Imagine how tired you would be after three nights of partying, drinking, barely sleeping and still working during the day. Imagine how hard it would be to have to drag yourself through the day like that. Every. Single. Day. That's my life, only I haven't been partying, in fact due to the neurological disorder I have I can have more than enough good quality sleep and yet I wake up feeling like I have had no sleep at all.

I cannot remember a time that I wasn't tired. My mum says I needed more sleep as a child than my sisters did, but other than that I seemed fine. Then when I was 13 I got Glandular Fever. My already excessive need for sleep got much worse and although I recovered from the Glandular Fever I still felt tired, fatigued and excessively sleepy. I was later diagnosed with hypoglycemia so I cut out sugar but my constant tiredness and fatigue didn't resolve.

Many doctors visits, blood tests and tears later and still no answers. I had many people telling me "it's the time of year", "it's your hormones", "we're all struggling with fatigue" later and still no resolve...

I ended up with a specialist who declared I had chronic fatigue syndrome, but I just knew it wasn't that. I'm not just fatigued, I am sleepy. All I can do is think about sleep. I literally don't care about anything else but sleep. I want to cry, then just sleep. Sleep, sleep, sleep. I feel tired, and I feel fatigued but most of the day I am fighting sleep. I couldn't go on living like this so I decided to try one more time to figure out what was wrong with me. By coincidence I read something in a psychology magazine about a sleep centre and I decided to make an appointment.

The best decision I ever made: I was diagnosed with Idiopathic Hypersomnia. What I had was real and there was medication to take it! I was over the moon!!!!

Taking medication doesn't mean I'm not tired. I can still have a full night of good quality sleep yet wake up every morning feeling like I only slept for 3 hours. It is so frustrating because I should feel refreshed but I'm not, I'm so tired I want to cry. Taking medication however does mean that I have more zest for life. Once I get through the haze of waking up medication helps lift the tired and depressing fog that I always carry with me.

Someone asked me once if I was afraid of the long term side effects. For me anything is better than to go through life with an all-overpowering feeling of ONLY ever wanting to sleep. Every. Single. Day.

Written by MIssa Vrswijk #LivingwithIH Idiopathic Hypersomnia Awareness Week 2021

