

FACT SHEET: NARCOLEPSY

KEY FACTS

- Narcolepsy affects about 1 in 2,000 people in the U.S. and Western Europe.
- Often occurs between 15 and 30 years of age.
- Currently there is no cure for narcolepsy. Treatments with CNS stimulants and lifestyle modifications are used to help control the symptoms.



Q: WHAT IS NARCOLEPSY?

A: Narcolepsy is a chronic sleep disorder characterized by overwhelming sleepiness and uncontrollable sleep attacks. People with narcolepsy often find it difficult to stay awake for long periods of time, regardless of the circumstances. Narcolepsy can cause serious disruptions in your daily routine.

Q: WHAT ARE THE SYMPTOMS OF NARCOLEPSY?

- A: Symptoms generally occur between the ages 15-30 years and include:
- Excessive Daytime Sleepiness – usually the first symptom to appear.
 - Cataplexy – sudden loss of muscle tone or muscle weakness that can last from a few seconds to a few minutes.
 - Sleep Paralysis – brief episodes of being unable to move or speak that can occur at sleep onset or when awakening.
 - Hypnagogic hallucinations – episodes of frightening dreams or hallucinations, when falling asleep. These dreams can often cause a sudden jerk and arousal just before sleep onset.

Q: WHAT ARE THE CAUSES OF NARCOLEPSY?

A: The exact cause of narcolepsy is unknown. Genetics and possibly other factors such as infection may play a role in the development of the disorder. Recent research, however, favors Orexin/Hypocretin (a Neuropeptide found in the hypothalamus) as playing a critical role in the development of narcolepsy. Orexin plays a role in regulating the sleep/wake state and specifically maintenance of wakefulness. Orexin deficiency has been shown to result in narcolepsy in humans, dogs and rodents. Research continues in this area with the goal of finding a cure for the disorder.



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Q: WHAT ARE THE IMPLICATIONS OF NARCOLEPSY?

A: Patients who have narcolepsy suffer life-long complications both personally and professionally.

- Narcoleptics are sometimes perceived as lazy, lethargic, unmotivated or rude.
- Narcoleptics have difficulty sustaining intimate relationships. Since intense feelings, such as anger or laughter can trigger symptoms of cataplexy, narcoleptic patients often withdraw from emotional interactions.
- Narcoleptic patients can sustain injury from cataplexy if they fall during the episode. They are also at increased risk of motor vehicle accidents due to uncontrollable sleep attacks or a cataplectic attack.
- Narcoleptics are at increased risk of developing obesity due to inactivity; binge eating resulting from Orexin deficiency or a combination of factors.

Q: HOW IS NARCOLEPSY TREATED?

A: Currently there is no cure for narcolepsy, but it can be managed with medication and lifestyle changes. Medications for narcolepsy target the major symptoms of sleepiness and cataplexy. Stimulant medications are used to manage excessive daytime sleepiness while antidepressants and other compounds address cataplexy. The FDA has approved two drugs specifically to manage and treat narcolepsy, and these are now considered the first-line treatments: Modafinil (Provigil), for uncontrollable, daytime sleepiness and Sodium oxybate (Xyrem) for cataplexy.

Q: CAN LIFESTYLE CHANGES HELP WITH MY SYMPTOMS?

A: Sticking to a strict sleep/wake schedule even on the weekend is beneficial in managing sleepiness along with medications. Taking frequent short naps that last up to 20 minutes at strategic times can also help control daytime sleepiness. Napping will also allow narcoleptics to take drug holidays (stopping medication for short periods) to improve the effectiveness of medications.

FURTHER READING

1. **Mayo Clinic** – www.mayoclinic.com
2. **US National Library of Medicine** – www.nlm.nih.gov
3. **American Academy of Sleep Medicine** – www.aasmnet.org