

At 27 years old Jane was diagnosed with Idiopathic Hypersomnia.

“A sleep disorder that helped me make sense of myself.”

Everyone who knew me understood how much I loved to nap. As I became more aware of my daily patterns,

I started to realise that my love for napping was actually a daily need. It wasn't uncommon for me to take multiple naps in the one day, even after sleeping 8 hours at night.

It didn't bother me where I slept and some of the time it felt almost impossible for me to stay awake. I have fallen asleep on the school bus, at my desk, when surrounded by noise, on aeroplanes, on trains, as a passenger while 4WDing with my head banging against the window, on a sea jet ferry with super rough waters, before the aeroplane takes off, on floorboards, while studying and alarmingly I have had micro sleeps while driving my car. For me, sleep was like an addiction.

I would constantly think about sleep, even counting down in my head how many hours were left until I could sleep again.

This would start from 10am, after waking up at 7am from an 8 hour sleep the night prior. I looked forward to sleeping more than most activities. I was completely obsessed by sleeping. Partners would notice that I fell asleep really quickly. As soon as I set my alarm, turned the light off and placed my head on the pillow I was asleep. Sleep is only difficult for me when I experience extreme emotions like when I am sad or anxious.

In 2006, after high school, I moved 300km from my hometown to attend university. As uni was flexible, I could always fit at least one nap into my day. Driving home to visit my family became dangerous and without realising I had created behavioural strategies to ensure safety for myself and others when on the road. Basically, I needed to start the 3-hour drive not long after waking up or having taken a nap. If I wasn't able to do this, then I would drink coke or eat food to get energy. I would call my mum to wake me up, force myself to sing, drive back with friends where possible, lower the windows in my car or park my car and sleep. It's like everyone including myself just accepted that I was someone who napped. I felt lazy and useless at times, so often I did not tell other's how much I was actually sleeping. Generally, I am a fairly busy person who has spent most of the past decade studying psychology and working, socialising with family and friends, attending workshops to expand my skills or doing something I loved, so my tiredness always seemed justifiable. However, when I wasn't busy with life, I was sleeping.

In 2012, I began studying honours in psychology full time and working 2 days per week as a research assistant. As this role was mostly at my desk, I frequently had to force myself to go for a walk, eat, drink or socialise to wake myself up. During that year, I was only productive with studying straight after waking up from a night of sleep or a nap. Otherwise, I would fall asleep at my desk or be in a zombie-like state where it was really hard to concentrate. In those 8 months of study, I would sleep, wake, study and eat whenever my body required within a 24-hour period to get work done. That year was really hard. There was loads of pressure on everyone in that course to get high marks to continue studying psychology and everyone was exhausted, so my behaviour seemed appropriate. I now realise an undiagnosed sleep disorder was a contributing factor in making that year hard.

The following year, I began training and working as a provisional psychologist working with clients. Once again I automatically developed coping strategies. Whenever I had a gap between clients of at least 2 hours I would drive back home, set my alarm, nap, then go back to work. I recall arriving at clients houses a little earlier than the session started and napping in my car. If I had 10 minutes to spare, you can guarantee I was using that to sleep. I would set my phone alarm, recline my chair and fall asleep. As my client load increased with my study requirements I wasn't able to nap

during the day. At this point in my life, I was thinking about food like I was thinking about sleep. It is clear to me now that food gave me the energy to stay awake when I wasn't able to sleep. I tried my best to eat healthier options but ended up gaining some weight.

Most days I would feel like a zombie who craved sleep and when I wasn't able to sleep I would be in a zombie haze where I felt as though I wasn't really there like I was operating on autopilot. Fortunately, I never fell asleep working 1:1 with a client. I made sure I kept awake by eating or moving around. It is much easier for me to stay awake working with clients as it is more interactive than when I am working at a desk.

I have missed out on some things in life while sleeping. I went on a 3-week family holiday driving to the middle of Australia and back and recall them jokingly commenting, 'Amanda, have you seen any of the amazing sights... you have been asleep the entire trip,' and they were right. I would sleep for 10 hours at night and in the daytime, I would fall asleep when I wasn't driving. I had organised audiobooks, albums and movies to watch but didn't listen to one audiobook and fell asleep during every movie. This really annoyed me at times as I didn't want to sleep, but I was relaxed on this holiday and felt powerless to stop myself from falling asleep.

After that holiday, I began trying to make sense of myself and started reading about sleep disorders. I wrote a list of my symptoms, when they had started, my daily habits and told my GP, "I think I may have a sleep disorder" and without asking me one question he responded, "you are a psychologist overanalysing yourself." **He wasn't interested in asking any questions or even hearing me explain why I thought this, he just handed me the referral.** I booked an appointment to see a respiratory and sleep medicine physician and was relieved when he asked questions, listened to my concerns and did not think I was a hypochondriac overanalysing myself. The specialist referred me to the sleep laboratory for an overnight and daytime sleep study. In April 2015, at 27 years old, I was diagnosed with Idiopathic Hypersomnia (IH), something I had never heard of. IH is a rare neurological sleep disorder manifested by excessive daytime sleep and sleepiness. Generally, I sleep 7-9 hours at night and naps during the day are irresistible which make my overall daily sleep time longer than others. IH treatment involves treating the symptoms with stimulants and wake-promoting medications for the excessive daytime sleepiness. I am fortunate because unlike most people with IH taking naps is beneficial for me because they are refreshing.

Since taking medication, my quality of life has improved, it is so much easier to get through an entire day. My diet has improved as I am not craving food for energy to stay awake and I have lost weight without making significant changes to exercise. Like everyone, it is important I maintain a regular sleep and wake pattern while taking medication. When this isn't maintained I have a nap. Initially, I felt strange not incorporating a nap into my day and I had all of these extra hours for activities. The difference with naps now is that they feel like a luxury rather than a necessity.

I am thankful to my specialist for investigating my concerns with sleep as an IH diagnosis has helped me to make sense of myself. The long term effects of taking medication worry me including tolerance and a decrease in effectiveness. My specialist informed me I will not be able to take Modafinil if pregnant and that most contraceptives are less effective, which in my experience GP's are not aware of.

I would love to contribute to research and I plan to write a case study to provide more information on Idiopathic Hypersomnia. Hopefully, by sharing this information, it is useful for others.

*Name changed to protect privacy