



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 with 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 which is characterised by 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 adequate sleep duration overnight. The sleepiness may be characterised by an inability to stay awake during passive situations, an irresistible urge to nap or, occasionally, falling asleep in situations where it is inappropriate to do so (such as in meetings, at school or when driving). Many people with narcolepsy find short naps to have a refreshing and restorative effect.

Cataplexy occurs with classic narcolepsy, now referred to as narcolepsy type 1. It involves a sudden loss of muscle power which is triggered by strong emotion such as laughter. Episodes of cataplexy typically last for up to a couple of minutes, during which time the person is both conscious and awake. Cataplexy does not affect the ability to breathe. Episodes of cataplexy can involve all muscles of the body (resulting in the person to fall over or buckle at the knees) or may only involve only 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, although these can occur in other conditions and in some healthy people. Sleep paralysis occurs when someone wakes during the night and is 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 perceive images, shapes or shadows within their bedroom environment and are often confused as to whether they are dreaming or not.

2. What causes narcolepsy?

Narcolepsy occurs in genetically susceptible people. Infections (such as streptococcus and influenza) and some vaccinations have been shown to trigger the onset of narcolepsy. It occurs due to autoimmune destruction 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), which is very important in both wakefulness and in stabilising the transition between being awake and sleeping.



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3. How common is narcolepsy?

It affects about 1 person in 2000. 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?

Most commonly, the symptoms of narcolepsy develop gradually over time, although in some cases symptoms can begin more suddenly. People will usually develop sleepiness as the first symptoms, with cataplexy and other features developing afterwards. The sleepiness can make it very difficult for people to function normally during the day. Learning, concentration and working can all be impacted, as can the ability to drive safely. Many 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 have an excessive need for sleep or are unable to stay awake during the day in situations where you should be able to do so (see [Excessive Daytime Sleepiness](#)). Sudden loss of muscle strength triggered by strong emotions should also prompt you to see your doctor. It is important that you do not drive if you are feeling excessively sleepy.

6. What might your doctor do?

If your GP feels you may have a sleep problem you will be referred to a [sleep specialist](#). Many patients have IH for many years without knowing it. To determine if you have IH or another sleep disorder (e.g. narcolepsy), you may have a "Multiple Sleep Latency Test" in a clinic that does [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 sessions, 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 experience significant daytime sleepiness, but unlike people with narcolepsy, the cause is currently unknown, and 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 antidepressants can be effective in controlling other symptoms such as cataplexy and hallucinations. People with narcolepsy often feel refreshed after short power naps during the day.

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. Planned power naps during the day can be effective at reducing 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?

<http://sleepeducation.org/essentials-in-sleep/narcolepsy/overview-facts>

Australian self-help group for narcolepsy: www.nodss.org.au

US self-help group for narcolepsy: <http://narcolepsynetwork.org>

For information on over 70 different sleep related topics, written by professionals, 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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