

At 28 I was diagnosed with Idiopathic Hypersomnia (IH). I had been visiting the doctors sporadically since I was 15 years old because I knew feeling as exhausted as I did despite sleeping for 15-20 hours a night was not normal. Sometimes I was told I would “grow out of it”, other times I was told I was depressed or that it may be Chronic Fatigue Syndrome. I was eating healthy and exercising which I was told should elevate my symptoms but it didn't.

I met my boyfriend at 25 and he struggled to understand how I could be so tired all the time when I slept so well. I would set 10-15 alarms in the morning and my boyfriend would still have to make sure I was awake before he left so that I wasn't late for work. Despite this I would sometimes fall asleep again without knowing and wake up panicked with ten minutes to get ready and leave the house. Turning up late to work became a regular occurrence and my mood was slowly dropping again. I was frustrated that no matter how much I tried I couldn't get my life together.

I went back the doctors who referred me to a specialist. I waited nearly a month and I was getting desperate. I called the hospital only to be told it could be over a year before I got an appointment. I was devastated. The next morning on my drive to work (which is only about 15 minutes) I fell asleep behind the wheel of my car. Luckily I was stationary at traffic lights but I was terrified. I had always found driving longer distances difficult. It would take serious amounts of caffeine, loud music and open windows to help me stay awake. I often arrived home with dry, grainy eyes for forcing them to be open when all they wanted was to be closed.

I managed to get another appointment with my GP the next morning and I told him what had happened, this time they took me seriously. By the end of that day, I had my driving license withdrawn and I was no longer able to work. My world stopped. I was angry with myself for telling anyone how I felt because now I couldn't do the one thing I loved, my job. For a month I sat at home and cried, desperate to find a way to get back to work. Initially, for 2 days, I tried walking to work... it took two hours each way. Realistically I could never keep that up but I had to try to keep my life going. Losing my job really broke me. I couldn't see how I was ever going to get my life back. Unfortunately I have a great boyfriend, friends and family who all rallied around to support me. Driving me to get my shopping, taking me out with them for the day, getting me up to walk their dog with them every morning to give my day some purpose.

Eventually I got to the sleep clinic. I was booked in straight away for overnight tests. That was a horrid experience. I was anxious and the matron was really unkind. After the overnight test I had to do a Multiple Sleep Latency Test where I had to have five naps throughout the day on command. By the end of the day I felt hungover, nauseated and exhausted. I had never been so pleased to see my boyfriend when he turned up to get me.

A few weeks later I had my diagnosis and I started taking medication that is supposed to assist me to stay awake. It hasn't been easy. I have had my dose increased and I struggle to remember to take my lunch time dose but I just keep trying every day. I have very mixed feelings a lot of the time. I am grateful to finally know that I'm not mad, or losing my mind, and that I don't imagine how sleepy and exhausted I feel. Knowing that there is a legitimate medical reason for the way I feel has given me permission to stop when things are getting too much. On the other hand, I hate having to take medication every day. I hate that there is something “wrong” with me that I will never fully understand. I hate the thought of never meeting another person who feels like I do. I hate hearing people that do not have IH say “I know what it's like to be tired”. I wish I could find the words to explain the constant battle that happens in my mind

several times a day between “I’m so exhausted I just want to sleep” and “I don’t want sleep to take over my life”.

I’m fortunate to have a wonderful boss in the NHS who gets it and because of my job I can be as flexible as I need to be. I try to exercise a few times a week but sometimes I haven’t got it in me. I struggle with the guilt I feel when I can’t exercise. I still never wake up feeling refreshed. I feel nauseous a lot, and it can take several hours for the sleep hangover to lift and for my brain to get on board, but by then the second round of sleepiness has usually hit.

I often wonder why it took something as significant as me saying I fell asleep at the wheel for anyone to pay attention to how I was feeling.

I’m grateful that the diagnosis has given me a level of understanding and permission to be sleepy and exhausted that I didn’t have before. But I’m frustrated by the lack of medical and general understanding of IH – people don’t get it. The usual ‘oh god, I know how you feel! Maybe I’ve got IH too’ wears a little thin. I am also frustrated by the lack of support available. I got told by my new consultant that I could get in touch with Narcolepsy UK, but narcolepsy isn’t Idiopathic Hypersomnia.

I decided a long time ago that I would not let my condition interfere with my life. I will not let this define who I am. I may have to adapt my life a little but my diagnosis allows me to do that, it doesn’t change who I am. I am lucky though, in comparison to a lot of sufferers who don’t have the support I do.

Written by Kelly for the Idiopathic Hypersomnia Awareness Week 2018



IDIOPATHIC HYPERSOMNIA
A W A R E N E S S W E E K[®]