



Keep S'myelin

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 probably makes you feel mad, 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 like to do fun things together.



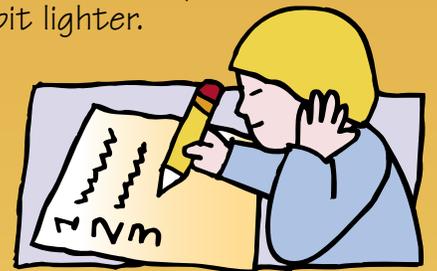
Sometimes the hardest thing about feelings is **sharing** them with others, but talking about feelings can be helpful. It can make you feel better and bring you closer to people you care about and let them know what some of your worries might be.



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.

Making a list of your feelings can help you see what

- you are carrying in your feelings backpack. You can do it.
- You can do this in your head, on a piece of paper, or in a poem or drawing. You can also try the 'Feeling Buddies' activity in this issue of Keep S'myelin. Then you can share your list with someone you trust—like your mom or dad. This will help make your feelings backpack feel a little bit lighter.



Find someone:

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

(Continued on page 2)

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.

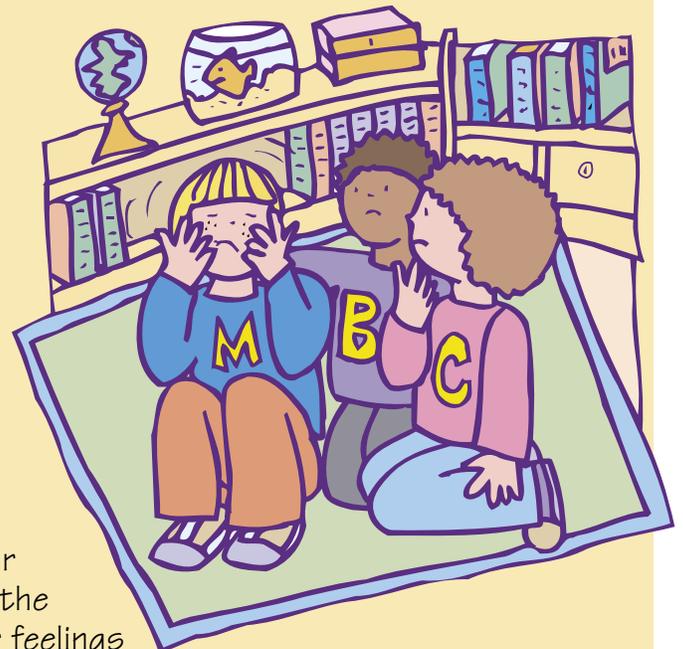
Interesting Fact:
Multiple means many. Sclerosis means scars. So, multiple sclerosis means "many scars."

(Continued from page 1)

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.

Talking about your feelings is the best way to learn more about yourself and find help for your worries, so 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 alone or strange, and you're 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.

things easier for her. We go to her doctor's as a family sometimes. Her doctor is so cool. He always sits down with us to make sure we understand what is happening to her body. 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

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 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.



questions. My mom's faith in God and her doctor are strong. That makes me feel there is hope always.



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

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, they 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



POEM
 BY
KRISTEN

Age 12, Winter Garden, Florida

There's no doubt,
 No need to shout,
 My mom's the best,
 Even with MS.

She gets through her
 days,
 In so many helpful ways.
 I still love my mom,
 No matter what is wrong.

I won't let MS
 Make me love her less.
 She's still the best
 out of the rest.

She's my mom!

JOKES

What do you call a camel
 with three humps?
 Humphrey

How did the skunk
 phone his mother?
 On a SMELL-ular
 phone!

What starts with
 'e' and ends with
 'e' and has one let-
 ter in it?
 An envelope! (one
 letter..get it?)

How many feet are in
 a yard?
 It depends on how
 many people are
 standing!

Who earns a living
 by driving customers
 away?
 A taxi driver!

PICTURE

BY

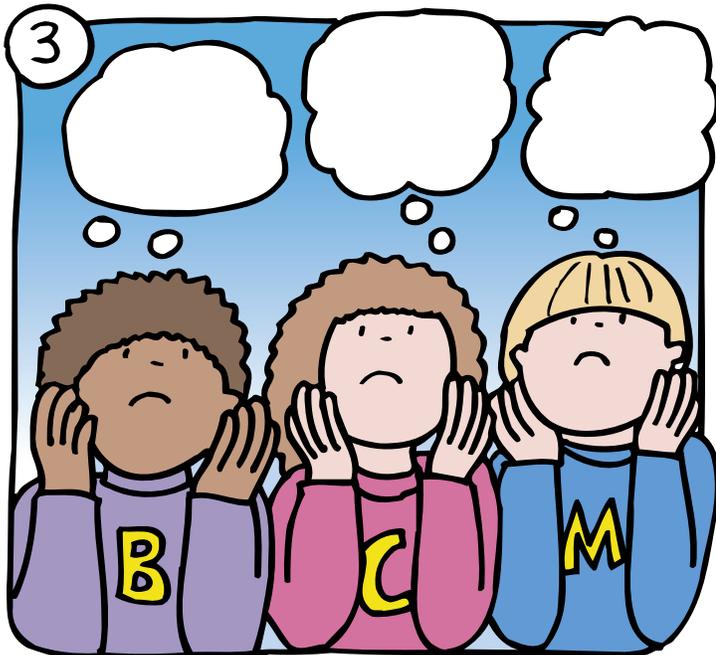
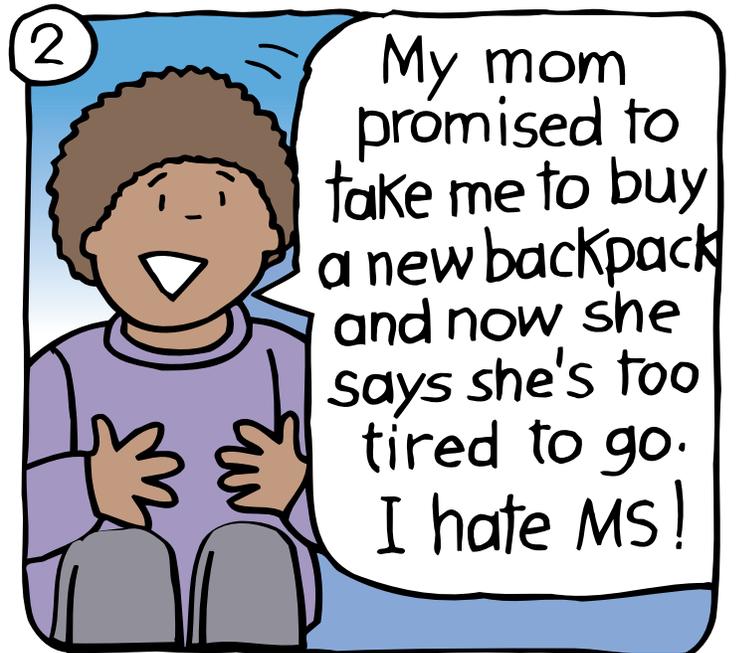
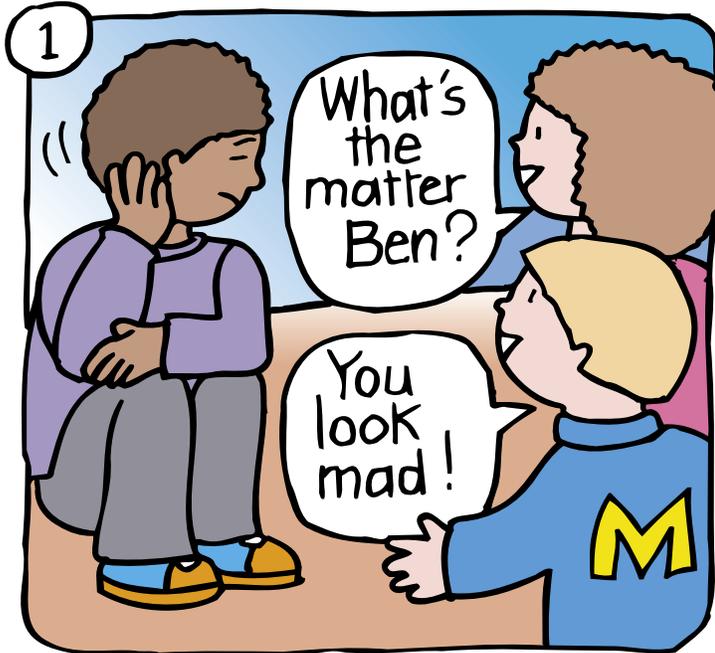
Sarah



This is a picture of Sarah's family snorkeling in a river

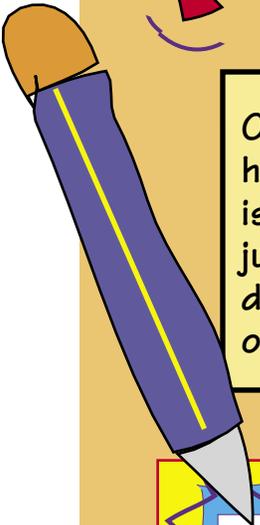
Sarah is six years and in first grade.
She likes to read, draw, dance ballet and tap,
camp, snorkel, swim, and play with dolls.

MICHAEL CRYSTAL AND BENJAMIN
S'MYELIN KIDS



FEELING

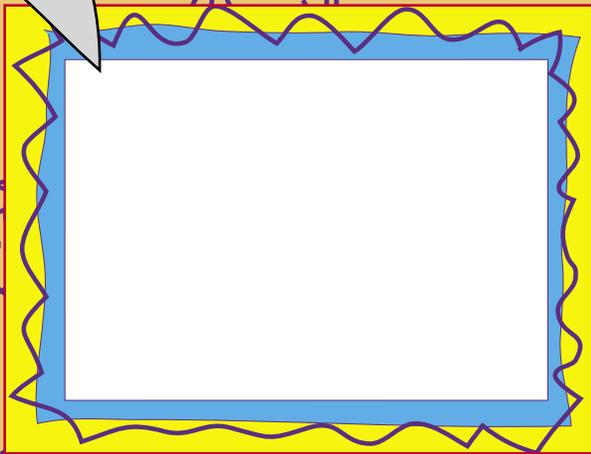
BUDDIES



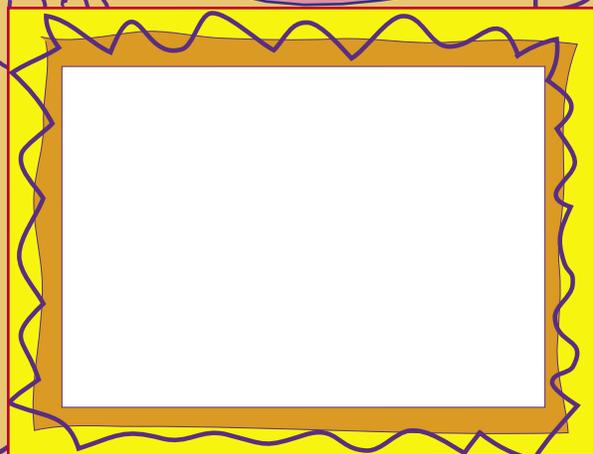
Our faces can look different when we are having different feelings. Sometimes it is easy to see how someone is feeling just by looking at their face. Feeling buddies can help you learn more about your own feelings..



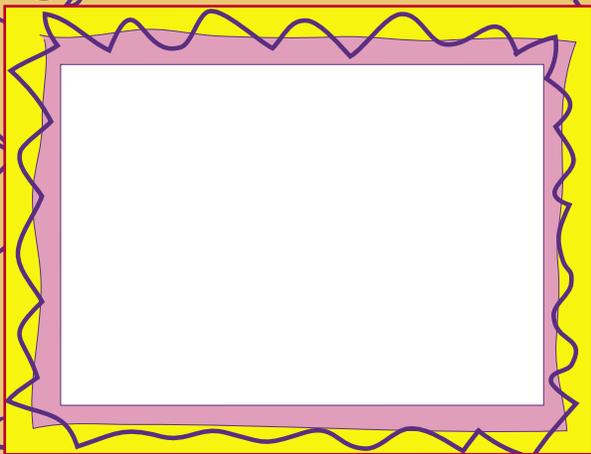
Draw a face that matches the feeling below the picture.



ANGRY



HAPPY



SURPRISED

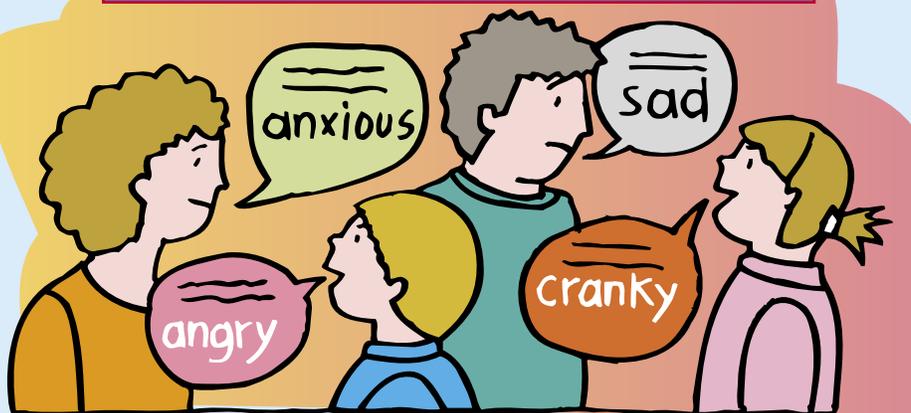


WORRIED

Keep S'myelin

PARENTS' PULL OUT

HOW TO READ THIS ISSUE with Your Children



Talking with your children about their feelings can be a real challenge, particularly at those times when you may be feeling overwhelmed by your own. 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 *Feeling Buddies* give all of you a great opportunity to talk about how feelings look—and sound. How do

we know when others are feeling happy, or sad, or scared, or cranky? The KS 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 for everyone in the family.



And you might want to look back at our issue about TOOLS that can make life easier (<http://www.nationalmssociety.org/keepsmyelin/index.html>).



RESOURCES

Here are some wonderful books about feelings that you can read together with your child. Talking about the characters in the book and how they are feeling can help start a discussion about the feelings you and your child have about MS.



Eric Carle: **The Grouchy Ladybug**



Judith Viorst, Ray Cruz (illustrator): **Alexander and the Terrible, Horrible, No Good, Very Bad Day**



Dr. Seuss and Steve Johnson and Lou Fancher (illustrators): **My Many Colored Days**



Jamie Lee Curtis and Laura Cornell (illustrator): **Today I Feel Silly: And Other Moods That Make My Day**

RESPONDING TO YOUR CHILDREN'S FEELING 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 them can ease the way for all of you.

Molly Garrett Bang: **When Sophie Gets Angry-Really, Really Angry ...**



Saxton Freymann and Joost Elffers: **How Are You Peeling?: Foods with Moods**



Anne Miranda and Ed Emberly (illustrators): **Glad Monster, Sad Monster: A Book About Feelings**



Aliki: **Feelings** (A Reading Rainbow Book)

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, you 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 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

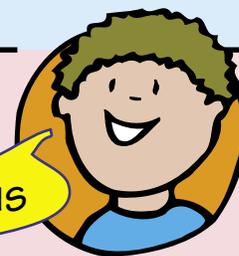
uncomfortable feeling, and helping put the anger where it belongs—on the MS rather than on oneself or each other. People—adults and children—vary in how much and how often they express feelings. It's important to keep in mind that feelings get expressed in many different ways—through words, body-language, 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 round about way. Your best strategy for finding out about your children's feelings may well 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, however, that talking often relieves the burden rather than creating it. 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!

How can you subscribe to Keep S'myelin?

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.

ACTIVITY

TASTY BUGS



SNAIL



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

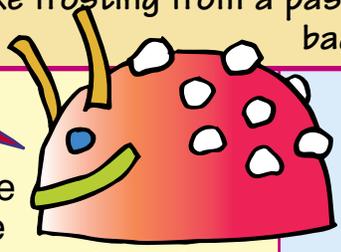
- ❁ Apples
- ❁ Celery
- ❁ Shredded carrots
- ❁ Creamy peanut butter
- ❁ Safety scissors
- ❁ Kitchen knife
- ❁ Raisins, Snow-caps
- ❁ Sealable plastic sandwich bag

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 into the corner of the bag and use to dispense peanut butter like frosting from a pastry bag!

- ❁ Cut a vertical slice from the whole apple just missing the core
- ❁ Cut a celery stick about 1 inch longer than the width of the apple slice
- ❁ Fill the trough of the celery stick with peanut butter
- ❁ Using the "pastry bag" draw a spiral on both sides of the apple slice
- ❁ Wedge the apple slice into the filled celery stick
- ❁ Decorate the snail's shell with raisins
- ❁ Add two raisins to one end of the celery stick to make eyes
- ❁ Add carrot shreds for antennae.

LADYBUG



- ❁ Cut apple 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

You can e-mail us at:
keepSmyelin@nmss.org
 Keep S'myelin on the web is made possible through an unrestricted grant from Berlex.Inc

 KEEP S'MYELIN is now available on line at www.nationalmssociety.org

(Remember: Adults should do all of the cutting. Let the kids have fun decorating!)

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This activity can be found at www.VeryBestKids.com



ISSUE #11
Keep
S'myelin

FEELINGS

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



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** and funded by a grant from our **Gateway Area Chapter**. 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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*The mission of the
National Multiple
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end the devastating effects
of multiple sclerosis.*