



AUSTRALIA

CMT SURVIVOR'S GUIDE

a resource for living life your way



CMT Survivor's Guide

provided by the

**Charcot-Marie-Tooth Association
&**

adapted with permission for Australia

by

CMT Australia



You are likely reading this because either you or a loved one has been diagnosed with CMT. Learning about CMT for the first time can be difficult, but it is important to know that you are not alone.

This 'Survivor's Guide' is just one of the things we do to come together, share, grow, and inform. Our Goal is to not just survive, but to thrive, and we want you to thrive too.

We are not alone.

This guide contains Seven Survivor Tips we wish we had known when we first received a CMT diagnosis.

CMT Australia thanks the Charcot-Marie-Tooth Association for their kind permission to adapt it for Australian use. We have included links useful for the Australian context.



Learn Everything

If you have this guide in your hands, then you are already unique in the world of CMT. About one out of every 2500 people in the world has CMT, but most do not have a proper diagnosis. Many do not even know they have CMT.



Now that you know you have CMT, you can become informed about what it is, how it may progress, and what you can do.

You will need to learn about genetics, inheritance, and your particular type of disease. Typically inherited, CMT can also appear spontaneously for the first time in a family. A good place to start learning about CMT is through genetic counseling. Think of this as your own private genetics lesson, where you learn what these diseases are, where they come from, and how they are passed down from generation to generation.

We suggest early genetic counseling because it can also help you avoid some costly CMT tests that may be unnecessary, given your family's history.

You Can **About** CMT

Survivor Tip #1

Three important facts to know:

- CMT is a group of inherited disorders which affect the peripheral nerves, the nerves outside the brain and spinal cord. [Click here](#) to learn what CMT is.
- There are over 100 different known genetic causes of CMT and each year we discover more. However, the vast majority of people have one of five types, caused by mutations in one of four genes. If possible, try to learn your type of CMT! [Click here](#) to learn more about different types of CMT.
- Everyone's CMT symptoms, strengths and weaknesses may be different. Each case is unique. Do not consider anyone else's experience with this disease as likely to be the same experience as yours, even in the case of close family members.

You will quickly become more of an expert than many doctors! Doctors have to treat thousands of potential diseases. You get to focus on one. If you start studying CMT, attending support groups, connecting with the CMT community, then you will quickly learn and know much more than your typical doctor about this disease. This is a good thing. Knowledge is power.

[Click Here to Read About Genetics and Inheritance](#)

[Click here to read about Genetic Testing in Australia](#)

Take Control,



When you have CMT, it is tempting to wait until something gets really bad before you seek assistance. That is, you keep walking until it gets so painful or so difficult that you decide you finally need to go for help.

This is a bad idea. There are some early interventions that are really useful.

For example:

- Learning exercises to maintain strength before you lose it.
- Getting shoe inserts to adjust your gait before you feel pain.
- Wearing braces to assist in correcting your gait and improving your balance before you “really need them” to walk.

Exercise
to gain strength
before you
lose it.

Be Proactive

Survivor Tip #2

There is real value in having an expert in orthotics (orthotist), who has seen a LOT of CMT patients watch you walk, examine your gait, and see if you could use correction. Otherwise, the risk is you will walk for years and years in a way that damages your feet unnecessarily.

This is a lesson many of us learn the hard way. If you have CMT, be proactive in seeking assistance regarding how you walk. Walking puts tremendous stress on your feet, and sometimes a simple shoe insert can mean the difference between painful and pain-free walking.

It is hard to recognize the peculiarity of your own gait, or of your child's gait, without training. Even though you think you are walking perfectly normally, a specialist may notice something correctable right away. If your walk hasn't been examined in the last couple of years, it may well be time to see a CMT-savvy orthotist.

For referrals to a good orthotist, look to the [CMT Australia Website](#) or [CMT Australia Support Group Coordinator](#). Be willing to take the time to find an expert.



ACT NOW!

FIND HELP

Be Kind

CMT is described as causing peripheral neuropathy. This simply means that the peripheral nerves are damaged. Peripheral means the outlying areas or the edge, and your peripheral nerves are any of the nerves OUTSIDE of your brain and spinal cord. Given that the peripheral nerves start out at your spinal cord, it should be no surprise that your feet and hands, the farthest from your spinal cord, are usually the first areas to display symptoms of CMT.

People with good CMT survival skills learn to view all foot problems as potentially dangerous, to prevent them if possible, and to seek podiatric care immediately if they occur. Foot care is essential for CMT survival.

Neuropathy can cause numbness, burning pain, and the inability to feel pain, heat, or cold. CMT may cause you to lose sensation in your feet, and foot care takes on an entirely new

dimension. You may not feel an injury to your foot, and you have to become acutely aware of the state of your feet using inspection (looking at your feet). Without inspection and proper care, serious problems, such as pressure ulcers and sores, can occur and go undetected. Infection may go unnoticed and appropriate care may be delayed, leading to potentially severe consequences.

If you are losing the sensation of pain in your feet, then you need to become serious about foot-care tips and techniques.

[Read more about CMT and your feet!](#)

You may feel sharp, shooting, or burning pain from CMT that is not directly related to a physical injury.

[Click here](#) to read Dr. Scherer's article on managing neuropathic pain.



Shoes

Appropriate footwear is important for people with CMT, but many patients struggle to find well-fitting shoes because of their high-arched feet and hammered toes. For this reason, custom-made shoes may be necessary. You may want to see a podiatrist, who can assess your feet, and where appropriate, design special inserts for ready made shoes, or custom make shoes for you. [Click here](#) for a list of podiatrists

If you have custom inserts, orthotics, or braces, remember to REMOVE THE INSERT that comes with the shoe before you put your brace or insert into the shoe. You would be surprised how easy this is to forget.

Rubbing

Frequently, people who get new braces won't wear them because of rubbing. Don't delay. If your braces are rubbing and causing blisters or sores, go back to your orthotist as soon as possible. The adjustment is likely covered in your original fee if you move quickly. Frequently, just a minor alteration can alleviate rubbing and unnecessary blisters.

Other people with CMT have learned how to become experts in applying Molefoam and other anti-rubbing padding. But first work with your foot specialist to prevent sores, blisters, and wounds. Just because you can't feel it doesn't mean it isn't a serious problem.

Connect with the

For you or a loved one, being diagnosed with CMT can be frightening, confusing, and overwhelming. Although family members will be supportive, there is tremendous power in connecting with others who are going through the same struggles.



"Does anyone else have trouble with opening jars?" "Am I the only one who trips all the time?" "My doctor said I should have a tendon transfer. Has anyone here had that surgery?"

These are the questions and conversations that occur every day on the [CMT Australia Facebook](#) page. We think they are invaluable.

Find a support group of others with CMT who know what you are experiencing. On a practical level, you have the opportunity to gather information about CMT from others who have gone through their own searches for answers. On an emotional level, you feel less alone and part of a larger family of nonjudgmental, supportive people who truly understand what you are feeling.

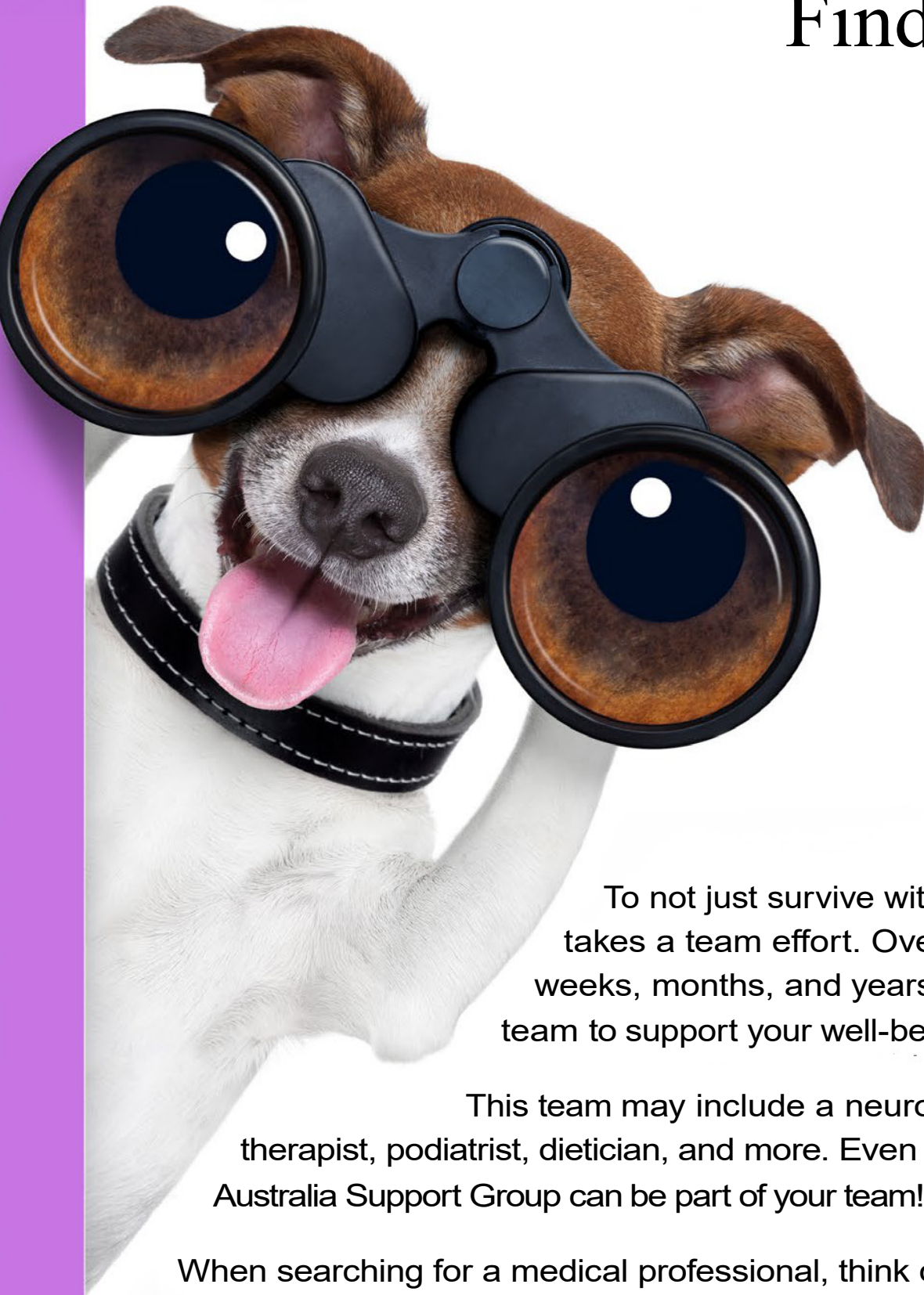
Often we don't experience the freedom to express ourselves in this way, even within our own families. Whether you have daily contact with others who have CMT, or simply touch base every once in a while, support groups provide an unspoken feeling of love and understanding, and we all need to feel less alone. Don't let CMT isolate you.

Reach out and meet the CMT community members face-to-face. The CMTA provides opportunities to make connections, share stories and be inspired.

Here is a summary of a few key ways to connect:

- [Find or Start a Local Support Group](#).
- Become a CMT Australia Member and receive the newsletter!
- Connect with CMT Australia on Social Media:
 - ◆ Follow CMT Australia on [Instagram](#), [Facebook](#), and [Twitter\(X\)](#)
 - ◆ Parents - check out the CMT Parents page on our [website](#)
 - ◆ Youth - Join [CMT Aussie Kids](#) Facebook Group [Follow us](#) on Instagram.

Find a Good



To not just survive with CMT, but thrive, takes a team effort. Over the coming weeks, months, and years, YOU will craft a team to support your well-being.

This team may include a neurologist, physical therapist, podiatrist, dietician, and more. Even your local CMT Australia Support Group can be part of your team!

When searching for a medical professional, think of it like shopping for shoes. People with CMT know that it can take a long time to find the right pair of shoes, and you may have to try on several before you find one that fits. Likewise, it can take a long time to find the right doctor or professional for you and your needs.

Good places to look for people to be a part of your team:

- [CMT Australia Support Groups](#): Members in your local CMT Support Group will share stories about competent and supportive providers.
- CMT Australia Conferences and Virtual Meetings: Guests who speak at our conferences and virtual meetings are highly informed about issues of CMT. CMT Australia hosts a national conference each year in different cities, as well as zoom meetings with experts in their fields on different topics related to living with CMT. An expert you enjoy listening to may be a good expert to visit. All CMT Australia conferences are available [here](#) to view. *(note: recordings from 2017 - present are only available for members to view)* and you can read about future events on the [website](#).

You are the ultimate judge of your CMT providers. Are they helping you deal with this disease or not? Just because there currently isn't a cure doesn't mean there are not dramatically better and worse ways of dealing with this disease and fighting back.

Practice **Exceptional** Eating

Ground turkey (or chicken) is a great substitute for ground beef to cut down on saturated fat and calories. Reminder: Because of the lower fat content, ground poultry often ends up drier than beef, but a few tablespoons of chicken stock can solve the problem in a snap!

Replacing the fat and sugar in icing with marshmallow achieves the perfect consistency with many fewer calories. While two tablespoons of marshmallow has just 40 calories and 6 grams of sugar (and no fat), the same amount of conventional icing can pack up to 100 calories, 14 grams of sugar and 5 grams of fat.

Bacon is often the go-to for that smoky flavour in savoury dishes (and even in some sweet ones). But opting for a few slices of prosciutto or pancetta can help cut both calories and fat. While bacon has about 70 calories and 6 grams of fat for two slices, prosciutto has just 30 calories and 4 grams of fat in an equally weighted sample.

Use Greek yogurt for sour cream. It has half the fat and calories, yet the taste and texture are virtually identical. Plus, nonfat Greek yogurt offers an extra dose of lean protein.

Substitute olive oil for butter when cooking eggs. This simple switch is a great way to cut down on saturated fats while getting a healthy dose of essential omega-3 fatty acids.

Using applesauce in place of sugar can give the necessary sweetness without the extra calories and, well, sugar. While one cup of unsweetened applesauce contains only about 100 calories, a cup of sugar can pack in more than 770 calories

While couscous is made from processed wheat flour, quinoa is a whole-grain superfood packed with protein and nutrients. Bonus points: they have almost the exact same texture.

& Exercise Habits

Survivor Tip #6



There is no magic nutritional diet to treat CMT, but it is important for CMT patients to control their weight. Not only does extra weight make physical activity more difficult, but it also increases the stress on already compromised joints and muscles.

It is also important for patients to maintain as much strength and flexibility as possible. Moderate activity and regular exercise can be tremendously beneficial. Generally, patients should consult a physical therapist or physician before beginning an exercise program and take care to avoid overwork and injury.

Leverage

A large, vibrant pink flower is held in the palms of several hands. The hands are positioned around the flower, with fingers spread, and all the visible fingernails are painted a bright red color. The background is a plain, light color.

Surgery is not a miracle cure, but it has the potential for life-changing outcomes.

If you have been proactive, kind to your feet, received proper bracing, done your exercises and you still have significant loss of foot or hand ability, there are potentially life-changing options. For some in our community, surgery has meant the difference to being confined to a wheelchair and walking a half-marathon.

Surgery When Necessary

Survivor Tip #7

Most of the deformities seen in the hands and feet are caused by unequal muscle balance. As the nerves lose function, the muscles atrophy in response to the loss of stimulation from the nerves. The feet and hands, having the longest nerves, lose strength first. The high arch is pulled up by unequal muscle pull. Normally, in the body, one muscle opposes another. In the CMT foot, for example, the muscle on the top of the foot remains strong after the one on the bottom has atrophied, so the stronger muscles pull the arch of the foot upward.

Hand and Foot Surgery

The final decision a patient might make in caring for his/her foot or leg deformities is to have surgery. Many patients choose to stabilize their feet or correct progressive problems. These procedures include straightening and pinning the toes, lowering the arch, and sometimes fusing the ankle joint to provide stability. Recovery from these surgeries can be long and sometimes difficult. Before considering surgery, a patient should always ask what the benefits are and weigh them against the risks.

After Surgery Tips:

KEEP DOING NUMBERS 1 THROUGH 6. Surgery is not a miracle cure. Most patients still require some type of orthotic bracing, manual therapy, and exercise plans. These may well be the difference between short- or long-term successful outcomes.

Survivors for Treatments

It is easy to feel powerless in the face of a disease like CMT.
Gain power back by joining the CMT Australia in the active fight against CMT. Gain power back by helping find a cure.

CMT Australia supports research to identify treatments and cures for CMT.
Fight with us!

Survivors can join together for a common cause: "A world without CMT!"

[Click here to learn how you can get involved!](#)

Search and Cures

**Bonus
Tip**





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