

LIVING WITH IDIOPATHIC HYPERSOMNIA

Living with Idiopathic Hypersomnia (IH) is terrible, it is a life-long condition that I never expected to be diagnosed with back in 2018.

Idiopathic Hypersomnia is a rare chronic neurological disorder where a person suffers from excessive long hours of sleep, difficulty waking up from sleep, daytime sleepiness, and brain fog. There is no cure for IH and the cause of IH is unknown.

Back in 2018, I went to a sleep specialist to see what was causing my extreme tiredness and sleepiness. My extreme tiredness and sleepiness were affecting all aspects of my daily life; however, the most concerning aspect was my driving. I was nodding off while driving without being aware of it and I scared my family when I almost went off the road driving on a road trip together!

At the time, I thought I would be diagnosed with Sleep Apnea, unaware that IH was a possibility. I had an Overnight Sleep Study and a Multiple Sleep Latency Test (MSLT), it was the MSLT test results that confirmed my Idiopathic Hypersomnia diagnosis, my test results showed that I fell asleep in 2 minutes for each of my naps, a person without IH usually takes approximately 10 minutes or more to fall asleep.

I remember receiving a phone call less than a week later telling me that I had to go see the sleep specialist right away to discuss my results...I was asked by the sleep specialist if I knew what "Idiopathic Hypersomnia" was...I told them I never heard of it before, they told me that I was being diagnosis with IH because my extreme sleepiness and tiredness matched the symptoms of IH as well they told me that was no known cause or cure for IH...the most shocking part of the whole experience was being told that I was being reported to the Ministry of Transportation and my driver's licence would be taken away unless I was put on medication right away for treatment for my IH!

At that moment in 2018 I was in disbelief and devastated, I was just given a life-changing diagnosis of Idiopathic Hypersomnia with very little information and resources to help me understand how to cope with IH...I was given a prescription for stimulant medication to keep me awake in order to keep my driver's licence and to book a follow up appointment to see how the medication were helping to keep me awake! This is why it's so important to increase "Idiopathic Hypersomnia Awareness" because it was very difficult for me to find information about IH when I was first diagnosed and not being able to find helpful information and resources made coping with my new diagnosis very difficult and very frustrating!

Learning to live with IH has been a daily struggle...wishing I could just wake up like everyone else and not needing 8 alarms to finally force myself out of bed to start my day!

It is not easy for people with Idiopathic Hypersomnia to explain to others how frustrating their extreme sleepiness and tiredness along with brain fog affects their daily lives...

some days I will have a burst of energy to start my day and other days I will have no energy and I must be dragged out of bed!

When I am not working and I am at home, I am usually sleeping to catch up on the sleep that I loss from working or I just so sleepy, tired, and exhausted mixed with brain fog that I don't want to do anything...living with IH is so frustrating because I have so many things to do!

Being on medication for my IH does help but it only helps for short periods of time...I find that staying active by always moving helps me to fight back against my IH symptoms however when I stop being active and sit down, my IH tells me that it's over and you are sleeping now!!! I push myself so hard that my body is overworked, and my mind is overworked too!

Living with IH is difficult. I feel guilty all the time for all the promises that I have broken to my family and friends! IH has taken away so much from my life and I have so much guilt for all the missed time with my family and friends all because I was sleeping!

It is important for people to understand that living with Idiopathic Hypersomnia is not my choice, I did not choose to have this rare, misunderstood, and extremely frustrating sleep disorder! "I want to live my life and I do not want to plan my life around my sleep! I do not want to miss time with my family and friends! It is not my choice, sleeping my life away, I do not want to sleep my life away!"

The most important thing that I have is that I am optimistic person, and I am a fighter, living with Idiopathic Hypersomnia is a daily struggle that needs more awareness and with more awareness brings hope that one day better treatments will be found to help all people who struggle with Idiopathic Hypersomnia!

I am sharing my story because I want others to know that they are not alone living with the daily struggles of Idiopathic Hypersomnia and to reach out for support* if you are struggling! Thank you for taking the time to read my story...my journey with IH is far from being over and I will do my best to fight to stay awake to spend my time with my family and friends...I do not want to sleep my life away!

Maryann – 2023

**Maryann is one of the Living with IH Canada Online Community Group facilitators. If you are struggling and need support or would just like to meet someone else living with IH in Canada reach out to the Living with IH Canada group, email: hypersomnolencecan@gmail.com*



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