

Mother and daughter battle Charcot-Marie-Tooth, a disease that is damaging — and easy to pass on

[ABC Southern Qld](#)

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Vanessa Moore and her mother, Dagmara Foster, both have Charcot-Marie-Tooth disorder. *(ABC Southern Qld: Anthea Moodie)*

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It is the school sports carnival, you are an eager nine-year-old who is ready to run ... but your feet won't let you and you don't know why.

Key points:

- Charcot-Marie-Tooth disorder affects one in 2,500 Australians
- The debilitating disease is caused by a genetic defect impacting the nervous system
- It is the most common inherited neurological disorder but most people have never heard of it

What sounds like something from a nightmare is the harsh reality facing many Australians diagnosed with Charcot-Marie-Tooth (CMT) disorder.

CMT is a lifelong muscle wasting disease and the most common inherited neurological disorder, affecting approximately one in 2,500 Australians.

The likelihood of passing it onto future generations can be as high as 50 per cent.

This was the case for Dagmara Foster who passed it on to three of her six children.

But it was not until she reached her 40s that a diagnosis made her realise what she had experienced her entire life.

"I remember my dad had funny feet," Mrs Foster said.

"But back then they didn't know what it was.

"I knew I was a bit different because I kept falling over and tripping over nothing — I couldn't play sport!"

But it was through an examination of her nephew that led to Mrs Foster's late diagnosis.

"My brother has it as well and his wife wanted to go further because their son has it," Mrs Foster said.

"So, she took him to a specialist, and they rang and told me all about it. That's when I first found out what it was."

Unknown disease



Even having a disabled parking sticker can present problems for those with CMT. *(ABC News: Billy Draper)*

CMT is the "unknown disease" with most people not aware of the condition.

This is something that Vanessa Moore has experienced since she was young.

"I remember as a young child being in hospital and the doctor would put sandbags under my feet every day," she said.

"He'd say 'What's wrong with your feet?'"

"Somebody made a comment to me, 'Your feet are ugly'.

"To have somebody randomly say that to you is confronting. I've even had a lady threaten to ring up the police because of my disability car sticker.

"She took my number and said, 'You haven't got a disability, I'm going to ring the police!'"

Navigating CMT

CMT is caused by a genetic fault that impacts the nervous system.

The disease varies in degrees of severity from person to person with more than 50 types of incurable variations.

But discovering you have such a rare disease can put you on a dark and lonely path.

Back in 1988, a small group of volunteers came together to try to light the way for Australians with CMT by offering accurate information about the condition and how to live with it.

They created an organisation called CMT Australia, which uses its website, social media, newsletters and seminars to give sufferers information they often struggle to find for themselves.

President and treasurer Robert Twin said the most crucial form of support it offered was community.

"Just to let people know they're not alone," Mr Twin said.

"We call it the CMT family so people understand that there are others."

The organisation also actively reaches out to kids with the condition with an annual camp, CMT Aussie Kids, where young people with the disease share their experiences and how they cope with its impact on their lives.

While there is no cure, CMT Australia also raises funds for research into the condition where the biggest breakthroughs have been in discovering the cause of the disease.

"They're finding that it's actually often caused by a duplication within a chromosome or a missing part or a space where there shouldn't be a space," Mr Twin said.

"So that's going to potentially lead to a cure."

But until a cure is discovered, Mr Twin said what his organisation most wanted to get across to the community was that CMT symptoms would not always be obvious.

"Because of its effect on balance, we have people who are challenged even getting on and off a bus," he said.

"People often think they're inebriated. But that's not why they're struggling."

Many people with CMT carry walking sticks — not because they necessarily need them, but because when they use one, people view them differently.



Some people with CMT carry walking sticks to fend off misperceptions associated with their movements. *(ABC News: Margaret Burn)*

Positive outlook

While the disorder is debilitating and there is no known cure, Ms Moore had a positive outlook on life.

"I have to have reality checks," she said.

"I'll get pissed off that my feet and back hurt, and you live in a state of chronic fatigue, but you just get on with life and do it.

"It's not life-threatening. You can live with it."

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