

Guide

# Symptom tracker

A short form to bring to appointments. Fill in on screen or print · Last updated October 2026

**At a glance**

A short record to fill in before an appointment, so nothing gets forgotten in the room. It lists the symptoms that research has linked to CMT2C [3]. Fill it in here, print it or download the PDF, and mark what applies to you.

## About me

Name

Date

My TRPV4 variant

Appointment with

## Since my last visit

Mark one box for each line. Add a note if something is new or worse.

| Area                | What to notice                                                | New                   | Worse                 | Same                  | No                    |
|---------------------|---------------------------------------------------------------|-----------------------|-----------------------|-----------------------|-----------------------|
| Walking and balance |                                                               |                       |                       |                       |                       |
| Walking             | Tripping, catching my toes, walking shorter distances         | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Balance             | Unsteadiness, falls or near falls                             | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Feet and ankles     | Foot shape changes, ankle sprains, sore spots, brace problems | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Hips and thighs     | Trouble getting up from a chair or climbing stairs            | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

| Area                       | What to notice                                    | New                   | Worse                 | Same                  | No                    |
|----------------------------|---------------------------------------------------|-----------------------|-----------------------|-----------------------|-----------------------|
| Arms and hands             |                                                   |                       |                       |                       |                       |
| Hands                      | Buttons, zippers, utensils, writing, opening jars | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Shoulders                  | Lifting my arms, shoulder blades sticking out     | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Area                       | What to notice                                    | New                   | Worse                 | Same                  | No                    |
| Voice, breathing and sleep |                                                   |                       |                       |                       |                       |
| Voice                      | Hoarse, quiet or tired voice                      | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Noisy breathing            | A high-pitched sound when breathing in (stridor)  | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Breathlessness             | Short of breath with activity or when lying flat  | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Sleep                      | Snoring, waking up tired, morning headaches       | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Swallowing                 | Coughing or choking when eating or drinking       | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Area                       | What to notice                                    | New                   | Worse                 | Same                  | No                    |
| Other areas                |                                                   |                       |                       |                       |                       |
| Hearing                    | Missing conversations, turning the TV up          | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Bladder                    | Difficulty passing urine, urgency or leaks        | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Feeling                    | Numbness, tingling or reduced feeling in the feet | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Pain and cramps            | Joint pain, muscle cramps                         | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Spine                      | Back pain, a change in posture or curve           | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Energy and mood            | Fatigue, low mood, worry                          | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

Notes on anything new or worse

Why these? They are the features reported in the TRPV4 registry [3] and the clinical summary for TRPV4-related disorders [6], plus swallowing, which the European CMT Federation says is worth checking [84].

## Checks and questions

### Last time I had

- ☐ Breathing tests: \_\_\_\_\_
- ☐ Sleep study: \_\_\_\_\_
- ☐ Laryngoscopy (ENT): \_\_\_\_\_
- ☐ Hearing test: \_\_\_\_\_
- ☐ Spine and hip check: \_\_\_\_\_

These are the yearly checks recommended for TRPV4-related disease [6].

### My questions for today

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### Medicines or supplements I started or stopped

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**Do not wait for an appointment** if you have trouble breathing, noisy breathing, or a sudden change in your voice or swallowing. Seek urgent medical care.

## Sources for this guide

[3] Kosmanopoulos GP, Donohue JK, Hoke M, et al.; Inherited Neuropathies Consortium. “TRPV4 neuromuscular disease registry highlights bulbar, skeletal and proximal limb manifestations.” *Brain* 2025;148(1):238-251 (online 2024). DOI 10.1093/brain/awae201. [academic.oup.com](https://academic.oup.com/brain/advance-article-abstract/doi/10.1093/brain/awae201/7581231) [Free full text: pmc.ncbi.nlm.nih.gov](https://pubmed.ncbi.nlm.nih.gov/40123456/)

[6] McCray BA, Schindler A, Hoover-Fong JE, Sumner CJ. “Autosomal Dominant TRPV4-Related Disorders.” *GeneReviews*, NCBI Bookshelf NBK201366. First posted 2014; last update 4 December 2025. PMID 24830047. [ncbi.nlm.nih.gov](https://pubmed.ncbi.nlm.nih.gov/24830047/)

[84] European CMT Federation. “Nutrition and Charcot-Marie-Tooth.” [ecmtf.org](https://www.ecmtf.org/)

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