



03

Chapter 03 – Home

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In a nutshell — Your home

1 You can create a positive home

Your home is a haven for all of you, but some things may cause your child difficulty.

Small changes can ensure they feel safe and comfortable. Some parents worry that their home will become too like a hospital. But it is entirely possible to make it feel homely.

2 Pushchairs and wheelchairs can help your child get more out of life

Your child can use a pushchair and a wheelchair to take them to the playground or school so that they have more energy to play and learn.

3 Equipment and adaptations to your home will make life easier

Life at home and school can be easier for your child and you if they have the equipment they need. And adaptations to your home can help make life easier for them and protect their muscles from unnecessary damage.

Equipment and adaptations will **increase your child's independence.**

Small changes can ensure they feel safe and comfortable.



Adaptations to your home can help make life easier.



Download Muscular Dystrophy UK's 'Adaptations Manual'.



4 You can get good advice about equipment and adaptations

Your child's occupational therapist will provide you with personalised advice about the equipment and adaptations to your home that your child needs. They will help you apply for grants to pay for them. And, if your home cannot be adapted, they can provide you with a medical referral for priority social housing.

Muscular Dystrophy UK also has excellent advice about equipment and adaptations which you can download from their website.

5 The Government's schemes can make transport easier

The Government can provide you with an adapted car through its Motability scheme and access to disabled parking spaces through its Blue Badge Scheme.

Ask your local authority for an occupational therapist sooner rather than later **because they often have long waiting lists.**



For more information

In this folder, you can find information about financial support for equipment and adaptations in the 'Financial Support' chapter.

On our website, you can find our 'Guide to Financial Support for DMD Families' which has more detailed information.

www.duchenneuk.org/resourcesforparents



Toys, games, books and pictures always create a bright stimulating environment for children.

Creating a positive home

When you create a positive home for your child, they'll be able to enjoy family life to the full.

Safety is the first consideration. Your child is likely to trip or fall, so remove hazards and provide support for the stairs. Then, they'll be able to move around comfortably.

Your child may also need more support in their seating at the table and in the living room.

These changes will increase their independence and security. And this will, in turn, increase your sense of well-being as a parent.

When you are making adaptations to your home, think about what your child will need in the coming years as well as in the next few months. It's much easier to start making changes before you need them than when things are already difficult.

**Duchenne UK
are here to support
you on your journey.**

Maclaren
has special
pushchairs for 2-8
year olds

Children find
their wheelchairs
liberating

Some
children
like playing tag in
their wheelchairs

Conserving your child's energy with pushchairs and wheelchairs

Pushchairs and wheelchairs can help your child get the most out of their energy.

If you wheel them to the park and back, they'll have more energy to run around and use the slides and swings with their friends.

And if you wheel them to nursery and school, they'll have more energy for learning and playing.

Pushchairs and wheelchairs don't have to be used all the time. Your child can just use them when they are tired or saving their energy for something fun or important.

Adaptive pushchairs

Your occupational therapist can recommend the best pushchair for your child.

Ask them about Maclaren's special needs pushchairs for 2- 8 year olds. You don't need to keep struggling with a little pram which was designed for toddlers.

Wheelchairs

Children and their parents often have very different feelings about wheelchairs.

Parents often see it as a sign that their child is deteriorating. So, they delay getting a wheelchair for as long as possible.

But many children see wheelchairs as liberating and want one much earlier than their parents.

Sometimes, the children will prefer a wheelchair to being in a specialist pushchair because it feels more grown up. The wheelchair gives them independence and helps them play with their friends. For example, some children use their electric wheelchair to play tag at lunch time.

Wheelchairs are typically provided by Wheelchair Services through the NHS, after a referral from your child's GP or occupational therapist.

Many NHS services have waiting lists so it does take time to get a wheelchair. So, you should start the process long before your child needs to use a wheelchair full-time.



Equipment for home and school

Night splints

Children with DMD often wear splints called ankle foot orthoses (AFOs). Splints help them to keep the range of movement in their ankles for as long as possible.

Every child needs to have splints which have been made specially for them. This is quick and painless and involves making plaster casts of their lower legs. The splints should be non-lined with breathable holes to minimise sweating.

Your child's orthotist or occupational therapist will order their night splints. They will also explain how the splints should be used.

Other equipment

Your child may also find it helpful to use the following equipment:

- Specialist chair
- Easy-grip cutlery
- Easy-grip pens
- Bathroom accessories
- Electric profiling bed

If your child can lift and lower their profiling bed using the electric controls, it will be much easier on your back.



Adapting your home

Your child will find daily life easier and more enjoyable if you are able to adapt your home to meet their needs.



They'll be able to be more independent and do more for themselves. And this will help them develop their skills and confidence.

Adaptations that your child will need soon

Many children are unstable coming down stairs. So, they find it safer to sit down on their bottom and go down one step at a time.

Ramps and handrails on steps can help to prevent stumbles and trips. But most local authorities won't pay for them or stairlifts because they are only temporary.

A lift can be a better option because you can get funding for them. Small lifts (called through-floor lifts) don't take up as much space as you might think.

Your child may have difficulties in the bathroom, so they may find it helpful to use specialist equipment. High potty chairs will provide support and reduce the strain on their thigh muscles. Bath chairs help them to get in and out of the bath. Chairs in the shower make it easier for them to wash. Your occupational therapist can give you advice about the different types of equipment available.

Adaptations that your child will need in the next three years

As your child comes to rely on support from their wheelchair, they will want to use it within your home. Then, the doors will need widening and the light switches will need to be moved to the right height. This will support their independence.

Voice-activated devices, such as wireless switches and Alexa-type devices, are helpful too.

As they need more support with washing and using the toilet, you'll need to get specialist equipment for bathing and toileting.

Adaptations that your child will need eventually

As their muscles deteriorate, your home will need more adaptations to meet your child's needs.

Renovations and moving house are expensive and stressful. So, it's best if you only have to do this once.

Advice about equipment and adaptations

You can get advice about the best equipment and adaptations for your child from your local authority and muscular dystrophy charities.

The process is the same for people who live in their own homes, rented homes and social housing.

Personalised advice from your local authority

Your local authority should refer your child to their occupational therapy team. If they don't, you should make the request yourself.

Occupational therapists often have waiting lists. And the process for adapting your current house or moving to a new house can take many years. So, it's best to get an occupational therapist for your child sooner rather than later.

Occupational therapists have two different roles:

- **Social care occupational therapy** – Equipment and adaptations in the home
- **Healthcare occupational therapy** – Bodily function

In some local authorities, these two roles are both performed by the same person. In other local authorities, they are performed by different people.

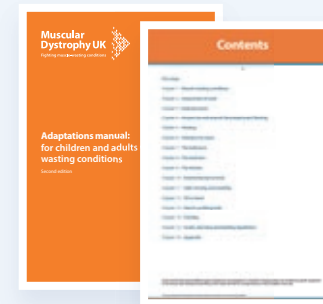
The social care occupational therapists will assess your family home by looking at whether it is suitable for your child over the long-term. For example, they'll see if it has level access or steps, and if the shower and bathing facilities are safe for them.

Once they have finished their assessment, they will give you personalised advice about your child's specific needs and the best ways to meet them. Then, you'll be able to plan changes to your current home or move to a new home.

They'll help you to apply for grants for equipment and adaptations. They'll also refer you to the NHS Wheelchair Services. If your home cannot be adapted to meet your child's needs, the occupational therapist can give you a medical referral for priority social housing.

General advice from charities and other organisations

You can get good general advice about equipment and adaptations from charities. But before spending money on changes, it's best to speak to your child's occupational therapist.



MUSCULAR DYSTROPHY UK

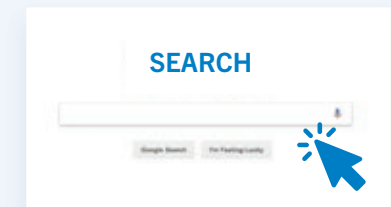
www.muscular dystrophyuk.org

Muscular Dystrophy UK have produced manuals about equipment, adaptations and wheelchairs which many families have found extremely helpful.

Their '**Adaptations Manual**' is a detailed guide to assessment of needs and solutions for stairs, bathrooms, bedrooms and kitchen.

OTHER SOURCES OF ADVICE

- **Contact a Family** – www.contact.org.uk
- **Carers' alliance** – Google the name of your local authority + carers' alliance
- **Disabled Children's Register** – Google the name of your local authority + disabled children's register
- **Home Improvements Agencies (can help with adaptations)** – Google the name of your local authority + home improvement agency



Assistance dogs can increase the well-being of the whole family.

These dogs provide companionship and emotional support.

Assistance dogs

When your child is about 8-10 years old, they might be able to get an assistance dog.

These dogs provide companionship and emotional support. They also help in practical ways, such as picking up things from the floor.

Assistance dogs can increase the well-being of the whole family.

You can find out more from Assistance Dogs UK.

www.assistedogs.org.uk

Transport

The Government can help you with transport, including providing a car and giving you access to disabled parking spaces.



MOTABILITY CAR
www.motability.co.uk

If your child is receiving the high level of Disability Living Allowance (DLA), then you are eligible for a motability car from the Government.

Under this scheme, you exchange all or part of your disability allowance for a lease on an adapted car of your choice.



BLUE BADGE FOR DISABLED PARKING SPACES
www.gov.uk/apply-blue-badge

You should probably get a blue badge so you can park in disabled parking spaces by the time your child is 3-4 years old.

Then, they won't have so far to walk in parks, shopping centres and leisure facilities. Also, disabled parking spaces tend to be bigger than standard spaces. This will make it easier for you to get their buggy or wheelchair in and out of your car.



