

WHAT IS NARCOLEPSY?

Dr Unnati Desai, national lead for GP services at Nuffield Health, says, "Narcolepsy is a rare neurological condition that means that the brain cannot regulate sleeping and waking patterns. Symptoms may include drowsiness during the day, falling asleep without warning (sleep attacks), hallucinations, the inability to move or speak when waking up or falling asleep (sleep paralysis), excessive dreaming and waking in the night, and cataplexy (sudden loss of muscle tone/weakness in muscles).

"Though it does not have a long-term impact on physical health, it can be difficult to live with the

condition and can affect quality of life. The condition is usually caused by reduced levels of hypocretin, or orexin, a chemical in the brain that regulates wakefulness, however, the exact cause of the problem can be unclear. Other potential triggers include hormonal changes, major stress and/or an infection such as flu.

"There is no cure for the condition, but lifestyle changes to improve sleeping habits together with medication can help to reduce the impact the condition can have. You might be prescribed medicine that can reduce daytime sleepiness and improve your sleep at night."

"I knew being a mother would be hard but it's something I've always wanted so we decided to just take each day as it comes."

Terrifyingly, hallucinations and sleep paralysis are symptoms of narcolepsy.

"Lying in bed, I believe I can hear people coming into my house. I'm so scared, I can't move. Sometimes I see my grandma, or I feel the dogs on my bed. When you're in that state it's terrifying.

"I was paralysed with fear when I looked at the baby camera one night and saw someone taking Billie. And then I woke up, looked again and she was sleeping."

Belle says she used to worry about what she would do after leaving school – but then she discovered exercise.

"I was always sporty at school so, at 17, I decided to run a 10k, but my sleep specialist warned me not to push myself because it could make my attacks worse. I did it anyway and got to the end and was so chatty, Mum thought I'd taken extra medication.

"That's when I took my personal training course. I had around five clients a day but I'd work

out with them because it stopped me falling asleep. Then I moved to Amsterdam and got a job at a gym."

Nowadays, if Belle doesn't schedule a nap as doctors advise, sleep is inevitable. Medication allows her to fall asleep less spontaneously but without scheduled shut-eye, she will eventually lose control again.

"It will pounce on me. Sometimes you won't even know I'm sleeping because my eyes are still open. Since lockdown, I stream workouts every morning to women around the world and that's how I manage my narcolepsy. I wake up and do my workout. A nine-to-five office job is almost impossible.

"My online business helps me spread the word for people with narcolepsy. All these people were being told not to exercise too much yet it was my saviour. It makes me feel on top of the world."

ALI GRAVES & RHONA MERCER



With husband Maikel and daughter Billie

were taking pictures of us! In the past, people would assume I was lazy or on a boring date."

She has also found herself in life-threatening situations. "I hurt myself sleepwalking. I fell asleep and tried to put milk in the fridge but walked straight past it and outside, into the front of my car. It was the biggest shock."

Driving has also got her into some hairy predicaments, and she admits Maikel does most of the driving now. "I've had times where I was driving and I'd feel a sleep attack coming. I'd do everything like slapping myself in the face or pinching my leg to stay awake, until I found somewhere safe to pull over. It's like being drunk, you're just completely out of it."

BECOMING A MUM

When considering motherhood, Belle, who admits her condition can be affected by hormones and her period, had to think hard. "When we were talking about having children

we did consider if I'd pass narcolepsy on – there is a 5% chance – but my husband said our baby would have the best mother to show them how it won't take your life away. It was the sweetest thing he could have said."

She says, "When I was pregnant, I had to stop my medicine, so it was a big decision because I'd been on it for 10 years. During pregnancy, the hormones were magical. I felt amazing. Even though I was off my medication, I was able to go for dinner and stay awake. Some mums with narcolepsy have said if they could bottle the pregnancy hormones and take them as medicine, it would be life-changing!"

Belle admits that there is one advantage to having narcolepsy and being a mum. "I'm used to broken sleep – I haven't had a full night's sleep since I was 16!

Have a story to tell? Email us at truelife@reachpic.com