Young people

A guide for young people with epilepsy

What is epilepsy?
Epilepsy is the tendency to have seizures that start in the brain. The brain uses electrical signals to pass messages between brain cells. If these signals are disrupted, this can lead to a seizure.

Epilepsy is usually diagnosed when someone has had more than one seizure.

Seizures can affect your feelings, awareness, or movement. Different types of seizures involve different things. These may include confusion, strange feelings, repetitive movements, 'blank' moments (when you are briefly unresponsive), muscle jerks, sudden falls, or jerking movements (while you are unconscious).

Sometimes other conditions can look like an epileptic seizure, for example fainting. Doctors will check for other conditions as well as epilepsy before you are diagnosed.
Visit epilepsysociety.org.uk/diagnosing-epilepsy and epilepsysociety.org.uk/epileptic-seizures

If you have epilepsy, you may feel OK about it, or you may have questions or worries. Your epilepsy and your choices in life may feel like big issues.

Treatment for epilepsy

The most common treatment for epilepsy is medication. Anti-seizure medication (ASM) aims to stop seizures from happening, but it doesn't cure epilepsy.

For ASM to work well, it is important to take it regularly, at the same time every day.

You may adjust well to your ASM, or you may have side effects, like feeling tired or unsteady. Some side effects go away once your body gets used to the drug. If you have concerns about side effects you can talk to your doctor about this.
Visit epilepsysociety.org.uk/treatment

It's my treatment, but who's in charge?
How you get on with the doctors you see for your epilepsy can make a big difference to how you feel about your treatment. Asking questions or making decisions with your doctor can help you to feel more involved.

At around age 16 to 18, you may start seeing a specialist for adults; usually a neurologist. This is called 'transition'. It can be a good time for you and your new specialist to talk about your epilepsy and adjust your treatment if necessary.

Do I really need ASM?
Doctors are not likely to prescribe ASM unless they feel you need it. Although many people can have a seizure and be fine afterwards, having seizures can be risky. Seizures can really disrupt someone's life; they can cause injuries, and in some rare cases, it is possible to die from a seizure.

This sounds very scary, but for most people with epilepsy, the risk of dying from a seizure is very low. Taking ASM regularly can help to stop seizures happening, or reduce the number of seizures to keep this risk low.

If you are unhappy about taking your ASM, you can talk to your doctor or specialist. They may be able to suggest a different ASM or change the dose.

They may also be able to tell you more about any possible risks around your specific epilepsy so you and your family can keep the risks of having seizures in perspective and not worry unnecessarily.

This information looks at what epilepsy is, medication, lifestyle, education, driving, work, how you might feel about your epilepsy, support, and how friends can help if you have a seizure. There is more information on our website.

Helpline 0300 102 0024
Confidential, information, and emotional support.
Visit epilepsysociety.org.uk/helpline for opening hours.

Sports, spare time, and seizures

Going out and having fun is important to us all – so does epilepsy have to get in the way? Epilepsy is a very individual condition. How it affects you can be quite different from how it affects someone else.

Knowing how your epilepsy affects you can help you to make your own decisions about what you can and can't do.

Can I still play sports?

Most people with epilepsy can do most sports, but it does depend on how your epilepsy affects you. Playing team sports like football can be fine but, with all sports that involve other people, there is a risk of injuries if you collide with someone.

Some sports and leisure activities may be risky if you still have seizures, particularly swimming and other water sports, or being at heights, but safety measures can reduce the risks in most cases.

Be realistic about what you want to do, what the possible risks could be for you, and how you can reduce those risks. For example, have a friend with you who knows what to do if you have a seizure.

Telling other people about your epilepsy, like your team coach or a lifeguard at the pool, means they can help you if you have a seizure.

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

TV and computer games

Most people with epilepsy can watch TV and play computer games without any problem.

However, some people have photosensitive epilepsy which means their seizures can be triggered (set off) by flashing or flickering lights, or by seeing moving patterns like stripes or checks.

This is not common – it affects about 3% of people with epilepsy. This means that around 97% of people with epilepsy do not have seizures that are set off by flashing lights or patterns.

You may be tested for photosensitive epilepsy when you have an EEG – a test that can help with diagnosing epilepsy. If you do have photosensitive epilepsy, some kinds of flashing images, lights, or patterns on computer games could trigger seizures for you. This will depend on what the images are, how close you are to the screen, how dark the room is, and whether you have any triggers for seizures that are specific to you.

If you're not sure whether you have photosensitive epilepsy, ask your GP or specialist.

Computer games that have flashing images may carry a warning on the packaging.

Modern TVs and computer screens have a very high flicker frequency and, generally are not likely in themselves to be a trigger for people with photosensitive epilepsy.

Visit epilepsysociety.org.uk/photosensitive-epilepsy

What about going to theme parks, festivals, or gigs?

Rides at theme parks, noise, loud music, crowds, and late nights can raise your excitement or stress levels, or can be tiring.

For some people these situations could trigger a seizure. Learning if your epilepsy has any triggers like these can help you make decisions about what you want to do.

Sex, drugs, and social life

Sex and relationships

Whether or not you are in a relationship, it's not unusual for people to worry about their sex life, whether they have epilepsy or not. You may worry about having a seizure during sex but, usually, this is no more likely than having a seizure at any other time.

Getting close to someone else can be great, but it can also leave you feeling vulnerable. What if they go off me? What if something embarrassing happens? Do I tell them about my epilepsy?

Going out with someone who you can really talk to, and who understands your epilepsy, can be great. Sometimes it can be helpful for you to find out how they feel about your epilepsy too.

Visit epilepsysociety.org.uk/relationships-and-sex

Contraception

Having safe sex protects against unwanted pregnancy and sexually transmitted infections (STIs). There are lots of different contraceptive methods available.

For girls and women with epilepsy, some ASMs can affect how well 'the pill' works and can increase the risk of getting pregnant. And 'the pill' can affect how well some ASMs work. You can talk to your epilepsy doctor or a family planning advisor about the combination of ASMs and contraception that is best for you.

If you are female and are taking sodium valproate (Epilim, Depakote, Convulex, Episenta, Epival, Kentlim, Orlept, Syonell, Valpal, Belvo, and Dyzantil), it is especially important that you talk to your epilepsy doctor, and that you have effective contraception.

Visit epilepsysociety.org.uk/women-and-girls
For more information about contraception visit fpa.org.uk and nhs.uk/conditions/contraception

Epilepsy and alcohol – do they mix?

Drinking alcohol is a personal choice, but for some people with epilepsy, alcohol makes their seizures worse. Having epilepsy doesn't necessarily mean you can't have an alcoholic drink, but it is important to be careful with alcohol for the following reasons:

- Alcohol disrupts sleep. Seizures can be triggered by tiredness for many people, so poor sleep may make seizures more likely. Drinking alcohol can trigger seizures for some people, but not always while they're actually drinking. Often it's later, during a hangover, when the alcohol level in the body is falling, that seizures happen.
- Drinking water in between alcoholic drinks can help reduce the chances of a hangover, but will not prevent seizures from occurring.
- Vomiting (being sick) may reduce the level of ASM in your system, so it may not work so well to control your seizures.
- ASM can increase the effects of alcohol and alcohol can make some of the side effects of ASM worse. The leaflet that comes with your medication should say if alcohol is not recommended. You can ask your doctor or pharmacist if you are not sure.

Recreational drugs

You might already know quite a bit about drugs and the risks of taking them, or you may have made a decision about what you'll do if you're offered drugs. Taking cannabis, ecstasy, speed, cocaine, and other recreational drugs can all increase your chances of having a seizure. There are no safe limits.

Visit talktofrank.com for more information about drugs or call their helpline on 0300 123 6600.

Going out

Having a good time when you go out is important and a fun part of being young. But for some people, a party lifestyle can make seizures more likely to happen.

Seizures can be triggered by being tired from late nights, alcohol, or drugs. Finding a balance, and working out what affects your epilepsy can be helpful.

Friends can also help you have a great time, if they know what you can handle. You may want to tell them about your seizures – what happens to you and what you would like them to do if you have a seizure when you are out.

School, college, or university

If you are at school, college, or university, and you have epilepsy, a law called the Equality Act 2010 aims to make sure you are treated fairly by everyone involved in your education. This includes lessons, trips out, practical subjects, and exams.

To find out more about what the Equality Act 2010 means for you, call Disability Rights UK Student Helpline on 0330 995 0414 or visit disabilityrightsuk.org/disabled-students-helpline

Wherever you are studying, it might be useful for other people to know about your epilepsy. This means they can help you if you have a seizure at school or college. But you may want to choose who you tell about your epilepsy. The important thing is to find a balance that you are happy with.

For some people, having epilepsy won't affect how well they get on at school, college, or university. However, it may be worth thinking about the following:

- If you take ASM, and it makes you feel sleepy or tired, it may be more difficult to concentrate or learn new information.
- After a seizure you might feel confused or tired, so it's important that you have time to fully recover.
- Your teacher or lecturer might go back over key information for you if you ask them. Or a friend might be able to explain what you missed.
- Schools, colleges, and universities are required to give you support if you need it. If your epilepsy affects your school or college work, talking to a teacher, or to the college, about ways they can support you may be helpful.

For more about epilepsy and education visit epilepsysociety.org.uk/university-and-epilepsy

Getting around

Learning to drive

If you have had no seizures for at least one year, you can learn to drive a car or motorbike at 17.

When you apply for your provisional driving licence, the Driver and Vehicle Licensing Agency (DVLA) will need to know about your epilepsy, even if you are not currently having seizures.

The DVLA will ask you to fill in some forms, and they may contact your doctor to ask about your epilepsy before they send you your Group 1 licence.

If you have a driving licence and have a seizure

If you have a seizure, by law you must stop driving, and tell the DVLA. This means all types of seizures, including those where you are conscious. This is the case whether you are on ASM or not.

The DVLA will ask you to return your licence to them. This can be a tough thing to face, especially if it affects your freedom and independence.

When you can reapply to get your new licence again depends on the number and type of seizures that you have.

Giving up your licence voluntarily can make it quicker for you to start driving again later.

Visit epilepsysociety.org.uk/driving

Public transport and help with travel costs

If you cannot drive because of your epilepsy, you may be able to apply for help with travel costs, including free bus travel, and reduced fares on trains using a Disabled Persons Railcard.

Visit gov.uk/apply-for-disabled-bus-pass and disabledpersons-railcard.co.uk

Travelling abroad

Having epilepsy does not usually stop people travelling by air. However, long journeys, 'jet lag', or a change in sleeping pattern can trigger seizures for some people. You might want to talk to your GP or specialist about when to take medication if you are planning long distance travel.

It is a good idea to take enough medication for the whole trip, as some drugs may not be available, or may have a different name, in other countries. Your GP or the drug company that makes your medication may be able to tell you more about this.

It is recommended that you keep all your medication (in its original containers) in your hand luggage. Current airport security regulations allow you to carry medication liquids up to 100ml in your hand luggage.

You will only be able to take liquid medication in a container larger than 100ml if you have a letter from your GP or specialist explaining about your epilepsy and the medication you take.

You will also need a copy of your prescription. Airport security staff may open the container to screen the liquids at the security point.

Visit epilepsysociety.org.uk/travel-and-holidays

Getting work

Jobs, epilepsy and the law

If you are employed (full-time or part-time) and have epilepsy, the Equality Act 2010 protects you from being treated unfairly.

The Equality Act covers you from when you apply for a job, through the interview, to getting the job, and continues to cover you once you are working.

The Equality Act means that most employers can't refuse you a job *just* because you have epilepsy.

However, by law, they must also ensure the safety of all their employees. To do this, an employer may need to find out more about your epilepsy, and how it actually affects you, for example, whether you still have seizures and, if so, whether your seizures could be a safety risk to you or others at work, or if they could affect your ability to do the job.

An employer can ask you for permission to contact your doctor if they feel they need more information about your epilepsy.

What jobs can I do?

If you have the right qualifications or experience, and your seizures don't put you or the people you work with at risk, then you should be able to apply for most jobs. If you have seizures, you may not be able to do jobs that risk your safety or the safety of other people.

These include jobs that involve driving, working at heights, near open water or fire, or working with unguarded machinery.

Whether or not you can work on active service in the Armed Forces (Army, Royal Air Force, and Royal Navy) depends on your epilepsy. For example, if you *have* epilepsy you would not be able to join the Armed Forces. But if you *had* epilepsy as a child (under five years old) or a single seizure more than ten years ago, you may be able to join.
Visit nationalcareers.service.gov.uk/careers-advice/careers-in-the-armed-forces

If I'm applying for a job do I have to mention my epilepsy?
No you don't have to, but, for safety reasons, it can be a good idea to tell an employer about your epilepsy (see page 4).

Employers can only ask you questions about your health to help keep you and others safe at work and to help you to be able to do your job.

An exception to this is that they can ask you whether you need any special requirements to help you get the job, for example to help you attend an interview.

Some people decide they will tell an employer about their epilepsy when they are offered the job.

If you do tell your employer, you can talk to them about how your epilepsy affects you so that they can treat you fairly and support you at work.
Visit epilepsysociety.org.uk/employment

If I'm already working, do I have to tell my colleagues?
You don't have to tell anyone at work about your epilepsy, but there are reasons why it can be helpful:

- You can tell your colleagues how you would like them to help you if you have a seizure at work.
- If you feel something at work is making your epilepsy worse, you may want to talk to colleagues about it.
  If you need to take time off work for medical appointments, these might be recorded separately from sick leave.
- If you need to stop driving (see page 4), your work colleagues may ask you why.

If you develop epilepsy, or if epilepsy is making your work difficult, the Equality Act 2010 means that your employer is expected to make 'reasonable adjustments' so that you can continue to work. For example, they might be able to change your working hours if a seizure leaves you too tired to come to work at the usual time.
Visit equalityadvisoryservice.com

Feelings and stuff

Let's be honest, having epilepsy can be overwhelming and, right now, it might seem that everything is going to become more complicated and difficult.

Whether you've had epilepsy for a while, or it's something that's new, there are bound to be questions and concerns that you may have. If you do, remember that you're not alone (see below).

Many young people with epilepsy may have the same worries that you have. Some people find that talking about their concerns can help. There are lots of ways you can connect with other people and get support (see below).

It doesn't matter who you decide to talk to, as long as you feel you can trust them and you think that they are good at listening. It could be a friend, a family member, your GP, or a teacher or tutor.

Some people find it helpful to talk to a counsellor. Or you might like to call our helpline.

Whoever you talk to, it's OK to be unsure of what you want to say. Sometimes just having the time and space to say what you want can help you feel better or get your thoughts in order.

Getting support

Follow us on social media @epilepsysociety
We regularly post updates from the world of epilepsy – everything from research, to medication updates, to changes in benefits, and support available for people with epilepsy.

Epilepsy Society helpline
If you want to know more about epilepsy, or talk to someone about your epilepsy, our confidential helpline offers information and emotional support.
See page 1 for contact details.

How do other young people deal with their epilepsy?
Visit healthtalk.org/introduction/epilepsy-young-people/ to see videos, audio, and text clips of young people talking about their epilepsy.
To read other people's experiences of living with epilepsy visit epilepsysociety.org.uk/about-epilepsy/personalstories

How friends can help if you have a seizure

If you tell your friends about your epilepsy and the type of seizures you have, they can help you if you have a seizure.

If you have seizures where you become confused or go blank, you might want a friend to stay with you, talk calmly and quietly, and gently guide you away from any danger.

If you have tonic clonic seizures, where you collapse and shake, they can help you by:

- keeping calm;
- timing your seizure;
- moving objects away from you that may cause injury;
- putting something soft under your head to protect it;
- not holding you down;
- not putting anything in your mouth;
- not moving you, unless you are in direct danger;
- gently putting you into the recovery position, after the shaking has stopped;
- staying with you until you have fully recovered; and
- calling for an ambulance, if your seizure lasts for two minutes more than is usual for you, or if they don't know how long your seizures last.

Visit epilepsysociety.org.uk/about-epilepsy/first-aid-epileptic-seizures or call our helpline for first aid cards to give to your friends or family (see page 1 for contact details).

Further information

My plus Students' Club
myplusstudentsclub.com
Offer careers advice for students and graduates with disabilities or long-term health conditions.

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For a printed copy of this information contact our helpline.

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