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Narcolepsy

Patient education guide · Sleep Disorders · Madison Neurology LLC

What is it?

Narcolepsy is a chronic neurological disorder of sleep-wake control causing overwhelming daytime sleepiness and sudden, irresistible sleep attacks despite adequate night sleep. In type 1, it is joined by cataplexy — sudden episodes of muscle weakness triggered by emotions (laughter, surprise, anger). It is caused by loss of the brain's hypocretin (orexin) system and usually begins in the teens to 20s, though diagnosis is often delayed by years.

How does it happen?

Type 1 narcolepsy results from autoimmune destruction of the hypothalamus cells that produce hypocretin/orexin — the brain's master 'stay awake' chemical. A strong genetic marker (HLA-DQB1*06:02) and triggers such as certain infections are implicated. Type 2 narcolepsy has sleepiness without cataplexy and preserved hypocretin.

Common symptoms

- Excessive daytime sleepiness — irresistible 'sleep attacks' even after full nights of sleep
- Cataplexy (type 1): sudden knee-buckling, jaw drop, or collapse triggered by laughter or emotion, with full awareness
- Sleep paralysis: brief inability to move when falling asleep or waking
- Hypnagogic hallucinations: vivid dreamlike experiences at sleep transitions
- Fragmented night sleep, vivid dreams, and automatic behaviors (doing tasks without awareness)

How is it diagnosed?

The sleep study pair — overnight polysomnography followed by a next-day Multiple Sleep Latency Test (MSLT) showing rapid sleep onset and early REM periods — is diagnostic. Spinal fluid hypocretin measurement is definitive for type 1 when needed. Diagnosis is often delayed 8-10 years because

sleepiness is attributed to lifestyle.

How is it treated?

Treatment is highly effective and lifelong: daytime wake-promoting medications (modafinil/armodafinil, solriamfetol, pitolisant, and oxybate salts — sodium or low-sodium oxybate, which treat both sleepiness and cataplexy) plus strategic scheduled naps. Cataplexy is additionally controlled by oxybates, pitolisant, or certain antidepressants. Regular sleep schedules, planned short naps, and avoiding sleep deprivation are core behavioral therapy. School and workplace accommodations are legitimate and available.

What does the future hold?

Narcolepsy is lifelong, but with modern medication most people achieve near-normal alertness and control of cataplexy. Safety adjustments (driving caution, avoiding sleep deprivation) are part of life; with treatment, education, careers, and family life proceed fully. New orexin-replacement drugs in trials may transform treatment in coming years.

Questions patients commonly ask

Q: Will I lose my driver's license?

A: Treated, well-controlled narcolepsy is generally compatible with driving per state rules; untreated sleepiness is the risk — control is the answer, not prohibition.

Q: Is cataplexy dangerous?

A: Full collapse can cause falls, but most episodes are partial and brief; avoiding injury settings and treating with medication controls it.

Q: Will I outgrow it?

A: Narcolepsy is chronic, but symptoms are very controllable — most treated patients describe a normal life with a managed condition.

National support groups & resources

- **Narcolepsy Network** — narcolepsynetwork.org
- **Wake Up Narcolepsy** — wakeupnarcolepsy.org
- **American Academy of Sleep Medicine — Sleep Education** — sleepeducation.org

(Organization contact details were current at the time of compilation; please verify online.)

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