



Diagnosis: Myotonic Dystrophy (DM)

Myotonic dystrophy is a chronic, slowly progressing and highly variable inherited disease. It affects multiple organ systems within the body and can manifest itself at any age from birth to adulthood. Due to the progressive nature of this disease, and the fact that fatigue in children with myotonic dystrophy usually impacts them while in the school environment, it is imperative that educational professionals who work with children living with this disorder are aware of their diagnosis, needs and abilities.

Intellectual development issues — including learning disabilities — may be seen in some children with myotonic dystrophy. Psychosocial problems such as attention deficit hyperactivity, difficulties with social interactions, depression and anxiety disorders can occur in some individuals. It is important that school officials understand that this disorder is not contagious and does not pose a health risk to the school. However, daytime sleepiness is a hallmark of this disease and may impact the student while in the school environment. It is important that school officials understand this disease is not contagious and does not make this student more of a health risk in school. The child does, however, have an increased risk of falls and injury, especially after becoming fatigued.

To learn more about myotonic dystrophy, visit MDA's website at mda.org/disease/myotonic-muscular-dystrophy.

NOTE:

The recommendations provided below are for students affected by juvenile-onset myotonic dystrophy. It's important to understand that myotonic dystrophy is also related to a severe form of the same disease known as congenital myotonic dystrophy. Students with congenital myotonic dystrophy often have mild to severe cognitive, speech and motor development delays. For guidance when working with students affected by congenital myotonic dystrophy, please ask the student's family to connect you with the MDA Care Center physician who is most familiar with

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



PHYSICAL THERAPY

Physical therapy enables children with myotonic dystrophy 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
- Hallway safety
- Accommodating activities of daily living (ADLs) to changing physical needs (toileting, lunch time/cafeteria safety, etc.)
- Range-of-motion exercises
- Safety training (on stairs and playground)
- Adapted/modified physical education (see next section)



PHYSICAL EDUCATION (ADAPTED)

Remaining physically active is recommended for anyone with myotonic dystrophy. It is also imperative that students remain included in the general education classroom for physical education (PE). Modifications for most activities can be done by consulting with a physical therapist, with the goal of the student's PE curriculum being recreation, rather than competition or increased strength and endurance. In some circumstances, physicians may require that a student be excused from PE activities.



OCCUPATIONAL THERAPY

As the muscles of children with myotonic dystrophy become weaker, an assistive technology evaluation will be needed. In addition, an occupational therapy consultation for fine motor function is recommended.



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 that 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 myotonic dystrophy to safely navigate the classroom and access their class environment.
- An emergency evacuation plan should take the 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 the student's needs into consideration. 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?
- Students with myotonic dystrophy occasionally experience symptoms of acid reflux following meals; in many cases, students will keep a supply of antacids in the nurse's office for instances of reflux or stomach discomfort.



A Message from MDA

Thank you for your commitment to your student(s) living with myotonic dystrophy. 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 myotonic dystrophy, and for additional support, contact the Muscular Dystrophy Association at 1-833-ASK-MDA1 and ResourceCenter@mdausa.org. Visit mda.org for additional resources.



*Designated a Top-Rated Charity by the American Institute of Philanthropy, MDA is the first nonprofit to receive a **Lifetime Achievement Award from the American Medical Association** for "significant and lasting contributions to the health and welfare of humanity."*



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