

From Me and My Friends to You and Yours: Epilepsy (ep-ill-ep-sy)

What is it?

Epilepsy is a neurological condition, meaning that it is the brain that is affected. If you think of the brain as a computer that sends electrical signals to different parts of the body in order to work, seizures occur when things go wrong with the computer and it fires electrical signals in random bursts. A person has epilepsy when they have frequent seizures.

There are over 40 different kinds of seizures! The most common type of seizure, which 60% of people with epilepsy experience, is a tonic clonic seizure, which is what people tend to think of when they hear “seizures”, where someone loses consciousness and falls to the floor and shakes. Other common seizures include absence seizures (where someone is in a “daydream” state for a few seconds/minutes), and myoclonic seizures (where a part of someone's body shakes or jerks uncontrollably), and so many more!

It is also useful to know that seizures tend to come in three stages, and you might hear the words used to refer to each stage: Firstly, the aura. These come before a seizure. The experience of an aura varies but could be anything from a visual disturbance to a weird taste, and they often act as a warning to a person that they may have a seizure. Secondly the Ictal phase, which is the seizure. Lastly, the postictal phase, which is the time directly after the seizure. Often people are confused, unsteady, and tired, and this can last anywhere from a few seconds to a few days.

People with epilepsy can experience symptoms in addition to seizures. Sometimes it is hard to know if these symptoms are seizures in themselves, or side effects of medications, but common ones include memory problems, balance problems, and “brain fog”, which is exactly what it sounds like! It is also worth thinking about the big impact epilepsy has on how a lot of people feel (around 40% of people with epilepsy also have depression).

Usually people are treated for epilepsy with a type of medication called “antiepileptics” that they take every day. For around 70% of people with epilepsy this helps to control their seizures, alongside lifestyle changes to minimise seizure triggers. There are other management strategies, but the only option that is a kind of “cure” is surgery, to try and fix what is causing the seizures, however only a small proportion of people with epilepsy are eligible for surgery.

How it affects me:

... my body ...

Epilepsy affects my body most obviously when I have seizures, and with all three stages of that as discussed above. Specifically for me an aura makes me feel quite seasick with my vision all blurred and dotted before a tonic clonic seizure, and afterwards I am very disoriented and initially can't remember my name or stand up, and for the following days am very tired and struggle to walk and perform simple tasks as my brain recalibrates. Sometimes I get “Todd's palsy” after a seizure, where I don't have control over the right side of my body. I take medications to prevent me from having seizures, however they come with side effects, and I have had to try a few to find some that balance side effects and managing seizures. The side effects, seizures, and symptoms, are all further confused by having migraines, which often present as a kind of headache. A combination of these things lead to me experiencing dizziness, nausea, pins and needles sensations, issues with my memory and balance, amongst other things, although it can be tricky to work out what is causing what!

... my mood ...

When I feel like my body isn't working properly, because of seizures or side effects, it can get me down and make me feel frustrated. It also gets me down when I have to miss out on things because I have been having seizures, or anticipate having a seizure. Even when I am not having seizures it can still make me feel anxious, especially about new situations or going to new places, because I still have the worry of what would happen if I have a seizure. This worrying about seizures can lead me to get stressed about seizure triggers. For me, being tired is my biggest seizure trigger and so I can get quite stressed about getting enough sleep.

... my life...

Trying to prevent seizures is really important, and this means making lifestyle changes. I pace what I do, often missing out on things I want to do in order to prevent getting close to my 'seizure threshold'. If I do have a seizure then that means missing out on even more things, often social things or education, or it can even mean an unexpected hospital stay which can be scary. I have to be more careful when doing things like cooking or showering, because I need to be thinking about what would happen if I fell and had a seizure- I am definitely more accident prone! Having seizures also means being unable to have baths, which I don't mind, or drive, but it does mean being eligible for a free bus pass!

Three ways friends can help...

1. SEIZURE FIRST AID... ask about your friend's epilepsy! What kind of seizures they have and what to do if they have one- this includes if they have any rescue medication you should administer and under what circumstances you should do this, or if there are any circumstances under which you should call an ambulance, or their parents/carers, or flatmates. The general rule is to call an ambulance if a seizure lasts over 5 minutes or if they have injured themselves, but this varies from person to person which is why you should ask! This helps keep your friend physically safe when you are out together, but also gives them peace of mind knowing you would know what to do.
2. SEIZURE TRIGGERS... Having conversations with your friend about what their seizure triggers (things that make them more likely to have a seizure) are, and being another pair of eyes for your friend in looking out for them and avoiding them!
3. TALKING... epilepsy can be scary and lonely, and so having friends asking about how things are is really lovely, and can make a really big difference!

A friend's perspective..

I had heard of epilepsy before but I knew very little about it; my perception of it was that people with epilepsy fall to the ground and jerk when they see a bright light (photosensitive

epilepsy only affects 3% of people with epilepsy!). I did some research and tried to understand what was making my friend ill. The resources I found online are useful in gaining a generalised understanding but they don't fully paint the picture of what living with epilepsy is like. I think the most comforting thing you can do if your friend is diagnosed with epilepsy is to have patience. Initially Ally was quite slow to talk about all of it, and I know that she probably felt out of control with everything so I completely wanted to be patient and for her to have control over who she told and what she told them. I would also say as a friend you can support by asking questions to normalise it, and to understand how you can support them, and to just be thoughtful and not freak out or treat them differently. Whatever you are feeling, they are experiencing that on a much deeper level. Be proactive and live your best lives. Ally and I have been travelling, gone to uni and created the best memories together.

Resources for finding out more...

If you would like to find out more about epilepsy, here are some other resources that are designed for young people...

- <https://epilepsyspace.org.uk/> The Epilepsy Space was created by Epilepsy Action with the help of a group of young people to make it completely what young people would want! I was lucky enough to be one of those young people. There is loads of factual information to answer your questions, but also lots of peoples experiences, which I find reassuring to read.
- <https://thechannel.org.uk/> The Channel is another space for young people with epilepsy, created by the charity Young Epilepsy, it is filled with loads of videos covering all sorts- interviews with famous people with epilepsy, vlogs from people with epilepsy and their friends, and medical professionals, such as epilepsy nurses.

It's also worth having a look at some of our blogs, or listening to our podcasts, which you can find through our social media channels. There are blog posts on socialising with epilepsy, the importance of meeting people in similar situations, and the gains as well as the losses.

About the authors

Ally (she/her) ...is 20 and is living in Glasgow. She enjoys going camping, even though it is usually just in rainy Scotland!

Ross (he/his) ... is also 20, and is getting ready to move to Spain for a year abroad next year!

Ross and Ally have been friends since school, and then ended up both going to uni together, which has been just one of many adventures! (although Ross prefers his adventures a bit sunnier than Ally as you can probably tell!)

Get involved!

We would love to get as many people involved in creating these resources as possible! If you are a young person living with a chronic illness, disability, or long term health condition, and would be interested in making a similar resource based on YOUR experiences, we would love to hear from you! You can email us at thelunaprojectuk@gmail.com ! You can also find us on social media [@thelunaprojectuk](#) !