



# **For colleges and universities**

Information about epilepsy.

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## Information about epilepsy

Epilepsy is a neurological condition that affects the brain and nervous system. It is characterised by the tendency to have repeated seizures that start in the brain.

**Visit [epilepsysociety.org.uk/what-epilepsy](https://epilepsysociety.org.uk/what-epilepsy)**

Epilepsy varies from one person to another and can change over time, and how the person feels about it can also change.

Unlike other conditions, it may not be obvious that someone has epilepsy and, for many people with epilepsy, their condition doesn't necessarily affect them all the time. Also, the frequency of seizures can vary from one person to the next.

Some people with epilepsy have their seizures controlled with medication and their condition has little effect on their daily lives. For other people, seizures are unpredictable and debilitating.

However, having epilepsy can be more than having seizures. It can affect every part of someone's life: physical, mental, and emotional.

While they might recover from the impact of seizures, they might not feel ok with having epilepsy, or how it feels to live with it.

Epilepsy can make the individual worried, stressed, anxious, or depressed. All these feelings can affect their overall well-being, and how they feel about life.

How epilepsy affects someone depends on lots of things:

- whether they have seizures and how often they happen;
- what their seizures are like and how they affect them;
- whether they are on medication and whether they have side effects, such as feeling tired or having trouble with concentration, thinking speed, or memory;
- how long they have had epilepsy – whether they have been diagnosed recently or a long time ago;
- the cause of their epilepsy;
- how they feel epilepsy affects their daily life and what it means to them; and
- whether epilepsy has affected their school life and learning so far.

## **Find out about a student's epilepsy**

Finding out more about a student's epilepsy, and their seizures, can help you to better understand how it affects them, and what help and support might be useful for them.

They may be very happy to discuss it, and talk through what help and support might be useful. Or they may not want you to know about their epilepsy. They may feel embarrassed or they may have had bad experiences in the past.

They might not have got the help and support they needed for their epilepsy. Or they may just not know much about their own epilepsy.

## **What causes epilepsy?**

Different epilepsies are due to many different underlying causes. The causes can be complex, and sometimes hard to identify. A person might start having seizures because they have one or more of the following:

- a genetic tendency, passed down from one or both parents (inherited);
- a genetic tendency that is not inherited, but is a new change in the person's genes;
- a structural ('symptomatic') change in the brain, such as the brain not developing properly, or damage caused by a brain injury, infections like meningitis, a stroke, or a tumour. A brain scan, such as Magnetic Resonance Imaging (MRI), may show this; or
- structural changes due to genetic conditions such as neurofibromatosis or tuberous sclerosis, which can cause growths affecting the brain.

Some researchers now believe that the chance of developing epilepsy is probably always genetic to some extent, in that any person who starts having seizures has always had some level of genetic likelihood to do so.

## Seizure types and how to help

Epileptic seizures start in the brain. The brain has millions of nerve cells which control the way we think, move, and feel, by passing electrical signals to each other. If these signals are disrupted, or too many signals are sent at once, this causes a seizure.

The brain has many different functions. Mood, memory, movement, consciousness, and our senses are all controlled by the brain, and any of these can be affected if someone has a seizure.

What happens to a person during a seizure depends on where in the brain the seizure happens and what that part of the brain normally does.

The person may feel strange or confused, behave in an unusual way, or lose some or all awareness during the seizure.

**[Visit epilepsysociety.org.uk/epileptic-seizures](https://epilepsysociety.org.uk/epileptic-seizures)**

Depending on where they start, seizures are described as being focal onset, generalised onset, or unknown onset.

**[Visit epilepsysociety.org.uk/seizure-types](https://epilepsysociety.org.uk/seizure-types)**

### **Focal onset seizures**

Focal seizures start in, and affect, part of the brain: either a large part or just one small area. What happens during the seizure depends on where in the brain the seizure happens and what that part of the brain normally does.

## **Focal aware seizures**

During a focal aware seizure the person is conscious and aware and usually knows that the seizure is happening. A focal aware seizure could be an unusual smell or taste, a twitching of an arm or hand, a strange 'rising' feeling in the stomach, or a sudden feeling of intense joy or fear.

### *How to help*

- As the person might feel strange or be upset, reassuring them might be helpful.

## **Focal impaired awareness seizures**

Focal impaired awareness seizures affect more of the brain than focal aware seizures. The person's consciousness is affected, and they may be confused and not know what they are doing.

They may wander around, behave strangely, pick up objects, or make chewing movements with their mouth. Afterwards they may be confused for a while or need to sleep. These seizures can last a few seconds or a few minutes.

### *How to help*

- Do not restrain the person as this might upset or confuse them.
- Speak gently and calmly as they may be confused. Don't speak loudly or grab them, they might not understand and may get upset or respond aggressively.
- Gently guide them away from any danger, for example from walking into the road.

### *After the seizure*

- They may feel tired and want to sleep. It might be helpful to remind them of where they are.
- Stay with them until they fully recover and can safely return to what they had been doing before the seizure.
- Some people recover quickly, but others may take longer to feel back to normal again.

### **Focal to bilateral tonic clonic seizures**

Sometimes a focal seizure spreads to affect both sides of the brain. This is called a focal to bilateral tonic clonic seizure. Some people call the focal seizure an 'aura' or 'warning', as it warns them that a tonic clonic seizure may follow (see page 10).

### *How to help*

- If you or the person is aware of the warning, they may need help to get to a safe place before the tonic clonic seizure happens.

### **Generalised seizures**

Generalised seizures affect both sides of the brain at once and happen without warning. The person usually becomes unconscious and will not remember the seizure afterwards.

### **Absence seizures**

During an absence seizure, the person becomes unconscious for a short time. They may look blank and stare and will not respond to what is happening around them.



If they are walking, they may carry on walking but will not be aware of what they are doing.

#### *How to help*

- Stay with the person, and gently guide them away from any danger.

### **Tonic and atonic seizures**

In a tonic seizure the person's muscles suddenly become stiff. If they are standing, they often fall, usually backwards, and may injure the back of their head.

In an atonic seizure (or 'drop attack') the person's muscles suddenly relax and become floppy. If they are standing, they often fall, usually forwards, and may injure their head or face.

Both seizures are brief and happen without warning. Most people usually recover quickly.

#### *How to help*

- Reassuring them may be helpful. If they are injured, they may need medical help.

### **Myoclonic seizures**

Myoclonic seizures involve jerking of a limb or part of a limb. They often happen shortly after waking up, are brief, and can happen in clusters.

#### *How to help*

- You don't need to do anything to help during the seizure other than make sure that the person has not hurt themselves.

## **Tonic clonic and clonic seizures**

During a tonic clonic seizure the person goes stiff ('tonic' phase), usually falls to the ground, and shakes or has jerking movements ('clonic' phase). Their breathing may be affected, and they may go pale or blue, particularly around their mouth. They may also bite their tongue or cheek. Some people have clonic seizures without going stiff to start with.

Although it can be frightening to see, this is not usually a medical emergency. Usually, once the movements have stopped, the person recovers and their breathing goes back to normal.

### *How to help*

If you don't know anything about the person's seizures, follow our basic first aid message: Calm, Cushion, Call.

**[Visit epilepsysociety.org.uk/ccs](https://www.epilepsysociety.org.uk/ccs)**

Here's how to help if you are familiar with the person's seizures:

- Try to stay calm.
- Check the time to see how long the seizure lasts (see page 22 for why this is important).
- Only move the person if they are in a dangerous place, for example in the road. Instead, move any objects (such as furniture) away from them so they don't hurt themselves.
- Put something soft (such as a jumper) under their head, or cup their head in your hands, to stop it hitting the ground.

- Look for medical jewellery or an ID card for information about how to help.
- Do not hold them down – allow the seizure to happen.
- Do not put anything in their mouth – they will not swallow their tongue.
- Try to stop other people crowding around.

### *After the seizure*

- Gently roll them on to their side into the recovery position.
- If their breathing sounds difficult or noisy, gently open their mouth to check that nothing is blocking their airway.
- Wipe away any spit from their mouth.
- Try to minimise any embarrassment. If they have wet themselves, deal with this as privately as possible (for example, put a coat over them).
- Stay with them until they have completely recovered. They may need reassurance.
- Do not give them anything to eat or drink until you are sure that they have fully recovered.

### **When to call an ambulance**

Usually, there is no need to call 999 for an ambulance. However, always call an ambulance if:

- you know it is the person's first seizure;

- they have injured themselves badly;
- they have trouble breathing after the seizure has stopped;
- one seizure immediately follows another with no recovery in between;
- the seizure lasts two minutes longer than is usual for them; or
- you do not know how long their seizures last.

If in any doubt, always call an ambulance.

Some people recover quickly from a tonic clonic seizure, but often they will be very tired, want to sleep, and may not feel back to normal for several hours or sometimes days.

**[Visit epilepsysociety.org.uk/first-aid-epileptic-seizures](https://www.epilepsysociety.org.uk/first-aid-epileptic-seizures)**

## **What are 'triggers'?**

Triggers are situations or events that bring on a seizure. Not everyone with epilepsy will have a trigger but common triggers are tiredness and stress. These are potentially important issues for young people at college or university. Other triggers can be alcohol or not taking medication.

If an individual knows what triggers their seizures, they may be able to try and avoid these situations but this may not always be possible.

**[Visit epilepsysociety.org.uk/seizure-triggers](https://www.epilepsysociety.org.uk/seizure-triggers)**

Photosensitive epilepsy is when seizures are triggered by certain frequencies of flashing or flickering lights or by certain geometric patterns or shapes. Photosensitive epilepsy is relatively rare and affects fewer than 5% of people with epilepsy.

Modern computer screens and laptops either do not flicker at all or have a very high flicker frequency that is unlikely to trigger seizures. However, the images on the screen may cause a problem if they have flashing lights.

**Visit [epilepsysociety.org.uk/photosensitive-epilepsy](https://epilepsysociety.org.uk/photosensitive-epilepsy)**

## **What is the impact on learning?**

Having epilepsy, having seizures, and having treatment for epilepsy can all impact on learning for some people with epilepsy.

## **The impact of seizures themselves**

The impact of seizures depends on what the seizures are like and how often they happen. If seizures are controlled with medication, or if the seizures are focal aware seizures, they may have little or no impact on the person at all. It may be helpful to plan ahead with the student about what to do if they have a seizure during classes or lectures, so they don't feel they will be taken out of class unnecessarily.

Some people recover quickly from a seizure and they may be able to stay and carry on straight away.

Other people may feel very tired or confused and they may need to find a suitable place to go to where they can take time to recover from the seizure.

### **Seizures can affect memory**

The ability to take on, store, and retrieve information can be affected.

This could happen with any type of seizure, and if the person has a lot of seizures, this could affect their memory more often. They may also find that, just after a seizure, they have problems remembering information and it may take time to recover.

Memory aids and techniques, or having a note taker, may help if this is possible.

**Visit [epilepsysociety.org.uk/memory](https://epilepsysociety.org.uk/memory)**

### **Seizures can affect concentration**

Concentration can be affected both during the seizure and while the person is coming around. If this happens during classes or lectures, they may not be able to concentrate on what is being said or on taking notes.

Concentration can also be affected by how they feel. If they feel low or tired because of seizures, they may not be able to concentrate well.

They may find it easier to study at certain times of the day when they are more able to concentrate. Making allowances for this can help to support the student.

## **Seizures can affect a person physically**

The effects of a seizure depend on the seizure type. Some seizures may not affect the person physically. Other seizures may cause them to behave strangely during the seizure with no physical effect afterwards.

Seizures that cause people to fall down and lose consciousness may cause injuries. It may be helpful to think about seating arrangements in lecture theatres or tutor rooms. Tonic clonic seizures, where the person shakes, can take a long time to recover from, sometimes days. These seizures can cause muscle aches, headaches, and feeling exhausted for a long time. If a person has a seizure like this, it can be very disruptive for them and they may need to go somewhere quiet to recover, or they may need medical assistance (see page 11).

Seizures at night can affect the amount and quality of sleep and may have a big impact on the person and their daily activities. An alarm to alert someone else that a seizure has happened at night may be useful.

**[Visit epilepsysociety.org.uk/alarms-and-safety-aids](https://www.epilepsysociety.org.uk/alarms-and-safety-aids)**

Some seizures can affect the person's mood or emotions and the way they feel can affect, and be affected, by their seizures. If they feel stressed or anxious this can affect their concentration and memory and could cause more seizures if they are a trigger for them.

## **The impact of treatment**

About 70% of people with epilepsy could have their seizures fully controlled with anti-seizure medication (ASM). But any form of treatment can have an impact.

ASM does not cure epilepsy. It works on the brain to stop seizures from happening and it can also have side effects that affect how the brain works. This can make the person tired or drowsy and can affect how they think and process information, or it can affect memory.

For some people, having brain surgery can help reduce or stop seizures, but surgery itself can potentially cause problems, particularly with memory.

**Visit [epilepsysociety.org.uk/treatment](https://epilepsysociety.org.uk/treatment)**

## **What are other possible impacts?**

In addition to having an impact on learning, having epilepsy can affect other aspects of studying.

### **Exams**

Seizures can affect exams in many ways. For many people, revision for, and sitting, exams is worrying and stressful.

This could cause more seizures if stress is a trigger for a student with epilepsy.



If having epilepsy affects their memory and thinking speed, this might make exams more challenging than for other students.

Having a seizure before an exam might mean that they are too tired to take the exam or do their best during the exam. Having a seizure during an exam could mean that they miss some or all of the exam.

Planning ahead might be helpful. If exams may be a problem for an individual, special provisions may help. For example, being able to take their exams in a separate room, having more time to complete the exam, or having someone to write for them during the exam might be helpful.

Preparing a revision schedule might also help them to revise at the best time of day for them, when they feel most alert and able to concentrate. Revising somewhere quiet might also help with concentration and memory.

Having support and a plan in place might help to make them feel more confident about revising.

## **Practical work and course work**

What consideration is needed depends on the work. For example, practical work in a laboratory could have safety implications if the person with epilepsy had a seizure.

Courses that include physical activities might need consideration so that they can be made safer for the individual to participate.

It is important to be realistic about potential risks. If the person has a warning before a seizure, this might give them enough time to get to a safe place before it starts.

Many situations can be made safer with simple measures, and it might help to talk this through with the student to ensure that their epilepsy does not unnecessarily restrict what they do.

## **Course placements**

Courses that include placements may need additional consideration. Support may be in place for a student while they are at their course, but will similar support be in place at their placements?

Getting in touch with the placement as early as possible might help to reassure them, and the individual with epilepsy, that appropriate support is in place throughout the course and placement.

It is important to be realistic about whether an individual's epilepsy might affect their placement. But it is also important to look at ways of making the placement safer, if necessary, so that the student can get the most out of the experience and is not unnecessarily restricted on their placements.

Some people may not be able to drive because of their epilepsy, so transport to a placement may need to be considered.

## What you can do to help

Although the student is in the best position to know about their epilepsy and how it affects them, you may know the best ways of supporting them with their academic or social life at college or university.

Having support in place before they start, might help make the transition to college or university as stress-free as possible.

### **Be up front about what you can do**

Having information on your website about what help and support you offer to students with epilepsy will help to encourage them to disclose their epilepsy and discuss their options.

This also shows that you are aware of the support needs that students with epilepsy might have, and that you understand that this help needs to be individualised to each new student's own situation.

- Make sure that your disability equality scheme is up to date and complies with the Equality Act (see page 20). Ensure students and potential students know about it, and can find out further information in different ways: your website, the admissions office, the students' union, and any disabled student support services.
- Make sure your messages are clear and consistent.

- List all the types of help and support which are available to students, including practical and financial support, such as Disabled Student Allowance, and tell them how to access this.

## **The Equality Act 2010**

The Equality Act protects the rights of individuals, and makes sure that a person with a disability has the same rights as a person without a disability. The act applies in many situations, from employment to transport, from property to education.

The act means that education providers (including schools, colleges, and universities) must not discriminate against someone with a disability, and must support them within education.

Colleges and universities must not discriminate, harass, or victimise a person with a disability in:

- how they offer places or enrol students;
- how they provide the educational course;
- how students gain qualifications; or
- how they treat a student or someone who applies to become a student.

### **Reasonable adjustments**

Colleges and universities also have a duty to make reasonable adjustments to support students with disabilities.

Because epilepsy varies from one person to another, a reasonable adjustment appropriate for an individual depends on how their epilepsy affects them. An example may be giving a student with epilepsy more time to complete a piece of coursework.

Another reasonable adjustment may be consideration about accommodation. Does the student need a room on the ground floor to avoid the risks around having a seizure on the stairs? Might it be possible to provide an alarm to alert someone if the student has a seizure in their room?

If the student can't drive because of their epilepsy, might they need accommodation close to the college or university buildings?

## **Risk assessments**

In some cases, a formal risk assessment is needed to identify the risks and solutions or reasonable adjustments. The important point to remember is that epilepsy varies from one person to another. Talking through these issues with the individual is useful to identify problems, and to start looking for ways to address and resolve any potential problems.

## **What are the risks?**

For a student whose seizures are controlled, their epilepsy may not put them at any greater risk than students who do not have epilepsy.

If a student is having seizures that affect their awareness, that may put them at greater risk. If they fall during their seizures, this may also put them at greater risk.

### **Status epilepticus or 'status'**

Usually a seizure will stop by itself. Sometimes this does not happen and a seizure is very long or one seizure happens after another without the person recovering in between. If this carries on for five minutes or more, it is called status epilepticus (or 'status').

Status is not common, but can happen in any type of seizure and the person may need to see a doctor.

Status in a tonic clonic seizure (see page 10) is a medical emergency and an ambulance needs to be called **immediately**. If a tonic clonic seizure goes on for 30 minutes or more, this could cause lasting damage to the brain, or even death.

Emergency medication may need to be given to stop the seizure. Anyone giving emergency medication needs to be trained. The student with epilepsy should have their own written protocol about when to give it, for the person giving the medication to follow.

**Epilepsy Society provides training on epilepsy awareness, seizure management, and emergency medication. For more information, visit [epilepsysociety.org.uk/training-courses-epilepsy](https://epilepsysociety.org.uk/training-courses-epilepsy)**

## SUDEP

On rare occasions people die suddenly for no clear reason. When this happens to someone with epilepsy it may be called sudden unexpected death in epilepsy (or 'SUDEP').

SUDEP is when a person with epilepsy dies suddenly and where no other cause of death is found. It may be that they died during or after a seizure. Because SUDEP often happens when the person is asleep and is not witnessed, it is hard to be sure why it happens. It may be that during a seizure the person's breathing or heartbeat have been affected.

SUDEP is relatively rare. But everyone's individual level of risk may depend on their epilepsy, lifestyle, any conditions they have alongside epilepsy, and other factors, such as their age and sex.

Students who have seizures at night may find it reassuring to have an alarm to alert someone if they have a seizure.

**Visit [epilepsysociety.org.uk/safety-and-risk](https://epilepsysociety.org.uk/safety-and-risk)**

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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.



## Helpline

**01494 601 400**

**[helpline@epilepsysociety.org.uk](mailto:helpline@epilepsysociety.org.uk)**

Confidential, national call rate.

Information and emotional support.

Visit [epilepsysociety.org.uk/helpline](https://epilepsysociety.org.uk/helpline) for opening hours.

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