

LIVING WITH IDIOPATHIC HYPERSOMNIA

Ever since I was a little girl, my answer to “How are you?” has always been “Tired.” For years, we couldn’t find the answer to why I was always tired. It wasn’t until I was in my 20s that we found the answer – idiopathic hypersomnia (IH).

I have gone my whole life feeling tired. It doesn’t matter if I get 12 hours of sleep or just 1, I have always woken up feeling like I haven’t slept and constantly craving more.

My constant complaint of tiredness was of great concern to my parents and to some of my teachers when I was at school. If I wasn’t actively doing something, I was likely falling asleep in my chair. One teacher counted 9 times where I fell asleep in assembly in front of the whole school. After years of doctors not finding answers and trying every sleep hygiene regime under the sun, I came to think that my level of tired was normal. My family and I tried countless ways to improve my wakefulness to no avail. I was first tested for any sleep disorders when I was 14. My parents spent countless hours trying to find doctors, specialists, treatments, and methods to help me feel more awake. It has taken years to arrive at this diagnosis and make sense of why life has been the way it has for me.

Having IH is incredibly difficult. It’s like being woken up every single day just as you are about to go into a deep sleep. Mundane everyday things take all my attention and energy. I don’t know what it’s like to wake up feeling completely refreshed and energised. I don’t know what it’s like to not worry about bumping into people or things as I walk down the street to work. I don’t know what it’s like to not have to focus all my energy on a task just to stay awake.

It is particularly hard to get up in the morning. I have 4 alarms, but it isn’t until my partner makes sure that I am awake that I can actually get out of bed. My body so desperately craves sleep that I often dream that I am awake and going about my day. These dreams are so convincing that without someone actually telling me to get out of bed, I might not wake up at all. When I do wake up, I barely function. I learnt young that I needed a routine to get ready so that I didn’t have to think about or forget to do something simple like brushing my teeth.

After years of struggling to stay awake and wanting to do better in my career, I reached out to doctors again, in search of answers. I was finally diagnosed with IH when I was 27 – after more than a decade of trying to find answers. Suddenly everything made sense. I wasn’t tired like my friends and family sometimes said they were – I was chronically sleepy because my brain has never properly registered what sleep I’ve had and constantly wants more. To help with my chronic sleepiness, I have been prescribed medication that simulates wakefulness. I take this medication 4 times a day. It’s almost like having a coffee to get that little bit of energy needed to get through. The

medication only works for a couple of hours at a time. Eventually, it wears off and if I don't get to take my next dose, everything is a struggle. Although the medication helps by making it less of a battle to focus on something beyond being as tired as I am, I can still feel the constant tiredness lingering behind it, and it does nothing to help me to wake up because I need to wake up first to be able to take my medication.

Having this diagnosis has been both a blessing and a curse. I now know that what I have experienced my whole life is not normal and have answers to some of my questions. Medication helps. The curse of it is that I will likely need medication and support from friends and family my whole life to wake up and have some semblance of a normal life.

Jacquie – 2023

