

My Mum Has Epilepsy

Me →

A story to
help parents
explain their
epilepsy

→ Rascal



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New Anstey House, Gate Way Drive,
Yeadon, LEEDS, LS19 7XY United Kingdom

Telephone: **0113 210 8800**

Email: **epilepsy@epilepsy.org.uk**

Epilepsy Action Helpline 0808 800 5050

Artwork & Illustration by Flokk Ltd

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Epilepsy Action



My Mum Has Epilepsy

This information is for anyone with epilepsy who is a parent or cares for a young child. When you decide to tell your children about your epilepsy is your decision.

This story aims to help you with that conversation. Children need to know what epilepsy is and that it's nothing to be afraid of. They also need to know what they should do if you have a seizure. This is a story about a young girl whose mother has epilepsy.

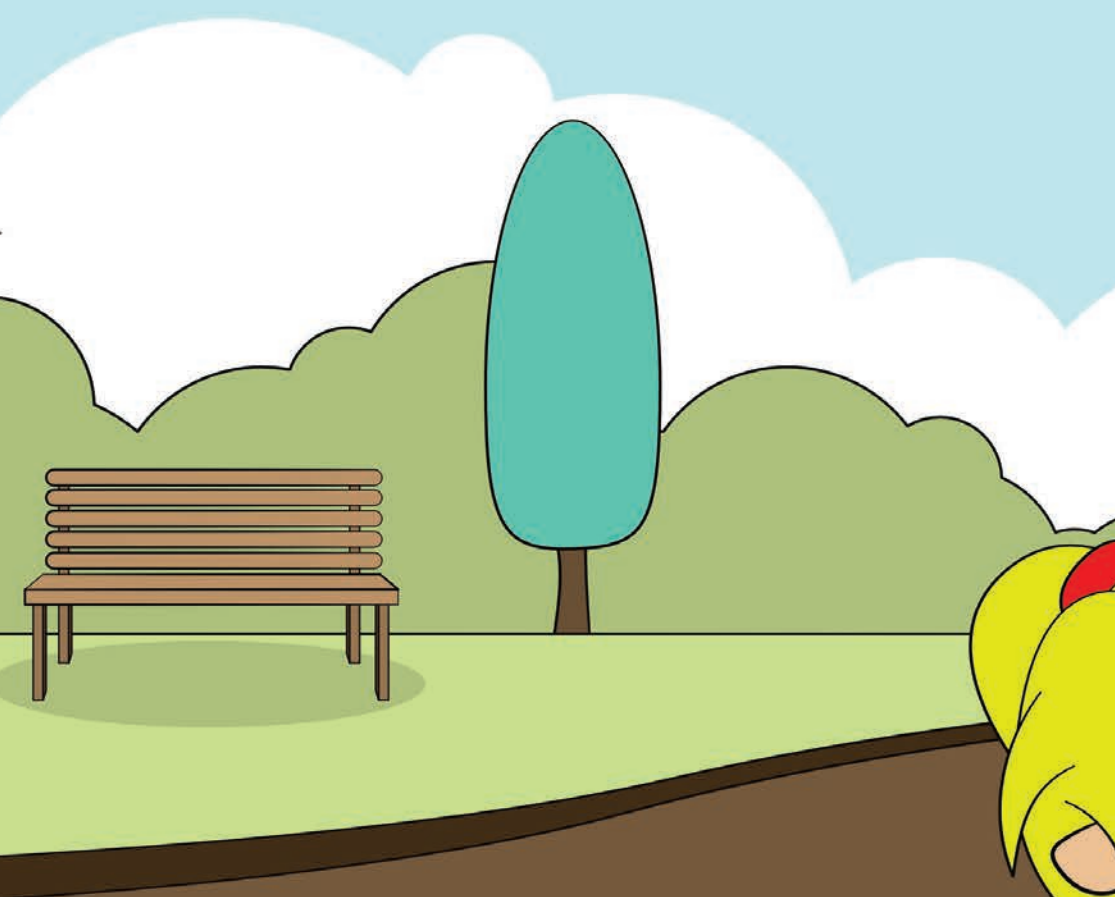


This is a story about me and my mum.
We live with my dad and my big sister Jess. Jess
is 17 and she goes to college.

We've got two dogs, called Rascal and Tiny.
Every day after school, me and my mum take
Rascal and Tiny for a walk in the park.

Sometimes Jess comes too.





One day me and Mum were in the park with Rascal and Tiny. We were throwing a stick for them to fetch. Jess was on the other side of the park, watching her boyfriend Ali play football.

Then Mum said she was feeling a bit funny.

"I think I'll go and sit down on the bench," she said.

I carried on throwing the stick for Rascal and Tiny. Then I threw the stick too high and it got caught in a tree. I couldn't reach it, so I went to get Mum.





Mum?

But when I looked round, Mum wasn't on the bench, she was lying on the ground. I ran over to her. Her arms and legs were jerking and she wasn't breathing properly.

"Mum, what's wrong? Mum!" I said. But she didn't answer me. I was really scared, but I ran and got Jess.

"Something's wrong with mum," I said. Jess ran over to mum and Ali came too. Ali took off his sweatshirt and put it under Mum's head.

"I think your mum is having an epileptic seizure," said Ali. "My cousin Ben has epilepsy. Is it the first time your mum's had a seizure?"

Me and Jess said yes, it had never happened before.

"Then we should call an ambulance," said Ali.







So Jess used her mobile phone to call an ambulance. Then she phoned Dad and told him to come over to the park.

Soon Mum stopped jerking and her breathing got better. Ali carefully put Mum in a special position on her side. Ali said that this was called the recovery position.

After a while, Mum started to move and she looked up at us. She was very confused and her mouth was bleeding because she'd bitten her tongue.

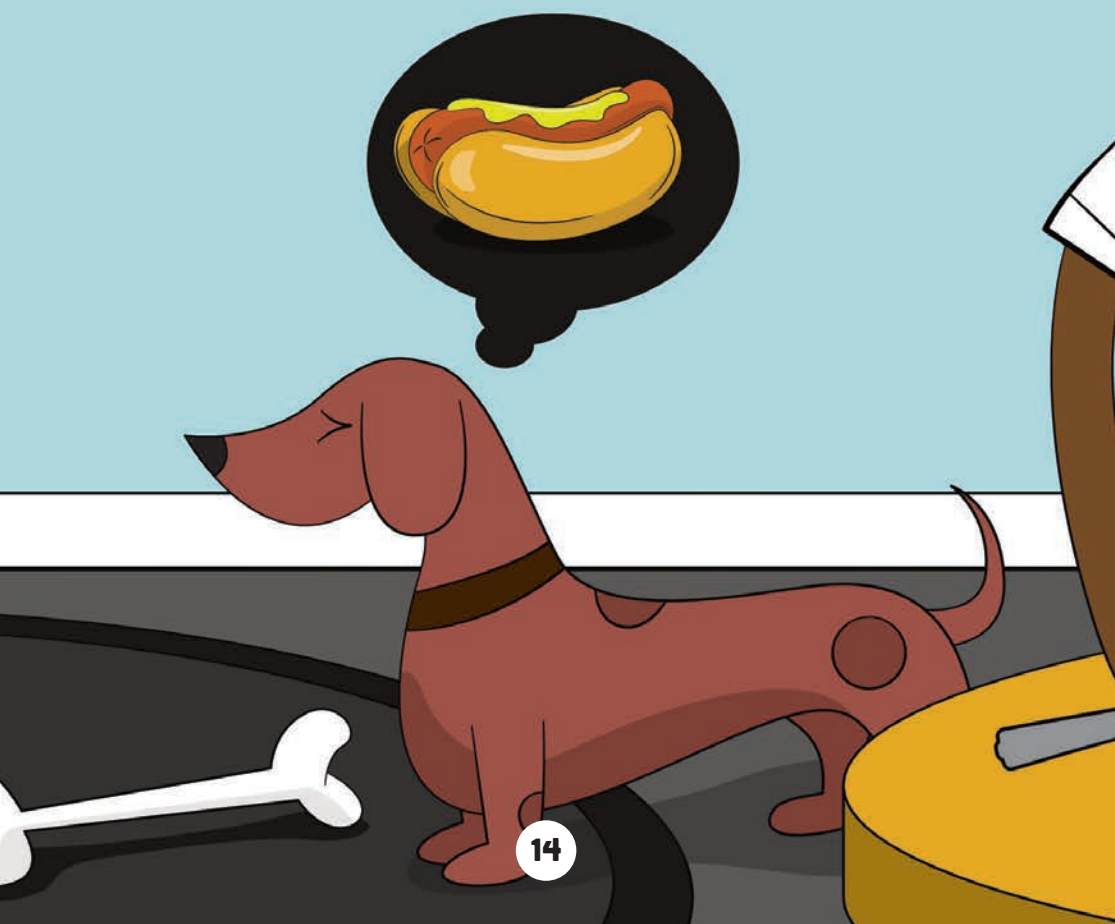
"What happened?" she said. "The last thing I remember is walking over to the bench."

"We think you might have had an epileptic seizure," said Ali. "Jess has called an ambulance and they'll be here soon. Have you ever had a seizure before?"

"No, never," said Mum.

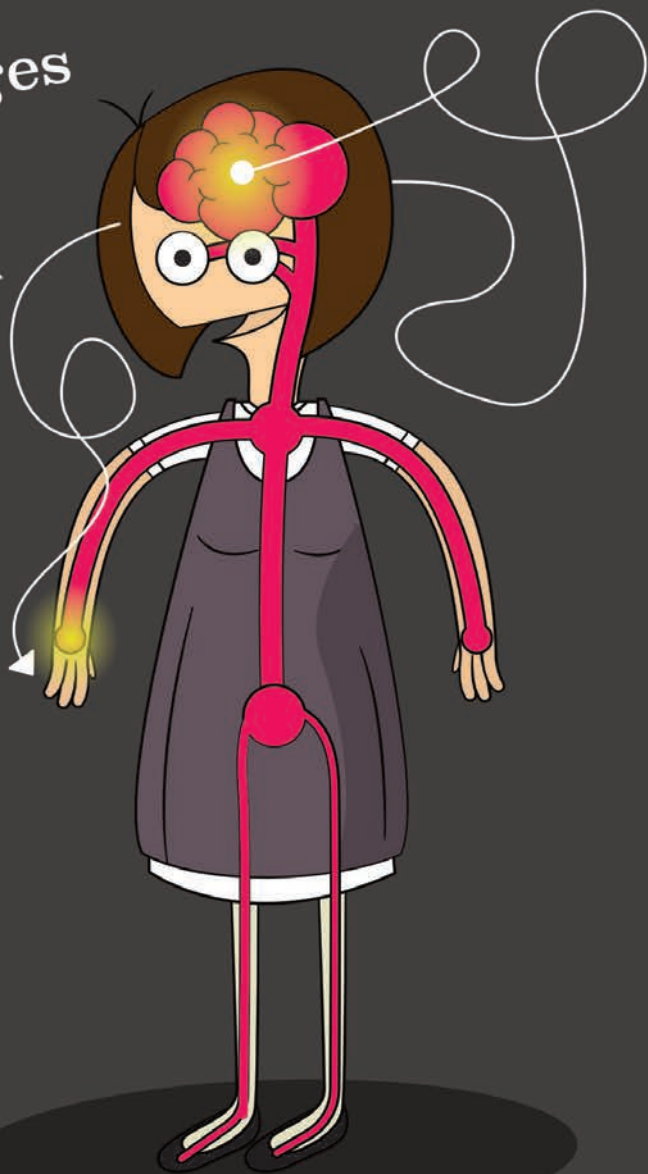
When the ambulance came, Dad
went with Mum to the hospital.
Jess and Ali took me home because
the dogs needed their dinner.

Then Ali made us some dinner too.
It was fish fingers and spaghetti rings,
which is my favourite. But I couldn't eat
it all because I was worried about Mum.





Messages



Ali told us about his cousin Ben.

"Ben's had epilepsy for a couple of years," he said.

"What is epilepsy?" I asked.

"It's to do with your brain," said Ali. "Something goes wrong for a few minutes and then it's okay again".

"How does your brain go wrong?" I asked.

"Your brain sends messages to the rest of your body to tell it what to do. Different bits of your brain work different bits of your body. If you've got epilepsy, these messages get a bit mixed up sometimes and that's why you have seizures," said Ali.

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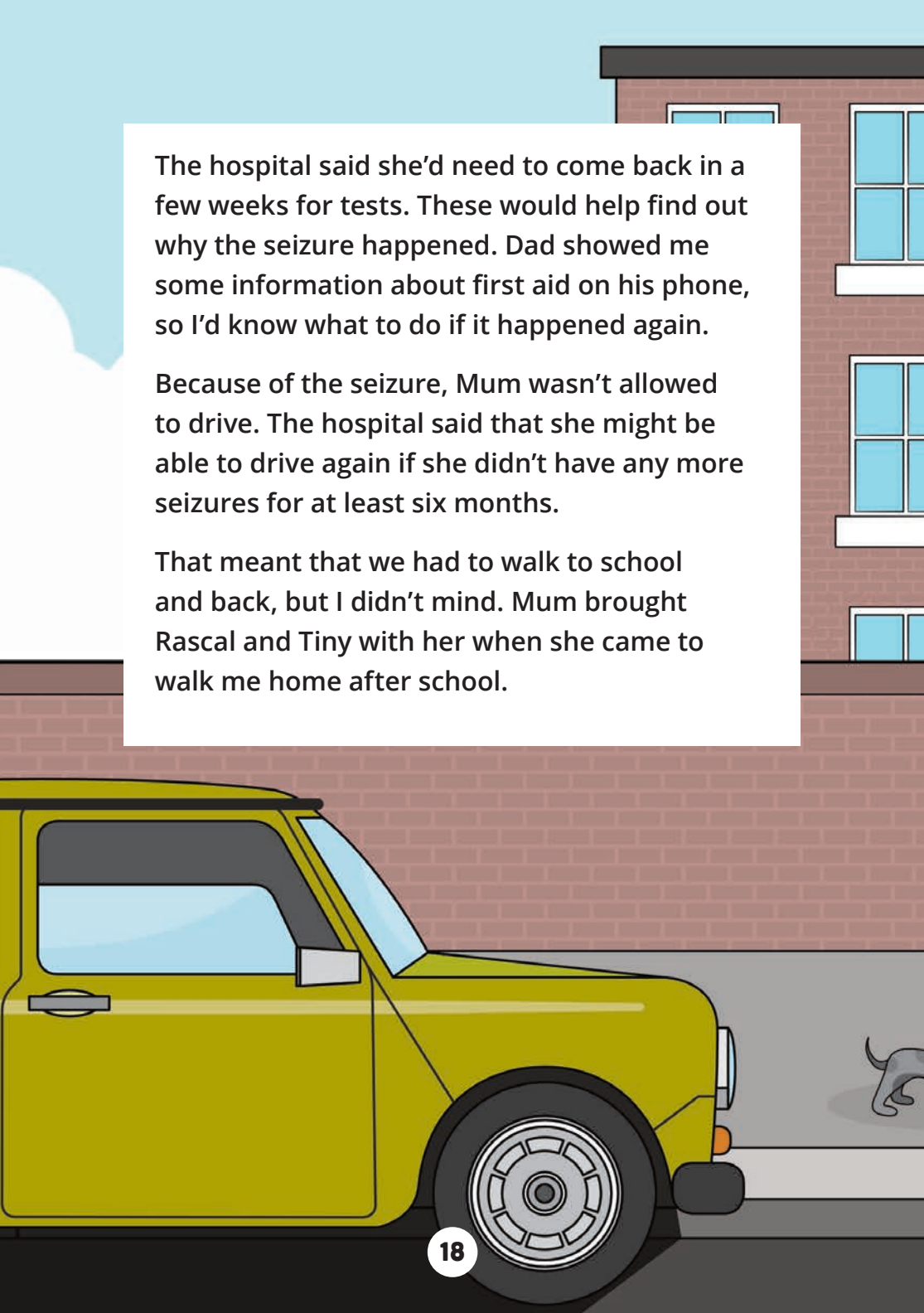
Mum was really tired when she came home.

Before she went to bed she gave me a big hug.

"I don't really remember what happened, but it must have been scary for you. Well done for being so brave," she said.

Mum had lots of leaflets about epilepsy from the hospital. And they told her about a website for grown-ups.

It's got loads of information about epilepsy, but too much writing for me. But there is another website for kids. I liked that one better. Less writing, more pictures.



The hospital said she'd need to come back in a few weeks for tests. These would help find out why the seizure happened. Dad showed me some information about first aid on his phone, so I'd know what to do if it happened again.

Because of the seizure, Mum wasn't allowed to drive. The hospital said that she might be able to drive again if she didn't have any more seizures for at least six months.

That meant that we had to walk to school and back, but I didn't mind. Mum brought Rascal and Tiny with her when she came to walk me home after school.





One day when we were walking home,
it happened again – Mum had another seizure.
This time I knew what to do. I tied the dogs' leads to
a lamp post.

Then I took my coat off and put it under her head.
A woman on the other side of the road ran over.

"What's wrong with her?" she said. "Is she drunk?"

"No!," I said. "She's having a seizure."

"Oh," she said. "Should we call an ambulance?"

"No," I said. "We just need to stay with her.

She should be okay in a few minutes.

We don't need to call an ambulance unless it lasts
longer than five minutes, or she hurts herself badly."

Soon the seizure stopped and I got the woman
to help me put Mum in the recovery position.

When Mum felt better, she got up.

Mum felt a bit wobbly but she said she was okay
to walk home. We were nearly home anyway so it
didn't take long.

I told Mum what had happened and we wrote it all
down in the special seizure diary that the hospital
had given Mum. I felt really proud of being able to
help my mum.

A few weeks later, Mum went to the hospital to have an EEG test. EEG stands for electroencephalogram, which is a very long word! I asked if I could go with her.

At the hospital we met the person doing the EEG test. His name was David. He measured Mum's head to see how big it was.

Then he drew some little marks on Mum's head, to show where to put the coloured EEG wires. The EEG wires had little round pads on the end of them.

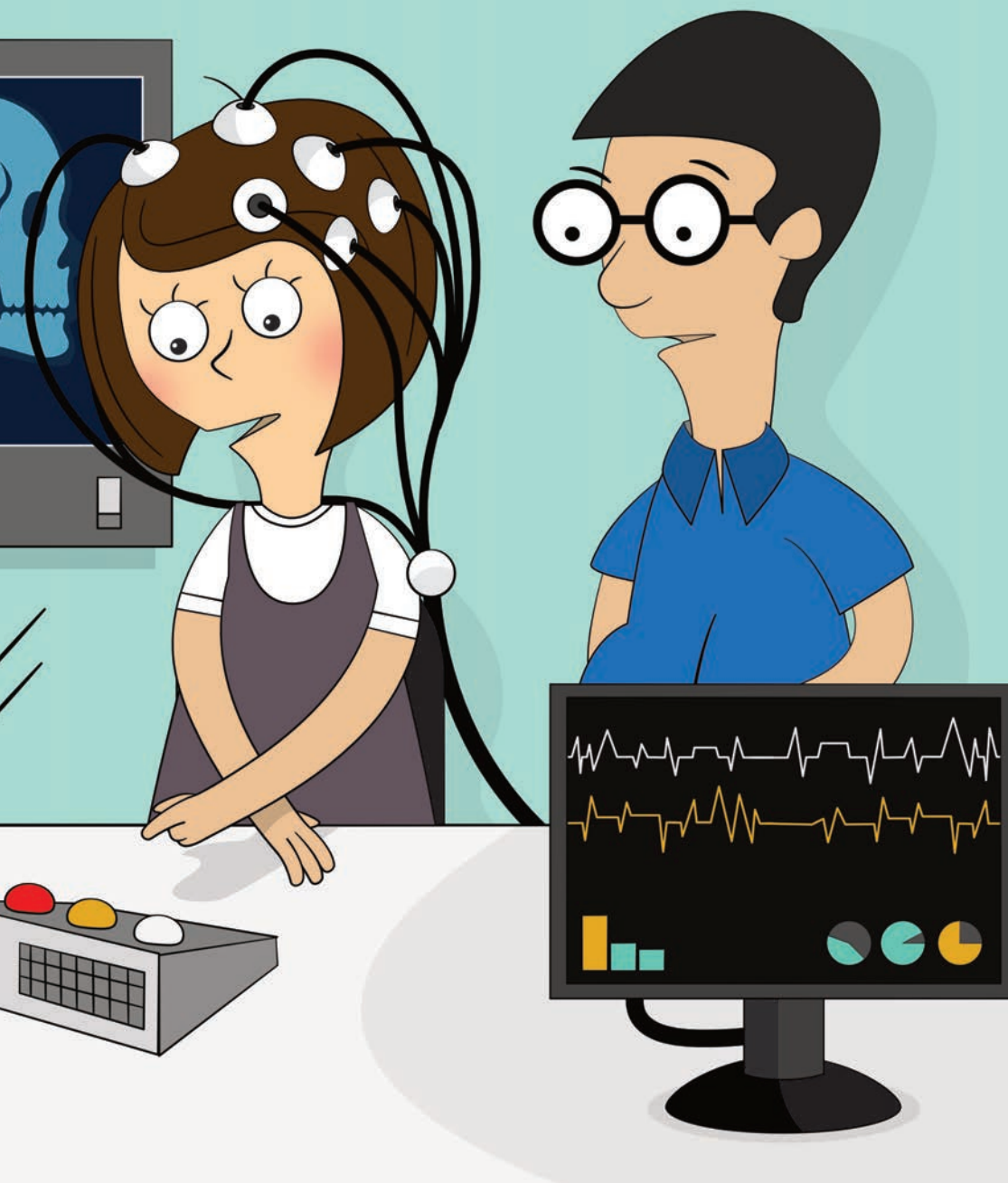
David put the pads on Mum's head. He used something that looked like jelly to keep the wires on her head, while she had her EEG. He said that sometimes people have a cap put on their head to hold the wires.

"It doesn't hurt," said Mum. "It just feels a bit funny!" The wires went from the pads on Mum's head into a machine.

"Sit back and relax. And try to stay as still as you can." The machine drew a pattern of squiggly lines.

"Take some big breaths. Now I want you to open and close your eyes. Now look at these flashing lights."

The whole test only took about half an hour. He said Mum would get the results in a couple of



weeks. "The EEG won't say for sure if you have epilepsy or not, but it should be helpful."

A couple of weeks later, Mum went to see the neurologist at the epilepsy clinic. A neurologist is a special doctor who knows lots about brains and nerves. I didn't go with Mum this time, but Dad did.

Before the appointment Dad got me to tell him exactly what happened both times Mum had the seizures. He wrote it all down, so he could tell the neurologist. He also took the seizure diary with him.

The neurologist asked Mum and Dad what happened when she had her seizures. She looked at Mum's EEG test results and the seizure diary. The neurologist decided that Mum did have epilepsy.

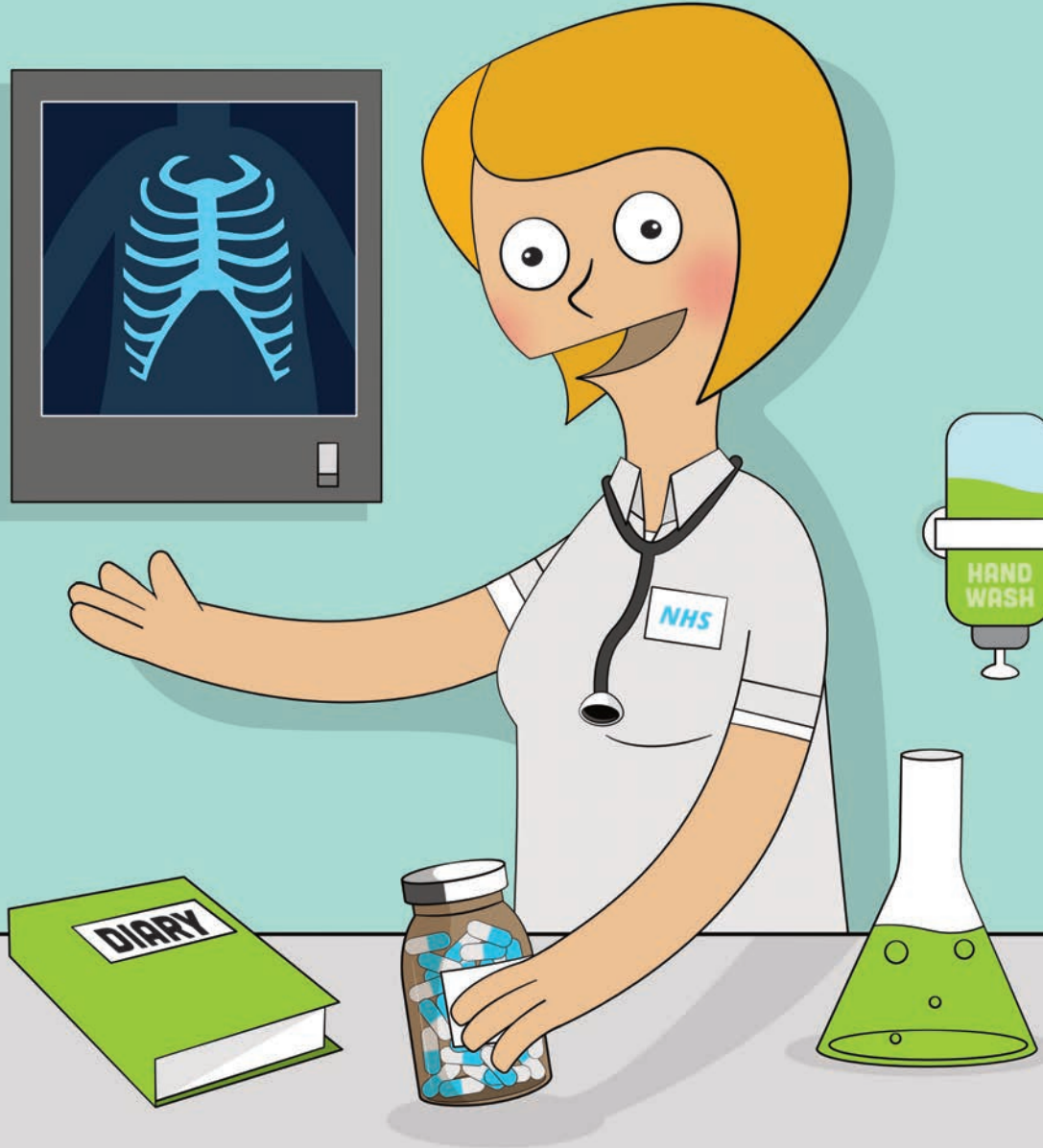
The neurologist gave Mum some special medicine to help stop the seizures happening.

"You need to take this medicine every day," she said. "This medicine can't cure epilepsy, but it can help stop you having seizures." said the neurologist.

"If this doesn't work, there are other medicines we can try."

Being told she had epilepsy was a big shock for Mum, but she was relieved to know why she'd had the seizures.

The neurologist couldn't find out why Mum had



epilepsy, but she said that was quite normal. For lots of people, doctors can't find out why someone has epilepsy. Epilepsy can happen to anyone at any time. Sometimes it just comes out of nowhere.

Mum had a few more seizures and went back to the epilepsy clinic to talk to the neurologist again.

I went with her to see the epilepsy nurse. The nurse was called Bobby and he gave my mum a card to keep in her pocket.

There was a space where she could write “I have epilepsy”, and my dad’s mobile phone number in case of an emergency.

At first it was strange to think of my mum having epilepsy. She’d looked after me lots of times when I’d been ill, but I’d never had to look after her.

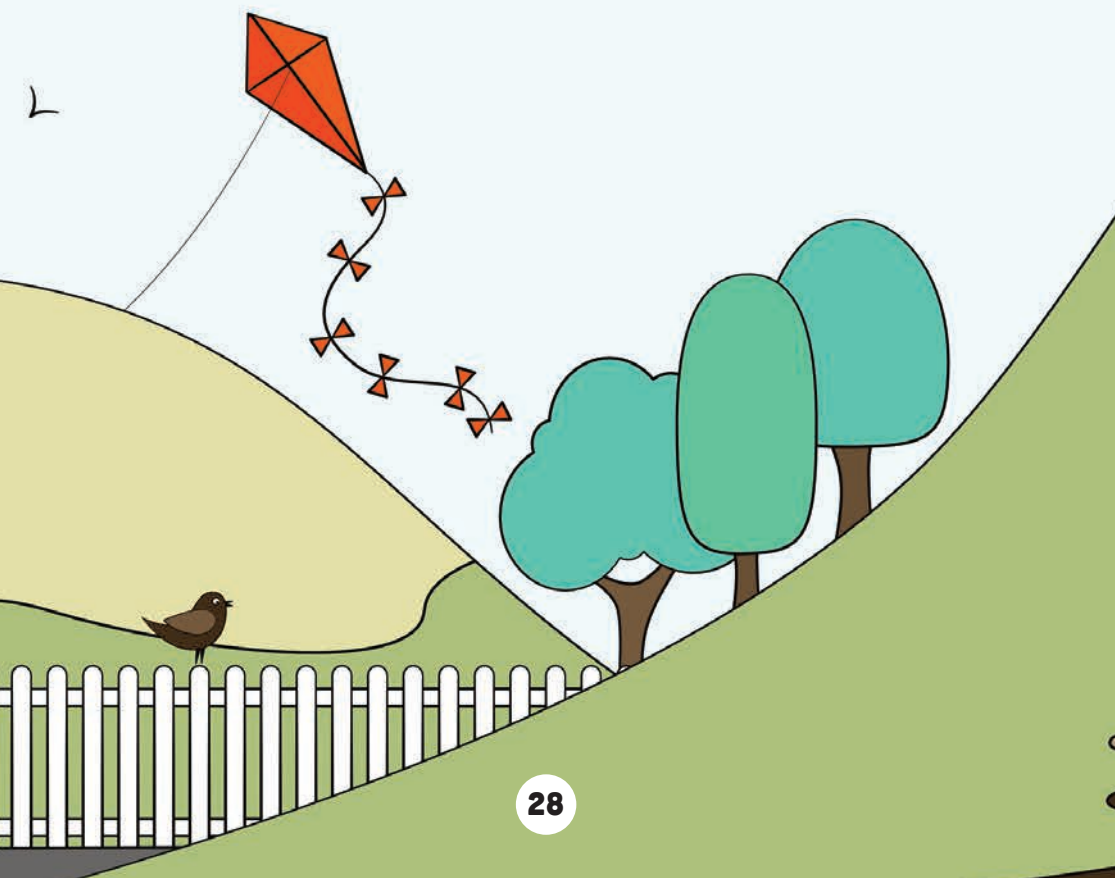
Knowing what to do if Mum has a seizure made me feel really grown up.



Mum decided to help set up a local Epilepsy Action group. Now we know lots of people with epilepsy who live near us. Sometimes me and Mum do sponsored walks for Epilepsy Action and Rascal and Tiny come too. I even did a talk about epilepsy for my class at school.

I want everyone to know more about epilepsy and that it's nothing to be scared of. Thank you for reading my story. I hope you enjoyed it.

The end.





**Tell us what
you thought about
the story...**

www.epilepsy.org.uk



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New Anstey House
Gate Way Drive
YEADON, LEEDS
LS19 7XY
United Kingdom

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Telephone: **0113 210 8800**
Email: **epilepsy@epilepsy.org.uk**

