

NARCOLEPSY



Narcolepsy. *Narcolepsy is an uncommon but very debilitating sleep disorder. Because the symptoms are similar to other more common conditions, the number of people with narcolepsy is hard to estimate, but it is likely to affect about 1 person in 2000. Usually the most worrying aspect of narcolepsy for the sufferer is uncontrollable sleepiness during the day.*

The symptoms of narcolepsy. Narcolepsy is characterised by a combination of symptoms. Sufferers differ in the combination and severity of these symptoms, but they are generally:-

- **Drowsiness during the day** - which results in an irresistible urge to sleep. Patients describe sleepiness, tiredness, lack of energy, exhaustion, or a combination of these feelings, either continuously or at various times throughout the day. Sometimes sleepiness occurs so suddenly and with such overwhelming power that it is referred to as a "sleep attack". These "sleep attacks" may be as short as one minute or as long as an hour. The sufferer usually wakes up feeling refreshed and may then be alert for another hour or more. However, drowsiness may continue throughout the day and be associated with poor memory of the events of the day. Similar symptoms are experienced every day and are not affected by how much sleep the person has had the night before.
- **Cataplexy** - where the narcoleptic experiences a sudden loss of muscle function. In severe instances the cataplexy may result in a collapse, although the person remains conscious throughout the episode. In less severe forms it may show as just a weakness in the knees, jaw or facial muscle droop, or possibly an inability to speak clearly, for example stuttering. The cataplectic attack may last from a few seconds to a few minutes and is usually triggered by a sudden emotional reaction such as laughter, anger or fear.
- **Sleep paralysis** - which happens on waking from sleep. Although the person is not fully awake they are aware of the paralysis and are unable to move any part of the body except perhaps the eyes. Eventually, after as long as ten minutes, they wake up fully and the paralysis resolves. This can be extremely frightening. Sleep paralysis is not restricted to people with narcolepsy - about 15% of the population may also experience it.
- **Hallucinations** - usually occur when the person is drowsy and about to fall asleep and may occur as abstract forms, for example coloured shapes, or be in the form of a person or animal. The sufferer may also hear things or feel things such as being lifted off the bed.
- **Disturbed night-time sleep** - The usual night-time sleeping pattern is disrupted in the narcoleptic and they may suffer from an increased number of awakenings.

What causes narcolepsy? Scientists believe that Type 1 Narcolepsy (Narcolepsy with cataplexy) is caused by a lack of the chemical known as hypocretin (also referred to as orexin) in the brain. Hypocretin is an important chemical for regulating wakefulness and rapid eye movement (REM) sleep. Type 2 Narcolepsy (without cataplexy) includes some of the same symptoms as Type 1 Narcolepsy, however, its cause is unknown.

Who gets narcolepsy? Both men and women get Narcolepsy. Symptoms typically appear between the ages of 10-30. Most cases of both forms of Narcolepsy occur in people with no history of the disorder in their family. While no clear pattern of inheritance has been established, first-degree relatives (parents, siblings, and children) of people with Narcolepsy with cataplexy have a 40 times greater risk of developing the condition compared with people in the general population.

How is narcolepsy diagnosed? Unfortunately, many patients have narcolepsy for 10 to 15 years before the disorder is correctly diagnosed. The symptoms of narcolepsy may be variable and the consequences of having narcolepsy are significant, so to be sure of the diagnosis doctors need to check that there isn't another condition that is causing the symptoms. This involves medical tests and a comprehensive medical history. A full sleep study that includes a polysomnogram (PSG) and a multiple sleep latency test (MSLT) is also done. The PSG is a nighttime test and a MSLT is the daytime component. During the MSLT patients are required to attempt to sleep at two hourly intervals throughout the day. The results of the sleep study combined with the medical tests and comprehensive medical history help doctors determine whether a patient has narcolepsy.

What happens to the person with narcolepsy? Initially symptoms may be subtle, but often become increasingly severe over the years. The symptom of sleepiness is usually the first to appear and paralysis and hallucinations may not show until many years later and may become less severe as the person becomes older. The irresistible sleepiness and inability to concentrate are often devastating to the individual who performs poorly at school and work. Learning is likely to be difficult because of the impact of the sleepiness on reading, studying, and concentrating. Parents, teachers, spouses, and employers often mistake the patient's sleepiness for lack of interest, or misconstrue it as a sign of hostility, rejection, or laziness. Patients may also suffer depression.

How is narcolepsy treated? There is no cure for narcolepsy, however some of the debilitating symptoms can be managed with medicines and lifestyle changes. It may take some time to find the best treatment as not all medicines and lifestyle changes are appropriate for everyone.

Narcolepsy and lifestyle. Narcoleptics need to adopt a lifestyle which is appropriate to their condition. This may mean avoiding situations in which sleepiness would be dangerous, for example driving, and adopting habits such as daytime naps to control the urge to sleep. With experience, it may also be possible for the narcoleptic to avoid situations likely to result in a cataplectic attack.

Will there ever be a cure for narcolepsy? As narcolepsy is thought to be a genetic condition, it is probable that scientists will eventually gain a much better understanding of the mechanisms of narcolepsy from mapping the human genome. This improved understanding is likely to lead to better treatments in due course.

Sources of help and information - If you are concerned about narcolepsy, you should consult your family doctor. Patient support groups such as Sleep Disorders Australia and Narcolepsy Australia have branches throughout Australia and may be able to provide additional resource material.

DISCLAIMER - Information provided in this fact sheet is general in content and should not be seen as a substitute for professional medical advice. Concerns over sleep or other medical conditions should be discussed with your family doctor.

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