

# Narcolepsy 101

Unfortunately, many people's only exposure to narcolepsy is a joke—a fictional character on TV or film suddenly falling asleep at an inopportune moment. In reality, narcolepsy is a complex disorder that affects 1 in every 2,000 people.

In the U.S. alone, it's estimated that 200,000 people are living with narcolepsy. Globally, it's closer to 3 million people. This chronic condition often presents in much subtler ways than in those comical depictions and can impact daily life in serious ways.

## What is Narcolepsy?

A lifelong disorder of the central nervous system, narcolepsy disrupts the brain's ability to regulate sleep-wake cycles. Sleep intrudes on wakefulness, and wakefulness intrudes on sleep.

There are two types of narcolepsy:

- Type 1 (narcolepsy with cataplexy)
- Type 2 (narcolepsy without cataplexy)

It's a highly misunderstood and underdiagnosed disorder. Studies suggest that 64 percent of children and adolescents with narcolepsy are initially misdiagnosed. Diagnosis is often delayed, taking an average of two to 10 years.

Why? Partly because the symptoms overlap with many other conditions. In addition, many doctors and even sleep specialists report feeling uncertainty in diagnosing narcolepsy or identifying its five key symptoms.



## Key Symptoms

Narcolepsy symptoms can look different for each person, making diagnosis challenging. The five key signs include:

- 1. Excessive daytime sleepiness.** The most universal symptom, excessive daytime sleepiness makes it difficult to stay awake and alert during the day, even after a full night's sleep. People with narcolepsy often feel as though they've been awake for 72 hours straight.
- 2. Sleep disruption.** Despite feeling tired all day, many people with narcolepsy also have trouble sleeping at night due to frequent awakenings that interrupt their sleep.
- 3. Sleep paralysis.** A brief inability to move or speak while falling asleep or waking up.
- 4. Hypnagogic and hypnopompic hallucinations.** Vivid dream-like experiences that occur while going to sleep or waking up.
- 5. Cataplexy.** Only occurring in people with type 1 narcolepsy, cataplexy causes

brief, sudden, and uncontrollable muscle weakness triggered by strong or intense emotions. In severe cases, it may cause individuals to slump to the ground unable to move or talk. Although it may look like they're asleep, they're actually still fully conscious.

Narcolepsy does not always look "sleepy." It can present as memory loss, poor concentration, irritability, and automatic behaviors, which can have a massive impact on your relationships, academic performance, and professional success.

Because it's an "invisible" disorder, people with narcolepsy often experience isolation, loss of confidence, depression, and anxiety. It's important to increase awareness to help more people get an accurate diagnosis sooner.

## Getting Help

If you suspect you have narcolepsy, your doctor may refer you to a sleep specialist, who can diagnose it through a sleep study and other tests.

While there is no cure, an increasing number of treatment options can help to manage symptoms, including medications that can improve wakefulness and regulate your sleep cycles. Lifestyle changes like good sleep hygiene and taking naps can also help.

In addition, there are many in-person and online support groups available through organizations like Wake Up Narcolepsy, which allow you to connect with others living with narcolepsy who understand. ■

## Notes

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This patient primer is written by Wake Up Narcolepsy, a nonprofit organization dedicated to driving narcolepsy awareness, education, and research toward improved treatments and a cure. For more information, visit [www.wakeupnarcolepsy.org](http://www.wakeupnarcolepsy.org).