Connecting healthcare professionals and patients to help improve awareness, recognition, screening, and diagnosis of narcolepsy.
Narcolepsy Link is designed to connect patients and their doctors to help improve the awareness, recognition, screening, and diagnosis of narcolepsy.

Narcolepsy is a chronic, life-disrupting neurologic (involving nerve cells and chemicals in the brain) disorder. Unfortunately, many people living with narcolepsy have not yet received a proper diagnosis. Narcolepsy Link provides information and resources for patients and their doctors. The goal is to assist people with narcolepsy by educating patients and their doctors about narcolepsy signs and symptoms and encouraging patients to seek help. The program also aims to help patients and their doctors talk to each other by providing tools to help patients recognize and record their symptoms and discuss these symptoms with their doctors.

This brochure is provided as a resource to help you recognize the symptoms of narcolepsy and to help you discuss your symptoms with your doctor. When talking with your doctor, it is important that you share all of your symptoms, as well as all medications you may be taking.

To learn more about Narcolepsy Link, visit www.NarcolepsyLink.com
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Overview of Narcolepsy

Narcolepsy is a chronic, life-disrupting neurologic (involving nerve cells and chemicals in the brain) disorder in which the brain is not able to regulate sleep-wake cycles normally.1-3

- Patients with narcolepsy may experience irresistible and sudden bouts of sleep, which typically last for a short period of time.1,2
- Patients may also fall asleep while at work or at school, in mid-conversation, playing a game, eating, or, in the worst case, driving or operating machinery.1
- Most patients also experience poor-quality sleep that may involve many awakenings.1
- Patients can also experience other symptoms, such as sudden muscle weakness, during the day and symptoms that occur while falling asleep or waking up.1

Proper diagnosis of narcolepsy requires a full clinical interview and a complete physical exam by your doctor.
The symptoms of narcolepsy include:

**Cataplexy** is a sudden, brief loss of muscle strength or control caused by strong emotions.\(^2\)\(^,\)\(^4\)

**Hypnagogic Hallucinations** are vivid dream-like events that occur while falling asleep or waking up.\(^2\)\(^,\)\(^4\)

**Excessive Daytime Sleepiness** is the inability to stay awake and alert during the day, resulting in unintended lapses into drowsiness or sleep.\(^2\)

**Sleep Paralysis** is a brief inability to move or speak while falling asleep or waking up.\(^2\)

**Sleep Disruption** is when sleep is broken up by many awakenings.\(^2\)\(^,\)\(^4\)

These symptoms are described in detail in this brochure. Not all patients have all 5 narcolepsy symptoms,\(^2\) but every patient with narcolepsy has excessive daytime sleepiness.\(^2\)\(^,\)\(^5\) If you think you may have some of the symptoms of narcolepsy, talk to your doctor. Proper diagnosis of narcolepsy requires a full clinical interview and a complete physical exam by your doctor.\(^6\)\(^,\)\(^7\) It is important to tell your doctor about all of your symptoms and all the medications you are taking. It is also important that your doctor speaks with someone who knows you well. This person may notice subtle symptoms that you might not see yourself.\(^7\)
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.\textsuperscript{5,8} Normal wake has characteristics that do not normally occur during sleep, such as staying alert and the control of most muscles.\textsuperscript{5,8,9} Normal sleep also has characteristics that do not normally occur during wake, such as dreaming and the inability to move most muscles (temporary muscle paralysis) while dreaming.\textsuperscript{5,8,9} This keeps us from acting out our dreams.\textsuperscript{9} Normally, there are strong boundaries that keep the characteristics of one of these states from occurring in the other.\textsuperscript{5,8}
Abnormal Sleep and Wake States

In people with narcolepsy, the brain is unable to maintain stable boundaries between sleep and wake.\textsuperscript{5,8}

**During the Day:** In individuals who have narcolepsy, characteristics of sleep can occur during the wake state, which may cause:

- Sudden brief loss of muscle strength or control—cataplexy\textsuperscript{2,4,5}
- Vivid dream-like events that occur while falling asleep or waking up—hypnagogic hallucinations\textsuperscript{2,4,5}
- Inability to stay awake and alert during the day, with lapses into drowsiness or sleep—excessive daytime sleepiness\textsuperscript{2,5,8}
- Brief inability to move or speak while falling asleep or waking up—sleep paralysis\textsuperscript{2,5}

**At Night:** In individuals who have narcolepsy, characteristics of wakefulness can also occur during sleep, which may cause:

- Frequent awakenings and poor-quality sleep—sleep disruption\textsuperscript{5,10}
Narcolepsy Symptoms

Cataplexy

CATAPLEXY is a sudden, brief loss of muscle strength or control caused by strong emotions.\(^2,4\)

- Patients with cataplexy may have a sudden feeling of weakness.\(^2\)
- Cataplectic attacks are not the same in everyone.\(^2,4\)
  - Most often, attacks affect only certain muscles. Sometimes the weakness is subtle, and people may not notice these attacks, but their close friends or family members may see them.\(^2,4,7\)
  - Some patients have weakness in their whole body and fall to the ground.\(^2,4\) This is less common than a partial attack.\(^4\)
  - The type of cataplexy attack (e.g., head dropping) within one individual is usually the same.\(^4,11\)
- Attacks are often caused by\(^2,4,11\):
  - 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.\(^2,11\)
- 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.\(^2\)
Do you ever have a sudden loss of muscle strength, loss of muscle control, muscle weakness, or limp muscles at the following times?\textsuperscript{2,4,11}

- When you are very happy
- When you are laughing
- When you are surprised

*If you answered yes for any of the above, how often do these attacks occur?*

During these attacks, do you have any of the following?\textsuperscript{2,4,11}

- Head dropping
- Neck weakness
- Eyelid drooping
- Drooping of the face or jaw
- Slurred speech
- Buckling of the knees
- Leg weakness
- Arm weakness
- Complete collapse to the ground
- Other ______________________

Have you ever avoided emotional situations or held back your feelings to avoid an attack? *If yes, please describe.*

Do these attacks cause you to avoid doing certain activities such as attending sporting events or attending movies? *If yes, please describe.*

“People began to tell me my face would droop.”
Hypnagogic Hallucinations

HYPNAGOGIC HALLUCINATIONS are vivid dream-like events that occur while falling asleep or waking up.\textsuperscript{2,4}

- Patients with these hallucinations often talk about unwanted visions or nightmares that occur when they are falling asleep or waking up.\textsuperscript{2,4}

- These hallucinations may also occur with “sleep paralysis,” which may be described as a strange or scary experience of being unable to move or speak when falling asleep or waking up (see Sleep Paralysis on page 12).\textsuperscript{2}

- Anyone can have one of these hallucinations at some time in his or her life.\textsuperscript{12} However, if they happen regularly, it could be a sign of narcolepsy.\textsuperscript{2}

- Patients may have realistic experiences such as\textsuperscript{2,4}:
  - 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.\textsuperscript{2,4,13} 

“It just materializes; it seems very real.”
Do you ever have vivid dream-like experiences at the following times?
- When you are falling asleep
- When you are just waking up
If you answered yes to either of the above, how often does this occur?

Do you ever avoid going to sleep to avoid one of these events?
If yes, please describe.

Do these events cause you to avoid or limit your participation in certain activities? If yes, please describe.

Hypnagogic hallucinations are vivid dream-like events that occur while falling asleep or waking up.
Excessive Daytime Sleepiness

EXCESSIVE DAYTIME SLEEPINESS is the inability to stay awake and alert during the day, resulting in unintended lapses into drowsiness or sleep.\(^2\)

- Every patient with narcolepsy has excessive daytime sleepiness.\(^2,5\)
- Excessive daytime sleepiness is often the first sign of narcolepsy to occur.\(^2\)
- Patients may not use the words “excessive daytime sleepiness” to describe what they’re feeling.\(^5,6,14\)
  Patients may say that they:
  - Have a hard time staying awake while doing everyday things\(^2\)
  - Are tired\(^6,14\)
  - Are fatigued\(^6,14\)
  - Have trouble concentrating or staying focused\(^5,6\)
  - Are forgetful or have poor memory\(^5,6\)
  - Get upset easily\(^6\)
  - Have changes in mood\(^6\)
- Excessive daytime sleepiness can be disabling. This is because of the high risk of falling asleep — or having a “sleep attack” — while doing everyday things,\(^2\) such as:
  - Sitting and reading\(^15\)
  - Riding in a car\(^15\)
  - Stopped in traffic while driving a car\(^15\)
  - Talking to someone\(^4,15\)

Your doctor may ask you to complete the Epworth Sleepiness Scale, a tool designed to rate your level of daytime sleepiness.
Throughout the day, it was difficult to stay awake.

- Some patients may do things, but not remember doing them. They may say that they felt that they were “on autopilot.”
- Some patients may take daytime naps, but these naps only help them feel refreshed for a short period of time.

Questions your doctor may ask you

Do you ever have “sleep attacks,” where you fall asleep without warning? *If yes, how often do these attacks occur?*

Do you ever take scheduled or unscheduled daytime naps? *If yes, how often do you nap?*

How long do your naps typically last?

Do your naps make you feel more alert, refreshed, or energized? *If yes, for how long?*

If you nap, do you dream during your naps? *If yes, please describe.*
Sleep Paralysis

SLEEP PARALYSIS is the brief inability to move or speak while falling asleep or waking up.\textsuperscript{2}

- Patients experiencing sleep paralysis may report:
  - Being aware of what is going on around them, but not being able to move or speak\textsuperscript{4}
  - Feeling like they are not able to breathe\textsuperscript{2}
- Sleep paralysis and hypnagogic hallucinations often occur together.\textsuperscript{2}
- Sleep paralysis can be frightening.\textsuperscript{2}
- Anyone can have sleep paralysis a few times in his or her life, especially if they have been deprived of sleep or have not been getting enough sleep.\textsuperscript{2,12} If sleep paralysis occurs regularly, it may be a sign of narcolepsy.\textsuperscript{2}

Questions your doctor may ask you

Are you ever unable to move or speak for a brief time when you are falling asleep or waking up? \textit{If yes, how often does this occur?}

Do you ever avoid going to sleep to avoid one of these events? \textit{If yes, please describe.}

Do these events ever cause you to avoid or limit your participation in certain activities? \textit{If yes, please describe.}

“I couldn’t move, open my eyes, or speak.”
Sleep Disruption

SLEEP DISRUPTION is the breaking up of sleep by many awakenings.2,4

- Patients with sleep disruption may:
  - Fall asleep easily but have trouble staying asleep for long periods of time2,4
  - Have frequent awakenings2,4
  - Report poor-quality sleep16

Questions your doctor may ask you

During the past month, how would you rate your sleep quality overall?
How long does it usually take you to fall asleep at night?
How much total time do you spend in bed each night?
How many hours of sleep do you usually get each night?
How many times do you wake up during the night?
Does your poor sleep ever interfere with your activities the next day?
*If yes, please describe.*

“Wake up, fall asleep, wake up, fall asleep...”

“...then I’d wake up feeling like I got hit by a truck.”
Making a Diagnosis

What else will my doctor want to know?

Your doctor may ask some or all of the above questions. Or, your doctor may ask you to fill out the Narcolepsy Symptoms Questionnaire, which includes questions about your symptoms. You should review your answers with your doctor, who will determine if your symptoms are consistent with narcolepsy.


It is important to tell your doctor about all of your symptoms and all medications you take. People who may have narcolepsy often see a doctor who is trained in sleep medicine. These doctors typically diagnose and manage sleep disorders, including narcolepsy. Usually, a narcolepsy diagnosis will be established with sleep laboratory tests. These tests are typically done and evaluated by a doctor specializing in sleep medicine. The American Academy of Sleep Medicine’s website (www.sleepeducation.com) provides information about doctors in your area who are trained in sleep medicine.
Two types of tests are often used to establish a diagnosis of narcolepsy. These tests are performed in a sleep laboratory.

The first test is an overnight test called polysomnography, or PSG, that measures brain activity, eye movements, muscle activity, and heart and breathing activity at night. This test can detect other sleep conditions that might cause similar symptoms or identify sleep patterns consistent with narcolepsy.

The second test is performed the next day after the nighttime PSG to measure a person’s tendency to fall asleep. The most commonly used test is the multiple sleep latency test (MSLT). As part of the MSLT, an individual is asked to take four or five short naps usually scheduled 2 hours apart. This test also measures brain activity, eye movements, and muscle activity.
Key Terms

Cataplexy
A sudden, brief loss of muscle strength or control caused by strong emotions.²,⁴

Epworth Sleepiness Scale
The Epworth Sleepiness Scale, or ESS, is a scale for evaluating daytime sleepiness.¹⁵ It is widely used to assess a person’s likelihood of falling asleep in common situations. The ESS takes only a few minutes to complete.⁶,¹⁵

Excessive daytime sleepiness (EDS)
The inability to stay awake and alert during the day, resulting in unintended lapses into drowsiness or sleep.²

Hypnagogic hallucinations
Vivid dream-like events that occur while falling asleep or waking up.²,⁴

Multiple sleep latency test (MSLT)
A sleep laboratory test performed during the day to measure a person’s tendency to fall asleep.² The MSLT consists of four or five short naps usually scheduled 2 hours apart. This test measures brain activity, eye movements, and muscle activity.¹

Polysomnography (PSG)
An overnight test that measures brain activity, eye movements, muscle activity, and heart and breathing activity throughout the night. This test can detect other conditions that might cause symptoms that are similar to the symptoms of narcolepsy.¹

Sleep disruption
The breaking up of sleep by many awakenings.²,⁴

Sleep paralysis
A brief inability to move or speak while falling asleep or waking up.²
References


Where can I get more information?

To learn more about narcolepsy, visit www.NarcolepsyLink.com

• Watch videos of patients talking about their experiences with narcolepsy symptoms
• Fill out the Symptom Recognition Guide and discuss your answers with your doctor
• Access links to other websites containing information about narcolepsy
• Find a sleep center near you by linking to the American Academy of Sleep Medicine’s website at www.sleepeducation.com
• Join Narcolepsy Link to receive information updates