

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. 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 innovatory 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:

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- David, my husband, who appreciated the need to postpone my 'real' retirement until this work was complete.

Philippa Harpin