

I don't ever remember a time when I woke up feeling refreshed. I came to believe that jumping out of bed eager to start the day after a refreshing sleep was a myth put forward by advertisers to sell mattresses. When I was a child I slept in because I was "lazy". My cousins, who lived nearby, would often come over in the mornings and ridicule me for still being in bed. When I was a teenager, I was still tired all the time and needed multiple alarms and my mother to physically wake me and get me out of bed and to school on time. Isn't that normal for teenagers? Problem was, when I was a young adult I was still tired all the time; sleeping in for as long as possible whenever I could. I was busy working, socialising, having fun and partying hard. Was my lifestyle was to blame? Then when I had kids I thought feeling tired all the time just comes with the territory. Aren't all parents tired all the time?

By my mid-forties, it had become apparent that what I was feeling was definitely not normal. I was still waking up unrefreshed and tired no matter how much sleep I had. I still struggled to wake up and to get out of bed each morning. I was needing afternoon naps which could last 2 hours or more. I'd only force myself to wake up due to the guilt I felt (I was being lazy!). I was quite zombie-like when I did eventually get up after a nap, and it would sometimes take me an hour or more to properly wake up.

When I sought help from my GP my concerns were initially dismissed. Of course I was tired, weren't we all these days? I had a busy lifestyle, I could do with losing some weight, I should exercise more. I wasn't happy with this, I knew what I had been feeling my whole life wasn't how other people felt but left it for a few months. The next time I saw him I broached the subject again, insisting that this was more than just normal tiredness. This time he decided to do some blood tests to placate me. This became the beginning of my 2 year journey that eventually lead to my Idiopathic Hypersomnia diagnosis. I had comprehensive blood tests including glucose and hormone level tests. I was slightly anaemic and I had a vitamin D deficiency, but otherwise all other results were normal. Alright then, maybe some vitamin D and iron supplements would help! They didn't, more blood tests periodically over the next 18 months showed that my iron and vitamin D was now normal but it didn't make any difference to the sleepy symptoms I had. I was sent to various specialists to have other possible causes ruled out and each time I was left still feeling tired and sleepy but with no answer why.

Making it through the day at work (a sedentary job) would involve multiple cups of coffee, trying to get some "micro naps" during lunch and struggling to stay awake and think coherently through the afternoon. Thankfully, I only work 3 days a week. The other days were spent doing as much as I could manage in the morning and then I would sleep for at least a couple of hours in the afternoon. On the days I had to pick my kids up from school I would set my alarm at least half an hour before I had to leave in order to have enough time to wake up sufficiently to drive. Sometimes I'd sleep through the alarm and wake up in a panic, driving to the school in what I'd describe as a "manic zombie" state. I was at the stage where I would get so thoroughly exhausted that I felt physically ill and could literally not function anymore unless I slept. It was debilitating. I was getting more and more irritable, snapping at my family, getting angry and upset over trivial things. Yet I felt so guilty! I was being lazy. I was selfish for not wanting to do

any activities with my husband or kids. I was missing out on life. Why was I like this? Why couldn't I be more active and do and enjoy more things like everyone else?

There had to be something causing the way I felt. There was no way I would have chosen the way my life had become. I just knew how I felt couldn't be normal. I knew I wasn't just imagining it or being "soft". I was now getting desperate for an answer.

I went to the GP again, this time my regular GP was not available so I saw someone different. All she could suggest was further blood tests, and perhaps a referral to a sleep specialist. I filled in a lengthy questionnaire about my sleep habits, symptoms and medical history and was booked in for an overnight sleep study, with a Multiple Sleep Latency Test (MSLT) the next day. A couple of weeks later I visited my sleep specialist to get my results. When he gave me a diagnosis of Idiopathic Hypersomnia, I cried. I felt so overwhelmed; finally, I had a reason for how I am and it wasn't just in my head or because I was lazy! I'd never heard of IH, but you can bet I soon learned as much as I could.

Unfortunately, there is currently no cure and the treatment available only assists with some of the symptoms, it doesn't treat the cause. The long-term effectiveness and potential consequences and side effects of the medication is also concerning. Getting up in the morning is still a huge battle but now at least, once I have my medication, I can function during the day at something closer to normal. I soon realise if I've missed my afternoon dose, as the blanket of fog and exhaustion quickly swoops in. The positive thing is I'm being kinder to myself! I pace out my daily activities. I have learnt where my limits are and I try not to take on too much in a day. I'm learning to forgive myself when I can't quite manage to get everything done that I'd hoped to. I'm still reluctant to share my diagnosis with family and friends. I feel the effort to explain the illness is too difficult and "It's kind of like Narcolepsy" just doesn't cut it. I guess I still feel that I'll just be judged as being lazy. My hope going forward is that this disease gets more exposure and funding for much more research, particularly as a disease separate from Narcolepsy. Hopefully soon we'll see better methods of diagnosis and more effective and targeted treatments. I'd love to see a greater awareness of IH, particularly among the medical community so people like me are taken seriously and don't have to suffer for years before getting a diagnosis and treatment.

Written by Teresa for the Idiopathic Hypersomnia Awareness Week 2018



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