



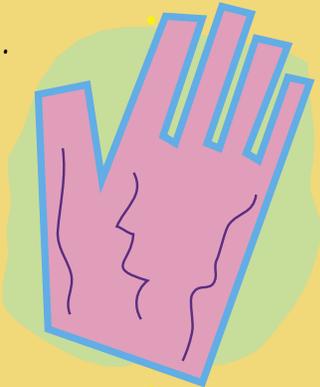
Keep S'myelin

A NEWSLETTER FOR KIDS ABOUT MULTIPLE SCLEROSIS



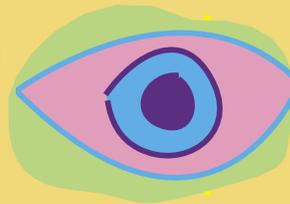
People with MS can have many different kinds of symptoms. Some are problems you can see—like difficulty walking. Others are invisible. The person with MS may be aware of these symptoms, but no one else can see them. Some of the invisible symptoms of MS are tiredness, strange feelings in different parts of the body, and changes in the person's ability to see.

The tiredness, called MS fatigue, is different from the tiredness most people feel. It can happen at any time of day, even after a long nap!



When moms or dads feel this tiredness, it is hard for them to do very much—even things they enjoy a lot.

The strange feelings can be painful or itchy or just plain uncomfortable. Some people get a **prickly feeling** in their arms or legs—just like you get when your hand or foot “falls asleep”—but their prickly feeling may not go away. This can make it hard for the person to walk or hold things without dropping them.



Problems with **eyesight** can make things look blurry or like a big movie screen with black holes in it. Sometimes people see two of everything! A person with vision problems may have trouble driving, reading, and watching TV. Invisible symptoms can be hard to understand. Your mom or dad may look fine to you, but still not be able to play a game or go to the mall. When your parent complains about a symptom you can't see, you will need to use your imagination to understand how he or she is feeling. **Issue #3** of Keep S'myelin has some activities you can try to better understand what those invisible symptoms might feel like.

MS

Multiple sclerosis (MS for short) is a disease that affects the central nervous system (the brain and the spinal cord). 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 from the brain, along the spinal cord, to the 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, or sometimes it's

hard to walk. 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. That is why we say that MS is unpredictable.

Interesting Fact:
Multiple means many. Sclerosis means scars. So, multiple sclerosis means "many scars."



My mom goes to an MS support group, and everyone there has different symptoms. Why is that?

No two people have MS in exactly the same way. The symptoms of MS—the ones you can see and the ones you can't—are caused by damaged myelin, and this damage can occur just about any place in the brain or spinal cord. Lesions in different places cause different kinds of symptoms. There are several medications that help to slow the damage caused by MS. Other medications can make the symptoms feel better.

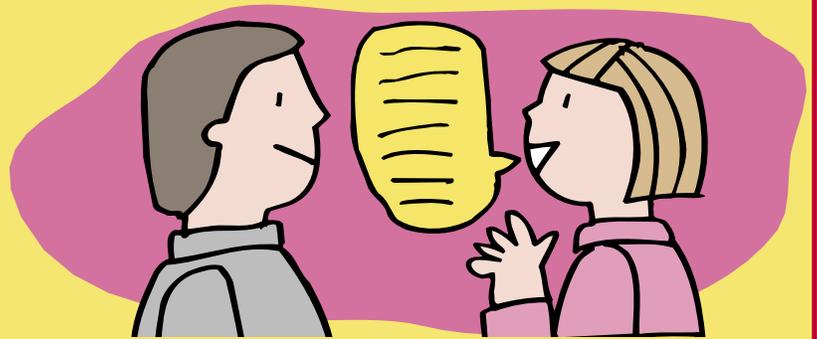
DISNEY'S STORY

It can be scary and confusing to find out your mom or dad has MS, whether the symptoms are visible or invisible, and whether there are a lot of them or only a few. Learning about MS (by reading *Keep S'myelin*, for example!) and talking to people you trust can help you feel less afraid. Here's how Disney, who lives in Colorado, learned how to feel better about her mom's MS.



Hi.

My name is Disney and I am 10 years old. My mom has had MS since I was in third grade. When she first got MS it was scary. She had to go to the hospital. She couldn't see and she couldn't feel her feet or fingers. At first I was afraid all the time because I thought she was going to die or be really, really, sick. I was sad all the time and I was afraid to have my mom or dad go away or to be away from them overnight. I had nightmares about people I loved dying or me not being able to help them. I would go in my mom and dad's room at night and want to sleep with them. I did this for a long time until my parents took me to a counselor and we talked about stuff. I learned not to be afraid and that I should talk to my mom and dad when I was scared. I also learned about MS.



I help my mom by comforting her and by doing what she asks me to do right away and not doing something else first. I think that if you are afraid, you need to talk to someone. I talk to a counselor but I learned to talk to other people about it, too. There are lots of things doctors can do for MS and your mom or dad with MS is still your mom or dad! So, just try not to be afraid.

WHAT'S IT LIKE

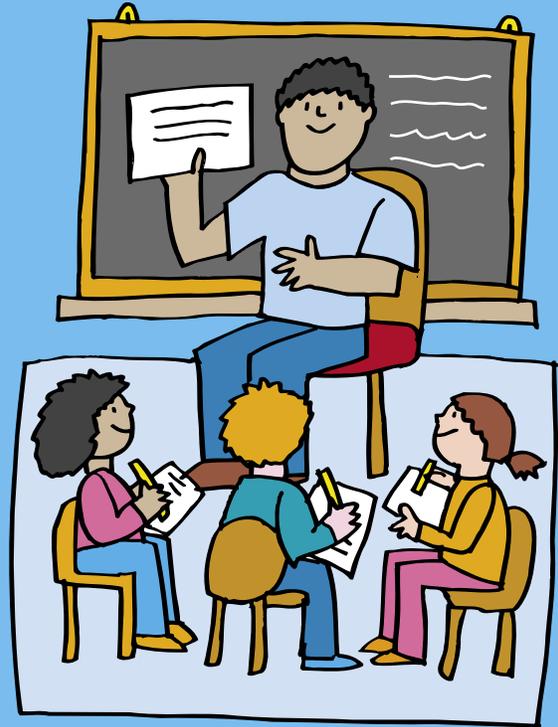
Some people with MS have only a few symptoms while others have lots of symptoms. Some people have trouble walking. Others have trouble seeing. One person may have “pins and needles” in his or her legs, while another may feel clumsy or lose balance.

That is why we say MS is “variable”—the symptoms vary from person to person. To help you learn about some of the ways MS can affect people, we would like you to meet some friends. You will notice that MS affects each of them in different ways:

1. KATHY



Kathy is the receptionist in a dentist office. She welcomes the patients and makes sure everything runs smoothly in the office. Kathy sits behind a big desk in the doctor's waiting room. Her MS has caused problems with her balance so she uses a cane to help her walk. Her fingers sometimes feel a little clumsy, so she uses a computer with a very big keyboard. That helps her avoid making typing mistakes!



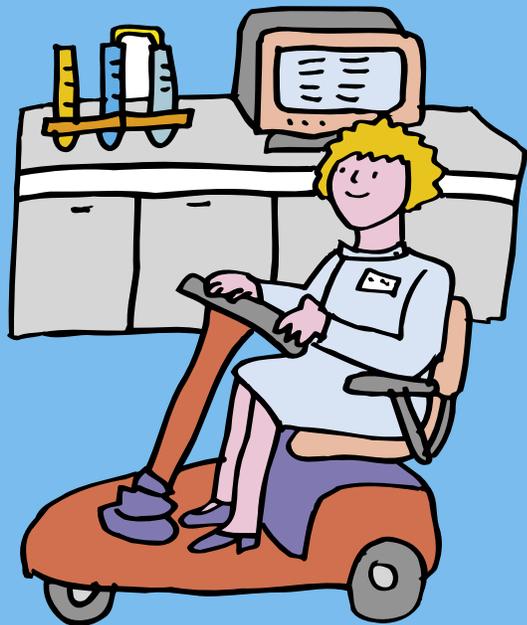
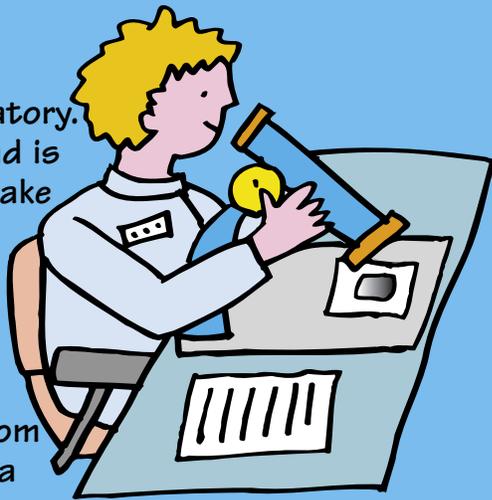
2. MALCOLM

Malcolm is a second grade teacher. He keeps very busy planning lessons and keeping his pupils happy and learning! His MS is “invisible.” That means no one can really tell he has MS from looking at him. He usually feels fine. He sometimes has “pins and needles” in his legs, but that is the only symptom he has and no one else can see it.

TO HAVE MS?

3. LYDIA

Lydia works in a laboratory. She is a researcher and is discovering ways to make new medicines. She uses a scooter because her MS makes it very difficult for her to walk or stand. She also gets very tired from her MS, so she takes a nap at lunchtime and again when she gets home from work. Lydia's lab has extra wide aisles so she can get around easily in her scooter and she has an easy chair in her office so she can rest.



4. CARLOS

Carlos is a stay-at-home dad. He takes care of his children, ages 6 and 9, when they come home from school. He helps them with their homework and makes dinner for the family. He used to work in a factory, but his MS made it too hard for him to use his tools safely. He uses a wheelchair around his house and his family installed a stair glide to help him go upstairs. He misses working in the factory sometimes, but he feels lucky to spend so much time with his children.

MICHAEL
CRYSTAL

AND
BENJAMIN

S'MYELIN KIDS

MY MOM INVITED SOME FRIENDS OVER FOR A BARBECUE. ALL OF THEM HAVE MS.

HOW CAN THEY LOOK SO DIFFERENT IF THEY ALL HAVE MS?

IT'S BECAUSE MS IS VARIABLE. IT'S A NEW WORD I LEARNED. IT MEANS THAT WHAT HAPPENS TO ONE PERSON WITH MS MAY BE DIFFERENT FROM WHAT HAPPENS TO ANOTHER PERSON WITH MS.

A little girl goes to see the doctor. She's got a pea in one nostril, a grape in the other, and a string bean stuck in her ear! She says to the doctor, "I don't feel good." The doctor replies, "The problem is clear to me. You're not eating right!"

JOKES

How could a cowboy ride into town on Friday, stay two days, and ride out on Friday?

His horse is named "Friday"

Michelle's mother had four children. The first was April, the second was May, and the third was June. What was the name of her fourth child?

Michelle

Why is it so hot after a ball game?

Because all the fans leave.

What vegetable do you get when an elephant walks through your garden?

Squash

Make a Rain Stick

These rain sticks really sound like rain!



MATERIALS

- ★ a cardboard tube from gift wrap or paper towels
- ★ paper, scissors, and tape
- ★ strips of cardboard (about 4" long and 1" wide)
- ★ 2 Tablespoons dried peas, popcorn, or lentils
- ★ 1 cup uncooked rice
- ★ markers, paint, ribbon, and other decorations

1. Cut two 4-inch circles out of paper. (You can trace a large coffee mug for the shape.)
2. Put one circle over the end of the cardboard tube. Fold the sides down, and tape around the tube. (Make sure the paper is sturdy and taped on well!)
3. Cut several cardboard strips. Fold each strip back and forth like a fan. Drop the strips into the tube. The first one should fall to the bottom. Keep adding strips until they reach the top of the tube.
4. Pour the rice and the dried peas, popcorn, or lentils into the tube.
5. Put the other paper circle over the open end of the tube. Tape in place.
6. Decorate your rain stick with markers, paints, paper shapes, ribbon, etc.
7. To hear the rain, slowly turn the cardboard tube so that first one end is up, and then the other.

PEANUT BUTTER Play dough

Mix together:

- ✿ 1/2 cup peanut butter
- ✿ 1/2 cup honey
- ✿ 1/2 cup to 1 cup powdered milk

- ✿ Make shapes and letters with your playdough.
- ✿ Decorate with raisins, then eat!

This play dough is good enough to eat!





Keep S'myelin

PARENTS' PULL OUT



HOW TO TALK ABOUT THE INVISIBLE SYMPTOMS



“How can you have a chronic illness and still look so healthy?” How many times has a family member, friend or colleague said... “I know you have MS, but you look so well!” How often do your children wonder why you can’t play with them or attend a school event, when you seem fine?

The variability of MS, and the fact that some of its symptoms are invisible, make this disease difficult for others to understand. Symptoms such as fatigue, cognitive problems, vision problems, stiffness, numbness, bladder problems, or tingly sensations may not be particularly visible to others, yet be troublesome

and distressing to you. And to make matters even more confusing to others, these symptoms may come and go.

Use this issue of Keep S’myelin to help your children understand the concepts of variability and unpredictability, and the frustration of having invisible symptoms. Friends, employers, and other family members may need help fully understanding this often confusing aspect of MS. If your employer knows about your MS, you may want to work with him or her to modify and adapt your work space, make assistive technology available to you, or make job task modifications (such as flexible hours or job

restructuring). Again, it is important to explain your symptoms (particularly when they are not visible or if they change frequently) to others so they are not misunderstood. Clear and honest communication is key. The same is true with friends and co-workers. If they know about your MS, all you can do is be honest about how your symptoms affect you and how you feel. Perhaps together you can come up with ideas on how they can help when you’re not feeling well.

Living with unpredictability is part of living with MS.

Make Your Own BUBBLES



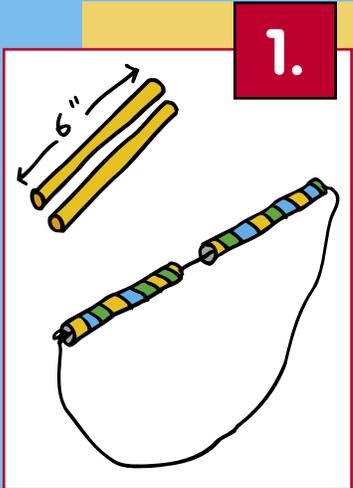
- BUBBLE MIXTURE #1**
.....
- 1 cup water
 - 1/3 cup Joy dishwashing liquid
 - 2 tablespoons corn syrup
-
- BUBBLE MIXTURE #2**
.....
- 1 cup water
 - 1/3 cup Joy or Dawn dishwashing liquid
 - 2 tablespoons glycerin
-
- BUBBLE MIXTURE #3**
.....
- 1 1/2 cups water
 - 1/2 cup dish soap
 - 2 teaspoons sugar

Keep S'myelin Readers:
WE WANT YOU!



We love to publish your articles, stories, illustrations, poems, and interviews about MS. Please send us your work! Tell us how your family learns about MS together, how you feel about having MS in your family, what advice you would give other kids about having a mom or dad with MS, how you help your mom or dad, and whom you talk with about MS. Send your stories and pictures to: **KEEP S'MYELIN, NMSS**, 700 Broadway, Suite 810, Denver, CO 80203 or e-mail them to keepsmyelin@nmss.org.

WAND Ideas



1.

- * Cut two 6-inch pieces from drinking straws.
- * Pull a piece of cotton string about 24 inches long through the straws.
- * Tie the string and hide the knot in one of the straw pieces.
- * Hold the loop of string by the straw handles and dip it into a pan of bubble solution.

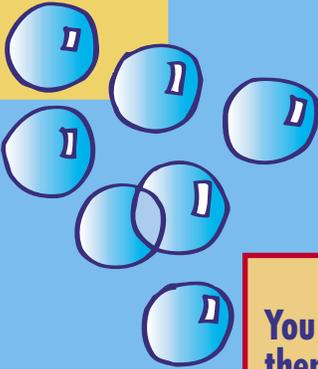


* Blow through the loop or gently wave it through the air to create a giant bubble.



2.

- * Use a plastic funnel.
- * Dip the wide end in the bubble mixture and blow through the small end.



Q: How can you subscribe to KEEP S'MYELIN?
 A: Call 1-800-FIGHT-MS.

You will be connected to your local chapter. Ask them to add your name to the Keep S'myelin distribution list. IT'S FREE! Keep S'myelin is published quarterly by the National MS Society. Past issues are also available at your local chapter.

RESOURCES

DOLLS WITH DISABILITIES:

www.multiculturalkids.com. These cute rag dolls come in a variety of skin tones and hair colors and can be outfitted with a variety of assistive devices, such as a wheelchair, cane, forearm crutches, walker, hearing aid, and more.



THROUGH THE LOOKING GLASS (TLG):

www.lookingglass.org

TLG provides direct services, information and referral to a diverse group of families of adults with disabilities. Lots of helpful information on parents with disabilities. TLGs' National Parent-to-Parent Network is designed to connect parents, as well as those who are considering becoming parents, with others who may have shared similar experiences or faced common barriers as parents with disabilities.



You can e-mail us at:
KeepSmyelin@nmss.org

KEEP S'MYELIN
is now available online at www.nationalmssociety.org
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The National MS Society...One thing people with MS can count on.



Keep S'myelin is a quarterly 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 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 therapeutic recommendations or prescriptions. For specific information and advice, consult a qualified physician.

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The mission of the National Multiple Sclerosis Society is to end the devastating effects of multiple sclerosis.