Really? I didn’t know there were any other kids with a parent with MS in our neighborhood!

I met another girl at school whose dad has MS!

Did you talk with her, Crystal?

I did. It was cool - I didn’t have to explain what MS was.

It felt really good to talk.
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...

____________________________________________________________________________________

____________________________________________________________________________________

____________________________________________________________________________________

____________________________________________________________________________________

My Favorite Things

Food: ___________________________________________________________

TV show: _________________________________________________________

Game: __________________________________________________________

Sport: __________________________________________________________

Animal: _________________________________________________________

Story: __________________________________________________________

Song: __________________________________________________________

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

____________________________________________________________________________________

____________________________________________________________________________________

____________________________________________________________________________________

(fill in the blanks!)
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.

- 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.
This is how I imagine MS might look:

Here are a few of the especially troubling ones.
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.

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.

(Some symptoms are mild and others are not. Remember that MS is different for each person, so your mom or dad may never have any of these symptoms.)
Symptoms of MS

Word Search

Every person with MS is different!

Every person with MS is different!

See if you can find the magic solution to this puzzle!

What do we know about symptoms and people with MS?

Every person with MS is different!
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.

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!
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.

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

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

Psychologist: A person who talks with people about their feelings and problems with memory or thinking.
“I like coming with you for your physical therapy appointment!”

“Well, you are a big help to me!”

“....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 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 to 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 tell them 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

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

**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.
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.
“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...”

“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?
There are lots of words that begin with can. How many words can you complete in this puzzle?

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   ___ ___ ___

Answers: 1. CANADA  2. CANARY  3. CAN CAN  4. CANOE  5. CANDLE  6. CANE  7. CANTEEN
Here are some of my favorite jokes...

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?

Answers: 1. A shampoodle! 2. I’ll deal with you later. 3. With tomato paste! 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. 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 cuddling and reading together
- A coupon good for making breakfast for the whole family (and cleaning up)
- A coupon good for cleaning 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...

“My dad just found out he has MS.”

What Would You Do?

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

“My dad just found out he has MS.”
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?**

__________________________________________________________________________
__________________________________________________________________________
__________________________________________________________________________
__________________________________________________________________________
__________________________________________________________________________

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*Hello, Doctor!*  

Bonjour, Monsieur le Docteur!*  

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!

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!**
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 ________________________________
**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:** 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:** 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:** 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...
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

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.

THIS ACTIVITY BOOK IS MADE POSSIBLE THROUGH AN EDUCATIONAL GRANT FROM: Genentech
A Member of the Roche Group