

I have been battling Idiopathic Hypersomnia (IH) in increasing degrees all my life and I'm over half a century old. It has been a long time. As every decade passes, I can't believe I've made it. I also can't believe that there are still no answers on the horizon or true public or general medical knowledge. It still carries many misconceptions and judgments.

This is what IH feels like for me, a general anesthetic. Try navigating your life through a leaded curtain which weighs the body and mind down, where you crave relief and find it in sleep but pseudo-wake up to find it's still with you. I say pseudo because you don't really feel awake, as with a general anesthetic I feel groggy and heavy as I start to gain consciousness only with IH it feels like a permanent state.

There may be periods in the day when I feel more lucid than others. Interaction happens with the world around me through a veil. Sometimes I don't know whether something happened in my dreams or was real. I travel in slow motion but the world is in warp-drive. I work, socialise, cook, plan, participate in milestones like grandchildren, weddings, deaths, moving, divorce, appointments, community activities etc in that state of being. I think the biggest loss is true human exchange which requires remembering, processing information and feelings promptly, finding my words quickly and succinctly, following a joke and laughing in time or remembering the sequence of a joke to tell it myself, or engaging in an exchange of activity. Life is happening around me but I seem to be floating by. I'm a spectator.

Written by Denise for the Idiopathic Hypersomnia Awareness Week 2018



IDIOPATHIC HYPERSOMNIA
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