

Non-epileptic seizures

a short guide for patients and families



What are non-epileptic seizures?

In a seizure people lose control of their body, often causing shaking or other movements of arms and legs, blacking out, or both. Seizures can happen for different reasons. During epileptic seizures, the brain produces electrical impulses, which stop it from working normally. Non-epileptic seizures look a little like epileptic seizures, but are not caused by abnormal electrical activity in the brain.

Non-epileptic seizures happen because of problems with handling thoughts, memories, emotions or sensations in the brain. Such problems are sometimes related to stress. However, they can also occur in people who seem calm and relaxed. Often people do not understand why they have developed non-epileptic seizures.

Are non-epileptic seizures rare?

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

One of the reasons why you may not have heard of non-epileptic seizures is that there are several other names for the same problem. Non-epileptic seizures are also known as pseudoseizures, psychogenic, dissociative or functional seizures. Sometimes people who have non-epileptic seizures are told that they suffer from non-epileptic attack disorder (NEAD).

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

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

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

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

Home video recordings or even photographs of a typical seizure can sometimes help in the diagnosis.

However, the most reliable test is video-EEG monitoring. During this test, we observe patients 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, we can make a diagnosis with almost complete certainty. However, video-EEG monitoring can only be done if a person's attacks are frequent enough (once a week or more). Sometimes we will also use triggers during the test to make it more likely that a seizure occurs.

Why was I told that I had epilepsy?

More than seven out of ten people with non-epileptic seizures 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. Remember that the diagnosis of seizures relies on the descriptions by observers, who may not have noticed important details. Often the diagnosis becomes clearer over time, when people have had a chance to observe more seizures. Also, epileptic seizures can be very harmful so, to be on the safe side, doctors may decide to start anti-epileptic drugs. They may only recognise that seizures are non-epileptic when anti-epileptic drugs do not work.

What about my abnormal EEG?

One in ten completely healthy people have an EEG showing “non-specific” abnormalities. Such abnormalities can also be caused by anti-epileptic drugs. It is therefore not uncommon that EEG abnormalities are seen in people with non-epileptic seizures, especially if they are taking anti-epileptic drugs. Another reason why the EEG may be abnormal in a person with non-epileptic seizures 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 seizures?

We do not know precisely what mechanisms in the brain cause non-epileptic seizures. Unlike epileptic seizures, non-epileptic seizures are not the result of physical abnormalities of the brain. Often they are related to emotions or stress, or they result from upsetting experiences, sometimes from the forgotten past.

It is well known that emotional stress can produce physical reactions in the body. For example, everyone has blushed in embarrassment or felt their heart thump in their chest when they were nervous or anxious. Today, we also know that more extreme stress can actually cause illness and disability. Non-epileptic seizures, fibromyalgia, chronic fatigue and irritable bowel syndrome are all examples of such disorders.

It is important to remember that people with these conditions have real physical symptoms, which are caused by real stresses and that people do not fake them. Often family members (and even health care professionals) do not understand the fact that non-epileptic seizures are not “put on”. An upset, such as physical or sexual abuse, divorce, death of a loved one, other great loss or sudden change, recently or in the distant past, often turns out to be the first trigger.

What about my other symptoms?

These are some other symptoms, which people with non-epileptic seizures can sometimes experience as part of their illness. Often these symptoms have causes similar to non-epileptic seizures. The symptoms are:

- 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 seizures. 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 seizures have found helpful:

- A good way to think about non-epileptic seizures is: “I am not bringing my seizures on but I can help myself to get better!”
- Find your triggers, sometimes people with non-epileptic seizures find ways of stopping their attacks. One way of finding triggers is to ask yourself “what is happening?” during a seizure. Are you frightened? Are you worried about something?
- Make sure your friends and family understand. This can help to make seizures shorter and less frightening. Friends and family are more likely to stay calm during an attack if they understand what’s happening and you are unlikely to come to any harm. Showing them this leaflet and discussing the seizures 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 seizures.

Do I really need to see a psychiatrist or psychologist?

Often the upsetting events or conflicts causing non-epileptic seizures have been bottled up 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 seizures, 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, people with non-epileptic seizures may not get better.

Some people diagnosed with non-epileptic seizures are reluctant to believe the diagnosis and so do not go to see a psychiatrist or psychologist. If you feel like this, it is worth keeping in mind that non-epileptic seizures are well recognised by experts in the treatment of seizure disorders and can be diagnosed with some certainty.

Some people believe that treatment by a psychiatrist or psychologist is a sign that they are thought of as “crazy” or “mental”. This is not the case. People with non-epileptic seizures are not crazy and can recover fully and lead normal lives. They may just need a little help from an expert first.

Many people become upset when they are told that their seizures are “psychological”. Remember that non-epileptic seizures 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 seizures 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 seizures.

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

Are there no tablets that I can take?

The most important treatment of non-epileptic seizures involves talking – to friends, family members and therapists or counsellors. Although there are no tablets to stop non-epileptic seizures, 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 control their non-epileptic seizures better.

Many people with non-epileptic seizures 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 seizures 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.

What should other people do when I have a seizure?

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

DO:

- Make sure that the person having the seizure is safe. This may involve removing dangerous objects or carefully placing a pillow or soft clothing under their head.
- Speak calmly to the person having the seizure. Non-epileptic seizures often stop more quickly if the person having the seizure is addressed in a calm, reassuring way.
- Remember that non-epileptic seizures 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 seizure. Holding people down can make the seizure worse and cause injury.
- Do not try to give them medication, as drugs have no role in the treatment of non-epileptic seizures.
- Do not immediately call for an ambulance. If an ambulance has to be called because a seizure simply won't stop or has caused an injury it is important to tell the ambulance about the diagnosis of non-epileptic seizures. Note that it is rarely necessary to call an ambulance with this kind of seizure.

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

What is the outlook?

People with non-epileptic seizures can recover fully and lead completely normal lives. On the other hand, seizures 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 seizures 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 seizures 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?

Many people with non-epileptic seizures have been stopped from driving because they have been given the diagnosis of epilepsy. There is no law that says anything about patients with non-epileptic seizures driving, and different neurologists recommend different things.

The decision as to whether you should be driving rests with the Drivers and Vehicle Licensing Authority (DVLA). However, the DVLA are likely to ask your neurologist for his or her opinion on your ability to hold a driving licence. If your seizures involve a sudden loss of consciousness without any warning, your neurologist may feel that it would not be safe for you to drive. If this is the case, talk to your neurologist about driving.

What about my benefits?

If you have received benefits or been unable to work because of your seizures, this should not change based on this new diagnosis. Your seizures 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 seizures. Treatment is available and is effective for most of the people who seek it.

A good way of thinking about your seizures is: You did not bring the attacks on but you can help yourself get better.

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

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