

and comfort, immediately relieving any unnatural bending of limbs or unusual body positions, assuring complete relaxation and then allowing him or her to recover naturally. Cataplexy for some can be so instantaneous that there is no time to prepare for safety, and injury may occur. Obviously, potentially life threatening situations should be avoided unless cataplexy is fully controlled.

**Question: How is a diagnosis of narcolepsy determined?**

**Answer:** Excessive daytime sleepiness (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 has been developed which measures certain antigens often found in people who have a predisposition to narcolepsy. Positive results suggest a predisposition, but do not prove the presence of narcolepsy. This test is sometimes used when the diagnosis is in question. A new test is currently in use at a limited number of research facilities, which measures the level of hypocretin in cerebrospinal fluid (CSF). The absence of detectable hypocretins can confirm the presence of narcolepsy/cataplexy, but normal levels of hypocretin cannot rule out the disorder.

**Question: How is narcolepsy treated?**

**Answer:** The goal is to decrease EDS and reduce occurrences of cataplexy using minimal medication. EDS and cataplexy must be treated separately. Traditionally, central nervous system

stimulants (i.e., Ritalin, Dexedrine, etc.) have been used for EDS. In 1999, Provigil (Modafinil) was the first stimulant approved for treatment of EDS associated with narcolepsy. Nuvigil, a longer-acting formulation of modafinil, has just been approved by the FDA. Tricyclic antidepressants (i.e., Vivactil, Tofranil, etc.) and serotonin reuptake inhibitors (SSRIs) have traditionally been used for treatment of cataplexy and other REM symptoms. Most recently, the antidepressants Effexor (an SSNRI), and Strattera (an SNRI), are showing excellent results in alleviating cataplexy and reducing other REM symptoms. In 2002, a new drug, Xyrem (sodium oxybate), was approved for the safe and effective treatment of cataplexy. In 2005, Xyrem was also approved to treat EDS associated with narcolepsy. Xyrem is the only medication that treats all major symptoms of narcolepsy. In addition to drug therapy, 2 or 3 short naps during the day may help control sleepiness and maintain alertness. Diet control, such as avoidance of sugar and refined carbohydrates, and regular exercise may also help. Continuing doctor-patient communication is essential. Equally important is educating family, friends, teachers, and co-workers about narcolepsy. Joining a support group is recommended.

**Question: What research is being conducted?**

**Answer:** Sleep scientists, at present, 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 are 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.

**Question: What is the Narcolepsy Network?**

**Answer:** We are a national non-profit corporation, founded in 1986. Our members include individuals with narcolepsy, their families and friends, and professionals involved in the study and treatment of narcolepsy. Our goals are to:

- Serve as a resource center
- Assist support groups
  - Educate the public
  - Facilitate early diagnosis
  - Protect the rights of those with narcolepsy
  - Encourage ongoing scientific research.
- The Network offers support and encouragement to Narcolepsy Support Groups around the country. Narcolepsy Network, Inc. will help to form and sustain Support Groups through advice, materials and networking with other successful groups and individual leaders.
- The Network offers a website-based communications link through which you can ask questions and seek guidance and help both in finding out if you have narcolepsy and in managing your symptoms.
- The Network publishes a members-only quarterly newsletter and educational material about narcolepsy and coexisting sleep disorders. These publications, available from Narcolepsy Network, Inc., cover subjects from explaining narcolepsy to children to issues like work and school accommodations and driving with narcolepsy.
- Narcolepsy Network, Inc. sponsors an Annual Conference that brings together people with Narcolepsy for peer support and presentations from leading narcolepsy experts on the newest advances in the recognition, diagnosis and treatment of narcolepsy. The Network welcomes people with narcolepsy, family, friends and other caregivers to these conferences. Each year the conference is held in a different part of the country to allow participants from all parts of the U.S. to attend.

NARCOLEPSY NETWORK, INC.

110 Ripple Lane • North Kingstown, RI 02852

Toll Free (888) 292-6522

Tel (401) 667-2523 • Fax (401) 633-6567

E-mail: [narnet@narcolepsynetwork.org](mailto:narnet@narcolepsynetwork.org)

[www.narcolepsynetwork.org](http://www.narcolepsynetwork.org)

(Revised July 09, 2009)

# NARCOLEPSY

## Questions and Answers



Please detach or copy and return to:  
**NARCOLEPSY NETWORK, INC.**  
**110 Ripple Lane**  
**North Kingstown, RI 02852**  
Tel (401) 667-2523; (888) 292-6522  
E-mail: narnet@narcolepsynetwork.org

NAME \_\_\_\_\_  
ADDRESS \_\_\_\_\_  
CITY \_\_\_\_\_  
STATE \_\_\_\_\_ ZIP \_\_\_\_\_  
PHONE \_\_\_\_\_  
E-mail \_\_\_\_\_

**MEMBERSHIP DUES:**

- \$35 Individual
- \$75 Sleep Professional
- \$150 -Sleep Center/Medical Facility

**DONATION INCLUDED:** \$ \_\_\_\_\_

A receipt will be sent for all tax deductible donations.

**SUPPORT GROUP INFORMATION:**

- I would like to find a support group in my area
- I would like to help in starting a support group
- I am a member of the following support group:

Name of group \_\_\_\_\_

Contact Person \_\_\_\_\_

City/State \_\_\_\_\_

Phone \_\_\_\_\_

E-mail \_\_\_\_\_

**INTEREST IN NARCOLEPSY NETWORK**

\_\_\_\_ I have narcolepsy

\_\_\_\_ Family member has narcolepsy

\_\_\_\_ Friend has narcolepsy

\_\_\_\_ I am a Sleep Medicine Professional

Facility \_\_\_\_\_

Position \_\_\_\_\_

You  MAY  MAY NOT give my name to others seeking support and/or contacts through Narcolepsy Network.

Note: Membership includes a quarterly newsletter, copies of our current brochures, a copy of "Narcolepsy: A Guide to Understanding", and a list of available educational materials.

**Question: What is narcolepsy?**

**Answer:** Narcolepsy is a neurological sleep disorder that can begin at any age and continues throughout life. The onset typically occurs during the teens or early twenties but it can also appear later in life. Predisposition to it is partially hereditary. It is believed to affect approximately 1 in every 2000 people of both sexes and all races. Once fully established, narcolepsy is generally stable and can be most often effectively treated. People with narcolepsy can expect to live a normal life span.

**Question: What causes narcolepsy?**

**Answer:** Much has been learned since 1998, when researchers discovered the two brain chemicals called hypocretins (aka orexins). These neurotransmitters are involved in the regulation of the sleep/wake cycle as well as other bodily functions (e.g., blood pressure and metabolism). Research has shown that the majority of hypocretin-producing cells, located in the hypothalamus, have been destroyed in the brains of those who develop narcolepsy and cataplexy. In 2009 scientists definitely demonstrated that hypocretin-deficient narcolepsy is an auto-immune disorder. The cause(s) of narcolepsy without cataplexy are unknown. 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 which may be uncontrollable; persistent drowsiness, which may continue for prolonged periods of time; and micro-sleeps, or fleeting moments of sleep, which may intrude into the waking state.
- **Cataplexy**, the second major symptom of narcolepsy, is a 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. The cataplectic attack may involve only a slight feeling of weakness and limp muscles (i.e., sagging facial muscles, a nodding head, buckling

knees, loss of arm strength, garbled speech), or it may result in 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. Cataplectic episodes are related to the loss of muscle tone usually associated with the normal dreaming stage of sleep called rapid eye movement (REM); as a protection against acting out one's dreams, the muscles become immobile or paralyzed.

- **Disrupted or fragmented nighttime sleep**, involves multiple periods of arousal.

The other two primary symptoms are:

- **Hypnagogic hallucinations** - vivid, realistic, and often frightening dreams; and
- **Sleep paralysis** - 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 any other symptoms?**

**Answer:** The following secondary or auxiliary symptoms may appear:

- **Automatic behavior** - the performance of a routine task, without conscious awareness of doing it, and often without later memory of it.
- **Other** - Side effects of the medications or problems resulting from a continual effort to cope with the symptoms may produce additional problems. 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, or 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 5 minutes. Since the brain may not be fully asleep when REM/dreaming begins, the dream 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. When automatic behavior occurs for a person with narcolepsy, sleep has partially overtaken the brain, but the body continues to perform familiar tasks.

**Question: Is narcolepsy a psychological or mental disorder?**

**Answer:** Narcolepsy is a neurologically-based sleep disorder involving the dissociation of sleep states. Psychological problems can result from the individual's inability to cope with the symptoms and their family's misunderstanding of the disorder. It is very difficult for a person with narcolepsy and those around him/her to understand that sleepiness and sleep attacks are uncontrollable. Failure to accept this fact may seriously impact self-esteem and/or personal relationships. Health care counseling for persons with narcolepsy and their families can help alleviate these secondary problems. Educating the public, especially school, health and human resource personnel, can help lessen or even prevent many of these problems.

**Question: Does narcolepsy affect learning?**

**Answer:** Although narcolepsy does not affect intelligence, learning cannot help but 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, thus fostering low self-esteem. Adjustments in study habits may be continually necessary. This can best be accomplished with the cooperation of school personnel.

**Question: Is cataplexy dangerous?**

**Answer:** Mild cataplexy, while perhaps embarrassing, is not dangerous. One can often find support for weakened head, neck, or arm muscles, so that others may not even be aware of the momentary loss of control. However, severe cataplexy, resulting in immediate and sudden body collapse, may cause injury. Companions should be told in advance what to expect and how to help. They should always check for the person's safety