



Better futures for
students with epilepsy



A Brief Guide to Epilepsy and Higher Education



What is epilepsy?

Epilepsy is a neurological condition that means someone is prone to having repeated seizures.

Epilepsy affects over 112,000 young people in the UK. It is estimated that approximately 15,000 are in higher education.

What are seizures?

A seizure is a sudden burst of excessive electrical activity in the brain, which temporarily interferes with the way it works.

The effects vary, but seizures can affect movement, sensation, behaviour, memory and/or consciousness.

The exact nature of what someone may experience during a seizure depends on many factors, including where in the brain the sudden excessive electrical activity occurs.

How much do you know about epilepsy?

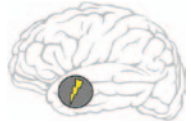
- 1) People with epilepsy should always avoid flashing lights.
True ☐ False ☐
- 2) You should restrain someone having a seizure so they don't hurt themselves.
True ☐ False ☐
- 3) You don't always need to call an ambulance when someone has a seizure.
True ☐ False ☐
- 4) Not all seizures cause the person to become unconscious.
True ☐ False ☐

Seizure types

Most people are aware of the classic 'tonic clonic' seizure. These involve muscle stiffening and jerking and a loss of consciousness.

However, there are over 40 different types of seizure. They affect the body and consciousness to varying degrees, although most fall into two main categories:

Focal seizures



- Only part of the brain is affected by the electrical activity.
- Consciousness may be disturbed or impaired, or the person may remain fully alert.
- The symptoms experienced will depend on the area of the brain that is affected.

There are many types of focal seizures with a vast array of possible symptoms including:

- A change in emotions.
- A feeling of déjà vu.
- Problems with speech, including confused speech.
- Problems with memory.
- Muscle weakness.
- Confusion/wandering around.
- Tingling or warm sensation.
- Feeling a limb is larger or smaller than usual.
- Unusual or repetitive body movements.
- Sight-related issues.



Problems with sight



Tingling or warm sensations



Problems with speech

Generalised seizures



- All of the brain is affected by the electrical activity.
- The person will become unconscious of their surroundings.



Tonic clonic seizures



Atonic seizures



Absence seizures

There are several distinctive generalised seizure types:

Tonic clonic seizures (used to be known as ‘grand mal’ seizures) - The person’s muscles stiffen (tonic) and then start to jerk (clonic). The person loses consciousness. A seizure lasts typically 2-4 minutes.

Tonic seizures - The person loses consciousness and their muscles suddenly stiffen causing them to become rigid. If standing, they will fall to the ground.

Atonic seizures - The person loses muscle tone, causing them to collapse to the ground. They will also lose consciousness, although this can be brief.

Absence seizures (used to be known as ‘petit mal’ seizures) - These seizures result in a sudden, but brief loss of consciousness. During the seizure, the person will usually stop what they are doing, stare blankly and become unaware of their surroundings. Absences are often mistaken for daydreaming.

Myoclonic seizures - The person’s muscles briefly jerk (as if they have had a sudden electric shock). Seizures often involve one or both arms, or the head. There is a brief loss of consciousness with each myoclonic jerk.

Treatment of Epilepsy

There are several different options for treating epilepsy, however the most common treatment method is antiepileptic drugs (AEDs).

The aim of AEDs is to stop all seizures or reduce them to a minimum with as few side effects as possible.

How effective are AEDS?

For about 70% of people with epilepsy, AEDs work well. However, some AEDs work better for certain types of seizures than others and finding the right AED can be a long and frustrating process.

Side effects

Not everyone experiences side effects from AEDs. They can also subside after their initial introduction. However, common side effects of AEDs includes:

- Memory, learning and attention problems.
- Drowsiness and lethargy.
- Dizziness.
- Coordination problems.
- Double vision.
- Changes in mood or behaviour.
- Increase or decrease in appetite.



Epilepsy and Higher Education

Life in higher education

Many students with epilepsy have their seizures well controlled by medication. However, it's important to remember that epilepsy can be unpredictable. It also affects people differently, both physically and socially.

Whilst many young people are confident and happy to talk about their epilepsy, some find it difficult and embarrassing - particularly if peers lack awareness.

*"The thought of having a seizure in front of other people...it terrifies me! I don't care that I have a seizure, I don't care that I feel sick and I'll go to bed. It's just the actual embarrassment of having a seizure in front of people." **Josh (19)***



Telling friends

Students with epilepsy should be aware that telling others about their epilepsy can be vital for their own safety, as well as that of their friends.

This can be daunting. Friends may be a little anxious at first - it may be their first experience of epilepsy. However, giving them information can really help.

"I was afraid it might freak my housemates out, but they were all really nice about it, which was good. I liked that." **Georgina (18)**

Changes in lifestyle

Moving from home to the heady new world of university life is often considered a rite of passage. However, for young people living with epilepsy, the impact of late nights, alcohol and increased study pressure can expose them to 'seizure triggers'.

Seizure triggers are the factors that can make a seizure more likely.

If a student has seizure triggers, they should consider adjusting their lifestyle to avoid them as much as possible.

For example:

- Getting sufficient sleep.
- Avoiding dehydration.
- Being sensible with alcohol intake.
- Reducing stress.



Education

Epilepsy is more than just a medical condition. Seizures and AEDs can affect memory, concentration and the way information is processed.

Seizures don't only affect a person at the time of their occurrence. Recovery periods can last for minutes, hours or even days. There may also be longer-term effects on learning and memory.

AEDs may also cause side effects that affect learning, such as:

- Drowsiness and lethargy.
- Slower information processing.
- Attention and memory difficulties.

The effects of epilepsy and AEDs can often be misconstrued in young people as laziness or disinterest. It is therefore vital to raise awareness amongst educators.

The reality is that students may miss lectures or need to extend assignment deadlines. Colleges and universities need to be aware and make provision for this. There are also support options that can really help, such as note-takers, mentors or the use of a dictaphone.

"I've had bad seizures and have taken falls, so I've missed out on classes." **Mark (21)**



Support

It is important for students with epilepsy to know who they can talk to when they need help.

There is plenty of support available in higher education. However, finding out what is available isn't always straightforward, but these support services should be the first place students could look:

Disability support services

Disability support services are a great place to start at most colleges and universities. They can help students with epilepsy to access practical and financial support, such as the Disabled Students Allowance.

Young Epilepsy

The Young Epilepsy website has an entire section dedicated to students that includes information on:

- Leaving home.
- Managing health.
- University lifestyle.
- Support services in higher education.

youngepilepsy.org.uk/students

The National Union of Students (NUS)

The NUS is a great source of information for students. It offers a range of advice and covers all the issues any student may face.

nus.org.uk



Test your Knowledge Answers

Answers:

- 1) **FALSE** – Photosensitive epilepsy only affects 5% of those with the condition.
- 2) **FALSE** – This is more likely to harm both you and them. It is better to move objects out of the way, place something soft under their head and let the seizure run its course.
- 3) **TRUE** – It is not always necessary to call an ambulance.
(See when to call an ambulance below.)
- 4) **TRUE** – Depending on the type of seizure, a person does not necessarily become unconscious. In focal seizures a person may be fully aware or could have their consciousness partially impaired.

When do you need to call an ambulance?

If someone is having a seizure, you should call an ambulance immediately if any of the following apply:

- You do not know the person.
- You do not know if the person has epilepsy.
- It is the person's first seizure.
- You are concerned about the person's breathing.
- The person has injured themselves.
- The person is having a convulsive seizure that has not stopped within 5 minutes.
- If you know the person but their seizure lasts for 2 minutes longer than is usual for them.

You should also refer to your institution's policy on what to do in the event of a student having a seizure.

Seizure First Aid

For more information on seizure First Aid, have a look at our website youngpilepsy.org.uk/seizure-first-aid



1. Time the seizure

2. Put something soft under the head

3. Move things out of the way

4. Keep the area safe

5. Explain to onlookers

6. Speak calmly and reassure



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Young Epilepsy Helpline

01342 831342 (Monday – Friday, 9am – 1pm)

helpline@youngpilepsy.org.uk

Text us: 07860 023 789

Better futures for young lives with epilepsy

Young Epilepsy

St Piers Lane, Lingfield, Surrey, RH7 6PW

Tel: 01342 832243

Fax: 01342 834639

Email: info@youngpilepsy.org.uk

youngpilepsy.org.uk

Young Epilepsy is the operating name of The National Centre for Young People with Epilepsy. Registered Charity No: 311877 (England and Wales).



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