

MS<sup>®</sup>

National  
Multiple Sclerosis  
Society

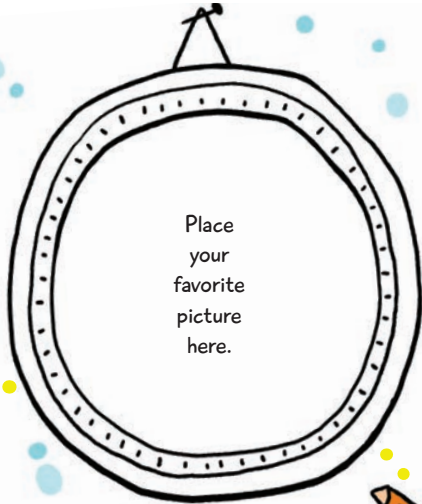
# KEEP S'MYELIN<sup>®</sup>

AN ACTIVITY BOOK FOR KIDS ABOUT MULTIPLE SCLEROSIS



# ALL ABOUT ME!

When a family member has **MS**, it is important to remember that each person in the family is special. Sometimes it may be hard for you to remember that you are special too!



My name is \_\_\_\_\_ . I am \_\_\_\_\_ years old.  
I was born in \_\_\_\_\_ . I am special because... \_\_\_\_\_

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## MY FAVORITE THINGS



What makes me the same and different from my mom, dad, brothers and sisters... \_\_\_\_\_

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(fill in the blanks!)



Food: \_\_\_\_\_

TV show: \_\_\_\_\_

Game: \_\_\_\_\_

Sport: \_\_\_\_\_

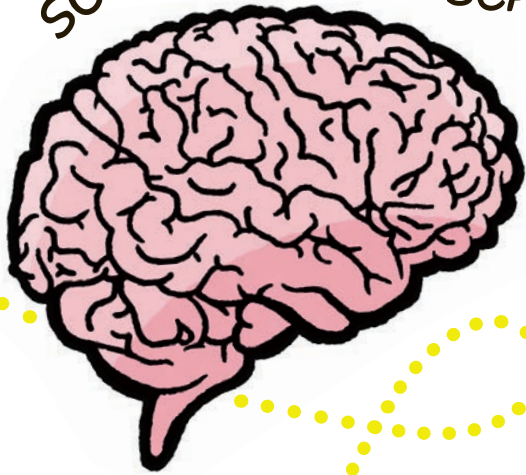
Animal: \_\_\_\_\_

Story: \_\_\_\_\_

Song: \_\_\_\_\_

## INTERESTING FACT:

MULTIPLE means MANY.  
SCLEROSIS means SCARS.



So, multiple sclerosis means  
"MANY SCARS."

# WHAT IS MS?

If you found out that your mom or dad or someone else you know has multiple sclerosis, or even if they've had it for a while, you probably have lots of questions.

**You're not alone! Lots of kids have questions about MS.**

Multiple sclerosis (**MS** for short) is hard to say and spell, and really hard to totally understand! **This activity book is for you.**

It will help answer some of your questions.

- **MS** is a disease that affects the central nervous system (the brain, spinal cord and optic nerves).
- The brain is like a computer that tells the body what to do.
- The spinal cord is like a thick wire attached to the computer.

## MESSAGES TRAVEL BETWEEN THE BRAIN, SPINAL CORD, AND OTHER PARTS OF THE BODY.

When a person has **MS**, the covering (myelin) that protects the nerves gets damaged. Scars form where the myelin is damaged.

As messages travel from the brain, they sometimes get stuck or slowed down by these scars. When this happens, the other parts of the body can't always do what the brain is telling them to do.

Healthy Myelin Sheath



Damaged Myelin Sheath



- Sometimes people with **MS** have trouble seeing.
- Sometimes their arms and legs feel weak or their skin feels tingly (like pins and needles).
- Sometimes they lose their balance, feel very tired, or have trouble walking.

**MS problems like these are called symptoms.**

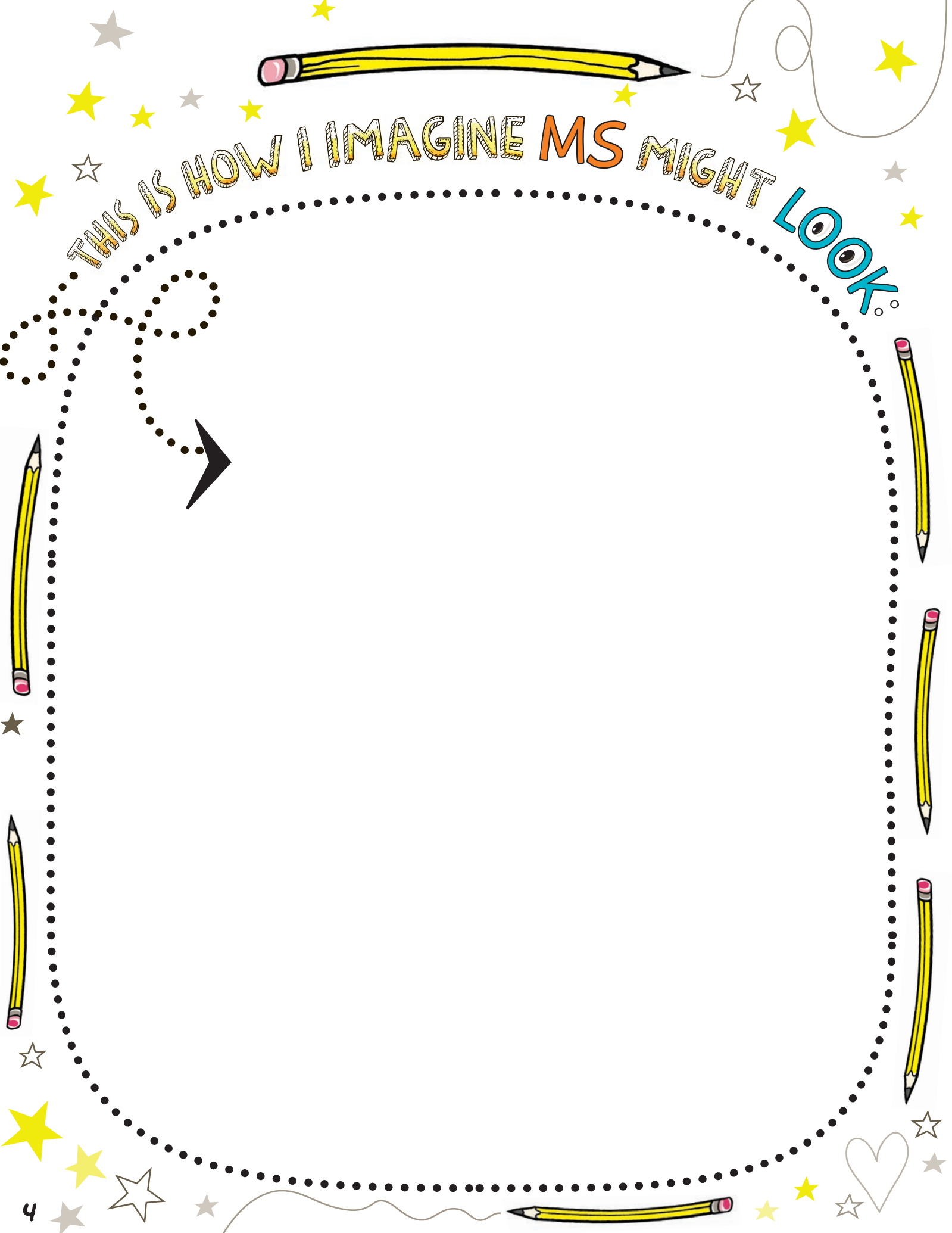
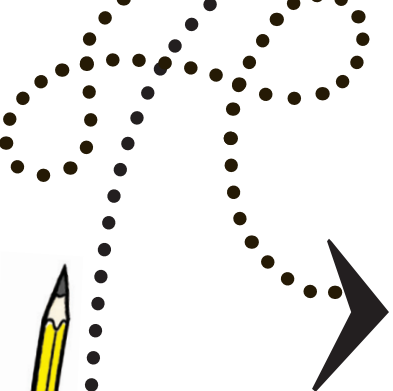
Symptoms of **MS** can come and go...we don't know exactly why. Sometimes you don't even notice the symptoms.

At other times they are pretty obvious.

★ It's hard for a person with **MS** to know from one day to the next how he or she will feel.



THIS IS HOW I IMAGINE MS MIGHT LOOK.



# WHAT ARE MS SYMPTOMS?

Your mom or dad with **MS** may be having trouble doing everyday things... putting on socks, making a sandwich, or walking the dog. Your mom's or dad's body may feel funny or different. These are called **symptoms**.

**MS** symptoms can be very mild, very serious, or somewhere in-between. They can come and go. Sometimes the symptoms disappear for a few days, weeks or months, and then come back again.

Sometimes these symptoms appear and disappear quickly. Other times they last for a long time.


SOME SYMPTOMS ARE MILD AND OTHERS ARE NOT.



## HERE ARE A FEW OF THE ESPECIALLY TROUBLING ONES.

(Remember that **MS** is different for each person, so your mom or dad may never have any of these symptoms.)

**FATIGUE:** Feeling very tired. Many people with **MS** feel very tired even when they get enough sleep.

**TROUBLE SEEING:**  Some people with **MS** see double or have vision that is very blurry. It may be hard to drive or read.

**SHAKING:** Some people with **MS** find that their arms or hands or head are shaky. It may be hard to hold a knife and fork, or write clearly, or put on lipstick.



### TROUBLE REMEMBERING THINGS:

Sometimes **MS** can make it hard to remember things, even things that just happened. It may also be hard to pay attention or get organized.

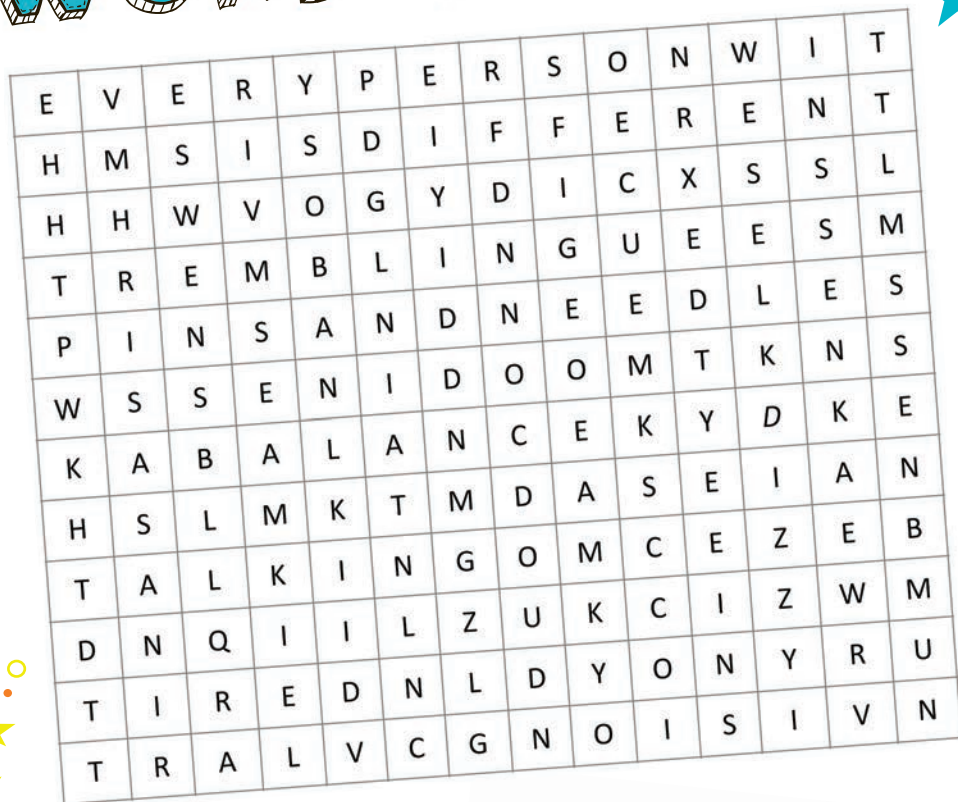
**PAIN:** **MS** can make different parts of the body hurt. It can make a person's skin feel tingly and painful.

**TROUBLE WALKING:** Sometimes a person may have more trouble walking and may need to use a cane or a walker or a wheelchair to get around.

Sometimes people only need these helpful devices for a short time. Sometimes they need to use them for a long time.



# SYMPTOMS OF MS WORD SEARCH



Hint: words are across, down and diagonal!

BALANCE

CLUMSY

DIZZY

MOODINESS

NUMBNESS

PINS AND NEEDLES

TALKING

TIRED

TREMBLING

VISION

WALKING

WEAKNESS

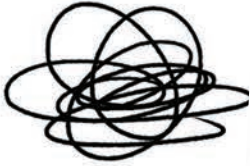
SEE IF YOU CAN FIND  
THE **MAGIC** SOLUTION  
TO THIS PUZZLE!

What do we know about symptoms and people with **MS**?

E V    P    S    T H    D    F    T !

ANSWER: EVERY PERSON WITH MS IS DIFFERENT!

# WHAT IS AN MS EXACERBATION?



Imagine sitting in school...

Suddenly the blackboard goes fuzzy and you can't read anything.

Or imagine it's your turn to bat and suddenly you don't have the energy to take a swing or even walk off the plate.

That is how it might feel to get an **MS** exacerbation.

**(EGG-ZASS-ER-BAY-SHUN)**

Exacerbation is a very big word that means a time when new **MS** symptoms appear or old symptoms become worse. Exacerbations are also called relapses or attacks.

No one knows what causes a person to get **MS** in the first place. And no one knows what causes a person with **MS** who has been feeling fine to have an exacerbation. But we do know that there's nothing a kid can do that can cause a parent to have an **MS** attack.

Forgetting your homework, skipping chores, or fighting with your sister might annoy your parents, but it can't cause an **MS** attack!

**Q:** My dad says that going to the beach isn't fun for him anymore. When he gets hot, his **MS** feels a lot worse. He has trouble walking and his vision gets blurry. Why does that happen? How can I help him feel better?

**A:** Many people with **MS** feel worse when their bodies get overheated. When the body's temperature goes up - even a tiny bit - the messages that travel from the brain to the rest of the body can't travel as fast. This makes a person's symptoms act up until his or her body cools down again. Hot weather, exercise, or a fever can all cause someone to feel uncomfortable for a while.

This is called a **pseudoexacerbation**

(soo-doe-egg-zass-er-bay-shun) - try saying that three times fast!

The good thing is that people begin to feel better as soon as their body temperature returns to normal. You can help your dad by helping him stay cool. He should stay out of the bright sun, drink lots of cold drinks, and maybe even wear a cooling collar or vest to help his body stay cool.



# MS IS UNPREDICTABLE

**MS** often changes. It may change over the course of a day, over the course of a week or month, and maybe over the course of a year. Why doesn't **MS** just stay the same? We don't know exactly why, but we do know that a person with **MS** may have lots of energy at certain times of the day, but feel very tired at other times. We know that some people with **MS** have days or weeks or months when they feel better, and then days or weeks or months when they feel worse.

**THIS CAN BE CONFUSING AND FRUSTRATING FOR EVERYONE!**



Sometimes when a person is sick with a cold or fever, his or her **MS** symptoms get worse for a while. When the cold goes away, the symptoms may get better.

**MS** may feel worse when the weather is very **HOT** and then feel better when the weather becomes **COOL** and dry.

**AND SOMETIMES MS JUST CHANGES!**

This is why we say **MS** is unpredictable.



★ **Unpredictable** means we don't always know what to expect. The best way to deal with something that is unpredictable is by being prepared to change your plans if you have to. So, if your family has planned a day at the zoo, but then your mom or dad doesn't feel up to it, try to change your plans to something less strenuous. For example, you could decide to stay home and watch a movie together or have a picnic in the backyard. That's called being flexible. It's an important thing to be when you have **MS** in your house!



# LET'S MEET THE PEOPLE WHO TAKE CARE OF PEOPLE WITH MS

When someone has **MS**, they may go to see different types of doctors and therapists who can help them feel better. Here are some of those people and what they do to help people with **MS**.



**Neurologist:** A doctor who takes care of people with MS and knows a lot about the brain, optic nerves and spinal cord.



**Urologist:** A doctor who knows a lot about the bladder and how it works. Sometimes people with MS have problems going to the bathroom and this doctor can help.



**Physical Therapist:** A therapist who can help someone learn how to walk better or learn exercises to become stronger and more fit.



**Occupational Therapist:** A therapist who can help people with MS learn how to do day-to-day activities more easily.



**Speech Therapist:** A therapist who helps people with speaking or swallowing.



**Nurse:** Someone who helps people learn about taking medicines and how to be as healthy as possible.



**Social Worker:** A person who helps families talk together about MS.



**Psychologist:** A person who talks with people about their feelings and problems with memory or thinking.

# KEEP S'MYELIN KIDS (CARTOON S'MYELIN KIDS)

"I like coming with you for your physical therapy appointment!"

"Well, you are a big help to me!"

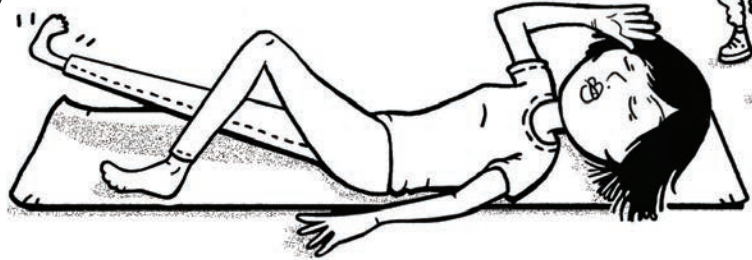
COLOR THIS IN!



"...and 9 and 10!  
Other leg now,  
Mom."



"We can both stay fit by  
doing exercises together!"





# TREATING MS

★ **WE DON'T HAVE A CURE FOR MS YET**, but we have several different ways to treat it and help people feel better. There are medicines that help people have fewer exacerbations and also help slow the disease.



SOME OF THESE MEDICATIONS ARE PILLS TO SWALLOW, WHILE OTHERS ARE GIVEN WITH A NEEDLE.

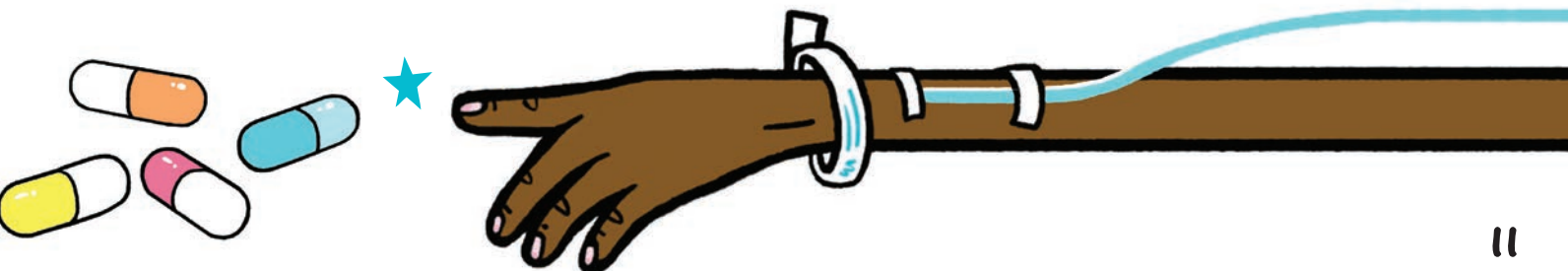
★ **SOME PEOPLE** taking these medicines have to give themselves shots or get what is called an infusion, which means that the medicine drips slowly through a small tube into the person's arm. The doctor and your mom or dad chooses the medicine that is best for her or him.

★ **MS** can cause many kinds of problems or symptoms, like making people feel very tired or stiff or weak. The doctor knows about different types of medicines that can make these problems feel better.

★ There are also medicines for people to take when their **MS** is acting up. Most people with **MS** have attacks every once in a while. They may feel very tired, or have new problems that they never had before - like trouble seeing or walking or remembering things.

★ **WHEN THIS HAPPENS**, they may be given a special medicine called methylprednisolone. This is a liquid medicine that drips through a small tube into the person's arm. Some people get this medicine at home and other people go the hospital for a few days to get it.

★ **BESIDES MEDICINES**, there are lots of other things that can help people with **MS** to feel better: such as exercise, rest, a healthy diet, and having **FUN!**



# YOUR FEELINGS

EVERYONE IN THE FAMILY HAS FEELINGS ABOUT MS—NOT JUST THE PERSON WHO HAS IT.

**SOMETIMES MS** might make you feel mad, or you might feel sad or scared if your parent isn't feeling well. Sometimes you might feel glad because you love your mom or dad and like to do fun things together.

**SOMETIMES** the hardest thing about feelings is sharing them with others, but talking about feelings can be helpful. It can make you feel better and bring you closer to people you care about and let them know what some of your worries might be.

## MAKING A LIST OF YOUR FEELINGS CAN HELP.

You can do this in your head, on a piece of paper, or in a poem or drawing. Then you can share your list with someone you trust—like your mom or dad. This will help make your feelings backpack feel a little bit lighter.

"I would say:  
Let out your feelings!  
And exercise!"

*Troy, New Jersey, USA*

"I would tell them that I deal  
with the same feelings."

*Tiffany, Toronto, Canada*

"I would say they should not  
worry. It will be OK. Well, they  
can worry a little bit, but not  
too much!"

*Sarah, Ghana*

"I would tell them to try to forget  
it's there most of the time. But  
don't put it totally out of your mind  
at all times, because your mom or  
dad still needs your help!"

*Shelby, Vancouver, Canada*



## FIND SOMEONE!

1. Who is easy to talk to
2. Whom you feel you like and trust
3. Who listens to your feelings

# MOOD CHART

**HAVING A MOM  
OR DAD WITH MS  
CAN BE TOUGH!**

Doing an activity like this can help you understand your feelings and your family's feelings.

1. **DRAW** a picture of each person in your family.

2. **COLOR** the picture with these colors to show each person feels:



Happy



mad



scared



Embarrassed



bored

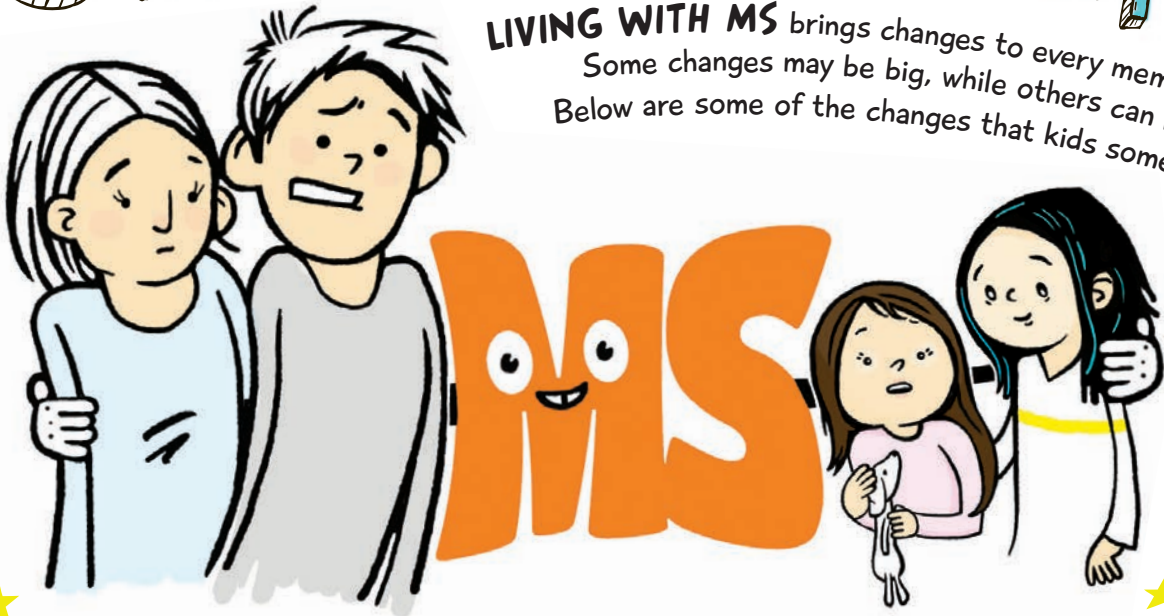


sad

3. **SHOW YOUR DRAWING** to the people in your family and talk to them about the feeling colors you used.

# WHAT HAPPENS WHEN MS JOINS THE FAMILY?

**LIVING WITH MS** brings changes to every member of a family. Some changes may be big, while others can be small. Below are some of the changes that kids sometimes see.



Your mom or dad may feel **DIFFERENT** from one day to the next – for example, having a lot of energy one day and feeling very tired the next. It's a good idea to have a back-up plan for days when your parent doesn't feel well.

**WHEN** people don't feel good, they sometimes get **CRANKY**. You may find that your mom or dad acts grumpy sometimes. If you get worried about that, be sure to talk it over with them or with another adult you like a lot.

Your mom and dad may also seem more **WORRIED** than usual. This can happen when someone in the family is diagnosed with **MS**, and no one is sure what to expect. If you start to get worried too, be sure to let them know. Worries feel better when you **TALK** about them.

When someone in the family has **MS**, everyone else may need to help. Sometimes moms and dads trade jobs and responsibilities because the parent with **MS** can't do the things that he or she used to do. Kids may be asked to do more **CHORES**.

While kids tell us that they don't always like the extra chores, they also say that helping their parent with **MS** makes them feel **PROUD**.

**Q: IS IT THE MS THAT MAKES MY MOM CRANKY?**

**A:** Moms and dads with **MS** can sometimes be cranky. They may feel tired, sad or frustrated by things they cannot do, or just plain grumpy.

The important thing to remember is that everyone feels cranky sometimes - even moms and dads who don't have **MS**. Maybe you and your mom or dad could talk about the kinds of things that make each of you feel cranky and the things that make you each feel better.

# (CARTOON) S'MYELIN KIDS



"Michael, want to go to the park with us to play Frisbee?"



"Can't now."

"I have to finish cleaning the yard and then do some laundry. I hate having all these extra chores because my mom has MS. Other kids don't have to do this stuff..."



**COLOR THIS IN!**

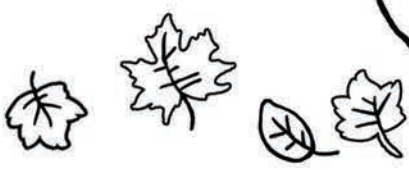
"Michael, why don't we help you? Then we can all go to the park."

"Yeah! That would be great."



"I guess it's not so bad. Anyway, this is good practice for tossing that frisbee!"

"Michael, you may not like it much, but I bet your mom feels real proud and happy that you help out when she does not feel well."



# WHAT IS WRONG WITH THIS PICTURE?

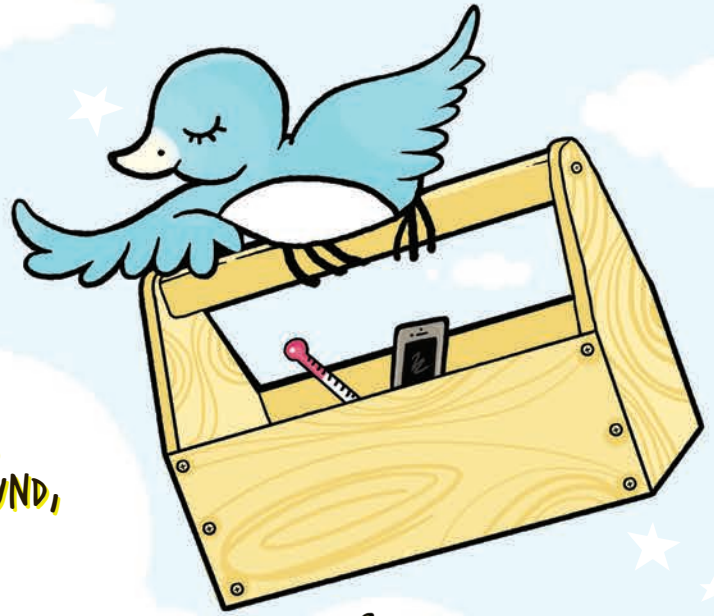




# TOOLS (CAN MAKE LIFE WITH MS EASIER!

MANY PEOPLE WITH MS USE DIFFERENT TYPES OF TOOLS OR GADGETS TO HELP THEM MOVE AROUND, HAVE FUN, AND DO EVERYDAY ACTIVITIES.

**FOR EXAMPLE,** someone you know may use a cane, a wheelchair or scooter, or a computer that works by talking to it! In fact, we all use tools to help us with everyday activities: a backpack to help us carry things, glasses to help us see more clearly, a shopping cart at the supermarket.



Perhaps your mom or dad has made changes to your house to make it easier and safer to get around, like building a ramp or adding a grab bar in the bathroom.

**CAN YOU THINK OF ANY OTHER TOOLS WE USE?**

# CAN GAME

ALL KINDS OF THINGS CAN MAKE OUR LIVES EASIER.

Glasses CAN help us see.

A calculator CAN help us add numbers more quickly.

A list CAN help us remember what we need to buy at the grocery store.



★ We all use tools everyday that **CAN** really make a difference.

THERE ARE LOTS OF WORDS THAT BEGIN WITH CAN.  
HOW MANY WORDS CAN YOU COMPLETE IN THIS CAN?

1. A country north of the United States.

CAN \_ \_ \_

2. A small, yellow songbird often kept in a cage.

CAN \_ \_ \_

3. A fun dance involving high kicks.

CAN \_ \_ \_

4. A light, narrow boat with pointed ends.  
You use a paddle to move it forward.

CAN \_ \_

5. A tall, narrow object made of wax with a wick inside it. It can help us see in the dark.

CAN \_ \_ \_

6. This stick can help people keep their balance when they walk.

CAN \_

7. A container for drinking water.  
Sometimes campers carry this.

CAN \_ \_ \_ \_

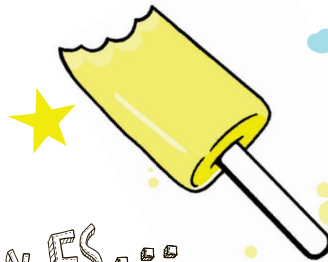
# FUN & GAMES

## JOKES AND RIDDLES TO USE

(Find the answers below...)



- 1 What dog loves to take bubble baths?
- 2 "Doctor, Doctor I feel like a pack of cards."
- 3 How do you fix a broken pizza?
- 4 Michelle's mother has four children. The first was April, the second was May, and the third was June. What was the name of the fourth child?
- 5 What do you call cheese that is not yours?
- 6 Why did the football coach go to the bank?



HERE ARE SOME OF MY FAVORITE JOKES...



ANSWERS: 1. A shampoo! 2. I'll deal with you later. 3. With tomato paste! 4. Michelle 5. NA-CHO cheese 6. To get his quarterback.



## ACTIVITIES

# PICTURE PUZZLES!

HERE'S A GREAT IDEA FOR YOUR BOX OF PICTURES!

- You will need a pair of scissors and photos.
- Cut the pictures into several different shapes and sizes.
- The fun starts when you try to put the pieces back together!
- To make the pieces easier to handle, mount them on cardboard.
- You can also store them in a box or zipper bag to play with again.

## COUPONS OF LOVE

HERE IS A GREAT GIFT IDEA FOR SOMEONE YOU LOVE WHO HAS MS.

Make a "coupon"! Here are some ideas for coupons you can give your mom or dad:

A COUPON GOOD FOR  
HUGS AND KISSES  
ANYTIME, ANYWHERE

A COUPON GOOD FOR  
AN AFTERNOON  
OF (UDDLING AND  
READING TOGETHER

A COUPON GOOD  
FOR MAKING BREAKFAST  
FOR THE WHOLE FAMILY  
(AND (LEANING UP)

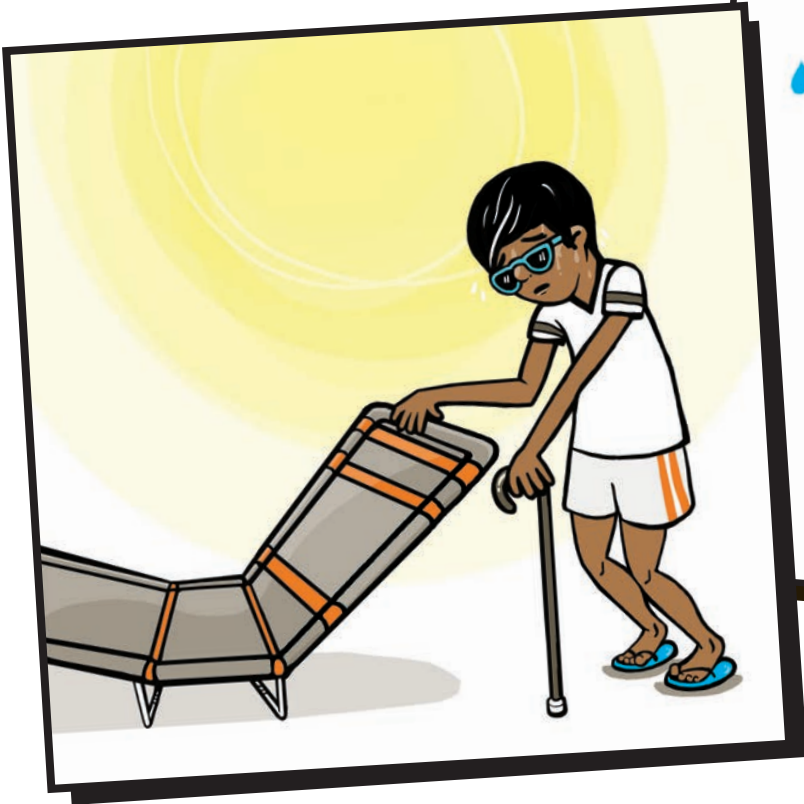
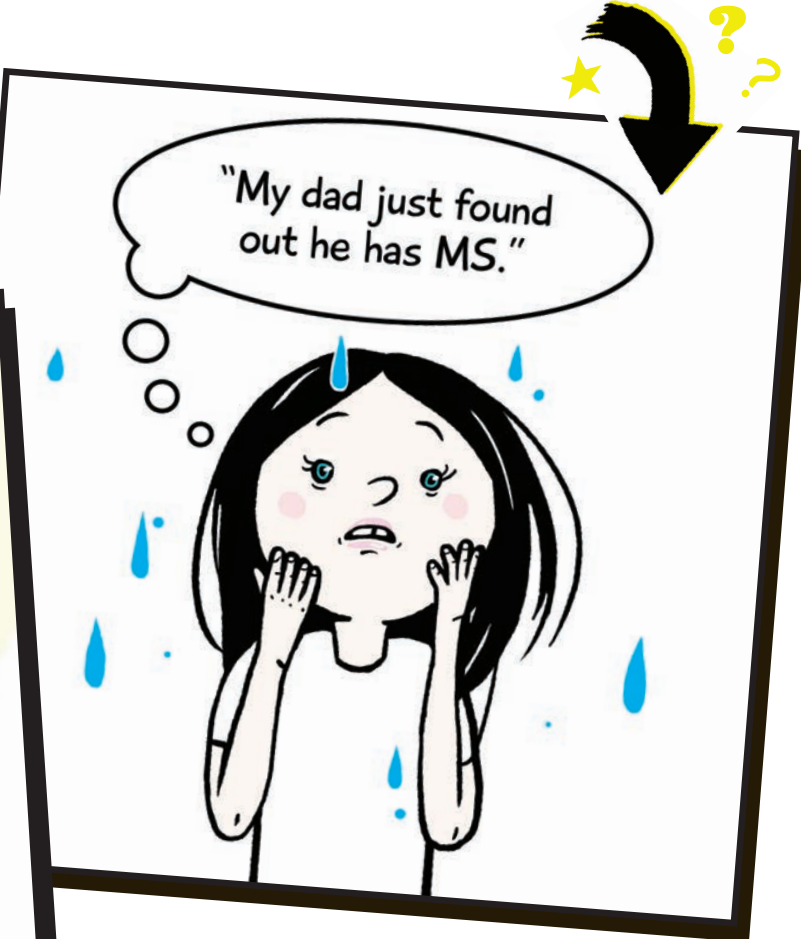
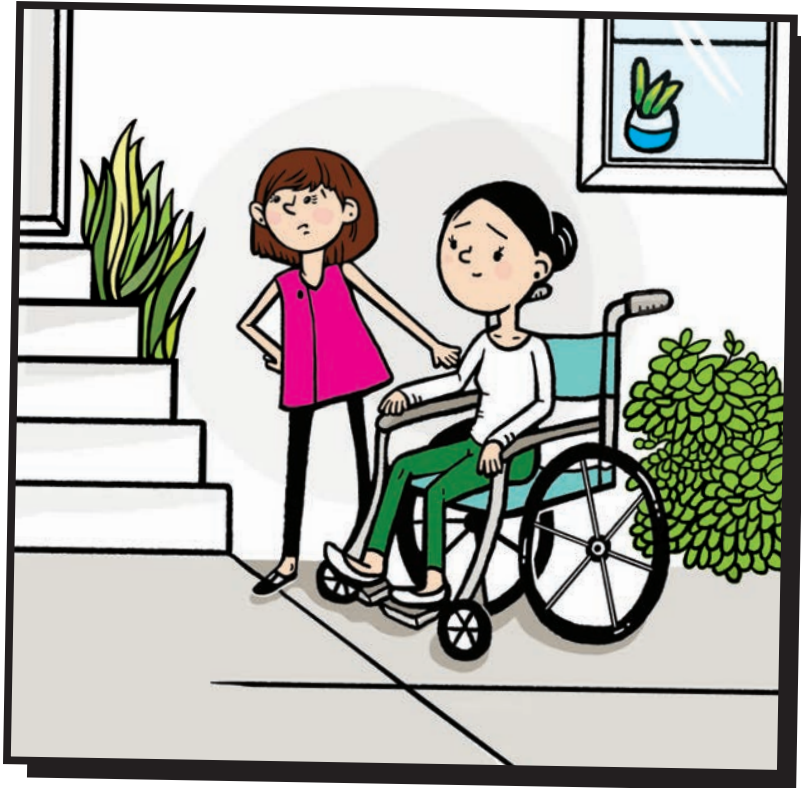
A COUPON GOOD FOR  
(LEANING OUT  
THE GARAGE

A COUPON GOOD FOR  
BRINGING OUT THE  
TRASH EVERY WEEK

YOUR MOM OR DAD WILL LOVE THIS KIND OF PRESENT  
BECAUSE IT TELLS THEM YOU LOVE THEM AND WANT TO HELP!

# WHAT WOULD YOU DO?

★ Talk to your mom or dad about what you would do in situations like these...



# WHERE'S THE CURE?

GROWNUPS ARE ALWAYS SAYING, "BE PATIENT".

But it's hard to be patient waiting for the cure for **MS**.

Do you ever wonder why it is taking so long?

**THERE ARE LOTS OF REASONS.**

For one, scientists can't figure out a cure without knowing what causes **MS**.

There are lots of clues, and these are like pieces of a gigantic jigsaw puzzle that scientists all over the world are trying to put together.



**THERE ARE SO MANY PUZZLE PIECES.**

**MS** attacks a very complicated part of the body - **the brain** and **the spinal cord** (called the central nervous system).

Scientists need special tools to figure out what's going on in there.

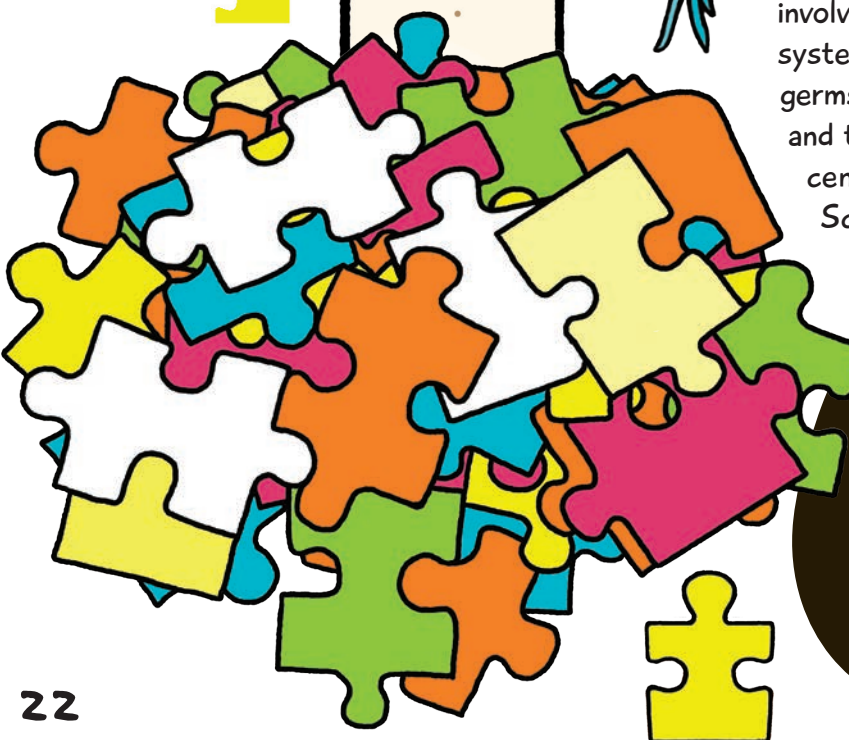
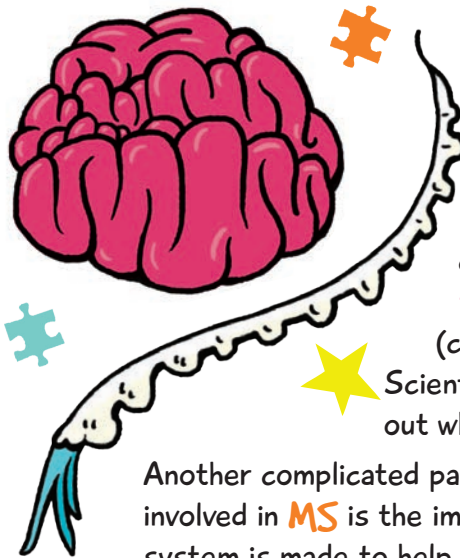
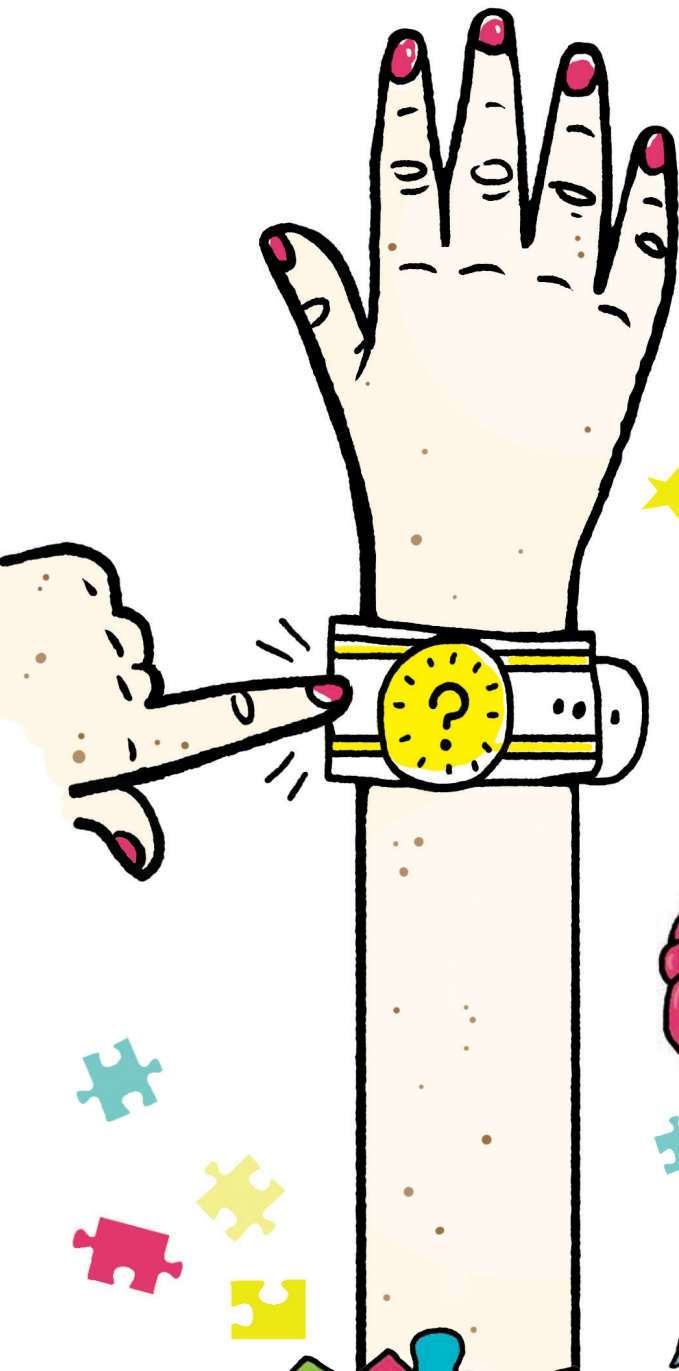
Another complicated part of the body that is involved in **MS** is the immune system. This system is made to help our bodies fight germs, but something goes wrong in **MS** and the immune system attacks the central nervous system instead.

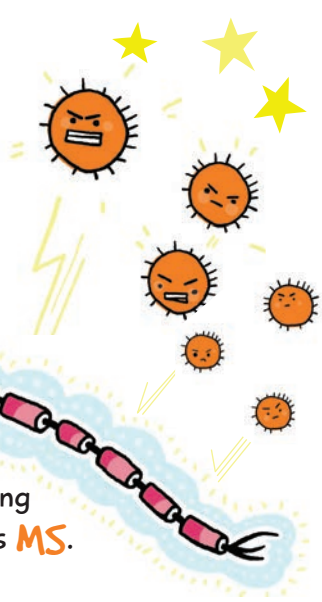
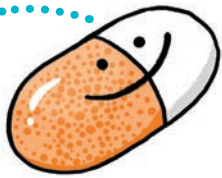
Scientists are looking for the puzzle piece that will give them the power to turn off the attack forever.

**THE GOOD NEWS** is that scientists are making lots of progress filling in pieces of the puzzle. They're also learning a lot from research being done in other diseases.

So, we hope soon that all of the pieces will come together and the answer will be in front of us.

Then we won't have to be patient anymore, because we'll have a **cure**.





# WHAT WOULD A CURE FOR

# MS



# LOOK LIKE?

**MAYBE**, it will be a vaccine to keep people from ever getting **MS**. This would be like the shot you get from your doctor so you won't ever get the measles or mumps.

Or, maybe it will be a medicine that makes **MS** go away once a person has it. Or maybe it will help cells in the immune system do what they are supposed to do - like fighting germs - rather than damaging the myelin and nerves the way they do in a person who has **MS**. Or maybe there will be a cure that reverses the damage.

Scientists are exploring all these possibilities, and more. And maybe, the cure will turn out to be something that no one has even thought about yet.

**WHAT DO YOU THINK IT WILL BE?** \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

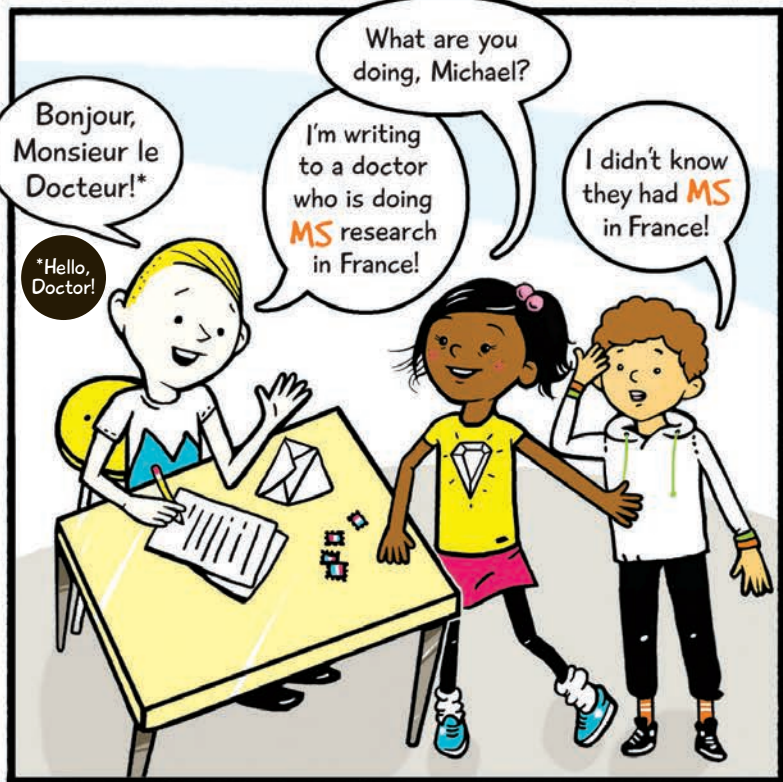
\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_



Bonjour, Monsieur le Docteur!\*

\*Hello, Doctor!

What are you doing, Michael?

I'm writing to a doctor who is doing **MS** research in France!

I didn't know they had **MS** in France!



More than two million people around the world have **MS**!

And I'm writing to tell him *Depechez-vous et bonne chance!*\*\*

\*\*Hurry up and good luck!

# MS QUIZ!

PICK OUT YOUR ANSWERS FROM THE WORDS BELOW:

computer      Symptoms      Many scars  
Unpredictable      Spinal cord      Myelin  
central nervous system

1. The covering around the nerves is called \_\_\_\_\_

2. The physical problems caused by **MS** are called \_\_\_\_\_

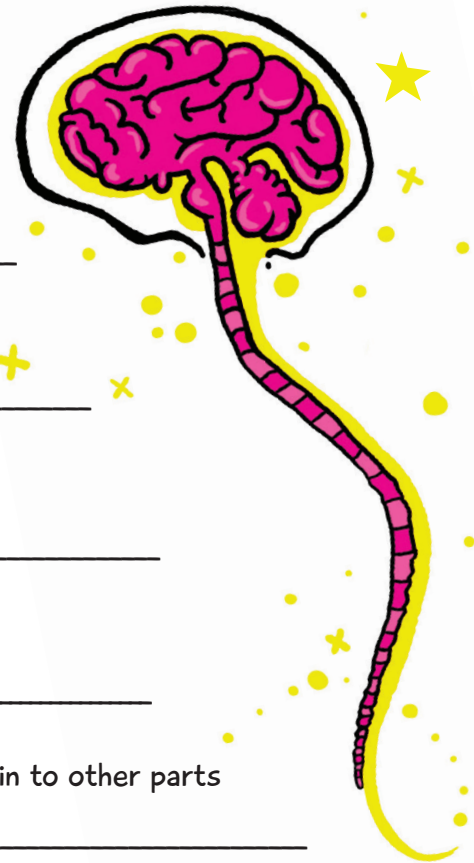
3. **MS** can change from one day to the next - that's why we say it's \_\_\_\_\_

4. **MS** affects the brain, optics nerves and spinal cord, which together make up the \_\_\_\_\_

5. Many of the messages going from the brain to other parts of the body travel along the \_\_\_\_\_

6. The brain acts like a \_\_\_\_\_

7. The words multiple sclerosis mean \_\_\_\_\_



1. Myelin! 2. Symptoms 3. Unpredictable 4. Central nervous system 5. Spinal cord 6. Computer 7. Many scars



# ★ YOU ASKED. WE ANSWERED. ★



**Q:** Can I catch **MS**?

**A:** No, you can't catch **MS** from your mom, dad or anyone. **MS** is not like a cold. You can give them lots of hugs without worrying about catching it.

**Q:** My dad was diagnosed with **MS**. What is going to happen next?

**A:** Every person's **MS** is different. Some people have just one or two symptoms, while others have more. Your dad's doctor will help him figure out the best ways to take care of himself. He may need to rest more than he used to, take medication, or use some special tools to help him do the things that are important to him.

**Q:** Can **MS** make parents forget things that they do, hear or say?

**A:** **MS** can cause many different kinds of symptoms, and problems remembering things may be one of them. Some people with **MS** have trouble remembering where they put things like the car keys or their glasses or remembering a conversation from earlier in the day, or thinking of a word they want to say. Keeping a family calendar, putting things away in the same place all the time, and being very organized can help people manage these problems.

**Q:** Do people die from **MS**?

**A:** People almost never die from **MS**. Once in a great while **MS** causes other problems that can make a person very sick or even die, but this does not happen very often.

# WHAT OTHER QUESTIONS DO YOU STILL HAVE ABOUT MS?

Write them down here and then find a good time to talk to your mom or dad about your questions...



These are the questions I still have about **MS**...





National  
Multiple Sclerosis  
Society

FAMILIES CAN COUNT ON THE NATIONAL MS SOCIETY.

To learn more about the resources available to you and your family, please contact an MS Navigator at:  
**1-800-344-4867** or visit [nationalMSSociety.org/familymatters](http://nationalMSSociety.org/familymatters)



# KEEP S'MYELIN

Keep S'myelin is a publication for children with parents or other relatives with multiple sclerosis. It is produced by the National Multiple Sclerosis Society. The National Multiple Sclerosis Society ("Society") is proud to be a source of information on multiple sclerosis related topics. The information provided is based on professional advice, published experience, and expert opinion, but does not constitute medical or legal advice. For specific medical advice, consult a qualified physician. For specific legal advice, consult a qualified attorney.

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The National MS Society mobilizes people and resources so that everyone affected by MS can live their best lives as we stop MS in its tracks, restore what has been lost and end MS forever. To fulfill this mission, the Society funds cutting-edge research, drives change through advocacy, facilitates professional education, collaborates with MS organizations around the world, and provides programs and services designed to help people with MS and their families move their lives forward.

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