



National
Multiple Sclerosis
Society

ISSUE #16/ FAMILY CHANGES

Keep S'myelin

A NEWSLETTER FOR KIDS ABOUT MULTIPLE SCLEROSIS

What Happens When MS Joins the Family?

This issue of Keep S'myelin is about some of the changes a family may go through when a mom or dad gets multiple sclerosis. Since every person's MS is different, and no two families are exactly alike, the experiences of each family will still be different.

Here are some of the changes that kids sometimes see:

Your mom or dad may feel different from one day to the next. For example, having a lot of energy one day and feeling very tired the next. This can make it hard to make plans. It's a good idea to have a back-up plan so that everyone won't be too disappointed.

When people don't feel good, they sometimes get cranky. You may find that your mom or dad acts grumpy sometimes. You may worry that your parent is angry with you or thinks that the MS is your fault—but you didn't do anything to make your parent get MS. If you get worried about that, be sure to talk it over with them or with another adult you trust.

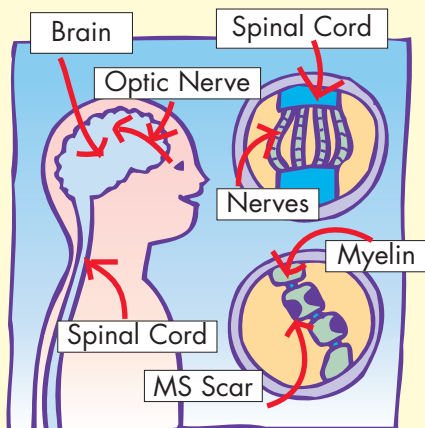
Your mom and dad may also seem more worried than usual. This can happen because no one is sure exactly what to expect. If you start to get worried too, be sure to let them know. Worries feel better when you talk about them.

(Continued on page 3)



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

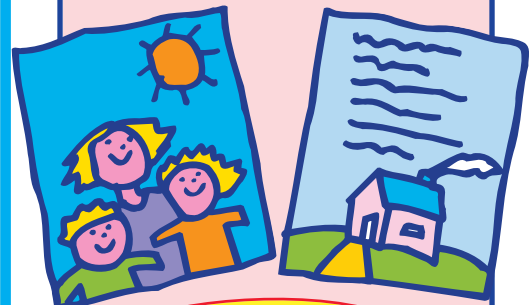
scars. When this happens, the other parts of the body can't always do what the brain is telling them to do.

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.



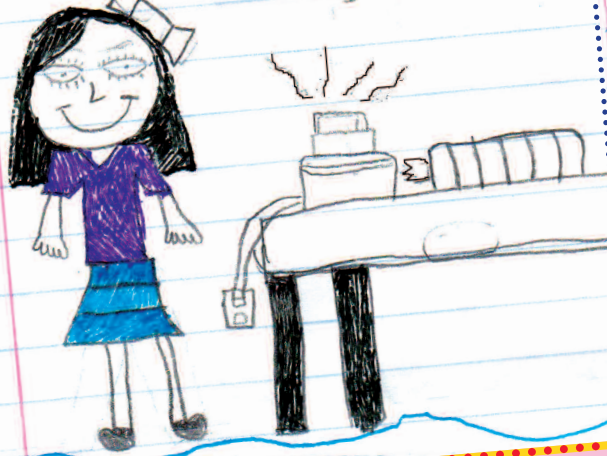
Send to:
National MS Society
KEEP S'MYELIN
BROADWAY STATION
 900 South Broadway
 Suite 200
 Denver CO 80209
 or e-mail to
keepsmyelin@nmss.org



PERLA' story

My name is Perla and I am 8 years old. I am in third grade. My mom has MS. I help my mom with washing dishes, making a sandwich and helping her when she is feeling sick. Oh and getting things.

a nice sandwich for my mom



Other side of story



(Continued from page 1)

Some moms and dads with MS need tools to help them do the things that are important to them. Canes, walkers, scooters, and wheelchairs are designed to help people get around when their legs are weak or they are having trouble with their balance. Your mom or dad may remind you to pick up all your toys from the floor so they won't get run over or cause someone to trip and fall!



When someone in a family gets MS, everyone in the family may need to help. Sometimes moms and dads trade jobs and responsibilities because the parent with MS can't do some of the things that he or she used to do. Kids may be asked to do more chores. While kids tell us that they don't always like the extra chores, they also say that helping makes them feel proud. Many kids have told us that living with MS, and all the changes it sometimes brings, has made their family feel closer.





MOOD CHART

by Emily

Emily lives in Cincinnati, Ohio.



Dear Keep S'myelin,

I really like your newsletter. It's very fun. I really want to try painting the bathtub (issue #13.) I have an idea for an activity. I call it "Mood Chart." Having a mom with MS can be tough. Doing an activity like this helps me understand my feelings and my family's feelings. Keep S'myelin helps, too!

Love, *Emily*

1

Draw a picture of each person in your family (including yourself).



2

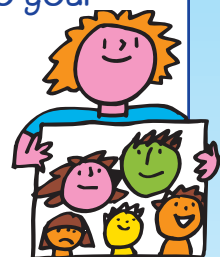
Use these colors to show how each person feels.



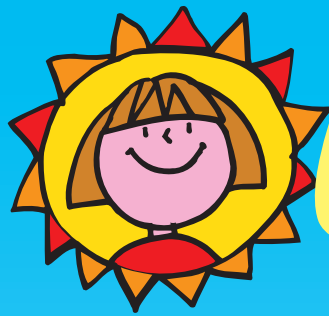
Mad Happy Mellow Bored Sad Scared

3

Show your drawing to your family and talk to them about the feeling colors you used. Were you correct? Talking about feelings can help everyone feel a little better!



4



BY AMY JO

HAVING A POSITIVE ATTITUDE

Amy Jo lives in Oldsmar, Florida.

My mom has multiple sclerosis. It all started one morning when her hands were tingling. She just thought they were asleep and didn't think too much about it, but soon her whole body was numb.

My mother and father sent my sister Molly and me to my grandparents' house while they went to the hospital to find out what was wrong. That's when they discovered she had MS.

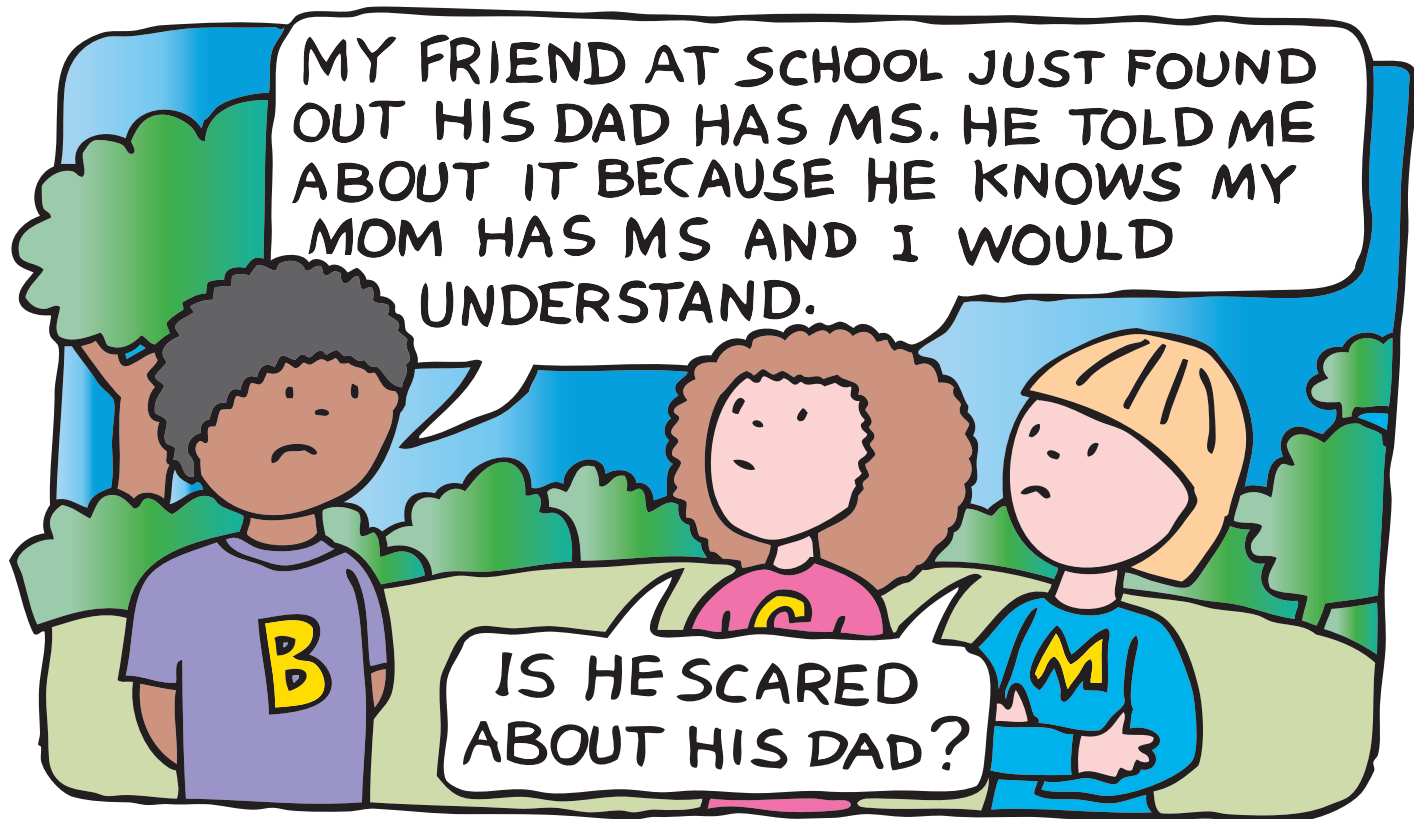
When we got the news, we cried for hours. My mom was afraid to tell us, but says she found the strength because she was able to tell us two of the most important things: We could not catch this from her and she would not die from MS. She explained to us that although she didn't know everything about the disease, we could ask her anything and if she didn't know the answer we would figure it out together.

My mom has gone through so much and I love her and am proud of her for that. My mom has a very positive attitude. She has helped me to understand that if you think the worst, the worst will come. We have all learned a lot about the power of having a positive attitude.

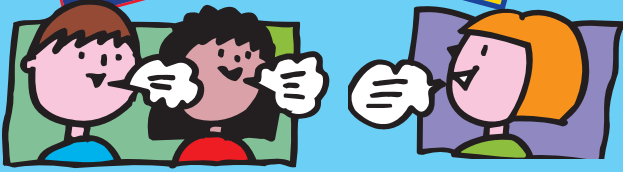
People wonder what happiness is. Some say it is a good grade on your report card, others say it is something that makes you happy forever. I now know you can choose to be happy even when things aren't going very well. My mom chooses to be happy when she doesn't have to be and it shows me how important a positive attitude is.

AMY JO

MICHAEL CRYSTAL AND BENJAMIN
S'MYELIN KIDS



Q **AND** **A**



Q My mom has MS. Why does she need to take so many shots?

A Your mom's doctor has given her a medicine to slow her MS. We still don't have a cure for MS, but the shots help people have fewer attacks. By taking her shots, your mom is doing the best she can to take care of herself. No one likes to get a shot, but the shots can help your mom keep doing the things that are important to her—like spending fun time with you.

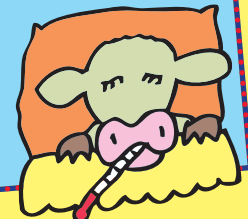
Q My dad was diagnosed with MS. What is going to happen next?

A That's a very hard question to answer because every person's MS is different. Some people have just one or two symptoms, while others have more. And those symptoms can change from one day to the next! Your dad's doctor will help him figure out the best ways to take care of himself. He may need to rest more than he used to, take medication, or use some special tools to help him do the things that are important to him.

JOKES

The first joke is from Mikala who lives in Maryville, Tennessee

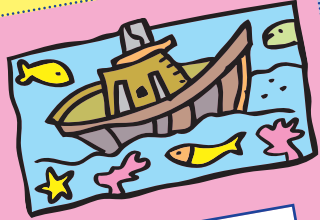
What does the veterinarian give to cows when they are sick?
 Moodicine



What do you get from a pampered cow?
 Spoiled milk



What lies at the bottom of the ocean and twitches?
 A nervous wreck



What do you call a boomerang that doesn't work?
 A stick





National Multiple Sclerosis Society



Contact the National MS Society at 1-800-344-4867.



These are the questions I have for my mom or dad about MS...



Q

A



Q

A



Q

A