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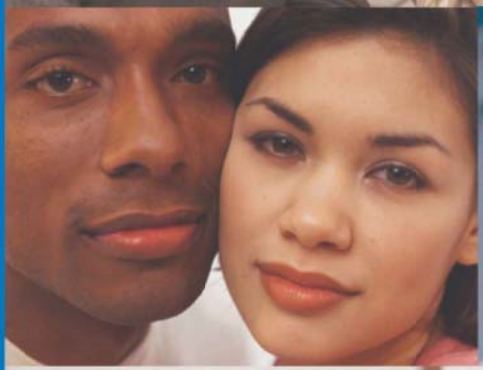
Non-epileptic attacks



Information for patients, family and friends

Non-epileptic Attacks

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NEST
(Non-Epileptic Seizures Treatment) Group 2006
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What are non-epileptic attacks?

Your attacks are called non-epileptic attacks. This simply means you have attacks that can look like epileptic attacks, but they are not related to epilepsy.

Epileptic attacks are caused by abnormal electrical signals in the brain. These signals stop the brain from working properly for a short time.

Your attacks are non-epileptic. This means they are not caused by abnormal electrical signals in the brain or brain damage.

During an attack you lose some control of your body.

You might

- Faint and fall to the floor
- Have shaking movements of your arms, legs or head
- Make other unusual movements
- Bite your tongue or injure yourself
- Lose control of your bladder or bowel
- Become blank or absent and out of touch with your surroundings
- Not be able to remember the attack

Some of these symptoms may lead people to confuse non-epileptic attacks with epileptic attacks.

Do I have epilepsy?

More than 7 out of 10 people with non-epileptic attacks have been given a diagnosis of epilepsy in the past and many have taken anti-epileptic drugs for several years. Better knowledge of non-epileptic attacks means they can now be identified more easily.

The initial diagnosis usually relied on the description of your attacks, and important details may have been missed.

1 in 10 healthy people have slight changes in their EEG which can be mistaken for an indication of epilepsy. It is not unusual for someone with non-epileptic attacks to have these changes, especially if they are taking anti-epileptic drugs.

This can lead the doctor to think you have epilepsy, or to be unsure about the cause of your attacks.

Doctors sometimes decide to start a trial period of anti-epileptic drugs even when the diagnosis is unclear. This is because epileptic attacks can be very harmful.

When anti-epileptic drugs don't work, more tests are usually carried out. Over time it becomes clearer that the attacks are not epileptic.

Most people with non-epileptic attacks do not have epilepsy as well.

Only 1 in 20 people with non-epileptic attacks do also have epilepsy. If this applies to you, your doctor will discuss it with you. It will be important to learn to tell the two types of attack apart so that each can be treated properly.

Are non-epileptic attacks rare?

Around 2 or 3 people in every 10,000 have non-epileptic attacks.

This means that in a typical town with around 300,000 people (such as Cardiff, Wigan or Doncaster) there will be about 60 to 90 people who have non-epileptic attacks.

Of all the people who come into hospital with attacks which do not settle quickly, nearly half turn out to have non-epileptic attacks.

Up to 1 in 8 people newly referred to specialist epilepsy clinics turn out to have non-epileptic attacks.

Different people use different names for non-epileptic attacks. Other names you may hear are non-epileptic seizures (NES), non-epileptic events, psychogenic seizures, functional seizures, dissociative seizures, pseudoseizures or pseudoepileptic seizures. People who have non-epileptic attacks may be told they have Non-Epileptic Attack Disorder (NEAD).

These are all names for non-epileptic attacks and they all mean the same thing.

Non-epileptic attacks are a known condition with recognised treatment.

What causes my attacks?

Non-epileptic attacks happen when there is a problem with the way the brain is working for a short while. They are not caused by physical problems in the brain or by a disease. They happen for different reasons in different people.

We don't yet know much about how they happen. Sometimes the brain seems to become overloaded and "shuts down", or parts of the brain stop working together properly.

Non-epileptic attacks can be linked to emotions or stress, but causes of attacks are not always obvious.

Often a person's first attacks are related to an upset or shock. Examples are deeply upsetting experiences, trauma, death of a loved one or any other great loss or change. This can be recent or in the past.

Ongoing stress in your life can sometimes explain why attacks still happen. Examples are relationship problems, bereavement and money worries.

Individual attacks can be set off by many different things. Something that brings on an attack as soon as it happens is called a trigger. Examples are flashbacks, difficult emotions and certain situations such as arguments. These can all be triggers for attacks.

Over time attacks can start to happen without any obvious trigger. They can happen randomly and with no warning.

You may be feeling calm and relaxed before an attack. This can make it difficult to work out what triggers your attacks.

How can stress be the cause?

It is well known that emotional stress can cause physical reactions in the body. Examples include blushing when you are embarrassed, a fast heart beat when you are nervous and headaches when you are worried.

Severe or ongoing stress is known to cause physical symptoms of illness which can lead to disability.

Non-epileptic attacks, chronic fatigue, fibromyalgia and irritable bowel syndrome are all examples of conditions which can be caused by stress.

You may feel that you are not believed by your friends and family and by doctors and nurses. Many people believe that symptoms such as your attacks must have a physical cause. It can be difficult to understand that attacks can be caused by stress. This could lead people to wrongly believe that you have control over your attacks.

Most people are familiar with the idea of people fainting when they are shocked. You may also have heard of examples of people going blind or deaf after a trauma. Like non-epileptic attacks there is no physical cause for these conditions, but they are known to be linked to stress.

It is important for others to remember that people with these conditions have real physical symptoms or sensations such as dizziness or pain. You are not faking or putting it on and you are not going crazy.

The people treating you understand about non-epileptic attacks and they know that your attacks are real.

Could it be something else?

Non-epileptic attacks often look like epileptic attacks. It is important to know what type of attacks you have, as they need different treatment.

Specialists in treating attacks can sometimes tell what type of attacks you have when they are described in detail by a person who has seen your attacks. Home video and photos of a typical attack can sometimes help.

The most reliable test is video-EEG monitoring. This test is used to watch a typical attack and to record brain waves during the attack. Using this test your doctor can make a diagnosis of non-epileptic attacks with almost complete certainty.

This test can show that your attacks are not caused by epilepsy. This is why they are called non-epileptic attacks. The test cannot show precisely what does cause your attacks.

Depending on the nature of your attacks other tests can be helpful, including brain scans, blood tests and heart recordings. These tests will look for different physical causes for your attacks. Your doctor will explain what tests you are having and why.

What about my other symptoms?

You may have other symptoms as part of your condition. These symptoms often have causes similar to the causes of non-epileptic attacks.

These symptoms can include

- Numbness
- Tingling
- Fatigue
- Pain
- Headache
- Dizziness
- Blurred vision
- Bladder problems
- Bowel problems
- Limb weakness or paralysis
- Poor concentration
- Memory problems
- Worry
- Panic
- Anger
- Frustration
- Low mood
- Trouble sleeping
- Speech problems
- Feeling distant or unreal

Treatment for non-epileptic attacks may also help in relieving some of your other symptoms.

What do I tell people?

Telling people that you have epilepsy is difficult although many people have heard of epilepsy and know something about it.

Telling people about non-epileptic attacks can be much harder. Most people have not heard of non-epileptic attacks, and it can be difficult to explain what they are. If you have a good understanding of your diagnosis it will be easier to explain to others.

Here are some things you can say:

“I have attacks that I cannot control. They are like epileptic attacks but they are not caused by the same things that cause epilepsy.”

“Even though they are not epileptic, my attacks can still be distressing for me.”

“The cause of my attacks isn’t fully understood.”

“They can be linked to stress.”

“I have a condition similar to epilepsy, which means I have attacks.”

It may be useful to discuss this booklet with your friends and family so that they know about your attacks and can support you.

What should people do when I have an attack?

Keep this card with you in case you have an attack. You could also give a copy of this page to family and friends.

I have non-epileptic attacks
This is what to do if I have an attack

- **Keep me safe from injury.** You may need to guide or move me from an unsafe place, move dangerous objects and protect my head by carefully placing some soft clothing under it.
- **Do not hold me down or try to restrict my movement**. This can make the attack worse or cause injury.
- **Do not put anything in my mouth** or try to give me medication.
- **Speak to me calmly.** I may be able to hear and feel what people are doing when I have an attack, and being spoken to in a calm reassuring manner can help to make the attack shorter.
- **My attacks do not cause damage to the brain**, even if they go on for several minutes.
- **Do not call an ambulance unless I am injured or the attack goes on for a long time**. It is important that the ambulance crew know that my attacks are non-epileptic. Show them this card.

How are non-epileptic attacks treated?

The goal of treatment for non-epileptic attacks is to reduce or stop your attacks. The first step is helping you and your family to understand the condition.

You may find it difficult to accept the diagnosis, particularly if you thought you had epilepsy for many years. However, if you have a definite diagnosis and you are still having attacks, it is important to consider all the treatment options available.

Anti-epileptic drugs do not control non-epileptic attacks. They can have unwanted side effects and should not be taken unnecessarily.

Unless you also have epilepsy, your anti-epileptic drugs will be reduced and stopped. Your neurologist will support you with this.

The most important treatment for non-epileptic attacks involves talking – to friends and family and to specialists in treating non-epileptic attacks. Your neurologist will be able to make a referral for you to see a specialist.

You can also learn to manage stress using things like relaxation and breathing exercises.

We call the treatment for non-epileptic attacks “psychological help”.

What is psychological help?

Psychological help is often called “talking therapy”. The aim is to explore the reasons why you have non-epileptic attacks and find out what triggers your attacks. There are different types of psychological help and they may be offered by people with slightly different types of training.

Your therapist will help you to understand your ways of coping with stressful events and explore stresses or problems that are affecting you.

You may also learn specific techniques of relaxation and stress reduction, which may help to control your attacks.

These therapies can help you to view past events differently and to view yourself and future stresses more positively.

You may be reluctant to take up psychological help because you fear you will be thought of as crazy. This is not the case. People with non-epileptic attacks are not seen as crazy, they are seen as needing some guidance to understand and overcome their problems.

Therapy or counselling can be a very positive experience. It’s a chance to talk things through, and explore your own thoughts and feelings about things that matter to you. It can also help you to live more easily with the physical effects of your attacks.

The processes which cause non-epileptic attacks may be related to other conditions such as depression and anxiety. These can be treated with psychological help, drugs or both. If they are not treated, your attacks may not improve.

Who can help?

- **Your neurologist or neuropsychiatrist** will explain the diagnosis to you. If you do not have epilepsy, they will help you to reduce and stop anti-epileptic drugs and they will monitor your progress as these changes are made.

- **A psychiatrist, clinical psychologist, psychotherapist, counsellor or clinical neuropsychologist** can help to explore the issues that may be causing or maintaining your non-epileptic attacks. They can also advise you about other types of medication that may help, for example for depression or anxiety.

- **An epilepsy specialist nurse** may be able support you, but they are not available at all hospitals. They can support you in understanding your diagnosis, advise you on how to deal with medication changes and help you to cope better with your attacks.

- **A hospital social worker or welfare rights officer** can give you information about benefits and job schemes that may be available to you.

- **Your GP** can give advice and support and can let you know about local psychology or counselling services.

- **Your local Citizens Advice Bureau or DSS** can give you social services and benefits advice.

What can I do to help myself get better?

- **Feel comfortable and clear about the diagnosis.** If you understand and accept the diagnosis you are more likely to get better.

- **Use the specialist help on offer**. Psychological help can help you to find out what caused your attacks to begin and what triggers each attack. It can help you to learn to control and stop your attacks. You can also learn techniques for relaxation and stress reduction.

- **Find your triggers.** Think about what is happening during an attack. Are you frightened? Are you worried about something? Understanding what triggers your attacks can help to prevent them. If your attacks seem to be brought on by a certain situation, then talking it through with someone can help to overcome the problem.

- **Learn to stop your attacks.** If you get a warning that an attack is going to happen you can learn to use breathing and stress reduction techniques. This may help to stop the attack. If your attacks happen without warning try to remain calm. Remind yourself that you do not have epilepsy and nothing serious is going to happen to you.

- **Talk to friends and family.** They are more likely to stay calm during an attack if they know what is happening. This can help to make the attacks shorter.

- **Remain positive.** Give yourself time to get better and remember that non-epileptic attacks can be overcome.

Should I stop doing anything?

Non-epileptic attacks can be frightening and you may feel worried about carrying on with your usual activities. Whilst this is understandable it is important to carry on as normal as much as possible.

Most people with non-epileptic attacks can carry out their normal daily activities without help. You should not assume that you can't do something just because of your attacks.

If you feel that you may be at risk of injury during an attack, discuss this with your friends and family. Work out a way to keep yourself safe.

Try to do as much as possible for yourself and be as independent as you can.

It is better if your friends and family encourage you to do things for yourself, and do not become too protective.

Will I recover?

People with non-epileptic attacks can fully recover and lead a normal life. It is also possible for attacks to become a long-term and disabling problem.

Understanding and accepting your diagnosis can help to improve your attacks.

It is important to recognise that your attacks are non-epileptic and start the right treatment. Trying more or different anti-epileptic drugs will not work.

Psychological help can be a long process, and it is likely to be weeks or months before your attacks improve. However, if treatment is started, you can expect your attacks to improve over time. Over the course of a year many peoples' attacks reduce a lot or stop completely.

Some people with non-epileptic attacks find it very difficult to accept the diagnosis and take up treatment. People who have this problem often continue to take anti-epileptic drugs. These drugs do not control the attacks and there can be harmful side effects.

If you do not take up psychological help you are less likely to recover fully and it is likely that your attacks will continue.

Even if your attacks continue you can lead a full and active life. You can learn to cope with your attacks in a similar way to how people deal with uncontrolled epilepsy.

How do you feel about your condition?

You may have a range of emotional reactions to finding out that you have non-epileptic attacks. This is normal and understandable.

- **Confused?** It can be hard to receive a diagnosis of non-epileptic attacks, especially if you believed you had epilepsy. Epilepsy is quite well known and understood and has a known cause in the brain. Non-epileptic attacks do not have a physical cause, and this can be very difficult to understand.

- **Angry?** You may feel angry that you have had a different diagnosis and treatment in the past. Some people also become angry because they do not accept that the cause of their attacks is not physical. You may feel angry at having lived with the stigma and restrictions of epilepsy for so long.

- **Disbelieving?** Some people do not accept the diagnosis and continue to believe they have epilepsy. These people may refuse to take up the right treatment, which means they are less likely to recover.

- **Relieved?** You may be glad to have a definite diagnosis of non-epileptic attacks. It means you do not have epilepsy and can stop taking anti-epileptic drugs. It also means you can begin appropriate treatment to stop or reduce the attacks.

Think about how you feel about your condition and why.
What can your friends and family, doctors and nurses do to help you to cope?

Driving

If your attacks involve a sudden loss of awareness with no warning then you will not be able to drive until your attacks have stopped. If you currently drive, you will need to inform the Drivers and Vehicle Licensing Authority (DVLA) and return your driving licence.

For more information you can contact the DVLA on 0870 600 0301 or go to the website www.dvla.gov.uk

The DVLA are likely to contact your neurologist for information about your attacks. You may want to discuss your individual circumstances with your neurologist.

If your attacks stop in the future you will be able to apply to the DVLA for a new driving licence.

Benefits

People who have attacks, whatever the cause, may be able to claim benefits depending upon the effect the attacks have on their life.

If you have received benefits or been unable to work because you thought you had epilepsy, this should not change based on your new diagnosis. You have real attacks which can be disabling.

There is a good chance that with the right treatment your attacks will improve and you may be able to work again in the future. If this happens, then getting off benefits and starting work again can in itself be stressful. You may not have worked for some time. You might want to discuss this with the doctor treating you.

The Job Centre Plus can give you advice about returning to work after claiming benefits. You can also talk to the Citizen's Advice Bureau or the Department of Social Services if you have any questions about benefits.

Tips to remember

- Your attacks are not caused by epilepsy, but they are real and can have a big impact on your life.
- People do not think you are faking the attacks or going crazy.
- The attacks are not your fault. You did not bring the attacks on, but you can help to stop them.
- The attacks will not cause damage to your brain, even if they go on for some time.
- Having a longer attack does not mean you have epilepsy. Epileptic attacks usually last for less than 2 minutes.
- Accepting and understanding your diagnosis is the first step to recovery.
- Psychological help can be very useful in finding out what causes your attacks and in helping you to control or stop your attacks.
- Non-epileptic attacks can be easier to deal with if your friends and family have a good understanding. Show them this booklet and discuss your attacks with them so that everyone knows what is happening when you have an attack and what to do.

How can I find out more?

The following websites have some information on non-epileptic attacks:

Epilepsy Action
www.epilepsy.org.uk/info/nonep.html

National Society for Epilepsy
www.epilepsynse.org.uk/pages/info/leaflets/factsnea.cfm

Enlighten – Tackling Epilepsy
www.enlighten.org.uk/factsheets/factsheet26.pdf

Further information about non-epileptic attacks is limited, but you may find out more about your attacks by looking at conditions which can have things in common with non-epileptic attacks.

Try searching the internet using a search engine such as www.google.co.uk. These are some words you could search for: Post Traumatic Stress Disorder; Conversion Disorder; Somatoform Disorder; Somatization; Dissociation; Hyperventilation; Panic Attacks; Stress; Psychological treatment; Therapy; Help; Advice.

The NHS Prodigy website has patient information leaflets about many topics. Try looking at some of these at www.prodigy.nhs.uk/Portal/PatientInformation/PilsListResults.aspx?GroupingId=20

Remember that information from the internet may not be accurate if it is not from a recognised organisation.

Are there any support groups?

This is an online support group for non-epileptic attacks.
http://groups.msn.com/Epilepsy----AreYouSure

This site has accounts by people living with non-epileptic attacks and an online support group.
www.growingstrong.org/epilepsy/nonepileptic.html

Your neurologist is ……

Your therapist is ……

You can call ……..… for advice

Glossary

Anti-epileptic drugs - Drugs used to treat or prevent seizures in epilepsy. They are also used to treat certain mental, emotional and pain disorders. Also known as anticonvulsants.

Anxiety - A state of apprehension, uncertainty, and fear resulting from the anticipation of a threatening event or situation.

Attack - An episode or onset of a disease, often sudden in nature.

Clinical Neuropsychologist - A specialist in the branch of psychology that deals with the relationship between the nervous system and mental functions such as language, memory, and perception. They understand broader aspects of peoples' problems such as anxiety and depression due to their training in clinical psychology.

Clinical Psychologist - A person trained to perform psychological research, testing, and therapy.

Convulsion - An abnormal violent and involuntary contraction or series of contractions of the muscles.

Counsellor - A person trained to listen to peoples' problems and help to find ways of dealing with them.

Depression - An emotional disorder in which people feel a loss of interest and enjoyment in life, and have problems with concentration, sleep patterns, loss of appetite, feelings of extreme sadness, guilt, helplessness and hopelessness, and in severe cases even thoughts of death.

Diagnosis - The act of identifying a disease from its signs and symptoms or a name for a condition or illness.

Dissociative seizures - Another name for non-epileptic attacks.

Epileptic - Relating to or associated with epilepsy.

Epilepsy - Various disorders in which attacks are caused by abnormal electrical signals in the central nervous system (brain).

Epilepsy Specialist Nurse - Provides support and advice for people with epilepsy and related conditions, their families and carers.

Functional seizures - Another name for non-epileptic attacks.

Neurologist - A medical specialist in the branch of medicine dealing with the nervous system and the disorders affecting it.

Neuropsychiatrist - A medical specialist in the study of disorders with both neurological and psychiatric features.

Non-epileptic attack - A clinical spell that resembles an epileptic seizure, but is not due to epilepsy. The EEG is normal during an attack, and the behaviour is often related to psychological distress.

Non-Epileptic Attack Disorder - Another name for non-epileptic attacks.

Non-epileptic events - Another name for non-epileptic attacks.

Non-epileptic seizures - Another name for non-epileptic attacks.

Pseudoepileptic seizures - Another name for non-epileptic attacks. This name is now not generally used because it implies that the seizures are an imitation of epilepsy

Pseudoseizures - Another name for non-epileptic attacks. This name is also not generally used now.

Psychiatrist - A doctor who specializes in psychiatry.

Psychiatry - The branch of medicine that deals with the diagnosis, treatment, and prevention of mental and emotional disorders

Psychogenic seizures - Another name for non-epileptic attacks.

Psychotherapist - A person trained in working with people with emotional problems to help resolve them.

Psychological - Relating to or arising from the mind or emotions.

Seizure - A sudden attack, spasm, or convulsion.

Stigma - A mark of shame or discredit.

Stress - Difficulty that causes worry or emotional and mental tension. Can produce physiological reactions that lead to illness.

Talking therapies - Treatment of problems through conversation between patient and therapist.

Therapist - A person skilled in a particular type of therapy.

Trigger - An event that sets other events in motion. An event, situation or emotion that sets off a non-epileptic attack.

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