



PARENTING with MS

REBECCA (RIGHT), DIAGNOSED IN 2013

Men and women who have been diagnosed with MS often have concerns about how the disease will affect their ability to have children and be good parents.

Their questions tend to fall into four main categories: Will MS interfere with my ability to have healthy children? Will pregnancy and delivery make my MS worse? Will I be able to be an effective parent and role model for growing children if I have a disability? What will be the impact of my MS on my children's emotional development? This chapter presents research and clinical findings in each of these important areas.

Having healthy children

Is MS inherited?

Although we still do not understand what causes MS, research suggests that a genetic component is involved in a person's susceptibility to developing the disease. In comparison to the general population, in which any person has a 1 in 750 chance of developing MS, children who have a parent with the disease have approximately a 2–5 in 100 chance of developing MS. Thus, the risk increases significantly for a person whose parent has MS, but still remains relatively low.

The risk is known to be somewhat higher in any family that has several members with the disease.

Does MS affect fertility?

While a woman's fertility is not affected by MS, men who experience MS-related problems with ejaculation will need medical intervention to assist with fertility. Since the majority of couples will not experience any reduction in fertility, you will probably be faced with the same decisions about birth control as any other couple. You are free to use any form of birth control that you find manageable and comfortable.

Keep in mind, however, that:

- Some forms require more manual dexterity than others.
- The diaphragm may increase a woman's risk of bladder infections.
- The effectiveness of birth control pills may be affected by medications such as Provigil®, Dilantin®, Tegretol® and some antibiotics.
- The effectiveness of an intrauterine device (IUD) may be compromised by antibiotics or immunosuppressive medications.

Because of these concerns, you may want to consider using additional birth control protection with any one of these methods.

How does MS affect pregnancy and childbirth?

A woman's MS will not affect her ability to have a normal, healthy baby. MS has not been found to affect the course of pregnancy and labor. Neither does it increase the risk of spontaneous abortions (miscarriages), complications during labor or delivery, birth defects or stillbirths. Any form of anesthesia is considered safe during labor, delivery or cesarean section for women with MS.

Can mothers who have MS breastfeed their babies?

Any mother who wishes to breastfeed can do so, provided that she has the strength to do it safely and does not require any medications that would be unsafe for the baby. And recent evidence suggests that exclusive breastfeeding for a period of time actually reduces a woman's chances of having a relapse after delivery. However, a woman whose MS was particularly active during the year prior to conception may be encouraged by her physician to bottle feed her infant so that she can re-start her disease-modifying therapy as soon as possible after delivery. Since fatigue can interfere with milk production, the new mother should get plenty of rest and have sufficient help available.

What medications are safe for use during pregnancy and breastfeeding?

As a general rule, the use of any medications during pregnancy and breastfeeding (including ones bought over-the-counter) should be done cautiously and under the supervision of a physician. If at all possible, a woman who wishes to become pregnant should consult a physician prior to conception about all the medications she is taking. The doctor will eliminate any unnecessary medications and substitute safer ones where necessary.

A woman who is taking any of the MS disease-modifying therapies (DMT) and wishes to become pregnant should review treatment options with her doctor. A woman who becomes pregnant while taking a DMT, or any other medications, should report the pregnancy to her physician as soon as possible.

Some of the manufacturers of the DMTs have created pregnancy registries to monitor women who have taken their DMT within a week of becoming pregnant or while they were pregnant. The purpose of the registries is to gather more information about the impact of the medications on pregnancy and unborn children. Information about the registries can be found at **nationalMSSociety.org/pregreg**.

Women can also get information about these registries from their healthcare professionals.

The impact of pregnancy and childbirth on the course of MS

Will having a baby make a woman's MS worse?

Before 1950, women with MS were routinely advised by their doctors not to have children. All of the published research since then, however, has pointed to a different conclusion.

Because of the protection provided by pregnancy-related hormones (approximately equal to the protection provided by the DMTs), a woman's MS is likely to be stable, or even improved, during the nine months of pregnancy. However, relapse rates tend to rise in the first three to six months following delivery — as the hormone levels gradually return to pre-pregnancy levels — with the risk of a relapse in the postpartum period estimated to be 20 to 40 percent. While these relapses do not generally increase women's long-term disability levels, they can add extra challenges for the new mother.

Have extra help on hand — just in case it's needed. Even if it turns out to be

unnecessary, new mothers and fathers are generally glad that it's there.

Researchers have concluded that pregnancy, delivery and nursing do not affect long-term disease course or level of disability. This means that a woman can make her decision knowing that becoming pregnant is unlikely to have any long-lasting impact on the course of her MS. Keep in mind, however, that group data from studies do not necessarily guarantee the outcome for a single individual. Given the unpredictability of MS, each woman with MS and her partner need to think through, and plan for, the possibility of a significant exacerbation following pregnancy.

Is adoption an option for a parent with MS?

If, after thinking carefully about all of these factors, a couple decides that pregnancy is not an option for them, they may want to consider adoption. People with MS can adopt both within the United States and internationally. A good adoption agency — either domestic or foreign — can help couples identify their options. Regardless of how one becomes a parent, it can be one of the most fulfilling and challenging experiences of a lifetime.



Cherish, diagnosed in 2002

Parenting effectively with MS

Will I be able to take care of my child?

Men and women with MS who ask this question are often concerned about caring for a brand new baby. Since babies don't stay babies very long, and since MS is such an unpredictable disease, prospective parents need to think constructively and creatively about the bigger picture. Like all parents, with or without MS, they need to look at their ability to provide a secure environment for their growing children. They need to think about their financial and emotional security, their individual views on parenting and their ability to work flexibly as a team. If the MS interferes with one

parent's ability to carry out certain roles and responsibilities, they will need to renegotiate their way of doing things — including parenting.

This is also true for single parents. When MS interferes, having a sound financial plan and a backup for parenting responsibilities can keep things running without a major crisis.

Will I be a good parent and role model for my child?

Most people have pretty strong opinions about what it takes to be a “good” parent. You may envision yourself playing sports or doing other kinds of physical activities as well as providing healthy meals, managing birthday parties and participating in school events. Fortunately (since many of us aren't particularly talented

in those areas anyway!), “good” parenting can come in a variety of different packages, and love can take many forms. The important thing is to provide children with a secure and loving environment in which to grow. Regardless of your physical abilities — or disabilities — you can model qualities for them like warmth, honesty, flexibility and the determination to meet whatever challenges come their way.

The impact of a parent’s MS on the children

How do children feel about their parent’s MS?

Research and clinical experience have demonstrated, by and large, that children who have a parent with MS continue to develop and thrive — emotionally, socially and academically. Having been reassured that their parent will be there to “parent” them, most children tend to go on about their business, focusing their attention on normal, everyday, child-centered things.

Research has also suggested that children cope quite well with a parent’s physical limitations, including the need for mobility aids like a cane or a wheelchair. Most children — particularly those in elementary school — would much rather have their parent at the

soccer game in a wheelchair than not have that parent there at all. Adolescents — who generally find their parents embarrassing or old-fashioned — may temporarily be less tolerant! The Society’s publication, **When a Parent has MS**, is designed to help teenagers understand the feelings they may have and suggests ways of dealing with changes in the family life that may occur.

In general, children have a much more difficult time understanding and coping with the less visible symptoms of MS such as fatigue, memory problems or mood changes. They may have a tendency to misinterpret these problems (e.g., mistaking a parent’s fatigue for laziness or disinterest, or memory problems for not caring enough to pay attention).

Children are also acutely sensitive to the emotional climate in the household. Thus, they may sense that their parents are tense, angry or anxious, and then try to come up with their own explanations for why this is so. Since children are, by nature, quite egocentric, they will tend to see themselves as the cause for their parent’s not feeling well or being upset. For these reasons, talk to children about MS and give them an age-appropriate explanation for their parent’s symptoms or any changes in the functioning of the household.

When should children be told about their parent's MS?

Research has shown that most parents tend to talk to their children about MS on a “need-to-know” basis. In other words, they begin to talk about MS when the parent has a symptom that the children can clearly see, or when the parent goes into the hospital for treatment, or the parent begins to use a new mobility aid.

We now know, however, that children sense problems, and react to them, even before they can be easily seen. When children sense that there is a problem or that their parent doesn't feel well, their imaginations go to work trying to come up with a reasonable explanation. Unfortunately, the reasons conjured up by a child's imagination are almost always far more dramatic and frightening than the reality. Therefore, it is usually a good idea to begin talking about the MS and its symptoms early on — so that a child's understanding of it can grow and develop over time. Children are less frightened by a reality they can talk about openly with their parents than by fantasies they create on their own.

What is the best way to talk about MS with children?

Unfortunately, there is no single, correct answer to this question. Each child has a unique learning

style. One may be fascinated by a picture book or video about MS while another responds best to small bits of information at a time. Some children enjoy going along when their parent visits the doctor, while others find this too upsetting. Your best strategy is to answer your child's questions as simply and honestly as you can.

This kind of open communication not only reassures children that it's okay to talk about MS, but also helps set the stage for effective parent-child communication about other important issues.

Explaining an invisible symptom of MS, such as fatigue or visual problems, will take some creativity on your part. Try to give your child the experience of the symptom in a concrete way. Examples of this might include:

- Walking for a few minutes with weights on both feet — to give the experience of MS fatigue.
- Looking through a pair of prescription glasses or sunglasses with a smear of petroleum jelly — to experience visual distortion.
- Wrapping an ace bandage around the knee — to mimic the stiffness caused by spasticity.
- Trying to unwrap a candy or button a shirt while wearing a pair of rubber kitchen gloves — to demonstrate the awkwardness that can come with sensory changes or weakness in the hands.

Once you have begun discussing MS openly within your household, you might want to consider giving your child the opportunity to talk with other children who have a parent with MS.

The National MS Society offers family programs where children can meet other kids and learn more about MS. The Society can also provide you with **Keep S'myelin Activity Book** for children ages 5–12, and point you toward other resources for older children.

What if the MS has not been disclosed outside the family?

This, too, 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. First, they are usually unable to do so. Second, being told that something needs to be kept a secret from others usually makes it seem shameful or bad, which it is not. Over the long run, children (and parents) should 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 their parent knowing about episodes of bed-wetting, but

would be very unhappy for classmates or strangers to know about them.

Let your children know whom they can talk to about your MS (e.g., parents, 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 the 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 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 their parent.

Over time, information about MS is useful to children in a variety of ways. The information can:

- Provide reassurance and help them feel more secure.
- Create a boundary around their fears so that overactive imaginations don't make things more frightening than they need to be.

- Provide children with a vocabulary for asking questions.
- Help prevent children from blaming themselves unnecessarily for turmoil or changes in the household.
- Reduce the need for secrecy and thereby promote an atmosphere of openness and trust within the family.

Things to think about

- MS does not determine a person's parenting skills.
- There is no single correct way to be a parent; love and security can come in a variety of packages.
- As a parent with MS, you may need to do things a bit differently than you would have otherwise.
- Accurate information about MS can be very reassuring to children.
- Communicating openly about the challenges that MS brings to your life, and the coping strategies you are using to meet those challenges, gives children the important message that family members can work together to meet life's challenges, whatever they may turn out to be.

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Resources

Thousands of resources, pieces of information and shared experiences about MS are available in print and on the internet. Some of the information you come across may be strictly experiential, anecdotal, unsupported or even inaccurate. Always consider the source; ask your healthcare provider or the National MS Society to help you identify credible resources.

From the National MS Society

For answers to questions about MS and its management, contact the National MS Society at 1-800-344-4867 or visit nationalMSSociety.org or the following topic-specific pages:

- nationalMSSociety.org/pregnancy
- nationalMSSociety.org/KIPparenting

The Society produces many other resources about various aspects of MS. These resources are available online or call 1-800-344-4867 to request.

- nationalMSSociety.org/educationalvideos
(also at youtube.com/nationalMSSociety)
- nationalMSSociety.org/brochures
(or see the Catalog of Informational Resources mailed with this book if you received it by mail)

- **Keep S'myelin Activity Book** — For younger children with a parent or loved one with MS. Discusses MS through stories and activities.
- **Timmy's Journey to Understanding MS (DVD)** — A cartoon designed to help children understand MS, which is available for home viewing.

Contact an MS Navigator® or visit our website to see what educational or recreational programs may be available to you and your family.

Books

Books may be available at bookstores and/or online booksellers.

- Kalb R (ed.). **Multiple Sclerosis: A Guide for Families** (3rd ed.) (2006). (NY:DemosHealth)
- Kalb R (ed.). **Multiple Sclerosis: The Questions You Have; The Answers You Need** (5th ed.) (2012). (NY:DemosHealth)
- Kalb R, Giesser B, Costello K. **Multiple Sclerosis for Dummies** (2nd Ed). (NJ:Wiley) (2012).

Other resources

- **Digesting Science** — An interactive website about MS designed specifically for children and teens at youngms.org.uk/home.

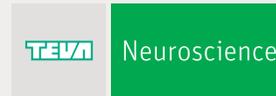
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The National MS Society’s mission is for people affected by MS to live their best lives as we stop MS in its tracks, restore what has been lost and end MS forever. To fulfill this mission, the Society funds cutting-edge research, drives change through advocacy, facilitates professional education, collaborates with MS organizations around the world, and provides services designed to help people with MS and their families move their lives forward.

The National Multiple Sclerosis Society (“Society”) is proud to be a source of information on multiple sclerosis related topics. The information provided is based on professional advice, published experience, and expert opinion, but does not constitute medical or legal advice. For specific medical advice, consult a qualified physician. For specific legal advice, consult a qualified attorney.

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Early and ongoing treatment with an FDA-approved therapy can make a difference for people with multiple sclerosis. Learn about your options by talking to your healthcare professional and contacting the National MS Society at **nationalMSsociety.org** or 1-800-344-4867.



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