

What is Narcolepsy

Narcolepsy is an incurable, neurological sleep disorder where the brain is unable to regulate typical sleep-wake cycles.

- **Excessive Daytime Sleepiness (EDS)**
The inability to stay awake and alert during the day.
- **Cataplexy**
A sudden, brief loss of muscle tone caused by experiencing strong emotions.
- **Sleep Disruption**
The breaking up of sleep by many awakenings. Poor-quality sleep at night: falling asleep easily, but having trouble staying asleep
- **Sleep Paralysis**
A brief inability to move or speak while falling asleep or waking up.
- **Hypnagogic Hallucinations**
Vivid dream-like events that occur while falling asleep or waking up. They can be experienced as multisensory hallucinations.



Fast Facts

- Narcolepsy affects **1 in every 2000** Americans and **3 million** people worldwide.
- Typical onset is between the ages of **10 and 20**.
- It is estimated that up to **50%** of patients with Narcolepsy may be **undiagnosed**.
- On average, patients have **6 physician** visits before receiving a Narcolepsy diagnosis.
- On average it can take **10 years or more** for patients to receive a Narcolepsy diagnosis.
- Narcolepsy can affect **academic and professional** performance and makes **interpersonal relationships** more challenging.
- While treatment can help lead a near normal life, there is **not yet a cure**.

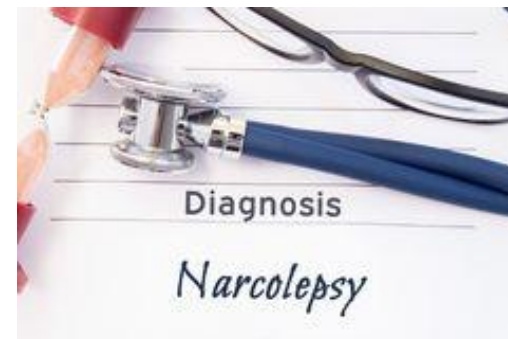


Narcolepsy Diagnosis

Narcolepsy can be misdiagnosed as laziness, ADHD, depression, sleep apnea or even Schizophrenia.

Current Diagnostic Tests

- A **Polysomnography (PSG)** is an overnight in-lab test used to diagnose narcolepsy, as well as other sleep disorders. A PSG works by recording your brain waves, oxygen level in your blood, heart rate and breathing, and eye and leg movements during the study.
- A **Multiple Sleep Latency Test (MSLT)** is a test that is performed on the morning following a PSG. An MSLT is used to diagnose narcolepsy and to measure the degree of daytime sleepiness. It measures how quickly you fall asleep in quiet situations during the day. It also monitors how quickly and how often you enter rapid eye movement (REM) sleep.



Impact of Narcolepsy

- Relationships (Personal/Professional)
- Emotional Wellbeing
- Public/Personal Safety (e.g., driving)
- Education/Professional Limitations
- Societal Engagement

Treatment Options

At this time, there is no cure for Narcolepsy, although symptoms can be managed through a range of different medications that address both daytime and nighttime symptoms. In addition, significant improvement can be made by specific lifestyle changes. For example:

- Effective Sleep Hygiene
 - Scheduled Daytime Naps
 - Regular Bedtime Routine
- Healthy Diet
- Consistent Exercise Routine
- Support Groups

What We Do

Education and Awareness

- Narcolepsy Education Days
- School Awareness Events
- Golf Outing Events
- Marathon Teams (Boston and L.A.)
- Swinging for Sleep Campaign
- Nashville Music Events
- Boston Comedy Events
- Michigan 5K Road Race

Research

- WUN awards unrestricted grants to leading scientists in the field to further research and find a cure (Boston Children's Hospital, Harvard, Northwestern, Stanford, SickKids Hospital of Toronto, and Vanderbilt)

Community of Support

- Online Support Groups
- Camp for our Children with Narcolepsy at the Center for Courageous Kids
- Peer to Peer Fundraising



Connect with WUN:

www.wakeupnarcolepsy.org



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Advancing the Knowledge of Narcolepsy to Find a Cure



Taking Narcolepsy from the Shadows into the Light

Wake Up Narcolepsy

WUN is a 501(c)(3) not for profit organization dedicated to advancing the knowledge of Narcolepsy to find a cure, as we strengthen families and individuals. We do this by raising awareness, funding research, and maintaining a strong community of support.

As an advocacy organization, we work with patients, caregivers, clinicians, researchers, and educators to facilitate a high level of understanding and expertise.



We are a professional organization spread across the United States & Canada, with international impact.

Our Team and Board Members all have a child, grandchild, or personal diagnosis of Narcolepsy and are expertly poised and committed to serving the wider Narcolepsy community.