

MDA Member Charcot Marie Tooth (CMT) Pain Management Suggestions

MDA members who live with CMT have chosen to share their experiences managing pain with others. When collating feedback it was identified that people with CMT have very variable presentations with regards to pain. Some people report no pain at all, while others struggle to keep on top of their pain levels with the medications that are available.

Stinging, aching and twitches are experienced by some, with aching being severe in some circumstances. Some of the reported pain was a side effect of falls or walking style indirectly affecting other parts of the body. It was identified that managing pain to ensure adequate sleep was important and that the timing of the night time medication can make a difference.

Medication

These are the medications that some members of the MDA with CMT are finding useful.

**Please be advised: None of these suggestions are meant to replace professional medical advice and any changes to your current medical management needs to be discussed with your Doctor.*

Comments and suggestions:

“Been using amitriptyline for a long time but try to keep it at a dose less than the prescribed dose but now find that I need to be topped up with gabapentin as the amitriptyline is wearing off sooner.”

Several people reported trying to avoid taking painkillers at all or only ‘taking the edge off’ with paracetamol or codeine generally at the suggested dose or as required.

Nortriptyline, amitriptyline, Gabapentin, Tegretol, were reported to affect people’s ability to concentration.

Care needed to be taken with the oxycontin and morphines are both narcotics and are addictive. Follow your doctor’s advice to avoid addition or overdose.

Paracetamol and tramadol were commonly mentioned being used in conjunction with each other to increase effectiveness.

“Gabapentin and Nortriptylene with tramadol when the pain increases.”

Naprosyn/naproxen used during the day with nightly paracetamol.

Gabapentine and amitriptyline for daily pain management.

Amitriptyline taken for night pain.

“A combination of tramadol, codeine phosphate, and amitriptyline and if the pain is really bad then oxycodone as well”

Alternative Therapies

Apart from medication, people with CMT also found a range of alternative things useful for managing pain. Some comments and suggestions are listed below:

Mindfulness - "I went through a mindfulness course with the pain clinic in Northshore hospital. Deter that runs the course can be contacted through the pain clinic Northshore hospital.

You need to keep an open mind with this course, as at first it sounds weird but by the time you finish the course you have a better understanding of yourself and your pain levels, it teaches a person to take back control of your own body and manage your pain with less drugs. I found it very interesting and took away a lot from it."

Talk to your Doctor about what is available to you in your area with regards to a pain clinic to assist you to manage your pain levels.

A good Osteopath.

Heat packs - one member specifically mentioned strapping the wheat packs to their ankles at night for this specific pain relief.

Night Strength Deep Heat.

Voltaren Emulgel.

Using a magnetic underlay on the bed.

Relaxation / breathing techniques, and visualisation / imagery techniques.

"I absolutely love Feldenkrais and think it has made a huge contribution to my wellbeing and I think reduced symptoms and I even think it is helping to prevent things getting worse. Even feeling in my lower legs and toes has improved. I would highly recommend it. My teacher is Janine Archer and she is fabulous." The Feldenkrais Method® is an educational system that uses movement to teach self-awareness and improve function. More information can be found here <http://www.feldenkrais.org.nz/>

Emotional Impact of CMT

It was also identified that some members with CMT may also be dealing with emotional pain, particularly around grief and loss. This type of pain is important to acknowledge and there are a range of suggestions for helping to cope with the emotional impacts of living with CMT.

Comments and suggestions:

Speak to your GP and discuss a referral or medication options available, for example:

- Psychotherapy or Counselling
- Anti-depressants
- Anti-anxiety medications

Access the MDA's 3 x 1hour free counselling service

Talk to your MDA Fieldworker

Join an MDA support group in your area

Find out more

These ideas were shared by New Zealanders with lived experience of CMT. If you want to find out more information about CMT, or any of the MDA services listed in this document, please visit www.mda.org.nz.