

Narcolepsy

WHAT IS NARCOLEPSY?

Narcolepsy is a chronic (lifelong) neurologic (affecting the brain or nerves) disorder that is characterized by a permanent and overwhelming feeling of sleepiness. Narcolepsy affects more than 1 in 2,000 Americans, and most cases go undiagnosed and untreated. Although it is a relatively uncommon condition, its impact on a child's life can be dramatic. It affects boys and girls equally, and symptoms usually develop after puberty, with most people reporting the first symptoms of narcolepsy between the ages of 15 and 30.

WHAT ARE THE SYMPTOMS OF NARCOLEPSY?

The symptoms of narcolepsy can appear all at once, or they can develop slowly over many years. The four most common symptoms are excessive daytime sleepiness, cataplexy, sleep paralysis, and hypnagogic hallucinations. In some cases, excessive daytime sleepiness is the only symptom.

- **Excessive daytime sleepiness** is usually the first symptom of narcolepsy. People with narcolepsy often report feeling tired all the time. They tend to fall asleep not only in situations in which many normal people feel sleepy (after meals or during a dull lecture), but also when most people would remain awake (while watching a movie or writing a letter). Individuals with narcolepsy may also fall asleep at unusual times (in the middle of a conversation) or dangerous times (driving a car).
- **Cataplexy** involves sudden, brief losses of muscle control triggered by stress or a strong emotion, such as laughter, anger, or surprise. Cataplexy can range from a brief feeling of weakness in the knees to complete collapse. Cataplexy is sometimes the first symptom of narcolepsy but usually develops several years after the daytime sleepiness.
- **Sleep paralysis** is a feeling of being paralyzed, including being unable to talk or move for a brief period, either when falling asleep or after waking up. Touching the person usually causes the paralysis to disappear.
- **Hypnagogic hallucinations** are vivid, dream-like experiences that are difficult to distinguish from reality, occurring at sleep onset or after awakening. The images are often scary, such as of strange animals or prowlers, and are particularly frightening because the child is awake but has no control over the action.

A child or adolescent with narcolepsy may also have other symptoms:

- **Automatic behavior** is the performance of familiar, routine, or boring tasks without full awareness or later memory of doing them. Sometimes a child may actually fall asleep and continue an activity, but not recall having done it when awakened. Examples of automatic behavior include writing a letter or doing homework.
- **Disturbed nighttime sleep** frequently occurs in children and adolescents with narcolepsy. Although they have difficulty staying awake during the day, they may also wake frequently during the night. These multiple nighttime awakenings make the daytime sleepiness even worse.

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- **Other symptoms** reported by children and adolescents with narcolepsy include lethargy, low motivation, inability to concentrate, and memory loss. Children often have problems in school and keeping up with friends.

WHAT CAUSES NARCOLEPSY?

Although narcolepsy has been extensively studied, its exact cause is not known. Narcolepsy appears to be a disorder of the part of the central nervous system that controls sleep and wakefulness. Cataplexy, sleep paralysis, and hypnagogic hallucinations are similar to the loss of muscle tone that accompanies a stage of sleep called REM (rapid eye movement) sleep. Narcolepsy often runs in families, but many people with narcolepsy do not have relatives who are affected. Narcolepsy is not caused by psychiatric or psychological problems.

HOW IS NARCOLEPSY DIAGNOSED?

Narcolepsy is usually diagnosed by medical history and an overnight sleep study. The next day following the sleep study, a multiple sleep latency test will also be done. This test evaluates for daytime sleepiness and involves taking four or five naps every 2 hours. The length of time needed to fall asleep and whether REM sleep occurs is recorded.

HOW IS NARCOLEPSY TREATED?

Narcolepsy cannot be cured, but its symptoms can usually be controlled so that a child or adolescent with narcolepsy can lead a normal life. Each treatment plan usually involves medication, life-style changes, and education.

- **Medication.** One or more medications are usually prescribed to control the excessive daytime sleepiness and cataplexy. Caffeine should be avoided, especially in the late afternoon and evening, so that nighttime sleep is not disturbed.
- **Lifestyle changes.** The effective treatment of narcolepsy requires not only medication but also adjustments in lifestyle. The following suggestions can lead to substantial improvement:
 - Follow a strict sleep–wake schedule that ensures adequate sleep. Your child should go to bed and get up at the same time each day.
 - Take scheduled short naps once or twice each day, as needed.
 - Increase physical activity; avoid boring or repetitive tasks.
 - Avoid activities that can be dangerous, such as driving, swimming, or cooking, except during times when you know your child will be alert.

- **Education.** Narcolepsy can be a devastating disorder if family, friends, and teachers do not understand it, so education is essential. Daytime sleepiness may be mistaken for laziness, boredom, or lack of ability. The experiences of cataplexy and dreaming during wakefulness may be wrongly seen as a psychiatric problem. Be sure to educate family members and help your child's friends and their parents understand narcolepsy. Most importantly, make sure your child's teachers understand the disorder. Small adjustments in the classroom, such as being seated in the front of the class and being chosen to run classroom errands, can make a tremendous difference in a child's academic performance.