



CADEN, DIAGNOSED IN 2011



HANNAH, DIAGNOSED IN 2017



PETER, DIAGNOSED IN 2015



# Kids Get MS Too: A GUIDE FOR PARENTS OF A CHILD OR TEEN WITH MS



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A GUIDE FOR  
PARENTS OF A  
CHILD OR TEEN  
WITH MS**

## Our MS Journey



Our son, Doug, was diagnosed with MS at the young age of 13. It was the most terrifying experience we had been through. We knew virtually nothing about MS and had to go back into the room to tell our son he had a disease we knew nothing about. The tears didn't stop for days. After a few days, and meeting with several doctors and specialists, we began to learn there was help. They had medication

available. As we researched and learned from some of the best doctors in the country, we began to feel some comfort.

As time progressed and we learned more, we felt empowered. We now focus on what we can do to help Doug stay healthy and feel his best. Doug focuses on exercise, eating healthy, taking his Vitamin D supplements, and never missing a dose of his disease modifying therapy, a doctor's appointment or MRI. He is reminded he has MS for 5 minutes a day as he does his injections. The other 1,435 minutes in the day, he focuses on being 18 and enjoying his life!

I know all too well how scared you might be right now. I promise it gets easier and that you and your child will be able to focus on things other than MS again, just like our family did. Learning about MS is the best way you can feel in control again. I encourage you to use this resource and connect to others who can relate and provide comfort in times of uncertainty. You are not alone—the National MS Society is there to be your supportive partner as you help your child live their best life with MS.

— John and Sarah Roderus

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# SECTION ONE—INTRODUCTION AND OVERVIEW

## Scary thoughts? ► Quick answers

You’ve just heard that your child has multiple sclerosis (MS). We’re here to help you learn about MS so you can feel confident in helping your child manage this disease. Before we go any further, let’s tackle some of those fears you have with some quick answers to help put your mind at ease.

<b>Is my child going to die?</b>	<b>No</b>
<b>Is there a cure?</b>	<b>Not yet</b>
<b>Did I do something to cause this?</b>	<b>No</b>
<b>Can my child give MS to someone?</b>	<b>No</b>
<b>Are my other kids going to get MS?</b>	<b>Probably not</b>
<b>Can my child continue to be active?</b>	<b>Absolutely</b>
<b>Will my child need a wheelchair?</b>	<b>Probably not</b>
<b>Can my child continue to go to school?</b>	<b>Yes</b>

Now that we’ve gotten those scary questions out of the way, let’s expand on these answers and help you feel empowered through knowledge.

### What is MS?

MS is a chronic, unpredictable disease of the central nervous system (CNS), which is made up of the brain, spinal cord and optic nerves. MS is thought to be an immune-mediated disease in which the body’s immune system mistakenly attacks normal tissue in the

CNS. This attack is aimed at myelin, the coating around nerve fibers (axons), and the cells that make myelin, which are called oligodendrocytes. The myelin coating around each nerve fiber serves as insulation, much like the plastic coating on an electrical wire. This helps to ensure the efficient transmission of nerve impulses (messages) between the brain and other parts of the body. When myelin or nerve fibers are damaged or destroyed in MS (called demyelination), messages within the CNS are altered or stopped completely.

## Who gets MS?

MS is most often diagnosed between the ages of 20 and 50, but, as you know, it is also diagnosed in children and older adults. Nearly one million people in the United States are living with MS. The disease is about three times more common in women than men and occurs in most ethnic groups. It was historically believed to be more common in Caucasians of northern European ancestry, but recent findings suggest that it is equally or possibly more common in African Americans, particularly African American women.

The International Pediatric MS Study Group estimates that less than 5,000 children and teens are living with MS in the United States and less than 10,000 worldwide. There are also another 10-15,000 children and teens with other CNS immune-mediated disorders with symptoms similar to those seen in MS, which makes the diagnosis of MS in children and teens challenging.

The average person in the United States has about one in 750 (.1%) chance of developing MS. For first-degree relatives of a person with MS, such as children, siblings or non-identical twins, the risk rises to approximately 2.5-5% — with the risk being potentially higher in families that have several family members with the disease. While that might seem like a significant increased risk, the relative risk of developing MS

even with a family member with MS is still very low.

## What are the Symptoms of MS?

The symptoms experienced from MS result from the damage done to myelin and nerve fibers in the CNS. Since demyelination can occur anywhere in the CNS, a person can experience a range of symptoms. Symptoms vary from person to person and from day to day.

Some common symptoms include:

- Limb numbness and tingling
- Vision changes (blurred, loss of, or double vision)
- Limb weakness
- Poor coordination
- Walking problems
- Depression
- Fatigue
- Concentration or memory problems

Fortunately, most people develop only a few of these symptoms over the course of their MS, and most can manage their symptoms quite effectively.

## What Causes MS in Children and Teens?

We do not yet know the answer to this question. The current thinking is similar to what we think causes adult onset MS: that the disease appears in individuals

who are genetically predisposed and then exposed to a trigger in the environment, including:

- Infection with Epstein-Barr virus (mononucleosis)
- Cigarette smoking
- Childhood and adolescent obesity
- Low levels of vitamin D

No one environmental trigger alone causes MS, but they all play a role in making someone with the right genetic make-up more likely to develop MS. Many people who have been exposed to these triggers do not develop MS. We still do not understand why a combination of genetic factors and these triggers causes MS to happen. Scientists are studying the possible triggers, both environmental and genetic, to learn more about the causes of MS.

While studies indicate that genetic factors may make certain individuals more susceptible to the disease, there is no evidence that MS is directly inherited. It's important to know MS is not caused by any factor over which you or your child had any control. MS is not a contagious disease — your child did not “catch MS,” and you do not need to be concerned that your child will give MS to other members of the family or to friends and classmates. There was nothing you did to cause this to happen and, similarly, nothing you could have done to prevent it.

## What are the Different Types of MS?

Children with MS exclusively have a relapsing-remitting course, which means there are clear attacks (relapses) of symptoms that subside (remit). During the periods of remission between attacks, there is no progression of the disease. Even though children may experience frequent attacks (possibly more than typically seen in adults), studies have shown that children also seem to have very good, often more rapid recovery than adults.

Other types of MS include:

- Clinically isolated syndrome
- Primary progressive MS
- Secondary progressive MS

If you would like to learn more, you can find information at [nationalMSSociety.org/What-is-MS](http://nationalMSSociety.org/What-is-MS) or by calling an MS Navigator® at 1-800-344-4867.

## Is There a Cure for MS?

There is no cure for MS at the present time. The important thing to note is that MS is not fatal. Almost all people with MS will live very close to a normal life span and eventually die of “natural causes” (e.g., heart disease, strokes or cancer).

There are many medications approved by the US Food and Drug Administration (FDA) to treat relapsing forms of MS in adults. One treatment, fingolimod (brand name Gilenya®), is also approved for use in children ages 10 and older who have relapsing remitting MS. Many of the treatments approved for adults with relapsing forms of MS are also used off-label for children with MS. Pediatric MS experts have extensive clinical experience with the use of these medications in children, and there is a growing amount of safety and efficacy data for their use. We'll talk more about these treatments in the "Managing MS" section of this publication.

## Do Children and Teens Need to be Told Their Diagnosis?

Parents sometimes wonder if they should delay telling their child or teen about their MS diagnosis. No parent wants to cause a child undue anxiety, and every parent would like his or her child to have as carefree and happy a childhood as possible. There are, however, very good reasons for talking about the diagnosis openly:

- Children and teens know when they don't feel well. They are also very sensitive to their parents' moods and states of mind. Without an open and honest explanation of what is happening, they might use their own imaginations to fill in the blanks.

- Open, honest communication in a family promotes trust and eliminates the need for secrets.
- Children and teens need to be included in decisions about their care. When children and teens are included in developing their treatment plan, they are more likely to adhere to it (e.g. if children and teens get to make the decision of which medication they use, they are more likely to use it as instructed).
- When parents talk comfortably about diagnosis and treatment issues, children feel more secure and less afraid. They know their parents and healthcare team are taking good care of them.
- Children and teens with MS are going to have ongoing relationships with a variety of healthcare professionals, and undergo periodic medical examinations and evaluations. Open, comfortable communication with these professionals, geared to the child's age and level of understanding, will promote a trusting relationship and help make these experiences less frightening.
- Many children, particularly younger ones, don't have the vocabulary or concepts they need to express their concerns or ask their questions. When parents talk openly with their children about MS, they are giving their children the vocabulary they need to say what's on their minds.



## SECTION TWO— MANAGING MS

### Your Child's Relationship with the Healthcare Team

Good relationships with healthcare professionals play an important part in living comfortably with MS. Depending on your child's age, you may have the dual challenge of helping the health professional understand what your child is experiencing, and helping your child understand what the professional is doing or saying.

Very few of us feel relaxed in the healthcare provider's office, and young children may find the diagnostic tests and neurologic exams frightening until they have developed trust in the healthcare providers. Your ability to stay calm and relaxed despite all the anxiety you are feeling will help your child feel more comfortable. To the extent possible, finding out ahead of time what is likely to occur during the visit will help you talk to your child about what to expect.

While teenagers may have some anxiety as well, they may gradually want to handle some of the healthcare provider visits on their own. Those who have been able to develop an open, trusting relationship with their healthcare provider may prefer to be examined and talk to the professional

without you there. This may be very difficult for you, given your own concerns and desire to hear everything that the professional is saying. But your teen's need for privacy and independence is normal. It will also help their transition to managing their own care as an adult easier.

One strategy is to arrive at a three-way agreement between you, your teenager, and the healthcare provider that acknowledges your child's wish for privacy and independence while making it clear that important medical decisions will be made by all of you together.

Because they do not want to "burden" or worry others, older children and teens may not open up about things that are bothering them either physically (such as new symptoms) or emotionally when you are present at visits. Giving teenagers time alone with their healthcare provider allows them to have an open discussion about things they might not otherwise share. After your teenager has had time alone with his or her healthcare provider, you can join them to review the details of the visit and make treatment plans.

In the case of older teens (18 and above), medical decisions are legally theirs to make. The provider will seek your input on medical decisions only with the older teen's permission.

## Where to Find Pediatric MS Healthcare Providers

Identifying a neurology provider who will partner with you and your child can be a daunting task. The National MS Society has a directory of pediatric providers, by state, to assist you in your search. The clinicians in the directory have experience diagnosing and treating children under the age of 18 who have MS and other central nervous system immune-mediated diseases. Many are also involved in researching pediatric MS.

If there are no providers with expertise in your area, you can consider traveling to a provider with MS expertise for a consultation and take his or her recommendations back to your local healthcare provider. The important thing to remember is that there are resources available to help you find the best possible treatment for your child.

Access the directory of pediatric providers at [nationalmssociety.org/pediatricMS](https://www.nationalmssociety.org/pediatricMS) or contact an MS Navigator at 1-800-344-4867 for further help.

## Treating Pediatric Onset MS

The treatment of MS, in children and teens as well as adults, involves several strategies:

- Modifying the disease course
- Managing relapses
- Maximizing lifestyle interventions
- Managing symptoms

## Modifying the Disease Course

There are medications that are very effective at preventing relapses and disability accumulation, which is referred to as modifying the disease course. Starting a disease modifying therapy (DMT) early and staying on it is the best available strategy to manage MS. There are several preventative goals of disease modifying therapies, including:

- Reducing the number of relapses
- Limiting the number of new lesions seen on magnetic resonance imaging (MRI)
- Delaying disease progression

DMTs do not cure MS, and they are not designed to relieve existing symptoms. Sometimes the effects of the medications on the disease are not apparent, especially in the first few months. This can make staying on a medication difficult, particularly for children and teens. It's important that your child be involved in choosing and understanding the goals of a treatment. The medications only work when they are taken as intended. Encourage your child or teen to talk openly with his or her healthcare provider if they are struggling with sticking to the treatment schedule. There are many medication options, and it's most important that your child or teen be on one that he or she will be committed to taking.

More than a dozen disease modifying therapies are approved by the U.S. Food and Drug Administration (FDA) to treat adults with relapsing forms of MS. In May 2018, the FDA approved the use of the oral MS therapy Gilenya® (fingolimod, Novartis AG) for the treatment of children and adolescents 10 years of age or older with relapsing MS.

Many of the medications used for adults with MS have been studied in children with MS in different centers throughout the world, and a wealth of experience has accumulated among many clinicians caring for children and adolescents with MS. Healthcare providers rely on published study findings as well as their own clinical judgment to adapt the treatments with FDA approval in adults for their younger patients. Work with your healthcare provider to determine the best treatment option for your child.

Due to the changing landscape of disease modifying agents currently available for MS, the specific treatments are not discussed here. For more information on the available therapies, visit [nationalMSSociety.org/DMT](http://nationalMSSociety.org/DMT).

### **Managing Relapses**

Relapses, also called attacks, flare-ups and exacerbations, are periods of new or a recurrence of old symptoms that last in a constant fashion for 24 hours or more. Other things, like a fever,

getting overheated or a urinary tract infection, can also make old relapse symptoms worsen—this is called a pseudo-relapse. To be a true relapse, the symptoms need to be experienced outside of having an infection, a fever, or being overheated.

Relapses can last anywhere from a few days to several weeks and will resolve on their own, but sometimes medications are used to speed up the recovery process. Although symptoms such as numbness, tingling or very mild weakness can be frightening and disconcerting, they will generally improve and resolve on their own without medication. Healthcare providers sometimes reserve medication only for those relapses that are significant enough to interfere with your child's functioning at home and at school, like a problem with vision or ability to walk safely.

If medication is used to treat a relapse, it's typically managed with a 3- or 5-day course of intravenous or oral (pill) corticosteroids. This course is sometimes followed by a tapering (gradually decreasing) dose of oral corticosteroids over several days. The goal of corticosteroid therapy is to improve symptoms and hasten recovery time. Corticosteroids do not, however, change the long-term course of MS or have any other long-term benefits. In other words, whether your child's relapse is treated with corticosteroids

will not impact his or her future disability or relapse likelihood.

### **Maximizing Lifestyle Interventions**

A healthy diet, regular exercise, stress management and other wellness strategies can help your child manage his or her overall health and MS.

Your child can feel his or her best by adopting the following preventive health strategies:

- Eat a healthy diet
- Get adequate exercise or physical activity
- Quit cigarette smoking or avoid starting
- Get enough rest
- Utilize effective stress management strategies
- Have regular medical checkups and age appropriate screening tests
- Develop an effective support system
- Build a good social network and have fun with friends
- Pay attention to his or her emotional and spiritual needs

Many parents ask about the use of herbal or naturopathic remedies for their child. In the face of a disease like MS, for which we have no cure, it may be tempting to try products that boast of their ability to cure MS. Discuss the use of any “natural” or alternative therapy with your child’s healthcare provider before trying it. Although there

may be a benefit from some of these remedies, most have never been studied in controlled clinical trials to assess their safety and efficacy. Even natural products can be toxic or have significant side effects, and some may interfere with your child’s other medications.

It is important to be wary of alternative therapies that claim to “boost” the immune system. Because MS is an illness in which the immune system appears to be overactive, in theory, boosting your child’s immune response could worsen their MS.

It is also important to keep in mind that herbal supplements and other over-the-counter products are not regulated in the U.S. in the same way that prescribed medications are. That means that manufacturers can make claims for their products without oversight by the FDA or any other regulatory agency.

Discuss all treatments being considered with your child’s healthcare team.

### **Managing the Symptoms of MS**

MS symptoms can be unpredictable and vary from person to person. It’s important to be familiar with the possible symptoms of MS so that your child can discuss them with his or her healthcare provider. There are medications available to manage the symptoms of MS and many of

the symptoms can be managed with strategies that don't involve the use of medication, like physical therapy, counseling and lifestyle changes. Be sure to discuss all the symptoms your child is experiencing with your child's healthcare team.

Although MS can cause symptoms in many parts of the body, it is not the cause of every symptom that may occur. Your child will still get the same viral illnesses and assorted problems that all children get, and potentially others as well. It is therefore important to maintain regular check-ups with your child's primary care provider.

To learn more about the specific symptoms of MS and their management, visit [nationalMSSociety.org/symptoms](http://nationalMSSociety.org/symptoms).

## SECTION THREE— RESOURCES AND SUPPORT

### The National Multiple Sclerosis Society

We are here to be your supportive partner throughout this journey. Find links to videos, social media and other resources for families and kids.

 [nationalmssociety.org/  
pediatricMS](http://nationalmssociety.org/pediatricMS)

### Pediatric MS Online Group for Parents


Share concerns and information in a supportive online community. Visit [msconnection.org](http://msconnection.org) to register and then search "Pediatric MS Group" to get started.

### MS Navigator®

Having the right information at the right time can help you make sound decisions. The National MS Society provides answers to questions and access to information on available resources. Our MS Navigators are highly skilled professionals equipped to respond to your individual needs. The National MS Society maintains strict confidentiality policies. Regardless of the types of programs or services you choose to utilize, your privacy will be respected and protected. Contact an MS Navigator to learn more.

 [nationalMSSociety.org/navigator](http://nationalMSSociety.org/navigator)

 [contactusnmss@nmss.org](mailto:contactusnmss@nmss.org)

 1-800-344-4867

## International Pediatric MS Study Group


Their mission is to improve the care of children with multiple sclerosis and acquired demyelinating diseases worldwide, promoting clinical initiatives, education and research.

 [ipmssg.org](http://ipmssg.org)

## Pediatric MS Alliance

Parents and families whose lives are affected by pediatric MS is what we're about. By sharing information, experiences, knowledge, resources, contacts, and providing educational opportunities, we can better build bridges and better help raise awareness for MS and other neuro-immunologic disorders.


 [pediatricms.org](http://pediatricms.org)


 [facebook.com/groups/PMSalliance](https://www.facebook.com/groups/PMSalliance)  
(Private Facebook Group)

## Oscar the Monkey

Supporting kids and families on their journey with MS.

 [mroscarmonkey.org](http://mroscarmonkey.org)

 Oscar the MS Monkey

  @mroscarmonkey

## Someonelikeme.ca

For youth and young adults who are living with MS either with a diagnosis of MS or personal connection to MS. The platform features blogs, forums and inspirational stories of young people living with MS and engages youth in a friendly environment that respects and values their opinions and input. There are multiple ways to get informed, to get involved, and to take action.

 [someonelikeme.ca](http://someonelikeme.ca)



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.



**National  
Multiple Sclerosis  
Society**

**[nationalMSSociety.org](http://nationalMSSociety.org)**

**1-800-344-4867**