

Relationships and epilepsy



Seizures are a physical symptom, but having epilepsy can mean far more than the physical impact of seizures, for the person with epilepsy, and their partner.

The wider impact of seizures

Many people manage seizures well, but seizures can be unpredictable, frightening, or upsetting, both for the person having seizures and for those who see them. It may be hard to deal with the memory of a seizure, what the person with epilepsy looked like, how you both felt, or with the fear that it might happen again.

It may be hard to face this or talk about it, as you may worry that how you feel might upset your partner. Talking it through with someone you trust may help.

Supporting each other

Everyone is different, and there may be many ways to help deal with issues around epilepsy. Many people with epilepsy do not need a carer, but some may need care and support sometimes, particularly when they have a seizure. Supporting someone with epilepsy may include giving them lifts, prompting them to take medication, or sharing activities to help them keep safe.

Supporting someone in this way can bring you closer together, but some people with epilepsy may feel this affects their independence. It may help to think that everyone needs support with something, whether they have a long term condition or not. It can also be important to make time to focus on your relationship separately from giving and receiving support.

Visit epilepsysociety.org.uk/information-carers and epilepsysociety.org.uk/finding-support

Many people with epilepsy have fulfilling relationships with a partner. Other people may find that their epilepsy can affect physical and emotional issues around relationships or sex.

New relationships and experiences

A new relationship can be both exciting and daunting for anyone. If you have epilepsy, you may wonder how to tell a new partner about your epilepsy and how they might react. The way other people have reacted in the past might also affect how you tell new people. Seizures can disrupt plans and activities and, for some people, having epilepsy affects their confidence.

However, some people find new relationships or interests through changes they make to their lifestyle because of epilepsy. New experiences could also strengthen an existing relationship through gaining confidence, sharing new things, and discovering what is important to you and to your partner.

Talking about epilepsy

Some people find that talking about epilepsy brings them closer to their partners. But sometimes one person in a relationship wants to talk about epilepsy and the other does not. For some people, epilepsy may feel like an unwanted intruder that has changed how things used to be. Talking about epilepsy may be upsetting, or you may feel that you can no longer talk about epilepsy because your partner has 'heard it all before'.

Being honest about your feelings may take courage, but your partner may be relieved to be able to share how they feel too. Some people use humour to help to deal with, or avoid, difficult feelings. Others may want to keep a balance between talking about epilepsy and other important things as well.

Our confidential helpline is for anyone who wants to talk about epilepsy (details are below).

Relationship support for couples

Some couples may choose to seek professional support for their relationship in the form of couples' counselling.

To find a therapist visit the [British Association for Counselling and Psychotherapy \(BACP\)](http://British Association for Counselling and Psychotherapy (BACP) at bacp.co.uk) at bacp.co.uk or [The Counselling Directory](http://The Counselling Directory at counselling-directory.org.uk) at counselling-directory.org.uk

Helpline 01494 601400
Confidential, national call rate.
Information and emotional support.
Visit epilepsysociety.org.uk/helpline
for opening hours.

Sex and epilepsy

Whether or not you are sexually active, sexual issues can be important at any time of life. Many people with epilepsy do not have specific issues with sex that are caused by their epilepsy. For some people, however, epilepsy may have an effect on their sex life.

Sexual desire and arousal

Sexual desire (or 'sex drive') is the feeling that you want to have sex, and sexual arousal means the physical changes in the body that help you to have sex, such as vaginal lubrication for women, or getting an erection for men.

There are many possible reasons why sexual desire or arousal are reduced at times, and this is common in both men and women. Stress, tiredness, illness, alcohol, depression, anxiety, or having a lot on your mind, can all affect sex. Viewing problems with sex as a personal failing or weakness may put more pressure on you, and stop you seeking help for the problem.

How might epilepsy affect sex?

Medical and physical factors

Studies suggest that over half of men and a third of women with epilepsy say they have problems with sex. The most commonly reported problems for men are a reduced interest in sex, and getting and keeping an erection. Women with epilepsy report a low interest in sex, difficulties in being able to orgasm, or painful sex due to vaginal dryness or vaginal spasms. These problems can all have more than one cause, but physical causes may include the following.

- Areas of the brain which control sexual function can be disrupted by epilepsy. For example, for some men with temporal lobe epilepsy, it may be more difficult to get and keep an erection.
- Certain hormones are needed to increase sexual desire and arousal. In some cases, epilepsy can affect these hormone levels.
- Some anti-seizure medication (ASM) can reduce hormone levels, or affect the way that hormones are broken down in the body.
- Side effects of some ASM include reduced interest in sex, or problems with getting aroused. Other side effects include tiredness, disrupted sleep, or feeling tense or depressed, which can affect interest in sex.

If you notice a problem with sex before you start taking medication, the problem may be linked to having epilepsy and how you feel about it, or to something unrelated to epilepsy, rather than to your medication.

How you feel

In general, we are more likely to want and have sex when we feel well and relaxed. Low self-esteem, low confidence, feeling down or anxious can all affect how you feel about having sex.

If living with epilepsy makes you feel vulnerable, scared, angry, helpless, or under pressure, this may affect your sex life. The physical and emotional impact of seizures may affect your interest in sex, including needing time to recover after a seizure, dealing with any injuries, or feeling tired, fragile, upset, or anxious.

Some people may fear having a seizure during sex, especially if their seizures are triggered by physical activity, excitement, or fast breathing. However, for most people, having a seizure during sex is no more likely than having one at any other time. Talking to your partner about what to do if you have a seizure during sex may help you both to manage this fear.

Who can I talk to?

Your GP can help you look at whether any sexual problems are caused by how you feel, or by medical reasons such as epilepsy or medication.

Your neurologist can advise about sexual problems that you feel are directly related to your epilepsy. It may feel difficult talking about sex or how you feel, but the problem may be treatable, or may even be linked to other medical conditions which are important to identify and manage.

You can also call our confidential helpline for emotional support and time to talk (see details on previous page).

Epilepsy Society is grateful to Dr F J Rugg-Gunn, Consultant Neurologist & Honorary Associate Professor, Clinical Lead, Chalfont Centre for Epilepsy, who reviewed this information.

For a printed copy of this information contact our helpline.

Epilepsy Society

Chesham Lane,
Chalfont St Peter,
Buckinghamshire
SL9 0RJ



@epilepsysociety

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.