

# Narcolepsy

## Quick Facts:

Narcolepsy is a neurologic disorder characterized by a decreased ability to regulate sleep-wake cycles. The cardinal symptom of narcolepsy is excessive daytime sleepiness that leads to an irrepensible need to sleep and daytime lapses into sleep. Although it affects 1 in 2000 people, it is often misdiagnosed and can lead to reduced sleep quality and reduced quality of life. Other symptoms of narcolepsy include sudden muscle weakness when experiencing an intense emotion such as laughter (cataplexy), vivid dream-like hallucinations while falling asleep or when waking up (hypnagogic and hypnopompic hallucinations), and feeling completely paralyzed when waking up or falling asleep (sleep paralysis). Most patients with narcolepsy have a deficiency of the neurotransmitter orexin (hypocretin) in the brain. After careful sleep history and examination, diagnosis of narcolepsy usually requires an overnight sleep study (polysomnography) followed by daytime nap testing (Multiple Sleep Latency Test).



## Why It Matters

- Narcolepsy reduces quality of life. It is a chronic neurologic condition and can seriously limit a patient's social, academic, and work activities and interfere with their psychological and cognitive development. It may also cause sleep fragmentation and difficulty sleeping at night.
- Narcolepsy can be overlooked. It usually develops in the teen years and can be misdiagnosed as a psychiatric disorder leading to delays in treatment.
- Narcolepsy can be dangerous. It causes persistent sleepiness and even "sleep attacks" where individuals unwillingly fall asleep during work, at school, while eating, or even while driving. Up to two-thirds of people with narcolepsy may also suffer from cataplexy, a sudden and brief loss of muscle tone (such as knees buckling, or jaw going slack while speaking) when experiencing a strong emotion.
- Narcolepsy can be managed. Although it is a chronic condition, it is manageable. Medications and lifestyle changes can help improve sleep quality, reduce daytime sleepiness, and improve quality of life.

## What You Can Do

- Recognize key symptoms of narcolepsy: excessive daytime sleepiness, cataplexy, hypnagogic and hypnopompic hallucinations, and sleep paralysis.
- Screen young adults with mood disorders or daytime sleepiness for auxiliary symptoms of narcolepsy.
- Ask patients about sleepiness while driving, and counsel patients against drowsy driving.
- Educate patients about the importance of getting adequate sleep, avoiding sleep deprivation, and following sleep hygiene measures (such as having a regular sleep-wake schedule).

## When to Refer?

- Refer any patient with suspected narcolepsy to a sleep center for diagnosis and management.
- It is generally preferable that a sleep physician order a polysomnography and Multiple Sleep Latency Test. They will instruct the patient on how to prepare for the test (weaning off medications that may interfere with REM sleep, maintaining a sleep diary prior to the test, obtaining urine toxicology at the time of the polysomnography, etc.). If not done correctly, testing may result in false negative results and delay treatment further.

## Patient Information Websites:

- American Academy of Sleep Medicine <http://sleepeducation.org/essentials-in-sleep/narcolepsy>
- National Institute of Neurological Disorders and Stroke <https://www.ninds.nih.gov/Disorders/Patient-Caregiver-Education/Fact-Sheets/Narcolepsy-Fact-Sheet>
- Narcolepsy Network <http://narcolepsynetwork.org/>
- Wake Up Narcolepsy <http://www.wakeupnarcolepsy.org/>
- National Sleep Foundation <https://sleepfoundation.org/sleep-disorders-problems/narcolepsy-and-sleep>

## References:

1. Scammell TE. Narcolepsy. *N Engl J Med*. 2015;373(27):2654-2662.
2. Morgenthaler TI, Kapur VK, Brown T, et al. Practice parameters for the treatment of narcolepsy and other hypersomnias of central origin. *Sleep*. 2007;30(12):1705-1711.
3. American Academy of Sleep Medicine. *International Classification of Sleep Disorders*. 3rd ed. Darien, IL: American Academy of Sleep Medicine; 2014.