

This booklet is for children in primary school.

Please read this booklet, it will help you understand your epilepsy.

This booklet was designed as part of a medical student project looking at the understanding and information needs of primary school children

It could not have been written without the help of some of the children (and their parents) who visit the Children's Epilepsy Clinics in Swansea. We would like to thank them for their time and input.

We hope that the information is helpful to children, their families and friends as they learn more about epilepsy.

Gemma Whiles - Medical Student Sharon Brown - Children's Epilepsy Nurse Cathy White - Consultant Paediatric Neurologist Children's Epilepsy Service, Swansea

What is epilepsy?

Rhys

This is Rhys. He is nine years old and loves to play football and rugby. His favourite teams are Swansea City and The Ospreys. He likes to watch them play with his dad.





Megan

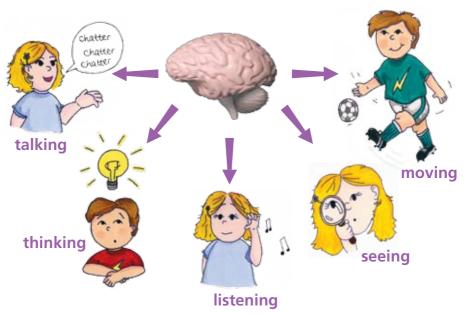
This is Megan. She lives two streets away from Rhys. They go to the same school but are not in the same class as Megan is six. Megan loves to have sleepovers with her friends from school. She also loves drawing and her funny pictures always make her friends laugh.

Rhys and Megan are just like all of the children at their school except that sometimes they have seizures.

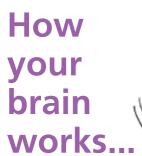
So... what is a seizure?

Seizures are called lots of different names. You might hear them being called fits, convulsions or funny do's. All of these words mean the same thing. Perhaps you have a different name for yours.

To understand what happens when you have a seizure, you first need to know a little bit about your brain...

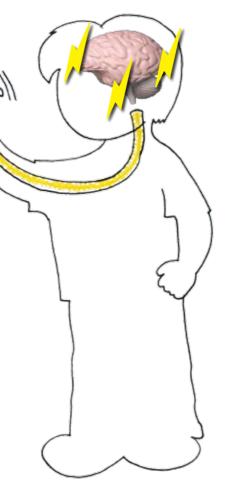


The brain Your brain is inside your head but it is in charge of your whole body.



Electrical sparks that start in the brain travel to different parts of the body to tell it what to do.

When Rhys wants to wave his arm, his brain sends a message to his arm using electrical sparks to tell it to move.



What is a seizure?

When you have a seizure, the electrical sparks in your brain get mixed up for a short time.



Having a seizure can be very tiring and you might feel very sleepy afterwards.

What does it look like when I have a seizure?

You might fall to the floor, go stiff and jerk for a little while. This type of seizure is called a tonic-clonic seizure.

Tonic-clonic and absence seizures are called generalised seizures because

they happen when the electrical sparks in the whole brain get mixed up.

There are other types of seizure where the electrical sparks in only a small part of the brain get mixed up. These are called partial seizures.

If you have absence seizures, you might just look like you are day-dreaming.



Rhys found out about his seizures on the website.

To learn more about the different types of seizure, look at www.epilepsy.org.uk/kids

What does Epilepsy mean to me?

Having epilepsy shouldn't change what you can do. Children with epilepsy still have to go to school.

TIPEL ISSUE

Children with epilepsy can still play their favourite sports -

even swimming as long as there is someone there to make sure they are safe in the water.



What should I tell my friends?

Your friends, and even your brothers and sisters might not know much about epilepsy. If you would like to help them to understand more about epilepsy, you could show them this booklet.

Megan read her booklet with her friend Carys.

Carys was happy to learn about Megan's epilepsy.



After reading about epilepsy, Carys wanted to know what she should do if Megan had a seizure.

What should you do if someone has a seizure?

It is not hard to look after someone who is having a seizure:

- If they have fallen to the ground put something soft under their head.
- Stay with them until they are back to normal.

DON'T:

- Try to put anything in their mouth.
- Try to stop the seizure or move them unless they are in danger of getting hurt.
- There is no need to call an ambulance unless the seizure lasts longer than five minutes or they are hurt.

If they have fallen and are not fully awake, put them into the recovery position.

The Recovery Position



Tests for Epilepsy

Sometimes, to find out more about your seizures, the doctor will ask you to have some tests. These are not tests like you have in school - there is no need to worry about having them. The tests will help the doctors to find the right medicine to help stop your seizures.

The EEG

The EEG is a short name for a test called the ELECTROENCEPHALOGRAM but don't worry – you don't have to remember

the name!

The picture shows Aled, a 10 year old boy, having his EEG. He doesn't look frightened, does he?

The EEG specialist has stuck 20 small electrodes onto



Aled's head. The electrodes measure the electrical sparks in his brain. The measurements are taken to an EEG machine which makes them into a pattern. The pattern is called an EEG recording. The recording is shown on a television screen or printed onto paper. The picture shows an EEG recording. The pattern tells the doctor about the electrical sparks in your brain.

During the test Aled will have to lie very still but it is only for a short time. Sometimes the EEG specialist asks Aled



to blink, breathe quickly and look at flashing lights.

These are to test the different parts of the brain – remember, each part of the brain has a different job!

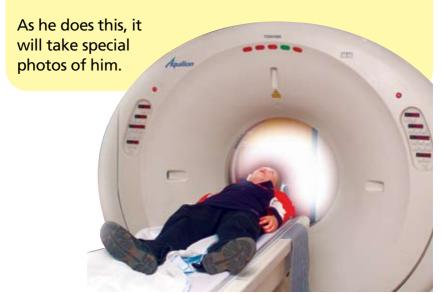
A scan is another type of test you might have. You may have an MRI scan or a CT scan. They are very similar.

During the scans you will have to lie down on a bed and then you will go into a tube that takes photos of your brain.

Having an EEG doesn't hurt and it might help the doctor to find the right medicine to make your seizures stop.

The Scan

This picture shows Huw, a seven-year-old boy, just before his scan. Huw thought the scanner looked a lot like a polo mint! In this scan Huw lies down on the bed and goes through the hole in the middle of the scanner.



The scanners are just big brain cameras. Having the pictures taken does not hurt but it can be a bit noisy.

Epilepsy

Anyone can have a seizure but some people have more than one seizure.

When someone has more than one seizure it is called epilepsy.

Rhys and Megan both have epilepsy because they have had more than one seizure.

Now that you have read a bit about epilepsy, you might have a few questions for your doctor. Write them down here and take them to your next appointment.

Treatment

Treatment of epilepsy means taking tablets or medicine to try and stop the seizures.

Tablets and medicines work by helping the electrical sparks in the brain to work normally and stop them getting mixed up. Remember - seizures happen when the electrical sparks in the brain get mixed up!



When you take a tablet or medicine, it doesn't work for very long as it soon gets used up by the body. This is just like when you eat some food - it doesn't fill you up for ever, you soon need more.

Just as you need to keep eating, you need to keep taking your tablets or medicine so that it can keep working to stop the seizures.

There are lots of different tablets and medicines for people with epilepsy.

Which tablet or medicine you take depends on lots of different things. The doctor tries to pick the best one for you.

Your doctor will tell you how many times a day you need to take your tablets or medicine. Megan takes her medicine twice a day. At first, she found it hard to remember but now she takes it at breakfast time and at bed time so she doesn't forget.

Where to find out more!

If you want to learn more about epilepsy there are lots of people who can help:

Mum Dad Doctors Nurses

They will be happy to answer any questions that you have about epilepsy. They will even tell you where to find more information if you need it!

If you can think of anything that you would like to ask

your doctor. Write it down here and take it to your next appointment.	

If you have access to the internet, a good place to find out more about epilepsy is the Epilepsy Action website: www.epilepsy.org.uk/kids

You can also pick up more leaflets about epilepsy. A good leaflet to read is 'Epilepsy – The Detective's Story'

Puzzles

Can you find the seven differences between the two pictures?



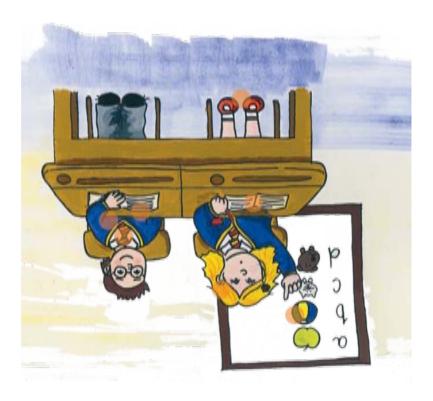


There are ten words hidden in the grid. Can you find them?

- Epilepsy
- Seizure
- Electrical sparks
- Brain
- Recovery position
- MRI scan
- EEG
- Doctor
- Rhys
- Megan

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answers



answers

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Useful Contact Details

EPILEPSY WALES P.O.Box 4168 Cardiff CF14 0WZ

Tel: 08457 413 774

www.epilepsywales.co.uk

NATIONAL SOCIETY FOR EPILEPSY

Chesham Lane Chalfont St. Peter Buckinghamshire

SL9 ORJ

Tel: 01494 601300

Helpline: 01494 601 400

Website: www.epilepsynse.org.uk

EPILEPSY ACTION SCOTLAND

48 Govan Road Glasgow G51 1JL

Tel: 0141 427 4911 Fax: 0141 419 1709

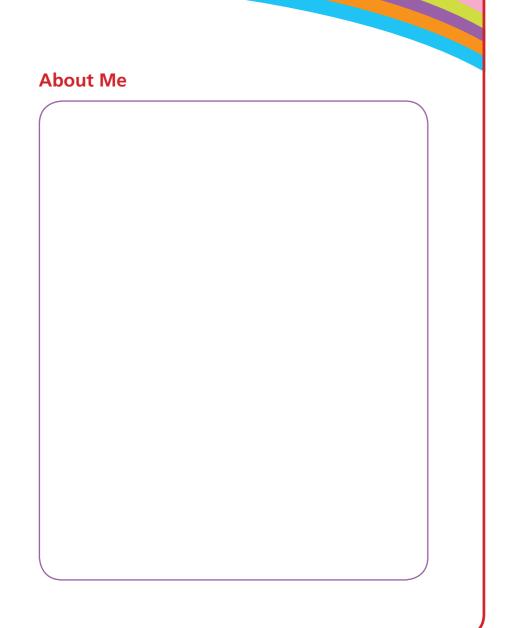
www.epilepsyscotland.co.uk

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Yeadon Leeds LS19 7XY

Helpline: 0808 800 5050 Website: www.epilepsy.org.uk

Local Contact Details



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