Social issues, lifestyle and epilepsy



University and epilepsy



Whatever your hopes and expectations, planning ahead, and making epilepsy just one part of your life may help you to get the most out of your experience at university.

Living arrangements

Choosing where you want to live is an important decision. You may choose to live at home, or to move into student accommodation. Or you may live on your own. It is worth thinking about what sort of accommodation you would prefer and what would suit you best:

- Could you live in student halls of residence where there may be a warden available if needed?
- Do you need any particular equipment to make your living environment safer? For example, an alarm, or a shower rather than a bath.
- Do you need help during or after a seizure? If so, who can help and how will you call them?

It may be an idea to get in touch with the university accommodation office as soon as possible to talk through the options, what your needs are, and how they can best help you.

Who should you tell?

Perhaps you have already thought about who you want to tell about your epilepsy. Or perhaps you don't want to tell anyone.

If your seizures are controlled, you may feel that there is no need. The choice is yours, but you might want to think about the following points:

- If you need any support or help, for example from your lecturers or the student disability service, you will need to tell them that you have epilepsy.
- If you need financial help, such as Disabled Students' Allowance, you will need to disclose that you have epilepsy in order to qualify.
- If you have seizures, it might be useful for people to know, so that they know how to help you.
- You might just want to tell the people you spend most time with, or your tutor.

It may not feel easy to tell someone that you have epilepsy. Planning what you want to say might make you feel more confident. You can then tell them how and when you want to, or not at all. It is your choice. You may want to call us for some first aid cards that you could give out, or visit the first aid section of our website to show people how they can help you if you have a seizure.

<u>Visit epilepsysociety.org.uk/first-aid-epileptic</u>-seizures

Going out and having fun

Going out and having fun is important and, at university, there are plenty of opportunities. So does your epilepsy have to get in the way? As epilepsy varies from person to person, what is right for one may not be right for another. If you know how your epilepsy affects you, you can make your own decisions about what you can do. For example, if your epilepsy makes you very tired, early morning activities might not be for you.

Freshers' week, theme parks, festivals, and gigs

Freshers' Week can be exciting with lots of events where you can make new friends and try new activities. But, it may also feel overwhelming and hectic. Remember, if you feel this way, many people will be feeling the same as you, if they have epilepsy or not.

Theme parks, noise, crowds, and late nights can be exciting or tiring, or can raise stress levels.

University can be an exciting time, offering many opportunities both socially and academically, and it is a time when you can be independent.

Helpline 0300 102 0024 Confidential, information, and emotional support. Visit epilepsysociety.org.uk/helpline for opening hours. For some people, these situations may trigger a seizure. Learning about your triggers can help you make decisions about what you do.

Visit epilepsysociety.org.uk/seizure-triggers

What sports can I do?

Most people with epilepsy can take part in most sports, but it depends how your epilepsy affects you.

Team sports that involve other people, like football, carry a risk of head injury. Sport and leisure activities in and around water, or done at heights, may be risky if you have seizures. Simple safety measures may help to reduce the risks.

Be realistic about what you want to do, what the possible risks could be for you, and how you can reduce them. For example, have a friend with you who knows what to do if you have a seizure, tell other people about your epilepsy, like your coach or a lifeguard at the pool, so they can help you if you have a seizure.

Visit epilepsysociety.org.uk/exercise-and-sport

TV and video games

For most people with epilepsy, TV and computer games won't cause any problems.

However, a small percentage (around 3%) have photosensitive epilepsy, where seizures are triggered by flashing lights, or contrasting light and dark patterns. Flatscreen computers and TVs either do not flicker at all, or flicker too fast to cause a problem. But, if you do have photosensitive epilepsy, the computer game itself could trigger seizures, depending on what the images are, how close you are to the screen, and how dark it is. Computer games that have flashing images may carry a warning on the packaging.

Visit epilepsysociety.org.uk/photosensitive-epilepsy

Alcohol and drugs

It may be worth thinking about how you might handle conversations, and opportunities, around alcohol and drugs. Having a good time when you go out is important, but some people's seizures can be triggered by alcohol or drugs, or by being tired from late nights.

Drinking alcohol is a personal choice and the effect of alcohol varies from one person to another.



Patient Information Forum

Every effort is made to ensure that all information is correct at the time of publishing. 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.

Some find that they are ok to drink, for others it may lead to a seizure the next day. If you drink too much and are sick, this could affect the level of anti-seizure medication (ASM) in your system, which may affect how well your seizures are controlled. Also, alcohol does not mix well with some ASM and can worsen some side effects. The information leaflet that comes with your ASM will normally say if it is best to avoid alcohol.

Not every student is interested in drugs. Whether you take drugs or not is your choice but it might be worth knowing that cannabis, ecstasy, speed, cocaine, and other drugs can increase the chance of a seizure.

Visit talktofrank.com

Safety and risk, status epilepticus, and SUDEP

Having epilepsy can bring risks, and there are safety issues to consider. But it is also important to keep any potential risks in perspective and to avoid making generalisations about what you 'can't do'.

Usually seizures stop by themselves. When a seizure goes on for a long time without stopping, or repeated seizures happen with no recovery in between, and this goes on for 5 minutes or more, the person is in status epilepticus (status). If status happens in a tonic clonic seizure (when the person is unconscious and shakes), an ambulance needs to be called **immediately**. Emergency medication may need to be given to stop the seizure.

Although it is very rare, it is possible to die as a result of a seizure. Sometimes this happens due to sudden unexpected death in epilepsy (SUDEP). SUDEP is when a person with epilepsy dies suddenly and no other cause of death is found. It is hard to be sure why SUDEP happens, but it may be that during a seizure the person's breathing or heartbeat are affected. You could wear an alarm to alert someone if you have a seizure. Getting the best seizure control possible is often the best way to reduce risks around epilepsy and seizures. If you are concerned about SUDEP you can speak to your doctor about your own individual risk.

Visit epilepsysociety.org.uk/safety-and-risk

For a printed copy of this information contact our helpline.

Epilepsy Society

Chesham Lane, Chalfont St Peter, Buckinghamshire SL9 0RJ



@epilepsysociety

