



Keep S'myelin

A NEWSLETTER FOR KIDS ABOUT MULTIPLE SCLEROSIS

MOVING WITH MS

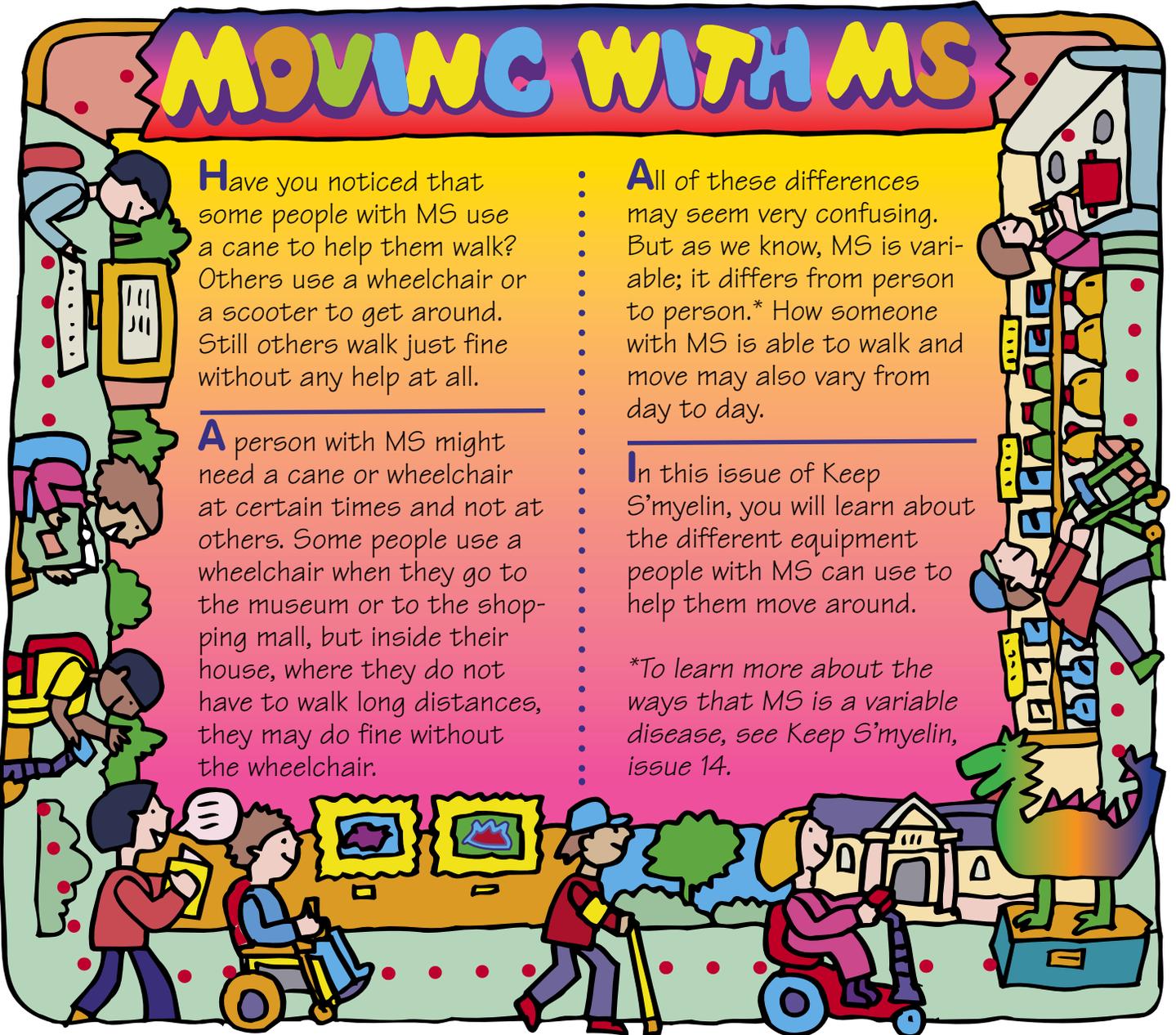
Have you noticed that some people with MS use a cane to help them walk? Others use a wheelchair or a scooter to get around. Still others walk just fine without any help at all.

A person with MS might need a cane or wheelchair at certain times and not at others. Some people use a wheelchair when they go to the museum or to the shopping mall, but inside their house, where they do not have to walk long distances, they may do fine without the wheelchair.

All of these differences may seem very confusing. But as we know, MS is variable; it differs from person to person.* How someone with MS is able to walk and move may also vary from day to day.

In this issue of Keep S'myelin, you will learn about the different equipment people with MS can use to help them move around.

**To learn more about the ways that MS is a variable disease, see Keep S'myelin, issue 14.*



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."

Q&A

Q: Some days my mom can walk pretty well with just a cane, but other days she can't go very far at all without her scooter. Why isn't her walking the same all the time?



A: When a person has MS, his or her symptoms can change from one day to the next, and even from morning to afternoon on the same day! These changes seem to be caused by many things, including how hot it is outside or how tired the person is that day. Some days, people just wake up feeling stronger or weaker than they did the day before, and no one really knows why. Your mom is very smart to use whichever piece of equipment helps her feel safe and steady, so she can go everywhere she wants to go.

COURTNEY

Thirteen-year-old Courtney lives in Rochester, Minnesota with her mom and dad, two sisters, and a golden retriever named Gypsy. She is home-schooled and loves to jump on her outdoor trampoline with her little sister and play Frisbee golf with her older sister and friends. Courtney's mom has had MS since Courtney was about 7 years old.



KS: What kind of equipment does your mom use to help her get around?

COURTNEY: At first, she didn't need to use anything. Then after a while, she started using a cane and now she uses a wheelchair to go to church and to go shopping, a walker around the house, and her scooter when she goes into the yard to pick things from the vegetable garden.

KS: Was it hard for you when she started to need these things?

COURTNEY: At first, she could do lots of stuff with us, and then, when she needed these things, we were sad about it. But now we're used to it and we're grateful that she is happy!



KS: How did you learn about MS?

COURTNEY: When my mom was first diagnosed, we didn't know anything about MS. My mom and dad talked to us about it and helped us understand. Also, now we go to **MS Camp*** and we see other kids who are in the same situation. We can ask questions there that we might not want to ask our mom or dad, because it might hurt their feelings.

KS: Have you ever tried your mom's scooter or wheelchair?

COURTNEY: When we first got the scooter, my mom let us ride it up and down the sidewalk and we tried the wheelchair too. They're hard to drive!

KS: Have you had to make any changes to your house for the wheelchair and scooter?

COURTNEY: Our neighbor is building us a ramp from the porch to the yard so my mom can get out to the garden. Also, we moved about two years ago to a house that is on one level. It's easier for my mom to get around.

KS: What advice would you give to a kid who just found out his or her mom or dad has MS?

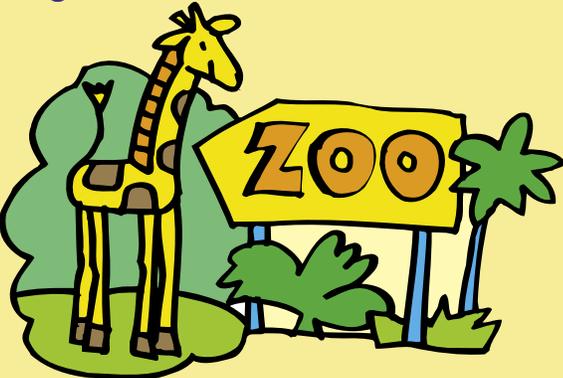
COURTNEY: It really helps to talk about it. Talk to your family about MS or go to MS Camp so you can ask questions. Remember, things could be a lot worse! Keep your mind set on the good things--MS has really brought our family closer together.

*MS Camp is a program sponsored by many chapters of the NMSS. Ask your chapter if they offer similar programs for children and families. Not all chapters have camps, but many do offer programs for families and kids.

LOTS OF WAYS TO

Here is some equipment that can help people with MS move around. Some people with MS don't need this type of help, or only use this equipment once in a while.

SCOOTER:
This scooter runs on a battery.



CANE:
These canes are pretty decorative.



POWER WHEELCHAIR:
This wheelchair runs on a battery. You steer the wheelchair by moving the "joy stick."

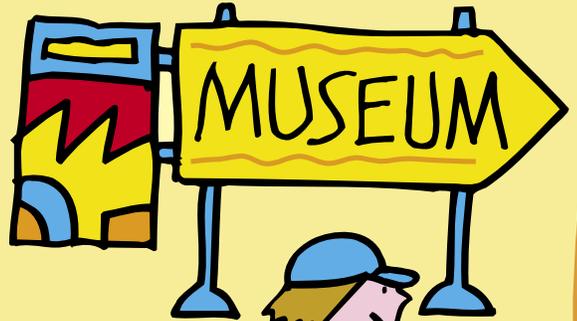


TO GET AROUND



WALKER:

This walker has wheels and is easy to push. It has a basket for carrying things and a little seat a person can use when he or she gets tired.



CRUTCHES:

These crutches attach to the forearms and help a person walk.



... have decorations!



MANUAL WHEELCHAIR:

The person sitting in this wheelchair moves and steers by pushing on the large wheels. This wheelchair folds up and is easy to put in a car.



MICHAEL CRYSTAL AND BENJAMIN

S'MYELIN KIDS

1. I'M SURE GLAD OUR TOWN MADE THESE LITTLE RAMPS AT ALL THE INTERSECTIONS. NOW, YOU CAN WALK ME TO SCHOOL EVERY DAY!

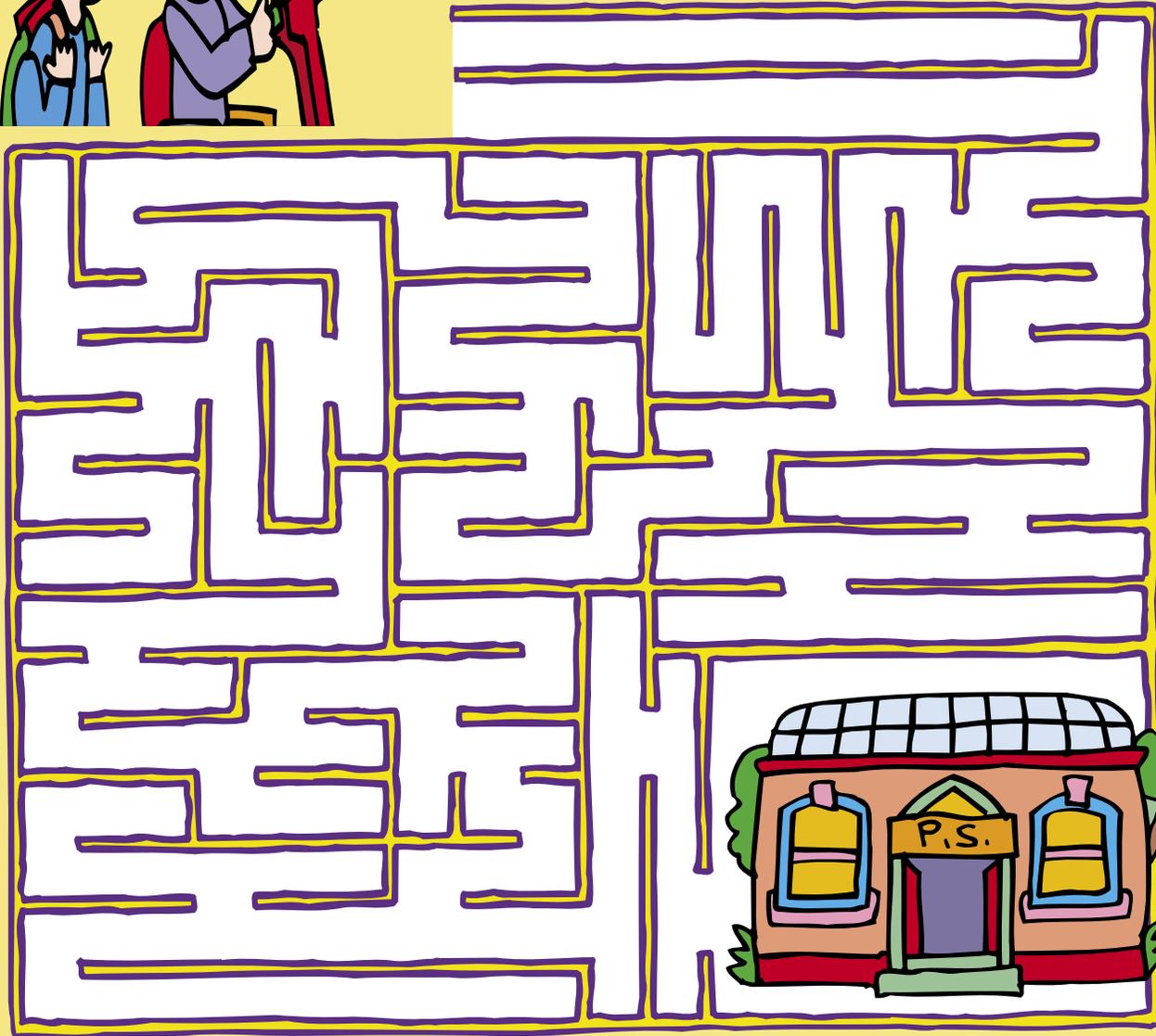
ME, TOO! AND IT'S NOT ONLY PEOPLE WHO USE WHEELCHAIRS WHO LIKE THE CURB CUTS!

2.

3. IT'S NICE WHEN PLACES ARE ACCESSIBLE TO EVERYONE. THAT'S A NEW WORD I LEARNED - IT MEANS A PLACE WHERE IT'S EASY FOR EVERYONE TO MOVE AROUND.

Can You Help Michael and his Mom get to school

ON TIME?



JOKES



Why can't the leopard escape from the zoo?

Because he keeps getting spotted.

What starts with E, ends with E, and only has one letter?

?????

An envelope

What does a dentist call his X-RAYS?

Tooth-pics





PARENTS' PULL OUT

BE PREPARED

Most people with MS are well aware of how variable and unpredictable MS can be. Some people's symptoms vary so much from day to day that they start each morning with a little "body check": How are my legs feeling today? Is my vision better in that eye? Is that arm still numb? How's my balance? One of the great frustrations of living with this degree of uncertainty is not knowing how to plan one's schedule for the day, the week, or the month. People worry about committing themselves to a plan or an activity that they may not be able to handle when the time comes.

One helpful strategy is to develop a "tool chest" of the various types of equipment that help you do the things that are important to you. Whether indoors or out, on the move or at your desk or kitchen sink, there are dozens of assistive devices designed to conserve energy, increase mobility and safety, and enhance function. Each person's tool chest is unique, filled with whatever tools are necessary to get the jobs done. One young father with MS had the trunk of his car filled with mobility aids, including a cane, forearm crutches, a walker, and a lightweight wheelchair. Each day, he would do his body check, look at his list of to-do's, and decide what kind of aid(s) he needed to get them done. He was determined that his MS

wasn't going to keep him from getting around and being productive. A side benefit of this kind of tool chest is that it gives a clear message to others about the variability of MS. Your children will quickly grasp the idea that you feel better and stronger some days than others, and they will see that you use whichever mobility aid you need to share activities and outings with them.

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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.

TIPS FOR HELPING KIDS ADJUST TO NEW MOBILITY AIDS

Have them choose a name for your cane or scooter or wheelchair.

LIGHTNING?

TRUSTY?

SKIPPY?

Let them help you decorate your cane with decoupage or make a banner for the back of your wheelchair.

Let them try out the device themselves. (with adult permission and supervision)

Let them help with ideas for your "tool chest."

MOBILITY: Helping the MIND MOVE

“Will I end up in a wheelchair?” It’s the first question many people ask when told they have MS. The use of any type of mobility device is often viewed as the hallmark of disability, the ultimate sign of defeat. Viewed from a different perspective, however, canes, walkers, motorized scooters, or wheelchairs help people live active lives. They promote independence, conserve energy, and generally make life easier.



Energy, for people with MS, is a valuable resource and people with MS can use mobility aids to protect this precious commodity. Devices can get them where they want to go with enough energy to be productive—and have fun—once they get there.

Using a mobility device is seen as “giving in to MS” by some. They are determined to resist any change that would crown MS the winner. However, mobility devices can become tools for winning, not giving in. A cane or a rolling walker, for example, can prevent falls and control a staggering gait. A scooter can make shopping trips manageable, and visits to a museum or zoo a pleasure instead of a trial. A person might use nothing at all on the best days, and go with a walker when feeling more fatigued. A wheelchair or scooter may even make a new sport possible or reopen the door to an old favorite. People in scooters bowl, fish, and play golf. Others use wheelchairs for tennis or basketball. Mobility devices allow people to go where they want without having to rely on others. They can keep pace with everyone else, “walk” side-by-side, and share laughter and conversation. Family members, friends, and

co-workers no longer find themselves worrying about the person with MS getting hurt in a fall or becoming too tired to stand.



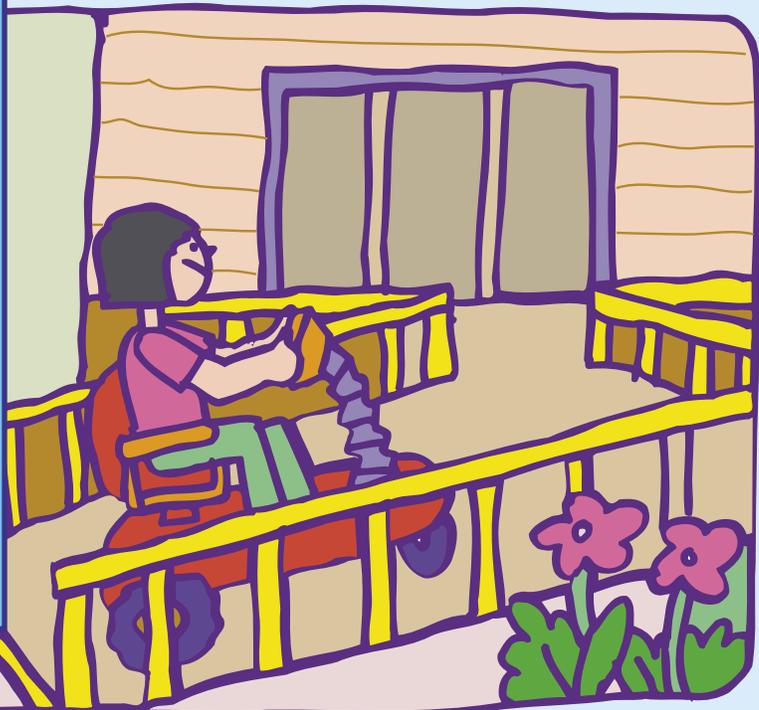
Many people struggle to walk unassisted so others won’t stare, feel sorry for them, or think less of them. In other words, they dread being stigmatized or labeled. It’s worth remembering that mobility devices often help people look less disabled. A person struggling to walk may attract attention. A person using a cane looks purposeful, and may even give off an aura of confidence. A person sitting comfortably in a power chair keeps up with others and arrives looking (and feeling) in control.

Excerpted from an article by Rosalind Kalb, PhD.

A TIP

ABOUT RAMPS:

Do not build ramps that are steeper than 1 in 12 (12 inches of ramp for every inch in rise) unless you have considered all the alternatives! The steeper the ramp, the more dangerous and difficult it is to maneuver on it. Building a ramp of appropriate dimensions maximizes independence and safety.



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.



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

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The National MS Society...One thing people with MS can count on.



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