

Narcolepsy Need-to-Know Guide

For Teachers

This guide has been designed to help teachers support children and young people with narcolepsy at school. It aims to promote better understanding of the condition and the challenges that children with narcolepsy face in education. It provides a basis for discussion with the child, their parent or carer, and 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 move through several cycles of Stages 2 to 5 every night, before returning to a state of wakefulness.

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. Even if not asleep, they may be very drowsy and preoccupied with trying to resist the urge to sleep. 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 sleepiness

A common misconception is that people with narcolepsy sleep well. In actual fact, they often experience restless, poor quality sleep at night. As a result, 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**. Microsleeps are often not obvious and are easily overlooked.

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.

Will the child always have narcolepsy?

Yes. Narcolepsy is a life-long condition. However, each individual child's condition will vary in severity and the impact it will have on their education will be different.

How is narcolepsy treated?

There are two main treatments for narcolepsy: lifestyle changes and medication.

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 to develop a plan to support independence and maintain personal safety.

Children strive to be the same as their peers and do not wish to be treated differently. They often ask that their teachers refrain from asking them if they are feeling tired.

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. The child will often need to take this medication during the school day, for instance at lunchtime. Individual arrangements must be made within the school to provide for medication administration and storage.
- Medication that changes the sleep cycle during the night, to promote wakefulness in the daytime and to reduce cataplexy. These medications are generally taken at night.
- Other medicines that help reduce cataplexy. Again, these medications are generally taken at night.

What impact will narcolepsy have on the child's ability to learn?

Narcolepsy does not result in reduced intellectual capacity. However, the severity of their symptoms will directly impact upon a child's educational progress. Excessive daytime sleepiness may mean that a child or young person has difficulty assimilating information or remembering instructions that have been given to them. However, with appropriate support, many children with narcolepsy cope well in school and go on to achieve academic success.

It is important that children with narcolepsy are not excluded from extra-curricular educational activities. An individualised plan may be necessary to support the child or young person during these events, dependent on need.

The guidance in this document is necessarily general in nature and will be applicable to a greater or lesser extent to any child or young person with narcolepsy. However, it is important to recognise that the nature and severity of narcolepsy symptoms, and the most effective approaches to the management of those symptoms, vary widely from individual to individual. It is therefore vital that the child's healthcare team, parents or carers, as well as the child him- or herself, work with the school to develop measures that yield the best outcomes for that particular child.

What should I look out for in the classroom?

It is important to recognise the symptoms of narcolepsy in the classroom, as this will help you to understand how the child is coping.

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

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

Some children may appear to be fidgeting or to be hyperactive, or they may misbehave in the classroom. It is important to understand that this may simply be their way of keeping themselves awake.

You may also notice some of the following indicators that the child is having difficulty within the class:

- Short episodes of sleep lasting a few seconds to a few minutes.
- Slow, slurred speech.
- Difficulty in holding a pen or pencil, resulting in a deterioration in their writing.
- Erratic handwriting or writing gobbledegook or doodling. This is an example of "automatic behaviour".
- Frequent head nods or loss of balance resulting in a fall.
- Carrying out tasks without having any memory of them, as they are asleep. They may be confused about what they should be working on in class and need to be reminded of how to continue.

Any of these signs are an indication that the child or young person is unable to achieve full concentration within the lesson and will need to sleep.

What can I do to support the child in the classroom?

There are a number of simple measures that you can take to help a child or young person with narcolepsy cope in school and to maintain wakefulness:

- Keep the classroom cool.
- Ask the child where they would like to sit. Some may prefer to be near the front of the classroom, if that helps them to stay alert; others may prefer to be seated where any sleepiness is less likely to be noticed by other children.
- The child's desk should be away from any radiators, preferably near the classroom door.
- Encourage the child or young person to actively participate in the lesson or to move around the classroom if appropriate.

It may be helpful to ensure that written instructions for the lesson are given, so that the child does not have to rely on verbal instructions that they may have difficulty recalling.

During practical lessons, it may be necessary to consider individual Health & Safety issues, particularly in relation to the possibility of injury in the event of sleepiness or a cataplexy attack.

For many people with narcolepsy, the most effective way of dealing with excessive daytime sleepiness is for them to take a brief nap. If the child is excessively sleepy, encourage them to nap, either at their desk or at another designated location in school, before continuing with class work.

What if the child falls asleep in class?

If the child does fall asleep, it is generally best to leave them to sleep for a brief period, say of 10 minutes. After that, gently wake the child and encourage them to get up and have a drink of water. The child may need you to remind them of where they are, and what task they need to be working on.

If they fall asleep again, leave them to sleep until the end of the lesson and then wake the child. They should feel refreshed following their sleep and be encouraged to go to their next class.

If a further period of sleep is required, the child should be accompanied to the school office where arrangements can be made for them to sleep.

Do children with narcolepsy require an individual Classroom Support Assistant?

Not necessarily. However, this may be required, depending on the severity of their symptoms. At times during the school day, the child or young person will need support, especially around scheduled napping and educational support within class. Such support may include supervision at break or lunch, toilet breaks (especially in primary school), support in practical subjects, accessing the curriculum and Health & Safety issues.

Are there restrictions regarding teaching activities?

No. Children and young people with narcolepsy should be encouraged to participate in all aspects of the school curriculum.

How does the school arrange for the child to sleep in school?

Arrangements may need to be made for the child or young person to have one or more scheduled naps during school time. The school needs to provide a safe environment for the child to sleep in. The optimum duration of a nap will vary from child to child, and may be anything from 10 to 30 minutes. A nap may be taken once per day, perhaps around mid-morning or at lunchtime. However, some children may require more than one sleep. A member of staff must be responsible for the child or young person's safety when asleep. The child's timetable may have to be altered so that time for naps is accommodated and to provide a balanced educational curriculum.

What about peer support in school?

Some children with narcolepsy find it difficult to maintain good peer relationships. They struggle to stay awake and participate in activities outside school. Cataplexy can make them self-conscious and reduce their confidence. Any opportunity to encourage peer participation within school is essential to support their psychological well-being. They should be encouraged to spend time with their peers at break times (though this may be difficult if breaktimes are used for napping).

What about homework?

It is important that you continue to support the child's ongoing educational progress by setting appropriate homework. However, many children will sleep for a number of hours in the evening, therefore limiting their time to do homework. When possible, try to reduce the quantity of work and extend timescales for large homework tasks. It should also be borne in mind that, where homework involves completion of a task begun in school, a child with narcolepsy may have made less progress on that task during the school day, and the homework element of the task may therefore be more onerous for them than for their peers.

Individualised Support Plans

It is essential that children with narcolepsy have an appropriate support plan within school to meet their needs. They require a multi-agency approach within education to support learning.

A variety of measures may be put in place to assist a child or young person with narcolepsy to cope with exams. The level of support should be decided on an individual basis and may include extra time, separate room, individual invigilator, support for regular breaks (for instance for naps or simply a walk around the playground to restore wakefulness), a prompter or scribe.

Involving the child in the decision-making process

The key to the child or young person's education is to help them to prioritise areas within the curriculum that they believe will be most helpful, as they plan their future after school.

This may involve a reduction in their timetable and in some cases for individual subjects to be dropped, in order to achieve success in others.

Offering early access to careers advice and regular support within this area for career planning is essential.

Discussions with the child or young person, their parents and their healthcare team will promote a positive learning environment and ensure that they achieve their potential.

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

British Sleep Society

www.sleeping.org.uk/

Center for Narcolepsy – Stanford University School of Medicines

www.med.stanford.edu/narcolepsy

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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.