Writing about MS in your family, or drawing pictures that tell a story about MS in your family, are great ways to share your ideas and feelings.

You don’t have to be an artist, poet or author to draw, write and tell stories.

Share your work with your parents or other grown-ups, such as your teacher, an aunt or uncle… They want to learn how you feel about MS. Sharing your work gives you a chance to talk over things that might be confusing, or that might be funny, sad or frustrating. Sharing may make you feel better too!

Most of the articles, drawings, and stories in this issue of Keep S’myelin were written by you. Thanks for sending us your wonderful work. If you would like to write a story or poem for Keep S’myelin, please send it to:

Keep S’myelin, National MS Society
Broadway Station
900 South Broadway Suite 200
Denver CO 80209

We look forward to your stories, poems, and drawings.
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
Ten years ago, my father was diagnosed with multiple sclerosis. Back then when I was only four or five, it wasn’t too bad. But now, as the days and years go by, my father’s legs are hardly able to balance him anymore, his eyesight is not great, his writing is sloppy, and at times he even gets tired of thinking!

Each of my family members plays a different role in helping to make our family life better. I have taken the responsibility of entertaining my father! I play soccer and my father loves the sport as much as I do! My mother takes the role of being my father’s legs. Whenever my father needs something, she does the walking. My sister, Laura, plays the role of thinker. My father always had a lot of ideas and thoughts. When Laura comes home from college, she does some of the thinking jobs that are harder for him now. My brother, Patrick plays the laborer. He has the physical strength to do all the jobs that require the hard work.

Finally, my father’s role on our team is team leader. He is the strongest member of the team. He’s always there when you need him. He taught us how to have a positive attitude and appreciate the good life.

Having MS in our family has taught us things that nothing else could ever teach us. I am lucky to be a part of such a meaningful team—my Dad’s team.

Teamwork is something that all children and teens need to experience. I have had chances to try teamwork in school and in sports and it has given me a boost in life. But the one team that means the most to me is my family. In my eyes, we work together better than any other family.
My mom is my hero,
My mom is my best friend
My hate for her is zero
My love has no end.

My mom has MS,
For it, there is no cure.
Sometimes she doesn’t seem so sure
To do the things she did before.

She has to use a cane,
Maybe a walker too,
but she always perseveres
Until the hard times are through.

My mom may not be able to ski,
Or go on trips to the mountains with me.
But she shops, she listens, and plays,
Draws, sews and puts away,
Sings, fixes, cooks and bakes,
Plans trips to lakes,
Helps, finds, laughs and smiles,
I could go on for miles and miles.

My mom has MS.
It comes with pain.
Sometimes her steps falter,
But she always gets up again.

I love my mom.

by Emily (age 12)
We Asked... You Answered...

Who do you talk with about MS? Why did you choose that person?

Sometimes my mom. Because it might offend my dad because that is the person who has it in my house.

Katie (age 6)

I talk about MS with my mom and my dad because my mom is the one who has MS, and my dad and my mom because they are very close to me.

Colleen (age 8)

My Mom. I really do love my mom! She got MS when I was about 5. I thought she was going to die at first, but then she said she wasn’t. She has pains in her neck every once and a while, and has to go somewhere else. When we go to the mall, or on a walk, she uses a cane or walker. Sometimes it’s hard because she can’t go skiing and stuff, but I still love her.

Giana (age 8)

I talk with my grandma. I choose her because she has MS.

Katherine (age 10)

Sometimes my mom. Because it might offend my dad because that is the person who has it in my house.

Katie (age 6)
We asked our readers: "How would you help other kids deal with their feelings about MS?"

You sent us lots of very good ideas. Here are some of your replies.

Our readers are really smart!

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Our readers are really smart!

Here are Some Tips for You!

I would tell other kids: "Don't be afraid of MS (your parent's or anybody's). They are still regular humans!"
CR, Pennsylvania

I would tell them that I deal with the same feelings.
TS, Wisconsin

I would tell other kids: "Don't be afraid of MS (your parent's or anybody's). They are still regular humans!"
CR, Pennsylvania

I would just say that you have to love your parents whether they have MS or not!
BM, Wisconsin

I would talk to my friends about it and ask them how they feel.
DD, South Carolina

I would say they should not worry. It will be OK.... Well, they can worry a little bit, but not too much!
SA, Ghana, West Africa

I would say: "Let out your feelings! And exercise!"
TR, New Jersey

I would say: "Just be happy and make sure you always love the person with MS!"
MS, Oregon

I would help my friend by saying, "It will be OK, my friend."
AH, California

I would write to Keep S'myelin and ask questions so they can feel more comfortable!
KH, Ohio

I would tell them to try to forget it's there most of the time. But don't put it totally out of your mind at all times, because your mom or dad still needs your help!
SM, Pennsylvania

We asked our readers: "How would you help other kids deal with their feelings about MS?"

You sent us lots of very good ideas. Here are some of your replies.

Our readers are really smart!
Here is a list of words that have two meanings. You can use these or other words to make up your own jokes or try some other words. Go ahead! Tickle your funny bone.

Keep S’myelin wants to hear from you. Send us your favorite jokes so we can include them in our newsletter. Or create your own new jokes and share them with us.

POEM

My mom is sweet.
My mom is neat.
My mom has MS.
Her younger kid is Tess.
I really think I have a mom
Who can't be beat!

Shane (Connecticut)
8 years old

Here is one way to write your own "play on words" jokes.

Some jokes start by using a word or phrase that has two different meanings. Here are some tips for writing your own “play on words” jokes.

1. Find a word or phrase with two meanings. Example: Digs rock


3. To make your joke, ask why the two things are like each other. Example: Why is a bulldozer like a musician? They both dig rock.

Try This

Here is a list of words that have two meanings. You can use these or other words to make up your own jokes or try some other words. Go ahead! Tickle your funny bone.

PEN
BILL
DUCK
SAW
RING

COW JOKES

Q: Why do cows have bells?
A: Because their horns don't work.

Q: What do you call a scared bull?
A: A cow-ard.

Q: What do cows get when they are sick?
A: Hay fever.

Q: Why does a milking stool have only three legs?
A: Because the cow has the udder.

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PEN
BILL
DUCK
SAW
RING
This girl just found out that her dad has MS. What would you do?

What would you do?

It's very hot out and this dad with MS has been out in the yard for a very long time. What would you do?

Please send us your answers!

Keep S'myelin
National MS Society
Broadway Station
900 South Broadway
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This issue of Keep S’myelin is filled with stories by children who have a parent with MS. Their stories reflect the variability of the disease itself, providing you with the opportunity to remind your child(ren) that every person’s MS is different. Regardless of their parents’ disability the message from these young authors is clear: Mom or Dad is there to love and take care of them.

As you read and talk about this issue, you and your child(ren) might want to draw pictures of your own family and the special things you like to do together.

This is a good opportunity to talk about your own symptoms and the ways you and your family have adapted to the changes MS has brought into your lives. Natalie’s story about her family’s teamwork may suggest ways for each member of your family to be an active player on your MS team.

You may find yourself startled—or even hurt at times—by your child(ren)’s reactions to your MS. They may laugh at a symptom, get angry about your inability to do something, or simply act as though there’s no problem at all. In other words, their feelings may seem to be totally out of sync with your own. The stories in this issue offer the opportunity to talk with your kids about how you all might be feeling. This is a great way to share feelings and worries about MS, see things from different perspectives, and remind yourself and your children that everyone’s feelings are unique.

You may worry that MS-related reading materials or educational programs will be too frightening for your children. You may be reluctant for your children to see or hear about people with MS who have different symptoms or are more disabled. We hope that this issue of Keep S’myelin will help you feel more comfortable with the idea of meeting and sharing experiences with other families who are living with MS.
A Fun Family Activity:

INVISIBLE INK

Write a secret message to a friend or family member! It’s very easy. Here’s how to make your own invisible ink.

What you need:

• Juice of one fresh lemon
• A thin paintbrush
• White paper

Directions:

1. Squeeze the juice from one fresh lemon. (Children may need the help of an adult.)
2. Dip the paintbrush in the lemon juice and write your message.
3. To read it, hold the paper near a light bulb or place it out in the sun. Your message will appear as brown writing.
• KEEP S’MYELIN: An Activity Book About MS for Kids is a 20-page booklet to help parents and their children talk and learn about MS together. The book features information on a variety of MS related topics such as, what is MS, who treats people with MS, feelings, and communication strategies, along with games and activities. (Available in English and Spanish.)

• SOMEONE YOU KNOW HAS MS: A Book for Families(*), a booklet for children, ages 5-12. A story about Michael and his family explains MS and explores children’s fears and concerns. Adapted by Martha King from original material by Cyrisse Jaffee, Debra Frankel, Barbara LaRoche, and Patricia Dick.

• TIMMY’S JOURNEY TO UNDERSTANDING MS Timmy’s Journey is a 15-minute cartoon featuring a young boy named Timmy and his trusted guide, Captain Kip S’myelin. When Timmy becomes frustrated by his dad’s MS, he is visited by his new friend, Captain S’myelin, who takes Timmy on an exciting trip through the human body to learn about MS. Through this journey, Timmy gains a better understanding of MS and becomes more accepting of the unpredictability MS can bring. (Available in English and Spanish.)

• PLAIN TALK: A Booklet about MS for Families(*) discusses some of the more difficult physical and emotional problems many families face. By Sarah Minden, MD, and Debra Frankel, MS, OTR

• WHEN A PARENT HAS MS: A TEENAGER’S GUIDE(*) A publication 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 these free National MS Society resources please call 1-800-344-4867. Publications identified with an* are available for download at www.nationalmssociety.org/multimedia-brochures.
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.

The National Multiple Sclerosis Society does not endorse products, services, or manufacturers. Such names appear here solely because they are considered valuable information. The Society assumes no liability whatsoever for the contents or use of any product or service mentioned.

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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:
National MS Society
KEEP S’MYELIN
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keepsmyelin@nmss.org