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MULTIPLE SCLEROSIS  
SOCIETY



Multiple  
Sclerosis  
Society of  
Canada

*The National Multiple Sclerosis Society...  
One thing people with MS can count on.*

# **KIDS GET MS TOO**

***A GUIDE FOR PARENTS WHOSE CHILD OR TEEN HAS MS***

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

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**KIDS GET MS TOO**  
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**SECTION I**  
**INTRODUCTION AND OVERVIEW**

## SECTION I—INTRODUCTION AND OVERVIEW

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

As parents, we all wish for our children to be healthy and happy—to have lives without discomfort or loss. We want to be able to protect them and keep them from harm. Although your child or teen has been diagnosed with MS, your mission remains the same, and the MS Society of Canada and the National MS Society are committed to helping you ensure the very best for your daughter or son.

Whether your child's symptoms are relatively new, or you have been searching for answers for quite some time, the words *multiple sclerosis* can be very frightening. The important thing to remember is that **each person's MS is different**. Some people may develop several symptoms while others have only one or two, but most will never become severely disabled. Youngsters with MS can grow up to lead full, enjoyable, and productive lives.

### **What is MS?**

MS is thought to be an **autoimmune** disease that affects the central nervous system (CNS), which is made up of the brain, spinal cord, and optic nerves. When a person has MS, 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 that facilitates nerve conduction. The nerve cells themselves can also be damaged. The attacks on myelin produce scarring at multiple sites in the CNS, and it is these scars that give the disease its name. The scars, in turn, begin to slow or interrupt the transmission of nerve impulses, resulting in the symptoms of MS.

### **What causes MS?**

We do not yet know the answer to this question. The current thinking is that the disease appears in those individuals who have a genetic predisposition to react to some infectious agent in the environment such as a virus or bacteria. This means that the disease is *not* genetically transmitted in the same way as hair or eye color, for example. There seem

to be, however, certain genes or combinations of genes that make one person more susceptible to the infectious agent(s) than someone else with a different genetic makeup. While several different viruses and bacteria have been studied for their possible role in MS, the trigger(s) have not yet been found. We do know, however, that MS is not a contagious disease—you do not need to be concerned that your child will give MS to other members of the family or to friends and classmates.

### **Who gets MS?**

It is estimated that there are approximately 450,000 people with MS in Canada and the United States, which means that approximately one in a thousand people have the disease at any given time. Although MS is typically diagnosed between the ages of 20 and 50, the disease has been known to appear in young children and people over the age of 65. Studies indicate that 2.7- 5% of people with MS are diagnosed before the age of 16. Although one study identified 49 children below the age of six, the majority of youngsters with MS are between the ages of 10 and 17.

Like most autoimmune diseases, MS is more common in women than in men. MS appears more frequently in Caucasians than in Hispanics or African Americans, and is relatively rare among Asians and other groups. The disease is more common in temperate areas of the world, away from the equator, and relatively rare in the tropics. The evidence suggests that the disease occurs most often in people of northern and central European ancestry who may share some common genetic predisposition.

The role of genetics in MS is an area of active research at this time. The experts in the field tell us that the estimates of risk for developing MS tend to be oversimplified and therefore easily misinterpreted. The important point to remember is that the risk is greatest in families in which there are several family members who have the disease, and significantly lower in other families. With that in mind, 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 happens when a person gets MS?

Misguided immune cells enter the CNS, causing inflammation in the brain, spinal cord, and/or optic nerves. It is this inflammation that can cause damage to the protective myelin coating around the nerve cells, producing scars (also called **plaques** or **lesions**) that interfere with nerve transmission. While many of these scars may have no apparent effect, others are responsible for the various symptoms of MS. Each person's symptoms will vary depending on the particular location(s) where the scarring (**demyelination**) occurs. The 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, sexual changes, emotional changes, speech difficulties, and problems with thinking and memory. 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.

## Are there different types of MS?

We do see different disease patterns in MS.

- Relapsing-remitting MS
- Primary-progressive MS
- Progressive-relapsing MS
- Secondary-progressive MS

Most adults—and virtually all children—start with a *relapsing-remitting* course, characterized by clearly defined 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. There are some people who have a more steadily progressive course right from the beginning—either *primary-progressive* (a disease course with no acute relapses) or *progressive-relapsing* (with some relapses along the way)--but these are rarely seen in children.

The majority of people with relapsing-remitting MS will eventually develop a *secondary-progressive* course of the disease, in which the disease progresses more steadily, with or without acute attacks. Regardless of the course, however, most people with MS do not become severely disabled. The doctor 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.

### **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 youngster 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. Studies indicate that the chances of a person developing MS depend in part on where he or she lived before adolescence. In other words, a child with a certain genetic disposition comes into contact with some kind of environmental trigger during the early years, but the MS does not become active in most people until adulthood. We still do not know what causes it to become active in some young children and adolescents.

### **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 it or make it go away. 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 over the past decade 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 each year brings us closer to the cure. In the meantime, we have also learned a great deal about slowing progression of the disease and helping people manage whatever symptoms may occur.

### **What is the treatment?**

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 manage symptoms and slow disease progression. These will be discussed in more detail in other sections of the manual.

- 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 five medications approved 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, the Medical Advisory Boards of the National MS Society and the MS Society of Canada recommend treatment with one or another of the four injectable medications (Avonex<sup>®</sup>, Betaseron<sup>®</sup>, Copaxone<sup>®</sup>, or Rebif<sup>®</sup>) 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. The fifth drug, Novantrone<sup>®</sup> (delivered by intravenous infusion), is available to treat more progressive forms of the disease.

### **Will my child become severely disabled?**

Because MS is such an unpredictable disease, it is not possible to predict what the outcome will be for any one person. The statistics tell us,

however, that two out of three people with MS remain able to walk, although some may need the help of a cane or other assistive device. Some will choose to use a motorized scooter or wheelchair to conserve energy, and some may eventually require a wheelchair to maintain mobility. While no one likes the idea of using a cane or other assistive devices, it may be helpful to think of them as useful tools that are available if and when the need arises. Like all other tools, they make life easier and help people meet their goals.

### **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 *National MS Society*?**

The National MS Society is a non-profit, voluntary health organization with a network of chapters and branches throughout the country. In addition to being the #1 source of accurate, up-to-date information about multiple sclerosis, the National MS Society provides more funding for research projects than any other MS voluntary organization in the country. This research has led to successful treatments, and will eventually find the cause and cure for MS. While the research continues, the Society's local chapters and branches 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.nationalmssociety.org](http://www.nationalmssociety.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 *Young Persons with MS: A Network for Families with a Child or Teen with MS*?**

The Multiple Sclerosis Society of Canada and the National Multiple Sclerosis Society (USA) have joined in collaboration to offer the ***Young Persons with MS: A Network for Families with a Child or Teen with MS***. With support from both organizations, we will be able to enlarge the scope of programs offered. The network currently provides multiple program options for families living with a child or teen that has been diagnosed with multiple sclerosis. The MS Society of Canada and the National MS Society recognize the unique needs of these youngsters and realize that their parents and siblings may also need a variety of support services and programs.

The network targets two distinct populations:

- Children with MS (18 or younger) residing in the home of their parents or guardian
- Parents of a child or teen with MS

### **What can the *Network for Families* do for our family?**

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.

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: 1-866-KIDS W MS  
 (866-543-7967)  
 Email: childhoodms@nmss.org

**For contact in Canada:**

National Information Resource Centre  
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 Multiple Sclerosis Society of Canada  
 175 Bloor St E, Suite 700, North Tower  
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 1-866-922-6065  
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*The MS Society of Canada and the National MS Society maintain strict confidentiality policies. Regardless of the types of programs or services you choose to utilize, your privacy will be respected and protected.*

This manual 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 of this manual 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 a U.S. and Canadian version in order to address issues that are unique to each country. To request a copy of the U.S. version of the handbook, please contact the National MS Society. Contact information is above.]*

## **YOUNG PERSONS WITH MS: A NETWORK FOR FAMILIES WITH A CHILD OR TEEN WITH MS**

Young Person with MS: A Network for Families with a Child or Teen with MS 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**

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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**

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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 to learn more about the Network and other available resources.

### **Emotional Support**

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

### **Connecting Families**

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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 1-866-KIDS W MS (1-866-543-7967) or  
Email: [childhoodms@nmss.org](mailto:childhoodms@nmss.org)**

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**SECTION II**  
**DIAGNOSIS AND TREATMENT**

## SECTION II—DIAGNOSIS AND TREATMENT

### Making the Diagnosis of MS in Children

#### What are the criteria for making the diagnosis of MS?

Currently, the criteria for making a diagnosis of MS in adults and children are the same. The 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 youngster for various neurologic signs, including altered reflexes, changes in the appearance of the optic nerve, a reduction in strength, 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.

### **What are the 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.

### **Why do Youngsters 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 is almost always 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, and helping youngsters and their families deal with the impact of MS symptoms on everyday life. Although many of the medical treatments described here have been studied extensively in adults, none has 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 has 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. The treatment information provided here comes primarily from the experiences gained at two MS Centers: Dr. Brenda Banwell's Pediatric Multiple Sclerosis Clinic at The Hospital for Sick Children in Toronto, Canada; and Dr. Lauren Krupp's Pediatric MS Center at the University of New York at Stony Brook.

### **Who Treats Children and Teens with MS?**

Youngsters 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 younger group of MS patients, and you may or may not have anyone in your area that is familiar with pediatric MS.

One important role of the National MS Society and the MS Society of Canada is to help people find physicians in their area who have the interest and the expertise to treat pediatric MS. They will gladly provide you with the names of local practitioners. If there are no MS specialists in your area, you have a couple of options:

- 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](mailto:MD_info@nmss.org); 1-866-MS-TREAT (1-866-678-7328) or contact Dr. Krupp (631-444-7802) or Dr. Banwell (416-813-6660) for a consultation.

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

## **Managing Acute Attacks**

*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 youngsters 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 youngster 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 adult MS patients with severe relapse symptoms, its use in children has been very limited.

## **Modifying the Disease Course**

There are currently five immunomodulatory therapies (medications that modify the immune system in order to reduce immune activity) that have been approved for use in adults with MS (See Table 1, page 29).

### **The Injectable Medications**

The four injectable medications—Avonex<sup>®</sup>, Betaseron<sup>®</sup>, Copaxone<sup>®</sup>, and Rebif<sup>®</sup>—are all approved for use in the relapsing-remitting form of the disease that most children have. Each of the three interferon medications (Avonex<sup>®</sup>, Betaseron<sup>®</sup>, Rebif<sup>®</sup>) is approved for all relapsing forms of the disease; in other words, they are also prescribed for progressive disease as long as the person is continuing to have relapses. At the present time, there are no medications approved for the treatment of primary-progressive MS.

### **How These Medications Work**

The beta-interferons (Avonex<sup>®</sup>, Rebif<sup>®</sup>, and Betaseron<sup>®</sup>) work differently than glatiramer acetate (Copaxone<sup>®</sup>), but all work to reduce the attack of immune cells on the white matter (myelin) in the brain. Interferons work in four ways:

- 1) by decreasing the ability of immune cells to make more immune cells
- 2) by reducing the ability of immune cells to make harmful chemicals (called cytokines)
- 3) by increasing cell death of these harmful immune cells, and
- 4) by blocking the access of the harmful immune cells into the central nervous system. Glatiramer acetate, which binds to certain types of immune cells, acts by “fooling” the immune system. As a result of the binding, the immune cells change from “bad” or inflammatory immune cells, into “good” suppressor immune cells that weaken the more harmful ones. Thus, although interferons and glatiramer acetate work differently, the net result is similar—they calm an over-active immune system.

## Using the Injectable Therapies in Children

Although none of the immunomodulatory 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. The interferons and Copaxone<sup>®</sup> are all given by injection—either intramuscular (into the muscle) or subcutaneous (under the skin). The concept of regular injections is difficult for many children (and adults), and parents may struggle with the idea of administering injections to their child. MS nurses are able to teach injection techniques, and no child or parent should expect to begin injections without extensive training and supervision. Home care nursing, usually coordinated through the patient help-line programs associated with each of the pharmaceutical companies that supply the medications, is also helpful for the first few home injections. Experience has shown that parents and children actually deal very well with injections, and many teenagers quickly learn how to administer the injections themselves. Copaxone<sup>®</sup> and Rebif<sup>®</sup> are now available with an “autoinjector,” a device that contains the needle inside and requires only a push of a button to deliver the medication. While older children tend to like to autoinjector, many younger children may find the device’s clicking noise to be frightening.

## What Dose of Medication to Use

There are no published guidelines on the use of these medications in children, and physicians differ in the dosing regimens they use. In general, older children who are close to adult size seem to tolerate the adult dosages of the interferons very well. Children under 100 pounds may need to be given a somewhat lower dose. Since the interferons can cause flu-like symptoms and changes in liver function, they are generally started at a low dose and increased gradually if side effects are manageable and liver function remains normal. Even younger children may need to be increased to the full adult dose if they have very frequent relapses or many lesions on MRI. Copaxone<sup>®</sup>, which does not produce the flu-like symptoms or changes in liver function, can generally be started at the full adult dose.

## **Medication Side Effects**

Table 1 (page 29) lists the common side effects experienced by patients taking the injectable medications. Although the side effects can be troublesome for some patients, most children actually tolerate the medications very well.

Flu-like symptoms and headache, which have been easily managed by giving either ibuprofen or acetaminophen before the dose, usually lessen after the first few months. Like adult patients, children on Copaxone<sup>®</sup> may experience a short-term, post-injection reaction that includes flushing; chest tightness or heart palpitations (pounding or fluttering; anxiety; and shortness of breath, but this side effect is transient and considered harmless.

## **Monitoring the Safety of the Drugs**

In order to monitor the safety of the interferon medications, the doctor will perform liver function and hematological (white blood cell and platelet counts) studies prior to starting treatment, and periodically thereafter. The monitoring schedule may vary from one doctor to another, but the goal is to track liver function and stop or reduce the dose of the medication if the liver is affected by the medication. No monitoring of this type is required with Copaxone<sup>®</sup>.

## **The Effectiveness of These Drugs**

Whenever one considers the use of a medication, one must weigh the benefits against the risks/side effects. Each of the four injectable drugs approved for use in MS has been carefully and rigorously tested. Large research trials, involving hundreds of MS patients, have been performed for each drug. Each drug has its own “claim to fame,” based on specific results in the large trials. All four drugs have been shown to reduce the annual relapse rate by approximately 30-35%, and all have been shown to reduce the number of brain and spinal cord lesions as shown on MRI. Avonex<sup>®</sup> and Rebif<sup>®</sup> have also been shown to delay the time to progression of physical disability. Thus, these medications are not “magic”—they do not prevent all attacks, and they do not guarantee that attacks will be mild, but they do seem to help people with MS live healthy and productive lives.

Children who experience a significant attack while on immunomodulatory therapy are still treated with corticosteroids as described on p. 22.

### **Treatment with an Injectable Medication After the First Attack**

As described in the section on diagnosis (pp. 18-19), the diagnosis of MS cannot be confirmed without evidence of *two* attacks of demyelination that have occurred at least a month apart. However, there is some evidence from studies in adults who have had one demyelinating attack and have abnormal MRI scans that are suggestive of MS, that treatment with Avonex<sup>®</sup> or Rebif<sup>®</sup> after the first attack of demyelination can delay the second attack and thus the development of MS.

The question of treating children with one of the injectable therapies before the diagnosis of MS can be confirmed is problematic for several reasons: there were no children in these studies of Avonex<sup>®</sup> and Rebif<sup>®</sup>; we don't yet know if the MRI criteria that have been identified for adults are the same for children; and as described in the diagnosis section, children often experience a single neurologic episode of acute disseminated encephalomyelitis (ADEM), which never recur.

Although it has not yet been proven, many MS experts believe that early treatment provides long-term benefit—that is to say, reduces the chances of disability. If this turns out to be the case, there is an urgent need to find ways to predict which children will go on to develop MS after a first attack of demyelination. These children could be offered treatment with immunomodulatory therapy even prior to their second attack. At the present time, however, we do not have a way to select these children, and thus most physicians would not feel it appropriate to start immunomodulatory treatment in a child who does not yet meet the criteria for the diagnosis of MS. More studies in this area are urgently needed.

### **Novantrone<sup>®</sup> (mitoxantrone)**

Many medications have been tried in an attempt to control MS disease activity and many more are currently under study. While we are fortunate to have four injectable medications that are approved for use in certain types of MS, we know that these medications are only partially effective in controlling disease activity. None of them stops the disease completely. In a small minority of individuals, the disease continues to progress rapidly in

spite of ongoing treatment. Since 2000, we have had another treatment to try when none of the injectable medications provides sufficient benefit. Novantrone<sup>®</sup> (mitoxantrone), a very potent drug that suppresses immune cell activity, is approved for treatment of secondary-progressive, progressive relapsing, and worsening relapsing-remitting MS in adults.

Novantrone<sup>®</sup> is also used for the treatment of leukemia, Hodgkin's disease, breast cancer, and prostate cancer. The dosage used in MS is significantly lower than that used in cancer treatment. Novantrone<sup>®</sup> is given by intravenous infusion, usually every three months until the maximum allowed dose is reached. Mitoxantrone has been shown to reduce the progression of disability, and to reduce the number of attacks. It is particularly useful for patients with very frequent relapses associated with early signs of progressive disability.

The most common side effect of Novantrone<sup>®</sup> therapy is nausea. A small number of women developed amenorrhea (absence of menstrual cycles) until they stopped taking the drug, but the effect on long-term fertility is still unknown. In the high doses used for cancer treatment, Novantrone<sup>®</sup> can impair heart function, and the cardiac risk increases with the total dose given. In order to avoid cardiac dysfunction, most patients with MS are treated for a maximum of 3 years. Treatment with Novantrone<sup>®</sup> can also increase the risk of future cancers.

For patients with rapidly worsening MS, Novantrone<sup>®</sup> therapy is now considered an appropriate, but limited, treatment option. The use of this drug in children and teens requires consultation with pediatric oncologists, who are more familiar with using similar medications for the treatment of childhood cancers. The long-term risks with Novantrone<sup>®</sup> (cardiac toxicity, menstrual irregularity and possible fertility issues, and an increased risk of future cancers) would suggest that Novantrone<sup>®</sup> be used for only a very select group of pediatric MS patients.

**Table 1: Comparing the Disease Modifying Drugs**

<b>Brand and Generic Name</b>	
<b>Avonex<sup>®</sup></b>	Interferon beta-1a
<b>Betaseron<sup>®</sup></b>	Interferon beta-1b
<b>Copaxone<sup>®</sup></b>	Glatiramer acetate
<b>Rebif<sup>®</sup></b>	Interferon beta-1a
<b>Novantrone<sup>®</sup></b>	Mitoxantrone
<b>Manufacturer/Distributor and FDA Approval</b>	
<b>Avonex<sup>®</sup></b>	Biogen, Inc.—1996
<b>Betaseron<sup>®</sup></b>	Berlex Laboratories, Inc.—1993
<b>Copaxone<sup>®</sup></b>	Teva Pharmaceutical Industries, Ltd.—1996
<b>Rebif<sup>®</sup></b>	Serono, Inc.—2002
<b>Novantrone<sup>®</sup></b>	Immunex—2002
<b>Indication</b>	
<b>Avonex<sup>®</sup></b>	For the treatment of relapsing forms of MS, and for a single clinical episode if MRI features consistent with MS are also present.
<b>Betaseron<sup>®</sup></b>	For the treatment of relapsing forms of MS including secondary-progressive MS with relapses.
<b>Copaxone<sup>®</sup></b>	For the treatment of relapsing-remitting forms of MS.
<b>Rebif<sup>®</sup></b>	For treatment of relapsing forms of MS.

<b>Novantrone<sup>®</sup></b>	For treatment of rapidly worsening relapsing-remitting MS and for progressive-relapsing or secondary-progressive MS. See p. 27 for additional information.
<b>Frequency/Route of Delivery/Usual Dose</b>	
<b>Avonex<sup>®</sup></b>	Weekly; intramuscular (into the muscle) injection; 30 mcg.
<b>Betaseron<sup>®</sup></b>	Every other day; subcutaneous (under the skin) injection; 250 mcg.
<b>Copaxone<sup>®</sup></b>	Daily; subcutaneous (under the skin) injection; 20 mg (20,000 mcg).
<b>Rebif<sup>®</sup></b>	Three times a week; subcutaneous (under the skin) injection; 44 mcg.
<b>Novantrone<sup>®</sup></b>	Four times a year by IV infusion in a medical facility. Lifetime limit of 8-12 doses.
<b>Common Side Effects of the Self-Injectables</b>	
<b>Avonex<sup>®</sup></b>	Flu symptoms following injection, which lessen over time for many people. Rarer: depression, mild anemia, elevated liver enzymes, allergic reactions.
<b>Betaseron<sup>®</sup></b>	Flu symptoms following injection, which lessen over time for many. Injection site reactions, about 5% of which need medical attention. Rarer: allergic reactions, depression, elevated liver enzymes, low white blood cell counts.
<b>Copaxone<sup>®</sup></b>	Injection site reactions. Rarer: a reaction immediately after injection, which includes anxiety, chest pain, palpitations, shortness of breath, and flushing. This lasts 15-30 minutes and has no known long-term effects. Also dilation of blood vessels.

<b>Rebif®</b>	Flu-like symptoms following injection, which lessen over time for many. Injection site reactions. Less common: Liver abnormalities, depression, allergic reactions, and low red or white blood cell counts.
<b>Patient and Financial Support; Other Sponsored Web sites</b>	
<b>Avonex®</b>	MS Active Source <sup>SM</sup> 800-456-2255 <a href="http://www.avonex.com">www.avonex.com</a> <a href="http://www.msactivesource.com">www.msactivesource.com</a> <a href="http://www.healthtalk.com">www.healthtalk.com</a>
<b>Betaseron®</b>	MSPathways <sup>SM</sup> 800-788-1467 <a href="http://www.betaseron.com">www.betaseron.com</a> <a href="http://www.mspathways.com">www.mspathways.com</a>
<b>Copaxone®</b>	Shared Solutions <sup>TM</sup> 800-887-8100 <a href="http://www.copaxone.com">www.copaxone.com</a> <a href="http://www.sharesolutions.com">www.sharesolutions.com</a> <a href="http://www.mswatch.com">www.mswatch.com</a> <a href="http://www.msdialogue.com">www.msdialogue.com</a>
<b>Rebif®</b>	MS LifeLines <sup>TM</sup> 877-447-3243 <a href="http://www.mslifelines.com">www.mslifelines.com</a>
<b>Novantrone®</b>	<a href="http://www.novantrone.com">www.novantrone.com</a>

## **Alternative Therapies**

Many parents ask about the use of herbal or naturopathic remedies for their child. 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. 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 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 physician.

## **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. Fevers or infections may temporarily worsen MS symptoms, but these symptoms will generally improve as the fever is brought under control. 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<sup>®</sup>; Alertec<sup>®</sup> in Canada) has been shown to significantly reduce fatigue in adult MS patients, 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 at some point over the course of the disease. The two 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<sup>®</sup>) to control it.

*Sensory symptoms*, which are very common in MS, include the feeling of “pins and needles”, numbness or tingling, dizziness, 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 frequently. 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 antispasticity 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 III. 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 youngsters with MS, and every effort must be made to recognize and address these problems in children before they have a significant impact on his or her school experience. Section IV deals in detail with the assessment and management of cognitive symptoms in children in MS.

# NOTES

**KIDS GET MS TOO**  
*A GUIDE FOR PARENTS WHOSE CHILD OR TEEN HAS MS*

**SECTION III**  
**EMOTIONAL ISSUES**

## **SECTION III—EMOTIONAL ISSUES**

### **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 we value in this 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 youngsters take their cues from their parents. If we are anxious, they will be too. If we worry, they will, too. They need reassurance that they will be okay and that we 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 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. If we are anxious or worried, they will be, too. 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 any more....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 youngster 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 (particularly grandparents!) 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 is.
- *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; and the ***Young Persons with MS: A Network for Families with a Child or Teen with MS*** is available to help you and your child along the way (see pp. 14-16).

### **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 Doctor and Nurse**

Learning to live comfortably with MS depends, at least in part, on a good working relationship with the health professionals who are treating it. You *and* your child need to be able to communicate with the healthcare 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 quite 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. They often worry about the important people in their lives, often they do not want to "burden" others, and 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 for them to have 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 mandate of 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 sexual 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.

### **Teenage 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, running errands, when teens are more likely to open up. Counselors at school may be a resource for your teen or a favorite teacher or clergy person. Your division of the MS Society of Canada or local chapter of the National MS Society is knowledgeable about its mental health community and can refer you and your teen to someone versed in MS.

# NOTES

**KIDS GET MS TOO**  
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**SECTION IV**  
**DEALING WITH COGNITIVE SYMPTOMS IN MS**

## SECTION IV—DEALING WITH COGNITIVE SYMPTOMS IN MS

### Dealing with Cognitive Symptoms in Pediatric and Adolescent 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*

In adult MS, research has shown that approximately 50% of patients experience some cognitive deficits. Sometimes, however, the cognitive changes are subtle enough to escape notice in everyday interactions. For this reason, patients, family members, and health care professionals may be slow to recognize these 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. 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. MS patients 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.

The 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 II.

### ***Should my child 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 youngster’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.

- **Academic Accommodations**

Academic accommodations refer to modifications in school curriculum, environment, and specialized services in school (or outside of school where necessary) to help the school system meet the needs of the child based on the nature and extent of the specific deficits they display. 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, modifications to 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 modifications 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 modifications can often be made for children with memory deficits.

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

- **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 adult 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 these academic issues in greater detail. It will be 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.

Additional information about cognitive symptoms in MS can be found at on the National MS Society web site at:

<http://www.nationalmssociety.org/spotlight-cognition.asp>.

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**SECTION V**  
**YOUR CHILD'S RIGHTS IN THE EDUCATIONAL  
SETTING (CANADA)**

## **SECTION V - YOUR CHILD'S RIGHTS IN THE EDUCATIONAL SETTING**

### **Canadian Ministries of Education**

In Canada, education is the responsibility of each province and territory. Each provincial ministry of education has been listed below, including contact information. Information regarding special education, or special assistance within the classroom, or otherwise should be available through your child's school, however, as an extra resource, each have been listed for your convenience.

#### **Council of Ministers of Education, Canada**

95 St. Clair Avenue West, Suite 1106 Toronto, Ontario M4V 1N6  
Telephone: (416) 962-8100

Fax: (416) 962-2800

E-mail: [cmec@cmec.ca](mailto:cmec@cmec.ca)

Web site: <http://www.cmec.ca/>

#### **Alberta Learning**

7th Floor, Commerce Place

10155 - 102 Street

Edmonton, Alberta

T5J 4L5

Tel: (780) 427-7219

For toll-free access within Alberta, first dial 310-0000

Fax: (780) 422-1263

E-mail: [comm.contact@learning.gov.ab.ca](mailto:comm.contact@learning.gov.ab.ca)

Web site: <http://www.learning.gov.ab.ca/>

#### **British Columbia Ministry of Education**

Ministry of Education

PO Box 9150, Stn Prov Govt

Victoria BC V8W 9H1

Tel: (250) 356-2500

Fax: (250) 356-5945

Web site: <http://www.gov.bc.ca/bced/>

**Manitoba Education, Training and Youth**

206-1181 Portage Avenue

Winnipeg, Manitoba

R3G 0T3

Phone: (204) 945-7912

Fax: (204) 945-7914

Web site: <http://www.edu.gov.mb.ca/>

- Individualized programming available for students

**New Brunswick Department of Education**

Place 2000

P.O. Box 6000

Fredericton, N.B.

E3B 5H1

Tel: (506) 453-3678,

Fax: (506) 453-3325

Web site: <http://www.gnb.ca/0000/>

**Newfoundland and Labrador Department of Education**

P.O. Box 8700

St. John's, NL

A1B 4J6

Tel: (709) 729-5097

Fax: (709) 729-5896

Web site: [www.gov.nl.ca/edu/](http://www.gov.nl.ca/edu/)

Student Support Services: <http://www.gov.nf.ca/edu/dept/sss.htm>

**Northwest Territories Department of Education**

NWT Education, Culture and Employment

Box 1320

Yellowknife, NT

X1A 2L9

**OR**

Early Childhood Education & School Services

3<sup>rd</sup> Floor, Lahm Ridge Towers

Yellowknife, NT

X1A 2L9

Tel: (867) 920-3416

Fax: (867) 873-0109

**Nova Scotia Department of Education**

P.O. Box 578  
2021 Brunswick Street, Suite 402  
Halifax, Nova Scotia  
B3J 2S9  
Tel: (902) 424-5168  
Fax: (902) 424-0511  
Web site: <http://www.ednet.ns.ca/>

**Ontario Ministry of Education**

Mowat Block, 900 Bay Street  
Toronto, Ontario  
M7A 1L2  
Tel: (416) 325-2929 or 1-800-387-5514  
Fax: (416) 325-6348  
e-mail: [info@edu.gov.on.ca](mailto:info@edu.gov.on.ca)  
Web site: <http://www.edu.gov.on.ca/eng/welcome.html>

- Individual Education Plans available (IEP)

**Prince Edward Island Department of Education**

Second Floor, Sullivan Building  
16 Fitzroy Street  
P.O. Box 2000  
Charlottetown, PEI  
C1A 7N8  
Tel: (902) 368-4600  
Fax: (902) 368-4663  
Web site: <http://www.edu.pe.ca/>

**Quebec Ministry of Education**

1035, rue De La Chevrotière, 16<sup>e</sup> étage  
Québec (Québec)  
G1R 5A5  
Tel : (418) 644-0664  
Fax : (418) 646-7551  
Web site : [http://www.meq.gouv.qc.ca/GR-PUB/m\\_englis.htm](http://www.meq.gouv.qc.ca/GR-PUB/m_englis.htm)

**Saskatchewan Education**

c/o Special Education Unit

2<sup>nd</sup> Floor

2220 College Avenue

Regina, Saskatchewan

S4P 3V7

Tel: (306) 787-1183

Fax: (306) 787-0277

<http://www.sasked.gov.sk.ca/>

**Yukon Department of Education**

Special Programs

Department of Education

Government of Yukon

Box 2703

Whitehorse, Yukon

Y1A 2C6

Tel: (867) 667-8000

Toll free (In Yukon) 1-800-661-0408 (local 8000)

Fx: (867) 393-6423

E-mail: [shirley.loo@gov.yk.ca](mailto:shirley.loo@gov.yk.ca)

Web site: [www.gov.yk.ca/depts/education/specialprograms/index.html](http://www.gov.yk.ca/depts/education/specialprograms/index.html)

# NOTES

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**SECTION VI**  
**INSURANCE ISSUES (CANADA)**

## **SECTION VI - INSURANCE ISSUES**

### **Tips on working With Your Insurance Plan**

As parents 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 most of the time. 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 your health plan fully.
- 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 MS Society of Canada's publication, *Insuring Your Future: Your guide to life insurance and multiple sclerosis* and other resources will always be available to you as a back up for any insurance issues you cannot resolve on your own.

### **Getting and Keeping Insurance Coverage for your Child**

Most people have coverage for their dependent children through their employer-based plans. Nonetheless, parents should be aware that factors affecting their own eligibility for coverage, such as a change of employers or employer's change in health plans, reduction in work hours, marriage or divorce, relocation out of province, 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.

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# NOTES

**KIDS GET MS TOO**  
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**SECTION VII**  
**RESOURCES**

## **SECTION VII—RESOURCES AND PUBLICATIONS**

### **RESOURCES**

#### **Information on Multiple Sclerosis:**

MS Society of Canada  
[www.mssociety.ca](http://www.mssociety.ca)

National Multiple Sclerosis Society  
[www.nationalmssociety.org](http://www.nationalmssociety.org)

#### **Publications:**

Multiple Sclerosis Society of Canada Publications  
[www.mssociety.ca/en/information/references.htm](http://www.mssociety.ca/en/information/references.htm)

National Multiple Sclerosis Society  
[www.nationalmssociety.org/Brochures.asp](http://www.nationalmssociety.org/Brochures.asp)

#### **Federal Government:**

Health Canada  
<http://www.hc-sc.gc.ca/>

#### **Disability Resources:**

Disability WebLinks  
<http://www.disabilityweblinks.ca/pls/dwl/dl.home>

Councils of Ministers of Education Canada  
<http://www.cmec.ca/index.en.html>

#### **Children with Disabilities / Chronic Illness**

Canadian Association of Family Resource Programs  
<http://www.frp.ca/>

Canadian Coalition for the Rights of Children  
<http://www.rightsofchildren.ca/>

Canadian Institute of Child Health  
<http://www.cich.ca/>

Canadian Mental Health Association  
<http://www.cmha.ca/>

Family Service Canada  
<http://www.familyservicecanada.org>

Hospital for Sick Children  
<http://www.sickkids.on.ca/>

### **Pharmaceutical Companies**

*(Though these drugs are not approved for use in children, they are, as is mentioned in the text, frequently prescribed for children.)*

Biogen Inc. – MS Active Source<sup>SM</sup> (Avonex<sup>®</sup>)  
1-800-456-2255      [www.msactivesource.com](http://www.msactivesource.com)

Teva Neuroscience – Shared Solutions<sup>TM</sup> (Copaxone<sup>®</sup>)  
1-800-887-8100      [www.sharedsolutions.com](http://www.sharedsolutions.com)

Berlex Laboratories – MS Pathways<sup>SM</sup> (Betaseron<sup>®</sup>)  
1-800-788-1467      [www.mspathways.com](http://www.mspathways.com)

Serono, Inc. – MS Lifelines<sup>TM</sup> (Rebif<sup>®</sup>)  
1-877-447-3243.1      [www.mslifelines.com](http://www.mslifelines.com)  
                                 [www.ms-network.com](http://www.ms-network.com)

Immunex Corporation (Novantrone<sup>®</sup>)  
1-800-566-8268

# NOTES

# **KIDS GET MS TOO**

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

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

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

**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).

**ADLs**—See Activities of daily living.

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

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

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

**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 adrenocorticotrophic 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<sup>®</sup>) 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<sup>®</sup>) 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<sup>®</sup> 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 of 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; and 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**—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. VEPs 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.

## ***YOUNG PERSONS WITH MS: A NETWORK FOR FAMILIES WITH A CHILD OR TEEN WITH MS***

Young Person with MS: A Network for Families with a Child or Teen with MS 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**

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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**

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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 to learn more about the Network and other available resources.

### **Emotional Support**

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

### **Connecting Families**

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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 1-866-KIDS W MS (1-866-543-7967) or  
Email: [childhoodms@nmss.org](mailto:childhoodms@nmss.org)**