



Narcolepsy is a chronic brain disorder that typically causes severe daytime sleepiness.

People with narcolepsy easily go into rapid eye movement (REM) sleep, a sleep stage in which the eyes may appear to be moving and dreams typically occur.

There are two types of narcolepsy, type 1 (narcolepsy with cataplexy) and type 2 (narcolepsy without cataplexy). The symptoms of both are very similar, but they may have different causes.

Symptoms and causes

The most common symptom of narcolepsy is excessive daytime sleepiness, especially when the person isn't active. Some people with narcolepsy may also have sleep attacks that last about 15 – 30 minutes and that can happen at any time.

About 60 percent of people with narcolepsy have a symptom called cataplexy — a sudden episode of muscle weakness while awake. Cataplexy is triggered by emotions, most often positive emotions, such as laughter. But it can also be triggered by negative emotions, such as anger and frustration.

Cataplexy is a symptom of brief muscle weakness in the face, jaw, neck, shoulder or knees. In mild cases, cataplexy can cause a sagging face, head drops or slurred speech. In severe cases, it can cause the child to fall to the ground, unable to move for a few minutes. Cataplexy only occurs in people with type 1 narcolepsy.

Other symptoms of narcolepsy can include:

- › visual hallucinations when falling asleep or waking up
- › sleep paralysis (feeling like the body is paralyzed or heavy when waking from sleep)
- › waking often during the night
- › attention problems, memory issues, hyperactivity or behavior problems
- › vivid dreams or nightmares
- › walking, talking or yelling in sleep
- › kicking or restless movement while sleeping
- › obesity
- › early puberty

Generally, people with type 1 narcolepsy have more severe symptoms.

The symptoms of narcolepsy most often start between ages 10 and 19. However, it's becoming more common for children to be diagnosed before 10.

Type 1 narcolepsy is caused by a severe loss of a certain cluster of neurons (brain cells) that produce a neurochemical in the brain that helps maintain wakefulness. Less is known about the cause of narcolepsy type 2, but it may be caused by a less severe loss of these same neurons.

There is also a link between type 1 narcolepsy and certain infections, such as the flu, and vaccinations. This has led experts to believe that narcolepsy may be caused by an autoimmune process. Researchers are still learning more about the causes of narcolepsy.



Diagnosis and treatment

At Boston Children’s Hospital, our team of specialists is experienced in diagnosing and treating narcolepsy in children and adolescents. Our Sleep Center, the only pediatric-focused center in the region, brings together clinicians from pediatric neurology, developmental medicine, psychology, and pulmonology to care for this disorder.

To diagnose narcolepsy, your clinician will ask for your child’s detailed medical history and perform a neurological exam. The clinician will review your child’s symptoms and sleep habits. He or she will also ask specific questions about your child’s sleepiness, such as what situations bring out sleepiness, how often it occurs and if it affects your child’s ability to pay attention in class.

If the clinician suspects your child may have narcolepsy or another type of sleep disorder, he or she may suggest a sleep study.

- › An **overnight sleep study (polysomnogram)** is done in a sleep lab to monitor and record brain waves, eye movements, muscle tone, breathing, oxygen levels, heart rate and rhythm, and leg movements.
- › A **daytime nap study or mean sleep latency test** records your child’s brain and body activity throughout the day to measure sleepiness.

Treatment for narcolepsy usually involves a combination of lifestyle changes and medication to reduce sleepiness and treat cataplexy.

Medications typically include drugs to help your child stay awake, such as stimulants.

You may need to work with your child’s school to make some of the lifestyle changes needed. These may include:

- › Taking one or two 15 – 20 minute naps during the day. Naps at mid-morning and after lunch may be especially helpful.
- › Taking frequent breaks from sitting or other sedentary activities to take short walks.
- › Avoiding heavy meals and medications that cause sleepiness.

Our locations

Boston Children’s Hospital

300 Longwood Avenue,
Fegan 9 / Fegan 11 / Farley 4
Boston, MA 02115
781-216-2570

Boston Children’s at Peabody

10 Centennial Drive
Peabody, MA 01960
781-216-2570

Boston Children’s at Lexington

482 Bedford Street
Lexington, MA 02420
781-216-2570

Boston Children’s at North Dartmouth

500 Faunce Corner Road
North Dartmouth, MA 02747
781-216-2570

Boston Children’s at Waltham

9 Hope Avenue
Waltham, MA 02453
781-216-2570



Meet our specialist

Kiran Maski, MD, MPH, is sleep clinics director and narcolepsy specialist at Boston Children’s Hospital .Dr. Maski is actively engaged in researching new ways of diagnosing narcolepsy, cognitive and emotional problems associated with narcolepsy, and treatments. She is also working on developing a screening tool to help other clinicians and school personnel identify concerning narcolepsy symptoms.



Make an appointment

If you’re concerned about your child’s sleep habits, give us a call. We diagnose and treat a full spectrum of sleep disorders. Our sleep lab — accredited by the American Academy of Sleep Medicine (AASM) — is the only dedicated sleep lab for children in the region.

Call us at 781-216-2570.



Jake: One patient shares his story

My talent is almost more like a superpower. I have the ability to fall asleep whenever and whenever. Now I know you're probably thinking all teenagers have this power, but trust me, I'm a little different. At any time or place, I have the ability to take a nap.

I first began developing my sleepy superpower in the fall of my junior year after transferring to Middlesex School. That autumn, I was eager to get to know my new teachers and peers and have them get to know me — and my year started strong both academically and socially. However, in November, my excitement quickly vanished as I began to involuntarily fall asleep in multiple classes. Teachers and coaches became frustrated with me, and my mental well-being promptly deteriorated.

I tried everything and anything to stay awake; I would bring scalding cups of black coffee to class in hopes that the bitter taste, caffeine and second-degree burns on my tongue would help keep my eyes open. As the pressure to stay awake in classes grew, a great deal of both anger and confusion built up inside me and, eventually, transformed into a sense of hopelessness. By February, my sleeping problem had reached a climax. I was referred to Dr. Kiran Maski at Boston Children's Hospital.

I met with Dr. Maski to discuss my symptoms, but had to wait until spring break to conduct a sleep study to make a diagnosis. For 24 hours, doctors had me wired

from head to toe collecting data on my sleeping habits. Once it was over, the results were undeniable — I had narcolepsy, a rare sleep disorder that causes sudden bouts of extreme sleepiness, and a condition that's still widely misunderstood by most people.

As grueling and frustrating as my diagnosis is, I am grateful for the experience because I gained an enormous amount of knowledge about the world and myself. Dr. Maski's guidance has been key to my understanding, management and acceptance of having narcolepsy. Because of her, I see my condition as something that can be sometimes annoying but is not a setback to success.

Everyone has their own struggles, problems and other bits of adversity to overcome. Plenty of narcoleptics, such as Winston Churchill and Thomas Edison, have accomplished amazing feats despite their tendency to take an afternoon snooze. Undoubtedly, my junior year was one of the more confusing, frustrating and challenging times of my life, and yet I have to be thankful for that because fighting through all of the confusion, frustration and challenge, I found within me unknown strength, resilience, and, most of all, pride for who I am.

Jake Shusterman is a graduate of Middlesex School. He's from Colorado and loves to ski and hike.





Maeve's journey from sleepiness

For as long as Maeve Sheehy can remember, she's had short spells of feeling like she was about to fall over.

"It wasn't like feeling faint, it was more like my knees would buckle underneath me," says Maeve, now 16. "I would instinctually try to keep from falling by bracing myself."

As she entered middle school, Maeve started to have other symptoms. She felt exhausted all the time, despite regular naps. Sometimes, she was so tired in class that she couldn't even hold her pen to take notes.

Convinced something was not right, Maeve did what any computer-savvy teen might — she Googled her symptoms. The results surprised her.

"I learned that the falling over feeling was a symptom of cataplexy, a loss of muscle control that's associated with narcolepsy," says Maeve. "I just didn't think it was possible I could have such a rare condition."

But a year later, as Maeve's symptoms continued to get worse, they were referred to Dr. Kiran Maski, sleep clinics director at Boston Children's Hospital. Maski met with Maeve and recommended a sleep study.

Diagnosis: Narcolepsy

Maeve and her parents met with Maski a few days later to get the results — narcolepsy with cataplexy.

"Dr. Maski spent a lot of time talking to me about the diagnosis and the science behind narcolepsy," says Maeve. "She didn't just talk to my parents. That was really important to me because I wanted to understand what was going on inside my brain."

It was an overwhelming diagnosis, but it brought Maeve a huge sense of relief.

"To have all my symptoms explained, and to finally have a name for it was a real turning point for me," says Maeve. "I knew it wasn't just in my head."

Learning to live with narcolepsy

The diagnosis was just the first step in getting back to a normal teenage life — the next step was finding a treatment plan.

"Maeve had sleepiness and cataplexy that were pretty difficult to control," says Maski. "She failed all conventional treatments for pediatric narcolepsy, so she was started on sodium oxybate, a potent sedating medication used at night, currently approved only for adults with narcolepsy with cataplexy." A pediatric clinical trial for sodium oxybate is currently ongoing and Maski is the principal investigator for this trial at Boston Children's.

"That medication was really a last resort," says Maeve. "But now that I'm taking it, I'm very grateful because it's been life changing. I finally feel like I have my condition under control."

Horses, running and TED

Now that her symptoms are under control, Maeve has turned her focus back to school and her two favorite hobbies, horseback riding and running. She also coaches middle school girls who are training for long distance races.

One of Maeve's proudest accomplishments since her diagnosis is having her very own TED Talk. It's just one way she's trying to spread awareness of narcolepsy.

"Having narcolepsy has given me a deeper understanding of the challenges other people face," says Maeve. "One real gift that TED gave to me was the chance to connect with other people who have this disease, and to see that they are doing the things they love. That made it less overwhelming, and that's what I hope people take away from what I'm doing."

