

Your 90-day action plan

From diagnosis to looking after yourself, step by step. About 6 minutes to read · Last updated October 2026

At a glance

When you are ready to move from taking in the diagnosis to actively managing it, this plan breaks the first three months into small steps. Go at your own pace: the days are a guide, not a deadline.

Days 1 to 30 · steps 1 and 2

Know your starting point

Baseline checks and a medicine review

Days 30 to 60 · step 3

Build a daily routine

Stretching and gentle exercise with your therapist

Days 60 to 90 · step 4

Make home and life easier

Fall-proof your home, then connect with others

1 Days 1 to 30: know your starting point

Baseline tests show where your body is today, so you and your doctors can spot changes later. The yearly checks recommended for TRPV4-related disease are [6]:

- Breathing tests (spirometry), and a sleep study, to check the diaphragm and breathing at night. Ask for the breathing tests both sitting and lying down, and for carbon dioxide to be measured at night as well as oxygen: a sleep study built for sleep apnea can read weak breathing as apneas and lead to CPAP, which does not help weak breathing muscles [288].
- A laryngoscopy by an ear, nose and throat (ENT) specialist to see how your vocal folds move.

- A hearing test.
- A physical therapy assessment of your strength, flexibility and feet, to see whether braces or insoles would help.
- A check of the spine, hips and joints.

The care team guide explains who does each of these.

If your genetic result is not confirmed yet, ask about genetic testing. Trials recruit by genetic subtype, so a confirmed result is essential if you want to take part in research [53].

2 Days 1 to 30: review your medicines

Bring your neurologist or pharmacist a list of everything you take, including prescriptions, over-the-counter medicines, vitamins and supplements.

- The Charcot-Marie-Tooth Association (CMTA) lists two medicines with evidence-backed potential for harm in CMT: the chemotherapy drugs vincristine and paclitaxel [35]. Medication decisions should be made with your healthcare provider [35].
- Too much vitamin B6 can itself damage nerves [58]. Add up the B6 in every multivitamin and “nerve support” product you take.
- A large review found no convincing evidence for warnings on other drugs, and stressed that people with CMT should not be denied effective treatments [36].

3 Days 30 to 60: build a daily routine

Physical therapy for CMT is about keeping muscles and joints working well and preventing problems such as tight tendons, not about lifting very heavy weights [65].

- Ask your physical therapist for a short daily stretching routine. Daily heel cord (Achilles tendon) stretching is part of standard care for TRPV4-related disease [6].
- Add moderate strengthening and balance work that suits you. These appear safe and helpful in CMT, while high-intensity training is discouraged [56].
- Start small. A routine you can keep every day matters more than a hard one you drop. Ideas for making it stick are in the Movement guide.

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Days 60 to 90: make home and life easier

CMT changes balance and how the feet clear the floor. In the TRPV4 registry, 79% of people had difficulty with balance [3]. A walk-through of your home and workplace, using a checklist like the one from the US Centers for Disease Control and Prevention, can make falls less likely [151]:

- Remove loose rugs, or give them a non-slip backing, and coil or tape cords against the wall.
- Add lights at the top and bottom of stairs, and night lights on the way to the bathroom.
- Fit handrails on both sides of the stairs, and grab bars in the bathroom.
- If hand weakness makes buttons or utensils hard to use, ask an occupational therapist about adaptive tools [152].

Then reach out. The CMTA, the Hereditary Neuropathy Foundation and the CMT Research Foundation all welcome people with CMT2C, and there is a peer group just for TRPV4 conditions. See [Organizations supporting CMT](#).

Your 90-day checklist

- ☐ **Breathing tests booked.** Baseline breathing and diaphragm strength, and a sleep study.
- ☐ **ENT check booked.** Baseline vocal fold movement.
- ☐ **Hearing test booked.**
- ☐ **Medicines reviewed.** Everything you take, checked with your neurologist or pharmacist.
- ☐ **Genetic result confirmed.** Or a test arranged.
- ☐ **Braces considered.** If you trip or have foot drop, ask about seeing an orthotist, who makes braces such as ankle-foot orthoses.
- ☐ **Daily routine started.** Stretching agreed with your physical therapist, focusing on heel cords.
- ☐ **Home walk-through done.** Rugs, cords, lighting and rails.
- ☐ **Connected with others.** A patient organization, a registry or a peer group.

Sources for this guide

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- [152]** Charcot-Marie-Tooth Association. “Occupational Therapy Can Help Your Hands Keep Working” (Simply CMT, 1 May 2026). [cmtausa.org](https://cmtausa.org/occupational-therapy-can-help-your-hands-keep-working/)
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Full details of every source are on the [Sources](#) page. This guide is patient-written education, not medical advice.