

LIVING WITH IDIOPATHIC HYPERSOMNIA

I admire the people that can share a photo of themselves during the awareness week. I'm not strong enough to do that or to use my full name with my story. I have been made fun of my whole life because I sleep a lot and because despite this, I still fall asleep at times I shouldn't. I've been called lazy more times than I can remember and I mean by people close to me, even my family. I've stopped trying to get them to understand that it's hurtful. I don't know if it's because they don't care or if it's because they just can't get their head around the fact that Idiopathic Hypersomnia is real medical disorder. Would they say the same things to someone with any other medical condition?

I'm not going to tell my whole life story. I thought I would just focus on the questions relevant to the Living with IH, share your experience project.

What was life like prior to diagnosis and how has receiving an IH diagnosis made you feel?

Life prior to diagnosis was HARD! And sadly, it's not much different to my life now. I take some medication to help me wake up in the morning but there is no point taking any more because it just leaves me feeling awful. I'm convinced it's because my brain NEEDS lots of sleep because without it, I'm hopeless. I mean, I'm hopeless despite lots of sleep but I'm worse if I try to live a 'normal' life, for example if I sleep say, 8 hours a night like 'normal' people do. I sleep at least 12 hours every night and I may nap during the day but I try not to because my naps are hours long and waking up is so hard I really don't want to go through that more than once a day.

Waking up is really a fight to turn sleep off. I use multiple alarms and if possible, a human to wake me. I take medication, go back to sleep and then I wake up some time later. I then have to use every ounce of strength I have to get myself through what is called sleep drunkenness which is kinda just like it sounds, I function like I am still half asleep *and* drunk. I can't communicate properly. If someone speaks to me, I can hear them speaking but I struggle to understand what they want from me. And then my response is typically slurred and doesn't make sense. I then get irritated. Actually, I'm irritated from the moment I try to wake up. Having someone communicate with me while I am going through this process can send me over the edge. This whole process from the moment I attempt to wake up until I am finally upright and capable of at least a normal conversation takes at least 2 hours, some times longer, and that's with medication. Suffice to say, every morning is a dumpster fire and sets the scene for the rest of my day, which is generally a few hours a suboptimal wakefulness followed by what I refer to as zombie time. I am clinically awake but I am not capable of doing anything that requires a properly functioning brain. And so, that is my day. Every day.

Receiving a diagnosis made me feel validated. And, initially it gave me the satisfaction of being

able to tell the people who judged me that they were wrong but the truth is many of them couldn't have cared less that I had a medical diagnosis that explained my symptoms. I ended up wishing that I had something else, something that people believed was real, like narcolepsy.

I spent many years suffering in silence. Meeting other people with IH has helped me so I am grateful to Hypersomnolence Australia and the support groups they have. I don't attend the meetings every month but it's just great to know there is a group of people that I can catch up with where I can talk openly with people that really do know what I am going through.

Laura - 2024



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