

One day I had a rare neurological disorder named Idiopathic Hypersomnia and the next it appeared I did not. How did this happen? Let me explain...

I was diagnosed with IH about 10 years ago. I work in the health sector but I had never heard of IH before. I have access to all the medical journals so I set out to read everything I could about IH and narcolepsy. Over the years I had many more tests. Every time I came across another possible cause for the relentless tiredness I experienced every day I would investigate it, driving my doctors insane in the process. It wasn't that I questioned my diagnosis but rather IH is a diagnosis of exclusion and knowing how many things can cause extreme daytime sleepiness I wanted to make sure everything had been excluded. Fast forward to March 2020 when I realized Idiopathic Hypersomnia isn't extreme daytime sleepiness. This is when I realized that I don't have Idiopathic Hypersomnia. So, what now?

Firstly I realize I sound a bit foolish. How could I not know what IH was with all the reading I did and all the conversations I had with doctors including sleep "specialists"? I think part of the reason for this is *because* of the conversations I had with doctors including sleep specialists. I often felt groggy in the morning. I found it difficult to get moving and no sooner would I be 'going' that I would start feeling so tired I could barely stay awake. In fact, I often didn't stay awake. I fell asleep in awkward situations a lot and most of the time I didn't even realize it. My doctor told me that was IH. When I questioned him about the fact that I didn't really sleep a lot he didn't hesitate, he would tell me I have IH. When I say I didn't sleep a lot I mean sometimes I did. Sometimes (mostly on weekends) I could sleep a whole 9 or 10 hours at once and sometimes I would sleep 7 or 8 hours at night and then nap for half an hour or maybe even a whole hour during the day. But overall while I did have lots of spontaneous and unexpected naps they were never for very long. Most notably was that I didn't really sleep more than 9 hours in a day and even if I did this didn't happen regularly. What did happen regularly was feeling extremely tired during the day and falling asleep at times I would often least expect it. I now realise that this alone isn't IH and this is why.

In February 2020 two papers were published. They were authored by a total of 21 IH and narcolepsy experts, the majority in the world. Both papers explained what IH is ("long and unrefreshing naps, prolonged and undisturbed nocturnal sleep, impaired daytime alertness and focus, and sleep inertia, in addition to EDS" [2]). I don't know that these papers explained it better than I had read it explained anywhere else but reading these papers was a kind of light bulb moment for me. I took the papers to my sleep specialist. It's difficult to explain in writing what that appointment was like but I came away knowing in my heart of hearts that I don't have IH. So back to the "so what now?"

According to the majority of experts they think what I live with should be called Idiopathic Excessive Sleepiness. I can't argue that the name isn't appropriate. I definitely don't have hypersomnia, idiopathic or otherwise because hypersomnia means to regularly sleep excessively and I don't do that, certainly not in a way described by any of these experts. And of course I definitely don't have narcolepsy so, after much thought I realized that while I still don't know why I am extremely tired during the day and why I sometimes fall asleep without warning in awkward situations I'm actually glad to know that I don't have Idiopathic Hypersomnia. IH is a disease with no known cause and no cure. Who wants any disease much less one that has so little hope?

My sleep specialist is a lovely man but I know he loathed me asking for advice about how to manage IH. He would always tell me that there wasn't really anything I could do apart from taking medication and "try naps". I always came away feeling that there was nothing I could do to make my life better and that felt awful. He made me feel like I just had to accept my situation and get on with it. I don't feel like that anymore. I have a new sleep specialist now. He told me that IH is over diagnosed (my old sleep specialist would say this too) and that one of the reasons is that there are no medications for EDS (excessive daytime sleepiness). He said "if there were (medications for EDS) the people being diagnosed with IH and narcolepsy would be greatly reduced". That makes sense. So, for now we are going to have to continue to write IH or narcolepsy or whatever it is on my medical records to get my medication but we both know I don't have IH. He is working with my GP on that basis too and it is such a positive approach. Rather than them dismissing my symptoms as 'IH' we now look at them through a completely different lens. I've even started taking less medication. I found while I thought I actually had a specific disease (IH) medicating it made sense but since realizing that I don't have a disease (or certainly not the one I thought I had, IH) I must approach medication simply as a means to help manage my symptoms which means using it sparingly. I've made some lifestyle changes too that have helped a lot.

So, this is my farewell to Idiopathic Hypersomnia. I no longer feel the need to read every paper written about IH and narcolepsy, desperately hoping for a cure or at the very least a treatment that targets the cause. I am going to spend my time working towards being as healthy as I can be because whatever is causing my symptoms it thrives when I am not looking after myself.

*The two papers mentioned above are;

1. 'Diagnosis of central disorders of hypersomnolence: A reappraisal by European experts' published in the journal *Sleep Medicine Reviews* and,
2. 'To split or to lump? Classifying the central disorders of hypersomnolence' published in the SRS's journal *Sleep*.

Written by Heather for the Idiopathic Hypersomnia Awareness Week 2020



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