National Multiple Sclerosis Society

Multiple Sclerosis Society of Canada

KIDS GET MS TOO:

A GUIDE FOR PARENTS WITH A CHILD OR TEEN WITH MS

A Publication of the National Multiple Sclerosis Society and the Multiple Sclerosis Society of Canada

This handbook is available in both U.S. and Canadian versions.
This is the U.S. version.

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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 hope to be able 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 and the MS Society of Canada, are 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:

1) You are not alone - there are both social and clinical networks to support your child and your family;
2) MS is not fatal - most people with MS have a normal or near-normal life expectancy;
3) Each person's experience with MS is different;
4) 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.

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. It is thought to be an ***autoimmune*** disease. This means the immune system, which usually works to protect the body from disease-producing organisms, mistakenly attacks the body's own tissue. The primary target of this attack is ***myelin***, the protective coating around the nerve cells in the CNS.

Myelin facilitates nerve conduction - the sending of messages from the CNS to rest of the body. The nerve cells themselves can also be damaged. 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 400,000 people with MS in the United States and between 55,000-75,000 people in Canada. 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 both the US and Canada, studies of children are underway to learn more about possible viral triggers.

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 www.nationalMSsociety.org 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 and closer to the cure. 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 eight medications approved for use in adults by the U.S. Food and Drug Administration and the Canadian Food and Drugs Act for relapsing forms of MS. Based on the demonstrated ability of these medications to impact disease activity in adults, the National Clinical Advisory Board of the National MS Society and the Medical Advisory Board of the MS Society of Canada recommend treatment with one 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. An International Pediatric MS Study Group carefully reviewed all the published literature and in combination with expert opinion, concluded that pediatric MS patients should receive these treatments, even though there have not been adequate studies of MS in children and adolescents. They feel that there may be an important benefit to starting these treatments in the earliest stages of the disease.

Reference: "Treatment of pediatric multiple sclerosis and variants" authors: D. Pohl, MD; E. Waubant, MD, PhD; B. Banwell, MD; D. Chabas, MD, PhD; T. Chitnis, MD; B. Weinstock-Guttman, MD; and S. Tenembaum, MD for the International Pediatric MS Study Group, published April, 2007 in Neurology, the official journal of the American Academy of Neurology.

What is the *National Multiple Sclerosis Society?*

The National Multiple Sclerosis Society is a non-profit, voluntary health organization with a 50-state network of chapters throughout the United States. The National MS Society provides more funding for research projects than any other MS voluntary organization in the United States. This research has led to successful treatments, and will eventually find the cause and cure for MS. While the research continues, the Society provide a wide range of educational, support, and wellness programs for people with MS and their family members across the country.

The Society's library contains the largest single collection of MS literature in the world, and our Web site (www.nationalMSociety.org) provides accurate and timely information from leading MS researchers and clinicians for people with MS, their family, friends, and healthcare providers.

What is the *Multiple Sclerosis Society of Canada?*

Founded in 1948, the Multiple Sclerosis Society of Canada is the only national voluntary organization in Canada that supports both MS research and services for people with MS and their families. The Multiple Sclerosis Society of Canada provides the most accurate and up-to-date information, in addition to making referrals to community support resources for the MS community. In addition to providing day-to-day support, the MS Society of Canada is a leader in the search to find a cure for MS and is the largest funder of MS research in Canada.

The Client Services Department of the MS Society of Canada assists individuals and their families by providing information and referral, support, education, individual advocacy and funding across Canada, within the seven divisions and their numerous chapters. Volunteers and staff provide MS Society of Canada publications; resources from the National Information Resource Centre (internal library); lending libraries; conferences and workshops; funding for equipment purchase and loan; special assistance funding; support counseling; support and self-help groups; and recreation and social programs.

What is the *Children and Teens with MS: A Network for Families?*

The National Multiple Sclerosis Society and the Multiple Sclerosis Society of Canada have joined in collaboration to offer ***Children and Teens with MS: A Network for Families.*** With support from both organizations, we are able to enlarge the scope of programs offered. The network currently provides a variety of program options for families with a child or teen with MS or related disorders. The National MS Society

and the MS Society of Canada recognize the unique needs of these young people and realize that their parents and siblings may also need a variety of support services and programs.

What can the *Network for Families* do for my family?

The network targets two distinct populations:

- Children with MS (18 or younger)
- Parents of a child or teen with MS

Your family and others whose lives are affected by MS are the reason for our existence. We think you will find us to be a valuable and trustworthy resource as you are learning to live with MS. We can help you and your child or teen learn about the disease, as well as how to manage the symptoms and adapt to the changes that MS brings to your family's life. We will keep you informed about the newest and most exciting MS research, as scientists work toward a better understanding of the disease, improved treatments, and eventually, the cure. You can count on us to give you the facts and opinions from the foremost MS experts in the world.

In addition to serving families with a child with MS, the 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

The *Network for Families* provides more than information, however. We can, if you wish, connect you with other parents—to learn from their experiences and share your own in a comfortable and confidential setting. We can help you with school and social issues related to MS, and with plans and strategies for the future.

For contact in the United States:

National Multiple Sclerosis Society
Telephone: 1-800-344-4867
Email: childhoodms@nmss.org

For contact in Canada:

Multiple Sclerosis Society of Canada
1-866-922-6065
info@mssociety.ca

The National MS Society and the MS Society of Canada maintain strict confidentiality policies. Regardless of the types of programs or services you choose to utilize, your privacy will be respected and protected.

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 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.

[*Note: The manual is available in both an American and a Canadian version in order to address issues that are unique to each country. To request a copy of the Canadian version of the handbook, please contact the MS Society of Canada. Contact information is above.*]

CHILDREN AND TEENS WITH MS: A NETWORK FOR FAMILIES

Children and Teens with MS: A Network for Families exists to support families who have a child diagnosed with multiple sclerosis (MS.) The Network for Families is a collaborative program of the National MS Society and the MS Society of Canada. The National MS Society and the MS Society of Canada recognize that the needs of children with MS, their parents, and siblings are unique and that these families may need a variety of supports. The Network for Families provides a wide spectrum of programs to meet these needs.

Education

The Network provides educational programs and written materials for children and their parents about childhood MS. The Network also introduces families to specialists working in the field of childhood MS.

Information and Referral

Parents can receive information about MS and local resources from the chapter in their area. For information more specific to childhood MS, families can use our toll free number (1-800-344-4867) to learn more about the Network and other available resources.

Emotional Support

Parents can gain emotional support through a variety of programs and services including individual parent or family support and group support programs.

Connecting Families

The Network connects parents through an e-mail list where they can share concerns and information, and develop a support network.

For more information or to register for the Network for Families, please call 1-800-FIGHT MS (1-800-344-4867) or Email: childhoodms@nmss.org

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?

Formal diagnostic criteria specific to pediatric MS are currently being developed by an international working group set up by the National MS Society. Currently, the criteria for making a diagnosis of MS in adults and children are the same. 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 doctor 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 sensitivity to touch, 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. Repeated MRI scans, done several months apart, are used to show separate episodes of disease activity, and are thus useful in meeting the criteria for a diagnosis.

  The recently-revised criteria for diagnosing MS in adults include very specific details about the numbers, types, and locations of lesions that need to be seen on MRI in order to make the diagnosis. Similar MRI criteria do not yet exist for children.

- **Laboratory tests**—Sometimes additional evidence is needed to demonstrate that more than one attack has occurred. Thus, even if a youngster has only experienced one attack, or is only experiencing one symptom, abnormal

responses on these tests can provide evidence of a second area of demyelination in the brain.

- 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 aren't sufficient to make the diagnosis.
- Evoked potentials (EPs) allow doctors to evaluate how well nerves are sending messages that are "evoked" (stimulated) by various types of stimuli. A flashing light, for example, is used in visual evoked potentials to assess the speed of responses from the eyes. A noise is used in auditory evoked potentials to assess the speed of information from the ear. If any of these pathways have been injured by demyelination, they will not send messages as quickly as they should.

Are there special challenges to diagnosing MS in children?

When a child or teen comes to the doctor with a single episode of neurologic symptoms characteristic of demyelination in the CNS, the doctor must decide if this is a one-time event in the youngster's lifetime, or the first event in what will eventually become MS. It is not that unusual for children to develop single neurologic events known as acute disseminated encephalomyelitis (ADEM). ADEM most often follows a viral illness or some other event such as a vaccination or immunization, or appears as an adverse reaction to medication.

While some neurologic symptoms and signs are similar to those of MS—such as optic neuritis or other vision problems, difficulties with balance, sensation, or strength—others are quite different. Youngsters 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, it does not require the ongoing treatment that is now recommended for MS. The challenge facing the doctor then, 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 that need to be distinguished from MS symptoms. Since not all physicians are in agreement regarding relapsing symptoms in ADEM, additional studies are needed to clarify this complex diagnostic issue.

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 childhood.
- MS has traditionally been thought of as a disease of adulthood.
- Childhood MS is seen so rarely by most doctors that the signs and symptoms go unrecognized.

Education of health professionals concerning the signs and symptoms of pediatric MS will gradually allow them to get more comfortable making 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 physicians are taking good care of them.
- Youngsters 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 the 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 and teens as well as adults, involves several strategies:

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

Although many of the medical treatments described in this handbook have been studied extensively in adults, none have been studied in children under 18. While some have been approved by the U.S. Food and Drug Administration (FDA) and the Canadian Food and Drugs Act for the treatment of MS in adults, none of these treatments have been approved for use in pediatric MS. This means that physicians have had to rely on their clinical judgment to adapt the treatments used in adults for their younger patients.

Who Treats Children and Teens with MS?

Children with MS are receiving treatment from their pediatricians, family doctors, general adult and pediatric neurologists, and neurologists who specialize in MS. The reality is that very few physicians have much experience with this pediatric population, and you may or may not have anyone in your area who is familiar with pediatric MS.

Pediatric MS Centers of Excellence

The National Multiple Sclerosis Society is excited to announce the establishment of the first-of-its kind national network of Pediatric MS Centers of Excellence. Never before has the Society made such a concerted effort to direct resources towards the care and treatment of childhood MS.

What does this mean to you and your child? The Centers of Excellence will diagnose and treat children under the age of 18 who have MS and other central nervous system

demyelinating diseases, and will set the standard for pediatric MS care. One of the main goals of the centers is to provide coordinated and comprehensive medical and psychosocial 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.

The six clinics that comprise the Pediatric MS Centers of Excellence Network are:

- Center for Pediatric-Onset Demyelinating Disease at the Children's Hospital of Alabama, University of Alabama at Birmingham
- Jacobs Center for Pediatric MS, Jacobs Neurological Institute, State University of New York at Buffalo
- Pediatric MS Clinic at Mayo Clinic Rochester, Minnesota
- National Pediatric MS Center at Stony Brook University Hospital, Long Island
- Partners Pediatric MS Center at the Massachusetts General Hospital for Children in Boston
- University of California, San Francisco Regional Pediatric MS Center

The centers are available and accessible to families across the country. Families who are not in geographic proximity to one of the centers can work through the National MS Society to determine the most convenient center to visit. For more information on the Pediatric MS Centers of Excellence, please see Section Seven (Resources and Publications), call 1-800-344-4867 or email childhoodms@nmss.org.

One important role of the National MS Society is to help you find physicians in your area who have the interest and the expertise to treat pediatric MS. In addition to referrals to the Pediatric MS Centers of Excellence, we can provide you with the names of local practitioners. If there are no MS specialists in your area:

- You can travel to an MS specialist for a consultation and take his or her recommendations back to your local physician.
- Your physician can consult with an MS specialist physician via the National MS Society's Professional Resource Center (MD_info@nmss.org; 1-866-MS-TREAT (1-866-678-7328).

The important thing to remember is that there are resources available to help you find the best possible treatment for your child.

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), 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 shorten 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 with a taper 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), which has been effective in improving symptoms in children diagnosed with ADEM, 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 has been shown to 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.

- A child whose symptoms return as soon as steroids are reduced. Unfortunately, some physicians have prescribed long-term steroid use for children in spite of the serious risks involved. Long-term use—a few months or more—can lead to steroid dependence. IVIg, given monthly for the duration of an extended steroid taper, has made it possible to wean these children off steroids. Once the last dose of prednisone is given, IVIg is continued once a month for three months, followed by three treatments at six-week intervals, followed by three treatments at eight-week intervals. This protocol has been successful in allowing patients to come off steroid therapy without a return of symptoms.

In certain, very rare 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 relapse symptoms, its use in children has been very limited.

Modifying the Disease Course

Treatments are available that reduce the number of MS attacks. Currently the treatments approved for adults are being used in children (although off-label). The treatments work by modifying the immune system response, which reduces immune activity, thereby decreasing some of the destructive activity in the CNS.

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, to include questions on side effects, monitoring safety, and patient assistance programs:

- Visit the National MS Society's website at www.nationalMSsociety.org and go to About MS>What We Know About MS>Treatments
- Contact an MS Navigator at 1-800-344-4867 (1-800-FIGHT MS)
- Review the Society publication, *The MS Disease Modifying Therapies – General Information* (available on the Society's website or by contacting an MS Navigator)

Using Therapies in Children

Although none of the medications have been formally studied in children, the increasing evidence of the importance of starting therapy as soon as possible after the diagnosis of MS is made has led to an increased use of these agents in younger patients. Which medication to use is a decision the doctor will reach after careful discussion with you and your child.

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 medical professional 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. and Canada 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, the Canadian Food and Drugs Act, 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 along the way.

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 the children 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®; Alertec® in Canada) 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. The 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 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, resulting from demyelination in the spinal cord. The 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, 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 3. 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 in MS.

SECTION THREE

MANAGING THE EMOTIONAL REACTIONS

SECTION III—MANAGING THE EMOTIONAL REACTIONS

Emotional Reactions to the Diagnosis of Multiple Sclerosis

A diagnosis of multiple sclerosis is 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 extremely common in MS, (see p. 35) 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.

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.
- *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 a lot of things: challenging, frightening, exhausting, discouraging. And yet, there is good news all around. Research into the cause and cure of MS is ongoing and very hopeful.

Adapting to Life with Multiple Sclerosis

The challenges of living with MS as a young person vary somewhat depending on the child's age. Having different frames of reference and levels of awareness, children and adolescents face somewhat different tasks in their development and adjustment to the disease.

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 medical 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 may be bothering them either physically (such as new symptoms) or emotionally. You may find that giving your teenager some time alone with the medical team on each visit will allow them to have an open discussion about things that they might not tell you for fear that you would worry. You can then join with your child and medical team to 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 or the MS Society of Canada 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 market 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. 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. They 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 health care 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, little is known about the ways in which MS affects cognition in children and adolescents. Fortunately, ongoing research efforts will help enhance our understanding of this important aspect of pediatric MS. Some clinicians have speculated, based on the fact that the child's brain is not fully developed, that children with MS may be especially vulnerable to cognitive impairment.

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. Other clinicians, however, have suggested that cognitive deficits may be less severe in children with MS. Future research will help us clarify this issue.

Clinical experience to date suggests that the frequency of children showing cognitive deficits is similar to adults with MS. Thus, it is important to highlight that not all children and adolescents with MS will demonstrate cognitive problems. While some children and adolescents have no problems, others develop varying degrees of difficulty ranging from mild to severe.

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. In fact, cognitive changes can even be the first symptom of MS to appear.

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 the 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 steps. 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, these 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.

Unfortunately, the overall progression of cognitive problems is not entirely understood at this point. Preliminary findings from individual case studies suggest that some people may show a progression of cognitive deficits in as little as a year. 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 2.

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 the 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 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?
Merely identifying cognitive decline is not very helpful. However, it serves as the 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 <u>how</u> 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 limits 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 the healthcare professionals who are providing treatment, 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 (United States)

A Few Questions Up Front

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 4)

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 7—Resources and Publications.

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 **f**ree **a**ppropriate **p**ublic **e**ducation (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.

- Mental Retardation
- Hearing Impairment, including deafness
- Speech or Language impairment
- Visual Impairment, including blindness
- Serious Emotional Disturbance
- Orthopedic Impairments
- Autism
- Traumatic Brain Injury
- Other Health Impairment
- Specific Learning Disability
- Deaf-Blindness
- Multiple Disabilities

In addition, children ages 3 through 9 might qualify for services if they are experiencing developmental delays in physical, cognitive, communicative, social, emotional, or adaptive development that require special education and related services.

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.

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.

Major life activities include (but are not limited to) performing manual tasks, walking, seeing, hearing, speaking, breathing and learning. Thus, although multiple sclerosis is an impairment, whether an individual has a disability as defined under Section 504 depends on whether the MS "substantially limits" a major life activity.

To be a *substantial limitation*, the impairment must significantly restrict the performance of a major life activity in comparison to most people. 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. As with IDEA, determining whether a student has a disability is less concerned with the diagnosis of an illness than with an individualized assessment of the student's ability and limitations.

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 has a disability
2. To gather information about the child's educational needs
3. To decide on strategies for meeting those needs

Under IDEA regulations, the evaluation is to be conducted by 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.)

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.

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 http://www.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 Publications.

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 brief overview is designed to provide some 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.

At this writing, millions of people in the United States are uninsured, and a disproportionate number of those uninsured are children. Studies show that children without insurance tend not to receive the health care their parents believe they need, often with serious consequences for the child's health. This means that your first priority regarding health insurance is making sure that your child *gets enrolled and stays enrolled* in a health plan.

Getting and Keeping Insurance Coverage for Your Child

Most people have coverage for their dependent children through their employer-based plans. 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.

Federal legislation: Federal legislation has been evolving in a generally positive way. The Affordable Care Act has implemented several provisions that protect children to make sure that coverage is available to them regardless of health status. At this point children have guarantee issue rights to coverage no matter what state they reside in.

Health Insurance Portability and Accountability Act (HIPAA): HIPAA guarantees that an individual cannot be denied enrollment in a group health plan on the basis of his/her health status, nor can she/he be charged a higher premium due to poor health. In other words, no one can be singled out and charged more or excluded from participating in an employer's group health plan no matter what health condition that individual may have. This goes a long way toward preserving fairness in the system.

Limits on Pre-Existing Condition Exclusions within HIPAA: Children cannot have any type of Pre-Existing Condition Exclusions placed on them due to health status. Group coverage must immediately offer coverage to children 19 and under.

COBRA: The basic protection COBRA affords is the right to continued enrollment in a parental group health plan for a certain number of months after coverage would otherwise end. With a few exceptions, all covered employees and their covered spouses and dependents in groups of 20 or more are guaranteed this right as qualified beneficiaries, provided they pay the former employer (or the COBRA administrator) their full portion of the premium plus a 2% surcharge. In other words, the employer no longer pays part of the cost of this coverage, but COBRA makes the group health plan available for individual purchase. COBRA is normally 18 months, but can be extended as long as 36 months depending on the qualifying event for COBRA.

Individual Insurance: Children have the right to purchase individual insurance plans without the threat of having a pre-existing condition exclusionary period placed on their coverage. Children are able to pick up individual plans during specific open enrollment periods set by states. To find out when these open enrollment periods are, contact the Division of Insurance for your state. Here is some very nice information about Individual Insurance regulations for children: http://www.healthcare.gov/law/provisions/ChildrensPCIP/childrenspcip.html .

Pre-Existing Condition Insurance Plan (PCIP): Children may qualify for the Federal Pre-Existing Condition Insurance Plan program if they can show either 1) the child has been accepted into an individual plan, but that plan's premium is twice the amount of the PCIP or 2) documentation can be shown that the child has a pre-existing condition verified by a licensed medical professional prior to the date of enrollment in the PCIP. Children must also have a break of six (6) months or more in their insurance coverage and be legal citizens of the United States. Here is state by state information about the PCIP programs: http://www.healthcare.gov/law/provisions/preexisting/index.html .

Medicaid and Children's Health Insurance Plans: All 50 states run a Medicaid program that offers coverage to low income families with children. The Medicaid guidelines vary for all states, but are based on income and assets to determine program eligibility. Contact your local department of Social Services to find out about possible Medicaid eligibility.

The other major advance in insurance-related legislation is specifically targeted to children from lower income families. Designed for families whose incomes are too high for Medicaid, but too low for individual coverage, the relatively new federal/state programs known as CHIP or the Children's Health Insurance Plans, are now available in all 50 states. In general, children in families with incomes up to $44,100/year (for a family of four) are likely to be eligible for coverage. In many states, families can have higher incomes and their children can still qualify. Here is a link to programs in all 50 states: http://www.insurekidsnow.gov/state/index.html .

Reform January 1, 2014-Navigating the Maze of Insurance: Come 2014 all states will have what is called an exchange, or an open market place, where consumers can come and effectively compare insurance plans in one spot. This will be one stop shopping for everything from Medicaid to CHIP and individual plans. The PCIPs will go away at this time. Individuals/Families at or below 400% of the federal poverty level will be eligible for a federal subsidy for their coverage.

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: Who enforces the plan? Larger employer-based and union plans are usually self-insured and regulated by the U.S. Department of Labor (through their regional offices.) Fully insured plans are subject to state insurance laws and enforced by state Departments of Insurance. Knowing who enforces your insurance plan will 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 stop-loss provisions of the plan, as well as your decisions about using in-network or preferred providers, or going out of plan altogether.

Appeals and grievance procedures: What are your appeal and grievance rights and how do you go through the process? These can vary between plans and may or may not be subject to state/federal law.

Getting the Care Your Child Needs and Deserves

The best source of detailed information about your own 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. A case manager at the insurance plan is also a good resource, as is your own employer or Human Resources department at work. An excellent Web-based resource on health insurance options in each state is

maintained by the Department of Health and Human Services at http://finder.healthcare.gov/ .

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: 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. The federal healthcare reform law assures the same level of appeal rights to everyone with private health insurance, if they buy their own policy or get coverage through a group plan provided from their job. Although you must exhaust the internal appeals process before pursuing an external review, these independent panels have overturned roughly half of the original denials in the few years they have been in existence. (If you are in a health plan that you or your employer purchased before March 23, 2010, check with your state insurance department, your employer, and your health plan to find out whether you have similar external appeal rights.)

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/living-with-multiple-sclerosis/insurance-and-money-matters/health-insurance/appeals/download.aspx?id=517.

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 through the Medical Information Bureau (MIB.) 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. However, you may contact the MIB to review the information they have on file and correct it (www.mib.com or 617-426-3660.)
- 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. Insurance companies base their decisions off of facts, not anecdotal 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 PUBLICATIONS

SECTION SEVEN—RESOURCES AND PUBLICATIONS

RESOURCES

Information on Multiple Sclerosis

National Multiple Sclerosis Society
www.nationalMSsociety.org
1-800-344-4867 (1-800-FIGHT MS)

Multiple Sclerosis Society of Canada
www.mssociety.ca
1-866-922-6065

General Resources

Federal Government

US Department of Health and Human Services
http://www.hhs.gov/

National Institute on Disability and Rehabilitation Research
http://www.ed.gov/offices/OSERS/NIDRR/

US Department of Education: Office of Special Ed. And Rehab Services
http://www.ed.gov/offices/OSERS/

Children with Disabilities/Chronic Illness

Family Village
Waisman Center, University of Wisconsin-Madison
http://www.familyvillage.wisc.edu/

American Council on Education
http://www.acenet.edu/

IRSC – Internet Resources for Special Children
http://www.irsc.org/

Education

Office of Special Education Programs at the U.S. Department of Education
OSEP funds a large information dissemination and technical assistance network plus there's a customer service specialist for each state.
http://www2.ed.gov/about/offices/list/osers/osep/index.html?src=mr
202-205-5507

Office for Civil Rights at the U.S. Department of Education
Technical assistance, pamphlets, complaint information on Section 504 of the Rehabilitation Act.
http://www2.ed.gov/about/offices/list/ocr/index.html?src=mr
800-421-3481 voice
877-521-2172 TTY

U.S. Department of Justice
Technical assistance, publications, complaint info on Titles II and III of the ADA
www.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.
www.adata.org
800-949-4232 voice/TTY

Parent Training and Information Centers and Community Parent Resource Centers
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
www.taalliance.org/PTIs.htm
888-248-0822 voice/TTY

National Dissemination Center for Children and Youth with Disabilities (NICHCY)
Provides technical assistance and publications on disability issues - focus is children and youth (birth to age 22) and IDEA.
www.nichcy.org
800-695-0285 · Voice/TTY

Association on Higher Education and Disability *(*AHEAD*)*
Publications, information and training on higher education and students with disabilities.
www.ahead.org
617-287-3880 voice
617-287-3882 TTY

Insurance

Georgetown University: Health insurance options for each state.
www.healthinsuranceinfo.net

Medical Information Bureau (MIB)
www.mib.com
617-426-3660

PUBLICATIONS

National Multiple Sclerosis Society
www.nationalmssociety.org/Brochures.asp

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.

Mighty Special Kids—An Activity Book for Children with MS
An activity book for children ages 5-12 with MS. The book includes educational games, activities, and age-appropriate articles to help children better understand their diagnosis.

Pediatric MS: Understanding for Today, Hope for Tomorrow A 20+ minute DVD that provides an overview of pediatric MS and how the Society is addressing the needs through programs and services and the Network of Pediatric MS Centers of Excellence. The piece includes interviews with three families with a child with MS, healthcare professionals from the six Pediatric MS Centers of Excellence, and Society staff and volunteers. The DVD is hosted by Society volunteer Channing Barker, a young adult who was diagnosed with MS in her teens.

Information for Parents

Exceptional Parent Magazine
www.eparent.com
1-877-372-7368

Abilitations Catalog
Adaptive equipment for children with special needs.
www.abilitations.com
1-800-850-8602

Education

IDEA Regulations 34 CFR Parts 300 and 303
www.ed.gov/offices/OSERS/Policy/IDEA
202-205-5507

Section 504 Regulations - Department of Education - 34 CFR Part 104
www.ed.gov
800-421-3481 voice
877-521-2172 TTY

ADA Title II Regulations for State and Local Government Services - 28 CFR Part 35
www.ed.gov
800-514-0301 voice
800-514-0383 TTY

ADA Title III Regulations for Public Accommodations and Commercial Facilities - 28 CFR Part 36
www.ada.gov/reg3a.html
800-514-0301 voice
800-514-0383 TTY

Pediatric MS Centers of Excellence

Center for Pediatric-Onset Demyelinating Disease at the Children's Hospital of Alabama

Birmingham, Alabama
Phone: (205) 996-7633
Web: www.uab.edu/cpodd/

UCSF Regional Pediatric MS Center

San Francisco, California
Phone: (415) 353-3939
Web: www.ucsfhealth.org/pedsms

Partners Pediatric MS Center at the Massachusetts General Hospital for Children

Massachusetts General Hospital
Boston, Massachusetts
Phone: (617) 726-2664
Web: partnersmscenter.org/index.php?id=62&mn=12

Mayo Clinic Pediatric MS Center

Rochester, Minnesota
Phone: (507) 293-0378
Web: www.mayoclinic.org/pediatric-center

Pediatric MS Center of the Jacobs Neurological Institute

Buffalo, New York
Phone: (877) 878-7367
Email: PedMS@thejni.org
Web: www.pedms.com

National Pediatric MS Center at Stony Brook University Hospital

Stony Brook, New York
Phone: (631) 444-7802
Email: info@pediatricmscenter@stonybrook.edu
Web: www.pediatricmscenter.org/

Online Communities

Someonelikeme.ca

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 www.someonelikeme.ca or email the Community Administrator: Mandy Joseph, at mandy.joseph@mssociety.ca.

SECTION EIGHT

REFERENCE LIST

SECTION EIGHT—Reference List

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GLOSSARY OF TERMS

Abductor muscle—A muscle used to pull a body part away from the midline of the body (e.g. the abductor leg muscles are used to spread the legs.)

ACTH (adrenocorticotropic 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.

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

Adductor muscle—A muscle that pulls inward toward the midline of the body (e.g. the adductor leg muscles are used to pull the legs together.)

ADL's—*See* Activities of daily living.

Adrenocorticotropic hormone (ACTH)—*See* ACTH.

Advance (medical) directive—Advance directives preserve the person's right to accept or reject a course of medical treatment even after the person becomes mentally or physically incapacitated to the point of being unable to communicate those wishes. Advance directives come in two basic forms:

1. A living will, in which the person outlines specific treatment guidelines that are to be followed by health care providers.

2. A health care proxy (also called a power of attorney for health care decision-making,) in which the person designates a trusted individual to make medical decisions in the event that he or she becomes too incapacitated to make such decisions.

Advance directive requirements vary greatly from one state to another and should therefore be drawn up in consultation with an attorney who is familiar with the laws of the particular state.

Affective release—Also called pseudo-bulbar affect; a condition in which episodes of laughing and/or crying occur with no apparent precipitating event. The person's actual mood may be unrelated to the emotion being expressed. This condition is thought to be caused by lesions in the limbic system, a group of brain structures involved in emotional feeling and expression.

Afferent pupillary defect—An abnormal reflex response to light that is a sign of nerve fiber damage due to optic neuritis. A pupil normally gets smaller when a light is shined either into that eye (direct response) or the other eye (indirect response.) In an afferent pupillary defect (also called Marcus Gunn pupil,) there is a relative decrease in the direct response. This is most clearly demonstrated by the "swinging flashlight test." When the flashlight is shined first in the abnormal eye, then in the healthy eye, and then again in the eye with the pupillary defect, the affected pupil becomes larger rather than smaller.

AFO—*See* Ankle-foot orthosis.

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.

Anticholinergic—Refers to the action of certain medications commonly used in the management of neurogenic bladder dysfunction. These medications inhibit the transmission of parasympathetic nerve impulses and thereby reduce spasms of smooth muscle in the bladder.

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

Aspiration—Inhalation of food particles or fluids into lungs.

Aspiration pneumonia—Inflammation of the lungs due to aspiration.

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 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.

Autonomic nervous system—The part of the nervous system that regulates involuntary vital functions, including the activity of the cardiac (heart) muscle, smooth muscles (e.g. of the gut,) and glands. The autonomic nervous system has two divisions: the sympathetic nervous system accelerates heart rate, constricts blood vessels, and raises blood pressure; the parasympathetic nervous system slows heart rate, increases intestinal and gland activity, and relaxes sphincter 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.

Brainstem auditory evoked potential (BAEP)—A test in which the brain's electrical activity in response to auditory stimuli (e.g. clicking sounds) is recorded by an electroencephalograph and analyzed by computer. Demyelination results in a slowing of response time. This test is sometimes useful in the diagnosis of MS because it can confirm the presence of a suspected lesion or identify the presence of an unsuspected lesion that has produced no symptoms. BAEP's have been shown to be less useful in the diagnosis of MS than either visual or somatosensory evoked potentials.

CAT scan—*See* Computerized axial tomography.

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.

Clonus—A sign of spasticity in which involuntary shaking or jerking of the leg occurs when the toe is placed on the floor with the knee slightly bent. The shaking is caused by repeated, rhythmic, reflex muscle contractions.

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.

Combined (bladder) dysfunction—A type of neurogenic bladder dysfunction in MS (also called detrusor-external sphincter dyssynergia—DESD.) Simultaneous contractions of the bladder's detrusor muscle and external sphincter cause urine to be trapped in the bladder, resulting in symptoms of urinary urgency, hesitancy, dribbling, and incontinence.

Computerized axial tomography (CAT scan)—A non-invasive diagnostic radiology technique for examining soft tissues of the body. A computer integrates X-ray scanned "slices" of the organ being examined into a cross-sectional picture.

Condom catheter—A tube connected to a thin, flexible sheath that is worn over the penis to allow drainage of urine into a collection system; can be used to manage male urinary incontinence.

Constipation—A condition in which bowel movements happen less frequently than is normal for the particular individual, or the stool is small, hard, and difficult or painful to pass.

Contraction—A shortening of muscle fibers that results in the movement of a joint.

Contracture—A permanent shortening of the muscles and tendons adjacent to a joint, which can result from severe, untreated spasticity and interferes with normal movement around the affected joint. If left untreated, the affected joint can become frozen in a flexed (bent) position.

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.

Cranial nerves—Nerves that carry sensory, motor, or parasympathetic fibers to the face and neck. Included among this group of twelve nerves are the optic nerve (vision,) trigeminal nerve (sensation along the face,) vagus nerve (pharynx and vocal

cords.) Evaluation of cranial nerve function is part of the standard neurologic exam.

Cystoscopy—A diagnostic procedure in which a special viewing device called a cystoscope is inserted into the urethra (a tubular structure that drains urine from the bladder) to examine the inside of the urinary bladder.

Cystostomy—A surgically created opening through the lower abdomen into the urinary bladder. A plastic tube inserted into the opening drains urine from the bladder into a plastic collection bag. This relatively simple procedure is done when a person requires an indwelling catheter to drain excess urine from the bladder but cannot, for some reason, have it pass through the urethral opening.

Decubitus—An ulcer (sore) of the skin resulting from pressure and lack of movement, such as occurs when a person is bed or wheelchair-bound. The ulcers occur most frequently in areas where the bone lies directly under the skin, such as elbow, hip, or over the coccyx (tailbone.) A decubitus ulcer may become infected and cause general worsening of the person's health.

Deep tendon reflexes—The involuntary jerks that are normally produced at certain spots on a limb when the tendons are tapped with a hammer. Reflexes are tested as part of the standard neurologic exam.

Dementia—A generally profound and progressive loss of intellectual function, sometimes associated with personality change, that results from loss of brain substance and is sufficient to interfere with a person's normal functional activities.

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

DESD—*See* Detrusor-external sphincter dyssynergia.

Detrusor muscle—A muscle of the urinary bladder that contracts and causes the bladder to empty.

Detrusor-external sphincter dyssynergia (DESD)—*See* Combined (bladder) dysfunction.

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.

Dysesthesia—Distorted or unpleasant sensations experienced by a person when the skin is touched, that are typically caused by abnormalities in the sensory pathways in the brain and spinal cord.

Dysmetria—A disturbance of coordination, caused by lesions in the cerebellum. A tendency to over or underestimate the extent of motion needed to place an arm or leg in a certain position as, for example, in overreaching for an object.

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.

Dysphonia—Disorders of voice quality (including poor pitch control, hoarseness, breathiness, and hypernasality) caused by spasticity, weakness, and incoordination of muscles in the mouth and throat.

EAE—*See* Experimental allergic encephalomyelitis.

EEG—*See* Electroencephalography.

Electroencephalography (EEG)—A diagnostic procedure that records, via electrodes attached to various areas of the person's head, electrical activity generated by brain cells.

Electromyography (EMG)—Electromyography is a diagnostic procedure that records muscle electrical potentials through a needle or small plate electrodes. The test can also measure the ability of peripheral nerves to conduct impulses.

EMG—*See* Electromyography.

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.

Euphoria—Unrealistic cheerfulness and optimism, accompanied by a lessening of critical faculties; generally considered to be a result of damage to the brain.

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 dmyelination 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.

Extensor spasm—A symptom of spasticity in which the legs straighten suddenly into a stiff, extended position. These spasms, which typically last for several minutes, occur most commonly in bed at night or on rising from bed.

Failure to empty (bladder)—A type of neurogenic bladder dysfunction in MS resulting from demyelination in the voiding reflex center of the spinal cord. The bladder tends to overfill and become flaccid, resulting in symptoms of urinary urgency, hesitancy, dribbling, and incontinence.

Failure to store (bladder)—A type of neurogenic bladder dysfunction in MS resulting from demyelination of the pathways between the spinal cord and brain. Typically seen in a small, spastic bladder, storage failure can cause symptoms of urinary urgency, frequency, incontinence, and nocturia.

FDA—*See* Food and Drug Administration.

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.

Flaccid—A decrease in muscle tone resulting in weakened muscles and therefore loose, "floppy" limbs.

Flexor spasm—Involuntary, sometimes painful contractions of the flexor muscles, which pull the legs upward into a clenched position. These spasms, which last two to three seconds, are symptoms of spasticity. They often occur during sleep, but can also occur when the person is in a seated position.

Foley catheter—*See* Indwelling catheter.

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.

Frontal lobes—The largest lobes of the brain. The anterior (front) part of each of the cerebral hemispheres that make up the cerebrum. The back part of the frontal lobe is the motor cortex, which controls voluntary movement; the area of the frontal lobe that is further forward is concerned with learning, behavior, judgment, and personality.

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

Gastrocolic reflex—A mass peristaltic (coordinated, rhythmic, smooth muscle contraction that acts to force food through the digestive tract) movement of the colon that often occurs fifteen to thirty minutes after ingesting a meal.

Gastrostomy—*See* Percutaneous endoscopic gastrostomy.

Glucocorticoid hormones—Steroid hormones that are produced by the adrenal glands in response to stimulation by adrenocorticotropic hormone (ACTH) from the pituitary. These hormones, which can also be manufactured synthetically (prednisone, prednisolone, methylprednisolone, betamethasone, dexamethasone,) serve both an immunosuppressive and an anti-inflammatory role in the treatment of MS exacerbations (they damage or destroy certain types of T-lymphocytes that are involved in the overactive immune response and interfere with the release of certain inflammation-producing enzymes.)

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.

Health care proxy—*See* Advance (medical) directive.

Heel-knee-shin test—A test of coordination in which the person is asked, with eyes closed, to place one heel on the opposite knee and slide it up and down the shin.

Helper T-lymphocytes—White blood cells that are a major contributor to the immune system's inflammatory response against myelin.

Hemiparesis—Weakness of one side of the body, including one arm and one leg.

Hemiplegia—Paralysis of one side of the body, including one arm and one leg.

Hyperbaric oxygen—A procedure in which the person breathes oxygen under greater than atmospheric pressure in a specially constructed chamber. Once thought to be a potential treatment for MS, it has been evaluated in several controlled, double-blind studies and found to be ineffective for this purpose.

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.

Incontinence—Also called spontaneous voiding; the inability to control passage of urine or bowel movements.

Indwelling catheter—A type of catheter (*see* Catheter) that remains in the bladder on a temporary or permanent basis. It is used only when intermittent catheterization is not possible or is medically contraindicated. The most common type of indwelling catheter is a Foley catheter, which consists of a flexible rubber tube that is inserted in the bladder to allow the urine to flow into an external drainage bag. A small balloon, inflated after insertion, holds the Foley catheter in place.

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

Intention tremor—Rhythmic shaking that occurs in the course of a purposeful movement, such as reaching to pick something up or bringing an outstretched finger in to touch one's nose.

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.

Intermittent self-catheterization (ISC)—A procedure in which the person periodically inserts a catheter into the urinary opening to drain urine from the bladder. ISC is used in the management of bladder dysfunction to drain urine that remains after voiding, prevent bladder distention, prevent kidney damage, and restore bladder function.

Internuclear ophthalmoplegia—A disturbance of coordinated eye movements in which the eye turned outward to look toward the side develops nystagmus (rapid, involuntary movements) while the other eye simultaneously fails to turn completely inward. This neurologic sign, of which the person is usually unaware, can be detected during the neurologic exam.

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.

Living will—*See* Advance (medical) directive.

Loftstrand crutch—A type of crutch with an attached holder for the forearm that provides extra support.

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.

Marcus Gunn pupil—*See* Afferent pupillary defect.

Minimal Record of Disability (MRD)—A standardized method for quantifying the clinical status of a person with MS. The MRD is made up of five parts:

- Demographic information
- The Neurological Functional Systems (developed by John Kurtzke,) which assign scores to clinical findings for each of the various neurologic systems in the brain and spinal cord (pyramidal, cerebellar, brainstem, sensory, visual, mental, bowel and bladder).
- The Disability Status Scale (developed by John Kurtzke,) which gives a single composite score for the person's disease.
- The Incapacity Status Scale, which is an inventory of functional disabilities relating to activities of daily living.
- The Environmental Status Scale, which provides an assessment of social handicap resulting from chronic illness.

The MRD has two main functions: to assist doctors and other professionals in planning and coordinating the care of persons with MS, and to provide a standardized means of recording repeated clinical evaluations of individuals for research purposes.

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

Motor neurons—Nerve cells of the brain and spinal cord that enable movement of various parts of the body.

Motor point block—*See* Nerve block.

MRI—*See* Magnetic resonance imaging.

Muscle tone—A characteristic of a muscle brought about by the constant flow of nerve stimuli to that muscle, which describes its resistance to stretching. Abnormal muscle tone can be defined as:

- Hypertonus (increased muscle tone, as in spasticity)
- Hypotonus (reduced muscle tone)
- Flaccid (paralysis)
- Atony (loss of muscle tone)

Muscle tone is evaluated as part of the standard neurologic exam in MS.

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.

Myelogram—An X-ray procedure by which the spinal canal and the spinal cord can be visualized. It is performed in conjunction with a lumbar puncture and injection of a special X-ray contrast material into the spinal canal.

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.)

Nerve block—A procedure used to relieve otherwise intractable spasticity, including painful flexor spasms. An injection of phenol into the affected nerve interferes with the function of that nerve for up to three months, potentially increasing a person's comfort and mobility.

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.

Neurogenic—Related to activity of the nervous system, as in "neurogenic bladder."

Neurogenic bladder—Bladder dysfunction associated with neurologic malfunction in the spinal cord and characterized by a failure to empty, failure to store, or a combination of the two. Symptoms that result from these three types of dysfunction include urinary urgency, frequency, hesitancy, nocturia, and incontinence.

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.

Nocturia—The need to urinate during the night.

Nystagmus—Rapid, involuntary movements of the eyes in the horizontal or, occasionally, the vertical direction.

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.

Ophthalmoscope—An instrument designed for examination of the interior of the eye.

Optic atrophy—A wasting of the optic disc that results from partial or complete degeneration of optic nerve fibers and is associated with a loss of visual acuity.

Optic disc—The small blind spot on the surface of the retina where cells of the retina converge to form the optic nerve; the only part of the retina that is insensitive to light.

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.

Orthotist—A person skilled in making mechanical appliances (orthotics) such as leg braces or splints that help to support limb function. *See* Orthotic.

Oscillopsia—Continuous, involuntary, and chaotic eye movements that result in a visual disturbance in which objects appear to be jumping or bouncing.

Osteoporosis—Decalcification of the bones, which can result from the lack of mobility experienced by wheelchair-bound individuals.

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.

Paresthesia—A spontaneously occurring sensation of burning, prickling, tingling, or creeping on the skin that may or may not be associated with any physical findings on neurologic examination.

Paroxysmal spasm—A sudden, uncontrolled limb contraction that occurs intermittently, lasts for a few moments, and then subsides.

Paroxysmal symptom—Any one of several symptoms that have sudden onset, apparently in response to some kind of movement or sensory stimulation, last for a few moments, and then subside. Paroxysmal symptoms tend to occur frequently in those individuals who have them, and follow a similar pattern from one episode to the next. Examples of paroxysmal symptoms include acute episodes of trigeminal neuralgia (sharp facial pain,) tonic seizures (intense spasm of limb or limbs on one side of the body,) dysarthria (slurred speech often accompanied by loss of balance and coordination,) and various paresthesias (sensory disturbances ranging from tingling to severe pain.)

PEG—*See* Percutaneous endoscopic gastrostomy.

Percutaneous endoscopic gastrostomy (PEG)—A PEG is a tube inserted into the stomach through the abdominal wall to provide food or other nutrients when eating by mouth is not possible. The tube is inserted in a bedside procedure using an endoscope to guide the tube through a small abdominal incision. An endoscope is a lighted instrument that allows the doctor to see inside the stomach.

Percutaneous rhizotomy—An outpatient surgical procedure used in the management of severe, intractable trigeminal neuralgia. The surgeon makes a tiny incision in the side of the person's face and blocks the function of the trigeminal nerve using laser surgery, cryosurgery (freezing,) or cauterization.

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.

Plantar reflex—A reflex response obtained by drawing a pointed object along the outer border of the sole of the foot from the heel to the little toe. The normal flexor response is a bunching and downward movement of the toes. An upward movement of the big toe is called an extensor response, or Babinski reflex, which is a sensitive indicator of disease in the brain or spinal cord.

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.

Position sense—The ability to tell, with one's eyes closed, where fingers and toes are in space. Position sense is evaluated during the standard neurologic exam in MS.

Post-void residual test (PVR)—The PVR test involves passing a catheter into the bladder following urination in order to drain and measure any urine that is left in the bladder after urination is completed. The PVR is a simple but effective technique for diagnosing bladder dysfunction in MS.

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

Power grading—A measurement of muscle strength used to evaluate weakness or paralysis. Power is tested as part of the standard neurologic exam in MS.

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.

Prospective memory—The ability to remember an event or commitment scheduled for the future. Thus, a person who agrees to meet or call someone at a given time on the following day must be able to remember the appointment when the time comes. People with MS-related memory impairment frequently report problems with this type of memory for upcoming appointments.

Pseudo-bulbar affect—*See* Affective release.

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.

Pyramidal tracts—Motor nerve pathways in the brain and spinal cord that connect nerve cells in the brain to the motor cells located in the cranial, thoracic, and

lumbar parts of the spinal cord. Damage to these tracts causes spastic paralysis or weakness.

Pyuria—The presence of pus in the urine, causing it to appear cloudy; indicative of bacterial infection in the urinary tract.

Quad cane—A cane that has a broad base on four short "feet," which provide extra stability.

Quadriplegia—The paralysis of both arms and both legs.

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.

Residual urine—Urine that remains in the bladder following urination.

Retrobulbar neuritis—*See* Optic neuritis.

Romberg's sign—The inability to maintain balance in a standing position with feet and legs drawn together and eyes closed.

Scanning speech—Abnormal speech characterized by staccato-like articulation that sounds clipped because the person unintentionally pauses between syllables and skips some of the sounds.

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

Scotoma—A gap or blind spot in the visual field.

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.

Sepsis—The presence of sufficient bacteria in the blood to cause illness.

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.

Somatosensory evoked potential—A test that measures the brain's electrical activity in response to repeated (mild) electrical stimulation of different parts of the body. Demyelination results in a slowing of response time. This test is useful in the diagnosis of MS because it can confirm the presence of a suspected lesion (area of demyelination) or identify the presence of an unsuspected lesion that has produced no symptoms.

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.

Sphincter—A circular band of muscle fibers that tightens or closes a natural opening of the body, such as the external anal sphincter, which closes the anus, and the internal and external urinary sphincters, which close the urinary canal.

Sphincterotomy—A surgical enlargement of the urinary sphincter in a male whose spasticity is so severe that he cannot empty his bladder. Once the surgery is performed, the man loses urinary control and must wear an external, condom catheter to collect the urine. This procedure is seldom required in MS. It is performed only on males because urinary drainage problems in females might lead to skin breakdown.

Spinal tap—*See* Lumbar puncture.

Spirometer—An instrument used to assess lung function; it measures the volume and flow rate of inhaled and exhaled air.

Spontaneous voiding—*See* Incontinence.

Stance ataxia—An inability to stand upright due to disturbed coordination of the involved muscles, which results in swaying and a tendency to fall in one or another direction.

Steroids—*See* ACTH; Corticosteroid; Glucocorticoid hormones.

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.

Tandem gait—A test of balance and coordination that involves alternately placing the heel of one foot directly against the toes of the other foot.

Tenotomy—An irreversible surgical procedure performed to cut severely contracted tendons attached to muscles that do not respond to any other type of spasticity control and are causing intractable pain and skin complications related to lack of physical movement.

Titubation—A form of tremor, resulting from demyelination in the cerebellum, that manifests itself primarily in the head and neck.

Tonic seizure—An intense spasm that lasts for a few minutes and affects one or both limbs on one side of the body. Like other types of paroxysmal symptoms in MS, these spasms occur abruptly and fairly frequently in those individuals who have them, and are similar from one brief episode to the next. The attacks may be triggered by movement or occur spontaneously. *See* Paroxysmal symptom.

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.

Transurethral resection—A procedure to remove excess thickened tissue at the point of connection between the bladder and the urethra. This thickened tissue, which occasionally develops with the prolonged use of a Foley catheter, obstructs the flow of urine when the catheter is removed. This procedure is quite uncommon and is done mostly in males.

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.

Urethra—Duct or tube that drains the urinary bladder.

Urinary frequency—Feeling the urge to urinate even when urination has occurred very recently.

Urinary hesitancy—The inability to void urine spontaneously even though the urge to do so is present.

Urinary incontinence—*See* Incontinence.

Urinary sphincter—The muscle closing the urethra, which in a state of flaccid paralysis causes urinary incontinence and in a state of spastic paralysis results in an inability to urinate.

Urinary urgency—The inability to postpone urination once the need to void has been felt.

Urine culture and sensitivity (C & S)—A diagnostic procedure to test for urinary tract infection and identify the appropriate treatment. Bacteria from a mid-stream urine sample is allowed to grow for three days in a laboratory medium and then tested for sensitivity to a variety of antibiotics.

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.

Vibration sense—The ability to feel vibrations against various parts of the body. Vibration sense is tested (with a tuning fork) as part of the sensory portion of the neurologic exam.

Videofluoroscopy—A radiographic study of a person's swallowing mechanism that is recorded on videotape. Videofluoroscopy shows the physiology of the pharynx, the location of the swallowing difficulty, and confirms whether or not food particles or fluids are being aspirated into the airway.

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.