

LIVING WITH NARCOLEPSY (pre-diagnosis)

I have lived with narcolepsy since around the age of 8 or 9, possibly earlier. Although I began to have symptoms in my childhood, I wasn't diagnosed until I was 49, which is a long time spent being sleep deprived without an answer.

I never realised that how I felt in the morning wasn't normal because I didn't know that other people didn't feel exhausted when they woke up every day. Starting your day feeling as though you have been awake for at least 24 hours isn't great, but I somehow managed to keep doing that until 2013 when my brain had simply had enough and refused to let me get up anymore.

Why did my brain give up? Nerd alert time! Anyone who wants to skip the next paragraph and not read my attempt to provide a scientific explanation please feel free to do so.

What most people don't know is that our brains constantly go through stages while we sleep and each stage plays an important function. Deep, slow-wave sleep is when big, slow waves sweep through our brain to clean out all the misfolded proteins, unfolded proteins, and other things that get broken down and need to be rebuilt when we're asleep, as well as doing other really important things to restore us from a day of wakefulness. The expansion and contraction of the neurons work in unison, pushing the fluid through, and cleaning out any misfolded proteins or debris that might occur on the basis of these metabolic pathways to leave the brain in a state of more pristine action for the next day. People who have narcolepsy frequently enter REM sleep rapidly, within 15 minutes or less of falling asleep which means that our brains are missing out on the washout that occurs in the brain during sleep. The slow waves get smaller in everyone as we age, so for people with narcolepsy who have already had less slow-wave sleep than those who don't have narcolepsy, getting older impacts our cognition. And this answers why my brain decided to give up on me, for a while at least.

Between 2013 and 2017 I along with the help of my excellent GP looked at every possible reason as to why this debilitating fatigue and extreme sleepiness had taken over my life. I was sent for an overnight sleep study because I was aware that I snored and thought that perhaps the reason for my fatigue and daytime sleepiness was that I had sleep apnea. I did the sleep test, and the result came back negative. Rather than look at any other possible cause the sleep specialist told me to lose weight and stop smoking. Great, thanks for that advice.

I experienced what my neurologist referred to as a clinically isolated MS attack on my brain in 2013. I had deteriorated so much by this stage that I had to take leave from work. I was determined to find out what was happening to me because I wanted to get better and I wanted to be able to return to work. But my employer was not at all supportive.

But did this mean that my fatigue and unexplained extreme sleepiness was due to Multiple Sclerosis? Well, after a few years of seeing a neurologist and having a yearly MRI to check if there had been any further demyelination in my brain, that too was ruled out. As a side note, I would like to mention here that despite the fact that an MRI machine is extremely loud, I managed to have a great nap every time I had an MRI! Surely that alone would prove to my work (who were pressuring me to return) that I wasn't making this all up? But no, they continued to have me seen by various specialists and psychiatrists of their own over this period as well. I had numerous tests. Depression was ruled out, I didn't have chronic fatigue syndrome. Nobody had an answer. But despite the debilitating symptoms their specialists kept insisting that I could return to full-time work. This constant pressure only made me feel worse, the stress was causing anxiety attacks and their decision to no longer accept any more medical certificates eventually resulted in my agreeing to leave the job that I loved with a package, which I did exactly 2 months before I finally received a diagnosis!

This search for an answer continued right up until my psychiatrist wrote a private prescription for me to try Modafinil to see if this medication would help me with my excessive daytime sleepiness. As this was a private rather than a PBS prescription, the medication was quite expensive, from memory, Modafinil back then was around \$150 for 30 tablets and I was going to need the maximum dose but it did give me some improvement. It was obvious that I was going to need to try a higher dose to see how much improvement I could get and that wasn't an option as I simply could not afford it. By this stage, I had been off work for a few years and I was trying to survive on sickness benefits which was made more difficult as I was still trying to juggle my finances after having an overnight loss of an income of over 60K a year (that ruined me financially). There was simply no way that I could stretch my budget any further.

When I had my next neurologist appointment, I mentioned having tried Modafinil, and my neurologist said that the only way to get this medication on PBS was if I had narcolepsy. Narcolepsy? All I knew about narcolepsy was from what I had seen in the movies, you know, people falling down or falling asleep in hilariously funny situations?

Well, I was adamant that I did not have narcolepsy, but I agreed to be referred to see a Pulmonologist in the Respiratory Clinic to see what they could suggest.

The Pulmonologist gave me a referral to have another overnight sleep study, but this time it was to be followed by a Multiple Sleep Latency Test (MSLT) the next day. Now it is bad enough trying to sleep in a hospital bed, so being a typical narcoleptic who is sleepy all day and then wide awake in the middle of the night, adding wiring all over your body, and then being told to lay down and go to sleep is not an easy thing to achieve. When they woke me up at 7am to start the MSLT I was extra tired and grumpy having had an uncomfortable night's sleep, and all I wanted to do was go home.

I stayed and suffered through the day, fighting a losing battle against the overwhelming urge to fall asleep in between naps. The only good thing about it is that you are allowed to close your eyes for 20 minutes during the nap, but it sure did get harder every time they came back in to wake me up again. I could really feel my desire to hit something or someone rising by the end of nap 4, so it was a great relief when they told me that I didn't have to stay for nap 5, they had enough information, and I was allowed to go home. You wouldn't believe how fast I managed to shower, get dressed, pack my things, and get the hell out of there! I even waited outside in the drizzle for my friend to come and pick me up rather than spend another minute inside the clinic!

Imagine my surprise a few weeks later when I returned to the Respiratory Clinic and was told that I had narcolepsy! WTF? No way, they have made a mistake surely. Apparently not, I fell asleep and hit REM sleep within 2 minutes of being told to take a nap. I slept in all 4 of the naps and had REM in 2 of them within the required timeframe to receive a narcolepsy diagnosis. Did you know that it normally takes a healthy adult over 45 minutes to enter REM sleep (the stage of sleep during which you dream) so people typically don't dream during the day? Well, I didn't know that, and nobody had ever asked me what happened during my naps before, in fact, nobody had really asked me much about my sleep before other than what my night time sleep was like. They certainly did not ask about all of the other symptoms that I had been having such as sleep paralysis, and automatic behavior, and definitely, no questions about hallucinations were ever asked, and hallucinations are the one thing that I was never going to willingly disclose in fear of being taken away in a straight jacked and locked up in a padded room for the rest of my life!

Do you know what I really find annoying? The fact that I had to find out about all of the symptoms myself, the specialist was not a source of this information. They did not help me understand that all of the symptoms that I have been experiencing for years were

related to the same cause. I had to learn about my disease through my own research. I did this by sifting through information online and joining chat groups. My first specialist knew so little about narcolepsy that she said that if I wasn't getting any benefit from taking the Dex that she had prescribed, I mustn't have narcolepsy, she was about to revoke my driver's license, so I walked out and got a referral to see a specialist that actually had an idea what narcolepsy actually was and how to treat it. Fortunately for me I know the difference between information from a reputable source and the nonsense that can be found online. I also know how to advocate for myself. This however, is not the case for everyone so I am passionate about seeing changes made to the information people receive when they are diagnosed and to the ongoing care and management of narcolepsy.

LIVING WITH NARCOLEPSY AND CATAPLEXY (post-diagnosis)

I am now going to fast forward to 2019, the year that I finally discovered what it was like to wake up in the morning without feeling exhausted. Did you notice that I have added Cataplexy to this section?

Being diagnosed at the age of 49 to me meant that I had already lost the majority of my life and therefore I was determined to find the best possible way to get through my remaining years as a person who is 'Living with Narcolepsy' the best way that I possibly can. I believe that it was late 2018 that I read in a chat group about an upcoming medical trial, that's right even specialist number two didn't tell me about this, I had to find out myself. I made the initial inquiries into this trial and decided that I would participate. One of the requirements was that I had to stop taking the antidepressants that I had been taking for over 20 years, I was fine with that, I had taken short breaks before, so it wasn't anything to worry about. Another thing that I was unaware of was that they treat cataplexy with antidepressant medication, so when I stopped taking them, I began to have all of this involuntary loss of muscle control whenever I laughed or was taken by surprise. Then I had a flashback to when I was first diagnosed with depression, I remembered telling the doctor that I was so exhausted that I was falling down or at the very least losing my balance all the time, God knows how many sprained ankles I have had over the years when I have been walking along with a friend and started to laugh about something! As it turns out, the medication had been doing a good job of masking my cataplexy, so my initial narcolepsy type 2 (without cataplexy) diagnosis became a narcolepsy type 1 (with cataplexy) diagnosis.

I was approved to do the trial for the once-a-night version of Xyrem, and when I had reached the full dose, I experienced what it was like to finally wake up and not be tired!

It was amazing, my head wasn't foggy, my mood was good, and I got up out of bed willingly!! I looked forward to going to bed every night knowing that within 20 minutes I would be dead to the world and that I would be able to get up and do things the next morning without feeling like I needed to go back to sleep. It was so exciting. I really do resent people who take this feeling for granted and purposefully do things to ruin a good night's sleep.

Having completed the trial and only getting to have a brief taste of a life that was as close to normal than anything that I had previously experienced was something that I desperately wanted more of. To my delight in May 2020, I was given extended access to the trial medication, my dreams had finally come true, I was able to live my life for the first time and it was so good. The longer that I had been on the medication the better it got. My horrible symptoms were almost completely gone, it was so life-changing. I managed to do things that I enjoyed all of the time instead of needing to take naps during the day. I could spend quality time with family and friends, go out, and participate in activities. I even managed to get a little bit of part-time work. I was even having long-lost memories gradually return and for once in my life could rely on my short-term memory, plus the extra bonus of still being under the care of my amazing trial sleep specialist.

Life was great, I had begun to record some of my original songs and was preparing to release my first single to coincide with World Narcolepsy Day in 2022 when I received the devastating news. The news was that the drug company had decided to stop providing me with extended access to the medication due to the delay in them getting their final FDA approval. I was to receive my final delivery of medication which would take me up to the middle of September 2022 and then that was going to be it. I couldn't honestly enjoy my final weeks of being medicated because knowing what was about to happen was depressing, but I was determined to have everything ready to be able to release my song ["The Underground Railroad"](#) on the 22nd of September as a way of Raising Narcolepsy Awareness, which I did age 54.

The rest of my songs remain in various stages of being partly completed. I no longer have my part-time work, I struggle to be reliable, I let people down all the time because I no longer have the energy to participate. I rarely leave my house, I avoid shopping, I only drive when it is absolutely necessary and never any great distance or at night. I struggle to clean my home or even to shower or get dressed. My hallucinations, automatic behavior, excessive daytime sleepiness, brain fog, and cataplexy have all returned with a vengeance. I actually feel worse than I did before I started the medication, and there is

no end to this new existence in sight. Why? Well, that is because I am unable to get compassionate access to that life-changing medication. I can't even try taking Xyrem as an alternative because, at the price of around \$1800 a month, it is not an affordable option for me. This is how I 'Live with Narcolepsy' in Australia and why I believe that it is so important to Raise Awareness of this rare disease. I deserve better, the Australian narcolepsy community deserves better, and our government needs to make it better for all of us.

Thanks for reading this part of my story.

Di Spillane – 2023

