

Building your care team

Who does what, and what to expect at each visit. About 8 minutes to read · Last updated October 2026

At a glance

CMT2C can affect the feet, hands, voice, breathing, hearing and skeleton, so good care is team care, with checks once a year [6]. This guide explains who does what and what to expect at each visit, and gives you a checklist to keep track of who you have seen.

Why a team?

Care for TRPV4-related disease is multidisciplinary: it can involve specialists in neurology, rehabilitation medicine, orthopedics, hearing, voice and the lungs, as well as physical and occupational therapists [6]. There are no published clinical guidelines for CMT2C yet, so current recommendations come from the experience of the clinicians who see the most patients [6].

A way to picture it

Think of your neuromuscular neurologist as the captain of a team. Each specialist looks after one area, and the captain keeps everyone working from the same plan.

How care usually comes together

1

Your family doctor

Notices the pattern of symptoms and refers you to a neurologist. Bring a list of what you have noticed: the symptom tracker can help.

2

Neuromuscular neurologist

Examines you and arranges nerve tests. In CMT2C these usually show smaller nerve signals that travel at normal speed [6].

3

Genetic testing and counseling

Confirms the *TRPV4* change. Genetic counseling is recommended to talk through what it means for you and your family [6].

4

Baseline checks with specialists

Your voice box, breathing, sleep, hearing, feet and skeleton are checked, so changes can be spotted later [6].

5

Yearly review

The same checks are repeated once a year, and weight and height are measured at each visit [6].

A **CMT Center of Excellence** can bring many of these specialists together in one clinic. The Charcot-Marie-Tooth Association (CMTA) keeps a directory of these clinics in the US and internationally, and the clinics offer specialist diagnosis, genetic counseling and multidisciplinary care [85]. If you can get to one, I think it is worth making a priority: see the [full list of centers](#).

Who does what

Neuromuscular neurologist

Role: the specialist in diseases of nerves and muscles. Confirms the diagnosis, tracks changes over the years and coordinates the rest of the team [6].

What to expect: a detailed examination of strength, reflexes and feeling, plus nerve conduction studies and EMG, which measure how well nerves and muscles carry signals [6].

Ask about: which yearly checks you need, and whether there are research studies you could join [53]. The CMTA keeps a directory of clinicians with CMT experience [128].

Lung specialist (pulmonologist)

Role: monitors breathing, because CMT2C can weaken the diaphragm [6]. Some lung specialists focus on breathing weakness caused by neuromuscular disease. They are not available everywhere, but if one is within reach, it is worth asking for a referral.

What to expect: breathing tests (spirometry), sometimes chest X-rays taken while you breathe, and a sleep study [6]. If the breathing muscles are weak, what helps is night-time ventilation: a bilevel (BiPAP) machine with a large enough gap between its two pressures, or a home ventilator [288]. CPAP is a different machine. It holds the airway open but does not help weak breathing muscles or treat the under-breathing they cause, so it is not the right choice when they are weak [307]. Some references still list “BiPAP or CPAP” together [6], so if you are offered CPAP, ask whether bilevel support or a ventilator would suit you better.

Worth asking for: breathing tests both sitting and lying down, carbon dioxide measured at night as well as oxygen, and a measure of how strong your cough is. These suggestions come from a review written for neuromuscular disease in general, not for CMT2C specifically [288]. The early signs of weak breathing are listed on the [Breathing and voice](#) page.

Oxygen alone is not safe: if you are ever treated in an emergency, tell the team that you have breathing-muscle weakness. Guidance written for other neuromuscular conditions warns that oxygen given on its own, without breathing support from a bilevel machine or ventilator, can hide or worsen a build-up of carbon dioxide [153]. Breathe with MD, Inc. says oxygen should never be given without constant monitoring of carbon dioxide [126].

Ear, nose and throat specialist (ENT or laryngologist)

Role: checks the voice box (larynx), because vocal fold weakness is common in CMT2C [6].

What to expect: a laryngoscopy, where a small camera looks at your vocal folds while you speak and breathe [6]. In the TRPV4 registry, 85% of people examined by an ENT specialist had vocal fold weakness, compared with 55% overall, so it is often missed until someone looks [3].

Works with: a speech-language pathologist, who can help with the voice [6].

Hearing specialist (audiologist)

Role: tests hearing once a year, because some people with CMT2C develop hearing loss [6].

What to expect: a hearing test in a sound booth. If hearing loss is found, hearing rehabilitation options are discussed [6].

Physical therapist (physiotherapist)

Role: keeps you moving safely. That includes daily stretching of tight heel cords (Achilles tendons), balance work, moderate strengthening and advice on braces [6].

What to expect: an assessment of strength, flexibility and walking, and a home exercise program. In CMT, moderate resistance and balance training appear safe and helpful, while very high-intensity training is discouraged [56]. A therapist who knows neuromuscular disease is ideal [65], and it is fine to ask whether they have worked with CMT before [127].

More detail is in the [Movement guide](#).

Occupational therapist

Role: helps with everyday tasks. In the same registry, 49% had difficulty with buttons or zippers [3].

What to expect: ideas and tools that make daily tasks easier, such as button hooks, weighted utensils and jar openers, and sometimes hand splints, so you can stay independent [152].

Orthotist

Role: designs and fits braces. For CMT this is often an ankle-foot orthosis (AFO), a light brace that fits inside the shoe and supports the ankle to help with foot drop [6].

What to expect: measurements and a fitting visit. Custom braces can be made in plastic or carbon fiber [83], and boots or high-top shoes can add ankle stability [83].

Orthopedic surgeon

Role: looks after the bones and joints: foot shape, contractures (tight joints that no longer move fully), scoliosis and hips [6].

What to expect: X-rays and a discussion of options. Surgery is considered for severe high arches, contractures or scoliosis causing pain or affecting breathing [6].

Counselor or psychologist

Role: supports your emotional health. Living with a progressive condition is hard, and talking to someone who understands chronic illness can help. See the [emotional health guide](#).

Your care team checklist

Use this to keep track of who you have seen. It prints well, so you can bring it to appointments.

Specialist	Main role in CMT2C	Status	Name and contact
Neuromuscular neurologist	Diagnosis, tracking, coordinating care	☐ Need referral ☐ Booked ☐ Seen	_____ _____
Genetic counselor	Explaining the gene result for you and your family	☐ Need referral ☐ Booked ☐ Seen	_____ _____
Lung specialist	Breathing tests, sleep study, breathing support	☐ Need referral ☐ Booked ☐ Seen	_____ _____
ENT or laryngologist	Vocal fold check (laryngoscopy), voice and swallowing	☐ Need referral ☐ Booked ☐ Seen	_____ _____
Audiologist	Yearly hearing test	☐ Need referral ☐ Booked ☐ Seen	_____ _____
Physical therapist	Stretching, balance, moderate strengthening, brace advice	☐ Need referral ☐ Booked ☐ Seen	_____ _____
Occupational therapist	Tools and techniques for daily tasks	☐ Need referral ☐ Booked ☐ Seen	_____ _____
Orthotist	Braces such as AFOs	☐ Need referral ☐ Booked ☐ Seen	_____ _____
Orthopedic surgeon	Feet, spine, hips and joints	☐ Need referral ☐ Booked ☐ Seen	_____ _____

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