

## Narcolepsy

### What is narcolepsy?

Narcolepsy is a neurological disorder that affects the control of sleep and wakefulness. People with narcolepsy experience excessive daytime sleepiness and uncontrollable episodes of falling asleep during the daytime despite adequate sleep. These sudden sleep “attacks” may occur during any type of activity and at any time of the day.

### Who gets narcolepsy?

Approximately 1 in every 2,000 Americans has narcolepsy. The risk of developing narcolepsy is greater in first-degree relatives (ie, parents, siblings, and offspring) of narcoleptics. Narcolepsy can occur in people of all ages, but the first sign of daytime sleepiness typically begins in the teenage years or twenties. In many cases, narcolepsy is undiagnosed and, therefore, untreated.

### What causes narcolepsy?

The cause of narcolepsy is not known; however, scientists have discovered abnormalities in various parts of the brain involved in regulating REM sleep (a phase of the sleep cycle noted by rapid eye movements). These abnormalities appear to contribute to symptom development. It is likely that narcolepsy involves multiple factors that interact to cause neurological dysfunction and REM sleep disturbances.

### What are the symptoms of narcolepsy?

- **Excessive daytime sleepiness (EDS):** Almost all patients with narcolepsy experience this symptom. In general, EDS interferes with normal activities (work, school, etc) on a daily basis, whether or not patients have sufficient sleep at night. People with EDS report mental cloudiness, a lack of energy and concentration, memory lapses, a depressed mood, or extreme exhaustion.
- **Cataplexy:** This symptom consists of a sudden loss of muscle tone that leads to feelings of weakness

and a loss of voluntary muscle control. The muscle tone is lost in reaction to strong emotions, such as laughter, joking, surprise, or anger. Attacks can occur at any time during the waking period. The severity of attacks ranges from a brief buckling of the knees or slackness in the jaw to total paralysis with collapse. Cataplexy usually lasts a few seconds to several minutes. The frequency of attacks varies from a few in a lifetime to many per day.

- **Sleep paralysis:** This symptom involves the temporary inability to move or speak while falling asleep or waking up. There is often a sensation of being unable to breathe, which can be frightening. Episodes of sleep paralysis typically resolve in a few minutes and are experienced by 40 to 80 percent of narcoleptics.
- **Hallucinations:** Usually, these experiences are vivid and frequently are frightening. The hallucinations occur at sleep onset or upon awakening. Examples include feelings of levitation and sensations of being touched by a person or thing that is not real. Hallucinations of this sort occur in 40 to 80 percent of narcoleptic patients. The hallucinations are called hypnagogic hallucinations when accompanying sleep onset and hypnopompic hallucinations when occurring during awakening.
- **Disturbed sleep:** Some patients with narcolepsy have disturbed night time sleep characterized by frequent awakenings and unrefreshed feeling in the morning.

### How is narcolepsy diagnosed?

The diagnosis of narcolepsy is made after performing a detailed medical and sleep history, physical examination, and usually accompanied by testing performed in a sleep laboratory.

The two tests that are usually required to confirm the diagnosis of narcolepsy are the polysomnogram (PSG) and the multiple sleep latency test (MSLT). The PSG

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## Narcolepsy, continued

is an overnight study that takes continuous multiple measurements while a patient is asleep to document abnormalities in the sleep cycle. A PSG can help reveal abnormalities in REM sleep seen commonly in narcoleptics and can eliminate the possibility that an individual's symptoms result from another condition. Most narcoleptics show disruptions in normal sleep patterns with frequent awakenings.

The MSLT is performed during the day to measure a person's tendency to fall asleep and to determine whether isolated elements of REM sleep intrude at inappropriate times during the waking hours. As part of the test, an individual is asked to take five short naps scheduled two hours apart. Narcoleptics generally fall asleep with every opportunity, often in less than 8 minutes on the average, while normal people stay awake the entire time or fall asleep no sooner than 10 minutes after the start of each trial. In addition, most people with narcolepsy fall quickly into REM sleep, known as sleep-onset REM periods (SOREMPs). Whenever possible, medications that reduce the amount of REM sleep, such as wake-promoting agents and antidepressants, should be discontinued for at least two weeks before testing.

### How is narcolepsy treated?

The treatment of narcolepsy is aimed at improving alertness during the desired time of the day based on the individual's needs and lifestyle. People with narcolepsy should maximize the quality and quantity of sleep by adhering to the following:

- Maintain a regular sleep-wake schedule
- Avoid intentional sleep loss, such as staying awake late on weekends
- Avoid alcohol and other central nervous system depressants
- Modify work and school schedules if possible, such as avoiding long work hours
- Take short naps (20-30 minutes) as needed to avoid unintentional sleep attacks
- Use modest amounts of caffeine to promote alertness as needed
- Operate motor vehicles and other heavy machinery with extreme caution and only when approved by your doctor

In addition to these measures, wake-promoting medications are often prescribed to improve daytime sleepiness. Examples include modafinil (Provigil®), methylphenidate (such as Ritalin®), amphetamine agents (such as Adderall®), and sodium oxybate (Xyrem®). Modafinil, methylphenidate and amphetamines can produce side effects similar to that of caffeine like agitation, nervousness, and palpitations. Wake-promoting agents are generally initiated at a low dose and increased gradually as needed. Careful monitoring is required as high blood pressure and heart arrhythmias have been reported.

Cataplexy, hypnagogic hallucinations, and sleep paralysis have been treated traditionally with low dose antidepressant medications, including tricyclic antidepressants and selective serotonin reuptake inhibitors (SSRIs). Sodium oxybate (Xyrem®) is approved by the FDA for the treatment of cataplexy.

Narcolepsy can be a debilitating disorder that interferes with one's ability to function in all aspects of life, including at school, home, on the job, and behind the wheel of a car. Sometimes narcoleptics are (mis)perceived as lazy and unmotivated. People with narcolepsy are at increased risk for motor vehicle accidents, occupational hazards, and academic underachievement. Therefore, prompt diagnosis and treatment is required. To achieve the highest degree of alertness and daytime functioning, communication with the healthcare professional is highly important.

### RESOURCES:

*The Cleveland Clinic Guide to Sleep Disorders*  
by Nancy Foldvary-Schaefer, DO

Narcolepsy Network, Inc.  
P.O. Box 294  
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