

Narcolepsy Need-to-Know Guide

Childhood Narcolepsy

This guide provides information for parents or carers of children and young people with narcolepsy. It aims to promote a clear understanding of the condition and the challenges faced by children and young people with narcolepsy, and to help you discuss the issues involved with your healthcare team.

Narcolepsy and its symptoms

To understand narcolepsy, we have to understand a little about sleep. Sleep is a complicated process involving several stages:

Awake	
Stage 1	Falling asleep
Stage 2	Light sleep
Stages 3 and 4	Deep sleep
Stage 5	Rapid Eye Movement (REM) or dreaming sleep

Normally, we go through Stages 2 to 5 a few times every night, before waking up in the morning.

In narcolepsy, the part of the brain that controls sleep and wakefulness does not function as it should. The messages about when to sleep and when to stay awake get mixed up. When you have narcolepsy, your brain moves between the stages of sleep at inappropriate times. These changes cannot be controlled and this results in a number of symptoms:

Excessive daytime sleepiness

A continual feeling of tiredness and an irresistible urge to fall asleep during the day. This may cause children to fall asleep at inappropriate times and in unusual places. When this happens, children will find it difficult to concentrate on their schoolwork.

Cataplexy

A sudden episode of muscle weakness, usually triggered by strong emotion, mainly laughter, anxiety and anger. These episodes can last a few seconds or minutes, and may involve the muscles of the face and neck and upper or lower limbs. The head may droop and speech may become slurred. More severe episodes may cause the child or young person to drop things or become unsteady, which may result in them falling to their knees or to the ground. It is important to note that cataplexy does not involve a loss of consciousness; the person affected is fully aware of what is happening.

Disturbed night-time sleep

Restless, poor quality sleep at night. Children may find it difficult to get up in the morning.

Sleep paralysis

An inability to move or talk when falling asleep or waking. These episodes may last a few seconds or minutes and can be frightening for the child.

Hypnagogic hallucinations

Vivid, dream-like and often frightening images experienced when falling asleep or waking. Particularly for small children, these hallucinations can be terrifying and distressing.

Microsleeps and Automatic Behaviour

You may recognise times when the child may seem to be dreaming or is unresponsive when spoken to. This may last from a few seconds to a minute, and during this time the child is asleep. These episodes are called **microsleeps**. During a microsleep, the child may carry on with a task that they are involved in. This is known as **automatic behaviour**. The child will have no memory of this. They may appear confused and disorientated following these episodes. If they occur frequently, you should encourage the child to have a short nap.

Not everyone with narcolepsy has all of these symptoms. However, almost all suffer from excessive daytime sleepiness and/or disturbed night-time sleep, and many also exhibit cataplexy. The severity of the symptoms may vary considerably from one person to another.

Trying to stay awake

Children develop their own strategies to try and maintain concentration and keep themselves awake. These include:

- Constant movement of their hands or feet
- Unusual posturing when sitting
- Unusual movements of their mouth – tongue thrusting
- Biting or pinching of the skin
- Frequent quiet numbling sounds
- Drinking water frequently

If your child shows any of these signs, you should encourage them to have a short nap.

Here are some questions you might want to ask:

Will my child always have Narcolepsy?

Yes. There is currently no cure for narcolepsy. However, as we learn more about the causes of narcolepsy, new and more effective treatments are being found to offer support. Each individual child or young person's condition will vary in severity and the impact that it has on their life will be different.

How did my child develop this condition?

It is now generally believed that, in most cases at least, narcolepsy is an auto-immune disorder, caused by the destruction of certain cells within the brain by the body's own immune system. Those cells are responsible for the production of a peptide molecule called hypocretin (sometimes also called orexin). The cells that produce hypocretin are found in an area of the brain known as the hypothalamus and extend to other parts of the brain that are

known to be involved in wake and sleep regulation. Recently, there has also been an upsurge in the number of cases of narcolepsy among young people, linked to the use of the swine flu vaccine Pandemrix.

What does a diagnosis of narcolepsy mean for my child?

Narcolepsy is a life-long condition, but many adults with narcolepsy lead normal lives, work in various professions and have families of their own.

Narcolepsy is a difficult condition for children to understand. It is important that we develop a positive attitude to the lifestyle changes that will help them to manage their condition.

Will my child have any tests?

It is important to make sure that your child has the diagnosis of narcolepsy confirmed and that other causes for their symptoms are ruled out. Therefore, your doctor may suggest some tests that will be helpful. These include:

Polysomnography (PSG)

This involves your child coming into hospital for one night to record what happens in their sleep cycle. You can stay with your child in hospital during this time.

Multiple Sleep Latency Test (MSLT)

Your child is encouraged to fall asleep on four or five occasions throughout the day. During this time a recording is made of what happens within their sleep cycle. Usually your child will have the MSLT done in the morning, during their stay in hospital.

Blood Tests

Your child may have a blood test to help identify other factors that are common in people with narcolepsy.

Lumbar Puncture

Hypocretin has been found to be low or absent in people with narcolepsy. To check your child's levels, a sample of spinal fluid would be required. Your doctor will decide if this test is necessary.

How often will my child have to attend hospital?

Your child will normally be seen at an outpatient clinic 3-4 times per year.

What treatment options are available?

There are two main treatments for narcolepsy: lifestyle changes and medication. A combination of both will best lead to a reduction in your child's symptoms.

Lifestyle changes

Narcolepsy impacts on all aspects of a child's life. They need to plan every activity within their day. In many cases, scheduled naps are required throughout the day, especially prior to activities. Children learn to develop individual strategies to help them cope with their symptoms such as excessive daytime sleepiness and cataplexy. It is important that you encourage your child to get into a routine that controls their narcolepsy symptoms. This should include:

- Going to bed at the normal time each night.
- Getting up at the normal time each day.
- Planning their day to include a few short naps especially before going out to participate in activities, clubs, or out with friends.
- Taking medication every day at the correct times.
- Maintaining a balanced diet. Some children find this difficult, which may lead to an increase in their weight.
- Discouraging your child from eating late at night as this can make night-time sleep more difficult.
- Keeping your child active and encouraging daily exercise, as this will make them feel more awake.
- Keeping the home environment cool as warm temperatures can make us feel more sleepy.
- Helping your child to become independent in the management of their condition, including daily life skills.
- Encouraging normal friendships.

Medication

There are numerous medications that are used to treat narcolepsy, and these are of three main types:

- Stimulant medication that helps to maintain wakefulness.
- Medication that changes the sleep cycle during the night, to promote wakefulness in the daytime and to reduce cataplexy.
- Other medicines that help reduce cataplexy.

Sometimes combinations of two or more medications are used. Your doctor or nurse will discuss which medication will be most effective for your child and will talk to you about potential side effects.

How can I help and support my child with the symptoms of Narcolepsy?

Narcolepsy is a difficult diagnosis for children and young people to understand. A positive outlook and set routines in your child's daily life including scheduled naps, will promote a positive lifestyle.

Having narcolepsy should not stop your child from doing all the things they enjoy and achieving what they want to achieve.

Here are some things to remember:

- Encourage family and friends to learn about narcolepsy so they can help you and your child.
- Encourage your child to be physically active and promote independence appropriate to their age when out with their peers.
- Encourage your child to organise their day to include short naps when required.
- Support your child to develop normal friendships.
- Discuss with your child and form a plan about what they should do if they fall asleep when they are out with their friends, in order that they remain safe.
- Encourage your child to participate in activities and hobbies that they enjoy. It may be necessary to inform the organisers of the event that your child has narcolepsy.

- Encourage a short nap if possible prior to activities, as this may help reduce cataplexy.
- Try and help your child to concentrate on something, an object or a thought, that will stop them from laughing, feeling anxious or angry, when they feel that they might develop cataplexy.
- Cataplexy will stop when your child no longer feels anxious, stops laughing or feels angry.
- Ask friends and family to stop what they are doing and to stop talking and laughing when your child has cataplexy. This will help your child recover more quickly.
- Encourage your child to concentrate when walking up or downstairs and to hold onto any railings.
- Remind your child to concentrate when crossing the road. They should avoid talking with friends and using a mobile phone during this time. Remind them to avoid thinking of things that provoke strong emotions.
- Remind your child to concentrate when they are near open water including the bath, swimming pools, rivers and lakes, in-case they develop cataplexy.
- Hypnagogic hallucinations, bad dreams, seem very real to your child. Children may find it difficult to talk about them as they often do not make sense, or can be frightening for them. Encourage your child to write down in a diary or draw what they remember about their hallucinations. This will help them to understand them better.
- Encourage your child to talk about what they remember about the hallucinations and reassure them that they are not real.

Sometimes children and young people find it difficult to deal with the symptoms of narcolepsy, especially the excessive daytime sleepiness, cataplexy and hallucinations. This can reduce their confidence. Sometimes they struggle with episodes of low mood. If you are concerned about these issues it is important to discuss this with your doctor or nurse.

What help is available to my child in school?

It is important to arrange a meeting with your child's school to discuss what help they will need. Class teachers need to be aware that your child has narcolepsy in order to provide the appropriate level of support within education. Your doctor, nurse and health care team will work with parents or carers and the school to support your child.

Additional help within education may include:

- Written information for teachers on how best to support your child within the classroom.
- Teachers may provide individual educational resources for your child to assist learning.
- Rearranging your child's timetable to allow for a scheduled sleep in school.
- Providing additional help if required in practical subjects and out of school activities when necessary.
- Special arrangements for exams. This may include extra time, use of a separate room with an individual invigilator, and support for regular breaks.
- The development of an Individualised Support Plan for your child. This involves developing an individual plan that will allow your child to have a range of support services to help them achieve their potential within education.

More information and useful links

Narcolepsy UK

www.narcolepsy.org.uk

info@narcolepsy.org.uk

Helpline: 0345 450 0394

NHS Website

www.nhs.uk/conditions

National Institute of Neurological Disorders

www.ninds.nih.gov/

British Sleep Society

www.sleeping.org.uk/

Center for Narcolepsy – Stanford University School of Medicines

www.med.stanford.edu/narcolepsy

American Academy of Sleep Medicines

www.aasmnet.org/practiceguidelines.aspx

American Sleep Association

www.sleepassociation.org/

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IMPORTANT NOTE: Whilst every effort has been made to ensure that the information in this Guide is accurate, it is for general guidance only. Specific advice on your individual circumstances should always be sought. Narcolepsy UK cannot accept any responsibility or liability for actions taken in reliance on the information contained in this Guide.