

# Duchenne Muscular Dystrophy

Advice for schools and parents

ERC-101146 Sept. 2010

## In the classroom

- adjust height of chair and table to encourage independence for as long as possible
- consider the position of seating within the classroom for ease of accessibility and access to the teaching area
- allow the student to precede the others out of the classroom or remain until last to avoid high traffic areas
- for floor-based activities, provide a chair for the student to use in getting up off the floor
- allow the use of a laptop computer to enable the student to keep up with school work, as writing will become harder with time.

## School activities

- include students in all activities and make modifications on an individual basis
- adapt Physical Education and sport programs
- carefully plan school excursions and camps in terms of transport, physical access and participation in the activities on offer.

On the enrolment of a student with DMD, the school will need to lodge an application for student disability funding (Program for Students with Disabilities, Visiting Teacher Service). This funding is provided to all government schools. Independent and Catholic schools also have a range of disability funding options.

## How can parents help?

- allow up to 18 months before starting school to contact the Principal, visit the school, and gather the relevant documentation for any applications
- share information about your son's condition with the school
- discuss with the school how a school-based Student Health Support Plan can be developed for your son
- discuss with the school about applications for student disability funding and funding for capital works, equipment and materials needed, such as rails, ramps and disabled toilets
- be aware that Student Welfare/Integration/Pastoral Care Coordinators and other support staff are available in all schools to support individual student needs. Ask the Principal about who is best to support your son at school.

## Useful information

- Muscular Dystrophy Australia  
[www.mda.org.au](http://www.mda.org.au)
- Victorian Department of Education and Early Childhood Development (DEECD)  
[www.education.vic.gov.au/about/publications/newsinfo/welcomeprimaryschool.htm](http://www.education.vic.gov.au/about/publications/newsinfo/welcomeprimaryschool.htm)
- The Duchenne Foundation (Australian site)  
[www.parentproject.org.au](http://www.parentproject.org.au)
- Parent Project MD (US site)  
[www.parentprojectmd.org](http://www.parentprojectmd.org)  
This site includes a Teachers' guide and an Adaptive PE guide that are useful.

Please note: while the internet can be a source of good information it is also a source of inaccurate and misleading information. Rely on your doctor for expert and professional advice if unsure about information you have read.

The Royal Children's Hospital Education Institute  
[www.rch.org.au/edinst](http://www.rch.org.au/edinst)

The RCH Education Institute ensures continuity of learning and ongoing connection to school for children and young people.

## Contact

### Children's Neurosciences Centre

The Royal Children's Hospital  
50 Flemington Road  
Parkville, Victoria 3052  
Telephone (03) 9345 5641  
Fax (03) 9345 5977



# What is Duchenne Muscular Dystrophy?

Duchenne Muscular Dystrophy (DMD) is a genetic disorder that affects the ability of muscles to make dystrophin. Dystrophin is used in muscle contraction to produce muscle strength.

Without the dystrophin, muscles are unable to contract properly and therefore are weakened. This process is degenerative and progressive. DMD only affects males as the gene for dystrophin is located on the X chromosome. Females have two X chromosomes so that if one is defective the other can still work to produce dystrophin. Males however, have only one X chromosome.

This brochure aims to help schools understand DMD, learn about what to expect if a student with DMD attends the school and offer ideas about how schools might help a student with the condition. Inclusion in all school activities, however modified, is important for social and emotional development. It is important to have expectations of students with DMD in terms of their achievements – academically, recreationally and in regards to further education, training and employment.

Information provided within may also assist parents of boys with DMD for when they are considering schools for their son. Useful websites and contact details are on the back of this brochure to help provide more information.

## Changes in mobility as DMD progresses

In relation to mobility, the progression of DMD can be divided roughly into three phases: walking, intermediate and full-time wheelchair use (see table below). Every student will be different, and there is overlap as to at what age and when the student will move into the next phase.

Walking	Intermediate	Full-time wheelchair use
Prep–Grade 2	Grade 3–4	Grade 6–Year 7
Walking	Walks short distances	Rarely walking but may still stand (+/- assistance) for transfers
May need help with access to toilets, rails and ramps	Manual wheelchair for longer distances	Electric wheelchair used in the majority of cases
Risk of falling	Increased likelihood of falling	Care with transfers

The use of a wheelchair in the intermediate phase is to support the student's mobility over distance.

### A wheelchair allows the student to:

- get from point A to point B so that he can participate in the relevant activity
- conserve energy and help balance fatigue levels with active participation
- get around the playground more efficiently and keep up with his peers
- be safe, as the student is less likely to fall.

## Students with DMD

### All students with DMD will:

- lose strength over time
- fatigue more quickly compared to their peers
- be at greater risk of falling and injury due to muscular weakness
- eventually require assistance for their mobility and functional activities.

### Students may find it difficult to:

- complete learning activities or undertake examinations
- maintain academic performance
- access the school environment
- participate in school activities
- maintain peer relationships
- maintain confidence and motivation
- maintain a positive self-image and high self-esteem.

### All students with DMD should:

- be encouraged to participate at the level of their endurance
- take short rests as needed
- rejoin activities when they feel ready
- participate in physical activities at their own pace
- not be pushed physically beyond their comfort level
- be given additional time to complete activities.

## How can schools help?

### Physical access

All school sectors can apply for relevant funding available for capital works, equipment and materials needed, such as rails, ramps and disabled toilets. It is important to consider many aspects of the school's physical environment including:

- access to all classrooms, lockers, indoor and outdoor areas, i.e. are there stairs or different surfaces to navigate?
- distances to walk between classrooms and outdoor areas
- assistance with carrying books and materials around the school environment, and to and from home
- after school care access
- fully accessible, private toilets for a wheelchair-bound student.