

LIVING WITH IDIOPATHIC HYPERSOMNIA

My name is Anna and I have been diagnosed with idiopathic hypersomnia since October 2018. I had been dealing with sleep related issues for years, starting in early high school. I was the kid that would come home after school and take a nap on the couch. In college, I would go to my room between classes to take a nap. My life was scheduled around when I could sleep or not; not that naps actually helped. Despite regularly sleeping 11-12 hours overnight and napping for up to 2-3 hours during the day I constantly craved sleep. I had been going to my doctor for about 8 years, getting regular blood work done, starting on medications for other health issues and constantly believing that this "new" medication and diagnosis would finally fix what was wrong. But nothing helped.

At one point a sleep therapist diagnosed me with Delayed Phase Sleep Disorder, thus switching my whole schedule and routine, only to find that didn't help either. It wasn't until I was in my last year of graduate school, working part time, sleeping in my car on lunch breaks and between classes that I finally convinced my doctor to be referred to a sleep specialist. After finally getting an appointment and meeting with the sleep doctor the first time, I was worried that I wouldn't be taken seriously as I was told that I was a "healthy and active young adult". After much pleading, and some crying, I was approved for an overnight sleep study and MSLT. Being woken up from my five MSLT naps was my first sign that something was truly wrong.

After a month of waiting for my follow up, I was seen by an amazing provider who read over the results with me, looked me in the eyes and said "Oh, you have Idiopathic Hypersomnia." I cried after finally getting a name to what was wrong, noting that my average sleep latency time was 3.9 minutes, and no REM. I was told at the time that the reality is that most treatments are bandaid approaches to managing the symptoms. I was started on Modafinil, and remember my first day taking it was a day that I had a morning supervisory group for my licensure, and I was awake! I had noted yawning maybe twice in three hours, my previous average being about 50 times. I was amazed at this feeling of being awake, something that I honestly don't remember ever experiencing.

Sadly, the medication didn't last long, and now 5 years later, I have been on 10 plus medications and combinations but nothing has worked. I still sleep excessively; I struggle to wake up and despite all the sleep I still never feel fully awake. When I am awake, I am consumed by an unrelenting brain fog.

I have a new doctor who specializes in idiopathic hypersomnia/narcolepsy/neurology, and we are at the point of possibly doing another sleep study or a spinal draw to check for narcolepsy since I have multiple symptoms that overlap between the two sleep disorders. I work about 25 hours a week, have a 15 month old daughter at home who keeps me on my toes, and a husband who is incredibly supportive. While I am not yet done searching for other answers as to what has caused my great need for sleep, I am closer to accepting that as of now I am doing my best with what I have. I'm sharing my story because I'm encouraged by the idiopathic hypersomnia community (our Facebook group has been an awesome resource), the research that is being done, and the understanding that just because we are "idiopathic" doesn't mean that our diagnosis is the end.

Anna – 2023



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