



Me and my dad: a story to help parents explain their epilepsy

This factsheet 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. However, from the many parents and carers that we speak to on our Epilepsy Helpline, we know that lots of you would like some information to help you know what and how to tell your child.

Perhaps most importantly, 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.

The story below is about a young girl whose father has epilepsy. You can either read this story to your child, or use some of the information about epilepsy in the story to help explain your epilepsy in your own words.

The story

This is a story about me and my dad. We live with my mum 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 dad take Rascal and Tiny for a walk in the park. Sometimes Jess comes too.

One day me and dad 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 dad said he was feeling a bit funny. 'I think I'll go and sit down on the bench,' he 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 dad.

But when I looked round, dad wasn't on the bench, he was lying on the ground. I ran over to him. His arms and legs were jerking and he wasn't breathing properly.

'Dad, what's wrong? Dad!', I said. But he didn't answer me.

I was really scared, but I ran and got Jess.

'Something's wrong with dad,' I said.

Jess ran over to dad and Ali came too. Ali took off his sweatshirt and put it under dad's head.

'I think your dad is having an epileptic seizure,' said Ali. 'My cousin Ben has epilepsy. Is it the first time your dad'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 mum and told her to come over to the park.

Soon dad stopped jerking and his breathing went back to normal. Ali carefully put dad in a special position on his side. Ali said that this was called the recovery position.

After a while, dad started to move and he looked up at us. He was very confused and his mouth was bleeding because he'd bitten his tongue.

'What happened?,' he 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 dad.

When the ambulance came, mum went with dad 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 dad.

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.

Dad was really tired when he came home. Before he went to bed he 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,' he said.

Dad had lots of leaflets about seizures and epilepsy from the hospital. They said he'd need to come back in a few weeks for tests to help find out why the seizure happened. Mum showed me some information about first aid, so I'd know what to do if it happened again.

Because of the seizure, dad wasn't allowed to drive. The hospital said that he would be able to drive again if he didn't have any more seizures for a

whole year. That meant that we had to walk to school and back, but I didn't mind. Dad brought Rascal and Tiny with him when he came to walk me home after school.

One day when we were walking home, it happened again – dad 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 his head. A woman on the other side of the road ran over. 'What's wrong with him?' she said. 'Is he drunk?' 'No!,' I said. 'He's having a seizure.' 'Oh,' she said. 'Should we call an ambulance?' 'No,' I said. 'We just need to stay with him. He should be okay in a few minutes. We don't need to call an ambulance unless it lasts longer than five minutes, or he hurts himself badly.'

Soon the seizure stopped and I got the woman to help me put dad in the recovery position. When dad felt better, he got up. Dad felt a bit wobbly but he said he 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 dad.

A few weeks later, dad 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 him.

When we got to the hospital, the doctor measured dad's head to see how big it was. Then he drew some little marks on dad's head, to show where to put the coloured EEG wires. The EEG wires had little round pads on the end of them.

Then the doctor put the pads on dad's head. He used something that looked like jelly to keep the wires on his head, while he had his EEG. The

doctor said that sometimes people have a cap put on their head to hold the wires.
'It doesn't hurt,' said dad. 'It just feels a bit weird!'

The wires went from the pads on dad's head into a machine.
'Sit back and relax,' said the doctor. 'And try to stay as still as you can.'

The machine drew a pattern of squiggly lines.
'Take some big breaths,' said the doctor.
'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. The doctor said dad would get the results in a couple of weeks.
'The EEG won't definitely say if you have epilepsy or not, but it should give us some useful information,' he said.

A couple of weeks later, dad 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 dad this time, but mum did. Before the appointment mum got me to tell her exactly what happened both times dad had the seizures. She wrote it all down, so she could tell the neurologist. She also took the seizure diary with her.

The neurologist asked mum and dad what happened when he had his seizures. He looked at dad's EEG test results and the seizure diary. The neurologist decided that dad did have epilepsy.

The neurologist gave dad some special tablets to help stop the seizures happening.
'You need to take these tablets every day,' he said.
'These tablets can't cure epilepsy, but they can help stop you having seizures,' said the neurologist. 'If

these ones don't work, there's other tablets we can try.' The tablets are called anti-epileptic drugs.

Being told he had epilepsy was a big shock for dad, but he was relieved to know why he'd had the seizures. The neurologist couldn't find what had caused dad to have epilepsy, but he said that was quite normal. For lots of people, doctors can't find what's caused their epilepsy. Epilepsy can happen to anyone at any time. Sometimes it just comes out of nowhere.

Dad had a few more seizures and went back to the epilepsy clinic to talk to the neurologist again. I went with him to see the Sapphire Nurse, who is a kind of epilepsy nurse. Her name was Janine and she gave me a card to keep in my pocket. There was a space where I could write 'My dad has epilepsy' and my mum's mobile phone number in case of an emergency.

At first it was strange to think of my dad having epilepsy. He'd looked after me lots of times when I'd been ill, but I'd never had to look after him. Knowing what to do if dad has a seizure made me feel really grown up.

Dad decided to help set up an Epilepsy Action support group. Now we know lots of people with epilepsy that live near us. Sometimes me and dad 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.

If you want to know more about epilepsy, you can call or email the Epilepsy Helpline, freephone 0808 800 5050, helpline@epilepsy.org.uk. You might also like to look at the Epilepsy Action website www.epilepsy.org.uk. There's lots of information about epilepsy and even a section just for children.

Thank you for reading my story. I hope you enjoyed it.

The end.

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