

CMT IS:

- A disease of the peripheral nerves that control the muscles (unlike the muscular dystrophies, which affect the muscles themselves).
- The most commonly inherited peripheral neuropathy, found in both genders and in all races and ethnic groups and affecting more than 3 million people worldwide. Although CMT is typically inherited from one's parents, it can also occur as a result of a new or spontaneous mutation. People who have these "de novo" mutations can then pass the condition on to their children.
- Usually slowly progressive, causing loss of normal function and/or sensation in the feet/legs and hands/arms.
- Currently incurable, but not usually fatal, though it can be severely disabling in some people.

WHAT ARE THE SYMPTOMS OF CMT?

First signs may include toe-walking, frequent tripping, ankle sprains, clumsiness and "burning" or pins-and-needles sensations in the feet or hands.

Structural foot deformities such as high arches and hammertoes are common, but some people have flat feet.

Foot drop, poor balance and problems walking as muscle wasting in the lower legs and feet progresses.

Difficulty with tasks involving manual dexterity, such as writing and manipulating zippers and buttons, often accompanies muscular wasting in the hands.

Abnormal sensation, loss of ability to feel light touch, inability to differentiate between hot/cold, and the loss of proprioception or the inability to sense where one's body is in space are also common, and many people experience neuropathic, muscle or joint pain.

Poor tolerance for cool, cold and/or hot temperatures is typical. Many people have chronically cold hands and feet.

Additional symptoms may include flexed fingers, contractures, tremor, knee and/or hip problems, cramps, thenar muscle atrophy (weakness of the muscles between the thumb and forefinger), muscle weakness and loss of hand strength, chronic fatigue, sleep apnea, breathing difficulties, swallowing difficulties, absent or reduced reflexes, poor circulation, scoliosis, kyphosis and hearing loss.

The psychological impact of having CMT can be devastating, leading to irritability, depression, anxiety, isolation, loss of pleasure, weight gain or loss, and feelings of hopelessness, worthlessness or guilt.

If you are having suicidal thoughts, immediately call your local suicide hotline or the National Suicide Prevention Lifeline: 1-800-273-TALK (1-800-273-8255), or seek help right away at a local emergency room.

A CMT diagnosis involves a clinical evaluation of muscle function and atrophy, testing of sensory responses, and electromyographic and nerve conduction studies. Many types of CMT can also be diagnosed by genetic testing. Click here for more information on diagnosing CMT.

IS THERE A TREATMENT FOR CMT?

Although there is no drug treatment for CMT, physical/occupational therapy and moderate activity (but not overexertion) can help maintain muscle strength, endurance and flexibility. Mechanical supports like AFOs (ankle-foot orthoses) and custom-made shoes can improve gait and balance. When medically indicated, orthopedic surgery can correct deformity and help maintain mobility and function. Occupational therapy and adaptive devices can help people perform activities of daily living.

ANY MEDICATIONS PEOPLE WITH CMT SHOULD AVOID?

YES! Some medications are potentially toxic to people with CMT.

Vincristine has been proven hazardous and should be avoided by all CMT patients. Taxols also pose a high risk to people with CMT. The complete list of potentially neurotoxic medications can be viewed at www.cmtausa.org/medicationlist. Before taking any medication or changing medications, be sure your physician is fully aware of your medical condition, and discuss any possible side effects they may have on CMT.

Have a drug/medication question? Visit www.cmtausa.org/medquest or email asktheexpert@cmtausa.org.

