



CMTA

CMT SURVIVOR'S GUIDE
a resource for living life your way



CMT Survivor's Guide provided by the Charcot-Marie-Tooth Association

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.

Thousands of us from around the globe have banded together to form the Charcot-Marie-Tooth Association. This "Survivor's Guide" is just one of hundreds of 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. In fact, we are even leading the way toward treatments and cures!

We are not alone.

We join hands with researchers, scientists, doctors, orthotists, business leaders, and others to make life better and to accelerate scientific research in the search for treatments and cures.

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

Learn Everything You Can About CMT

**Survivor
Tip #1**

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.

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 70 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 Learn How to Get Genetic Testing Cheaper](#)

[Click Here for a List of Medications that May Worsen Neuropathy](#)

Take Control, Be Proactive

Survivor Tip #2

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.

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 your nearest [CMT Center of Excellence](#) or [CMTA Support and Action Group Facilitator](#). Be willing to take the time to find an expert.

ACT NOW!

FIND HELP

Be Kind to Your Feet

Survivor Tip #3

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 THIS LIST.](#)

[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. Large shoe stores often have pedorthists on staff who are certified in fitting shoes for the special foot. They can cast the foot for custom-made shoes or design inserts to make ready-made shoes fit more correctly.

Many members like New Balance shoes for off-the-shelf choices. If you are willing to order shoes, consider Aetrex. Aetrex is a leader in both shoes and orthotics, and is also a partner with the CMTA. They have offered an incredible promotion to our community for 2014. All new Premium Members of the CMTA will get a coupon for FREE shoes!

[Click here for details.](#)

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.

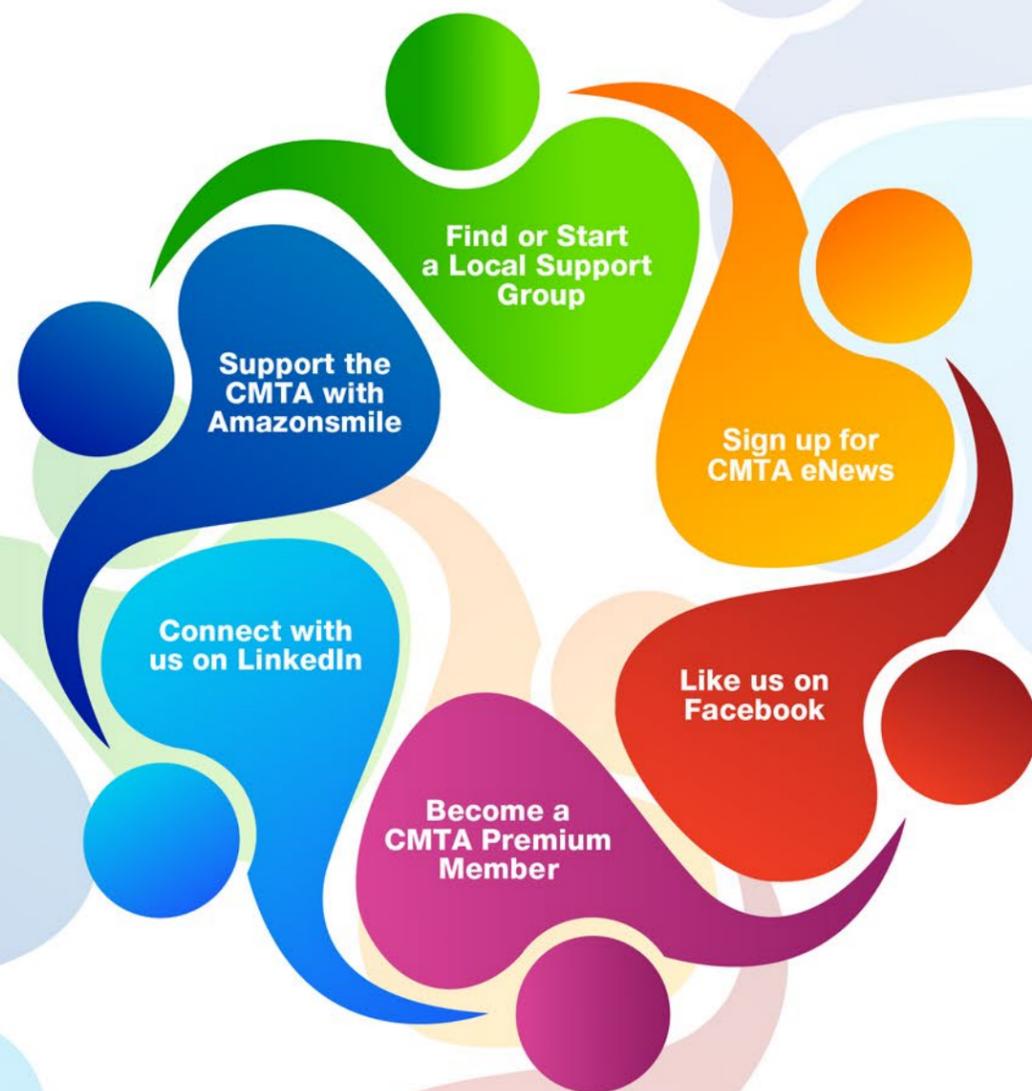
Other people with CMT have learned how to become experts in applying Molefoam and other anti-rubbing padding. But first work with your foot specialist to prevent sores, blisters, and wounds. Just because you can't feel it doesn't mean it isn't a serious problem.



Connect with the CMT Community

Survivor Tip #4

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.



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.

The CMTA sponsors over 67 Support and Action Groups in North America where you can physically meet people in your local community with CMT. In addition, we sponsor special conferences and events. To be informed about special events, connect with our [Facebook Page](#) and [sign up for CMTA eNews](#).

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 & Action Group](#).
- [Watch this video](#) and be inspired to attend!
- Become a [CMTA Premium Member](#) and receive the printed newsletter!
- Connect with the CMTA on Social Media:
 - [Like us on Facebook](#).
 - Join the [CMTA Group](#) on Facebook.
 - Parents—Join the [CMTA Parents Group](#) on Facebook!
 - Youth—Join the [CMTA Youth Group!](#)
 - [Follow us](#) on Twitter.

“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 in the [CMTA Facebook Group](#). We think they are invaluable.

Find a **Good** Neurologist/**Support Team**

Survivor Tip #5

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

- [CMT Support and Action Groups](#): Members in your local CMT Support and Action Group will share stories about competent and supportive providers.
- CMTA [Conferences](#) and [Webinars](#): Guests who speak at our conferences and webinars are highly informed about issues of CMT. The CMTA hosts patient conferences each year in different cities, as well as monthly webinars 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 CMTA webinars are available on the CMTA website and you can hear about future webinars by signing up for eNews.
- [CMT Centers of Excellence](#): One of the best ways to find a physician who knows CMT is by going to a CMT Center of Excellence. The Centers of Excellence have been established to ensure that CMT patients are provided with high-quality medical care. Patients will be evaluated in a uniform manner, and the information that is gathered will provide valuable data for clinical research in CMT.

The Centers of Excellence are funded by both the Charcot-Marie-Tooth Association and the Muscular Dystrophy Association. These Centers have been chosen because of the quality and experience of the doctors.

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. Shop, and keep shopping, for a team that will truly support you in this battle.



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 CMTA Support and Action 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.

Practice **Exceptional** Eating & **Exercise** Habits

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 frosting 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 frosting can pack up to 100 calories, 14 grams of sugar, and 5 grams of fat.

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.

Bacon is often the go-to for that smoky flavor in savory 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 in an equally weighted sample.

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.

**Survivor
Tip #6**



There is no magic nutritional diet to treat CMT, but it is important for CMT patients to control their weight. Obesity is an epidemic in the United States, which means it is also an epidemic in our CMT community. 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.

We have a vibrant CMTAthletes community for those who are active or who are seeking to become more active. Join the [CMTAthletes Facebook Group](#) today and be inspired to take steps toward a healthier you!

Leverage **Surgery** When **Necessary**

Survivor Tip #7



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 between being confined to a wheelchair and walking a half-marathon.

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 Search for Treatments and Cures

Bonus
Tip

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

In 2008, the CMTA launched [STAR \(Strategy to Accelerate Research\)](#) to capitalize on breakthroughs in drug discovery, genetics, and research. Together, we have dramatically increased the pace of CMT research and gained international recognition as a model for patient-led research; STAR is getting noticed, supported, and praised worldwide. This initiative is our best hope for finding treatments and cures for CMT.

We have reached major milestones in CMT research and are close to the first human pharmaceutical trials. We have galvanized our researchers and accelerated the pace of research. We committed \$1,000,000 to research in 2013 alone and, with your help, 2014 will set a new record.

The CMTA is leading the most advanced and collaborative research anywhere 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!](#)





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