



# CMT AUSTRALIA

Charcot-Marie-Tooth Association Australia Inc.

## A Teacher's Guide to Charcot Marie Tooth

### **CMT - What Is It?**

- It is a peripheral neuropathy ie. It affects the nerve supply to the body's extremities, - the arms and hands, legs and feet. It causes progressive weakness and wasting of the muscles.
- It is genetic although there can be sporadic cases.
- It is not life threatening, but there is no cure.
- It is not contagious and does not affect the sufferer cognitively.
- Charcot and Marie were the two French doctors and Tooth was an English doctor who simultaneously discovered the syndrome in 1886. It is named after them

### **How does it affect your student?**

- CMT often affects coordination and balance because of loss of foot and leg muscles. This may make the child appear clumsy and have a tendency to trip and fall over.
- CMT sometimes affects fine motor skills like holding pens, and doing up buttons and shoelaces. This can often lead to misunderstanding and appear that the child's handwriting is messy or that they are lazy and not trying hard enough.
- CMT makes the child feel tired just trying to keep up with her peers on day to day tasks.

### **Potential Obstacles to Learning**

- 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 a 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 from a chair to a standing position.
- Inability to move from classroom to classroom as quickly as is normally expected, especially if stairs are involved.

### **Adaptive Equipment**

- Some children may have orthotics in their shoes or ankle foot orthosis (AFOs) making it more difficult to take shoes on and off.
- Occasionally the child may need a wheelchair or crutches.
- Some other examples of equipment the child may use range from foam that fits over pencils to make it easier to grip; devices to aid buttoning and zipping; and some children may use a laptop or class PC.

## How Can Teachers Help?

- A perceptive and concerned teacher can make the difference to schooling years for the student and her family.
- Allow extra time for the student to gather equipment before a task, write information down and stand from a sitting position.
- Timed tests and those that create a great deal of writing often penalise a child who is unable to write quickly or for long periods of time.
- Encourage the use of the laptop/PC if one is available.
- Discuss with the child and parents their feelings about the disability and how they would like it shared with their classmates (if at all). Some families are keen for others to know, others may want to hide it.
- It can help the class to know about the type of disability that affects their classmate, the treatment, and ways it may affect a child's appearance, abilities and behaviour.
- With accurate information peers are less likely to tease and make cruel comments.
- Be sure that the child has a voice in the decision and is comfortable with the plan.

## School Services

- Each child should receive adequate services based on measured rather than assumed capabilities.
- Information from allied health professionals such as Occupational Therapist and Physiotherapists should be taken into consideration to enable a physical therapy program to be devised and provided as part of the PE program.
- The physical school environment can have numerous obstacles and may 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 in a suitable, accessible location provided to store books, rather than carrying too heavy-a-load.
- Wheelchair access for a child recovering from surgery, or more severely affected by CMT.

## Further Information

CMT Australia is an organisation run by volunteers with personal experience with CMT, either as an individual or through a family member. They provide support through contact with people with CMT, distribute information related to the welfare of people with CMT and actively support CMT research.

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