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ADVANCES IN MULTIPLE SCLEROSIS

A Practical Guide to Rehabilitation in MULTIPLE SCLEROSIS

SECOND EDITION

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AUTHORS

Susan Bennett, PT, DPT, EdD, NCS, MSCS
Patty Bobryk, MHS, PT, MSCS, ATP
Carolyn Knoechel, MSc, SLP, R.SLP
Anjali Shah, MD
Christine Smith, OTR/L, MSCS

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Overview

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. In addition, 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 potential severity of outcomes over time, a comprehensive care approach, including disease modifying therapies (DMTs), symptomatic management, mental health support, and rehabilitation may be recommended for patients throughout a lifetime with the disease.

Rehabilitation in MS involves “the intermittent or ongoing use of interdisciplinary strategies to promote functional independence, prevent complications, and enhance overall quality of life.”¹ By nature, rehabilitation focuses on function, emphasizes a multidisciplinary team approach, and bases the treatment plan on goals individualized to the patient’s specific needs. Components of rehabilitation interventions include:

- Education for patients and families
- Assessment of patient needs to inform the treatment plan
- Promotion of behavioral changes (eg, exercise, smoking cessation)
- Task-specific functional training
- Guidance and training regarding the use of assistive devices and technology
- Ongoing assessment to track the impact of rehabilitation efforts and determine when changes are needed

MS rehabilitation is challenging in many ways. Some challenges are related to the nature of the disease—for example, the complexity of factors limiting functional performance, the fluctuating patterns of symptoms and progression over time, and the low tolerance to exertion. Other challenges include lack of awareness among patients, as well as healthcare professionals, of the services available and the benefits of rehabilitation. Barriers sometimes prevent patient access to specialized rehabilitation services. These include scarcity of professionals with expertise in MS rehabilitation, transportation and accessibility issues, and limitations of insurance coverage. In addition, while there is a rapidly growing body of evidence supporting the use of rehabilitation interventions in MS, further research is needed.

This Primer compiles state-of-the-art information about the use of rehabilitation in managing major symptoms of MS, including mobility and related impairments, cognitive limitations, and speech and swallowing disturbances. The focus is on practical topics, with use of case scenarios to illustrate how the information presented can be applied in clinical practice. The hope is that this Primer will provide invaluable tools for clinicians across multiple disciplines, provide direction for accessing and establishing a team-based approach to MS rehabilitation, and increase awareness of the wide variety of rehabilitation interventions and techniques to help optimize patients’ functional status and quality of life.



Patient Case Scenarios *continued on page 48*

CHARLOTTE



Charlotte is 67 years old
with a 35-year history of MS



Listen to Charlotte's MS story

TOMMY



Tommy is 11 years old with a
recent diagnosis of MS



Listen to Tommy's mother
discuss his MS story

ASHLEY



Ashley is 30 years old;
MS diagnosed 3 years ago



Listen to Ashley's MS story



Introduction

THE MS DISEASE COURSE

Multiple sclerosis (MS) is a chronic autoimmune disorder that affects the central nervous system (CNS). More than 2.3 million people worldwide, including nearly 1 million people in the United States, have a diagnosis of MS.^{2,3} The disease is associated with numerous symptoms including visual disturbances, spasticity, weakness, impairment in walking, coordination difficulties, balance problems, tremor, ataxia, sensory problems, and bladder dysfunction.² Various “invisible symptoms”—such as fatigue, depression, and cognitive changes—are also common in MS.

Key features of MS pathology include demyelination, oligodendrocyte loss, and axonal/neuronal injury and loss. While complete understanding of MS disease mechanisms continues to evolve, it is clear that an immune-mediated, inflammatory process involving activated T-cells, B-cells, and antigen-presenting cells contributes to the CNS damage observed. Activated T-cells in the periphery (reactive to CNS proteins, particularly myelin), along with other immune cells, cross a “leaky” blood brain barrier. In the CNS, amplified immune responses attack myelin and oligodendrocytes, causing axonal injury. Resulting lesions in the brain, spinal cord, and optic nerves contribute to the clinical features of MS (Table 1).

Table 1: MS Lesion Sites and Clinical Features of MS⁵

Lesion Site	Clinical Symptoms
Cerebrum; cortex	<ul style="list-style-type: none">• Cognitive deficits• Psychiatric features• Hemiparesis, monoparesis, paraparesis, quadriparesis• Motor impairments, spasticity
Optic nerve	<ul style="list-style-type: none">• Optic neuritis
Cerebellum	<ul style="list-style-type: none">• Postural and action tremor• Limb incoordination• Gait instability• Ataxia
Brainstem	<ul style="list-style-type: none">• Diplopia• Vertigo• Impaired speech and swallowing• Paroxysmal symptoms
Spinal cord	<ul style="list-style-type: none">• Weakness• Spasticity• Diminished dexterity• Autonomic disturbances (sexual, bladder, bowel)• Pain• Nerve disorders/neuropathic pain
Other	<ul style="list-style-type: none">• Fatigue• Temperature sensitivity

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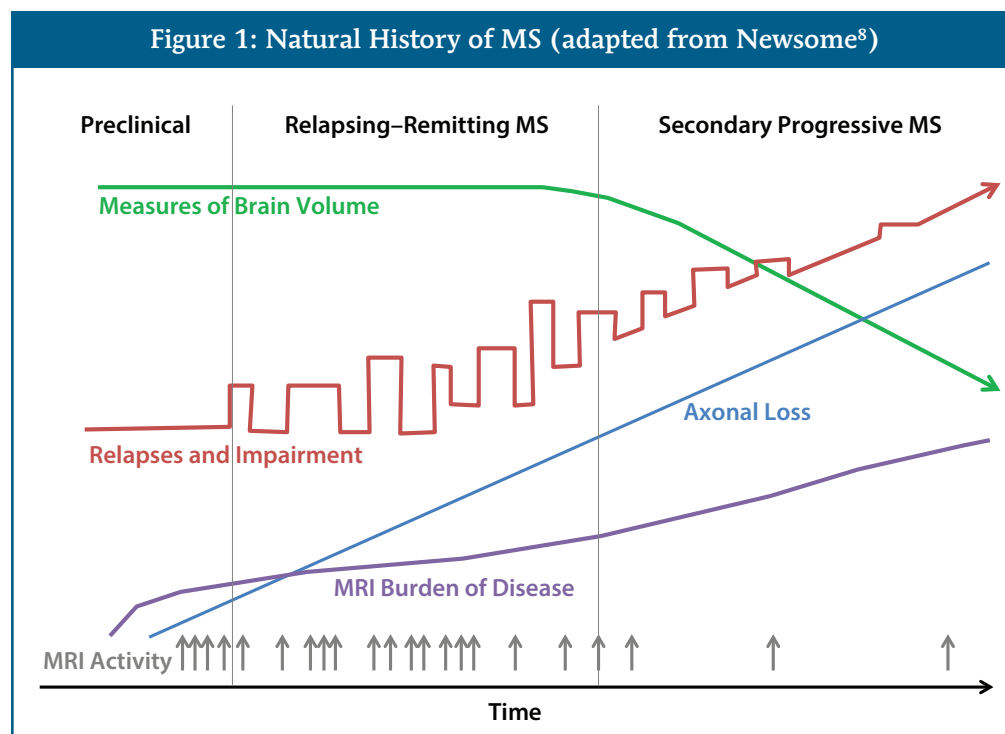


In recent years, an emerging role for B-cells as central to immunopathology of MS has been explored based on observations of reduced MS relapses with anti-CD20 antibody treatment.⁴ B-cells' roles in disease may encompass antigen presentation, T-cell activation, and production of inflammatory cytokines.

The MS disease course varies, with patterns traditionally categorized as relapsing-remitting, secondary progressive, primary progressive, or progressive-relapsing MS.⁶ Refined descriptors for the MS disease course were updated in 2013 to include measures of clinical relapse rate, imaging findings, and disease progression to describe overall MS activity.⁷ Core phenotypes of relapsing and progressive disease were retained, and clinically isolated syndrome (CIS, defined as an initial neurological disturbance lasting more than 24 hours, with signs and symptoms consistent with an inflammatory demyelinating disorder that could be MS) was added.⁷ CIS and relapsing forms

of MS (RMS) 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).⁷ 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*.⁷ In this context, "progression" refers to accumulation of disability.

Most patients with MS (~85%) initially have a relapsing form of the disease, characterized by distinct relapses followed by periods of remission with minimal or no increase in disability between attacks. As illustrated in **Figure 1**, early stages of disease are associated with increasing inflammatory activity, as evidenced by relapses and MRI activity.⁸ Over time, many patients with RMS transition to secondary progressive MS (SPMS), with progressive worsening of neurologic function and accumulation of disability over time.



In SPMS, inflammatory and MRI activity declines, axonal loss and disability increase, and brain atrophy occurs. Some patients with MS have progressive disease from the onset; in such cases functional decline is steady and unpunctuated by acute attacks or periods of remission. Studies conducted before



the availability of DMTs showed that 50% of patients progress from RMS to SPMS within about 10 years, and about 90% progress within 25 years.⁹ There is general agreement that DMTs may alter or delay progression to SPMS, but supporting evidence is, to date, limited.

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, work and social participation, and overall quality of life. MS profoundly affects patients, their families, and the community at large.¹⁰

COMPREHENSIVE MS CARE

A multidimensional, comprehensive care approach is advocated to promote positive outcomes for patients with MS.¹⁰ Comprehensive care is patient-centered and provided by a multidisciplinary team that adopts a whole-person orientation. The patient is viewed as an integral team member who is empowered to actively participate in care planning and self-care actions. In MS, comprehensive care encompasses relapse management, DMTs, symptom management, psychosocial support, and rehabilitation.

While the focus of this Primer is on rehabilitation, a brief review of pharmacologic treatment for MS (relapse management, DMTs, and symptomatic therapy) is included for reference.

Relapse Management

In RMS, a relapse—also known as an exacerbation or a flare—are sudden attacks of worsening or new symptoms that occur in the absence of fever, infection, or environmental stimuli (eg, heat) and are consistent with inflammation and demyelination.^{11,12,13} By definition, relapses in RMS are at least 24 hours in duration and separated from a previous relapse by at least

30 days,^{12,13} and they may last several days to weeks. Medical management often involves short-term (3-5 days), high-dose, intravenous or oral corticosteroids. Adrenocorticotrophic hormone (ACTH) is FDA-approved for MS relapses, but is infrequently prescribed for this purpose because it is expensive. Plasmapheresis may be used as second-line treatment for steroid-resistant relapses, as may intravenous immunoglobulin (based on limited evidence).¹⁴

Disease Modifying Therapies

The number of FDA-approved DMTs for patients with MS has grown considerably over the last 2 decades. In addition, 2 very recent (2019) approvals include siponimod (for relapsing disease to include CID); and cladribine (for relapsing disease to include active secondary progressive disease).¹⁵

DMTs currently approved for patients with RMS are summarized in **Table 2**. These agents vary by mechanism of action, mode of administration, dosing frequency, side effect profiles, and monitoring recommendations. Demonstrated benefits of DMTs include reductions in relapse rate, MRI activity, and disability progression.^{5,8} Choosing a specific DMT should involve consideration of clinical benefits, as well as patient preference, disease course, risks of adverse events associated with treatment, lifestyle, work needs, and the presence of medical and/or psychiatric comorbidities. Based on a study of 7,009 participants in the North American Research Committee on Multiple Sclerosis Registry showing that 91% of patients prefer to be highly involved in decisions about their treatment, DMT choices should preferably be arrived at through a process of patient-centered or shared decision-making (SDM).¹⁶ SDM has also been linked to improved DMT adherence.¹⁷

Symptom Management

Medical management of symptoms is part of comprehensive care to help reduce their negative impact of MS on activities of daily living and

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Table 2: Disease Modifying Therapies for MS¹⁵

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 proinflammatory cytokine production, down regulation of antigen presentation, inhibition of lymphocyte trafficking into the CNS
IFNβ-1a (Avonex®)	1996	30 mcg, IM, QW	
IFNβ-1a (Rebif®)	2002	22 mcg or 44 mcg, SC, TIW	
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 Th2 cells; and inhibition of antigen-specific T-cell activation
Glatiramer acetate (Copaxone®)	2014	40 mg, SC, TIW	
Glatiramer acetate (Glatopa™)	2015	20 mg, SC QD	
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 α4β1-integrin mediated adhesion of leukocytes to VCAM-1 on vascular endothelial 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	Anti-CD20 B-cell depletion
Ocrelizumab (Ocrevus®)	2017	Loading dose, 300 mg IV x 2, separated over two weeks, then 600 mg IV q6 months	



Table 2: Disease Modifying Therapies for MS¹⁵ (cont.)

Treatment	Approval	Dose & Route of Administration	Mechanism of Action
Oral			
Fingolimod (Gilenya®)	2010	0.5 mg, PO, QD	Sphingosine 1-phosphate receptor modulator; prevents egress of lymphocytes from lymphoid tissues into the periphery
Siponimod (Mayzent®)*	2019	2 mg/day (after 5-day titration), PO	Selective sphingosine-1-phosphate receptor (subtypes 1 and 5) 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
Cladribine (Mavenclad®)†	2019	PO, twice annual, weight based dosage: 3.5 mg/kg divided into 2 treatment cycles (1.75 mg/kg per treatment course)	Thought to have cytotoxic effects on B- and T-lymphocytes through interference with DNA repair
<p>*Also FDA-approved for treatment of clinically isolated syndrome and active secondary progressive disease. †Also FDA-approved for treatment of active secondary progressive disease.</p>			

overall quality of life. Pharmacologic agents used for the medical management of MS symptoms are summarized in **Table 3 (page 9)**. (Note: uses of some of the agents shown are off-label/not FDA-approved).

Rehabilitation in MS

Rehabilitation is an integral part of comprehensive MS care. The goals of MS rehabilitation are to maintain and/or improve functioning and reduce the impact of the disease on personal activities, social participation, independence, and quality of life.²⁰ The approach

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Table 3: Symptomatic Medications for Patients with MS^{18,19}

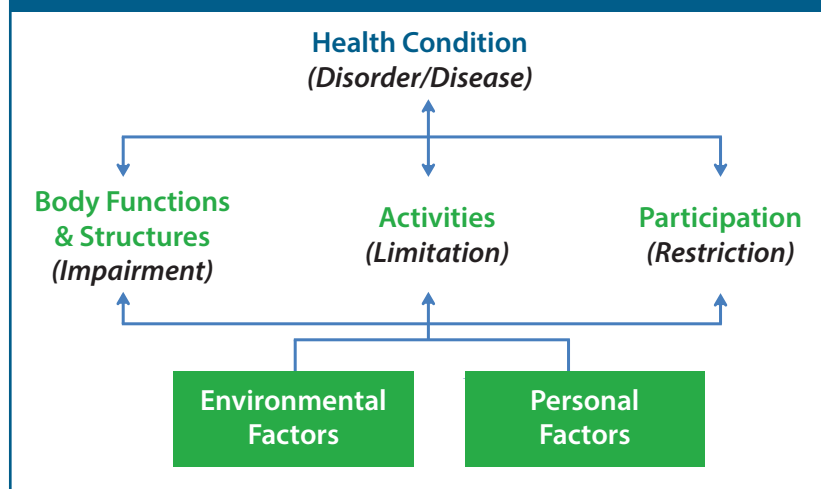
Symptom	Pharmacologic Agent
Fatigue	Amantadine, modafinil, armodafinil, methylphenidate, amphetamine/dextroamphetamine
Spasticity	Baclofen (oral or intrathecal), tizanidine, botulinum toxin type A, diazepam, dantrolene, clonazepam, gabapentin, phenol
Gait problems	Dalfampridine
Pain	Gabapentin, pregabalin, 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, botulinum toxin type A, tamsulosin
Bowel symptoms	For constipation: psyllium, calcium polycarbophil, magnesium oxide, polyethylene glycol, lactulose, senna, docusate sodium, lubiprostone, bisacodyl, fiber; for bowel incontinence: loperamide
Sexual dysfunction	For males: sildenafil, vardenafil, tadalafil, vardenafil, avanafil
Depression	Selective serotonin reuptake inhibitors, serotonin norepinephrine reuptake inhibitors, bupropion

to rehabilitation in MS recognizes the dynamic interaction between disease, environmental factors, and personal factors, as embodied in the World Health Organization's International Classification of Functioning, Disability, and Health framework (Figure 2).²¹

When providing MS care, rehabilitation professionals need to consider patients' overall functionality and ability to participate in their home environment, community, and professions—with attention both to limitations early in the diagnosis and those that may emerge long term. Often, rehabilitation is coordinated by a neurologist specializing in the diagnosis and management of MS. Ideally, it is provided at single rehabilitation or MS

Center, and requires a team effort that includes—in addition to the patient—physiatrists, physical therapists (PTs), occupational therapists (OTs), speech/language pathologists (SLPs), vocational rehabilitation counselors, neuropsychologists, and

Figure 2: WHO International Classification of Functioning, Disability and Health²¹





Listen to Patricia Bobryk, MHS, PT, MSCS, ATP discuss shared decision-making and its role in MS rehabilitation



Table 4: Roles of MS Rehabilitation Specialists²²

Specialist	Role
Physiatrist	<ul style="list-style-type: none">• Direct and coordinate delivery of care for persons with MS• Manage treatment of MS symptoms as well as common disorders secondary to MS (eg, fatigue, gait, spasticity, neurogenic bowel and bladder issues)
Physician assistant	<ul style="list-style-type: none">• Manage treatment of MS symptoms as well as common disorders secondary to MS (eg, fatigue, gait, spasticity, neurogenic bowel and bladder issues)
Physical therapist	<ul style="list-style-type: none">• Evaluate and address the body's ability to move and function, with particular emphasis on walking, strength, balance, posture, fatigue, and pain
Occupational therapist	<ul style="list-style-type: none">• Provide training in energy conservation techniques and the use of adaptive tools and devices to simplify tasks at home and work
Speech-language pathologist	<ul style="list-style-type: none">• Evaluate and treat problems with cognitive communication, speech, and/or swallowing—all of which can result from MS-related damage in the CNS
Vocational rehabilitation specialist	<ul style="list-style-type: none">• 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
Neuropsychologist, other mental health professional	<ul style="list-style-type: none">• Evaluate and treat changes in ability to think, reason, concentrate, or remember
Nurse, nurse practitioner	<ul style="list-style-type: none">• Provide education and referrals, assist with coordinating care, promote adherence to DMT and rehabilitation regimens, help prevent symptoms and exacerbations
Social worker	<ul style="list-style-type: none">• Provide counseling and education to support coping with MS-related problems, assist with navigating access to rehabilitation services and resources needed to continue functioning at work and at home, knowledgeable about health insurance, Medicare and Medicaid, and disability coverage
Registered dietitian	<ul style="list-style-type: none">• Provide nutritional counseling through diet management to promote good nutrition• Develop individual care plans for each person with MS to promote good nutritional status

registered dietitians. Nurses, physician assistants (PAs), and social workers may also be involved in MS rehabilitation. The roles of these rehabilitation team members are summarized in [Table 4](#).

Effective communication with the patient and among the members of the rehabilitation team is critical to ensuring coordination of care that efficiently and optimally addresses all of the

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patient's needs. Such communication can be facilitated by:

- Frequent, routine opportunities for free-flowing sharing of ideas
- Transfer of knowledge and skills across discipline boundaries, without territorialism
- Commitment to collaboration
- Ability to ask for help without feeling diminished or intimidated (mutual respect and trust)
- Shared decision-making with the patient and care partner

Having all team members within a single department or facility (such as rehabilitation center or MS center) enhances the flow of communication. Challenges arise when members of the team are at various locations, or even in different organizations or hospital systems. Regardless, creating strong working relationships and a seamless communication process with the various team members is essential to coordinating care.

Tools and strategies to facilitate communication include virtual team meetings, electronic medical records, encrypted email communication, faxes, and traditional paper documentation. Ideally, communication within the network can be facilitated by a point person, such as a case manager or other care coordinator.

Patients with MS have unique needs due to the long term, chronic, progressive nature of the disease and the variability and unpredictability of symptoms. Rehabilitation in MS is a dynamic and cyclical process (**Figure 3**), and MS rehabilitation professionals often have long-term—sometimes lifelong—relationships with their patients. They play critical roles in empowering patients to manage symptoms that affect physical and cognitive functioning, maintain life roles, and promote active exercise and other healthy habits to help maintain health and wellness.

A variety of standardized measures are used for evaluation and ongoing assessment of persons

with MS; commonly used measures are listed in **Table 5** and found in **Appendix 1**. Due to the dynamic nature of the disease, these tools provide structured ways to gauge, over time, the extent to which a patient is able to perform activities of daily living, sustain vocational roles, and maintain independence. They are employed periodically to help develop and revise treatment goals, identify the need for treatment modification, and measure results of specific interventions. The use of many of these measures in the context of rehabilitation will be developed further in sections to follow. The Academy of Neurologic Physical Therapy (affiliated with the American Physical Therapy Association) has made recommendations about use of these tools.²⁴

Figure 3: The Rehabilitation Cycle in MS^{Adapted from 23}

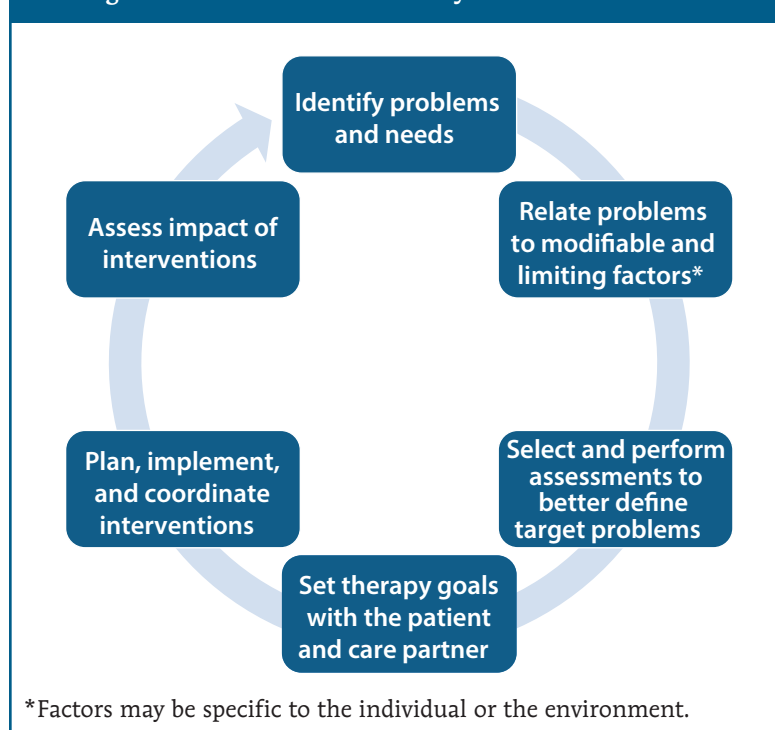




Table 5: Standardized Measures Used in MS²⁴

- 2-Minute Walk
- 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)

All professionals involved in the care of persons with MS should develop a keen awareness of signs and symptoms suggesting 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 infections can exacerbate symptoms. Frequent re-evaluations can help to identify such changes and facilitate appropriate and timely interventions and adjustments.

REHABILITATION CONSIDERATIONS FOR SPECIAL POPULATIONS

Pediatric MS

Up to 10% of all individuals with MS are less than 18 years of age.²⁵ Most patients (>90%) with pediatric MS have the relapsing type of disease. Although symptoms in children are similar to those in adults, children have a higher incidence of seizures and cerebellar signs and a higher T2

lesion burden, suggesting a more inflammatory pathology.²⁶ Children with MS may have more frequent relapses but an overall slower disease course; however, because the duration of MS may be many years longer over the lifespan, accumulated disability over time may be greater. Poor prognostic indicators for pediatric MS include relapses associated with brainstem involvement, progressive course at onset, and number of relapses in the first 2 years.^{27,28} MS in children and adolescents may impact academic performance, self-image, and relationships with family and peers.²⁹

Currently, the only FDA-approved treatment for pediatric MS is fingolimod (for treatment of relapsing forms of MS in children 10 years and older).¹⁵ However, many of the DMTs approved for adults are prescribed off-label for children with MS; they are helpful in managing the disease, and should be started immediately upon confirmation of an MS diagnosis.³⁰ Rehabilitation is essential and should be provided in an age-appropriate environment with interventions that can aptly engage the child. Involving and engaging the family is also crucial, as is collaborating with the school system to ensure appropriate accommodations and academic success. A comprehensive approach is needed to manage symptoms and long-term use of DMTs; provide social and school support, intermittent cognitive assessments, and mental health assessments and treatment; and promote a healthy lifestyle.^{10,22} Whenever possible, pediatric patients should receive care in specialized centers with experts in the pediatric field.²² The United States Network of Pediatric Multiple Sclerosis Centers lists locations and associated experts (<http://www.usnpmsc.org/clinicalcenters.html>).

Aging with MS

Management of elderly patients with MS is an emerging area of need. The prevalence of older adults with MS is on the rise, in part due to the aging of the population as a whole, and because advances in managing MS and comorbid

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conditions (in particular, vascular comorbidities) has increased the lifespan of individuals with MS. In addition, though unusual, individuals may be diagnosed with MS after age 50 years (termed late-onset MS or LOMS) and even after age 60 years (termed very late-onset MS or VLOMS).³¹

Management of MS in the elderly has some unique challenges. Older individuals with MS tend to be more physically disabled and are more likely to have progressive disease. They have more age-related and MS-related comorbidities than their younger counterparts,³¹ and distinguishing symptoms of MS from those of normal aging can be tricky. In addition, in later life, the inflammatory aspects of MS tend to recede, giving way to neurodegenerative disease. While DMTs have been shown effective for preventing relapses, many are ineffective in limiting the accrual of disability seen with progressive disease.^{31,32} Older individuals also may be more sensitive to side effects of DMTs due to decreased ability to process metabolites.³³

Symptoms often reported in older adults with MS include diminished muscle strength, weakness, fatigue, reduced sensation, balance issues, visual changes, changes in bowel and bladder function, cognitive impairment, and sleep disturbances.³¹ All of these overlap with symptoms of the normal aging process. Distinguishing symptoms of aging from those of worsening MS is critical, as is considering the possibility of other neurological disorders that are common with advancing age, and may mimic MS.³¹

As for any other population, management of older individuals with MS requires a multidisciplinary approach. Given their likely physical limitations, they may need assistance with daily activities. They may require assistive devices, which can help maintain mobility and independence and reduce fall risk. Participation in educational programs and support groups can be beneficial. Clinicians should screen for depression and anxiety, which

are common in MS population, including those aging with MS.³¹

Pregnancy and MS

MS is a disease that predominantly affects women of childbearing age. Fortunately, for women who wish to become pregnant, MS does not seem to affect fertility, nor does it seem to increase miscarriages, stillbirths, pregnancy complications, congenital malformations, or cesarean deliveries.³⁴ However, vaginal delivery may be impaired in women with greater disability, especially when the lower body is affected.

Current standard of care is to avoid DMTs during pregnancy and conception, although some (IFN β , glatiramer acetate) are likely safe.³⁵ There is strong evidence that pregnancy has a short-term protective effect in patients with MS, with fewer relapses, especially during the third trimester.³³ Long-term benefits of pregnancy have also been observed, specifically in delaying wheelchair dependence, reducing risk of disability, and preventing disability accrual.^{36,37,38} However, in the first 3-6 months post-partum, relapses tend to increase; risk of relapse is about 20-40% higher during this period.³² Exclusive breastfeeding and breastfeeding-associated amenorrhea offers some protection from relapses, but women often forgo breastfeeding to restart DMT.³⁹

Rehabilitation has a significant role during and after pregnancy in patients with MS. Hormonal changes and changing body morphology during pregnancy can cause increased joint laxity and pain; physical therapy and exercise can help manage these symptoms. Assessing gait and mobility safety is imperative, especially as the pregnancy progresses, and assistive devices may be required to maintain mobility and reduce fall risk. Plans for care of the baby (including managing mobility with the baby) and resumption of DMTs and symptomatic therapies should be reviewed before delivery.



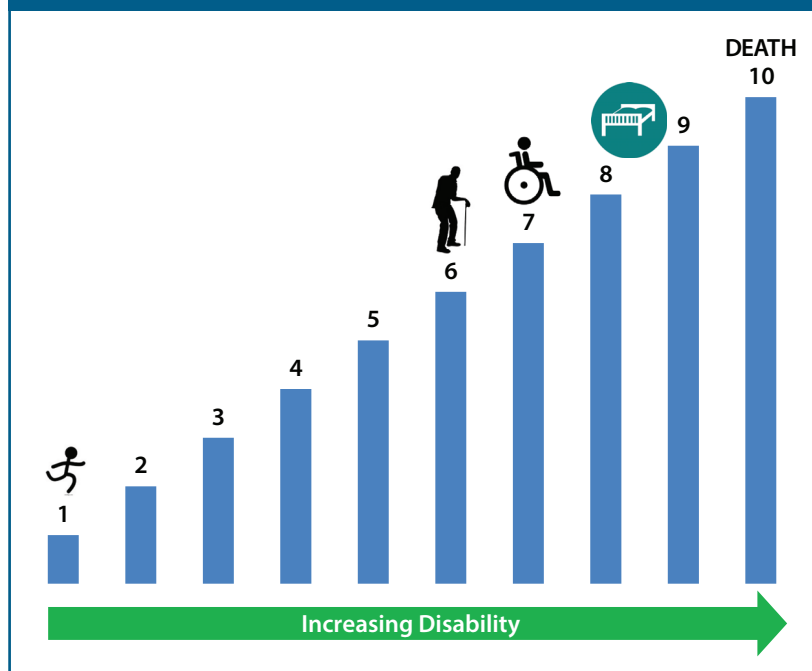
Mobility

Mobility is a critical dimension of independence, and loss of mobility is indicative of disease progression in MS. People with MS rate ambulation in particular as their most important function,⁴⁰ yet an estimated 75% have walking disturbances, with some limitations present early in the disease course.⁴¹ Primary symptoms of MS such as weakness, spasticity, balance and coordination difficulties, fatigue, and sensory deficits can impair mobility, as can as cognitive dysfunction, bowel and bladder issues, and pain. Limitations in mobility may directly impact participation in the community, occupational pursuits, and family activities. Further, increasing disability and reduced mobility can affect health generally, and may contribute to skin breakdown, risk of pneumonia, and cardiovascular disease.

Weakness, spasticity, and impaired balance can impact mobility in persons with MS. Weakness and spasticity are associated with gait deviations such as circumduction, vaulting to clear a weak leg, genu recurvatum, foot drag, shuffling feet, lateral trunk flexion, and decreased push-off/acceleration. When developing rehabilitation plans for patients with MS, the inter-relatedness of multiple factors affecting mobility should be considered with all assessments.

Numerous measures can be used in clinical practice to evaluate mobility in MS. One is the Expanded Disability Status Scale (EDSS) (Figure 4). Higher scores on this assessment correspond to greater limitations in mobility. For example, a score of 6.0 indicates a need for unilateral device for ambulation, 7.0 indicates a need for a wheelchair, and 8.0 indicates restriction to a bed or chair.⁴²

Figure 4: Expanded Disability Status Scale (EDSS)⁴²



Measures for evaluating mobility in ambulatory patients include the Timed 25-foot Walk (also part of the MS Functional Composite), the Timed Up and Go (TUG), 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 that is strongly correlated with the EDSS.^{43,44} 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, starting with the first heel strike beyond the start line and stopping at the first heel strike beyond the second line. Two trials are performed, and the faster trial is used for analysis.

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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, walk as quickly but safely as possible 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 reseated. Two trials are performed, with the faster trial used for analysis. Modifications of the TUG incorporate other tasks while walking; for example, the TUG (Manual) involves carrying a full cup of water and the TUG (Cognitive) involves performing mental calculations (such as subtracting 3 from a random number).

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 also 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 on a 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 maximum possible total score of 24. A score of 19 or below indicates an increased 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).⁴⁴

Mobility assessments are also conducted in patients with EDSS scores of 7.0 and above. Such patients may have difficulty with core

muscle strength, posture, and balance. Some muscle groups can become elongated and weak, while others can shorten and become weak. Evaluations appropriate for this patient population include the Five Times Sit-to-Stand Test (measured as time to complete this task); the Standing Tolerance (timed up to a maximum of 2 minutes); and the Functional Reach Test (measured as how far the patient can reach in front, to the left, and to the right without loss of balance). The Functional Reach Test can be performed sitting or standing; when performed standing, it can also provide an indicator of fall risk.

WEAKNESS

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, and even paralysis. Primary MS weakness is most often 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 by using other muscle groups. From poor positioning, muscles can become elongated and weak, (along with development of contractures, tissue changes in the muscles, pain, proprioceptive loss, and tendonitis). These changes contribute to the patient’s inability to use their muscles appropriately. Spasticity, ataxia, and an imbalance between agonist and antagonistic muscles also contribute to secondary weakness in MS.

Weakness can be assessed using the Manual Muscle Test, which can be performed in gravity and gravity-eliminated positions. Procedures and scoring are summarized in [Table 6](#).



Table 6: Manual Muscle Testing Procedures: Key to Muscle Grading⁴⁵

Function of the Muscle	Grade	
Normal strength	5	Normal
Uncertain muscle weakness	5-	
Inability to resist against maximal pressure throughout range of motion (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

SPASTICITY

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 up to approximately 80% patients with MS,⁴⁶ and occurs across the spectrum of disease progression, from early on, at lower EDSS scores through advanced stages of disease. Factors that increase spasticity include relapses, infections (such as a urinary tract infections), fatigue, excessive activity, pain, stress, anxiety, and constrictive clothing. Potential consequences of spasticity include increased energy cost of movement (which can worsen fatigue), impairments in gait and transferability, poor posture and positioning in a chair, safety issues (for example, a patient unable to sit properly may

slide forward); development of contractures, pain, discomfort, sleep interruption (especially with spasms that occur in the lower extremities during sleep), skin breakdown in patients unable to reposition themselves, interference with hygiene and self-catheterization, sexual difficulties, and breathing difficulties.

The Modified Ashworth Spasticity Scale is used for the assessment of spasticity in persons with MS.⁴⁷ This is an ordinal scale that runs from 0 to 4 according to the following:

- 0** Normal tone, no increase in tone
- 1** Slight increase in muscle tone, manifested by a catch and release or by minimal resistance at the end of the ROM when the affected part(s) is moved in flexion or extension
- 1+** Slight increase in muscle tone, manifested by a catch followed by minimal resistance throughout the remainder of the ROM

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- 2 More marked increase in muscle tone through most of the ROM, increased resistance with quick stretch
- 3 Considerable increase in muscle tone, passive movement difficult
- 4 Affected part(s) rigid in flexion or extension

BALANCE

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.

Physiological components necessary for balance are adequate strength and postural control; visual, vestibular, and somatosensory processing; and integration and processing of this information for appropriate equilibrium reactions, righting reactions, and upright postural control to support functional sitting, standing, and ambulation. In people with MS, weakness or spasticity in lower extremities, ataxia, weak trunk control, sensory deficits, internuclear ophthalmoplegia (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 for minimal to no spasticity)
- **Somatosensory** (proprioception, kinesthesia, and localization)
- **Visual** (smooth pursuits, saccades, convergence)
- **Vestibulo-ocular reflex (VOR) and cancellation**
- **Vestibular** (benign paroxysmal positional vertigo [BPPV])

Assessment of posture and trunk strength involves examining the patient's static and dynamic posture while sitting and standing. Righting reactions should be evaluated when the postural alignment is challenged. Extremity strength can be tested with manual muscle testing. Somatosensory assessments include proprioception, kinesthesia, and localization. Proprioception can be assessed as follows: with the patient in a supine position and eyes closed, the rehabilitation professional moves a joint to a stationary position, then asks the patient to match that position with the opposite extremity. Similarly, kinesthesia can be evaluated by asking the patient to mimic the opposite extremity while movement is taking place. For localization, the patient, with eyes closed, is asked to give (verbally or by pointing) the location of the examiner's touch.

Ocular motor deficits in MS include INO and nystagmus and may cause diplopia, oscillopsia, blurred vision, and reading fatigue.⁴⁸ These abnormalities are often attributed to brainstem or cerebellar lesions.⁴⁹ Visual testing can be conducted with the patient in a seated position, with the examiner moving a finger or other object in front of 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, while the examiner is watching for smoothness of eye movements
- **Saccades:** The patient moves his or her eyes between 2 points, while the examiner is assessing velocity, accuracy of movement, and ability of the eyes to move together
- **Convergence:** The patient follows the examiner's finger as it moves in toward the patient's nose (no closer than 6-8 cm away).



The patient is asked if his or her vision is blurred or doubled, and the examiner is watching for 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 moving his or her head side to side in a "no" movement, then up and down in a "yes" movement. The examiner is looking for the patient's ability to maintain gaze and asking about blurred vision, double vision, or dizziness
- **VOR cancellation:** The patient is asked to focus on the examiner's nose, while the examiner moves the patient's head. The examiner is testing the ability of the patient to move the eyes together with the head, cancelling the VOR.
- **Dynamic visual acuity:** Keeping his or her head still, the patient is asked to read the lowest line he or she can clearly and accurately see on a Snellen chart. The examiner then passively shakes the patient's head at approximately 2 Hz and again asks the patient to read the lowest line possible on the Snellen chart. A difference of 3 lines or greater between these 2 tasks 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 type of 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). For the head thrust test, the patient (while seated) is 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 30 degrees from midline. The patient's inability to maintain

fixation on the examiner's nose indicates a defective VOR. The head thrust may also be used to determine the presence of vestibular neuritis, an inflammation or infection of cranial nerve VIII (vestibulocochlear).

The **Berg Balance Scale** is useful for providing a more general assessment of balance with relevance to need for ambulatory assistive devices.⁵⁰ It includes 14 predetermined tasks, listed below, that together require about 20 minutes to complete.

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 1 leg

Each task is scored from 0 to 4, with 0 being the lowest level of functioning and 4 the highest. A score of 56 indicates functional balance. Scores below 45 indicate a greater risk of falling. Scores can also be broken out to inform the need for an assistive device. Scores of 0-20 indicate a high fall risk with ambulatory assistive device required. Scores of 21-40 indicate a moderate fall risk, warranting consideration of an ambulatory assistive device. Scores of 41 and higher indicate a low fall risk, supporting safe independent ambulation.⁵⁰

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FATIGUE

Fatigue in MS is not well understood, but is thought to arise from a combination of primary disease mechanisms such as inflammation, demyelination, and axonal destruction, with disease-related factors such as sleep disturbance, depression, and lack of exercise. Up to 90% of patients with MS report fatigue, and most consider it to be one of their most troublesome symptoms.^{51,52,53} Fatigue may worsen perception of other MS symptoms, and several studies have documented its negative impact on quality of life.^{51,54} In addition, a recent study has linked higher levels of fatigue with greater impairments in performance-based and self-reported functional mobility.⁵⁵

Exploring the impact of fatigue on function may be helpful when evaluating and designing appropriate therapy regimens. A useful tool for this purpose is the **Modified Fatigue Impact Scale (MFIS)**, a 21-item self-report assessment (see below), requiring 5-10 minutes to complete.⁵⁶ Items on the MFIS can provide a total score or may be aggregated into cognitive items (1, 2, 3, 5, 11, 12, 15, 16, 18, 19), physical items (4, 6, 7, 10, 13, 14, 17, 20, 21), and psychosocial items (8 and 9).

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.

Individuals are asked to rate how often each item below has occurred because of their fatigue on a scale of 0 (never) to 4 (almost always) over the previous 4 weeks. Higher scores overall or on any subscale indicate a greater impact of fatigue on activities.

An abbreviated version of the MFIS is scored in the same way, and includes the following 5 items to quickly and reliably rate fatigue:⁵⁷

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.

THERAPEUTIC APPROACHES TO IMPROVE MOBILITY IN PATIENTS WITH MS

Consideration of how changes in mobility impair daily activities, home management, and participation in social and occupational functions is an important part of comprehensive care in MS. A wide range of functions and activities may be affected, including supine-to-short sit; static and dynamic balance while sitting (eg, for hygiene activities or meals); static or dynamic balance while standing (eg, for hygiene activities, food preparation, and cleanup); transfers on and off all surfaces (eg, toilet, seat, bed); ambulation; and



stair climbing. Participation considerations include ambulation on uneven surfaces and inclines or up and down curbs; ability to cross the street with head scanning and gait velocity; ambulation in the community with an assistive device; and mobility in the community with a wheelchair or scooter.

As part of establishing a treatment plan to improve mobility, the patient and rehabilitation therapist should identify goals and priorities together. The therapist's role is critical in helping the patient determine realistic goals while sustaining self-esteem and hope. Goals must be attainable, measurable, and functionally focused. The plan should be designed to achieve the patient's goals and should include exercises and activities that are enjoyable, varied, and task-specific. Whenever possible, exercises should include endurance or aerobic conditioning. Resources should be considered for home and community-based treatment plans. This individualized approach can help to optimize all aspects of life function and maximize participation in everyday activities.

Identifying underlying impairments that limit a patient's function, such as strength, sensation, balance, coordination, or spasticity, will help to inform the treatment plan. Task-specific training provides opportunities to practice activities that present difficulties, work through progressive challenges, and modify the environment to gain function, as needed.

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 can promote neuroplasticity. Coordination activities may include repetitive practice of a functional task, such as reaching for the toothbrush, but slowly and in a shortened range of movement. A light weight can be added to the wrist to enhance kinesthetic awareness of the movement. The patient should practice the task in a seated position, so that balance is not challenged. As accuracy of the movement improves, the patient can first increase the distance moved and then increase the rate of movement.

Balance strategies to address INO, spontaneous nystagmus, and positive VOR include visual focusing. For example, having the patient focus on a stationary target while moving from sitting to standing can help override distorted information from vestibular nuclei and promote postural stability. This activity can be progressed to dynamic standing. This involves having the patient stand with 2-hand support, visually focusing while turning the head to the left and the right. Next, the patient first removes 1 hand support, then the other as the brain reorganizes with activation of silent synapses to complete the task.

Recently, a landmark study demonstrated benefits of a multifaceted vestibular intervention program, Balance and Eye-Movement Exercises for People with Multiple Sclerosis (BEEMS), in patients with MS and balance impairments.^{57a} The study showed that compared to control patients who received no intervention, patients who received BEEMS had significant improvements not only in balance, but also in dizziness and fatigue.



Listen to Susan Bennett, PT, DPT, EdD, NCS, MSCS discuss key findings from the BEEMS study



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Pharmacologic agents 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, such as oral baclofen or tizanidine. If tolerability to these drugs is challenging (side effects may include lethargy and fatigue), or when spasticity is more diffuse or generalized, intrathecal baclofen (delivered via an implanted pump with a catheter) may be appropriate. Injection of botulinum toxin A into specific muscle groups is another option when spasticity is more focal or localized to 1 or 2 muscle groups. Dalfampridine, an oral potassium channel blocker, has been shown to improve walking ability in patients with MS and mild-to-moderate walking impairment.^{58,59} It is important to note that any

medication for symptom management should be managed in 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 for many patients essential to maintaining or improving mobility. When working with patients to select such devices, it is important to recognize current needs and also anticipate future needs (possibly as long as 5 years out). Most insurance companies will not consider payment for a new product sooner, unless the patient has demonstrated significant permanent changes. [Table 7](#) summarizes various mobility devices of benefit to patients with MS.

Table 7: Mobility Aids for Individuals with MS

Device	Indications for Use	Types
Canes	<ul style="list-style-type: none"> • Can provide a small measure of balance • Not meant to support 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 while standing tall with arms relaxed at the sides 	<ul style="list-style-type: none"> • Single point • 4-point • Small-based quad • Large-based quad
Crutches	<ul style="list-style-type: none"> • Provide greater stability when weakness and imbalance is more significant • Can use one or both depending on how the patient feels • Loftstrand crutch: cuff allows the hand to be free and prevents dropping the crutch • Hand piece should fit the same as a cane 	<ul style="list-style-type: none"> • Axillary • Forearm/Loftstrand/Canadian • Trekking poles
Walkers	<ul style="list-style-type: none"> • Give more support for weakness and balance problems • Hand grips should be as tall as the hip bone or as high as the bend in the wrist when standing tall with arms relaxed at sides 	<ul style="list-style-type: none"> • Standard (no wheels) • Front wheeled • 4-wheeled • 4-wheeled with seat and hand brakes
Manual Wheelchairs	<ul style="list-style-type: none"> • Require good upper body strength and endurance to propel for all mobility 	<ul style="list-style-type: none"> • "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 (cont.)

Device	Indications for Use	Types
Motorized Scooters	<ul style="list-style-type: none"> For individuals who can ambulate fully but need assistance for long distances or when fatigued 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 if individual's needs change 	<ul style="list-style-type: none"> 3-wheeled 4-wheeled (greater stability)
Power Wheelchairs	<ul style="list-style-type: none"> Provide mobility but also any need for proper seating Can have optional power seating functions that allow leg rests to be elevated or seat to lift, tilt, or recline Can be modified if individual's needs change 	<ul style="list-style-type: none"> Numerous options available; range from basic chairs with captain's seating through chairs with complex seating and positioning options Mid-wheel, rear-wheel, or front-wheel drive)

Table 8: Ambulatory Assistive Devices

Device	Description
L300 GO (www.bioness.com)	<ul style="list-style-type: none"> 3-axis gyroscope Accelerometer embedded in the stimulator to monitor movement Deploy electrical stimulation within .01 seconds of detecting a gait event
L300 Plus for foot drop plus thigh weakness (www.bioness.com)	<ul style="list-style-type: none"> As above, but provides additional stimulation that can be programmed for activation of quadriceps or hamstrings to aid in knee control
Walk-Aide Wireless FES (www.walkaide.com)	<ul style="list-style-type: none"> 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)	<ul style="list-style-type: none"> 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	<ul style="list-style-type: none"> Ankle strap with band that provides dorsiflexion assist by attaching to anchor point on shoe
Carbon Fiber or Traditional Ankle-Foot Orthosis (AFO)	<ul style="list-style-type: none"> 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	<ul style="list-style-type: none"> Used to control genu recurvatum (knee hyperextension) Examples include Swedish knee cage and OrthoPro HyperEX Knee Orthosis

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When considering powered scooters vs wheelchairs, both provide mobility when fatigue and weakness are present. Scooters are relatively portable and may be perceived as having less stigma, but disadvantages include lack of specialty seating, transfer limitations, poor maneuverability, inability to upgrade, need for good trunk stability and upper extremity function to operate, and lack of options for pressure relief. Scooters may also contribute to upper extremity fatigue and poor postural alignment. Advantages of power wheelchairs include custom seating, multiple power specialty features, and good maneuverability. Further, they can be modified as individuals' needs change. Disadvantages include cost, specific criteria needed for insurance qualification, and transportation challenges.

Ambulatory assistive devices are summarized in [Table 8](#); examples are shown in [Figures 5 and 6](#).

Figure 5: Ambulatory Assistive Devices



A,B: Prefabricated ankle foot orthosis
C: Custom ankle foot orthosis
D: Swedish knee cage



Figure 6: Ambulatory Assistive Devices



Numerous aids are available to support individuals with MS in activities of daily living ([Table 9](#)). Among technology aids, an ever-increasing number of smartphone applications (“apps”) are available to help patients remain independent. Examples include apps that remind patients to take and/or refill their medications, demonstrate exercises with reminders to complete them, and provide accessibility routes and maps for wheelchair users.

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Table 9: Aids for Activities of Daily Living

Activity	Aids	Description
Bathing	<ul style="list-style-type: none"> • Tub bench • Hand-held shower head • Grab bars installed in shower, bathtub • Anti-slip mat 	<ul style="list-style-type: none"> • Adaptive equipment designed for use in the shower or bathtub can make bathing tasks easier and minimize associated risks
Toileting	<ul style="list-style-type: none"> • Bedside commode • Grab bars near toilet • Toilet seat with armrests • Raised toilet seat • Toilet riser • Toilet tissue aid • Bidet/bidet toilet seat 	<ul style="list-style-type: none"> • Toileting aids can enhance safety, transfers, hygiene, and clothing management
Dressing	<ul style="list-style-type: none"> • Velcro, buttons, zippers, hooks on clothing • Sock aid • Long-handled shoehorn • Buttonhook/zipper pull • Sturdy seat for sitting while dressing 	<ul style="list-style-type: none"> • Adaptive dressing aids can maintain or increase independence despite symptoms of fatigue, decreased fine motor control, or decreased strength or balance
Cooking	<ul style="list-style-type: none"> • Microwave oven • Wheeled utility cart • Electric can opener • Pot stabilizer • Large handled cooking utensils • Light cookware and dishware 	<ul style="list-style-type: none"> • Numerous modified cooking techniques can be incorporated into cooking tasks • Modifications can be further enhanced with tools that simplify the process
Eating	<ul style="list-style-type: none"> • Specialized utensils, eg, large-handled spoons and forks, “sporks,” rocker knives • Plate guard • Wrist supports • Non-slip/anti-slip materials 	<ul style="list-style-type: none"> • Adaptive equipment can help minimize fatigue and manage tremor and decreased fine motor skills
Writing	<ul style="list-style-type: none"> • Special grips for pens and pencils • Wrist supports • Slant boards • Weighted writing implements • Dictation system (if speech is intelligible) 	<ul style="list-style-type: none"> • Various aids are available to assist with written communications; recommendations vary depending on patient preferences and symptoms



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

Activity	Aids	Description
Sleeping	<ul style="list-style-type: none">• Electric beds or mattresses• Bed assist rails handles and poles• Pressure relief mattresses	<ul style="list-style-type: none">• Individuals need to be able to safely get in and out of bed, remain comfortable in bed, and manage pressure relief
Technology	<ul style="list-style-type: none">• Automatic medication reminder/refill apps• Hydration apps• Online shopping with home delivery• Daily reminders and calendars• Online banking and bill pay	<ul style="list-style-type: none">• Access to smartphone apps and computer websites can help maintain independence and self-care and manage fatigue
Miscellaneous	<ul style="list-style-type: none">• Reacher devices• Grab bars	<ul style="list-style-type: none">• Many types of equipment are available help maximize independence• Recommendations should be matched with patients' needs and preferences



Selected Aspects of Cognition in Multiple Sclerosis

The entire treatment team must keep in mind the possibility of cognitive changes in patients with MS. Cognitive changes can complicate medical care, interpersonal relationships, employment, and overall quality of life.

Reports of cognitive impairment in the MS population vary widely, due to many different factors, such as patient population sampled, disease duration, neuropsychological measures used, and cognitive domains assessed.^{60,61,62} But cognitive impairment is common, with observed frequencies of 35%-45% in patients with RMS,^{63,64} 28% in PPMS,⁶⁵ and up to 83% in SPMS.^{66,67}

Cognitive impairment in MS does not follow a single pattern, and its presence cannot be predicted by disease duration or physical disability level.⁶⁸ One person may have no physical limitations but significant cognitive impairment, while another may have significant disability but fully intact cognitive functioning. Studies have correlated cognitive impairment with brain MRI lesion volume and extent of regional atrophy, and pathology in both gray and white matter appear to contribute.⁶⁸ Commonly affected aspects of cognition include attention and concentration, word retrieval, memory, visual perceptual skills, speed of information processing, and executive function.^{66,69} Others include ease of doing calculations, comprehending spoken and/or

written information, expressing thoughts or ideas, and conversational and social skills. Intelligence and long-term memory are typically not affected, and until recently, language skills were thought to remain intact. However, research has revealed deficits in cognitive communication (eg, naming, comprehension, sentence repetition, word fluency, verbal explanation, verbal reasoning, sentence reconstruction, word definitions, and interpretation of absurdities, ambiguities, and metaphors).^{70,71} Changes in cognitive communications in MS are described in greater detail later in this Primer.

The impact of cognitive impairment can extend to health care. For example, patients may have difficulty understanding, remembering, and carefully following treatment instructions—especially if instructions are complicated. They may also struggle to sort through and make decisions about treatment options.⁷²

Clinicians involved in evaluating and treating cognitive changes in people with MS include neuropsychologists, speech-language pathologists, occupational therapists, or others, such as vocational rehabilitation specialists ([Table 10](#)). If an MS Certified Specialist (MSCS) is unavailable, a specialist or program in traumatic brain injury (TBI) or similar disorders is a good option, because the types of cognitive deficits and

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

Clinician	Scope
Psychologist or neuropsychologist	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
Vocational Rehabilitation Specialist	Cognitive testing and interventions, job site training



interventions seen with MS are similar—more so than those seen with stroke or degenerative dementias.

SCREENING FOR COGNITIVE CHANGES IN MS

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)**.^{73,74} These composite measures are summarized in **Table 11**. Both are validated and reliable. A **Brief Neuropsychological Battery for Children (BNBC)** is also available to assess expressive vocabulary, cognitive flexibility, processing speed, and learning and memory in pediatric MS. The use of these screening protocols may be limited in routine clinical practice, as clinicians may lack access to and experience with some of the specific tests and normative data on MS.

Because people with MS may not be aware of cognitive deficits,⁷⁶ self-report measures, such as the **Multiple Sclerosis Neuropsychological Questionnaire (MSNQ)**, may not be helpful.⁷⁷

Several studies have found the **Montreal Cognitive Assessment (MoCA)** to be useful for screening patients with MS.^{78,79,80} Other brief screening measures used for cognitive changes, such as the **Mini-Mental State Examination (MMSE)**, are not sensitive to deficits typically present with MS.⁸¹ A detailed history of vocational and avocational performance may be informative. Further, reports from family members or caregivers are more likely to be accurate than patient self-reports.⁸²

Whether all individuals who have MS should be screened for cognitive deficits is a matter of some debate. However, once a patient presents with cognitive concerns, comprehensive evaluation is warranted and may require measures tailored to the specific clinical issues at hand.

Patients should be referred for evaluation of cognition in certain circumstances or when particular symptoms appear. Examples include:

- Behaviors that pose a safety or hazard risk
- Decrease in work performance
- Forgetfulness

Table 11: Brief Neuropsychological Batteries for Assessment of Cognitive Change in MS^{Adapted from 75}

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	---

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- Forgetting to take medications or taking medicines incorrectly
- Disorganization when approaching or carrying out a task
- Distractibility or inattention (visual or auditory)
- Difficulty assembling things
- Delay in thought processing
- Delay in responding (verbal or physical)
- Difficulty planning, sequencing, and carrying out activities or schedules
- Difficulty problem solving
- Getting easily overwhelmed
- Poor reading comprehension
- Difficulty with mathematical calculations
- Difficulty expressing thoughts and 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, it is important to be mindful of possible comorbid or independent deficits in motor, sensory, coordination, vision, and hearing capabilities. For example, visual impairment occurs frequently in MS, and hearing impairments (though usually not severe) may be present.⁸³ 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, or pain. Cognitive fatigue (decline in cognitive performance over a single testing session) is now an accepted reality in people with MS.^{84,85} Recognition and documentation of this finding may help patients maximize function or obtain workplace accommodations.

TREATMENT TO MAINTAIN OR IMPROVE COGNITION IN MS

To date, no medications have consistently shown efficacy for treatment of cognitive changes in MS, although research continues.^{86,87} However, neuropsychological and cognitive rehabilitation strategies show promise.

Neuropsychological rehabilitation is concerned with mitigating the cognitive, emotional, psychosocial, and behavioral deficits caused by damage in the brain.⁸⁸ Cognitive rehabilitation is the process of improving or supplementing cognitive skills needed for activities of daily living, with treatment approaches that may be restorative or compensatory in nature. An increasing body of literature supports the use of neuropsychological and cognitive rehabilitation in patients with MS. For example, a 2014 Cochrane review of 20 studies found that neuropsychological rehabilitation improved cognitive symptoms.⁸⁹ Cognitive training was associated with improvements in memory span and working memory, and cognitive training combined with other neuropsychological methods was associated with improvements in attention, immediate verbal memory, and delayed memory.⁹⁰ Other recent studies have shown benefits of various cognitive rehabilitation strategies in patients with MS, including retrieval practice for memory-impaired patients,^{90,91} a modified Story Memory Technique,⁹² and a computer-assisted intervention focused on memory, attention, and problem-solving skills.⁹³ A variety of compensatory strategies employed for cognitive challenges in MS are summarized in [Table 12](#) (page 30).

For a patient with MS, a typical cognitive rehabilitation session might include reviewing what has happened since the previous session, outlining goals for the current session, practicing cognitive exercises, developing and/or practicing compensatory strategies, self-evaluating performance, reviewing the session, discussing homework, and formulating a to-do list. Cognitive rehabilitation strategies need to be specific to the patient's goals, as well as realistic and applicable to day-to-day life. Having a means for accountability—for tracking if or how a given strategy is used—is key, as is establishing a timeline for when the strategy will be implemented, and for how long.⁹⁴



Table 12: Compensatory Cognitive Rehabilitation Strategies

Cognitive Target	Rehabilitation Strategy
Attention/concentration Ability to focus and maintain focus, shift focus, select	<ul style="list-style-type: none"> Minimize distractions, reduce clutter, and work in a quiet area (low-traffic, low-noise) Reduce interruptions, establish “ground rules” with family and friends, let the answering machine or voicemail pick up phone calls, and use timers
Memory Learning, storing, and retrieving information	<ul style="list-style-type: none"> Notepads, planners, calendars Voice recorders Personal alarms Memory buddy/partner Colored baskets for specific items, always to be found in the same place Location devices for parked cars Reminder apps
Word retrieval Saying the word you want to say, when you want to say it	<ul style="list-style-type: none"> 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.	<ul style="list-style-type: none"> 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 frequently used numbers in the phone book
Speed of information processing Ability to quickly analyze and use information from the surrounding environment	<ul style="list-style-type: none"> Ask others to slow down when they speak Rephrase what others say Repetition of information Use voice recorders; review recorded information several times
Executive functions Organizing, planning, sequencing, prioritizing thoughts, reasoning, judgment, problem solving, self-monitoring	<ul style="list-style-type: none"> Make lists; rank items in order of priority Write things down; make sure steps or ideas are in proper or logical order Take a moment to organize thoughts before responding

Cognitive rehabilitation services for patients with MS may be accessed at comprehensive MS centers, rehabilitation facilities, home health care agencies, private practitioners’ offices, hospital outpatient services, and occupational and vocational rehabilitation agencies. Patients and/or caregivers can connect with cognitive

rehabilitation services by contacting the local rehabilitation facility, asking the patient’s clinician for a referral, identifying providers in the area through the local chapter of the National Multiple Sclerosis Society, asking other people with MS, or asking other health care professionals.



Communication, Swallowing Issues, and Oral Health

SPEECH AND VOICE IN MS

Studies of speech-related changes in individuals with MS show that 25-70% may experience some change in speech and/or voice over their disease course.^{95,96,97,98}

To better appreciate these changes, it is useful to review the components of normal speech production (**Figure 7**).⁹⁹

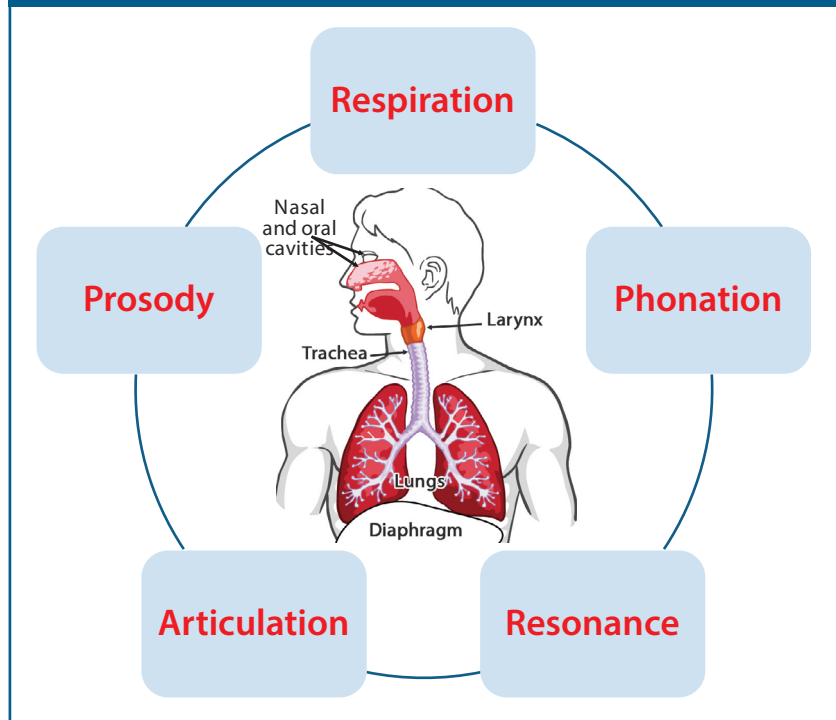
Dysarthria is the most commonly observed communication disorder in the MS population.^{96,97} Dysarthria is a collection of motor speech disorders caused by weakness, slowness, and/or lack of coordination of the muscles used for speech. Readers are referred to the work of Darley and colleagues for classification and description of dysarthria.^{97,100}

Spastic, ataxic, and mixed forms of dysarthria (spastic/ataxic) are typical in MS.^{95,101,102,103}

Dysarthria impacts the speed and coordination of movements of the tongue, lip, soft palate, and pharynx.¹⁰⁴ In MS, tongue movement is more affected than lip movement; although abnormal tongue movement alone is not considered dysarthria, it frequently impairs speech production and can negatively impact performance on cognitive tests requiring a timed oral response.¹⁰⁵

Dysphonia, often seen with dysarthria, is a voice disorder that affects respiration, phonation, articulation, pitch, speech rate, stress, prosody, intelligibility, loudness, and vocal quality.^{96,97} Spasmodic dysphonia is associated with MS, and a recent pilot study found injections of botulinum toxin type A to be safe and effective for treatment of this condition.¹⁰⁶

Figure 7. Five Components of Normal Speech
Click on each component for a description



Testing for dysarthria includes informal approaches, such as observation and description of speech samples or spontaneous, ongoing speech;¹⁰⁷ as well as formalized instruments, such as the **Frenchay Dysarthria Assessment**, the **Assessment of Intelligibility and Dysarthric Speech**, and the **Speech Intelligibility Test**.^{108,109,110}

The Frenchay Dysarthria Assessment is appropriate for individuals ages 12 and older.¹⁰⁸ It takes about 20 minutes to complete, and it can help determine which speech systems are most involved in impairment. Specifically, it examines:

- Reflexes (cough, swallow, dribble/drool)
- Respiration (at rest, in speech)
- Lips (at rest, spread, seal, alternate, in speech)
- Palate (fluids, maintenance, in speech)
- Laryngeal (time, pitch, volume, in speech)
- Tongue (at rest, protrusion, elevation, lateral, alternate, in speech)



- Intelligibility (words, sentences, conversations)
- Influencing factors (hearing, sight, teeth, language, mood, posture, rate, sensation)

The Assessment of Intelligibility of Dysarthric Speech can be used for adolescents and adults, and requires 30 minutes to complete. This test quantifies single word intelligibility, sentence intelligibility, and speaking rate. It provides an index of severity and can be used to monitor progress on speech-language interventions.¹⁰⁹

The Speech Intelligibility Test¹¹¹ can also be used to monitor progress. Computer software randomizes stimuli, and the test can be performed on screen or as printed hard copy. Words and sentences are judged by an unfamiliar listener. It takes 10 minutes to complete.

Individuals with MS should be referred to an SLP for evaluation when any of the following speech changes are noted:

- Slurring of speech sounds
- Changes in loudness (too loud, too soft, or fluctuating loudness)
- Changes in voice quality (hoarse, breathy, strained, or strangled)
- Abnormal pauses during speech (may also indicate word retrieval difficulties)
- Abnormal stress/emphasis on words
- Impaired pitch control
- Change in normal pitch (higher, lower, pitch breaks)
- Hyper- or hyponasality
- “Running out of air” while speaking
- Anterior loss of saliva or food when chewing
- Weakness or decreased range of motion in lips, cheeks, tongue, soft palate, and/or muscles of the head, neck, and trunk

Among the most frequently reported speech change in persons with MS is decreased loudness.^{100,112} Vocal fold weakness can also be present.^{113,114} In addition, weakness in expiratory and laryngeal muscles is noted in the MS population.^{115,116,117,118} Expiratory muscle weakness

may be present early in the disease course and in patients with mild to moderate disability.¹¹⁹

To date, expiratory muscle strength training (EMST) has not been shown to limit the impact of expiratory strength in speech and cough function, although more research is needed to determine possible benefits.^{119,120,121} Conversely, Lee Silverman Voice Treatment administered by a trained SLP may provide benefit in increasing loudness, prosodic variation, and articulatory accuracy.^{122,123}

An important consideration when evaluating and treating speech and voice impairments is the demands of the environment on the speaker. MS fatigue can have a significant impact on all parameters of speech and voice, and fluctuations in the quality and efficiency of speech and voice throughout the day are common. 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, gastroesophageal reflux, pseudoexacerbation, medication effects, or lifestyle habits, such as tobacco and alcohol use and vocal abuse or misuse.

Together with patient history and physical findings, informal and formal dysarthria testing informs diagnosis, recommendations for treatment, development of individualized intervention strategies, and referral to other disciplines if necessary. Patient and family/caregiver education is essential. Verbal and written information explaining results of speech and voice assessments in easily understandable vocabulary should be provided to patients and the support team. The rationale for recommendations and any referrals should also be carefully explained, as should augmentative and alternative communications when beneficial. Patient, family, and caregiver input regarding desires and expectations from treatments should always be solicited during such discussions.

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SLP treatment of dysarthria has been shown effective and should focus on improvement and/or use of compensatory strategies.¹²⁴ Interventions should be individually tailored and typically involve exercises to increase strength and control of muscles used for speech and modifications to the rate of speech and/or loudness to enhance intelligibility.

The American Speech-Language-Hearing Association (ASHA) provides the practical suggestions for persons with dysarthria and for listeners.¹²⁵

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 your listeners to make sure that they understand you
- Speak slowly and as loudly as you can 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 as he or she talks
- Let the speaker know when you have difficulty understanding him or her
- Repeat 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 and no questions or have the speaker write the message

Recovering speech function and maintaining communication is essential for the well-being of the patient and family, and for maximizing quality of life.¹²⁶

Augmentative and alternative communication (AAC) strategies can be helpful when speech alone is insufficient. AAC is a system comprised of symbols, aids (books, devices, apps), strategies, and techniques. The goal of AAC is to supplement existing speech or replace speech that is not adequate for functional purposes. The most effective AAC systems allow the user to initiate, maintain, and terminate the communication process. In addition to basic needs, AAC should help patients to connect and share ideas and stories. Examples of low-tech options for AAC include manual signs, natural gestures, pictures/photos, alphabet, eye-gaze boards, and buzzers (**Figure 8, page 34**). Fingers, other body parts, pointers, or eye tracking can be used to indicate selections.

High-tech AAC options include apps for mobile devices, computer programs, and speech-generating devices that provide computerized voice output. Voice banking is becoming increasingly popular, particularly among individuals with neurodegenerative diseases. Voice banking should be undertaken as early as possible in order to preserve voice and intelligibility. A popular provider is ModelTalker,¹²⁷ however other voice banking services continue to emerge. ASHA provides links to organizations with information on the range of AAC devices and aids.¹²⁸





















With the increasing availability of communication apps for tablets and smartphones, clients may be keen to independently select and program their own systems. However, some apps may be too complex for patients with cognitive challenges. Assistance with device selection and programming from an experienced professional can improve the usefulness of these tools and associated outcomes.

Selection and use of AAC strategies and devices should be individualized and practical. AAC users and their caregivers should have the final decision when choosing a device or system. Devices should be selected with consideration of both current and



Figure 8 Examples of Basic Augmentative and Alternative Communication Options

Alphabet Board							Simple Eye Gaze Board		
1	A	B	C	D	space		Family PEOPLE Friends	Travel ALPHABET Emotions	Medical CARE Bathroom
2	E	F	G	H	end of word				
3	I	J	K	L	M	N	Homework CLASSES Phone		Books/Magazines MUSIC Videos/Movies
4	O	P	Q	R	S	T			
5	U	V	W	X	Y	Z	Clothing FOOD Shopping	News POLITICS Newspaper	Sports COMPUTER Weather

Food 	Burger 	Pizza 	Chicken 	Pasta 
Bread 	Cheese 	Vegetables 	Hot Dog 	Fries 
Fruit 	Bananas 	Ice cream 	Cookie 	Candy 
Drink 	Water 	Juice 	Soda 	Coffee 

future needs. If the client uses a mobility aid, OT and PT input for mounting the chosen system is essential. Additionally, environmental controls may be possible with some devices, and OT can provide valuable input into their utility and use, particularly for patients with limited mobility.

Attention to visual, cognitive, sensory, and motor strengths/weaknesses is important to selection, as is understanding the role of fatigue and

fluctuating symptoms in MS. Patients with MS and their caregivers need to be aware that AAC use may be intermittent depending on the patient's communication skills at any given time. AAC users should be able to fluently alternate between speech and AAC, especially in the event of an emergency. Patients and families must also receive education in how to use the ACC system and, if applicable, how to program devices.

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IMPACT OF COGNITIVE CHANGES ON COMMUNICATION

Cognitive changes may have a significant impact on the communication skills of individuals with MS. Cognitive communication is defined as “difficulties in communicative competence (listening, speaking, reading, writing, conversation and social interaction) that result from underlying cognitive impairments (attention, memory, organization, information processing, problem solving, and executive functions).”¹²⁹ The impact of communication on interpersonal and family relationships is profound and cannot be ignored.

A recent systematic review found that, in individuals with MS, the most frequent language impairments are verbal fluency, naming, comprehension, and semantic processing.¹³⁰ These were thought to be more related to changes in cognition than to changes in basic language abilities, because the tasks involved relied on executive function. Matotek and colleagues found that, compared to individuals without MS, individuals with mild MS had twice as many errors in production and 8 times as many unfinished sentences in conversation.¹³¹ Another study noted restricted participation from a communication perspective among individuals with MS, even among those who perceived themselves as having normal speech function.¹³²

Assessment of cognitive communication in MS can be difficult because many standard-language batteries fail to capture the subtle ways cognitive changes affect communication.¹³³ Assessment can be facilitated via a thorough interview, to include the person with MS as well as family and friends. Assessments for cognitive communication are most typically normed for TBI, but can still be used to determine areas of cognitive-communication need in MS. Valuable tools include the Cognitive Communication Checklist for Acquired Brain Injury, which provides an overview of functional changes related to cognitive communication (Figure 9);¹³⁴ and the

Figure 9. Cognitive Communication Checklist for Acquired Brain Injury (Click to enlarge)

SLP Cognitive-Communication CHECKLIST Checklist for Acquired Brain Injury (CCABI)
©Sheila MacDonald M.C.I.Sc. SLP (C)

Individual _____ Significant Other _____
Interviewer _____ Date _____

Functional Daily Communications (Activity/Participation)
Decreased amount, quality, effectiveness, speed, frequency, independence, or stamina. Changed since the injury.

1. ☐ Difficulties with Family or Social Communications
2. ☐ Difficulties with Communication in the Community (stores, services, internet, telephone, medical, financial, legal)
3. ☐ Difficulties with Workplace Communications
4. ☐ Difficulties with School Communications/Academic Performance
5. ☐ Difficulties with Communications needed for Problem Solving/Decision Making or Self Advocacy

Specific Functional Difficulties (Check all noted) Refer to Speech-Language Pathologist/Therapist if problems noted.

Auditory Comprehension & Information Processing Possible factors: hearing, attention, memory, receptive language; comprehension, integration, reasoning, and speed of information processing	6. <input type="checkbox"/> Hearing what is said, sensitivity to sounds, ringing in ears – Refer to Audiologist 7. <input type="checkbox"/> Understanding words and sentences 8. <input type="checkbox"/> Understanding long statements (discussions, lectures, news, TV) 9. <input type="checkbox"/> Understanding complex statements (humour, subtle, implied information) 10. <input type="checkbox"/> Integrating information – Cannot 'glue' information together to draw a conclusion or get the gist 11. <input type="checkbox"/> Tendency to misunderstand or misinterpret discussions 12. <input type="checkbox"/> Focusing attention on what is said (distraction, fatigue, interest) 13. <input type="checkbox"/> Shifting attention from one speaker to another 14. <input type="checkbox"/> Staying on track with the conversation, staying on topic 15. <input type="checkbox"/> Holding thoughts in mind while talking or listening 16. <input type="checkbox"/> Remembering new conversations, events, new information
Expression, Discourse & Social Communication articulation, word finding, language, memory, attention, social communication, fatigue, fluency, reasoning, executive functions, social cognition, perception, self-regulation	17. <input type="checkbox"/> Speech sounds, muscle movements, voice, fluency, stuttering 18. <input type="checkbox"/> Word finding, word retrieval, thinking of the word, vocabulary, word choice 19. <input type="checkbox"/> Sentence planning, sentence construction, grammar 20. <input type="checkbox"/> Initiating conversation 21. <input type="checkbox"/> Generating topics of conversation, thinking of what to say, elaborating, adding 22. <input type="checkbox"/> Vague, nonspecific, disorganized conversation 23. <input type="checkbox"/> Overly talkative, rambling, verbose conversation 24. <input type="checkbox"/> Socially unsuccessful comments (impulsivity, anger, swearing, joking, topic selection) 25. <input type="checkbox"/> Nonverbal skills (eye contact, personal space, facial expression, tone of voice, mannerisms, gestures) 26. <input type="checkbox"/> Perceiving or understanding conversation partner cues, emotions, context, views
Reading Comprehension any written materials, print or electronic	27. <input type="checkbox"/> Physical difficulties (vision: double, blurred, field, tracking, pain, fatigue, dizziness) – Refer to Optometrist, Ophthalmologist 28. <input type="checkbox"/> Decoding letters or words, reading aloud fluently 29. <input type="checkbox"/> Comprehending read sentences, paragraphs, text 30. <input type="checkbox"/> Retaining read information over time, remembering, organizing 31. <input type="checkbox"/> Attending to what is read, need to read everything twice 32. <input type="checkbox"/> Reduced stamina for reading (Reads for ____ min now; ____ min prior to onset)
Written Expression any written materials, print or electronic	33. <input type="checkbox"/> Physical aspects of writing, hand movements – refer to Occupational Therapist 34. <input type="checkbox"/> Writing words 35. <input type="checkbox"/> Constructing sentences, formulating ideas for writing (sentence formulation) 36. <input type="checkbox"/> Organizing thoughts in writing (written discourse) 37. <input type="checkbox"/> Spelling difficulties relative to pre-injury abilities
Thinking, Reasoning, Problem Solving, Executive Functions, Self-Regulation (required for communication)	38. <input type="checkbox"/> Insight, awareness, recognizing there is a problem 39. <input type="checkbox"/> Making & expressing decisions (getting facts, weighing facts, pros & cons, deciding) 40. <input type="checkbox"/> Discussing without being overwhelmed, upset, withdrawn 41. <input type="checkbox"/> Filtering out less relevant information, focusing on priorities, main points 42. <input type="checkbox"/> Organizing, integrating, analyzing, inferring, seeing the whole picture 43. <input type="checkbox"/> Summarizing, getting the gist or the bottom line, drawing conclusions 44. <input type="checkbox"/> Brainstorming, generating ideas, alternatives, thinking creatively 45. <input type="checkbox"/> Planning, prioritizing, implementing, following through, evaluating, self-monitoring of communication
Total	_____ # of Communication Concerns Identified

© Reproductions are permitted if referenced as MacDonald, Sheila (2015) Cognitive Communication Checklist for Acquired Brain Injury (CCABI) CCD Publishing: Guelph, Ontario, Canada, N1H 6J2, www.ccdpublishing.com

Functional Assessment of Verbal Reasoning and Executive Strategies (FAVRES),¹³⁵ which provides an excellent measure of cognitive communication performance on everyday executive functioning tasks. For individuals who report more significant difficulty with word retrieval and verbal



Table 13. Cognitive-Communication Testing

Functional Assessment of Verbal Reasoning and Executive Strategies (FAVRES)¹³⁵

- Time to administer: 1 hour
- 4 subtests with functional planning and organizing activities
- Follow-up verbal reasoning questions for each task
- Norms for accuracy and rationale, and time to complete each subtest; can administer individual subtests
- Tasks relate to everyday planning and work tasks
- School version available for younger clients
- May be fatiguing for some to complete

Mt. Wilga High Level Language Test (MWHLLT)¹³⁶

- Time to administer: 45 minutes–1 hour
- Most recent (2016) version is not normed
- Assesses higher-level verbal formulation and reasoning problems
- More complex than confrontation naming and verbal fluency assessments
- Available online free of charge

Scales of Cognitive and Communication Ability for Neurorehabilitation (SCCAN)¹³⁷

- Time to administer: 45 minutes
- Normed assessment of cognitive-linguistic abilities
- Generally more focused on linguistic tasks than CLQT
- Appropriate for those with mild-moderate cognitive changes

Cognitive Linguistic Quick Test¹³⁸

- Time to administer: less than 30 minutes
- Normed assessment of cognitive linguistic abilities
- Comprehensive, 10 subtests, encompasses all cognitive domains
- Appropriate for individuals with moderate cognitive changes

Cognitive Communication Checklist for Acquired Brain Injury¹³⁴

- Checklist of cognitive communication behaviors
- Can be easily provided as a take-home to complete
- May be provided to individuals by family physicians, neurology, physiatry, or nursing to flag cognitive communication concerns

formulation, the **Mount Wilga High Level Language Test (MWHLLT)**, while not standardized in the current (revised) version, can provide a screen for various aspects of higher-level language¹³⁶ Descriptions of these assessments are provided in **Table 13**.

In patients with MS, changes in cognition may begin early. Often, cognitive communication disorders will affect participation and performance at work and in social settings. Working closely with patients to develop and troubleshoot strategies for their specific concerns can help minimize the impact and may prolong employment. Common concerns and strategies for dealing with them are listed below, however, individualized strategies will provide the best

success. Such strategies may overlap with those recommended for other cognition-based difficulties. Coordination of care between OT, SLP, and neuropsychology can reduce potentially conflicting strategies and allow the patient to focus on a few effective approaches and avoid getting overwhelmed.

- **Common concern:** Reduced recall of conversations
- **Possible management strategies**
 - Keep one notebook to record details of important conversations; notebook as “source of truth;” Reference notebook for details of previous conversation prior to raising topic again

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- Ask on the phone for details to be emailed or texted
- Plan conversations for when communication is optimal (i.e., when not fatigued)
- Verify important points of conversation with communication partner
- Reduce distraction during conversation (quiet, face-to-face environment)
- **Common concern:** Difficulty explaining complex ideas
- **Possible management strategies:**
 - Reduce distraction during conversation
 - Simplify message
 - Write down important ideas or messages before communicating them (eg, in a meeting)
 - Use visual cues during conversation to track explanation (e.g., drawing, writing key words as you go)
- **Common concern:** Straying from topic
- **Possible management strategies:**
 - Ask others to let you know when you have strayed from topic
 - Write keywords down
 - Attempt to verify that listener has all necessary information
 - Use pat phrases for when topic has changed unintentionally (eg, “Where was I...” or “but back to...”)
- **Common concern:** Disorganized planning and carrying out of tasks
- **Possible management strategies:** (also discussed above)
 - Consistently use organizational strategies
 - Use written and visual reminders at work and school
 - Use checklists, alarms, and reminders on devices such as a smart phone

Reasons for referring individuals with MS to an SLP include difficulty following and recalling

conversation, difficulty organizing and planning, difficulty staying on topic, difficulty elaborating and providing sufficient details or explaining complex thoughts and ideas, frequent errors at work, and patient or family concerns about conversational abilities.

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).

Stages of Swallowing

The 3 stages of swallowing—oral, pharyngeal, and esophageal—are shown in **Figure 10** (page 38).¹³⁹ SLP focuses on management of oral and pharyngeal phases, whereas the esophageal phase is mainly within the purview of gastroenterology. However, a change in any one phase will typically affect the others.

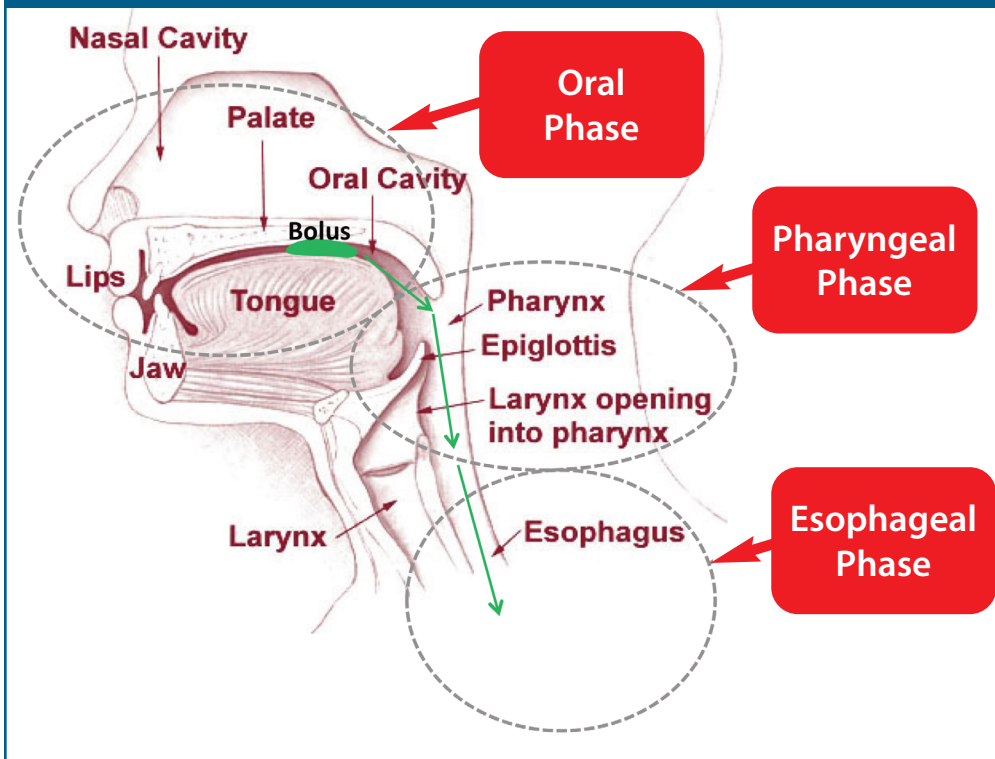
Swallowing is a rapid process, with the oral and pharyngeal stages normally lasting 1 second each and the esophageal stage lasting 8 to 10 seconds.

Dysphagia in MS

The prevalence of swallowing disorders in MS varies from study to study, but tends toward approximately 40%.^{140,141,142} Self-reports underestimate the frequency of dysphagia in MS^{143,144} and discrepancies have been observed between radiologic findings and subjective symptoms of dysphagia.¹⁴⁵ Dysphagia may occur at any point in the disease course but prevalence increases with increasing EDSS scores.^{146,147} In addition, symptomatic dysphagia in MS is significantly correlated with cognitive impairment,¹⁴⁸ depressed mood,¹⁴³ and severity of illness.¹⁴⁹



Figure 10: Stages of Swallowing
Click on each phase for a description



the trachea (aspiration). Penetration and aspiration may be symptomatic and visible or silent. Signs of overt aspiration are visible and include coughing, choking, and gagging during or after eating or drinking; coughing may force food or liquid back into the mouth or out the nose. Aspiration may be silent when there is reduced sensation, with food or liquid entering the airway without the patient noticing. Silent aspiration may be discovered

Causes of dysphagia in MS include disruptions in the central or peripheral nervous system (corticobulbar nerve tract, cerebellum, brainstem, and lower cranial nerves) and/or abnormalities in respiratory control and capacity.¹⁴² Cognitive changes, abnormal respiratory control, postural problems, and tremor may also contribute. Efficient swallowing requires adequate movement and coordination of anatomical 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.

When swallowing is impaired, the bolus of material from the mouth may enter the larynx and remain above the vocal cords (penetration), or pass farther down through the cords and into

following recurrent pneumonias; signs at bedside may include red, watery eyes after swallowing and/or an audibly wet or “gurgly” voice. Silent aspiration is particularly concerning because it indicates the body is not providing protection to the airway and lungs after an aspiration event.

Signs of dysphagia include:

- Slowed or delayed swallowing
- Coughing, choking, or gagging during eating or drinking
- Coughing, choking, or gagging after meals, particularly when changing positions (eg, from sitting to reclining)
- Copious secretions
- Weight loss of unknown origin
- Pneumonia (especially recurrent pneumonia)
- Wet or gurgly voice sounds during or after meals

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- 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)

A recent review and meta-analysis found that the most frequently reported symptoms of dysphagia in people with MS were coughing/clearing the throat (61-66%); feeling of food sticking in throat (63%), choking on liquid/food (57%), and spillage of food/liquid from lips or drooling (34%).¹⁵⁰

Common complications of dysphagia include:

- Dehydration
- Malnutrition
- Upper respiratory infections
- Aspiration pneumonia
- Reduced participation and quality of life

Malnutrition can have downstream effects on physical health, lead to increases in fatigue, decreases in muscle mass, and slow wound healing. Changes in weight and muscle mass can also affect impact mobility, activities of daily living, and overall success of rehabilitation.¹⁵¹ When these changes occur it is important to consult with a dietitian as soon as possible, to find ways to maintain nutrition with consideration of food and liquid texture changes and to help limit negative health effects of dysphagia.

Dysphagia-associated changes in participation and quality of life are sometimes underappreciated. People may be embarrassed by their symptoms and may have difficulty finding restaurant items that are comfortable to eat or that fit diet texture modifications. The additional time they may require to eat can change the

dynamic of mealtimes. In a culture that centers social gatherings around food, dysphagia can be isolating. People with MS-related dysphagia report it as a major distraction in life. They describe being frustrated, depressed or annoyed, having difficulty selecting appropriate foods, and having reduced social participation surrounding eating.¹⁵⁰ Few assessments and screens capture such changes. The Swallowing Quality of Life Questionnaire (SWAL-QOL, described below) can be used to initiate a discussion and help assess quality of life in relation to feeding and swallowing.

Screening Tools for Swallowing

Several screening tests are commercially available for the evaluation of dysphagia. A recent review of self-reported swallowing measures in neurological disorders recommends the **Eating Assessment Tool (EAT 10)** and **SWAL-QOL** as valid, reliable, and easy to administer.¹⁵² However, the authors note that the length of the SWAL-QOL may be limiting for some individuals. The Dysphagia in Multiple Sclerosis (DYMUS) Questionnaire was developed specifically for MS and can be used as a preliminary assessment.¹⁵³ Each is described below.

EAT 10¹⁵⁴

- Time to administer: 5-10 minutes
- Focused on impairment
- Can be used to assess change in swallow function

SWAL-QoL¹⁵⁵

- Time to administer: 15-20 minutes
- Focused on impairment, participation, and quality of life
- Can be used to assess changes in swallow function and quality of life
- May be lengthy and difficult to complete for individuals with cognitive changes

DYMUS¹⁵³

- Time to administer: 5-10 minutes
- Focused on impairment and body function
- Subscales for liquids and solids



SLPs are encouraged to use objective assessments, including instrumental evaluations, to determine the presence of aspiration-penetration and to monitor potential benefits of swallowing maneuvers and positioning changes. Objective assessments are ideal when recommending exercises to improve swallowing or when considering changes to food/liquid textures, to ensure that these changes will positively impact on swallow safety and/or function. During instrumental evaluation of swallowing, the patient is given foods and liquids of varying consistencies (eg, soft/hard foods and thin/thicker liquids), in amounts progressing from smaller to larger bolus sizes. To assess oropharyngeal swallowing, speech-language pathologists may use videofluoroscopy or fiberoptic endoscopy.

The **videofluoroscopic swallow study (VFSS)**, also called the **modified barium swallow (MBS)** study or cookie swallow study, provides a “moving x-ray” of chewing and swallowing.¹⁵⁶ It is performed in a radiology suite with the patient in a sitting or standing position. To visualize swallowing, the test employs small amounts of barium mixed with foods and liquids. Exposure to radiation is limited, with the fluoroscope turned off and on during the procedure. VFSS is not useful for assessing saliva control due to lack of contrast in the saliva. A VFSS may also include a screen of esophageal function. However, SLPs do not diagnose esophageal dysphagia; this requires involvement of a radiologist or gastroenterologist.

The **Modified Barium Swallow Impairment Profile (MBSImp)**—while not an assessment per se—is gaining attention as an objective way to interpret and score VFSS studies. Training is available online and scoring allows for attention to 17 different components of the swallow, including esophageal clearance. Results can be used to determine the impact of swallowing interventions and exercises and to track change in functioning over time.¹⁵⁷

Fiberoptic endoscopic evaluation of swallowing (FEES) is useful for visualizing saliva control, assessing sensory components of swallowing, and detecting signs of gastroesophageal reflux above the upper esophageal sphincter. A flexible endoscope is inserted through the nasal cavity and toward the throat, and provides direct visualization of the base of tongue, larynx, and pyriform sinuses. A colored dye may be used to visualize food, but no radiation exposure is involved.¹⁵⁸ Because no fluoroscopy is involved, this assessment can be more easily performed in a mobile setting or in acute care units, where it may be difficult to move a patient to diagnostic imaging for assessment.

Management of Dysphagia in MS

When intervention for swallowing difficulties is necessary in patients with MS, goals are to reduce the risk of aspiration and aspiration pneumonia; improve comfort of swallowing, nutrition and hydration; and increase independence, participation, and quality of life.

Management strategies for dysphagia include¹⁵⁹

- Positioning of trunk, legs, and arms
- Specialized positioning of the head and neck
- Manipulation of food/liquid consistencies
- Modifications to eating schedules
- Modifications to bolus size
- Consuming smaller, more frequent meals
- Use of nutritional supplements
- Reducing the rate of eating
- Adding moisture to foods to improve bolus lubrication
- Alternating solids and liquids
- Specialized feeding equipment
- Manipulating the patient’s environment
- Training the patient, family, and caregivers
- Following up with appropriate professionals (eg, a dietitian, gastroenterologist, or otolaryngologist)

Education for patients and family or caregivers is crucial for management of dysphagia. Education

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should cover the importance of oral care and feeding and their relationship to aspiration pneumonia—dysphagia is necessary but not sufficient for development of aspiration pneumonia, and several other modifiable factors increase risk.¹⁶⁰ If there is cognitive or mobility impairment, patients may need assistance with feeding, food preparation, and swallowing strategies or maneuvers. Education can also help guide decision-making about oral feeding at the risk of aspiration pneumonia or if alternatives to oral feeding for nutrition are being explored.

Various direct treatments are available for dysphagia. These include strengthening and resistance exercises, swallowing maneuvers, respiratory training, strategies to increase sensory awareness, and neuromuscular electrical stimulation or transcranial stimulation.^{161,162,163} Some techniques, such as chin tuck (a maneuver involving tucking the chin to the chest while swallowing), may actually increase swallowing risk for some individuals. Exercises and maneuvers should be recommended only after objective assessments are performed to determine targets and effectiveness. Similarly, it is ideal to objectively assess changes to food or liquid textures. In some cases, what is considered an “easier” diet texture

may actually increase risk (eg, thickening of fluids can also increase the risk of impaired swallowing safety in ways that are not easily observed at bedside).

Patients unable to acquire or maintain food or nutritional supplement intake by mouth, or unable to eat or drink safely due to aspiration, are candidates for tube feeding. In general, greater involvement of the brainstem in MS translates to greater difficulty with swallowing. If tube feeding is being considered, the gastrointestinal tract must be accessible and sufficiently functional. A dietitian should be involved to assist in implementing plans and ensuring nutritional balance is achieved.

The use of alternatives to oral feeding is complex and emotional for many individuals. It may help to understand a few myths and facts related to tube feeding ([Table 14](#)).

Coyle and Matthews note: “Placement of feeding tubes in patients with documented gastroesophageal reflux or other upper digestive conditions—even in a patient with dysphagia— may dramatically increase the risk of aspiration far beyond the patient’s aspiration risk related to oropharyngeal dysphagia.”¹⁶⁵

Table 14. Myths and Facts Associated with Tube Feeding

Myths	Facts
<ul style="list-style-type: none"> • Aspiration and aspiration pneumonia are the direct result of oropharyngeal dysphagia • Feeding tube placement is the only way to eliminate the risk of aspiration pneumonia • When a feeding tube is in place, it is the only source of nutrition and hydration • Feeding tube placement means dysphagia therapy stops • Tube feeding is the best choice for all individuals with significant dysphagia 	<ul style="list-style-type: none"> • Aspiration comes from the mouth and/or stomach • Feeding tube placement does not eliminate the risk of aspiration pneumonia • Many patients can continue eating and drinking by mouth after feeding tube placement • Good oral hygiene makes aspiration less risky • Quality of life should be considered in all decisions about alternatives to oral feeding • The patient and/or family or caregiver—not the medical team—makes the final decision regarding tube feeding



Further, D'Amico et al note: "if...we do not contemporarily assess the quality of life and overall disability level [at the time of tube feeding in advanced progressive MS] we will describe a reduction in death but thereby...create a surviving population of patients with significant impairment and disability."¹⁶⁶

A number of factors may complicate treatment of swallowing dysfunction in patients with MS. These include:

- Lack of patient or caregiver understanding
- Lack of professional awareness or training
- Lack of adequate food or drink preparation, or poor availability of pre-prepared foods and drinks
- Cost of modified consistencies and thickening agents
- Limited options for re-assessment
- Poor palatability of suggested consistencies
- Lack of caregiver support
- Lack of resources (eg, adaptive equipment, trained professionals)
- Patient/family embarrassment
- Confusing and changing terminology, eg,
 - Drink consistencies: thin, nectar, mildly thick, moderately thick, thickened, regular, honey, pudding
 - Food consistencies: pureed, ground, chopped, soft, mechanical soft, easy to chew, regular
- Patient not wanting dietary modifications or alternative to oral feeding

Some patients may choose not to pursue management of swallowing changes. For example, patients who are approaching end of life may wish to know what foods they can eat with relative safety, even if there is an increased risk of choking and aspiration pneumonia. This is well within their rights, and SLPs have a responsibility to respect patients' decisions and provide education and consultation to help reduce the risks.

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
- Dental disease
- Depression
- Changes in MS (exacerbations, remission, progression)
- Other medical conditions in addition to MS

ORAL HEALTH

Oral care and hygiene is a crucial aspect of MS care, yet healthcare professionals may be focused on DMTs, urinary tract infections, and other medical complications associated with MS, to the detriment of oral health. Simple things that can help improve oral 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. Indeed, studies suggest that patients with poor oral hygiene and high pathogen loads in their saliva are at increased risk of pneumonia.^{167,168}

For patients with MS, dental care may take low priority. Possible reasons include lack of, or inadequate, dental insurance; lack of transportation or accessibility; dependence on caregivers; cognitive impairment; depression; and fatigue. Other challenges may include neurologic dysfunction in the trunk and/or extremities that make oral self-care difficult or impossible; pain caused by temporomandibular joint dysfunction, or glossopharyngeal or trigeminal neuralgia; or atypical facial pain.¹⁶⁹ Patients may lack tools or products (eg, rinses) that could make oral care easier and more effective, and sometimes their MS-associated healthcare issues simply take precedence over oral health.

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

Xerostomia, also known as “dry mouth,” results from decreased or lack of saliva production. It is a symptom, not a disease. Xerostomia can affect both hard and soft tissues in the mouth, and decreased saliva increases the risk of caries, fungal infections, and periodontal disease.^{170,171} Factors that increase risk of xerostomia include decreased oral intake, dysphagia, oral infections, and infections in other parts of the body.¹⁷⁰

Signs and symptoms of xerostomia include:¹⁷⁰

- Excessive thirst
- Decreased taste
- Burning/tingling sensation of the mouth and/or tongue
- Red, raw tongue
- Sores in the mouth or at the corners of the lips
- Dry, cracked lips
- Difficulty swallowing
- Sore throat/hoarseness
- Bad breath
- Speech problems, including slurred speech
- Dry nasal passages
- Difficulty wearing dentures

Good oral hygiene lessens the impact of xerostomia. Treatment for xerostomia focuses on relief of symptoms and prevention of oral complications, and includes:^{170,172}

- Routine visits to dental professionals
- Twice daily brushing (teeth and tongue), flossing, and rinsing; use high-fluoride toothpaste to help prevent caries, and a soft-bristled toothbrush (manual or electric) to avoid damaging enamel, gingiva, and other mouth tissues
- Use of over-the-counter oral lubricants
- Review medications that may contribute to xerostomia (baclofen, oxybutynin) with the physician or nurse to consider dose reductions or other modifications
- Consider medications that stimulate salivary glands (eg, locarpine, cevimeline);
- Avoid alcohol and alcohol-containing mouth rinses (including toothettes)
- Avoid smoking (tobacco or cannabis), chewing tobacco, and vaping
- Increase hydration (but avoid alcohol, caffeine, and sugary drinks)
- Use sugar-free gum or hard candy to moisten the mouth; avoid use of menthol lozenges (menthol can be dehydrating)
- Avoid highly spicy foods, foods with high sugar content, and fruits and vegetables with high acid content¹⁷³
- Monitor sodium intake
- Manage gastroesophageal reflux



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 that sometimes culminate in a vicious circle. 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.

EXERCISE

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."¹⁷⁴ Indeed, exercise training in patients with MS has been shown to provide improvements in walking, balance, fatigue, cognitive function, depression, and quality of life.^{175,176,177} Exercise can improve muscular and aerobic fitness in patients with MS, and may also benefit sleep quality and reduce cardiovascular and metabolic comorbidities.¹⁷⁴ Moreover, exercise has been associated with reductions in MS relapse rates and slowing of disability progression.^{178,179}

Available evidence has been used to develop guidance for aerobic and strength training in patients with MS who have mild-to-moderate disability (**Table 15**)¹⁸⁰ Note, however, that the guidance below is not intended for individuals with more severe disease. Further, regardless of

Table 15. Guidance for Exercise in Patients with MS and Mild to Moderate Disability^{Adapted from 180}

	Aerobic Activity	Types
Frequency	2x weekly <ul style="list-style-type: none">Aerobic and strength training activities can be done on the same dayMuscles should be rested for ≥ 1 day between strength training sessions	2x weekly
Quantity	<ul style="list-style-type: none">Gradually increase activity to ≥ 30 minutes during each workout session	<ul style="list-style-type: none">Try to do 10-15 repetitions of each exerciseGradually work up to doing 2 sets of 10-15 repetitions of each exercise
Intensity	<ul style="list-style-type: none">Perform exercises at moderate intensity<ul style="list-style-type: none">Usually defined as 5-6 on a scale of 10 and causes heart rate to increaseAs a general rule, can talk but not sing a song during the activity	<ul style="list-style-type: none">Pick a resistance (eg, free weights, cable pulleys, bands) heavy enough to barely, but safely allow completing 10-15 repetitions of the last setRest for 1-2 minutes between each set and exercise
Examples	<ul style="list-style-type: none">Upper body exercises: arm cyclingLower body exercises: walking, leg cyclingCombined upper and lower body exercises: elliptical trainer <p>Other types of exercise with potential benefits</p> <ul style="list-style-type: none">Elastic resistance bandsAquatic exerciseCalisthenicsYoga or Tai Chi	<p>Upper and lower body</p> <ul style="list-style-type: none">Weight machinesFree weightsCable pulleys

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disease severity, many factors should be considered when developing an exercise program. The program should be tailored specifically to the patient's needs, abilities, and impairments (eg, specific muscle weaknesses, fatigue requiring longer rest breaks), and the frequency, quantity, and intensity of exercise should be flexible given the variable nature of MS disease manifestations.

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), high salt intake (increased risk of autoimmune inflammation)^{182,183} and the gut microbiome (dysbiotic gut microbiota associated with inflammation and autoimmune diseases).¹⁸⁴ There is great interest in the role of dietary interventions in autoimmune diseases such as MS, however to date no specific diet has been advocated.¹⁸⁵

General dietary recommendations for individuals with MS include:

- Eat calcium-rich foods
- Eat foods containing or fortified with vitamin D
- Choose lean cuts of meat, poultry, and fish
- Increase omega-3 and omega-6 fatty acids in the diet
- Eat 5–9 servings of vegetables (including dark green leafy vegetables) daily, and fresh fruit daily
- Avoid saturated fats
- Eat whole-grain breads and fiber-rich foods
- Stay hydrated
- 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 3 meals a day or more—preferably 5–6 small meals a day including breakfast
- Watch 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. Patients can begin with small steps and approach dietary adjustments as a lifestyle change rather than a 'diet.'

SMOKING

Cigarette smoking is a known risk factor for MS, and smokers are more likely to be diagnosed with progressive MS than never-smokers.^{186,187} In addition, Healy et al reported that among patients with MS, current smokers had significantly worse disease at baseline (based on EDSS scores, multiple sclerosis severity score, and brain parenchymal fraction) and also converted from RMS to secondary progressive MS more quickly compared to never-smokers.¹⁸⁸ As mentioned previously, individuals with MS should avoid smoking, and current smokers should be encouraged to quit and provided with appropriate support and referrals for smoking cessation.

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. Brass and colleagues reported that in a survey of 2,375 individuals with MS, 70% screened positive for one or more sleep disorders—most of which were previously undiagnosed.¹⁸⁹ Sleep disorders identified included obstructive sleep apnea, insomnia, and restless leg syndrome.¹⁸⁹

The Epworth Sleepiness Scale is a screening instrument for sleepiness used in research.^{190,191} However familiarity with the questions may be useful for informal assessment of sleepiness in clinical practice. Patients score their likelihood of dozing off on each item below using a scale of 0 ("no chance") to 3 ("high chance").

- 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

Patients with total score of 10–15 “may” have excessive sleepiness; those with a total score of 16–24 “are” excessively sleepy; both groups should “consider medical attention” for their sleepiness.

Strategies for improving sleep habits include avoiding caffeine later in the day, establishing a consistent sleep schedule, effective management of MS symptoms that impact sleep, exercising, sleeping in a cool room, and avoiding TV or electronics in bed.

PSYCHOSOCIAL WELL-BEING

Psychosocial well-being is another important dimension of the ‘total patient’ with MS. The lifetime prevalence for depression in MS is ~50%, with reported values that vary depending on rating scales and screening measures used.^{192,193,194} In addition, Mohr and colleagues have reported that only about one-third of patients with MS diagnosed with major depressive disorder receive antidepressant medications.¹⁹⁵ Factors contributing to depression in patients with MS include the psychosocial effects of MS-related disability, including losses in social and vocational roles, loss of participation abilities, uncertainty about disease course, and lack of hope. Additional factors include direct effects of lesions on brain structures related to mood state and side effects of therapeutic agents such as interferon beta or steroids.^{197,198} 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.¹⁹²

For these reasons and because depression increases risk of suicide, the entire MS care team should routinely screen patients for depression.

To this end, a 2-question rapid screen for depression can be useful:¹⁹⁶

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?

An affirmative to either of these questions should prompt further evaluation for depression.

Another screening tool is the **Patient Health Questionnaire (PHQ-9)**, a 9-item depression scale based on DSM-IV.¹⁹⁷ This tool is ideally used in primary care settings. It is available in the public domain¹⁹⁸ and can be completed in the waiting room. The PHQ-9 can be used to make a tentative, criteria-based diagnosis of depression and provides a severity score that can be used to guide treatment and monitor treatment response.

A combination of psychotherapy and pharmacological therapy is advocated for patients with MS and depression.^{192,199} **Table 16** lists 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%).¹⁹⁵ Antidepressants with indications for generalized anxiety disorder are noted in **Table 16**. Depending on the practice environment, mental health care for patients with MS may be provided by neurologists, primary care clinicians, and mental health professionals. Clinicians who treat patients with MS should maintain a strong referral network that includes mental health professionals, services, and resources.

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Table 16: 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 Inhibitors		
Duloxetine (Cymbalta®)	40–120 mg	✓
Desvenlafaxine (Pristiq®)	50–100 mg	---
Venlafaxine (Effexor®)	75–225 mg	✓
Other		
Bupropion (Wellbutrin®)	150–450 mg	---

COMPLEMENTARY AND ALTERNATIVE MEDICINE

It is important for clinicians to be familiar with, and to ask patients about, complementary and alternative medicines and supplements that they may be taking or have interest in. Patients should know that caution is sometimes warranted for some of these interventions. For example some treatments may stimulate the immune system, which is undesirable for patients with MS. Drs. Allen and Nathaniel Bowling provide information about a range of complementary and alternative medicinal approaches along with considerations for their use in patients with MS.²⁰⁰



Putting it All Together—Case Scenario 1

CHARLOTTE



Charlotte is 67 years old. She was diagnosed with MS 35 years ago. She lives at home with her husband, who is 70 years old and is generally in good health, but somewhat frail.

Charlotte's current MS challenges include late-onset cerebellar issues presenting as ataxia, problems with fine motor coordination, and fatigue. She reports some difficulty with dressing and transfers (toilet and shower). Her husband has been trying to help but is finding it increasingly difficult. She reports having one significant fall in the recent past, along with several other "close calls."

Charlotte is a former smoker (24 pack year); she quit 10 years ago. Last year, she was diagnosed with chronic obstructive pulmonary disease (COPD), which currently is considered mild (GOLD Stage 1). Charlotte also has osteoarthritis primarily affecting her hips and right hand.

ASSESSMENTS

• Physical Therapy

- 2-minute Walk Test, with no assistive device: 320 feet; norm for age is 508 feet
- 25-Foot Walk, with no assistive device: 9.3 seconds; norm is < 6.1 seconds
- Berg Balance Scale: 25/56; consistent with high fall risk
- Five Times Sit to Stand: 19 seconds; consistent with high fall risk

• Occupational Therapy

- 9-hole Peg Test: 48 seconds (right hand); 27 seconds (left hand)
- Box and Block Test: 20 blocks (right hand); 28 blocks (left hand)

- Dynamometry (hand grip strength): 11 lbs (right hand); 18 lbs (left hand)
- Canadian Occupational Performance Measure for goal identification

- **Speech-Language Pathology:** Charlotte was referred to SLP for speech and swallowing (no issues noted) and for breathing support.

• Other assessments:

- PHQ-9 score: 7 (suggests mild depression, need for watchful waiting)
- Home evaluation identifies a need for grab bars and an anti-slip mat in the combined tub/shower, removal of throw rugs and mats in hallways

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PATIENT GOALS

- Improve balance
- Use adaptive equipment and aids to help with dressing and balance
- Safely navigate the home and community with the least restrictive assistive device
- Reduce fatigue
- Independently participate in a home or community exercise program
- Participate in a home exercise program (HEP)
- Participate in education
- Address fine motor skills

INTERVENTIONS

- Energy management education
- Exercise program designed to promote stretch, strength, endurance, and balance
 - Cool water aerobics class once weekly at her gym
 - HEP for upper extremity gentle strengthening and coordination, focusing on hands
- Trial adaptive equipment and assistive devices; selections:
 - Button hook, sock aid, long-handled shoe horn, elastic shoelaces (aids that limit her need to bend over may also help with her COPD)
 - 4-wheel walker with a seat
- Install grab bars in the bathroom

- Education
 - Exercise philosophy, precautions, parameters
 - Energy management techniques
 - Joint protection techniques
 - Floor transfers
 - Falls Prevention Program at the Senior Center

FOLLOW-UP

- Initial schedule:
 - Once weekly for 6 visits
 - Education on HEP, energy management, use of adaptive equipment, etc
 - Review/adjustments to rehab plan as needed

3-MONTH RE-ASSESSMENT

- Charlotte is adhering to HEP, attending swim classes, and thinking about starting a yoga class at the Senior Center
 - She is finding her 4-wheel walker with seat very beneficial because she can sit when fatigued or short of breath
 - 25-foot Walk, with walker: 6.3 seconds (a 20% change is clinically meaningful)
 - 2-minute Walk Test, with walker: 475 feet (may be restricted by COPD)
 - Berg Balance Scale: 40/56
 - Five-time Sit to Stand: 13.2 seconds (now within normal limits)
 - 9-hole peg Test: 38 (right) and 25 (left)
 - Box and Block Test: 26 (right) and 32 (left)
 - Dynamometry: 15 (right) and 22 (left) case



Listen to Christine Smith, OTR/L, MSCS,
discuss key takeaways for this case





CASE QUESTIONS

Please click on your answer choice

1. When choosing an assistive device for Charlotte, which of the following should be taken into consideration?
 - A. Patient acceptance of recommended equipment
 - B. Safe mobility with demonstration of optimized motor control
 - C. Comorbidities that may influence device selection
 - D. All of the above

2. Which is/are true of Charlotte's HEP?
 - A. To provide her with the greatest benefit, it should be MS-specific
 - B. To facilitate the greatest amount of progress, it should be updated regularly by her rehab team
 - C. On a daily basis, it should be prioritized as the most important use of her energy
 - D. All of the above



Putting it All Together—Case Scenario 2

TOMMY



Tommy is an 11-year-old boy who was diagnosed with multiple sclerosis 1 year ago following 2, or possibly 3, episodes of visual disturbance and sensory motor weakness

MRI findings showed multiple periventricular white matter changes as well as gadolinium enhancing lesions in the cortical region and the brainstem. He started treatment with a DMT soon after diagnosis. He had a recent relapse manifesting as INO, sensory symptoms (vertigo, tingling, numbness), and mild cognitive impairment affecting his speech and slowing his ability to complete classwork and homework. His mother is particularly concerned about the cognitive changes, and told the neurologist “we want to do everything we can” to keep Tommy healthy and functioning well at home and at school. The neurologist has changed Tommy’s DMT and referred him for rehabilitation.



Listen to Susan Bennett, PT, DPT, EdD, NCS, MSCS discuss Tommy’s PT assessment, with a focus on balance



ASSESSMENTS

Physical Therapy

- Sensation to touch/localization
- Proprioception
- Oculomotor testing
 - Saccades
 - Convergence
 - Smooth pursuits
 - Vestibulo-ocular reflex
 - Gait
- Running
- Kicking/dribbling a ball

- Balance
 - Tandem walk
 - 1-legged stand
 - Standing on an uneven surface with eyes open or closed
- Manual muscle test, both lower extremities

Occupational Therapy

- Interview with Tommy and parent(s) to understand specific struggles

Speech-Language Pathology

- Brief Neuropsychological Battery for Children



GOALS

- Return to baseline visual status
- Return to baseline balance
- Improvement in timely completion homework and classwork

REFERRALS

- Ophthalmology
- Physiatry

INTERVENTIONS

- BEEMs
- Encourage physical activity/exercise
- Practice activities of daily living – dressing (buttoning, etc)
- Liaise with school counselors and teachers to ensure appropriate accommodations



Listen to Anjali Shah, MD, discuss key takeaways from this case



CASE QUESTIONS

Please click on your answer choice

1. Which of the following DMTs is FDA-approved for treatment of Tommy's MS?

- A. Glatiramer acetate
- B. Fingolimod
- C. IFN β -1a
- D. Siponimod

2. How would Tommy's MS be expected to differ from adult-onset MS?

- A. Less accumulated disability over time
- B. Less severe relapses with more rapid recovery
- C. More frequent relapses early in the disease course
- D. Progressive disease from onset



Putting it All Together—Case Scenario 3

ASHLEY



Ashley is a 30-year-old first grade teacher who was diagnosed with RRMS 3 years ago

She has 2 young children. In the first few months after her diagnosis, she experienced 3 relapses, involving left optic neuritis, bilateral leg sensory loss, and mild left-sided weakness. Since then she had felt she was stable until a new relapse 1 month ago, at the beginning of the summer. During this relapse, Ashley experienced diplopia, new swallowing difficulty, ataxia with falls, weakness, difficulty following conversations and remembering details, and urinary urgency.

At an appointment with her neurologist during the relapse, which she attended with her husband, her general medical examination was normal. Her neurologic exam revealed grossly normal mental status, but also cranial nerve abnormalities including left optic nerve pallor with a partial afferent pupillary defect, right INO, and subtle right lower facial weakness. Her motor exam revealed mild weakness in the right arm and leg (4/5 power), with increased reflexes in both legs and a right-sided Babinski's sign. A moderate sensory loss of proprioception and vibration was present in her legs. Pinprick and temperature sensations were intact. 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 or walk in tandem gait. She repeatedly asked for clarification and appeared to be distracted during the conversation. Her husband took

notes throughout, frequently answered questions for her, and appeared frustrated by her repeated requests for clarification.

The neurologist ordered a brain MRI, which revealed 3 new lesions, including an enhancing brainstem lesion. Ashley was treated with high-dose corticosteroid therapy for 3 days, and her DMT was changed. She received baclofen (10 mg TID) to help manage her increased reflexes and oxybutynin (5 mg TID) for urinary urgency.

At follow-up with the neurologist 1 week after completing steroid therapy, Ashley reported marked fatigue, changes in her voice ("not as loud"), ongoing frustration with communication at home and feeling like she is "dropping the ball," loss of left hand dexterity, leg weakness and spasticity with intermittent stumbling, and ongoing urinary urgency. She also complained of memory problems and disorganization. She was concerned about how she will manage scheduling for her children and at her workplace, given the new school year starting and struggles she experienced with handling the kids' schedules over the summer. She was referred for physical therapy to address balance issues and speech therapy to address changes in communication and swallowing.



ASSESSMENTS

Physical Therapy

- Records from her PT evaluation at an outside agency were unavailable. When asked about it, Ashley reported difficulty with getting time off work and affording co-payments for services. She said she “went one time” to PT, and was given a list of exercises, but she has since misplaced the list.

Speech Therapy

- Ashley was initially seen at the university swallowing center, in the radiology department, for an MBS
- During the interview, Ashley reported occasional difficulties “getting the swallow started” and “a feeling of choking”
- On evaluation of intra-oral structures, the SLP noted very dry oral mucous membranes; otherwise all was normal
- There was no history of aspiration pneumonia
- The MBS was unremarkable for safety concerns (no penetration or aspiration observed). Vallecular residue was observed, but cleared with multiple swallows. Ashley had an overall delay in initiation of pharyngeal swallow and mildly reduced tongue base retraction
- Ashley was referred to a regional voice program for visualization of her larynx to further assess vocal changes. She was found to have no structural changes in her larynx. She declined further voice intervention and chose instead to focus on other communication concerns.
- Today, Ashley and her husband have a lengthy conversation with the SLP regarding frustrations and conflict between them at home. Her husband feels she is ignoring things he says. He complains that when they are with friends, her stories go on and on and “she never gets to the point.” Ashley expresses fear that won’t be able to handle both work and her kids’ schedule this fall because she struggled over the summer and had to check details over and over.

- The SLP completes a high-level assessment of Ashley’s verbal reasoning and executive strategy skills using the FAVRES. Results show that Ashley is having difficulty filtering important vs irrelevant information from large bodies of text and uses organization strategies inconsistently. She also has difficulty recalling details of instructions during the assessment and frequently refers back to the written instructions; as a result, she exceeded the typical time range for completion.

REHABILITATION GOALS

1. Develop and practice memory and organization strategies for use in conversation and at work and home
2. Practice in identifying relevant and irrelevant information in text
3. Practice in conversational topic maintenance
4. Conversational coaching and communication education for the family
5. Liaise with workplace regarding work accommodations and modifications if Ashley is agreeable

PLANS AND INTERVENTIONS

- Ask the neurologist about discontinuing or decreasing doses of oxybutynin and baclofen, which may be contributing to xerostomia; or considering alternatives to treat her overactive bladder; Ashley is given a urology referral
- Provide education about the role of xerostomia in speech and swallowing; suggest strategies for management, eg,
 - Use of over-the-counter oral lubricants and xylitol-containing chewing gum; alcohol avoidance (beverages and mouthwashes) and smoking avoidance.
 - Add moisture to foods to improve bolus lubrication, to include taking medications in applesauce or yogurt swallowing multiple times as needed.
- Advise consultation with a dietitian if she has concerns about maintaining nutrition

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- Provide oral and written information about swallowing issues in MS, with explicit instructions to notify the SLP or treatment team
 - Provide strategies to facilitate conversation at home at home and at work, and to assist with organization and planning.
 - Encourage routine communication with the SLP by telephone, to check in and troubleshoot strategies
 - Recommend proper vocal hygiene and use of a voice amplification system in the classroom
 - Explain how exercise can improve strength, stamina, and balance, and how stretching can improve spasticity; encourage follow up with the PT
 - Provide education about fatigue management, including energy conservation strategies.
 - Suggest an OT consult to help with dexterity and coordination issues (however, Ashley defers, citing challenges with co-payments and child care)
- ### FOLLOW-UP 3 MONTHS LATER
- Ashley reports improvements in swallowing after her neurologist stopped the oxybutynin and reduced the baclofen dose. She still occasionally has difficulty with initiating a swallow, but says that adding moisture to foods seems to help. Her weight has remained stable, so she has not consulted a dietitian.
 - She purchased a wearable amplification system and is using it in the classroom to protect her voice and reduce strain. She chose to pay out of pocket as she did not wish to involve her employer at this time.
- She has been successfully using strategies to organize her duties within the classroom and is better able to determine important vs irrelevant information in work-related written communications. To allow more time to focus on organizing and to manage her fatigue, she has cut back on work-related extracurricular commitments.
 - She and her husband have been successfully using strategies to help her remember conversations at home, among them recording important details and plans in a central notebook and organizing activities using a shared online calendar.
 - Her balance and strength have not returned to normal, but have improved.
 - She has been consulting periodically with the PT and now has an organized exercise routine focused on balance, stretching, and strength.
 - She is using energy management strategies recently learned, and reports a marked decrease in her fatigue.
 - Her overactive bladder symptoms have resolved.
 - Impaired dexterity continues to interfere with activities of daily living and work. She is again encouraged to seek OT evaluation and treatment.
 - A baseline cognitive assessment is suggested, but she declines, citing concerns about possible employment implications and her husband's reaction if deficits are documented



Listen to Carolyn Knoechel, MSc, SLP, R.SLP,
discuss key takeaways for this case





CASE QUESTIONS

Please click on your answer choice

- 1. Ashley arrives at a follow-up appointment and tells you that she has been called by HR due to trouble keeping up with her work tasks. What would you recommend?**
 - A. Work harder to focus on her strategies and have her report back in 6 months
 - B. Coordinate OT and SLP services to support her at work; reconsider neuropsychological testing
 - C. Consider an alternative career that would allow more flexible scheduling and less pressure
 - D. Urge her to pursue legal action for discrimination

- 2. Ashley calls to report that last night at dinner, a piece of meat got stuck in her throat near her ribs for about 20 minutes. She tried to drink water and began to vomit the water. She used deep breathing until finally “it felt like everything unplugged”. This was frightening for her and her husband, as well as her children. She is worried she will never be able to eat again without panicking. What should you advise her to do?**
 - A. Tell her to go straight to the emergency room
 - B. Refer her to a gastroenterologist and advise her to seek urgent care if it happens again
 - C. Consider medication for anxiety
 - D. Request FEES



Conclusion

Rehabilitation is an essential aspect of comprehensive MS care. Overarching goals are to maintain and/or improve function and reduce the impact of the disease on personal activities, social participation, independence, and quality of life. Rehabilitation specialists provide assessments, interventions, and education to address specific MS symptoms, improve fitness and conditioning, promote health and wellness, and optimize function at work and at home.

The rehabilitation team is multidisciplinary and includes a network of neurologists, physiatrists, PTs, OTs, SLPs, dietitians, and neuropsychologists with the patient at the center. Decisions about rehabilitation should be individualized with input from the patient and family members or caregivers, in accordance with their specific needs and wishes.

Specific examples of situations warranting rehabilitation include:

- A sudden or gradual worsening of function that affects mobility, independence, safety, or quality of life
- Specific symptoms of MS, such as difficulty with mobility; fatigue; dysphagia; dysarthria; pain; bladder or bowel dysfunction; cognitive dysfunction; depression, anxiety, or other affective disorders; and diminished quality of life.

Rehabilitation for patients with MS can be helpful at any age and at many times over the course of the disease. Assessment for rehabilitation services may be especially beneficial early in the disease course, when behavioral and lifestyle changes may be easier to make. Early interventions can help prevent or delay functional and cognitive decline. Rehabilitation plans should be flexible and require frequent re-assessment so that they may be adapted to changing patient needs.



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Appendix 1

Assessments Used in Multiple Sclerosis*

Name	Abbreviation	Function Assessed
2-Minute Walk Test	2MWT	Distance walked over 2 minutes, as a test of endurance
6-Minute Walk Test	6MWT	Distance walked over 6 minutes, as a sub- maximal test of aerobic capacity and endurance
9-Hole Peg Test	9-HPT	Upper body function; manual dexterity
12-Item MS Walking Scale	MSWS-12	Impact of MS on walking ability
Assessment of Intelligibility of Dysarthric Speech	N/A	Single word and sentence intelligibility, speaking rate
Berg Balance Scale	BBS	Static balance and risk of falls in adults
Box and Block Test	BBT	Unilateral gross manual dexterity
Brief Neuropsychological Battery for Children	BNBC	Cerebral function and cognitive impairment (including verbal reasoning, learning, and memory) in children
Brief Repeatable Neuropsychological Battery	BRNB	Auditory processing speed and working memory, visual processing speed and working memory, auditory/verbal episodic memory, visual/spatial episodic memory, expressive language, spatial processing, executive function
Canadian Occupational Performance Measure	COPM	Patients' self-perception of performance in everyday living (self-care, leisure, and productivity)
Cognitive Communication Checklist for Acquired Brain Injury	CCCABI	Cognitive communication deficits
Cognitive Linguistic Quick Test	CLQT	Cognitive communication
Dix-Hallpike Test	N/A	Diagnostic for benign paroxysmal positional vertigo (BPPV) caused by otoliths (calcium particles) in the posterior semicircular canal
Dynamic Gait Index	DGI	Ability to modify balance while walking in various situations representing external demands
Dysphagia in Multiple Sclerosis Questionnaire	DYMUS	Swallowing difficulties
Eating Assessment Tool-10	EAT-10	Swallowing difficulties
Expanded Disability Status Scale	EDSS	Level of functioning and impairment, including limitations in mobility
Fiberoptic Endoscopic Evaluation of Swallowing Study	FEES	Sensory components of swallowing, saliva control, gastroesophageal reflux (visualization)
5 Times Sit-to-Stand Test	5XSST	Functional lower extremity strength, transitional movements, balance, fall risk, exercise capacity

*Identified here are assessments mentioned specifically in this Primer; many others are available and in use for evaluating patients with MS.

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Assessments Used in Multiple Sclerosis (cont.)

Name	Abbreviation	Function Assessed
Frenchay Dysarthria Assessment	N/A	Multiple speech systems (eg, palate, tongue, laryngeal, reflexes)
Functional Assessment of Verbal Reasoning and Executive Strategies	FAVRES	Cognitive communication and executive function
Functional Reach Test	FRT	Stability assessed as maximum distance the patient can reach in front, to the left, and to the right without loss of balance
Head Thrust Test (or Head Impulse Test)	HTT (HIT)	Angular vestibulo-ocular reflex
Manual Muscle Test	MMT	Muscle strength and function
Minimal Assessment of Cognitive Function in MS	MACFIMS	Auditory processing speed and working memory, visual processing speed and working memory, auditory/verbal episodic memory, visual/spatial episodic memory, expressive language, spatial processing, executive function
Modified Ashworth Spasticity Scale	MAS	Spasticity in patients with lesions in the central nervous system
Modified Fatigue Impact Scale	MFIS	Impact of fatigue in terms of physical, cognitive, and psychosocial functioning
Montreal Cognitive Assessment	MoCA	Mild cognitive change across multiple domains: attention/ concentration, executive function, memory, language, visuoconstructional skills, conceptual thinking, calculations, and orientation
MS Functional Composite	MSFC	Timed 25-foot Walk + 9-Hole Peg Test + Paced Auditory Serial Addition Test (PASAT) (used in research)
MS Neuropsychological Screening Questionnaire	MSNQ	Self-reported cognitive functioning in multiple domains
Mt. Wilga High Level Language Test	N/A	Cognitive communication
Paced Auditory Serial Addition Test	PASAT	Cognitive function assessed as calculation ability and auditory information processing speed and flexibility
Patient Health Questionnaire 9	PHQ-9	Depression
Scales of Cognitive and Communication Ability for Neurorehabilitation	SCCAN	Cognitive communication deficits and functional ability
Swallowing Quality of Life Questionnaire	SWAL-QOL	Impact of dysphagia on quality of life
Timed 25-Foot Walk	T25-FW	Quantitative mobility and leg function performance
Timed Up and Go	TUG	Mobility, balance, walking ability, fall risk
Videofluoroscopic Swallow Study (or Modified Barium Swallow study)	VFSS (MBS study)	Swallowing (visualization)



Appendix 2

Abbreviations

2MWT = 2-minute Walk Test	HTT (HIT) = Head Thrust Test (or Head Impulse Test)
5XSST = Five Times Sit-to-Stand	INO = internuclear ophthalmoplegia
6MWT = 6-minute Walk Test	IV = intravenous
9-HPT = Nine-hole Peg Test	LOMS = late-onset multiple sclerosis
AAC = Augmentative and alternative communication	MACFIMS = Minimal Assessment of Cognitive Function in MS
ACTH = adrenocorticotrophic hormone	MAS = Modified Ashworth Spasticity Scale
ADL = activities of daily living	MBS = Modified Barium Swallow
AFO = ankle-foot orthosis	MBSImp = Modified Barium Swallow Impairment Profile
ASHA = American Speech-Language-Hearing Association	MFIS = Modified Fatigue Impact Scale
BBS = Berg Balance Scale	MoCA = Montreal Cognitive Assessment
BBT = Box and Block Test	MS = multiple sclerosis
BEEMS = Balance and Eye-Movement Exercises for People with Multiple Sclerosis	MSFC = MS Functional Composite
BID = 2 times daily	MSCS = Multiple Sclerosis Certified Specialist
BNBC = Brief Neuropsychological Battery for Children	MSNQ = MS Neuropsychological Screening Questionnaire
BRNB = Brief Repeatable Neuropsychological Battery	MSWS-12 = 12-Item MS Walking Scale
BPPV = benign paroxysmal positional vertigo	MWHLT = Mount Wilga High Level Language Test
CCCABI = Cognitive Communication Checklist for Acquired Brain Injury	NP = nurse practitioner
CIS = clinically isolated syndrome	OT = occupational therapy
CLQT = Cognitive Linguistic Quick Test	PA = physician assistant
CNS = central nervous system	PASAT = Paced Auditory Serial Addition Test
COPD = chronic obstructive pulmonary disease	PHQ-9 = Patient Healthcare Question 9
COPM = Canadian Occupational Performance Measure	PO = per mouth
DGI = Dynamic Gait Index	PT = physical therapy
DMT = disease-modifying therapy	QD = once a day
DYMUS = Dysphagia in Multiple Sclerosis	QOD = every other day
EAT-10 = Eating Assessment Tool	QW = once a week
EDSS = Expanded Disability Status Scale	RMS = relapsing MS
FAVRES = Fiberoptic Endoscopic Evaluation of Swallowing Study	SC = subcutaneous
FDA = Food and Drug Administration	SCCAN = Scales of Cognitive and Communication Ability for Neurorehabilitation
FEES = Fiberoptic Evaluation of Swallowing	SDM = shared decision-making
FES = functional electrical stimulation system	SPMS = secondary progressive multiple sclerosis
GOLD = Global Initiative for Chronic Obstructive Lung Disease	SWAL-QOL = Swallowing Quality of Life
HEP = home exercise program	T25-FW = Timed 25-Foot Walk
HFAD = hip flexion assist device	TID = 3 times a day
	TBI = traumatic brain injury
	TUG = Timed Up-and-Go
	VFSS = Videofluoroscopic Swallow Study
	VLOMS = very late-onset multiple sclerosis

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AUTHORS

Susan Bennett, PT, DPT, EdD, NCS, MSCS
Patty Bobryk, MHS, PT, MSCS, ATP
Carolyn Knoechel, MSc, SLP, R.SLP
Anjali Shah, MD
Christine Smith, OTR/L, MSCS

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