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 quietening 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 not unknown. The disease is rare, estimated to affect 1 in 2,500 people 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.

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 suffers, 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 0345 450 0394.
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 known to increase the risk of 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. Your GP may ask you a number of questions or you may 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 neurological department or a sleep centre. The Narcolepsy UK website has a list of all the major units.

The specialist 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 they have the equipment available they may carry out another test 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.

As people vary widely in their response to drugs, patients and doctors have to find a pragmatic approach to dosages 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 routinely prescribed for the treatment of narcolepsy. It is an even older drug that still has a place in medication for sleepiness, as do several other in the amphetamine class. Pitutin is another drug used to reduce this effect of narcolepsy and it is often used in combination with other drugs 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 and the majority are those that 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 (SSRI) such as Fluoxetine (Prozac) will help cataplexy if it is severe. Drugs such as clonipramine, 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. Licensed 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 a drug called modafinil to improve symptoms during the day. Large studies have shown that it is currently a very effective drug. Xyrem is not generally available in either Scotland or Wales and is only available in special circumstances in England.

Treatment of Narcolepsy

At the moment there is no cure for narcolepsy but the symptoms can be reduced or even suppressed using a variety of ‘sleep hygiene’ and drugs. With increasing evidence that immune damage is ultimately responsible, the possibility of targeted drugs being available has increased significantly.

Before drug treatment is considered at 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 recognize situations which provoke attacks of cataplexy and avoid these as far as possible.
• Avoid work that involves long periods of concentrated attention and little opportunity for 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 and effective treatment regime of medication with minimal side effects.

How relatives & friends can help

The behaviour of friends, relatives and business colleagues can have a marked or even suppressive effect on a number of factors associated with narcolepsy to cope with the condition and to get the best out of life. When 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. It is particularly difficult for 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, although this is often not observed. It is important that they receive 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 have a legal duty to make reasonable changes for employees who are employed with debilitating illness or become ill during their employment.

If an employee 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 from 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 learn about someone with narcolepsy and cataplexy you may be entitled to a carer’s allowance. 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 is an embarrassing and difficult experience 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 interest and inattention. If you notice the person has discovered something quite quickly even though an individual may appear asleep, during an episode of cataplexy, full awareness and memory for the event is maintained.

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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 been done is encouraging and the future on the horizon for someone with narcolepsy is starting to show good 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 codes 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 your work and life style and take up some enjoyable activity to deal with this and other everyday problems.

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

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