

NARCOLEPSY

WHAT IS 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 OF NARCOLEPSY

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 encounter extreme sleepiness during the day and regardless of how much they sleep, never feel refreshed or recharged. For someone without narcolepsy to understand the impact of this relentless sleepiness they would have to stay awake for 24 to 72 hours and then carry out their usual day-to-day activities

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. While these episodes generally last a few seconds to a few minutes, there is a thing called Status Cataplecticus, which are longer episodes of cataplexy. They can be very scary for the individual and depending on their surroundings, they can also be extremely vulnerable.



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.

HOW IS NARCOLEPSY DIAGNOSED?

Diagnosis for narcolepsy usually includes a 24-hour full sleep study which records the patient's brain waves. The sleep study is comprised of two parts, a polysomnogram (PSG), which is the night-time component and a multiple sleep latency test (MSLT), which is the daytime component where the patient is required to attempt to sleep at two hourly intervals throughout the day. Doctors look at how quickly and frequently the patient goes into rapid eye movement (REM)/dream sleep stage during the sleep study. The results of the sleep study combined with any medical tests performed and a comprehensive medical history help doctors determine whether a patient has narcolepsy.

It is important to note that any medication the patient is on prior to undergoing a sleep study may impact the results and therefore delay not only a correct diagnosis, but also delay the patient receiving appropriate and effective treatment and support.

HOW IS NARCOLEPSY TREATED?

There is currently no cure for narcolepsy. Left untreated the individual's symptoms will usually increase in severity over the years, often resulting in ongoing consequences not only for them but for those around them as well. These consequences can include poor performance at school, university and/or work, social phobia, failed relationships, depression, and isolation. Many, if not all of these consequences can be devastating and have long lasting effects.

Therefore, access to and timeliness of receiving effective and affordable treatment (tailored to the individual), is not only paramount, but necessary. So too is considering the side effects of some medications as they can add challenges of their own.

Treatment for narcolepsy symptoms varies among individual's but may include:

- Stimulant medications to increase wakefulness during the day.
- Daytime naps.
- Antidepressant medication to help reduce severity and number of cataplexy episodes.

DISCLAIMER:

Information in this fact sheet is general in nature. It is not a substitute for professional medical advice. Discuss with your doctor if you are concerned about your sleep or other medical conditions.

- Central nervous system depressant medications at night to help with deep sleep.
- 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.

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

HELP AND INFORMATION

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. Sleep Disorders Australia can provide information and support via our [website](#) and our Living with Narcolepsy support group.


ABOUT US


Sleep Disorders Australia (SDA) is a voluntary not-for-profit organisation that provides information and support to people affected by sleep disorders throughout Australia. SDA advocates the needs of people with sleep disorders by raising awareness of sleep disorders and their impact on our lives. We also offer support and education with regards to preventing and treating sleep disorders.


We would be delighted if you joined us. Membership is open to sufferers, family members, medical professionals, and the general public. You can join via our website or email our membership officer for more information.

If you would like to support us financially, you can donate via our website, or send a cheque to our address.


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