

I sleep a lot. I always have. 10+ hours a night. Every night.

I nap a lot, too. 2 hour naps. More than once a day. Everyday. This is my normal.

The theme of this year's (2016) Idiopathic Hypersomnia Awareness Week is "Improving Quality of Life".

I love this theme as it is something that I have been personally working towards this year.

Until a few months ago I was working full time and had a great career. To the outside world I appeared normal. But only those closest to me knew my secret. You see, when you need as much sleep as I do working full time means you have no time for anything else. No time to cook or clean or look after yourself properly. No time to see family or friends and maintain healthy relationships. No time to enjoy life. Even with neglecting every other area of my life my continued drive to work full time was leaving me so sleep deprived that I was living life feeling like a zombie. My constant state of sleep deprivation had left me numb to life.

Three years ago, my need for excessive sleep was diagnosed as a rare sleep disorder, Idiopathic Hypersomnia. I clearly have no problems sleeping and my sleep quality is great but I have a daily struggle with being awake. Unfortunately, currently available medications have not reduced the amount of sleep I need every day.

I am often asked how I managed to work full time through to my mid thirties. The answer is in two parts.

The first is that I didn't know anything different. The second is that I made a lot of small compromises and adjustments through my twenties that allowed me to increase the amount of sleep I was able to get. When I was at Uni I would sleep in the library or in the common room between classes. Every day. Between every class. Some students get to hang out at the tav. I didn't get to spend any time there. A very good friend and classmate would prep me before exams and her efforts saw me graduate with distinction. As I look back and reflect on this accomplishment, I am filled with extreme pride. I also wonder what I could have achieved if I didn't spend all my time at Uni sleeping.

In my working life, I used public transport to commute to work which allowed me additional sleeping time. One hour to work, another hour on the way home. Every day. I lived at the end of the line so I couldn't miss my stop.

And then I moved closer to work. Only a 10 minute walk. Crossing roads was a hazard in my sleep deprived state so I made sure to always use pedestrian crossings and the green man at the traffic lights.

At work I implemented methods that allowed me to recognise any sleep deprived mistakes I may have made. My job was quite active and didn't involve me sitting in the one place for long periods of time. I find it easier to fight off sleep when I am physically active. Sitting still is the worst.

After I came home from work I would crash. Some days I would attempt to cook dinner but more often I would just sleep without eating. I actually find it hard to eat when I have been awake for 10+ hrs even though I am hungry. My weekends would be spent sleeping. Most weekends this would be 18+hrs each day. I would prioritise laundry over preparing meals and other household chores so I had clothes to wear to work. Most weekends my need for sleep trumped the laundry so I would buy new clothes to wear to work.

In May I made a big decision. A scary decision. I decided to take a risk and stop working full time.

I spoke with my doctors and we decided that I should try working 15 hours a week, spread over three shifts. I was so scared of losing my financial independence but I had finally come to the realisation that continuing to restrict my sleep by working full time had never been a healthy choice. My workplace initially agreed to the reduced hours and the positive change to my life has been nothing short of amazing. I could not have imagined how much better life could be with more time for sleep. I was still a zombie but I was so much less stressed and I saw that maybe there was a chance of me getting some balance back in my life. And on 15 hrs of work per week I still had some financial independence.

Then work advised me that they really needed me to work full days. I trialed doing two full days a week and it was terrible. The effects of the increased sleep deprivation was so apparent that I made the decision that the increased financial security was not worth the sleep deprivation it would cost in order to work full days.

Discussing my capabilities with my doctors it was decided that I should try and reduce my shifts from 5hrs to 4hrs and I am currently working two 4hr shifts a week. Financially I am struggling but I know I will survive and I will find a way to get through. I enjoy my short shifts for a number of reasons: I am less irritable; I am less clumsy; I don't need to lean against walls, benches and door frames for support to stand; I can enjoy conversations with my colleagues; and I don't walk into so many door frames.

By giving up my financial independence I have given myself more time for sleep and I am now living a less sleep deprived life.

My need for sleep is costly and I have missed out on a lot of life by giving all of my waking hours to maintaining full time work. I only wish I had been prescribed a formula for a balanced life when I was given my diagnosis three years ago. But I don't regret my life. I am learning to appreciate just how strong and determined I can be. I very much appreciate my doctors, close family, colleagues and friends who are supporting me through this transition.

The disorder I live with is rare and I hope that one day there will be more resources available for doctors and patients that could guide a more holistic approach to treatment that would explain to patients what changes they might consider to help them manage a more sustainable and well balanced life. If I'd had this guidance perhaps I would have seen and been encouraged to look at my need for sleep differently and been able to recognise that continuing to try and work full time was not a good management plan. I hope that with increased understanding and awareness such resources will one day be available to doctors to share with their patients as a part of the post diagnosis journey.

Written by Tiffany for the IH Awareness Week 2016

