Sheffield Teaching Hospitals NHS
NHS Foundation Trust

Non-epileptic attacks

A short guide for patients and families

Information for patients
Neurology - Psychotherapy Service

What are non-epileptic attacks?

Non-epileptic attacks are episodes in which people lose control of their body, often causing shaking or other movements of arms and legs, blacking out, or both. They are also known as non-epileptic seizures and can look a little like epileptic seizures but they happen for a different reason. Epileptic seizures are caused by abnormal electrical activity in the brain, which stops it from working normally, and non-epileptic attacks are not. Instead they are emotionally generated.

Non-epileptic attacks are often (but not always) related to previous experience of trauma, i.e. something outside your control which is intolerable or unacceptable. They appear to be an automatic (reflex) response to overwhelmingly intense thoughts, memories or emotions. However, they can occur when you feel calm and relaxed, and often people find it difficult to understand why they have developed non-epileptic attacks or what triggers them.

Are non-epileptic attacks rare?

For every 100,000 people, between 15 and 30 have non-epileptic attacks. Nearly half of all people brought into hospital with suspected serious epilepsy turn out to have non-epileptic attacks instead.

Non-epileptic attacks are also known as dissociative seizures, functional, psychogenic or pseudoseizures. Sometimes people who have non-epileptic attacks are told that they suffer from non-epileptic attack disorder (NEAD).

How can I be sure that this is the right diagnosis?

Non-epileptic attacks often seem like epileptic seizures to friends, family members and even doctors. Like epilepsy, non-epileptic attacks can cause falls, injuries and loss of control over bladder and sometimes bowel function.

However, specialists in the treatment of seizures (neurologists, neurophysiologists or epileptologists) are often able to tell that seizures are non-epileptic when they are described in detail or recorded on video. For instance, the movements, length, triggers and frequency of non-epileptic attacks are slightly different from epileptic seizures.

In some people, a firm diagnosis of non-epileptic attacks can be made without any tests. In others, typical attacks can be recorded during an EEG (electroencephalogram) examination. This is a useful test because it can show up the electrical changes in the brain, which are only present during epileptic seizures.

Home video recordings, perhaps using a mobile phone, or even photographs of a typical seizure can sometimes help in the diagnosis.

The most reliable test is video-EEG monitoring. During this test, patients are observed for several hours or even days with a video camera and an EEG until they have a seizure. By examining the video and EEG recordings, a diagnosis can be made with almost complete certainty. Video-EEG monitoring can only be done if attacks are frequent enough (once a week or more). Sometimes the likelihood of an attack occurring is increased by possible triggers such as over-breathing during the test to make it more likely that an attack occurs.

Why was I told that I had epilepsy?

More than seven out of ten people with non-epileptic attacks are treated with anti-epileptic drugs for several years before the correct diagnosis is made. This does not mean that doctors who have treated you for epilepsy have been incompetent. The diagnosis of seizures relies on descriptions by observers, who may not have noticed or been able to describe important details. Often the diagnosis becomes clearer over time, when people have had a chance to observe more seizures. Also, epileptic seizures can be harmful so, to be on the safe side, doctors may decide to start anti-epileptic drugs. They may only have recognised that seizures are non-epileptic when anti-epileptic drugs have not worked.

What about my abnormal EEG?

One in ten completely healthy people have an EEG showing "non-specific" abnormalities. Such abnormalities do not mean that there is anything wrong with brain function. They can also be detected when the brain is functioning normally and are more likely to be found when people take a range of medications. It is therefore not uncommon that "non-specific" EEG abnormalities are seen in people with non-epileptic attacks, especially if they are taking anti-epileptic drugs. Another reason why the EEG may be abnormal in a person with non-epileptic attacks is that some also have epilepsy or other neurological brain disorders. If you have both seizure types, it is important that you and your family learn to tell them apart.

What causes non-epileptic attacks?

Non-epileptic attacks can sometimes be caused by extreme emotional reactions. However, more often the attacks represent an automatic (i.e. reflex) switching of attention away from a disturbing or unacceptable trigger inside or outside of the body. Triggers inside the body can include physical sensations (such as fatigue or pain) but also intense feelings (such as fear, sadness, anger or frustration) or even upsetting thoughts or memories. Outside triggers may involve situations you find yourself in or things that you pick up with your senses. The involuntary reflex response may be so quick, that people remain unaware what the trigger was.

After the non-epileptic attack is over, you may feel exhausted, embarrassed or distressed, but you may not remember what triggered the attack. This means that the non-epileptic attack has stopped the trigger from coming into your awareness and may have protected you from more intense emotional upset or memories that could otherwise have been very distressing or even make you emotionally unwell.

Non-epileptic attacks occur more commonly in people who have had traumatic experiences in the past or who are continuing to deal with trauma or difficult situations in their current life. Some people seem to develop non-epileptic attacks if they have a tendency to always put other people first. However, sometimes it is very difficult to understand why someone would have developed these symptoms.

It is important to remember that non-epileptic attacks are real physical symptoms, which are a response to real stresses and that people do not fake them. Often family members (and even healthcare professionals) do not understand the fact that non-epileptic attacks are not "put on".

What about my other symptoms?

These are some other symptoms, which people with non-epileptic seizures can sometimes experience as part of their illness. These are likely to be emotionally generated and related to experiences of periods of high stress in the past:

- Numbness, tingling
- Pain
- Poor concentration
- Poor sleep
- Blurred vision
- Dizziness
- Frustration, anger
- Worry
- Bladder problems
- Fatigue
- Headache
- Memory problems
- Difficulty speaking
- Feeling distant
- Limb weakness
- Low mood
- Panic
- Bowel problems

What can I do to help myself get better?

The first step may be the hardest. People often find it very difficult to feel comfortable with the diagnosis of non-epileptic attacks. It is difficult for them to get better if they are not convinced of the diagnosis. Here are some points which people with non-epileptic attacks have found helpful:

- A good way to think about non-epileptic attacks is: "I am not bringing my attacks on but I can help myself to get better!"
- Find your triggers. Sometimes people with non-epileptic attacks find ways of stopping their attacks by working out what set them off. One way of finding triggers is to ask yourself "what is happening?" before and during an attack. Are you frightened? Are you worried about something?
- Make sure your friends and family understand. This can help to make attacks shorter and less frightening. Friends and family are

more likely to stay calm during an attack if they understand what's happening and that you are unlikely to come to any harm. Showing them this leaflet and discussing the attacks with them may help with this.

- Use the specialist help on offer. Although you can help yourself to get better, your doctor may offer you an appointment with a psychologist, psychotherapist or counsellor to discuss the causes and treatment of your attacks.

Do I need to see a psychiatrist or psychotherapist?

Often the upsetting events or conflicts causing non-epileptic attacks have been avoided, or blocked from memory, and people can only work out why they have developed seizures with the help of an expert. The processes in the brain, which cause non-epileptic attacks, may also cause other conditions, such as depression and anxiety. These conditions can be treated with talking treatment (psychotherapy) or drugs. If they are not addressed, non-epileptic attacks may continue to happen.

Some people diagnosed with non-epileptic attacks are reluctant to believe the diagnosis and so do not go to see a psychiatrist, psychologist or psychotherapist. Sometimes the significant events happened a long time ago and people think they are no longer important in their lives. If you feel like this, it is worth keeping in mind that non-epileptic attacks are well recognised by experts in the treatment of seizure disorders and can be diagnosed with some certainty.

Some people believe that they will be thought of as "crazy" or "mental" if they have psychological or psychiatric treatment. This is not the case. Non-epileptic attacks should be seen as a way in which normal people cope with extraordinary difficulties in their lives. People with non-epileptic attacks are not crazy and can recover fully and lead happy and productive lives. They may just need a little help from an expert first.

Many people become upset when they are told that their attacks are "psychological". Remember that non-epileptic attacks are not produced on purpose - it is not your "fault" that you have them. It makes sense to seek treatment from the person most able to help you. Triggers for attacks can best be identified with the help of those with special training in psychology: psychotherapists, psychologists, psychiatrists or counsellors.

As with many other medical conditions, sometimes the exact cause remains unknown. Even then, the most important goal is to reduce or stop the attacks.

Your neurologist may continue to see you, but your treatment will mainly come from a psychologist or psychotherapist. Treatment may involve attack prevention techniques, psychotherapy, stress-reduction (such as relaxation and mindfulness), and personal support to help you cope with your attacks.

Are there no tablets that I can take?

The most important treatment of non-epileptic attacks involves talking to friends, family members and therapists or counsellors. Many people with non-epileptic attacks have been given anti-epileptic drugs. Such drugs are only useful if people have both non-epileptic and epileptic seizures. Anti-epileptic drugs have no effect on non-epileptic attacks and they often cause side effects. This is why, if you are on these drugs and don't need them, we will gradually reduce your dose until it is safe to stop taking them. You should only change the dose of your anti-epileptic drugs under the supervision of your doctor. Although there are no tablets to stop non-epileptic attacks, a number of people also suffer from depression and anxiety. Sometimes the treatment of these conditions with anti-depressants or drugs to reduce anxiety can help people to better control their attacks.

How can talking help?

Many people ask how a treatment that just involves talking could help with their attacks and feel very doubtful about starting psychotherapy. However, over 100 years of experience with talking treatments has demonstrated that talking can change how the brain works, including how it:

- responds to certain situations
- addresses problems
- deals with anxiety, stress, anger or low mood

When we gradually start to face a situation that we have avoided, such as going to busy places, we slowly build up our confidence so that it feels less stressful. It is similar to the way we can build up strength in a weak muscle by doing physiotherapy exercises.

What should other people do when I have an attack?

Most people get very frightened when they see a non-epileptic attack. However, it is best if people who are there when an attack happens try to stay calm. Here are some "Do's" and "Don'ts" for people helping you during a non-epileptic attack:

Do:

- Keep calm – anxiety can be contagious.
- Make sure that the person having the attack is safe. This may involve removing dangerous objects or carefully placing a pillow or soft clothing under their head.
- Speak calmly to a person having a non-epileptic attack. Non-epileptic attacks often stop more quickly if the person having the attack is addressed in a calm, reassuring way.
- Remember that non-epileptic attacks do not cause any damage to the brain, even if they go on for several minutes.

- Call for an ambulance if you do not yet know whether someone's seizures are non-epileptic or epileptic, and if the seizure goes on for more than five minutes. This is because longer epileptic seizures (status epilepticus) can damage the brain.

Don't:

- Do not hold the person down during the attack. Holding people down can make the attack worse and cause injury.
- Do not try to give them medication, as drugs have no role in the treatment of non-epileptic attacks.
- Do not immediately call for an ambulance. If an ambulance has to be called because an episode simply won't stop or has caused an injury it is important to tell the ambulance about the diagnosis of non-epileptic attacks. Note that it is rarely necessary to call an ambulance with this kind of seizure.

Having attacks that last for more than five minutes does not mean that you have epilepsy. In fact, non-epileptic attacks are more likely to go on for longer than epileptic seizures.

What is the outlook?

People with non-epileptic attacks can recover fully and lead completely normal lives. On the other hand, non-epileptic attacks can become a persistent and disabling problem, which can make them depend on their friends and families or on benefits. This is why it is important to recognise non-epileptic attacks quickly and to start appropriate treatment. It is important to bear in mind that psychological treatment is not a quick-fix and may take time. Some people improve at first but then need further treatment later.

People with non-epileptic attacks often find it impossible to accept the diagnosis and to take up the offer of treatment. Unfortunately, patients who make this choice often continue taking anti-epileptic drugs, which have already failed and so they do not get better.

Am I allowed to drive?

The DVLA requires that a patient suffering from non-epileptic attacks does not drive and must notify the DVLA. Licensing may be considered once episodes have been satisfactorily controlled for three months.

What about my benefits?

If you have received benefits or been unable to work because of your attacks, this should not change based on this new diagnosis. Your attacks are real, and they may be disabling whether they are epileptic or non-epileptic in origin.

A final thought

We realise that this booklet may not have answered all your questions. It is not intended to replace discussions with your doctor. It can perhaps help you understand that you have a known and treatable condition. You are not alone in having non-epileptic attacks. Treatment is available and is effective for most of the people who seek it.

A good way of thinking about your attacks is:

You did not bring the attacks on but you can help yourself to get better.

Further information

You can find more information about non-epileptic attacks from these sources on our websites:

- **www.nonepilepticattacks.info** (a website with information about non-epileptic attacks)
- **www.sth.nhs.uk/neurosciences/neurology/neurology-psychotherapy-service** (a website providing more information about psychotherapy for non-epileptic attacks)
- **'dis-sociated'** (a documentary about non-epileptic attacks, www.youtube.com/watch?v=MA1EYAg9y5k)
- **'In our words – personal accounts of living with non-epileptic seizures'** (a book with personal accounts of over 100 people with personal experience of non-epileptic attacks)

If you have any questions or would like more information then ask your GP for help or talk to your consultant when you come for your next appointment.

For alternative formats please see
www.sth.nhs.uk/patients/patient-information

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