has been developed which measures certain antigens often found in people who have a predisposition to narcolepsy. Positive results suggest a predisposition, but does not prove the presence of narcolepsy. This test is sometimes used when the diagnosis is in question. Another test that is available at a limited number of research facilities measures the level of hypocretin in cerebrospinal fluid (CSF). The absence of detectable hypocretins can confirm the presence of narcolepsy/cataplexy. However, normal levels of hypocretin cannot rule out the disorder.

Question: How is narcolepsy treated?

Answer: The goal is to decrease EDS and reduce cataplexy occurrences using minimal medication. EDS and cataplexy were traditionally treated separately, although the medication Xyrem (sodium oxybate), is approved to treat both. Xyrem has also been approved by the FDA for pediatric use. Xyrem is the only medication that treats all major symptoms of narcolepsy. Once a night dosing formulations of sodium oxybate are currently being developed.

Drugs commonly used for EDS include Provigil (modafinil) and a longer lasting formulation, Nuvigil (armodafinil). Central nervous system stimulants (Ritalin, Dexedrine, etc.) are sometimes used as well. In addition to Xyrem, a variety of antidepressants have been used to treat cataplexy. Effexor (venlafaxine), a SNRI and Strattera (Atomoxetine), an NRI, are commonly used. Older SSRIs are sometimes also prescribed.

Other medications are currently in development and will hopefully become available in the future.

Lifestyle management strategies such as short naps during the day, maintaining a healthy diet low in sugar and refined carbohydrates, and getting regular exercise can also help control symptoms and maintain alertness. Good doctor-patient communication is essential. It is also important to educate family, friends, teachers, and co-workers about narcolepsy. Joining a support group is recommended.

Question: What research is being conducted?

Answer: Sleep scientists are focusing on genetics, neurotransmitters, and the autoimmune system. Researchers also believe that other factors, such as viral and bacterial agents, abrupt changes in wake-sleep cycles, illnesses, accidents, stressors, and even hormonal changes, may act as triggers, which determine whether or not someone with a genetic predisposition to narcolepsy will eventually develop the disorder.

Question: What are the long-term problems of narcolepsy?

Answer: The consequences of narcolepsy may be many and far-reaching. Cataplexy may interfere with physical activities, and efforts to avoid emotions may lead to social withdrawal. Sleep attacks and cataplexy in public can be embarrassing and can cause serious social difficulties. Inability to work and/or drive may result in loss of independence, financial difficulties, and various other problems. In these situations, a person can easily lose touch with others and become depressed.

Additionally, some research suggests that hypocretin is also involved in several key functions involved in integrating several body functions regulated by the brain such as metabolism, circadian rhythms, and reward seeking behavior. This can have far reaching implications into many aspects of health than just sleep. Several population studies have shown that people with narcolepsy have increased rates of gastrointestinal, cardiac, and metabolic disease.

Question: What is Narcolepsy Network?

Answer: Narcolepsy Network is a national nonprofit organization dedicated to increasing early diagnosis of narcolepsy, advocating for and supporting people with narcolepsy and their families, and promoting critical research for narcolepsy treatments and a cure. Members include people with narcolepsy (PWNs), their families and friends, and professionals involved in the study and treatment of narcolepsy.

We offer assistance and encouragement to narcolepsy support groups around the country. We help to form and sustain support groups through advice, materials, and networking.

Our Youth Ambassador program trains young members of Narcolepsy Network to advocate for people with narcolepsy.

On our website, we offer a wide range of information and we maintain a closed Facebook support group for people with narcolepsy and their supporters.

We publish a members-only newsletter and produce educational materials about narcolepsy.

We host an annual conference and one day meetings that bring together PWNs for peer support and presentations from leading narcolepsy experts. PWNs, family, friends, and caregivers are all welcome!

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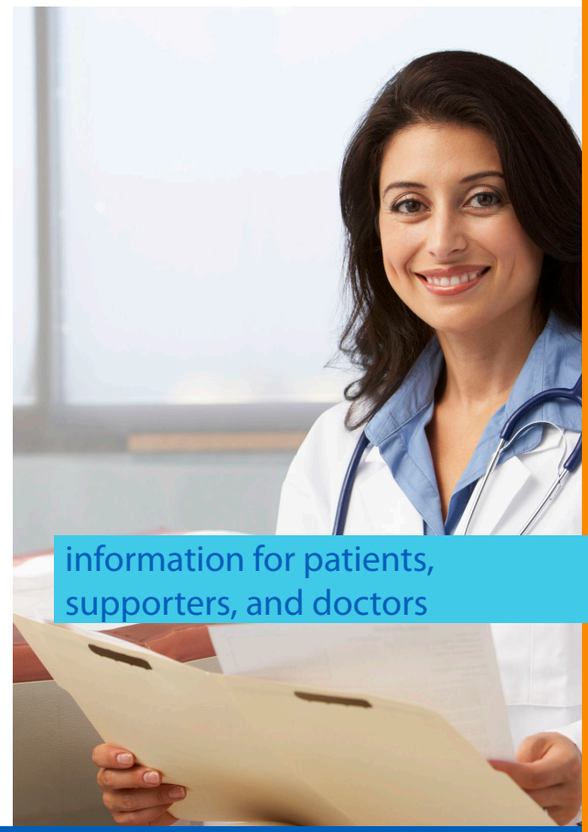
Narcolepsy Questions and Answers



information for patients, supporters, and doctors

Question: What is narcolepsy?

Answer: Narcolepsy is a neurological sleep disorder that can begin at any age and continues throughout life. Although the onset typically occurs during the teens or early twenties, it can also appear later in life. Predisposition to it is partially hereditary. It is believed to affect approximately 1 in every 2,000 people of both sexes and all races in the US. Once fully established, narcolepsy is generally stable and can be effectively treated. Life span is not affected.

Narcolepsy with cataplexy is caused by the destruction of hypocretin-producing cells in the hypothalamus region of the brain. Hypocretin (aka orexin) is a neurotransmitter involved in the regulation of the sleep/wake cycle as well as other bodily functions such as blood pressure and metabolism. Narcolepsy with cataplexy is an autoimmune disorder. Further research is needed to determine why hypocretin cells are destroyed and to identify the exact trigger(s) of both forms of narcolepsy.

Question: What are the symptoms?

Answer: There are five primary symptoms.

Excessive Daytime Sleepiness (EDS), which includes daytime sleep attacks that may occur with or without warning and may be uncontrollable. Persistent drowsiness may continue for prolonged periods of time and microsleeps, or fleeting moments of sleep, may intrude into the waking state.

Cataplexy is the sudden loss of voluntary muscle control, usually triggered by emotions such as laughter, surprise, fear, or anger. Cataplexy may occur more frequently during times of stress or fatigue. Cataplexy attacks may involve only a slight feeling of weakness and limp muscles (for example, sagging facial muscles, a nodding head, buckling knees, loss of arm strength, or garbled speech), or it may result in an immediate and total body collapse during which the person may appear unconscious, but is actually awake and alert. These attacks may last from a few seconds up to several minutes. These episodes are related to the loss of muscle tone usually associated with the normal dreaming stage of sleep called rapid eye movement (REM) during which muscles normally become immobile or paralyzed to protect from acting out one's dreams.

Disrupted or fragmented nighttime sleep involves multiple periods of arousal.

Hypnagogic hallucinations are vivid, realistic, and often frightening dreams.

Sleep paralysis is a temporary inability to move. Either one or both of these can occur during the transition between sleep and wakefulness, while the brain is neither fully awake nor fully asleep.

Question: Are there other symptoms?

Answer: Secondary symptoms can include **Automatic behavior** which is the performance of a routine task, without conscious awareness of doing it, and often without later memory of it.

Other side effects may be a result of medications or from additional problems that come from a continual effort to cope with the symptoms. Feelings of intense fatigue and continual lack of energy are often reported, and depression is not uncommon. The ability to concentrate and memorize may be compromised. Vision or focusing problems, sleep eating or eating binges, may also occur. Alcohol may amplify or neutralize the effects of medications taken for the primary symptoms.

Question: How are these symptoms all related to narcolepsy?

Answer: For the average person, a sleep period begins with about 90 minutes of non-REM sleep before the REM cycles begin. When a person with narcolepsy falls asleep, REM episodes often begin within five minutes. Since the brain may not be fully asleep when REM/dreaming begins, dreams may be experienced far more vividly and realistically. This is defined as a hallucination. After waking, REM periods, or fragments of REM, may occur inappropriately throughout the day. For example, during automatic behavior, sleep has partially overtaken the brain, but the body continues to perform familiar tasks.

Question: Is cataplexy dangerous?

Answer: While mild cataplexy can be embarrassing, it is not dangerous. It is often relatively easy to find support for briefly weakened head, neck, or arm muscles so that others may not even be aware. Many PWNs take medications to control cataplexy. Severe attacks are rare, but may happen with a sudden full-body collapse that can cause injuries. Companions should be told in advance what to expect and how to help. They should always check for the person's safety and comfort, immediately relieve any unnatural bending of limbs or unusual body positions, ensuring complete relaxation and then allowing the individual to recover naturally. Obviously, potentially dangerous situations should be avoided unless cataplexy is fully controlled. Cataplexy is unique to narcolepsy and is under recognized, so many PWNs wear medical alert jewelry or carry informational wallet cards alerting potential first responders about their condition. Service dogs have helped some PWNs with severe cataplexy.

Question: Is narcolepsy a psychological or mental disorder?

Answer: Narcolepsy is a neurological sleep disorder. Psychological problems can result from an individuals' inability to cope with the symptoms and a lack of understanding from family and friends. Involuntary sleepiness can be stigmatized as laziness. It can be difficult for someone with narcolepsy and those around them to understand that sleepiness and sleep attacks are uncontrollable. This can seriously impact self-esteem and/or personal relationships. Health care counseling for a person with narcolepsy and their families can help. Education and raising awareness can lessen the impact as well.

Question: Does narcolepsy affect learning?

Answer: Although narcolepsy does not affect intelligence, learning can be affected by the symptoms. Study, concentration, memory, and attention span may be periodically impaired by sleepiness. Children with narcolepsy should be identified at the earliest possible age to prevent a pattern of failure from developing and fostering low self-esteem. Adjustments in study habits may be continually necessary. This can best be accomplished with the cooperation of school personnel.

Question: How is narcolepsy diagnosed?

Answer: EDS is often the first symptom to appear, and, for some, the primary symptom of narcolepsy. However, EDS is also a symptom of various other medical conditions. Cataplexy, on the other hand, is unique to narcolepsy. The combination of EDS and cataplexy allow for a clinical diagnosis of narcolepsy. Even when cataplexy is present, laboratory tests may still be needed to confirm diagnosis and determine a treatment plan. The usual diagnostic procedure includes an overnight polysomnogram (PSG or sleep study) to rule out other causes of EDS and to determine the presence of unusual REM patterns. This is followed by the Multiple Sleep Latency Test (MSLT), or daytime nap test, which measures rapidity of sleep onset and how quickly REM sleep follows. The MSLT is the most widely accepted diagnostic test for narcolepsy. In addition, a genetic blood test