

# Narcolepsy

**Narcolepsy is a chronic sleep disorder, but you can put a stop to daytime sleepiness. Here's all you need to know about the symptoms, causes, and treatments.**



## What is narcolepsy?

Narcolepsy is a chronic neurological disorder affecting the part of your brain that regulates sleep. As a result, you can experience excessive daytime sleepiness and a sudden loss of muscle control (called cataplexy) causing you to fall asleep during normal daytime activities such as working or studying. These episodes are often triggered by strong emotions. And while they can be brief, lasting just a few seconds, they can be frightening, embarrassing, and cause serious disruption in your life. Ordinary daily activities such as driving, cooking, or even walking can become dangerous, and extreme daytime sleepiness can put a strain on

work, school, and intimate relationships.

Narcolepsy can also create memory and concentration problems, and take a toll on your self-esteem and mental health.

Narcolepsy is more common than you probably realize—affecting about 1 in 2,000 people—and while there is not yet a cure, there are plenty of ways you can reduce the symptoms. A combination of lifestyle changes, self-help strategies, counseling, and medical support can help you manage narcolepsy, improve your alertness, and enjoy a full and active life.

## The effects of narcolepsy

**Physical well-being and safety** — Many ordinary daily activities, such as cooking or walking, can become very dangerous if you fall asleep or lose muscle control unexpectedly.

**Mental health** — Narcolepsy can disrupt your life to the extent that it may lead to depression and anxiety.

**Social and professional relationships** — Unfortunately, sudden sleep episodes are often found humorous to those not familiar with narcolepsy. Some people may assume that you are lazy, rude, or even faking the sudden sleep episodes.

**Intimate relationships** — Your personal relationships, especially romantic relationships, can often suffer as a result of narcolepsy. Extreme sleepiness may also cause low sex drive and impotence.

**Memory and attention** — Narcolepsy may cause you to have problems remembering things and concentrating, creating more disruption to your daily activities.

## Signs and symptoms of narcolepsy

Most people with narcolepsy experience their first symptoms between the ages of 10 and 25, and they can be especially debilitating for children or young people facing the challenges of school, college, or the early stages of their careers. While symptoms can vary greatly from one person to another, the main narcolepsy symptoms are **excessive daytime sleepiness** (with or without sudden sleep episodes) and **abnormal REM sleep**. Other symptoms of narcolepsy may be related to your abnormal REM sleep, including hallucinations, sleep paralysis, and cataplexy (sudden loss of muscle control).

Two of the most common narcolepsy symptoms—excessive daytime sleepiness and cataplexy—are often connected to your emotional state. You may tend to exhibit these symptoms when you experience intense emotions, such as laughter, sadness, surprise, or frustration.

## **Common narcolepsy symptoms include:**

**Cataplexy (loss of muscle control).** Often, narcolepsy may cause you to have sudden loss of muscle control while awake, usually triggered by strong emotions, such as laughing or crying.

**Hallucinations.** Some people with narcolepsy experience vivid, sometimes frightening, visual or auditory sensations while falling asleep or upon awakening.

**Sleep paralysis.** You may be unable to move or talk at the beginning or end of sleep.

**Microsleep** is a very brief sleep episode during which you continue to function (talk, put things away, etc.) and then awaken with no memory of the activities.

**Nighttime wakefulness.** If you suffer from narcolepsy, you may have periods of wakefulness at night with hot flashes, elevated heart rate, and sometimes intense alertness.

**Rapid entry to REM sleep.** Narcoleptics have unique sleep cycles where they may enter the REM or dream phase of sleep right after falling asleep, whereas most people take about 90 minutes to enter REM. Therefore, you'll experience the characteristics of REM sleep (vivid dreams and muscle paralysis) at the beginning of sleep, even if that sleep is during the day.

## **The causes of narcolepsy**

While researchers continue to seek out the root cause of narcolepsy, the general consensus is that your genetics, accompanied by an environmental trigger of some sort—a virus, for example—may affect your brain chemicals and cause narcolepsy.

Scientists have discovered that people with narcolepsy are lacking in *hypocretin* (also called *orexin*), a chemical in the brain that activates arousal and regulates sleep. Narcoleptics generally do not have as many Hcrt cells (neurons that secrete hypocretin), inhibiting their ability to fully control alertness, which accounts for their tendency to fall asleep. Scientists are working on developing treatments to supplement hypocretin levels to reduce narcolepsy

symptoms.

## Diagnosing narcolepsy

Narcolepsy can often be either mis- or undiagnosed. People with narcolepsy often wait to consult a doctor because the most common (and sometimes the only) symptom is excessive daytime sleepiness, a symptom that could be indicative of many conditions. Additionally, narcolepsy symptoms are often falsely attributed to other sleep disorders or medical conditions (such as depression or epilepsy).

As the only unique symptom of narcolepsy is cataplexy (sudden loss of muscle control), diagnosis of the condition can take a long time. If you suspect you have narcolepsy, be sure to speak with your doctor about ALL of the symptoms you are experiencing.

Along with your list of symptoms, physicians and sleep specialists use the following methods to diagnose narcolepsy:

**Nocturnal polysomnogram** - This overnight test measures the electrical activity of your brain and heart, and the movement of your muscles and eyes.

**Multiple sleep latency test (MSLT)** - This test measures how long it takes for you to fall asleep during the day.

**Spinal fluid analysis** - The lack of hypocretin in the cerebrospinal fluid may be a marker for narcolepsy. Examining spinal fluid is a new diagnostic test for narcolepsy.

## Narcolepsy treatment

Although no cure yet exists for narcolepsy, a combination of treatments can help control your narcolepsy symptoms and enable you to enjoy many normal activities. The treatment that works best for you will vary according to your specific narcolepsy symptoms, but will likely include a combination of counseling, medication, and lifestyle changes.

### Narcolepsy treatment: counseling and support groups

It's very common for those with narcolepsy to suffer from [depression](#). Many symptoms of narcolepsy—particularly sleep attacks and cataplexy—can cause great embarrassment and wreak havoc on your ability to live a normal life. These episodes can be frightening, and you may become depressed because of the sudden lack of control. Fear of falling asleep or

collapsing suddenly leads some people to become reclusive and withdrawn. Reaching out to a psychologist, counselor, or narcolepsy support group can help you cope with the effects of the disorder.

Reaching out may seem overwhelming at first, but being with others who face the same problems can help reduce your sense of isolation and remove any stigma you may feel. It can also be inspiring to share experiences and learn how others have coped with their symptoms of narcolepsy. For help finding a therapist or narcolepsy support group, see below.

## **Lifestyle changes to ease the symptoms of narcolepsy**

Making healthy lifestyle changes can help you manage narcolepsy symptoms, in conjunction with counseling and support, and any recommendations from your doctor. Daytime habits—such as exercise, diet, and how you [manage stress](#)—play a large role in helping you maintain a healthy sleep-wake cycle. It's important to follow a regular sleep schedule, a relaxing bedtime routine, and take practical steps to counter the effects of narcolepsy during the day.

Combining these various self-help treatments can help to not only improve your daytime alertness but also help reduce the symptoms of narcolepsy.

**Schedule your sleep periods** - Take a few brief, scheduled naps during the daytime (10-15 minutes each). Try to get a good night's sleep during the same hours each night. Planned naps can prevent unplanned lapses into sleep.

**Avoid caffeine, alcohol, and nicotine** - These substances interfere with sleep when you need it.

**Avoid over-the-counter drugs that cause drowsiness** - Some allergy and cold medications can cause drowsiness, so they should be avoided.

**Involve your employers, coworkers, and friends** - Alert others so they can help when needed.

**Carry a tape recorder** - Record important conversations and meetings, in case you fall asleep.

**Break up larger tasks into small pieces** - Focus on one small thing at a time

**Exercise on a regular basis** - Exercise can make you feel more awake during the day and stimulate sleep at night. For example, take several short walks during the day.

**Avoid activities that would be dangerous if you had a sudden sleep attack** - If possible, don't drive, climb ladders, or use dangerous machinery. Taking a nap before driving may help you manage any possible sleepiness.

**Wear a medical alert bracelet or necklace** - A bracelet or necklace will alert others if you suddenly fall asleep or become unable to move or speak.

**Eat a healthy diet** - Aim for a diet rich in whole grains, vegetables, fruits, low fat dairy, and lean sources of protein. Eat light or vegetarian meals during the day and avoid heavy meals before important activities.

**Relax and manage emotions** - Narcolepsy symptoms can be triggered by intense emotions, so you may benefit from practicing [relaxation techniques](#), such as breathing exercises, yoga, or massage.

## Medications for the treatment of narcolepsy

Medication can be helpful in treating the major symptoms of narcolepsy: sleepiness and cataplexy. Commonly prescribed drugs for narcolepsy are stimulants, antidepressants, and sodium oxybate.

All medications have side effects and in the case of antidepressants, those side effects can be dangerous, including an increased risk of suicide. Even if your narcolepsy symptoms require the use of prescription medication, experts recommend combining a drug regimen with lifestyle changes and counseling or therapy.



[Get more help](#)

[Narcolepsy Fact Sheet](#) - Including symptoms, types, causes, diagnosis, and treatment. (National Institute of Neurological Disorders and Stroke)

[Narcolepsy](#) - Symptoms, causes, and treatment. (Mayo Clinic)

[Medications](#) - A list of medications most commonly used in the treatment of narcolepsy. (Harvard Medical School)

## **Finding support**

[Narcolepsy Support Groups](#) - Located in the U.S. (Narcolepsy Network)

[International Organizations](#) - List of organizations around the globe that provide information and support to people with narcolepsy. (Narcolepsy Network)

[Find a therapist](#) - Directory of therapists in the U.S. and Canada schooled in cognitive and behavioral techniques including those familiar with treating sleep disorders such as narcolepsy. (Association for Behavioral and Cognitive Therapies)

[Narcolepsy UK](#) - Information, support, and a helpline for narcolepsy sufferers in the UK. (Narcolepsy UK)

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