Multiple Sclerosis in 2000

A Model of Psychosocial Support

An Interactive Teleconference Broadcast to Sites Across the United States and Canada

December 6 and 7, 2000
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DEDICATION

We dedicate this program with deepest appreciation to Pamela F. Cavallo, MSW, CSW. During her 23 years of service and commitment to the National Multiple Sclerosis Society, she introduced the national teleconference as a model for client and professional education programs. This innovative approach has dramatically increased the acquisition of information by people with MS, their families, and the professionals who serve them.
ACKNOWLEDGEMENTS

In addition to funding from the National Multiple Sclerosis Society and the Consortium of MS Centers, this program gratefully acknowledges the generous unrestricted educational grants from:

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ACKNOWLEDGEMENTS

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PREFACE

It is our pleasure to welcome you to this year’s professional teleconference, Multiple Sclerosis in 2000: A Model of Psychosocial Support. Along with thousands of other nurses, social workers and psychologists across the United States and Canada, you are participating in the fourth year of this professional education program. Designed initially to meet the needs of nurses working in MS, the program expanded in 1999 to include rehabilitation professionals, and this year to address the needs of mental health professionals.

On behalf of the National MS Society and the Consortium of MS Centers, we wish to express our appreciation to the program faculty who have given so generously of their time and expertise, and to the people with MS who have shared their experiences with us. Their valuable contributions have made this program possible.

In addition, we would like to thank the staff and volunteers of the local chapters of the National MS Society. It is through their efforts that a program like this can reach its audience.

Now, join us in learning about the role of interdisciplinary psychosocial support in people’s efforts to live and cope with multiple sclerosis, from some of the most respected experts in the field. Their knowledge and clinical experience will enhance your cooperative efforts to provide care and support for people with MS.

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PROGRAM

- Program Overview
- Agenda
- Educational Objectives
- Continuing Education Units/Certificate of Attendance
- Faculty
- Program Advisors
- Program Staff
- Medical Reviewer
- Clinical Vignettes
Program Overview

Multiple sclerosis (MS)—a chronic, unpredictable, and often debilitating neuro-immunologic disease with no known cause or cure—is one of the most life-altering diagnoses a person can receive. Because the effects of multiple sclerosis are so variable, each person’s experience of MS is unique, presenting its own set of symptoms and challenges.

While we still don’t know exactly what causes multiple sclerosis, the last seven years have seen encouraging advances in disease course management, symptom management, enhancement of function, and improvement in quality of life. These hopeful advances have transformed the treatment of multiple sclerosis into a complex process that can be challenging, time-consuming, and demanding for everyone involved—people with multiple sclerosis, their families, care partners, and healthcare providers.

In this program, we will focus on the psychological and social challenges confronting people affected by this disease—those who are diagnosed with it as well as their family members and friends. We will describe how people with multiple sclerosis cope with their symptoms, their treatments, their responsibilities at home and at work, and their relationships, and present a model of psychosocial support for these coping efforts. The model illustrates the pivotal role to be played by the healthcare team and the National MS Society in

1. providing information, education, and support.
2. identifying problem areas that require additional intervention.
3. connecting people with formal (professional) and less formal (family and community) resources available to address these problems.

MS experts from the disciplines of nursing, social work, psychology, and neuropsychiatry will utilize two case vignettes to share their perspectives on MS care. The discussion will emphasize the need for cooperative, interdisciplinary interventions to address the psychosocial needs of people living with MS.
Agenda
This two-hour mixed media conference features case vignettes, with interactive discussion via audioteleconference following each video segment.

- Introduction and Overview
- Case Vignette: Karen—a 35-year-old woman with relapsing-remitting MS
- Case Vignette: David—a 50-year-old man with secondary-progressive MS
- Conclusion

Educational Objectives
After participating in this program, attendees will be able to:

- Provide a brief description of MS, including the characteristics of the disease that make it so challenging for patients and their families.
- Identify the common symptoms of MS and their psychosocial implications.
- Describe common emotional responses to the disease—at the time of diagnosis and over the course of the disease.
- Discuss depression and cognitive dysfunction in MS, including prevalence, possible cause(s), diagnosis, and treatments.
- Discuss the role of multidisciplinary and collaborative psychosocial support for people living with MS.

Continuing Education Units (CEU’s)/Certificate of Attendance

Note to Canadian attendees: CEU’s are offered only to health professionals practicing in the United States.

A Certificate of Attendance will be distributed to all attendees.

Psychologists: This program is co-sponsored by the Consortium of Multiple Sclerosis Centers (CMSC) and the National Multiple Sclerosis Society. The CMSC is approved by the American Psychological Association to offer continuing education for psychologists. The CMSC maintains responsibility for the program, which is approved for 2.4 Continuing Education Hours.
Nurses: This offering for 2.4 contact hours is provided by Serono Symposia USA, Inc., which is accredited as a provider of continuing education in nursing by the American Nurses Credentialing Center’s Commission on Accreditation. Serono Symposia USA, Inc., is approved by the California Board of Registered Nursing, Provider Number CEP 8210.

The American Nurses Association’s accreditation refers to recognition of educational activities only and does not imply approval or endorsement of any product of any company displayed in any form during the presentation of educational activities.

Social Workers: This program has been approved for .2 CEU’s by the National Association of Social Workers, and may be used to meet some of the continuing education requirements for Social Work Licensure/Certification renewal.

Note: There will be a $10 fee for social workers that must be mailed to request a CEU certificate. Information will be provided on the day of the program.

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The following faculty indicated no significant relationship with commercial supporters:

Rosalind C. Kalb, PhD; Marie A. Namey, RN, MSN; Dorothy E. Northrop, MSW, ACSW; Randolph B. Schiffer, MD
Faculty

Randolph Schiffer, M.D.
Dr. Schiffer has had a career-long interest in understanding and treating the behavioral disorders associated with neurologic diseases, especially multiple sclerosis. He was Professor of Neurology, Psychiatry, and Environmental Medicine at the University of Rochester before becoming the Chair of the Department of Neuropsychiatry and Behavioral Sciences at Texas Tech University Health Sciences Center in Lubbock, Texas, where he is attempting to facilitate a practical integration of neurology and psychiatry. Dr. Schiffer has published numerous articles on the diagnosis and treatment of depression and other affective disorders in multiple sclerosis. In addition, he was a member of the core planning group of the copolymer 1 project, and has served on the Medical Advisory Committee of the National Multiple Sclerosis Society, as well as several grant review committees.

Marie Namey, RN, MSN
Marie A. Namey received her Master of Science degree in nursing from Frances Payne Bolton School of Nursing at Case Western Reserve University. She received her Bachelor of Science degree in nursing from Villa Maria College in Erie, Pennsylvania. She has been part of the interdisciplinary team at the Mellen Center for Multiple Sclerosis Treatment and Research at the Cleveland Clinic Foundation since its inception in 1985. Ms. Namey is a member of her local National MS Society chapter’s Clinical Advisory Committee and the Chapter Programs Committee. She is also a member of professional advisory groups for pharmaceutical companies. Ms. Namey has published numerous articles on MS nursing care, focusing primarily on bladder and bowel management and treatment adherence, and is on the Editorial Board for Real Living with MS. Ms. Namey is currently President for the Consortium of MS Centers (CMSC), having already served as Vice President and Secretary, each for one year, and Chairman of the Education and Abstract Review Committees for two years.
Dorothy Northrop, MSW, ACSW

Dorothy Northrop recently joined the National Multiple Sclerosis Society (NMSS) as Director of Clinical Programs in the Clinical Programs Department in New York. Prior to coming to the Home Office, Ms. Northrop was Director of Chapter Services of the Greater North Jersey Chapter of the NMSS for five and one-half years. She is a licensed social worker in the state of New Jersey. Ms. Northrop received her B.A. in Sociology from the University of Massachusetts and her Masters Degree in Social Work from Columbia University in New York City. She specialized in the field of child welfare and family services prior to her position with the Greater North Jersey Chapter. Ms. Northrop serves as a social work consultant to community home health care agencies, and is a member of the Multiple Sclerosis Medical Advisory Council of Merck-Medco Managed Care. In 1999 she was appointed to the Advisory Board of the Office of Disability Services of Bergen County, New Jersey.

Rosalind Kalb, PhD

Rosalind Kalb is a clinical psychologist at the MS Care Center at St. Agnes Hospital in White Plains, New York, and a Clinical Assistant Professor of Neurology at New York Medical College. She is also Director of Information Resources for the National Multiple Sclerosis Society, developing educational materials for both professional and lay audiences. Dr. Kalb has authored or edited a number of publications about multiple sclerosis. She wrote Families Affected by Multiple Sclerosis: Disease Impacts and Coping Strategies, a monograph published in 1995 by the National MS Society, and is the senior author of the Knowledge is Power series for individuals newly diagnosed with MS, published by the National MS Society in 1998. Dr. Kalb has edited two books—Multiple Sclerosis: A Guide for Families, published in 1998, and Multiple Sclerosis: The Questions You Have, The Answers You Need (2nd ed.), published this year.
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Clinical Vignettes

Karen

Karen, a 35-year-old special education teacher, is married with a four-year-old daughter. Following her daughter's birth, Karen experienced an episode of optic neuritis that resolved without treatment. She was told at that time that she might have MS. Two months ago, Karen was given a definite diagnosis of relapsing-remitting MS following an episode involving impaired balance and weakness on her right side that was treated with high-dose intravenous steroids. Her balance remains somewhat impaired, and Karen is currently on medical leave from her teaching job.

During the three-and-a-half years between her first and second episodes, Karen had decided that the doctor must be wrong—that she could not possibly have MS. She was, after all, a healthy and energetic woman who had always been very conscientious about taking care of herself. With the second episode, and the confirmation of the diagnosis, Karen became very distraught. Now she seems to cry a lot and worries constantly about how she is going to be able to take care of her family and get back to the job she needs and enjoys. Keeping up with her active daughter and her students had been hard enough before the MS came along. Karen also feels guilty that her husband is having to take on so many extra chores in addition to his difficult job. With all this turmoil, she finds it hard to sleep at night even though the MS seems to be making her extremely fatigued.

Karen's doctor has recommended that she begin treatment with one of the disease-modifying medications, but Karen doesn't feel ready for that. She's never been a believer in taking a lot of medicines and doesn't think she's “bad enough” to need all those injections. Besides, she's scared of needles. She read on the Internet about some herbal treatments that “work really well in MS” and she's going to stick with those for now. She and her husband had been planning to have a second child relatively soon and wanted to be sure she was not taking anything that would interfere with that. In the meantime, however, Karen has started to think that having another child may not be realistic, particularly since she has not been interested in having sex in weeks. She feels disgusted with her body and cannot imagine why her husband would want to get anywhere near her.

Since Karen remains somewhat unsteady on her feet, especially when she’s tired, the doctor has prescribed a cane to help with her balance. She has not used the cane because she doesn't want people staring at her all the time—she would be too embarrassed. She uses the wall or the furniture if she needs to catch her balance.
Karen’s husband Steve is starting to feel pretty overwhelmed himself. He doesn’t want to upset Karen by talking about it, but he’s really worried about being able to handle the extra work at home on top of everything that has been going on at work. He’s also concerned about what will happen if Karen can’t get back to work. Steve has never mentioned it to Karen, but he knows someone at work whose father ended up in a nursing home because of his MS. Steve isn’t sure he would be able to handle it if she ended up in a wheelchair.

**David**

David is a 50-year-old divorced accountant who lives alone. Originally diagnosed with relapsing-remitting MS at age 35, David had no major problems until three years ago, when his MS became secondary-progressive. At that point he started using a cane to compensate for his weakness and fatigue, and began experiencing increasing spasticity. He was given medication to relieve the spasticity and started on one of the injectable disease-modifying agents. At the same time, David developed some problems with his bladder, including urinary urgency and frequency. Having had two bladder accidents, he now wears a protective pad whenever he goes out of the house, and looks for the nearest bathroom any time he goes to an unfamiliar place. David has been reluctant to discuss the urinary problems with the neurologist or the nurse because he finds it too embarrassing. Recently, however, he participated in a National MS Society on-line educational program and learned about treatment strategies for the common bladder symptoms in MS. He called the National MS Society to request some literature on bladder symptoms so he’d be more prepared to discuss them during his next visit to the doctor.

David’s MS has progressed to the point where he needs bilateral support for walking. Although he has fallen a few times, he is unwilling to switch from forearm crutches to a motorized scooter. While the scooter would reduce his fatigue and enable him get around much more safely and easily, David is afraid that it would make him look more disabled. He doesn’t want to use any mobility device that would threaten his job or cause his colleagues in the accounting firm to lose confidence in him. He’s also concerned that using a scooter would interfere with his ability to meet women. He is convinced that no woman would want to go out with someone who uses a scooter (or wears a diaper, for that matter). Besides, David is sure that if he started using a scooter, he would lose his ability to walk. Once an active outdoorsman, David clings to the hope that he will one day be able to resume the hunting, fishing, and sports activities that were so important in his life.

In addition to his physical problems, David is worried that he’s not able to think the way he used to. He has always prided himself on being highly organized, as well
as a sharp, decisive thinker who did a good job for his clients. Lately, he’s been making mistakes at work and can’t seem to get himself organized. He’s begun to feel as though it’s all slipping away from him. David wonders if that is why he has been feeling so irritable and angry all the time. He used to be a pretty even-tempered individual, but lately has been experiencing episodes of rage that seem totally out of proportion to the situation. He has begun to yell at other drivers and has been known to lose control of his temper in other situations as well. David has started to wonder if he’s losing his mind. When he mentioned his concerns to the doctor, she suggested he consult a psychiatrist. David keeps putting off making the phone call because he feels he should be able to handle these problems on his own. Having his body fall apart is bad enough, he’s determined not let MS wreck his mind as well.
DISEASE OVERVIEW

- Pathophysiology
- Etiology
- Epidemiology
- Disease Course Classifications
- Diagnosis
- Symptoms
- Prognosis
- Treatment
Pathophysiology

Multiple sclerosis is a chronic neuroimmunologic disease of the central nervous system (CNS)—the brain, spinal cord, and optic nerves. Random attacks of inflammation (also called relapses or exacerbations) damage the myelin sheath (the fatty insulating substance surrounding nerve fibers in the white matter of the brain and spinal cord) causing scarring (also called plaques or lesions). The name multiple sclerosis comes from the multiple areas of scarring that characterize the disease process. The inflammatory attacks—along with the scarring they produce—occur randomly, varying widely in number and frequency from one person to another. The scars along the myelin sheath interfere with the transmission of nerve impulses, thereby producing the symptoms experienced by people with MS. Because of the randomness of the plaques within the CNS, no two people with MS will have exactly the same symptoms.

Until recently, it was believed that any damage to the nerve fibers (axons) themselves was secondary and less substantial than the damage to the myelin sheath. A recent study (Trapp et al., 1998), however, provided new evidence that the nerve fibers (axons) can become irreversibly damaged as a consequence of the immune system’s attacks on myelin and the inflammation that occurs. This irreversible axonal loss, which can occur even in the earliest stages of the disease, may be a major cause of the persistent neurologic deficits in multiple sclerosis. Thus, symptoms may become permanent when the ability to conduct nerve impulses is lost. In light of this new information, medical experts in multiple sclerosis recommend early intervention with one of the available disease-modifying agents. See a summary of the “Consensus Statement” in this book (page 38) for specific recommendations in the U.S.

Etiology

While the precise cause of MS is still unknown, decades of research indicate that multiple sclerosis may be the result of an abnormal autoimmune response to some infection or environmental trigger in a genetically susceptible individual. Each of these factors—immunologic, environmental, infectious, and genetic—is the subject of intensive ongoing research.

Immunologic

MS is thought to be an autoimmune disease, in which the body’s immune system attacks apparently healthy tissues (i.e., the myelin sheath surrounding the nerve
fibers and the nerve fibers themselves) in the CNS. The exact antigen (the target that the immune cells are sensitized to attack) remains unknown. Recently, however, researchers have been able to identify which immune cells are mounting the attack, how these cells are activated to attack, and some of the sites on the attacking cells that seem to be attracted to the myelin to begin the destructive process. Researchers are looking for highly specific immune modulating therapies to stop this abnormal immune response without harming normal immune cells.

**Environmental**

Migration patterns and epidemiologic studies (that take into account variations in geography, socioeconomics, genetics, and other factors) have demonstrated that people who are born in an area of the world with a high risk of MS, and move to an area with a lower risk before 15 years of age, acquire the risk level of their new home. These data suggest that exposure before puberty to some environmental agent may predispose a person to develop MS.

**Infectious**

While researchers do not yet know what factors within the environment cause MS to become active, most believe that some unidentified infectious agent—either viral or bacterial—is responsible. Although dozens of viruses and bacteria have been investigated to determine if they are involved in the development of MS, we still do not know which, if any, might be the culprit.

**Genetic**

MS is not hereditary—like hair or eye color, for example. Support for this conclusion comes from the fact that an identical twin of a person with MS has only a 30 percent chance of developing MS rather than a 100 percent chance. However, a person who has a first-degree relative (e.g., a parent or sibling) with MS, has a significantly greater risk of developing MS than a person with no MS in the family. While the risk of MS in the general population is 1/1000, the risk for a person with a family member who has MS is 2–5/100. This means that the child of a parent with MS is 20–50 times more likely to develop MS than a child who does not have a parent with MS. Scientists theorize that MS develops in individuals who are born with a genetic predisposition to react to some environmental agent. Exposure to that agent then triggers the autoimmune response. Research has demonstrated a higher prevalence of certain genes in populations with high rates of MS. Common genetic factors have also been found in some families where there is more than one person with MS.
Epidemiology

MS is typically diagnosed between the ages of 20 and 40. Although 90 percent of people are diagnosed between the ages of 16 and 60, MS can develop in infancy or well after the age of 60. MS is more common in women than men by a ratio of 2–3:1, and appears more frequently in Caucasians (particularly of northern European ancestry) than in Hispanics or African-Americans. The disease is relatively rare among Asians and certain other groups. MS is more prevalent in temperate areas of the world and relatively rare in the tropical areas closer to the equator. At the present time, it is estimated that there are more than 400,000 people with MS in the United States and Canada.

Disease Course Classifications

The charts on the following pages describe the results of an international survey of disease patterns in MS conducted by Fred D. Lublin, M.D. and Stephen C. Reingold, Ph.D. (1991).

It is important to keep in mind that these disease categories serve primarily as a tool for the development of clinical research protocols, and as a guide for certain types of treatment decisions. The disease categories became a focus of attention for people with MS when they were used by researchers to describe participants in the clinical trials of Avonex™, Betaseron®, Copaxone®, and Rebif®, and then by insurance companies, to determine a person’s eligibility for reimbursement of these drugs. Although the categories have come to play a significant role in MS research and management decisions, they were designed to be descriptive in nature rather than a “report card” or rating scale of a person’s disease. A particular individual may not fit neatly into one category or another. The categories can, however, provide people with MS and their healthcare providers with a useful guide to treatment options.
Relapsing-Remitting MS (RRMS)

RRMS characterized by clearly defined acute attacks with full recovery (Figure 1a) or with residual deficit upon recovery (Figure 1b). Periods between disease relapses are characterized by a lack of disease progression. Approximately 70–75 percent of people are diagnosed initially with *relapsing-remitting* MS.

Secondary-Progressive MS (SPMS)

SPMS begins with an initial relapsing-remitting disease course, followed by progression of variable rate (Figure 2a) that may also include occasional relapses and minor remissions and plateaus (Figure 2b). Of the 70–75 percent who start with relapsing-remitting disease, more than 50 percent will develop SPMS within 10 years; 90 percent within 25 years.
**Primary Progressive MS (PPMS)**

PPMS is characterized by progression of disability from onset, without plateaus or remissions (Figure 3a) or with occasional plateaus and temporary minor improvements (Figure 3b). Fifteen percent of people are diagnosed with PPMS.

**Progressive-Relapsing MS (PRMS)**

PRMS, which is the least common disease course, shows progression from onset but with clear acute relapses, with (Figure 4a) or without (Figure 4b) full recovery. Approximately 6–10 percent of people appear to have PRMS at diagnosis.

Diagnosis

There is no single test that can determine whether a person has MS. The diagnosis is a clinical one, made on the basis of medical history, signs detected by the physician during a neurologic exam, and symptoms reported by the patient. A definitive diagnosis of MS requires the following:

- Evidence of plaques or lesions in two distinct areas of the CNS.
- Evidence that the plaques occurred at discrete points in time.
- The plaques in the white matter of the CNS have no explanation other than MS.

Because there is no specific test for MS, and the time between attacks can range from months to years, the diagnostic process can be a long and frustrating one. In addition, the symptoms are so variable and sometimes so subjective, that people’s complaints may be ignored or misinterpreted as “psychiatric.” Although the advent of magnetic resonance imaging (MRI) has greatly facilitated the diagnostic process, MRIs of the brain are abnormal in only 90 percent of people with MS. They can therefore be used only as confirmatory evidence of MS. Other tests used to confirm the diagnosis and/or rule out other problems include visual or somatosensory evoked potentials and a lumbar puncture.

Symptoms

As a result of the inflammatory process in the CNS, people with MS can experience a variety of neurologic symptoms, the most common being: fatigue, visual disturbances, spasticity, weakness, imbalance, sensory changes, pain, bladder and/or bowel dysfunction, sexual dysfunction, speech impairment (*dysarthria*), swallowing problems (*dysphagia*), emotional changes, and cognitive impairment. In a large (*N* = 697), population-based survey of individuals with MS (Aronson et al., 1996), the following symptoms were reported:

- Fatigue—88%
- Ambulation problems—87%
- Bowel/bladder problems—65%
- Visual disturbances—58%
- Cognitive problems—44%
- Tremor—41%
- Movement problems in the arms—41%
The consensus from other studies is that more than 50 percent of people with MS will experience some degree of cognitive dysfunction (Rao et al., 1991). A recent prevalence study found that 73.1 percent of people with MS reported sexual dysfunction (Zorzon, 1999). Studies of depression in MS indicate that 50 percent of people with MS will experience a major depressive episode at some point over the course of the disease—a higher prevalence than is seen in other, equally disabling chronic illnesses, perhaps resulting in part from the disease process itself (Rabins et al., 1986; Minden, 1987).

**Prognosis**

Although prognosis in MS is uncertain, there are certain factors that seem to predict a more favorable course:

- Female gender
- Onset before age 35
- Monoregional (single area of CNS involvement) vs. polyregional (multiple areas) attacks early in the illness
- Complete recovery after an exacerbation, leaving little or no residual impairment

Factors that tend to be associated with a poor prognosis include:

- Male gender
- Onset after age 35
- Brainstem symptoms such as *nystagmus*, tremor, *ataxia*, and *dysarthria*
- Poor recovery following exacerbations
- Frequent attacks
- Primary progressive course
Treatment

Treatment strategies in MS fall into five general categories:

1. Treatment of acute exacerbations (attacks)
2. Symptom management
3. Disease modification
4. Rehabilitation (to enhance and maintain physical function)
5. Psychosocial support

Categories 1–4 will be summarized here. Category 5, the subject of this teleconference, is covered in the remainder of the book.

Treatment of Acute Exacerbations

Although the exact protocol may differ, most neurologists use a high-dose intravenous (IV) corticosteroid agent such as methylprednisolone. Most commonly used is a 3- to 5-day course of treatment, either in the hospital or as an outpatient, which may or may not be followed by a gradually tapering dose of an oral corticosteroid such as prednisone. Steroids work to decrease acute inflammation in the CNS, but have no long-term benefits in MS. Many people feel better while taking steroids, in part because steroids can sometimes have a mood-elevating effect. The chronic use of steroids, however, causes serious side effects including hypertension, diabetes, bone loss (osteoporosis), cataracts, and ulcers.

Short courses of steroids tend to be well-tolerated by most people. Mood changes, however, are relatively common, with people reporting feeling “high,” energetic, and unable to sleep, and/or depressed, particularly as they come off the medication. A small percentage of people may experience quite severe disturbances in mood or behavior. Lithium, divalproex (Depakote®), and carbamazepine (Tegretol®) have all been shown to be effective in preventing or managing these symptoms. Patients should be alerted to these potential side effects before taking corticosteroids, and reminded that a person can react very differently to corticosteroids from one course to the next.

Symptom Management

Table 1 presents the symptoms of MS, the treatments recommended to manage them, and the potential emotional and social impact of these symptoms on people's lives.
### Table 1. Symptoms of MS: Their Treatments and Psychosocial Impact

<table>
<thead>
<tr>
<th>SYMPTOM</th>
<th>TREATMENT</th>
<th>PSYCHOSOCIAL IMPLICATIONS</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Ambulation Problems</strong></td>
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<tr>
<td>• Spasticity</td>
<td>See: Spasticity</td>
<td>See: Spasticity</td>
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<tr>
<td>• Impaired balance</td>
<td>Mobility aids and exercise</td>
<td>Resistance to use of mobility aids:</td>
</tr>
<tr>
<td>• Weakness</td>
<td>Mobility aids and exercise</td>
<td>• Perceptions of self: damaged, weak; giving in</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Others’ perceptions: less intelligent; less competent</td>
</tr>
<tr>
<td><strong>Bladder Dysfunction</strong>*</td>
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<tr>
<td>• Failure to store (urgency,</td>
<td>Anti-cholinergic agents (oxybutynin—Ditropan®; hyoscyamine sulfate—Pro-Banthine®), or anti-muscarinic agents (tolterodine—Detrol®); scheduled voiding; avoidance of diuretics</td>
<td>Fear of drinking liquids; anxiety over loss of control; fear of leaving vicinity of bathroom; embarrassment/shame; fear of incontinence during intercourse; increased fatigue due to interrupted sleep</td>
</tr>
<tr>
<td>frequency, incontinence,</td>
<td>Intermittent self-catheterization (ISC); may require indwelling catheter</td>
<td>Anxiety about loss of control; fear of ISC</td>
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<td>nocturia)</td>
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<td>Same as above</td>
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<td>• Failure to empty (urgency,</td>
<td>Combination of the above</td>
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<td>hesitancy, double voiding,</td>
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<td>feelings of incomplete</td>
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<td>emptying)</td>
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<td>• Combined failure to store/failure to empty</td>
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<td><strong>Bowel Dysfunction</strong>*</td>
<td>Bowel training; high-fiber diet; digital stimulation; exercise; medication (e.g., softeners, mild laxatives, mini-enemas)</td>
<td>Discomfort; exacerbation of spasticity</td>
</tr>
<tr>
<td>• Constipation</td>
<td>Manual disimpaction</td>
<td>Discomfort; embarrassment</td>
</tr>
<tr>
<td>• Fecal impaction</td>
<td>Disimpact and relieve constipation</td>
<td>Discomfort; embarrassment</td>
</tr>
<tr>
<td>• Diarrhea (usually from</td>
<td>Bowel program; anti-cholinergic medication (for hyperreflexic bowel)</td>
<td>Loss of control; anxiety about leaving home/being around others; shame</td>
</tr>
<tr>
<td>constipation)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Fecal incontinence</td>
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</tbody>
</table>
Table 1. Continued

<table>
<thead>
<tr>
<th>SYMPTOM</th>
<th>TREATMENT</th>
<th>PSYCHOSOCIAL IMPLICATIONS</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Cognitive Symptoms</strong>*</td>
<td><strong>Non-medical:</strong> cognitive rehabilitation</td>
<td><strong>Individual:</strong> denial; anxiety; loss of self-esteem/self-confidence; depression; may interfere with self-care and independence.</td>
</tr>
<tr>
<td>• Memory impairment</td>
<td>• Restorative approach: direct retraining exercises (have only limited benefit for daily activities)</td>
<td><strong>Interpersonal:</strong> family strain; marital strain; impaired communication; role shifts within the family</td>
</tr>
<tr>
<td>• Impaired attention/concentration</td>
<td>• Compensatory approach: aims to improve function via substitution of compensatory strategies/tools for the impaired function</td>
<td><strong>Employment:</strong> major cause of high unemployment rate in people with MS</td>
</tr>
<tr>
<td>• Slowed processing speed</td>
<td><strong>Medical:</strong> donepezil hydrochloride—Aricept® may be useful; disease-modifying agents may be beneficial</td>
<td><strong>Healthcare:</strong> may affect communication with providers and compliance with treatment</td>
</tr>
<tr>
<td>• Impaired executive functions</td>
<td>Non-medical:** naps; moderate aerobic exercise; work simplification; use of assistive devices (e.g., electric scooter); cooling strategies/devices</td>
<td><strong>Individual:</strong> denial; anxiety; loss of self-esteem/self-confidence; depression; may interfere with self-care and independence.</td>
</tr>
<tr>
<td>• Impaired spatial relations</td>
<td><strong>Medical:</strong> amantadine; pemoline—Cylert®; modafinil—Provigil®; fluoxetine—Prozac®</td>
<td><strong>Interpersonal:</strong> family strain; marital strain; impaired communication; role shifts within the family</td>
</tr>
<tr>
<td>• Impaired word-finding ability</td>
<td></td>
<td><strong>Employment:</strong> major cause of high unemployment rate in people with MS</td>
</tr>
</tbody>
</table>

*Note: Cognitive deficits are often missed in a standard neurologic exam*

**Fatigue***

- **Primary** (neurologic): overwhelming lassitude or tiredness that can strike at any time of day
- **Secondary:** resulting from disturbed sleep; depression; extra exertion due to impairments; medications

<table>
<thead>
<tr>
<th>SYMPTOM</th>
<th>TREATMENT</th>
<th>PSYCHOSOCIAL IMPLICATIONS</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Non-medical:</strong> naps; moderate aerobic exercise; work simplification; use of assistive devices (e.g., electric scooter); cooling strategies/devices</td>
<td></td>
<td><strong>Inability to carry out activities at home and at work; fatigue of this magnitude is depressing; invisible symptom that is easily misinterpreted by others</strong></td>
</tr>
<tr>
<td><strong>Medical:</strong> amantadine; pemoline—Cylert®; modafinil—Provigil®; fluoxetine—Prozac®</td>
<td></td>
<td></td>
</tr>
<tr>
<td>SYMPTOM</td>
<td>TREATMENT</td>
<td>PSYCHOSOCIAL IMPLICATIONS</td>
</tr>
<tr>
<td>---------</td>
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</tr>
<tr>
<td><strong>Sensory Problems/Pain</strong>*</td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Sensory symptoms (from loss of myelin): numbness, tingling</td>
<td>No treatment required unless bothersome; medication if necessary</td>
<td>Anxiety; discomfort; clumsiness; fatigue increased by medications and interrupted sleep</td>
</tr>
<tr>
<td>• Primary pain (from loss of myelin):</td>
<td></td>
<td>Medications increase fatigue</td>
</tr>
<tr>
<td>• trigeminal neuralgia (sharp facial pain);</td>
<td></td>
<td></td>
</tr>
<tr>
<td>• dysesthesias (electric shock-like sensations in trunk or extremities);</td>
<td></td>
<td></td>
</tr>
<tr>
<td>• retro-orbital pain (with optic neuritis)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Secondary pain (musculoskeletal): resulting from poor posture/balance in ambulatory individuals or improper use/fitting of wheelchair</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Medications: gabapentin—Neurontin®; carbamazepine—Tegretol®; phenytoin—Dilantin®, baclofen—Lioresal®; Surgery</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Medications (same as above, or topical application of capsaicin cream)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>High-dose IV steroids</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Analgesics; gait training; wheelchair assessment; exercise</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Note: People often told by doctors that MS does not cause pain</td>
<td></td>
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</tbody>
</table>

*Note: Some people may experience sensory symptoms without sensory problems.
**Table 1. Continued**

<table>
<thead>
<tr>
<th>SYMPTOM</th>
<th>TREATMENT</th>
<th>PSYCHOSOCIAL IMPLICATIONS</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Sexual Dysfunction</strong>*</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
| *Primary* (result of neurologic impairment): impaired arousal, sensory changes, reduced vaginal lubrication, erectile dysfunction, inability to reach orgasm | Evaluation of medications that might be interfering with sexual function  
*Men:* Oral medication (sildenafil—Viagra®); injectable or insertable medication (alprostadil—Prostin VR®, Muse®), prosthetic devices  
*Women:* lubricating substances; enhanced stimulation | *Individual:* Significant impact on gratification, self-esteem, self-confidence; difficult/embarrassing to discuss with healthcare providers  
*Interpersonal:* Significant impact on all intimate relationships:  
- Sexual activity can be difficult, exhausting, painful, and unsatisfying  
- Lack of arousal can be misunderstood and resented by partner  
- Learning new ways to be intimate can be frightening and difficult  
- Caregivers may become disinterested in, or uncomfortable with, their disabled partner  
- Person with MS may be reluctant to become intimate with new partner |
| *Secondary* (resulting from other MS symptoms): fatigue, spasticity, bladder/bowel problems, sensory changes interfere with sexual activity. | Effective management of MS symptoms to reduce impact on sexual function |                                                                 |
| [Note: Impaired arousal, erectile dysfunction, and inability to orgasm can also result from medications taken to relieve other symptoms, most notably antidepressants] | Individual and couple’s counseling and education |                                                                 |
| *Tertiary* (resulting from disability-related attitudes/feelings): feeling unattractive; unable to attract a partner; believing that sexuality is incompatible with disability | | |
### Table 1. Continued

<table>
<thead>
<tr>
<th>SYMPTOM</th>
<th>TREATMENT</th>
<th>PSYCHOSOCIAL IMPLICATIONS</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Spasticity</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Phasic spasms (flexor or extensor)</td>
<td>1. Rehabilitative PT (stretching)</td>
<td>Oral medications increase fatigue and weakness</td>
</tr>
<tr>
<td>• Sustained increase in muscle tone</td>
<td>2. Oral medications (baclofen—Lioresal®; tizanidine—Zanaflex®; diazepam—Valium®)</td>
<td>Surgical implantation of pump in abdomen can be frightening</td>
</tr>
<tr>
<td>Spasticity can range from relatively mild to quite severe, and treatment is approached in a step-wise fashion. Note: Some degree of spasticity may be required to support weakened limbs</td>
<td>3. Intrathecal baclofen pump</td>
<td>Severing of tendons is irreversible</td>
</tr>
<tr>
<td></td>
<td>4. Surgery</td>
<td></td>
</tr>
<tr>
<td><strong>Speech/Swallowing Problems</strong></td>
<td>Assessment, exercise program, training with augmentative or alternative communication devices, if needed.</td>
<td>Slurring can be misinterpreted as drunkenness or lack of intelligence</td>
</tr>
<tr>
<td>• <em>Dysarthria</em>: poorly articulated, slurred speech</td>
<td>Assessment, exercise program, modified diet, non-oral feeding strategies, if needed.</td>
<td>Slow, slurred speech interferes with communication</td>
</tr>
<tr>
<td>• <em>Dysphagia</em>: difficulty in swallowing that can lead to aspiration and/or inadequate nutrition</td>
<td></td>
<td>Fear of loss of control, choking</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Food needs to be blenderized</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Eating is exhausting</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Loss of pleasurable mealtimes</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Loss of ability to eat orally</td>
</tr>
<tr>
<td><strong>Tremor</strong></td>
<td><em>Nonmedical</em>: balance/coordination exercises; weights on limbs or utensils</td>
<td>Fear of loss of control—severe tremor is a major threat to independence</td>
</tr>
<tr>
<td>• Involuntary movements of the arms, legs, or head; tremor can be the least treatable and most debilitating symptom of MS</td>
<td><em>Medical</em>: Medications (propranolol—Inderal®; clonazepam—Klonopin®; primidone—Mysoline®; isoniazid—Laniazid®; buspirone—BuSpar®; ondansetron—Zofran®)</td>
<td>Medications can increase fatigue</td>
</tr>
</tbody>
</table>
Disease-Modifying Treatments

Relapsing-Remitting Disease
There are currently four injectable drugs that have been shown in clinical trials to be effective in the treatment of relapsing-remitting MS. Of these, interferon beta 1a (Rebif®) is approved only in Canada and Europe, while interferon beta 1a (Avonex®), interferon beta 1b (Betaseron®), and glatiramer acetate (Copaxone®) have all been approved for use in the United States (See Table 2). While these drugs are neither a cure for the disease, nor designed to make people feel better, they have each been shown to slow or modify the course of the disease.

- Betaseron® has been shown in clinical trials to reduce the frequency and severity of exacerbations and reduce new or active lesions on MRI.
- Avonex® has been shown to reduce the frequency of relapses, reduce new or active lesions on MRI, and may slow disease progression.
### Table 2. Disease-Modifying Treatments for Relapsing-Remitting MS

<table>
<thead>
<tr>
<th>BRAND AND GENERIC NAME</th>
<th>MANUFACTURER/DISTRIBUTOR</th>
<th>APPROVAL</th>
<th>FREQUENCY/ROUTE OF DELIVERY</th>
<th>COMMON SIDE EFFECTS</th>
<th>RETAIL COST, APPROXIMATE</th>
</tr>
</thead>
<tbody>
<tr>
<td>Betaseron</td>
<td>Berlex</td>
<td>1993 US</td>
<td>Every other day; subcutaneous injection</td>
<td>Flu-like symptoms following injection, which lessen over time for many people; injection site reactions, about 5% of which need medical attention. <em>Rarer:</em> elevated liver enzymes, low white blood cell counts</td>
<td>$10,800/year (US)* $17,000/year (Can)</td>
</tr>
<tr>
<td>Interferon beta-1b</td>
<td>Biogen</td>
<td>1995 Can—RRMS 1998 Can</td>
<td>Weekly; intramuscular injection</td>
<td>Flu symptoms following injection, which lessen over time for many people. <em>Rarer:</em> mild anemia, elevated liver enzymes, headache</td>
<td>$11,000/year (US)* $16,970/year (Can)</td>
</tr>
<tr>
<td>Avonex</td>
<td>Teva Marion Partners</td>
<td>1996 US</td>
<td>Daily; subcutaneous injection</td>
<td>Injection site reactions. <em>Rarer:</em> a reaction immediately after injection which includes anxiety, chest tightness, shortness of breath, and flushing. This lasts 5–10 minutes and has no known long-term effects</td>
<td>$10,000/year (US)* $12,300/year (Can)</td>
</tr>
<tr>
<td>Interferon beta-1a</td>
<td>Serono Laboratories</td>
<td>1999 Can—SPMS 1997 Can</td>
<td>Three times per week; subcutaneous injection</td>
<td>Flu symptoms following injection, which lessen over time for many people; injection site reactions. <em>Rarer:</em> elevated liver enzymes, low white blood cell counts</td>
<td>$17,000/year (Can)—lower dose $21,000/year (Can)—higher dose</td>
</tr>
<tr>
<td>Copaxone</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Glatiramer acetate</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Rebif</td>
<td></td>
<td>1998 Can</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Interferon beta-1a</td>
<td></td>
<td></td>
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</table>

*source: www.drugstore.com*
Copaxone® has been shown to reduce the frequency of exacerbations and number of new or active lesions on MRI. An oral form of this drug is currently being evaluated in a large-scale clinical trial.

Rebif® has been shown to reduce attack frequency, reduce new or active lesions on MRI, and may slow progression of disability. The FDA has ruled, under the Orphan Drug Law, that Rebif® cannot be marketed in the US until 2003 because it has not been shown to be sufficiently different from Avonex®. A head-to-head trial, sponsored by the makers of Rebif®, is currently underway.

Progressive Disease

To date, there have been no drugs approved in the United States for treatment of primary- or secondary-progressive disease.

Betaseron® has been approved for treatment of secondary-progressive MS in Canada and Europe, following a successful European trial. In a North American trial for secondary-progressive disease, Betaseron® was found to be no more effective than the placebo in slowing progression of disability (the primary outcome measure for the study). The FDA will evaluate the findings from both of these studies to determine whether the drug should be approved for secondary-progressive disease in the US.

Avonex® is currently being studied in trials for primary-progressive and secondary-progressive MS.

Copaxone® is currently being evaluated in a large-scale primary-progressive trial.

Rebif® did not have a positive effect on progression in its secondary-progressive trial, and its approval for treatment of secondary-progressive MS in Canada is still in question.

Mitoxantrone (Novantrone®—a potent immunosuppressant already approved for use in adult myeloid leukemia) was shown in secondary-progressive trials to slow progression of disability, reduce the relapse rate, and reduce the numbers of inflammatory lesions in the brain. FDA approval is expected shortly.

Other immunosuppressive agents, including azathioprine (Imuran®), cladribine (Leustatin®), cyclophosphamide (Cytoxan®), and methotrexate are also used to treat progressive disease. Since chemotherapies such as these are associated in people’s minds with cancer, they tend to be viewed with a great deal of anxiety. People resist the idea that their MS is “as bad as cancer,” and have a genuine fear of the side effects. Although the dosages used in MS are significantly lower than those used for cancer treatment, the short-term side effects (e.g., nausea,
hair loss) and the long-term side effects (e.g., sterility, cardiotoxicity, liver toxicity) are valid concerns. The role of medical and mental health professionals is to assist people to weigh their options and make informed decisions on their own behalf.

The Role of Early Intervention

Based on clinical experience with the disease-modifying agents, Betaseron®, Avonex®, and Copaxone®, and the results of recent studies confirming that early relapses can cause permanent axonal damage as well as destruction of myelin, the National MS Society Medical Advisory Board supports early intervention with one of these agents. The Consensus Statement by the Medical Advisory Board recommends that:

- Therapy with one of the three drugs should be started as soon as the diagnosis of relapsing-remitting MS is confirmed.
- Therapy should be continued indefinitely unless there is clear lack of benefit, intolerable side effects, or a better therapy is identified.

Adherence to the Disease-Modifying Therapies

The challenge to medical and mental health providers is to support the patient’s optimism and hope for a benign disease course while emphasizing the potential benefit of early treatment for a disease that is chronic, unpredictable and largely invisible. At the present time, only 70,000 of the 350,000 individuals with MS are receiving treatment with one of the three disease-modifying agents. A recent study by the North American Research Committee on Multiple Sclerosis (NARCOMS) found that one third of people stopped treatment within the first nine months. The major obstacle to long-term use of these treatments was the perceived lack of effectiveness as evidenced by the fact that the symptoms stayed the same or got worse. These therapies are known to be partially effective—i.e. they slow disease progression but do not stop progression or cure the disease. This means that people are stopping the medications because they do not understand why they are taking them in the first place. They start with unrealistic expectations, and stop in frustration when those expectations are not met. Based on these findings, the researchers recommend improved education for people with MS and their families in order to bring their expectations more in line with those of their physicians. They further recommend careful monitoring by healthcare providers, in order to address patients’ concerns, clarify misconceptions, and manage side effects (NARCOMS, 1999).
It has been demonstrated that interventions to promote adherence will be more effective if they match the patient's readiness for change (Cassidy, 1999). The Transtheoretical Model of Behavior Change as it applies to MS comprises several stages. While this is essentially a nursing model, the principles are basically the same for mental health providers working with persons with MS.

1. **Pre-contemplative stage:** The newly-diagnosed patient is not yet contemplating treatment (“I’m not sick enough for that yet”). The provider’s role is to explore the patient's understanding of MS, personal beliefs about therapy, and perceived obstacles to starting therapy in an effort to foster awareness of the disease and understanding of his/her personal barriers to treatment.

2. **Contemplative stage:** The patient is actively considering therapy but with some ambivalence. The provider’s role is to educate with a focus on anticipated benefits, the risks associated with no treatment, and a clarification of the patient's goals.

3. **Preparation stage:** The patient expresses a determination to start treatment within the next month and together with the physician and nurse, chooses the most appropriate of the three available drugs. The provider’s role is to work with the patient to develop a treatment regimen, address financial arrangements, and establish a support system.

4. **Action stage:** The patient is engaging in therapy with one of the three agents. The provider’s role is to be available to address concerns, problem-solve, and provide continuing support.

5. **Maintenance stage:** Patients strive to adhere to commitment to treatment. The provider’s role is to provide continued support and follow-up, reinforce realistic expectations, and repeat the intervention stages in the event that the patient goes off therapy (Cassidy, 1999).

**Rehabilitation**

Although we now have disease-modifying therapies available to help slow the progression of multiple sclerosis, most people with MS will continue to have limitations. Rehabilitation in MS involves the intermittent or ongoing use of multidisciplinary strategies to promote functional independence, prevent complications, and enhance overall quality of life. It is an active, constantly evolving process directed toward helping the person recover and/or maintain the highest possible level of functioning and realize his or her optimal physical, mental, and social potential given any limitations that exist.
Rehabilitation specialists target the following impairments in their work with individuals with MS: spasticity, movement disorders, weakness, imbalance, fatigue, paralysis, bowel and bladder problems, sexual dysfunction, visual disturbance, pain, sensory loss, speech and swallowing problems, and cognitive impairment. The goal of these rehabilitation interventions is to reduce “disablement,” as defined by the World Health Organization (WHO) in the International Classification of Impairments, Activities, and Participation: A Manual of Dimensions of Disablement and Health (ICIDH-2). Disablement is an umbrella term used to describe the consequences of any health condition (disease, disorder, or injury) on a person’s body structures or functions, personal activities, and participation in society. Although rehabilitation interventions cannot reverse the neurologic damage caused by MS, they can reduce disablement by:

- minimizing the impact of existing impairment(s) on day-to-day functioning
- enhancing the person’s ability to carry out daily activities and participate to the fullest extent possible in all of his or her life roles.

The Unique Role of Rehabilitation in MS

In general medical practice, the skills of rehabilitation professionals are called upon following a patient’s acute injury or illness, with the goal being one of partial or complete recovery. The specialist enters the picture to solve a problem, and leaves when the problem is solved. Rehabilitation specialists have a somewhat different role in a chronic disease like MS. From the time of diagnosis onward—even before the advent of obvious impairment—the rehabilitation specialist can provide education and treatment designed to promote good health and general conditioning, and reduce fatigue. With the progression of the disease, the rehabilitation specialist’s role becomes a more active one involving structured, problem-focused interventions to manage symptoms, enhance function, facilitate activities of daily living, identify appropriate assistive devices and environmental modifications, and prevent injuries and unnecessary complications. While each intervention might be of relatively short duration, the expectation is that the chronic, often progressive nature of MS will necessitate repeated assessments and interventions over the course of the illness.

Restorative and Preventative Goals of Rehabilitation in MS

In multiple sclerosis, rehabilitation has both restorative and preventative goals. *Restorative rehabilitation* is designed to help the person reach his or her highest physical, emotional, and functional level given the limitations imposed by the illness. Thus, individuals who have recently experienced an exacerbation and accom-
panying decrease in functional abilities, may require rehab interventions designed to help them regain as much as possible of their previous functional abilities. While total restoration of function may not be possible, the goal is always to maximize independence, productivity, comfort, and self-care while minimizing the impact of the impairment on the person’s activities and participation.

When multiple sclerosis has a progressive course, rehabilitation interventions are also designed to help people maintain maximal function in the face of disease progression, and prevent injuries and complications resulting from immobility. Remaining stable, or “holding one’s own,” replaces improvement as the targeted outcome. It is important to keep in mind that accepting limitations of function can be emotionally devastating. Mental health professionals may have a critical role to play in helping people with MS modify their expectations and develop realistic goals, while maintaining their self-esteem in the process.
PSYCHOSOCIAL SUPPORT

- An Interdisciplinary Model of Care
- Common Emotional Reactions to MS
- Emotional Changes Observed in MS
- The Role of Stress in MS
- Cognitive Impairment
- Psychosocial Issues Over the Disease Course
- Impact of MS on the Family
- Challenges to Medical and Mental Health Providers
Psychosocial support is the fifth major category of treatment in MS, encompassing:

1. Disease-related education (more recently termed psychoeducation—a supportive educational process designed to enhance people’s understanding of the disease, adaptive coping strategies, and available resources).

2. Diagnosis/treatment of emotional and/or cognitive problems.

3. Family interventions designed to support family members’ efforts to cope with the intrusion of MS into the household.

4. Support for people’s efforts to remain productively employed as long as they are able and interested, and to transition out of the workforce when, and if, it is necessary to do so.

5. Helping individuals with MS and their families to access available resources.

The remaining sections of this book present a model of interdisciplinary psychosocial support, and describe the psychological and social challenges posed by MS as well as the recommended interventions for helping people with MS and their family members to cope with these challenges.

**An Interdisciplinary Model of Care**

Figure 5 presents a working model of interdisciplinary psychosocial support for people with MS and their families. The patient and family are at the center since it is their needs that determine the flow of information and support services over the course of the disease. Within this model, primary psychosocial support for people living with MS comes from two sources—healthcare providers and the National MS Society (NMSS)—and either one of these may be the initial source of information and support services. Some individuals are diagnosed with MS and then call the NMSS for additional information and/or support programs. Others are referred to the NMSS by their physician or given NMSS informational materials before leaving the doctor’s office. Still others, thinking that they or a family member may have MS, contact the NMSS looking for information and a referral to a local physician. The black rectangle connecting the healthcare team and the NMSS conveys the importance of this bi-directional loop: regardless of how the initial contact is made, the goal is for people living with MS to have easy, ongoing access to quality care, accurate information, and adequate support.

The relationship between the healthcare team and the NMSS is a mutually supportive one. Healthcare practitioners can rely on the NMSS for the most current
Professional Resources

Social Worker
- Psychotherapy - individual, family, group
- Social services
- Case management

Psychol./Neuropsychol.
- Cognitive assess./remed. [also by OT, S/L pathol.]
- Psychotherapy - individual, family, group

Psychiatrist
- Assessment
- Medication management
- (Psychotherapy)

Doctor
- Monitoring
- Referrals
- (Counseling)

Nurse
- Monitoring
- Support. Counsel.
- Psycho-education

Patient & Family

Informal Supports

 NMSS
- Information
- Support groups
- Family programs
- Community resources

Personal Network
- Family
- Friends

Community Network
- Religious institutions
- Community agencies/organizations

Figure 5
information about the disease and its treatments; the local chapters of the NMSS can utilize the expertise of area practitioners in the development and implementation of educational programs and materials for people with MS.

As the remainder of this book will describe, psychosocial challenges confronting people with MS are ongoing and complex. As a result, the need for additional support and/or referral to a mental health professional is fairly common. For several important reasons, this need often goes unmet.

1. The presence of emotional and/or cognitive problems often goes unrecognized in standard follow-up visits to the physician. In one study of cognitive function in MS, for example, more than half of the subjects were impaired on standardized neuropsychological testing. When those same individuals were evaluated by a neurologist using a brief “mental status” examination, half of those impaired on testing were rated as “normal” by the neurologist (Peyser et al., 1980). In addition, patients and/or family members may not mention emotional or cognitive difficulties, either out of embarrassment or because they do not know the possible connection between these problems and MS.

2. The individual or family may not have the necessary financial resources or insurance coverage.

3. There may be a lack of professionals in the community who are able or willing to handle these types of problems or these types of patients.

4. The patient may be reluctant to follow up on a referral for support services.

5. There may simply be a lack of communication between the healthcare team, the NMSS, and available professionals in the community.

It is these issues that the model seeks to address by emphasizing communication and collaboration between all the parties involved in MS care.

Referrals to professionals in the community may come from the healthcare team or from the National MS Society. The treating physician and/or the nurse may be the first to identify a psychosocial need. Or, a patient or family member may bring a problem to the attention of the physician or nurse, and request a referral. It is important to keep in mind that mental health services may also be available at MS specialty centers, including member centers of the Consortium of MS Centers (CMSC) or affiliated clinics of the National MS Society. A person whose MS is managed on a routine basis by a non-MS specialist may be referred to an MS specialty center for mental health services because the providers at these centers are familiar with MS and its unique social and psychological challenges.
The solid black arrow to and from the professionals in the community indicates the need for referral as well as ongoing communication. With the patient’s permission, the healthcare team and mental health professional can provide optimum care by staying in contact with one another. Although mental health professionals do not maintain contact with the National MS Society about a particular patient they are seeing, they should keep in mind that the NMSS provides education and support programs that can enhance their clinical efforts. For example, a psychotherapist in the community who is treating a person with MS for depression, or treating a family in which one of the parents has MS, might refer the patient(s) to the local chapter of the MS Society for a support group, educational program, or family event.

The bi-directional arrows connecting the professionals in the community refer to the need for cross-referrals and communication. For example, a social worker whose client has MS, may refer that person for a neuropsychological evaluation or medication assessment for an antidepressant. The success of the psychotherapy may very well depend on the outcome of those referrals, and on the willingness of the professionals involved to communicate with one another. Or, a person with MS may be seeing a social worker or psychologist for psychotherapy and a psychiatrist for medication management. It is very important for these providers to be in contact with one another, and with the healthcare team, in order to ensure that they are not working at cross-purposes. This is particularly true when any kind of medication is involved. Many people with MS require a variety of medications to manage their symptoms. Some of the medications used in MS can affect mood, affect, energy level, and cognitive function. Therefore, any mental health professional needs to be aware of, and familiar with, the medications a person with MS is taking, since they may be impacting the person’s mood and functioning.

In addition to the Professional Resources shown at the top of the model, there are equally important Informal Supports available to people with MS. When looking for ways to support people’s efforts to live with MS, the healthcare team and the National MS Society need to help people reach out to family and friends, and to the religious institutions and community agencies that can provide invaluable support. The uni-directional arrows leading to a person’s informal support systems indicate that the flow of information goes only one way. The healthcare team and the National MS Society guide people in the direction of these resources but do not necessarily expect follow-up or exchange of information.

What follows is an overview of the psychosocial impact of multiple sclerosis on the individual with the disease and his or her family members. As you review the challenges faced by people you may encounter in your professional work, use the model as a tool to enhance the care you provide.
Common Emotional Reactions to MS

While each person’s emotional reactions to a chronic, unpredictable disease like MS will be different, there are some fairly common ones that you would expect to encounter.

Initial Reactions to the Diagnosis

While each person’s reactions are different, the following are fairly common initial responses to the diagnosis:

- **Shock:** “This can’t be happening to me.”
- **Denial:** “This isn’t happening to me.”
- **Anxiety:** “What else will happen to me?”
- **Anger:** “Why can’t you fix what’s happening to me!”
- **Relief:** “At least I have a name for what’s happening to me.”

Longer Range Emotional Reactions

- **Grief** is an ongoing, if intermittent, response over the course of the disease. From the time of diagnosis, and continuing throughout the course of the illness, the person will experience periods of grief—anormal reaction to any kind of loss. Every change or symptom represents a loss—of self or personal identity, of feelings of autonomy and personal control, or of a particular skill or ability—things that all adults cherish. Every loss of ability or control requires a change in the person’s self-image; every time the self-image undergoes a change, the person needs to grieve.

- **Anxiety** is a common response to the unpredictability of MS. From one day to the next as well as one year to the next, people don’t know how they are going to feel, what parts of their bodies are going to be affected, and what the future is going to hold for them. This kind of unpredictability makes people feel out of control of their bodies and their lives, and when people feel out of control, they get anxious. Family members share a similar anxiety over the unpredictable impact MS may have on their lives.

- **Resentment** is another common response to unpredictability and loss of control—for both people with MS and their family members. One of the biggest challenges people face is finding a satisfactory outlet for this resentment. They need to learn how to express their anger in a constructive way, focusing it on the disease rather than each other or the doctor. Even when people with MS feel legitimate anger toward their loved ones for one reason or another, they may be
afraid to express it and risk driving their partner/caregiver away. They tend to feel stuck with an anger that has no end.

• **Guilt** may also be experienced by people with MS and their family members. For the patients themselves, the guilt has to do with their inability to fulfill their roles and obligations in different areas of their lives. They worry that they are letting everybody down, no longer pulling their own weight. There is also guilt over uncomfortable feelings—particularly the anger toward care partners, children, and God.

### Emotional Changes Observed in MS
(Adapted from N. LaRocca. Cognitive and emotional disorders in MS. In J Burks & K Johnson (eds.) *Multiple Sclerosis: Diagnosis, Medical Management, and Rehabilitation*. New York: Demos, 2000.)

- **Depression** (including major depressive episodes and less severe dysphoric states)
  - Following the onset of MS, the lifetime prevalence of major depression increases from 15 percent (similar to that of the general population) to approximately 50 percent (Joffe et al., 1987; Minden et al., 1987; Sadovnik et al., 1996).
  - Depression is more common among people with MS than it is among patients with other chronic conditions that are equally disabling (Rabins et al., 1986; Minden et al., 1987).
  - Possible causes of depression in MS include: disease activity (especially onset of exacerbation); neuropathologic changes in areas of the brain related to affective states; neuroendocrine or psychoneuroimmunologic changes; reaction to life changes; side effects of medications (particularly steroid treatment).
  - Major depression can occur at any point in the disease course, even as an initial symptom.
  - Depression is treated most effectively with a combination of psychotherapy and antidepressant medication (keeping in mind that antidepressant medications tend to interfere with sexual response, thereby adding to a person’s distress).
  - Bipolar disorder has a lifetime prevalence in MS of 15 percent, which is more than 10 times the rate in the general population (Joffe et al., 1987).
• Suicidal ideation, intent, and action, which are possible concomitants of depression, are more common in MS than in the general population (Sadovnik et al., 1991). People with MS should be screened for depression on a regular basis.

• Mood swings are common in MS and can be as disruptive for individuals and families as physical impairments.
  • Periods of anger, irritability, dysphoria that come and go fairly rapidly may be reactions to stress and/or the result of MS-related changes in the brain.
  • Effective treatment involves psychotherapy, often in conjunction with a mood-stabilizing agent such as divalproex sodium (Depakote®).

• Affective release (also known as “pseudobulbar affect”) refers to unpredictable episodes of laughing or crying often having nothing to do with the person’s underlying mood (LaRocca & Fischer, 2000).
  • Probably caused by lesions in the limbic system or related structures.
  • Has been successfully treated with 25 to 75 mg per day of amitriptyline (Elavil®) and may also respond well to selective serotonin reuptake inhibitors (SSRIs).

• Emotional crescendo describes an experience in which a person becomes very emotional, crying very easily in response to any stimulus that triggers intense emotion or tension.
  • Once the response is stimulated, it feels uncontrollable until it reaches a crescendo and resolves on its own.
  • It differs from affective release in that the person’s mood and expression are more consistent with one another.
  • While not as upsetting or embarrassing as affective release, emotional crescendo interferes significantly with any efforts to resolve a conflict or have any kind of disagreement.
  • Some success has been achieved with a behavioral intervention involving focused attention on the build-up of tension, deep-breathing, and relaxation to dampen or halt the response.

• Euphoria, defined as a sustained mood state involving exaggerated and inappropriate happiness and optimism in the context of a very bleak situation, is generally associated with extensive cerebral demyelination and dementia.
  • Once considered the hallmark of MS, it is actually seen in less than 10 percent of patients.
• There is no known treatment for this phenomenon; supportive interventions for the family are essential.

• Antisocial behavior, sexual inappropriateness, outbursts of rage, and psychotic states may also be related in the underlying disease process in some few individuals with MS.

• Treatment involves both psychiatric and medical care, as well as education and support for the family.

The Role of Stress in MS

• While people with MS often report that stress precipitated the onset or the worsening of their disease, the research findings in this area remain inconclusive. No causal relationships have ever been confirmed.

• People with MS are often advised by family members and/or their healthcare providers to “avoid stress”—a recommendation that is difficult if not impossible to follow. People may be encouraged to leave their jobs to reduce stress in their lives, only to find that premature retirement causes financial hardship, reduced self-esteem, and a whole new set of stressors.

• Since the effort to “avoid stress” can itself become highly stressful, the recommended strategy is to develop effective stress management techniques for coping with the unavoidable stresses of everyday life.

Cognitive Impairment

• Approximately 50 percent of people with MS will experience some changes in cognitive functioning. While most will experience mild to moderate deficits that can be managed with compensatory strategies and/or an altered approach to everyday activities, 10 percent of people with MS will experience changes that are severely disabling. (Peyser et al., 1990; Rao et al., 1991).

• Cognitive changes can occur at any time during the course of the disease (even as the initial symptom), and may appear in both mildly and severely disabled individuals.

• Cognitive deficits are related to both the extent and location of demyelinative lesions.
• Cognitive impairment can worsen during exacerbations and improve during
periods of remission (Fischer et al., 1994).

• Although a full neuropsychological battery of tests is the most effective way to
evaluate cognitive changes in MS, various brief batteries have been developed
that can identify those individuals who would likely benefit from a more com-
plete evaluation (Beatty, 1995).

• Regardless of the specific tests used, it is important to evaluate memory,
abstract reasoning, verbal fluency, attention and concentration, visual-spatial
skills, etc. with reliable and valid measures.

• Medical treatments of cognitive dysfunction include:
  • Symptomatic pharmacologic management: Aricept® (a drug currently
approved for use in Alzheimer’s disease) is now being evaluated in several
clinical trials for use in MS. Based on positive anecdotal reports, many physi-
cians are already prescribing it for their patients with MS.
  • Treatment with disease-modifying agents: little is currently known about the
impact of the disease-modifying agents on cognitive function because cogni-
tion was not evaluated in many of the initial trials. There is some indication,
however, that disease-modifying agents may play a modest role in the treat-
ment of cognitive impairment in MS. In a study of progressive disease, sub-
jects receiving methotrexate demonstrated improvements relative to those in
the placebo group in verbal ability, visuospatial ability, information process-
ing speed, memory, and problem-solving (Fischer et al., 1997). Relapsing-
remitting patients receiving interferon beta-1a (Avonex®) in a large
controlled clinical trial improved somewhat, relative to the placebo group, in
information processing, memory and visuospatial abilities, and executive
functions, but not in verbal abilities or attention span (Fischer et al., 1998).
A recent study with glatiramer acetate (Copaxone®), however, failed to find
any benefit on cognitive function (Weinstein et al., 1999).
  • Cognitive rehabilitation in MS received little attention until recently because of
the progressive nature of the disease. With evidence to suggest that cognitive
problems in MS tend to progress slowly, there is growing interest in cognitive
rehabilitation as a viable treatment intervention.
    • The restorative approach attempts to restore impaired function through
direct retraining exercises. Because this approach has not been shown to
have much impact on everyday life, practitioners are moving more toward a
compensatory approach.
The compensatory approach teaches people how to substitute viable strategies and tools for the impaired cognitive functions. Memory books, family calendars, filing systems are tailored to the person’s individual needs, capabilities, and lifestyle.

Cognitive evaluation/rehabilitation is typically offered by neuropsychologists, speech/language pathologists, and occupational therapists. While their assessment tools and interventions vary somewhat, their shared goal is to support the person’s efforts to function more effectively in his or her environment.

Medical and mental health providers may need to alter their working styles to accommodate the needs of cognitively-impaired individuals. People with MS should be encouraged to prepare for their healthcare visits, and ask family members and friends to help them make a list of concerns. They may need to bring notes to their appointments to remind themselves of their questions/concerns, take notes of their meetings, or bring a tape recorder. Providers may need to speak more slowly, repeat themselves, or provide written suggestions for the person to take home.

Psychosocial Issues Over the Disease Course

Psychosocial Issues in Early Relapsing Disease

The most important point to remember in your work with patients in the early-relapsing stage of the disease is that there are no fixed or pre-determined stages of adaptation to this illness. The person’s emotional reactions, and the reactions of his or her family members, ebb and flow with changes in the illness. Each attack, each new symptom or change in function is going to require the person to re-adjust all over again. Therefore, the goal of supportive interventions is not for people to reach a point of acceptance. Instead, the goal is for the person to learn how to adapt to the presence of MS in his or her life—to make room for its ever-changing demands without giving it more emotional space than it absolutely needs.

Care providers need to be alert to cognitive and emotional changes that can occur at any point in the illness, even in the absence of visible, physical changes. Memory problems, word-finding difficulties, slowed processing speed, mood swings, and even depression, can be among the initial symptoms. They can occur in anyone, not just the more severely disabled. These changes need prompt attention not only because they are difficult and uncomfortable to live with, but because they will have an impact on the care provided. To a large extent, they will determine a
patient’s ability to hear what the provider is saying, learn what needs to be learned, and develop the kinds of problem-solving and self-management skills that are needed to cope with MS.

It is important to keep in mind that the corticosteroids that are so often used in the management of exacerbations, can have a significant impact on a person’s moods. Just at a point in time when the person is feeling vulnerable and emotionally challenged by the exacerbation, the steroids can contribute significantly to the emotional upheaval. In some instances, medication may be needed to manage the mood disturbance.

**The Role of Denial**

For many people, the second attack is the most emotionally devastating. In the period of remission following the diagnosis, the person whose symptoms have all but disappeared may come to believe that it was either a mistake or something that he or she managed to conquer. The second attack confronts the person with the reality of the illness. Providers need to be particularly alert to their patients’ emotional needs at this time.

When people are in remission, their natural tendency is to want everything to “be normal”—the way things were before MS came along. While this is a very healthy response in some respects, it brings with it a certain amount of resistance—to treatment, and to effective life planning. One of the major challenges for healthcare providers is finding the means to help patients and family members see early treatment and life planning as ways of taking charge of the MS rather than as signs of giving in to it. The recent emphasis on early intervention flies in the face of people’s emotional defenses. From the physician’s point of view, the new disease-modifying drugs represent a revolution in MS care. Many people with MS, however, perceive them very differently. “I feel fine. Why should I give myself a shot all the time?” “I’m trying to forget about this MS and get on with my life. How can I possibly do that if I have to do these injections? They’re depressing.” “I feel worse with the shots than I do without.” Thus, the treatments are seen as a painful confirmation of the very thing the person is trying to deny.

Similarly, people who are feeling fine don’t want to think about the potential impact of MS on their future. The instinct of many is to put off thinking about employment or financial issues, for example, as long as possible, or until they are in a crisis. Providers need to help them think about the potential impact of MS so that they can do some constructive planning and problem-solving. Then, if all goes well, and no significant disability occurs, nothing has really been lost. But if their disability does become progressive, they already have in place the kind of safety net
that helps to avert crises and allows them to feel more prepared for whatever comes along.

**The Question of Disclosure**

One of the major challenges confronting the early relapsing patient is dealing with invisible symptoms like fatigue, visual difficulties, bladder or bowel problems, or cognitive changes. During the early days of the illness, people begin to make decisions about disclosure—to family, friends, colleagues, and employers. “When should I be telling people about a disease they can’t even see?” This is a difficult and stressful decision that can have major emotional, social, and financial repercussions. Again, the goal is to provide people with enough early education and information that they can think through their options deliberately and carefully and avoid making impulsive disclosure decisions.

**“But You Look So Good”**

Another challenge facing people with early, remitting disease is how to educate others about the illness. Invisible symptoms are very difficult for others to understand, and the expectations of others are most often based on what they can see. The person with MS needs to communicate with others—particularly family members—in ways that will help them understand his or her abilities and limitations. The familiar refrain, “But you look so good” is a painful one for many people with MS. While it is sometimes meant as a comforting or reassuring compliment, it can also be a not-so-subtle message to people with MS that they aren’t meeting the needs or expectations of others in a satisfactory way. In other words, “You look too good to be sick, so how come you’re not doing all the things I need you to be doing for me?” The message actually denies how the person with MS is feeling, with the result that he or she often begins to feel guilty, anxious, and plagued with self-doubts.

*In summary, the early-relapsing patient is reacting to the personal assault of MS, while simultaneously having to deal with the feelings, reactions, and expectations of others.*

**Psychosocial Issues for the Patient in Transition**

**The Meaning Attributed to Disease Progression**

As impairments begin to accumulate, and disability creeps into more and more areas of daily life, people may begin to attribute all kinds of meaning to it. At best, MS is seen as lousy luck. For others, however, it’s experienced as something they have brought on themselves.
A sign of personal failure: “I must not be trying hard enough . . . or praying hard enough . . . or exercising enough . . . ”

A sign of personal weakness: “I’m just not strong enough to fight this thing.”

A punishment for past failures or weaknesses: “I must have done something really bad for God to let this happen to me.”

Since the beginning of the clinical trials for the disease-modifying agents (Betaseron®, Avonex®, and Copaxone®), greater attention has been paid to disease course nomenclature in MS. Those who were diagnosed as relapsing-remitting had an entrée into the world of treatment; those who were primary- or secondary-progressive did not. As a result, people with MS are exhibiting an anxiety about disease course that they never had before (“Will I become secondary-progressive? Does this mean I’ve become secondary-progressive? I don’t want to be secondary-progressive!”). This anxiety can prevent people from thinking ahead and planning constructively for the uncertain future. It may engender feelings of failure and hopelessness, and it can certainly give rise to feelings of anger at their healthcare providers and the medications for not making the disease go away.

The Role of Resistance

With disease progression may come more resistance. “I don’t feel any better and my MS is getting worse, so why should I keep giving myself shots all the time?” “I don’t feel any better, and my MS is getting worse, so why should I bother seeing the doctor?” This is the time when people become tempted to turn away from standard treatment and try all the miracle cures. Money and hope may be poured into alternative treatments that are touted as “the answer,” but have no proven effectiveness. The solution to MS is always at the end of the rainbow. Providers need to be alert to signs of fear, frustration and despair as more of the realities of MS begin to sink in. This is a time when patients need support and encouragement to adhere to their treatment regimen and resist the temptation to pursue quackery.

The Impact on Role Performance

Cumulative disability can interfere with the performance of a person’s roles at home and at work. A primary breadwinner may need to give up working. A parent may need help with childcare activities. A homemaker may be unable to manage household tasks. As with every other loss brought about by MS, these major life changes need to be grieved over before the person can begin to make constructive adaptations. The next step is for the person to establish new goals and priorities that are meaningful and satisfying, and negotiate these changes with the significant people in his or her life. Family members, employers, and colleagues may all
need to be involved in these renegotiations. This is no simple exercise, and people with MS and their families may need support and guidance in their efforts to redesign their world and re-define their interlocking roles.

**Utilization of Supportive Resources**

Fortunately, this is also the time when many who were initially unwilling, may be ready to make use of available resources like support groups, counseling, and educational programs. It is often at this juncture that the person with MS might be referred to a professional in the community.

**Psychosocial Issues for the Progressive Patient**

Disease progression usually translates into progressive loss—of abilities, activities, and important life roles. With progression can also come personal growth and the development of new skills, but progression is always challenging and always painful. The grief work continues as the person deals with the impact of MS in more and more areas of daily life. The psychosocial challenges confronting the person with progressive disease include the following:

**Finding New Personal Meaning for the Concepts of Self, Independence, and Control**

For example, the person who becomes increasingly dependent upon assistive devices, personal aides, and other forms of outside assistance, needs to take pride and satisfaction in being able to identify, obtain and manage these resources. In other words, he or she needs to find new ways to think about exerting independence and control in everyday life.

**Finding the “MS-Free Zone”**

Severely disabled individuals, who feel that every aspect of their lives has been altered by MS, need to be encouraged to look for their personal, MS-free zone—places that MS has not reached. For one it might be a sense of humor or love of music, for another a particular skill or talent, or a religious faith. Whatever it is, the MS-free zone provides an emotional respite from the day-to-day challenges and losses.

**Identifying New Life Goals and Areas of Focus**

The progressively disabled person needs to redefine him- or herself, finding new goals, making different plans, and identifying new ways to feel useful and productive. Counseling can be particularly helpful at this juncture, supporting the person’s efforts to deal with painful feelings and identify satisfying and meaningful personal goals. People with severe disability are called upon to make important life
decisions at a time when they are least equipped physically, emotionally—and perhaps cognitively—to do so. In spite of efforts by healthcare providers to encourage people with MS to plan for the worst even while hoping for the best, most people are very reluctant to think about problems or limitations until they really have to. The result, unfortunately, is that severely disabled individuals and their families are often confronted with difficult realities for which they are totally unprepared (e.g., loss of income, the need for long-term care, inaccessible housing, etc.). They often end up in crisis, having to make an emergency decision rather than a thoughtful plan. Medical and mental healthcare providers have a valuable role to play—helping individuals and families cope with their feelings of loss, tap into available resources, identify their options, and make sound choices—in other words, to act with deliberation rather than react to crisis.

The possible presence of cognitive impairment is a key variable in all of these disease stages. The person who has experienced impairment may have much greater difficulty identifying and implementing the changes that need to be made and negotiating them with loved ones and employers. Similarly, the presence of depression can significantly affect the person’s ability to navigate these challenges. Healthcare providers need to monitor cognitive and emotional functions carefully, providing prompt diagnosis and treatment as appropriate.

Impact of MS on the Family

Challenges to the Family’s Coping Efforts

- MS is a chronic disease. Most families will be living with its effects for several decades.
- MS is a drain on important family resources, including money, time, and energy.
- MS can necessitate significant role changes within the family.
- MS can disrupt the family’s “rhythm,” the patterns of everyday life that give each family its own unique identity. Just as the individual with MS needs to redefine him- or herself in the context of limitations imposed by the disease, the family needs to do the same.
- A family is made up of individuals, with different personalities and coping styles. While there are certain common emotional reactions to the presence of MS in the household, family members will experience these feelings each in their own way and in their own time. These differences can significantly impact the ability
of family members to communicate with one another. One goal of mental health professionals is to help family members recognize the feelings they are experiencing and express them more comfortably with one another. The sharing of feelings facilitates mutual support and joint problem-solving.

**Parenting Issues**

**Fertility, Pregnancy, and Childbirth**


- Fertility is, for the most part, unaffected by MS. The erectile/ejaculatory problems experienced by some men with MS can interfere with a couple’s ability to conceive.

- Women should be encouraged to seek medical advice *before* conception in order to review the medications they are taking and make necessary changes. None of the disease-modifying agents are considered safe for use during pregnancy. A woman who is taking one of these drugs will need to weigh the risks of stopping the medication long enough to conceive and bear a child. The drug can be resumed following delivery if the mother does not plan to breastfeed.

- MS does not affect the course of pregnancy, labor, or delivery.

- Women who wish to breastfeed are encouraged to do so as long as they have the necessary strength and stamina.

- The hormones of pregnancy seem to exert a protective effect on the immune system: A woman is likely to experience fewer exacerbations during the nine months of pregnancy (particularly the second and third trimester). The risk of exacerbation in the few months following delivery, however, has been found to range from 20 to 75 percent (whether the pregnancy goes to term or ends prematurely).

- The consensus is that pregnancy does not affect the long-term course of MS. Nevertheless, a woman with MS needs to come to terms with the fact that there is no way to predict the long-term course of her disease.

- In addition to the unpredictability of MS, couples need to consider their financial and emotional security as a couple, their individual views of parenting; and their ability to handle role shifts in the family should the need arise.
Issues for the Parent with MS


• Recent studies have reported no significant, long-term psychological or behavioral difficulties in children who have a parent with MS. Once reassured that their mom or dad will be there for them, and that the MS is not catching, most children make a very satisfactory adjustment to the presence of MS in the family.

• However, parents who need to believe that their MS is not going to have a negative impact on their children’s lives, may tend to deny the obvious impact of MS on family life and minimize or overlook their children’s MS-related worries. These parents may shy away from educational programs, family counseling, or other interventions designed to facilitate the family’s coping efforts.

• Men and women with MS who are worried that they will not be “good” parents need to be reassured that there is no single way to be a “good” or effective parent, and that it is possible to provide love, security, and nurturance whether one is standing up or sitting down.

• Symptoms that are less visible (fatigue, mood swings, cognitive changes, etc.) are generally more difficult for children to understand than the more obvious, physical ones. Children are often “easy targets” for the frustration experienced by parents with MS; many youngsters describe MS as a disease that “makes people cranky.”

• Every effort should be made to help parents with severe disabilities find adult caregivers or helpers so that young children do not have to serve as primary caregivers for their parents.

• Parents are often reluctant to talk about MS with their children for fear of worrying them unnecessarily. They should be encouraged to talk to their children about MS for the following reasons:
  • Children should not be the last to know about a parent’s MS, and should not hear about it inadvertently from a relative or friend.
  • Children are very sensitive to their parents’ moods and the emotional climate in the household. When they are not told what is going on, their imaginations tend to fill in the blanks—often with something that is even scarier than the reality.
  • Providing children with information about MS gives them permission to ask their questions, as well as a vocabulary with which to do so.
Psychosocial Support

- Parents who share information and feelings about MS provide a model for coping with life’s challenges.
- Parents who communicate openly with their children about MS lay the groundwork for open family communication about issues that may come up in the children’s lives.

Caregiver Issues


Approximately one-quarter of the people in the United States who have MS need help with daily activities or personal care. The care consists mainly of instrumental or hands-on assistance and help with planning and decision-making. Most of this help comes from spouses.

- Caregiving can affect the couple’s relationship in a variety of ways:
  - No young couple in which both members are healthy can fully appreciate the meaning of “in sickness and in health,” or foresee the impact that a chronic disease like MS can have on a marital relationship.
  - The couple’s partnership may shift gradually to a caregiver-patient relationship.
  - There may be a gradual erosion of communication caused by anxiety, guilt, resentment, and possible cognitive impairment.
  - Partners may engage in a “contest” over who has it worst—the person with MS or the caregiver who is living with a disease that isn’t even his or her own.
  - Caregivers experience significant stress and “burn-out” that seems to have little to do with their partner’s degree of physical impairment or length of time with MS, and more to do with the feeling of being trapped.
  - Changes occur in the sexual relationship whereby sexual intimacy is gradually replaced by the unwanted intimacy of caregiving activities.
  - Caregivers report more stress associated with their partner’s cognitive and emotional changes than with their physical ones (e.g., “This isn’t the same person I married”).
  - Differences of opinion about the amount and type of assistance needed is a common source of strain.
Stress and frustration can lead to abuse and neglect in even the most loving of couples. Verbal and physical abuse (by either partner), as well as patient neglect, can and does occur regardless of a family’s ethnic or socioeconomic background. A study recently conducted by Abt Associates (Cambridge, Massachusetts) suggests that abuse by caregivers of people disabled by MS is more widespread than previously suspected. The study was initiated after case workers for the Protective Service Program noticed that more of the alleged victims of abuse had multiple sclerosis than any other condition. Investigation into 59 substantiated reports of abuse over a 28-month period revealed that over 83 percent had been abused by a family caregiver (often a spouse), and 20 percent by a paid caregiver. Eighty percent of those experienced abuse in the form of neglect, 61 percent in the form of verbal and emotional abuse, and 41 percent in the form of physical abuse.

Supportive interventions include:

- Facilitating the development of a care partnership, in which the needs of both partners continue to be met.
- Facilitating a couple’s efforts to communicate openly and problem-solve jointly.
- Encouraging caregivers to attend to their own health and emotional needs, know their own limits, seek out and utilize available support.
- Facilitating access to available community resources.

Economic Issues

Although 90 percent of people with MS have an employment history, and approximately two-thirds are employed at the time of diagnosis, only 25–40 percent of people with MS are employed at the present time. This accounts for a substantial part of the total economic impact of the disease. The major predictors of job loss in MS are:

- mobility impairments
- jobs requiring physical exertion
- cognitive impairments
- MS is expensive compared to other disease because of its relatively early onset, chronicity, wide range of symptoms, and expensive treatments.
- Most MS costs are uncompensated. Health insurance and income replacement benefits replace less than half of the costs of the disease.
- Individuals and families bear most of the cost of the disease.
Challenges to Medical and Mental Health Providers

No Provider Can Do It Alone

People with MS and their families face a very complex set of challenges. No provider working in isolation can address all the medical, emotional, and social needs that arise. It wasn’t so long ago that the prevailing approach to MS care was “Diagnose and Adios” (as coined by Dr. Labe C. Scheinberg, the acknowledged father of comprehensive care in MS). Physicians, with no cure to offer and little in the way of effective treatment or symptom management, sent their patients home to deal with MS on their own. Often, they didn’t even tell them the name of the disease.

Even now, with all the progress made in symptom management and disease-modifying strategies, providers may sometimes feel overwhelmed by their inability to control disease progression and address the many kinds of problems that can arise. Collaborative care, utilizing the skills of a variety of medical and mental health professionals, is the most effective way to support people’s efforts to live comfortably with MS. The model of psychosocial support presented here emphasizes the ways in which mental health professionals can work collaboratively with the healthcare team, and with each other, to provide quality care.

Patients with MS Sometimes Require More Assistance Than You Are Used to Giving

Mental health professionals have all been taught the importance of maintaining “appropriate boundaries” with patients. In your work with people with MS, you will find that the boundaries are much less clear. The person with MS who comes to your office for a consultation or ongoing treatment may have physical limitations that restrict his or her independence. You may find yourself called upon to provide hands-on help that you would never consider offering or providing to your other patients. For example, you might need to help someone get in or out of a chair, remove a jacket, manage a glass of water, or even get in and out of the bathroom. One of the side effects of the bladder medications used in MS is dry mouth; you may need to provide water for the patient who is having difficulty talking during an appointment with you. The heat sensitivity that is so common in MS can also affect your sessions. If your office is slightly warm, or if it is a very hot or humid day, you may find that the person has difficulty getting up and out of the office, or out to the car.
Knowing How to Deal With an Emotionally Healthy Patient

You are likely to encounter patients with MS who, under other circumstances, would never have sought out your services. Until MS intruded on their lives, they were emotionally stable, productive individuals who would never have considered consulting a mental health professional. They may never have experienced an episode of depression, or even any periods of dysphoria or significant distress. With the diagnosis of MS or a major change in their physical or cognitive functioning, they may seek you out in the same way they would an attorney or an accountant—as the professional most suited to advise them in their current crisis. They come for one session or a few, and then say that they feel ready to “go it alone” again. Many therapists who have worked in MS over an extended period of time, find themselves providing “intermittent psychological support,” i.e., working with the same individual or family for short periods, at many different points over the course of the disease. Thus, for example, a person may come to you:

- Following the diagnosis to deal with the grief and discuss issues relating to disclosure to friends or colleagues.
- A few years later, with a girl- or boyfriend, to discuss marriage plans and concerns around family planning decisions.
- When symptoms develop that begin to interfere with activities at home or at work.
- Some time later, to discuss the possibility of disability-related retirement.
- Following significant disease progression to discuss relationship issues, advance directives, or long-term care.

In other words, you may be called upon to accompany the person through difficult transition periods, providing support—and the opportunity to identify and discuss options. Some providers find it difficult to deal with their patients’ disease progression, and may even shy away from people with progressive disability. You are an invaluable resource to these individuals; you can provide a safe, comfortable place in which to express feelings, explore options, and make difficult decisions.

Recognizing When MS is Not the Issue

Although MS poses an inordinate number of challenges to individuals and families, it is not always the issue that brings people into treatment. It is important to keep in mind that a person with a chronic illness or disability can have all the same issues as any other patient, many having nothing to do with the MS. Similarly, you may need to help the person with MS (or a family member)
recognize that the MS is not "to blame" for all of the stresses or conflicts of daily life.

**Managed Care**

Managed care is designed to control costs. While the intermittent psychological support needed by some individuals with MS can fit rather well into the limited sessions allowed per year by many insurance companies, the more intensive care required by some with MS does not. It may be difficult to convince companies that there are some people with MS, particularly those with a progressive course, who need ongoing support even though they don't fit readily into DSM-IV diagnostic categories. Fortunately, the case can usually be made for the diagnosis of Adjustment Reaction with Depressed and/or Anxious Mood. Some companies have even gone out of their way to meet the needs of these patients.

Insurance coverage for neuropsychological testing and cognitive remediation is much more difficult to obtain. It can be particularly frustrating to be confronted with a person you know to be in need of help, and whom you know you could help, and find there are no resources to pay for the necessary interventions.

**The Internet**

The easy access to information about MS on the Internet has both positive and negative implications for people with MS. On the one hand, there is more information available to more people than ever before (see Appendix C for a list of recommended websites). In the privacy of their own homes, people can read about the disease, talk to others who have it, ask questions of MS experts, and participate in interactive educational programs. On the other hand, the available information varies tremendously in quality and reliability. It is not uncommon for people to focus on the information they want to hear and believe, and ignore the rest, regardless of its validity and reliability or the source from which it comes. One important role of medical and mental health providers, as well as of the National MS Society, is to help people sort out the good from the bad.

Many people arrive at their doctor’s office armed with information off the Internet about treatments or “cures” that they want the doctor to comment on or prescribe. Since most physicians simply do not have the time to engage in this kind of lengthy discussion, nurses and psychotherapists may find themselves in the role of addressing these issues. The National MS Society is equipped to handle questions from people with MS, family members, and medical and mental health providers about information gleaned from the Internet. Providers should feel free to refer patients to their local chapter of the National MS Society (1-800-FIGHT-MS, press
option 1) or call themselves for information. If the personnel at the chapter are unable to answer the questions, they will contact the Information Resource Center and Library at the home office of the National MS Society to get the answer to your question. In addition, the National MS Society publishes numerous pamphlets, booklets, and brochures covering many aspects of MS and its treatment (see Appendix C). These are available from the local chapters at no cost for people with MS and for their providers.
SOURCES FOR INFORMATION IN THIS BOOK


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.

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.

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

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.

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.

Axon: The extension or prolongation of a nerve cell (neuron) that conducts impulses to other nerve cells or muscles. Axons are generally smaller than 1 micron (1 micron = 1/1,000,000 of a meter) in diameter, but can be as much as a half meter in length.

Axonal damage: Injury to the axon in the nervous system, generally as a consequence of trauma or disease. This damage may involve temporary, reversible effects or permanent severing of the axon. Axonal damage usually results in short-term changes in nervous system activity, or permanent inability of nerve fibers to send their signals from one part of the nervous system to another, or from nerve fibers to muscles. The damage can thus result in a variety of symptoms relating to sensory or motor function.

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 (CNS): The part of the nervous system that includes the brain, optic nerves, and spinal cord.

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.

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

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

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

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

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

**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.

**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.

**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.

**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, optic nerves, spinal cord).

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

**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.
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.

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.

Erectile dysfunction: The inability to attain or retain a rigid penile erection.

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.

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.

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.
**Glossary**

**Foley catheter:** See Indwelling catheter.

**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.

**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, 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.

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

**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.

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

**Immunomodulation:** Modification of immune system function, which may happen naturally, as a result of infection, or with treatment. In MS, the disease-modifying agents Betaseron®, Avonex®, Copaxone®, and Rebif®, as well as certain chemotherapeutic agents, serve as immunomodulators.

**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 mitoxantrone, cyclosporine, methotrexate, and azathioprine.

**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.

**Intention tremor:** Rhythmic shaking that occurs in the course of a purposeful movement, such as reaching to pick something up or bringing an outstretched finger in to touch one’s nose.
Interferon: A group of immune system proteins, produced and released by cells infected by a virus, which inhibit viral multiplication and modify the body’s immune response. One of the interferons, interferon beta-1b (Betaseron®) was approved by the Food and Drug Administration in 1993 for treatment of relapsing-remitting MS. It was found in a clinical trial to reduce the frequency and severity of exacerbations by approximately 30 percent. A second interferon, interferon beta-1a (Avonex®) has also been shown to reduce the frequency and severity of MS exacerbations in people with relapsing-remitting disease, as well as to reduce the risk of clinically significant disease progression. Avonex® was approved for use in MS in 1996. Rebif® (another form of interferon beta-1a) has been approved in Europe and Canada for relapsing-remitting MS.

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.

Lesion: See Plaque.

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).

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.

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, bladder); the Disability Status Scale (developed by John Kurtzke), which gives a single composite score for the person’s disease; the Incapacity Status Scale, which is an inventory of functional disabilities relating to activities of daily living; the Environmental Status Scale, which provides an assessment of social handicap resulting from chronic illness. The MRD has two main functions: to assist doctors and other professionals in planning and coordinating the care of persons with MS, and to provide a standardized means of recording repeated clinical evaluations of individuals for research purposes.
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.

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.

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.

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 individuals confined to wheelchairs.

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).

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

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).

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.

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

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. Post-void residual urine can also be measured by bladder ultrasound.

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.

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.

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.

**Rehabilitation:** Rehabilitation in MS involves the intermittent or ongoing use of multidisciplinary strategies to promote functional independence, prevent unnecessary complications, and enhance overall quality of life. It is an active process directed toward helping the person recover and/or maintain the highest possible level of functioning and realize his or her optimal physical, mental, and social potential given any limitations that exist. Rehabilitation is also an interactive, ongoing process of education and enablement in which people with MS and their care partners are active participants rather than passive recipients.

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

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

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

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

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

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

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

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

**Spasticity:** Abnormal increase in muscle tone, manifested as a spring-like resistance to moving or being moved.
Speech/language pathologist: Speech/language pathologists specialize in the diagnosis and treatment of speech and swallowing disorders. A person with MS may be referred to a speech/language pathologist for help with either one or both of these problems. Because of their expertise with speech and language difficulties, these specialists also provide cognitive remediation for individuals with cognitive impairment.

Spinal tap: See Lumbar puncture.

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.

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.

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.

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 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.

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 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.
# Medications Commonly Used in MS

<table>
<thead>
<tr>
<th>Generic Name</th>
<th>Brand Name</th>
<th>Usage in MS</th>
</tr>
</thead>
<tbody>
<tr>
<td>Alprostadil</td>
<td>Prostin VR</td>
<td>Erectile dysfunction</td>
</tr>
<tr>
<td>Alprostadil</td>
<td>Muse</td>
<td>Erectile dysfunction</td>
</tr>
<tr>
<td>Amantadine</td>
<td></td>
<td>Fatigue</td>
</tr>
<tr>
<td>Amitriptyline</td>
<td>Elavil</td>
<td>Pain (paresthesias)</td>
</tr>
<tr>
<td>Baclofen</td>
<td>Lioresal</td>
<td>Spasticity</td>
</tr>
<tr>
<td>Bisacodyl¹</td>
<td>Dulcolax</td>
<td>Constipation</td>
</tr>
<tr>
<td>Bupropion</td>
<td>Wellbutrin</td>
<td>Depression</td>
</tr>
<tr>
<td>Carbamazepine</td>
<td>Tegretol</td>
<td>Pain (trigeminal neuralgia)</td>
</tr>
<tr>
<td>Ciprofloxacin</td>
<td>Cipro</td>
<td>Urinary tract infections</td>
</tr>
<tr>
<td>Citalopram</td>
<td>Celexa</td>
<td>Depression</td>
</tr>
<tr>
<td>Clonazepam</td>
<td>Klonopin (US)</td>
<td>Tremor; pain; spasticity</td>
</tr>
<tr>
<td></td>
<td>Rivotril (Can)</td>
<td></td>
</tr>
<tr>
<td>Dantrolene</td>
<td>Dantrium</td>
<td>Spasticity</td>
</tr>
<tr>
<td>Desmopressin</td>
<td>DDAVP Nasal Spray</td>
<td>Urinary frequency</td>
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<tr>
<td>Diazepam</td>
<td>Valium</td>
<td>Spasticity (muscle spasms)</td>
</tr>
<tr>
<td>Docusate¹</td>
<td>Colace</td>
<td>Constipation</td>
</tr>
<tr>
<td>Docusate mini enema¹</td>
<td>Therevac Plus (US)</td>
<td>Constipation</td>
</tr>
<tr>
<td>Fluoxetine</td>
<td>Prozac</td>
<td>Depression; fatigue</td>
</tr>
<tr>
<td>Gabapentin</td>
<td>Neurontin</td>
<td>Pain</td>
</tr>
<tr>
<td>Glatiramer acetate</td>
<td>Copaxone</td>
<td>Disease modifying agent</td>
</tr>
<tr>
<td>Glycerin¹</td>
<td>Sani-Supp suppository (US)</td>
<td>Constipation</td>
</tr>
<tr>
<td>Imipramine</td>
<td>Tofranil</td>
<td>Bladder dysfunction; pain</td>
</tr>
<tr>
<td>Interferon beta-1a</td>
<td>Avonex</td>
<td>Disease modifying agent</td>
</tr>
<tr>
<td>GENERIC NAME</td>
<td>BRAND NAME2</td>
<td>USAGE IN MS</td>
</tr>
<tr>
<td>------------------------------------</td>
<td>---------------------------------------</td>
<td>----------------------------------</td>
</tr>
<tr>
<td>Interferon beta-1a</td>
<td>Rebif (Canada)</td>
<td>Disease modifying agent</td>
</tr>
<tr>
<td>Interferon beta-1b</td>
<td>Betaseron</td>
<td>Disease modifying agent</td>
</tr>
<tr>
<td>Isoniazid</td>
<td>Laniazid; Nydrazid</td>
<td>Tremor</td>
</tr>
<tr>
<td>Magnesium hydroxide¹</td>
<td>Phillips’ Milk of Magnesia</td>
<td>Constipation</td>
</tr>
<tr>
<td>Meclizine</td>
<td>Antivert (US); Bonamine (Can)</td>
<td>Nausea; vomiting; dizziness</td>
</tr>
<tr>
<td>Methenamine</td>
<td>Hiprex, Mandelamine (US); Hip-rex, Mandelamine (Can)</td>
<td>Urinary tract infections (preventative)</td>
</tr>
<tr>
<td>Methylprednisolone</td>
<td>Depo-Medrol</td>
<td>Acute exacerbations</td>
</tr>
<tr>
<td>Mineral oil¹</td>
<td></td>
<td>Constipation</td>
</tr>
<tr>
<td>Mitoxantrone</td>
<td>Novantrone</td>
<td>Immunosuppression</td>
</tr>
<tr>
<td>Modafinil</td>
<td>Provigil</td>
<td>Fatigue</td>
</tr>
<tr>
<td>Nitrofurantoin</td>
<td>Macrodantin</td>
<td>Urinary tract infections</td>
</tr>
<tr>
<td>Nortriptyline</td>
<td>Pamelor</td>
<td>Depression</td>
</tr>
<tr>
<td>Oxybutynin</td>
<td>Ditropan</td>
<td>Bladder dysfunction</td>
</tr>
<tr>
<td>Oxybutynin (extended release formula)</td>
<td>Ditropan XL</td>
<td>Bladder dysfunction</td>
</tr>
<tr>
<td>Papaverine</td>
<td></td>
<td>Erectile dysfunction</td>
</tr>
<tr>
<td>Paroxetine</td>
<td>Paxil</td>
<td>Depression</td>
</tr>
<tr>
<td>Pemoline</td>
<td>Cylert</td>
<td>Fatigue</td>
</tr>
<tr>
<td>Phenazopyridine</td>
<td>Pyridium</td>
<td>Urinary tract infections (symptom relief)</td>
</tr>
<tr>
<td>Phenytoin</td>
<td>Dilantin</td>
<td>Pain (dyesthesias)</td>
</tr>
<tr>
<td>Prednisone</td>
<td>Deltasone</td>
<td>Acute exacerbations</td>
</tr>
<tr>
<td>Propantheline bromide</td>
<td>Pro-Banthine</td>
<td>Bladder dysfunction</td>
</tr>
<tr>
<td>Psyllium hydrophilic¹ muciloid</td>
<td>Metamucil</td>
<td>Constipation</td>
</tr>
<tr>
<td>Sertraline</td>
<td>Zoloft</td>
<td>Depression</td>
</tr>
<tr>
<td>Sildenafil</td>
<td>Viagra</td>
<td>Erectile dysfunction</td>
</tr>
<tr>
<td>Sodium phosphate¹</td>
<td>Fleet Enema</td>
<td>Constipation</td>
</tr>
<tr>
<td>Sulfamethoxazole</td>
<td>Bactrim; Septra</td>
<td>Urinary tract infections</td>
</tr>
<tr>
<td>Tizanidine</td>
<td>Zanaflex</td>
<td>Spasticity</td>
</tr>
<tr>
<td>Tolterodine</td>
<td>Detrol (US)</td>
<td>Bladder dysfunction</td>
</tr>
<tr>
<td>Venlafaxine</td>
<td>Effexor</td>
<td>Depression</td>
</tr>
</tbody>
</table>

¹ Available without a prescription.
² Available in US and Canada unless otherwise noted.
**RECOMMENDED RESOURCES**

**Readings**

**Demos Medical Publishing, New York (Tel: 1-800-532-8663)**


Halper J, Holland N (eds.). (1996). *Comprehensive Nursing Care in Multiple Sclerosis.*


Schapiro RT. (1998). *Symptom Management in Multiple Sclerosis* (3rd ed.).

Schwarz SP. (1999). *300 Tips for Making Life with Multiple Sclerosis Easier.*

**Additional Recommendations**


**National Multiple Sclerosis Society Publications (1-800-FIGHTMS, option 1)**

**Booklets**

Living with MS—ES 0087

What Everyone Should Know About Multiple Sclerosis—ER 100

Research Directions in Multiple Sclerosis—ES 6017

ADA and People with MS—ECS 6021

Enhancing Productivity On Your Job: The Win-Win Approach—ES 6025

Managing MS Through Rehabilitation—ECS 6022

Food for Thought: MS and Nutrition—ES 6020

Multiple Sclerosis and Your Emotions—ES 6007

Taming Stress in Multiple Sclerosis—ES 6034

At Home with MS: Adapting Your Environment—ECS 6035

Solving Cognitive Problems—ECS 6029

Controlling Bladder Problems in MS—ES 0039

Understanding Bowel Problems in MS—ECS 6036
Resources

PLAINTALK: A Booklet About MS for Families—ECS 55
Someone You Know Has MS: A Book for Families—ES 0045
When a Parent Has MS: A Teenager’s Guide—ECS 6024
A Guide for Caregivers—ES 6010
Clear Thinking About Alternative Therapies—ECS 6038
Controlling Spasticity—ECS 6037

Materials Available in Spanish
Hacia una Comprensión de los Problemas de la Vejiga en la Esclerosis Múltiple
Lo qué Todo el Mundo Debe Saber sobre la Esclerosis Múltiple
Qué es la Esclerosis Múltiple?
Qué le Interesa Conocer sobre la Esclerosis Múltiple?
Sobre la Conservación de Energía
Sobre la Fatiga
Sobre los Problemas Sexuales que no Mencionan los Medicos
Sobre el Diagnóstico: Atando Los Cabos de una Larga Historia . . .

Other MS Society Publications
The History of Multiple Sclerosis (reprint)—Loren Rolak, M.D.
Inside MS—A 32-page magazine for people living with MS published three times yearly
Inside MS Bulletin—An 8-page newsletter for donors and friends published three times yearly
Knowledge is Power—A series of articles for individuals newly diagnosed with MS
Living Well with MS—A series of workbooks written for, and by, people who have been living with MS for some time.

Monograph Series (1995)
Families Affected by Multiple Sclerosis: Disease Impacts and Coping Strategies—Rosalind C. Kalb, Ph.D.
Long-Term Care and Multiple Sclerosis—Debra Frankel, M.S., O.T.R.
Employment and Multiple Sclerosis—Nicholas G. LaRocca, Ph.D.
Economic Costs of Multiple Sclerosis: How Much and Who Pays—Carol Harvey, Ph.D.
Utilization and Perceptions of Healthcare Services by People with MS—Leon Sternfeld, M.D., Ph.D., M.P.H.
Websites

ABLEDATA
Information on Assistive Technology
http://www.abledata.com/

Allsup, Inc
Assists Individuals Applying for Social Security Disability Benefits
http://www.allsupinc.com/

Apple Computer Disability Resources

The Ares-Serono Group/Rebif
http://www.serono.com/ms/

Berlex/Betaseron
http://www.betaseron.com/

Biogen/Avonex
http://www.biogen.com/

CenterWatch Clinical Trials Listing Service™
http://www.centerwatch.com/

CLAMS—Computer Literate Advocates for Multiple Sclerosis
http://www.clams.org/

The Consortium of Multiple Sclerosis Centers
http://www.mscare.org/

IBM Special Needs Systems
http://www.austin.ibm.com/sns/

Infosci
Selected Links on MS
http://www.infosci.org/

International Federation of Multiple Sclerosis Societies/The World of Multiple Sclerosis
http://www.nmss.org/

The International Journal of MS Care
http://www.mscare.com/

Medicare Information
http://www.hcfa.gov/medicare/medicare.htm
Resources

Microsoft Accessibility Technology for Everyone
http://www.microsoft.com/enable/

MS Crossroads
Personal Website of Aapo Halko, Ph.D., mathematician with MS in Finland
http://www.helsinki.fi/~ahalko/ms.html

The Multiple Sclerosis Information Gateway
Schering AG, Berlin, Germany
http://www.ms-gateway.com/

The Multiple Sclerosis Society of Canada
http://www.mssoc.ca/

The Myelin Project
http://www.myelin.org/

The National Family Caregivers Association
http://www.nfcacares.org/

The National Institute of Neurological Disorders and Stroke
http://www.ninds.nih.gov/

The National Library of Medicine
http://www.nlm.nih.gov/

The National Multiple Sclerosis Society
http://www.nationalmssociety.org/

The National Organization for Rare Disorders
http://www.rarediseases.org/

NARIC—The National Rehabilitation Information Center
http://www.naric.com/

Rocky Mountain MS Center
Website on alternative/complementary medicine (CAM)
http://www.ms-cam.org

Teva Marion Partners/Copaxone
http://www.tevamarionpartners.com/
Resources

Organizations

- **Consortium of Multiple Sclerosis Centers (CMSC)** (c/o Gimbel MS Center at Holy Name Hospital, 718 Teaneck Road, Teaneck, NJ 07666; tel: 201-837-0727; Internet: www.mscare.org). The CMSC is made up of numerous MS centers throughout the United States and Canada. The Consortium’s mission is to disseminate information to clinicians, increase resources and opportunities for research, and advance the standard of care for multiple sclerosis. The CMSC is a multidisciplinary organization, bringing together health care professionals from many fields involved in MS patient care.

- **Department of Veterans Affairs (VA)** (810 Vermont Avenue, N.W., Washington, DC 20420; tel: 202-273-5400; Internet: www.va.org). The VA provides a wide range of benefits and services to those who have served in the armed forces, their dependents, beneficiaries of deceased veterans, and dependent children of veterans with severe disabilities.

- **Eastern Paralyzed Veterans Association (EPVA)** (75-20 Astoria Boulevard, Jackson Heights, NY 11370; tel: 718-803-EPVA; Internet: www.epva.org). EPVA is a private, nonprofit organization dedicated to serving the needs of its members as well as other people with disabilities. While offering a wide range of benefits to member veterans with spinal cord dysfunction (including hospital liaison, sports and recreation, wheelchair repair, adaptive architectural consultations, research and educational services, communications, and library and information services, they will also provide brochures and information on a variety of subjects, free of charge to the general public (see Appendix C).

- **Equal Employment Opportunity Commission (EEOC)** (Office of Communication and Legislative Affairs, 1801 L Street, N.W., 10th Floor, Washington, DC 20507; tel: 800-669-3362 (to order publications); 800-669-4000 (to speak to an investigator); 202-663-4900; Internet: www.eeoc.gov). The EEOC is responsible for monitoring the section of the ADA on employment regulations. Copies of the regulations are available.

- **Handicapped Organized Women (HOW)** (P.O. Box 35481, Charlotte, NC 28235; tel: 704-376-4735). HOW strives to build self-esteem and confidence among women with disabilities by encouraging volunteer community involvement. HOW seeks to train women with disabilities for leadership positions and works in conjunction with the National Organization of Women (NOW).

- **Health Resource Center for Women with Disabilities** (Rehabilitation Institute of Chicago, 345 East Superior Street, Chicago, IL 60611; tel: 312-908-7997; Internet: www.rehabchicago.org). The Center is a project run by and for women with disabilities. It publishes a free newsletter, “Resourceful Women,” and offers support groups and educational seminars addressing issues from a disabled woman's perspective. Among its many educational resources, the Center has developed a video on mothering with a disability.

- **International Organization of Multiple Sclerosis Nurses (IOMSN)** (P.O. Box 450, Teaneck, NJ 07666; tel: 201-384-2752; fax: 201-384-3954; e-mail: iomsn@aol.com; website: www.iomsn.org). An organization of licensed nurses whose professional interests and activities are related to the care of people with multiple sclerosis either through direct practice, research, education, or administration.

- **Multiple Sclerosis Society of Canada** (250 Bloor Street East, Suite 1000, Toronto, Ontario M4W 3P9, Canada; tel: 416-922-6065; in Canada: 800-268-7582; Internet: www.msssoc.ca). A national organization that funds research, promotes public education, and produces publications in both English and French. They provide an “ASK MS Information System” database of articles on...
Resources

a wide variety of topics including treatment, research, and social services. Regional divisions and chapters are located throughout Canada.


- National Family Caregivers Association (NFCA) (10605 Concord Street, Kensington, MD 20895; tel: 301-942-6430; Internet: www.nfcacares.org). NFCA is dedicated to improving the quality of life of America’s 18,000,000 caregivers. It publishes a quarterly newsletter and has a resource guide, an information clearinghouse, and a toll-free hotline: 800-896-3650.

- National Multiple Sclerosis Society (NMSS) (733 Third Avenue, New York, NY 10017; tel: 800-FIGHT MS; Internet: www.nationalmssociety.org). The NMSS is a nonprofit organization that supports national and international research into the prevention, cure, and treatment of MS and partnership with the medical community to promote quality care for people with MS. Goals include provision of information and nationwide services to assist people with MS, their families, professionals, and the public. The programs of the Society promote knowledge, health, and independence:
  - Toll-free access to the local chapter by selecting “option one” at 800-FIGHT MS.
  - Internet web site with updated information about treatments, current research, and programs (http://www.nationalmssociety.org), local home page in many areas.
  - Knowledge Is Power self-study program (serial mailings) for people newly diagnosed with MS and their families, available through most chapters.
  - Learning on Line, an on-line education series for people newly diagnosed with MS and their families, available on the NMSS website.
  - Printed materials available on a variety of topics from the local chapter.
  - Educational programs on various topics throughout the year, provided through the local chapter.
  - Annual national teleconferences for people with MS and health professionals.
  - Wellness programs in some chapters.

- Office on the Americans with Disabilities Act (Department of Justice, Civil Rights Division, P.O. Box 66118, Washington, DC 20035; tel: 202-514-0301). This office is responsible for enforcing the ADA. To order copies of its regulations, call 202-514-6193.

- Paralyzed Veterans of America (PVA) (801 Eighteenth Street N.W., Washington, DC 20006; tel: 800-424-8200; Internet: www.pva.org). PVA is a national information and advocacy agency working to restore function and quality of life for veterans with spinal cord dysfunction. It supports and funds education and research and has a national advocacy program that focuses on accessibility issues. PVA publishes brochures on many issues related to rehabilitation.

- Social Security Administration (6401 Security Boulevard, Baltimore, MD 21235; tel: 800-772-1213; Internet: www.ssa.gov). To apply for social security benefits based on disability, call this office or visit your local social security branch office. The Office of Disability within the Social Security Administration publishes a free brochure entitled “Social Security Regulations: Rules for Determining Disability and Blindness.”
• Through the Looking Glass: National Research and Training Center on Families of Adults with Disabilities (2198 Sixth Street, Suite 100, Berkeley, CA 94710; tel: 510-848-4445; 800-644-2666; Internet: www.lookingglass.org).

• Well Spouse Foundation (610 Lexington Avenue, New York, NY 10022-6005; tel: 212-644-1241; 800-838-0879). An emotional support network for people married to or living with a chronically ill partner. Advocacy for home health and long-term care and a newsletter are among the services offered.
ORGANIZATIONS OF NOTE

The National Multiple Sclerosis Society (NMSS)

THE NATIONAL MS SOCIETY IS DEDICATED TO ENDING THE DEVASTATING EFFECTS OF MULTIPLE SCLEROSIS

WHAT IS SPECIAL ABOUT THE NATIONAL MULTIPLE SCLEROSIS SOCIETY?
The National Multiple Sclerosis Society supports more MS research and serves more people with MS than any national voluntary MS organization in the world.
The National Multiple Sclerosis Society is the only national voluntary MS organization that meets the standards of ALL major agencies that rate not-for-profit groups in the U.S.

HOW MANY PEOPLE DOES THE SOCIETY SERVE?
Through the Society’s fifty-state network of chapters and divisions, assistance is provided to over a million people annually.

HOW MANY VOLUNTEERS DOES THE NATIONAL MS SOCIETY HAVE?
Across the country, over a million volunteers carry out the mission to end the devastating effects of MS, supported by 2,700 volunteer leaders.

HOW MANY PEOPLE ARE MEMBERS OF THE SOCIETY?
The Society has some 600,000 dues-paying general members.

ARE THE NATIONAL MS SOCIETY’S PROGRAMS FREE?
Free and nominal-fee programs for people with MS are available in every chapter and division. These include counseling, self-help groups, help with medical equipment, information about MS and referral to professionals specializing in MS. The National Multiple Sclerosis Society has the largest library on MS in the world, along with major databases. Information specialists research any questions for lay people and professionals that the local staff is unable to answer.

HOW DO I REACH THE SOCIETY?
By calling toll free, 1-800-FIGHT MS (1-800-344-4867), and pressing 1 to access your local chapter. Our E-mail address: info@nmss.org. Website: http://www.nmss.org.

The National MS Society . . . One thing people with MS can count on.
CONSORTIUM OF MULTIPLE SCLEROSIS CENTERS (CMSC)

ACTIVITIES
• The Annual Education Conference, at which the theme and research presentations cover MS with a depth and scope not found in other clinical programs.
• Conferences designed for healthcare professionals who specialize in MS.
• Specialty roundtable discussions annually to enhance communications between professionals.
• The North American Research Consortium on MS (NARCOMS) established to conduct multi-center trials, develop and manage a patient registry and maintain a website on the Internet.

PARTNERSHIPS
• Partnership in Education with the National MS Society, the MS Society of Canada, PVA and EPVA for education and outreach projects.
• NASA and CMSC are collaborating to seek applications of space technology to help people with MS.

ARCHIVAL SERVICES
• The CMSC serves as a clearinghouse for research results, the latest treatments, clinical trials and patient education programs.

PUBLICATIONS
• Consort, the CMSC Newsletter, provides news about members, answers questions about treatment strategies and profiles MS Centers in the U.S. and Canada.
• Directory is a listing of all members in MS Centers in the U.S. and Canada—including staff.
• Patient Information Guide
• All members are entitled to a free subscription to the journal Multiple Sclerosis.

MISSION
1. To implement an organizational structure, which will optimize the ability to improve the care of those afflicted by MS.
2. To be the principal organization of MS professionals.
3. To provide leadership in clinical research and education.
4. To develop vehicles to share information and knowledge among members, disseminate information to persons affected by MS and disseminate information to the healthcare community.
5. To develop and implement mechanisms to influence healthcare delivery.
# CMSC MEMBERSHIP DUES—2000 (U.S. Dollars only)

<table>
<thead>
<tr>
<th>Membership Type</th>
<th>Fee</th>
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<tbody>
<tr>
<td>Individual Physician</td>
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<tr>
<td>Individual Health Professional</td>
<td>$100.00</td>
</tr>
<tr>
<td>Health Professional Student</td>
<td>$25.00</td>
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<tr>
<td>PVA</td>
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<tr>
<td>Full</td>
<td>$600.00</td>
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<tr>
<td>Associate</td>
<td>$600.00</td>
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<tr>
<td>Liaison</td>
<td>$300.00</td>
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<tr>
<td>Emeritus (Gratis)</td>
<td></td>
</tr>
</tbody>
</table>

Amount Paid: $_________________________ Date __________________

Center Director _____________________________________________________________

Center Contact Person ______________________________________________________

Center Name _______________________________________________________________

Street Address ______________________________________________________________

City/State/Zip ______________________________________________________________

Phone __________________ Fax __________________

URL:http:// __________________________________ email ________________________

Please charge to my credit card.

- [ ] MasterCard
- [ ] Visa
- [ ] American Express

Account Number _________________ Expiration Date _________________

Signature ________________________________________________________________

Name as it appears on card (please print) ____________________________________

Check enclosed _____________________

Please return this invoice to assist us in properly crediting dues to your account. Make checks payable to: Consortium of Multiple Sclerosis Centers. Please remit to:

June Halper, MSN, ANP, FAAN  
Bernard W. Gimbel Multiple Sclerosis—Administrative Office  
Comprehensive Care Center at Holy Name Hospital  
718 Teaneck Road, Teaneck, NJ 07666  
Tel: 201-837-0727 Fax: 201-837-8504 email: jhalper24@aol.com  
Website: http://info.med.yale.edu/cmsc
International Organization of Multiple Sclerosis Nurses

P.O Box 450 Teaneck, New Jersey 07666
Tel: (201) 384-2752
Fax: (201) 384-3954
e-mail: iomsn@aol.com
Website: www.iomsn.org

GOALS

• Facilitate the development of a specialized branch of nursing in MS
• Establish standards of nursing care in MS
• Support MS research
• Educate the healthcare community about MS

MEMBERSHIP

Active Members: An active member shall be a licensed nurse, located anywhere in the world, whose professional interests and activities are related to the care of people with multiple sclerosis either through direct practical research, education or administration.

Junior Members: A Junior member shall be an individual who is enrolled in a nursing program with special interest in the furtherance of the purposes of the organization.

Affiliate Members: An affiliate member shall be a healthcare professional interested in the care of people with Multiple Sclerosis.

Dues: Annual Dues are $25.00 (US currency).

Please make checks payable to IOMSN and mail to: IOMSN, PO Box 450, Teaneck, NJ 07666.

BENEFITS

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