

# Dissociative Seizures

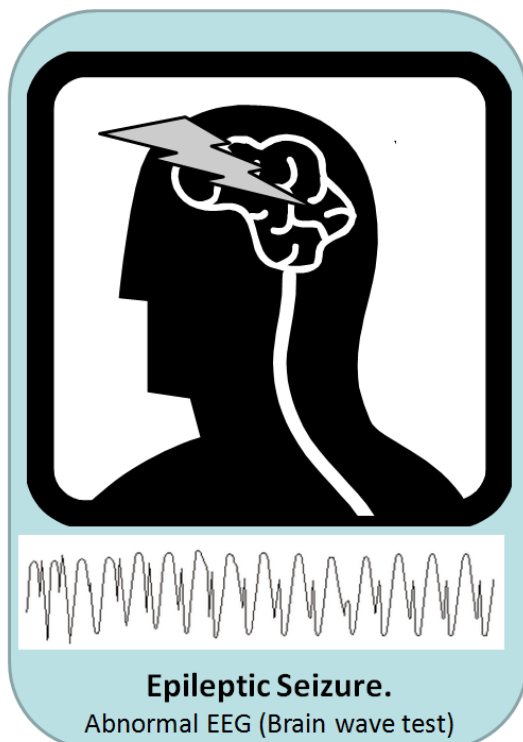
This information sheet is written for people with dissociative seizures. It could also be helpful to family members, friends and carers of people with dissociative seizures. It's designed to give information about what dissociative seizures are, what causes them, how they're diagnosed and how they can be treated.

## What are Dissociative Seizures?

There are many different names for dissociative seizures. Other names you may hear are non-epileptic seizures, non-epileptic attacks or events, non-epileptic attack disorder (NEAD), psychogenic seizures, functional seizures, pseudoseizures or pseudoepileptic seizures. Some of these names sound like the seizures are 'put on' or 'imagined' which they certainly are not.

*Seizure* is a word describing any sudden, temporary loss of control over nervous system functioning. You may hear other words used, such as 'attacks', 'fits', 'turns', 'blackouts'.

*Whereas epileptic seizures* are caused by a sudden, abnormal electrical discharge in the brain, *dissociative seizures* happen through a process in the brain known as *dissociation*.



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What happens during a dissociative seizure varies greatly from one person to another. Some people lose awareness during the attack; others remain aware but may be unable to respond normally to those around them. Some people fall to the ground and their arms or legs may shake, which is why the attacks can look so similar to an epileptic seizure. Some people with dissociative seizures just stare or lie still. Their breathing may change, and they might lose bladder control, bite their tongue or hurt themselves. The seizures may go on for some time and can be quite frightening to watch.

It's not difficult to see why many people with dissociative seizures are diagnosed with epilepsy; the attacks do often look just like an epileptic seizure.

*Dissociative seizures may cause shaking or jerking movements that looks very similar to an epileptic seizure....*

*..... or may just result in a sudden collapse to the ground in which the person is motionless but unresponsive*

## What is dissociation?

*Dissociation* is a medical word that describes a feeling of being cut off or disconnected from your surroundings or from your own body. Dissociation can be quite mild e.g. when someone is in a daydream or a bit "spaced out", or it can be more severe e.g. being able to hear but not respond to those around you. It's an altered state of awareness which some people describe as being in a 'trance-like' state or 'zoned out'. Other people describe less severe forms of dissociation as being 'spaced out', 'in a place of my own', 'there but not there'. During a dissociative state people report a loss of control such as being able to hear but not being able to speak. Dissociation can be a weird feeling that's hard to describe but is actually common. It is nothing to do with 'going crazy'.

Dissociation is a 'switching off' process in the brain that happens unconsciously, without you thinking about it or even being aware of it. It happens to all of us e.g. when you're concentrating on getting something done and you don't hear someone speak to you. If our minds weren't able to do this, we would never be able to get on with anything because we would be constantly bombarded by too many other sights, sounds and sensations.

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*Dissociation describes a strange, trance like feeling in which you may feel 'cut off' or 'there but not there'. If it's very strong you may have a slight out of body experience*

Dissociation is common in people who are very tired. It can also be protective, so if something very frightening or upsetting happens the brain switches off so that we can experience it more calmly e.g. if someone is in a car accident, they often say they felt detached from what happened.

Mild dissociation can be normal and sometimes even useful (for instance when it happens to help you put up with an unpleasant situation – like lying on a dentist's chair). But in dissociative seizures this switching off happens over and over again in a way that is a problem and can be very disabling. During a dissociative seizure the brain switches off and the person loses control of the body.

## **How are dissociative seizures diagnosed?**

A specialist can usually diagnose what the problem is when you describe your seizures. It's also very helpful for the doctor to hear a description from someone who has seen your seizures. This helps experts make a correct diagnosis in at least 8 out of 10 cases.

Specialists can diagnose attacks more accurately (in 9 out of 10 cases) if they can see a video of them (such as a video recorded on a mobile phone). They can also often be quite certain about the diagnosis if they've seen and examined you during one of your attacks.

Sometimes, if doctors are unsure, they can use an EEG (Electroencephalogram) to look at electrical activity in the brain. It shows an abnormal pattern of electrical activity during epileptic seizures, but these patterns are not seen in dissociative seizures. The EEG is most useful when it is combined with a video recording of one of your seizures.

Brain scans, such MRI or CT scans, are NOT helpful in diagnosing dissociative seizures.



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## How common are dissociative seizures?

Dissociative seizures are not that rare, even though most people have never heard of them. About one in eight people newly referred to specialist epilepsy clinics turn out to have dissociative seizures. In the general populations around 2 or 3 people in every 10,000 have dissociative seizures. This means that in a typical town with about 300,000 (such as Cardiff, Brighton, Doncaster, or the London Borough of Lambeth) there will be about 60 to 90 people who have them.

Of all the people who come into hospital with attacks that don't settle quickly, nearly half turn out to have dissociative seizures.

## What causes dissociative seizures?

Dissociative seizures are caused by the sudden, often random, experience of 'dissociation'. This has many different causes depending on the person experiencing them. Trying to explain why they happen is similar to trying to explain why panic attacks happen. Dissociative seizures are not the same as panic attacks but they share some common features.

Some people with dissociative seizures describe having attacks that are clearly brought on by stress. Having a seizure after an upsetting argument or when you're in a busy, noisy place such as a supermarket are examples.



*"It's common for people to have seizures that seem to "come out of the blue" when they're relaxed and not aware of any stress"*

It's more common for people to have seizures that seem to "come out of the blue" when they're relaxed and not aware of any stress. This is probably because it's easier to 'dissociate' or go into a trance like state when you're relaxed or not focusing on anything.

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Research gives some clues as to what might be going on. Studies have shown that in the warning phase of dissociative seizures people can have physical symptoms that show their bodies are in a state of red alert. These symptoms include a racing pulse, rapid and shallow breathing, sweating and a dry mouth. Symptoms like these often go with strong emotions like anger or panic, but people are often not aware of these feelings during their attacks. In fact, if people are conscious during the seizures, they often describe feeling detached, being “there but not there” or feeling “numb”. In some people it appears that the brain is ‘switching off’ (dissociating) because it gets rid of the horrible feelings that people get as part of the seizure.

Some people are actually aware of this build-up of symptoms before a seizure. Sometimes family members can tell when attacks are going to happen even though the person themselves can’t remember them. However, there may not be any warning signs at all, especially if the attacks have been going on for some time.

How people feel after a seizure can also give us clues about why they happen. Immediately after a seizure people often feel upset, frustrated, embarrassed, exhausted and have a headache, muscle pain and weakness. Sometimes, after recovering from these *physical* symptoms following a seizure, people may feel a sense of *emotional release or relief*, For example feeling “lighter”, as if a “pressure” or “tension” has been released, or as if they have been “re-booted”. These feelings are partly related to relief that the seizure has stopped but they also suggest that switching off (dissociation) is one way the brain has of dealing with unpleasant sensations or feelings. Some people describe the build up to their seizures as like a “pressure cooker” and the seizures themselves as “like a pressure-release valve”. However, it’s important to emphasise again that this doesn’t apply to everyone with dissociative seizures.

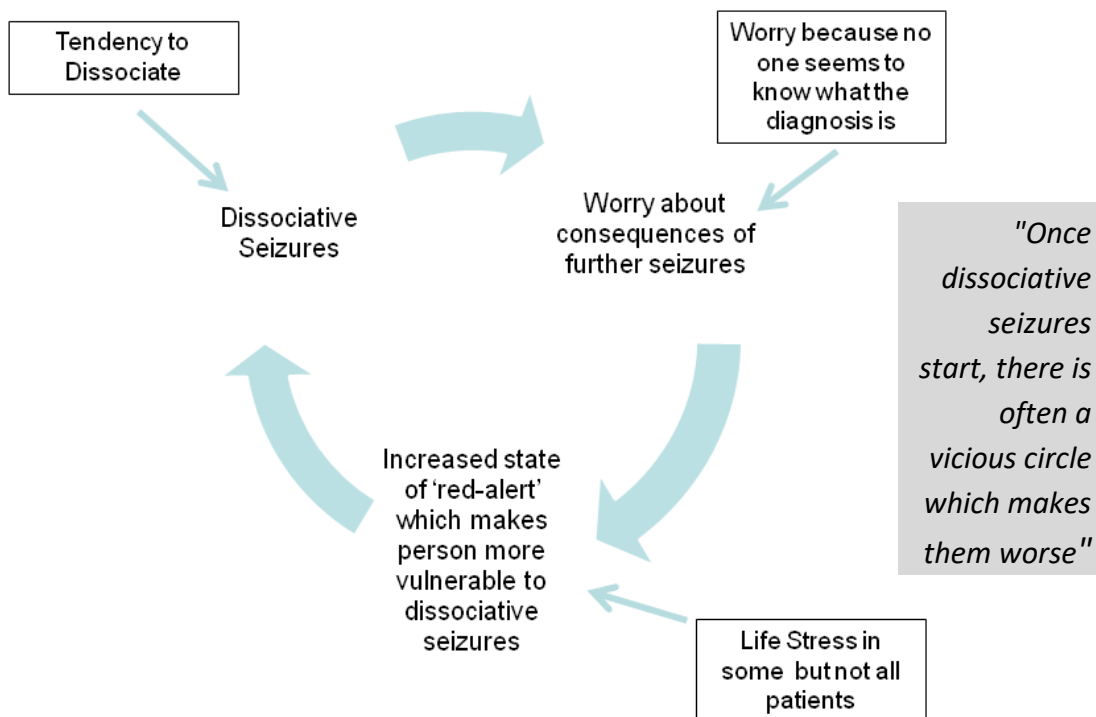
## What things happen over time to make seizures worse?

It may never be possible to say why someone has dissociative seizures, but once seizures start, many things can happen to make them worse. For most people, simply worrying about the seizures can actually make them a lot worse. A kind of “vicious circle” sets in where worry about the seizures means they happen more often, leading to more worry and more seizures.

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Examples of things that make people worry about their seizures (and which can, in turn, make them worse) include:

- fear of being injured during a seizure
- fear of being embarrassed by having a seizure in public
- fear of losing control
- being told different things by different doctors
- feeling that none of the doctors know what's wrong with you
- fearing that you have a serious underlying illness that hasn't been picked up
- taking medication that doesn't help
- having unpleasant side-effects from medication
- fear of not being believed.



It's common for people to become more and more restricted by their seizures over time. First of all they might have to take time off work or do less around the house. They might stop seeing friends, avoid going to shops at busy times or stop using public transport for fear of having a seizure. For some people the seizures eventually become so disabling that they dare not leave their home at all. We know that the more life becomes restricted in this way, the more distressed the person and their family become.

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Over time, the things that bring seizures on may change. Eventually the seizures can become a sort of “reflex” or “habit” – they seem to happen automatically in situations that have little to do with why the seizures started in the first place. Like any other reflex or habit, they can be very difficult to stop without help - but understanding how seizures happen and what makes them worse can be enough to start your recovery.

## Why did my seizures first start happening?

Most people with dissociative seizures can't pinpoint a single event that explains why the seizures started and may never work out why their seizures began when they did. For others the initial seizure trigger may be a panic attack or a faint.

When people do see a link between their first seizures and things that were happening in their lives at the time, it's almost never just one single distressing event or situation that's to blame. Much more commonly it's a combination of stresses, disappointments or losses that occurred around the same time in several different areas of life. For example, there may have been a family bereavement, problems with a difficult boss at work, and difficulties in relationships at home. While a person might be able to cope with some of these problems on their own, when they all happen together they can be overwhelming.

We think that the way people deal with their feelings and emotions, including how they usually manage stress and worry, can make them prone to this kind of illness. Many people who experience dissociative seizures say they tend to “bottle up” their feelings and avoid confrontation in their daily lives.

Some people with dissociative seizures will have had some sort of traumatic experience in the past. We know that people who have had distressing experiences can begin to switch off automatically (dissociate) as a way of coping.

While dissociation can be helpful for dealing with overwhelming experiences at the time, it may make the person vulnerable to dissociative seizures in later life. This means that stressful times in the past can be important, at least in some people, for understanding dissociative seizures. Most people with dissociative seizures find it difficult to understand why their seizures happened in the first place and what brings them on. Even when they've had distressing experiences in the past, it can be difficult to see how they could be related.



## What about other symptoms?

Many people are vulnerable to other symptoms which are also genuine but can't be seen on x-rays or blood tests. About 8 out of 10 patients will have some other health problem such as irritable bowel syndrome (IBS), headaches, pain, tiredness, or limb weakness. You can read more about this at [www.neurosymptoms.org](http://www.neurosymptoms.org).

Anxiety and depression in the past are also more common in patients with dissociative seizures although this doesn't apply to everyone.

## What treatments are there for dissociative seizures?

We know that understanding and accepting the diagnosis of dissociative seizures helps many people recover from the condition. Coming off unnecessary and potentially harmful anti-epileptic drugs can also help.

A neurologist is well placed to give the diagnosis and initial information. But a neurologist may not be the best person to help you learn more about your attacks and how you might start to overcome them. This process can take time and may need to take into account other things going on in your life.

For this reason, most people with dissociative seizures are referred on to a psychiatrist or psychologist for further treatment.

Many people referred to a psychiatrist wonder if this means the doctor thinks they are "making it all up" or have "gone crazy" after all! This is not the case. Here are some reasons why psychiatrists can be helpful for people with dissociative seizures:

- psychiatrists working with neurologists are experienced in assessing and treating dissociative seizures and have successfully helped many other patients overcome their seizures
- a psychiatrist can spend longer with you explaining and helping you understand the diagnosis.
- psychological factors are often important in understanding dissociative seizures. - a psychiatrist can look sensitively into this side of things
- psychiatrists can help look at things that might be making the attacks worse, for example worry about leaving the house in case the person has an attack.

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Not uncommonly, neither the psychiatrist nor the patient can find any relevant psychological factors, but, the psychiatrist can still help by talking about the attacks themselves and simple techniques to try when they come on.

Some health professionals think that specific “talking treatments” may help but we still need to do research to find out whether these treatments really do work.

## What should I do about my anti-epileptic drugs?

Some people with dissociative seizures (about 10-15%) also have a history of epilepsy and if you're one of them you may need to carry on taking these drugs. Your doctor will tell you if this applies to you. But most people who have dissociative seizures have never had epilepsy and don't need to take anti-epileptic medication. If you come off anti-epileptic medication you should find that your condition improves and you feel more alert. You need to come off it gradually, though, as suddenly stopping your drugs could trigger withdrawal symptoms. We understand that coming off these drugs can be a worrying time for you because you may have thought the drugs were helping. Your doctor will advise you about this and how to gradually come off the drugs.



*"People with dissociative seizures may worry about being injured in a seizure or the embarrassment of having a seizure in public"*

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## Is there anything else I can do about the seizures?

If you do get warning symptoms then you might try using some simple distraction techniques, like talking to someone or playing with your phone, to see if you can make the warning symptoms before the blackout last longer.

If you keep practising, you may find that sometimes you don't have an attack at all. Being able to make the warning last longer often helps patients feel as confident as the doctor about the diagnosis because it's very hard to do that with an epileptic seizure.

This is something a psychiatrist or psychologist can talk to you more about.

## Talking about dissociative seizures

Most people (including some doctors and nurses) haven't heard of dissociative seizures, and it can be difficult to explain what they are. Having a good understanding of the diagnosis can make it easier to explain to others.

Here are some things you could say:

*"I have dissociative seizures. They're attacks that I cannot control. They're like epileptic seizures but they're not caused by the same things that cause epilepsy."*

*"I have attacks which are similar to panic attacks, except that I can pass out with them."*

Encourage close family and friends to read through this information as well so that they know about your attacks and can support you.

## What should people do when I have a dissociative seizure?

Seeing someone have a dissociative seizure can be quite frightening. It helps if people know that the seizures are not life threatening and that you don't need emergency medical attention. In fact, treatments that are given for epileptic seizures in an emergency can make dissociative seizures worse and can be dangerous.

You don't need to have someone around all the time in case you have a seizure. People may bump and bruise themselves during a seizure but there are no recorded

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cases of anyone coming to severe harm. It's not possible, for example, to stop breathing during a dissociative seizure.

It is important to tell people who are likely to be around what to do if you have a seizure.

Anyone present should try to:

- take simple steps to prevent you from injuring yourself (e.g. look for any hazards in the immediate environment).
- take simple steps to save you from embarrassment if the seizure happens in a public place, (e.g. if you have a warning and there's enough time, move you to a quiet more private place: adjust your clothing if necessary).

It's best if they don't talk to you during a seizure. This is because if the person you are with is feeling frightened by what is happening you may pick up on this and this can make your seizure worse. Although you may not remember being in the seizure it's likely that some part of your brain can take in what's going on.

Other people should not try to restrain you during an attack as this could make it worse.

## Can I drive if I have Dissociative Seizures?

In the UK the Driving and Vehicle Licensing Authority (DVLA) is responsible for the rules around driving and medical conditions. These rules often change. As of 2020 there are regulations about dissociative seizures and the DVLA expect you to inform them if you have this diagnosis. We suggest you look at the DVLA website - <https://www.gov.uk/health-conditions-and-driving> and discuss this with your doctor.

## Disability Benefits

Whatever the cause, you may be able to claim benefits depending on the effect the attacks have on your life.

If you've had state benefits or been unable to work because you thought you had epilepsy, this shouldn't change just because the diagnosis has changed to dissociative seizures. These are real attacks which can be disabling.

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There's a good chance that your seizures will improve and you may be able to work again in the future. If this happens, then getting off benefits and starting work again can be stressful in itself. People have often not worked for some time. It can be useful to discuss this with any doctors involved. Health professionals may need to speak to your employers so they don't over-react to your attacks

The Job Centre Plus provides advice about returning to work after claiming benefits. You can also talk to the Citizens Advice Bureau or the Department for Work and Pensions if you have any questions about benefits.

## Is there more information out there?

You may want to find out more about dissociative seizures. Some useful websites are:



**Non-epileptic (dissociative) attacks: A guide for patients and families** [www.nonepilepticattacks.info](http://www.nonepilepticattacks.info)

This website is specifically for dissociative seizures and was written by a neurologist



**Functional and Dissociative Neurological Symptoms: A patient's guide** [www.neurosymptoms.org](http://www.neurosymptoms.org)

This website, also written by a neurologist, has information about dissociative seizures and many other physical symptoms that patients with dissociative seizures may be vulnerable to

Think carefully about what you've learned about dissociative seizures and how it applies to you. Understanding and accepting what dissociative seizures are is a really important first step of treatment.

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## Who wrote this leaflet?

This information leaflet has been produced by a group of clinicians and researchers who work with people with dissociative seizures.

This information was designed to make sure that all patients have a good level of information before having any further assessment or treatment. If you wish to read this leaflet online or to find out more about the people who have written it please go to [www.codestrial.org/](http://www.codestrial.org/). The authors included the following:

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Cognitive Behavioural Therapy for Dissociative (Non-Epileptic) Seizures

## The CODES trial

This information leaflet was produced by the research team involved in the CODES trial. This was a multicentre UK trial funded by the National Institute for Health Research.

The trial tested whether having cognitive behavioural therapy leads to better outcomes for patients if it is added to standardised specialised psychiatry treatment. The trial has now finished. You can read more including links to research papers and watch a video describing the trial results at [www.codestrial.org](http://www.codestrial.org)

This factsheet is an updated version of the one used by psychiatrists in the trial, edited in October 2020. It has not been changed at all, except for a revision to the driving section, to reflect the fact that DVLA advice often changes and to consult your doctor, and to reflect the fact that the trial has now finished.

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