# **Could Your Child Have Narcolepsy?**





#### Narcolepsy isn't always easy to recognize

It can take more than 10 years to get the right diagnosis

- About 50% of people with narcolepsy say their symptoms started before age 18
- Narcolepsy in children can be misdiagnosed as insomnia, learning difficulties, attentiondeficit hyperactivity disorder (ADHD), or other psychological disorders

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

This guide is intended to help you, as the caregiver, and a sleep specialist have a more informed discussion about narcolepsy and its symptoms. Bring this to your child's 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 feeling tired all the time, which makes it hard to stay awake throughout the day and causes unintended lapses into sleep. In children, EDS may also appear similar to symptoms of ADHD.



**Cataplexy** is sudden muscle weakness triggered by strong emotions like embarrassment, laughter, surprise, or anger. In children, cataplexy may be most noticeable as odd facial movements, such as grimacing or mouth movements.



**Disrupted nighttime sleep.** With disrupted sleep associated with narcolepsy, your child may fall asleep quickly but wake up frequently throughout the night.



**Sleep paralysis.** This is when your child feels unable to move or speak when falling asleep or waking up.



**Hypnagogic/hypnopompic hallucinations.** These vivid dreamlike experiences occur when your child is falling asleep (hypnagogic) or waking up (hypnopompic). They can be extremely scary for children.

Your child doesn't need to have all of these symptoms to be diagnosed with narcolepsy.

Likewise, having any of these symptoms doesn't necessarily mean your child has narcolepsy. A diagnosis of narcolepsy should be made by a sleep specialist, who will review your child's symptoms and conduct appropriate in-lab diagnostic sleep tests.

# Help your child take a screener and share the score with a sleep specialist

The Epworth Sleepiness Scale for Children and Adolescents (ESS-CHAD) can help measure your child's sleepiness and provide information to share with the sleep specialist.

Help your child take a screener at MoreThanTired.com and share the score with a sleep specialist

### Questions to ask a sleep specialist

- What causes narcolepsy and its symptoms?
- What does my child's ESS-CHAD score mean?
- What type of sleep tests help diagnose narcolepsy?
- Does my child 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 child's symptoms, and your options will help you make more informed decisions with your child's healthcare team.



