

Emotional health and CMT2C

Grief, uncertainty and finding support. About 6 minutes to read · Last updated October 2026

At a glance

Living with a condition like CMT2C is not only physical. It is emotional too, and the feelings it brings are normal. This guide covers grief, living with uncertainty, focusing on what you can control, and finding support.

Grief is a normal response

Being told you have a progressive condition is a heavy thing to carry. Many people grieve: for abilities that have changed, for the ease of moving they once had, or for the life they had pictured.

Researchers who study long-term illness describe “chronic sorrow”: grief that comes back in waves, often when something changes or a new adaptation is needed [144]. Feeling this way does not mean you are coping badly. You can let yourself feel it without judgment or guilt.

Living with uncertainty

One of the hardest parts of CMT2C is how much it varies. The type of symptoms, when they start and how severe they become cannot be accurately predicted, even by experts [6]. Not knowing is stressful, and researchers who study long-term illness describe living with continual uncertainty as a real part of the experience [145]. The mind tends to fill the gaps with worst-case pictures.

A way to picture it

Uncertainty is like driving in fog. You cannot see the whole road, but you can see the next stretch clearly, and that is enough to keep going safely.

Having words for this helps. Why CMT2C is so hard to live with describes illness uncertainty, anticipatory anxiety and other hidden parts of life with CMT2C, with phrases you can use to explain them to the people around you.

Focus on what you can control today

When worry about the future builds, it can help to come back to the present. You cannot control what your nerves will do in ten years, but you can choose what you do today:

- Whether you do your stretches.
- How you set up your home to be safe and easy.
- What you eat and how you rest.
- Who you let into your support system.

Small, concrete daily actions take some of the power away from worries about the future. The 90-day action plan is one place to start.

Build your support system

CMT2C is rare: Orphanet lists it at fewer than 1 in 1,000,000 people [1]. Being the only person you know with it can feel isolating, and connecting with people who understand the daily reality of braces, breathing checks and a changing body can make a real difference.

Charcot-Marie-Tooth Association (CMTA)

Runs a monthly virtual emotional support group [148], local branches that act as support groups [110], and youth programs [111], and welcomes people with every type of CMT.

[Visit cmtausa.org](https://www.cmtausa.org)

Hereditary Neuropathy Foundation (HNF)

Has a dedicated CMT2C page, runs the GRIN patient registry and offers practical resources for daily life [2].

[Visit curecmt.org](https://www.curecmt.org)

CMT Research Foundation (CMTRF)

Funds research toward treatments and brings patients and researchers together at its yearly convention [116].

[Visit cmtrf.org](https://www.cmtrf.org)

TRPV4 peer group

A Facebook group for people with TRPV4-related conditions, including CMT2C, SPSMA and congenital distal SMA [105].

[Visit the group on Facebook](#)

More are listed on [Organizations supporting CMT](#).

Professional support

Managing appointments, insurance and daily physical limits can feel like a part-time job, and it is tiring. A review of 20 studies found that people with CMT tend to have more depressive symptoms and lower quality of life than the general population [146]. In the Italian CMT registry, depression was five times as common as in a comparison group (10% compared with 2%), and about half of those affected were not receiving medication for it [147]. A licensed therapist or counselor, ideally one who lists chronic illness or disability as a specialty, gives you a neutral space to talk without worrying about burdening your family. You can ask your neurologist or family doctor for a referral, and the Mental Health Hub of the Muscular Dystrophy Association explains how to find support and providers [149].

Pain and mood affect each other. [Pain and mental health](#) covers the kinds of pain in CMT, medicines and non-drug options such as mindfulness-based stress reduction.

If you are in crisis

If you are thinking about harming yourself, contact your local emergency number now, or one of the lines below. You do not have to cope with this alone.

Call 112

The emergency number anywhere in the EU

Call 988

In the US: the 988 Suicide and Crisis Lifeline

Text 988

In the US: the 988 Suicide and Crisis Lifeline

Numbers checked against the European Commission's 112 page [158] and the 988 Lifeline's site [150].

Your emotional toolkit

- ✓ **Accept your feelings.** Grief, anger and frustration are natural responses to a progressive diagnosis. You do not have to force yourself to be positive.
- ✓ **Come back to the present.** When worst-case pictures crowd in, turn to the things you can do today.
- ✓ **Get specialist support.** Your mental health matters as much as your physical health. A counselor who understands chronic illness can help with medical burnout.
- ✓ **Connect with the community.** Patient organizations and peer groups put you in touch with people who understand life with CMT.

Sources for this guide

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- [158]** European Commission. “112: the EU's emergency phone number” (Shaping Europe's digital future; accessed 10 October 2026). digital-strategy.ec.europa.eu

Full details of every source are on the [Sources](#) page. This guide is patient-written education, not medical advice.