What is MS to Me?

Created by the MS Society

Illustrated by Margaret Sturton

MS
Society

This book is about me, my family and MS.
My name is

.....

This is what me and my family look like:

We're the MS Society and we're here for you, your family and your friends.

Funding world-leading research, sharing information, making voices heard and campaigning for everyone's rights. Together we are a community. **And together we will stop MS.**

Adults can get support and information from our MS Helpline **0808 800 8000** and at **mssociety.org.uk**

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Patient Information Forum

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Oh, hi!

I didn’t see you there.

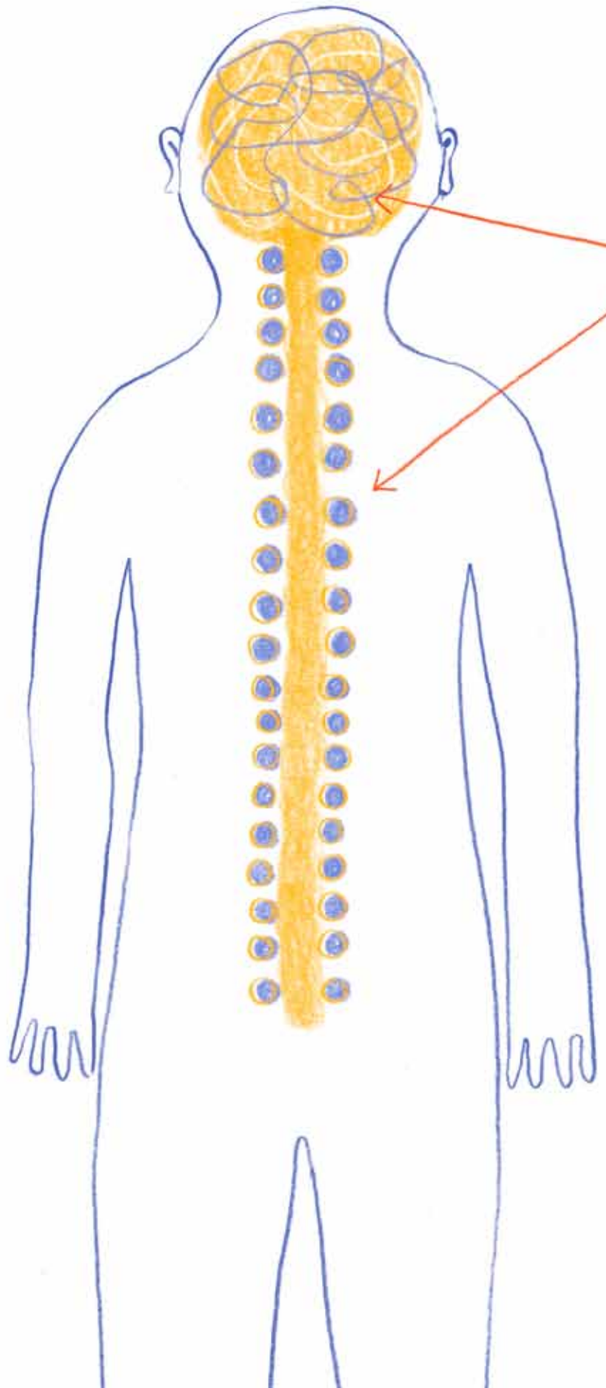
I was busy, delivering messages.

Here’s another!

“Make sure this gets to the legs. Our human needs to take a step forward.”

My name’s Tingo.

I’m a nerve cell.
And I live in the brain.
There are billions of nerves in every human.

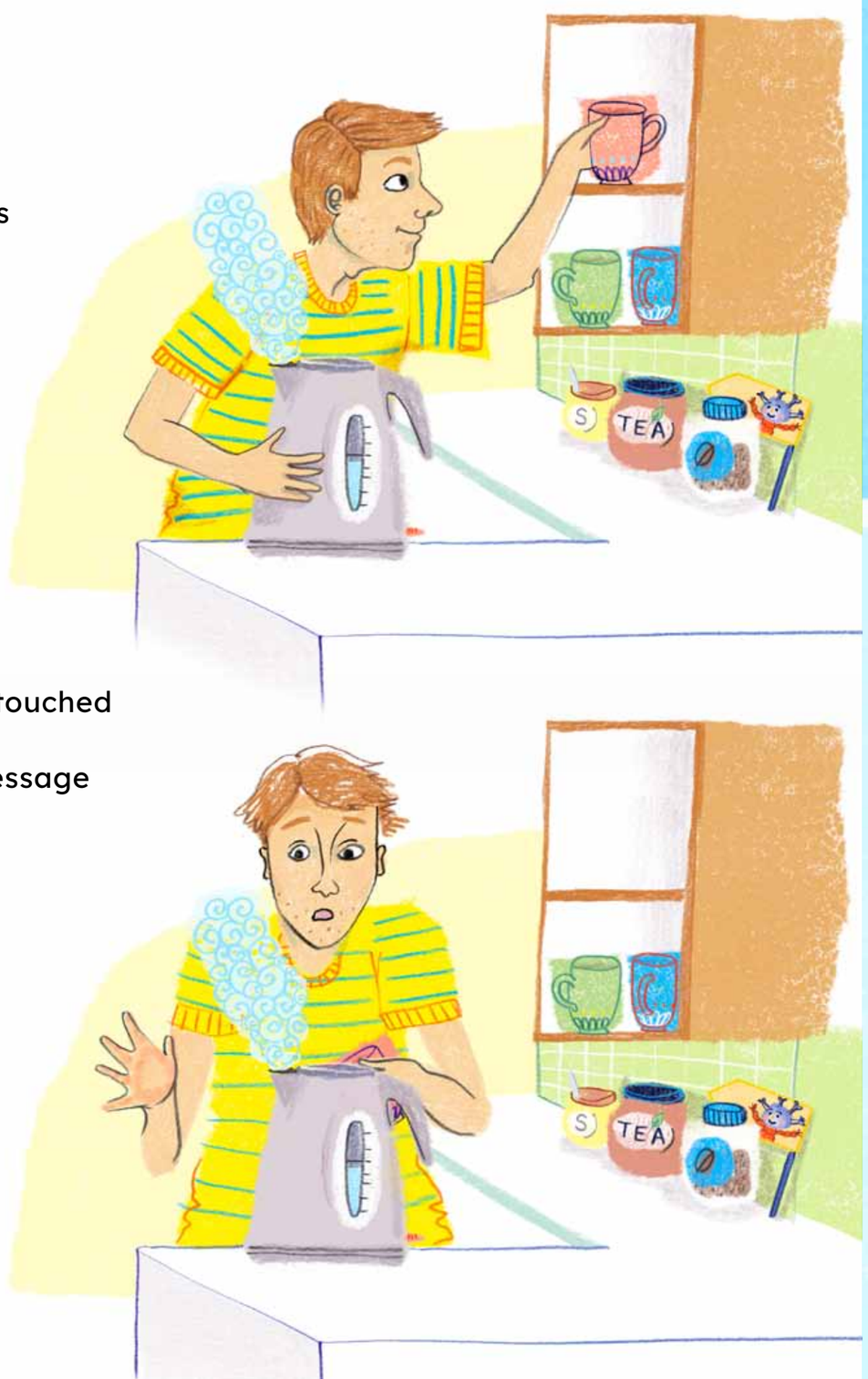


My kind mostly live in the brain and in the spinal cord – here, and here.

If you want to see what we really look like, there’s a picture at the end of this book.

You can tell we’re important because our home has a fancy name. The ‘central nervous system’.

Our job is to pass on messages. Messages about everything.



This human just touched something hot.
So they get a message from the fingers.

And super quick we reply… move your hand!

Listening to a story like this little human?
We pass on messages all about the sounds from your ears, the meanings of the words, the pictures you imagine….
The whole lot. That’s us, working away.

Every move, every thought.

We’re involved somewhere.

Hundreds of billions of
messages every second.

On our own, we’re not much to look at.
But together…
We help our human whenever we can.
We’re part of them, after all.

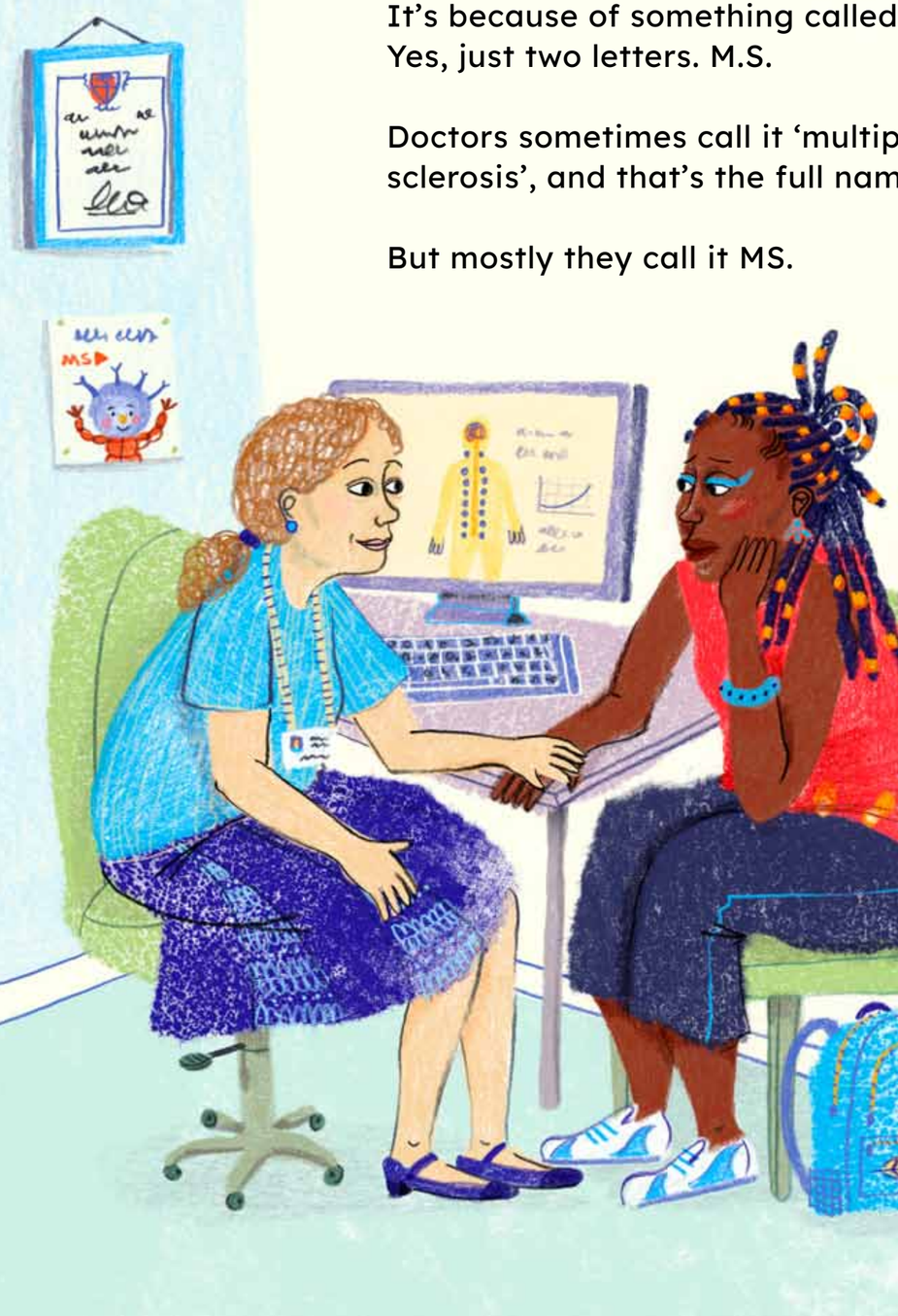
But sometimes our messages go slow, or go wrong.
And when they do, our human doesn't feel so well.

Sometimes they feel wobbly when they walk, or have a tingly hand. One time my human had blurry eyes for a while.

It's because of something called MS.
Yes, just two letters. M.S.

Doctors sometimes call it 'multiple sclerosis', and that's the full name.

But mostly they call it MS.



MS is an illness - but not one people can catch or spread like a cold.

It’s when something goes wrong where I live - in the central nervous system.

MS damages us nerves, and our lovely thick jackets.

Do you like my jacket? It’s made from something called myelin (you say it ‘MY-lin’).

It protects me, and it helps keep messages safe and speedy.

If MS damages our jackets, we can’t send messages so fast.

Sometimes we can’t send messages at all and then we hope another nerve can pass it on instead. But that can take longer.

And when messages go slow or go wrong,
that's when my human gets really tired,
wobbly on their feet, or tingly and numb.

Doctors call these things 'symptoms'.

I know that other humans with MS have
different symptoms.

So that's what MS is to me –
looking at it from the inside.
But I think my human
would have more to say.
About what MS means for them.
And I bet you do too.

How do you feel about MS?
What questions do you have?
I've left space at the back of this book so you
can write or draw things when you want to.

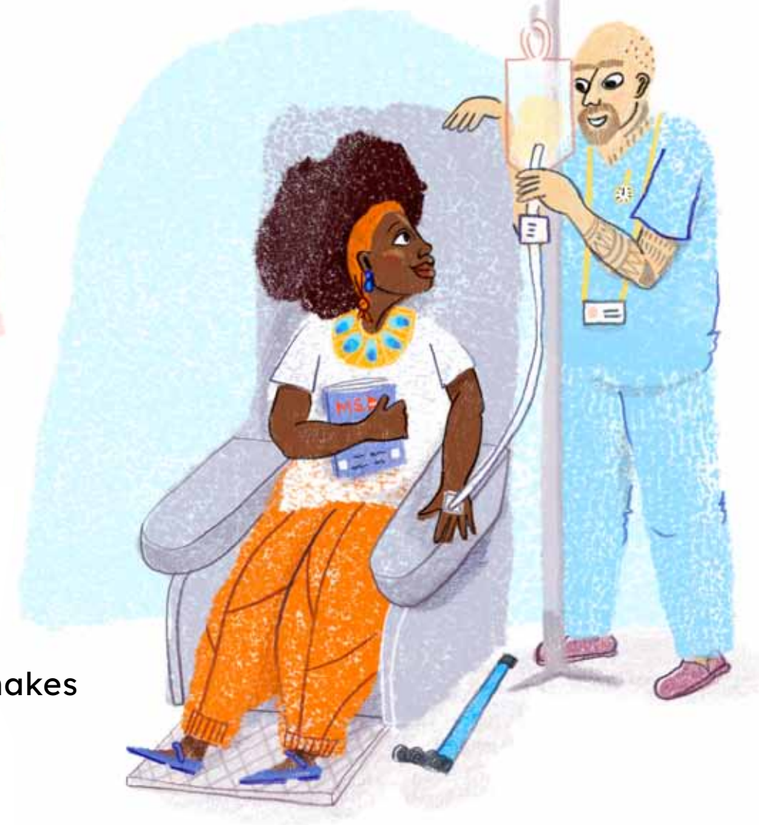
I love the way humans ask questions, share ideas, find the answers together.

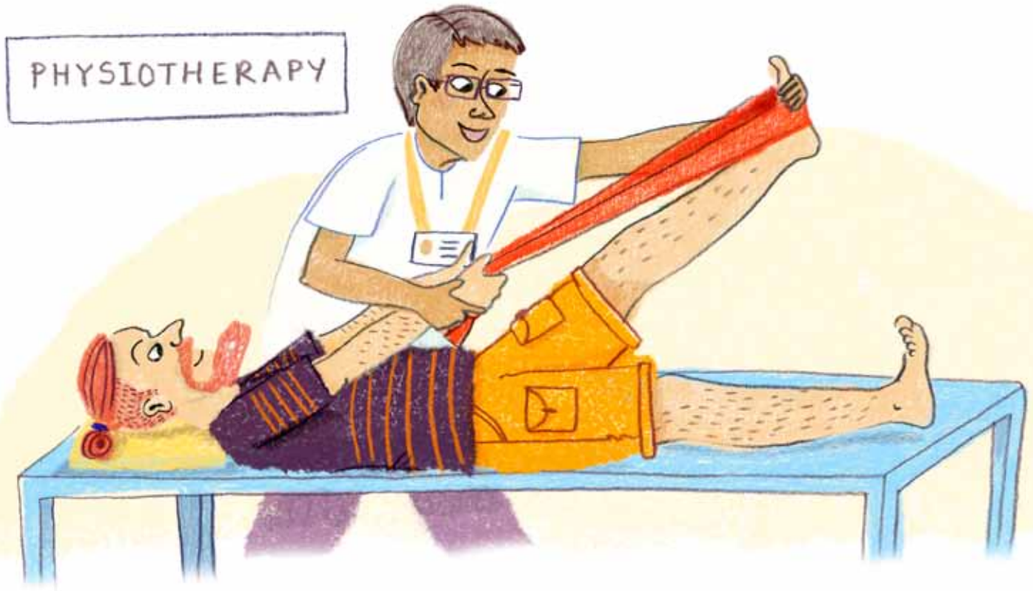
But it's not just about answers – nobody has all the answers. It's sharing how you feel too.

Over time, I've learned a bit about MS.

I've learned that some people take medicine to keep the MS away as much as possible.

Sometimes the medicine makes them tired the next day.





And I’ve learned that MS doesn’t go away completely, even if people do take medicine. But lots of different things can help. Like special exercises called physiotherapy (you say it: ‘FIZZ-eeyoh-THEH-rappy’).

Or talking with experts who know about MS.

The experts might visit at home. But my human usually pops to the hospital to see them. Or to a place called a ‘neuro rehab centre’.

I know that sometimes my human can't manage everything they want to do. But they think a lot about staying as fit and healthy as they can.

I think I've learned a lot. Now, I'm the one explaining it to my friends. Sometimes I do feel sad that MS won't go away. But other times I feel much happier, because I think of everything my human does.

They've got MS, but they're still great at so many things.

I used to worry that I'm only a tiny little nerve.
But I realise now that's all I need to be.
I'm doing the best I can. Just like my human.

They don't expect me to make them well.
They don't expect me to be perfect.
And we've got so much in common...

We like looking at pictures.

We like being together.

We like the Olympics.
We DON'T like rain.
We like trying new things.

And we find new ways
to do old things.
What do you like doing together?
Can you can write it down or do a drawing of it?

And now I have to
get back to work.

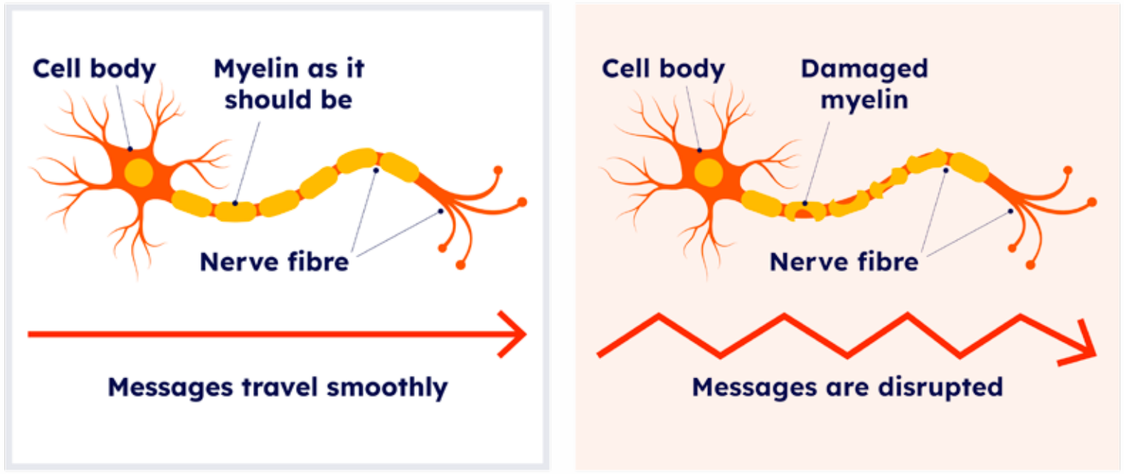
My human is on the phone
to the family. Plenty
of messages for me to
deliver.

Oh, before I go, I've
written some facts about
MS on the next page.
In case you want to know
more.

And remember, you
humans are brilliant at
asking questions.

MS facts page

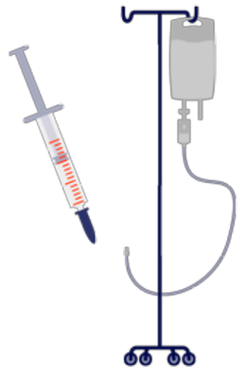
This is what me and my nerve cell friends in the brain really look like:



You can’t catch MS or spread it to anyone else.

MS affects people in different ways. And sometimes you can’t see how someone is feeling. That’s why it’s good to ask questions if you’re wondering what someone’s MS is like.

Lots of people with MS take medicines. Some people take a medicine called a ‘disease modifying therapy’ – DMT for short. They can be tablets or an injection they give themselves at home. Or they might visit hospital for their DMT.



People sometimes do other things to help them feel better. Like exercises called physiotherapy. Or they might take special care over what they eat.

Lots of different experts can help someone with MS. Like the family doctor (the GP), an MS nurse, and a doctor called a neurologist who’s an expert in nerves. Lots of experts work at hospitals, but sometimes they might visit at home.

Adults can find out more about MS on our website **mssociety.org.uk,** or by asking our MS Helpline on **0808 800 8000.**

Here is space for you to write how you feel about MS.

Who has MS? Who can you talk to about it?

My.....has MS. I can talk to.....

Here is space for you to draw what you like doing together.

Did you find Tingo on every page?
Tip: Tingo's the one with a yellow nose!

Tingo knows about MS. Well, as much as a little nerve cell can. Everyone's MS story is different, and this book is for **you** and **your family**.

Who wrote this book? People living with MS, health professionals, artists and writers created this book together. A real mix of ages, experiences and backgrounds.

We hope it helps you talk about MS in your own unique family.

MS Society

MS Helpline
0808 800 8000

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