

# Sleep Disorders: Narcolepsy

**On screen, for decades,** narcolepsy is a trope played for laughs: A couple is on a date. A woman regales her partner with the trials and tribulations of her day. The partner laughs, then falls face first into their pastrami on rye, snoring. When they come to, they apologize. “Going through a bout of narcolepsy,” they confess. We’ve seen it a hundred times. It’s also the reason why, of the estimated 200,000 adult and children Americans living with narcolepsy, fewer than 50% have been accurately diagnosed and provided treatment. Narcolepsy, as depicted in film and TV, is so wildly inaccurate that real people living with this disorder assume that what they’re going through couldn’t possibly have narcolepsy because they’ve never fallen asleep in the middle of their tennis serve.

200,000

Estimated number of Americans with narcolepsy. Only about 25% have been accurately diagnosed and treated.



**Due to low awareness (even among physicians) and misperceptions, there is an average of 8 to 15 years between narcolepsy symptom onset and diagnosis.**



## What Is Narcolepsy?

It is a chronic neurological condition that impairs the brain’s ability to regulate the sleep-wake cycle, often caused by low levels of hypocretins, a brain neurotransmitter responsible for such regulation. It can appear in teens and young adults and it can be treated, but it does not go away.

## How Is Narcolepsy Diagnosed?

Sleep specialists diagnose narcolepsy using a 24-hour sleep study that includes a nighttime portion (polysomnogram) and daytime nap portion (multiple sleep latency test). The diagnosis is mainly based on how quickly and frequently one’s brain enters rapid eye movement sleep (REM)/ dream sleep during these tests.



## What Does It Actually Look Like?



### EXCESSIVE DAYTIME SLEEPINESS

The sleepiness feels comparable to how someone without narcolepsy would feel after staying awake for 48-72 hours. People with narcolepsy don't fall asleep mid-jog, but they do have to battle with their brain and body to stay awake as if they'd been awake for days.



### CATAPLEXY

Sudden muscle weakness triggered by emotions like laughter, surprise, annoyance, stress. It could even happen during sex. It could be a slackening of the jaw, buckling of the knees, or falling down. It can last a few seconds or a few minutes, and the person remains fully conscious even if they're unable to speak. It can look like someone is drunk, clumsy or crumbling to the ground.



### HALLUCINATIONS

Visual, auditory, or tactile hallucinations upon falling asleep (hypnagogic) or waking up (hypnopompic). These hallucinations are vivid experiences taking place in the room where the person is sleeping. Imagine paranormal activity, an alien invasion, or a burglar who isn't there.



### DISRUPTED NIGHTTIME SLEEP

Narcolepsy disrupts the sleep-wake cycle. So the timing of sleepiness is "off"—one may fight sleepiness during the day but struggle to stay asleep at night.



### SLEEP PARALYSIS

The inability to move for a few seconds or minutes upon falling asleep or waking up, often accompanied by the aforementioned hallucinations.

**Type 1 narcolepsy** with cataplexy is caused by a lack of hypocretin (also called orexin), a key neurotransmitter that helps sustain alertness and regulate the sleep-wake cycle.

**Type 2 narcolepsy** does not involve cataplexy, and less is known about the cause.



## How Is It Treated?

There is currently no cure but treatment options are available. Once diagnosed by a sleep specialist, symptom management varies person to person and it can take a long time to find the right combination of treatments.

- Nighttime or histamine-directed medications to decrease excessive daytime sleepiness and cataplexy.
- Wake-promoting or stimulant medications to increase alertness.
- Antidepressant medication to decrease cataplexy.
- Scheduled daytime naps.

➡ Coping strategies may include meet-up groups or social media, and improving general health and wellness through sleep hygiene, diet and fitness.

### How to Avoid the Narcolepsy Trope

*It's not a punchline, but its symptoms can be scary and offer a lot of opportunities for drama. Imagine:*

- Losing muscle control while crossing the street in front of an oncoming bus
- Hallucinations of being attacked but paralysis keeping you from fighting back or calling for help
- Fighting to stay awake during an argument with your spouse
- Performing a séance to get rid of haunting spirits (which turn out to be hallucinations).

#### BOTTOM LINE

If representation of narcolepsy can begin to approach the truth, people who are struggling might be able to identify their symptoms and get life-changing help.

Instead of disease-first language (a narcoleptic; I'm narcoleptic; narcoleptic patients), please use person-first language (a person with narcolepsy; a mother diagnosed with narcolepsy; a student living with narcolepsy).

