



Powered Profiling Beds

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 related neuromuscular conditions.

Why are electric beds needed?

They have eight main uses:

1) To alter the height of the bed to help the user to get in and out

- ▶ People able to walk or stand to transfer - many people 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. The bed must also rise 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. (Unless their knees are fully extended and braced they will collapse to the floor).
- ▶ **Wheelchair users** - people with a neuromuscular condition usually have severe arm weakness, so 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.
- ▶ **Minimum and maximum height** – the height range is crucial, as along with the depth of the mattress, and the firmness of the edge of the mattress it will influence the person's ability to stand up from the bed. The minimum height may be crucial for sideways transfer from a wheelchair, and for anyone who has difficulty lifting their legs into bed. A low height may be important for a small child (eg with SMA) who, with the help of an electric bed, can get out of bed independently

2) To 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 on the electric bed with their back supported. An electric bed and a ceiling hoist, when used in conjunction with a wheeled shower-toilet chair or an extended track into the bathroom, can eliminate all manual lifting within the home.

3) To change the user's position in bed during the night

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 lie down again in a different position. This can relieve cramp, or release a trapped arm or ear for example, thus eliminating the need to call for attention. Many parents and/or carers have to get up during the night to help their child (sometimes up to 10 times per night), so 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.

4) To 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 by preventing the lower body from becoming jammed against the knee break, thus maintaining comfort while sitting.

- ▶ **Mattress Platform - number of 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.
- ▶ **Number of motors - four-motor beds** are recommended for people with muscular dystrophy and SMA. Two motors alternate the leg actions, providing support behind the knees when knee contractures are present, and raising 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).

5) To 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. In addition, the leg section of the bed must be capable of lowering, ideally electrically, to allow the adoption of a comfortable sitting position.



6) To help postural drainage

Many children with either DMD or SMA, and some adults, need postural drainage when they have a chest infection. It is recommended that individuals and their families discuss the advisability of using the bed to assist with this with their GP or hospital consultant, and also whether the knee bend in the mattress platform can be used to achieve a satisfactory position.

7) To allow the carers to work at the optimum height to protect their backs.

This is invaluable eg when dressing the person in bed, or positioning a hoist sling, particularly if the carers are of different heights.

8) To 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 or 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?

People with neuromuscular conditions have specific needs which must be taken into account when a bed is being selected. These needs are covered in detail in the Muscular Dystrophy Campaign's Adaptations Manual (chapter 8c) and on the website www.muscular-dystrophy.org, in relation 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

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

There is a wide range of electric beds available on the market. Many of these “community beds” may be easier to transport and install in a private house, but they are unlikely to have the robustness and stability of well-tried and tested models, nor to 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 are needed, are included in chapter 8c of the Adaptations Manual, and can be found on our website.

What are the specifications of the recommended beds?

Chapter 8c itemises the relevant features of each bed in relation to the needs of people with muscular dystrophy or a related condition. If other beds are to be considered, the specifications must be comparable.

Who should supply the funding and maintain the bed (&/or specialist mattress and turning unit)?

From experience, electric beds have proved so invaluable to those with Duchenne muscular dystrophy or other neuromuscular conditions that, following a thorough assessment, there should be no difficulty in justifying the need. The provision of beds, specialist mattresses and other 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.

Electric beds and 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 some areas, beds are regarded as equipment to increase independence and so are supplied by Social Services. With the introduction of Integrated Community Equipment Stores (eg in England), NHS organisations and local councils have aimed to remove these barriers by pooling budgets and integrating services; this may be the best way to fund the correct bed.

Whilst there may still be areas where neither the Health Authority nor Social Services Department have accepted the responsibility for supplying beds and mattresses, this document should help to rectify that situation, and justify the need and provision of electric bed.



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Here for you

The friendly staff in the care and support team at the Muscular Dystrophy UK's London office are available on **0800 652 6352** or **info@musculardystrophyuk.org** from 8.30am to 6pm Monday to Friday to offer free information and emotional support.

If they can't help you, they are more than happy to signpost you to specialist services close to you, or to other people who can help.

www.musculardystrophyuk.org