### Young Epilepsy 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.

#### Your brain

Your brain is the boss of your body; everything you do, think and feel needs your brain to make it happen! Here are some examples. Can you think of any more?







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

Inside

pilepsy stories

#### Seizures

Your brain works by sending messages around your body using a type of electricity. In epilepsy, this **electricity** can suddenly go wrong, causing the brain to become **muddled**. This is called a **seizure**.



When somebody is having a seizure, they might behave differently or feel strange in some way. They cannot stop what is happening to them but their brain usually only takes a short time to sort out the muddle and work properly again.

What do seizures look like?

### Seizures that make all of the brain muddled

Some seizures cause the whole of the brain to become muddled. This usually happens suddenly and makes the person



unconscious (a very deep sleep where they cannot be made to wake up). Different things can happen to different people during this time.

## Tonic clonic seizures

### What happens?

- 1. The person's body will suddenly stiffen. 2. They will become unconscious and fall over if standing.
- 4. After a few minutes, the person should stop shaking and 'wake up'. 3. Their body will begin to shake.

### Absence seizures

### What happens?

- 1. The person will suddenly stop what they are doing.
- 2. They will stare into space and look like they are day dreaming. 3. The person will come around and may not even know that

FACT

- anything has happened to them.



Usually lasts 2-4 minutes



Somebody having a tonic clonic seizure does not feel any pain, even if it looks like they do. Their brain is in too much of a muddle to feel anything at this time.

### Seizures that make part of the brain muddled

In focal seizures, only one part of the brain becomes muddled. Think back to all of the brilliant things our brains do; any of these things could go wrong during a focal seizure if the part of the brain that makes it happen has become muddled.

### So, what might happen to someone during a focal seizure?

The bit of the brain that helps with speech has become muddled, making this girl say things that don't make any sense.

The bit of the brain that helps this boy move has become muddled, making him wander around in a confused way.



The bit of the brain that helps with touch has become muddled, making this girl pluck at her clothes.

Somebody who is having a focal seizure may be very confused. A healthy lifestyle, such as getting enough sleep and avoiding stress, can sometimes reduce the number of seizures a person has,



Find out more about seizures at youngepilepsy.org.uk/what-are-seizures

### How to help

Seeing somebody have a seizure can be scary and confusing, but knowing what to do will help you stay calm. The person with epilepsy will also feel better about going out and enjoying themselves if the people around them know how to help!



- Call for help
- Cushion their head
- Time how long the seizure lasts
- Move nearby objects away
- When the shaking has stopped, place them on their side
- Talk to them during the seizure and stay with them until they are okay

#### DON'T

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

### Call 999 if:

It is the person's first seizure.

The seizure goes on for more than 5 minutes.

They have injured themselves.

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

FAC

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!

Z

# 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 to 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?

Children with epilepsy usually take special tablets everyday called **antiepileptic drugs (AEDs)**. These are meant to stop seizures from happening, or at least make them happen less often or last a shorter time. The tablets can make some children feel unwell such as feeling tired, dizzy or sick. Staring and crowding around somebody having a seizure can make them feel embarrassed.

5



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

### Living with epilepsy

#### Worries

Children with epilepsy may worry about some things, especially when they first find out they have epilepsy. Having people around them who they can talk to will really help!

Will I have a seizure today? Will my tablets always make me feel tired?

### Staying safe

Children with epilepsy sometimes get left out of activities because people worry they could get hurt if they have a seizure. The good news is that most children with epilepsy can carry on doing the activities they enjoy as long as they are careful and do some simple things to help keep safe – just like we all do!

What could someone with epilepsy do to stay safe whilst doing these activities? Suggestions are at the bottom of the page. Will I hurt myself during a seizure?

Sleepovers

Swimming

Will I always have epilepsy?

Do friends think I'm strange?

Leon Legge, central defender for Brentford United FC has epilepsy and says: 'I don't let epilepsy get in the way of what I do.'

what to do if they have a seizure. Skateboarding – Wear a helmet and shin and elbow pads, don't go alone, avoid high ramps and traffic if seizures occur often.

is mega busy. Sleepovers – Put the mattress on the floor if they have seizures during their sleep, make sure friends and their parents know

ANSWERS: Swimming – Tell the life guard, don't go alone or when the pool

Skateboarding

# Ask Charlie

Here are some problems children with epilepsy and their friends and family may have.

Can you help?

### My parents are treating me like a prisoner!

I got told a couple of months Dear Charlie, ago that I have epilepsy. My parents have said that



I can't go swimming with my friends or to a sleepover this Saturday- it's so unfair! I haven't had a seizure for weeks but they are still treating me like a prisoner! Dad said I'm only allowed a sleepover if my friends come to our house. I'm worried my friends are just going to give up on me! Help! R, Wembley.

#### I'm scared I'll do the wrong thing!

Dear Charlie, My brother has epilepsy and sometimes falls down and shakes all

over. My mum and dad and our teachers know what to do if he needs help, but I'm scared it might happen when they are not around and I do the wrong thing. I know I should put something soft under his head but is that it? Is there anything else I need to do?

Jake, Manchester.

#### It's really embarrassing!



Dear Charlie, I have absence seizures which last for

a few seconds but can happen many times each day. When they happen in class, I usually miss something I've been told or a question someone's asked. I have to keep asking people to repeat things and it's really embarrassing. I used to do really well at school but don't think I am now. I don't want to talk to my teacher because I don't think there is anything she can do to help. It makes me really upset. What should I do?

#### They keep whispering about me!

Dear Charlie, A few weeks ago

something strange happened to me at school. I don't remember anything but my mum said I was wandering around and really confused. When people tried to speak to me, I didn't answer. I have since found out that I have epilepsy. I am taking tablets but it could still happen again. My friends are avoiding me and I think they are whispering about me behind my back. I don't know what to do. I feel alone and I'm worried it might happen again. X, Scotland.

For suggested answers visit youngepilepsy.org.uk/ charlies-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 seizures. I would have very strange feelings and I was terrified because I didn't know what was happening to me.'

'Over all, my friends have reacted in a good 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.'



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

Rhys's story



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 other people too.



Young Epilepsy is the operating name of The National Centre for Young People with Epilepsy. Registered Charity No. 311877 (England and Wales).© Young Epilepsy 2012