Could It Be Narcolepsy?





Narcolepsy isn't always easy to recognize

Getting help can take a long time:

- It can take more than 10 years to get the right diagnosis
- An estimated 50% of people with narcolepsy may not be diagnosed yet
- Narcolepsy can be misdiagnosed as depression, insomnia, sleep apnea, or other conditions

That's why it's important to recognize the symptoms.

This guide is intended to help you and a sleep specialist have a more informed discussion about narcolepsy and its symptoms. Bring this to your visit to help you get the information you need.

Know the 5 major symptoms of narcolepsy

Ask a sleep specialist for information about these symptoms.



Excessive daytime sleepiness (EDS) is when you feel tired all the time, which makes it hard to stay awake throughout the day and causes unintended lapses into drowsiness or sleep.



Cataplexy is sudden muscle weakness triggered by strong emotions like embarrassment, laughter, surprise, or anger.



Disrupted nighttime sleep. When you have disrupted sleep associated with narcolepsy, you may fall asleep quickly but wake up frequently throughout the night.



Sleep paralysis. This is when you feel unable to move or speak when falling asleep or waking up.



Hypnagogic/hypnopompic hallucinations. These vivid or dreamlike experiences can seem real, often be frightening, and occur when falling asleep (hypnagogic) or waking up (hypnopompic).

You don't need to have all of these symptoms to be diagnosed with narcolepsy. Likewise, having any of these symptoms doesn't necessarily mean you have narcolepsy. A diagnosis of narcolepsy should be made by a sleep specialist, who will review your symptoms and conduct appropriate in-lab diagnostic sleep tests.

Take a screener and share your scores with a sleep specialist

These tools can help you and a sleep specialist assess some of the symptoms of narcolepsy:

- The Epworth Sleepiness Scale (ESS) helps to screen for EDS
- The Swiss Narcolepsy Scale (SNS) helps to screen for narcolepsy with cataplexy

Take a screener at <u>MoreThanTired.com</u> and share your scores with a sleep specialist

Questions to ask a sleep specialist

- What causes narcolepsy and its symptoms?
- What do my ESS and SNS scores mean?
- What type of sleep tests help diagnose narcolepsy?
- Do I need an overnight in-lab test? How about a daytime test?
- How do narcolepsy symptoms differ among different people?
- What is the difference between narcolepsy type 1 and type 2?
- How does cataplexy differ among different people?
- What else do I need to know about narcolepsy?

Ask a sleep specialist any other questions you may have

The above are just a few key questions to discuss with a sleep specialist. You may have other questions or concerns that you want to address at your visit. Be sure to write down all the questions, concerns, or expectations you have and share them at your visit.

Learning as much as you can about narcolepsy, your symptoms, and your options will help you make more informed decisions with your healthcare team.



