

## How Can We Help?



The Woolcock's Narcolepsy and Excessive Sleepiness Clinic offers a range of services including:

- Early diagnosis with overnight and daytime sleep tests
- Assessment to ensure a patient is matched to the treatment option best suited to their needs
- Regular reviews to monitor effectiveness of treatment
- Access to specialists working across multiple disciplines to ensure every aspect of the patient's health and wellbeing are supported through the treatment journey
- Access to cutting-edge research including clinical trials
- Advice on driving and safety
- Research into new treatments



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**P** 02 9114 0000  
**F** 02 9114 0010  
**E** [info@woolcock.org.au](mailto:info@woolcock.org.au)

[www.woolcock.org.au](http://www.woolcock.org.au)

# Narcolepsy & excessive sleepiness



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## WHAT IS NARCOLEPSY?

Narcolepsy is a chronic neurological disorder characterised by excessive daytime sleepiness and uncontrollable bouts of sleep. It is caused by an inability of the central nervous system to appropriately regulate wakefulness and sleep. As a result, people with narcolepsy experience excessive drowsiness and may have a lack of energy.

During the day when normally awake and active, people with narcolepsy can fall asleep with little warning. Strong urges to nap can also happen at any time of the day. Naps might last for minutes or up to an hour or more. After a nap you may be alert for several hours and, while this may happen every day, it is not because you aren't sleeping enough at night.

## WHAT IS CATAPLEXY?

About 60-70 percent of people with narcolepsy also suffer cataplexy, a sudden loss of muscle tone while conscious. You may have a total collapse or just weakness in the knees (buckling) or face (jaw dropping). It may last a few seconds or a few minutes and is often triggered by laughter, anger or fear.

## WHAT IS SLEEP PARALYSIS?

Occasionally you might wake up or fall asleep and be momentarily unable to move any part of your body. This is called sleep paralysis. Usually it lasts between a few seconds and a few minutes and, while it may be frightening, will not cause you harm. While narcolepsy is uncommon, isolated episodes of sleep paralysis occur in about 15 percent of people.

People with narcolepsy also report hallucinations as they fall asleep or on waking in the morning.

## WHAT ARE SLEEP HALLUCINATIONS?

Some people with narcolepsy report hallucinations, especially when drowsy. You may see or hear things that are not really there, especially if you are drowsy. They may occur when you fall asleep or when you wake up in the morning.

## WHAT ELSE CAUSES EXCESSIVE SLEEPINESS?

Some people do not have narcolepsy but are sleepy no matter how much sleep they appear to get. This may be due to co-existing obstructive sleep apnea or less common disorders of excessive sleepiness such as idiopathic hypersomnia. Our Clinic also specialises in diagnosing and treating these conditions.

## WHAT CAUSES NARCOLEPSY?

The part of the brain which controls falling asleep functions abnormally in people who suffer from narcolepsy. This results in an intrusion of REM (Rapid Eye Movement) sleep and its associated dreaming and temporary loss of muscle tone into wakefulness. Little is known about the mechanisms that underpin these disorders, but it has been discovered that people with narcolepsy and cataplexy have low or undetectable levels of a brain chemical called orexin.

## HOW COMMON IS NARCOLEPSY?

Narcolepsy affects about 1 in every 2,000 to 3,000 people. Both men and women get narcolepsy. It can occur at any age but is usually first noted between the ages of 20 and 30.

## HOW DOES NARCOLEPSY AFFECT PEOPLE?

Narcolepsy can start gradually or come on suddenly. You may notice the irresistible sleepiness first with other symptoms only appearing many years later. Working and learning is likely to be difficult because of sleepiness. Others often mistake your sleepiness for a lack of interest or motivation. You may also feel depressed. You should only drive a car if your symptoms are well controlled with medication.

## WHEN SHOULD YOU SEEK HELP?

If you have been struggling with unexplained sleepiness you should talk to your doctor. Ask your GP to refer you to a sleep specialist who may arrange for an overnight sleep test called polysomnography (PSG) followed by a daytime sleep test called Multiple Sleep Latency Test (MSLT).

During an MSLT, you will be asked to try to nap every two hours throughout the day. Each time, you will be given a 20-minute opportunity to fall asleep. The test measures how long it takes you to fall asleep and whether you go straight into REM sleep. Falling asleep quickly within an average of eight minutes and going quickly into REM sleep (during two out of the four naps) are likely to indicate narcolepsy.

## WHAT ELSE MIGHT CAUSE EXCESSIVE SLEEPINESS?

There are many possible reasons you may be feeling sleepy or tired. Think about all the possible options. If you have eliminated all other possible reasons and you do not meet the criteria for narcolepsy you may be diagnosed with idiopathic hypersomnia.

Unlike people with narcolepsy, people with idiopathic hypersomnia do not fall rapidly into REM sleep following the onset of sleep and do not have other symptoms like cataplexy. There are a number of potential causes of idiopathic hypersomnia.

## HOW IS NARCOLEPSY TREATED?

While there is no cure for narcolepsy, some of the symptoms may be controlled with medication. Stimulants may be prescribed to help with sleepiness and antidepressant medications to control cataplexy. The side-effects of these drugs will be explained to you. Many patients do very well with medication, improving their symptoms and quality of sleep.

## WHAT CAN YOU DO TO HELP MANAGE SYMPTOMS?

Try to adapt your lifestyle to avoid situations where sleepiness is dangerous, such as driving. Keep regular night sleep hours and plan daytime naps to help control the urge to sleep. Cataplexy may also be reduced by learning to flatten your emotional responses. Ensure family and friends understand how the condition affects you. The Woolcock Sleep Clinic will help you if you need letters of support to your school, college or work.

To find out more, go to [www.woolcock.org.au/clinic](http://www.woolcock.org.au/clinic).