epilepsy society

non-epileptic seizures

Describing dissociative seizures





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Further information is available.

You can find any further updates at epilepsysociety.org.uk/non-epileptic-seizures

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describing dissociative seizures

There are several different types of seizures, and they can happen for many different reasons. Epilepsy and 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 (NES) are dissociative seizures (see page 4).

You may have picked up this leaflet if you, or someone you know, has been diagnosed with non-epileptic seizures. It may help you to identify different types of seizures, and why they might be happening for you or for someone you know.

Call our helpline for more information.

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).

See our leaflet what is epilepsy?

Our brain controls the way we think, move, and feel, by passing electrical messages from

one brain cell to another. If these messages are disrupted, or too many messages are sent at once, this causes an epileptic seizure.

What happens to the person during the seizure depends on where in the brain the seizure activity happens and what that part of the brain does.

Different types of epileptic seizures are explained in more detail in our seizures leaflet.

Around 1 in 5 people (20%) diagnosed with epilepsy who are then assessed at specialist epilepsy centres are found to have NES.

This may be partly because epilepsy and NES can look very similar, and can affect people in similar ways. However, the difference between epileptic and non-epileptic seizures is their underlying cause.

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.

dissociative seizures

Some NES are caused by mental or emotional processes, rather than by a physical cause. This type of seizure may happen when someone's reaction to painful or difficult thoughts and feelings affects them physically. These are called dissociative 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.

Dissociative 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.

Dissociative 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 because they describe the condition by saying what it is not, rather than by saying what it is.

The newer name of dissociative seizures is more helpful because it does not describe seizures in terms of epilepsy. It is also recognised by the World Health Organization (this means that it is included in the International Classification of Diseases: a list of all known diseases and conditions).

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

This leaflet looks at dissociative seizures, why they happen and how they are treated, and at other types of NES (see page 14).

what causes dissociative seizures?

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 can sometimes 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 the memories of these painful past events can suddenly come back or intrude into their thoughts or awareness. This might happen during an emotional or stressful situation, or when there is something in the environment that unconsciously triggers a distressing memory.

Dissociative 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.

One way to describe this is by comparing it to 'domestic deafness'. This is the experience of concentrating so hard on something that we

don't realise when someone is talking to us. It can feel like 'turning the volume down' to drown out what is happening around you so you can concentrate. Dissociative 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. Dissociative seizures are often caused by traumatic events such as:

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

It can be hard to find the cause for dissociative seizures. For some, they 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 dissociative 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 dissociative seizures may not recognise their feelings of stress before a seizure, and so 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 a disaster, are a response to past events. These seizures may be 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.

What are the symptoms?

Although dissociative seizures start as an emotional reaction, they cause a physical effect. Features of the seizures can include palpitations (being able to feel your heart beat), sweating, a dry mouth, and hyperventilation (over-breathing).

Some features of dissociative 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 dissociative seizures?

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

- · more common in women;
- · more likely to start in young adults;
- 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 dissociative 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 dissociative 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.

Dissociative seizures can be difficult to diagnose because they can appear similar to

epileptic seizures. There are no symptoms that will definitely identify dissociative seizures from epileptic seizures.

Taking a personal history

Tests used to find the cause of seizures cannot, on their own, confirm a diagnosis. However, taking a personal history can help to find the cause of your seizures. This includes looking at:

- your neurological history (about your brain and nervous system and its development);
- your psychological development and mental health, including whether you have had depression or other psychiatric conditions, or have been subject to stress and trauma in the past;
- whether there is a family history of depression or other conditions;
- the history of your seizures, such as when they first started and when they happen; and
- whether you have been diagnosed with epilepsy but your seizures have never been controlled with anti-epileptic drugs.

What happens during the seizure

Asking you about what happens to you during a seizure can be helpful to find the cause. If you don't remember your seizures, you might like to bring someone to the appointment who has seen your seizures.



The specialist might ask you:

- · when your seizures happen;
- whether you get any warning before a seizure happens;
- what happens to you during the seizure.
 If you don't remember, a witness can help describe what happens to you;
- how long the seizures last;
- what you remember, if anything, about the seizure afterwards; and
- how you feel afterwards and how long it takes you to recover.

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. This may show
 a physical cause for epileptic seizures, such as
 scarring on the brain, but would not usually be
 helpful in diagnosing dissociative seizures.
- An EEG (electroencephalogram) records the electrical activity of the brain. It is often used to see if seizures are caused by disrupted brain activity, which helps to diagnose epilepsy.

Dissociative seizures are not caused by changes in the brain's electrical activity.

 Video telemetry involves having an EEG and being filmed at the same time. This compares what a person is doing with what is happening in their brain during the seizure, and can often show the difference between epileptic and dissociative seizures. This can help to diagnose epilepsy (if, during a seizure, your brain activity changes), or to diagnose dissociative seizures (if, during a seizure, your brain activity does not change).

See our leaflet *diagnosis*.

If the tests show no neurological or physical cause for your seizures, and your specialist thinks it might be dissociative 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-epileptic drugs (AEDs).

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

If you have dissociative seizures and epilepsy, you will usually continue to take AEDs 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 dissociative 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 any condition can cause different emotions, and may affect many parts of your life. You may be relieved to know what is causing your seizures.

Or you may find it hard to come to terms with, particularly if you had been diagnosed with epilepsy and have now been diagnosed with dissociative seizures.

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

Understanding that dissociative 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 your seizure control.

other types of non-epileptic seizures

There are other types of NES and these can be divided into two types: 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 such as diabetes.

Because organic NES have a physical cause, they may be relatively easy to diagnose and the underlying cause can be found.

For example, a faint may be diagnosed as being caused by a physical problem in the heart. In these cases, if the underlying cause can be treated, the seizures will stop.

NES that have a psychological cause

In addition to dissociative 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 of this 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.

Contact our helpline (see back page for details).

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.

See our leaflet *first aid*.

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.

Treatment for NES may work best when someone is active in life, including working, studying, or taking part in other activities which are meaningful and satisfying.

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.

See our leaflet *employment*.

Financial help

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

See our factsheet what help is available?

Driving regulations for dissociative seizures

Driving regulations for the UK are set by the Driver and Vehicle Licensing Agency (DVLA).

You will need to stop driving and tell the DVLA that you have dissociative seizures.

You may be able to apply for a new driving licence once you have been seizure free for three months.

If seizures are considered likely to happen while driving, a specialist review would also be needed.

These regulations are based on the risks of having a seizure while driving.

Nisit 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

Here, 'substantial' means it is difficult or time-consuming to do activities compared to someone without a disability, and 'long-term' means at least 12 months. 'Day-to-day activities' include being able to get around, hear, see, remember, and concentrate.

The Equality Act does not include a list of every disability covered. Although epilepsy is listed as a physical disability, dissociative seizures is not listed. To be covered by the Equality Act, you need to show that you meet the definition above.

Visit equalityadvisoryservice.com for more about the Equality Act.

further information

Epilepsy Society information

Diagnosis
Employment
First aid
Seizures
What help is available?
What is epilepsy?



other organisations

FND Action

fndaction.org.uk

Raises awareness of Functional neurological disorder (FND) and Non-epileptic attack disorder (NEAD) and provides support across the UK.

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

To find a counsellor or therapist in your area. Your GP or specialist may also refer you for counselling or psychotherapy.

British Association for Counselling and Psychotherapy

bacp.co.uk

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

Every effort is made to ensure that all information is correct at the time of printing. Please note that information is intended for a UK audience. This information is not a substitute for advice from your own doctors. Epilepsy Society is not responsible for any actions taken as a result of using this information.

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