

Idiopathic Hypersomnia (IH) runs my life more than I would like to admit. I am a very social person and love doing all of the things but IH makes doing what I'm expected to do difficult. When I can't hide my IH I get very anti social and irritable, which isn't me. That isn't my personality. I need to just lay down but I want to participate in all the activities I don't want to miss out on life. I get anxious about not being fully awake for all of the things I want to do with friends and family. I want to be able to take a nap in-between a busy weekend of activities but I fear that I won't wake up feeling any better but instead worse because this is what generally happens.

I have been clinically diagnosed with IH for almost 2 years. It is not just an excuse. It's a real medical condition and it runs my life, there is no cure. I'm lucky compared to a lot of people who suffer from this chronic illness because I can still successfully work and carry on a somewhat normal social life but it still very hard.

I find myself trying to make acceptable excuses instead of being honest that my IH is making my life really hard today. Sometimes I will have a really great week or a few days and I'm so thankful for that time. Then when I want to enjoy time with friends and family I just can't. I can't make myself be social. I can't make myself stay awake. My body doesn't cooperate with what my mind wants. I fake a smile and a laugh to try and make it through whatever event that is going on. If my behavior seems off or not typical, please give me kindness and grace. I am still struggling to figure out how to have a good quality of life and manage this illness.

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#LivingwithIH

Idiopathic Hypersomnia Awareness Week 2021



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