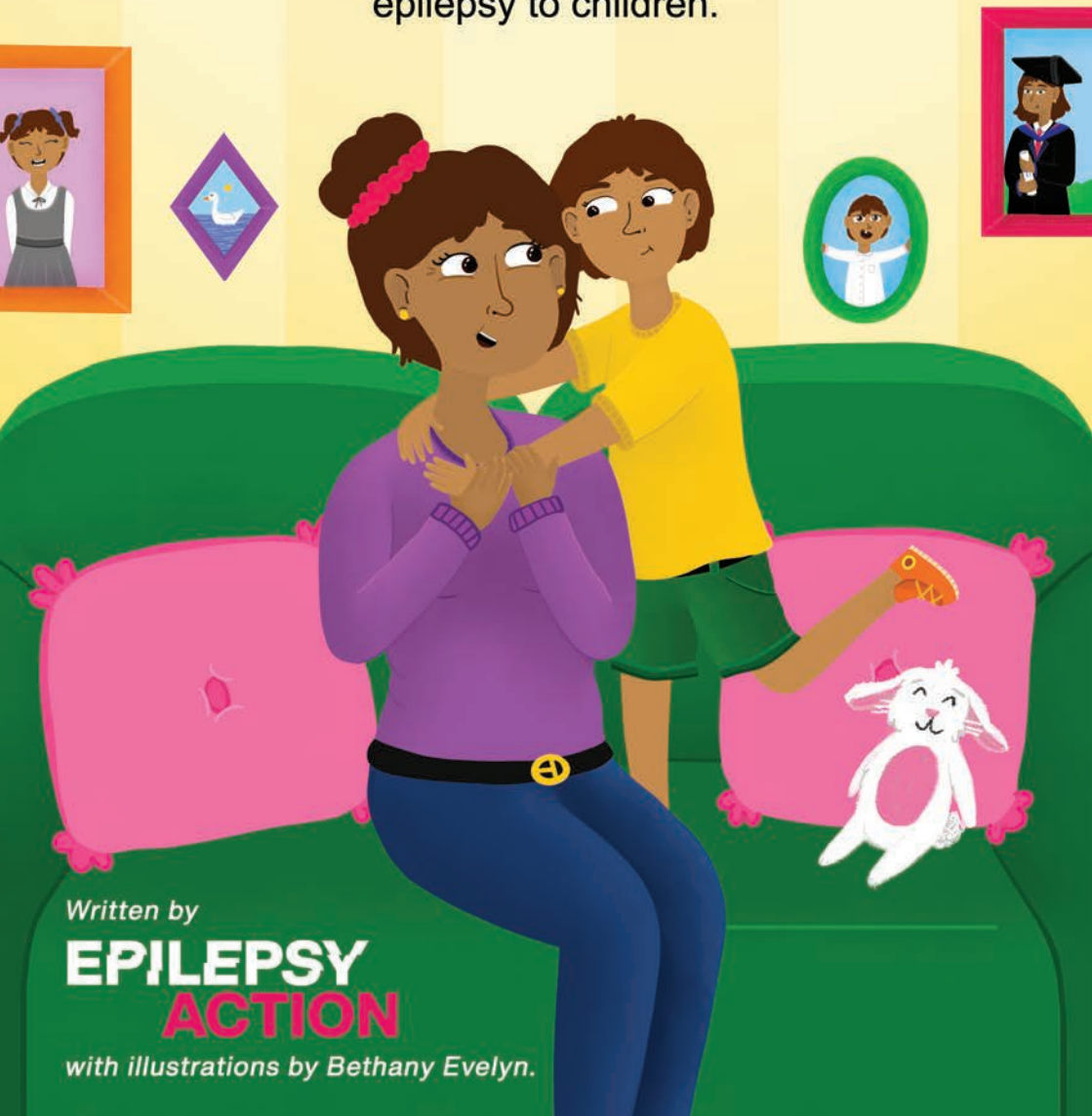
My mum has EPILEPSY

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 mum. I would like to live with a dog too, but Mum says “Maybe next year.” She says that every year!

Doctors have told my mum that she has epilepsy. I’d never heard of it. But Mum explained it to me and now I can explain it to you.

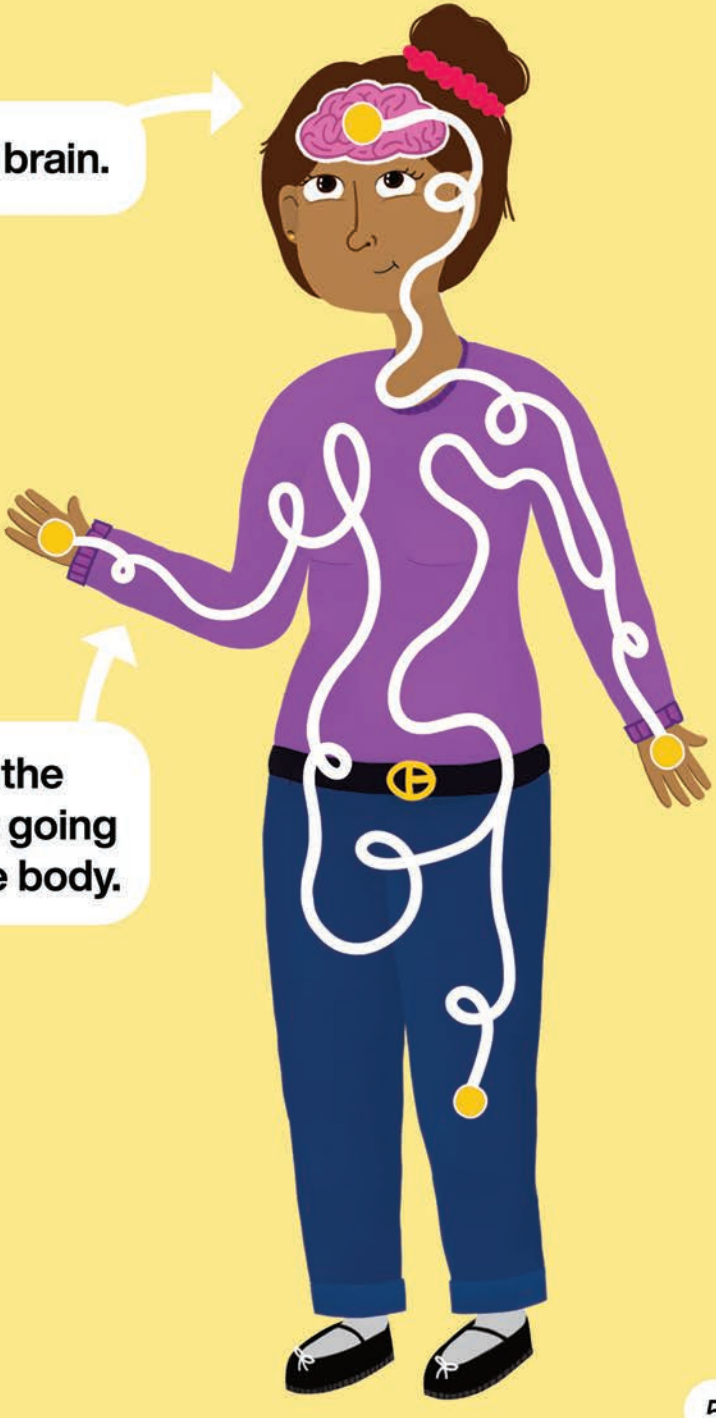
Epilepsy happens in the brain.

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 mums.

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 mum has tonic-clonic seizures. This means that:

- Her body goes still and she falls to the floor
- Her arms and legs look like they are jerking or shaking
- Sometimes she wets herself or bites her tongue by accident

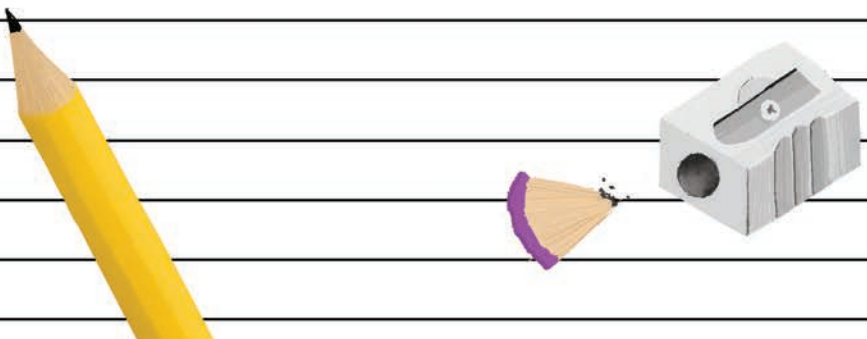
Mum says that she doesn't know what's going on when she has a seizure. She can't hear what people are saying around her and she can't stop it.

It takes a while for Mum to feel better after this happens. Sometimes she has a headache or feels a bit sore. She usually needs to sleep for a while to recover.

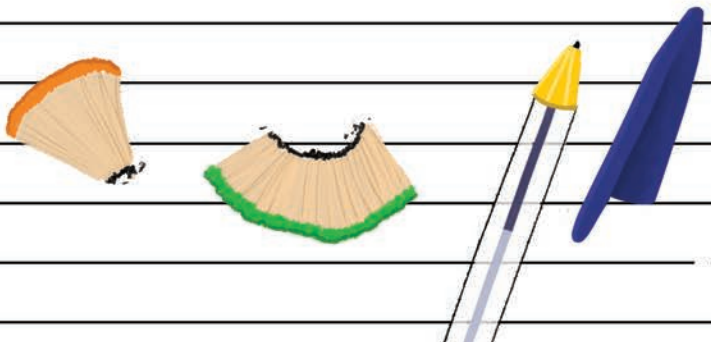
I know she's okay, she just needs a bit of time.

What type of seizure does your mum have?

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



What happens when she has a seizure?



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

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

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

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

2 I give Mum space and move things out of her way so she doesn't get hurt.

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

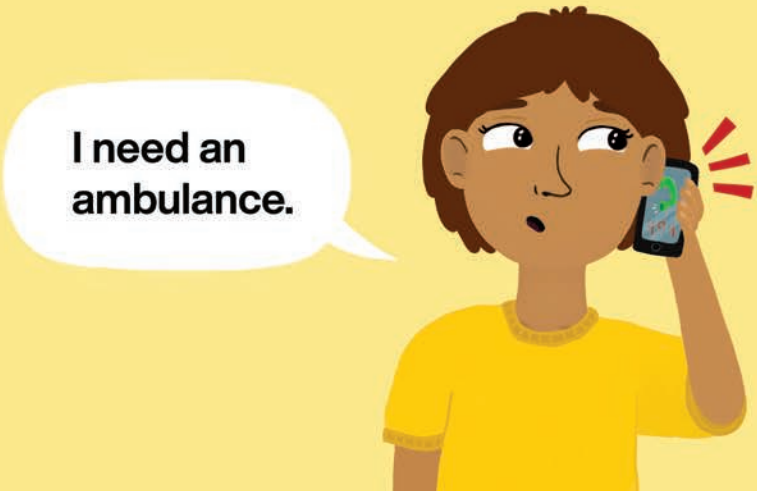
4 I stay calm and keep an eye on her until the seizure is over.

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

If Mum'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 Mum feel better.

Mum 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 mum has a seizure?

Do you need to call anyone?

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

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

My mum is still my mum. She looks after me and keeps me safe.

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

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

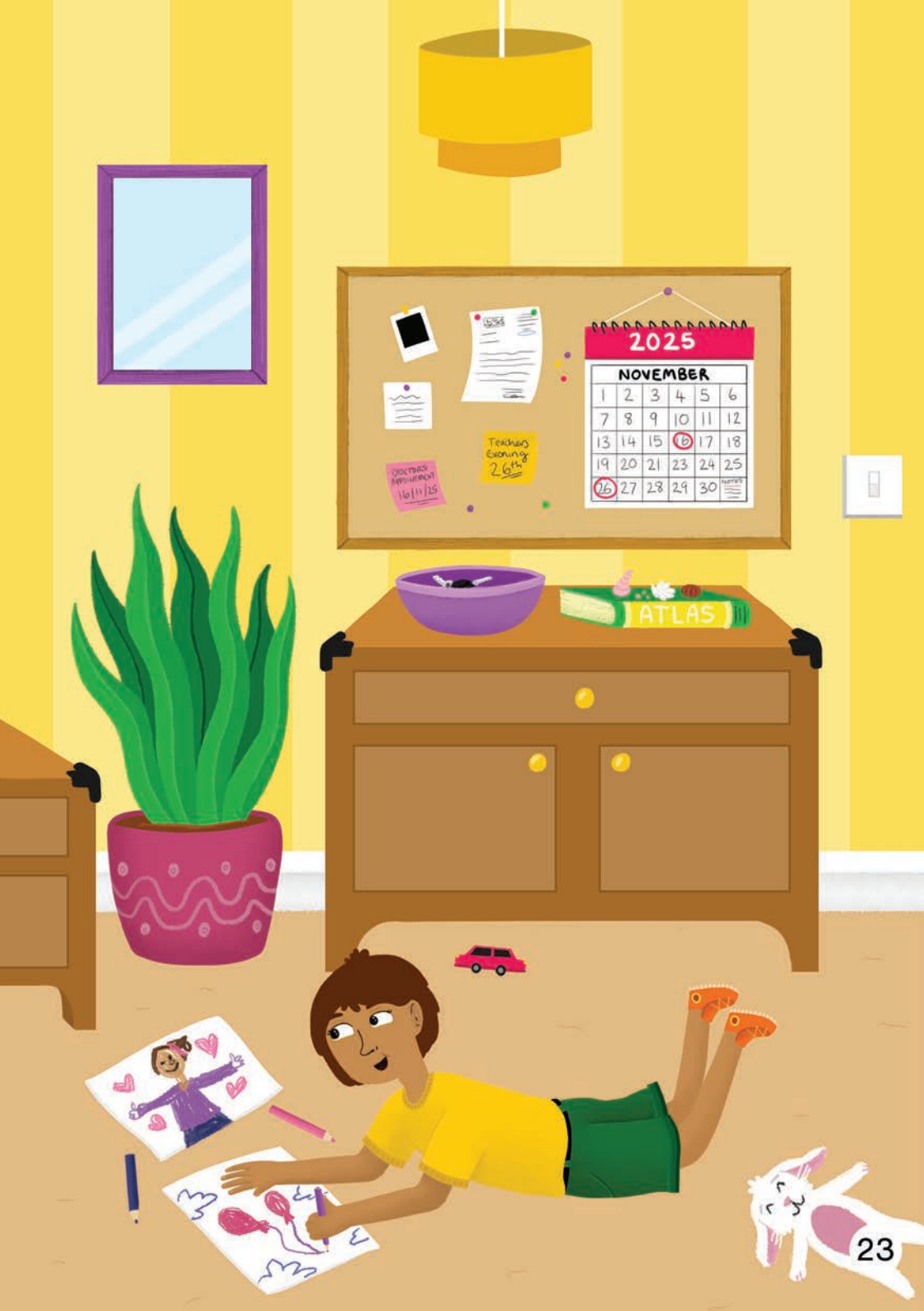
Mum says things like feeling tired can trigger her seizures. So she tries to sleep well and goes to an exercise class every week.

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

Mum takes medicine for her epilepsy. She keeps it in a safe place and I'm not allowed to touch it.

This medicine helps Mum have less seizures, which is great! But it can make her feel other things. Sometimes she feels very tired or she gets dizzy. Sometimes she forgets things easily. She says it's like her brain feels "foggy".

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

The Heart!
HEALTH & MEDICINE
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First aid for epilepsy
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When Mum told me she 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.

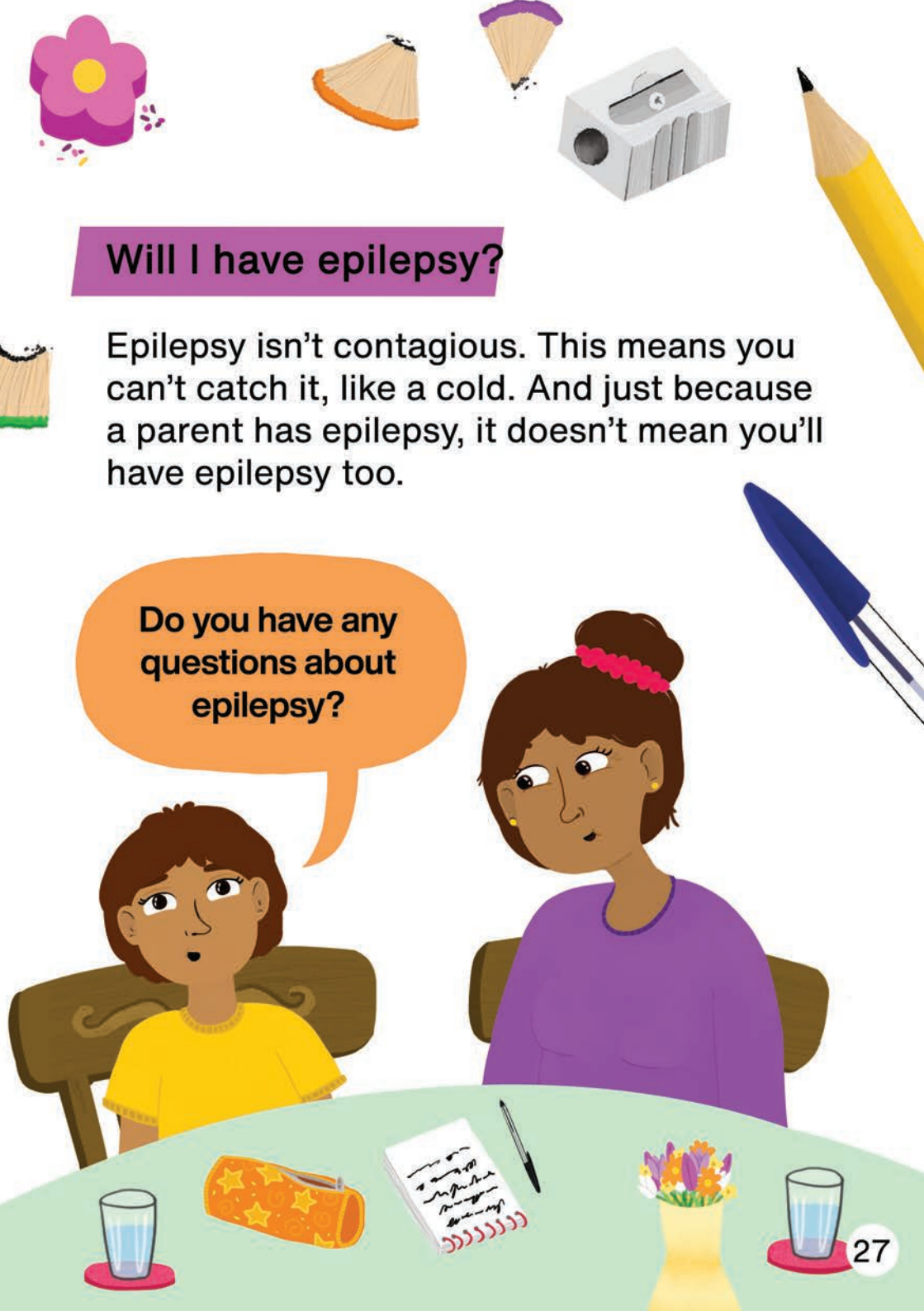
Will it go away?

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?

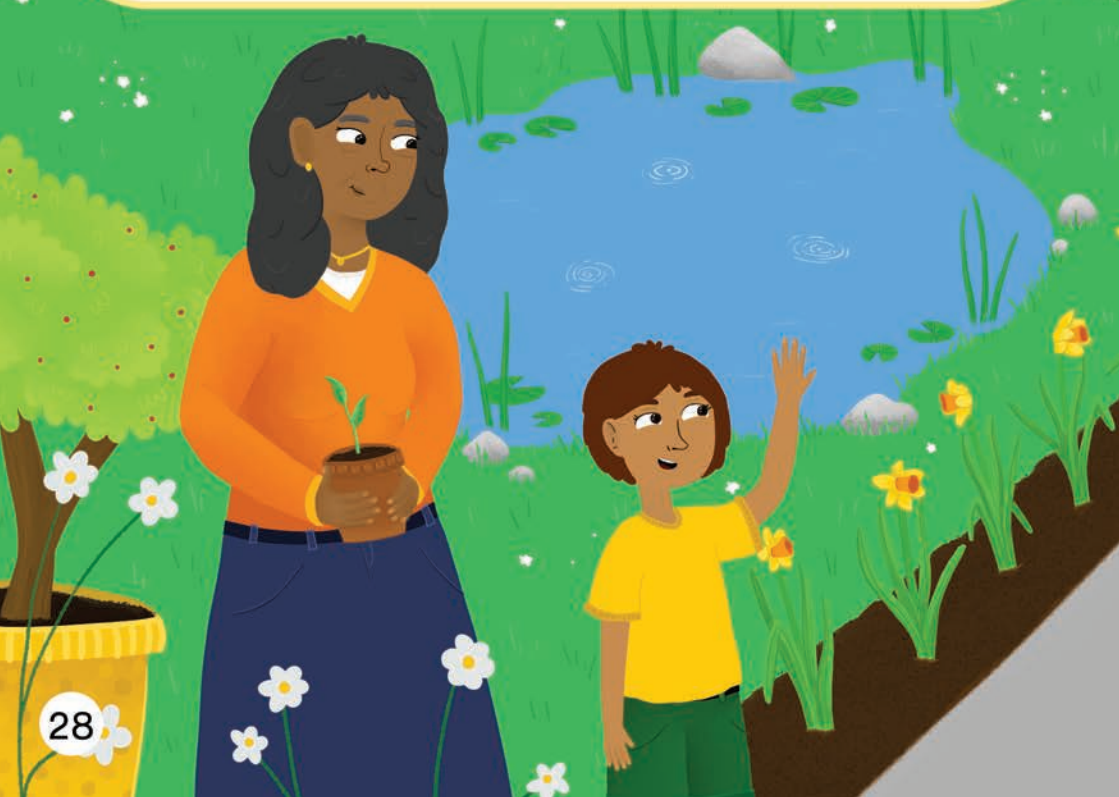
Epilepsy isn't contagious. This means you can't catch it, like a cold. And just because a parent has epilepsy, it doesn't mean you'll have epilepsy too.



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

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

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



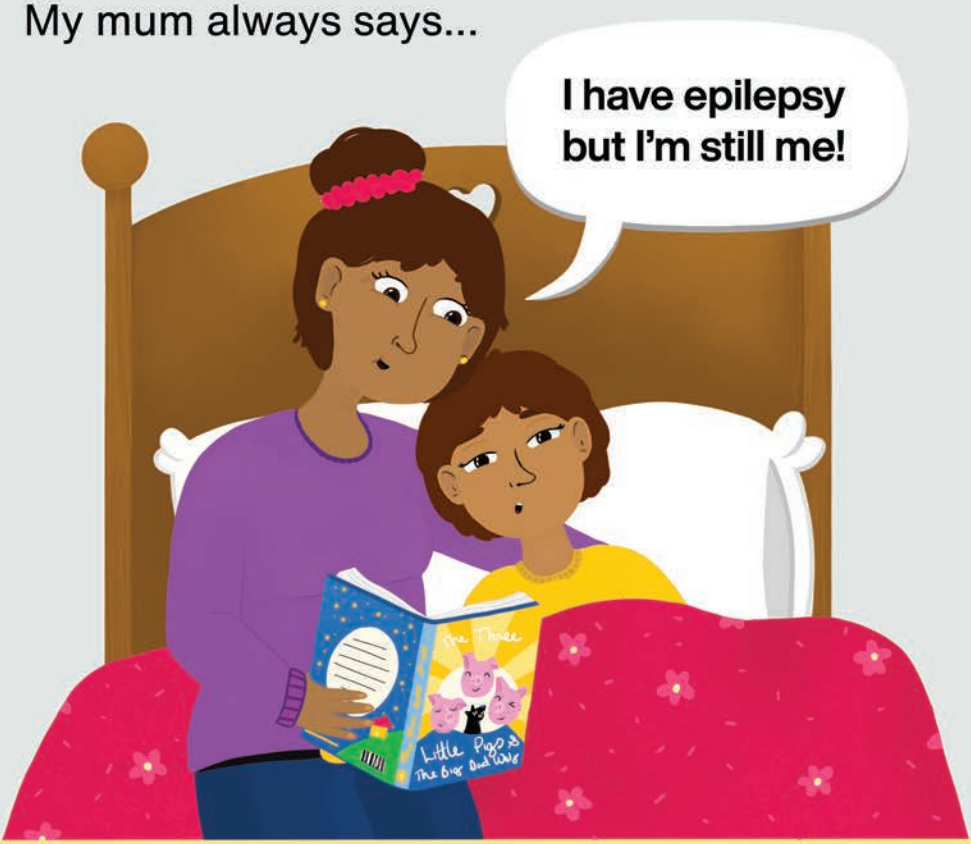
Mum says it's okay to have all these feelings. She even says she has them too. She says it's really important to talk about how I feel to someone I trust. I talk to Mum a lot about epilepsy. Sometimes I talk to Nana too, who lives down the street.

How do you feel about epilepsy?

Do you have any worries?

Who do you trust to talk to about your feelings?

My mum always says...



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

My mum isn't poorly all the time. She goes to work and likes to go out with her friends. She also has the best job in the world — looking after me!

Wait, there's more! Mum showed me how to put her 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 mum 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
Registered charity in England and Wales (No. 234343)

This book is for parents and carers with epilepsy who look after young children aged 6 and above.

Charlie's mum 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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