The National MS Society’s Professional Resource Center provides:

- Easy access to comprehensive information about MS management in a variety of formats;
- Dynamic, engaging tools and resources for clinicians and their patients; and
- Consultations and literature search services to support high quality clinical care.

FOR FURTHER INFORMATION:

VISIT OUR WEBSITE:
nationalMSsociety.org/PRC

To receive periodic research and clinical updates and/or e-news for healthcare professionals,

EMAIL:
healthprof_info@nmss.org

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Continuing Education
This book has as its focus the psychological and social challenges confronting people affected by multiple sclerosis — those who are diagnosed with the disease as well as their family members and friends. It describes how people living with MS cope with their symptoms, their treatments, their responsibilities at home and at work, and their relationships, and presents 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:

- Providing information, education, and support
- Identifying problem areas that require additional intervention
- Connecting people with formal (professional) and less formal (family and community) resources available to address these problems

This publication has been adapted and updated from the book developed in conjunction with the 2000 professional teleconference, co-sponsored by the National Multiple Sclerosis Society and the Consortium of MS Centers, entitled *Multiple Sclerosis in 2000: A Model of Psychosocial Support*. The expert panel for this teleconference included: Randolph Schiffer, MD, Marie Namey, RN, MSN, Dorothy Northrop, MSW, ACSW, and Rosalind Kalb, Ph.D.
PART ONE:

CLINICAL VIGNETTES

The following vignettes serve to illustrate many of the medical, emotional, and social issues confronting people with multiple sclerosis (MS) and their families. The remaining sections of the book will provide an overview of the disease and its treatment, highlighting the role of an interdisciplinary model of psychosocial support in addressing these medical and psychosocial issues.

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
Karen is 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 has had 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, he has been taking a disease modifying medication since that time. David had no major problems until three years ago, when his MS became secondary-progressive — at which point he started using a cane to compensate for his increasing weakness and fatigue. He also began experiencing uncomfortable spasticity for which he was given a stretching regimen and medication. 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 the forearm (Lofstrand) 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 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 avid 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 to let MS wreck his mind as well.

David is angry about his increasing limitations over the past three years. Having carefully adhered to his treatment regimen, he doesn’t understand why the MS continues to progress. He thought all those injections were supposed to keep this from happening.
Multiple sclerosis is thought to be an immune-mediated (most likely auto-immune) disease that primarily affects 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 fairly 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 study by Trapp et al. (1998), however, confirmed that the nerve fibers can become irreversibly damaged as a consequence of the immune system’s attacks on myelin and the inflammation that occurs during relapses. This irreversible axonal loss, which can occur even in the earliest stages of the disease, is thought to 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 information, medical experts in multiple sclerosis recommend that early intervention with one of the available disease modifying agents be considered for any person with a confirmed diagnosis of MS and active disease. See the Disease Management Consensus Statement, Appendix C, page 70, for specific recommendations in the United States.
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.

MS is believed by most MS experts 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 25 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. Thus, while the risk of MS in the general population is 1/750, it rises to 1/40 for a person who has a parent or sibling 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 50. 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 500,000 people with MS in the United States and Canada, and more than 2.1 million worldwide.

Disease Course Classifications

Figures 1–4 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. (Neurology 1996, 46:907–911).

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 identify participants for the clinical trials of the disease modifying therapies (see page 24), 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 is characterized by clearly defined acute attacks with full recovery (1A) or with residual deficit upon recovery (1B). Periods between disease relapses are characterized by a lack of disease progression. Approximately 85% 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 (2A) that may also include occasional relapses and minor remissions and plateaus (2B). Natural history data suggest that of the 85% who start with relapsing-remitting disease, more than 50% will develop SPMS within 10 years; 90% within 25 years. The full impact of the disease modifying therapies on this transition to progressive disease in not yet known.

**PRIMARY-PROGRESSIVE MS (PPMS)**

PPMS is characterized by progression of disability from onset, without plateaus or remissions (3A) or with occasional plateaus and temporary minor improvements (3B). Approximately 10% of people are diagnosed with PPMS.

**FIGURE 3: PRIMARY-PROGRESSIVE MS**

**FIGURE 4: PROGRESSIVE-RELAPSING MS**
PROGRESSIVE-RELAPSING MS (PRMS)

PRMS, which is the least common disease course, shows progression from onset but with clear acute relapses, with (4A) or without (4B) full recovery. Approximately 5% 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 95% of newly-diagnosed individuals. They can therefore be used only as confirmatory evidence of the disease. Other tests used to confirm the diagnosis and/or rule out other problems include visual evoked potentials and a lumbar puncture.

SYMPTOMS

As a result of the inflammatory process in the CNS, people with MS can experience any or all of the following symptoms: 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 living with MS will experience some degree of cognitive dysfunction (LaRocca & Kalb, 2006; Rao et al., 1991). A prevalence study found that 73.1 percent of people living with MS reported sexual dysfunction (Zorzon et al., 2001; 1999). Studies of depression in MS indicate that 50 percent of people living 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, resulting in part from the disease process itself (Patten et al., 2003; Minden et al., 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
- 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

Studies have also indicated that although African-Americans are less likely than Caucasians to develop MS, they tend to experience a more progressive disease course (Naismith et al., 2006).
Treatment strategies in MS fall into five general categories:

1. Treatment of acute exacerbations (attacks)
2. Symptom management
3. Disease modification — For up-to-date information about disease modifying therapy in MS, go to nationalMSsociety.org/DMTUpdate
4. Rehabilitation (to enhance and maintain physical function)
5. Psychosocial support

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, and thus may shorten the duration of an exacerbation, but have no long-term benefits in MS.

Many people feel better while taking them, 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 side effects. Patients should be alerted to these potential side effects before taking corticosteroids, and be
reminded that a person can react very differently to corticosteroids from one course to the next.

A second option for the treatment of acute exacerbations is ACTH (H.P. Acthar Gel — repository corticotropin injection). ACTH has been approved by the FDA for this purpose since 1978. Although there was a period when its availability in the U.S. and elsewhere became very restricted due to limited manufacturing production, the product is once again available.

Other treatment options for an acute exacerbation, which are only used if someone cannot tolerate or has not responded to steroids, are IVIG, which is a mixture of immune proteins, and plasmapheresis. Plasmapheresis ‘washes’ a person’s blood, and is thought to remove antibodies and other immune-stimulating substances.

**Symptom Management**

*Table 1* on the following pages 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.

**Discussing Difficult Topics with Your Patients**

As demonstrated in *Table 1*, MS can cause a wide variety of symptoms. Identifying and discussing a person’s symptoms can be challenging at times, for several important reasons.

- While some changes are readily apparent — such as walking problems, speech impairments, or tremor — others, including fatigue, bladder and bowel changes, and cognitive and emotional changes, are less visible to the observer.
- While some symptoms are relatively easy for people to discuss — like fatigue, or double vision, stiffness, or pain — others are more embarrassing, such as cognitive symptoms, bladder and bowel dysfunction, sexual dysfunction, and even depression.

*Note: The series entitled Talking with Your MS Patients about Difficult Topics can be downloaded in PDF format from the Society’s professional website at: nationalMSsociety.org/PRC Publications.*

- While some symptoms are easy for people to associate with a disease that affects the nervous system — including sensory problems, weakness, loss of balance, or visual symptoms — people may neglect to mention other problems that they assume are unrelated to the MS (e.g., fatigue, bladder or bowel changes, sexual dysfunction, cognitive changes, or pain).

For all these reasons, it is important to do a complete assessment at every visit, asking about symptoms or changes whether or not a person has mentioned any difficulties. It is equally important to make sure that people with MS have access to accurate and comprehensive information about the disease so that they are aware of the kinds of changes and symptoms it can cause. Publications about virtually every aspect of MS and its management can be downloaded from the National MS Society website nationalMSsociety.org/Library or requested in hard copy (800-344-4867). The Society is happy to make materials available for you and your patients.
### TABLE 1: SYMPTOM MANAGEMENT & ITS PSYCHOSOCIAL IMPLICATIONS *

<table>
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<tr>
<th>SYMPTOM</th>
<th>TREATMENT</th>
<th>PSYCHOSOCIAL IMPLICATIONS</th>
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<tbody>
<tr>
<td><strong>AMBULATION PROBLEMS</strong></td>
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<tr>
<td>Spasticity</td>
<td>See page 21</td>
<td>See page 21</td>
</tr>
</tbody>
</table>
| Impaired balance | **INTERVENTION:** Referral to PT: mobility aids; exercise | Resistance to use of mobility aids:  
   - Perceptions of self: damaged; weak; giving in  
   - Others’ perceptions: less intelligent; less competent |
| Sensory deficit | **INTERVENTION:** Referral to PT: mobility aids; exercise |                           |
| Weakness       | **INTERVENTION:** Referral to PT: mobility aids; exercise  
   **MEDICATION:** dalfampridine (Ampyra) to improve walking speed |                           |

* Visit nationalMSsociety.org/PRCPublications to read the Clinical Bulletins and Expert Opinion Papers relating to symptom management
<table>
<thead>
<tr>
<th>Symptom</th>
<th>Intervention</th>
<th>Psychosocial Implications</th>
</tr>
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</table>
| Failure to store (urgency, frequency, incontinence, nocturia) | **INTERVENTION:** Scheduled voiding; avoidance of diuretics  
**MEDICATION:** Anti-cholinergic/anti-muscarinic agents [oxybutynin (Ditropan); toterodine (Detrol); hyoscyamine sulfate; trospium chloride (Sanctura); solifenacin succinate (Vesicare)]; scheduled voiding; avoidance of diuretics; onabotulinoxinA (Botox) | 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 |
| Failure to empty (urgency, hesitancy, double voiding, feelings of incomplete emptying) | Intermittent self-catheterization (ISC); may require indwelling catheter | Anxiety about loss of control; fear of ISC |
| Combined failure to store/failure to empty | Combination of the above |                                                                                                                                 |

* Visit nationalMSsociety.org/PRCPublications to read the Clinical Bulletins and Expert Opinion Papers relating to symptom management

** Invisible symptoms can be stressful since they tend to be ignored, misunderstood, or misinterpreted by other people.
<table>
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<th>SYMPTOM</th>
<th>TREATMENT</th>
<th>PSYCHOSOCIAL IMPLICATIONS</th>
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<tbody>
<tr>
<td>BOWEL DYSFUNCTION**</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Constipation</td>
<td><strong>INTERVENTION:</strong> Bowel training; high fiber diet; diet; exercise; medication (e.g., softeners, mild laxatives, mini-enemas)</td>
<td>Discomfort; exacerbation of spasticity</td>
</tr>
<tr>
<td>Fecal impaction</td>
<td>Manual disimpaction</td>
<td>Discomfort; embarrassment</td>
</tr>
<tr>
<td>Diarrhea (usually from constipation)</td>
<td>Disimpact and relieve constipation</td>
<td>Discomfort; embarrassment</td>
</tr>
<tr>
<td>Fecal incontinence</td>
<td>Bowel program; anticholinergic medication (for hyperreflexic bowel)</td>
<td>Loss of control; anxiety about leaving home/being around others; shame</td>
</tr>
</tbody>
</table>

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<tbody>
<tr>
<td><strong>COGNITIVE SYMPTOMS</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Memory impairment</td>
<td></td>
<td></td>
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<tr>
<td>Impaired attention/concentration</td>
<td></td>
<td></td>
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<tr>
<td>Slowed processing speed</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Impaired executive functions</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Impaired spatial relations</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Impaired word-finding ability</td>
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</tbody>
</table>

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

**INTERVENTIONS:**
- Cognitive rehabilitation
  - Restorative approach: direct retraining exercises (have only limited benefit for daily activities)
  - Compensatory approach: aims to improve function via substitution of compensatory strategies/tools for the impaired function

**MEDICATIONS:**
- Disease-modifying agents may slow onset/progression

**INDIVIDUAL:**
- Denial; anxiety; loss of self-esteem/self-confidence; depression; may interfere with self-care and independence

**INTERPERSONAL:**
- Family strain; marital strain; impaired communication; role shifts within the family

**EMPLOYMENT:**
- Major cause of high unemployment rate in people living with MS

**HEALTHCARE:**
- May affect communication with providers and compliance with treatment

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* Visit nationalMSociety.org/PRCPublications to read the Clinical Bulletins and Expert Opinion Papers relating to symptom management

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<tbody>
<tr>
<td><strong>FATIGUE</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>PRIMARY (NEUROLOGIC):</td>
<td>REFERRALS TO PT AND OT; NAPS; MODERATE AEROBIC EXERCISE; WORK SIMPLIFICATION; USE OF ASSISTIVE DEVICES (E.G., ELECTRIC SCOOTER); COOLING STRATEGIES/DEVICES</td>
<td>INABILITY TO CARRY OUT ACTIVITIES AT HOME AND AT WORK; FATIGUE OF THIS MAGNITUDE IS DEPRESSING; INVISIBLE SYMPTOM THAT IS EASILY MISINTERPRETED BY OTHERS</td>
</tr>
<tr>
<td>OVERWHELMING LASSIDUTE OR TIREDNESS THAT CAN STRIKE AT ANY TIME OF DAY</td>
<td>MEDICATIONS: AMANTADINE (SYMMENTREL); MODAFINIL (PROVIGIL); ARMODAFINIL (NUVIGIL)</td>
<td></td>
</tr>
<tr>
<td>SECONDARY:</td>
<td>INTERVENTION: APPROPRIATE SYMPTOM MANAGEMENT; MEDICATION ADJUSTMENTS IF NECESSARY</td>
<td></td>
</tr>
<tr>
<td>RESULTING FROM DISTURBED SLEEP; DEPRESSION; EXTRA EXERTION DUE TO IMPAIRMENTS; MEDICATIONS</td>
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<tr>
<td>MOOD CHANGES**</td>
<td>Intervention: Periodic screenings by physician to identify changes in mood; referral to mental health professional for assessment and management, which may include a combination of psychotherapy, medication, and exercise.</td>
<td>Can interfere with self-care, role performance at home and work; interpersonal relationships, and quality of life. Emotional issues tend to be underreported to the healthcare team, and undertreated when they are reported.</td>
</tr>
<tr>
<td>Mood changes are common in MS with major depression, anxiety, and irritability being the most common. Pseudobulbar affect (uncontrolled episodes of crying and/or laughing) occurs in about 10 percent of people with MS.</td>
<td>Depression</td>
<td>Invisible symptoms can be stressful since they tend to be ignored, misunderstood, or misinterpreted by other people.</td>
</tr>
<tr>
<td>Anxiety</td>
<td><strong>_visited nationalMSsociety.org/PRCPublications to read the Clinical Bulletins and Expert Opinion Papers relating to symptom management</strong></td>
<td></td>
</tr>
<tr>
<td>Irritability</td>
<td>Anxiety Medications: Antidepressent medication (e.g. duloxetine (Cymbalta), fluoxetine (Prozac), escitalopram (Lexapro), citalopram (Celexa), venlafaxine (Effexor).</td>
<td></td>
</tr>
<tr>
<td>Pseudobulbar affect (uncontrollable episodes of crying and/or laughing)</td>
<td>Moodiness/Irritability Medications: Low doses of a mood stabilizing medication such as depakene (Depakote).</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Pseudobulbar Affect Medications: dextromethorphan + quinidine sulfate (Nuedexta)</td>
<td></td>
</tr>
</tbody>
</table>
### Sensory Problems/Pain **

<table>
<thead>
<tr>
<th><strong>Symptom</strong></th>
<th><strong>Treatment</strong></th>
<th><strong>Psychosocial Implications</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Sensory Symptoms (from loss of myelin):</strong> Numbness, tingling</td>
<td><strong>Intervention:</strong> No treatment required unless interfering with function; referral to PT/OT if necessary</td>
<td>Anxiety; discomfort; clumsiness; fatigue increased by medications and interrupted sleep</td>
</tr>
<tr>
<td><strong>Medications (if necessary):</strong> gabapentin (Neurontin); pregabalin (Lyrica); amitriptyline (Elavil); cambamazepine (Tegretol); duloxetine HCL (Cymbalta)</td>
<td>Medications increase fatigue</td>
<td></td>
</tr>
<tr>
<td><strong>Primary Pain (from loss of myelin):</strong></td>
<td><strong>Medications:</strong> carbamazepine (Tegretol); gabapentin (Neurontin); phenytoin (Dilantin); duloxetine (Cymbalta); baclofen (Lioresal)</td>
<td>Medications increase fatigue</td>
</tr>
<tr>
<td>- Trigeminal neuralgia (sharp facial pain)</td>
<td><strong>Surgery:</strong> Radiofrequency rhizotomy; radio frequency electrocoagulation; glycerol rhizotomy</td>
<td></td>
</tr>
<tr>
<td>- Dysesthesias (electric shock-like sensations in trunk or extremities)</td>
<td><strong>Medications:</strong> Same as above, or topical application of capsaicin acid cream</td>
<td>Medications increase fatigue</td>
</tr>
<tr>
<td>- Retro-orbital pain (with optic neuritis)</td>
<td><strong>High-dose IV steroids</strong></td>
<td>Steroids can affect mood</td>
</tr>
<tr>
<td><strong>Secondary Pain (musculoskeletal):</strong> Resulting from poor posture/balance in ambulatory individuals or improper use/fitting of wheelchair</td>
<td><strong>Analgesics; gait training; assessment of all seating (home, automobile, work, and wheelchair/scooter)</strong></td>
<td>Discomfort</td>
</tr>
<tr>
<td></td>
<td><em>Note: People often told by doctors that MS does not cause pain.</em></td>
<td></td>
</tr>
</tbody>
</table>
### Sexual Dysfunction**

<table>
<thead>
<tr>
<th>Symptom</th>
<th>Treatment</th>
<th>Psychosocial Implications</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Primary (Result of Neurologic Impairment):</strong> Impaired arousal; sensory changes; reduced vaginal lubrication; erectile dysfunction; inability to orgasm</td>
<td>Evaluation of all symptom management medications that might be interfering with sexual function</td>
<td>Individual: Significant impact on gratification, self-esteem, self-confidence; difficult/embarrassing to discuss with healthcare providers</td>
</tr>
</tbody>
</table>
| **MEN Medications:** Oral medications (sildenafil — Viagra; vardenafil — Levitra; tadalafil — Cialis); injectable or insertable medication (alprostadil — Prostin VE, MUSE); prosthetic devices | **Women:** Lubricating substances; enhanced stimulation | **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 reach orgasm can also result from medications taken to relieve other symptoms, most notably antidepressants.* |

* Visit [nationalMSsociety.org/PRCPublications](http://nationalMSsociety.org/PRCPublications) to read the Clinical Bulletins and Expert Opinion Papers relating to symptom management

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### SPASTICITY

- Phasic spasms (flexor or extensor)
- Sustained increase in muscle tone

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.*

#### TREATMENT

<table>
<thead>
<tr>
<th>SYMPTOM</th>
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<th>PSYCHOSOCIAL IMPLICATIONS</th>
</tr>
</thead>
<tbody>
<tr>
<td>Phasic spasms (flexor or extensor)</td>
<td>1. Rehabilitative PT (stretching; gait assessment)</td>
<td></td>
</tr>
<tr>
<td>Sustained increase in muscle tone</td>
<td>2. Oral medications: baclofen (Lioresal); tizanidine (Zanaflex); diazepam (Valium); dantrolene sodium (Dantrium)</td>
<td>Oral medications increase fatigue and weakness</td>
</tr>
<tr>
<td></td>
<td>3. Intrathecal baclofen pump</td>
<td>Surgical implantation of pump in abdomen can be frightening</td>
</tr>
<tr>
<td></td>
<td>4. onabotulinumtox A (Botox) injections into individual muscles</td>
<td>Severing of tendons is irreversible</td>
</tr>
<tr>
<td></td>
<td>5. Surgery</td>
<td></td>
</tr>
</tbody>
</table>

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</thead>
<tbody>
<tr>
<td><strong>SPEECH/SWALLOWING PROBLEMS</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>■ Dysarthria — poorly</td>
<td>Assessment; exercise program; training with augmentative or alternative</td>
<td>Slurring can be misinterpreted as drunkenness or lack of intelligence; slow, slurred speech</td>
</tr>
<tr>
<td>articulated, slurred speech</td>
<td>communication devices, if needed</td>
<td>interferes with communication</td>
</tr>
<tr>
<td>■ Dysphagia — difficulty in</td>
<td>Assessment; oral exercise program; modified diet; non-oral feeding</td>
<td>Fear of loss of control, choking; food needs to be blended; eating is exhausting; loss of</td>
</tr>
<tr>
<td>swallowing that can lead to</td>
<td>strategies, if needed</td>
<td>pleasurable mealtimes; loss of ability to eat orally</td>
</tr>
<tr>
<td>aspiration and/or</td>
<td></td>
<td></td>
</tr>
<tr>
<td>inadequate nutrition</td>
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</tbody>
</table>

| TREMOR                       |                                                                           |                                                                                            |
| Involuntary movements of the | **INTERVENTIONS:** Balance/coordination exercises; weights on limbs or    | Fear of loss of control — severe tremor is a major threat to independence                   |
| arms, legs, or head; tremor  | utensils                                                                   |                                                                                            |
| can be the least treatable   |                                                                           |                                                                                            |
| and most debilitating       |                                                                           |                                                                                            |
| symptom of MS               |                                                                           |                                                                                            |
| **MEDICATIONS:** propranolol|                                                                           | Medications can increase fatigue                                                          |
| (Klonopin); primidone (Mysoline); isoniazid (Laniazid); buspirone (BuSpar); ondansetron (Zofran) |                                                                           |                                                                                            |

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</tr>
</thead>
<tbody>
<tr>
<td><strong>VERTIGO</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Severe dizziness and nausea caused by inflammation in the brainstem</td>
<td><strong>MEDICATIONS:</strong> meclizine (Antivert); diazepam (Valium); scopolamine patch IV fluids and high-dose corticosteroids if nausea prevents the use of oral medications</td>
<td>Vertigo interferes with functioning at home and at work Steroids can impact mood</td>
</tr>
<tr>
<td><strong>VISUAL IMPAIRMENT</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Optic neuritis — temporary loss or disturbance of vision, often accompanied by pain; may also cause “blind spot” (scotoma) in center of vision</td>
<td><strong>MEDICATIONS:</strong> High-dose corticosteroids <strong>INTERVENTIONS:</strong> Training in visual compensation, environmental modifications, adaptive equipment, as needed</td>
<td>Visual symptoms can threaten independent functioning (e.g., driving), increase fatigue, and interfere with activities at work and at home</td>
</tr>
<tr>
<td>Diplopia — double vision</td>
<td><strong>MEDICATIONS:</strong> High-dose corticosteroids <strong>INTERVENTIONS:</strong> Training in visual compensation, environmental modifications, adaptive equipment, as needed</td>
<td>Steroids can impact mood</td>
</tr>
<tr>
<td>Nystagmus — rhythmic jerkiness or bounce in one or both eyes</td>
<td><strong>MEDICATIONS:</strong> clonazepam (Klonopin) if necessary <strong>INTERVENTIONS:</strong> Training in visual compensation, environmental modifications, adaptive equipment, as needed</td>
<td>Medication can increase fatigue</td>
</tr>
</tbody>
</table>

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DISEASE MODIFICATION

Since 1993, the U.S. Food and Drug Administration (FDA) has approved several medications for use in multiple sclerosis. For the first time, we have the ability to reduce disease activity for many people living with MS. These medications are not designed to cure MS or provide relief from current symptoms — in fact, the effects on the disease may not be immediately apparent. However, each of these medications has been shown in phase III clinical trials to provide significant long-term benefit for people with relapsing forms of MS. Unfortunately, no medications have yet been approved for the treatment of primary-progressive MS.

And none of these medications are recommended for use by women who are pregnant or trying to become pregnant, or who are breastfeeding. Women should be encouraged to discuss all of their medications with their physician and/or nurse prior to trying to conceive.

The most current information for clinicians about the disease modifying therapies can be found on the Society's website at nationalMSsociety.org/DMTUUpdate and for patients at nationalMSsociety.org/Treatments.

Ongoing clinical trials are listed at: nationalMSsociety.org/ClinicalTrials. Since new trials are announced periodically, and additional information becomes available as trials are completed, it is important to check these sites on a routine basis.

THE ROLE OF EARLY INTERVENTION

Based on clinical experience with the interferon beta medications and glatiramer acetate — 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 Clinical Advisory Board (NCAB) supports early intervention with one of these agents. The Consensus Statement by the NCAB (last revised in 2008 — see Appendix C) recommends that:

- Initiation of therapy with an immunomodulatory medication should be considered as soon as possible following a definite diagnosis of MS with active disease, and may also be considered for selected patients with a first attack who are at high risk of MS.

- Therapy should be continued indefinitely unless there is clear lack of benefit, intolerable side effects, or a better therapy is identified.

- Natalizumab is generally recommended by the FDA for patients who have had an inadequate response to, or are unable to tolerate, other multiple sclerosis therapies.

- Immunosuppressant therapy with Novantrone may be considered for selected relapsing patients with worsening disease.

The full text of the Consensus Statement, which is currently under revision, can be downloaded from the website at: nationalMSsociety.org/Consensus.

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, about 60 percent of the 400,000 individuals with MS in the U.S. are receiving treatment with one of the disease-
modifying therapies. A study by the North American Research Committee on Multiple Sclerosis (NARCOMS) found that one-third of people stop 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 recommended improved education for people living with MS and their families in order to bring their expectations more in line with those of their physicians. They further recommended 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 all health professionals 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 five 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 five 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. Professionals continue to provide support and follow-up, reinforce realistic expectations, and repeat the intervention stages in the event that the patient goes off therapy (Cassidy, 1999; Holland et al., 2001).

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 process directed toward helping the person recover and/or main-
tain 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: fatigue, weakness, spasticity, cognitive impairments, imbalance, sensory loss, ataxia/tremor, pain, paraparesis, speech and swallowing problems, visual disturbances, and bowel and bladder problems. 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, reduce fatigue, and maximize participation in all life roles. 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 & PREVENTIVE GOALS OF REHABILITATION IN MS

In multiple sclerosis, rehabilitation has both restorative and preventive 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 accompanying 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 and secondary complications 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 at any point in the disease process can be emotionally devastating. Rehabilitation professionals and 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.


THE REHABILITATION “TEAM”

The “team” concept is critical to the rehabilitation of people with MS whether or not the various members of the team actually work in tandem within a single setting. Because MS strikes at the peak years of career formation and family life, and because it can affect so many different physical and psychological functions, it demands the coordinated efforts of an interdisciplinary team of professionals working collaboratively with the person with MS and his or her care partners (significant other, other family members, paid assistant(s)).

PERSON WITH MS

As the hub of the rehabilitation team, the person with MS and his or her care partners are the driving force behind the rehabilitation process. In order for the process to be successful, the needs and priorities of the person with MS must always serve to guide the rehabilitation plan. The other members of the team educate the person with MS about his or her options for care, and work collaboratively with that person, and each other, to coordinate and facilitate the interventions that are chosen.

PHYSICIAN (GENERALLY A NEUROLOGIST OR PHYSIATRIST)

The physician often functions as the team leader. Beginning with the initial assessment, the physician works with the person to identify treatment needs and initiate the treatment process. Ideally, referrals to rehabilitation specialists are made during these early days of treatment, while problems are smaller and more manageable, and before medical or psychosocial crises have had a chance to develop. These early interventions can begin the educational process that will help the person with MS to become an active, well-informed partner in his or her own care.
NURSE
The nurse generally functions as the team’s coordinator. While this nursing role may vary from one setting to another, it is generally true that the nurse, who has the most frequent contact with the person with MS, is in the best position to identify the person’s ongoing needs and coordinate referrals to, and communication with, other team members. The nurse can also serve in the role of case manager for those individuals with MS who are unable — or unwilling — to handle that role themselves.

As a member of the rehabilitation team, the nurse provides education about MS, teaches self-management skills (self-injection and symptom management strategies, bowel/bladder care, and skin care), facilitates referrals, and provides ongoing support for the rehabilitation process.

PHYSICAL THERAPIST
The physical therapist’s goal is to evaluate and improve movement and function, with particular emphasis on physical mobility, balance, posture, exercise, and fatigue and pain management.

As part of the rehabilitative process, the physical therapist helps people meet the mobility challenges and identifies and orders appropriate equipment. Physical therapy also assists people in managing the physical demands in their family, work, and social lives while accommodating the physical changes brought about by the disease.

OCCUPATIONAL THERAPIST
The occupational therapist’s role on the rehabilitation team is to help people maintain the everyday skills that are essential for independent living and that allow for productivity at home and at work.

The major areas targeted by the occupational therapist include: fatigue, cognition, upper body strength and coordination, the use of assistive technology, and instruction in behavioral and environmental modifications to maintain maximal home, work, and community participation.

SPEECH-LANGUAGE PATHOLOGIST
The speech-language pathologist primarily addresses problems resulting from impaired muscle control in the lips, tongue, soft palate, vocal cords, and diaphragm, which interfere with speech production, voice quality, and swallowing. The goals are to promote effective communication and identify and address swallowing problems that can compromise a person’s health, comfort, and safety. Speech-language pathologists are also involved in the assessment and management of cognitive dysfunction in people with MS, particularly as it relates to communication.

ADDITIONAL REHABILITATION RESOURCES
The comprehensive rehabilitation team must have access to a variety of other resources, including psychologists, neuropsychologists, social workers, dieticians, orthotists, vocational rehabilitation specialists, and any other professionals whose services might be enlisted to enhance a person’s health and safety, functional independence, and quality of life.
PART FOUR:
PSYCHOSOCIAL SUPPORT

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 — medical providers and the National MS Society — 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 Society for additional information and/or support programs. Others are referred to the Society by their physician or given Society informational materials before leaving the doctor’s office.

Still others, thinking that they or a family member may have MS, contact the Society looking for information and a referral to a local physician.

The teal rectangle connecting the medical team and the Society 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 medical team and the Society is a mutually supportive one. Healthcare professionals can rely on the Society’s Professional Resource Center (HealthProf_info@nmss.org), as well as the Society’s website (nationalMSsociety.org/PRC) for the most current information about the disease and its treatments, as well as for educational programs and materials for people with MS (nationalMSsociety.org/library).
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 the 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 medical team, the Society, 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 — www.mscare.org) or National MS Society-affiliated clinical facilities. 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 teal 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 Society 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 provider, 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 medical team and the National MS Society guide people in the direction of these resources but do not expect any 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.

**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 — a normal 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 carepartners, children, and God.

EMOTIONAL CHANGES OBSERVED IN MS
(Adapted from Feinstein A. The Clinical Neuropsychiatry of Multiple Sclerosis (2nd ed.). New York: Cambridge University Press, 2007.)

- 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; Patton et al., 2003).

- 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; Patton et al., 2003).

- Possible causes of depression in MS include: disease activity (especially onset of exacerbation); neuropathologic changes in the fronto-temporal areas of the brain; neuroendocrine and/or psycho-neuroimmunologic changes; side effects of medications — particularly steroid treatment; and psychosocial factors (including coping style and social stressors (Feinstein, 2007).

- Major depression can occur at any point in the disease course, even as an initial symptom. It is underdiagnosed and undertreated in people with MS (Mohr et al., 2006; Marrie et al., 2009), with the major challenges to diagnosis being: patient’s reluctance to report it, physicians’ failure to ask about mood changes or screen for them; the overlap of symptoms between the vegetative symptoms of depressive disorder and the neurological manifestations of MS (e.g., insomnia, fatigue, weight loss, poor concentration); physicians’ failure to
prescribe adequate doses of antidepressant medication once depression has been diagnosed.

— Tools for assessing depression in MS patients include: Beck Depression Inventory (BDI), Beck Fast Screen for Medically-Ill Patients (B-FS), Yale Single Question Screen for Depression, psychiatric interview (Benedict et al., 2003).

— 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; Edwards & Constantinescu, 2004).

■ 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).

■ Pseudobulbar affect (also known as pathological laughing or weeping) refers to unpredictable episodes of laughing or crying that are unrelated to the person’s underlying mood (Ghaffar et al., 2008).

— Probably caused by lesions in the limbic system or related structures.

— Nuedexta (dextromethorphan + quinidine) was approved by the FDA in 2010 for the treatment of pseudobulbar affect in MS and other neurologic conditions.

— 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).

■ 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 to 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

(Adapted from Mohr D. Talking about Stress. From the booklet series, Talking with Your MS Patients about Difficult Topics. National Multiple Sclerosis Society, 2009)
While people with MS often report that stress precipitated the onset or worsening of their disease, the research findings in this area remain inconclusive. No causal relationships have been confirmed.

Research findings suggest that not all stress is the same. Traumatic stress (e.g., severe, acute stress) may have no effect, or may even be associated with reduced risk of exacerbation, while chronic stress/distress may be associated with increased risk of exacerbation.

If a relationship between stressful life events and MS exacerbations is confirmed, it is likely to be quite variable across individuals, with some people being more resilient than others.

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 50–66 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 demyelinating 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 complete evaluation (e.g., 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:
  - As of 2012, no symptomatic medications have been found to be effective in managing MS-related cognitive changes.
  - Treatment with disease modifying agents: little is currently known about the impact of the disease modifying agents on cognitive function because cognition was not evaluated in many of the initial trials. There is some evidence, however, that disease modifying therapies may prevent or delay the onset or progression of cognitive deficits (Tumani & Uttner, 2007).
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 re-training 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.

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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 phase 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 a person’s care. To a large extent, they will determine the person’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 next big attack following an early remission is the most emotionally devastating. During a 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 next 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 (interferon beta-1a, interferon beta-1b, and glatiramer acetate), 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 parenting activities. A primary breadwinner may need to give up working. A mother or father may need help with parenting 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 re-design 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 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 & 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 re-define 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 his or her own way and in his or her 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, & 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 or labor, but recent evidence suggests that women with MS are slightly more likely than the general population to deliver by C-section and to have babies with a lower birth weight (Kelly et al., 2009).
- Women who wish to breastfeed are encouraged to do so as long as they have the necessary strength and stamina.
- Because the hormones of pregnancy exert a protective (suppressive) 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 or not the pregnancy goes to term).
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 severely disabled parents find adult caregivers or helpers so that young children do not have to serve as primary caregivers for their parents.

“

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.

“
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.
— 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 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% had been abused by a family caregiver (often a spouse), and 20% by a paid caregiver. Eighty percent of those experienced abuse in the form of neglect, 61% in the form of verbal and emotional abuse, and 41% 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 any given time. This accounts for a substantial part of the total economic impact of the disease. The major predictors of job loss in MS are:
  - fatigue
  - cognitive impairments
  - mobility impairments
  - jobs requiring physical exertion

MS is expensive compared to other diseases 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 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 occur. 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 this type of individual; 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) to recognize that the MS is not “to blame” for all of the stresses or conflicts in the household.

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 D 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 the Society (1-800-344-4867) for information. Providers can also contact the Professional Resource Center directly at (HealthProf_info@nmss.org). In addition, the Society publishes numerous pamphlets, booklets, and brochures covering many aspects of MS and its treatment (see Appendix D). These are available at no cost for people with MS and for their providers.

**Sources for Information in This Book**


APPENDIX A:
GLOSSARY


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

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 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.

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.

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.

**BABINSKI REFLEX**

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

**BLOOD-BRAIN BARRIER**

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

**CT SCAN**

See Computerized axial tomography.

**CATHETER**

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

**CENTRAL NERVOUS SYSTEM**

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

**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 FINDING**

An observation made during a medical examination indicating change or impairment in a physical or mental function.
CLINICAL TRIAL
Rigorously controlled studies designed to provide extensive data that will allow for statistically valid evaluation of the safety and efficacy of a particular treatment. See also Double-blind clinical study; Placebo.

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

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

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

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.

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

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

CRANIAL NERVES
Nerves that carry sensory, motor, or parasympathetic fibers to the face and neck. Included among this group of twelve nerves are the optic nerve (vision), trigeminal nerve (sensation along the face), vagus nerve (pharynx and vocal cords). Evaluation of cranial nerve function is part of the standard neurologic exam.
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.

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

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

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

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

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

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

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

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

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

EAE
See Experimental allergic encephalomyelitis.
**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.

**EVOKE POTENTIALS (EPS)**

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

**EXACERBATION**

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

**EXPERIMENTAL ALLERGIC ENCEPHALOMYELITIS (EAE)**

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

**EXTENSOR SPASM**

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

**FAILURE TO EMPTY (BLADDER)**

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

**FAILURE TO STORE (BLADDER)**

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

**FLEXOR SPASM**

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

**FOLEY CATHETER**

See Indwelling catheter.
FOOD & DRUG ADMINISTRATION (FDA)

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

FOOT DROP

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

FRONTAL LOBES

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

GADOLINIUM

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

HANDICAP

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

HEALTH CARE PROXY

See Advance (medical) directive.

HEEL-KNEE-SHIN TEST

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

HELPER T-LYMPHOCYTES

White blood cells that are a major contributor to the immune system’s inflammatory response against myelin.

HEMIPARESIS

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

HEMIPLEGIA

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

IMMUNE SYSTEM

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

IMMUNOSUPPRESSION

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

IMPAIRMENT

As defined by the World Health Organization, an impairment is any loss or abnormality of psychological, physiological, or anatomical structure or function. It represents a deviation from the person’s usual biomedical state. An impairment is thus any loss of function directly resulting from injury or disease.
INCONTINENCE
Also called spontaneous voiding; the inability to control passage of urine or bowel movements.

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

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. There are currently four interferon medications approved for the treatment of MS: Avonex (interferon beta-1a); Betaseron (interferon beta-1b); Rebif (interferon beta-1a); Extavia (interferon beta-1b).

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.

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

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.

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

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

LYMPHOCYTE
A type of white blood cell that is part of the immune system. Lymphocytes can be subdivided into two main groups: B-lymphocytes, which originate in the bone marrow and produce antibodies; T-lymphocytes, which are produced in the bone marrow and mature in the thymus. Helper T-lymphocytes heighten the production of antibodies by B-lymphocytes; suppressor T-lymphocytes suppress B-lymphocyte activity and seem to be in short supply during an MS exacerbation.
MACROPHAGE
A white blood cell with scavenger characteristics that has the ability to ingest and destroy foreign substances such as bacteria and cell debris.

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

MINIMAL RECORD OF DISABILITY (MRD)
A standardized method for quantifying the clinical status of a person with MS. The MRD is made up of five parts: demographic information; the Neurological Functional Systems (developed by John Kurtzke), which assign scores to clinical findings for each of the various neurologic systems in the brain and spinal cord (pyramidal, cerebellar, brainstem, sensory, visual, mental, bowel and bladder); the Disability Status Scale (developed by John Kurtzke), which gives a single composite score for the person’s disease; the Incapacity Status Scale, which is an inventory of functional disabilities relating to activities of daily living; the Environmental Status Scale, which provides an assessment of social handicap resulting from chronic illness. The MRD has two main functions: to assist doctors and other professionals in planning and coordinating the care of persons with MS, and to provide a standardized means of recording repeated clinical evaluations of individuals for research purposes.

MONOCLONAL ANTIBODIES
Laboratory-produced antibodies, which can be programmed to react against a specific antigen in order to suppress the immune response. Tysabri (Natalizumab), one of the disease modifying therapies approved for the treatment of MS is a monoclonal antibody.

MUSCLE TONE
A characteristic of a muscle brought about by the constant flow of nerve stimuli to that muscle, which describes its resistance to stretching. Abnormal muscle tone can be defined as: hypertonus (increased muscle tone, as in spasticity); hypotonus (reduced muscle tone); flaccid (paralysis); atony (loss of muscle tone). Muscle tone is evaluated as part of the standard neurologic exam in MS.

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

MYELIN BASIC PROTEIN
Proteins associated with the myelin of the central nervous system that may be found in higher than normal concentrations in the cerebrospinal fluid (CSF).
fluid of individuals with MS and other diseases that damage myelin.

**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.

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**NEUROGENIC**

Related to activity of the nervous system, as in “neurogenic bladder.”

**NEUROGENIC BLADDER**

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

**NEUROLOGIST**

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

**NEUROLOGY**

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

**NEURON**

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

**NEUROPSYCHOLOGIST**

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

**NOCTURIA**

The need to urinate during the night.

**NYSTAGMUS**

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

**OCCUPATIONAL THERAPIST (OT)**

Occupational therapists assess functioning in activities of everyday living, including dressing, bathing, grooming, meal preparation, writing, and driving, which are essential for independent living. In making treatment recommendations, the OT addresses (1) fatigue management, (2) upper body strength, movement, and coor-
dination, (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 wheelchair-bound individuals.

**Paralysis**
Inability to move a part of the body.

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

**Paraplegia**
Paralysis of both lower extremities (legs).

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

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

**Paroxysmal Spasm**
A sudden, uncontrolled contraction that occurs intermittently, lasts for a few moments, and then subsides.

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

**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.

**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.
PRESSURE SORE
An ulcer (sore) of the skin resulting from pressure and lack of movement such as occurs when a person uses a bed or wheelchair most of the day. 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 pressure sore may become infected and cause general worsening of the person’s health.

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

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

PROGNOSIS
Prediction of the future course of the disease.

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

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

PSEUDOBULBAR AFFECT
Also called pathological laughing or weeping; a condition in which episodes of laughing and/or crying occur with no apparent precipitating event. The hallmark of this condition is that the person’s actual mood is unrelated to/disconnected from the emotion being expressed. Pseudobulbar affect is thought to be caused by lesions in the limbic system, a group of brain structures involved in emotional feeling and expression.

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.

REM ESSION
A lessening in the severity of symptoms or their temporary disappearance during the course of the illness.

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

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

RESIDUAL URINE
Urine that remains in the bladder following urination.

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

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

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.

**TANDEM GAIT**
A test of balance and coordination that involves alternately placing the heel of one foot directly against the toes of the other foot.

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

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

**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 INCONTINENCE**
*See* Incontinence.

**URINARY SPHINCTER**
The muscle closing the urethra, which in a state of flaccid paralysis causes urinary incontinence and in a state of spastic paralysis results in an inability to urinate.
URINARY URGENCY
The inability to postpone urination once the need to void has been felt.

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

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

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

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

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 (VEP)
A test in which the brain’s electrical activity in response to visual stimuli (e.g., a flashing checkerboard) is recorded by an electroencephalograph and analyzed by computer. Demyelination results in a slowing of response time. Because this test is able to confirm the presence of a suspected brain lesion (area of demyelination) as well as identify the presence of an unsuspected lesion that has produced no symptoms, it is extremely useful in diagnosing MS. 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.
## APPENDIX B: 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>adrenocorticotropic hormone (ACTH)</td>
<td>H.P. Acthar Gel</td>
<td>Acute exacerbations</td>
</tr>
<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>Symmetrel</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>baclofen (intrathecal)</td>
<td>Intrathecal Baclofen (ITB)</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>
</tbody>
</table>

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

Note: The materials in this appendix are adapted with permission from Rosalind C. Kalb (ed.), Multiple Sclerosis: The Questions You Have; The Answers You Need (4th ed.). New York: Demos Medical Publishing, 2008. They are also available on the website of the National MS Society (nationalMSsociety.org) in the Treatments section.
<table>
<thead>
<tr>
<th>GENERIC NAME</th>
<th>BRAND NAME&lt;sup&gt;2&lt;/sup&gt;</th>
<th>USAGE IN MS</th>
</tr>
</thead>
<tbody>
<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); Rivotril (Can)</td>
<td>Tremor; Pain; Spasticity</td>
</tr>
<tr>
<td>dalfampridine (formerly called fampridine, 4-aminopyridine, and 4-AP)</td>
<td>Ampyra</td>
<td>Walking</td>
</tr>
<tr>
<td>dantrolene</td>
<td>Dantrium</td>
<td>Spasticity</td>
</tr>
<tr>
<td>desmopressin</td>
<td>DDAVP nasal spray; DDAVP tablets</td>
<td>Urinary frequency</td>
</tr>
<tr>
<td>dexamethasone</td>
<td>Decadron</td>
<td>Acute exacerbations</td>
</tr>
<tr>
<td>dextromethorphan HBr and quinidine sulfate</td>
<td>Nuedexta</td>
<td>Pseudobulbar affect</td>
</tr>
<tr>
<td>diazepam</td>
<td>Valium</td>
<td>Spasticity (muscle spasms)</td>
</tr>
<tr>
<td>docusate&lt;sup&gt;1&lt;/sup&gt;</td>
<td>Colace</td>
<td>Constipation</td>
</tr>
<tr>
<td>docusate&lt;sup&gt;1&lt;/sup&gt;</td>
<td>Enemeez Mini Enema</td>
<td>Constipation</td>
</tr>
<tr>
<td>duloxetine hydrochloride</td>
<td>Cymbalta</td>
<td>Depression; Neuropathic pain</td>
</tr>
<tr>
<td>fingolimod</td>
<td>Gilenya</td>
<td>Disease modifying agent</td>
</tr>
<tr>
<td>fluoxetine</td>
<td>Prozac</td>
<td>Depression; Fatigue</td>
</tr>
</tbody>
</table>

<sup>1</sup> Available without a prescription.  <sup>2</sup> Available in US and Canada unless otherwise noted.
<table>
<thead>
<tr>
<th>GENERIC NAME</th>
<th>BRAND NAME(^2)</th>
<th>USAGE IN MS</th>
</tr>
</thead>
<tbody>
<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>glycerin(^1)</td>
<td>Sani-Supp Suppository (US)</td>
<td>Constipation</td>
</tr>
<tr>
<td>hydroxyzine</td>
<td>Atarax</td>
<td>Itching</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>interferon beta-1a</td>
<td>Rebif</td>
<td>Disease modifying agent</td>
</tr>
<tr>
<td>interferon beta-1b</td>
<td>Betaseron; Extavia</td>
<td>Disease modifying agent</td>
</tr>
<tr>
<td>isoniazid</td>
<td>Laniazid; Nydrazid</td>
<td>Tremor</td>
</tr>
<tr>
<td>magnesium hydroxide(^1)</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</td>
<td>Urinary tract infections (preventative)</td>
</tr>
<tr>
<td>methylprednisolone</td>
<td>Depo-Medrol</td>
<td>Acute exacerbations</td>
</tr>
<tr>
<td>mineral oil(^1)</td>
<td></td>
<td>Constipation</td>
</tr>
<tr>
<td>mitoxantrone</td>
<td>Novantrone</td>
<td>Disease modifying agent</td>
</tr>
<tr>
<td>modafinil</td>
<td>Provigil</td>
<td>Fatigue</td>
</tr>
<tr>
<td>natalizumab</td>
<td>Tysabri</td>
<td>Disease modifying agent</td>
</tr>
</tbody>
</table>

\(^1\) Available without a prescription. \(^2\) Available in US and Canada unless otherwise noted.
<table>
<thead>
<tr>
<th>GENERIC NAME</th>
<th>BRAND NAME</th>
<th>USAGE IN MS</th>
</tr>
</thead>
<tbody>
<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 chloride (extended release formula)</td>
<td>Ditropan XL</td>
<td>Bladder dysfunction</td>
</tr>
<tr>
<td>oxybutynin (transdermal patch)</td>
<td>Oxytrol</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>phenazopyridine</td>
<td>Pyridium</td>
<td>Urinary tract infections (symptom relief)</td>
</tr>
<tr>
<td>phenytoin</td>
<td>Dilantin</td>
<td>Pain (dysesthesia)</td>
</tr>
<tr>
<td>prazosin</td>
<td>Minipress</td>
<td>Bladder dysfunction</td>
</tr>
<tr>
<td>prednisone</td>
<td>Deltasone</td>
<td>Acute exacerbations</td>
</tr>
<tr>
<td>psyllium hydrophilic mucilloid&lt;sup&gt;1&lt;/sup&gt;</td>
<td>Metamucil</td>
<td>Constipation</td>
</tr>
<tr>
<td>sertraline</td>
<td>Zoloft</td>
<td>Depression</td>
</tr>
</tbody>
</table>

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<table>
<thead>
<tr>
<th>GENERIC NAME</th>
<th>BRAND NAME&lt;sup&gt;2&lt;/sup&gt;</th>
<th>USAGE IN MS</th>
</tr>
</thead>
<tbody>
<tr>
<td>sildenafil</td>
<td>Viagra</td>
<td>Erectile dysfunction</td>
</tr>
<tr>
<td>sodium phosphate&lt;sup&gt;1&lt;/sup&gt;</td>
<td>Fleet Enema</td>
<td>Constipation</td>
</tr>
<tr>
<td>solifenacin succinate</td>
<td>Vesicare (US)</td>
<td>Bladder dysfunction</td>
</tr>
<tr>
<td>sulfamethoxazole + trimethoprim combination</td>
<td>Bactrim; Septra</td>
<td>Urinary tract infections</td>
</tr>
<tr>
<td>tadalafil</td>
<td>Cialis</td>
<td>Erectile dysfunction</td>
</tr>
<tr>
<td>tamsulosin</td>
<td>Flomax</td>
<td>Bladder dysfunction</td>
</tr>
<tr>
<td>terazosin</td>
<td>Hytrin</td>
<td>Bladder dysfunction</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>trospium chloride</td>
<td>Sanctura</td>
<td>Bladder dysfunction</td>
</tr>
<tr>
<td>vardenafil</td>
<td>Levitra</td>
<td>Erectile dysfunction</td>
</tr>
<tr>
<td>venlafaxine</td>
<td>Effexor</td>
<td>Depression</td>
</tr>
</tbody>
</table>

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APPENDIX C:

NATIONAL MS SOCIETY CONSENSUS STATEMENT

(©2008; CURRENTLY UNDER REVISION)

RECOMMENDATIONS

The Executive Committee of the National Clinical Advisory Board of the National Multiple Sclerosis Society has adopted the following recommendations regarding use of the current MS disease modifying agents (in alphabetical order):

- glatiramer acetate (Copaxone®)
- interferon beta 1a — intramuscular (Avonex®)
- interferon beta 1a — subcutaneous (Rebif®)
- interferon beta 1b (Betaseron®)
- mitoxantrone (Novantrone®)
- natalizumab (Tysabri®)

The Society recognizes that the factors that enter into a decision to treat are complex and best analyzed by the individual patient's neurologist.

Initiation of treatment with an interferon beta medication or glatiramer acetate should be considered as soon as possible following a definite diagnosis of MS with active, relapsing disease, and may also be considered for selected patients with a first attack who are at high risk of MS.*

Natalizumab is generally recommended by the Food and Drug Administration (FDA) for patients who have had an inadequate response to, or are unable to tolerate, other multiple sclerosis therapies.

Treatment with mitoxantrone may be considered for selected relapsing patients with worsening disease or patients with secondary-progressive multiple sclerosis who are worsening, whether or not relapses are occurring.

Patients’ access to medication should not be limited by the frequency of relapses, age, or level of disability.
A relapse (also known as an exacerbation or attack) is conventionally defined as the development of new or recurring symptoms lasting at least 24 hours and separated from a previous attack by at least one month.

- Treatment is not to be stopped while insurers evaluate for continuing coverage of treatment, as this would put patients at increased risk for recurrent disease activity.
- Therapy is to be continued indefinitely, except for the following circumstances: there is clear lack of benefit; there are intolerable side effects; better therapy becomes available.
- All of these FDA-approved agents should be included in formularies and covered by third party payors so that physicians and patients can determine the most appropriate agent on an individual basis; failure to do so is unethical and discriminatory.
- Movement from one disease-modifying medication to another should occur only for medically appropriate reasons.
- None of the therapies has been approved for use by women who are trying to become pregnant, are pregnant, or are nursing mothers.

**INTRODUCTION**

The management of multiple sclerosis (MS) has been substantially advanced by the availability of the disease modifying agents, glatiramer acetate and interferon beta 1a and 1b, mitoxantrone, and natalizumab. A number of positive outcomes have been demonstrated in people with relapsing disease: reduction in the frequency of relapses [Betaseron; Avonex; Copaxone; Rebif; Novantrone; Tysabri]; reduction of brain lesion development, as evidenced by magnetic resonance imaging (MRI) [Betaseron; Avonex; Copaxone; Rebif; Novantrone; Tysabri] and the possible reduction of disability progression [Betaseron; Avonex; Copaxone; Rebif; Novantrone; Tysabri].

Based on several years of experience with glatiramer acetate, interferon beta 1a and 1b and mitoxantrone, and the more recent experience with natalizumab, it is the consensus of researchers and clinicians with expertise in MS that these agents are likely to reduce future disease activity and improve quality of life for many individuals with relapsing forms of MS, including those with secondary progressive disease who continue to have relapses. For those who are appropriate candidates for one of these drugs, treatment must be sustained for years. Cessation of treatment may result in a resumption of pre-treatment disease activity.

Clinical trials are designed to evaluate the smallest number of people, over the shortest period of time, at the lowest cost. In order to accomplish this, inclusion criteria are necessarily narrow. These restricted parameters of clinical trials are not intended to regulate subsequent clinical use of the agent. With demonstrated benefit to people living with MS from continued use of glatiramer acetate, interferon beta 1a, or interferon beta 1b, it is critical that these therapies be made available early in the disease process to appropriate candidates as indicated in the labeling of each of these medications, and that mitoxantrone and natalizumab be available for judicious use in aggressive relapsing disease and for those not responding to other disease modifying therapies.

If a copy of the entire document with references is desired, call 1-800-344-4867 or go to nationalMSsociety.org/Consensus.
APPENDIX D:
RECOMMENDED RESOURCES

READINGS

JOURNAL ARTICLES


— Harrington CB. (2008). *Barrier-Free Travel: A Nuts and Bolts Guide for Wheelers and Slow Walkers* (3rd ed.).
— Schapiro RT. (2007). *Symptom Management in Multiple Sclerosis* (5th ed.).

**ADDITIONAL RECOMMENDATIONS**


INFORMATION FROM THE NATIONAL MS SOCIETY

MATERIALS FOR HEALTHCARE PROFESSIONALS

Available from the PRC: healthprof_info@nmss.org

PAMELLA CAVALLO PROFESSIONAL EDUCATION SERIES

- Multiple Sclerosis: A Focus on Rehabilitation
- Multiple Sclerosis: A Model of Psychosocial Support
- Multiple Sclerosis: The Nursing Perspective
- Multiple Sclerosis: Medication Management

TALKING WITH YOUR MS PATIENT ABOUT DIFFICULT TOPICS

nationalMSociety.org/PRCPublications

- Talking about the Diagnosis of Multiple Sclerosis
- Talking about Progressive Disease
- Talking about Elimination Problems
- Talking about Sexual Dysfunction
- Talking about Depression and Other Emotional Changes
- Talking about Cognitive Dysfunction
- Talking about Initiating and Adhering to Treatment with Injectable Disease Modifying Agents
- Talking about Family Issues
- Talking about Life Planning
- Talking about the Role of Rehabilitation
- Talking about Stress
- Talking about Reproductive Issues
- Talking about Primary Progressive MS
- Talking about Palliative Care, Hospice, and Dying

CLINICAL BULLETINS

nationalMSociety.org/ClinicalBulletins

- Overview of MS
- Primary Care in MS
- Reproductive Issues in Persons with Multiple Sclerosis
- Bladder Dysfunction in Multiple Sclerosis
- Surgical Management of Bladder Dysfunction in Multiple Sclerosis
- Bowel Management in Multiple Sclerosis
- Cognitive Loss in Multiple Sclerosis
- Management of Fatigue in Multiple Sclerosis
- Emotional Issues of the Person with MS
- Pain in Multiple Sclerosis
- Palliative Care
- Spasticity
- Diagnosis and Management of Vision Problems in Multiple Sclerosis
- Occupational Therapy in Multiple Sclerosis Rehabilitation
- Complementary and Alternative Medicine in Multiple Sclerosis
- Improving Adherence to Therapy with Immunomodulating Agents
- Aging with Multiple Sclerosis
Pseudobulbar Affect
Pulmonary Functional Rehabilitation in Multiple Sclerosis
Lymphedema
Physical Therapy in Multiple Sclerosis Rehabilitation
Dysarthria in Multiple Sclerosis
Assessment and Treatment of Sexual Dysfunction in Multiple Sclerosis
Swallowing Disorders and Their Management in Patients with Multiple Sclerosis
Vitamin D and MS: Implications for Clinical Practice

EXPERT OPINION PAPERS
nationalMSsociety.org/ExpertOpinionPapers

Disease Management Consensus Statement
Management of MS-Related Fatigue
Assessment and Management of Cognitive Impairment in Multiple Sclerosis
Changing Therapy in Relapsing Multiple Sclerosis: Considerations and Recommendations
Rehabilitation: Recommendations for Persons with Multiple Sclerosis
Recommendations Regarding Cannabis in Multiple Sclerosis

Recommendations Regarding Corticosteroids in the Management of Multiple Sclerosis
Patient Access to Tysabri

LONG-TERM CARE GUIDELINES & RECOMMENDATIONS
nationalMSsociety.org/PRCPublications
Nursing Home Care
Adult Day Programs
Assisted Living
Home Care
Caring for Loved Ones with Advanced MD

BOOKLETS FOR LAY READERS
Available by calling 1-800-344-4867 or online at nationalMSsociety.org/library

INFORMATION IN ENGLISH

ADA and People with MS
At Home with MS
Bowel Problems: Basic Facts
“But You Look So Good!”
Choosing the Right Healthcare Provider
Clear Thinking about Alternative Therapies
Comparing the Disease-Modifying Drugs

Controlling Bladder Problems
Depression and Multiple Sclerosis
Diagnosis: Basic Facts
Disclosure: Basic Facts
Exercise as Part of Everyday Life
Fatigue: What You Should Know
Food for Thought
Gait or Walking Problems: Basic Facts
Genetics: Basic Facts
A Guide for Caregivers
Hiring Help at Home: Basic Facts
The History of Multiple Sclerosis
Hormones: Basic Facts
Information for Employers
Just the Facts
Living with MS
Managing MS through Rehabilitation
MS and Intimacy
MS and the Mind
MS and Your Emotions
MS and Pregnancy
Pain: Basic Facts
A Place in the Workforce
PLAINTALK: A Booklet about MS for Families
Información en Español

- Comparación de los Medicamentos Modificadores de la Enfermedad
- Controlando los Problemas de la Vejiga en la Esclerosis Multiple
- Debo Trabajar? Información para Empleados
- Diagnóstico: Hechos Básicos
- Ejercicios Prácticos de Estiramiento
- Ejercicios Prácticos de Estiramiento con un Ayudante
- La Fatiga: Lo que Usted Debe Saber
- Información para Empleadores
- Lo que Todo el Mundo Debe Saber sobre la Esclerosis Múltiple
- ¿Qué es la Esclerosis Múltiple?
- Sobre los Problemas Sexuales

Otros Publicaciones de la Smithsonian National MS Society

- Knowledge Is Power — A series of articles for individuals newly diagnosed with MS
- Keep S’myelin — A print and online newsletter for young children who have a parent with MS.

Sitios web

Nota: Se advierte a los lectores que los sitios web están sujetos a cambio sin previo aviso.

- ABLEDATA
  Información sobre Tecnología Asistiva
  abledata.com
- Allsup, Inc — Asistente a las solicitudes de beneficios de discapacidad de la Seguridad Social
  allsupinc.com
- Can Do Multiple Sclerosis (antiguamente The Heuga Center) — Ofrece programas de empoderamiento de estilo de vida para personas con MS y sus socios
  MSCanDo.org
- CenterWatch Clinical Trials
  Listing Service AA
  centerwatch.com
- CLAMS: Computer Literate Advocates for Multiple Sclerosis
  clams.org
- Consortium of Multiple Sclerosis Centers
  mscare.org
- IBM Accessibility Center
  ibm.com/able
- International Journal of MS Care
  mscare.com
- Medicare Information
  medicare.com
- Microsoft Accessibility Technology for Everyone
  microsoft.com/enable
- Multiple Sclerosis Information Gateway — Schering AG, Berlin, Germany
  ms-gateway.com
- Multiple Sclerosis International Federation
  msif.org
- Multiple Sclerosis Rehabilitation Research and Training Center — George H. Kraft, MD
  msrrtc.washington.edu
- The Multiple Sclerosis Society of Canada
  mssociety.ca
- The Myelin Project
  myelin.org
- MyMSMyWay — A free resource (developed by The Technology Collaborative) dedicated to connecting people with Multiple Sclerosis to accessible technologies that can help them live their lives better
  MyMSMyWay.com
- The National Family Caregivers Association
  nfcacares.org
- The National Institute of Neurological Disorders and Stroke
  ninds.nih.gov
- The National Library of Medicine
  nlm.nih.gov
- The National Multiple Sclerosis Society
  nationalMSsociety.org
- The National Organization for Rare Disorders
  rarediseases.org
- NARIC — The National Rehabilitation Information Center
  naric.com
- Rocky Mountain MS Center Website on alternative/complementary medicine (CAM)
  ms-cam.org
APPENDIX E:
ORGANIZATIONS OF NOTE

CONSORTIUM OF MULTIPLE SCLEROSIS CENTERS (CMSC)

359 Main Street, Suite A
Hackensack, NJ 07601
tel: 201-678-2290
website: mscar.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
website: 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.

EQUAL EMPLOYMENT OPPORTUNITY COMMISSION (EEOC)

Office of Communication and Legislative Affairs
1801 L Street, N.W., 10th Floor
Washington, DC 20507
tel: 1-800-669-3362
(to order publications)

1-800-669-4000
(to speak to an investigator)
202-663-4900
website: eeoic.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 disabled women by encouraging volunteer community involvement. HOW seeks to train disabled women for leadership positions and works in conjunction with the National Organization of Women (NOW).
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 MS NURSES (IOMSN)**

359 Main Street, Suite A
Hackensack, NJ 07601
tel: 201-487-1050
website: iomsn.org

An organization of licensed nurses whose professional interests and activities are related to the care of people living with multiple sclerosis either through direct practice, research, education, or administration.

**MULTIPLE SCLEROSIS SOCIETY OF CANADA**

250 Bloor Street East #1000
Toronto, Ontario
M4W 3P9, Canada
tel: 416-922-6065
in Canada: 1-800-268-7582
website: mssoc.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 a wide variety of topics including treatment, research, and social services. Regional divisions and chapters are located throughout Canada.

**NATIONAL COUNCIL ON DISABILITY (NCD)**

1331 F Street, N.W., Suite 1050
Washington, DC 20004
tel: 202-272-2004
website: ncd.gov

The Council is an independent federal agency whose role is to study and make recommendations about public policy for people with disabilities. Publishes a free newsletter, “Focus.”

**NATIONAL FAMILY CAREGIVERS ASSOCIATION (NFCA)**

10605 Concord Street
Kensington, MD 20895
tel: 301-942-6430
website: nfca.cares.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: 1-800-896-3650.

**NATIONAL MS SOCIETY**

733 Third Avenue
New York, NY 10017
tel: 1-800-344-4867
website: nationalMSsociety.org

The National MS Society is the largest nonprofit organization in the United States supporting research for the treatment, prevention and cure of multiple sclerosis. Through its 50-state network of chapter and the combined efforts of volunteers, donors, researchers and health professionals, the Society provides significant outreach, education and support to individuals and families who are impacted by the disease.
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: 1-800-424-8200
website: 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: 1-800-772-1213
website: 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 and 1-800-644-2666
website: lookingglass.org

UNITED SPINAL ASSOCIATION

Formerly the Eastern Paralyzed Veterans Association

75-20 Astoria Boulevard
Jackson Heights, NY 11370
tel: 718-803-3782

email: info@unitedspinal.org
website: unitedspinal.org

United Spinal is a membership organization that was incorporated in New York in 1947 under the name Eastern Paralyzed Veterans Association (Eastern). In January of 2004, EPVA became the United Spinal Association, with the expanded mission of advocacy for all individuals with a spinal cord injury or disease, regardless of their age, gender, or veteran status. United Spinal offers a wide range of benefits, including hospital liaison, sports and recreation, wheelchair repair, adaptive architectural consultations, research and educational services, communications, and library and information services, as well as publications on a variety of subjects.

WELL SPOUSE FOUNDATION

610 Lexington Avenue
New York, NY 10022-6005
tel: 212-644-1241 and 1-800-838-0879

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.
APPENDIX F:
CONTINUING EDUCATION

It is our pleasure to provide you with the self-study course, “Multiple Sclerosis: A Model of Psychosocial Support”, in partnership with the National Multiple Sclerosis Society.

Completing the course is as simple as 1-2-3!
1. Read the course material.
2. Complete the test for self-assessment.
3. Correct your answers by using the answer key provided.

It’s that easy! When complete, return the corrected test along with your evaluation, personal record, and a check or money order for $25.00 in the envelope provided. Once we have received your materials, we will mail your Certificate of Completion.

Providership information is indicated below.

We invite you to visit us on the web at: http://www.HealthCE.com
Your Personal Record Form

(Thank you for completing the information below. This will become a part of your personal record – information that is required that we keep by the various State Boards of Nursing.

Email will be utilized only to inform you of important information regarding your self-study purchase, i.e., pass/fail, date certificate is mailed, etc. Email addresses will NEVER be sold to third parties).

Name______________________________________________________________
(as you would like it to appear on your certificate – please print legibly)

Address________________________________________________________________

City, ST, ZIP________________________________________ Telephone:______________

Email Address:________________________________________ License State:______________

Professional License # ________________ _____ Profession:______________________________

FOR OFFICE USE ONLY:
Course #:_______ Start Date:_____/_____/_____ End Date:_____/_____/_____ Cust.#_______
Multiple Sclerosis: A Model of Psychosocial Support

Description:

Multiple sclerosis (abbreviated MS) is thought to be an immune-mediated (most likely autoimmune) disease that primarily affects 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.

Purpose:

The mental health practitioner and other healthcare professionals working with the MS patient will better understand the disease process and how it affects the patient and family psychosocially.

Objectives:

Upon completion of this course, the participant will be able to...

1. Define multiple sclerosis.
2. Discuss the pathophysiology, etiology, and epidemiology of the disease.
3. List and discuss common emotional reactions to MS.
4. Explore the role of stress in MS.
5. Discuss cognitive impairment in MS.
6. Describe psychosocial issues that may present over the course of the disease.
7. Discuss the impact of MS on the family.
8. Explore unique challenges that mental health providers must recognize and address when working with MS patients.
Audience:

This course is appropriate for: Social Workers, Psychologists, LPNs, RNs, ARNPs, and other healthcare personnel interested in this subject matter.

Credit:

Nursing – 2.5 contact hours (based on a 60-minute hour); 3 contact hours (based on a 50-minute hour).

CE Solutions, a Division of VGM Education is an approved provider of continuing nursing education by the Alabama State Nurses Association, an accredited approver by the American Nurses Credentialing Center’s COA.

CE Solutions, a Division of VGM Education is an approved provider of continuing education for the Iowa Board of Nursing, #335.

CE Solutions, a Division of VGM Education is an approved provider by the Florida Board of Nursing through CE Broker, #50-4572. This approval is also under effect for the District of Columbia Board of Nursing.

CE Solutions, a Division of VGM Education is a California Board of Registered Nursing Provider Number CEP 14033 for 3 contact hours.

Important information

To access the most current information about disease modifying therapies available to treat multiple sclerosis go to http://nationalmssociety.org/DMTUpdate. If you do not have access to a computer, call the National MS Society’s Professional Resource Center at 212-467-0475 or CE Solutions, a Division of VGM Education toll-free at 1-866-650-3400, to have that information mailed to you.
Test for
MS: A Model of Psychosocial Support

1. Multiple Sclerosis (MS) is thought to be an immune-mediated (most likely autoimmune) disease that primarily affects the central nervous system – the brain, spinal cord, and optic nerves.
   a. True
   b. False

2. Research indicates that MS may be the result of an abnormal autoimmune response to some infectious agent or environmental trigger in a genetically susceptible individual.
   a. True
   b. False

3. MS is a hereditary disease.
   a. True
   b. False

4. MS is more common in African American and Hispanic males than in other population groups.
   a. True
   b. False

5. It is estimated that there are more than 500,000 people with MS in the United States and Canada, and more than 2.5 million worldwide.
   a. True
   b. False

6. Disease categories are meant to serve primarily as a tool for the development of clinical research protocols, and as a guide for certain types of treatment decisions. These disease categories are meant to be descriptive in nature rather than a “report card” or rating scale of a person’s disease. An individual may not fit neatly into one category or another.
   a. True
   b. False
7. _______ is a normal, intermittent emotional response to losses incurred over the course of the disease.
   a. Flat affect
   b. Euphoria
   c. Grief
   d. Satisfaction

8. Some people with MS experience feelings of _______. They worry that they are letting everybody down and are no longer pulling their own weight.
   a. transference
   b. embarrassment
   c. dissatisfaction
   d. guilt

9. _______ is more common among people with MS than it is among patients with other chronic conditions that are equally disabling.
   a. Lethargy
   b. Malaise
   c. Depression
   d. Euphoria

10. It has been proven that stress can precipitate or worsen the MS disease process.
    a. True
    b. False

11. Approximately _______ of people with MS will experience some changes in cognitive functioning.
    a. 10-25%
    b. 26 -30%
    c. 50-66%
    d. 75%

12. In the individual with MS, 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.
    a. True
    b. False
13. The treatment of cognitive dysfunction in MS involves
   a. symptom management medications.
   b. disease modification.
   c. cognitive rehabilitation.
   d. all of the above.

14. The most effective treatment(s) for cognitive dysfunction is(are):
   a. medication.
   b. strategies and tools to compensate for the impaired cognitive functions.
   c. direct retraining exercises to restore impaired cognitive functions.
   d. Omega-3 dietary supplements.

15. Mental health providers may need to alter their working styles to accommodate the
    needs of cognitively-impaired individuals. This may include all of the following, EXCEPT
    a. speaking more quickly.
    b. repeating themselves.
    c. providing written suggestions for the person to take home.
    d. suggesting family members and friends help the individual with MS make a list of
       concerns prior to an appointment.

16. A *key point* in working with MS patients in the early relapsing course of the disease
    process is to recognize
    a. resentment towards family members will always occur at this stage.
    b. there are no fixed or pre-determined stages of adaptation to this illness.
    c. care providers will easily be able to discern cognitive and emotional changes.
    d. mood swings are common but not necessarily a concern at this phase of the
       disease process.

17. During an early remission, the person with MS, whose symptoms have all but
    disappeared, may believe that the diagnosis was either a mistake or something that he
    or she managed to conquer. This is an example of
    a. grief.
    b. depression.
    c. denial.
    d. bargaining.
18. Following diagnosis, decisions about disclosure can have major emotional, social, and financial repercussions.
   a. True
   b. False

19. Grief and anxiety about disease progression may lead some people to resist
   a. consulting a financial planner.
   b. anticipating future needs.
   c. using adaptive equipment.
   d. All of the above
   e. None of the above

20. As disease progression continues, resistance can impact medication compliance and the individual’s role as a parent or homemaker. As these losses continue, it is important to allow the individual time to _________ so that he or she can begin to make constructive adaptations.
   a. contemplate
   b. grieve
   c. withdraw
   d. plan

21. As the disease progresses, individuals should be encouraged to find his or her “MS-Free Zone”,
   a. a place that MS has not reached – like the individual’s love for music or poetry, his or her religious faith or other avenues that provide a personal emotional respite.
   b. a national support group for MS patients with locations in all 50 states.
   c. a financial support system developed especially for the needs of the MS patient.
   d. All of the above
22. Medical and mental healthcare providers have a valuable role to play when working with the progressively disabled person and family with MS
   a. by helping individuals and families cope with their feelings of loss.
   b. by helping individuals and families acquire available resources.
   c. by helping individuals and families identify options and make good choices.
   d. by helping individuals and families act with deliberation rather than react to crisis.
   e. All of the above.

23. MS impacts the whole family. All of the following are challenges to the family’s coping efforts, EXCEPT
   a. Family members always share similar coping mechanisms.
   b. MS is a chronic disease and families may be living with its effects for several decades.
   c. MS can necessitate significant role changes within the family.
   d. MS may affect family communication as each family member struggles to emotionally adapt and cope with the effect of the disease on the family unit.

24. A pregnant woman with MS is more likely to experience exacerbations during the nine months of her pregnancy.
   a. True
   b. False

25. Recent studies report significant, long-term psychological and behavioral difficulties in children who have a parent with MS.
   a. True
   b. False

26. Often youngsters describe MS as a disease that “makes people cranky.”
   a. True
   b. False

27. Often the primary caregiver for an individual with MS is a spouse.
   a. True
   b. False
28. Economically, most MS costs are uncompensated and 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.
   a. True
   b. False

29. Challenges a mental health provider may face with the MS patient are
   a. patients requiring more assistance than you are used to providing.
   b. knowing how to deal with an emotionally health patient.
   c. recognizing when MS is not the primary issue.
   d. effectively dealing with information obtained on the internet – both positive and negative.
   e. All of the above

30. Mental health providers, because of the complex set of challenges posed by the MS patient, should work collaboratively with a variety of medical and mental health professionals to more effectively support people’s efforts to live comfortably with MS.
   a. True
   b. False
Answer Sheet
Multiple Sclerosis: The Nursing Perspective

Name: ____________________________  Date: ________________

1. a b c d e f  21. a b c d e f
2. a b c d e f  22. a b c d e f
3. a b c d e f  23. a b c d e f
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6. a b c d e f  26. a b c d e f
7. a b c d e f  27. a b c d e f
8. a b c d e f  28. a b c d e f
9. a b c d e f  29. a b c d e f
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17. a b c d e f
18. a b c d e f
19. a b c d e f
20. a b c d e f

Please continue by checking your answers against the answer key provided. Then return your corrected answer sheet, the course evaluation form, your Personal Record Form, and a personal check or money order in the amount of $25.00 to:

The CE Solutions
A Division of VGM Education
1111 W San Mar nan Dr.
Waterloo, Iowa 50701
Toll-Free Telephone: 1-866-650-3400
Test Key for
Multiple Sclerosis: A Model of Psychosocial Support

1. Multiple Sclerosis (MS) is thought to be an immune-mediated (most likely autoimmune) disease that primarily affects the central nervous system – the brain, spinal cord, and optic nerves.
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2. Research indicates that MS may be the result of an abnormal autoimmune response to some infectious agent or environmental trigger in a genetically susceptible individual.
   a. True
   b. False

3. MS is a hereditary disease.
   a. True
   b. False

   *(MS is not hereditary; 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.)*

4. MS is more common in African American and Hispanic males than in other population groups.
   a. True
   b. False

   *(MS occurs more frequently in Caucasians of northern European ancestry than either African American or Hispanic population groups.)*

5. It is estimated that there are more than 500,000 people with MS in the United States and Canada, and more than 2.5 million worldwide.
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6. Disease categories are meant to serve primarily as a tool for the development of clinical research protocols, and as a guide for certain types of treatment decisions. These disease categories are meant to be descriptive in nature rather than a “report card” or rating scale of a person’s disease. An individual may not fit neatly into one category or another.
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   c. Depression
   d. Euphoria

10. It has been proven that stress can precipitate or worsen the MS disease process.
    a. True
    b. False

   *(Research findings in this area remain inconclusive. No causal relationships have been confirmed.)*

11. Approximately _______ of people with MS will experience some changes in cognitive functioning.
    a. 10-25%
    b. 26-30%
    c. 50-66%
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   d. MS may affect family communication as each family member struggles to emotionally adapt and cope with the effect of the disease on the family unit.

24. A pregnant woman with MS is more likely to experience exacerbations during the nine months of her pregnancy.
   a. True
   b. False
   (Because the hormones of pregnancy exert a protective or suppressive effect on the immune system, a woman is likely to experience fewer exacerbations during the nine months of pregnancy, particularly in the second and third trimester.)
25. Recent studies report significant, long-term psychological and behavioral difficulties in children who have a parent with MS.
   a. True
   b. False

   *(Recent studies have reported no significant, long-term psychological or behavioral difficulties in children who have a parent with MS.)*

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30. Mental health providers, because of the complex set of challenges posed by the MS patient, should work collaboratively with a variety of medical and mental health professionals to more effectively support people’s efforts to live comfortably with MS.
   a. True
   b. False
Self-Study Evaluation (ED II)

Course Title: Multiple Sclerosis: A Model of Psychosocial Support

Date completed: ________________

Please score your responses (1 – 5) with one (1) being the least effective and five (5) being the most effective.

<table>
<thead>
<tr>
<th>1. Evaluate the relationship of objectives to overall purpose/goal of the educational program.</th>
<th>Most</th>
<th>Least</th>
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<tr>
<td>2. Define multiple sclerosis.</td>
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<td>3. Discuss the pathophysiology, etiology, and epidemiology of MS.</td>
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<td>5. Explore the role of stress in MS.</td>
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<td>9. Explore unique challenges that mental health providers must recognize and address when working with MS patients.</td>
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<td>10. Use of teaching/learning resources:</td>
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<td>Text</td>
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<td>Drawings, Figures</td>
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<td>Internet sites (when listed)</td>
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<tr>
<td>Other</td>
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5 4 3 2 1
11. Please indicate the amount of time actually taken to complete the reading material (hours)________________

12. Please indicate the amount of time actually taken to complete the testing portion (minutes or hours)________________

13. Other comments are welcomed:

14. How did you hear of us?
   (  ) Newspaper  (  ) Web
   (  ) Flier  (  ) A friend
   (  ) Direct Mail  (  ) Other______________________________

15. How might we serve you better?

16. What other course offerings might you be interested in?

If you prefer, this evaluation may be sent directly to the Iowa Board of Nursing at 400 S.W. 8th Street, Suite B, Des Moines, Iowa 50309-4685

Thank you. We have appreciated this opportunity to serve you.
The National Multiple Sclerosis Society is dedicated to a world free of multiple sclerosis.

WHAT IS SPECIAL ABOUT THE NATIONAL MS SOCIETY?

MS stops people from moving. The National MS Society exists to make sure it doesn’t. The Society is dedicated to achieving a world free of MS. We are people who want to do something about MS, now. Join the movement® at nationalMSsociety.org.

HOW MANY PEOPLE DOES THE SOCIETY SERVE?

Through the organization’s fifty-state network of chapters and divisions, assistance is provided to over one million people annually. Through its Professional Resource Center, the Society also provides information, support, and education to healthcare professionals involved in the care of people with MS and their families.

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 thousands of volunteer leaders.

HOW MANY PEOPLE ARE MEMBERS OF THE SOCIETY?

The Society has some 600,000 general members.

ARE THE PROGRAMS OFFERED BY THE NATIONAL MS SOCIETY 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.

HOW DO I REACH THE SOCIETY?

Website: nationalMSsociety.org or call toll free: 1-800-344-4867

WHAT IS THE PROFESSIONAL RESOURCE CENTER?

The Society’s Professional Resource Center (PRC), which houses a comprehensive library of MS information, supports the work of health professionals involved in the care of people with MS and their families. The PRC provides a range of library and literature search services, as well as information and consultation about the disease and its management, insurance, long-term care, and the Society’s professional education opportunities. The goal of these services is to enhance quality of care and increase access to care for people with multiple sclerosis. Email: HealthProf_info@nmss.org.
Organized in 1986 under the direction of neurologists interested in the clinical care of multiple sclerosis, the CMSC has grown to become a multi-disciplinary organization providing a team approach to MS care and a network for all health care professionals and others specializing in the care of persons with MS. Since 1986, the CMSC has grown to more than 200 member centers in the United States, Canada, and Europe, representing over 4,000 health care professionals worldwide who provide care for more than 150,000 individuals with multiple sclerosis.

**THE VISION OF THE CMSC**

To be the pre-eminent organization of multiple sclerosis health care providers improving the lives of those affected by multiple sclerosis.

**THE MISSION OF THE CMSC:**

- Stimulating and facilitating research in the field of multiple sclerosis.
- Developing vehicles to share information and knowledge among CMSC members and the health care community, for the benefit of those affected by MS.
- Developing and implementing mechanisms to influence health care delivery.
- Partnering with other organizations to accomplish the above

Through its North American Research Committee on Multiple Sclerosis (CMSC-NARCOMS) based at University of Alabama, CMSC-NARCOMS maintains a patient registry, website, expert forum and research registry to promote MS research. The CMSC also has an online journal, the International Journal of Multiple Sclerosis Care (IJMSc) (www.mscare.com) to promote multi-disciplinary approaches to treating persons with Multiple Sclerosis.

For more information about the organization, the categories of membership, and the online membership application, go to www.mscare.org/cmsc/CMSC-Information-Membership.html.