



NATIONAL
MULTIPLE SCLEROSIS
SOCIETY



Multiple
Sclerosis
Society of
Canada

MIGHTY SPECIAL KIDS

AN ACTIVITY BOOK FOR KIDS WITH MS





Dear Parent,

This activity book is brought to you by **Young Persons with MS: A Network for Families with a Child or Teen with MS**. The Network is a collaborative effort of the National Multiple Sclerosis Society and the Multiple Sclerosis Society of Canada. This activity book is a tool to help you talk to your child about his or her diagnosis of MS. We hope this will allow you to discuss different issues with your child and use it to open up conversation about sometimes difficult topics. This book is designed for children ages 5-12. Resources for older children can be found at the National MS Society website (www.nationalmssociety.org) or the MS Society of Canada website (www.mssociety.ca).

As you read, your child may see him or herself in the material or they may see something that is nothing like their disease. Please remember that MS affects everyone differently and we tried to include something for every child with MS.

If you have questions or would like further information on your child's MS, please contact the **Young Persons with MS Network** at childhoodms@nmss.org or 1-866 KIDS W MS (1-866-543-7967).

In the United States you may contact your local chapter by dialing 1-800-FIGHT MS (1-800-344-4867).

For information in Canada, please contact the National Information Resource Center of the MS Society at 1-866-922-6065 or email kidswithms@mssociety.ca

What is MS?

LET'S LEARN ABOUT MS

If you just found out that you have multiple sclerosis (MS for short), or even if you've had it for a while, you probably have lots of questions. You're not alone! All kids with MS have questions. Here's some information that will help answer some of your questions. Reading this with your mom or dad may help you to talk about the changes MS can bring.

First, remember that it's not your fault that you have MS. It's not anyone else's fault either. Second, you may not know any other children who have MS, but there are.

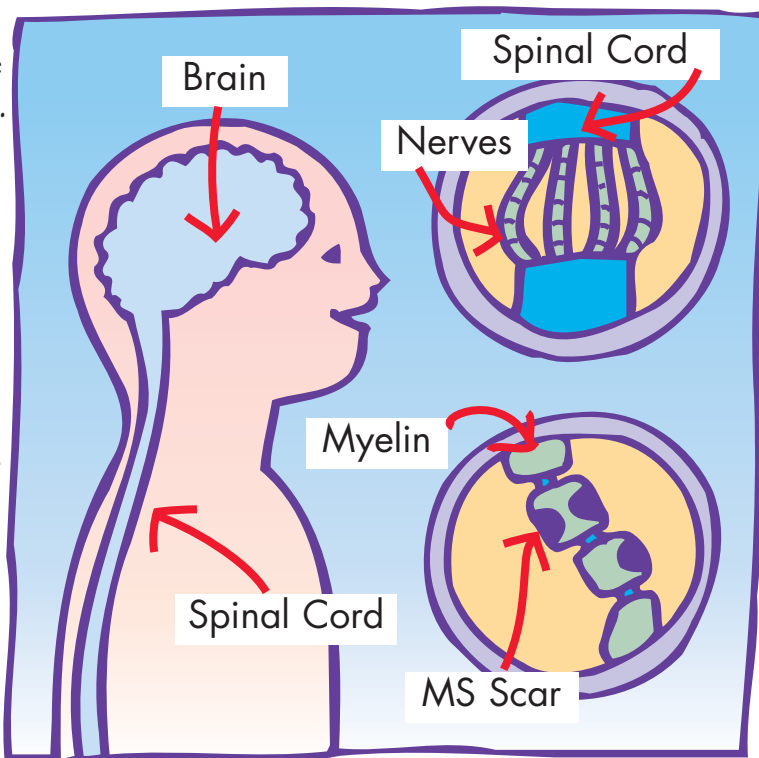
MS is a sickness that affects the **central nervous system** (the brain and the spinal cord.) The brain is like a computer that sends messages to the body telling it what to do. The **spinal cord** is like a thick cable of wires attached to the computer. Messages travel from the brain, along the spinal cord, to the

muscles and other parts of the body. If the brain wants the fingers to wiggle, it sends a message along the spinal cord out to the arm and down to the fingers, and they wiggle. When a person has MS,

the covering or coating (called myelin) that protects the nerves in the brain and spinal cord gets damaged. As messages travel from the brain, they sometimes get stuck or slowed because the myelin is damaged. When this happens, muscles or other parts of the body can't

always do what the brain is telling them to do.

The most important thing to remember is that having MS doesn't change some very important things...you are the same lovable you and your family will always love you and keep you safe. They want to know when you are worried or scared, and they want you to feel OK about learning about MS.



SYMPTOMS

What are the problems you may have?

You may be having trouble doing everyday things...putting on your socks, making a sandwich, or walking the dog. Your body may feel “funny” or different. These are called “symptoms.” 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.

MS symptoms can be very mild, very serious, or somewhere in-between. They can come and go. Sometimes the symptoms disappear for a few days, weeks or months, and then come back again. There are many different symptoms. You won’t have them all.



Ask your mom or dad about the symptoms you’re having. Learning about MS symptoms and talking to your parents about them can make you feel better.

Here are some that many people with MS have:

♥ Weak arms and legs.

Your arms and legs feel very tired, as if there were weights tied on them.



♥ Losing your balance.

You might lose your balance, even if you haven’t done anything to make yourself dizzy. It may feel a little like when you spin around in a circle. It’s hard to walk straight.

♥ Having trouble concentrating or remembering.

Sometimes MS makes it hard for you to remember things or pay attention at school.





You may have symptoms others can't see



As we just read, you can have many different kinds of symptoms. Some are problems you can see, however, others are **invisible**. You know you have these symptoms, but no one else can see them.

Some of these invisible symptoms are:

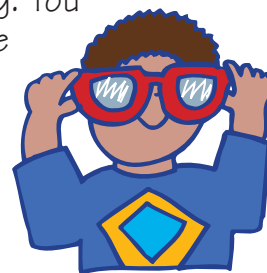
♥ **Tiredness**, called MS fatigue. This is different from the tiredness most people feel. It can happen at any time of day, even after a long nap! When you feel this way, it's hard for you to do very much—even things you enjoy a lot.



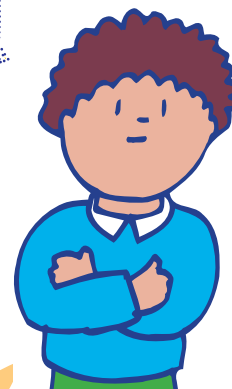
♥ **Strange feelings** that can hurt or itch or are just plain uncomfortable. You may get a prickly feeling (like pins and needles) in your arms or legs—just like you get when your hand or foot “falls asleep”—but the feeling may not go away. This can make it hard to walk or hold things without dropping them.



♥ **Poor eyesight**, so things look blurry or like a big movie screen with black holes in it. Sometimes you may see two of everything. You may have trouble reading or watching TV.



Invisible symptoms can be hard to understand. You may look just fine, but still not be able to play a game with your friends or run with your dog. When you have a symptom others can't see, you will need to help them by telling them about it.

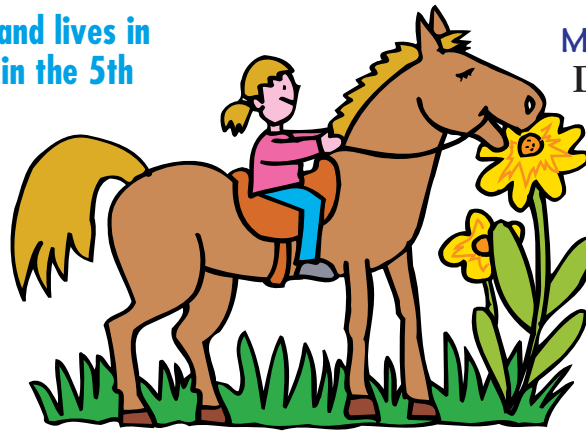


MEET SOME FRIENDS WITH MS

INTERVIEW WITH

MADISON

Madison is 10 years old and lives in Wildwood, Illinois. She's in the 5th grade and has 2 cats, named Scooby-Doo and Roach, and one dog, named Little Bit. She has had MS for 3 years.



Mighty Special Kids:
How did you know you had MS?

Madison: All of a sudden I fell down and my right side felt numb. Then, I had trouble walking and kicking a ball. Then we knew something was wrong.

Mighty Special Kids:
How does MS affect you now?

Madison: I need a wheelchair and have trouble talking clearly.

Mighty Special Kids:
Do you have any special therapy?

Madison: I go to "hippo therapy!" That means horseback riding. I go riding every other week and it's a lot of fun. Also, it helps me exercise and that is good for my MS. My horse is "Chipper." He's very gentle and he's silly sometimes, especially when it's time for him to eat! It helps me get stronger and it helps with my balance.



Mighty Special Kids:
Do you take any medicine for your MS?

Madison: I have to take a shot every day. It was hard at first, but my mom and dad made a **Treasure Box** with lots of little presents.



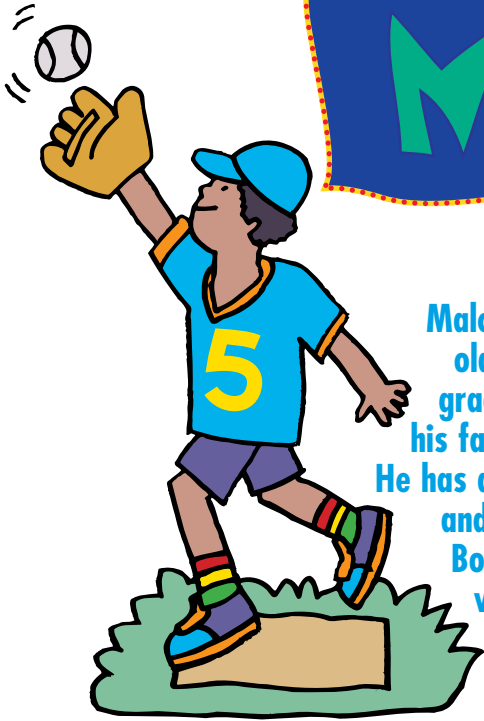
I take a present each time I have a shot. That helps! Now, it's not so bad.

Mighty Special Kids:
What would you tell another kid who just found out that she had MS?

Madison: Well, you might have a hard time running. You might have a hard time with small things like Legos, but if you work on it, you can do it. You might have to rest more because you get very tired. We have movie nights where we just watch movies so I can rest. You might have to take shots (but the Treasure Box helps!); you might need an MRI (it is cool to see what your brain really looks like!); you might get to ride on a horse!; and, you learn a lot about yourself.

INTERVIEW WITH

MALCOLM



Malcolm is 9 years old and in the 4th grade. He lives with his family in Colorado. He has a younger sister and a dog named Bodie. He keeps very busy playing baseball in little league and going to the pool

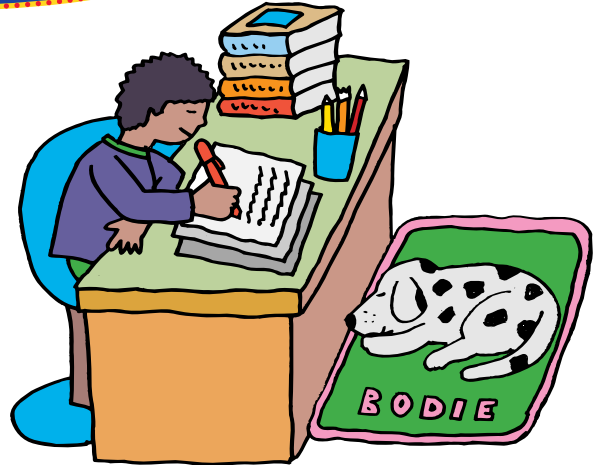
with his friends. Malcolm was diagnosed with MS when he was 6 years old.

Mighty Special Kids:
How did MS begin for you?

Malcolm: I had "pins and needles" feeling in my hands that would not go away. This made it hard for me to hold onto things, so my mom and dad took me to the doctor.

Mighty Special Kids:
How does MS affect you now?

Malcolm: Well, most days I feel fine. My MS is mostly "invisible." That means no one can really tell I have MS from looking at me. I still get "pins and needles," and have trouble concentrating at school. Sometimes I get very tired during school and need to take a nap in the nurse's office.



Mighty Special Kids:
What do you do that makes it easier to live with MS?

Malcolm: I have a tutor after school to help me keep up with my schoolwork. I have a few friends who help me at school.

Mighty Special Kids:
What would you tell another kid who just found out that he had MS?

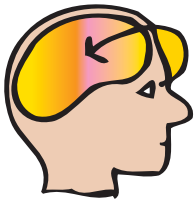
Malcolm: I'd say let your family care for you.



MORE ABOUT MS

How does the doctor know you have MS?

The doctor can't tell that you have MS by looking down your throat or listening to your chest. There isn't a simple test that can show for sure if you have MS.



The doctor probably asked lots of questions: **“How do you feel? What problems are you having? Have you felt anything**

like this before?” The doctor looked in your eyes, watched you walk, and used a small hammer to test your knees and ankles. The doctor also may have checked your arms and legs to see how strong they were and if there was any stiffness in them.

The doctor may have taken a picture of your brain and spinal cord using an **MRI** (those letters stand for Magnetic Resonance Imaging). You may have been poked in the back with a needle (called a spinal tap) to find out if the liquid around your spinal cord had any changes



in it. And, you may have had a test called a **VEP** (Visual Evoked Potential), to tell if the messages going from your eyes to your brain were moving more slowly than they

should.

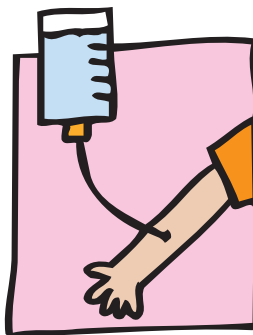
The doctor uses these tests to decide if the problem is MS or something else. Once the doctor has decided that it's

Is there a cure for MS?

We don't have a cure for MS yet, but we have ways to treat it and help you feel better. There are medicines, that help your body fight MS. If you take these medicines you have to have a shot. Nobody likes to get a shot, but these shots are the best treatment we have for MS right now.

MS can make you feel very tired or stiff or weak. The doctor knows about different types of medicines that may make these problems better.

There are also medicines when your MS



is acting up. You may have attacks every once in a while. You may have trouble seeing or walking or remembering things. (When this happens, you may be given a special medicine with a big, long name—

methylprednisolone. This is a liquid medicine that drips through a needle into your arm. You might go the hospital for a few days to get it.)

There are lots of other things that can help you to feel better: exercise, rest, healthy food, and having fun!

LET'S MEET THE PEOPLE WHO TAKE CARE OF CHILDREN

Here are some of the people you may go to who can try to help you feel better. You might want to have one of these jobs when you grow up!



UROLOGIST:

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

PHYSICAL THERAPIST:

A person who can help someone learn how to walk better, learn exercises to become stronger, or to find out about special tools that can help him or

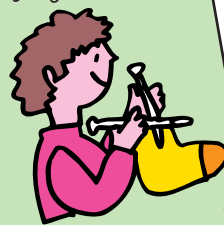


SOCIAL WORKER, PSYCHOLOGIST OR COUNSELOR:

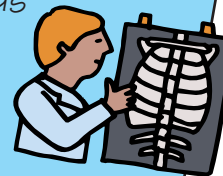
A person who helps families talk about MS together.



OCCUPATIONAL THERAPIST: A person who can help people with MS learn how to do day-to-day activities more easily and how to have fun in a less tiring way.



RADIOLOGIST: A doctor who understands what an MRI shows.



NURSE:

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



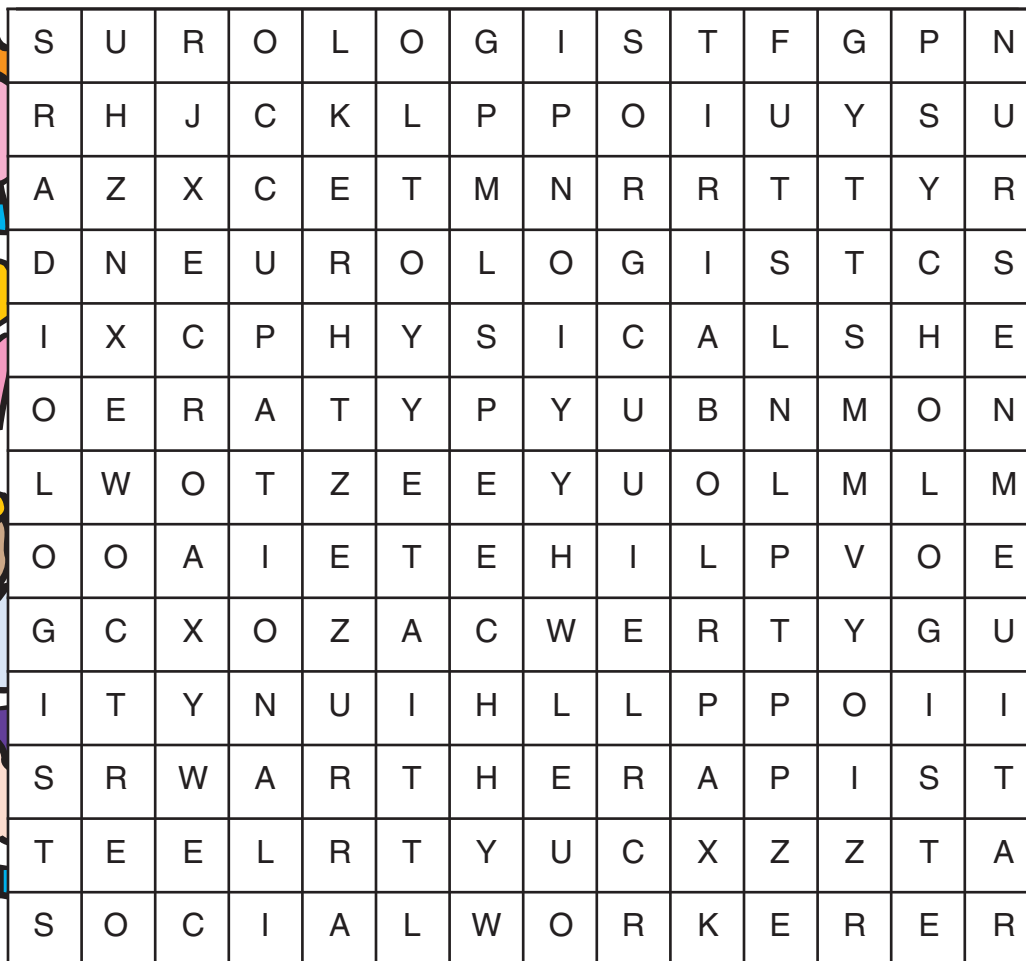
SPEECH THERAPIST:

A person who helps people speak or swallow better.



WORD SEARCH

FIND THE SPECIALISTS



S	U	R	O	L	O	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	S	H	E
O	E	R	A	T	Y	P	Y	U	B	N	M	O	N
L	W	O	T	Z	E	E	Y	U	O	L	M	L	M
O	O	A	I	E	T	E	H	I	L	P	V	O	E
G	C	X	O	Z	A	C	W	E	R	T	Y	G	U
I	T	Y	N	U	I	H	L	L	P	P	O	I	I
S	R	W	A	R	T	H	E	R	A	P	I	S	T
T	E	E	L	R	T	Y	U	C	X	Z	Z	T	A
S	O	C	I	A	L	W	O	R	K	E	R	E	R

NURSE

RADIOLOGIST

SPEECH

UROLOGIST

SOCIAL WORKER

PSYCHOLOGIST

PHYSICAL

THERAPIST

NEUROLOGIST

OCCUPATIONAL

A VISIT TO THE DOCTOR



Now that you have been told you have MS, you probably go to the doctor for checkups and when you are having a problem. Checkups give the doctor a chance to find out how you are doing, and they give you and your mom or dad a chance to ask questions.



“How are you doing?”

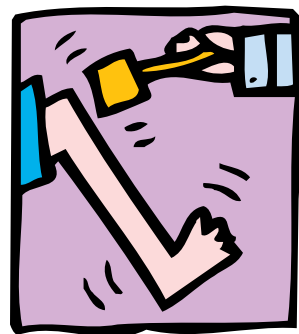
“Have you had any new symptoms?”

“Are you having any problems with your medications?”

“What can I do about feeling tired all the time?”

“Why are my legs so stiff?”

The doctor may need to examine you. She or he 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.



FEELINGS

You probably have lots of feelings about MS. MS probably makes you feel mad, especially if you can't do some of the things you like to do. Sometimes you might feel sad because someone at school said something mean to you. You might feel scared if you have to go to the hospital. Sometimes you might feel glad because, in spite of MS, you can do fun things with your friends and family.



Sometimes the hardest thing about feelings is sharing them. Talking about feelings can make you feel better and bring you closer to people you love.

Having feelings you keep secret is like having a heavy backpack with lots of stuff inside. You can't really lighten it if you don't look in there yourself. And it can get too



Make a list of the feelings you are carrying in your feelings backpack. You can do it in your head, on a piece of paper, or in a poem or drawing. You can also try the "Feeling Buddy" activity that follows.



There are lots of people you can talk to—your mom and dad, brothers and sisters, teachers, doctors, school

Find someone:

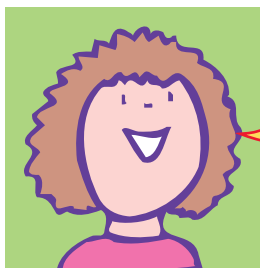
- Who is easy to talk to
- Who you like and trust
- Who listens to your feelings



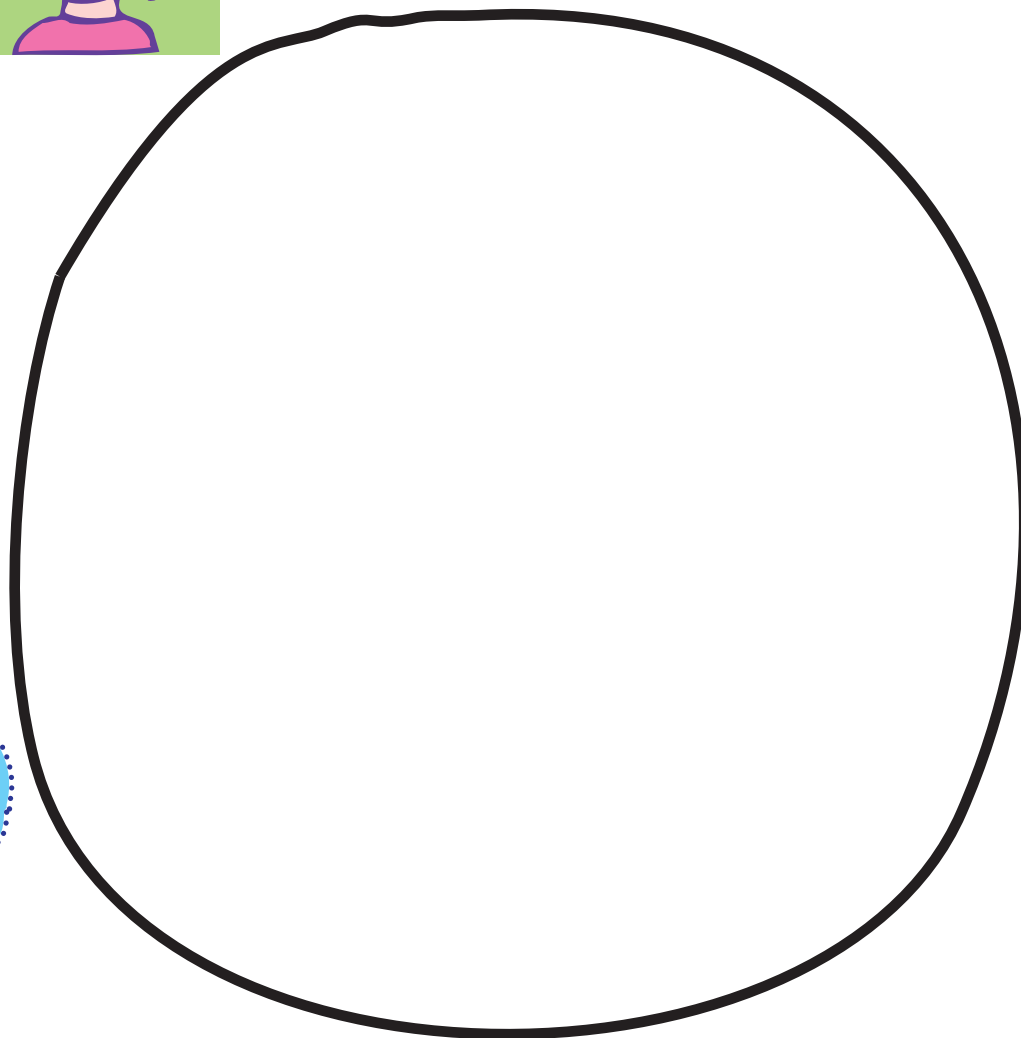
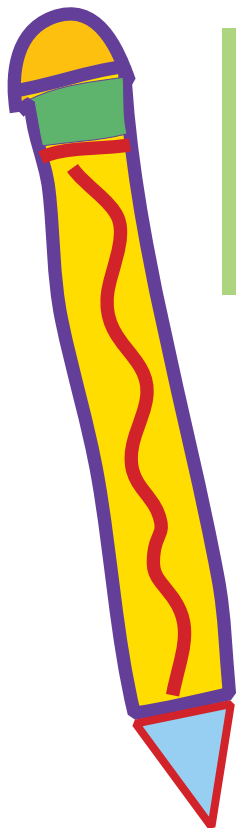
counselors, grandparents, and friends.

Talking about your feelings is the best way to learn more about yourself and find help for your worries, so don't be afraid to talk to someone the next time you want to sort out your feel-

FEELING BUDDY



Use this outline to draw a face that shows how you are feeling today.



Below the picture, write the name of the feeling.

.....

FAMILY

ACTIVITIES



MAKE A RAIN STICK

These rain sticks really sound like rain!



MATERIALS

- ★ a cardboard tube from gift wrap or paper towels
- ★ paper, scissors, and tape
- ★ strips of cardboard (about 4" long and 1" wide)
- ★ 2 tablespoons dried peas, unpopped popcorn, or lentils
- ★ 1 cup uncooked rice
- ★ markers, paint, ribbon, and other decorations

INSTRUCTIONS

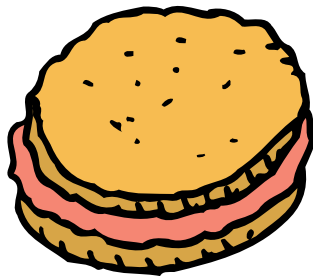
1. Cut two 4-inch circles out of paper. (You can trace a large coffee mug for the shape.)
2. Put one circle over the end of the cardboard tube. Fold the sides down, and tape around the tube. (Make sure the paper is sturdy and taped on well.)
3. Cut several cardboard strips. Fold each strip back and forth like a fan. Drop the strips into the tube. The first one should fall to the bottom. Keep adding strips until they reach the top of the tube.
4. Pour the rice and the dried peas, popcorn, or lentils into the tube.
5. Put the other paper circle over the open end of the tube. Tape in place.
6. Decorate your rain stick with markers, paints, paper shapes, ribbon, etc.
7. To hear the rain, slowly turn the cardboard tube so that first one end is up, and then the other.



YOU WILL NEED:

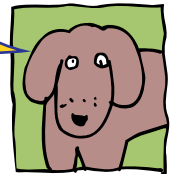
- ♥ 1 1/2 cups cold milk
- ♥ 1/2 cup peanut butter
- ♥ 1 package instant chocolate or vanilla pudding
- ♥ 24 graham crackers or chocolate wafers
- ♥ One large mixing bowl
- ♥ A cookie sheet
- ♥ Wax paper
- ♥ Hand mixer

"ICE CREAM" SANDWICHES



- ♥ Line the cookie sheet with the wax paper. Spread 12 graham crackers or wafers on the cookie sheet.
- ♥ Add the milk to the peanut butter and blend until smooth.
- ♥ Next add the pudding mix and beat at a low speed for two minutes.
- ♥ Let the mixture stand for five minutes.
- ♥ Spoon 1/2 inch of mixture onto each graham cracker/wafer. Spread to the edges of the cracker.
- ♥ Top each cracker with one cracker.
- ♥ Freeze until firm; about 3 hours. Makes 12 sandwiches.

Please note: if you are allergic to peanut butter, find an acceptable substitute.

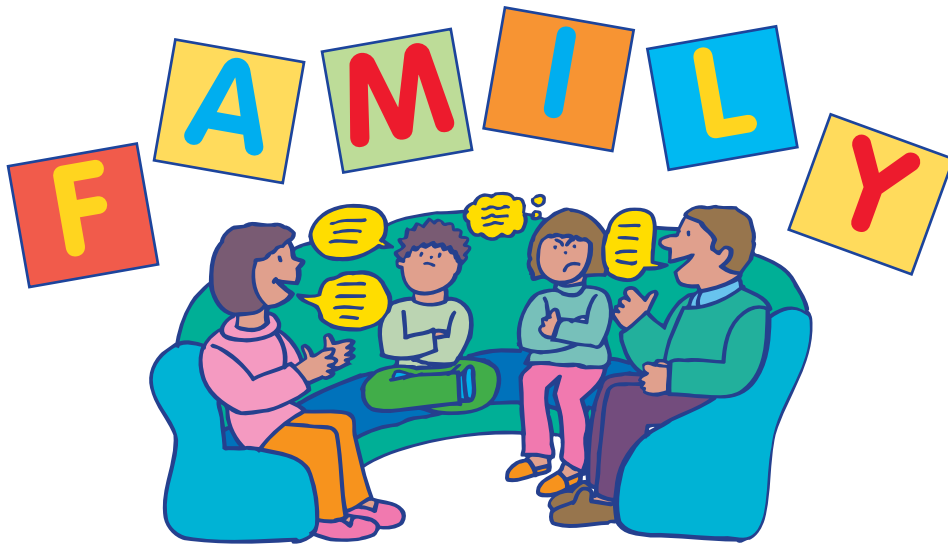


GIGGLE BELLY GAME

Have one player lie down on his back. The next player lies down with his head resting on the first player's belly and the next player lies down with her head on the second player's belly. Arrange all the players until everyone is zigzagged around the lawn or floor, each with his or her head on someone else's belly. If possible, make the line into a loop so that the last player can put her head on the first player's belly.



Then, the first player shouts loud and clear, "Ha!" The second player responds with a vigorous, "Ha, ha!" then the third player chimes in, "Ha, ha, ha!" Continue until all players have shouted out their "Ha's" or (more likely) have dissolved into uncontrollable laughter, with heads bouncing on the bellies of friends, brothers and sisters, uncles, cousins or grandmothers.



Everyone in the family is thinking about MS

When one person in a family has MS, everyone thinks about it, worries about it, and has lots of other feelings about it. When families talk about their feelings to one another, it helps everyone feel better.

Your parents love you and want you to be safe and happy. And they want to help you deal with your MS the best you can. They may also be frustrated and sad sometimes because they would like to be able to make MS go away and they don't always know how to make you feel better.

- **Brothers and sisters** may have lots of feelings about MS, too. They may be angry or jealous or sad. They may feel forgotten about or ignored as they watch you receive a lot of attention and time from your parents and other adults. They may wonder if anyone still cares about them! Brothers and sisters also can be frustrated because life seems so different now. They may feel mad that you even have to have this disease and may take out their anger on you even though it is the MS they are really mad at.

Here are some other feelings that brothers and sisters might have:

• **FEAR** – they worry about you; they might worry that they caused your MS or that they will get MS too.

• **SADNESS** – they hate seeing what you have to go through and hate not knowing how to help you feel better.

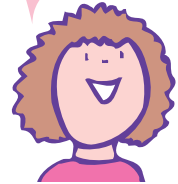
• **GUILT** – they feel bad about their bad feelings. They think they should be sick instead of you.

In fact, everyone in your family probably has felt these things. That's part of living with MS.



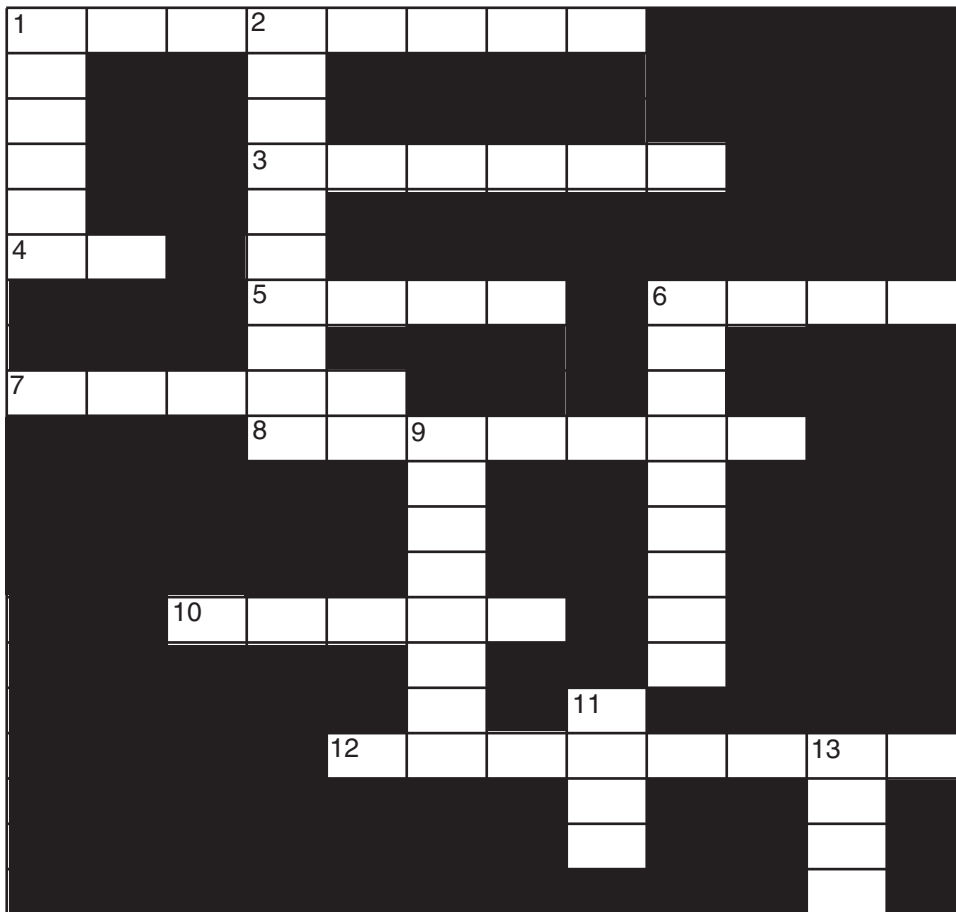
MS CROSSWORDS

DID YOU KNOW...? Multiple means many. Sclerosis means scars. So multiple sclerosis means 'many scars'. No one can see these scars unless they take a special picture called an MRI.



CHOOSE FROM THESE ANSWERS:

- * Sclerosis
- * Medicine
- * Damaged
- * Coat
- * No
- * Messages
- * Multiple
- * Pins
- * Shot
- * Myelin
- * Nerves
- * NMSS
- * Scars
- * Brain
- * Spinal cord



ACROSS

1. The brain sends _____ to other parts of the body
3. Myelin protects the _____ in the brain and spinal cord
4. Is MS 'catching'?
5. Myelin is like a _____ around the nerve
6. Some MS medicines are given in a _____
7. Sclerosis means _____
8. MS causes the myelin to be _____
10. This part of the body is like a computer
12. What might prevent MS from getting worse?

DOWN

1. The covering on the nerve
2. The part of the body that is like a thick cable of wires
6. This word means scar
9. This word means "many"
11. One of the symptoms of MS is _____ and needles
13. These are the initials for the National Multiple Sclerosis Society

FRIENDS AND SCHOOL

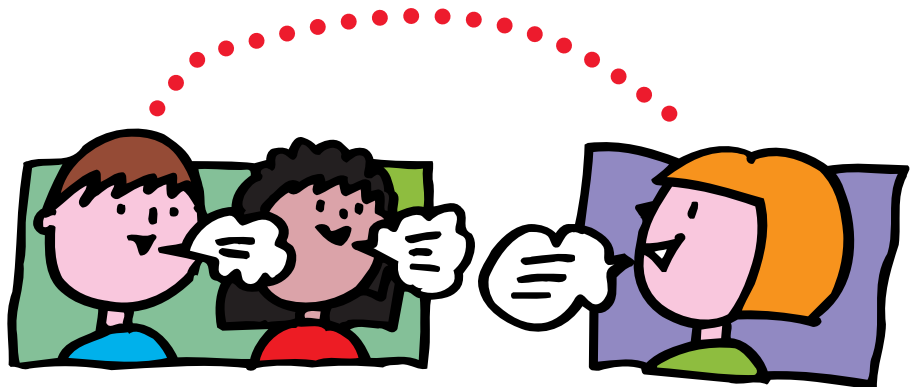
Telling friends about MS

You may wonder just what to tell your friends about MS. They are probably curious about what is causing your problems. Remember, you decide how much you want to tell your friends and classmates. Talk to your mom and dad about how to talk about it. You can even bring this booklet to your school.



Tell your friends that they won't get MS from being with you. You can tell them that it might make you miss school and that sometimes you may not be able to do things with them.

Tell them what symptoms you have and how you deal with them. You're still the same person you were before the MS! Some friends will be kind and helpful; others may tease you or say mean things. Talk to adults or other friends when someone isn't nice. Sometimes it's better to just stop being around people who tease you. Your good friends will understand that you are still you and that you can still have lots of fun together.



ACTIVITY

The "NEED TO KNOW" Notebook

If you are not sure which friends to tell and how much to tell about your MS, try making a page with three columns.

Here are some examples:



In the first column, make a list of friends,	In the third column write down why you think you should tell or not tell them.	
JANE:	Tell her all about my MS.	She's a good friend, a good listener, and a nice person.
ALEX:	Don't tell him about my MS.	He's got a big mouth and likes to tease.

In the **middle** column write what you think you should tell them

WHAT'S NEXT?



Here are some tips for living with multiple sclerosis:

♥ Even though you have MS, you are still the same, lovable you!

♥ Be proud of who you are. Who you are is more important than what you can or can't do.

♥ Keep asking questions and learn all you can about MS.

The National Multiple Sclerosis Society and the Multiple Sclerosis Society of Canada are 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, consult a qualified physician.

Neither the National MS Society, nor the MS Society of Canada approve, endorse or recommend products, therapies, services or manufacturers. The Societies assume no liability whatsoever for the contents or use of any product or service mentioned.

The mission of the National Multiple Sclerosis Society is to end the devastating effects of MS.

The mission of the Multiple Sclerosis Society of Canada is to be a leader in finding a cure for multiple sclerosis and enabling people affected by MS to enhance their quality of life.

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