what is

Narcolepsy?

Surveys show that most people do not know what narcolepsy is, and many people have never heard of it.

UKAN
Narcolepsy Association UK
www.narcolepsy.org.uk

What is narcolepsy?

THE condition of narcolepsy is due to a malfunction of the sleep/wake regulating system in the brain. Until very recently the cause was unknown but there are now suggestions that it may be due to a lack of an important chemical in the part of the brain responsible for controlling sleep. Its most common manifestation is an irresistible tendency to fall asleep, even in unlikely circumstances such as in the middle of a conversation or at a meal.

These episodes are called ‘sleep attacks’ and a characteristic of these in people with narcolepsy is that, when the person wakes up after the attack he feels refreshed.

The other notable symptom is a sudden loss of muscular control triggered by emotions such as amusement, anger or excitement, which is called ‘cataplexy’. The effects of cataplexy range from dropping of the jaw and slumping of the head, to buckling of the legs and even collapse of the whole body; attacks may last from a few seconds up to many minutes.

Other symptoms of narcolepsy are:

- Temporary paralysis on falling asleep or awakening.
- Hallucinations or nightmares when falling asleep or awakening.
- Moments (but sometimes extended periods) of trance-like behaviour in which routine activities are continued on 'autopilot'.
- Interruption of night-time sleep by waking periods, marked by quickening of the heartbeat, agitation, and an intense craving for sweets. This poor quality of night time sleep often contributes to a feeling of sleepiness in the morning.

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

Narcolepsy usually begins in adolescence but onset earlier, or as late as middle age, are on record.

The incidence of narcolepsy in the population is not accurately known as the condition is under-diagnosed. Many people believe that about 1 in 2000 people are affected in the UK. It could be more than this.

An inheritable factor has been identified which can increase the likelihood of developing narcolepsy by up to 10 times in persons with the factor compared with those without it.

I think I have narcolepsy – what do I do?

IF you think you have narcolepsy you should discuss this with your GP. Before you go make sure you have a list of the symptoms which you feel are important. Several other conditions have symptoms which are similar to those of narcolepsy and your doctor may decide that it is unlikely that you have narcolepsy. However, if he considers you may have the condition he will refer you to a specialist centre such as a sleep centre or neurology department. The specialists 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. They may decide to study your sleep patterns – if they do that you will need to stay overnight in the hospital. In some cases they may take a blood sample to determine whether you have the 'tissue type' which is often found in people with narcolepsy. When they have completed the tests they will write to your GP with the results and give guidance on the type of treatment which may be necessary.

Treatment of narcolepsy

ALTHOUGH there is no cure at present for narcolepsy, the symptoms can be reduced or even suppressed by drugs. First, before drug treatment is considered, all practicable steps should be taken to change working habits and lifestyle, in particular by:

- Avoiding occupations that involve long periods of concentrated attention and physical immobility, especially in an environment that is poorly lit or ventilated.
- Avoiding shift work and irregularity of retiring and rising times.
- Opting for jobs without monotony and in which brief naps and breaks are feasible.
- Avoiding excess alcohol and heavy meals and generally keeping one's weight down.
- Adopting a routine of brief naps during periods of diminished alertness and of breaks in the open air or vigorous physical activity to maintain alertness at other times.
- Learning to recognise and avoid situations which tend to provoke attacks of cataplexy.

If the person with narcolepsy keeps to these guidelines, the physician can then devise an effective regime of medication with minimal side effects.

As people vary widely in their response to drugs, patient and doctor have to work closely together and be ready to 'experiment', both in the initial stages and during subsequent periodic reviews of the treatment.

No one drug exists which can deal with all the symptoms. Central nervous system stimulants (such as amphetamine, methylphenidate or mazindol) or a wake-promoter (modafinil) are prescribed to combat excessive daytime sleepiness, and antidepressants (such as clomipramine, or SSRIs) to control cataplexy. The fact that antidepressants are used to treat cataplexy does not mean that people with cataplexy are depressed –this group of medication is used because one of their 'side effects' is to reduce the cause of cataplexy in the brain.

Treatment for sleepiness should not be taken late in the day because, by causing sleeplessness at night, they may increase sleepiness the next day.

All medications are dispensed with a Patient Information Leaflet (PIL). It is important that the patients reads this before starting treatment. The PIL contains useful information regarding side effects, cautions etc

How relatives and friends can help

THE behaviour of relatives and friends and indeed business contacts critically affects the ability of a person with narcolepsy to cope with the disorder and get the best out of life.

Depression and a sense of isolation can develop if the person with narcolepsy continually meets with misunderstanding of his condition. This is particularly true of children who do not have the experience of adults nor their self-confidence in the face of adversity.

Narcolepsy is a well recognised organic neurological disorder, and it is quite wrong to regard the sleepiness as a manifestation of laziness or malingering.

> **When a narcoleptic drops off to sleep it is not due to lack of interest, but because he is quite incapable of resisting the urge to sleep.**

Nor are there grounds for assuming that a narcoleptic is mentally or emotionally ill.

> **Even during an episode of cataplexy the sufferer reasons quite normally.**

People suffering an attack of cataplexy may need support to prevent their falling but no other help or professional medical care is needed.

> **Although it is disconcerting to witness such an episode, the victim will recover very quickly.**

During automatic behaviour the narcoleptic is unaware of what is happening. Apparent forgetfulness is a common result.

> **One should watch for signs of automatic behaviour (eyelids lowered, eyes glazed, apparent inattention) and be ready to arouse the narcoleptic if it is perceived that he is exposed to risk, eg when using a power tool or driving.**

At work, a person with narcolepsy should be permitted, even encouraged, to

nap during periods of excessive sleepiness. After awakening from such a nap the person will be refreshed and able to work effectively.

The outlook for a person with narcolepsy

AT first, the symptoms of narcolepsy are barely distinguishable from what healthy people occasionally experience, but as the disorder develops they come to be perceived as clearly abnormal.

The degree to which they interfere with the life and activity of the sufferer depends as much on the occupational and social demands made by his/her way of life as on the severity of the condition.

Although he or she could become unemployable, socially isolated and chronically depressed, such extreme effects can be mitigated.

> **Adjusting lifestyle and creating an unprejudiced attitude at work and at home make it possible for the narcoleptic to lead a near normal life.**

In more severe cases, that end can be achieved by continuous medication, tailored to individual needs.

> **Narcolepsy neither shortens the lifespan nor impairs the individual's inherent mental and physical capabilities.**

What is UKAN?

UKAN, The Narcolepsy Association UK (Registered Charity No.326361) is an association of people with narcolepsy, their relatives and others interested in improving their lot. Its registered objectives are the *benefit, relief and aid of persons suffering from narcolepsy.* Its aims are:

- To promote awareness of narcolepsy and provide authoritative information about it to sufferers, to the health care professions and to the general public;
- To support the establishment of local self-help groups in which people with narcolepsy can exchange experience and provide mutual support;
- To press for the recognition of narcolepsy as a disability by the social services;
- To encourage research into the causes and treatment of narcolepsy;
- To co-operate with narcolepsy associations overseas to further these aims.

A regular newsletter *(Catnap)* is published reporting developments from home and abroad, with articles and correspondence.

Annual Subscription:

UK & Europe - £10.

Outside Europe - £15 (payable in sterling).

Membership is confidential if so desired.

The organisation is managed by volunteers from among the members and has only one part-time paid member of staff. The Association receives no major funding from the health authorities and depends almost entirely on donations from individuals.

For membership details or other information, visit our website (www. narcolepsy.org.uk) or contact us using the details below

Narcolepsy Association UK,
PO Box 13842,
Penicuik
EH25 8WX

Tel: 0845 450 0394
Fax: 0870 777 3039
e-mail: info@narcolepsy.org.uk

Donations and subscription should be made payable to ‘UKAN’.

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