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The National Women's Health Information Center

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Frequently Asked Questions about Narcolepsy

What is narcolepsy?

Narcolepsy is a chronic, or long-lasting, sleep disorder with no known cause. It affects the body's central nervous system, which is made up of nerves that carry messages from the brain to other parts of the body. When a person has narcolepsy, messages about when to sleep and when to be awake can get mixed up. This can cause a person to fall asleep when they do not want to, and often without any warning like feeling drowsy.

The desire to sleep can be overwhelming and hard to resist, and can happen to a person several times during the day. Night sleep may also be poor, broken up by waking up often during the night. If not controlled with medication, narcolepsy can cause serious problems in a person's personal, social, and work life. It can also limit a person's activities, such as driving a car, work, and exercising. Studies indicate that narcolepsy may run in families.

What are the symptoms of narcolepsy?

While it can happen at any age, symptoms of narcolepsy most often begin between the ages of 15 and 30. The main symptoms are cataplexy and being extremely sleepy during the day, even after a good night's sleep. There are other symptoms of narcolepsy, listed below, which may not occur in all people. These symptoms often come and go. But being very sleepy during the day is a symptom that can be chronic, or long lasting. Other symptoms include waking up during the night, tossing and turning in bed, leg jerks, and nightmares.

- Cataplexy – sudden loss of muscle control, ranging from slight weakness (such as limpness at the neck or knees, sagging facial muscles, or slurred speech) to complete body collapse. Attacks can be triggered by sudden and strong emotions such as laughter, anger, or fear. Attacks can last from a few seconds to several minutes.
- Sleep paralysis – not being able to talk or move when falling asleep or waking up. This is temporary and may last from a few seconds to several minutes.
- Hypnagogic hallucinations – seeing things that are not there. These images can seem very vivid and dreamlike and sometimes scary. They happen when a person is dozing or falling asleep.
- Automatic behavior – doing tasks that are familiar, routine, or boring without knowing that you are doing them. Like getting to work with no memory of actually driving there.

Should I worry about getting narcolepsy?

Some 200,000 Americans are thought to have narcolepsy. It is sometimes mistaken for depression, epilepsy, or the side effects of medications. You should be checked by a sleep medicine specialist for narcolepsy if:

- You often feel extremely sleepy during the day, even after having had a full night's sleep.
- You fall asleep when you do not want to, such as while having dinner, talking, driving, or working.
- You collapse suddenly or your neck muscles feel too weak to hold up your head when you laugh or become angry, surprised, or shocked.
- You are not able to talk or move for a short period of time when falling asleep or waking up.

How is narcolepsy diagnosed?

After having a complete medical history and physical exam, a person's doctor may order further tests. It is important to see a sleep medicine specialist at a sleep center for evaluation, since narcolepsy can be hard to diagnose and treat effectively. It can be mistaken for other conditions like depression and epilepsy, or the side effects of medications.

Two common tests for narcolepsy are:

- Polysomnogram – records brain activity and body movements during nighttime sleep, along with nerve and muscle function. This test is done in an overnight sleep lab.
- Multiple Sleep Latency Test – a person is given a chance to sleep every two hours during the day, when they are normally awake. This test measures the time it takes to fall asleep and the time it takes to go into rapid eye movement (REM) sleep (dreaming).

How is narcolepsy treated?

There is no cure for narcolepsy. It is a life-long condition, but there is help for a person with this condition to have a good and productive life. Symptoms can be controlled with medicine and lifestyle changes. The extreme daytime sleepiness can be treated with *stimulant drugs* (or drugs that keep you awake) such as *modafinil* (Provigil). Caffeine and over-the-counter stimulants do not work to reduce daytime sleepiness. *Antidepressants* are sometimes used to treat cataplexy, hypnagogic hallucinations, and sleep paralysis.

People with narcolepsy who have other health conditions, such as high blood pressure, diabetes, or heart disease, should talk with their doctor about other medicines they are taking. Some over-the-counter and prescription drugs may interact with those drugs taken for narcolepsy.

Changes in lifestyle can help to treat and control narcolepsy. Taking daytime naps and developing good sleep habits are important. Taking short naps (10 to 15 minutes) 2 to 3 times a day can help control extreme daytime sleepiness and sleep attacks. Having good sleep habits helps a person to get good quality nighttime sleep. What helps is to: not have caffeine or alcohol and not smoke in the late afternoon or evening; get regular exercise, but don't exercise up to 3 hours before you go to bed; don't use your bed for anything but sleeping; and get enough sleep (around 8 hours) every night.

If you have narcolepsy, it is important to talk on a regular basis with your health care provider. This will help you to get the best treatment possible for your symptoms.

What can I do to cope with narcolepsy?

You can manage your condition so you can enjoy life the way you want to. Ways to manage narcolepsy include:

- Learn as much as you can about narcolepsy and your symptoms, including knowing what causes you to have cataplexy. This can help you make changes in your daily routine to better cope with whatever symptoms you are having and avoid physical injury.
- Talk with your health care provider often. Tell her or him about any changes in your symptoms or what you are experiencing in daily life. Let her or him know about any side effects you may be having from medications you are taking for narcolepsy or other conditions.
- Join a *support group* of individuals who are going through the same things you are. You can learn a lot about how others cope with similar symptoms and get emotional support.
- Build a support system. This can include a support group, as well as your family, friends, employer, and teachers. Talk with them about your condition and what they can do to help you manage it. This will help them to avoid wrong thinking that you may be lazy, hostile, unmotivated, or not interested. Talk with an employer or teacher about being able to plan naps during the workday.
- Don't forget to schedule regular nap times during the day, exercise regularly, and make sure you get enough sleep (around 8 hours) every night.
- Talk to a counselor or mental health provider who works with people with disabilities. Counseling can help you to better cope with personal, family, and work-related issues.
- Avoid jobs that require driving long distances or handling hazardous equipment, or that need you to be alert for long times.

For more information...

You can find out more about sleep and sleep disorders by contacting the National Women's Health Information Center at (800) 994-9662 or the following organizations:

National Center on Sleep Disorders Research (NCSDR) (NHLBI)

Phone Number(s): (301) 435-0199

Internet Address: <http://www.nhlbi.nih.gov/sleep>

National Heart, Lung, and Blood Institute

Phone Number(s): (301) 592-8573

Internet Address: <http://www.nhlbi.nih.gov/index.htm>

American Academy of Sleep Medicine

Phone Number(s): (708) 492-0930

Internet Address: <http://www.aasmnet.org>

Narcolepsy Network, Inc.

Phone Number(s): (513) 891-3522

Internet Address: <http://www.narcolepsynetwork.org>

National Sleep Foundation

Phone Number(s): (202) 347-3471

Internet Address: <http://www.sleepfoundation.org>

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*This FAQ was reviewed by Carl E. Hunt, M.D., of the National Center on Sleep Disorders Research, National Heart, Lung, and Blood Institute, National Institutes of Health.
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