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IT HAPPENED TO ME

What it's like ... to have a young son with narcolepsy and cataplexy



A rare neurological disorder that involves excessive daytime sleepiness, sleep paralysis, hallucinogenic dreams and cataplexy (sudden loss of muscle control), narcolepsy isn't usually diagnosed until adolescence and there is no cure.

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We knew something was wrong with Dylan early on. He went from being a happy baby to sleeping constantly. When he was awake, he was angry, irritable and aggressive. We hoped he was suffering from sleep apnea and that he would be better after a tonsillectomy. Surgery didn't help and doctors didn't know what was wrong. One day I came across an online video of a girl with narcolepsy: it looked like Dylan. Suddenly I knew what he had.

A rare neurological disorder that involves excessive daytime sleepiness, sleep paralysis, hallucinogenic dreams and cataplexy (sudden loss of muscle control), narcolepsy isn't usually diagnosed until adolescence and there is no cure. At 3, Dylan became the youngest Canadian ever to be diagnosed with it. Doctors had never seen a case like it.

I felt a certain sense of relief when we had a diagnosis, but I didn't realize what lay ahead. We tried one drug after the next to help him sleep at night and stay awake during the day. Our last resort was [a medication] that is known as one of the most effective drugs available for narcolepsy and cataplexy. We were petrified when we gave it to him because, if it didn't work, there was nothing else that could. Fortunately, it's been helping him get more sleep than he has in the past, and even then it's only six broken hours at night at most.

This is what a typical night entails: We give Dylan his first dose of medication at 10:30 p.m. He is usually so agitated from exhaustion and vivid dreams that he wakes up the house screaming and fighting. We prefer he sleep with us because he is so fast asleep that he could (and has) thrown up in his sleep. The medicine also makes you really thirsty, so he pees through his night diapers and pyjamas, and we have to change his clothes, the sheets, and move him to a different bed. We do it all over again at 2:30 a.m. for his second dose. The second dose doesn't last as long so he's up at 5 a.m. and hungry out of his mind. Certain foods are too tiring for him to chew, so his diet is poor, and sometimes he falls asleep while eating.

By 8:45 a.m. it's time to go to school, but Dylan often falls asleep again. His teacher has a bed for him beside her desk; he naps there at least once a day. He often falls asleep during play dates, so our eight-year-old daughter, Rylie, has to play with his friends. If he's having fun at gymnastics or with friends, he often has multiple cataplexy attacks which cause full-body collapses. It's hard on Rylie because we can't take family vacations and even outings are difficult. Sometimes she has said she wishes she had narcolepsy. We do our best to make sure she feels special.

There have been some positive aspects of this life-changing diagnosis. My relationship with my husband has solidified. When nobody else can relate, we always have each other. As Dylan gets older, we hope it will get easier to manage. This is uncharted territory and we are doing the best for our family that we can.

Lanna Barrison and her family live in Thornhill, Ont. Since Dylan's diagnosis, it has become Barrison's mission to help people understand the depths of this disease. To learn more, visit her blog at wakeupdylan.com.

As told to Erin Silver

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