

Dissociative seizures

This factsheet explains about dissociative seizures. They are completely different to epileptic seizures.

You may also come across other names being used to describe dissociative seizures, such as:

- Functional seizures
- Non-epileptic seizures (NES) this can be confusing as the term 'non-epileptic seizures' also includes those seizures which may be caused by another physical condition such as a heart issue.
- Non-epileptic Attack Disorder (NEAD)
- Psychogenic Non-epileptic seizures (PNES) or psychogenic seizures
- Pseudo seizures this term is not very helpful as it could imply that a
 person is faking their seizures, when, in fact, this is not the case. A
 person has no control over dissociative seizures.

What is a dissociative seizure?

A dissociative seizure is a Functional Neurological Disorder (FND). This name refers to problems with how the brain receives and sends information to the rest of the body.

It is completely different to epilepsy, which is a neurological condition.

Epileptic seizures are triggered by excessive electrical activity in the brain, but there is no excessive electrical activity with dissociative seizures.

Dissociative seizures can be caused by a psychological (mental health) issue, but other factors also play a part in why some people may develop dissociative seizures.

A dissociative seizure affects people in different ways. Some may experience heart palpitations (an increased awareness of your heartbeat), or hyperventilation (over-breathing). Others black out, or suddenly collapse and start jerking, which can look very similar to an epileptic seizure. Some people can be aware throughout their seizure but are unable to stop it.

We believe that around 1 in 5 people who are referred to hospital for a seizure may have dissociative seizures.

Diagnosing dissociative seizures

Dissociative seizures are usually diagnosed by a neurologist or other epilepsy specialist. They may request further tests and will also look at the person's medical history as well as any social and psychological factors.

If anyone has witnessed the seizure, they should write down a detailed description of what happened to the person before, during and after the suspected seizure. A video recording of the seizure(s) will also be helpful. All of this can help the neurologist potentially rule out epilepsy and confirm a diagnosis of dissociative seizures.

Possible tests for dissociative seizures

You may need some or all of the following tests:

- an EEG (electroencephalogram) this looks at the brain's electrical
 activity. If the person has a seizure and the EEG recording shows
 excessive electrical activity in the brain, this is usually a clear sign of
 an epileptic seizure. If there is no change in electrical activity during
 the seizure, then the seizure is likely to be dissociative.
- video telemetry the person may be asked to stay in hospital for a few days for this test. They will be wired up to an EEG machine recording possible seizure activity but will also be video recorded at the same time. Footage of a seizure can also help the neurologist determine whether the seizure is an epileptic seizure or a dissociative seizure.
- a brain scan (usually a MRI scan) to see if there is an obvious physical cause for the seizure. This could be a tumour or scarring on the brain.
 If the scan picks up a possible physical cause, the seizure is likely to be epileptic.

Misdiagnosing epilepsy and dissociative seizures

Because some dissociative seizures can look very similar to epileptic seizures, investigations can sometimes take a long time before a diagnosis of dissociative seizures is made.

Misdiagnosis is also common. Some people may have been living with an epilepsy diagnosis for many years, taking anti-seizure medication, only for their diagnosis to be changed to dissociative seizures. Or it could be the other way round, with people being told they have dissociative seizures when in fact they have epilepsy and should be taking anti-seizure medication.

Some people also have both dissociative and epileptic seizures at the same time, which makes treatment more complex.

What causes dissociative seizures?

Dissociative seizures seem to be more common in women and young adulthood, but it can affect all genders, all ages, all backgrounds. It is also more common in those who have other diagnosed mental health conditions such as PTSD (Post-traumatic Stress Disorder), anxiety or depression.

Dissociative seizures can be the physical reaction to a traumatic life event. This event can be in the past or present, and could be:

- an accident resulting in serious or life changing injuries
- the diagnosis of a serious, long term or life limiting health condition
- a bereavement

- the breakup of a relationship
- domestic or child abuse, both physical, emotional or sexual
- other past or current stressful situations

It is not always possible to identify the event, which may be causing the dissociative seizures. The person may not remember it. Suppressing painful and difficult memories can be a coping mechanism.

It is important to stress that some people will develop dissociative seizures without having experienced a traumatic event in their life, and may not currently feel stressed, anxious or depressed.

Treating dissociative seizures

The treatment offered is usually talking therapies like CBT (Cognitive Behavioural Therapy) or counselling. Dissociative seizures can often be reduced or successfully treated with appropriate professional support.

Some people may also be prescribed anti-depressants or anti-anxiety medication if appropriate. Anti-seizure medication is ineffective for dissociative seizures.

If the person previously had a diagnosis of epilepsy and was taking antiseizure medication, this will usually be slowly withdrawn under medical supervision.

People who experience both epileptic and dissociative seizures will often continue to take anti-seizure medication for their epileptic seizures, although in some cases this might be reduced.

Managing dissociative seizures

In addition to any talking therapies offered to you, if you have a clear seizure trigger such as stress or anxiety, you may also be able to reduce your dissociative seizures by managing your triggers.

Some people with dissociative seizures who get a seizure warning may also be able to stop a seizure in its tracks with breathing or grounding techniques.

Have a look at this helpful resource, which explains some of the techniques. It was published by Sheffield Teaching Hospitals NHS Foundation Trust https://publicdocuments.sth.nhs.uk/pil2072.pdf.

First aid for dissociative seizures

Generally, this is the same or very similar to first aid for epileptic seizures. If the person is convulsing (jerking), place something soft under the person's head, move any objects that may cause injury out of the way, and put them into the recovery position once the convulsions have stopped.

Do not restrain the person or restrict their movements, unless they are walking into danger, such as trying to cross a busy road while having the seizure.

Allow the seizure to run its natural course. Stay with the person until they are fully recovered, remain calm and ensure the person is safe.

Talk gently and explain to the person what has happened. This can help to reorientate the person once the seizure has finished.

Coming to terms with dissociative seizures

Many people seem to think that dissociative seizures have less of an impact than epileptic seizures. However, they can change almost every aspect of a person's life in a profound way and can be very challenging to live with. For example, a person may lose their job as a result of being diagnosed with dissociative seizures.

People often find it difficult to accept a diagnosis of dissociative seizures, especially if they were previously diagnosed with epilepsy. There seems to be a lack of understanding for this condition and a degree of prejudice and stigma.

Some of the names used, possibly by medical professionals, to describe these types of seizures, particularly 'pseudo seizures', can be confusing and understandably hurtful. It can feel like someone is implying that the person is faking or lying about their seizures or is seeking attention. However, this is simply an outdated term which is still occasionally being used.

For most people experiencing dissociative seizures, there is nothing they can do to prevent or control these seizures, they are very real and will happen anyway. In fact, dissociative seizures can be as disruptive of people's lives as uncontrolled epileptic seizures.

Find yourself a good support network and have a look at our last section in this factsheet for more information, support and resources.

Driving regulations for dissociative seizures

As soon as you have had a seizure (at this point you may not know if this is an epileptic or dissociative seizure) you will need to stop driving immediately and contact the DVLA.

The driving regulations for dissociative seizures are slightly more relaxed than for epileptic seizures. You usually need to be free of any dissociative seizures for three months before the DVLA may consider reissuing your driving licence. In some cases, they may also require confirmation from a specialist to say you are safe to drive again.

Finding further information and support

Dissociative seizures can be an isolating condition. Not many people understand this condition, and most resources and support tend to be focused on people with epilepsy.

We have pulled together some resources and sources of help and support you may find helpful:

- Epilepsy Scotland Helpline 0808 800 2200 if you do not know where
 to start, or just want to have a chat about how this is all affecting you,
 you are more than welcome to contact us. We can also signpost you
 to more appropriate sources of support and help.
- <u>FND Action</u> have a helpful section about dissociative seizures on their website.

FND Action also host a number of private online FB support groups for individuals and carers affected by FND. Look up their <u>Support</u> section for more information.

- <u>FND Hope UK</u>- a patient-led charity supporting those with Functional Neurological disorders
- Dis-sociated a YouTube channel providing video resources for people with dissociative seizures

Our resources are always free. If you would like to support our work, please text FACTS to 70085 to donate £3. Texts cost £3 plus one standard rate message.



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