



A School Nurse's Guide for Helping Children with
**Charcot-Marie-Tooth
Disease**





While most school nurses are familiar with a wide variety of pediatric illnesses, Charcot-Marie-Tooth disease (CMT) poses some particular challenges due to its progressive nature, fluctuating symptoms and the child's changing needs.

All of this can create a stressful and challenging environment for children with CMT and their families.

The Charcot-Marie-Tooth Association created this guide to assist school nurses in caring for children with CMT.

- Charcot-Marie-Tooth disease (CMT) is the most common inherited peripheral neuropathy, affecting one in 2,500 people in the United States and 2.8 million people worldwide, many of them young children.
- As the peripheral nerves die, the muscles in the arms, hands, legs and feet, weaken and waste, causing children to lose normal use of these extremities.
- There is no cure and no current drug treatment. For more information go to www.cmtausa.org.
- It is important for school nurses to be familiar with how CMT can affect a child's school experience. They are often the first ones to notice a change in the child.
- Being aware of CMT and its effects can help in planning and supporting a child's school involvement, making it easier on the child, family and school.
- CMT does NOT cause learning difficulties, however, a child may experience problems with coordination, fatigue, pain, tremors, anxiety and emotional factors related to having a disability.

Preparing for School

Ideally, a meeting between the school nurse and the parents of the affected child would take place before the new school year begins, or no later than the first few months of the school year. The goal of the meeting is to educate the school staff about CMT, to provide parents with information regarding school policies and to foster a good working relationship.

Action Items:

- Request information regarding the child’s diagnosis and treatment.
- Inquire about medication administration and obtain the prescriptions/ orders, if necessary to administer during the school day.
- Identify any necessary activity restrictions or modifications
- Ask about any upcoming surgeries and if the child will require crutches or a wheelchair.
- Be included in all 504 and Individualized Education Plan (IEP) meetings.
- Request information on how best to reach the parents during the school day.

Many students find “invisible” symptoms like pain and fatigue the most difficult part of living with CMT. People tell them: “But you look so good ... you can’t possibly be sick.” It is important to understand the “invisible” symptoms as well as the ones that can be seen.





Visible & Invisible Symptoms

One of the biggest challenges of CMT is the unpredictability and varying degree of symptoms. Symptoms come and go without rhyme or reason and children with CMT never know how they are going to feel from day to day. They can feel good one moment and fatigue or pain can set in the next.

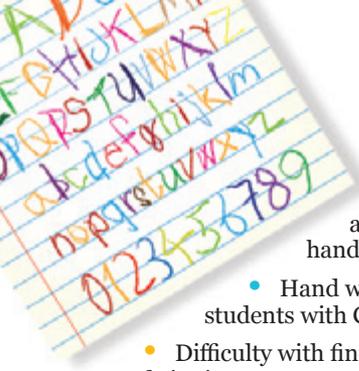
Each person with CMT is different. Some may have visible symptoms, others invisible symptoms and some have both. The rate of progression varies from month to month and year to year.

Visible Symptoms

- Difficulty walking, abnormal gait and “clumsiness” due to muscle weakness, atrophy and fatigue.
- Difficulty walking up stairs/ramps.
- Characteristic “drop foot” gait.
- Frequent tripping, falls and injuries from falls.
- Skeletal abnormalities like hammer toes, high arches, scoliosis and kyphosis.
- Tremors.
- Use of orthotics or braces.
- Inability to keep up with peers during physical activities.
- Need for mobility aids such as wheelchairs or crutches.

Invisible Symptoms

- Fatigue is the most common complaint among people with CMT and can be significant enough to interfere with their daily activities. Fatigue usually occurs daily, comes and goes without warning and gets worse as the day goes on.
- Pain is a frequent companion for people with CMT. It too comes and goes without warning and can get worse as the day goes on. It can be a sharp shooting pain, tingling, or a burning sensation in the feet, legs, arms or hands. If the diaphragm is involved, there may even be chest pain.
- Cramping can occur in the hands and feet.
- Slow, progressive weakness and atrophy of muscles in feet, legs, arms and hands.
- Proprioception (one’s sense of where the body is in space) is impaired.
- Depression, anxiety and mood swings are common among children with CMT, who may have one, two or all of these symptoms. This is related to having a progressive, chronic disease and feeling different from their peers.



Physical Limitations

- Lack of muscle strength and dexterity in the fingers and hands may make holding a pen/pencil difficult and handwriting may be perceived as “messy.”
 - Hand weakness, tremors and cramping make it difficult for some students with CMT to take notes quickly or write for long periods.
- Difficulty with fine motor skills such as buttoning, tying, opening and zipping.
- Difficulty rising from a seated position on the floor or from a chair to standing position.
- Inability to move from classroom to classroom as quickly as other students.
- Inability to keep up with peers in physical activities like running, jumping, squatting, walking, climbing, balancing and heel-to-toe movement.

Adaptive Devices

- Foam and/or pencil grips that fit over pencils to make them easier to grasp.
- Laptops, tablets or computers can replace writing.
- Assistive speech-to-text software.
- Devices to aid in buttoning and zipping.
- Ankle/Foot Orthotics (AFOs) or other lower extremity braces.



Many different physical and emotional stressors, affect children with CMT while in school. They include:

- Difficulty navigating stairs due to loss of balance, weakness or fatigue.
- Pain, tremors or cramping may come and go, unbeknownst to others and affect classroom work.
- Sensory disturbances (burning, tingling, shooting pain) and/or the absence of sensation in hands/feet (paresthesia).
- Anxiety or depression.

As with any chronic illness, students with CMT often feel anxious about missing school due to their illness and worry about how their peers and teachers view them. It is important for the school to provide support and accommodations to ease the child's anxiety.

Accommodations for School

- An IEP is the product of a collaboration among parents, school nurse, and school staff and ensures that every student obtains a free and appropriate education.
- A 504 Plan ensures “an even playing field” for students and is available to any student who has a documented disability. The 504 Plan also requires a collaboration with parents, school nurse, and school staff.
- Plans are reviewed and revised annually.
- Each child should receive adequate services based on measured rather than assumed capabilities.
- Information from physiotherapists should be taken into consideration to enable an adaptive physical therapy program and/or physical therapy to be provided as part of physical education. Physiotherapy programs can prevent contractures that can lead to further disability and are essential to slow down progression of the disease, especially during the growth spurts associated with puberty.
- Heavy doors, stairs and long distances can be cumbersome and should be avoided.
- Providing an elevator pass can be extremely helpful, along with handrails on stairs that cannot be avoided.
- Eliminate the need for a heavy backpack by providing students with CMT a locker or storage space so they can keep books and binders at an easy, accessible and central location.
- Wheelchair access for a child recovering from surgery or more severely affected by CMT.
- Two sets of books, one for home, one for school to avoid carrying a heavy book load.
- Providing copies of teachers' notes eliminates the need for students to take notes by hand.
- Modifications to PE activities (fewer reps, breaks).



CMTA resources

CMTA WEBSITE

www.cmtausa.org

CMTA FACEBOOK PAGE

www.facebook.com/CMTAssociation

CMTA YOUTUBE CHANNEL

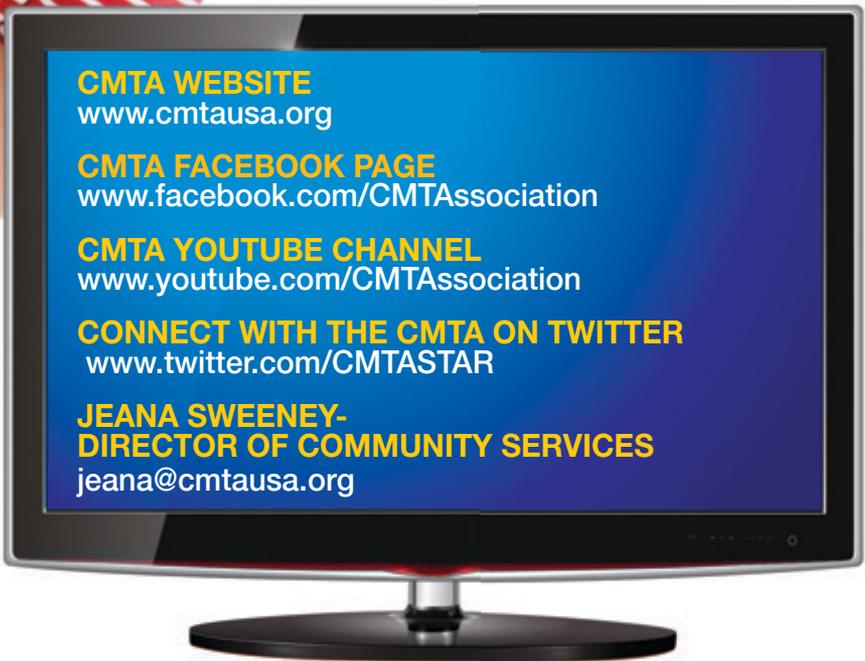
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School
Nurses & Kids
With CMT
Rock!

