

KEEP S'MYELIN

A NEWSLETTER FOR KIDS ABOUT MULTIPLE SCLEROSIS

What is an Exacerbation?

EGG-ZAS-SER-BAY-SHUN

Imagine sitting in school. Suddenly the blackboard goes fuzzy and you can't read anything. Or imagine it's your turn to bat and suddenly you don't have the energy to take a swing or even walk off the plate. That is how it might feel to have an MS exacerbation (egg-zas-ser-BAY-shun). EXACERBATIONS is a very big word that means a time when new MS symptoms appear or old symptoms become worse.

- ★ EXACERBATIONS are also called relapses or attacks.
- ★ No one knows what causes a person to get MS in the first place. And no one knows what causes a person with MS who has been feeling fine to have an exacerbation. But we do know that there's nothing a kid can do that can cause a parent to have an MS attack: forgetting your homework, skipping chores, or fighting with your sister might annoy your parents, but it can't cause an MS attack!
- ★ MS exacerbations are usually temporary. Most go away within a couple of weeks or months. Sometimes, the person might need to go to the hospital for a while. The doctor may give the person some medicine that will help make the attack go away more quickly.

★ Sometimes MS EXACERBATIONS happen at the WORST TIME...

Your parent might have an attack on the day of your school play or when you are just about to leave on a family vacation. But there are two important things to remember:

#1 AN MS ATTACK USUALLY GOES AWAY.

#2 YOUR PARENT'S MS ATTACK IS NEVER CAUSED BY ANYTHING YOU DO.



MULTIPLE SCLEROSIS

(MS for short) is a disease that affects the central nervous system (the brain, optic nerves 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 between the brain, spinal cord, and 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, feel very tired, or have trouble walking. 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!"

HEALTHY MYELIN SHEATH



DAMAGED MYELIN SHEATH



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.

MS
National Multiple Sclerosis Society

KEEP S'MYELIN

900 South Broadway, Suite 200
Denver, CO 80209
or e-mail to:
KEEPSMYELIN@NMSS.ORG

TROUBLING SYMPTOMS

IF YOUR MOM OR DAD HAS AN EXACERBATION, HE OR SHE MAY NOTICE NEW MS SYMPTOMS.

Sometimes these symptoms appear and disappear quickly. Other times they last for a long time.

Some symptoms are mild and others are not. Here are a few of the especially troubling ones.

(REMEMBER THAT MS IS DIFFERENT FOR EACH PERSON, SO YOUR MOM OR DAD MAY NEVER HAVE ANY OF THESE SYMPTOMS.)



FATIGUE:

Feeling very tired. Many people with MS feel very tired even when they get enough sleep.

TROUBLE SEEING:

Some people with MS see double or have vision that is very blurry. It may be hard to drive or read.



TROUBLE REMEMBERING THINGS:

Sometimes MS can make it hard to remember things, even things that just happened. It may also be hard to pay attention or get organized.



SHAKING:

Some people with MS find that their arms or hands or head are shaky. It may be hard to hold a knife and fork, or write clearly, or put on lipstick.

PAIN:

MS can make different parts of the body hurt. It can make a person's skin feel itchy and painful.



TROUBLE WALKING:

Sometimes during an exacerbation a person may start to have more trouble walking and may need to use a cane or a walker or a wheelchair to get around.

Sometimes people only need these helpful devices for a short time. Sometimes they need to use them for a long time.

IF YOUR MOM OR DAD HAS ANY OF THESE SYMPTOMS DURING AN MS EXACERBATION, TALK ABOUT THEM TOGETHER.



LEARNING ABOUT MS CAN HELP EVERYONE FEEL A LITTLE BETTER.

KEEP S'MYELIN

KIDS

My mom is having a lot of trouble walking lately.

Her doctor said she's having an 'exacerbation'.

Try not to worry too much, Ben. We're your friends and that won't ever change!

I know what that means. Her MS may get worse for a while, but then it usually gets better again. **MS** is hard to understand because it keeps changing.



WAYS TO HELP IF YOUR MOM OR DAD HAS PROBLEMS WITH MEMORY OR THINKING...

Some moms and dads with MS have trouble remembering things or thinking as fast as they used to, no matter how smart they are. This can happen especially when people are tired.

Here are some suggestions for ways you can help if your mom or dad has this kind of problem:

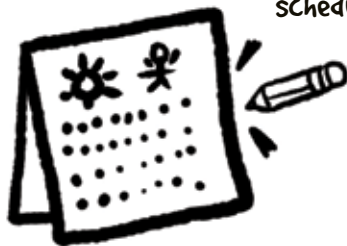
★ Try not to interrupt when your parent is thinking hard about something.

It may be hard for him or her to pay attention to two things at the same time....

★ Turn down the TV or music when you want to have a conversation.



★ Help your mom or dad make a family calendar with everyone's schedule on it.



★ Remember that a person who has trouble remembering may need to ask you a question more than once.

It doesn't mean that he or she wasn't listening the first time!



★ Try to keep things organized by putting them back where they belong. That way your mom or dad will always know where to find them.

ASK YOUR PARENT TO TELL YOU WHAT WOULD BE MOST HELPFUL. TOGETHER, YOU AND YOUR MOM OR DAD CAN THINK OF WAYS TO BEAT THIS PROBLEM.

REHABILITATION

AFTER AN EXACERBATION, YOUR MOM OR DAD MIGHT HAVE PHYSICAL THERAPY.

In physical therapy, people do exercises to try to get **STRONGER** and be able to do things the way they did before.

You can help by doing exercises with your mom or dad! That way everyone in the family can be as fit as they can be.



KYLIE'S STORY



Hi! My name is **Kylie**.
I am 10 years old and I wrote this
story when I was 9 years old
for Father's Day. Here it is:

MY DAD IS THE WORLD'S
FUNNIEST DAD BECAUSE
HE IS ALWAYS PLAYING JOKES,
SINGING, DANCING, OR PLAYING
HIS GUITAR WHILE SMILING.

HE IS THE **COOLEST** DAD BECAUSE HE
PUTS ME ON HIS SHOULDERS - AND I AM
9 YEARS OLD, SO I AM NOT SO LITTLE!

MY DAD IS THE MOST AWESOME,
BRAVEST DAD BECAUSE HE HAS MS
AND WHEN HE GETS HIS SHOT EVERY
WEEK, HE NEVER SAYS "OW" TO ME,
AND MOST OF ALL, HE ALWAYS
LOVES ME.

♥ KYLIE ♥

RIDDLES!

MULTIPLE SCLEROSIS IS A RIDDLE FOR RESEARCHERS
ALL OVER THE WORLD WHO ARE TRYING TO FIND A CURE.

HERE ARE SOME RIDDLES
FOR YOU TO SOLVE:

The more of them you
take, the more you leave
behind. What are they?

Answer: foot-steps

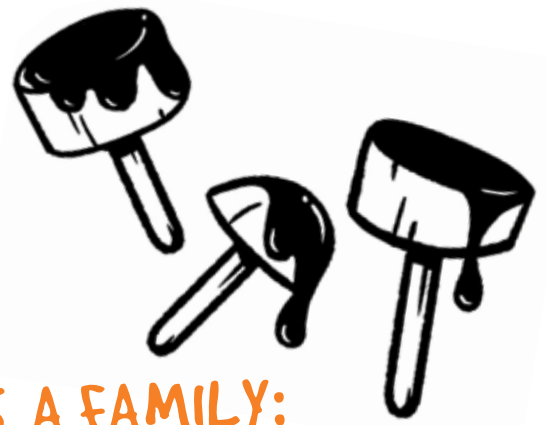
What's full of holes
but still holds water?

Answer: A sponge

What weighs more,
a ton of feathers or a
ton of rocks?

Answer: Both
weigh a ton, so they
both weigh the same!

FUN FAMILY ACTIVITY



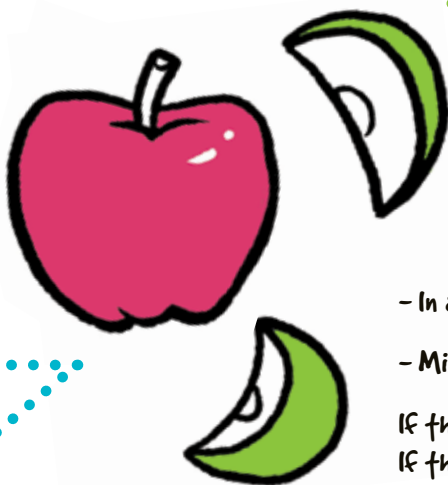
HERE ARE SOME FUN RECIPES TO TRY AS A FAMILY:

CHOCOLATE-DIPPED FROZEN BANANAS

- 8 medium bananas, peeled
- 8 wooden popsicle sticks
- 32 ounces semisweet chocolate, chopped or chips
- 4 tablespoons unsalted butter
- Dipping decorations: granola, chopped nuts, sprinkles, jimmies, crushed cookies, toasted coconut

- Line a sheet pan with waxed paper. Cut 1-inch off the end of each banana. Insert a popsicle stick into the cut-end of each banana, pushing the stick halfway in, leaving the other end exposed for use as a handle. Place the bananas on the sheet pan and freeze for one hour.
- Melt the chocolate and butter in a bowl over a saucepan of simmering water, stirring occasionally. This could also be done in a bowl in the microwave on a low setting.
- Arrange the dipping decorations on several flat plates. Working with 1 banana at a time, dip it in the chocolate and turn to completely coat (spoon some on, if needed). Roll the dipped banana in the desired decorations, transfer to the sheet pan, and return to the freezer.

★ Once frozen, store the bananas in an airtight container.



"APPLE" DIP

- 1 (8 ounce) package cream cheese
- 1/2 cup brown sugar
- 1 tablespoon vanilla extract

- In a medium-sized mixing bowl, combine cream cheese, brown sugar and vanilla.
 - Mix well until all of the brown sugar is blended into the cream cheese and vanilla.
- If the mixture is too thin, add a small amount of brown sugar to the mixture.
If the mixture is too thick, add a small amount of vanilla extract.

★ Serve with slices of apple, pear, bananas, etc. You can add peanut butter, nuts or chocolate sauce, or try using strawberry flavored cream cheese.

Have fun and enjoy!





National Multiple Sclerosis Society

900 S. Broadway, 2nd Floor
Denver, CO 80209-4198

Welcome to the new Keep S'myelin newsletter – we hope you enjoy the new look and feel. We want to thank you for your subscription.

We know there is a time when our subscribers outgrow the Keep S'myelin newsletter. If this is the case and you would like to be removed from the mailing list please call 1-800-344-4867 or email keepsmyelin@nmss.org. If we don't hear from you we look forward to sending you additional issues in the future.



ISSUE #18
KEEP S'MYELIN
EXACERBATIONS



TO LEARN MORE ABOUT THE RESOURCES AVAILABLE TO YOU AND YOUR FAMILY, PLEASE CONTACT AN MS NAVIGATOR AT 1-800-344-4867.

FAMILIES CAN COUNT ON THE NATIONAL MS SOCIETY.

YOU ASKED. WE ANSWERED.

Q: When it's very hot outside, my dad has more trouble walking. Is this an exacerbation?



A: No. Sometimes MS problems get worse for a while when a person gets very warm. This happens to your dad when it's hot outside. It may also happen when he takes a hot bath or has a fever. Usually, the symptoms get better when the person cools off.

So, this isn't a true EXACERBATION.

MANAGING AN EXACERBATION & THE FEELINGS THAT GO WITH IT

Once your healthcare provider has confirmed that you are experiencing an MS exacerbation (also called a relapse, episode or attack), your next steps will be to identify strategies for managing the situation.

An exacerbation is like an acute illness superimposed on a chronic one. It feels like a crisis because the status quo is disrupted, symptoms feel worse, the outcome is uncertain, and everyone has strong feelings about it. The uncertainty of the situation is often as difficult for people as the physical challenges.

RESOURCES FOR YOU AND YOUR FAMILY



WHEN ONE MEMBER OF A FAMILY HAS MS, IT IS IMPORTANT THAT THE ENTIRE FAMILY LEARN ABOUT IT.

★ “When a Parent Has MS: A Teenager’s Guide” For older children and teenagers who have a parent with MS. Discusses real issues brought up by real teenagers.

★ “Someone You Know Has MS: A Book for Families” For children, 5–12. A story about Michael and his family explains MS and explores children’s fears and concerns.

★ “Just the Facts” Frequently asked questions about MS and the National MS Society.



The National MS Society offers over 60 publications on a variety of topics related to managing and living with MS. To learn more, contact an MS Navigator at: 1-800-344-4867 or visit nationalMSSociety.org/brochures.

HERE ARE SOME PRACTICAL TIPS FOR MAKING IT THROUGH THIS CHALLENGING TIME:

- ★ Follow your doctor's treatment recommendations and take steps to deal with the new or increased symptoms that you are having. If the doctor prescribes corticosteroids to help speed recovery from the attack, keep in mind that they can affect your mood and interfere with sleep.



- ★ To the extent possible, give yourself and your body time to regroup. You may need extra rest, help with daily

activities, and the luxury of focusing on your own needs for a little while. Talking this over with your family will give all of you the opportunity to brainstorm strategies for handling the daily routines. You may want to consider hiring help at home for this time to help with household chores or personal care.

- ★ If your functional abilities have changed as a result of the attack, be sure to ask your physician about rehabilitation options that might be helpful. Physical and occupational therapists specialize in helping people maintain their mobility and ability to carry out their chosen activities at home and at work. Remember that exacerbations are part of this disease; nothing you did or didn't do caused the attack to happen, and neither you nor your family members.

- ★ Feelings of grief and loss are normal reactions to change and loss. If an exacerbation temporarily or permanently changes your ability to do things that are important to you, or requires you to do them differently, you will need to allow yourself - and your family - to grieve. This grieving process is the first step toward re-establishing your shaken identity and starting the coping process that will enable you to meet the challenges ahead.

- ★ Be patient. It may take a few weeks or months for you to feel like yourself again. In the meantime, mobilize your resources, including your healthcare team, the National MS Society, and family and friends. There is no need to deal with an exacerbation all by yourself.



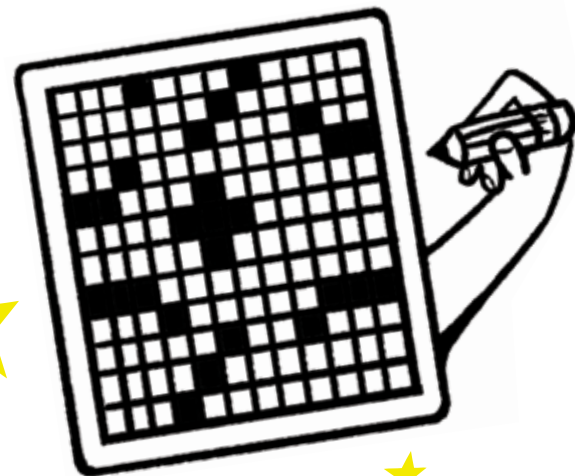
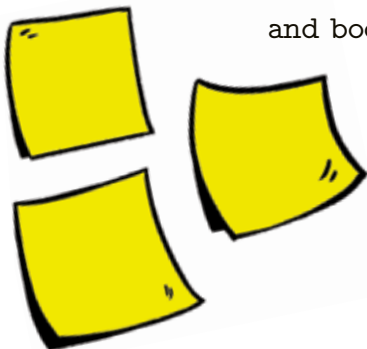


COPIING WITH COGNITIVE CHALLENGES:

Memory, planning, foresight, and judgment are part of what makes us human. This is what we call cognition. More than half of people with MS experience some type of cognitive impairment, although, most (80%) exhibit relatively mild symptoms such as difficulties remembering lists of food items to buy in the supermarket or performing tasks in distracting environments. These symptoms are generally mild enough that people can learn ways to compensate for them. The remaining 20 percent experience more serious cognitive problems that may interfere with their ability to work and engage in activities such as driving and cooking.

Most people experiencing memory impairments can compensate by relying more on visual cues such as post-it notes, calendars, date books, and day planners. An electronic organizer, Smartphone, or a handheld tape recorder can be particularly helpful. Also, you may want to keep a family calendar to help everyone in the household keep track of each other's activities and commitments.

Making lists will help to organize and prioritize information, errands, and tasks, and will aid recall. It is important to check items off as you accomplish them. Exercising the mind - reading newspapers and books, playing cards, doing crossword puzzles,



engaging in stimulating conversation - can also be helpful. For people with attention problems, directing concentration on a single task is preferable to doing too many things at once. When engaging in tasks requiring intense concentration, try to avoid noisy or distracting environments.

For people with more severe cognitive problems, cognitive retraining programs are available through some medical centers. Typically these programs are conducted by rehabilitation specialists from a variety of disciplines, including clinical neuropsychologists, speech pathologists, and occupational therapists.

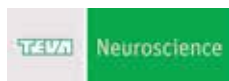


**TO LOCATE A COGNITIVE SPECIALIST NEAR YOU,
(CALL AN MS NAVIGATOR AT 1-800-344-4867.**

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Keep S'myelin is a publication for children with parents or other relatives with multiple sclerosis. The National Multiple Sclerosis Society ("Society") is proud to be a source of information on multiple sclerosis. The information provided is based on professional advice, published experience, and expert opinion, but does not constitute medical advice. For specific information and advice, consult a qualified physician. The Society does not endorse products, services or manufacturers. Such names appear here solely because they are considered helpful information. The Society assumes no liability for the recipient's use of any product or service mentioned.

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The National MS Society mobilizes people and resources to drive research for a cure and to address the challenges of everyone affected by MS.