

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 the Narcolepsy Association have branches throughout Australia and may be able to provide additional resource material.

For further information contact

New South Wales Branch – 02 9990 3514

PO Box 303, Roseville NSW 2065

Queensland Branch – 07 3378 1610

PO Box 1182, Coorparoo DC, Qld 4151

South Australia Branch – 08 8232 5319 (City)

1800 813 629 (Country)

PO Box 153, Kent Town, SA 5071

Tasmania Branch – 03 6326 7889

PO Box 302, Mowbray, Tas 7248

Victoria Branch – 03 9578 3795

PO Box 238, Nunawading, Vic 3131

Western Australia Branch – 08 9332 1037

36 Darley Circle, Bullcreek WA 6149

Web Page

www.sleepoz.org.au

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NARCOLEPSY



SLEEP DISORDERS AUSTRALIA

ABN 98 075 427 459

Sleep Disorders Australia is a voluntary group offering assistance and support to those persons and their families who are living with sleep disorders throughout Australia.

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 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? The reason that people with narcolepsy get these symptoms is not fully understood but scientists now think that the symptoms are due to problems in the part of the brain which controls the transition between sleep and waking. People with narcolepsy often fall straight into a stage of sleep called Rapid Eye Movement or REM sleep and this type of sleep is associated with dreaming (hallucinations) and paralysis (cataplexy, sleep paralysis). It is thought that if transitions from REM to awake and awake to REM sleep occur at inappropriate times it may result in some of the symptoms.

Who gets narcolepsy? There is good evidence that in some cases it is an inherited condition. Most people with narcolepsy have a close relative with the disorder and if both mother and father have narcolepsy, children will have narcolepsy. Scientists have identified a genetic marker which may be a pointer to narcolepsy but unfortunately many people without narcolepsy also have this marker. Both men and women get narcolepsy. It is most common for it to first become noticeable between the ages of 10 and 30.

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 may do what is called a "multiple sleep latency test" in the sleep disorders laboratory. This involves the patient attempting to sleep at two hourly intervals throughout the day while the laboratory measures the sleep. If the patient falls straight into REM sleep this is taken to be diagnostic of 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. Because of unpredictable sleepiness, narcoleptics are usually advised not to drive a car.

How is narcolepsy treated? There is no cure for narcolepsy but some of the debilitating symptoms may be controlled by the use of drugs. The standard treatment for sleepiness has been amphetamines which have a bad reputation due to their use as recreational drugs, for example "speed". A newer alerting drug called modafinil shows promise as a more acceptable treatment for daytime sleepiness but is very expensive. Companies are working on newer drugs and as more is understood about the condition, it is likely that better drugs will become available. Anti-depressant medications may be used to control cataplexy.

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 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.