

Cultural Daily

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Narcolepsy

Evie Sullivan · Wednesday, March 28th, 2018

***Narcolepsy:** a neurological disorder that affects one's ability to regulate between sleep and wakefulness cycles. Famous narcoleptics include Winston Churchill, Thomas Edison, Harriet Tubman, Kurt Cobain, Louis Braille, and Jimmy Kimmel...*

I'm in bed, counting sheep, thinking pleasant thoughts, interrupted by angry bouts of sleeplessness. "Two hundred and ten, two hundred and eleven..." How many more damned sheep are there to count? It's finally 6 am and I'm allowed to wake my parents. I have been up for two hours, maybe three.

I shake my father first, show him my smiley face, then wake my mother. "Get up, it's 6 in the morning!" I say. My father snorts, "It's also Sunday! Let us sleep!" But my mother knows I won't leave her alone until she gets up and prepares breakfast for me. She has suffered now for 10 years through my sleeplessness.

It started when I was a toddler. I'd wake up in the dark, lay in bed, sometimes crying, sometimes silent, but unable to fall back asleep. Dr. Baer, our pediatrician, told my mother this was normal toddler behavior, and she should leave a glass of milk with honey on the nightstand for me to drink when I woke up. "That should help!" he smiled. But it didn't. When I was older, he prescribed valerian drops. "Evie is a nervous child, that's why she can't sleep through the night!" Dr. Smartypants was wrong again. I wasn't nervous, nor was I worried at age 7, or 8, or 9. I just couldn't sleep through the night. At age 10, he suggested combining warm milk with honey, valerian and chamomile drops. I had no problem taking the remedy before bed because I liked the sweet-bitter taste, but it didn't make me sleep. Now it was my mother who needed sleeping pills to deal with an insomniac child. "Evie is so difficult," she'd tell everybody. "She doesn't eat, she doesn't sleep. I have no idea how this child functions."

I functioned alright. A straight-A student, a wild card on the softball team and an ardent reader, my mother had no complaints about my accomplishments. But she was constantly worried about my lack of sleep and appetite. What was wrong, and whether those two symptoms went together, was a mystery.

When I turned 12, Dr. Baer threw "gummy bears" into the mix of warm milk with honey, valerian and chamomile drops and a warm bath before bedtime. But nothing helped. I hated going to bed, I had panic attacks, afraid of yet another sleepless night. I also refused the regimen my mother dutifully prepared for me. "I just want to sleep, not to get fattened up!" I told her. Restful nights were rare; I awoke each night around 3 am.

My mother was called into school to talk to the principal.

“Evie sleeps during classes,” she told her. “We can’t even wake her up. Sometimes she snores. What’s going on in your house? Is your husband drinking, or is he beating her up so she can’t sleep at night? Are you home with her?”

“Evie is bright but very difficult,” my mother sighed. “I don’t know what to do. And, by the way, my husband doesn’t drink. We go to bed around 10, we don’t watch TV in bed. No parties, no alcohol, no loud music. It is not us. It is Evie, and I’m at the end of my wits.”

We were all at the end of our wits, me, my parents, teachers, and friends. My childhood was overshadowed by my inability to sleep regular hours. Later, when I had to take the train to high school, I always slept on both commutes. At least the sleepiness at school had stopped because of it. My struggle with my sleeping disorder didn’t stop when I got married. I kept my husband up at night. He wasn’t amused, nor did he administer the same patience as my mother. Pretty soon, I slept on the couch in the living room.

Over the years, I participated in a sleep study, went to sleep classes, took melatonin, sleeping pills and sleep water. It seemed all the stuff I put into my mouth was bad for my stomach but had no effect on my sleeping patterns.

The internist I saw at the Kaiser Sleeping Department deluged me with questions and told me he had never seen a case like mine. I live a quiet life without alcohol, drugs or tobacco. I’ve never smoked pot, but I tried edibles and cbd-oil to help me sleep with no effect. I go to bed at 10, I exercise regularly, and I have stimulating work. What’s wrong with me?

“Would you like to go to a sleep lab for a night and a day?” the doctor asked. “There, we can measure your patterns while you sleep.”

While I was waiting for the lab results, I read about Jimmy Kimmel’s sleeping disorder. “I have narcolepsy,” he shared. And he joked about it: “Truth be told, I’d rather have narcolepsy than not have it. When I get on a flight to Vegas, I’ll fall asleep before the plane takes off and wake up after it’s landed. I’m always very close to sleep.” And so am I. I travel extensively for work and pleasure but it’s safe to say that I’ve never experienced the take-off of a plane. I sit down and fall asleep. I wake up when the flight attendant shakes me before landing.

Until I read about Jimmy Kimmel’s sleeplessness, I’d never heard of narcolepsy. Not one doctor ever mentioned it to me. I got my diagnosis from Jimmy Kimmel. Isn’t that a sign of the times?

The bottom line? Narcolepsy can’t be cured. There is no treatment. So, like the late-night talk show host and countless others who are affected, I’ve chosen to make the best of it. This morning, at 3 am, I made a wonderful dish of stuffed zucchini that I will eat for lunch (after I take a nap around noon, so I can be alert for the rest of the day). That schedule works for me. I’ve surrendered to the weirdness of it all. After all, if it works for Jimmy Kimmel...

(Featured photo by Nina Prommer)

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