



Neuromuscular conditions

A guide for families with a child aged 5 – 12 years



Muscular
Dystrophy
Campaign



Neuromuscular Conditions: A guide for families with a child aged 5 – 12 years

Jane Stein
Muscular Dystrophy Campaign Regional Care Advisor
Oxford Muscle Centre

CONTENTS

| | |
|--|----|
| FOREWORD | 1 |
| INTRODUCTION | 2 |
| 1. MEDICAL ISSUES | 3 |
| 2. GETTING AROUND | 10 |
| 3. AT HOME: HOUSING AND EQUIPMENT ISSUES | 19 |
| 4. EDUCATION | 28 |
| 5. LEISURE AND HOLIDAYS | 34 |
| 6. SUPPORT FOR FAMILIES | 40 |
| 7. PERSONAL AND FAMILY MATTERS | 46 |
| 8. FURTHER READING | 53 |

FOREWORD

ABOUT THE MUSCULAR DYSTROPHY CAMPAIGN

The Muscular Dystrophy Campaign is the only UK charity focusing on all muscular dystrophies and related muscle diseases and has pioneered the search for treatments and cures for nearly 50 years. Staff provide practical and emotional support to people affected, and campaign to increase government spending on research, and the provision of vital equipment, such as powered wheelchairs. The charity raises public awareness about muscular dystrophies and aims to empower the people affected, their families and friends.

The Muscular Dystrophy Campaign has a nationwide grassroots network of Branches and organises hundreds of fundraising events to support its work.

ABOUT THE AUTHOR

Jane Stein is a qualified social worker and has been employed by the Muscular Dystrophy Campaign since 1993. She is based at the Oxford Muscle Centre.

Thank you to all the families whose photographs are featured in this booklet.

INTRODUCTION

This booklet has been written as a reference guide for families with a child aged approximately 5-12 years with a neuromuscular condition. It looks at the issues that may arise and offers guidance as to where to go for additional information.

It is important to remember that in this booklet we are talking about children with a range of neuromuscular conditions, including Spinal Muscular Atrophy (SMA types II and III), congenital muscular dystrophy, Becker muscular dystrophy, myotonic dystrophy and many other (rarer) conditions covered by the Muscular Dystrophy Campaign. All children (even if they have the same diagnosis) are different and not everything written here will be relevant to you. If in doubt seek advice from your specialist clinic or from the Muscular Dystrophy Campaign.

The Muscular Dystrophy Campaign publishes factsheets on a range of specific neuromuscular conditions. It also publishes the following items which you may like to read in conjunction with this book.

- Factsheets on a range of medical management and lifestyle issues
- Research updates
- *Target MD* – the charity's quarterly magazine
- Booklets for children
- *Inclusive Education Guidelines* (aimed at schools) 2nd edition
- *Adaptations Manual* – a guide to adapting and equipping your home.
- *Wheelchair Provision for Children and Adults with Muscular Dystrophy and other Neuromuscular Conditions* (aimed at Wheelchair Services staff but also useful for service users)
- *Hey, I'm here too!* (for siblings)

1. MEDICAL ISSUES



AN OVERVIEW

All children with a neuromuscular condition should be under the care of a senior doctor (usually known as a “consultant”) with specialist knowledge of this group of conditions. Advice on the location of specialist clinics is available from the Muscular Dystrophy Campaign. As a parent it is important that you learn all you can about your child’s condition so that you can prepare yourself, and your child, for the road ahead and make the choices that are right for you. You will need to work closely with a range of professionals in your locality to achieve this.

LEARNING ABOUT YOUR CHILD’S CONDITION

Unless other members of your family are already known to be affected by the same neuromuscular condition that your child has, it is unlikely that you will be familiar with the condition. At some point after the diagnosis you will want to learn more and it is important that you seek this information from appropriate sources. The senior doctors at your specialist clinic should be able to answer your medical queries. For more general advice and support you may like to talk to the Muscular Dystrophy Campaign or one of the condition specific support groups listed at the back of this book. Remember that whilst it is important to take on board information at a pace you are comfortable with, many of the neuromuscular conditions are progressive (that is, they get worse with time) and some advance planning (for which you need knowledge) is essential.

MEDICAL ISSUES WHICH MAY BE OF RELEVANCE

In a general booklet such as this it is difficult to cover every topic that will be of relevance to every individual but the following may need to be thought about.

FRACTURES

If a child should fracture (break) an arm or a leg it is important that the team that normally cares for your child is notified as quickly as possible. This is because immobilisation for long periods of time, particularly in plaster casts, should be avoided, as muscle strength once lost, cannot easily be regained. Despite the risk of fractures, in most cases you should not unduly restrict the physical activities of a child with a neuromuscular condition – play is very important at this age.

CONTINENCE

Most children with neuromuscular conditions do not experience problems with bladder or bowel continence. The notable exception to this is congenital myotonic dystrophy where significant problems may be seen. If a child has very restricted mobility or is wheelchair dependent, problems with constipation may be seen (especially in young children with SMA type II). Management of this difficulty is normally through a diet rich in fibre (found in foods like bran, brown bread, fruit and vegetables). Doctors can advise on the use of medication to help if necessary. Constipation can be painful and parents should seek help for their child sooner rather than later.

Obviously the less mobile a child is the greater the difficulty they will have in accessing the toilet facilities quickly. The best thing to do is to try to establish a regular pattern of using the toilet facilities, especially in school. Do not encourage your child to restrict their liquid intake as this can cause dehydration.

VACCINATIONS

In many children with neuromuscular conditions chest infections are very troublesome. For this reason the specialist may recommend an annual flu vaccination and perhaps a pneumococcal vaccination. Take expert advice from your consultant on this issue. A new pneumococcal vaccine is now being added to the child immunisation programme to fight against pneumococcal meningitis pneumonia.

CHEST INFECTIONS

Chest infections usually need to be treated aggressively with early antibiotics and chest physiotherapy. Your child's GP should be made aware of this. Admission to hospital may be necessary if the chest infection does not respond to the antibiotics.

Try to ensure that you know how to perform chest physiotherapy and how to operate any specialist equipment you have been supplied with such as a suction machine. Occasionally some consultants/GPs may suggest that you have prophylactic (preventative) antibiotics all of the time or that you have a stock at home ready for use as soon as a chest infection starts. Discuss this further with your consultant if it is a concern.

HEART MONITORING

The heart is a muscle and in some (but not all) neuromuscular conditions there is a need to monitor the heart's condition and function. Your child's neuromuscular specialist will advise on this need. If problems are detected there are often things which can be done to help. The Muscular Dystrophy Campaign publishes a factsheet *Heart check* which gives general information.

ANAESTHETICS

In some neuromuscular conditions respiratory function may be compromised and where this is the case, as far as possible, general anaesthetics should be avoided. Particular care needs to be taken by people with myotonic dystrophy. If a child does need a general anaesthetic it is important that the anaesthetist has advance knowledge of the child's medical condition. The Muscular Dystrophy Campaign publishes a factsheet called *Anaesthetics* which gives general information but you should also seek advice on this issue from your consultant.

VENTILATION

For a small number of children with a neuromuscular condition the use of a ventilator may be either essential or desirable. Non invasive ventilation involves the use of a ventilator and facial mask, often only at night whilst sleeping. No surgery is involved. Children with SMA II or some types of congenital muscular dystrophy, amongst others, may fall into this category. A much smaller number of children may need to use a ventilator in the daytime as well, and very occasionally, a child may require a tracheostomy to assist with breathing.

Lung function is usually monitored in specialist muscle clinics and if there are concerns further studies are undertaken. Children who use ventilators are generally under the care of a respiratory consultant in addition to the neuromuscular specialist. The Muscular Dystrophy Campaign publishes a factsheet, called *Making Breathing Easier*, on this issue, along with a factsheet called *Ventilation – Questions To Ask Your Consultant*.

SPINAL SURGERY

Some children (generally, but not always, those who are unable to walk) may develop a scoliosis (a sideways curvature of the spine). Spinal surgery may be suggested to try to fully or partially correct the curve. The surgery requires a skilled and experienced surgeon and anaesthetist. If spinal surgery is being considered it is vital that you and your child obtain all the information that you feel that you need to make the decision about whether to go ahead with surgery, and that you are aware of the after care that will be needed. The Muscular Dystrophy Campaign publishes two factsheets on spinal surgery that may be helpful – *Surgical Correction of Spinal Deformity in Muscular Dystrophy and other Neuromuscular Conditions* and *Spinal Surgery – Questions to Ask* – but the surgeon and his/her team should always be fully consulted.

PAIN

Pain is not usually a feature of any of the neuromuscular conditions. Discomfort can be felt if joints become stiff – stretching exercises (as shown by a physiotherapist) should help prevent this happening. Some children may complain of occasional muscle cramps – warm baths and gentle massages generally help.

DIET

Generally speaking there is no evidence that any special diet assists a child with a neuromuscular condition. Aim to maintain weight within the normal range as putting on weight can make many activities more difficult. If your child is failing to gain weight appropriately the advice of the specialist should be sought and referral to a specialist dietician may then be made. Sometimes children with congenital muscular dystrophy or with SMA II face these difficulties and alternative methods of feeding (for example, gastrostomy) may be suggested. The Muscular Dystrophy Campaign publishes two factsheets that may be useful: *Gastrostomy* and *Nutrition and Feeding in Individuals with Neuromuscular Conditions*.

ALTERNATIVE THERAPIES

Sadly there is no evidence of any alternative therapy proving helpful in the treatment of neuromuscular conditions. Some non-invasive therapies may be pleasant and relaxing but do seek guidance from your child's specialist first. You should avoid expensive "treatments", invasive therapies or trips

abroad which promise cures. Remember that research is well co-ordinated internationally and your child's specialist will be pleased to share with you any advances that are made. You can refer to the Muscular Dystrophy Campaign's factsheet, *Alternative Therapies* for more information.

GENETICS

Most (but not all) of the neuromuscular conditions are genetic (that is, inherited) conditions, although sometimes a condition arises as a result of a new mutation in the child themselves. It is important that you are offered genetic counselling at an early stage. There are specialist teams of genetic counsellors across the UK and your child's consultant should be able to make the appropriate referral for you. The Genetics Interest Group can help you find your nearest clinical genetics centre. Contact them at **www.gig.org.uk** or **020 7704 3141**. You may like to read the Muscular Dystrophy Campaign's factsheet *Inheritance and the Muscular Dystrophies*.

RESEARCH

Most families like to be kept up to date with research advances. The latest information is available through the Muscular Dystrophy Campaign website **www.muscular-dystrophy.org** and in its quarterly magazine, *Target md*. Staff at the charity can also answer research questions. Additionally you can subscribe to our monthly e-newsletter by emailing **news@muscular-dystrophy.org**.

PHYSIOTHERAPY

Physiotherapy is concerned with the physical treatment and management of a condition with the aim of maintaining maximum possible ability at every stage of the condition. All children with a neuromuscular condition should see a physiotherapist regularly, and most should be shown a daily programme of stretching exercises. Physiotherapy should be provided by the NHS, free of charge. If your child is not seeing a physiotherapist regularly speak to your child's consultant as a matter of urgency. Some children may be offered hydrotherapy – this involves a programme of exercises in a warm water swimming pool.

The Muscular Dystrophy Campaign has set up a network for physiotherapists to share information about good practice. Please encourage your physio to join. Email **info@muscular-dystrophy.org** for details.

ORTHOSES

Orthoses are splints, callipers or anything worn externally to support the limbs or body.

Common orthoses include:

- Night splints – as the name suggests these are meant to be worn at night. They hold a joint in a neutral position. They are lightweight and lower limb splints are not designed to be walked in. Many children find night splints uncomfortable especially in hot weather. If your child cannot tolerate wearing them at night you could compromise by suggesting they wear them in the evening when watching TV.
- Callipers (also known as KAFOs – **k**nee, **a**nkle, **f**oot, **o**rthoses) – these extend from the toes to the hips and are designed to support the legs, making it possible to continue to walk or stand, despite the muscle weakness. Children will walk with straight legs and swing from the hip, perhaps holding on to someone's hand for extra support. Usually you are only able to walk short distances in callipers – mostly indoors.
- Spinal jacket/brace – this is a jacket made to support the back. It is frequently used in children who are wheelchair users from an early age and who have a scoliosis. The Muscular Dystrophy Campaign publishes a factsheet called *Guidelines for Exercise and Orthoses in Children with Neuromuscular Disorders*.

STANDING FRAMES

If walking is difficult but a child is able to take weight through their legs and stand it is important to encourage this. Standing has health benefits in terms of maintaining the range of movements in the joints and good posture. It is also beneficial to the function of the bladder and the circulatory, digestive and respiratory systems. Having the ability to stand also makes transfers much easier.

Standing frames and tilt tables (supplied on the advice of your physiotherapist) are available to support a child in a standing position. Some people may make use of a sophisticated wheelchair with a built in standing facility. Such chairs are almost never provided by Wheelchair Services and it is essential that you take expert advice from a professional prior to purchasing specialised equipment like this as contractures at the ankles, knees or hips may mean that such a facility cannot be used safely.

2. GETTING AROUND



ACHIEVING MOBILITY THROUGH THE USE OF A WHEELCHAIR

Some children with a neuromuscular condition will require the use of a wheelchair to get about – even if they are able to walk short distances. The type of chair that is needed will depend upon a range of things including the child's condition, age and where the chair will be used. Many parents worry about telling their child that they need to use a wheelchair but most children are very accepting of the fact. To a child a wheelchair (especially a powered one) can represent freedom of movement and independence and this in itself is extremely important.

PROVISION OF WHEELCHAIRS

For people who have difficulty walking, wheelchairs are provided by NHS Wheelchair Services. Ask your child's physiotherapist or occupational therapist about the service in your local area. They should be able to make a referral for your child. Alternatively, in some areas you can refer yourself, or a referral can be made via your GP. All Wheelchair Services have criteria for provision and these vary from area to area so it is a good idea to ask for a copy. In a few areas, no wheelchair will be provided unless a person is completely unable to walk but in most places, your child will initially be supplied with a manual wheelchair to assist with distances. The Muscular Dystrophy Campaign is campaigning to ensure people's needs in this area are met and has produced guidelines called *Wheelchair Provision for Children and Adults with Muscular Dystrophy and Other Neuromuscular Conditions*.

MANUAL WHEELCHAIRS

A manual wheelchair is one that needs to be pushed either by the user or a carer. It has no battery. Manual wheelchairs are usually available free of charge from Wheelchair Services. It is important to discuss your child's needs with the physiotherapist, occupational therapist and the staff at Wheelchair Services. For example, if your child is going to be pushing themselves around in the chair it is vital that the chair is lightweight, however if it is only an occasional back up to a powered chair, then a more basic manual chair may be fine. The chair must be the right size for the child, must promote a good sitting posture and must be suited to the environment it will be used in. Most children will require supportive seating. Wheelchair Services staff should assess your child for this and provide what is needed. Seating must be reviewed regularly.

If a child will be travelling in a vehicle whilst sitting in the chair (common on school runs) then a headrest is essential, as is a secure way of clamping the chair down and supporting the user in a safe sitting position. Everybody who has a powered chair also needs a manual chair. Not everywhere is accessible in a powered chair and powered chairs can break down.

POWERED WHEELCHAIRS

A powered wheelchair is a chair which nobody needs to push – it has a battery. Even children who can walk a little will benefit from the use of a powered chair if their arms are too weak to push themselves far in a manual wheelchair. It is a question of getting the balance right – you wish to encourage your child to continue to walk/push their manual wheelchair, but you also need to ensure they have a means of mobility that lets them get about easily and quickly, allowing them to participate more fully in activities with their friends.

Powered wheelchairs are available through Wheelchair Services but only for those individuals who meet the criteria. As mentioned earlier, there are different eligibility criteria in each area but parents of young children should note that it is not acceptable to discriminate on grounds of age and we have seen children as young as 14 or 15 months successfully use powered chairs (under adult supervision, of course). It is possible to have a powered chair fitted with dual controls whereby the parent/carer can take control of the powered functions of the chair when necessary.

Almost everybody who requires the use of a powered wheelchair needs one that can be used outdoors but initially Wheelchair Services will often only offer an indoor chair. It is not usually a valid argument to say that a child must learn to control a chair indoors for a period of several months first. A child of average intelligence will master this skill very quickly. Wheelchair Services will only be able to fund the most basic chair that meets a child's needs. Usually they will not fund more sophisticated chairs that, for example, have height adjustable seats. If you wish to obtain a more sophisticated chair than Wheelchair Services can provide then a voucher towards the cost of the chair of your choice may be offered (provided they agree that your chosen chair meets your child's requirements). Vouchers are not available in all areas or in Scotland.

An indoor/outdoor powered chair is referred to as an EPIOC (**e**lectrically **p**owered **i**ndoor/**o**utdoor chair). A chair which can only be used indoors is referred to as an EPIC (**e**lectrically **p**owered **i**ndoor **c**hair). Powered wheelchairs can be user operated or they can be dual or attendant controlled. For young children, or those with learning difficulties, a dual controlled chair is preferred as it allows a carer to operate the chair where necessary.

Initially you should discuss your child's powered wheelchair needs with their physiotherapist or occupational therapist. A referral should then be made to Wheelchair Services, even if you do not think that your child will meet the criteria for a powered chair. Explain your child's condition to them and ask them to consider assessing for and providing an EPIOC. If they refuse, ask them for a letter detailing their reason for the refusal. Such letters are often required when trying to raise funds privately and you may also like to use it to show unmet need in your locality. Occasionally education departments will fund powered chairs – it is worth asking. They may do this if the distances to be covered around the school are large.

Privately funded powered wheelchairs

Some families decide to purchase a wheelchair privately. If you decide to do this it is vital to get a proper assessment done – do not rely on sales reps for this. There are assessment centres which offer this service. To find your local centre, call **0800 559 3636** or visit **www.mobility-centres.org.uk**, or your occupational therapist/physiotherapist may be able to help. Whizz-Kidz offers an assessment service, tel: **020 7233 6600** or web: **www.whizz-kidz.org.uk**. Some NHS Wheelchair Services will also help with assessments – especially if they are giving a voucher towards the cost.

With respect to funding a private chair the following options are open to you:

- To purchase it yourselves (this is difficult for most families as chairs cost upwards of £3,500);
- To use the mobility component of your child's Disability Living Allowance and purchase a chair through the Motability Scheme (see below for contact details);
- To use the mobility component of your child's Disability Living Allowance to take out a loan to fund a wheelchair (consider the interest rates very carefully);

- To approach charities. The Muscular Dystrophy Campaign's equipment charity, the Joseph Patrick Trust, will usually offer some help towards the cost. The Variety Club may assist as may Whizz-Kidz or the Caudwell Charitable Trust. Try to find a professional to write letters of support and, ideally, to co-ordinate the fundraising.

Details for these organisations are given below. See also the section headed *Charities that can help fund equipment* for a list of other charities who can also be approached for help.

Joseph Patrick Trust
Muscular Dystrophy Campaign
61 Southwark Street
London SE1 0HL
Tel: **020 7803 4800**
Information and Support Line: **0800 652 6352** (freephone)
Email: **JPTgrants@muscular-dystrophy.org**
Web: **www.muscular-dystrophy.org**

Motability (Dept for Wheelchairs and Scooters)
Route2Mobility
Newbury Road
Enham Alamein, Andover
Hampshire SP11 6JS
Tel: **0845 607 6260**
Web: **www.motability.co.uk**

The Variety Club
93 Bayham House
London NW1 0AG
Tel: **020 7428 8100**
Web: **www.varietyclub.org.uk**

Whizz-Kidz
Elliott House
10-12 Allington Street
London SW1E 5EH
Tel: **020 7233 6600**
Web: **www.whizz-kidz.org.uk**

The Caudwell Charitable Trust
Minton Hollins
Shelton Old Rd
Stoke on Trent
ST4 7RY
Tel: **0845 300 1348**
Web: **www.caudwellcharitabletrust.com**

If your child has SMA the Jennifer Trust for Spinal Muscular Atrophy may also be able to assist.

JTSMA
Elta House
Birmingham Rd
Stratford-upon-Avon
Warwickshire
CV37 0AQ
Tel: **01789 267520**
Web: **www.jtsma.org.uk**

Remember that in addition to the cost of the chair you will need to allow for the ongoing costs of insurance (at least third party in case your child hurts anyone accidentally – this is not expensive) and maintenance/repairs. Be wary of expensive maintenance contracts but if you choose not to take out a contract do put money aside to meet these expenses and know who to contact for repairs/maintenance. It is a good idea to keep records of service dates and any problems with the chair.

VEHICLES

If your child has mobility difficulties you need to select your vehicle carefully. Children who can walk, or who can stand to transfer, will find it easier to get into a vehicle that has reasonably high seats that do not slope backwards. Cars where the child's seat can only be accessed by tipping forward the front passenger seat should be avoided. If you need to assist your child into/out of the car try to ensure that you have sufficient room to manoeuvre. Consider using a sliding board. If your child uses a wheelchair you will need to look at how you will get the chair in and out of the car and where you can store it in the car.

If your child needs to travel sitting in their wheelchair (ensure that their wheelchair has a headrest) you will have to consider a specialised wheelchair accessible vehicle. These are very expensive when purchased new. Second-hand vehicles are advertised in several disability organisation magazines – for example in *Target md* and *Disability Now*. To help ensure that you choose a suitable vehicle you might like to consider having an assessment at a specialist centre. The addresses of these independent centres are available from: The Forum of Mobility Centres on **0800 559 3636** or visit **www.mobility-centres.org.uk**

These centres can also give up to date advice on which firms adapt vehicles. There is a small charge for assessments as the centres are not for profit organisations.

If your child has been awarded the high rate mobility component of Disability Living Allowance and the award is valid for at least another year (children with most neuromuscular conditions should have DLA awards that are for life, or at least until their 16th birthday) you should be eligible to use the Motability Scheme if you wish. Motability is a charity which, in partnership with the government (Department of Work and Pensions) and private companies, aims to provide vehicles and wheelchairs to disabled people. Through this scheme you can elect to use the mobility component of DLA to lease a new vehicle for three years, buy (on hire purchase) a new or second hand vehicle over a period of two to five years or purchase a new or second hand wheelchair/scooter over a period of one to three years. Parents can do this on behalf of their disabled child.

For advice on the Motability car schemes contact:

Motability Operations
City Gate House
22 Southwark Bridge Road
London SE1 9HB
Tel: **0845 456 4566**
Web: **www.motability.co.uk**

Assessment centres will also be able to provide information about the Mobility Road shows which are held in various locations on an occasional basis. These shows provide an opportunity to view vehicles and vehicle adaptations. You can also visit **www.mobilityroadshow.co.uk**

DRIVING

It is strongly recommended that parents (both parents in the case of two parent families) learn to drive as there will be many occasions when you will need to attend appointments and get out and about as a family. For families on annual incomes below £23,000 and with savings below £18,000 (2008 figure) the Family Fund will often help fund driving lessons. They are at:

The Family Fund
Unit 4, Alpha Court
Monks Cross Drive
Huntingdon, York YO32 9WN
Tel: **0845 1304542**
Web: **www.familyfund.org.uk**

THE BLUE BADGE (PARKING) SCHEME

The Blue Badge scheme provides a national arrangement of parking concessions for people with severe mobility difficulties. It has replaced the old orange badge scheme and can also be used in some places within the European Union.

To qualify for a blue badge the disabled person must meet one of these criteria:

- Be in receipt of the higher rate of Disability Living Allowance mobility component
- Have a permanent and substantial disability that means that they have very considerable difficulty in walking.

Children under two are not eligible. (There are some other criteria that are not usually applicable to people with a neuromuscular condition – for example, you are registered blind). The blue badge allows you to park in areas where others are not allowed to, providing that it is safe to do so. The badge can also entitle you to free parking in some areas. You can obtain information on the blue badge scheme from your local social services department (social work department in Scotland). The blue badge can only be used when the disabled person is in the car or is being picked up/dropped off.

ACCESSIBLE TOILETS

A major anxiety when travelling around can be the availability of accessible public toilets. The charity RADAR operates a national key scheme whereby disabled people can purchase a key which opens most disabled public toilets. You can also purchase a directory listing the location of these toilets. The key costs £3.50 and the directory £10.25 (2008 figures – includes postage costs).

You can contact RADAR at:

12 City Forum

250 City Rd

London EC1V 8AF

Tel: **0207 250 3222**

Web: **www.radar.org.uk**

3. AT HOME: HOUSING AND EQUIPMENT ISSUES



HOUSING ISSUES

This is a huge topic. If you have a child with a neuromuscular condition you will need to ensure that your home is suited to their needs. The Muscular Dystrophy Campaign publishes an *Adaptations Manual* which is a very detailed guide to all aspects of adapting your home (including the planning of what is required and the equipment to consider). It is strongly recommended that you obtain a copy of our CD. It was last updated in 2004.

Generally speaking children who are wheelchair users require a wheelchair accessible bedroom with an en suite bathroom, properly equipped to maximise independence. In addition they must be able to get in and out of the property and around all the communal rooms. Your local occupational therapist will advise you but the important thing is to start discussions at an early stage as the whole process usually takes 18 months to two years. Ensure that your occupational therapist has a thorough understanding of your child's condition and how it may change over time. Do not assume that you will have to move to a bungalow. Bungalows can be poor choices if they have small, narrow corridors or tiny rooms. Alternatives to moving to a bungalow are to build an extension or to install a through-floor lift.

If you are the tenant of a council or housing association owned property talk to them at an early stage and get support from your occupational therapist. The council or housing association may consider adapting your current home or they may arrange a transfer. Tenants of privately rented properties are in a difficult position as you cannot easily carry out major adaptations to someone else's property. A move to a council /housing association property may be sensible – this usually needs to be looked at whilst a child is still very young.

Stair lifts are rarely a good long term option because usually they do not maximise a child's independence as a child will need lifting on/off them and may not be able to safely balance during use. However they can sometimes prove useful as a temporary measure if your child is unable to climb stairs and adaptations are not yet completed.

Disabled Facilities Grants (known as DFGs) are available to assist families with the cost of essential adaptations to their home. The maximum payable under the DFG scheme is £25,000 in England and Northern Ireland and £30,000 in Wales. Prior to December 2005 families applying for a DFG

faced a means test, but, thanks to campaigning by charities including the Muscular Dystrophy Campaign, where the adaptations are for a child under 18, the means test is no longer applied.

If you have access to a specialist Care Advisor/Neuromuscular worker do involve them in discussions about your adaptation plans as their expertise can be invaluable. It is essential to note that the DFG can only be used to finance adaptations approved by your occupational therapist and the Grants Officer at your local council. DFGs cannot be paid retrospectively and you should never agree to work being carried out until you have the correct approval in writing.

In Scotland the grant used to assist families with adaptations is the 'home improvement grant'. This was increased to £20,000 in October 2004 but is now means tested. The Muscular Dystrophy Campaign continues to lobby the Scottish Executive on this issue. It is hoped that the grant will ultimately be non-means tested for children under 18. Updates on the situation are available via the Scottish Executive website.

BATHS/SHOWERS

You will need to make a decision as to whether a bath or a shower is preferred. For many children a bath is the preferable option as the child is better supported in a bath, a carer gets less wet assisting the child and a bath tends to be warmer and more relaxing. Of course, it may well be necessary to look at the use of a hoist to get in/out of the bath.

BATHROOM EQUIPMENT

When planning an adaptation much thought needs to be given to the bathroom equipment to ensure that a child's independence is maximised and their dignity maintained. Advice on equipment to consider is detailed in the *Adaptations Manual*. It includes details on toilets with a wash/dry facility and adjustable height washbasins.

HOISTS

A hoist is a piece of equipment used to transfer a person from one place to another in a supportive sling. Slings are available in different shapes and sizes, so you may need to try a few before your child is comfortable.

There are special slings available for use in the bathroom. They are often made of a lightweight netting material which drains and dries easily. Your occupational therapist will be able to offer advice.

As a child gets older it may be necessary to look at the use of a hoist for transfers and you will need to consider this when planning housing adaptations. You should not lift your child as you risk injuring yourself. If carers come into the home to assist your child, you will find that they are not allowed to lift at all – they will insist on using a hoist. There are several types of hoists available and several situations where their use is needed. Mobile hoists are on wheels and can be moved around a building to be used in different places. Such hoists are often seen in hospitals and may be suggested for use in your child's school. Ceiling track hoists, as the name implies, are fixed to the ceiling. These have the advantage of not taking up floor space and being a little more "out of sight". They tend to be used in the home where there are regular transfers between set places (for example, from the bedroom into the en suite bathroom). Other hoists are available, for example, to assist with transfers in and out of a vehicle or in and out of a bath.

BEDS

For many young children no special bed is required but beds which are difficult to get into (for example, because they involve climbing up a ladder to access them) should be avoided. It is usually easier to get into and out of a bed that is fairly high. If the child has a low bed it may be possible to use bed riser blocks to make it higher. (Blocks are available from occupational therapists or can be purchased by mail order.) For children who are wheelchair users, beds which are electrically height and section adjustable are often beneficial to both the carer and child. For the carer, the ability to alter the height of the bed makes assistance with dressing easier and can make transfers simpler. The section adjustability allows the child to alter their position and to sit up/lie down unaided. You can get advice on the type of bed to assess from the Muscular Dystrophy Campaign – it is important to get advice as not all adjustable beds are suitable.

In different areas different arrangements are in place for the supply of adjustable beds. Initially contact should be made with the district nurse at your GP's surgery. There is often a specialist nurse who is responsible for the assessment and supply of specialist beds. In some areas social service

occupational therapists may be involved in the process. Occasionally such beds may need to be privately funded. The cost of such beds is a little over £2000 (2008 prices).

It is important to look at your child's positioning in bed. Lying all night in some positions can exacerbate postural problems. Your physiotherapist/occupational therapist can advise and may recommend using pillows, T rolls or a sleep system to hold a position.

COMPUTERS

Most children will benefit from acquiring computer skills. They may find doing large amounts of writing tiring and so speed and accuracy on the computer are important.

If you would like to acquire a computer for home use the Aidis Trust may be able to assist with the cost (and with assessment of the type of equipment needed). The Joseph Patrick Trust, which is part of the Muscular Dystrophy Campaign, may also assist towards the cost.

Aidis Trust
54 Commercial Street
London E1 6LT
Tel: **020 7426 2130**
Web: **www.aidis.org**

Joseph Patrick Trust
Muscular Dystrophy Campaign
61 Southwark Street
London SE1 0HL
Tel: **020 7803 4800**
Information and Support Line: **0800 652 6352** (freephone)
Email: **jptgrants@muscular-dystrophy.org**
Web: **www.muscular-dystrophy.org**

Operating systems such as Windows XP have built in accessibility provision and you can find it in All Programmes/Accessories/Accessibility – Access wizard, magnifier, narrator, on screen keyboard, utility manager. Using an on screen keyboard enables a person with restricted hand or arm movement to write text easily by using the mouse or trackball.

Within school it is worth pushing for extra computer lessons/time from an early age. A laptop should be provided as early as possible. If your child has a statement of Special Educational Needs or, in Scotland, a Co-ordinated Support Plan, this provision should be written into their statement.

VIEWING EQUIPMENT

There will be times when you will find it helpful to view equipment, just to know what is available. Big equipment shows held annually include Naidex and Independent Living Scotland, organised by Emap Healthcare. Emap can be contacted on **020 7874 0200** or see the Naidex website at: **www.naidex.co.uk**

Entry to these shows is free. The venues are fully wheelchair accessible with nearby parking for blue badge holders. Wheelchairs and scooters to get around the exhibition can usually be hired (book in advance).

Specialised bathroom equipment, hoists, special beds, wheelchairs and environmental controls are all exhibited at Naidex and the Independent Living Shows. The equipment stands are commercial ones staffed by sales reps. There are also some related stands, for example stands with information about specialised holiday companies, charities and disability benefits. The Muscular Dystrophy Campaign often has a stand at these exhibitions.

If you wish to look at vehicles suited to the needs of a wheelchair user then the Mobility Roadshow is worth visiting. You can get information from the website: **www.mobilityroadshow.co.uk**

There are smaller exhibitions of equipment and you can find details of these on the Muscular Dystrophy Campaigns website: **www.muscular-dystrophy.org.uk** or call **020 7803 4800**.

You can also view equipment at Independent Living Centres (sometimes called Disabled Living Centres). You can obtain a list of the location of these from:

Assist UK, Redbarn House
4 St Chads Street, Manchester M8 8QA
Tel: **0870 770 2866**
Web: **www.assist-uk.org**

At Independent Living Centres you will have access to independent advice from a therapist. Make an appointment to go along – do not just turn up. It may be helpful to go with your occupational therapist when assessing for equipment your child will use at home.

Some catalogue firms have stores where you can view equipment. You can view equipment in the following catalogues:

Care Shop

Tel: **01204 540350**

Web: **www.careshop.co.uk**

Keep Able

Tel: **08705 20 21 22**

Web: **www.keepable.co.uk**

It is unusual to find the specialised equipment you will need in catalogues but they can be useful for small pieces of equipment (for example, transfer boards and riser blocks for chairs). Often the equipment they sell is available free of charge via the occupational therapy services. Never purchase expensive or very specialised equipment without a demonstration and a proper assessment from a qualified professional.

CHARITIES THAT CAN HELP TOWARDS EQUIPMENT

There may be times when you will choose to consider approaching charities for assistance with the cost of specialised equipment for your child. It can be helpful if a professional will take on the role of co-ordinating this but if you do it yourself you will need letters of support from professionals. Charities that may assist include the following:

Joseph Patrick Trust

Muscular Dystrophy Campaign

61 Southwark Street

London SE1 0HL

Tel: **020 7803 4800**

Information and Support Line: **0800 652 6352** (freephone)

Email: **JPTgrants@muscular-dystrophy.org**

Web: **www.muscular-dystrophy.org**

The Family Fund
Unit 4, Alpha Court
Monks Cross Drive
Huntingdon
York YO32 9WN
Tel: **0845 1304542**
Web: **www.familyfund.org.uk**
(Please see section in this book on the Family Fund)

REACT
St Lukes House
270 Sandycombe Lane
Richmond
Surrey TN9 3NP
Tel: **020 8940 2575**
Email: **react@reactcharity.org**
Web: **www.reactcharity.org**
(For children with life limiting/life-threatening conditions)

Family Welfare Association
501-505 Kingsland
London E8 4AU
Tel: **020 7254 6251**
Email: **fwa.headoffice@fwa.org.uk**
Web: **www.fwa.org.uk**

Independence At Home
Bamford Cottage
South Hill Avenue
Harrow HA1 3PA
Tel: **020 8864 3818**

The ACT Foundation
The Gate House
2 Park Street, Windsor
Berks SL4 1LU
Tel: **01753 753900**
Email: **info@theactfoundation.co.uk**
Web: **www.theactfoundation.co.uk**

The Catharine House Trust
Ridge Cottage
New Cut
Westfield
East Sussex TN35 4RL

BDF Newlife
Hemlock Way
Cannock
Staffordshire WS11 7GF
Tel: **01543 468888**
Email: **info@bdfnewlife.co.uk**
Web: **www.bdfcharity.co.uk**

Within each area there will also be local charities. Your Citizens Advice Bureau (CAB) will have lists of these as well as local contacts for the Rotary Club, Lions and so on. Sometimes local solicitors manage private charitable trusts. If your family has any connections with the services their charities may help.

If you or a family member works in a specific area (for example, banking, teaching, transport) check if there is a relevant charity that could help. Again the CAB can advise you.

The Information Officers at the Muscular Dystrophy Campaign have access to the computer software package called *Funder Finder for People in Need*. This form helps to identify sources of charitable funding relevant to you and your situation.

Libraries will carry guides to grant making organisations. Do check carefully that the organisation you are writing to is relevant to your situation otherwise you will waste your time and money in writing to people who cannot help.

4. EDUCATION



ISSUES TO CONSIDER

There are many issues to consider here from choosing the right school to obtaining a statement of Special Educational Needs. The important thing with educational issues is to plan in advance. Most children with a neuromuscular condition can be educated at a mainstream school throughout their school careers but if your child has significant learning difficulties it may be appropriate to consider a special school. The Local Education Authority (known as the LEA) has a duty to provide appropriate education for your child but they do not have a legal duty to provide “the very best”.

If you live in Scotland please note that the education system is slightly different from the rest of the UK. Local Education Authorities are known as Education Authorities (EA's) and instead of a Statement of Educational Needs your child may have a Co-ordinated Support Plan. Further information is available from:

Enquire
Children in Scotland
4 Shandwick Place
Edinburgh, EH2 4RG
Helpline: **0845 123 2303**
Email: **info@enquire.org.uk**
Web: **www.enquire.org.uk**

This service provides independent advice and information to parents, carers and students on special educational needs within the Scottish educational framework.

There is some helpful literature available that you might like to take a look at. From the Muscular Dystrophy Campaign:

- *Inclusive Education – a guide for schools.*
- *Education* (a factsheet about schooling for children with muscular dystrophy)

From Network 81:

The booklet *How to get support for your child with Special Educational Needs* is excellent and is very clear on the schools responsibilities and on statements of special educational needs.

Network 81
1-7 Woodfield Terrace
Chapel Hill
Stansted
Essex CM24 8AJ
Tel: **0870 7703306**
Web: **www.network81.org**

From Contact A Family:
A range of factsheets on educational issues from pre school education to Special Educational Needs. Its contact details are:

Contact A Family
209-211 City Rd
London
EC1V 1JN
Tel: **020 7608 8700**
Web: **www.cafamily.org.uk**

From RADAR:
Children first: Educational services

RADAR
12 City Forum
250 City Road
London EC1V 8AF
Tel: **020 7250 3222**
Web: **www.radar.org.uk**

From The Advisory Centre for Education (ACE):

A range of little booklets:

- *Asking for A Statutory Assessment*
- *Early Years Extra Help*
- *Getting Extra Help*
- *Disability Discrimination*
- *Children with SEN: Sources of Help*
- *Tackling Bullying*

All the above cost under £2 each. (2008 prices)

The ACE Special Education Handbook is £17.99 plus p+p.

ACE

1C Aberdeen Studios

22 Highbury Grove

London N5 2DQ

Tel: **0808 8005793**

Web: **www.ace-ed.org.uk**

The Department for Education and Skills publishes a booklet called *Special Educational Needs* and the *Special Educational Needs Code of Practice*.

DfES Publications Centre

PO Box 5050

Sherwood Park

Annersley

Nottingham NG15 0DJ

Web: **www.dfes.gov.uk/sen**

CHOOSING A PRIMARY SCHOOL

Take advice from your LEA or EA, and from professionals involved in your child's care. Visit a number of schools and talk to the head teacher and the Special Educational Needs Co-ordinator (known as the SENCo) or, in Scotland, the person with responsibility for disabled pupils. It is important to feel that these staff have a positive approach to your child joining the school – goodwill and support are going to be important. Try to select a school which is on one level and which does not have lots of steps. Consider the toilet facilities that your child will require.

STATEMENTS AND SUPPORT PLANS

At some stage almost all children with significant mobility difficulties (and/or significant learning difficulties) will need a Statement of Educational Needs or Co-ordinated Support Plan. This is a document that details the provision that your child must have in school. You, as parents, will have the opportunity to contribute to this document along with the professionals involved with your child and teaching/Education Authority staff. By law Statements must be reviewed at least annually.

In some areas LEAs are no longer issuing statements and in other areas few statements are issued. In these situations you should ask the LEA what arrangements are made to ensure that a child's special educational needs are still met.

PROBLEMS WITHIN SCHOOL

It is important to have good liaison with the school staff so that difficulties are picked up early. Stress to staff that you would rather hear about difficulties before they become major issues. It can be helpful to build in formal ways of communicating such as a home/school book or termly reviews.

CHOOSING A SECONDARY SCHOOL

Thought needs to be given to the choice of secondary school at an early stage – say from about the age of nine. The reason for this is that you, as parents, need to allow yourselves time to visit schools in your area (and perhaps further afield). You need to consider whether you are seeking a mainstream school, a special school or a private school. Is a specialist boarding school an option which you wish to consider? Your LEA/EA has a duty to provide educational facilities that meet your child's needs but, as mentioned earlier, they do not have a duty to provide the very best – or to provide for non educational needs (for example, physiotherapy) unless they impact on your child's ability to access their educational opportunities.

It is, of course, essential that your child can move around the secondary school easily and that they can access all the relevant rooms and the toilet facilities. Thought needs to be given to moving and handling issues (for example, the provision of a hoist).

The education that the school can offer your child must meet their needs. Your child's natural abilities need to be encouraged and extra help should be available for specific areas they finds difficult. The Statement or Support Plan needs to be properly updated prior to secondary school admission and the secondary school must be named on the revised document.

LEARNING DIFFICULTIES

Some children have learning difficulties in specific areas. These children may be helped by specialist computer programmes. Advice on these is available through the schools' specialist teaching services and/or through the ACE centres listed below:

Ace Centre Advisory Trust

92 Windmill Rd

Oxford OX3 7DR

Tel: **01865 759800**

Web: **www.ace-centre.org.uk**

(This centre is an independent charity that gives specialist advice to parents and professionals.)

Ace Centre North

Hollinwood Business Centre

Albert Street

Hollinwood, Oldham OL8 3QP

Tel: **0161 684 2333**

Web: **www.ace-north.org.uk**

(This centre is a company with charitable status.)

Children with learning difficulties should be properly assessed by an educational psychologist and a programme of support agreed. Learning difficulties in children with neuromuscular conditions almost never get worse and with the right support from an early age children often make significant progress.

BULLYING

Every school has to have a policy on bullying. Ask to see a copy. Always report suspected bullying to the class teacher and the head teacher. Talk to your child about what is happening and what you can do about it. Share your thoughts with teaching staff and agree some strategies with them. Monitor the situation closely. You may find that other children are less likely to tease/bully your child if they have an appreciation of the difficulties he or she faces. Consider organising a session whereby someone comes in to talk to the class about your child's mobility difficulties – a Care Advisor or a physiotherapist may be willing to do this. If difficulties remain you may need to consider changing schools.

5. LEISURE AND HOLIDAYS



LEISURE ACTIVITIES

It is important that your child has an opportunity to develop leisure interests and that their natural interests and talents are encouraged. Activities that might be of interest include:

Swimming

For most children this is an excellent form of exercise and it is an activity that the whole family can enjoy together. You may need to check out the accessibility of local pools and their changing facilities. Your child may be interested in joining a swimming club for disabled people. Physiotherapists often have good knowledge of local facilities/clubs.

Horse Riding

Riding for the Disabled has clubs across the country. For further details contact:

Riding for the Disabled Association
Lavinia Norfolk House
Avenue "R", Stoneleigh Park
Warwickshire CV8 2LY
Tel: **0845 658 1082**
Web: **www.riding-for-disabled.org.uk**

Fishing

The British Disabled Angling Association is an organisation that can advise on fishing opportunities in the UK.

BDAA
9 Yew Tree Rd
Delves, Walsall
West Midlands WS5 4NQ
Tel: **01922 860912**
Email: **info@bdaa.co.uk**
Web: **www.bdaa.co.uk**

Photography

The Disabled Photographers' Society may be able to offer advice.

DPS
PO Box 130, Richmond
Surrey TW10 6XQ
Tel: **01454 317754**
Web: **www.dps-uk.org.uk**

Sport

The English Federation of Disabled Sport is a national body covering all types of sport. Contact them at:

EFDS

Manchester Metropolitan University, Alsager Campus

Hassal Rd, Alsager

Stoke on Trent ST7 2HL

Tel: **0161 247 5294**

Web: **www.efds.net**

In Scotland, Scottish Disability Sports is the national body covering all sports:

Scottish Disability Sports

Caledonia House, South Gyle

Edinburgh, EH12 9DQ

Tel: **0131 317 1130**

Email: **admin@scottishdisabilitysport.com**

Web: **www.scottishdisabilitysport.com**

PHAB clubs

PHAB clubs aim to offer opportunities for disabled people and able bodied people to meet together for social activities. Details of activities in your area can be found via:

PHAB England

Summit House, 50 Wandle Rd

Croydon, Surrey CR0 1DF

Tel: **020 8667 9443**

Email: **info@phabengland.org.uk**

Web: **www.phabengland.org.uk**

Think also about opportunities locally for participation in music, the arts, computer clubs, board games clubs (chess, scrabble etc) and drama. Your local library should hold details of clubs in your area. An excellent factsheet is available from Contact A Family entitled Play and Leisure.

Contact A Family

209-211 City Road

London EC1V 1JN

Tel: **020 7608 8700**

Web: **www.cafamily.org.uk**

FAMILY HOLIDAYS

Holidays should be fun and stress free. When you book your holiday ask lots of questions to ensure that the facilities will meet your family's needs. If accessible accommodation is required, Tourism For All can advise you.

Tourism For All
Hawkins Suite, Enham Place
Enham Alamein, Andover SP11 6JS
Tel: **0845 124 9971**
Email: **info@tourismforall.org.uk**
Web: **www.tourismforall.org.uk**

Tourism For All is a registered charity supported by the UK's national tourist boards. It can help with planning of holidays in the UK and overseas. It has lists of adapted accommodation, information on travel etc.

RADAR has useful publications on holidays and accessible accommodation.
RADAR
12 City Forum, 250 City Road, London EC1V 8AF
Tel: **020 7250 3222**
Web: **www.radar.org.uk**

Certain charities own and run accessible self catering accommodation – for example:

- The Scout Holiday Homes Trust (**020 8433 7290**),
- John Grooms Holiday Homes (**0845 658 4478**)
- The Calvert Trust (**017687 72255** for Keswick, **01434 250232** for Hexham and **01598 763221** for Exmoor).
- Vitalise (**0845 345 1970**) has well equipped family chalets in Cornwall.
- The Stackpole Trust in West Wales (**01646 661 425**).

Advertisements for accessible accommodation are to be found in many disability magazines.

- PHAB (Physically Handicapped and Able Bodied) organises holidays and leisure activities (**020 8667 9443**).

The Muscular Dystrophy Campaign publishes a factsheet on holidays (**020 7803 4800**, email: **info@muscular-dystrophy.org**) as do Contact A Family (**020 7608 8700**, email: **info@cafamily.org.uk**).

SPECIAL HOLIDAYS FOR CHILDREN

There are several charities that organise dream trips (often to Disneyland) for children with serious medical conditions. Some of these will be family holidays but others will be for the child alone. In the later case the child would be part of an organised group, which includes qualified care staff. The Muscular Dystrophy Campaign publishes a factsheet called *Dream Holidays and Wishes for Children and Young Adults*.

Starlight Children's Foundation
PO Box 4267
Goring, Reading RG8 0AP
Tel: **020 7262 2881**
Email: **PRW1@starlight.org.uk**
Web: **www.starlight.org.uk**

Dreams Come True
York House, Knockhundred Row
Midhurst, West Sussex GU29 9DQ
Tel: **01730 815000**
Web: **www.dctc.org.uk**

Make A Wish Foundation UK
329/331 London Rd
Camberley, Surrey, GU15 3HO
Tel: **01276 405060**
Web: **www.make-a-wish.org.uk**

When You Wish Upon A Star
Futurist House
Valley Rd, Basford
Nottingham NG5 1JE
Tel: **0115 979 1720**
Web: **www.whenyowishuponastar.org.uk**

Please note that the Muscular Dystrophy Campaign is not in a position to recommend any organisation whether listed here or not. You must make your own investigations and satisfy yourself of the safety and suitability of the event/holiday.

FUNDING OF HOLIDAYS

It is usually only possible to get funding for family holidays if you have a low income and have not had a holiday for some time. The Family Fund may help.

The Family Fund
Unit 4, Alpha Court
Monks Cross Drive
Huntingdon
York YO32 9WN
Tel: **0845 130 4542**
Web: **www.familyfund.org.uk**

Social services will occasionally assist – do ask. Tourism for All mentioned earlier keeps lists of charities that may help. Social services may well fund respite care/holidays for your disabled child.

One charity offering breaks to disabled children is:

Break
1 Montague Rd, Sheringham
Norfolk NR26 8WN
Tel: **01263 822161**
Web: **www.break-charity.org**

HOLIDAY INSURANCE

It is essential to take out insurance that covers your child's medical condition. If you fail to declare the condition you may invalidate your child's insurance in the event of any type of accident/illness – even if it is not related to the condition. Your child's consultant may be willing to write a letter for your insurers explaining the nature of their condition. In Europe remember to take a new style E111 card– now called the European Health Insurance Card (EHIC). This provides some cover but is not designed to replace other medical insurance. You can apply at a post office, over the phone **0845 605 0707** or online at **www.ehic.org.uk**

6. SUPPORT FOR FAMILIES



BENEFITS SYSTEM

The benefits system changes frequently so check the current situation with a recognised source, for example, your local Citizens Advice Bureau or Welfare Rights Office – or look on the Department of Work and Pensions' website at: **www.dwp.gov.uk**

One of the best guides to benefits is the *Disability Rights Handbook*. This is published annually in April by the Disability Alliance.

Universal House

88-94 Wentworth Street, London E1 7SA

Tel: **020 7247 8776**

Web: **www.disabilityalliance.org**

Benefits to ask about include:

■ **Disability Living Allowance (DLA)**

This is a non means-tested, non taxable benefit paid to people who need extra help with their care and/or who have restricted mobility. In the case of a child under 16 the money is paid to a parent/guardian. If you have to assist your child with personal care (dressing, bathing etc) to a greater extent than another child their age, they may be eligible for the care component of DLA.

If your child has restricted mobility they may be eligible for the mobility component. You cannot apply for this component until a child is two years and nine months old, and it payable from the age of three.

The care component is paid at one of three rates and the mobility component at one of two rates. You need to remember to check periodically that the rate they are receiving is still applicable. It is your responsibility to request a review if you think your child now meets the criteria for more help. You can request a review by writing to the office that dealt with your claim – the address will be on the letter.

Remember to quote your child's date of birth and reference number/ National Insurance number.

If DLA is refused and you are unhappy with the decision do challenge it. For most children with a neuromuscular condition the DLA should be awarded for life or at least until the child's 16th birthday. (At age 16, benefits are usually paid to the young person themselves).

■ Carers Allowance (CA)

This benefit is paid to people who spend 35 hours or more a week caring for a disabled person. It can be paid to a parent of a disabled child. It is not payable to anyone who earns more than £95 per week (2008 rates), after allowable expenses are deducted. You can only get one award of CA – even if you care for more than one disabled person. Only one person can claim CA for caring for any one disabled person.

There are many other benefits that may be applicable – do check (preferably not with a doctor – they tend not to be knowledgeable on the benefits system).

If you receive tax credits you need to inform the Inland Revenue that your child is disabled as you may be eligible for increased credit.

If your house has been adapted to accommodate a disabled person you may be entitled to have your council tax banding reduced by one band – speak to your local council about this.

THE FAMILY FUND

The Family Fund Trust is a registered charity covering the whole of the UK. It is government financed and aims to support the families of severely disabled/severely ill children under the age of 16 (17 in England). It does this in two main ways. Firstly by providing grants for equipment and outings and secondly by gathering information on the needs of disabled/ill children and sharing this information with policy makers and service providers.

The Family Fund grants are usually only available to those families with a gross annual income of below £23,000 (in England, Northern Ireland and Scotland), or £25,000 if you live in Wales, and with savings below £18,000 (2008 figures). Grants can be made annually. You can refer yourself or a professional can make a referral on your behalf. The Family Fund will then contact you direct and may arrange for a worker to visit you at home.

The Family Fund Trust
Unit 4, Alpha Court, Monks Cross Drive
Huntingdon, York, YO32 9WN
Tel: **0845 130 4542**
Web: **www.familyfund.org.uk**

HELP FROM SOCIAL SERVICES

Social service departments are able to offer a range of support to families caring for a disabled child. You can request an assessment of your child's needs and an assessment of your own needs as a carer. If brothers and sisters are also helping with care their needs, as young carers, should be assessed. You may refer yourself to your local social services department. Ask to speak to the duty officer.

The types of things social services can help with include personal care (to get your child washed, dressed and ready for the day, or ready for bed), respite care (care aimed at giving the regular carer a break – during the day or overnight), summer play schemes and general advice on accessing other benefits and services. In most areas the occupational therapy service (dealing with equipment and adaptations) is part of social services.

CARERS' SERVICES

There are specific services for carers, included in this are services for parents and siblings who care for a disabled child. Visit this government website for more information: **www.direct.gov.uk** and click '**carers**'

The Princess Royal Trust for Carers is a long established organisation with branches, staffed by qualified workers, across the UK. They offer advice and support to carers on a whole range of issues.

The Princess Royal Trust for Carers
142 Minorities, London, EC3N 1LB
Tel: **020 7480 7788**
Web: **www.carers.org**

CHILDREN'S HOSPICES

Children's hospices offer care and support to families with a child with a life limiting or life threatening condition. This usually includes children with SMA type II and some other neuromuscular conditions. Care can be offered over a period of many years.

Children's hospices take children from birth to 18. Although children's hospices do care for children who are very poorly the majority of their visitors are there for respite care, and few of the children have illnesses like cancer. The atmosphere is a positive one. You can refer yourself to a children's hospice or you can ask a professional (consultant, social worker etc) to do it for you. The hospice will need your permission to contact your child's consultant/GP.

In the last 20 years there has been a huge expansion in the number of children's hospices and most areas of the UK are now within reasonable travelling distance of one.

Initially you and your child may be invited to look around the hospice and meet the staff team. When a first overnight visit is arranged you will be able to stay at the hospice (in separate accommodation if you wish).

Hospices have a policy of honestly answering children's questions – you may need to discuss this issue with staff – but be assured that their approach will be a sensitive one. No charge is made to families using the hospice. Almost all the children we work with love the time they spend at their local hospice. They have lots of 1:1 attention and fun! They make friends and enjoy meeting up with them each time. Hospices are well equipped with computers, music, hot tubs etc. To find the hospice nearest to you contact:

The Association of Children's Hospices
First Floor, Canningford House
38 Victoria Street
Bristol BS1 6BY
Tel: **0117 989 7820**
Web: **www.childhospice.org.uk**

MEETING OTHERS

Some families enjoy the opportunity of meeting others who also have a child with a neuromuscular condition. You may find this happens without you having to arrange anything – there may be other children at the same school, attending the same clinic or seeing the same physiotherapist.

You could also consider:

- Joining a condition specific support group (for example, the Jennifer Trust for SMA or the Myotonic Dystrophy Support Group – see the back of this book for details)
- Attending a Muscular Dystrophy Campaign event
- Joining a Muscular Dystrophy Campaign Branch
- Asking your Care Advisor/physiotherapist etc to put you in touch with others
- Joining Contact A Family (see the back of this book for details)

COPING WITH PROFESSIONALS

When a diagnosis of a neuromuscular condition is made various professionals will come into your lives and at times this can feel a little overwhelming. The aim of the professionals involved will be to establish a good long term relationship with you so that they can offer you the right support at the right times. As time goes by you will feel more confident in deciding what the priorities for you and your family are and in sharing these thoughts with the professionals involved. Feel free to question things and to offer your own opinion. Tell people if you feel overwhelmed with appointments and occasionally give yourself a week or so off from all appointments.

It helps to be organised. Try to keep copies of letters and reports concerning your child in a folder, separated out into sections such as 'School', 'Medical', 'Respite care' and so on. When you attend appointments take the folder with you. Ask professionals to copy their letters to each other – it is important that they do this so that their approach to your child's care is well co-ordinated.

7. PERSONAL AND FAMILY MATTERS



TALKING TO CHILDREN

Most parents worry a great deal about what to say to their child about their disability. What you say will, of course, depend upon your child's age and level of understanding but it is important to try to ensure that whatever you say is truthful and makes sense to your child. Avoid the temptation to say nothing - this is almost never a good idea as a child will create their own explanation if you do not provide one.

Some doctors will advise using the full name of the condition from the point of diagnosis. This way the child grows up knowing that the condition they have is recognised by doctors and has a definite name. Of course, some people reading this book may not be in a position to do this because the condition their child has may not have been fully identified. This is an enormously difficult situation for the parents and the child and all you can do is share this fact with your child.

Whether or not you put a name to your child's condition it is important to acknowledge the difficulties your child is facing. You should avoid denying that there is a problem, or promising that it can be made better if it can't be. Children need to be able to trust their parents and if parents are not honest this bond of trust is strained. Remind your child that it is not their fault (or anybody's fault), that they have this muscle weakness. Let your child know that it is okay to ask questions about their condition – even if you can not guarantee to know the answers.

When talking to your child avoid putting your own (adult) interpretation on things and instead listen to their concerns. They will be different to yours. For example, do not assume that your child will refuse to use a wheelchair – he/she may be relieved to do so as they will be less likely to fall over and will be able to get around quicker.

If your child has unaffected brothers and sisters you will also need to consider what to say to them. Again, much will depend upon their ages and levels of understanding. You know your children best. Except where siblings are much older it is important to try not to share information with them that they must then "keep secret". Do, however, acknowledge that their brother or sister has a muscle weakness that causes them to struggle with some activities – that way they can be supportive.

The Muscular Dystrophy Campaign publishes a little booklet called *Hey! I'm Here Too!* which whilst perhaps most relevant to Duchenne muscular dystrophy has uses for families where a different neuromuscular condition is relevant.

The other children you need to consider are your child's friends and classmates. Most families find that sharing some information is helpful as that way you control the accuracy of the information, gain support, and reduce the likelihood of teasing and bullying. (You may, however, run the risk of other children being overprotective!). A professional worker involved in your child's care may be able to come into school (with your child's permission) and give a short talk about the things your child finds it difficult to do and how the class can help them. Never give other children more information about your child's condition than he/she has and avoid talking to other children about your child's condition without their permission. Involve your child in decision making. They have a right to be consulted and listened to.

If your child is very angry or upset and you feel that you need assistance in understanding and managing the situation, talk to your child's consultant. It may be that a referral to a child psychologist would be helpful or that your child may benefit from something like art or music therapy. This can sometimes be arranged so that sessions take place in school.

BEHAVIOURAL ISSUES

Partly depending upon the condition, many parents of primary school age children will report problems with their child's behaviour. This can range from poor concentration (a very common problem) to aggressive and disruptive behaviour. Challenging behaviour is sometimes seen only in the school setting or only in the home setting but usually there is no distinction. It is important not to ignore the issue. Try not to feel sorry for your child and try not to "give in" to challenging behaviour or unreasonable demands. Instead address the issue and look at what may be causing problems.

Your child may be experiencing many difficulties coping with a changing situation in terms of their functional ability. It is important that a child is able to make sense of what is happening otherwise they will become confused and unhappy. Often this can be the reason behind challenging

behaviour. Talk to your child, listen to their anxieties and be honest (but positive) in what you say to them. See page 47 for guidance on talking to your child about their condition.

It is possible that your child is being bullied at school, or teased, or that they are being ignored. Talk to staff at the school. As mentioned earlier, consider sharing information with your child's classmates so that they too can understand what is happening and offer their support. Be alert to the fact that the increased adult presence around your child may be restricting their ability to make friends and enjoy being a child. Try not to be over protective – allow your child to be a child. All children need some adult-free time!

It is important that you set boundaries and that your child knows what these are and what sanctions you will use if they go beyond these boundaries. Try to set the same (age related) boundaries for all your children. It is important to teach respect of others – in the future your child will need to develop good working relationships with their carers.

SEX AND RELATIONSHIPS

It is important to realise that your child has as much need as any other to learn about sex and relationships. Do not ignore the topic in the belief that these issues will not be relevant to your child. They will be. All children, regardless of their disability, need to understand the changes that will be taking place in their bodies. They need to be able to explore their feelings and they need to know how to form successful relationships. They also need to know where to go for help and advice. Contact A Family has published some excellent guides – one for young people, one for parents and one for teachers.

Contact A Family
209-211 City Road
London EC1V 1JN
Tel: **020 7608 8700**
Web: **www.cafamily.org.uk**

Young people with neuromuscular conditions usually have normal sexual development. Some have parented children and many enjoy fulfilling relationships. They need information on sexual activities/choices,

contraception and the avoidance of sexually transmitted diseases. Brook Advisory centres may give helpful guidance. Contact them at:

Brook

421 Highgate Studios, 53-79 Highgate Road

London NW5 1JL

Tel: **020 7284 6040**

Web: **www.brook.org.uk**

Be aware that sex education is part of the school curriculum. You may like to talk to teaching staff about what is involved and request extra sensitivity in respect of topics such as termination of pregnancy, testing for disabling conditions during pregnancy and other such ethical issues.

HOW TO HELP YOUR CHILD

For all children a happy childhood in a supportive home environment is important. This is just as true for children with neuromuscular conditions as for other children. Life should not become a series of overly structured regimes! You can help your child (as well as their brothers and sisters and yourself) by taking a positive approach. Take the time to enjoy activities as a family. Try to have a “can do” approach to life. Encourage your child to develop their interests and talents and to make friendships. Be supportive of their wish for independence.

It is essential to provide a supportive environment with some routine and “normality” to it. Children need to learn social skills and must know how to respect the norms of their society. Sometimes others will want to “spoil” your child. Do try to prevent this. It may cause resentment within the family and will not help your child.

THE IMPACT ON FAMILY RELATIONSHIPS

Having a child with a neuromuscular condition in the family will clearly have an impact on everyone in the family, particularly those living in the same household. With respect to your child’s brothers and sisters remember to talk to them about what is going on. Wherever possible involve them in decision making but respect the fact that they are children too and avoid burdening them with too many demands for practical help. (If this seems unavoidable you should ask social services to offer them an assessment of their needs as a “young carer”) Listen to their

thoughts and concerns and recognise that feelings of anger, frustration and jealousy are normal emotions that we all feel at times. Brothers and sisters may feel anxious about what is happening to their sibling, experience embarrassment about their sibling's disability or feel jealous of all the attention that they receive.

Although it can be difficult to arrange your other children need some "protected time" too. That is, they need to know that there will be times when they can talk to you, share their concerns about their own lives and go out alone with you. To make this possible you may need to request help with respite care. You can find guidance on obtaining respite care elsewhere in this book. Allow your other children to participate in activities that interest them even if these are things that your disabled child cannot do. They will be able to achieve in different areas and recognising the value of difference is an important lesson for all of your children to learn.

There may be occasions when your child's brothers and sisters would like to talk to someone outside the family about how things are for them. Some children find counselling helpful, others would like to meet up with someone else who "knows how it feels" to have a disabled sibling. Children's hospices will sometimes run sessions for siblings, and carers groups can have activities specifically designed for siblings. Your local social services should be able to advise you on what is available in your area.

Contact a Family publishes a leaflet called *Siblings*, which is available via its website: www.cfamily.org.uk or by calling **0808 808 3555**. This publication gives details of support groups for siblings and ideas on further reading.

The fact that everybody copes with difficult situations differently can lead to tensions between partners. It is important to accept that this difference is normal – no two people are the same. Respect your differences and try to work out what your individual areas of responsibility will be. Try to negotiate some agreed "talking time" and also some time when you will concentrate on other things. You and your partner need time for yourselves and you each need some time alone too. It helps if you know when this time will be so that you can plan for what you would like to do. When friends and relatives ask how they can help you might like to suggest that they support you by offering regular help with childcare.

Contact a Family (see above) publishes a leaflet called *Relationships and caring for a disabled child*. This gives lots of practical advice.

Some parents, particularly those struggling with depression, find that structured counselling support from a professional such as a clinical psychologist is helpful. Your GP should be able to arrange such a referral and another professional involved in your child's care (such as the consultant or the Care Advisor) can alert the psychologist to the issues a family with a child with a neuromuscular condition faces.

Grandparents are in a challenging position. Although they will be upset do share your child's diagnosis with them (unless of course, there are very good reasons not to) and accept their support. Let them know what help you would appreciate – and what is not helpful. Explain to them, for example, that you are keen to ensure that your child does not become “spoilt” or that they do not put on too much weight. The time they can spend with your children and the interest and pleasure they can show in their activities are invaluable. Contact a Family (see earlier in this section for details) publishes a leaflet for grandparents. This leaflet lists support organisations that grandparents themselves may find helpful. Remember that grandparents will also have concerns for **your** wellbeing – to them you too are a child!

PLANNING FOR THE FUTURE

It is important to try to maintain a positive approach to life. In recent years advances in the management of neuromuscular conditions has greatly improved the outlook for many people affected. From an early age we should encourage children to plan for the future and to gain what skills in independence they can. Education has an increasingly important role to play. Personal relationships outside of the family home are to be encouraged and children should be given opportunities to consider their options in terms of future lifestyle arrangements.

We hope that this book will have answered some of your queries and will have helped to alleviate some of your anxieties. Remember that your child is the same child they were before the diagnosis and that giving them a happy family life is the thing of greatest importance.

8. FURTHER READING

FURTHER READING

Apart from the literature recommended throughout this book you may find the following of interest.

Muscular Dystrophy: The Facts

Professor Alan Emery

Oxford University Press

ISBN 0192632175

This is written for families. It covers several types of muscular dystrophy.

What makes me me?

Professor Robert Winston

Dorling Kindersley

ISBN 14053059X

A Short History of Almost Everything

Bill Bryson

Black Swan

ISBN 0552997048

Counselling Children with Chronic Medical Conditions

Melinda Edwards and Hilton Davis

BPS Blackwell

ISBN 1854332414

This is a textbook written for professionals but it contains useful sections relevant to parents.

CONDITION SPECIFIC ORGANISATIONS

Muscular Dystrophy Campaign

61 Southwark Street

London SE1 0HL

Tel: **020 7803 4800**

Information and Support Line: **0800 652 6352** (freephone)

Email: **info@muscular-dystrophy.org**

Web: **www.muscular-dystrophy.org**

Association for Glycogen Storage Disease (UK)

Tel: 01332 669670

Email: **info@agsd.org.uk**

Web: **www.agsd.org.uk**

Becker United

Email: **beckersmd@hotmail.com**

Web: **www.beckerunited.com**

Contact A Family

209-211 City Road

London EC1V 1JN

Tel: **020 7608 8700**

Web: **www.cafamily.org.uk**

CLIMB Children Living with Inherited Metabolic Diseases

CLIMB Building,

176 Nantwich Road

Crewe CW2 6BG

Tel: **0800 652 3181**

Web: **www.climb.org.uk**

CMT United Kingdom

PO Box 5089

Christchurch BH23 7ZX

Tel: **0800 652 6316**

Email: **Secretary@cmt.org.uk**

Web: **www.cmt.org.uk**

FSH Support Group

Please contact the Muscular Dystrophy Campaign on

0800 652 6352 (freephone) or **020 7803 4800**

GBS Support Group

Room 4, Lincolnshire County Council

Council Offices

Eastgate

Sleaford

Lincolnshire NG34 7BG

Tel: **01529 304615**

Helpline: **0800 374803**

Web: **www.gbs.org.uk**

The Jennifer Trust for Spinal Muscular Atrophy (JTSMA)

Elta House

Birmingham Road

Stratford upon Avon

Warwickshire CV37 0AQ

Tel: **0870 774 3651**

Helpline: **01789 267520** (9am to 9pm)

Email: **jennifer@jtsma.org**

Web: **www.jtsma.org.uk**

Mitochondrial Myopathies

This is an information point, not a support group.

Web: **www.communicate.co.uk/ne/mitolinks**

Myasthenia Gravis

First Floor

Southgate Business Centre

Normanton Road

Derby DE23 6UQ

Tel: **01332 290219**

Web: **www.mgawk.org**

Myositis Support Group
146 Newtown Road
Woolston
Southampton
Hampshire SO19 9HR
Tel: **023 8044 9708**
Email: **msg@myositis.org.uk**
Web: **www.myositis.org.uk**

Myotonic Dystrophy Support Group
35a Carlton Hill, Carlton
Nottingham NG4 1BG
Tel: **0115 987 0080**
Web: **www.mdsgek.org**

Myotubular Trust
10 Penshurst Close
Chalfont St Peter
Buckinghamshire SL9 9HB
Tel: **078 1320 0298**
Email: **contact@myotubulartrust.com**
Web: **www.myotubulartrust.com**

Nemaline Myopathy
5 Cairnbank Gardens
Penicuik
Midlothian EH26 9EA
Tel: **01968 674998**
Web: **www.nemaline.org**

Neuropathy Trust
PO Box 26
Nantwich
Cheshire CW5 5FP
Tel: **01270 611828**
Email: **info@neurocentre.com**
Web: **www.neuropathy-trust.org**

SBMA UK

(This group covers spinal bulbar muscular atrophy also known as Kennedy's Disease.)

57 Keysbrook

Tattenhall

Cheshire CH3 9QP

Tel: **01829 771 266**

Email: **info@sbma.org.uk**

BE PART OF THE MUSCULAR DYSTROPHY CAMPAIGN

The Muscular Dystrophy Campaign is the only national UK charity focusing on all muscle disease. We have pioneered the search for treatments and cures since 1959, and are dedicated to improving the lives of all people affected by muscle disease.

More than 60,000 people in the UK have a muscle disease or related condition, and 300,000 people are indirectly affected as relatives, friends and carers. There are no cures or treatments which prevent the breakdown of muscle but increased knowledge has improved the quality of people's lives and – in many cases – length of life.

We rely entirely on donations from individuals, charitable trusts and foundations, statutory funding bodies and corporate partners to finance the valuable work we do. If you would like to contribute to our fight against muscular dystrophy and related muscle diseases, please email **donations@muscular-dystrophy.org**

The Muscular Dystrophy Campaign has launched a new Schools' Network which is designed to help all children with neuromuscular conditions. We are asking for schools to register with us so we can offer staff training sessions and appropriate support information. A school forum, where ideas and information can be shared and exchanged between schools, will also be set up. Personal information about the child will not be collected and specific personal issues will not be discussed without the written consent of parents/guardians, and of course, the children themselves, where applicable. To join the Schools Network, simply call the Muscular Dystrophy Campaign on **020 7803 4800** or email **info@muscular-dystrophy.org**

You can also get involved with the work of the Muscular Dystrophy Campaign. We are always looking for people willing to donate their time, experience or expertise to help in a variety of ways. There are opportunities to volunteer at head office, to work as a media volunteer or campaigner, to work in the regions with support groups or help with fundraising. If you can help in anyway, please get in touch using the contact details below.

Together we're stronger

Muscular Dystrophy Campaign

61 Southwark Street

London SE1 0HL

Tel: **020 7803 4800**

Information and Support Line: **0800 652 6352** (freephone)

Email: **info@muscular-dystrophy.org**

Web: **www.muscular-dystrophy.org**