



National
Multiple Sclerosis
Society

Multiple Sclerosis:

The Nurse Practitioner's Handbook

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Introduction

Multiple sclerosis (MS) is a complex, unpredictable disease that challenges patients and clinicians alike. As nurse practitioners (NPs), our role is to guide our patients on their journey with MS, providing education, treatment, and support. This book was designed as a practical reference tool — offering easy access to the information you need to help your patients manage their disease, enhance their quality of life, and make healthy, informed decisions.

We structured this handbook to be accessible and user-friendly for the busy clinician. The book opens with case studies that are intended to set the stage for all that follows. They represent real people, living with all the challenges that they — and you — are likely to confront over the course of the disease. The case studies are followed by an *Overview of MS* and then chapters dealing with *Diagnosis and Treatment*. Each of the symptom chapters includes a *Snapshot* to give a quick overview, followed by expanded information on assessment and management.

We know that no one — patient or clinician — can manage the complexities of MS alone so the section on *Comprehensive Care for the MS Patient* highlights the interdisciplinary healthcare team, strategies for engaging the patient’s family, and the pivotal role of the Multiple Sclerosis Nurse Practitioner in managing these intricate issues.

Included throughout the book, and expanded upon in the final section, are recommended resources and suggestions for additional learning. Our goal is to offer you and your patients access to current, evidence-based resources that complement and enhance effective MS management.

We hope that you will slip this book into your pocket as a quick reference during daily practice. For those of you who prefer electronic resources this text is located in its most up-to-date version on-line at www.nationalMSSociety.org/NPHandbook.

Our involvement with patients with MS over the years has been challenging and ultimately incredibly rewarding for each of us. We hope that you find this book to be a useful and encouraging resource that enhances your ability to provide optimal care and support to your patients with MS.

And now we'd like to introduce you to Chloe, Suzanne, and Owen.

Chloe: Relapsing-Remitting MS (RRMS)

Chloe is a 27-year-old right-handed high school teacher with no family history of MS. She is married with one child and has a history of anxiety and depression. Upon examination, she has a trace reduction in light touch distal RUE. Her cranial nerves, motor, sensory, reflexes, coordination, and gait are intact.

History of Present Illness

2007–2008

- Episode of right-hand numbness and clumsiness followed by OS blurred vision and pain with eye movement (*Ch. 12*).
- MRI of the brain/cervical spine consistent with active demyelinating disease (*Ch. 2*).
- OS symptoms successfully treated with a short course of IV methylprednisolone (IVMP) (*Ch. 12*).
- Diagnosed with RRMS and started on glatiramer acetate (*Ch. 5*).

2009–2010

- Episodic fatigue managed with exercise (*Ch. 10*); ongoing depression managed with antidepressant medication and counseling (*Ch. 9*); vaginal dryness managed with lubricant (*Ch. 14*).
- Clinically and radiologically stable on DMT, with no relapses; married; discontinued DMT upon becoming pregnant (*Ch. 21*).

2011

- Clinically stable during pregnancy; delivered healthy baby girl and breastfed x 3 months.
- “Brain fog,” memory issues, and fatigue; referred for cognitive evaluation (*Ch. 8*).
- Episode of left leg weakness and altered gait; treated with IVMP for relapse and referred to PT for evaluation and management (*Ch. 11*).
- Repeat brain and cervical imaging revealed new disease activity
- Treatment initiated with natalizumab (*Ch. 5*).

2012

- Clinically and radiographically stable. Natalizumab continued, with antibody testing every six months (*Ch. 5*).
- Returned to teaching job with accommodations recommended by OT for energy conservation and by neuropsychologist for memory and attention problems (*Ch. 8 and 10*).

Management of Chloe's MS

Optimal Management

Sub-Optimal Management

2007–2008

- | | |
|---|--|
| <ul style="list-style-type: none">• Thorough workup• Treatment of presenting symptom(s)• Prompt diagnosis• Education about the disease• Initiation of disease-modifying therapy (following discussion of reproductive issues)• Continued management of depression• Follow-up appointments scheduled | <ul style="list-style-type: none">• “Wait and see” approach• Symptom management delayed• Diagnosis and education delayed• Treatment with DMT delayed, increasing risk for recurrent disease activity• Without scheduled follow-up, sub-clinical disease goes untreated |
|---|--|

2009–2010

- | | |
|--|--|
| <ul style="list-style-type: none">• Referral to rehabilitation for fatigue evaluation and management• Ongoing management of depression• Monitoring of disease with yearly MRI and regular check-ups• Discussion of treatment options during pregnancy with patient/spouse• Support system for childbirth in place• Continued monitoring | <ul style="list-style-type: none">• Inadequately managed symptoms interfere with quality of life and primary roles• Uninformed about risk of postpartum relapse |
|--|--|

2011

- | | |
|---|---|
| <ul style="list-style-type: none">• Relapse management postpartum• Clinical and radiographic changes prompt treatment change• Referral for cognitive evaluation | <ul style="list-style-type: none">• Birth of first child, significant relapse, and initiation of treatment start simultaneously• Gait impairment, fatigue, and cognitive symptoms go unmanaged |
|---|---|

2012

- | | |
|--|--|
| <ul style="list-style-type: none">• Rehabilitation referral to support return to work• Ongoing monitoring and follow-up | <ul style="list-style-type: none">• Retires on disability instead of returning to work; marital stress; diminished quality of life |
|--|--|

Suzanne: Transitioning from RRMS to SPMS

Suzanne is a 36 old -year-old right-handed woman on short-term disability (jewelry engraver). She has a maternal aunt and nephew with MS. She is married with twin seven-year-old boys and has a history of osteoarthritis. Upon examination, she has cerebellar tremor with dysmetria in right upper extremity, a spastic, ataxic gait with bilateral hip flexor weakness and right foot drop and ambulates with right ankle foot orthotic (AFO). Recent episodes of choking on liquids.

History of Present Illness

2006:

- Developed bilateral leg weakness three months after delivering twin boys. Diagnosed with multiple sclerosis, treated with IV methylprednisolone and initiated interferon beta 1a SC tiw (*Ch. 5 and Ch. 21*).

2008:

- Acute right leg weakness, spasticity and altered gait. Treated with IVMP with residual leg weakness and mobility limitation. Spasticity managed with baclofen and exercises recommended by PT. Began using cane for balance and weakness (*Ch. 11*). Continued interferon beta 1a SC tiw.

2009:

- Acute bilateral leg weakness, spasticity and altered gait; referral to OT because of left-hand weakness and tremor; Treated with IVMP and switched to natalizumab monthly infusions (*Ch. 11*).

2010–2012:

- Relapse-free on natalizumab, but increasing leg weakness and gait limitations over past 24 months.
- Onset of right hand tremor and dysesthesias (*Ch. 13*). Gabapentin initiated and natalizumab discontinued in 2012.
- Symptoms interfering with ADLs and impacting ability to function at work. Loss of ability to drive leads to strong grief reaction; referral for counseling (*Ch. 9*).
- Extensive discussion of long-term treatment options focusing on intensive symptom management and rehabilitation.
- Continued PT and OT to promote optimal function given her limitations. Referred to S/LP for dysphagia evaluation (*Ch. 16*).

Management of Suzanne's MS

Optimal Management

Sub-Optimal Management

2006

- | | |
|---|---|
| <ul style="list-style-type: none">• Comprehensive workup — to evaluate current symptom management strategies, general health, mood• Continue PT to ensure adequate gait evaluation, assess need for assistive devices for mobility• Continue OT to optimize hand function and ensure adaptation of work/home environments to enhance safety and function• Adequate management of dysphagia | <ul style="list-style-type: none">• Failure to do a thorough workup leads to inadequate management of symptoms• Gait limitations progress; limited function, mobility and increased disability• Failure to involve rehabilitation specialists, leading to reduced function at home and inability to remain in workforce• Increased risk for aspiration; increased social isolation |
|---|---|

2008

- | | |
|---|---|
| <ul style="list-style-type: none">• Discussion of medication options with Susan and her husband — addressing realistic expectations about use of DMTs in SPMS | <ul style="list-style-type: none">• Poor understanding of role of DMTs in disease management in SPMS may lead to unrealistic expectations |
|---|---|

2009

- | | |
|---|--|
| <ul style="list-style-type: none">• Referral to social worker to:<ul style="list-style-type: none">– Discuss workplace options– Discuss financial/ insurance arrangements– Deal with loss of function and driving | <ul style="list-style-type: none">• Early departure from work force; financial implications; marital stress; unresolved grief potentially leading to severe depression |
|---|--|

2010–2012

- | | |
|--|---|
| <ul style="list-style-type: none">• Follow-up visits scheduled every 3–4 months to monitor:<ul style="list-style-type: none">– Spasticity– Ambulation– Mood– Swallowing | <ul style="list-style-type: none">• Inadequate follow-up, possibly resulting in sub-optimal symptom management, unnecessary complications, reduced function and quality of life |
|--|---|

Owen: Primary Progressive MS (PPMS)

Owen, a 42-year-old African American man, is retired on disability from his job as police chief. A divorced father of a 14-year-old daughter, he has a history of hypertension and hyperlipidemia. James now lives with his mother and father and requires full assistance with ADLs and IADLs. Upon examination, he presents in a manual wheel chair propelled by his father, with spastic quadriplegia.

History of Present Illness

2004:

- Conspicuous signs of gait instability; re-assigned to desk duty and started using cane.
- Diagnosed with MS based on clinical and radiographic findings; started on interferon beta 1b in spite of no clinical or radiographic relapses (*Ch. 4*).

2005–2007:

- Switched to glatiramer acetate due to intolerable side effects of interferon injections (*Ch. 5*).
- Progressive lower extremity weakness, spasticity and balance necessitated bi-lateral assistance. Moved in with parents and retired on disability.
- Continued progressive decline — with increased spasticity, lower > upper limb weakness, bladder and bowel dysfunction (*Ch. 6 and 7*). Assistance required with all ADLs.
- IVMP pulse steroids tried with no benefit.
- Began using manual wheelchair in- and outside the house.

2008:

- Continued progressive decline without clinical or radiographic relapses, consistent with primary progressive MS (*Ch. 1*).
- Glatiramer acetate discontinued due to lack of perceived efficacy.
- Depression diagnosed; James reluctant to see a counselor or start medication (*Ch. 9*).

2009–2010:

- Stage 1 sacral sores managed by visiting nurse
- Supra-pubic catheter placed for neurogenic bladder; bowel incontinence
- Spasticity in legs interfered with personal care; ITB pump implanted to address sedation caused by high-dose oral baclofen (*Ch. 11*).
- Suicidal ideation; Lexapro prescribed but counseling again rejected.

2012:

- Mother had stroke; parents no longer able to act as caregivers.
- Placement in long-term care (LTC) facility is recommended and arranged.

Management of Owen's MS

Optimal Management

Sub-Optimal Management

2004–2011

- Comprehensive work-up — to evaluate current symptom management strategies, treatment of pressure ulcer, general health, mood
 - Bowel regimen initiated to address constipation and control issues
 - Referral to PT for exercise (stretching, ROM) regimen
 - Referral to wheeled mobility specialist for suitable power chair with appropriate seating to ensure adequate comfort, safety, and independence
- Failure to do a thorough workup, including issues subjects that patient may not mention (constipation/bowel control issues, skin breakdown, mood)
 - Inadequate bowel management, leading to increased discomfort, continued incontinence
 - Failure to involve rehabilitation specialists, leading to greater discomfort, skin breakdown, reduced independence

2012

- Discussion with James and parents about his health and theirs, leading to a conversation about possible placement in a long-term care facility
- Follow-up discussion to address their fears and parents' guilt feelings
- Referral to social worker to:
 - Continue discussion
 - Identify nearby facilities
 - Discuss financial/insurance arrangements
 - Assist with transition
 - Ensure that James, his parents, and his daughter will have regular visits
- Follow-up visits scheduled every six months to monitor:
 - Spasticity/baclofen pump
 - Skin integrity
 - Bladder/bowel function
 - Mood
- Delayed conversation with James and parents, resulting in subsequent emergency admission to LTC, without time for the family to prepare for transition, pick the optimal location, or deal with the financial implications
- Inadequate attention to James' deepening depression/suicidal ideation, potentially resulting in suicide
- Inadequate follow-up, possibly resulting in sub-optimal symptom management, unnecessary complications, premature death



Section I:

Multiple Sclerosis: A Brief Overview

Chapter 1: Introduction to Multiple Sclerosis

Multiple sclerosis (MS) is the most common immune-mediated inflammatory demyelinating disease of the central nervous system (CNS) — the brain, spinal cord, and optic nerves — and is a leading cause of disability in young adults.

- MS is a chronic, often disabling disease of the CNS with unknown etiology.
- It is hypothesized by many experts in the field to be an immune-mediated disease — in which the immune system attacks the central nervous system. Primary targets of this attack include the myelin coating that surrounds the nerve fibers (axons), the cells that make myelin (oligodendrocytes), and the nerve fibers themselves.
- Damaged myelin (demyelination) forms scar tissue (sclerosis) in multiple sites in the CNS, giving the disease its name. The damaged myelin and axons interfere with the transmission of nerve signals, resulting in the symptoms of MS.

- While always considered to be a disease of the white matter, it is now known that gray matter lesions also occur early in the disease, and may even precede damage to the white matter (Popescu & Lucchinetti, 2012; Lucchinetti et al., 2011) in some individuals.
- The collective damage to white and gray matter results in a broad spectrum of clinical signs and symptoms.

What causes MS?

- The etiology of MS is unknown but believed to be multifactorial and immune-mediated.
 - MS may be the result of an abnormal immune response to some infectious or environmental trigger in a genetically susceptible individual.
 - Each of these factors — immunologic, environmental, infectious, and genetic — is the subject of intensive ongoing research.
- The pathologic process in MS begins with the activation of CD4+ T cells in the periphery after they are presented with an antigen — possibly a virus.
 - These activated T cells cross the blood-brain barrier (BBB) with the help of intercellular adhesion molecules and become reactivated when encountering additional antigens in the CNS.
 - The activated CD4+ T cells along with B cells, macrophages, and CD8+ T cells interact to produce an inflammatory response and subsequent myelin damage through multiple mechanisms, including the B-cell — mediated antibody/complement pathway (e.g., antibodies to myelin basic protein), macrophage-induced oxidative damage, and TNF-alpha secretion.

- These cells interact to produce an inflammatory response directed at components of the CNS. This inflammation — considered the hallmark of MS — is followed by demyelination, tissue scarring (gliotic sclerosis), axonal degeneration, and neurodegeneration.

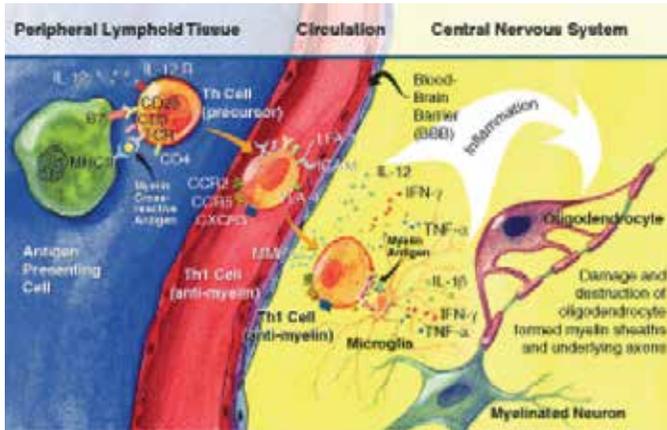


Figure 1. Precursor T cells become myelin-reactive following interaction with antigen presenting cells displaying myelin-cross-reactive antigens. Myelin-reactive T cells may express several chemokine receptors including CCR2, CCR5, and CXCR3. They breach the blood-brain barrier (BBB) and enter the CNS with the help of upregulated cell adhesion molecules and MMPs. In the brain they encounter myelin antigens, presented mainly by microglia, inciting an inflammatory response that damages or destroys oligodendrocyte-formed myelin sheaths and underlying neurons. [Figure adapted from Weiner, H.L. & D.J. Selkoe (2002) Nature 420:879.]

Classifications of MS

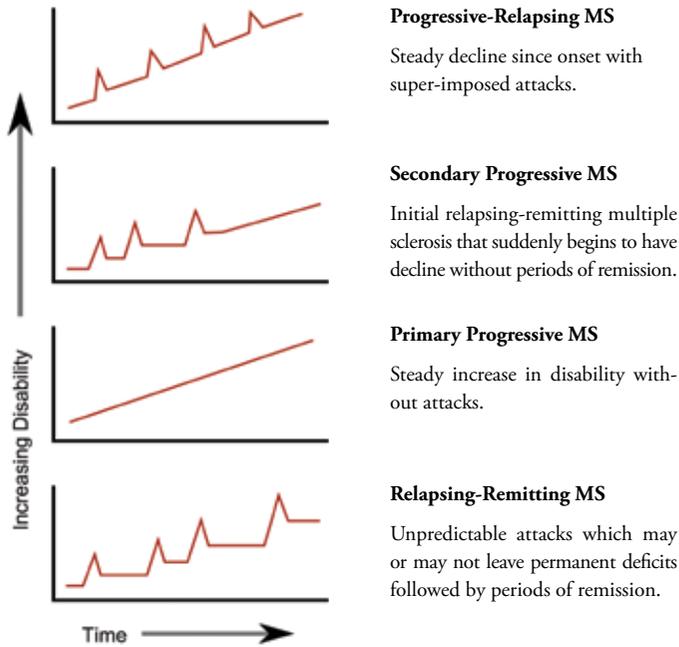
Four disease courses have been identified in MS (Lublin & Reingold, 1996):

- **Relapsing-remitting (RRMS):** Episodes of acute worsening of neurologic function, with some amount of recovery (the most common form) and no progression in between. The remissions

can be months to years with no new signs of disease activity. Deficits suffered during attacks or exacerbations may either resolve entirely or result in ongoing deficits. About 85% of people are diagnosed with RRMS initially.

- **Secondary-progressive (SPMS):** Following an initial relapsing-remitting course, the disease transitions in many people to a steadily progressive form with increased loss of function. Of the 85% who start with RRMS, more than 50% will develop SPMS within 10 years and 90% within 25 years.
- **Primary-progressive (PPMS):** Continuing worsening of disease from onset, without distinct relapses. Approximately 10% of people are diagnosed with PPMS.
- **Progressive-relapsing (PRMS):** Progressive steady neurologic decline with occasional acute relapses. About 5% of people appear to have PRMS at diagnosis.
- **Benign MS:** About 10% of MS patients experience a ‘benign course’ of MS — which can only be determined retrospectively.
 - Patients who have rare attacks and are minimally disabled 20 years after being diagnosed with MS are said to have benign MS (Hutchinson, 2012).
 - However, with increasing awareness of the potential for significant cognitive impairment (*Ch. 8*) in patients with early MS (Khalil et al., 2011) and in patients with little or no physical disability (Reuter et al., 2011; Amato et al., 2006), defining benign MS, and determining the patients for whom early and ongoing treatment with a disease-modifying agent (*Ch. 5*) is appropriate, are the subject of some debate: Hawkins, 2012 vs. Amato, 2012; Pittock et al., 2006 vs. Frohman et al., 2006.

Figure 1-1 Disease Courses in MS



The Natural History of MS

Epidemiologic studies show the following:

- In the absence of treatment, most patients with MS exhibit progressive neurological deterioration.
- Ten years after diagnosis, half of patients use a cane to ambulate, and 15% require a wheelchair.
- In the same 10 year span, approximately half of patients convert to the secondary progressive phase of the disease where there is acceleration of disability and a paucity of effective therapy.

- The risk of progression to disability over the first decade may be influenced by several factors. For instance, although MS is more common in women (3:1), men are more likely to have a progressive, even malignant, clinical course (Zaffaroni & Ghezzi, 2000). Further, African Americans have been shown to have a more rapidly progressive disease course (Kister et al., 2010).
- MS relapse rates decrease by ~ 70% in the third trimester of pregnancy. The risk of exacerbation again increases following delivery of the baby. These observations underscore the principle that hormonal factors figure prominently in the mechanisms of immune modulation and the ultimate expression of MS.

Table 1-1: Factors that Affect Prognosis (Mowry, 2011)

Favorable	Unfavorable
<ul style="list-style-type: none"> • Female • Low rate of relapses per year • Complete recovery from first attack • Long interval between 1st and 2nd attack • Symptoms predominantly from afferent systems (i.e., sensory symptoms) • Younger age at onset • Low disability at 2–5 years from the disease onset • Later cerebellar involvement • Involvement of only one CNS system at the time of onset 	<ul style="list-style-type: none"> • Male • High rate of relapses per year • Incomplete recovery from first attack • Short interval between 1st and 2nd attack • Symptoms predominantly from efferent systems (i.e., symptoms of motor tract involvement) • Older age at onset • Significant disability at 2–5 years from the onset • Earlier cerebellar involvement • Involvement of more than one CNS system at the time of onset

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Amato MP, Zipoli V, Goretti B, et al. Benign multiple sclerosis: cognitive, psychological and social aspects in a clinical cohort. *J Neurol* 2006 Aug;253(8):1054–9.

Frohman EM, Havrdova E, Lublin F, et al. Most patients with multiple sclerosis or a clinically isolated demyelinating syndrome should be treated at the time of diagnosis. *Arch Neurol* 2006 Apr;63(4):614–9.

Hawkins S. Truly benign multiple sclerosis is rare: let's stop fooling ourselves — NO. *Mult Scler* 18(1) 11–12.

Khalil M, Enzinger C, Langkammer C et al. Cognitive impairment in relation to MRI metrics in patients with clinically isolated syndrome. *Mult Scler* 2011 Feb;17(2):173–80.

Kister I, Chamot E, Bacon JH et al. Rapid disease course in African Americans with multiple sclerosis. *Neurology*. 2010 Jul 20;75(3):217–23.

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Recommended Resources

National Multiple Sclerosis Society — www.nationalMSSociety.org

Consortium of Multiple Sclerosis Centers — www.ms-care.org

Recommended Readings

Frohman TC, O'Donoghue DL, Northrop D (eds.) *Multiple Sclerosis for the Physician Assistant: A Practical Primer*. National MS Society, 2011. www.nationalMSSociety.org/PAPrimer

Giesser B. *Primer on Multiple Sclerosis*. New York: Oxford University Press, 2011.

Recommended Resources for Your Patients

Organizations

National Multiple Sclerosis Society — www.nationalMSSociety.org

Multiple Sclerosis Association of America — www.msassociation.org

Multiple Sclerosis Foundation — www.msfocus.org

Books

Kalb R (ed.) *Multiple Sclerosis: The Questions You Have; The Answers You Need* (5th ed.). New York: Demos Health, 2012.

Kalb R, Giesser B, Costello K. *Multiple Sclerosis for Dummies* (2nd ed.). Hoboken NJ: Wiley, 2012.

Kennedy P (ed.). *The Can Do Multiple Sclerosis Guide to Lifestyle Empowerment*. New York: Demos Health, 2012.

Chapter 2: Immunology

The Immune System

- The *function* of the immune system is to protect against pathogens, which it accomplishes through:
 - **Innate immunity**
 - Immune response to certain pathogens, which occurs in all healthy individuals and does not require prior exposure to the pathogen
 - Immediate destruction of some pathogens by phagocytic cells such as macrophage and neutrophils
 - **Adaptive immunity**
 - Antibodies that are produced to pathogens serve as an ‘immunologic memory’
 - Comprised primarily of lymphocytic B cells, which produce the antibodies that attach to specific antigens and T cells (Kasper, 2010)
- The *benefits* of the immune system
 - Protection from outside invaders
 - Elimination of altered self
- The *risks* of the immune system
 - Discomfort and collateral damage resulting from inflammation
 - Damage to self resulting from hypersensitivity or autoimmunity

The Immune System and MS

- MS is thought to be an immune-mediated disease.
- The cause of the immune mediated damage is unknown.

- Much of the evidence supporting autoimmunity is derived from the ability to replicate clinical and pathologic features of MS in animal experiments. The animal model of MS is experimental autoimmune encephalomyelitis (EAE).
- The key difference between EAE and MS is that the cause of the autoimmunity in EAE is known (immunization with myelin antigens or insertion of transgenes to generate encephalitogenic T lymphocytes), whereas the cause of the autoimmunity in MS is unknown (Pender, 2007).
- The immune mechanisms thought to contribute to the pathogenesis (development) of MS are as follows:
 - TH1 cells are stimulated/activated in the periphery by presentation with antigen, possibly a virus.
 - Once activated, these cells proliferate and release cytokines and metalloproteinases (MMP) that break down the extracellular matrix of the blood brain barrier (BBB).
 - Once in the CNS, TH2 cells are presented with myelin protein that is similar to the antigen presented in the periphery.
 - The reactivated T cells along with B cells, macrophages, and CD8+ T cells interact to produce an inflammatory response and subsequent myelin damage through multiple mechanisms, including the B-cell — mediated antibody/complement pathway (eg, antibodies to myelin basic protein), macrophage-induced oxidative damage, and TNF-alpha secretion.
 - These cells interact to produce an inflammatory response directed at components of the CNS.
 - This Inflammation leads to demyelination, as well as axonal degeneration followed by chronic neurodegeneration. It is this process that results in clinical manifestations (Cravens et al., 2011; Matsui, 2008).

Evidence of Immune Response Seen in Clinical Practice

- Inflammation in conjunction with blood-brain-barrier disruption, characterized by gadolinium enhancement on MRI, is seen in the early stages of most demyelinating lesions in patients with relapsing-remitting and secondary progressive MS (Bar-Or, 2007).
- Inflammatory T cells, B cells, and macrophages are typically seen on histopathologic examination of MS lesions at biopsy and autopsy (Lucchinetti et al., 2000).
- Increased oligoclonal IgM and IgG levels are found in the cerebrospinal fluid (CSF) of patients with MS. (Matsui, 2008)
- Myelin reactive T cells are found in MS plaques and in the CSF and peripheral circulation of patients with MS (Oksenberg et al., 1993).

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Chapter 3: Neuroimaging

Introduction

Magnetic resonance imaging (MRI) currently offers the most sensitive, non-invasive way of imaging the brain, spinal cord, or other areas of the body. It is the preferred imaging method to help establish a diagnosis of MS and to monitor the course of the disease. And this technology has made it possible to visualize and understand much more about the underlying pathology of the disease.

Although MRI helps to support the diagnosis of MS, is not diagnostic by itself (*Ch. 4*). The revised McDonald diagnostic criteria published in 2010 provide specific guidelines for making an MS diagnosis, based on clinical findings and objective evidence obtained from MRI. (*p. 40*)

MRI Technology

- How the technology works:
 - MRI uses a powerful magnetic field. Tissues in the body consist mainly of fat and water, which means that they contain an abundance of hydrogen atoms.
 - Each atom contains a proton that has a property called spin. The magnetic field causes the hydrogen protons in water molecules to line up.
 - Once the hydrogen protons are lined up, they are knocked out of line by a radiofrequency (RF) pulse that is transmitted to the person's body in short bursts.
 - When the radio waves are stopped, the protons relax back into line, releasing resonance signals that are transmitted to a computer.

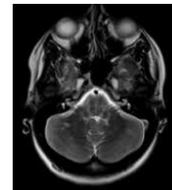
- The various types of MRI scans that are used — most commonly the T1-weighted scan and the T2-weighted scan — measure this relaxation time differently. Computer programs translate these data into cross-sectional pictures of the water in human tissue resulting in MRI images.
- Why the technology is particularly useful in MS:
 - Subtle details in soft tissue might be missed using conventional imaging techniques such as CT scans or x-rays. Magnetic resonance imaging is very well tolerated and poses little or no risk to the average individual.
 - The layer of myelin that protects nerve-cell fibers is fatty and therefore repels water. In the areas where the myelin has been damaged by MS, the fat is stripped away. With the fat gone, the area holds more water, and shows up on an MRI scan as either a bright white spot or a darkened area, depending on the type of scan that is used. The magnitude and timing of the RF pulses can be manipulated in specific ways so protons in different tissues relax at varying rates. This produces images with greater contrast between different tissues types.
- Types of scans used most commonly in MS: Conventional methods of MRI include T2 imaging, variations of T2 imaging such as FLAIR, T1 imaging, and T1 with gadolinium enhancement.
 - **T2-weighted images**
 - On T2 scans, gray matter appears lighter and brighter than white matter; cerebral spinal fluid (CSF) appears bright.
 - The information provided by T2 is often referred to as disease burden or lesion load (meaning the total amount of lesion area).
 - T2 images are sensitive to increased water content and are often superior at demonstrating pathological changes in the brain parenchyma.

- T2 images have a high degree of sensitivity and allow us to detect lesions that might be missed on T1 scans.
- A patient may have numerous T2 lesions while T1 hypo-intense areas may not be visible.
- MS lesions are hyperintense or bright — which can make differentiation from ventricles challenging.
- Hyperintense areas of T2 images are not specific — they may represent inflammation, edema, or mild demyelination as well as gliosis, severe demyelination, and axonal loss — making it difficult to assess the degree of irreversible tissue damage.



Axial T2WI Image:

Lesions in the spinal cord.
(courtesy of J. Howard)



Axial T2WI:

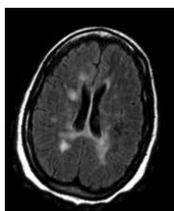
Lesions throughout the brainstem and cerebellum in a patient with MS. Lesions in the brainstem and cerebellum are termed infratentorial lesions. These are best seen on T2-weighted MRIs.



Sagittal T2WI Image:

Lesions in the cervical spinal cord.
(courtesy of J. Wolinsky)

- T1 images are most useful in demonstrating the detailed anatomy of the CNS.
- Gray matter appears dark and white matter is a lighter shade of gray.
- Areas of abnormality are usually hypointense (dark) and referred to as black holes — which are thought to indicate areas of permanent damage.
- T1 images emphasize tissue differences and show clear anatomic detail.



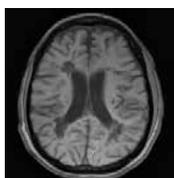
Axial FLAIR Image

Demonstrates typical periventricular lesions in MS.
(courtesy of J. Howard)

– **FLAIR (Fluid-Attenuated Inversion Recovery) Image**

- FLAIR is a type of T2 image that is better than standard T2 images at demonstrating demyelinating lesions because it shows both new and old lesions clearly.
- The signal from the CSF is suppressed in FLAIR imaging so that it's easier to visualize lesions.
- FLAIR imaging best depicts lesions located along the lateral borders of the corpus callosum.

– **T1-weighted images**

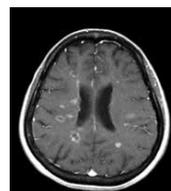


Axial T1 Weighted Image

Demonstrates hypointense lesions in the white matter.
(courtesy of J. Howard)

– **Gadolinium enhanced images**

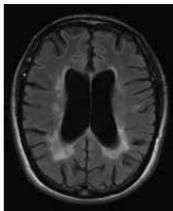
- Gadolinium (gd), which acts as a marker for active inflammation, can be injected intravenously to further enhance the sensitivity of the T1-weighted MRI scan.
- Gadolinium only penetrates the brain where the blood-brain barrier has been disrupted, which occurs in MS during active, inflammation. The result is enhancement or bright white areas that represent active lesions and provide an indication of current disease activity.
- T1 background is utilized because areas that are enhancing will show the greatest amount of contrast on a T1 weighted image.
- New and active lesions appear bright and easy to visualize with gadolinium enhancement.
- MS lesions seen on a Gd-enhanced T1 scan may not be detected on a non-contrast T1 scan or T2-weighted images.
- Enhancement may last from 1 to 4 weeks or even for months in some cases.
- Gadolinium enhancing lesions are detected 5–10 times more frequently than clinical relapses — which suggests that most of the enhancing lesions are clinically silent.
- *Note:* Many MRI centers request renal function testing prior to the administration of gadolinium; patients with acute or chronic renal insufficiency are at risk for nephrogenic systemic fibrosis after exposure to gadolinium-based contrast agents.



Post-Contrast Axial T1 Weighted Image:

Numerous enhancing lesions; incomplete ring-enhancing lesions highly suggestive of MS.
(courtesy of J. Howard)

- Where MS lesions are located
 - MS lesions can be found throughout the brain, but have a predilection for periventricular white matter (PVWM) and tend to have an ovoid configuration with the major axes perpendicular to the ventricular surface.
 - Early in MS, these PVWM lesions are typically thin and appear to be linear (referred to as “Dawson’s fingers”).
 - The corpus callosum, subcortical region, brainstem, U-fibers, optic nerves, and visual pathway are also regions where MS lesions occur with some frequency. The lesions in the corpus callosum, U-fibers, and optic nerve lesions can assist in differentiating MS from cerebrovascular disease.
 - White matter lesions occur more often than grey matter lesions.
 - Grey matter lesions are best detected on FLAIR.
 - Optic neuritis (inflammation of optic nerve) can be detected by using a fat-suppression technique combined with contrast-enhanced imaging or by using long-echo short-tau inversion recovery (STIR) imaging.
- The planes in which MRI images are provided:
 - **Axial:** a horizontal cut away slice of the body as seen from the top of the head.
 - Lesions are most likely to be seen in the optic nerve, the brain stem and the cerebellum.
 - Changes consistent with MS can be visualized on any plane but are most often viewed on the axial plane.

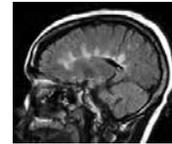


Axial FLAIR Image:

Atrophy and ventricular enlargement in a patient with MS. Significant brain atrophy is typically a feature of advanced disease, however some degree of atrophy is often present even in early MS.

(courtesy of J. Howard)

- **Sagittal:** a vertical cut away slice of the body as seen from the left side of the head.
 - Lesions can be seen in the deep white matter in the periventricular area, brain stem, cerebellum, and spinal cord.
 - Juxtacortical lesions can also be viewed on the sagittal image.
 - White matter lesions are aligned perpendicular to the long axis of the lateral ventricle. This appearance in multiple sclerosis is known as Dawson’s fingers.



Sagittal FLAIR image:

Demonstrates characteristics Dawson’s fingers of MS.

(courtesy of J. Howard)

- **Coronal:** vertical cut away slice as seen from the front of the body.

In addition to brain imaging, spinal cord imaging is very important in MS because many symptoms may be associated with cord pathology. Both axial and sagittal views of the spinal cord are used in MRI imaging for multiple sclerosis.

- The role of MRI in MS Diagnosis
 - Because MRI is particularly useful in detecting central nervous system demyelination, it is a powerful tool in helping to establish the diagnosis of MS (*Ch. 4*).
 - It should be remembered, however, that approximately 5% of patients with clinically definite MS do not show lesions on MRI at the time of diagnosis.

- Also, since many lesions seen on MRI may be in so-called “silent” areas of the brain, it is not always possible to make a specific correlation between what is seen on the MRI scan and the patient’s clinical signs and symptoms.
- With advancing age (probably over age 50), there are often small areas seen on MRI in healthy people that resemble MS but are actually related to the aging process.
- The role of MRI in clinically isolated syndromes
 - MRI is particularly helpful in patients who have had a single demyelinating attack that is suggestive of MS, also called a clinically isolated syndrome (CIS). The number of lesions on an initial MRI of the brain (or spinal cord) can help the clinician assess the patient’s risk of developing a second attack (and therefore “clinically-definite MS”) in the future. Some of the treatments for MS have been shown to delay the occurrence of a second episode of symptomatic demyelination in patients who have had only one.
- The role of MRI in assessing disease progression and prognosis
 - Once a diagnosis of MS has been established, there is no reason why an MS patient should have further diagnostic MRI scans. Subsequent scans, however, may be useful in tracking the progress of the disease, or possibly helping to establish a prognosis—a prediction of the course of a disease. For example, researchers have demonstrated that the degree of cognitive impairment as demonstrated by neuropsychologic testing can be correlated with the total amount of demyelination seen in certain areas of the brain on MRI.

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Neuroimaging in Multiple Sclerosis: Key Concepts for Nurses, 2009. Educational DVD available at <http://iomsn.org/educational-materials/audio-visual/107>.

Recommended Readings

Filippi M, Rocca M, Barkhof F, et al. Association between pathological and MRI findings in multiple sclerosis. *Lancet Neurology* 2012; 11(4):349-60.

Resources for Patients

www.radiology.ucsf.edu/patient-care/prepare/mri

www.mayoclinic.com/health/mri/MY00227/DSECTION=what-you-can-expect



Section II:

Diagnosis & Treatment

Chapter 4: Diagnosing Multiple Sclerosis

Multiple sclerosis (MS) can be challenging to diagnose because there are no unique symptoms, physical findings or laboratory tests that are specific to the diagnosis. The diagnosis is a clinical one, requiring several strategies to determine if a person meets the long-established diagnostic criteria.

Multiple Sclerosis Diagnostic Criteria

In order to make a diagnosis of MS, the clinician must:

- Find evidence of damage in at least two separate areas of the central nervous system (CNS), which includes the brain, spinal cord and optic nerves (Dissemination in Space) AND
- Find evidence that the damage occurred at least one month apart (Dissemination in Time) AND
- Rule out all other possible diagnoses

2010 Revised McDonald MS Diagnostic Criteria

With the advent of increasingly sophisticated MRI technology, MRI findings have been incorporated into the diagnostic criteria in order to help speed the process of confirming dissemination in time and space.

MS. National Multiple Sclerosis Society		2010 Revised McDonald MS Diagnostic Criteria ¹		ECTRIMS EUROPEAN COMMITTEE FOR TREATMENT AND RESEARCH IN MULTIPLE SCLEROSIS	
Diagnosis of MS requires elimination of more likely diagnoses and demonstration of dissemination of lesions in space (DIS) and time (DIT)*					
CLINICAL (ATTACKS)	LESIONS	ADDITIONAL CRITERIA TO MAKE DX			
2 or more	Objective clinical evidence of ≥ 2 lesions or objective clinical evidence of 1 lesion with reasonable historical evidence of a prior attack	None. Clinical evidence alone will suffice; additional evidence desirable but must be consistent with MS			
2 or more	Objective clinical evidence of 1 lesion	DIS; OR await further clinical attack implicating a different CNS site			
1	Objective clinical evidence of ≥ 2 lesions	DIT; OR await a second clinical attack			
1	Objective clinical evidence of 1 lesion	DIS OR await further clinical attack implicating a different CNS site AND DIT; OR await a second clinical attack			
0 (progression from onset)		One year of disease progression (retrospective or prospective) AND at least two of: DIS in the brain based on ≥ 1 T2 lesion in periventricular, juxtacortical or infratentorial regions; DIS in the spinal cord based on ≥ 2 T2 lesions; or positive CSF			

1 Polman et al. Diagnostic criteria for multiple sclerosis: 2010 revisions to the McDonald Criteria. Ann Neurol 2011;69:292-302 * See reverse for DIS and DIT

MS. National Multiple Sclerosis Society		Paraclinical Evidence in MS Diagnosis		ECTRIMS EUROPEAN COMMITTEE FOR TREATMENT AND RESEARCH IN MULTIPLE SCLEROSIS	
Evidence for Dissemination of Lesions in Space (DIS)² ≥ 1 T2 lesion in at least two out of four areas of the CNS: periventricular, juxtacortical, infratentorial, or spinal cord • Gadolinium enhancement of lesions is not required for DIS • If a subject has a brainstem or spinal cord syndrome, the symptomatic lesions are excluded and do not contribute to lesion count		Evidence for Dissemination of Lesions in Time (DIT)³ • A new T2 and/or gadolinium-enhancing lesion(s) on follow-up MRI, with reference to a baseline scan, irrespective of the timing of the baseline MRI or • Simultaneous presence of asymptomatic gadolinium-enhancing and non-enhancing lesions at any time			
Evidence for Positive CSF Oligoclonal IgG bands in CSF (and not serum) or elevated IgG index		² Swanton KL et al. Lancet Neurology 2007;6:677-686 / Swanton KL et al. J Neurol Neurosurg Psychiatry 2006;77:830-833 ³ Montalban X, et al. Neurology 2010;74:427-434			

These diagnostic criteria were developed through the consensus of the International Panel on the Diagnosis of MS. See cited articles for details. Funding through National Multiple Sclerosis Society (USA) and European Committee for Treatment and Research in MS; additional support from the Multiple Sclerosis International Federation and MS Ireland

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http://www.nationalMSSociety.org/PRC_MD_info@nmss.org
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Tools for Making the MS Diagnosis

- Medical history and neurologic exam
 - A systematic and extensive history should always accompany a careful and detailed physical and neurological examination as the cornerstones for making any neurologic diagnosis.
 - In many instances, the person’s medical history and neurologic exam provide enough evidence to meet the diagnostic criteria.
- Laboratory testing
 - There is no definitive blood test for MS.
 - Blood tests can rule out other conditions that cause symptoms similar to those of MS, including Lyme disease, a group of diseases known as collagen-vascular diseases, certain rare hereditary disorders, and AIDS.
- Magnetic Resonance Imaging (MRI)
 - MRI is the best imaging technology for detecting the presence of MS plaques or scarring (also called lesions) in different parts of the CNS. It can also differentiate old lesions from those that are new or active.
 - The diagnosis of MS cannot be made solely on the basis of MRI because there are other diseases that cause lesions in the CNS that look like those caused by MS. And even people without any disease — particularly the elderly — can have spots on the brain that are similar to those seen in MS.
 - Although MRI is a very useful diagnostic tool, a normal MRI of the brain does not rule out the possibility of MS. About 5% of people who are confirmed to have MS do not initially have brain lesions on MRI. However, the longer a person goes without brain or spinal cord lesions on MRI, the more important it becomes to look for other possible diagnoses.

- Evoked potential testing (EP)
 - Evoked potential (EP) tests are recordings of the nervous system’s electrical response to the stimulation of specific sensory pathways (e.g., visual, auditory, general sensory).
 - Because damage to myelin (demyelination) results in a slowing of response time, EPs can sometimes provide evidence of scarring along nerve pathways that does not show up during the neurologic exam.
 - Visual evoked potentials (VEPs) are considered the most useful for confirming the MS diagnosis.
- Cerebrospinal fluid analysis (Lumbar puncture [LP])
 - Analysis of the cerebrospinal fluid, which is sampled by a spinal tap, detects the levels of certain immune system proteins and the presence of oligoclonal bands.
 - These bands, which indicate an immune response within the CNS, are found in the spinal fluid of about 90–95% of people with MS. But because they are present in other diseases as well, oligoclonal bands cannot be relied on as positive proof of MS.

Because permanent neurologic damage can occur even in the earliest stages of MS — and subclinical disease activity is occurring even before clinical symptoms appear (See Figure 1) — it is important that a confirmed diagnosis is made so that the appropriate treatment(s) can be initiated early in the disease process (Coyle, 2008).

Clinically Isolated Syndrome

Clinically isolated syndrome (CIS) is a term that describes a first clinical episode with features suggestive of multiple sclerosis (MS). It usually occurs in young adults and affects optic nerves, the brainstem, or the spinal cord. Although patients usually recover from their presenting episode, CIS is often the first manifestation of MS.

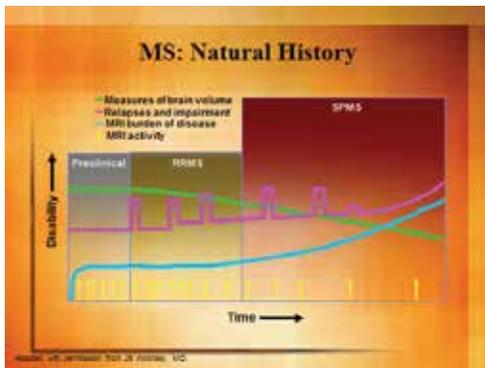


Figure 4-1: The Natural History of MS

Table 4-1: Most Common Clinically Isolated Syndrome Presentations (Miller et al. 2008)

Optic Neuritis	Brainstem	Spinal Cord
<p>Typical for MS: Unilateral visual loss, orbital pain, afferent pupillary defect, retrobulbar or mild disc swelling, visual loss does not progress beyond two weeks</p> <p>▼</p> <p>Brain & Spinal MRI</p>	<p>Typical for MS: Internuclear ophthalmoplegia, 6th nerve palsy, multifocal signs (e.g., facial sensory loss, vertigo, hearing loss, ataxia, dysarthria)</p> <p>▼</p> <p>Brain & Spinal MRI</p> <p>▼</p> <p>Within 5 years:</p>	<p>Typical for MS: Evolution over hours to days, partial myelitis, Lhermitte's sign, partial Brown-Séquard, spontaneous remission</p> <p>▼</p> <p>Brain & Spinal MRI</p>

Normal brain MRI: 20% risk of conversion to clinically definite MS (CDMS).

Abnormal brain MRI: (> 2 lesions consistent with demyelination) = 80–90% risk of conversion to CDMS, depending on CIS presentation.

The most notable risk factors for MS are clinically silent MRI lesions and CSF oligoclonal bands; weak or uncertain risk factors include vitamin D deficiency, Epstein-Barr virus infection, smoking, HLA genes, and miscellaneous immunological abnormalities (Miller et al., 2012). Disease-modifying treatments delay the conversion of CIS to MS.

Ruling Out Other Conditions that Mimic MS

- The diagnosis of MS needs to exclude conditions that mimic MS and that can confuse the clinical picture.
- Any conditions that can cause intermittent neurologic dysfunction can mimic MS.
- As in any differential diagnosis, there are vascular, metabolic, autoimmune and physiologic processes that have symptoms reminiscent of MS.

The typical workup for suspected demyelination disease includes a variety of tests. The exact battery may vary based on the presentation. Table 1 summarizes a standard workup that most patients should have, but is not comprehensive for all circumstances.

Table 4-2: Basic workup for patients with suspected demyelinating disease

Test	Reason
Brain MRI	Multifocal brain lesions suggest MS
NMS IgG	Neuromyelitis Optica (NMO)
SSA/SSB	Siogren's Associated Transverse Myelitis

ANA	Lupus Associated Transverse Myelitis
Anticardiolipin Antibody	Antiphospholipid Syndrome Associated Transverse Myelitis
Copper and Zinc	Copper Deficiency (and/ or Zinc excess) Associated Myelopathy
Vitamin B12	Subacute Combined Degeneration
RPR	Tabes Dorsales
Chest CT Scan (consider gallium or indium scan); Angiotensin converting enzyme (ACE)	Sarcoidosis
CSF Oligoclonal Bands/ IgG Index/IgG rate	Associated with MS

References

Coyle PK. Early treatment of multiple sclerosis to prevent neurologic damage. *Neurology* 2008; 71: S3–S7.

Miller DH, Chard DT, Ciccarelli O. Clinically isolated syndromes. *Lancet Neurol* 2012; 11(2):157–169.

Miller DH, Weinshenker BG, Filippi M, et al. Differential diagnosis of suspected multiple sclerosis: a consensus approach. *Mult Scler* 2008; 14(9):1157–1174

Polman C et al. Diagnostic criteria for multiple sclerosis: 2010 Revisions to the McDonald criteria. *Annals of Neurology* 2011; 69:292–302)

Recommended Readings

Awad A, Hemmer B, Hartung HP, et al. Analyses of cerebrospinal fluid in the diagnosis and monitoring of multiple sclerosis. *J Neuroimmunol* 2010; 219(1–2):1–7.

Barkhof F, Filippi M, Miller DH, et al. Comparison of MRI criteria at first presentation to predict conversion to clinically definite multiple sclerosis. *Brain*, 1997; 120:2059–2069

Resources

National MS Society — www.nationalMSSociety.org

- MS Clinical Care Network — www.nationalMSSociety.org/MSClinicalCare
 - Free downloadable Diagnosis and Management App for smartphones.

Chapter 5: Treatment Strategies Over the Disease Course

Treatment strategies in multiple sclerosis fall into five general categories (Reitman & Kalb, 2012).

Treatment of Acute Exacerbations (relapses)

An exacerbation of MS (also known as a relapse, attack, or flare-up) is caused by inflammation in the central nervous system (CNS) that causes damage to the myelin and slows or blocks the transmission of nerve impulses.

- To be a true exacerbation, the attack must last at least 24 hours and be separated from a previous exacerbation by at least 30 days — with most lasting from a few days to several weeks or even months.
 - A pseudo-exacerbation — a brief flare-up of old symptoms that is unrelated to new damage in the CNS — can result from an elevation in core body temperature caused infection (UTI, URI, viral infection), exertion during exercise, heat or humidity. Pseudo-exacerbations resolve once the body temperature returns to normal.
- Exacerbations can be mild or severe enough to interfere with a person's ability to function at home and at work. Severe exacerbations are most commonly treated with high-dose corticosteroids to reduce the inflammation.
 - Most common protocol: 3–5 day course of high-dose intravenous (IV) corticosteroid (methylprednisolone) treatment, which may or may not be followed by a gradually tapering dose of an oral corticosteroid such as prednisone (Beck et al., 1992).
 - Steroids work to decrease acute inflammation in the CNS, but have no long-term benefits in MS.

- Many people feel better while taking them, in part because steroids can sometimes have a mood-elevating effect.
- Chronic use steroids causes serious side effects, including hypertension, diabetes, bone loss (osteoporosis), cataracts, and ulcers.
- Short courses are generally well tolerated; side effects include: gastric problems; feeling 'high'; insomnia; depression; mood swings (effectively treated with a low-dose mood stabilizing medication)
- Other treatment options for exacerbations are available
 - High-dose oral corticosteroids are also used by some MS clinicians (Morrow et al., 2009).
 - ACTH (H.P. Acthar Gel — repository corticotropin injection) has been approved by the FDA for this purpose since 1978. Especially useful for patients who: are unable to tolerate high dose corticosteroids; have not responded to corticosteroids; do not have access to intravenous therapy; have insufficient venous access. The approved dosing schedule is 80–120 units daily for 2–3 weeks.
 - Plasmapheresis (Plasma exchange) may be considered for the 10 percent of very severe exacerbations that do not respond adequately to the standard steroid treatment.

Symptom Management

Symptom management is an essential component (Cohen, 2008; Henze et al., 2006) of comprehensive MS care. While disease management therapies reduce disease activity and slow progression for many people, it is the ongoing management of symptoms that allows people to function in their daily lives with optimal comfort, safety, participation, and quality of life. Given the wide variety of neurological symptoms that can occur in MS, interdisciplinary care is the key to effective management (*Ch. 18*).

Working with patients to manage their symptoms requires awareness not only of the functional impact each symptom might be having, but also the ways in these visible and not-so-visible symptoms affect them emotionally, socially, and vocationally. The most common symptoms, discussed in detail in *Chapters 6–16*, include:

- Ambulation problems
- Bladder dysfunction
- Bowel dysfunction
- Cognitive dysfunction
- Fatigue
- Mood disturbances
- Pain and other sensory changes
- Sexual dysfunction
- Speech problems
- Swallowing difficulties
- Tremor
- Vision problems

Disease Modification

Since 1993, the U.S. Food and Drug Administration (FDA) has approved several drugs for use in MS. These drugs do not cure MS or provide relief from current symptoms — in fact, the effects on the disease may not be immediately apparent. No medications have yet been approved for the treatment of primary-progressive MS.

For the most current information on disease-modifying therapies, go to:

www.nationalMSsociety.org/DMTupdate

Table 5-1: First-Line Disease-Modifying Medications

Generic Name & Brand Name	Interferon Beta 1B <i>Betaseron/Extavia</i>
Manufacturer/Distributor	Bayer Healthcare Pharmaceuticals/ Novartis Pharmaceuticals
Approval in US	Betaseron: 1993 Extavia: 2009
Frequency/Route of Delivery/Dose	Every other day; subcutaneous injection/ Autoinjector
Usual Dose	250 mcg
Common Side Effects	Flu-like symptoms following injection, which lessen overtime for many people; injection site reactions, about 5% of which need medical attention. Less common: depression, elevated liver enzymes, low white blood cell count
Warnings & Precautions	For a complete listing, go to: <i>www.nationalMSsociety.org/DMTupdate</i>
Patient Info & Financial Support Programs	Betaplus 800-788-1467 <i>betaseron.com</i> Extavia Patient Support Program 866-925-2333

Table 5-1 (cont'd): First-Line Disease-Modifying Medications

Generic Name & Brand Name	Interferon Beta 1A <i>Avonex</i>
Manufacturer/Distributor	Biogen Idec
Approval in US	1996
Frequency/Route of Delivery/Dose	Weekly; intramuscular injection/ Autoinjector
Usual Dose	30 mcg
Common Side Effects	Flu-like symptoms following injection, which lessen over time for many people. Less common: depression, mild anemia, elevated liver enzymes, liver toxicity
Warnings & Precautions	For a complete listing, go to: www.nationalMSSociety.org/DMTupdate
Patient Info & Financial Support Programs	MS Active Sources 800-456-2255 avonex.com / msactivesources.com

Table 5-1 (cont'd): First-Line Disease-Modifying Medications

Generic Name & Brand Name	Interferon Beta 1A <i>Rebif</i>
Manufacturer/Distributor	EMD Serono, Pfizer
Approval in US	2002
Frequency/Route of Delivery/Dose	Three times per week; subcutaneous injection/Autoinjector
Usual Dose	44 mcg
Common Side Effects	Flu-like symptoms following injection, which lessen overtime for many people; injection site reactions. Less common: depression, elevated liver enzymes, low white blood cell counts
Warnings & Precautions	For a complete listing, go to: www.nationalMSSociety.org/DMTupdate
Patient Info & Financial Support Programs	MS Lifelines 877-447-3243 rebif.com / mslifelines.com

Table 5-1 (cont'd): First-Line Disease-Modifying Medications

Generic Name & Brand Name	Glatiramer Acetate <i>Copaxone</i>
Manufacturer/Distributor	Teva Pharmaceuticals
Approval in US	1996
Frequency/Route of Delivery/Dose	Daily; subcutaneous injection/ Autoinjector
Usual Dose	20 mg (20,000 mcg)
Common Side Effects	Injection site reactions. Less common: a reaction immediately after injection that includes anxiety, chest tightness, shortness of breath, and flushing. This lasts 5–10 minutes and has no known long-term effects
Warnings & Precautions	For a complete listing, go to: www.nationalMSSociety.org/DMTupdate
Patient Info & Financial Support Programs	Shared Solutions 800-877-8100 copaxone.com / sharedsolutions.com / mswatch.com

Table 5-1 (cont'd): First-Line Disease-Modifying Medications

Generic Name & Brand Name	Fingolimod <i>Gilenya</i>
Manufacturer/Distributor	Novartis Pharmaceuticals
Approval in US	2010
Frequency/Route of Delivery/Dose	Daily; capsule taken orally
Usual Dose	0.5 mg
Common Side Effects	Headache, flu, diarrhea, back pain, liver enzyme elevations, and cough. Less common: slowed heart rate following first dose, infections, and macular edema
Warnings & Precautions	For a complete listing, go to: www.nationalMSSociety.org/DMTupdate
Patient Info & Financial Support Programs	<i>Gilenya Go Program</i> 800-445-3692 gilenya.com

Managing Skin & Injection Site Reactions

(McEwan et al., 2010)

Five of the first-line medications are delivered by injection. Teaching optimal self-injection techniques and management of injection site reactions when they occur are key roles for the MS nurse. Injection-site reactions (ISRs), which can include pain and erythema, lipoatrophy, abscesses and infections, necrosis, rash, swelling, and lumps, are more common with subcutaneous injections than with intramuscular injections. Autoinjectors, when available, can be very helpful.

- Erythema and pain
 - Pain may be reduced by applying warm compresses before injection and cold compresses after injection for up to 5 minutes.
 - Lidocaine/prilocaine cream has been shown to reduce pain/fear of pain after injection.
 - Pain may be reduced by use of a smaller, thinner needle.
- Lipoatrophy
 - Emphasize importance of regular site rotation.
 - Emphasize importance of injecting only into healthy tissue.
 - Teach patient visual and manual inspection strategies.
 - Inspect injection areas at every visit.
- Injection Site Infections: cellulitis and soft-tissue abscesses
 - Optimal skin preparation is the best prevention.
 - Antibiotic or surgical treatment may be warranted.
- Induration, Swelling, Lumps, Rash, and Necrosis
 - Emphasize proper injection-site rotation.
 - Review preparation techniques and sites.
 - Substitute soap and water for alcohol, which can irritate indurations.

Table 5-2: Additional Approved Treatment Options

Generic Name & Brand Name	Natalizumab <i>Tysabri</i>
Manufacturer/Distributor	Biogen Idec and Elan Pharmaceuticals
Approval in US	2006
Frequency/Route of Delivery/Dose	IV infusion every 4 weeks in registered infusion facility
Common Side Effects	Headache, fatigue, UTI, depression, lower RTI, joint pain, chest discomfort
Warnings & Precautions	For a complete listing, go to: <i>www.nationalMSSociety.org/DMTupdate</i> Tysabri increases a person's risk for a rare brain infection called progressive multifocal leukoencephalopathy (PML), which usually results in death or severe disability. For the most current infor- mation about PML in Tysabri-treated patients, go to <i>http://www.tysabri.com/ pdfs/I61061-13_PL.pdf</i> .
Patient Info & Financial Support Programs	800-456-2255 <i>tysabri.com / biogenidec.com</i>

Table 5-2: Additional Approved Treatment Options

Generic Name & Brand Name	Mitoxantrone <i>Novantrone</i>
Manufacturer/Distributor	Serono, Inc.
Approval in US	2000
Frequency/Route of Delivery/Dose	4 times a year by IV infusion in a medical facility. Lifetime cumulative dose limit of 8–12 doses over 2–3 years.
Common Side Effects	Blue-green urine 24 hours after administration; infections, bone marrow suppression, nausea, hair thinning, UTI, mouth sores
Warnings & Precautions	For a complete listing, go to: www.nationalMSSociety.org/DMTupdate Because of its potential long-term impact on cardiac function, the drug should only be used in those with normal heart function, and cardiac monitoring should continue for the duration of treatment and after treatment has been concluded. Mitoxantrone is also known to increase a person's risk of acute myelogenous leukemia (AML).
Patient Info & Financial Support Programs	None at this time

Emerging Therapies in Multiple Sclerosis

Several medications are expected to be approved for the treatment of MS in the months following the printing of this book. To ensure that you have the most current information, log on to www.nationalMSSociety.org/DMTupdate for important updates or email healthprof_info@nmss.org to request these and other important announcements by email.

Three medications are currently under review by the FDA, with expected approval by the end of 2013:

- **Teriflunomide** (Genzyme/Sanofi-Aventis) is an oral, once-daily medication that decreases B-cells and T-cells to reduce inflammation. In a large, phase III trial in relapsing MS, two doses were compared. Both doses reduced the relapse rate by 37% and reduced total lesion volume by 39–67%. The high dose also reduced risk of disability progression by 30%. Overall adverse events were the same across treatment and placebo groups. The most common side effects were mild hair thinning, nausea, and diarrhea (O'Connor et al., 2011).

Note: In September, 2012, both doses of teriflunomide were approved by the FDA for the treatment of relapsing forms of MS.

- **Alemtuzumab** (Genzyme) is a monoclonal antibody that depletes circulating immune (T and B) cells that are thought to be responsible for MS relapses. It is given by intravenous infusion for 5 days initially and for 3 days one year later. In one phase III clinical trial, alemtuzumab significantly reduced relapse rates when compared to Rebif (interferon beta-1a). In a second phase III trial, alemtuzumab significantly reduced relapse rates and worsening of disability compared to Rebif over the two-year study period. In the trial, 15.9 percent of alemtuzumab-treated patients developed an autoimmune thyroid-related adverse event compared to 5.0 percent with Rebif, and 0.9 percent of alemtuzumab-treated patients developed immune thrombocytopenia (ITP).

- **BG-12** (dimethyl fumarate — Biogen Idec) is an oral medication that appears to be neuroprotective and anti-inflammatory. In a phase III trial comparing two doses to placebo, both doses of BG-12 significantly reduced the risk of relapses, the annualized relapse rate, the risk of disability progression, and lesion activity on MRI, compared to placebo. The most common side effects were flushing or reddening of the skin and mild gastrointestinal issues, including diarrhea and nausea.

Rehabilitation (to enhance & maintain physical function)

Rehabilitation in MS involves the intermittent or ongoing use of multidisciplinary strategies to promote functional independence, prevent complications, and enhance overall quality of life (Kalb, 2010)

- From disease onset (and intermittently throughout the disease course), providing education and treatment designed to promote good health and general conditioning, reduce fatigue, and maximize participation
- Helping the person restore and/or maintain the highest possible level of functioning and realize his or her optimal physical, mental, and social potential
- Targeting fatigue, mobility impairment (weakness, spasticity, imbalance, sensory loss, ataxia); tremor, pain, speech and swallowing problems, cognitive dysfunction, visual disturbances, and bowel and bladder problems
- Reducing disablement by minimizing the impact of existing impairment(s) on day-to-day functioning and enhancing the person's ability to carry out daily activities and participate to the fullest extent possible in all of his or her life roles

- Providing structured, problem-focused interventions to manage advanced symptoms, enhance function, facilitate activities of daily living, identify appropriate assistive devices and environmental modifications, and prevent injuries and unnecessary complications.
- Utilizing a team approach, rehabilitation specialists work collaboratively with each other, the person with MS and his or her care partners (significant other, other family members, paid assistant(s), to set achievable goals, assess outcomes, and establish new goals as the person's condition changes.

Psychosocial Support

- Disease-related education/psychoeducation — a supportive educational process designed to enhance people's understanding of the disease, adaptive coping strategies, and available resources)
- Diagnosis/treatment of emotional and/or cognitive problems
- Family interventions designed to support family members' efforts to cope with the intrusion of MS into the household
- Support for people's efforts to remain productively employed as long as they are able and interested, and to transition out of the workforce when, and if, it is necessary to do so
- Assistance for patients and families in accessing available resources

The Role of Complementary & Alternative Medicine (CAM) in MS

CAM includes everything from exercise and diet to food supplements, stress management strategies, and lifestyle changes. Examples include yoga, hypnosis, relaxation techniques, traditional herbal healing, Chinese medicine, macrobiotics, naturopathy, and many others. (Bowling, 2007)

Be sure to ask patients about their use of CAM therapies as they can interfere/interact with prescribed treatment regimens.

The Key Role of the Nurse Practitioner in Treatment of MS

The education, training, and support of patients to enhance adherence is critical given the often complex treatment regimens which are developed.

- NPs need to provide patients with relevant, up-to-date information and guidance on new therapies or advances in existing therapies.
- NPs can help patients interpret health information (and misinformation), leading to meaningful participation in their treatment decision-making process.
- NPs may be the primary source of information for the patient and family members and is in the best position to involve them in the care continuum (*Ch. 17*).
- “The proactive involvement of the MS APN can raise patients’ and their care partners’ awareness of, and access to, complementary non-drug modalities and resources, such as support groups, that may ameliorate some of the burden of disease.” (Costello & Halper, no date provided)

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Kalb R (Ed.). *Multiple Sclerosis: The Questions You Have; The Answers You Need* (5th ed.). NY: Demos Health, 2012.

Kalb R, Giesser B, Costello K. *Multiple Sclerosis for Dummies*. Hoboken, NJ: Wiley, 2012.

Mohr DC, Cox D, Merluzzi N. Self-injection anxiety training: a treatment for patients unable to self-inject injectable medications. *Mult Scler* 2005; 11(2):182–5.

Resources from the National MS Society

For Clinicians

MS Clinical Management:

www.nationalMSSociety.org/MSClinicalCare

Disease Modifying Therapy — Updated Information:

www.nationalMSSociety.org/DMTupdate

Emerging Therapies Collaborative:

www.ms-care.org/EmergingTherapies

Clinical Trial Listing:

www.nationalMSSociety.org/research/clinical-trials/clinical-trials-in-ms/index.aspx

Self-Injection for Anxiety Counseling (SIAC):

www.nationalMSSociety.org/ClinicalResourcesTools

For Patients

www.nationalMSSociety.org/Treatments

Emerging Therapies Collaborative:

www.ms-care.org/EmergingTherapies

Participate in Clinical Trials:

www.nationalMSSociety.org/ClinicalTrialParticip

Chapter 6: Bladder Dysfunction SNAPSHOT

Patient Presentation

- Failure to Store
 - *Subjective:* “I can’t hold it.” or “I can’t get to the bathroom on time.”
 - *Objective:* Urinary urgency, frequency, or nocturia.
- Failure to Empty
 - *Subjective:* “I can’t get it out.” Or “I have to push on my bladder.”
 - *Objective:* Urinary frequency, hesitation, double-voiding, and/or dribbling

Assessment

- Rule out infection
 - Inquire about signs of symptoms of infection
 - Order UA with culture and CBC, if appropriate
- Determine primary issue: Storage vs. Emptying
 - Obtain history of voiding patterns and episodes of incontinence
- Check post-void residual (PVR): abnormal if >100ml
- Refer to urology
 - Pelvic exam to rule out comorbidities
 - Urodynamic testing

Intervention

- Patient education and empowerment
 - Set goals for adequate hydration
 - Recommend dietary modifications: limit spicy or acidic foods, caffeine, alcohol
 - Recommend behavioral modifications: limit fluid intake 2–3 hours before bedtime
 - Discuss medication side effects
 - Other interventions: Kegel exercises, Valsalva, Interstim
- Consider medications
 - Failure to Store: anticholinergics; antimuscarinics
 - Failure to Empty: alpha antagonists
- Following pelvic exam, explore need for clean intermittent catheterization (CIC)
- Complex or high-risk patients may require more invasive solutions (Litwiller & Kalota, 2012)
 - OnabotulinumtoxinA injections for refractory incontinence
 - Surgical interventions

Chapter 6: Bladder Dysfunction

Patient Presentation

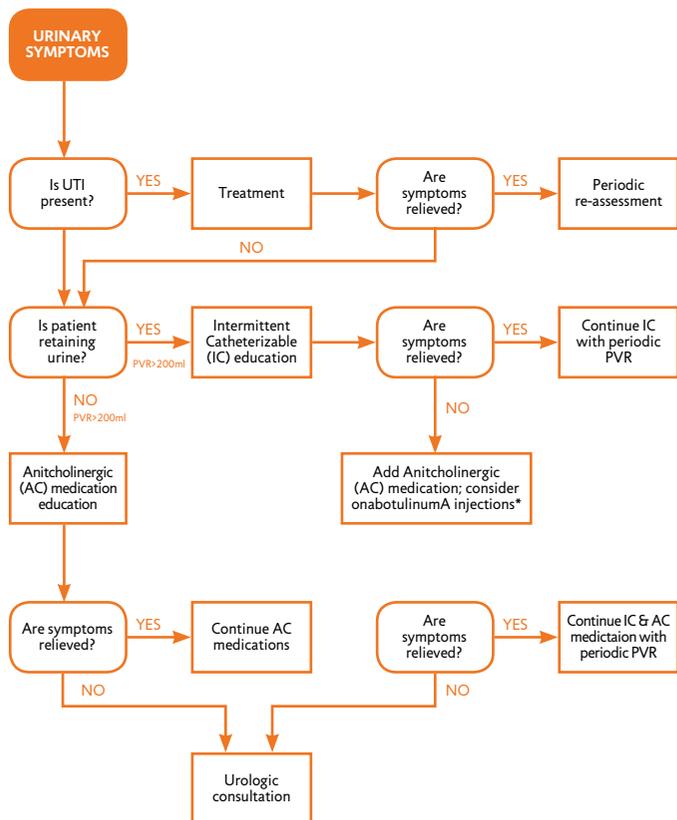
- **Failure to Store** may be caused by an over-active detrusor muscle that contracts as soon as a small amount of urine enters the bladder — continually signaling the need to void. The bladder does not fill to normal capacity, which results in urgency, frequency, nocturia or incontinence.
- **Failure to Empty** occurs when demyelination in the spine interrupts signals to the voiding reflex. The bladder fills, but the spinal cord is unable to send the signal to the brain to relax the sphincter, and/or the bladder to contract adequately, causing the bladder to retain urine and sometimes fill beyond normal capacity. Emptying dysfunction can lead to urgency, dribbling, hesitancy, incontinence or infection.
- **Combined Dysfunction** is a combination of failure to store and empty. This occurs as a result of the lack of coordination between muscle groups. Urine is trapped in the bladder, leading to urgency, hesitancy, dribbling, incontinence, infection and renal injury.

Assessment

Clinical

- Bladder emptying dysfunction increases patient's risk for UTI.
 - Common UTI symptoms: urgency, frequency dysuria, abdominal or lower back pain, fever, increased spasticity, dark, foul-smelling urine
 - Careful attention should be paid to changes in the color or smell of urine, or any abrupt increase in other MS symptoms, because MS-related sensory loss may prevent people from noticing typical UTI symptoms.

Intervention: Algorithm for Analysis & Management of Bladder Symptoms



*In 2011, onabotulinumtoxinA (Cruz et al., 2011) was approved to treat detrusor overactivity associated with a neurologic condition (www.allergan.com/assets/pdf/botox_pi.pdf).

Surgical interventions are available to help manage intractable bladder symptoms (Litwiller & Kalota, 2012).

– *Note:* An abrupt increase in symptoms could signal a *pseudo-exacerbation* (a temporary flare-up of symptoms — unrelated to new damage in the central nervous system — which is typically caused by an elevation in core body temperature resulting from an infection, heat and/or humidity, or strenuous exercise)

Quality of Life

- Social isolation can occur due to fear of loss of bladder control. A thorough assessment and evaluation by the healthcare professional is imperative.

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Litwiller S, Kalota S. *Surgical Management of Bladder Dysfunction in Multiple Sclerosis*. 2012; www.nationalMSSociety.org/ClinicalBulletins.

Recommended Resources

- National MS Society resources for clinicians (www.nationalMSSociety.org/PRCPublications)
 - Talking about Elimination Problems
 - Bladder Dysfunction in Multiple Sclerosis
- National MS Society resources for patients
 - Web page: www.nationalMSSociety.org/bladderdysfunction
 - Brochure: Urinary Dysfunction & MS: www.nationalMSSociety.org/Brochures
 - Video — Managing Symptoms in MS: Bladder Dysfunction: www.youtube.com/watch?v=UF8i1So4ot8
- Books from Demos Health (www.demoshealth.com)
 - Halper J, Holland NJ (Eds.). *Comprehensive Nursing Care in Multiple Sclerosis* (3rd ed.), 2011.
 - Kalb R (Ed.) *Multiple Sclerosis: The Questions You Have: The Answers You Need* (5th ed.), 2012.
 - Schapiro R. *Managing the Symptoms of Multiple Sclerosis* (5th ed.), 2007.
 - Saunders C. *What Nurses Know... Multiple Sclerosis*, 2011.

Organizations

National Association for Continence
www.nafc.org
1-800-BLADDER

Chapter 7: Bowel Dysfunction SNAPSHOT

Patient Presentation

Failure to Empty Common Complaints

Subjective: “I stay constipated” or “I feel I need to go but can’t get it out”

Objective: < 3 bowel movements a week (or significant change in the person’s regular bowel schedule), hard stools, hemorrhoids, abdominal pain

OR

Failure to Store Common Complaints

Subjective: “I soil my clothes” or “I can’t get to the bathroom on time”

Objective: Bowel urgency, incontinence of stool **Assessment**

- Iatrogenic effects of medications
- Fluid and Dietary Intake
- Level of physical activity
- Determine primary issue: Failure to store vs. Failure to empty
- Refer to gastroenterology

Intervention

- Failure to Empty: step-wise use of behavioral and medication strategies
- Failure to Store: similar management; rule out other causes of diarrhea
- Patient Education and Empowerment
 - Set goals for adequate fluid and fiber intake
 - Recommend behavioral modifications — bowel regimen
 - Consider medication side effects

Chapter 7: Bowel Dysfunction

Patient Presentation

Failure to Empty (constipation): most common complaint

OR

Failure to Store: Bowel urgency; incontinence of stool (most often caused by stool leaking around impacted stool)

Assessment — Failure to Empty (Constipation)

- Rule out iatrogenic effects of medications: anticholinergics, anti-hypertensives, analgesics/narcotics, iron supplements, antacids, tricyclic antidepressants, tranquilizers, some antibiotics, diuretics
- Evaluate fluid and dietary Intake
- Evaluate change in level of physical activity
- Determine primary issue: Failure to empty vs. Failure to store
 - Obtain a good history of bowel patterns and issues of incontinence
 - Determine use of mechanical techniques such as digital stimulation and enemas
- Refer to gastroenterology
 - Blood in stool
 - Abdominal pain/ alternating constipation and diarrhea
 - Bowel dysfunction that does not resolve with consistent dietary changes and persistent bowel regimen

Assessment — Failure to Store (involuntary bowel movements)

- Sphincter dysfunction
- Constipation: rectal overload/overflow-distends the rectum
- Diminished rectal sensation
- Dietary Irritants (caffeine and alcohol)
- Medications that reduce spasticity (Baclofen and Tizanidine)

Intervention — Failure to Empty (Constipation)

- **Medication Review:** anti-hypertensives, analgesics/narcotics, tricyclic antidepressants, antacids, iron supplements, anticholinergics, sedatives/tranquilizers, antibiotics, diuretics
- **Behavioral interventions:**
 - Educate to promote adherence to whatever plan is developed.
 - Take into account the person's lifestyle and cultural mores; promote confidence that bowel problems can be successfully managed.
 - Initiate and maintain a regular program of physical exercise.
 - Schedule a regular time for evacuation that takes into account the person's normal frequency and takes advantage of the gastrocolic reflex 20–30 minutes after meals, especially breakfast.
 - Recommend adequate fluid intake (6–8 glasses of fluid daily): many patients will restrict fluids if they have bladder problems, which can lead to constipation; address bladder problems first.
 - Recommend adequate fiber intake: High fiber diet: 25gms for females, 38gms for males — if unable to achieve, recommend bulk supplements: Metamucil, Fibercon, Per Diem, Citrucel, Benefiber.

- **Oral agents**

- A variety of oral agents facilitate the passage of stool through the GI tract:
 - Colace (docusate 100 mg)
 - Surfax (docusate 240mg)
 - Peri-Colace (docusate and casanthranol)
 - Phillips' Milk of Magnesia
 - MiraLAX (polyethelene glycol 3350)

- **Suppositories:**

- Glycerin suppository
- Bisacodyl suppository

- **Manual Stimulation by patient or caregiver**

- **Enemas**

- Mini enemas preferred: Therevac, Enemeez, Colace microenema
- Fleet or tap water enemas should be reserved for episodic use

Intervention — Failure to Store (involuntary bowel movements)

- **Similar to management of constipation**

- Bulk agents used regularly will promote fecal consistency
- Anticholinergic drugs can be helpful when a hyperactive bowel is the cause
 - Monitor bladder function
 - Initiate and titrate slowly
 - Monitor post-void residual volume (drugs can precipitate urinary retention)

- **Diarrhea is uncommon in MS**

- Impaction can result in leakage that is reported as diarrhea
- With true diarrhea, look for underlying cause — e.g., viral or bacterial

Remember: Bowel symptoms in MS can generally be managed with a systematic bowel regimen. Referral to gastroenterology is appropriate when conservative measures have been unsuccessful.

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Recommended Reading

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Recommended Resources

- National MS Society resources for clinicians
www.nationalMSsociety.org/PRCPublications
 - Talking about Elimination Problems
- National MS Society resources for patients
 - Web page: *www.nationalMSsociety.org/bowel*
 - Brochure: Bowel Problems: The Basic Facts
www.nationalMSsociety.org/Brochures

- Books from Demos Health
www.demoshealth.com

- Halper J, Holland NJ (Eds.). *Comprehensive Nursing Care in Multiple Sclerosis* (3rd ed.), 2011.
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Chapter 8: Cognitive Dysfunction SNAPSHOT

Patient Presentation

Subjective: “I can’t remember anything!” “I’m having difficulty finding words.” “I used to be able to multi-task and now I can’t even keep up with my work.” “My thinking is slow as molasses.”

Objective: impairments in processing speed, memory, attention and concentration, executive functioning, and verbal fluency

Assessment

- Query patient about functioning at home and at work
- Query family/caregiver about changes they have noticed
- Rule out secondary etiologies: depression, fatigue, stress, concomitant medications, other medical conditions
- Consider brief cognitive screen (*Multiple Sclerosis Neuropsychological Screening Questionnaire (MSNQ)*)
- Establish baseline function and encourage longitudinal follow-up

Intervention

- Patient education and empowerment
 - Prevalence of cognitive impairment in MS — approximately 60–65%
 - Poorly correlated with physical impairment or time since diagnosis
 - Impairment generally mild to moderate
 - Progression of impairment generally slow
 - Common factor in early departure from the workforce
 - Compensatory tools and strategies for management

- Referrals to specialists
 - Neuropsychologist, occupational therapist (OT), or speech/language pathologist (S/LP) for evaluation and treatment
 - Vocational rehabilitation counselor for employment-related issues
- Accommodations in your treatment
 - Written instructions and other supportive strategies to reinforce learning and enhance treatment adherence

Chapter 8: Cognitive Dysfunction

Patient Presentation

- Because cognitive function is poorly correlated with physical disability or time since diagnosis, *you cannot tell by looking what a person's cognitive abilities/disabilities might be* (Feinstein, 2007).
 - A person with little or no physical disability may be severely cognitively impaired.
 - A person with severe physical disability may be cognitively intact.
- Cognitive changes can appear early or late in the disease, even as an initial symptom.
- While some patients may report cognitive changes (e.g., problems with memory, processing speed, attention, word-finding, visual-spatial skills), others will not mention them until asked.
- Missed appointments, getting lost on the way to appointments, poor compliance may suggest cognitive difficulties.

Assessment

- Early identification and management of cognitive challenges can promote understanding in the family and help people with MS remain working as long as they want to and are able.
- Ask patient (and family members, if present) about cognitive functioning *at every visit* — focusing on changes in activities at home and at work.
- Assessment for depression is essential whenever cognitive changes are suspected or reported; depression affects cognition.
- The bedside mini-mental status exam misses 50% of MS patients with cognitive dysfunction (Peysers, 1984).

- The MSNQ (<http://www.ms-care.org/cmscl/images/pdf/MSNQ.pdf>) can identify patients who might benefit from a full evaluation.
- A full neuropsychological assessment (6–8 hours) over two days identifies cognitive deficits and strengths; a person's strengths can be used to help compensate for areas of deficit (DeLuca, 2006)
 - Functions most commonly affected: recent memory (acquisition and retrieval; attention and concentration; speed of information processing; executive functions (planning, prioritizing, problem-solving); visuospatial organization; verbal fluency
 - Functions that are unaffected in MS: general intellect; long-term (remote) memory; recognition memory; reading comprehension
- Brief (25–90 minutes) neuropsychological screening batteries are available (Benedict et al., 2012; National MS Society, 2008).
- Occupational therapists (OTs) and speech/language pathologists (S/LPs) use different, briefer assessment tools to assess functioning at home and at work.
- The National MS Society (800-344-4867) can refer patients to clinicians with experience in the evaluation and treatment of MS-related cognitive changes.

Intervention

- Education and empowerment
 - Discuss the prevalence of cognitive changes in MS (> 60 percent; DeLuca, 2006), as well as the prevalence of mood issues, emphasizing the potential impact of depression on cognitive functioning (*Ch. 9*).
 - Acknowledge the profound impact cognitive changes can have on self-esteem, confidence, and interpersonal relationships (Kalb, 2006).

- Emphasize the importance of early assessment and management in order to reduce the impact on relationships and productivity at home and at work.
- Provide reassurance that MS-related cognitive symptoms: differ from Alzheimer's disease; tend to progress slowly; can be effectively managed with compensatory tools and strategies, may be slowed by adherence to treatment with a disease-modifying therapy.
- Involve family members in the conversation to promote understanding, communication, and cooperation with the management strategies.
- Provide additional support to spouses and partners, as needed, to deal with this change in their partner and possible impact on their respective roles in the relationship.
- Treatment adherence supported by appointment reminders, written instructions, ample time for questions and repetition, encouragement to bring a family member and/or a tape recorder to appointments
- Referral for treatment (LaRocca, 2006)
 - No medications to improve cognition have demonstrated efficacy in large-scale controlled clinical trials.
 - Disease-modifying therapies (*Ch. 5*) may help slow help slow progression of cognitive dysfunction.
 - Cognitive rehabilitation (primarily compensatory tools and strategies offered by neuropsychologists, OTs, and S/LPs) is likely to be the most practical, effective intervention (LaRocca, 2006).
- Family calendar; organizational strategies (e.g., filing system, mail/bill-paying strategy; memory aids; GPS; project templates (e.g., meal-planning, work assignments, report-writing).

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Gingold J. *Facing the cognitive challenges of multiple sclerosis*. NY: DemosHealth, 2011.

Gingold J. *Mental sharpening stones*. New York: Demos Health, 2008.

Recommended Resources

- National MS Society resources for you (www.nationalMSSociety.org/PRCPublications)
 - LaRocca N. *Talking with Your MS Patient about Cognitive Dysfunction*
 - Benedict R. *Cognitive Dysfunction in Multiple Sclerosis* (www.nationalMSSociety.org/ExpertOpinionPapers)
 - *Assessment and Management of Cognitive Impairment in Multiple Sclerosis*
- National MS Society resources for your patients
 - www.nationalMSSociety.org/Cognition
 - *Solving Cognitive Problems* (www.nationalMSSociety.org/Brochures)
 - *Hold that Thought! Cognition and MS — Program Book* (www.nationalMSSociety.org/download.aspx?id=1392)
 - *Hold that Thought! Cognition and MS — Video Part I* (www.youtube.com/watch?v=LvsRIG-CQwc)
 - *Hold that Thought! Cognition and MS — Video Part II* (www.youtube.com/watch?v=L02XYf06UXs)

Chapter 9: Depression & Other Mood Changes

SNAPSHOT

Patient Presentation

Subjective: “I feel sad all the time.” “I’m overwhelmed!”; “I have no energy.” “I’m cranky and irritable.” “I don’t enjoy anything any more.” “I can’t stop crying [or laughing].”

Objective: flat affect; tearfulness; anxiety; irritability; uncontrolled crying or laughing episodes

Assessment

- **Grief:** discuss this normal reaction to loss (function, roles, identity)
- **Depression:** two-question depression screening tool validated in MS (Mohr et al., 2007); assess for suicidality
- **Anxiety:** ask about overwhelming anxiety
- **Mood swings:** ask patient and family members about temper outbursts, uncharacteristic moodiness and irritability, even in the absence of depression
- **Pseudobulbar affect:** Center for Neurological Study-Lability Scale (CNS-LS) (Smith et al., 2004).

Refer to mental health professional for diagnosis and treatment

Intervention

- Education and empowerment: prevalence; importance of treatment and social support/connection
- Psychotherapy + medication + exercise
- Medications to consider:
 - Depression — selective serotonin reuptake inhibitors
 - Anxiety — anxiolytics
 - Mood swings — low-dose valproic acid
 - Pseudobulbar affect — antidepressants; dextromethorphan + quinidine (Nuedexta)

Chapter 9: Depression & Other Mood Changes

Patient Presentation

- Patients often “put on a good face” during office visits; it is essential to assess for signs of mood changes or extreme distress. Asking about mood at every visit normalizes the issue and makes it easier for patients to talk about emotional changes.
- Depression is a symptom of MS as well as a reaction to its challenges — as demonstrated by evidence of changes in the brain and immune system.
- At least 50% of MS patients will experience a major depressive episode, with the greatest risk at time of diagnosis, during relapses, or with major changes in function.
- Depression may present as excessive irritability in MS rather than tearfulness or guilty rumination (Minden, 1987).
- Mood swings and temper outbursts are common even without depression. Patient and family members will describe this as “out-of-character” and difficult to live with.
- Periodic anxiety is to be expected; however, overwhelming anxiety that interferes with sleep, daily activities, and quality of life, needs to be diagnosed and treated.
- MS patients with pseudobulbar affect (about 10% of the population) will have frequent uncontrolled episodes of crying and or laughing *that are unrelated to their mood or to the present circumstances*. This symptom is embarrassing and distressing for patients and family members.

Assessment

- Grief is a *normal* reaction to loss of function, roles, and identity. Unlike depression, it tends to occur and then resolve with time, and the patient remains able to engage in and enjoy other aspects of life.
- In spite of the progressive, unpredictable nature of MS, depression and severe anxiety are never “normal,” and need to be assessed promptly. Ask for input from partners as well, *including their own mood issues*.
- The major risk for suicide (more common in MS than in other disabling conditions) is depression that is under-recognized and/or under-treated. Co-morbid anxiety adds to the risk. Additional options for assessing depression:
 - Beck Depression Inventory
 - Beck Fast Screen for Medically Ill Patients
 - Center for Epidemiologic Studies-Depression (CES-D) (<http://counsellingresource.com/quizzes/cesd/index.html>)
- Although anxiety receives less attention, it can be as crippling as depression. Assess frequency and intensity of anxiety on a regular basis.
- Patient or family reports of uncontrolled episodes of crying or laughing that seem *inappropriate or out of proportion* should be assessed with the CNS-LS.

Intervention

- Education and empowerment: prevalence of mood issues; importance of social support/connection; value of consultation with/treatment by a mental health professional with experience in MS (the National MS Society can provide referrals)

- Self-help groups are effective for dealing with healthy grieving, enhancing connection and mutual support; major depression requires the synergistic effect of psychotherapy, medication, and exercise
- Patients may resist treatment for emotional changes.
 - Do not want to be perceived as weak or disturbed
 - Resist taking additional medications
 - Dislike the impact of antidepressant medications on sexual function
- Patients with a history of depression may experience an increase of depressive symptoms on interferon-beta medications. Patients who become depressed on an interferon-beta medication may need to switch to a non-interferon.
- Mental health professionals provide:
 - Differential diagnosis
 - Support for the normal grieving process
 - Link between effective mood management and enhanced cognitive function (i.e., effective depression management improves cognition)
 - Training in effective coping strategies
 - Interventions to support family adaptation and communication
 - An interdisciplinary partnership between the NP, rehabilitation team, and mental health professional facilitates optimal treatment of mood issues in MS

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Recommended Readings

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Paparrigopoulos T, Ferentinos P, Kouzoupis A., et al. The neuropsychiatry of multiple sclerosis: Focus on disorders of mood, affect, and behavior. *Int Rev Psychiatry* 2010; 22(1):14–21.

Recommended Resources

- National MS Society resources for clinicians (www.nationalMSSociety.org/PRCPublications)
 - *Talking about Depression and Other Emotional Changes*
 - *Pseudobulbar Affect (Uncontrollable Laughing and/or Crying)*
- National MS Society resources for your patients
 - Web page: www.nationalMSSociety.org/Depression
 - Brochure: *Multiple Sclerosis and Your Emotions* www.nationalMSSociety.org/Brochures
 - Videos: www.nationalMSSociety.org/LearnOnline
 - The Role of Healthy Grieving
 - Understanding Depression
 - Diagnosing and Treating Depression
 - Managing Anxiety
 - Practical Ways to Deal with Mood Swings
 - Emotional Impact on the Family
- Books
 - Kalb R (Ed.) *Multiple Sclerosis: The Questions You Have: The Answers You Need* (5th ed.). NY: Demos Health, 2012.
 - Feinstein A. *The Clinical Neuropsychiatry of Multiple Sclerosis* Oxford: Oxford University Press, 2007.

Chapter 10: Fatigue, Sleep Disorders & Energy Management SNAPSHOT

Patient Presentation

Subjective: “I’m always tired.” “I can’t make it through the day.”

Objective: Fatigue is a subjective symptom for which there are no objective parameters. Assess for actions or inaction that could be prompted by fatigue — e.g., reduced engagement in social activities considering departure from the workforce.

Assessment

- Consider administration of Modified Fatigue Impact Scale or Fatigue Severity Scale
- Identify secondary causes of fatigue — co-existing medical illnesses, medications, depression, disrupted sleep, impaired mobility, impaired lung function
- Determine if primary MS fatigue is present
- Heat, infection, physical/emotional stress, menses can transiently worsen symptoms (Uhthoff’s phenomenon)
- Refer to occupational and/or physical therapy evaluation
- Refer for sleep evaluation

Intervention

- Evaluate rest to activity ratio
- Manage and eliminate secondary causes
 - Treat sleep disturbances, depression and other MS symptoms; adjust medications
- Consider medications for primary MS fatigue
- Consider environmental modifications — cooling strategies; assistive devices; organization of home and work spaces
- Teach stress management strategies
- Recommend aerobic exercise

Chapter 10: Fatigue, Sleep Disorders & Energy Management

Patient Presentation

MS fatigue is a lack of physical energy, mental energy, or both (Krupp, 2004).

- Most common symptom of MS — affecting 75–95%
- 50-60% report fatigue to be one of their worst problems
- Major cause of early departure from the workforce
- No clear etiology, but appears to be related to impaired nerve conduction in the CNS

Chronic persistent fatigue: Activity-limiting sluggishness or lassitude that goes on for more than six weeks, more than 50% of the days, during some part of the day.

Acute fatigue: Activity-limiting sluggishness that has either appeared for the first time or become noticeably worse during the previous six weeks. Acute fatigue can be an early warning that other MS symptoms are about to flare up or become worse.

Assessment

Assess impact of fatigue on activities and quality of life

- Fatigue Severity Scale
(www.sarmc.org/pdfs/sleep-Fatigue-Severity-Scale.pdf)
- Modified Fatigue Impact Scale
(www.nationalMSSociety.org/ClinicalStudyMeasures)

Fatigue in MS is multi-determined:

- Primary MS fatigue (lassitude) is a diagnosis of exclusion:
 - Rule out issues related to impaired mobility (strength, coordination, spasticity, gait); impaired lung function; effects of medication; sleep disturbance; mood issues; temperature sensitivity
 - Consider laboratory testing for co-morbid conditions: CBC differential, CMP, thyroid panel, vitamin B12
 - Refer to physical or occupation therapy evaluation
 - Consider psychological evaluation
 - Consider sleep evaluation

Intervention

- Factors contributing to fatigue
 - Address respiratory problems: breathing techniques; proper seating and support; referral to respiratory therapist
 - Manage mobility issues that result in extra energy expenditure: assistive devices; stretching regimen; exercise program; referral to PT or OT
 - Manage co-existing medical conditions (including depression)
 - Assess/adjust medications that may be producing excessive fatigue/sleepiness, such as anticonvulsants, antihistamines, antihypertensives, sedatives, and certain antidepressants
 - Manage conditions or symptoms that interfere with sleep (e.g., sleep apnea, leg spasms, depression, MS symptoms such as bladder dysfunction, spasticity, or pain). *Research indicates that 25 to 35% of people with MS experience disturbed sleep, which may contribute significantly to daytime fatigue.*

- Primary MS fatigue
 - Prescription medications: amantadine; modafinil (Provigil); armodafinil (Nuvigil); antidepressant medications; psychostimulants
 - Lifestyle changes: a nutritionist or dietitian to help with meal and snack planning; occupational and physical therapies to help with activity planning, energy conservation, and exercise programs; and a therapist or nurse to help with relaxation techniques
- Life Style Management
 - Encourage smoking cessation; healthy diet; cooling techniques; sleep hygiene, balancing activity and rest; taking naps, establishing an exercise program
 - Encourage stress management strategies and healthy coping mechanisms. Refer to a mental health professional who specializes in chronic illness.

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Krupp L. *Fatigue in Multiple Sclerosis: A Guide to Diagnosis and Management*. NY: Demos Medical Publishing, 2004.

Recommended Readings

Amato M, Portaccio E. Management options in multiple sclerosis related fatigue. *Expert Opinion Pharmacotherapy* 2012; 13(2): 207–16.

Johnson CM. Managing fatigue in patients with multiple sclerosis. *Nursing* 2012; 42(6):26–9.

Perrin-Ross, A. Helping People with Multiple Sclerosis to Improve Sleep Quality. *Counseling Points* 2012; Vol 8, Number 2.

Resources for Patients

- From Demos Health (www.demoshealth.com)
 - Kennedy P. (2012) *The Can Do Multiple Sclerosis Guide to Lifestyle Empowerment*.
 - Lowenstein N. (2009). *Fighting Fatigue in Multiple Sclerosis: Practical Ways to Create New Habits and Increase Your Energy*.
 - Peterman Schwarz S. (2006). *Multiple Sclerosis: 300 Tips for Making Life Easier* (2nd ed.).
 - Schapiro R. (2007). *Managing the Symptoms of Multiple Sclerosis* (5th ed.).
- National MS Society information and resources — www.nationalMSSociety.org/Fatigue
 - *Fatigue — Take Control* — an educational video
 - *Fatigue — What You Should Know* — A consumer guide to clinical practice guidelines
 - *Sleep Disorders in MS — The Basic Facts* www.nationalMSSociety.org/SleepDisorders
- *Fatigue in MS*. MS in Focus, Jan 2012. <http://www.msif.org/docs/MSinFocusIssue19EN.pdf>

Chapter 11: Mobility Restrictions — Gait, Balance, Coordination, Vestibular Function & Spasticity SNAPSHOT

Patient Presentation

Subjective: “I’m very tight.” “I can’t move like I used to.” “I’m falling.”

Objective: impaired movements; increased tone; altered gait

Assessment

- Rule out infection (*pseudorelapse* — Ch. 5)
- Determine issue: weakness, spasticity, loss of balance, sensory deficit; fatigue; pain
- Assess activity limitations at home, work, and in the community
- Evaluate skin integrity
- Refer to physical, occupational, vestibular therapy

Intervention

- Rehabilitation — inpatient or outpatient, as needed
 - Energy conservation strategies
 - Exercise regimen: stretching, strengthening, range of motion
 - Gait training
 - Mobility aids — assessment, fitting, training
 - Environmental modifications at home and work

- Medications
 - Spasticity: oral; intrathecal baclofen; botulinum toxin
 - Walking speed: dalfampridine
 - Fatigue: amantadine, modafinil, armodafinil, psychostimulants
- Consider ablative surgical procedures for intractable spasticity/contractures

Patient Education and Empowerment

- Safety at home, work, and in the community
- The use of assistive devices to increase *functional mobility* that allows for active participation and interaction
- Environmental modifications to conserve energy and enhance productivity

Chapter 11: Mobility Restrictions — Gait, Balance, Coordination, Vestibular Function & Spasticity

Patient Presentation

Impairment or loss of functional mobility; increased tone; altered gait; increased risk of falls and/or frequent falls

Assessment

- Rule out infection (*Ch. 5*)
 - Inquire about signs or symptoms of infection; order UA with culture and CBC, if appropriate
- Ask patient (and family) about ability to navigate in the home, work, and community environment
- Assess changes in participation due to restricted mobility
- Determine issue:
 - **Weakness:**
 - Toe drag, foot drop, vaulting (compensatory technique — raising heel on stronger leg to make it easier to swing the weak leg through), compensatory hip hike, trunk lean, or circumduction (swinging leg out to the side)
 - Paraparesis — weakness of both legs
 - Monoparesis — weakness of one leg
 - **Spasticity (increased tone):**
 - Increased fatigue and/or impaired gait
 - Muscle spasms
 - **Loss of balance**
 - Ataxia — swaying and drunken type of gait

- **Sensory deficit**
 - Sensory ataxia — severe numbness in feet that makes it difficult for the person to feel the floor
- **Fatigue**
 - Gait problems → increased fatigue → reduced mobility
- **Skin integrity**
 - Risk for pressure sores related to limited mobility or improper seating

Interventions

- **Physical Therapy** (Provance, 2012)
 - Exercises (stretching, strengthening and flexibility)
 - Although de-enervated muscles cannot be strengthened, surrounding muscles may be strengthened to help compensate
 - Gait training
 - Mobility aids — Evaluate mobility and seating needs; provide training in the use of the device(s) that allow people to function optimally (safely, efficiently, and comfortably) in their various environments, and that protect skin integrity (Minkel, 2012).
 - Canes
 - Braces (AFOs)
 - Functional electrical stimulation (FES: Walk Aide, Bioness): sends low-level electrical impulses to the peroneal nerve, which signals leg muscles to lift the foot; PT evaluation necessary to determine if person is a suitable candidate; FES typically not covered by insurance
 - Walkers/rollators
 - Motorized scooters
 - Manual wheelchairs and power chairs

- **Spasticity Management** (Kushner & Brandfass, 2012)

Spasticity management is best handled in a step-wise fashion. If stretching is insufficient to relieve spasticity, consider medications (baclofen, tizanidine for systemic relief; botulinum toxin injections for targeted small muscle groups such as the ankle, wrist, elbow); the goal of spasticity management is to provide relieve without depriving the person of the degree of spasticity needed to compensate for weakness; some patient need some degree of spasticity in order to stand.

 - Intrathecal baclofen (administered via an implanted pump) is effective for patients who cannot tolerate high doses of oral medication
 - If none of the above options provide relief, ablative surgical procedures may be considered.
- **Walking speed:** Walking speed can be increased in some people with dalfampridine (Goodman et al., 2010).
- **Balance interventions**
 - Comprehensive evaluation by a physical therapist is essential
 - Evaluation of muscle strength, spasticity, balance system (vision, inner ear, sensation in the legs)
 - Therapeutic strategies for balance deficits:
 - Eye muscle exercises
 - Movements of the head activating the inner ear
 - Core strengthening
 - Stretching and strengthening the legs
 - Aerobic activity
 - Strengthening specific muscles to address secondary issues

Patient Education and Empowerment

- Rehabilitation specialists (physical therapists, occupational therapists, physiatrists) can offer valuable information, assessment, and management strategies even in the earliest stages of the disease)
- The effective use of mobility aids is a way to *take charge* of one's MS rather than a sign of *giving in* to one's MS. Optimal users of mobility aids create a “tool chest” of devices that allow them to go where they want to go and do what they want to do on any given day.
- Visual cues may help with balance; watching one's feet can help compensate for loss of sensation.
- Some degree of spasticity can help preserve function by compensating for weakness. The goal of spasticity management is to relieve severe tightness without causing too much weakness.
- Modifications to the environment (e.g., ramps, grab bars) , devices (e.g., cane, walker, scooter) and common sense all can help people enjoy an active life without excessive fatigue or risk of injury from falling

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Goodman AD, Brown TR, Edwards KR, et al. A phase 3 trial of extended release oral dalfampridine in multiple sclerosis. *Ann Neurol*. 2010 Oct;68(4):494–502.

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Minkel JL. *Seating and Mobility Evaluations for Persons with Multiple Sclerosis*, 2012. www.nationalMSSociety.org/ClinicalBulletins.

Provance PG. *Physical Therapy in Multiple Sclerosis Rehabilitation*, 2011. www.nationalMSSociety.org/ClinicalBulletins.

Resources

Minkel JL. *Talking with Your MS Patients about Wheeled Mobility*, 2012. www.nationalMSSociety.org/PRCPublications.

Resources for Patients

National MS Society — www.nationalMSSociety.org/Mobility.

Iezzoni L. *Choosing the Right Mobility Guide for You*. National MS Society, 2012. www.nationalMSSociety.org/MobilityGuide.

Chapter 12: Optic Neuritis & Eye Movement Disorders

SNAPSHOT

Patient Presentation

Subjective: “My vision is all blurry.” “I have a terrible pain in my eye.” “Colors are all faded.” “I’m seeing two of everything.” “There are big holes in my vision.”

Objective: Inflammation of the optic nerve; reduced visual acuity; impaired color vision; visual field defects

Assessment

- Rule out infection (*Ch. 5*).
- Assess afferent visual system (visual acuity; visual fields; color vision; pupils; fundoscopic examination); assess oculomotor function (ocular alignment; ocular motility; nystagmus).
- Refer to neuroophthalmology/ophthalmology.
- Assess impact of visual symptoms on function and quality of life.

Intervention

- Patient education and empowerment
 - Visual symptoms in MS include those that affect vision directly and those that affect eye movement. Neither benefits from standard eyeglasses because they are the result of damage in the CNS.
 - Steroid treatment may shorten duration of symptoms, but recovery of visual deficits may take many months and may be incomplete.
- 3–5 day course of high-dose corticosteroids (*Ch. 5*)
- Accommodations recommended as needed

Chapter 12: Optic Neuritis & Eye Movement Disorders

Patient Presentation

Acute optic neuritis (AON) (Conger et al., 2011)

- Common characteristics: visual acuity loss, impaired color vision (typically variations of green and red), visual field defects (central), periocular pain, alterations in light perception (often a reduction in light intensity).
- ≈ 40% of patients have AON as the presenting symptom of MS and up to 80% of MS patients will experience an episode of AON during their lifetime.
- In more than 90% of patients, recovery begins within 30 days of onset.
- If AON occurs with transverse myelitis consider neuromyelitis optica (NMO) and check serum NMO-IgG. (Wingerchuck, 2007)

Internuclear ophthalmoplegia (INO) (Conger et al., 2011)

- The most common eye movement disorder in MS
- Adduction slowing and abduction nystagmus when the patient moves the eyes horizontally.
- Causes double vision during tasks that involve horizontal saccadic movements (e.g., reading or looking over the left shoulder while driving)

Assessment

- Clinical
 - Assess for signs & symptoms of infection and other triggers of Uhthoff's phenomenon (*Ch. 5*).
 - Perform ophthalmoscopy and cranial nerve exam:
 - Assess: visual acuity, color vision, RAPD (swinging flash-light test), reduced light perception in affected eye, visual field defects.
 - > 60% have normal fundus exams and most acute cases do not show disc pallor for > a few weeks after onset of symptoms
 - Order brain MRI with and without contrast, including orbits.
 - Consider referral for ophthalmology if atypical clinical features exist: Rule out non-MS causes: anterior ischemic optic neuropathy (AION) and Leber's hereditary optic neuropathy (LHON).
 - Consider additional diagnostics: Optical coherence tomography (OCT), Visual Evoked Potentials (VEP).
- Quality of Life
 - Evaluate: impact on driving; need for work modifications, short-term disability, or resources for visually impaired, including low-vision specialist if visual deficits persist.

Intervention

- Treat with IV methylprednisolone 1 gram for 3–5 days (Beck et al., 1993).
- For refractory visual symptoms, consider additional therapy.

Table 12-1: Bedside Ocularmotor Examination (Conger et al., 2011)

Visual acuity	Spectacle correction Pinhole correction Near card or distance
Visual fields (by confrontation)	Monocular testing Static versus dynamic
Color vision	Color plates Red-green desaturation
Pupils	Anisocoria Shape and position Reactivity Relative afferent pupillary defect (RAPD) during swinging flashlight test
Fundoscopy examination	Optic disc pallor Nerve fiber loss Occult nystagmus Pervenular phlebitis (peripheral retina)

Table 12-2: Bedside Oculartmotor Examination (Conger et al., 2011)

Ocular alignment	Tropia Crosscover for phorias Hyperdeviation Skew deviation Ptosis Head tilt
Ocular motility	Ductions (monocular motility) Versions (binocular motility) Diplopia CN VI>III>IV in MS
Nystagmus	Visual inspection Primary position and with eccentric gaze Fundusoscopic exam (occult nystagmus)

References

Beck RW, Cleary PA, Trobe JD, et al. The Optic Neuritis Study Group. The effect of corticosteroids for acute optic neuritis on the subsequent development of multiple sclerosis. *N Engl J Med* 1993; 329(24): 1764–1769.

Conger A, Conger D, Frohman TC. Optic Neuritis and Eye Movement Abnormalities. In T Frohman, D O'Donoghue. *Multiple Sclerosis for the Physician Assistant*. National MS Society, 2012.

Wingerchuk D. Diagnosis and treatment of neuromyelitis optica; *The Neurologist* 2007;13(1): 2–11.

Recommended Readings

Balcer LJ. Clinical practice: optic neuritis. *N Engl J Med* 2006; 354(12): 1273–1280.

Burton EV, Greenberg BM, Frohman EM. Optic neuritis: A mechanistic view. *Pathophysiology* 2011; 18: 81–92.

Frohman EM, Fujimoto JG, Frohman TC, et al. Optical coherence tomography: a window into the mechanisms of multiple sclerosis, *Nat. Clin. Pract. Neurol.* 4 (2008) 664–675.

Thurtell MJ, Joshi AC, Tomask RI, et al. Crossover trial of gabapentin and memantine as treatment for acquired nystagmus. *Ann Neurol* 2010 May;67(5):676–80.

Resources for Patients from the National MS Society

Vision Problems: The Basic Facts
(www.nationalMSSociety.org/download.aspx?id=65)

Low Vision Alert: Home Safety
(www.nationalMSSociety.org/download.aspx?id=843)

Chapter 13: Pain & Sensory Abnormalities

SNAPSHOT

Patient Presentation

Central neuropathic sensory symptoms

Subjective: “I feel like my skin is on fire.” “I have this tight band around my middle.” “The side of my face hurts so much I can’t brush my teeth.” “My feet are numb.”

OR

Non-neuropathic sensory symptoms

Subjective: “I ache all over my body.” “My hips...back...knees hurt”

Objective: Grimacing, gait problems, spasticity, agitation

Assessment

- Analogue pain scale: 1–10
- Rule out infection UA/UC, CBC
- Determine type of pain: central neuropathic or non-neuropathic
- Rule out disc disease, avascular necrosis, osteoporosis, constipation, and other non-MS related sources of pain or discomfort

Intervention

- The biopsychosocial model of pain management includes medical interventions, behavioral self-management, and social support.
- Central neuropathic pain
 - Medication options: anticonvulsants, antidepressants
- Combining lower doses of multiple medications may provide more benefit with less sedation
 - Percutaneous rhizotomy or gamma knife radiosurgery for trigeminal neuralgia that does not respond to medication
- Nonneuropathic pain
 - Physical therapy
- Stretching
- Exercise
- Proper use of appropriate mobility devices
 - Spasticity management (*Ch.11*)
 - Non-steroidal antiinflammatories
- Patient Education and Empowerment
 - Encourage accurate, descriptive reporting of pain symptoms
 - Provide information about the types of pain MS can cause
 - Emphasize the interaction between pain and mood (anxiety and depression)
 - Encourage effective stress management strategies
 - Enhance social support
 - Recommend Increased physical activity

Chapter 13: Pain & Sensory Abnormalities

Patient Presentation

Pain is a common symptom of multiple sclerosis (MS), with a mean prevalence of 63.5% (Solaro & Uccelli, 2008). Compared to the various types of pain described by the general population, MS pain is reported as more intense, having greater impact on activities of daily living, and necessitating greater use of analgesia (Ehde, 2005).

- Burning sensation (most common in lower extremities but can occur in upper extremities and perineum)
- Tight banding around the chest or abdomen
- Facial pain (trigeminal neuralgia)
- Lhermitte's sign
- Headache
- Low back pain
- Painful tonic spasms

Assessment

- Analogue pain scale 1–10
- Rule out infection: (*see pseudo relapse*): Order UA/UC, CBC if appropriate
- Determine origin of pain (Maloni, 2012)
 - **Central neuropathic:**
 - *Intermittent:* spontaneous, paroxysmal pain, described as: shooting, stabbing, shock-like, lancinating, crushing, or searing.

- **Trigeminal neuralgia** (intense, shock-like pain in a branch of the trigeminal nerve along the cheek); spontaneous or triggered by touch or movement of the jaw; 20 times more common in MS than in general population
- **Lhermitte's sign** (shock-like sensation in the neck and back that occurs with neck flexion); seen in 40% of patients
- **Painful tonic spasms** (abrupt, brief tightening of a limb, clawing of a hand or arm, or kicking of a leg); often evoked by touch, movement, hyperventilation, emotion
- *Continuous:* Dysesthetic pain (burning, tingling, aching, throbbing, vice- or band-like) is the most common; either spontaneous or evoked by touch or bed clothes; persistent, often symmetric — typically affecting both legs and feet but also arms, trunk and perineum; associated with feelings of warmth or cold; more common in those with minimal disability
- **Non neuropathic:** indirect consequence of disability associated with MS
 - Weakness; deconditioning
 - Stress on bones muscles, joints
 - Altered gait and/or posture
 - Mobility aids that are inappropriate, ill-fitting, or used incorrectly
- **Mixed neuropathic and non-neuropathic:** headache (more common in MS than in the general population, with migraines being three times more common than in the general population), painful muscle spasms or spasticity

Intervention (Maloni, 2012)

Continuous Central Neuropathic Pain

Dysesthetic extremity pain (Maloni, 2012)

Treatment based on neuro-modulation and interruption of pain pathways:

- Tricyclic antidepressants (e.g., amitriptyline; nortriptyline)
- Anticonvulsants (pregabalin; gabapentin)

Intermittent Central Neuropathic Pain

Lhermitte's sign

No treatment required — resolves with cessation of neck flexion

Painful tonic spasms

- Anticonvulsants
- Lidocaine
- Botulinum toxin

Intervention (Maloni, 2012) (cont'd)

Nonneuropathic Pain

Musculoskeletal pain

- Preventive
 - Bone anti-resorptive therapies as needed; smoking cessation; calcium and vitamin D supplementation
- Physical therapy: assessment and management of safety, gait, positioning, seating, effective use of mobility aids
- Frequent position changes and use of proper support
- Medications: acetaminophen and nonsteroidal anti-inflammatories (at lowest effective dose)

Mixed Neuropathic and Nonneuropathic Pain

Muscle spasms

Standard spasticity management protocol (*Ch. 11*)

Headache

Follow existing treatment guidelines for headache type

A word about opioids: Opioids have minimal effect in central MS pain and are not recommended.

A word about cannabinoids: The use of cannabinoids for MS pain treatment is supported by trials outside the U.S. Nabiximols and nabilone are licensed in the United Kingdom and Canada, but not in the U.S. Inhaled cannabis and THC in any form have an effect on cognition.

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Hirsh A, Turner A, Ehde D, Haselkorn J. Prevalence and impact of pain on multiple sclerosis: Physical and psychological contributors. *Archives of Physical and Medical Rehabilitation* 2009;90(4) 646–651.

Jensen MP. Psychosocial factors and adjustment to chronic pain in persons with physical disabilities: A systematic review. *Archives of Physical and Medical Rehabilitation* 2011;92:146–160.

Nurmikko TJ, Gupta S, Maclver K. Multiple sclerosis-related central pain disorders. *Current Pain and Headache Reports* 2010; 14(3): 189–195.

Solaro C, Ucelli MM. Pharmacologic management of pain in patients with multiple sclerosis. *Drugs* 2010;70(10): 1245–1254.

Resource for Patients from the National MS Society

Society website — www.nationalMSSociety.org/Pain

Pain: The Basic Facts — www.nationalMSSociety.org/Brochures

Chapter 14: Sexual Dysfunction

SNAPSHOT

Patient Presentation

Women:

Subjective: “I’m just not in the mood — it’s like someone turned off the switch.” “I have vaginal numbness.” “It’s painful.” “I can’t achieve orgasm.”

Objective: decreased or altered sensation, vaginal dryness, anorgasmia, decreased libido

Men:

Subjective: “I can’t get/keep an erection”; “I have numbness”; “I can’t orgasm”; “I’m just not in the mood.”

Objective: Decreased or altered sensation, erectile dysfunction, anorgasmia, decreased libido

Assessment

- Primary factors — CNS demyelination affecting sexual arousal, sensation, orgasm
- Secondary factors — other MS symptoms (fatigue, spasticity, weakness, bladder/bowel, pain, tremor, mood) and medication side effects
- Tertiary factors — depression and other emotional issues; social
- Refer for counseling, sex therapy (women and men)
- Refer to urology (men)

Intervention

- Women: vaginal lubricants
- Men: oral, injectable, or suppository medications for erectile dysfunction; penile implants
- Women and men: Management of MS symptoms and medication side effects that interfere with sexual function/activities; counseling for emotional or attitudinal barriers
- Patient Education and Empowerment
 - Behavioral modifications — communication with partner; alternate positions; body mapping; sexual aids; choosing optimal, higher-energy times of day
 - Management of medication side effects
 - Catheter management

Chapter 14: Sexual Dysfunction

Patient Presentation

- The prevalence of sexual dysfunction (SD) in patients with MS ranges from 50–73%, and 45–70% in women.
- **Primary SD** — caused directly by CNS lesions: decreased libido, altered genital sensations, decreased arousal (vaginal lubrication, erectile function), decreased intensity of orgasm or inability to reach orgasm
- **Secondary SD** — caused by other MS symptoms and/or medication side effects:
 - **MS symptoms:** fatigue, weakness, spasticity, poor coordination, numbness, burning, pain or girdling sensations in the torso or limbs, bladder and/or bowel dysfunction, cognitive dysfunction resulting in distractibility and loss of arousal
 - **Medication side effects:** antidepressants, anticholinergics, medications causing sleepiness or sedation
- **Tertiary SD** — related to psychosocial, spiritual, and cultural issues (self-image, self-esteem, mood disorders, body image, fears of rejection, communication difficulties) that impact sexual feelings and expression.

Assessment

- Ask about past and recent changes in sexual function.
- Consider administering the MS Intimacy and sexuality questionnaire — 19 (MSISQ-19; Saunders, et al., 2000) — identifies primary, secondary, and tertiary factors.
- Evaluate MS symptoms (fatigue, spasticity, weakness, bladder/bowel dysfunction, dyesthesias, cognitive dysfunction) that may be contributing to secondary SD.

- Assess medications (schedule and dosage) that may be impacting sexual function: e.g., antidepressants, anticholinergics, antihypertensives.
- Rule out other health factors that may contribute to sexual dysfunction.
- Consider tertiary factors: mood issues (grief, depression, anxiety); relationship issues (communication, past sexual history, shared activities); patient safety issues (domestic violence).

Intervention (Foley, 2008)

- Education about primary, secondary, and tertiary factors in MS that can affect sexual feelings and activities in order to facilitate patient communication about any problems that may be occurring
- Treatment for primary SD in women
 - Water-soluble lubricating agents to ease vaginal dryness
 - Enhanced, focal clitoral stimulation (manual, oral, vibrator), coupled with psychogenic audio-visual stimulation can enhance vaginal vasocongestion response (High-intensity, wall-power)
- Treatment for primary SD in men:
 - Oral agents: phosphodiesterase type 5 (PDE5) inhibitors (sildenafil citrate, vardenafil, tadalafil)
 - Intracavernosal injections with alprostadil alone or in combination with phentolamine; papavarine + phentolamine
 - Urethral suppository — alprostadil
 - Penile prostheses
- Treatment for secondary SD in women and men
 - Recommend anti-spasticity agents and stretching prior to sexual activity to subdue spasticity and pain during intercourse
 - Encourage a cool environment, pre-cooling strategies, and energy conservation techniques to prevent Uhthoff's phenomenon

- Teach body-mapping to enhance body awareness and effective communication with the sexual partner. The patient systematically explores her/his body to identify erogenous areas and types of touch that feel good, and then teaches the partner how to provide pleasure.
- Explore different positions for sexual activity
- Refer to urology, gynecology, and endocrinology specialists to assist with treatment of secondary SD and rule out non-MS associated diagnoses (e.g., vasculogenic abnormalities, hormonal changes).
- If patient is being treated for depression, consider bupropion XL, alone or in combination with another antidepressant, to reduce impact on sexual function.
- Refer to a mental health professional for counseling, communication skills training. Partners can easily misinterpret a loved one's SD as a loss of interest in them or the relationship.

References

Demirkiran M et al. Multiple sclerosis patients with and without sexual dysfunction: are there any differences. *Mult Scler* 2006; 12: 209–214.

Foley F. *Assessment and Treatment of Sexual Dysfunction in Multiple Sclerosis*. 2008. www.nationalMSSociety.org/ClinicalBulletins.

Sanders AS, Foley FW, LaRocca GL, Zemon V. The multiple sclerosis intimacy and sexuality questionnaire-19 (MSISQ-19). *Sex Disabil* 2000; 18: 3–26.

Recommended Readings

Fletcher SG, Castro-Borrero W, Remington G, et al. Sexual dysfunction in patients with multiple sclerosis: a multidisciplinary approach to evaluation and management. *Nature Clinical Practice Urology* 2009; 6: 96–107.

Foley FW, LaRocca NG, Sorgen A, Zemon V. Rehabilitation of intimacy and sexual dysfunction in couples with multiple sclerosis. *Multiple Sclerosis: Clin Lab Res*. 2001;7(6):417–421.

Resources for Patients

Catalogs

Discreet catalog services containing products that may be helpful to both disabled and non-disabled people.

- Eve's Garden: www.evesgarden.com
- Good Vibrations, Inc.: www.goodvibes.com
- Xandria Collection: www.xandria.com

Books

Foley F, Werner M. How MS affects sexuality and intimacy. In R Kalb (Ed.). *Multiple Sclerosis: The Questions You Have; The Answers You Need* (5th ed.). NY: Demos Medical Publishing, 2012.

Joannides P, Gross, D. *Guide to Getting It On*. Oregon: Goofy Food Press, 2011.

Chapter 15: Speech Disorders

SNAPSHOT

Patient Presentation

Subjective: “I’m slurring.” “Others can’t hear me when I speak.” “People can’t understand me.” “My boss thinks I’ve been drinking.” “I get exhausted when I try to have a conversation.”

Objective:

- Dysarthria: problems with articulation, speaking rate, intelligibility, and natural flow of speech in conversation
- Dysphonia: speech that is slurred, nasal, hoarse, scanning, hyperphonic

Assessment

- Listen for changes in speech quality and patterns
- Inquire about speech/communication issues at home and work (including input from family members)
- If changes occur, refer to speech/language pathologist for: informal and formal measures of a variety of oral-motor, speech, and voice functions; perceptual analysis of recorded speech; communication profile and needs assessment to determine the adequacy of speech and voice at home, at work, and in the community.

Intervention

- Patient Education and Empowerment
 - Education about impact of MS on normal speech and voice production
 - Management of contributory factors, including spasticity, weakness, tremor, ataxia, and fatigue
 - Strategies to educate others about MS-related speech problems
- Exercises and compensatory techniques for improving speech clarity
- Augmentative communication devices; voice amplifiers

Chapter 15: Speech Disorders

Patient Presentation

As many as 40% of people with MS may experience speech problems at some time over the disease course, making it difficult to carry on conversations and significantly impacting quality of life. These problems typically result from muscle weakness, spasticity, tremor or ataxia caused by neurologic impairment.

The primary types of speech problems in MS are (Miller, 2008):

- **Dysarthria:** slurred or poorly articulated speech, reduced loudness, unnatural emphasis, and slower rate of speech
 - Spastic dysarthria caused by bilateral lesions of corticobulbar tracts
 - Ataxic dysarthria caused by bilateral or generalized lesions in the cerebellum
 - Mixed dysarthria caused by bilateral, generalized lesions of multiple areas in the cerebral white matter, brainstem, cerebellum, and/or spinal cord
- **Dysphonia:** changes in vocal quality (harshness, hoarseness, breathiness, or a hypernasal sound) that often accompany dysarthria

Assessment

- Refer to Speech/language pathologist for evaluation and treatment
 - Examination oral muscles: lips tongue, soft palate
 - Assessment of muscle control and its impact on strength, speed, range, accuracy, timing, and coordination of speech
 - Assessment of breath support and control and their impact on pronunciation and clarity of speech

Intervention (Miller, 2008)

The goal of intervention is to improve speech intelligibility and naturalness so that the person can communicate comfortably and successfully in the home, work, and community environments. To be successful, treatment must be tailored to the person's specific problems and lifestyle.

- Ongoing collaboration with S/LP and patient to manage spasticity, weakness, tremor, ataxia, and fatigue that may underlie or accompany the speech problems.
- Evidence-based treatment strategies for dysarthria (Spencer & Yorkston, 2002):
 - Improve breath support — biofeedback to gauge respiration during speech tasks, and when learning a new breath pattern with deeper inhalation, increased force at exhalation, and use of abdomen
 - Improve respiratory/phonatory coordination — increase awareness of the irregular speech-respiratory pattern; determine optimal words per breath groups; practice flexibility in cued and non-cued conversational scripts
 - Improve phonatory functioning according to voice quality:
 - Hyperadduction (harsh voice quality, typical of MS) — often not directly treated because it is difficult to modify, with negligible impact on intelligibility
 - Hypoadduction (soft, breathy, whispered quality) — Lee Silverman Voice Treatment (LSVT) seeks to increase vocal loudness
- Patient Education and Empowerment
 - Family members can provide valuable input about communication changes and can assist in correcting it by encouraging exercises
 - Exercises can improve muscle control, breath support, and speech production

- Helpful techniques include slowing down, over-articulating, and phrasing to help make speech clearer
- Speech therapy can occur in individual and/or group settings
- Use of a voice recorder can facilitate self-correction of speech
- Augmentative and Alternative Communication
 - Need for AAC devices in MS is relatively uncommon
 - When severe dysarthria interferes with individual's well-being, safety and functional communication, evaluation of appropriate speech-generating devices (SGD) is indicated (Information about AAC devices: www.asha.org/public/speech/disorders/AAC; <http://aac.unl.edu>)

National MS Society. *Speech and Swallowing: The Basic Facts*. 2009. www.nationalMSSociety.org/Brochures

Resources for Patients

For information about dysarthria symptoms, evaluation, and treatment, as well as practical communication tips for both the person with dysarthria and the listener — www.asha.org/public/speech/disorders/dysarthria.

References

Miller P. Dysarthria in Multiple Sclerosis. National MS Society, 2008. www.nationalMSSociety.org/PRC/clinicalbulletins.

Spencer KA, Yorkston KM. Evidence for the treatment of respiratory/phonatory dysfunction from dysarthria. In Strand EA (ed): *Treatment of dysarthria: Support by evidence-based research and expert opinion*. ASHA Perspectives (Division 2) 2002; 12(4):4-16

Recommended Readings

Miller P. Speech and voice problems: assessment and management. In R Kalb (Ed.) *Multiple Sclerosis: The Questions You Have; The Answers You Need* (5th ed.). New York: Demos Health, 2012.

Yorkston KM, Beukelman DR. Decision-making in AAC intervention. In: Beukelman DR Yorkston KM, Reichle J (eds.). *Augmentative and Alternative Communication for Adults with Acquired Neurologic Disorders*. Baltimore: Paul H. Brookes, 2000

Chapter 16: Swallowing Problems (Dysphagia)

SNAPSHOT

Patient Presentation

Subjective: “I’m having difficulty swallowing”; “I cough when I eat or drink something” “I’ve started to choke a few times.” “It’s taking me forever to eat a meal and I get exhausted before I finish.”

Objective: facial weakness; asymmetrical palate movement; decreased gag reflex; weight changes

Assessment

- Ask for input from family members related to: coughing/choking episodes during meals (including the types of foods that seem to cause a problem; time taken to eat a meal; weight loss)
- Refer to speech/language pathologist (S/LP) if a significant choking episode occurs or a problem is reported by the patient or family member
- Diagnostics — Esophagram (modified barium swallow)

Intervention

- Rehabilitation strategies (S/LP) to strengthen muscles and improve the swallow
- Referral to a dietician for dietary modifications and nutritional information
- Patient Education and Empowerment
 - Information about the relationship between MS and swallowing problems, as well as the role of the speech/language pathologist
 - Dietary modifications — consistency of foods
 - Behavioral modifications — postural change; food preparation; mealtime strategies
 - Engagement of family members in the management process
- Complex or high-risk patients may require feeding tube

Chapter 16: Swallowing Problems (Dysphagia)

Patient Presentation

Choking, facial weakness, asymmetrical palate movement, decreased gag reflex, weight change

Assessment

- Seek input from family members about coughing/choking episodes, changes in mealtime habits, unusual fatigue during meals, significant weight loss
- Refer to speech/language pathologist

Diagnostic Evaluation

Baseline swallow assessment: Esophagram (modified barium swallow) — examines oral and pharyngeal swallowing physiology after the patient drinks a barium solution that coats and outlines the walls of the esophagus). The modified barium swallow is preferred because the patient may aspirate when given usual large-volume swallows (Logemann, 2011).

Intervention

- Goals:
 - Maintain patient on oral diet as much as possible
 - prevent weight loss
 - prevent pneumonia
- Dysphagia management plans
 - Promote safe and efficient swallowing for oral intake with education, dietary modification, behavioral modification, exercise

Strategies (Logemann, 2011)

- Dietary modifications depending on results of Modified Barium Swallow
 - Increase viscosity of thin liquids
 - Restrict intake of foods that are difficult to chew or swallow (e.g., peanut butter)
 - Provide instruction on how to prepare, serve, cut foods
- Postural change during meals — directs food away from the airway
- Heightened oral sensation prior to swallow-enables faster swallow
- Voluntary control over swallows — holding breath, increasing effort
- Exercises to improve ROM of both oral and pharyngeal structures and improve tongue strength
- If regularly aspirating all foods despite viscosity, non-oral feeding is recommended for two reasons: regular aspiration can cause pneumonia/ whatever is aspirated does not provide nutrition/ hydration. Non-oral feeding can be used temporarily until patient's condition improves, or on a permanent basis if necessary.
 - Nasogastric tube — used only on a temporary basis because of irritation to the nose and throat
 - Percutaneous endoscopic gastrostomy (PEG)
- If weight loss and/or fatigue while eating are severe, consider non-oral supplements.

Patient Education and Empowerment

- Patients and family members need the following information (Logemann, 2011)
 - The swallowing process is complex, involving approximately 30 muscles in the mouth and throat and eight cranial nerves. MS lesions in various parts of the brain including the brain-

stem and/or the cranial nerves can cause problems in the swallowing process, from the time the food enters the mouth until it reaches the stomach.

- Swallowing difficulties are relatively uncommon in MS, but can occur even early in the disease course.
- Reduced muscle strength or coordination can allow food particles to remain in the mouth, throat, or esophagus after the swallow is completed. Those food particles may be accidentally aspirated into the lungs after the swallow when breathing resumes, potentially leading to aspiration pneumonia.
- Coughing or choking while eating, severe fatigue while eating, significant weight loss should be reported to the nurse and physician, and a referral requested to a speech/language pathologist.
- The role of the speech/language pathologist is to assess the problem, provide a regimen of exercises to address loss of strength/coordination in the muscles involved in eating and swallowing, and work with the dietician to recommend a safe/healthy dietary regimen.
- Dietary changes may be necessary in order to promote safety, comfort, and a healthy nutritional status.
- The support of family members is essential during mealtimes and in the event that significant dietary modifications are required
- MS patients and/or their family members should contact both the physician and the speech/language pathologist about any significant changes in swallowing

References

Logemann JA. *Swallowing Disorders and Their Management in Patients with Multiple Sclerosis*. National MS Society, 2011. www.nationalMSSociety.org/ClinicalBulletins.

Recommended Readings

Bergamaschi R, Crivelli P, Rezzani C. et al. The DYMUS questionnaire for the assessment of dysphagia in multiple sclerosis. *J Neurol Sci* 2008 June 15;269 (1–2):49–43. Epub.

Calcagno P, Ruoppolo G, Grass MG, et al. Dysphagia in multiple sclerosis: Prevalence and prognostic factors. *Acta Neurol Scand* 2002 Jan 105(1):40–43.

Logemann JA. *A Manual for Videofluoroscopic Evaluation of Swallowing* (2nd ed). Austin, TX:Pro-Ed, 1993.

Wiesner W, Wetzel SG, Kappos L, et al. Swallowing abnormalities in multiple sclerosis: Correlation between videofluoroscopy and subjective symptoms. *Eur Radiol* 2002 Apr 12(4):789–792.

Resources for Patients

National MS Society

- Website: www.nationalMSSociety.org/Symptoms
- Brochure: Speech and Swallowing — The Basic Facts www.nationalMSSociety.org/Brochures

Books

Kalb R, Giesser B, Costello K. *Multiple Sclerosis for Dummies* (2nd ed.). Hoboken NJ: Wiley, 2012.

Logemann JA. Swallowing. In Kalb R (Ed): *Multiple Sclerosis: The Questions You Have — The Answers You Need* (5th ed.). New York: Demos Health, 2012.

Chapter 17: Continuum of Care

Introduction

The continuum of care in multiple sclerosis (MS) can be defined as an integrated healthcare process that guides patients — from diagnosis to end of life — through a comprehensive and coordinated array of personalized, interdisciplinary health services.

The concept of *palliative care* is at the core of this integrated process. Palliative care includes not only traditional disease-model medical care but also the goals of enhancing quality of life for patient and family; managing distressing symptoms; facilitating communication, decision-making and advance care planning; and providing opportunities for personal growth throughout the disease course. Furthermore, palliative care can be provided in all care settings — home, outpatient clinic, long-term-care facility, hospital, or intensive care unit (Brandes et al, 2012).

The nurse practitioner plays a central role in coordinating the interventions and resources required at all stages of multiple sclerosis (MS) care and in creating appropriate expectations for the patient and family based on patient-oriented goals.

Outpatient Care

- Goals should center on optimizing the patient's independence level, role performance, mobility, and quality of life.
- Optimal care involves collaboration among providers in primary care, neurology, nursing, social work, urology, psychology, physical therapy, occupational therapy, speech therapy, and vocational rehabilitation, as needed.
- The care plan is focused on primary management of MS (diagnosis, relapse, disease, and symptom management, along with, patient education, and resource identification)

Hospitalization

- Relapse management — (if admission is warranted due to complicating comorbidities) may involve steroid administration, plasma exchange, or a combination of both, as well as acute rehabilitation strategies to promote optimal recovery from the relapse
- Discharge planning — team that includes the hospitalist, navigation nurse, referral services coordinator, and case manager or social worker
- Other possible admissions: PML management or telemetry monitoring for first-dose administration of fingolimod (*Ch. 5*).

Rehabilitation

- Outpatient rehabilitation
 - From diagnosis onward, rehabilitation specialists (physical and occupational therapists, and speech/language pathologists) provide strategies for energy management, promote functional mobility with environmental modifications, gait training and the optimal use of appropriate mobility aids, recommend individualized exercise programs, identify and address issues related to cognition, swallowing and/or speech.
 - Refer for changes in function: increased spasticity; reduced mobility; slurred speech or an increase in difficulty communicating; swallowing difficulty, tremor, increasing fatigue
- Inpatient rehabilitation
 - Complex, high-risk patients whose symptoms require treatment in an inpatient setting (e.g., severe relapse, loss of functional mobility, reduced nutritional status, pressure sores)

Home Health Services

- Home care provides personalized services by a skilled professional, which are developed collaboratively with the patient and the family to foster health, safety, and quality of life.
- According to Medicare, skilled nursing visits can also be reasonable and necessary in the following circumstances:
 - Observation and assessment of an individual's condition when only the specialized skills of a healthcare professional can: (1) determine an individual's status and the potential for a change in condition, and (2) evaluate the need for possible modifications of treatment or the need for new services until the individual is stable.
 - Teaching and training activities requiring a skilled nurse to teach an individual, family member, or caregiver how to manage the beneficiary's course of treatment, unless it becomes apparent that he/she is not willing or capable of being trained.
 - Management and evaluation of an individual Plan of Care where the individual's condition or complications require the services of a skilled nurse to ensure that non-skilled care, e.g., home health aide services, is achieving its purpose.
- Services that may be provided in the home include:
 - Health-related services (e.g., skilled nursing, medication management, wound care).
 - Social services (e.g., family and personal support/counseling, facilitating access to social and recreational activities, care management).
 - Personal care services (i.e., assistance with activities of daily living, service dogs).
 - Homemaker and chore services (e.g., assistance with laundry, meal preparation)

- Rehabilitation services (e.g., physical, occupational, speech therapies, durable medical equipment).
- Child care (special arrangements are generally required and availability and coverage vary from state to state).

Adult Day Care

- Offers the opportunity to meet others, make friends, develop new interests, have a life outside of the home and something to talk about at the end of the day
- May provide the support needed to enable the individual to remain in her or his home and delay out-of-home placement
- Offers respite for family caregivers
- Possible funding sources: Medicaid, Medicare, state and country funding, private and community agencies

Assisted Living

- Provides a personalized residential environment and consumer-directed services that foster quality of life, right to privacy, choice, dignity, and independence.
- Helps to bridge the gap for people with MS who are able to maintain a fairly high level of independence but need some assistance to meet the demands of the disease.
- General criteria of the assisted living resident with MS include:
 - Need for supervision to optimize safety when mobility problems (balance, lack of coordination, sensory loss, and/or weakness) increase the likelihood of falls or other injuries.
 - Need for supervision due to cognitive deficits that impair judgment, memory, ability to make good decisions, and/or the ability to safely implement one's daily routine.
 - Need for assistance with activities of daily living.

Nursing Home Services

- MS patients in nursing homes are generally younger, more mentally alert, more physically dependent, at greater risk for depression, and have a longer length of stay than other residents (Buchanan & Wang, 2002)
- Considerations when choosing a location:
 - Financial Planning
 - Designation of Health Care Proxy and Advanced Directives
 - Pre-admission Assessments (past medical history and medical records)
 - Special equipment
 - Family preparation and assessment of expectations

Hospice Care

- Care is accessed when it is determined that the person's remaining lifespan is likely to be 6 months or less and potentially curative treatments are no longer in the picture.
- Hospice teams generally provide additional services, including spiritual counseling, volunteer visitors, massage and music therapy, nutritionist, and home health aides.
- Some of the common core indicators of end-stage disease include the following: Significant physical decline, weight loss, multiple co-morbidities, dependence in most ADLs, desire to avoid aggressive medical intervention and allow a natural death.
- Patients with repeat respiratory infection or a stage III or IV pressure ulcer, who recover and go on to live many more months may be considered appropriate candidates for hospice services.

References

- Brandes M, Reitman NC, Gruenwald D, Del Bene M. *Opening Doors: The Palliative Care Continuum in Multiple Sclerosis*.
- Buchanan RJ, Wang S, Ju H. Analyses of the minimum data set: Comparisons of nursing residents with multiple sclerosis to other nursing home residents. *Mult Scler*. 2002 Dec;8(6):512–22.

Recommended Readings

- Golla H, Galushko M, Pfaff H, Voltz R. Unmet needs of severely affected multiple sclerosis patients: the health professionals' view. *Palliat Med*. 2011.
- Wollin JA, Yates PM, Kristjanson LJ. Supportive and palliative care needs identified by multiple sclerosis patients and their families. *International Journal of Palliative Nursing* 2006; 12(1): 20–26.

Resources from the National MS Society

Talking with Your Patients about Life Planning —
www.nationalMSSociety.org/TalkingAboutLifePlanning

Talking with Your Patients about Palliative Care —
www.nationalMSSociety.org/TalkingAboutPalliativeCare

Serving Adults with MS in the Home —
www.nationalMSSociety.org/Homecare

Serving Individuals with MS in Adult Day Programs —
www.nationalMSSociety.org/AdultDayPrograms

Assisted Living for Individuals with Multiple Sclerosis —
www.nationalMSSociety.org/AssistedLiving

Nursing Home Care of Individuals with Multiple Sclerosis —
www.nationalMSSociety.org/NursingHomeCare



Section III:

Comprehensive Care for the MS Patient

Chapter 18: The Interdisciplinary Team Approach to MS Care

Multiple sclerosis (MS) has a significant impact on all quality of life domains:

- **Physical health:** ADLS, energy and fatigue, mobility, pain, sleep, work capacity
- **Psychological:** body image, negative feelings, self-esteem, spirituality/religion/personal beliefs
- **Social relationships:** personal relationships, social support, sexual activity
- **Environment:** financial resources, freedom, physical safety and security, access to quality healthcare, home environment, opportunities for acquiring new information and skills, leisure activities, physical environment (noise, pollution, traffic, safety concerns), transportation

An interdisciplinary, *patient-centered* team approach is needed to manage the complexities of the disease, address the needs of patients and families, and avoid burn-out among clinicians caring for this rewarding but challenging population.

Over the course of the disease, the following professionals may be involved:

- **Physician:** neurologist, primary care physician, OB/GYN, ophthalmologist, urologist, physiatrist, pulmonologist, pain management specialist, psychiatrist
- **Nurse Practitioner/Physician Assistant**
- **Nurse**
- **Pharmacist**
- **Mental Health Professional:** Psychologist, neuropsychologist, counselor
- **Social Worker**
- **Rehabilitation Professional:** Physical therapist, occupational therapist, speech/language pathologist, orthotist, seating expert
- **Nutritionist/Dietician**
- **Vocational Rehabilitation Counselor**

Each of these professionals has an important role to play in the management of MS:

Neurologist (or other primary MS physician)	Team leader; diagnosis, symptom, relapse and disease management; plans of care
NP/PA	Diagnosis; symptom, relapse and disease management; coordination with other team members
Nurse	Coordinates care among providers, performs nursing procedures, offers injection training and patient education
Pharmacist	Offers medication guidance through specialty pharmacies
Speech/Language Pathologist	Assess and manages speech and swallowing problems
Social worker	Psychosocial assessment; case management; discharge planning; referral resource
Psychologist	Psychotherapy for individuals and families
Neuropsychologist	Assessment and treatment of cognitive dysfunction

Physical therapist	Gait training; exercise for strength and flexibility; mobility aids and seating; fall prevention; functional electrical stimulation and AFOs Team leader; diagnosis, symptom, relapse and disease management; plans of care
Occupational therapist	Energy conservation, environmental adaptations, upper body strength and coordination, assistive technology, compensatory strategies for cognitive deficits
Nutritionist/Dietician	Nutritional assessments; dietary recommendations for weight management, energy management, enhanced nutrition
Vocational Rehabilitation Counselor	Career counseling, workplace modifications, educational opportunities to re-enter workforce

Recommended Resources for Patients from the National MS Society

- Choosing the Right Healthcare Provider (www.nationalMSSociety.org/Brochures)
- Getting to Know the MS Healthcare Team (www.nationalMSSociety.org/MSHealthcareTeam)

Chapter 19: The Nurse Practitioner in MS Care

The Multiple Sclerosis Nurse Practitioner (MSNP) is an advanced practice nurse who provides high-quality healthcare to patients with MS. In addition to being trained at the masters or doctoral level in nursing, the MSNP is certified in Multiple Sclerosis nursing (Multiple Sclerosis Certified Nurse — MSCN), and plays a vital role in caring for the individual with MS.

Key Components of MSNP Role

- **Expert clinician**
 - **Evaluate** an individual’s MS by taking a history, performing a neurologic examination and ordering and interpreting results from appropriate laboratory and diagnostic tests/procedures such as MRIs
 - **Diagnose** health and medical conditions related to MS by reviewing all available health information, and applying advanced clinical decision making processes
 - **Manage** health and acute problems by developing an individualized plan of care; prescribing disease modifying therapies, symptomatic care (non-pharmacological and pharmacological) and acute relapse management
 - **Promote Health** by ordering screenings, prescribing preventive therapies (diets, exercise, etc.) teaching and counseling individuals, families, and groups regarding MS
 - **Collaborate** with patients, families, and other health care providers to promote comprehensive care for the individual with MS

- **Refer & Consult** with rehabilitation professionals and other specialty services; obtaining consultations and coordinating health care services with MS Team
- **Administrator** — responsible for staff (including hiring, supervision, and scheduling), budget, policies and procedures, and quality assurance outcomes
- **Educator** — teaching a variety of audiences about MS, including patients and their families, health professionals, students, employers, and the community
- **Collaborator** — works with a variety of health professionals, including physicians, rehabilitation, specialists, and psychologists, to ensure that patients receive appropriate care and follow-up
- **Consultant** — makes his or her expert knowledge available to others via internal or external consulting
- **Researcher** — active role in clinical practice research, development of practice guidelines, and review of outcome and performance measures
- **Advocate** — serves as an advocate for patients and staff members, and as an agent for change in dealings with healthcare providers, allied health professionals, the community, and healthcare systems

Stepping Stones to MS Nursing Expertise

- Increasing knowledge about MS
 - The National MS Society, which houses a comprehensive library of MS information, offers information, publications, clinical consultations, and literature search services at www.nationalMSSociety.org.
 - The International Organization of MS Nurses (IOMSN) has a wide variety of tools and resources for the nursing professional at www.iomsn.org.

- The Consortium of Multiple Sclerosis Centers (CMSC) holds an annual interdisciplinary education meeting, publishes the free International Journal of MS Care (<http://ijmsc.org>), and offers a wide variety of educational opportunities. www.ms-care.org.
- Educating yourself and patients about clinical trials at: <http://clinicaltrials.gov/>
- Interacting with MS specialists
- Exploring new healthcare and wellness resources
- Nurturing relationships with non-MS clinicians and agencies
- Attending professional education and network meetings
- Attaining specialist MS certification (MSCN) — www.ms-nicb.org

Recommended Readings

Burke T, Dishon S, McEwan L, Smrtka J. The evolving role of the MS nurse. *International Journal of MS Care* 2011; 13(3):105–112. doi: <http://dx.doi.org/10.7224/1537-2073-13.3.105>

Costello K, Halper J. *Advanced Practice Nursing in Multiple Sclerosis — Advanced Skills, Advancing Responsibilities*, (3rd ed.), 2010. http://iomsn.org/images/pdf/APN_Monograph_3rdEd.pdf.

Halper J. Role of Advanced Practice Nurse in Management of Multiple Sclerosis. *International Journal of MS Care* 2006; 7(2):33–38. doi: <http://dx.doi.org/10.7224/1537-2073-8.2.33>

Harris CJ, Halper J. *Multiple sclerosis: Best practices in nursing care — Disease management, pharmacologic treatments, nursing research* (4th ed.). http://iomsn.org/images/pdf/BestPractices_4th.pdf.

New York City Coalition of Multiple Sclerosis Nurses. (2010). *The Dynamic Multiple Sclerosis Nurse: Challenges, Expanding Role, and Future Directions*. Monograph sponsored by the National Multiple Sclerosis Society NYC Chapter.

Sammarco CL. *Doctor of nursing practice. International Journal of MS Care* 2008; 10(1):21–23. doi: <http://dx.doi.org/10.7224/1537-2073-10.1.21>.

Organizations of Note

Consortium of Multiple Sclerosis Centers (CMSC):
www.ms-care.org

International Organization of MS Nurses (IOMSN):
www.iomsn.org

Chapter 20: Coordinating Patient & Family Care

Although the person with multiple sclerosis (MS) may come alone to the nurse practitioner's (NP) office, the entire family needs care and support. The NP is in an ideal position to identify the needs of patients and family members and assist them in accessing appropriate information, services, and other resources.

When one person has MS, the whole family lives with the disease

- MS is like an uninvited guest that moves in and never leaves (Kalb, 2006).
- Each family member must develop a relationship with this unpredictable stranger.
- Family members often have differing coping styles that may not be in synch with one another.
- The family's task is to make room for MS in their lives and households without giving it more attention or resources than it actually needs.

Family members need education and support from the beginning

- Information about the disease and available resources is as important for the partner or parent as it is for the patient.
- Treatment plans involving the partner should always take his or her needs into account.
- Partners and parents need to be reminded that taking care of one's own health and wellness is the first step to being a good care partner; self-care ≠ selfish.
- The goal for couples is to maintain a balanced partnership, with each partner receiving and giving care and support.

Communication is the key to healthy relationships

Family adaptation, effective problem-solving, and comprehensive long-term planning depend upon good communication. Challenges to communication include:

- Differing coping and communication styles
- Worrying about upsetting the other person
- Finding ways to put uncomfortable feelings into words
- Believing that people who love you can read your mind
- Carving out the time for honest, in-depth conversations

Children benefit from age-appropriate information about the disease

- Even very young children sense when a parent is ill or upset about something.
- All children have 3 major concerns: *Will my parent die? Can I catch it? Did I cause this to happen?*
- In the absence of accurate information, children's imaginations will fill in the blanks with thoughts that are even scarier than the reality.
- Age-appropriate information helps give active imaginations a rest.
- Providing information gives children "permission" to ask questions and a vocabulary with which to do so.
- Children have different learning styles; information can be provided through conversation, stories, games, videos, National MS Society children's events

Hands-on caregivers are our "invisible patients"

(Andolsek et al., 1988)

- MS caregivers often neglect their own physical and emotional well-being
- Home-based, interdisciplinary services assist both the patient and the informal caregiver, promoting quality of life and avoiding premature nursing home placement
- Aging, bowel dysfunction, poorer health, and symptom-related functional decline increase the risk of nursing home placement (Buchanan, 2010).
- Caregivers need greater access to community services and encouragement to carve out time for self-care, social interaction, recreation (Buhse, 2008).

Nurse practitioners link family members to the resources they need — and the National MS Society can help

- For general information and support
 - MS Navigator® — providing information, referrals, support (1-800-344-4867; generalmailbox@nmss.org)
 - Web site: www.nationalMSsociety.org
- For newly-diagnosed patients
 - MS Next Step® — Answers to the very first questions (www.nationalMSsociety.org/NextStep)
 - Knowledge is Power — in-home education series (www.nationalMSsociety.org/KnowledgeIsPower)
 - Client publications (www.nationalMSsociety.org/Brochures)
- Connection programs
 - Peer to Peer — in-person and online connection opportunities (www.nationalMSsociety.org/PeerToPeer)
 - MS Connection Online Community — MSconnection.org

- Financial assistance programs — guidance and resources to help families manage the financial impact of MS (www.nationalMSSociety.org/FinancialAssistance)
- Resources for families (www.nationalMSSociety.org/FamilyMatters)
 - *Plaintalk: A booklet about MS for Families*
 - Timmy’s Journey to Understanding MS (animated cartoon)
 - *Keep Smylein* — A print and online newsletter for children ages 6–12
- Pediatric MS resources (www.nationalMSSociety.org/PediatricMS)
 - Network of Pediatric Centers of Excellence
 - *Kids Get MS Too: A Guide for Parents*
 - *Managing School-Related Issues: A Guide for Parents*
 - *Students with MS & the Academic Setting: A Handbook for School Personnel*
 - Scholarships — www.nationalMSSociety.org/Scholarship
 - Highly-qualified children diagnosed with MS
 - Highly-qualified children who have a parent with MS
- Online learning
 - MS Learn Online — educational webcast series (www.nationalMSSociety.org/MSLearnOnline)
 - Online Courses — treatment decisions, financial planning, relationship issues, career decisions (www.nationalMSSociety.org/OnlineCourses)
- Employment resources (www.nationalMSSociety.org/Employment)
 - *Career Crossroads* — video program with workbook
 - *Disclosing MS in the Workplace* (www.nationalMSSociety.org/DisclosureTool)

- *MS & the Workplace: Employer Education DVD* — basic information for employers on managing the impact of MS in the workplace ([youtube.com/watch?v=4-HzZqPLAdI](https://www.youtube.com/watch?v=4-HzZqPLAdI))
- Social Security Disability applications — information and toolkit (www.nationalMSSociety.org/SocialSecurityDisability)
- Spanish resources (www.nationalMSSociety.org/Espanol)
 - Spanish-translated brochures
 - *Take Control of Your MS* — a Spanish toolkit
 - Café con Leche — a monthly telephone support group

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- Buchanan RJ, Radin D, Huang C, Zhu L. Caregiver perceptions associated with risk of nursing home admission for people with multiple sclerosis. *Disabil Health J.* 2010 Apr;3(2):117–24.
- Buhse M. Assessment of caregiver burden in families of persons with multiple sclerosis. *J Neurosci Nurs.* 2008;40(1):25–31.
- Kalb R (ed.). *Multiple Sclerosis: A Guide for Families 3rd ed.* NY: Demos Health, 2006.

Recommended Readings

Kalb R, Giesser B, Costello K. *Multiple Sclerosis for Dummies*. Hoboken, NJ: 2012.

Recommended Resources

Allsup — assists people applying for Social Security Disability benefits (www.allsup.com).

Job Accommodation Network (JAN) — free consulting service around worksite accommodations (800-526-7234; www.jan.wvu.edu).

National Family Caregivers Association (NFCAs) — newsletter; information clearinghouse (800-896-3650; www.nfcacares.org).

Chapter 21: Reproductive Issues

Multiple sclerosis (MS) is diagnosed most commonly in young adulthood. Reproductive issues are of great concern women and men living with this unpredictable, chronic disease, and the concerns are emotional and social as well as medical. The following facts can help inform **conversations** with your patients (Giesser, 2010).

Conception

- Multiple sclerosis (MS) does not interfere with a woman's ability to conceive. Any form of birth control can be used. Oral contraceptives may sometimes interact with other agents, e.g. anti-epileptic medications. A woman with decreased UE function may find it difficult to use a diaphragm.

The Impact of Pregnancy on MS

- Pregnancy is characterized by a down-regulation of cellular immune responses and the presence of potentially neuroprotective hormones, both of which protect the developing fetus. The combined anti-inflammatory and neuroprotective effects of pregnancy appear to have a positive impact on MS as well (Voskhul & Giesser, 2011).
 - The risk of relapse drops over the nine months of pregnancy (with the risk being lowest in the third trimester), rises significantly in the three-six months post partum, and then returns to the woman's pre-pregnancy rate.
 - The more active a woman's disease is during pregnancy and the year prior, the higher her risk of post partum relapse (Vukusic et al., 2004).
- Available data suggest that pregnancy in healthy women has no long-lasting effects with regard to reducing their risk of developing MS (Voskuhl & Giesser, 2011).

Disease Management Before, During, & After Pregnancy

- None of the available disease-modifying therapies are approved **for use during pregnancy** or breastfeeding. Women are generally advised to stop their medication one to two menstrual cycles prior to trying to conceive (Ferrero et al., 2004).
- If a woman's disease has been particularly active prior to and during pregnancy, the recommendation may be for her to resume her medication as soon as possible (within approximately two weeks after delivery). Intravenous immunoglobulin (IVIG) administered during the post-partum period may reduce the risk of relapse (Achiron et al., 2004).
- The impact of a father's disease-modifying therapy regimen on spermatogenesis or fetal development has never been studied; a man may want to consider stopping medication during efforts to conceive.
- Women or men who are considering an immunosuppressant medication (e.g., mitoxantrone), may want to harvest and preserve eggs/sperm for future use.

Symptom & Relapse Management During Pregnancy

- Many of the medications used to manage MS symptoms are Category C drugs (e.g., baclofen for spasticity; fluoxetine for depression; solifenacin succinate for bladder management) and should not be used during pregnancy; other management strategies should be implemented.
- MS-related fatigue may augment the normal fatigue of pregnancy; bladder and bowel symptoms may increase, including a higher risk of urinary tract infections and increased constipation; balance problems may worsen with weight gain.

- Relapses severe enough to warrant treatment can be safely managed with a short course of corticosteroids *after the first trimester*. Methylprednisolone is the preferred drug because it is metabolized before crossing the placenta (Ferrero et al., 2004). IVIG is safe for use during pregnancy and may provide some benefit (Ferrero et al., 2004).

Delivery Considerations and the Post-Partum Period

- All forms of anesthesia are considered safe for women with MS; anesthesia management does not need to be altered. (Vukusic & Confavreux, 2006). (*This information should be discussed with the anesthesia team during the early weeks of pregnancy*).
- Compared to the general population, women with MS are at significantly-increased risk for depression, which means that may also be at greater risk of depression in the post-partum period. Antidepressant medications should be used with caution during pregnancy (Patil et al., 2011).
- Women who wish to breastfeed should be encouraged to do so unless it is judged critical that they resume their disease-modifying treatment as soon as possible after delivery. Breastfeeding does not affect the likelihood of relapse post partum (Vukusic & Confavreux, 2006).
- Glucocorticoids are excreted in breast milk, which means that a woman may need to stop breastfeeding before receiving glucocorticoid treatment for a relapse.

MS and the Menstrual Cycle

- Self-report studies suggest that women commonly experience transient worsening of their neurologic symptoms during the premenstrual (Voskuhl & Giesser, 2011).
- Two studies — with conflicting results — have looked at the relationship between hormone levels over the course of the menstrual cycle and gadolinium-enhancing lesion activity on MRI (Bansil et al., 1999; Pozzilli et al., 1999).

MS and Menopause

- In the only study to date of the impact of menopause on MS, 54% of post-menopausal women reported worsening of their neurologic symptoms (Studd, 1992).
- There are no known neurologic contraindications for women with MS to use to HRT.

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Bansil S, Lee HJ, Jindal S, et al. Correlation between sex hormones and magnetic resonance imaging lesions in multiple sclerosis. *Acta Neurol Scand* 1999; 99(2):91–4.

Ferrero S, Pretta S, Ragni N. Multiple sclerosis: management issues during pregnancy. *Eur J Obstet Gynecol Reprod Biol* 2004; 15(1):3–9.

Giesser B. *Reproductive Issues in Persons with Multiple Sclerosis*. www.nationalMSSociety.org/ClinicalBulletins.

Patil AS, Kuller JA, Rhee EH. Antidepressants in pregnancy: a review of commonly prescribed medications. *Obstet Gynecol Surv* 2011; 66(12):777–787.

Pozzilli C, Falaschi P, Mainero C, et al. MRI in multiple sclerosis during the menstrual cycle: relationship with sex hormone patterns. *Neurology* 1999; 53(3):622–4.

Voskuhl R & Giesser B. Gender and reproductive issues. In Giesser (ed.) *Primer on Multiple Sclerosis*, NY: Oxford University Press, 2011.

Vukusic S, Confavreux C. Pregnancy and multiple sclerosis: the children of PRIMS. *Clin Neurol Neurosurg* 2006; 108(3):266–70.

Vukusic S, Hutchinson M, Hours M, et al. Pregnancy and multiple sclerosis (the PRIMS study): clinical predictors of post-partum relapse. *Brain*. 2004; 127(Pt 6):1353–60.

Recommended Resources

Giesser B, Benedetto-Anzai, M. Talking about Reproductive Issues. www.nationalMSSociety.org/TalkingAboutReproduction

Recommended Resources for Patients

National MS Society — www.nationalMSSociety.org/Pregnancy

Giesser B, Benedetto M, Werner, M. *Fertility, pregnancy, childbirth, and gynecologic Care*. In R Kalb (Ed.) *Multiple Sclerosis: The Questions You Have; The Answers You Need* (5th ed.). NY: Demos Health, 2012.



Conclusion

We hope that you have found this book to be the accessible, informative tool that we envisioned. We invite you to refer to the extensive resources mentioned throughout these pages, and highlighted in the Appendix, to optimize your professional growth and the wellness of your patients with MS. And we urge you to reach out to other clinicians in the field to collaborate, share ideas, and support one another. Our interactions with colleagues over the years have enhanced our careers, informed our clinical work, and been the basis of countless professional partnerships and meaningful friendships. When we work together the possibilities are limitless!

An electronic version of this book — with updates inserted as needed — is available on the National MS Society's website at www.nationalMSSociety.org/NPHandbook.



Appendix: Recommended Resources

National MS Society Resources for You

Visit the Multiple Sclerosis Clinical Care Network (www.nationalMSSociety.org/MSClinicalCare) for:

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

To sign up for periodic research and clinical updates by email or to receive the Society's quarterly e-newsletter for healthcare professionals, email healthprof_info@nmss.org.

Clinical Bulletins

(www.nationalMSSociety.org/ClinicalBulletins)

- **General**
 - Overview of Multiple Sclerosis
 - Primary Care Needs

- Aging with MS
- The Role of Hormones
- Reproductive Issues
- Complementary and Alternative Medicine
- The Role of Vitamin D
- **Symptom Management**
 - Fatigue
 - Spasticity
 - Bladder Dysfunction
 - Bladder Dysfunction — Surgical Management
 - Bowel Dysfunction
 - Cognitive Loss
 - Vision Problems
 - Dysarthria
 - Swallowing Disorders
 - Pain
 - Emotional Issues
 - Pseudobulbar Affect
 - Sexual Dysfunction
 - Pulmonary Function
- **Treatments and Therapies**
 - Occupational Therapy
 - Physical Therapy
 - The Palliative Care Continuum in MS
 - Adherence to Immunomodulating Agents

Expert Opinion Papers

(www.nationalMSSociety.org/ExpertOpinionPapers)

- Disease Management Consensus Statement
- Changing Therapy in Relapsing Multiple Sclerosis
- Goldman Consensus Statement on Depression
- Assessment and Management of Cognitive Impairment
- Rehabilitation for Persons with Multiple Sclerosis
- Management of MS-Related Fatigue
- Patient Access to Tysabri
- Corticosteroids in the Management of MS
- The Use of Cannabis in MS

Quick Reference Tools

- Multiple Sclerosis Diagnosis and Management Pocketcard — *www.nationalMSSociety.org/ClinicianResources*
- Free downloadable Pocketcard App (*App Store — National MS Society*)
- Diagnostic Criteria Card (plastic) — *www.nationalMSSociety.org/ClinicianResources*
- Health Insurance Appeal Letters (CD) — *www.nationalMSSociety.org/ClinicianResources*
- Guide to Supporting MS Social Security Claims — *www.nationalMSSociety.org/SocialSecurityDisability*
- Guide to Supporting MS Private Disability Claims — *www.nationalMSSociety.org/ClinicianResources*

Talking with your MS Patients About Difficult Topics

www.nationalMSSociety.org/ProfPublications

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

Continuum of Care Guidelines

www.nationalMSSociety.org/ProfPublications

- Nursing Home Care of Individuals with MS
- Assisted Living for Individuals with MS
- Serving Individuals with MS in Adult Day Programs
- Serving Individuals with MS in the Home

Continuing Education Self-Studies & Webinars

www.nationalMSSociety.org/ProfEdTrng

- Nurses
- Rehabilitation Therapists
- Mental Health Professionals

Resource Publications by Discipline

www.nationalMSSociety.org/ProfPublications

- Multiple Sclerosis: The Nursing Perspective
- Multiple Sclerosis: A Focus on Rehabilitation
- Multiple Sclerosis: A Model of Psychosocial Support
- Multiple Sclerosis for Physician Assistants
- Multiple Sclerosis: The Nurse Practitioner's Handbook

Pediatric MS Resources

www.nationalMSSociety.org/PediatricMS

- Network of Pediatric Centers of Excellence
- Students with MS & the Academic Setting: A Handbook for School Personnel

National MS Society Resources for Your Patients

1-800-344-4867 or **www.nationalMSsociety.org**

Finding answers and making sound decisions relies on having the right information at the right time. The National MS Society provides answers to questions and access to information about all of the options available. The Society's MS Navigators are highly-skilled professionals — equipped to respond to patient needs.

Contact the National MS Society to learn more or request copies of the resources listed.

For the Newly Diagnosed

- **MS Next Step**[®] — www.nationalMSsociety.org/MSNextStep
Hearing the diagnosis of MS is never easy. MS Next Step is designed to answer questions that are commonly asked immediately following a diagnosis and provides an introduction to MS and the programs and services of the National MS Society. *(Available in Spanish.)*
- **Knowledge is Power**
www.nationalMSsociety.org/KnowledgeIsPower
Knowledge Is Power is a free, in-home educational series for people newly diagnosed with MS and their families. This comprehensive program provides up-to-date facts about many aspects of MS. *(Available in Spanish.)*
- **Client Publications** — www.nationalMSsociety.org/Brochures
More than 60 booklets and brochures are available to people with MS and their families. Categories include General Information, Newly Diagnosed, Employment Issues, Staying Well, Managing Specific Problems, Managing Major Changes, and For Children & Teenagers.

Connection Programs

- **Peer to Peer** — www.nationalMSsociety.org/PeerToPeer
The Society helps people living with MS connect with others to share experiences and provide support. Connection programs include traditional, in-person self-help groups, peer-to-peer support, online communities, and other means of bringing people together.
- **MS Connection Online Community**
www.MSconnection.org
MSconnection.org is an online community that provides the opportunity to connect with people involved in the MS movement with valuable content, activities and resources.

Financial Assistance Programs

www.nationalMSsociety.org/FinancialAssistance

- This nationwide program is comprised of a range of initiatives that support independence, safety, health and quality of life for people living with MS, as well as their families. This program offers guidance and resources to help contain the financial impact of MS. The Financial Education Partners program provides pro bono financial planning and education to individuals with special health or financial circumstances.

Resources for Families

www.nationalMSsociety.org/FamilyMatters

- **PLAINTALK: A Booklet about MS for Families**
Discusses some of the more difficult physical and emotional problems many families face.
- **Timmy's Journey to Understanding MS (DVD)**
A 15-minute animated cartoon that follows a boy's journey to learning about MS.

- **Keep S'myelin'** — www.nationalMSSociety.org/KS
A newsletter about MS for children — with articles, interviews, games, activities, and a special pullout section for parents. Published 3-4 times a year in both PDF and online versions.

Pediatric MS Resources

www.nationalMSSociety.org/PediatricMS

- Network of Pediatric Centers of Excellence
- *Kids Get MS Too: A Guide for Parents*
- *Managing School-related Issues: A Guide for Parents with a Child or Teen Living with MS*
- *Students with MS & the Academic Setting: A Handbook for School Personnel*

Scholarships

www.nationalMSSociety.org/Scholarship

- The Society's Scholarship Program helps highly qualified students who have been diagnosed with MS, or who have a parent with MS, achieve their dreams of going to college.

Online Learning

• MS Learn Online

www.nationalMSSociety.org/MSLearnOnline

MS Learn Online is the Society's educational webcast series. New webcasts and past webcasts, many in Spanish, can be viewed at any time from the Society's Web site.

- **Online Courses** — www.nationalMSSociety.org/OnlineCourses
 - My Life, My MS, My Decisions
 - Adapting: Financial Planning for a Life with MS Together
 - Intimacy: Enriching Your Relationship
 - Career Decisions: Relationship Matters

Employment

www.nationalMSSociety.org/Employment

• Career Crossroads

This video program focuses on the legal rights of employees with MS and examines ways to mitigate the effects of MS on work performance. A self-study companion workbook is also available.

• MS & the Workplace: Employer Education DVD —

[youtube.com/watch?v=4-HzZqPLAdI](https://www.youtube.com/watch?v=4-HzZqPLAdI)

Provides basic information to employers about managing the impact of MS in the work setting.

Spanish Resources (Recursos en Español)

www.nationalMSSociety.org/Espanol

- A variety of resources are available for people who speak Spanish, including: Spanish-translated brochures; "Take Control of Your MS," a Spanish toolkit on our website; and "Café con Leche," a monthly telephone support group for Spanish-speaking people living with MS.



Appendix B:

Glossary of Terms

Acute attack: *See* Exacerbation.

Advance (medical) directive: Advance directives preserve the person's right to accept or reject a course of medical treatment even after the person becomes mentally or physically incapacitated to the point of being unable to communicate those wishes. Advance directives come in two basic forms: (1) a living will, in which the person outlines specific treatment guidelines that are to be followed by health care providers; (2) a health care proxy (also called a power of attorney for health care decision-making), in which the person designates a trusted individual to make medical decisions in the event that he or she becomes too incapacitated to make such decisions. Advance directive requirements vary greatly from one state to another and should therefore be drawn up in consultation with an attorney who is familiar with the laws of the particular state.

Afferent pupillary defect: An abnormal reflex response to light that is a sign of nerve fiber damage due to optic neuritis. A pupil normally gets smaller when a light is shined either into that eye (direct response) or the other eye (indirect response). In an afferent pupillary defect (also called Marcus Gunn pupil), there is a relative decrease in the direct response. This is most clearly demonstrated by the "swinging flashlight test." When the flashlight is shined first in the abnormal eye, then in the healthy eye, and then again in the eye with the pupillary defect, the affected pupil becomes larger rather than smaller.

Ankle-foot orthosis (AFO): An ankle-foot orthosis is a brace, usually plastic, that is worn on the lower leg and foot to support the ankle and correct foot drop. By holding the foot and ankle in the correct position, the AFO promotes correct heel-toe walking. *See* Foot drop.

Antibody: Protein produced by certain cells of the immune system in response to bacteria, viruses, and other types of foreign antigens. *See* Antigen.

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

Assistive devices: Any tools that are designed, fabricated, and/or adapted to assist a person in performing a particular task, e.g., cane, walker, shower chair.

Assistive technology: A term used to describe all of the tools, products, and devices, from the simplest to the most complex, which can make a particular function easier or possible to perform.

Ataxia: The incoordination and unsteadiness that result from the brain's failure to regulate the body's posture and the strength and direction of limb movements. Ataxia is most often caused by disease activity in the cerebellum.

Atrophy: A wasting away or decrease in size of a cell, tissue, or organ of the body because of disease or lack of use. *See* Brain atrophy

Autoimmune disease: A process in which the body's immune system causes illness by mistakenly attacking healthy cells, organs, or tissues in the body that are essential for good health. Multiple sclerosis is believed to be an autoimmune disease, along with systemic lupus erythematosus, rheumatoid arthritis, scleroderma, and many others. The precise origin and pathophysiologic processes of these diseases are unknown.

Autonomic nervous system: The part of the nervous system that regulates involuntary vital functions, including the activity of the cardiac (heart) muscle, smooth muscles (e.g., of the gut), and glands. The autonomic nervous system has two divisions: the sympathetic nervous system accelerates heart rate, constricts blood vessels, and raises blood pressure; the parasympathetic nervous system slows heart rate, increases intestinal and gland activity, and relaxes sphincter muscles.

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

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

B-cell: A type of lymphocyte (white blood cell) manufactured in the bone marrow that makes antibodies.

Babinski reflex: A neurologic sign in MS in which stroking the outside sole of the foot with a pointed object causes an upward (extensor) movement of the big toe rather than the normal (flexor) bunching and downward movement of the toes. This abnormal response indicates damage to the motor pathways in the brain and spinal cord. *See* Sign.

Bell's palsy: A paralysis of the facial nerve (usually on one side of the face), which can occur as a consequence of MS, viral infection, or other infections. It has acute onset and can be transient or permanent.

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

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

Cerebrospinal fluid (CSF): A watery, colorless, clear fluid that bathes and protects the brain and spinal cord. The composition of this fluid can be altered by a variety of diseases. Certain changes in CSF that are characteristic of MS can be detected with a lumbar puncture (spinal tap), a test sometimes used to help make the MS diagnosis. *See* Lumbar puncture.

Chronic progressive: A former “catch-all” term for progressive forms of MS. *See* Primary-progressive MS, Secondary-progressive MS, and Progressive-relapsing MS.

Clinically isolated syndrome (CIS): A first neurologic episode, lasting at least 24 hours, which is caused by inflammation/demyelination in one or more sites in the central nervous system (CNS). A person with CIS can have a single neurologic sign or symptom — for example, an attack of optic neuritis — that’s caused by a single lesion (and referred to as *monofocal*), or more than one sign or symptom — for example, an attack of optic neuritis accompanied by weakness on one side — caused by lesions in more than one place (and referred to as *multifocal*). Individuals who experience a clinically isolated syndrome may or may not go on to develop multiple sclerosis. Studies have shown that when the CIS is accompanied by MRI-detected brain lesions that are consistent with those seen in MS, there is a high risk of a second neurologic event, and therefore a diagnosis of clinically definite MS, within several years. Individuals who experience CIS with no evidence of MRI-detected lesions are at relatively low risk for developing MS over the same time period.

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

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

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

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

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

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

Cystoscopy: A diagnostic procedure in which a special viewing device called a cystoscope is inserted into the urethra (a tubular structure that drains urine from the bladder) to examine the inside of the urinary bladder.

Cystostomy: A surgically-created opening through the lower abdomen into the urinary bladder. A plastic tube inserted into the opening drains urine from the bladder into a plastic collection bag. This relatively simple procedure is done when a person requires an indwelling catheter to drain urine from the bladder but passage through the urethral opening is not desirable for reasons such as uncontrollable frequency or incontinence. *See* Indwelling catheter.

Cytokines: Messenger chemicals produced by various cells, particularly those of the immune system, to influence the activity of other cells.

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

Demyelination: A loss of myelin in the white matter of the central nervous system (brain, spinal cord, optic nerves).

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

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

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

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

Dysesthesia: Distorted or unpleasant sensations experienced by a person when the skin is touched, which are typically caused by abnormalities in the sensory pathways in the brain and spinal cord.

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

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

Electroencephalography (EEG): A diagnostic procedure that records, via electrodes attached to various areas of the person's head, electrical activity generated by brain cells.

Electromyography (EMG): Electromyography is a diagnostic procedure that records muscle electrical potentials through a needle or small plate electrodes. The test can also measure the ability of peripheral nerves to conduct impulses.

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

Expanded Disability Status Scale (EDSS): A part of the Minimal Record of Disability that summarizes the neurologic examination and provides a measure of overall disability. The EDSS is a 20-point scale, ranging from 0 (normal examination) to 10 (death due to MS) by half-points. A person with a score of 4.5 can walk three blocks without stopping; a score of 6.0 means that a cane or a leg brace is needed to walk one block; a score over 7.5 indicates that a person cannot take more than a few steps, even with crutches or help from another person. The EDSS is used for many reasons, including deciding future medical treatment, establishing rehabilitation goals, choosing subjects for participation in clinical trials, and measuring treatment outcomes. This is currently the most widely used scale in clinical trials.

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

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

Finger-to-noise test: As a test of dysmetria and intention tremor, the person is asked, with eyes closed, to bring an outstretched index finger in repeatedly to touch the tip of his or her nose. This test is part of the standard neurologic exam.

Flaccid: A decrease in muscle tone resulting in weakened muscles and therefore loose, “floppy” limbs.

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

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

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

Function magnetic resonance imaging (fMRI): A relatively new MRI technique that studies brain function. Using fMRI technology, scientists can determine which part of the brain is active during a given task by tracking blood oxygen levels. Brain regions that are active require more oxygen. Oxygen is delivered by increasing the blood flow to these active brain regions. In MS, researchers are using fMRI to look at how the brain compensates for damage in one area by recruiting other areas of the brain to help perform a task.

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

Gadolinium-enhancing lesion: A lesion appearing on magnetic resonance imagery, following injection of the chemical compound gadolinium, which reveals a breakdown in the blood-brain barrier. This breakdown of the blood-brain barrier indicates either a newly active lesion or the re-activation of an old one. *See* Gadolinium.

Glucocorticoid hormones: Steroid hormones that are produced by the adrenal glands in response to stimulation by adrenocorticotrophic hormone (ACTH) from the pituitary. These hormones, which can also be manufactured synthetically (prednisone, prednisolone, methylprednisolone, betamethasone, dexamethasone), serve both an immunosuppressive and an anti-inflammatory role in the treatment of MS exacerbations: they damage or destroy certain types of T-lymphocytes that are involved in the overactive immune response, and interfere with the release of certain inflammation-producing enzymes.

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

Helper T-lymphocytes: White blood cells that are a major contributor to the immune system's inflammatory response against myelin.

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

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

Immune-mediated disease: A disease in which components of the immune system — T cells, antibodies, and others — are responsible for the disease either directly (as occurs in autoimmunity) or indirectly (for example, when damage to the body occurs secondary to an immune assault on a foreign antigen such as a bacteria or virus).

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

Impairment: Any loss or abnormality of psychological, physiological, or anatomical structure or function. It represents a deviation from the person's usual biomedical state. An impairment is thus any loss of function directly resulting from injury or disease.

Incidence: The number of new cases of a disease in a specified population over a defined period of time. The incidence of MS in the United States is approximately 10,000 newly-diagnosed people per year.

Inflammation: A tissue's immunologic response to injury, characterized by mobilization of white blood cells and antibodies, swelling, and fluid accumulation.

Intention tremor: Rhythmic shaking that occurs in the course of a purposeful movement, such as reaching to pick something up or bringing an outstretched finger in to touch one's nose.

Interferon: A group of immune system proteins, produced and released by cells infected by a virus, which inhibit viral multiplication and modify the body's immune response. Three interferon beta medications have been approved by the U.S. Food and Drug Administration (FDA) for treating relapsing forms of MS: IFN beta-1b (Betaseron and Extavia); IFN beta-1a (Avonex); and IFN beta-1a (Rebif).

Intermittent self-catheterization (ISC): A procedure in which the person periodically inserts a catheter into the urinary opening to drain urine from the bladder. ISC is used in the management of bladder dysfunction to drain urine that remains after voiding, prevent bladder distention, prevent kidney damage, and restore bladder function.

Internuclear ophthalmoplegia: A disturbance of coordinated eye movements in which the eye turned outward to look toward the side develops nystagmus (rapid, involuntary movements) while the other eye simultaneously fails to turn completely inward. This neurologic sign, of which the person is usually unaware, can be detected during the neurologic exam.

Intrathecal space: The space surrounding the brain and spinal cord that contains cerebrospinal fluid.

Lhermitte’s sign: An abnormal sensation of electricity or “pins and needles” going down the spine into the arms and legs that occurs when the neck is bent forward so that the chin touches the chest.

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

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

Lymphocyte: A type of white blood cell that is part of the immune system. Lymphocytes can be subdivided into two main groups: B-lymphocytes, which originate in the bone marrow and produce antibodies, and T- lymphocytes, which are produced in the bone marrow and mature in the thymus. Helper T-lymphocytes heighten the production of antibodies by B-lymphocytes; suppressor T- lymphocytes suppress B-lymphocyte activity and seem to be in short supply during an MS exacerbation.

Macrophage: A white blood cell with scavenger characteristics that has the ability to ingest and destroy foreign substances such as bacteria and cell debris.

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

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

Monoclonal antibody: Antibodies are proteins that are generated by the immune system, specifically the white blood cells. They circulate in the blood and attach to foreign proteins called antigens in order to destroy or neutralize them. Monoclonal antibodies are laboratory-produced, customized proteins, made from a single cell or its clones, which are designed to locate and bind to specific target molecules. Producing man-made proteins is an intricate process that involves placing cells in large stainless steel vats filled with nutrients to produce the specified protein. It is extensively tested to ensure purity before it is ready for patient use. *See* Antibody.

Multiple sclerosis functional composite (MSFC): A three-part, standardized, quantitative assessment instrument for use in clinical trials in MS, that was developed by the Task Force on Clinical Outcomes Assessment appointed by the National MS Society's Advisory Committee on Clinical Trials of New Agents in Multiple Sclerosis. The three components of the MSFC measure leg function/ambulation (Timed 25-Foot Walk), arm/hand function (9-Hole Peg Test), and cognitive function (Paced Auditory Serial Addition Test [PASAT]).

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

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

Myelin basic protein: One of several proteins associated with the myelin of the central nervous system, which may be found in higher than normal concentrations in the cerebrospinal fluid of individuals with MS and other diseases that damage myelin.

Nerve block: A procedure used to relieve otherwise intractable spasticity, including painful flexor spasms. An injection of phenol into the affected nerve interferes with the function of that nerve for up to three months, potentially increasing a person's comfort and mobility.

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

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

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

Nocturia: The need to urinate during the night.

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

Occupational therapist (OC): Occupational therapists assess functioning in activities of everyday living, including dressing, bathing, grooming, meal preparation, writing, and driving, which are essential for independent living. In making treatment recommendations, the OT addresses (1) fatigue management, (2) upper body strength, movement, and coordination, (3) adaptations to the home and work environment, including both structural changes and specialized equipment for particular activities, and (4) compensatory strategies for impairments in thinking, sensation, or vision.

Oligoclonal bands: A diagnostic sign indicating abnormal levels of certain antibodies in the cerebrospinal fluid; seen in approximately 90 percent of people with multiple sclerosis, but not specific to MS.

Oligodendrocyte: A type of cell in the central nervous system that is responsible for making and supporting myelin.

Olmstead decision: The Supreme Court decision in *Olmstead v L.C.* (1999) is an interpretation of Title II of the Americans with Disabilities Act (ADA) that affirms the right of people with disabilities to receive services in the most integrated setting appropriate to their needs. The decision recognizes that unnecessary segregation of persons in long-term care facilities constitutes discrimination under the ADA.

Optic atrophy: A wasting of the optic disc that results from partial or complete degeneration of optic nerve fibers and is associated with a loss of visual acuity.

Optic disc: The small blind spot on the surface of the retina where cells of the retina converge to form the optic nerve; the only part of the retina that is insensitive to light.

Optic neuritis: Inflammation or demyelination of the optic (visual) nerve with transient or permanent impairment of vision and occasionally pain.

Orthotic: Also called orthosis; a mechanical appliance such as a leg brace or splint that is specially designed by an orthotist to control, correct, or compensate for impaired limb function.

Oscillopsia: Continuous, involuntary, and chaotic eye movements that result in a visual disturbance in which objects appear to be jumping or bouncing.

Osteoporosis: Decalcification of the bones, which can result from the lack of mobility and weight-bearing exercise experienced by individuals who regularly use a wheelchair.

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

Paraplegia: Paralysis of both lower extremities (legs).

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

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

Paroxysmal spasm: A sudden, uncontrolled limb contraction that occurs intermittently, lasts for a few moments, and then subsides.

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

Percutaneous endoscopic gastrostomy (PEG): A PEG is a tube inserted into the stomach through the abdominal wall to provide food or other nutrients when eating by mouth is not possible. The tube is inserted in a bedside procedure using an endoscope to guide the tube through a small abdominal incision. An endoscope is a lighted instrument that allows the doctor to see inside the stomach.

Periventricular region: The area surrounding the four fluid-filled cavities within the brain. MS plaques are commonly found within this region.

Physical therapist (PT): Physical therapists are trained to evaluate and improve movement and function of the body, with particular attention to physical mobility, balance, posture, fatigue, and pain. The physical therapy program typically involves (1) educating the person with MS about the physical problems caused by the disease, (2) designing an individualized exercise program to address the problems, and (3) enhancing mobility and energy conservation through the use of a variety of mobility aids and adaptive equipment.

Placebo effect: An apparently beneficial result of therapy that occurs because of the patient's expectation that the therapy will help.

Plantar reflex: A reflex response obtained by drawing a pointed object along the outer border of the sole of the foot from the heel to the little toe. The normal flexor response is a bunching and downward movement of the toes. An upward movement of the big toe is called an extensor response, or Babinski reflex, which is a sensitive indicator of disease in the brain or spinal cord. Also called Babinski reflex.

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

Post-void residual test (PVR): The PVR test determines how much urine is left in the bladder after an attempt to empty the bladder through urination has been made. It involves passing a catheter into the bladder following urination to drain and measure any urine remaining in the bladder. The PVR is a simple but effective technique for diagnosing bladder dysfunction in MS.

Postural tremor: Rhythmic shaking that occurs when the muscles are tensed to hold an object or stay in a given position.

Pressure sore: An ulcer of the skin — also referred to as a “bed sore” — resulting from pressure and lack of movement such as occurs when a person is limited to bed or requires a wheelchair for mobility. The ulcers occur most frequently in areas where the bone lies directly under the skin, such as elbow, hip, or over the coccyx (tailbone). A pressure sore may become infected and cause general worsening of the person's health.

Prevalence: The number of all new and old cases of a disease in a defined population at a particular point in time. The prevalence of MS in the United States at any given time is about 1/750 — approximately 400,000 people.

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

Prognosis: Prediction of the future course of the disease.

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

Pseudobulbar affect: Also called pathological laughing and crying; an involuntary emotional expression disorder in which episodes of laughing and/or crying occur with no apparent precipitating event. The person's actual mood may be unrelated to the emotion being expressed. This condition is thought to be caused by lesions in the limbic system, a group of brain structures involved in emotional feeling and expression.

Pseudo-exacerbation: A temporary aggravation of disease symptoms, resulting from an elevation in body temperature or other stressor (e.g., an infection, severe fatigue, constipation), that disappears once the stressor is removed. A pseudo-exacerbation involves symptom flare-up rather than new disease activity or progression.

Quad cane: A cane that has a broad base on four short “feet,” which provides extra stability.

Quadriplegia: The paralysis of both arms and both legs.

Recent memory: The ability to remember events, conversations, content of reading material or television programs from a short time ago, i.e., an hour or two ago or last night. People with MS-related memory impairment typically experience greatest difficulty remembering these types of things in the recent past.

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

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

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

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

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

Retrobulbar neuritis: *See* Optic neuritis.

Romberg's sign: The inability to maintain balance in a standing position with feet and legs drawn together and eyes closed.

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

Sclerosis: Hardening of tissue. In MS, sclerosis is the scar tissue that forms when myelin around CNS nerve cells is damaged or destroyed.

Scotoma: A gap or blind spot in the visual field.

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

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

Spasticity: Involuntary muscle stiffness and/or spasms resulting from increased muscle tone. Spasticity is a common symptom of MS. *See* Muscle tone.

Speech/language pathologist: Speech/language pathologists specialize in the diagnosis and treatment of speech and swallowing disorders. A person with MS may be referred to a speech/language pathologist for help with either one or both of these problems. Because of their expertise with speech and language difficulties, these specialists also provide cognitive remediation for individuals with cognitive impairment.

Suppressor T-lymphocytes: White blood cells that act as part of the immune system and may be in short supply during an MS exacerbation.

T-cell: A lymphocyte (white blood cell) that develops in the bone marrow, matures in the thymus, and works as part of the immune system in the body.

Tandem gait: A test of balance and coordination that involves alternately placing the heel of one foot directly against the toes of the other foot.

Titubation: A form of tremor, resulting from demyelination in the cerebellum, which manifests itself primarily in the head and neck.

Transcutaneous electric nerve stimulation (TENS): TENS is a nonaddictive and noninvasive method of pain control that applies electric impulses to nerve endings via electrodes that are attached to a stimulator by flexible wires and placed on the skin. The electric impulses block the transmission of pain signals to the brain.

Trigeminal neuralgia: Lightning-like, acute pain in the face caused by demyelination of nerve fibers at the site where the sensory (trigeminal) nerve root for that part of the face enters the brainstem.

Twins-dizygotic: Also known as fraternal twins, two babies that come from separate, simultaneously-fertilized eggs. If one dizygotic twin develops MS, the other has the same genetic risk for MS (approximately 2–5 in 100 or 3 percent) as any other sibling or first-degree relative.

Twins-monozygotic: Also known as identical twins, two babies that come from single fertilized egg and share identical genetic makeup. If one monozygotic twin develops MS, the other has a 25–30 percent risk of developing the disease, indicating that factors other than genetic makeup contribute to the etiology of MS.

Urethra: Duct or tube that drains the urinary bladder.

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

Vibration sense: The ability to feel vibrations against various parts of the body. Vibration sense is tested (with a tuning fork) as part of the sensory portion of the neurologic exam.

Videofluoroscopy: A radiographic study of a person's swallowing mechanism that is recorded on videotape. Videofluoroscopy shows the physiology of the pharynx, the location of the swallowing difficulty, and confirms whether or not food particles or fluids are being aspirated into the airway.

Visual acuity: Clarity of vision. Acuity is measured as a fraction of normal vision. 20/20 vision indicates an eye that sees at 20 feet what a normal eye should see at 20 feet; 20/400 vision indicates an eye that sees at 20 feet what a normal eye sees at 400 feet.

Visual evoke potential: A test in which the brain's electrical activity in response to visual stimuli (e.g., a flashing checker-board) is recorded by an electroencephalograph and analyzed by computer. Demyelination results in a slowing of response time. Because this test is able to confirm the presence of a suspected brain lesion (area of demyelination) as well as identify the presence of an unsuspected lesion that has produced no symptoms, it is extremely useful in diagnosing MS. VEPs are abnormal in approximately 90 percent of people with MS.

Vocational rehabilitation (VR): Vocational rehabilitation is a program of services designed to enable people with disabilities to become or remain employed. Originally mandated by the Rehabilitation Act of 1973, VR programs are carried out by individually created state agencies. To be eligible for VR, a person must have a physical or mental disability that results in a substantial handicap to employment. VR programs typically involve evaluation of the disability and need for adaptive equipment or mobility aids, vocational guidance, training, job-placement, and follow-up.

White matter: The part of the brain that contains myelinated nerve fibers and appears white, in contrast to the cortex of the brain, which contains nerve cell bodies and appears gray.



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Diana is a Family Nurse Practitioner who serves as a clinical provider in the UT Southwestern Medical Center's Clinical Center for Multiple Sclerosis in Dallas, Texas. She is also director of the Total Life Care (TLC) Clinic at UTSW, which focuses on quality of life issues of people with MS. A native Texan, Diana did her initial nurses' training in the United Kingdom and eventually went on to receive her MSN and FNP from the University of Texas at Arlington. She has been involved in nursing for 39 years, and for 15 years of that time was a hospice and palliative care nurse. Diana received her certification as a MS-certified nurse (MSCN) following her six-month National MS Society John Dystel Nursing Fellowship in 2009.

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As the Nurse Practitioner for the New York University Multiple Sclerosis Comprehensive Care Center, Carrie provides clinical care and education to patients with MS and their families, promotes wellness-oriented care in the community, and collaborates with other health care professionals on the team.

Carrie received her Bachelor of Science in Nursing and Master of Science in Nursing from Rutgers, the State University of New Jersey and was awarded her Doctor in Nursing Practice from Columbia University. In addition, Carrie completed a National MS Society John Dystel Nursing Fellowship in 2007, during which she focused on evaluating and defining the role of the nurse practitioner in MS Centers around the country. She is a certified Multiple Sclerosis Nurse (MSCN).

All three authors are proud members of the International Organization of MS Nurses.

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