

Talking about MS: A Guide for Families



TALKING ABOUT MS: A GUIDE FOR FAMILIES

The following resources were adapted, with permission, to develop this booklet: *Talking with your kids about MS* (MS Trust, 2010) and *How to Talk About MS with Your Children* (MS Society of Canada, 2001).

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Further acknowledgments: Special thanks to Jason Shein, Gillian Gunn, MSW, RSW, The Hospital for Sick Children, Toronto, Ontario and Jennifer Boyd, RN, MHSc, CNN(C), MSCN, The Hospital for Sick Children, Toronto, Ontario for their contributions.

This publication was made possible through the generosity of the Estate of Stella Shein and the Shein Family.

Design and Publishing: Greenwood Tamad Inc.

ISBN: 978-1-926803-11-1



Multiple Sclerosis Society of Canada
(National Client Services and Research), 2014
Legal Deposit -
National Library of Canada

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Introduction

Living with MS can be difficult and at times frightening, especially when you are newly diagnosed. While you may be the person diagnosed with MS, the diagnosis can affect the whole family. Each family is unique and each person's experience of MS will be different.

Many parents with MS question when, what and how to tell their children about their diagnosis. Some parents choose not to tell their children right away because they don't want to worry or scare them. Studies have shown that children know when something is wrong, even when parents try their best to conceal the truth. Children are quick to notice physical and emotional changes and can sense anxiety in the home. When children are not told about MS, they may seek answers using their imagination. This can sometimes lead to self-blame for the perceived physical and emotional changes in their parent.

It's natural to want to protect your children. If your symptoms are mild, you may prefer not to tell them about your MS right away. Your decision will depend on the age of your children and how you usually talk to them about health and other issues that arise in the family.

Before you talk to your children

Following a diagnosis, it is common for people to experience anger, fear, sadness and confusion. Typically, people need time to work through some of these feelings and consider what MS means to them before they feel ready to talk about it with their children and other family members. This time also provides an opportunity for parents to learn as much as possible about MS – not only for their own knowledge, but also in preparation for the discussions that lie ahead with their children. A parent knows their child's personality and emotions best, and will know when they are ready to talk about MS. The MS Society has a wide variety of resources to help educate those affected by MS; however, no parent will ever have all the answers. It is okay to tell your children that you don't have the answers to certain questions.

Children should be included in discussions, encouraged to talk about their own feelings and made to feel that their opinions or concerns matter. They need to be able to trust you, and being honest with them will help to achieve that. Keeping things hidden can be very stressful, and it is often a relief to get things out in the open.

Children can be very supportive, and they may surprise you by doing or saying something that shows they understand. Not all children will demonstrate understanding; some may appear unconcerned and, like some adults, try to ignore the issue. Others may have a more negative reaction – they may express

indifference, hostility or become withdrawn. These are all normal responses. Be prepared that children process information differently than adults and they may bring up feelings, questions and/or concerns at unexpected times.

TALKING ABOUT MS FOR THE FIRST TIME

Talking about MS for the first time can be scary; you might find it helpful to talk through what you plan to say with your partner or a friend first. Many parents prefer not to have a formal family meeting. If you have more than one child, it may be best to tell them all at the same time so that they start with the same information. You can talk to them individually at a later date when needed.

You must take the lead in talking about MS. Some children won't ask questions, especially if they are worried about upsetting you. There are several factors that might influence when you decide to have the first talk about MS.

- ➔ the ages of your children
- ➔ the type of MS you have
- ➔ your relationship with each child
- ➔ your own personal feelings about MS

The first talk you have with your children about MS is important. It opens up the subject for discussion and sets the tone for further conversations. If you are overly positive they might think that they can't admit their own negative feelings.

It is better to admit that you don't have all of the answers; if you tell them things that are not true, they may find out and feel unable to believe your reassurances in the future.

Don't try to cover everything in the first conversation. Keep it simple. The most important message is that while things might change, you will always love and care for them. Depending on their age, you may want to ask them if they know anything about MS so you can correct any misunderstandings.

Older children may overhear conversations about MS, and it may be helpful to speak to them about it sooner than later. You could explain that multiple sclerosis or MS is a name for some of the health problems you've been experiencing. It may be helpful to link symptoms such as fatigue and forgetfulness with MS, and tell them how these might affect you and the family.

Younger children may find the mechanics of MS too difficult to understand, and it may be helpful to talk about physical symptoms as they come up. Some children will accept a short chat and happily resume playing. If this is the case for you, don't push them to talk, as they may need time to process what you have told them. The important message is that all of their feelings and questions are fine and that MS can be talked about as much or as little as they need.

KEEP TALKING

Talking about MS is not a one-time occurrence. MS is unpredictable and can lead to continual changes in family life. Children need to be reassured during these times of change that their basic needs to be loved, fed and housed will always be met, regardless of how the disease progresses.

There may be times when you experience strong emotions like fear, anger or sadness, which you may want to hide from your children. Despite efforts to hide such feelings, children will likely notice them. They may also want to hide their feelings from you. Being honest with your children about what is making you feel sad may reassure them that the feelings are not directed at or caused by them. This may also give them an opportunity to share their feelings with you. Some parents feel that MS has brought them closer with their children. As they grow up, their understanding of MS will change. They may ask for more detailed information, so it's important to keep the lines of communication open.

Some children may feel more comfortable turning to the parent who does not have MS, a grandparent or a family friend for support. They may also choose to talk to a sibling rather than a parent.

Sometimes children may ask questions that upset you. While it is important to be open and honest with your children, it is essential that they don't stop asking questions for fear of upsetting you. If a question or comment takes you by surprise,

it might be helpful to say something like, “That’s a good question, but I need some time to think about it. Can we talk about it later?” This will give you time to deal with your immediate emotional reaction and think about how to respond. It’s important that your children know they can talk freely about MS, including their feelings about it.

HOW WILL THEY REACT?

Evidence shows that children can usually cope with quite a lot of information when adults are open and honest, and when children are made to feel that their feelings and opinions are important. Everybody experiences negative feelings in life, and children need to learn to cope with upsetting things. Giving your children the ability to understand and express their negative emotions about MS provides good skills for life.

Some children will seem completely unaffected by a parent’s diagnosis; others may become withdrawn or demonstrate changes in their behaviour. All these reactions are normal, and children need to be reassured that whatever they are feeling is reasonable and most likely how other children might feel in the same situation. You can help them most by expressing your own feelings, happy or sad.

WHAT SHOULD I TELL MY KIDS ABOUT MS?

Conversations about MS with younger children may be much simpler and shorter than conversations with older children and teenagers. Your children are unique individuals, and they may ask many interesting and challenging questions.

The following questions about MS are asked most frequently by children:

What's going to happen?

Most children will want to know if the MS will get worse and if it will affect their lives. They may worry about what will happen to them if you have to be hospitalized and can't look after them. It is important to acknowledge the unpredictability of MS and also admit that it worries you too. Reassure them that they will always be involved in decision-making when big changes occur.

How did you get MS and will I get it?

Children will ask why a parent has MS, and they will often wonder if they will get it too. Younger children may only be familiar with infectious illnesses like colds or the stomach flu; they may presume MS is contagious and then worry that they will get it through physical contact. Older children may be more aware of genetics and may be concerned that they will inherit it. You can explain that MS is not contagious and that, while some families have more than one person living with MS, it is actually not very common.

Can you die from MS?

Most children who are old enough to understand that people die will want to know if you can die from MS. They need reassurance that although MS can sometimes make people very sick, this does not happen very often. The vast majority of people with MS will live a long life.

Is it my fault you got MS?

Younger children relate everything to themselves, and they may worry that they have caused the MS. Some people may relate MS to life events such as pregnancy and birth. They may say, “My MS was fine until my son was two” or “My MS got worse after I had my first child.” Children may misunderstand these statements to mean that they were the cause of your MS. Remind them that MS is no one’s fault and that if they behave badly, it may make you angry, but it won’t make your MS worse. If you feel that your children are trying too hard, let them know that you appreciate their efforts but that good behaviour won’t change your MS.

GENERAL REACTIONS TO A PARENT'S DIAGNOSIS

Depending on their age, children may go through the same stages of grief you went through after your diagnosis. The following is a common sequence of reactions that children may experience when you tell them about your diagnosis. For many children, the sequence is not linear and they may experience these responses in a different order or move back and forth between stages. This is normal.

Shock

Depending on the age of your children, they may be surprised or shocked to learn of your MS, especially if there are no visible symptoms. Children may deal with shock differently. Some may not have the skills to effectively communicate their emotions and instead will act out at school or home. Some may not react at all, either because they are hiding their feelings or they do not understand what you have told them.

MS can mean many different things to children. It is important to find out your child's understanding of the situation. They may be worried and scared. This is expected and normal. They may ask you the same questions over and over again. Be patient with them – as you repeat the information they will start to feel reassured.

If your child is not asking questions, it may be helpful to ask him/her open-ended questions such as, "What's it like for you, knowing about my diagnosis" or "What do you feel/think

about it?" to get the conversation going and to gauge their level of understanding. These questions will make him/her recognize that it is okay to be scared and that talking about it is helpful.

Denial

After learning about the diagnosis, it is normal for children to act as though nothing has happened. They may not ask questions because they think that if they ignore it, it will go away. Some children may act out at school or home, while others may express themselves through drawings or play. Some denial is helpful as a coping strategy early on, but at some point it is helpful for them to express their emotions.

Anger & frustration

MS can disrupt usual family business. Children may be asked to take on more responsibilities at home; planned family or extra-curricular activities may have to be postponed or cancelled. Income loss may impact standards of living, and the child may feel a lack of attention from one or both parents. Children will react differently depending on what they have lost (i.e., missing a hockey game or a planned family trip to the zoo). They may give the impression that they are upset with you, when really these feelings of anger are directed at the MS.

If children become physically or verbally aggressive towards other members of the family, including the parent living with MS, additional support is usually required. In these situations, a family doctor will be able to recommend a family or individual

therapist. It is best to find a therapist who has worked with families who are affected by MS or other chronic conditions. Your local mental health agency may also be a helpful resource at no cost. To find the nearest location visit the Canadian Mental Health Association at www.cmha.ca.

Sadness

Children may feel sad and guilty. They will want the MS to go away and have the “old” you back. They may feel guilty for being angry at you when you are sick and decide that they are responsible for your relapses. Encourage them to express their hurt feelings and at the same time make sure they understand they are not responsible for your MS.

Some children will not cope as well and may need additional help. Not all of their behaviour will be due to MS. Some changes in behaviour may reflect other issues, like the birth of a new sibling or a problem at school. If you talk to your children about MS as they grow up, you will be in a better position to judge whether their behaviour represents a serious problem.

REACTIONS BY AGE

What and how you tell a child about MS will depend on their age and intellectual maturity. In addition, a parent’s state of mind will have a major impact on a child at any stage of development. The following section discusses the developmental stages linked to children’s understanding of MS, including their possible reactions.

Age	Developmental stage	Red flags: Things to watch for
0-3 years	<p>Child is affected by changes that occur to them personally.</p> <p>Separation from parent(s) is their biggest concern.</p>	<ul style="list-style-type: none"> • Regression (going back to bottles, pacifiers, diapers) • Separation anxiety • Agitation • More frequent crying or increased irritability
3-6 years	<p>Children in this age are still self-centred.</p> <p>Understand concepts of right and wrong, good and bad, etc.</p> <p>TIP: Role playing and drawing pictures of the “good” cells and the “bad” cells, and explaining that medicine helps the good cells beat the bad cells may be helpful.</p>	<ul style="list-style-type: none"> • Aggressiveness • Guilt • Nightmares • Fear of abandonment • Complaining about various ailments

Age	Developmental stage	Red flags: Things to watch for
6-12 years	<p>Understanding a disease like MS may still be challenging in this age range.</p> <p>Recognize that an illness can have more than one symptom.</p> <p>More aware of helping out when asked.</p> <p>Can assume more responsibility at home.</p>	<ul style="list-style-type: none"> • Aggressiveness • Sadness • Excessive fear • Feeling of heavy responsibility • Guilt • Problems at school
Teen-agers	<p>Trying to define their own identity.</p> <p>Tend to distance themselves from their parents at this age but in doing so may feel guilty if they think they need to be at home to help.</p>	<ul style="list-style-type: none"> • Apprehensiveness about the future • Lack of motivation • Difficulties at school • Behavioural problems

A word on teenagers

In families affected by MS, many teenagers take on added responsibilities at home, both in relationships and chores around the family home. These responsibilities will generally enhance their maturity and foster greater independence. At the same time, however, the extra responsibilities at home can hinder their personal development because it is important for young adults to begin taking on new responsibilities outside the home.

In addition, when a teen must stay at home to help with chores and other family business, he or she will have less time to spend with friends at a time when friends play a critical role in his or her life. They may feel different and isolated. It's important to give teenagers opportunities to socialize with their friends and to engage in activities of their choice. When there are any big changes that occur to the family, teenagers should be involved in the planning process as it will likely impact their daily or weekly routines. Teens should be encouraged to live their lives and participate in extra-curricular activities, take on part-time jobs, engage in social or sports clubs and hang out with friends outside the home to provide a balance between the added work at home and their own personal development.

The usual teenager issues should be addressed early on, as some teens may turn to certain self-harming behaviours as a way of coping, including alcohol and other substance use, promiscuous sexual activity, anti-social behaviour and mental health issues including depression, anxiety or eating disorders.

If any of these behaviours are suspected, it is important to address them right away. School counselors or family doctors can help to identify the appropriate guidance.

Young caregivers

Some of the added responsibilities that children and teens take on may also include providing care for younger siblings and the parent living with MS. There are some caregiving activities that children should not perform when possible, such as the personal care activities (bathing, bladder and bowel care) of their parent. This can be uncomfortable for both the young caregiver and the parent.

Some young caregivers become the primary caregiver for their parent, which can impact their school work, social and personal development. A balance should be established between their caregiving responsibilities and living their own lives. Developing a care plan with children or teens in a caregiving role will help to maintain that balance – with the understanding that there may be times when the plan needs to be flexible to accommodate the unpredictability that MS can sometimes bring. It is important that teens feel they can communicate their stress, and to talk about it before it becomes overwhelming. Encourage them to find activities that will help relieve stress such as exercising, hanging out with friends, talking to someone about their feelings (a social worker, teacher, guidance counsellor, etc.) or simply putting aside time for themselves to do something they enjoy doing.

DEVELOPING A CARE PLAN

Care plans provide caregivers, care recipients and other family members and friends with a regular yet flexible routine outlining the roles and responsibilities of everyone involved in the care of the person with MS.

Care plans can also assist with the day-to-day management of the household, which may provide primary caregivers with a little respite.

Start by making three separate lists. The first list should include daily caregiving responsibilities. The second list should include everyone's daily self-care activities (i.e., physical, emotional and spiritual activities). The final list should include household management activities that take place on a daily, weekly or monthly basis (i.e., grocery shopping, house cleaning and yard maintenance).

The goal of a care plan is to achieve balance between caregiving, household and self-care activities. Here are a few tips on achieving this balance:

- Hold a family meeting to discuss responsibility sharing, and where possible delegate responsibilities so that everyone is somehow involved.
- Adapt spaces around your home to encourage independence of the parent with MS and other family members.
- Some caregivers take on more than they need to because family members fail to communicate effectively; don't be afraid to ask for help. Everyone has a limit, and you need to recognize and communicate your boundaries.

Symptoms or situations that may affect your children

Fatigue

Fatigue is one of the most common and disrupting MS symptoms. Approximately 90 per cent of people with MS will experience fatigue over the course of the disease. Children may find it difficult to understand why their parent requires extra time to rest. Let your children know that MS can make some people feel very tired and that you need a little extra “quiet” or rest time. Parents with infants and toddlers may need to ask for extra help from other family members or close friends to manage fatigue. It may also be helpful for the parent living with MS to work with their MS care team to optimize their fatigue management through medication and energy conservation strategies to reduce its impact on family activities.

Loss of balance and mobility limitations

Parents with mobility issues may find it more challenging to play with their children like they did before MS. There are many ways to adapt activities so that parents are still able to play with their children. For example, you may want to play catch or basketball with children from a seated position. The important thing is to spend time with your children doing things you enjoy doing together.

Children may be unsure about mobility aids at first. If you use a mobility aid, encourage them to become familiar with it through supervised use or play to help remove any fear or

uncertainty they may have around it. If you have fallen in their presence, they may feel more secure about your safety knowing you are using your wheelchair, scooter, cane or other mobility aid.

Heat sensitivity (Uhtoff's phenomena)

Many people with MS experience sensitivity to increased body temperature, which can temporarily cause symptoms to flare up. Demyelinated fibers in the central nervous system can be very sensitive to even small elevations of core body temperature resulting in conduction (nerve impulse) delays or even conduction block. This sensitivity can be brought out by prolonged exposure to heat such as sunbathing, hot weather, hot baths/showers and saunas, exercise, fever (from illness or infection), or any other factor associated with an increase in body core temperature. Once the body temperature returns to normal, the symptoms generally subside.

Avoid illness by encouraging hand washing for the whole family, and to keep cool parent(s) may find some benefit in using:

- ➔ fans, air conditioners and keeping windows open
- ➔ wearing cooling vests/head wear
- ➔ choosing activities for play time with the kids in pools
- ➔ during rest times, have ice chips or ice water

Cognition

Invisible symptoms are difficult for children to understand. If you have a problem with memory, your children may misinterpret forgetfulness and assume you aren't paying attention. It is important to let your children know that you are paying attention but that sometimes MS can make you forgetful. Keeping a family calendar or reminders on your personal device will be helpful to keep track of activities and appointments. If you feel as though the cognitive changes are becoming more difficult to manage you may want to speak to your doctor about a cognitive assessment, which can identify areas of difficulty and ways to manage them.

Emotional or mood changes

Mood disturbances can be hard on children, especially mood swings, quick-temper and bouts of irritability. Children usually assume they have caused the altered mood, but they should be reassured that not all emotional changes are because of them. At the same time, it's important to let them know that sometimes their behaviour can upset you and that not everything is related to the MS.

Depression is more common in people living with MS than the general population and can be particularly troublesome for families, as it can impact how children are parented. For single parents, it is important to have a support network to avoid relying too heavily on the emotional support and companionship of your children. Talk to your doctor if you are feeling depressed. Depression can be managed successfully with medication and therapy.

EMERGENCY OR CRISIS PLAN

If you need to unexpectedly go in to hospital, it is best to have a plan in place to lessen the potential impact your absence will have on your family. As a family, discuss what might happen if you must go in to hospital for a while. Children should be comfortable with the plan and help make some of the decisions where possible. If a guardian is required, try to find someone who knows the family and family home well. Sometimes this is not possible, so once an appropriate guardian is identified it might be a good idea to have them join the family for dinners and other family activities so that the children can get used to having them around.

Make sure important phone numbers and other contacts are readily accessible to the guardian and ensure that they are well-versed in any morning, school or bedtime routines.

If you do need to go in to hospital, maintaining daily contact with your children is very important, either through hospital visits or phone calls. Some children are fine in a hospital environment but others may not be comfortable with it. Although it may be hard, their preferences should be respected and they should be encouraged to talk about their feelings.

FINDING THE POSITIVES

Any life-changing experience can alter your perspective on life. Children can gain from their experiences of having a parent with MS. Many children grow up with a greater sensitivity to the needs of others.

Children often enjoy quality time with a parent, doing things like talking, reading or playing games on a PlayStation or Wii, all of which can improve the quality of the relationship. Children may need to learn to be more independent than others their age, and it is well established that increased skills lead to greater self-esteem, coping ability and confidence. They will grow up with a better understanding of health and how to cope with negative emotions.

SUGGESTED RESOURCES

Multiple Sclerosis: Its Effects on you and those you love
MS Society of Canada, 2014.

A resource that answers some of the most frequently asked questions about the disease and also describes effective coping mechanisms.

Keep S'Myelin

MS Society of Canada and National MS Society, 2006.

A colourful activity book for children of parents with MS, intended to help children find answers to questions about MS.

When a Parent has MS: A Teenager's Guide

National MS Society, 2014.

<http://www.nationalmssociety.org/NationalMSSociety/media/MSNationalFiles/Brochures/Brochure-When-a-Parent-Has-MS-A-Teenagers-Guide.pdf>

Keep S'Myelin Newsletter

National MS Society - english only

Keep Your Balance

MS Society of Canada, 2006.

A colourful publication for teens, which includes basic information about MS and testimonies from teens who have a parent with MS.

Multiple Sclerosis: A Guide for Families, 3rd edition. Rosalind Kalb, Ph.D., Demos Medical Publishing, New York, New York. 2006

This book describes strategies and resources available to effectively help families manage living with MS.

Medikidz Explain Multiple Sclerosis, 2012.

Medikidz is an educational comic book about MS geared to children and teens aged 8 to 15. To obtain a copy please contact your MS Society Division office at 1-800-268-7582.



Contact the Multiple Sclerosis Society of Canada:

Toll-free in Canada: 1-800-268-7582

Email: info@mssociety.ca

Website: www.mssociety.ca

Our Mission

To be a leader in finding a cure for multiple sclerosis and enabling people affected by MS to enhance their quality of life.