Duchenne muscular dystrophy: 
A guide for families with a child 
aged 5 – 12 years 

Jane Stein 
Muscular Dystrophy Campaign Care Advisor 
Oxford Muscle Centre
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Thank you to all the families whose photographs are featured in this booklet.
FOREWORD

ABOUT THE MUSCULAR DYSTROPHY CAMPAIGN
The Muscular Dystrophy Campaign is the only UK charity focusing on all muscular dystrophies and allied conditions and has pioneered the search for treatments and cures for over 45 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.

OTHER PUBLICATIONS
The Muscular Dystrophy Campaign publishes two factsheets on Duchenne muscular dystrophy:

- Duchenne Muscular Dystrophy
- Duchenne Muscular Dystrophy – the older child

It also publishes the following:

- Factsheets on a range of medical management and lifestyle issues
- Research updates
- Target md – a quarterly magazine
- An introductory guide for families with a child newly diagnosed with Duchenne muscular dystrophy
- Physiotherapy Management for Duchenne Muscular Dystrophy
- Inclusive Education (aimed at schools)
- Wheelchair Provision for Children and Adults with Muscular Dystrophy and other Neuromuscular Conditions (aimed at Wheelchair Services staff but also useful for service users)
- Adaptations Manual – a guide to adapting and equipping your home
- Everybody’s different, nobody’s perfect (for children aged 4-10)
- On the Ball (for children aged 11-14)
- Hey, I’m here too! (for siblings)
This book has been written as a reference guide for families with a child aged approximately 5-12 years with Duchenne muscular dystrophy (known as DMD or Duchenne). 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 all children are different and that not everything written here will be relevant to you. If in doubt seek advice from your specialist clinic or from the Muscular Dystrophy Campaign.

Throughout this book we refer to the child with Duchenne as “he” because, except in extremely rare cases, only boys are affected by Duchenne.
1. MEDICAL ISSUES
AN OVERVIEW

Duchenne muscular dystrophy (referred to as “Duchenne” throughout this book) is, as we know, a serious and progressive muscle disorder. Whilst there is, as yet, no cure for this condition this does not mean that there are not things which can be done to help, nor that children with this condition do not live fulfilling and happy lives. In this section we look at the progression and the management of the condition during the primary school years.

For a child with Duchenne the primary school years are usually a time of significant change in terms of their independent mobility. When particular changes occur is a little variable but the pattern of change is generally predictable and allows for appropriate planning to take place. With a condition like Duchenne advance planning is essential. This ensures that you will have the things that you and your son are going to need available at the right time.

With Duchenne, weakness is first noticed in the thigh muscles. Weakness here makes activities using these muscles difficult. Activities such as climbing stairs, walking uphill, getting up from the floor and running are affected. Poor balance combined with muscle weakness makes a child prone to falls. His knees may just "give way" without warning. Some children with Duchenne are never able to hop or balance on one leg. Children should be encouraged to remain physically active but you will need to recognise when your child is tired and needs to stop – this will occur more quickly than for another child his age.

In Duchenne, muscle fibres break down and are replaced by fibrous and/or fatty tissue causing the muscle to gradually weaken and lose its "stretchiness". It may also cause the muscle to look bulky. Some muscles weaken earlier than others, resulting in an imbalance of strength around the joints. These factors mean that joints stiffen and contractures (when a joint is no longer able to move through its complete range of movement) may develop. In a young child with Duchenne this is most frequently seen in the ankle joint. At some stage, due to a combination of tightness and weakness of the trunk, hip and knee muscles, your child will start to walk on tiptoes with his feet apart, his knees locked and his back arched. This method of walking is termed a "waddling gait".
As the weakness progresses (and the condition will always cause increasing weakness) mobility becomes more restricted and a child will tire more quickly. Falls will be more frequent and the use of a manual wheelchair may be required.

Although initially weakness is seen in the legs, the arms are also affected. The pattern of weakness is known as proximal – more at the hips and shoulders than in the hands and feet. During the primary school years the muscles of the shoulder and upper arm weaken and children start to have more difficulty raising their arms above their head. Activities like pulling on a jumper or holding your hand up in class can be a struggle.

The trunk muscles are weak so maintaining a good sitting posture is not easy. Advice on appropriate seating may need to be obtained from your physiotherapist or occupational therapist. Some children will develop a scoliosis (sideways curvature of the spine) but this is usually more of a problem after the ability to walk is lost.

By the age of 12 many children with Duchenne will need to use a wheelchair all of the time. A powered wheelchair is preferred to a manual as it offers a greater degree of independence.

During the primary school years, a child's heart and lung function should be monitored by the specialist neuromuscular team. Problems in these areas are, however, rare at this stage. If problems are discovered there are often things that can be done to help.

**MAINTAINING MOBILITY**

It is important to try to maintain a child’s mobility for as long as possible. Although he will eventually reach a point where mobility is lost there is much that can be done to prolong ambulation (walking). In a young child gentle encouragement to participate in physical activity is the order of the day. Keep activities fun. Swimming is especially good as it offers an all over body workout and can continue to be enjoyed even when other activities become difficult. Your child will also get a sense of achievement from learning to swim.
PHYSIOTHERAPY

Physiotherapy involves the physical treatment and management of a condition with the aim of maintaining maximum possible ability at every stage of the condition.

Physiotherapy is important during the primary school years to help maintain independent movement for as long as possible and to prevent contractures from developing. All children with Duchenne should see a physiotherapist regularly and should be shown a daily programme of stretching exercises. These exercises are usually done once or twice a day (with the assistance of a parent or carer) for 10 to 15 minutes at a time. Sometimes these exercises can be done at school. A physiotherapist may also be able to offer hydrotherapy which involves a programme of exercises in a warm water swimming pool.

If your child is not seeing a physiotherapist, speak to their consultant as a matter of urgency. Physiotherapy for children with Duchenne should be provided by the NHS, free of charge.

The Muscular Dystrophy Campaign publishes a physiotherapy booklet for parents who have a child with Duchenne. This booklet should be used under the guidance of your physiotherapist who can tell you which exercises to concentrate on at each stage. The booklet is available free of charge from the Muscular Dystrophy Campaign.

THE USE OF STEROIDS

One option for maintaining and prolonging mobility is to consider the use of steroids. In some studies, steroids have been shown to help maintain muscle strength and prolong ambulation but they are not without side effects. A large scale study of the use of steroids in children with Duchenne is now in progress. Steroids can be used in quite young boys with Duchenne. If the use of steroids is of interest to you talk to your child’s consultant about it. The Muscular Dystrophy Campaign publishes a factsheet on steroids and on some of the questions you might like to ask your consultant about their use. Prior to starting steroids certain tests and checks must be completed. Children on steroids should always be monitored regularly by the medical team and side effects noted and discussed. There is some evidence that steroids may aid heart and lung function too.
ORTHOTICS (SPLINTS)
To try to prevent contractures at the ankles your consultant or physiotherapist might suggest that your son wears night splints. These are lightweight splints made by an orthotist and are designed to be worn only at night. They hold the ankle in a neutral position (that is, at 90 degrees or as close as possible) and support the foot and calf areas. Some children find night splints uncomfortable, especially in hot weather. If your child cannot tolerate wearing them at night you could compromise by suggesting he wears them in the evening when watching television, or on one leg one night and the other leg the next night. Night splints are not designed to be walked in.

A little later, when even walking around the house becomes a struggle, the use of long leg callipers might be discussed with you. These are sometimes known as KAFOs (knee ankle foot orthoses). They support the legs and can help prolong walking for up to 18 months. Callipers are worn under trousers and extend from the foot to the hip. They are fairly lightweight. The child’s style of walking will be different in callipers – he will walk with straight legs and swing from the hip, perhaps holding onto someone’s hand for extra support. Callipers are designed for walking short distances, mostly indoors.

If a child cannot get their foot flat on the floor it may be necessary to do a small operation under a general anaesthetic to release their Achilles (ankle) tendons before supplying callipers. This will entail a stay in hospital and intensive physiotherapy. Remember that using callipers is an option for some children but it is not a “must do”. Callipers are used most successfully in children who are able to comply with a programme of physiotherapy and who have a strong desire to continue walking.

STANDING FRAMES
Once walking becomes difficult it is important to continue to encourage standing if possible. Standing helps maintain range of movement in the joints and good posture. It is also beneficial to the function of the bladder, the circulatory, digestive and respiratory systems. If a child can still take weight through their legs, having the ability to stand also makes transfers 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. Ensure that you take expert advice 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.

PAIN

Pain is not usually a very significant feature of Duchenne, even in much later stages of the condition. Some boys of primary school age will occasionally complain of muscle cramps in their legs. There is no specific treatment – warm baths and gentle massages generally help.

Discomfort can be felt if joints become stiff – stretching exercises (as shown by a physiotherapist) should help prevent this happening.

VACCINATIONS

We are keen to prevent boys with Duchenne developing chest infections. For this reason the consultant may recommend an annual flu vaccination and a pneumococcal vaccination (you will need to check with your child’s consultant about when, or if, this needs repeating).

If your child is being started on steroids and he has not had chickenpox, he may need a blood test, and if he is not immune, may need chickenpox vaccine before starting the steroids.

CHEST INFECTIONS

Chest infections usually need to be treated aggressively with early antibiotics and chest physiotherapy. Your son’s GP should be made aware of this by the consultant. On occasions, admission to hospital (especially for older boys) may be necessary if the chest infection becomes very troublesome or does not respond to the antibiotics.

VENTILATION

As chest wall muscles become weaker, in order to aid breathing which is shallower (hypoventilation), many teenagers (and occasionally boys a little younger than this) may need to use non-invasive ventilation at
night. This involves the use of a ventilator and facial mask. It does not involve any sort of surgery and is not painful. Non-invasive ventilation can be enormously helpful in maintaining good respiratory function and in fighting off chest infections.

Lung function is usually monitored by your son’s neuromuscular consultant and if there are concerns, a sleep study (done overnight) may be recommended. If this shows that your son would benefit from using a ventilator, further discussion will be arranged with the relevant respiratory consultant. A sleep study involves monitoring oxygen levels in the blood by using a clip on the finger – it is not painful.

ANAESTHETICS

Children with Duchenne are likely to have reduced respiratory function, and where possible general anaesthetics should be avoided. If a child does need a general anaesthetic the anaesthetist must have advance knowledge of the child’s medical condition. Lung function should be tested. Ideally, the child’s neuromuscular consultant should be informed. The Muscular Dystrophy Campaign publishes a factsheet on anaesthetics which gives general advice.

HEART MONITORING

The heart is a muscle and it is important that its function is monitored over the years. Weakening of heart muscles occurs in boys with Duchenne but usually only late in the course of the condition. Most children with Duchenne will not be aware of any problem with their heart but if a problem is identified advice can be sought and medication may be offered.

In some clinics boys may be offered early medication to boost the pumping function of the heart, even before there are any symptoms of weakening heart muscle function.

CONTINENCE

Most children with Duchenne do not experience problems with bladder or bowel incontinence. There is usually no loss of sensation in Duchenne and children will generally be aware of when they need the toilet. Some children (especially if they have learning difficulties) may be late in achieving continence and a few will have problems in the longer term.
As a child becomes less mobile, accessing the toilet facilities quickly enough can be an issue, particularly in school. The best way round this is to establish a regular pattern of using the toilet facilities during break and lunchtimes. Do not encourage your child to restrict his liquid intake or he may become dehydrated.

Constipation is a frequent problem for children who are wheelchair dependent. This difficulty can be managed by encouraging 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 sooner rather than later.

Children may be embarrassed about needing assistance to use the toilet. Try to ensure that their privacy and dignity are respected – close doors, only provide the help needed/requested and ask permission before touching them. Remind a child that his body is private and nobody has the right to touch him without his permission. Let him know that if he feels he is being touched inappropriately whilst being assisted to use the toilet, he should share this information with a trusted adult.

**FRACTURES**

Like other children, boys with Duchenne may fracture (break) an arm or a leg. If this should happen, notify the team that normally cares for your son as quickly as possible. Immobilisation for long periods of time, particularly in plaster casts, should be avoided as muscle strength once lost, cannot easily be regained.

Boys who are on steroids should have their bone density checked at regular intervals (by a DEXA scan) as steroids can cause thinning of the bones, making fractures more likely.

Do not unduly restrict the physical activities of a young child (as play is very important) but as your son gets older the risks need to be re-evaluated. Some situations (for example, school playgrounds) may be more risky environments than others but, as mentioned earlier, inactivity should also be avoided!
SPINAL SURGERY

Spinal surgery may or may not be an issue during the primary school years. Spinal surgery may be offered to boys with Duchenne if they develop a scoliosis (a sideways curvature of the spine). This usually only becomes an issue once boys have stopped walking and standing.

Usually the most effective way to manage scoliosis is through spinal surgery. This is complex surgery that requires a skilled and experienced surgeon and anaesthetist. If spinal surgery is being considered it is vital that you and your son have all the information that you feel you need to make the decision about whether to go ahead with the surgery, and that you are aware of the after care that will be needed. The Muscular Dystrophy Campaign publishes information on spinal surgery (and the questions to ask when it is being considered) but the surgeon and his/her team should always be fully consulted. Your son will be taller after surgery (this has implications for wheelchair accessible transport), may have different seating needs, will not be able to be manually lifted (a hoist will be essential) and will not be able to bend to reach food. A high table or mobile arm support (a device that supports the arm) are often helpful at this stage. Your son’s occupational therapist can give advice in this area.

If spinal surgery is not considered appropriate, or a family decides against it, ensuring that a person has comfortable and supportive seating is vital. In some cases spinal jackets may be used but there is little evidence that they are helpful for boys with Duchenne.

DIET

There is no evidence that a primary school age child with Duchenne benefits from a special diet. The important thing is to establish a healthy eating pattern that will maintain their weight within the normal range. Try to avoid giving in to requests for fatty or sugary foods too often as excess weight will make walking harder for your son, and will make moving and handling more risky for you. Some children put on extra weight when taking steroids and this needs to be monitored. As your child becomes less physically active he will require fewer calories and his intake should be adjusted accordingly. Ask your child’s consultant for advice or for a referral to a dietician if you require guidance in this area.
ALTERNATIVE THERAPIES

Sadly there is no evidence of any alternative therapies proving helpful to a child with Duchenne. Some non-invasive therapies may be pleasant and relaxing but seek guidance from your child’s specialist first. You should avoid expensive “treatments,” invasive alternative therapies or trips abroad which promise cures. Remember that research into Duchenne is well co-ordinated internationally and your child’s specialist will be pleased to share with you any advances that are made. The Muscular Dystrophy Campaign publishes a factsheet on alternative therapies which gives further information.

GENETICS

There may be a known family history of Duchenne but if not, most parents will want to know how their child came to be affected. Duchenne is caused by a fault on a gene on the X chromosome. Females have two X chromosomes, males one X chromosome and one Y chromosome. If females have the fault on one of their X chromosomes it does not usually cause them any difficulties because they have an unaffected one as well. With males this is not the case. So, in Duchenne muscular dystrophy, we talk about women being carriers and boys being affected. (If a woman is definitely a carrier of Duchenne she has a 1 in 4 risk in each pregnancy of having a child with Duchenne.)

It is also possible for Duchenne to occur as a result of a new change in the gene of the boy himself. We call this a “new mutation.” It is possible to undertake testing to try to establish if a person is a “carrier” of Duchenne – this is usually offered as part of the genetic counselling process. If you do not wish to be tested this wish will, of course, be respected. Some people may choose to wait a while before considering whether they wish to find out if they are a carrier.

Genetic counselling is about giving you the information that you require (about the risks of future pregnancies being affected) to make the choices that are right for you. It is not about telling people what they should do.

It is important that you are offered genetic counselling at an early stage. This is especially so if you are planning further children and/or you are a female with a female relative in this position. If you have not been offered this service, speak to your son’s consultant about it.
If a woman is a carrier then her daughters have a 50:50 risk of also being carriers. Clinical genetics departments do not usually offer to test young girls to see if they are carriers because there is nothing to be gained from having this information, and it is a decision a girl can make for herself at a later date (usually after the age of about 15 but sometimes earlier, depending on personal circumstances/wishes).

If you are a carrier with a teenage daughter do explain to her that she can get advice in her own right when she is ready.

**RESEARCH**

Most families like to be kept up to date with research advances. The latest information is available through the Muscular Dystrophy Campaign’s website [www.muscular-dystrophy.org/research](http://www.muscular-dystrophy.org/research), and in the charity’s quarterly magazine, *Target md*. Staff at the charity can also answer research questions.

Each year there are conferences for families run by the Muscular Dystrophy Campaign, the Duchenne Family Support Group and Parent Project UK, where research speakers give presentations and are available to talk to. These three charities also campaign for the government to fund research.

Although great advances have been made in recent years in terms of our understanding of Duchenne, we still do not have any cures available for this, or any other type, of muscular dystrophy. Management of many aspects of the condition is now much improved and this is important in its own right and in terms of trying to ensure that if/when treatments do become available people are in the best possible position to take advantage of them.

When reading about Duchenne, ensure you consult up to date books written by recognised professionals. If you use the internet, try to restrict yourself to reputable sites – for example those of national charities directly concerned with muscular dystrophy. Remember that there are many different types of muscular dystrophy and it is only Duchenne that is relevant to you.
2. GETTING AROUND
MAINTAINING MOBILITY THROUGH THE USE OF A WHEELCHAIR

As your son gets older and his muscles weaken, changes in his walking ability will become more apparent. He may begin to tire more quickly, have problems maintaining his balance and begin to fall more frequently. This is the time to introduce a manual wheelchair for longer distances.

Coping with losing the ability to walk may be difficult for a child and is likely to be extremely hard for you as parents. Try to present the introduction of the use of a wheelchair in a positive light. Look at it as something that assists your child, enabling him to be more mobile and more independent, allowing him to participate in activities with his friends. Many children find being “allowed” to use a wheelchair a huge relief from the effort of having to walk and accept it without difficulty. If your child does find it hard to accept that he needs a wheelchair, allow him to use it initially in places where he is unlikely to meet people who know him, for example, on holiday.

The Muscular Dystrophy Campaign has published guidelines for NHS Wheelchair Services to help ensure all people with a neuromuscular condition get the right wheelchair. Although the guidelines are aimed at Wheelchair Service staff, this publication is free to families, and there is information about Duchenne that you, as parents or carers, are likely to find useful.

PROVISION OF WHEELCHAIRS

For people who have difficulty walking, wheelchairs are provided by the NHS Wheelchair Service. 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 son. 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 would be a good idea to ask for specific details. In a few areas, no wheelchair will be provided until a person is completely unable to walk but in most places some provision is offered when people find walking difficult.
TYPES OF WHEELCHAIR AND REQUIREMENTS

Your son will need to be assessed and to begin with he is likely to be provided with a manual wheelchair (preferably lightweight) that either you can push or he can push himself. The distance he can push himself may be quite limited, particularly outside, but at least he will have some degree of independence.

Your son will gradually need to use his wheelchair more and more and will benefit from the provision of a powered wheelchair, initially for use outdoors. This type of wheelchair is often referred to as an EPIOC (electrically powered indoor/outdoor chair). Some EPIOCs have specialist features like tilt, recline and seat height adjustment which may be useful for some children. An EPIOC will allow your son to be independently mobile and keep up with his friends. This type of wheelchair is available from the Wheelchair Service but usually one of the criteria for provision is that a person requires it both indoors and out. In some areas Wheelchair Services will not provide this type of wheelchair until your son completely loses the ability to walk. In other areas an EPIOC may be provided at an earlier stage as the service may accept that your son has a progressive condition meaning that he will meet the criteria in due course.

Funding within most Wheelchair Services for powered wheelchairs is very limited and there is often a waiting list. There is an assessment process which can also be quite lengthy so start to make enquiries before the need arises – your child’s physiotherapist or occupational therapist is likely to know about the situation locally.

In some areas the Wheelchair Service will only provide children with a powered wheelchair for indoor use at first. This type of chair is known as an EPIC (electrically powered indoor chair). It may be felt that a child needs to learn to control a powered chair indoors before being allowed outdoors. This is essential but most children will pick up this skill very quickly and EPICs are of very limited use to a child with Duchenne as they are not designed for outdoor use and cannot cover the distances required.

Children with severe learning difficulties may not be able to safely use a powered chair of any kind and for these children an attendant controlled manual wheelchair may be the best option.
SEATING

Children with Duchenne can develop poor postures if they are not properly supported when they are sitting in a wheelchair. Good postural support should be provided from the start as children are often reluctant to accept change at a later date. The child’s back should be straight with the weight evenly distributed through the buttocks. The feet should be flat on the footplates. Please refer to the Wheelchair Guidelines for detailed information about posture and seating.

PRIVATE FUNDING OF WHEELCHAIRS

Initially you should talk to your Wheelchair Services department about funding. Explain your son’s condition to them and ask them to consider providing an EPIOC. If they refuse, ask them to put their decision in writing to you. Also ask them to flag up the fact that your son will, in the future, meet their criteria. This proves that they are aware of your son’s potential need and helps when fundraising for a privately purchased chair. Wheelchair Services may help with assessing the chair even if they are not paying for it.

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.

If you do have to privately fund a chair it is vital to get an assessment by a qualified professional with expertise in this area – do not rely on sales representatives. There are assessment centres which offer this service and/or your occupational therapist/physiotherapist may help. The chair needs to be the right size and it needs to support your child in a good sitting posture. You need to consider where the chair will be used (at school, in your locality, etc) and ideally you should arrange for the assessment to take place there. You need somewhere dry and secure with an electricity supply to store and charge a powered chair.

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

- To purchase it yourselves (this is difficult for most families – chairs cost upwards of £2500).
- To use the mobility component of your son’s Disability Living Allowance to purchase a chair through the Motability Scheme (see below for contact details).
To use the mobility component of your son’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 Trust. A letter of support from a professional will be essential. Ideally, you also need a professional to co-ordinate the fundraising.

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

Joseph Patrick Trust
Muscular Dystrophy Campaign
7-11 Prescott Place
London, SW4 6BS
Tel: 020 7720 8055
Web: www.muscular-dystrophy.org

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
For information on the Motability scheme for wheelchairs, contact:
Route2Mobility
Newbury Road
Enham Alamein
Andover
Hants, SP11 6JS
Tel: **0845 6076 260**
Web: [www.motability.co.uk](http://www.motability.co.uk)

Remember that in addition to the cost of the chair you will need to allow for the ongoing costs of insurance (at least 3rd 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 wheelchair.

**THE VOUCHER SCHEME**

In some cases Wheelchair Services may offer you a voucher towards the cost of a chair of your choice, although this is not available in Scotland. This can be a good option if you need a chair with additional features (for example, a chair that is height adjustable) that Wheelchair Services will not provide. Vouchers will usually only cover part of the cost of the chair. In some cases you may also get help with the cost of maintenance. Not all Wheelchair Services offer vouchers for powered wheelchairs.

**WHEELCHAIRS – REVIEWS**

It is important that the suitability of your son's wheelchair is regularly reviewed by a qualified therapist and that they check that the appropriate seating system is in place. Your son's needs will change as he grows and as his condition progresses.

**VEHICLES**

For families with a son with Duchenne, choosing a suitable vehicle can be a challenge. You must try to plan for the fact that your son's needs will change. Getting in and out of a car can be difficult and lifting someone in and out of a car is to be avoided – you risk injuring yourself. It is easier to get in/out of a car that is mid-height off the ground and which has
upright seats (as opposed to seats that tip backwards slightly). You may also need to allow for space to carry a wheelchair.

Once a child is either using a powered wheelchair most of the time or is entirely dependent upon a chair he may prefer to remain seated in his chair while travelling. (If so, a headrest on the wheelchair is essential while travelling.) This requires a wheelchair accessible vehicle. Wheelchair accessible vehicles are very costly when purchased new. Second-hand vehicles are advertised in some disability organisation magazines – your local library will have copies of these. Adverts also appear in *Target md*.

If your son receives the high rate mobility component of Disability Living Allowance (DLA) and has an award valid for at least another year (and you can reasonably expect to continue to receive the benefit for at least three years) you should be eligible to use the Motability Scheme if you wish. Motability is a charity which, in partnership with the government (the 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 or buy (on hire purchase) a new or second-hand vehicle over a period of two to five 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

Do note that Motability is not necessarily the cheapest option and you may be better off taking out a bank loan, especially if you are purchasing a heavily adapted vehicle. Motability grants towards the cost may be available, especially if you are an existing customer on a limited income. Motability can also advise on the suitability of vehicles.

To help ensure that you choose a suitable vehicle you might also like to consider having an assessment at a specialist centre. The addresses of these independent specialist centres are available from:
The Forum of Mobility Centres on 0800 559 3636.
These centres can also give up to date advice on which firms adapt vehicles. There is a modest charge for assessments – the centres are not for profit organisations.

One extra point to note is that if your son is likely to require spinal surgery this will make him taller and unable to bend his head down. Headroom height access does need careful consideration.

An excellent source of information on all issues to do with driving/vehicles is the 2005 Annual Handbook from the Disabled Drivers’ Motor Club, which after merging with the Disabled Drivers’ Association is now known as Mobilise. It lists all the mobility assessment centres and car adaptation companies. This is a 24 page magazine available from:

Mobilise
Ashwellthorpe
Norwich NR16 1EX
Tel: 01508 489449
Email: enquiries@mobilise.info
Web: www.justwebs.co.uk/mobilise

Assessment centres can also 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.

**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 around £23,000 and savings below £18,000 (2006 figure), the Family Fund will often help fund driving lessons.

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 either of these criteria:

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

Facts about The Blue Badge Scheme

- Children under 2 are not eligible. (There are some other criteria that are not usually applicable to people with Duchenne– 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 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 £10.70 (2006 figures – includes postage).

RADAR
12 City Forum, 250 City Rd
London EC1V 8AF
Tel: 0207 250 3222
Web: www.radar.org.uk
HOUSING ISSUES

This is a huge topic. If you have a son with Duchenne you will need to ensure that your home is suited to his needs. The *Adaptations Manual*, published by the Muscular Dystrophy Campaign, is a detailed guide to adapting your home and includes information on planning and equipment issues. It is strongly recommended that you obtain a copy of this book.

Generally speaking, boys with Duchenne require an 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 can offer advice but it is important to start discussions at an early stage as the whole process usually takes 18 months to two years. If you have access to a specialist care advisor/neuromuscular worker, do use them as their expertise can be invaluable.

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 Housing Association or council 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 try to 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 needs to be looked at whilst a child with Duchenne is still very young.

Stairlifts are never a good long term option for a child with Duchenne because they do not maximise a child’s independence and 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 no longer able to climb stairs and adaptations are not yet completed.
In England, Wales and Northern Ireland, Disabled Facilities Grants (known as DFGs) are available to assist families with the cost of essential adaptations to their home. In Scotland these are not available. Instead, Home Improvement Grants of up to £20,000 are available. These are means tested.

Prior to December 2005 families applying for a DFG faced a means test, but thanks to campaigning by a coalition of charities, including the Muscular Dystrophy Campaign, where the adaptations are for a child under 18, the means test is no longer applied.

Your social services occupational therapist will be able to advise you on the procedure for applying for a DFG (up to the value of £25,000 in England and £30,000 in Wales) and for any additional funding you may require. 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.

**BATHS/SHOWERS**

You will need to make a decision as to whether a bath or a shower is preferred. For many boys with Duchenne a bath is a better option as you are better supported in a bath, a carer gets less wet assisting you and a bath tends to be warmer and more relaxing. It will be necessary to look at the use of a hoist to get your son in and out of the bath.

**BATHROOM EQUIPMENT**

The right bathroom equipment helps to maximise a child’s independence and maintain his dignity. The *Adaptations Manual* contains advice on what equipment to consider and 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. As your child gets older it will 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 son, 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 have 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 son’s school. Ceiling track hoists 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 types of hoists are available to assist with transfers in and out of a vehicle.

BEDS

For a young child with Duchenne 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 – see page 29 for details.)

When walking becomes more difficult it might be the time to look at obtaining an electrically adjustable bed. Beds which are electrically height and section adjustable are beneficial to both the carer and user. 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 user to alter their position and to sit up/lie down unaided.

It is recommended that you get advice on which bed is right for your son as not all adjustable beds are suitable for boys with Duchenne. Advice is available from the Muscular Dystrophy Campaign.

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 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. In other areas, such beds (particularly for younger boys) may have to be privately funded. The cost of these beds is a little over £2,000 (2006 prices).
Consider your child’s positioning in bed. Lying all night in some positions can exacerbate postural problems. This is particularly the case with older boys. Your physiotherapist/occupational therapist can advise and may recommend using pillows, T rolls or a sleep system to hold a position.

**ARMCHAIRS**

Getting from sitting to standing will become difficult for a child with Duchenne. It will be especially difficult if the chair is low. The height of armchairs can be increased by using riser blocks (available from your occupational therapist).

Specialist armchairs are available that are suitable for slightly older boys. These offer supportive seating and, in some cases, will bring the user to standing at the touch of a button. Such chairs tend to be used only while a child is still able to walk because of the difficulty of getting the child in/out of the chair. Details on these chairs are available from the Muscular Dystrophy Campaign or your occupational therapist.

**COMPUTERS**

Most children with Duchenne will benefit from acquiring computer skills. As teenagers, boys with Duchenne 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 assessing the type of equipment needed. The Joseph Patrick Trust may also assist towards the cost.

Aidis Trust  
First Floor, 54 Commercial Street  
London, E1 6LT  
Tel: **020 7426 2130**  
Web: [www.aidis.org](http://www.aidis.org)

The Joseph Patrick Trust  
Muscular Dystrophy Campaign  
7-11 Prescott Place  
London, SW4 6BS  
Tel: **020 7720 805**  
Web: [www.muscular-dystrophy.org](http://www.muscular-dystrophy.org)
The Golden Freeway is a private website/information network for people with Duchenne and their families/carers. Any family with a child of any age with Duchenne can ask to be linked into the network by visiting: www.thegoldenfreeway.com

Information about Duchenne is not directly supplied on the website but parents are advised by email where such information can be found. If you do not have access to a computer, the team at the Golden Freeway may be able to advise you on provision.

Within school it is worth pushing for extra computer lessons/time from an early age. As early as possible a laptop should be provided (certainly at secondary school). This provision should be written into your son's Statement of Special Educational Needs, or in Scotland, into your son's Co-ordinated Support Plan.

**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 the Independent Living Shows, organised by Emap Healthcare. Emap can be contacted on 020 7874 0200 or see the Naidex website: 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 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 so sales representatives may try to sell you things. There are also some related stands, for example stands from specialised holiday companies, charities and government agencies.

If you are interested in vehicles suitable for a wheelchair user then the Mobility Roadshow is worth visiting. Look at its website for further details: www.mobilityroadshow.co.uk
MAVIS (Mobility Advice and Vehicle Information Service) on 01344 661000 can give more information. Or try the website – www.dft.gov.uk – and type 'MAVIS' into the search function.

For details of smaller equipment exhibitions, visit the Muscular Dystrophy Campaign's website: www.muscular-dystrophy.org or call 020 7720 8055.

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
  Redbank House, 4 St Chad's Street
  Cheetham, Manchester, M8 8QA
  Tel: 0870 770 2866
  Web: www.assist-uk.org

Dialability also has access to equipment you can assess on site. Contact them at 01865 763600 or visit www.dialability.org.uk

At Independent Living Centres/Dialability 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 son will use at home.

Some catalogue firms have stores where you can view equipment:

- Keep Able  Tel: 08705 20 21 22  Web: www.keepable.co.uk
- Chester Care  Tel: 01623 722337  Web: www.homecraftability.com
- Care Shop  Tel: 0845 600 1204  Web: www.careshop@careshop.co.uk

It is unusual to find the specialised equipment you will need in catalogues but they can be useful for obtaining small items 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 COSTS

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. If you do it yourself you will need letters of support from professionals. Charities that may assist include the following:

Joseph Patrick Trust (part of the Muscular Dystrophy Campaign)
7-11 Prescott Place, London, SW4 6BS
Tel: 020 7720 8055
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 130 4542
Email: info@familyfund.org.uk
Web: www.familyfund.org.uk
(Please see section in this book on the Family Fund)

REACT
St Lukes House, 270 Sandycombe Lane
Kew, Richmond, Surrey, TN9 3NP
Tel: 020 8940 2575
Email: react@reactcharity.org
Web: www.reactcharity.org

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

Invalids At Home
Bamford Cottage
South Hill Avenue
Harrow, HA1 3PA
Tel: 020 8864 3818
The ACT Foundation
The Gatehouse, 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 Centre
Hemlock Business Park
Hemlock Way, Cannock
Staffordshire, WS11 7GF
Tel: 01543 468888
Email: info@bdfnewlife.co.uk
Web: www.bdfnewlife.co.uk

There will also be charities in your area. 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 (army, air force, navy), their charities may be able to help you.

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 Muscular Dystrophy Campaign’s Information Officers have access to a computer software package called *Funder Finder for People in Need*. They are willing to undertake searches but cannot make applications for individuals.

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. SCHOOL
ISSUES TO CONSIDER

There are many issues to consider with regard to schooling – from choosing the right school to obtaining the right in-school support for your child. The important thing with educational issues is to plan in advance.

If you live in Scotland, please note that your educational system is a little different from the rest of the UK. Local Education Authorities are known as Education Authorities and instead of a Statement of Educational Needs your son may have a Record of Needs or (from November 2007) a Co-ordinated Support Plan. Further information is available from: Enquire, Children in Scotland, 5 Shandwick Place, Edinburgh, EH2 4RG Tel: 0845 123 2303 Web: www.enquire.org.uk

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

Most children with Duchenne 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 (LEA) or in Scotland, the Education Authority (EA), has a duty to provide appropriate education for your child but it does not have a legal duty to provide “the very best.” With the increasingly good management of Duchenne the future for boys with the condition is improving. With this in mind we need to attach more importance than ever before to education and learning, and help equip children with the skills they will need as young adults.

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

- Education factsheet
  This covers schooling for children with muscular dystrophy
- Inclusive Education – a guide for schools.

From Network 81:

- How to get support for your child with Special Educational Needs.
  This is excellent and is very clear on the school’s responsibilities and on Statements of Special Educational Needs or Co-ordinated Support Plans.
Network 81
1-7 Woodfield Terrace
Chapel Hill, Stansted
Essex, CM24 8AJ
Tel: 0870 7703306  Web: www.network81.co.uk

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

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 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. (2006 prices).

The ACE Special Education Handbook is £17.99 +pp (2006)
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*. Both are free.

**DFES**  
Tel: 0870 000 2288  
Email: info@dfes.gsi.gov.uk  
Web: www.teachernet.gov.uk

Your LEA or EA will publish literature about schools in your area and can supply details of mainstream and special schools. Talk to them at an early stage about your son’s special educational needs. Even if your son is academically able and has few physical difficulties, it is important to plan for his future physical needs and to make the right choice of school.

**CHOOSING A PRIMARY SCHOOL**

Take advice from your LEA or EA, and from the professionals involved in your son’s care. Visit several schools and talk to both 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 staff have a positive approach to your son joining the school as goodwill and support are going to be vital.

Try to select a school which is on one level and does not have lots of steps. Consider the toilet facilities that your son will require.

**STATEMENTS AND SUPPORT PLANS**

At some stage almost all children with Duchenne 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 son 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
Good liaison with the school staff means that any difficulties can be 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, when your child is about nine years old. 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 son's needs but, as mentioned earlier, it does not have a duty to provide the very best – or to provide for non-educational needs (for example, physiotherapy) unless they impact on your son's ability to access his educational opportunities.

It is essential that your son can move around the secondary school site in his powered wheelchair and that he 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 offers your son must meet his needs. Your son's natural abilities need to be encouraged and extra help should be available for any specific areas of difficulty.

The Statement or Support Plan needs to be properly updated prior to secondary school admission and the secondary school named on the revised document.

LEARNING DIFFICULTIES
About a third of all children with Duchenne have a degree of learning difficulty. Often this difficulty is quite mild and easily managed within a mainstream school setting. Many children with Duchenne appear (anecdotal evidence only) to have particular difficulties with literacy. Unlike the muscle weakness, the learning difficulties do not become more severe with time and it is important to get the right help at an early stage. One to
one help within school is often vital to ensure that your child reaches his full potential.

Parent Project UK (PPUK) published a booklet called "Learning and Behaviour Toolkit for Duchenne Muscular Dystrophy" in October 2006. It is available free of charge by calling PPUK on 020 8556 9955.

Some 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
(An independent charity that gives specialist advice to parents and professionals.)

Ace Centre North
Units 11 &12 Gatehead Business Park
Delph New Road, Delph, Saddleworth, OL3 5DE
Tel: 01457 829444 Web: www.ace-north.org.uk
(A company with charitable status.)

A number of children will have significant learning difficulties and may be happier in a special school environment. Some boys with Duchenne are academically bright and are able to go onto higher education after leaving school. Whatever your son’s abilities it is important to maintain a positive focus and encourage his natural talents and interests. It is noticeable how many children with Duchenne are artistic.

BULLYING

Every school has to have a policy on bullying so 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 faces. Consider organising a session whereby someone comes in to talk to the class about your son’s mobility difficulties – a Care Advisor or a physiotherapist may be willing to do this. It is, of course, essential to ensure that your child is in agreement first. 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 his natural interests and talents are encouraged. Activities that might be of interest include:

Swimming
This is excellent exercise and 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. Contact them at:
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. Contact the organisation at:
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 on photography as a hobby. Contact the organisation at:
DPS, PO Box 130, Richmond, Surrey, TW10 6XQ
Web: www.dps-uk.org.uk

Sport
The English Federation of Disabled Sport is a national body covering all types of sport. Contact it at:
EFDS, Manchester Metropolitan University, Alsager Campus, Hassall Rd Alsager, Stoke-on-Trent, ST7 2HL
Tel: 0161 247 5294   Web: www.efds.net

PHAB clubs
PHAB clubs aim to offer opportunities for disabled 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 the area.

FAMILY HOLIDAYS
Holidays should be fun and stress free. When you book your holiday remember to ask lots of questions to ensure that the facilities will meet your family’s needs. If accessible accommodation is required contact Tourism for All, The Hawkins Suite, Enham Place, Enham Alamein, Andover SP11 6JS
Tel: 0845 124 9974  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.

Certain charities own and run accessible self catering accommodation – for example:
The Scout Holiday Homes Trust (0208 433 7100), 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. Another option is 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) organise holidays and leisure activities (020 8667 9443).

The Duchenne Family Support Group (a separate charity to the Muscular Dystrophy Campaign) organises family holidays. Contact it on:
Tel: 08702 411857  Web: www.dfsg.org.uk
The Muscular Dystrophy Campaign has a factsheet about holidays.
Tel: 020 7720 8055  Email: info@muscular-dystrophy.org
Web: www.muscular-dystrophy.org

Contact A Family also has information about holidays:
209-211 City Rd, London, EC1V 1JN
Tel: 020 7608 8700  Email: info@cafamily.org.uk
Web: www.cafamily.org.uk

SPECIAL HOLIDAYS FOR CHILDREN
There are several charities which organise “dream holidays” (often to
Disneyland) for children with Duchenne. Some of these will be family
holidays but others will be for the child alone. In the latter case the child
would be part of an organised group that includes qualified care staff.
The Muscular Dystrophy Campaign publishes a factsheet called ‘Dream
trips and wishes for children and young adults’:

Dreams Come True
Knockhundred House, Knockhundred Row, Midhurst
West Sussex, GU29 9DQ
Tel: 0800 018 6013  Web: www.dctc.org.uk

Dreamflight
7c Hill Ave, Amersham, Bucks, HP6 5BD
Tel: 01494 722733  Web: www.dreamflight.org

Make A Wish Foundation UK
329/331 London Rd, Camberley, Surrey, GU15 3HO
Tel: 01276 24127  Web: www.make-a-wish.org.uk

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

When You Wish Upon A Star
Futurist House, Valley Rd, Basford
Nottingham, NG5 1JE
Tel: 0115 979 1720  Web: www.whenyouwishuponastar.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 with regard to the safety and suitability of the event/holiday.

**HOLIDAY FUNDING**

It is usually only possible to get funding for family holidays if you are holidaying in the UK, 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, Y032 9WN  
Web: [www.familyfund.org.uk](http://www.familyfund.org.uk)

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

One charity offering breaks to disabled children is:  
Break  
Davison House, 1 Montague Rd,  
Sheringham, Norfolk, NR26 8WN  
Tel: [01263 822161](tel:01263%20822161)  
Web: [www.break-charity.org](http://www.break-charity.org)

**HOLIDAY INSURANCE**

It is essential to take out insurance that covers your child’s condition. If you fail to declare that they have Duchenne you may invalidate your son’s insurance in the event of any type of accident/illness – even if it is not related to the Duchenne. Your child’s consultant may be willing to write a letter for your insurers explaining about Duchenne muscular dystrophy.

In Europe, remember to take a new style 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, on the phone at [0845 605 0707](tel:0845%20605%200707) or online at [www.ehic.org.uk](http://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.

  Once your child has significantly restricted mobility they may become eligible for the mobility component. You cannot apply for this component until a child is two years and nine months old.

  The care component is paid at one of three rates and the mobility component at one of two rates. For children with Duchenne 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.

  *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 then do challenge it. Advice on how to do this should be sent to you with the decision. Children with Duchenne should be awarded DLA for life, or at least until the child’s 16th birthday (when 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 who receives the middle or high rate care component of DLA. It can be paid to a parent of a disabled child. It is not payable to anyone who earns over £84 per week (after allowable expenses are deducted – 2006 figure). 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. The Family Fund aims to support the families of severely disabled/severely ill children under the age of 16.

The Family Fund 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 of below £18,000. (2006 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 son’s needs and an assessment of your own needs as a carer. If brothers and sisters are helping to care for their disabled sibling their needs, as young carers, should also be assessed. You can refer yourself to your local social services department. Ask to speak to the duty officer.

  Your social service department can help with personal care (to get your son washed, dressed and ready for the day, or ready for bed) and respite care (care aimed at giving the regular carer a break – during the day or overnight). It may also provide summer play schemes and offer 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.carers.gov.uk](http://www.carers.gov.uk)

  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 Minories, London, EC3N 1LB
  Tel: 020 7480 7788
  Web: [www.carers.org](http://www.carers.org)
CHILDREN’S HOSPICES

Children's hospices offer care and support to families who have a child with a life limiting or life threatening condition. This includes children with Duchenne. Care can be offered over a period of many years.

Children's hospices often support children with Duchenne from the age of eight or nine years, particularly if they use a wheelchair to get about. Although children's hospices do care for children who are very poorly, the majority of their visitors are there for respite care, and not many of the children they work with 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. No charge is made to families using the hospice.

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 will 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 answering children's questions honestly. You may need to discuss this issue with staff but be assured that their approach will be a sensitive one.

Almost all children 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
Email: info@childhospice.org.uk
Web: www.childhospice.org.uk
MEETING OTHERS
Some families enjoy meeting others who also have a child with Duchenne. You may find that this happens without you having to arrange anything – there may be other children at the same school, attending the same clinic, seeing the same physiotherapist etc.

If you do wish to meet up with other families you could also:
- attend a Duchenne muscular dystrophy information day (organised by the Muscular Dystrophy Campaign)
- join a Muscular Dystrophy Campaign Branch
- join the Duchenne Family Support Group (a separate charity to the Muscular Dystrophy Campaign)
- join the Parent Project UK (also a separate charity – their focus is on persuading government to fund research)
- ask your care advisor/physiotherapist etc to put you in touch with other families

You can have email contact via the Muscular Dystrophy Campaign’s community pages on the website at www.muscular-dystrophy.org. Or visit the Golden Freeway website at www.thegoldenfreeway.com.

SUPPORT GROUPS
As mentioned above, there are three support groups directly concerned with Duchenne in the UK.

Muscular Dystrophy Campaign (MDC)
7-11 Prescott Place
London, SW4 6BS
Tel: 020 7720 8055
Email: info@muscular-dystrophy.org
Web: www.muscular-dystrophy.org

The Muscular Dystrophy Campaign is the largest national charity focusing on muscular dystrophy and related muscle diseases and supports over 60 different neuromuscular conditions. It has pioneered the search for treatments and cures for over 45 years, and provides practical, medical and emotional support to people affected by these diseases.
Duchenne Family Support Group (DFSG)
78 York Street
London W1H 1DP
Tel: **0870 241 1857** (office), **0870 606 1604** (helpline)
Email: dfsg@duchennedemon.co.uk
Web: www.dfsg.org.uk

This support group is run by families, for families. It publishes a regular
magazine and organises social events. It joins with the Muscular
Dystrophy Campaign and PPUK to lobby for funding for research.

Parent Project UK (PPUK)
PPUK Epicentre
41 West Street
London, E11 4LJ
Tel: **020 8556 9955**
Email: info@ppuk.org
Web: www.ppuk.org

PPUK is actively involved in campaigning for government funding into
research into Duchenne and has set up the DMD Registry database.

**COPING WITH PROFESSIONALS**

When a diagnosis of Duchenne is made various professionals will come
into your lives and at times this can feel a little overwhelming. The
professionals involved will want 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. Do 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 as this helps to ensure that your son’s care is well co-ordinated.
7. PERSONAL AND FAMILY MATTERS
TALKING TO CHILDREN

Most parents worry about what to say to their son and his brothers and sisters about his diagnosis of Duchenne. This is a very difficult area. People are frightened of saying the wrong thing and instead often say nothing. This is almost never a good idea as your child will create his own explanation if you do not provide one.

What you say will of course depend on your child's age and level of understanding. Some doctors advise using the full term “Duchenne muscular dystrophy” with your child from the beginning. What is important is to try to ensure that what you say is truthful and makes sense to your child. Some parents will say things like “the doctors have found out that you have a problem with your legs being rather weak. They can't make it better at the moment but lots of people are working very hard to see what they can do to help.” This is a good starting point – it is honest without being frightening. You can then build on this information in a “drip feed” approach. You should avoid denying that there is a problem, or promising that it can be made better. 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't guarantee to know the answers.

As your child progresses through primary school he will realise that his condition has got worse. Do not deny that this is the case. Listen to your child. Avoid putting your own (adult) interpretation on things and instead look at his concerns. They will be different to yours. For example do not assume that your child will refuse to use a wheelchair – he may be relieved to as he will be less likely to fall over and will be able to get around quickly.

At some point you will need to put a name to your son's condition. You may like to just use the term “a dystrophy” at first. Remind your child that everyone is different and none of us know what the future holds. In that way he is the same as everybody else. Also talk about the fact that worldwide research is ongoing.

The Muscular Dystrophy Campaign publishes some booklets that you might find helpful including Everybody's different, nobody's perfect and On the Ball.
Both of these use the term “muscular dystrophy” and *On the Ball* talks about Duchenne.

What you say to your son’s siblings will, again, depend upon their age and level of understanding. You know your children best. Unless the siblings are much older it is important to try not to share information with them that they then have to “keep secret”. Do acknowledge that their brother has a muscle problem that causes him to struggle with some activities – that way they can be supportive of him. The Muscular Dystrophy Campaign publishes a booklet specifically for brothers and sisters. It’s called *Hey! I’m here too!* and mentions the term Duchenne.

The other children you need to consider are your son’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 (although you may run the risk of other children being overprotective!). A professional involved in your child’s care may be able to come into school (with your son’s permission) and give a short talk about the things your son finds it difficult to do and how the class can help him. Never give other children more information about your son’s condition than he has, and avoid talking to other children about his condition without his permission. Involve your son in decision making – he has a right to be consulted and listened to.

If your son 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**

Many parents of primary school age children (particularly from about age eight to about age 11) will report problems with their son’s behaviour. This can range from poor concentration (a very common problem) to aggressive and disruptive behaviour. Poor 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 poor behaviour or unreasonable demands.
Instead address the issue and look at what may be causing the unacceptable behaviour.

A primary school child with Duchenne is experiencing many changes and is facing an ever changing situation in terms of his functional ability. It is important that a child is able to make sense of what is happening, otherwise he will become confused and unhappy. Often this can be the reason behind poor behaviour. Talk to your son, listen to his anxieties and be honest (but positive) in what you say to him. Earlier in this chapter you will find guidance on talking to your child about his condition.

Your child may be tiring quickly with a lot of physical activity and if he is taking steroids it is possible that they have an impact on how he is feeling.

It is also possible that your child is being bullied at school, or teased, or that he is being ignored. Talk to staff at the school. As mentioned earlier, consider sharing information with your son’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 son may be restricting his ability to make friends and enjoy being a child. Try not to be over protective, allow your child to be a child. He needs some adult-free time!

It is important that you set boundaries and that your son knows what these are and what sanctions you will use if he goes 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 son will need to develop good working relationships with his carers.

Be encouraged by the fact that aggressive and disruptive behaviour is rarely seen in secondary school age children with Duchenne and poor concentration definitely improves.

**SEX AND RELATIONSHIPS**

It is important to realise that your child has as much need as any other child to learn about sex and relationships. Do not ignore the topic in the belief that these issues will not be relevant to your son. 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 men with Duchenne usually have normal sexual development although some may remain a little underdeveloped. Some men with Duchenne have fathered children and many enjoy fulfilling relationships. Usually if a man with Duchenne has children, all his sons will be free of Duchenne and all his daughters will be carriers. (Assuming his partner is not a carrier or there is no new mutation in the child themselves.)

People with Duchenne need information on sexual activities/choices, contraception and the avoidance of sexually transmitted diseases. 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. The Brook Advisory Service may have a role to play here. Contact them at:

Brook
421 Highgate Studios
53-79 Highgate Road
London NW5 1TL
Tel: 020 7284 6040
Email: admin@brook.centres.org.uk

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 Duchenne as for other children. Life must not become a series of overly structured regimes! It is particularly important that a child with Duchenne enjoys his early
years as this is when he is best able to participate in a wide range of activities. You can help your child (as well as his brothers and sisters and yourself) by taking a positive approach. Try to have a “can do” approach to life. Take the time to enjoy activities as a family.

Encourage your child to develop his interests and talents and to make friendships. Support his wish for independence.

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

THE IMPACT ON FAMILY RELATIONSHIPS

Having a child with Duchenne will have an impact on everyone in the family, particularly those living in the same household.

With respect to your son’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 brother, they may feel embarrassment about their brother’s disability and they may feel jealous of all the attention that he receives.

Although it can be difficult to arrange, your other children need some “protected time” too. They need to know that there will be times when they can talk to you, share their concerns about their own lives with you 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 son with Duchenne cannot do. He will be able to achieve in different areas and recognising the value of difference is an important lesson for all your children to learn.

There may be occasions when your son’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 brother with Duchenne. 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.cafamily.org.uk](http://www.cafamily.org.uk) or you can call **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 alike. 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 a little 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* which 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 a referral, and another professional involved in your son’s care (such as the consultant or the care advisor) can alert the psychologist to the issues facing a family with a child with Duchenne.
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 son does not become “spoilt” or that he does 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 above for details) publishes a leaflet for grandparents. This leaflet lists support organisations that grandparents 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. Recent advances in the management of Duchenne have greatly improved the outlook for people affected by the condition. Encourage your son to plan for his future and to gain what skills he can. Education has an increasingly important role to play. Personal relationships outside of the family home are to be encouraged and boys 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 he was before the diagnosis and that giving him 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 – just read the sections on Duchenne.

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.