

LIVING WITH NARCOLEPSY

Narcolepsy is an extremely challenging rare disease. It affects both physical and mental aspects of health and is incredibly debilitating.

It's incurable and lifelong.

How it affects people varies enormously and an individual's capacity to manage it is influenced by lots of different factors.

In many ways, I feel quite fortunate. My Narcolepsy didn't kick in until I was fifty and I'm grateful for that. I really feel for teenagers trying to get through school, for young people going to uni or starting a career, and for women trying to start a family. They all have it way harder than me. I'm older, have a supportive partner and family, an established career, and financial means and that all helps enormously.

One of the things that makes it really hard for all of us though, is that most people know nothing about Narcolepsy. Occasionally, if you're lucky, you might meet someone who's heard of it, but even then, it's likely to be the 'movie version'. That's where people randomly fall asleep in mid-sentence. That can happen, but that's not what Narcolepsy is about.

The reality is very different.

So, in the spirit of raising awareness, this is a snapshot of how Narcolepsy affects me. Like I say, everyone's capacity to manage it is different. I'm a pretty driven, A-type personality and I bring that to my illness.

Probably the most challenging aspect are the 'sleep attacks'. I think that's a very good term, because I do actually feel like I'm being attacked by sleep!

It's not about feeling really tired or exhausted; it's about an overwhelming and non-negotiable *need* to sleep – and quickly. It's a bit like jet-lag, but way more powerful, or if you've ever had a medical procedure, it's like those few seconds when they inject the anaesthetic and you're conscious...and then you're not. That's what a sleep attack feels like for me.

When I'm managing my illness really well (I'll come to that later), I have three or four sleep attacks a day (more when things are rough). I have some warning of them – anything from a few seconds to ten minutes – and they generally last between fifteen to twenty minutes each.

So, imagine your day today and in your day, you will have to sleep at short notice, wherever you are, three or four times. Tricky eh?

Then imagine doing that every day – work days, holidays, important days, Christmas day.

I make a choice every day to leave my house and try to live my life as fully and productively as possible. That's not easy, but the alternative seems worse to me. So, you wouldn't believe some of the places I've slept (and it's okay, you can laugh).

Many, many public toilets (private, quiet and safe, if a little unsavoury!)

Couches and soft chairs in shopping malls (very not private, but more comfortable)

Park benches (neither comfortable nor private)

Changing rooms in department stores (can be tricky and generally not super comfy)

Breastfeeding or family rooms in shopping malls (better, private and quiet)

The car (safe, private, and reasonably comfortable. I keep a blanket and cushions in there at all times. More difficult in summer)

Lots of first aid rooms (love St John's Ambulance) (Though I was once told I couldn't sleep in a first aid room for 'occupational health and safety reasons!')

Trams and trains (pretty good)

On the grass (sounds nice, but get covered in bugs and creepy crawlies pretty quickly)

Luggage trolleys while transiting through airports (definitely not recommended).

I have also slept in a snow flurry on the trail to base camp in Nepal, on the peak of Mt Feathertop in the High Plains of Victoria and, my all-time favourite, sitting on the side of a raft on a white-water rafting trip in Whistler (in the calmer waters at the end!)

Narcolepsy also affects my nighttime sleeping and I'm often awake and up when the rest of the house is asleep. Some days I just feel exhausted and extremely fatigued, especially after about eight o'clock. Socially, I'm not great in the evenings and I generally prefer a lunch to a dinner.

It also has a significant and seemingly worsening impact on my executive function, particularly recall and memory. My short-term memory is shot. I write everything down immediately. I have detailed calendars that I check repeatedly.

So, in order to be able to get through any given day (I have three children, a partner, and run a small consultancy business) I need to manage a whole range of factors really, really carefully. I'm like a toddler: routine is my friend, change and spontaneity are not.

To be as functional as I can possibly be, I need to pay attention to: my diet (low carb, high protein), exercise (regularly, daily walks), alcohol consumption (very limited and not late at night), mental health (mindfulness, stress management and occasional counselling), medication (careful and consistent use and management of side-effects), fun, play or

positive activities (time in the garden, walks with my partner, or lunches with friends), and decent times with my kids.

By managing all of these daily aspect of my life, I can function effectively in the world. And that's exhausting in itself! I put a massive amount of effort behind the scenes just to function 'normally' every day. If you know someone with Narcolepsy, I think that's one of the most important things to understand.

Some days, it really gets me down and I think about what my life would look like without this really crap illness, but that's never really very helpful. Some days, I think about all the other people in my life who have worse, or life-threatening illnesses, or who didn't even make it to fifty. And then some days I just feel really sorry for myself. I think they're all ok.

Mostly I'm grateful for my friends and family who support me – and for the many good things in my life. My work is really important to me and is incredibly rewarding and that really helps too. At the end of the day, I try to be philosophical about it and find some joy wherever I can.

Jac Tomlins
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