

All about epilepsy

Epilepsy is a medical condition that affects just over half a million people in the UK, including children. It is caused by a problem in the brain that can sometimes stop the body from working the way it should.

Inside

- What are seizures?
- First aid
- Real life stories

The brain

Your brain is the control centre of your body - here are just a few examples of things it makes possible:



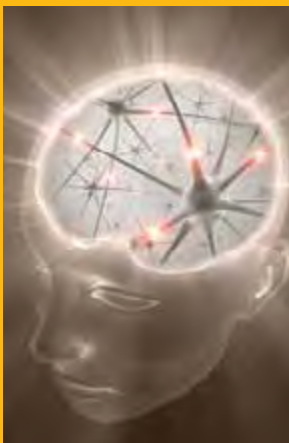
FACT

63,000 young people in the UK aged 18yrs and under have epilepsy. That's enough to fill Arsenal's Emirates Stadium!

Seizures

Your brain works by sending and receiving information in the form of **electrical messages**. People with epilepsy experience sudden and uncontrolled bursts of electrical activity in their brain – called a **seizure**.

Seizures interfere with the way the brain works for a short time. During this time, the person's **behaviour** may change or they may experience a **strange sensation** of some kind. They cannot stop what is happening and must wait for their brain to sort out the disruption.



What do seizures look like?

Generalised seizures

In these types of seizures, a random burst of electrical activity disrupts the entire brain and the person becomes unconscious. This can affect people in different ways. Here are 3 examples:



Tonic clonic seizures

What happens?

1. The person's body will suddenly stiffen (tonic = stiff) as the brain sends electrical messages out to all of the body's muscles at once.



2. They will become unconscious and fall over if standing.
3. Their body will begin to shake or convulse (clonic = convulsions).



4. After a short time, the person should stop shaking and come around.



Usually lasts 2-4 minutes.

Atonic seizures

What happens?

1. The person's body will suddenly become floppy and they will become unconscious.



Usually lasts less than 20 seconds.



2. The person will drop to the floor.
3. After a short time, the person will come around.

Absence seizures

What happens?

1. The person will suddenly stop what they are doing.

2. They will stare into space and look as though they are day dreaming but will not respond to you.
3. After a short time they will come around and may be unaware that anything happened to them.



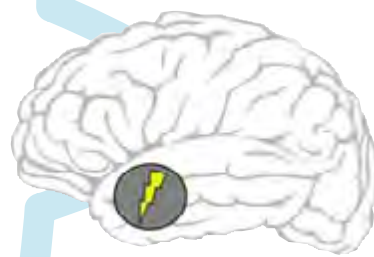
Usually lasts 5-10 seconds.



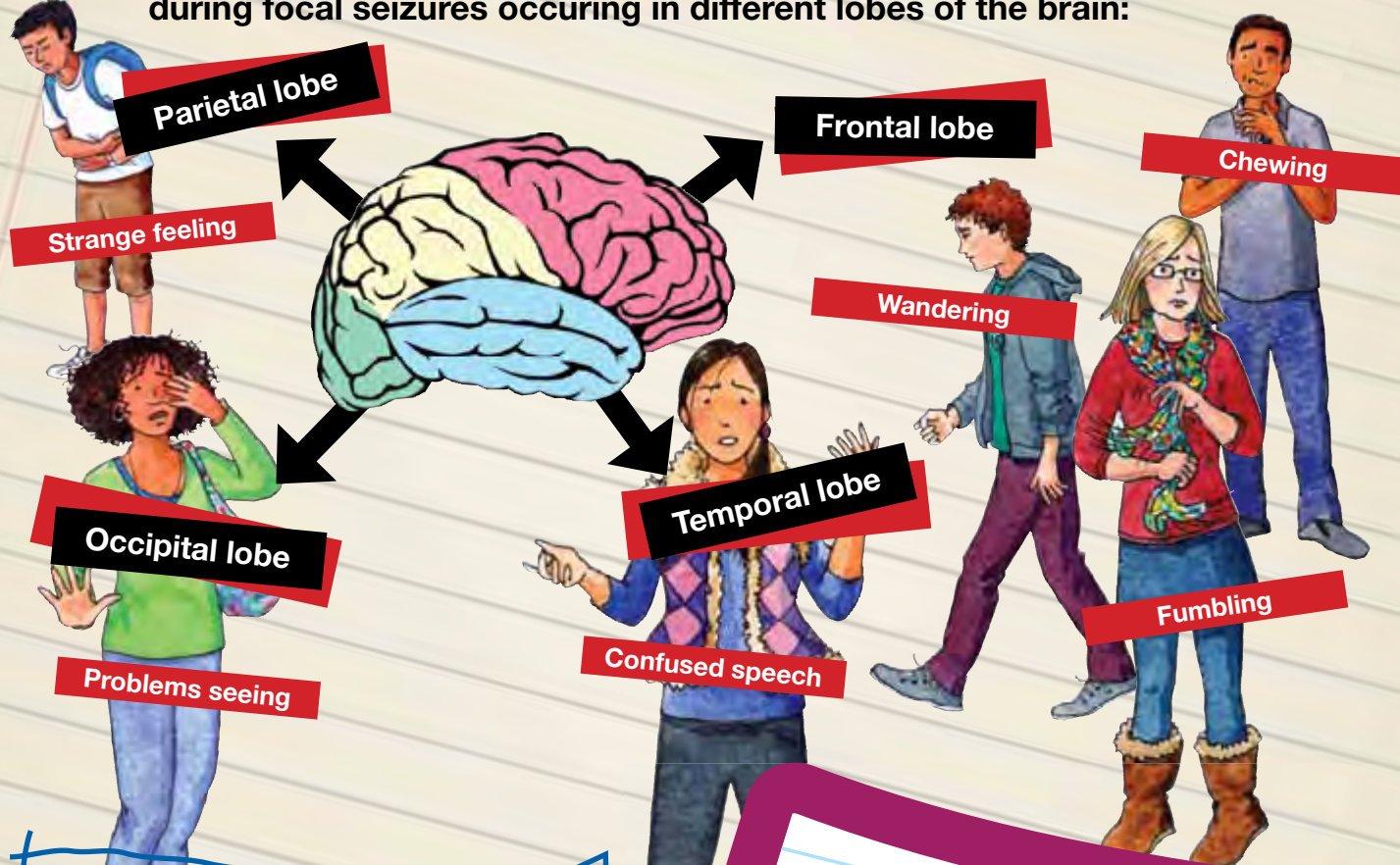
Focal seizures

In these types of seizures, only one part of the brain becomes disrupted.

Our brains are made up of different parts called **lobes**, each of which is responsible for making different things happen in our bodies. What happens to someone during a focal seizure depends on what job the disrupted part of the brain normally does. They may appear very confused or be completely aware of what is happening to them.



Here are some examples of what might happen to people during focal seizures occurring in different lobes of the brain:



How do you get epilepsy?

Some people have epilepsy because a part of their brain has been **injured**. This may have happened whilst they were a developing baby, or during a difficult birth. An illness or a serious head injury could also be to blame. Some types of epilepsy can be **inherited** and are passed down through families in their **genes**.



FACT

The cause of epilepsy is unknown for 6 in 10 people with epilepsy, in the UK.

How to help

Seeing somebody have a seizure can be scary, confusing and very unsettling. However, knowing what to do will help you stay calm and give you peace of mind. The person with epilepsy will also feel much more confident getting on with life if the people around them know how to help!



DO

- Time the seizure
- Call for help
- Cushion their head
- Move nearby objects away
- When the shaking has stopped, place them on their side
- Stay with the person until they are fully recovered and reassure them



DON'T

- Panic
- Move the person (unless there is unavoidable danger)
- Restrain the person
- Try to wake them up



FACT

Call 999 if:

It is the person's first seizure.

The seizure goes on for more than 5 minutes.

They have injured themselves.

Fundraise for Young Epilepsy!

Young Epilepsy relies on lovely people like you to help us raise money so we can continue supporting children living with epilepsy!



For ideas about how you could help, visit youngepilepsy.org.uk/get-involved



Design a seizure first aid poster!

This picture shows what people should do to help someone having a tonic clonic seizure. If your class designs some seizure first aid posters and

sends them into Young Epilepsy, we will send your class a certificate! (Please send them to Education 4 Schools, Young Epilepsy, St Piers Lane, Lingfield, RH7 6PW.)



Can you stop seizures from happening?

There are various treatments available for epilepsy that are intended to stop seizures from happening or at least make them occur less often or last a shorter time.

The most common treatment is with **antiepileptic drugs (AEDs)**. These are tablets which are taken every day and work well for the majority of young people who take them. However, some people may experience side effects such as feeling sick, dizzy or tired.

Brain surgery is another possible treatment for certain types of epilepsy.

FACT

People who have atonic seizures (see page 2) may need to wear protective headgear to prevent injury to their head and face.



For more information on the treatment of epilepsy visit youngepilepsy.org.uk/epilepsy-types

Living with epilepsy

Staying safe

Young people with epilepsy, and the people around them, often worry if it is safe for them to do certain activities in case they have a seizure and get hurt.

We all do things to keep safe when doing activities - so somebody with epilepsy is no different! One of the best things they can do is to make sure there are people around them who know what to do if they have a seizure.

Should someone with epilepsy take part in these activities? If so, how can we make them safe?

Answers at the bottom of the page.



Driving



Swimming



Sleepovers

Worries

There are lots of things a young person with epilepsy might worry about; especially when they first find out they have the condition.

FACT

A seizure trigger is something that can make a seizure more likely to occur for some people. Examples include being ill, stressed, tired and flashing lights (although quite rare!) A healthy lifestyle can make seizure triggers less of a problem.

Are the tablets going to make me feel ill?

Will I have a seizure today?

Will I always have epilepsy?

Will I hurt myself during a seizure?

How will my mates react?



Driving – A young person with epilepsy is only allowed to drive if they have not had a seizure in the last year.
Swimming – Tell the life guard, don't go alone or when the pool is mega busy.
Sleepovers – Put the mattress on the floor if they have seizures during their sleep, make sure their friends and parents know what to do if they have a seizure.

ANSWERS

Ask Charlie

I've been ignoring his texts.

Dear Charlie,
A friend of mine with epilepsy had a seizure when we were out on our bikes last week. He fell over and his body shook all over for a while - I was so scared! Luckily, a man in the park came to help because I had no idea what to do! He's fine now but I'm worried about going out with him in case it happens again. I've been ignoring his texts because I don't know what to say! I feel really bad, what should I do?

X, London



My boyfriend won't talk to me about his epilepsy.

Dear Charlie,
I have been going out with my boyfriend for 6 weeks now and I really like him. The other day, his mum asked if I knew about his epilepsy but he quickly changed the subject. Whenever I ask him about it he gets the hump and we have a huge row! Can you tell me what epilepsy is and should I be worried?

Catrina, Wales



My parents are treating me like a prisoner.

Dear Charlie,
I got told a couple of months ago that I have epilepsy. My parents are not letting me do anything anymore and have said that I can't go swimming or to a sleepover this Saturday- it's so unfair! I'm taking my tablets and haven't had a seizure for weeks but they are still treating me like a prisoner! Dad said I'm only allowed a sleep over if my friends come to our house, but it's all arranged now. I'm worried my friends are just going to give up on me! Help!

R, Wembley



Should I tell them about my epilepsy?

Dear Charlie,
I want to be a professional footballer and have a trial for my local team in a few weeks. I have atonic seizures which make me fall down suddenly and I usually get a strange taste in my mouth just before it happens. My cousin thinks I should tell the club in case I have a seizure and they don't know what to do, but I reckon they won't want me if I tell them and won't even bother giving me a trial! What should I do?

X



For suggested answers visit
youngepilepsy.org.uk/ask-charlie-the-answers

Real life stories

Dai Greene



Welsh hurdler and Olympic athlete Dai Greene.

Dai is an official ambassador for Young Epilepsy and commented: 'As an elite athlete, I hope to inspire all young people that you can live a normal life with epilepsy and follow your dreams to do whatever you want. I was diagnosed with epilepsy at the age of 17, and I'm lucky that my condition is not severe but I have learned to change my lifestyle and know my trigger points to stay away from seizures.'

'I was 11 when I started having temporal lobe seizures. They were in the form of very unpleasant feelings and I was terrified because I didn't know what was happening to me.'

'Overall, my friends have reacted in a good way. They are accepting although I do get teased a bit (though in a friendly way). When it comes to doing all the things my friends can do, like paintballing, swimming etc, I feel more secure and safe if the people around me know about my epilepsy and what to do in the event of a seizure.'

Rhys's story



For more real life stories about epilepsy visit youngepilepsy.org.uk/real-stories

Better futures for young lives with epilepsy

Young Epilepsy, St Piers Lane, Lingfield, Surrey, RH7 6PW
Tel: 01342 832243 Fax: 01342 834639
Email: info@youngepilepsy.org.uk
Visit: youngepilepsy.org.uk

Like us on Facebook: Young Epilepsy
Follow us on Twitter: @youngepilepsy



Young Epilepsy Helpline
01342 831342 (Monday-Friday, 9am-1pm)
helpline@youngepilepsy.org.uk



What is Young Epilepsy?

Young Epilepsy is a charity which aims to improve the lives of children and young people with epilepsy in the UK.

Young Epilepsy has over 100 years experience and provides expert medical, education and support services for young people with epilepsy, their families and professionals too.

