Living with MS brings changes to every member of a family. Some changes may be big; others may be small. Some changes are easy to deal with. Others are harder and take longer to get used to.

Because MS is different for each person that has it, different families deal with different changes.

Many times, family members take on new responsibilities because of MS. For example, maybe you’ve had to do more chores since your mom or dad got MS. Maybe your dad has started doing the laundry because your mom is so tired from the MS. Or maybe your grandmother takes you to school because your dad is not able to drive anymore.

Each person in a family reacts in his or her own way to the changes MS brings. Be honest about how you are feeling. Whether you feel confident, sad, angry, or confused, it is important to share your feelings with your family, a teacher, or a good friend.

Your family members are able to love and support you whether or not they have MS. Remember, having MS in your family can strengthen your love for one another. Show it and share it.
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.”
My mom has had MS since I was ten. I always wished that my mom didn’t need to use a wheelchair. I didn’t want my family to be any different than those of my friends. I just wanted a healthy mother who could do all the things that my friends’ mothers could do—drive me places, chaperone field trips, cook big dinners. (Of course, my mother will never win any cooking awards no matter what, but that’s another story!)

However, I now realize that everyone has something a little bit different about his or her family. When my prom date, Carrie, was going to meet my mom for the first time, I said casually, "By the way, my mother has MS and uses a wheelchair." She smiled at me and replied, "Oh really? Well, my dad’s blind!" We both laughed because we each felt a little awkward at first, but then realized it wasn’t that big of a deal. We each wanted the other to feel comfortable. If you don’t make a big deal of it, your friends won’t either.

Your friends will want you to feel comfortable when you talk to them about your parent’s MS. I’m sure that you’d want your friend to feel relaxed if he or she was confiding in you about something personal. Some friends asked me questions about MS (most kids don’t know exactly what it is), but others didn’t know how to ask me about it. I learned that both responses were normal.

There’s no right or wrong way to talk to your friends about your parent’s MS. Just do it when you feel ready. Once you tell a good friend or two, you’ll have someone else you can talk to. And that’s a nice thing.

Either way, it’s normal if it feels a little weird telling your friends about your mother or father having MS. After all, it’s a very grown-up topic to talk about.

I didn’t always know how to tell my friends about my mother’s illness. I felt strange talking about it because it’s not something that just comes up while you’re chatting about the latest movie or school project. Sometimes I would tell my friends and other times I chose not to tell until they met my mom for the first time.

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We asked, You Answered...

**HOW WOULD YOU HELP OTHER KIDS DEAL WITH THEIR FEELINGS ABOUT MS?**

Knock, Knock
Who’s there? Olive.
Olive who?
Door don’t open the
Olga home if you

Knock, Knock
Luke who?
and you’ll see
Like through the keyhole

Knock, Knock
Who’s there? Olga.
Olga who?
Nona (age 8)

What’s the longest word in the dictionary?
Other
mile from one b to the a
Whistles’ because it’s a

What gets wetter and wetter each time it dries?
A towel

I would help them with their problems. I would draw them a picture.
Shelby (age 8)

Make cards and home-made gifts.
Nona (age 8)

I would play with them and tell them funny jokes.
Katherine (age 10)

Ask your mom or dad questions about MS and talk to people you trust. Don’t get mad at whoever has MS because it is not their fault.
Colleen (age 8)
Family Fun Time

These are some of the fun things we do together as a family:
MICHAEL, WANT TO GO TO THE PARK WITH US TO PLAY FRISBEE?

CANT NOW. I HAVE TO FINISH CLEANING THE YARD AND THEN DO SOME LAUNDRY. I HATE HAVING ALL THESE EXTRA CHORES BECAUSE MY MOM HAS MS. OTHER KIDS DONT HAVE TO DO THIS STUFF...

MICHAEL, WHY DON'T WE HELP YOU? THEN WE CAN ALL GO TO THE PARK.

YEAH! THAT WILL BE GREAT.

MICHAEL, YOU MAY NOT LIKE IT MUCH, BUT I BET YOUR MOM FEELS REAL PROUD AND HAPPY WHEN WE HELP OUT. SHE DOESNT FEEL WELL

I GUESS ITS NOT SO BAD. ANYWAY, THIS IS GOOD PRACTICE FOR TOSSEND THAT FRISBEE!
WORDS TO FIND:

BROTHER  DAD
MOM   SISTER
PETS
MULTIPLE SCLEROSIS
LOVE     HUGS
Contact your National MS Society chapter at 1-800-344-4867.

Use the space below to draw a picture of your family.
This issue of Keep S’myelin is about families. You can use the articles and games to talk with your children about the ways MS has changed your family’s routines or affected different members of the family.

Use the cartoon about Michael and his friends as an opportunity to talk about how family members and friends pitch in to help one another. Make sure your children know how proud you are of the “extras” they do for you and around the house.

As you read Family Life and MS, encourage your children to share their feelings about MS and the changes it has made in their lives. Don’t be afraid to share some of your feelings at the same time. See if you can work together to think up some new projects or activities to enjoy. These family activities will help remind all of you that even though MS may bring some changes into your lives, you can still have family fun.

Use Jeremy’s story to talk about how it feels for your children to talk about the MS with their friends. You might even want to try a role play game to give your kids a chance to practice.

The “What is MS?” article is a good introduction to talking about your own symptoms, especially those that your children can’t easily see for themselves—like fatigue, stiffness, or vision problems.

As you laugh together over the riddles and games, see if you can come up with other ways to share laughter. Encourage your kids to make up their own knock-knock jokes about MS—or anything else—and send them to us for future issues.
It is easy to make spending time together as a family a last priority in this busy world. Work days and school days are spent with families going in many different directions. When everyone finally gets home, one parent may be checking the e-mail while another is working on laundry. The kids are off doing homework or watching TV. Does this sound familiar?

Sometimes families have to schedule time together just like all the other things that are scheduled in our lives. But the payoffs are tremendous! Set the day and time. Choose things that everyone will enjoy—a drive to a special place for a picnic, a day at a museum, or a trip to the zoo. Or try just playing cards or a game around the kitchen table with a big bowl of popcorn and some hot chocolate!

During exacerbations or if your MS progresses, you may need help from family, neighbors, or home health aides. The addition of these adults to the household can be confusing for your children, particularly if the newcomers begin to help with parenting activities. If they introduce different rules or routines, your children may wonder who is in charge. To minimize conflict, clarify with your helpers what their role with the children is to be. Whatever you decide, it is important for your children to know that you will always be the parent and that the other adults are there to help you.

At times it may feel as though you and your children have traded roles.
During an exacerbation, or if you experience long-term changes in your symptoms, you may start to depend on them to help you or manage things around the house. This kind of role-reversal should, however, be avoided as much as possible. Even though you may not be as active as other parents, it is important that you remain in the parent role. The structure and guidance you provide helps your children grow into their responsibilities gradually and gives them a sense of security.

The best strategy is to keep the household as normal as possible, while being realistic about the changes that MS may require. Children need to feel comfortable in their own home. The comfort level may drop significantly if you have a lot of medical equipment in the general living area, or if the children have no private space to see their friends. If major adjustments or home modifications need to be made, it is a good idea to include your children in planning and implementing these changes.

MS is a part of your life – it doesn’t help to ignore it or, on the other hand, to make it your main focus. A good way to achieve this realistic balance is to be honest with your children about what you need to do to manage your illness, get their ideas about how to do this, and show them that being their parent is one of the most important things that you do.

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.

Here’s a fun activity to do as a family…

The BEETLE Game

See directions on page 4
To create his/her beetle, the player must roll each number from 1-5 in order. After all, players can’t draw the eyes until the beetle has a head. The first player to put the whole beetle together is the winner!

**Roll a 1** = draw the body (a large oval).
**Roll a 2** = draw the head (a circle attached to the body).
**Roll a 3** = draw three legs on one side of the body.
**Roll another 3** = draw another 3 legs on the other side of the body.
**Roll a 4** = draw one antenna.
**Roll another 4** = draw the second antenna.
**Roll a 5** = draw one eye, another eye and a... 

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**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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