

KEEP SIMPLY IN

A NEWSLETTER FOR KIDS ABOUT MULTIPLE SCLEROSIS

FEELINGS AND MS

If your mom or dad—or someone else you love—has MS, you probably have lots of feelings about it. Feelings about MS can be different for different people. Sometimes MS might make you feel angry, for example if your mom or dad can't play with you or drive you somewhere. Sometimes you might feel sad if your parent isn't feeling well, or scared if he or she has to go to the hospital. Sometimes you might feel glad because you love your mom or dad and enjoy doing fun things together.

Sometimes the hardest thing about feelings is sharing them with others, but talking about feelings can be helpful. It can make you feel better and bring you closer to the people you care about.

Having feelings is kind of like having a heavy backpack with lots of stuff inside. You can't really lighten it or tell anyone what is in your backpack if you don't look in there yourself. And it can get too heavy if you don't clean it out once in a while. Make a list of the

feelings you are carrying in your feelings backpack. You can do it in your head, on a piece of paper or in a poem or drawing.



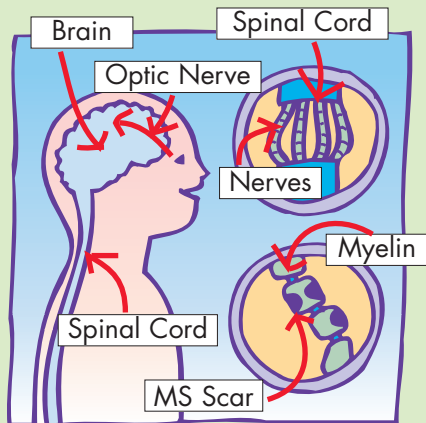
You can also try the 'Feelings Activity' in this issue. Share your picture with someone you trust—like your mom or dad. This will help make your feelings backpack feel a little bit lighter.



(Continued on page 2)

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."

(Continued from cover page)

FEELINGS AND MS

There are lots of other people you can talk to, such as teachers, brothers and sisters, doctors, school counselors, grandparents and friends.

Find someone:

- Who is easy to talk to.
- Whom you like and trust.
- Who listens to your feelings.



Talking about your feelings is the best way to learn more about yourself and find help for your worries. Don't be afraid to talk to someone the next time you want to sort out what is in your feelings backpack. You are not the only kid who has lots of feelings about MS!

SEAN'S STORY

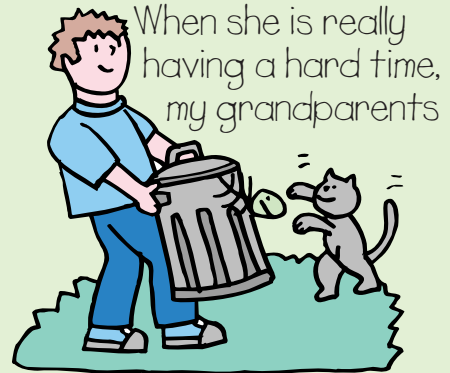
Sean is eight years old and in third grade. He lives in the country and has two sisters, Sarah and Victoria. He has a dog, a barn cat, a gecko and a few other reptiles as pets. He likes to draw, read, do martial arts, go camping and snorkeling, and do science experiments. He also loves to play chess and other games.



My favorite parts of the day are spent with my mom. She swims a lot and plays lots of games. The part about MS that is hard is watching her take a shot every day. She doesn't complain, so why should I? But I don't like anything that hurts her. I know the most frustrating part of MS for her is that she is so tired. With medicine, this is a little better.

When I was five years old, my mom lost her eyesight in one eye. So, we went from one doctor to another and after many tests, we found out she had MS. I remember that she was happy to finally know what was happening with her body. I can't say we are happy she has MS, but at least we can do things to make things easier for her. We go to her doctor's as a family sometimes. Her doctor is

Sometimes after we leave, I have questions. My mom stays informed about MS. Working in a hospital for years has helped her to be able to answer my questions. My mom's faith in God and her doctor are strong. That makes me feel there is always hope.



When she is really having a hard time, my grandparents and church family come to help. I do more chores than most of my friends, but that's OK. That's what family is all about. I would do anything to help my mom.

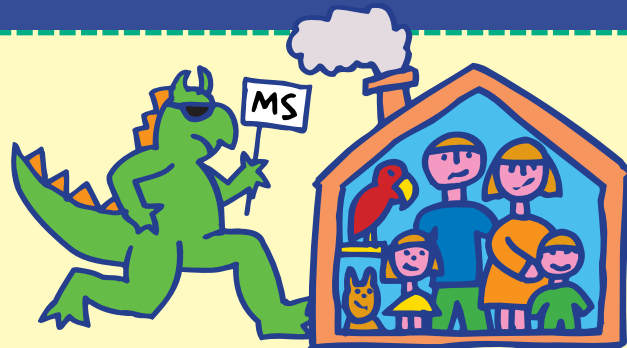


so cool. He always sits down with us to make sure we understand what is happening.



Sean

WHAT HAPPENS When MS Joins the Family?



Living with MS can bring changes to every member of the family. Some changes may be big, others might be small. 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. It's a good idea to have back-up plan for days when your parent doesn't feel well.

When people don't feel good, they sometimes get cranky. You may find that your mom or dad acts grumpy sometimes. If you get worried about that, be sure to talk it over with them or with another adult you like a lot.



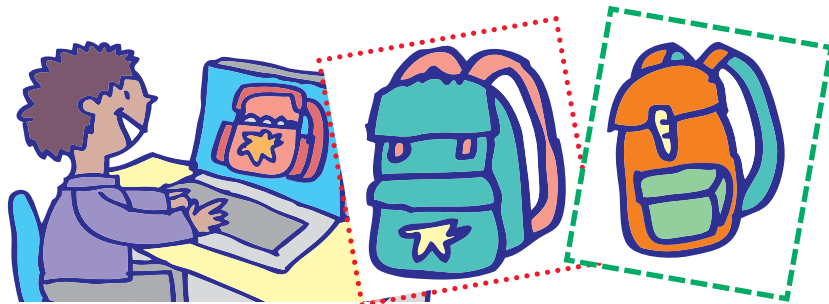
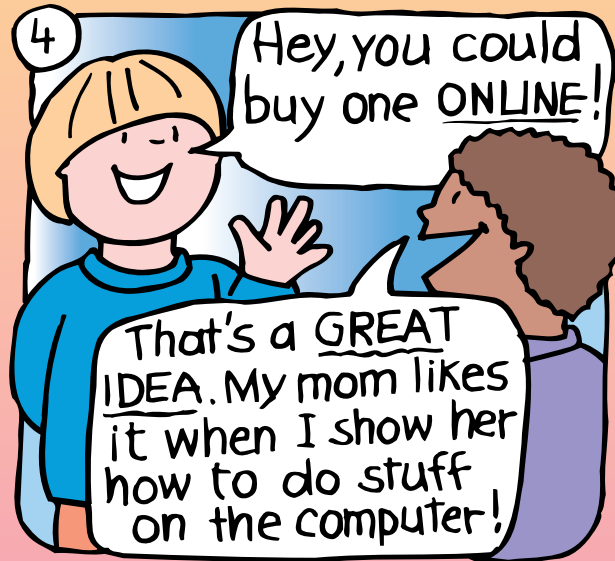
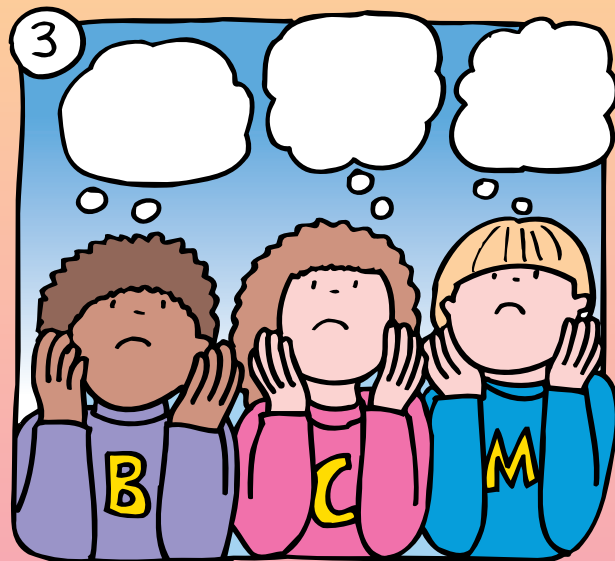
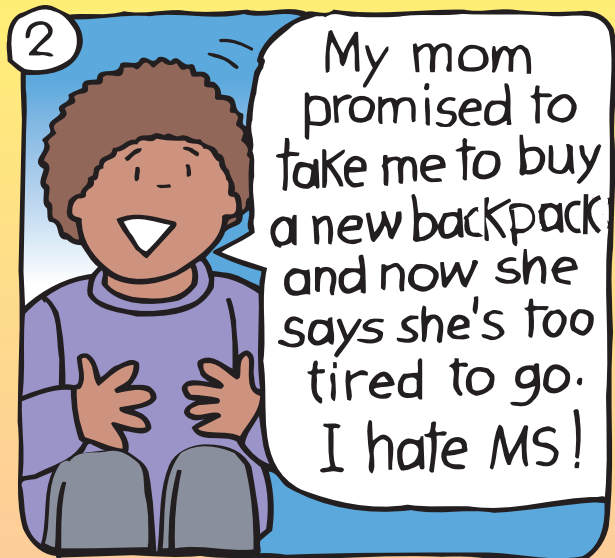
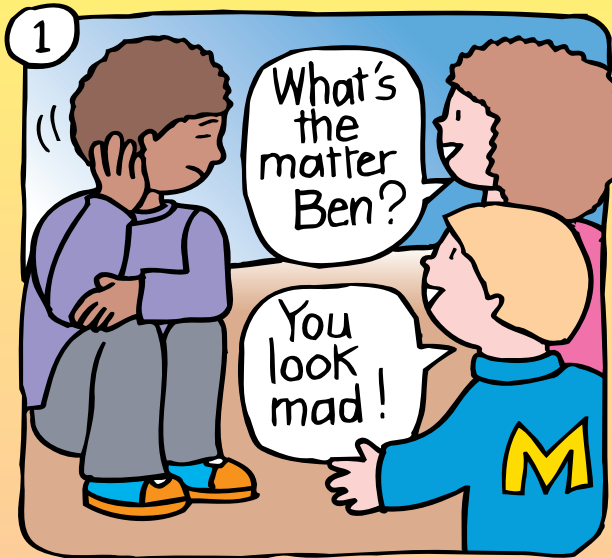
Your mom and dad may also seem more worried than usual. This can happen because no one is sure what to expect. If you start to get worried too, be sure to let them know. Worries feel better when you talk about them.



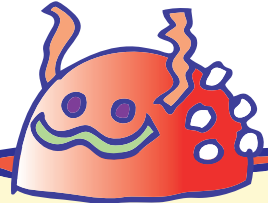
When someone in the family has MS, everyone else may need to help. Sometimes moms and dads trade jobs and responsibilities because the parent with MS can't do the things that he or she used to do. Kids may be asked to do more chores. While kids tell us that they don't always like the extra chores, they also say that helping their parent with MS makes them feel proud.



MICHAEL
CRYSTAL AND
BENJAMIN
S'MYELIN KIDS



FUN IDEAS FOR YOUR FAMILY



Tasty Ladybugs

Doing an activity together—cooking, coloring, crafts, reading—offers an opportunity to talk to your child. Sometimes while hands are busy with an activity, conversation flows more easily. Try this fun activity with your child:

What You Need

- * Apples
- * Celery
- * Shredded carrots
- * Creamy peanut butter
- * Safety scissors
- * Kitchen knife
- * Raisins, Snow-caps
- * Sealable plastic sandwich bag



- **Before You Begin**
- Spoon the peanut butter into the sealable plastic bag. Seal the bag and cut off one corner of the bottom of the bag. Squeeze the peanut butter through the hole in the corner of the bag—just like squeezing frosting from a pastry bag!
- Cut the apples in half. Place one half, cut side down on a plate. Using peanut butter as glue, make a face using raisins and a small 'smile' of celery.
- Again, using peanut butter as glue, give the ladybug snow-cap spots.
- **PARENTS:** With the tip of a knife, poke 2 small holes in the apple above the ladybug's eyes and insert one carrot shred into each hole for antennae.

Remember: Adults should do all of the cutting. Let the kids have fun decorating! This activity can be found at www.VeryBestKids.com.



JOKES TO SHARE

What do you call a camel with three humps?

Humpheyl!

How did the skunk phone his mother?

On a SMELL-ular phone!

Who earns a living by driving customers away?

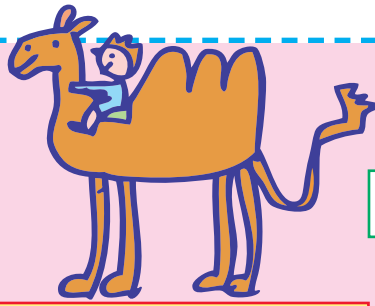
A taxi driver!

What starts with 'e' and ends with 'e' and has one letter in it?

An envelope! (one letter...get it?)

How many feet are in a yard?

It depends on how many people are standing in it.



FEELINGS ACTIVITY



1.

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

2.

Color the pictures using these colors to show how each person feels.



Mad



Happy



Embarrassed



Bored



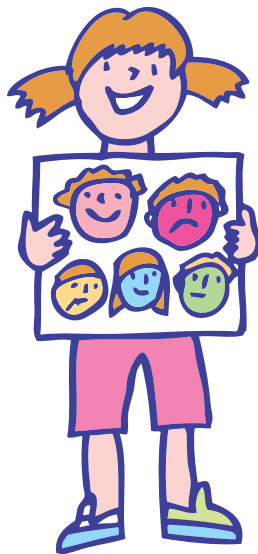
Sad



Scared

3.

Show your drawing to your family and talk to them about the feeling colors you used.



Having a mom or a dad with MS can be tough. Talking about feelings can help everyone feel a little better!



ISSUE #11
Keep
S'myelin
FEELINGS

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

THINGS
THAT MAKE ME HAPPY...



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KEEP S'MYELIN

PARENTS' PULL OUT

How to Read This Issue of Keep S'myelin with Your Kids

Talking with your children about their feelings can be a real challenge, particularly when your own feelings are running strong. This issue of Keep S'myelin is designed to give you and your children ideas and opportunities for recognizing and sharing feelings about MS.



As you read the feature story, you might try peeking in your backpacks together to compare the kinds of feelings you find inside. Are everyone's feelings pretty much the same—or are they very different? The **Feelings Activity** gives all of you a great opportunity to talk about how feelings look—and sound. How do we know when others are feeling happy, sad, scared or cranky?



The **Keep S'myelin Kids** helped Ben figure out a way to work around his mom's fatigue—he and his mom could shop online for a new backpack.

Brainstorming together about ways to outsmart MS can become a new kind of family game that lifts everyone's spirits.

Sharing the jokes is a wonderful way to remind yourselves that laughter is good medicine.



RESPONDING TO YOUR CHILDREN'S FEELINGS ABOUT MS



Everyone in the family is likely to have feelings about MS—the most common being anxiety, anger, sadness and guilt. One of the biggest challenges for families is that each person will experience these reactions at different times and in different ways. You may sometimes find it very difficult to deal with your children's feelings about MS at the same time that you're trying to deal with your own. It will help all of you to keep in mind that these feelings about MS are normal reactions to the kinds of changes that the disease brings to people's lives. Talking about these feelings can ease the way for all of you.

ANXIETY is a common response to uncertainty and unpredictability—the hallmarks of MS. While you

are worrying about how you will feel from one day to the next, your children are likely to be worried that you will die or not be able to take care of them. You can respond to their fears by reassuring them that MS is not a fatal disease, that you will always take care of them and that the family will work together to meet the challenges MS may bring.

ANGER is a natural reaction to feeling out of control—to not being able to have our own way. MS can certainly disrupt people's plans, create obstacles and change the usual way of doing things. Children get angry when their parent can't do everything he or she used to do, or when they have to take on more responsibilities than some of their friends. It helps to share your own feelings of

loss and frustration and work together to come up with creative solutions to the problems.

SADNESS is part of adjusting to change and loss. It's important for parents and children alike to grieve over any changes that MS brings to their lives. Healthy grieving lays the groundwork for coping, adaptation and shared problem-solving.

GUILT is a feeling often experienced by parents with MS who are worried about disappointing their loved ones—about not holding up their end of the bargain. Children tend to feel guilty about their angry feelings—at their parent with MS or perhaps at God for letting this happen. Guilt can also result from their mistaken belief that they have somehow caused the MS or made it worse. Talking together about guilt can go a long way toward relieving this uncomfortable feeling and helping put the anger where it belongs—on the MS rather than on oneself or each other.

People—adults and children—vary in how much and how often they express feelings. It's important to keep

PARENTS' PULL OUT

in mind that feelings can be expressed in many different ways—through words, body-language, behavior, eating and sleeping habits, and so on. One child may be quite out-spoken while another shows his or her feelings in a more roundabout way. Your best strategy for finding out about your children's feelings may be to talk about some of your own. This gives you the opportunity to share ideas for helping yourselves and each other with the feelings that can be part of life with MS.

Parents sometimes worry that talking about their own feelings will place a burden on their children. The fact is that talking often relieves the burden rather than creating one. Children are acutely aware of their parents' feelings. In fact, young kids tend to describe MS as "a disease that makes people cranky." Sharing feelings helps kids understand why a parent is behaving a certain way and relieves their worries about being the cause of the parent's distress. And being able to talk about some of their feelings may help parents feel less cranky!



RESOURCES

Here are some wonderful resources for you and your child. Talking about what you hear and read can help start discussions about the feelings you and your child have about MS.

TIMMY'S JOURNEY TO UNDERSTANDING MS

Timmy's Journey is an animated cartoon that shares a little boy's adventure learning about MS. David Lander is the voice of Captain Kip S'myelin, Timmy's guide on his journey. The cartoon is an excellent resource to talk with children about MS. Developed for children ages 5-12, but appropriate for all ages.

SOMEONE YOU KNOW HAS MS: A BOOK FOR FAMILIES

For children ages 5-12. This story about Michael and his family explains MS and explores children's fears and concerns. Adapted by Martha King from original material by Cynisse Jaffee, Debra Frankel, Barbara LaRoche, and Patricia Dick.

WHEN A PARENT HAS MS: A TEENAGER'S GUIDE

For older children and teenagers who have a parent with MS. Discusses real issues brought up by real teenagers. By Diane O'Connell with the Programs staff of the National MS Society.

To request your **FREE** copies of these materials or to learn more about the family programs available at your chapter, please call 1-800-344-4867.

PARENTS' PULL OUT

How Can You Subscribe to Keep S'myelin?

Call 1-800-344-4867 and ask to be added to the *Keep S'myelin* mailing list. IT'S FREE! You can also email us at keepsmyelin@nmss.org. Please be sure to include your name and mailing address.



If your child is submitting something to *Keep S'myelin*, be sure to include your **NAME, ADDRESS and PHONE NUMBER.**



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