NATIONAL MULTIPLE SCLEROSIS SOCIETY

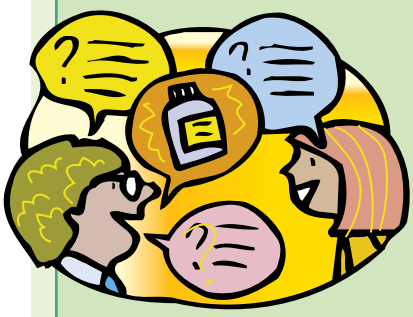
ISSUE #10/TREATMENTS

Kep S'Myelin

A NEWSLETTER[1] FOR KIDS ABOUT MULTIPLE SCLEROSIS

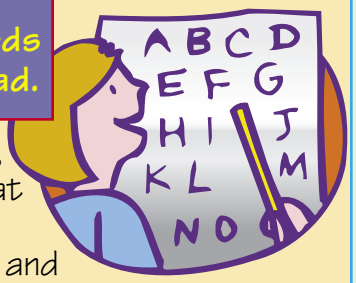
Did you ever wonder what happens when your mom or dad visits the MS doctor? Regular check-ups give the doctor a chance to find out how your mom or dad is doing, and they give your mom or dad a chance to ask questions. This helps the doctor find any small problems before they become big ones.

The doctor begins by asking some questions:

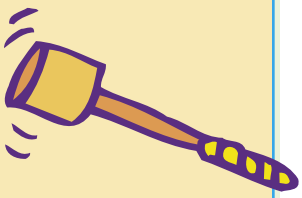


"How are you doing? Have you had any new symptoms? Are you having any problems with your medications?" And of course, your mom or dad may have questions too: "What can I do about feeling so tired all the time? Why are my legs so stiff? Am I taking the right medicines?"

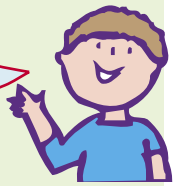
Sometimes the doctor needs to examine your mom or dad.



The doctor may test vision, walking, reflexes (that's what the hammer is for!), strength, and a lot of other things that can be changed by MS. Based on this examination, the doctor may want to add or change a medication or do some more tests—maybe a blood test or another MRI.



By the time the visit is over, both your parent and the doctor have learned important things that will help them work together to reduce the effects of MS.



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."

SINCE YOU'VE ASKED...

Q Why don't the shots my grandma takes for her MS make the MS go away?

A The shots your grandma takes won't make her MS go away, but they can slow it down. These medicines aren't a cure for MS but they are the best treatment we have right now. Scientists are working very hard to find new medicines to make MS go away all together. That is something we all would like to see!

JOKES

SPIKE ATTACKS THE MS MONSTER

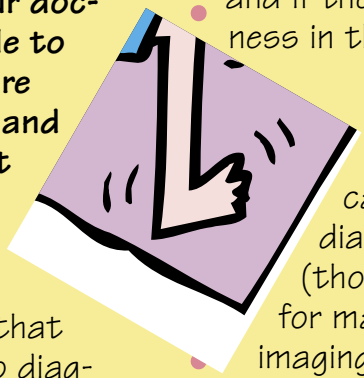
Hi, my name is Michelle . I am 12 years old, a 7th grader in middle school in Denver, PA. I have four brothers and a step sister. You and I already have something in common. We have someone we love who has been 'attacked' by the multiple sclerosis monster. For me this is my mom. Though she seems normal most of the time, there have been times MS has caused lots of problems for all of us.

For example, one morning I was home sick from school and my mom had to write a note for me to be excused. I rushed to give my mom a pen and paper to write my note. As she began writing, the pen kept slipping out of her hand and she could not write. It was just a bunch of scribbles. My mom began crying and I knew that the MS monster had attacked again. I ended up writing the letter for her and my dad came home later to sign it. I hate MS! Well, one good thing that I know helps me with my fears is that I began attending the seminars my mom goes to at the MS Society. Most of the time, I am the youngest one there! I don't mind though, because I get to learn a lot of information about the "monster" and I ask a lot of questions. My mom started to take daily injections for her MS. Talk about another shocking site! My brothers and I watched my mom as she explained what she had to do. At first I felt it was horrible to see a needle going into her soft skin. Then mom explained how this could help slow down the MS.

Mom decided since this would be a daily routine, we would each learn to administer it in case she couldn't. I named the injection, "Spike." Spike was named since he's now part of the family. I still feel afraid at times, but I understand better how the 'monster' works.

Diagnosing MS

When you aren't feeling well, the doctor examines you to find out what's the matter. Maybe the doctor checks your throat, or looks in your ears, or listens to your chest. By examining you this way, your doctor is usually able to diagnose, or figure out the problem and give you the right medicine.



Unfortunately, MS is a disease that is very difficult to diagnose. The doctor can't tell by looking or listening, and there isn't a simple test that can show for sure if a person has MS. So, it may take a long time for a person to find out if MS is causing the problems he or she is having.

When the person in your family with MS first began to have problems or symptoms, the doctor started by asking lots of questions: "How do you feel? What problems are you having? Have you felt anything like this before?" The doctor looked in the person's eyes, watched the person walk, and used a reflex hammer to test knee and ankle reflexes. The doctor also checked the person's arms and legs to see how strong they were and if there was any stiffness in them.

There are special tests that can help a doctor diagnose MS. An **MRI** (those letters stand for magnetic resonance imaging) is a special picture that is almost like an x-ray. It shows the changes or scars that MS can cause in a person's brain and spinal cord.

A spinal tap (also called a lumbar puncture) is a test to find out if the liquid around the person's spinal cord has any changes in it that can be caused by MS. Another test, called a **VEP** (visual evoked potential), can tell if the messages going from the eyes to the brain are moving more slowly than they should.

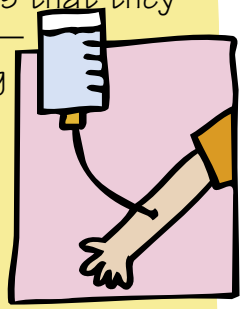
The doctor uses all this information to decide if the problem is MS, and to make sure that there isn't any other problem or disease that could be causing the symptoms the person is having. Once the doctor has decided that MS is the problem, treatment can begin.

Treating MS

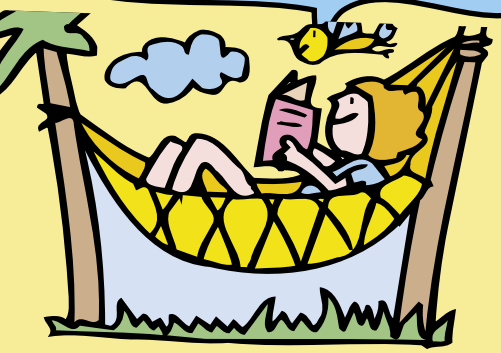
We don't have a cure for MS yet, but we have several different ways to treat it and help people feel better. There are medicines to slow the disease and keep it from getting worse. People taking these medicines have to give themselves shots. Nobody likes to get a shot, but these shots are the best treatment we have for MS!

MS can cause many kinds of problems or symptoms, like making people feel very tired or stiff or weak. The doctor knows about different types of medicines that can make these problems feel better. There are

also medicines for relapses (also called exacerbations). They may feel very tired, or have new problems that they never had before—like trouble seeing or walking or remembering things. When this happens, they may be given a special medicine called **methylprednisolone.** (Isn't that a mouthful?) This is a liquid medicine that drips through a needle into the person's arm. Some people get this medicine at home and other people go to the hospital for a few days to get it.



Besides medicines, there are lots of other things that can help people with MS to feel better: exercise, rest, a healthy diet, and having fun!



SPECIALISTS WHO HELP

When someone has MS, they may go to see different types of doctors and therapists who can help them feel better. Here are some of those people and what they do to help people with MS.

PHYSICAL THERAPIST

A therapist who can help someone become more physically fit. Many people with MS see physical therapists to learn how to walk better, to learn exercises to become stronger, or to find out about special tools that can help them

NEUROLOGIST

A doctor who takes care of people with MS and knows a lot about the brain and the spinal cord.

UROLOGIST

A doctor who knows a lot about the bladder and how it works. Sometime people with MS have problems going to the bathroom and this doctor can help.

SPEECH THERAPIST

A therapist who helps people who have difficulty speaking or swallowing.

PSYCHIATRIST

A doctor who helps people with their feelings about MS.

NURSE

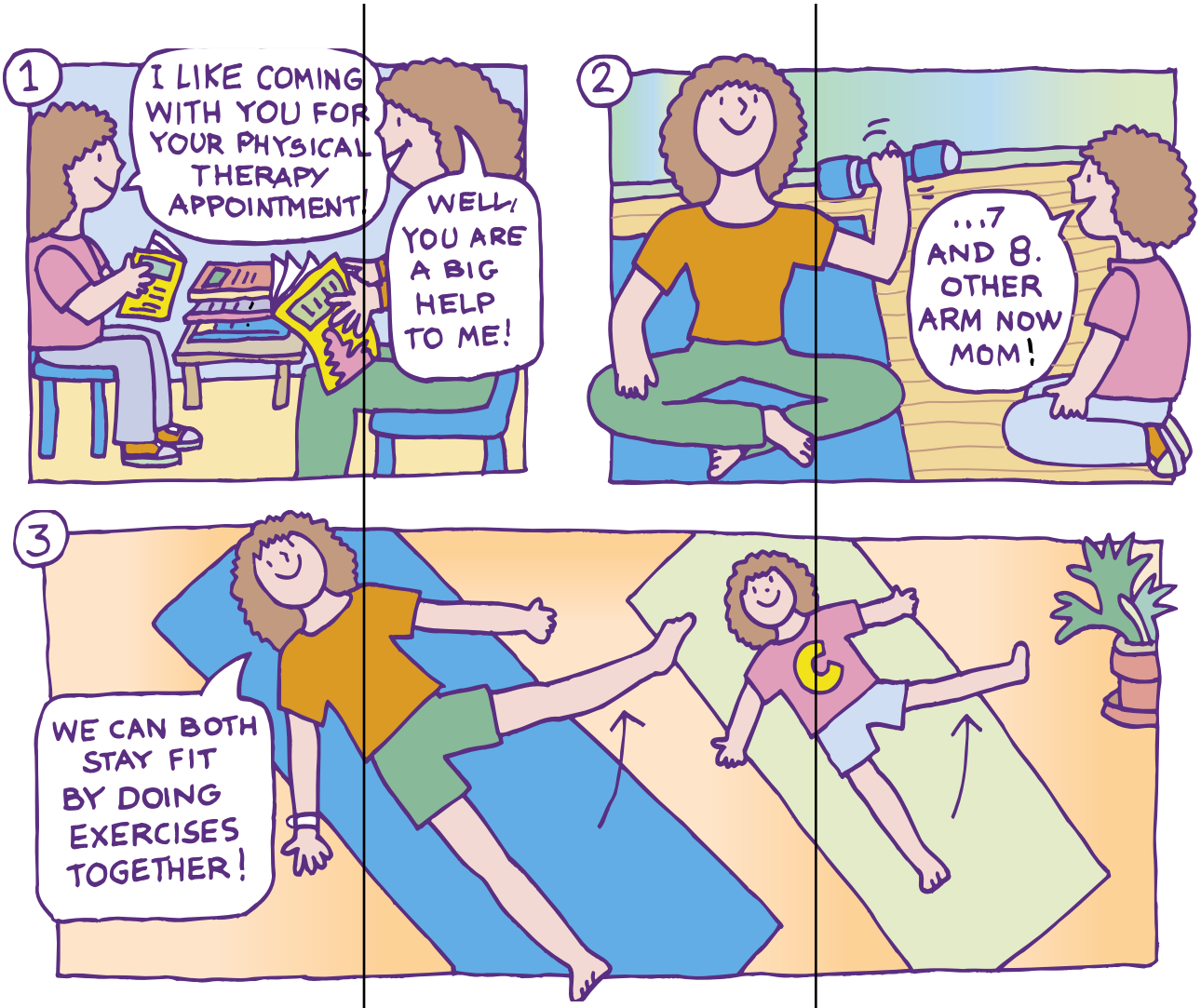
Someone who helps people learn about taking medi cines and how to be as healthy as they can in spite of MS.

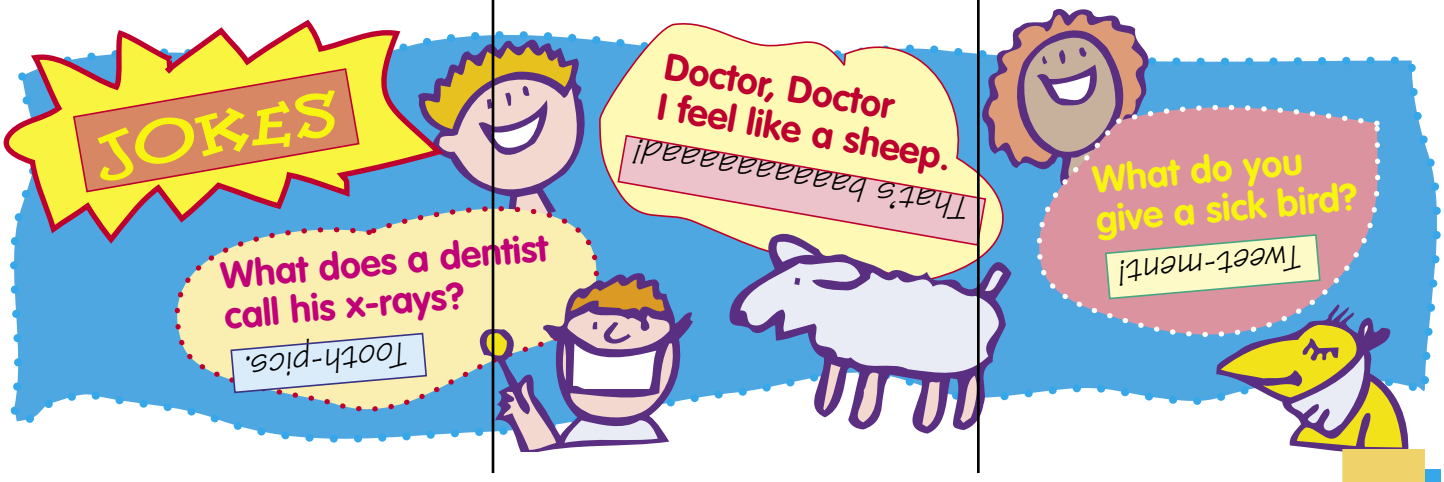
OCCUPATIONAL THERAPIST

A therapist who can help people with MS learn how to do day-to-day activities more easily and in a less tiring way.

SOCIAL WORKER

A person who helps families talk about MS together.


1
I LIKE COMING WITH YOU FOR YOUR PHYSICAL THERAPY APPOINTMENT!
WELL, YOU ARE A BIG HELP TO ME!
2
...7 AND 8. OTHER ARM NOW MOM!
3
WE CAN BOTH STAY FIT BY DOING EXERCISES TOGETHER!


JOKES
What does a dentist call his x-rays?
Tooth-pics.
Doctor, Doctor I feel like a sheep.
That's baaaaaaaaaad!
What do you give a sick bird?
Tweet-ment!

HEALTH CARE WORD SEARCH

S	U	R	O	L	0	G	I	S	T	F	G	P	N
R	H	J	C	K	L	P	P	O	I	U	Y	S	U
A	Z	X	C	E	T	M	N	R	R	T	T	Y	R
D	N	E	U	R	O	L	O	G	I	S	T	C	S
I	X	C	P	H	Y	S	I	C	A	L	B	H	E
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RADIOLOGIST
SOCIAL WORKER
NURSE
UROLOGIST
OCCUPATIONAL
PHYSICAL
SPEECH
PSYCHIATRIST
THERAPIST
NEUROLOGIST

NATIONAL MULTIPLE SCLEROSIS SOCIETY

ISSUE #10/TREATMENTS

Keep S'myelin

PARENTS' PULL OUT

How to Read This Issue of Keep S'myelin with Your Kids

This issue is designed to help children understand the diagnosis and medical management of MS. This is complex material and not easy to explain to young children. One of the underlying messages is that physicians and other health care specialists are there to help you and will work with you to be sure you are as healthy as you can be.

You might consider having your child accompany you to a medical appointment; for example, a routine physician appointment or physical therapy visit. Speak to your health care provider in advance, to be sure it is OK and to discuss what might take place during the appointment. Avoid bringing your child to an appointment that might involve a painful procedure or unwelcome news. Read the Keep S'myelin Kids cartoon together to talk about how going to an appointment together might reduce anxiety for your child.

Talk about the various MS specialists who are there to help you. Do the word search together and read the article about MS specialists. Talking about these various professionals can be reassuring to your child.

If you take one of the MS disease-modifying agents, reading this issue together may facilitate a conversation about why the drug does not make MS go away all together. This is a good opportunity to talk about how scientists are doing research to develop treatments that stop MS progression or reverse damage to the central nervous system. It is OK to tell children that there are still unanswered questions about MS. We don't yet know how to cure MS, but we are moving closer to that goal every year.

Clear Thinking *About* Alternative Therapies

How do you choose the right medical treatment from everything that is available to you? This is one of the biggest questions you face as a person with MS. Not so long ago, you wouldn't have had a choice. Your doctor would have decided for you from a limited list of possibilities. But today there are several treatments for MS itself and a long list of ways to manage MS symptoms. You can no longer afford to be passive about the medical care you receive. In order to understand and evaluate your options, you must be an active, informed consumer.

This is even more important should you choose to pursue an alternative or complementary therapy. Here, it is much harder to identify and evaluate the risks and benefits. Therapies range from the widely accepted to the truly bizarre. To protect your health and your pocketbook, you must track down and scrutinize information from as many sources as possible.

What are alternative therapies?

The term "alternative" is difficult to define. When applied to health care, it encompasses everything from drugs and diets to food supplements, mental exercises, hands-on techniques, and lifestyle changes. Alternative therapies come from many disciplines and traditions. They include acupuncture, aromatherapy, Ayurvedic medicine, biofeedback, chiropractic, guided imagery, herbal medicine, homeopathy, hypnosis, hypnotherapy, iridology, macrobiotics, naturopathy, reflexology, relaxation techniques, traditional Chinese medicine, yoga, "touch therapy," and various schools of massage, among others. Recent research indicate that about sixty per cent of people with MS have tried some form of non-conventional therapy.

How do you know what to avoid and what might be worth a try?

Gather information. Carefully and thoroughly inquire about any therapy you are considering. Ask:

- What does the treatment involve?
- How and why is it supposed to work?
- How effective is it?
- What are the risks?
- How much does it cost?

Here's how to decide whether a particular treatment is right for you.

Contact a variety of sources to get reliable, objective information. Begin by calling the National Multiple Sclerosis Society at 1-800-FIGHT-MS (1-800-344-4867).

- Discuss the therapy with your doctor.
- Find out if the alternative practitioner works with conventional doctors.
- Talk to people who have used the treatment.
- Investigate the background of any treatment provider.

- Find out how much experience this person has had treating people with MS.
- Thoroughly investigate any clinic that requires inpatient stays. Be particularly vigilant about getting information on any clinic, in the U.S. or abroad, that will not treat you as an outpatient.
- Determine the costs. Some alternative therapies cost thousands of dollars, and most are not covered by health insurance.
- Proceed with caution. Do not abandon your conventional therapy. Only use alternative therapy in addition to, not in place of, your current treatment. Keep your doctor up to date.

Here's another valuable resource: **ALTERNATIVE MEDICINE AND MULTIPLE SCLEROSIS**, by Allen C. Bowling, MD, PhD. New York: Demos Medical Publishing, 800-532-8663

Excerpted from: ***Clear Thinking About Alternative Therapies*** *by Virginia Foster, with a contribution by Ellen Burstein MacFarlane, a publication of the National Multiple Sclerosis Society.*

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.

Keep S'myelin Readers: WE WANT YOU!

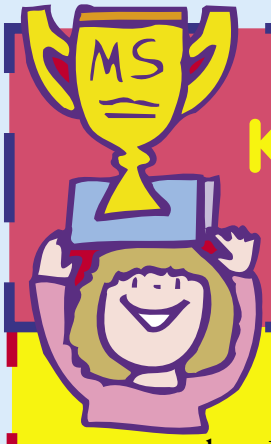
We love to publish your articles, stories, illustrations, poems, and interviews about MS. Please send us your work! Tell us how your family learns about MS together, how you feel about having MS in your family, what advice you would give other kids about having a mom or dad with MS, how you help your mom or dad, and whom you talk with about MS. Send your stories and pictures to:

KEEP S'MYELIN, NMSS, 700 Broadway, Denver, CO 80203 or e-mail them to **keepsmyelin@nmss.org.**

If your child is submitting something to Keep S'myelin, be sure to include the parent's name, address, and phone number.

(Note to parents: Space prohibits us from using all submitted material. We require written permission to use your child's material. Also, we reserve the right to edit for space and accuracy.)

PARENTS' PULL OUT



KEEP S'MYELIN IS AN AWARD WINNER!

We are very proud to announce that Keep S'myelin is a winner of the 2002 International Summit Creative Award Competition. Among the thousands of entries from 17 different countries, our children's newsletter was one of the very best! Judges looked for innovative and creative concepts, strong executions, and the ability to communicate and persuade. We are pleased to acknowledge and thank Claude Martinot of Claude Martinot Designs for her original and imaginative design and delightful illustrations for each issue of Keep S'myelin.

RESOURCES

Alternative Medicine and Multiple Sclerosis Allen C. Bowling, M.D. Ph.D. 2001

Multiple Sclerosis: A Guide for the Newly Diagnosed, 2nd Edition. Nancy J. Holland, R.N. Ed.D. T. Jock Murray, M.D. Stephen C. Reingold, Ph.D. 2002

Multiple Sclerosis: The Questions You Have-The Answers You Need, 2nd Edition. Rosalind C. Kalb, Ph.D.2000

Meeting the Challenge of Progressive Multiple Sclerosis. Patricia K. MD & June Halper, MSN, ANP, FAAN 2001

Symptom Management in Multiple Sclerosis 3rd Edition Randall T. Schapiro, M.D. 1998

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NATIONAL MULTIPLE SCLEROSIS SOCIETY

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

Keep S'myelin

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 Sclerosis Society is to end the devastating effects of multiple sclerosis.