

## Do you....?

Do you feel tired?

Do you feel sleepy?

Do you feel exhausted?

Do you see the difference?

To the Idiopathic Hypersomnia (IH) sufferer I find myself to be, there are distinct differences between these words that are often used interchangeably by others. I think perhaps the various meanings of these are so distinct to me because I live my life in a perpetual balance of the three.

Idiopathic Hypersomnia is characterized by excessive daytime sleepiness (EDS). I sleep for approximately 12 hours a night, fitting me into the long sleep category, whilst some sufferers will still sleep within normal bounds (up to 9 hours a night). Getting this amount of sleep doesn't diminish the EDS but reducing sleep time reduces my cognitive functioning and below eight hours leaves me feeling physically ill. Waking up is another struggle, I often sleep through multiple alarms and fall back asleep after being woken by someone. Thus, I'm very reliant on my lovely mum to keep waking me up and making sure I actually make it out of bed (and medications to keep me awake), though this is an art that is still being mastered. The video below may help you understand some of the difficulties us Idiopathic Hypersomniacs deal with each day:

<http://youtu.be/ROipDjNYK4k>

I cannot remember how it feels to be tired or sleepy or exhausted in the way a normal person feels. These words have taken on a different meaning to me because of my experience with IH. So what does tired feel like? For me feeling tired is part of my every hour, it's being awake but not aware. My eyes are open but my mind isn't embracing my physical awakening, it's as if my brain stays in no mans land, between awake and asleep, opposing, warring states. When I am tired I can still think and read and write, do pretty much anything, sometimes I can do it well, other times I can spend two hours to do 15 minutes of work.

Sleepiness, on the other hand, is very difficult to get past. It's the unquenchable need for sleep, you can fight it and you know it's coming but there's only so much you can do before it inevitably wins and your eyes flutter shut. Feeling sleepy leads to a long unrefreshing nap which is typical of IH sufferers or just going to bed for the night even if it's only 4pm. I can be falling asleep/feeling sleepy, when all I want to do is go for a run, when my body is longing for movement yet my brain is disregarding this other part of me. Exhaustion, to me, is both mental and physical fatigue, I feel exhausted if I've spent five hours up and doing daily activities. My body is tired from exertion, despite how little I may have actually moved and my head longs for the calm which it is denied during the

day. The constant “stay awake, eyes open” on repeat inside my head is mentally taxing, particularly when you’re trying to learn something at the same time.

None of these words can truly describe how one feels with Idiopathic Hypersomnia. It’s different for each of us, just as words for everyone else can hold a different meaning to those around you, there are innumerable ways for us to define and explain words that fit into our individual notion of what they should mean or what they mean to us. I find it strange that such common words can take on new heightened meanings when we are forced to find a way to fit them into our own experiences. The word future has also been tainted by this disorder. Whilst I know the future is what’s before me, it has been tainted with thoughts of ‘long term cognitive functioning’ and the many unknowns of this disorder, the reason Idiopathic is yet to be dropped.

Having this disorder has changed the way I look at words and how I interpret them. In my view one can be tired, yet not sleepy. You can be sleepy yet not exhausted. You can be exhausted but not sleepy.

I’m sure I could go on but right now I’m feeling a bit tired. Or maybe sleepy? Hell, I’m exhausted. Goodnight.

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