Non-epileptic seizures



Seizures that are not due to epilepsy



There are several different types of seizures, and they can happen for many different reasons. Epileptic seizures are explained below. Seizures that are not due to epilepsy are sometimes called 'non-epileptic seizures'. They can have a physical cause such as low blood sugar (hypoglycaemia), or may be related to how the heart is working. Or they may have a psychological cause. The most common type of non-epileptic seizures are functional or dissociative seizures. See below.

What causes epileptic seizures?

Epileptic seizures are caused by a disturbance in the electrical activity of the brain (and so they always start in the brain).

Visit epilepsysociety.org.uk/what-epilepsy

Up to 30% of adults diagnosed with epilepsy who are then assessed at specialist epilepsy centres are found to have non-epileptic seizures (NES). This may be partly because epileptic seizures and NES can look very similar, and can affect people in similar ways. However, non-epileptic seizures are not caused by disrupted electrical activity in the brain and so are different from epilepsy. They can have a number of different causes. They can sometimes look different to epileptic seizures.

Functional (dissociative) seizures

Some NES are caused by mental or emotional processes, rather than by a physical cause.

These may happen when someone's reaction to painful or difficult thoughts and feelings affects them physically. These are called functional seizures.

These NES used to be called 'pseudoseizures' but this name is unhelpful because it sounds like the person is not having real seizures, or their seizures are deliberately put on. Functional seizures happen unconsciously, which means that the person has no control over them and they are not put on. This is the most common type of NES.

Functional seizures are also sometimes known as non-epileptic attacks. People who have non-epileptic attacks may be described as having non-epileptic attack disorder (NEAD). These terms are not always helpful as they describe the condition by saying what it is not, rather than what it is. The newer name of functional seizures is more helpful as it does not describe seizures in terms of epilepsy.

However, it can be confusing as sometimes doctors use the terms NES or NEAD when they talk about functional seizures. Other terms for functional seizures are dissociative, or psychogenic seizures.

What causes functional seizures?

Like many illnesses we don't know exactly why it happens but there are risk factors. For example, we all react to frightening or stressful situations differently. When we are frightened we might feel physical symptoms such as a racing heartbeat or feeling sweaty. When we feel sad, we might cry. So how we feel emotionally might cause a physical reaction.

An extremely frightening or upsetting experience may be so emotionally difficult for some people to think about that they cannot consciously cope with how this makes them feel.

In some cases, they will unconsciously hide or repress the memory of these events. These memories may always remain hidden and the person may never remember the events that happened.

For some people, memories of these painful past events can suddenly come back or intrude into their thoughts or awareness.

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Helpline 0300 102 0024 Confidential, information and emotional support. Visit epilepsysociety.org.uk/helpline for opening hours. This might happen during an emotional or stressful situation, or when something unconsciously triggers a distressing memory.

Functional seizures can happen as a cut-off mechanism to stop bad memories from being re-lived. The person splits off, or dissociates, from their feelings about the experience because it is too difficult to cope with. The seizure happens because their emotional reaction causes a physical effect. These seizures are an unconscious reaction so they are not deliberate and the person has no control over them.

Functional seizures are like the body's way of 'drowning out' a frightening or painful memory so that it doesn't enter into our thoughts.

Any experiences that we have, whether good or bad, can have a deep and long-lasting effect on us, and everyone has their own way of dealing with them. Functional seizures are often caused by traumatic events such as:

- major accidents;
- severe emotional upset (such as the death of a loved one);
- · psychological distress (such as a divorce);
- · physical or sexual abuse; or
- being bullied.

It can be hard to find the cause of functional seizures. For some, they can start shortly after a specific event. For others, they may not start until years later, or they may start suddenly for no apparent reason.

Once functional seizures have started, they might be triggered, or brought on, when the person is stressed or frightened. Or they might happen spontaneously in situations that are not stressful or frightening. Some people with functional seizures may not recognise their feelings of stress before a seizure, and so they may not understand why the seizure has happened.

Sometimes, the fear of having a seizure can, in itself, trigger a seizure. Finding the original event that caused the seizures to start might help to find a way to treat them. But this is not always possible, and it can be hard to talk about traumatic or difficult events.

Seizures caused by a delayed response to a very stressful event or situation, for example, being in a war or disaster, are a response to past events. These seizures may be a part of a post-traumatic stress disorder (PTSD – a condition that sometimes starts after a traumatic event. During the seizure, the person may cry, scream, or have flashbacks (sudden, vivid memories of the event). They may not remember the seizure afterwards.

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What are the symptoms?

Although functional seizures start as an emotional reaction, they cause a physical effect, such as palpitations (being able to feel your heart beat), sweating, a dry mouth, and hyperventilation (overbreathing). Some features of functional seizures are very similar to epileptic seizures. These physical features may include loss of awareness, loss of sensation, and loss of control of bodily movement.

Who has functional seizures?

Functional seizures can happen to anyone, at any age, although some factors make them more likely. Functional seizures are:

- more common in women;
- more likely to happen to people who have had an injury or disease, or who have had severe emotional upset or stressful life events; and
- more common in people with other psychiatric conditions (such as depression, anxiety, personality disorders, or people who self-harm).

How are functional seizures diagnosed?

If you have seizures, your GP will usually refer you to a specialist for diagnosis. This will usually be a neurologist (a doctor who specialises in the brain and nervous system) to see if the seizures are epileptic. Or you may be referred to a psychiatrist or psychologist (as functional seizures are usually classified as a psychiatric condition).

It may be easier for doctors to try and rule out possible physical causes first, including epilepsy. This will influence the types of tests you might have.

Functional seizures can be difficult to diagnose as they can appear similar to epileptic seizures. There are no symptoms that will definitely identify functional seizures from epileptic seizures. The specialist will ask you about what happens to you during a seizure. If you don't remember your seizures, you might like to bring someone to your appointment who has seen them.

Medical tests

Some tests are used to rule out other causes of seizures, including epilepsy:

- Medical examinations and blood tests can be used to check your overall health and see if your seizures have a physical cause, such as diabetes.
- Scans such as CT (computerised tomography) or MRI (magnetic resonance imaging) are used to form a picture of your brain.

Visit epilepsysociety.org.uk/diagnosing-epilepsy





If the tests show no neurological or physical cause for your seizures, and your specialist thinks it might be functional seizures, you may be referred to a psychiatrist or a psychologist for diagnosis.

Treatment options

Treatment may depend on the cause of your seizures, and your medical history. Your specialist may talk to you about what treatment options might be helpful.

Medication

Seizures that are not epileptic will not be controlled by anti-seizure medication (ASM).

If you already take ASM, for example if you were previously diagnosed with epilepsy, your specialist may suggest that you gradually reduce them.

If you have functional seizures and epilepsy, you will usually continue to take ASM for your epileptic seizures. If you also have anxiety or depression, your specialist might talk to you about whether other medication, such as anti-depressants, might be helpful.

Other forms of treatment

Psychotherapy is the recommended treatment for functional seizures. Psychotherapy is the name for a group of different 'talking' therapies (treatments). Mental health professionals, including psychiatrists and psychologists, are trained in different forms of psychotherapy.

Cognitive behavioural therapy (CBT) is often recommended. CBT looks at how you think about things, how this affects you physically and emotionally, and how it affects what you do (your behaviour). By changing the way you think about yourself, other people, and the world around you, this may change the way that you behave.

CBT tends to focus on how things are affecting you in the present, and ways to help you to view current situations more positively and cope with stressful events. CBT can take several months or longer, as it may take time for you to feel comfortable talking about your experiences and feelings.

How you feel about your diagnosis

Being diagnosed with functional seizures can feel quite scary or upsetting because of the stigma around how psychiatric conditions are sometimes viewed.

Understanding that functional seizures can be your body's natural way of reacting to stressful situations might be helpful.

There is no 'right' way to feel about your diagnosis, but being able to accept it can be part of helping to improve seizure control.

Other types of non-epileptic seizures

There are other types of NES and these can be divided into two groups: those that have an organic cause and those that have a psychological cause.

NES that have an organic cause

These seizures have a physical cause (relating to the body). They include fainting (syncope), and metabolic (biochemical processes in the body) causes like diabetes. Because organic NES have a physical cause, they may be relatively easy to diagnose and treat.

NES that have a psychological cause

In addition to functional seizures, there are other types of seizures that have a psychological cause:

- Panic attacks can happen in frightening situations, when remembering previous frightening experiences, or in a situation that the person expects to be frightening. Panic attacks can cause sweating, trembling, palpitations (being able to feel your heart beat), and difficulty breathing. The person may lose consciousness and shake.
- Factitious seizures means that the person has some level of conscious control over them. An example is when seizures form part of Münchausen's syndrome, a rare psychiatric condition where a person is driven by a need to have medical investigations and treatments.

Whatever type of seizure you are having, you might like to talk to someone about your diagnosis and how you feel about it.

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Living with non-epileptic seizures

First aid

The general first aid guidelines for dissociative seizures are the same as for epileptic seizures:

- keep the person safe from injury or harm;
- only move them if they are in danger;
- if they have fallen, put something soft under their head to protect it;
- allow the seizure to happen, don't restrain or hold them down; and
- stay with them until they have recovered.

Visit epilepsysociety.org.uk/first-aid-epileptic-seizures

Keep a normal routine if possible

For some people, NES may disrupt their daily life or they may want to avoid activities in case they have a seizure.

However, studies show that it can help to keep as normal a routine as possible, and to try to take part in activities with other people. This may help to avoid becoming isolated and anxious, which may make seizures more likely.

If you are working, your employer has a responsibility to keep you and other employees safe at work.

To do this, they may need to know about any medical conditions that may affect you at work, including NES.

Your employer may need to do a 'risk assessment' to see if your condition might affect safety at work.

Visit epilepsysociety.org.uk/work-employment
-and-epilepsy

Financial help

You may be able to apply for financial help, depending on how your seizures affect you. Seizures can affect different areas of life for some people.

Visit epilepsysociety.org.uk/what-help-available

Driving

Driving regulations for the UK are set by the Driver and Vehicle Licensing Agency (DVLA). You will need to stop driving and contact the DVLA to check the regulations for functional seizures.

Visit gov.uk/driving-medical-conditions

Seizures and disability

The Equality Act 2010 aims to protect people against discrimination if they have a disability. Someone has a disability if they have "a physical or mental impairment which has a substantial and long-term adverse effect on the ability to carry out normal day-to-day activities".

Equality Act 2010

To be covered by the Equality Act, you need to show that you meet this definition.

Visit equalityadvisoryservice.com

Other organisations

FND Action

fndaction.org.uk

Raises awareness of Functional Neurological Disorder (FND) and (NEAD). Provides support across the UK.

FND Guide

neurosymptoms.org Information about Functional Neurological Disorder. (FND).

FND Hope

fndhope.org.uk

Information on Functional Neurological Disorder (FND).

STARS (Syncope Trust And Reflex anoxic Seizures)

heartrhythmalliance.org

Provides support and information on syncope and reflex anoxic seizures.

Counselling Directory

counselling-directory.org.uk

Find a counsellor or therapist in your area. Your GP or specialist may be able to refer you.

British Association for Counselling and Psychotherapy bacp.co.uk

The professional association for members of the counselling professions in the UK and has a register of trained therapists

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For a printed copy of this information contact our helpline

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