

Keep Smiling

A NEWSLETTER FOR KIDS ABOUT MULTIPLE SCLEROSIS

ABOUT MS AND FEELINGS

From time to time, people with MS may feel sad or cranky or angry about having MS. You may feel cranky or sad



or angry too, about having MS in your family. Nobody likes MS, but there are lots of ways you can deal with your feelings.

First, try talking to your mom and dad about how you feel about MS. They can help you understand your feelings and reassure you that it's OK to be angry or frightened or confused about MS. Second, find other grown-ups you like to talk to... people you trust and who make you feel good just by



being with them. It might be your teacher, your neighbor, your aunt or uncle or someone else!



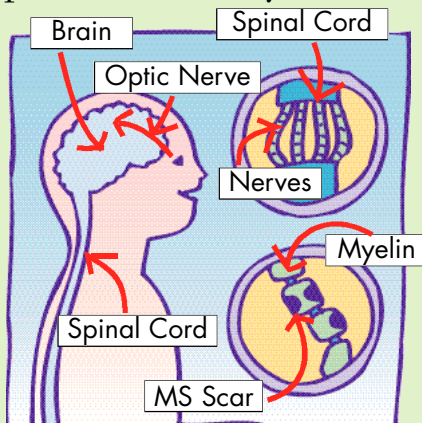
You will find that sharing your feelings with others can help to make you feel better! Also, find activities that are fun for you to do, like sports, arts

and crafts, games, walking your dog or playing with friends. These are fun ways to use your energy, and having MS in your family doesn't mean you can't have fun!

The most important thing to remember is that having MS doesn't change one very important thing about your family at all—your mom or dad will always love you and keep you safe. They want to know when you are curious, worried, or scared, and they want you to feel OK about having feelings about MS.

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,

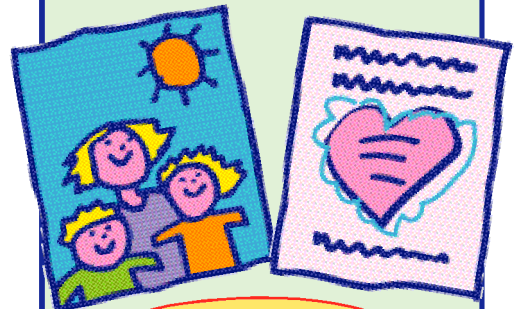
the other parts of the body can't always do what the brain is telling them to do.

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, and interviews 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.



HAVING A DAD WITH MS IS UNIQUE!

by Galen, age 10

Most kids have dads that are able to do most things themselves. They can play sports with you. They don't have to go through special elevators in stores—they can just go up the stairs, but not my dad. He has a disease called MS that affects the nerves so he can't walk. I will tell you some advantages and disadvantages that make having a dad with MS unique.

One of the disadvantages is I have to do things other kids may not have to. Some of them are minor jobs like putting on shoes and going up and down stairs to get things—those are easy. But it also requires a lot of responsibility and patience. For example, about a month ago I was really interested in a book and my dad asked me to help him plug things in; I said yes expecting it to take only a few seconds, but it took 30 minutes!

On the other hand there are some advantages. I get to ride/drive his wheelchair, go on special lifts, get special attention, and cut through long lines in airports and such. When this happens people look at us. Sometimes this makes me feel uncomfortable when all the people see us go to the front of the long lines, but it also makes me feel that my dad really is unique.

Although I get to do cool things like ride his wheelchair, this also means that he can't play sports with me. It is not only being able to play sports with me but people talking about playing sports with their dad. Once my second grade teacher said to the class, "the next time you play catch with your dad, do an underhand pitch like you learned in gym." And I thought "my dad can't play catch with me." Even though my dad can't play sports with me he is a great soccer coach and he gives really good advice.

Even though my dad is different and has different needs, it doesn't affect how I act. Some people think they should feel sorry for him, but he is my dad—a kind, loving person who takes care of me and does fun things with me and that's all that matters.

Galen



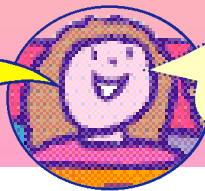
FUN AND GAMES

Can you find these feeling words?

HAPPY
PROUD
SILLY
SCARED
HURT
BOLD
GLAD
SHY
MAD

H	S	R	M	B	C	F	E	S
A	M	M	U	O	E	R	R	I
P	I	N	G	L	A	D	O	L
P	L	U	L	D	H	I	U	L
Y	E	P	R	O	U	D	O	Y
O	S	P	T	L	R	E	H	M
L	H	R	I	E	T	N	A	A
F	Y	O	P	S	E	T	P	D
S	C	A	R	E	D	T	S	D

**BONUS
SCORE!**



Find the hidden word!

Hint: When I feel happy, I _____

FEELINGS GAME

DIRECTIONS

- Cut out the Feelings Faces.
- Mix up the cards and lay them face down.
- Begin by turning over two cards to try to make a match.
- If the cards DO match, set that pair aside until the game is over. Take another turn.
- If the cards do NOT match, turn them back over. Now it is the next player's turn.
- Continue to take turns. The game ends when all the faces have been matched and there are no more cards to turn over.

Have fun!



COLOR ME

Sometimes MS makes my mom drop things.
She gets mad at MS. She's not mad at me.



FOR YOU TO SHARE WITH OTHER KIDS



We know you like to hear what other kids think and feel about MS. Your answers to the questions below could show up in the next Keep S'myelin.



Send to: KEEP S'MYELIN
National Multiple Sclerosis Society
700 Broadway, Suite 810
Denver, CO 80203
or Fax: 303-813-1513
or email keepsmyelin@nmss.org.

1. What questions do you have about MS?
2. How would you help other kids deal with their feelings about MS?
3. Who do you talk with about MS? Why do you choose that person?

My name is _____ My age is _____

My address is _____
Street City State Zip

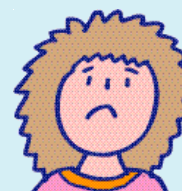
My phone number is (_____) _____
area code

KEEP S'MYELIN

PARENTS' PULL OUT



FEELINGS



This issue of Keep S'myelin is all about feelings. As you share the stories and activities with your children, you might want to reflect on some of your own feelings and help your kids identify theirs. This is a chance to share and compare.

Kids sometimes have a hard time giving a name to their feelings or knowing what's making them feel upset or cranky. Perhaps Galen's story will give them some ideas about the feelings they are having. They might even want to try making up a story of their own using the feeling words they find in the word search.

You may find that reading and talking about feelings is difficult for you—

that you become teary or upset. Keep in mind that it is OK for your children to see your feelings. When you show feelings and talk about them, you are modeling ways for your kids to deal with their own uncomfortable feelings.

If either you or your children are having a very difficult time dealing with feelings about MS, remember that your chapter of the National MS Society can provide you with names of mental health professionals in your area.

Parents and children living with MS may be surprised to discover they have happy feelings as well as sad or angry ones. It's just as important to share the positive feelings as the more painful ones.

Perhaps you feel proud of your own ability to problem solve and meet the MS challenge, or of your children's increased sensitivity to the needs of people with disabilities.

Maybe you've shared some special cuddle times during those all important rest periods, or found that having to slow down a bit has allowed you to talk more with one another. You may even find that your family is able to enjoy some special jokes about life with MS—jokes that no one else could appreciate in just the same way! Don't forget to make the most of this lighter side of life with MS.



*Laughter
is good
for
everyone.*

RESPONDING TO YOUR CHILD

You have feelings about having MS. Your children have feelings about MS, too. Some kids will let their parents know about their feelings. Other kids tend to keep their feelings to themselves. Every kid is different.



Children notice your feelings.

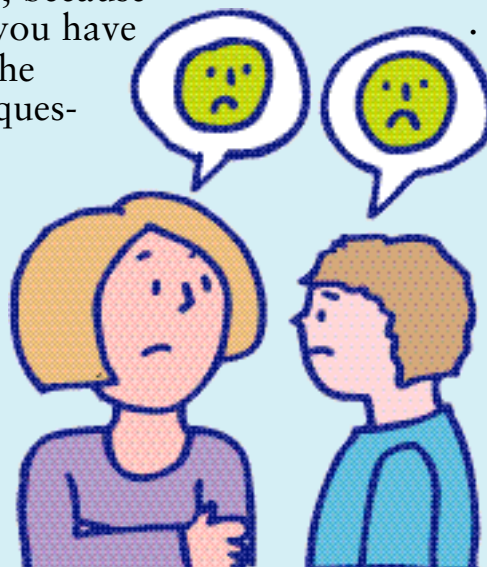
Kids sometimes think MS is a disease of crankiness. For adults with MS, there's certainly plenty to be cranky about! Explain to your child that you are grouchy or cranky because MS makes you feel tired or uncomfortable, but that you are not angry at him or her. You might also say that you are working at not being so grouchy. This might be a good opportunity to talk about MS symptoms with your child.

Children who have a parent with MS may see their family as different from their friends' families.

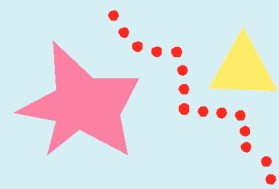
They may have more chores and responsibilities than their friends. The parent with MS may need more assistance than the parents of their friends.

Although for the most part these differences are taken in stride, kids will often say that it's "unfair" that it's their mom or dad who has the MS, and "why couldn't it have been someone else's mom or dad?" It's not that easy for parents to respond to these questions, because it's likely that you have struggled with the same kinds of questions!

You can let your child know that it's natural to feel this way and that you feel the same way too. If you found an answer that works for you, consider sharing it with your child. If not, you might affirm that you don't like having MS in your family either, but that MS is a part of your family's life. Reassure your child that by working together, your family is coping with life with MS.



CHILD'S FEELINGS ABOUT MS



Kids' fears regarding their parent's MS may be very different than their parents' fears.

Kids tend to apply what they know about other illnesses to MS. They have heard about people dying from illnesses like heart disease and cancer. It's natural for them to be afraid that you will die from MS. They might apply other aspects of illness as well, and worry that MS is contagious, like chicken pox, or the flu. It's important to encourage your child to tell you when he or she is afraid or concerned about MS.



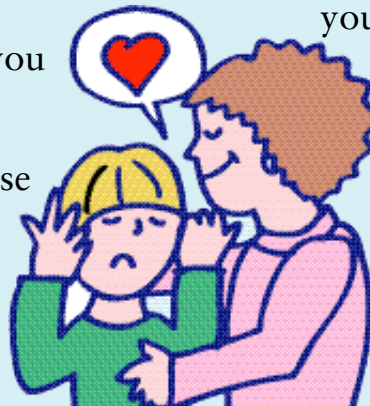
Children often become angry when things don't work out the way they would like.

Experiencing and learning to manage anger are part of growing up. It is natural that your child will be angry that you have MS. Young children may sometimes direct this anger at you. Although this may hurt your feelings, you can help your child direct his or her anger at the disease by sharing your own feelings about MS. You might explain that it makes you angry when MS interferes with the things you want to do. Rather than fight against your child's anger, try to join with your child.



Most parents wish to protect their children from their own sadness.

It is likely that there are times when your child feels sad about it as well. When your child feels sad about MS, try to acknowledge the feeling, and let him or her know that it is okay. Sometimes kids just need to feel sad for a while. You don't need to try to fix things, provide a distraction, or cheer him or her up. It is helpful for your child to know you are there.



KEEP S'MYELIN is available on line at www.nationalMSSociety.org
You can e-mail us at: keepsmyelin@nmss.org

LET'S
MAKE...



Ants on a Log

Cooking can be a family project that brings everyone close together and can be a special time of learning for children of all ages. Children can learn organization, healthy eating habits, safety, and most importantly, independence. Here is a recipe your family might like to try.

What you need:

Celery stalks, Peanut butter, Raisins

Preparation:

- Wash the celery stalks thoroughly.
- Cut the ends off as needed.
- Peel the celery for younger children.



With a spoon or a safe butter knife, spread the peanut butter into the celery stalk. Place raisins in a row on top. You may want to put other things, like yogurt-covered raisins, or fill the celery with other healthy spreads. Just be sure to have fun! Cut the stalks into bite size pieces and chew carefully.



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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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:
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National Multiple Sclerosis Society

ISSUE #2
Keep S'myelin
ABOUT MS and FEELINGS

Contact your National MS Society chapter at 1-800-344-4867.

JOKES and RIDDLES

HA! HA!

What did the ocean say to the shore?
Nothing, it just waved.

You're a bus driver. At the first stop 4 people get on. At the second stop 8 people get on, at the third stop 2 people get off and, at the fourth stop everyone gets off. The question is -what color are the bus driver's eyes?
The same as yours, you're the bus driver.