PATIENT TEACHING AID

Narcolepsy



Disorder of Severe Daytime Sleepiness

Narcolepsy is a sleep disorder that causes extreme daytime sleepiness, or EDS. People suffering from narcolepsy have an overwhelming need to sleep, often several times during the day. A person with this disorder can suddenly fall asleep while talking, walking, or driving. After a brief nap, the person awakens refreshed, but feels sleepy again after a few hours. Narcolepsy can lead to dangerous situations, such as falls or auto accidents. Although narcolepsy has no cure, medications and changes in lifestyle can help control this condition.

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Treatment Goals Are to Reduce Daytime Symptoms and Improve Nighttime Sleep

Narcolepsy usually begins during adolescence or young adulthood. It affects about 1 in 2,000 people, although the actual number may be higher because mild cases can go undiagnosed. Narcolepsy is associated with low levels of *hypocretin*, a brain chemical that regulates the sleep-wake cycle.

Symptoms

The symptoms of narcolepsy include cataplexy, EDS, and sleep paralysis with or without hallucinations.

Cataplexy is a sudden muscle weakness that can last several seconds or minutes. During a cataplexic attack, a person stays



After other conditions that can cause the symptoms common in narcolepsy are ruled out, sleep studies are performed to confirm the diagnosis.

awake but cannot move or speak, making the attack appear similar to a seizure. Cataplexy is often triggered by a strong emotional response, such as laughter, excitement, anger, or fear. This condition has been linked to a loss of the brain cells that make hypocretin. It is believed that these brain cells are destroyed by the body, possibly as a result of an autoimmune reaction.

EDS is an urge to sleep at intervals throughout the day. This powerful need to sleep results in a person nodding off abruptly, even while eating or talking. This "sleep attack" may last from a few seconds or minutes to a longer nap. This cycle is repeated up to several times per day. At night, the person usually falls asleep rapidly, but has a hard time staying asleep for more than a few hours.

Sleep paralysis is a temporary paralysis that occurs just before falling asleep or immediately upon waking. This symptom is alarming because the person is conscious but unable to move for up to several minutes. Sometimes, realistic hallucinations occur along with the paralysis, making this a highly disturbing experience.

Diagnosis

The symptoms of narcolepsy can be confused with those of other conditions, such as epilepsy, insomnia, restless legs syndrome, or sleep apnea. After other common causes of symptoms are ruled out, sleep studies—including the Multiple Sleep Latency Test (MSLT) and the polysomnogram (PSG)—are used to confirm the diagnosis. The MSLT measures the time it takes for a person to fall asleep for scheduled naps throughout the day and the qualities of the daytime sleep. The PSG measures breathing, heart rate, and brainwave activity during nighttime sleep and records sleep cycles. If a person enters the REM stage of sleep quickly after falling asleep, narcolepsy is the likely diagnosis.

Treatment

Treatment focuses on reducing daytime symptoms and improving nighttime sleep. Regularly scheduled bedtimes and morning wake-up times are advised, and some people benefit from taking scheduled short naps during the day when they feel most sleepy. Avoiding caffeine and large meals before bedtime is best. Exercising early in the day is helpful, and some people find it advantageous to take a relaxing warm bath before bedtime. It may be necessary to limit certain activities that could be dangerous during a sleep attack or cataplexic attack, such as driving, until symptoms are well controlled.

Prescription medications used to control symptoms include stimulants to avoid daytime sleepiness and antidepressants to control cataplexy, sleep paralysis, and hallucinations. Xyrem (sodium oxybate) is available through a restricted-enrollment program for the treatment of narco-lepsy. Xyrem helps regulate nighttime sleep, which leads to better control of EDS and cataplexy. Because it results in a rapid onset of sleep, Xyrem must be taken exactly as prescribed.

