

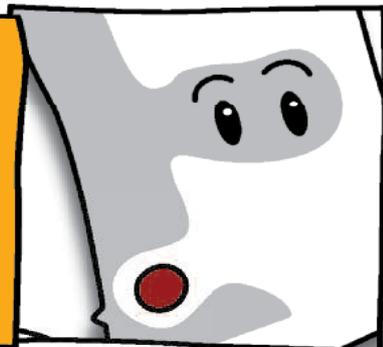
Multiple
Sclerosis
Trust



MS



Kids' guide to MS



The MS Trust helps people with MS, their family and friends as well as the doctors and nurses who look after them.

We get loads of phone calls and emails from people asking us all sorts of questions about MS. We answer most of them ourselves but if we don't know about something we'll find someone else who does.

We've written lots of other books and leaflets on MS and every year we send out thousands of copies to people who want to know more about MS.

You can read all our books and lots more on our website www.ms-trust.org.uk.

Janice Sykes
Information Officer, MS Trust

MS Trust Kids' guide to MS
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A very big

THANK YOU
to

- all the kids and their mums and dads who helped us with this book
- for their help in getting the words right
Dr Alexander Burnfield
Julia Segal
Kerry Mutch

And a special

THANK YOU
for their support to

- Joanna Gardner and her sister Sarah Joiner. Joanna was Mayor of the Royal Borough of Kensington and Chelsea in 2008-09 and chose the MS Trust as the Mayor's Charity. With the help of family, friends, neighbours and colleagues, her fantastic fundraising, including a dog show and a carol concert, supported the production of this book.
- Mrs F B Laurence Charitable Trust
- William and Mabel Morris Charitable Trust
- John Lewis Partnership

This book has been written for you to explain a bit about MS, but it won't give you all the answers.

It's OK TO ASK QUESTIONS ABOUT MS

That way you can learn more about it and understand it better. Grown ups ask questions too.

Some questions are a bit scary. Most people, young or old, feel upset and mixed up about MS at times.

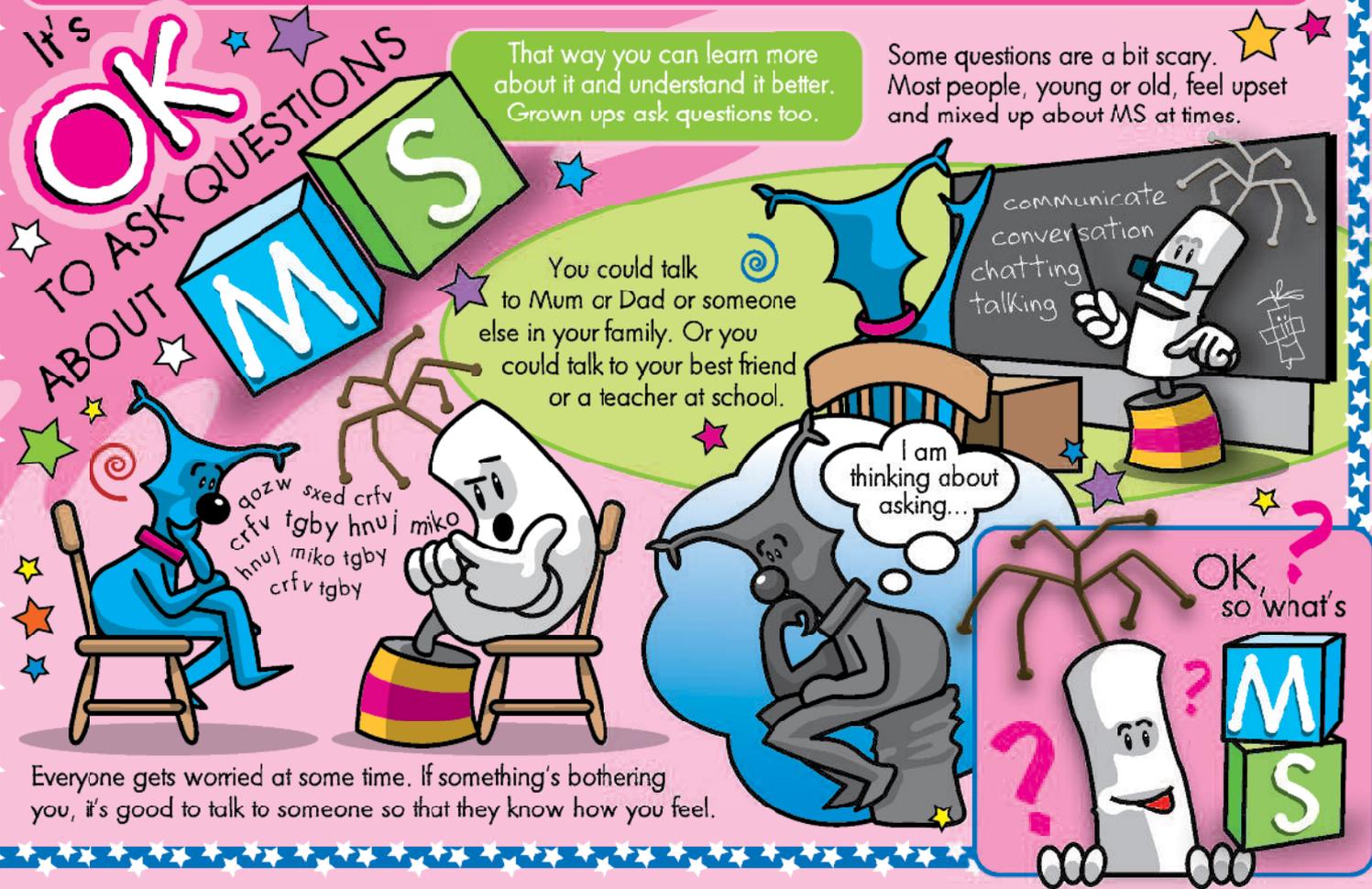
You could talk to Mum or Dad or someone else in your family. Or you could talk to your best friend or a teacher at school.

communicate
conversation
chatting
talking

I am thinking about asking...

OK, so what's

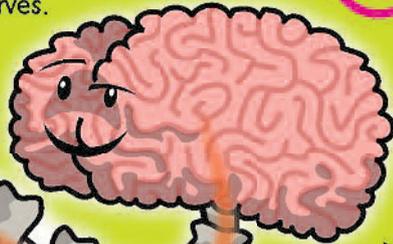
Everyone gets worried at some time. If something's bothering you, it's good to talk to someone so that they know how you feel.



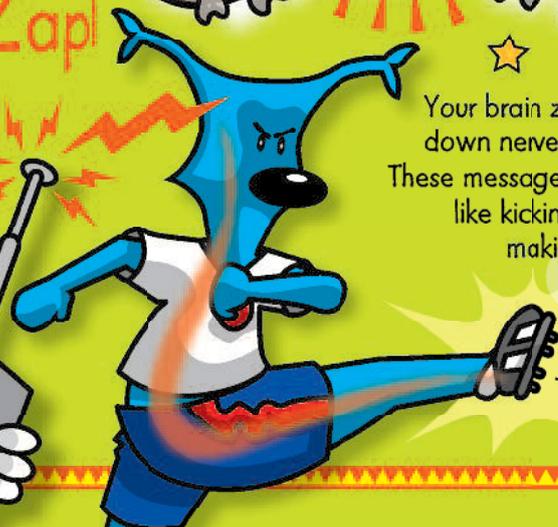
about

MULTIPLE

Your brain is bulging with loads of nerves. It may look like a weird pink sponge but it's actually more complicated than the most powerful computer. Your brain is wired up to the rest of your body through the spinal cord which runs down the middle of your backbone.

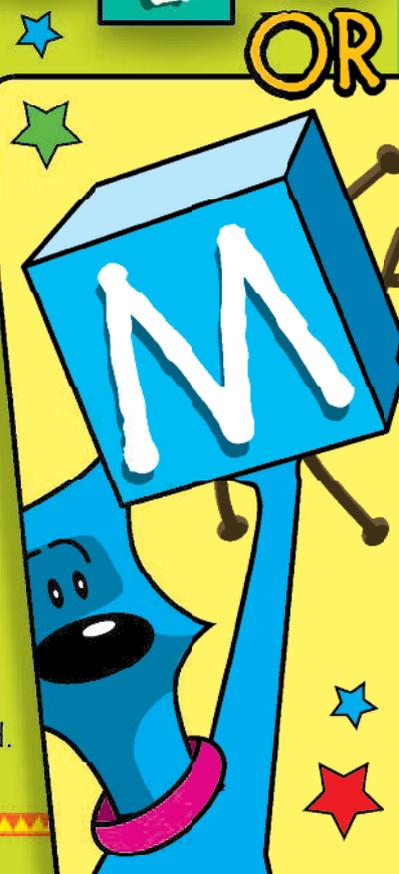


Zap!



Your brain zaps electrical signals down nerves to tell your body what to do. These messages let you do all sorts of things, like kicking a football, watching the TV, making a sandwich, even touching your nose with your tongue.

Can you do that?
Try doing it with your best friend.



SCLEROSIS

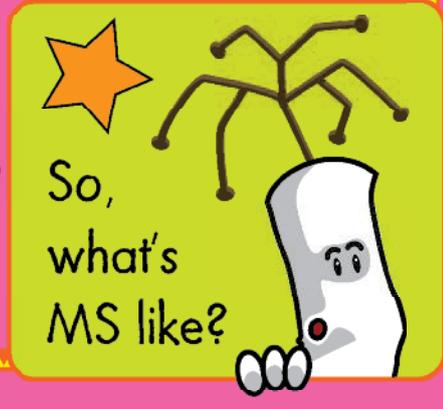
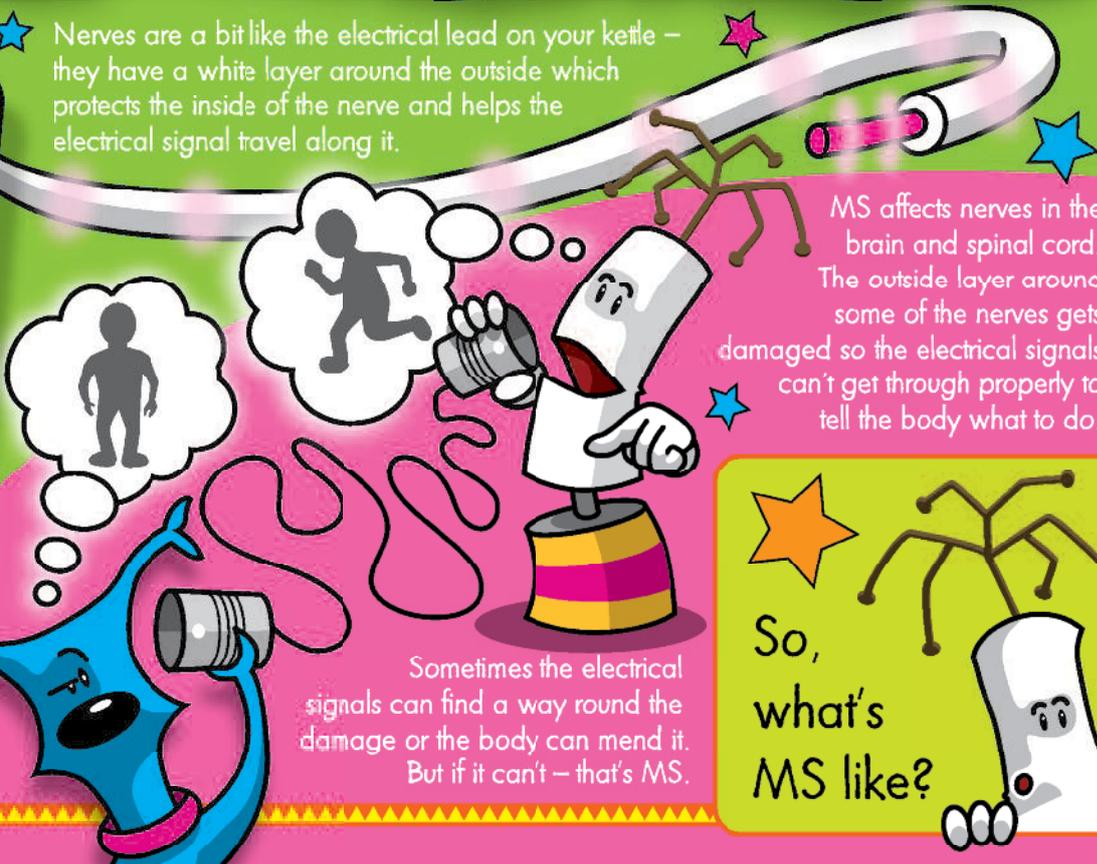
Nerves are a bit like the electrical lead on your kettle – they have a white layer around the outside which protects the inside of the nerve and helps the electrical signal travel along it.

MS affects nerves in the brain and spinal cord. The outside layer around some of the nerves gets damaged so the electrical signals can't get through properly to tell the body what to do.

Sometimes the electrical signals can find a way round the damage or the body can mend it. But if it can't – that's MS.

So,
what's
MS like?

MS is short for multiple sclerosis – mull tippel sclair oh sis. Let's stick with MS.



What's MS like

MS is different for everybody.



MS doesn't go away completely, one day Mum or Dad can feel better, and then the next day they might feel worse.

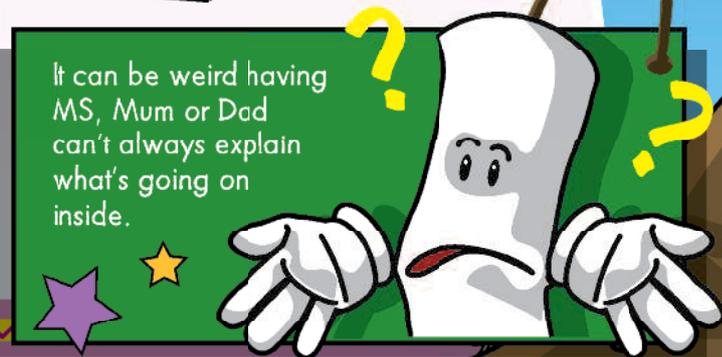
One day, they might feel a lot worse suddenly and this is called a relapse. It can take a while to get better after one of these. And then they might feel fine for ages.



Some MS things are on the inside, like feeling really, really tired. Or prickly, pins and needles feelings, like ants in your pants. Or feeling grumpy or sad.



It can be weird having MS, Mum or Dad can't always explain what's going on inside.





Other MS things show on the outside like finding it difficult to walk, which is why some people with MS need to use a stick or a scooter.

Being hot or tired can make some of these things show up more for a while, but that doesn't mean MS is getting worse.

Sometimes kids think they can make MS worse by things they do or say or think, but they can't. Mum or Dad might get cross though! But being cross doesn't make MS worse either.

Yeah, but what does it really feel like?

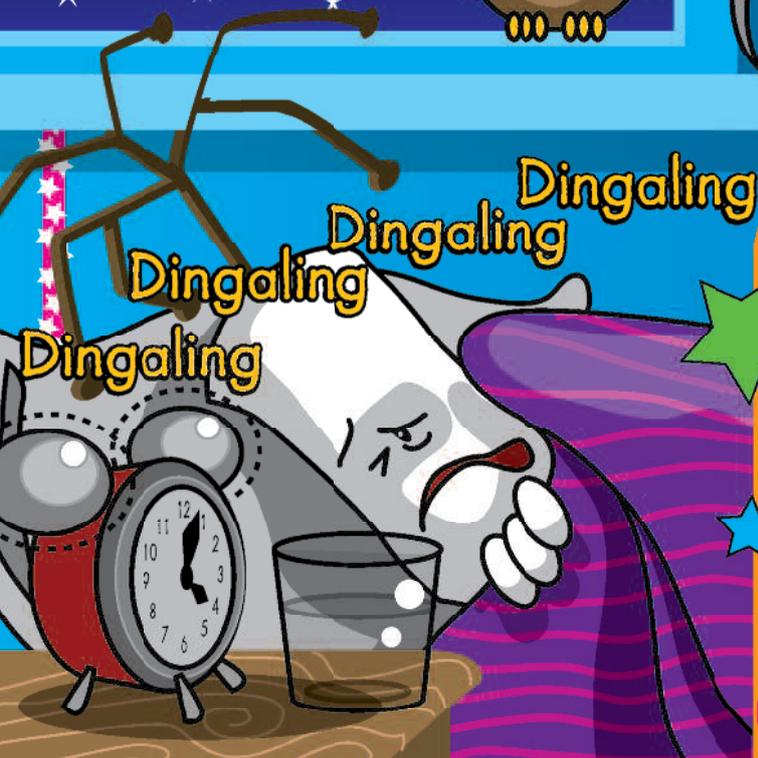
Scratch

Z Z Z Z

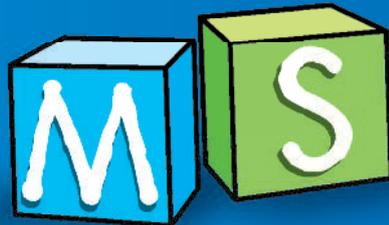
Feeling really, really tired –

have you ever had to get up really early?
Do you remember what it felt like?
Imagine feeling like that all the time –

that's what it's like for lots of
people with MS, even though
they get lots of rest.



If you have ever



Hands feeling clumsy – put on a pair of big gloves and try to read
a comic. Can you turn one page at a time? Do you find it difficult?
Or try tying shoelaces with the gloves on. That's even harder.

wondered what feels like

here are some things you can try yourself

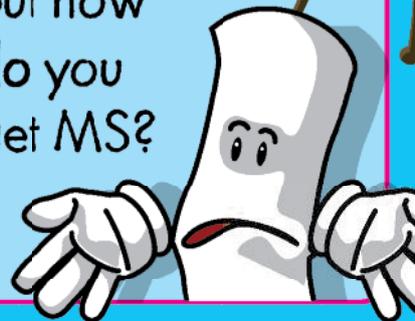
★
Trouble seeing things – borrow someone's glasses. Things look blurry, don't they, or you might even see two of everything.



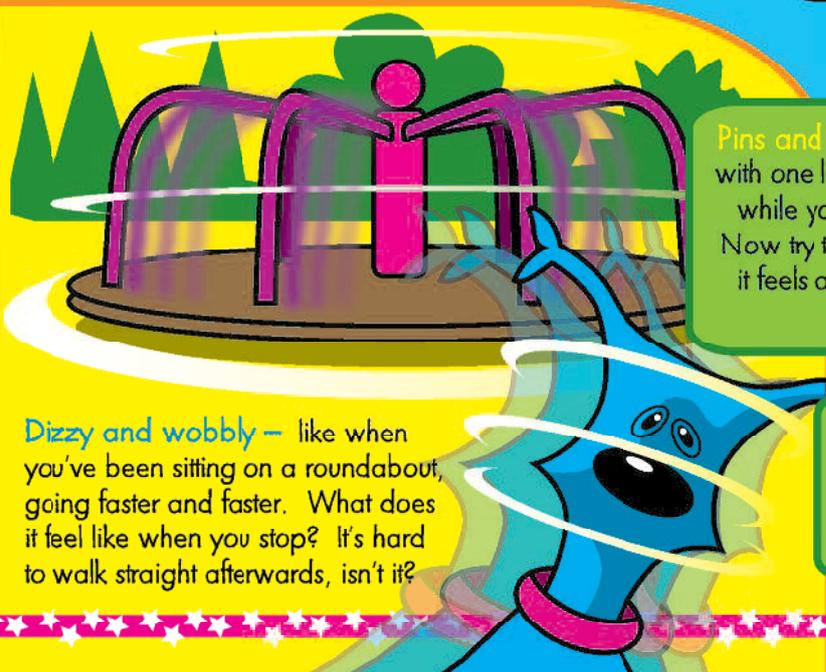
Pins and needles – sit down with one leg tucked under you while you're eating lunch. Now try to stand on that leg – it feels all tingly and funny, doesn't it?

You could ask Mum or Dad what MS feels like for them.

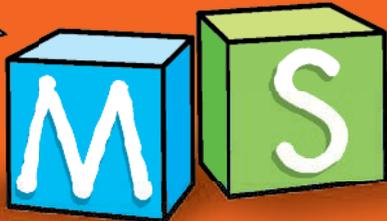
But how do you get MS?



Dizzy and wobbly – like when you've been sitting on a roundabout, going faster and faster. What does it feel like when you stop? It's hard to walk straight afterwards, isn't it?



How do you get



You can't catch MS from someone, like you can a cold or a tummy bug. You can't get MS from bumping your head. Most people who get MS are older than 20.

Sometimes, kids think they caused the MS. But no one is to blame. It's nobody's fault. It's just something that happens.

No one knows exactly how you get MS. It's still a mystery. Scientists all around the world are looking at why people get MS. Here are a couple of ideas they're looking at:



Is it where you live?

We know that more people get MS in countries that have long, dark winters. So, it might have something to do with how much sunlight you get. But very few Eskimos get MS so that's not the whole answer.



Is it caused by a germ?

Some scientists think MS might be started off by a bug, but so far they haven't found one. They're still looking.



Some **SCARY** QUESTIONS

Can MS be cured?

At the moment no one can make MS go away completely, but there are lots of ways to make the bad bits better. There are different kinds of medicines people can take. A healthy diet, exercises and other things, like massages, can help. Telling Mum or Dad about your day at school or something else you've been doing will make them feel better too!

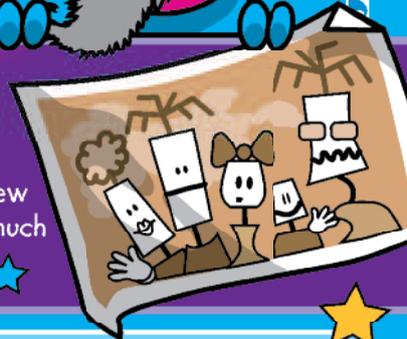
Can someone die from MS?

Most people with MS live a long life. Sometimes MS can make people very ill, but this doesn't happen very often.



Will I get MS?

Some kids worry they'll get MS because their mum or dad has it. But only a very few people get it, so it's much, much more likely that you won't.



We know a lot more about MS now than we did. Doctors and nurses all over the world are finding new ways to make people with MS feel better and looking for ways to mend damaged nerves.

You could ask Mum or Dad to teach you how to explain MS to your friends or teacher or you could show them this book.

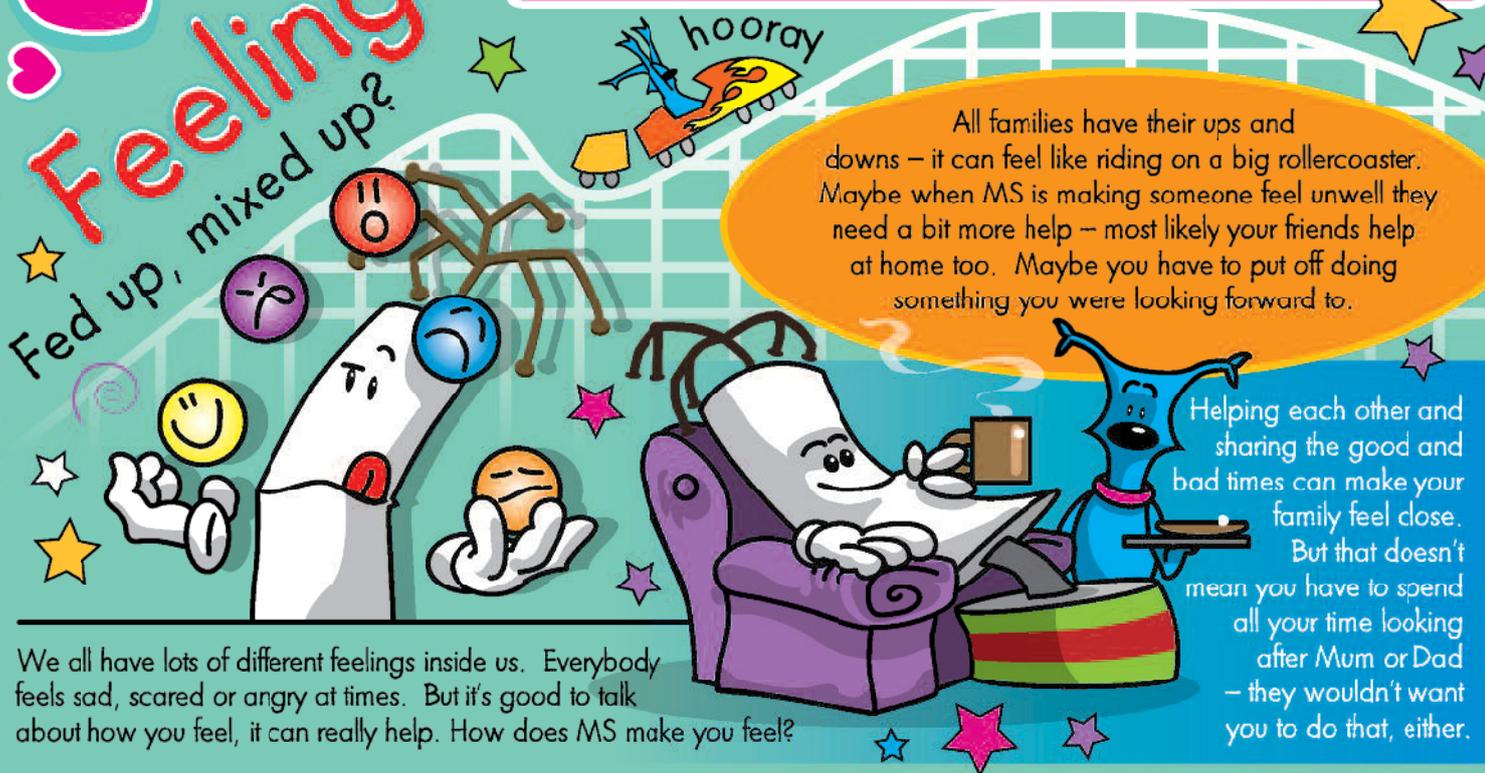
Yeah, but sometimes I feel **angry** and picked on



Knock knock... Who's there?...MS...MS who?.....MS the menace
MS can be a bit of a drag sometimes. It can make you feel mad, sad or bad.
And sometimes glad. MS doesn't make everything horrible.

Feelings

Fed up, mixed up?



All families have their ups and downs – it can feel like riding on a big rollercoaster. Maybe when MS is making someone feel unwell they need a bit more help – most likely your friends help at home too. Maybe you have to put off doing something you were looking forward to.

Helping each other and sharing the good and bad times can make your family feel close. But that doesn't mean you have to spend all your time looking after Mum or Dad – they wouldn't want you to do that, either.

We all have lots of different feelings inside us. Everybody feels sad, scared or angry at times. But it's good to talk about how you feel, it can really help. How does MS make you feel?

Sometimes you might want to make Mum or Dad get better. Sometimes you might be very angry with them and not want to help at all. Or you might be angry with the rest of your family. But it's not really their fault, or yours or the dog's, the cat's, or the budgie's!

Ways to feel better

Sometimes, even after talking about things you still want to let off steam. Which of these do you like best?

- Shout into your pillow (it probably won't shout back)
- Give someone a hug
- Run around the garden five times, hop on one leg seven times, hop on the other leg eleven times, sit down, stand up, sit down, stand up and eat a banana. Maybe Mum or Dad could make up another Mission Impossible challenge like that?
- Read a favourite book



If there's anything on your mind, even if you think it's silly, talk to someone you trust – Mum or Dad, an aunt or uncle or grandparent, someone at school. You can also call Childline free on **0800 1111**.

Did you know?

Messages from your body (like if someone treads on your toe) whizz along your nerves at very high speeds, even faster than a racing car (that's why you feel pain very quickly).



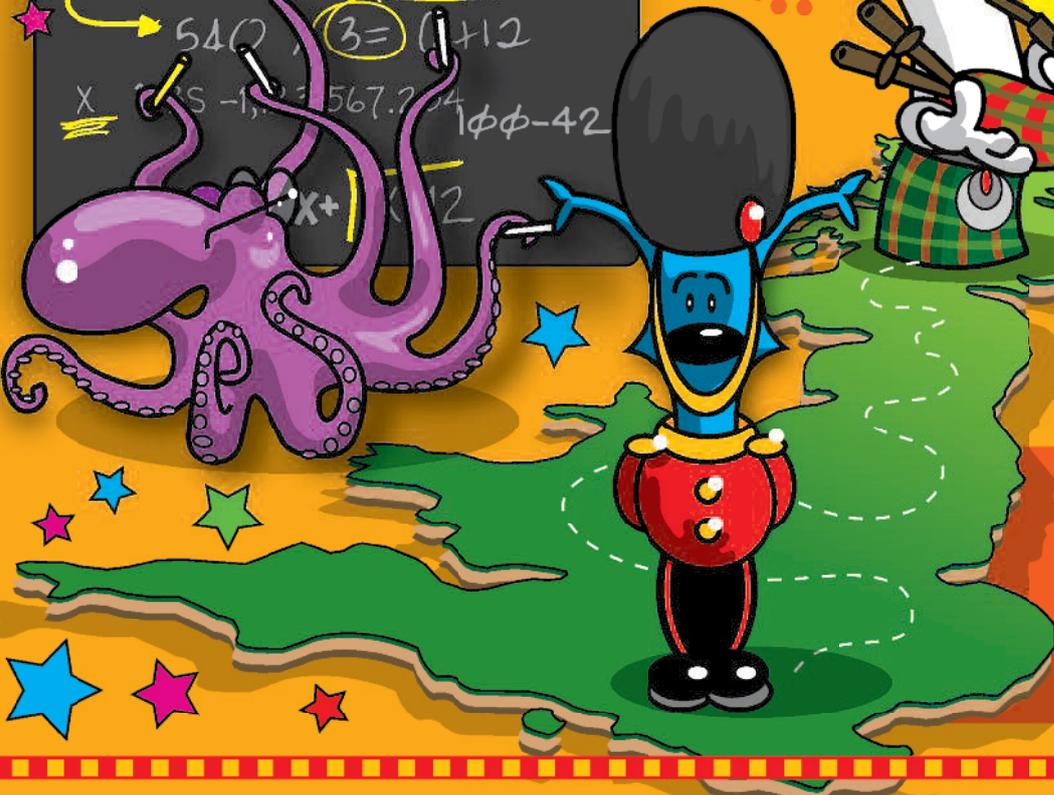
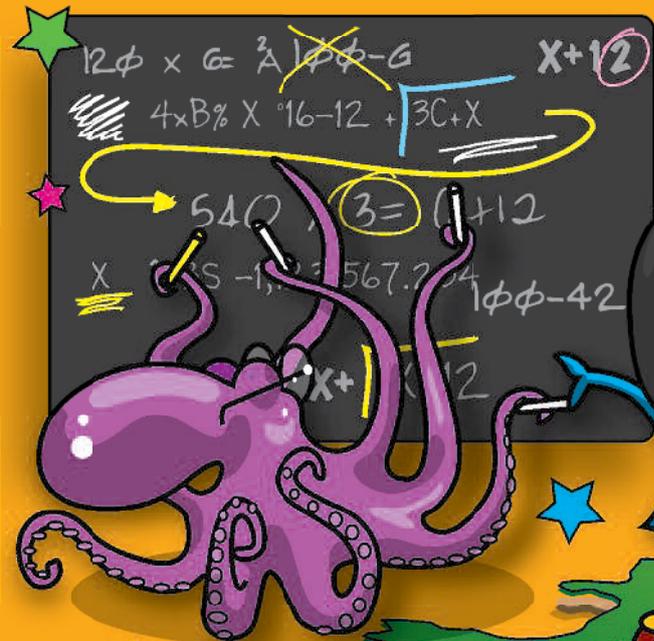
The average human brain weighs 1.4 kilos.
That's about 40 doughnuts.
An elephant's brain weighs 6 kilos.
That's a mountain of doughnuts!



ONE, TWO,
THREE...OH..
..ER..ONE,
TWO, THREE..
AH...UMM...
ONE, TWO,
THREE, FOUR...

Your brain is bulging with 100,000,000,000 – that's 100 billion – nerve cells. That's as many as there are stars in our galaxy. If you don't believe it, try counting them yourself!

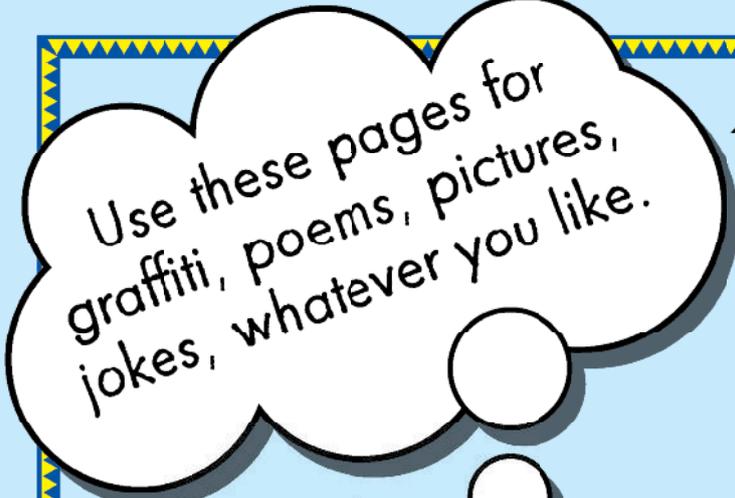
Octopuses are smart suckers - maybe as brainy as dogs.

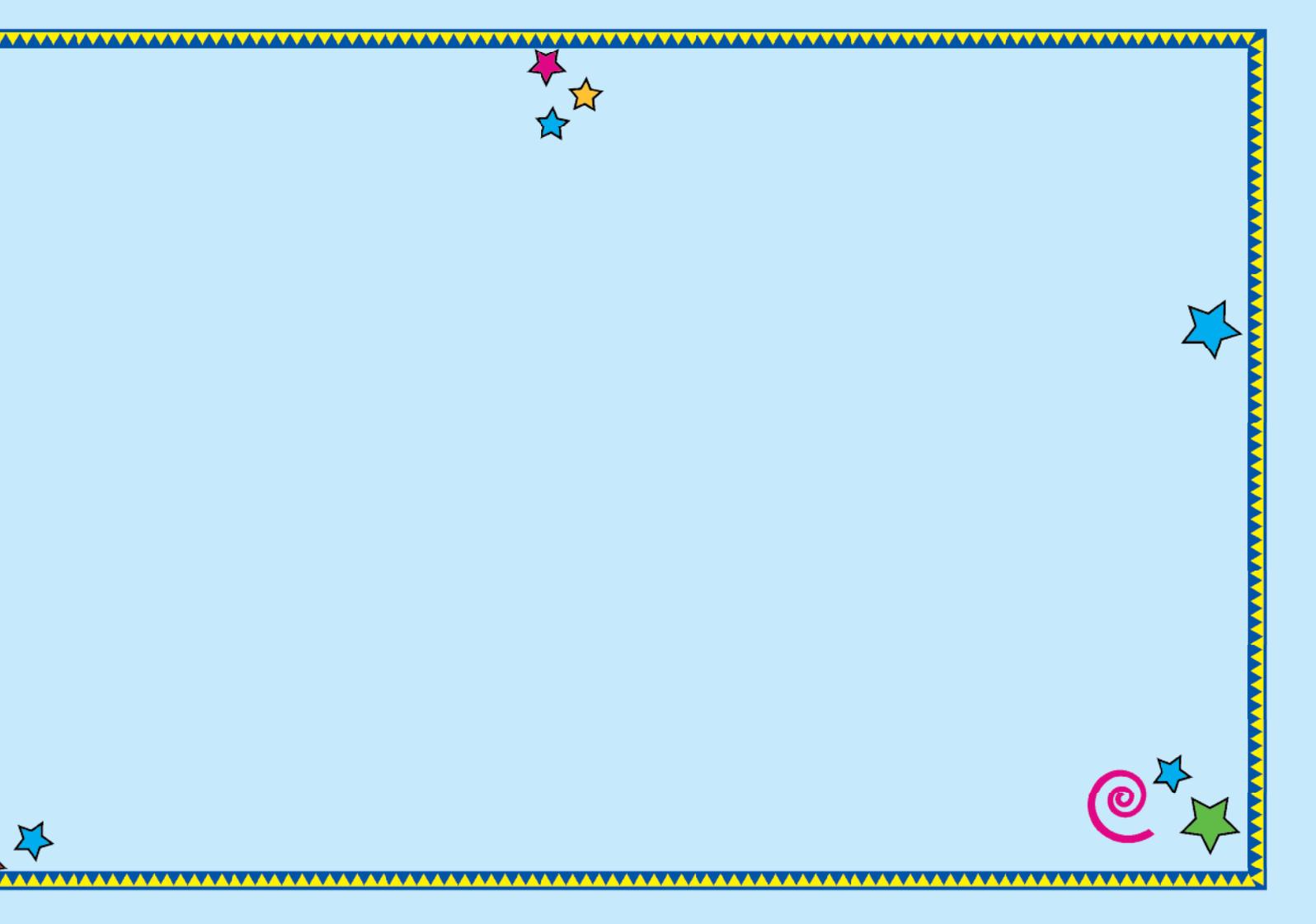


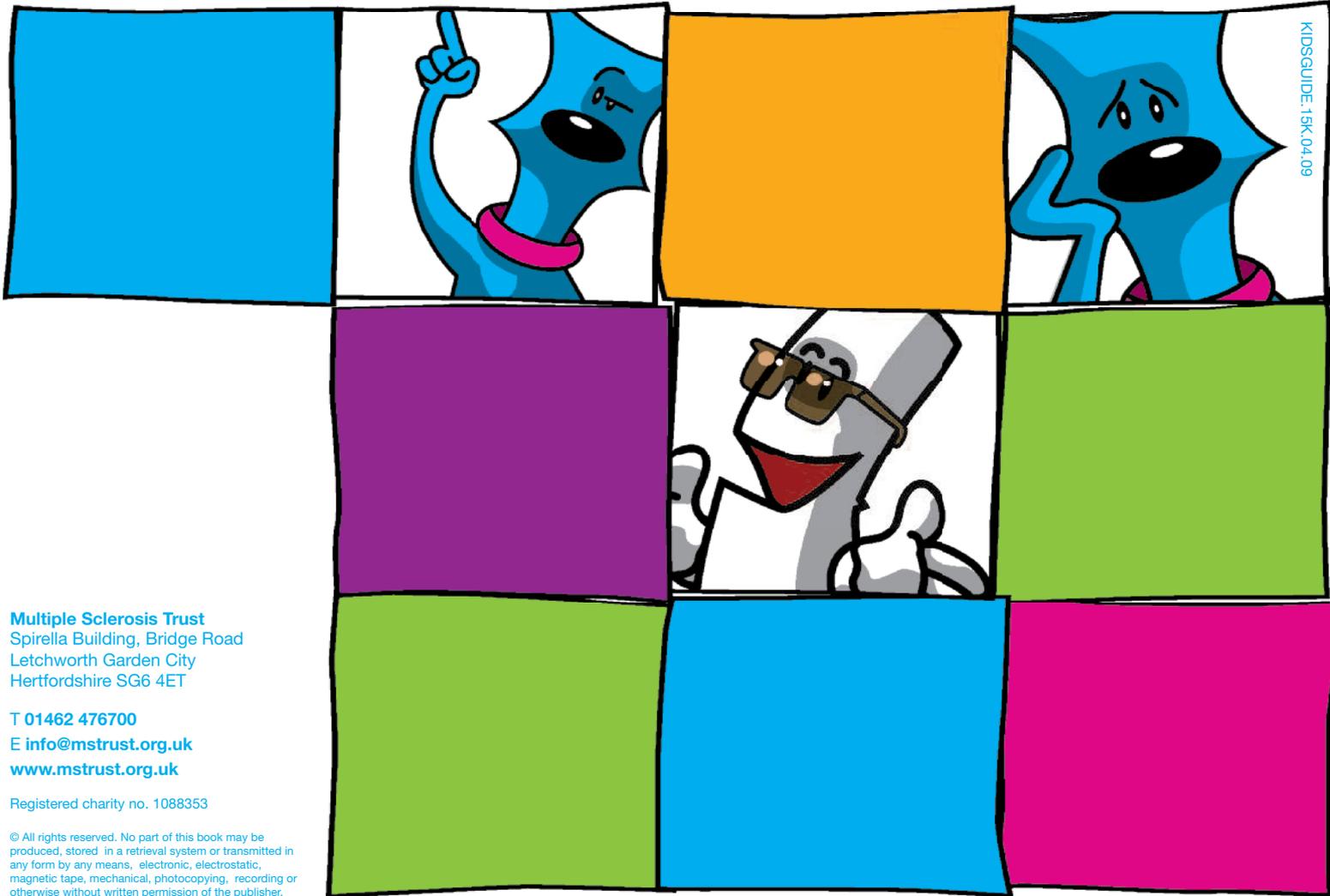
If you laid the cells from just one brain in a line they would stretch 1000 km – that's almost all the way from London to Edinburgh... and back again.



Use these pages for
graffiti, poems, pictures,
jokes, whatever you like.







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