

Narcolepsy



Important Things to Know About Narcolepsy

- It is a disorder of excessive daytime sleepiness
- It may have other symptoms that involve a loss of muscle function
- · Symptoms can be treated
- It can occur at any age but often starts in early adulthood
- Diagnosis is best done by a sleep specialist or neurologist

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.

- All people with narcolepsy have excessive drowsiness.
 You 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.
- Cataplexy is a sudden loss of muscle function while conscious. You may have a total collapse or just weakness in the knees or face muscles. It may last from a few seconds to a few minutes. Cataplexy is triggered by sudden emotions such as laughter, anger or fear.
- Occasionally you may wake up 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 (see below) isolated episodes of sleep paralysis can occur in about 15% of the population.
- Some people with narcolepsy also report

hallucinations. You may see or hear things that are not really there, especially if you are drowsy.

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 (or REM) sleep. During normal REM sleep there is both dreaming and temporary loss of muscle tone. With the shift to REM sleep in narcolepsy, there might be hallucinations, cataplexy and sleep paralysis. It is thought that narcolepsy is related to lack of a brain chemical called hypocretin. In some cases (but not all) it is an inherited condition.

How common is narcolepsy?

It affects about 1 person in 2000. 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?

Onset may be gradual or sudden. 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 (see Excessive Daytime Sleepiness). 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.

What might your doctor do?

If your GP feels you may have a sleep disorder they will refer you to a sleep specialist. Many patients have had narcolepsy for many years before it is diagnosed. To be diagnosed with narcolepsy you are likely to need a "Multiple Sleep Latency Test" in a clinic that conducts sleep studies.

What is the Multiple Sleep Latency Test?

After doing a night-time sleep test 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 times at two-hourly intervals – often at times 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. (See Facts about Sleep to read about REM sleep). Falling asleep quickly and going quickly into REM sleep are likely to indicate narcolepsy.

This information is produced by:

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A voluntary group offering assistance and support to people and their families living with sleep disorders

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 (see Excessive Daytime Sleepiness). 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 this condition do not fall rapidly into REM sleep following the onset of sleep and do not have other symptoms like cataplexy. They may nevertheless be just as sleepy as a person with narcolepsy. There are a number of potential causes of idiopathic hypersomnia but the condition is not well understood. It may be related to narcolepsy and responds to similar stimulant treatment.

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. Anti-depressant medications may be used to control cataplexy. You will feel more alert if you build in power naps across the day.

What could you do to help with symptoms?

You need to adapt your lifestyle. Avoid situations where sleepiness is dangerous, such as driving. Planned daytime naps will help control the urge to sleep. Keep regular night sleep hours. Cataplexy may be reduced by learning to flatten your emotional responses.

Where can I find out more?

http://www.virtualmedicalcentre.com/diseases.asp?did=650 Australian self- help group for narcolepsy: http://www.nodss.org.au/

> Australasian Sleep Association ABN 32 172 170 561 www.sleep.org.au

The peak national association of clinicians and scientists devoted to investigation of sleep and its disorders

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Ongoing concerns about sleep or other medical conditions should be discussed with your local doctor.

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Sleep Health Foundation ABN 91 138 737 854 114/30 Campbell Street, Blacktown NSW 2148 T: +61 (0) 2 8814 8655 F: +61 (0) 2 9672 3884