

PATIENT EDUCATION | INFORMATION SERIES

What is Narcolepsy?

Narcolepsy is a neurologic problem in which your brain is not able to control your sleep-wake cycle. It can cause you to have sudden and overwhelming sleepiness any time of the day. This can cause you to fall asleep at inappropriate times, such as while talking to someone, driving a car, eating, or while at school or work. This can at times put you in danger such as when driving.

Narcolepsy is a lifelong condition that never goes away. About 1 in 2,000 people have narcolepsy. It affects men and women equally. Most people with narcolepsy will begin to have symptoms between the ages of 10 and 30 years old.



Sometimes a person with narcolepsy can also have problems with sudden muscle weakness known as cataplexy. Cataplexy can cause weakness of one area of your body such as an arm or a leg, slurred speech, or the complete inability to move. These abrupt episodes of weakness are often triggered by strong emotions such as surprise, laughter, happiness, fear, or anger.

What causes narcolepsy?

The cause of narcolepsy is unknown. Many people with narcolepsy have low levels of a brain chemical called hypocretin (also known as orexin). Narcolepsy can 'run in families' which suggests it could be inherited (genetic = passed down from family members). An "autoimmune" reaction, where your own body attacks itself, may also play a role. Certain viruses have also been associated with narcolepsy.

How do I know if I have narcolepsy?

There are 5 main symptoms of narcolepsy, but not very many people have all of them. One way to remember what they are is to think of the first letters of the word—CHES:

- **C**ataplexy: This is sudden muscle weakness. The weakness may affect your entire body or just one part of it. Some common symptoms are: getting "weak in the knees", drooping face or eyelids, slurred speech, head dropping, arm or leg weakness, and even falling down. These episodes of weakness usually last for a very short time, sometimes just a few seconds. Cataplexy is usually brought on by strong emotions such as surprise, laughter, happiness, fear, or anger. Most people with

cataplexy have narcolepsy; however, not everyone with narcolepsy will have cataplexy.

- **H**allucinations: These are dream-like "visions" where you may hear or see things that are not really there. The hallucinations usually happen just as you are falling asleep or waking up. These events are often described as very scary or upsetting.
- **E**xcessive daytime sleepiness: This is the main symptom of narcolepsy and is often the first symptom you get. This sleepiness makes it difficult for you to stay awake during the day even though you are getting enough sleep at night. You may fall asleep at inappropriate times, such as while talking to someone, driving a car, eating, or while at school or work. Some people say that they do not fall asleep during the day but they feel fatigued, weak, or tired. Everyone with narcolepsy has excessive daytime sleepiness.
- **S**leep paralysis: Just as you are falling asleep or waking up, you may find that you feel paralyzed and cannot move or talk. This is called sleep paralysis. The inability to move or talk only lasts for a very short time, not longer than a couple of minutes. Sometimes this happens at the same time as a hallucination. After the sleep paralysis is gone, you should have no difficulty moving or talking at all.
- **S**leep disruption: You may have trouble staying asleep and wake up many times throughout the night. This can be frustrating for people with narcolepsy because you feel so sleepy throughout the day yet cannot get a full night of sleep because you wake up too often.



Sometimes you may have trouble getting back to sleep as well.

How is narcolepsy diagnosed?

The first step to finding out if you have narcolepsy is talking with your healthcare provider about your symptoms. If your symptoms suggest narcolepsy he or she will usually order the following tests:

- **Overnight sleep study (Polysomnogram):** For this test you must stay overnight at a sleep center. The rooms at the sleep center are usually designed to look and feel like a normal bedroom. You will be hooked up to sensors that will monitor your brain waves, your eye movements, your muscle movements, your heart rate, and your breathing. Your doctor will be able to measure how well you sleep and see if there are signs of narcolepsy or other sleep problems that may be causing your symptoms. Also see ATS Patient Information Series fact sheet on Sleep Studies.
- **Multiple Sleep Latency Test (MSLT):** This test is usually done during the day after you finish your overnight sleep study. For this test you are hooked up to some of the same sensors as the sleep study and will be given four or five chances to take a nap throughout the day. You will be observed to see if you fall asleep during these nap times, how fast you fall asleep, and the stages of sleep you have.

How is narcolepsy treated?

There is no cure for narcolepsy – once you develop it, you will always have it. However, there are many treatment options. Which treatment is right for you depends on the symptoms you have, how bad your symptoms are, and other medical problems you may have.

The first steps in controlling symptoms of narcolepsy are lifestyle changes.

- Go to sleep at the same time each night, even on weekends.
- Wake up at the same time each morning, even on weekends.
- Try to get at least 8 hours of sleep each night, although you may require more.
- Schedule two 15-minute naps during the day to refresh yourself.
- Get some form of exercise every day.
- Avoid things that can disrupt your sleep, such as tobacco, alcohol, caffeine and drugs.
- Avoid using electronics in bed or close to bedtime.
- Ask your healthcare provider for more healthy sleep tips. Also see ATS Patient Information Series fact sheet on Healthy Sleep in Adults.

There are medications that may help control your symptoms and your health care provider can help you decide which one is right for you to try.

- Stimulants and “wakefulness-promoting agents” are medications that can decrease your daytime sleepiness. If you have medical problems such heart disease or abnormal heart rhythms, then you may not be able to take these medications.
- Although they were originally developed for treating depression, certain antidepressant medications have been found to be effective at decreasing cataplexy, sleep paralysis, and the hallucinations associated with narcolepsy.
- Sodium oxybate is another medication that can decrease your symptoms of cataplexy and excessive daytime sleepiness.

Your healthcare provider may try one or several of these medications to find what works best for you. You should always follow-up closely with your health care provider while taking these medications because they can have side effects that could be dangerous if not identified and managed.

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Rx Action Steps

- ✓ Talk with your healthcare provider if you are having symptoms of narcolepsy.
- ✓ Do not perform tasks that could be dangerous to yourself or others (such as driving or operating machinery) while you are sleepy.
- ✓ Making the suggested lifestyle changes can help you feel better whether you have narcolepsy or not.
- ✓ Talk with your healthcare provider if you are on medication for narcolepsy and having side effects or uncontrolled symptoms.

For More Information:

American Thoracic Society

<https://www.thoracic.org>

American Academy of Sleep Medicine Sleep Education

<http://www.sleepeducation.org/essentials-in-sleep/narcolepsy>

Narcolepsy Network

<http://narcolepsynetwork.org>

National Heart, Lung, and Blood Institute

<http://www.nhlbi.nih.gov/health/health-topics/topics/nar>

National Institute of Neurological Disorders and Stroke

<https://www.ninds.nih.gov/Disorders/All-Disorders/Narcolepsy-Information-Page>

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