

KEEP S'MYELIN[®]

ACTIVITY BOOK



★ **WHEN** one member of a family is diagnosed with **MS**, it is important that the entire family learn how to live with it - and finding comfortable ways to talk about **MS** can be an important step in that process.

★ **OUR GOAL** is to provide children with accurate information about a complicated disease in a format that is easy to understand and fun to use.



★ **AS YOU KNOW, CHILDREN LEARN IN MANY DIFFERENT WAYS.** One likes to read or do activities alone, while another enjoys reading aloud with you or playing games. One has lots of questions for you while another asks nothing at all.

* This activity booklet can be used in any way that is fun and comfortable for your children and you. As you read, you may think of things you would like your kids to know about your **MS**.



SHARING INFORMATION

IS HELPFUL IN SOME VERY SPECIFIC WAYS:

- ★ Without any information to explain the changes they sense going on around them, children use their imaginations to fill in the blanks. Often, the things they imagine are far worse than reality.
- ★ Younger children tend to see events in their lives as connected to their own actions. This way of thinking sometimes leads children to believe that they may have caused their parent's **MS** or caused it to worsen. Accurate information about **MS** reassures them that they have not caused their parents to get **MS** and helps alleviate any guilt they may be feeling.



- ★ Kids often have no idea how to express their questions and feelings about **MS**.
- ★ **KEEP S'MYELIN** provides them with the **vocabulary** they need to share their concerns.
- ★ By reading this booklet with your children, you are also reassuring them that it is okay for them to talk to you about **MS**.
- ★ Information about **MS**, and about other families who are living with it, assures children that they are not alone. Through the **S'MYELIN KIDS** cartoons, they will read about other kids who share similar experiences.
- ★ When you share important information about **MS** and your efforts to cope with it, you are modeling the kind of openness and communication that parents and children need to have in today's world. As a result of your openness, they will be more likely to share with you the issues that come up in their own lives.

★ **REMEMBER** that too much information at one time can be overwhelming, so try to answer only the question they are asking. When they're ready for more, they'll ask. There may be times when some questions may be difficult or upsetting for you to answer. That is where the **MS** Society can help. Our **MS** Navigators are available to assist. Please contact us at 1-800-344-4867 or contactusNMSS@nmss.org.

TALKING WITH YOUR CHILDREN ABOUT MS



EVEN in the face of a serious illness in the family, children can be helped to adjust and go on with their lives. They can learn what they need to know, and be given support and understanding.

EVEN if the parent with **MS** returns to full health, a child can be greatly affected by the idea of mom or dad's serious illness. Children sense that something is different at home and try to figure out what the problem may be.

IT IS IMPORTANT TO BE HONEST WITH YOUR CHILDREN ABOUT WHAT IS GOING ON, BECAUSE:

1. Children are affected by everything that happens in the family.
2. The more serious the situation, the more they will be impacted.
3. Withholding information and keeping secrets from your children, in any way, will inevitably make things worse.

FROM THE BEGINNING IT IS RECOMMENDED THAT YOU TELL YOUR CHILDREN:

- That mom or dad has a disease.
- The name of the disease.
- Your best understanding of what may happen.

BECAUSE CHILDREN CAN IMAGINE THINGS THAT ARE MUCH WORSE THAN THE TRUTH, IT IS IMPORTANT TO INCLUDE THEM AS SOON AS POSSIBLE.

★ OPENNESS AND HONESTY ARE SOUND, GUIDING PRINCIPLES FOR DEALING WITH YOUR CHILDREN.



WHAT IF
MS HAS NOT
BEEN DISCLOSED
OUTSIDE THE
FAMILY?

*THIS IS A
DIFFICULT QUESTION
TO ANSWER, AND
EACH FAMILY NEEDS
TO ASSESS ITS OWN
NEEDS AND PRIORITIES.

THERE ARE TWO MAIN REASONS WHY YOUNG CHILDREN
★ SHOULD NOT BE ASKED TO KEEP SECRETS:

1. They are usually unable to do so.
2. Being told that something needs to be kept a secret from others usually makes it seem shameful or bad.

★ **IT IS PARTICULARLY IMPORTANT** over the long run that children (and parents) **NOT** think of **MS** as either *shameful* or *bad*.

★ On the other hand, children can and do develop an understanding of the need for **PRIVACY** - which means not sharing *everything* with *everyone*. A young child, for example, might be comfortable with Mom and Dad knowing about episodes of bed-wetting, but would be very unhappy for classmates or strangers to know about them.

★ It will be important for you to let your children know whom they can talk to about your **MS** (e.g., mom, dad, grandparents, and Aunt Karen) and who doesn't have any need to know about it (e.g., strangers, kids at school or neighbors).

In deciding whether or not to talk openly with children about the **MS**, each family must evaluate the potential consequences.

★ **FOR EXAMPLE**, a parent might not want **MS** to be talked about outside the family if it poses a threat to employment. Balanced against this concern is the fact that children sense very clearly when one or another parent is ill or distressed and may develop their own worries about what is going on.

★ As you sort out your own priorities and concerns in this area, stay alert to your children's signals. While they may not come right out and ask what is wrong, they may demonstrate in other ways that they are curious, worried, or upset by changes in Mom or Dad.



How can I explain my illness to my children?

HOW INFORMATION ABOUT MS HELPS KIDS



PARENTS OFTEN WONDER HOW MUCH TO TELL THEIR CHILDREN ABOUT MS.

They worry that talking about the MS will be too frightening, too confusing and too burdensome for the kids to handle.

They don't want their young children to have to deal with Mom or Dad's MS "until they are older."

In our experience, children with a parent with MS are already dealing with the impact of the disease, whether or not it is being talked about openly in the household. This is because kids of all ages have a remarkable ability to sense what is going on around them, particularly when it affects their parents.

They can tell when their parents are worried, upset, preoccupied, or feeling tired or blue.

HOW CAN YOU EXPLAIN YOUR ILLNESS TO YOUR CHILDREN?

THE MAIN WORRIES, QUESTIONS AND FEARS MOST CHILDREN HAVE ARE:

That something they did made your MS worse.

Suggested answer: "No one knows what makes MS worse, so nothing you said or did or could say or do will make my MS worse."

Who will take care of them. Who will do the "Daddy" things while Daddy is sick.

Suggested answer: Reassure them that you and/or other family members/family friends will take care of them, and that everyone will help each other and share responsibilities so that all the important stuff gets done.

That they caused your MS by something they did or did not do.

Suggested answer: "Nothing you did made me get MS."

That MS is contagious.

Suggested answer: "You can't get this from mom/dad. You don't catch MS like you catch a cold."

Faced with the news of a parent's serious illness or disease, all but the youngest children will wonder: Will my parent die? They may or may not ask the question out loud, but it is important address it.

Suggested answer: "Most people with MS live as long as everyone else – MS is not a fatal disease most of the time."

That something you did caused your MS. One child said that his mom got MS because she worked too hard.

Suggested answer: "Nothing I did made me get MS."



★ CHILDREN OFTEN HAVE DIFFICULTY UNDERSTANDING MS SYMPTOMS

- particularly ones that are not easy to see, like sensory changes, weakness, and fatigue.

USE the following activities to initiate conversations with your child about the symptoms you are experiencing. Having a better understanding of your symptoms may help allay your child's fears and confusion.

EXPLAIN to your child that these activities will give a sense of what your symptoms feel like. It will be a similar feeling, but not exactly the same.

* After each activity, ask your child to tell you what it felt like to "try on" the symptom (frustrating, funny, clumsy, scary...). Some children may giggle and find the activities fun. Other children may feel uncomfortable, frightened or sad.

*** Be alert to your child's reaction, so you can tailor your response.**

1. WHAT DOES IT FEEL LIKE TO HAVE TROUBLE MOVING YOUR LEGS?

Have your child put on ankle weights and walk around the house or up the stairs. (If you don't have ankle weights, a long tube sock filled with sand and tied around the ankle is an easy substitute.)

2. HOW DOES IT FEEL TO DO THINGS WHEN YOUR FINGERS ARE NUMB?

Have your child put on a pair of work gloves (like gardening gloves) or a thin pair of winter gloves. Have your child remove the wrapper from a granola bar or pick up kernels of popcorn from a table with the gloves on.

3. WHAT DOES THE WORLD LOOK LIKE WHEN YOU HAVE BLURRED VISION?

Take a pair of sunglasses and smear petroleum jelly over the lenses. Have your child wear the glasses and then try to read a book or make a peanut butter and jelly sandwich.

4. WHAT IS IT LIKE TO DO THINGS WITH ONLY ONE HAND?

Have your child try some routine activities using only one hand, such as buttoning a shirt or making a bed.

5. WHAT IS IT LIKE TO DO THINGS WHEN YOUR ARMS FEEL WEAK OR HEAVY?

Have your child put on a set of wrist weights and try setting the table, doing homework, typing on the computer, or giving you a hug.

WHILE WAITING FOR A CURE...



★ **EVERYBODY WANTS A CURE FOR MS.**
And everyone feels impatient waiting for it to come.

★ The best thing someone with **MS** can do while waiting for the cure, is to keep as healthy as he or she can, and try to be positive and upbeat.

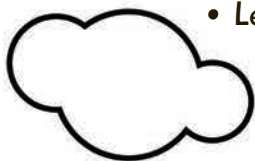
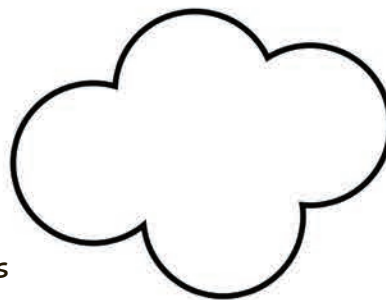


CAN SOMEONE WITH MS BE HEALTHY?

YES! And while thinking about a cure makes everyone feel hopeful, it is also important to enjoy life every day.

★ **HERE ARE SOME WAYS SOMEONE WITH MS AND HIS OR HER FAMILY CAN KEEP HEALTHY AND HAPPY WHILE WAITING:**

- Laugh and have fun together as a family
- Eat nutritious meals together as a family
- Talk to one another about important things
- Get regular medical and dental check-ups
- Work with the doctor to manage **MS** symptoms and slow progression of the disease
- Exercise
- Learn new things



From fundraising events to influencing policy to volunteering to help others

MS
HAPPENS
TO FAMILIES,
NOT JUST TO
INDIVIDUALS.

EVERYONE CAN MAKE A DIFFERENCE.

CONNECT NOW! Families can count on the National MS Society.

THE NATIONAL MS SOCIETY is here to help you and your family navigate the challenges of living **MS** with a personalized response to your unique needs. Our **MS** Navigators can answer your questions and access information about the options available to you. We are your partner in your journey living with this disease.

Join the conversation
Visit **MSconnection.org**
to meet other families living with MS.

Contact an **MS** Navigator at
1-800-344-4867 or email
contactusNMSS@nmss.org

★ BROCHURES, DVDS AND EDUCATIONAL VIDEOS

The National MS Society has more than 60 publications and 200 videos and DVDs on a wide range of topics related to MS.

LIVING WITH MS (brochure) addresses questions frequently asked after diagnosis of MS is received - from possible causes to advice on coping.

MULTIPLE SCLEROSIS: JUST THE FACTS (brochure) answers frequently asked questions about MS and the National MS Society.

SOMEONE YOU KNOW HAS MS: A BOOK FOR FAMILIES (brochure) For children, ages 5-12. A story about Michael and his family explains MS and explores children's fears and concerns.

PARENTING WITH MS
nationalMSSociety.org/parenting

MOMENTUM MAGAZINE
nationalMSSociety.org/Momentum

PLAINTALK - A Booklet about MS for Families (brochure) discusses some of the more difficult physical and emotional problems many families face.

TIMMY'S JOURNEY TO UNDERSTANDING MS (DVD) is an animated cartoon that shares a little boy's adventure learning about MS.

WHEN A PARENT HAS MS: A TEENAGER'S GUIDE (brochure) For older children and teenagers who have a parent with MS. Discusses real issues brought up by real teenagers.