

This Is What It's Like To Have Narcolepsy

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By Ashley Starr, As told to Stephanie Booth January 3, 2017



ashley starr narcolepsy

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When I was 15, I suddenly found myself unable to stay awake during school. Exhaustion would hit, and the only thing that woke me was my head jerking backward as it fell toward my desk. I liked school, was in good health, and went to bed by 9 PM every night. Still, my teachers thought I was being lazy—the stereotypical "tired teenager"—and called my parents. "I sleep all the time!" I kept insisting. I knew this wasn't run-of-the-mill fatigue, but I couldn't figure out what was going on.

Soon I started nodding off anytime I sat still for more than a few minutes, including during basketball practice. After we finished working out, we'd all sit down in the gym while our coach went over new plays. I'd lean against the wall and feel myself nodding off. "Move your arm!" I remember telling myself. "Snap out of it!" I'd try to lift a finger but couldn't—until my coach's voice rose to make sure everyone was paying attention.

Each time I fell asleep, I had extremely vivid dreams. If I fell asleep after school, I'd dream I was doing my homework. But when I woke up 10 minutes later, I'd realize I hadn't finished anything. (Heal your whole body with Rodale's 12-day liver detox for total body health.)

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When anything scared me or made me laugh, I wouldn't fall asleep, but my entire body would go limp. My jaw would lock and I'd find it hard to stay upright. I remember I was leaving my cousin's house one day when she said something funny; I had to hang on to the door to keep from falling down. My body felt like Jell-O.

My symptoms were so weird that I didn't feel comfortable talking about them with anyone besides my parents, who were as confused and concerned as I was. They took me to a series of doctors and I had test after test, but no one seemed to know what was wrong. So when I was assigned a research paper for school, I decided to investigate my symptoms myself. That's when I came across a condition called narcolepsy. The more I learned about it, the more sure I became that I had it. Although the exact cause of narcolepsy isn't known, it's linked to low levels of chemicals called hypocretins, which regulate wakefulness.

My mom suggested I bring my paper to my next doctor's appointment. He was skeptical because no one else in my family had narcolepsy. Still, he agreed that I should undergo a sleep study. Falling asleep in less than 2 minutes would indicate an underlying sleep disorder. When I was asked to try to nap, I fell asleep almost instantly. And I did that three times in a row.

I found out that narcoleptics don't cycle through all the normal phases of sleep. Instead, I was going straight into and out of REM, the phase in which dreams happen. I was sleeping, but not getting quality rest. Try to imagine how you'd feel if you stayed up 72 hours straight. That's how I feel all the time.

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Learning to cope

Knowing the cause of my symptoms was a relief, but I still had to figure out how to manage them. Medication helped control my impulse to sleep, and finally, I wouldn't fall down if someone made me laugh! But emotionally, it wasn't easy. There were so many changes I had to make.

I was always tired, yet I couldn't sleep as much as I wanted because doing so only made it harder to wake up. And even though I'd be in bed 7 to 8 hours each night, I'd really sleep only 4 or 5. The rest of the time, I'd have vivid dreams that left me exhausted when I woke. I used to love to read, but doing so put me to sleep, so I had to get used to listening to audiobooks. Meanwhile, I was so embarrassed about my condition that I almost didn't apply to college.



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My mom was the one who finally encouraged me to stop hiding my condition and go to a support group offered by Narcolepsy Network, a national nonprofit working to improve awareness of the disorder. At the first meeting, I met about 20 people who either had narcolepsy or had a child diagnosed with it. Finding out that there were others going through the same thing and hearing about how well they were managing was inspiring. I realized that if they could live normal lives with this condition, so could I. Not only did I graduate college, but I also went on to get a master's degree in public health.

An ongoing struggle

I'm now 28, and I live with my amazingly supportive husband in Boston.

Although I feel that I'm mostly in control of my condition—I even speak to others about it through a group called Wake Up Narcolepsy—I still have to factor it in to almost every decision I make: I go to bed and get up at the same time every day, and I hit the gym as much as possible to keep my energy levels up. For the same reason, I eat lots of small snacks instead of large meals. And I'll never eat something heavy like pizza unless it's late at night and I'm already headed to bed.

Over the years, I've tried nearly two dozen medications to manage my symptoms. Finding ones that help and are affordable hasn't been easy. (One I no longer take costs thousands of dollars each month.) The two medicines I currently use help me stay alert and keep me functioning. But at least once a day, I feel a narcolepsy attack coming on and have to drop everything and nap for 10 minutes.

Narcolepsy is an invisible disability, and it takes time to figure out how to best manage it. Although I feel I'm doing pretty well, it's a struggle sometimes. I wish people without it knew how lucky they are to get a good night's rest.