

NARCOLEPSY

Patient Information Fact Sheet

›What is narcolepsy?

Narcolepsy is not a little-understood medical problem that affects approximately 5 in 10,000 people in Europe and North America. It is a disorder that causes people to fall asleep involuntarily during the day. It is a life-long condition, often starting during the teens or young adulthood but can begin in people as young as 10 years or as old as 50 years. The symptoms can vary widely, and may cause many problems in everyday living. People with narcolepsy may lose their jobs, have accidents and become isolated by their condition. For people who do not suffer narcolepsy, the symptoms may be difficult to understand.

›What causes narcolepsy?

Currently, the exact cause of narcolepsy is not known, although studies of the nervous system in people with the condition have shown there to be a mechanism of sleep disturbance. There is some evidence to show that this disruption of the normal sleep-wake cycle may be caused by the absence of a certain chemical substance in the brain that is required for normal functioning of the sleep cycle, although there is no evidence to indicate a psychological basis. In women, the severity of narcolepsy may be affected by the menstrual cycle. Narcolepsy or the predisposition for the condition may run in families, although the way in which it may be inherited is not completely clear.

›What are the symptoms of narcolepsy?

The initial symptom is usually excessive daytime sleepiness. The condition causes people to fall asleep involuntarily. This sleepiness occurs regardless of how many hours the individual has slept the previous night. The feeling has been described as trying to stay awake after three days without sleep. Because the person is often unaware of falling asleep, they may do so at inappropriate times such as while eating or during a conversation. It can be dangerous if the person falls asleep while operating machinery or driving. Sleep attacks usually last between 10 and 30 minutes although they may be much shorter or as long as 2 hours.

The other main symptom associated with narcolepsy is cataplexy. Cataplexy is the sudden loss of strength in voluntary muscles, which causes loss of physical control. An attack of cataplexy may be triggered by intense emotions such as laughter, fear, excitement, or anger. The person may drop an object they are holding or be unable to do a task. An attack can last from under 1 minute up to 10 minutes in some cases. The severity of muscle weakness experienced in an attack can vary widely. Sufferers may also experience moments of trance-like behavior where they continue with routine activities. In some cases, this behavior may continue for extended periods. In addition, night sleep may become disturbed with nightmares, frequent awakening, and tossing and turning in bed. Sleep paralysis may also occur. This is an inability to move while going to sleep or waking up. An episode of paralysis may last as long as 10 minutes, during which time the patient cannot move or speak although they are completely aware of what is happening. Some people may also experience visual or auditory (hearing) hallucinations at the beginning or end of a sleep period, which may be very distressing. These are referred to as hypnagogic hallucinations.

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›What tests confirm a diagnosis of narcolepsy?

If your doctor suspects that you may have narcolepsy, he or she will usually refer you to a specialized sleep center where you will undergo polysomnographic testing. This involves measurement of the electrical activity in your brain as you fall asleep and while asleep and will usually entail an overnight stay. Staff at the center will also take a detailed history of your symptoms.

›How is narcolepsy treated?

There is no known cure for this life-long condition. Lifestyle changes may be needed to take account of the symptoms. The changes required will depend on the individual sufferer and may include changes in employment. A person with severe symptoms may potentially cause harm to themselves and others. Therefore, some people may be unable to drive or follow occupations involving operation of machinery or use of hazardous products. There are three medicines available that may help the symptoms: **dextroamphetamine** (Dexedrine), **modafinil** (Provigil), or **armodafinil** (Nuvigil). These medicines are available only by prescription. **Sodium oxybate** (Xyrem) may be used to treat cataplexy in adults with narcolepsy.

›Self-help measures

- Try to go to bed at the same time each night and sleep for 8 hours
- Avoid moderate exercise within 3 hours of going to bed
- Keep the bedroom as a quiet room without distractions such as television or a computer
- Try to do something relaxing before bed such as taking a warm bath
- Avoid tea, coffee or other caffeinated drinks
- Avoid alcohol

›Further information

National Institute of Neurological Disorders and Stroke:
www.ninds.nih.gov/disorders/narcolepsy/narcolepsy.htm

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