

What are the links?



Potential links between epilepsy and mood may be to do with:

- how epilepsy affects your life; and
- how epilepsy affects your brain.

If any of these links are true for you, focusing on one or two issues may be easier than trying to deal with several at once.

Life, mood and epilepsy

- Fear of seizures is understandable. Seizures can be frightening, unpredictable, and risky. Learning about what happens during your seizures, or talking about your fear, may help to reduce any anxiety.
- **Safety** is important, but so is being able to live as fully as possible. Learning about your epilepsy may help you get a balance between keeping safe and being independent.
- Employment or education may be disrupted by epilepsy. We can provide epilepsy awareness training for colleges, universities, and employers.
 Visit epilepsysociety.org.uk/epilepsy-training
- Losing your driving licence can be hard practically and psychologically. However, some people find that travel alternatives lead to getting fitter or meeting new people.

Other people

Family and friends may not know how you feel or what you need from them.

If you can tell them clearly how you feel, they may be able to support you better. Or it may help to talk to other people who have epilepsy.

Details of epilepsy support groups are available from our helpline (see below). People around you may also need support. Our confidential helpline provides information and emotional support and is open to anyone who is affected by epilepsy.

The brain, genes and epilepsy

- **Before a seizure** you may feel irritable, anxious, depressed, or aggressive. This may last for a few hours or days, and your mood may get better after the seizure happens.
- **During a seizure.** Some people with focal seizures may feel fear or joy as part of their seizures.
- After a seizure you may feel anxious or depressed for days or weeks if the parts of the brain that affect mood are recovering from the seizure. Confusion or memory loss after a seizure can also be worrying or depressing.
- **Medication** can have both positive and negative effects on mood (see page 2). Finding the right dose for you may help avoid side effects.
- Family history. Being anxious or depressed may be part of your genetic makeup (the characteristics that are passed on from your parents). Or being anxious can sometimes be learned, as part of how you are brought up.
- Structural changes or damage to some parts of the brain may, for some people, cause both epilepsy and mood changes.

Mood problems as a side effect of medication

Possible side effects of anti-seizure medication (ASM) include mood changes, irritability, agitation, or depression. However, ASM can also improve mood for some people.

The patient information leaflet (PIL) that comes with your medication lists possible side effects. If a side effect is listed as common, this means that, at the most, 1 in 10 people will get it and 9 in 10 people will not.

Some people may find that epilepsy affects their mood. For some people, there is no link between their epilepsy and mood problems, they just happen to have both. Helpline 01494 601400 Confidential, national call rate. Information and emotional support. Visit epilepsysociety.org.uk/helpline for opening hours. The list of side effects from ASM may make you expect to have side effects, increasing your anxiety or low mood. However, the risk of you having a side effect may be lower than you think.

Visit epilepsysociety.org.uk/side-effects -and-interactions

Keeping a diary of any mood changes, along with a record of any medication, may help to identify any links. This may help discussions with your doctor or nurse, especially when you are new to taking medication.

Our seizure diary has a section for comments about your medication and any side effects.

Free seizure diaries are available from our helpline or visit epilepsysociety.org.uk/seizure-diaries

When you may need to ask for help

Some feelings should not be ignored, especially if you are having thoughts about taking your own life, or death generally. Telling anyone how you feel is the first step to feeling less alone. Your GP and your local A&E department offer support whenever you need it. Telling your epilepsy team how you feel means they can also help. Or you can call our confidential helpline. **Visit epilepsysociety.org.uk/your-appointment-or-review Or visit samaritans.org/how-we-can-help/if-youre -having-difficult-time**

Breaking the links - when mood affects epilepsy

• Anxiety and low mood may affect your epilepsy and how it is managed. You may be able to help break some of these links. Focusing on something that you enjoy or breaking large tasks into smaller ones may help.

Visit epilepsysociety.org.uk/anxiety

 Stress may lead to feeling that you can't cope, anxiety, depression, or a higher risk of seizures.
Exercise and keeping active may help to lower stress.
Activities and therapies that relax you may help to reduce the risk of seizures.

Visit epilepsysociety.org.uk/stress

Low self-esteem can make it hard to socialise, and lower self-confidence may make it hard to talk to doctors about managing epilepsy, leading to a higher risk of seizures. Joining a group where you have a shared interest may help lift your mood and boost your confidence and self-esteem. Helping a friend, a community activity, or voluntary work can be valuable for you and for other people.

Visit epilepsysociety.org.uk/mental-health-epilepsy

• Lack of sleep may lead to tiredness and low mood. It may make it difficult to concentrate. You may miss medication, with an increased risk of seizures. Keeping active and going to bed and getting up at the same time each day may help improve sleep. If poor sleep is a problem for you, your GP may be able to recommend further help.

Visit epilepsysociety.org.uk/sleep-epilepsy

• **Concentration or memory problems** may make it hard to take in information. You may miss medication with the higher risk of seizures. Lists, alarms, sticky notes, drug wallets, or memory apps can help you remember and focus on one thing at a time.

Visit epilepsysociety.org.uk/memory-and-epilepsy

Talk to someone

It can be hard to imagine yourself asking for help but there are many sources of support and care you can turn to. Looking after your mental health is positive and getting treatment can make a big difference. **Visit epilepsysociety.org.uk/helpline**

Epilepsy Society is grateful to Dr Dorothea Bindman, Consultant Psychiatrist, Consultant in Neuropsychiatry, National Hospital for Neurology & Neurosurgery, University College London Hospitals NHS Trust, who reviewed this information.

For a printed copy of this information contact our helpline.

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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.