

NARCOLEPSY

Narcolepsy is a chronic and incurable neurological disorder that impairs the brain's ability to regulate the sleep-wake cycle. While symptoms often start in childhood and adolescence, they can occur at any age, in any gender, and with no previous history of narcolepsy in the family.

Due to low awareness (even among health professionals) and misperceptions, it usually takes several years for people with narcolepsy to receive a diagnosis, while even more are currently undiagnosed or misdiagnosed. This also makes it difficult to provide an exact number for people living with narcolepsy, but it is estimated to be 1 in 2000.



SYMPTOMS

While not all symptoms are experienced by or in the same way in people with narcolepsy, the main symptoms are:

EXCESSIVE DAYTIME SLEEPINESS: People with narcolepsy experience extreme sleepiness during the day, which often results in an irresistible urge to sleep. Sometimes sleepiness occurs so suddenly and with such overwhelming power that it is referred to as a 'sleep attack'.

CATAPLEXY: Episodes of muscle weakness usually triggered by strong emotions such as laughter, surprise, or anger, but can also be triggered by stress, exhaustion, or feeling anxious or overwhelmed. The severity and duration of cataplexy episodes vary among individuals. Some may feel their head nod, jaw slacken, or knees buckle momentarily, while others may have a full body collapse. During a full-body collapse, the individual is fully conscious but unable to move, speak, or open their eyes. These episodes generally last a few seconds to a few minutes.

SLEEP PARALYSIS: The individual is unable to move for a few seconds or minutes, usually upon falling asleep or waking up. Sleep paralysis may be experienced by about 15% of the population, whether they have narcolepsy or not.

HALLUCINATIONS: People with narcolepsy can have visual, auditory, or tactile hallucinations that can occur upon falling asleep (hypnagogic) or waking up (hypnopompic). They can be both frightening and confusing.

DISTURBED, FRAGMENTED NIGHTTIME SLEEP AND VIVID DREAMS: The sleep-wake cycle is different in people with narcolepsy. They may have trouble staying awake during the day but then struggle to fall asleep or stay asleep at night.

THERE ARE TWO TYPES OF NARCOLEPSY

Type 1 Narcolepsy (narcolepsy with cataplexy) is caused by a lack of hypocretin in the brain. Hypocretin (also known as orexin) is a key neurotransmitter that helps regulate wakefulness and rapid eye movement (REM) sleep.

Type 2 Narcolepsy (narcolepsy without cataplexy). Less is known about type 2 narcolepsy. Researchers believe it could encompass a variety of different conditions, including the incomplete form of Idiopathic Hypersomnia. People with type 2 narcolepsy do not experience cataplexy, and many do not experience sleep paralysis or hallucinations.

DIAGNOSIS

Diagnosing narcolepsy requires a comprehensive medical history and a proper clinical evaluation, including a thorough physical examination. Medical tests are necessary to rule out all other possible causes.

Sleep studies involving a polysomnography (PSG) followed immediately by a multiple sleep latency test (MSLT) are also carried out. The results of the sleep study, combined with other medical tests and a comprehensive medical history, help doctors determine whether a patient has narcolepsy.

TREATMENT & MANAGEMENT

Treatment for narcolepsy symptoms varies among individuals but may include:

- Stimulant and wake-promoting medications to increase wakefulness during the day.
- Daytime naps.
- Antidepressant medication to help reduce the severity and number of cataplexy episodes.
- Central nervous system depressant medications at night to help with deep sleep, e.g., Xyrem (Sodium Oxybate).
- Lifestyle changes such as maintaining a regular sleep schedule, diet and exercise, relaxation, and social support through face-to-face or online support groups.

Stimulant and wake-promoting medications can be helpful to relieve sleepiness for some people, but they are generally not effective long-term. There are also potential unpleasant side effects, which can include sleep deprivation, heart problems, and anxiety.

IMPORTANT: Modafinil and armodafinil can interact with hormonal birth control, such as birth control pills, patches, and vaginal rings, making them less effective. If you take modafinil or armodafinil and use hormonal birth control, please speak with your doctor for more advice.

For more information, visit the [Resource](#) page on our website to view our factsheets on stimulant medication (e.g., dexamphetamine), modafinil/armodafinil, our tips for living with hypersomnia, and more.

While there is currently no cure for narcolepsy, ongoing research by dedicated experts and specialists gives hope for better treatments in the near future.

If you think you may have narcolepsy, it's important to first consult your family doctor. They can provide a referral for you to see a sleep physician.

Living with Narcolepsy

Meet others you can relate to at our Living with Narcolepsy community catch ups. We meet monthly via Google Meet.

Please visit the [Support Group](#) page on our website for more information.



ABOUT US

Hypersomnolence Australia is a not for profit health promotion charity dedicated to advocating, raising awareness and providing support for central disorders of hypersomnolence, eg; Narcolepsy and Idiopathic Hypersomnia.

We do not receive funding, and we do not charge membership fees. Our small team work on a volunteer basis. Your support is vital to our continued operation.



Help make a difference! Go to the [Get Involved](#) page on our website for ways to donate or scan to support us today.



Hypersomnolence Australia has full DGR Item 1 status. Donations are tax deductible. ABN: 19662120036

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