

I'm a high achiever so finding myself in a constant battle with sleep doesn't sit well with me. I don't want to sleep my life away. I don't want to battle with the overwhelming urge to sleep either but I have no choice. It engulfs me every day. I have spent my whole life fighting to achieve even the simplest things, education, hold down a job, have a family. I want so much more but every time I have pushed myself to achieve more it usually ends up a mess or I do! I'm older and wiser now so I've worked out my limitations and I have accepted them. I still take on too much but I now know when to say to myself "you know how this is going to end, stop now before you go to far". I stop, re-evaluate my life, make (more) adjustments and carry on.

What have I learned?

The medications that are currently prescribed for Idiopathic Hypersomnia (IH) are not life changing in the way many people expect them to be. They don't treat the cause, they don't even address all of the symptoms. At best they assist me to wake up and stay awake long enough to achieve part of what I want to do in a day. My daily 'to-do' list is never unreasonable (it was ridiculously unreasonable when I was younger) but I still *never* tick off everything on it. I'm always re-scheduling and re-prioritising. Once I've managed to wake up properly ie: gotten through the sleep drunkenness, and I'm functioning at 'my' normal I get about 3-4 hours where I can get things done. If I'm active I might get 4-6 hours. Office work or anything I need to do at my computer will always mean I have less quality wakefulness. And then the sleepiness kicks in. Like anyone with IH I push myself through this for as long as possible (no one likes sleeping their life away). But I eventually have to stop what I'm doing.

People with IH have an amazing ability to fight sleep but I guess that's inevitable considering the training we get in it (we fight sleep every day). The problem is while we are desperately fighting sleep our ability to do even the simplest tasks can become very complex and time consuming. Also, a lot of what we do is automatic behaviour (we do it without consciously being aware of it) so we may not remember later on where we are up to with a certain task or that we even started one. That's not so bad when it's a load of washing – people with IH will relate to that, how many of you have put washing on and only realise it when you go to use the washing machine again or when you are looking for a certain item of clothing? But automatic behaviour can be dangerous and the consequences much worse than a washing machine of stinky laundry. I have left pots on my stove until the bottom has burnt out and the fire alarm goes off. I have left my daughter in her car seat too... I don't even want to relive that story, suffice to say not all of my automatic behaviour are "silly mistakes".

I've also learned that no matter how many times I tell people the quality of my sleep, and everyone else with IH is good I'm still given advice about what will help me sleep better so I have stopped telling people about IH. But I'm glad the Idiopathic Hypersomnia Awareness Week gives me and others the opportunity and the platform to

express how we feel.

There is so much more I could say but if I could get people to understand just one thing it's that people with IH have good quality sleep, lots of it. Even with medication it still means we have an enormous battle to wake up in the morning and our wakefulness is short lived. What we go through when we fight sleep is horrible and we have to do it every day.

So please note: IH tired is not normal people tired. To start with when normal people are tired it's generally because they are sleep deprived or their sleep quality isn't good. IH tired is sleepy, we are sleepy **DESPITE** having lots of good quality sleep. We can't turn our sleep switch off. With normal people they are tired because they either can't or don't allow their sleep switch to turn on. That's a huge difference – one I wish people would understand.

Written by Shelly for the Idiopathic Hypersomnia Awareness Week 2018

