

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, it 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 happiness, laughter, surprise, or anger, but can also be triggered by stress, exhaustion, over stimulation, or feeling anxious or overwhelmed. The severity and duration of cataplexy episodes varies among individuals. Some may feel their head nod, jaw slacken, or their knees buckle momentarily, while others may have a full body collapse. During a full body collapse the individual is fully conscious however they are 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 which can occur upon falling asleep (hypnagogic) or waking up (hypnopompic). They can be both frightening and confusing.

DISTURBED, FRAGMENTED NIGHTTIME SLEEP AND VIVID DREAMS: Because the sleep-wake cycle is different for people with narcolepsy, they may struggle to stay awake during the day but then also struggle to go to sleep and stay asleep at night. Individuals will often wake up multiple times during the night due to things like insomnia, vivid-dreams, and restless legs.

THERE ARE TWO TYPES OF NARCOLEPSY

Type 1 Narcolepsy (narcolepsy with cataplexy), research suggests is caused by a lack of hypocretin in the brain. Hypocretin (also referred to 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, some 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 proper clinical evaluation including a thorough physical examination and 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 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. 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 meet up groups.

Note: Medications such as modafinil/armodafinil can interact with hormonal birth control making it less effective.

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, you should consult your family doctor. You will need a referral before you can consult a sleep physician.

LIVING WITH NARCOLEPSY

Meet others you can relate to at our regular 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 staff work on a volunteer basis. Your support is vital to our continued operation.



Go to the [Get Involved](#) page on our website for ways to donate or

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



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