



CMTAA

Charcot-Marie-Tooth Association Australia Inc.

HAVE YOU BEEN NEWLY DIAGNOSED WITH CHARCOT MARIE TOOTH?

What is CMT?

CMT or Charcot-Marie-Tooth disease, also known as Hereditary Motor and Sensory Neuropathy (HMSN), is a common but frequently undiagnosed condition. It is not a contagious disease but it is an inherited neurological disease with a 50% chance of being passed on to the next generations in some families. Research has indicated that as many as 1 in 2,500 people in Australia could have CMT.

How does it affect most people?

Generally your legs, feet, arms and fingers will mainly be affected. You may feel weakness or lack of strength, as well as aches and pains and lethargy. This is all due to your muscles working harder to keep up with you!

How do I know what type of CMT I might have?

There are over 50 types of CMT already discovered with various traits and symptoms and more types are being identified every year. Each type can have different causes and effects. It is important to realise that there are also varying degrees of severity when it comes to CMT and therefore an accurate diagnosis of your particular type of CMT is important in the appropriate treatment. In some cases a simple blood test is all that is necessary. In many cases there is still no accurate way of diagnosing what CMT type you may have. Sometimes a family history may help, but a consultation with a genetic specialist may be advised to give you the best chance at establishing your type. You may, however never know.

Who Can Help?

Your **General Practitioner** will probably be your first stop. They can refer you to various health and allied health services and should already have a good idea of your general wellbeing.

You are likely to have been diagnosed with the help of a **Genetic Counsellor** who may be a source of information at the time of diagnosis.

Occupational Therapists can assist with aids and help with ways around physical problems in everyday life.

An **Orthopaedic Surgeon** might be someone you may consider 'bringing on board' at some time to identify any ongoing problems that might be treated successfully with surgical intervention.

Physiotherapists can help with exercises and rehabilitation after surgery.

Is there anything I can do to maintain my current health and fitness?

It should be understood at the outset that CMT is a degenerative disease. However a CMT sufferer can help slow down it's progression by exercising and stretching. A physiotherapist will be able to help you in your quest for a healthy life by giving you detailed suggestions on how to stretch your weak leg and hand muscles and give you the best possible opportunity for a healthy life with CMT.

Is my level of health likely to deteriorate throughout my life?

Like everyone, our bodies begin to wear out over time. The same applies to CMT sufferers. Parts of your body may wear out quicker than others, but with a positive attitude you will find ways around most of your problems.

Why do I feel so tired?

CMT affects the muscles in your body and at times it is hard to keep up with everyone else. This is normal. Your muscles have to work harder to do the same things other people take for granted.

Will CMT affect me mentally?

The clear answer to this is NO! CMT is a peripheral neuropathy. It does not interfere in the workings of the brain and therefore does not alter the abilities of the brain in the person with CMT. You'll have to find another excuse for forgetting where you put your car keys!

Are there devices that can help me with the simple things I find difficult in life?

There are many support services like the Independent Living Centres that can help. These centres can provide anything from jar openers to major hardware that can be installed in your bathroom to aid with bathing (etc) Contact numbers are available online.

Medication and CMT

CMTAA chooses not to comment on drugs that may aggravate or exacerbate CMT. We suggest you speak to your medical physician for any further advice on this matter, considering your individual circumstances. The CMTAA strongly suggests that people with CMT alert their medical and allied professionals to the fact that CMT is a Degenerative Peripheral Neuropathy. In the light of this fact, we suggest that the following question be asked:

“Will the medication/treatment that is prescribed have an adverse effect on a Degenerative Peripheral Neuropathy?”

What is the prognosis for children with CMT?

Early diagnosis is important to help your child set up good healthy habits for life. Recent research has demonstrated an increase in flexibility through stretching and general physiotherapy. Night casting, serial casting and other forms of prolonged foot stretches have been shown to help in varying degrees.

Am I likely to pass my CMT on to any children I might have?

This will depend on the type of CMT that you have. The most common form (CMT1a) has a 50% chance of being inherited by each child. Other forms (like X linked) have a 25% inheritance rate. It is best to talk to a geneticist or neurologist about this.

How can I test the children I have now for CMT?

In most cases the way that you were tested is the way your children will be tested. Either a blood test, nerve conduction study or other form of diagnosis is possible. Talk to your specialist.

What other complications might my children have?

Recent studies have shown an increase in the incidence of hip dysplasia in children and young adults with CMT. An estimate of 6-8% of CMT children will develop hip dysplasia, a condition that affects the growth of the hip 'ball and socket'. It generally requires surgical intervention to realign the hip socket to enable the child to walk successfully and not deteriorate to a point where they will need a full hip replacement.

Should I expect my child to have problems at school because they have CMT?

There are a number of problems that can occur due to CMT. Making the teacher aware of these problems early will help your child settle well into school life, and constant communication between you and the school is essential. Such things as handwriting, balance issues & gross and fine motor skills are some of the major issues. Simple things like getting up and down stairs, doing up zippers, shoelaces or school bags, and generally organising oneself will all need to be addressed at some time. This is when an occupational therapist will come in handy.

Check the Youth Section of this website for more information including a Teacher's Guide to CMT.

Can I Assist With Medical Research?

There are often many research projects being undertaken which you or your child may be willing and eligible to participate in. As with all children with additional needs, early intervention is important to the long term outlook.

As with all medical conditions there is always more to discover. CMT is the most common peripheral neuropathy in Australia (approximately 1 in 2500) and research is particularly prevalent in major hospitals across Australia. These include The Children's Hospital at Westmead which has the Institute of Neuromuscular Research attached to it, and the Royal Melbourne Children's Hospital. A separate page is attached to this website with details of research currently being undertaken.

Is there a cure for CMT?

Because CMT is a genetically inherited condition there is currently no known cure. Future developments may lead us in a direction that will help us modify or eliminate the genes responsible for the various types of CMT. Until that time we can strive to better our lives through exercise, perseverance and humour.

You are a person with CMT – not a CMT person. Good Health!!

