Muscular Dystrophy UK

Fighting muscle-wasting conditions

Adaptations manual: for children and adults with muscle-wasting conditions

Second edition

Developing this guide

The first edition of the Muscular Dystrophy UK *Adaptations manual* was written in 2000 by Occupational Therapist, Phillipa Harpin and was available on CD-Rom. Over the last decade, it proved to be a great source of information for health professionals and clients alike. Muscular Dystrophy UK continues to receive requests for the information.

However, the landscape of health and social care has changed greatly since then. Legislation has also changed. So it was felt this was a good time to revise the manual in line with today's health and social care services, and to introduce some new developments, such as environmental controls.

A working party was put together comprising of occupational therapists, care advisors, moving and handling and back care specialists, specialist voluntary organisations and independent practitioners from all corners of the UK.

This publication can be found on the Muscular Dystrophy UK website:
www.musculardystrophyuk.org

All sections are downloadable as PDFs.

"The previous adaptations manual was a great source of information for myself and OT colleagues working in social care. At that time (over 10 years ago), there was little information like that readily available in an easily accessible format."

Pru Jones, Paediatric Occupational Therapy Lead, Cornwall Council

The College of Occupational Therapists has reviewed this second edition of Muscular Dystrophy UK's *Adaptations Manual* and is pleased to endorse this document thus, assuring the quality of its contents. Muscular Dystrophy UK would like to thank the College of Occupational Therapists for contributing to this document and its quality.

College of Occupational Therapists

Foreword

At Muscular Dystrophy UK, we know there can be real difficulties in securing funds for adaptations, planning the changes needed or in finding accessible properties to rent. We are here to support people in such circumstances in every part of the UK. Publishing this second edition of this *Adaptations manual* is one way we do that.

Since the first edition was published in 2000, the Adaptations manual has been an invaluable resource for people living with muscle-wasting conditions, as well as health and social care professionals. This second edition takes into account important developments and legislation affecting health and social care, as well as environmental controls and assistive technology.

The manual also has updated information about funding, potential grants and financial support and we want to encourage people to contact the information team at Muscular Dystrophy UK if they need further information or advice.

We'd like to thank all the health and social care professionals UK-wide who generously gave their time and shared their expertise to make this such a valuable resource. We also want to give our warm thanks to all the individuals and families living with muscle-wasting conditions who shared their experience of planning adaptations to their home or in finding a suitable, accessible property.

Robert Meadowcroft, Chief Executive
Muscular Dystrophy UK

"MDUK's Adaptations manual has proven to be an invaluable resource to my family as we prepare to adapt our home to make it more accessible for our son, Luke, in the future. I thought I had a good understanding of what we needed, but the manual has helped me think about lots of things I would not have thought about. This could save us from additional costly alterations in future.

"The information is practical and the authors have thought of everything to help us feel adequately prepared for the future. I feel much more confident to discuss with our OT Luke's changing needs (he has Duchenne muscular dystrophy) – it's not easy to think of this when he's still so active.

"The manual is easy to use and guides you through the whole process. You can pick and choose the sections that are relevant to you, and having everything together in one place makes life so much easier for a busy family like ours."

Claire O'Hanlon, Northern Ireland

Acknowledgements

Muscular Dystrophy UK would like to extend a warm thanks to all the contributors who gave their time to make this publication possible.

It is hoped that this manual will empower all healthcare professionals and family members to enable individuals living with muscle-wasting conditions to reach their maximum functional potential within their own home environment, while partaking in meaningful activities.

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Contents

As all councils have access to different types of equipment, and equipment is constantly changing, we have not included any specific equipment in this manual. Each individual should discuss their needs with their OT, and get advice on what is available in their area.

First steps

Changing needs

There are approximately 70,000 people living with muscle-wasting conditions in the UK.

These rare and very rare genetic conditions can be inherited or acquired out of the blue, and can present in childhood or adult life. Many healthcare professionals, therefore, may have no experience of working with people with these conditions, or any knowledge of how to assist them in the best way they can.

Unlike many other people with physical disabilities, people with muscle-wasting conditions will have changing needs, as their muscle strength deteriorates. An individual may be fully mobile at first, and after a number of years, could be in a powered wheelchair, needing help with feeding and personal care.

Understanding the progression of the individual's condition will enable the occupational therapist (OT) and architect to design the best possible adaptations to the individual's home. It is always easier to plan for the future than to react to a crisis, thus 'future-proofing' the home where possible.

The following sections detail the key areas that need to be considered in putting together any plan.

Putting the individual's needs first

In order to enable an individual to maximise his or her function, their needs and the needs of their carers must be assessed. While it is important to address the individual's needs at the time of assessment, it is essential for all concerned to consider their potential needs in the future.

Understanding their condition and its progression will assist in making those judgments.

Working together

It is vital for people with muscle-wasting conditions to have clear communication between them, their carer and their health professionals.

Good awareness training for staff can produce positive outcomes and experiences for the individual and their families. Good communication skills are vital, such as listening, being flexible and responding appropriately to the individual's changing needs.

Your local neuromuscular care advisor will also be able to provide useful information and advice regarding the progression of the condition and possible future needs of the individual.

Planning ahead

Careful planning is needed to anticipate the needs of the individual. Adaptations to the home environment often take more time than you think. You need to have healthcare, moving and handling and risk assessments in place from the start.

It is never too early to begin planning ahead.

Chapter 1
Muscle-wasting conditions

Muscle-wasting conditions

More than 70,000 children and adults in the UK have a muscle-wasting condition (please note that we use the umbrella term 'muscle-wasting conditions' to refer to muscular dystrophy and related conditions). A further 350,000 people are affected indirectly as family, friends or carers.

Muscle-wasting conditions cause muscles to weaken and waste over time, leading to increasing disability. These rare and very rare genetic conditions may affect not only the muscles in the limbs, but also those of the heart and lungs, sometimes significantly shortening life-expectancy.

Genetic conditions result from alterations in the genetic make-up of an individual. They may be caused by defects in single genes or whole chromosomes, parts of which may be lost, duplicated, misplaced or replaced. Genetic disorders can be caused by defects in one or more genes. (Contact Muscular Dystrophy UK to find out more.)

In these conditions, a gene may fail to produce one of the proteins needed for normal muscle function. While the conditions are generally inherited, in some cases, they occur 'out of the blue' with no family history of the condition.

Muscular Dystrophy UK also supports families living with conditions that affect nerves, including spinal muscular atrophy (SMA) and the hereditary sensory neuropathies, which cause muscle weakness. The junction between the nerve and muscle (neuromuscular junction) is affected in the myasthenias. Below is a brief summary of some of the more frequently encountered conditions. For more in-depth information on a specific condition please read the Muscular Dystrophy UK factsheets available to download from www.musculardystrophyuk.org or call 0800 652 6352.

Duchenne muscular dystrophy

Duchenne muscular dystrophy, one of the more common conditions, is a life-shortening muscle-wasting condition, caused by the lack of a vital muscle protein called dystrophin. The condition causes muscles to weaken and waste over time, leading to increasing and severe disability.

Duchenne muscular dystrophy currently affects around 2,500 people in the UK and around 100 babies are born in the UK with the condition each year. It is caused by genetic mutations on the 'X' chromosome, meaning almost all of those affected are male. These mutations prevent the body from producing the vital protein, dystrophin, which is needed to build and repair muscle.

Most children with Duchenne muscular dystrophy are diagnosed by the age of five. Most will use a wheelchair by the age of 12, and will face life-threatening health problems by their late teens as the muscles of the heart and lungs weaken. Few of those born with the condition currently live to see their 30th birthday; with medical advances, however, life-expectancy is improving.

The right specialist healthcare and equipment, including access to heart and respiratory experts and regular physiotherapy, can make a significant difference to both quality and length of the life for people with Duchenne muscular dystrophy.

While the condition is severely disabling, many of those living with Duchenne muscular dystrophy lead full and active lives. There are authors, designers, campaigners and Paralympians with Duchenne muscular dystrophy.

Becker muscular dystrophy

Becker muscular dystrophy is a genetic muscle-wasting condition, which causes muscles to weaken and waste over time leading to increasing disability. It is caused when the body's ability to produce a fully-functioning version of a vital muscle protein called dystrophin is compromised.

Over 2,400 people in the UK are thought to have Becker muscular dystrophy. Most people with the condition are diagnosed by the time they reach their 20s and indeed, some are severely affected from childhood. However, others do not know they are affected until well into adult life.

Becker muscular dystrophy almost always affects boys and men. It is not uncommon for several members of a family across generations to be affected. The severity of the condition varies. People with Becker muscular dystrophy may struggle with sport as children, with muscle weakness becoming more pronounced in their teens or 20s, causing difficulty in walking quickly, running and climbing stairs. In most cases they will continue to be able to walk until their 40s or 50s, but for some the decline in mobility will be much faster.

Spinal muscular atrophy

Spinal muscular atrophy (SMA) is a rare inherited neuromuscular condition, of which there are several distinct types. The condition may affect crawling and walking ability, arm, hand, head and neck movement, breathing and swallowing. SMA does not affect a child's intellectual development.

There are four main types of SMA, and they vary in severity:

SMA Type 1

The symptoms of SMA Type 1 appear within the first few months of life, sometimes before birth. It is the most severe form of SMA. Children are never able to sit unaided and rarely survive their second birthday.

SMA Type 2

The symptoms of SMA Type 2 usually appear between the ages of seven and 18 months. The condition is severely physically disabling, with children never able to stand unaided. Though this is a serious inherited neuromuscular condition that may shorten life-expectancy, improvements in care standards mean that the majority of people can live long, fulfilling and productive lives.

SMA Type 3

The symptoms of SMA Type 3 appear after 18 months of age. Children are able to stand and walk, though will experience reduced walking ability over time. It is a less disabling condition. Life-expectancy for children diagnosed with SMA Type 3 is normal and most people can live long productive lives.

SMA Type 4

The symptoms of SMA Type 4 appear in adulthood. It is also known as Adult Onset SMA and is not life-threatening.

Myotonic and congenital myotonic dystrophy

Myotonic dystrophy is a genetic condition, which causes muscles to weaken, stiffen and waste over time, leading to increasing disability.

Myotonic dystrophy affects approximately 9,500 people in the UK. The age at which symptoms appear can vary from birth to old age. The condition is progressive and the earlier symptoms appear, the more severe they will become.

Muscle stiffness or 'myotonia' is a characteristic symptom, especially in the hands. People may also experience muscle weakness in the face, jaw and neck, often resulting in speech and swallowing difficulties. Heart problems, digestive problems, and cataracts may also be caused by myotonic dystrophy.

High-risk complications for people with myotonic dystrophy include an irregular heart rhythm and chest infections caused by weakened chest muscles.

Congenital (from birth) myotonic dystrophy

Children with congenital myotonic dystrophy tend to reach physical and learning milestones later than their peers.

The severity of the condition varies considerably from child to child. A few affected children need to use a wheelchair. Significant features, particularly in congenital myotonic dystrophy, are learning difficulties (which can be severe), tiredness, lethargy and cataracts at an unusually early age.

Congenital muscular dystrophy

Congenital (from birth) muscular dystrophy (CMD) refers to a number of genetic muscle-wasting conditions which take effect from infancy, causing muscles to weaken and waste over time and leading to increasing disability.

It is thought that around 500 people in the UK have CMD, the main forms being Ullrich congenital muscular dystrophy and merosin-deficient congenital muscular dystrophy.

CMD is caused by mutations in genes affecting the production and repair of muscle. Mutations causing the condition have been discovered across at least 19 genes and there are likely to be many more. Owing to the complexity of the condition and the number of genes affected, some people will never know which type they have.

The types fit into two groups: the first cause weakness in all the muscles in the body, but do not affect the intellect; the second cause muscle weakness, along with learning difficulties, and sometimes seizures.

The severity of CMD varies greatly between types and individuals. Some children affected will walk, but sometimes this can be delayed until five years of age or older. Some children who have achieved independent walking may lose this ability later on because, as they grow heavier, the muscles are unable to cope with a greater strain. Other children may never be able to walk.

Facioscapulohumeral muscular dystrophy

Facioscapulohumeral muscular dystrophy (FSHD) is a genetic muscle-wasting condition that particularly affects the muscles of the limbs, shoulders and face. It is thought to be the third most common form of muscular dystrophy, affecting over 1,300 people in the UK and at least 140,000 worldwide.

FSHD is caused by a genetic mutation that causes the production of a toxic protein in the muscle, which kills the muscle cells. Often several generations of a family may be affected by FSHD, which can be diagnosed at any age and varies widely between individuals, even within the same family. The earlier muscle weakness appears, the more severe it is likely to become.

Approximately 10 to 20 percent of people with the condition eventually require a wheelchair. The muscles of the eyes and mouth can also be involved, affecting facial expression, and the ability to smile.

Limb girdle muscular dystrophy

Limb girdle muscular dystrophy is a large group of conditions that cause weakness of the large muscles at the top of arms and legs, attached to the shoulder and pelvic 'girdles'. In some people, the muscles of the heart and lungs are also affected, leading to life-threatening health problems. Around 1,400

people in the UK have one of the many types of limb girdle muscular dystrophy.

A very wide range of genetic mutations, all affecting the production and repair of muscles, cause limb girdle muscular dystrophy. Owing to this complexity, approximately 25 percent of all people with limb girdle muscular dystrophy do not receive a precise genetic diagnosis.

Some people with milder forms will never become seriously affected, while others may struggle to lift their arms above their heads, or lose the ability to walk. The muscles of the legs may deteriorate faster than those of the upper body, resulting in frequent falls, difficulty in running and climbing stairs, and rising from the floor. Usually, the earlier the symptoms become apparent, the more severe the condition will be.

Congenital myopathies

This is a group of inherited muscle conditions that are present from birth.

Congenital myopathies include central core disease, congenital myopathy with fibre-type disproportion, multi (mini) core disease, myotubular (centronuclear) myopathy and nemaline myopathy.

Congenital myopathies are conditions where changes in the muscle cells make them less able to contract. All these forms of congenital muscular dystrophy lead to muscle weakness and a decrease of muscle tone in early childhood. Later in life they are sometimes associated with delayed motor development and speech and learning difficulties.

About 1,000 people in the UK have a form of congenital myopathy.

Charcot-Marie-Tooth disease

Charcot-Marie-Tooth disease (CMT) is a progressive, inherited condition which affects nerves controlling movement of the hands and lower legs. It affects around 23,000 people in the UK, an equal spread of male and female.

Also commonly referred to as hereditary motor and sensory neuropathy (HMSN), CMT can involve loss of feeling in the hands and feet (the 'sensory' component). The term 'neuropathy' refers to the peripheral nerves, which connect the spinal cord to the muscles, joints and skin, carrying messages in both directions, and which do not function normally.

The first symptoms of CMT include difficulties picking up the feet and very high foot arches. These are usually apparent from childhood. Those affected may have problems with balance and walking longer distances, bone abnormalities, loss of reflexes and weakness of the hands. It is unusual for people to lose the ability to walk, however some will need to use walking aids as they grow older.

Owing to loss of sensation in the hands and feet, people with CMT need to be very careful to prevent and detect injuries to these areas. This is particularly important when planning PE activities, as the foot or ankle can be damaged without the pupil's being aware. Fine motor skills may also be affected as the pupil may not receive sensory feedback from the equipment. This could result in difficulties with handwriting, manipulating science or technology equipment, distinguishing temperature, sharpness or pain.

Myasthenia gravis

Myasthenia gravis is an autoimmune condition. It is caused when the body's immune system attacks the junctions responsible for transferring messages from the nerves to the muscles. It causes weakness and fatigue in the muscles of the limbs, face, eyes and throat, and also in the respiratory muscles vital for breathing.

Myasthenia gravis is thought to affect between 5,000 and 10,000 people in the UK – about 15 in every 100,000 individuals. It can develop at any age from childhood to extreme old age. Most of those affected are female, although men are more likely than women to develop it in later life.

The impact of the condition is very unpredictable and can vary dramatically day-to-day and between individuals. Frequently, the muscles of the eyes and face are affected, causing double vision, drooping of the eyelids (the person can look as if he or she is sleepy) and making it difficult to smile. The arms and legs may be weak and, in severe cases, there can be problems with breathing muscles.

Myasthenia gravis can also cause speech disturbances, such as slurred speech. Swallowing difficulties are also common in myasthenia gravis. Swallowing is a complex process involving around 50 pairs of muscles. These muscles can become fatigued, particularly towards the end of a meal or when food has required a lot of chewing. It is important that anyone with swallowing difficulties has an assessment with a speech and language therapist, so that recommendations can be put in place to help manage the symptoms.

Congenital myasthenic syndrome

This condition, which is very rare, can be difficult to distinguish from myasthenia gravis. It is a genetic condition in which one of the proteins at the neuromuscular junction functions abnormally. The symptoms and signs are similar to myasthenia gravis. The first evidence of the condition is at birth or shortly afterwards. In some cases there can be potentially fatal episodes of breathing failure. Drugs can help the weakness and it may improve spontaneously. Again, speech and swallowing difficulties can be common.

Mitochondrial myopathy

Mitochondrial myopathies are a group of conditions that particularly affect muscle, but may also affect every other part of the body, including the brain and the eye.

Mitochondrial myopathy is caused by genetic faults, which affect the function of mitochondria (the parts of muscle cells that generate the energy required for a muscle to contract). The causes and results of mitochondrial myopathy vary but most lead to some form of muscle weakness, and some affect specific parts of the body.

About 3,500 people in the UK have mitochondrial myopathy. The impact of mitochondrial myopathy varies dramatically from person to person. Many of those diagnosed are unaware that there is a family history of the condition.

The most common symptom is a combination of mild weakness of the arms and legs, droopy eyelids and difficulty moving the eyes. Some people only have the weakness in their arms and legs and find this gets worse if they exert themselves. In others it is more severe. For example, some babies with the condition may have difficulties with swallowing and feeding, which can affect their life-expectancy.

Metabolic myopathies

Also known as metabolic muscle conditions, these are conditions that interfere with the way muscles provide energy.

Metabolic myopathies, which include McArdle's disease and Pompe disease (also known as acid maltase deficiency, or glycogen storage disease type II) are caused by mutations in the genes involved the production of energy in skeletal muscles. The mutations generally block the chemical reactions that take place during energy production, so the muscle cells cannot work properly. In some cases, this can lead to episodes of muscle damage, causing acute kidney failure. In others there is progressive muscle weakness.

Metabolic myopathies that affect young children tend to be the most severe and can, in some cases, be fatal. Those with a later onset tend to have less severe symptoms, and in very mild cases changes in diet and lifestyle can ease symptoms. About 700 people in the UK have a form of metabolic myopathy.

Neuromuscular conditions (non-specified)

Despite medical and technological advantages, a number of people will not have a definitive diagnosis of their muscle-wasting condition.

Not having a diagnosis can be difficult for families. However, they should keep in close contact with their care advisor or specialist nurse to find out what research is taking place or if there are any clinical trials.

Information resources

Muscular Dystrophy UK has alert cards and Information Standard-accredited factsheets on a number of muscle-wasting conditions – including those without a specific diagnosis. The alert cards include information on the vital and specific issues that affect people with these conditions. They also outline key recommendations and precautions that non-specialist clinicians would need to know in times of worsening health.

Chapter 2
Assessment of need

This chapter aims to guide a disabled person and their family through a housing adaptation assessment. It covers the main issues and considerations to bear in mind.

An assessment aims to identify:

- what a person needs and wants to do in their own home
- how their lifestyle is affected by the condition at present
- whether or not the individual will need to plan for their condition as it changes in the future
- what the problems are within the home that stop a person living as independently as possible
- who also lives in the home, and what their needs are.

This information can then be used to help you to work with the relevant professionals, to solve the problems. This may mean the family needs to make changes to their present home or maybe move to a property which is better suited to their needs. It could be as simple as getting equipment that allows for independence, or it could be commissioning building work to provide new facilities.

Who needs to be involved in an assessment?

1. The disabled person and their family and/or carers need to be involved in all parts of the assessment.
2. Across the UK, OTs work in both health and social services settings. In some areas, these teams are integrated into one single team. The appropriate community OT will lead on the assessment and provision of specialist adaptations in the home. The OT needs to be involved to help get access to available grants (see funding section). If there is a hospital OT involved, he/she will have up-to-date information about how the condition is likely to progress and what difficulties the person may have in the future. They can then provide vital details to the community team. Where there are two OTs working together on one case, the assessment of need will be more accurate. It is helpful if the disabled person gives their consent to their information being shared.
3. Neuromuscular care advisors can also support families through the assessment process. They can contribute their condition-specific knowledge to help make plans to meet ongoing needs.
4. The family will choose an architect from the council's approved register of Disabled Facilities Grants architects, who will work alongside them and the OT to achieve plans to meet everyone's needs. They, of course, work within the *Building Regulations 2010: access to and use of buildings*.
5. Grants Officers will often oversee and support the whole application for the Disabled Facilities Grant (DFG). They or the OT will check that the work is completed to standard.

Health professionals often have broad experience, but may not have dealt with families living with muscle-wasting conditions before. Building professionals who have not worked with such families before often seek advice from specialist workers in the field.

Starting the assessment process

It is important to plan ahead as much as possible for adaptations as the process can be lengthy. The contribution of a health

professional who knows the condition and how it is likely to progress will help to establish a time scale. Budgets and the granting of planning permission are major factors in determining how long a project takes.

It is also important to get the detail right for the person using the adaptations, as well as their family and anyone else who shares the house with them. While these discussions can be lengthy, they are essential.

Adaptations process

1. Identification of change in function as a result of a diagnosed condition.
2. Referral to the local Social Services/ Community Occupational Therapy Service. Referral can be made by the disabled person, a family member or any healthcare professional involved in their care.
3. Assessment of need and suitability of accommodation.
4. Social Services/Community OT to liaise with architect/housing surveyor on options for plans.
5. Choices for specialist equipment such as toilet, specialist bath, height-adjustable washbasin discussed with the family. Assessments carried out for suitability and specification.
6. Social Services/Community OT to look at plans with family and with the care advisor/ OT involved from the healthcare setting.
7. Plans adjusted.
8. All relevant permissions sought. Planning permissions may not be required if the adaptations fall within the existing building or within the permitted level of development. The architect/surveyor may be able to tell you this but you can seek a definite answer from the planning department.
9. Builders from the council's approved list are asked by the family to quote for the work and a builder is chosen.
10. A meeting held before work starts, with the builder, OT, surveyor, family and any other interested parties.
11. Work commences.
12. Social Services/Community OT to check completed work and housing surveyor to sign works off for DFG funds to be paid.
13. Arrangements made to demonstrate use of specialist equipment.

Adaptations for children's needs

Once a child receives a diagnosis of a progressive muscle-wasting condition, it is important for the family to start to think about the environment at home. How can it be altered to enable the child to grow and develop, with as little restriction from the environment as possible? This can be an emotive subject. It needs to be managed sensitively while also delivering the facts about options for changes to the family home, realistic timescales and who can actually support the family.

Acceptance of a diagnosis and what the future holds can delay the start of work to change the home environment. Supporting the family to make timely choices is essential so that the child and family are not placed at any risk.

Referral can be made to the local Social Services/Community OT by the disabled person, their family or a professional from the team supporting them. This generates an assessment which informs the early planning stages. It may be necessary to make interim arrangements to support a person while major adaptations are being planned and put in place.

It is often important to plan for future adaptations for the changing needs of children. Remember to consider the space required by teenagers, who may use larger wheelchairs, have more equipment and things they want to keep in their rooms, as well as the space required by carers to carry out daily tasks.

Adaptations for adults' needs

An adult can self-refer to their local Social Services/Community OT when they first identify that they are struggling to manage day-to-day activities in their home. This could include difficulty moving around the property, climbing the stairs, managing personal or domestic care tasks.

An assessment, carried out by an OT, may help the adult to look at a range of simple techniques or equipment or could start the process of major adaptations.

Knowledge of the person's muscle-wasting condition and its progression is vital to ensure that plans are made that will last several years and meet the person's changing needs. It is suggested that the Social Services/Community OT liaise with the care advisor (where available) for expert advice about the muscle-wasting condition.

Planning ahead

Often at the time major changes are made to the home environment, the person does not yet need a full range of adaptations or equipment. It is important to work with the person and the family to help them to think about 'future-proofing' their plans. This could mean:

- putting equipment in before it is required, or
- ensuring the electric spur points are already in situ for door openers, bidet toilets and so forth, and
- ensuring the construction of the building will be suitable to support a hoist to be fitted.

If the adaptation is to be made on a more gradual provision, which responds to the person's needs as they change, the family must be made aware of up-to-date information about the DFG at the time of planning work.

Often adults see only subtle changes in their condition, which can make it more difficult for them to plan ahead. So the guidance of an experienced health professional can mean less upheaval and cost later on, and help the person to make informed choices about independence and home.

Considerations when planning changes to the home

1. Planning ahead is essential. Most (but not all) muscle-wasting conditions are progressive and this can be both physically and emotionally demanding for the individual and family.
2. For many people, when they find it difficult or impossible to walk , they will need to use a wheelchair. Often this is a powered chair, as a self-propelling chair can be tiring or too tricky.
3. If the person is still walking, it is often recommended that they try to keep walking for as long as possible. When this becomes difficult, using a standing frame daily may be recommended. The importance of standing is to help delay/ avoid hip and knee contractures so the person can lie flat, be comfortable in a range of positions and avoid getting sore skin. If standing is part of the person's daily routine (or will be in the future), it is important to plan for this. This could mean having space to store a standing frame or ensuring there are work tops at the right height for the person to stand and perform certain activities.
4. It is recommended that everyone with a muscle-wasting condition, who needs a wheelchair or will need one in the future, has en suite bathroom facilities. This can, or will, enable them to be undressed on their bed and be taken to the bathroom (possibly on an extended track of the ceiling hoist), within the privacy and warmth of the two rooms.
   The provision of en suite bathroom facilities is a real need. 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 will be needed.
5. Some people with a muscle-wasting condition may be able to raise their arms above shoulder height. However, as their condition progresses, this may become impossible. The effect of arm weakness can be debilitating and is not always fully appreciated. The assessment of need, therefore, should capture the person's daily activities so that changes can be made to maintain as much independence as possible. This could mean looking at table-top or worktop heights, or considering which technology could support the person.
6. Trunk weakness can result in a lack of balance and stability, making support necessary when sitting in a chair or a bath.
7. The progression of some muscle-wasting conditions is predictable, which means that adaptations can be planned for the future.
8. Muscle weakness can result in sudden, extreme and abnormal tiredness. As their conditions progress, many people start off using a wheelchair for part of the day only. This may be a way of pacing themselves and can vary according to the time of day or week, or if they are not well. It is important to plan sensitively, according to these potential variations in function.

Identification of need

There is a checklist in the Appendix which highlights points to consider when planning changes to a property.

Considerations for the assessment of the suitability of the present home

There are a number of factors to consider when looking at the suitability of a family home for adaptations.

1. Is there level access from the road?
2. Is the land around the house level and accessible?
3. Are there steps up to the front door?
4. Is the house in a well-maintained state and therefore suitable to be adapted?
5. Can an en suite bathroom be provided upstairs or downstairs in this property?
6. If facilities can be upstairs, is there space for a through-floor lift?

7. Will changes to the building mean that the family will have to change their normal routines and practices, for example will there be a space for a husband and wife to continue to sleep in the bedroom together?
8. Can any of the existing rooms be adapted or have changed use?
9. Will this leave the family with insufficient living/dining/prayer space? (The continuity of family activities cannot be underestimated in terms of family cohesion and self-support.) In many areas, the assessment looks at the number of people requiring living space. Any additional space could be used for an extension under the DFG application. In some cases it can be cheaper to extend rather than to adapt the existing building as, for example, a hoist set-up can be difficult between an old and a new building.
10. Can any of the existing rooms be increased in size, with an extension to provide bedroom / en suite bathroom?
11. Is there more than one person with a muscle-wasting condition living in the house, who will also need adapted accommodation?
12. Is there sufficient space for a wheelchair, equipment and care tasks in the planned rooms? (The importance of sufficient space cannot be overestimated, and the plans should be for the largest possible space.)
13. Does the person need to have an overnight carer staying near them? How will this person be accommodated without compromising family privacy?
14. Will changes that make the house accessible cost so much that the budget for internal changes – such as adapting the bedroom and bathroom – is considerably reduced?

These factors will help the family to make a decision about whether or not the present family home is suitable for adaptation, or whether or not they will need to consider a house move.

Moving house

Moving house is a huge life event for any family. For families trying to come to terms with the diagnosis of a potentially life-changing muscle-wasting condition, it can be even bigger. So families need to consider many factors about timing, cost, gaining or losing a support network, the impact on access to schools and jobs, and so on.

There are two options available: private purchase or renting.

1. Private purchase can be a lengthy process and often depends on selling the present house before finding and moving to a new home. This can mean having to move into temporary accommodation while finding a suitable house. When a member of the family has a disability, this can be tricky and needs careful planning and some interim solutions.
2. Renting is an alternative and can be done through either social housing or private letting. Social housing is often the preferred option as support will be provided in the selection of the most appropriate property to meet the needs of the individual as well as their family. The Council is also obliged to provide accessible accommodation under their duty to 'arrange practical assistance in the home, and any works of adaptation or the provision of additional facilities designed to secure greater safety, comfort or convenience' (Chronically Sick and Disabled Persons Act 1970).

Applications for social housing

When making a housing application, it is important to be clear about the housing needs, as this information will be essential to inform the Housing Provider. Your local care advisor can help you with this.

Privately rented property

Often landlords who manage privately rented accommodation are unable to grant permission for adaptations to the property.

However, some families will find that a privately rented home will meet their needs for the short time between living in unsuitable accommodation, and having fully-adapted accommodation.

Considerations when looking at properties with a view to major adaptations

1. Look at similar properties on the same road to see if they have extensions or have been adapted in any way. This will give you some indication (although it is no guarantee) whether or not the Council has previously allowed development of local properties.
2. Check the space at the side or rear of the property for a potential extension. 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.
3. Consider whether or not an extension would be too narrow without building right up to the boundary or having an impact on the neighbour's property.
4. Ask for advice before making the final decision about whether or not to accept a lease or to buy a particular house. In this way, you'll ensure that if it needs to be adapted, it is suitable. This advice can be sought from the Social Services OT or the care advisor.

Bungalows

Many people begin their journey of looking for a new home by thinking about a bungalow. There are considerations to make before embarking on such a purchase.

Pros	Cons
Level accommodation	Bungalows can be more expensive than houses
Everyone sleeps on the same floor	Other bungalows in the area may be occupied by people of a different age group
If a parent has a mobility problem they can more easily get to their child in the night	They can be noisy as there is no ceiling to muffle sound between floors
	Passageways are often narrow, creating difficult wheelchair turning spaces
	It can be tricky to justify adaptations under the criteria specified in the DFG

The need for a child to have a separate bedroom

Many children with muscle-wasting conditions need attention during the night, and care-giving may disturb other children. Therefore, it is more suitable for children to have separate bedrooms. In some cultures, however, sleeping arrangements may vary and individual choice must be respected. If the home is rented, it is wise to check the local policy on children of different genders sharing a bedroom.

The proposed plans

Families will often have ideas about how changes to their home may take place, so it is important to try to capture these at the planning stage. This is especially important when the home is owner-occupied. Architects can often provide a selection of different plans, but if the family does not feel that these meet their needs, an open discussion needs to take place before the plans are agreed and work starts. This may delay the process, but is important to get what the family needs and wants.

When there is more than one set of plans, grants are usually awarded on the simplest plan to meet the needs of the person. If, however, the family wants additional or alternative features, this becomes the Preferred Plan and the additional costs would have to be funded by the family.

Assessment for specialist equipment

It is important that the person who will be using specialist equipment in the home has an opportunity to see and try the available options. The OT involved can offer a clinical assessment and explanation of need to ensure the correct piece of equipment is chosen. The OT would then be able to advise the individual and their family about funding options: statutory funding, charitable support or private purchase.

The individual and their family will need to be aware of their responsibility to keep the equipment maintained, how training needs will be met, and where to get help and advice from once the equipment is installed.
The local Independent Living Centre (ILC – not available in Northern Ireland) can arrange appointments for families to go with their OT to look at different pieces of equipment. The ILC offers impartial advice and professional assessments but does not sell equipment. Your local OT can advise you.

It can be daunting for families of children with muscle-wasting conditions who are going to an assessment and seeing assistive equipment for the first time. It is helpful to prepare beforehand with explanations and brochures. The staff at the ILC will be able to put the child and family at ease as they are experienced, and sensitive to this.

References

- www.gov.uk/government/publications/inclusive-communication/inclusive-language-words-to-use-and-avoid-when-writing-about-disability
- www.gov.uk/government/publications/access-to-and-use-of-buildings-approved-document-m
- www.nihe.gov.uk/adapting_your_home_public_sector_december_2002.pdf

Whether to adapt or to relocate?

If the family lives in accommodation which may not suit the person's long-term needs, it may be necessary for them to relocate. Depending on the progression of the children's conditions, there may be enough time to seek alternative accommodation. This can often be better in the long term, than adapting the current home. This will depend on the family's needs, the availability of accommodation of their tenure type in their chosen location, and the suitability or adaptability of that accommodation.

Funding for housing adaptations

The DFG is not means-tested where the housing adaptations are needed for children and young people (under 19 years of age). After the age of 19, the DFG is means-tested.

If there is more than one disabled child or adult living in the home, an assessment of need should be carried out for each disabled person. This is because separate or different facilities may be needed within the same home.

An application for a DFG should be made for each disabled person. Local authorities are likely to consider whether or not the same facility could meet all the needs in the home. If this is not the case, then the DFGs should be granted individually.

Adapting the home for more than one disabled child

The needs of all disabled children in the home should be assessed and taken into account, ideally by the same professional. If this is not possible, then professionals should work together on planning adaptations for each disabled child.

The following questions should be taken into account when recommending adaptations for a home with more than one disabled child:

- will the proposed layout suit all of the children and young people in the home currently, and into the foreseeable future, as far as possible?
- will the proposed access into and out of house, and to the garden, meet the requirements of all the children and young people?
- will the proposed means of access to the first floor (if required) by means of a stairlift or through-floor lift, meet the needs of all disabled occupants?
- does each person need access to a bathroom with a bath, shower or wet room?
- does each person need access to a specialist or adapted toilet, or changing facilities?
- are the rooms big enough for two or more disabled occupants, including wheelchair circulation space in family living rooms and bedrooms, as well as storage space for specialist equipment?
- when assessing the needs of siblings with disabilities, will they need separate bedrooms or can they share a bedroom? Young children and twin siblings often want to share a bedroom as part of ordinary family life. However, think about the future needs of each sibling, and whether or not their needs are likely to change over time. For example, one sibling may require waking overnight care and the other may not.

If the children are of different sexes, then as they become older, they will need separate bedrooms. Discuss this with the family and take into account their views and wishes. In shared or separate bedrooms, think about space requirements for specialist beds (if required), and for carers if more than one carer is present. Adaptations should always be 'future-proofed' as much as possible to avoid additional cost and disruption later on.

Chapter 3
External access

When planning home adaptations for people with muscle-wasting conditions, it is important to look at the whole property in terms of access and independence. This will mean considering all the daily activities that the disabled person likes to engage in and looking at options to make this easy. It is likely specialist equipment may be considered. The OT should be involved in all stages of the discussion and planning to ensure that plans meet standards and are future-proof.

All information about equipment in this chapter has been included because it influences decisions relating to the adaptations, if it needs to be plumbed in or installed, or involves the provision of adequate space. In every case, the alternatives must be assessed before the final brief is given to the architectural designer.

You may find it useful to read this chapter in conjunction with Chapter 15: Scales, building and planning regulations.

Car parking

Where possible, a car parking space should be made available to enable the disabled person get into and out of an adapted vehicle safely. There needs to be sufficient space for the vehicle, the tail lift, and for the person to manoeuvre their powered chair between the vehicle and the property. This usually means allowing at least 1,200mm to the side and rear of a standard car parking space. A car port may be worth considering, as it would provide shelter for the passengers in inclement weather.

The garden

All paths in the garden should be firm, slip-resistant and reasonably smooth. Where possible, maintain sufficient space down the side of the property not only for wheelchair access, but also so garden equipment, bins, and so on, can be moved.

Think about how the disabled person will get to the garden, and where a patio area can be provided for social and leisure activities. This space should be no less than 3m x 3m, ideally. If there is a change of level between the edge of the patio and the garden, make sure there is a 100mm raised edge. Garden gates should not be spring-loaded.

Access to the house

Where possible, there should be level access into a property. It needs to be safe and convenient for all the occupants of the property and be at the least steep gradient. The path/ramp access to your property needs to be 1,200mm and there need to be platform areas measuring 1,500mm x 1,500mm at both ends of a slope, or at 10m intervals. Gates need to have an accessible width of at least 850mm and the pathway should be illuminated. (*Part M Building Regulations.*)

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. However, if the person walks and uses a wheelchair, supplementary ramping will also be required. The person may need rails for balance and support, and these should be assessed according to the person's height.

If there are steps into the garden, it may be possible to install equipment to facilitate access for a wheelchair user. Your OT will be able to advise you.

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 for heights of between 500mm and 1,000mm. It's very similar to the step lift described below.

Step lift

In situations where it is impossible to build a ramp of the correct gradient, a step lift may be installed for access to the house. This consists of a platform (with safety rails and a folding front ramp), which rises hydraulically. This does not provide a solution for gardens with multiple sets of steps.

Portable ramps

Portable ramps may overcome difficult access into a house, usually as a temporary measure. They can be used until adaptations have been completed or suitable housing has been found.

They can also be used for houses fronting straight on to the pavement where there is insufficient space for a ramp, short-rise lift or step lift.

Portable ramps should be strong yet lightweight enough to be moved safely by a carer. There are two choices – channel ramps and full-width ramps.

Channel ramps: these are usually easy to carry and store. However, if a significant height is involved, it can cause great strain on the carer's lower back if they need to push the wheelchair user up the ramp.

Full-width ramps: these ramps are more cumbersome and therefore more difficult to handle. However, the carer can walk up the ramp, which makes this manoeuvre easier.

Various sizes of ramp are available and the length needed will depend upon the height of the steps to be bridged. Safe gradients and the Safe Working Load must be incorporated into an assessment.

When considering portable ramps, a moving and handling risk assessment needs to be carried out. This is to capture risks to all carers who will need to move and handle the ramps, as well as those pushing the wheelchair. (The OT will carry out this risk assessment.)

Ramps

Refer to building regulations when providing a permanent ramp. In general, a ramp should:

- have a gradient of between 1:20 and 1:15
- be 1,000 – 1,200mm wide
- have a top and bottom landing for every length of ramp (to provide a level area for the wheelchair while the door is opening/closing)
- include railing – a handrail height (about 900mm) and a second rail (about 550mm) for wheelchair safety (these should be continuous and extend beyond the ramp by about 300mm)
- have an upstanding edge of a minimum of 60 – 1,000m
- have a slip-resistant surface.

Consider a channel drain across the entrance door to stop rain water getting into the house.

Find out more at
www.wheelchair-ramps.co.uk/information

Chapter 4
Access into and around the property and flooring

It may be useful to read this chapter in conjunction with Chapter 15: Scales, planning and building regulations.

There are a number of things to consider when planning for adaptations, to ensure access into and around a property, as well as ensuring appropriate flooring.

Planning for access around the family home is as important as looking at specific rooms. Doorways may need to be moved to enable access to all parts of the house. But it is usually best to plan for these when the major adaptations are being mapped out to avoid unnecessary upheaval at a later stage.

Access into the house

Entrance doors

When considering the external door to the home, think about the following:

- the door width should be at least 850mm opening width and the threshold must be flush
- there should be at least 300mm between the opening edge of the door and the nearest obstruction to the side, such as the wall
- there must be an external landing measuring 1,500mm x 1,500mm clear of the door swing
- the door must have an automatic light for night-time access
- the wheelchair turning circle inside the door should be 1,500mm
- there should be kick plates on the door to prevent damage from a powered wheelchair
- a letterbox cage on the inside of the door makes access to post easier
- the doorbell should be located at a suitable height and a spy hole – if appropriate – placed at a height that is useful to the disabled person
- the door lock needs to be easy for the individual to manage; if not (now or in the future), think about automatic door openers.

Electronic door-opener

It is important to a disabled person's independence to be able to open and close their front and back doors. In cases where this is not possible, an electronic door-opener is really helpful. This is also true for young disabled people who are old enough to be left in the house on their own.

Companies who specialise in these systems should assess the property to see if the door and electricity supply are suitable. If they aren't, the company can advise on what work needs to be done to achieve compliance.

With an electronic door-opener system, the door can be opened with a simple fob. It can also be opened with keys.

If the person gets locked out of the house, it's a good idea to have a discreet, coded key-safe available, with a front door key inside it.

A DFG can usually cover the cost of an electronic door-opener.

If this is not needed at the time of the adaptations but may be needed in future, it is a good idea still to install the fused spur. This will avoid affecting the decoration in the future. The installation can then be delayed until necessary, and funded through a subsequent housing grant or with help from a charity.

Access inside the house

Internal doors

Consider how the disabled person will move around inside the property and what equipment they may need.

It is difficult to move through narrow passageways, with limited turning space to get into rooms, when you're in a powered wheelchair. Radiators and skirting boards can also reduce the width of the passageways in a house.

Creative solutions may include:

- widening doorways, or
- re-siting a doorway on the diagonal by re-building walls (this creates a larger turning space in the hallway).

Often door widths are adjusted as part of an initial adaptation project, and thought needs to be given to which kind of door to choose.

The choices for internal doors are:

- conventional
- swing
- sliding.

Conventional doors: anyone with restricted upper limb movement will find it hard to open this type of door.

Swing doors: these move through 180º and can be pushed open with the footrests on a powered wheelchair. They can be fitted as single or double swing doors. Think about privacy, independence and location before deciding on this type of door. There is a viewing panel on the door so you can see if someone is on the other side of the door before pushing it open. Kick plates may be needed to protect the door and prevent the paint being chipped.

Sliding doors: these are economical on space, but not easy for disabled people with weak upper limbs to open. The runners can also cause a floor-level obstruction. However, in some circumstances these may be the best option.

Upstairs access

A number of factors need to be considered when choosing a lift. Refer to Chapter 6: Solutions for stairs.

Floor coverings

Bathroom: the architectural designer will advise about the type of floor coverings which would suit the type of adaptation. However, when a disabled person is able to walk but is unsteady, the type of surface is crucial. The surface should be non-slip but not too abrasive, as the texture grips the sole of the shoe making it difficult to lift the foot. Any surface must be easy to clean or mop when it gets wet.

Bedroom /living rooms: a laminate floor covering is often the most suitable as it is easy to clean when a powered wheelchair is used indoors. It also offers less resistance to the wheelchair and to a manual hoist, if one is needed. If a carpet is preferred, it is probably best to choose one with a short pile and one that does not offer a soft, cushioned surface.

Please refer to Chapter 7: The bathroom and Chapter 8: The bedroom for additional information.

Before entering the house

Some wheelchair users may choose to have an area outside where dirt can be cleaned off the wheelchair before going inside. This may be an outside tap with a hose to wash down the wheels, along with a coarse mat, which helps to dry the wheels.

Electrical fittings

For specific advice on this section please refer to *Part M Building Regulations*.

For people who find it hard to raise their arms, the height of switches and sockets needs to be considered. Ideally, it is 900mm up from the floor. In addition, all outlets, switches and controls should be positioned consistently in relation to doorways and corners, and in a logical sequence throughout the building.

To make light switches easy to find, they should be aligned horizontally with the door handles.

If it is too difficult or impossible to press switches on or off, think about alternative assistive technology. The local Environmental Assistive Technology (EAT) Service or your OT will be able to advise you.

Please refer to Chapter 15: Scales, planning and building regulations for additional information.

Chapter 5
Heating

Muscles are the main source of heat production and maintenance of body temperatures; cold muscles do not work as well as warm muscles. For people with muscle-wasting conditions, and their inevitable lack of mobility, it is essential to provide higher than average levels of heating. This is especially important for the bedroom, bathroom and living room areas.

Heating is particularly important in the bathroom, especially where it has more than one external wall. Without adequate heating, it is likely the bathroom will not be used.

Most children with muscle-wasting conditions feel the cold from a very young age. As their conditions progress and their mobility decreases, the problem becomes more severe. This is common to people of all ages with similar muscle-wasting conditions.

When planning an adaptation that requires an extension, it's important to ensure the boiler has the capacity to heat the new rooms and contain sufficient water.

A wall-mounted heater should be installed in the bathroom to provide supplementary heating in the winter and in the summer when the central heating is not required.

Where there is medical need, it may be possible to grant-fund the installation of a new central heating system, or the extension of an existing one, if necessary with an upgraded boiler. The grant may not cover the cost of installing radiators in rooms that are either inaccessible to the disabled person or not used by them.

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. In no circumstances should the disabled person return to an unheated house.

Consider carefully the type of control and its location so that it can be operated safely and easily by the user. With the advances in technology, there is now the potential to operate heating from smart phones and computers. These may be worth considering where an individual may not be able to manage a fixed thermostatic control.

Please also refer to the ventilation section in Chapter 15: Scales, building and planning regulations.

Chapter 6
Solutions for stairs

Deciding where to locate a bedroom and bathroom can be tricky. The following factors should be considered by a disabled person and/or their family to help them make well-informed choices.

Once an Assessment of Need has been carried out, an assessment of the space available needs to follow. This is one of the main determining factors in the choice between extending downstairs or adapting upstairs. The decision is about which option meets the needs better in the space available.

When a housing adaptations grant application is being made, use of internal space and perhaps the use of a lift to access first floor facilities is considered. However, where both a lift and an extension are structurally possible, consider the most cost-effective solution that will meet the needs of the disabled person and their carers, bearing in mind the long-term effects of the particular disability. So the following questions should help to guide planning.

Initial considerations

Is there space for a lift, and can the rooms upstairs provide enough space for a bedroom and bathroom?

The total space required for a lift, both upstairs and downstairs, is considerable. It includes both the size of the lift and the access needed. The recommended size is 1,650mm in length and 1,100mm in width for the lift (external dimensions), plus space for the door to swing open and the wheelchair to turn. (This space may be shared if the person in the wheelchair can move clear of the door swing to close the lift door.) This means that if the disabled person can move clear of the doorway, it may be possible for the door of the through-floor lift to open into this space. However, this should only be considered where space has been measured with care. If it is a child requiring adaptations it is important to consider the need to increase the size of the wheelchair as the child grows.

There should be enough space for a double bedroom with an en suite bathroom, a lift, an electric profiling bed and essential fittings. This is important because people with muscle-wasting conditions are often undressed on their bed and transferred into the bathroom on a mobile shower-chair, or a ceiling hoist. Adjoining/en suite bathrooms of a suitable size enable personal care to be carried out with a higher degree of privacy and dignity.

Is there sufficient space upstairs for a powered wheelchair?

It is important to be aware of the space needed now and in the future. The size of the wheelchair is likely to increase and additional equipment may be required.

Is there enough space to create facilities in the bathroom and bedroom?

Look at the space available when considering wheelchair accessible accommodation in the upstairs of a house. Refer to *The Building Regulations 2010. Access to and use of buildings: M4(3)*.

a. Bathroom

The bathroom should comply with *Part M of the Building Regulations*, though additional considerations need to be considered for people with muscle-wasting conditions.

1. There should be wheelchair turning space of at least 1,500mm as the person enters the room space. This should be clear of

obstructions. It may be worth considering a door that swings outwards to create more unobstructed space.
2. Toilet must be positioned so that there is at least 650mm available to one side for side transfers. However, it is advisable to aim for 500mm at either side of the toilet for carers to assist. This space, in the early years of a condition is sufficient for a drop-down rail.
3. The washbasin space should be considered and the model aim to protrude minimally.
4. The bath:
   - should be positioned so that there is at least 500mm to the side of the bath for the carer (if it is possible to achieve 500mm on either side of the bath, this offers the option for two carers to assist though this depends on the bath being in a 'peninsular' position, where carers can access both sides of the bath, and the taps being at the wall end for plumbing)
   - there also needs to be sufficient height around the bath, should an adjustable-height bath be selected
   - if a bath with an integral seat is selected, there needs to be sufficient space for this to swivel away from the bath(there also needs to be space for the disabled person to transfer and a carer to assist).

Please refer to Chapter 7: The bathroom for further information.

b. Bedroom

The lift will usually rise into the bedroom and sufficient clear floor space must be available. There also needs to be wheelchair circulation space and room for the bed and furniture.

The bedroom must comply with the building regulations' requirements:

1. a space of at least 1,100mm x 1,650mm available for the through-floor lift
2. the lift must be accessed from the same narrower end from each floor
3. a minimum 1,500mm turning circle of the lift door when it opens at 90º (this needs to be available on each floor).

The bedroom furniture also needs to be considered. It is important to establish who will occupy the bedroom; if it is a couple who share a bed, the extra space must be factored in.

If however, it is for single occupancy, consider the following:

1. space for a single electric profiling bed (approx. 2,150mm x 1,100mm)
2. turning space of at least 1,500mm for the wheelchair
3. storage facilities – wardrobe, chest of drawers, necessary medical equipment.

c. Access between the two rooms

It is always recommended that a wheelchair user have a bedroom and bathroom which are linked with a joining door of no less than 850mm. This enhances dignity, privacy and also enables both rooms to be easily accessed. Often a dropped-height wall divides the two rooms to enable free movement of a ceiling tracking hoist.

Please refer to Chapter 7: The bathroom and Chapter 8: The bedroom for further information.

Types of lift

If the upstairs facilities are possible in the disabled person's home, consideration needs to be given to the types of lift available. While there are several lift options available, consider the person's diagnosis, prognosis, preferences and the structure of the building.

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 a muscle-wasting condition.

Stairlift with an integral seat

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 a muscle-wasting condition. 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. They can, however offer a useful solution, for example, in schools.

Vertical through-floor lift

These models are open and not enclosed in the same way as a shaft 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. Safety advice states that these lifts are for a single occupant.

Forward planning is essential. This will ensure that, where possible, the lift will be suitable for the size of any wheelchair used in the future, and for the combined weight of the chair and the occupant.

Shaft lift

These require a dedicated space of about 1,600mm x 1,800mm and have an enclosed car. They cover up to 12m of travel with up to six stops, and can be used by more than one person. It is possible to have a door opening on different sides for different landings. They are rarely used in domestic situations as it is unlikely that space is available. However they are worth knowing about as a possible solution where more than two stops are required. They are costly and would only be considered via a DFG if they are the only solution to meet the need.

Choosing the right type of lift

For many people with a muscle-wasting condition, it is necessary to have a lift that will accommodate a wheelchair. Planning ahead avoids the additional and considerable expense of changing the lift at a later date. It is best to opt for the largest model possible, also considering the Safer Working Load.

The most appropriate model

1. Does the through-floor lift comply with BS 5900:2012?
2. Does the specification suit the building? The approximate space has been mentioned, but it is important to find the most suitable model of lift and to check the specific dimensions. The ceiling height also needs to be considered. It is important that the lift company provides a structural assessment of the property, to determine the feasibility and position.
3. What is the load capacity? It is important to be certain that the lift will take the weight of the wheelchair as well as that of the person travelling. This is particularly important to consider as children get bigger or a person's needs change and they require a larger or more sophisticated wheelchair. Care must be taken to ensure that the lift that is installed will not limit the choice of wheelchair in the future.
4. The position and type of controls. The position of the controls and their accessibility, on the ground floor, first floor and in the lift are very important to ensure continued independent use. Controls are hand-held remote controls in most cases. Some have magnetic mounting to position on the lift car or wheelchair. Remote controls without a magnetic backing can be secured with sticky back Velcro to enable flexible positions. Controls are usually push-button but can be altered by some manufacturers to provide switch control. The person who needs to use the lift should be assessed with the controls to ensure that they are independent. Discuss this with your OT and the lift company.
5. Maintenance and servicing. Providers may have a contract with a specific company as a cost-effective way to secure the best price for purchase, maintenance and servicing. However, if the lift has been purchased with a housing grant, it is likely that maintenance and servicing will be the responsibility of the home owner. It may, however, be possible to include a servicing package in the cost of the lift.
6. Safety. The lift company should be able to provide reassurances that:
   - the product has pressure sensors to stop travel should there be something above or below the lift when it is operated
   - the lift cannot travel if the door is open
   - the door can't open when the lift is travelling
   - there is a battery back-up in the event of a mains power failure
   - there is an alarm.

Choices when upstairs facilities are not an option

If the use of upstairs is not an option, consideration needs to be given to downstairs facilities. This may include an extension. It's helpful to consider the following questions.

Can some of the existing living space be used to form all or part of the accessible bedroom/bathroom?

Many providers will calculate the occupancy of the house and compare it to the living space available for all family members. This can mean that an existing reception room or part of that space could be borrowed to create bedroom or bathroom space. This may still require an extension but work and costs would be reduced.

If an extension is required, is there sufficient space in the garden?

Is the space around the house sufficient for a bedroom/bathroom extension of adequate size? Will this retain access down the side of the house as well as a suitable garden area? One of the barriers may be in obtaining planning permission.

If there is sufficient space around the house for an extension, planning permission will be required. A supporting letter from a relevant professional may assist the planning officer in understanding the requirement for an extension that may not fall within normal permitted planning.

Can the extension be accessed from the hall or family area?

Ideally an extension should not be accessed via a kitchen because of the increased risk of fire. Consideration should be given to whether the layout of the property can be modified to improve wheelchair access.

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. This could be via French windows or a glazed door with an adjacent window. It is essential to ensure that the doors have a level-access threshold.

Seek advice from your local Fire and Rescue Service Prevention Officer if there are concerns in relation to access being possible only via a kitchen.

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.

For some people, it may be possible to choose a preferred scheme as upstairs could be made accessible and there is space for an extension.

Please refer to Chapter 15: Scales, building and planning regulations for further information.

Making the choice between a lift and a ground floor extension

Advantages of a lift

Potential access to more rooms within the house

This is likely to be essential to parents who want to be able to get into their children's bedrooms and 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.

Easier and more convenient for parents/carers to provide night-time supervision and attention when required

The level of supervision and interventions required (medical, emotional, postural, manual handling) will vary. These may have an important bearing on the decision of whether upstairs living is required.

Shared occupancy of bedrooms

For couples, it is often that they continue to share a bedroom and the importance of this should not be underestimated in the planning of major adaptations.

Noise levels

For a child, upstairs may be quieter than downstairs when the child is going to bed earlier than other family members.

Disadvantages of a lift

The space needed

The configuration of the rooms, door widths, room sizes and additional works can be expensive and disruptive.

The 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 (for example, while the carer is cooking a meal).

A lift may isolate a young person

Teenagers often choose to spend many hours in their bedrooms. Because of the distance between upstairs and downstairs they may feel isolated from family activities, compared with direct access from the family living areas into an extension.

Lift maintenance is expensive

Maintenance of equipment provided with a grant is usually the responsibility of the applicant and this may be expensive. A lift may come with a warranty but as a homeowner you are likely to be responsible for any ongoing service and maintenance costs. Some local authorities/health trusts may assist with funding of maintenance to the lift but this cannot be guaranteed. There is additional stress if the lift is unreliable.

Fire safety

It is always advisable to seek advice from the local Fire and Rescue Service to ensure all safety considerations are in place.

Advantages of an extension

Allows a child or young person to move freely and quickly between the family areas and their bedroom

This provides independence and freedom that should not be underestimated. As a child develops, they will increasingly value being able to spend time in their bedroom without requiring the intervention of a parent. A ground floor bedroom also assists the child to have close access to living space and remain more involved with family life.

Provides the convenience of a ceiling hoist on the ground floor

Allows a ceiling hoist, installed in the bedroom, to be used to transfer a person from a wheelchair to another piece of equipment (alternate wheelchair, home chair, standing frame, and so on), without having to go upstairs. In addition, it makes it easy to wheel a child's easy chair with castors, which is used in the family sitting room, into the bedroom, in order to use the hoist for lifting in and out of the chair.

Immediate attention

If the disabled person is unwell, carers are more able to respond quickly.

Provides purpose-built facilities

A purpose-built extension is likely to provide more bespoke 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.

Disadvantages of an extension

Reduces the size of the garden

It is important to ensure the garden remains a suitable size to meet the recreational and play needs of all family members.

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.

It may be possible to have space for an occasional bed to be used by the carer in the ground floor bedroom during times of illness.

Disrupted sleep for carer

Some carers feel that they are not able to settle to sleep knowing that the person on the ground floor may need care.

May be a difficult adjustment for some children and parents

There are numerous listening and monitoring devices available for parents to use. Initially, there can be a period of adjustment while both child and parent get used to the new sleeping arrangement.

There is not full access to the whole property
There will only be wheelchair access to the rooms on the ground floor of the property.

Cost

It is likely that the cost of extending a property and other associated works will exceed the amount of eligible grant funding available. Consideration will need to be given as to how these costs will be met. Some local authorities/ health trusts may have processes in place to assist families with funding required above the grant limit but this cannot be guaranteed.

Access to upstairs as an interim measure

If the disabled person needs to access upstairs facilities until adaptations are complete, a stair climber should be considered.

Stair climbers

A stair climber is equipment rather than an adaptation. It is a mechanical piece of equipment, which is operated by a carer to safely transport the person between floors. An assessment would be required to ensure that:

- the stairs are suitable for the safe use of the stair climber
- the carer is competent to use the equipment
- there is space for it to be wheeled into the bedroom and bathroom upstairs
- the moving and handling needs of the person can be met once they are upstairs.

There are a number of seating options that can be introduced on to the stair climber to support the person in transit. Full training on the safe use of the stair climber within the home is required by anyone who will be responsible for operating the equipment.

This equipment offers a satisfactory temporary solution only, as independence of the disabled person is achievable with other solutions.

Summary

It is unlikely that just one option will offer a complete solution for someone with a muscle-wasting condition. Future planning is crucial in terms of the cost and disruption for the whole family. It is often possible to predict future need where a diagnosis has been given.

Local authorities are cost-driven, so it is important to consider future-proofing. It is therefore the responsibility of the OT to consider the needs and justify this in the specification. You may need to refer to legislation in order to support your request.

Chapter 7
The bathroom

Accessible and dignified bathing and toileting facilities are vital to any disabled person. It is important to plan the equipment that goes into an adaptation with a view to changing needs and individual preferences. It is also important for the disabled person to be as independent as possible in their self-care activities. This chapter aims to describe the key equipment considerations and to provide information to help OTs to justify why certain pieces of equipment have been selected.

You may find it useful to read all the sections below in conjunction with Chapter 15: Scales, building and planning regulations.

Bath or 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, although it is likely that in some Local authorities/Trusts the more economic option will be the first suggestion.

Most people with a muscle-wasting condition find a bath more satisfactory as it provides the opportunity to relax tired and aching muscles. The depth of the water also provides buoyancy to limbs, which the person might otherwise have difficulty moving.

The choice must also consider the carer's preferences in addition to the needs and views of the disabled person. Carers often find it is less of a strain on their back to assist with washing, by either standing at the correct height of bath or even kneeling at the side of a bath, rather than leaning over a shower screen or trying to keep dry behind a shower curtain. It is also very difficult to wash a person's feet and the lower part of their body in a shower, without getting into the shower.

Level-access shower

There are several issues to be considered if a level-access shower is the preferred option.

Standing or sitting use: many people who can still walk may opt for a shower. 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 muscle-wasting conditions, standing may not be very safe. Using a wall-mounted seat or shower-chair should be considered. Also, if the shower is to be used standing, the use of rails and their positioning will be important.

Choice of shower base

The choice of shower 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 two options are specialised flooring and shower trays.

Specialised flooring: the conventional tiled floor that slopes to a drain outlet is not recommended. Any gradient is difficult for anyone with a muscle-wasting condition either to walk up or to propel a shower-chair up. The floor has to be level so that the wheels of the wheelchair are stable to ensure safety while transferring. A specialist surface, which consists of a level-access shower grille, is an option. 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.

Shower trays: if a shower tray is to be installed, it has to have level access and be produced from a non-slip material. The surrounding area also needs to be covered with a non-slip material.

For both types of shower, the drain should have rodding access. A waste pump will often be needed to remove waste water, as it is not always possible to get full drainage for these types of shower.

Seating in the shower

a) Shower seats: if a shower is selected, it is important to consider the advantages of seating. There is a wide range of shower-chair products available on the market, including modular systems which can be altered as a person's needs change. Any selected product needs to offer sufficient support for the user to feel stable and safe. An assessment needs to take into account whether or not it will also be used as a toileting chair.

Consider:

- seat depth and width – can extra cushioning be inserted for additional postural support?
- does the user need to have head support? If the chair has a tilt-in space or recline function this needs to be included in the prescription
- foot plate design – single foot plates, a full width pad, angle, and so on?
- does the aperture offer sufficient space and appropriate positioning for intimate hygiene
- what type of pelvic strap or harness is suitable
- is the chair comfortable
- are the dimensions of the seat suitable for moving to the shower
- is there space for a carer alongside the seat in the shower.

b) Static height wall-mounted seat or a mobile shower-chair: this decision will be determined by the person's ability to walk or stand up from a chair, and whether the person has sufficient arm strength to propel a shower-chair. The difficulty with 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, consider how the user stands up from the chair. These difficulties are shared by many adults, resulting in the need for height-adjustability of the seat.

c) Electric, height-adjustable, wall-mounted shower-seat: one that rises with supportive back rest and arms may be considered.

Please refer to Chapter 12: Sit to stand for further information

Wall-mounted rails

Rails can be wall-mounted or floor-mounted. Wall-mounted rails are recommended, as they do not obstruct the wheelchair circulation areas.

Many people with muscle-wasting conditions have insufficient arm strength either to pull up or push down with their arms, to help themselves to stand up. In these cases, rails will have limited value and are more often considered to be in the way.

In a shower area, however, they may be useful if positioned for an elbow to rest on when hair washing. They also provide support, particularly around a bathroom, for someone unsteady on their feet.

Textured plastic rails are considered to be the safest option in a bathroom. The OT can advise on the optimal positioning of these rails.

If a shower is not a suitable solution, a bath should be considered.

Bath with an over-bath shower

Frequently, people with muscle-wasting conditions prefer bathing. It means they can relax their muscles in the warm water, while keeping warm and enjoying the buoyancy.

When an assessment is carried out, clarify what is important for people with muscle-wasting conditions and also familiarise yourself with alternative solutions.

It is important to consider the following:

- 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 carer
- positioning of the person in the water, for comfort and safety.

Consider these issues in relation to the other factors that influence the choice between a bath and a shower:

- 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.

It's important to consider how to get in/out of the bath, preferably independently. There are a few options, some of which require alternative equipment to provide support, which may influence the process.

Portable equipment: if the bather does not need support in the bath, assess their ability to get in and out of a standard bath independently. If they need support, then they should be assessed for simple portable bathing equipment, such as bath seats that can be raised and lowered between the bottom of the bath and the bath rim.

Installed equipment: if help is needed to get in and out of the bath, the use of specialist equipment can restore or maintain independence. It is always important to try to provide equipment that the disabled person can use independently, if possible, that will also be suitable for use with a carer in the longer term.

This might consist of a bath with an integral seat, which raises and swings away from the bath. It can also attach to a wheeled base to enable the disabled person to be wheeled back into the bedroom. Features to consider are:

- safe working load
- support in the seat, such as a foot plate or armrests.

It may also be possible to consider different styles of bath, such as those with opening sides and support. Alternatively, consideration could be given to a contoured reclining-style bath, which provides the option to step into the bath but can be reclined to a comfortable tilt.

Multi-functional hoist: these provide a lifting system, which offers a range of lifting options in a single unit. They change quickly from a seat lift, to a leg-supporting seat lift, to a full stretcher. These systems can be used to move a person from the bedroom directly into the bath.

Equipment to help the carer: always risk assess the carer's needs and look for safe moving and handling options, such as high-low products, bath lifts or suitable hoisting.

Please refer to Chapter 11: Safer moving and handling for further information and advice

When considering support in the bath, think about what is needed now as well as in the future, as safety is the first priority. People with muscle-wasting conditions often feel like they are going to float forward when they are unable to support themselves. This can be very distressing.

The sitting position of an adult can be crucial. Some people need to sit upright to gain full function in their arms; others may find it easier to be washed when reclining. This makes the choice of bath and support important.

It is not satisfactory to leave a ceiling hoist sling in position, as this will make washing difficult.

The assessment must capture the elements of a comfortable lying or sitting position, so the correct support can be emulated in the bath. This may mean looking at relatively simple cushioning to support the user, or the provision of a more complex modular system with the option of added support.

For children, bathtime is a useful playtime. So, the OT should assess suitable options to support the child so that they can both play and be safe.

Vacuum support cushions: these systems consist of waterproof-covered, shaped cushions filled with beads. When the air is extracted from them, they become rigid enough to provide support. They come in a number of shapes, and can be used in conjunction with a firm wedge to rest in the bath.

Seats for children: basic seats may provide limited support in a seated position for children who have some postural control. They have a pommel and pelvic strap but require the parent or carer to lift the child in and out of the bath.

There are other products that can be raised or lowered into the water and offer postural support, with the added advantage of height adjustment. With these products, the parent or carer does not have to lean all the way into the bath to lift the child. These products often offer lateral support with straps to support the child. Any electrically-operated devices are plugged in outside the bathroom and are safe to use in a wet room environment.

Some seats for children sit securely on the base of the bath and provide full postural support with the support of pelvic straps, lateral thigh and trunk supports, head rests and even vest-style harnesses. These enable the child to sit and play or to be reclined, though need the parent or carer to lift the child in and out of the bath.

The OT will best advise families on the type of bath most appropriate to their needs. They will assess the person's needs, the structure of the bath and the carer's needs.

Additional features

Spa facility

Many people enjoy spa features, although they have no proven medical benefit for anyone with a muscle-wasting condition. Caution is advised in using these facilities, such as on a low setting and only for short periods, until the effect on the person is assessed. These facilities are not provided as a statutory provision, but may be an extra that some people would like to pay for.

There are additional extras, such as lights, music or an air spa facility, which the person may consider as an addition to statutory funded provision.

The need for a changing table

In small properties that cannot be extended, or space is confined, it may be possible to provide a changing table within the bathroom. This can be helpful for undressing, drying and dressing the person.

Many baths can be fitted with an over-bath stretcher, which means that the disabled person can complete all parts of the bathing, drying and dressing task in one room. This clearly has advantages for the dignity of the person.

Body dryers

This is an option for many people who would prefer the privacy of drying themselves, or don't feel completely dry after being towel-dried. An additional advantage of the dryer is that it doubles up as a booster heater for the bathroom.

If a standard bath with equipment to increase safety and independence is not an option, a specialist bath should be considered.

Specialist baths

Standard baths with bath support seats or cushions are not always suitable or safe for the needs of some disabled people. This is often the case when a person is hoisted for the bath transfers, as there are several 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 carer
- the sling is made of fabric, so there will be a gush of water and a dripping wet sling after using the bath.

In justifying the expense of a specialist bath, it is important to consider:

- safety of the disabled person in the bath
- maintenance of as much independence and dignity as possible
- safety of the carer helping with self-care tasks
- the sitting posture of the disabled person: will they be able to maintain a safe sitting position or will they need further support?
- the other members of the household and their bathing or self-care requirements
- transfers in and out of the bath
- the environment to ensure adequate space for hoist and care tasks to be performed
- the abilities of the carer to assist: whether they have any physical impairments or restrictions of their own, which may affect their ability in both their own self-care and in domestic activity, such as cleaning the bath
- the weight of the specialist bath plus other possible pieces of equipment, the person and the structural suitability and strength of the property (particularly if the bath will be situated above ground floor level)
- appropriate waste water/drainage pipe work
- if a bath will continue to be suitable as the person's condition changes
- if there are any other medical considerations or needs, such as epilepsy or skin conditions that require emollient creams in the bath?

B. The toilet

In making decisions in relation to the most suitable toilet, the choice will be influenced by the age and size of the user, their ability to balance and their ability to clean themselves. It must also be chosen in relation to the type of support that they will use over the toilet. There are two solutions:

1. 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.

Consideration should also be given to the type of support that a person needs in order to be stable, comfortable and suitably positioned to open their bowels. This may mean the provision, initially, of a relatively simple toilet surround with arms. Alternatives may include a wheeled toilet/shower-chair, which has the additional benefit of foot support. It is deemed helpful for everyone to sit with their hips at a little more than 90 degrees to achieve a position which helps excretion.

2. wash and dry toilets

An electrically-operated wash and dry toilet should be considered for anyone who is unable to manage effective intimate hygiene owing to muscle weakness or reduced range of movement. This equipment facilitates effective cleansing after using the toilet and can be useful for girls and women during menstruation.

Assess the use of this equipment before supply. You can ask the firm to bring a unit to the house to demonstrate its use. However, the most satisfactory way of ensuring that the equipment will be suitable is to ask the firm where there is a unit plumbed in and ready to use.

In addition, there are now portable wash and dry systems available. These can be fitted to an existing toilet at a lower cost, and can even be taken with the person when they go on holiday, and so on. These may be not as robust as a more permanent solution. While they may meet some people's needs, they are not suitable for all as they should not be transferred on to side-ways. They also have their limitations in regards to being used with other equipment.

In choosing a specialist toilet like these, there is a choice of multiple operational switches according to the individual's specific needs. For example, you can choose:

- a plate that can be used with a whole hand
- a remote flush
- soft hand or foot control.

They can also be fitted with lateral supports, arms and other accessories to meet the individual's needs. It is strongly recommended that a site survey takes place. This should be with the suppliers of both the wash/dry toilet and the support, such as a toilet surround or a shower-chair used over the toilet. Check compatibility in terms of height, effectiveness of douche arm and access over the toilet in the right place. It is often sensible to carry out a visit to the property with representatives from both companies so that any compatibility problems can be solved.

Using a ceiling hoist can ensure flexibility in the user's seating position. In this case, 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.

Privacy on the toilet is very important and, as this need is widely understood, there is not usually a problem in justifying the cost.

Wash and dry toilets can be used in conjunction with a ceiling hoist. It enables 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 and is floor fixed for stability.

C. Washbasins

One of the greatest problems for anyone with a muscle-wasting condition is muscle weakness in their arms, although they usually retain reasonable hand function. As a result, they are unable to lift their arms and have to rely on either creeping their hands or sliding their forearms across a surface, often helped by a forwards and backwards movement of the trunk.

Often the type of washbasin provided impedes access for a wheelchair and the taps and plughole are inaccessible. A number of features are needed to make a washbasin suitable for a person with a muscle-wasting condition.

Washbasins must be suitable for someone with severe weakness in their arms, who is not able to lean forward and then regain their position in the wheelchair. The basin should have a shallow front and as much clearance under the unit as possible for the disabled person to get their knees underneath. Flexible supply and waste pipes allow for the unit to be raised in the future if necessary.

For some people it may be possible to look at supplying a height-adjustable washbasin with a hand control to operate the taps and the waste. These designs offer a wide plinth for the person to lean on with their arms to enable them to carry out personal care tasks.

These washbasins are costly and consideration needs to be given to ongoing servicing and maintenance costs.

Taps should be single mixer taps, although if the person is not able to use these, it may be possible to source infra-red taps that operate with movement. Both designs of tap require the person to have sufficient movement at the shoulder to operate the tap. It is also wise to consider temperature regulation, particularly for disabled people who have sensory loss as part of their condition.

For all sink units, it is important that there is a charging socket for electric toothbrushes and shavers directly next to the basin.

Points to consider:

- there may be variance in the working height a disabled person can use e.g. he may stand to wash though when fatigued use a wheelchair. Additionally, a disabled person is likely to access a range of wheelchairs over a period of time and subtle height differences or seating systems can affect access to the basin.
- the wheelchair armrests will need to be raised after a more erect posture is achieved following spinal surgery; this prevents access to the basin and also may affect upper limb range of movement.
- 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.

A washbasin should, where possible, be:

- of the correct profile, with the bottle trap against the wall – both of which will allow knee access for a wheelchair user
- large enough front-to-back to allow the person to get close up to the front edge without the wheelchair footrests hitting the wall below the basin and preventing close access
- without a fascia at the front, which would obstruct the wheelchair armrests and/or the joystick control of a powered wheelchair
- a surface less than 15mm thick, which enables the person to creep with their fingers to raise their hands and forearms to the front or side of the basin
- installed with an area at its side that is large enough to provide forearms support, the storage of toiletries and a towel within reach
- fitted with a surround that is shiny and smooth to help users top-slide their arms to reach forward
- set without a raised edge, so that sliding arms into the water is not impeded
- shaped so that the person does not need to lean forward to get to the water, which may then make it difficult to sit back upright against the wheelchair backrest
- fitted with tap controls which require no hand strength or pressure to operate, and do not need to be reached for (automatic taps may be an option)
- low enough to enable the person to reach into the water, but at the same time set into a surface which can be raised high enough to allow a person's hands to be at the same level as their mouth for teeth cleaning, or their head for combing hair; a surface that behaves as a mobile arm support
- fitted with flexible waste and water pipes to allow electric height-adjustment
- fitted with a mirror with a light that raises with the basin (optional).

Please note that if a height-adjustable unit is to be placed next to a wall, there needs to be a gap of at least 25mm between the unit and the wall.

D. The method of transfer between the bedroom and bathroom

It is essential to consider how to move between the bedroom and bathroom to maintain the person's dignity, and keep them safe and warm. The carer also needs to be able to assist comfortably.

The choice is between:

- using a wheelchair – this is not a satisfactory option, unless the toilet is needed and there is not enough time to hoist the person on to the pan, or when using the washbasin
- shower-chair/wheeled bathing equipment
- hoist – this would require two separate tracks in the bedroom and bathroom, so it is not a recommended option. Also, raising and lowering the disabled person is time-consuming and requires access to a changing bed.

Please refer to Chapter 8: The bedroom and Chapter 11: Safer moving and handling, for further information and advice

E. Shared facilities

The aim should be to have en suite bathroom facilities. Whether or not 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 adapted, the facilities are usually for the exclusive use of the disabled person.

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. In this way, the bathroom can still be used by the rest of the household. Family preferences should be taken into account but work also needs to fit within the parameters of cost.

Conclusion

The choice of bathing facilities should not be controlled by financial restraints. It should be considered following a full assessment of need for both the disabled person and the carer. Safety and dignity are paramount considerations and cannot be underestimated.

Chapter 8
The bedroom

It is important that the bedroom and bathroom are en suite and that the disabled person's privacy, dignity and comfort are of highest priority. The bedroom should be as large as the build allows to ensure there is space for an electric profiling bed, a powered wheelchair, medical equipment, storage and sufficient space for carers to carry out tasks. Consider, also, whether or not the disabled person usually shares a room with a partner and how the needs of both can be accommodated in the adaptation.

Electric profiling bed

Please refer to Chapter 13: Electric profiling beds

Position of the bed

If the bed has the headboard against the centre of a wall, this allows space on either side for care tasks to take place. It may of course be possible to move the bed away from the wall for this but it is better to avoid extra handling tasks where possible.

There also needs to be sufficient space around the bed for wheelchair circulation and hoisting. Please refer to Chapter 15: Scales, planning and building regulations.

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 11: Safer moving and handling.

Work/equipment surface

Work surfaces in the bedroom are not always a huge priority. Nowadays, many young people do their homework on laptops, which are easily transportable. Suitable solutions include robust height-adjustable camping tables and desks. Families might need advice on the product most appropriate to their needs. Please refer to Chapter 15: Scales, planning and building regulations for further information and advice.

Storage

Wardrobe and drawer space is an important consideration to remember when planning adaptations. It can sometimes be overlooked when planning adaptations for children and young people.

Communication

Carers usually feel more reassured if there is a way to hear or listen for their child/relative or to communicate with them when they are in different rooms. Often a simple intercom, two-way radio, a simple, stand-alone pager or a mobile phone serves this purpose initially. They are also wireless and have few ongoing costs. However, seek advice from the local Environmental Assistive Technology (EAT) Service or the relevant local provider as Telecare options may be considered. Please refer to Chapter 10: Environmental controls for further information.

Flooring

Often families opt for wooden or laminate flooring for ease of cleaning and passage of the wheelchair. Please refer to Chapter 4: Access into and around the property and flooring, for further information.

Lighting

Many people select more subtle lighting in the bedroom. Although flush light fittings are required to enable the hoist to pass with ease, it is possible to select softer glow bulbs. It may also be possible to install remote control sockets to activate bedside lamps. Please refer to Chapter 10: Environmental controls for further information.

Electrical sockets

When an adaptation is being planned, it is always best to try to optimise the number of electrical sockets available. There are often many pieces of equipment as well as home entertainment hardware that need to be plugged in. These may include the bed, a turning/air mattress, ventilatory support, cough assist machine, suction, computer, games console, and lights. Please refer to Chapter 15: Scales, building and planning regulations for further information.

Chapter 9
The kitchen

Equipment in the kitchen

Before adapting a kitchen, it is important to establish through the Assessment of Need, what activities the disabled person will need to undertake in the kitchen. This should look at how they:

- manage snacks and drinks
- prepare meals
- manage tasks, such as washing up
- manage laundry, including using the washing machine, tumble drier and ironing.

The type of occupation will determine the extent that the kitchen facilities need to be altered.

You may find it useful to read this chapter in conjunction with Chapter 15: Scales, building and planning regulations.

Considerations for people who use wheelchairs

Knee recesses for worktops: if the person is a wheelchair user and they have sufficient upper body and upper limb strength, they may want to carry out kitchen tasks. They may choose to stand to undertake some activities. If they don't, provision will need to be made for knee recesses. These should be the depth of the work surface and at least 800mm wide. They should be provided below or adjacent to key task areas, including the hob, sink and food preparation areas. A recess should also be available next to appliances such as the fridge/freezer, oven and washing machine.

Worktop heights: should be adjustable or positioned at a suitable height for the user. However, consideration needs to be given to the needs of the other people in the house who may also need to use the kitchen. Where possible, work surfaces should be continuous and enable the user to push items between areas in the kitchen without interruption. The surface therefore needs to be smooth to allow for pushing but also to enable equipment with suction pads to be held down effectively. It may be possible to provide a pull-out, heat-resistant workboard below worktop height, in cases where the cupboards restrict the disabled person's access to the worktop.

Storage: should be accessible, though this is likely to be limited. A reasonable adjustment might be to store the most commonly needed equipment and ingredients in areas that are most accessible to the person, and keep other items in higher or lower cupboards. Cupboard and drawer handles are often best being D-shaped. It may be possible to install pull-down baskets within cupboards. These are useful if a person has enough strength to use them. It may also be possible to use electrically-operated cupboards, which will lower as an alternative, though these are a more expensive option.

Pull-out carousels in corner cupboards make good use of space and are easy to pull out if the person is in a wheelchair. Pull-out drawer dishwashers are also available and easy to use from a wheelchair.

The kitchen sink: should be inset with a shallow bowl (140-150mm deep). It needs to enable the user to reach into the bowl to wash up. The tap should be a lever design and the bottom of the bowl heat-proof, as this is likely to sit against the disabled person's knees.

The cooker

Induction hobs with controls at the front are usually recommended. The hob should:

- be located near to the oven with a preparation area between the two
- have a work surface on at least one side
- be insulated on the underside
- have a means of indicating if the rings are hot
- have controls at the front of the appliance
- be self-igniting where gas rings are used
- have knee space underneath
- have clear knee space between the hob and the sink
- have an extractor fan with accessible controls.

Ovens should be right-side or left-side opening, rather than with drop-down doors. They should also have telescopic rails so the metal shelf can be pulled out and slid back in again, but they remain sturdy. The oven should:

- be set in a housing unit that allows for height adjustment
- have a pull-out worktop to one side of the oven
- have a reversible side-hung door opening to 180º so that the door swing should not impede access for a wheelchair user
- have slide-out non-tip shelves
- have easy-to-use controls.

Pull-out ironing boards: can be an option. They can however be difficult to pull out and also have a dip in the middle (where they fold) so clothes don't get ironed properly.

Fridge freezer: should have a gap of 610mm to enable the door to be opened fully and shelves to be removed. If the fridge and freezer are separate units, they should be on 200mm plinths.

Washing machines/tumble driers/ dishwashers: these should be on a 200mm plinth for wheelchair users.

Smaller utensils

Many people need advice about grasp, release and practical aspects of domestic life, such as:

- cutting, or opening tins or jars
- lifting heavier pans and trays
- using utensils.

The OT should be able to give advice about this, though in many areas, equipment will need to be purchased by the user.

References

- Portsmouth City Council (2006) *Design Guide for Wheelchair Accessible Housing* www.portsmouth.gov.uk/ext/documents-external/pln-dev-affording-housing-wheelchair-access-plan.pdf
- BSI Standards Publication. *Design of Accessible and Adaptable General Needs Housing – Code of Practice* www.leeds.gov.uk/docs/CD6-10%20BS9266%202013%20Design%20of%20Accessible%20Housing.pdf
- HM Government. *The Building Regulations 2010 - Access to and Use of Buildings. Approved Document M.* www.gov.uk/government/uploads/system/uploads/attachment_data/file/506503/BR_PDF_AD_M1_2015_with_2016_amendments_V3.pdf

Chapter 10
Environmental controls

When a disabled person has significant arm and hand weakness, they may find it difficult to control appliances and devices in the home. An environmental control system aims to provide some independence in carrying out everyday tasks. It can allow the person to take charge of their surroundings at home.

Environmental controls may also be used in school, college or the workplace. Functions can include control of:

- lights
- heating
- electric profiling beds
- computers
- door openers
- telephones
- television
- radio.

Often a range of gadgets or appliances can be controlled by only the smallest movement. It can also get you help or assistance.

There is much assistive technology available. It can help people with muscle-wasting conditions to live more comfortably and independently, and enhance their quality of life. As most muscle-wasting conditions are progressive, it is likely that as needs change, so will the type of technology. The local healthcare team can help determine the best equipment to meet the person's needs.

As technology is constantly changing and developing, the EAT Service provider is best-placed to advise on what is currently on the market and best meets the needs. This chapter will discuss some important points to consider when thinking about environmental control systems and the process of obtaining them.

Considerations

What is the person's main difficulty and is there a solution that is available at relatively low cost on the commercial market?

If there is no easy solution, is there advice from the EAT provider?

If a more specialised option is required, what are the eligibility criteria for referral to the EAT provider?

These may vary between services, so seek advice from the local team and the OT will be able to signpost the person to the correct service.

Who can refer someone for an environmental control system?

This can vary from area to area but it is usually health and social care professionals who can refer. Self-referrals may be accepted if endorsed by a health or social care professional. If the need has to be justified, it is usually helpful to discuss the supply with the neuromuscular care advisor or OT.

A referral is made to the co-ordinator in the relevant area who is responsible for the local administrative arrangements for supply and installation of environmental controls. Social Care can usually give you the address of the co-ordinator, but this can vary by area.

What does the assessment involve?

Although it can vary in different areas, assessment is usually completed by a Clinical Specialist appointed to do this work in your area. He/she will come and do the assessment in the environment where the equipment is to be used.

The assessment aims to:

- determine eligibility
- identify functional abilities, which may include assessment of upper and lower limb function, cognition, vision, hearing, communication, environment
- assess normal daily routine.

The Clinical Specialist will match this to the range of equipment available.

Referral may be made to other specialist services if, at assessment, it is found that the equipment is primarily for school or work use.

Process

- Referral is triaged by Regional Environmental Control Service to determine eligibility and priority.
- Initial assessment is completed by the Clinical Specialist.
- Case conference – joint home-visit organised by the Co-ordinator. A representative of the suppliers of environmental controls will complete an assessment and discuss with the user, the carer and any other Health or Social Care staff involved, the specific items that may be supplied. The equipment will be demonstrated, technical questions answered and installation arrangements discussed.
- The installation of electrical sockets, joinery work or minor adaptation work may be required. The local OT or social worker can advise on how to access these minor works.
- Such minor works mentioned above will be the responsibility of Social Care under the Chronically Sick and Disabled Person's Act. Ensure that an OT or social worker from the Department is present at the case conference in order for them to make the necessary arrangements. They can co-ordinate the installation, demonstration of and training for the environmental controls to ensure the person is confident in their use.

Who owns the equipment

Conditions of loan exist to identify both the client and the service provider's responsibilities around appropriate use of equipment, and repairs and maintenance.

Who should be contacted if the equipment needs repair?

The supplier of the equipment and the Co-ordinator will leave their contact details for repair, maintenance, queries and faults.

Can additional equipment and functions be added at a later date?

Contact the Co-ordinator from the Regional EAT service, as additional equipment would require a re-assessment to identify needs.

Additional functions, such as control of a light or television, can normally be added upon request to the suppliers.

Service and repair of privately-funded environmental control equipment is the responsibility of the individual.

Removal of equipment

If the equipment is no longer required, the Regional Environmental Control Service will arrange for it to be withdrawn.

Muscular Dystrophy UK can give people with muscle-wasting conditions advice and assistance with assistive technology.

- *Switched On* – the Trailblazers' report into assistive technology (2015) www.musculardystrophyuk.org/news/news/trailblazers-to-launch-assistive-technology-report-in-westminster/
  This report highlights the vital role technology plays in helping disabled people to live independently, work, socialise and study.
- *Touch, Tap, Swipe* dmdpathfinders.org.uk/about/advice-guides/
  This guide was created by DMD Pathfinders' members to share their

experience, and provide information, videos and top tips to anyone with very limited mobility who wants to start using a phone or tablet.

References

- NHS England UK (2013) *Environmental Control Equipment for Patients with Complex Disability*. Available at: www.england.nhs.uk/wp-content/uploads/2013/06/d01-com-dis-equ-env-con.pdf (Accessed: 16 March 2016).
- Disabilities, Opportunities, Internetworking, and Technology (2015) *What are environmental control units?* Available at: www.washington.edu/doit/what-are-environmental-control-units (Accessed: 16 March 2016).

Chapter 11
Safer moving and handling

Moving and handling

This term is used to describe a range of activities where a disabled person is assisted to move with the help of another person and/or equipment.

For many people with muscle-wasting conditions, it is important to assess their need and then tell them about the suitable options available. This will need to be repeated as their condition changes.

Musculoskeletal health

Consider the implications for both the disabled person and their carer, when planning solutions to moving and handling problems.

Moving and handling includes activities such as:

- pushing
- pulling
- holding a static position to support a person
- carrying objects
- helping another person to move from one place to another using simple equipment or a hoist.

Any assessment must consider the health and fitness of the carer, and suitable advice given to minimise handling. When the possibility of injury is minimised, ongoing care at home becomes more sustainable.

Legislation

As moving and handling tasks can be risky, it is important that the assessment considers the needs of the person being assisted as well as the carers. These are both covered by legislation, listed below. These are useful documents to refer to in conjunction with this chapter.

- Manual Handling Operations Regulations 1992 (amended 2004).
- Lifting Operations and Lifting Equipment Regulations 1998 (amended 2015)
- The Provision and Use of Work Equipment Regulations 1998
- The Management of Health & Safety at Work Regulations 1999
- The Workplace (Health, Safety & Welfare) Regulations 1992
- The Human Rights Act 1998
- The Mental Capacity Act 2005.

Getting the right advice

If day-to-day activities are becoming difficult, the disabled person can refer themselves to their relevant local community team for advice.

Information from the referral is analysed and a suitable service is then asked to provide an assessment, possibly in liaison with NHS healthcare professionals. Since April 2015, local authorities have a duty to provide eligible people with support in their care needs.

This is explained in more detail in these factsheets:
www.nhs.uk/Conditions/social-care-and-support-guide/Pages/assessment-care-needs.aspx

Accessing needs and determining eligibility (gov.uk).

Examples of the types of activity that may become trickier include:

- standing from sitting
- transfers between different surfaces
- getting in and out of the bath
- sitting up or rolling in bed

- getting in and out of the car at home
- getting up from the floor after a fall.

The information on the Health and Safety at Work website regarding general principles of moving and handling is very helpful: www.hse.gov.uk/pubns/INDG143.pdf

Assessment

An assessor will meet with the disabled person and their carer to identify the key problems and develop strategies. The aim must always be to prevent injury to the disabled person or the carer, while maintaining dignity and independence where possible.

A range of solutions may need to be tried before a Moving and Handling Plan is formulated. The plan must also consider that the person's needs may change in the future. The person also needs to be advised how to seek advice in the future.

In general, all assessments should consider who, what, where and when an activity is to take place. The Health and Safety Executive Manual Handling Operations (1992) as amended, defines that an assessment should include task, load, working environments and equipment.

Often the acronym TILEO is used:

- task
- individual
- load
- environment/equipment
- other factors.

The assessment should identify hazards that may appear on a day-to-day basis owing to the changing nature of the disabled person's condition. Factors such as fatigue, discomfort, the need to use a ventilator, and so on, need to be taken into account. Any assessment must also consider the needs of the carer.

The HSE Manual Handling Operations Regulations (1992) include a template to use with a list of TILEO questions to ask. A copy of the regulations can be downloaded for free at: www.hse.gov.uk/pubns/books/l23.htm

Moving and Handling plan

Some people need minimal assistance to help them with transfers initially, but as their condition changes they may need more help and equipment. Sometimes the plan is simply related to techniques, but more often it will recommend simple changes and equipment, such as a transfer board or raising a chair. As new problems appear, ensure the disabled person and carer know who to contact for a reassessment.

As part of the plan, the disabled person may be offered equipment on loan from the local Equipment Loan Service. This might include transfer boards, slide sheets, hoists, and stand aids. The assessment will also investigate if existing furniture could be adapted or changed to assist independence. For example, a profiling bed could be used to assist independent transfers, or rails in the bathroom might help with toilet transfers.

Any equipment provided should be demonstrated to the disabled person and their carer. Both should be given sufficient opportunity to practise until the assessor is satisfied of competence.

The plan must state:

- specific equipment to be used
- techniques to be used
- number of people to carry out the task
- if a hoist is recommended, sling attachment loops to use, and leg configurations
- other relevant details.

The Moving and Handling plan must be shared with all those involved with care, so that everyone knows the agreed way to handle a disabled person. Carers must be trained in specific techniques so they:

- have the appropriate skills and levels of competence
- understand the risks
- know what measures are in place to reduce risk.

Hoisting

If a hoist is suggested as a solution, choices need to be made about the type of hoist to use.

Hoists are used to transfer people who are unable to move themselves between two surfaces, such as a wheelchair and a bed. They are not a mode of transport so, unless there is a fixed hoist between a bedroom and bathroom, they should not be used to transport a person around the home.

There are predominantly two types of hoist:

active – or standing –

hoists are almost always mobile, and are used as care or therapy devices. Care devices are less sophisticated and provide a simple, active stand with a sling. It has minimal fabric and therefore less support and control.

The user needs to be able to participate throughout the transfer, by following commands, maintaining posture and grip. They may not be a suitable solution for all people with muscle-wasting conditions, but can be useful when a person's function is reducing but they do not yet require a passive hoist.

The therapist involved can advise should the hoist be used as a therapy device.

passive

hoists can be subdivided into:

- **mobile** – which can be moved between the locations it will be used in
- **fixed** – to the ceiling or the wall
- **tracking** – this can be a gantry or fixed to the ceiling/walls.

Planning ahead for a hoist installation

If the hoist is not needed at the time when the adaptations are carried out, ensure that the ceiling joists are suitable. Also, by installing the electrical supply required, the decorations won't have to be spoilt in the future.

It may be useful to read this section in conjunction with Chapter 7: The bathroom, Chapter 8: The bedroom, and Chapter 15: Scales, building and planning regulations.

Mobile hoists

Key advantages	Key disadvantages
Mobile between locations to enable hoisting in different living spaces.	Generally considered best practice for two people to assist when a mobile hoist is used.
The hoist may be transported for use away from home. May be transported in a car or van, making it ideal for lifting in other locations and suitable for holiday use.	Pushing and pulling a moving mobile hoist is not always easy. The carer has to push/pull the weight of the disabled person as well as the hoist.
Suitable for floor-level rescues in the house or garden.	The flooring can affect how easy it is to manoeuvre a hoist. Carpets increase effort and also make it more difficult for the carer.
	Space – there needs to be enough room to move the hoist, transfer the person and keep the carer safe.
	It must be checked that the hoist legs will fit around the furniture and go underneath the bed.

NB: A mobile hoist is not a transportation device between locations.

If choosing a hoist to be transported in the car, you must ensure that the model chosen either breaks down into component parts or folds and can be wheeled into a suitable vehicle. If it is to be transported in a vehicle, however, it must be securely fixed in to the car.

If choosing a hoist to lift someone off the floor, you must ensure that the boom is able to go low enough for this purpose or extension loops have to be attached to the sling.

Questions

- Does the hoist have the required lift range?
- Will there be enough head room clearance to lift to the required height?
- Does the boom have sufficient range to lift from the floor and on to a bed?
- Where will the hoist be stored when not in use?
- Is there a power charging point?
- Will it cause an escape obstruction?
- Are the sling and sling bar adequately shaped and configured for the client's needs?
- Do the hoist, sling and any accessories have a service and a maintenance contract every six months under the provisions of PUWER (Provision and Use of Work Equipment Regulations) and LOLER (Lifting Operations and Lifting Equipment Regulations)?
- Is the sling bar too close to the patient's head?

Ceiling tracking and gantry hoist

These hoists are most commonly installed in the rooms that the disabled person uses most often, such as the bedroom, bathroom and sometimes the living room. They offer a more discreet and space-economic solution for the home and can often be used by one carer (though two is considered best practice).

They are frequently installed into adaptations where the bathroom wall is incomplete, leaving a gap at the top of the wall. This enables the cassette pod to move freely to cover all parts the bathroom and bedroom.

Most often the configuration is a straight or curved single track between two locations, or an H or XY frame providing greater ease of coverage of an entire room. H configurations consist of two primary rails installed on two opposite sides in the room, with a traverse rail at right-angles between the primary rails. The cost difference between the two systems being minimal, the H system offers the greater flexibility of the two.

Gantry hoists are mobile installations which are either a single or dual rail system with one or two cassette pods. They may provide a quick alternative/intermediate solution while a tracking hoist is installed or structural adaptations are taking place. They are obtrusive, take up considerable space, may decrease potential lift height, and the large chassis can be an obstruction and potential trip hazard.

Key advantages	Key disadvantages
Allows disabled person to be lifted from any area of the room – H frame is more versatile.	Cost of equipment and installation.
Space between disabled person's head and spreader bar.	
Spreader rises vertically resulting in less drag and shearing forces that could potentially damage the skin.	
Allows access to more than one room on more sophisticated systems, with points or turntables.	
Not dependent or restricted by width or height of furniture.	
Generally no issues on inadequate lifting range – limited only by ceiling height minus depth of track and cassette pod. This can be overcome with webbing bands rather than a spreader bar if necessary.	
A wide range of accessories and sling bars offers bariatric and asymmetrical people more comfortable positioning. Sling loops attached to the well-spaced spreader bar hook points decrease abdominal pressure.	
Provides a smoother transfer experience for the individual.	

Positioning of the ceiling track (single track)

Points to consider

- The spur point should, where possible, not be located above the bed, as the person may find the charging hoist obtrusive and disruptive. The charging point can be positioned above the bed where otherwise it may cause an obstruction to carers or other family members. The hoist can be left off charge at night if required and charged through the day.
- Single track – consider the future needs of the disabled person so that the hoist does not have to be relocated later on as needs change.
- The track should be positioned at right-angles to the length of the bed, parallel to the wall behind the bed headboard. The centre of this track to the wall is 900mm from the front of the headboard. This means that the disabled person is lowered on to the correct position in the bed and should not need to be later re-positioned. This may need to be adjusted according to the person, the environment and the room.
- The bed may need to be pulled away from the wall for some care tasks. The siting of the hoist may mean that hoisting tasks are less easy to undertake.
- The track will take the disabled person in to the bathroom, where it is possible to have a turntable installed that will enable access to the toilet and the bath. (The cost of adapting a door between bedroom and bathroom is often more than the cost of two separate hoist systems.)
- 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. This is particularly critical for the optimum washing and drying action of a washdry toilet. It may be useful to consider a shower/toilet chair to transfer from the bedroom and thus give full assessed support.
- 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. This can be maintained if the track passes front to back over the toilet. The only contraindication to this is if the hoist is needed to transfer from a wheelchair positioned at the side of the pan.
- The model of the chosen bath, along with the preferred bathing position of the person, need to be considered when installing a track above a bath.
- Use of a 'Swing Kit'/track-to-track/door-transfer system may be considered. When there is a supporting lintel above the door, 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. This also avoids the expense and structural difficulty of removing a supporting beam to install a track between the two 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 the two hoists.
- The issue with these systems is that it is difficult to get past the person in the sling while trying to transfer through the doorway. It is often necessary to have a second carer to complete this type of manoeuvre.
- Cassette-to-cassette transfer devices (Swing Kits) decrease the need for structural interference in the home. They also allow a transfer from one rail to another without lowering and re-lifting the person.

Slings

A number of issues need to be considered:

- compatibility of slings and hoists
- safety checking
- assessment
- type of sling
- sling material
- training.

Compatibility of slings and hoists – it is essential to ensure that a hoist is compatible with the provided slings. Guidance on this is available from: www.gov.uk/drug-device-alerts/medical-device-alert-patient-hoists-and-slings-ensure-you-follow-manufacturer-s-instructions-for-use-and-that-you-carry-out-risk-assessments

Stringent and robust risk assessments of the compatibility of slings and hoists is a requirement to decrease risk. Angle of position when suspended, shape and sizing of slings is not regulated and one medium high back universal sling may perform very differently from another manufacturer's product with the same description.

Safety checking – lifting equipment is subject to stringent safety checking including a thorough examination and LOLER check every six months by a competent person as detailed in the *Lifting Operations and Lifting Equipment Regulations 1998 (LOLER)* www.hse.gov.uk/work-equipment-machinery/loler.htm.

The responsibility for formal checking will be with the provider, which is usually the Equipment Loan Service. However, the carer must also know how to make a visual check of the sling and hoist and know who to report any problems to.

Assessment

There are risks associated with hoisting so a thorough assessment of the disabled person's needs must take place before issuing the equipment.

Initially the assessment needs to state that the hoist is the best piece of equipment to meet the needs of the disabled person. It should specify the type of hoist and the compatible, type and size of sling.

The size of the sling must be assessed as there are dangers associated with using a sling which is too large and one which is too small may be uncomfortable.

An assessment needs to be carried out and the information described in the Moving and Handling Plan. Often this is undertaken by the OT and the hoist and sling provider to ensure compatibility and safety.

Type of sling

Individual and ongoing assessment for slings is essential to maintain safe transfers. It is important to consider the size and the weight of the person as well as their physical abilities and the type of the transfers that they will be hoisted for. Considerations should also include curvature of the spine, contractures, reduced head control, use of equipment such as a ventilator and fragile skin.

Universal slings are often selected as these can have head support, padded leg sections and also have a wide aperture to use over the toilet. There is often a choice of the materials they can be made from, making choice relevant to personal preference as well as the task.

MD slings are universal style slings, which are quilted. They provide additional head and back support, and have removable boning for extra comfort.

Access slings may be useful for some people with muscle-wasting conditions, though they do not provide head support and are not used when there is significant weakness around the shoulder girdle (however, some versions now enable people to be hoisted in these slings). For most people with a muscle-wasting

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. If the sling fastening is loosened the person is not supported in the sling and risk of falling through the back is increased.

Bespoke slings are sometimes required to meet the needs of a disabled person, and the firm supplying the hoist should be approached to advise, assess and supply to ensure.

Sling material

Slings are manufactured in a range of fabrics with different qualities:

Standard material – polyester. These drain just as well and are far less likely to mark the skin of the person being transferred.

Slip fit – an easy sling to apply as this reduces friction and is comfortable to apply especially when the disabled person has little active movement or sits in a moulded seat.

Mesh – this material drains easily when a disabled person has been in the bath.

For people with a muscle-wasting condition, who require additional firm padding, the choice is usually polyester 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 carer) 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 slings to be washed one at a time.

Positioning the sling

Slings are designed so that they are positioned symmetrically behind the 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, (slide sheets may help this insertion) and are then taken under the legs in one of two ways:

1. **under both thighs to form a bucket seat**: this method is likely to be suitable for smaller people only, as most users in this position will feel too restricted in the sling. This may also work for higher bilateral amputees.

2. **under each thigh separately, and then brought up between the legs**: this is the recommended method for most people (except if using clip- rather than loop-type slings which are not designed to be crossed if using a wishbone configuration spreader bar) with a muscle-wasting condition.

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 a bespoke 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.

Training

Anyone who operates a hoist needs to be deemed competent to do so. It is the assessor's responsibility to ensure that all equipment and techniques are demonstrated to the carer and that they can show that they are proficient. They also need to discuss who can advise further if needs change.

References

- www.gov.uk/government/publications/care-act-2014-part-1-factsheets/care-act-factsheets#factsheet-3-assessing-needs-and-determining-eligibility
- www.hse.gov.uk/pubns/INDG143.pdf
- www.hse.gov.uk/pubns/books/l23.htm
- rospaworkplacesafety.com/2013/02/18/manual-handling-definition/
- www.hse.gov.uk/healthservices/moving-handling.htm
- www.hse.gov.uk/pubns/hsis3.pdf

- www.nhs.uk/Conditions/social-care-and-support-guide/Pages/mobility-problems-carers.aspx
- www.hse.gov.uk/work-equipment-machinery/loler.htm
- www.hse.gov.uk/pubns/hsis3.pdf
- *'Checklist to Help with Hoisting HSE @getting to Grips with Hoisting People'* www.hse.gov.uk/pubns/hsis3.pdf
- Fletcher, B., Holmes, D., Tarling C., Tracy M., *The Guide to the Handling of Patients*. National Back Pain Association, 1997.

There may also be regional/local guidelines available in your area. Your OT team will be able to advise you.

Chapter 12
Sit to stand

Many people with muscle-wasting conditions are able to walk, but find it increasingly difficult to stand up from a seated position. They need to seek advice from their OT to help them identify options available to support them to stay independent. This problem may begin as a Safer Moving and Handling problem, when a carer struggles to assist with a transfer to standing. It is important to consider that the needs of both the disabled person and the carer when looking at the range of possible solutions.

The method of standing up

When a person has muscle weakness, they often stand from a seated position in one of a few ways.

1. After moving forwards on the chair or bed, they position their legs in a wide stance with the knee joint locked and the legs straight. They then lean forward on to a stable surface, such as a table, before bringing their feet closer together. They then either climb up the furniture or push up on their thighs to extend their back and achieve standing.

2. Some people sit forwards in their chair, then twist sideways to lean on one arm. From this position they then push their legs out to the rear so that the knee joint is straight. They then lever their body up, using furniture as support.

Choice of equipment and the importance of assessment

The OT or physiotherapist will be able to assess the disabled person's ability to stand up from a seated position and recommend some relatively simple techniques or equipment. However, a time may come when these simple solutions no longer meet the person's needs and alternative pieces of equipment may be sought.

Most people with muscle-wasting conditions find that equipment, which throws them forward with their knees flexed, is inappropriate. It then becomes impossible to straighten the knees to stand up. Assessment and discussion about the problem and the solutions available are essential to ensure the provision assists rather than causes further problems. The OT will also be able to advise regarding funding.

Equipment features that assist standing up from a seated position

- A seat that rises horizontally on which the user can inch forward without being thrown forward. A small tilt at the last stage in the process of standing up can help some disabled people achieve an upright position.
- A seat that rises to a sufficient height to enable the user to lower themselves to their feet with the knees extended.
- Armrests that rise up with the seat. These 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

Many disabled people will try to manage sit to stand transfers for as long as possible as they feel that this activity helps to keep their

muscles active. Early discussions with the therapist involved will help the person and their family to make informed choices based on their ability and the range of available solutions. Often it is useful to talk about pacing and grading activity. The right equipment can help the person to conserve energy for self-chosen and meaningful activities.

Also, there may be a need to alter the method of standing up when initially using the new equipment. It is important to consider the timing of these items as it is easier to adapt to a new technique when less disabled, in other words when standing up is just becoming difficult. This will save the frustration of struggling, particularly if there is a delay in securing funding.

It is likely that several of the items mentioned will be required. If the need is staggered or planned ahead, this may help Social Services to budget the funding. Also, it is more likely equipment will be funded if it will be needed for several years, rather than for a short time only.

Sit to stand equipment

Easy chairs

A chair that has a seat that rises horizontally, as well as an electronically-controlled backrest and footrest can offer a wide scope for postural change. Look for a model where each of the features can be used independently and not one which has a one-button profile (this will often be a model with more than one motor).

Chairs that have an angled seat also help the user to stand. However, this can be frightening for someone with muscle weakness. They can feel they have less control and the armrests also tilt at the same angle as the seat.

If the disabled person needs increased support around their pelvis or trunk, it is advisable to consider a chair made by a specialist company. Often these seats are modular, so they can be adapted and changed as a person's needs alter. Before buying, try the chair, relax in it and check that the height range of the riser meets the needs of the user.

The OT can advise on suitable models. They can also work with the disabled person to organise an assessment and advise on funding. For some people, a more bespoke arm chair may provide a better solution. The OT should work with the disabled person to look at a range of seats and products, and make clinical recommendations about the chair's postural support for the person.

For children with muscle-wasting conditions, there is a wide range of chairs on the market that have a high-low base. Some can be activated by the child, while others need to be controlled by an adult.

A children's OT should advise and arrange assessments with a range of products to help the young person stay independent for as long as possible. Look at the options they may need as they grow, and plan for the changing postural needs of the child.

Consider the type of activity the child will carry out when sat in the chair. Ensure that it not only fits into the setting but also provides suitable support and flexibility to be usable.

A recliner chair may need more space as they often have a 'wallhugger' feature. This means that they move forward as the chair reclines.

Pressure relief

With any type of seating for a disabled user, pressure relief should be considered. If the person is relatively static most of the time, it is important to move frequently to help keep joints mobile, maintain circulation and reduce pressure. For others, this may be more difficult so consider other options, such as a recline or tilt-in-space function, or a memory foam/gel cushion that spreads weight more evenly. The tilt-in-space option is the more useful for weight distribution and reduction of shearing on the skin.

Office chairs

Many people will use their powered wheelchair to enable them to work from home. However, for people who need an office chair at home, there are products that combine powered controls with all the manual adjustments and comfort of an office chair. Features of such a chair may include:

- powered seat lift
- compact base for space
- brakes for stability both when transferring and when sat statically
- a 'walk on, walk off' footplate
- the possibility of additional support through the use of a modular system.

For disabled people who need a high-low seat combined with some postural support, but are able to walk indoors, office-style modular seats can be operated with a simple switch that flips out from the arm of the chair. These chairs have a small base, which means that they fit into a home/office or school environment with minimal risk. They have a handbrake, which can be reached at the rear of the seat, so this would need to be assessed for suitability. These chairs are often raised to a suitable height and pushed by the user between areas. They can also be used to facilitate independence in carrying a bag or books.

Funding for products in the workplace may be available through Access to Work. See www.direct.gov.uk

Toilets

It may be possible to install a wall-mounted toilet that is completely height-adjustable using a hand control. Consider what support around the toilet is needed, and whether a wash-and-dry style toilet would be needed in the future. There are wash-and-dry products with height adjustment that can have supports around them too.

There are other products available, which sit over the top of the toilet. Careful assessment is required as these often rise horizontally initially but then tip on the diagonal. This may be suitable for some people but for others this action makes them feel much less stable as they rise to the standing position. Please refer to Chapter 7: The bathroom for further information.

Showers

Electric height-adjustable shower seats

Many adults with muscle-wasting conditions have difficulty standing safely in a shower for any length of time. However, if they sit down on a shower-seat or chair, they are unable to stand up independently. An electrical height-adjustable seat, which rises sufficiently for the user to stand up and lowers to allow feet to rest firmly on the floor, can enable them to , reach 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. Many models have height-adjustable arms to help the user to stand from sitting. The model should fold up when not being used. Consider carefully whether additional rails are needed when the person achieves a standing position.

Please see Chapter 7: The bathroom for further information.

Baths

Bathing can represent a huge challenge. Many disabled people gain much benefit from bathing, so all solutions to enable them to continue to be independent should be looked at.

Often a simple solution is the provision of a hydraulic bath seat. This enables the user to access the bath using a seat that rises to the rim of the bath. It enables them to transfer in and lower themselves to the bath floor. The seat needs to provide sufficient support for the user to feel safe even when they are relaxed. It also needs to lower as near to the bath floor as possible to enable the user to sit in the water.

Alternatively, a number of firms manufacture baths that have integral seats that swing in and out of the bath. These can be raised and lowered electrically into the bath. The seat should pivot from the corner of the bath, projecting as far as possible from the side of the bath to ease the process of transfer.

They should also have the maximum range of height adjustment. This may be essential for achieving the height needed to stand up, and also to transfer on to another seat. Please see Chapter 7: The bathroom, for further information.

Beds

Electric beds

The most important feature of these beds is that they are height-adjustable. An additional advantage is that at a lower height, the user is able to transfer from a higher to lower surface. This offers gravitational assistance from most wheelchairs into bed, and raises the height of the bed above the wheelchair seat height to get out of bed.

Beds with a wider height range may need to be considered if the disabled person is short and requires a low surface for stand to sit, but a higher surface for sit to stand. It's important to note that the lower setting may have implications for the use of the bedrail. A full assessment with the OT is essential to ensure that the right bed and prescription are provided.

The need for an electric double bed will have space implications in the bedroom, further substantiating the need for adaptations. Please see Chapter 8: The bedroom, and Chapter 13: Electric profiling beds, for further information.

Cars

Seat raise to standing

This equipment enables a disabled person to get in and out of the car. It can take the form of a fold-down seat platform or a height-adjustable swivel seat.

The former comprises a fold-down seat platform that is positioned at the side of the car seat and is lowered to a horizontal position when the car door is opened. This enables the person either to stand from a higher level or transfer sideways at the same level as the wheelchair seat.

The seat platform is raised electrically, operated from a control button. It folds back next to the seat when not required so that the door can be closed. It is important to check the height range and also the safe working load.

When equipment is assessed the potential user needs to decide:

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

Raising from the floor, following a fall

People with muscle-wasting conditions may be prone to falling and getting up from the floor may eventually be impossible. A portable unit that lies flat on the floor can be placed under the person. It rises up to a height from which the person can be helped to stand up or transfer to a wheelchair.

An inflatable cushion system lifts the person from the floor to a seated position but relies on them having sufficient sitting balance. It folds flat and is easy to store when not required.

An alternative is a piece of apparatus that is inserted and assembled under the fallen person and lifts them horizontally into a seated position. With either type of equipment, full assessment of the person, apparatus, carer and home circumstances is required to ensure the need is met safely. The OT will need to advise.

Wheelchairs

Please refer to Muscular Dystrophy UK's *Wheelchair Guidelines* for more information.

Some models of wheelchair can have a high-low facility. This facilitates independent sit-

to-stand transfers, enables users to transfer sideways and adjust the height according to the surface they are moving on to.

Legislation

Check with the supplier which current legislation governs the installation, maintenance and safety of any product chosen.

Chapter 13
Electric profiling beds

It has been shown that electric profiling beds (EPBs) are invaluable for children and adults with Duchenne muscular dystrophy, spinal muscular dystrophy (SMA) and other muscle-wasting conditions.

What is an EPB?

This is a bed with a sectioned mattress platform, which enables the bed to be used to support a user a in a range of positions. The height can be adjusted. Both the position and height are controlled with a handset by either the user or a carer.

Benefits of an EPB

1. **Health benefits**: an EPB may reduce some potential complications of immobility and have a beneficial effect on major body systems, such as:
   - improved lung function
   - reduced cardiac workload and improved cardiac output
   - improved urinary drainage and reduced infection risk
   - improved gut mobility and nutrient absorption.

There is also evidence of a positive impact on patient satisfaction and staff morale.
Health and Safety Executive (04/11)

2. **More independence for the person**: as there is less need for someone to help them to sit up and reposition in bed.

3. **Reduction in moving and handling for the carer**: this complies with the Manual Handling Operations (1992):

'A Royal College of Nursing (RCN) study identified that 52 percent of manual handling accidents involve hospital beds. Typically, they happen while moving patients up or down the bed, helping them to sit up or turning them in bed'. *Health and Safety Executive (04/11)*

4. **Height adjustment between 40cm and 80cm**: this is beneficial to both the person and their carer. The person may be able to adjust the bed height to enable them to make independent transfers in and out of bed. This may mean adjusting the bed to a height that enables the person to stand from the edge of the mattress by dropping on to their feet with their legs extended or that enables an easier sliding transfer. Some people also lower the bed once they are sitting on the bed so there is a shorter distance for them to lift their legs to the mattress.

   The carer can also adjust the bed to the right height for them to avoid excessive strain on their back during personal care tasks and exercises.

   It is recommended that the bed be used at its lowest setting when the person is sleeping/resting on the bed.

5. **Hoist slings**: can be easier to apply if the bed is accessible from both sides. This also lowers the risks associated with using hoists. Always refer to your Moving and Handling plan for details of fitting the person's appropriate sling. Compatible hoist equipment needs to be considered.

6. **Change of position in bed**: can be easier when the profiling mechanism is used. This may mean that the person can sit up independently and change position, therefore reducing the need for carers to provide attention during the night. The backrest angle can be used to gain comfort and may help when a person has a chest infection or is having a gastrostomy feed. It also provides a comfortable sitting position for rest and leisure. Benefits to this include redistribution of pressure, comfort, and function.

EPBs enable the person's feet to be elevated, which can be beneficial when there is oedema in the lower limbs. Elevation of the lower limbs supports the reduction of oedema. The knee-break facility prevents the person from sliding down the bed when the head is elevated. Some beds will also enable the user to sit in an 'armchair' position.

When is the right time to supply an EPB?

The OT can advise on equipment or adaptations that can be made to a standard bed. The person's needs should be considered and appropriate adaptations made to the original bed. These may be relatively simple changes initially, such as bed raisers, bed rails, and pillow or mattress elevators. However, changes in function will need to be carefully monitored and further considerations made, such as the provision of an EPB.

The supply of an EPB is justified when a person is finding it hard to sit up in bed and/or has some difficulty standing from sitting on the edge of the bed. It should also be considered when a carer needs to perform care tasks or assist the person, since the height adjustment enables the carer to work at a safer working level.

Safety considerations when selecting a bed

There is a wide range of products available. It is important to have a full, individual assessment with the person and their family or carer, including function and risk. Consider:

1. **standard**: the bed must comply with BS EN 6060-2-52-2010 (April 2013). Beds supplied after this date must come with confirmation of compliance with this standard. Those manufactured before April 2013 that met the pre-existing standard may still be used unless the Standards body deems the risk unacceptable. Any bed produced and sold before April 2013 can be used even though it may not comply with this British Standard. Exercise caution when carrying out a risk assessment with anyone who has one of these beds, and put appropriate control measures in place.

   Please note that some details are expected to change in 2017 and they will be updated when this happens.

2. **stability and robustness**: there are many beds available for community use on the specialist market. Not all products are robust enough to be used for both night-time as well as day-time rest. It is also important to consider whether the bed is durable enough to cope with 'snatch weight'. This is where a person may 'flop' on to the bed if they are able to transfer independently.

3. **general safety**: the distances between the moving parts of the bed need to be within normal range for the fingers: less than 8mm or more than 25mm. In addition, the distance between moving parts and the floor, within normal reach for feet of the disabled person or carer, must always be a maximum 20mm.

   Open ends of tubular components must be capped or closed.

A visual inspection should show that:

- all edges and corners are smooth with no burrs or sharp edges
- there are no protruding parts
- gaps – locations identified as trapping zones have distances between moving parts of less than 8mm or more than 25mm (Carebase)
- the design of the foot end panel prevents feet slipping through holes in the panel
- the design of the bed allows for the mounting of side rails and lifting poles
- the design of the bed prevents incorrect assembly of knock down parts and accessories
- the design of the bed prevents unintentional activation of the moving parts and accessories
- there are no single use components required if the bed needs to be taken apart and moved or stored
- in case of a malfunction in the system, the back rest section can be brought back to the horizontal position
- a control unit can be reached easily by the person and carer
- the control unit has a hold-to-run function, in other words you hold the button down to make a profile action happen
- it is not possible to position the bed in a hazardous position for the user
- the bed and removable parts are supplied with manufacturer's identification, name and trademark for traceability
- the bed is supplied with the maximum Safe Working Load.

Beds for children: there are shorter beds available for children. (A child is considered to be someone up to the age of 12, or under 145cm in height.) The product choice needs to be appropriate for the child, and must comply with the Standard. Also, consider the child's potential growth.

These products are much larger than standard cots and beds for children, so the profile mechanism is unlikely to match the body size and shape of a younger child. The law governing the issue of children's equipment states that there must not be any gaps larger than 6cm. The choice of a bed must, therefore, take into consideration the entrapment risks. If an adult bed is used, this will mean side-rail gaps could be bigger than 6cm and fall short of the Standard.

Some products may enable the mattress platform to be lengthened with an inserted section and an extra length of mattress inserted (a mattress squab) or a longer mattress provided. However, this may only extend the foot section of the bed. It's advisable to have appropriately trained and experienced children's healthcare professionals carry out careful assessments, and to adhere to current guidance about sleep positions and safety.

Children should always have an individualised risk assessment, with controls negotiated with the family/carers.

An EPB may be used with a sleep system for children. Where this is a possibility, follow local pathways for assessment and provision. A sleep system can be used on a bed to support a person's position during sleep and rest. The bed and the sleep system must be compatible and must be assessed together. (Your OT can advise you.) It is also important to review and adjust the product as the child grows and their needs change.

Mattresses: should be supplied with the bed. The supplier is responsible for ensuring compatibility, to reduce the entrapment gaps between bed frame and mattress. Mattress prescription varies between localities, however, it is important to consider the pressure relieving qualities in relation to the needs of the individual user. The distance between the top of the mattress and the top of the bed rail should be no less than 22cm.

The firmness of the mattress will also determine whether or not the individual can stand from the edge of the bed. This will have an impact on maintaining or promoting independence. Liaise with the nursing team to help decide this.

What to consider when selecting a bed

1. Is there a socket nearby?

2. **Space**: it is important to measure the space needed before installation. If anti-Trendelenburg (this is when the bed is tilted with the foot end downwards and the head up) is to be used, the footprint space for the bed to occupy will need to be much larger than the actual size of the bed frame. This position may be helpful when used with other features of the bed.

3. **Light touch handsets**: discuss and assess options such as a light touch handset or an infra red handset, which can be used with environmental controls. Consider the potential progression of the muscle-wasting condition, as light touch controls might become an essential feature. Not all beds, however, are compatible with these handsets that usually attach to the bed with a curly cord of at least 2.5m. The cord might be tight initially; they usually stretch with use but might need some help. It is useful to liaise with the local EAT Service to ensure the bed is compatible with environmental controls. (See Chapter 10 Environmental controls for further details.)

4. **Auto regression**: the bed platform should have four sections. The profiling mechanism of some beds includes auto regression of the backrest, where the backrest slides rather than pivots towards the head of the bed. This option offers a more comfortable profile and reduces pressure on the abdomen.

5. **Extending the mattress platform**: an extension section can be inserted in to the mattress platform on some bed models. Consider where the extension fits though, as some slide in at the foot end of the bed while others extend the middle section of the profiling.

6. **Transportation**: many beds divide into sections to be transported on a transporter unit, but assess the access into the bedroom before ordering the bed. Consider the mechanism for locking together the parts and the need to check this regularly. Also check whether the mechanism (which protrudes) causes a hazard to the carer and whether young children could interfere with the mechanism.

7. **Profile angles**: the angles that each profiling section can achieve are important. Backrest height should be at least 70 to enable the person to sit forward, and the knee break should be 90 to allow for knee contractures. In addition, it should be possible to lower the lower leg section to provide a comfortable sitting position.

8. **Sleep systems**: some people with muscle-wasting conditions may use a sleep system to promote appropriate posture. It is important that the bed and sleep system are compatible and assessed together.

9. **Height**: the choice of bed will depend on the transfer and care needs of the individual. The height of the bed can be adjusted so standing transfers can be done independently. In these cases, make sure that the side rails do not obstruct the transfer when the mattress is depressed. The height of the bed may also be adjusted to suit carers who are carrying out care tasks.

   When the space underneath the mattress platform is essential for mobile hoist access, there should be at least 15cm clearance.

Consider the safety of siblings, pets, and so on, when assessing and risk assessing a bed. The height adjustment should be isolated so the bed cannot be raised or lowered when an adult is not present.

10. **Side rails**: EPBs should be provided with integral bed rails, which may be considered essential for safety and the person feeling secure. For young people under the age of 12, ensure the gaps are not more than 6cm. Washable, breathable bumpers should be supplied with the bed. When people carry out sideways transfers, consider whether the rail increases the gap between the two surfaces. Also check that when the rail is lowered, when the bed is in its lowest position, it is clear of the mattress to enable independent and unobstructed transfers.

11. **Specialist mattresses**: when an air mattress or an overlay is used, there are a few points to consider. It should be compatible with the bed frame, and also should not increase the distance between the mattress surface and the top of the bed rails. If this is a problem, a three-bar bed rail, which meets the top of the foot and headboard, may be necessary.

    Since it is unlikely that a mobile person would need to use an air mattress, it is worth considering the facility to vary the pressure. Care tasks may be easier to carry out if pressure can be increased temporarily.

    Adjustable pressure on an air mattress can help to facilitate moving and handling. You can increase the pressure, and use slide sheets to turn a person.

    These considerations need to be made for both double beds and single beds.

Further considerations

1. **Turning in bed**: a person with a muscle-wasting condition may have problems turning themselves in bed. A 'turning mattress', 'turning bed' or Lateral Turning Device (LTD) may be considered. These mattresses, which have air bags that inflate and deflate alternately, can move the person between lying positions. They can also move the mattress platforms. Often, products can be programmed to turn a person to a comfortable degree over a period of time to suit the person.

   The benefits to the disabled person:
   - pressure relief
   - overnight comfort, as they can change position
   - as the mattresses redistribute pressure, they reduce friction and sheer force, and can reduce the risk of pressure ulceration.

   The benefits to the carer:
   - less manual handling required overnight
   - no disrupted sleep
   - lowered risk (as the risk is higher when a person has not 'warmed up' before carrying out handling tasks).

   Drawbacks are that some people do not feel comfortable being turned and, with reduced active movement, can feel vulnerable. When using an LTD, if the person's arms and legs get caught underneath them as they are turned, they would still require assistance from their carer to gain full comfort.

   Another technique for turning involves using a two-way slide sheet attached to a hoist carry bar. When the person wants to roll, they raise the hoist to move the slide sheet which rolls them on to their side. This affords some independence of movement, where appropriate. Local healthcare professionals should be able to advise.

These devices are expensive but in some cases the cost can be offset against the price of an overnight care package.

In all cases, it is recommended that a piece of equipment is trialled with a person for several nights. In this way, they can gain an informed opinion about whether the equipment works for them or not.

2. **Repositioning in bed**: (including turning for care) can be tricky for both users and carers. Health professionals can advise about techniques with slide sheets to reduce friction and make manoeuvres safer and easier. Alternatively, you can buy repositioning systems. These often involve mechanised turn-sheets, which may be operated using a hand control. The benefits of this type of equipment:
   - one carer can turn a person
   - a reduced risk of injury
   - reduced risk of shearing.

3. **Extra low beds**: there is a range of beds on the market, ranging in height from 80cm to 20cm from the floor. These can be useful if the carer is particularly tall and needs to raise the bed to give care. They are also useful when set in the lowest position for some children who are developing independence skills and are at an age when they would normally get out of bed by themselves. When the bed is set at its lowest position and used with a soft mat, the child can transfer out. This would remove the risk of a child climbing over bed rails and injuring themselves, or the need to confine them to a cot with high sides. It should be considered with assessment of all risk and possible modification to the bedroom to ensure the room is completely safe.

4. **Bariatric equipment**: there is a range of beds available on the market to provide for the needs of larger people. Complete an individualised assessment of need alongside appropriate equipment. It is important to consider all aspects of care, such as safer moving and handling – not just the bed in isolation.

5. **Thermoregulation**: some people have difficulty regulating their temperature in bed and complain of getting hot and sweaty on a specialist mattress. This may be resolved relatively easily through the use of more absorbent bedding such as cotton or bamboo sheets. If it is a persistent problem, it may be worth seeking the advice of the bed supplier.

Assessment

It is essential to have an opportunity to see and lie on a bed before deciding on a specific model of bed or mattress. Though the clinical need is paramount, the aesthetics of the product are an essential consideration for many families. When demonstrating a bed to a family it is often worth taking the time to dress the bed with some basic bed linen (and, for children, some appropriate toys). The presentation of the bed initially can be key to acceptance that it is required and will be beneficial to both the person and their carer.

For many people, the team of healthcare professionals they see regularly will have contributions to make to the bed assessment. It is important to ask for their thoughts particularly about safety, nursing/care needs and independence.

Electric profiling beds (EPBs): the features

Brakes	All wheels need to be lockable. Some beds will have a lock on each castor, while others will have a central locking system operated with a bar at each end of the bed. At least two castors should have the brakes applied and all need to be locked if the bed is to be used in anti-Trendelenburg. A test of the safety of castors should ensure that they do not allow the bed to move more than 10mm.
Handset	The buttons on the left side of a handset raise the relevant section and those on the right lower each section. The buttons should be clearly marked with symbols that state each function. To make it easy to operate, buttons should be at least 15mm in diameter and the distance between buttons more than 10mm. The handset comes with a lock facility to increase safety by allowing the carer to lock out all or some of the functions. This is essential when there is a risk of younger siblings playing with the controls. All handsets should be 'hold to run' to ensure that the user retains full control of the bed's angle of profile.
Auto-profiling	Some beds allow the user to profile the knee break and the backrest simultaneously. This one-button control can prove helpful for those with any hand weakness.
Knee break	When auto-profiling is not used, the knee break should be raised before the back rest when the user is profiling the bed from lying flat. This reduces the risk of shearing on the lower back and buttocks, and stops the user from sliding down the bed. The angle between the mattress platform and the upper leg section should be at least 12.
Backrest	On some beds, the mattress platform moves slightly backwards and upwards away from the fixed seat section of the mattress platform. This reduces compression, friction, shearing and compression on the abdomen, and users report a more comfortable profiling action. The angle between the backrest and the upper leg section should be greater than 90. With a four-section profiling bed, the angle should not exceed 85. To stop the pillow sliding down the backrest when the bed is profiled, fold a single sheet in half and make a loop around the pillow. This can then be tucked in between the mattress and the platform.
Foot section	On many beds the foot section can be raised so that feet are raised to remove pressure from heels. This is known as the semi-Fowler's position. The mechanism can be operated electrically or by hand.
Height adjustment	It is generally considered to be good practice for the user to sleep with the bed at the lowest height setting. Carers need to be shown how to set the bed at a safe height for care tasks.
Bed rails	It suggested that bed rails be considered part of the bed and not an additional feature. Careful risk assessment is needed to ensure that they are used safely. Bed rails are not intended as an aid to turning or moving – if required, assess for grab handles which can be fitted to the mattress platform. The bed rails may have gaps of more than 6cm; this gap size does not conform to legislation governing children's equipment. If this is the case, these gaps should be covered with bed rail covers, and covers that Velcro around from the rail to the bed head or foot end.

Bed rail covers	Bed rail covers should be provided with all bed rails. They provide protection from injury and minimise risk of entrapment. Covers that are continuous beneath the mattress platform offer the best protection from entrapment between the mattress and bed frame. Risk assessments are essential in choosing the right bed for the user and each case must be considered on its own merits. Consider the material chosen for the covers. Clinical judgment should guide whether the covers should be made from cotton, which is washable to a high temperature, or oil cloth-type material which can be wiped. Oil cloth may cause a risk, if the child is likely to roll or have seizures causing their face to come into contact with the material.
Mattress	The mattress choice should be made at the time of the assessment and reviewed as the needs change. It is important to consider the pressure risks to the user, especially if they are not able to move around the bed independently. The mattress must be compatible with the bed and it is recommended that both are ordered from the same company to reduce risks of incompatibility. This also prevents the increased risk of entrapment gaps if the mattress is too small for the bed frame. Mattresses wear out and regular checks can be made by pressing with both hands cupped together on to the mattress in the middle of the bed. If it has 'bottomed out', the mattress platform will be felt. Make sure any replacement ordered is compatible with the bed.
Other	The profiling sections of a bed are built to take a proportion of the user's weight. For this reason, it is usually recommended that users and carers do not sit on any of the moving parts of the bed, for example the lower leg section.

Bed rails

The Medicines and Healthcare products Regulatory Agency (MHRA) has published a comprehensive document in response to numerous serious incidents with bed rails. Many incidents have resulted in serious harm or death.

Refer to this document – *Safe Use of Bed Rails* – should any type of bed rail be considered for use with a disabled person.

References

- Health and Safety Executive (04/11) *Electric Profiling Beds in Health Care. HSE.England.*
- Carebase (2014) BS EN 6060-2-52-2010 Part 2-52: *Particular requirements for basic safety and essential performance of medical beds. A review and explanation of the new Standard for health care beds. Yorkshire, England.*
- Felgains (2014) Vendlet V5 – *Turning & Repositioning* www.felgains.com/vendlet-v5 (Accessed 08/03/2016)
- Medicines and Healthcare Products Regulatory Agency (2013) *Safe Use of Bed Rails*. Crown copyright.

Chapter 14
Funding

Funding adaptations and equipment

Understanding the grants system and VAT

Following an assessment of need, equipment and/or adaptations to a property may be recommended to enable an individual to remain as independent as possible for as long as possible. It is important to have an open discussion between the individual, their carer/family and the health professional involved. This would cover the types of equipment/adaptations needed and the various ways in which they are funded. Equipment and adaptations have been discussed in great detail in other chapters.

While funding exists, the amount available and the application processes differ right across the UK. It is the responsibility of each individual and their carers to find out from their local health or local authority team what is available in their area, who is eligible and how to apply. Legislation, local guidance and practice continually change. The aim of this chapter is to provide an overview of funding and to signpost the reader to more local and up-to-date information.

What types of funding are available?

Equipment/adaptations can be:

self-funded: the individual and/or carer decide to purchase the piece of equipment/pay for the adaptation themselves. It is always advisable to seek impartial, independent advice before taking this approach. This advice can be provided from the healthcare professional (OT/social worker). Where possible it is also beneficial to try the piece of equipment before buying it to ensure it meets the need.

NHS/local authority-funded: if, following your needs assessment, the piece of equipment/minor adaptation required costs less than £1,000, the local NHS/local authority will usually provide it. For anything over £1,000, it is helpful to discuss the options with the healthcare professional.

charity-funded: some charities assist individuals with small grants towards the cost of specialist equipment that they cannot get through statutory services (for example, mobility equipment, electric beds, adapted computers). Charitable funds rarely cover the full cost of the equipment; they provide a sum of money towards it. The criteria for each fund will vary from charity to charity. It is helpful to check out their guidance before applying.

The following websites are useful as they list many charitable funds available throughout the UK:

- www.disability-grants.org/
- www.communitycare.co.uk/2009/07/10/list-of-charities-giving-grants-to-people-with-long-term-disabililties-and-chronic-health-conditions/

Muscular Dystrophy UK has its own fund called the Joseph Patrick Trust (JPT). Anyone living with a muscle-wasting condition can apply for a grant from the JPT. Up-to-date information on its criteria, tariffs, application forms and meetings can be found on:

- www.musculardystrophyuk.org/get-the-right-care-and-support/equipment-grants/jpt-grants/

DFG: these grants are provided by the local authorities in England, Wales and Northern Ireland. They fund more expensive adaptations to properties to meet the needs of a disabled

person. In order to be eligible for a DFG, you must be:

- an owner occupier
- a private tenant
- a tenant of a housing association or local authority
- a landlord of a disabled tenant.

The maximum grant available differs in each of the three countries and is dependent on the income and savings of the disabled person.

Children up to the age of 19 are not means-tested for DFGs. The maximum grant is £30,000. The OT who recommends the adaptation will also be involved in applying for the DFG and overseeing the work through to completion.

It is important to note that:

- a DFG will often not be granted after the work has started so it is not advisable to commence work yourself before you are assessed or your application processed
- the disabled person may need to make a financial contribution dependent on the work involved and the outcome of the means test (if possible)
- the homeowner will usually be responsible for all servicing, routine maintenance and repair costs.

Make sure the above points are discussed with the OT in advance so everyone is aware of their responsibilities.

You can find up-to-date information on DFGs at www.gov.uk/disabled-facilities-grants

In Scotland, the undertaking and funding of housing adaptations differs depending on the tenure of the property. A means test is used to determine the amount of grant available to each individual. At the moment, the amount varies between 80 percent and 100 percent of the total cost of the work.

At time of writing, the Scottish Government is in the process of a two-year project (2014 – 2016) to develop and reform the national policy framework for housing adaptations, and to provide learning to improve practice. www.ccpscotland.org/wp-content/uploads/sites/2/2015/03/Adapting-for-Change_Margaret-Moore-JIT.pdf

Legislation, guidance and local practice continually change. For this reason, it is important for each individual to refer to their local authority/provider for information on their funding schemes. Have a look at the end of this chapter for useful websites to refer to.

How is funding obtained?

To be successful in securing grants and funding for adaptations and equipment, it is essential to have:

- insight and knowledge of the challenges faced by the disabled person to ensure a client-centred and holistic assessment is carried out (see Chapter 1: Assessment of need, for further advice)
- knowledge of the statutory sources of funding and an understanding of the legislation, guidance and practice in your local area
- awareness of any additional/alternative funding that may be available
- an understanding of muscle-wasting conditions and the challenges they pose to the individual. (Where a professional does not have experience in muscle-wasting conditions, it is important to know where to seek advice and guidance. There are various sources, such as relevant chapters in this manual, Muscular Dystrophy UK, other specialist health professionals, and the neuromuscular clinical network.)

The above points will give OTs and other healthcare professionals the information required to:

- identify the client's need
- justify their recommendations
- identify the best source of funding
- support the grant application.

What support will I be entitled to if I am not eligible for a grant?

For those who are not eligible for a DFG, the support they get may vary from area to area. While everyone is entitled to an assessment of their needs, some people (depending on their financial situation) may not be entitled to financial support to obtain the adaptations or equipment they require. In this situation, the local OT/social worker can advise on what support is available and how to access it.

VAT exemption

If a person is disabled or has a long-term illness, they won't be charged VAT on products designed or adapted for personal or domestic use. Also, they won't be charged VAT on:

- the installation and any extra work needed as part of this
- repairs or maintenance
- spare parts or accessories.

To be eligible for VAT exemption, individuals must have evidence of a:

- physical or mental impairment that has a major long-term effect on their ability to do everyday activities
- condition that the medical profession treats as a chronic sickness (for example, a muscle-wasting condition)
- terminal illness.

Adaptations include:

- building a ramp
- widening (but not building) a doorway or passage
- installing, extending or adapting a bathroom, washroom or lavatory to suit their condition
- installing, repairing or maintaining a lift to help them move between floors
- preparation and restoration of the immediately surrounding décor.

Equipment is for personal use in the home and includes:

- adjustable beds
- hoists
- chair and stair lifts
- sanitary devices
- alarms
- parts and accessories for qualifying equipment
- the cost of adapting something for a disabled person.

It is important to have evidence from a trusted medical professional and the product must also qualify for exemption.

Please check the Government's website for further details.

- www.gov.uk/financial-help-disabled/vat-relief
- www.gov.uk/vat-builders/disabled-people

See below a VAT exemption form (2016)

VAT relief for disabled people - eligibility declaration by a disabled person

Part 1. Supplier

Note to supplier
The production of this declaration does not automatically justify the zero-rating of your supply. You must ensure that the goods and/or services you are supplying qualify for zero-rating. Please consult Notice 701/7 *VAT reliefs for disabled people*, before applying VAT relief to your supplies. You must keep this declaration with your records for production to your VAT officer as required. Please do not return it to the customer or send it to HM Revenue and Customs (HMRC).

I (full name) _____ of _____

(company name and address) _____

_____

_____

_____

I am supplying the following goods and/or services to the disabled person named overleaf. Please tick the appropriate box and give details of the goods and/or services in the space provided:

✓		Insert details
☐	Goods which are being supplied for the customer's personal use	
☐	Services of adapting goods to suit the needs of the customer	
☐	Services of installation, repair or maintenance	
☐	Alterations to a private residence	
☐	Monitoring a personal alarm call system for the personal use of the disabled person	

Signed _____ Date _____

Part 2. Customer's declaration

Note to customer

You should complete this declaration if you are 'chronically sick or disabled' and the goods or services are for your own personal or domestic use. A family member or carer can complete this on your behalf if you wish.

You can find out more from the Helpsheets on the gov.uk website or by telephoning the VAT Disabled Reliefs Helpline on 0300 123 1073. HMRC staff cannot advise whether or not an individual is chronically sick or disabled.

A person is 'chronically sick or disabled' if he or she is a person:

- with a physical or mental impairment which has a long-term and substantial adverse effect upon his or her ability to carry out everyday activities
- with a condition which the medical profession treats as a chronic sickness.

It does not include an elderly person who is not disabled or chronically sick, or any person who is only temporarily disabled or incapacitated, such as with a broken limb.

If you are unsure, you should seek guidance from your GP or other medical professional.
Please give this completed form back to the supplier. They will keep it with their VAT records. Please do not send it to HMRC.

I (full name) _____ of _____

(address) _____

_____

_____

_____

declare that I have the following disability or chronic sickness: _____

_____

_____

_____

_____

I am receiving the goods and/or services detailed overleaf, which are being supplied to me for domestic or my personal use and I claim relief from VAT.

Signed _____ Date _____

It is very important that each individual and carer receives advice and information to enable them to participate in informed decisions about the outcomes they wish to achieve. Any decisions made, and the reasons behind them, should be transparent from the outset for individuals, carers, family and staff.

Useful resources

Muscular Dystrophy UK can help anyone with a muscle-wasting condition to get the benefits, services and equipment they are entitled to.

Get in touch with the advocacy team on 0800 652 6352 or email info@musculardystrophyuk.org

Charitable funds

Muscular Dystrophy UK has its own grant scheme, the Joseph Patrick Trust (JPT) www.musculardystrophyuk.org/get-the-right-care-and-support/equipment-grants/jpt-grants

Disability Grants and Community Care provide a useful list of charities that provide grants www.disability-grants.org

www.communitycare.co.uk/2009/07/10/list-of-charities-giving-grants-to-people-with-long-term-disabililties-and-chronic-health-conditions

The Family Fund is an independent organisation, funded by the national governments of England, Northern Ireland, Scotland and Wales. It assists families with a disabled or seriously ill child under the age of 17 to fund equipment that relates to the needs of a disabled child. They also fund family breaks.
www.familyfund.org.uk

DFGs

Useful websites with up-to-date information:

- www.disabilityrightsuk.org/housing-grants
- www.dls.org.uk
- www.dls.org.uk/Pages/Advice/Factsheet/community_care/disabled_facilities_grants/Disabled_Facilities_Grants.pdf
- councilfordisabledchildren.org.uk/sites/default/files/uploads/documents/import/CDC_LH_Chap_6c.pdf
- www.scope.org.uk
- www.citizensadvice.org.uk

In England

- www.gov.uk/disabled-facilities-grants
- www.gov.uk/government/uploads/system/uploads/attachment_data/file/365345/Making_Sure_the_Care_Act_Works_EASY_READ.pdf

In Wales

- gov.wales/topics/people-and-communities/communities/grants/dfgs/?lang=en
- www.careandrepair.org.uk/uploads/Publications/Housing_Adaptations_e-leaflet_E.pdf
- www.careandrepair.org.uk/housing-adaptations

In Scotland

- www.gov.scot/resource/doc/266465/0079748.pdf
- www.sehd.scot.nhs.uk/publications/CC2009_05.pdf
- www.gov.scot/Resource/0047/00476043.pdf
- www.gov.scot/Publications/Recent

In Northern Ireland

- www.nidirect.gov.uk/information-and-services/home-and-housing-options/your-home-adaptations-and-equipment
- www.nidirect.gov.uk/articles/disabled-facilities-grants-0

For up-to-date legislation

- www.legislation.gov.uk
- www.citizensadvice.org.uk

Chapter 15
Scales, planning and building regulations

Scales

Most plans are drawn to a scale of 1:50. Most rooms are drawn to 1:20 and most floor plans (of individual domestic properties) are drawn to 1:50.

Templates

In previous editions of the *Adaptations manual* there have been templates which OTs have found useful when checking the size of proposed rooms and equipment. Because there has been such an increase in variety and specification of equipment, these templates have been removed from this edition of the manual. In addition, furniture rarely comes in standard measurements, and personal choice in design of furniture influences the size and design.

It is recommended however, that OTs look carefully at the plans and calculate the measurements of required essential and everyday furniture. In this way, they can establish distances for movement of powered chairs, carers' space to assist, and so on.

Any templates need to be drawn to scale. The exact dimensions of both furniture and any specialised equipment, turning space, and so on, superimposed on to the outline drawing.

It must be stressed that in time, the size of fixtures may change. 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. They are no substitute, however, for the professional services of a designer experienced in these types of schemes.

Templates are unlikely to be used by the architectural designer. 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.

Considerations

Wheelchairs and their turning spaces and carer space

Average size of powered chair – occupied
Length: 1,384mm
Width: 760mm
(Source: British Standard BS8300:2009+A1:2010)

Space for carers around wheelchair (and hoist)
1,800mm x 1,800 mm (good practice)

Many children and adults with muscle-wasting conditions use a wheelchair, or will need one in the future. 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 have the sophisticated features that are needed (for example, powered reclining backrests, tilt-in-space seats and elevating legrests). It is important that the size of the chair is taken into account in the planning. In this way, every disabled person can get the chair best suited for them in the future.

Wheelchair turning circle
1,800mm (good practice)
The choice of turning circle is:

- 1,500mm (minimum - source: *Approved Document to Part M of the Building Regulations, Volume 1 - Category 3, 2015*)
- 1,700mm (minimum - source: Approved Document to Part M of the Building Regulations, Volume 1 - Category 3, 2015)
- 1,800mm (good practice – source: British Standard BS8300:2009+A1:2010).

This also includes planning for children's wheelchairs. There is often the feeling that facilities for young children can be smaller; in fact, the reverse is the case. Young children need space for playing and their wheelchairs frequently have a long base, so they 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. Please refer to Chapter 7: The bathroom for further information.

Galley kitchen

When the kitchen has been adapted, the chair can be turned under the wheelchair-accessible units. Please refer to Chapter 9: The kitchen for further information.

Wheelchair through-floor lift (approximate size)
There are three different sets of dimensions you can give for through-floor lifts:

- aperture/shaft dimensions
- external dimensions
- internal car dimensions.

The dimensions that are most important are the 'internal car dimensions':

- the minimum standard for communal passenger lifts in blocks of flats, for example, is 1,400mm long x 1,100mm wide
- the minimum 'aperture/shaft' size for two-storey dwellings is 1,500mm long x 1,000mm wide (the exact terminology given in Part M for aperture is 'Liftway').

These are minimum sizes. The OT will need to measure up carefully for their prospective user, as often the lifts that are put into dwellings, even though to standard, in practice are too small.

The choice of lift must not exclude the largest and heaviest wheelchairs available (140kg + weight of user). It must also not require removing or swinging away the footrests (which may be impossible for someone with a muscle-wasting condition).

Access to lift

Turning circle:

- 1,800mm (good practice)
- 1,700mm (preferred - source: general design guidance)
- 1,500mm (minimum -source M4(3)).
- 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

Please see Chapter 6: Solutions for stairs for further information.

Equipment storage

- For powered wheelchair: 1,250mm x 750mm
- For transit wheelchair (folded): 1,000mm x 300mm
- For standing frame: 1,550mm x 560mm

Many people who depend on their wheelchair for all their mobility, have a spare chair for use when their main chair needs repair. The storage space must be adequate.

Shelf in charging area for wheelchair charger

Length: 500mm
Depth: 300mm
Bottom of shelf to finished floor level (FFL): 850mm

The Building Regulations 2010; Access to and use of buildings details the exact requirements when planning:

hard standing/car port/wheelchair transfers to/from vehicle
Calculating the length of ramps: ramps need to have the correct gradient for wheelchair stability and safety.

Detailed descriptions of exact requirements can be found in the *Building Regulations 2010; Access to and use of buildings*.

Door sizes and swings

Existing doors with straight access

- Minimum clear opening: 750mm (*Part M-Vol 1 (categories 1 & 2 - general)*)
- Minimum clear opening: 800mm (*Part M-Vol 1 (category 3 – new-build wheelchair dwellings*)
- Good practice (space permitting): 850mm-900mm
- Clear opening: 850mm – 900mm

New building

- Single leaf, standard doors – clear opening: 900mm
- Single-leaf, double-swing doors – 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 the mark left by the wheelchair armrests and/or tray: 800mm

Bedroom

Bed (sizes vary)

Consider whether a standard single bed, a wide single bed or a double bed will suit current and future needs:

- single: 1,080mm x 2,155mm
- wide single: 1,220mm x 2,155mm
- double: 2,160mm x 2,155mm.

Space around beds

It is important to identify which side of the bed the disabled person prefers to get in and out of – or in the case of a double bed, which side the person sleeps. The architectural designer will need to plan the position of the bed with the appropriate side nearer to the bathroom.

- 1,800mm – side of bed (single or double) nearest to bathroom for wheelchair transfers:
- 1,000mm – exposed side of single bed, if head of bed is near a doorway (this needs to allow for the bed to be pulled away from the wall for a carer to gain access without obstructing the doorway)
- 1,000mm – space at other side of double bed
- 700mm – foot of bed for carer to attend to feet

Standing frame

- Storage space: 1,550mm x 560mm
- Adjacent to bed for ceiling hoist transfers, and wheeled to the front of the standing surface: 1,900mm x 560mm

Shelf by bed

- Length: 1,000mm. To extend from position of track to end of bed in front of footboard (in other words, 1,020mm from wall behind bed headboard).
- Depth: 260mm
- Height: under-surface to clear maximum height of bed *900mm – 950mm

*Check the optimum measurement against the model of bed.

Ceiling hoist over bed

Centre of track to wall behind bed headboard: 1,020mm (or 900mm from headboard)

Pick-up point on a toilet: centre-line of hoist to be 50mm forward of WC pan aperture

Pick-up point from bath: 250mm from base of slope at rear of bath to centre-line of hoist.

(Source: *Prism Medical UK – Architects Pack (2010)*).

Wardrobe

Width: 1,000mm
Front to back: 600mm

Chest of drawers

Width: 900mm
Front to back: 500mm

Bathroom

When the bathroom fittings are being considered, plan around the measurements of the bath as well as space for carer. If a model with a swing-away seat is selected, the bathroom must also include space for the seat to move away from the bath. Approximate measurements:

- space at side for swing of integral bath seat: 675mm
- space in front of seat for movement of carer: 700mm (a total of 1,375mm)
- space at end of bath (side of seat to wall): 700mm

Level access shower bases

- Square: 1,000mm x 1,000mm (minimum)
- Oblong: 1,500mm x 850mm
- Bath replacement level-access tray (see standard bath for approximate size): 1,700 x 750mm

Height-adjustable washbasin

- Maximum width: 1,200mm
- Front to back: 675mm (at level of wheelchair footrest)

In front of basin for wheelchair access

- Minimum clear access zone: 900mm long x 700mm wide
- Ideal clear access zone: 1,500mm x 1,000mm

Toilet (low-level pan with long flush pipe)

- Front of WC pan to rear wall or boxing: minimum of 750mm to allow wheelchair to be positioned at the side
- Front of cistern to front of bowl: 600mm

Wash/dry toilet

- Front to back: 710mm
- Width: 500mm

Space around toilet and wash/dry toilet

- Centre of toilet pan to adjacent wall or (nearest obstruction): 400mm-500mm (average 450mm)
- Exposed side of toilet pan (for sideways wheelchair transfers): 1,000mm (minimum)
- From centre-line of WC pan; 1,500mm (ideal) so that the wheelchair can be angled, if this makes transfer easier.

Please see Chapter 7: The bathroom for further information.

Sitting room and dining room furniture

For average sizes of household furniture, refer to *Part M (AD-M Volume 1 – Appendix D (furniture schedule)* of the Building and Planning Regulations.

Kitchen

Kitchen units

There can be variance in width and depth of unit of between 400mm and 600mm and the options should be considered when drawing plans for a kitchen layout.

- Depth of all sizes: 600mm
- Kitchen appliances, such as washers, dishwashers
- Width: 600mm
- Depth: 600mm

Please see Chapter 9: The kitchen for further information.

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
  Under track – 1,020mm from the wall behind the bed headboard
- By bed
  Head of bed – bottom of plate to FFL: 760mm
  Foot of bed – at skirting board level and marginally under 2,155mm length to ensure that power cords are not a hazard and the switch can still be reached.

Over L-shaped work surface

Where a disabled person stands to undertake tasks at home consideration should be given to provision of the right type of surface for the task. A free-standing surface often will suffice though some people may choose to fix the height or wall-mount the surface at their preferred height. This provides sufficient clearance for knees under the table top, and if the person has sufficient upper limb range of movement, this often proves to be functional. Please see Chapter 8: The bedroom for further information.

Requirement for fused spur outlets should be built into the original plans and will require consultation with the individual equipment companies. These may include:

- height-adjustable bath
- body dryer
- rise and fall washbasin
- wash/dry toilet
- wall-mounted bathroom heater
- ceiling hoist
- automatic door opener
- curtain control
- height-adjustable changing/shower table.

Dimensions of these items may need to be checked with individual suppliers.

References

Approved Document to Part M of the Building Regulations – Volume 1 (dwellings) (2015 edition, incorporating 2016 amendments). Application: England only.
Approved Document to Part K of the Building Regulations (2013)
British Standard BS8300:2009+A1:2010
Prism Medical UK – Architects Pack (2010).

Other useful resources

- www.nihe.gov.uk/adaptations_design_communications_toolkit.pdf
- www.nihe.gov.uk/adapting_your_home_private_sector.pdf
- www.nihe.gov.uk/adaptations
- www.nihe.gov.uk/index/advice/disability/adaptations/advice-review-of-housing-adaptations-services.htm
- www.nidirect.gov.uk/information-and-services/home-and-housing-options/your-home-adaptations-and-equipment
- www.communities-ni.gov.uk/wheelchair-housing

Planning and building regulations

Building legislation throughout the UK is under frequent review and these notes should be viewed as a guide only. The OT and 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 all 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)

Some minor developments do not require planning permission as they would have little or no impact on the local environment. These developments are known as 'permitted development'.

Visit the Planning Portal: www.planningportal.co.uk/info/200125/do_you_need_permission for further guidance on the types of home extensions that fall under permitted development. It is advisable to contact your local planning authority if you are unsure whether your home development counts as permitted development. Don't forget that you may still require Building Regulations approval for permitted home developments.

Your local planning authority is responsible for granting local planning permission. It is normally helpful to informally discuss your development plans with a local planning officer, before moving to the formal application process.

These preliminary discussions are free of charge for domestic works. They help to establish if planning permission is required and how it can be obtained.

If you have to proceed with the formal planning application process, your local planning authority will supply you with:

- an application form (1APP)
- guidance information on how to make the application
- the supporting documents required for the application.

Further information is available from www.gov.uk/government/publications/permitted-development-rights-for-householders-technical-guidance

Contact with neighbours

Before commissioning a designer to prepare drawings, it is wise to discuss the proposed adaptations with neighbours to assess their reaction. They will be consulted by the LA when the formal application is made. It is usually more effective to contact them informally first and note any concerns. Any adverse comments should be made known to the architectural designer who may then be able to avoid any confrontation.

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:

1. information:

- 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.

2. drawings:

- 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 muscle-wasting conditions are often larger than normally encountered by planning officers. So applications frequently take longer and require sympathetic negotiation – usually with the assistance of your OT – to gain approval.

It will be helpful for your architectural designer 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 helps (when the scheme is submitted formally) to include 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 Muscular Dystrophy UK, stressing the specialist needs for the particular scheme and why other alternatives (usually smaller) would not be satisfactory
- the architectural designer, giving reasons why the scheme cannot be altered.

Contact with the local councillor and other councillors on the Planning Committee (possibly the local MP too) can help 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.

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. This may, however, be a lengthy process.

Building regulations

Is building regulations approval 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
- energy efficiency
- connections to the drainage system
- access arrangements
- 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 extensions 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:

1. full plans submission

This method is self-explanatory. It 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 adherence to the approved scheme.

2. building notice

A building notice is a less bureaucratic method of achieving building regulations approval for use where smaller, simpler schemes are being undertaken. 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. 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 building control officers.

Building regulations approval does not constitute approval under planning legislation. Both Planning approval and Building Regulations approval are needed.

With all building work, the owner of the property (or land) in question is ultimately

responsible for complying with the relevant planning rules and building regulations. This is regardless of the need to apply for planning permission and/or building regulations approval.

Failure to comply with the relevant rules will result in the owner being liable for any remedial action (which could go as far as demolition and/or restoration). The general advice is to always discuss your proposals with the relevant Local Planning Authority and Building Control Service before starting work.

Your architect and/or technical officer from the Home Improvement Service (delivering the DFG) should guide you in this matter and have these discussions on your behalf.

Building regulations of particular relevance to adaptations

The designer will be familiar with all the building regulations, but some regulations may be of particular interest to families and OTs.

Ramped access

When planning the construction and siting of a ramp, the *Building Regulations 2010 Access to and Use of Buildings Approved Document M* stipulates that the ramp should have the following features:

- a surface that reduces the risk of slipping
- flights with surface widths of at least 1,200mm and with unobstructed widths of at least 1,000mm
- a gradient between 1:20 and 1:15
- the length of each flight at a given gradient meets the provision of diagram 3.1 in *Approved Document M*
- top and bottom landings, are provided to each flight
- an intermediate landing is provided between individual flights and any change of direction
- every landing is level and with a minimum of 1,200mm clear of any door (or gate)
- 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 2,000mm.

Please refer to Chapter 3: External access for further information.

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 kitchens or bathrooms) will have rapid ventilation (such as opening windows) of 1/20th of the floor area of the room, and background ventilation (through trickle vents in windows) of 8,000sq mm
- kitchens need not have an opening window, but must have background ventilation of 4,000sq mm and a mechanical ventilation unit providing extraction at the rate of 30 litres/second adjacent to a hob or 60 litres/second elsewhere
- bathrooms do not need to have a window that opens, but must have background ventilation of 4,000sq mm and a mechanical ventilation unit providing extraction at the rate of 15 litres/second – or passive stack ventilation.

Daylight

Habitable rooms must have windows with a glazed area equivalent to 1/15th of the floor area of the room.

The Party Wall etc Act 1996

This Act comes into play 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.

In these cases, you must establish whether the work falls within the Act. If it does, arrange for the notification of all affected neighbours and obtain formal consent for the work.

At least two 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'.

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).

The 'award' document:

- sets out the work that will be carried out
- says when and how the work will be carried out (for example, 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. 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 in good time. Any problems can then be identified before the scheme becomes detailed and expense is incurred. (See the Department for Communities and Local Government's explanatory booklet: *Party Wall etc ACT 1996*.)

The Party Wall etc Act 1996 only applies to England and Wales. Scotland and Northern Ireland rely on common law rather than legislation to settle party wall disputes. Neighbouring owners can negotiate to allow work to proceed – and access can be forced through the courts if necessary.

Regional variations

Any variations between countries in the UK have been removed as it is presumed that the local services would have access to up-to-date differences in planning, regulations and implementation.

References

- *The Building Regulations 1991*. *HMSO, 1991*. (Also subsequent amendments.)
- *The Building Standards (Scotland) Regulations, 1990*. HMSO, 1990. (Also subsequent amendments.)
- *The Building Regulations (Northern Ireland) 1994 Part R – Access and facilities for disabled people*.
- *The Building Regulations 2010 and the Building (Approved Inspectors etc.) Regulations 2010 (for England and Wales)*
- *The Party Wall etc Act 1996*. The Stationery Office, 1996.

- *HM Government. The Building Regulations 2010 - Access to and Use of Buildings Approved Document M.* www.gov.uk/government/uploads/system/uploads/attachment_data/file/506503/BR_PDF_AD_M1_2015_with_2016_amendments_V3.pdf

Appendix

Points to consider when considering adaptations

What type of home does the person live in currently?

house ☐ detached ☐ semi-detached ☐ terrace ☐ townhouse ☐ bungalow ☐ flat ☐
ground floor ☐ first floor or more ☐ caravan/mobile home ☐

Ownership details:
owner-occupied ☐ rented/private landlord ☐ Housing Association ☐ council ☐

Current external access: front/back/side

Consider parking, paths, steps, gradients

Internal access:
Consider: if stairs are straight or curved, internal steps, door widths, corridor/hallway widths

Bedroom:
Consider: location, access, size, contents to date, what equipment will be needed in the future, siblings and sexual overcrowding

Position of bedroom in relation to parents' bedroom?
Some parents may want to be on the same level as the child

Night-time care arrangements:
Consider: sleeping/waking night carers required, where they will be situated, room sharing - may disturb the other person, social, religious or cultural factors to be considered

Bathroom:

Consider: location, access, size, contents to date, measurements of existing bathware, what equipment will be needed in the future, is this bathroom shared?

Kitchen facilities:

Consider: location, access, size, contents to date, measurements of existing work surfaces, what equipment will be needed in the future, where feeds are prepared, requirements for clean preparation of feeds

Living room:

Consider: location, access, size, contents to date, what activities are carried out in here, equipment needs

Current adaptations/equipment used:

Considerations:

Size of patient:

Consider: how old the person is, and have they completed their growth?

Size and make of wheelchair:

Consider: how big the turning circle is, how long it is when used in tilt in space or reclined, if the person is likely to change their chair as they grow or their needs change, the weight of the wheelchair if a through-floor lift is being considered

Storage of equipment and everyday necessities:

Consider: standing frames/powered and manual wheelchairs/nippy/suction machines/ humidifier/lvr bag/ consumables/ feeds/pads, space for clothes and storage of personal items

Which equipment needs a power supply nearby? Are there appropriately located power supplies?

Consider: electric profiling bed/ventilator/suction/air mattress/bedside light/computer/TV

What are the functional implications of diagnosis now and in the future?

Consider: if the person is likely to require hoisting, wheelchair accessibility, ventilatory support

Manual handling:

Consider: number of carers/access required/space for safe moving and handling by the advised number of carers

Summary:

Goals: