

## **Narcolepsy and cataplexy**

Narcolepsy is a long-term (chronic) problem that affects your sleep. You feel excessively tired during the daytime but have disturbed night-time sleep. You can also have sleep attacks where you fall asleep during the day without any warning. Many people with narcolepsy also have cataplexy. This is a condition in which you have sudden loss of control over some of your muscles. Narcolepsy is usually diagnosed by monitoring you while you sleep in a special sleep laboratory. There is no cure for narcolepsy. However, various treatments are available that can help to control your symptoms. These include stimulant medicines to stop you feeling so sleepy.

### **What are the symptoms of narcolepsy?**

#### **Excessive daytime sleepiness**

This is the main symptom. You need to have been experiencing this for at least three months for the diagnosis to be made. It is normal to become a little sleepy during boring situations – for example, whilst you are sitting on the sofa watching TV in the evenings. However, if you have narcolepsy, you feel sleepy a lot of the time. The sleepiness is severe and often occurs in situations where you are more active – for example, whilst driving, talking or eating.

You have no control over the sleepiness and you can have sleep attacks where you fall asleep with no warning. These sleep attacks or naps can happen a number of times a day and can last from a few minutes to an hour. You usually feel refreshed when you wake up but can soon become sleepy again.

#### **Cataplexy**

About 7 in 10 people with narcolepsy also have cataplexy. In cataplexy, you suddenly lose the strength and control in some of your muscles whilst you are awake. For example, it can mean that you suddenly nod your head, your knees may suddenly give way, you may drop something that you are holding or, in extreme cases, you may suddenly fall to the ground. Emotions such as laughter, elation and anger can trigger cataplexy. You still have awareness during the attacks. They usually last for under a minute but they can happen several times a day. Sometimes you can have twitching of your muscles during an attack and some people confuse this with epilepsy.

### **Sleep-related hallucinations**

Hallucinations occur when you, for example, see, hear or feel something that is not actually there. They can happen either as you are falling asleep (hypnagogic) or as you are waking up (hypnopompic). It may seem like you are having a vivid dream.

### **Disturbed sleep during the night**

This is common. Because of disturbed night-time sleep, even though you may have frequent daytime naps, the total amount of time that you are asleep in 24 hours is about the same as normal. People with narcolepsy are also more likely to sleepwalk.

### **Sleep paralysis**

[In sleep paralysis, you are conscious but are unable to move your body](#) (called paralysis) when you wake up from sleep. Sometimes it can occur as you are falling asleep. If someone touches you or speaks to you, the paralysis is relieved and you are able to move again. The paralysis just lasts for a minute or two. It does not affect your breathing and is not dangerous.

### **Automatic behaviour**

If you are feeling tired and sleepy, there is also a tendency towards automatic behaviour (doing something without really thinking about it and without having any memory of it). For example, you may be driving and you may drive to a different, or the wrong, destination. You might write something unsuitable, or you might say something out of context in a conversation. With this automatic behaviour, there is an increased chance that tasks that you are performing go wrong and this can lead to accidents.

### **Other symptoms**

Sleepiness can also lead to problems with your memory and ability to concentrate. You may notice problems with your vision such as blurred or double vision. Weight gain also seems to be more common in people with narcolepsy.

## What are narcolepsy and cataplexy?

Narcolepsy is a long-term (chronic) problem. The name comes from the Greek 'seized by somnolence' (somnolence is another word for drowsiness). Your sleep is affected so that you feel excessively tired and drowsy during the daytime but have disturbed night-time sleep. You can also have sleep attacks where you fall asleep during the day without any warning.

Many people with narcolepsy also have cataplexy. This name comes from the Greek 'down'. In cataplexy you have sudden loss of control over some of your muscles. There are other symptoms of narcolepsy including seeing, hearing or feeling something that is not really there (having hallucinations) as you are falling off to sleep or waking up from sleep.

## Understanding normal sleep

During normal sleep there are different types or phases of sleep that you go through. Read more about normal sleep in the [Insomnia leaflet](#).

## What causes narcolepsy?

If you have narcolepsy, your sleep-wake cycle is disrupted. You enter REM sleep more quickly than usual and at some unsuitable times. The exact cause of this is uncertain.

People with narcolepsy have been found to have reduced levels of a neurotransmitter chemical called hypocretin in their brain. Hypocretin helps to control your sleep-wake cycle. In someone with narcolepsy, lack of hypocretin is thought to play a part in the rapid switching between being awake and entering REM sleep.

It has been suggested that narcolepsy may be a type of autoimmune disease where there is damage to the cells in the brain that produce hypocretin. (Normally, our body makes antibodies to fight infections – for example, when we catch a cold or have a sore throat. These antibodies help to kill the cells of the germs (bacteria), viruses or other germs causing the infection. In autoimmune diseases, the body makes similar antibodies (autoantibodies) which attack its normal cells.) It has also been suggested that other things such as a virus may trigger the damage to hypocretin-producing cells in susceptible people.

Your genes may possibly play a part in the development of narcolepsy. About 2 in 100 people with narcolepsy have a close family member with the condition.

In 2009 there was a sudden increase in narcolepsy in children. This was seen mainly in Finland but a few cases were reported in the UK. Studies have suggested a link to the use of Pandemrix®, a vaccine launched to cope with swine flu. Underlying genetic factors are also thought to have contributed. Genetic means that the condition is passed on through families through special codes inside cells called genes. The vaccine has not been used since 2010.

## **How common is narcolepsy and who develops it?**

Narcolepsy is not common. It is thought to affect around 25 people per 100,000, although numbers may be a little higher than this. It is most commonly diagnosed in your teenage years but it has also been diagnosed in younger children. However, narcolepsy may go unrecognised for many years and, once you are diagnosed as an adult, you may be able to look back to your teens and recognise some of the symptoms.

Narcolepsy seems to affect both men and women equally. If you have a close family member (mother, father, brother or sister) who has narcolepsy, you have an increased risk of developing it yourself.

## **How may narcolepsy affect my life?**

Narcolepsy affects different people in different ways. Some people can have more severe symptoms than others.

Many people with narcolepsy find their symptoms embarrassing. In children it can affect their progress at school and can lead to teasing and bullying by their peers. If you are an adult, it may affect your ability to work. Sleepiness and memory problems may make your colleagues perceive you as lazy and lacking in motivation. Your relationships may also be affected. Your mood can be affected if you have narcolepsy, and depression is common.

However, with the correct treatment, most people with narcolepsy do well. They are able to develop relationships, to work and to lead a productive life.

## How is narcolepsy diagnosed?

### Information from you or others

Your doctor will usually ask questions about your sleep pattern and quality. He or she may also ask if you (or other people) have noticed any signs that you may have cataplexy. They may ask about any medication that you are taking, any other health problems that you may have, whether you snore and also about your mood. This is to rule out other causes of excessive daytime sleepiness, including depression and [obstructive sleep apnoea](#). In obstructive sleep apnoea, your breathing stops for short spells when you are asleep. It can be helpful for your bed partner to be present (if you have one) when you talk to your doctor.

Your doctor may ask you to complete the Epworth Sleepiness Scale to assess how sleepy you are. A total score of 11 or more may mean that you have a sleeping disorder such as obstructive sleep apnoea. A very high score such as 17 or more may indicate that you have narcolepsy. See references below.

### Sleep studies

If your doctor is concerned that you may have narcolepsy, he or she will usually refer you to a doctor who is a specialist so that you can have some sleep studies. This typically means your sleeping overnight in a sleep laboratory and having a test called a polysomnogram. Your heart, brain, muscles and eyes are monitored closely whilst you are sleeping overnight, using electrodes attached to your scalp, chin, eyelids and chest. A video camera may also record you while you are sleeping. This test can show your brainwaves, breathing patterns, eye and muscle movements and the phases of sleep that you cycle through during the night.

Your level of sleepiness the next day can also be measured using a test called the multiple sleep latency test. This test looks at how long it takes for you to fall asleep during the daytime. It is usual for people with narcolepsy to fall asleep very quickly when they are asked to try to take a nap.

### **Other tests**

Sometimes other tests may be done to confirm narcolepsy, or to rule out other causes of excessive daytime sleepiness. These can include the measurement of the levels of the chemical hypocretin in the fluid that bathes your brain and spinal cord (your cerebrospinal fluid). A lumbar puncture is done to collect the fluid. (A needle is pushed through the skin and tissues between two bones of your spine (vertebrae) into the space around the spinal cord which is filled with cerebrospinal fluid.) [See separate leaflet called Lumbar Puncture for more details.](#) An [MRI scan of the brain](#) or certain [blood tests](#) may also be suggested.

## **What is the treatment for narcolepsy?**

There is no cure for narcolepsy. However, treatment can help to control symptoms.

### **Sleep routines**

Having a regular sleep routine can be helpful. Aim to have around eight hours of sleep at night if possible. You should try to go to sleep and get up at about the same time each day. Some people find that scheduled naps during the day can help to reduce their sleepiness. These may only need to be 10-15 minutes long. You will often wake up feeling quite refreshed from a nap.

### **Treatments using medicines**

The most common medicine now used to treat sleepiness in narcolepsy is [modafinil](#). It is a newer medicine that works as a stimulant and helps to stop you feeling as sleepy. Many people notice a good improvement in their symptoms when they take modafinil. It has the advantage that tolerance does not seem to develop as it can with the older stimulant medicines, described below. Modafinil also seems to have a lower rate of side-effects compared to the older medicines.

The most common side-effects include headache, nausea and a feeling of a blocked or runny nose. Modafinil can also affect the oral contraceptive pill. If you are taking 'the pill' you should discuss this with your doctor.

Older stimulant medicines used to treat narcolepsy include methylphenidate and amfetamines. However, these medicines are not used as often now, as you can develop a tolerance to them. They may also affect your sleep at night and therefore reduce your total sleep time.

Various medicines can help to treat cataplexy if this is a problem. Commonly, a medicine called [sodium oxybate](#) is used. As well as helping with the symptom of cataplexy, sodium oxybate may also help with:

- Excessive daytime sleepiness.
- Disturbed night-time sleep.
- Seeing, hearing or feeling something that is not really there (hallucinations).
- Sleep paralysis (where you are conscious but unable to move your body).

It may sometimes be used in combination with modafinil. You should not drink alcohol if you are taking sodium oxybate. Some antidepressant medicines, including [clomipramine](#) and the [selective serotonin reuptake inhibitor \(SSRI\) antidepressants](#) such as [fluoxetine](#), may also be used if you have cataplexy. (**Note:** they are not used here because of depression. The way that these medicines work on the chemicals in the brain appears to also ease the symptoms of cataplexy.)

Dr Sarah Jarvis, 12th January 2022

### **Solriamfetol for narcolepsy**

For people with narcolepsy who have not responded to (or who cannot take) modafanil, the next step for treatment is often another stimulant such as dexamfetamine or methylphenidate. However, these medicines are not suitable for everyone.

The National Institute for Health and Care Excellence (NICE) has looked at the evidence for using solriamfetol, which works in a different way to these drugs. It has advised that for adults who cannot take or have not responded to modafanil and at least one stimulant medicine, solriamfetol should be recommended as an option. This guidance only applies to adults who have narcolepsy and excessive daytime sleepiness.

More details about NICE's recommendations are available in the link in the further reading section below.

### **Other treatments**

There are various other things that may be helpful if you have narcolepsy. You should try to avoid heavy meals and alcohol, as these can bring on (induce) sleepiness. [Doing regular exercise](#) may be of benefit and may help your symptoms.

If you or your child are diagnosed with narcolepsy, you may find it helpful to communicate this to other people. For example, informing schoolteachers may help to explain your child's behaviour at school and get them any extra help that they may need. As an adult, explaining your diagnosis to your work colleagues and to your boss can also help them to understand. Some people arrange with their employer or school to include scheduled naps into their work or school routine. You may also find career counselling helpful.

A low mood is quite common in people who have narcolepsy. If you are feeling low or depressed, you should see your doctor. They may be able to help or to suggest other people who can help, such as a counsellor or psychologist.



# Narcolepsy and driving

In the UK, you are required by law to let the Driver and Vehicle Licensing Authority (DVLA) know if you are diagnosed with narcolepsy. You should stop driving immediately and you should not start to drive again until the DVLA has reached a decision on your case.

For a regular (group 1) driving licence you will usually be allowed to drive when your symptoms are well controlled with medication but you will need to have a regular review. It is unusual for someone to be granted an LGV(HGV)/bus (group 2) licence if they have narcolepsy. Your case should be treated on an individual basis and it will depend on how well controlled your symptoms are.

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## Further reading

- [Guidelines on management of narcolepsy](#); European Federation of Neurological Societies (2006)
- [Ingravallo F, Gnucci V, Pizza F, et al](#); The burden of narcolepsy with cataplexy: how disease history and clinical features influence socio-economic outcomes. *Sleep Med.* 2012 Dec;13(10):1293–300. doi: 10.1016/j.sleep.2012.08.002. Epub 2012 Sep 28.
- [Nishino S, Okuro M](#); Emerging treatments for narcolepsy and its related disorders. *Expert Opin Emerg Drugs.* 2010 Mar;15(1):139–58. doi: 10.1517/14728210903559852.
- [Billiard M et al](#); Management of narcolepsy in adults, *European Handbook of Neurological Management: Volume 1, 2nd Edition, 2011.*
- [Solriamfetol for treating excessive daytime sleepiness caused by narcolepsy](#); NICE Technology appraisal guidance, January 2022

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