



Keep Smiling

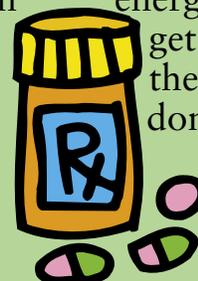
A NEWSLETTER FOR KIDS ABOUT MULTIPLE SCLEROSIS



Fatigue is another word for feeling VERY tired. Almost everyone with MS has fatigue. MS fatigue is different from just being tired after a busy day at school or a tough game of soccer. Someone with MS may have no energy even in the morning, after a restful night's sleep!

Being tired from MS can make it hard to do everyday activities like shopping, cooking, working, or enjoying activities with the family. People who have MS fatigue may look healthy and fine even though they feel exhausted. Friends and family members may think the person is being lazy or not trying hard enough. That's just not true!

Doctors and researchers are learning more about why people with MS are so tired. They have found that some medicines can help MS fatigue. People with MS can also learn energy-saving ways to get around and do their work so they don't feel quite as exhausted.



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)

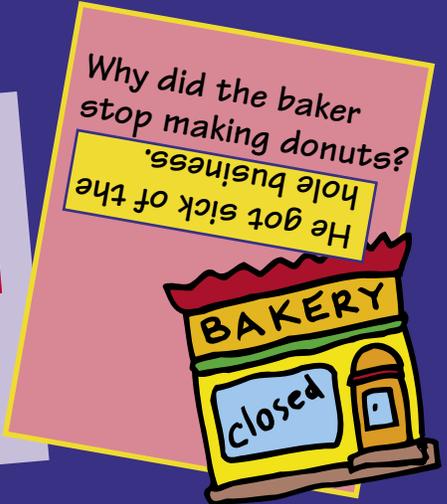
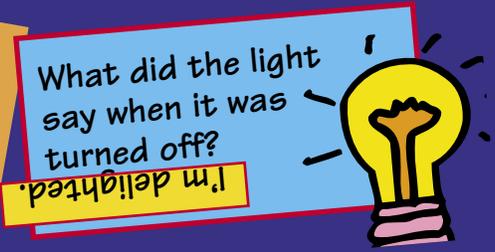
that protects the nerves gets damaged. Scars form where the myelin is damaged. As messages travel from the brain, they sometimes get stuck or slowed down by these scars. When this happens, the other parts of the body can't always do what the brain is telling them to do.

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."

JOKES





BOBBY

Bobby is 13 years old and in the 8th grade in Danvers, MA. His mom has had MS since he was three years old. Bobby has a younger brother, a dog, and a cat. He likes to play football and lacrosse (he plays on his school teams), draw with oil pastels, and go snowboarding.

Keep S'myelin: Does your mom have MS fatigue? _____

Bobby: Yes. She used to have it a lot. Now it's mostly when she has her MS treatments, but it comes and goes.

Keep S'myelin: What does your family do to deal with it? _____

Bobby: We all try to be quiet and not go upstairs too much when she's resting. We try to make it easier for her and do things like fold the laundry and not ask too much of her when she's tired.

Keep S'myelin: Has your family ever had to change plans because of your mom's fatigue? _____

Bobby: Once we planned to spend the day at Water Country, and then she didn't feel well so we couldn't go. We were a little disappointed, but it's not like she didn't want to go. We understand when she isn't feeling well. She's had MS for so long that we're used to it. We've learned to be flexible.

Keep S'myelin: What does your mom do to help her fatigue? _____

Bobby: She rests. She takes medicine that her doctor gave her. And she tries to plan her day so she'll have energy for the important things. Like, if she knows she's going into Boston in the afternoon, she won't volunteer at my school that day.

Keep S'myelin: What advice would you give other kids whose parent is tired a lot of the time? _____

Bobby: Try to make it easier for him or her. Think about how it must feel. My mom's had to cancel her own plans with friends when she isn't feeling well, so it's disappointing for her too. Volunteer to help! Saving one trip up the stairs and doing little things can really add up.

Keep S'myelin: How do you and your brother help? _____

Bobby: I do the dishes and vacuum and fold laundry. My brother empties the litter box and also does some dishes and laundry. I was mad at the beginning, but we're used to it now.



THINGS YOU CAN DO TO HELP WHEN YOUR MOM OR DAD Feels Very Tired

FIND A QUIET ACTIVITY TO DO TOGETHER

HERE ARE SOME IDEAS

- Listen to a book on tape
- Listen to music
- Play quiet board games
- Watch a movie on TV
- Talk
- Sing
- Tell stories
- Cuddle



HELP WITH CHORES AROUND YOUR HOUSE

HERE ARE SOME IDEAS

- Fold the laundry
- Bring stuff up and down stairs
- Pick up your toys and books
- Bring in the mail or the newspaper from outside
- Feed the dog
- Ask you mom or dad what else you can do to help!



Try to keep the noise level down when mom or dad is resting.



Feeling tired & FATIGUE ?

When MS makes your mom or dad very tired, your family may have to change plans at the last minute. Your parent may be too tired to go to your baseball game or shopping at the mall. It can be very disappointing for you. Remember, your parent was also to having fun with you!

EXERCISE CAN HELP MS FATIGUE



Here's a surprise—even people with MS who are very tired can be helped by exercise! Activities like walking, riding a bicycle, and swimming are called aerobic exercise because they make the heart stronger and give people more energy. Aerobic exercise is just as important for people with MS as it is for everyone else. Almost everyone is able to do some kind of aerobic exercise, even someone who has a lot of MS symptoms.

Doctors often recommend that their patients with MS see a physical therapist or an occupational therapist to find out exactly what kinds of exercise would be best for them. These therapists know how to create an exercise program that is just right for each person. They can also help people figure out ways to save their energy for the things that are most important—like doing special things with you. Maybe you can think of some physical activities that would be fun



? There are many ways to handle MS fatigue. Since fatigue can get worse as the day goes on, doing activities in the morning may help. Try making a list of activities that are most important to you to do with your mom or dad. Then, talk to your mom or about when it would be best to do them.

MS is frustrating. You may find it easy to go along with some of the changes MS brings and very hard to put up with others. You're bound to have some mixed-up feelings. Even if your parent can't always go hiking with you or go out to dinner, there are many things you can still do together. Look at the list on page 4 for some ideas!



everyone.
o looking forward





MICHAEL
CRYSTAL



AND
BENJAMIN

S'MYELIN KIDS



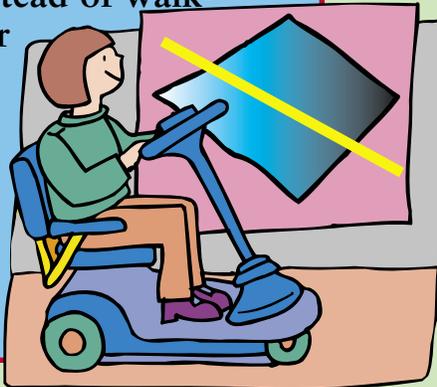
TOOLS

THAT SAVE ENERGY

Many people with MS use different types of tools or gadgets to help them move about, have fun, and do everyday activities more easily. Some of these tools help by lessening the amount of energy you need to do an activity. If MS fatigue is a problem for your mom or dad, these tools might help!

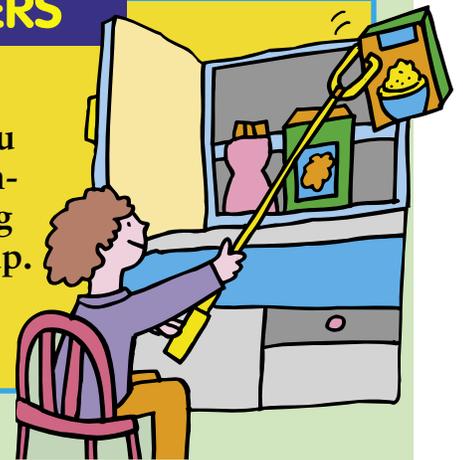
SCOOTER

By riding instead of walking, a scooter can make it less tiring to go shopping at the mall, or to visit the museum.



REACHERS

This handy tool lets you get things without bending or standing up.



ROLLING CART

A wheeled cart to carry things from one place to another saves trips and energy.



ELECTRIC CAN OPENER

You don't need a lot of energy to open a can with this!



Keep S'myelin

PARENTS' PULL OUT

HOW TO READ THIS ISSUE WITH YOUR KIDS

Fatigue is one of the most common symptoms of MS yet because it is often “invisible,” it is hard for others to understand. This issue of Keep S'myelin can help you talk to your children about this troubling symptom.



■ **Read** the Keep S'myelin Kids cartoon together and talk about the differences between being tired after a busy day on the playground and MS fatigue.

■ **Look** at the list of quiet and calm things you can do together and add more favorites that your family can do when you are feeling very tired. Maybe you like to read to one another, or you can be the audience while your child performs a skit! Be creative!



■ **Use the article** “Feeling Tired about Fatigue” and the interview with Bobby to talk about disappointments and feelings about MS fatigue. **Talk** about ways your family can be flexible and accommodating when plans have to change.

■ **Refer back to other issues of Keep S'myelin** that address feelings, equipment and tools that help people with MS, and healthy families. Those newsletters have lots of ideas for coping with the many complex issues MS might bring to your family's life.



FIND PAST ISSUES OF KEEP S'MYELIN AT www.nationalmssociety.org

MANAGING FATIGUE

Parenting without MS is enough of a challenge. Parenting with MS, and the fatigue it can cause, may sometimes feel overwhelming. How can I take care of others when I feel too tired to take care of myself? Can't they see how tired I am? How can I ask them to help—they already have more to do than their friends? How can I be a good parent?

Parenting comfortably with MS fatigue involves: 1) developing strategies for managing your fatigue; 2) making the best use of the energy you have available each day; 3) finding ways to talk with your children about a symptom they cannot easily see or understand; 4) developing the kind of family teamwork that will reduce the energy spent on the routine chores so you'll have more energy to share the fun stuff.

Each person's fatigue is different, so it may take time to find the management strategies that work best for you. Sufficient rest, including nighttime sleep and periodic rest breaks, aerobic exercise tailored to your abilities, assistive devices and mobility aids, staying cool if your MS is heat-sensitive, and medication such as **modafinil (Provigil®)** or **amantadine**, are possible strategies to discuss with your healthcare provider. Together, you will develop an effective plan to manage your fatigue.

For some people, energy begins to feel like their most precious resource—so it may help you to think of your energy supply as a bank account. You have a certain amount to “spend,” so it's up to you to decide when and how you're going to spend it. Saving the hardest jobs for the times when you have most energy, not spending what you have all at once, planning (and saving) for those times when you know you'll need more energy, are just a few ways to manage your account wisely.



PARENTS' PULL OUT

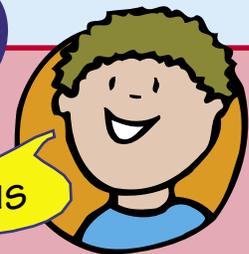
Children often have a hard time understanding symptoms they cannot see. They may think their parent is being lazy or simply doesn't care enough to do something. As we described in issue 11 of *Keep S'myelin* (available at your local chapter), it can be helpful to give your kids an opportunity to "feel" your fatigue. You can play a game in which they walk with light weights on their ankles, or imagine walking through sand or mud. You can explain that the way they feel right before their nap or when they stay up late at night is often the way you feel when you wake up in the morning or after a nap. It may also be helpful to describe your bank account of energy.

Family teamwork can help maximize your energy. Kids have an easier time taking on extra responsibilities when they know that the end result will be more time for fun with you. Try to spread the chores evenly, and rotate them so no one has to do the same chores month after month. A family calendar of rotating responsibilities can help the process go more smoothly. Like Bobby (see our interview on page 3), kids may be "mad at the beginning," but they will feel proud of their ability to help you and each other.



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.



RECOMMENDED RESOURCES

BOOKS

Living with Multiple Sclerosis: A Wellness Approach (2nd ed.) by GH Kraft & M Catanzaro. New York: Demos Medical Publishing, 2000.

300 Tips for Making Life with Multiple Sclerosis Easier by SP Schwarz. New York: Demos Medical Publishing, 1999

Sick and Tired of Feeling Sick and Tired: Living with Invisible Chronic Illness by PJ Donoghue & ME Siegel, New York: WW Norton, 1992

National MS Society BOOKLETS

FATIGUE: What You Should Know (ES6046)

EXERCISE as Part of Everyday Life (ES 6008)

You can e-mail us at: KeepSmyelin@nmss.org

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Keep
S'myelin

MS FATIGUE

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



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Editors

Jennifer Ricklefs, MS
Debra Frankel, MS, OTR
Rosalind Kalb, PhD

Advisors

David Rintell, EdD
Vicki Dodge-Pamplin, CIR
Shannon Stapleton, MSW
Kevin Dougherty, MA
Debbie Rios, MPA
Deborah Miller, PhD
Elly Schottman
George Garmany, MD

Design/Illustrations

Claude Martinot Design

*The mission of the
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end the devastating effects
of multiple sclerosis.*