Dissociative seizures

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Is this page for me?

You may find this information useful if you:

- Have just been diagnosed with dissociative seizures
- Have been told for years you have epilepsy and you’re now being told the diagnosis was wrong. And that you have dissociative seizures instead
- Have been told that you have both epilepsy and dissociative seizures
- Are waiting for a diagnosis and wondering whether you may have dissociative seizures
- Are wanting to understand and support someone who has been diagnosed with dissociative seizures

Other names for dissociative seizures

Many different names are used for dissociative seizures. We have chosen the name used in the International Classification of Diseases.\(^1\) Other commonly used names are non-epileptic attack disorder or non-epileptic seizures. However some people are unhappy to have a diagnosis that is 'not' something. Other names that are used for the same condition are:

- Psychogenic non-epileptic seizures
- Psychogenic seizures
- Functional seizures

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In the past dissociative seizures were also often called “pseudoseizures”. This term is now discouraged because it wrongly implies that these seizures are consciously produced to look like epileptic seizures.

Whichever name you have come across, this information is for you.

**Getting a diagnosis for dissociative seizures**

Dissociative seizures are often mistaken for epilepsy. They can be difficult to diagnose. In fact, it can take several years after someone starts having seizures for them to get an accurate diagnosis of dissociative seizures. Even experienced doctors can find diagnosing dissociative seizures a challenge.  

It’s very important to get the right diagnosis. This is because if you’re wrongly diagnosed with epilepsy instead of dissociative seizures, the doctor will probably prescribe you epilepsy medicines. These can have side-effects and will not control your dissociative seizures. Being on these medicines also means that the true cause of your seizures may never be investigated or treated.

If you have been prescribed epilepsy medicine and you don’t have good seizure control you could ask to be referred to a specialist epilepsy centre for assessment. You would need to ask either your neurologist or your family doctor. You could have a type of epilepsy that doesn’t respond well to epilepsy medicines. This is sometimes called intractable or refractory epilepsy. Or you could have dissociative seizures and that’s the reason why you aren’t responding to epilepsy medicines.

Some people have both epilepsy and dissociative seizures. Mostly dissociative seizures start a while after the epileptic ones (and possibly once the epileptic ones have stopped). Occasionally people can have both types of seizures at the same time. If you think you may have both types of seizures you could talk to your consultant.

**How can you tell the difference between epilepsy and dissociative seizures?**

It can sometimes be difficult to tell the difference between an epileptic seizure and a dissociative seizure. If you are not an expert in this field you may not be able to tell by looking whether someone is having an epileptic or a dissociative seizure.  

One of the ways in which a professional will tell the difference between dissociative seizures and epilepsy, is from an electroencephalogram (EEG). This picks up and records the electrical activity in the brain. If someone is having an epileptic seizure, an EEG will usually

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show abnormal electrical activity. If someone is having a dissociative seizure, an EEG will not show abnormal electrical activity.

The doctor may also suggest using video-telemetry. This involves you wearing EEG equipment for a few days, and being observed by a video camera linked to the EEG machine. This makes it possible for any seizures you have to be recorded on video and EEG at the same time.\textsuperscript{6}

Epilepsy Action has more information about video-telemetry

**What makes dissociative seizures happen?**

Dissociative seizures happen for psychological reasons rather than physical ones. Often dissociative seizures are how the brain reacts to thoughts or feelings related to present and past experiences. This is different from epilepsy. Epileptic seizures happen because of abnormal electrical activity in the brain.\textsuperscript{7}

**I have just been told I have dissociative seizures. What do I do now?**

It can be really tough to be told you have dissociative seizures. This is especially true if you’ve spent years thinking you have epilepsy, and you’ve been trying to adapt to that. It’s quite usual for it to take time to understand the new diagnosis. Also, if the diagnosis of dissociative seizures is not explained well, it can sound like the doctor is saying you don’t have a real health condition, or that you are ‘putting it on.’ This is not true. Dissociative seizures are a real medical condition. And the dissociative seizures you experience can be just as disruptive and unsettling as epileptic seizures. You’ll need the support of friends, family and medical people during this time of adjustment. If you have been diagnosed with dissociative seizures you could ask the consultant for a referral to a talking therapy. In some parts of the country this could be a psychologist.\textsuperscript{8}

**What is the treatment for dissociative seizures?**

If you have dissociative seizures, epilepsy medicine won’t work for you. But don’t stop taking the medicine suddenly because this may be dangerous for you. Your doctor will tell you the right speed to do this at.

Often just getting a correct diagnosis and understanding a bit more about your seizures can mean that they start to happen less often.\textsuperscript{9}

It is important to remember:

\textsuperscript{8} Mayor, R.; Smith, P.; Reuber, M. Management of patients with Nonepileptic Attack Disorder in the United Kingdom: a survey of healthcare professionals. Epilepsy and Behavior. 2011;21,402-06
“You didn’t bring the attacks on, but you can help yourself to get better.”

If seizures don’t stop once you have your diagnosis, a number of more specialist treatments may be offered to you:

- Cognitive behaviour therapy (CBT)
- Counselling
- Psychotherapy
- Anti-depressants

The aim of CBT is to help you explore and change how you think about your life, and free yourself from unhelpful patterns of behaviour. You set goals with your therapist and may carry out tasks between sessions. A course usually involves around 12 to 20 sessions.

The NHS website has information on [counselling, CBT and psychotherapy](https://www.nhs.uk/conditions/stress-anxiety-depression/types-of-therapy/ (accessed 12.11.18)).

You may feel you’ve been dismissed with no offer of treatment. But something you could do without the help of a doctor is look at the NHS website. It describes the various types of therapies you may want to think about. And the [IAPT service](http://www.medscape.com/viewarticle/827808 [Accessed June 25, 2015]) (Improving Access to Psychological Therapies) links you to the resources in your area. There are likely to be waiting lists for any of these services, so the sooner you make contact with them the better.

Whichever therapy you choose it will ideally be with someone who also understands about dissociative seizures. Your neurologist or epilepsy nurse may be able to recommend someone. If this all feels a bit overwhelming your GP may be able to help.

Some common causes of dissociative seizures are stress, anxiety and post-traumatic stress disorder (PTSD). Anything that helps with an understanding of how these affect the body may help with managing your seizures. There are many ways to help manage your stress and anxiety levels. These include activities such as mindfulness and yoga.


Dealing with stress levels and trying to get the right amount of sleep are 2 particularly important things to consider when managing your seizures.

For more tips on how to manage your dissociative seizures see links to the websites at the bottom of the page.

Evelina Children’s Hospital has made a film about dissociative seizures (they call it NEAD in the film). The film talks about the service at Evelina. Services at other hospitals may be different.

### What first aid do I need?

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10 “Information for patients: non-epileptic seizures” Royal Hallamshire Hospital Jan 2011 p 11


This is what someone needs to do if they see you having a seizure.

Do

- Cushion your head
- Move any harmful objects away from you
- Be calm and reassuring
- Call an ambulance if they don’t know if you have epilepsy or dissociative seizures
  (This may not be necessary if they have experience of looking after you during your seizures)

Don’t

- Call an ambulance unless you are injured or they don’t know about your condition
- Restrain you in any way
- Try to give you any medicine

Dissociative seizures are not dangerous and do not cause damage to the brain. The only reason someone would need to call an ambulance is if you injured yourself. Dissociative seizures often go on longer than epileptic seizures.

Where can I get more information and support?

Website: nonepilepticattackdisorder.org.uk
This website has been set up by people with non-epileptic attack disorder (NEAD) to provide information and support for those with NEAD/dissociative seizures and their family and friends. The medical information has been checked and approved by a medical advisor, Professor Markus Reuber, who specialises in non-epileptic attack disorder/dissociative seizures. It has a wide range of very useful information.

nonepilepticattacks.info
As well as a wide range of information, the website includes a leaflet which you can download. You are also invited to send in your account of life with NEAD.

Website: neurosymptoms.org

Website: codestrial.org/dissociative-seizures

Website: fndaction.org.uk. The aim of this website is to raise awareness of functional neurological disorder (FND) and dissociative seizures

Website: neurokid.co.uk. This is a website for children and young people with dissociative seizures

There are a number of groups for people with dissociative seizures on Facebook.

In Our Words: Personal Accounts of Living with Non-epileptic seizures.
This book has over 100 contributions from people with personal experience with dissociative seizures. Reading this may make you feel less alone with your problem and give you some ideas about what you could do about it.

About this information
This information is written by Epilepsy Action’s advice and information team, with guidance and input from people living with epilepsy and medical experts. If you would like to know where our information is from, or there is anything you would like to say about the information, please contact us at epilepsy.org.uk/feedback

Epilepsy Action makes every effort to ensure the accuracy of information but cannot be held liable for any actions taken based on this information.

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Markus Reuber has declared a conflict of interest. He is one of the editors of the book In Our Words: Personal Accounts of Living with Non-epileptic seizures mentioned above. Epilepsy Action does not believe this interest has influenced the content of this information, or Professor Reuber’s impartiality as an adviser.

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Your support
We hope you have found this information helpful. As a charity, we rely on donations to provide our advice and information. If you would like to make a donation, here are some ways you can do this.

- Visit www.epilepsy.org.uk/donate
- Text ACT NOW to 70700 (This will cost you £5 plus your usual cost of sending a text. Epilepsy Action will receive £5.)
- Send a cheque payable to Epilepsy Action to the address below.

Did you know you can also become a member of Epilepsy Action from as little as £1 a month? To find out more, visit epilepsy.org.uk/join or call 0113 210 8800.

Epilepsy Action Helpline
Freephone 0808 800 5050, text 0753 741 0044, email helpline@epilepsy.org.uk, tweet @epilepsyadvice

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