

Narcolepsy and You

Information for young people diagnosed with narcolepsy

You have just found out that you have narcolepsy. This guide will help you to understand more about narcolepsy and what you can do to feel better.

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 work 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 the wrong times. Children with narcolepsy may feel a number of changes:

Feeling sleepy during the daytime

You may fall asleep in different or unusual places. It may be hard to concentrate on activities and on your schoolwork. This is called **excessive daytime sleepiness**.

You don't sleep well at night

You may wake up during the night and will often feel tired in the morning. This is called **disturbed night-time sleep**.

You may have bad dreams or hallucinations

They seem very real and sometimes they seem frightening. Some children find it difficult to talk about them at first.

If they happen when you are falling asleep they are called **hypnagogic hallucinations**.

You may not be able to move when you are going to sleep or waking up

This feeling will only last a few seconds or minutes. You know that you are awake, but you can't move or shout out to anyone, as your muscles are asleep. This is called **sleep paralysis**.

Some muscles in your body become weak

This might happen when you are laughing, are angry or when you are anxious. It will only last a few seconds or minutes. It may be muscles in your face and neck, arms or legs. You may drop something or feel as if your legs are wobbly, making you become unsteady for a few seconds and sometimes you may fall onto your knees or to the ground. This is called **cataplexy**.

People with narcolepsy do not always have all of these feelings. You may recognise some of these feelings and not others. Many children also describe times when they may feel a little confused when someone is talking to them, or when they are doing an activity. This is because they have fallen asleep for a few seconds without warning. This can happen several times throughout the day. These are called **microsleeps**.

Here are some questions you might want to ask:

Will I always have narcolepsy?

Yes, unfortunately once you have narcolepsy it will not go away. However, as we learn more about the condition, new treatments are being found to support you.

How did I get narcolepsy?

We do not fully understand why people get narcolepsy. We think that narcolepsy is caused by a number of different factors that control when we are awake and when we sleep. One of these is a chemical in the brain called hypocretin.

Will I have to come into hospital and have any tests?

You may need to come into hospital and stay for one night, so that the doctors and nurses can understand what happens when you sleep. Your mum, dad or carer can stay with you in the hospital. Your doctor or nurse will explain what will happen when you come into hospital and you can ask them any questions you have about your stay.

What should I tell my friends?

Your friends may have noticed that you are often sleepy. They will be interested to know all about narcolepsy and what they can do to help you.

What will make me feel more awake?

There are a lot of things that you can do to help you feel more awake:

- Go to bed at the normal time each night.
- Get up at the normal time each day.
- Plan your day to include a few short naps when you are feeling tired.
- Have a sleep before you go out to your activities, clubs, or out with friends.
- Move around and keep active. Try not to sit down for long periods of time.
- Try to get some exercise during the day, as this will make you feel more awake.
- Keep cool and try not to get too warm, as this can make you feel more sleepy.
- Sit near the door in the classroom, as it is cooler. Sit away from the radiators.
- Drink plenty of water during the day and in school.

- Try not to eat late at night as this can make your night-time sleep more disturbed.
- Your doctor or nurse may give you some medicines to take that will help you to stay awake. These medicines come as tablets or liquid and are easy to take.

What can help reduce episodes of cataplexy?

When you are tired cataplexy will become more troublesome so it may help to have a short nap.

Try and concentrate on something, an object or a thought, that will stop you from laughing, feeling anxious or angry, when you feel that you might have cataplexy.

Cataplexy will stop when you stop laughing, feeling anxious or angry.

Tell your friends and family to stop what they are doing and to stop talking or laughing when you have cataplexy. This will help you to recover more quickly.

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Having narcolepsy should not stop you from continuing to do all the things that you like to do and all the things you want to achieve.

It will be helpful if you plan your day carefully.

Here are some things to remember:

- Keep active and plan your day to include small short naps.
- Take your medicine every day at the correct times.
- If you have cataplexy, think about when it is most troublesome.
- Having a short nap may help reduce the episodes of cataplexy.
- When you are in situations that you know may cause you to have cataplexy, take care to be safe.
- Concentrate when walking up or down stairs and hold onto any railing.
- When crossing the road, concentrate and try not to think about anything that will make you laugh, or become anxious or angry. Avoid talking with your friends at this time and do not use a mobile phone, so that you can reduce the chance of having cataplexy.
- Remember to concentrate when you are near open water including the bath, swimming pools, rivers and lakes, in case you have cataplexy.
- Help your friends to understand about narcolepsy so that they can support you.
- Talk with your friends about what they should do if you fall asleep when you are out.
- Help your friends to understand how to help you if you have a cataplexy event.
- Remember that you hallucinations are not real and they cannot harm you. If you can, try and write them down in a diary or draw them. This will help you to understand them better.
- Talk to your parent or carer about what you remember about the hallucinations, as this will help you to understand that they are not real.
- Sometimes children can feel a little down or anxious when they have narcolepsy. Talk to your parent or carer about this so they can help you deal with these feelings.

Your teachers will have information that helps them to understand all about narcolepsy.

Your class teachers will be able to help you with anything you may be finding difficult with your school work.

It is important to have a short nap during the day in school so that you can feel more awake in your class. Your nurse or doctor will speak to the school to help to arrange this.

You can have extra support at times of exams if you feel this would be helpful.

How often will you have to go to the hospital?

You will usually go to the hospital every few months to see your doctor every few months, so that you can talk about how you are getting on.

More information and useful links

Narcolepsy UK is the charity that helps people with narcolepsy:

Narcolepsy UK

www.narcolepsy.org.uk

info@narcolepsy.org.uk

Helpline: 0345 450 0394

Other websites that you, or your parent or carer, may find helpful are these:

NHS Website

www.nhs.uk/conditions

British Sleep Society

www.sleeping.org.uk/

Last updated: October 2015

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.