

LIVING WITH IDIOPATHIC HYPERSOMNIA

I tried writing this 3 times and each time my eyes get heavy and I start to fall asleep. I'm not great with words anyway so I could just give up but this is important to me.

I was diagnosed with Idiopathic Hypersomnia when I was 28, I'm 39 now. I had been sleepy for as long as I could remember but if I had to put my finger on it, I'd say I really noticed symptoms intensify towards the end of high school. I was always a bright kid but by year 10 I was really struggling to get assignments done and I was just hopeless in exams. Retaining information seemed like a super power that I just didn't have. I couldn't even remember what class I was supposed to be in next. My hands were full of reminder notes I had written on myself. Sadly, in the end school ended up being a total write off. I left in year 11. I declared myself medically unfit to continue. I knew I couldn't keep up the charade any longer. I wasn't coping and I needed to find out what was happening to me and why. So, I spent the next 10 years trying to find out why I needed to sleep so much. Why despite all this sleep I still felt incredibly tired and why my memory and ability to concentrate and focus on anything was beginning to resemble someone with ADHD.

Fast forward to just after my 28th birthday. After many doctors, tests, misdiagnosis and unnecessary and damaging medications I found myself diagnosed with Idiopathic Hypersomnia (IH). My doctor somehow knew the diagnosis wasn't going to be a relief to me. He was right. It wasn't. I've had to change GP's 3 times because each of them not only knew nothing about IH they didn't seem to care to learn either. One of them treated me like I was doing something to cause my symptoms which showed just how much he knew about IH, and me. I sleep a lot, and deeply. So deeply that literally nothing wakes me the first time, or the second and quite often the third and fourth time. I have been asleep on the lounge during a house party. I have slept through a fire alarm in a hotel. I have even fallen asleep during a Foo Fighters concert. And most importantly I do this despite sleeping at least 10 hours most nights, more if given a chance but rarely less. I never sleep less than 8 hours. I can't. I simply wouldn't be able to function at all. Medication doesn't help much. It helps a little during the wake up process but it does nothing for the cognitive issues (my memory and concentration are greatly affected) I have, which seem to get worse the more I force myself to stay awake so it doesn't even make sense for me to use medication to try to get by on 8-9 hours of sleep (something my sleep specialist doesn't seem to understand).

What I want people to understand most about my life with IH is that this never leaves me. I am never free of the chains of sleep. If I am not in a constant state of sleepiness, I am asleep. There is no reprieve. There is no getting my 'spoons' back. I never have any spoons to begin with! When I say my sleep is 'unrefreshing' it means that despite loads of good quality sleep I have to fight against invisible forces to wake up and I have to continue to fight all day to stay awake. Napping is pointless (although sometimes unavoidable) because it can take hours for me to wake up and reach my normal. This means more hours wasted. So, unless that is what you experience you don't know how I feel. There is something particularly defeating in knowing that it doesn't matter how much good quality sleep you have you will NEVER feel properly awake.

This is not my fault.

I am not lazy.

I try harder than you will ever know. The fact it never seems to make any difference is heartbreaking for me. I don't need anyone reminding me of my 'failures'.

Annie – 2023

