

Someone You Know Has MS

A BOOK FOR FAMILIES

FOR CHILDREN AND TEENAGERS



National
Multiple Sclerosis
Society

Someone You Know Has MS

A BOOK FOR FAMILIES

ADAPTED BY: MARTHA KING FROM
ORIGINAL MATERIAL BY CYRISSE JAFFEE,
DEBRA FRANKEL, BARBARA LAROCHE, AND
PATRICIA DICK

ILLUSTRATIONS BY: CLAUDE MARTINOT

Martha King was senior director of Publications at the National MS Society (retired).

Claude Martinot is a professional artist and illustrator who specializes in educational materials for children.

This publication is supported by contributions to the National MS Society from its members and friends.

© 2020 NATIONAL MS SOCIETY. ALL RIGHTS RESERVED.

Our thanks to the parents, children, and staff of the Society's Greater New England and Wisconsin Chapters, who shared insights and experiences for this booklet: Eric, Marilyn, and Michelle Bernstein; Anthony, Chuck, John, and Nancy Delgreco; Jennifer and John Dick; Judy and Pamela DiPalma; Mary Hooley; Nicole Klabunde; Gail and Kristin Lubanski; Ann Shuman; and Andrea Ternes. Thanks, also, for ideas and encouragement, to: Mike Boni, Alan Brightman, Pat Cunning, Marie Harrison, James Lehrich, MD, Marjorie O'Byrne, Joyce Rich, and the volunteers of the Greater New England and Wisconsin Chapters of the National MS Society.

A Note to Parents

Children are far less fragile, and more able to accept painful realities than we generally assume. Parents often try to protect their children by hiding painful issues, but open and honest communication among family members is valuable and important. In the long run it builds trust.

Not all the issues identified in this booklet will be relevant to your family's situation. Because MS is so variable and each family is unique, you may want to personalize this booklet when you read it with your child.

There are many unanswered questions about multiple sclerosis. While it may be frustrating to you and your child, sharing this frustration can actually reassure her/him.

We hope you and your family members will contact the National Multiple Sclerosis Society for additional support and information. Resources and referrals are available by contacting an MS Navigator®.

Call 1-800-344-4867.

— Debra Frankel

Someone You Know Has MS



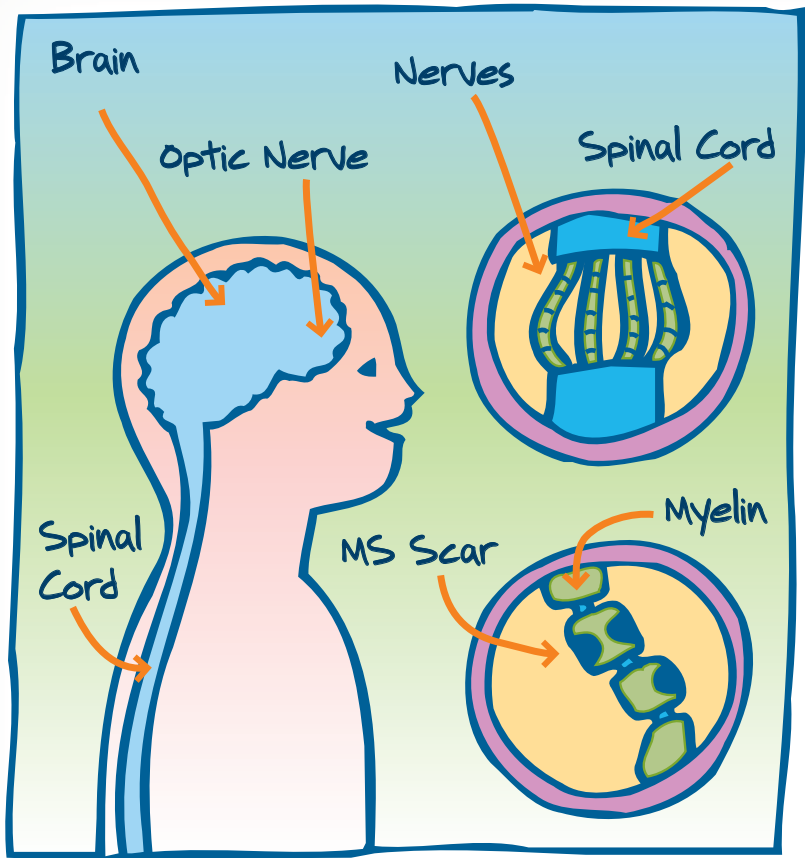
“My name is Michael. My mom has multiple sclerosis (MS for short). At first I didn’t understand it. I just knew it was a disease that doesn’t go away.”



What Is Multiple Sclerosis?

Michael wondered, “How do people get it? Why did it happen in my family?”

He wondered if it would happen to him. And it’s so hard to say “Mull-TA-pul-skler-Oh-sis!”



“MS is short for multiple sclerosis,” Michael’s mom said. “The brain is like a computer that sends messages to the body telling it what to do,” she explained. “The spinal cord is like a thick bunch of wires attached to the computer. Messages travel from the brain, along the spinal cord, to the muscles and other parts of the body.”

“If you want to wave at someone, your brain sends a message down your spinal cord and out to your arm, telling your arm to lift up and wave,” Michael’s dad said.



But when a person has MS, a special covering that protects the nerves gets damaged. This covering is called myelin (MI-a-lin). Scars form where good myelin used to be.

These scars slow down or stop the messages. Multiple sclerosis means “many scars.”



When Michael’s mom reaches out to get a coffee cup, sometimes the message doesn’t get through to her hand, and she misses.

How Do People Know They Have MS?

“We have trouble doing things. These troubles are called symptoms (SIM-toms). Not all people with MS have the same symptoms I have, and I don’t have all my symptoms all the time,” Michael’s mother said. “The one I have the most is feeling very, very tired. Sometimes it happens all of a sudden.”

You may notice your mom or dad just doesn’t have much energy sometimes.



“When we went to the supermarket she’d say, ‘My legs are getting tired.’ And I’d say, ‘Mom, just a couple more minutes.’ And she’d say, ‘No, we really have to go home right now.’ I thought she was being lazy. Then I found out about the MS.”

Some Other MS Symptoms



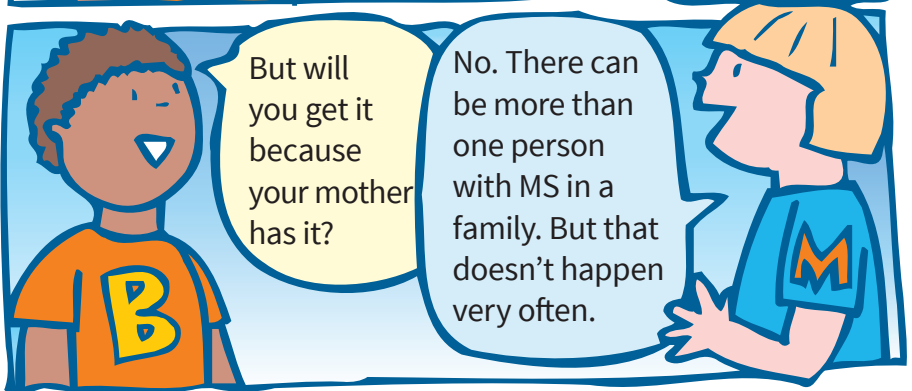
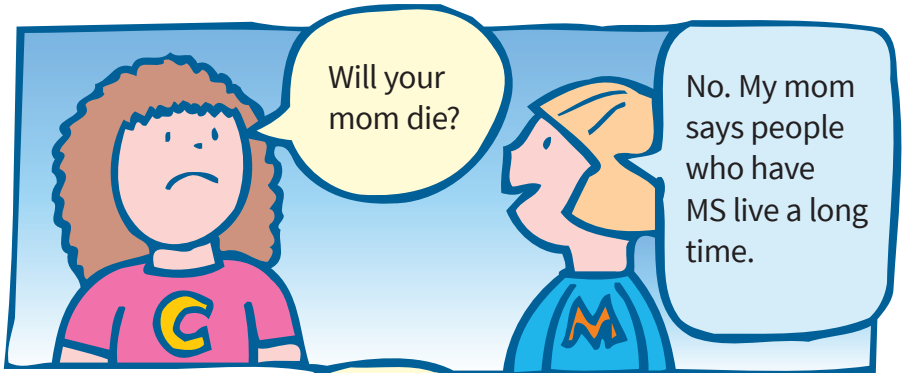
Who Gets MS and Why?

Most people who get MS are older than 20 and younger than 50. Doctors don't know what causes it. They do know that MS isn't a catching disease. It's not like a cold. You can't catch it from someone else.

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

Some Scary Questions

Michael told Crystal and Ben about MS. It's a good thing his parents had told him all about it, because his friends were worried.



Some Hard Things



“My mom had to go to the hospital and the house was different. Mrs. Jenkins had to come. I tried to like her but I didn’t.”

Sometimes MS symptoms suddenly get worse. It’s called an attack or exacerbation (ex-asser-BAY-shun). An attack can go on for several weeks. One time Michael’s mother even had to go to the hospital for a few hours every day for over a week for special medicines. Other times she can take the medicine at home.

“When Mom came home, she had to rest in bed. It was embarrassing because my dad was asking people to drive me to my piano lesson. Mom kept saying, ‘It’s just going to take me some time.’”



Some Good Things

Doctors can't cure MS yet, but there are medicines for attacks and for symptoms. There are medicines that can slow MS down. Michael's mom takes shots. She takes good care of herself, and she exercises when she can.



"I'm used to the idea now. Mom says the shots keep her MS quiet."



Some people do their shots themselves. Most of the time Michael's dad does it for her.

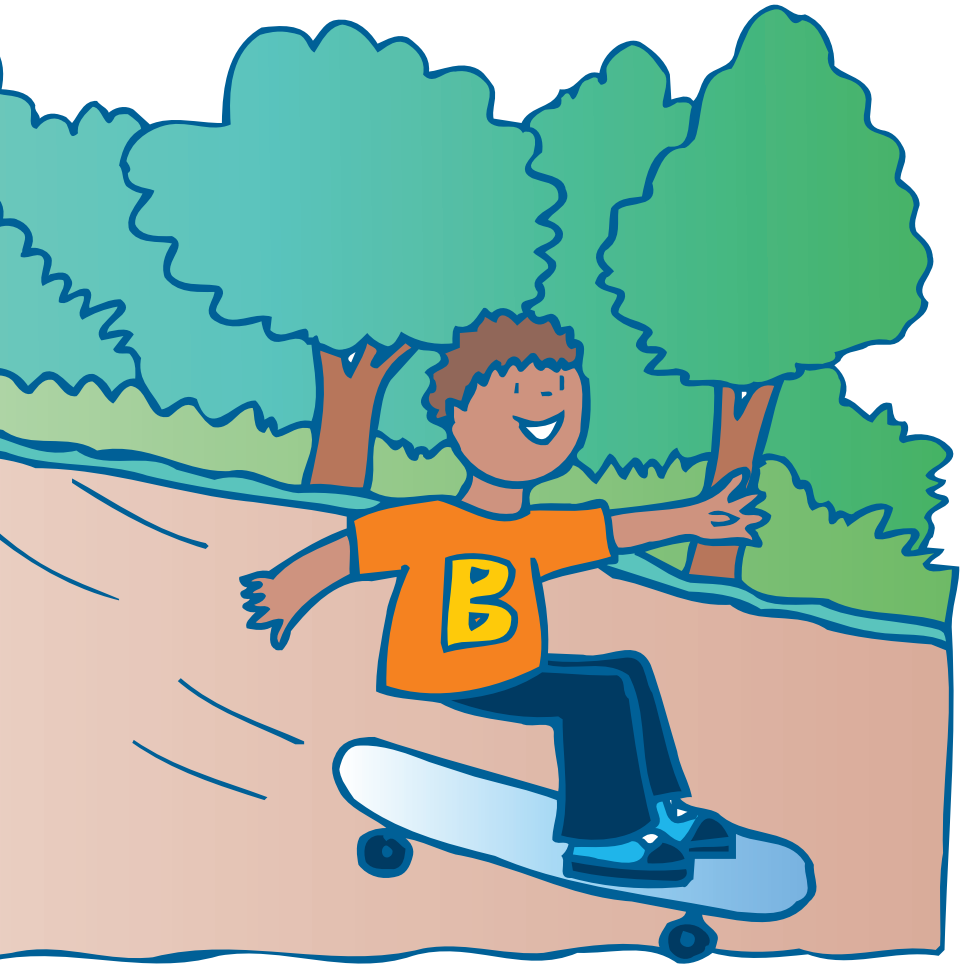
What Happens Now?

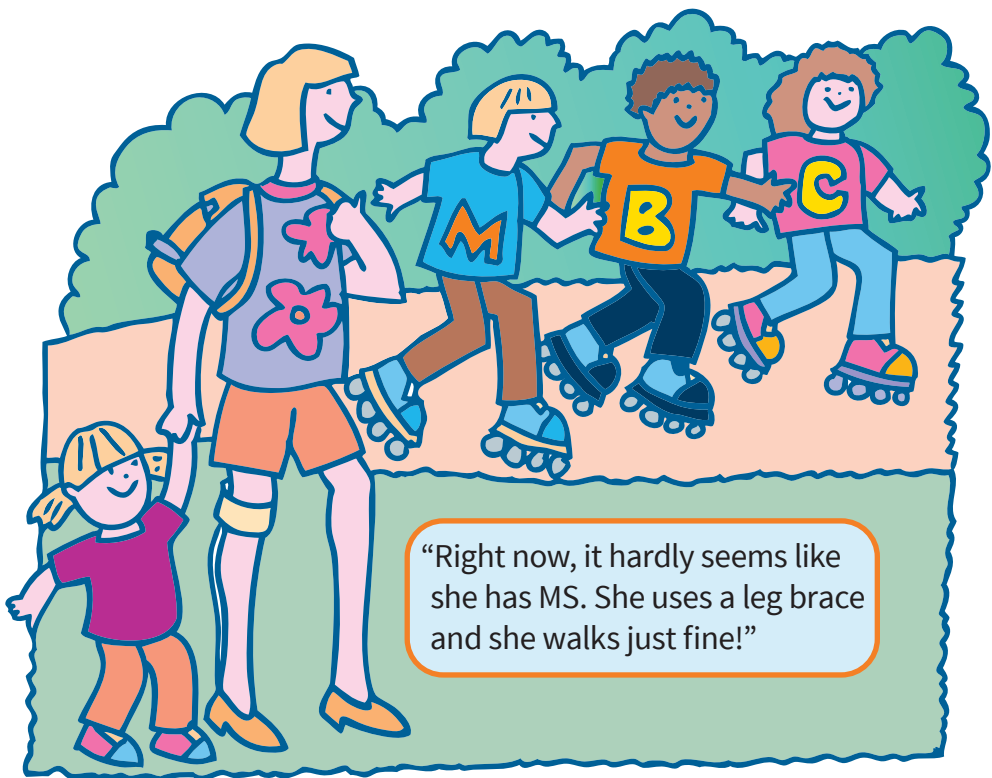
“The doctor told me to go ahead with my normal life and work around any challenges,” Michael’s mom said.

Like Michael’s mom, your parent will always be the same person, but some things may need to be done differently.



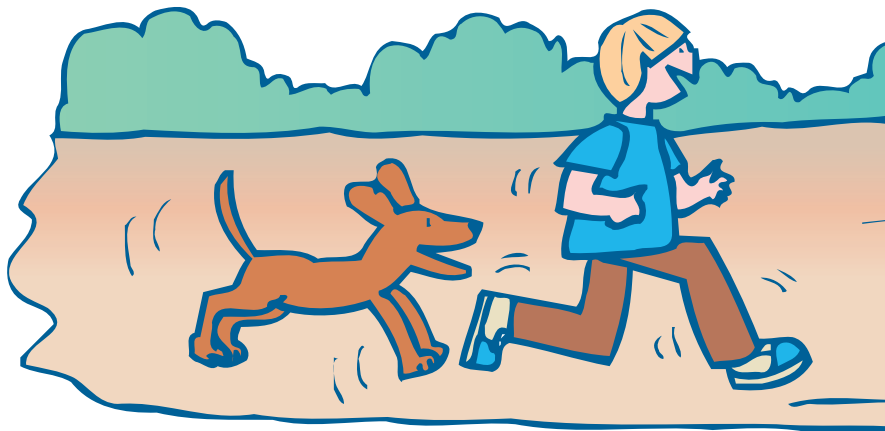
MS can get worse, better or stay the same. Sometimes it practically disappears. This is called a remission (re-MISH-en). A remission can last for a few weeks or for years. Then symptoms come back. This is what makes MS unpredictable.





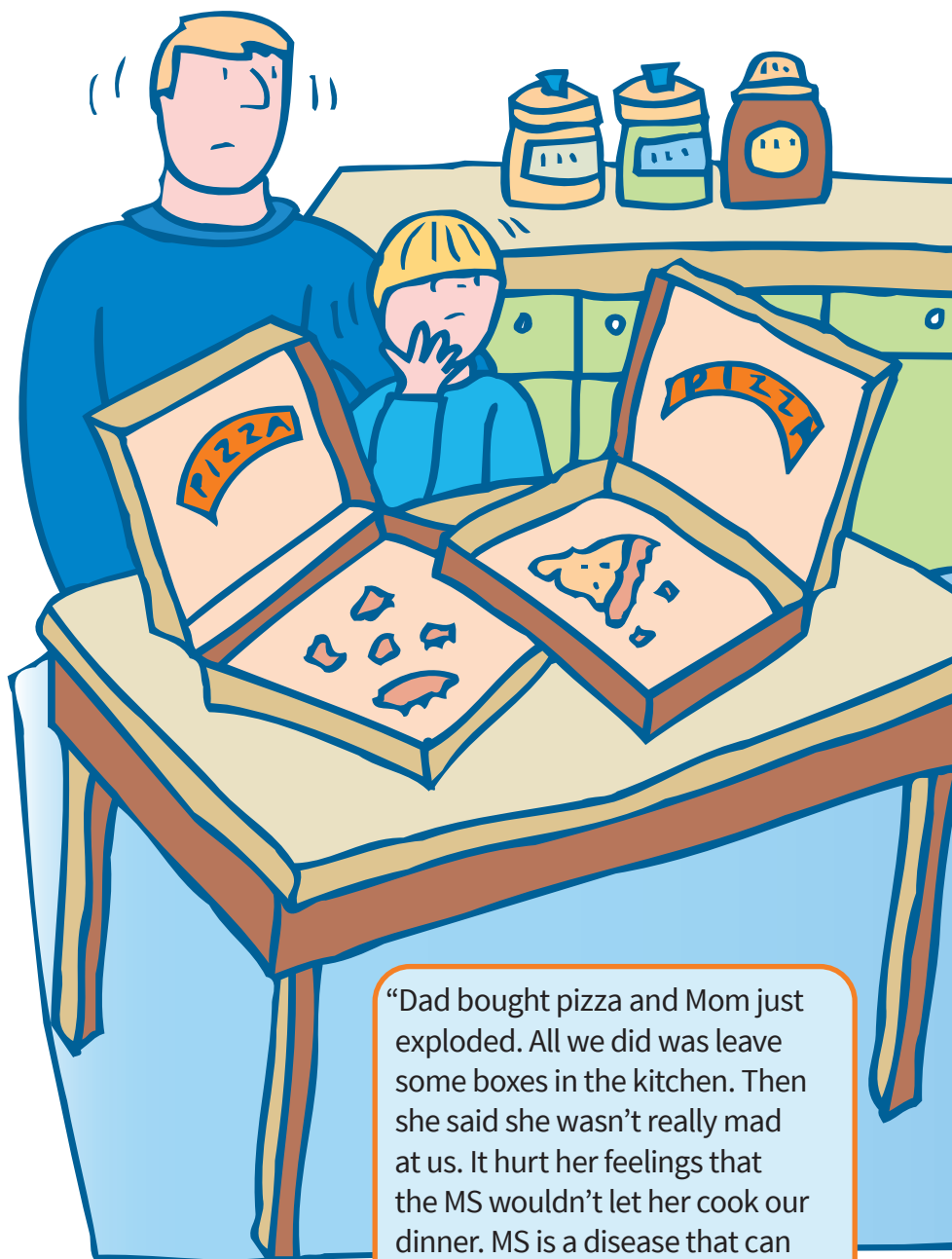
“Right now, it hardly seems like she has MS. She uses a leg brace and she walks just fine!”

Your parent might need a brace, a cane, a walker or a wheelchair. Your parent might use a scooter, even inside the house.



Some kids feel embarrassed seeing their mom or dad using special equipment like that. But equipment helps people with MS get around. Instead of waiting for your dad, you might have to chase him! And you might even get to ride on your parent's lap once in a while.





“Dad bought pizza and Mom just exploded. All we did was leave some boxes in the kitchen. Then she said she wasn’t really mad at us. It hurt her feelings that the MS wouldn’t let her cook our dinner. MS is a disease that can sometimes make a person crabby.”

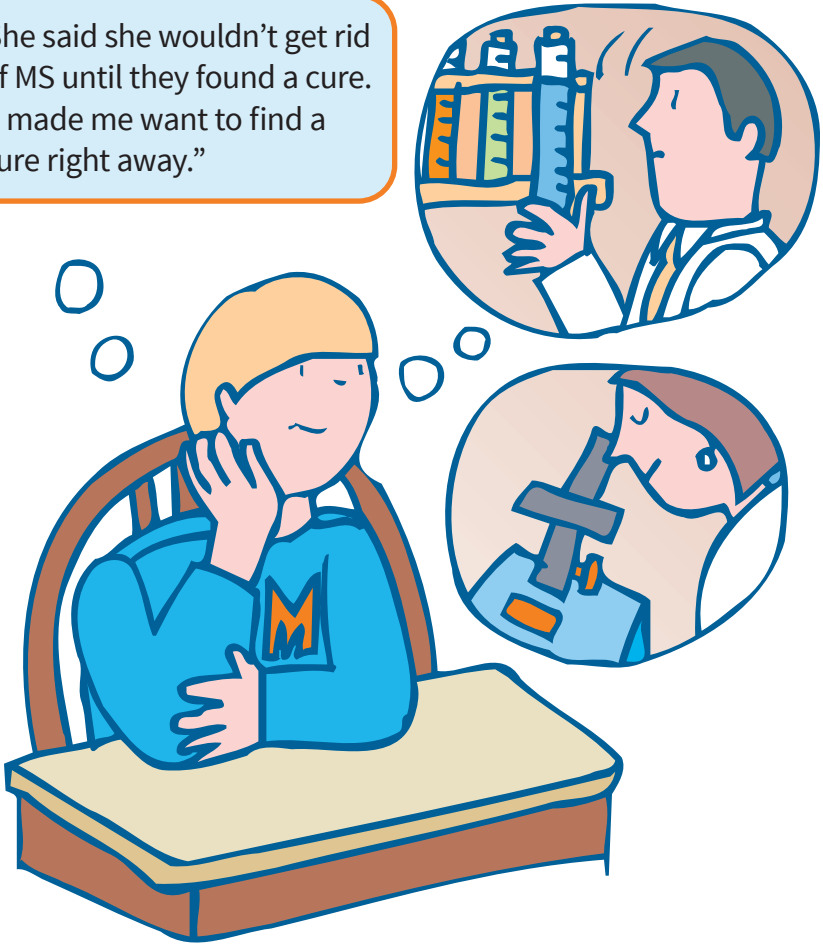


The Feelings

MS is frustrating. You may find it easy to go along with some of the changes MS brings and very hard to put up with others. You're bound to have some mixed up feelings.

Feeling Scared or Sad

“She said she wouldn’t get rid of MS until they found a cure. It made me want to find a cure right away.”



No one knows the cause of MS, and no one knows how to cure MS — at least not yet. Everyone in Michael’s family has a hard time with that.



“I like it when she draws pictures and explains what’s happening. It helps to know what’s going on because Mom can be very sad and then she’s okay an hour later.”

You may notice that other things in your life seem to go wrong. Your grades may suddenly drop, or your softball game is off. There may be things your family can’t do together anymore.



When Michael got low grades on his report card, he felt so bad he started to cry. Things looked really bad, and Michael just felt like crying — so he did. Some sad and angry feelings that were stuck inside him got out. A good cry made him feel better.

Michael’s dad said, “Life is different for us all now.” They made a special time each day to talk about Michael’s feelings and help him with his homework.

“I said, ‘Mom, you’re a regular mother.’ And she said, ‘Yes.’ I said, ‘But you don’t ride your bike anymore.’ She knew what I meant, and she said, ‘But I can still be a regular mother.’ And she is. She’s good at cards, and tells me stories, and does a lot of things. She came on my school field trip.”



Making Hard Feelings Better

Not everyone finds it easy to tell private feelings. But there are lots of things to do with feelings that are hard to talk about.

Here are some things Michael does: Draws a picture. Makes something out of wood. Writes a poem or a story. Runs around the block. Goes bike riding. Plays basketball.

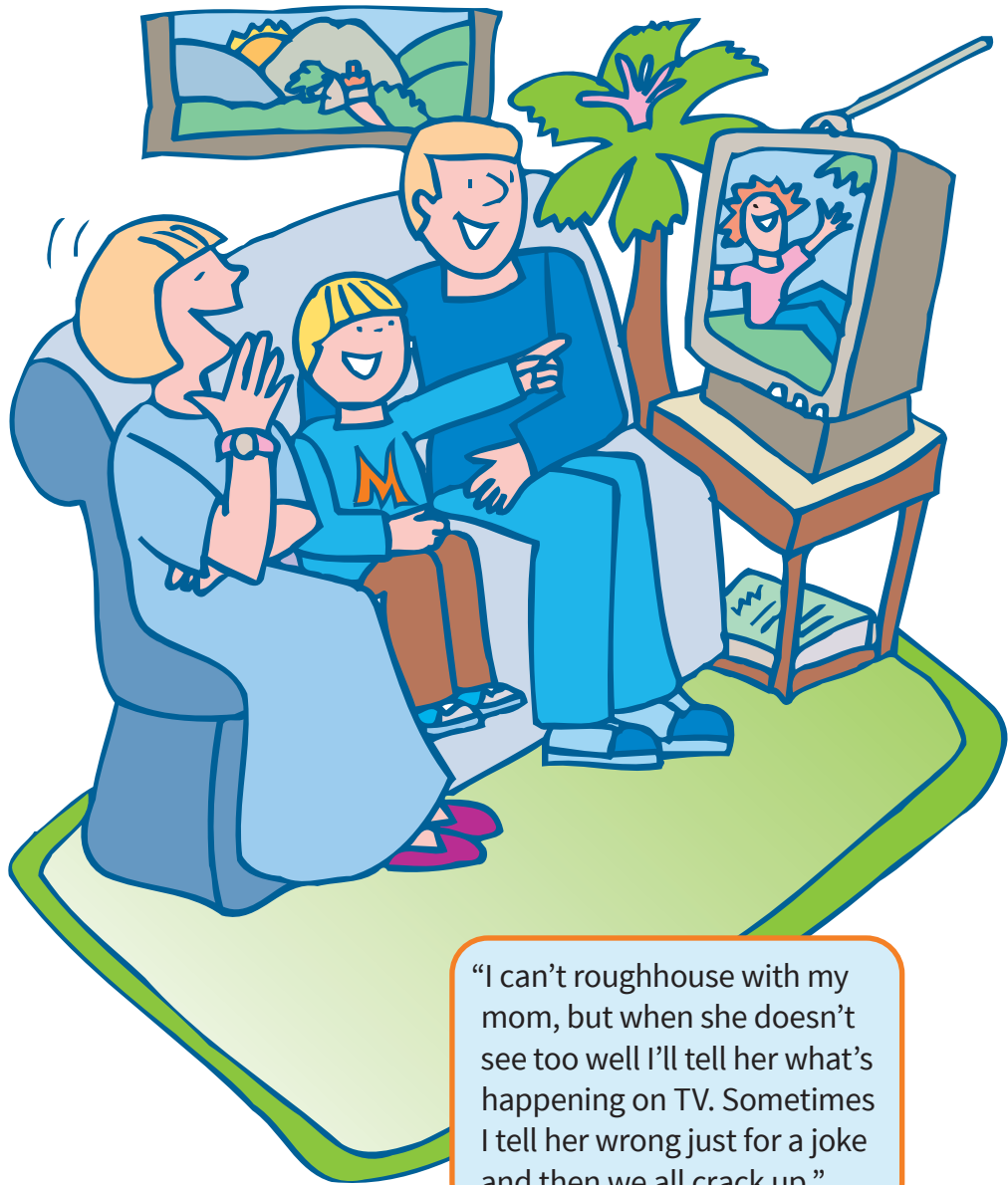


“Hammering makes me feel good!”



“I throw the ball really hard!”

Sometimes Michael goes into his room and takes it out on his pillow. He punches it and punches it and that makes him feel better.



“I can’t roughhouse with my mom, but when she doesn’t see too well I’ll tell her what’s happening on TV. Sometimes I tell her wrong just for a joke and then we all crack up.”

Feeling Angry and Picked On

You aren't being mean if you don't like how your life has changed. Getting angry isn't a terrible thing, especially if things seem unfair. Sometimes, family fun gets canceled with no warning. Michael's family never goes to the beach anymore, because the hot sun makes his mom's MS feel worse.



“It just isn't fair! Why did this have to happen to us? I wish I had never heard of MS!”

Michael even wondered if anyone cared about him any more. People asked him about his mother and not about him. “I feel left out!” he shouted one night. His dad wasn’t angry. They sat down and talked about it.

Later, the whole family went to a National Multiple Sclerosis Society Family Day, and there were lots of other kids with parents who have MS. Michael had fun playing with Robin. Her mom uses a scooter all the time.



Getting Things Done

Michael has a lot of housework. Of course, his friends Steve and Lisa have chores too. Lisa has to rake leaves and fold laundry. Steve clears the table. And they don't have a parent with MS.

Still, Michael has to do more. There's no way to make that seem fair. But his mom and dad are proud that he can be so responsible.



"I have to make my bed, take out the garbage, and set the table every day. On weekends, I pick up my room, run the vacuum cleaner, and help my dad in the yard. I know I'm helping, and that's good, but inside I sometimes feel mad."

Michael and his dad found it helps to plan the chores. They made a chart and put it up in the kitchen to keep track of who does what. Now Michael doesn't always get stuck loading the dishwasher. He hates that job. And Michael and his dad are learning to cook together.



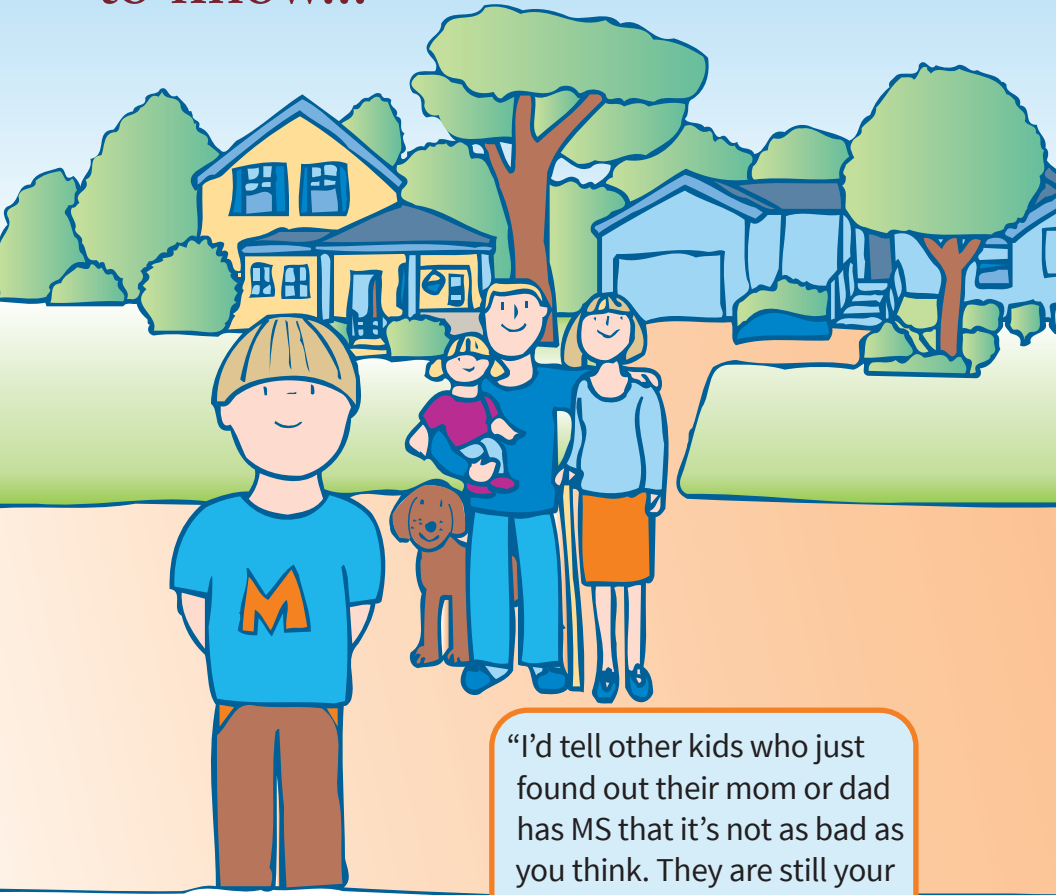
You Are a Special Family

No one likes MS, but it's not all doom and gloom. Like Michael, you are special. Your family includes a person who has MS, doesn't always feel well and may need extra help sometimes. The sharing you do together can make your family feel close.



“If Mom isn’t feeling well, I have to put myself to bed, because Dad has to take care of my little sister. That’s okay though. I like knowing how much I can do on my own.”

Here's what Michael wants you to know...



“I’d tell other kids who just found out their mom or dad has MS that it’s not as bad as you think. They are still your parent no matter what.”

Even if your parent can’t go skating with you or take you on long hikes, there are many things you can do together. If your parent is at home during the day, you may have extra time together that other kids don’t have.

“My dad says it’s important to remember that scientists all over the world are working very hard to find a cure for MS. They are discovering more and more about MS every day. And my mom says it’s important to remember we can solve some of the problems MS makes by helping each other.”

“We all raise money for MS research. Lots of people come to Walk MS®, and it’s fun!”



The National Multiple Sclerosis Society is proud to be a source of information about multiple sclerosis. Our comments are based on professional advice, published experience and expert opinion, but do not represent individual therapeutic recommendations or prescriptions. For specific information and advice, consult your physician.

Early and ongoing treatment with an FDA-approved therapy can make a difference for people with multiple sclerosis. Learn about your options by talking to your healthcare professional and contacting the National MS Society at **[nationalMSSociety.org](https://www.nationalmssociety.org)** or 1-800-344-4867.

The Society publishes many other pamphlets and articles about various aspects of MS. To download them, visit **[nationalMSSociety.org/brochures](https://www.nationalmssociety.org/brochures)**, or contact a MS Navigator® at 1-800-344-4867 to have copies mailed to you.

**TOGETHER
WE ARE STRONGER.**

**TOGETHER WE WILL
CHANGE THE WORLD
FOR PEOPLE WITH MS.**



**National
Multiple Sclerosis
Society**

nationalMSsociety.org

**For information:
1-800-344-4867**