

Duchenne Muscular Dystrophy School information

What is Duchenne Muscular Dystrophy (DMD)?

- Most common form of childhood onset Muscular Dystrophies.
- About 100 boys are born with DMD in the UK each year, 1:3500 male births. For slightly more than half of these DMD has been inherited, usually from the mother who is a carrier (but unaffected). In the other cases DMD has been caused by a gene mutation during or before conception.
- Affects boys (very rarely girls are affected)
- It is a neuromuscular condition caused by the lack of protein called dystrophin
- It is a progressive disease causing muscle weakness
- There is no cure for DMD

Other issues:

- About 1/3 of children have some degree of learning difficulty. Unlike the muscle weakness, the learning difficulties do not become more severe over time. The majority of children with DMD attend mainstream schools.
- Concentration and behaviour can be affected.
- There is an increased risk of neurodevelopmental disorders such as Autistic Spectrum Disorders.
- Life expectancy is shortened, but young men with DMD are often living well into their 30s.
- DMD is not usually painful for the child, although he may feel cramps in his legs or discomfort if joints become stiff. A physiotherapist can demonstrate stretching exercises that can help.
- Most boys do not have problems with bowel or bladder control.

For more information:

Muscular Dystrophy Campaign, www.muscular-dystrophy.org.

“Inclusive Education for children with muscular dystrophy, Guidance for primary and secondary schools”, Muscular Dystrophy Campaign, 2007.

Educational Implications of Muscular Dystrophy
Key Stage 1

- Most children receive a diagnosis in KS1 unless there is a family history of DMD and it is identified earlier.
- By the age of 4 some loss of balance and signs of weakness are often seen. Other early signs include: Enlarged calves, difficulties getting up from the floor- using hands or furniture to help and difficulties using stairs.
- As the condition progresses a distinctive walking pattern emerges with the boy walking on his toes with his abdomen pushed forward to compensate for the increasing weakness of the hip and pelvic muscles.
- Most children will have a physiotherapist allocated and may have a programme of passive stretches to do in school.
- Some boys take steroids to prolong mobility for as long as possible. These can have side effects such as weight gain and sometimes mood changes.

Issue	Strategy	Resources
Identifying the problem		
Diagnosis may only be available after child starts school	<p>Refer to the Physical & Medical Team</p> <p>Hold a multi agency meeting with all professionals involved and parents</p> <p>Monitor condition and access to environment. This will be done in conjunction with health professionals and specialist teacher.</p> <p>Talk to family and listen to their concerns</p> <p>Provide staff with information about DMD. It may be possible for staff to have a talk from the neuromuscular team in Leeds to discuss DMD and the impact on school life.</p>	<p>Referral form on Bradford Schools Online</p> <p>Inclusive Education for children with Muscular Dystrophy and other Neuromuscular conditions Guidance for Primary and Secondary Schools. (Produced by Muscular Dystrophy Campaign)</p> <p>Contact A Family directory (The essential guide to medical conditions, disabilities and support) www.cafamily.org.uk</p>
Assessing the Pupil		
<p>Monitor any physical changes and pass on any concerns to parents and professionals involved</p> <p>Use Bradford's Matrix of Need to identify the level of support needed and when to request a statutory assessment.</p>	<p>Monitor, record and review the situation.</p> <p>Call multiagency meetings with parents as and when necessary</p> <p>Assess whether the physical condition is affecting his learning or mobility</p> <p>Provide additional adult support if</p>	<p>Risk assess the environment and individual activities as and when necessary.</p> <p>See Educational Visits Guidance for pupils with physical difficulties for trips and swimming.</p> <p>Education and Health Care Plan Guidance.</p>

	<p>needed and record on provision map</p> <p>The pupil should be able to access all regular classroom activities.</p>	
Inability to sit comfortably and safely.	<p>When child is able to sit on school chair see that feet are flat on floor and back supported.</p> <p>In KS1 pupils may need a chair that gives extra support. Initially this will be light support including side support and footrests.</p> <p>If getting up from the floor is difficult, allow the child to sit on a chair during carpet time with a buddy if preferred. This applies to assembly and during P.E. Limit the amount of movement from floor to standing to conserve energy.</p>	Occupational Therapist will advise on seating options. These will be provided through your specialist teacher. Make contact if you are concerned about seating or posture.
Tiredness	Encourage the child to be physically active but recognise when he is tired and needs a break.	Speak to specialist teacher if advice is needed on pacing and energy conservation.
Assessing the environment		
How accessible is the school?	<p>At this stage no major adaptations are usually needed. However, it is essential that schools start to plan for the future and look at wheelchair access and hygiene facilities.</p> <p>It is never too early to plan for any adaptations to the buildings as often these take a long time to plan and fund. These should be written in to the school's accessibility plan.</p> <p>If there is any building work planned for the school consider whether this will be accessible for a wheelchair user.</p>	Meet with the occupational therapist and specialist teacher to discuss long term school access.

P.E. and Duchenne Muscular Dystrophy (Ambulant Children)

Effects of Muscular Dystrophy on P.E. Performance

- Extreme weakness, which limits the range of activities.
- Difficulty getting from the floor to standing.
- Excessive weight and “floppiness”, making floor level work difficult because of the need to lift from the chair to floor, and back to chair.
- Becoming breathless on exertion and tiring easily.
- Team games becoming difficult to participate in

Muscular Dystrophy in P.E.

Issue	Strategy
Extreme Weakness and fatigue	<ul style="list-style-type: none"> • Encourage use of bench to sit on rather than floor. • Reduce pace or distances involved- the child may not be as fast so reduced distances for the child can help even the competition. • Adapt rules to suit • Hopping and jumping may be difficult- assess what the child can do and swap the activities to suit. • Use lighter balls or beanbags so they don't roll away
Breathlessness or Exertion	<ul style="list-style-type: none"> • Change to less strenuous activities • Monitor tiredness and encourage rest break before returning to the activity • Include “blowing” games to help to maintenance chest function.
Team Games	<ul style="list-style-type: none"> • Small team games may be easier to differentiate than whole class games. • Plan games so there is a role for the child. • Introduce a competitive element into an activity within the child's capabilities.
Useful publications	<ul style="list-style-type: none"> • “Meeting SEN in the Curriculum:PE/Sports”, David Fulton,2005.

If differentiation is still challenging, please contact your Specialist Teacher.

P.E. and Duchenne Muscular Dystrophy (Children using wheelchairs)

Effects of Muscular Dystrophy on P.E. Performance

- Wheelchair access which limits the range of activities.
- Low self esteem
- Team games becoming difficult to participate in

Issue	Strategy
Wheelchair access	<ul style="list-style-type: none"> • Modifications to activities from a seated position using upper body • Large wheelchair football used instead of regular ball • Larger/lighter bat Larger goal/target Lower goal/target Scoops for catching Vary balls (size, weight, airflow balls)Use of ramps/ chutes to roll balls down • If the topic is not wheelchair accessible think of a good alternative activities e.g. swimming/ hydrotherapy that could be done instead.
Low self esteem	<ul style="list-style-type: none"> • Make sure group games are structured so teams are not disadvantaged to have a pupil with DMD on their team • Give child a special role- e.g. referee • Make sure modifications are discrete and not obvious if child does not want to appear different
Team Games	<ul style="list-style-type: none"> • Games such as Boccia, table cricket or wheelchair hockey can be played. • See CP Sport website for more information and rules: http://www.cpsport.org/sports/ • Introduce a competitive element into an activity within the child's capabilities.
Useful publications	<ul style="list-style-type: none"> • "Meeting SEN in the Curriculum:PE/Sports", David Fulton,2005.

If differentiation is still challenging, please contact your Specialist Teacher.

Educational Implications of Muscular Dystrophy Key Stage 2

- In KS2 it is likely the child will have received a diagnosis and is starting to show more signs of muscle weakness
- Often boys are prescribed steroids to maintain muscle strength and prolong walking. These can have side effects such as weight gain and mood swings.
- This is the time when there can be lots of physical changes with most boys losing the ability to walk.
- By about 8- 11 years a wheelchair will usually be required. Initially this may be one that can be self-propelled. As boys get older they tend to get power wheelchairs as this can give more independence. It is good preparation for secondary school if a power wheelchair can be used at the end of KS2
- Pre- planning for this stage is essential in terms of building adaptations
- Usually an EHCP assessment will need to be made at this stage.
- Additional equipment such as seating and standing frames may be needed.

Issue	Strategy	Resources
<p>Monitor any physical changes and pass on any concerns to parents and professionals involved</p> <p>Use Bradford's Matrix of Need to identify the level of support needed and when to request a statutory assessment.</p>	<p>Monitor, record and review the situation.</p> <p>Call multiagency meetings with parents as and when necessary</p> <p>Assess whether the physical condition is affecting his learning or mobility</p> <p>Provide additional adult support if needed and record on provision map</p>	<p>Risk assess the environment and individual activities as and when necessary.</p> <p>See Educational Visits Guidance for pupils with physical difficulties for trips and swimming. These need more planning but lots of children with DMD have accessed residential trips successfully.</p> <p>Educational, Social and Health Care Plan Guidance.</p>
<p>Inability to sit comfortably and safely.</p>	<p>In KS2 pupils may need a chair that gives greater levels of support. This is usually a height adjustable chair on wheels that can be used indoors.</p> <p>Make sure they sit straight facing the board so they do not have to move their body to see the front.</p>	<p>Occupational therapy will advise on seating requirements and a seating assessment will be made. Your specialist teacher will discuss current funding arrangements for seating.</p>
<p>Extra equipment may be needed</p>	<p>Standing frames are sometimes used in school for short times in the school day.</p>	<p>Standing frames are provided by physiotherapy. Wheelchairs are provided and maintained by wheelchair services.</p>
<p>Loss of Independence</p>	<p>Provide aids eg. rails, toilet aids.</p>	<p>Occupational therapy will advise on adaptations to toilets so they are accessible. These need to be planned for in anticipation. Intimate Care Policy- ask your specialist teacher.</p>
<p>Reduced ability to join in school</p>	<p>Activities should be adapted where possible so the child is included fully.</p>	<p>It is likely adult support will be needed to help the child</p>



activities Increased instances of falling or losing balance	Record all falls or trips and monitor their occurrence. There may be differences in balance and tiredness levels at the end of the day or week. Boys may need to start to have more support or equipment at these times.	participate in all activities. Often children access hydrotherapy session blocks through their physiotherapist.
Learning ability affected	Allow extra time to complete tasks. Ensure activities are differentiated appropriately. Give additional adult support.	
Manual handling difficulties	Staff should have Manual Handling Training. Seek advice from physiotherapist and occupational therapist. Equipment such as hoists may be needed in the hygiene room. A manual handling plan will need to be written by a trained assessor and updated by a competent person annually.	Manual handling training and hoist training for staff and manual handling plan written by qualified person. Contact your specialist teacher for details of training.
Hand function	Activities recommended by Physical and Medical Team Seek advice from occupational therapist. Consider use of ICT for recording.	A fine motor, IT or handwriting assessment can be completed by your specialist teacher to look at strategies to help participation in class.
Development of Deformities	Splints and braces may be provided. Advice of management on school will be given by the physiotherapist.	
Depression and Frustration	Use positive role models eg: Para-Olympians. Have a positive attitude. Seek advice and help in management when abilities reduce. Always include activities in which child can succeed.	Sue Manning is the regional care advisor at Leeds Teaching Hospital NHS Trust. Sue.manning@leedsth.nhs.uk (0113 3923113) supports children and families with practical and emotional support for people with DMD
Stamina	Pacing of activities to reduce fatigue during the day and towards the end of the week.	Your specialist teacher can help advise on pacing and fatigue.
How accessible is the school?	Once children start to have mobility difficulties they may need to access the disabled toilet. When children are unable to walk they may need more support including a hygiene room with hoist facilities to access the toilet. These need to be planned for well in advance of the child needing it. If there is any building work planned for the school consider whether this will be accessible for a wheelchair user.	Meet with occupational therapist and specialist teacher to discuss long term school access.