



UNDERSTANDING NARCOLEPSY

What is Narcolepsy?

Narcolepsy, a chronic neurological disorder, is the second leading cause of excessive daytime sleepiness (after obstructive sleep apnea).

People with narcolepsy typically experience:

- * excessive daytime sleepiness,
- * intermittent, uncontrollable episodes of sleep and
- * loss of muscle control (cataplexy) during the day.

If you experience narcolepsy, you may have fallen asleep while working, cooking, or even driving. You are not alone. The National Center on Sleep Disorders Research reports that narcolepsy affects about 1 in 2,000 people and most people experience their first symptoms between the ages of 15 and 30. Evidence suggests that the condition is genetic.

What are the signs and symptoms of Narcolepsy?

In addition to excessive daytime sleepiness and sudden episodes of falling asleep, other symptoms typically associated with narcolepsy are:

- **Cataplexy** – Cataplexy is a sudden episode of muscle weakness, usually triggered by strong emotions. It is estimated that the majority of narcoleptics experience excessive daytime sleepiness and cataplexy.
- **Hypnagogic hallucinations** – Hypnagogic hallucinations are vivid, frightening dreams experienced while falling asleep or waking. About 25-50% of narcolepsy sufferers experience them.
- **Sleep paralysis** – Sleep paralysis is paralysis experienced while falling asleep or waking. About 25-50% of narcolepsy sufferers experience sleep paralysis.
- **Automatic behavior** – Automatic behavior occurs when a person continues to function (talking, putting things away, etc.) during sleep episodes, but awakens with no memory of performing such activities. It is estimated that up to 40 percent of people with narcolepsy experience automatic behavior during sleep episodes.

Narcolepsy can be diagnosed through the presence of symptoms, although some of the symptoms are associated with other sleep disorders and depression. The most common and sometimes the only symptom of narcolepsy present is excessive daytime sleepiness. In a case where excessive daytime sleepiness is the primary symptom, the disorder can be difficult to diagnose. If you also experience cataplexy, a unique symptom of narcolepsy, it may be easier to identify the problem as narcolepsy.

Other methods physicians and sleep specialists use to diagnose narcolepsy include:

- **Epworth Sleepiness Scale** – This sleep questionnaire asks you to rank whether certain situations make you sleepy and, if so, how sleepy. Your responses will assist your doctor in providing a formal diagnosis.
- **Nocturnal polysomnogram** - This test will measure the electrical activity of your brain (electroencephalogram) and heart (electrocardiogram), and the movement of your muscles (electromyogram) and eyes (electro-oculogram) and usually requires an overnight stay at a sleep clinic for observation purposes.
- **Multiple sleep latency test (MSLT)** – This test measures how long it takes for you to fall asleep during the day. Sleep specialists will observe your sleep patterns through several naps during daytime hours.
- **Blood test** – A blood test that measures antigens, often found in people with a family history of narcolepsy, can also be done. The blood test is not conclusive but it can be helpful in establishing the possibility and probability of narcolepsy.

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What treatments are available for Narcolepsy?

Recommended treatment for narcolepsy often includes a combination of counseling, medication and behavioral changes.

Counseling and support groups

The symptoms of narcolepsy—particularly sleep attacks and cataplexy—can wreak havoc on your ability to live a normal life. The episodes can be frightening and you may become depressed because of the sudden lack of control. Fear of falling asleep or collapsing suddenly may force some people to become reclusive and withdrawn. The University of Maryland Medical Center reports that rates of depression in people with narcolepsy can range from 30% to 57% (compared to 8% for the general public). Reaching out to a psychologist, counselor or support group can provide additional support to help you cope with the effects of the disorder.

Medications

Medication can be very helpful for treating the symptoms of narcolepsy. The Mayo Clinic notes four types of commonly prescribed medications for narcolepsy:

Stimulants. Drugs that stimulate the central nervous system are the primary treatment to help people with narcolepsy stay awake during the day. These include methylphenidate (Ritalin) and various amphetamines. Although these medications are effective, they may cause side effects, such as nervousness and heart palpitations, and can be addictive.

Modafinil. The drug modafinil (Provigil) may help people with narcolepsy stay awake. Modafinil isn't as addictive and doesn't produce the highs and lows often associated with stimulants.

Antidepressants. Doctors often prescribe antidepressant medications, which suppress REM sleep, to help alleviate the symptoms of cataplexy, hypnagogic hallucinations and sleep paralysis. These medications include the tricyclic antidepressants protriptyline (Vivactil) and imipramine (Tofranil).

Sodium oxybate (Xyrem). This medication controls cataplexy, sleep paralysis and hallucinations in people with narcolepsy. Sodium oxybate helps to improve nighttime sleep, a lack of which may contribute to excessive daytime sleepiness.

A combination of medication and lifestyle changes help a person with narcolepsy to improve their alertness and enjoy a full and active life.

What are some coping and self-help tips for Narcolepsy sufferers?

Doctors generally agree that lifestyle changes can be very helpful to those suffering with narcolepsy. Suggested self-care tips, from the National Sleep Foundation, University at Buffalo, and Mayo Clinic, include:

- Take several short daily naps (10-15 minutes) to combat excessive sleepiness and sleep attacks.
- Develop a routine sleep schedule – try to go to sleep and awaken at the same time every day.
- Alert your employers, coworkers and friends in the hope that others will accommodate your condition and help when needed.
- Do not drive or operate dangerous equipment if you are sleepy. Take a nap before driving if possible.
- Join a support group.
- Break up larger tasks into small pieces and focus on one small thing at a time.
- Stand whenever possible.
- Take several short walks during the day.
- Avoid caffeine and nicotine.
- Consider taking a break for a nap during a long driving trip.
- Carry a tape recorder, if possible, to record important conversations and meetings.