



## WHAT IS NARCOLEPSY?

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

# Narcolepsy



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## WHAT IS NARCOLEPSY?

All people with narcolepsy have excessive drowsiness and may have a lack of energy. Strong urges to nap can 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. While this may happen every day it is not because you aren't sleeping enough at night.

## WHAT IS CATAPLEXY?

Cataplexy is a sudden loss of muscle function while conscious. You may have a total collapse or just weakness in the knees (buckling) or face muscles (jaw dropping). It may last from a few seconds to a few minutes. Cataplexy is triggered by sudden emotions such as 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. You may feel frightened by it, although it will not cause you harm. Sleep paralysis also happens in people without narcolepsy. While narcolepsy is uncommon, isolated episodes of sleep paralysis can occur in about 15% of the population.

## WHAT ARE SLEEP HALLUCINATIONS?

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

## WHAT CAUSES NARCOLEPSY?

The part of the brain which controls falling asleep functions abnormally.

During the day when normally awake and active, you might fall asleep with little warning, rapidly going into a stage of sleep called Rapid Eye Movement (REM) sleep. During normal REM sleep there is both dreaming and temporary loss of muscle tone. In narcolepsy, normal REM sleep may become disrupted and there might be hallucinations, cataplexy and sleep paralysis. It is thought that narcolepsy is related to lack of a brain chemical called orexin.



## HOW COMMON IS NARCOLEPSY?

It affects about 1 in 2000 people. Both men and women get narcolepsy.

It can occur at any age but is usually first noted between the ages of 10 and 30.

## HOW DOES IT AFFECT PEOPLE?

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

## WHERE AND WHEN SHOULD YOU SEEK HELP?

If you have been struggling with unexplained sleepiness you should talk to your doctor. Any symptoms that could be cataplexy should not be ignored. You are not likely to have narcolepsy if you feel tired and/or fatigued without the urge to sleep across the day. Ask your GP to refer you to a sleep specialist. The sleep specialist will arrange for an overnight sleep test called Polysomnography followed by a daytime sleep test called Multiple Sleep Latency Test (MSLT).

## WHAT IS THE MULTIPLE SLEEP LATENCY TEST (MSLT)?

After doing an overnight sleep study you will be asked to try to nap every two hours throughout the day while your sleep is measured. You will be given a 20 minute opportunity to fall asleep at two-hourly intervals – such as 9am, 11am, 1pm and 3pm. There are two things being measured. One is how long it takes you to fall asleep. The other is whether you go straight into REM sleep when you fall asleep. Falling asleep quickly within an average of 8 minutes and going quickly into REM sleep (during two out of the four naps) are likely to indicate narcolepsy.

## WHAT ELSE MIGHT CAUSE THE SYMPTOMS?

There are many possible reasons why 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.

## WHAT IS 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?

There is no cure for narcolepsy but some of the symptoms may be controlled with medication. Stimulants are prescribed to help with sleepiness. These drugs are controlled drugs and are best taken under advice by your sleep specialist. Anti-depressant medications may also be used to control cataplexy. The side-effects of the drugs will be explained to you by your sleep specialist. Many patients do very well when using the stimulants and anti-cataplexy medication, improving their symptoms and quality of life. You will also feel more alert if you can build in power naps across the day.

## 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.

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