



## Diagnosis: Charcot–Marie–Tooth disease (CMT)

Charcot–Marie–Tooth disease (pronounced Shar–Co–Mar–ee–Tooth) is a neurological disorder that causes damage to the nerves that connect the brain and spinal cord to the muscles and sensory organs. In CMT, nerve damage can cause muscle weakness, muscle wasting and decreased sensation in the feet, lower legs, forearms and hands. There are many different forms of CMT, which can present at any age and in both genders depending upon which type of CMT is involved. Due to the progressive nature of this disease, and the fact that physical fatigue in children with CMT usually impacts them while in the school environment, it is imperative that educational professionals who work with students affected by this condition be aware of their diagnosis, needs and abilities.

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 CMT, visit MDA's website at [mda.org/disease/charcot-marie-tooth](https://mda.org/disease/charcot-marie-tooth).

In the school setting, the following aids, interventions and supports are recommended for students with CMT 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 CMT 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
- 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)

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 with CMT be excused from PE activities.

### Occupational Therapy

As a student's CMT progresses, an assistive technology evaluation will be needed. In addition, an occupational therapy consultation for body positioning, seating, and gross and fine motor function is recommended. Many students with CMT use computers, AlphaSmart devices, or they may have modified written assignments.

## 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 CMT 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 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 the student's needs?

### A Message from MDA

Thank you for your commitment to your student(s) living with Charcot-Marie-Tooth disease (CMT). 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 CMT, and for additional support, contact the Muscular Dystrophy Association at **800-572-1717** and **ResourceCenter@mdausa.org**. Visit **mda.org** for additional resources.

