

PATIENT  
GUIDE



# UNDERSTANDING NARCOLEPSY

This brochure is designed to help you understand the symptoms of narcolepsy, so that you can discuss any symptoms you may be having with your 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, 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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An estimated 50% of people with narcolepsy have not been diagnosed.<sup>1</sup>

## 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.<sup>2-4</sup>

- Narcolepsy symptoms often start between ages 10 and 25<sup>3</sup>
- Getting the right diagnosis can take more than 10 years<sup>5</sup>
  - Many disorders have some of the same symptoms<sup>3</sup>
  - People can see an average of 6 doctors before diagnosis<sup>6</sup>

A narcolepsy diagnosis should be made by a sleep specialist, who will review your symptoms and conduct appropriate sleep laboratory testing.<sup>3</sup>

## The 5 Major Symptoms of Narcolepsy



**Excessive daytime sleepiness** makes you feel an irresistible urge to sleep during the day, making it hard to stay awake and alert.<sup>1,3,7</sup>



**Cataplexy** is a weakening of muscles when you experience strong emotions such as embarrassment, laughter, surprise, or anger.<sup>1,3,8</sup>



**Sleep disruption** is when you often fall asleep quickly but wake up frequently during the night.<sup>1,3</sup>



**Sleep paralysis** is a brief inability to move or speak while falling asleep or waking up.<sup>3</sup>



**Hypnagogic hallucinations** are vivid dream-like events that occur while falling asleep. When they occur while waking up, they are called hypnopompic hallucinations.<sup>1,3</sup>

These symptoms are described in more detail in this brochure. 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 that you have narcolepsy.

It is important to tell your sleep specialist about all your symptoms and all the medications you are taking. It may be helpful that he or she speaks with someone who knows you well. This person may notice subtle symptoms that you might not see yourself.<sup>9</sup>



## 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.<sup>10,11</sup>

**Normal wake:** Wake has characteristics that do not normally occur during sleep, such as alertness and muscle control.<sup>10-12</sup>

**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.<sup>10-12</sup>

Normally, there are strong boundaries that keep the characteristics of one of these states from occurring in the other.<sup>10,11</sup>



### 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.<sup>2</sup>

**During the day:** Certain brain signals that promote wakefulness may be decreased, resulting in some of the symptoms of narcolepsy.<sup>11,13-16</sup>



**At night:** Characteristics of wakefulness can occur during sleep, causing frequent awakenings and poor-quality sleep.<sup>10,17</sup>



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

# Narcolepsy Symptoms

## 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.<sup>3</sup>

- Every patient with narcolepsy has EDS, and it is often the first symptom<sup>3,10</sup>
- When describing this symptom, patients may say that they:
  - Have a hard time staying awake while doing everyday things<sup>3</sup>
  - Are tired or fatigued<sup>7,18</sup>
  - Have trouble concentrating or staying focused<sup>7,10</sup>
  - Are forgetful or have poor memory<sup>7,10</sup>
  - Have mood changes or get upset easily<sup>7</sup>
- EDS may be disabling because of the high risk of falling asleep—or having a “sleep attack”—while you are doing everyday things,<sup>3</sup> such as:
  - Sitting and reading<sup>19</sup>
  - Riding in a car<sup>19</sup>
  - Stopped in traffic while driving a car<sup>19</sup>
  - Talking to someone<sup>1,19</sup>
- You may take daytime naps, but these naps likely only help you feel refreshed for a short period of time<sup>1,3</sup>

### THE EPWORTH SLEEPINESS SCALE (ESS)

can help rate your level of EDS.<sup>19,20</sup> Take the Symptom Screener at **MoreThanTired.com**.

## Cataplexy

Cataplexy is a sudden, brief loss of muscle strength or control caused by strong emotions.<sup>1,3</sup>

- Cataplexy may cause a sudden feeling of weakness<sup>3</sup>
- Cataplectic attacks are not the same in everyone<sup>1,3</sup>
  - Usually, attacks affect only certain muscle groups, such as the arms, neck, or face. You may not even recognize these subtle attacks, but your friends or family may notice them<sup>1,3,9</sup>
  - Less commonly, you can have weakness in your whole body and fall to the ground<sup>1,3</sup>
  - The type of cataplexy attack experienced by one person is usually the same (eg, head dropping)<sup>1,9</sup>
- Attacks are often caused by<sup>1,3,8</sup>:
  - Sudden, strong emotions such as happiness, laughter, surprise, or anger
  - Hearing or telling a joke
- These attacks usually last for only a short time—from a few seconds to several minutes<sup>3,8</sup>
- All people with cataplexy do not have the same number of attacks. For some people, they are rare. Other people have many attacks each day<sup>3</sup>

### THE SWISS NARCOLEPSY SCALE (SNS)

can help find out if you have narcolepsy with cataplexy.<sup>21-23</sup> Take the Symptom Screener at **MoreThanTired.com**.

## Sleep Disruption

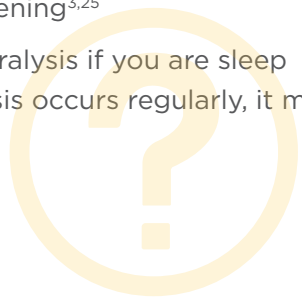
Sleep disruption is when you often fall asleep quickly but wake up frequently during the night.<sup>1,3</sup>

- With sleep disruption, you may:
  - Fall asleep easily but have trouble staying asleep for long periods of time<sup>1,3</sup>
  - Report poor-quality sleep<sup>24</sup>

## Sleep Paralysis

Sleep paralysis is the brief inability to move or speak while falling asleep or waking up.<sup>3</sup>

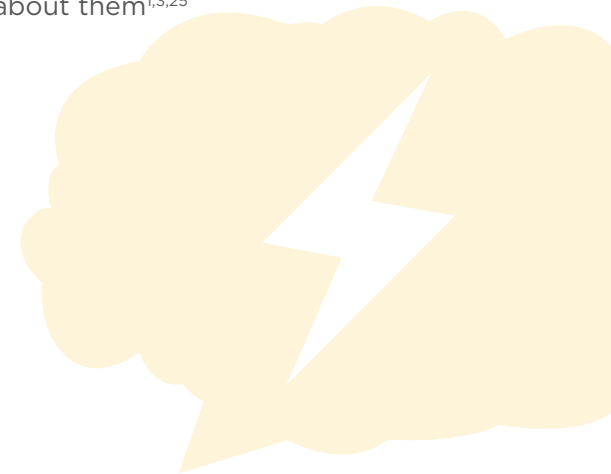
- Sleep paralysis and hypnagogic hallucinations often occur together<sup>1</sup>
- Patients experiencing sleep paralysis may report:
  - Being aware of what is going on around them but not being able to move or speak<sup>1,25</sup>
  - Feeling like they are not able to breathe<sup>25</sup>
- Sleep paralysis can be frightening<sup>3,25</sup>
- You can experience sleep paralysis if you are sleep deprived, but if sleep paralysis occurs regularly, it may be a sign of narcolepsy<sup>25</sup>



## Hypnagogic Hallucinations

Hypnagogic hallucinations are vivid dream-like events that occur while you are falling asleep. When they occur while waking up, they are called hypnopompic hallucinations.<sup>1,3</sup>

- Patients with these hallucinations often talk about unwanted visions or nightmares<sup>1,3</sup>
- These hallucinations may also occur with “sleep paralysis”<sup>1</sup>
- Anyone can have one of these hallucinations at some time in his or her life.<sup>25</sup> However, if you have them regularly, it could be a sign of narcolepsy<sup>3</sup>
- You may have experiences such as<sup>1,3</sup>:
  - Hearing sounds or words when drifting off to sleep
  - Having a strong feeling that someone or something is in the room
- These events can be so scary and realistic, some patients may not want to talk about them<sup>1,3,25</sup>





## Getting a Diagnosis

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

Your sleep specialist will likely ask you many questions to find out about and understand all your symptoms. You may also be asked to fill out the Narcolepsy Symptom Screener.

To determine whether you have narcolepsy, your sleep specialist will likely perform sleep laboratory testing in addition to taking a detailed history of your health and symptoms.<sup>3</sup> The sleep tests used to diagnose narcolepsy are not performed at your home and generally require an overnight stay at a sleep laboratory.<sup>2,3</sup>

### 2 Tests Used to Diagnose Narcolepsy<sup>3</sup>



**Polysomnography (PSG):** PSG is performed during an overnight stay in a sleep lab.<sup>2</sup>

- Records your heart rate, breathing, brain activity, and nerve activity in your muscles while you are asleep



**Multiple sleep latency test (MSLT):** An MSLT is performed the morning following a PSG.<sup>2,3</sup>

- Used to diagnose narcolepsy and to measure your degree of daytime sleepiness
- Measures how quickly you fall asleep in quiet situations during the day
- Monitors how quickly and how often you enter rapid eye movement (REM) sleep



Visit **MoreThanTired.com** to find a sleep specialist and take the Narcolepsy Symptom Screener.

## Questions to Ask Your Sleep Specialist

Below are a few key questions to discuss with your sleep specialist. You 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 do my ESS and SNS scores mean? (Take the Narcolepsy Symptom Screener at [MoreThanTired.com](http://MoreThanTired.com) and take your scores 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 I need to know about narcolepsy?

Visit **MoreThanTired.com** and download the Narcolepsy Conversation Starter to help you have a more informed discussion with your sleep specialist.

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for more information about narcolepsy**

- Take the Narcolepsy Symptom Screener.
- Find a sleep specialist near you and set up an appointment.
- Watch videos of patients talking about their experiences with narcolepsy symptoms.
- Access links to other websites containing information about narcolepsy.