

Narcolepsy

What Is Narcolepsy?

Narcolepsy is a chronic sleep disorder with no known cause. The main characteristic of narcolepsy is excessive and overwhelming daytime sleepiness, even after adequate nighttime sleep. A person with narcolepsy is likely to become drowsy or to fall asleep, often at inappropriate times and places. Daytime sleep attacks may occur with or without warning and may be irresistible. These attacks can occur repeatedly in a single day. Drowsiness may persist for prolonged periods of time. In addition, nighttime sleep may be fragmented with frequent awakenings.

Three other classic symptoms of narcolepsy, which may not occur in all patients, are:

- **Cataplexy:** sudden episodes of loss of muscle function, ranging from slight weakness (such as limpness at the neck or knees, sagging facial muscles, or inability to speak clearly) to complete body collapse. Attacks may be triggered by sudden emotional reactions such as laughter, anger, or fear and may last from a few seconds to several minutes. The person remains conscious throughout the episode.
- **Sleep paralysis:** temporary inability to talk or move when falling asleep or waking up. It may last a few seconds to minutes.

- **Hypnagogic hallucinations:** vivid, often frightening, dream-like experiences that occur while dozing or falling asleep.

Daytime sleepiness, sleep paralysis, and hypnagogic hallucinations can also occur in people who do not have narcolepsy.

In most cases, the first symptom of narcolepsy to appear is excessive and overwhelming daytime sleepiness. The other symptoms may begin alone or in combination months or years after the onset of the daytime sleep attacks. There are wide variations in the development, severity, and order of appearance of cataplexy, sleep paralysis, and hypnagogic hallucinations in individuals. Only about 20 to 25 percent of people with narcolepsy experience all four symptoms. The excessive daytime sleepiness generally persists throughout life, but sleep paralysis and hypnagogic hallucinations may not.

The symptoms of narcolepsy, especially the excessive daytime sleepiness and cataplexy, often become severe enough to cause serious disruptions in a person's social, personal, and professional lives and severely limit activities.

When Should You Suspect Narcolepsy?

You should be checked for narcolepsy if:

- you often feel excessively and overwhelmingly sleepy during the day, even after having had a full night's sleep;
- you fall asleep when you do not intend 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 find yourself briefly unable to talk or move while falling asleep or waking up.

How Common Is Narcolepsy?

Although it is estimated that narcolepsy afflicts as many as 200,000 Americans, fewer than 50,000 are diagnosed. It is as widespread as Parkinson's disease or multiple sclerosis and more prevalent than cystic fibrosis, but it is less well known. Narcolepsy is often mistaken for depression, epilepsy, or the side effects of medications.

Who Gets Narcolepsy?

Narcolepsy can occur in both men and women at any age, although its symptoms are usually first noticed in teenagers or young adults. There is strong evidence that narcolepsy may run in families; 8 to 12 percent of people with narcolepsy have a close relative with the disease.

What Happens in Narcolepsy?

Normally, when an individual is awake, brain waves show a regular rhythm. When a person first falls asleep, the brain waves become slower and less regular. This sleep

state is called non-rapid eye movement (NREM) sleep. After about an hour and a half of NREM sleep, the brain waves begin to show a more active pattern again, even though the person is in deep sleep. This sleep state, called rapid eye movement (REM) sleep, is when dreaming occurs.

In narcolepsy, the order and length of NREM and REM sleep periods are disturbed, with REM sleep occurring at sleep onset instead of after a period of NREM sleep. Thus, narcolepsy is a disorder in which REM sleep appears at an abnormal time. Also, some of the aspects of REM sleep that normally occur only during sleep—lack of muscle tone, sleep paralysis, and vivid dreams—occur at other times in people with narcolepsy. For example, the lack of muscle tone can occur during wakefulness in a cataplexy episode. Sleep paralysis and vivid dreams can occur while falling asleep or waking up.

How Is Narcolepsy Diagnosed?

Diagnosis is relatively easy when all the symptoms of narcolepsy are present. But if the sleep attacks are isolated and cataplexy is mild or absent, diagnosis is more difficult.

Two tests that are commonly used in diagnosing narcolepsy are the polysomnogram and the multiple sleep latency test. These tests are usually performed by a sleep specialist. The polysomnogram involves continuous recording of sleep brain waves and a number of nerve and muscle functions during nighttime sleep. When tested, people with narcolepsy fall asleep rapidly, enter REM sleep early, and may awaken often during the night. The polysomnogram also helps to detect other possible sleep disorders that could cause daytime sleepiness.

For the multiple sleep latency test, a person is given a chance to sleep every 2 hours during normal wake times. Observations are made of the time taken to reach various stages of sleep. This test measures the degree of daytime sleepiness and also detects how soon REM sleep begins. Again, people with narcolepsy fall asleep rapidly and enter REM sleep early.

How Is Narcolepsy Treated?

Although there is no cure for narcolepsy, treatment options are available to help reduce the various symptoms. Treatment is individualized depending on the severity of

the symptoms, and it may take weeks or months for an optimal regimen to be worked out. Complete control of sleepiness and cataplexy is rarely possible. Treatment is primarily by medications, but lifestyle changes are also important. The main treatment of excessive daytime sleepiness in narcolepsy is with a group of drugs called central nervous system stimulants. For cataplexy and other REM-sleep symptoms, antidepressant medications and other drugs that suppress REM sleep are prescribed. Caffeine and over-the-counter drugs have not been shown to be effective and are not recommended.

In addition to drug therapy, an important part of treatment is scheduling short naps (10 to 15 minutes) two to three times per day to help control excessive daytime sleepiness and help the person stay as alert as possible. Daytime naps are not a replacement for nighttime sleep.

Ongoing communication among the physician, the person with narcolepsy, and family members about the response to treatment is necessary to achieve and maintain the best control.

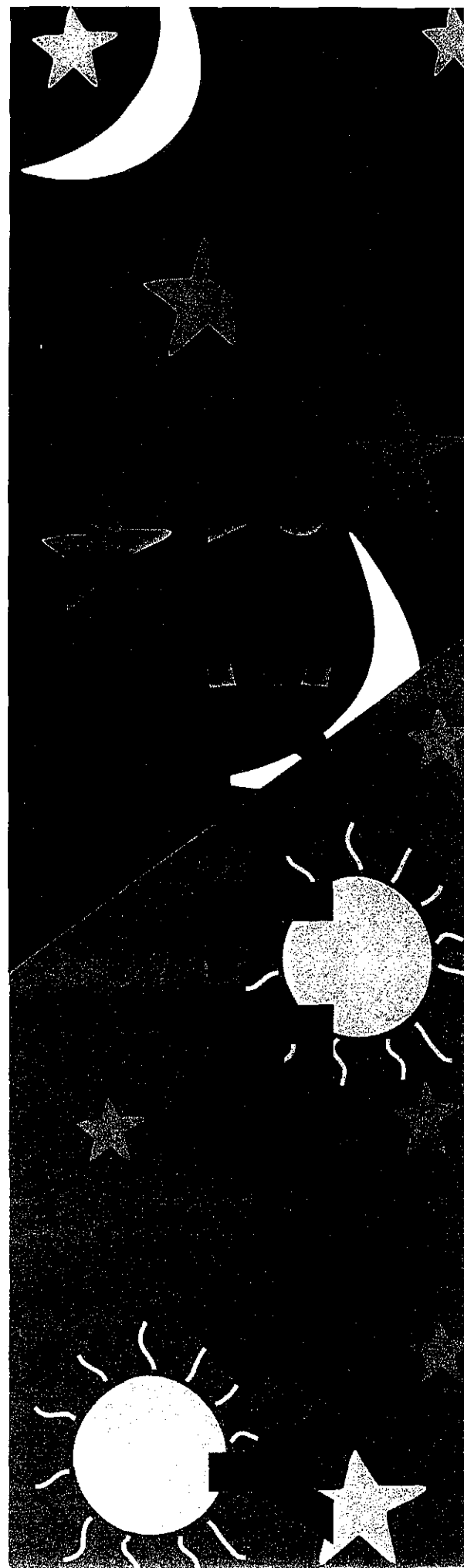
What Is Being Done To Better Understand Narcolepsy?

Studies supported by the National Institutes of Health (NIH) are trying to increase understanding of what causes narcolepsy and

improve physicians' ability to detect and treat the disease. Scientists are studying narcolepsy patients and families, looking for clues to the causes, course, and effective treatment of this sleep disorder. Recent discovery of families of dogs that are naturally afflicted with narcolepsy has been of great help in these studies. Some of the specific questions being addressed in NIH-supported studies are the nature of genetic and environmental factors that might combine to cause narcolepsy and the immunological, biochemical, physiological, and neuromuscular disturbances associated with narcolepsy. Scientists are also working to better understand sleep mechanisms and the physical and psychological effects of sleep deprivation and to develop better ways of measuring sleepiness and cataplexy.

How Can Individuals and Their Families and Friends Cope With Narcolepsy?

Learning as much about narcolepsy as possible and finding a support system can help patients and families deal with the practical and emotional effects of the disease, possible occupational limitations, and situations that might cause injury. A variety of educational and other materials are available from sleep medicine or narcolepsy organizations. Support groups exist to help persons with narcolepsy and their families.



Individuals with narcolepsy, their families, friends, and potential employers should know that:

- **Narcolepsy is a life-long condition that requires continuous medication.**
- **Although there is not a cure for narcolepsy at present, several medications can help reduce its symptoms.**
- **People with narcolepsy can lead productive lives if they are provided with proper medical care.**
- **If possible, individuals with narcolepsy should avoid jobs that require driving long distances or handling hazardous equipment or that require alertness for lengthy periods.**
- **Parents, teachers, spouses, and employers should be aware of the symptoms of narcolepsy. This will help them avoid the mistake of confusing the person's behavior with laziness, hostility, rejection, or lack of interest and motivation. It will also help them provide essential support and cooperation.**
- **Employers can promote better working opportunities for individuals with narcolepsy by permitting special work schedules and nap breaks.**

For More Information

For additional information on sleep and sleep disorders, contact the following offices of the National Heart, Lung, and Blood Institute of the National Institutes of Health:

- **National Center on Sleep Disorders Research (NCSDR)**

The NCSDR supports research, scientist training, dissemination of health information, and other activities on sleep and sleep disorders. The NCSDR also coordinates sleep research activities with other Federal agencies and with public and nonprofit organizations.

National Center on Sleep Disorders
Research
Two Rockledge Centre
Suite 7024
6701 Rockledge Drive, MSC 7920
Bethesda, MD 20892-7920
(301) 435-0199
(301) 480-3451 (fax)

- **National Heart, Lung, and Blood Institute Information Center**

The Information Center acquires, analyzes, promotes, maintains, and disseminates programmatic and educational information related to sleep and sleep disorders. Write for a list of available publications or to order additional copies of this fact sheet.

NHLBI Information Center
P.O. Box 30105
Bethesda, MD 20824-0105
(301) 251-1222
(301) 251-1223 (fax)

For more information about narcolepsy and patient support groups, contact the Narcolepsy Network at P.O. Box 42460, Cincinnati, OH 45242.



U.S. DEPARTMENT OF HEALTH
AND HUMAN SERVICES
Public Health Service
National Institutes of Health
National Heart, Lung, and
Blood Institute
NIH Publication (OS) 96-3649
October 1996