

Narcolepsy

Jodi Mindell "A Clinical Guide to Pediatric Sleep"

WHAT IS NARCOLEPSY?

Narcolepsy is a chronic neurological disorder. That means it is lifelong. The main symptom of narcolepsy is being severely sleepy during the day. This occurs despite getting enough sleep at night. Narcolepsy affects about 200,000 people in the United States. However, most children and adolescents are not diagnosed or treated. Narcolepsy can have a dramatic impact on a child's life. It affects boys and girls equally. It usually develops after puberty. Some younger children, though, have narcolepsy.

WHAT ARE THE SYMPTOMS OF NARCOLEPSY?

The symptoms of narcolepsy can appear all at once. Or, they can develop over many years. The main symptom is being severely sleepy during the day. The daytime sleepiness is often the only symptom in children and adolescents. Other symptoms include cataplexy, sleep paralysis, hypnagogic hallucinations, automatic behaviors, and disrupted nighttime sleep.

Excessive daytime sleepiness is the main symptom of narcolepsy. Children and adolescents with narcolepsy often report feeling sleepy all the time. They have a very hard time fighting the urge to fall asleep. They will fall asleep even when they are very motivated to stay awake. The sleepiness occurs not only when many people feel sleepy, such as during a dull lecture, but also when other people usually don't, such as while eating or talking to someone. The sleep period may be very brief, just several seconds. They may be so brief that sometimes the person with narcolepsy nor other people realize that the person is asleep. But they can result in major problems, such as "zoning out" in school or falling asleep while driving.

Cataplexy is a sudden loss of muscle tone. It is usually brief. It is always temporary. It may involve the whole body such as collapsing to the floor. But it is more likely to just involve certain muscles, such as drooping of the head or jaw or weakness of the knees. Cataplexy is most often triggered by a strong positive emotion, such as laughing or being surprised. It can also be triggered by stress or other strong emotions, such as anger. Cataplexy can be the first symptom of narcolepsy. But it usually develops after the daytime sleepiness.

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Sleep paralysis is a feeling of not being able to talk or move for a brief period either when falling asleep or just after waking up. Touching the person usually causes the paralysis to disappear. Although it usually just ends on its own.

Hypnagogic hallucinations are vivid images. They often seem very real. They occur when a person is falling asleep or just after waking up. The person may see, hear, or feel things that aren't there. The images can be scary, such as of strange animals or prowlers. These often occur at the same time as sleep paralysis. They may be very scary because a child may feel that there is no way to escape from the scary images.

Automatic behaviors involve keeping doing a familiar, routine, or boring task without being fully aware or later remembering doing it. The person is actually asleep. An example of automatic behavior is writing a page of nonsense while doing homework.

Disturbed nighttime sleep frequently occurs in children and adolescents with narcolepsy. Although those with narcolepsy have difficulty staying awake during the day, they may also have problems staying asleep at night. These frequent wakings make the daytime sleepiness even worse.

Other symptoms of narcolepsy may include lethargy and low motivation. Some people get depressed and have a hard time concentrating. Many have problems in school. Children and adolescents with narcolepsy may at first be diagnosed with depression, ADHD, or another mental health disorders before the true condition is recognized. Children and adolescents with narcolepsy also may have migraines and be overweight.

WHAT CAUSES NARCOLEPSY?

Narcolepsy is a disorder of the central nervous system. It affects the part of the brain that controls sleep and wake. The underlying cause of narcolepsy seems to be a decrease in specific brain chemicals that help keep us awake. These chemicals are called hypocretin or orexin. They have two different names. Most people who have narcolepsy have a gene (HLA) that makes it more likely they will develop narcolepsy.

Many symptoms of narcolepsy (cataplexy, sleep paralysis, and hypnagogic hallucinations) are features of rapid eye movement (REM) sleep or "dream sleep." They occur instead when a person is awake. For example, hypnagogic hallucinations look like "awake dreams." Narcolepsy sometimes runs in families. However, most children do not have any relatives with narcolepsy.

HOW IS NARCOLEPSY DIAGNOSED?

Narcolepsy is diagnosed by conducting an overnight sleep study (to check for other possible causes of sleep disruption) followed by a multiple sleep latency test (MSLT). The MSLT is a daytime test that measures sleepiness. It involves a series of four or five 20-minute opportunities (naps) to fall asleep. These are scheduled 2 hours apart on the

day following a sleep study. The MSLT measures whether the person falls asleep and how long it takes to fall asleep.

HOW IS NARCOLEPSY TREATED?

At this time, there is no cure for narcolepsy. But the symptoms can usually be controlled so that a child or adolescent with narcolepsy can lead a normal life. Treatment usually involves medication. Other things will also help.

Medication: One or more medications are usually prescribed for narcolepsy. The daytime sleepiness is often treated with a medicine, like Modafinil or Ritalin. Cataplexy may be treated with another medicine, like Prozac. Sodium oxybate is also sometimes prescribed.

Lifestyle changes: Changes in lifestyle are also important.

Get enough sleep. Your child should get plenty of sleep at night. Your child should, also, go to bed and get up around the same time each day.

Naps. One or two scheduled short naps during the day can be very helpful.

Be active. Be as active as possible during the day. Your child should also avoid boring or repetitive tasks.

Avoid certain activities. Some activities can be dangerous, such as swimming or cooking, if your child is very sleepy. Have your child only do these things when you know your child will be alert. Driving is major concern for adolescents with narcolepsy. Your teen should not drive until the daytime sleepiness is well treated.

Avoid late day caffeine. Caffeine should be avoided, especially in the late afternoon and evening, so that sleep at night is not disturbed.

Education: Narcolepsy is a chronic disorder that affects every aspect of a child's life. Therefore, education of everyone in your child's life is essential. This includes family members, friends, teachers, school nurses, and coaches. Daytime sleepiness may be mistaken for laziness, boredom, or lack of ability. Cataplexy may be misinterpreted as a psychiatric problem. So 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 and other school personnel understand the disorder. Small changes in class, such as allowing a child to get up and walk around the room to reduce sleepiness or providing the opportunity to take an afternoon nap, can make a tremendous difference in your child's quality of life and academic performance.