

What is Narcolepsy?

Narcolepsy is a sleep disorder characterized by excessive sleepiness. People with narcolepsy may feel very sleepy, have an overwhelming urge to sleep and may doze off or fall asleep while at work, in school or even when driving. Many people do not get enough sleep, but people with narcolepsy feel sleepy and tired even when they get plenty of sleep. There is no cure for narcolepsy, but the sleepiness can be effectively controlled with a combination of medication and behavior therapy.

What causes Narcolepsy?

The exact cause of narcolepsy is not known but it is thought to be a disorder of the part of the brain that affects sleep and wakefulness. The primary symptom of narcolepsy- excessive sleepiness- interrupts normal daytime alertness. Other symptoms of narcolepsy include cataplexy, hypnagogic hallucinations and sleep paralysis. Cataplexy is sudden muscle weakness, typically in response to strong emotion, which happens when awake. Sleep paralysis is an inability to move which occurs when falling asleep (but while still awake) or right after waking up in the morning. The inability to move may be accompanied by hallucinations, either visual (seeing a person or object) or auditory (hearing music or voices). This can be very frightening.

Narcolepsy is not caused by psychological factors; nor is it caused by not getting enough sleep. Narcolepsy tends to run in families, but many people with narcolepsy do not have a family member with narcolepsy. Recent studies have found low levels of hypocretin in people with narcolepsy. There is ongoing research into the gene responsible for making hypocretin and how a hypocretin deficiency combined with environmental influences may cause narcolepsy.

What are the Symptoms of Narcolepsy?

1. Excessive sleepiness. This is often the first symptom that appears. The excessive sleepiness is NOT due to an insufficient amount of sleep each day or an irregular sleep schedule.
2. Cataplexy. This brief loss of muscle strength, usually triggered by strong emotion, can be mild or it can result in complete physical collapse.
3. Sleep Paralysis. This is a brief loss of muscle strength that occurs during wakefulness- typically right before falling asleep or right after waking up from sleep.
4. Hypnagogic hallucinations. These are vivid dreams that occur during the transition from wake to sleep or from sleep to wake (in which case they are called hypnopompic hallucinations).
5. Automatic Behavior. Performing a routine task with little or no memory of having performed it.
6. Disturbed nighttime sleep. While many people with narcolepsy have long, deep and uninterrupted nighttime sleep, other people with narcolepsy report trouble staying asleep, with frequent nighttime awakenings and restlessness

How is Narcolepsy Diagnosed?

A sleep specialist will take a thorough sleep history and inquire about the symptoms listed above. The sleep history will also include asking about habitual bedtime, wake time and average total amount of sleep each night. This is to determine whether insufficient sleep or an irregular sleep schedule might be contributing to excessive sleepiness. A review of the medical history, list of current medications and a

physical examination will be performed. For some patients, laboratory tests may be performed to determine if an underlying medical condition is contributing to the excessive sleepiness.

A sleep study, or overnight polysomnogram (PSG), followed by a multiple sleep latency test (MSLT) are used to diagnose narcolepsy. The PSG is performed overnight at the sleep center in a comfortable and private room. Recording sensors are placed on the skin to measure brain waves (EEG), eye movements, muscle activity, heart rate, breathing and oxygen level. The MSLT is performed the day after an overnight sleep study. Four or 5 trials are conducted at two hour intervals during the day, the first trial beginning about 90 minutes after the overnight study ends. The purpose of the overnight PSG is to determine if another sleep disorder is present (such as sleep apnea) and to examine nighttime sleep quality. On the MSLT, the time it takes to fall asleep on nap trials and whether or not REM sleep is present on the naps is used to diagnose narcolepsy. The shorter the time to fall asleep, and the more REM sleep that is seen on the naps, the more likely a person is to have narcolepsy, especially if cataplexy is present.

How is Narcolepsy Treated?

Medication. There are several FDA-approved medications for the treatment of narcolepsy.

1. Methylphenidate (generic for Ritalin) and the amphetamines (Adderall, Dexedrine and Desoxyn).
2. Wake promoting agents (Provigil and Nuvigil).
3. Xyrem- approved to treat both narcolepsy and cataplexy.

Behavioral Treatment.

1. Maintain a stable and consistent sleep/wake schedule. It is important to get plenty of sleep each day.
2. Short scheduled naps can be helpful since people with narcolepsy will often feel alert for an hour or two after a nap.
3. Be careful while driving, operating heavy machinery or engaging in a task which requires vigilance when feeling sleepy.
4. Take medication as prescribed and contact your sleep provider if there are any changes or problems with medication.

What is Idiopathic Hypersomnia?

The primary feature that both narcolepsy and idiopathic hypersomnia share is excessive sleepiness in the presence of a stable sleep schedule and an adequate amount of sleep per day.

People with idiopathic hypersomnia do not have cataplexy (as this is a defining feature of narcolepsy), and usually do not have sleep paralysis or hypnagogic hallucinations. However, automatic behavior and disturbed nighttime sleep may be present.

An overnight PSG followed by an MSLT is used to diagnose idiopathic hypersomnia. REM sleep is usually not present on the naps (or is present on fewer naps compared to narcolepsy). Sleep latency (time to fall asleep) is usually short.

The same medications and behavioral recommendations used for narcolepsy are also effective for idiopathic hypersomnia.

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