

# Diagnosis: Duchenne Muscular Dystrophy (DMD)

Duchenne muscular dystrophy (DMD) is a progressive genetic neuromuscular disease that affects all major muscle groups in the body, beginning with those in the legs and arms. Due to the progressive nature of this disease, and the fact that physical fatigue in children with DMD can impact them while in the school environment, it is imperative that educational professionals working with students affected by DMD be aware of their diagnosis, needs and abilities.

About one-third of those affected by DMD have a learning disability to some degree, with the most common including difficulty with attention and focusing, verbal learning, memory and emotional interaction — all of which may impact academic achievement.

It is important that school officials understand this disorder is not contagious and does not pose a health risk to the school. Absences from school, however, can accumulate due to an increased risk of respiratory illness resulting from respiratory muscle weakness. The student also has an increased risk of falls and injury if they become fatigued.

To learn more about DMD, visit the MDA website at **mda.org/disease/** duchenne-muscular-dystrophy.

In the school setting, the following aids, interventions and supports are recommended for students with DMD to be able to fully access their school environment and have the opportunity to excel academically and socially.

#### **Physical Therapy**

Physical therapy enables children with DMD to make maximum use of healthy muscle function, helping them maintain independence and prevent the onset of muscle contractures. This is a list of accommodations students may need during the school day:

- Stretching
- Range-of-motion exercises
- Muscle cramp massage
- · Safety training (on stairs and playground)
- · Hallway safety
- Accommodating activities of daily living (ADLs) to changing physical needs (toileting, lunch time/cafeteria safety, etc.)
- · Adapted/modified physical education (see next section)

## Physical Education (Adapted)

Physical activity plays an important role in the health and well-being of those with DMD, but care must be taken so that students do not exercise to the point of exhaustion. It also is recommended that students remain included in the general education classroom for physical education (PE). The modification of most activities can be done by consulting with the physical therapist, with the goal of the student's PE curriculum being recreation, rather than competition or increased strength and endurance. It is critical that students with DMD be restricted from eccentric exercises because these may cause muscle damage. Under no circumstances should the student lift weights, or do push-ups, pull ups and abdominal crunches. These activities can be detrimental to the student's health.

### **Occupational Therapy**

As students with DMD lose muscle strength, an assistive technology evaluation will be indicated. Also, an occupational therapy consultation for body positioning, seating, and gross and fine motor function is recommended. Many students with DMD use assistive devices such as manual or power wheelchairs. Students also may require modified written assignments or computer technology that maximizes fine motor skills or utilizes voice command/dictation typing systems.

#### School Accommodations

Every child is unique and has different physical needs. The following are accommodations to consider in the classroom/school environment:

- An additional set of textbooks should be provided to the student so they do not need to transport heavy textbooks to and from school (or from one classroom to another).
- If the school has multiple levels, the student should have access to an elevator.
- Whenever possible, the student's physical needs should be taken into consideration when designing their class schedule (classrooms should be close together to minimize distance walked throughout the day, etc.).
- Preferential seating in the classroom will allow a student with DMD to safely navigate the classroom and access their class environment.
- An emergency evacuation plan should take this student's physical needs into consideration. School personnel should be assigned to accompany the student during an emergency. If the school has multiple levels, a "safe room" should be established with the local fire department.
- Field trips and school events should take into consideration the student's needs. For example, how far will students have to walk from the bus to the front door? Is the field trip destination wheelchair-accessible? Is there a wheelchair lift on the bus? Have chaperones been informed of this student's needs?

## A Message from MDA

Thank you for your commitment to your student(s) living with Duchenne muscular dystrophy (DMD). With your support, your student(s) will have the opportunity to achieve their academic goals while also learning to adapt to their changing physical needs. For more information about DMD, and for additional support, contact the Muscular Dystrophy Association at 800–572–1717 and ResourceCenter@mdausa.org. Visit mda.org for additional resources.



Muscular Dystrophy Association mda.org • 800–572–1717