

When I was diagnosed with a rare neurological disorder my life changed. At first I was in a state of denial about my diagnosis. I had been complaining to doctors about being “tired” (see note regarding terminology) for 8 years. After finally having an answer I felt like there’d been some sort of mistake. Initially after my diagnosis I had trouble allowing myself to accept that I do in fact have a rare neurological disorder. And all I wanted, leading up to that appointment was to have answers, to be diagnosed with *something*. I was diagnosed with idiopathic hypersomnia (IH). IH is a rare neurological sleep disorder. So little is known about it they don’t know the cause so there is no cure.

For a bit of background history, my struggles started when I was in high school – I’d struggle to stay awake during class and would take micro naps while the teacher was writing on the whiteboard with their back turned to the class. Sometimes I’d be reprimanded if I was caught “sleeping” and other times the teachers would question me with concern. I spent my study periods napping with my head on the desk and when I had study periods first thing in the morning my mum would let me sleep in and take me to school at morning tea instead. I used to snooze on the bus every morning and every afternoon while all the other kids chattered and made plans for the weekend. My weekends usually were spent sleeping in late and napping in the afternoon. When I was in my early 20s I was sleeping a minimum of 12 hours every night. I’d go to bed around 10-10:30pm and would not wake up until 10 the next morning. This was ok when I was living with my parents and not working because I could sleep as much as I’d like and I didn’t have any responsibilities. I’d also often have a nap in the afternoon.

Then when I started working and had to get up at 7am (absolute torture) I would be so absolutely exhausted by the time I got home that I’d promptly fall asleep for an hour as soon as my body hit the couch. Often still in my work uniform. Not to mention being able to focus at work was really difficult and driving home, looking back was probably quite dangerous. Working full time was do-able (but not ideal) while I was living at home because my mum cooked dinner and did all the chores like laundry. It was a different story when I moved out on my own. I never had the energy to both go to work and look after the house. Going shopping for groceries as well as cooking was such a monumental task. I lived in an apartment that was 5 mins from my work and I’d come home during my hour lunch break to lie down on the couch before dragging myself back for the afternoon stint. Looking back now, I honestly don’t know how I did it.

When I moved in with my partner Ben I cut back to 3 days a week (at the time I used online study as an excuse) but going to work just got harder and harder. I then dropped back to casual and would work no more than 2 shifts a week.

After seeing multiple specialists and having countless tests I finally saw a sleep specialist who ordered a sleep study. He diagnosed me with IH and I was prescribed stimulant medication. They are great while they are working, and the effect is somewhat cumulative in that I feel better in the afternoon. Initially when I was taking the immediate release form they were so effective when they reached their peak I felt as though I could go for a run! On one of the days shortly after I first started taking them I was able to do more in three hours than I’d

normally get done in an entire day. Something else I noticed was that I started being able to wake up in the morning without it feeling like absolute torture. It felt like I'd seen the other side, what it is to be awake! After taking medication I realised "is this what people feel like ALL THE TIME? After a restful 8 hours they have THIS much energy?!" It was very eye opening. On the flip side, now when I don't take it at all, I feel like a complete zombie. When I first tried stimulant medication I sort of wanted to go back to before, because at least then I wouldn't have known what it could feel like to be awake. I didn't know how to handle all this energy and I would over exert myself and crash later. I also felt really jealous of everyone else who didn't have these problems and it made me feel like I was defective. It was very emotionally difficult for me to come to terms with my diagnosis and all the challenges that came with having a sleepy brain. For a bit there I kind of wished I'd never seen what I was missing out on. Ignorance is bliss right. But what sort of life is it being constantly half asleep? Things like parties aren't enjoyable, I don't have energy to exercise, going shopping wipes me out. It's like being a toy who comes to life when you pull the string. The stimulant is the string and when it runs out I become lifeless again.

That was nearly a year ago. Now I take a once-a-day extended release version. It's not as potent as the immediate release but it's much easier to handle. I don't feel like that doll that keeps having its string pulled with energy levels up and down like a yo-yo.

My body is now used to the medications and I make sure I take them every day (they are long acting and last all day). Without them I would need to have several naps and pretty much don't get anything done. I joke every time I get my script refilled that it's like "having a subscription to life". I am also really lucky that I now have a job where I can work shorter hours. Honouring my body and listening to its cues for sleep is one of the best things I can do for my health, even if it means FOMO. Without doing that I'd be missing out on a hell of a lot more.

So what do I wish other people knew about IH?

- "Just sleep more" isn't helpful at all. We live in a society where the amount of sleep I need is not nearly enough to function without sacrificing a lot (time, a job, a clean house, cooking healthy food, spending time with others).
- Medication doesn't "fix" IH – it is merely another tool in the toolbox which can help manage life with IH. It can't replace other healthy habits. The stimulants can be a bit like a coffee – they help to perk me up but I can't solely rely on them. That would be unsustainable in the long term if not used in conjunction with other management behaviours like self-care, pacing and recognising when my body really does need sleep. Sometimes I just have to say "no" and accept I can't do everything.
- Terminology is really important. My sleep specialist explained that tired, fatigue and sleepy mean really different things. To be tired is to feel "can't be bothered" or have had enough mentally. Fatigue is when your body physically has had enough like after a hard day's work and you need to rest. Sleepy is when you feel as though you just want to close your eyes and go to sleep. You can be tired without being fatigued, fatigued without being sleepy and sleepy without being tired. (Or you can be all three

at once!) I wish I'd known this earlier. I would have described myself as being "sleepy" all the time instead of tired.

I also just want to shout out to Ben, my beautiful partner who has been there for me every step of the way. He's been an amazing support and love him so much.

I'm hoping to start a family soon and I'm not going to let IH stop me!

Written by Caitlin O'Rourke

#LivingwithIH

Idiopathic Hypersomnia Awareness Week 2021

