

# Living with narcolepsy: Lindsay and Matt’s journey with a life-changing diagnosis



(BPT) - Imagine you haven't slept in 72 hours and every step you take feels like you're walking through wet cement. Then imagine you experience this feeling every day. This is how excessive daytime sleepiness can feel for people living with narcolepsy, a rare neurological disorder that can affect all aspects of a person's daily life. Approximately 170,000 people in the United States are thought to be living with narcolepsy.

All people living with narcolepsy experience excessive daytime sleepiness, which means they struggle to stay awake and alert during the day, or they constantly feel sleepy. This can impact their daily lives at work or at home in many ways. They may have trouble staying awake while being sedentary or inactive, such as during meetings or while reading. Some may also experience difficulty with memory, concentration, and attention due to excessive daytime sleepiness. Their sleepiness may affect interactions and relationships with family and friends. Excessive daytime sleepiness can be mistaken for symptoms of other disorders, making a narcolepsy diagnosis challenging.

Many people living with narcolepsy struggle with symptoms for years before getting the right diagnosis, often taking 8 to 15 years. For Lindsay and Matt, it was no different.



## The road to a diagnosis

Lindsay was just 16 years old when she began experiencing excessive daytime sleepiness. "When I go back through my memory, some days are perfectly clear. Then there are other days, months, seasons, and even years that feel like looking through a diary with blank pages. That reflects how sleepy I was at that time," Lindsay described. "I was going through life feeling like I was moving underneath a weighted blanket."

For nearly two decades, Lindsay pursued an explanation for her excessive daytime sleepiness with different healthcare providers, but to no avail. It wasn't until she was 35 years old that she found a sleep specialist and was ultimately diagnosed with narcolepsy.

Matt's excessive daytime sleepiness became very disruptive when he was 12 years old, long before his diagnosis of narcolepsy. He tried to sneak in what he called "mini-sleeps," or 15-minute naps, whenever possible to make it through the different activities in his day, often taking two such naps between waking up in the morning and arriving at school. "I would find myself waking up, taking a shower, eating breakfast, taking a nap on the couch. Going to school, while my mom drove, I would be taking a nap," Matt recalled. His sleepiness led to feelings of depression, which impacted his life and may have delayed his eventual diagnosis of narcolepsy.

By the time he was in his mid-twenties, Matt had seen various healthcare providers but still had no answers. Then he found a sleep specialist. "I went into his office, and he gave me a very exhaustive questionnaire. It asked questions about clumsiness and about slumping over — things that I thought were actually normal," he said. After hearing Matt's history, how he was feeling, and evaluating his sleep study results, the sleep specialist diagnosed Matt with narcolepsy with cataplexy. Cataplexy is the sudden and brief loss of muscle strength often brought on by strong emotions or certain situations.

"When assessing someone for narcolepsy, healthcare providers often use questionnaires such as the Epworth Sleepiness Scale (commonly called ESS) along with a diagnostic test such as the MSLT (Multiple Sleep Latency Test) to aid in their diagnosis," explained, Dr. Alcibiades Rodriguez, MD, a board-certified neurologist and sleep specialist at New York University Langone Medical Center. "While sleep tests are an important part of confirming a diagnosis, it is important for me to ask how sleepiness impacts someone's daily life. Questions like, what are some things you would like to be doing that you can't do because of your excessive daytime sleepiness?"



## The impact of a narcolepsy diagnosis

Receiving an official diagnosis can bring a sense of relief since it provides validation and an official name for what people are experiencing, but it's just the first step to living with narcolepsy. Narcolepsy is a lifelong disorder and is often portrayed inaccurately in the media. This can add to the burden and stigma people living with narcolepsy often feel because others often aren't familiar with the disorder or only know what they've seen portrayed in the media.

Matt found comfort in his diagnosis and was open about his disorder with others, but he struggled to find information about what he was experiencing. When he was diagnosed in 2007 at age 25, there wasn't a lot of support and resources available, so he did his own research through university websites and textbooks. Matt had trouble understanding his diagnosis because the excessive daytime sleepiness and cataplexy he'd experienced differed from the way narcolepsy was shown in the media. "I was trying to project my own experiences onto what I was seeing, and that wasn't what the reality was," he shared.

For Lindsay, receiving a narcolepsy diagnosis made her feel grief for who she once was. "When I first got diagnosed, I really did not want anybody to know," Lindsay recounted. "I did not talk about it, which is very counter to who I am. The idea of people knowing that I had narcolepsy felt really scary to me."

## The importance of sharing lived experiences and community support

Connecting with the narcolepsy community helped give Lindsay a new perspective on living with her disorder. "Getting involved was an opportunity to not just be surrounded by other people living with narcolepsy, but to be surrounded by people with narcolepsy who were using their voices to make positive change," Lindsay said. Now, Lindsay regularly writes and speaks publicly about her diagnosis and sleep health to help others on their journey.

Matt also found inspiration within the community. Recalling the lack of resources available to him after diagnosis, he wanted to share his story, his lived experience to help raise awareness for others. On social media and other online platforms, he was able to support others in the narcolepsy community and feel more supported himself.

"Getting the right diagnosis is just the first step in a person living with narcolepsy's journey. Even though life after diagnosis can be challenging, the right resources, support system, and the narcolepsy community are there to help," shared Dr. Rodriguez. "Organizations like Narcolepsy Network, Project Sleep, and Wake Up Narcolepsy host events, offer programs and have different ways for people living with narcolepsy to connect with each other, share experiences, and help to drive broader awareness," he said. "Access to resources can help people with narcolepsy stay informed and feel supported in their journey."

In addition to these organizations, Know Narcolepsy is another resource. Visit [KnowNarcolepsy.com](https://www.knownarcolepsy.com) to learn more.

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