

**KIDS GET MS TOO:
A GUIDE FOR PARENTS WITH A CHILD OR TEEN WITH MS**

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SECTION ONE

INTRODUCTION AND OVERVIEW

SECTION ONE—INTRODUCTION AND OVERVIEW

Hearing the diagnosis of multiple sclerosis (MS) is never easy.

All parents wish for their children to be healthy and happy—to have lives without discomfort or loss—and want to protect them and keep them from harm. Although your child has been diagnosed with MS, your mission remains the same, and the National MS Society is committed to helping you ensure the very best for your daughter or son.

Whether your child’s diagnosis is relatively new, or you have been searching for answers for quite some time, the words *multiple sclerosis* can be very frightening. It is important to remember that:

- You are not alone - there are networks to support your child and your family
- MS is generally not a fatal disease. Most people with MS have a normal or near-normal life expectancy
- Each person’s experience with MS is different
- This is a hopeful time. While the cause of MS is unknown and there isn’t a cure yet, there are treatments available, and an increasing number of clinicians and researchers have taken a specific interest in better understanding diagnosis and treatment of children with MS and related disorders.
- Research and ask questions to learn all you can about your child’s condition, diagnosis and potential therapies

What is MS and who gets it?

MS is a disease of the central nervous system (CNS), which includes the brain, the spinal cord and the optic nerves. Although MS is thought by some scientists to be an *autoimmune disease*, others disagree strongly because the specific target of the immune attack in MS has not yet been identified. For this reason, MS is referred to as an *immune-mediated disease*.

As part of the immune attack on the CNS, myelin (the fatty substance that surrounds and protects the nerve fibers in the central nervous system) is damaged, as well as the nerve fibers themselves.

The attacks on myelin produce scarring at multiple sites in the CNS, and these scars begin to slow or interrupt the transmission of nerve impulses, resulting in the symptoms of MS. This is called demyelination. The “multiple” scars is what gives the disease its name.

MS affects approximately 2.3 million people worldwide. Because MS is most commonly diagnosed in individuals between the ages of 20 and 50, you may not know another family with a child who has MS, but we estimate that there are 8-10,000 children and teens with MS in the United States. We also believe there are another 10-15,000 children and teens with other central nervous system demyelinating disorders with symptoms similar to those seen in MS. This makes a diagnosis of MS in children challenging. These disorders include acute

disseminated encephalomyelitis (ADEM), optic neuritis, transverse myelitis and neuromyelitis optica (also known as Devic's disease).

It might help you to remember that the risk of an MS diagnosis is greatest in families in which there are several family members who have the disease, and significantly lower in other families. The average risk for any person in the general population is 1 in 750. The risk for the child of a parent with MS rises to 1 in 40. Although this represents a significant increase, the absolute risk remains fairly low.

What are the symptoms of MS?

The location of the scarring in the CNS has a lot to do with the symptoms your child may experience. This is why there is such a variation between people with MS. Possible symptoms of MS include: fatigue, changes in vision, stiffness, weakness, imbalance, sensory problems such as numbness, tingling, and pain, changes in bladder and/or bowel function, emotional changes, speech difficulties, and problems with thinking and memory.

There are also, symptoms occasionally experienced by children that are not typical in adults, such as seizures and mental status changes such as lethargy, which is drowsiness or sluggishness. Many of these symptoms are "invisible," vary in intensity, and come and go without a warning. Fortunately, most people develop only a few of these symptoms over the course of their MS, and most are able to manage their symptoms in relative comfort.

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 about adult onset MS, that the disease appears in individuals who have a genetic predisposition to react to some infectious agent in the environment such as a virus or bacterium. Research suggests that some individuals are more susceptible than others to the infectious agent(s).

It is believed that an individual is exposed to the environmental agent ("trigger") during the first 15 years of life, although for most people with MS, there is a long period of time between exposure and developing MS. For some unknown reason, in some children, the period of time between exposure to the agent and development of MS is shortened and so MS occurs at a young age. Some researchers, however, believe that between 2 and 5 % of all people with MS had their first symptoms before the age of 16.

While several different viruses and bacteria have been and continue to be studied for their possible role in MS, the trigger(s) have not yet been found. In the US, studies of children are underway to learn more about possible viral triggers as well as studies about the potential impact of Vitamin D, obesity and smoking.

Also, while studies indicate that genetic factors may make certain individuals more susceptible to the disease, there is no evidence that MS is directly inherited. There are many studies being conducted to learn more about the role of genetics in MS.

Why did my child get MS?

We do not know the specific reasons why one person gets MS and another person does not. What we do know is that MS is not caused by any factor over which you or your child had any control. There was nothing you did to cause this to happen and, similarly, nothing you could have done to prevent it. While it is natural to look for some recent event or trauma or stress to explain the onset of MS, there is no evidence to suggest a direct relationship between specific life events and the onset of MS.

We also know that 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.

I’ve heard there are different types of MS, what does this mean?

Almost all children start with a *relapsing-remitting* course, which means there are clear attacks (relapses) of symptoms that subside (remit) on their own or with treatment. During the periods of remission between attacks, there are no new symptoms or 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 recovery that is often more rapid than adults.

Other patterns in MS include:

- Primary-progressive MS
- Progressive-relapsing MS
- Secondary-progressive MS

If you would like to learn more about these, you can find information on the National MS Society website at nationalMSSociety.org and go to “What is MS” or by calling an MS Navigator at 1-800-344-4867.

Your child’s healthcare team will work with you to determine the best ways to manage your child’s particular situation in order to minimize the impact of MS on his or her life.

Is there a cure for MS?

There is no cure for MS at the present time. Because we do not yet know the underlying cause of the disease, it is very difficult for scientists to develop treatments to prevent or cure it. The important thing to remember is that most people with MS can expect to live very close to a normal life span, and eventually die of “natural causes” (e.g., heart disease, strokes, or cancer) like everyone else.

Fortunately, more has been learned about the disease process in MS since the 1990’s than in all the preceding decades combined. While no one can promise that a cure is just around the corner, you can be confident that research is proceeding at a faster rate than ever before. Each year brings us more answers. In the meantime, we have learned a great deal about slowing progression of the disease and helping people manage whatever symptoms may occur.

What treatments are available?

NOTE: Most of the current information that exists about MS comes from research and experiences of treating physicians with the adult population. We think there are many similarities between the experiences of adults and children, but we are in the early stages of understanding the disease in children. Most clinicians have limited experience treating children with MS, and the treatments described below need further research. You can expect that over the next several years, there will be much more information available, since throughout the world there is a growing interest in learning how best to diagnose and treat children with multiple sclerosis. The treatments that have been tested and approved by the FDA in adults are being used “off label” in children.

Most of us are used to thinking about treatment as something the doctor prescribes to prevent or cure an illness. While we do not have any treatments in MS that can prevent the disease from happening, or make it go away once it has appeared, there are various strategies to reduce inflammation during an exacerbation, manage symptoms and slow disease progression. These will be discussed in more detail in other sections of this handbook.

- The majority of people with MS experience attacks (also called *exacerbations* or *flare-ups*), particularly in the early phases of the disease. Exacerbations are usually associated with inflammation and demyelination in the CNS, resulting in new symptoms or the aggravation of old ones. Many physicians prescribe corticosteroids (either orally or by intravenous infusion) to reduce the inflammation that occurs during exacerbations and thereby reduce the symptoms that occur.
- The symptoms of MS are unpredictable. Some may come and go while others seem to come and stay. Symptoms initially appear as a result of inflammation in the CNS, and will tend to disappear as the inflammation subsides. Once the inflammation has resulted in scarring (demyelination) or damage to the nerve cell itself, however, the symptoms will tend to remain. In either case, there are a variety of medications and strategies to help manage your child’s symptoms comfortably.

- An exciting new era in MS care was ushered in by the development of disease-modifying medications designed to alter disease activity and slow disease progression. There are currently eleven medications approved for use in adults by the U.S. Food and Drug Administration for relapsing forms of MS. Based on the demonstrated ability of these medications to impact disease activity in adults, the National Medical Advisory Committee of the National MS Society recommend treatment with one of the medications as soon as the diagnosis of relapsing MS has been confirmed. The goal of early intervention is to reduce the frequency and severity of exacerbations, thereby reducing the risk of permanent disability.

NOTE: The safety and effectiveness of disease-modifying therapies have not yet been well studied in children and adolescents. A few small studies have looked at safety issues in the use of these medications in young patients. In 2014 a few clinical trials have been initiated. For more information please visit the International Pediatric MS Study Group website at ipmssg.org

This handbook is just a beginning. We hope that it will serve as an overview and guide to answer some of your questions and provide a roadmap for the months and years ahead. We are here to help you and your child. There is no reason to try and deal with the challenges of MS on your own.

The remaining sections will describe what we know today about the diagnosis and treatment of MS in children, and provide you with the information and resources you need to deal with the social, psychological, academic, and financial challenges that MS sometimes poses.

Related Demyelinating Diseases

In addition to serving families with a child with a diagnosis of MS, the National MS Society also serves families with children with a related demyelinating disease, to include those within the medical category of idiopathic inflammatory demyelinating diseases of the central nervous system:

- Clinically isolated syndrome, e.g. optic neuritis
- Diffuse cerebral sclerosis (including Schilder's Disease)
- Acute disseminated encephalomyelitis (post-infectious Encephalomyelitis or ADEM)
- Balo's disease
- Neuromyelitis optica (Devic's disease or Devic's syndrome)
- Transverse myelitis

For more information on these related diseases please visit nationalmssociety.org/about-multiple-sclerosis/do-i-have-ms/other-conditions-your-doctor-needs-to-rule-out/index.aspx or contact an MS Navigator at 1-800-344-4867.

SECTION TWO

DIAGNOSIS AND TREATMENT

SECTION TWO—DIAGNOSIS AND TREATMENT

Making the Diagnosis of MS in Children

What are the criteria for making the diagnosis of MS?

Currently, the criteria for making a diagnosis of MS in adults and children are the same. The key to diagnosis is in the word “multiple”: multiple events of neurologic dysfunction multiple times. Specifically, the doctor must be able to find evidence of at least two separate and distinct neurologic events (attacks), which occurred at least one month apart and in different areas of the brain and/or spinal cord. The doctor must also be able to rule out all other possible explanations for those attacks and the symptoms they caused.

In order to meet these criteria, the doctor will look for various types of evidence:

- **Medical history**—By taking a careful medical history, the physician will be able to identify any current or past symptoms or events that might indicate that an episode of inflammation and demyelination had occurred in the brain or spinal cord.
- **Neurologic exam**—The physician will examine your child for various neurologic signs, including altered reflexes, changes in the appearance of the optic nerve, a reduction in strength or coordination, and changes in sensation among others. You and your child may not even be aware of these subtle neurologic signs.
- **Magnetic resonance imaging (MRI)**—This technology allows the physician to see areas of demyelination in the brain and spinal cord. A follow-up MRI scan can be used to show separate episodes of disease activity, and are thus useful in meeting the criteria for a diagnosis.

While specific criteria do not yet exist for young children, the current MRI criteria for use for diagnosing MS in adults apply to children 12 years of age and older.

- **Laboratory tests**— Often additional evidence is needed to demonstrate that more than one attack has occurred. Thus, even if a child or teen has only experienced one attack, or is only experiencing one symptom, abnormal results from these tests can provide evidence for a second area of demyelination in the brain which may have occurred prior to the current event.
 - An examination of the cerebrospinal fluid (CSF), a fluid that is made in the brain and normally bathes both the brain and spinal cord, may be helpful in diagnosing MS and ruling out other possible diseases. Although there are certain abnormalities that typically occur in MS, they are not unique to MS and therefore are not sufficient to make the diagnosis.
 - In some cases, evoked potentials (EPs) are recommended as these allow doctors to evaluate how well nerves carry messages from specific sensory stimuli, such

as from visual or auditory stimuli. For example, visual evoked potentials measure the speed of visual responses to changing patterns on a screen. Similarly, Brainstem Auditory Evoked Potentials (BAEP) measure the speed at which a sound travels from the ear to the brainstem.

Are there special challenges to diagnosing MS in children?

When a child, adolescent or teen first comes to a doctor with neurologic symptoms characteristic of demyelination in the CNS, the doctor must decide if this is a one-time event, or the first event in what will eventually become MS. Not all children with a first episode of demyelination will eventually be diagnosed with MS. Some children may develop single neurologic events known as acute disseminated encephalomyelitis (ADEM).

ADEM often occurs most commonly in younger children (typically under 10) and most often follows a viral illness. While some neurologic symptoms and signs children with ADEM experience are similar to those of MS—such as optic neuritis (inflammation of the optic nerve), difficulties with balance, sensation, or strength—others are quite different. Kids with ADEM, for example, are more likely to have fever, headache, nausea and vomiting before the onset of neurologic symptoms. They may also become very irritable or sleepy, or develop seizures.

Since ADEM typically consists of a single episode, children with this diagnosis do not require ongoing therapy to prevent further relapses. The challenge is to determine if the current episode is caused by a condition that is likely to resolve on its own, or is the beginning of a chronic disease that requires ongoing treatment. This diagnostic challenge is made even more complicated by the fact that children with ADEM occasionally have recurrent symptoms soon after their initial event (within the first three months). Careful monitoring, often repeat MRIs, will help with making the proper diagnosis.

Pediatricians and pediatric neurologists have been reluctant to diagnose MS in children and teens for several reasons:

- ADEM is much more common than MS in young children.
- MS has traditionally been thought of as a disease of adulthood.
- Childhood MS is rarely seen by most doctors. While physicians recognize the significant neurologic impairment, that many children experience, a diagnosis may not be made.

However, ongoing efforts to raise awareness, increase education and provide forums for neurologists to consult with one another about pediatric MS, are starting to make a difference at improving the ability of physicians to make this difficult and relatively rare diagnosis.

Do Children and Teens Need to be Told Their Diagnosis?

Parents sometimes wonder if they should delay telling their child or teen about the MS diagnosis. No parent wants to cause a child undue anxiety and every parent would like his or

her child to have as care-free 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 state of mind. Without an open and honest explanation of what is happening, they will use their own imaginations to fill in the blanks—and what youngsters can conjure up with their imaginations may well be even scarier than the reality.
- Open, honest communication in a family promotes a feeling of trust and eliminates the need for secrets in regard to MS and any other issue that comes along.
- Children and teens need to be included in decisions about their care. When children are included in their own treatment planning, they are more likely to be active participants in their own care.
- When parents can talk comfortably about diagnosis and treatment issues, children feel more secure and less afraid. They know that 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; they are also going to be undergoing periodic medical examinations, evaluations, and tests of various kinds. 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, as well as permission to say it.

Treating Early-Onset MS

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

- Managing the acute attacks
- Modifying the disease course
- Managing the symptoms
- Helping families deal with the impact of MS symptoms on everyday life

While MS treatments have been approved by the U.S. Food and Drug Administration (FDA) for the treatment of MS in adults, none of these treatments have been approved for use in pediatric MS. Nonetheless, many of the medications have been studied in children with MS in different centers throughout the world, and a large experience has accumulated among many clinicians caring for children and adolescents with MS. Physicians rely on the published experience as well as their own clinical judgment to adapt the treatments used in adults for their younger patients.

Who Treats Children and Teens with MS?

Children with MS receive treatment from their pediatricians, family doctors, general adult and pediatric neurologists, and neurologists who specialize in MS. Few physicians have much experience with pediatric MS: you may or may not have anyone in your area familiar with pediatric MS.

Network of Pediatric MS Centers

In 2006, the National Multiple Sclerosis Society established a national network of Pediatric MS Centers. Never before had the Society made such a concerted effort to direct resources towards the care and treatment of children/adolescents/teens with MS.

The Network has clinicians with experience diagnosing and treating children under the age of 18 who have MS and other central nervous system demyelinating diseases. They are also involved in clinical trials as well as other studies evaluating the use of therapies for MS in children, and environmental triggers in MS. The centers are set up to provide comprehensive care and support to your child and your family. You and your child will have access to the leaders in the field of pediatric MS and will benefit from the collective wisdom and resources of MS experts across the country.

There are currently nine centers in the Network of Pediatric MS Centers. To see the complete list, go to Section Seven (Resources and Support, page 58), call 1-800-344-4867 or email contactUSNMSS@nmss.org.

One important role of the National MS Society is to help you find healthcare providers in your area who have the experience in treating children and teens with MS. In addition to referrals to the Pediatric MS Centers, we can provide you with the names of local practitioners with experience treating MS. If there are no providers with expertise in your area:

- You can travel to a provider with MS expertise for a consultation and take his or her recommendations back to your local physician.
- Your physician can request consultation with a physician with MS expertise through nationalMSSociety.org/prc.

The important thing to remember is that there are resources available to help you find the best possible treatment for your child. Please contact an MS Navigator for more information.

Managing Attacks/Exacerbations

When to treat: Whether symptoms result from the first attack of demyelination or from a relapse in a patient with established MS, the treatment is very similar. Prior to initiating any treatment, however, it is important to decide if the attack requires any treatment at all. Although symptoms such as numbness, tingling, or very mild weakness can be frightening and disconcerting to your child, they will generally resolve on their own without medication.

Physicians tend to prescribe medication only for those acute attacks that are significant enough to interfere with your child's functioning at home and at school.

How to treat: Acute attacks are typically managed with a 3-5 day course of intravenous corticosteroids (methylprednisolone), often followed by a gradually tapering dose of oral corticosteroids (prednisone) over several days. While there is some evidence that high dose methylprednisolone can be given in pill form rather than intravenously, the evidence is still preliminary. Most clinicians continue to favor intravenous treatment.

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.

Side effects of Corticosteroids: The potential side effects of corticosteroids are significant, including elevation of blood sugar, increased blood pressure, osteopenia (thinning of the bones), reduced ability to fight infection, weight gain, slowed or reduced growth, irritability, and severe deterioration of the hip joint. In order to avoid corticosteroid-related side effects, the physician will only treat those attacks that are interfering with your child's functioning, and will use the minimum effective dose. Patients receiving the short 3-5 day course typically tolerate the treatment very well, with weight gain, acne, mild mood changes, and poor sleep being the most common side effects. The total number of steroid treatments given per year is important; children and teens who receive more than two courses of steroid treatment in a year should have bone density measures performed.

What to do when corticosteroids are not enough: In those children who do not improve sufficiently on steroid therapy, intravenous immune globulin (IVIg), may be of benefit. IVIg may also be beneficial in the rare child who cannot safely take steroids (e.g., a child who already has high blood pressure, blood sugar abnormalities, or very thin bones). IVIg may be effective in the following circumstances:

- A child with an acute demyelinating attack for whom steroids have not led to a dramatic improvement in symptoms.
- IVIG may be of benefit as an alternative to steroids in children who develop new neurologic symptoms upon weaning or discontinuation of steroids. Using monthly IVIG as an alternative to steroids may lead to a reduction in the long-term side effects that can be associated with chronic steroid use.

In certain instances, a technique called plasma exchange (PLEX) may be utilized to treat a severe acute attack that does not respond to other interventions. PLEX involves insertion of a catheter (tube) into a vein in order to withdraw plasma (a portion of the blood from which the red blood cells have been removed). The plasma, which is believed to contain immune proteins that are contributing to demyelination, is replaced by a clear protein called albumin and put back into the body. In theory, this technique "cleanses" the plasma of harmful immune proteins. Although PLEX has been shown to help some adults with MS with severe relapses, there are few reports of its use in children with demyelination.

Modifying the Disease Course and Using These Therapies in Children

The U.S. Food and Drug Administration (FDA)-has approved 11 disease-modifying agents to reduce disease activity and disease progression for adults with relapsing forms of MS.

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, including information on side effects, monitoring safety, and patient assistance programs:

- Visit the National MS Society’s website at nationalMSSociety.org and go to Treating MS>Medications
- Contact an MS Navigator at 1-800-344-4867 or contact USNMSS@nmss.org
- Review the Society publication, *The MS Disease Modifying Therapies – General Information* (available on the Society’s website at nationalMSSociety.org/brochures or by contacting an MS Navigator)

Although none of the currently approved MS therapies have been studied in a randomized, double-blind, controlled clinical trial in children, descriptive studies of groups of children who have been treated with many of the MS therapies approved for use in adults have been published. (Although there are now a few studies in initial stages in the US and abroad.) Within the adult population, increasing evidence of the importance of starting therapy as soon as possible after the diagnosis of MS is made has led to increased use of these agents in younger patients. Which medication to use is a decision you and your child will reach after careful discussion with your child’s physician.

Alternative Therapies

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 or totally effective medications, it may be tempting to try products that boast of their ability to cure MS. It is advisable to discuss the use of any “natural” or alternative therapy with your child’s physician; 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. MS is an illness in which the immune system appears to be overactive. In theory, boosting your child’s immune response could result in further damage to myelin. It is best to consult with your child’s healthcare team before using any alternative treatments.

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 medications are. That means that manufacturers can make whatever claims they want for their products, and mix them in with whatever they choose, without having to answer to the FDA, or any other regulatory agency. Your best strategy is to discuss all treatments with your child’s healthcare team.

Managing the Symptoms of MS

One of the greatest challenges posed by MS is the unpredictability and variability of its symptoms. Changes in function and sensation can occur in virtually any part of the body, and symptoms may come and go with no apparent rhyme or reason. People with MS often say that they never know how they are going to feel from one day to the next or even from morning to afternoon. It is important to remember that while MS can cause a variety of physical and sensory changes, most children and adults will experience only a few of them.

Try to keep in mind, as well, that although MS can cause symptoms in many parts of the body, it is not the cause of everything that occurs. Your child will still get the same viral illnesses and assorted problems that all children get.

Your child may also experience pseudo-exacerbations. A pseudo-exacerbation is a temporary increase in symptoms due to an outside stressor such as heat or a fever that temporarily raises the core body temperature. The increase in symptoms disappears shortly after the stressor is removed. For example, your child may see an increase in symptoms during a bout with the flu. As the infection subsides and your child's body temperature returns to normal, the MS symptoms return to baseline. Your son or daughter will likely look to you to help sort out which symptoms or changes are related to MS and which are not.

Fatigue is one of the most common complaints of adults and children with MS. Approximately 30% of children with MS complain of fatigue that is significant enough to limit their daily activities. The fatigue experienced by people with MS can be caused by a variety of factors:

- Sleep disturbances (caused by emotional upset, bladder symptoms, other physical symptoms that cause discomfort) can cause people to experience excessive daytime tiredness.
- Some of the medications used to treat MS symptoms can cause fatigue as a side effect.
- The extra amounts of effort and energy it make take to accomplish everyday activities can result in feelings of fatigue.
- There is a primary lassitude or tiredness that is unique to MS, which results from impaired nerve conduction. This lassitude, which is part of everyday life for many people with MS, can come on very suddenly and tends to worsen over the course of the day. It can, however, happen at any time of day, even after a full night's sleep.

The first step in the effective management of MS fatigue is to identify its source. Your child's doctor can address any symptoms that may be disturbing your child's sleep, make medication adjustments if necessary, and provide a referral to an occupational or physical therapist who can recommend energy-conservation strategies at home and at school.

Primary MS lassitude can often be treated effectively with medication. Modafinil (Provigil®) has been shown to significantly reduce fatigue in adults with MS, and was safe and well tolerated in

a recent study. Amantadine has also been shown to reduce fatigue. Children who have been treated with either of these medications have responded well.

Visual symptoms are among the most common manifestations of MS. They appear as the first symptom of MS in many people, and affect as many as 80% of people with MS at some point over the course of the disease. The three major types of visual symptoms are:

- Optic neuritis—inflammation of the optic nerve, can cause temporary loss or disturbance in vision, changes in color vision, and sometimes pain in the affected eye. Although episodes of optic neuritis typically get better on their own, treatment with high-dose intravenous corticosteroids may be required if the visual symptoms interfere significantly with your child’s ability to function at school.
- Double vision (diplopia)—the experience of seeing two of everything, is caused by the weakening or incoordination of eye muscles. Double vision can be treated with a short course of corticosteroids. Patching one eye for brief periods will prevent the double image, but patching for extended periods of time is not recommended because it prevents the brain from accommodating to the weakness on its own in order to create a single image.
- Nystagmus—a rhythmic jerking of the eye(s) that the doctor may detect during the neurologic exam, but which tends not to cause noticeable symptoms. If your child develops nystagmus that causes significant disruption of vision or comfort, the doctor may prescribe a medication such as Clonazepam (Klonopin®) to control it.

Sensory symptoms, which are very common in MS, include the feeling of “pins and needles”, numbness or tingling, or pain. While these sensations can be very annoying and uncomfortable, they are not considered as worrisome as some other symptoms because they tend to come and go without interfering significantly with a person’s ability to function. Children, however, may find them frightening and difficult to describe. There are no specific medications for most of these symptoms, but various anti-seizure medications have been found to relieve these sensations in adults.

Bladder and bowel symptoms are also common in people with MS. Bladder symptoms, resulting from either a failure to store urine properly or empty the bladder completely, can include feelings of urgency, a need to urinate very frequently, a hesitancy in starting the flow of urine, and/or awakening several times during the night to urinate. There are a variety of medications and behavioral strategies that can alleviate these common urinary symptoms.

People with MS who have difficulty emptying their bladders completely are also more prone to urinary tract infections (UTIs). It is important to recognize and treat UTIs promptly since they, like all other types of infections, can temporarily worsen other MS symptoms.

Spasticity or muscle stiffness in MS is caused by uneven nerve stimulation to the muscles. This symptom tends to occur most frequently in the legs, but can also occur in the arms. Mild

spasticity responds well to stretching exercises, but may sometimes require treatment with an anti-spasticity medication.

Depression and other emotional changes, which are as important and complex as the physical symptoms caused by MS, are discussed in detail in Section Three. The important point to remember is that depression and mood swings are very common in adults with MS, and seem to occur frequently in children with MS as well. The risk of depression is higher in MS than in the general population or other chronic illnesses, suggesting that it may be a symptom of the disease itself, rather than simply a reaction to it. The same seems to be true for mood swings.

These problems are most effectively treated with some combination of education, supportive counseling and medication. While grief and anger are natural and normal reactions to the diagnosis of a chronic, potentially disabling illness, depression and other significant mood changes should be brought to the attention of your child's doctor so that appropriate evaluation and treatment can be recommended.

Cognitive changes: Approximately 50% of adults with MS experience some degree of change in their ability to think, reason, and remember. While these symptoms remain relatively mild and manageable for most people, they can significantly impact daily activities for a small percentage of adults with MS. There is evidence that the same is true for children and teens with MS, and every effort must be made to recognize and address these problems before they have a significant impact on a child's school experience. Section Four deals in detail with the assessment and management of cognitive symptoms in children with MS.

SECTION THREE

MANAGING THE EMOTIONAL REACTIONS

SECTION THREE—MANAGING THE EMOTIONAL REACTIONS

Emotional Reactions to the Diagnosis of Multiple Sclerosis

A diagnosis of multiple sclerosis can be very frightening. The chronic and unpredictable nature of the disease runs counter to qualities valued in our culture. We like being in control, knowing what to expect, and solving problems quickly. Although some people are initially relieved to have a name for their multiple, seemingly unrelated symptoms, they and their family members are likely to experience a wide range of feelings as they try to understand and adapt to the presence of MS in their lives.

Younger Children’s Reactions to the Diagnosis

How young people cope with their diagnosis differs depending on their age, but virtually all children take their cues from their parents. If you are anxious, your child will be too. If you worry, your child will too. Children need reassurance that they will be okay and that you are in charge. Young children are concrete thinkers who live in the moment and don’t often express any fears about the future. To help them begin the coping process:

- Share information appropriate to their level of understanding. Answer their questions matter-of-factly without giving more information than they can absorb.
- Be alert for changes in behavior that may indicate your child is feeling stress:
 - Reluctance to go to school, loss of concentration, trouble sleeping, and unusual aggressiveness are all signs of stress that need attention and understanding.
 - Regressive behavior, such as thumb sucking, bed-wetting, and tantrums in a child who has long since moved beyond these behaviors, is also a sign of stress.

Lacking skills for coping effectively or even describing how they feel, children often need their parents’ help to express and deal with the feelings they are experiencing. Listen carefully to what they say—and don’t say—and look for ways to help them talk about what’s on their mind. Voicing fear has a way of reducing it and helping children feel reassured.

The Reactions of Adolescents

The reactions of adolescents are similar in many ways to those of younger children; they too need the truth and as much information as they can digest, as well as reassurance that they will be okay and that their parents are in charge. Like younger children, younger teens often cannot grasp the diagnosis and are likely to experience fears that they do not or cannot express. Older teens may have a greater sense of the implications, and thus a much greater fear about the future. Teens, like children, take their cues from parents. Honest communication, support, and love will help them cope with MS challenges and reassure them about the future.

Be alert for signs of depression that seem beyond normal adolescent withdrawal. Depression, which is common in MS, is sometimes difficult to diagnose in adults because several of the

common symptoms of depression—fatigue or lack of energy, a general slowing, changes in sleep patterns, inability to think clearly or concentrate, and feelings of worthlessness—are also very common in MS.

Depression can be even more difficult to recognize in teenagers, who may express depressive feelings by acting out at home or at school, rather than by withdrawing or looking sad or down. Depression can also be a potential side effects some of the DMTs, so exploring signs of depression is important.

Siblings Have Reactions Too

Similar to others in the family, siblings experience a host of feelings when their brother or sister is diagnosed with MS:

- *Fear about the future*—What will happen to our family?...Will I get MS too?...Will my brother (sister) be okay?
- *Anger*—Why is this happening to us?...Why is this happening to me?...It isn't fair....Everything is different around here...No one is paying any attention to me any more...Why are Mom and Dad so upset?
- *Sadness*—Will things ever go back to normal?...My sister (brother) doesn't do stuff with me anymore...Mom and Dad are so sad all the time.
- *Guilt*—Did I do something to cause this?...Why am I feeling so angry?

Siblings often resent losing their parents' attention and feel guilty about their resentment. As with the child who has been diagnosed, parents set the emotional tone for siblings as well. Answering their questions in an age-appropriate way and including them in conversations about MS may be helpful. Letting them know that you recognize how distracted or unavailable you may sometimes be can also be reassuring. Siblings are often quiet about their feelings and may need extra attention to voice what is on their minds. To the extent you are able, try to find some special time to spend with the other kids, sharing and hugging, and also talking about and doing things that have nothing to do with MS—it will be helpful for all of you.

Parents Have Their Own Set of Feelings

Parents ride a roller coaster of feelings that is similar to that of their children, but with the greater intensity that comes with knowledge and understanding. Fear, anger, sadness, and worry are universal feelings for parents when their child's health and safety are jeopardized. Many parents also feel guilty and wonder what they did wrong. Uncertainty about the cause of MS tends to exacerbate the guilt and leads to a search for some mistake or omission that may explain the diagnosis. Parents also feel helpless and scared in the face of a problem they cannot solve. For many, it is the first time in their child's life that they haven't been able to "kiss it and make it better." Parents often feel isolated, particularly when interfacing with school and medical communities. Lack of public awareness about childhood MS increases feelings of isolation and makes coping with the diagnosis more difficult.

The feelings can be compounded by loving and well-meaning family members and friends, who express their need to help by pressuring parents to try every “cure” that is touted in the news or on the Internet. Letting them know what kinds of help and support you need—and don’t need—can help them *and* you.

There is Good News

The human spirit is remarkably resilient. In the face of adversity, families can flourish—marshalling resources from within themselves and their communities. Some strategies that have helped other families cope well with MS include:

- *Reaching out for support.* Families who search for and use support do better day to day in their efforts to cope with MS. All of us do better when we are connected to others who understand and support us. Please see Section Seven (Resources and Support) for information on online peer to peer connection opportunities for parents and teens with MS.
- *Promoting honest communication.* This involves more than not lying. It is **talking** about the feelings that hurt, even though it is hard. It is **hearing** each other, not just listening to the words. It is tolerance for feelings expressed and encouragement to keep talking.
- *Holding on to hope.* Hope is a powerful life force that sustains us. In the face of despair, it’s a lifeline. And the marvelous thing about hope is that it is contagious. If you don’t feel hopeful, seek out someone who does.
- *Maintaining a sense of spirituality.* There is growing scientific agreement about the benefits of spirituality. Having a spiritual sense about life fosters other positive traits: connectedness to others, positive self-perception, optimism about the future.

Living with multiple sclerosis is challenging, frightening, exhausting, discouraging. And yet, there is good news as well. Research into the cause and cure of MS is ongoing and very hopeful.

Adapting to Life with Multiple Sclerosis

Children and teens with MS show over and over how resilient they can be to living with the challenges MS may present. The unpredictable nature of the disease can be frustrating, but with planning and open communication it should not limit what your child is able to do. The ultimate goal is for your child to be as active and engaged in a wide range of activities and pursuits, while balancing this with overall health and well-being.

It's very important that parents discourage their child from using their disease as a reason why they CAN'T do something. Whether at school or out in the everyday world, they have to learn to adapt to the challenges they now face. It is important that parents not change the way they relate to their child. Doing so, especially easing up on discipline and changing rules for behavior will only create problems further down the road.

It can also be easy to let worries make you overprotect your child. This may result in the child missing out on activities that are essential for their healthy development, such as playing games

with other children, or taking part in a sporting activity. Your child's healthcare team can let you know whether there are any restrictions on activities.

Your Child's Relationship with the Healthcare Team

Learning to live comfortably with MS depends, at least in part, on a good working relationship with the healthcare professionals who are treating it. You *and* your child need to be able to communicate with the doctors, nurses, and other professionals on the team. 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 are at our most relaxed in the doctor's office, and young children may find the diagnostic tests and neurologic exams frightening until they have developed trust in the doctors and nurses. Your ability to stay calm and relaxed in spite of all the anxiety you are feeling will help your child to become 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 and avoid too many surprises.

While teenagers may have some anxiety as well, they may gradually feel the need to handle some of the doctor visits on their own. Particularly those who have been able to develop an open, trusting relationship with the doctor and/or nurse, may prefer to be examined and talk to the professional without you there. This may be very difficult for you to handle, given your own concerns and wish to hear everything that the professional is saying, but your teen's need for privacy and independence needs to be respected.

The best strategy is to arrive at a three-way agreement between your teenager, the doctor, and yourself, which 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. In the case of older teens (18 and above), the physician's primary relationship will be with them, with the understanding that medical decisions are theirs to make. The physician will seek your input into medical decisions only with the older teen's permission.

Often, older children and teens discuss concerns that they have for their parents, family and friends. Because they worry about the important people in their lives, and do not want to "burden" others, they may not be open about things that are bothering them either physically (such as new symptoms) or emotionally. Giving teenagers some time alone with the medical team on each visit allows them to have an open discussion about things that they might not tell their parents for fear of worrying or upsetting them. After your teenager has had time alone with the healthcare team, you can then review the details of the visit and make further treatment plans.

Adaptation in the Under-Twelves

Children below the age of 12 are working on two essential developmental tasks— social and emotional growth, and academic achievement. As they enter the world of elementary school, they form friendships, learn the give and take of teamwork, and develop a comfort level with adults to whom they are not related. Self-discipline increases, as does initiative and a strong desire to succeed. Building on a foundation of trust and a natural inclination to please others, they begin the process of finding their place in the wider community. Friendships take on increased importance and are influential on a child’s self-esteem. Although more pronounced in adolescence, fitting in is important to younger children as well. They begin to notice cultural messages and, while less so than in early and mid-teens, are starting to be concerned about what the culture defines as desirable.

Helping younger children cope with the intrusion of MS in their lives means supporting their efforts to: understand what is going on, express their feelings, concerns, and questions, and continue with their age-appropriate developmental tasks. This means making every effort to ensure that the normal “work” of childhood can continue with as few disruptions as possible. An effective collaboration between parents, physicians, school personnel, and the National MS Society can help make this happen.

Adaptation in the Teen Years

Coping with MS as a teenager is somewhat more complex. While in the process of moving away from family and towards the wider community, teens gradually transition from reliance on others to reliance on self. They establish their autonomy and form a separate identity, while gaining the ability to think about possibilities and options, and make well-reasoned decisions. As kids move to the edge of their family orbit, self-discovery becomes a primary task. *Who am I? What do I think? What are my values? Where am I heading? And the biggest question of all—Where do I belong?* A diagnosis of multiple sclerosis adds a complicated layer to these questions, as the need for independence collides with the possibility of increased dependence.

Spanning the years 12-19, adolescence can be divided into three parts—early, middle, and late. Though each individual is unique, there are some common developmental issues facing each of these age groups.

- *Early Adolescence (12-14)* The movement towards independence begins. The peer group gains importance as the young teen begins moving away from family and looking to friends for support and validation. For young teens, self-esteem is tied to how well they fit in, while self-concept rests with how adequately they feel they reflect cultural messages. This age group is the most vulnerable to marketing messages about what’s cool and what’s not. Fitting in becomes increasingly important.
- *Middle Adolescence (15-16)* Continuing the move towards independence, mid-teens turn away from the influence and idealization of parents. All of the adults in their life are seen more realistically. Conflict around autonomy increases, as does vulnerability to

peer pressure and cultural messages. Self-esteem continues to be shaped by how well they think they fit in and how they evaluate their personal appearance. Being different is avoided by most in this age group. Concerns often evolve around physical attractiveness, along with a growing interest in dating. Concrete thinking decreases somewhat as the movement towards abstract thinking accelerates.

- *Late Adolescence (17-19)* The task remains to further increase independence. Identity formation continues, with many late-teens having a consistent sense of self that is not as easily influenced by the culture. There is a clearer sense of “who I am” and “who I’m going to be.” Peer groups are still very important and many in this stage experience their first serious relationship. With further brain development, teens are more able to control impulses, delay gratification, see possibilities, and plan for the future. Looking ahead to life after high school, there is a mixture of excitement and fear. Old self-doubt may surface temporarily but can usually be self-regulated.

The multi-stage journey of adolescence is one of trying on new identities. The “me” of the moment is just one version of the “me” that might be. It is a time of possibilities. It can be confusing, frightening, relatively smooth, or fairly turbulent. With the mandate of independence as a constant backdrop, the threat of losing independence to a chronic illness is extremely hard.

Teenagers’ Responses to MS

Most teenagers want to be like everyone else and an MS diagnosis can threaten just that. Naturally believing they are invincible, it’s a challenge for teens with MS to accept the limits of their body. Fatigue can be enormous and often unpredictable. Long hours studying or out with friends can exact a price for the next several days. Older teens naturally look ahead to their post-high school years and worry about their future. Can I go to college? Can I live independently? Will I have enough energy to do the work? Will I make new friends? Questions we all ask ourselves have a heightened intensity with a backdrop of MS.

Teenagers typically withdraw from parents and don’t talk much about what’s going on. This may be more pronounced for a teen with MS. In the face of wanting and needing to be like everyone else, avoiding MS in the short-term can make sense. Teens gravitate towards others they wish to be like and often refuse to acknowledge their MS to anyone. Understandably angry, and feeling cheated by life, they may withdraw from friends as well as family and become depressed.

Depending on their age, young people are more or less able to voice how they feel. Younger teens often lack awareness about how they feel and need help talking about what’s bothering them. Mid-to-late teens have more tools for self-expression but may be reluctant to discuss things with their parents.

Gauging Your Teen's Reactions

Although it's a challenge to separate what's typical adolescent turmoil and what's a reaction to having multiple sclerosis, it is possible. Listen carefully to what your teen says and be alert for signs of depression, such as feelings of hopelessness, loss of pleasure or interest in activities, and persistent sleep problems, and thoughts of suicide. Difficulty with concentration or decision-making, significant weight loss or gain, and feelings of worthlessness are symptoms as well, and all warrant your attention.

Help your teen talk about what's bothering him or her. Often these conversations happen in the car, while running errands, when teens are more likely to open up. Counselors at school or a favorite teacher or clergy person may be a resource for your teen. The National MS Society is knowledgeable about the mental health community and can refer you and your teen to someone versed in MS.

SECTION FOUR

COGNITIVE ISSUES AND CHILDREN WITH MS

SECTION FOUR—COGNITIVE ISSUES AND CHILDREN WITH MS

Managing Cognitive Symptoms in Children and Teens with MS

Introduction

Cognition refers to the high-level functions that are carried out by the human brain and include a person's ability to:

- Understand and use language
- Have a visual understanding of the world—*visual-spatial functions*
- Perform calculations
- Focus, maintain, and shift attention as needed—*information processing*
- Learn and remember information—*memory*
- Perform complex tasks involving organization, planning, decision-making, and problem-solving—*executive functions*

Research has shown that approximately 50-60% of adults with MS experience some cognitive deficits. Sometimes, however, the cognitive changes are subtle enough to escape notice in everyday interactions. For this reason, people with MS, family members, and healthcare professionals may be slow to recognize the changes. Memory, attention, speed of information processing, and verbal fluency are the most frequently impaired functions. Reasoning, planning, and visual perception are also impaired in some people.

At this time, it is estimated that about one-third of children and adolescents with MS may have some cognitive changes from disease. Fortunately, ongoing research efforts will help enhance our understanding and treatment of this important aspect of pediatric MS.

Myelination, the process of developing the myelin sheath along the axons of nerve cells in the central nervous system, is a slow and gradual process that begins prior to birth and continues into adulthood. The inflammation, damage to the blood brain barrier, and demyelination that occur in MS may disrupt the normal development of myelin, making children more susceptible than adults to changes in cognitive function. On the other hand, children may have better ability to adapt and compensate to cognitive changes associated with MS. Future research will help us clarify these issues.

In adults with MS, level of physical disability is only slightly related to level of cognitive disability. In other words, a person can have significant physical symptoms without any cognitive symptoms whatsoever, while someone with little or no physical impairment can have significant cognitive problems. The same disassociation between physical and cognitive problems seems to be the case in children as well.

Attention/Information Processing

Typically, simple attentional tasks, such as focusing briefly to repeat a phone number, are not a problem for children and adolescents with cognitive issues related to MS. However, as tasks become more complex, these children may have more difficulties. For example, attentional problems may not be observable in a child with MS who is speaking one-on-one with someone in a quiet environment. Unfortunately, real world environments tend to be more complex. Classrooms are often noisy, with multiple distractions.

Children with MS may be at an increased disadvantage when required to focus their attention in the face of distractions. Furthermore, these children may have trouble with “working memory”—the ability to hold information in mind while working on it. This ability is necessary, for example, when performing mathematical computations that require “carrying” numbers, or other more complex operations. Also, the speed at which information is processed can be adversely affected, necessitating longer time to think about responses in general. People with MS may become fatigued very easily when performing demanding tasks (either physical or cognitive.) This fatigue may exacerbate attentional problems as well as other cognitive deficits.

Memory

Among children reporting cognitive changes, memory problems are perhaps the most common complaint. This likely reflects the fact that memory problems are among the most easily observable deficits and the ones with the most immediate negative feedback. For example, these children will have difficulty remembering conversations and forget to do chores or will be unable to remember teachers’ lectures or to keep track of assignments. It is important to note, however, that attention plays an important role here as well. For example, children who have difficulty paying attention will encode and store less information, and thus report poor “memory” for that information.

Neuropsychologists (specialists who study how we think and how our ability to think and process information relates to the “work” that we do in our world...school, home, etc.) often consider memory as having three components:

- **Encoding**—which involves the initial learning of the information
- **Storage**—which involves holding it there for a period of time
- **Recall**—which involves accessing the information at a later time

Children and adolescents with memory problems may demonstrate difficulty with one, two, or all three of these components. Thus, they may have difficulty learning information, have increased rates of forgetting in comparison to other children, or be unable to report information without cueing or prompting. Children may have difficulty with memory for verbal information (information they hear), as well as visual information (information they see.) Children with deficits in verbal memory will have trouble remembering what they are told—a class lecture, for example. Children with deficits in visual memory may have difficulty

remembering where they put their school books or their keys, or may get lost more easily, especially when in unfamiliar neighborhoods or buildings. This latter point is an important consideration for teenagers who may soon be getting their driver's license.

Language

Language deficits in children and adolescents, like the deficits seen in adults, tend to be quite subtle. They are generally related to speed of information processing and usually involve a reduction in fluency (the speed with which language is produced.) As a result, these children may speak more slowly than before. They may also exhibit "naming" deficits (also referred to as "word finding" problems) in which the word is "on the tip of their tongue" but they can't produce it. Adults or children with these kinds of deficits may say a related (but incorrect) word in place of the target word (e.g. sister rather than brother,) or "talk around" the word, using unnecessarily indirect and wordy speech to explain something that could be stated with one or two words. This is often referred to as "circumlocution." Such language deficits can cause embarrassment and frustration in social situations or when speaking aloud in school.

Visual Spatial Functions

The term "visual-spatial functions" does not refer to visual acuity (correctable with eyeglasses,) but rather how one's brain interprets and works with visual information. These functions may include the ability to judge angles and distances, and comprehend how objects relate to one another or are put together. Deficits in these areas can cause trouble with tasks such as reading maps, drawing, and/or building things. These functions have not yet been extensively evaluated in children with MS.

Motor Functions

When MS affects the ability to walk, it is quite apparent. More subtle, however, are the problems with fine motor coordination that may be caused by the disease. When manual dexterity is affected, children may exhibit slowed movements and/or tremors that affect their ability to complete certain kinds of tasks. For example, handwriting may be adversely affected and hobbies such as building models or competing in sports that require fine motor coordination may become more challenging.

It is important to keep in mind that while a child or adult with MS can experience a change in any of these cognitive functions, many people do not experience any of these symptoms and others may experience symptoms in only one or two functional areas. The key to dealing with cognitive changes is to recognize them when they develop and find ways to minimize their impact on daily life.

Answers to Common Questions about Cognitive Symptoms

What type of progression of cognitive symptoms can we expect? Cognitive symptoms, much like sensory and motor functions, may fluctuate along with clinical relapses. However, just as sensory and motor functions generally improve following an acute relapse, cognitive skills are likely to as well. Some deficits, however, may remain.

It is important to note that steroid interventions used during the acute treatment of relapses are known to affect cognition. For example, attentional and memory deficits are common during steroid treatment. Rest assured, however, that these are only temporary medication side effects that will lessen as your child is tapered off of these medications.

The overall progression of cognitive problems is not yet understood. In general, however, progression of symptoms is likely to be related to a number of factors, including the length of time the person has had the disease and the severity of disease activity. Disease severity is indicated by the frequency and number of relapses, the total lesion area as seen on MRI, and the particular areas in which the lesions occur. Therefore, the best way to prevent progression of symptoms—including cognitive changes—is to try and prevent the relapses from occurring. Disease-modifying treatments are discussed in detail in Section Two.

What is a neuropsychological evaluation?

A neuropsychological evaluation is a comprehensive assessment of cognitive and behavioral functions using a set of standardized tests and procedures. Various mental functions are systematically tested, which may include but are not limited to: problem solving and conceptualization, planning and organization, attention, memory and learning, language, perceptual and motor abilities, emotions, behavior, and personality.

How do I know if my child should have a neuropsychological evaluation?

If your child is reporting or showing signs of cognitive symptoms such as those discussed above, a neuropsychological evaluation is appropriate. Evidence suggests, however, that neither adults nor children are always accurate in their perception of their own cognitive abilities and limitations. Often family members and/or teachers recognize cognitive problems that are not apparent to the child. Accordingly, if you or your child's teacher have observed changes in your child's cognitive functioning, a referral to a neuropsychologist will be helpful. The neuropsychological report should include specific recommendations tailored to each child regarding treatment interventions and accommodations that will help your child overcome cognitive limitations.

Even if cognitive changes are not evident, a neuropsychological evaluation may in some cases be helpful for several reasons.

- Cognitive changes are often subtle, progressing gradually over time. Therefore, it may be difficult to observe them in casual interactions, and a neuropsychological evaluation may be more sensitive to subtle decline.

- Neuropsychological evaluations rely on normative data to make comparisons regarding how well an individual is performing relative to age-matched peers. For this reason, deficits may be difficult to detect in children who are very high functioning. That is to say, for those that once had excellent memory, a performance in the “average range” may represent a relative decline for them. Thus, another function of the neuropsychological evaluation is to establish a baseline level of functioning for your child, with which to compare future results should he or she experience any cognitive decline in the future. A neuropsychological evaluation may, therefore, be a prudent decision regardless of whether or not cognitive deficits are currently evident.

What can be done about a child’s cognitive deficits?

Everybody has strengths and weaknesses and helping a child/adolescent find cognitive strengths may help him/her learn to compensate in areas where s/he may be more vulnerable. Furthermore, neuropsychological evaluation serves as a first important step toward effective interventions. Typical interventions are described below.

When discussing education, it is important to note that there are differences between accommodations and modifications:

- Academic Accommodations (see Section Five)
Academic accommodations do not change or alter what is being measured and are considered a teaching support or service that a student needs in order to meet the expectations of the general education curriculum. An accommodation addresses the question of how a student will learn. For example, when children or adolescents display attentional deficits, they are often provided with preferential seating in class (e.g. placing the child near the teacher at the front of the room.) This simple accommodation helps the child in two ways. First, it minimizes the distractions the child faces (i.e. the child need not look through a sea of twenty other students to see the teacher.) Second, having the child sit up front allows the teacher to more easily monitor the child’s level of attention and engagement in the classroom activities. This allows the teacher to reorient the child when necessary.

Due to attentional problems as well as reductions in the speed at which these students process information, accommodations in test settings are also common. A child with MS may perform better when placed in a quiet, distraction-free environment (such as a resource room) when completing tests. Furthermore, extended time to complete tests addresses processing speed issues as well as any physical challenges that may exist, and allows the child the best opportunity to demonstrate his or her level of mastery of the material. These accommodations are often applied not only to classroom tests, but also to standardized state examinations.

Memory deficits obviously have serious implications for learning. As these children often display “retrieval deficits” (i.e. poor access to information stored in the brain,) they are greatly aided by recognition measures. Accordingly, a multiple choice test may be the

optimal format for these children to show what they have learned. Such accommodations can often be made for children with memory deficits.

With respect to visual spatial and motor deficits, occupational therapy is often recommended to identify and provide appropriate strategies and tools. Depending on the school system, these services may be provided either in or outside of the school.

- **Academic Modifications**

Modifications change or alter what is being measured and are considered substantial changes in the general education curriculum. If the goals or expectations of the general education curriculum are beyond the student's level of ability, a modification is needed. A modification addresses what a student will learn: instructional level, conduct and performance criteria. For example, a student who has mental retardation may work on functional academics or life skills rather than the traditional curriculum. Or, a student who has a learning disability or other health impairment, and is learning at a slower pace, may be provided materials at a lower grade level.

Cognitive Rehabilitation

Cognitive rehabilitation refers to behavioral interventions geared toward improving cognitive functioning. Generally speaking, there are two types of strategies employed—*restorative* and *compensatory*. Restorative techniques involve repetitive practice of certain tasks to strengthen the functions involved. Compensatory strategies refer to learning new skills to replace skills that have been lost (i.e. learning to keep lists or use a day planner to avoid forgetting assignments.) Also, mnemonic strategies (memory tricks) are often taught to enhance memory functions in various settings.

Cognitive rehabilitation (typically with a neuropsychologist, occupational therapist, or speech-language pathologist) is available at most major medical centers. At this time there are only a few studies supporting the use of cognitive rehabilitation in adults with MS and no studies examining its effectiveness in children and adolescents. However, it is expected that these techniques will be effective when specific cognitive functions are targeted and specific skills are taught to address real world problems.

As a parent, you may well find yourself needing to advocate for your child in his or her academic setting. With the assistance of your child's healthcare team, you will have the job of helping the school to understand and respond to your child's needs. The next section of this manual will discuss academic issues in greater detail.

It is helpful to keep in mind that teachers and administrators, like most other people, will have an easier time recognizing and responding to symptoms they can easily see and understand (i.e. walking difficulties, balance problems, or tremor) than less obvious symptoms like fatigue and the cognitive changes described here. The more you understand about the symptoms your

child is experiencing, the better prepared you will be to help others understand them. Do not hesitate to ask questions of the healthcare team.

SECTION FIVE

YOUR CHILD'S RIGHTS IN THE EDUCATIONAL SETTING

SECTION FIVE—YOUR CHILD’S RIGHTS IN THE EDUCATIONAL SETTING

A Few Questions Up Front

Developmental disabilities are severe, chronic disabilities attributable to mental and/or physical impairment, which manifest before age 22 and are likely to continue indefinitely. They result in substantial limitations in three or more areas: self-care, receptive and expressive language, learning, mobility, self-direction, capacity for independent living, and economic self-sufficiency, as well as the continuous need for individually planned and coordinated services.

It is not uncommon for parents to ask if because their child has MS, does this mean she/he will experience developmental disabilities. Having MS does not mean that your child is/or will become developmentally disabled. He/she does have a chronic disease that is unpredictable in nature and can lead to temporary or rarely permanent disabilities during the childhood or adolescent years.

Most children and teens with MS have the relapsing-remitting type which means that any disabilities they develop because of a relapse usually resolve and they either quickly or gradually return to their normal function. It is uncommon for MS to cause severe permanent disability in a child or teen. However, some children do report difficulty with learning due to memory and/or concentration problems, or their participation in some activities are affected by fatigue. Occasionally, symptoms like a hand tremor can affect writing ability.

There may come a time when you want to find out if your child has any disabilities related to his/her MS. The first step would be for your child to be assessed by a physical therapist (PT) and occupational therapist (OT.) These rehabilitation specialists help determine how your child's function is affected by MS (if at all) and recommend strategies to maximize function. A PT assesses for gross motor deficits such as weakness or balance problems and identifies potential safety issues with respect to walking or participation in sports.

An OT assesses for fine motor problems such as poor hand coordination that can affect the ability to write or carry out tasks like cutting meat or doing up buttons. They can also recommend ways to conserve energy when fatigue is an issue. If you have concerns about your child's learning, the school may be able to conduct some testing, but he/she should have a neuropsychological assessment. Based on the results of various tests, neuropsychologists can better assess the impact that MS has on the child's ability to learn and can make recommendations for the child, as well as, teachers and parents on how to maximize learning potential (see Section Four.) Your local public school system will likely conduct additional evaluations and observations to aid in developing an educational plan.

Regarding the potential for future disability, many people with relapsing-remitting MS eventually go on to develop secondary-progressive MS which can lead to permanent disabilities. This usually occurs well into the adult years. Starting treatment early in the disease process can slow the progression of the disease and delay the onset of the more permanent

effects. Most children and teens with MS live active lives with limited or no effect on their function. It is not possible to predict what the outcome will be for any one person.

Your Child's Rights in the Educational Setting

IEP, IDEA, 504, ADA, LRE—Confused? You are not alone. The rights of children in education are both important and confusing. This section begins to address the rights of children in public school districts, private schools, and post-secondary schools. For additional information, see Section Seven—Resources and Support.

Some legal basics about K-12 public schools.

The Individuals with Disabilities Education Act (IDEA) is a federal law intended to ensure that children with disabilities receive a **free appropriate public education (FAPE)**, which emphasizes special education and related services designed to meet their unique needs and prepare them for employment and independent living. IDEA provides federal funding to states and public school districts to cover part of their IDEA expenses.

The Office of Special Education Programs within the U.S. Department of Education administers the IDEA regulations. State departments of education are required to ensure that public school districts comply with IDEA.

Special education means “specially designed instruction” – instruction that’s been tailored for the child’s unique needs.

Related services means “transportation and such developmental, corrective and supportive services as may be required to assist a child with a disability to benefit from special education.” Transportation could be to and from school, between schools, or in and around school buildings.

The following related services are listed in the IDEA regulations:

- Speech-language pathology and audiology services
- Psychological services
- Physical and occupational therapy
- Therapeutic recreation
- Early identification and assessment of disabilities in children
- Counseling services
- Orientation and mobility services
- Medical services for diagnostic or evaluation purposes only
- School health services by a school nurse or other qualified personnel
- Social work services
- Parent counseling and training

The list in the regulations is not exhaustive; if a child needs a service that is developmental, supportive, or corrective to benefit from special education that service should be provided even if it is not listed in the regulations. For instance, a student might need a note-taker or full or part-time aide.

To qualify for services under IDEA, a child must fall into one of the following categories *and* need special education and related services:

- Intellectual Disability
- Developmental Delay
- Hearing Impairment, including deafness
- Speech and/or Language impairment
- Visual Impairment, including blindness
- Serious Emotional Disability
- Orthopedic Impairments
- Autism
- Traumatic Brain Injury
- Other Health Impairment
- Specific Learning Disability
- Deaf-Blindness
- Multiple Disabilities

Children ages 3 through 9 might qualify for services in their local school system, if they are experiencing developmental delays in physical, cognitive, communicative, social, emotional, or adaptive development that require special education and related services. Any child ages 3-5 with a suspected disability can be evaluated for school services through the local school system, even though the child has not started school. This IDEA federal regulation process is called Child Find.

States are required to serve children with disabilities aged 3 through 21 years unless, with respect to 3 through 5-year-olds and 18 through 21-year-olds, this requirement would be inconsistent with a state law or practice or court order.

Section 504 of the Rehabilitation Act of 1973 is a civil rights law intended to prohibit discrimination on the basis of disability and to ensure that people with disabilities are provided an equal opportunity. Section 504, which applies to recipients of federal funds, is implemented and enforced by the Office for Civil Rights within the U.S. Department of Education. Since all (or nearly all) public school districts receive federal funds, they must comply with the U.S. Department of Education's Section 504 regulations.

Section 504 protects any individual with a disability: students, parents, teachers, guests, and the public. Under Section 504, an *individual with a disability* is any individual who:

Has a physical or mental impairment which substantially limits one or more major life activities; has a record of such an impairment; *or* is regarded as having such an impairment.

The ADA Amendments Act of 2008 (effective January 1, 2009) significantly changes how the term "disability" is to be interpreted.

“The determination of whether a student has a physical or mental impairment that *substantially limits a major life activity* must be made on the basis of an individual inquiry. The Section 504 regulatory provision defines a physical or mental impairment as any physiological disorder or condition, cosmetic disfigurement, or anatomical loss affecting one or more of the following body systems: ***neurological***; musculoskeletal; special sense organs; respiratory, including speech organs; cardiovascular; reproductive; digestive; genito-urinary; hemic and lymphatic; skin; and endocrine; or any mental or psychological disorder, such as intellectual disability, organic brain syndrome, emotional or mental illness, and specific learning disabilities. The regulatory provision does not set forth an exhaustive list of specific diseases and conditions that may constitute physical or mental impairments because of the difficulty of ensuring the comprehensiveness of such a list.

Major life activities, as defined in the Section 504 regulations, include functions such as caring for one’s self, performing manual tasks, walking, seeing, hearing, speaking, breathing, learning, and working. This list is not exhaustive. Other functions can be major life activities for purposes of Section 504. In the Amendments Act, Congress provided additional examples of general activities that are major life activities, including eating, sleeping, standing, lifting, bending, reading, concentrating, thinking, and communicating. Congress also provided a non-exhaustive list of examples of “major bodily functions” that are major life activities, such as the functions of the immune system, normal cell growth, digestive, bowel, bladder, neurological, brain, respiratory, circulatory, endocrine, and reproductive functions... the Section 504 regulatory provision’s list of examples of major life activities is not exclusive, and an activity or function not specifically listed in the Section 504 regulatory provision can nonetheless be a major life activity.”

Thus, multiple sclerosis is an impairment; however whether an individual has a disability as defined under Section 504 depends on whether the MS “substantially limits” a major life activity, which as stated above is made on the basis of an individual inquiry

Thus if a ten-year-old child who has MS is unable to walk half a mile without resting, he or she may be considered to have a substantial limitation in the major life activity of walking because most ten-year-old children can walk half a mile without resting.

Most, if not all, children who are eligible under IDEA meet the Section 504 definition of disability and are protected under Section 504 as well. However, Section 504 also protects many children who are *not* eligible for IDEA services. For example, a child with MS who does not need special education (specially designed instruction) is still covered by Section 504 if he or she needs aids and services within the regular educational setting.

As with the IDEA regulations, the Department of Education's Section 504 regulations require school districts to provide a free appropriate public education (FAPE) to students with disabilities. Under Section 504, FAPE is special *or* regular education and related aids and services, which are designed to meet the individual needs of students with disabilities as adequately as the needs of non-disabled students are met by the regular school programs.

Examples of related aids and services include extended test-taking time, relocation of classrooms, readers for students with visual impairments, equipment modifications, speech therapy, psychological services, physical and occupational therapy, and school health services. If a student with a disability needs a related aid or service to benefit from the educational program, the school should provide it.

The Americans with Disabilities Act (ADA) is a broad civil rights law with five titles, which prohibits discrimination on the basis of disability and requires an equal opportunity regardless of whether an entity receives federal funds:

- Title I – employment
- Title II – state and local government services (including public entities such as school districts)
- Title III – private entities
- Title IV – telecommunications
- Title V – miscellaneous

The ADA definition of disability is the same as the Section 504 definition, and also applies to students, parents, teachers, guests and the public. The ADA basically provides the same protections for students with disabilities in public schools as Section 504.

In the context of public school districts, the ADA is enforced by the Office for Civil Rights within the U.S. Department of Education.

Other Health Impairment Classification and MS

The Other Health Impairment (OHI) classification in special education may be an option for your child. If you or your child's teachers feel that MS could be negatively impacting his or her learning, your child may be eligible for a modified curriculum in special education, for example, if he or she is unable to remember things or has lost academic skills he or she had once mastered. To qualify for OHI, your child must meet the following requirements:

(a) Definition. Other Health Impairment means limited strength, vitality or alertness, including a heightened alertness to environmental stimuli, that results in limited alertness with respect to the educational environment, that is due to chronic or acute health problems such as a heart condition, tuberculosis, rheumatic fever, nephritis, asthma, sickle cell anemia, hemophilia, epilepsy, lead poisoning, leukemia, attention deficit disorder, attention deficit hyperactivity disorder, or diabetes. Having a medical diagnosis alone is not enough to justify

being identified in the area of other health impairment. The impairment must adversely affect educational performance.

(b) Criteria.

1. Evidence of a health impairment.
2. Evidence that the health impairment adversely affects educational performance.
3. Accommodations have been tried in general education class(es.)

(c) Evaluations Required.

1. Documentation of the impairment (medical diagnosis/statement, if available.)
2. Performance measures such as group or individual intelligence scores, individual/group education achievement and/or diagnostic tests, classroom observations, motor assessments, criterion-referenced tests, curriculum-based assessments, review of child's existing records, (e.g. attendance, health, discipline.)
3. Documentation of accommodations that may include, but are not limited to, teacher interview(s,) anecdotal records, classroom observation(s,) health records, and therapy evaluations.

State Laws

Some states have laws that pertain to students with disabilities. They may provide greater benefits than the federal laws. Contact your state department of education for more information.

How a Child Receives Services from a School District

Under all three federal laws, the school district must conduct an individual evaluation before a plan can be developed for a student. An evaluation happens in one of two ways:

1. The school district contacts the parents and asks to evaluate the child. If the school believes, or has reason to believe, that a student has a disability and needs special education and/or related services, the school should contact the parents in writing for permission to conduct an evaluation (at no cost to the parents.)
2. A parent may request an evaluation, preferably by hand delivered letter, as it is important to always keep copies of every communication with the school system. Parents can contact the teacher, principal, special education director (if the parents believe their child needs special education,) or Section 504 coordinator (if special education is not an issue.) If the school agrees with the parent, the student must be evaluated (at no cost to the parent.)

If the school disagrees with a parent's request for an evaluation, the parent must be given a reason for the refusal and a notice of *parents' procedural safeguards rights* in writing. These

rights include the right to request an impartial due process hearing concerning whether or not the student should get an evaluation.

Evaluation and Placement

The evaluation has three purposes:

1. To determine if the child meets qualifications for services
2. To gather information about the child's educational needs
3. To decide on strategies for meeting those needs

Under IDEA regulations, a group that includes the parents, a regular education teacher, a special education teacher or provider, someone who can interpret the evaluation results, a representative of the school district, and any others who have special knowledge or expertise regarding the student, and the student (whenever appropriate) must be included to determine what (if any) services the child qualifies for in the educational setting.

Section 504 regulations and ADA require that the placement decision be made by a group of people knowledgeable about the meaning of the evaluation data and the placement options. Parents are not mentioned in the regulations but most school districts include the parents on the team.

Under IDEA, if the parent disagrees with the results of the evaluation, he or she may request an *Independent Educational Evaluation* (IEE) at public expense. If the school district does not want to pay for an IEE, it must initiate a hearing and prove to the hearing officer that its evaluation was appropriate. The Section 504 regulations and ADA do not mention IEEs. If the parent disagrees with the results of the evaluation, however, he or she may request a hearing with an impartial hearing officer.

If a student is found to be eligible for services under IDEA, the evaluation team develops an *Individualized Education Program* (IEP.) The IEP is developed by a team of people knowledgeable about the student (including the parents.) This written document must include statements of the following:

1. Child's present educational performance, including how his or her disability affects progress in the general curriculum
2. For children with disabilities who take alternate assessments, a description of benchmarks or short-term objectives should be included
3. A statement of measurable annual goals including academic and functional goals
4. How the child's progress toward meeting the annual goals described will be measured and when periodic reports on the progress the child is making toward meeting the annual goals (such as through the use of quarterly or other periodic reports, concurrent with the issuance of report cards) will be provided
5. A statement of the special education and related services and supplementary aids and services, based on peer-reviewed research to the extent practicable, to be provided to

the child, or on behalf of the child, and a statement of the program modifications or supports for school personnel that will be provided for the child

6. Explanation of the extent, if any, to which the child will not be participating in the regular class and general curriculum
7. A statement of any individual appropriate accommodations that are necessary to measure the academic achievement and functional performance of the child on state and district wide assessments
8. Date when services, modifications, etc. that are described in the IEP will begin, and their frequency, duration and location
9. Transition services (beginning at age 16)

Section 504 and ADA are much simpler. Although an IEP can be developed, the regulations only require that when the school district has identified the educational and related services needed by a child with a disability, it must describe the program in writing and provide those services.

Under all three laws, students with disabilities must be integrated into the regular education setting to the maximum extent appropriate.

What to Do When You Disagree with the School District's Decisions

It is usually best to resolve disagreements with a school district informally and cooperatively (if possible.) If informal meetings are not successful, the first step should be to contact the department of special education in your state and request mediation, in which a non-biased mediator (or go-between) works separately with the family and school to determine a compromise. However, all three laws entitle parents to an impartial due process hearing on anything related to the FAPE provisions including the school district's decisions concerning identification of the child as a child with a disability, evaluation, and placement issues.

Complaints can also be filed with the state educational agency (for IDEA) and with the Office for Civil Rights at the U.S. Department of Education (for Section 504 and ADA.) These agencies will *not* look at issues that can be addressed through due process. They will look at whether a school district has failed to implement a due process hearing decision or whether a school district has failed to follow the FAPE procedures for identification, evaluation, and placement.

Private Schools

If a school district is unable to provide a free appropriate public education to a child with a disability within the school district, it may need to place a child in a private school or facility and pay for that placement. Alternatively, parents may choose to place their child in a private school. If the parents are doing so because they believe the school district is not providing a free appropriate public education, the parents can request an independent due process hearing and try to get the school district to pay for the private education. Under IDEA, a school district that is offering the child a free appropriate public education within the district is only

responsible to pay for children who are “parentally placed” in private schools under certain, very limited and complicated circumstances that are beyond the scope of this discussion.

Under Section 504 and ADA, public school districts have obligations to students *with* disabilities who have been “parentally placed” in private schools only to the extent the districts provide services to students *without* disabilities who have been placed by their parents in private schools.

Private schools themselves have no obligations under IDEA.

Under the Department of Education’s Section 504 regulations, a private school that receives federal financial assistance must include a student with a disability if the student can, “with minor adjustments,” be provided an appropriate education (regular or special education and related aids and services that are designed to meet the students’ educational needs as adequately as the needs of non-disabled students.)

Title III of the ADA applies to all private schools except schools owned or controlled by religious organizations. Title III requires that private schools make reasonable modifications to policies, practices, or procedures for students with disabilities who need those modifications to ensure an equal opportunity to participate, unless the modifications would fundamentally alter the nature of the services. Title III also requires that private schools provide auxiliary aids and services that are needed to ensure equal access for students who have vision, speech, or hearing disabilities, unless an undue burden or fundamental alteration would result.

Higher Education

The change from public school to higher education can be a bit of a shock. Colleges and universities have no obligation under IDEA. Since most (if not all) of them receive federal financial assistance, the Section 504 regulations will apply to most post-secondary schools. These regulations require that schools make the following academic adjustments if a student with a disability needs them to ensure an equal opportunity to participate:

- Modification of academic requirements (such as time permitted for degree completion, course substitutions, adaptation of how courses are conducted)—unless the requirements are fundamental to the school’s program
- Allowance for tape recorders in classrooms and service dogs in buildings
- Modification of course examinations so that they evaluate the student’s achievement in the course, rather than reflecting the student’s disability
- Provision of auxiliary aids to students with impaired sensory, manual, and speaking skills.

The ADA makes a distinction between public higher education (Title II) and private higher education (Title III.) Many requirements in the two titles are the same:

- Reasonable modifications to policies, practices or procedures for students with disabilities who need those modifications to ensure an equal opportunity to participate, unless the modifications would fundamentally alter the nature of the services
- Provision of auxiliary aids and services that are needed to ensure equal access for students who have vision, speech or hearing disabilities, unless an undue burden or fundamental alteration would result

The big difference between public school districts K-12 and higher education is that in higher education the student must be proactive:

- The student must request the adjustments, modifications or auxiliary aids and services
- The student must provide current documentation of his/her disability (if requested by the school,) including documentation of the need for the adjustments, modifications or auxiliary aids and services
- The student must provide a history of documented services from high school

Most schools have procedures for making such requests and many schools have disability services coordinators or disability services offices.

Other Resources

In addition to federally and state mandated services for children with developmental disabilities (discussed above,) there may be additional community-based resources and services available.

At the federal level, the Administration on Developmental Disabilities (ADD) (<http://www.acf.hhs.gov/programs/add/index.htm>) ensures that individuals with developmental disabilities and their families participate in the design of, and have access to, culturally competent services, supports, and other assistance and opportunities that promotes independence, productivity, and integration and inclusion into the community.

The major goal of the ADD is to establish partnerships with state governments, local communities, and the private sector to assist people with developmental disabilities to reach maximum potential through increased independence, productivity, and community integration.

They address all elements of the life cycle:

- Prevention
- Diagnosis
- Early intervention
- Therapy
- Education
- Training
- Employment
- Community living and leisure opportunities

Every state has a Council on Developmental Disabilities.

The ADD accomplishes these partnerships through formula grants that support local Councils in capacity building and advocacy activities, to develop a consumer and family-centered comprehensive system, and a coordinated array of culturally competent services, supports, and other assistance designed to help people with developmental disabilities achieve independence, productivity, and integration and inclusion into the community. The Councils address employment issues, and may also address community living activities, child development activities, system coordination and community education activities, and other activities.

Programs and services made possible through these partnerships will vary from state to state. To find your state's council on developmental disabilities go to acf.dhhs.gov/programs/add/states/ddcs.htm or call the public information number (202-690-6590).

For a list of publications and resources on education, see Section Seven —Resources and Support.

SECTION SIX
HEALTH INSURANCE ISSUES

SECTION SIX—HEALTH INSURANCE ISSUES

Tips on Working with Your Insurance Plan

As a parent of a child with MS, you know that your child needs health insurance coverage to finance his or her health care. If you associate health insurance with dread, confusion and cost, rest assured. Despite the complexity of health insurance today, most insurance plans work very well for most people. And you can minimize the amount of time, worry, and aggravation you envision having to dedicate to insurance matters for your child by taking the time to:

- Understand the basic rules of your health plan
- Clarify your specific questions and needs
- Determine your best resource(s) in the event that a question or concern arises.

This overview provides basic information about getting and keeping your child insured, and about ways to make the best use of his or her coverage. In addition, the National MS Society and other resources will always be available to you as a back- up for any insurance issues you cannot resolve on your own.

Getting and Keeping Insurance Coverage for Your Child

Most people have coverage for their dependent children through their employer-based plans. As of 2014, the healthcare reform law known as the Affordable Care Act (ACA) assures that employers of 50 or more workers must offer health coverage to their employees and their dependents. Smaller employers are encouraged to do so through tax and other incentives.

Regardless of your child's past or present health, he or she can stay on a parent's employer-sponsored coverage until their 26th birthday. Address any questions about your child's eligibility to employer-sponsored coverage to the employer or the US Department of Labor.

Nonetheless, parents should be aware that factors affecting their own eligibility for coverage, such as a change of employers, employer's change in health plans, reduction in work hours, marriage or divorce, relocation out of state, or death, can have a major impact on their child's ability to access the care he or she needs. Your goal should be maintaining coverage without interruption, no matter what changes occur in your employment, insurance, or circumstances. Making transitions from one type of insurance coverage to another can be complex, and should be carefully planned in advance to assure that no gaps in coverage and access to care occur. Fortunately, no cost help is readily available through the federal government and other sources.

Other Sources of Health Coverage for Your Child

- Private health insurance policies are available to purchase for any child not eligible for coverage from another source.

- The Children’s Health Insurance Program (CHIP) provides low-cost health coverage to children in families that earn too much money to qualify for Medicaid. In some states, CHIP covers parents and pregnant women. Each state offers CHIP coverage, and works closely with its state Medicaid programs.

Start your research into these health insurance options at www.healthcare.gov. Expert counselors are available at no cost at 1-800-398-2596.

What to Look for When Comparing Plans

Parents of children with MS should carefully compare any/all health insurance options available for their child with MS before selecting a plan. By outlining ten “essential health benefits” for certain types of health insurance plans, the Affordable Care Act sets new standards for coverage, and likely to have an impact on all health insurance plans in the future. Among them are doctor, hospital and emergency services, prescription drugs, rehabilitation (physical, occupational or speech therapy); durable medical equipment; laboratory services; plus dental and vision care for children.

- Check the prescription drug formularies (list of covered drugs) to make sure his/her medications are covered. Also check the, “cost-sharing” amounts and any limitations in drug coverage to clearly understand what you might have to pay for needed drugs;
- Check and verify the list of doctors, pharmacies, therapists and other providers in the provider network. Using providers out of network will cost significantly more in out-of-pocket costs, and should be avoided as much as possible.
- Many ‘preventive health services’ such as vaccinations, annual check-ups and recommended screening tests must be covered by all health insurance plans. Take best advantage of these benefits to help keep your child as health as possible, and to identify health problems as soon as possible.
- Lab work, MRIs and other tests are used routinely to monitor MS. Although these will be covered by most health plans, the amount of cost-sharing (amount you have to pay) can vary, or limits may apply. Although some of these tests may seem the same as some covered “screening tests”, they are not covered the same way if they are being done to monitor a condition after a diagnosis. Check the fine print on these benefits, and ask questions about any plan you are considering for your child.

Advocating Effectively for Your Child

Regardless of the type of coverage you and your child have, you will be able to advocate most effectively for your child if you familiarize yourself with a few critical elements of the plan. You do not have to memorize all of these elements, but it would be prudent to review certain aspects of your existing plan or any new plan before you or your child enroll in it. Additionally, when or if problems with the plan do arise, you would do well to understand what type of problem or question you have.

For example:

Eligibility: Who is covered under what circumstances, including the exact dates the coverage starts and stops (i.e. the effective date)?

Access: How will your child actually get health care; is it through a HMO or other managed care plan? Are you limited to certain hospitals, doctors, pharmacies, and other services? Are there exceptions under certain circumstances? What are your rights and responsibilities as a plan member?

Benefits: What benefits are included and specifically excluded, from the plan? What other limitations, such as the amount, duration or scope of a covered benefit may affect your child's care? It is important to keep in mind that although a particular type of treatment or service may be covered by your policy, an individual claim must nevertheless be judged to be "medically necessary."

For example, while prescription coverage may be included in your policy, you may initially be denied coverage of any of the disease modifying drug therapies for your child because they have been studied and approved for use by the U.S. Food and Drug Administration only in adults. Use of a drug outside of the FDA approval can be considered "experimental" or "off label". If you receive a denial due to it being "experimental" or "off label" you will need to file an appeal. Do not hesitate to contact the National MS Society at 1-800-344-4867 for clinical information to help with the appeal (more appeals information below.)

Regulation: What law(s) is your health plan subject to, and what government agency enforces it? Larger employer-based and union plans are usually "self-insured" and regulated by the U.S. Department of Labor (www.dol.gov). Individual and smaller employer plans (less than 50 employees) are subject to state insurance laws and enforced by state Departments of Insurance. Knowing who enforces your insurance plan could be important if you need to appeal a decision affecting your child's coverage.

Financial Responsibility: What are the best ways for you to minimize your out-of-pocket expenses? Look into the implications of the deductible, co-payment, co-insurance and annual out-of-pocket maximum provisions of the plan, as well as your decisions about using in-network or preferred providers, or going out of plan altogether.

Getting the Care Your Child Needs and Deserves

The best source of detailed information about your own, or your child's health insurance plan and how it works is your insurance policy's manual or handbook. It is your legal right and personal responsibility to have an up-to-date copy provided by your employer or insurer. Comparable information should also be available for parents of children covered through CHIP or Medicaid plans.

Addressing a problem: If you have a problem with the plan, such as your child's access to a certain treatment or specialist, it is sound practice to prepare your argument in advance so you are clear, concise and under control. Have all applicable data available:

- ID number
- Claim number
- Name of the group plan
- Dates of service
- Provider's name
- Doctor's reason for recommending the test or treatment
- Reason—if known—for insurer's wish to deny, limit, or change your doctor's recommended treatment

In order to make the most of your calls with the insurance company:

- Keep detailed records of each call, including:
 - Date and time of your conversation with the case manager or other employee of your insurance plan
 - Name and phone number of the person you spoke to
- Review your understanding of what you heard in the conversation *before* you get off the phone
- Follow up in writing and ask for a response

Appealing a claim: Health insurers often deny or limit coverage for health services, medicines and equipment prescribed to people with expensive health condition such as MS. Fortunately, everyone with health insurance has the legal right to appeal if they or their prescribing provider disagrees with a decision by a health plan. Make sure you are in agreement about the process for appealing a denied claim, and ask for clarification about the terminology being used if it confuses you. Even if you are agreeing to disagree with the person in the insurance office, or intend to take the appeal further, remember that it is worth your while to appeal a denied claim—many of them can be overturned.

Your physician can help: Do not hesitate to ask your doctor for help in building your case. Most are now experienced with insurance denials and appeals, and their office managers and staff are often quite savvy about advocating with certain plans and programs. Articles from recent medical journals, clinical guidelines from professional associations, or other evidence-based recommendations are the best tools to present to an insurer in an appeal or external review panel.

The National Multiple Sclerosis Society has a Health Insurance Appeal Letters Toolkit for assistance with your appeal:

<http://www.nationalmssociety.org/NationalMSSociety/media/MSNationalFiles/Brochures/Paper-Health-Insurance-Appeal-Letters-Toolkit.pdf>

Health Insurance and Cost-Saving Tips

- Never lie on an application for any kind of health, disability, or life insurance. To protect against fraud (which hurts everyone) the insurance industry shares application information.) For example, if you were caught omitting a diagnosis of MS on a life insurance application after disclosing it on an application for health insurance, you could face cancellation of both your policies and denial of future insurance applications. Remember that insurance is a business, and when requesting clarification or making an appeal, it is always best to do so in writing and to limit it to the facts. Emotions are understandable, but will not be as helpful as factual information.
- Carefully watch the timeframes for submitting claims, filing grievances and appeals, and other requirements of your plan. These can really make a difference in your coverage and reimbursement amounts.
- Always pay your COBRA and/or other premiums on time. ***Non-payment is the one reason for legitimately canceling a policy.***
- Ask for help from hospital billing offices or your doctor's office. If you owe a provider more than you can afford to pay, demonstrate good faith by negotiating a payment plan. In the meantime, you can continue advocating for better coverage from your health plan. You may also want to utilize this guide for other tips on handling medical debt: <http://www.healthinsuranceinfo.net/managing-medical-bills/Avoid and Manage Medical Debt.pdf> .
- Remember to claim medical expenses if you itemize your tax deductions, including transportation to/from your child's doctors, uncovered supplies, vitamins, special foods and more.

While the many steps involved in dealing with your child's insurance coverage may seem daunting, keep in mind that there are resources available to help you. An MS Navigator is available to answer your questions and provide guidance at 1-800-344-4867. As with other aspects of living with MS, there is no reason to feel you have to go it alone.

SECTION SEVEN

RESOURCES AND SUPPORT

SECTION SEVEN—RESOURCES AND SUPPORT

MS NAVIGATOR®

Finding answers and making sound decisions relies on having the right information at the right time. The National MS Society provides answers to questions and access to information about all of the options available. Our MS Navigators are highly-skilled professionals equipped to respond to your 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 the MS Society to learn more.

nationalMSSociety.org
contactUSNMSS@nmss.org
1.800.344.4867

RESOURCES

Information on Multiple Sclerosis

National Multiple Sclerosis Society

nationalMSSociety.org
1.800.344.4867

International Pediatric MS Study Group

ipmssg.org

General

Federal Government

US Department of Health and Human Services

hhs.gov

National Institute on Disability and Rehabilitation Research

ed.gov/about/offices/list/osers/nidrr/index.html?src=mr

Children with Disabilities/Chronic Illness

Administration on Intellectual Developmental Disabilities (AIDD)

acf.hhs.gov/programs/add/index.htm

American Council on Education

acenet.edu

Education

Office of Special Education and Rehabilitative Services at the U.S. Department of Education

OSERS funds a large information dissemination and technical assistance network plus there's a customer service specialist for each state.

ed.gov/about/offices/list/osers/index.html

1.800.872.5327

Office for Civil Rights at the U.S. Department of Education

Technical assistance, pamphlets, complaint information on Section 504 of the Rehabilitation Act.

ed.gov/about/offices/list/ocr/index.html?src=mr

1.800.872.5327

U.S. Department of Justice

Technical assistance, publications, complaint info on Titles II and III of the ADA

ada.gov

800.514.0301 voice

800.514.0383 TTY

ADA & Accessible IT Centers

Technical assistance and publications on all aspects of the ADA and accessible information technology in educational settings.

adata.org

800.949.4232 voice/TTY

Association on Higher Education and Disability (AHEAD)

Publications, information and training on higher education and students with disabilities.

ahead.org

704.947.7779 voice

Center for Parent Information and Resources

Parent centers in each state provide training and information to help parents participate more effectively with professionals in meeting the educational needs of children with disabilities

parentcenterhub.org

973.642.8100

IDEA Regulations 34 CFR Parts 300 and 303

ed.gov/offices/OSERS/Policy/IDEA

Section 504 Regulations - Department of Education - 34 CFR Part 104

ed.gov

1.800.872.5327

ADA Title II Regulations for State and Local Government Services - 28 CFR Part 35

ada.gov

1.800.872.5327

ADA Title III Regulations for Public Accommodations and Commercial Facilities - 28 CFR Part 36

ada.gov/regs2010/titleIII_2010/titleIII_2010_regulations.htm

800.514.0301 voice

800.514.0383 TTY

Insurance

Medical Information Bureau (MIB)

mib.com

646.450.4633

Independent Student's Guide to Healthcare

bestcolleges.com/resources/student-healthcare-guide

National MS Society

nationalMSSociety.org/insurance

1.800.344.4867

National Multiple Sclerosis Society Health Insurance Appeal Letters Toolkit

nationalmssociety.org/NationalMSSociety/media/MSNationalFiles/Brochures/Paper-Health-Insurance-Appeal-Letters-Toolkit.pdf

PUBLICATIONS

National Multiple Sclerosis Society

nationalMSSociety.org/Brochures

The National MS Society offers over 60 publications on a wide variety of topics related to managing and living with MS.

Momentum, the award-winning magazine of the National MS Society, is the largest MS-related publication in the world. The award-winning quarterly magazine includes first-person stories by people living with MS, consumer reports, expert opinion from MS specialists, and reports on current events, MS activism and recent advances in MS research.

nationalMSSociety.org/momentum

Knowledge is Power

nationalMSSociety.org/knowledge

A free, in-home educational series for people newly diagnosed with MS and their families. Provides comprehensive up-to-date information about many aspects of MS.

Publications Specific to Children and Teens with MS and Their Families

nationalMSSociety.org/pediatricMS

Managing School-Related Issues: A Guide for Parents with a Child or Teen Living with MS provides parents with the tools and resources to be their child's best advocate in the school system. The guide includes a discussion on the potential impact of MS in the school setting, recommended accommodations and modifications, transition issues, and sample 504 plans and request for academic accommodations.

Students with MS & the Academic Setting: A Handbook for School Personnel is an informational guide for school staff working with children and teens with MS. The handbook includes a discussion on the issues children and teens with MS may face, recommended accommodations and modifications in the school setting, transition issues, as well as basic information on MS.

Your Education Rights as a Student with MS Every person has a right to strive for his or her education goals despite having a disability. This brochure explains the differences in rights and responsibilities both for students and the schools they attend, and includes information for the college-bound student.

CLINICAL CARE

One important role of the National MS Society is to help you find health care providers in your area who have the experience in treating children and teens with MS. In addition to referrals to the Pediatric MS Centers (see below), we can provide you with the names of local practitioners with experience treating MS. Contact an MS Navigator at 1.800.344.4867 or contactUSNMSS@nmss.org for more information.

If there are no providers with expertise in your area:

- You can travel to a provider with MS expertise for a consultation and take his or her recommendations back to your local physician.
- Your physician can request consultation with a physician with MS expertise through nationalMSSociety.org/prc

Network of Pediatric MS Centers (listed alphabetically by state)

Center for Pediatric-Onset Demyelinating Disease at the Children's Hospital of Alabama
CHB 314K, 1600 7th Ave South, Birmingham, AL 35233
205.996.7850

UCSF Regional Pediatric MS Center
350 Parnassus Avenue, Suite 304, San Francisco, CA 94117
415.353.3939

Pediatric Multiple Sclerosis Center at Loma Linda University Children's Hospital
2195 Club Center Drive, Suite A, San Bernardino, CA 92408
909.835.1810

Partners Pediatric MS Center at the Massachusetts General Hospital for Children
Yawkey Center for Outpatient Care, Suite 6B, 55 Fruit St., Massachusetts General Hospital,
Boston, MA 02114
617.726.2664

Pediatric Multiple Sclerosis and Related Disorders Program at Boston Children's Hospital
Fegan 11, 300 Longwood Avenue, Boston, MA 02115
617.355.2751

Mayo Clinic Pediatric MS Center
200 1st St. SW, Rochester, MN 55905
507.293.0378

Pediatric MS Center of the Jacobs Neurological Institute
219 Bryant St., Buffalo, NY 14222
877.878.7367

Lourie Center for Pediatric MS at Stony Brook University Hospital
Department of Neurology, HSC-T12-020, Stony Brook University, Stony Brook, NY 11794-8121
631.444.7802

The Blue Bird Circle Clinic for Multiple Sclerosis, Texas Children's Hospital
6701 Fannin Street, 9th Floor, Houston, TX 77030
832.822.5046

ONLINE COMMUNITIES AND CONNECTIONS

Pediatric MS Online Group for Parents connects parents through an online group where parents can share concerns and information. Please visit msconnection.org to register and then search on Pediatric MS Online Group to get started.

Teens with MS Facebook Group is a place for teens ages 13-19 to connect with other teens living with MS to share experiences and offer and receive support. For more information on how to register, please contact Kim Koch (vice president, programs and services, National MS Society) at Kimberly.koch@nmss.org.

Digesting Science Find out about MS, ask questions, see the latest news, links to useful sites and connect with other people your age. You may be a teenager who has MS yourself, or you know someone else who does. Everything you want to know about MS is here.

youngms.org.uk

Someonelikeme.ca is an on-line community for youth and young adults who are living with multiple sclerosis; 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.

To learn more, visit someonelikeme.ca.

GLOSSARY OF TERMS

For a complete list of Glossary of Terms, please visit nationalMSSociety.org/glossary or contact an MS Navigator at 1.800-344.4867.

ACTH (adrenocorticotrophic hormone)—ACTH is extracted from the pituitary glands of animals or made synthetically. ACTH stimulates the adrenal glands to release glucocorticoid hormones. These hormones are anti-inflammatory in nature, reducing edema and other aspects of inflammation. Data from the early 1970s indicate that ACTH may reduce the duration of MS exacerbations. In recent years it has been determined that synthetically produced glucocorticoid hormones (e.g. cortisone, prednisone, prednisolone, methylprednisolone, betamethasone, dexamethasone,) which can be directly administered without the use of ACTH, are more potent, cause less sodium retention and less potassium loss, and are longer-acting than ACTH.

Activities of daily living (ADLs)—Activities of daily living include any daily activity a person performs for self-care (feeding, grooming, bathing, dressing,) work, homemaking, and leisure. The ability to perform ADLs is often used as a measure of ability/disability in MS.

Acute disseminated encephalomyelitis (ADEM)—a single neurologic event that most often follows a viral illness or other event such as a vaccination or immunization, or appears as an adverse reaction to medication. In diagnosing childhood MS, the physician must determine whether a single episode of neurologic symptoms is ADEM, which will resolve on its own, or the beginning of MS, which requires early treatment. Complicating this diagnosis is the fact the ADEM sometimes recurs.

Acute—Having rapid onset, usually with recovery; not chronic or long-lasting.

ADL's—See Activities of daily living.

Ankle-foot orthosis (AFO)—An ankle-foot orthosis is a brace, usually plastic, that is worn on the lower leg and foot to support the ankle and correct foot drop. By holding the foot and ankle in the correct position, the AFO promotes correct heel-toe walking. See Foot drop.

Antibodies—Proteins of the immune system that are soluble (dissolved) in blood serum or other body fluids and which are produced in response to bacteria, viruses, and other types of foreign antigens. See Antigen.

Antigen—Any substance that triggers the immune system to produce an antibody; generally refers to infectious or toxic substances. See Antibody.

Assistive devices—Any tools that are designed, fabricated, and/or adapted to assist a person in performing a particular task, e.g. cane, walker, shower chair.

Ataxia—The incoordination and unsteadiness that result from the brain's failure to regulate the body's posture and the strength and direction of limb movements. Ataxia is most often caused by disease activity in the cerebellum.

Atrophy—A wasting or decrease in size of a part of the body because of disease or lack of use.

Autoimmune disease—A process in which the body's immune system causes illness by mistakenly attacking healthy cells, organs, or tissues in the body that are essential for good health. Multiple sclerosis is believed by most MS neurologists to be an autoimmune disease, along with systemic lupus erythematosus, rheumatoid arthritis, scleroderma, and many others. The precise origin and pathophysiologic processes of these diseases are unknown. Because of the debate among MS clinicians and scientists about this issue, MS is commonly referred to an immune-mediated disease, meaning that it is a disease of the immune system for which the precise mechanism is not yet fully understood.

Axon – The extension of a nerve cell (neuron) that conducts impulses to other nerve cells or muscles.

B-cell—A type of lymphocyte (white blood cell) manufactured in the bone marrow that makes antibodies.

Babinski reflex—A neurological sign in MS in which stroking the outside sole of the foot with a pointed object causes an upward (extensor) movement of the big toe rather than the normal (flexor) bunching and downward movement of the toes. *See Sign.*

Bell's palsy—A paralysis of the facial nerve (usually on one side of the face,) which can occur as a consequence of MS, viral infection, or other infections. It has acute onset and can be transient or permanent.

Blood-brain barrier—A semi-permeable cell layer around blood vessels in the brain and spinal cord that prevents large molecules, immune cells, and potentially damaging substances and disease-causing organisms (e.g. viruses) from passing out of the blood stream into the central nervous system (brain and spinal cord.) A break in the blood-brain barrier may underlie the disease process in MS.

Brainstem—The part of the central nervous system that houses the nerve centers of the head as well as the centers for respiration and heart control. It extends from the base of the brain to the spinal cord.

Catheter—A hollow, flexible tube, made of plastic or rubber, which can be inserted through the urinary opening into the bladder to drain excess urine that cannot be excreted normally.

Central nervous system—The part of the nervous system that includes the brain, optic nerves, and spinal cord.

Cerebellum—A part of the brain situated above the brainstem that controls balance and coordination of movement.

Cerebrospinal fluid (CSF)—A watery, colorless, clear fluid that bathes and protects the brain and spinal cord. The composition of this fluid can be altered by a variety of diseases. Certain changes in CSF that are characteristic of MS can be detected with a lumbar puncture (spinal tap,) a test sometimes used to help make the MS diagnosis. *See* Lumbar puncture.

Cerebrum—The large, upper part of the brain, which acts as a master control system and is responsible for initiating thought and motor activity.

Chronic—Of long duration, not acute; a term often used to describe a disease that shows gradual worsening.

Clinical finding—An observation made during a medical examination indicating change or impairment in a physical or mental function.

Clinical trial—Rigorously controlled studies designed to provide extensive data that will allow for statistically valid evaluation of the safety and efficacy of a particular treatment. *See also* Double-blind clinical study; Placebo.

Cognition—High level functions carried out by the human brain, including comprehension and use of speech, visual perception and construction, calculation ability, attention (information processing,) memory, and executive functions such as planning, problem-solving, and self-monitoring.

Cognitive impairment—Changes in cognitive function caused by trauma or disease process. Some degree of cognitive impairment occurs in approximately 50-60 percent of people with MS, with memory, information processing, and executive functions being the most commonly affected functions. *See* Cognition.

Cognitive rehabilitation—Techniques designed to improve the functioning of individuals whose cognition is impaired because of physical trauma or disease. Rehabilitation strategies are designed to improve the impaired function via repetitive drills or practice, or to compensate for impaired functions that are not likely to improve. Cognitive rehabilitation is provided by psychologists and neuropsychologists, speech/language pathologists, and occupational therapists. While these three types of specialists use different assessment tools and treatment strategies, they share the common goal of improving the individual's ability to function as independently and safely as possible in the home and work environment.

Coordination—An organized working together of muscles and groups of muscles aimed at bringing about a purposeful movement such as walking or standing.

Corpus callosum—The broad band of nerve fibers tissue that connects the two cerebral hemispheres of the brain.

Cortex—The outer layer of brain tissue.

Corticosteroid—Any of the natural or synthetic hormones associated with the adrenal cortex (which influences or controls many body processes.) Corticosteroids include glucocorticoids, which have an anti-inflammatory and immunosuppressive role in the treatment of MS exacerbations. *See also* Glucocorticoids; Immunosuppression; Exacerbation.

Cortisone—A glucocorticoid steroid hormone, produced by the adrenal glands or synthetically, that has anti-inflammatory and immune-system suppressing properties. Prednisone and prednisolone also belong to this group of substances.

Demyelination—A loss of myelin in the white matter of the central nervous system (brain, spinal cord.)

Diplopia—Double vision, or the simultaneous awareness of two images of the same object that results from a failure of the two eyes to work in a coordinated fashion. Covering one eye will erase one of the images.

Disability—As defined by the World Health Organization, a disability (resulting from an impairment) is a restriction or lack of ability to perform an activity in the manner, or within the range, considered normal for a human being.

Double-blind clinical study—A study in which none of the participants, including experimental subjects, examining doctors, attending nurses, or any other research staff, know who is taking the test drug and who is taking a control or placebo agent. The purpose of this research design is to avoid inadvertent bias of the test results. In all studies, procedures are designed to “break the blind” if medical circumstances require it.

Dysarthria—Poorly articulated speech resulting from dysfunction of the muscles controlling speech, usually caused by damage to the central nervous system or a peripheral motor nerve. The content and meaning of the spoken words remain normal.

Dysphagia—Difficulty in swallowing. It is a neurologic or neuromuscular symptom that may result in aspiration (whereby food or saliva enters the airway,) slow swallowing (possibly resulting in inadequate nutrition,) or both.

Etiology—The study of all factors that may be involved in the development of a disease, including the patient’s susceptibility, the nature of the disease-causing agent, and the way in which the person’s body is invaded by the agent.

Evoked potentials (EP’s)—EP’s are recordings of the nervous system’s electrical response to the stimulation of specific sensory pathways (e.g. visual, auditory, general sensory.) In tests of evoked potentials, a person’s recorded responses are displayed on an oscilloscope and analyzed on a computer that allows comparison with normal response times. Demyelination results in a slowing of response time. EPs can demonstrate lesions along specific nerve pathways whether or not the lesions are producing symptoms, thus making this test useful in confirming the diagnosis of MS.

Exacerbation—The appearance of new symptoms or the aggravation of old ones, lasting at least twenty-four hours (synonymous with attack, relapse, flare-up, or worsening;) usually associated with inflammation and demyelination in the brain or spinal cord.

Experimental allergic encephalomyelitis (EAE)—Experimental allergic encephalomyelitis is an autoimmune disease resembling MS that has been induced in some genetically susceptible research animals. Before testing on humans, a potential treatment for MS may first be tested on laboratory animals with EAE in order to determine the treatment’s efficacy and safety.

Finger-to-nose test—As a test of dysmetria and intention tremor, the person is asked, with eyes closed, to touch the tip of the nose with the tip of the index finger. This test is part of the standard neurologic exam.

Food and Drug Administration (FDA)—The U.S. federal agency that is responsible for enforcing governmental regulations pertaining to the manufacture and sale of food, drugs, and cosmetics. Its role is to prevent the sale of impure or dangerous substances. Any new drug that is proposed for the treatment of MS must be approved by the FDA.

Foot drop—A condition of weakness in the muscles of the foot and ankle, caused by poor nerve conduction, which interferes with a person’s ability to flex the ankle and walk with a normal heel-toe pattern. The toes touch the ground before the heel, causing the person to trip or lose balance.

Gadolinium—A chemical compound that can be administered to a person during magnetic resonance imaging to help distinguish between new lesions and old lesions.

Handicap—As defined by the World Health Organization, a handicap is a disadvantage, resulting from an impairment or a disability, that interferes with a person’s efforts to fulfill a role that is normal for that person. Handicap is therefore a social concept, representing the social and environmental consequences of a person’s impairments and disabilities.

Immune system—A complex system of various types of cells that protects the body against disease-producing organisms and other foreign invaders.

Immunocompetent cells—White blood cells (B- and T-lymphocytes and others) that defend against invading agents in the body.

Immunoglobulin—*See* Antibody.

Immunosuppression—In MS, a form of treatment that slows or inhibits the body's natural immune responses, including those directed against the body's own tissues. Examples of immunosuppressive treatments in MS include cyclosporine, methotrexate, and azathioprine.

Impairment—As defined by the World Health Organization, an impairment is any loss or abnormality of psychological, physiological, or anatomical structure or function. It represents a deviation from the person's usual biomedical state. An impairment is thus any loss of function directly resulting from injury or disease.

Incidence—The number of new cases of a disease in a specified population over a defined period of time.

Inflammation—A tissue's immunologic response to injury, characterized by mobilization of white blood cells and antibodies, swelling, and fluid accumulation.

Interferon—A group of immune system proteins, produced and released by cells infected by a virus, which inhibit viral multiplication and modify the body's immune response. One of the interferons, interferon beta-1b (Betaseron[®]) was approved by the Food and Drug Administration in 1993 for treatment of relapsing-remitting MS. It was found in a clinical trial to reduce the frequency and severity of exacerbations by approximately 30 percent. A second interferon, interferon beta-1a (Avonex[®]) has also been shown to reduce the frequency and severity of MS exacerbations in people with relapsing-remitting disease, as well as to reduce the risk of clinically significant disease progression. Avonex[®] was approved for use in MS in 1996.

Intrathecal space—The space surrounding the brain and spinal cord that contains cerebrospinal fluid.

Intravenous—Within a vein; often used in the context of an injection into a vein with medication dissolved in a liquid.

Lesion—*See* Plaque.

Leukocyte—White blood cell.

L’Hermitte’s sign—An abnormal sensation of electricity or “pins and needles” going down the spine into the arms and legs that occurs when the neck is bent forward so that the chin touches the chest.

Lumbar puncture—A diagnostic procedure that uses a hollow needle (canula) to penetrate the spinal canal at the level of third-fourth or fourth-fifth lumbar vertebrae to remove cerebrospinal fluid for analysis. This procedure is used to examine the cerebrospinal fluid for changes in composition that are characteristic of MS (e.g. elevated white cell count, elevated protein content, the presence of oligoclonal bands.)

Lymphocyte—A type of white blood cell that is part of the immune system. Lymphocytes can be subdivided into two main groups: B-lymphocytes, which originate in the bone marrow and produce antibodies; and T-lymphocytes, which are produced in the bone marrow and mature in the thymus. Helper T-lymphocytes heighten the production of antibodies by B-lymphocytes; suppressor T-lymphocytes suppress B-lymphocyte activity and seem to be in short supply during an MS exacerbation.

Macrophage—A white blood cell with scavenger characteristics that has the ability to ingest and destroy foreign substances such as bacteria and cell debris.

Magnetic resonance imaging (MRI)—A diagnostic procedure that produces visual images of different body parts without the use of X-rays. Nuclei of atoms are influenced by a high frequency electromagnetic impulse inside a strong magnetic field. The nuclei then give off resonating signals that can produce pictures of parts of the body. An important diagnostic tool in MS, MRI makes it possible to visualize and count lesions in the white matter of the brain and spinal cord.

Monoclonal antibodies—Laboratory-produced antibodies, which can be programmed to react against a specific antigen in order to suppress the immune response.

MRI—See Magnetic resonance imaging.

Muscle tone—A characteristic of a muscle brought about by the constant flow of nerve stimuli

Myelin—A soft, white coating of nerve fibers in the central nervous system, composed of lipids (fats) and protein. Myelin serves as insulation and as an aid to efficient nerve fiber conduction. When myelin is damaged in MS, nerve fiber conduction is faulty or absent. Impaired bodily functions or altered sensations associated with those demyelinated nerve fibers are identified as symptoms of MS in various parts of the body.

Myelin basic protein—Proteins associated with the myelin of the central nervous system that may be found in higher than normal concentrations in the cerebrospinal fluid of individuals with MS and other diseases that damage myelin.

Myelitis—An inflammatory disease of the spinal cord. In transverse myelitis, the inflammation spreads across the tissue of the spinal cord, resulting in a loss of its normal function to transmit nerve impulses up and down, as though the spinal cord had been severed.

Nerve—A bundle of nerve fibers (axons.) The fibers are either afferent (leading toward the brain and serving in the perception of sensory stimuli of the skin, joints, muscles, and inner organs) or efferent (leading away from the brain and mediating contractions of muscles or organs.)

Nervous system—Includes all of the neural structures in the body: the central nervous system consists of the brain, spinal cord, and optic nerves; the peripheral nervous system consists of the nerve roots, nerve plexi, and nerves throughout the body.

Neurologist—Physician who specializes in the diagnosis and treatment of conditions related to the nervous system.

Neurology—Study of the central, peripheral, and autonomic nervous system.

Neuron—The basic nerve cell of the nervous system. A neuron consists of a nucleus within a cell body and one or more processes (extensions) called dendrites and axons.

Neuropsychologist—A psychologist with specialized training in the evaluation of cognitive functions. Neuropsychologists use a battery of standardized tests to assess specific cognitive functions and identify areas of cognitive impairment. They also provide remediation for individuals with MS-related cognitive impairment. *See* Cognition and Cognitive impairment.

Occupational therapist (OT)—Occupational therapists assess functioning in activities of everyday living, including dressing, bathing, grooming, meal preparation, writing, and driving, which are essential for independent living. In making treatment recommendations, the OT addresses (1) fatigue management, (2) upper body strength, movement, and coordination, (3) adaptations to the home and work environment, including both structural changes and specialized equipment for particular activities, and (4) compensatory strategies for impairments in thinking, sensation, or vision.

Oligoclonal bands—A diagnostic sign indicating abnormal levels of certain antibodies in the cerebrospinal fluid; seen in approximately 90 percent of people with multiple sclerosis, but not specific to MS.

Oligodendrocyte—A type of cell in the central nervous system that is responsible for making and supporting myelin.

Optic neuritis—Inflammation or demyelination of the optic (visual) nerve with transient or permanent impairment of vision and occasionally pain.

Orthotic—Also called orthosis; a mechanical appliance such as a leg brace or splint that is specially designed to control, correct, or compensate for impaired limb function.

Paralysis—Inability to move a part of the body.

Paraparesis—A weakness but not total paralysis of the lower extremities (legs.)

Paraplegia—Paralysis of both lower extremities (legs.)

Paresis—Partial or incomplete paralysis of a part of the body.

Periventricular region—The area surrounding the four fluid-filled cavities within the brain. MS plaques are commonly found within this region.

Physiatrist—Physicians who specialize in physical medicine and rehabilitation of physical impairments.

Physical therapist (PT)—Physical therapists are trained to evaluate and improve movement and function of the body, with particular attention to physical mobility, balance, posture, fatigue, and pain. The physical therapy program typically involves (1) educating the person with MS about the physical problems caused by the disease, (2) designing an individualized exercise program to address the problems, and (3) enhancing mobility and energy conservation through the use of a variety of mobility aids and adaptive equipment.

Placebo—An inactive, non-drug compound that is designed to look just like the test drug. It is administered to control group subjects in double-blind clinical trials (in which neither the researchers nor the subjects know who is getting the drug and who is getting the placebo) as a means of assessing the benefits and liabilities of the test drug taken by experimental group subjects.

Placebo effect—An apparently beneficial result of therapy that occurs because of the patient's expectation that the therapy will help.

Plaque—An area of inflamed or demyelinated central nervous system tissue.

Plasma cell—A lymphocyte-like cell found in the bone marrow, connective tissue, and blood that is involved in the body's immune system. *See also* Lymphocyte.

Postural tremor—Rhythmic shaking that occurs when the muscles are tensed to hold an object or stay in a given position.

Prevalence—The number of all new and old cases of a disease in a defined population at a particular point in time.

Primary progressive MS—A clinical course of MS characterized from the beginning by progressive disease, with no plateaus or remissions, or an occasional plateau and very short-lived, minor improvements.

Prognosis—Prediction of the future course of the disease.

Progressive-relapsing MS—A clinical course of MS that shows disease progression from the beginning, but with clear, acute relapses, with or without full recovery from those relapses along the way.

Pseudo-exacerbation—A temporary aggravation of disease symptoms, resulting from an elevation in body temperature or other stressor (e.g. an infection, severe fatigue, constipation) that disappears once the stressor is removed. A pseudo-exacerbation involves symptom flare-up rather than new disease activity or progression.

Recent memory—The ability to remember events, conversations, content of reading material or television programs from a short time ago (i.e. an hour or two ago or last night.) People with MS-related memory impairment typically experience greatest difficulty remembering these types of things in the recent past.

Reflex—An involuntary response of the nervous system to a stimulus, such as the stretch reflex, which is elicited by tapping a tendon with a reflex hammer, resulting in a contraction. Increased, diminished, or absent reflexes can be indicative of neurologic damage, including MS, and are therefore tested as part of the standard neurologic exam.

Relapsing-remitting MS—A clinical course of MS that is characterized by clearly defined, acute attacks with full or partial recovery and no disease progression between attacks.

Remission—A lessening in the severity of symptoms or their temporary disappearance during the course of the illness.

Remote memory—The ability to remember people or events from the distant past. People with MS tend to experience few, if any, problems with their remote memory.

Remyelination—The repair of damaged myelin. Myelin repair occurs spontaneously in MS but very slowly. Research is currently underway to find a way to speed the healing process.

Sclerosis—Hardening of tissue. In MS, sclerosis is the body's replacement of lost myelin around CNS nerve cells with scar tissue.

Secondary progressive MS—A clinical course of MS that initially is relapsing-remitting and then becomes progressive at a variable rate, possibly with an occasional relapse and minor remission.

Sensory—Related to bodily sensations such as pain, smell, taste, temperature, vision, hearing, acceleration, and position in space.

Sign—An objective physical problem or abnormality identified by the physician during the neurologic examination. Neurologic signs may differ significantly from the symptoms reported by the patient because they are identifiable only with specific tests and may cause no overt symptoms. Common neurologic signs in multiple sclerosis include altered eye movements and other changes in the appearance or function of the visual system; altered reflexes; weakness; spasticity; circumscribed sensory changes.

Spasticity—Abnormal increase in muscle tone, manifested as a spring-like resistance to moving or being moved.

Speech/language pathologist—Speech/language pathologists specialize in the diagnosis and treatment of speech and swallowing disorders. A person with MS may be referred to a speech/language pathologist for help with either one or both of these problems. Because of their expertise with speech and language difficulties, these specialists also provide cognitive remediation for individuals with cognitive impairment.

Spinal tap—See Lumbar puncture.

Suppressor T-lymphocytes—White blood cells that act as part of the immune system and may be in short supply during an MS exacerbation.

Symptom—A subjectively perceived problem or complaint reported by the patient. In multiple sclerosis, common symptoms include visual problems, fatigue, sensory changes, weakness or paralysis of limbs, tremor, lack of coordination, poor balance, bladder or bowel changes, and psychological changes.

T-cell—A lymphocyte (white blood cell) that develops in the bone marrow, matures in the thymus, and works as part of the immune system in the body.

Transcutaneous electric nerve stimulation (TENS)—TENS is a nonaddictive and noninvasive method of pain control that applies electric impulses to nerve endings via electrodes that are attached to a stimulator by flexible wires and placed on the skin. The electric impulses block the transmission of pain signals to the brain.

Transverse myelitis—An acute attack of inflammatory demyelination that involves both sides of the spinal cord. The spinal cord loses its ability to transmit nerve impulses up and down. Paralysis and numbness are experienced in the legs and trunk below the level of the inflammation.

Trigeminal neuralgia—Lightning-like, acute pain in the face caused by demyelination of nerve fibers at the site where the sensory (trigeminal) nerve root for that part of the face enters the brainstem.

Urologist—A physician who specializes in the branch of medicine (urology) concerned with the anatomy, physiology, disorders, and care of the male and female urinary tract, as well as the male genital tract.

Urology—A medical specialty that deals with disturbances of the urinary (male and female) and reproductive (male) organs.

Vertigo—A dizzying sensation of the environment spinning, often accompanied by nausea and vomiting.

Visual acuity—Clarity of vision. Acuity is measured as a fraction of normal vision. 20/20 vision indicates an eye that sees at 20 feet what a normal eye should see at 20 feet; 20/400 vision indicates an eye that sees at 20 feet what a normal eye sees at 400 feet.

Visual evoked potential (VEP)—A test in which the brain's electrical activity in response to visual stimuli (e.g. a flashing checkerboard) is recorded by an electroencephalograph and analyzed by computer. Demyelination results in a slowing of response time. Because this test is able to confirm the presence of a suspected brain lesion (area of demyelination) as well as identify the presence of an unsuspected lesion that has produced no symptoms, it is extremely useful in diagnosing MS. VEP's are abnormal in approximately 90 percent of people with MS.

Vocational rehabilitation (VR)—Vocational rehabilitation is a program of services designed to enable people with disabilities to become or remain employed. Originally mandated by the Rehabilitation Act of 1973, VR programs are carried out by individually created state agencies. In order to be eligible for VR, a person must have a physical or mental disability that results in a substantial handicap to employment. VR programs typically involve evaluation of the disability and need for adaptive equipment or mobility aids, vocational guidance, training, job-placement, and follow-up.

White matter—The part of the brain that contains myelinated nerve fibers and appears white, in contrast to the cortex of the brain, which contains nerve cell bodies and appears gray.

The National Multiple Sclerosis Society is proud to be a source of information about multiple sclerosis. Our comments are based on professional advice, published experience and expert opinion, but do not represent individual therapeutic recommendations or prescriptions. For specific information and advice, consult your physician.

The National MS Society is a collective of passionate individuals who want to do something about MS now — to move together toward a world free of multiple sclerosis. We help each person address the challenges of living with MS through our 50-state network of chapters. The Society helps people affected by MS by funding cutting-edge research, driving change through advocacy, facilitating professional education, and providing programs and services that help people with MS and their families move their lives forward

nationalMSSociety.org

1.800.344.4867