

# FACT SHEET

# CHARCOT-MARIE-TOOTH DISEASE



**Charcot-Marie-Tooth Disease (CMT) is the name given to a group of nerve disorders.**

**INCIDENCE:** 1 : 2,500 people

**AVERAGE AGE OF DIAGNOSIS:** infancy to adulthood depending on type

**OCCURRENCE:** both males and females – depends on genetic subtype

**LIFE EXPECTANCY:** variable depending on type. CMT1A normal life span. Life span can be limited to infancy in some types

**Charcot-Marie-Tooth Disease (CMT)** is the most common form of motor and sensory peripheral neuropathy (nerve disorder). CMT is a genetic condition that people are born with but may not show symptoms until later in life. There are currently over 80 genetic types of CMT. The most common is CMT1A. Peripheral nerves control movement by sending and receiving messages from the spinal cord to the muscles. Peripheral nerves carry pain and temperature from the hands and feet to the spinal cord. CMT leads to loss of nerve function so that person with CMT has difficulty with movement, balance and sensation. There is currently no cure for CMT.

Symptoms of CMT may be present in early infancy (CMT1E) or arise many years later in adolescence or adulthood (CMT1A). CMT1E in infants can cause severe physical disability and limited life span. CMT1A slowly progresses over a normal life span. Symptoms include progressive muscle weakness and wasting of the arms, hands, legs and feet are particularly affected. People with CMT may have the characteristic high-arched foot deformity which may be painful. They may also have muscle wasting and weakness of the lower legs, experience muscle cramps and have foot deformities such as hammer-toes. Hand function can become difficult due to pain, weakness and deformity. CMT may affect all aspects of the individual's quality of life.

Important primary health care for people affected by CMT starts with allied health assessments and planning to maintain good health and care of their

extremities. Essential care of finger and toe nails and skin integrity; properly fitted footwear; ankle and foot orthoses (AFO's), and stretching and strengthening exercises needs to be tailored to the individual's requirements.

To date there is no proven way to prevent foot deformities. Stretching and orthoses may be beneficial in redistributing the load of the body through the foot and possibly help to reduce pain and further damage. There are several surgical approaches for feet deformity, however the long-term outcomes in maintaining foot position and reducing pain are varied. People with CMT may also experience hip complications as the wear and tear over the years of walking with an abnormal gait takes its toll.

*Planning ahead for services and equipment is essential, particularly given the nature of CMT can lead to feet and hand injuries*

Psychological support is paramount over the course of a persons' condition as they grapple with the change in their disability. A person with CMT may rely on others for a certain level of care support, which may have an effect on family dynamics. Enough support needs to be provided to the person with CMT so that their carer can have a break. Independent living can be achieved with the right supports in place.

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Genetic testing and counselling should be offered to people with CMT, parents and family members for future pregnancy planning. Families and individuals affected by chronic conditions need to be empowered in order to have control over their life choices.

*It is important that service provision is centered around quality of life outcomes and meets the needs of the individual*

By seeking out what support is available, people will be empowered to make the right decisions for themselves. Despite the challenges that a person with CMT faces, there are many opportunities available to support people to live fulfilled and productive lives. Goal setting and positive attitudes contribute to achieving success in many facets of life.

CONSIDERATIONS FOR PLANNING SHOULD INCLUDE BUT ARE NOT LIMITED TO THE FOLLOWING:

- A consistent General Practitioner (GP)
- Hospital visits to see specialists for monitoring and medical care planning
- Support coordination for complex care needs
- Physiotherapy programs eg. stretching & strengthening exercises
- Occupational therapy to support activities of everyday living
- Assistive technology eg. scooter, manual wheelchair
- Orthotics eg. ankle-foot orthoses (AFO's)
- Opportunities to socialise and be away from home eg. MDNSW Camps, accessible travel
- Home modifications eg. ramps, bathrooms, kitchen taps
- Vehicle modifications eg. steering wheel conversion
- Support workers for in home care needs eg. cleaning
- Professional psychological support eg. counsellor or clinical psychologist
- Future goal planning eg. independent living, study, work choices
- Information on financial entitlements eg. Centrelink, Medicare, Companion Card

## USEFUL RESOURCES

**MDNSW** [www.mdnsw.org.au](http://www.mdnsw.org.au)

**MDNSW NDIS Toolkit** [www.mdnsw.org.au/ndis](http://www.mdnsw.org.au/ndis)

**Charcot-Marie-Tooth Association of Australia (CMTAA)** [www.cmt.org.au](http://www.cmt.org.au)