

KEEP S'MYELIN

A NEWSLETTER FOR KIDS ABOUT MULTIPLE SCLEROSIS

OUR NEW NAME

In response to suggestions from our readers, we've decided to change the name of our newsletter from **Nervo's News** to **"Keep S'myelin"**. Get it? We think it's a funny way to say "Keep Smiling" and keep reading our newsletter! If you don't remember what myelin is, be sure to ask your Mom or Dad. (Many thanks to our friends at the Consortium of MS Centers for the new name idea!)

ABOUT

SYMPTOMS AND MS




People with MS may notice that they are having trouble doing everyday things... putting on their socks, making a sandwich, or walking the dog. Their bodies may feel "funny" or different. These troubles and discomforts 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.

(Continued on page 2)



•• HERE ARE SOME



Feeling very tired.

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

Having weak arms and legs.

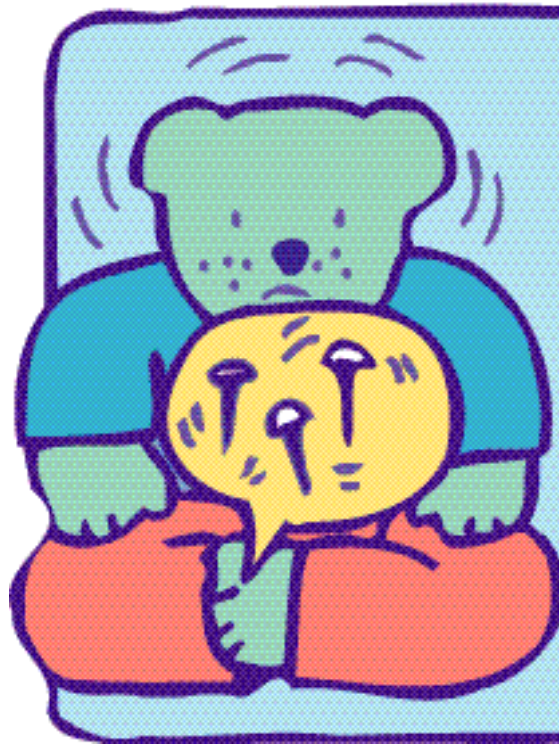
Some people with MS find that their arms and legs feel very tired, as if there were weights tied to them. It makes it hard to move.



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.

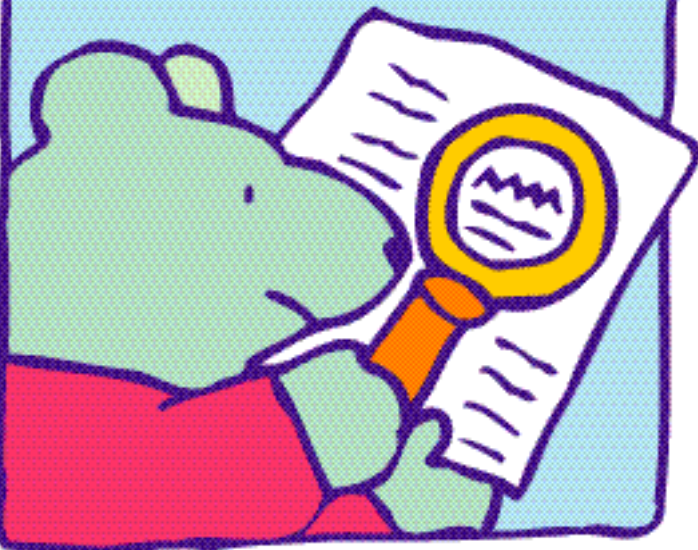


COMMON

SYMPTOMS

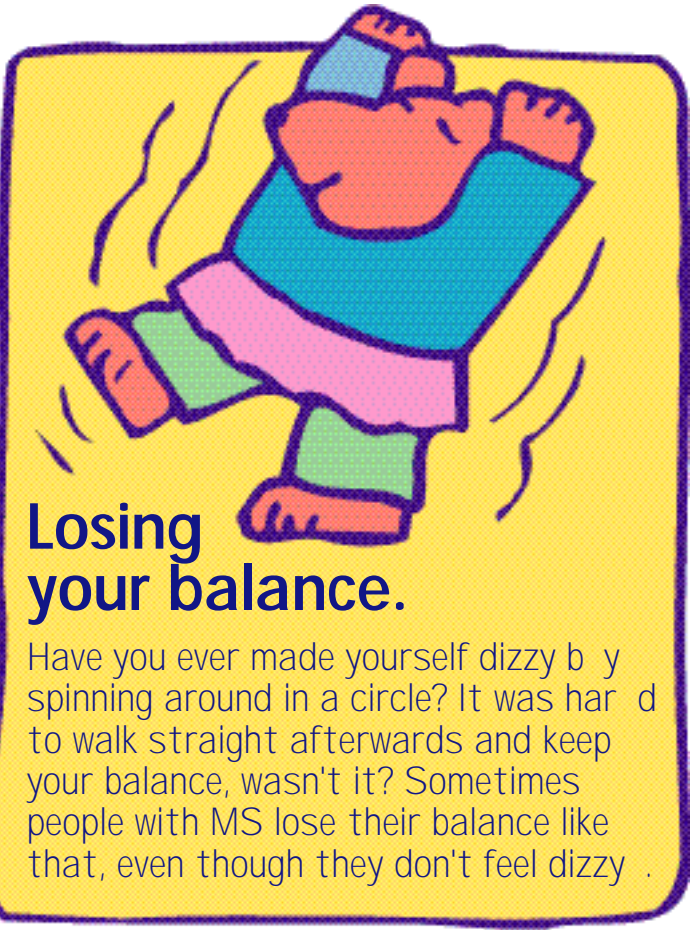
Having trouble seeing.

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).

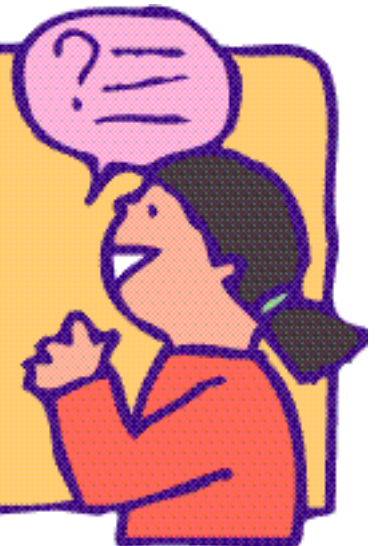


Losing your balance.

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 like that, even though they don't feel dizzy.



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.



SINCE YOU'VE ASKED....



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

Signed, Sam

Sam

Dear Sam:

Your Dad may have had a flare-up or exacerbation 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.

Signed, Jana

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 the sickness 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 parent may have to take shots with a needle. Many people learn to give themselves shots; others have someone in the family help. Your parent may feel comfortable with you in the room or he or she may prefer privacy. Getting a shot may look scary at first, but it doesn't hurt much.

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.

S.Y.M.P.T.O.M.S OF M.S.

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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!

Anne's Story.



Anne is an adult now. She was raised by a parent with MS and wants to share her story with you.

As long as I can remember, MS has been part of my life. MS did make some things more difficult for me, my brother, my dad, and certainly my mom, but it also gave us a lot. It gave us the opportunity to spend more time together (probably because it took longer to do just about everything!) It also made us closer to each other. Even though MS has

been part of my family, this is the family I love. And to me, that's normal.

I don't remember the exact day my Mom was diagnosed with MS because I was only three years old. But I do

- remember how it
- changed her body. She
- started using a cane
- when I was in first
- grade, and she needed
- an electric scooter when
- I was in fourth grade.
- Sometimes I was scared
- by all these changes.
- Could she still take care
- of me? Would we have to
- stop having fun together?
- Stop going on vacations?
- Stop being a family?
- When I think about what
- actually happened, I realize
- that we were definitely
- still a family with a Mom
- who took care of us--and
- a family that had a lot of
- fun!






Even though my Mom could't do all kinds of things she used to do, I didn't really notice because she never made us feel as though we were leaving her out. Whatever we were doing, my Mom was right there with us. She always asked us questions about our activities,

ports, friends, school- whatever we were interested in. Her support made it easier for us not to feel bad that she couldn't do everything we could do.

I always knew my life was different in some ways from my


- friends' lives. After all,
- how many fourth graders
- know how to do laundry
- or make dinner? I wish
- someone had told me it
- was OK to get mad at MS
- sometimes. Looking back,
- I guess I had a lot of feel-
- ings about my Mom's MS.
- I've been angry sometimes,
- sad sometimes, and even
- scared. But I have always
- been proud. My Mom has
- always been a great Mom.



Knock, Knock.
Who's there?
Howie.
Howie who?
I'm all right,
How are you?



Knock, Knock.
Who's there?
Dishwasher.
Dishwasher who?
Dishwasher way
I shpoke when I losht
my fwront teeft.



Knock, Knock.
Who's there?
Henrietta.
Henrietta who?
Henry ate
a boiled egg.



Knock, Knock.
Who's there?
Tish
Tish who?
Certainly, do you
have a cold?

KEEP SIMPLY IN

PARENTS' PULL OUT

TRYING ON

SYMPTOMS



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 allay 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 to be fun. Others children may feel uncomfortable, frightened or sad... Be alert to your child's emotional reaction, so you can tailor your response.

1. What does it feel like to have trouble moving your legs?

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Have your child put on ankle weights and try to walk up the stairs. (If you do not have ankle weights, a long tube sock filled with sand and tied around the ankle is an easy substitute.)

2. How does it feel to do things when your fingers are numb?

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Give your child a pair of work gloves or thin winter gloves. Have your child remove the wrapper from a candy bar or pick up kernels of popcorn from the table while wearing the gloves



3. What does the world look like when you have blurred vision?

????????



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



4. What is it like to do things with only one hand?

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



5. What is it like to do things when your arms feel weak or heavy?

????????

Have your child put on a set of wrist weights and try setting the table, writing a letter, or giving you a hug.



HOW TO ENJOY "KEEP S'MYELIN" WITH YOUR KIDS



Parents sometimes find it difficult to talk about MS symptoms with their children. They wonder when to talk about them, and how to describe the symptoms in ways that are informative without being scary. Some parents also find that their own feelings of anxiety or sadness get in the way. We hope this issue of Keep S'myelin will give you ideas for how to make this conversation with your kids easier and more comfortable for all of you.

As you talk about our newsletter's new name, be sure your child knows what myelin means.

As you read **"About: Symptoms and MS"** 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 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, "black and white" sort of way. They find it hard to understand why their parent feels OK sometimes and not others, particularly if the symptoms are not very visible.

The Disability Awareness Activities

are designed to help your kids imagine 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.

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—both yours and theirs—even while sharing some giggles.

(cont'd p.4)

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, as well, 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.



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 of different kinds, 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.

RESOURCE



"Disabled Parenting Today"

is a Canada-based, international newsletter that provides support and information to parents with a disability. A variety of subjects and disabilities are covered in each issue. Look for articles on getting involved with your child's school, sharing a modified vehicle with your child, and accessing resources around the world. The bi-monthly publication is available for \$20 in the United States. **Check out their website at HYPERLINK** "<http://www.sp-dpt.com>" For information on books, chat rooms, and select articles, or for a subscription contact:

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BERLEX



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

