

## How you feel

Having epilepsy is more than just having seizures. It can affect every part and every aspect of your life: physical, mental and emotional.

While you might recover from the impact of seizures, you might not feel OK with your epilepsy, or how it feels to live with it. You might want to know where you can get more support.

There's no right or wrong way to feel about epilepsy. How you feel about it might change from month to month, or from moment to moment. It may depend on how often you have seizures and how they affect you. It might also depend on how those around you feel about your epilepsy, and what emotional support you get.

## Talking about it

You may feel as though no one understands what epilepsy is like or how it feels to have it. You might want to talk about it or you might want to shut down and not even think about it any more.

If your epilepsy is getting you down, talking to someone might help you. It doesn't really matter who you decide to talk to, as long as you feel you can trust them and you think they are good at listening. Your university may have a counsellor you can talk to about how you are feeling.

## Sex and relationships

Many young people worry about sex and relationships, whether they have epilepsy or not. Getting close to someone else can be great, but it may also leave you feeling vulnerable.

If you have epilepsy, you might also be thinking about when to tell your partner and how it will affect your relationship, if at all.

You might be worried about having a seizure during sex. While this is possible, it is probably no more likely than having a seizure at any other time.

Planning contraception and safe sex is important to protect you and your partner against unwanted pregnancy and sexually transmitted infections (STIs).

For girls and young women with epilepsy, there are particular issues around contraception that can affect both seizures and the effectiveness of contraception, as some methods of contraception affect and are affected by anti-seizure medication (ASM).

[Visit epilepsysociety.org.uk/contraception-and-epilepsy](https://www.epilepsysociety.org.uk/contraception-and-epilepsy)

## Get in touch with other people

It can be really helpful to talk to other people who have epilepsy and to share experiences with them. This can help you feel that there are other people 'out there' who understand what you are going through. Here are some places you can get in touch with others:

- Other young people share their experiences on the YouthHealthTalk website.  
[Visit healthtalk.org/Young\\_people\\_with\\_epilepsy](https://www.healthtalk.org/Young_people_with_epilepsy)
- Call our confidential helpline. It can give you the time and space you need to say what you want, to let off some steam, or just to get your thoughts in order (details below).
- The NHS run Expert Patients Programmes and 'Staying Positive' courses for young people with health conditions. The courses cover lots of topics from getting the best from your appointments to self-confidence and how you may feel about your condition. They also have staying positive and self-management apps. Contact your local NHS Foundation Trust to see what is available locally.

**For a printed copy of this information contact our helpline.**

**Epilepsy Society**  
Chesham Lane,  
Chalfont St Peter,  
Buckinghamshire  
SL9 0RJ

Let's be honest, you probably didn't plan on your university suitcase having 'epilepsy' in it.

Epilepsy Society Helpline  
01494 601400  
[helpline@epilepsysociety.org.uk](mailto:helpline@epilepsysociety.org.uk)  
Confidential, national call rate.  
Information and emotional support.

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.



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