

BRYN BEAR'S GUIDE TO INFANTILE SPASMS

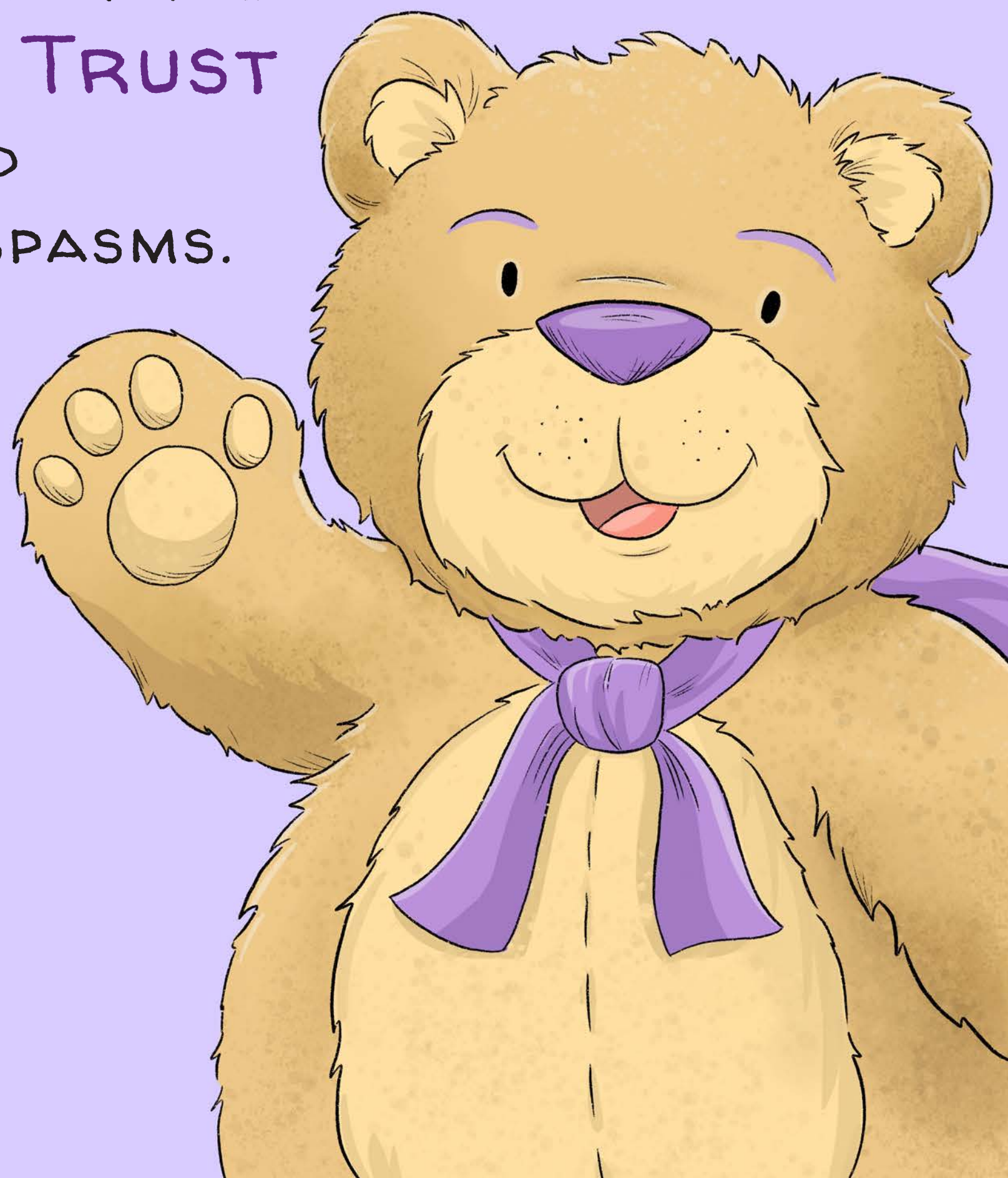


THIS BOOK HAS BEEN WRITTEN BY THE
UK INFANTILE SPASMS TRUST
TO HELP CHILDREN FIND
OUT MORE ABOUT INFANTILE SPASMS.

This book is dedicated to families around the world who have been affected by infantile spasms, and to all our amazing supporters who continue to raise awareness of this rare type of childhood epilepsy.

Copyright ©2020 UK Infantile Spasms Trust. All rights reserved.
Cover and illustrations by Zoe Saunders.

No part of this book can be reproduced in any form or by written, electronic or mechanical, including photocopying, recording, or by any information retrieval system, without written permission in writing from UK Infantile Spasms Trust.





An infant is another word for a baby, and a spasm is a jerky movement.

So an infantile spasm is a baby making a jerky movement.

Usually the baby does the same thing again and again for several minutes.

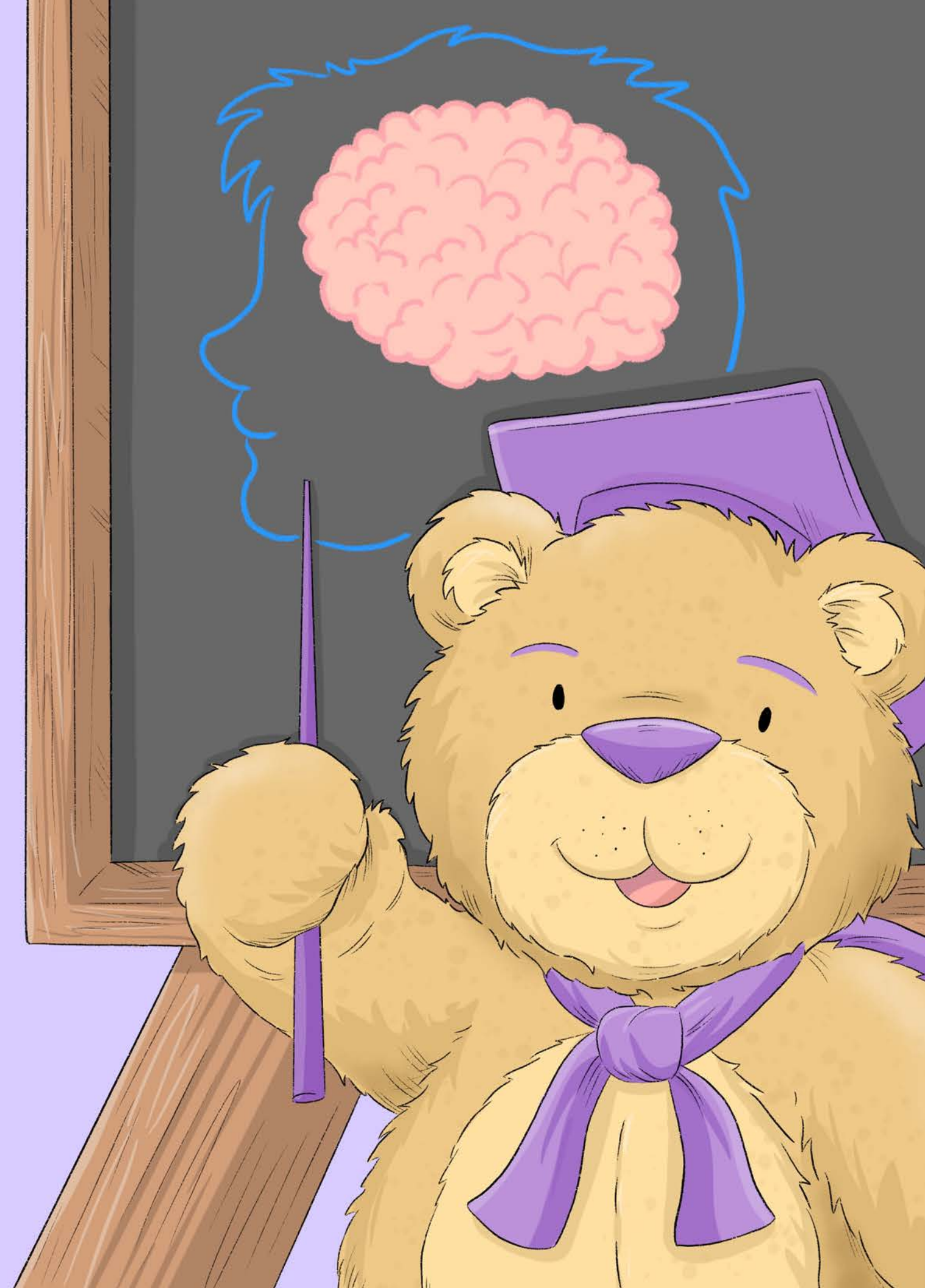
Well that doesn't sound so bad... ?

On the outside, spasms don't look too serious.

But we worry about them because of what's happening inside the body, especially in the brain.

How much do you know about your amazing brain?

Did you know that inside your head, your amazing brain controls everything you think, feel, do and remember?



Your brain allows you to

...ride a bike



... play games



...talk to your friends



...remember your three times table



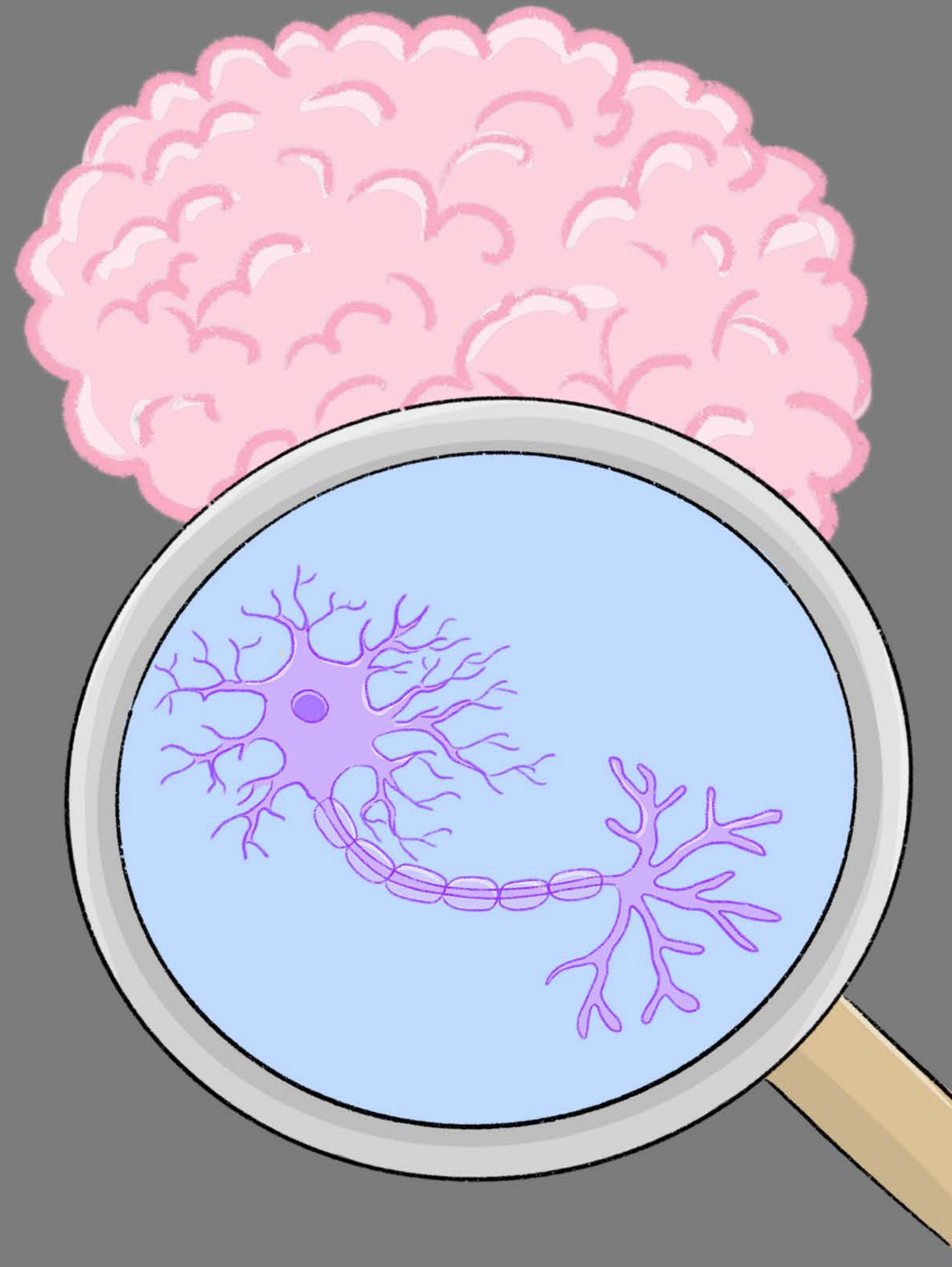
... plan your next birthday party

If we could zoom in even closer,
then we would see that your brain
contains millions of tiny cells called
neurons.

These neurons send messages to each
other, every second of every day.

The neuron pathways that are used
get a lot stronger, just like your
muscles when you exercise.
That's how we learn.

Your brain is always making new
pathways and improving the most
useful ones.



We can't see the neurons as they're too small; but a doctor can look at what they are doing with a test called an **electroencephalogram** – this is such a long and difficult word, that even the doctor calls it an **EEG**.

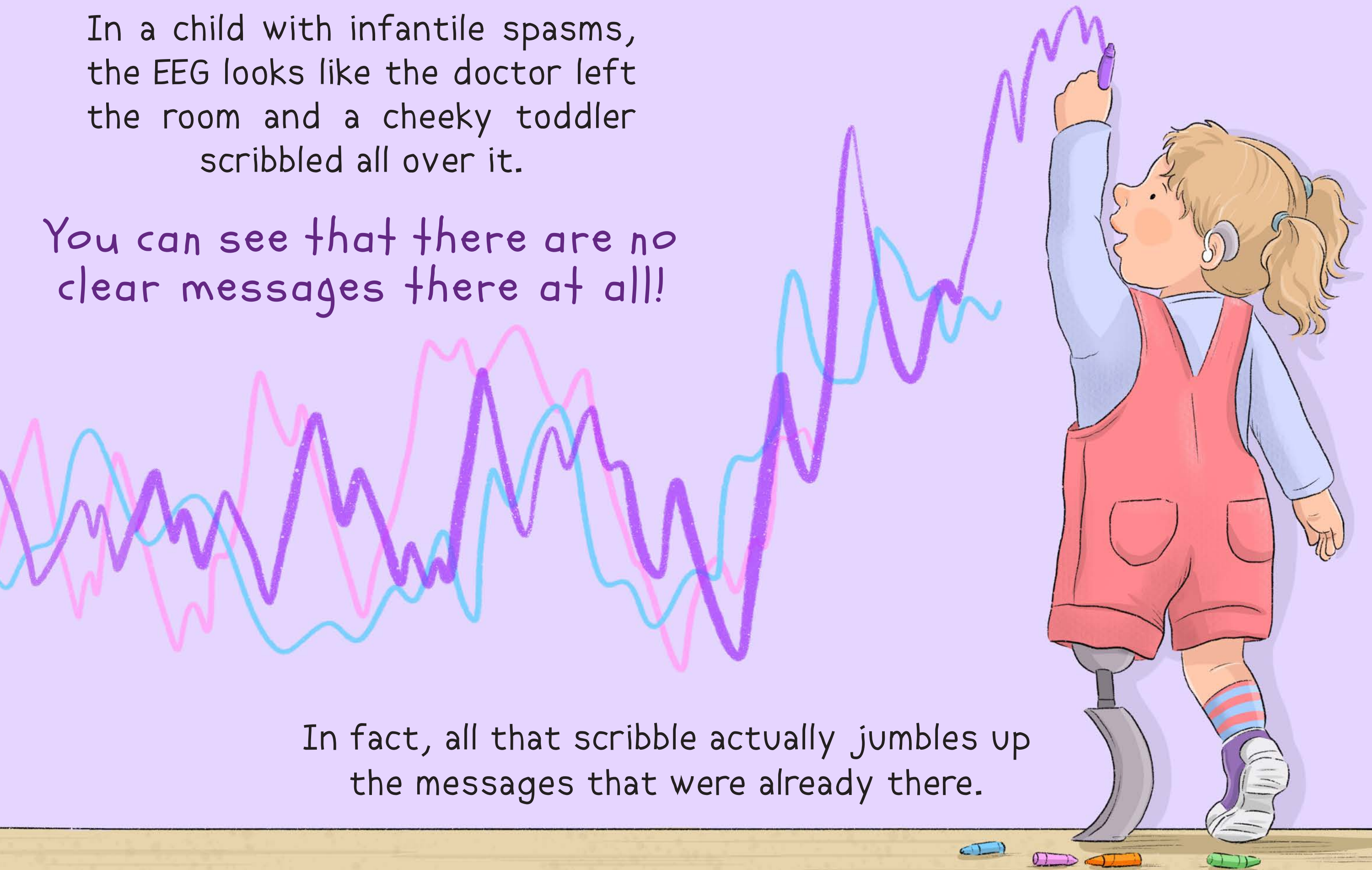
During this test, wires are stuck all over the child's head to measure the messages the brain is sending.

It doesn't hurt at all, but it can make your hair quite messy!



In a child with infantile spasms,
the EEG looks like the doctor left
the room and a cheeky toddler
scribbled all over it.

You can see that there are no
clear messages there at all!



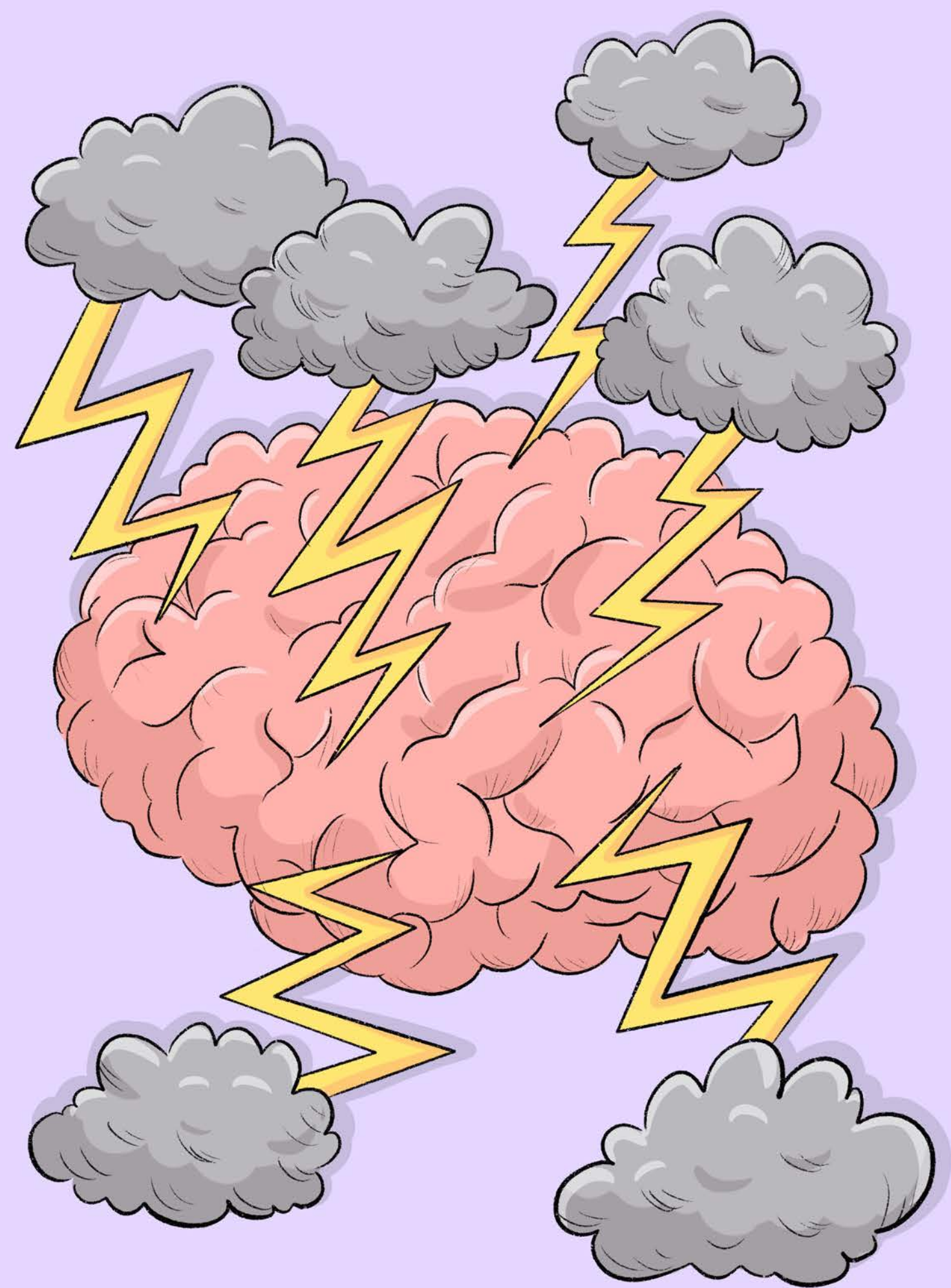
In fact, all that scribble actually jumbles up
the messages that were already there.

The other way to think about it
is...

inside the brain a big storm
is happening,
with flashes of lightning
and crashes of thunder.

It makes it very hard to
concentrate.

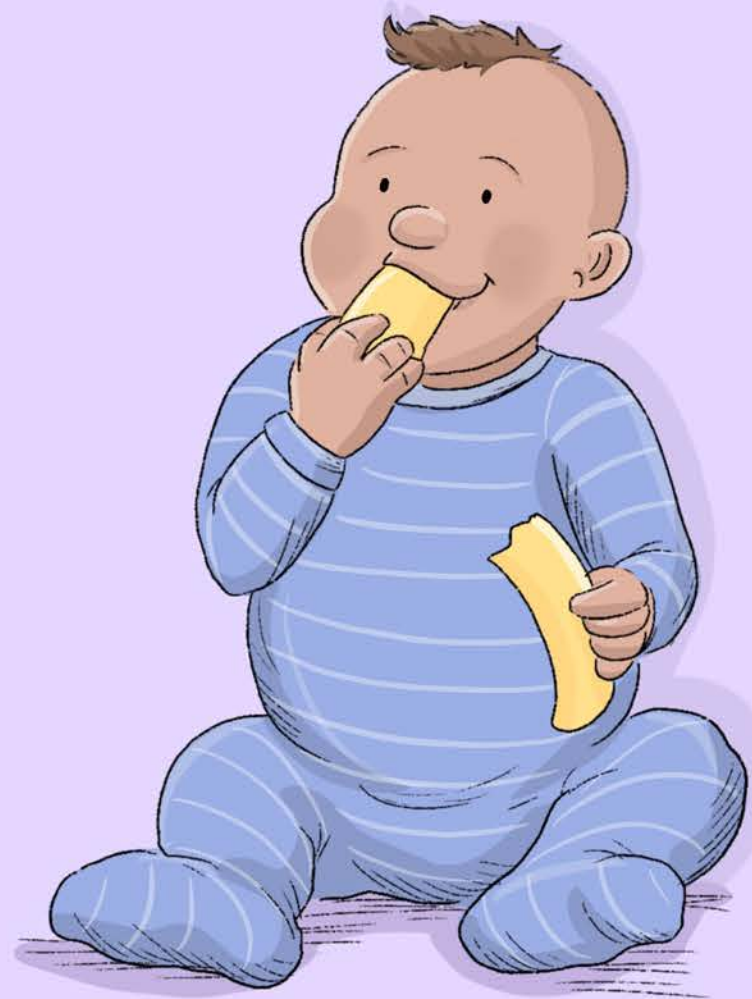
These electric storms in the brain
are sometimes called a
'seizure' or 'epilepsy'.



Think about how much a baby learns in their first year.

A very new baby can't do much other than cry, and the grown-ups have to try and work out if the baby is hungry, or cold, or tired, or has a dirty nappy.

But by their first birthday many babies can sit up, crawl, and feed themselves – they might even be able to say a few words and walk a few steps.



Anything that interrupts or stops all that important learning happening, can be a big problem for the baby.

So, it's really important that the doctors stop the spasms and calm the brain down as quickly as they can.

Sometimes that means the baby has to stay in hospital for a while.



Most babies are given medicine to stop their spasms – but the medicine itself can cause some problems.

It can make the baby tired, floppy, hungry, really chubby, cross and miserable – it might also make the baby cry a lot.

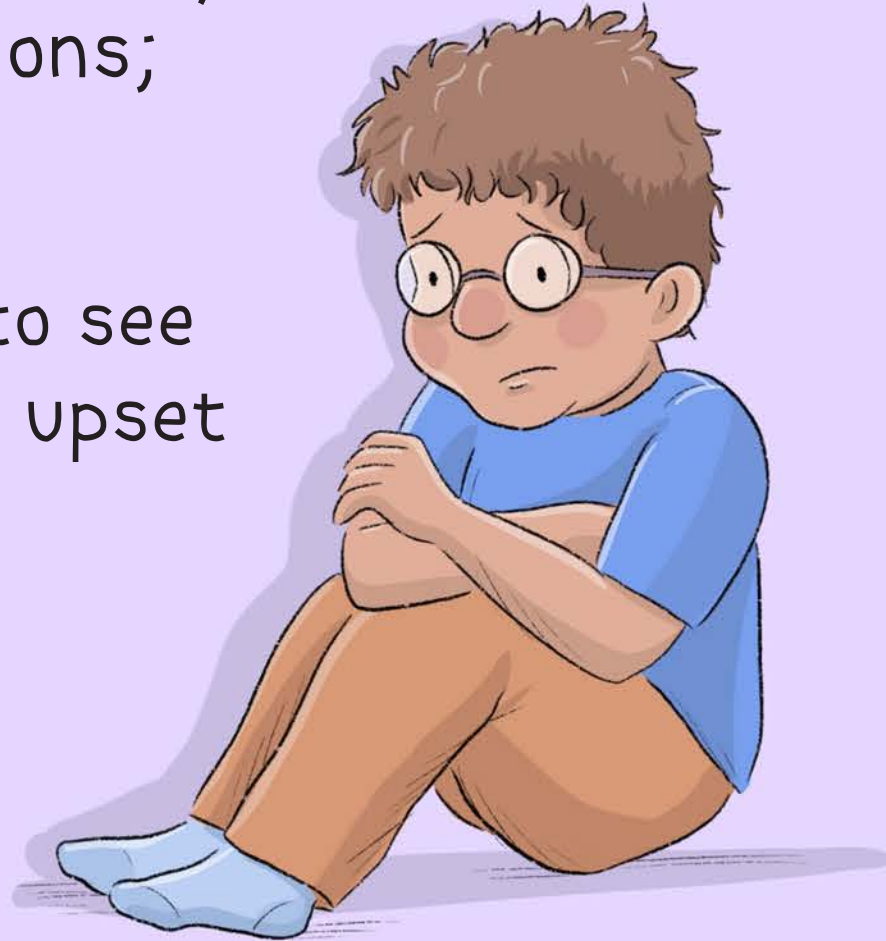
It's not much fun caring for a very unhappy baby. But it's important to remember it's not the baby's fault.

Looking after a baby that is unwell is hard on everyone in the family – the grown-ups may be tired and unhappy too.



Having a baby in your family who is not well might make you feel lots of different emotions;

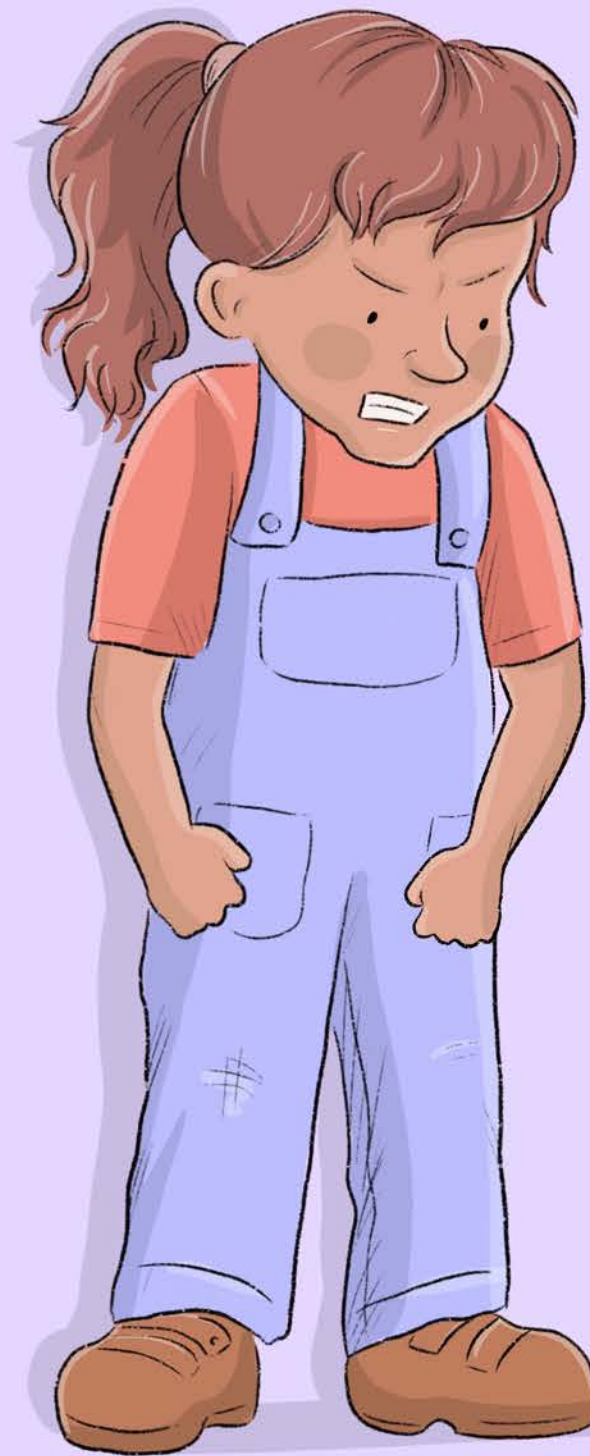
... sadness to see everyone so upset



... jealousy that the baby is getting all the attention



...frightened because it's all so new and overwhelming

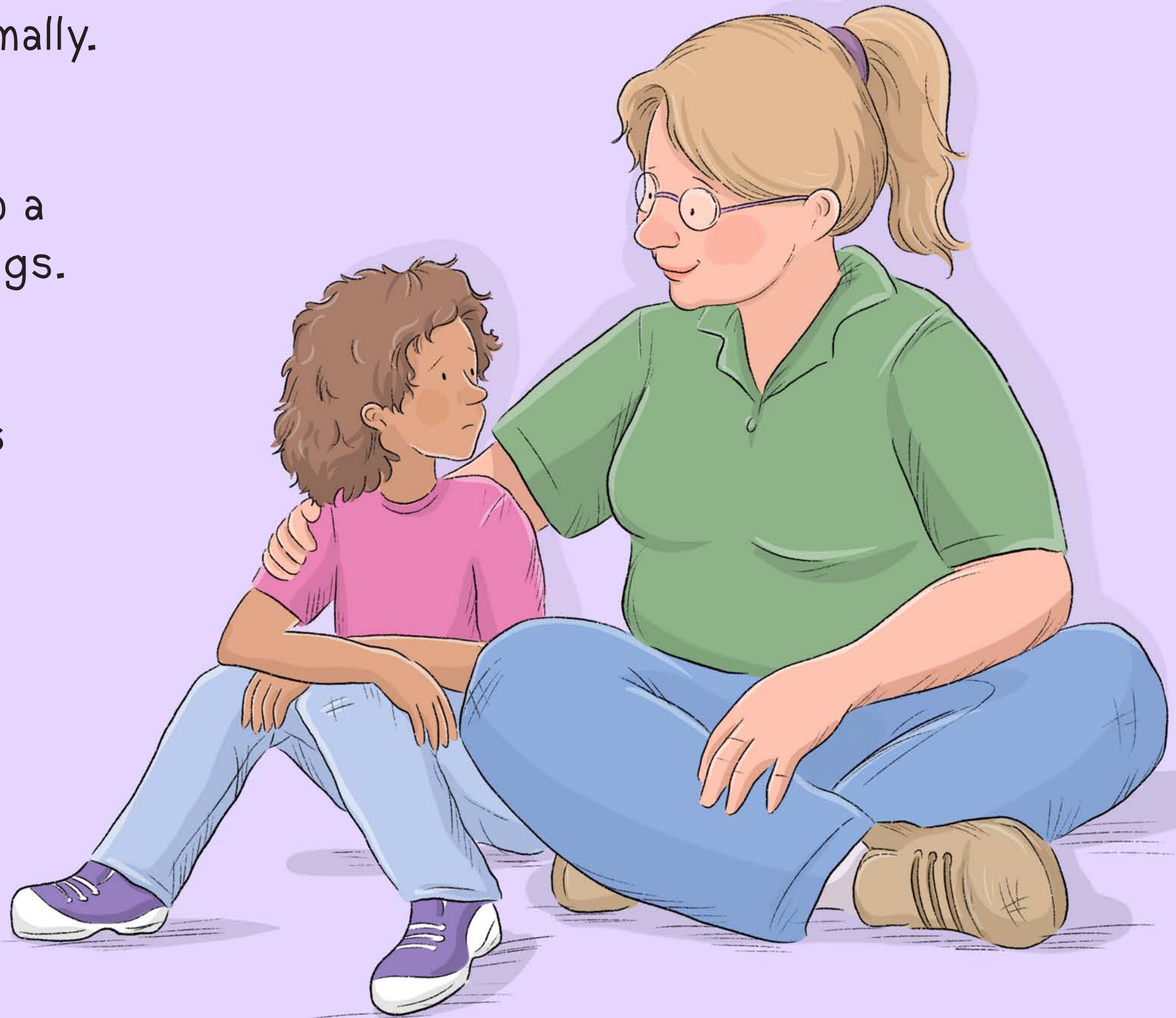


... anger that everything has had to change

These feelings might make you do or say things you wouldn't normally.

It can be helpful to talk to a grown-up about your feelings.

Remember, your grown-ups love all their children, but sometimes the one that is poorly needs them more.



Although you might be feeling unsure about how you can help,
your baby will still enjoy

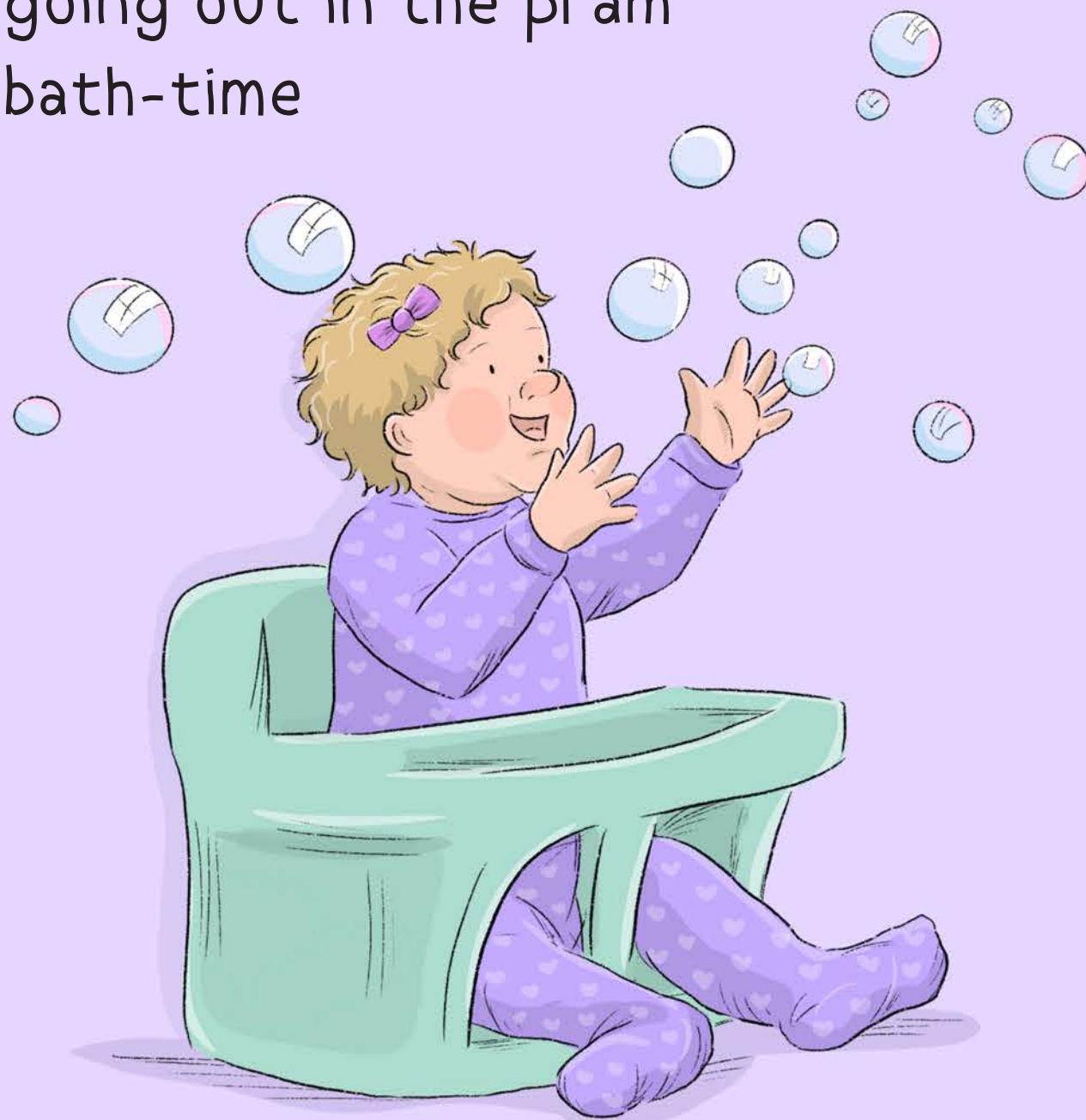
...bubbles

...music

...peek-a-boo

...going out in the pram

...bath-time



...and having
you around.

For some children,
the medicine doesn't work.

The doctor might recommend a
special high fat (ketogenic)
diet.



Sometimes a child may have to have an operation to remove part of their brain.

One of the most amazing things about the brain is that the healthy bits can take over from the poorly bits.



Sometimes nothing stops the spasms completely.

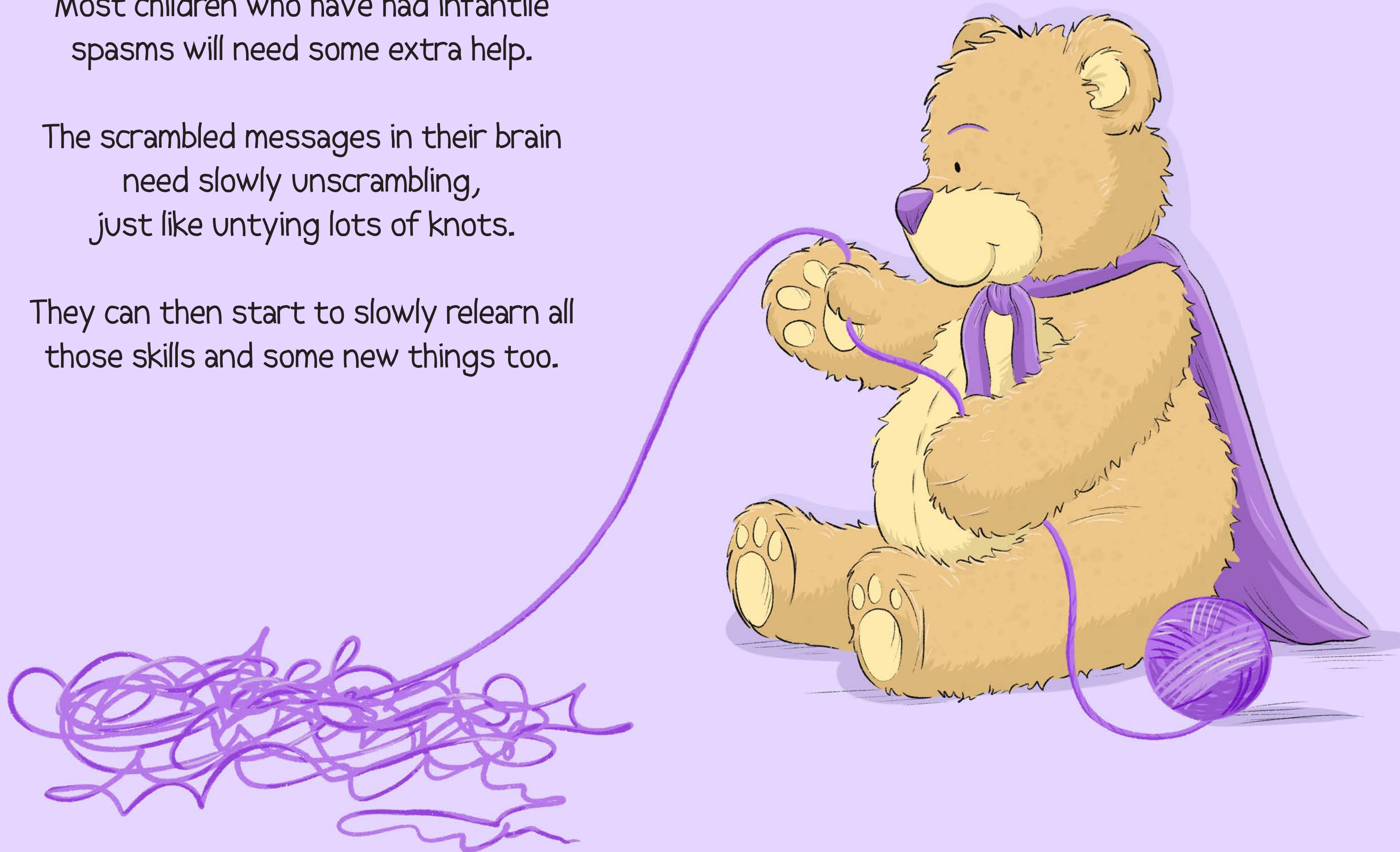
Then a team of doctors and nurses work together to reduce them as much as possible.



Most children who have had infantile spasms will need some extra help.

The scrambled messages in their brain need slowly unscrambling, just like untying lots of knots.

They can then start to slowly relearn all those skills and some new things too.



And children are amazingly strong, brave, resilient and courageous to face these challenges.



Luckily there are lots of people who can help;

Physiotherapists...



Teachers...



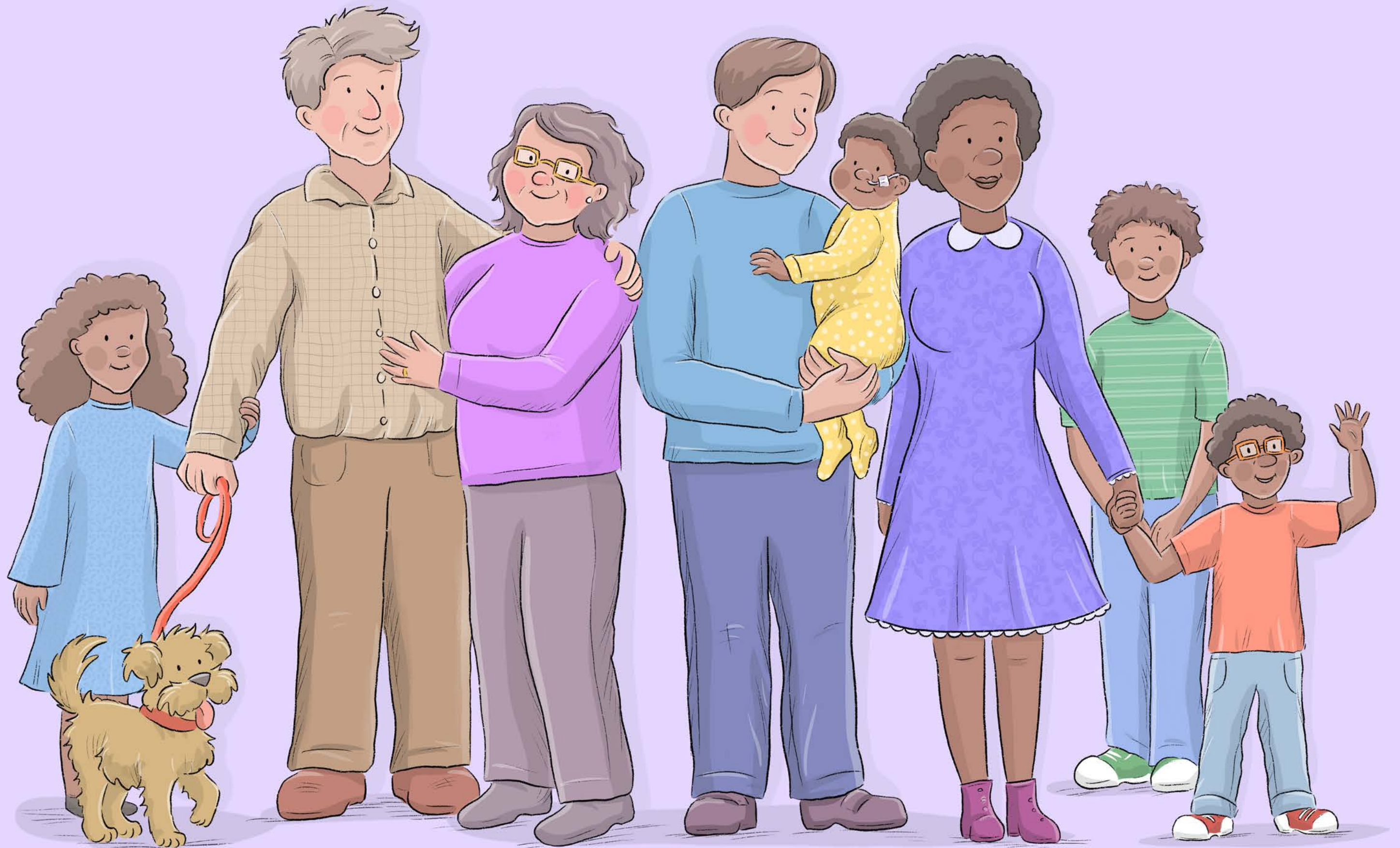
Speech therapists...



Portage workers...



And not forgetting family and friends... you are the most important teachers of all!





I really hope that you've found this book helpful.

I'd like to invite you, and your friends and family to join our community around the world in raising awareness and supporting families affected by infantile spasms.



LINKS AND OTHER INFORMATION



Child Neurology Foundation
<https://www.childneurologyfoundation.org>



Infantile Spasms Action Network
<https://infantilespasms.org>



UK Infantile Spasms Trust
<https://ukinfantilespasmstrust.org>



And you can also find us on Facebook,
Twitter and Instagram.