

## LIVING WITH IDIOPATHIC HYPERSOMNIA

I started to notice the exhaustion my senior year of college. I was told it was because I was a busy college student, so it was "normal" to be tired all the time. So that's what I thought. My attention started to falter during class, I couldn't focus on tests, I even started to fall asleep during class and between classes. I still managed to graduate, but I postponed going to grad school. I was too tired and knew I wouldn't be able to keep up.

I got a job, about 40 minutes from home, so I commuted to and from work. I started to notice I felt drowsy when I drove. I tried caffeine, rolling down my window, blasting music, going to bed earlier. You name it, I probably tried it. I still felt drowsy and ended up nearly falling asleep behind the wheel several times. I nearly went off the road a handful of times. I had lapses in memory, and was constantly forgetting where I put things, conversations I had, and things I experienced. I saw my doctor because I KNEW this wasn't normal at 22 years old, and now it was potentially dangerous. He was a doctor who was very inclined to order tests, so luckily, he ordered a sleep study and referred me to a sleep specialist right away.

The home sleep study showed no sleep apneas, so I had a polysomnogram and multiple sleep latency test a few months later. That was the first time I heard the term "idiopathic hypersomnia." I had no idea what that was. I was prescribed a stimulant, which I quickly seemed to build a tolerance for, so my dose increased rapidly. I dove into research, trying to find out as much as I could about IH. Everything I found said there was no known cause, it was a rare diagnosis, it was potentially lifelong, and there is no known cure, only treatments to help the symptoms. Every time I remember there is no known cause and no known cure for IH, my heart sinks. I am 27 years old with the physical and mental endurance of someone much much older. I can't stay out late. I can't function without medication to keep me awake through the day. I quit my job in childcare, mostly due to being so exhausted. I couldn't keep up with the kids.

It has been 4.5 years since my diagnosis. For the most part, I am doing a little better, mostly because I take meds. When I don't take my meds, I can't mentally or physically function. It takes enormous effort to get out of bed, to take a shower, to do the little, everyday things that always seemed so simple. I have to allocate time for myself to rest, especially after events or trips, because I know I'll be too tired to do anything, sometimes for days afterward. My thought process is still foggy and sluggish. I used to write poetry, but the words don't come anymore. They get lost. Some days, I am even too tired to do the things I enjoy, like painting or reading.

I have to fight with my insurance company and doctor at times so I can get my medication covered, so I can afford it. If insurance doesn't cover the medication, it's over \$2,000 for 3 months. I've had to "ration" my medication before, make it stretch longer, just in case I have issues with insurance.

The most frustrating part of living with IH is definitely the effect it has on my memory and mental functioning. My brain can't retain memories for very long. I often get distracted and lose focus while at my job. My brain takes longer to process information than it used to. Sometimes I can't find simple words or phrases, or completely lose my train of thought. It's frustrating for me, and frustrating for those around me.

I try my best. I try to be patient, and remind myself that it's not because I'm incompetent, it's because I have IH. It's because this disease wreaks havoc on my body and my brain; it isn't a fatal personal flaw.

Thank you for allowing me, and others, to share our stories and experiences. It's my hope that IH will become more understood, that a cause may be found, and a treatment discovered to cure the disease, not just make the symptoms slightly more manageable. I give permission for my story/pieces of my story to be shared in order to bring awareness, and to make others with IH feel understood and not alone.

**Nicole – 2023**



**IDIOPATHIC HYPERSOMNIA  
AWARENESS WEEK®**