

# Non-Epileptic Seizures (or NES) (also called Non-Epileptic Attack Disorder)



Information for young people and families

# What are non-epileptic seizures?

Some young people experience periods where they 'black out' or lose awareness of their surroundings for a few moments or sometimes a bit longer. Their body may start shaking and they could fall over and hurt themselves. A doctor may at first think that they could have epilepsy.

However, young people with non-epileptic seizures (NES) are not actually having an epileptic seizure. They don't have the electrical changes in their brains which happen in an epileptic seizure. Instead, their body is stressed in some way and they lose awareness of their surroundings for different reasons. Some people have both NES and epileptic seizures.

We have met lots of young people with NES and have lots of ways to help them get back to normal life. It is important for you to understand about NES and this leaflet from Great Ormond Street Hospital (GOSH) will help you do this.

## What are they not?

- You are not making them up or doing them on purpose
- You are not being mad or crazy
- They are not a type of epilepsy – they are something different
- They are not your fault and may be difficult for you to control.

## What else do non-epileptic seizures get called?

People use lots of different names:

**Dissociative  
seizures**

**Pseudoseizures**

**Psychogenic  
non-epileptic  
seizures**

**Non-epileptic  
attack disorder**

You need to find a name which works for **YOU** which you can share with your family, friends and your school.

## How do NES get diagnosed and by which health professionals?

There could be several different types of doctor who help make the diagnosis. You and your family will be asked to explain exactly what happens to you during a seizure or non-epileptic seizure, and what you are doing when they happen.

It is also important to find out about all aspects of your health, your school, your friendships and your emotions. You and your family might be asked to fill out some questionnaires.

Having all this information often allows a doctor to make the diagnosis. However, some young people may be asked to have some further tests, such as an electroencephalogram (EEG). This involves you wearing a cap that measures electrical signals in your brain. If doctors also decide to video you at the same time, then they can see what happens in your brain and body when you have a NES.

## Why do people get NES?

We don't really know why people get them, but it seems people get them for different reasons. They might be linked to stressful situations, but they might happen at other times too. Some people with NES don't feel stressed. When people feel upset, their bodies respond in different ways. Lots of people get headaches.

Other people feel sick. Have you ever been nervous and it's made you need to go to the toilet? NES is another way that some people's bodies react when they feel under pressure or upset. The important thing to know is that NES are often related to things that are going on in your life, even when it isn't obvious what!

Scientists have shown that some people are more likely than others to have physical symptoms as the result of stress or emotions.



# What kind of stress might be linked to non-epileptic seizures?

NES can happen when you are dealing with stressful situations. These are different for different people. It could be something small which bothers you or a much bigger stressful situation, such as:

- Going to a new school
- Being bullied
- Someone in your family going away or getting ill
- Having bad things happen to you.



For some people something really horrible has happened to them. If you have been sexually or physically abused, then it is really important to talk to an adult you trust. This could be your parents, a teacher, a nurse or someone else.

NES can also come about when you have another problem that hasn't been recognised or treated, for example anxiety, depression, autism or dyslexia.

# Who can help and what might they do?

The people looking after you need to work together to understand your problem and help you recover. This might include paediatricians, neurologists, psychologists or psychiatrists. They will also assess whether you have other problems that could benefit from some help.

Then they will help you to think about your NES differently and find ways to improve things for you. They might use a method of understanding problems called Cognitive Behavioural Therapy (CBT). This helps you think of new ways of coping, changing your behaviour, and considering your thoughts.

If you do not also have epilepsy your doctor will want gradually to take you off any epilepsy medication you are taking. We know that anti-epileptic medicines do not help NES, and they might give you some side-effects.

If you have another problem such as anxiety or depression your doctor might suggest a different sort of medicine, in combination with talking treatment.

Your school also needs to understand how best to help you when you have an NES. Health professionals might contact them.

## What else might help?

There is a lot that you and your family can do yourselves, for example:

- Try to pay little attention to the NES and carry on with your daily activities.
- Tell your family, school and friends about NES so they can help you too.
- Find out what triggers your NES or makes them worse and work to find better ways of coping.
- When you feel like a NES might happen, try to relax and stay calm. Distraction or keeping active might help, or talking to someone who knows you well.
- Psychologists, nurses and doctors at your local Child and Adolescent Mental Health teams can help.

## What about the future?

All the young people we have met have found ways to deal with NES. It can take time, but usually they go away and we hope that happens for you. The fact that you have read this leaflet means that you are already thinking about finding a way to move forward. Good luck!



## More information

Have a look at these two websites:

- [www.sheffield.ac.uk/polopoly\\_fs/1.125591!/file/NEST\\_Patient-Booklet-Revised-v2-130511.pdf](http://www.sheffield.ac.uk/polopoly_fs/1.125591!/file/NEST_Patient-Booklet-Revised-v2-130511.pdf)
- [www.neurokid.co.uk](http://www.neurokid.co.uk)

**We hope you have  
found this leaflet helpful!**

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