

## Respiratory

- In an emergency, medical professionals should assess breathing and oxygen levels and look for subtle signs of respiratory distress.
- Most individuals with CMT do not have significant respiratory weakness, however some severe or rare subtypes can lead to respiratory issues.
- Sleep apnoea (significant pauses or shallow and infrequent breathing during sleep) may be present in individuals with CMT. This can result in fatigue and difficulty concentrating during the day. Ask the individual whether they use a non-invasive ventilator regularly and contact their respiratory team.

## Medication and anaesthetic precautions

- Doctors must be aware of a CMT diagnosis when prescribing new medication – some can be toxic for individuals with CMT. Some chemotherapy medications can make CMT worse, specifically vincristine and paclitaxel. Speak to the specialist team if concerned or about to start treatment with potentially neurotoxic medications.
- If having surgery, the anaesthetist must be made aware of a CMT diagnosis. It is generally safe to use anaesthetics, providing the correct protocol for people with neuromuscular conditions is followed including pre-operative assessment and post-operative monitoring.

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## Fatigue

- Fatigue is common for individuals living with CMT, and can be severe. Fatigue can be triggered when a person does a high level of physical activity for their abilities and requires rest. Some people describe a more overwhelming feeling of exhaustion that is not refreshed by rest.
- Individuals with CMT may benefit from fatigue management techniques such as pacing activities, gentle exercise, and energy conservation techniques.

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## Alert card

### Charcot-Marie-Tooth disease (CMT)

Name ..... Date of birth .....

NHS/CHI/H&C number .....

If presenting at A&E, contact the specialist team at:  
.....

as soon as possible on: .....

For information and support, contact us on our helpline  
**0800 652 6352** or email [info@musculardystrophyuk.org](mailto:info@musculardystrophyuk.org)

## Charcot-Marie-Tooth disease (CMT)

CMT is a progressive genetic condition affecting the peripheral nerves. These nerves carry messages and control movement. CMT affects the feet, lower legs, hands, and forearms most, resulting in muscle weakness and wasting in these areas.

### Muscle weakness

- Weakness and loss of sensation in the lower legs and ankles will affect mobility and balance. Many people with CMT walk with foot drop (difficulty raising the front part of their foot), take shorter steps, and feel unsteady. Increased effort is required to walk and this can cause fatigue. Changes in foot shape and pain can also affect walking and balance.

- Individuals with CMT may find it difficult to stand still, walk on uneven ground, and to climb stairs. They are at higher risk of falls and may need assistance getting up.
- Some people with CMT develop weakness and loss of sensation in the hands. This particularly affects the smaller hand muscles and the thumb, impacting dexterity and grip strength.
- This can make daily tasks more difficult and tiring. This includes self-care, using devices, preparing a meal, using walking aids, and carrying heavier objects. Occupational therapy can help with strategies and equipment to make daily tasks manageable.
- As the condition progresses, orthoses and walking aids may be necessary.

### Orthoses

- Symptoms resulting from CMT such as foot drop, pain, and joints out of alignment can be improved using orthoses.
- Orthoses are devices worn on the body to provide support and stability. These include insoles, footwear, and ankle foot orthoses (AFOs), or a combination. Assessment must be carried out by a specialist or local orthotics service. Orthoses should be individually prescribed to address specific symptoms and may need to be custom made.
- Using orthoses aims to improve balance and reduce pain and risk of falls. They can also improve alignment and function of the knees and hips. Long term benefits can include improved joint integrity, reduced fatigue, maintenance of muscle length, and improved posture.

### Pain

- Joint and muscle pain or aches may be present, caused by foot deformities or strain on other parts of the body because of CMT. Painkillers like paracetamol or NSAIDs (if no contraindications) can usually be used to manage this.
- Some individuals may experience neuropathic pain from nerve damage. There are different types of medications available to treat this. Ask the individual whether they are already on medication.
- NOTE: Certain medications, such as higher doses of Gabapentin, carry a risk of withdrawal symptoms if stopped abruptly.