

CAREGIVER  
GUIDE

A photograph of a young person with dark hair, wearing a maroon hoodie, sleeping peacefully in a school bus. They are seated in the aisle, leaning back against a dark blue seat. Large windows on the left side of the bus show a bright, sunny outdoor scene with green grass and a fence. The interior of the bus is visible, including the ceiling and other seats.

# UNDERSTANDING PEDIATRIC NARCOLEPSY

This brochure is designed to help you understand the symptoms of narcolepsy so you can discuss any symptoms your child may be having with a sleep specialist.

MORE THAN™  
**tired**



The **More Than Tired** campaign was created to help improve awareness, recognition, screening, and diagnosis of narcolepsy. By providing education, information, and resources for people who may be experiencing symptoms of narcolepsy or their caregivers, More Than Tired hopes to encourage and empower them to seek a diagnosis and get the help they need.

To learn more about narcolepsy and find a sleep specialist, visit [MoreThanTired.com](http://MoreThanTired.com)

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More than 50% of people with narcolepsy say **their symptoms started before age 18.**

## Overview of Narcolepsy

Narcolepsy is a chronic, life-disrupting neurologic disorder (involving nerve cells and chemicals in the brain) in which the brain is not able to control sleep-wake cycles normally. Diagnosis in children can be a challenge.

- Narcolepsy symptoms are more likely to be missed if they start before age 18.
- Getting an accurate diagnosis can take 10 or more years, so many children may not receive a narcolepsy diagnosis until adulthood.

A narcolepsy diagnosis should be made by a sleep specialist, who will review your child’s symptoms and conduct appropriate sleep laboratory testing.

## The 5 Major Symptoms of Narcolepsy



**Excessive daytime sleepiness** makes people feel an irresistible urge to sleep during the day, making it hard to stay awake and alert.



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



**Disrupted nighttime sleep** occurs when people fall asleep quickly but wake up frequently during the night.



**Sleep paralysis** is a brief inability to move or speak while falling asleep or waking up.



**Vivid dreamlike experiences** that seem real and are often frightening are called hypnagogic hallucinations if they occur while falling asleep and hypnopompic hallucinations if they occur while waking up.

These symptoms and how they may appear in children and adolescents are described in more detail in this brochure.

**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 that your child has narcolepsy.

It is important to tell your sleep specialist about all your child’s symptoms and all the medications he or she is taking.

## Causes of Narcolepsy Symptoms

### Normal Sleep and Wake States

Stable sleep and wakefulness require the proper boundaries between the brain's wake- and sleep-promoting systems.

**Normal wake:** Wake has characteristics that do not normally occur during sleep, such as alertness and muscle control.

**Normal sleep:** Sleep has characteristics that do not normally occur during wake, such as dreaming and the inability to move most muscles while dreaming, which keeps us from acting out our dreams.

Normally, there are strong boundaries that keep the characteristics of one of these states from occurring in the other.



### Abnormal Sleep and Wake States

Narcolepsy is a chronic neurologic condition (involving nerve cells and chemicals in the brain) in which the brain is not able to control sleep-wake cycles normally.

**During the day:** Certain brain signals that promote wakefulness may be decreased, resulting in some of the symptoms of narcolepsy.



**At night:** Characteristics of wakefulness can occur during sleep, causing frequent awakenings and poor-quality sleep.



Visit [MoreThanTired.com](https://www.morethantired.com) to learn more about narcolepsy and its symptoms.

# Narcolepsy Symptoms in Children and Adolescents

## Excessive Daytime Sleepiness

Excessive daytime sleepiness, or EDS, is the inability to stay awake and alert during the day, resulting in unintended lapses into drowsiness or sleep.

- All patients with narcolepsy have EDS, and it is often the first symptom.

EDS can look different in children than in adults and can be harder to identify.

- Older children may start taking naps again, and younger children may start taking longer daytime naps.
- Children with narcolepsy often show symptoms associated with attention deficit hyperactivity disorder (ADHD).
  - EDS may appear as hyperactivity, problems paying attention, or bad behavior, which can lead to a misdiagnosis of ADHD or other psychiatric disorders.
- Children and adolescents may not use the words “sleepy” or “sleepiness” when describing EDS.
  - It’s important to differentiate sleepiness from fatigue, tiredness, or lack of energy.
- EDS in young children may be mistaken as a normal need to nap.
- EDS in older children may be mistaken for laziness or lack of motivation.



## Cataplexy

Cataplexy is a sudden, brief loss of muscle strength or control triggered by strong emotions.

- Cataplexy may cause a sudden feeling of weakness.
- Cataplectic attacks are not the same in everyone.
  - Usually, attacks affect only certain muscle groups, such as the arms, neck, or face.
  - Less commonly, a person can have weakness in the whole body and actually fall to the ground.
- Strong emotions can include happiness, laughter, surprise, or anger—or feelings brought on by hearing or telling a joke.

Cataplexy attacks in children may be most noticeable as odd facial movements, such as:

- Raised eyebrows
- Droopy eyelids or eyes closing
- Mouth opening or mouth movements
- Tongue sticking out
- Grimacing
- Lip licking, biting, or chewing
- Slowed or slurred speech

In children, cataplexy is sometimes mistaken for other conditions, such as fainting, epilepsy, or movement or nervous system disorders.

### THE EPWORTH SLEEPINESS SCALE FOR CHILDREN AND ADOLESCENTS (ESS-CHAD)

can help rate your child’s level of EDS. If you believe your child is showing symptoms of narcolepsy, help him or her take the ESS-CHAD at [MoreThanTired.com](http://MoreThanTired.com).

### THE PEDIATRIC NARCOLEPSY CONVERSATION STARTER

can help you discuss your child’s symptoms with a sleep specialist. Find it at [MoreThanTired.com](http://MoreThanTired.com).

## Disrupted Nighttime Sleep

Disrupted nighttime sleep means that your child may fall asleep quickly but wake up frequently during the night.

- Disturbed sleep affects children's attention, memory, and ability to think and reason normally.
- Sleep problems are also a cause of distress for parents and stress in families.

## Sleep Paralysis

Sleep paralysis is the brief inability to move or speak while falling asleep or waking up.

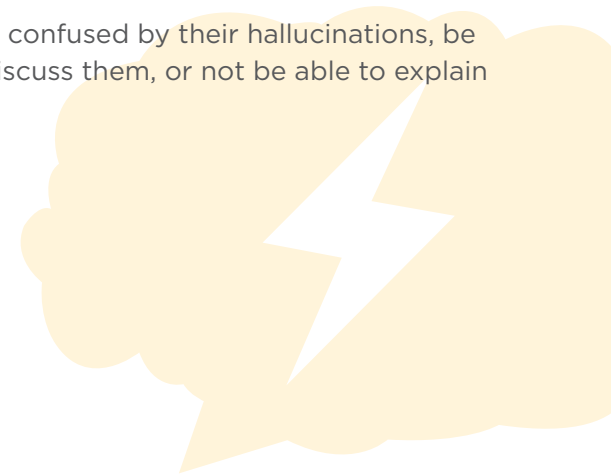
- Sleep paralysis and hypnagogic/hypnopompic hallucinations often occur together (see page 9).
- People experiencing sleep paralysis may report:
  - Being aware of what is going on around them but not being able to move or speak
  - Feeling like they are not able to breathe
- Sleep paralysis can be frightening.
- Sleep-deprived people can experience sleep paralysis, but if sleep paralysis occurs regularly, it may be a sign of narcolepsy.



## Hypnagogic/Hypnopompic Hallucinations

Vivid dreamlike experiences that seem real are called hypnagogic or hypnopompic hallucinations. They may be mistaken for nightmares and can occur while falling asleep (hypnagogic) or waking up (hypnopompic).

- These experiences can be extremely scary for children.
  - Children who have them may become afraid to go to sleep and may resist bedtime.
- These hallucinations may also occur with sleep paralysis.
- Anyone can have one of these hallucinations at some time in his or her life. However, if they occur regularly, it could be a sign of narcolepsy.
- Sufferers may have experiences such as:
  - Hearing sounds or words when drifting off to sleep
  - Having a strong feeling that someone or something is in the room
- Children may become confused by their hallucinations, be too embarrassed to discuss them, or not be able to explain their feelings to you.



## Getting a Diagnosis

### What Else Will the Sleep Specialist Want to Know?

The sleep specialist will likely ask you and your child many questions to find out about and understand all your child's symptoms. Your child may also be asked to fill out the Epworth Sleepiness Scale for Children and Adolescents (ESS-CHAD).

To determine whether your child has narcolepsy, the sleep specialist will likely perform sleep laboratory testing in addition to taking a detailed history of your child's health and symptoms. The sleep tests used to diagnose narcolepsy are not performed at your home and generally require an overnight stay at a sleep laboratory.

### 2 Tests Used to Diagnose Narcolepsy



**Polysomnography (PSG):** PSG is performed during an overnight stay in a sleep lab.

- Records your child's heart rate, breathing, brain activity, and nerve activity in the muscles while your child is asleep



**Multiple sleep latency test (MSLT):** An MSLT is performed the morning following a PSG.

- Used to diagnose narcolepsy and to measure your child's degree of daytime sleepiness
- Measures how quickly your child falls asleep in quiet situations during the day
- Monitors how quickly and how often your child enters rapid eye movement (REM) sleep

The American Academy of Sleep Medicine recommends overnight PSG followed by an MSLT for pediatric patients whose doctors suspect they may have narcolepsy.



Visit **MoreThanTired.com** to help your child take a screener and find a sleep specialist.

## Questions to Ask the Sleep Specialist

Below are a few key questions to discuss with the sleep specialist. You or your child may have additional 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.

- What causes narcolepsy and its symptoms?
- What does my child's ESS-CHAD score mean? (Help your child take a screener at [MoreThanTired.com](https://www.morethantired.com) and bring his or her score to your visit)
- How is narcolepsy diagnosed?
- 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 we need to know about narcolepsy?

Visit [MoreThanTired.com](https://www.morethantired.com) and download the Pediatric Narcolepsy Conversation Starter to help you have a more informed discussion with a sleep specialist.

Follow us!



For peer support, interesting facts, videos from people with narcolepsy, and more! Join our growing community today!



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Visit [MoreThanTired.com](https://MoreThanTired.com) today  
for more information about narcolepsy

- Help your child take a screener.
- Find a sleep specialist near you and set up an appointment.
- Watch videos of pediatric patients and their caregivers talking about their experiences with narcolepsy symptoms.
- Download the Pediatric Narcolepsy Conversation Starter.