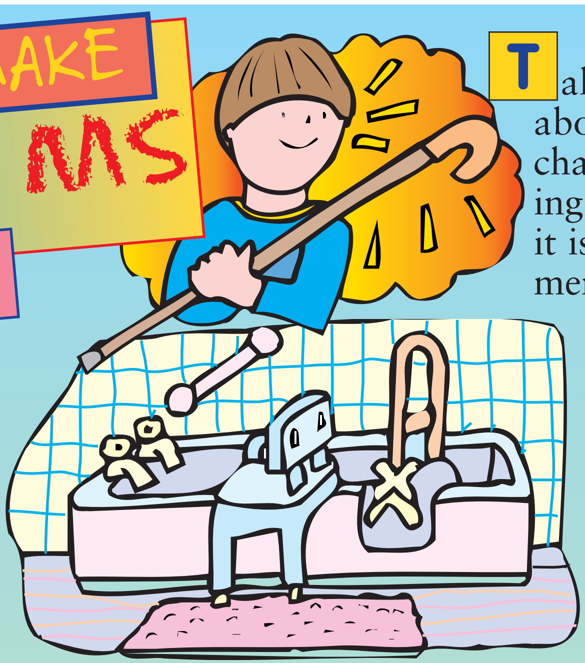
National
Multiple Sclerosis
Society

ISSUE #6/ EQUIPMENT

Keep S'myelin®

A NEWSLETTER FOR KIDS ABOUT MULTIPLE SCLEROSIS

TOOLS CAN MAKE LIFE WITH MS Easier

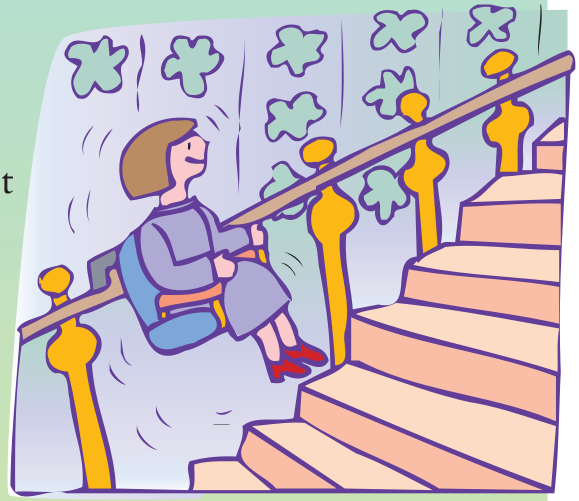


Many people with MS use different types of tools or gadgets to help them move about, have fun, and do everyday activities. For example, someone you know may use a cane, a wheelchair, a special chair glide that goes up stairs, grab bars in the bathroom, a sit-ski (a way to ski sitting down!), or a computer that works by talking to it! In fact, we all use tools to help us with every day activities: a back pack to help us carry things, glasses to help us see more clearly, a shopping cart at the super market...

Can you think of any other tools we use?

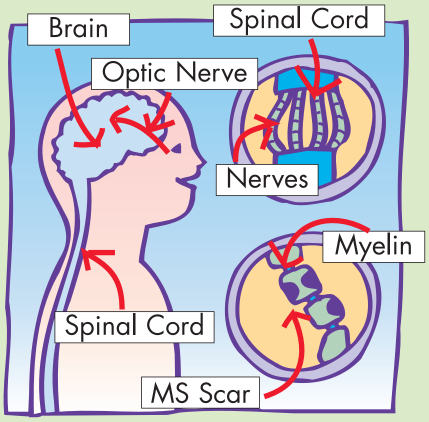
Perhaps your mom or dad has made changes to your house to make it easier and safer to get around, like building a ramp or adding a grab bar in the bathroom. All of these things can be very helpful for someone with MS, but some may seem strange at first.

Talk to your mom or dad about any new tools or changes that may be coming to your house. Ask if it is safe to try the equipment yourself (with adult supervision). And ask lots of questions about how it works and why your mom or dad needs it. That way, the new things will soon become familiar. And you will understand how these things can really be helpful in your house!



MS

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.



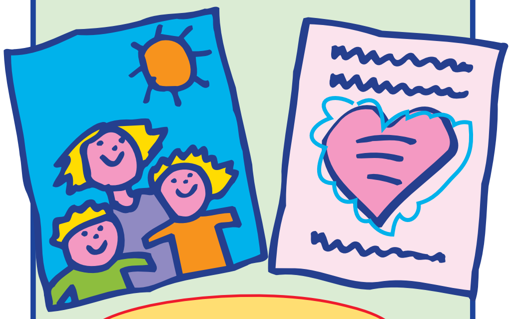
When a person has MS, the covering (myelin) that protects the nerves gets damaged. Scars form where the myelin is damaged. As messages travel from the brain, they sometimes get stuck or slowed down by these scars. When this happens, the other parts of the body can't always do what the brain is telling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

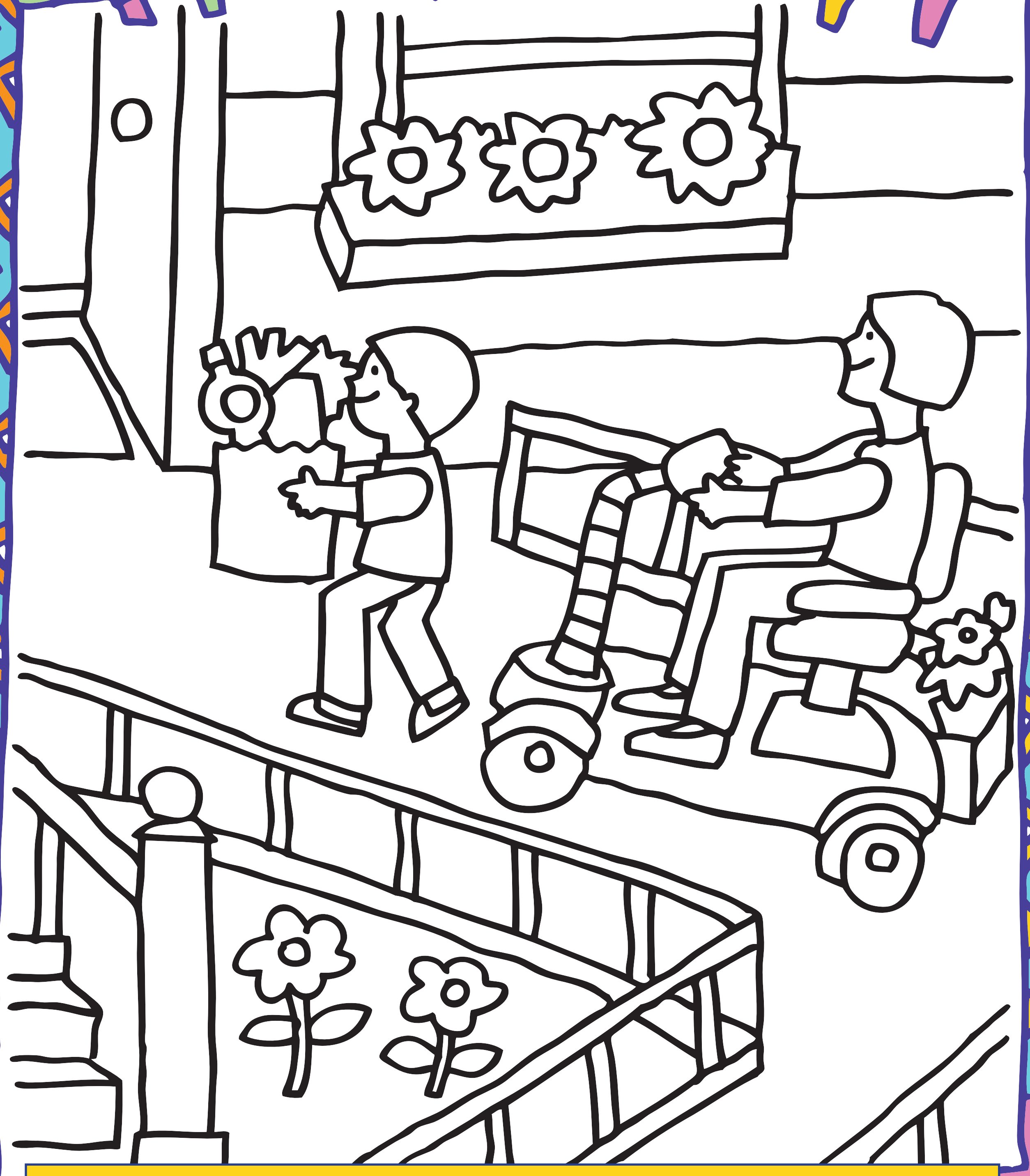
Keep S'myelin Readers: WE WANT YOU!

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 S. Broadway Ste. 200
Denver CO 80209
or e-mail
keepsmyelin@nmss.org

COLOR ME



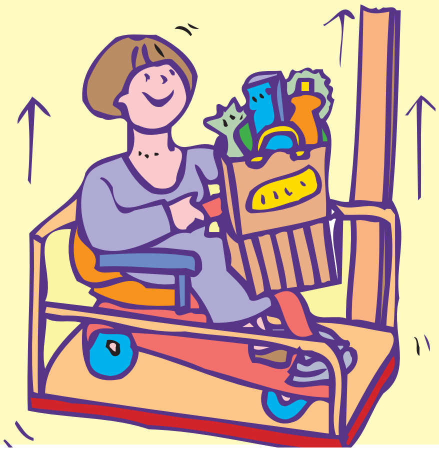
Sometimes my mom rides a scooter. We have a ramp to our house.

INTERVIEW WITH SCOTT

Scott's mom has had MS since he was two years old. She volunteers at Scott's school. She's helped to make changes at the school. This year, she succeeded in having the school build a curb cut and put in a new door. Soon they will install an elevator so it will be easier for people with wheelchairs to get around.

KEEP S'MYELIN: Does your mom use any special tools or have you made any changes to your house to help her do everyday things?

SCOTT: Yes. My mom uses a walker and a wheelchair. We have a porch lift on our house. This year, we moved my mom and dad's bedroom downstairs and built a bathroom with a roll-in shower and grab bars.



We also changed the kitchen so there's a roll-under sink and a laundry in the kitchen. And we put in an intercom so I can talk to my mom and dad's room from my room!

KEEP S'MYELIN: How did you feel about all those changes in your house?

SCOTT: I liked watching the workmen when they were here. The house feels bigger now and more organized. It's easier for my mom. Before, I helped carry her walker up the stairs and it was hard for me, too. I like watching movies with her and eating junk food in bed in her new room! And I really like the intercom.

KEEP S'MYELIN: What do your friends think of all the new things at your house?

SCOTT: I gave my friends a ride in the lift. They think it's cool. At my birthday they asked my mom why she uses a wheelchair. She told them that she has MS and it makes it hard to get around.

My Grandma has MS!

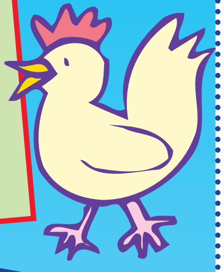
By Emily Anne

My name is Emily Anne and I am 10 years old. My grandma has MS. She lives with me, so I see her all the time having trouble walking around and doing things. She does the dishes, laundry and cleaning. I keep telling her to stop doing what she is doing, but she won't. She has a chair lift to go upstairs. I would put all the money in the world to get my grandma to get better. That is my opinion.

JOKES

What did the eggs do when the mother hen told them a joke?

They all cracked up.



Why was Thomas Edison able to invent the light bulb?

He was very BRIGHT.

What do you call cheese that is not your own?

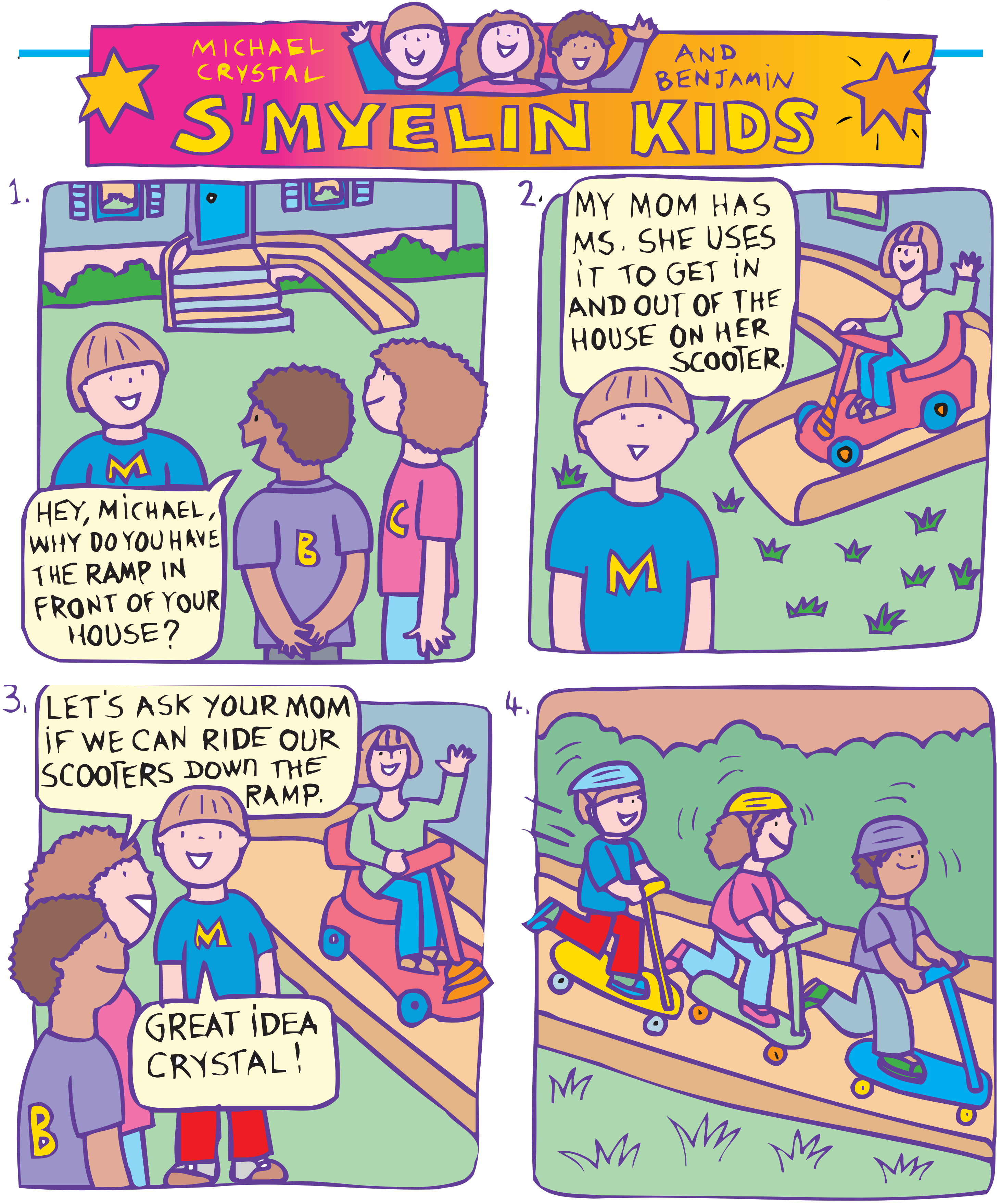
NA-CHO cheese

Why do witches use brooms?

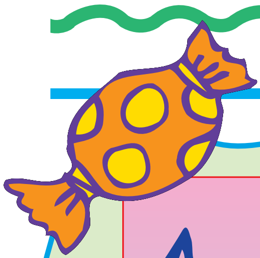
Because vacuum cleaners are too heavy.

What would you get if you crossed a frog with a bunny?

A bunny ribbit.


MICHAEL CRYSTAL AND BENJAMIN
S'MYELIN KIDS
1.
HEY, MICHAEL, WHY DO YOU HAVE THE RAMP IN FRONT OF YOUR HOUSE?
M
B
C
2.
MY MOM HAS MS. SHE USES IT TO GET IN AND OUT OF THE HOUSE ON HER SCOOTER.
M
3.
LET'S ASK YOUR MOM IF WE CAN RIDE OUR SCOOTERS DOWN THE RAMP.
GREAT IDEA CRYSTAL!
M
B
4.

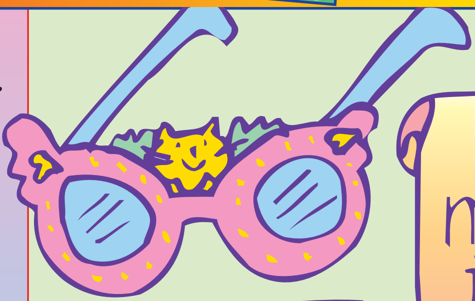
CAN GAME

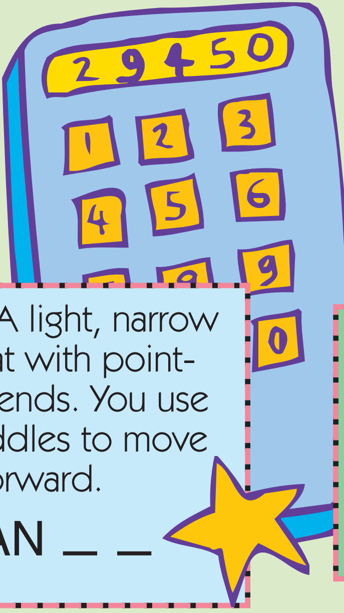


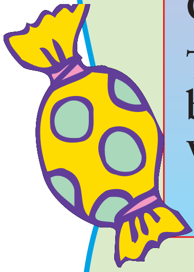
All kinds of things CAN make our lives easier. Glasses CAN help us see. A calculator CAN help us add numbers more quickly. A list CAN help us remember what we need to buy at the grocery store.

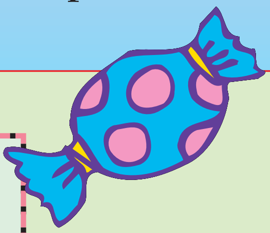
We all use tools everyday that CAN really make a difference.

There are lots of words that begin with CAN. How many words can you complete?









1. Sweet treats made with sugar that children especially enjoy at Halloween.

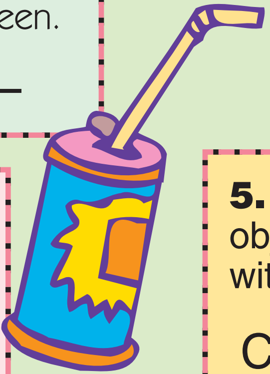
CAN _ _

2. A light, narrow boat with pointed ends. You use paddles to move it forward.

CAN _ _

3. A small, yellow songbird often kept in a cage.

CAN _ _ _



4. A fun dance involving high kicks.

CAN _ _ _

5. A tall, narrow tube object made of wax with a wick inside.

CAN _ _ _

6. A stick used as an aid in walking can help people keep their balance.

CAN _

7. A container for drinking water. Sometimes often carried by campers.

CAN _ _ _ _

ANSWERS

1.Candy 2.Canoe 3.Canary
4.Cancan 5.Candle 6.Cane
7.Canteen

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Contact your National MS Society chapter at 1-800-344-4867.

SINCE YOU ASKED...

Q. Why does my mom need to use a cane on some days, but not on others?

A. People with MS can feel different from day to day. On some days your mom's legs may feel tired or weak, or she may not have very good balance. On other days she may be just fine. That's why we say MS is unpredictable.

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PARENTS' PULL OUT

HOW TO READ KEEP S'MYELIN WITH YOUR CHILDREN

Introducing new equipment to your home or making home modifications may be disconcerting for some young children. Children, for the most part, are creatures of routine! They like finding things the way they left them and may find changes to their home environment disturbing and disruptive to their sense of security. As with all change, a little preparation can ease the way. So, if you are planning on purchasing a new scooter, wheelchair or a cane, installing a grab bar, building a ramp, or making other changes to your home, here are some tips on using this issue of Keep S'myelin to prepare your children :

READ **"Tools Can Make Life with MS Easier"** together and talk about the different tools your children use to make their life easier.

READ **the interview with Scott** about the changes his family made to their house. If you are having renovations done, prepare your children by telling them what is going to happen (e.g. the workmen will come tomorrow and start to build a ramp right next to the front steps so that I can get in and out of the house in my wheelchair. They will be here for 3 days and will probably make a lot of noise. When they are finished, you will be able to use the ramp or the steps to come in the house. And I will be able to go in and out of the house more easily!)

TALK **about the equipment** mentioned and illustrated in this issue. Talk to your children about new tools or equipment you plan to purchase. (e.g. "I am going to buy a new kind of wheelchair. It has a battery and I can drive it by just moving a switch on the armrest. I'll probably keep it in my bedroom when I'm not using it. It's only for me to use but I will give you rides on my lap!")

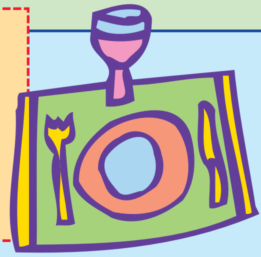
RESOURCES FO

ABLEDATA

Provides information on assistive technology and rehabilitation equipment to consumers, professionals and businesses. The ABLEDATA database contains information on products from canes to voice output programs. The database contains detailed descriptions of each product including price and company information.

From the ABLEDATA website, www.abledata.com you can search for different models of a specific device, such as powered wheelchairs, or for products which address a functional need, such as eating.

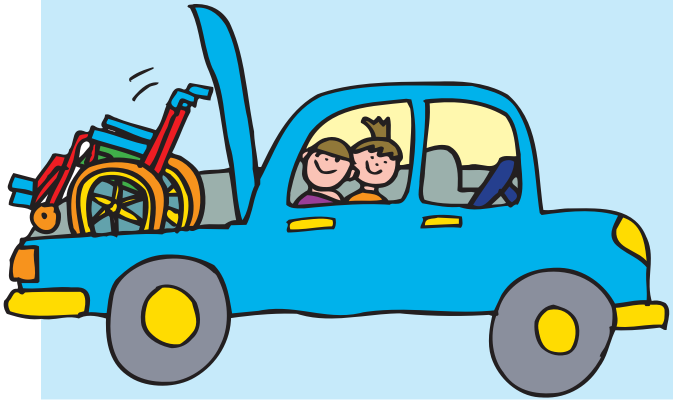
If you do not have access to the internet, you may contact one of their information specialists at 1-800-227-0216.



ALLIANCE FOR
TECHNOLOGY ACCE
(ATA)

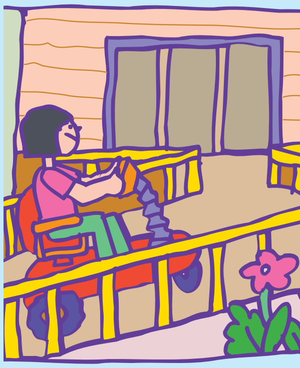
Is a non-profit organization with
sion to connect adults and childr
disabilities to technology. ATA pr
technical assistance, training and
port to 40 resource centers arour
country and to technology vendo
resource centers are places where
can explore computer, telecommu
tion systems and adaptive device
get connectd to technology and a
equipment vendors.

For more information contact ATA at 707-778-3011 or www.ATAccess.org.



THE HOME WHEELCHAIR RAMP PROJECT

Offers plans for design and construction of modular wheelchair ramps.
www.wheelchairramp.org



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THE BOULEVARD

Is a resource directory for the physically challenged.
www.blvd.com

To learn more about the National MS Society resources available to you and your family contact your chapter at 1-800-344-4867 or www.nationalMSsociety.org.

TIPS FOR MAKING LIFE WITH MULTIPLE SCLEROSIS EASIER

Book by Shelley Peterman Schwarz

Demos Medical Publishing
1-800-532-8663 or
www.demosmedpub.com

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.

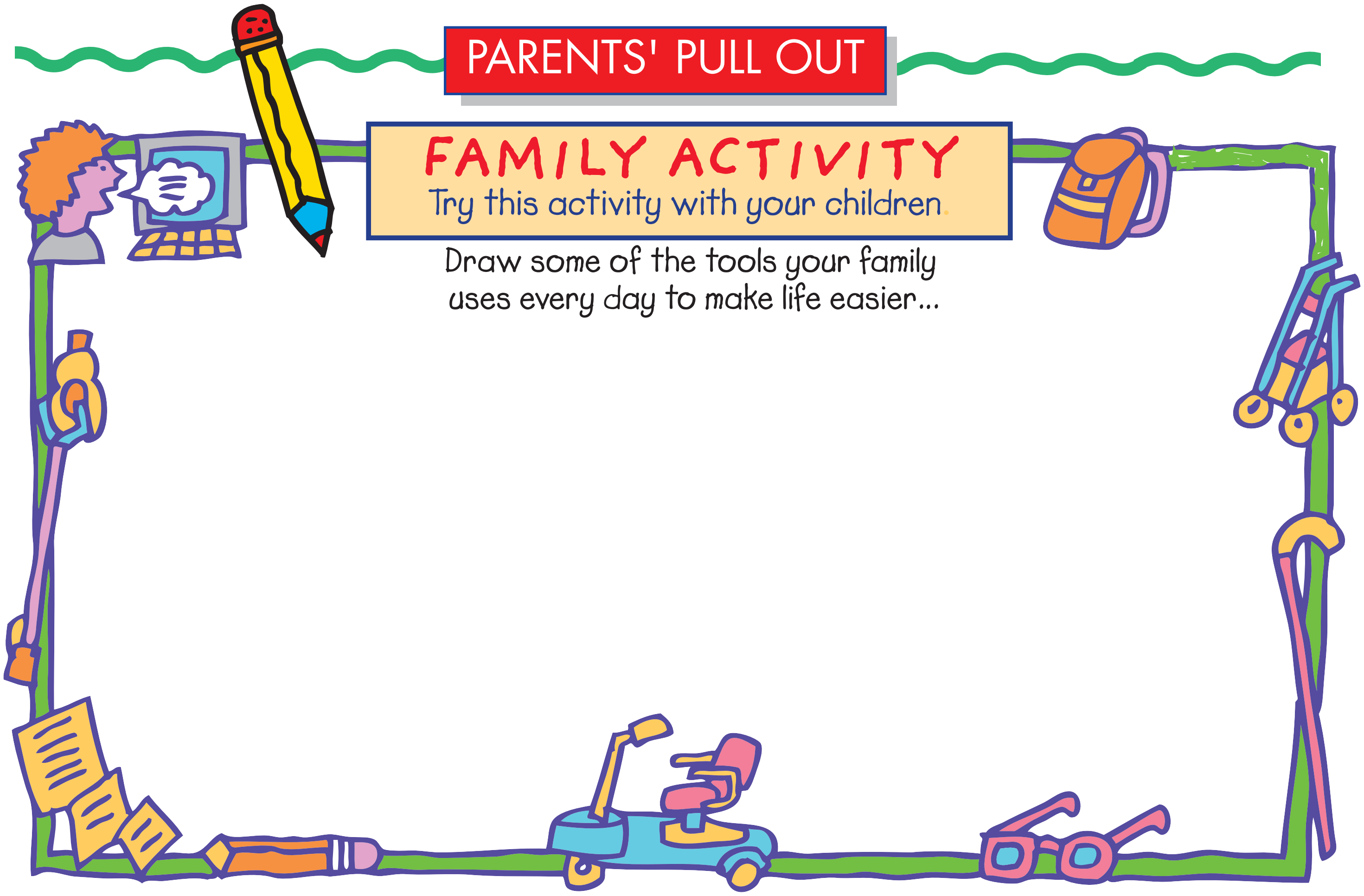
As of the printing of this newsletter, all phone numbers and web addresses were accurate. These are subject to change, however. If you discover an inaccuracy, we encourage you to check with Directory Assistance or an internet search engine.

PARENTS' PULL OUT

FAMILY ACTIVITY

Try this activity with your children.

Draw some of the tools your family
uses every day to make life easier...



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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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:

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