

School Accommodation Recommendations

Diagnosis: Myotonic Muscular Dystrophy (DM1)

Myotonic muscular 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 muscular dystrophy usually impacts them within the school environment, it is imperative that educational professionals who work with children living with this disorder be aware of their diagnosis, needs, and abilities.

Intellectual development issues -- including learning disabilities -- may be seen in some children with myotonic muscular dystrophy. Psychosocial problems such as attention deficit hyperactivity, antisocial behavior, depression and anxiety disorders do occur in some individuals. It is important that school officials understand that this disease is not contagious, and does not make this student more of a health risk in school. However, daytime sleepiness is a hallmark of this disease and can be debilitating.

Within the school setting, the following aids, interventions, and supports are recommended for students with myotonic muscular dystrophy to be able to fully access their school environment and excel academically and socially.

Please be aware the myotonic muscular dystrophy is also related to a much more severe form of the same disease known as congenital myotonic muscular dystrophy. Students with congenital myotonic muscular dystrophy often have mild to severe cognitive, speech, and motor development delays. The following recommendations are for students with the milder forms of myotonic muscular dystrophy. For guidance when working with students affected by congenital myotonic muscular dystrophy, please ask the student's family to connect you with the MDA clinic physician who is most familiar with the student's needs and strengths.

Physical Education (Adapted)

Remaining physically active is recommended for anyone with myotonic muscular dystrophy. It is also imperative that students remain included in the general education classroom for PE. Modification of most activities can be done through consultation with a physical therapist, with the goal of this student's PE curriculum being recreation, rather than competition or increased strength & endurance.

Occupational Therapy

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

School Accommodations

- An additional set of text books should be provided to the student so that he/she does not need to transport heavy text books to and from school (or from one classroom to another).
- Whenever possible, this student's physical needs should be taken into consideration when designing his/her 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 muscular dystrophy to safely navigate the classroom and access his/her class environment.
- An emergency evacuation plan should take the student's physical needs into consideration. School personnel should be assigned to accompany him/her 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 needs of this student. For example, how far will students have to walk from the bus to the front door?
- Students with myotonic muscular dystrophy occasionally experience symptoms of acid reflux following meals; in many cases students will keep a supply of anti-acids in the nurse's office for instances of reflux or stomach discomfort.

Thank you . . .

for your commitment to your student. With your support, this student will successfully achieve his/her academic goals while also learning to adapt to his/her body's changing physical needs.

For more information regarding myotonic muscular dystrophy, please feel free to contact the Muscular Dystrophy Association at (800) 572-1717, or visit our website at www.mda.org.

