

Kelly

My day began with a severe toothache and my only panic was, "Do I need another root canal?" After a dental appointment, OPG scan and GP appointment, I was relieved to think I only had a sinus infection. After dinner, the headache began, but just on the left side - same as the toothache and sinus pain. So I applied heat and took brufen and it eased. For 5 minutes. And the headache continued to increase in severity, so I did what anyone else would do - called it a night to sleep it off. But the pain became intense, stabbing pain throughout my entire head. If someone split my head open, it would have been less painful. After 5 hours of suffering, it was off to the ED but frustratingly (and thankfully) the pain had gone but the attending initially diagnosed TN and prescribed Lyrica. I got back home and the pain was back. Thankfully the Lyrica (an anti-convulsant) eased the pain enough that I could sleep for a few hours. Happy Australia Day!

For the next few weeks, my daily routine now involved heat packs and crying on the couch after a sip of coffee, or a bit of cereal, caused stabbing pain in all the teeth on the left side. Then once it eased, I had to try to brush my teeth without setting off the pain again - no chance! You learn very quickly it's room temperature drinks/food or nothing, and eat on the other side..

After a couple days, my medication was doubled and the teeth pain and headaches became tolerable to minor. But now I was a zombie until at least 2pm everyday for several months which isn't great when you are an administration assistant/Manager. Not only was I a zombie, I lost words and had issues with my memory. I would have conversations with friends and family and could not simple words. Having been an avid reader and writing advices for clients, not only was this frustrating but disheartening. And I had to keep to do lists so I could remember what I was supposed to be doing. It got better with time - once I got used to the medication

Apart from medications, I also use alternative therapies - chiropractic, physiotherapy, acupuncture. My TN is paired with neck pain so adjustments take the pressure of any inflammation off the trigeminal nerve. But like any time you get a massage to relieve muscular pain, it'll either make it better or aggravate it, but if I don't do it... ? Maybe the pain will get worse and I fear that. Every day. That debilitating day 1 pain.

And my fear was realised. After lunch on Christmas Day. Imagine having to abruptly leave the table because of stabbing head and teeth pain, to find a place to sit and cry away from anyone. And seeing my family feeling absolutely helpless, which is even more heartbreaking. Don't I know how to bring the joy?!

I came across Botox as another alternative treatment. So for the last 2 years, every 3 months, I get 30-40 injections in my face, head, neck and sub-scapular region. I have to take the day off work because as you can imagine, being stabbed in the head that many times is painful - like walking through an active beehive - but having needles injected into already painful muscles and nerves can be excruciating and takes time to ease.

My diagnosis was eventually confirmed. The neurosurgeon showed me exactly where the nerve and artery are touching. He told me that this could have been in place since birth, so now I can understand how there are a young people suffering from this chronic condition - it's not something that people in the latter stages of their life get as was once believed.

Although I am fortunate enough to essentially live a normal life, I do have the odd day that I'm in too much pain to leave the house. Or I have leave work early because I can no longer tolerate the pain levels or I'm afraid that pain I'm starting to feel will build to the point of that day 1 level. Because stress is a trigger! I've had to leave bars and even a friend's wedding reception because the music was too loud and caused a flare-up of pain. And now I have been given an option to undergo surgery - inserting a sheet between the nerve and artery near the brain stem. Scary right?! It's not a light decision to be made, considering recovery and the immediate after effects of surgery.

I'm still learning what my triggers are - stress, bad posture, hot/cold drinks/food, spicy food, cold weather/wind and low pressure systems/storms. I used to love electrical storms - sitting on the deck watching the lightening. Now, I can taste the electricity and feel those lightning strikes in my head, pressure headaches. I only hope that I'm at home when they hit.

For most of winter, I had to wear a beanie and a knitted snood just to tolerate the outside. I would go for long walks in shorts and a crop with a beanie and a Fighting TN head skinz or snood - what a sight that was for anyone driving by! No, I'm not scouting out the neighbourhood. Even as the weather is warming up, that air-con on the bus is like an ice-cream headache so I'd much rather get looks for wearing a beanie in summer.

From a mental health perspective, it's easy to see why this is called the suicide disease. Any chronic pain is going to get you down. Add on medications that exacerbate depressive and suicidal feelings. And seeing how helpless family or your inner circle feel seeing you go through the symptoms, or being made to feel guilty by people who don't understand that today you just can't, adds to mental ill-health. This is why it is so important to raise awareness.

So my day to day now involves carrying around a pharmacy - pain medication (prescribed and OTC), Lyrica, muscle relaxants, Valium, anaesthetic creams/ointments/patches and numbing gel for gums, hand warmers, head skinz and ear plugs. Just in case. I have to put my employers on notice so I don't have to explain it when I need to leave suddenly. I carry a TN card with me to hand to medical practitioners if I'm taken to hospital.

I hope this has helped you understand this invisible condition. So next time your friend/family member with TN says they're in flare up, you don't get angry or frustrated that they're not attending yet another event or not immediately responding to calls/messages. Next time maybe you'll ask if you can bring them OTC medication or a meal or help out with mundane household tasks. Because there are brave warriors out there who are 100x worse than me and are bedridden, living in a cone of silence, silently suffering.