm**
- Both sides: **900 – 1500mm**
- Exposed side: **900mm** (minimum required if space is limited)
- Centre of toilet to wall/obstruction: min. **500mm**

### Type of toilet

- Low-level cistern with long flush pipe  
*Twyford Ltd*
  - From the back wall: **700mm** min.
  - Front of cistern to front of pan: **600mm**
    - Narrow cistern
    - Spatulate flush lever  
*N & C Building Products Ltd/Phlexicare Division*
    - Backrest  
*Pressalit Care Ltd*
- Back to the wall with a concealed system
- Shower toilet
  - Clos-o-Mat  
*Total Hygiene Ltd*
  - Geberit  
*ESL Healthcare Ltd*

## Toilet seat

- Colani
- Ergosit
- Dania
- Raised toilet seat **50mm** or **100mm**
  - B84 hinges
  - B85 hinges

*Pressalit Care Ltd*

## ✓ Raised toilet plinths

- 50mm**
  - 75mm**
  - 100mm**
- Autumn Mobility Ltd*

## Support arms

- Fixed height
  - Variable height
  - Vertically and laterally adjustable
  - Frontal crossbar
- Pressalit Care Ltd*

## Accessories

- Toilet-roll holder
  - Soap dish
  - Towel rail
  - Shelf
  - Baskets
- Pressalit Care Ltd*

## Bathing

- Sovereign bath + shower  
*Arjo Ltd*
- Other alternatives .....
- Level-access shower
- Bath and level-access shower

## Level-access shower

- Sloping floor
- Shower trays  
*Autumn Mobility Ltd*  
*Go Independent*
- Impey Level-Dec  
*Creative Healthcare Ltd*
- Neatdek  
*Go Independent*

**Shower seat**

- Wall mounted
- Backrest without folding arms
- Height-adjustable support arms
- Ribbed seat
- Seat with aperture  
*Otto Bock Healthcare plc*  
*Pressalit Care Ltd*
- Manual height adjustment  
*Pressalit Care Ltd*
- Electrical height adjustment  
*Astor-Bannerman (Medical) Ltd*  
*Pressalit Care Ltd*

**Shower chair**

- Self-propelled
- Attendant shower chair
- Aquability  
*ASM Accessories Ltd*
- Freeway  
*Westholme Ltd*

**Shower/changing bench**

- Astor-Bannerman* powered (optional backrest)
- Otto Bock* fixed height with brackets (with backrest)
- Pressalit* powered or fixed height on Multi track
- Scanflex* powered or fixed height (with backrest)
- Southern Care Systems* powered or fixed height (with backrest)
- Other .....

**Confining the water**

- Portable screen
- Wall-mounted screen  
*Autumn Mobility Ltd*  
*Go Independent*
- Full-length curtain
- Half-height curtain  
*Autumn Mobility Ltd*
- Full-length and half-height curtain  
*Pressalit Care Ltd*

**Thermostatic shower valve**

- Fixed position  
*Triton*
- On Multi shower valve bracket  
*N & C Building Products Ltd/Phlexicare Division*

## Shower-head holder mounted on

- Multi grab rail  
*Pressalit Care Ltd*
- Standard shower head holder on lightweight rail
- Two shower rails at different heights/positions  
*Pressalit Care Ltd*

## Space in front of basin

- 1000mm
- 1700mm (to provide turning circle for large wheelchairs)

## Height-adjustable washbasin mounting

- Electric  
*Astor-Bannerman (Medical) Ltd*  
*Pressalit Care Ltd*  
*Southern Care Systems Ltd*
- Manual
- Counterbalanced  
*Pressalit Care Ltd*

## Model of washbasin (for use with *Pressalit Care* Multi track)

- ABW4  
*Astor-Bannerman (Medical) Ltd*
- Beaumonde  
*N & C Building Products Ltd/Phlexicare Division*

## Taps

- Lever  
*Astor-Bannerman (Medical) Ltd*
- Novalever basin pillar  
*N & C Building Products Ltd/Phlexicare Division*

## Accessories for basins

- Modular shelves
- Multi baskets
- Towel rails  
*Pressalit Care Ltd*

## Position of mirror

- On wall 50mm above Multi track – up to 2000mm from floor

## Heating

- Radiators
- Under-floor heating

## Colour contrast/matching

- White
- Blue
- Red

## Bathroom flooring

- Non-slip ceramic tiles
- Altro Safety
- Marley Safetred Aqua/Dimension
- Nairn Surestep
- Other .....

## Hoisting

- Single track wall-to-wall in bedroom
- Extended track into bathroom
- Single track with turntable in bathroom  
See Chapter 9 *Hoisting*
- Room-covering hoist in bedroom
- Room-covering system in bathroom  
*Arjo Ltd*  
*Chiltern Invadex Ltd*  
*Liko (UK) Ltd*  
*Moderna Contracts Ltd*  
*Southern Care Systems Ltd*  
*Westholme Ltd*
- Mobile hoist

## Electric bed

- Child's single  
*Ashworth Trading*  
*Bakare Beds Ltd*  
*Scan Mobility Ltd*
- Single  
*Bakare Beds Ltd*  
*Huntleigh Healthcare Ltd*  
*Scan Mobility Ltd*  
*Moderna Contracts Ltd*
- Wide single  
*Ashworth Trading*  
*Bakare Beds Ltd*  
*Scan Mobility Ltd*
- Double  
*Ashworth Trading*  
*Scan Mobility Ltd*  
*Theraposture Ltd*

# Addresses

## manufacturers/suppliers/sources of advice

### Muscular Dystrophy Campaign Family Care Officers & National OT Advisor

To be used in conjunction with the following:

Chapter 8	<i>Equipment for Adaptations/Seat to Standing/Electric Beds/Wheelchairs;</i>
Chapter 9	<i>Hoisting;</i>
Chapter 10	<i>Disability Needs Assessment Form/Architectural Designer's Brief;</i>
Chapter 15	<i>Adaptation Specifications.</i>

#### Action Assist Ltd

43 Kirkgate  
Sherburn In Elmet  
Leeds  
LS25 6BH  
tel: 01977 689 400  
fax: 01977 689 401  
e-mail: actionassistltd@aol.com

#### Adaptachair Ltd

The Old Laundry  
Mole Bridge  
South Molton  
Devon  
EX36 3DT  
tel: 01769 573 197  
fax: 01769 574 511  
e-mail: sales@adaptachair.co.uk  
web: www.adaptachair.co.uk

#### Advance Seating Designs

Unit H Field Way  
Metropolitan Park  
Greenford  
Middlesex  
UB6 8UN  
tel: 020 8578 4308  
fax: 020 8578 4352  
e-mail: chairs@asd.co.uk  
web: www.asd.co.uk

#### Aldersley Battery Chairs Ltd

New Cross Street  
Wednesbury  
West Midlands  
WS10 7ST  
tel: 0121 568 8999  
fax: 0121 568 8868  
e-mail: sales@aldersleyexcel.co.uk  
web: www.aldersleyexcel.co.uk

#### Altro Ltd

Works Road  
Letchworth  
Hertfordshire  
SG6 1NW  
tel: 01462 480 480  
fax: 01462 480 010  
e-mail: info@altro.co.uk  
web: www.altro.co.uk

#### Apres Shower Dryers Ltd

Apres House  
Woodhill Street  
Bury  
Lancs  
BL8 1AT  
tel: 0161 761 3131  
fax: 0161 764 5588  
e-mail: info@apresshower.com  
web: www.apresshower.com

### **Arjo Ltd**

St Catherine Street  
Gloucester  
GL1 2SL  
tel: 08702 430 430  
fax: 01452 428 344  
e-mail: [uksales@arjo.co.uk](mailto:uksales@arjo.co.uk)  
e-mail: [ukservice@arjo.co.uk](mailto:ukservice@arjo.co.uk)  
web: [www.arjo.com](http://www.arjo.com)

### **Ashworth Trading**

"The Beeches"  
Narrow Lane  
Clieves Hills  
Aughton  
Lancs  
L39 7HD  
tel: 01704 840 525  
fax: 01704 841 677  
e-mail: [s.ashworth@fsbdial.co.uk](mailto:s.ashworth@fsbdial.co.uk)

### **ASM (Accessories) Ltd**

Picow Farm Industrial Estate  
Runcorn  
Cheshire  
WA7 4UG  
tel: 01928 574 301  
fax: 01928 575 130  
e-mail: [sales@asmmedicare.com](mailto:sales@asmmedicare.com)  
web: [www.asmmedicare.com](http://www.asmmedicare.com)

### **Association for Glycogen Storage Disease**

(see Chapter 5 *Muscular Dystrophy & Allied Neuromuscular Conditions*)

### **Astor-Bannerman (Medical) Ltd**

Unit 11f  
Coln Park  
Andoversford  
Cheltenham  
GL54 4LB  
tel: 01242 820 820  
fax: 01242 821 110  
e-mail: [sales@astorbannerman.co.uk](mailto:sales@astorbannerman.co.uk)  
web: [www.astorbannerman.co.uk](http://www.astorbannerman.co.uk)

### **Autumn Mobility Ltd**

Autumn House  
10–16 Shepherds Street  
Royton  
Oldham  
OL2 5PB  
tel: 0161 652 8996  
fax: 0161 633 1552  
e-mail: [info@autumnmobility.co.uk](mailto:info@autumnmobility.co.uk)  
web: [www.autumnmobility.co.uk](http://www.autumnmobility.co.uk)

### **BaKare Beds Ltd**

Unit 8  
Bell Park  
Bell Close  
Plympton  
Plymouth  
PL7 4JH  
tel: 01752 512 222  
fax: 01752 511 117  
e-mail: [info@bakare.co.uk](mailto:info@bakare.co.uk)  
web: [www.bakare.co.uk](http://www.bakare.co.uk)

### **Balder (UK) Ltd**

Unit 24  
Murrell Green Business Park  
London Road  
Hook  
Hampshire  
RG27 9GR  
tel: 01256 767 181  
fax: 01256 768 887  
e-mail: [balder.sales@btinternet.com](mailto:balder.sales@btinternet.com)  
web: [www.balder.co.uk](http://www.balder.co.uk)

### **Bonar Floors Ltd**

High Holborn Road  
Ripley  
Derbyshire  
DE5 3NT  
tel: 01773 744 121  
fax: 01773 744 142  
e-mail: [w\\_infouk@bonarfloors.com](mailto:w_infouk@bonarfloors.com)  
web: [www.bonarfloors.com](http://www.bonarfloors.com)

### **Cane & Able Ltd**

Grindleford  
Hope Valley  
S32 2HE  
tel: 01433 631 170  
fax: 01433 631 267  
e-mail: [info@cane-and-able.com](mailto:info@cane-and-able.com)  
web: [www.cane-and-able.co.uk](http://www.cane-and-able.co.uk)

**Centromed Ltd**

Anglo House  
Wotton Road  
Kingsnorth Industrial Estate  
Ashford  
Kent  
TN23 6LN  
tel: 01233 635 353  
fax: 01233 635 351  
e-mail: sales@centromed.com  
web: www.centromed.com

**Chiltern Invadex Ltd**

Chiltern House  
6 Wedgwood Road  
Bicester  
Oxon  
OX6 4UL  
tel: 01869 246 470  
fax: 01869 247 214  
e-mail: sales@chilterninvadex.co.uk  
web: www.chilterninvadex.co.uk

**CLIMB Children Living with Inherited Metabolic Diseases**

(see Chapter 5 *Muscular Dystrophy & Allied Neuromuscular Conditions*)

**CMT United Kingdom**

(see Chapter 5 *Muscular Dystrophy & Allied Neuromuscular Conditions*)

**Congenital Muscular Dystrophy Support Group**

(see Chapter 5 *Muscular Dystrophy & Allied Neuromuscular Conditions*)

**Creative Healthcare Ltd**

Unit 5  
Victoria Business Park  
Chard  
TA20 1HE  
tel: 0146 067 144  
fax: 0146 066 913  
e-mail: info@creative-healthcare.co.uk  
web: www.creative-healthcare.co.uk

**Cyclone Mobility & Fitness Ltd**

Unit 5  
Apex Court  
Croft Business Park  
Bromborough  
Wirral  
CH62 3RE  
tel: 0151 346 2310  
fax: 0151 346 2311  
e-mail: info@cyclone-mf.co.uk  
web: www.cyclone-mf.co.uk

**D & E Architectural Hardware Ltd**

17 Royce Road  
Carr Road Industrial Estate  
Peterborough  
PE1 5YB  
tel: 01733 896 123  
fax: 01733 894 466  
e-mail: info@dande.co.uk  
web: www.dande.co.uk

**Daily Care Ltd**

Unit 4/5  
The Coach House  
Phoenix Business Centre  
Low Mill Road  
Ripon  
North Yorkshire  
HG4 1NQ  
tel: 01765 600 234  
fax: 08700 345 201  
e-mail: sue@dailycare.co.uk  
web: www.dailycare.co.uk

**Dan Medica Ltd - North**

Dolphin House  
36 Liverpool Road  
Eccles  
Manchester  
M30 OWA  
tel: 0161 788 8676  
fax: 0161 788 8665  
e-mail: sales@danmedica.com  
web: www.danmedica.co.uk

### **Dan Medica Ltd - South**

The Village House  
Church Street  
West Chiltington  
West Sussex  
RH20 2JW  
tel: 01798 815 903  
fax: 01798 815 293  
e-mail: danmedicasouth@aol.com  
web: www.danmedica.co.uk

### **DCS Joncare Ltd**

4 Radley Road Industrial Estate  
Abingdon  
Oxon  
OX14 3RY  
tel: 01235 523 353  
fax: 01235 531 019  
e-mail: marketing@dcsjoncare.freemove.co.uk  
web: www.dcsjoncare.com

### **Design Matters KBB Ltd**

Aries House  
Straight Bit  
Flackwell Heath  
High Wycombe  
Bucks  
HP10 9NB  
tel: 01628 531 584  
fax: 01628 532 389  
e-mail: info@dmkbb.co.uk  
web: www.dmkbb.co.uk

### **Disability Law Service**

Ground Floor  
39-45 Cavell Street  
London  
E1 2BP  
tel: 020 7791 9800  
fax: 020 7791 9802  
e-mail: advice@dls.org.uk

### **Disabled Living Centres Council**

Redbank House  
4 St Chad's Street  
Manchester  
M8 8QA  
tel: 0161 834 1044  
fax: 0161 839 0802  
minicom: 0161 839 0885  
e-mail: dlcc@dlcc.org.uk  
web: www.dlcc.org.uk

### **Disabled Living Foundation**

380-384 Harrow Road  
London  
W9 2HU  
tel: 020 7289 6111  
helpline: 0845 130 9177  
fax: 020 7266 2922  
e-mail: advice@dlf.org.uk  
web: www.dlf.org.uk

### **Duchenne Family Support Group**

(see Chapter 5 *Muscular Dystrophy & Allied Neuromuscular Conditions*)

### **Easy Care Products Ltd**

Park Lane  
Old Park  
Telford  
Shropshire  
TF3 4TE  
tel: 01952 610 300  
fax: 01952 616 588  
e-mail: postmaster@easycareproducts.co.uk  
web: www.easycareproducts.co.uk

### **ESL Healthcare Ltd**

Potts Marsh Industrial Estate  
Eastbourne Road  
Westham  
Pevensey  
East Sussex  
BN24 5NH  
tel: 01323 465 800  
fax: 01323 460 248  
e-mail: sales@eslindustries.com  
web: www.eslindustries.com

### **Family Care Officers/ Muscular Dystrophy Campaign**

see page 11

### **Family Fund**

P.O. Box 50  
York  
YO1 9ZX  
tel: 0845 1304 542  
fax: 01904 652 625  
e-mail: info@familyfund.org.uk  
web: www.familyfund.org.uk

**Forbo-Nairn Ltd**

PO Box 1  
Kirkcaldy  
Fife  
Scotland  
KY1 2SB  
tel: 01592 643 777  
fax: 01592 643 999  
e-mail: info.uk@forbo.com  
web: www.forbo.com

**FSH-MD Support Group  
(Facioscapulohumeral md)**

(see Chapter 5 *Muscular Dystrophy & Allied Neuromuscular Conditions*)

**FunderFinder Ltd**

65 Raglan Road  
Leeds  
LS2 9DZ  
tel: 0113 243 3008  
fax: 0113 243 2966  
e-mail: info@funderfinder.org.uk  
web: www.funderfinder.org.uk

**Gerald Simonds Healthcare Ltd**

9 March Place  
Gatehouse Way  
Aylesbury  
Bucks  
HP19 8UA  
tel: 01296 380 200  
fax: 01296 380 279  
e-mail: info@gerald-simonds.co.uk  
web: www.gerald-simonds.co.uk

**Glycogen Storage Disease  
Support Group**

(see Chapter 5 *Muscular Dystrophy & Allied Neuromuscular Conditions*)

**Go Independent**

Unit A2  
Kingfisher Business Park  
Hawthorne Road  
Bootle  
Merseyside  
L20 6PF  
tel: 0151 922 4455  
fax: 0151 922 2112  
e-mail: info@goin.co.uk  
web: www.goin.co.uk

**Gordon Medical &  
Rehabilitation Services Ltd**

26a North Street  
Stilton  
Peterborough  
PE7 3RP  
tel: 01733 243 933  
fax: 01733 244 605  
e-mail: info@gordon-rehab.co.uk  
web: www.gordon-rehab.co.uk

**Guillain-Barre Syndrome  
Support Group**

(see Chapter 5 *Muscular Dystrophy & Allied Neuromuscular Conditions*)

**Harrison Thompson & Co Ltd**

Yeoman House  
Whitehall Estate  
Whitehall Road  
Leeds  
LS12 5JB  
tel: 0113 279 5854  
fax: 0113 231 0406  
e-mail: info@yeomanshield.com  
web: www.yeomanshield.com

**Huntleigh Healthcare Ltd**

310-312 Dallow Road  
Luton  
Bedfordshire  
LU1 1TD  
tel: 01582 745 700  
fax: 01582 745 745  
e-mail: sales.admin@hunhcare.co.uk  
web: www.huntleigh-healthcare.com

**Huntleigh Renray Ltd**

Road Five  
Winsford Industrial Estate  
Winsford  
Cheshire  
CW7 3RB  
tel: 01606 593 456  
fax: 01606 861 354  
e-mail: sales@renraydavidbaker.co.uk  
web: www.renraydavidbaker.co.uk

### **Independence Kitchens**

40 Clifton Drive  
Foxlow Park  
Harperhill  
Buxton  
Derbyshire  
SK17 9LY  
tel: 01298 23 496  
fax: 01298 72 232

### **Invacare Ltd**

South Road  
Bridgend Industrial Estate  
Bridgend  
Mid Glamorgan  
CF31 3PY  
tel: 01656 647 327  
fax: 01656 649 016  
e-mail: uk@invacare.com  
web: www.invacare.com

### **The Jennifer Trust for Spinal Muscular Atrophy (JTSMA)**

(see Chapter 5 *Muscular Dystrophy & Allied Neuromuscular Conditions*)

### **Joseph Patrick Trust**

(see Muscular Dystrophy Campaign)

### **K.C. Mobility Services Ltd**

K.C. House  
Carlinghow Mills  
501 Bradford Road  
Batley  
West Yorkshire  
WF17 8LL  
tel: 01924 442 386  
fax: 01924 420 183  
e-mail: sales@kcmobility.co.uk  
web: www.kcmobility.co.uk

### **Kingkraft Ltd**

4 Meverill Road  
Tideswell  
Buxton  
Derbyshire  
SK17 8PY  
tel: 01298 872 309  
fax: 01298 872 609  
e-mail: easibath@kingkraft.co.uk  
web: www.kingkraft.co.uk

### **Legrand Electric Ltd**

Great King Street North  
Birmingham  
B19 2LF  
tel: 0121 515 0515  
fax: 0121 515 0658  
e-mail: legrand.sales@legrand.co.uk  
web: www.legrand.co.uk

### **Liko (UK) Ltd**

Liko House  
Brunel Centre  
Stroudwater Business Park  
Stone House  
Gloucester  
GL10 3RU  
tel: 01453 827 272  
fax: 01453 828 844  
e-mail: info@liko.co.uk  
web: www.liko.co.uk

### **Lomax Mobility Ltd**

The Chalmers Building  
Charles Bowman Avenue  
Claverhouse Industrial Park  
Dundee  
Scotland  
DD4 9UB  
tel: 01382 503 000  
fax: 01382 503 550  
e-mail: info@lomaxmobility.co.uk  
web: www.lomaxmobility.com

### **Mangar International Ltd**

Presteigne  
Powys  
LD8 2UF  
tel: 01544 267 674  
fax: 01544 260 287  
e-mail: sales@mangar.co.uk  
web: www.mangar.co.uk

### **Marcon (Turnblade Ltd)**

Unit 4b  
Northlands Business Park  
Warnham  
West Sussex  
RH12 3SH  
tel: 01306 628 164  
fax: 01306 627 161  
e-mail: mail@marcon-uk.com  
web: www.marcon-uk.com

**Marshall Sports Chairs Ltd**

8 Lamorna Gardens  
 Ferring  
 West Sussex  
 BN12 5QD  
 tel: 01903 246 146  
 fax: 01903 500 523  
 e-mail: philatmsc@aol.com

**Mitochondrial Myopathies**

(see Chapter 5 *Muscular Dystrophy & Allied Neuromuscular Conditions*)

**Moderna Contracts Ltd**

161 Commercial Street  
 London  
 E1 6BW  
 tel: 020 7650 5363  
 fax: 020 7650 5393  
 e-mail: moderna.installations@nichollsandclarke.com  
 web: www.nichollsandclarke.co.uk

**Movingpeople.net UK Ltd**

68 High Street  
 Weybridge  
 Surrey  
 KT13 8BL  
 tel: 01932 858 687  
 fax: 01932 848 384  
 e-mail: uk@movingpeople.net  
 web: www.movingpeople.net

**Muscular Dystrophy Campaign**

7-11 Prescott Place  
 London  
 SW4 6BS  
 tel: 020 7720 8055  
 fax: 020 7498 0670  
 e-mail: info@muscular-dystrophy.org  
 web: www.muscular-dystrophy.org

**Myasthenia Gravis Association**

(see Chapter 5 *Muscular Dystrophy & Allied Neuromuscular Conditions*)

**Myositis Support Group**

(see Chapter 5 *Muscular Dystrophy & Allied Neuromuscular Conditions*)

**Myotonic Dystrophy Support Group**

(see Chapter 5 *Muscular Dystrophy & Allied Neuromuscular Conditions*)

**National Occupational Therapy Advisor/Muscular Dystrophy Campaign**

(see page 11)

**N & C Building Products Ltd  
Phlexicare Division**

3-10 Shoreditch High Street  
 London  
 E1 6PE  
 tel: 020 7247 5432  
 fax: 020 7247 7738  
 and branches throughout the UK  
 e-mail: info@phlexicare.com  
 web: www.phlexicare.com

**Newton Products Ltd**

71-75 Allcock Street  
 Deritend  
 Birmingham  
 B9 4DY  
 tel: 0121 773 9111  
 fax: 0121 773 0200  
 e-mail: sales@newtonproducts.co.uk

**Ortho-Kinetics (UK) Ltd**

Planetary Road  
 Wednesfield  
 Wolverhampton  
 West Midlands  
 WV13 3XA  
 tel: 01902 866 166  
 fax: 01902 865 844  
 e-mail: lance@virgin.net

**Otto Bock Healthcare plc**

32 Parsonage Road  
 Englefield Green  
 Egham  
 Surrey  
 TW20 0LD  
 tel: 01784 744 900  
 fax: 01784 744 901  
 e-mail: bockuk@uk.ottobock.de  
 web: www.ottobock.co.uk

### **Panilet Tables**

Unit 17 Dragon Court  
Crofts End Road  
St George  
Bristol  
BS5 7XX  
tel: 0117 951 1858  
fax: 0117 951 1858  
e-mail: sales@panilettables.co.uk  
web: www.panilettables.co.uk

### **Portaramp Ltd**

Roman House  
Roman Way  
Fison Way Industrial Estate  
Thetford  
Norfolk  
IP24 1HT  
tel: 01842 821 400  
fax: 01842 821 401  
e-mail: ramps@globalnet.co.uk  
web: www.portaramp.co.uk

### **Possum Controls Ltd**

8 Farmbrough Close  
Stocklake  
Aylesbury  
Buckinghamshire  
HP20 1DQ  
tel: 01296 461 000  
fax: 01296 461 001  
e-mail: info@possum.co.uk  
web: www.possum.co.uk

### **Pressalit Care Ltd**

Riverside Business Park  
Dansk Way  
Leeds Road  
Ilkley  
West Yorkshire  
LS29 8JZ  
tel: 01943 607 651  
fax: 01943 607 214  
e-mail: uk@pressalitcare.com  
web: www.pressalitcare.com

### **Pride Mobility Products Ltd**

Unit 106  
Heyford Park Camp Road  
Upper Heyford  
Oxfordshire  
OX25 5HA  
tel: 01869 233 100  
fax: 01869 233 400  
e-mail: debbie@pride-mobility.co.uk  
web: www.pridemobility.com

### **Rainbow Rehab**

The Coach House  
134 Purewell  
Christchurch  
Dorset  
BH23 1EU  
tel: 01202 481 818  
fax: 01202 476 688  
e-mail: info@rainbow-rehab.co.uk  
web: www.rainbow-rehab.co.uk

### **Ridley Electronics Ltd**

66a Capworth Street  
Leyton  
London  
E10 7HA  
tel: 020 8558 7112  
fax: 020 8558 7113  
e-mail: ridleyelect@netscape.net

### **RGK Wheelchairs Ltd**

Unit 8B/C  
Chasepark Industrial Estate  
Ring Road  
Burntwood  
Staffs  
WS7 8JQ  
tel: 01543 670 077  
fax: 01543 670 088  
e-mail: info@rgk-wheelchairs.co.uk  
web: www.rgk-wheelchairs.co.uk

### **RSL Steeper Ltd**

Riverside Orthopaedic Centre  
Medway City Estate  
Rochester  
Kent  
ME2 4DP  
tel: 01634 297 010  
fax: 01634 297 011  
e-mail: enquiries@rehab.co.uk  
web: www.rslsteeper.com

**Scanflex Ltd**

2 Thursby Road  
 Croft Business Park  
 Bromborough  
 Wirral  
 CH62 3PW  
 tel: 0151 343 1523  
 fax: 0151 343 1514  
 e-mail: info@scanflex.co.uk  
 web: www.scanflex.co.uk

**Scan Mobility Ltd**

91 Zetland Street  
 Southport  
 Merseyside  
 PR9 9DL  
 tel: 01704 534 483  
 fax: 01704 500 084  
 e-mail: info@scanmobility.co.uk  
 web: www.scanmobility.co.uk

**Silvalea Ltd**

Unit 3 & 4  
 Silverhills Road  
 Decoy Industrial Estate  
 Newton Abbot  
 Devon  
 TQ12 5LZ  
 tel: 01626 331 655/333 793  
 fax: 01626 335 171  
 e-mail: sales@silvaleatextiles.co.uk  
 e-mail: enquiries@silvaleatextiles.co.uk  
 web: www.silvaleatextiles.co.uk

**Smile Rehab Ltd**

Ability House  
 109 New Greenham Park  
 Newbury  
 Berkshire  
 RG19 6HN  
 tel: 01635 375 50  
 fax: 01635 528 221  
 e-mail: info@smilerehab.com  
 e-mail: sales@smilerehab.com  
 web: www.smilerehab.com

**Southern Care Systems Ltd**

Unit 1A  
 Hightown Industrial Estate  
 Crow Arch Lane  
 Ringwood  
 Hants  
 BH24 1NZ  
 tel: 01425 471 522  
 fax: 01425 479 130  
 e-mail: sales@southerncaresystems.co.uk  
 web: www.disabilityequipment.com

**SRS Technology Ltd**

SRS House  
 The Shrubbery  
 Erdington Road  
 Aldridge  
 West Midlands  
 WS9 8UH  
 tel: 01922 456 882  
 fax: 01922 456 883  
 e-mail: enquiries@srstechnology.co.uk  
 web: www.srstechnology.co.uk

**Sumed International (UK) Ltd**

Unit 1  
 Wildmere Road  
 Wildmere Road Industrial Estate  
 Banbury  
 Oxon  
 OX16 7TL  
 tel: 01295 270 499  
 fax: 01295 358 924  
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### **Theraposture Ltd**

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### **Thomas Gideon Design**

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### **Thorworld Industries Ltd**

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### **Total Hygiene Ltd**

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### **Twyford Ltd**

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ST7 2DF  
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web: www.twyfordbathrooms.com

### **Wessex Medical Equipment Company Ltd**

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tel: 01794 830 303  
fax: 01794 512 621  
e-mail: info@wessexmedical.co.uk  
web: www.wessexmedical.co.uk

### **Westholme Ltd**

Newcombe Street  
Elland  
Halifax  
West Yorkshire  
HX5 0EG  
tel: 01422 260 011  
fax: 01422 371 783  
e-mail: info@westholme.co.uk

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New Cross Street  
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e-mail: wheelchaircorp@lineone.net

### **Wintun Ltd**

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# Equipment Literature

*Leaflets of the most widely-used products that are discussed in the manual are included for the convenience of readers. The manufacturers' information was considered to be more useful than illustrations as many of the details are vital in helping to understand the equipment prior to planning adaptations*

- The tick boxes can be used to help to identify the products and the literature included – and where necessary to itemise the other leaflets that are not present and would be useful to obtain. (This will involve buying an additional binder.)

The information is divided into four sections:

- ⇒ adaptation equipment;
- ⇒ 'seat to standing';
- ⇒ beds & related equipment;
- ⇒ wheelchairs.

## Adaptation equipment

- Altro Ltd: **Altro safety flooring**
- Apres Shower Dryers Ltd: **Apres Shower Body Dryer**
- Arjo Ltd: **Bianca room-covering hoist**
- Arjo Ltd: **Sovereign bath**
- Arjo Ltd: **Solo bath**
- Arjo Ltd: **Trixi & Lisa hoists**
- ASM Accessories Ltd: **Aquability toilet/shower chairs**
- ASM Accessories Ltd: **Multi-System**
- ASM Accessories Ltd: **Sunrise Medical Mermaid Ranger**
- ASM Accessories Ltd: **Sutton Shower Cradle**
- Astor-Bannerman (Medical) Ltd: **Adjustable brackets**
- Astor-Bannerman (Medical) Ltd: **Changing & showering tables**
- Astor-Bannerman (Medical) Ltd: **ABW4/ABW4SP washbasin/SC.EL shower chair**
- Autumn Mobility Ltd: **Level-entry shower trays**
- Bonar Floors Ltd: **Flotex 'carpet' flooring**
- Chiltern Invadex Ltd: **Chiltern shower chair**
- Creative Healthcare Ltd: **Impey Level-Dec**
- D & E Architectural Hardware Ltd: **Liobex hinges**
- Daily Care Ltd: **MD toilet frame**
- Design Matters KBB Ltd: **Kitchen Design Service**
- ESL Healthcare Ltd: **Geberit shower toilet**

- Forbo-Nairn Ltd: **Nairn Surestep flooring**
- Go Independent: **Cambridge shower grille**
- Go Independent: **Apres Shower Body Dryer**
- Go Independent: **Neaco Support System**
- Go Independent: **Neatdek shower grille/Shower trays/Half-height doors**
- Harrison Thompson & Co Ltd: **Yeoman Shield door-protection 'kick' plates**
- Huntleigh Healthcare Ltd: **Akron Tilt Table**
- Huntleigh Renray Ltd: **Independence Range adjustable-height working surfaces**
- Huntleigh Renray Ltd: **Kitchens**
- Independence Kitchens: **Kitchens/Work surface drawer unit**
- Kingkraft Ltd: **Easibath Hi-Lift/Support cushions**
- Kingkraft Ltd: **Contour bath**
- Legrand Electric Ltd: **Tenby Clipper switches**
- Liko (UK) Ltd: **Golvo 7000ES/7007ES/ 240 & 240R2R hoists**
- Mothercare Ltd: **Softee Trainer/Step stool**
- N & C Building Products Ltd/Moderna Contracts Ltd: **Guldmann Dan-Hoist ceiling-mounted system**
- N & C Building Products Ltd/Phlexicare Division: **Phlexicare kitchens**
- Otto Bock Healthcare PLC: **Linido shower stretcher**
- Panilet Tables: **Sit-Easi height-adjustable ironing board**
- Portaramp/Division of Trident Industrial Ltd: **Portable and threshold ramps**
- Possum Controls Ltd: **Companion environmental control**
- Pressalit Care Ltd: **Shower bench**
- Pressalit Care Ltd: **Multi System/toilet seats**
- Ridley Electronics Ltd: **Automatic door opener/switches/intercoms**
- RSL Steeper Ltd: **Fox environmental control**
- RSL Steeper Ltd: **Automatic door opener**
- Scanflex: **Shower bench**
- Scan Mobility Ltd: **Ozomatic hydrotherapy unit**
- Silvalea Ltd: **Specialist slings**
- Southern Care Systems Ltd: **Spectra automatic door opener**
- Southern Care Systems Ltd: **Spectra hoist system**
- Southern Care Systems Ltd: **Spectra washbasin**
- SRS Technology Ltd: **SRS 100 environmental control**
- Sumed International (UK) Ltd: **Bath & commode cushion**
- Terry Group Ltd: **Harmony wheelchair lift**
- Terry Group Ltd: **Steplift**
- Thomas Gideon Design: **Height-Right trolley**
- Thorworld Industries Ltd: **Ramps for the disabled**
- Total Hygiene Ltd: **Clos-o-Mat shower toilet**
- Twyford Ltd: **Low-level cistern with long flush pipe**
- Wessex Medical Equipment Co Ltd: **The Ultimate Lifting Platform LP1000**
- Wessex Medical Equipment Co Ltd: **VM31/51 & VM36/56 vertical lifts**
- Westholme Ltd: **Freeway shower chairs**
- Westholme Ltd: **Transactive track hoist**
- Wintun Ltd: **Wintun RX100 threshold**

## 'Seat to Standing'

- Advance Seating Designs: eMove powered office chair*
- BaKare Beds Ltd: Devon Recliner chair*
- Gordon Medical Rehabilitation Services Ltd: Made-to-measure powered self-lift chairs*
- Cane & Able Ltd: MK2 Elevator Recovery System*
- Huntleigh Healthcare Ltd: Porta Toilet Riser*
- KC Mobility Services Ltd: Seat Raise to Standing*
- Mangar International Ltd: Mangar Booster*
- Mangar International Ltd: Mangar Elk*
- Moderna Contracts Ltd: Ginnerup Toilet Lift*
- Ortho-Kinetics (UK) Ltd: Regent 2745 chair*

## Beds & related products

- Action Assist Ltd: Princess 5000 Lateral Tilting bed*
- Ashworth Trading: Homecare bed*
- BaKare Beds Ltd: 3080PH Volker bed*
- Centromed Ltd: Baltic bed*
- Centromed Ltd: Mattress Variator Technology*
- Huntleigh Healthcare Ltd: Super Baltimore bed*
- Marcon Lifting Systems (Turnblade Ltd): Kineticare Tilting Bed System*
- Marcon Lifting Systems (Turnblade Ltd): Marcon Bed Elevator*
- Moderna Contracts Ltd: Goldmann Flexus 2 bed*
- Scan Mobility Ltd: Scan 750 bed*
- Theraposture Ltd: Bed in Bed*

## Wheelchairs

Wheelchair information has not been included because of the wide range of models available and the varying individual needs of wheelchair users.

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## Foreword to 2nd edition

The Muscular Dystrophy Campaign is pleased to be able to publish the second edition of the Adaptations Manual. Although written for those affected by muscular dystrophy and allied conditions and professionals working with them, feedback has indicated that it is useful to other disabled people.

This second edition retains the format of the first, but details have been updated and in some cases chapters have been rewritten. Since the first edition, the UK and devolved Governments have amended the grant funding systems for adaptations and equipment. Scotland's system is in the process of changing and in England, Northern Ireland and Wales greater flexibility has been given to Local Authorities, but although this will influence the way adaptations are funded, it should not affect the adaptations that people are able to receive across the country (see Chapter 12). Other chapters in the manual that have significantly changed are Chapters 5, 8, 9, 10, 11i, 13a and 18.

Chapter 13b is a questionnaire, which asks about your experience of adapting your home. Please photocopy and complete this and return it to us – you will be providing the Muscular Dystrophy Campaign with useful evidence of the problems faced by people with muscular dystrophy, and on the effectiveness of different solutions.

Much of this second edition is now available on the MDC website at [www.muscular-dystrophy.org](http://www.muscular-dystrophy.org). The Muscular Dystrophy Campaign also publishes factsheets, including some about equipment and adaptations in addition to those listed in Chapter 5. These are available from our information service or can be printed from our website.

As ever, legislation, techniques and products change and evolve. The Muscular Dystrophy Campaign would welcome being advised of any changes, omissions or errors; please contact our National Occupational Therapy Advisor at our Head Office.

The importance of Occupational Therapy in enabling people with muscular dystrophy to live independent lives, should not be underestimated.



Christine Cryne  
Chief Executive  
Muscular Dystrophy Campaign

## Foreword to 1st edition

It was over 39 years ago, in October 1961, that I began work on the research programme that was to lead in November 1963 to the publication by the Royal Institute of British Architects of the first edition of my *“Designing for the Disabled”*. The concern that had prompted the venture was that architects needed to be informed about how to design houses convenient for wheelchair users to live in. It was a topic which, at the time, had barely been explored in Britain; to find out more, I went first to learn from occupational therapists in Sweden and Denmark about the innovative ideas they were developing for homes for housewives who used wheelchairs, in particular about how kitchens and bathrooms could be planned and equipped so that they could be managed independently.

At that time, the professional work undertaken by occupational therapists in Britain was increasingly focused on programmes aimed at helping disabled people manage in their own homes, on tackling daily living tasks. From 1971 – when local authority social services departments came to be established – the opportunities open to them expanded. Philippa Harpin was among those who led the way. Trained at the London School of Occupational Therapy, she practised first in Bradford, before working with children with cerebral palsy in a residential school in Cumberland, followed by work in a rehabilitation centre for elderly people in Northumberland. Philippa was then appointed as National Occupational Therapy Advisor to the Muscular Dystrophy Campaign and has worked tirelessly with adults, parents and children with muscular dystrophy and allied conditions. She has become an acknowledged authority in that field and, while contributing articles to numerous professional journals, lecturing and presenting papers with great enthusiasm, wrote *“With a Little Help”* – a book about equipment for people with muscular dystrophy. Research has included the projects *“Why do some, but not all, boys with muscular dystrophy need attention in the night?”* (gaining a Diploma in Social Research) and *“A focus on attitudes and counselling skills, and their role during the milestones and experiences in the lives of a boy with Duchenne muscular dystrophy and his family”* (for a Diploma in Counselling skills). She then set herself the demanding task of writing this book and urging it through to publication.

This book – the fruit of Philippa’s unique knowledge of her field and long experience in it – tells how families and individuals faced by the challenges that come with muscular dystrophy can be helped to make day-to-day life at home more convenient, more easily manageable and more rewarding. It is a book of practical information, advice and guidance, which will be widely welcomed and which I am pleased to commend.

Selwyn Goldsmith  
April 2000

## Preface

Why has this manual been written and for whom? Disabled people and their families often feel that they have been left on their own to find out all they need to know, before embarking on adaptations – and the main impetus for the manual has been to try to redress this problem. Also, we know from a housing adaptations survey carried out several years ago, that families feel that community staff do not always have the experience necessary to understand the specialist needs of people with muscular dystrophy and allied neuromuscular conditions; it has to be acknowledged that many of these disabilities are rare. So the manual is for disabled people, their families and carers, occupational therapists and other professionals including architectural designers, who are involved in advising. Writing for a diverse group with different perspectives is difficult and the emphasis varies according to the information discussed.

The purpose of successful adaptations is to provide accessibility into and around the house and garden, so that if a wheelchair is used there is sufficient circulation space for the most appropriate model, to provide the most suitable equipment and facilities and to safeguard the privacy and dignity of the users, making life easier for both them and their carers. The ultimate goal is to try to help disabled people to maintain or regain as much independence as possible, and thereby to improve the quality of life for everyone concerned.

The aim of the manual has been to bring together all the strands of the decision-making involved in achieving the most satisfactory outcome, while at the same time obtaining the best value for money. This is not easy – as anyone disabled will tell you. Some people know exactly what they need; others are seeking advice. When the disability is progressive, as in most types of muscular dystrophy and allied neuromuscular conditions, the future may be uncertain and the people concerned may not be aware of what they are likely to need or of the solutions that are available. This manual seeks to provide all the necessary information and, where possible, to offer alternatives, so that disabled people and their families can be involved in the choices.

I am also fully aware of the financial constraints. Nevertheless, I hope that the content of this manual will demonstrate and justify the needs, to try to eliminate much of the controversy that, unhappily, many people feel is involved before they are able to have what they need.

Some of the information, although updated, will be familiar to readers because it has been made available and has been well tried and tested. Gathered over the 25 years that I worked for the Muscular Dystrophy Campaign, it is the result of one-to-one work with disabled people and their families. I hope that I listened carefully and I am indebted to you all. I have learnt, too, from all the occupational therapists and workers with other professional backgrounds, including the Muscular Dystrophy Family Care Officers, social workers, healthcare staff, architects, designers, researchers, grant officers and other funding agencies, and I thank them for their help. It was good to work with so many people who have the best interests of disabled people at heart. I hope the outcome is useful to all those who are involved in the important and rewarding work of all aspects of adaptations and ‘new-build’ schemes – now and in the future.

*Philippa Harpin*

# Acknowledgements

## ... from the Muscular Dystrophy Campaign

We would like to thank Philippa Harpin for her dedication and commitment. She not only wrote the first edition of this manual, but also devoted considerable time and energy to updating the second edition, both before and after her retirement as National Occupational Therapy Advisor at MDC in 2002.

## ... from the author

Writing a detail manual of this kind is complicated and updating the information was far more involved and time consuming than I had ever imagined. Many people have helped not only with this task, but also with the production and funding to ensure that the Manual is available to the people for whom it was written. The Muscular Dystrophy Campaign and I would particularly like to thank the following:

- everyone who helped with the first edition, which formed the basis of the revision;
- Somerfield for their very generous sponsorship of this edition;
- The Epigoni Trust, who have been generous enough to contribute sponsorship to both editions;
- Southern Care Systems for help in subsidising copies for families;
- Brian Sewart, who was always at the end of the phone, willing to help and with a ready answer to every question, but sadly, died shortly before printing started. A special dedication to his memory is included on the front page;
- Alan Lynch who went the extra mile in helping with the Medical Devices Agency regulations and guidance included in the wheelchair chapter;
- Rachel Coombes - OT manager, Richard Farr and Louise Quinn - grants officers in England who looked through the relevant grants section in the funding chapter and whose comments and corrections ensured that the information is accurate;
- Anne Smyth and Karen Rainey from the Northern Ireland Housing Executive and Huw McLean from the Welsh Assembly Housing Directorate for their helpful comments and suggestions;
- the Scottish Executive Development Department for their generous and time-consuming help and guidance on the amended grants system in Scotland;
- Miranda Parrott, policy manager of the Family Fund who checked the section relating to the help provided;
- Ruth Geall and Pat Copcutt for their support and friendship throughout the trials of the project;
- Yvonne Masset, my successor at MDC who brought a fresh pair of eyes to each chapter, updated the address list and was one of the two people who proof read the final copy;
- Robin Scott for help with many sections of text, his generous offer to proof read - and for the time he devoted to this meticulous task;
- Jan Normanton, for her invaluable help and the positive way she tackled the updating and retyping of the index;
- Peter Holmes and John Woods at The Newcastle Printing Co. for all their patience and help over many months with both the production and printing;
- everyone with muscular dystrophy or an allied condition, with whom I was privileged not only to work for 25 years, but also to share some of the frustrations, joys and sorrows - all of which gave me the experience to write and update the text;
- David, my husband, who appreciated the need to postpone my 'real' retirement until this work was complete.

*Philippa Harpin*

# The Adaptations Process

*A guide to the stages involved, with the precise order varying according to the procedures of individual Local Authorities*

1. **Contact with Social Services/Social Work Department**  
to request a visit from the community occupational therapist (OT).
2. **Meeting to discuss with occupational therapist (community and/or paediatric)**  
needs and alternative schemes (lift vs extension etc.) in relation to the disability. Where possible, enlist the help of a Muscular Dystrophy Family Care Officer (FCO) or the National OT Advisor.
3. **Assessment of equipment.**
4. **Preliminary appointment of architectural designer.**
5. **Decisions made in relation to adapting or re-housing,**  
and also about equipment, with the help of the architectural designer, if possible.
6. **Estimation of preliminary costs.**
7. **Exploration of funding**  
with Improvement Grant (Scotland) or informal Disabled Facilities Grant (DFG) 'Test of Resources' by grants officer as a means of assessing the ability of the disabled person or the family to contribute to the costs of the adaptation, and the contribution that they are likely to have to make.
8. **Review of decision to adapt, re-house or 'new-build'**  
in the light of available funding, and approximate costs.
9.
  - a. **Formal appointment of architectural designer.**
  - b. **Meeting to discuss details of architectural brief and equipment**  
with architectural designer, OT, FCO and, possibly, grants officer.
10. **Submission by OT of recommendations on disability needs**  
to Grants Department.
11. **Initial sketches drawn by architectural designer**  
who has informal discussions with the area planning officer, where appropriate.
12. **Meeting of family, architectural designer, OT, FCO and, possibly, grants officer to:**
  - a) choose draft layout;
  - b) clarify which items will be grant eligible;
  - c) discuss architectural services to be provided. The choice is between:
    - i. drawing of plans, submission for Planning and Building Regulations Approval and writing up detailed specifications only; or preferably
    - ii. overall responsibility, as above, but also including submission of scheme for a grant, administration of the building contract and inspection of the building work.
13. **Preparation of plan by architectural designer;**  
if agreed by family and OT, submission for Planning Approval and for Building Regulations Approval.

- 14. Drawing up of specifications (including specialist equipment)**  
by the architectural designer on receipt of Planning Approval (usually 4–8 weeks after submission). May submit for Building Regulations Approval at this stage.
- 15. Receipt of Building Regulations Approval.**
- 16. Checking of specifications**  
at meeting of disabled person and/or the family, with the architectural designer, OT and FCO.
- 17. Establishment of responsibility for inspections of work**  
(in addition to Local Authority building inspectors) is essential if the architectural designer is unable or has not been allowed to provide the full service: will inspections be provided by technical services through the Grants Department, and what responsibility will be taken by the community/paediatric OT, disabled person and/or the family?
- 18. Sending out of plan and specifications for builders' estimates or formal tenders**  
depending on the scale of the building works.
- 19. Completion of final 'Test of Resources'.**
- 20. Receipt of tenders from builders,**  
evaluation by the architectural designer, and submission (with additional paperwork) to the Grants Department.
- 21. Selection of contractor.**
- 22. Approval of grant;**  
notification to the disabled person or the family of their contribution (if any).
- 23. START of WORK.**
- 24. Work regularly inspected;**  
disabled person or the family knows whom to contact if any problems arise.
- 25. Checking of finished work against plan**  
by everyone involved *before* the builder receives final payment.

# Be Your Own Keyworker

## *Suggestions for a DIY approach to the adaptations process for disabled people and/or their family and carers*

This manual is intended to make the process of adaptations easier for disabled people and their families and carers. It is primarily for everyone with muscular dystrophy or an allied neuromuscular condition and the wide range of professionals trying to help them. However, it is hoped that the manual will be useful to a much wider audience.

Although some disabled people may prefer to take a less active part in the process, there are many of you for whom there is no better solution than being your own keyworker. No one will care more than you about the adaptations and decisions made to achieve the optimum result. This manual should help you from the outset to understand the whole process. Although time-consuming, it will put you in control of the stages to be worked through, from the first referral to the Social Services Department and the assessment procedure, to the completion of the building work. However, the whole process of adaptations can be very stressful and you must ask for help at each stage if you need it – and particularly if you feel bogged down by it all.

## Use the following 10-point plan

### 1. File correspondence

Keep all correspondence together. Many families experience reluctance on the part of advisors to put anything on paper. Therefore, always ask for important decisions to be put in writing and press for a written reply to any query. Copies of all communications keep the file up to date and make it easier to back-track if, for example, your trusted occupational therapist (OT) leaves and no-one else seems to know what is going on.

### 2. Record contact details

Record the name, address and telephone number of everyone involved. It is also useful to know on which days and hours they are at work, and when it is best to contact them (particularly as many OTs work part-time). A form is included for you to photocopy and use to record this information. File it with your correspondence.

### 3. Accurate diary recording

In the same way, photocopy the sample diary page or draw up your own. Make enough copies, punched to fit your file, to ensure that they are readily available. Use the diary as a simple means of recording the date and time that each telephone call is made or received, and every meeting held, in relation to the adaptations. Make an accurate record of the conversation and ask for an explanation of anything you do not understand. Ensure that you are given a time-scale (even if only approximate) for the completion of each stage and what happens next. This enables you to monitor the progress and check that the work is followed through by the appropriate person. If you are unhappy with the progress of the scheme, then your record of the dates of all the calls and meetings puts you in a strong position if you need to make a complaint.

### 4. Chase up outcomes

While acknowledging that all workers are trying to keep up with very heavy workloads, keep track of these time-scales. If they are not met, make contact to find out what is happening. Most workers will welcome a timely reminder.

### 5. Muscular Dystrophy Adaptations & Building Design Network

Where possible, use this scheme to find a designer who has attended a workshop about people with neuromuscular conditions, and has experience of planning for their disabilities and needs.

### 6. Want vs needs

The word 'want' always creates a negative response from workers in statutory services and should be replaced with the word 'need'. This is probably because of the wording in the Disabled Facilities Grant guidelines which states "... distinguish between what are desirable and possibly legitimate aspirations of the disabled person, and what is actually needed and for which grant support is fully justified".<sup>1</sup>

## 7. Outcome of the assessment

Always aim for the best but, if necessary be prepared to compromise on the less important items, if these can be funded with an additional grant (but no contribution) and included at a later date. The priority is space, as this is difficult to add on in the future.

## 8. Funding

Many schemes break down from the outset because of the emphasis placed on funding issues. Therefore, the needs assessment becomes overlooked. If you have to fund your own adaptations, the Local Authority still has a responsibility to provide advice. You must contact the community OT and ask for assistance.

The priority is to establish what is needed and only then to consider the funding problems. It may sound negative to talk about funding as a problem, but it is necessary to be aware that there are few schemes where it is not a problem. The majority of people experience similar difficulties.

## 9. Complete the adaptations questionnaire

It is important, for future schemes, that the Muscular Dystrophy Campaign learns from your experience. We would, therefore, be very grateful if you would complete the questionnaire included in Chapter 13, whether or not you have used the Muscular Dystrophy Adaptations & Building Design Network. This will enable us to monitor the standard of adaptations and plan services to families.

## 10. Pass on your experience

If you are able to master the process, your experience will be invaluable to others. This is the value of belonging to a Muscular Dystrophy Branch, as it enables disabled people and their families to benefit from the support of learning from each other.

## Reference

- 1 *Circular 17/96 Private Sector Renewal: A Strategic Approach, Annex I.* HMSO, 1996, pg. 198.

# Keyworker

## Adaptations Scheme: Contact Names & Addresses

*(Sample pages for photocopying)*

Name: ..... Date of Birth: .....

Address: .....

Postcode: .....

Telephone No. (Home): ..... (Work): ..... Fax No: .....

Name	Role	Address inc. postcode	Tel no.	Fax no.	Best time to contact
	G.P.				
	Consultant				
	Muscular Dystrophy Family Care Officer				
	Muscular Dystrophy National OT Advisor	Muscular Dystrophy Campaign 7-11 Prescottt Place London SW4 6BS info@muscular-dystrophy.org www.muscular-dystrophy.org	Tel: 020 7720 8055	Fax: 020 7498 0670	

## Adaptations Scheme: Contact Names & Addresses

Name	Role	Address inc. postcode	Tel no.	Fax no.	Best time to contact
	Social worker				
	Physiotherapist				
	Paediatric OT				
	Community OT				
	Grants officer				
	Architectural designer				

## Adaptations Scheme: Contact Names & Addresses

Name	Role	Address inc. postcode	Tel no.	Fax no.	Best time to contact



# Assessment of Need

## for children & adults with muscular dystrophy & allied neuromuscular conditions

### *A discussion of the main issues involved in a housing and equipment assessment*

This chapter spans most of the sections in this manual and should be used in conjunction with them.

⇒ The purpose of the assessment	1
⇒ Who should be involved?	2
⇒ Starting the assessment process	4
⇒ Should the assessment cover the short-term or the long-term needs?	5
⇒ Catering for the difficulties in the assessment	6
⇒ The outcome options	12

## The purpose of the assessment

The overall aim of an assessment is to:

- provide greater independence for you or your disabled child to enable you to achieve your full potential;
- help to overcome the mobility difficulties;
- identify the present and future needs to ensure that, as far as possible, the same facilities are provided as those enjoyed by non-disabled people;
- ease the role of the carer/s.

The effect of suitable housing and appropriate facilities should not be underestimated. To quote one parent from the research project *Homes unfit for children: housing disabled children and their families*:

*"If you get your home right you can cope. This house is like a cocoon. It doesn't matter what is coming to us now. How can you make a tough decision in a house that's not a home? Within 24 hours of being in this house it was like WOW! She was a different child. Her confidence increased overnight. I can't describe to you the difference in Debbie".<sup>1</sup>*

## Who should be involved?

There are several groups of people who need to be involved in the assessment:

- ⇒ the disabled child or adult and the family or carers;
- ⇒ the hospital, school or paediatric OT, and/or;
- ⇒ the community OT;
- ⇒ a Muscular Dystrophy Family Care Officer (FCO)/National OT Advisor;
- ⇒ a designer from the Muscular Dystrophy Adaptations & Building Design Network;
- ⇒ a grants officer.

### The disabled child or adult and the family or carers

In addition to adults, it is important that any teenagers or younger children who are interested are involved in every stage and that no meetings take place without them. When contentious issues are to be discussed, it is sometimes suggested that meetings are held away from the home to exclude the family: this is a practice that should not be encouraged, unless the applicant, or the family, chooses not to be present.

### The hospital, school or paediatric OT

The involvement of an OT, other than the community OT, will depend upon whether the person attends a hospital. In the case of children, staff working in a Child Development Centre, the Social Services Children's and Family Disability Team, or school may also know them. The best possible professional practice is for Health Trust/paediatric OTs and community OTs to work together; in many areas liaison is excellent. A paediatric OT is likely to have worked with the individual child and to know both the child and the parents. This, together with insight into the needs of children and knowledge of children's equipment, will result in a first-class assessment to pass on to the community OT, who arranges for this information to be included in the adaptation scheme.

### The community OT

Frequently, OTs working in the community are placed in a difficult position, when they are asked to assess the needs and to worry about the budgets at the same time. However, the OT role is very clearly that of an advocate and the prime function is to assess the need. This is set out in the *Code of Ethics and Professional Conduct for OTs* which states:

***“Services should be client centred and needs led”.***

*“When relevant and appropriate, occupational therapists should negotiate and act on behalf of the clients in relation to upholding and promoting the autonomy of the individual”.*

... *“Occupational therapists have a duty to take reasonable care for clients whom they accept for treatment/intervention.*

*Every client should have a clearly recorded assessment of need and objectives of treatment/intervention.*

*Occupational therapists should always record unmet needs.*

*Failure to do so would be considered professionally unacceptable”.*

... *“Occupational therapists should state and substantiate their views to employers about resource and service deficiencies which may have implications for clients and carers”.*<sup>2</sup>

The community OT is, in fact, the key person in the assessment process because, although others can make recommendations, unless the community OT agrees that the need exists, the work will not be covered by a grant.

### **A Muscular Dystrophy Family Care Officer (FCO)/National OT Advisor**

The Muscular Dystrophy Campaign employs FCOs, with either a social work or healthcare background, to work with families with muscular dystrophy or an allied neuromuscular condition. Their knowledge of the disabilities and their experience of the wide range of problems encountered is a useful resource, not only for the disabled person and the family but also for the other professionals working with them. In addition, the National OT Advisor is available to help, when necessary. Their contact details are included in the address list in Chapter 18.

OTs and other professionals working with disabled people have a very broad knowledge of disability, but cannot be expected to be experts in relation to every type of physical disability, or to know the most relevant solutions to difficulties associated with each medical condition. Competent professionals recognise this and are always keen to ask for the advice of a specialist worker who has greater experience in a particular field. Several years ago, during a housing survey among families with muscular dystrophy and allied neuromuscular conditions, many of the respondents expressed the following opinions:

*"The Local Authority - even if willing - works with too wide a range of disabilities to know specialist answers".*

*"A specialist in muscular dystrophy knows the needs in the future, not what others appear to see when assessing".*

### **A designer from the Muscular Dystrophy Adaptations & Building Design Network**

Using an architectural designer with specialist knowledge of planning housing and facilities for people with muscular dystrophy and allied neuromuscular conditions will be invaluable; this innovative service is discussed in detail in Chapter 13.

### **A grants officer**

Local authorities (LAs) adopt different procedures, but if grants officers are going to question the OT's assessment, it is helpful for them to attend one of the initial meetings. It is more constructive to be aware from the outset, rather than at a later date, of any item that will not be covered by the grant. In addition, if grants officers are present when Disability Needs forms are completed (see Chapter 10), they will have a greater understanding of the needs, which will be essential to help to justify the cost of these expensive schemes. Although many Social Services Departments will have a similar form, it will not highlight the details specific to neuromuscular conditions.

## Starting the assessment process

The aim is to plan ahead, so that the adaptations are completed by the time that they are needed. Therefore, the timing is influenced not only by the physical disability – and in many cases by its progression – but also by the length of the adaptations process. The start of the assessment process is, therefore, influenced by the following:

- ⇒ the expected time-scale and delay;
- ⇒ the timing of adaptations for children;
- ⇒ the timing of adaptations for adults.

### The expected time-scale and delay

This is considered first because it is usually a surprise to people anticipating the need for adaptations, to know how long the process takes. In most areas it would not be pessimistic to anticipate that the time from the first referral to the Social Services Department to completion of the building work is likely to be 2 years. This time-scale will be a problem to any family where there has been a delay in diagnosis or where re-housing has been delayed.

After the lengthy procedure of planning the scheme, there is frequently a delay between the submission of the paperwork for the grant (the plans, estimates for the building work and equipment, formal grant application, etc.) and grant approval. This is usually because the Grants Department is waiting for more money to become available in the next financial year and the delay cannot be prevented. This underlines the importance of starting the adaptation process in good time before the improved facilities are needed.

### The timing of adaptations for children

The emphasis is on trying, with sensitivity, to help anyone who is having difficulty facing the need for adaptations and for the facilities which will be essential in the long term, and (for children still able to walk) to carry these out in preparation for the time when, for example, climbing the stairs becomes impossible. Because of the lengthy process involved in adaptations it will be appropriate for most families with a boy with Duchenne muscular dystrophy (DMD) to start the process when he is 6. For those children who have never been able to walk, the adaptations must be planned and completed before the child uses a wheelchair or is too heavy to be carried up and down the stairs.

### The timing of adaptations for adults

The initial problem for many adults with a neuromuscular condition who are able to walk, is the increasing difficulty in getting up from a seated position; however, fortunately, there are several excellent pieces of equipment available to help (see Chapter 8b *Seat to Standing*). The correct time to start planning adaptations is when this equipment is needed, so that the work is completed before a wheelchair is essential for at least part of the day.

## Should the assessment cover the short-term or the long-term needs?

In assessing the needs, there are two conflicting views as to whether the adaptations should be carried out:

- ⇒ piecemeal, to solve the problems as they occur;
- ⇒ for both the short term and long term.

### Piecemeal adaptations

Adaptations should never be carried out at an earlier stage than you or your family feel is necessary, and, on a few occasions, someone disabled or their family may feel that staged adaptations are the best course of action. However, if this is because you are having difficulty looking into the future and facing the problems in advance, it will be more constructive for you to be given time and sensitive help. This will give you the opportunity to come to terms with any fears and to delay the start of the adaptations until the process has been worked through and you feel more able to plan for the future.

There are many disadvantages to piecemeal adaptations and, if possible, these should be avoided, for the following reasons:

- they involve you in intermittent upheaval;
- they accentuate any physical deterioration resulting in the need for constant psychological adjustment;
- they are likely to increase the cost in providing the necessary facilities;
- they may preclude better solutions in the future, because the initial work is not compatible structurally with the long-term plans and needs.

### Adaptations for both the short term and long term

Research has shown that, for parents of a boy with DMD, the way in which the diagnosis is given and the help and support that the family receives at that time and in the subsequent months, influences their acceptance and their ability to cope.<sup>3</sup> However, no two people are the same and reactions will vary. The core service of the Muscular Dystrophy Campaign Family Care Officers recognises the importance of giving priority to newly diagnosed families. All families need time to adjust before having to face adaptations and the need to consider the long-term solutions. This is particularly difficult when there is a delay in diagnosis, as you may then have to start adaptations before you are ready psychologically.

## Catering for the difficulties in the assessment

The main emphasis is to establish the present and future housing and equipment needs, which will depend on the following:

- ⇒ understanding the condition and the progression of the disability, with reference to the medical and social model;
- ⇒ identification of the needs;
- ⇒ demonstration and trial of the most appropriate equipment;
- ⇒ suitability of the present housing;
- ⇒ availability of funding and grants.

### Understanding the condition and the progression of the disability

At this stage in the discussion of the assessment of needs it is necessary to itemise the effects of neuromuscular conditions, because a knowledge and understanding of the problems experienced justifies the need, and therefore the funding, of sophisticated adaptations and equipment. The aim is not to give credence to the medical model of disability; the Muscular Dystrophy Campaign is committed to the social model of disability discussed on the next page.

### The medical model of disability

It is important to establish the medical condition because the severity of the disability, the rate of progression and the possible need of a wheelchair will influence the decisions. Factsheets are available from the Muscular Dystrophy Campaign covering most types of muscular dystrophy and allied neuromuscular conditions (see Chapter 5). However, most of these conditions have several factors in common, which affect the assessment of need.

- **Most (but not all) are progressive** and the deterioration can be both physically and emotionally demanding.
- **They are selective muscle wasting conditions** (muscular dystrophies) **or conditions in which the nerve impulses fail to reach the muscles** (spinal muscular atrophy), resulting in severe muscle weakness in the legs, arms, neck and the trunk.
- **Many people either find it difficult or impossible to walk** and the wheelchair used is usually powered, because of the inability to propel a wheelchair owing to arm weakness.
- **If walking is possible, the emphasis is usually placed on the need to continue walking** for as long as possible and, when this becomes difficult, to use a standing frame daily, for as long as practical and for as many years as can be tolerated. The importance of erect posture is to delay hip and knee contractures in order to maintain the ability to lie flat and to extend the legs. Also – and even more important – this encourages a lordosis (which is a forward curvature of the spine), in order to delay a scoliosis or side curvature. This standing routine has important implications for adaptations, as it involves the need to provide work surfaces to encourage standing and the simultaneous opportunity for purposeful activities, and also the space to store a standing frame.

- **The effect of the arm weakness is particularly debilitating** and is not always fully understood. Very few people with a neuromuscular condition can raise their arms above shoulder height and, as the condition progresses, they are unable to lift their arms off the wheelchair armrests and rely on creeping with their fingers, or moving their arm by grasping clothing or a finger with teeth. This means that the height of the work surfaces needs to be very precise, so that hand function can be maximised.
- **The trunk weakness results in lack of balance** and stability making support necessary when sitting in a chair or a bath.
- **Some disabilities are stereotyped, (although the rate of deterioration is variable),** which means that adaptations can be planned for the future.
- **The muscle weakness results in sudden, extreme and abnormal tiredness,** to the extent that many adults initially use a wheelchair for part of the day only – either for specific activities or when too tired to walk. This means that the height of surfaces needs to be suitable for both standing and sitting and, because of the arm weakness, the adjustment has to be operated electrically.

### The social model of disability

As long ago as 1976, disabled people themselves have been using the so-called ‘social model of disability’ to define themselves and their own experiences. The Union of the Physically Impaired Against Segregation in that year gave the following definition:

*"In our view it is society which disables physically impaired people. Disability is something imposed on top of our impairments by the way we are unnecessarily isolated and excluded from full participation in society. Disabled people are therefore an oppressed group in society".<sup>4</sup>*

The social model today is taken to include people with all impairments – physical, intellectual and sensory – and those with mental health problems. By placing the emphasis on the barriers to disabled people’s participation in society, it provides a cure to the ‘problem’ of disability – removal of those barriers. Although it does not avoid mention of the symptoms or functional limitations linked to impairments, it does not locate disabled people’s problems entirely in their own bodies. Thus, the social model is in distinction to an individual or medical model of disability.

There is no written statement regarding agreed terminology adopted by the disability movement. However, it is generally considered that ‘disabled people’ is preferred to ‘people with a disability’ because this fits in with the social model, i.e. people are just people until they are disabled by a barrier or policy. This is supported in the writing of this manual, as the aim is to build an environment within the home that eliminates barriers and allows the maximum degree of independence in the use of the facilities.

This philosophy is shared by Selwyn Goldsmith, the architect who for many years has set the disability architectural standards. In the preface of his latest book he writes:

*"The disabled' is an ambiguous term. It can mean, as it usually does, people with disabilities, those who have something wrong with them that a physician can describe. That is the medical model. Or it can mean people, whether or not they be 'medically' disabled, who are in some other way disabled – who are financially disabled, for example or socially disabled, or architecturally disabled. It is architecturally disabled people with whom this book is concerned, those who when using or attempting to use buildings can find themselves confronted by impediments which prevent them from doing so, or allow them to do so only with difficulty and inconvenience. They are disabled because the architect who designed the building did not anticipate their needs, or did not care about them".<sup>5</sup>*

Perhaps this manual will go some way to put things right in the homes of people with neuromuscular conditions.

## Identification of the needs

A *Disability Needs Assessment Form* (Chapter 10) has been compiled and piloted for several months, in preparation for the publication of this manual. The aim has been to make the assessment process as easy and thorough as possible, while at the same time identifying the choices to be made – (e.g. lift vs extension and bath vs shower), the equipment to be assessed, housing specifications to be considered – and recording the initial funding issues. In addition, these are all discussed in greater detail in this manual, as follows:

Chapter 6	<i>Lift vs Extension;</i>
Chapter 7	<i>Bath vs Shower;</i>
Chapter 8a	<i>Equipment for Adaptations;</i>
Chapter 11	<i>Justification for Funding;</i>
Chapter 12	<i>Funding of Adaptations/Understanding the Grant Systems/VAT;</i>
Chapter 15	<i>Adaptation Specifications: Access/Bathroom/Bedroom/Electrics/Heating/Storage;</i>
Chapter 16	<i>Kitchens.</i>

## Demonstration and trial of the most appropriate equipment

Chapter 8a itemises the equipment that should be assessed and the order in which decisions should be made. In *every* case, it is essential that the equipment is assessed in conjunction with an OT who knows the family circumstances and whose responsibility it will be to both establish the need and justify the expense. There are three ways in which this can be carried out:

- ⇒ a visit to a Disabled Living Centre;
- ⇒ assessment in the home;
- ⇒ visiting another house where a similar adaptation has been carried out.

## A visit to a Disabled Living Centre

This may be an enlightening occasion for an adult who has not received much practical help, but for parents the visit should be handled with great sensitivity and approached with a positive attitude. The aim is to counteract the disabling features of the condition and to increase the independence (and, therefore, the happiness) of the child. It should also be emphasised that the early and appropriate timing in assessing equipment will prevent delay and the subsequent frustrations in having to cope without adequate facilities. A child is likely to enjoy the visit: trying out the high-tech equipment and flying through the air in a hoist can be an interesting experience, provided that it is introduced in a positive and enjoyable way.

## Assessment in the home

If an item of equipment is not held in the nearest Disabled Living Centre or if a Centre is difficult to visit, most firms will carry out a home demonstration. In addition, a specialist service has been arranged by *Daily Care* (see Chapter 18 *Addresses*) who will visit your house and bring most of the adaptations equipment on one visit. This will be much easier than having different firms demonstrating individual items. Alternatively, the firms may be able to let you know if the equipment has been installed in the area and arrangements can be made for the assessment. This may be particularly important where a realistic trial is not possible unless the equipment is plumbed into a water supply, e.g. a shower toilet.

## Visiting another house where a similar adaptation has been carried out

In many cases, this is a supportive way to carry out the assessment. This may be particularly true if the adults have the same difficulties or if the children are close in age. The Muscular Dystrophy FCO or community OT may be able to make the arrangements, and this is likely to be the most satisfactory way of assessing equipment.

## Suitability of the present housing

A number of factors are involved, as follows:

- ⇒ access and suitability of the garden and the area surrounding the house;
- ⇒ suitability of the existing facilities or the adaptability of the house;
- ⇒ the importance of space;
- ⇒ recommended size of rooms;
- ⇒ the use of existing rooms;
- ⇒ the need for a disabled child with a neuromuscular condition to have a separate bedroom.

Other issues will be involved if moving is considered, and these are included in the discussion on the outcome options (see page 12).

## Access and suitability of the garden and the area surrounding the house

The importance of access into the garden and a suitable paved area is discussed in Chapter 15 *Adaptation Specifications*. The area surrounding the existing house is not usually of great importance, because a powered wheelchair can climb a gradient of 1 in 4 and any road is unlikely to be as steep (although this is frequently a problem with private drives). Although a sloping site should be avoided when selecting a new house, this feature in the existing house need not be the sole reason for a family move.

## Suitability of the existing facilities or the adaptability of the house

- The aim is to ensure that there are en-suite facilities with a bedroom and bathroom large enough for the person (and partner) and for the essential furniture and fittings, in addition to adequate circulation space for a wheelchair. See Chapter 11 for details of the space requirements.
- Are these facilities currently available either on the ground floor or upstairs? If upstairs,
  - Can a through-floor lift be installed (i.e. is there a suitable position on the ground floor with a suitable position directly above – either on the landing or in the bedroom) or are the stairs suitable for a wheelchair-platform lift?
  - If a through-floor lift is proposed up to a bedroom, is the room large enough for both the lift and for the fittings that are needed in the room?
  - If not, is the garden suitable for a large-enough extension?

## The importance of space

This should not be underestimated and frequently is the reason for adaptations needing to be reconsidered within 5 years of completion. It is important to justify the need for space to either of the following:

- a grants officer, to ensure that the proposed extension is large enough when there is concern about the cost;
- a planning officer or Planning Committee who are anxious to reduce the size of an extension.

This information has been presented in Chapter 11a *The Long-Term Housing Needs, including the Importance of Space*, and Chapter 11b *Space Requirements*, to enable them to be photocopied, and submitted with other information to justify the need for space.

## Recommended size of rooms

Questions are frequently asked about the optimum size of the rooms. These are difficult to answer without details of access, the shape of the rooms, the number and size of windows and (if an extension is to be built) how this will dovetail with the existing house. It is more constructive for the architectural designer to be given an accurate brief early in the process; when the essential features and space dimensions have been considered. These will determine the size of the rooms.

## The use of existing rooms

There may be several issues to be discussed on the number and use of existing rooms, which may include the need to retain the following:

- ⇒ a dining room;
- ⇒ a room for a temple or a room to be used for prayer;
- ⇒ a spare room for a carer.

## The need to retain a dining room

Grants officers are responsible for seeing that the grant is spent appropriately. In this respect, they may suggest that a dining room is used to provide a ground-floor bedroom. However, this is not practical for someone with a neuromuscular condition. It is essential to have wheelchair access under a dining-room table in order to have a surface large enough to support the forearms and to provide adequate space for the dinner plate, side plate and mug; the use of a wheelchair tray is not adequate for meals.

For many families, quality family time is achieved when sharing a meal around a table and, for active families, this may be the only opportunity to talk and listen to each other. Many disabled people do not have the same opportunities as others to go out in the evenings. The ability to entertain friends at home may be an important factor to prevent isolation, and to provide a break from caring for someone who is severely disabled. Some families may need the dining room for business entertaining.

Where a dining room adjoins the sitting room, creating a throughroom may increase the wheelchair circulation space and provide a family room. In the same way, a kitchen and dining room may be opened up to create a kitchen/diner and thereby improve access, increase circulation space, or borrow natural light where a window has been lost due to the building of an extension.

### **The need to retain a room as a temple or a room to be used for prayer**

This need is the easiest to establish as race relations and racial tolerance are recognised as important and clearly understood. It is also important to respect the Asian tradition of having separate sitting rooms for men and women.

### **The need to retain a spare room for a carer**

One of the great distresses to anyone disabled and their partner (or parents) is that their private lives become exposed when they ask for help from a statutory service. It can be difficult to explain the need to retain a spare room. Many disabled people can be very restless at night and, for a partner who has to work the following day, it is often essential to retain a room in which they can periodically get a less disturbed night. This may be particularly important when either is ill or recovering from an operation.

It may also be necessary to accommodate a carer, on a temporary or permanent basis – or friends who stay overnight to help. To have extensive adaptations carried out that would not be adequate in the future and would involve either restarting the adaptation process or involve re-housing, is shortsighted and will prove more expensive in the long term.

A bed-sit is invaluable if a carer is needed for a teenager or young adult living at home with parents; problems can arise if the carer has to share the living area with the rest of the family, who subsequently lose their privacy, resulting in the build-up of family tensions.

### **The need for a disabled child with a neuromuscular condition to have a separate bedroom**

Many children need attention in the night and it is unfair to constantly disturb another child sharing the room, who will then be tired at school the next day. Where a family has two affected children, if the parents get up to see one child and the other is disturbed, the parents will never get back to bed. Giving attention to both children at the same time does not always reduce the number of times it will be necessary to get up; repositioning is to increase comfort when necessary, rather than to turn the disabled child routinely to prevent pressure sores. An age gap – and therefore a difference in bedtimes – may also make it unsatisfactory for two children to share a room.

### **Availability of funding and grants**

These are considered in Chapter 12 *Funding of Adaptations*.

## The outcome options

Having assessed the needs, and considered the suitability of the present house – and depending upon the financial circumstances – a decision will need to be made between the following:

- ⇒ adapting the house;
- ⇒ moving.

### Adapting the house

Before adapting a house, it is wise for the grant applicant, or their family, to give serious thought to the proposals. If there are any doubts, re-housing – or house-hunting, if you own your own house – should be considered. It is essential, where it is decided to go ahead with the adaptations, to be certain that all the alternatives were carefully examined for reassurance that the right decision was made. It is also important that, if you have any misgivings during the adaptation process, you should voice these doubts and be prepared to reconsider the alternative options. If this is difficult, it may help to enlist the support of a Muscular Dystrophy Family Care Officer.

Architectural services are grant eligible. However, a Disabled Facilities Grant (DFG) or an Improvement Grant will not be approved unless the adaptations are carried out. If the adaptations do not go ahead, it will be necessary to pay the architectural designer for the work completed without a grant to cover the cost.

### Dissatisfaction with the proposed adaptation plan

In owner-occupied houses it is important to remember that the house belongs to the grant applicant or the family: you are the people who have to cope with the disability in the home and the grant is payable to you. Details of the grant are included in Chapter 12 *Understanding the Grant Systems*, but if the plans are not what you or your family feel that you need, it is important that your concerns are voiced. This is equally important in rented property. If there is disagreement on the best options and a position of stalemate is reached, discuss with the grants officer about drawing up alternative plans. Provided that the two sets of plans are equally suitable from the disability point of view, they can be priced separately, the grant paid on the cheaper scheme and you could be given the opportunity to pay the difference and build your preferred plan.

### Moving

There are a number of issues to be considered:

- ⇒ social and family factors;
- ⇒ long-term housing needs;
- ⇒ housing pitfalls to avoid;
- ⇒ suitability of the proposed house, if necessary with adaptations;
- ⇒ re-housing to a rented property;
- ⇒ advice before accepting a re-housing offer;
- ⇒ mortgages for disabled people;
- ⇒ buying or renting a bungalow;
- ⇒ building a new home.

## Social and family factors

The importance will vary according to the priorities of each individual family:

- Is the timing right psychologically for everyone concerned?
- Will the move involve losing the support of neighbours, friends and relations?
- Is there an appropriate school for the disabled child, within reasonable distance?
- Will the move affect the rest of the family, including the education of siblings?
- The needs of siblings are discussed in the publication *Hey, I'm Here Too*.<sup>6</sup>
- What are the local facilities?
- What effect, if any, will a move have on the jobs or careers of the family?

Following a move to a suitable house that needs adaptations, a grant application can be made in the normal way.

*N.B.* Because bungalows offer ground-floor accommodation, there may be difficulties in justifying the need for adaptations. See further advice on page 16.

## Long-term housing needs

When making a re-housing application, it is important to be clear about the housing needs, as this information will be essential to send to the lettings officer of the Housing Department or to the allocation or development officer of a Housing Association.

Separate pages have been prepared on the long-term housing needs and the need for space, and are included in Chapter 11. They can be photocopied to include with applications.

## Housing pitfalls to avoid

### Houses built into a hillside

The expense of excavating the site and building retaining walls will reduce the amount of funding available to provide the access and facilities needed.

### Houses with insufficient space for an extension at sides or rear

It would be unusual to gain planning consent for an extension other than a porch on to the front of the house, unless it is not in front of the building line.

### Where an extension would be too narrow without building up to the boundary or impacting on neighbours

Look to see if a precedent has been set by extensions to other houses in the road.

## Suitability of the proposed house, if necessary with adaptations

Ask for advice before making the final decision on whether to accept a lease or to buy a particular house, to ensure that, if it needs to be adapted, it is suitable. There are some houses that are either impossible to adapt or that would prove so expensive as to be impractical. Seek this advice from someone that you can trust and who will be considering your best interests – and the best person to help you will be an architect/designer with relevant experience, a Muscular Dystrophy Family Care Officer or an OT.

The dilemma for some LA personnel looking at a house before purchase, may be that their responsibility is to look for the cheapest way to adapt it. If the house is suitable for a lift, there may be the temptation, in the case of a disabled child, to dictate how the bedrooms should be allocated, suggesting that the child uses the double room intended for the parents. Where there is a dining room, it may be insisted that this is used as a bedroom, making it more difficult later to argue the case for retaining a room for meals.

## Re-housing to a rented property

If you rent your home you may choose to remain in rented property or you may have no alternative. You will have to apply to be re-housed in a more suitable council house or a Housing Association or privately-owned property. However, if you are a council tenant and would consider buying a house, you should enquire if the LA operates an incentive scheme which provides capital to help families to move out of the rented sector.

## Advice before accepting a re-housing offer

The following must be discussed:

- ⇒ the suitability of the house;
- ⇒ availability of grants;
- ⇒ the willingness of the Housing Department, Housing Association or private landlord to adapt the property, if necessary;
- ⇒ rent;
- ⇒ security of tenure.

### The suitability of the house

See page 9.

### Availability of grants

This issue is discussed in Chapter 12 *Funding*.

### The willingness of the Housing Department, Housing Association or private landlord to adapt the property, if necessary

This should be discussed with the community OT and a commitment received in writing from the appropriate department, before accepting the property. If the adaptations cannot be carried out before moving into the house, the commitment should also include a time-scale for the work to begin – and the arrangements for alternative accommodation, if it proves impossible to remain in the house with builders on site.

### Rent

Housing Association property can be expensive to rent and, if you are not receiving housing benefit, it may be wise to discuss the proposed rent before being re-housed or before a house is purpose built.

### Security of tenure

There may be a number of issues, including security of tenure, which will be relevant to rented property irrespective of who owns the house. These should be checked out with care, with legal advice if necessary. A solicitor can be contacted at a Citizens Advice Bureau or at the nearest Disability Law Centre – both of which will be listed in the telephone directory – or by contacting the Disability Law Service (see Chapter 18 *Addresses*).

If the property has been specifically built or adapted for a disabled person, or is to be adapted for them, the partner or family should find out what the future position would be if the person dies:

- Will you be allowed to remain in the house or be asked to move?
- If you have to move, how long will you be allowed to stay after the bereavement (as it is difficult to cope with a move while the grieving is very acute)?
- If the house belongs to a Housing Association, will you be offered another of their properties or will you have to go on to the council housing waiting list?
- Will you be allowed to wait until you have been offered a house that you like – in an area in which you want to live – or will you be expected to accept the first offer?

### Mortgages for disabled people

Do not assume that disability and possibly a shortened life expectancy make it impossible to get a mortgage. Seek advice from building societies or independent financial or mortgage advisors.

### Buying or renting a bungalow

A bungalow can be the ultimate solution for anyone unable to climb stairs or using a wheelchair. However, before thinking of moving to a bungalow the following should be considered:

- ⇒ advantages of a bungalow;
- ⇒ disadvantages of a bungalow;
- ⇒ the need to justify adaptations;
- ⇒ advice before purchase.

#### Advantages of a bungalow

- ***Instant access to every room in the home***

Clearly, this is the main reason for choosing a bungalow, and is achieved with none of the disadvantages of a lift. The advantages of single-floor accommodation are:

- if a child needs attention in the night, the parents do not have to go downstairs;
- disabled parents who are unable to climb stairs, will be able to go into their children's bedrooms;
- it is feasible for anyone unable to climb stairs to assume the responsibility for supervision of the maintenance and cleaning of the house.

#### Disadvantages of a bungalow

These are as follows:

- ⇒ cost;
- ⇒ noise;
- ⇒ situation;
- ⇒ difficulty in justifying adaptations.

- **Cost**  
The cost of a bungalow is much greater than the equivalent floor area in a house and, as a result, you may have to buy a bungalow smaller than ideal and/or increase your mortgage. The size of the mortgage is not taken into account in the ‘Test of Resources’; the means test of the Disabled Facilities Grant (DFG). These additional outgoings may make it impossible to pay your assessed contribution.
- **Noise**  
There is no ceiling to deaden the sound of your children’s music!
- **Situation**  
If the bungalow is sited among other bungalows, you are likely to be surrounded by older people who may be less tolerant of children and their noise.
- **Difficulty in justifying adaptations**  
When considering buying or renting a bungalow you must be aware of the problems you may subsequently experience in obtaining a grant for adaptations, as the bedroom and bathroom are already on the ground floor. It is easier to justify an extension for a disabled person who has an upstairs bedroom and who cannot climb stairs or who uses a wheelchair. It may also be difficult to convince the landlord of a rented bungalow that adaptations are essential.

The DFG legislation includes a number of facilities for which grant is mandatory and in the context of this discussion the following are relevant:

*“facilitating access by the disabled occupant to:*

- *and from the dwelling or the building in which the dwelling or, as the case may be, flat is situated;*
- *a room used or usable as the principal family room;*
- *or providing for the disabled occupant, a room used or usable for sleeping;*
- *or providing for the disabled occupant, a room in which there is a lavatory, or facilitating the use by the disabled occupant of such a facility;*
- *or providing for the disabled occupant, a room in which there is a bath or shower (or both), or facilitating the use by the disabled occupant of such a facility;*
- *or providing for the disabled occupant, a room in which there is a wash hand basin or facilitating the use by the disabled occupant of such a facility”;*<sup>7</sup>...

In a bungalow the ‘disabled occupant’, will have access to *a room for sleeping and a room in which there is a lavatory, bath, shower or washhand basin* and may be denied a grant to provide a bedroom and bathroom which are both *large enough and adjacent* for provision of en-suite rooms. If you or your family try to help yourselves by moving into a more suitable home and use up your savings in the process, it is an injustice if you are then denied a grant. If necessary, this must be challenged. Had you remained in your previous house you would have been given (depending upon need and the means test) a DFG (England, Wales and Northern Ireland) or Improvement Grant (Scotland) with the possibility of a top-up grant or loan to provide an accessible and en-suite bedroom and bathroom. See Chapter 12 *Funding of Adaptations*.

## The need to justify adaptations

- **The need for en-suite facilities**

It is recommended that everyone with a neuromuscular condition, who needs a wheelchair or will need one in the future, should have en-suite facilities. This enables them to be undressed on their bed and be taken to the bathroom (possibly on an extended track of the ceiling hoist) within the warmth and privacy of the two rooms.

The provision of en-suite facilities *is* a real need and, if the bathroom or bedroom is too small to allow sufficient space for the additional door, necessary equipment and the circulation space for a wheelchair, then an extension *is* needed.

## Advice before purchase

When considering moving to a bungalow, it may be wise to involve the Muscular Dystrophy FCO and subsequently to check the position with the community OT, who can be contacted through the local Social Services Department. The alternative is to seek other advice – or be prepared to fight the case after purchase.

## Building a new home

Replacement grants are available in Northern Ireland and these are discussed in Chapter 12 *Funding*. In the past, in the rest of the UK, although it may sound illogical, if you decided to build, there were no Housing Department Grants unless you moved in first and then asked for adaptations – and in some areas this may still be the situation. However, the Social Services Department will usually provide a ceiling hoist and may consider helping with essential fittings such as a lift, shower toilet, specialist bath and washbasin.

With the introduction of amendments to the grants system in 2003, depending upon the LA's policy, discretionary grants/loans may be available to help with the purchase of a more suitable house and this might extend to the provision of purpose-built facilities within a proposed 'new-build' house. It would be wise to approach the community OT or grants officer as early as possible, to discuss the options of both financial help and/or the provision of equipment.

## References

- 1 Oldham, Christine, Beresford Bryony. *Homes unfit for children: Housing disabled children and their families*. Policy Press in conjunction with the Joseph Rowntree Foundation, 1998.
2. *Code of Ethics and Professional Conduct for Occupational Therapists*. College of Occupational Therapists, 2000, pg. 5-6.
3. Green, Josephine M, Murton, Frances B. *Duchenne muscular dystrophy: The experiences of 158 families*. Centre for Family Research, University of Cambridge, 1993.
4. Oliver, Mike. *Understanding Disability: From Theory to Practice*. Macmillan Press, 1996.
5. Goldsmith, Selwyn. *Designing for the Disabled*. Architectural Press, 1997.
- 6 Siegel, Irwin M. *Hey, I'm Here Too!* Muscular Dystrophy Campaign, 1998.
- 7 *The Housing Grants, Construction and Regeneration Act 1996, Chapter 53*. HMSO, pg. 13-14.

# Muscular Dystrophy & Allied Neuromuscular Conditions

## Introduction

Factsheets on a range of neuromuscular conditions, and on some disability issues, are available from the Muscular Dystrophy Campaign. These are constantly reviewed and updated. A full set can be found on and printed off from the organisation's website: [www.muscular-dystrophy.org](http://www.muscular-dystrophy.org)

Alternatively, photocopy the page, indicate the factsheet required  and return to:

Information Service  
Muscular Dystrophy Campaign  
7–11 Prescott Place  
London SW4 6BS  
tel: 020 7720 8055  
fax: 020 7498 0670  
e-mail: [info@muscular-dystrophy.org](mailto:info@muscular-dystrophy.org)

- Alternative Therapies
- Annual Review
- Anaesthetics
- Becker muscular dystrophy
- Booklist on the muscular dystrophies and neuromuscular disorders
- Carrier detection tests and prenatal diagnosis
- Children with muscular dystrophy in mainstream schools

### **Congenital Myopathies**

- Central core myopathy
- Congenital fibre type disproportion myopathy
- Minicore (multicore) myopathy
- Myotubular or centronuclear myopathy
- Nemaline myopathy
- Congenital muscular dystrophy
- Congenital myotonic dystrophy
- Duchenne muscular dystrophy
- Duchenne muscular dystrophy: the older child
- Education
- Emery-Dreifuss muscular dystrophy
- Facioscapulohumeral muscular dystrophy (FSH)
- Facts about muscular dystrophy
- Gastrostomy

- Heart check
- Hereditary Motor and Sensory Neuropathies - HMSN (Charcot-Marie-Tooth disease)
- Holiday factsheet
- Hospital card
- Inclusion Body Myositis
- Inheritance and the muscular dystrophies
- JPT Annual Review
- Joining the Campaign
- Juvenile Dermatomyositis
- Limb-Girdle muscular dystrophy
- Manifesting carriers
- Muscle biopsies
- Making breathing easier
- Metabolic disorders that cause pain and/or weakness on exercise
- Mitochondrial myopathies
- McArdle's disease
- Myasthenia Gravis
- Myositis Ossificans Progressiva
- The Myotonias
- Myotonic dystrophy
- Ocular myopathies
- Periodic paralyses
- Personal relationships and sexuality
- Polymyositis and Dermatomyositis
- Pregnancy and reproduction in muscle disorders
- Student pack
- Surgical correction of spinal deformity
- Target MD
- Transport factsheet
- Weight control in patients with muscular dystrophy
- Would it help to talk? (Emotional needs)

## Support Groups

Support Groups are run by and for people with neuromuscular conditions, and their families and friends - and those listed below have very close links with the Muscular Dystrophy Campaign. They offer a variety of services such as a newsletter, providing information and emotional support - and putting individuals and families in touch with each other.

### Association for Glycogen Storage Disease

9 Lindop Road  
Hale  
Altrincham  
Cheshire  
WA15 9DZ  
tel: 0161 980 7303 (after 6pm)  
e-mail: [info@agsd.org.uk](mailto:info@agsd.org.uk)  
contact: Mrs Ann Phillips  
web: [www.agsd.org.uk](http://www.agsd.org.uk)  
*Glycogen Storage diseases including:  
Von Gierke's disease, Pompe's disease  
Andersen's disease, McArdle's disease*

### CLIMB Children Living with Inherited Metabolic Diseases

Climb Building  
176 Nantwich Road  
Crewe  
CW2 6BG  
tel: 0800 652 3181  
e-mail: [info@climb.org.uk](mailto:info@climb.org.uk)  
contact: Mrs Lesley Greene  
web: [www.climb.org.uk](http://www.climb.org.uk)  
*Includes Mitochondrial Myopathy*

### CMT United Kingdom

PO Box 5089  
Christchurch  
BH23 2WJ  
tel: 0870 7744 314  
e-mail: [secretary@cmt.org.uk](mailto:secretary@cmt.org.uk)  
contact: Karen Butcher  
web: [www.cmt.org.uk](http://www.cmt.org.uk)  
*Hereditary Motor and Sensory Neuropathy,  
also known as Peroneal muscular atrophy and  
Charcot-Marie-Tooth disease*

### Congenital Muscular Dystrophy Support Group

21 Morrison Drive  
Pitcorthie  
Dunfermline  
Fife  
KY11 5DJ  
tel: 01383 736 084

### Duchenne Family Support Group

37a Highbury New Park  
Islington  
London  
N5 2EN  
tel: 0870 241 1857  
e-mail: [dfsg@duchenne.demon.co.uk](mailto:dfsg@duchenne.demon.co.uk)  
helpline: 0870 606 1604  
contact: Rosemary Matthews  
web: [www.dfsg.org.uk](http://www.dfsg.org.uk)  
*Duchenne muscular dystrophy*

### FSH-MD Support Group

8 Caldecote Gardens  
Bushey Heath  
Herts  
WD23 4GP  
tel: 020 8950 7500  
fax: 020 8950 7300  
e-mail: [fshgroup@hotmail.com](mailto:fshgroup@hotmail.com)  
contact: Mr Norman Jonas  
web: [www.fsh-group.org](http://www.fsh-group.org)  
*Facioscapulohumeral muscular dystrophy*

### **Guillain-Barre Syndrome Support Group**

Lincolnshire County Council  
Council Offices  
Eastgate  
Sleaford  
Lincs  
NG34 7EB  
tel: 01529 304 615  
helpline: 0800 374 803  
e-mail: admin@gbs.org.uk  
contact: Mrs Glenys Sanders  
web: www.gbs.org.uk

### **The Jennifer Trust for Spinal Muscular Atrophy**

Elta House  
Birmingham Road  
Stratford upon Avon  
Warwickshire  
CV37 0AQ  
tel: 0870 774 3651  
helpline: 0800 975 3100  
(Mon-Fri 9-5)  
fax: 0870 774 3652  
e-mail: jennifer@jtsma.org.uk  
contact: Mrs Anita Macaulay  
web: www.jtsma.org.uk  
*Severe SMA (Werdnig-Hoffman disease)*  
*Intermediate SMA*  
*Mild SMA (Kugelberg-Welander disease)*  
*Adult SMA*

### **Mitochondrial Myopathies**

3 Home Farm Cottages  
Yearby  
Nr Redcar  
Cleveland  
TS11 8HQ  
tel: 01642 480 973  
email: mitolinks@aol.com  
contact: Vic/June Wood  
*Mitochondrial myopathies*

### **Myasthenia Gravis Association**

Central Office  
Keynes House  
Chester Park  
Alfreton Road  
Derby  
DE21 4AS  
tel: 01332 290 219  
helpline: 0800 919 922  
e-mail: mg@mgauk.org.uk  
web: www.mgauk.org  
*Myasthenia Gravis, Lambert-Eaton*  
*Myasthenia, syndrome and Congenital*  
*Myasthenia*

### **Myositis Support Group**

146 Newtown Road  
Woolston  
Southampton  
SO19 9HR  
tel: 02380 449 708  
Mon-Fri 9am-3pm  
e-mail: enquiries@myositis.org.uk  
contact: Mr & Mrs Oakley  
web: www.myositis.org.uk  
*Dermatomyositis and Polymyositis*  
*Juvenile Dermatomyositis*  
*Inclusion Body Myositis*

### **Myotonic Dystrophy Support Group**

35a Carlton Hill  
Carlton  
Nottingham  
NG4 1BG  
tel: (Answerphone) 0115 987 0080  
fax: 0115 987 6462  
e-mail: mdsg@tesco.net  
contact: Mrs Margaret Bowler  
web: www.mdsguk.org  
*Myotonic dystrophy (also known as*  
*Steinert's disease and Dystrophia Myotonica)*  
*Congenital myotonic dystrophy*

# Lift vs Extension

## for children & adults with muscular dystrophy & allied neuromuscular conditions

*The factors to be considered by a disabled person and/or their family to help make a well-informed choice*

To be used in conjunction with:

Chapter 8a	<i>Equipment for Adaptations;</i>
Chapter 11	<i>Justification for Funding;</i>
Chapter 14	<i>Scales &amp; Templates;</i>
Chapter 15	<i>Adaptation Specifications;</i>
Chapter 18	<i>Addresses: Manufacturers/Suppliers/Sources of Advice.</i>

The main issue involved in the choice is an assessment of the best use of space. The decision is about which option either uses up the least space or gives access to the most space and the opportunity to provide the best facilities, within both the house and garden.

A lift is usually the first option to be considered, particularly if a grant application is being made, as grants officers prefer to approve adaptations that are within the structure of the house. However, where both a lift and an extension are possible structurally, the final decision must depend upon which option will be the most appropriate for the disabled person and the carers, bearing in mind the long-term effects of the particular disability.

Guidance is presented under the following headings:

	⇨ Lift	2
	⇨ Ground-floor extension	5
⇨ Making the choice between a lift & a ground-floor extension		6
	⇨ Summary	9

## Lift

The issues to be considered are:

- ⇒ types of lifts available;
- ⇒ is a lift appropriate?
- ⇒ choice of model.

### Types of lifts available

These are as follows:

- ⇒ stairlift with a platform for a standing passenger;
- ⇒ stairlift with an integral chair;
- ⇒ stairlift with a platform for a wheelchair;
- ⇒ vertical through-floor lift.

#### Stairlift with a platform for a standing passenger

Unless there are unusual circumstances or a lift is needed for only a short period, this type is not recommended for the safety of anyone with muscular dystrophy.

#### Stairlift with an integral chair

Many adults prefer this type of lift; however, unless such lifts are used as a 'stop-gap' solution, they are not suitable for anyone with muscular dystrophy. This is because of the difficulty in transferring on and off the seat, the problems of both balancing and carrying objects, and, if/when a wheelchair is necessary, the need for a second wheelchair upstairs.

#### Stairlift with a platform for a wheelchair

Although these lifts do not take up valuable space in a house, there has to be a large enough area, both at the base of the flight of stairs and at the top, to accommodate the platform. In addition, there must be sufficient space to enable the user to manoeuvre the wheelchair with ease, on and off the platform. These lifts also take up the full width of the stairs and therefore prevent anyone else using the stairs at the same time.

#### Vertical through-floor lift

These models are usually open and not enclosed in the same way as a public service lift. Initially, even if a wheelchair is not needed, this type of lift will be invaluable as a means of going between the two floors and carrying small items such as toys and washing. If necessary, a wall-mounted seat can be fitted prior to the use of a wheelchair in the future. However, this may be contraindicated because of the difficulty of standing up from the seat unless it is high enough to be used as a 'perching' seat.

Forward planning is essential to ensure that, where possible, the lift will be suitable for the size of any wheelchair that may be used in the future, and for the combined weight of the chair (which could be **140kg**) and the occupant.

## Is a lift appropriate?

The following questions need to be answered:

- ⇒ Is the house large enough for the loss of space taken up by the lift and access to the lift to be unimportant?
- ⇒ Is there a suitable position for the lift on the ground floor and directly above on the first floor – or are the stairs suitable for a wheelchair-platform lift?
- ⇒ Are the first-floor facilities suitable in space and layout for a wheelchair?

### Is the house large enough for the loss of space taken up by the lift and access to the lift to be unimportant?

Most houses lack space and are unsuitable for the installation of a lift. The space needed for a lift is considerable, because of the area needed for both the lift and access to the lift. The recommended size is likely to be approximately **1500mm** in length and **1000mm** in width for the lift – and an area of the same size in order to approach the lift in a wheelchair and open the door.

### Is there a suitable position for the lift on the ground floor and directly above on the first floor – or are the stairs suitable for a wheelchair-platform lift?

Does the layout of the rooms allow for a double bedroom, large enough for the essential fittings and a lift, to have en-suite facilities? Boys with Duchenne muscular dystrophy and other children and adults with neuromuscular conditions are often undressed on their bed and then they transfer into the bathroom either on a mobile bath or shower chair, or on an extended track of the ceiling hoist. The latter option is usually chosen when a shower toilet and/or bath with an integral seat is installed. Adjoining rooms enable this procedure to be carried out within the warmth and privacy of the two rooms – and respects the dignity of the disabled person.

### Are the first-floor facilities suitable in space and layout for a wheelchair?

There is no point in installing a lift if either the bathroom or bedroom is too small. It is important to be aware of the space needed in the future as the need for additional equipment and the size of the wheelchair increases.

#### Bathroom

There must be sufficient space for the following:

- **A suitable bath or shower**

Where possible, the choice of equipment must be made on the basis of need and not space, and the choice will be between:

- an *Arjo* Sovereign bath with space to cover the arc of the seat;
- Mermaid Ranger with a pillar at the side or end of the bath, with space to cover the arc of the seat;
- ASM Multi-System;
- level-access shower.

- **Vanity washbasin**
    - 1050-1200mm in width and a front-to-back depth of 675-695mm.
    - 1000mm in front of the basin to allow sufficient space for a wheelchair to approach squarely.
  - **Toilet**
    - 900mm at the exposed side of the toilet for positioning a wheelchair for sideways transfer.
    - 500mm from the centre of the pan to the wall or nearest obstruction. This allows space for wall-mounted rails and for a chair to be superimposed over the pan, if either are needed.
  - **Additional door**
    - 926mm width door to provide direct access to the bedroom.
- The circulation of a powered wheelchair**
- 1700mm turning circle or the space to carry out a 3-point turn.

## Bedroom

There must be a suitable position for the lift (if it cannot be accommodated on the landing) and yet enough space for the essential items, as follows:

- **Wall space for an electric bed**
  - Length: 2155mm.
  - Width: 2160mm for a double bed, and either 1080 or 1220mm for a single bed. It is always wise to allow for the wider single bed because this option will then be possible in the future - or will allow a single bed to be pulled away from the wall to enable a carer to work from both sides of the bed.
  - Side: 1800mm to enable the ceiling hoist over the bed to be used for transferring from one wheelchair to another, or from wheelchair to easy chair or Mermaid Ranger/shower chair.
- **Standard storage facilities**
  - Wardrobe and chest of drawers.
- **L-shaped working surface**
  - A minimum length of 1800mm x 1200mm.
- **Door**
  - 926mm width door to provide direct access to the bathroom.
- **The circulation of a powered wheelchair**
  - 1700mm turning circle.

## Choice of model

The factors to consider are as follows:

- ⇒ whether the lift has to be suitable for a wheelchair;
- ⇒ the space available for the most appropriate model;
- ⇒ the size of lift and weight limitations;
- ⇒ the availability of electronic doors and the sensitivity of the switches;
- ⇒ the position of the controls;
- ⇒ choice of lift.

## Whether the lift has to be suitable for a wheelchair

For most people with a neuromuscular condition, it is vital to have a wheelchair model of lift installed, if a wheelchair is needed now or is likely to be needed in the future. This will avoid incurring the additional and considerable expense of changing the lift at a later date, usually to a vertical through-floor lift.

## The space available for the most appropriate model

The approximate space has been discussed, but it is important to find the most suitable model of lift and to check the dimensions.

## The size of lift and weight limitations

These may be crucial, particularly for adults, and children as they get older and use more sophisticated, larger and heavier wheelchairs. Care must be taken to ensure that the lift that is installed will not limit the choice of wheelchair in the future. The recommended size is approximately **1000mm** in width and **1500mm** in length (which may be a 'special' car size in the wheelchair model).

## The availability of electronic doors and the sensitivity of the switches

The lift must have electronic doors and accessible, sensitive controls to ensure that it can be operated independently, particularly in the long term when the disability may have increased.

## The position of the controls

The position of the controls and their accessibility, on the ground floor, first floor and in the lift is very important. The height of the switches and the space at either side will be crucial, and these measurements are discussed under *electrical fittings* in Chapter 15 *Adaptation Specifications*.

## Choice of lift

A number of firms manufacture or supply lifts, and individual Local Authorities tend to prefer to use one firm only, as this makes servicing and repairs more straightforward, although if the lift has been bought with a housing grant, maintenance may be the responsibility of the applicant. Two firms have frequently supplied lifts to people with neuromuscular conditions and, when exploring the options, these firms may be a good place to start. However, this does not mean that other lifts are not satisfactory, provided that they are the recommended size, travel the required height and are available with suitably-positioned, touch-sensitive controls.

Harmony wheelchair lift: *Terry Group Ltd*  
VM31/VM51 or VM36/VM56 vertical lifts: *Wessex Medical Equipment Co Ltd*

## Ground-floor extension

The questions to be answered are:

- ⇒ Is there sufficient space in the garden?
- ⇒ Can the extension be accessed from the hall or family area and (ideally) not through the kitchen?
- ⇒ Can the extension be used to provide wheelchair access into and out of the house?
- ⇒ Can the extension be used to provide wheelchair access between the house and garden?

### **Is there sufficient space in the garden?**

Is the garden large enough for a bedroom/bathroom extension of adequate size, preferably retaining access down the side of the house? One of the problems may be in getting planning permission, but many Planning Departments will look more favourably and 'bend' their rules where disabled facilities are needed. See Chapter 11 *Space Requirements*, Chapter 14 *Scales & Templates* and details in Chapter 15 *Adaptation Specifications*.

### **Can the extension be accessed from the hall or family area and (ideally) not through the kitchen?**

If the kitchen is a narrow galley kitchen, can this be widened to make access safer?

### **Can the extension be used to provide wheelchair access into and out of the house?**

In some situations, where a ramp is not possible at either the front or back door, or where a second fire exit is needed, wheelchair access to the house can be provided into the person's bedroom via French windows or a glazed door with an adjacent window. It is essential to ensure that the doors have a level-access threshold.

*N.B.* It is important to have a fire exit from the bedroom, if the kitchen (which is often the seat of the fire) lies between the extension and the rest of the house.

### **Can the extension be used to provide wheelchair access between the house and garden?**

An external door from the bedroom is also needed in adaptations where there is no other alternative wheelchair access into the garden or patio at the back of the house. However, because access to the garden is a discretionary item in the Grant, the need may have to be fully justified.

## **Making the choice between a lift and a ground-floor extension**

If the house is equally suitable for *either* a lift *or* extension the following should be considered:

### **Lift – Advantages**

These are as follows:

- ⇒ provided that the doors are wide enough, every room in the house is accessible to the disabled person;
- ⇒ the opportunity for disabled children with particular problems to sleep near their parents;
- ⇒ the carer does not need to go downstairs if the child or adult needs attention in the night.

## **Provided that the doors are wide enough, every room in the house is accessible to the disabled person**

This is likely to be essential to parents who want to be able to get into their children's bedrooms and want to maintain responsibility for the housekeeping and maintenance of the first-floor rooms. In addition, it ensures that the wheelchair user is not excluded from the different areas of family life; this may be important psychologically.

## **The opportunity for disabled children with particular problems to sleep near their parents**

This may be important to families who have a timid, anxious child or a very severely disabled toddler who needs constant attention in the night.

## **The carer does not need to go downstairs if the child or adult needs attention in the night**

This may be particularly important when either the carer is not well or the disabled person is ill and may need even more help than usual.

## **Lift – Disadvantages**

The factors to consider are as follows:

- ⇒ the space needed;
- ⇒ a person with a neuromuscular condition may not be independent in the use of a lift;
- ⇒ the possible need to use the lift to access a toilet;
- ⇒ if the disabled person is in the bedroom or bathroom and needs help, the carer has to go upstairs;
- ⇒ a lift may isolate a young person;
- ⇒ lift maintenance is expensive.

## **The space needed**

A lift takes up valuable space in a home; it is not a thing of beauty; and, although it is expensive, it is unlikely to add to the value of a house.

## **A person with a neuromuscular condition may not be independent in the use of a lift**

Having to be helped places an additional burden upon the carers; if the user is independent, the procedure in using the lift will take time. Consequently, the lift may be used only a few times during the day.

## **The possible need to use the lift to access a toilet**

Unless there is an existing wheelchair-accessible toilet (with a ceiling hoist, if needed) on the ground floor, or the space and funding to provide one, the user would have to go upstairs in the lift each time the toilet was needed.

## **If the disabled person is in the bedroom or bathroom and needs help, the carer has to go upstairs**

This may occur many times each day, and possibly at inconvenient times (e.g. while the carer is cooking a meal).

## **A lift may isolate a young person**

Teenagers often choose to spend many hours in their bedrooms and, because of the length of time taken to use the lift, (compared with the time for direct access from the family living areas into an extension), this may tend to isolate them from family activities.

## **Lift maintenance is expensive**

Maintenance of equipment provided with a grant is usually the responsibility of the applicant and this may be expensive. Social Services sometimes provide this help and this should be checked when decisions are being made.

## **Extension – Advantages**

These are as follows:

- ⇒ provides the facility of a purpose-built bed-sit;
- ⇒ allows a teenager to move freely and quickly between the family areas and their bedroom;
- ⇒ provides the convenience of a ceiling hoist on the ground floor;
- ⇒ enlarges a home;
- ⇒ provides purpose-built facilities;
- ⇒ provides a ground-floor, wheelchair-accessible toilet.

### **Provides the facility of a purpose-built bed-sit**

This is likely to be important to a teenager and, with the installation of double-swing doors, allows independent and instant access to and from the room, in a powered wheelchair.

### **Allows a teenager to move freely and quickly between the family areas and their bedroom**

This provides independence and freedom that should not be underrated. Anyone with a teenage child will confirm that often teenagers prefer the privacy of their own rooms and tend to spend much of their free time amongst their possessions. A ground-floor room provides this privacy without the tendency to become isolated.

### **Provides the convenience of a ceiling hoist on the ground floor**

Allows a ceiling hoist, installed over a bed, to be used to transfer a person from one wheelchair to another during the day, without having to go upstairs. In addition, it enables a child's easy chair with castors, which is used in the family sitting room, to be wheeled into the bedroom, in order to use the hoist for lifting in and out of the chair.

### **Enlarges a home**

An extension provides an additional facility that will add to the value of the house.

### **Provides purpose-built facilities**

A purpose-built extension is likely to provide better facilities than adaptation of existing rooms.

## Provides a ground-floor, wheelchair-accessible toilet

This will be very important in a house where there may not be an existing suitable toilet. Also, as the user will always be on the same floor as the toilet, it will be quicker to access.

### Extension – Disadvantages

These are as follows:

- ⇒ reduces the size of the garden;
- ⇒ if the child or adult needs attention in the night the carer has to go downstairs;
- ⇒ not suitable for a timid child.

### Reduces the size of the garden

Limiting the garden may be a disappointment to keen gardeners and unless the garden is large, will restrict the space for siblings to play.

### If the child or adult needs attention in the night the carer has to go downstairs

This may be a frequent problem, particularly during times of illness and chest infections.

### Not suitable for a timid child

In spite of the provision of intercoms, a timid child may not like sleeping downstairs alone and may feel anxious and isolated from the rest of the family. As a result, one or both parents may end up bringing their bed downstairs to be near their child.

### Summary

The ideal solution is a large house where there is an activities room on the ground floor and sufficient space for a lift, without having a detrimental effect on the circulation of a wheelchair. However, the majority of people live in houses in which there is insufficient space for a lift and the retrospective experience of many families is that (unless there are special circumstances) an extension is a more suitable choice for most – but not all – children. This is because it increases the wheelchair circulation space in the house and will enable children to move quickly and easily between the family areas and their hobbies in their bedroom. With the same value of hindsight, a lift is essential for adults who want to retain access to their children's bedrooms, or for housekeeping and maintenance of the rooms on the first floor.

In deciding between a lift and an extension, as can be seen, there are advantages and disadvantages to both options. The issue is one in which many people feel the need to defend their choice. The problem is that opinions will vary, not only between different families but within the same family, as the importance of the advantages and disadvantages will vary from week to week and from year to year, depending upon the individual situation or problem experienced at any particular time. The aim of this chapter is to provide information based on these factors, so that where both options are possible, each family can make the most informed choice.

# Bath vs Shower

## for children & adults with muscular dystrophy & allied neuromuscular conditions

*A guide to help disabled children, adults and their families make a well-informed choice*

To be used in conjunction with:

- Chapter 8a     *Equipment for Adaptations;*
- Chapter 9     *Hoisting;*
- Chapter 18    *Addresses: Manufacturers/Suppliers/Sources of Advice.*

### Factors influencing the choice

- ⇒ Outcome of the equipment assessment 2
  - ⇒ Available space 2
- ⇒ Whether the bathroom is for the exclusive use of the disabled person 2
  - ⇒ Bath – Advantages 2
  - ⇒ Bath – Disadvantages 3
  - ⇒ Level-access shower – Advantages 4
- ⇒ Level-access shower – Disadvantages 5
  - ⇒ Personal preference 5
  - ⇒ Long-term solutions 5

## Outcome of the equipment assessment

The assessment of both showering and bathing equipment is the key to the choices available. The following criteria need to be considered:

- the optimum shower/toilet chair and the person's ability to use the shower independently;
- a comparison of the ease of showering with that of bathing for both the disabled person and the carer;
- the most suitable method for getting in and out of the bath independently or with help;
- the need to provide support in the bath;
- the need to provide support on the toilet, and, if a shower toilet is needed, to ensure the support provides the optimum washing and drying facility;
- the optimum method of transfer between the bedroom and bathroom.

These issues are discussed in greater detail in Chapter 8a *Equipment for Adaptations*.

## Available space

The space within the existing bathroom should not be the main criterion unless there is no opportunity to enlarge the room. Ideally, an alternative bathroom for the exclusive use of the disabled person should be provided, if necessary by building an extension.

## Whether the bathroom is for the exclusive use of the disabled person

Where possible, facilities should be for the exclusive use of the disabled person. They are likely to be slow in the bathroom, making it impractical for sharing with others. Also, much of the equipment is specialised and not ideal for the rest of the family. It is important that the needs of all the family are considered.

## Bath - Advantages

- Bathtime for a young family can be an important playtime and social occasion to be shared with other members of the family.
- Deep water provides buoyancy and freedom of movement. This is a great advantage to anyone with no voluntary movement in their limbs. It can be the most important reason for choosing a bath for a boy with Duchenne muscular dystrophy (DMD). A bath is relaxing and soothing and can help with sleep if taken before going to bed.
- A whirlpool bath can be fitted, or a standard bath can be used with a spa bath mat and separate motor; these facilities may provide great pleasure and increased relaxation to someone who has little or no movement in their limbs. It is unlikely that this would be grant aided with a Disabled Facilities Grant or an Improvement Grant, but can be purchased privately or might be funded by a Charitable Trust.
- A bath provides the opportunity to soak, which may be important for anyone who uses a wheelchair and gets hot and sticky around the bottom, particularly in the summer. It also makes it easier for feet to be soaked.

- People with neuromuscular conditions tend to feel the cold because of their immobility and muscle wasting; immersion in hot water helps them to keep warm while bathing.
- A bath can be supplied with a chair to provide support. This equipment should be provided in advance of urgent need, to help the user to feel confident in the bath.
- Anyone who leans forwards or sideways because of spinal curvature may lack balance and feel safer in a bath than in a shower.
- Equipment is available to lift someone safely in and out of the bath and avoid dangers of lifting manually. The choice is between a Mermaid Ranger (MD model) or ASM Multi-System, or a ceiling hoist, used in conjunction with an integral seat which swings in and out of the bath and is raised and lowered electrically. In addition to children, this type of bath is a solution for adults who can transfer independently. See Chapters 8a and 8b.
- If knee contractures are likely to be a problem, the *Arjo* Sovereign baths, which provide support under the knees, are available.
- Carers are able to remain dry when helping to wash the bather.
- Carers can take their own weight on the bath rim and eliminate the need to lean forwards without support that causes back strain.
- To protect the carer's back, baths can be installed raised up from the floor or a height-adjustable model used, e.g. *Arjo* Sovereign or *Kingkraft* Easibath Hi-Lift.
- A bath can (and should) be fitted with an over-bath shower or integral showerhead providing some of the additional advantages of a shower, particularly for hair washing. At a later stage, if the person has knee contractures that make it impossible to extend the legs forwards to lower the Mermaid Ranger seat to the bottom of the bath, the bath seat can be raised and the shower used to wash the top half of the body. Alternatively, an *Arjo* Sovereign bath should be considered or, if reclining is not satisfactory, one of the other bath models with an integral seat.

## Bath - Disadvantages

- From quite an early age, children may need help to get in and out of the bath. Parents who are not ready to accept the need for specialised equipment will take a risk with their backs by continuing to lift. It is difficult to observe good lifting techniques (i.e. keeping the back straight and the knees bent) when lifting out of a bath. However, simple bathing equipment with a seat, which is lowered and raised using battery power, is likely to help at this stage and is discussed in Chapter 8a.
- A bath takes up more space than most level-access showers, and equipment such as a Mermaid Ranger can take up valuable circulation space in a smaller bathroom. The alternative of a ceiling hoist may be satisfactory for a minority of adults, but will not provide enough support for others or for a boy with DMD, unless used with a bath with an integral seat.

- If the person develops very severe knee and hip contractures and/or a spinal curvature, it may be difficult to sit in a comfortable and well-supported position on any other bath seat. The seat may have to be used higher in the water because the legs cannot be extended forwards and this means that more water is needed in the bath.
- A Mermaid Ranger (MD model) can be used to lift into and out of the bath. Although the chassis can be raised **32mm** to superimpose the seat over a shower toilet, the washing and drying action will not be as effective as it would be when sitting directly on the toilet seat. For this reason it is *not* recommended that a Mermaid Ranger and shower toilet are used together.
- Baths are considered to be less hygienic than a shower, particularly by many Asian people, and also use more water.
- Although some larger adults and older boys with DMD support themselves with the side of the bath, others may find a standard bath too constricting and need a corner bath with the installation of a ceiling hoist extending from the bedroom. However, in these cases, support in the bath must be considered and a Mermaid Ranger may be satisfactory.

## Level-access shower - Advantages

- Takes up less space than a bath, which is important where there is no alternative to using a small existing room.
- When sited adjacent to the toilet pan, the level-access area, provided it is truly level, can also be the transfer space needed at the side of the pan for positioning a wheelchair.
- When not in use, the shower area increases the circulation space in the bathroom.
- A shower may help maintain independence where the user is able to walk or propel a shower chair, but is unable to get in and out of a bath without help. This can be the most important reason for choosing a shower for those expecting to remain independent in the foreseeable future. Assessment of an electrical height-adjustable shower seat is recommended for anyone able to walk, but having difficulty getting up from the seat (see Chapter 8b).
- Showering is likely to be quicker than having a bath.
- Showers are considered more hygienic than baths, and more economical as they use much less water.
- When showering a child, you can get in with them and create a 'fun' time.
- People of some faiths, including Hindus, Muslims and Sikhs, wash in running water.

## Level-access shower - Disadvantages

- Leaning over a waist-high shower screen can be difficult for a helper and reaching down to wash the bather's feet is impossible. The alternative may be a waist-high rail with a short shower curtain, but this will not keep water within the shower area as satisfactorily.
- People with neuromuscular conditions often complain of feeling cold in a shower, particularly if they are not independent and are unable to move under the spray.
- It is impossible to have a good soak and it is more difficult for a carer to wash the bottom of a bather who is sitting in a shower chair.
- Some older boys with DMD dislike the pressure of the water on their body.
- Some adults with muscular dystrophy may be able to wash independently in a bath, but unless the height of the shower seat can be adjusted electrically, they have difficulty in washing their feet in a shower.
- Some types of floor construction can make a level-access shower impossible and/or expensive to install.

## Personal preference

It is important that the individual person or the family make the choice, having had the opportunity to discuss all the issues involved.

## Long-term solutions

The difficulty with many neuromuscular conditions is that their progressive nature makes it not always possible to choose one method of bathing suitable in the long term. The ideal answer would be a bathroom large enough to accommodate both a bath *and* a level-access shower area. Although Housing Associations who provide purpose-built accommodation may choose this option, grants officers and community OTs may not agree that the space needed for dual installation is justifiable. However, it is worth noting that the *“purposes for which an application for a Disabled Facilities Grant must be approved”* include *“a room in which there is a bath or shower (or both)”*. See Chapter 12 *Funding*. An alternative is to ensure that the space allocated for the shower is sufficient to accommodate a bath in the future, and vice versa. Thus the option can be changed with an additional grant that is justified on the grounds of changing needs. Conversely, the practicality of installing a bath over a floor area prepared for a shower can be considered. If a shower is needed in the future, the only cost involved is that of removing the bath and either tiling the floor or installing a shower tray.

Readers will be aware of the difficulties of offering advice without knowing the personal preferences and circumstances of everyone involved. Feedback on any of the above would therefore be appreciated.

# Equipment for Adaptations

## for children & adults with muscular dystrophy & allied neuromuscular conditions

### *A guide to the equipment to be considered when planning adaptations*

To be used in conjunction with:

- Chapter 4      *Assessment of Need;*
- Chapter 10    *Disability Needs Assessment Form/Architect Brief;*
- Chapter 11    *Justification for Funding;*
- Chapter 12    *Funding/Understanding the Grant Systems/VAT;*
- Chapter 15    *Adaptation Specifications;*
- Chapter 18    *Addresses: Manufacturers/Suppliers/Sources of Advice.*

## Introduction

When planning adaptations for people with a neuromuscular condition, a number of items of specialist equipment should be considered. All the equipment in this manual has been included because it influences decisions relating to the adaptations, it needs to be plumbed in or installed, or it involves the provision of adequate space. In every case, the alternatives must be assessed before the final brief is given to the architectural designer.

The discussion is included under the following headings:

- ⇒ Providing access into the house & to the first floor 2
  - ⇒ Equipment in the bathroom 5
  - ⇒ Equipment in the bedroom 22
- ⇒ Justification of funding of equipment 24
  - ⇒ Equipment in the kitchen 25
    - ⇒ Ordering equipment 25
    - ⇒ Environmental controls 26
- ⇒ Providers & funding of equipment, adaptations & services 28

## Providing access into the house and to the first floor

A number of items of equipment may have to be considered, as follows:

- ⇒ short-rise lift;
- ⇒ Steplift;
- ⇒ portable ramps;
- ⇒ automatic door opener;
- ⇒ lift.

### Short-rise lift

This type of lift may be needed where there is a very steep approach to a house (particularly from the pavement) and there is insufficient space for a ramp. A number of firms produce short-rise lifts that overcome heights of up to **1000mm** and their specifications in relation to the cost should be compared. One suggestion is given below.

*The Ultimate Lifting Platform LP1000: Wessex Medical Equipment Ltd*

### Steplift

There are situations where it is impossible to build a ramp of the correct gradient, either because there is insufficient space or because the garden is too steep. In these instances, access to the house can be provided by installing a Steplift and the model discussed has been well tried and tested over a number of years. This consists of a platform (with safety rails and a folding front ramp) which rises hydraulically, with the standard model overcoming any height up to a maximum of **1000mm**. Bridging options for up to 3 treads are available, if necessary.

The platform, which is **1400 x 800mm**, is large enough for most wheelchairs and has a lifting capacity of **250kg**. However, the size of the platform can be increased by special order. A number of safety features are included and the unit is suitable for outdoor use, with in-built protection for the electrical unit and against corrosion.

*Terry Group Ltd*

### Portable ramps

In the context of an adaptations manual, the purpose of including portable ramps is to overcome difficult access into a house, usually as a temporary measure until adaptations have been completed or suitable housing has been found. However, there are also houses fronting straight on to the pavement where there is insufficient space for a ramp, short-rise lift or Steplift.

Portable ramps have improved considerably in recent years as they are manufactured in lightweight aluminium or fibreglass, which makes them easy to handle and fold either into one-half or one-third of their length. The choice is between channel ramps of between **150** and **250mm** width and full-width ramps. Channel ramps are usually easier to carry and store; however, if the disabled person needs to be pushed up the ramps and the carer is small, it can cause great strain on the carer's lower back because of the height involved. A wide ramp, where the carer walks up the ramp, makes this manoeuvre easier; however, this has to be offset against the fact that the ramps are more cumbersome and difficult to handle.

Various sizes are available and the length needed will depend upon the height of the steps to be bridged; as a rough guide this is likely to be a gradient of between **1 in 4** and **1 in 8**. However, the maximum and recommended heights and weights that are suitable for each ramp must be discussed with the manufacturer or supplier. There are many suppliers of ramps and the following are two suggestions:

*Portaramp/Division of Trident Industrial Ltd  
Thorworld Industries Ltd*

### Automatic door opener

The inability to open either the front or back door is very limiting to anyone wanting independence and can result in a disabled person becoming housebound. There is little value in being supplied with an indoor/outdoor powered wheelchair to increase independence if you then have to ask for help to open the door to get out of the house. In the past, supply of an automatic door opener has been limited to a disabled person living alone; however, now that disability needs are better recognised, these should be considered to increase the independence of *all* disabled people, including children, and particularly those who are old enough to be left in the house on their own.

Although automatic doors are widely used in commercial situations, the choice of domestic models is limited. However, there are a number of features and options that need to be discussed and considered either before or at the time of the assessment/choice of model, as follows:

<b>Comparative chart of features of automatic door openers</b>			
	Abloy from <i>RSL Steeper Ltd</i>	Spectra from <i>Southern Care Systems Ltd</i>	R.F. Door opener from <i>Ridley Electronics Ltd</i>
Door can be opened and closed manually when the opener is not activated electrically.	✓	✓	✓
'Finger protection' is installed along the hinged side of the door (as recommended by British Standard guidelines where doors are opened automatically and manually).	✓ as standard	✓ as optional extra	✓ as optional extra
Model suitable for standard opening and/or sliding doors.	standard only	standard only	standard & sliding
Model suitable for wood, aluminium & uPVC doors. (The latter usually supplied with multi-point locking, which may have to be opened manually in the morning and door closed with single lock.)	✓ including multi-point locking	✓ depending on locking system	✓ depending on locking system
Wide range of handset options.	✓	✓	✓
Operated by choice of push-button, infrared or radio controls.	✓	✓	✓
Speed of opening is automatically set, but time delay before closure can be altered to suit individual needs.	✓	✓	✓
Ability to detect a temporary obstacle & stop.	✓	✓	✓
Ability to distinguish between a temporary obstacle & the resistance of weather-proofing seal on the door frame.	✓	✓	✓

<b>Comparative chart of features of automatic door openers (cont.)</b>			
	Abloy from <i>RSL Steeper Ltd</i>	Spectra from <i>Southern Care Systems Ltd</i>	R.F. Door opener from <i>Ridley Electronics Ltd</i>
Weather-proofing seal compresses for the first half-second of the opening cycle to take pressure off the electric latch release, to enhance reliable operation.	✗	✓ as standard	✓ as optional extra
Advice available to choose optimum position for 13amp fused-spur, power source.	✓	✓	✓
Battery back-up for use in a power cut & as safety feature in the event of fire.	✓	✓ as standard	✓ as optional extra
Can be linked to door intercom & environmental control.	✓	✓	✓

If this equipment is not essential at the time that the adaptations are carried out, and if funding is tight, the fused spur should be installed to avoid affecting the decorations in the future, with the installation delayed until necessary, and then funded either through a subsequent housing grant or with help from a voluntary charity.

## Lift

A number of factors need to be considered when a lift is being chosen, and these have been included in Chapter 6 *Lift vs Extension*.

A telephone in the lift in case of lift breakdown may give a greater feeling of security for people using a lift when alone in the house. Phones may be an integral part of the lift, although mobile and cordless phones may make this safety feature more straightforward.

The model chosen must be large enough for any wheelchair likely to be needed in the future and able to take the weight of the chair and occupant. For this reason, the 'special' car size or the largest wheelchair lift are recommended, but there may be situations where the most appropriate position for the lift is too small and alternative options may need to be considered.

## Vertical wheelchair lifts

A number of firms manufacture or supply lifts, and individual Local Authorities (LAs) tend to prefer to use one firm only, as this makes servicing and repairs more straightforward, although maintenance of the lift is usually the responsibility of the grant applicant. Two firms have frequently supplied lifts to people with neuromuscular conditions and, when exploring the options, these firms may be a good place to start. However, this does not mean that other lifts are not satisfactory, provided they are the recommended size (see Chapter 6 *Lift vs Extension*).

Harmony wheelchair lifts: *Terry Group Ltd*  
VM31/VM51 or VM36/VM56 vertical lifts: *Wessex Medical Equipment Co Ltd*

## Equipment in the bathroom

Decisions to be made in relation to the choice of bathroom equipment are as follows:

- ⇒ bath vs shower;
- ⇒ level-access shower;
- ⇒ bath with an over-bath shower;
- ⇒ the need for a changing table;
- ⇒ body dryers;
- ⇒ the most suitable toilet;
- ⇒ essential washbasin features;
- ⇒ flooring.

### Bath vs shower

The first decision to be made is whether a bath with an over-bath shower, or a level-access shower, is the more appropriate. Personal choice will be very important; however, from a disability point of view, as a very rough guide, if you are independent in a shower but not in a bath, a shower is likely to be the better solution. With this exception, most people with a muscle problem feel that a bath is more satisfactory as it provides the opportunity to relax tired and aching muscles, and the depth of the water provides buoyancy to limbs which might otherwise have difficulty in moving.

A helper usually finds it is less of a strain on their back to assist with washing, by kneeling at the side of a bath and taking their weight on the bath rim, rather than leaning over a shower screen or trying to keep dry behind a shower curtain. It is also very difficult to wash a dependent person's feet and the lower part of their body in a shower, without getting into the shower with them.

A separate chapter is included in the manual itemising the issues that need to be considered. This should be read and discussed, and the relevant equipment demonstrated and assessed, before a decision is made.

### Level-access shower

The issues to be considered are:

- ⇒ standing or sitting use;
- ⇒ wall-mounted rails;
- ⇒ wall-mounted seat or a mobile shower chair;
- ⇒ most appropriate type of shower base.

### Standing or sitting use

Many people opt for a shower because they can walk; and having a shower while standing is easier than getting into a bath. For anyone likely to be able to continue standing, this may be the best solution; however, for many people with a neuromuscular condition, standing may not be very safe, and using a wall-mounted seat or shower chair should be considered. However, if the shower is to be used standing, the use of rails and their positioning will be important.

## Wall-mounted rails

Rails can be wall mounted or floor mounted; the former are recommended as they do not obstruct the circulation areas. Most people with a neuromuscular condition have insufficient arm strength either to pull with their arms or to push down, to help themselves to stand up; consequently, rails will have very limited value and are more often considered to be in the way. However, in a shower area they may be useful if positioned for an elbow to rest on when hair washing and to provide support, particularly around a room for someone unsteady on their feet. Because rails might be considered unsightly in a living area, furniture or even the wall will be used for support; however, in the bathroom, rails will be more appropriate, particularly if the user has bare feet and safety would otherwise be jeopardised.

The appearance of rails in this situation has improved enormously in recent years and two possible ranges have been included in this manual. If rails are needed, their height and position will be critical to each individual and should be assessed carefully.

Neaco Support System: *Go Independent*

Multi System with hand rail or support arms and wall-mounted rails: *Pressalit Care Ltd*

## Wall-mounted seat or a mobile shower chair

This information covers:

- ⇒ the factors to be considered;
- ⇒ electric, height-adjustable, wall-mounted shower seat;
- ⇒ mobile toilet/shower chair/cradle.

### The factors to be considered

The decision will be influenced by the ability to walk, the ability to stand up from a chair and whether the person has sufficient arm strength to propel a shower chair. The difficulty of a wall-mounted seat is that, if it is installed at the correct height for standing up, it will be too high to get down to wash the feet; however, if a shower chair is used, how does the user stand up from the chair? These difficulties are shared by many adults, resulting in the need for height adjustability.

### Electric, height-adjustable, wall-mounted shower seat

The answer is an electrical height-adjustable seat which rises sufficiently for the user to stand up and yet can be lowered near enough to the floor to allow the bather to sit with their feet firmly supported on the floor and their forearms supported on their thighs, and also enables the bather to be able to get down to wash their feet. The seat should have a supportive backrest and arms that project beyond the front of the seat to provide support when standing. See Chapter 8b '*Seat to Standing*', page 6.

SC.EL: *Astor-Bannerman (Medical) Ltd*

Multi System shower seat and support arms: *Pressalit Care Ltd*

### Mobile toilet/shower chairs/cradle

The choice is between:

- ⇒ Aquability/Freeway, toilet/shower chairs;
- ⇒ Sutton Shower Cradle.

- **Aquability/Freeway, toilet/shower chairs**

These are the two models that are particularly recommended as they are modular chairs that are available in alternative frame sizes, and have a detachable front arm and choice of backrest, footrest and seat. They can be supplied with straight and splayed side arms, to either increase the seat width or provide trunk support. When the assessment is carried out, the chair should be built up around the person to ensure that the correct support is achieved. If necessary, the frame and armrests can be manufactured to a specific height and made-to-measure models are available.

Aquability: *ASM (Accessories) Ltd*  
Freeway: *Westholme Ltd*

- **Sutton Shower Cradle**

This is recommended for anyone who needs more trunk support than is provided with either the Aquability or Freeway chairs and is supplied in three standard sizes with the option of a seat aperture. It may be necessary to alter the specifications of this chair to suit the individual user and made-to-measure models are available.

*ASM (Accessories) Ltd*

### Most appropriate type of shower base

The choice depends on:

- if the shower is to be used independently;
- if the shower area is adjacent to the toilet and needs to be used for positioning a wheelchair for sideways transfers on to the pan;
- the need for help from a carer.

The choice is between:

- ⇒ Neatdek;
- ⇒ shower trays;
- ⇒ sloping tiled floor.

#### Neatdek

In the first two situations the priority is not only to have a wheelchair-accessible shower but also for the floor of the shower to be absolutely level. The conventional tiled floor that slopes to a drain outlet is not recommended, because any gradient is difficult for anyone with a neuromuscular condition either to walk up or to propel a shower chair up – and it will be essential for the floor to be level so that the wheels of the wheelchair are stable to ensure safety while transferring. The answer is to install a Neatdek, which is an attractive and truly level-access shower grille. One of its advantages is that the water drains across the whole shower area and the grille can be supplied in a variety of sizes, depending on whether the floor is concrete or wood. The largest size is a replacement for a bath, which is a good recommendation if a bath is needed in the future. The grille is usually nylon coated in a choice of white, beige or red. The Neatdek is supplied with a lever to lift up the grille for cleaning and the Cambridge model which is now available for concrete floors is manufactured in four parts to make this easier.

*Go Independent*

## Shower trays

It is recommended that the largest shower tray that is possible in the space available is used and if a bath is likely to be needed in the future, a bath-replacement tray should be installed. If the proposed shower is for an existing room, site surveys can be arranged.

A number of trays are available from different firms and several ranges of level-access trays that are widely used, and are very satisfactory, are recommended.

Level-entry trays (a range of 39 different sizes below and above floor level): *Autumn Mobility Ltd*  
Impey Level-Dec: *Creative Healthcare Ltd*  
Dove, ESL and Chiltern Invadex ranges: *Go Independent*

## Sloping floor

If the shower is to be used with help, a sloping floor will be satisfactory, provided that it is laid properly and water drains away satisfactorily. Unfortunately, experience shows that this work needs to be supervised to ensure that the gradient is introduced competently without being extreme (thereby creating difficulty in pushing the shower chair) and to ensure that the water is contained within the shower area.

## Bath with an over-bath shower

The main factor in choosing a bath instead of a shower is to enable bathers to relax their muscles in the warm water while keeping warm and enjoying the buoyancy. When an assessment is carried out, it is important to clarify the issues in relation to bathing that are important for people with neuromuscular conditions and also to be familiar with the alternative equipment to provide the solutions.

In addition, there are three interdependent issues to be considered in relation to the use of a bath and movement between the bedroom and bathroom. These are:

- safety for the bather in the water;
- eliminating manual lifting in and out of the bath;
- ease of transfer between the bedroom and bathroom, for both the disabled person and the carers.

These priority issues need to be considered in relation to the other factors that influence the choice between a bath and a shower, and these are listed below in the order in which they should be discussed. It is then necessary to consider:

- the length of time for which this solution is likely to be satisfactory;
- the effect of the choice of equipment on the rest of the family.

Therefore, when carrying out the assessment, the following issues need to be resolved:

- ⇒ the support in the bath, needed now or in the future to ensure safety;
- ⇒ the ability to move limbs and enjoy the buoyancy of the water;
- ⇒ ease of washing or being washed;
- ⇒ how to get in/out of the bath (preferably independently), and how the alternative equipment to provide support influences the process;
- ⇒ the method of transfer between the bedroom and bathroom;
- ⇒ whether the method chosen is likely to be a short-term or long-term solution;
- ⇒ whether the facilities are exclusively for the use of the disabled person or to be shared.

## The support in the bath, needed now or in the future to ensure safety

This is the crucial decision to be made, as safety is obviously the first priority. The inability to support yourself, with the result that you feel that you are going to float forwards, is very distressing. Bathtime is a useful playtime for a child; if a method is to be found for a child to be left to play safely without constant supervision, the parents must have complete confidence in the equipment. Unless the bather gains support from the side of the bath, a supportive seat will be necessary, with arms to lean on to provide trunk control.

The choice of equipment to provide the correct support is limited and there are seven alternatives, as follows:

- ⇒ vacuum support cushions;
- ⇒ *Kingkraft Easibath Hi-Lift*;
- ⇒ *Kingkraft Contour*;
- ⇒ *Oxford Mermaid Ranger*;
- ⇒ *ASM Multi-System*;
- ⇒ *Arjo Sovereign*;
- ⇒ *Arjo Solo bath* (or similar model).

### Vacuum support cushions

These systems consist of waterproof-covered shaped cushions filled with beads which, when the air is extracted, become rigid enough to provide support. A number of shapes are available and they can be used in conjunction with a ceiling hoist. Although useful for small, floppy children in an Easibath (see below), this option is not usually recommended for people with neuromuscular conditions in a standard bath as there are problems in providing enough support and yet allowing access to wash and sufficient freedom of movement to enjoy the buoyancy of limbs in the water. In addition, many bathers want the hoist sling removing in the bath, with the subsequent difficulties for the carer to reposition the sling while leaning over the bath with a rotated spine. This is a difficult manoeuvre as it is impossible to maintain the advice to bend the knees and keep the back straight, when reaching into the bottom of the bath.

Support cushions: *Kingkraft Ltd*

### *Kingkraft Easibath Hi-Lift*

This model is particularly suitable for small, floppy children because it combines a supportive bath with a shower platform and a changing table – and there is the opportunity to have a spa facility. Although the bath depth is standard, the length (up to **1970mm**) or width (up to **970mm**) can be made to fit the space available.

The unique fold-down side of the bath is level with the seat height of a standard wheelchair, which will help with transferring a child, if initially, a ceiling hoist is not used. The manual or powered height adjustability allows individual carers to work at the optimum level for their back. The shape and design of the cushioned, internal supports can be made to measure and redesigned when necessary.

The option of twin wastes is recommended to allow the water to drain quickly so that the child can be dried and dressed without feeling cold.

Advice with plumbing and electrical specifications is offered.

*Kingkraft Ltd*

### **Kingkraft Contour**

This model provides the same facilities as the Easibath, but is deeper and the internal space is larger, without increasing the overall length or width. Aesthetically it may be preferred to the Easibath.

*Kingkraft Ltd*

### **Sunrise Medical Mermaid Ranger**

This bath hoist consists of a pillar installed at either the end or (more usually) the side of the bath, to which the seat is attached, prior to winding a handle and lifting the seat into the bath. Winding this handle at the top of the pillar is strenuous and particularly difficult for small carers (and especially for those mothers of boys with Duchenne muscular dystrophy (DMD) who are manifesting carriers). Therefore, it is very pleasing that the Ranger is available with an electric motor, which can be bought as an 'add on' unit for existing models. In the future, it is recommended that it is always supplied with this motor.

The advantage of the seat is that it is comparable to a toilet seat, which usually makes it comfortable, particularly as it should always be supplied with a padded seat and backrest. If additional padding is needed, a *Sumed* bath or commode cushion can be superimposed. If the seat aperture is too large for small children, the size can be reduced with a *Mothercare* Softee Trainer seat, placed under the padded seat.

*Sumed International (UK) Ltd*

*Mothercare Ltd*

The Mermaid Ranger footrest has always been height adjustable if the MD model was ordered, but this is now available as standard. However, if an existing unit is supplied from the Social Services stock, it must be checked that the footrest is suitable.

The Mermaid Ranger hoist is supplied with a chassis that is invaluable as a means of moving between the bedroom and bathroom and to provide support over a toilet. However, the Mermaid Ranger is not recommended if a shower toilet is to be used initially or in the future. This is because if it is superimposed over a shower toilet, the chassis has to be raised **32mm**, with the subsequent compromise of the washing and drying action which is discussed on page 17. A ceiling hoist used with the shower toilet is more satisfactory, as the user sits directly on the seat. It then becomes necessary for a supportive frame to be used, (see also page 17).

Bathers who subsequently develop knee contractures, which prevent their legs from being extended forwards, will be more comfortable with the seat raised up from the bottom of the bath. However, the disadvantage is that the depth of water covering the bather will be reduced. It will then be necessary to install a shower unit over the bath which will be useful also for hairwashing, and essential for anyone who needs to shower rather than use a bath, for religious reasons. Ideally there should be space at the end of the bath to enable a helper to reach a shower, wall-mounted at the side of the bath - with the bonus of being able to move freely behind the bather.

This equipment was first recommended about 10 years ago and although it has proved invaluable for many boys with DMD in the early stages, it is not often a long-term solution. With the passage of time, some larger boys have found it too constricting and others have found that it does not provide the support that is needed. In the latter case there is the advantage that, with the supply of a new mast arm, the Mermaid Ranger can be exchanged for the *ASM* Multi-System.

One of the advantages of this equipment is that it can be used with a standard bath and a Jacuzzi bath mat (see next page). For anyone who lacks trunk stability, the need for a supportive seat is important, as the spa bubbles may affect the bather's ability to balance.

*ASM (Accessories) Ltd*

*Daily Care Ltd*

- **Ozomatic Hydrotherapy Unit (Jacuzzi bath mat)**

Many people with muscular dystrophy have gained a great deal of enjoyment and pleasure from these mats (or a spa built into an *Arjo* Sovereign bath). Although they have no proven medical benefit for anyone with a neuromuscular condition, the effects of the buoyancy and stimulation caused by the pressure from the bubbles may help muscle relaxation. It is important to stress that, initially, the unit must be used on a low setting, for less than five minutes, so that the bather can assess the effect on their body before building up the pressure and the time span used. The firm is offering a substantial discount to anyone with muscular dystrophy and will demonstrate the unit in the home.

*Scan Mobility Ltd*

### **ASM Multi-System**

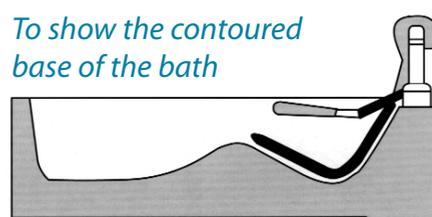
This seat offers excellent support and is very suitable for smaller children who cannot sit upright in a bath and for teenagers who have been using the Mermaid Ranger but have subsequently lost weight and it no longer provides the support needed. The ASM Multi-System can be placed in the bath using the same mast as the Mermaid Ranger (with a replacement arm) or alternatively using straps to attach it to a ceiling hoist. In either case the cradle will need to be used in conjunction with a mobile chassis either to move between the bathroom and bedroom or to support the cradle while a hoist sling is used to lift the child or young person on to the bed. The cradle is available in three sizes, but where necessary can be made to measure. The frame allows the seating angle to be changed so that, in a more upright position, with an aperture in the mesh, it can be used to provide support on the toilet.

*ASM (Accessories) Ltd*

### **Arjo Sovereign bath**

Many bathers prefer to recline, in which case the *Arjo* Sovereign baths are ideal and there are many features that make these baths particularly suitable for people with neuromuscular conditions, as follows:

- the baths have an integral seat which lowers into the bath and raises out of the bath electrically;
- the arms of the seat provide good support particularly as they extend in front of the bather;
- because the seat reclines as it lowers into the bath, the resting position takes full advantage of the depth of the water;
- the seat incorporates an excellent head support which is necessary for anyone who has had a spinal fusion, or has difficulty in controlling their head;
- the base of the bath has a raised central contour which provides support to anyone with knee contractures and prevents the bather from floating forward;
- in the past there has been the option of electrical rotation of the seat, which is recommended for people with a neuromuscular condition because it will provide an opportunity to increase independence and where necessary, make it easier for the carer to lift the legs over the bath rim. In future models, hopefully, this facility might be available again;
- when the bath is used in conjunction with a ceiling hoist and as the seat swings out of the bath above the rim, the seat is at the correct height for the carer to remove, or reposition the ceiling hoist sling.



There is the choice of three models, as follows:

- **Sovereign Standard:** The standard model in which the bath rests on the floor with a rim height of **610mm**. This model enables the carer to kneel at the side of the bath and support their trunk against the bath and their arms on the rim.
- **Sovereign Fixed Height:** The bath is raised up on small legs so that the bath rim is at a height of **840mm**, making this model a better choice for any carers who are unable to kneel at the side of the bath.
- **Sovereign Hi-Lo:** This model moves up and down electrically from rim height **615 - 960mm**, so that the bath is at the correct height to prevent the need for the carers to stoop and for bathers to transfer in and out of the bath. The additional cost will be justified in a multi-use situation where there will be the varied needs of each individual and their carers to consider.

Justification for the funding of these baths is included in Chapter 11c.

*Arjo Ltd*

### **Arjo Solo bath (or similar model)**

A number of firms manufacture baths that have integral seats that swing into and out of the bath (some with powered rotation) and can be raised and lowered electrically into the bath. The seat should pivot from the corner of the bath, so that it projects as far as possible from the side of the bath to ease the process of transfer; the bath should be a model that has the maximum range of seat-height adjustment. This may be essential for achieving the height needed to stand up; eventually, the minimum height may be of equal importance to ensure that a sliding downhill transfer can be achieved from a wheelchair that may not have a height-adjustable seat.

With the exception of the *Arjo* Sovereign, all these baths have a seat that supports the bather in an upright position; for many adults this may be the ideal sitting position to enable them to lean forward to wash.

*Arjo Ltd*

Having established which equipment will ensure safety, it then needs to be considered in relation to the other important issues listed on page 8.

### **The ability to move limbs and enjoy the buoyancy of the water**

Buoyancy is particularly important to anyone with restricted movement of the limbs and can be therapeutic to aching arms and legs to help to relax the muscles and relieve cramp; this feeling of well-being can be enhanced by a whirlpool or spa facility. Many boys with DMD find it easier to do their physiotherapy exercises and stretches after a long soak in a bath. However, the buoyancy will be restricted by the use of a hoist sling and it is therefore important for the bather to be well supported so that the sling can be removed (preferably before the bather gets into the bath) or loosened while in the bath. The spa facility can be built into the bath, as in the *Arjo* Sovereign bath, or supplied with the use of a jacuzzi bath mat with a separate motor. This alternative has been discussed on the previous page.

### **Ease of washing or being washed**

The sitting position of an adult can be crucial; some people need to sit upright to gain full function in their arms; others who are not able to be independent may find it easier to be washed when reclining. This makes the choice of bath important, and is discussed above and on the previous page, in relation to the *Arjo* baths. It is not satisfactory to leave a ceiling hoist sling in position, as this will make it difficult to gain access to wash.

## How to get in/out of the bath (preferably independently), and how the alternative equipment to provide support influences the process

The options are as follows:

- ⇒ using portable equipment;
- ⇒ using installed equipment to increase independence;
- ⇒ using equipment to help the carer.

### Using portable equipment

If the bather does not need support in the bath, is it possible to get in and out of a standard bath independently, or will simple portable bathing equipment be adequate to make this possible? Such equipment consists of bath seats that can be raised and lowered between the bottom of the bath and the bath rim. The choice is not covered in this manual, as it does not affect the provision of an adaptation; however, it may be a useful ‘stop-gap’ solution while waiting for adaptations to be carried out.

### Using installed equipment to increase independence

If help is needed to get in and out of the bath, can independence be restored or maintained with the use of a specialist bath? It is always important to try to provide equipment that the disabled person can use independently, at least initially and, if possible, that will also be suitable for use with a carer in the longer term.

Of the equipment included, the specialist baths will be ideal for increasing independence in getting in and out of the bath for both children and adults who are still able to walk. An *Arjo* Sovereign bath (see page 11) may appear to be unnecessarily sophisticated for a boy with DMD who can still walk and the suggestion may be made to delay the supply. In fact, the reverse is true, as this bath will maintain his independence in getting in and out until he is unable to walk with bare feet, but even at this stage it will make it easier for his parents to help him.

### Using equipment to help the carer

If help is needed, how will the carer lift the bather out of the bath without involving lifting manually? This must be with either a ceiling hoist or a bath seat like the Mermaid Ranger that lowers on to a chassis. If a ceiling hoist is used in conjunction with an integral seat, as in the *Arjo* baths, the sling is much easier to position as helpers can work at the correct height for their backs.

## The method of transfer between the bedroom and bathroom

The choice is between the following:

- ⇒ using a wheelchair;
- ⇒ using wheeled bathing equipment;
- ⇒ on an extended track of a ceiling hoist.

### Using a wheelchair

This is not a satisfactory option, apart from when the toilet is needed, and there is insufficient time to hoist the person on to the pan – or when using the washbasin. Two separate tracks in the bedroom and bathroom, using the wheelchair in between, is not a recommended option – raising and lowering the bather from the wheelchair is time consuming and necessitates readjusting the person’s sitting position each time.

## Using wheeled bathing equipment

There are two options:

- a shower chair, self-propelled or pushed by a carer (this has already been discussed on page 6 in relation to a level-access shower);
- a bath seat on a wheeled chassis, e.g. a Mermaid Ranger or an ASM Multi-System which were discussed on pages 10 and 11.

## On an extended track of a ceiling hoist

This option is discussed in Chapter 9 *Hoisting*. It is particularly satisfactory when used with a bath with an integral seat (e.g. an *Arjo* Sovereign or an *Arjo* Solo bath, or another similar model), which makes the process of putting on the sling and taking it off very straightforward for the carer. It allows the carer to work at the right height for their back and keeps the sling dry, as it is taken off before the bather enters the bath. A ceiling hoist eliminates the need for a bulky mobile hoist that may be a problem to store (particularly when a bathroom is used by the rest of the family).

## Whether the method chosen is likely to be a short-term or long-term solution

The aim should be to provide a long-term solution and in 90% of cases this will be possible; however, as many of the conditions discussed in this manual are progressive, a solution at an initial stage may not always be appropriate several years later. The progression of the disability in most neuromuscular conditions is stereotyped, but the finer details – such as the degree of knee contractures, the weight gain or loss and the shape of the spine, and therefore the ability to balance – will not be known and may influence the future success of equipment. Nevertheless, this is no excuse for not trying to achieve the ultimate solution; but rather a justification for possible failure!

## Whether the facilities are exclusively for the disabled person or to be shared

The aim should be to provide en-suite facilities, as discussed fully in Chapter 4 *Assessment of Need*. However, whether the disabled person has exclusive use of a bathroom may influence the choice of equipment. Where en-suite facilities are to be provided, unless the existing bathroom is to be used, the facilities are usually for the exclusive use of the disabled person, as partners and the rest of the family can use the house bathroom. However, in bungalows, or when a lift has been installed in a house and therefore the disabled person has access to the bathroom, it is often felt to be adequate for the disabled person to have to travel across the hall or landing to go to the bathroom. Alternatively the en-suite facilities may be provided by installing an additional door between a bedroom and bathroom and retaining the existing door from the hall or landing, so that the bathroom can still be used by the rest of the household. Neither is ideal or recommended, because of the lack of privacy, the length of time that the disabled person is likely to take in the bathroom and because the equipment provided may not be suitable for the rest of the family.

If a lift is installed, ideally there should be a wheelchair-accessible toilet on the ground floor, because it is a real hassle for a disabled person to have to use the lift each time; a ground-floor toilet has the additional advantage of being available for the rest of the family and partially overcoming the difficulties ensuing from the length of time taken in the bathroom by the disabled person. The exclusive use of en-suite facilities for a disabled person in a house where a lift has been installed is rare, as few houses are large enough for two bathrooms on the first floor; however, this may be a compromise that is necessary where the choice is for a lift, rather than a ground-floor extension. See Chapter 6 *Lift vs Extension*.

## The need for a changing table

There are a few houses in which it is structurally impossible to provide en-suite facilities because the rooms cannot be reorganised internally and because there is insufficient space in the garden to build an extension. In these unusual circumstances only, an alternative may be to provide a changing table within the bathroom, on which the disabled person can be undressed prior to bathing - and subsequently dried and dressed.

The most satisfactory type of changing table has the following features:

- ⇒ height adjustment;
- ⇒ an adjustable, elevating backrest.

### Height adjustment

This simulates an electric bed with a high/low facility to allow the surface to be placed at the optimum height for carers in order to protect their backs.

### An adjustable, elevating backrest

This will allow the disabled person to be supported in the most comfortable sitting position when this is easier for dressing.

### Recommended models

There are a number of options, including the following models:

- CT120/CT150 Child's changing table
- CT190 Adult-sized changing and showering table.  
These models are powered and have a height adjustability of **800mm**. The adult model travels from **150 - 950mm** and the child's can be mounted at the most suitable height for the carer. Both are wall mounted with the adult model gaining additional support from the floor.  
*Astor-Bannerman (Medical) Ltd*
- Linido hinged showerstretcher. The stretcher is hinged on the wall and lowers on to folding floor supports. The mild steel frame can be supplied coloured at no extra cost and special modifications are available.  
*Otto Bock UK Ltd*
- Shower bench. This can be powered or installed on the Multi System (see Chapter 17 *Multi-use Facilities*).  
*Scanflex Ltd*  
*Southern Care Systems Ltd*  
*Pressalit Care Ltd*

## Body dryers

Many people who have been towel dried by a carer following bathing never feel completely dry, and would prefer the privacy of drying themselves. An additional advantage of the dryer is that it doubles up as a booster heater for the bathroom.

### Apres Shower Body Dryer/heater

The advantage of the Apres Shower Body Dryer is that its height and length ensure that the warm air reaches every part of the body. The dryer is controlled by an air-pressure switch that can be mounted in the optimum position for the user, which is likely to be at a height and position similar to that of a light switch (see Chapter 14 *Scales and Templates*).

*Apres Shower Dryers Ltd*  
*Go Independent*  
*Total Hygiene Ltd*

## The most suitable toilet

In making decisions in relation to the most suitable pan, the choice will be influenced by the age and size of the user, their ability to balance and their ability to clean themselves. There are three solutions:

- ⇒ infant toilet;
- ⇒ low-level cistern with a long flush pipe;
- ⇒ shower toilet.

### Infant toilet

Usually, the only situation in which infant toilets are fitted is in schools where children of a particular age will be using the pan. However, many young children would find a smaller pan at home a great help, both in balancing and in getting on and off the pan. Installation will depend upon three factors:

- whether the child is using the same bathroom as the rest of the family;
- the success of the alternative of a toilet-trainer seat (e.g. Softee Trainer) to reduce the size of the seat hole on a standard pan and a Step Stool (both from *Mothercare Ltd*);
- whether a superimposed chair or frame is a better and longer-term solution for a child who is likely to have difficulty in balancing.

### Low-level cistern with a long flush pipe

This type of pan has an inlet pipe between the cistern and the pan and is not close-coupled. The importance of the inlet pipe is that the pan can be installed sufficiently far forwards from the cistern to allow a chair to be superimposed over the pan, with the chair seat correctly lined up with the bowl underneath (see Chapter 15 *Adaptation Specifications*).

*Twyford Ltd*

### Shower toilet

There are a number of issues to be considered in relation to this specialised equipment:

- ⇒ the purpose of the shower toilet;
- ⇒ use with a superimposed toilet chair;
- ⇒ MD toilet frame;
- ⇒ use with a ceiling hoist;
- ⇒ justifying the cost;
- ⇒ choice of models;
- ⇒ comparative chart.

### The purpose of the shower toilet

Shower toilets were previously known as a combined WC and bidet. Their function is to wash and then dry the user's bottom to eliminate the need for toilet paper. They are essential equipment for anyone unable to reach to clean themselves.

### Use with a superimposed toilet chair

In the past these toilets have been used by people with neuromuscular conditions, with a superimposed Mermaid Ranger (or a special toilet chair made to be used in conjunction with this equipment); however, neither option is recommended because it is important that the user's bottom forms a seal with the seat, to ensure a satisfactory washing and drying action. Obviously, when the user is sitting on a chair over the top of the pan, the water and hot air have to travel further and their action and, therefore, effectiveness, are compromised. The better solution is to use the toilet with a ceiling hoist and for the disabled person to use a special frame for support (see below).

### MD toilet frame

This height-adjustable frame was designed for use with the Clos-o-Mat (see below) and a ceiling hoist, enabling the user's bottom to form a seal on the toilet seat to allow the most effective washing and drying action; a superimposed chair will be a poor compromise. The frame has a mesh backrest, a height-adjustable footrest and armrests; and where necessary, it can be made to measure. The frame must be floor-fixed for stability.

*Daily Care Ltd*

### Use with a ceiling hoist

To ensure flexibility in the user's seating position, the ceiling hoist track should run from front to back over the pan, rather than from side to side. This is important to ensure that the water washes the correct parts.

### Justifying the cost

Privacy on the toilet is very important and, as this need is widely understood, there is not usually a problem in justifying the cost; however, for the occasions where this is necessary, see Chapters 11d and 11e.

### Choice of models

There are two models to consider:

- **Clos-o-Mat**

A decision will have to be made whether a plinth (available in **25, 50, 75** and **100mm** heights) will be required; this will be influenced by the user's leg length (because of the need to place their feet on the floor) and the optimum height for transfers.

**N.B.** *The optional super-sensitive switch must be supplied.*

*Total Hygiene Ltd*

- **Geberit**

This unit offers a wide range of adjustable rocker and infrared switches. As with the Clos-o-Mat, it can be supplied with a cushion seat and douche washing to suit male or female users.

*ESL Healthcare Ltd*

The chart on the following page is included to help with the choice.

<b>Comparative chart of shower toilet features</b>	
<b>Geberit: ESL Healthcare</b>	<b>Clos-o-Mat: Total Hygiene</b>
<b>Floor or wall mounted?</b>	
In a domestic situation, units are normally floor mounted; but, in a residential setting, it is easier to keep the floor clean if they are wall mounted.	Usually floor mounted; if wall-mounted units are to be installed, wall construction must be checked.
<b>What height are the pans?</b>	
Optimum height will be important for tall users, for side transfer from wheelchairs and to reduce gap between a superimposed chair and the pan.	
Floor mounted: <b>430mm</b> plus choice of 16 measurements, up to additional <b>110mm</b> height Wall mounted: from minimum height of <b>345mm</b> to height required. Mounted on wall frame: <b>415 - 615mm</b>	<b>400mm</b> (top of pan) plus <b>25, 50, 75</b> or <b>100mm</b> plinths, placed under floor-mounted pan
<b>Overall dimensions: height x width x depth</b>	
<b>910mm x 460mm x 710mm</b>	<b>820mm x 500mm x 710mm</b>
<b>Can a chair be superimposed?</b>	
Height and width of pan will need to be checked carefully. Assisted and self-propelling Westholme Freeway and Chiltern Invadex chairs are manufactured for use over both units. If the seat size is too wide, this can be reduced, if necessary, using side and backpads.	
<b>Are these bidets satisfactory when used with a superimposed chair?</b>	
Use of a chair is a compromise, as the water has further to travel and (more important) the warm air escapes. When a user sits directly on the seat (see <i>Daily Care MD</i> toilet frame, on previous page) their bottom forms a seal, which contains both the water and the warm air. It is important that the disabled person's bottom is properly dried to prevent sores.	
<b>Does the shower toilet need to be modified for use with the superimposed chair?</b>	
Would be supplied with a remote control.	When commissioned, the seat switch (normally activated when the user is sitting directly on to the seat) is wired out.
<b>What height should the unit be when used with a superimposed chair?</b>	
If a superimposed chair (not a frame) is essential, both shower toilets should be raised so that the seat of the chair fits as closely as possible to the top of the bowl.	
Pan height can be set to individual requirements	<b>50mm</b> is the recommended plinth to raise pan to height of <b>450mm</b>
<b>Can the unit's settings be adjusted to suit user requirements?</b>	
Water spray intensity and the drying temperature can be adjusted to ensure optimum effectiveness and comfort. This may be particularly important when used with a superimposed chair.	Douche temperature and pressure can be adjusted by the Clos-o-Mat engineer.
<b>Is the water pressure significant?</b>	
Works on water pressure and if this is low, the problem would be identified at site survey and installation of booster pump would be advised.	Integral pump ensures that external water pressure does not affect the use of the shower toilet.

<b>Comparative chart of shower toilet features (cont.)</b>	
<b>How is the water heated?</b>	
A heat exchanger warms the water prior to use.	Stores sufficient warm water for each wash.
<b>How are the functions operated?</b>	
There is a choice of 3 remote-control switch handsets to activate the washing, drying and flushing cycles.	The operating lever should be depressed for 20-25 seconds so all the warm water is used, and to ensure maximum time of drying air. Flushing is simultaneous with douche wash, which is important for infection control, particularly for multi-use.
<b>Is an odour extractor available?</b>	
Pressure on the seat activates the odour extractor.	Optional extra.
<b>Country of manufacture</b>	
Switzerland	UK
In Europe, shower toilets are personal hygiene/luxury bathroom products not used exclusively by disabled people.	
<b>Colours</b>	
White is standard, but if a colour is required, the manufacturers can be contacted.	White is standard, but coloured pans (manufactured abroad) are an optional extra N.B. Continental colours differ from British.
<b>Who commissions the installation?</b>	
Standard commissioning service is not provided. It is important to check that the installer is fully trained and has been on the firm's course. All ESL surveyors have been trained to commission.	It is important to check that unit has been fitted correctly, conforms to water/electricity regulations, is suitable for client - and that switches or isolator switches are fitted. Total Hygiene's own service engineers commission all installations, irrespective of who has carried out the work.
<b>Guarantees/Maintenance contract</b>	
12 months, with a maintenance contract (after guarantee expires) of up to 5 years.	
Cost: £80 per annum + parts and includes service.	Cost: £100 parts and labour per annum and includes service.
It may be wise to have this included in the grant, unless Social Services Dept. agree to pay for maintenance.	
<b>Available from:</b>	
Imported by <i>ESL Healthcare Ltd.</i>	May be purchased direct from <i>Total Hygiene Ltd</i> or from one of their local distributors.
Contact the firms above to request on-site demonstration	

## Essential washbasin features

A number of features are needed to make a washbasin suitable for a person with a neuromuscular condition. The ideal basin for anyone with severe weakness in their arms, and who is not able to lean forward and then regain their position in the wheelchair, did not exist until the two models discussed in the chart below were specifically designed.

<b>Comparative chart of height-adjustable washbasin features</b>	
<b>ABW4/ABW4SP:</b> <i>Astor-Bannerman (Medical) Ltd</i>	<b>Spectra:</b> <i>Southern Care Systems Ltd</i>
<b>Width along front edge</b>	
Any width <b>750 - 1200mm</b> . Surface can be cut to any shape, if necessary; size and shape do not affect cost.	Two widths <b>700mm or 1050mm</b> ; size does not affect cost.
<b>Front-to-back measurement</b>	
<b>675mm</b> from front edge to wall is standard, but can be made any measurement.	<b>645mm</b> (standard) or <b>695mm</b> (to order). Latter recommended to allow for length of chair under basin - from front edge to housing containing mechanism.
<b>Front profile thickness</b>	
<b>13mm</b>	<b>19mm</b>
<b>Are there any other special features to the bowl and surface?</b>	
The basin is shaped to allow wheelchair access.	
Surface recessed for soap on right-hand side (optional left).	Surface recessed to allow splashes to drain back into bowl.
<b>What material is used for the basin and surrounding surface?</b>	
Corian, a solid, 'marble-like' material, which is non-scratch and easy-to-clean.	One-piece epoxy moulding with glossy, scratch-resistant finish.
<b>Colours available</b>	
12 standard colours for surface, with further range of 80 colours for which there is additional charge; bowl white.	Choice of 4 colours; bowl same colour as surround.
<b>Vertical travel</b>	
<b>450mm</b> with minimum and maximum heights depending on wall-fixing height.	<b>400mm</b>
<b>Is there a safety device to prevent the basin lowering too far and crushing the user's knees?</b>	
Yes	Yes
<b>How are the functions operated (i.e. height-adjustability, tap &amp; plug control)?</b>	
Handset with touch-sensitive switches (standard) or infrared controls for any function. Option of custom-designed handset to operate any/all functions. Controls can be fixed to basin surface with additional option of touch-free tap control.	

<b>Comparative chart of height-adjustable washbasins (cont.)</b>	
<b>ABW4/ABW4SP: Astor-Bannerman (Medical) Ltd</b>	<b>Spectra: Southern Care Systems Ltd</b>
<b>Does it matter if the control handset falls in the water?</b>	
No, handset and switches are waterproof.	
<b>Does the basin have electrical safety protection?</b>	
Yes. Because the basin is supplied at mains voltage and transformed within the appliance, an RCD (residual current device) is built-in. In the event of an electrical fault, this device isolates the mains supply, so that the power switches off immediately.	Yes. The transformer is mounted remotely and therefore the appliance is entirely mains free.
<b>Does the basin have a battery back up?</b>	
Yes, it will continue working for up to 24 hours after a power cut.	No
<b>Is there a choice of taps?</b>	
Yes. Basins are supplied with lever (150mm) taps, operated manually - or on ABW4SP, also controlled with touch-sensitive switch on handset. Further option is touch-free, infrared tap system, which if likely to be needed in the future, would be more cost effective to fit initially.	Yes. Full electronic control of water is standard using touch-sensitive switches or infrared controls. Choice of manually-operated lever taps (single or two) supplied to order, positioned as required.
<b>Is the water temperature thermostatically controlled?</b>	
Not normally needed, but can be included as an option when required	Yes, as standard.
<b>Is the basin supplied with a touch-controlled, pop-up plug?</b>	
ABW4: No. ABW4SP: Yes	Yes, as standard.
<b>Does the unit include a shaver socket?</b>	
Yes, on right-hand side, with advantage that socket rises with basin.	No, shaver socket has to be positioned on adjacent wall.
<b>Does the unit include a mirror?</b>	
Rectangular mirror (standard).	Circular mirror.
<b>Is the mirror supplied with a light?</b>	
ABW4: No. ABW4SP: Yes. Strip light is fitted over mirror, switched on and off from handset.	Yes, low voltage halogen spotlights each side and above mirror, operated by switch on handset.
<b>If light is left on inadvertently, is there a timer to switch it off automatically?</b>	
Yes, after 15 minutes.	Yes, after 10 minutes.
<b>Can the basin be fitted in front of a window?</b>	
No, electronics are fitted behind mirror, which cannot be removed.	Yes, basin can be supplied without mirror and light, with price reduced.

<b>Comparative chart of height-adjustable washbasins (cont.)</b>	
<b>ABW4/ABW4SP:</b> <i>Astor-Bannerman (Medical) Ltd</i>	<b>Spectra:</b> <i>Southern Care Systems Ltd</i>
<b>Can the basin be supplied in modular units?</b>	
If height adjustability is not needed initially, basin, integral surface, mirror and standard taps can be supplied, mounted on wall brackets and include option of flexible plumbing. At a later stage, a handset, which includes, touch-sensitive/infrared control of height adjustability, taps and pop-up plug - or entirely touch-free control of taps - can be added, when necessary.	Special handset including infrared controls may be added later.
N.B. If features are likely to be needed in the future, modular supply is not cost effective.	
<b>Is the flexible plumbing supplied with the basin?</b>	
Yes. If basin is initially installed at a fixed height, it is prudent to install flexible plumbing so that this does not need to be changed later.	Yes, concealed behind an <b>80mm</b> - deep cover under basin. This will reduce space for chair length from user's chest to tip of footrests and must be reflected in the front-to-back surface measurement.
<b>Are there any special fitting arrangements?</b>	
Supplier is able to carry out installation. However, fitting is straightforward and specialist flexible plumbing can be supplied in advance to builder, if required. Unit may need commissioning if installed by local, inexperienced contractor.	2-stage fitting process, Wall frame containing fixed plumbing is usually sent to site to enable contractor to complete all plumbing in advance of basin delivery. Basin is then fixed to wall and plumbing plugs into this frame. Manufacturer or network of agents can carry out this part of installation – or both stages, when there are no contractors on site.

### Justifying the cost

See Chapters 11f and 11g.

### Flooring

This is discussed in Chapter 15 *Adaptation Specifications*.

## Equipment in the bedroom

The following need to be included:

- ⇒ electric bed;
- ⇒ ceiling hoist;
- ⇒ work/equipment surface;
- ⇒ intercom.

## Electric bed

The need, the essential features required and the recommended models are covered in Chapter 8c *Electric Beds*.

## Ceiling hoist

The need for a ceiling hoist, the features to be considered, the most appropriate type of slings and all other aspects of hoisting are included in Chapter 9 *Hoisting*.

## Work/equipment surface

All the details of this recommended surface are included in Chapter 15 *Adaptation Specifications*. However, here it is appropriate to discuss:

- ⇒ medical importance;
- ⇒ choice of brackets.

### Medical importance

Modern management of DMD and other forms of muscular dystrophy is to aim to maintain walking and standing for as long as possible, sometimes with the use of long leg calipers and standing frames. It is unrealistic to expect children to stand in a frame without an activity in front of them; therefore, it is necessary to provide them with surfaces that are suitable for use from a wheelchair and with a standing frame, in order that they may use a computer, music centre, etc.

**N.B.** *The importance of this surface from the point of view of a child's medical management and happiness in the future cannot be stressed strongly enough. In addition, now that so many of the GCSE exams include project work, adequate working space is essential. An easily-accessible surface will enable children to slide their forearms on the surface to gain the maximum benefit from their hand function. See Chapter 11 Justification for the Need & Funding of Working Surfaces.*

### Choice of brackets

The difference in the two recommended types of adjustable brackets should be mentioned:

#### Independence Range

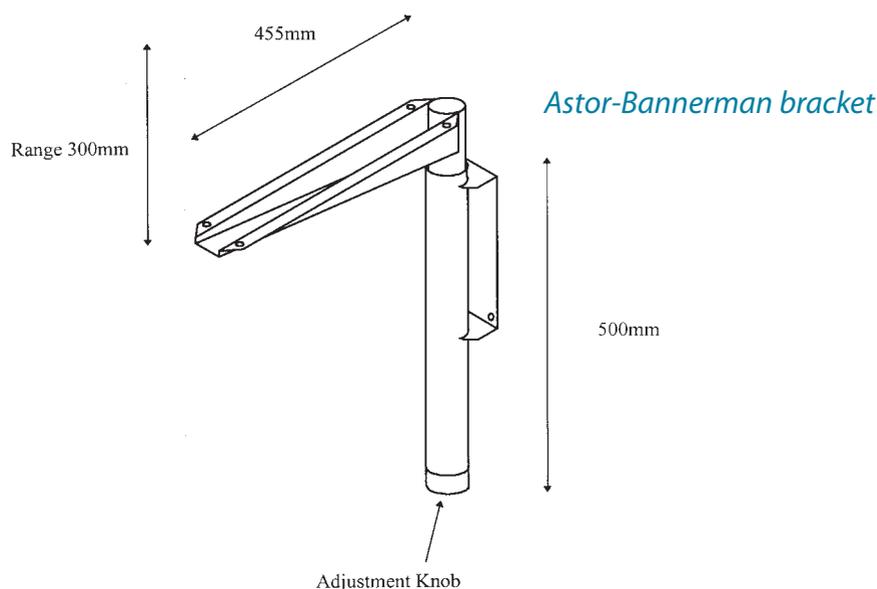
These are the less expensive and have been used over a number of years with great satisfaction. The firm will supply the wall rail, brackets and a four-drawer unit, of which the top drawer is a pull-out surface. Shallow drawers are essential to limit the weight and allow the user, at least initially, to open the drawers independently. It is advisable to buy the **40mm** (not **30mm**) worktop from the local DIY store, so that the design and colour is easier to choose and also to reduce the carriage costs. However, it may be more satisfactory for some families to have the worktops supplied cut to size and ready to install. The wall rail allows the height to be altered in 10 stages of **20mm**.

*Huntleigh Renray Ltd*

## Adjustable brackets

The advantage of these brackets is that the height of the surface can be altered by turning the screw at the bottom of the bracket without removing the surface or anything on it, and the adjustment is infinite and not predetermined.

*Astor-Bannerman (Medical) Ltd*



## Intercom

Parents usually feel more reassured if there is an intercom between the child's room and their bedroom and the sitting room, so that they know that they will hear when the child calls. Initially, it is usually adequate to use unsophisticated units that plug into a **13amp** socket, until the disabled child qualifies for an NHS environmental control, which incorporates a series of intercoms between rooms and to an external door.

*Ridley Electronics Ltd*

## Justification of funding of equipment

The expense of all the bathroom and bedroom equipment included in this manual can be fully justified, which is very important when a grant application is made. For this reason, the value and need of each of the more expensive items are discussed and included in Chapter 11 *Justification for Funding*.

## Equipment in the kitchen

### Height-Right trolley

For many years there has been a need for a powered height-adjustable trolley, and this model was designed for people with neuromuscular conditions. The table has innumerable uses for anyone with difficulty in bending and lifting, or who becomes tired when standing for any length of time. It could also (partially) eliminate the need for height-adjustable kitchen units. The main purpose is to provide a height-adjustable surface controlled from any position and this adjustability can be very important where different heights are needed for different activities. The trolley is invaluable in the kitchen, where it can be used to prepare food (a casserole for example) and then the surface can be raised to the same height as that of any of the oven shelves and the dish safely slid into the oven. Even more important, the hot dish can be removed from the oven without any risk.

This simple unit provides much more versatility than any fixed unit. The difference between its minimum and maximum height (**600** and **1000mm**) is far greater than that of any available height-adjustable but fixed unit. Because it is not fixed in one place and runs on castors, it can be used in any room.

The trolley is both functional and visually pleasing. The **600 x 480mm** wipe-clean top, in heat-proof Corian, an easy-to-clean, non-scratch, marble-like material has been designed to blend well into a home. The trolley is mounted on four castors, which make it relatively easy to move in spite of the weight of the batteries housed in the base which aid stability, together with the fact that the castors can be locked with ease using the control switch. The charging point at the side of this switch uses a small charger similar to that used for a mobile phone.

When the user is unable to stand and needs a wheelchair all the time, the height-adjustability of this trolley is still invaluable.

*Thomas Gideon Design*

### Sit-Easi height-adjustable ironing board

The board is housed in a slimline wall-mounted cupboard and the gas spring provides controlled downward and assisted upward movement. The height can be altered for use either standing or sitting and the cantilevered supports do not obstruct wheelchair access.

*Panilet Tables*

## Ordering equipment

Some specialist items are made to order to incorporate optional features. Lead times may vary during holiday or busy periods. Orders should be placed in advance, with a required date of delivery.

## Environmental controls

The following questions are frequently asked about environmental controls and their supply:

- ⇒ What are environmental controls?
- ⇒ Who pays for the system?
- ⇒ What systems are supplied?
- ⇒ Who is eligible?
- ⇒ Who can refer someone for an environmental control?
- ⇒ Which system would be best?
- ⇒ Who is the assessor?
- ⇒ How long will it take to supply the equipment?
- ⇒ Will anyone demonstrate the equipment following installation?
- ⇒ Who should be contacted if the equipment needs repair?
- ⇒ Can additional equipment be linked to the control at a later date?
- ⇒ Removal of equipment.

### What are environmental controls?

Environmental control systems are designed to provide independence to severely disabled people, by enabling them to operate domestic appliances and equipment by remote control from a display panel. Examples are:

- an alarm;
- intercoms to an external door and to as many rooms as necessary;
- an unlocking system linked to either the front or back door used with an intercom so that the user can ascertain who is at the door before allowing them into the house; and
- use of a loudspeaking telephone, which is supplied with the system and which has the capacity to store numerous numbers.

Accessories are available to enable other domestic appliances, such as lights, heaters, radios, television, beds and curtains, to be operated. Many disabled people may prefer to control some of their appliances, such as their television, with an existing standard remote control. This may apply also to an automatic door opener and an electric bed.

### Who pays for the system?

The Department of Health supplies the systems free of charge, where the disabled person conforms to the eligibility criteria. However, other than alarms and intercoms, accessories are not included in the contract and justification will need to be made to the Social Services Department. Examples would be a curtain control and (in exceptional circumstances) an automatic door opener.

### What systems are supplied?

Although the contracting arrangements are reviewed from time to time, the present contracts for systems funded by the department are with three suppliers:

- *Possum Controls Ltd* who supply the Companion, Freeway and Compact – of which the Companion is likely to be the most suitable for people with neuromuscular conditions;
- *RSL Steeper Ltd* who supply the Fox, Personna, and Lynx (with speech) – of which the Fox will be ideal.
- *SRS Technology Ltd* who supply the SRS100.

## Relevant features

These are as follows:

- units operated by infrared or radio signals, allowing use from anywhere in the house and garden and away from home;
- selection of functions is achieved with the use of a scanning light on the small portable display panel, and the scan speed and an audible tone can be adjusted.
- the selection can be voice announced for anyone with a visual impairment, or who has difficulty in seeing the display when in bed;
- if the standard switch is not suitable, a variety of alternative switches can be plugged into the control panel;
- the Companion and SRS100 can be interfaced with a computer.

## Who is eligible?

Usually disabled people with a neuromuscular condition can be considered for the equipment if they:

- are sufficiently disabled to need the equipment;
- require the independence that the system provides;
- are sufficiently motivated to use it.

The age at which a boy with DMD, or any child, should be referred will depend upon the level of disability and the need, and this should be discussed with the Family Care Officer (FCO) or occupational therapist (OT). However, unfortunately the supply is budget limited and different areas use different criteria, which if necessary can be challenged.

## Who can refer someone for an environmental control?

Usually anyone, but the arrangements will vary from one area to another. If the need has to be justified it is usually a help to discuss the supply with the FCO or OT. Referral is to the co-ordinator in the relevant area, who is responsible for the local administrative arrangements for supply and installation. The address of the co-ordinator can be obtained through the Social Services Department.

## Which system would be best?

*Possum Controls*, *RSL Steeper* and *SRS Technology* will send out information and videos, which are also available from the Muscular Dystrophy Campaign's National OT Advisor. If, as a result, one particular system appears to be the most appropriate, this should be discussed with the medical assessor.

## Who is the assessor?

The assessor will be a medical consultant in the area who has been appointed to do this work and will make home visits to:

- ascertain eligibility;
- help with the choice of system;
- ensure that other cheaper systems would not suffice.

Following this assessment, a report will be sent to the co-ordinator.

## How long will it take to supply the equipment?

There are a number of stages to be followed:

- medical assessment;
- case conference, organised by the co-ordinator and held in the user's home, when a representative of the firm will discuss with the user, the carer and any other health or Social Services staff who are involved, the specific items to be supplied and details of their installation. The equipment will be demonstrated, technical questions answered and installation arrangements discussed;
- installation of electrical sockets or joinery work, if required. This will be the responsibility of Social Services under the *Chronically Sick and Disabled Person's Act* – and it would be wise to ensure that an OT or social worker from the department is present at the case conference, to be delegated the task of making the necessary arrangements;
- installation of the environmental control.

## Will anyone demonstrate the equipment following installation?

Yes, the supplier will demonstrate the equipment and ensure that the user is confident in its use. If an OT is present, they would expect to be available to help if any problems arise in using the equipment in the future, and to provide a follow-up and review, if and when necessary.

## Who should be contacted if the equipment needs repair?

A telephone helpline is available to report problems or to ask for advice on the use of the equipment. In the event of difficulty contacting the firm, the co-ordinator should be notified.

## Can additional equipment be linked to the control at a later date?

Yes. The co-ordinator should be contacted, to make any necessary arrangements. However, if additional equipment is to be provided privately, the firm can be contacted directly.

## Removal of equipment

If the equipment is no longer required, the co-ordinator will arrange for it to be removed by the contractor.

## Providers and funding of equipment, adaptations and services

See Chapter 12 *Funding of Adaptations*.

# Acknowledgements

## ... from the Muscular Dystrophy Campaign

We would like to thank Philippa Harpin for her dedication and commitment. She not only wrote the first edition of this manual, but also devoted considerable time and energy to updating the second edition, both before and after her retirement as National Occupational Therapy Advisor at MDC in 2002.

## ... from the author

Writing a detail manual of this kind is complicated and updating the information was far more involved and time consuming than I had ever imagined. Many people have helped not only with this task, but also with the production and funding to ensure that the Manual is available to the people for whom it was written. The Muscular Dystrophy Campaign and I would particularly like to thank the following:

- everyone who helped with the first edition, which formed the basis of the revision;
- Somerfield for their very generous sponsorship of this edition;
- The Epigoni Trust, who have been generous enough to contribute sponsorship to both editions;
- Southern Care Systems for help in subsidising copies for families;
- Brian Sewart, who was always at the end of the phone, willing to help and with a ready answer to every question, but sadly, died shortly before printing started. A special dedication to his memory is included on the front page;
- Alan Lynch who went the extra mile in helping with the Medical Devices Agency regulations and guidance included in the wheelchair chapter;
- Rachel Coombes - OT manager, Richard Farr and Louise Quinn - grants officers in England who looked through the relevant grants section in the funding chapter and whose comments and corrections ensured that the information is accurate;
- Anne Smyth and Karen Rainey from the Northern Ireland Housing Executive and Huw McLean from the Welsh Assembly Housing Directorate for their helpful comments and suggestions;
- the Scottish Executive Development Department for their generous and time-consuming help and guidance on the amended grants system in Scotland;
- Miranda Parrott, policy manager of the Family Fund who checked the section relating to the help provided;
- Ruth Geall and Pat Copcutt for their support and friendship throughout the trials of the project;
- Yvonne Masset, my successor at MDC who brought a fresh pair of eyes to each chapter, updated the address list and was one of the two people who proof read the final copy;
- Robin Scott for help with many sections of text, his generous offer to proof read - and for the time he devoted to this meticulous task;
- Jan Normanton, for her invaluable help and the positive way she tackled the updating and retyping of the index;
- Peter Holmes and John Woods at The Newcastle Printing Co. for all their patience and help over many months with both the production and printing;
- everyone with muscular dystrophy or an allied condition, with whom I was privileged not only to work for 25 years, but also to share some of the frustrations, joys and sorrows - all of which gave me the experience to write and update the text;
- David, my husband, who appreciated the need to postpone my 'real' retirement until this work was complete.

*Philippa Harpin*