

LIVING WITH IDIOPATHIC HYPERSOMNIA

Sleep wasn't something I thought much about until I had glandular fever in my final year of high school. The virus knocked me sideways, causing a level of fatigue that was previously unfathomable to me. It was such an exciting time, and there was so much I wanted to do and achieve, but I was suddenly a zombified lump. I can remember how intolerable it felt, and how I longed to feel like myself again. But sadly, the sleepiness never left, and now I struggle to remember how life felt without it.

I wasn't officially diagnosed with Idiopathic Hypersomnia (IH) until I was 24 years old. After years and years of struggling to wake up and to stay awake, with dragging myself through each day feeling a sleepiness so extreme I couldn't begin to explain, despite sleeping more than anyone I've ever know, I did feel a sense of relief to have a name to put to it. I was prescribed medication, and at first this made a world of difference. Taking the medication, I felt more awake than I had in years and felt like I'd found a solution. But slowly the medication's effectiveness began to wear off, and I became increasingly immune to it. The drug also comes with negative side effects – I don't feel like myself on it, I'm more anxious.

There isn't an area of my life that IH hasn't affected. The smallest tasks overwhelm me, I have trouble staying in contact with friends, I'm easily depressed, and find it nearly impossible to maintain regular employment. I've always been an ambitious person, who has prided myself on my work ethic and I hate not being able to live up to my own expectations.

Obviously, there are far worse illnesses in the world and there is something inherently comedic about sleeping conditions - my friends have countless pictures of me sleeping in bizarre places, and I laugh about it too because making light of it is easier than admitting how much I feel I have lost. But that's part of the problem, and what makes it so hard for others to understand. Staying awake is such an infuriatingly simple concept, and something so many people do without thinking. For me, it's a constant challenge. So much of my life is swallowed by sleep – huge 16-hour chunks of my day are eaten up by deep, uninterrupted slumber that is entirely unrefreshing. My sleep inertia is so severe that multiple alarms barely scratch the surface, and I often rely on family to ensure that I don't fall back to sleep.

Nowadays, I'm much better at handling many aspects of my condition. I'm an expert at sleeping in public (sunglasses are key), I've figured out how to manage regular exercise, and I am better able to conserve my energy for what matters most to me. I don't think I'll ever feel at ease with the way my life is curtailed by IH, but I'm a lot better at looking at the bright side – long haul flights are always a breeze!

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