



Fact Sheet 5 - Charcot-Marie-Tooth Disease A guide for Teachers

Introduction

- Charcot-Marie-Tooth Disease (CMT) is the most common inherited neurological condition, affecting 1 in 2500 of the population.
- It causes progressive weakness and wasting of muscles in the lower arms and lower legs, due to damage to the nerves leading to the arms and legs. It is hereditary and there is no cure. Further information can be found on www.cmt.org.uk
- It is important for a teacher to be familiar with all the ramifications of CMT that could affect school experiences.
- Information can help plan and support the child's school involvement
- CMT does not cause learning difficulties
- A child may, however, experience problems from a variety of factors such as coordination, fatigue, anxiety, and emotional factors related to the disability.

Effects of Muscle Weakness

- These may be visible in a variety of ways
 - The manner of walking and apparent clumsiness
 - Use of foot splints (orthoses)
 - Frequent falls and minor, fall related, injuries
 - Occasionally the need for use of adaptive equipment, or mobility aids such as a wheelchair or crutches
- The rate of progression will vary from month to month or year to year.
- It is important to notice changes in a child's ability to do various activities to accommodate the child as their disability progresses

Potential Obstacles

- Lack of muscle/dexterity in the fingers and hands sometimes make holding a pen difficult, leading to teachers perceiving the handwriting to be merely "messy"
- Hand and arm weaknesses are typical challenges making it difficult to take notes quickly or over a long period of time
- Slowness or inability to get ready for class such as getting out pen and paper or lifting a book and opening it to the correct page.
- Inability to rise from a seated position on the floor or in a chair to standing position
- Inability to move from classroom to classroom as quickly as is normally expected

"Working to support those who are affected by Charcot-Marie-Tooth Disease, also known as Hereditary Motor and Sensory Neuropathy or Peroneal Muscular Atrophy."



Adaptive Equipment

- It is rare for a child with CMT to require a large range of adaptive equipment, but some of the following can be useful:
 - Foam that fits over pencils to make it easier to grasp
 - Devices to aid buttoning and zipping
 - Laptop or class PC

Responding to Classmates

- Accurate information is important so peers can cope with a classmates' disability, however everyone is different about others knowing
- Discuss with the child and parents their feelings about this before giving information to classmates
- Some children want to hide their disability as they wish to be the same as the others.
- Go at the student's pace.
- Avoid spotlighting or embarrassing
- Be sensitive to issues such as rising off the floor and poor performance during P.E.
- It can help the class to know about the type of disability that affects their classmate, the treatment, ways it may effect a child's appearance, abilities and behaviour
- The open approach can be useful in helping children develop an understanding of matters such as the disability progressing
- With accurate knowledge peers are less likely to tease and make cruel remarks.
- Be sure the child has a voice in this decision and is comfortable with a plan no matter how young

Cognitive Development

- Is not usually a feature of CMT
- It is important to evaluate each child independently.
- Keep in mind that slowness and limitations in physical abilities can often be misinterpreted as a cognitive problem.

How Teachers can Help

- A perceptive and concerned teacher can make the difference to schooling years for a student and their family.
- Writing assignments for class and homework can be at the price of great fatigue for the rest of the day
- Timed tests and those that create a great deal of writing often penalise a child who is unable to write quickly for long periods of time.
- It can take extra time to get books, paper, pens ready which may cause a child to miss instructions.
- Encourage use of laptop/PC if one is available
- Low marks may be because not enough time has been allocated
- May need to think of doing a smaller volume of work that will still meet the criteria
- Plenty of notification on assignments to enable effective pacing of work each day
- Notes from a teacher or another student helps



School Services

- 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 programme and / or physical therapy to be provided as part of PE. Physiotherapy programmes can prevent contractures that lead to further disability and are essential to slow down progression, particularly during the growth spurts associated with puberty
 - The physical environment can have numerous obstacles and will need to be discussed with an occupational therapist
 - Heavy doors, stairs and long distances can be obstacles
 - Handrails on steps, where steps cannot be avoided, can be extremely helpful
 - Locker and/or storage space provided to facilitate storing of books, rather than carrying too heavy a load - and in a suitable, accessible, location
 - Going through a queue such as the cafeteria at lunchtime may need to be facilitated
 - Wheelchair access for a child recovering from surgery, or more severely affected by CMT
- Adequate information about statementing should be provided to parents if appropriate.

Physical Education

- This is often a dread for the child and parents of children with CMT
- Allow sufficient time for changing into (and out of) PE kit, bearing in mind the child may have to deal with complicated orthotics (splints)
- Provide suitable, accessible, changing facilities, with seating to enable a child to sit whilst dressing and undressing
- Children are hesitant because they perceive themselves as clumsy, slow and unskilled as others - and often feel more of a "freak" during these lessons than at any other time
- Evaluate the child for efforts in regard to potential rather than his skill level
- Adapt games and PE by allowing the child to keep scores or be an assistant instead of forcing them to try something beyond their capability which can be humiliating
- However, swimming is excellent therapy for children with CMT, and if there is access to a pool, should be actively encouraged. The child should be able to participate on an equal basis in the pool, as the water supports the body. Care should be taken, however, that the child doesn't slip or fall on the wet surfaces around the pool. Additionally, children with CMT may be unable to leap far enough forward to avoid hitting themselves on the side of the pool, due to lack of "bounce" in the lower legs.

How CMT United Kingdom can assist you

- Teacher education often doesn't prepare you to cope with physical disability.
- CMT United Kingdom can help by providing detailed leaflets on the condition and what it will entail for a child