

## Factsheet: Muscular Dystrophy

### What is it?

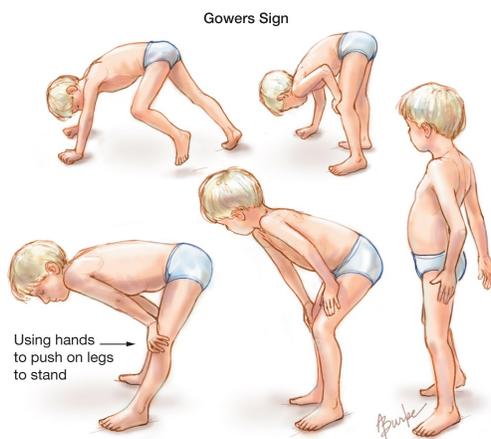
Muscular dystrophy is a broad label used to describe a group of genetic disorders that cause muscle degeneration and weakness. Muscles in the body become progressively weak as the muscles break down and are replaced by fat deposits. There are a total of 9 types of MD; the most common forms are Duchenne's muscular dystrophy (DMD) and Becker muscular dystrophy (BMD). DMD is caused by an absence of the protein called *dystrophin*, causing muscles to weaken.



DMD is diagnosed young, usually around 3-6 years of age and primarily affects boys because the gene mutation is located on the X chromosome. BMD is less severe and usually onset is much later; late teens to early 20's. Affected children will demonstrate a delay in walking, frequent falling, and difficulty getting up from a lying down or sitting position. When children have a hard time standing from a sitting or lying down position, they compensate by pulling to their hands and knees, raising their bottom in the air, then "walking" their hands up their legs until they can brace themselves; called the Gower's maneuver. Calve muscles become enlarged as thigh muscles weaken. Pelvic and shoulder muscles are also affected.

By the age of 12, most children will need a wheelchair for mobility. By the late teens, the child may suffer heart and lung complications. Cardiomyopathy can develop as the heart muscle weakens. Effects on the diaphragm and other lung muscles make breathing more difficult. A child will therefore suffer increased risk of respiratory infection because of decreased airway clearance. Other common diagnosis include scoliosis and obesity.

There is no cure for muscular dystrophy or delay of the progressive degeneration of muscles. The goal of treatment is to delay symptoms, prevent deformity and promote functional quality of life. Breakdown of the muscles is not painful and does not directly affect the nerves. A child maintains control of muscles in the bowel and bladder and sexual functions.



### What are the characteristics?

- Clumsy, frequent trips and falls
- Walking on toes
- Unable to hop or jump
- Trouble with stairs
- Leg pain
- Facial weakness
- Unable to close eyes
- Shoulder and arm weakness
- Enlarged calf muscles
- Stiffening, contractures of joints

### Suggested school accommodations

- PT/OT services
- Aids, tutors, note takers
- Rest time or breaks
- Pencil grips
- Bathroom pass or assistance
- Rolling backpack
- Adaptive technology
- Oral vs. written reports or tests
- Maintain routines and schedules
- Clear, concise instruction
- Advanced warning of change
- Avoid stairs, use elevator
- "Buddy" for hallways, near desk, etc.
- Extra textbooks to keep at home
- Extra time to get to classes

## Suggested school accommodations, cont'd

Physical Considerations	Occupational Considerations	Medical Consideration
<ul style="list-style-type: none"><li>• ROM exercise</li><li>• Muscle massage</li><li>• Safety training for stairs, hallways, playground, etc.</li><li>• ADL's including toileting</li><li>• Adapted PE</li></ul>	<ul style="list-style-type: none"><li>• Manual or power wheelchair</li><li>• Orthotics or braces</li><li>• Walker</li><li>• Chair with arms in classroom</li><li>• Computer technology</li></ul>	<ul style="list-style-type: none"><li>• Prednisone is a steroid medication used in children as it works to slow muscle wasting. However, it causes many side effects like weight gain, sleepiness, difficulty concentrating, depression and aggression.</li><li>• A child's condition can deteriorate rapidly</li><li>• Emotional support for all involved</li></ul>

Tips/Phrases for teachers to use/not use in the classroom from the *Parent Project Muscular Dystrophy*:



- Suffers from
- Terrible, debilitating disease
- Afflicted with
- Wheelchair bound
- Disease (viral)
- Fatal / terminal
- Crippling or crippled



- Diagnosed with
- Progressive muscle disorder
- Affected by
- Needs the assistance of a wheelchair
- Disorder (genetic) / condition
- Devastating / life-limiting
- Progressive muscle disorder

### SHNIC school nurses information:

#### Specific health issues for individual health care plans

- Diagnosis including type of MD and age diagnosed
- Child specific characteristics and symptoms
- Up to date medications, respiratory treatments, PRN medications
- Baseline respiratory assessment including pulse ox parameters
- Nutrition orders/OM protocol
- Aspiration precautions, positioning for meals, location of meals and snacks
- Emergency care plan
- Adaptive equipment or orthotics, including hours of wear time for use
- Transfers, any equipment involved for safety (slings, lifts)
- User manual for power wheelchair, battery life and/or charge accessibility
- Toileting protocol
- Evacuation plan

#### Resources & Manuals

**Muscular Dystrophy Association**  
<http://www.mda.org/>

**Pediatric Muscular Dystrophy**  
<http://childrensnational.org/choose-childrens/conditions-and-treatments/movement-disorders/muscular-dystrophies>

**Parent project muscular dystrophy**  
[http://www.parentprojectmd.org/site/PageServer?pagename=nws\\_index](http://www.parentprojectmd.org/site/PageServer?pagename=nws_index)

**Education matters: A teacher's guide to Duchenne muscular dystrophy**  
<http://www.parentprojectmd.org/site/DocServer/EdMatters-TeachersGuide.pdf?docID=2403>