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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WHAT’S INSIDE?

PREFACE ..................................................................................... 1

PART ONE: CLINICAL VIGNETTES ............................... 2

PART TWO: DISEASE OVERVIEW ................................. 5

Pathophysiology ................................................................. 5

Etiology .................................................................................. 6

Epidemiology ................................................................. 7

Disease Course Classifications ............................................. 7

Diagnosis ............................................................................. 9

Symptoms ............................................................................ 10

Prognosis ............................................................................. 10

Treatment ........................................................................... 11

Source Materials .................................................................... 23

PART THREE: REHABILITATION ................................. 24

The Unique Role of Rehabilitation in MS ........................ 25

Restorative & Preventive Goals of Rehabilitation in MS .... 25

The Rehabilitation “Team” .................................................. 25

Challenges in MS Rehabilitation ........................................ 27

The Rehabilitation Paradigm ............................................... 30

Source Materials for Rehabilitation .................................... 47
The progressive nature of multiple sclerosis (MS), the unpredictability & variability of its symptoms, and the emotional and social changes it can cause, combine to create a complex, clinical challenge for rehabilitation professionals.

In the course of their work with people living with MS, rehab specialists evaluate and explain disease-related impairments and provide interventions to maximize function, promote health, and prevent unnecessary complications. This book provides an overview of MS and its treatment, with an emphasis on the unique role of rehabilitation professionals in the treatment process.

This publication was originally adapted and updated from the book developed in conjunction with the 1999 professional teleconference, co-sponsored by the National Multiple Sclerosis Society and the Consortium of MS Centers, entitled Multiple Sclerosis in 1999: A Focus on Rehabilitation. The expert panel for this teleconference included Linda Morgante, RN, MSN, CRRN, Lois Copperman, PhD, OTR/L, and Cinda Hugos, MS, PT. We gratefully acknowledge the review and revisions provided by Ms. Hugos and Dr. Copperman.
The following vignettes serve to illustrate some of the medical, rehabilitative, and psychosocial issues confronting people living with multiple sclerosis (MS). The remaining sections of the book will provide an overview of the disease and its management, highlighting the role of rehabilitation professionals in addressing symptoms, maintaining function, preventing unnecessary complications, and promoting wellness.

**Valerie**, a 31-year-old married woman with a 5-year-old daughter, teaches at the local high school. She was diagnosed four-and-a-half years ago, following her daughter’s birth, when she experienced an episode of optic neuritis and numbness and tingling in her right hand. She was treated with IV methylprednisolone and started on one of the disease-modifying drugs. Her symptoms cleared, to be followed about a year later by a second attack of optic neuritis, an intensification of the sensory symptoms, and severe fatigue.

The symptoms cleared partially with a course of steroids, but Valerie continued to experience significant fatigue almost every day. By the time she got home from school, Valerie had no energy left to do much of anything. The lingering fatigue was beginning to make her busy, satisfying life feel unmanageable. In addition, she sometimes had difficulty seeing her computer screen or managing tasks requiring fine
motor skills at home and at work. Her handwriting deteriorated and small objects tended to fall out of her hand.

Valerie and her husband, Steven, scheduled an appointment with the neurologist to discuss Valerie’s new limitations. While Steven was willing and able to take on a larger share of the more physically-demanding parenting activities and household responsibilities, Valerie and Steven shared a concern about her ability to maintain her teaching job and still have the energy to be a mom and wife. Neither wanted her to have to give up a career that gave her so much enjoyment and also helped pay the bills.

Valerie’s neurologist referred her to rehabilitation specialists for help with energy management. The physical therapist (PT) designed a personalized aerobic exercise plan for Valerie to enhance her energy and talked to Valerie about a motorized scooter that would enable her to participate more comfortably in activities and outings with her family. Valerie followed the therapist’s suggestion that she talk to her school about some reasonable accommodations that would allow her to use her energy for teaching rather than for simply navigating her way around the school. With a letter from the doctor, the school was happy to provide Valerie with a parking spot closer to the building, a first-floor classroom that was close to the bathroom, and a short rest period in the middle of the afternoon.

The neurologist also referred Valerie to an occupational therapist for additional energy saving strategies at home and at work, and for help with her sensory symptoms and occasional visual problems. Valerie is now equipped with tools for writing, for holding objects more securely, and for seeing her computer screen more clearly. With the encouragement of the OT, she has also learned to ask for more help from her students who, she was delighted to discover, were happy to pass out papers, write on the blackboard, or run occasional errands to the office. As Valerie continues to use more assistive equipment and adaptive strategies, she has discovered that these, too, have helped reduce her fatigue and enhance her teaching.

JAMES is a 47-year-old divorced accountant who lives alone. Originally diagnosed with relapsing-remitting MS at age 35, James had no major problems until five years ago, when his MS started to become more progressive. The neurologist prescribed baclofen to relieve James’ increased spasticity and recommended that he start on one of the disease-modifying agents. The PT recommended a cane to compensate for his weakness and fatigue. James and the PT developed a stretching program for his spasticity and an aerobic exercise program to help with his endurance and deconditioning.

A short time later, James developed some problems with his bladder, including urinary urgency and frequency. Having had two bladder accidents, he began wearing a protective pad whenever he went out of the house, and looked for the nearest bathroom any time he went to an unfamiliar place.

James was initially reluctant to discuss the urinary problems with his neurologist or nurse because he found it all too embarrassing. However, after reading on the National MS Society website (nationalMSsociety.org) about the treatment of MS-related bladder problems, he realized that these problems are fairly common and readily managed. This encouraged him to speak openly with his neurologist and nurse, and he now manages his bladder symptoms with medication and intermittent self-catheterization.
James’ MS progressed to the point where he needed bilateral support for walking. Although he had fallen a few times, he was unwilling to switch from the forearm crutches to a motorized scooter. While the scooter would reduce his fatigue and enable him to get around much more safely and easily, James was afraid it would make him look more disabled. He didn’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 was also concerned that using a scooter would interfere with his ability to meet women. Besides, James was sure that if he started using a scooter, he would lose his ability to walk. Once an avid athlete, James was clinging to the hope that he would one day be able to resume the sports activities that were so important in his life. The PT helped James recognize that his job was more threatened by his unsteady gait and tendency to fall than it would be by a new mobility aid. She helped him select and obtain insurance coverage for a motorized scooter, which he now uses for the long trips up and down the corridors at work and between the building and his car. During the day, James leaves the scooter in the closet and uses his forearm crutches to walk around his office. Using these mobility aids in combination with the bilateral ankle/foot orthoses recommended by his PT, James has found that he is much less fatigued. Both he and his co-workers are pleased with his productivity and new-found stability.

At those times when James still feels particularly fatigued, he finds it difficult to speak clearly. His words sometimes slur to the point that friends have teased him about “having one too many.” Fortunately, the speech problems tend to occur late in the day when James is less likely to be speaking to clients. The neurologist prescribed amantadine to relieve the fatigue and referred James to an OT to learn energy effectiveness strategies. He also referred James to a speech-language pathologist for an evaluation. In addition to his physical problems, James is now concerned that he’s not able to think as clearly as 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 has made some mistakes at work and feels that his thinking is less organized. He’s begun to feel “as though it’s all slipping away from him.” He recently heard a National MS Society online program about cognitive dysfunction and has decided to ask the OT about this problem as well.
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 A, page 51, 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 living 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 with MS, with the risk being higher for girls than boys. 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 living 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 living with MS in the United States and Canada, and more than 2.1 million worldwide.

**Disease Course Classifications**

The charts on the following pages (Figures 1–4) 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. (1996).

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 living with MS when they were used by researchers to identify participants for the clinical trials of the disease-modifying therapies, 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 living 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 is 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.
PROGRESSIVE-RELAPSING MS (PRMS)

PRMS, which is the least common disease course, shows progression from onset but with clear acute relapses, with (A) or without (B) full recovery. Approximately 5% of people appear to have PRMS at diagnosis.

(Figures 1 through 4 adapted from Fred D. Lublin, M.D., and Stephen C. Reingold, Ph.D., Neurology, April 1996, 46:907–911.)

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.

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.
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

Treatment strategies in MS fall into five general categories:

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

Categories 1–3 and 5 will be summarized here. Category 4, rehabilitation, is discussed in the remainder of the book.

TREATMENT OF ACUTE EXACERBATIONS

Although the exact protocol may differ, most neurologists use a high-dose intravenous (IV) corticosteroid agent such as methylprednisolone plus sodium succinate. Most commonly used is a 3- to 5-day course of treatment, either in the hospital or as an outpatient, which may or may not be followed by a gradually tapering dose of an oral corticosteroid such as prednisone. Steroids work to decrease acute inflammation in the CNS, but have no long-term benefits in MS.

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

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.

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.
### TABLE 1: SYMPTOM MANAGEMENT & ITS PSYCHOSOCIAL IMPLICATIONS *

<table>
<thead>
<tr>
<th>SYMPTOM</th>
<th>TREATMENT</th>
<th>PSYCHOSOCIAL IMPLICATIONS</th>
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<tbody>
<tr>
<td><strong>AMBULATION PROBLEMS</strong></td>
<td></td>
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<tr>
<td>Spasticity</td>
<td><strong>SEE:</strong> Spasticity</td>
<td><strong>SEE:</strong> Spasticity</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 |
| Weakness                 | **INTERVENTION:** Referral to PT: mobility aids; exercise  
  **MEDICATION:** Fampridine-SR (Ampyra) to improve walking speed |                           |
| **BLADDER DYSFUNCTION**  |                                                |                           |
| Failure to store (urgency, frequency, incontinence, nocturia) | Anti-cholinergic/anti-muscarinic agents (oxybutynin (Ditropan); tolterodine (Detrol); hyoscyamine sulfate; propantheline bromide (Pro-Banthine); trospium chloride (Sanctura); solifenacin succinate (Vesicare)); scheduled voiding; avoidance of diuretics | Fear of drinking liquids; anxiety over loss of control; fear of leaving the vicinity of bathroom; embarrassment/shame; fear of incontinence during intercourse; increased fatigue due to interrupted sleep |

* 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.
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<tr>
<td><strong>BLADDER DYSFUNCTION</strong>**</td>
<td></td>
<td></td>
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<tr>
<td>Failure to empty (urgency, hesitancy, double voiding, feelings of incomplete emptying)</td>
<td>Intermittent self-catheterization (ISC); may require indwelling catheter</td>
<td>Anxiety about loss of control; fear of ISC</td>
</tr>
<tr>
<td>Combined failure to store/failure to empty</td>
<td>Combination of the above</td>
<td></td>
</tr>
<tr>
<td><strong>BOWEL DYSFUNCTION</strong>**</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Constipation</td>
<td>Bowel training; high fiber 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>INTERVENTIONS: Cognitive rehabilitation</td>
<td>INDIVIDUAL: Denial; anxiety; loss of self-esteem/self-confidence; depression; may interfere with self-care and independence</td>
</tr>
<tr>
<td>■ Impaired attention/concentration</td>
<td>■ Restorative approach: direct retraining exercises (have only limited benefit for daily activities)</td>
<td>INTERPERSONAL: Family strain; marital strain; impaired communication; role shifts within the family</td>
</tr>
<tr>
<td>■ Slowed processing speed</td>
<td>■ Compensatory approach: aims to improve function via substitution of compensatory strategies/tools for the impaired function</td>
<td>EMPLOYMENT: Major cause of high unemployment rate in people living with MS</td>
</tr>
<tr>
<td>■ Impaired executive functions</td>
<td>MEDICATIONS: Donepezil hydrochloride (Aricept) may be useful; disease-modifying agents may be beneficial</td>
<td>HEALTHCARE: May affect communication with providers and compliance with treatment</td>
</tr>
<tr>
<td>■ Impaired spatial relations</td>
<td></td>
<td></td>
</tr>
<tr>
<td>■ Impaired word-finding ability</td>
<td></td>
<td></td>
</tr>
<tr>
<td><em>Note: Cognitive deficits are often missed in a standard neurologic exam.</em></td>
<td></td>
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| **FATIGUE**              | INTERVENTIONS: Referrals to PT and OT; naps; moderate aerobic exercise; work simplification; use of assistive devices (e.g., electric scooter); cooling strategies/devices | Inability to carry out activities at home and at work; fatigue of this magnitude is depressing; invisible symptom that is easily misinterpreted by others |
| PRIMARY (NEUROLOGIC):   | MEDICATIONS: Amantadine (Symmetrel); modafinil (Provigil); fluoxetine (Prozac) |                                                                |
| Overwhelming lassitude or tiredness that can strike at any time of day |                                                |                                                                |
| SECONDARY:              |                                                |                                                                |
| Resulting from disturbed sleep; depression; extra exertion due to impairments; medications |                                                |                                                                |

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<tr>
<td><strong>SENSORY PROBLEMS/PAIN</strong>**</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>SENSORY SYMPTOMS (FROM LOSS OF MYELIN):</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Numbness, tingling</td>
<td>No treatment required unless interfering with function; medication if necessary; referral to PT/OT if necessary</td>
<td>Anxiety; discomfort; clumsiness; fatigue increased by medications and interrupted sleep</td>
</tr>
<tr>
<td><strong>PRIMARY PAIN (FROM LOSS OF MYELIN):</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Trigeminal neuralgia (sharp facial pain)</td>
<td><strong>MEDICATIONS:</strong> Carbamazepine (Tegretol); gabapentin (Neurontin); phenytoin (Dilantin); duloxetine (Cymbalta); baclofen (Lioresal)</td>
<td>Medications increase fatigue</td>
</tr>
<tr>
<td>Dysesthesias (electric shock-like sensations in trunk or extremeties)</td>
<td><strong>SURGERY:</strong> Radiofrequency rhizotomy; radiofrequency electro-coagulation; glycerol rhizotomy</td>
<td>Medications increase fatigue</td>
</tr>
<tr>
<td>Numbness, tingling: Retro-orbital pain (with optic neuritis)</td>
<td><strong>MEDICATIONS:</strong> Same as above, or topical application of capsaicin cream</td>
<td>Steroids can affect mood</td>
</tr>
<tr>
<td><strong>SECONDARY PAIN (MUSCULOSKELETAL):</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Resulting from poor posture/balance in ambulatory individuals or improper use/fitting of wheelchair</td>
<td>Analgesics; gait training; assessment of all seating (home, automobile, work, and wheelchair/scooter)</td>
<td>Discomfort</td>
</tr>
</tbody>
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| PRIMARY (RESULT OF NEUROLOGIC IMPAIRMENT): Impaired arousal; sensory changes; reduced vaginal lubrication; erectile dysfunction; inability to reach orgasm | Evaluation of medications that might be interfering with sexual function (e.g. antidepressants)  
**MEN:** Oral medications (sildenafil — Viagra; vardenafil — Levitra; tadalafil — Cialis); injectable or insertable medication (alprostadil—Prostin VE, Muse); prosthetic devices  
**WOMEN:** Lubricating substances; enhanced stimulation | **INDIVIDUAL:** Significant impact on gratification; self-esteem; self-confidence; difficult/embarrassing to discuss with healthcare providers  
**INTERPERSONAL:** Significant impact on 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 living 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  
*Note: Impaired arousal, erectile dysfunction, and inability to reach orgasm can also result from medications taken to relieve other symptoms, most notably antidepressants.* | Effective management of MS symptoms to reduce impact on sexual function |  

* 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.*
## 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.*

<table>
<thead>
<tr>
<th>SYMPTOM</th>
<th>TREATMENT</th>
<th>PSYCHOSOCIAL IMPLICATIONS</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sexual Dysfunction**</td>
<td>Individual and couple’s counseling and education</td>
<td>Same as listed on page 16</td>
</tr>
<tr>
<td>Spasticity</td>
<td></td>
<td></td>
</tr>
<tr>
<td>1.</td>
<td>Rehabilitative PT (stretching; gait assessment)</td>
<td></td>
</tr>
<tr>
<td>2.</td>
<td>Oral medications (baclofen — Lioresal; tizanidine — Zanaflex; diazepam — Valium)</td>
<td>Oral medications increase fatigue and weakness</td>
</tr>
<tr>
<td>3.</td>
<td>Intrathecal baclofen pump</td>
<td>Surgical implantation of pump in abdomen can be frightening</td>
</tr>
<tr>
<td>4.</td>
<td>Botulinum toxin injections into individual muscles</td>
<td></td>
</tr>
<tr>
<td>5.</td>
<td>Surgery</td>
<td>Severing of tendons is irreversible</td>
</tr>
</tbody>
</table>

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<tbody>
<tr>
<td><strong>SPEECH/SWALLOWING PROBLEMS</strong></td>
<td><strong>TREMOR</strong></td>
<td></td>
</tr>
<tr>
<td>■ Dysarthria — poorly articulated, slurred speech</td>
<td>Assessment; exercise program; training with augmentative or alternative communication devices, if needed</td>
<td>Slurring can be misinterpreted as drunkenness or lack of intelligence; slow, slurred speech interferes with communication</td>
</tr>
<tr>
<td>■ Dysphagia — difficulty in swallowing that can lead to aspiration and/or inadequate nutrition</td>
<td>Assessment; oral exercise program; modified diet; non-oral feeding strategies, if needed</td>
<td>Fear of loss of control, choking; food needs to be blenderized; eating is exhausting; loss of pleasurable mealtimes; loss of ability to eat orally</td>
</tr>
<tr>
<td><strong>TREMOR</strong></td>
<td><strong>INTERVENTIONS:</strong> Balance/coordination exercises; weights on limbs or utensils</td>
<td>Fear of loss of control — severe tremor is a major threat to independence</td>
</tr>
<tr>
<td>Involuntary movements of the arms, legs, or head; tremor can be the least treatable and most debilitating symptom of MS</td>
<td><strong>MEDICATIONS:</strong> Propranolol; clonazepam (Klonopin); primidone (Mysoline); isoniazid (Laniazid); buspirone (BuSpar); ondansetron (Zofran)</td>
<td>Medications can increase fatigue</td>
</tr>
</tbody>
</table>

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</thead>
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<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>Oral medication (meclizine — Antivert); 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</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</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>

* Visit [nationalMSsociety.org/PRCPublications](http://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. **
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.

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/DMTUpdate 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).

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
SOURCE MATERIALS


Although we now have disease-modifying therapies available to help slow the progression of multiple sclerosis, most people living 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 maintain the highest possible level of functioning and realize his or her optimal physical, mental, and social potential given any limitations that exist. The National Clinical Advisory Board of the National MS Society has adopted a series of recommendations to provide guidance to health professionals, insurers, and policy makers regarding the appropriate use of rehabilitative therapies in MS (See Rehabilitation Consensus Statement, Appendix D; also available in PDF format at nationalMSsociety.org/Expert-OpinionPapers.

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 living 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 living 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 LIVING WITH MS

As the hub of the rehabilitation team, the person living 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 living with MS must always serve to guide the rehabilitation plan. The other members of the team educate the person living 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 living 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 living 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 living 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, physical therapy helps people meet the mobility challenges with exercise and the appropriate use of ambulation aids. 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 living 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.

CHALLENGES IN MS REHABILITATION

MS has several relatively unique characteristics that make rehabilitation interventions particularly challenging:

MS IS A CHRONIC DISEASE

Although significant progress has been made in our efforts to alter the course of MS, it remains an incurable disease. For healthcare professionals who are used to achieving a cure or bringing an end to a problem, MS poses a daunting challenge. MS forces us to re-frame our treatment priorities and change the yardstick by which we measure our successes. The person we treat today will probably be back — often more impaired than the first time, and less impaired than the next time. We need to learn to measure our degree of success not by our ability to make the person well, but by our ability to help that person function optimally and maximize his or her quality of life given the current level of impairment.

We also need to be able to convey this message to people living with MS and their care partners. Most people are accustomed to the acute illness model in which one gets sick, gets treatment, and gets well. The challenge posed by a chronic illness is to maintain a positive, hopeful outlook in the face of disease progression. The person living with MS needs to deal with the realities of MS — whatever they turn out to be — and recognize that disease progression is not a sign of personal weakness or failure. He or she needs to be able to acknowledge the limitations posed by the disease and establish personal goals that are possible to achieve. Thus, the goal “to be able to walk without assistance” may need to be replaced by the goal “to remain comfortably and independently mobile.” We need to maintain our confidence and hope in the rehabilitation process so that we can pass it on to our clients when their own faith in the process is challenged.

Within the context of a chronic, often disabling disease like MS, the person’s outlook fluctuates between hopelessness and hope. As defined by Morgante and McCann (2002), “Hope is the smallest or largest expression of the spirit of optimism.”
While this concept was conceived within the field of nursing, it pertains equally to any health-care provider working with individuals with MS. We are all in a position to provide the resources needed to promote optimism and hope, and prevent hopelessness and despair. To do this, we must be sensitive to these feelings in ourselves as well as in the people with whom we are working. Figure 5 is a diagram representing the fluctuations from hope to hopelessness and back again that are present in all of us.

**MS IS CHARACTERIZED BY VARIABILITY & UNPREDICTABILITY**

Because MS is so variable from one individual to the next, and from time to time in any given individual, the importance of realistic goal-setting cannot be over-emphasized. The goals must be flexible and problem-focused so that they can be altered in response to changes in the disease. In addition, it is critical that the therapist, patient, and even the patient’s care partner(s) share an understanding and acceptance of the goals being targeted at any given point in time.

The variability of MS also has an impact on treatment adherence. The person with relapsing disease may find it difficult to adhere to a treatment regimen during periods of remission, because of a wish to believe that the MS has disappeared forever, and during relapses because of increased fatigue, debilitating symptoms, and feelings of anger or despair. In addition, the day-to-day unpredictability of the disease can gradually chip away at a person’s confidence in, and commitment to, the rehabilitation process. Rehabilitation specialists need to be creative in supporting the person’s efforts to re-adjust his or her goals as the disease changes from day-to-day or year-to-year, while emphasizing the importance of adaptive modifications.

**MS IS ASSOCIATED WITH HIGH LEVELS OF FATIGUE**

Fatigue, the most common symptom reported by people living with MS, is caused by the disease itself (called primary MS fatigue), as well as by secondary factors associated with the disease. Common secondary causes of fatigue include weakness (including nerve fiber fatigue) leading to disability, sleep disturbance, aerobic and muscular deconditioning, side effects of medications, other medical conditions, heat sensitivity, and depression. Rehabilitation professionals should be alert to these potentially treatable secondary sources of fatigue.

For people living with MS who find it difficult to make it through their daily activities, there is often little energy left for therapy visits, exercise programs, or any other types of interventions.
These may readily come to be seen as extra burdens on an already overburdened day. Furthermore, people living with MS often resist using the kinds of gait/mobility assistive devices that would help them manage their fatigue because they do not want to “give in to the disease.” Effective fatigue management and education are the keys to this particular challenge. People living with MS and their care partners need to be educated about the causes of fatigue and effective fatigue management strategies including exercise, the use of assistive devices as tools to reduce fatigue and enhance independent functioning, good sleep hygiene, emotional well-being, and medication management. The National MS Society has created a small-group video training series entitled Fatigue: Take Control, which can assist rehab professionals’ efforts to treat fatigue. The series, based on the Clinical Practice Guideline, “Fatigue and Multiple Sclerosis,” developed by the Multiple Sclerosis Council for Clinical Practice Guidelines, is available by calling 1-800-344-4867.

**DEPRESSION IS PREVALENT IN MS**

Depression is more common in MS than in other chronic diseases, including those that are equally disabling. At least 50% of people living with MS will experience a major depressive episode at some point in the course of their illness. Although the reasons for this are not clear, it appears that depression in MS is related not only to the stresses it imposes on everyday life, but also to lesion damage and atrophy in particular areas of the brain. And there is suggestive evidence that immune abnormalities may be involved as well. Whatever its causes, however, depression can profoundly impact our rehabilitation efforts. A person who is depressed or dysphoric finds it difficult if not impossible to collaborate in his or her own care. The rehabilitation team can only succeed if the person living with MS is an active, participating member. Therefore, adequate assessment, diagnosis, and treatment of depressive symptoms are essential to the rehabilitation process.

**COGNITIVE DYSFUNCTION OCCURS IN HALF OF THE MS POPULATION**

Cognitive dysfunction is common in MS. Approximately 50–60% of people living with MS will experience some degree of impairment over the course of the illness. While for most, the changes will be relatively mild, and therefore manageable with the use of appropriate compensatory strategies, approximately 10% of those with cognitive dysfunction will experience changes severe enough to interfere significantly with daily functioning. Among the cognitive problems that can occur in MS, the ones most commonly seen include: memory impairment, problems with attention and concentration, slowed information processing, impairments in executive functions (i.e., the ability to plan, organize, and problem-solve), visual-spatial deficits, and word-finding difficulties.

_Degree of cognitive impairment in MS is unrelated to severity of physical disability._ A person with significant physical impairment might remain cognitively intact while a person with no physical limitations might demonstrate significant cognitive deficits.
In addition, cognitive impairment can occur very early in the disease, even as one of the presenting symptoms, or appear much later in the disease course. Therefore, we cannot make any assumptions about a person's cognitive status based on physical symptoms or time since diagnosis.

A person's ability to participate effectively in the planning and implementation of the rehabilitation process will depend, at least in part, on his or her cognitive status. Therefore, the interventions we offer need to take into account any cognitive problems that might interfere with that participation. Our communication style, teaching strategies, and intervention methods must be suited to the person's cognitive abilities and deficits. It is because of these challenges that rehabilitation only recently came to have a major role in the care of people living with MS. Early specialists argued that there was no justification for rehabilitation in a chronic, progressive illness. Why put effort and resources into people who would only get worse? Research demonstrates, however, that multidisciplinary rehabilitation programs are beneficial for people living with MS (Baker et al., 2001; Mathiowetz et al., 2001; Aisen, 1999; Freeman et al., 1999; Solari et al., 1999; LaRocca & Kalb, 1992).

Even in the presence of deteriorating neurologic status, people receiving intensive rehabilitation have demonstrated improvements in activity level and participation, as well as emotional well-being. Future research is needed to determine the relative efficacy of different lengths of inpatient rehabilitation stay and outpatient rehabilitation programs. Future research in MS rehabilitation will also attempt to identify new types of treatment protocols, including those that move beyond the goal of optimizing functional recovery with compensatory techniques to therapies that actually enhance neuronal compensation and nervous system regeneration. The future of MS rehabilitation will be looking to exploit the nervous system's capacity for reorganization and recovery (Aisen, 1999).

In the meantime, the goal is to intervene in ways that help people regain a sense of control over their bodies and their lives, and increase their self-esteem. Rehabilitation, regardless of the discipline that is providing the care, is a process not of curing, but of self-healing, both physical and emotional.

**THE REHABILITATION PARADIGM**

The rehabilitation process is both multidimensional and dynamic. Using the paradigm shown in Figure 6, each member of the team is working with the person living with MS to enhance or preserve function in a given area.
Since goal-setting always leads to further interventions, and interventions are always followed by outcomes assessments and re-evaluation, the process is theoretically a never-ending one. Furthermore, the person living with MS may be working simultaneously on a different set of goals with each member of the team. It is possible, therefore, to visualize this process as a set of interlocking rings (Figure 7), with the person with MS being the unifying link.

THE INITIAL ASSESSMENT

The quality of our rehabilitation interventions can only be as good as the assessments on which they are based. Since the person living with MS may be experiencing a range of interrelated problems, the ideal approach to assessment is a collaborative one, in which the members of the rehabilitation team pool their findings. Using this information, they can work with the person with MS to identify areas of potential change, and establish priorities for the interventions that are needed. Even those rehabilitation specialists who work independently, on a private referral basis, will find it mutually beneficial to communicate with one another about a person living with MS whose care they share. Beginning in this earliest phase of the rehabilitation process, the person with MS takes center stage, providing the focus and direction of the assessment process.

While each rehabilitation specialty has its own particular assessment protocols, they share a commitment to the biopsychosocial approach to disablement. Within this biopsychosocial model, as defined by the ICIDH-2 of the World Health Organization (see Appendix C), assessment is required not only of a specific impairment, but of the consequences of that impairment for a person’s daily activities and participation in his or her world. Given our current healthcare systems, quick and efficient patient assessments are essential.

The initial assessments set the stage for the rehabilitative process by establishing a baseline for the various aspects of a person’s functioning. Because of the unpredictable nature of the disease, however, re-assessments are recommended whenever there is a sustained change in a person’s condition. While the ideal situation would allow for the individual specialist to schedule periodic assessments, the realities of the current healthcare environment seldom allow for this. In most cases, it is the nurse who has frequent enough contact with a person to identify sustained changes in his or her condition that warrant referral back to the rehabilitation specialist for a thorough re-assessment.
GOAL SETTING

Once the members of the rehabilitation team have completed their individual assessments, they can begin to work with one another, and with the person living with MS, to establish meaningful treatment goals. This is a critical point in the intervention process because *appropriate goals are the key to a successful outcome.* Realistic goals based on accurate baseline assessment prevent us from encouraging the person to function below his or her actual capacity, or to overcompensate by attempting to achieve activity levels beyond realistic expectations (LaBan et al., 1998).

The role of the rehabilitation specialist in this process is to help the person living with MS understand the problems he or she is experiencing, and the treatment/management options that are available to address those problems. Because the goal of rehabilitation is to enhance function within the context of a person’s life, rehabilitation specialists need to take particular care to elicit and address the person’s own priorities. A person whose goals are being ignored is unlikely to bring much enthusiasm or persistence to the rehabilitation process.

Since the person may tend to focus on goals that are unrealistic (e.g., “My only goal is to walk unassisted.”), it is the responsibility of the rehabilitation team to provide adequate emotional support while educating the person about the importance of realistic goal setting for meeting his or her priorities. Trading unrealistic goals for realistic ones can be a painful process. The person may need the additional support of a psychotherapist at this time, particularly if his or her reluctance or inability to engage in realistic goal-setting is blocking the rehabilitation process.

INTERVENTIONS

NURSING

The nurse involved in rehabilitation of the person with MS functions as a ‘change agent’ and patient advocate, empowering a patient and family to know, envision, and evaluate options and to work together formulating problem-solving strategies and behaviors to achieve outcomes. In addition to providing direct physical care, the nurse evaluates the health status of the patient, helps determine short- and long-term goals, interprets medical terms, acts as a resource for community services, and provides education for the patient and family. Often the nurse can provide fellow team members with valuable insights regarding the patient’s motivation, problem-solving skills, and family process. The nurse effectively functions as a coordinator or care/case manager, overseeing cost-effective, efficient, and beneficial coordination of therapies.

EVALUATION

At the time of initial contact, and periodically throughout the course of the disease, the nurse evaluates the person’s overall health status and identifies specific needs in the areas of:

- MS education: including information about the disease, available treatments and symptom management strategies, and helpful resources
- Medical symptom management: focusing on implementation of the physician’s prescribed interventions
- Self-care strategies: including bowel and bladder regimens and self-injection techniques
- Referrals to other members of the rehabilitation team: assessing the need for evaluations and interventions by specialists on the team
Treatment adherence: focusing primarily on the person’s compliance with early treatment recommendations and adherence to the immunomodulating therapy protocol

Cognitive status: alerting team members to early signs of cognitive changes that might interfere with the treatment process

Emotional well-being: assessing the person’s emotional state and the presence of depressive symptomatology

Psychosocial adjustment: assessing the person’s support system, family relationships and communication, and employment situation

Personal assistance: assessing the person’s need for help with personal care or household management

In many respects, the nurse functions as the eyes and ears of the team, providing information and feedback to team members about the person’s physical, emotional, and cognitive state, and ability to be an active participant in his or her own care. Having identified the person’s needs, the nurse acts to coordinate the necessary interventions, thus helping to ensure that the identified needs are adequately addressed.

**NURSING INTERVENTIONS**

The specific interventions carried out by the nurse fall under three main categories: education and support; implementation of symptom management strategies; and training and support for immunomodulating therapies.

Education and support: The nurse is a supportive presence throughout the person’s experience of MS providing comprehensive but comprehensible information about MS, responding to questions, clarifying communications to and from the physician, identifying useful resources, and helping to ensure that the person is a comfortable and informed participant in his or her own care. The information and ongoing support provided by the nurse is often a determining factor in the person’s ability to understand and follow through with the treatment recommendations of the members of the rehabilitation team.

Implementation of medical management strategies: The nurse assists the person with MS in implementing the physician’s symptom management strategies (see Table 1, pages 12–19).

Training and support for immunomodulating therapies: The nurse has a primary role in education and training in the use of immunomodulating therapies. The nurse’s availability to clarify and reiterate the rationale for early treatment in MS, teach self-injection techniques, outline management strategies for possible side effects, and provide support during the learning and adjustment phase, seem to be key elements in promoting adherence to treatment.

**PHYSICAL & OCCUPATIONAL THERAPY**

The primary goal of physical and occupational therapy (PT and OT) in MS is to minimize the impact of existing impairments on a person’s ability to carry out daily activities and participate comfortably and effectively in his or her world. To accomplish this goal, PTs and OTs must have an in-depth, working knowledge of multiple sclerosis and the symptoms it can cause, and be able to translate the multiple, often interactive, presenting complaints into their underlying impairments. Regardless of the specific impairment(s) being addressed, however, the strategies utilized by these specialists emphasize a thorough assessment.
For additional information about the role of physical and occupational therapy in MS, refer to the Clinical Bulletins, “Occupational Therapy in Multiple Sclerosis Rehabilitation” and “Physical Therapy in Multiple Sclerosis Rehabilitation” in Appendix D or at nationalMSsociety.org/ClinicalBulletins.

EVALUATION

A thorough neuromusculoskeletal evaluation provides baseline information about the person’s physical status and present level of function. The initial evaluation should include assessment of all symptoms currently affecting the individual’s performance, including those listed in Appendix E, pp. 108-111. The evaluation focuses on the following areas:

- Early intervention: Early intervention can help people continue to function effectively in their life roles and prevent premature retirement from the workforce. The increased stability provided by the new disease-modifying drugs allows more opportunities for therapists to intervene to preserve a person’s individual activities and overall participation.

- Modification and compensation more than restoration: While some restoration of function may occur following an acute exacerbation, the primary emphasis in OT and PT is on teaching the person effective ways to compensate for existing impairments and make the necessary adaptation to behavioral and environmental modifications. It is these adaptations that will allow the person to remain functionally independent and productive, regardless of the extent of impairment.

- Education, support, and motivation: A major focus of the interaction between the therapist and the person with MS is motivational. The therapist helps the person to understand the connection between the intervention being prescribed (e.g., exercise regimen, assistive device, environmental modification, etc.) and the person’s own goals. It is only with this understanding that the person will develop the motivation and commitment necessary to follow through on a lifetime of adaptation and change.

- Self-management via skills training and the use of adaptive equipment: A primary objective of PT/OT interventions is to help people with MS learn to manage their own disease as comfortably and effectively as possible. Skills training and the proper use of adaptive equipment will make it possible for people to keep their lives as full, active, and satisfying as they want them to be. PT and OT are discussed together in this section because there is considerable overlap in the evaluation and treatment strategies used by these two specialty areas. Furthermore, the same problem that is treated with PT in one setting may well be treated by OT in another setting. The following factors are likely to determine which of these specialists evaluates/treats a particular person with MS:

  - The person’s insurance plan, which may cover one specialty but not the other
  - The particular background and training of the OT and PT at a given facility
  - The availability of only one of these specialists in a given facility or geographic area
  - Institutional variation
ASSESSMENTS & INTERVENTIONS

Taking these factors into account, *Table 3 (see p. 36-38)* presents the assessments and interventions used by PT and/or OT to address specific impairments, and points out specific areas in which one or the other specialty is most likely to be involved.

In order for interventions to be successful, they must:

- **Target the appropriate underlying impairment:** A thorough and careful assessment should precede any intervention in order to ensure that the sources of the presenting complaint have been correctly identified.

- **Be consistent with the person’s goals:** The person with MS is the focal point of the rehabilitation effort. His or her goals need to drive the rehabilitation process if the process is to succeed. When people understand the connection between their own goals and the recommended treatment interventions, they are more likely to follow through with treatment recommendations.

- **Be realistic, given the person’s goals, abilities, and resources:** For example, prescribing a water exercise program for a person who dislikes the water, has no access to a swimming pool, or whose presenting complaint is overwhelming fatigue that prevents her from lasting a full day at work, is unlikely to prove beneficial. A successful intervention for this person would identify the possible source(s) of her fatigue, and evaluate and modify her home and work environment and energy effectiveness strategies. The intervention should also evaluate her need for assistive equipment, provide training in its use, and provide her with an aerobics exercise program that fits realistically into her lifestyle.

Although the table lists various scales and questionnaires among the assessment strategies, it is important to remember that most have not been standardized in MS. PT and OT assessments of people living with MS involve a mixture of art and science, calling upon the professional to be thorough, intuitive, and creative in his or her approach. Ideally, persons with MS should be re-evaluated periodically by PT and/or OT because the symptoms of MS can change significantly over time. Although the realities of today’s healthcare system(s) preclude ongoing PT/OT interventions for people living with MS, the continuity of care can be assured with periodic reassessment to update the recommendations for exercise, energy effectiveness strategies, behavioral and environmental modifications, and assistive technology.

With the advent of disease-modifying agents to prolong time between attacks and slow disease progression, PT and OT interventions are more important and more cost-effective than ever before. Therapy interventions have the potential to last longer and have a greater impact on people’s efforts to live comfortable and satisfying lives with MS.

**SPEECH & LANGUAGE**

Speech-language pathologists play an integral role in the rehabilitation of people living with MS. Their focus is in three primary areas the assessment and treatment of speech, swallowing, and cognitive disorders. Along with neuropsychologists and occupational therapists, speech-language pathologists provide evaluations of cognitive function and provide interventions to help cognitively-impaired individuals function more comfortably and effectively.
### TABLE 3: COMPLAINTS, ASSESSMENTS, & INTERVENTIONS *

#### FATIGUE

<table>
<thead>
<tr>
<th>Complaint</th>
<th>Assessments</th>
<th>Interventions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Modified Fatigue Impact Scale; 25-foot walk; Manual Muscle Test before and after 6-minute walk; aerobic fitness assessment (before prescribing aerobic program); equipment assessment; activity diary; Sleep Questionnaire; evaluation of medications for impact on fatigue level; depression instrument</td>
<td>Energy effectiveness strategies; aerobic exercise program; equipment modifications (mobility, self-care, and ergonomic); environmental and behavioral modifications (home and job-site); transportation</td>
<td></td>
</tr>
</tbody>
</table>

#### FALLING/WALKING DIFFICULTIES

<table>
<thead>
<tr>
<th>Complaint</th>
<th>Assessments</th>
<th>Interventions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Manual Muscle Test; 25-foot walk; 6-minute walk; gait analysis; analysis of environment and tasks; vestibular and sensory/proprioceptive assessments; safety evaluations</td>
<td>Gait training; gait assistive devices; behavioral and environmental modifications; powered mobility equipment; cooling strategies</td>
<td></td>
</tr>
</tbody>
</table>

#### WEAKNESS

<table>
<thead>
<tr>
<th>Complaint</th>
<th>Assessments</th>
<th>Interventions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Manual Muscle Test; Dynamometer; Pinch Meter; gait analysis; analysis of environment and tasks</td>
<td>Exercises for deconditioning; adaptive equipment; environmental modifications; cooling strategies</td>
<td></td>
</tr>
</tbody>
</table>

#### POOR BALANCE

<table>
<thead>
<tr>
<th>Complaint</th>
<th>Assessments</th>
<th>Interventions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Vestibular, proprioceptive, sensory, spasticity, and gait analyses; Berg Balance Scale; 6-minute walk; 25-foot walk; Manual Muscle Test</td>
<td>Vestibular exercise program; supportive footwear; gait assistive devices; gait training; behavioral modification; environmental modification; cooling strategies</td>
<td></td>
</tr>
</tbody>
</table>

#### STIFFNESS, SPASMS, SPASTICITY

<table>
<thead>
<tr>
<th>Complaint</th>
<th>Assessments</th>
<th>Interventions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Range of motion; Ashworth or Modified Ashworth; assessment for baclofen pump if severe</td>
<td>Stretching exercise program; environmental modifications; cooling strategies; standing frame; AFO; positioning; baclofen pump</td>
<td></td>
</tr>
</tbody>
</table>
### COGNITIVE CHANGES (OT)

| Referral to a neuropsychologist; Modified Fatigue Impact Scale; Perceived Deficits Questionnaire; PASAT and possibly other neuropsychological screens | Instruction on compensatory strategies; assistive devices and environmental modifications |

### REDUCED MANUAL DEXTERITY (OT)

| 9-Hole Peg Test; Box and Block; Dynamometer; Pinch Meter; Semmes-Weinstein Sensory Test; spasticity; coordination | Environmental modification; behavioral modification; voice-activated software; bigger grips; assistive devices; stretching; positioning |

### PAIN

| Trigger point assessment; pain scales; posture assessment; equipment/seating assessment; central vs. peripheral symptoms | Equipment/seating modifications; relaxation; exercise; pain management techniques; behavioral/environmental modifications |

### TREMOR/ATAXIA

| 9-Hole Peg Test; ADL assessment; 25-foot walk; Manual Muscle Test; safety evaluation; Canadian Occupational Performance Measure (COPM); FIM, or other ADL assessment | Gait assistive devices; powered mobility equipment; weighting; proximal stabilization; behavioral modification |

### SENSORY CHANGES (INCLUDING PROPRIOCEPTION)

| Proprioception; Semmes-Weinstein Sensory Test; hot/cold discrimination | Larger grips; textured surfaces; supportive footwear; voice-activated software; sensory precautions |
**POOR VISION (OT)**

Visual acuity; tracking; peripheral vision; visual-perceptual assessment

Behavioral modification; environmental modification

**DECREASED FUNCTIONAL INDEPENDENCE**

COPM; FIM, or other ADL assessment

Assistive equipment; powered mobility equipment; behavior and environmental modifications

* Examples presented should not be considered exhaustive.

### TABLE 4: RANK ORDER OF DEVIATIONS IN SPEECH & VOICE IN MS

<table>
<thead>
<tr>
<th>Percent (N = 168)</th>
<th>Deviation</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>77%</td>
<td>Loudness control</td>
<td>Reduced, mono, excess or variable</td>
</tr>
<tr>
<td>72%</td>
<td>Harsh voice quality</td>
<td>Strained, excess tone in vocal cords</td>
</tr>
<tr>
<td>46%</td>
<td>Imprecise articulation</td>
<td>Distorted, prolonged, irregular</td>
</tr>
<tr>
<td>39%</td>
<td>Impaired emphasis</td>
<td>Phrasing, rate, stress, intonation</td>
</tr>
<tr>
<td>37%</td>
<td>Impaired pitch control</td>
<td>Monopitch, pitch breaks, high, low</td>
</tr>
<tr>
<td>35%</td>
<td>Decreased vital capacity</td>
<td>Reduced breath support and control</td>
</tr>
<tr>
<td>24%</td>
<td>Hyponasality</td>
<td>Excessive nasal resonance</td>
</tr>
</tbody>
</table>
Because the subject of cognitive dysfunction and its management is covered in depth in *Multiple Sclerosis: A Model of Psychosocial Support*, the emphasis here will be on the rehabilitation of speech and swallowing problems.

MS lesions in the brain can interfere with muscle control in the lips, tongue, soft palate, vocal cords, and diaphragm. These muscles control speech production and voice quality as well as the process of swallowing.

**Dysarthria**

*(For additional information see Appendix D, page 60)*

Dysarthria is defined as impairments of articulation, voice, or resonance, resulting from neurologic disease, injury, or surgery. Approximately 41% of individuals with MS will experience voice (dysphonia) and articulation problems (dysarthria) in the course of their disease. These deficits are more likely to occur in those people with demyelination in the brain stem, cerebrum, and cerebellum. The severity of symptoms will tend to correspond with overall disease severity, but not with duration of illness, age, or age of onset. The prevalence of MS-related speech and voice problems is presented in *Table 4* (Darley et al., 1972).

The most common speech and voice disorders in MS have been characterized by Darley and colleagues as mixed spastic-ataxic dysarthria, consisting of impaired loudness control, voice harshness, defective articulation, impaired emphasis, and impaired pitch control. Mixed dysarthria results from bilateral, generalized lesions in multiple areas in the cerebral white matter, brainstem, cerebellum, and/or spinal cord. The speech processes in MS may improve with remission of the disease and worsen during exacerbations. Furthermore, MS-related fatigue can periodically alter a person’s ability to speak clearly. Therefore, the evaluation, goal-setting, and intervention components of rehabilitation need to take into account this variability in symptoms.

**Evaluation**

The evaluation of the speech-language system determines which areas are contributing to the communication problems, and provides the basis for goal-setting and development of a treatment plan. An evaluation should assess the following elements of normal speech (Sorensen, 2008):

- **Respiration:** use of the diaphragm to fill the lungs fully, followed by slow, controlled exhalation for speech
- **Phonation:** use of the vocal cords and airflow to produce voice of different pitch, loudness, and quality
- **Resonance:** raising and lowering of the soft palate to direct the voice to vibrate in either the mouth or nose, further affecting quality
- **Articulation:** quick, precise movements of the lips, tongue, and soft palate for clarity of speech
- **Prosody:** combination of the preceding elements to create a natural flow of speech, with adequate rate, appropriate pauses, and meaningful variations in loudness and emphasis to convey meaning

**Treatment Goals**

Not every MS patient with dysarthria is a potential candidate for treatment (Johns, 1978).
A person’s suitability for treatment will depend upon several factors, including: the severity of the disease course and speed of progression; the number and types of speech problems the person has; the person’s cognitive and emotional status; and the availability of supportive communication partner(s). Realistic goal-setting in the treatment of persons with MS recognizes that recovery of normal speech and neuromuscular function is unlikely to occur. Therefore, therapy should be focused primarily on enhancing communication and ensuring that the person is communicating at the optimal level given his or her remaining level of function. Unfortunately, referrals to the speech-language pathologist are frequently made only after the person has become severely impaired.

The earlier a person is referred for help in this area, the more potential there is for maintaining adequate, comfortable speech. It is incumbent on the entire rehabilitation team to be alert to early signs of speech-language deficits so that interventions can be made in a timely fashion. (Klitzke & Schapiro, 1991).

The following questions can be used to guide appropriate referrals to a speech-language pathologist (Sorensen, 2000):

1. Are problematic speech and voice characteristics detracting from the message that is being communicated?
2. Are speech and voice adequate for the person’s daily communication needs (keeping in mind that the needs of an unemployed person who lives with a spouse of 20 years are different from those of a teacher or public speaker)?
3. Are speech, voice, and communication problems interfering with the person’s quality of life (e.g., resulting in social isolation or problems on the job)?
4. Are speech, voice, and communication problems perceived as troublesome by the patient or family?

The treatment for spastic-ataxic dysarthria is different in scope and expected outcome from the treatment for the dysarthria seen in Parkinson’s disease or following a cerebrovascular event. The goal in MS is to identify any problems with respiration, phonation, articulation, resonance, and prosody, and work to strengthen and/or maintain motor skills that facilitate functional verbal communication. The treatment strategies utilized in MS will vary with the specific symptoms as well as the individual’s capabilities and willingness to participate in treatment (Merson & Rolnick, 1998).

The treatment strategies for spastic-ataxic dysarthria may include both pharmacologic interventions and rehabilitative techniques. See Table 5 (adapted from Sorensen, 2000) for an overview of treatment strategies.
# Table 5: Treatment Interventions for MS-Related Speech Problems

<table>
<thead>
<tr>
<th>Problem</th>
<th>Treatment Approaches</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Loudness Control</strong></td>
<td></td>
</tr>
</tbody>
</table>
| **Reduced Loudness**          | - Medication trial for spasticity and/or fatigue  
- Proper positioning, head/trunk support  
- Breath support and control exercises  
- Improved diaphragmatic breathing technique  
- Spirometer to monitor inspiration for speech  
- Tape recorder or speech lab computer software to monitor loudness  
- Practice of phrasing (maximum # or words/breath unit) when reading aloud and talking  
- Portable voice amplifier                                                                                               |
| **MonoLoudness**              | - Tape-recording of passages to practice reading aloud with specific words underlined to enhance meaningfulness  
- Transfer of new skill from oral reading to conversation                                                                     |
| **Excess & Variable Loudness**| - Medication trial for tremor and ataxia  
- Proper sitting posture, trunk stabilization, head control  
- Relaxation techniques and EMG/biofeedback to promote smooth respiration for speech and easy onset of voicing  
- Tape recorder or speech lab computer software to monitor loudness bursts  
- Practice of new skill during oral reading and conversation                                                                   |
<table>
<thead>
<tr>
<th>PROBLEM</th>
<th>TREATMENT APPROACHES</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>VOICE QUALITY</strong></td>
<td></td>
</tr>
<tr>
<td><strong>HARSH, STRAINED</strong></td>
<td>- Medication trial for spasticity&lt;br&gt;- Relaxation techniques/biofeedback to monitor laryngeal muscle control&lt;br&gt;- Open mouth and &quot;yawn-sigh&quot; approaches during speech drill&lt;br&gt;- Tape recorder and computer software such as Visi-Pitch™ for identifying and matching target voice quality&lt;br&gt;- Practice of new skill in words, sentences, and conversation</td>
</tr>
<tr>
<td><strong>HYPERNASALITY</strong></td>
<td>- Soft palate exercises to improve velo-pharyngeal competence&lt;br&gt;- Increased breath support&lt;br&gt;- Articulation drill with plosives and their contrasting nasal glides&lt;br&gt;- Open mouth approach to direct more oral than nasal air flow&lt;br&gt;- Slowed rate of speech to allow extra time for velar movements&lt;br&gt;- Tape-recording to identify and match target voice quality&lt;br&gt;- Practice in words, sentences, and conversational groups</td>
</tr>
<tr>
<td><strong>VOCAL TREMOR</strong></td>
<td>- Medication trial for tremor and ataxia&lt;br&gt;- Evaluation for botulinum toxin&lt;br&gt;- Proper sitting posture, trunk stabilization, head control&lt;br&gt;- Relaxation techniques and EMG/biofeedback to control tremor&lt;br&gt;- Tape recorder and speech lab computer software for monitoring phonation breaks and identifying target voice quality&lt;br&gt;- Practice during reading aloud and conversation</td>
</tr>
</tbody>
</table>
## Articulation

<table>
<thead>
<tr>
<th>Problem: Imprecise Articulation or Irregular Articulatory Breakdowns</th>
</tr>
</thead>
<tbody>
<tr>
<td>■ Medication trial for spasticity, tremor, ataxia, and/or fatigue</td>
</tr>
<tr>
<td>■ Oral exercise to improve range of motion, strength, speed, and coordination</td>
</tr>
<tr>
<td>■ Enhancement of breath support and respiratory control</td>
</tr>
<tr>
<td>■ Relaxation techniques and EMG/biofeedback to monitor and control</td>
</tr>
<tr>
<td>■ Tone and movement of specific articulators and the timing of respiration, phonation, and articulation</td>
</tr>
<tr>
<td>■ Identification of error patterns; articulation drill</td>
</tr>
<tr>
<td>■ Practice of behavioral compensations: slow rate; overarticulation; phrasing</td>
</tr>
<tr>
<td>■ Use of pacing board or delayed auditory feedback unit to slow speech rate</td>
</tr>
<tr>
<td>■ Use of tape recorder or speech lab computer software to monitor articulation</td>
</tr>
<tr>
<td>■ Practice of new skill during reading aloud and conversational groups</td>
</tr>
<tr>
<td>■ Training of dysarthric speaker to attend to listener and solicit feedback; training of communication partners to provide cues</td>
</tr>
<tr>
<td>■ Use of alternative communication devices</td>
</tr>
</tbody>
</table>

## Prosody

<table>
<thead>
<tr>
<th>Problem: Reduced Loudest Stress Patternning</th>
</tr>
</thead>
<tbody>
<tr>
<td>■ Stress patterning techniques to practice natural variation in loudness and pitch of key words</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Problem: Monoloudness</th>
</tr>
</thead>
<tbody>
<tr>
<td>■ Use of tape recorder to compare monotonous patterning with stress patterning</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Problem: Monopitch</th>
</tr>
</thead>
<tbody>
<tr>
<td>■ Practice of emphasis on most important word in a Q&amp;A drill</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Problem: Reduced, Excess, or Equal Stress</th>
</tr>
</thead>
<tbody>
<tr>
<td>■ Read-aloud tasks utilizing underlined key words; use of tape recorder to self-evaluate effectiveness of different stress parameters (loudness, duration, pitch)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Problem: Excess &amp; Variable Loudness</th>
</tr>
</thead>
<tbody>
<tr>
<td>■ Use of speech lab computer software to visualize and match targeted variations in fundamental frequency and intensity</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Problem: Slow or Variable Rate</th>
</tr>
</thead>
<tbody>
<tr>
<td>■ Controlling speech rate by interjecting pauses in logical places; use of rigid rate control devices such as a pacing board, DAF unit, or alphabet board supplementation, with plan to achieve rate control without devices</td>
</tr>
</tbody>
</table>
Because dysarthria typically combines spastic and ataxic elements, either of which can be complicated by the person’s fatigue level, medications that address these underlying problems may enhance speech production and communication. While no drug trials have specifically been done in MS-related speech disorders, the following interventions may prove beneficial:

— Oral spasticity medications such as baclofen (Lioresal) or tizanidine (Zanaflex) to reduce excess muscle tone in the diaphragm, vocal cords, lips, jaw, tongue, and soft palate

— Injections of botulinum toxin to treat adductor spasmodic dysphonia, abductor spasmodic dysphonia, and vocal tremor

— Oral medications of various types that may help to reduce tremor, including propranolol (Inderal), clonazepam (Klonopin), primidone (Mysoline), laniazid (Isoniazid)

— Oral medications to reduce fatigue, including amantadine (Symmetrel), modafinil (Provigil)

Rehabilitative techniques include helping the person to:

— Slow the rate of speech in order to allow the tongue to compensate for loss of speed, strength, and coordination

— Improve articulation by pronouncing words, or even individual syllables separately and deliberately (i.e., over-pronouncing syllables and words)

— Over-articulate certain consonants in order to prevent their being slighted or omitted

— Control phrase shifts and reduce phrase length

— Increase voice power

(Merson & Rolnick, 1998; Smith & Scheinberg, 1996; Klitzke & Schapiro, 1991)

Once the person has achieved some improvement in articulation, he or she can begin to establish normal syllabic stress and word emphasis by varying the loudness, altering the pitch, and varying the duration of syllables to produce more normal-sounding speech.

In the event that a person’s oral communication becomes unintelligible, there are a variety of augmentative and alternative communication (AAC) devices such as communication boards, alpha-numeric keyboards, speech synthesizers, and sophisticated computer software that can supplement or completely replace verbal communication skills. The choice of an AAC will be dependent upon the person’s physical and cognitive abilities, social support, and willingness to make use of this type of assistive technology.

DYSPHAGIA

(for additional information see Appendix D, page 60)

Dysphagia is defined as a difficulty in swallowing. It is a neurologic or neuromuscular symptom that can result in aspiration of food particles or liquids into the lungs, slowed swallowing, or both. Dysphagia may result when lesions in the brainstem alter the functioning of the brainstem and cranial nerves. The type of swallowing disorder will depend on how many, and which, cranial nerves are affected. Those having significant control of the muscles for swallowing include the trigeminal (5th), facial (7th), glossopharyngeal (9th), vagus (10th), spinal accessory (11th), and hypoglossal (12th) cranial nerves.
The term “swallowing” refers to a complex, but safe and efficient process that occurs in four stages:

1. Oral preparatory: foods are placed in the oral cavity, chewed, manipulated, and formed into a bolus.

2. Oral stage: the bolus is propelled backward by the tongue, in turn triggering the swallowing reflex at the point of the anterior faucial arches.

3. Pharyngeal: as the swallowing reflex is triggered, the soft palate closes the passage to the nasal cavity, pharyngeal peristalsis squeezes the bolus through the pharynx, the larynx elevates and closes at three sphincters, and the cricopharyngeal sphincter relaxes to allow the bolus to pass into the esophagus.

4. Esophageal: the bolus passes through the cricopharyngeal sphincter and moves through the esophagus to the stomach.

The most common problems seen in persons with MS include:

- Delayed swallowing response
- Reduced pharyngeal peristalsis
- Reduced laryngeal function
- Reduced lingual function
- Reduced sensation in the oral, pharyngeal, and laryngeal areas

These problems can occur in combination, and may worsen or change with disease progression. Swallowing problems can appear or worsen during an exacerbation, and improve or subside during periods of remission. Therefore, periodic evaluations are recommended for individuals who have evidenced swallowing difficulties.

The signs of a swallowing problem include:

- Pocketing of food in the mouth
- Multiple swallows on a single mouthful of food
- Unexplained weight loss or dehydration in association with slowed eating
- Hoarse, weak voice
- Temperature rise 30 minutes to an hour after eating
- Frequent throat-clearing during meals
- Reported changes in diet
- Drooling
- Regurgitation
- Decreased intake of food
- Reports of food sticking in the throat

If any of these symptoms are observed by the person with MS, the healthcare team, or family members, a referral for a swallowing evaluation should be made.

Signs of aspiration or potential aspiration include:

- “Gurgly” quality of the voice
- Coughing, sputtering, or choking before, during, or after eating or drinking
- Cyanosis
- Rales
- Wheezing
- Fever
- Increased mucous production
- Repeated pneumonias

It is important to note that approximately 40% of all individuals with dysphagia do not present with obvious signs of swallowing distress such as choking or coughing. Neither the person with MS nor family members may be aware of the swallowing problems. The person with MS may not be able to feel any of the changes that are occurring, and the changes may have occurred so gradually over time that the family is not aware of them either. “Silent aspiration” occurs when liquid or food particles are aspirated into the lungs without any associated discomfort, coughing, or other obvious signs.
EVALUATION

The assessment of swallowing dysfunction consists of four parts — detailed interview, clinical evaluation, mealtime evaluation, and videofluoroscopy. The detailed interview of the person with MS and family members is designed to identify the following:

- Food preferences
- Changes in food preferences—particularly those relating to texture
- History of swallowing difficulties
- Typical meal patterns
- Changes in meal patterns or habits
- History of weight fluctuation
- Fluid intake

During the clinical evaluation, the speech-language pathologist reviews the person's swallowing history and examines the structure and function of all visible parts of the eating/swallowing mechanism. The structure and function of the pharynx and larynx can be indirectly examined by placing fingers on the jaw, hyoid bone, and thyroid cartilage areas while the person swallows. If the swallow reflex is present, the larynx should rise. To obtain information about airway strength and protection, the clinician then asks the person to clear the throat, cough, and vocalize a loud sustained tone. A weak, breathy tone and significant air escape may indicate difficulty in maintaining closure of the airway during the swallow, or in expelling material from the airway. The meal-time evaluation provides information about the person's ability to chew and swallow a variety of food textures, eat without pain, coughing, or choking, and manage a meal without excessive fatigue. The speech-language pathologist is also alert to signs of silent aspiration such as watering of the eyes, loss of breath or voice, or gurgling sounds in the throat.

Videofluoroscopy, also called a modified barium swallow (MBS), is a radiographic procedure that provides a view of the oropharyngeal anatomy and physiology as the person swallows a variety of barium-coated liquids, soft foods, or cracker mixes. This procedure allows the swallowing rehabilitation team (typically consisting of the speech-language pathologist, radiologist, radiology technician, and perhaps the OT) to assess the person's ability to chew and transfer the food bolus from the oral cavity to the oropharynx without leakage into the larynx. This procedure identifies the presence of aspiration as well as the reasons for its occurrence, including impaired tongue movement, delayed swallowing reflex, reduced pharyngeal peristalsis, weak airway closure, cricopharyngeal muscle dysfunction, reduced sensation, and/or functional/behavioral abnormalities. Observations can also be made of the person's posture and head position, and their impact on swallowing.

TREATMENT GOALS

The goals of a swallowing intervention are to help the person maintain his or her nutritional status while eating safely, and to facilitate independent eating and swallowing for as long as it is possible.

TREATMENT INTERVENTIONS

- Poor tongue control: 1) compensatory positional changes (e.g., holding the head forward when preparing the bolus for swallowing, and then throwing it back to allow the bolus to fall into the pharynx), or 2) exercises to increase tongue range of motion, strength, and control, to prevent the bolus from entering the pharynx prematurely.
Impaired swallowing reflex: 1) head flexion in preparation for swallowing, in order to enlarge the vallecular space, help to trap the material in the valleculae during the reflex delay, and reduce the risk of aspiration; 2) a diet of thicker foods and liquids that tend to enhance the reflex trigger by remaining in the valleculae for a longer period; 3) thermal stimulation of the anterior faucial arches, soft palate, or posterior tongue.

Incomplete closure of the larynx during the swallow: the supraglottic swallow procedure may be effective. The person inhales, holds the breath at the height of the inspiration, then swallows. During exhalation, the person coughs to get rid of any residue that might remain in the pharynx or upper airway.

Aspiration resulting from reduced pharyngeal peristalsis, reduced laryngeal elevation, or oropharyngeal dysfunction: the person is taught to cough after each swallow to clear any residue from the pharynx.

Severe fatigue that interferes with eating: best addressed with smaller, more frequent meals.

Severe, intractable dysphagia: managed through the use of non-oral feeding alternatives. The percutaneous endoscopic gastrostomy (PEG) is a safe, simple, inexpensive, and reversible method of providing enteral nutrition. The PEG is inserted into the stomach under endoscopic guidance and a liquid diet (Isocal, Osmolite, Ensure) is used for feedings. It is important to watch for the possible, common complication of any enteral feeding, such as aspiration, hyperglycemia, diarrhea, abdominal distention, and fecal impaction.

OUTCOMES
Outcome assessment lays the groundwork for future planning. Careful and accurate assessment of the outcomes of our interventions will enhance our ability to help the person with MS establish additional short-term and long-term goals. Each area of specialty has the responsibility to identify and utilize meaningful outcome measures. Not only will these measures help us provide more effective rehabilitation interventions over the course of a person’s illness, but they will also increase the likelihood of obtaining insurance coverage for those interventions. Thus, it is imperative that we begin each intervention with a particular outcome in mind, as well as the means we are going to use to evaluate that outcome.

SOURCE MATERIALS FOR REHABILITATION


**ADDITIONAL RECOMMENDATIONS**

— Brown SA. Swallowing and speaking: Challenges for the MS patient. *International Journal of MS Care* September 2000; 2. mscare.com/a0009/page_02.htm


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.
- 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.

*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.*

■ All of these FDA-approved agents should be included in formularies and covered by third party payers 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 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>bisacodyl&lt;sup&gt;1&lt;/sup&gt;</td>
<td>Dulcolax</td>
<td>Constipation</td>
</tr>
<tr>
<td>bupropion</td>
<td>Wellbutrin</td>
<td>Depression</td>
</tr>
</tbody>
</table>

<sup>1</sup> Available without a prescription.  <sup>2</sup> 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</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</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>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>fluoxetine</td>
<td>Prozac</td>
<td>Depression; Fatigue</td>
</tr>
<tr>
<td>gabapentin</td>
<td>Neurontin</td>
<td>Pain</td>
</tr>
<tr>
<td>glatiramer acetate</td>
<td>Copaxone</td>
<td>Disease modifying agent</td>
</tr>
</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>glycerin$^1$</td>
<td>Sani-Supp Suppository</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</td>
<td>Nausea; Vomiting; Dizziness</td>
</tr>
<tr>
<td>methenamine</td>
<td>Hiprex, Mandelamine (preventive)</td>
<td>Urinary tract infections</td>
</tr>
<tr>
<td>methylprednisolone</td>
<td>Depo-Medrol; Solu-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><strong>GENERIC NAME</strong></th>
<th><strong>BRAND NAME</strong></th>
<th><strong>USAGE IN MS</strong></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>propantheline bromide</td>
<td>Pro-Banthine</td>
<td>Bladder dysfunction</td>
</tr>
<tr>
<td>psyllium hydrophilic mucilloid</td>
<td>Metamucil</td>
<td>Constipation</td>
</tr>
<tr>
<td>sertraline</td>
<td>Zoloft</td>
<td>Depression</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>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</td>
<td>Bladder dysfunction</td>
</tr>
<tr>
<td>sulfamethoxazole + trimethoprim combination</td>
<td>Bactrim; Septra</td>
<td>Urinary tract infections</td>
</tr>
<tr>
<td>imipramine</td>
<td>Tofranil</td>
<td>Bladder dysfunction; Pain</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</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>

<sup>1</sup> Available without a prescription.  
<sup>2</sup> Available in US and Canada unless otherwise noted.
APPENDIX C: INTERNATIONAL CLASSIFICATION OF IMPAIRMENTS, ACTIVITIES, & PARTICIPATION

A MANUAL OF DIMENSIONS OF DISABLEMENT AND HEALTH (ICIDH-2)

The ICIDH-2 is an international classification system designed to describe the personal and social consequences of health conditions, including diseases, disorders, and injuries. With the increasing prevalence of chronic and non-communicable illnesses, and the aging of the population, the consequences of health conditions have come to include the life-long management needs of this growing segment of the population.

The ICIDH-2 is a revision of the International Classification of Impairments, Disabilities, and Handicaps (ICIDH) that was developed by the World Health Organization (WHO) in 1980. The initial ICIDH was a classification of “disablements” — an umbrella term covering three dimensions: 1) impairment; 2) disability; and 3) handicap that could be visualized in the above diagram.

A disease or condition was seen to cause certain impairments of body structure or function (impairment). These impairments might interfere with a person’s abilities (disability), potentially preventing the person from being able to function fully in society (handicap).

Twenty years of experience with this model found it to be lacking in certain areas. While it was not designed to be a linear, or causal model, it was too easily interpreted as such.
It failed to allow for movement from handicap and disability back to impairment, and it did not adequately reflect the role of the social and physical environment in the disablement process.

ICIDH-2 attempts to provide a multi-dimensional and multi-perspective approach to the concept of disablement. The concept of disability has been replaced by *activity*, which deals with a person’s ability to execute particular tasks or activities in everyday life. The concept of *handicap* has been replaced by *participation*, which refers to the total experience of people with health conditions within their societal context (including society’s role in either facilitating or hindering that participation).

As can be seen in Figure 8, ICIDH-2 is an interactive rather than a unidirectional model that implies a dynamic interaction between the disease and contextual factors (i.e., environmental and personal factors). Environmental factors might include attitudes of society, architectural barriers, the legal system, etc., while personal factors might include gender, age, other health conditions, lifestyle, coping styles, education, and so on.
DEFINITION

Rehabilitation in MS is a process that helps a person achieve and maintain maximal physical, psychological, social and vocational potential,
and quality of life consistent with physiologic impairment, environment, and life goals. Achievement and maintenance of optimal function are essential in a progressive disease such as MS.

While the disease course cannot be altered by rehabilitation, a growing body of evidence indicates that improvement in mobility, activities of daily living (ADL), quality of life, prevention of complications, reduction in health care utilization, and gains in safety and independence, may be realized by a carefully planned program of exercise, functional training, and activities that address the specific needs of the individual. Thus, rehabilitation is considered a necessary component of comprehensive, quality health care for people living with MS, at all stages of the disease.

- The physician* should consider referral of individuals with MS for assessment by rehabilitation professionals** when there is an abrupt or gradual worsening of function or increase in impairment that has a significant impact on the individual’s mobility, safety, independence, and/or quality of life.

- Patients who present with any functional limitation should have an initial evaluation and appropriate management.

- Assessment for rehabilitation services should be considered early in the disease when behavioral and lifestyle changes may be easier to implement.

- The complex interaction of motor, sensory, cognitive, functional, and affective impairments in an unpredictable, progressive, and fluctuating disease such as MS, requires periodic reassessment, monitoring, and rehabilitative interventions.

- The frequency, intensity and setting of the rehabilitative intervention must be based on individual needs. Some complex needs are best met in an interdisciplinary, inpatient setting, while other needs are best met at home or in outpatient settings. The health care team should determine the most appropriate setting. Whenever possible, patients should be seen by rehabilitation therapists who are familiar with neurological degenerative disorders.

- Research and professional experience support the use of rehabilitative interventions*** in concert with other medical interventions, for the following impairments in MS:
  - Mobility impairments (i.e. impaired strength, gait, balance, range of motion, coordination, tone and endurance)
  - Fatigue
  - Pain
  - Dysphagia
  - Bladder/bowel dysfunction
  - Decreased independence in activities of daily living
  - Impaired communication
  - Diminished quality of life (often caused by inability to work, engage in leisure activities and/or to pursue usual life roles)
  - Depression and other affective disorders
  - Cognitive dysfunction

- Appropriate assessments and outcome measures must be applied periodically to establish and revise goals, identify the need for treatment modification, and measure the results of the intervention.

* Or nurse practitioner or physician’s assistant.

** Includes: rehabilitation physician, occupational, physical, speech and language therapists and others.

*** Includes: exercise, functional training, equipment prescription, provision of assistive technology, orthotics prescription, teaching of compensatory strategies, caregiver/family support and education, counseling, and referral to community resources.
Known complications of MS, such as contractures, disuse atrophy, decubiti, risk of falls, and increased dependence may be reduced or prevented by specific rehabilitative interventions.

In a fluctuating and progressive disease, maintenance of function, optimal participation, and quality of life are essential outcomes.

Maintenance therapy includes rehabilitation interventions designed to preserve current status of ADLs, safety, mobility, and quality of life, and to reduce the rate of deterioration and development of complications.

A thorough assessment for wheelchairs, positioning devices, other durable medical equipment (DME) and environmental modification by rehabilitation professionals is recommended and will result in the use of the most appropriate equipment.

Regular and systematic communication between the referring health care provider and rehabilitation professionals will facilitate comprehensive, quality care.

Third party payers should cover appropriate and individualized restorative and maintenance rehabilitation services for people with MS.

**BACKGROUND**

While multiple sclerosis is highly variable, most patients experience functional losses and increasing impairment over time. Many people living with MS face obstacles accessing rehabilitative services because of inadequate referrals and/or inadequate third party coverage. The National MS Society determined that a statement by its expert medical advisors was therefore necessary to support the use of rehabilitative interventions and thus promote physician referral to these services and third party coverage of them.

A number of studies have demonstrated positive outcomes of rehabilitation on people living with MS, and data support the use of rehabilitative interventions for a number of specific MS impairments. Patients with MS who received multidisciplinary rehabilitation in addition to IV steroids demonstrated increased improvement in functional status, mobility, quality of life, and disability over those who received steroids alone (Craig et al., 2003).

A study of the effect of inpatient rehabilitation on individuals with relapsing/remitting (RR) MS suggested that inpatient rehabilitation is useful for patients with incomplete recovery from relapses who have accumulated moderate to severe disability (Liu et al., 2003). Another study showed a significant decrease in length of stay in a rehabilitation inpatient unit for patients who were given more intensive rehabilitation therapies (Slade et al., 2002). Patients with progressive MS who received out-patient rehabilitation, experienced reductions in fatigue and MS related symptoms (DiFabio et al., 1997, 2003). Furthermore, a physiotherapy program conducted at home or in a hospital outpatient clinic resulted in significant improvements in mobility, subjective well-being, and mood in patients with chronic MS (Wiles et al., 2001). This study suggests that ongoing physiotherapy might be necessary for sustaining improvement in mobility or prevention of deterioration. Other studies demonstrated positive impact of multidisciplinary rehabilitative care on the daily life of patients with multiple sclerosis (Freeman et al., 1999; Solari et al., 1999).

In studies regarding access to rehabilitation services by people with disabilities, respondents report difficulty in accessing services, largely due to insurance coverage limitations (Beatty et al., 2003). Many insurance policies and state/federal regulations require that rehabilitation services be ‘restorative’ rather than oriented to maintenance of function and
prevention of avoidable disability and complications. However, for individuals with chronic, progressive or disabling conditions such as MS, maintenance therapy is critical for preserving overall health and functioning, maintaining independence, avoiding institutionalization, and preventing secondary medical conditions and the associated need for costly hospitalizations that may include surgeries.

While additional research is needed, recent findings along with expert opinion and clinical experience demonstrate the value of rehabilitation in MS. Physicians should prescribe appropriate rehabilitation therapies for their patients with MS and insurers should cover these therapies.

**PROCESS**

The clinical care committee of the National MS Society’s National Clinical Advisory Board identified the need to develop and periodically update a formal position about rehabilitation as a necessary component of quality health care for people living with MS, at all stages of the disease. They convened a multidisciplinary task force of MS experts to develop recommendations.

The task force conducted a comprehensive review of the literature and compiled professional opinion based on the literature and clinical practice. The National Clinical Advisory Board’s Executive Committee provided final review and approval of the document.

**USE OF THE RECOMMENDATIONS**

The National MS Society rehabilitation and MS statement is an educational and advocacy tool. It will be a component of the Society’s professional education programs and will be used to promote increased access to rehabilitative therapies through legislative and regulatory determinations. It will serve as a communication device for interactions with insurers both nationally and locally. It supports self-advocacy for persons with MS and will encourage them to talk with their health care providers and insurers about whether rehabilitation is indicated.

**ROLE OF THE NATIONAL MS SOCIETY**

The National MS Society mobilizes people and resources to drive research for a cure and to address the challenges of everyone affected by MS. Various strategies are employed to do so, including professional education and advocacy. As a representative body and advocate for people living with MS and medical/health professionals who provide their care, the Society is positioned to provide structure and support for the development of an expert opinion document to facilitate access to rehabilitative therapies for disease management. The National MS Society has a nationwide network of chapters and regular contact with persons living with MS and their families as well as with health care professionals. This extensive network and process for dissemination of information will ensure that the recommendations regarding rehabilitation and MS will be communicated to providers, insurers, and people living with MS.
REFERENCES & RELATED PUBLICATIONS


THIS ADVISORY STATEMENT WAS REVIEWED & ADOPTED BY THE EXECUTIVE COMMITTEE OF THE NATIONAL CLINICAL ADVISORY BOARD OF THE NATIONAL MS SOCIETY

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Introduction

Rehabilitation is an important part of health care delivery for persons with multiple sclerosis. Since the majority of people are diagnosed between the ages of 20 and 50, the challenges of MS affect those at the peak of their career and childrearing years. Although MS can affect children and teens, it is much less common that this age group.

Rehabilitation team members need information, experience, and sensitivity relating to the variability of symptoms between individuals, and to the unpredictable and fluctuating nature of this challenging, generally progressive disease.

Unlike most other neurological disorders, including spinal cord injury, traumatic brain injury, and stroke, there is no “fixed deficit” in MS; symptom profile, lesion burden on MRI, and disease course vary over time. Therapists must be prepared to treat each MS patient individually, and with flexibility, over the long term.

In the treatment of people living with MS, there are no protocols or time limits — just a unique opportunity to employ numerous problem-solving skills, interventions, and resources. And because MS affects not just an individual, but a whole family, it is a disease that benefits from a team approach — making coordination and communication with other health care providers extremely important.

Clinical Challenges

MS poses a variety of clinical challenges that can impact therapy interventions: For example, the very common symptoms of weakness and fatigue caused by impaired nerve conduction in the central nervous system, can be exacerbated by a variety of factors:

- An elevated core body temperature (from overheating, overexertion, or infection with fever)
- Certain medications, such as those used to treat spasticity and pain
- Obesity
- Disrupted sleep (caused by bladder urgency, periodic limb movements, spasticity, and pain, among other factors)
- Affective disorders such as depression
- Stress
- Other medical conditions, such as anemia

Many other “invisible” symptoms are cause for frustration in patients, including impairments of sensation, vision, cognition, bowel and bladder, and sexual function — all of which need to be acknowledged and addressed by the rehabilitation specialist.
THE ONGOING ROLE OF PHYSICAL THERAPY IN MS

The role of physical therapy will vary across the disease course. In general, however, interventions should focus on helping the patient to achieve and maintain optimal functional independence, safety, and quality of life, with the understanding that needs will vary and likely grow over time. In all care delivery models — inpatient (acute, transitional, rehabilitation or long-term care), outpatient, or home care — physical therapists (PTs) must:

- Be prepared to educate patients and their care partners about the critical role of rehabilitation, provide training in specific strategies, and provide resources for equipment and accessible, appropriate community programs.

- Be ready to assist with case-management and provide emotional support.

INTERVENTIONS THROUGHOUT THE DISEASE COURSE

AT THE TIME OF DIAGNOSIS

Patients newly diagnosed with MS benefit from education, support and a baseline evaluation by an experienced PT. At this time, misunderstandings about the disease and its management, the importance of appropriate exercise/activity, fatigue issues, and any subtle gait or balance impairments can be addressed. Follow-up should be on an “as needed” basis.

FOLLOWING ACUTE EXACERBATIONS

Physical therapy following an acute exacerbation (also called a relapse or attack) should have the goal of carefully helping the person return to baseline functioning. It is customary to wait two weeks after the attack before starting or resuming outpatient PT, because of weakness, lack of sleep from IV steroids, or other factors.

PROGRESSIVE DISEASE

Patients with primary-progressive MS do not have remissions; their functioning declines gradually, but steadily, over time. Patients who transition from relapsing-remitting MS to secondary-progressive MS are not able to return to baseline (due to progression of the disease that occurs between exacerbations) and demonstrate a slow decline in function. Because both groups have a huge emotional burden in addition to their physical challenges, physicians are encouraged to refer a person proactively to PT rather than waiting until he or she is struggling. Focus should be on support, resourcing, avoiding de-conditioning, maintaining safety, and maximizing health and independent function. Assessment of the need for mobility aids now and in the future is essential for these patients, and it is especially beneficial for the PT to assist the physician in assuring that the appropriate detailed prescription or letter of medical necessity (LOMN) is provided.
ADVANCED MS

Patients in advanced stages of MS have significant disease burden, are non-ambulatory, and at risk for other secondary health conditions. Physical therapy for this population will likely be focused on seated trunk positioning and control, transfers, upper extremity strength, respiratory function, and equipment needs. The use of standing devices or standing wheelchairs can be very helpful, providing weight bearing on the long bones, stretching to ease spasticity, relief for bowel and bladder, and improved respiration and speech projection.

PHYSICAL THERAPY ASSESSMENT

At the initial session, taking a thorough history is critical. The history should include date of diagnosis, date and nature of initial symptom(s), other health conditions, medications, prior level of activity, and “top three problems” in the order that they interfere with quality of life. This prioritization will guide the goal-setting.

The PT evaluation should be structured to respect fatigue, but provide a good overview of the patient’s baseline. Some standardized testing might be spread out over several follow-up sessions to avoid patient burnout and frustration. If a patient’s primary problem is “wobbly walking”, for example, a gait assessment should be performed both at the beginning and the end of the initial session to determine impact of fatigue on weakness and balance. It is also very important to have a variety of trial ambulation aids in the clinic — to introduce them to the patient (initial reluctance to accept an aid is common) and to determine “best fit” for the physician prescription.

The use of some standardized assessment tools in the assessment process is recommended; however few of those tests routinely used in PT have been evaluated specifically for the MS population. The few measures currently standardized for MS are:

- MS Functional Composite (MSFC), which includes the 25-foot walk
- Expanded Disability Status Scale (EDSS) — performed by trained physicians and nurse practitioners
- MS Fatigue Impact Scale (MSFIS)
- Disease Steps (DS)
- MS Walking Scale-12 (MSWS-12), a patient self-report

Other tests that are useful include:

- Berg Balance Scale
- Tinetti Gait and Balance Assessment
- Activities Specific Balance Confidence (ABC)
- Timed Up and Go (TUG)
- Dynamic Gait Index (DGI)
- Functional Independence Measure (FIM)
- 2-minute walk, 6-minute walk
- Borg’s Rate of Perceived Exertion

Two compelling articles by Pearson and colleagues challenge the usefulness of many current clinical ambulation measures. He proposes that “the gold standard for measuring ambulatory mobility in neurological disorders should be the total ambulatory activity undertaken by an individual in their usual environment in performing their usual range of daily activities.” This may herald increased use of pedometers, accelerometers, or even global positioning systems as better measures of true activity over time.

The PT evaluation can include a broad overview, so it’s important to prioritize time spent, with the patient’s primary issues addressed first.
**POSTURE, TRUNK CONTROL, BALANCE, TRANSFERS**

It is important to assess seated and standing posture and static and dynamic balance. Balance impairments are common in MS, increasing the risk of falls.11–13 When appropriate, transfers to and from bed, chair, toilet, car and floor should be evaluated — noting quality, safety, and level of assistance needed. Begin a fall risk/safety profile to guide treatment planning.

**AMBULATION/ MOBILITY**

For the ambulatory individual, the desire to continue walking or “to walk better” is usually a primary goal. Vision, sensation, vestibular or cerebellar deficits, spasticity, muscle weakness, fatigue and shoe wear need to be considered in addition to posture and balance. The most appropriate ambulation aid(s) should “normalize” the gait pattern with improved alignment, stability, control and confidence and a decrease in energy expenditure. A person’s needs often vary with level of fatigue, temperature, distance to be walked or time of day. Popular options are folding canes (with palm grip handles), lightweight forearm crutches, and four-wheeled rolling walkers (with large swivel wheels for easier maneuvering outdoors and on carpets, a flip-up seat without a front cross bar for more erect posture when walking and the opportunity to sit and rest when needed, a flexible backrest, and user-friendly hand-brakes). Other effective ambulatory aids for patients with foot drop include custom ankle-foot-orthoses (AFOs) made of lightweight plastics — articulated or solid — or the newer ultra lightweight carbon composite materials, hip-flexion-assist-orthoses (HFAO), or the new wireless functional electrical stimulators (FES).

**RANGE OF MOTION (ROM)**

Both passive and active functional ROM should be assessed in the extremities and trunk, limiting detailed goniometric measurement to noted problem areas for time and fatigue reasons. Sedentary or inactive persons with MS often present with significant tightness in hip flexors, adductors, hamstrings and heel cords. Limited overhead reach is often noted in those with slumped posture due to tightness in the pectoralis minor, major and latissimus dorsi. Poor head control due to postural and substitution patterns often leads to tightness in the upper trapezius and posterolateral cervical muscles.14

**MOTOR FUNCTION**

Assessment should focus on gross strength, with emphasis on function, in the extremities and trunk. Focus specific muscle testing on problem areas to minimize fatigue. Quality and control of movements, as well as substitution patterns, need to be noted. A key is to prevent or correct “secondary” or “disuse” weakness, commonly seen in persons with MS who have assumed a sedentary lifestyle or embraced compensatory movement patterns. Weakness due to inactivity and poor posture is frequently found in the trunk, lower abdominals, gluteus medius and maximus, middle and lower trapezius, and high anterior next flexors. Muscle imbalances of anterior/posterior tightness versus weakness (such as the iliopsoas and gluteus maximus) frequently respond favorably to a corrective exercise program and postural correction and awareness.14

**NEUROLOGICAL FUNCTION**

Assessment of neurological symptoms is necessary for development of treatment interventions (to supplement pharmacologic therapies) for improved safety, control and function. Common problems include abnormal tone — usually hyper-tonicity (which may be constant, fluctuating,
or intermittent) — clonus, and tremors (can be “resting”, “intention” or both). Note interference with function. Other deficits relate to coordination, sensation (hyper or hypo), proprioception and pain. Referral to a neurologist, physiatrist, or pain specialist for additional treatment interventions may be warranted.

**RESPIRATORY FUNCTION**

It is important to recognize that respiratory problems are common in more disabled patients, but also exist in a large number of persons with MS that have minimal disability.

**WHEELED MOBILITY**

The use of a wheelchair or scooter is often appropriate when long distances must be covered and energy conservation is required, allowing needed community access. Some persons with MS prefer a standard wheelchair because of its portability, but adequate upper body strength and endurance are needed. In most cases, motorized wheeled mobility is the better choice for long term independence.

A scooter (or “power operated vehicle”) is useful for individuals with significant fatigue, weakness, paraparesis or ataxia who retain good dynamic sitting balance and transfer skills. A power wheelchair would be more appropriate for individuals who are minimally or non-ambulatory and require additional seat and trunk support. In all cases, consideration must be given to vision, cognition, safety awareness, and access to home and vehicle.

**OTHER IMPORTANT CONSIDERATIONS**

Persons with MS have many other issues that need to be considered as part of the PT evaluation, goal-setting and when making referrals to other team members. In addition to vision, cognition and speech or swallowing problems, it’s important to consider each patient’s support/social network, emotional stability (depression is common), and vocational/homemaking history.

**GOAL SETTING & TREATMENT PLANS**

It is essential that the short-term therapy goals be *patient driven* (their “wish list”), functionally focused, realistic and attainable. Each PT should attempt to teach corrective exercises and activities that can easily be followed in the home or community to supplement any clinic equipment that might be used. Some “food for thought”: If leg weakness, fatigue, and impaired gait are primary issues, the patient will benefit more from functional activities done in (supported) standing than s/he will from 3 sets of 10 leg lifts or 20 minutes on a stationary bicycle. There is a lot to be said for specificity of training with this population. In every case, fatigue must be respected, over-heating avoided, and rest intervals provided — excellent opportunities for education and resourcing (which should be billed as “therapeutic activities”) during the treatment session. Long-term goals should include an effective home and community program with less dependence on formal physical therapy.
HOME PHYSICAL THERAPY PROGRAMS

The key components of a successful home program are that it is enjoyable, varied, goal-oriented and realistic. Compliance issues include fatigue, poor motivation, depression, lack of needed support or assistance from family and friends, time constraints, and cognitive dysfunction (usually short-term memory, attentional, or sequencing deficits, which requires the therapist to provide the exercises in written instructions and pictures). Emphasis needs to be placed on corrective exercises to: (1) improve function (restoring alignment, mobility, and strength/ endurance lost due to inactivity/disuse or compensatory movement patterns), (2) manage spasticity (slow stretching, cold packs, controlled position changes), and (3) control energy management (careful pacing, flexible work and activity schedules, pro-active resting vs. reactive “collapse”, avoiding overexertion/overheating, and sub-stitution of less stressful/strenuous/frustrating activities). Compliance is enhanced if the patient notes slow steady progress toward reaching the goals of improved symptom management and increased activity and participation both at home and in the community.

EXERCISE & MS

Historically, exercise was “something to be avoided” by persons with MS, as physicians feared the ramifications of fatigue and overheating. As a result, generations became de-conditioned prematurely due to inactivity. Although the benefits of exercise and activity have long been recognized as an important part of wellness, it was felt that this could not be tolerated by those challenged by MS. Petajan15 and colleagues published a pivotal study in 1996 that demonstrated the tolerance for and benefits of aerobic training for some individuals with MS. Since then, the literature has slowly increased in quality and volume to show positive statistical outcomes for various interventions to improve balance, gait, endurance, strength and quality of life (QOL).15–31

A guideline: All exercises and activity should be a “challenge”, but never a “struggle.”

Ideally, many persons with MS will eventually be able to participate in community-based activity programs such as water exercise in a cool (<85 degrees) pool,32 gentle yoga,33 tai chi34 (or water-based tai chi), hippo-therapy,35 or carefully guided fitness center and aerobic activities. In each case, it’s important that the program leader be aware of the special needs of those with MS and be willing to modify the programs appropriately. MS Day Programs are another excellent outlet for therapeutic recreational and social activities.

FOLLOW-UP

Optimal follow-up for outpatient therapy will vary according to individual needs, and typically varies from the “traditional” (orthopedic or fixed deficit neurological condition) model of 2–3 times/week for 6–8 weeks. Dedicated one-on-one sessions should be scheduled “as needed” since the need for rehabilitation is life long and likely to increase with age. Consideration must be given to the numerous compliance challenges, including transportation, weather (cold causes stiffness, high heat and humidity cause weakness), and lack of energy, motivation or support. Continuity with therapy provider(s) is another important consideration for improved compliance with follow-up. Initially it might be appropriate for patients to be scheduled 1–2 times a week to meet short-term goals. Then the frequency should lessen to weekly or every other week until symptoms are controlled and an effective home/community program has been established.
At that time follow-up should be “prn” to revise or augment the program or trouble-shoot any new problems.

Another major factor is insurance constraints, since the patient may have limits on number of visits per year, per condition, or per lifetime. Physical Therapists have the opportunity to advocate for coverage of appropriate and cost-effective follow-up for this challenging chronic condition, since attaining and then maintaining (by periodic therapy oversight) safe independent function is a worthwhile and cost-effective goal. Here is a statement from the National Multiple Sclerosis Society’s National Clinical Advisory Board that can be used effectively with case managers and insurers:36

Rehab in MS is a process that helps a person achieve and maintain maximal physical, psychological, social and vocational potential, and quality of life consistent with physiologic impairment, environment, and life goals. Achievement and maintenance of optimal function are essential in a progressive disease such as MS.

SUMMARY

Physical therapists are extremely important members of the health-care team for persons with MS, as this challenging disease can be frustrating for the patient, therapist, and family. There are no special treatments to learn, but to be a successful MS therapist, one must be willing to:

- Learn about this unique chronic disease
- Listen with sensitivity
- Evaluate with patience and care
- Be flexible and prepared to think “out of the box” in establishing effective individual treatment plans
- Be a “cheerleader” and problem-solver in empowering patients and families to better manage symptoms and overall health
- Be there for the long term
- Develop and maintain a current file of resources (equipment suppliers, orthotists, AT specialists, other rehab professionals, cooling products, accessible community programs, useful websites, etc.)

A FINAL QUOTE WORTH SHARING

With the advent of disease modifying agents to prolong time between attacks and slow disease progression, OT and PT interventions are more important and more cost-effective than ever before. Interventions have the potential to last longer and have greater impact on improving quality of life.37

REFERENCES


OCCUPATIONAL THERAPY IN MS REHABILITATION

National MS Society
Clinical Bulletin by Marcia Finlayson, PhD, OT (C), OTR/L

Multiple sclerosis (MS) is a chronic, frequently progressive disease of the central nervous system that is usually diagnosed between the ages of 20 and 50. While MS can result in considerable disability, it does not significantly reduce life expectancy. Consequently, people living with MS are often required to manage some level of MS-related disability for many years, making rehabilitation an important part of their healthcare. Occupational therapists are integral members of the MS healthcare team, working with patients and their families to develop and implement practical solutions to the challenges of everyday living with MS. The intent of this clinical bulletin is to describe the general focus of occupational therapy, explain the process of occupational therapy service delivery, and give an overview of the typical roles and activities of occupational therapists in MS care.

FOCUS OF OCCUPATIONAL THERAPY

Occupational therapists focus on “occupation,” which is defined as all of those tasks and activities that take our time and energy, and provide meaning and focus in our everyday lives (Canadian Association of Occupational Therapists, 1997). Occupational therapists identify and evaluate functional challenges, and offer interventions to address three broad areas of occupation:

- Self-care activities — including functional mobility, dressing, bathing, grooming, and eating
- Productive activities — including paid work, home management, caregiving, and volunteer activities
- Leisure activities — including involvement in social and recreational pursuits

Occupational therapy focuses on enabling people to participate in those occupations that have value and meaning to them. Evaluation by an occupational therapist identifies the current and anticipated occupational challenges an individual is experiencing due to disease, disability, injury or change in life roles. Intervention then focuses on removing or reducing those challenges to promote and enable participation in meaningful occupations. Intervention can be preventive, educational, compensatory, remedial, or consultative in nature, and involves the therapeutic use of purposeful and meaningful goal-directed activities to achieve therapy goals. For people living with MS, intervention may also focus on maintenance of current functional abilities.

PROCESS OF OCCUPATIONAL THERAPY SERVICE DELIVERY

Occupational therapists offer their services in a wide variety of settings including community and home care agencies, outpatient clinics, rehabilitation hospitals, skilled nursing facilities, acute care facilities, school systems, and private practices. Occupational therapy services are covered by most health insurance plans. Regardless of the setting in which they work, occupational therapists in most states require a physician’s referral in order to provide evaluation and treatment. In some locations treatment that is not medically related, or that is consultative or educational in nature, does not require a referral. For more information about the referral requirements in a particular jurisdiction, contact the state
office of professional regulation or the state occupational therapy association.

Once a referral is received, the occupational therapy process starts with a thorough, client-centered evaluation. Initially, the occupational therapist focuses on learning about the specific tasks and activities a client is concerned about being able to continue to do, is having difficulty doing efficiently or safely, and/or is interested in starting to do again or for the first time. Typically, the occupational therapist will use a structured interview for this part of the evaluation process. Two commonly used tools include the Canadian Occupational Performance Measure (Law et al., 1998) or the Occupational Performance History Interview II (Kielhofner et al., 2004).

After learning about the tasks and activities a client wants or needs to perform, the occupational therapist will then move on to identify the factors that are restricting or supporting current performance. Occupational therapists focus on three specific types of factors (Canadian Association of Occupational Therapists, 1997):

**PERSONAL FACTORS:**
- Symptoms of MS and other health conditions (e.g., fatigue, pain, balance)
- Physical capacities (e.g., strength, joint motion)
- Cognitive and perceptual capacities (e.g., memory, attention, problem solving, visual-spatial abilities)
- Psychological and emotional issues (e.g., self-efficacy, mental health)
- Specific skills and knowledge relative to performance of the tasks and activities in question (e.g., knowledge of meal preparation)

**ENVIRONMENTAL FACTORS:**
- Physical environment (e.g., accessibility, use of assistive technology)
- Social environment (e.g., presence and type of social supports)
- Cultural environment (e.g., values, expectations)
- Socio-economic issues (e.g., cost)

**OCCUPATIONAL FACTORS:**
- The physical demands of the task or activity (e.g., need to bend, reach, lift, carry)
- The cognitive and perceptual demands of the task/activity (e.g., need to multi-task, remember complex sequences, visual-spatial demands)
- The steps and sequencing of the activity (e.g., number of steps, flexibility of sequences)
- The temporal aspects of the activity (e.g., when it is performed, for how long)
- The need for or use of specific tools and technology during the activity (e.g., computer, appliances, adapted devices)

The process of identifying factors that restrict or support current performance can involve a wide range of evaluative procedures. For example, the evaluation of personal factors may involve physical assessments such as goniometric measures for joint range of motion, or manual muscle testing for strength. An occupational therapist may also use questionnaires such as the Fatigue Impact Scale (Fisk, Pontefract, Ritvo, et al., 1994) or the Perceived Cognitive Deficits Scale (Sullivan, Edgley, & Dehoux, 1990) to evaluate relevant factors.
Depending on the setting in which they work, some occupational therapists develop significant expertise in cognitive evaluations, particularly ones that involve the performance of contextually-relevant functional activities (Katz, 2005). Evaluation of environmental factors is ideally achieved through a home or workplace visit done together with the patient and family. If such a visit is not possible, interviews with the patient, family, or other relevant individuals can be used to obtain the information necessary for determining the extent to which the patient’s environment is supporting or restricting performance of tasks and activities.

At this point in the occupational therapy process, the occupational therapist has worked with the patient to identify what tasks and activities he/she wants or needs to do, and the factors that are restricting or supporting performance. This information is then used to set goals for intervention. Occupational therapy interventions may focus on prevention, education for health and disease management, compensation or remediation for lost or restricted abilities, or maintenance of function (Pedretti & Early, 2001; Trombly & Radomski, 2002).

**OCCUPATIONAL THERAPISTS IN MS CARE**

The focus of occupational therapy on the person’s ability to participate in valued and meaningful everyday activities is relevant throughout the course of MS. Beginning with the diagnosis, the prevention of activity curtailment and secondary disability is critical; throughout the advanced stages of the disease, maintenance of function and compensation for lost function are necessary. To illustrate the different ways that occupational therapists may work with people living with MS, several case illustrations will be shared.

**CASE #1**

Elizabeth is a 35-year-old woman who was recently diagnosed with MS. She works part-time as a data processor and is the mother of an active two-year old. Visual and cognitive changes and extreme fatigue are making it difficult for her to fulfill her responsibilities. To enable Elizabeth to continue working and parenting, the occupational therapist offers several interventions: The therapist works with Elizabeth to make modifications at her workplace to accommodate her visual symptoms. Changes include adjusting the lighting in Elizabeth’s office, repositioning her monitor and obtaining an anti-glare filter to reduce glare, and adjusting the accessibility options available through her computer settings to maximize contrast and font sizes.

Adjustments in lighting and contrast were also made in Elizabeth’s home to address her visual changes, particularly in the areas where she must supervise her child’s safety. Elizabeth is comfortable using new technologies, so the occupational therapist works with Elizabeth to select and set up a personal digital assistant (PDA) to compensate for some of her memory problems. The PDA is set up to give Elizabeth reminders to take medications, go to appointments, and do shopping and banking tasks. The occupational therapist also teaches Elizabeth how to analyze and modify her activities and use adapted equipment in order to reduce her energy expenditure and manage her fatigue.

**CASE #2**

Mark is a 47-year-old man who has primary progressive MS. He lives alone and uses a power wheelchair full-time. Mark just hired a personal care attendant to help him with daily self-care.
tasks. Mark has not previously directed a personal care aide and wants to ensure that he gets the help he needs in a safe and respectful manner. The occupational therapist works with Mark to develop strategies for communicating his needs to his personal care attendant, for example, explaining what he needs, giving clear directions about how to help, and providing constructive feedback about the attendant’s actual performance of duties. The occupational therapist has Mark role play different communication situations to increase his confidence in his ability to direct his personal care attendant. Once Mark feels comfortable giving direction and feedback, the occupational therapist works with Mark and the personal care attendant to practice safe and efficient techniques for dressing, transfers, and bathing that optimize and maintain Mark’s current abilities.

The occupational therapist also shows Mark and the personal care attendant how to check and maintain the safety of his wheelchair and transfer equipment.

CASE #3
Georgia is a 67-year-old woman whose MS has recently become progressive. She is experiencing an increased number of falls, which has caused her to become quite fearful. Her fear has led to a curtailing of her activities and increasing social isolation. Since Georgia does not like to exercise, the occupational therapist shows her ways to increase her lower extremity strength and maintain her balance while doing everyday activities like cooking and cleaning. The occupational therapist also works with Georgia to select a walker that meets her needs and then teaches her to use it safely in different situations around her home, yard, and community. To address environmental hazards around Georgia’s home, the occupational therapist completes a home safety checklist with Georgia, and together they make some simple changes to reduce her risk of falling (e.g., rearranging furniture, adding lighting on the stairs, tacking down loose flooring, throwing out worn shoes).

Throughout these interactions, the occupational therapist utilizes cognitive behavioral techniques to address Georgia’s fear of falling. Together they plan strategies for Georgia to use when she does fall so that she feels confident in her ability to handle the situation. Finally, the occupational therapist coaches Georgia on ways to reconnect with her friends and community activities in order to reverse her social isolation and prevent depression.

CASE #4
Amy is a 50-year-old woman who has been hospitalized for a recent exacerbation that resulted in loss of function on her left side. It is very important to Amy that she be able to prepare simple meals and do her own dressing and bathing before she returns home. The occupational therapist works with Amy to teach her one-handed dressing and bathing techniques, and makes arrangements for Amy to obtain a shower chair and grab-bar for home. Amy learns how to transfer safely onto the shower chair using the grab-bar, and the occupational therapist corrects Amy’s technique to ensure that she can do the transfer safely on her own.

1. See: sammonspreston.com/Supply/Product.asp?Leaf_Id=AA5208
2. See: sammonspreston.com/Supply/Product.asp?Leaf_Id=555644#
Amy is also given guidelines for selecting a contractor to install the grab-bar properly in her bathroom, and the occupational therapist leaves instructions about how to position the bar for Amy’s maximum safety and functional independence. For meal preparation, the occupational therapist teaches Amy to use a number of assistive devices in the kitchen so that she can safely prepare simple meals with one hand, for example, a wall-mounted jar opener, a clamp-on peeler, a kitchen workstation, and a rocker knife. Together, they practice preparing simple meals using these devices so that Amy feels comfortable that she will be able to use them independently once she returns home.

These four case illustrations provide a glimpse into the potential interventions that occupational therapists might offer a person with MS from initial diagnosis through the remainder of the disease course. Many occupational therapists develop special skills in important areas that are relevant to people living with MS, for example, home modifications, driver rehabilitation, wheelchair selection and prescription, cognitive rehabilitation, vocational rehabilitation, and assistive technology. In addition, occupational therapists often become involved in developing and implementing large scale, community-based programs such as Gateway to Wellness (Neufeld & Kniepmann, 2001) and Managing Fatigue (Packer, Brink, & Sauriol, 1995).

Ultimately, occupational therapists work together with their clients to find ways to enable people with MS to continue to live active and productive lives despite the personal, environmental and occupational challenges that they face.

**FINDING AN OCCUPATIONAL THERAPIST**

To find an occupational therapist with expertise in MS care, contact the National MS Society at 1-800-344-4867.

**REFERENCES & ADDITIONAL READINGS ON OCCUPATIONAL THERAPY IN MS CARE**


Studies of dysarthria in MS indicate a prevalence ranging from 41% to 51%.\textsuperscript{1–3} Self-reporting of speech and other communication disorders has varied widely: 23% in a study in the United States (N=656);\textsuperscript{4} 44% in a Swedish study (N=200);\textsuperscript{5} and 57% in a preliminary South African study (N=30).\textsuperscript{6} The range in prevalence figures reflects inconsistencies in study design, including the size and characteristics of the study samples, and the terminology and assessment tools used. In addition, a lack of congruence between evaluation results by a speech/language pathologist and self-report by individuals with MS has been proposed, and needs further study.

Speech and voice problems may be identified by the person with MS, a family member, or a healthcare professional. Common complaints include difficulty with precision of articulation, speech intelligibility, ease of conversational flow, speaking rate, loudness, and voice quality. When these problems interfere with a person’s quality of life — particularly the ability to communicate daily needs — a referral for evaluation and treatment by a speech/language pathologist is recommended.

**NORMAL SPEECH PRODUCTION**

The normal processes of speech and voice production are overlapping and require the following five processes to work together smoothly and rapidly:\textsuperscript{7–8}
**RESPIRATION**

Using the diaphragm to quickly fill the lungs fully, followed by slow, controlled exhalation for speech.

**PHONATION**

Using the vocal cords and airflow to produce voice of varying pitch, loudness, and quality.

**RESONANCE**

Raising and lowering the soft palate to direct the voice to resonate in the oral and/or nasal cavities to further affect voice quality.

**ARTICULATION**

Coordinating quick, precise movements of the lips, tongue, mandible, and soft palate for clarity of speech.

**PROSODY**

Combining all elements for a natural flow of conversational speech, with adequate loudness, emphasis, and melodic line to enhance meaning.

**DEFINITION OF DYSARTHRIA & DYSPHONIA**

**DYSARTHRIA**

Dysarthria refers to a speech disorder, caused by neuromuscular impairment, which results in disturbances in motor control of the speech mechanism. The demyelinating lesions caused by multiple sclerosis may result in spasticity, weakness, slowness, and/or ataxic incoordination of the lips, tongue, mandible, soft palate, vocal cords, and diaphragm. Therefore, articulation, speaking rate, intelligibility, and natural flow of speech in conversation are the areas most likely to be affected in those with multiple sclerosis.

**DYSPHONIA**

Dysphonia, which refers to a voice disorder, often accompanies dysarthria because the same muscles, structures, and neural pathways are used for both speech and voice production. Therefore, voice quality, nasal resonance, pitch control, loudness, and emphasis may also be affected in those with MS.

**COMMON FEATURES OF DYSARTHRIA IN MS**

Dysarthria is considered the most common communication disorder in those with MS. It is typically mild, with severity of dysarthria symptoms related to neurological involvement.

Darley and colleagues published the first comprehensive, scientific study identifying common features of dysarthria in 168 people living with MS. Analyses of speech characteristics and description of deviations in the five processes of respiration, phonation, resonance, articulation and prosody were rank ordered (see Table 6).

Since then, three replication studies have reported insufficient reliability of clinicians' judgments in the more specific areas, yet high agreement in such overall speech dimensions as intelligibility and naturalness.

A cross-linguistic analysis of dysarthria in Australian (N=56) and Swedish (N=77) speakers with MS, using a 33-point protocol, identified six deviant features: harsh voice, imprecise articulation, impaired stress patterns, rate, breath support, and pitch variations. Even though different rank orders and problem frequencies were seen, agreement with
TABLE 6: RANK ORDER OF DEVIATIONS IN SPEECH & VOICE IN MS

<table>
<thead>
<tr>
<th>PERCENT (N=168)</th>
<th>DEVIATION</th>
<th>DESCRIPTION</th>
</tr>
</thead>
<tbody>
<tr>
<td>77%</td>
<td>Loudness control</td>
<td>Reduced, mono, excess or variable</td>
</tr>
<tr>
<td>72%</td>
<td>Harsh voice quality</td>
<td>Strained, excess tone in vocal cords</td>
</tr>
<tr>
<td>46%</td>
<td>Imprecise articulation</td>
<td>Distorted, prolonged, irregular</td>
</tr>
<tr>
<td>39%</td>
<td>Impaired emphasis</td>
<td>Phrasing, rate, stress, intonation</td>
</tr>
<tr>
<td>37%</td>
<td>Impaired pitch control</td>
<td>Monopitch, pitch breaks, high, low</td>
</tr>
<tr>
<td>35%</td>
<td>Decreased vital capacity</td>
<td>Reduced breath support and control</td>
</tr>
<tr>
<td>24%</td>
<td>Hypernasality</td>
<td>Excessive nasal resonance</td>
</tr>
</tbody>
</table>

Darley’s list of seven most common features was noted, with the exception of loudness and hypernasality.

DIFFERENTIAL DIAGNOSIS

There are three types of dysarthria associated with MS (see Table 7): spastic, ataxic or mixed. Differential diagnosis depends on the extent and location of MS lesions, and the specific speech, voice, and accompanying physical signs that result. Mixed dysarthria is most common in MS, because multiple neurological systems are typically involved.13

SYMPTOM MANAGEMENT OF CONTRIBUTING FACTORS

Differential diagnosis of the type of dysarthria has important implications for treatment planning by the speech/language pathologist, as well as decision-making by the physician regarding pharmacologic management. Dysarthria and dysphonia in MS may be accompanied by the underlying symptoms of spasticity, weakness, tremor and ataxia; and complicated by fatigue.

Therefore, evaluation of medication trials to treat these symptoms, and ongoing communication with the patient and physician about the impact on speech and voice, is recommended during therapy.1
### TABLE 7: COMPARING THE THREE TYPES OF DYSARTHRIA

<table>
<thead>
<tr>
<th>SPEECH &amp; VOICE SIGNS</th>
<th>RELATED NEUROMUSCULAR/PHYSICAL SIGNS</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>SPASTIC DYSARTHRIA: DUE TO BILATERAL LESIONS OF CORTICOBULBAR TRACTS</strong></td>
<td></td>
</tr>
<tr>
<td>Harsh, strained voice quality</td>
<td>Hypertonicity (excess muscle tone)</td>
</tr>
<tr>
<td>Pitch breaks</td>
<td>Bilateral spasticity</td>
</tr>
<tr>
<td>Imprecise articulation</td>
<td>Restricted range of motion (jaw)</td>
</tr>
<tr>
<td>Slow rate of speech</td>
<td>Reduced speed of movement</td>
</tr>
<tr>
<td>Reduced breath support and/or control</td>
<td>Bilateral hyperreflexia</td>
</tr>
<tr>
<td>Reduced or mono-loudness</td>
<td>Sucking and jaw jerk reflexes</td>
</tr>
<tr>
<td>Short phrases, reduced stress</td>
<td>Cortical disinhibition</td>
</tr>
<tr>
<td>Hypermnasality</td>
<td></td>
</tr>
<tr>
<td><strong>ATACTIC DYSARTHRIA: DUE TO BILATERAL OR GENERALIZED LESIONS OF THE CEREBELLUM</strong></td>
<td></td>
</tr>
<tr>
<td>Vocal tremor</td>
<td>Intention tremor: head, trunk, arms, hands</td>
</tr>
<tr>
<td>Irregular articulation breakdown</td>
<td>Broad-based, ataxic gait</td>
</tr>
<tr>
<td>Dysrhythmic rapid alternating movements of the tongue, lips, and mandible</td>
<td>Nystagmus and irregular eye movements</td>
</tr>
<tr>
<td>Excess and equal stress (scanning speech)</td>
<td>Balance or equilibrium problems</td>
</tr>
<tr>
<td>Excess and variable loudness</td>
<td>Hypertonicity</td>
</tr>
<tr>
<td>Prolonged phonemes and intervals</td>
<td>Overshooting; slow, voluntary movements</td>
</tr>
</tbody>
</table>
**SPEECH & VOICE SIGNS**

**RELATED NEUROMUSCULAR/PHYSICAL SIGNS**

**MIXED DYSA RTHRIA: DUE TO BILATERAL, GENERALIZED LESIONS OF MULTIPLE AREAS IN THE CEREBRAL WHITE MATTER, BRAINSTEM, CEREBELLUM, AND/OR SPINAL CORD**

- Impaired loudness control (reduced, monoloudness, or excess and variable)
- Harsh or hypernasal voice quality
- Impaired articulation (imprecise, distorted, prolonged or irregular breakdowns)
- Impaired emphasis (slow, prolonged intervals or sounds, reduced, or excess and equal stress)
- Impaired pitch control (monopitch or pitch breaks, too low or too high)

- Any combination of spastic and ataxic features as mentioned above

**ASSESSMENT OF DYSA RTHRIA**

Evaluation of dysarthria and dysphonia in MS typically involves three main aspects:

1. Assessment of oral-motor function of the peripheral speech mechanism by:
   - Examining the structure and function of the articulators (lips, teeth, tongue, mandible, hard and soft palates) for symmetry, strength, speed, and coordination.
   - Evaluating respiratory support and control for speech.

   Analyzing laryngeal control of loudness, pitch and voice quality during phonation.

2. Perceptual analysis to describe the various dimensions of respiration, phonation, articulation, resonance, and prosody. To classify type and severity of dysarthria.


Dysarthria evaluation in MS has traditionally included both informal and formal measures of a variety of oral-motor, speech, and voice functions, with comparison to referenced norms.

Formal articulation tests are not commonly used because MS-related dysarthria tends to have an irregular pattern of breakdown that is not necessarily based on misarticulation of specific speech sounds. Rather, measures of oral reading rate in phonetically balanced passages (e.g., *My Grandfather* — one of many standardized, phonetically-balanced oral reading passages) and analysis of a brief, recorded spontaneous speech sample (e.g., describe job, family, interests, etc.) are standard procedures. Speaking rate, articulation precision, number of words/breath unit, pauses within and between words, intelligibility, and
naturalness of conversational flow are then measured and described. Speaking rate varies according to the task: oral reading of sentences — 190 words per minute; oral reading of paragraphs — 160–170 words per minute; speaking rate in conversation — 150–250 words per minute. The wide range in conversation is due to a variety of cognitive-language factors, including the complex verbal formulations that are used, word retrieval/fluency abilities, turn-taking, and lack of concrete cues for pauses (such as the commas and periods in reading materials).

Some formal, published measures used in dysarthria evaluation in MS include:

- **Assessment of Intelligibility in Dysarthric Speech** (word and sentence levels), in which a judge, unfamiliar with the material, transcribes the recorded responses.14

- **Dysartri-test**, which includes 54 test items, scored on a five point interval scale. Items measured in each speech parameter include: respiration, phonation, oral-motor performance (divided into lips, jaw, tongue, and soft palate, plus a diadochokinesis rating), articulation, prosody and intelligibility.15

- **Queensland Protocol**, an adapted version of the perceptual analysis/dysarthria classification procedure introduced by Darley and colleagues. This protocol includes 33 items relating to the five speech dimensions of respiration, phonation, resonance, articulation and prosody, and uses a 4-point descriptive equal-interval scale to measure rate, intelligibility, articulation precision of consonants and vowels, and phoneme length.16

**NEW DIRECTIONS IN ASSESSMENT**

There has been a trend in recent years, to supplement perceptual analyses of dysarthria with acoustic analyses of speech parameters. Advancement in physiological instrumentation for assessment is aimed at improving objectivity in measurement, refining our understanding of dysarthria features specific to MS, and ultimately aiding clinical decision-making and treatment planning.

- **Spectrographic displays** have been used to obtain specific measures of acoustic distinctiveness during speech samples. For example, Tjaden and Wilding used a sound treated booth, head-mounted microphone, and recording software (such as the CSpeechSP 4.0 or windows-based version TF32, Turbo Pascal 5.5) to objectively measure variations in sound/syllable duration, rate of articulation, vocal intensity, and size of working space for vowel and consonant production.17–18

- **Lip and tongue transducers** have been used to objectively measure range, force, and diadochokinesis (or rapid alternating movements) of their function. Results of a recent study by Hartelius and Lillvik using this technique found that tongue function is more severely affected than lip function in MS, that tongue dysfunction can be detected subclinically (in non-dysarthric subjects), and that there was a moderate correlation to severity of neurological deficit and years in disease progression. Based on their findings, the importance of targeting improvement in tongue functioning early in articulation therapy was suggested.19

Despite advances in the development of instrumental assessment techniques in recent years, perceptual analysis of recorded speech remains a primary tool for differential diagnosis and treatment planning.
TREATMENT

Evaluation of evidence-based research and expert opinion to support the treatment of dysarthria and to develop practice guidelines has been a project of the American Speech/Language Hearing Association (ASHA) and Academy of Neurologic Communication Disorders and Sciences (ANCDS) since 1997. A series of four practice guideline reports were published in the *Journal of Medical Speech/Language Pathology* (2001–2004) and are available at ancds.org. Guidelines for improving speech intelligibility and naturalness are forthcoming.

The World Health Organization’s 2002 international classification of function, disability and health has had a significant impact in the field of rehabilitation. The goal of addressing physical function and structure within the broader context of a person’s ability to participate actively in his or her world, has influenced both assessment protocols and treatment planning. In dysarthria therapy, the trend has been away from a focus on specific impairments (e.g., oral exercises to normalize movement patterns), toward the acquisition of specific skills to facilitate participation in functional real-world activities (e.g., speaking with adequate loudness and intelligibility for telephone activities at work or home).

Clinical decision-making in treatment planning is individualized according to the person’s specific problems and communication needs. Improving speech intelligibility and naturalness should be the ultimate goal of therapy. Selection of appropriate treatment approaches, and where to begin therapy, depend on which deviant speech dimension(s) are most disabling in these two areas. Work on one target behavior can have overlapping, indirect effects on other physiological and acoustic variables. For example, improving breath support/control can increase loudness and indirectly reduce rate, thus allowing more precise articulation and improving overall speech intelligibility. Measuring impact on participation and quality of life are recommended, to assess functional outcomes of dysarthria therapy.

Traditional dysarthric compensations taught to MS speakers include: improving breath support and control; reducing the rate of speech; using strategic pauses within and between words; exaggerating articulation; and actively self-monitoring/self-correcting speech.

In a recent review of the intervention literature on respiratory/phonatory dysfunction in dysarthria, evidence was found to support the following:

**IMPROVING BREATHE SUPPORT**

Improving breath support by using biofeedback to gauge respiration (and loudness or phrase length) during speech tasks, and when learning a new breath pattern with deeper inhalation, increased force at exhalation, and use of abdomen. Physiological and acoustic biofeedback methods, such as a Visi-pitch, Computer software, VU meter, recorder, respitrace, water manometer, velocity/air pressure transducer, oscilloscope, and EMG were mentioned.
Improving respiratory/phonatory coordination by increasing awareness of the irregular speech-respiratory pattern, determining optimal words/breath groups, gradually increasing them, and practicing flexibility in cued and non-cued conversational scripts.

Improving phonatory functioning

- Hyperadduction (harsh voice quality, typical of MS): Often not directly treated because it is difficult to modify, with negligible impact on intelligibility.
- Hypoadduction (soft, breathy, whispered voice quality): Significant improvement has been demonstrated using the Lee Silverman Voice Treatment (LSVT) in those with Parkinson’s disease and hypokinetic dysarthria. The LSVT seeks to increase vocal loudness, by increasing phonatory effort, which has been shown to improve speech intelligibility. Variable results with the LSVT technique have been noted in MS speakers and their spastic, ataxic, and mixed types of dysarthria.

RIGID

Use of external aids — such as finger tapping, a pacing board, or a metronome — to slow speaking rate and allow more precise articulation of each word or syllable. Although this technique provides the fastest and greatest improvement in intelligibility, naturalness in flow of speech can suffer. It can be a motivating starting point, when combined with rhythmic rate control.

RHYTHMIC

Rate control techniques that also attempt to preserve naturalness by using biofeedback systems — including the Pacer/Tally software, Visi-pitch, and delayed auditory feedback (DAF) — during speech tasks. The direct magnitude production technique (DMP), which uses no external device, can also be effective. The DMP is self-devised, and asks the individual to speak at half his habitual rate. Whereas the rhythmic techniques take more time to learn, both speech intelligibility and naturalness may be improved.

Imprecise articulation of consonants has been noted as the greatest contributor to reduced overall speech intelligibility. In two studies specific to dysarthria treatment in MS speakers, the combined/overlapping effects of multiple techniques (increasing loudness, reducing rate, and exaggerating articulation) showed a positive impact on preciseness and speech intelligibility. Hartelius found tongue function to be more severely affected than lip function in dysarthric and non-dysarthric speakers with MS (N=77). Therefore, increasing articulatory excursions while reducing rate is recommended.
Increasing loudness and reducing rate have also been associated with increasing the size of the articulatory-acoustic working space, and thus improving articulation precision and acoustic distinctiveness. Tjaden and Wilding performed acoustic and perceptual analyses of 15 mild to moderate spastic, ataxic, and mixed dysarthric speakers with MS and found that acoustic distinctiveness of vowels, as indexed by vowel space, was maximized in the slow condition, whereas distinctiveness of stop consonants was maximized in the loud condition. These findings are important for treatment planning.

AUGMENTATIVE & ALTERNATIVE COMMUNICATION

The need for augmentative and alternative communication (AAC) devices in individuals with MS is relatively uncommon. However, when severe dysarthria interferes with the individual’s well-being, safety, and functional communication of daily needs, evaluation for an appropriate speech generating device (SGD) is indicated. Speech supplementation devices (such as voice amplifiers) and non-speech alternatives are also available.

There are low-tech alternatives, such as: alphabet, picture, or eye gaze boards, as well as bells, buzzers, and yes–no systems — any of which offer manual, optical, or partner-assisted selection. And there are high-tech alternatives with dedicated devices such as Link or LightWRITER or multi-purpose/integrated devices, such as Mercury or Dynavox that use special PC software such as a keyboard with word-prediction software, EZ keys, touch screen, joystick, mouse, optical or switch scan as input, and text to digitized or synthesized speech output. Information about AAC devices, vendors, materials, and tutorials can be found at aac.unl.edu.

Yorkston and Beukelman (2000) developed a functional staging system for AAC intervention to aid in clinical decision-making. It rates five areas — speech, cognition, literacy, vision, and upper and lower extremity functioning — on a 5-point scale. A team approach to AAC evaluation (including a physical therapist, occupational therapist, and speech/language pathologist) that takes into account the full range of a person’s symptoms, is recommended. Once assessment and training on the appropriate device has been completed, routine re-evaluation and update is essential.

In 2001, Medicare began providing reimbursement for evaluation, treatment, and appropriately prescribed SGD devices. Medicare’s assessment protocol and guidelines set the standard for state, federal, and private health plans. For example, prior to SLP recommendation and physician prescription, an assessment trial of at least three systems that incorporate the necessary features is required before Medicare will provide authorization. Information about Medicare funding is available at aac-rerc.com.

CONCLUSION

In a preliminary MS study in South Africa, 62% of the respondents experiencing speech and language problems reported that these difficulties had a negative impact on their quality of life (QOL). Although the prevalence of dysarthria in MS has been reported to be at least 41%, referral rate is low — a significant gap that needs to be addressed.

Assessment protocols and treatment procedures for dysarthria in MS have shown recent advances. Trends have included the refinement of perceptual and acoustic analyses, and incorporation of the World Health Organization’s...
A Focus on Rehabilitation

international classification of function, disability and health, which aids functional goal-setting. Specific treatments are being studied with the MS population and controls, to add evidence-based research to the expert opinion of clinicians.

More MS research is needed in the international community in the areas of prevalence, acoustic and physiological dimensions as they relate to perceptual analysis, treatment outcomes as they relate to quality of life, and cross-linguistic perceptual ratings.

REFERENCES


Swallowing Disorders & Their Management in Patients with MS

National MS Society
Clinical Bulletin by Jeri A. Logemann, PhD, CCC-SLP, BRS-S

Introduction

Permanent and transitory swallowing disorders (dysphagia) occur with high frequency in patients with multiple sclerosis (MS) (Abrahams & Yun, 2002; Calcagno et al., 2002; De Pauw et al., 2002; Prosiegel et al., 2004; Wiesner et al., 2002). In fact, swallowing disorders may be present long before the person with MS experiences any related symptoms.

In 1987, Dr. Angie Fabiszak studied three groups of individuals: healthy controls with no diagnosis of multiple sclerosis or other medical problems; patients with MS but no complaints of swallowing problems; and patients with multiple sclerosis who were complaining of a swallowing disorder. Results of x-ray studies (modified barium swallow) on these patients revealed that both of the groups of patients with multiple sclerosis exhibited similar abnormalities in swallowing, whereas the normal control group exhibited no swallowing disorders. In recent years, several other investigators have corroborated the fact that patients with multiple sclerosis frequently exhibit swallowing disorders, even if they have no such complaints.

It is, therefore, important for the MS patient’s primary care physician to refer the patient with multiple sclerosis — with or without a complaint of swallowing problems — for a full workup of his or her oropharyngeal and esophageal swallowing function as soon as the patient has a diagnosis of multiple sclerosis, in order to establish a baseline swallow physiology against which to compare any future changes.

Normal Swallowing

Normal swallowing involves cortical control of the facial muscles and tongue in placing food in the mouth, manipulating and tasting the food, chewing it, and forming it into a ball or bolus to be swallowed. Once the bolus is formed, the tongue begins to propel the food, or part of it, into the pharynx (throat), where control of the process is taken. The movements of the tongue and bolus stimulate sensory nerve endings which, in turn, trigger contractions in the pharynx, initiating the pharyngeal stage of the swallow. When the pharyngeal swallow is triggered, a number of motor components are initiated:

- The soft palate closes to prevent food or liquid from going into the nose.
- The larynx (entrance to the airway) lifts and closes to prevent food or liquid from entering the trachea.
- The base of the tongue and walls of the throat converge to create pressure at the back of the bolus, propelling it throughout the pharynx into the esophagus.
- The upper esophageal sphincter (located at the top of the esophagus) opens to enable the food to enter the esophagus.

Once in the esophagus, sequential esophageal motor contraction (peristalsis) propels the bolus through the esophagus to the stomach. The lower esophageal sphincter opens to allow the bolus to enter the stomach. The entire swallow, from placement of food in the mouth through entrance to the stomach, occurs rapidly (1 second in the oral cavity, 1 second in the pharynx, and 8–10 seconds in the esophagus).
safely (with no aspiration), and efficiently (with minimal residue).

The normal swallow depends upon a well-functioning central nervous system, including cortical and sub-cortical areas, the brainstem, and peripheral nerves — particularly cranial nerves. If the patient’s MS lesions affect any of these areas, swallowing may be challenged. Many patients with MS will cough if food enters their airway or will require multiple swallows to clear food that has been left behind in the pharynx. Keep in mind, however, that patients who are experiencing reduced sensation may be unaware that food particles have entered the airway or that residual food particles have been left in the pharynx; they will not cough or repeat their swallows in spite of the need to do so.

BASELINE SWALLOW ASSESSMENT: THE MODIFIED BARIUM SWALLOW & ESOPHAGRAM

The patient with multiple sclerosis should receive a modified barium swallow to examine oral and pharyngeal swallow physiology, followed by an esophagram to examine esophageal function.

The modified barium swallow is preferred because the MS patient may aspirate when given the usual large-volume swallows, including cup drinking, which are used for a standard barium swallow. In contrast to the standard barium swallow, the modified barium swallow is designed to introduce calibrated, measured volumes of thin liquids first, beginning with 1 ml, which is similar to a saliva swallow, and building to 3 ml, 5 ml, and 10 ml as tolerated by the patient without aspiration.

Then, the patient is given a cup to drink from, followed by several swallows of 3 ml of pudding, and then 2 pieces of Lorna Doone cookie (¼ of a cookie) coated with barium pudding (Logemann, 1993). This procedure, which involves a total of 14 swallows, allows the clinician to identify any abnormalities in the swallow as it progresses from small to large volumes of thin liquids, and thin to thicker viscosities. In healthy individuals, both volume and viscosity sequentially change the physiology of the swallow; it is important to determine whether the person with MS exhibits a similar systematic change in his or her swallow physiology in response to changing volume and viscosity (Logemann, 1998).

In addition to demonstrating the individual patient’s swallow physiology, the modified barium swallow makes it possible to introduce and evaluate management strategies should they be needed. Strategies for management are introduced and evaluated on x-ray when the patient aspirates or has significant residual food left in the pharynx after the swallow. By the time the patient has completed the modified barium swallow procedure, the clinician should have an outline of recommendations for: 1) effective management strategies, including any swallowing therapy procedures that are needed; and 2) optimal, safe diet consistencies. The radiographic study should involve a speech-language pathologist who is familiar with the various management strategies and can introduce and evaluate the immediate effectiveness of the therapies during the radiographic study.

COMMON SWALLOWING DISORDERS IN MS

The most common MS-related swallowing disorders in the oral and pharyngeal areas are:
DELAY IN TRIGGERING THE PHARYNGEAL SWALLOW

The delay in triggering the pharyngeal swallow, which is the most common problem seen in MS patients, can cause particular difficulties with liquid swallowing, including aspiration (Logemann, 2000). When the pharyngeal swallow is delayed, liquid may splash from the mouth into the pharynx. Because motor control of the pharynx has not been activated by the brainstem, the airway remains open and the upper esophageal sphincter remains closed, causing liquid that enters the pharynx to splash into the open airway and be aspirated.

REDUCTION IN LARYNGEAL ELEVATION

Reduced laryngeal elevation can contribute to weakened closure of the airway during the swallow and to reduced clearance of material from the pharynx, thereby causing residue after the swallow and possible aspiration.

REDUCTION IN TONGUE BASE RETRACTION

Reduction in tongue base activity reduces the pressure generated during the swallow, allowing residual food to remain in the pharynx and be aspirated when the patient resumes breathing.

These disorders can be mild, without causing any significant difficulties such as aspiration or inefficient swallow; or, they can be more severe and require therapeutic (behavioral) management.

THE BARIUM SWALLOW EVALUATION

Esophageal disorders require a standard barium swallow evaluation in which the patient is given a cup of barium and asked to swallow sequentially. A typical swallow from a cup or glass includes approximately 15 to 20 ml per swallow, a large volume that can cause difficulty if the patient has any significant abnormality. For this reason, the modified barium swallow should always precede the barium swallow to identify the locus of oropharyngeal swallow difficulty prior to giving the patient a large volume of liquid in a barium swallow or esophagram.

DYSPHAGIA MANAGEMENT

The goal of dysphagia management is to maintain the patient on a normal diet as much as possible. Generally, two management plans are devised for each patient — one to promote safe and efficient swallowing for oral intake and one focused on exercise/therapy (Logemann, 2006). There are various kinds of strategies that can be introduced, including:

- Postural change — which helps to redirect food along the correct pathway (i.e., away from the airway);
- Heightened oral sensation prior to the swallow — which enables the patient to get a faster pharyngeal swallow;
- Voluntary control over swallows, such as holding one’s breath to protect the airway, or increasing effort, if possible, to clear a greater amount of bolus.
- Exercises to improve range of motion or coordination of the movement in the oral and pharyngeal structures as well as techniques to improve strength in the tongue.
One factor that can play a role in the selection of strategies for swallowing therapy is the patient’s level of fatigue. If the patient is extremely fatigued, some swallow therapy strategies are not appropriate.

If the patient experiences significant exacerbations and/or the disease progresses, the nature or severity of his or her swallowing disorder could be expected to change as well. A re-assessment of the person’s swallowing problems and a revised treatment plan are appropriate at that time.

RECOMMENDATIONS FOR NON-ORAL VERSUS ORAL FEEDING

After the videofluoroscopic study of oropharyngeal swallow, the clinician will recommend continued oral feeding, or partial or complete non-oral feeding — depending upon the patient’s safety and efficiency of swallow. If the patient is regularly aspirating on all foods, no matter what food viscosity is presented or therapy is used, non-oral feeding may be recommended for two reasons: First, regular aspiration can cause pneumonia; second, whatever the patient aspires will not provide nutrition or hydration.

Several studies have shown that patients who aspirate during the x-ray study have a significantly increased risk of pneumonia in the next 6 months than patients who do not aspirate during the study (Pikus et al., 2003; Schmidt et al., 1994). Non-oral supplements to ensure adequate nutrition and hydration may also be recommended for patients who have been exhibiting weight loss and fatigue when taking food orally. Whether or not the patient exhibits chronic aspiration or fatigue, partial non-oral feeding may be helpful. For example, the patient who aspirates may do so only on certain foods and be able to eat other foods orally. Or, the patient who fatigues easily may eat some foods orally and initiate non-oral nutrition when fatigue sets in.

The two basic types of non-oral feeding that allow food and liquids to be taken into the body without being swallowed are the nasogastric tube that goes through the nose and throat into the esophagus and stomach (generally used only on a very temporary basis because of the irritation it can cause to the nose and throat), and the percutaneous endoscopic gastrostomy (PEG) that involves inserting a feeding tube through the abdominal wall directly into the stomach.

Both of these options for non-oral feeding are temporary and can be removed or not used when desired. Often patients and their significant others think that a decision to introduce partial or full non-oral feeding means that the patient will never eat by mouth again. This, however, is not the case. Non-oral feeding can serve as a temporary bridge while the patient improves and returns to oral feeding. Thus, at the end of the radiographic study, the recommendation for continued oral feeding, partial non-oral, or full non-oral feeding will be made. This is a recommendation to be carefully considered by the patient’s physician, the patient, and their significant others.

PATIENT & FAMILY COUNSELING REGARDING SWALLOWING MANAGEMENT

The speech-language pathologist can also provide counseling to the patient and their family regarding the importance of completing the exercises given in therapy and ways in which the family can facilitate the patient’s practice of exercise and application of techniques for swallowing improvement during mealtime.
FOLLOW-UP

It is important for MS patients and their family members to contact both their physician and their speech-language pathologist if the swallow appears to worsen. It is common for dysphagia in patients with multiple sclerosis to wax and wane. This does not mean that swallowing management cannot be done, but rather that the therapy procedures used may need to be changed. The goal of swallowing management is to keep the MS patient from getting pneumonia or losing weight because of a swallowing difficulty.

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Jeri A. Logemann, PhD, CCC-SLP, BRS-S, is Ralph and Jean Sundin Professor, Communication Sciences and Disorders, and Professor, Neurology and Otolaryngology — Head and Neck Surgery, Northwestern University, Evanston and Chicago, Illinois, USA.
While the following list is not intended to be comprehensive, it represents many of the tools commonly used in rehabilitation assessment of patients with MS.

**ASHWORTH & MODIFIED ASHWORTH SPASTICITY SCALE**

These are ordinal scales of tone intensity. The Ashworth rates tone on a scale of 0–4, while the Modified Ashworth was developed to further define the lower end of the scale making it more discrete by adding the grade 1+. The scale is provided in your slides. Reference: Lee KC, Carson L, Kinnin E, and Patterson V. The Ashworth Scale: A reliable and reproducible method of measuring spasticity. *J Neuro Rehab* 1989; 3:205–209.

**BARTHEL INDEX**


**BERG BALANCE SCALE**

**BOX & BLOCK TEST OF MANUAL DEXTERITY (BBT)**

The Box and Block test was originally developed to evaluate the gross manual dexterity of adults with cerebral palsy. The test is made up of a box with a partition directly in the centre creating two equal sides. A number of small wooden blocks are placed in one side of the box.

The subject being tested is required to use the dominant hand to grasp one block at a time and transport it over the partition and release it into the opposite side. The subject is given 60 seconds in which to complete the test, and the number of blocks transported to the other side is counted. The test is then repeated with the non-dominant hand.


**CANADIAN OCCUPATIONAL PERFORMANCE MEASURE (COPM)**

An individualized, client-centered measure of three areas: self-care, productivity and leisure. Information about this measure can be found at caot.ca/copm/index.htm.

**THE DALLAS PAIN QUESTIONNAIRE**

The Dallas Pain Questionnaire was developed to assess the amount of chronic spinal pain that affects daily and work activities, leisure activities, anxiety-depression, and social interest. There is a 16 item self-report that takes about 5 minutes to complete. Each item contains its own visual analog scale. The scales are divided into five to eight small segments in which the subject is asked to mark an “X” which indicates where his or her pain impact falls on the continuum.

The visual scales are anchored at the beginning with words such as “no pain” and 0%, close to the middle “some,” and at the end with “all the time” and 100% impact of pain. Reference: Lawlis G, Cuencas R, Selby D, McCoy CE. The development of the Dallas pain questionnaire. *Spine* 1989; 14:511–516.

**FUNCTIONAL INDEPENDENCE MEASURE (FIM)**

An ordinal scale of functioning in multiple areas including feeding, grooming, bathing, dressing, toileting, transferring, locomotion, comprehension, expression, social interaction and problem solving. Information about obtaining the FIM may be obtained from Uniform Data for Medical Rehabilitation UB Foundation Activities, Inc. at (716) 817-7800 or udsmr.org.

**HEALTH STATUS QUESTIONNAIRE (SF-36)**

This is a 36-item patient self-report regarding the patient’s perception of health and physical limitations. It is widely used in the US. It is a component of the MSQLI. It is a registered trademark of the Medical Outcomes Trust, Inc. (20 Park Plaza, Suite 1014, Boston, Massachusetts 02116) Additional references: mcw.edu/midas/health/SF-36.html and nationalMSsociety.org/MUCS_health.asp.
KURTZKE FUNCTIONAL SYSTEM SCORES (FSS) & EXPANDED DISABILITY STATUS SCALE (EDSS)

The FSS and EDSS constitute one of the oldest and probably the most widely utilized assessment instruments in MS. Based on a standard neurological examination, the 7 functional systems (plus “other”) are rated. These ratings are then used in conjunction with observations and information concerning gait and use of assistive devices to rate the EDSS. Each of the FSS is an ordinal clinical rating scale ranging from 0 to 5 or 6. The EDSS is an ordinal clinical rating scale ranging from 0 (normal neurologic examination) to 10 (death due to MS) in half-point increments. These may be found at nationalMSsociety.org/MUCS_FSS.asp.

MINIMAL ASSESSMENT OF COGNITIVE FUNCTION IN MS (MACFIMS)


MODIFIED FATIGUE IMPACT SCALE (MFIS)

Consists of 21 items to determine the effects of fatigue in terms of cognitive, physical, and psychosocial functioning. An abbreviated version consists of 5 items. The MFIS is part of the MSQOLI and can be downloaded in PDF format from nationalMSsociety.org/MUCS_MSFC.asp.

MS FUNCTIONAL COMPOSITE (MSFC)

Includes the Timed 25-foot walk (T25-FW), 9-hole peg test (9HPT), and the Paced Auditory Serial Addition Test (PASAT): The MSFC Administration and Scoring Manual can be downloaded in PDF format from the National MS Society website nationalMSsociety.org/MUCS_MSFC.asp.

MS QUALITY OF LIFE-54 (MSQOL-54)

A multidimensional health-related quality of life measure that combines the SF-36 and 18 items that are MS-specific including fatigue and cognitive function. It can be downloaded in PDF format from nationalMSsociety.org/MUCS_MSQOL-54.asp.
MS QUALITY OF LIFE INVENTORY (MSQLI)

A structured self report encompassing the following components: SF-36, Modified Fatigue Impact Scale, Pain Effects Scale (PES), Sexual Satisfaction Scale (SSS), Bladder Control Scale (BLCS), Bowel Control Scale (BWCS), Impact of Visual Impairment Scale (IVIS), Perceived Deficits Questionnaire (PDQ), Mental Health Inventory (MHI), Modified Social Support Survey (MSSS). The MSQLI: A User’s Manual can be downloaded as a PDF file from nationalMS-society.org/ MUCS_MSQLI.asp.

RANGE OF MOTION (ROM) & MANUAL MUSCLE TEST (MMT) & GRASP DYNAMOMETRY

Range of Motion at selected joints is assessed using a goniometer that measures the angle of the joint through its range. Manual Muscle testing uses a 6 point grading system (0 = no contractile ability; 5 = strength through full ROM with maximum resistance) to assess strength where the patient has selective joint control. Grasp Dynamometer Testing uses a dynamometer to measure grasp and pinch strength in pounds.

TINETTI ASSESSMENT TOOL

Easily administered test that measures gait and balance. The test is scored on a three-point scale to assess the patient’s ability to perform specific tasks. Scores are combined to form three measures — an overall gait assessment score, an overall balance assessment score, and a gait and balance score. The scores can be interpreted with regard to risk for falls. Reference: Lewis C. Balance, gait test proves simple yet useful. PT Bulletin 1993; 2/10:9, 40. Also, Tinetti ME. Performance-oriented assessment of mobility problems in elderly patients. JAGS 1986; 34:119–126.
APPENDIX F:
RECOMMENDED RESOURCES

READINGS

JOURNAL ARTICLES


— Harrington CB. (2008). *Barrier-Free Travel: A Nuts and Bolts Guide for Wheelers and Slow Walkers* (3rd ed.).

BOOKS FROM DEMOS MEDICAL PUBLISHING
tel: 1-800-532-8663;
website: demosmedpub.com
— 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

nationalMSsociety.org/PRCPublications

- Talking about the Diagnosis of Multiple Sclerosis
- Talking about Progressive Disease

CLINICAL BULLETINS

nationalMSsociety.org/ClinicalBulletins

- Overview of MS
- Primary Care in MS
- Reproductive Issues in Persons with Multiple Sclerosis
- The Role of Hormones in MS
- 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
- 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
- Public Policy Awareness
- Aging with Multiple Sclerosis
- 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
- Changing Therapy in Relapsing Multiple Sclerosis: Considerations and Recommendations
- Rehabilitation: Recommendations for Persons with Multiple Sclerosis
- The Goldman Consensus Statement on Depression in Multiple Sclerosis (not available on Web)
- Recommendations Regarding Cannabis in Multiple Sclerosis
- Recommendations Regarding Corticosteroids in the Management of Multiple Sclerosis
- Patient Access to Tysabri
- Assessment and Management of Cognitive Impairment in Multiple Sclerosis

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 Health-Care 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 2003–2004
- 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
Preventive Care Recommendations for Adults with MS
Putting the Brakes on MS
Research Directions in MS
Should I Work?
Sleep Disorders and MS: Basic Facts
So You Have Progressive MS?
Solving Cognitive Problems
Someone You Know Has MS
Spasticity: Basic Facts
Speech and Swallowing: Basic Facts
Stretching for People with MS
Stretching with a Helper
Taming Stress in Multiple Sclerosis
Tremor: Basic Facts
Urinary Dysfunction and MS
Vision Problems: Basic Facts
Vitamins, Minerals, & Herbs in MS: An Introduction
What Everyone Should Know About Multiple Sclerosis
What Is Multiple Sclerosis?
When a Parent Has MS: Teen Guide
The Win-Win Approach to Reasonable Accommodations

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

OTHER NATIONAL MS SOCIETY PUBLICATIONS

Available at 1-800-344-4867, and on the website at nationalmssociety.org/library

Momentum — A magazine for people living with MS
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.

WEBSITES

Note: Please be aware that website URLs are subject to change without notice.

ABLEDATA
Information on Assistive Technology
abledata.com

Allsup, Inc — Assists Individuals Applying for Social Security Disability Benefits
allsupinc.com

Can Do Multiple Sclerosis (formerly The Heuga Center) — A provider of innovative lifestyle empowerment programs for people with MS and their support partners
MSCanDo.org

106 National Multiple Sclerosis Society
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 G:

ORGANIZATIONS OF NOTE

CAN DO MULTIPLE SCLEROSIS

Formerly The Heuga Center for Multiple Sclerosis

27 Main Street, Suite 303
Edwards, CO 81632
tel: 800-367-3101
website: mscando.org

Can Do MS is a national, non-profit organization that provides unique lifestyle empowerment programs for people living with MS and their support partners. Programs focus on giving people the knowledge, skills, tools and confidence to adopt healthy life-style behaviors, actively co-manage their disease and live their best lives.

CONSORTIUM OF MULTIPLE SCLEROSIS CENTERS (CMSC)

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

The CMSC is made up of numerous MS centers throughout the United States and Canada. The Consortium’s mission is to disseminate information to clinicians, increase resources and opportunities for research, and advance the standard of care for multiple sclerosis. The CMSC is a multidisciplinary organization, bringing together health care professionals from many fields involved in MS patient care.

DEPARTMENT OF VETERANS AFFAIRS (VA)

810 Vermont Avenue, N.W.
Washington, DC 20420
tel: 202-273-5400
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: eeeo.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).

HEALTH RESOURCE CENTER FOR WOMEN WITH DISABILITIES

Rehabilitation Institute of Chicago

345 East Superior Street
Chicago, IL 60611
tel: 312-908-7997
website: rehabchicago.org

The Center is a project run by and for women with disabilities. It publishes a free newsletter, “Resourceful Women,” and offers support groups and educational seminars addressing issues from a disabled woman’s perspective. Among its many educational resources, the Center has developed a video on mothering with a disability.

INTERNATIONAL ORGANIZATION OF 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 ASSOCIATION OF AMERICA (MSAA)

706 Haddonfield Road
Cherry Hill, NJ 08002
tel: 800-532-7667
website: msassociation.org

MSAA is a non-profit organization that offers programs and services aimed at providing individualized assistance to people living with MS, their families, and their care partners.
MULTIPLE SCLEROSIS COALITION

359 Main Street, Suite A
Hackensack, NJ 07601
tel: 201-487-1050, ext. 104
website: multiplesclerosis-coalition.org

The Coalition is an affiliation of independent MS organizations dedicated to the enhancement of the quality of life for all those affected by MS. Its mission is to increase opportunities for cooperation and provide greater opportunity to leverage the effective use of resources for the benefit of the MS community. Coalition members: Accelerated Cure Project for Multiple Sclerosis; Can Do Multiple Sclerosis; Consortium of MS Centers; International Organization of MS Nurses; Multiple Sclerosis Association of America; Multiple Sclerosis Foundation; National Multiple Sclerosis Society; United Spinal Association; Vision Works Foundation, Inc/MS Friends Initiative.

MULTIPLE SCLEROSIS FOUNDATION (MSF)

6350 North Andrews Avenue
Fort Lauderdale, Florida 33309
tel: 888-MS-FOCUS
website: msfocus.org

MSF is a service-based, non-profit organization that provides programming and support to help people remain self-sufficient and safe in their homes, and educational programs to heighten public awareness and promote understanding about the disease.

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: nfcacares.org

NFCA is dedicated to improving the quality of life of America’s 18,000,000 caregivers. It publishes a quarterly newsletter and has a resource guide, an information clearinghouse, and a toll-free hotline: 1-800-896-3650.
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
e-mail: 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 H:

CONTINUING EDUCATION

The CE Solutions Group
A Division of VGM Education
1111 W San Marnan Dr
Waterloo, IA 50701
Toll-Free Telephone: 1-866-650-3400

It is our pleasure to provide you with the self-study course, “Multiple Sclerosis: A Focus on Rehabilitation”, 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:____________________

SSN____________________________________________________________ Email Address:___________________________

Professional License # & State:________________________ Profession:____________________________

________
Multiple Sclerosis: A Focus on Rehabilitation

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). 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. Although rehabilitation interventions cannot reverse the neurologic damage caused by MS, they can reduce disablement by:

- Improving and maintaining function in spite of existing impairment.
- Promoting the person’s independence, safety, and quality of life.
- Enhancing the person’s ability to participate to the fullest extent possible in all of his or her life roles.

Purpose:

The rehabilitation specialist will better understand the role of rehabilitation in helping people maintain optimal functioning in the face of a chronic, unpredictable illness.

Objectives:

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

1. Define multiple sclerosis
2. Discuss the pathophysiology, etiology, and epidemiology of MS.
3. List and discuss disease course classifications.
4. Discuss diagnosis, symptoms, prognosis and treatment modalities for the MS patient.
5. Explain the unique role of rehabilitation in MS.
6. Discuss challenges in MS rehabilitation
7. Explore interventions related to nursing, physical and occupational therapy, and speech and language.
8. Discuss the concept of goal-setting and outcome assessment in rehabilitative interventions.
Audience:

This course is appropriate for: LPNs, RNs, ARNPs, Rehabilitation Nurses, Rehabilitation Aides, Physical Therapists, Physical Therapy Assistants, and other healthcare personnel interested in this subject matter.

Credit:

Nursing - 4 contact hours (based on a 60-minute hour); 4.8 contact hours (based on a 50-minute hour). Rehabilitation Aides – 4 contact hours; Physical Therapists will need to attain approval for this course from their state licensing board.

The CE Solutions Group, 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.

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

The CE Solutions Group, 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.

The CE Solutions Group, a Division of VGM Education is a California Board of Registered Nursing Provider Number CEP 14033 for 4.8 contact hours.
Test for
Multiple Sclerosis: A Focus on Rehabilitation

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 approximately 500,000 people with MS in the United States and Canada, and 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. With Primary-Progressive MS (PPMS), the individual may expect clearly defined acute attacks with full recovery or with residual deficit upon recovery.
   a. True
   b. False
8. Secondary-Progressive MS (SPMS), which follows an initial relapsing-remitting disease course, is characterized by progression of variable rate that may also include occasional relapses and minor remissions and plateaus.
   a. True
   b. False

9. Primary-Progressive MS (PPMS) is the least common disease course, characterized by progression from onset but with clear acute relapses with or without full recovery.
   a. True
   b. False

10. Magnetic resonance imaging (MRI) can independently determine if a person has MS
    a. True
    b. False

11. In a population-based survey of individuals with MS, the most common symptom reported was
    a. visual disturbances.
    b. tremor.
    c. fatigue.
    d. ambulation problems.

12. Although prognosis with MS is uncertain, there are certain factors that seem to predict a more favorable course. They include all of the following EXCEPT:
    a. female gender,
    b. monoregional vs. polyregional attack,
    c. complete recovery after an exacerbation, leaving little or no residual impairment,
    d. onset after age 35.

13. Studies in MS indicate that 50% of people with MS will experience _________ at some point of the course of the disease, a higher prevalence than is seen in other, equally disabling chronic illnesses, perhaps resulting in part from the disease process itself.
    a. receptive aphasia
    b. a major depressive episode
    c. tremor of the neck and head
    d. restless leg syndrome
14. Although ______ are less likely than Caucasians to develop MS, studies indicate they tend to experience a more progressive disease course.
   a. Hispanics  
   b. Asians  
   c. African-Americans  
   d. None of the above

15. The primary purpose of rehabilitation in the treatment of MS is to:
   a. enhance and maintain physical function.  
   b. sustain mental acuity.  
   c. enhance symptom management.  
   d. treat acute exacerbations.

16. With the chronic and progressive nature of MS, which of the following does NOT describe the rehabilitation specialist’s role involving structured, problem-focused interventions to manage symptoms, enhance function, facilitate activities of daily living, identify appropriate assist devices and environmental modifications, and prevent injuries and unnecessary complications.
   a. Active  
   b. Passive  
   c. Instructional  
   d. Motivational

17. A **critical role** that rehabilitation specialists play in helping people with the progression of MS is:
   a. to guide their career path.  
   b. to modify expectations and develop realistic goals, while maintaining their self-esteem in the process.  
   c. to function as the rehabilitation team coordinator.  
   d. None of the above.

18. Challenges in MS rehabilitation include
   a. MS is a chronic disease,  
   b. MS is characterized by variability and unpredictability  
   c. MS is associated with high levels of fatigue,  
   d. depression is prevalent in MS,  
   e. cognitive dysfunction occurs in half of the MS population.  
   f. All of the above.
19. The importance of realistic ______________ cannot be over-emphasized in the individual with MS.
   a. progression
   b. prevention
   c. goal-setting
   d. None of the above

20. Secondary causes of fatigue in MS include all of the following EXCEPT
   a. MS-related neurologic changes.
   b. depression.
   c. sleep disturbance.
   d. aerobic and muscular deconditioning.

21. At least _____ of people with MS experience cognitive changes, including problems with learning and memory, attention and concentration, slowed information processing, and executive functions.
   a. 10%
   b. 25%
   c. 50%
   d. 95%

22. Cognitive dysfunction in MS may impact a person’s ability to participate effectively in the planning and implementation of the rehabilitation process.
   a. True
   b. False

23. The ideal approach to assessment in the person with MS is a(an) ________ one.
   a. independent
   b. dynamic
   c. collaborative
   d. static

24. Critical to the intervention process is
   a. team involvement.
   b. setting appropriate goals aimed at a successful outcome.
   c. periodic re-evaluation process.
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Answer Sheet
Multiple Sclerosis: A Focus on Rehabilitation

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
4. a b c d e f  24. a b c d e f
5. a b c d e f  25. a b c d e f
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
10. a b c d e f  30. a b c d e f
11. a b c d e f
12. a b c d e f
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15. a b c d e f
16. a b c d e f
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 Group
A Division of VGM Education
1111 W San Marnan Dr
Waterloo, Iowa 50701
Toll-Free Telephone: 1-866-650-3400
Answer Key for
Multiple Sclerosis: A Focus on Rehabilitation

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

   (Research conclusions indicate that MS is not hereditary. 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).

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

   (Caucasians [particularly of northern European ancestry] are more prone to develop MS than African Americans and Hispanics).

5. It is estimated that there are approximately 500,000 people with MS in the United States and Canada, and 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. With Primary-Progressive MS (PPMS), the individual may expect clearly defined acute attacks with full recovery or with residual deficit upon recovery.
   a. True
   b. False

   *(PPMS is characterized by progression of disability from onset, without plateaus or remissions).*

8. Secondary-Progressive MS (SPMS), which follows an initial relapsing-remitting disease course, is characterized by progression of variable rate that may also include occasional relapses and minor remissions and plateaus.
   a. True
   b. False

9. Primary-Progressive MS (PPMS) is the least common disease course, characterized by progression from onset but with clear acute relapses with or without full recovery.
   a. True
   b. False

   *(Progressive-Relapsing MS is the least common disease course, characterized by progression from onset but with clear acute relapses with or without full recovery).*

10. Magnetic resonance imaging (MRI) can independently determine if a person has MS
    a. True
    b. False

    *(There is no single test that can determine whether a person has MS. MRIs of the brain are abnormal in only 95% of people with MS; therefore, MRI can only be used as confirmatory evidence of the disease).*

11. In a population-based survey of individuals with MS, the most common symptom reported was
    a. visual disturbances.
    b. tremor.
    c. fatigue.
    d. ambulation problems.

12. Although prognosis with MS is uncertain, there are certain factors that seem to predict a more favorable course. They include all of the following EXCEPT:
    a. female gender,
    b. monoregional vs. polyregional attack,
    c. complete recovery after an exacerbation, leaving little or no residual impairment,
    d. **onset after age 35**
13. Studies in MS indicate that 50% of people with MS will experience __________ at some point of the course of the disease, a higher prevalence than is seen in other, equally disabling chronic illnesses, perhaps resulting in part from the disease process itself.
   a. receptive aphasia
   b. a major depressive episode
   c. tremor of the neck and head
   d. restless leg syndrome

14. Although ______ are less likely than Caucasians to develop MS, studies indicate they tend to experience a more progressive disease course.
   a. Hispanics
   b. Asians
   c. African-Americans
   d. None of the above

15. The primary purpose of rehabilitation in the treatment of MS is to
   a. enhance and maintain physical function.
   b. sustain mental acuity.
   c. enhance symptom management.
   d. treat acute exacerbations.

16. With the chronic and progressive nature of MS, which of the following does NOT describe the rehabilitation specialist’s role involving structured, problem-focused interventions to manage symptoms, enhance function, facilitate activities of daily living, identify appropriate assist devices and environmental modifications, and prevent injuries and unnecessary complications.
   a. Active
   b. Passive
   c. Instructional
   d. Motivational

17. A critical role that rehabilitation specialists play in helping people with the progression of MS is
   a. to guide their career path.
   b. to modify expectations and develop realistic goals, while maintaining their self-esteem in the process.
   c. to function as the rehabilitation team coordinator.
   d. None of the above.

18. Challenges in MS rehabilitation include
   a. MS is a chronic disease,
   b. MS is characterized by variability and unpredictability
   c. MS is associated with high levels of fatigue,
   d. depression is prevalent in MS,
   e. cognitive dysfunction occurs in half of the MS population.
   f. All of the above.
19. The importance of realistic ____________ cannot be over-emphasized in the individual with MS.
   a. progression
   b. prevention
   c. goal-setting
   d. None of the above

20. Secondary causes of fatigue in MS include all of the following EXCEPT
   a. MS-related neurologic changes.
   b. depression.
   c. sleep disturbance.
   d. aerobic and muscular deconditioning.

21. At least ____ of people with MS experience cognitive changes, including problems with learning and memory, attention and concentration, slowed information processing, and executive functions.
   a. 10%
   b. 25%
   c. 50%
   d. 95%

22. Cognitive dysfunction in MS may impact a person’s ability to participate effectively in the planning and implementation of the rehabilitation process.
   a. True
   b. False

23. The ideal approach to assessment in the person with MS is a(an) ________ one.
   a. independent
   b. dynamic
   c. collaborative
   d. static

24. Critical to the intervention process is
   a. team involvement.
   b. setting appropriate goals aimed at a successful outcome.
   c. periodic re-evaluation process.
   d. All of the above.

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Self-Study Evaluation (ED II)

Course Title: **Multiple Sclerosis: A Focus on Rehabilitation**

Date completed: ________________

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

<table>
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<tr>
<th></th>
<th>Most</th>
<th>Least</th>
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<tbody>
<tr>
<td>1. Evaluate the relationship of objectives to overall purpose/goal of the educational program.</td>
<td>5 4 3 2 1</td>
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<tr>
<td>2. Define multiple sclerosis.</td>
<td>5 4 3 2 1</td>
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<td>3. Discuss the pathophysiology, etiology, and epidemiology of MS.</td>
<td>5 4 3 2 1</td>
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<td>4. List and discuss disease course classifications.</td>
<td>5 4 3 2 1</td>
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<td>5. Discuss diagnosis, symptoms, prognosis, and treatment modalities for the MS patient.</td>
<td>5 4 3 2 1</td>
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<td>6. Explain the unique role of rehabilitation in MS.</td>
<td>5 4 3 2 1</td>
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<tr>
<td>7. Discuss challenges in MS rehabilitation.</td>
<td>5 4 3 2 1</td>
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<tr>
<td>8. Explore interventions related to nursing, physical and occupational therapy, and speech and language.</td>
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<tr>
<td>9. Discuss the concept of goal-setting and outcome assessment in rehabilitative interventions.</td>
<td>5 4 3 2 1</td>
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10. Use of teaching/learning resources:
   Text  5  4  3  2  1
   Drawings, Figures  5  4  3  2  1
   Internet sites (when listed)  5  4  3  2  1
   Other  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.