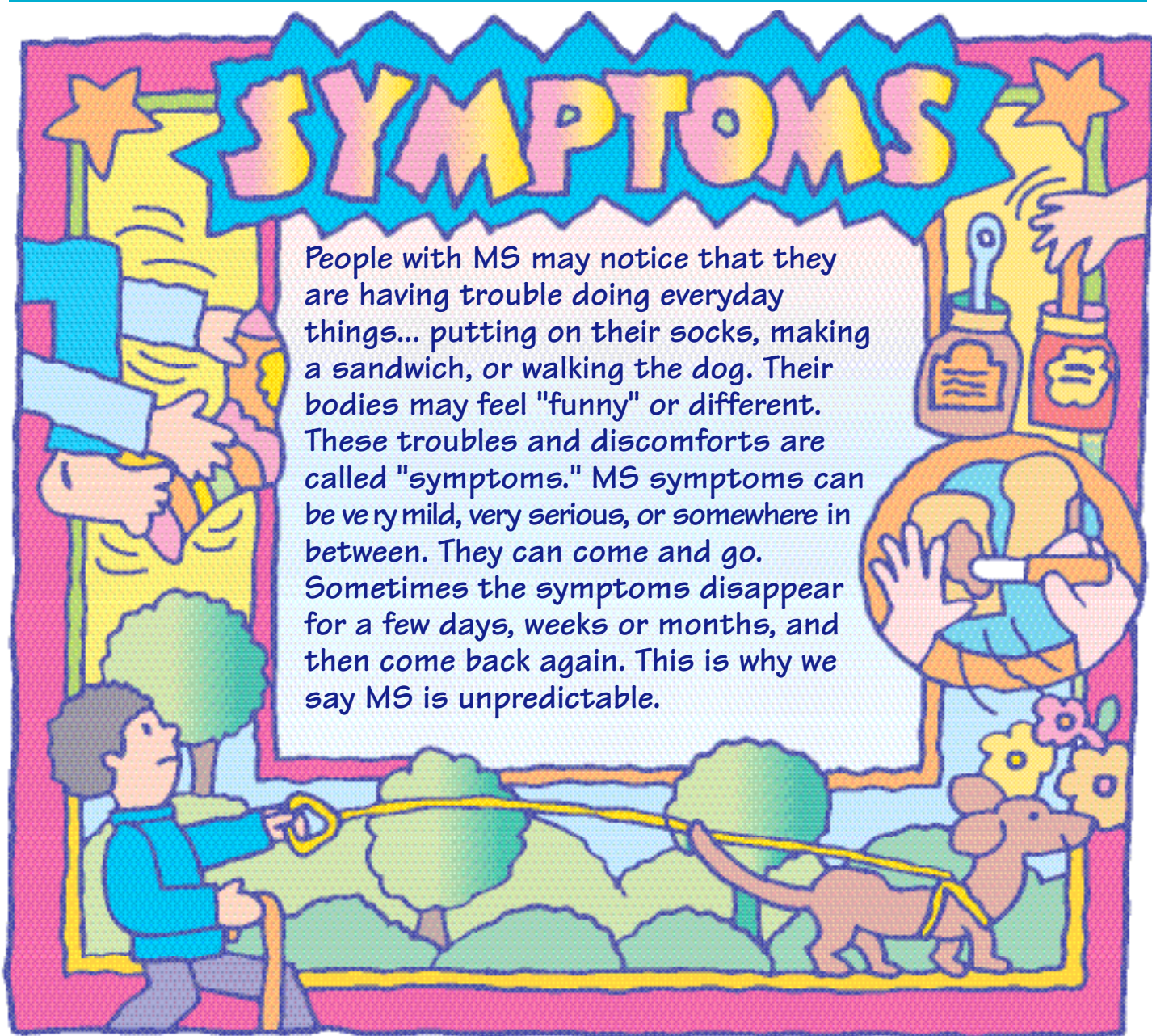


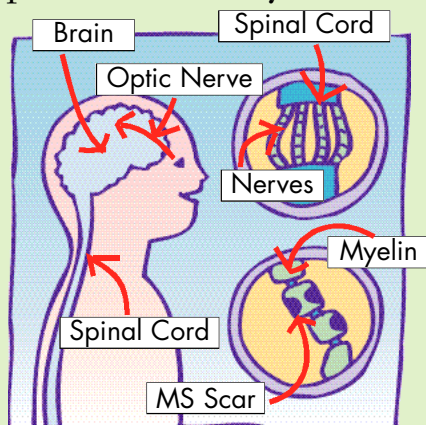
Keep Smiling

A NEWSLETTER FOR KIDS ABOUT MULTIPLE SCLEROSIS



MS

Multiple sclerosis (MS for short) is a disease that affects the central nervous system (the brain, optic nerve 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,

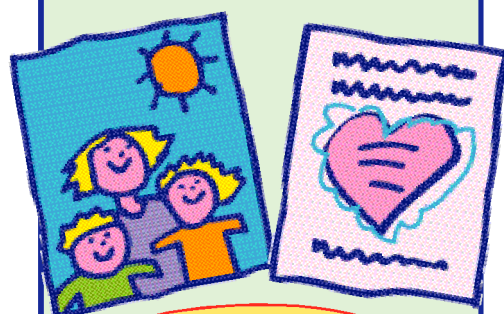
the other parts of the body can't always do what the brain is telling them to do.

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."

**Keep S'myelin Readers:
WE WANT YOU!**

We love to publish your pictures, stories, and poems 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, or whom you talk with about MS.



Send to:
KEEP S'MYELIN,
National MS Society
700 Broadway,
Suite 810,
Denver, CO 80203
or e-mail to
keepsmyelin@nmss.org.



Since You've Asked

My dad's symptoms got worse and he had to go to the hospital. Why did he have to go?

Sam

Dear Sam:

Your Dad may have had a flare-up of his MS that made his symptoms worse. He may have needed special medicines to treat the symptoms. It is easier for the doctors and nurses to take care of him in the hospital than at home. I hope you got the chance to visit while he was there.

My mom fell down when she was walking the dog. It was embarrassing and scary.

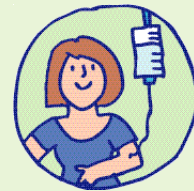
Jana

Dear Jana:

Sometimes people with MS lose their balance and fall down. Your mom didn't fall on purpose and she probably felt a little embarrassed and scared herself! Talk with your Mom. Tell her how you feel. She may be able to tell you more about what happened and how she's feeling.

MEDICINES AND MS

When you have a cold or fever or cough, your mom or dad may give you medicine to make you get better. Unfortunately, we don't yet have medicines to make MS go away.



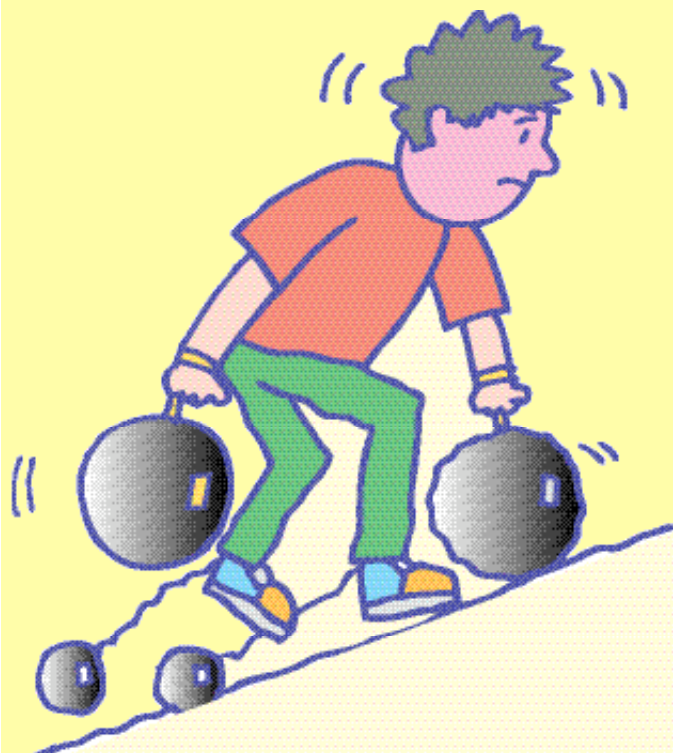
But there are medicines that can help! Some medicines make MS symptoms feel better. Other medicines help to slow down the MS so that it will cause fewer troubles. With some of these special MS medicines, your mom or dad may have to take shots with a needle. Many people learn to give themselves shots; others have someone in the family help. Your mom or dad may feel comfortable with you in the room or he or she may prefer privacy.

Sometimes people feel a little sick for a day or two after the shot, but it's usually not too bad, and the medicine is helping to control MS.

HERE ARE SOME COMMON MS SYMPTOMS

HAVING WEAK ARMS AND LEGS.

Some people with MS find that their arms and legs feel very tired, as if there were weights tied to them. It makes it hard to move.



FEELING PINS AND NEEDLES

Remember the last time you sat on your leg the wrong way and your foot fell asleep and felt tingly and funny?

Sometimes MS gives people that pins and needles feeling in their arms, legs, or other parts of their body.



HAVING TROUBLE SEEING

Did you ever try to look through someone else's glasses? Some people with MS have blurry vision or see two of everything (double vision.)



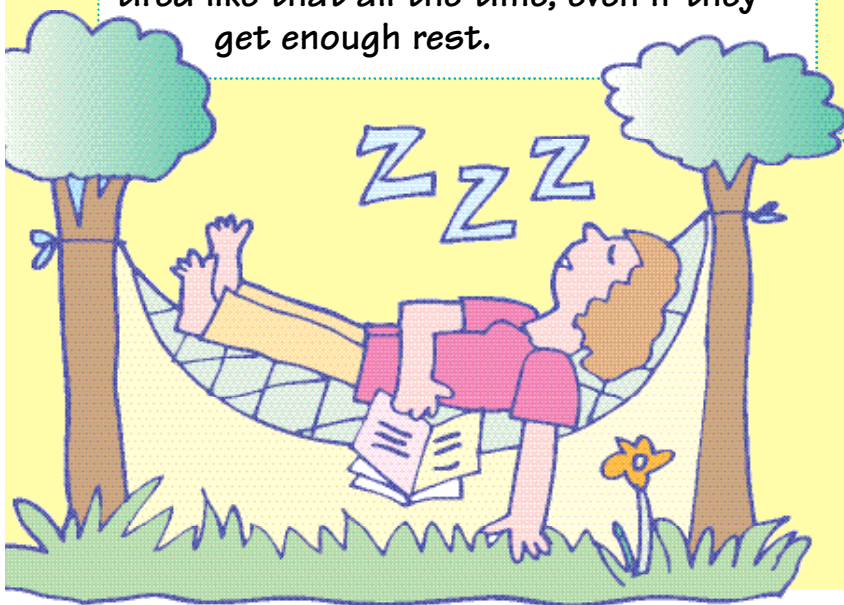
LOSING YOUR BALANCE

Have you ever made yourself dizzy by spinning around in a circle? It was hard to walk straight afterwards and keep your balance, wasn't it? Sometimes people with MS lose their balance, even though they don't feel dizzy.



FEELING VERY TIRED

Have you ever stayed up really late, way past your bedtime? Remember how tired you were? Many people with MS feel tired like that all the time, even if they get enough rest.



There are many different MS symptoms. Ask your mom or dad about the kinds of symptoms he or she is having. Not everyone with MS has the same ones. Learning about MS symptoms and talking to your parents about them can make you feel better.

WORD SEARCH

E	V	E	R	Y	P	E	R	S	O	N	W	I	T
H	M	S	I	S	D	I	F	F	E	R	E	N	T
H	H	W	V	O	G	Y	D	I	C	A	S	S	L
T	R	E	M	B	L	I	N	G	U	E	E	S	M
P	I	N	S	A	N	D	N	E	E	D	L	E	S
W	S	S	E	N	I	D	O	O	M	T	Y	N	S
K	A	B	A	L	A	N	C	E	K	S	D	K	E
H	S	L	M	K	T	M	D	A	B	E	I	A	N
T	A	L	K	I	N	G	O	M	C	E	Z	E	B
D	N	Q	I	I	L	Z	A	K	C	I	Z	W	M
T	I	R	E	D	N	L	D	Y	O	N	Y	R	U
Y	S	M	U	L	C	G	M	V	I	G	W	Z	N



BALANCE
MOODINESS
SEEING
TREMBLING

CLUMSY
NUMBNESS
TALKING
WALKING

DIZZY
PINS AND NEEDLES
TIRED
WEAKNESS







See if you can find the important message in this word search.
What do we know about symptoms and people with MS?

ANSWER: EVERY PERSON WITH MS IS DIFFERENT!





READER-SUBMITTED STORY

ARIANA'S STORY



Hi, I am Ariana and I am 11 years old. I have a GREAT dad with MS. I know it is hard to have a dad with MS, but it has a good side too. My dad and I have so much in common - we both love basketball, and we love other sports too. I love him so much no matter what he has. He will always be the nice, caring, and funny dad I know on the inside.

Ariana 



P.S. I have some advice for kids whose parents have MS. My dad has had MS for awhile, and I've learned how to adapt to that. I've talked to my dad about MS ever since I was little, and have learned a lot about it by just talking to him. My friends have always comforted me too. All you have to do is find a quiet place for you and someone to talk about MS and how you feel.



PARENTS' PULL OUT

How to Enjoy Keep S'myelin with Your Kids

As you read this issue with your child, you might take the opportunity to talk about your own symptoms and the ways they are the same or different from the ones described in the article. Be sure to mention that no two people with MS have exactly the same symptoms, and no one person has the same symptoms all the time. This can be difficult to explain to young children who tend to see things in a fairly concrete way. They find it hard to understand why their mom or dad feels OK sometimes and not others, particularly if the symptoms are invisible.

The symptoms activity is designed to help your kids get a better sense of what some of your symptoms might feel like. "Trying on" symptoms may be a little frightening for some children; others may think it's a very funny game. You know your child best.

Sometimes, your feelings about the symptoms you are having may be a bit out of synch with the feelings your kids are expressing about them. If, for example, you

are feeling sad or scared about the numbness in your hand or the weakness in your leg, and your child begins to giggle and joke while doing some of the activities, you may start to feel hurt or angry. Try to remember that the point of the activities is to help children understand the symptoms and feel comfortable talking about them. You can talk about serious feelings, even while sharing some giggles.

As with other important MS topics, you will probably need to have more than one conversation about your symptoms. Not only will your symptoms ebb and flow over time, but your child's need for information will also change as he or she gets older. Simple explanations are usually sufficient for young children. Once you have opened the door to discussion by talking and sharing, your kids will feel freer to ask more questions as the need arises. Keep in mind, that each child may have a unique learning style. One might want to ask a lot of questions, another might want to draw a picture or act out a little skit.

Continued on page 2

Continued from page 1

You may find that conversations about MS—or any difficult topic, for that matter—are easier when you and your child are engaged in some other activity like riding in the car, playing a game, or taking a walk. This diffuses some of the tension and allows everyone to feel more relaxed. As you talk about symptoms, you can expand your conversation to include other children or adults with disabilities whom your child might have met or seen. This is a good opportunity for your child to try and guess what these other people's feelings and experiences might be.



★ TRYING

Children often have difficulty understanding MS symptoms—particularly ones that are not easy to see, like sensory changes, weakness, and fatigue. You can use the following activities to initiate conversations with your child about the symptoms you are experiencing. Having a better understanding of your symptoms may help put to rest your child's fears and confusion.

Explain to your child that these activities will give a sense of what your symptoms feel like. It will be a similar feeling, but not exactly the same. After each activity, ask your child to tell you what it felt like to "try on" the symptom (frustrating, funny, clumsy, scary...)

Some children may giggle and find the activities fun. Other children may feel uncomfortable, frightened or sad... Be alert to your child's reaction, so you can tailor your response.

WHAT DOES IT FEEL LIKE TO HAVE TROUBLE MOVING YOUR LEGS?

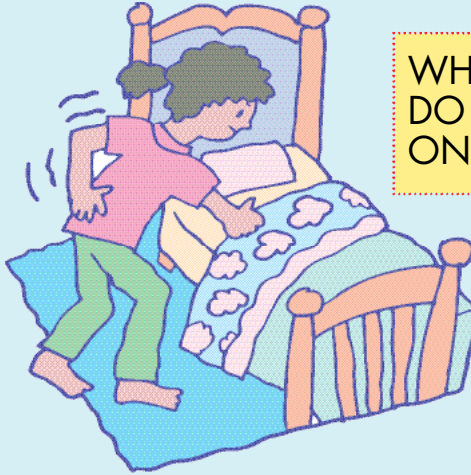
Have your child put on ankle weights and walk around the house or up the stairs. (If you don't have ankle weights, a long tube sock filled with sand and tied around the ankle is an easy substitute.)



ON SYMPTOMS

WHAT IS IT LIKE TO DO THINGS WHEN YOUR ARMS FEEL WEAK OR HEAVY?

Have your child put on wrist weights and try setting the table, doing homework, typing on the computer, or giving you a hug.



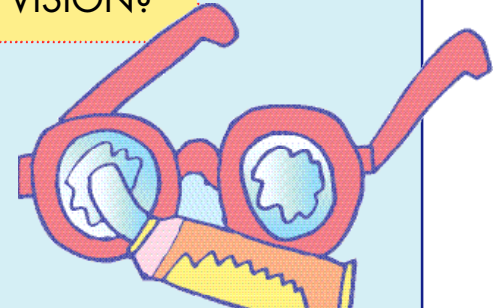
WHAT IS IT LIKE TO DO THINGS WITH ONLY ONE HAND?

Have your child try some routine activities using only one hand, such as buttoning a shirt or making a bed.



WHAT DOES THE WORLD LOOK LIKE WHEN YOU HAVE BLURRED VISION?

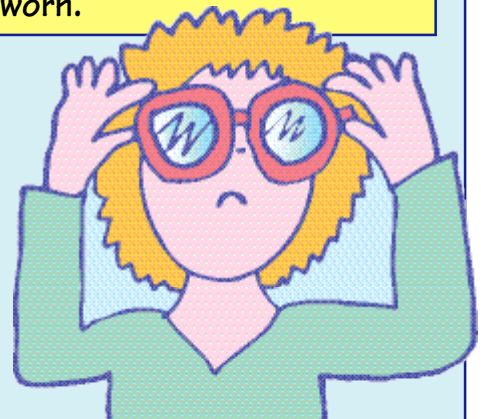
Take a pair of old glasses and smear petroleum jelly over the lenses*. Have your child wear the glasses and then try to read a book or make a peanut butter and jelly sandwich.



***Please note:** this will ruin the glasses, so use an old pair that are no longer worn.

HOW DOES IT FEEL TO DO THINGS WHEN YOUR FINGERS ARE NUMB?

Have your child put on a pair of work gloves (like gardening gloves) or a thin pair of winter gloves. Have your child remove the wrapper from a granola bar or pick up kernels of popcorn from a table with the gloves on.



SYMPTOMS LOG

You can use this log to explain your symptoms to your children.

When I have this symptom...

I feel...



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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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This issue is made possible through the support of the following Program Honor Roll chapters: Central New England, Central Pennsylvania, Gateway Area, Greater Connecticut, Greater Delaware Valley, Greater Washington, Indiana State, and Mid-Atlantic.

Editors

Rosalind Kalb, PhD
Kimberly Koch, MPA

Design/Illustrations

Claude Martinot Design

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

Please give us feedback.

Send your questions or ideas to:
KEEP S'MYELIN
National MS Society
700 Broadway Suite 810
Denver CO 80203
keepsmylelin@nmss.org

ISSUE #3
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SYMPTOMS

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