



NARCOLEPSY

- **Narcolepsy is a disorder characterised by excessive daytime sleepiness.**
- **People may also experience temporary episodes of muscles weakness, known as cataplexy.**
- **It can occur at any age but often starts in early adulthood.**
- **Diagnosis is best made by a sleep physician using specialised sleep studies.**
- **There are treatments available for sleepiness and cataplexy.**

Note: All words that are underlined relate to topics in the Sleep Health Foundation Information Library at www.sleephealthfoundation.org.au

1. What is narcolepsy?

Narcolepsy is a chronic disorder of excessive daytime sleepiness. It may occur with other symptoms such as cataplexy, sleep paralysis and hallucinations.

People with narcolepsy have excessive sleepiness during the day despite sufficient sleep length overnight. The sleepiness involves difficulty staying awake in passive situations, an irresistible urge to nap and falling asleep inappropriately (such as in meetings, classes or cinemas).

Cataplexy occurs with 'classic' narcolepsy, now referred to as narcolepsy type 1. It involves a sudden loss of muscle power which is set off by strong emotion such as laughter. Cataplexy typically lasts for up to a couple of minutes and the person is both conscious and awake. Cataplexy does not affect breathing. Episodes of cataplexy can involve all muscles of the body (with the person falling over or buckling at the knees) or may only involve some muscle groups (causing head nodding or jaw sagging, for example).

Many people with narcolepsy also experience other symptoms such as sleep paralysis and hallucinations. However, these can also occur in

people who do not have narcolepsy. Sleep paralysis typically occurs on waking up and being unable to move for a short period of time. Hallucinations can occur at the beginning of sleep (known as hypnagogic hallucinations) and end of sleep (known as hypnopompic hallucinations). People will 'see' images, shapes or shadows around them. They may be confused as to whether they are dreaming or not. Although those with narcolepsy may fall asleep quickly at night, their sleep may be broken.

2. What causes narcolepsy?

Narcolepsy is linked to a person's genetic make-up. Sometimes infections (such as streptococcus or influenza) or severe stress can trigger the onset of narcolepsy. It occurs due to the death (from autoimmune activity) of a small group of cells in an area of the brain known as the lateral hypothalamus. These cells normally produce a chemical called hypocretin (also known as orexin). Hypocretin is very important in wakefulness and in keeping the states of being either awake and asleep more stable.



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3. How common is narcolepsy?

Worldwide it affects about 4 people per 10,000. Both men and women get narcolepsy. It can occur at any age but most commonly develops in the second decade of life, with a smaller peak at around the age of 40.

4. How does it affect people?

Usually the symptoms of narcolepsy develop slowly over time, although sometimes symptoms start more suddenly. Sleepiness is usually the first symptom, with cataplexy and other features possibly developing later. The sleepiness can make it very hard for people to function normally during the day. Learning, concentration and attention can all be reduced, as can the ability to drive safely. Some people with narcolepsy can also experience depression.

5. Where and when should you seek help?

Many patients have had narcolepsy for several years before it is diagnosed. You should see your doctor if you are unable to stay awake during the day in situations where you should be able to do so and the sleepiness is unexplained (see Excessive Daytime Sleepiness). Sudden loss of muscle strength triggered by strong emotions such as laughter, surprise or fear, indicating cataplexy, should also prompt you to see your doctor. It is important that you do not drive if you are feeling sleepy or fall asleep suddenly.

6. What might your doctor do?

If your GP feels you may have a sleep disorder they will refer you to a sleep specialist. After a thorough evaluation, the sleep specialist will organise an overnight sleep study and a "Multiple Sleep Latency Test" in a clinic that conducts sleep studies.

7. What is the Multiple Sleep Latency Test?

After waking from an overnight sleep study, you will stay in the sleep laboratory until late that afternoon. Every two hours after waking in the morning, you will be asked to return to bed for 20 minutes and try to fall asleep. There will usually be 4-5 of these nap opportunities through the day. During each of the nap opportunities the time taken to fall asleep and whether any REM sleep occurs are recorded. (See Facts about Sleep to read about REM sleep). Falling asleep quickly and experiencing REM sleep during the Multiple Sleep Latency Test are features of narcolepsy.

8. What else might cause the symptoms?

There are many possible reasons why you may be feeling sleepy or tired. In addition to narcolepsy, there are other sleep disorders (such as obstructive sleep apnoea and idiopathic hypersomnia) which can also cause sleepiness during the day. Insufficient sleep, depression and other medical conditions can also cause sleepiness (see Excessive Daytime Sleepiness).

9. What is idiopathic hypersomnia?

People with idiopathic hypersomnia also have significant daytime sleepiness, but unlike people with narcolepsy, the cause is currently unknown, and such people do not experience cataplexy. (See idiopathic hypersomnia.)

10. How is narcolepsy treated?

There is currently no cure for narcolepsy although symptoms may be controlled with medication. Wake-promoting medications are used to control excessive sleepiness and some particular antidepressants can help control other symptoms such as cataplexy and hallucinations.

11. What could you do to help with symptoms?

It is important to maintain a healthy lifestyle including minimising alcohol and ensuring enough sleep at night (See How much sleep do you really need? to learn about sleep needs across the lifespan). Planned power naps during the day can reduce sleepiness. Some people with cataplexy are able to 'flatten' their emotions to reduce episodes of cataplexy. Driving should be avoided where there is excessive daytime sleepiness or uncontrolled cataplexy. Make family and friends aware of your diagnosis so they can provide support where needed.

Where can I find out more?

The following site provides more details about wake-promoting medications in Australia:

<https://sleephub.com.au/wake-promoting-medication>

Australian self-help groups for narcolepsy:

<http://www.narcolepsyaustralia.org.au>

www.nodss.org.au

For information on other sleep related topics visit the Sleep Health Foundation Information Library at www.sleephealthfoundation.org.au. The underlined topics in this article are covered in detail there.



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