

A Patient's Guide to

Living With Narcolepsy



Comprehensive Sleep
Medicine Associates
CSMA


From Diagnosis to daily life—your
roadmap to better sleep health.

What is Narcolepsy?

Narcolepsy is a chronic neurological sleep disorder that affects the brain's ability to regulate sleep and wake cycles. People with narcolepsy often experience overwhelming sleepiness during the day and disruptions in their nighttime sleep.

- Affects 1 in every 2,000 people.
- Symptoms often begin between the ages of 10–30 years old.
- Two main types:
 - Type 1 Narcolepsy: includes cataplexy (*sudden muscle weakness*).
 - Type 2 Narcolepsy: does not include cataplexy.



Narcolepsy Symptoms

While not all patients experience every symptom, here are some of the most common symptoms seen in patients with narcolepsy:



EXCESSIVE DAYTIME SLEEPINESS (EDS)

This is the primary symptom, characterized by overwhelming drowsiness and a tendency to fall asleep at inappropriate times, even during activities like driving or eating.

SLEEP PARALYSIS

A temporary inability to move or speak while falling asleep or upon waking, leaving individuals conscious but unable to act.

CATAPLEXY

This involves a sudden, temporary loss of muscle tone, triggered by strong emotions like laughter, surprise, or anger. It can range from mild weakness in the knees to a complete collapse.

FRAGMENTS NIGHTTIME SLEEP

People with narcolepsy often experience disrupted sleep with frequent awakenings during the night, despite excessive daytime sleepiness.

HALLUCINATIONS

Vivid, often frightening, sensory experiences (*visual, auditory, or tactile*) that occur when falling asleep (Hypnagogic) or upon waking (Hypnopompic).

It's important to note that not all individuals with narcolepsy experience all of these symptoms, and the severity can vary greatly. If you suspect you may have narcolepsy, it's crucial to consult with a healthcare professional for proper diagnosis and management.

Diagnosis & Research

Treatment for narcolepsy involves various medications tailored to the patient's needs, often requiring a combination approach.

Treatment often combines wake-promoting agents (*e.g.*, *modafinil*, *solriamfetol*, *sodium oxybate*) with behavioral strategies like scheduled naps and optimal sleep hygiene.

Other standard protocols which may be used include:

- Medical History & Questionnaires (*e.g.*, Epworth Sleepiness Scale).
- Polysomnography (PSG): overnight sleep study.
- Multiple Sleep Latency Test (MSLT): daytime nap study.
- Rule Out Other Causes: sleep apnea, insomnia, depression.

CSMA is actively engaged in clinical research to develop new treatments for narcolepsy. Visit csma.clinic/crs to find out more.

Treatment Options

While there is no cure for narcolepsy, it can be managed with the right treatment plan and medical support. Some of the more popular options include:

Medications:

- Wake-promoting agents (Modafinil, Solriamfetol)
- Nighttime medications (Sodium Oxybate)
- Stimulants (in some cases)

Lifestyle Strategies:

- Scheduled naps during the day
- Consistent sleep schedule
- Healthy diet and exercise routine

Supportive Care:

- Cognitive behavioral therapy (CBT)
- Workplace or school accommodations
- Safety planning (especially around driving or machinery)

Living with Narcolepsy

With the right medical support and strategies in place, you can live a happy and fulfilling life with narcolepsy. While your provider will be able to guide you in a more personalized plan, here are a few basic daily strategies to consider:

- Keep a consistent sleep schedule.
- Take planned daytime naps.
- Avoid alcohol and heavy meals before important activities.
- Stay active with gentle daily exercise.
- Use reminders and alarms for tasks and medications.
- Regular follow-ups with your CSMA specialist.



Frequently Asked Questions

Q: Is narcolepsy curable?

A: No – however, with proper treatment and lifestyle adjustments, symptoms can be managed.

Q: Can children have narcolepsy?

A: Yes. Symptoms can appear in children as young as 10 years old and can often impact their school performance if undiagnosed or left untreated.

Q: Does narcolepsy affect life expectancy?

A: Narcolepsy does not shorten lifespan, but untreated symptoms can increase risk of accidents.



HAVE MORE QUESTIONS?

CONTACT CSMA AT
(888) 503-2762

OR VISIT US ONLINE AT
CSMA.CLINIC

Sleep Dirary

One way you can prepare for your visit with your sleep specialist is to keep a sleep diary. Here is a template to help get you started.

Date	Bedtime	Wake Time	Naps (Times/Length)	Notes

Resources & Support

Trusted Organizations

Wake Up Narcolepsy: www.wakeupnarcolepsy.org

Narcolepsy Network: www.narcolepsynetwork.org

Child Narcolepsy Foundation: www.childneurologyfoundation.org



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Schedule a consultation today to take control of
your sleep health and start living with more
energy and focus.