

STUDENT GUIDE



A New Chapter...

Going to college or university can be an exciting time with plenty of new challenges. For many young people it often means being away from home for the first time. If you have epilepsy, this may also mean having to manage your epilepsy yourself for the first time and taking full responsibility for taking your medication and managing your safety.

We've pulled together some information for you, to help you make the right decisions and keep you healthy and safe while embarking on this new chapter of your life.



Before you head off

Request a repeat prescription

If you are moving away from home, ask your current GP for a repeat prescription just before you go. This will give you time to settle in and register with your new GP before you need to request a repeat prescription.

The NHS can issue a prescription covering a maximum period of up to three months under certain circumstances. This might, for example, be helpful if you move abroad and you need time to work out the local health system.

Update your vaccines before you go

Having epilepsy does not make it more likely you get the flu, COVID-19, or some of the diseases we can vaccinate against, but seizures are more likely to be triggered when you are ill. Common seizure triggers include running a temperature or fever, diarrhoea, vomiting, disrupted sleep, or dehydration.

All vaccines such as the flu, COVID-19, or Meningitis ACWY vaccine, are safe for people with epilepsy.



epilepsy scotland

Accessing your local health services

Register with a GIP where you stay

If your university/college is in Scotland or elsewhere in the UK, register with a local GP surgery as soon as possible. If your planned stay is for no more than three months, you can register as a temporary resident. If you stay longer, you need to register as a permanent resident. If you become ill or need medical advice while on holiday back home, you can ask for emergency treatment from your surgery at home.

Once you are registered, it might be helpful to make an appointment with your new surgery to provide more information about your epilepsy. If your epilepsy is not well controlled, you may need to ask your new GP to make a referral to your local neurology service to ensure continuity of care for you.

Prescription charges

In Scotland, as well as Wales and Northern Ireland, all prescriptions are free. If you move to England, you will need to apply for an exemption certificate by completing a FP92A form. You can get this from your doctor's surgery. The exemption certificate is usually issued for up to five years.

Accessing your local health services

Health care abroad

If you are moving abroad to study at a foreign university, you need to give yourself plenty of time to find out how to access local health services. You may also have to look into getting health insurance which covers you for preexisting conditions such as your epilepsy.

For detailed country by country information check out the travelling and living abroad section on the UK government website www.gov.uk. It covers countries both inside and outside the European Economic Area (EEA) explaining each country's health care provisions and the steps you need to take to access local health services.

After Brexit: health care in the European Union

You can apply for a Student Global Health Insurance Card (GHIC) if you normally live in the UK but study in the EU. This card covers you for medical emergencies and pre-existing medical conditions, such as epilepsy, for reduced cost, sometimes free, state healthcare of the EU country you are studying in. It does not, at the moment, cover you if you study in Norway, Iceland, Liechtenstein and Switzerland.

If you are an EU national (including those nationals from Norway, Iceland, Liechtenstein and Switzerland) who has ordinarily been resident in the UK before 1 January 2021 you are entitled to a new style EHIC card, which, unlike the GHIC card, also covers you in Norway, Iceland, Liechtenstein and Switzerland.

Applying for a Student GHIC or new style EHIC card on the NHS (UK) website is free. Beware unofficial websites which may charge you a fee. Find out more information on who may be eligible and how to apply for a Student GHIC or new style EHIC on the NHS (UK) website.



Support from student disability services

Most colleges and universities in the UK have a student disability service providing guidance and support to students affected by a mental health condition or disability such as epilepsy.

The service can help you access counselling and one to one support. It can also help you access funding for technology to support you with anything directly linked to your epilepsy, such as memory issues.

The service can also help liaise with lecturers over adjustments to help you in your studies, such as sitting exams in a smaller room, getting more time sitting exams, or longer deadlines for submission of course work and essays.

To provide you with the most effective support, student disability services will need to have a good understanding of the effects epilepsy may have on you. This includes type of seizures, whether you get a warning before a seizure, side effects of your anti-epileptic drugs, memory issues, lack of confidence, anxiety, low mood, and the risk of injury. With the right support there is no reason for you not to be able to study and complete your course work.





Working while studying

You may need to work to support yourself while studying. Having to work in addition to attending lectures and studying can be demanding on any student, but when you have epilepsy, you need to be mindful of possible increased stress and lack of sleep from doing too many hours, which could be a seizure trigger.

Try and avoid working nights or evening shifts as this disrupts your sleep pattern. It can also disrupt your medication routines, and you may end up taking your medication later than usual or even forget to take it.

Explore all options for financial support and benefits first to reduce the need to work.



Financial help

ttelp with tuition fees and cost of living

Whether you will have to pay tuition fees depends on where you will study and where you normally live.

If your college or university is based in Scotland, and you are normally a resident in Scotland, and a UK citizen or a citizen of an EU country with settled or pre-settled status, and if you are studying for your first undergraduate degree then you will not need to pay tuition fees.

You can also apply for a student loan if you need help with living costs.

Studying in all other countries of the UK will incur tuition fees.

If you are an international student from the EU (without settled or pre-settled status in the UK), or from outside the EU, you will also incur student fees.

You may also get some financial help if studying abroad.

For more information on eligibility of tuition fee loans, student loans, and other financial support such as bursaries, grants and loans, please check out <u>Student Awards Agency</u> <u>Scotland</u>, <u>mygov.scot</u> or the <u>Student finance</u> sections on the UK.Gov website.

Benefits and discounts

Disabled Students' Allowance (DSA)

You are eligible to apply for DSA if you are an undergraduate or postgraduate student with a physical condition such as epilepsy, any other long-term medical condition, a learning difficulty, or a mental health condition. This is to cover some of the extra costs which might arise from having epilepsy (or any other condition), or to purchase specialist equipment to help you with your studies.

You can apply for this allowance on top of any other student finance you may be eligible for. You do not need to repay it, as it is not a loan. Provided you meet certain other criteria, your eligibility will be solely assessed on your individual needs, not your income or capital. Your university/college's student disability service can provide you with further information to see if you are eligible, and help you apply for DSA.

DSA is available to students in England, Wales, Scotland and Northern Ireland.

Personal Independence Payment (PIP)

You may be entitled to apply for this non-means tested benefit depending on the effects your epilepsy has on your day to day life. Always seek professional advice and help with completing this form from your local Citizens Advice Bureau or a welfare rights service before you apply for this benefit to maximise your chance of success. Your local welfare rights service or Citizens Advice Bureau can also advise you on any other benefits or financial help you may be entitled to.

Discounted travel

If you have had one seizure (any type) within the last 12 months, you may be eligible for a free National Entitlement Card in Scotland which allows you to travel free of charge across the whole of Scotland on most short and long distance bus services, and some local train routes. There are no time restrictions for using the card.

As of 31 January 2022, anyone under the age of 22 will be eligible for free Scotland wide bus travel.

There are similar discounted travel schemes in England, Wales and Northern Ireland. Check with the relevant local authority to find out more.

A Disabled Person's railcard is valid for rail travel across the whole of the UK and gives you one third off standard adult rail fares, and one third off for any adult travelling with you. For more information and eligibility criteria, check out the Disabled Persons Railcard website www.disabledpersons-railcard.org.uk

CEA Cinema Card

You may get a CEA cinema card if you are in receipt of certain benefits such as Personal Independence Payment (PIP). The card entitles you to get one complimentary ticket for another person accompanying you, but you will need to purchase a full price ticket for yourself. It is accepted by most cinemas across the UK. Check out their website www.ceacard.co.uk for more information.

Your rights under the Equality Act

Epilepsy is covered by the Equality Act 2010. This gives you certain rights such as the right not to be discriminated against, either directly or indirectly, because of your epilepsy or because of something directly linked to your epilepsy, such as memory issues. It also gives you the right to make a request for reasonable adjustments to your university or college course, to allow you the same chances as everyone else.

A reasonable adjustment could for example be a longer deadline to submit your essays if your medication and seizures affect your level of concentration.

For more information on the Equality Act check out the Equality and Human Rights Commission's website www.equalityhumanrights.com. Your local student disability service can also give you more information on your rights as a student with a disability and help you resolve any issues you may have with your college/university.



Studying with epilepsy

Medication side effects and seizure activity can often cause tiredness, affecting your ability to focus and concentrate. It may also affect your mood, which can sometimes make it difficult to get through the course work. Not everyone will be affected in the same way. You can experience more side effects during medication changes or dosage adjustments until your body gets used to the new medication/dosage. Frequent seizures can also have a similar effect.

Effect on memory & concentration

Epilepsy can affect memory, particularly our short-term memory, and it might take longer for information to be processed and be stored in the long-term memory bank. Avoid last minute cramming before exams. The only way for information to be retained in your long-term memory, is for you to go over the information many times.

Give yourself frequent breaks as this can help with processing information and prevent possible seizures triggered by tiredness. Avoid studying when you are tired, take advantage of those times you feel alert and function best.

Seizures and medication side effects might also affect the speed with which you take on board and process information in lectures. It can help to record lectures and to use a speech to text app or software to produce a written record of the lecture.

Additional time for essay deadlines, exams and dissertations can help take the pressure off you. Your student disability service can help you negotiate this.

Taking notes while you study can help you focus on the information, allowing you to process and memorise it better. Other memory techniques can be helpful such as breaking down information into chunks and creating mental associations. You will find plenty of resources online to help with memory issues. Student disability services will also be able to signpost you to further sources of support and help.

Be mindful that other factors can affect your memory too. This includes tiredness, a diet high in sugar, fat and salt, too much alcohol, dehydration, taking recreational drugs, as well as a lack of exercise, and stress.



It can be helpful to take notes & record lectures





Recognising and beating stress

Managing stress levels is particularly important if you have epilepsy, as stress is a common seizure trigger for some people. Stress can also affect how well your memory works and how well you can concentrate and focus.

Stress can often be subtle, going on for weeks or months before you notice. This might manifest itself as an underlying feeling of constant anxiety or generally an inability to cope with less than you used to. Stress can have an accumulative effect. You might feel like you are coping, but then discover that it only takes one small event to trigger a mental health crisis.

Obvious signs of stress include constantly feeling weepy and low in mood, no longer enjoying some of the things you used to enjoy, feeling tired all the time, or an inability to sleep at night.

Some people find that keeping busy can help, but this tends to be a short term fix. It is important that you seek help and try to address the actual sources of stress before it impacts on your mental and physical health. Don't be alone, ask for help. If you don't know where to start, call our freephone helpline 0808 800 2200.

Look at your diet, is it full of junk food? You need to feed your brain and promote good mental health with a healthy balanced diet. Introduce more fresh unprocessed foods.

Are you drinking too much alcohol? Alcohol is often seen as a quick fix for problems but makes things worse in the long run. Drink more water and keep yourself well hydrated.

Do you take recreational drugs? These can sometimes interfere with your antiepileptic drug's effectiveness, leading to more seizures, and increasing your stress levels.

Are you sitting too many hours in front of your computer? Lack of exercise can make us more stressed and unable to cope with normal daily levels of stress.

Are you neglecting your sleep? Sleep plays an important part in your mental and physical health. Cut down use of TVs, laptops and mobile devices before you go to sleep, or switch to night mode, as the blue light emitted from mobile devices can affect the production of the sleep hormone melatonin which is essential for sleep.

How much coffee or energy drinks do you consume? Excessive caffeine can lead to irritability, affect your sleep and cause anxiety.





Who needs to know about your epilepsy?

Not everyone needs to know or needs to be told straight away. Even if you decide to tell people, how much you disclose is up to you. In most cases it is enough to provide information about the type of seizures you have, and what to do if you have a seizure.

If your studies place you in situations where there are genuine health and safety considerations such as working with machinery, near or on water, at heights, or in laboratories, you will have to disclose your epilepsy because you may put yourself and others at risk if you have a seizure. The university or college will need to carry out a risk assessment and look at ways to minimise any risks.

If you have regular seizures, consider telling some of the people you socialise with, and those living with or around you in your rented accommodation or student halls, so they can help if you have a seizure.

If you want to ask for reasonable adjustments, you will of course need to disclose your epilepsy to your college/university lecturer(s). The university/college's student disability service can help liaise with lecturers to ensure you get the right help and support for your studies.

You can choose how tell much your peers



New life, new challenges

Starting college or university means starting new routines and getting used to making your own decisions. Do not neglect looking after your health and epilepsy. Epilepsy does not need to rule your life, but you need to take it seriously and take sensible precautions to stay safe.

Stick to your medication routine

Going out, partying, late nights studying, and sleeping in can make it easy to forget to take medication or take it on time increasing the chance of seizures. If your new routines make it more difficult to stick to set medication times, speak to your epilepsy specialist nurse. Never make changes to how you take your medication yourself or stop taking it.

Risk assess your living space

If you stay in student halls, the provider will usually arrange a risk assessment if you have disclosed your epilepsy on your application form. An assessment should be based on the type of seizures you have, whether you get any warning, whether you have any known triggers or pattern.

You can do a basic risk assessment yourself. Pay particular attention to bathing and showering. Generally, if you live on your own, avoid taking a bath as there is a serious risk of drowning. A wet room or shower with level access is usually safer.

Declutter your accommodation to create more space and/or cover sharp furniture edges with plastic shaped pieces. This can reduce the risk of injury during a seizure. Internal and external stairs can be dangerous if your seizures are uncontrolled.

Contact your university or college's student disability service, or the company providing student accommodation if you require adjustments to your accommodation. You have a right to ask for reasonable adjustments under the Equality Act.

You may also consider having an epilepsy alarm installed. This could be a passive alarm picking up on a fall or convulsive seizures during the night, or a push button which you could use to alert a designated person within the building or someone who could attend you quickly if you need help.

If you need specific advice on safety, speak to your epilepsy specialist nurse. Also check out our 'Staying safe with epilepsy' guide which offers many more hints and tips on making your living environment safer. You can request a free copy by phoning our helpline 0808 800 2200 or download it at www.epilepsyscotland.org.uk.



New life, new challenges

Going out

Having epilepsy does not mean you cannot go out partying and have fun. Be mindful of possible seizure triggers and take some precautions to keep you safe and well.

Take your medication with you if you know you might be out late or stay the night at a friend's house. Rest during the day if you know it is going to be a late night. Tiredness from a lack of sleep is a common seizure trigger for some people.

If you have photosensitive epilepsy, which affects only around 2-3% of people with epilepsy, find out in advance if clubs and concert venues use strobe lighting effects.

Make sure that at least some people in your group of friends know you have epilepsy and know what to do if you have a seizure.

Alcohol & recreational drugs

Usually, drinking in moderation is ok, but always follow medical advice or check with your epilepsy specialist nurse, as alcohol can sometimes interfere with the effectiveness of some anti-seizure medications. Avoid binge drinking, as this increases the risk of seizures.

Beware of the after-effects of a hangover. Being dehydrated, tiredness, sleeping in and forgetting to take your medication can all be potential triggers for seizures.

Taking recreational drugs, including any synthetic legal highs, especially mixed with alcohol, increase the risk of a seizure.

Dating, sex and contraception

It is not always easy to know when you should tell a potential partner about your epilepsy. Some people tell straightaway, others wait until they get to know the person a bit better. There is no right or wrong way.

Some anti-seizure medications can reduce a person's sex drive as a side effect. Always seek medical advice from your epilepsy specialist nurse or GP if you are affected by this. Do not suffer in silence, seek help before it has a negative impact on your self-esteem and relationship.

If you are a woman, always seek medical advice on contraception. Some contraceptive methods can interfere with your anti-seizure medication's effectiveness and vice versa, increasing the chance of seizures or an unplanned pregnancy. Your epilepsy specialist nurse will be able to advise you on the right type of contraceptive method for you.

Never stop taking your anti-epileptic drug without medical advice, even if you have an unplanned pregnancy. A breakthrough seizure could put you or your unborn baby in danger.



Looking after your mental health

Starting a new life in a different city or even a different country can be exciting but also challenging for some students. Make the most of social media and technology to keep in touch with family and friends back home. Freshers' week is full of social events to help you get to know your fellow students and find out what's on to help you settle into student life. Feeling a level of anxiety in the beginning is completely normal.

Low mood can sometimes be a side effect of anti-seizure medications. Always seek medical advice if you feel you are affected by this. A medically advised change in dosage or even a different medication can often improve this side effect.

You may also feel initially anxious about meeting new people who don't know about your epilepsy and having a seizure in front of others.

Speak to someone if you feel your mental health continues to be affected. This is particularly important if you have epilepsy because stress and anxiety can be a seizure trigger for some people. Your student disability service can refer you to local mental health services. You can also contact our freephone confidential helpline on 0808 800 2200. We are always here to listen and provide guidance to make sure you get the help you need.



Feeling suicidal

While certain levels of stress are completely normal when you settle into a new life, there may be times when you may feel overwhelmed and struggling to cope. If you feel there is no way out for you, and you feel suicidal, please reach out for help. This can be your GP, a national helpline such as the Samaritans on 116 123 (open 24/7), or Breathing Space in Scotland on 0800 83 85 87. You can also phone our freephone confidential helpline on 0808 800 2200 during office hours.

Suicidal feelings can sometimes be a side effect of certain anti-seizure medications. Always contact your epilepsy specialist nurse for advice and a medication review if you start to feel suicidal.

Even if you suspect it might be your medication, never stop taking your medication without medical advice.



Contact us

We are here to help. Our helpline and information officers are great at listening. If you have any questions, have any concerns, or simply want to talk to someone, please contact our helpline on 0808 800 2200. There is no time limit on our calls, and we guarantee you a warm and friendly welcome.

Our resources are always free. If you text FACTS to 70085 to donate rate message.

get in touch

Freephone: 0808 800 2200

Text: 07786 209 501

Email: contact@epilepsyscotland.org.uk

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