

What is Narcolepsy?



Cataplexy Dreams

Automatic Behaviours

EDS Sleep Paralysis

Disturbed Nocturnal Sleep

The other common symptom found in up to 80% of people with narcolepsy is a sudden loss of muscular control. This is usually triggered by intense emotions, particularly positive emotions such as laughter or pleasant surprise. This is called CATAPLEXY. The effects of cataplexy range from subtle dropping of the jaw and slumping of the head to buckling of the legs and even collapse of the whole body, attacks may last for a few seconds up to several minutes.

Despite appearances during a cataplexy attack the individual stays conscious and is aware to a large extent of their surroundings. The paralysed state resembles that which is normally seen in dream (REM) sleep although, in cataplexy, the subject is clearly not dreaming and should be treated as awake.

Other symptoms of narcolepsy are:

- Temporary and often disturbing paralysis on falling asleep or waking
- Hallucinations or vivid nightmares when falling asleep or awakening – these are known as hypnagogic hallucinations
- Moments of trance like behaviour where routine activities are continued as if on "autopilot".
- Disturbed night time sleep, often marked by a quickening heartbeat, agitation and an increase in body temperature. This poor quality and fragmented nature of night time sleep often contributes to a feeling of sleepiness in the morning. Someone with narcolepsy does not simply sleep more than average; rather they sleep in the wrong places. Many narcoleptics actually sleep less than the typical eight hours a day.

Not all of these symptoms are present in everybody with narcolepsy. The type and severity of symptoms vary from person to person and may sometimes improve or worsen with time.

The incidence of Narcolepsy in the population is not accurately known but is believed that 6 people in 2,500 are affected in the UK but it could be considerably more than that.

Narcolepsy usually begins in adolescence but onset in early childhood or late middle age is not unknown.

Benefits, Support, Advice
Helpline:
0345 450 0394

Narcolepsy will not kill you or shorten your life; it will not reduce your physical and mental abilities.

Many people with narcolepsy are able to lead normal lives, get qualifications, have good careers and legally hold a driving licence.

We suspect that narcolepsy is a so-called auto immune disorder. This is when the body's defence mechanism attacks parts of the body that are not sick. Rheumatoid Arthritis, Lupus and Addison's Disease are all common types of auto immune disorders. With narcolepsy it seems likely a small area of the brain called the HYPOTHALAMUS is damaged from an immune attack. In particular, from a total of around 10 billion nerve cells in the brain, about 40,000 specific nerve cells inside the hypothalamus are lost, leading to a deficiency of a brain chemical called OREXIN. Orexin regulates the sleep-wake cycle and, without this sleep control people with narcolepsy are unable to stay awake for more than a couple of hours or so. Narcoleptics will typically fall asleep in unusual situations such as in the middle of a conversation or during a meal and not just when bored or unoccupied.

Such naps or episodes of excessive daytime sleepiness are sometimes known as sleep attacks or EDS. Most people with narcolepsy have relatively short naps and often feel refreshed afterwards, at least for a period of time.

Narcolepsy UK

In 1981 a group of narcoleptics in Manchester formed The Narcolepsy Association UK, this became better known as UKAN. Today, Narcolepsy UK is the oldest narcolepsy charity in the world. It continues to be a registered charity whose objects are the benefit, relief and aid of persons suffering from narcolepsy. Its aims are:

- To promote awareness of narcolepsy and provide information about it to sufferers, to the health care profession and to the public
- To organise conferences (both national and local) relating to narcolepsy and its effects
- To collect and publish information via our publication "Catnap" and the Narcolepsy UK website
- To support members trying to obtain specific medication, disabled and social benefits and support in places of education
- To campaign to influence the policies of legislators and funding bodies

Narcolepsy UK is managed by a Board of Volunteer Trustees which must include narcoleptics. At the time of printing there are 4 part-time staff working for the charity, along with a growing band of Volunteers throughout the UK. Narcolepsy UK receives no major funding from health authorities, drug companies or the Department of Health. It relies almost entirely on donations from individuals and grant giving trusts. A newsletter Catnap is published four times a year for members. It reports developments from home and abroad, articles that might be of interest to the narcoleptic community and also provides information on forthcoming regional meetings and conferences.

The website holds considerable information and resources. The Helpline Advisor works with specific clients to support people with Disability and Benefit Applications, general support and guidance. The Helpline is not manned 24/7 but phone messages and emails are responded to within a reasonable period.

Narcolepsy UK is available to anyone with Narcolepsy, their family and friends, along with anyone having an interest in the illness. *Registration is free for persons living in the UK. Members from outside the UK need to contact Narcolepsy UK for details of fees.

*correct at time of going to press.

For details and other information visit our website at www.narcolepsy.org.uk or contact the charity by phone

Telephone: 0345 450 0394
Email: info@narcolepsy.org.uk

Company Registration No: 07790071 (England)
Charity Registration No: 1144342 Scottish Charity No SC043576

Understanding Narcolepsy

Information Leaflet



Help is at hand
Helpline:
0345 450 0394

- What is Narcolepsy?
- How do I get Narcolepsy?
- Treatment of Narcolepsy
- How relatives and friends can help
- The outlook for someone with Narcolepsy



Wake up to
Narcolepsy



How did I get Narcolepsy?

At the moment we don't know what causes narcolepsy. The race is on to understand the causes of narcolepsy and certain factors are being studied very closely. One genetic marker in particular is found in 20% of the total population but over 90% of people with narcolepsy have it. Scientists have yet to explain if this genetic marker affects the immune system and may predispose individuals to narcolepsy.



We do know that women are more likely to develop narcolepsy than men and if you have a direct relation with narcolepsy the possibility of you getting the condition increases. However, knowing if a family member had narcolepsy can be difficult due to the problems of getting a diagnosis.

I think I have narcolepsy – what do I do?

If you think you have narcolepsy you should discuss this first with your GP. Many other conditions have similar symptoms to narcolepsy and the sooner these are ruled out the better. When you see your doctor make sure you have a list of the symptoms you feel are important. A tool that can be downloaded from our Narcolepsy UK website is a sleep diary or the Epworth Sleepiness Scale and filling one of these out could be of great help to your doctor. If he considers that you might have the condition, you will be referred to a specialist centre such as a neurology department or a sleep centre. The Narcolepsy UK website has a list of all the major units.

The specialist there will take your history and possibly carry out tests to see how easily you fall asleep or how difficult it is for you to keep awake. This is called a sleep latency test. They may also decide to study your night-time sleep patterns and if that happens you will need at some stage, to stay overnight in the hospital. Amongst other things they will check how quickly you move into a part of sleep called REM sleep, the stage most associated with vivid dreaming and which is often abnormal in narcolepsy. A move directly into rapid eye movement sleep is usually considered as a positive test for narcolepsy.

In some cases blood samples may be taken to determine if you have the genetic marker. It is also possible to measure the levels of orexin by taking a sample of cerebrospinal fluid (often called CSF) via a lumbar puncture. This is a very specialised test and is usually only positive in classical cases of narcolepsy with cataplexy. This means it is not a particularly useful diagnostic test if there is doubt from the clinical picture. It is hoped that in the future orexin levels may be checked by a blood sample rather than the CSF sample.

When they have completed all the tests the centre will write to your GP with the results and give guidance on the type of treatment that may be necessary. It is possible that you will be expected to visit your consultant on a regular basis while a treatment regime that is suitable for you is worked out. During this period your GP will be kept aware of developments and will approve any drug regime that you are placed on.

Treatment of Narcolepsy

At the moment there is no cure for narcolepsy, but the symptoms can be reduced or even suppressed by a series of measures including "sleep hygiene" and drugs. With the increasing evidence that immune damage is ultimately responsible, the possibility of targeted drugs being available has increased significantly. Before drug treatment is considered all practical steps should be taken to change work and lifestyle habits that could make your narcolepsy worse, in particular;

- **Avoid shift work if possible and try to keep to the same going to bed and waking times**
- **Avoid excess alcohol and heavy meals; generally trying to keep your weight down**
- **Learn to recognise situations which provoke attacks of cataplexy**
- **Adopt a routine of brief naps and breaks to maintain alertness**
- **Avoid work that involves long periods of concentrated attention and little movement**
- **Try to work (and live) in a well lit and well ventilated environment**
- **If the person with narcolepsy keeps to these guidelines, the doctors should be able to devise an effective treatment regime of medication with minimal side effects**

As people vary widely in their response to drugs, patients and doctors have to take a pragmatic view on experimenting with doses and different types of medication until the optimum state is reached. Medication will be reviewed on a regular basis and it is quite possible that you will be asked to come off certain medication occasionally to "detox" your system. This is normal and should be considered as part of your treatment regime.

No one drug exists that can deal with all the symptoms of narcolepsy. The most commonly used for excessive sleepiness is modafinil which is marketed as Provigil. This is a drug that is well tolerated and is now only routinely prescribed to those with narcolepsy. Dexamphetamine is an even older drug that still has a place in medication for sleepiness, as do several other in the amphetamine class. Ritalin is another drug given to help reduce the effects of narcolepsy; sold under the brand names Equasym, Metadate and several others it is available in standard or slow release form and has an action very similar to amphetamine. There are several drugs that are prescribed specifically to reduce the effects of cataplexy, the majority of which are more commonly used as anti-depressants. It so happens that most anti-depressants also suppress the tendency to enter REM sleep and this is why they may help in cataplexy and other narcoleptic symptoms.

Most selective serotonin reuptake inhibitors (SSRIs) such as fluoxetine (Prozac) will help cataplexy if it is severe. Drugs such as clomipramine, also known as a Tricyclic Antidepressant (TCA), are also often prescribed to reduce cataplexy and hypnagogic hallucinations.

Sodium Oxybate, which is marketed as Xyrem is a drug that has been on the market for several years. Licenced for use for those with narcolepsy and cataplexy it has been shown to have a marked effect on improving night time sleep as well as the daytime problems of sleepiness and cataplexy. It is often used together with an amphetamine or modafinil to maintain alertness during the day. Largely because it is currently a very expensive drug, Xyrem is not generally available in either Scotland or Wales and is only available in special circumstances in England.

How relatives & friends can help

The behaviour of friends, relatives and business colleagues can have a marked effect on the ability of a person with narcolepsy to cope with the condition and to get the best out of life.

While narcolepsy is not a mental or emotional illness, it is not unusual or surprising for people with narcolepsy to feel depressed. They have an unusual illness that people don't understand, a diagnosis can take time and they can be made to feel strange and isolated. This is particularly true with children who do not have the experience of adults, nor the self-confidence. Schools have a duty of care to support children with illnesses such as narcolepsy and it is crucial that schools are informed as soon as possible so support packages can be put in place. It is your right to have this support.

At work, a person with narcolepsy should be permitted, perhaps even encouraged to nap during periods of excessive sleepiness. Under the Equality Act 2010 it is unlawful for employers to discriminate against those people with a disability or long term illness. All employers now have a legal duty to make reasonable changes for employees who are employed with debilitating illness or become ill during their employment.

If an employer does not allow the employee who has been diagnosed with narcolepsy the opportunity to nap, this could be considered direct discrimination. Allowing an individual to have short nap at break time and lunch should be considered reasonable. Especially when the employer learns that on awakening from such a nap the person will be refreshed and able to work effectively again. Benefits are available to those who are unable to work due to their narcolepsy. Full information is available on the Narcolepsy UK website. If you support or look after someone with narcolepsy and cataplexy you may be entitled to a carers allowance; again more information is on the website.

Narcolepsy is a well recognised neurological disorder. When a Narcoleptic falls asleep it is not due to lack of interest, it's because it is impossible to resist the urge to sleep.

People suffering an attack of cataplexy may need help to prevent them falling but no other help or medical support is needed. Although an attack of cataplexy can be difficult to witness, recovery happens quite quickly. Even though an individual may appear asleep, during an episode of cataplexy, full awareness and memory for the event is maintained.

During automatic behaviours, however, the narcoleptic is not fully aware of what is happening. Apparent forgetfulness is a common result. It is important to watch for automatic behaviour and to be ready to "wake" the person if needed.

Signs of automatic behaviour include, lowered eyelids, eyes glazed, apparent lack of attention even if they are doing something like writing or reading. If you think that leaving the individual in this state could expose them to risk, say if they are cooking or using power tools, do stay with them and try to gently bring them back to reality. Loud voices, touch and using their names can often bring them out of this state.

The outlook for someone with Narcolepsy

Narcolepsy is a "spectrum disorder"; no two people experience the same range of effects at the same time. For some sleep hygiene as outlined above is enough to maintain a near normal life, while others, probably the majority, will need support and medication. It will take time to tailor the treatment to the individual. Then trial and error will be needed to take food and drug interactions into consideration. Even when the individual has reached a stable regime, switching drugs or changing doses may be needed to prevent drug tolerances developing.

The good news is there are more drug regimes available now than ever before. While no one drug, at the moment, cures all the problems, several drugs used in union, can provide significant support for people with narcolepsy. Narcolepsy neither shortens your life nor reduces your inherent physical and mental abilities.

Much has been achieved over the last ten years and individuals with narcolepsy should look forward with hope. The work being done in Europe and America on the causes of narcolepsy are starting to show promise. If the trigger could be found that activates the immune response that may cause narcolepsy, it could potentially be switched off and the possibility exists of stopping the disease before it starts. Work is going on in several countries to find that trigger. In the shorter term, producing a treatment that erases the symptoms of narcolepsy is possible. The unlocking of the genetic code allied with better imaging equipment open up some tantalising areas of research.

For all of this to come about it is important that the public are aware of and understand narcolepsy. It is crucial that people with narcolepsy are diagnosed quickly and that adequate support is given to them throughout school and work life and beyond. Knowing what is wrong with you is very important, both medically and psychologically.

In the meantime it is important to stay fit and healthy, adjust your lifestyle to work with your condition and help create an unprejudiced attitude at work and home. By doing this it is possible for the narcoleptic to live a normal or near normal life.

**A Lasting Legacy
Gifts in wills
Helping Future Generations**

For details and other information visit our website at www.narcolepsy.org.uk