

What is Narcolepsy?

Narcolepsy is a chronic neurological disorder affecting sleep-wake cycles. The most common symptom is excessive sleepiness. This can significantly impact daily activities. There are two forms of narcolepsy – type 1 and type 2. Type 1 is associated with low spinal fluid levels of a neurotransmitter called orexin. It is also associated with a phenomenon known as cataplexy (see below). It can take many years from the first symptom until the time of diagnosis and there are many people with narcolepsy who are unaware they have this disorder. Because it is a lifelong disorder, it may be difficult to understand that their level of sleepiness is atypical since they are unable to compare it to an average level of sleepiness

People with narcolepsy typically experience:

- Excessive daytime sleepiness,
- Intermittent, uncontrollable episodes of sleep
- Some may experience loss of muscle control (cataplexy) during the day
- Hallucinations when falling asleep or waking up

How is Narcolepsy diagnosed?

Sleepiness is usually the first reason that people seek evaluation. If the clinician suspects narcolepsy, a series of tests are performed to confirm the diagnosis, including an overnight sleep study and a daytime nap study. Often, this is preceded by collecting information about sleep schedules and timing either with a sleep log or an actigraphy watch. This is a wearable device that collects information about when you are awake and asleep. This allows the clinician to make sure that you are not experiencing another sleep disorder such as a circadian rhythm sleep-wake disorder that might better explain your symptoms.

What are the symptoms of Narcolepsy?

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

Cataplexy – Cataplexy is a sudden episode of muscle weakness, usually triggered by strong emotions such as laughing or crying. This might feel like clumsiness or facial drooping that lasts for a short while. Not everyone with narcolepsy will experience 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 – This can be a frightening experience where people feel awake but are unable to move. It typically resolves quickly but can be disturbing. It can occur when falling asleep or waking up, and even during naps. About 25-50% of people with narcolepsy experience sleep paralysis. It can also be experienced by people without narcolepsy, especially when they are sleep-deprived.

Automatic behavior – Automatic behavior occurs when a person does complex activities (driving, speaking, putting things away, etc.) during sleep. Sometimes this is unnoticed when people fall asleep during the day or while driving. There may not be any memory of these episodes. This may explain how people with narcolepsy can sleep during the day without anyone else realizing they are asleep. It is estimated that up to 40 percent of people with narcolepsy experience automatic behavior during

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What treatments are available for Narcolepsy?

Recommended treatment for narcolepsy often includes a combination of medication and behavioral changes including scheduled naps. There are newer medications that are being developed specifically for narcolepsy and not just the sleepiness. Support groups and counseling are also important for both the person with narcolepsy and their family.

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 may prescribe antidepressant medications, which suppress REM sleep, to help alleviate the symptoms of cataplexy, hypnagogic hallucinations and sleep paralysis.

Sodium oxybate (Xyrem). This medication helps to control cataplexy, sleep paralysis and hallucinations in people with narcolepsy. Sodium oxybate helps to improve nighttime sleep, which may improve 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.

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. Many of those with narcolepsy have not yet been diagnosed.