

## LIVING WITH IDIOPATHIC HYPERSOMNIA

Becca was always a very athletic, busy and happy-go-lucky child. Participating in all types of sport activities at school and giving it all a good go. Basketball was (and is) her favourite sport, and as it turned out, she had a talent for it. Playing at quite a high level through primary school, she then added netball to it and was playing intense sport every day and loved it. Suffering two significant injuries, she reduced the amount of sport, and focused on basketball only, right about the time she entered high school. In hindsight we think that subconsciously the start of her Idiopathic Hypersomnia (IH) also impacted her choice to play less sport.

Starting in year 7, she would go to school, come home and start to sleep for a bit, maybe an hour or two. During years 8 and 9 it would increase to two hours, then three hours, and then basically she would be sleeping all afternoon and weekends. She would get migraines that knocked her out for a couple of days (we now know the migraines came on when she didn't get enough sleep). She would also nap while being at friends' places and during school. The minute she'd get in the car, she'd fall asleep. Basically, if she didn't have to be awake for anything important, she was sleeping.

Looking back, the signs were there much earlier. For example, with her older siblings we have photos of them being active doing things throughout their childhood. With Becca we have countless photos of her sleeping, in all kinds of unusual places and positions, from when she was primary school age.

During the second half of year 8, her sleep was getting out of control and the associated migraines meant she'd miss on average two days of school per week. During this time, we had been to see our GP to seek help. It proved fruitless. First, he said it's all because she is quite tall, and her fast-growing body needed a lot of sleep. I explained that all the girls in her basketball team are tall and they don't sleep this much. Then he said that she is tall and active, so it must be tiring. I again explained that there are a lot of tall kids who play a lot of sport that don't sleep like Becca (plus she was not playing that much sport anymore at all). He then suggested she has chronic fatigue and we should let her rest full stop. He also said to take iron tablets and see if that would help. When we said that her symptoms don't line up with chronic fatigue, we were told she's simply being a teenager who sleeps a lot. It was infuriating and I didn't know what else to do.

The one thing I am very grateful for is that Becca is our third child. Comparing her sleeping needs to her two older siblings made it clear to us that it simply was not normal. After almost a year of consulting our GP, with no answer, during middle of year 9, we changed to a new GP, who would finally take us seriously. She said "this is not normal and we will find out what's going on". She started with an iron infusion, but this didn't make any difference. For the first time she said it could be sleep related. It sounds so simple and logical in hindsight. The feeling of finally being heard was incredible. This GP referred us to a

paediatrician, who organised blood tests and referred us to a paediatric respiratory and sleep physician, who asked us to complete a sleep diary. The sleep diary was quite confronting for us as parents as it showed how much Becca really was sleeping. Based on the results of the sleep diary, the specialist then booked a night/day sleep study at Monash (Multiple Sleep Latency Test). The whole process took about six months (including wait times, etc). Eventually Becca was diagnosed with Idiopathic Hypersomnia (IH), something we had never heard of.

I remember the morning of the sleep study, and Becca being fully wired up at 9am and being asked to go to sleep, and I thought there is no way she'll sleep with all these cables. Turns out she fell asleep within a couple of minutes and by ¾ of the day, they said the answer is obvious, and we could go home.

Having two older kids made it clear to me that something was different with Becca. I don't know that I would have been as determined to find an answer if I didn't have the older children to compare her to. What I have learnt from this is that parents know best, and to never give up.

Becca is now in year 10 and has adjusted her life to live with IH, and we as a family have adjusted around her, to support as her much as we can, without it being too obvious. This is our new normal. Becca plans social outings for Friday afternoon and Saturday nights only, as she can sleep all day Saturday and Sunday. Mind you, these outings are short, usually no longer than three hours. We have also increased her pocket money, as most of her friends have casual jobs. When they work, she sleeps.

What does Becca's week look like? Waking up in the morning takes a herculean effort, and she starts her day with a double espresso and four x Modafinil (medication to keep her awake). This usually gets her through school, but it's not always enough. Particularly when she's got exams and has to study, it's very hard for her to balance the need for sleep. She makes about 8.5 out of 10 school days. The school has been very supportive. We drive her to school so she can sleep as long as possible. When she comes home from school at 3.45pm, she eats and by 4.15pm she's asleep until about 8pm. She then eats, does some homework, watches TV and goes to sleep at about 10pm. Two nights a week she does sport. Her sport input is about 30% of what it used to be, and we're so happy she can play in a team where they are happy to have her just the way she is. Saturdays and Sundays she sleeps most of the days and goes out Saturday night and has a 1 hour training session of sport on Sundays. During the school holidays she only takes Modafinil when she goes out, and mostly sleeps the remainder of the time.

If you saw Becca out and about or at school you probably wouldn't pick that she has a chronic illness. She's so good at holding it together when needed, only to fall into a deep sleep for hours or days to recoup.

Being 16, Becca lives in the moment and is pragmatic about her IH diagnoses. She has adjusted her life and doesn't give IH any more attention than it needs to get through the day. She generally doesn't want to talk about it either. We are not sure how much she is aware, but her life is a constant tradeoff, as her energy is so limited.

The specialist said Becca's IH could stay the way it is, it could get better, it could get worse. We don't know what the future holds for Becca.

To be honest, I have not bothered to talk about it much at all with anyone. When we told some people after she was diagnosed, they just didn't get it. They suggested herbs, or 'more sleep' or vitamin D. It is a neurological disorder, herbs and vitamins don't fix this, in fact there is no cure. Medication merely masks the symptoms. Hopefully research will offer a cure one day.

For all the parents out there, who think your child has IH, push, push, push until you've been heard.

My heartfelt thank you to Michelle Chadwick for what she does. When Becca was diagnosed with IH, I read every word on her site, as it was (and still is) the only proper and useful information available in Australia.

Anne – 2023

