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A Practical Guide to **Rehabilitation in** MULTIPLE SCLEROSIS

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TARGET AUDIENCE

This activity is intended for rehabilitation clinicians such as physiatrists, occupational therapists (OT), physical therapists (PT), speech language pathologists (SLP), and other clinicians, such as neurologists, nurses, and others involved in the management and rehabilitation of patients with MS.

STATEMENT OF NEED

A multi-dimensional, comprehensive care approach is advocated to promote positive outcomes for individuals with MS, and rehabilitation is an integral part of comprehensive MS care. There is a documented need for improvements in rehabilitative services, including incorporation of standardized measures for the evaluation and ongoing assessment of persons with MS, increased awareness for the signs and symptoms of a change in patient status, and a need for patient engagement in identification of rehabilitation goals and treatment strategies. Increased collaboration and communication between disciplines is needed to fully realize the goals of MS rehabilitation and optimize quality of life for those with MS.

LEARNING OBJECTIVES

Upon completion of the activity, participants should be able to:

- Identify MS symptoms causing functional impairments that require specialized assessments and interventions by rehabilitation specialists, and describe the roles of physical, occupational, and speech/language therapists in developing and implementing strategies that will lead to sustained, improved outcomes
- Describe evidenced-based assessment techniques that can be used at baseline appraisal and throughout the spectrum of MS that support the development of targeted, consistent, and individualized therapies

- Distinguish between fluctuations of MS symptoms versus relapses and/or progression and adjust interventions to accommodate for the dynamic nature of MS
- Analyze monitoring strategies, communication tools, and interviewing techniques that will develop and sustain a long-term productive relationship between the rehabilitation team and MS patients
- Provide appropriate education and information to the patient, family, and members of the rehabilitation team throughout the course of treatment
- Analyze specific strategies and tools that can facilitate communication between disciplines, and between clinician and patient
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- Susan Bennett, PT, DPT, EdD, NCS, MSCS, has received grants/research support and honoraria from Acorda Therapeutics. She has served as a consultant to Acorda Therapeutics and Medtronics.
- Patty Bobryk, MHS, PT, MSCS, ATP, was a program consultant for Can Do MS.
- Christine Smith, OTR/L, MSCS, is a stock shareholder of Teva.

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Forward

Multiple sclerosis (MS) causes damage to the central nervous system, and as a result impairs neurological functions, limits daily activities and participation, and compromises quality of life. The impact of MS is mediated by personal and environmental factors. Considering the heterogeneity of clinical presentations, the unpredictability of the disease course, and the widespread consequences of MS, a comprehensive care approach is recommended.

Rehabilitation can be defined as, "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."¹ By nature, rehabilitation focuses on function, emphasizes a multidisciplinary approach, and bases the treatment plan on individualized goals agreed upon with the patient. It is therefore not surprising that rehabilitation is a major component of the comprehensive care of MS. Components of rehabilitation interventions include education of patients and families; promotion of behavioral changes (e.g. exercise programs); task-specific functional training; and guidance and training regarding the use of assistive devices and technology.

At the same time, MS rehabilitation faces a variety of challenges. Some of these challenges are related to the nature of the disease (complexity of factors limiting functional performance, symptom fluctuations and progression over time, low tolerance to exertion), to a lack of awareness of the services available and of the benefits of MS rehabilitation among patients and health care professionals, and to barriers to patient access to specialized rehabilitation services (scarcity of professionals with expertise in MS rehabilitation, transportation and accessibility issues, limitations to insurance coverage).

While the body of evidence supporting the use of rehabilitation interventions in MS is rapidly growing, there is a need for further research. Examples of areas in need of further evidence include investigating the neurophysiological effects of rehabilitation, determining which patients are more likely to benefit from specific interventions or treatment strategies, assessing the benefits of combining treatment modalities, and determining the most cost-effective ways to deliver rehabilitation and achieve optimal results.

This primer compiles state-of-the-art information regarding the rehabilitation approach in the management of major symptoms of MS, including mobility and related impairments, cognitive limitations, speech and swallowing disturbance, and a variety of health and wellness issues. The focus on practical topics, the clarity and thoroughness of the material presented, and the inclusion of case scenarios to illustrate how this information can be used in clinical practice, make this primer an invaluable tool for clinicians of all disciplines who are involved in the care of MS patients. We are also hopeful that it will help increase awareness of the wide variety of rehabilitation interventions and techniques that can be implemented to optimize our patients' functional status and quality of life, and in turn enhance patient access to rehabilitation.

Francois Bethoux, MD

Editor in Chief, *International Journal of MS Care* Director of Rehabilitation Services, Mellen Center for MS Treatment and Research Cleveland Clinic

1. Medical Advisory Board of the National Multiple Sclerosis Society, Rehabilitation: Recommendations for Persons with Multiple Sclerosis. National Multiple Sclerosis Society, 2004.



Patient Case Scenarios continued on page 50

JEFF

Jeff is 59-years-old and was diagnosed with MS 4 years ago. Following his diagnosis, he has never had a relapse, only slow progression. Jeff currently walks with a single point cane and is falling at least once a week. He no longer works; he reports that he sleeps poorly, and feels that it is too much of an effort to eat a whole meal. Jeff was referred to PT/OT/ST for assessment and intervention.

BEN

Ben is a 49-year-old high school teacher with complaints of imbalance and dizziness lasting a few minutes to all day, and fatigue. He continues to work full-time, but has recently been cutting back on extracurricular activities. Ben was referred by a neurologist for outpatient PT due to dizziness.

CAROLYN

Carolyn is a 30-year-old first grade teacher who developed RRMS 3 years ago. She had a relapse one month ago in which she reported diplopia, ataxia with falls, and weakness. She is currently experiencing marked fatigue, changes in her voice (not as loud), loss of left hand dexterity, and leg weakness with intermittent stumbling; she also complains of memory problems and disorganization. Due to her concerns about returning to work, her neurologist referred her for PT/OT/ST.



Introduction

MS AND THE DISEASE COURSE

Multiple sclerosis (MS) is a chronic autoimmune disorder that affects the central nervous system (CNS), impacting more than 2.3 million people worldwide.¹ MS is associated with numerous symptoms including visual disturbances, spasticity, and weakness, impairment in walking, coordination difficulties, tremor/ataxia, sensory problems and bladder disturbances.² 'Invisible symptoms' are also commonly associated with MS, such as fatigue, depression, and cognitive dysfunction.

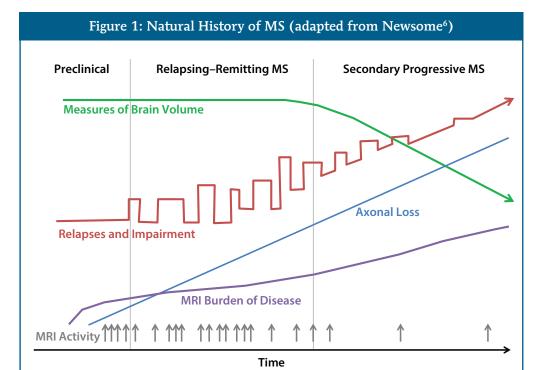
Demyelination, oligodendrocyte loss and axonal/neuronal injury and loss are features of MS pathology. While complete understanding of the pathophysiology of MS continues to evolve, it is clear that an inflammatory process contributes to the CNS damage observed in MS. Activated T cells in the periphery (reactive to CNS proteins, particularly myelin) and other immune cells cross the blood brain barrier, and once in the CNS, an amplified immune response produces an attack on myelin and oligodendrocytes, ultimately resulting in axonal injury.³ The resulting lesions in the brain, spinal cord, and optic nerves contribute to the clinical features of MS (Table 1).

Different patterns of disease course are observed in MS; these were traditionally categorized as relapsing-remitting (RRMS), secondary progressive, primary progressive or

Lesion Site	Clinical Symptoms	
Cerebrum; cortex	 Cognitive deficits Psychiatric features Hemiparesis, monoparesis, paraparesis, quadriparesis Motor impairments, spasticity 	
Optic nerve	• Optic neuritis	
Cerebellum	 Postural and action tremor Limb incoordination Gait instability Ataxia 	
Brainstem	 Diplopia Vertigo Impaired speech and swallowing Paroxysmal symptoms 	
Spinal cord	 Weakness Spasticity Diminished dexterity Autonomic disturbances (sexual, bladder, bowel) Pain 	
Other	FatigueTemperature sensitivity	

Table 1: MS Lesion Sites and Clinical Features of MS³

progressive-relapsing MS.⁴ Refined descriptors for MS disease course have recently been published, and these updates include measures of clinical relapse rate, imaging findings, and disease progression to describe overall MS activity.⁵ The core phenotypes of relapsing-remitting and progressive disease have been retained. Clinically isolated syndrome (CIS), an initial neurological disturbance lasting



more than 24 hours with signs and symptoms consistent with an inflammatory demyelinating disorder (that could be MS), is now included in the 2013 phenotypes. CIS and RRMS are further classified as 'active' or 'not active,' with 'active' indicating clinical and/or radiological activity (relapses, gadolinium- enhancing MRI lesions, new or enlarging T2 lesions). Progressive disease (primary or secondary) is now sub-classified as 'active with progression;' 'active but without progression;' 'not active but with progression;' and 'not active and without progression.'⁵ 'Progression' in this context refers to accumulation of disability.⁵

AIMS

The majority of patients with MS (~85%) initially have a relapsing-remitting course, which is characterized by distinct relapses followed by periods of remission with no (or minimal) increase in disability between attacks. Over time, many patients with RRMS transition to secondary progressive MS (SPMS) with progressive disability with or without distinct relapses. Some patients with MS have progressive disease from the onset, in which functional decline is steady, without acute attacks or periods of remission. As illustrated in **Figure 1**, the early stages of disease are associated with increasing inflammatory activity, as evidenced by relapses and MRI activity. As noted above, often patients with RRMS transition to SPMS (after ~10 years of the disease process), during which inflammatory (and MRI) activity declines, axonal loss and disability increase, and brain atrophy occurs.

It should be noted that Figure 1 is a simple generalization; the disease course, symptoms and/or impairments associated with MS are unpredictable and vary among individuals. The manifestations of MS negatively impact activities of daily living (ADLs), social participation, and overall quality of life. MS profoundly affects patients, their families, and the community at large.⁷

COMPREHENSIVE MS CARE

A multidimensional, comprehensive care approach is advocated to promote positive



outcomes for patients with MS.⁷ Comprehensive care is patient-centered, multidisciplinary care provided by a team that adopts a whole-person orientation. The patient is viewed as an integral team member, and is empowered to actively participate in care planning and self-care actions. Comprehensive care encompasses relapse management, disease modifying therapies (DMTs), symptom management, psychosocial support, and rehabilitation.

While the focus of this document is on rehabilitation, a brief review of pharmacologic treatment of MS (relapse management, disease modifying therapies (DMTs), and symptomatic therapy) is included for reference. Relapses are sudden flare-ups or attacks, with worsening of symptoms or potentially the onset of new symptoms, consistent with inflammation and demyelination, which can last from several days to weeks.⁸ Medical treatment of relapses often involves short-term (3-5 days) intravenous or oral steroids.⁸ Clinicians should be aware that infection, fever, and heat can exacerbate MS symptoms, and indeed may mimic a relapse, yet medical relapse management is not warranted.

The number of FDA-approved DMTs for patients with MS has grown considerably over the last 2 decades. DMTs currently approved for patients with RRMS are summarized in **Table 2**. These agents vary by mechanism of action, mode of administration, dosing frequency, side effect profiles, and monitoring recommendations. The demonstrated benefits of DMTs include reduction in relapse rate, reduction in MRI activity, and reduced disability progression.^{3,6} Individualized treatment decisions involve consideration of these treatment-related factors, patient preference, disease course, and the presence of medical and/or psychiatric comorbidities.

Treatment	Approval	Dose & Route of Administration	Mechanism of Action	
Injection				
Interferon (IFN) β-1b (Betaseron®)	1993	250 mcg, SC, QOD	Enhancement of suppressor T-cell activity, reduction of	
IFNβ-1a (Avonex®)	1996	30 mcg, IM, QW	proinflammatory cytokine production, down regulation of	
IFNβ-1a (Rebif®)	2002	22 mcg or 44 mcg, SC, TIW	antigen presentation, inhibition of lymphocyte trafficking into the CNS	
IFNβ-1b (Extavia®)	2009	250 mcg, SC, QOD		
Pegylated IFNβ-1a (Plegridy™)	2014	125 mcg SC every 14 days		
Glatiramer acetate (Copaxone®)	1996	20 mg, SC, QD	Immunomodulatory; preferential differentiation of	
Glatiramer acetate (Copaxone®)	2014	40 mg, SC, TIW	Th2 cells; and inhibition of antigen-specific T-cell activation	
Glatiramer acetate (Glatopa™)	2015	20 mg, SC QD		

Table 2: Disease Modifying Therapies for MS⁹

Table 2: Disease Modifying Therapies for MS⁹ (cont.)

AIMS

Treatment	Approval	Dose & Route of Administration	Mechanism of Action		
Infusion					
Mitoxantrone (Novantrone®)	2000	12 mg/m², IV, every 3 months	DNA topoisomerase II inhibitor suppresses proliferation of T and B cells, macrophages		
Natalizumab (Tysabri®)	2004	300 mg, IV, every 4 weeks	Inhibition of $\alpha 4\beta 1$ -integrin mediated adhesion of leukocytes to VCAM-1 on vascular endo- thelial cells at the blood brain barrier, which prevents leukocyte migration into the brain		
Alemtuzumab (Lemtrada™)	2014	12 mg/day, IV for 5 days; then 12 mg/day for 3 days 12 months after the 1st treatment course	Humanized monoclonal antibody, anti-CD52; T and B cell depletion		
Oral					
Fingolimod (Gilenya®)	2010	0.5 mg, PO, QD	Sphingosine1-phosphate receptor modulator; prevents egress of lymphocytes from lymphoid tissues into the periphery		
Teriflunomide (Aubagio®)	2012	7 mg or 14 mg, PO, QD	Inhibition of dihydro-orotate dehydrogenase, a key enzyme in de novo pyrimidine synthesis required by rapidly dividing lymphocytes; diminishes the numbers of activated T- and B-cells available to migrate to the CNS		
Dimethyl fumarate (Tecfidera®)	2013	240 mg, PO, BID	Anti-inflammatory properties via effects on the Nrf2 pathway; Th1 to Th2 shift, anti-oxidant properties, potential neuroprotective effects		

Medical management of symptoms is part of comprehensive care to help reduce the negative impact of MS on activities of daily living and overall quality of life. Common MS symptoms include fatigue, focal muscle weakness, gait problems, spasticity, neuropathic pain, paresthesias, visual changes, bowel, bladder, and sexual dysfunction, depression and disordered sleep.^{10,11} Pharmacologic agents used for the medical management of MS symptoms are summarized in **Table 3** (some of the agents shown are off-label indications).



Table 3: Symptomatic Medications for Patients with MS^{12,13}

Symptom	Pharmacologic Agent	
Fatigue	Amantadine, modafinil, armodafinil, methylphenidate	
Spasticity	Baclofen (oral or intrathecal), tizanidine, onabotulinumtoxinA, diazepam, dantrolene, clonazepam, gabapentin, phenol	
Gait problems	Dalfampridine	
Pain	Gabapentin, pregabalin, nortriptyline, desipramine, carbamazepine, oxcarbazepine, amitriptyline, lamotrigine, topiramate, venlafaxine, duloxetine, baclofen, common non-prescription analgesics, topical agents (capsaicin, lidocaine)	
Visual changes	High-dose corticosteroids for optic neuritis; for nystagmus: baclofen, clonazepam, gabapentin, memantine	
Bladder dysfunction	Oxybutynin (oral, transdermal), tolterodine, fesoterodine, solifenacin, darifenacin, trospium, desmopressin, intravesical onabotulinumtoxinA	
Bowel symptoms	For constipation: psyllium, calcium polycarbophil, magnesium oxide, polyethylene glycol, lactulose, senna, docusate sodium, lubiprostone, bisacodyl; for bowel incontinence: loperamide	
Sexual dysfunction	For males: sildenafil, vardenafil, tadalafil	
Depression	Selective serotonin reuptake inhibitors, serotonin norepinephrine reuptake inhibitors, bupropion	

Rehabilitation is an integral part of comprehensive MS care. The goals of MS rehabilitation are to improve/maintain functioning and reduce the disease impact on personal activities, social participation, independence, and quality of life.¹⁴ The approach

to rehabilitation in MS recognizes the dynamic interaction between disease, environmental factors, and personal factors, embodied in the WHO International Classification of Functioning, Disability, and Health framework (Figure 2).

Rehabilitation professionals need to consider the overall functionality of the patient, their participation in community, their professions, and in their home environment—what are the limitations for patients with MS early in the diagnosis; and how does this change 10-15 years into the disease course, and beyond? The team of rehabilitation specialists who help individuals with MS includes physical therapists (PT), occupational therapists (OT), speech/language pathologists, vocational

Figure 2: WHO International Classification of Functioning, Disability and Health¹⁵

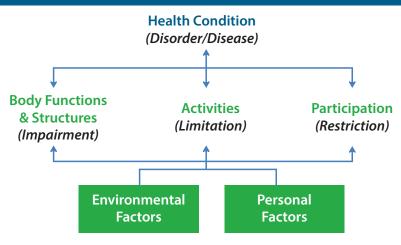




Table 4: The MS Rehabilitation Team [adapted from CMSC's "Essential Elements"]

Specialist	Role	
Physical therapists	Evaluate and address the body's ability to move and function, with particular emphasis on walking, strength, balance, posture, fatigue, and pain	
Occupational therapists	Provide training in energy conservation techniques and the use of adaptive tools and devices to simplify tasks at home and work	
Speech/language pathologists	Evaluate and treat problems with cognitive communication, speech and/or swallowing—all of which can result from damage in the CNS due to MS	
Vocational rehabilitation counselors	Offer job readiness evaluation and training, job coaching, job placement assistance, mobility training, and assistive technology assessments. Help people maintain their current employment or find new employment that accommodates their needs	
Registered dieticians	Provide nutritional counseling through diet management to promote good nutrition. Develop individual care plans for each person with MS to promote a good nutritional status	

rehabilitation counselors, and registered dieticians. A brief description of the roles of these rehabilitation professionals is shown in Table 4.

long-term (sometimes lifelong) relationships with persons with MS. Patients with MS have unique needs due to the chronic, progressive nature of the disease, and the variability/unpredictability of symptoms. MS rehabilitation professionals play a critical role in the lives of MS patients by

Unlike PTs or OTs who support patients following an acute injury, MS rehabilitation specialists have



Evaluation

• Identifying and quantifying effects of disablement (limitation in activity and participation)

Treatment

Arrest the pathophysiologic processes causing tissue injury

Therapeutic Exercise

Focuses on enhancement of organ performance

Task Reaquisition

Emphasizes total body adaptive techniques

Environmental Modification

Directs efforts towards environmental enhancement to improve participation

empowering them to manage symptoms that impact on function, maintain life roles with short-term rehabilitation as needed, and promote active exercise for health and wellness. The phases of the rehabilitation process are illustrated in **Figure 3**.

A variety of standardized measures are used for the evaluation and ongoing assessment of persons with MS. Due to the dynamic nature

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of MS, the use of outcomes measures provides a structured way to gauge over time the extent to which a patient is able to perform activities of daily living, vocational roles, and maintain independence. The Neurology Section of the American Physical Therapy Association website includes recommendations for the use of measures for persons with MS.¹⁶ These recommendations and instructions for administering outcomes measures are available for download at www.neuropt.org/ professional-resources/neurology-sectionoutcome-measures-recommendations/multiplesclerosis. Such assessments are applied periodically to develop and revise goals, identify the need for treatment modification, and measure results of specific interventions. While the use of these measures will be further developed in the sections to follow, a summary of commonly used measures for MS is included in Table 5.

The commonly used Expanded Disability Status Scale (EDSS) reflects disease severity, ranging from 0 (normal neurologic exam, regardless of symptoms) to 10.0 (death due to MS) (Figure 4).

Table 5: Standardized Measures Used in MS¹⁷

- 2-Minute Walk and 6-Minute Walk Test
- Berg Balance Scale
- Dynamic Gait Index
- Expanded Disability Status Scale (EDSS)
- Modified Ashworth Spasticity Scale
- Modified Fatigue Impact Scale (MFIS)
- MS 12-Item Walking Scale
- MS Functional Composite (MSFC)
 - Timed 25-Foot Walk (T25-FW)
 - 9-Hole Peg Test (9-HPT)
 - Paced Auditory Serial Addition Test (PASAT)
- MS Neuropsychological Screening Questionnaire (MSNQ)
- Timed Up and Go (TUG)

EDSS is scored in 0.5 unit steps and incorporates 8 functional systems (cerebral, cerebellar,

Figure 4: Expanded Disability Status Scale (EDSS)

pyramidal, visual, brainstem, sensory, bowel and bladder, and other/ miscellaneous).¹⁸

All professionals involved in the care of persons with MS should develop a keen awareness for signs and symptoms of a change in status. The nature of MS and the potential for the development of new brain lesions can significantly impact functionality. In addition, other factors such as hot temperatures in the summer months or underlying infection can exacerbate symptoms. Frequent reevaluations (including brief assessments) help to identify such changes and allow appropriate interventions/ adjustments in a timely manner.

Mobility, Gait, Fatigue, Weakness, Spasticity, and Balance

In a recent review, Motl et al noted that "exercise training represents a behavioral approach for safely managing many of the functional, symptomatic, and quality of life consequences of multiple sclerosis."¹⁹ Indeed, improvements in walking, balance, fatigue, depression, and quality of life have been reported with exercise training; and accumulating evidence points to benefits of exercise on cognitive function for individuals with MS.^{19,20,21} By capitalizing on the neuroplastic potential of the central nervous system, it is extremely exciting to consider the opportunities to promote functional recovery in MS through an individualized rehabilitation program.²²

AIMS

Mobility is a critical dimension of independence, and the loss of mobility is symptomatic of disease progression in MS. Ambulation in particular has been rated by persons with MS as their most important function;²³ yet an estimated 75% of patients with MS have walking disturbances, with some limitations present early in the disease course.²⁴ Primary symptoms of MS such as weakness, spasticity, balance and coordination difficulties, sensory deficits, and fatigue can impact mobility. In addition, cognitive dysfunction, bowel and bladder issues, and pain can negatively impact mobility in MS. Mobility limitations may directly impact a person's participation in their community, occupational pursuits, and family activities. Environmental factors (excessive heat) or personal factors (stress, anxiety, or depression) can further impact activities of daily living and participation. The inter-relatedness of the many factors impacting function for patients with MS should be considered with any assessments and rehabilitation plans.

MOBILITY ASSESSMENTS

A number of measures are used in clinical practice for evaluating mobility in the MS population. Scores on the EDSS correspond to limitations in mobility, such 6.0 (a need for unilateral device for ambulation), 6.5 (a need for a bilateral device). 7.0 (need for a wheelchair), and 8.0 (restriction to bed or chair).¹⁸ The MS Functional Composite includes a gait measure (the Timed 25-foot Walk), in addition to the 9-Hole Peg Test, and Paced Auditory Serial Addition Test.²⁵ Specific measures for evaluating mobility for those who are ambulatory include the Timed 25-foot Walk, the Timed Up and Go, the 2 and 6 Minute Walk Tests, the Dynamic Gait Index, and the 12-Item MS Walking Scale (MSWS-12, a self-report measure of walking ability, strongly correlated with the EDSS).^{2426,} Walking tests are typically performed in a tiled hallway of ~60 feet in length and free of obstruction. Each of these measures is described briefly below:

Timed 25-Foot Walk: Subjects start at a line on the floor and are instructed to 'walk as quickly as possible, but safely' beyond a second line on the floor (25 feet away). Time is recorded in seconds beginning with the first heel strike beyond the start line and stopped at the first heel strike after the second line. Two trials are performed and the faster of the two trials is used for analysis.

Timed Up and Go (TUG): The subject is seated in a chair with 2 arm rests, and is instructed at the word 'Go' to rise from the chair, walk as quickly as possible, but safely to a mark 10 feet away, turn around, walk back to the chair and sit down. The stopwatch is started at the verbal cue 'Go' and stopped when the subject is safely seated in the chair. Two trials are performed and the faster of



the two trials is used for analysis. Modifications of the TUG include TUG manual, conducted in the same manner except the individual is carrying a full cup of water; and the TUG cognitive, conducted in the same way but doing calculations (such as subtracting 3 from a random number) while performing the task.

2 and 6 Minute Walk Tests: The subject is instructed to 'walk at your comfortable pace' back and forth along a hallway for 2 (or 6 minutes). The maximum distance walked is measured and recorded. MS-related fatigue may be apparent in this test.

Dynamic Gait Index: This assessment includes 8 walking tests, conducted in a hallway with tape markers on the floor every 5 feet for 20 feet total. The tests include gait level surface; change in gait speed (change at 5 feet marks); gait with horizontal head turns; gait with vertical head turns; gait and pivot turn; step over obstacle; step around obstacles; and steps. Each of these tests is rated from 0 (severe impairment, inability to perform) to 3 (normal, without challenge), for a total possible score of 24. A score of 19 or below is indicative of fall risk.

12-Item MS Walking Scale: This is a patient self-report instrument. Patients are asked to answer 12 questions about limitations to their walking due to MS over the past 2 weeks, circling a number that best describes their degree of limitation (1, not at all; 2, a little; 3, moderately; 4, quite a bit; 5, extremely).²⁶

An additional functional assessment for ambulatory individuals is the Berg Balance Scale.²⁷ This is not a gait measure per se, but a general measure of ability to balance during activity, and thus relevant to walking. This 20 minute test includes 14 predetermined tasks; each scored from 0 to 4, with 0 being the lowest level of functioning and 4 the highest. The 14 tasks that comprise the Berg Balance Scale include:

- **1**. Sitting to standing
- 2. Standing unsupported
- **3.** Sitting with back unsupported but feet supported on floor or on a stool
- 4. Standing to sitting
- 5. Transfers
- 6. Standing unsupported with eyes closed
- 7. Standing unsupported with feet together
- 8. Reaching forward with outstretched arm while standing
- **9.** Pick up object from the floor from a standing position
- **10.** Turning to look behind over left and right shoulders while standing
- 11. Turn 360 degrees
- **12.** Place alternate foot on step or stool while standing unsupported
- **13.** Standing unsupported one front in front
- **14.** Standing on one leg

A score of 56 indicates functional balance; and scores below 45 indicate greater risk for falling.¹⁶

Mobility assessments are also conducted in those with EDSS scores of 7.0 and above. At this stage, there may be difficulties with core muscle strength, posture, and balance. Some muscle groups may get long and weak, while others get tight and weak. Evaluations appropriate for this patient population include the Five Times Sit to Stand (time how long this takes); Standing Tolerance (not a scale, but timed up to a maximum of 2 minutes); and Functional Reach (how far out in front, to the left, and to the right can the patient reach without loss of balance (the clinician documents an actual measurement). The functional reach is performed sitting, and can also be performed standing as an indicator of fall potential. Clinicians should be aware of considerations such as skin breakdown, pulmonary health (risk for pneumonia), malaise, and cardiovascular health in persons with EDSS \geq 7.0.

Table 6: Manual Muscle Testing Procedures: Key to Muscle Grading²⁸

AIMS

Function of the Muscle	Grade	
Normal strength	5	Normal
Uncertain muscle weakness	5-	
Inability to resist against maximal pressure throughout ROM	4+	Good +
Ability to resist against moderate pressure throughout ROM	4	Good
Ability to resist against minimal pressure throughout ROM	4-	Good -
Ability to move through full ROM anti-gravity and resist against minimal pressure through partial ROM, then contraction breaks abruptly	3+	Fair+
Ability to move through full ROM anti-gravity	3	Fair
Ability to move through > 50% ROM anti-gravity	3-	Fair -
Ability to move through < 50% ROM anti-gravity	2+	Poor +
Ability to move through full ROM gravity-eliminated	2	Poor
Ability to move in any arc of motion with gravity-eliminated	2-	Poor -
Visible or palpable muscle contraction	1	Trace
No contraction palpable	0	0

ROM: range of motion

Weakness, spasticity, and balance affect mobility for persons with MS. Common gait deviations associated with weakness and spasticity are circumduction, vaulting to clear a weak leg, genu recurvatum, foot drag, shuffling feet, lateral trunk flexion, and decreased push-off/acceleration. Primary weakness observed in MS is due to the demyelination and axonal degeneration characteristic of the disorder. Demyelination negatively impacts propagation of action potentials along the axons, resulting in physiologic fatigue, paresis, or even paralysis. Primary MS weakness is most commonly evident in anti-gravity muscles in the lower extremities, specifically the iliopsoas, the rectus femoris, the hamstrings, and the anterior tibialis. Secondary weakness in MS often occurs due to disuse, deconditioning, and development of compensatory movement. Individuals challenged with primary weakness may start compensating

their motion by using other muscle groups. From poor positioning, one can observe muscles that are elongated and become weak, see the development of contractures, tissue changes in the muscles, pain, proprioceptive loss, and tendonitis. All of these contribute to the patient not utilizing their muscles appropriately. Spasticity, ataxia, and an imbalance of the agonist and antagonistic muscles also contribute to secondary weakness in MS. The Manual Muscle Test is used for the assessment of weakness; performing the evaluation in gravity and gravity-eliminated positions. Manual Muscle Testing procedures are summarized in Table 6.

Spasticity is characterized by abnormal muscle firing, impaired voluntary control of skeletal muscles, hyperactive reflexes, the presence of clonus (which signifies a more significant state of spasticity), and pain from the muscles being in



this constant state of spasm. Spasticity is reported to affect 85% to 90% of patients with MS, and it can occur early on in the disease process (lower EDSS scores) through advanced levels of disease. Factors that increase spasticity include relapses, infection (such as a urinary tract infection), fatigue, excessive activity, pain, stress, anxiety, and clothes that are constricted in nature. The potential consequences of spasticity include increased energy cost of movement (which contributes to more fatigue), an impact on gait and transferability, poor posture and positioning in the chair, safety issues (for example, a patient may not be able to sit properly in the chair and start to slide forward), the development of contractures, pain, discomfort, sleep interruption (especially with spasms that occur in the lower extremities during hours of sleep), skin breakdown if the patient is not able to reposition themselves in the chair due to the presence of spasticity, interference with hygiene, self-catheterization, sexual difficulties, and breathing difficulties.

The Modified Ashworth Scale (MAS) is used for the assessment of spasticity in persons with MS.²⁹ The MAS is an ordinal scale that runs from 0 to 4 according to the following:

- **0:** No increase in tone
- 1: Slight increase in muscle tone, manifested by a catch and release
- 1+: Catch followed by minimal resistance throughout the remainder of the range of motion
- 2: More marked increase in muscle tone through most of the range of motion, increased resistance with quick stretch
- **3:** Considerable increase in muscle tone, passive movement difficult
- 4: Affected part(s) rigid in flexion or extension

Balance dysfunction in MS directly impacts mobility and performance of activities of daily living. Common gait deviations observed in individuals with balance and coordination difficulties include hesitation to move, slow deliberate movement, small range of motion in movements, stiff movements, sliding or shuffling feet forward, increased stance time bilaterally, wide base of support, and ataxia of foot placement. There are 3 physiological components needed for balance: 1) adequate strength and postural control; 2) visual, vestibular, and somatosensory processing; and 3) integration and processing of this information for appropriate equilibrium reactions, righting reactions and upright postural control for functional sitting, standing and ambulation. In MS, weakness in lower extremities, spasticity in lower extremities, ataxia, weak trunk control, sensory deficits, internuclear opthalmoplegia (INO), and vestibular disorders may all contribute to balance dysfunction. The following elements are part of a comprehensive examination to assess balance in persons with MS:

- **Musculoskeletal** (adequate strength and active range of motion—minimal to no spasticity)
- **Somatosensory** (proprioception and kinesthesia)
- Visual (smooth pursuits, saccades, convergence)
- Vestibulo Ocular (vestibular ocular reflex [VOR] and cancellation)
- Vestibular (benign paroxysmal positional vertigo [BPPV] and Dix Hallpike test) and Head Thrust to test for vestibular neuritis

Assessment of posture and trunk strength involves examining posture during sitting (both static and dynamic) and standing (static and dynamic). Righting reactions should be evaluated when a patient's postural alignment is challenged. Extremity strength can be evaluated with manual muscle testing. Somatosensory assessments include proprioception, kinesthesia, and localization. With a patient in a supine position and eyes closed, the rehabilitation professional can move a joint to a stationary position and ask the patient to match with the opposite extremity to gauge the patient's proprioception. In a similar way, kinesthesia can be evaluated by asking the patient to mimic the opposite extremity while movement is taking place. For localization, a patient is asked with eyes closed to give (verbally or by pointing) the location of the examiner's touch.

AIMS

Ocular motor deficits in MS include INO and nystagmus, resulting in diplopia, oscillopsia, blurred vision, and reading fatigue.³⁰ These abnormalities are often attributed to brainstem or cerebellar lesions.³¹ Visual testing should be conducted with the patient sitting with an examiner's finger (or other object) 12 inches away from the patient's face.

Visual assessments include:

- Spontaneous and gaze holding nystagmus: the patient is asked to focus on the examiner's finger in midline, and at 30 degrees horizontally to both sides and vertically up and down (the examiner is looking for the presence of nystagmus in each position)
- Smooth pursuits: the patient follows the examiner's finger, typically in an 'H' pattern (the examiner is watching for smoothness of eye movements)
- Saccades: the patient moves his/her eyes between two points (assessing the velocity, accuracy of movement, and the ability of the eyes to move together)
- **Convergence:** the patient follows the examiner's finger as it moves in towards the patient's nose (no closer than 6-8 cm away); the patient is asked if they see blurred or double vision (examining the ability of the eyes to adduct)

Vestibulo ocular assessments include the following:

• VOR: the patient is asked to focus on the examiner's finger while the patient moves his/her head side-to-side in a 'no' movement,

then up and down in a 'yes' movement (the examiner is looking for the ability of the patient to maintain gaze, and is asking for reports of blurred, double vision, or dizziness)

- VOR cancellation: the examiner holds the patient's head and asks them to focus on the examiner's nose. The patient should maintain fixation on the examiner's nose while the patient's head is moved (this is testing the ability of the patient to move his/her eyes with the head, cancelling the VOR)
- Dynamic visual acuity: the patient is asked to read the lowest line that they can clearly and accurately read on a Snellen chart with their head still. The examiner passively shakes the patient's head at approximately 2 Hz and the patients is asked to read the lowest line possible on the Snellen chart. A difference of 3 lines or greater is indicative of a VOR deficit.

Vestibular examinations include the Dix Hallpike and head thrust tests. For the Dix Hallpike test, the patient is on a plinth table in a long sitting position. The head is turned 45 degrees and the patient is rapidly brought into supine position with the head extended off the table. The most common nystagmus in this position is torsional and vertical, usually of short duration and indicative of BPPV, which is not associated with MS, but if present would alter the patient's balance. The head thrust test involves having the patient in a sitting position and asked to focus on the examiner's nose. The examiner moves the patient's head from side to side in a 'no' motion, then quickly "thrusts' the patient's head to 30 degrees from midline (thus assessing the ability of the patient to hold their gaze on the examiner's nose during the thrust without making a corrective saccade). The head thrust is used to determine the presence of vestibular neurtitis, an inflammation or infection of cranial nerve VIII (vestibulocochlear).

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THERAPEUTIC APPROACHES TO IMPROVE MOBILITY IN PATIENTS WITH MS

As will be illustrated in the patient case scenarios (beginning on page 50), part of the comprehensive evaluation of a patient with MS should be consideration for how their mobility impacts daily activities, home management, and participation in social and occupational functions. Activities include bed mobility; supine to short sit; sitting balance (static and dynamic) for hygiene; transfers on and off all surfaces (toilet, bed, etc); standing balance (static and dynamic) such as for hygiene activities, food preparation, meals or clean-up; ambulation; and stair climbing. Participation considerations include ambulation on uneven surfaces and inclines; ambulation up and down curbs; the ability to cross the street with head scanning and gait velocity; ambulation in the community with an assistive device; and community mobility with a wheelchair or scooter.

Based on the examination and assessments, the patient and rehabilitation therapist identify goals and priorities together. The therapist's role is critical in helping the patient identify realistic goals, while sustaining self-esteem and hope. These goals must be attainable, measureable, realistic, and functionally focused. A treatment plan should be established to achieve the goals for the patient, and include exercises and activities that are enjoyable, varied and task-specific. Resources should be considered for home and community-based programs; and whenever possible, endurance or aerobic conditioning should be included in the exercise program. Through such an individualized approach, these efforts can help to optimize all aspects of life function and maximize participation in everyday activities.

Identification of the underlying impairment that is limiting a patient's function (such as strength, sensation, balance, coordination, or spasticity) will help to inform a treatment plan. Task-specific training provides the opportunity to practice activities that present difficulties, work through progressive challenges, and modify the environment as applicable to gain function. Strengthening, stretching and core strength training are components of therapeutic exercise for individuals with MS. Weak core muscles are very common, therefore core strengthening exercises should be included for individuals at all EDSS levels. Coordination strategies and balance retraining based on underlying symptoms may be part of a rehabilitation plan and promote neuroplasticity.

Coordination activities may include repetitive practice of a functional task, such as reaching for the toothbrush, but in a shortened range of movement and slowly. A light weight could be added to the wrist to enhance kinesthetic awareness of the movement. The patient should practice the task in a seated position (so balance is not challenged) and as accuracy of the movement improves increase the distance moving and then the rate of movement. Balance strategies to address when the patient has an INO, spontaneous nystagmus and/or positive VOR, encompass visual focusing. Instructing the patient to focus on a stationary target when moving from a sitting to standing position can over-ride distorted information from the vestibular nuclei in the brainstem and promote postural stability. This activity can be progressed to dynamic standing with 2-hand support with visual focusing as the head turns to the left and then to the right. Progressively the patient removes one hand support, and then the second hand, as the brain reorganizes with activation of silent synapses to complete this task.

Pharmacologic management strategies may also be part of a rehabilitation plan for persons with MS. For example, patients with spasticity may benefit from a combination of exercise and medication. Commonly used oral spasticity medications include baclofen and tizanidine. When tolerability with oral baclofen or tizanidine (lethargy and fatigue) is challenging, and spasticity is more diffuse or generalized,



intrathecal baclofen (delivered via an implanted pump with a catheter) may be an appropriate choice. Injection of botulinum toxin into specific muscle groups is also an option for the management of spasticity that is more focal or localized to one or two muscle groups. Dalfampridine, an orally administered potassium channel blocker, may be prescribed for patients with walking impairment.³² In two placebo-controlled studies, dalfampridine was associated with statistically significant improvement in walking ability (measured with the Timed 25-Foot Walk) in patients with MS and mild to moderate walking impairment.^{33,34} Dalfampridine is contraindicated in persons with a history of seizure, those with moderate or severe renal impairment, or history of hypersensitivity to 4-aminopyridine.³² It is important to note that medications for symptom management in MS are managed through consultation with the patient's physician/neurologist.



Adaptive/Assistive Devices

In addition to strengthening exercises, stretching, task-specific training, and pharmacologic therapies, assistive devices are part of the therapeutic approach for improving mobility in patients with MS. When selecting a mobility product for a given patient, it is important to not only recognize current needs, but also to anticipate the needs of the individual in the future (possibly as long as 5 years). Most insurance companies will not consider a new product sooner than this unless the individual has demonstrated dramatic, permanent changes. A variety of mobility devices of benefit to patients with MS are summarized in Table 7.

When considering the powered devices in **Table 7**, scooters are relatively portable, provide mobility when fatigue and weakness are present, and may be perceived to have less stigma than other assistive products. However, disadvantages associated with scooters include lack of specialty seating, upper extremity fatigue, poor postural alignment, transfer limitations, poor maneuverability, inability to upgrade, good trunk stability and upper extremity function needed to operate, and there is no option for pressure relief. Power wheelchairs have the advantages of custom seating, they can be modified if an individual's needs change, have multiple power specialty

Mobility Device	Indications for Use	Туреѕ
Canes	 Can provide a small measure of balance, not meant to take a large amount of weight Held in hand opposite the weak side Should be as tall as the hip bone or as high as the bend of the wrist when one is standing tall with arms relaxed at the side 	 Single Point Four Point Small-based Quad Canes Large-based Quad Canes
Crutches	 Provide greater stability when weakness and imbalance is more significant Can use one or both depending on how the patient feels Cuff on Lofstrand crutch allows the individual to have a hand free and not lose the crutch Hand piece should fit the same as a cane 	 Axillary Forearm/Loftstrand/ Canadian
Walkers	 Gives more support when weakness and balance problems occur Hand grips should be as tall as the bend in the wrist when one is standing tall with arms are relaxed at sides or at the height of the hip bone 	 Standard (no wheels) Front wheeled 4-wheeled 4-wheeled with seat and hand brakes
Manual Wheelchairs	 Must have good strength and endurance in the upper body to be able to propel for all mobility 	 "Transport wheelchair" (lightweight but the individual must be pushed) Custom wheelchairs (customized seating and many optional features)

Table 7: Mobility Aids for Individuals with MS

Table 7: Mobility Aids for Individuals with MS (cont.)

AIMS

Mobility Device	Indications for Use	Туреѕ
Scooters	 A motorized scooter should be used for an individual who can ambulate fully. It should only be used for long distances or when an individual fatigues. May be broken down to get into the trunk of a car, but pieces are still large and may weigh up to 30 pounds. No ability to modify the scooter if the individual's needs change. 	 3-wheel 4-wheel (increased stability)
Power Wheelchairs	 Provide mobility but also can provide any needs for proper seating Can have optional power seating functions that allow you to tilt in space, recline, elevate the entire seat or elevate your leg rests Can be modified if your needs change 	 Numerous options are available, ranging from a basic chair with Captain's type seating through chairs with complex seating and positioning. Chairs can have mid-wheel, rear-wheel, and front-wheel drives.

Table 8: Ambulatory Assistive Devices

Device	Description
NESS L300™ Neuroprosthesis [wireless] (www.bioness.com)	 3 components: electronic orthosis, control unit, and gait sensor Heel pad in shoe connects via wire to clip on outside of shoe Small stimulator is encased in washable cuff around calf Remote device is programmed by a PDA (can be set for exercise or walking)
Walk-Aide Wireless FES (www.walkaide.com)	 Needs to be fitted and customized by a trained professional Walk-Aide communicates using Bluetooth wireless technology Battery-operated single channel Utilizes a "tilt sensor" to control stimulation during normal gait
Hip Flexion Assist Device (HFAD)	 For individuals who are experiencing hip flexor weakness HFAD is designed to improve walking by assisting hip flexion, as well as knee flexion (knee bend) and ankle dorsiflexion (foot lift)
Dictus Band or Foot-up	 Ankle strap with band that provides dorsiflexion assist by attaching to anchor point on shoe
Carbon Ankle Foot Orthotics or Traditional AFO	 Can be prefabricated or custom made Carbon fiber are lighter weight and usually prefabricated Custom AFOs can have solid ankle or articulating ankle; ankle angle can influence knee control
Knee Braces	 Used to control genu recurvatum (knee hyperextension) Examples include Swedish knee cage and Ortho Pro Hyper Ex Brace



features, and are maneuverable. Transportation issues, cost, and specific qualification criteria are disadvantages associated with power wheelchairs.

Ambulatory assistive devices are summarized in Table 8.

Examples of ambulatory assistive devices are shown in Figures 5 and 6.









Numerous aids are available to support individuals with MS in activities of daily living (Table 9)

Activity	Aids	Description
Bathing	 Tub bench Hand-held shower head Grab bars installed in shower/tub 	Bathing is an area with a significant risk for injury. One way for patients to minimize risk is to utilize adaptive equipment designed for use in the shower/bathtub
Toileting	 Bedside commode Grab bars near toilet Toilet seat with armrests (a raised seat with armrests can be placed over a regular toilet) Easy toilet riser Toilet tissue aides Bidets 	There are a variety of aids for toileting not only for safety and transfers, but for clothing management, and hygienic purposes as well
Dressing	 Velcro, buttons, zippers, and hooks on clothing Sock pull Long-handled shoehorn Buttonhook A stool for sitting while dressing 	Adaptive dressing aides can foster increased independence despite symptoms of fatigue, decreased fine motor control, or decreased strength/balance
Cooking	 Microwave oven Wheeled utility cart Electric can opener Pot stabilizer Large handled cooking utensils 	There are numerous modified cooking techniques that can be incorporated into the way an individual performs cooking tasks. These modifications, while helpful in their own right, can be enhanced by utilizing a variety of tools to simplify the process.
Eating	 Specialized utensils, such as large-handled spoons and forks, or "sporks," and rocker knives Plate guard Wrist supports Non-slip material such as Dycem 	Fatigue can be a significant factor during feeding tasks. Utilizing adaptive equipment can help in minimizing symptoms of fatigue, as well as helping an individual deal with tremor and decreased fine motor skills.
Writing	 Special grips for pens and pencils Wrist supports Slant boards Weighted writing implements 	There are a variety of aides to assist the individual with MS improve their ability to communicate through writing. Which implements are recommended depends on patient preference coupled with their presenting symptoms.

Table 9: Aids for Activities of Daily Living



Table 9: Aids for Activities of Daily Living (cont.)

Activity	Aids	Description
Sleeping	 Electric beds or mattresses Bed assist rails handles and poles Pressure relief mattresses 	The individual needs to safely get into bed in order to get a restful sleep. Just as importantly, individuals need to maintain an ability to remain comfortable and manage pressure relief techniques.
Miscellaneous	Reacher devicesGrab bars	There are a wealth of miscellaneous equipment types for maximizing independence for the person with MS. Therapists must balance their recommendations with the needs and preferences of their patients.



Selected Aspects of Cognition in Multiple Sclerosis

The possibility of cognitive change(s) in people with MS must be kept in mind by the entire treatment team. Cognitive changes can complicate employment, medical care, interpersonal relationships, and overall quality of life. Reports of cognitive impairment in the MS population vary considerably, depending on the study design, patient population sampled, and neuropsychological measures utilized. Approximately 30-40% of people recently diagnosed with MS are reported to have cognitive deficits on formal testing, while ~60% of patients with more longstanding disease or attending an MS center may have cognitive changes.^{35,36,37,38}

Cognitive impairment in people with MS does not follow a single pattern. It cannot be predicted by disease duration or physical disability level. A person may have no physical limitations, but may have a significant level of cognitive impairment; and conversely, a person may be significantly disabled physically, but may have fully intact cognitive functioning. Studies have shown correlation of cognitive dysfunction with brain MRI lesion volume and extent of regional atrophy; both gray and white matter pathology contribute to cognitive impairment.³⁹ Commonly seen changes in persons with MS include attention/concentration, word retrieval, memory, visual perceptual skills, speed of information processing, and executive functions.^{36,37} Other

challenges include ease of doing calculations, comprehension in spoken and/or written information, expressing thoughts or ideas, and conversational/social skills. Intelligence and long-term memory are typically not affected by MS. Language skills in MS were thought to remain intact, however research has reflected deficits in linguistic skills such as naming, comprehension, sentence repetition, word fluency, verbal explanation, verbal reasoning, sentence reconstruction, word definitions, absurdities, ambiguities and metaphors.⁴⁰ The impact of cognitive impairment extends to health care: difficulty understanding instructions, problems remembering instructions, forgetting to take medications, not following treatment instructions carefully, particularly if they are complicated, and altered ability to analyze treatment options and arrive at a sound decision.41

The evaluation and treatment of cognition in people with MS may be performed by a neuropsychologist, speech language pathologist, occupational therapist and/ or other entities such as vocational rehabilitation (Table 10).

If an MS Certified Specialist (MSCS) is not available to evaluate the patient, an individual or program that treats people with traumatic brain injury or similar disorders is a good option. The types of cognitive deficits and interventions in MS

Clinician	Scope		
Neuropsychologists	Cognition, mood, behavior, IQ, achievement		
Speech-Language Pathologists	Cognitive-communication (speech, language, augmentative alternative communication, pragmatics)		
Occupational Therapists	Cognition, activities of daily living, home and work issues		
Office of Vocational Rehabilitation	Cognitive testing and interventions, job site training		

Table 10: Clinicians Involved in the Evaluation and Treatment of Cognition in MS

are more similar to those seen in traumatic brain injury than to stroke or degenerative dementias.

AIMS

In MS, cognitive deficits are often mild-to-moderate in nature. Less than 10% of those with MS will develop severe to profound cognitive impairment.⁴² Mild cognitive changes may not be readily evident without formal testing. The person with MS may not be aware of the presence of (or severity of) cognitive deficit.⁴³ Therefore, self-report measures such as the Multiple Sclerosis Neuropsychological Ouestionnaire (MSNO) may not be helpful in this area, particularly given the effects of mood on this measure.⁴⁴ Brief screening measures such as the Mini-Mental State Examination (MMSE) are not sensitive to deficits typically present with MS.⁴⁵ Recent reports of use of the Montreal Cognitive Assessment (MoCA) have been made, however larger sample size and comparison with a more complete neuropsychological battery sensitive to MS, are needed.⁴⁶ A detailed history regarding vocational and avocational performance may be informative, and further, domestic partner reports are more likely to be accurate than patient self-report.44

The most widely accepted screening batteries for cognitive change in MS are the Brief Repeatable Neuropsychological Battery (BRNB) and the Minimal Assessment of Cognitive Function in MS (MACFIMS).^{47,48} These are composite measures (Table 11); both include the PASAT, (as a measure of auditory processing speed and working memory) and the SDMT (visual processing speed and working memory). Auditory/Verbal episodic memory is tested with the Selective Reminding Test in the BRNB and the California Verbal Learning Test second edition in the MACFIMS.⁴⁹ Visual-Spatial episodic memory is tested with the 10/36 Spatial Recall Test (BRNB) and the Brief Visuospatial Memory Test - Revised (MACFIMS). Both batteries use the Controlled Oral Word Association Test for expressive language. The MACFIMS also uses a spatial processing test (Judgment of Line Orientation) and an executive function test (Delis-Kaplan Executive Function System). The use of such screening protocols, while characterized by reliable psychometric properties, may be limited in routine clinical practice. Not all clinicians have access to and experience with some of the specific tests or normative data on MS.

Cognitive Domain	MACFIMS	BRNB		
Auditory processing speed and working memory	Paced Auditory Serial Addition Test	Paced Auditory Serial Addition Test		
Visual processing speed and working memory	Symbol Digit Modalities Test	Symbol Digit Modalities Test		
Auditory/verbal episodic memory	California Verbal Learning Test-2nd Edition	Selective Reminding Test		
Visual/spatial episodic memory	Brief Visuospatial Memory Test-Revised	10/36 Spatial Recall Test		
Expressive language	Controlled Oral Word Association Test	Controlled Oral Word Association Test		
Spatial processing	Judgment of Line Orientation			
Executive function	Delis-Kaplan Executive Function System sorting			

Table 11: Brief Neuropsychological Batteries for Assessment of Cognitive Change in MS⁴⁹ (adapted)



There has been extensive debate about screening of *all* people with MS for cognitive deficits, however, once a person with MS presents to a rehabilitation team member with cognitive concerns, evaluation should be more comprehensive and may also require more specific measures tailored to the clinical concerns.

When to refer for evaluation of cognition (list is not totally inclusive):

- Behavior that poses a safety or hazard risk
- Decrease in work performance
- Forgetting to take medications/taking medicines incorrectly
- Disorganization when approaching or carrying out a task
- Distractibility/inattention visual, auditory
- Forgetfulness
- Difficulty assembling things
- Delay in thought processing
- Delay in responding-verbal, physical
- Difficulty planning, sequencing and carrying out activities/schedules
- Easily overwhelmed
- Difficulty problem-solving
- Poor reading comprehension
- Difficulty with mathematical calculations
- Difficulty expressing thoughts/ideas
- Difficulty answering questions directly
- Asking for the same information over and over
- Poor interpersonal skills
- Difficulty learning new tasks
- Lack of awareness of problems
- Unexplained failure to succeed

When considering cognitive evaluation of a person with MS, it is important to be mindful of the possibility of comorbid or independent deficits in motor, sensory, coordination, vision and hearing capabilities. For example, visual impairment is seen frequently in MS, and hearing impairments (although usually not severe) may be present.² It merits comment that urinary urgency and continence issues must be managed to allow for accurate, humane testing. Clinicians should be aware that functional performance below the level of a patient's ability as shown on testing may suggest aggravating factors such as fatigue, mood disturbance, pain, etc. Cognitive fatigue (decline in cognitive performance over a single testing session) is now accepted as a real finding in people with MS.^{50,51} Documentation of this finding may be beneficial to help the patient maximize function or obtain workplace accommodations.

Cognitive rehabilitation is the process of improving or supplementing cognitive skills necessary for activities of daily living, and treatment approaches can be restorative or compensatory in nature. There is an increasing body of literature on neuropsychological rehabilitation for MS. A 2014 Cochrane review that included 20 studies meeting inclusion criteria reported low-level evidence supporting beneficial effects of neuropsychological rehabilitation on cognitive symptoms in MS.⁵² Improvements in memory span and working memory were associated with cognitive training, and cognitive training combined with other neuropsychological methods was associated with improvement in attention, immediate verbal memory, and delayed memory.⁵² Recent studies have provided positive results with different cognitive rehabilitation strategies for patients with MS, including retrieval practice for memory-impaired patient^{53,54} the modified Story Memory Technique for improving learning and memory abilities,⁵⁵ and a computer-assisted cognitive rehabilitation intervention focused on memory, attention and problem-solving skills for persons with MS.⁵⁶

A variety of compensatory strategies employed for cognitive challenges in MS are summarized in Table 12.



Table 12: Compensatory Cognitive Rehabilitation Strategies

Challenge	Rehabilitation Strategy
Attention/concentration (ability to focus and maintain focus, shift focus, select)	 Minimize distractions: reduce clutter; work in a quiet area (low traffic, low noise) Reduce interruptions: establish 'ground rules' with family and friends; let answering machine or voice mail pick up phone calls; use timers
Memory (learning, storing, and retrieving information)	 Notepads, planners, calendars Voice recorders Personal alarms Memory buddy/partner Colored baskets for specific items; always to be found in the same place Locating devices for parked cars
Word retrieval (saying the word you want to say, when you want to say it)	 Describe the item Substitute one word for another Free associate words Use gestures
Visuoperceptual skills (focusing on words when reading, recognizing left and right, driving, assembling something, designing, etc)	 Finger or index card when reading Large print books Books on tape Use brightly colored markers to mark left and right margins on a page Highlight numbers that are frequently used in the phone book Occupational therapists have great expertise in this area
Speed of information processing (ability to quickly analyze and use information from the surrounding environment)	 Ask others to slow down when they speak Rephrase what others say Repetition of information Use voice recorders—go back and review information several times
Executive functions (organizing, planning, sequencing, prioritizing thoughts, reasoning, judgment, problem solving, self-monitoring)	 Make lists, and rank in order of priority Write things down and make sure steps or ideas are in proper order Take a moment to organize thoughts before responding

No medications have consistently demonstrated efficacy for cognitive changes in MS; therefore no pharmaceutical agents are currently FDA-approved with this indication.⁵⁷ Promising results with the acetylcholinesterase inhibitor donepezil were reported by Krupp et al in 2004; however a larger, multicenter trial failed to demonstrate cognitive benefits with this agent.^{58,59} A placebo-controlled study with rivastigmine also failed to demonstrate a treatment benefit on memory and cognitive dysfunction in patients with MS. Stimulant medications have also been explored for MS cognitive change. These agents may primarily be used to treat symptomatic MS fatigue. The largest of these trials (108 subjects) evaluated amphetamine and did not show an

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effect on primary outcome measures, however there were benefits noted on some secondary endpoints.⁶¹ Positive findings have been reported in small studies with methylphenidate and modafinil; however larger studies are needed to confirm and expand upon these results.^{62,63}

The structure of a typical cognitive treatment session for a person with MS often includes a review of what has happened since the last session, an outline of the goals for the current session, cognitive exercises, development and/or practice of compensatory strategies, self-evaluation of performance/review of the session, assignment of homework, and formulation of a 'to-do' list. It is important that a cognitive rehabilitation strategy is specific (what exactly do you want to do?); it needs to be realistic (can this strategy realistically be carried out in day-to-day life?); there needs to be a means for accountability (how are you going to keep track of how or if you use it?); and it needs to be put on a timeline (when do you intend to implement the strategy, and for how long?).⁶⁴ Cognitive rehabilitation facilities, home health care agencies, private offices/private practitioners, hospital outpatient services, occupational and vocational rehabilitation agencies. Patients and/or caregivers connect with cognitive rehabilitation services by contacting the local rehabilitation facility, asking the patient's physician for a referral, or identifying providers in the area through the local NMSS chapter, asking other people with MS, or other health care professionals.

Speech, Swallowing Issues, and Oral Health

SPEECH AND VOICE IN MS

Studies of speech-related changes in individuals with MS indicate that 25-70% may experience some change in speech and/or voice over their disease course.^{65,66,67,68} The variability reported in the literature may reflect differences in study design, evaluative approaches, and research subject selection. Studies conducted with self-report questionnaires have reported a 23-44% incidence; ^{66,67,69} whereas studies with instrumental analysis have described speech-related changes in 41-51% of persons with MS.⁷⁰

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To better appreciate speech-related changes in MS, it is useful to review the elements involved in normal speech production—5 processes that work in a smooth and coordinated manner:^{71 (adapted)}

- **Respiration** (using the diaphragm to rapidly fill the lungs fully; followed by slow, controlled exhalation for speech)
- **Phonation** (using vocal cords and air flow 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)

Dysarthria and dysphonia are the most commonly observed speech-related disorders in the MS population.⁷² Dysarthria is a collection of motor speech disorders caused by weakness, slowness and/or lack of coordination of the muscles utilized for speech. Dysarthria classification systems are based on site of lesion and speech perceptual characteristics. The reader is referred to the work of Darley, Aronson, and Brown for classification and description of the dysarthrias.^{68,73} Spastic, ataxic and mixed dysarthrias (spastic/ataxic) are typically seen in MS.^{70,74,75,76} Tongue weakness alone is not considered dysarthria. Dysarthria impacts extremely rapid changes of the tongue, lip, soft palate and pharyngeal movements.⁷⁷ In MS, tongue movement is more affected than lip movement and can negatively impact performance on cognitive testing that requires an oral response.78,79,80 Dysphonia is a disorder of voice, often seen with dysarthria, and affects respiration, phonation, articulation, pitch, speech rate, stress, prosody, intelligibility, loudness and vocal quality.

Among the most frequently reported speech changes is decreased loudness; less frequently reported symptoms are impaired pitch control, inappropriate pitch level, breathiness and hypernasality.^{73,81} Vocal fold weakness can also be present.^{82,83} In addition, weakness in expiratory and laryngeal muscles is noted in the MS population.^{67,68,84,85} Weakness in expiratory muscles can be present even with limited disability and early on in the disease.⁸⁶

An important consideration when evaluating and treating speech and voice impairments is to note the demands of the environment on the speaker. MS fatigue can have a significant impact on all parameters of speech and voice, and it is not uncommon to see fluctuations in the quality and efficiency of speech and voice even throughout the day. MS exacerbations or progression of the disease can worsen or bring on new symptoms. In addition, speech and voice parameters can worsen due to xerostomia (dry mouth), gastroesophageal reflux, pseudoexacerbation, medication effects, or lifestyle habits such as tobacco and alcohol use and vocal abuse/misuse.



Individuals with MS should be referred to a speech/language pathologist for evaluation when any of the following are noted:

- Speech sounds "slurred"
- Changes in loudness (too loud, soft or fluctuating in nature)
- Harsh/hoarse/breathy voice
- Strained/strangled voice
- Abnormal pauses during speech (may also be an indication of word retrieval difficulties)
- Abnormal stress/emphasis on words
- Impaired pitch control
- Change in normal pitch of voice (higher, lower, pitch breaks)
- Hyper/hyponasality
- "Running out of air" during speaking
- Loss of saliva
- Loss of food when chewing
- Weakness or decreased range of motion in lips, cheeks, tongue, soft palate and/or muscles of the head, neck and trunk.

Considerations in the assessment of speech and voice in MS include:

- Medical history and complete chart review
 - General non-MS medical history
 - Medication review
 - Hearing status
 - Family medical history
 - Educational history
 - Occupation
 - Native (or other) languages
 - Cultural practices
 - Questions specific to MS
 - Date of diagnosis
 - Who made the diagnosis (neurologist, primary care clinicians, etc)?
 - Current and past DMTs and/or symptomatic treatments (including complementary and alternative medicines and supplements)

• What are the patient's symptoms?

 Changes in speech, voice, chewing/ swallowing, cognition, fatigue, mood, physical/sensory?

- Do the symptoms fluctuate? If so, when and what triggers the symptoms?
- Is there anything that helps to reduce the symptoms, such as resting, cooling, taking a break, etc.?
- Overall MS symptoms, "How are you feeling today?"
- What are the most prominent changes and what changes concern the patient/family/ caregiver the most?

• Physical Exam

- Patient observation, with special attention to positioning, breathing and saliva control
- Oral peripheral/neuromotor exam
 - Special attention to oral hygiene and dry mouth
 - Evidence of fatigue on repetitive movements or during range of motion

• Dysarthria Testing

- Informal
 - Observation and description; speech sample in structured levels and in spontaneous, ongoing speech⁸⁷
- Formalized Instruments
 - Frenchay Dysarthria Assessment 2nd Edition⁸⁸
 - Examines the following:
 - 1. Reflexes (cough, swallow, and dribble/drool)
 - 2. Respiration (at rest and in speech)
 - **3.** Lips (at rest, spread, seal, alternate, and in speech)
 - **4.** Palate (fluids, maintenance, and in speech)
 - 5. Laryngeal (time, pitch, volume, and in speech)
 - 6. Tongue (at rest, protrusion, elevation, lateral, alternate, and in speech)
 - **7.** Intelligibility (words, sentences, and conversation)
 - 8. Influencing Factors (hearing, sight, teeth, language, mood, posture, rate [words per minute], and sensation)
 - For ages 12 years through adults
 - Testing time 20 minutes

- Assessment of Intelligibility of Dysarthric Speech⁸⁹
 - Quantifies single word intelligibility, sentence intelligibility, and speaking rate

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- For adolescents and adults
- Provides an index of severity and can be used to monitor progress
- Testing time: 30 minutes
- Additional products are available commercially for assessing dysarthria

Collectively, patient history, physical exam, informal and formal dysarthria testing will be used to inform diagnosis and recommendations for treatment (no treatment or monitoring). This information may also indicate a need for referral to other disciplines. Patient and family/caregiver education is essential. Verbal and written information in easily understandable vocabulary should be provided to the patient and his or her support team explaining the results of speech and voice assessments. The rationale for treatment/no treatment/monitoring and any referrals (if indicated) should be carefully explained. In situations where augmentative and alternative communication may be beneficial, this approach should be described. It is extremely important to always solicit patient, family, and caregiver input during such discussions and to inquire about desires or expectations from treatment.

The American Speech-Language and Hearing Association (ASHA) has determined that the treatment of dysarthria is effective for congenital and acquired disorders.⁹⁰ Treatment should focus on improvement and/or use of compensatory strategies. Intervention should be individually tailored. Treatment usually involves exercises to increase strength and control of muscles used for speech, as well as modifying the rate of speech and/or loudness to enhance intelligibility.

ASHA has provided the following practical suggestions for optimizing communication for persons with dysarthria:⁹¹

Tips for the Person with Dysarthria

- Introduce your topic with a single word or short phrase before beginning to speak in more complete sentences
- Check with the listeners to make sure that they understand you
- Speak slowly and loudly and pause frequently
- Try to limit conversations when you feel tired—when your speech will be harder to understand
- If you become frustrated, try to use other methods, such as pointing or gesturing, to get your message across or take a rest and try again later

Tips for the Listener

- Reduce distractions and background noise
- Pay attention to the speaker
- Watch the person as he or she talks
- Let the speaker know when you have difficulty understanding him or her
- Repeat only the part of the message that you understood so that the speaker does not have to repeat the entire message
- If you still don't understand the message, ask yes/no questions or have the speaker write his or her message to you

Augmentative and alternative communication (AAC) strategies are helpful when speech alone is insufficient. The goal of AAC is to supplement existing speech or replace speech that is not adequate for functional purposes. AAC is a system comprised of symbols, aids, strategies and techniques. The most effective AAC systems allow the user to initiate, maintain and terminate the communication process. Low tech options include (but are not limited to) manual signs, natural gestures, pictures/photos, alphabet, eye-gaze boards, and buzzers (Figure 7). Fingers, other body parts, pointers, or eye tracking can be used to indicate selections.

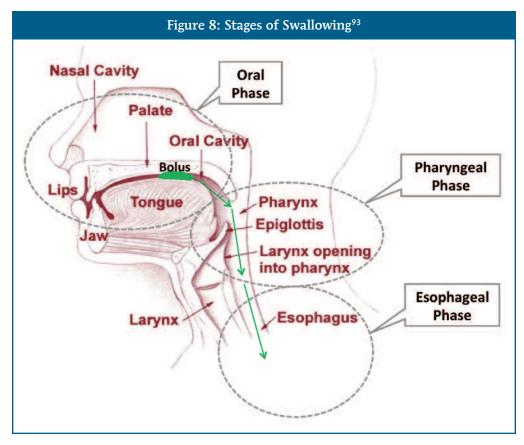


Figure 7: Examples of Basic Augmentative and Alternative Communication Options										
Alphabet Board Simple Eye Gaze Board										
1	Α	В	с	D	sp	ace	and the second se	Family PEOPLE	Travel ALPHABET	Medical CARE
2	E	F	G	н	end of word			Friends	Emotions	Bathroom
3	I	J	к	L	м	N		Homework CLASSES Phone		Books/Magazines MUSIC Videos/Movies
4	0	Ρ	Q	R	s	т		Clothing	News	Sports
5	U	v	w	Х	Y	z	FOOD Shopping	POLITICS Newspaper	COMPUTER Weather	
			Pizza	er e	Chicken	Pasta				
			Bread		Cheese		eese Vegetables		Fries	
			Fruit	Ba	Bananas		am	Cookie	Candy	
			Drink	V	Water			Soda	Coffee	

High tech AAC options include apps for mobile devices, computer programs, and speech generating devices that provide computerized voice output. The ASHA website has links to other organizations with information on the range of AAC devices and aids

(www.asha.org/public/speech/disorders/AAC/).

Selection and use of AAC strategies and devices should be individualized and practical. AAC users and their caregivers should have final decision in the choice of the AAC device or system. Attention to visual, cognitive, sensory and motor strengths/ weaknesses is important as well as understanding the role of fatigue and fluctuating symptoms in MS. People with MS and their caregivers need to be aware that the use of AAC may be intermittent depending on their communication skills at any given time. AAC users should be able to fluently alternate between speech and AACparticularly in the event of an emergency. Due to the frequent comorbidities of fatigue and cognitive change as well as the common progression of neurologic deficits, this writer's experience suggests that simple or low to mid-level



technology approaches are often more successful than more sophisticated devices. It is essential to maintain communication if quality of life is to be maximized.⁹²

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SWALLOWING

Swallowing safely is a complex integrated neurologic function of facial, oral, pharyngeal, and laryngeal structures, combined with respiratory and postural function. Safe swallowing involves not only motor activity, but also sensory, coordination, and autonomic functions. This integrated function may be transiently or permanently altered resulting in difficulty swallowing (dysphagia).

Normal swallowing can be divided into multiple stages. The changes associated with swallowing however begin even before food reaches the lips. The production of saliva may increase and posture will be altered before food is taken into the mouth. You can observe these changes when you place a box of donuts in front of your rehabilitation team. Not only can the impairment of vision, smell and taste alter the process of swallowing, but also the dining environment and the preparation/attractiveness of the food. Traditional swallowing stages include the oral phase, pharyngeal phase, and the esophageal phase (Figure 8).

• During the **Oral Phase**, food is placed in to the mouth and is chewed and mixed with saliva into a softer cohesive consistency called a bolus. The tongue and other muscles propel the bolus toward the back of the mouth with a front-to-back squeezing action. As the bolus is propelled over the back of the tongue, specialized sensory receptors activate the involuntary phase of the swallow.



- During the next phase, the **Pharyngeal Phase**, a number of things occur simultaneously. As the food enters the upper portion of the throat (pharynx), the soft palate elevates to prevent the bolus from going into the nose. The larynx (voice box) elevates and moves forward. The vocal folds close and the epiglottis drops down to the cover the trachea (windpipe). The bolus is propelled down the throat toward the esophagus where the upper esophageal sphincter opens to allow the bolus to pass into the esophagus. During the pharyngeal phase, breathing is temporarily suspended.
- The Esophageal Phase occurs when a series of sequential motor contractions moves the bolus down the esophagus where the lower esophageal sphincter opens and allows the bolus to pass in to the stomach.

Swallowing is a rapid process with the oral and pharyngeal stages lasting 1 second each and the esophageal stage lasting 8 to 10 seconds. Normal swallowing is controlled by cortical and subcortical areas of the brain as well as the brain stem cranial and other (phrenic) nerves. Cranial nerves directly involved in swallowing include the trigeminal (V), facial (VII), glossopharyngeal (IX), vagus (X), spinal accessory (XI) and hypoglossal (XII) nerves.

Efficient swallowing requires adequate movement and coordination of structures, coordinated rate and timing of structural movements, adequate pressure to form and propel the bolus, adequate oral lubrication, intact sensation of involved structures, and coordination with respiration. Dysphagia may occur in MS due to disruption of corticobulbar tracts, cerebellar dysfunction, brainstem and lower central nervous system involvement, abnormal respiratory control and capacity, and/or postural problems and tremor.^{94,95} A small study by Abraham and Yun reported laryngeal movement abnormalities in all MS patients evaluated; 84% had pharyngeal constrictor dysmotility, and 69% had laryngeal penetration.⁹⁶ Herrera et al found dysphagia in their study of patients with MS, including aspiration (28%), poor oral stage execution (50%), and delayed triggering of the swallow (70%).⁹⁷ When swallowing is impaired the bolus of material from the mouth may enter the opening into the trachea (penetration) or even pass through the vocal folds down into the trachea (aspiration). Penetration and aspiration may be either symptomatic or asymptomatic (silent). Symptoms of *overt* aspiration are visible and include coughing, choking, gagging during or after eating and/or drinking. The person with MS may cough food or liquid back up into the mouth or out the nose. Aspiration can be *silent*, meaning food and/or liquid is entering the airway without noticeable, observable symptoms. Silent aspiration is most prevalent in the neurologic population.

Symptoms of dysphagia include:

- Slowed or delayed swallow
- Coughing, choking, or gagging during eating or drinking
- Coughing, choking or gagging **after** meals particularly when changing positions (such as going from a sitting to a reclining position)
- Copious secretions
- Weight loss of unknown origin
- Pneumonia-especially pneumonias that reoccur
- Wet or "gurgly" voice sounds during or after meals
- Residual food on tongue or in the mouth after swallowing
- Feeling of food or pills being "stuck" in the throat or chest
- Increased chest congestion after eating or drinking
- Difficulty chewing
- Changes in loudness of voice or ability to clearly pronounce words may be a precursor to swallowing problems

Complications of dysphagia are:

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- Dehydration
- Malnutrition
- Upper respiratory infections
- Aspiration pneumonia

Guan et al recently conducted a systematic review and meta-analysis of the prevalence of dysphagia in MS.⁹⁵ These authors identified 15 studies meeting inclusion criteria, reflecting data from 4,510 patients. The combined prevalence estimate from 12 studies based subjective screening methods was 36%, and the pooled prevalence from four studies based on objective measurements (clinical, videofluoroscopic, and/or fiber endoscopic tools) was 81%.95 Dysphagia may occur at any point in the disease course; however the prevalence increases with increasing EDSS scores.^{98,99} Symptomatic dysphagia is significantly correlated with cognitive impairment,¹⁰⁰ depressed mood,¹⁰¹ and severity of illness.¹⁰² Wiesner et al have reported on the discrepancy between radiologic findings and subjective symptoms of dysphagia in patients with MS,¹⁰³ and indeed self-reports underestimate the frequency of dysphagia.^{101,104}

It is worth noting that other gastroesophageal conditions such as dyspepsia or gastroparesis may also be present in the MS population.^{105,106}

Bedside and/or instrumental approaches are used for the evaluation of swallowing. In order to conduct an evaluation of swallowing, the patient needs to be medically stable, alert, cooperative and able to follow simple directives.

A bedside evaluation of swallowing includes:

- Case history-review of medical records
- Patient/family/caregiver interviews
- Questions specific to the patient's MS
 - How are you feeling now?
 - When was your last relapse?
 - Do you feel that you are having a relapse now?

- Are you currently taking steroids?
- Are you taking your DMTs as prescribed?
- Are there times that you skip doses on purpose to make your prescription last or forget to take your medication?
- Speech language pathologist (SLP) observations of the patient
- Oral peripheral and neuromotor exam
- Assess quality of speech and voice
- Assess volitional cough
- Evaluate laryngeal elevation
- Observation of coordination of respiration and swallowing
- Oral trials of thin and thick liquids, purees, pudding textures and solids
- Assess patient's skills and overall functioning in their environment

Readers should be aware that there are commercial screening tests available for the evaluation of dysphagia.

Bedside Evaluation of Dysphagia (B.E.D.)– Revised Edition by Hardy (1999)¹⁰⁷

- This protocol includes 4 components:
 - **1. Prescreening**-cognitive, linguistic and behavioral factors pertinent to safe swallowing
 - 2. Oral motor assessment-structure, function and touch sensitivity of lips, cheeks, tongue and soft palate, corresponding sensory or motor cranial nerves
 - **3.** Oral-pharyngeal dysphagia symptoms assessment-oral and limited pharyngeal abilities to handle graded amounts of foods and liquids
 - 4. Bedside screening form-1 page

The B.E.D. manual describes administration instructions, implications of disorders, diet consistency recommendations, and compensatory and rehabilitation strategies to try at bedside.



Yale Swallow Protocol: An Evidence-Based Approach to Decision Making by Leder and Suiter (2014)¹⁰⁸

- This protocol includes the following features:
 - 1. Screening instrument
 - 2. Identifies aspiration risk
 - **3.** Can provide recommendations for specific oral diets if screening is passed
 - 4. Can be administered by cross-disciplinary (medical) team members
 - **5.** Can be used in a variety of environments
 - 6. Validated with instrumental findings (fiberoptic endoscopic evaluation of swallow)
- The volume includes:
 - Building a Foundation and Defining Terms
 - Screening Basics: Differentiating a Screen from a Diagnostic Tool
 - Criteria Necessary for a Successful and Reliable Swallow Screen
 - Development of a Programmatic Line of Research for Swallow Screening for Aspiration Risk: The First Step
 - Development of a Protocol: Why You Need More Than Just an Isolated 3-Ounce Water Swallow Challenge
 - Generalizing the Yale Swallow Protocol to Different Patient Populations: Time to Change
 - Recommending Specific Oral Diets Based on Passing the Yale Swallow Protocol
 - Yale Swallow Protocol Administration and Interpretation: Passing and Failing
 - Implementation of the Yale Swallow
 Protocol by Other Health Care Professionals
 - Question: What about silent aspiration? Answer: Silent aspiration is volume-dependent
 - In Support of Use of the Yale Swallow Protocol: Longer-Term Success of Diet Recommendations and Oral Alimentation
 - Final Thoughts
 - The Yale Swallow Protocol Administration Forms

Videofluoroscopy, endoscopy, ultrasound, scintigraphy, esophageal manometry and electromyography are instrumental methods by which to evaluate swallowing. Two of the most commonly employed procedures are videofluoroscopy and fiberoptic endoscopy.

Video Fluoroscopic Swallow Study (VFSS)

- Also referred to as modified barium swallow (MBS), videofluoroscopy, cookie swallow study or esophagram
- Is a "moving x-ray" of chewing and swallowing
- Performed in radiology suite
- Is performed with the patient in sitting or standing position
- Small amounts of barium are mixed with food and liquids for visualization during procedure
- Limited radiation exposure-fluoroscope intermittently turned on and off during evaluation

The ASHA website includes a description of VFSS: www.asha.org/public/speech/swallowing/Video fluoroscopic-Swallowing-Study/.

Fiberoptic Endoscopic Evaluation of Swallow (FEES)

- Can be performed in a variety of environments including bedside
- No radiation exposure can be used repeatedly and for longer periods than VFSS
- Flexible endoscope inserted through nasal cavity and down throat
- May use colored dye to visualize food
- Sensory testing
- Can visualize signs of reflux above the level of the upper esophageal sphincter

The ASHA website includes a description of FEES: www.asha.org/public/speech/swallowing/endos copy/.

During instrumental evaluation of swallowing, the patient is given various food and liquid consistencies, such as soft/hard foods and thin/thicker liquids, in progressive amounts from smaller to larger bolus size. The American Speech-Language-Hearing Association has provided guidelines for the instrumental assessment of dysphagia.¹⁰⁹ The reader is encouraged to review the guidelines in their entirety (www.asha.org/policy/GL2000-00047/). According to the guidelines, the purposes of the instrumental exam are to:¹⁰⁹

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- 1. Visualize the structures of the upper airway and digestive tract
- 2. Assess the physiologic functioning of the muscles and structures involved in swallowing
- **3.** Assess coordination and effectiveness of lingual, velopharyngeal, pharyngeal, and laryngeal movement during swallowing
- 4. Determine presence, cause, severity, and timing of aspiration
- 5. Visualize the presence, location, and amount of secretions in the hypopharynx and larynx
- 6. Screen esophageal anatomy and function for evidence of dysphagia
- 7. Assist in determining the safest and most efficient route (oral vs. nonoral) of nutrition and hydration intake
- 8. Determine with specificity the relative safety and efficiency of various bolus consistencies and volumes
- **9.** Determine the rate or method of oral intake delivery (i.e., selection of utensils, bolus placement, bolus modifications)
- **10.** Determine the postures, positioning, maneuvers, and/or other management/ treatment techniques that enhance the safety and efficiency of feeding

Table 13 includes indications, possibleindications, and contraindications forinstrumental exam according to the ASHAguidelines.

The goals for treatment of swallowing difficulties in patients with MS are to reduce the risk for aspiration, increase nutrition and hydration, increase quality of life, increase independence, and increase participation. Treatment approaches can be divided into two categories: management and direct treatment. Management strategies for dysphagia include:

- Positioning of trunk, legs, and arms
- Specialized head/neck positioning
- Manipulation of consistencies of foods/liquids
- Modifications in eating schedules
- Modifications in bolus size
- Smaller, more frequent meals
- Use of nutritional supplements
- Reducing the rate of eating
- Alternating solids and liquids
- Specialized feeding equipment
- Manipulation of the patient's environment
- Training-person with MS, family, caregivers
- Follow-up with appropriate professionalsespecially the SLP

Direct treatments for dysphagia include strengthening/resistance exercises; techniques such as supraglottic swallow, super-supraglottic swallow, effortful swallow, and increasing sensory awareness; respiratory training; and neuromuscular electrical stimulation specifically designed to treat dysphagia.¹¹⁰ Medications have been identified that cause or aggravate many issues in the mouth, throat, esophagus and stomach. No credible trials have shown benefits associated with pharmacological approaches for dysphagia in MS.

Patients who cannot acquire or maintain intake of food and/or nutritional supplements orally or are unable to eat or drink safely due to aspiration are candidates for tube feeding. In general, the more brainstem involvement with regard to MS lesions, the more difficulty a patient is likely to have with swallowing. It is important to note that the gastrointestinal tract must be accessible and function sufficiently to absorb the tube-feed.



Table 13: ASHA Guidelines for Instrumental Assessment of Dysphagia¹⁰⁹

Indications for Instrumental Exam	 The patient's signs and symptoms are inconsistent with findings on the clinical examination There is a need to confirm a suspected medical diagnosis and/or assist in the determination of a differential medical diagnosis Confirmation and/or differential diagnosis of the dysphagia is needed There is either nutritional or pulmonary compromise and a question of whether the oropharyngeal dysphagia is contributing to these conditions The safety and efficiency of the swallow remains a concern The patient is identified as a swallow rehabilitation candidate and specific information is needed to guide management and treatment
Possible Indications for Instrumental Exam	 The patient has a medical condition or diagnosis associated with a high risk for dysphagia, including but not limited to neurologic, pulmonary or cardiopulmonary, gastrointestinal problems; immune system compromise; surgery and/or radiotherapy to the head and neck; and craniofacial abnormalities The patient has a previously diagnosed dysphagia and a change in swallow function is suspected The patient has a condition such as cognitive or communication deficits that preclude completion of a valid clinical examination The patient has a chronic degenerative disease or a disease with a known progression, or is in a stable or recovering condition for which oropharyngeal function may require further definition for management
Contraindications of Instrumental Examination	 The patient is too medically unstable to tolerate a procedure The patient is unable to cooperate or participate in an instrumental examination In the speech-language pathologist's judgment, the instrumental examination would not change the clinical management of the patient

A few myths and facts related to tube feeding are:

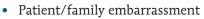
- Myth: Aspiration and resulting pneumonia occur directly as a result of oropharyngeal dysphagia
- Myth: Placement of a feeding tube is the only way to eliminate aspiration pneumonia
- Fact: Aspiration comes from the mouth and/or stomach
- Fact: Placement of a feeding tube does not eliminate aspiration pneumonia
- Fact: Good oral hygiene makes aspiration less risky

Coyle and Matthews note:

"Placement of feeding tubes in patients with documented gastroesophageal reflux or other upper digestive conditions – even a patient with dysphagia – may dramatically increase the risk of aspiration far beyond the patient's aspiration risk related to oropharyngeal dysphagia."¹¹¹

Based on this author's clinical experience, it is possible to identify a number of complicating factors that impact the treatment of swallowing dysfunction in patients with MS, including:

- Lack of patient/caregiver understanding
- Lack of professional awareness or training
- Lack of adequate food/drink preparation
- Poor palatability of suggested consistencies
- Lack of caregiver support
- Lack of resources adaptive equipment, trained professionals



- Confusing terminology
 - Drink-thin, nectar, thick, thickened, regular, honey, pudding

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 Food-pureed, ground, chopped, soft, mechanical soft, regular

Rehabilitation professionals should have an awareness of potential comorbid conditions in persons with MS that may impact the evaluation and treatment of dysphagia. These include:

- Cognitive dysfunction
- Poor postural alignment
- Fatigue
- Xerostomia (dry mouth) and dental disease
- Depression
- Changes in MS-exacerbation, remission, progression
- Other medical conditions in addition to MS

ORAL HEALTH

Why is oral care/hygiene important? Mouth and throat secretions contain many types of microorganisms and dysphagia can promote aspiration of these secretions. In addition, gastroesophageal reflux is common in the general population (including persons with MS), is detrimental to dental and oral health, and has the potential to cause pneumonia when aspirated. Aspiration pneumonia can further aggravate MS. Health care professionals often focus on DMTs, urinary tract infections, and other medical complications of MS. Simple things that can lead to better health are easily overlooked. Lack of care makes the mouth prone to disease and infection that can be spread to other parts of the body, including the lungs. Studies have suggested that patients with poor oral hygiene who have high pathogen loads in their saliva are at increased risk of pneumonia^{112,113}

Dental care tends to be a lower priority in people with MS. Possible reasons (based on the author's clinical experience) are:

• Other aspects of the disease are more urgent

- Lack of insurance/finances
- Lack of transportation/accessibility
- Cognitive/behavioral impairment
- Depression
- Fatigue
- Dependency on caregivers
- Abnormal neurologic function of trunk and/or extremities (numbness, parathesia, spasm, spasticity, weakness); oral self-care can be difficult if not impossible.
- Lack of appropriate utensils, rinses, etc.
- Pain-temporomandibular joint (TMJ) dysfunction
 - Glossopharyngeal neuralgia
 - Trigeminal neuralgia
 - Periodontal disease

Adequate levels of saliva production are critical not only for a healthy mouth, but overall physical health. Saliva moistens the mouth and throat and aids in taste, swallowing and digestion. It assists in washing food and plaque off the teeth and out of pockets in the mouth. Saliva neutralizes acids in the mouth and aids in healing mouth injuries. It also facilitates speech.

Xerostomia, also known as "dry mouth," is the result of decreased or lack of saliva production. Xerostomia is a symptom, not a disease. A study in 2004 reported that 50% of adults in the United States take at least one prescription medicine, and a study by Guggenheimer and Moore indicated that 64% of xerostomia cases are caused by medications.^{114,115} The prevalence of xerostomia in MS is unknown but believed to be common; attributed to side effects of medications that are often used to manage symptoms of MS.

Symptoms of xerostomia include:¹¹⁶

- Excessive thirst
- Burning/tingling sensation of the mouth and/or tongue
- Red, raw tongue
- Sores in the mouth or at the corners of the lips
- Difficulty swallowing



- Decreased taste
- Sore throat/hoarseness
- Bad breath
- Speech problems "slurred speech"
- Dry nasal passages
- Dry, cracked lips
- Cavities and periodontal disease
- Problems wearing dentures
- Chronic oral yeast infections

As a result of xerostomia, both soft and hard tissues of the mouth can be seriously affected by periodontal disease, dental caries, tooth loss, and oral candidiasis (yeast).¹¹⁴ Risks of xerostomia are decreased oral intake, dysphagia, oral infections, and infections in other parts of the body. Reduction in salivation is not necessarily obvious; Guggenheimer and Moore reported that there is a 50% reduction in saliva production before xerostomia is noted by dental professionals.¹¹⁵

Good oral hygiene practices lessen the impact of xerostomia. Treatment for xerostomia focuses on management for the relief of symptoms and prevention of oral complications:¹¹⁷

- Routine visits to dental professionals. Report dry mouth symptoms and ask for suggestions on management
- Artificial oral lubricants (such as Biotene) are available over the counter and can be helpful
- Brush, floss and rinse twice daily. Make sure to brush the tongue as well. Use a soft bristled tooth brush to avoid damaging gingiva and other mouth tissues as well as tooth enamel. Manual and electric toothbrushes remove biofilm and clean food, debris and stains from teeth, as well as stimulate gum tissue
- Avoid alcohol and mouth rinses (including toothettes) that have alcohol as an ingredient. Alcohol is drying and can be painful to use
- Rinse the mouth after drinking and snacking
- Review medications talk to the physician or nurse to see if changes or modifications are possible

- Avoid smoking tobacco and cannabis, chewing tobacco and vaping
- Increase hydration (no alcohol, caffeine, sugary drinks; manage bladder issues)
- Chew gum or use hard candy to moisten the mouth. Products that are sugar-free or made with xylitol are recommended. Bacteria don't survive when they ingest Xylitol. Xylitol is toxic to dogs and products containing this should be kept out of reach of pets
- Dietary selection Avoid highly spicy foods, fruits and vegetables with high acid content¹¹⁸
- Monitor sodium intake
- Avoid/monitor/ manage foods with high sugar content. Foods that are high in sugar increase bacteria in the mouth and predispose the teeth to cavities. Brushing after eating these foods is optimal, but if tooth brushing is not possible, chew sugarless gum or rinse the mouth with water
- Change medication regimen (if possible)
- Use of medications to stimulate salivary glands

AIMS

Health and Wellness in MS

MS is a chronic condition that can impact many dimensions of quality of life. Clinicians must be mindful of the inter-relatedness of MS symptoms, for example fatigue may limit a person's willingness or motivation to exercise, reduced exercise may lead to spasticity or constipation, spasticity may interfere with sleep quality, and sleeplessness may amplify fatigue. The rehabilitation team can support positive, healthy choices to promote an overall balance of physical, social, spiritual, and emotional well-being for individuals with MS throughout the course of this chronic disease.

NUTRITION

In addition to physical activity and fitness, good nutrition is essential for promoting wellness. Noteworthy dietary factors related to MS include vitamin D (insufficiency is a risk factor for MS),¹¹⁹ high salt intake (increased risk for MS and autoimmunity)^{120,121} and the gut microbiome (dysbiotic gut microbiota associated with inflammation and autoimmune diseases).¹²² There is great interest in possible dietary interventions in autoimmune diseases such as MS, however to date no one specific diet has been advocated.¹²³ General dietary recommendations include:^{123,124}

- Eat calcium-rich foods
- Eat foods containing or fortified with vitamin D
- Use low-fat dairy products
- Choose lean cuts of meat, chicken, poultry and fish
- Increase omega-3 fatty acids in the diet
- Eat 5-9 servings of fruits and vegetables a day, including dark, green leafy vegetables, and fresh fruit
- Avoid saturated fats
- Avoid trans fats, cholesterol, salt, and added sugars
- Eat whole-grain breads and fiber-rich foods
- Drink at least 8-10 cups of fluid a day

- Grill, bake, steam, or poach foods (instead of frying)
- Use poly- and monounsaturated margarines and oils, such as canola and olive oil
- Avoid mega-doses of vitamin supplements
- Avoid sugar-containing and caffeinated beverages
- Eat no fewer than 3 meals a day, and preferably 5-6 small meals a day, including breakfast
- Monitor portion sizes

A good starting place for addressing dietary issues can be to sensitize patients to their current diet. This can be accomplished by using an online or smartphone app to monitor diet for a few days. Begin with small steps, and approach dietary adjustments as a lifestyle change rather than a 'diet.'

SMOKING

Smoking cessation is another aspect of wellness for persons with MS. Cigarette smoking is a known risk factor for MS, and smokers are more likely to be diagnosed with progressive MS than never-smokers.^{125,126} In addition, Healy et al reported that compared with never-smokers, current smokers had significantly worse disease at baseline (EDSS scores, multiple sclerosis severity score, and brain parenchymal fraction), and converted from RRMS to secondary progressive MS faster than non-smokers.¹²⁷

SLEEP

Fatigue is one of the most common and disabling symptoms for those with MS, and restorative sleep may be negatively impacted by other MS symptoms such as spasticity, nocturia, pain and mood. In a cyclical way, poor sleep can impact fatigue, depression, pain, and cognition. A study by Brass et al reported that in a survey of 2,375 individuals with MS, 70% screened positive for one or more sleep disorders, including obstructive sleep apnea, insomnia, and restless leg



syndrome.¹²⁸ Most of the patients in this study who screened positive for sleep disorders were undiagnosed. The Epworth Sleepiness Scale (https://www.slhn.org/docs/pdf/neuro-epwort hsleepscale.pdf) is a screening instrument for sleepiness used in research studies; however familiarity with the questions may be useful in clinical practice for an informal assessment of sleepiness.¹²⁹ For example:

How likely are you to doze or fall asleep in the following situations?

- Sitting and reading
- Watching TV
- Sitting inactive in a public place (such as a theater or a meeting)
- As a passenger in a car for an hour without a break
- Lying down to rest in the afternoon when circumstances permit
- Sitting and talking to someone
- Sitting quietly after a lunch without alcohol
- In a car, while stopped for a few minutes in traffic

Strategies for good sleep habits include avoidance of caffeine later in the day; establishment of a consistent sleep schedule; effective management of MS symptoms that impact sleep; exercise; sleep in a cool room; and no TV or electronics in bed.

PSYCHOSOCIAL WELL-BEING

Psychosocial well-being is another important dimension when we consider the 'total patient' with MS. The lifetime prevalence for depression in MS is ~50% (values reported in the literature vary depending on the rating scales or screening measures used).^{130,131,132} While major depressive disorder is a treatable condition, Mohr et al have reported that only a third of patients with MS diagnosed with depression receive antidepressant treatment.¹³³ Factors contributing to depression in patients with MS include the psychosocial effects of MS-related disability (social and vocational roles, participation abilities, uncertainty about disease course, and lack of hope), direct effect of lesions on brain structures related to mood state, and side effects of therapeutic agents (such as interferon beta, or steroids).¹³² Consequences of depression in persons with MS include reduced quality of life and social support, poor performance on cognitive function tests, and poor treatment adherence compared with non-depressed MS patients.¹³⁰ For these reasons and the increased risk for suicide associated with depression, the entire MS care team should be familiar with screening approaches for depression.

A 2-question rapid screen for depression can be used:¹³⁴

- 1. During the past 2 weeks, have you often been bothered by feeling down, depressed, or hopeless?
- 2. During the past 2 weeks, have you often been bothered by little interest or pleasure in doing things?

Endorsement of either of these questions should prompt further evaluation for the presence of depression. Another approach to screening for depression is the Patient Health Questionnaire (PHQ-9), a 9-item depression scale based on DSM-IV.¹³⁵ Widely used in primary care settings, this can be filled out by patients while in the waiting room, and then scored by the clinician. This tool can be used to make a tentative criteria-based diagnosis of depression, and obtain a severity score that can be used to guide treatment and monitor treatment response. The PHQ-9 is in the public domain: http://www.med.umich.edu/1info/FHP/practic eguides/depress/phq-9.pdf. A combination of psychotherapy and pharmacological therapy is advocated for patients with MS and depression.^{130,136} **Table 13** includes antidepressants that may be used for the treatment of depression in patients with MS. Anxiety has also been reported in MS (lifetime prevalence of 36%).¹³⁰ Antidepressants with indications for generalized anxiety disorder have been noted in Table 13.

AIMS

Table 13: Pharmacologic Treatments for Depression

Drug	Daily Dose	Indicated for Generalized Anxiety Disorder
Selective Serotonin Reuptake Inhibitors		
Fluoxetine (Prozac®)	20-80 mg	
Sertraline (Zoloft®)	50-200 mg	✓ (social anxiety)
Paroxetine (Paxil®)	20-50 mg	√
Citalopram (Celexa®)	20-40 mg	
Escitalopram (Lexapro®)	10-20 mg	√
Serotonin Norepinephrine Reuptake Inhi	bitors	
Duloxetine (Cymbalta®)	40-120 mg	√
Desvenlafaxine (Pristiq®)	50-100 mg	
Venlafaxine (Effexor®)	75–225 mg	√
Other		
Bupropion (Wellbutrin [®])	150-450 mg	

Depending on the practice environment, mental health care for patients with MS may be provided by neurologists, primary care clinicians, and mental health professionals. A strong referral network to mental health professions and identification of mental health services/resources for patients are recommended.

COMPLEMENTARY AND ALTERNATIVE MEDICINE

It is important to inquire about and be familiar with complementary and alternative medicines and supplements that patients with MS may be taking (or have an interest in taking). Caution is warranted, as some strategies may actually stimulate the immune system, which would not be advantageous for patients with MS. Drs. Allen and Nathaniel Bowling provide information about a range of alternative medicinal approaches and considerations for use in patients with MS (website: http://www.neurologycare.net/cam).¹³⁷



Conclusion

A 2010 Consortium of Multiple Sclerosis Centers white paper, noted, "Those in the MS healthcare community must ensure that all patients receive a wide range of rehabilitative, cognitive, psychosocial, and therapeutic treatments in line with the course of disease progression and current symptoms. Each care plan must be tailored to the individual needs of the patient and his or her family; MS is a disease where "one size" certainly does not fit all. It has been recommended that healthcare professionals adopt an integrated model that encompasses therapeutic, rehabilitative, and palliative care; equal weight should be given to medical and psychosocial models of *disability.*"¹³⁸ The patient is at the center of the comprehensive care model, with the entire multidisciplinary care team engaged in optimizing the patient's whole health including physical, emotional, psychological, and social needs (Figure 9).

The complexity of MS lends itself to the team approach. Effective communication among team members is critical to insure the individual receives not only optimal care, but receives care in a coordinated manner that addresses all their needs and that the care is not redundant. The rationale for the team approach for chronic illnesses is embodied by:

- **Case complexity**—multiple issues, multiple solutions needing multiple professionals contributing their unique expertise
- **Client-centered approach**—the person with MS drives the professional interventions
- Unity in problem-solving and goal achievement—everyone on the team is working towards shared objectives
- **Best practices**—use of techniques that have consistently shown results superior to those achieved with other means
- Efficacy—interventions should be effective, useful and have value

Team qualities for effective communication are driven by:

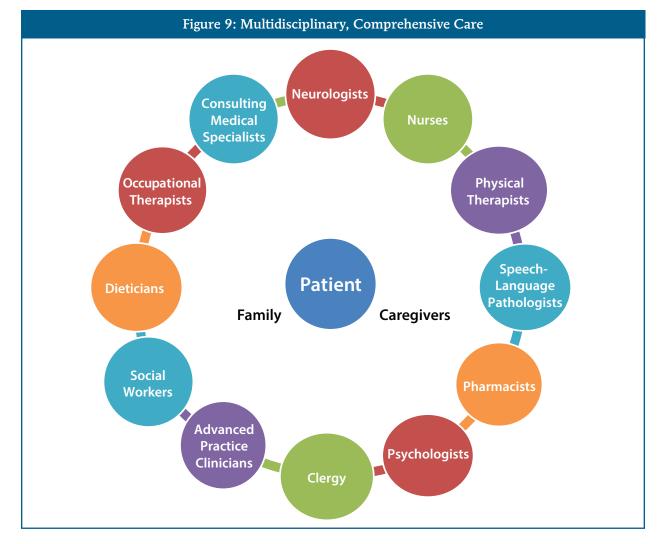
- Free flowing sharing of ideas frequently and on a regular basis
- Transfer of knowledge and skills across discipline boundaries; team members are not territorial
- Commitment to collaboration
- Ability to ask for help without feeling lessened (mutual respect and trust)

Certainly, when all the team members are housed within a single facility or department it increases the ease of the flow of communication. The challenge becomes when members of the team are at various locations or even located in different hospital systems or organizations. Regardless of the location of the professionals, creating strong working relationships and a seamless communication process with the various team members is essential to provide optimal care. Virtual team meetings, electronic medical records, encrypted email communication, faxes, and traditional paper documentation and letters will facilitate communication. Ideally, network communication will be facilitated by a point person, such as a case manager or other care coordinator when available.

A few take-home considerations regarding the impact of MS pathophysiology on assessment and intervention are summarized below.

Successful evaluation and treatment of the person with MS requires recognition and accommodation of other MS related challenges. Some of the more significant challenges include MS fatigue, urinary and bowel control problems, temperature sensitivity, medication effects and mental health. Although not discussed below, pain and other sensory phenomena can negatively impact assessment and treatment.





MS FATIGUE: Fatigue, as opposed to sleepiness, is very common and the person with MS may need to rest between assessments and treatments from other therapists. Exploring the impact of fatigue on function may be helpful when evaluating and designing appropriate therapy regimens. MS fatigue is usually absent upon awakening and worse in heat. Other causes of fatigue that are common in people with MS may relate to impaired sleep quality or quantity, medications and deconditioning.

Urinary and Bowel Control Problems: Urinary and bowel frequency and urgency can pose

challenges and be severe. Trips to the restroom may need to be planned, especially during assessments. It is not uncommon to hear people living with MS express concern they did not perform well during their testing. They report being distracted by the concern of soiling themselves during the session when told to "hold it." Obviously, it is imperative to respect the dignity of the individual we are helping.

Sensitivity to Temperature: Many people with MS may have a worsening of symptoms (not the disease) with increased body core temperature. Body core temperature increases may be brought



on by infection, fever, exercise and/or being in a too warm environment (such as a room that is too hot or being out of doors when the temperature is too warm or humid). Marked changes in function can occur with slight changes in body temperature. Fever is common after interferon injections. Use of cooling techniques such as fans, cold beverages, cooling vests/wrist bands/headbands/hats, ice packs, lowering the thermostat and so forth can be effective in helping a person with MS perform optimally. Very cold temperatures may aggravate spasticity and should be used judiciously. A person with heat sensitive MS may need to rest and/or cool before transitioning to another therapy.

Medications: A number of medications prescribed for managing symptoms in MS can decrease alertness and cognitive functioning. It is important to be aware of all medications the person with MS is taking (including supplements and herbals as well as recreational drugs) and have a working understanding of medication side effects.

Psychiatric Conditions: Undiagnosed and untreated or undertreated depression and anxiety are common in MS and can interfere with all aspects of compliance in assessment and treatment as well as activities of daily living and overall quality of life. Referral to a mental health specialist may be necessary if mental health conditions interfere with successful diagnosis and treatment of MS related problems. For the person with MS, inadequately addressed mental health problems may impact the ability to follow through and succeed with management. Clinicians spend significant time with patients and they may be able to alert other members of the treatment team, including physicians, when mood issues appear significant.

Treatment vs Management: It is important for the clinician to be aware when selecting goals to differentiate between treatment and management of deficits. Treatment consists of direct attempts to remediate the impairment itself while management is the employment of techniques/ strategies to compensate the impairment. Both have a role in improving functional abilities in MS.

Individual vs Group Therapy: Individual therapy is preferred, unless treatment goals are best met through a group setting. Therapy goals should target specific outcomes. Goals, treatments and compensatory strategies should be tailored to each person's individual needs and learning style. People receiving treatment and/or caregivers should be actively included in the selection of treatment goals.

Realistic Expectations of Treatment: It is

imperative to educate the person with MS as well as family members and other caregivers regarding expected treatment outcomes. While the clinician may use the term "treatment" in their communication, it is not uncommon for the person and significant others living with MS to hear "cure." At this point, there is no "cure" for MS or the deficits caused by the disease. The goal of assessment and treatment is to help people get some degree of control over the impact MS has in their life and the lives of those around them by enabling them to function more effectively on a daily basis.

Putting it All Together–Case Scenarios

JEFF

AIMS

Jeff is 59-years-old and was diagnosed with MS 4 years ago. Following his diagnosis, he has never had a relapse, only slow progression. Jeff currently walks with a single point cane and is falling at least once a week. He no longer works; he reports that he sleeps poorly, and feels that it is too much of an effort to eat a whole meal. Jeff was referred to PT/OT/ST for assessment and intervention.

HISTORY

Jeff is a 59-year-old male with symptoms dating back 4 years. His initial complaints were paresthesias in both hands and feet, visual blurriness, balance loss and headaches. At that time he was busy caregiving for his ill father and did not seek medical attention. Jeff's symptoms never abated and he finally saw a neurologist one year later after worsening visual complaints and progressive gait problems. MRIs of the brain and spinal cord were obtained as well as a lumbar puncture. The MRI demonstrated multiple periventricular and subcortical lesions with no enhancement. Lumbar puncture revealed positive oligoclonal bands. He was diagnosed with MS at that time.

Since diagnosis Jeff has never had a relapse, only slow progression. He is self-injecting daily with glatiramer acetate, but feels he is getting worse despite this therapy. Jeff currently walks with a single point cane (EDSS 6.0) and is falling at least once a week. He no longer works, reports he sleeps poorly and he feels it is too much of an effort to eat a whole meal.

Jeff was referred to PT/OT/ST for assessment and intervention.

ASSESSMENT

Physical Therapy

- Increased tone bilateral LE's
- Modified Ashworth 2 in hip adductors, quadriceps and plantarflexors bilateral
- T25-FW: with single point cane 18.1 seconds
- 6MWT: only able to complete 4:26, and cover 360 feet before gait deteriorated and became unsafe
- Dynamic Gait Index: 13/24

Occupational Therapy

- 9 Hole Peg Test: right (dominate) 28.1 seconds, left 32.2 seconds
- Modified Fatigue Impact Scale: Physical: 28/36, Cognitive 24/40, Psychosocial 8/8, Total 60/84
- PHQ-9: 18 (moderately severely depressed)
- MoCA: 24/30
- Patient is driving with his LEs during the day. He is modified independent in basic ADLs (shower bench, sits to get dressed and groom, uses microwave for meals when he does eat)

Speech Therapy

- Sustained phonation: 8 seconds
- Rare instances of word retrieval errors during conversational output
- Recommendation for Modified Barium Swallow Study to assess swallowing function



Body Function and Structures

- Sensory abnormality
- Impaired vision
- Pain-headache
- Spasticity
- Impaired motor control
- Fatigue
- Depression
- Poor respiratory support

Activities

- Walking safely and long distances
- Sleep
- Driving
- Eating
- Writing

Participation

- No longer working
- Unable to go to the movies with friends
- Missing out on social invitations to dinner

Personal

• Attitude that assistive devices are "giving in" to the disease

Environmental Factors

- Cost of hand controls for car
- Lack of knowledge of community resources

INTERVENTIONS

- Gaze stabilization exercises
- Stretching/weight bearing for tone management
- Aerobic conditioning to improve CV status and decrease fatigue
- Balance re-training with goals set around items on dynamic gait index which were problematic
- Equipment assessment
- Energy management strategies
- Cognitive retraining
- Fine motor coordination activities
- Functional skills training to include meal prep and eval of current equipment for ADL's

- Respiratory exercises
- Strategies for word retrieval
- Education on symptom management

REFERRALS

- Swallow study
- Local chapter of MS Society for resources/support groups/educational opportunities
- Driving evaluation
- Refer back to MD for assessment of depression/counseling
- Back to MD for medication modifications (antispasmodics, dalfampridine)
- Vocational rehab for possible job retraining or referral for disability determination
- Community referrals adaptive sports, consider a service animal

REHABILITATION GOALS

- Patient will be independent in utilizing spasticity management strategies including a stretching and standing program to increase ease of movement to participate in meal preparation.
- Patient will decrease 25 foot walk to <14 seconds (to increase speed in which to get to the bathroom)
- Patient will ambulate with appropriate assistive device continuously x 6 minutes and cover >500 feet without gait deterioration (to allow him to walk into and out of his medical appointments)
- Patient will step over an obstacle (shoebox height) without loss of balance using single point cane.
- Patient will incorporate energy management strategies independently in his daily routine to allow him to participate in an evening activity once per week without undue fatigue and decrease score on MFIS to <45/84

FOLLOW-UP ASSESSMENT AT 3 MONTHS (Initial assessments noted in parentheses below)

Physical Therapy

- Increased tone bilateral LE's
- Modified Ashworth 1 in hip adductors, quadriceps and plantarflexors bilateral (2)
- T25-FW: with single point cane 12.5 seconds (18.1)

AIMS

- 6MWT: completes 6 minutes of nonstop walking with single point cane and covers 625 feet (360 ft)
- Dynamic Gait Index: 16/24 (13/24)

Occupational Therapy

- 9 Hole Peg Test: right (dominate) 25.0 seconds, left 27.6 seconds (28.1; 32.2)
- Modified Fatigue Impact Scale: Physical: 18/36, Cognitive 20/40, Psychosocial 4/8, Total 42/84 (28/36; 24/40; 8/8; 60/84)
- PHQ-9: 7 (mild depression) (18)
- MoCA: 26/30 (24/30)
- Patient is driving with hand controls. He is now cooking larger meals 2 times per week and freezing the extra.

Speech Therapy

- Sustained phonation: 15 seconds (8)
- Using strategies if word retrieval issues occur

SUMMARY

Functionally, Jeff is driving with hand controls. He is using energy management strategies to manage his tasks, but in particular shopping and meal prep. He is prioritizing his tasks and plans at least one social event out of the house per week with friends. Jeff has applied for disability and also is investigating getting a service dog. Subjectively, he reports that he is in better control of his life, feels less depressed and that he now has things to look forward to. Jeff has transitioned to exercising in a community-based exercise program and will be rechecked by his rehab professionals in 6 months or sooner if any issues arise.



Putting it All Together–Case Scenarios

BEN

Ben is a 49-year-old high school teacher with complaints of imbalance and dizziness lasting a few minutes to all day, and fatigue. He continues to work full-time, but has recently been cutting back on extracurricular activities. Ben was referred by a neurologist for outpatient PT due to dizziness.

HISTORY

February 2015: Ben is a 49-year-old male with complaints of imbalance and dizziness lasting a few minutes to a full day, and fatigue. All symptoms have increased in intensity over the past 2 years. In August 2014, he had an increase of symptoms for 2 weeks which then diminished but never completely resolved. Ben works full time as a high-school teacher and remains independent in all activities and participation, though recently cutting back on extracurricular activities. Ben was referred by a neurologist to outpatient PT due to dizziness. [MRI at this time reported to be normal]

ASSESSMENT

Physical Therapy

- PMH back and neck pain, episodic numbness in arms, tinnitus
- BP 140/90, HR 74 and regular
- Ambulation without assistive device
- T25-FW: 5.3 sec
- TUG: 8.2 sec
- DGI: 20/24
- Posture abnormal with forward head and thoracic kyphosis; weak core
- MMT all extremities 5/5
- Romberg test loss of balance at 10 sec, wide base of support intact

- VOR abnormal in horizontal with diplopia at 15 repetitions; vertical 26 repetitions diplopia
- Oculomotor testing intact
- Dynamic Visual Acuity (DVA objective testing of VOR) abnormal by 3 lines; 10 to 7
- AROM cervical spine: abnormal in rotation left 65 degrees, right 88 degrees; side flexion left 40 degrees, right 30 degrees. Increased c/o dizziness with flexion and c/o paresthesia both hands – resolved with supine cervical distraction

Physical Therapy Differential Diagnosis

Cervical dysfunction with possible cervicogenic vertigo; concern brainstem findings VOR and DVA

INTERVENTIONS

Ben to be seen 1 time/week for:

- Manual therapy C-spine
- Decompression traction C-spine
- Therapeutic exercise focus on core strengthening (Home Exercise Program)
- Neuromuscular re-education with focus on VOR and balance retraining (Home Exercise Program)
- Aerobic exercise (Home Exercise Program)



REHABILITATION GOALS Short Term

- Seated VOR x 30 without increased symptoms
- Bending over in sitting 5x without increased symptoms
- Standing head and eye turns on an uneven surface 5x without loss of balance or increased symptoms
- Stand with 2" base of support eyes closed 30 seconds without loss of balance
- Ambulate on treadmill at self-selected speed x 5 minutes

Long Term

- Sit to stand 5x with eyes closed without imbalance or symptoms
- Bend over in standing with eyes closed 5x without imbalance or symptoms
- Standing head and eye turns on an uneven surface with eyes closed 5x without loss of balance or increased symptoms
- Stand with 2" base of support eyes closed 30 seconds without loss of balance
- Ambulation with head scanning without imbalance or symptoms
- Hold plank 20 sec x 4 for core strengthening
- Ambulate on treadmill at self-selected speed x 10 minutes without symptoms

RE-EVALUATION AT 2 WEEKS

- Improvement in core strength and posture, neck pain 0/10, numbness/paresthesia 0/10, still with dizziness, positive VOR at challenging postures and DVA
- He continues with complaints of fatigue
- Reviewed medications with patient, he is taking 3 meclizine/day per physician who diagnosed hypofunctioning vestibulopathy
- Contacted referring MD and requested MRI of C-spine and posterior fossa, wean off meclizine

RE-EVALUATION AT 4 WEEKS

- Recent MRI per request of PT "a few non-specific very small lesions: parietal and one corpus callosum. Questionable lesion left cerebellar peduncle. MRI of cervical spine suggested a central lesion C3-C5 on sagittal images "
- Ben has been continuing PT treatment with continued improvement in strength, especially core, ambulating on treadmill 10 min at self-selected speed, but requires 2 hand support. Numbness in arms and tinnitus resolved. Back and neck pain 0/10, however still with complaints of fatigue and imbalance. Discussed with patient getting a second opinion. Based on review of most recent MRI report, the PT suggested that the patient obtain second opinion from a neurologist specializing in demyelinating conditions. Ben is in agreement, PT facilitated referral.
- Continued with PT now one time every other week as patient is independent in Home Exercise Program for strengthening, and is progressed every other week with Habituation Exercise and Balance Retraining with visual focus.

FOLLOW-UP AT 6 WEEKS

Ben saw an MS neurologist, obtained new MRIs, and had a spinal tap.

- MRI: T2 hyperintensity posterior aspect of the pons/middle cerebellar peduncle. Hyperintense lesion posterior body of corpus callosum. Two small hyperintense lesions on borders of lateral ventricles. IMPRESSION: Abnormal MRI consistent with MS. Three discrete T2 hyperintense lesions in the cervical cord. (C1, C3-C5)
- Cerebrospinal fluid: mild increase in proteins, IgG within normal limits



• Medical Management: patient received 3 day methylprednisolone and prescribed glatiramer acetate and diazepam

• Physical Therapy Status:

Ben reports less fatigue, had weaned off meclizine and received IV steroids. Neck pain O/10, patient feels 80% better. He is scheduled to return to teaching. Continue PT 1x /week for progressive high-level balance training and core strengthening. Ben is riding a stationary bike at home 15 minutes and continues with home exercise program consisting of planks, resistive band in standing for upper and lower trapezius, standing VOR on uneven surface, ambulation with head scanning with visual focus as needed.

SUMMARY

Ben was seen for 10 visits over 8 weeks. At discharge, he achieved all short and long term goals and returned to teaching full time. Ben continues on glatiramer acetate and attends Post Rehab program 1-2x/week.

Short term goals – all achieved

- Seated VOR x 30 without increased symptoms
- Bending over in sitting 5x without increased symptoms
- Standing head and eye turns on an uneven surface 5x without loss of balance or increased symptoms
- Stand with 2" base of support eyes closed 30 seconds without loss of balance
- Ambulate on treadmill at self-selected speed x 5 minutes

Long Term goals – all achieved

- Sit to stand 5x with eyes closed without imbalance or symptoms
- Bend over in standing with eyes closed 5x without imbalance or symptoms
- Standing head and eye turns on an uneven surface with eyes closed 5x without loss of balance or increased symptoms
- Stand with 2" base of support eyes closed 30 seconds without loss of balance
- Ambulation with head scanning without imbalance or symptoms
- Hold plank 20 sec x 4 for core strengthening
- Ambulate on treadmill at self-selected speed x 10 minutes without symptoms

Putting it All Together–Case Scenarios

CAROLYN

AIMS

Carolyn is a 30-year-old first grade teacher who developed RRMS 3 years ago. She had a relapse one month ago in which she reported diplopia, ataxia with falls, and weakness. She is currently experiencing marked fatigue, changes in her voice (not as loud), loss of left hand dexterity, and leg weakness with intermittent stumbling; she also complains of memory problems and disorganization. Due to her concerns about returning to work, her neurologist referred her for PT/OT/ST.

HISTORY

Carolyn is a 30-year-old right handed woman who developed relapsing remitting MS 3 years ago. She experienced three relapses (left optic neuritis, bilateral leg sensory loss, and mild left sided weakness) in the first few months after her diagnosis, but had felt she was stable until a new relapse one month ago. With her recent relapse Carolyn reported diplopia, ataxia with falls, and weakness. She was seen by her neurologist who also noted complaints of urinary urgency and fatigue. Her past medical history is notable only for right sided hearing loss since childhood.

At her recent neurology visit, Carolyn's general medical examination was normal. Her neurologic exam revealed grossly normal mental status; cranial nerve abnormalities included left optic nerve pallor with a partial afferent pupillary defect, right internuclear ophthalmoplegia, and subtle right lower facial weakness. Her motor exam revealed mild right arm and leg weakness (4/5 power) with right arm and bilateral leg increased reflexes and a right sided Babinski's sign. A moderate sensory loss of proprioception and vibration was present in the legs with intact pinprick and temperature sensation. Rapid alternating movements of the hands were slow, minimally on the right and mildly on the left. Left sided finger to nose dysmetria was also present. She could not perform Romberg's maneuver and could not walk a tandem line.

The neurologist obtained a brain MRI that revealed three new lesions, including an enhancing brainstem lesion. She was treated with three days of high dose corticosteroid therapy and her disease modifying therapy was changed. Baclofen 10 mg three times per day was started for her increased reflexes and oxybutynin 5 mg three times per day was given for reports of urinary urgency. She was referred for PT due to her balance issues.

Carolyn was seen by her neurologist's office for a follow-up one week after completion of steroid therapy. She reported concerns about returning to work as a first grade teacher. She reported marked fatigue, changes in her voice (not as loud), memory problems and disorganization, loss of left hand dexterity, leg weakness, and continues to intermittently stumble. Due to the voice change, she is referred to speech pathology for speech and swallowing evaluation.



ASSESSMENT

- Carolyn was initially seen at the university swallowing center in the radiology department for a modified barium swallow
- During the interview, Carolyn mentioned that she occasionally had difficulty "getting the swallow started"
- Evaluation of intra-oral structures by the SLP noted very dry oral mucous membranes, but was otherwise normal
- There was no history of aspiration pneumonia
- The modified barium swallow was unremarkable for impairment
- Records from her PT evaluation at an outside agency were not available. When asked by the SLP about her PT evaluation, the patient reported difficulty with getting time off work for testing and treatments and affording co-payments for services. Carolyn indicated that she lost the list of exercises she was given by the PT

PLANS & INTERVENTIONS

- Given the xerostomia, the SLP contacted Carolyn's neurologist about the potential for the oxybutynin and baclofen to be decreased in dose or tapered
- Carolyn was educated about how oral dryness may impair speech and swallowing
- The use of over the counter oral lubricants and use of xylitol containing chewing gum was discussed
- Carolyn was advised to avoid alcohol (in beverages and mouthwashes) and smoking
- She was provided with oral and written information regarding swallowing issues in MS with explicit instructions to notify the SLP/MS Center immediately if swallow integrity changes or medically related conditions arise
- Although cognitive complaints were present, formal neuropsychological testing was deferred given the multiple recent medication changes (steroids, baclofen, and oxybutynin)

- Carolyn was encouraged that her strength, stamina, and balance could improve with treatment and was encouraged to contact her PT for a copy of the list of exercises she was provided
- She was counseled that it would likely be beneficial to do these exercises and that the regimen could be refined with a follow-up PT appointment
- Carolyn was directed to educational materials from the MS Society about spasticity and informed that stretching might allow her to decrease or stop the baclofen that was recently started and that her overactive reflexes did not necessarily require use of baclofen or another medication. She was advised to discuss this with her neurologist
- Her fatigue was also addressed. She was directed to educational materials about fatigue and advised of a course being run by the regional MS Society where fatigue management including energy management strategies that were being taught by an OT. It was suggested that individual OT would be useful as well for her dexterity and coordination issues; however she again deferred reporting co-payment and sick time off work issues
- Carolyn reported 3 to 5 sleep interruptions per night due to her overactive bladder symptoms. She was advised to contact her neurologist's office for evaluation and treatment of this and a separate call was made by her SLP to the neurologist's nurse



FOLLOW-UP WITH SLP 3 MONTHS LATER

- Carolyn reported that her voice changes resolved after her oxybutynin was discontinued and her baclofen dose was lowered
- She denied any swallowing issues
- Her concerns about memory and disorganization were much less
- At this time it was suggested that baseline cognitive assessment would be appropriate, however she declined due to concerns about employment implications and spousal reaction if cognitive deficits were documented
- Balance and strength had not returned to normal however she had improved. She had an organized exercise routine. She maintained contact with her PT for periodic assessments and revisions of her balance, stretching and strength exercises
- Carolyn reported that her fatigue was markedly decreased
- Her neurologist had stopped her oxybutynin and referred her to urology for botulinum toxin injections of her overactive bladder wall. She was now able to sleep through most nights without interruption. She continued to utilize the energy management strategies
- Her impaired dexterity continued to impair her ADL's and work. She was encouraged to see OT for evaluation and treatment and to use the regional government's vocation rehabilitation services to obtain needed services and workplace modifications if her medical insurance did not cover these



Appendix–Outcomes Measures^{16,139}

STANDARDIZED GAIT MEASURES RECOMMENDED BY THE CMSC

Timed Up and Go

- The subject is seated in a chair with 2 arm rests, and is instructed at the word 'Go' to rise from the chair, walk as quickly as possible, but safely to a mark 10 feet away, turn around, walk back to the chair and sit down
- The stopwatch is started at the verbal cue 'Go' and stopped when the subject is safely seated in the chair
- Two trials are performed and the faster of the two trials is used for analysis
- Modifications of the TUG include TUG manual, conducted in the same manner except the individual is carrying a full cup of water; and the TUG cognitive, conducted in the same way but doing calculations (such as subtracting 3 from a random number) while performing the task

Timed 25-Foot Walk

- Subjects start at a line on the floor and are instructed to 'walk as quickly as possible, but safely' beyond a second line on the floor (25 feet away)
- Time is recorded in seconds beginning with the first heel strike beyond the start line and stopped at the first heel strike after the second line
- Two trials are performed and the faster of the two trials is used for analysis

Dynamic Gait Index

- This assessment includes 8 walking tests, conducted in a hallway with tape markers on the floor every 5 feet for 20 feet total. The tests include:
 - **1**. Gait level surface
 - 2. Change in gait speed (change at 5 feet marks)

- 3. Gait with horizontal head turns
- 4. Gait with vertical head turns
- 5. Gait and pivot turn
- 6. Step over obstacle
- 7. Step around obstacles
- 8. Steps
- Each of these tests is rated from 0 (severe impairment, inability to perform) to 3 (normal, without challenge), for a total possible score of 24
- A score of 19 or below is indicative of fall risk

2-Minute Walk and 6-Minute Walk

- The subject is instructed to 'walk at your comfortable pace' back and forth along a hallway for 2 (or 6 minutes)
- The maximum distance walked is measured and recorded
- MS-related fatigue may be apparent in this test

MS 12-Item Walking Scale

- This is a patient self-report instrument
- Patients are asked to answer 12 questions about limitations to their walking due to MS over the past 2 weeks, circling a number that best describes their degree of limitation (1, not at all; 2, a little; 3, moderately;
 - 4, quite a bit; 5, extremely)

In the past two weeks, how much has your MS ...

- 1. Limited your ability to walk?
- 2. Limited your ability to run?
- **3.** Limited your ability to climb up and down stairs?
- 4. Made standing when doing things more difficult?
- 5. Limited your balance when standing or walking?
- 6. Limited how far you are able to walk?
- 7. Increased the effort needed for you to walk?



- 8. Made it necessary for you to use support when walking indoors (eg, holding on to furniture, using a stick, etc)?
- 9. Made it necessary for you to use support when walking outdoors (eg, using a stick, a frame, etc)?
- 10. Slowed down your walking?
- **11.** Affected how smoothly you walk?
- 12. Made you concentrate on your walking?

ADDITIONAL MEASURES Modified Fatigue Impact Scale (MFIS)

- The full-length MFIS includes 21 items that assess the effects of fatigue on physical, cognitive, and psychosocial functioning
- Individuals are asked to read each statement and indicate how often fatigue has affected them in this particular way over the past 4 weeks
- Responses include 0: Never; 1: Rarely;
 2: Sometimes; 3: Often; 4: Almost Always

Because of my fatigue during the past 4 weeks ...

- **1**. I have been less alert
- **2.** I have had difficulty paying attention for long periods of time
- **3.** I have been unable to think clearly
- 4. I have been clumsy and uncoordinated
- 5. I have been forgetful
- 6. I have had to pace myself in my physical activities
- **7.** I have been less motivated to do anything that requires physical effort
- 8. I have been less motivated to participate in social activities
- **9.** I have been limited in my ability to do things away from home
- **10.** I have had trouble maintaining physical effort for long periods
- **11.** I have had difficulty making decisions
- **12.** I have been less motivated to do anything that requires thinking
- **13.** My muscles have felt weak
- 14. I have been physically uncomfortable

- **15.** I have had trouble finishing tasks that require thinking
- **16.** I have had difficulty organizing my thoughts when doing things at home or at work
- **17.** I have been less able to complete tasks that require physical effort
- **18.** My thinking has been slowed down
- **19.** I have had trouble concentrating
- **20.** I have limited my physical activities
- **21.** I have needed to rest more often or for longer periods

The abbreviated, 5-item version of the MFIS is scored in the same manner, and includes the following 5 questions:

- **1**. I have been less alert
- 2. I have been limited in my ability to do things away from home
- **3.** I have had trouble maintaining physical effort for long periods
- 4. I have been less able to complete tasks that require physical effort
- 5. I have had trouble concentrating

Berg Balance Scale

- This is a general measure of ability to balance during activity, and thus relevant to walking
- This 20 minute test includes 14 predetermined tasks; each scored from 0 to 4, with 0 being the lowest level of functioning and 4 the highest
- The 14 tasks that comprise the Berg Balance Scale include:
 - **1**. Sitting to standing
 - 2. Standing unsupported
 - **3.** Sitting with back unsupported but feet supported on floor or on a stool
 - 4. Standing to sitting
 - 5. Transfers
 - 6. Standing unsupported with eyes closed
 - 7. Standing unsupported with feet together
 - 8. Reaching forward with outstretched arm while standing
 - **9.** Pick up object from the floor from a standing position



- **10.** Turning to look behind over left and right shoulders while standing
- 11. Turn 360 degrees
- **12.** Place alternate foot on step or stool while standing unsupported
- 13. Standing unsupported one front in front
- **14.** Standing on one leg
- A score of 56 indicates functional balance; and scores below 45 indicate greater risk for falling

The Modified Ashworth Scale (MAS) is used for the assessment of spasticity in persons with MS.

- The MAS is an ordinal scale that runs from 0 to 4 according to the following:
 - **0**: No increase in tone
 - 1: Slight increase in muscle tone, manifested by a catch and release
 - 1+: Catch followed by minimal resistance throughout the remainder of the range of motion
 - 2: More marked increase in muscle tone through most of the range of motion, increased resistance with quick stretch
 - **3**: Considerable increase in muscle tone, passive movement difficult
 - 4: Affected part(s) rigid in flexion or extension

Romberg Test

- The Romberg test is used to evaluate static standing balance
- The individual stands on the floor with shoes off and the feet together
- The person is asked to maintain the position first with eyes open, and then with eyes closed
- The test was described as positive if a person could not maintain their position with eyes closed; an adapted version of the test notes the maximum time for holding the position (eyes closed), with an upper limit of 30 seconds

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