Duchenne muscular dystrophy: the teenage years

A guide for young people aged 13-19 years and their parents/carers

Jane Stein
Regional Care Advisor
Oxford Muscle Centre
This book has been written for people aged 13-19 with Duchenne muscular dystrophy (hereafter referred to as Duchenne) and their parents/carers. The aim of this book is to provide advice and information on issues related to living with a diagnosis of Duchenne.

Remember that we are all different and not everyone will face the same issues or have the same priorities. What matters is that you have an opportunity to set the priorities that are right for you and that you can access the support that you require. Throughout the book the “you” we are referring to is the young person with Duchenne.

Thank you to all the people whose photographs feature in this booklet.
1. MEDICAL ISSUES

SPECIALIST SUPPORT
Whether you are 13 or 19 it is important to ensure that you remain under the care of a consultant with a specialist knowledge of, and interest in, Duchenne. Ideally such a consultant should be based in a centre where there is access to a multi-disciplinary team of professionals who can also offer support and advice.

Information about the location of specialist clinics for both children and adults is available from the Muscular Dystrophy Campaign.

STAYING HEALTHY
As you get older you will assume increasing responsibility for making decisions about your own health needs. You will need to learn more about your condition and what you can do to keep yourself in good health. This will include continuing with a physiotherapy programme, ensuring that you maintain a good posture when sitting in your wheelchair (and lying in bed), eating a healthy diet and treating chest infections promptly. We will look at these issues in more detail in this section.

MAINTAINING GOOD NUTRITION
We have no evidence that any special diet helps people with Duchenne. What is important is to eat a varied, well balanced diet, avoiding foods with a high fat and/or sugar content. Try to keep your weight at a reasonable level and seek advice from your consultant if you are gaining or losing weight without apparent cause. Remember that people who are wheelchair users and who are unable to be physically active require fewer calories than able bodied people of the same age. Putting on excess weight will make you feel sluggish and tired. It will also make moving and handling transfers harder for your carers.

Some people with Duchenne find that they lose rather too much weight. We tend to notice this especially in people in their late teens. Your consultant may refer you to a specialist dietician if this is the case.
Occasionally alternative feeding methods like a gastrostomy are required but this is certainly not the case for most people. Those people who require a gastrostomy might like to talk to others who have one. Experience shows that gastrostomies are often successful in helping to maintain/increase weight and in reducing the huge anxiety that can be felt over ensuring an adequate intake orally.

**MAINTAINING RANGE OF MOVEMENT**

When muscles are not used or become weak they, and their tendons, become tight and contractures (when the joint becomes fixed in one position) can develop. Contractures limit your range of movement and can cause discomfort.

It is important to try to maintain mobility for as long as possible. Some boys with Duchenne can prolong their mobility through the use of long leg callipers. Even after the ability to walk has been lost, try to maintain, for as long as possible, the ability to stand. The longer you can retain this ability the easier transfers will be for you and your carers.

Standing frames and tilt tables (supplied on the advice of your physiotherapist) are available to help support someone in a standing position. Some very sophisticated powered wheelchairs can also support you in a standing position but it is absolutely essential that you seek the advice of a physiotherapist or occupational therapist prior to purchasing such a chair as contractures at the ankles, knees or hips may mean that such a facility cannot be used safely.

Everybody with a diagnosis of Duchenne should see a NHS physiotherapist regularly and should be shown a daily programme of stretching exercises. By regularly stretching the muscles you will minimise the risk of developing contractures.

Some people find hydrotherapy helpful. Hydrotherapy involves a programme of exercises in a warm water swimming pool. Your physiotherapist would be the person responsible for designing and delivering such a programme.
The Muscular Dystrophy Campaign publishes a free booklet on physiotherapy for people with Duchenne. This booklet should be used under the guidance of your physiotherapist.

**MAINTAINING GOOD POSTURAL SUPPORT**

Maintaining good postural support is important for your health and well being. As you become older and spend more time sitting in your wheelchair, the spinal muscles weaken and are unable to support the spinal column in the upright position. This is when a scoliosis (a sideways or twisting curvature of the spine) can develop. If a scoliosis is left untreated it can cause increasing difficulty in sitting comfortably as the weight is no longer evenly distributed through the buttocks. Scoliosis can also cause an alteration to the shape of the chest which could eventually restrict the capacity of the lungs which might make breathing more difficult and chest infections harder to clear.

The most effective way to manage scoliosis is usually 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 obtain all the information that you feel you need to make the decision about whether to go ahead with the surgery. The Muscular Dystrophy Campaign publishes some information on spinal surgery (and the questions to ask when it is being considered) but the surgeon and his or her team should always be fully consulted.

Remember that you 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. Mobile arm supports (devices which support the arm), are often helpful at this stage.

On the plus side, many people find that sitting better boosts their confidence and helps them feel they look their best. Most people find their clothes fit better.

If spinal surgery is not considered appropriate, or a family decide 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 very helpful for people with Duchenne.
ANAESTHETICS

In Duchenne, respiratory function may be reduced and where possible general anaesthetics should be avoided. If a general anaesthetic is required ensure that the anaesthetist is aware of your diagnosis and that your lung function is tested. The Muscular Dystrophy Campaign publishes a factsheet on anaesthetics, which gives general advice but it is strongly recommended that you seek advice from your neuromuscular or respiratory consultant wherever possible.

MANAGEMENT OF CHEST INFECTIONS

Do all that you can to avoid chest infections. Your consultant is likely to suggest that you have an annual flu vaccination and that you have a one off pneumococcal vaccination. As far as possible, avoid contact with people with coughs and colds.

If you develop a chest infection seek medical advice immediately. Chest infections usually need to be treated aggressively with early antibiotics and chest physiotherapy. Your GP should be aware of this, if not, ask your consultant to write to him/her. If the chest infection becomes very troublesome or does not respond to antibiotics admission to hospital may be necessary.

ISSUES AROUND VENTILATION

As chest wall muscles become weaker, in order to aid breathing which is shallower (hypoventilation), many teenagers may need to use non-invasive ventilation at night. This involves the use of a ventilator and facial mask. It does not involve any 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 consultant and if there are concerns a sleep study (done overnight) may be recommended.

If this shows that you would benefit from the use of a ventilator, further discussion will be arranged with the relevant respiratory consultant.

Some early symptoms of hypoventilation include morning headaches, loss of appetite and a disturbed sleep pattern.
After using non invasive ventilation at night most teenagers report that they feel brighter and more alert during the day. The use of non-invasive ventilation has greatly improved the outlook for people with Duchenne, enabling them to achieve more in the day and therefore to enjoy a better quality of life.

**MONITORING THE HEART MUSCLE**
The heart is a muscle and it is important that its function is monitored over the years. Most people with Duchenne will not be troubled by any symptoms of heart involvement but if a problem is identified treatment can be sought and medication offered.

Medication to boost the pump function of the heart may be offered at an early stage – even before there are any symptoms of weakening heart muscle function.

**CONTINENCE**
Most people with Duchenne do not experience problems with bladder or bowel incontinence but a study in Australia in 2004 found that over a third of people with Duchenne experienced some difficulties with urinary urgency, urinary hesitancy, bowel urgency and constipation.

Constipation is usually more of a problem if you are wheelchair dependent. Management of this is usually through a diet rich in fibre (found in foods like bran, brown bread, fruit and vegetables). Doctors can advise on the use of medication if necessary.

Obviously the less mobile you are the harder it is to access toilet facilities quickly. A urine bottle can be kept handy for passing water and it helps if you can establish a routine with respect to bowel management. Do not be shy about insisting that your privacy and dignity are maintained.

There is usually no loss of sensation in Duchenne.

**GENETICS**
At some stage you may feel that you need more information about the genetics of your condition, especially if you are in a relationship and considering children of your own.
All the daughters of men with Duchenne will be carriers of the condition (usually meaning that they will not experience any muscle weakness themselves) and all sons will be free of the condition (unless the man’s partner is a carrier of Duchenne or there is a new mutation in the child himself).

Staff from Clinical Genetics departments are happy to meet people affected by Duchenne (and their partners if they wish) to discuss this issue, in confidence, in more depth. Your GP or consultant can arrange this referral for you.

**RESEARCH**

Most families like to be kept up to date with research advances. The latest information is available through the Muscular Dystrophy Campaign website at [www.muscular-dystrophy.org](http://www.muscular-dystrophy.org) and through the charity’s quarterly magazine, *Target MD*. For information about *Target MD*, please call [020 7803 4800](tel:+442078034800) or email [info@muscular-dystrophy.org](mailto:info@muscular-dystrophy.org)

Staff from the Research Team at the Muscular Dystrophy Campaign are also on hand to answer any questions you may have. Each year there are conferences for families run by the Muscular Dystrophy Campaign, the Duchenne Family Support Group (DFSG) and Action Duchenne, where scientists and clinicians give presentations on current research and run question and answer sessions. The three charities also campaign for the government to fund research.

**TRANSFER TO ADULT SERVICES**

At some point during your teenage years your paediatric consultant is likely to suggest a transfer to adult services. This can be quite a difficult time as your care may need to be co-ordinated by a new team of people who will need time to get to know you. They may also be based at a different hospital.

It is important that you continue to see a consultant with an interest in your condition, preferably one who works within a multi-disciplinary setting. At your first appointment it can be really helpful if you can take along a list of all the staff involved in your care (medical staff, physiotherapist, occupational therapist, etc).
WISHES IN RESPECT OF MEDICAL CARE

Because of your diagnosis of Duchenne muscular dystrophy you are likely to have considerable contact with doctors over the years. Try to take an increasing role in the decision making about things to do with the management of your condition. Talk to both your family and the doctors caring for you about your wishes in respect of various types of medical interventions (for example, spinal surgery, use of a ventilator, etc). On occasions people with Duchenne have become acutely unwell and doctors and family members have had to make decisions about the right course of action to take. It can be a comfort to you and your family if they are aware of your wishes in advance of any crisis with your health.
WHEELCHAIR MOBILITY NEEDS

Most people with Duchenne require the use of both a manual wheelchair and an electrically powered indoor/outdoor chair (known as an EPIOC). Wheelchairs are available through Wheelchair Services – part of the NHS – and are provided to people who have considerable difficulty walking, or who are unable to walk at all. All Wheelchair Services set criteria for the provision of different types of wheelchair but these vary from area to area. Your local Wheelchair Services will be able to provide you with a written document outlining their criteria.

A manual wheelchair is essential even if you have a powered chair as there will be places that you will be unable to access in your powered chair and occasions when your powered chair might be out of action. An EPIOC is generally the chair of choice for teenagers with Duchenne. The only exception to this might be a teenager with severe learning difficulties where safety could be an issue.

An electrically powered indoor chair (EPIC) is not usually suitable as it can obviously only be used indoors. Do not accept this in place of an EPIOC – you will quickly acquire the skills you need to control an EPIOC.

It is essential that you are properly assessed by a qualified professional for any type of wheelchair that you are provided with. It is also important that you are regularly reassessed as your needs may change over time. Some EPIOCs have specialist features such as electrically operated seat height adjustment, tilt or recline. Tilt and recline facilities are important for most people with Duchenne as they allow you to alter your position and relieve pressure areas. Further advice on the justification of these needs may be found in the Muscular Dystrophy Campaign’s guidelines on wheelchairs called Best Practice Guidelines for Wheelchair Provision for Adults and Children with Muscular Dystrophy and other Neuromuscular Conditions. To order a copy call 020 7803 4800 or email info@muscular-dystrophy.org
Wheelchair services also have a responsibility to ensure that good postural support is provided in your wheelchair. Your back should be straight with your weight evenly distributed through your buttocks. If possible, your feet should be flat on the footplates. A headrest should be provided and is essential if you are travelling in a vehicle while seated in your wheelchair.

**FUNDING OF WHEELCHAIRS**

Generally speaking wheelchairs should be funded by Wheelchair Services but there may be occasions when you do not meet their criteria or you wish to purchase a more sophisticated chair than they are able to provide. In these circumstances you may need to provide at least some of the funding from an alternative source.

If you meet Wheelchair Services’ criteria but wish to purchase a more sophisticated wheelchair (one which Wheelchair Services staff agree will still meet your needs) they may offer you a voucher towards the cost and possibly some help towards maintenance. Not all Wheelchair Services offer vouchers for powered chairs.

If you need to find funding for your wheelchair the following options are open to you:

- Purchase the chair yourself (this is difficult for most families because of the great expense)

- Use the mobility component of your Disability Living Allowance to purchase a chair through the Motability scheme (provided you are not already using your money for a Motability vehicle) – contact:
  
  **Motability – route2mobility**
  
  Newbury Road
  
  Enham Alamein, Andover
  
  Hants SP11 6JS
  
  **0845 60 76 260**
  
  **www.motability.co.uk**

- Use the mobility component of your Disability Living Allowance to fund a loan (consider the interest rates very carefully)
Approach charities. The Muscular Dystrophy Campaign’s welfare fund, the Joseph Patrick Trust, will usually offer some help towards the cost. Other charities you could approach are listed below. Note that some charities have age restrictions. You may also be able to find local charities through your Citizens Advice Bureau or charities associated with trades or professions your family has a link with. The Muscular Dystrophy Campaign’s Information Officers can search the computer software package Funder Finder for you.

Joseph Patrick Trust
Muscular Dystrophy Campaign
61 Southwark Street
London SE1 0HL
020 7803 4814
jptgrants@muscular-dystrophy.org
www.muscular-dystrophy.org

The Variety Club
93 Bayham House
London NW1 0AG
020 7428 8100
info@varietyclub.org
www.varietyclub.org
N.B. Under 18s only

Whizz Kidz
Elliott House, 10-12 Allington Street
London SW1E 5EH
020 7233 6600
info@whizz-kidz.org.uk
www.whizz-kidz.org.uk
N.B. Under 18s only

The Caudwell Charitable Trust
Minton Hollins, Shelton Old Road
Stoke on Trent ST4 7RY
0845 300 1348
www.caudwellcharitabletrust.com
N.B. Under 19s only
Never purchase a wheelchair privately without obtaining independent advice from a qualified professional (not the sales rep!). When purchasing a chair privately consider the need for insurance and allow for maintenance costs. Be wary of taking out expensive maintenance contracts.

**VEHICLES**

For people with Duchenne, choosing a suitable vehicle can be a challenge. You should ideally look for a vehicle that allows you to travel while seated in your powered wheelchair. The vehicle can be accessed via ramps or a tail lift. Such vehicles are, of course, very costly.

To help ensure that you choose a suitable vehicle you might like to consider having an assessment at a specialist centre. The addresses of these independent 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 as the centres are not for profit organisations.

Provided that you receive the high rate mobility component of Disability Living Allowance (DLA) you should be eligible to use the Motability Scheme if you wish. Motability is a charity which, in partnership with the government (Department of Work and Pensions) and private companies, aims to provide vehicles and wheelchairs to disabled people. Through this scheme you can elect to use the mobility component of DLA to lease a new vehicle for three years; buy, (on HP), a new or second-hand vehicle over a period of two to five years or purchase a new or second-hand wheelchair/scooter over a period of one to three years. Parents can do this on behalf of their disabled child.

For advice on the Motability vehicle schemes contact:

Motability Operations
City Gate House, 22 Southwark Bridge Road
London SE1 9HB
**0845 456 4566**
[www.motability.co.uk](http://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 staff can also advise on the suitability of vehicles.

One extra point to note is that if you have not had spinal surgery but may do so in the future this will make you taller and may mean you are unable to bend your head down. You will therefore require a vehicle with extra headroom.

An excellent source of information on all issues to do with driving and vehicles is Mobilise (formed from the merger of the Disabled Drivers’ Motor Club and the Disabled Drivers Association).

Mobilise
Ashwellthorpe
Norwich NR16 1EX
01508 489449
enquiries@mobilise.info
www.mobilise.info

Assessment centres (see www.mobility-centres.org.uk or ring 0800 559 3636) can provide information on a wide range of issues relating to mobility and will also be able to provide information about the Mobility Road Shows, which are held in various locations on an occasional basis. These shows provide an opportunity to view vehicles and vehicle adaptations. Visit www.mobilityroadshow.co.uk

**DRIVING**

It is strongly recommended that parents (both parents in the case of two parent families) learn to drive as there will be many occasions when you will need to attend appointments and get out and about as a family. For families with a child under 17 in Scotland and Northern Ireland, and under 18 in England or Wales on annual incomes below around £23,000, or £25,000 in Wales, (2008 figures) and savings below £18,000 the Family Fund will often help pay for driving lessons.
If anyone with Duchenne is interested in learning to drive an adapted vehicle (and obtaining such a vehicle) they should seek advice through a mobility centre:

0800 559 3636
www.mobility-centres.org.uk.

Be warned – waiting lists are long and it is never easy to obtain the large amount of finance required to purchase the vehicle.

**THE BLUE BADGE (PARKING) SCHEME**

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

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

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

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 or the Social Work department in Scotland. The blue badge can only be used when the disabled person is in the car or is being picked up/dropped off.

ACCESSIBLE TOILETS

A major anxiety when travelling around can be the availability of accessible public toilets. The charity RADAR, operate 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 £12.25 (2008 figures – includes postage costs).

You can contact RADAR at:

12 City Forum
250 City Rd
London EC1V 8AF
020 7250 3222
radar@radar.org.uk
www.radar.org.uk
HOUSING ADAPTATIONS

Most teenagers with Duchenne will already be living in a home which has been adapted to suit their needs. If this is not the case, urgent thought needs to be given to moving, or getting the required work done so that your independence is maximised. Recent changes in government legislation mean that owner occupier families of disabled people under the age of 19 are no longer means tested under the Disabled Facilities Grant (DFG) system. Grants are available to carry out approved adaptations. If you are 19 or over you, (not your parents), will be means tested. In Scotland there is a different system.

If you live in a home owned by the council or a housing association then you should talk with them and your occupational therapist about what your needs are. You should not be charged for any essential adaptations.

Your community occupational therapist is responsible for assessing your needs in consultation with you and your family. An Adaptations Manual written by the Muscular Dystrophy Campaign’s former National Occupational Therapy Advisor, Philippa Harpin, is available from the Muscular Dystrophy Campaign. This very detailed guide describes how to plan adaptations to your home and what equipment to assess. Note that your bedroom and bathroom need to be on the ground floor or accessible via a through floor lift. Stair lifts are never a suitable long term solution. Call 020 7803 4800 or email info@muscular-dystrophy.org to order a copy.

EQUIPMENT IN THE HOME

Most of the specialist equipment that you are likely to require is detailed in the Adaptations Manual mentioned above. Provision of most specialist equipment in the home is usually the responsibility of the Social Services occupational therapist. The exceptions to this are medical equipment (e.g. ventilators) and complex environmental control systems which are an NHS responsibility. In most areas electrically adjustable beds are provided by the health service via the nursing services.
HOISTS
As you get older it will become more essential to use a hoist for all your transfers. Your carers should not lift you as they risk injuring themselves. If carers come into the home to assist you, you will find that they are not allowed to lift at all – they will insist on using a hoist. There are several types of hoists available and several situations where their use is needed. Mobile hoists are on wheels and can be moved around a building to be used in different places. Such hoists are often seen in hospitals and may be suggested for use in your school or college. Ceiling track hoists, as the name implies, are fixed to the ceiling. These have the advantage of not taking up floor space and being a little more “out of sight”. They tend to be used in the home where there are regular transfers between set places (for example, from the bedroom into the en-suite bathroom). Other hoists are available, for example, to assist with transfers in and out of a vehicle or in and out of a bath.

BEDS
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. You can get advice on the type of bed to assess from the Muscular Dystrophy Campaign – it is important to get advice as not all adjustable beds are suitable for people with Duchenne.

ENVIRONMENTAL CONTROLS
An environmental control system enables anyone to operate a wide range of domestic appliances and other vital functions by remote control. For further information speak to your occupational therapist or staff at your specialist clinical centre.

COMPUTERS
People with Duchenne may find doing large amounts of writing tiring and so acquiring speed and accuracy on the computer are important.

If you would like a computer for home use the Aidis Trust may be able to help with the cost (and with assessment of type of equipment needed). The Joseph Patrick Trust may also contribute towards the cost.
Aidis Trust  
54 Commercial Street 
London E1 6LT 
020 7426 2130 
info@aidis.org 
www.aidis.org 

Joseph Patrick Trust  
Muscular Dystrophy Campaign  
61 Southwark Street 
London SE1 0HL 
020 7803 4814 
jptgrants@muscular-dystrophy.org 
www.muscular-dystrophy.org 

The Golden Freeway is a private website/information network for people with Duchenne and their families/carers.

People with Duchenne and their families can ask to be linked into the network by contacting admin@thegoldenfreeway.com

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 a computer (usually a laptop) should be provided to assist you with your schoolwork. This provision should be written into your Statement of Special Educational Needs, or Co-ordinated Support Plan in Scotland.

For those in further education the Disabled Students’ Allowance can help cover the cost of purchasing a computer or other specialist study related equipment.

**VIEWING EQUIPMENT**

There will be times when you will find it helpful to view equipment – just to know what is available.
Each year there are several big equipment exhibitions (Naidex and the Independent Living Shows) organised by Emap Healthcare. You can contact the organisers on: **020 7874 0200**. The website for Naidex is [www.naidex.co.uk](http://www.naidex.co.uk)

Entry to these shows is free. The venues are fully wheelchair accessible with nearby parking for blue badge holders. You can usually hire wheelchairs and scooters in advance to use at the exhibition.

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 reps there may try to sell you things. There are also some related stands, for example stands from specialised holiday companies, charities and disability benefits organisations.

There are smaller exhibitions of equipment and you can find details of these on the Muscular Dystrophy Campaign’s website [www.muscular-dystrophy.org](http://www.muscular-dystrophy.org) or by calling the Information Line on **0800 652 6352** (freephone).

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
**0870 770 2866**
[general.info@assist-uk.org](mailto:general.info@assist-uk.org)
[www.assist-uk.org](http://www.assist-uk.org)

At Independent Living Centres you will have access to independent advice from a therapist. Make an appointment to go along – do not just turn up. It may be helpful to go with your community occupational therapist when assessing for equipment you will use at home.
Some catalogue firms have stores where you can view equipment. You can view equipment in the following catalogues:

Keep Able
08705 20 21 22
www.keepable.co.uk

Betterlife
0800 328 9338
www.betterlifehealthcare.com

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

CHARITIES THAT CAN HELP TOWARDS Equipment

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

Joseph Patrick Trust
Muscular Dystrophy Campaign
61 Southwark Street
London SE1 0HL
020 7803 4814
JPTgrants@muscular-dystrophy.org
www.muscular-dystrophy.org

BDF Newlife
Hemlock Way
Cannock
Staffordshire WS11 7GF
01543 468 888
info@bdfnewlife.co.uk
www.bdfcharity.co.uk
Family Welfare Association
501-505 Kingsland Road
London E8 4AU
020 7254 6251
fwa.headoffice@fwa.org.uk
www.family-action.org.uk

Independence At Home
Congress House, 4th Floor
14 Lyon Road
Harrow
Middlesex HA1 2EN
020 8427 7929

REACT
St Lukes’ House
270 Sandycombe Lane
Kew, Richmond
Surrey TN9 3NP
020 8940 2575
react@reactcharity.org
www.reactcharity.org
(Please note that you need to be under 18 to qualify for help.)

The ACT Foundation
The Gate House
2 Park Street
Windsor
Berks SL4 1LU
01753 753900
info@theactfoundation.co.uk
www.theactfoundation.co.uk

The Catharine House Trust
Ridge Cottage
New Cut
Westfield
East Sussex TN35 4RL
Within each area there will also be local charities. Your Citizens Advice Bureau (CAB) will have lists of these as well as local contacts for the Rotary Club, Lions and so on. Sometimes local solicitors manage private charitable trusts.

If your family has any connections with the armed services, their charities may help. If anyone in the family works in a specific profession (for example, banking, teaching, transport) check if there is a relevant charity that could help. Again the CAB can advise you.

The Information Officers at the Muscular Dystrophy Campaign have access to a computer software package called *Funder Finder for People in Need*. They can undertake searches for you but cannot make applications on your behalf.

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. CARE SUPPORT AND RESPITE CARE

AN OVERVIEW

Most people who have Duchenne require care support from people outside of the family at some stage in their lives. The rules are generally different for those under 16. There is also a distinction between social care and health care.

A detailed description of the regulations around care support can be found in the Disability Rights Handbook. This is published annually (in April/May) by the Disability Alliance. You can contact the Disability Alliance on 020 7247 8776.

If you and/or your family/carers feel you require additional care support the first thing to do is to contact your local Social Services or Social Work department if you live in Scotland to request an assessment of your needs. Your parents/partner/carers can also request a carer’s assessment which will look at their own needs. Each local authority is free to set its own criteria in respect of those it will help but these criteria have to be published and available to the public.

In respect of social care (this would include help with washing, dressing and feeding yourself) you can be means tested for any practical help that Social Services provide. People aged 16 and over are means tested in their own right in respect of social care and their parent’s income is not taken into account. The care component of Disability Living Allowance can be taken into account.

If you have more complex care needs (for example, you use a ventilator during the day or have a gastrostomy) some, or all, of your care needs might be classified as being healthcare needs. If this is the case the NHS has a role to play in providing your care and you should not be charged for any element of care provided to meet your health needs. Healthcare does not have to be provided in a hospital or nursing home – it can be provided in your own home. If you have urgent needs a service can be provided prior to a detailed assessment taking place.
It is not necessary to be registered disabled with the local authority to receive help but some authorities will automatically register you at the assessment stage.

Ensure that you are in receipt of the right level of Disability Living Allowance and any other benefits you may be entitled to. Chapter six of this book deals with these issues.

In respect of respite care in hospices for children or young adults no charges are made to families.

**SOCIAL CARE AT HOME – UNDER 16s**

Many parents and carers of children under 16 receive practical help to care for their son. Such help would include assisting a young person to get washed and dressed, to have a meal and/or to access local leisure facilities.

To obtain help you will need to contact your local Social Services or Social Work department. If you are not already known to them (or have no current involvement) ask to speak to the duty worker. Explain what help you need and request an assessment of need and, where applicable, a carer’s assessment (for example, a parent who needs respite from caring or help delivering the care might ask for a carer’s assessment).

Parents might be charged for help provided. Charges are means tested, however if you are on Income Support you don’t usually have to pay. Disability Living Allowance (care component) can be taken into account but if, for example, you receive the high rate care component but only receive daytime support from Social Services the local authority can not take all of your benefit into account – only the part for daytime care.

Social Services may provide the carers themselves or your parents can (as a carer of someone under 16) request direct payments. Social Services can advise further on this. Under the direct payment scheme, instead of receiving the care, you receive the money to employ carers or to pay for the care services you need. Direct payments can not be used to purchase care in a care home apart from short breaks of up to 120 days in any one year.

Families can not be forced to use the direct payment scheme. They have to be willing and able to manage the payments. Sometimes there are local
agencies that can help you with this but the final responsibility for how the money is spent is yours or the parent’s in the case of someone under 16. You can have a combination, for example, some services provided by Social Services and some organised yourself via a direct payment. Under direct payments you may still be assessed as being able to contribute. The rules are as for care provided by the local authority.

For further information contact:
The National Centre for Independent Living
250 Kennington Lane
London SE11 5RD
020 7587 166
info@ncil.org.uk
www.ncil.org.uk

SOCIAL CARE AT HOME FOR THOSE AGED 16+

Much of what is written immediately above is relevant to those aged over 16 too so please read that section first. The main difference regarding direct payments is that it will be you and not your parents, who will be means tested. Direct payments can have many advantages as they usually allow you to arrange more flexible care, concentrating on what your own priorities are. However, you need to remember that you will be responsible for recruiting, training, employing and insuring your carers. You will need to ensure that you can still get the cover you need when carers are sick or on holiday.

In addition to the direct payments scheme you could consider using the Independent Living (1993) Fund. The eligibility criteria include being 16+, being in receipt of the high rate care component of Disability Living Allowance and receiving services from the local authority worth at least £200 per week. You must also have relatively stable healthcare needs and be living alone or with people who cannot meet all your needs.

Help is means tested. If you have savings over £18,500 (2008 figure) you will not be eligible. You always have to contribute some of your Disability Living Allowance.

If you want to use the Independent Living Fund the first thing to do is to talk to your local authority social worker about it. The Independent Living Fund is based at:
HEALTH CARE NEEDS – AT HOME

It is not always easy to distinguish between what is a health care need and what is a social care need. Legislation allows Social Services and health authorities to use pooled budgets but there is still often much debate over who is responsible for certain aspects of a person’s care. It is important that you are clear about who is arranging what as healthcare is free and social care might not be.

If you have complex needs it would be appropriate to involve healthcare professionals (district nurses for example) in any assessments.

In many areas there are paediatric district nursing teams who may offer skilled help to families with a child under 16. Such care would be free and is accessed via the GP or hospital consultant.

RESPITE CARE

Various types of respite care are available. Respite care can be for short periods in the day or can be overnight. It may be in a person’s home, in someone else’s home or in a centre of some kind.

In respect of daytime respite care Social Services can sometimes arrange this as part of your care package. Care may be offered in your own home or in a daycentre. Charges can be made for this service but in every case the ability to pay should be taken into account.

Sometimes other agencies can assist. Crossroads is a charity which aims to give carers a short break by caring for disabled people for a few hours a week. Care is provided in the disabled person’s home. The type of care provided is social care – not specialised nursing care. You can usually refer yourself.
With respect to overnight respite care, this might be offered in a specialised centre by social services, or in a local community hospital via the GP.

Many young people with Duchenne visit a children’s hospice or a hospice specialising in teenage care. Hospices are usually charities, not part of the NHS. These hospices offer care not only to those who are very sick, but respite care over the years to people with serious conditions like Duchenne. You can refer yourself to a hospice but they will need your permission to contact your medical team.

To find the nearest children’s hospice to you (which can also advise on teenage care) contact:

Children’s Hospices UK
First Floor, Canningford House
38 Victoria Street
Bristol BS1 6BY
0117 989 7820
info@childhospice.org.uk
www.childhospice.org.uk

No charge is made to families using the hospice but finance may be sought from local authorities for those aged 16+ attending a teenage facility. All hospices are well equipped to meet the needs of powered wheelchair users.

For people who are ventilator dependent another option might be to use the specialist provision at Netley, near Southampton. This is run by Refresh and you can contact them on 020 7188 0627 at St Thomas’ hospital in London (dept of anaesthetics) or via Vitalic on 0845 345 1972 or see the website www.vitalic.org.uk
5. EDUCATION AND EMPLOYMENT

SCHOOL

Most younger teenagers will be in school. A minority might be educated at home. The Muscular Dystrophy Campaign publishes two factsheets that may be useful Education and Home education as well as the booklet Inclusive Education: Guidance for Primary and Secondary Schools. This booklet is aimed at staff in mainstream schools and gives specialist advice about the needs of people with neuromuscular conditions. A parents/families guide will be published shortly.

It is important that young people are happy in school and that they feel appropriately placed. Assessment of an individual’s needs (involving that individual and their family) on an ongoing basis is essential. Modifications may need to be made to the curriculum or special equipment/support supplied.

Some young people may find that they are better placed in a special school environment because the academic work is less challenging and/or there are smaller classes and more input from physiotherapists, occupational therapists and other specialist staff.

Academically able students who wish to be in a mainstream school should always have this option made available to them within their local area. Do note that the Local Education Authority (LEA) is required to meet a student’s educational needs but it is not obliged to “provide the very best” nor to adapt every school in each area and some compromises may need to be considered.

Choosing a school where you feel comfortable and which has supportive staff and friendly students is vital. Try to build in good systems of communication so that small difficulties don’t escalate into big problems. Raise any concerns at an early stage.

In most secondary schools you are likely to be working with more than one Learning Support Assistant. The way you use their support will be very different to how it was in your primary school. You will be expected
to assume more responsibility for decision making and for requesting the help you require. Try to see this as a positive thing which will help you acquire the skills you will need after you have left school and are planning care packages, independent living etc.

Everybody has different talents and interests. Within a school setting there should be room to develop these and to achieve in areas that matter to you (and some that don’t!).

From the age of 14 all students should be involved in “transition planning.” Staff from the Connexions/Careers Service should meet with you to discuss your 16+ options. Early planning is important so that applications can be made, visits arranged and funding organised. Care needs must be planned for. You may need to attain certain educational qualifications to progress to college or university, or into the world of work, and you need to know at an early stage what is expected of you and where to concentrate your energies.

At 16+ you may have the following options:
1) To remain at school until age 18/19 (at a mainstream or special school)
2) To attend a local college
3) To attend a specialist school/college
4) To leave school (possibly to seek employment)

Post 18 choices would include going to university.

**16+ EDUCATION AT A LOCAL FURTHER EDUCATION COLLEGE**

Further Education (FE) refers to post 16 education that does not involve study for a degree or higher level of qualification. Generally a wide range of academic and vocational courses are offered by the college leading to a variety of different qualifications. FE colleges are not residential and students usually attend a college close to their home. Courses can be full or part time. Funding for such courses is generally supplied by the LEA for teenage students.

**16+ EDUCATION AT A SPECIAL FE COLLEGE**

If you are over 16 and not continuing at school you may be interested in attending a special FE college. Special colleges offer a range of academic, vocational and life skills courses. They usually provide on site care and accommodation suited to the needs of those who are physically disabled. A
good range of social and leisure activities is available. Usually you can only obtain funding for such colleges if your LEA can not meet your needs locally. In these cases you may obtain funding via the Learning and Skills Council (LSC). Note that you do not have to have a statement of inability to meet your provision locally before requesting help from the LSC but it will certainly help. If care is a substantial part of the package being provided some funding may come from social services.

Advisors from your school, the careers service or the Connexions service (0800 13 219) will advise you on how to liaise with your LEA/LSC on this issue.

Learning and Skills Council
National Office, Cheylesmore House
Quinton Rd, Coventry CV1 2WT
0845 019 3675
info@lsc.gov.uk
www.lsc.gov.uk

The National Bureau for Students with Disabilities (Skill) is a voluntary organisation that can provide information on education, training and employment to those aged 16+ with disabilities. They have lots of useful information on their website, particularly in the frequently asked questions section.

Skill
Unit 3, Floor 3, Radisson Court
219 Long Lane, London SE1 4PR
020 7450 0620
skill@skill.org.uk
www.skill.org.uk

NATSPEC is an organisation which supports specialist independent colleges who provide FE training to students with learning disabilities and/or disabilities. They can supply lists of specialist colleges, some residential.

NATSPEC
39 Sanders Rd, Quorn,
Loughborough, Leicestershire LE12 8JN
01509 554352
www.natspec.org.uk

Residential colleges with a history of catering for students with Duchenne include:
Beaumont College
Slyne Rd, Lancaster
Lancs LA2 2AP
01524 541400
response@scope.org.uk
www.scope.org.uk/education

Hereward College
Bramston Crescent
Tile Hill Lane, Coventry CV4 9SW
02476 461 1231
enquiries@hereward.ac.uk
www.hereward.ac.uk

Hinwick Hall
Hinwick, Wellingborough
Northants NN29 7JD
01933 312470
principal@hinwickhall.ac.uk
www.livability.org.uk

Nash College
Croydon Rd, Hayes
Bromley, Kent BR2 7AC
020 8315 4800
pa@nash.ac.uk
www.livability.org.uk

Portland College
Nottingham Rd, Mansfield
Nottinghamshire NG18 4TJ
01623 499111
college@portland.ac.uk
www.portland.org.uk

The National Star Centre for Further Education
Ullenwood Manor, Cheltenham
Gloucestershire GL53 9QU
01242 527631
principal@natstar.ac.uk
www.natstar.ac.uk
Some academically able students may wish to attend university. Applications will need to be made in the normal way and acceptance onto a course will depend upon you reaching the relevant exam passes made in the conditional offer to you. Financial arrangements for your course will also be as for all other students with the exception that you may also apply for a Disabled Students Allowance (DSA) to help with the cost of essential non medical equipment or help (e.g. a computer, a scribe, etc).

All universities will employ someone who can advise their disabled students. You should contact this person at an early stage so that they can assist you in your planning. One of the major difficulties for disabled students applying straight from school/college is that they do not know their exam results until a few weeks before the university term starts. This gives a very short time to finalise care and accommodation arrangements.

Your local Social Services are responsible for meeting the cost of your non medical care needs regardless of where in the UK you attend university. They will need to carry out an assessment which will look in detail (with you) at the activities that you require support with. A plan of how these needs will be met must then be made. In most cases an agency in your university town will actually provide the term time care. If you require assistance at night then this too will need to be provided.

The university is likely to provide the accommodation but any specialised adaptations or equipment must be provided by your home authority (shower chairs, hoists, etc).

Some students defer their places for a year. This gives much more time for planning as your exam results are already known and your place on the course secure.
EMPLOYMENT

Employment is preferred to study by some young people. The Connexions and/or careers service should be involved in advising you on your options whilst you are still at school.

Disability Employment Advisers (known as DEAs) based at your local Job Centre Plus should also be able to help you seek work. They can advise on schemes like Access to Work and can sometimes arrange further training where necessary.

Through Access to Work you can get help with the cost of special aids or equipment and help with transport to work. Your employers can get help with the funding of adaptations to the workplace. You can refer yourself to the DEA by phoning your local Job Centre Plus and requesting an appointment.

You will need to think about the type of work you wish to do and whether this will be full-time or part-time. Be clear about your needs in terms of physical access (e.g. a disabled toilet, wide doorways, etc) and care support.

Enham and Papworth villages (in Hampshire and Cambridgeshire respectively) offer training, care and accommodation for disabled adults.

Contact them:

0800 952 5000 (freephone) or 01480 357200
www.papworth.org.uk
01264 345800
www.enham.co.uk

Some teenagers may feel they are not fit enough to work. If the Department of Work and Pensions (the DWP) agree with you they should provide advice on your benefit entitlements. Everyone is also well advised to seek advice from an independent welfare rights agency like the Citizens Advice Bureau on their entitlement to benefits in and out of work. It is not always the case that you are better off financially in work but you will need to think beyond purely monetary issues (work can provide you with an interesting career, an increased social life, self esteem, etc).
6. FINANCIAL MATTERS

BENEFITS
There are many issues to consider here but having a basic understanding of the benefits system is a good starting point. Things change 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 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
020 7247 8776
office.da@dial.pipex.com
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. Most people with Duchenne will already be in receipt of Disability Living Allowance (DLA) and for young people under 16 this allowance continues to be paid to your parent(s) until your 16th birthday. After this the allowance is payable to you – in your own name.

If, at any stage in your teens, you are not already in receipt of the highest rates of Disability Living Allowance (both the care and mobility components) you should check if you now meet the criteria for these. To receive the highest rate mobility component you need to show that you are unable or virtually unable to walk. To receive the highest rate care component you need to show that you require frequent help with personal care 24 during both the day and night.
To obtain a review of your benefit you should write to the office that dealt with your claim, quoting your name, address, date of birth, national insurance number (if you have one) and any other reference numbers quoted on their correspondence with you. Be aware that a review of your benefit can result in benefit being reduced – this is, of course, extremely unlikely to be justified in the case of someone with Duchenne. If you feel the wrong decision has been made do consider appealing and taking to a tribunal if necessary. Your local Citizens Advice Bureau will advise you and may take on your case.

For those over 16 remember that saving large amounts of DLA may affect your entitlement to some other benefits like Income Support.

- **Carers Allowance (CA)**
  This benefit is paid to people who spend 35 hours or more a week caring for a disabled person. It can be paid to a parent of a disabled child. It is not payable to anyone who earns over £95 per week, after allowable expenses are deducted. (2008 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.

- **Incapacity Benefit/Employment and Support Allowance**
  This may be paid to people aged 16 or over who are unable to work. It is now sometimes paid to people in full time education – check your entitlement. From October 2008 new claimants are assessed instead for eligibility for the Employment Support Allowance.

  There are many other benefits that may be applicable – do check. Such benefits include entitlement to Housing Benefit, Council Tax Benefit and Income Support for those aged 16 plus, especially (but not exclusively) for those living independently.

  If you receive tax credits you need to inform the Inland Revenue that you are 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 direct about this (this is different to the council tax benefit mentioned above).

**BUDGETING/DEBT PROBLEMS**

Having the ability to manage your money and budget appropriately is an important skill to have. Before taking out any loan or credit card think carefully about your ability to repay and the interest charges involved. People on a fixed income (e.g. not in employment) usually find it especially hard to repay debts. If you do experience debt problems do not ignore them and avoid commercially run debt advisory services who will charge you money to sort out your difficulties. Your local Citizens Advice Bureau can help as can either of the charities listed below. Both offer free, impartial advice.

Consumer Credit Counselling Service  
**0800 138 1111**  
[www.cccs.co.uk](http://www.cccs.co.uk)

National Debt Line  
**0808 808 4000**  
[www.nationaldebtline.co.uk](http://www.nationaldebtline.co.uk)

**CHARITABLE HELP**

If you need to purchase expensive items related to the maintenance of your independence or comfort charitable help may be available – see elsewhere in this book. Always check whether the item can be funded by the NHS or Social Services first.

**THE FAMILY FUND**

The Family Fund Trust is a government financed registered charity covering the whole of the UK. It aims to support the families of severely disabled/severely ill children and 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 earned annual income of below about £23,000, or, in Wales £25,000 (2008 figures). Grants can be made annually.

You can refer yourself or a professional can make a referral on your behalf. The Family Fund will then contact you direct and may arrange for a worker to visit you at home.

The Family Fund Trust  
Unit 4, Alpha Court  
Monks Cross Drive  
Huntingdon  
York YO32 9WN  
www.familyfund.org.uk
LEISURE OPPORTUNITIES

As you get older you may wish to pursue more leisure activities independently from your family. You may also like to go away on holiday with friends or in a group.

Try to have a positive attitude to trying new things – you never know what you might enjoy! Art and music based activities are often very popular. Your local library will have details of clubs and events that you could look into. Concert, cinema and theatre venues are generally accessible – phone to discuss your requirements before booking tickets. Activities that might be of interest include:

Swimming
This is an excellent form of physical activity for most people. You may like to locate a warm water pool and you will certainly require a pool with easy access in and out (with a hoist if necessary) and good changing facilities. Physiotherapists usually know about local facilities and clubs. Special schools often have hydrotherapy pools which groups of people can get together and hire on a regular basis (ask about lifeguard provision).

Fishing
The British Disabled Angling Association is an organisation that can advise on fishing opportunities in the UK.
BDAA
9 Yew Tree Rd
Delves Walsall
West Midlands WS5 4NQ
01922 860912
www.bdaa.co.uk
Photography
The Disabled Photographers Society may be able to offer advice
DPS
PO BOX 130
Richmond
Surrey TW10 6XQ
enquiries@disabledphotographers.co.uk
www.disabledphotographers.co.uk

Sport
The English Federation of Disabled Sport is a national body covering all
types of sport.
EFDS
Manchester Metropolitan University
Alsager Campus, Hassal Rd
Stoke-on-Trent ST7 2HL
0161 247 5294
federation@efds.co.uk
www.efds.co.uk

Arts/Music
Share Music is an organisation for physically disabled people wishing to
participate in high quality creative activity in music and the performing
arts. Originally begun in Northern Ireland it now works with people across
the UK.
020 7403 3844
jaci@sharemusic.org.uk
www.sharemusic.org.uk

Shape Arts describes itself as the country’s leading disability arts
organisation. Contact them at:
020 7619 6166
www.shapearts.org.uk

PHAB clubs
PHAB clubs aim to offer opportunities for disabled people and able
bodied people to meet together for social activities/holidays. Details of
clubs in your area can be found via:
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 needs. If accessible accommodation is required Tourism for All can advise you.

The Hawkins Suite
Enham Place
Enham Alamein
Andover
Hants SP11 6JS
0845 124 9971
info@tourismforall.org.uk
www.tourismforall.org.uk

Tourism for All is a registered charity supported by the UK’s national tourist boards. They can help with planning of holidays in the UK and overseas. They have 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 – 01768 772 255 for Keswick, 01434 250 232 for Hexham and 01598 763 221 for Exmoor.
Vitalise – 0845 345 1970 have 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. You can contact them on: **08702 411857**

www.dfsg.org.uk

Vitalise and the Calvert Trust (see above) both organise independent holidays for those aged 16-18+ years where care support is provided.

A factsheet on holidays is published by the Muscular Dystrophy Campaign ([020 7803 4800/info@muscular-dystrophy.org](mailto:info@muscular-dystrophy.org)) and Contact A Family ([020 7608 8700/info@cafamily.org.uk](mailto:info@cafamily.org.uk))

**SPECIAL HOLIDAYS FOR CHILDREN/YOUNG PEOPLE**

There are several charities which organise “dream holidays” (often to Disneyland) for people with Duchenne. Some of these will be family holidays but others will be group holidays. In the later case you would be part of an organised group including qualified care staff. The organisations listed have a cut off point of 18 years except where stated.

Dreamflight (ages 8-14 years)
7c Hill Avenue
Amersham
Bucks HP6 5BD
**01494 722733**
office@dreamflight.org
www.dreamflight.org

Dreams Come True (caters for those aged up to 21)
Knockhundred House
Knockhundred Row
Midhurst
West Sussex GU29 9DQ
**0800 018 6013**
info@dctc.org.uk
www.dctc.org.uk
Make A Wish Foundation UK
329/331 London Road
Camberley
Surrey GU15 3HO
01276 24127
info@make-a-wish.org.uk
www.make-a-wish.org.uk

Starlight Children’s Foundation
PO Box 4267
Goring
Reading RG8 0AP
020 7262 2881
PRW1@starlight.org.uk
www.starlight.org.uk

The Willow Foundation (caters for those aged 16-40 years)
Willow House
18 Salisbury Square
Hatfield
Herts AL9 5BE
01707 259 777
www.willowfoundation.org.uk

When You Wish Upon A Star
Futurist House
Valley Rd
Basford
Nottingham NG5 1JE
0115 979 1720
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.
FUNDING OF HOLIDAYS

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

The Family Fund
Unit 4, Alpha Court
Monks Cross Drive
Huntingdon
York Y032 9WN
www.familyfund.org.uk

Tourism for All mentioned earlier has lists of charities that may help. Social Services will occasionally assist – especially if it is perceived as “respite care” – do ask. One charity offering breaks to unaccompanied disabled children/young people is:

Break
1 Montague Rd
Sheringham
Norfolk NR26 8WN
01263 822161
office@break-charity.org
www.break-charity.org

HOLIDAY INSURANCE

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

In Europe remember to take a new style E111 card – this provides some cover but is not designed to replace other medical insurance. You can apply at a post office, over the phone 0845 605 0707 or online at www.ehic.org.uk
As people grow up it is important that they have increasing autonomy over the decisions affecting their lives. This is the same for a person with Duchenne as for anyone else. Physical dependence should not affect independent decision making.

HOW TO ACQUIRE INDEPENDENT DECISION MAKING SKILLS

Maintaining good, open relationships with parents, carers and siblings is helpful in aiding discussions about your wish for greater autonomy. You will need to show that you can be trusted and that you are ready to accept responsibility for any mistakes you might make. Younger teenagers should start to take responsibility for themselves. For example, do not rely on others to tell you to put your coat on when it’s cold or to remember your homework, etc. Tell those supporting you that you would like them to expect you to show this degree of maturity. Have ideas and plans of your own and work out how you can implement them.

Try to raise difficult issues when you feel calm and when people have the time to discuss them. Accept that instant answers might not be possible and look for compromise solutions you can build on. If you take things in stages you will achieve more.

FAMILY RELATIONSHIPS

Family relationships can be complex and, at times, difficult. Remember that parents and family members love you and want the best for you so, even if things go through difficult stages, don’t lose sight of this. Try to treat your family with respect and show your appreciation for their love and support. Apologise if you lose your temper or get things wrong.

Parents face difficult times too and may have their own worries – these may, or may not, be connected with you. Different family members tend to see things from different perspectives and what worries them may not worry you and vice versa. Sharing information and concerns can be very helpful.
Siblings can sometimes be supportive but they too will have issues of their own to deal with. Try to be a good listener, and suggest activities you can enjoy together. They may have anxieties of their own around your health – it helps to talk.

**PHYSICAL CHANGES/SEXUAL ISSUES**

The teenage years are times of rapid physical change and development. A young person with Duchenne has the same need as everyone else their age to have access to information about puberty and sexual development and to form relationships outside of the family circle. You should have access to basic information through sex education lessons in school but if you need further information or would like to talk to someone in confidence you can contact Brook. They provide information about sexual health and relationships to people under the age of 25.

Brook  
**020 7284 6040**  
**0800 018 5023** (helpline)  
admin@brookcentres.org.uk  
www.brook.org.uk  
There are Brook centres in most areas so that you can visit a centre personally if you wish.

The Family Planning Association publishes some useful guides on a range of issues connected with growing up.  
**0845 310 1334** (helpline)  
www.fpa.org.uk

Contact A Family publishes a useful booklet: Growing up, sex and relationships: a booklet for young disabled people (They publish booklets for parents and teachers too). To obtain a booklet ring **0808 808 3555** or see www.cafamily.org.uk

You can also request a consultation with your GP if you wish – this will be confidential for those aged 16 plus and for those under 16 information would only be shared with others in exceptional circumstances.
Young men with Duchenne develop sexually in the same way as others but remember that everyone is different and bodily changes occur at different times.

People with Duchenne are able to enjoy fulfilling sex lives and a few have chosen to father children of their own. Confidential genetic advice is available if issues of inheritance are a concern. You can access this via a GP referral to your local clinical genetics centre or ask your neuromuscular consultant to arrange this service.

**EMOTIONAL ISSUES**

Growing up is about learning to be comfortable with yourself, your beliefs and your values. It takes time to work these things out and it can be hard when the society around you is so diverse. Try to be true to yourself and trust your own instincts about what feels right and wrong.

Recognise that the teenage years are a time of strong emotional feelings. Life can feel very intense at times. Dealing with these emotions can be exhausting! Don’t be hard on yourself or over critical. Everybody makes mistakes and errors of judgement – whatever age they are – and these contribute to our learning; it’s a lifelong process.

Learn to enjoy spending time alone but try not to isolate yourself. Friendships are very important and need to be worked at. Join in with new activities and try new things. Remember it’s your life and it’s your responsibility to put into it the things that are important to you.

**PLANNING FOR THE FUTURE**

It is important to try to maintain a positive approach to life, making plans and having ambitions. The professionals around you have a role to play in supporting you in this process so don’t be afraid to seek their help.

If we at the Muscular Dystrophy Campaign can help in any way do please let us know. We will always be happy to hear from you.
BE PART OF THE MUSCULAR DYSTROPHY CAMPAIGN

The Muscular Dystrophy Campaign is the leading UK charity focusing on all muscle disease. We have pioneered the search for treatments and cures since 1959, and are dedicated to improving the lives of all people affected by muscle disease. More than 60,000 people in the UK have a muscle disease or related condition, and 300,000 people are indirectly affected as relatives, friends and carers. There are no cures or treatments which prevent the breakdown of muscle but increased knowledge has improved the quality of people’s lives and – in many cases – length of life.

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

The Muscular Dystrophy Campaign has launched a new Schools’ Network which is designed to help all children with neuromuscular conditions. We are asking schools to register with us so we can offer staff training sessions and appropriate support information. A school forum, where ideas and information can be shared and exchanged between schools, will also be set up. Personal information about the child will not be collected and specific personal issues will not be discussed without the written consent of parents/guardians, and of course, the children themselves, where applicable. To join the Schools’ Network, simply call the Muscular Dystrophy Campaign on 0800 652 6352 (freephone) or email info@muscular-dystrophy.org

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

Together we’re stronger

Muscular Dystrophy Campaign
61 Southwark Street
London SE1 0Hl
020 7803 4800
Information Line: 0800 652 6352 (freephone)
info@muscular-dystrophy.org
www.muscular-dystrophy.org

Registered Charity No. 205395 and
Registered Scottish Charity No. SC039445