

Education

What is muscular dystrophy?

Muscular dystrophy is the name for a group of conditions which have in common the breakdown of muscle fibres that leads to weak and wasted muscles. Symptoms of some disorders appear at birth or in young babies, but in other conditions symptoms may only start to show in childhood or even in adulthood. Some of these conditions can be very severely disabling and can have a marked impact on life expectancy, whereas others can be much milder. An estimated 30,000 adults and children in the UK have muscular dystrophy or one of the related neuromuscular conditions.

The dystrophies are usually inherited but the patterns of inheritance and the muscles affected differ with each type. The most common childhood dystrophy is called Duchenne muscular dystrophy (often abbreviated to DMD) which, with very rare exceptions, affects only boys. Duchenne muscular dystrophy is a progressive, life-limiting condition in which significant change in a child's physical abilities is usually seen during the primary school years. This factsheet is of most relevance to those with Duchenne muscular dystrophy but much of what is written will be appropriate to those with other types of dystrophy or neuromuscular condition (which can affect children of either sex).

The importance of school

Some people have asked about the importance of school attendance for children with progressive conditions like Duchenne muscular dystrophy, particularly if there are also associated learning difficulties (this is the case for at least a third of all children with Duchenne muscular dystrophy). Families, understandably, may feel that the most important thing is to ensure that their child has as an enjoyable life as possible. However, with careful planning, it is possible to ensure that a child's time at school enhances their range of experiences and quality of life, leading to opportunities to enjoy a variety of activities and to develop friendships. Many boys with Duchenne muscular dystrophy have done very well at school, passing external exams. Some have been able to attend university and obtain degrees. Others have moved on to jobs. These achievements would not have been possible if they had not been encouraged and supported from an early age.

For every child the important thing is to recognise and support their talents and abilities. The pleasure that can be gained by reading, painting, playing an instrument or using a computer should not be underestimated.

The choice of school

At each stage of a child's school career there will be choices to make about the type of school - mainstream or special, day or boarding, local or further away (with better facilities). The choice that a family make will depend a great deal on the individual child and the wishes of the family. It will also depend upon practicalities such as the physical layout of local schools and whether they can be adapted to meet a child's needs.

Whether or not a child has significant learning disabilities or behavioural difficulties also needs to be considered. In some cases a child may feel more comfortable and better supported in a special school. This, however, must be an active choice that is made after assessment and discussion, and not an assumption by parents, teachers or the Local Education Authority. Most children with Duchenne muscular dystrophy and other neuromuscular conditions can, with the right planning, be educated at a local mainstream school.

Planning for future needs

Many children with muscular dystrophy, entering school at four or five years old, have few physical difficulties. Most children with Duchenne muscular dystrophy will notice significant changes in their physical abilities during their primary school years and the majority will require the use of a powered wheelchair, at least some of the time, by the age of twelve. The rate of progression for children with other dystrophies and neuromuscular conditions will vary, some may notice little change.

Planning for future needs is vital. It is essential to make plans in good time so that if (and when) a child requires something it can be quickly put in place.

To make good plans it is important that all concerned have an understanding of the child's condition and how it might change. A child's needs should be regularly reviewed and reassessed as necessary. Statements of Special Educational Needs, where in place, should be kept up to date.

Thought needs to be given to the following:

- Physical access and safety around the building (including accessibility of toilet facilities). Determine who will finance any adaptations and what the time scale will be.
- Equipment needs including specialised seating, a hoist, provision of a laptop computer and so on. Determine who will assess for need and who will finance the equipment.
- Support from another person (usually a learning support assistant) for help with physical tasks and maintenance of personal safety in the school environment.
- Support from another person for additional learning needs. This could for example cover additional support with literacy, numeracy, extra support to acquire typing skills and extra one to one support on school trips.
- Support from outside agencies for advice. For example, from a physiotherapist on a programme of stretching exercises to be carried out in school or advice on moving and handling from specialist advisors.
- Staff training. Staff will need advice on the child's changing needs, on the physical management of the child and on answering children's questions.
- Some children may need the curriculum to be modified. For example, swimming is usually an excellent exercise for children with muscular dystrophy to participate in, perhaps in preference to other parts of the PE curriculum. Other children may need parts of practical lessons to be modified.
- Working together. The greatest success is seen when teaching staff and parents work together. Roles within the school should be clearly defined to ensure that everyone is clear about who does what and that class teachers and learning support workers are not left unsupported.

- Transition planning for transfer between schools or on to college needs good, advance planning beginning about two years before any planned transition.

Developing independence

One tends to think about independence in young children as gradually learning to do things without adult help. Children with a progressive neuromuscular condition may find themselves gradually losing the ability to do things by themselves. This can be very upsetting and a severe blow to a child's self image. Care needs to be taken to ensure that a child is allowed to develop independence of thought and allowed to make choices.

Unless we are aware of the need for independence through choice it is easy for adults to encourage the child to become passive. Being passive is a way of avoiding making decisions and allowing others to take control. For example, you could encourage a child to make a decision by saying "Let me know if you need your jumper on and if you need any help." Instead of "It's cold so I'm going to put your jumper on". As a child matures we need to respect their right to make choices and, like others, to make mistakes.

Physical development

Although a child with muscular dystrophy will be becoming physically weaker it is important to try to maintain activities like walking or standing for as long as possible. The child's physiotherapist should visit the school on an occasional basis to review what is possible and to recommend how to manage a child's physical education programme. Children with muscular dystrophy will tire more quickly than their peers and therefore it is important to listen to the child and to respect their limitations.

As mentioned earlier, swimming is often recommended as it allows for a supported all over body work out. If extra swimming time can be negotiated this may be helpful (provided the child enjoys it!). Ensure the child does not become very cold and recognise the need for extra time and support for dressing and undressing.

In PE sessions it is usually possible to adapt sessions so that a child can at least partially participate. Ball and racquet games using lightweight equipment are often enjoyable. Encourage children to come up with their own ideas since this helps develop their independence.

Other children

Working towards social integration is probably the most difficult part of the integration process in a mainstream school. It is not enough to place a child in a school (physical integration), make arrangements for access to the curriculum (academic integration) and then regard the integration as complete. Integration is a process, not an end result. How children relate to each other and how children and adults interact is as much part of the education as any part of the curriculum.

The earlier a child can be integrated into a school the easier the process will be. As muscular dystrophy is a progressive condition it may take some time before other children realise their

friend is different in some way. Early questions usually centre on why they can't run as fast as everyone else or why they sometimes get tired.

Adult attitudes and responses are very important in fostering positive attitudes in children. Teachers and parents should discuss the need to answer questions simply and honestly. An explanation like "He can't run as fast as you because his muscles get tired" is adequate for small children. As a child starts to have more physical difficulties it may be worth discussing with the child and their parents what information can be shared with others. Sometimes a teacher or health care professional can talk to the class. This often helps a group of children to understand the situation better and to be more supportive. School staff should remain alert to difficulties and should encourage participation in activities that all children can enjoy. They should also know when to step back and allow the child some adult-free time!

Training and support

Staff working with children with a neuromuscular condition will need training and ongoing support. Some education authorities may provide training for staff working with disabled students. Schools could also look at external training opportunities (for example occasional courses run by the Muscular Dystrophy Campaign or by children's hospices). Sometimes local physiotherapists and occupational therapists will offer small group training.

Opportunities to review practice and share concerns should be offered on a regular basis to all staff caring for a disabled child. There should be recognition that the caring role can be upsetting and stressful as well as very rewarding. All staff should be aware of health and safety issues, particularly around moving and handling. Schools have legal obligations in this respect.

Planning for success

With a positive attitude and a policy of open discussion most children enjoy their time at school. The agencies listed below may be able to offer further information and support.

Where to go for further information:

There are a number of organisations that can provide further information and advice to young people, parents and teachers.

Advisory Centre for Education (ACE)

1c Aberdeen Studios

22 Highbury Grove

London

N5 2DQ

Tel: **020 7704 3370**

General advice line: **0800 800 5793**

Email: **enquires@ace-dialnet.com**

Web: www.ace-ed.org.uk

ACE provides information and advice to parents and all those involved in the education service. It publishes a range of guides and leaflets about special educational needs.

Independent Panel for Special Educational Advice (IPSEA)
6 Carlow Mews
Woodbridge
Suffolk
IP12 1EA
Tel: advice line **0800 0184 016**, Scotland **0131 454 0096**,
Northern Ireland **02890 795779**
Email: **ipsea.info@intamail.com** (information only, not advice)
Web: www.ipsea.org.uk

IPSEA is a voluntary organisation made up of independent experts who give advice to parents of children with special educational needs. They work independently from the Local Education Authority. IPSEA can help parents through every stage of the assessment process including assisting at educational tribunals.

Network 81
1-7 Woodfield Terrace
Stansted
Essex
CM24 8AJ
Tel: helpline **0870 770 3306**
Email: **info@networks81.org**
Web: **www.network81.org**

Network 81 is a national network of parents who have children with special educational needs. It publishes a very useful guide for parents called "*How to get support for your child with Special Educational Needs*".

Centre for Studies on Inclusive Education (CSIE)
Room 2S 203
S-Block, Frenchay Campus
Coldharbour Lane
Bristol BS16 1QU
Tel: **0117 344 407**
Web: www.inclusion.org.uk

CSIE publishes literature on inclusive education and the "Index for Inclusion" which helps schools break down barriers to learning.

Children's Legal Centre (CLC)
University of Essex
Wivenhoe Park
Colchester
Essex CO4 3SQ
Tel: general advice line **01206 872 466** or education advice line **0845 345 4345**

Email: clc@essex.ac.uk

Web: www.childrenslegalcentre.com

The CLC is a national organisation which can advise on policies and laws which affect children and young people in England and Wales. In 1997 an education advocacy unit was set up which can give (limited) free legal advice to children and their parents about educational issues.

Some other organisations which, whilst not concerned solely with education issues, have helpful information to give, include:

Contact a Family

209-211 City Road

London EC1V 1JN

Tel: **020 7608 8700** or helpline **0808 808 3555**

Email: info@cafamily.org.uk

Web: www.cafamily.org.uk

Contact a Family specialises in supporting families where someone is affected by a rare condition (this includes all the muscular dystrophies). It publishes helpful literature on education issues and much of their website is devoted to educational matters.

The Royal Association of Disability and Rehabilitation (RADAR)

12 City Forum

250 City Road

London EC1V 8AF

Tel: **020 7250 3222**

Email: radar@radar.org.uk

Web: www.radar.org.uk

On its website RADAR has a section called "Education FAQs". This includes information on assessment of educational needs and what parents can do to assist their child to obtain the educational provision that is right for them.

Disability Action

Portside Business Park

189 Airport Road West

Belfast BT3 9ED

Tel: **028 9029 7880**

Email: hq@disabilityaction.org

Web: www.disabilityaction.org

Disability Action is a forum for a number of organisations based in Northern Ireland. Advice and information on educational issues is available.

Further reading:

There are also many helpful publications including *“Inclusive Education for Children with Muscular Dystrophy and Other Neuromuscular Conditions – Guidance for Primary and Secondary Schools”*, published by the Muscular Dystrophy Campaign in 2004. You can read or download the guide from our website: www.muscular-dystrophy.org

The Department of Education and Skills has published a booklet called *“Special Educational Needs (SEN). A guide for parents and carers”*. This booklet describes what special educational needs are, what parents, schools and Local Educational Authorities should do and what your rights are. The booklet is available in a range of languages and in Braille from:

Department of Childrens’ Schools and Families Publications Centre
PO Box 5050
Sherwood Park
Annesley
Nottingham NG15 0DJ
Tel: **0845 602 2260**
Web: **dcscf.gov.uk**
Email: **dcscf@prolog.uk.com**

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