

Narcolepsy Fact Sheet

Definition

Narcolepsy is a neurological autoimmune sleep disorder in which the brain loses the ability to maintain normal sleep and wake states. Affects 1 in every 2,000 people (200,000-250,000 Americans).

Symptoms

- **Periods of extreme sleepiness** every 3 to 4 hours during the day, comparable to how a normal person would feel after staying awake for 48-72 hours straight.
- **Cataplexy** is a sudden loss of muscle tone while awake, resulting in the inability to move. Strong emotions, such as laughter or anger, will often bring on cataplexy. In severe cases, cataplexy may cause a person to collapse to ground and stay paralyzed for as long as several minutes.
- **Hallucinations** while falling asleep or waking that are often frightening
- **Sleep paralysis** upon falling asleep or waking, during which an individual is awake but cannot move

Causes

- Narcolepsy is a nervous system disorder, not a mental illness. Narcolepsy isn't related to seizure disorders, fainting, simple lack of sleep or other conditions that may cause abnormal sleep patterns.
- There are two forms of narcolepsy, Narcolepsy with Cataplexy (N+C) and Narcolepsy without Cataplexy (N-C).
 - In N+C, an **autoimmune reaction** destroys the brain's 70,000 *hypocretin*-producing cells. Hypocretin neurotransmitters are essential to proper regulation of sleep and wakefulness.
 - The cause(s) of N-C are not at all understood.

Diagnosis

- Most doctors are unfamiliar with the basic symptoms of narcolepsy.
- Individuals experience symptoms for an average of 3 -5 years before receiving an accurate diagnosis and 10 -15 year delays are not uncommon.

Treatment

- Narcolepsy is a chronic, lifelong condition. There is no cure for narcolepsy.
- Three newer medications are approved for narcolepsy, Provigil, Nuvigil and Xyrem. A variety of older medications are prescribed off-label as well.
- Medications improve symptoms somewhat, but have serious side effects and cannot normalize individuals. At best, symptoms are relieved by 70%.

Living with Narcolepsy

- Narcolepsy can cause serious disruptions to daily routine and compromise education, employment, and family opportunities.
- Studies indicate narcolepsy's affect upon quality of life is comparable to **epilepsy** and **Parkinson's disease**.