My dad has EPILEPSY

A story to help parents and carers explain their epilepsy to children.

Written by

EPILEPSY ACTION

with illustrations by Bethany Evelyn.

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This book is for parents and carers with epilepsy who are looking after young children. We suggest reading it together, so you can talk about what's inside.

This book was written by Epilepsy Action, with help from medical experts and parents with epilepsy.

Hello! My name is Charlie and I live with my dad. I would like to live with a dog too, but Dad says "Maybe next year." He says that every year!

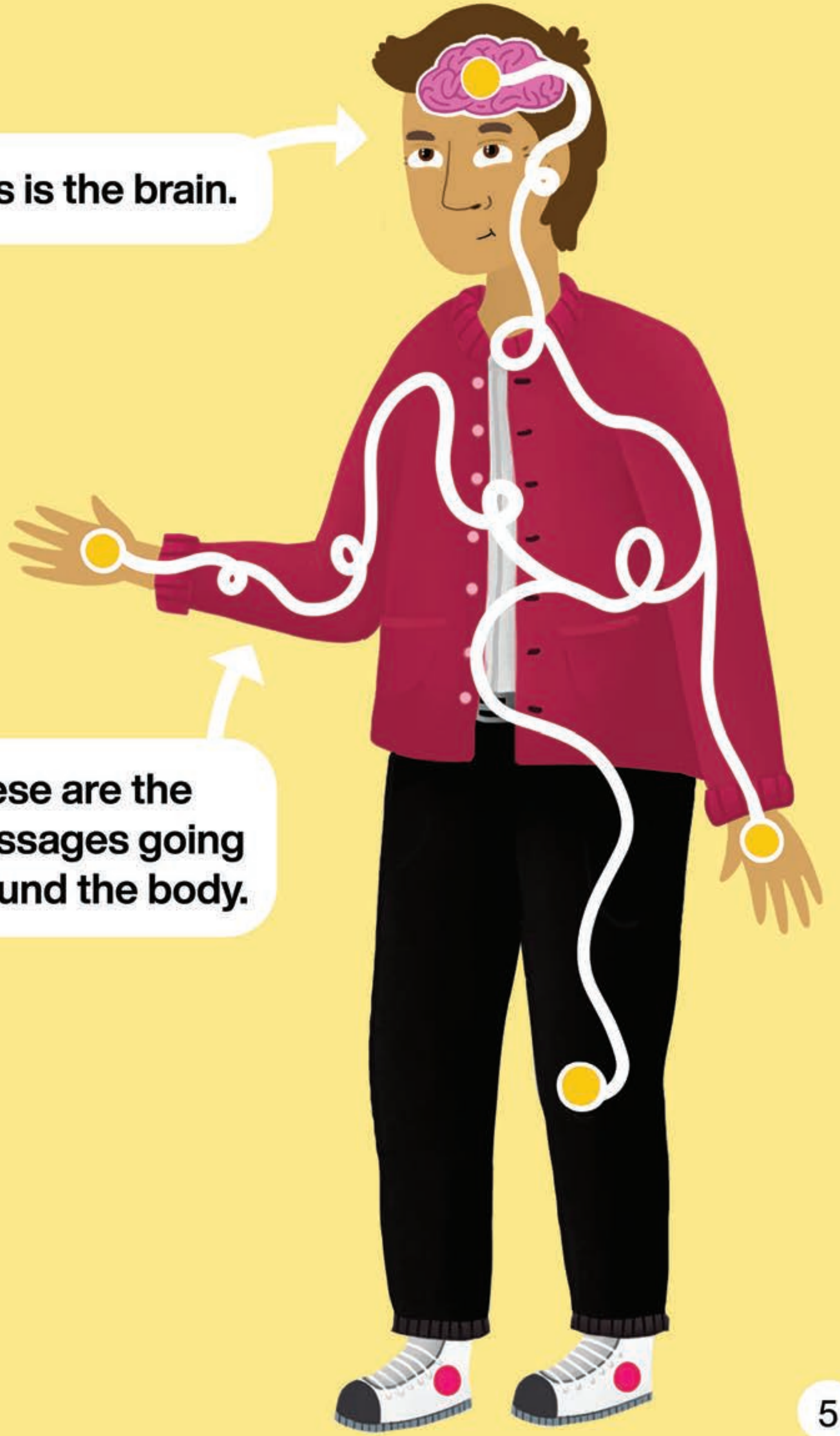
Doctors have told my dad that he has epilepsy. I'd never heard of it. But Dad explained it to me and now I can explain it to you.

Epilepsy happens in the brain.

Our brains are very clever. They help us talk, think and move. They do this by sending messages around our bodies.

But if you have epilepsy, these messages can get mixed up. This makes a ‘seizure’ happen.

A seizure is when our body does something we can’t control.



This is the brain.

These are the messages going around the body.

There are millions of people around the world with epilepsy, and everyone is different. Anyone can have epilepsy, not just dads.

Some people have lots of seizures and some people don't have many at all. There are also different types of seizures.

Sarah's dad has focal seizures. When these happen, he starts doing something over and over again, like tugging on his clothes.

Amber's cousin has absence seizures. When these happen, he stops what he's doing for a few seconds, but he doesn't fall down. It looks a bit like he is daydreaming.

Harry's sister has myoclonic seizures. When these happen, her arm moves very quickly. It's a bit like she's throwing something.

My dad has tonic-clonic seizures. This means that:

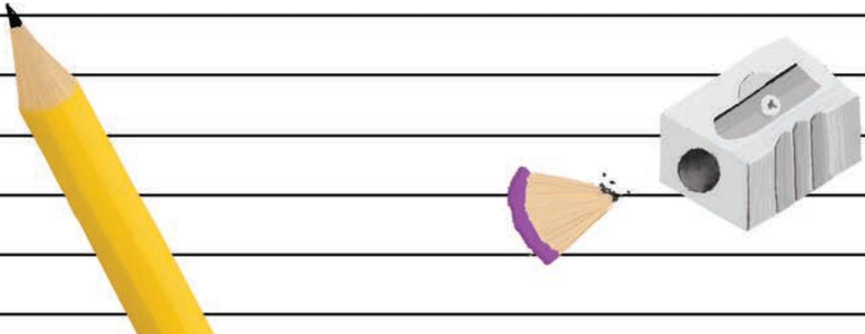
- His body goes still and he falls to the floor
- His arms and legs look like they are jerking or shaking
- Sometimes he wets himself or bites his tongue by accident

Dad says that he doesn't know what's going on when he has a seizure. He can't hear what people are saying around him and he can't stop it.

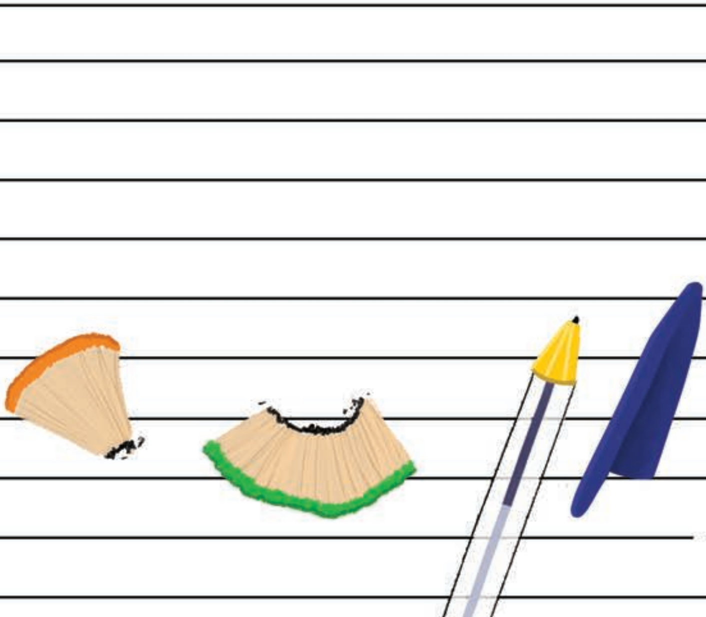
It takes a while for Dad to feel better after this happens. Sometimes he has a headache or feels a bit sore. He usually needs to sleep for a while to recover.

I know he's okay, he just needs a bit of time.

You could write it down or ask your dad to help.




What happens when he has a seizure?



I thought Dad's seizures were a bit scary at first, because I didn't know what was happening. Did you?

Dad said he understood why I'd feel like that. But he thought that knowing what to do when he has a seizure would make me feel better.

Here's what I do if my dad has a seizure:

1 I get help! Dad's taught me to use his phone, so I can call Uncle John.

2 I give Dad space and move things out of his way so he doesn't get hurt.

3 I put something soft under his head, like a jumper.

4 I stay calm and keep an eye on him until the seizure is over.

My dad's taught me what to do in an emergency.

If Dad's seizure goes on for too long, or if something doesn't feel right, I can call **999** and say "I need an ambulance."

I tell them where we live and open the front door so they can come in quickly. The ambulance people will help Dad feel better.

Dad says I probably won't need to do this. But it's always good to know how, just in case.

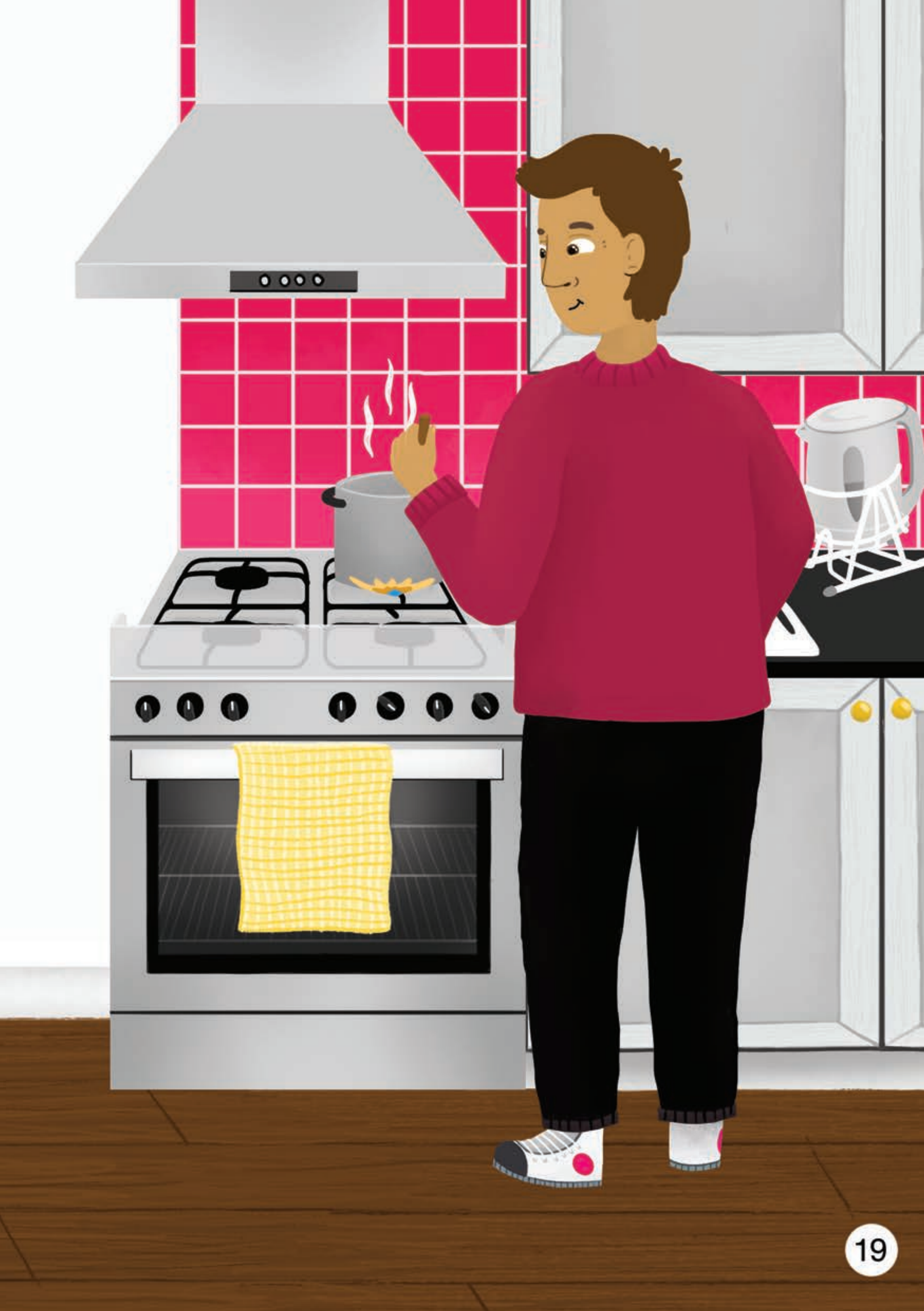

What can you do if your dad has a seizure?

Do you need to call anyone?

Although Dad needs my help sometimes, he likes to remind me that he's still the boss!

He says it's his way of telling me that I don't have to fix everything. I can help with the little things, and he takes care of everything else.

My dad is still my dad. He looks after me and keeps me safe.



Dad doesn't have seizures very often. Sometimes he can feel them starting and sometimes they seem to come from nowhere.

There are some things that can make Dad more likely to have a seizure. These are called 'triggers'. Different people with epilepsy have different triggers.

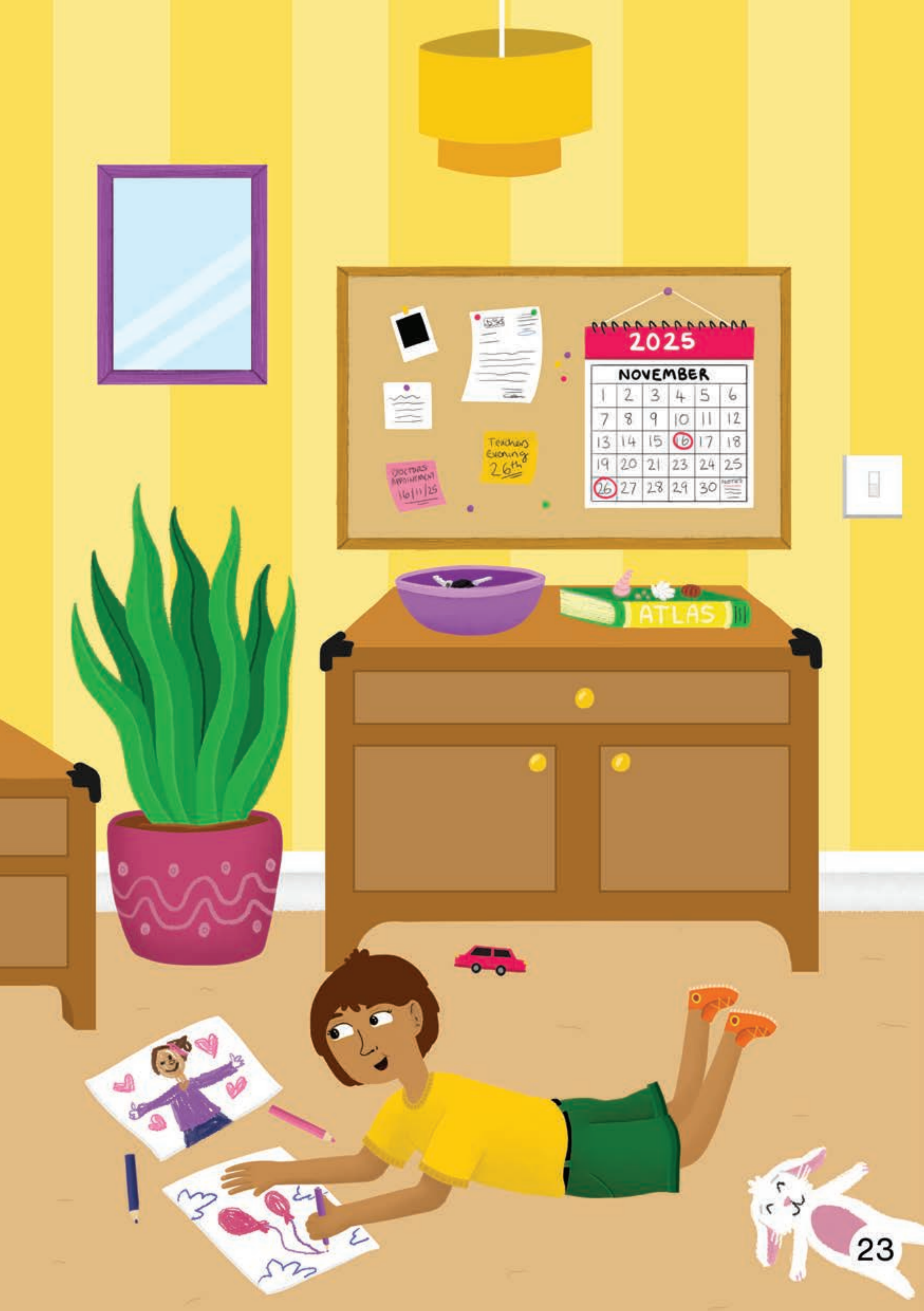
Dad says things like feeling tired can trigger his seizures. So he tries to sleep well and goes to an exercise class every week.

He also tries to eat healthy food, which means I have to eat it too! But we still have treats sometimes.

Dad takes medicine for his epilepsy. He keeps it in a safe place and I'm not allowed to touch it.

This medicine helps Dad have less seizures, which is great! But it can make him feel other things. Sometimes he feels very tired or he gets dizzy. Sometimes he forgets things easily. He says it's like his brain feels "foggy".

These are called side effects.
Does your dad get side effects?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Dad has a lot of appointments with doctors and nurses. This doesn't mean there's anything wrong. They just like to check that Dad is okay and that his medicine is helping. They help keep Dad safe.


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When Dad told me he had epilepsy, I had a lot of questions. Like these:

Why do some people have epilepsy?

Doctors don't always know why people have it. But they do know that epilepsy is not caused by anything people do or don't do. Epilepsy isn't anyone's fault.

Some people have it after banging their head really badly. Sometimes it's caused by an illness or infection. Sometimes it's because of how our brains develop before we're born.

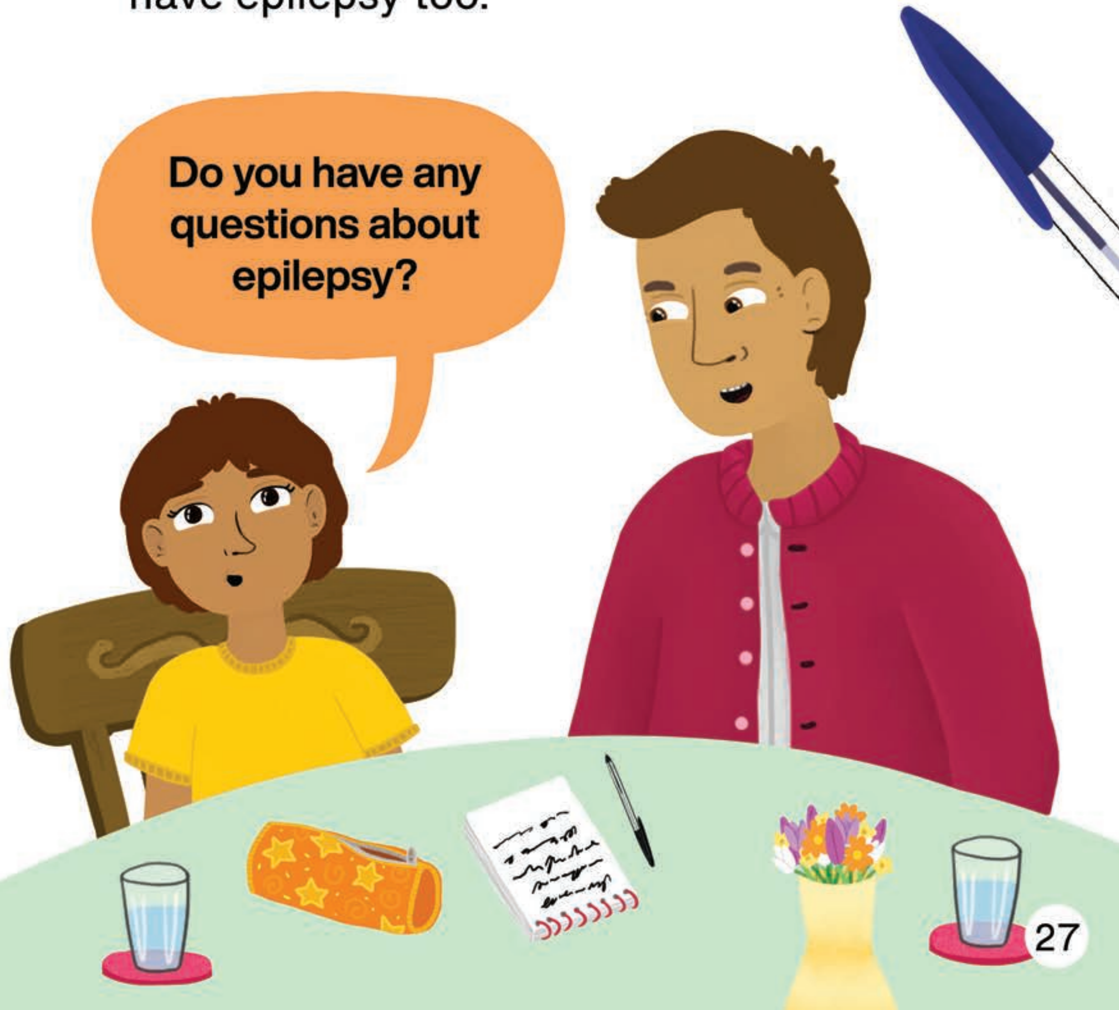
Will it go away?

Sometimes epilepsy goes away, and sometimes it doesn't.

Some people go to hospital to have an operation on their brain to help them get better. Other people take medicine. Things like this can help people stop having seizures or have less seizures than before.

Will I have epilepsy?

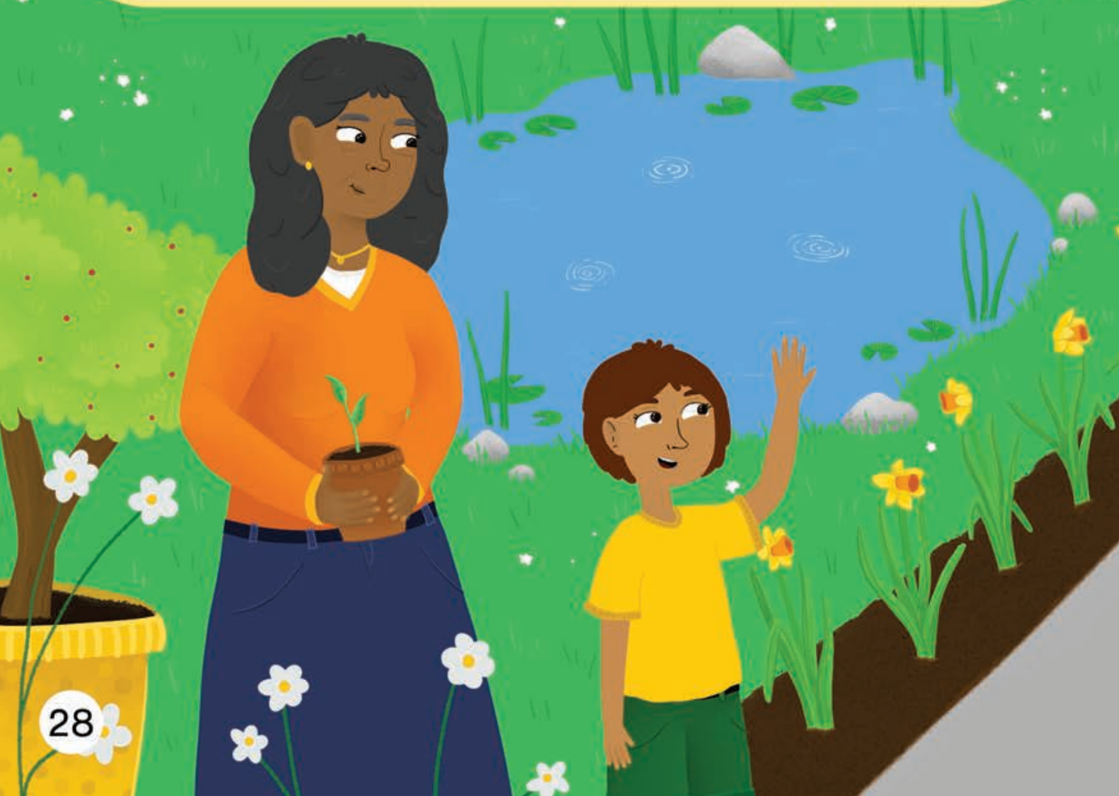
Epilepsy isn't contagious. This means you can't catch it, like a cold. And just because a parent has epilepsy, it doesn't mean you'll have epilepsy too.



I have lots of feelings about my dad's epilepsy. Sometimes I feel angry at epilepsy for making my dad feel ill. Other times I worry about him.

Sometimes I feel brave and sometimes I feel scared. And sometimes I feel frustrated when he can't do things I want him to do, like play with me or take me places in the car.

And sometimes I don't even think about it at all!



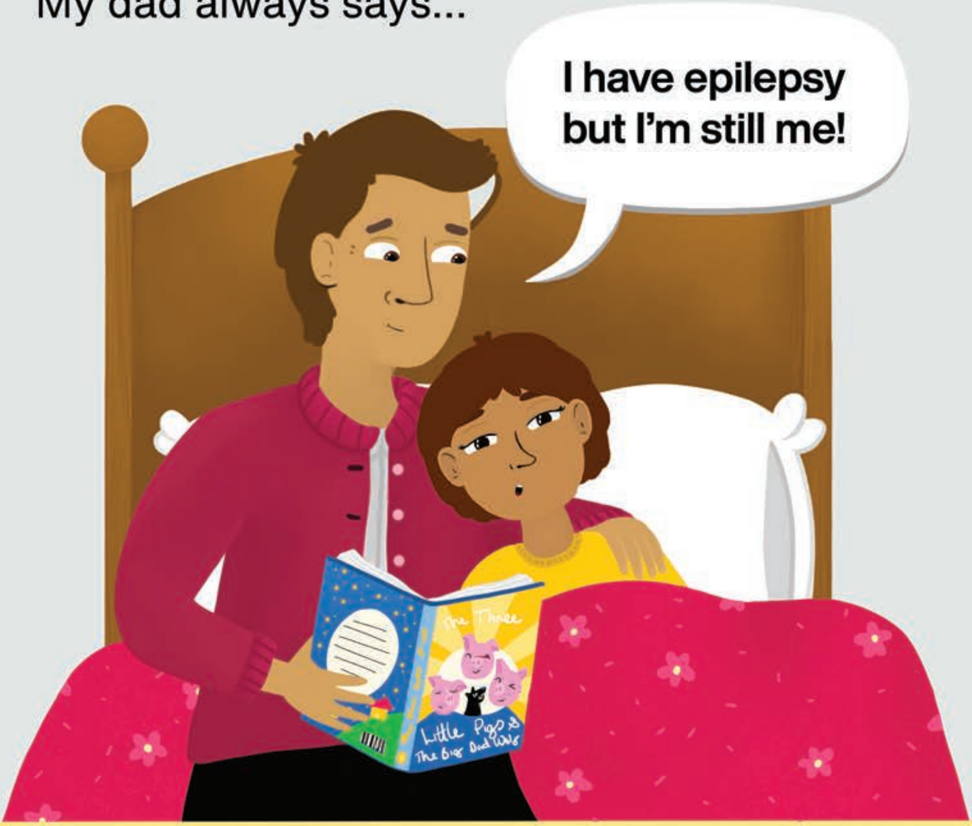
Dad says it's okay to have all these feelings. He even says he has them too. He says it's really important to talk about how I feel to someone I trust. I talk to Dad a lot about epilepsy. Sometimes I talk to Nana too, who lives down the street.

How do you feel about epilepsy?

Do you have any worries?

Who do you trust to talk to about your feelings?

My dad always says...



He says this to remind me that epilepsy isn't the only thing about him. It's just something we have to think about now and again.

My dad isn't poorly all the time. He goes to work and likes to go out with his friends. He also has the best job in the world – looking after me!

Wait, there's more! Dad showed me how to put him in the recovery position.*

This is a special way to help someone who is poorly and won't wake up. It can help them to breathe easier and stay safe until an adult can help.

Your dad can tell you if it's something you need to know.

*This information was provided by St John Ambulance

Remember: call **999** if the person you are with is not breathing or they are having many seizures.

1. Take their arm nearest to you and put it up like they are waving.

2. Bring the other arm across the person's chest and tuck their hand under their cheek.

3. Hold their knee furthest away from you and pull it up so their foot is flat on the floor.

4. Pull this leg towards you at the knee, so their knee comes over their other leg.

5. Pull them so they are on their side and their leg is over the other leg.

6. Tilt their head back slightly to help them breathe easily.

EPILEPSY
ACTION

Epilepsy Action are here to support anyone affected by epilepsy. To find out how we can help you visit **epilepsy.org.uk/support-for-you** or contact our free helpline on **0808 800 5050**.

Your voice matters

We'd love to hear what you thought of this book. We'll use your feedback to improve the next one. Use this link to complete a short survey:
epilepsy.org.uk/my-mum-my-dad

Epilepsy Action
Email: epilepsy@epilepsy.org.uk
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This book is for parents and carers with epilepsy who look after young children aged 6 and above.

Charlie's dad has epilepsy. After some honest chats, Charlie now understands that it's not something to be afraid of, just something to be aware of.

When you're ready, Charlie can help you explain what epilepsy is, how it affects you and what they can do to help if you have a seizure.

This story is a gentle way to start open, confident conversations with a little help from Charlie!

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