

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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