

COMPREHENSIVE
NURSING CARE
IN



MULTIPLE
SCLEROSIS



JUNE HALPER
NANCY JOYCE HOLLAND

THIRD EDITION

SPRINGER  PUBLISHING COMPANY

**Comprehensive Nursing
Care in Multiple Sclerosis**
Third Edition

June Halper, MSN, APN-C, FAAN, MSCN, is an adult nurse practitioner (ANP) who has specialized in multiple sclerosis (MS) since 1978. She was a founder of the MS Center in Teaneck, NJ, and was the executive director until 2008. Ms. Halper was president of the Consortium of Multiple Sclerosis Centers (CMSC) from 1995–1997 and has been the executive director since 1992. Ms. Halper has published and lectured extensively on MS and its ramifications. Her numerous publications include *Comprehensive Nursing Care in Multiple Sclerosis* and *Advanced Concepts in Nursing Care in Multiple Sclerosis*, coeditor of *Staying Well With Multiple Sclerosis: A Self-Care Guide*, and coeditor of *Nursing Practices in Multiple Sclerosis: A Core Curriculum*. Ms. Halper chaired the first Multiple Sclerosis Nurse Specialist Consensus Committee’s development of a monograph on the nurses’ role in adherence to complex protocols, the impact of cognitive impairment in MS nursing care, and the nurses’ role in patients’ and families’ quality of life. She is a member of the American Academy of Nurse Practitioners (AANP), the founding director of International Organization of Multiple Sclerosis Nurses (IOMSN), and the recipient of the IOMSN’s first June Halper Award for Excellence in Nursing in Multiple Sclerosis. She was inducted as a Fellow into the American Academy of Nursing in November 1999. In 2000, she spearheaded the establishment of the Multiple Sclerosis International Credentialing Board who developed the first international certification examination in MS nursing offered in June 2002 and biannually thereafter. As executive director of the CMSC, she initiated the first certification examination for multidisciplinary MS specialists in 2004.

Ms. Halper is certified as an ANP (by both the American Nurses Credentialing Center [ANCC] and the AANP), is certified as an MS nurse, and is registered in both NY and NJ as registered nurse (RN) and an advanced practice nurse (APN).

Nancy Joyce Holland, EdD, RN, MSCN, in 2009 retired from her role as vice president of Clinical Programs at the National MS Society in New York, where she served in various capacities since 1988, including as national director and later vice president of Chapter and Community Services and vice president of Client and Community Services. Previous to these positions, Dr. Holland was coordinator of Clinical Services and director of training at the Medical Rehabilitation Research and Training Center for MS at Albert Einstein College of Medicine, Bronx, NY, and worked in Thoracic, Orthopedic, and Acute Medicine at Hospital of Albert Einstein College of Medicine (1968–1974) and later as nurse specialist in Neurology-Neurosurgery and coordinator of Clinical Services, MS Treatment Center, St. Barnabas Hospital, Bronx, NY (1974–1979). Dr. Holland earned her MA (1987) and EdD (1992) in Higher and Adult Education from Teachers College, Columbia University, earned her MA (1977) in Delivery of Nursing Services from New York University (NYU), and is certified as an MS nurse (MSCN) and as MS specialist in information and resources (MSIR). Dr. Holland is well-published, having written more than 60 journal articles on various aspects of MS along with 8 books (including the previous editions of this proposed revision), *Multiple Sclerosis for Dummies* (2007, Wiley), and several books for patients and caregivers.

Comprehensive Nursing Care in Multiple Sclerosis

Third Edition

June Halper, MSN, APN-C, FAAN, MSCN
Senior Editor

Nancy Joyce Holland, EdD, RN, MSCN
Contributing Editor

 **SPRINGER PUBLISHING COMPANY**
NEW YORK

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Springer Publishing Company, LLC
11 West 42nd Street
New York, NY 10036
www.springerpub.com

Acquisitions Editor: Margaret Zuccarini

Senior Editor: Rose Mary Piscitelli

Cover design: Steven Pisano

Project Manager: Gil Rafanan

Composition: Absolute Service, Inc.

ISBN: 978-0-8261-1852-3

E-book ISBN: 978-0-8261-1853-0

10 11 12 13/ 5 4 3 2 1

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Library of Congress Cataloging-in-Publication Data

Comprehensive nursing care in multiple sclerosis / [edited by] June Halper, Nancy J. Holland.
— 3rd ed.

p. ; cm.

Includes bibliographical references and index.

ISBN 978-0-8261-1852-3 — ISBN 978-0-8261-1853-0 (E-book)

1. Multiple sclerosis—Nursing. I. Halper, June. II. Holland, Nancy J.

[DNLM: 1. Multiple Sclerosis—nursing. 2. Multiple Sclerosis—psychology. WY 160.5]

RC377.C56 2011

616.8'340231—dc22

2010026044

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Printed in the United States of America by Hamilton Printing Company.

We would like to dedicate the third edition to the memory of the late Linda A. Morgante, whose loving legacy of caring and hope still resonates in the souls of her family, friends, colleagues, students, patients with MS, and their families. Her hope for tomorrow still is alive within all of us.

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Foreword

Multiple sclerosis (MS) is a chronic, inflammatory, and demyelinating disease of the central nervous system (CNS) that is characterized by axonal degeneration and gradual loss of neurological function. MS significantly impacts the lives of individuals with the disease and their families. Recent advances in the understanding of the immunopathology and management of MS have made this field of care dynamic and challenging.

In the 8 years since the second edition of *Comprehensive Nursing Care in Multiple Sclerosis* was published, the role of the nurse has evolved from that of supportive caregiver to include educator, researcher, and patient advocate. Nurses are challenged to go beyond traditional symptom management and assist the patient and family in addressing issues such as the psychosocial impact of the disease, risk or benefit evaluation of new therapies, and negotiating the health care system.

This book begins with a comprehensive overview of MS starting with a case study. This real world approach allows the reader to identify with issues faced by nurses every day. Current information about the pathophysiology and epidemiology of MS is reviewed and the reader will be updated about current diagnostic criteria and care patterns in MS. A wellness model approach is highlighted in the care of people with MS. Implementing the concept of hope into practice describes how nurses are now in a position to integrate the concept of hope into the clinical management of a disease once thought to be hopeless. Acting as an advocate for patients and their families, nurses can enable the patient to navigate the complex health care system today. The International Organization of MS Nurses (IOMSN) formally identifies patient advocacy as an organizational responsibility. It considers advocacy a fundamental role of the MS nurse and a commitment that must be shared by all health care providers involved in helping patients along their MS journey. This approach fully encompasses the concept of hope so vital in the lives of patients with MS.

Patients with MS today have increased access to information about the disease from many sources including the World Wide Web. The nurse in the role of educator is increasingly challenged to assist patients in understanding the information they gather and evaluate its credibility.

Part II of the text focuses on managing the disease and its symptoms and promoting healthy coping. In addition to a comprehensive review of current symptom management, this part includes new chapters. Incorporating complementary and alternative medicine (CAM) in practice is covered in detail. Increasingly, nurses are seeing the use of CAM by patients with MS who are seeking additional options to help manage their symptoms and their lives. MS nurses must keep abreast of the various CAM therapies to better educate and advocate for their patients. The pediatric population is explored in another new chapter. As our understanding of the pathology of the disease increases and our diagnostic abilities increase, we are all facing special populations including pediatrics. This chapter comprehensively covers issues such as developmental considerations and treatment challenges specific to the pediatric population.

Outcomes in the care and management of people with MS are a high priority in health care today. This section focuses on rehabilitation, managing resources, and maximizing the effectiveness of pharmacotherapeutics. A comprehensive pharmacology overview allows the reader to explore managing relapses and symptoms. The appendixes provide a list of various treatments along with the associated nursing care priorities.

This text differs from others on MS because it explores current issues that face patients, their families, and care provider today in the era of global uncertainty and managed care. Prevention of complications in the disabled, rehabilitation approaches to disease management, as well as women's issues are explored along with current nursing implications. The use of the case study approach is particularly useful in bringing the real world of MS challenges to light.

Comprehensive Nursing Care in Multiple Sclerosis is the collaborative effort of many health care professionals edited by June Halper and Nancy J. Holland. Their many years of experience in the field of MS and their commitment to MS nursing are evident in every chapter. This book represents the most current information on the care of patients with MS and their families. This will be an unparalleled resource for all nurses caring for patients with MS and their families. Thank you, June and Nancy, for updating this wonderful contribution to the MS literature.

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Introduction

THE MORGANTE CONCEPTUAL FRAMEWORK OF HOPE: SETTING THE STAGE

Welcome to the third edition of *Comprehensive Nursing Care in Multiple Sclerosis*, a book that has evolved over the past decade concurrently with changes we have seen in our profession. When this book was originally written, the world of multiple sclerosis was changing significantly. From a disease strictly envisioned as a neurologic problem, we began to learn about the immunologic origins of underlying damage. From a medical model spearheaded by neurologists, multiple sclerosis became a focus of nurses, rehabilitation specialists, counselors, and advocates. Your editors were honored to be part of these changes and now we feel that this current edition requires a new focus on our new understanding of multiple sclerosis as well as the new and emerging responsibilities of MS nursing professionals. We also believe that it is time for us to present a conceptual framework for MS nursing, one that encompasses the many roles and responsibilities that challenge us in our work and that could give us a leitmotif for our nursing activities. The late Linda A. Morgante espoused the *concept of hope* throughout her nursing activities in multiple sclerosis. She had a Hope Jar in her office, which her patients touched during their visits with her. They also added hope rocks to Linda's collection. Linda lectured throughout the world on this concept and she published several articles applying this conceptual framework. She believed that to be successful in helping patients and their families, nurses must focus on positive yet realistic outcomes of activities that involved managing multiple sclerosis. Her philosophy was that the glass was half full rather than half empty. She inspired her nursing colleagues throughout the world, her MS team members, and most importantly, her patients and their families.

Your editors have redesigned *Comprehensive Nursing Care in Multiple Sclerosis* to incorporate this conceptual framework to honor and sustain the memory of the late Linda A. Morgante. This new edition is designed to incorporate this framework into every chapter to provide our readers with practical applications of this model into professional practices. This new view of multiple sclerosis is appropriate both in concept and in

reality. When your authors began their MS nursing practice, professional practice focused on symptomatic management, rehabilitative services (if they were available), and a fairly bleak outlook leading to disease progression. During the past decade, the world of MS has evolved to a wide array of treatment options, an international focus on MS research and care, and an expanded cadre of MS nurses. Your authors have redesigned the content of this book to be consistent with a new and more positive philosophy of MS care and research. We hope that this new model of care will provide our readers with a new view of multiple sclerosis that will contribute to their professional practice and improve patient outcomes throughout the spectrum of the disease.

June Halper, MSN, APN-C, FAAN, MSCN
Nancy Joyce Holland, EdD, RN, MSCN

CHAPTER **1**

An Overview of Multiple Sclerosis

June Halper and Nancy Joyce Holland

Janet is a 21-year-old single woman who presents at her neurologist's office with a history of optic neuritis and persistent facial pain. She was seen in the local emergency room by the emergency room physician and a neurologist. An MRI was ordered along with blood work. She was given an intravenous medication and told to follow up with her neurologist. She is very anxious and does not understand the reason for the visit. She is very frightened because no one explained the results of her tests or what her symptoms mean.

INTRODUCTION

Since first thoroughly described by Charcot in 1868, multiple sclerosis (MS) has been viewed as a chronic and frequently debilitating neurologic disease that affects young adults in the prime of their lives (Murray, 2005). Diagnosis was tedious and difficult. Those affected faced a bleak future. This was the picture of MS until recently. During the latter part of the 20th century, technological advances, such as diagnostic imaging (MRI) and neurophysiologic testing (evoked potentials), and more sensitive biologic testing, such as spinal fluid analysis, facilitated the diagnosis of MS and led to more prompt attention and treatment by health care providers. This is in direct contrast to care in the early and mid-20th century that was frequently referred to as the “diagnose and adios” era (L. Scheinberg, personal communication, 1980–1990). The treatment of MS has subsequently advanced from a focus on episodic, acute care and rudimentary symptom management, to early treatment with disease modification and the potential for altering the natural history of what was previously thought to be an unbroken path to severe disability. In addition, a greater understanding

and acceptance of the value of comprehensive symptomatic care, psychosocial interventions, and rehabilitative services has emerged as a leitmotif of MS care throughout the professional MS community.

With its emphasis on acute patient care needs, technological and surgical advances, and primary care interventions, basic and advanced nursing education has not traditionally stressed care of the chronically ill or disabled. The complex nature of MS and its lifelong problems require the skills and direct services of numerous health care professionals in addition to neurologists. Nurses who enter this field are often confronted with information gaps about the disease, its courses, and current treatment.

Nurses, often placed in a key position related to patient and family interaction, may be uncertain of roles, responsibilities, and required skills to provide effective care. MS care can be viewed as either predominantly difficult or rewarding based on the information and support given to a nurse entering this specialty. From the authors' perspective, MS patient care, interaction with various health care professionals (e.g., nursing colleagues, rehabilitation specialists, social workers, counselors), and interaction with numerous medical specialists such as neurologists, urologists, orthopedists, physiatrists, and ophthalmologists can sustain a nurse throughout many years within this sphere of practice.

There are numerous opportunities for the nursing professional, as well as members of the MS team, to enhance care for all those affected by MS. We have planned this book to support and sustain nursing care of people with MS, and to support their families throughout a lifetime with this disease.

EPIDEMIOLOGY, INCIDENCE, AND PREVALENCE

In the United States, there are estimated to be 400,000 people with MS with approximately 2 million worldwide. Although more people are being diagnosed with MS today than in the past, the reasons for this are not clear. Likely contributors, however, include greater awareness of the disease, better access to medical care, and improved diagnostic capabilities. There is no definitive evidence that the rate of MS is generally on the increase. Most people are diagnosed between the ages of 20 and 50, although MS can occur in young children and significantly older adults (www.nmss.org).

Worldwide, MS occurs with much greater frequency above 40° latitude than closer to the equator. However, prevalence rates may differ significantly even within a geographic area, where latitude and climate are fairly consistent. These differences demonstrate that geographical factors are not the only ones involved (www.nmss.org).

MS is more common among Caucasians (particularly those of northern European ancestry) than other ethnic groups, but people of African, Asian, and Hispanic ancestry also develop the disease. Despite the latitude at which they live, MS is almost unheard of in some populations, such as Inuit, Yakutes, Hutterites, Hungarian Romani, Norwegian Lapps, Australian Aborigines, and New Zealand Maoris, which indicates that ethnicity and geography interact in some complex way to impact prevalence figures in different parts of the world (Compston & Coles, 2008).

It is now believed that MS is the result of an interaction of both genetic and environmental factors (Sadovnick, 1994; Stewart & Kilpatrick, 2006). It has been theorized that MS susceptibility is under the control of several genes. By inheriting these genes, a person is susceptible to an immunologic stimulus (possibly a virus) that in turn leads to myelin damage and clinical MS (Oksenberg & Hauser, 2006; Sadovnick). The specific genes and how they interact have yet to be identified. For this reason, the interpretation of the data on geographic distribution of MS is difficult (Oksenberg & Hauser; Sadovnick) and remains a topic of controversy. De Jager et al. in 2009 published a work describing the integration of genetic risk factors into a clinical algorithm to predict MS but work is still required in this very complex area of research.

The human herpesvirus (HHV; Epstein-Barr virus [EBV]) has long been considered as a trigger of MS along with some interest in other likely candidates. Lunemann and Munz published an interesting article in 2009 and many other investigators are now looking at EBV as a potential viral trigger in MS. Other viruses, such as canine distemper, measles, and HHV-6, have been considered as likely candidates over the past few decades with no substantial evidence to link any of these as a causative agent.

There appears to be a markedly uneven geographic distribution of the disease. Kurtzke (1985) identified areas of high, medium, and low risk, according to latitude. In the United States, states south of the 37th parallel of north latitude showed lower death rates than those north of that line, which were well above the national mean. Prevalence studies for groups of Northern Europeans and North Americans who migrated from high-risk areas to low-risk areas (Alter, Okihiro, Rowley, & Morris, 1971; Dean, 1967; Moffie, 1966) showed that they remained at high risk if they emigrated after the age of 15. Those who emigrated prior to age 15 acquired the low risk of the countries to which they emigrated. Such differences have given rise to a hypothesis that there is a critical age of exposure to unknown causal or triggering factors (possibly a virus), and suggest that there is a long period of latency between exposure and onset of the disease (Ebers, 1998; Granieri et al., 1993).

This geographic model of distribution has been criticized on the basis that the comparison of prevalence rates was “reported from very different areas, countries, and communities at different times” (Granieri et al., 1993, p. S17). Granieri et al. also pointed out that more recent European prevalence studies have contradicted earlier studies. A study in Italy showed that prevalence was actually higher in the southern islands of Sicily and Sardinia (Rosati, 1990; Savettieri, 1983), with similar results from studies done in Yugoslavia (Sepcic, Antonelli, Materljian, & Rukavina, 1989) and Spain (Martin, Matias-Guiu, Calatayud, Moltó, & Aranaz, 1988).

According to Granieri et al. (1993), the “lower MS prevalence ascribed to a lower latitude may in part reflect differences in level, quality, and organization of health services as well as accessibility and case ascertainment, variables that affect the accuracy of the reports and produce bias in prevalence estimates” (p. S17). Studies done in Australia, however, support the correlation with latitude, showing higher prevalence rates in the southern regions, where it is cooler, with no significant differences in ethnic composition that might account for this difference (Hammond et al., 1988).

It has also been shown that the prevalence and pattern of MS can vary over time within a given geographic area. One notable study was done in the Faroe Islands, which experienced a dramatic increase in cases of MS after the arrival of British troops during World War II (Kurtzke & Hyllested, 1979). Kurtzke’s interpretation of this increase was that the British introduced MS to the Faroe Islands, stating that “the only possible explanations are that the British brought either a persistent toxin or a transmissible infection. A toxin cannot explain successive epidemics. Therefore, the cause of MS in the Faroes is a transmissible infection” and that “MS exists in a widespread, transmissible, but neurologically asymptomatic form” (Kurtzke, 1993, p. 412). Kurtzke went on to say that this asymptomatic form, which he calls *primary MS affection* (PMSA), is common in a population in which there is MS, but that it only rarely produces clinical MS symptoms.

It should be pointed out that there is no evidence that MS is a directly transmissible disease because it has not been demonstrated that people who live with, or have frequent contact with, MS patients are at greater risk for the disease (i.e., there is no reason to believe that MS patients are infectious; Granieri et al., 1993; see Exhibit 1.1).

There is an increasing interest in the immunomodulatory effects of vitamin D in MS with many published articles as well as presentations at national and international meetings. There is no conclusive statement that can be made at this time but there is great interest into “a possible link between the onset of MS and its worsening because of lack of vitamin D” (Correale, Ysraelit, & Gaitan, 2009).

EXHIBIT 1.1 ■ Familial Risks for Multiple Sclerosis

Up to 2% of people with MS have at least one relative with MS

Empiric recurrence risks (age-adjusted)

- Parent with MS, risk for child 4%
- Person with MS, risk for sibling 4–5%
- Twin with MS, risk for co-twin (fraternal) 3–5%
- Twin with MS, risk for co-twin (identical) 26–36%

Note. From “A Population-Based Study of Multiple Sclerosis in Twins: Update,” by A. D. Sadovnick, H. Armstrong, G. P. Rice, D. Bulman, L. Hashimoto, D. W. Paty, . . . T. J. Murray, 1993, *Annals of Neurology*, 33(3), 281–285. Copyright 1993 by Wiley-Liss. Adapted with permission. From *Multiple Sclerosis in Clinical Practice* by S. Van den Noort & N. J. Holland, 1999 by New York: Demos Medical Publishing. Copyright 1999 by Demos Medical Publishing. Adapted with permission.

THE PATHOLOGY AND ETIOLOGY OF MULTIPLE SCLEROSIS

MS is a disease of the central nervous system (CNS) in which the myelin sheath surrounding certain nerve fibers becomes damaged, interrupting the conduction of nerve impulses. The pathologic process begins with the destruction of the myelin, which may slow down or interrupt conduction (Allen, 1991). Irregularly shaped macroscopic lesions, which appear to be the result of destruction of the myelin sheath, are scattered throughout the CNS. These lesions, or *plaques*, are found in the white matter and have a predilection for the optic nerves and the white matter of the spinal cord, brain stem, cerebellum, and cerebrum, especially the area surrounding the ventricles (Pallett & O’Brien, 1985). Recently formed lesions show partial or complete degeneration of myelin and perivascular infiltration with lymphocytes and other mononuclear cells, suggestive of an inflammatory process (Pallett & O’Brien). Axonal damage has been identified in both acute and chronic MS lesions and is believed to be the cause of permanent and irreversible physical and cognitive disability (Trapp et al., 1998). Recent evidence suggests that axonal loss may occur much earlier in the disease course than previously believed. In addition, MS has always been described as a disease affecting white matter (myelinated fibers). During the past decade, there is a strong evidence of gray matter involvement (Peterson, 2001). MRI has emerged not only as a diagnostic tool, but also as a means of monitoring disease activity. Advancing technology and increased research has given the health care community a

larger window on the subclinical disease alongside its clinical implications (Lincoln et al., 2009).

The etiology of MS is not known although there is believed to be a genetic predisposition in susceptible individuals combined with an unknown environmental trigger (Compson, 1991). The environmental factor is not known but is thought to be viral in origin (Compson, 1991). MS has been shown to occur frequently in specific families, and current theory is that it is multigenic (i.e., results from more than one gene; Compson, 1991; Compson, 2001).

THE COURSE OF THE DISEASE

One of the hallmarks of MS is its unpredictability from person to person and within a given individual over time. Its prognosis is uncertain although there are general prognostic indicators that can suggest whether a patient's disease will follow a specific pattern. In general, women have a better prognosis than men (Coyle, 1996). Onset at an early age, a monoregional versus a polyregional attack, and complete recovery from an exacerbation portend a favorable prognosis (Coyle). Brain stem symptoms (such as nystagmus, tremor, ataxia, and dysarthria), poor recovery from exacerbations, and frequent attack rate are indicators of a poor prognosis (Coyle).

The diagnosis of MS is usually made by a neurologist after two or more episodes of unexplained neurologic symptoms have occurred. Recent research studies have indicated that clinically isolated syndromes (CIS)—one exacerbation and positive MRI findings—are the first indication of MS. There is no specific laboratory test for MS, and the diagnosis usually depends on a history that indicates the probability of the disease, a neurologic examination with findings consistent with MS, and positive paraclinical evidence (Sibley, 1990). Most patients fall into the age group of 15–60 years although recent data suggest that as many as 10% of MS patients have their first symptoms in their 60s (Sibley). Although the average age of onset is between 20 and 50 years, the disease may start in children. Initial symptoms include numbness, tingling, or weakness of the extremities; visual changes; vertigo; dysarthria; ataxia; and urinary frequency and urgency. *L'Hermitte's* phenomenon, a transient paresthesia resembling an electrical shock that occurs with forward flexion of the neck, is also common (Sibley). The diagnostic criteria for MS have evolved from Schumacher et al. (1965; see Exhibit 1.2), the Poser Committee (Poser et al., 1983; see Table 1.1), and the McDonald consensus (2001, revised 2005; McDonald et al., 2001; see Table 1.2).

EXHIBIT 1.2 ■ Schumacher Criteria for the Clinical Diagnosis of Multiple Sclerosis

- Appropriate age (10–50 years)
- CNS white matter disease
- Lesions disseminated in time and space
- Two or more separate lesions
- Objective abnormalities
- Consistent time course
- Attacks lasting more than 24 hours, spaced 1 month apart
- Slow and stepwise progression for more than 6 months
- No better explanation
- Minimum routine laboratory investigation
- Diagnosis by a physician competent in clinical neurology

TABLE 1.1 Poser Committee Criteria for the Diagnosis of Multiple Sclerosis

Category	Clinical				Paraclinical Evidence	
	Attacks	Evidence			Evidence	
Clinical diagnosis:						
Definite	1	2	2		—	
	2	2	1	and	1	
Probable	1	2	1		—	
	2	1	2		—	
	3	1	1	and	1	
Category	Clinical				Paraclinical	
	Attacks	Evidence			Evidence	CSF*
Laboratory-supported diagnosis:						
Definite	1	2	1	or	1	1
	2	1	2		—	1
	3	1	1		—	1
Probable	1	2	—		—	1

*CSF = cerebrospinal fluid.

TABLE 1.2 2005 Revised McDonald Diagnostic Criteria

Clinical Presentation	Additional Data Needed for MS Diagnosis
≥2 attacks; objective clinical evidence of ≥2 lesions	None
≥2 attacks; objective clinical evidence of 1 lesion	Dissemination in space, demonstrated by <ul style="list-style-type: none"> • MRI or • ≥2 MRI-detected lesions consistent with MS plus positive CSF or • Await further clinical attack implicating a different site
1 attack; objective clinical evidence of ≥2 lesions	Dissemination in time, demonstrated by <ul style="list-style-type: none"> • MRI or • Second clinical attack
1 attack; objective clinical evidence of 1 lesion (monosymptomatic presentation; clinically isolated syndrome)	Dissemination in space, demonstrated by <ul style="list-style-type: none"> • MRI or • ≥2 MRI-detected lesions consistent with MS plus positive CSF and Dissemination in time, demonstrated by • MRI or • Second clinical attack
Insidious neurological progression suggestive of MS	1 year of disease progression (retrospectively or prospectively determined) and 2 of the following: <ul style="list-style-type: none"> • Positive brain MRI (9 T2 lesions or ≥4 T2 lesions with positive VEP) • Positive spinal cord MRI (2 focal T2 lesions) • Positive CSF

Note. From “Diagnostic Criteria for Multiple Sclerosis: 2005 Revisions to the ‘McDonald Criteria’” by C. H. Polman, S. C. Reingold, G. Edan, M. Filippi, H. P. Hartung, L. Kappos, . . . J. S. Wolinsky, 2005, *Annals of Neurology*, 58(6), 840–846. Copyright 2005 by Wiley-Liss. Reprinted with permission.

MS remains a clinical diagnosis although emerging technology, specifically the use of neuroimaging has shortened the time between the first clinical attack and the diagnosis of “clinically definite MS.” The Poser criteria for clinically definite MS required two clinical deficits referable to white matter lesions or a physician’s observation of one deficit with paraclinical evidence of another, either through MRI or evoked potentials. Deficits must be separated in onset by at least 1 month and each must last at least 24 hours (Poser et al., 1983). The McDonald criteria (2001, revised 2005; McDonald et al., 2001) incorporate increased understanding of MRI parameters and more precisely define the number and location of MRI lesions required for diagnosis. Additionally, no more appropriate diagnoses should exist to account for clinical findings. It is important to emphasize that although MS remains a clinical diagnosis,

the time in which first symptoms appear and the diagnosis is made is now shortened because of the use of this advanced technology, the MRI, which enables the clinician to document a second attack based on neuroimaging. MS has thus been made treatable much earlier in its course with potential for altering its long-term outcome.

Patients can be categorized as having either relapsing–remitting, primary progressive, secondary progressive, progressive–relapsing, benign, or malignant disease (Lublin & Reingold, 1996). The latter two categories, benign and malignant, are rare presentations of MS and are not commonly referred to when describing the most frequently encountered courses of the disease.

- Relapsing–remitting MS is characterized by clearly defined disease relapses with full recovery, and periods between relapses characterized by a lack of disease progression.
- Patients with primary progressive MS demonstrate disease progression from the onset with occasional and temporary minor episodes of improvement.
- Secondary progressive MS begins with a relapsing–remitting course followed by progression with or without occasional relapses, minor remissions, and plateaus.
- Progressive–relapsing MS is progressive disease from the onset, but there are clear acute relapses with or without recovery. The periods between relapses are marked by continued progression.
- Benign MS allows patients to remain fully functional in all neurologic systems 15 years after disease onset. This type of course has been referred to as a *retrospective diagnosis*, one that is made after many years in which the patient and clinician look back and are able to determine that the disease has not worsened over time. There are no “landmarks” early in MS that distinguish this type of prognosis.
- Malignant MS (Marburg’s variant) has a rapid progressive course leading to significant disability or death within a relatively short time after onset (Lublin & Reingold, 1996).
- CIS has been recognized as early MS has been defined as “an acute or subacute neurologic episode indicative of demyelination in the CNS and often associated with silent lesions on MRI” (Moser, Picone, & Smith, 2009).

DOMAINS OF MULTIPLE SCLEROSIS NURSING PRACTICE

The practice of MS nursing requires that the full range of nursing skills and practice be called in use to serve the MS patient and the family (Maloni, 2001). MS nursing encompasses broad areas of accountability

and practice and includes specific knowledge, skills, and tasks. The domains of MS nursing have been defined as clinical practice, advocacy, education, and research (Multiple Sclerosis Nursing International Credentialing Board [MSNICB], 2001).

Universal tasks of all nursing care are the establishment of a therapeutic partnership, the performance of a comprehensive assessment, the formulation of a collaborative treatment plan and its implementation, and the assessment of outcomes. Specific requirements in MS nursing care involve full knowledge of the disease and its range of physical, functional, and neurologic implications. Other requirements include skills to teach and empower patients and their families, as well as the ability to advocate for treatments, programs, and services needed by individuals and families affected by MS (Maloni, 2001). The late 20th and early 21st centuries have seen a change in MS care—and a new recognition of the role of the MS nurse and others who provide nursing services. Nursing care in MS requires creativity, caring, empathy, hope, and a great deal of stamina (Halper, 2001).

THE WELLNESS MODEL IN MULTIPLE SCLEROSIS NURSING

The variable pattern of MS, along with the uncertainty and loss of control that the diagnosis brings to the patient and family, impels the nurse to respond with cultural sensitivity and individualized care. Positive approaches to restore control and quality of life tend to reassure anxious patients and their families as they face an unknown future. Nursing care can be divided into direct delivery of services, counseling, education, and support through difficult transitional periods (i.e., following the diagnosis, during an acute exacerbation, during worsening of the disease, or while learning to live with advanced disability). Clark's wellness model has implications for the nursing process in MS (Clark, 1986; see Table 1.3).

In a disease with no cure, the patient and family must assume ongoing responsibility for health care and self-monitoring. In the traditional nursing model, the nurse performs and the patient receives care. The wellness model is a collaboration between the patient and the nurse—a therapeutic partnership whose goal is self-awareness and self-responsibility. Clark defines wellness as a positive striving unique to the individual, in which a person can be ill and still have wellness with a deep appreciation for the joy of living and with a life purpose (Clark, 1986). This wellness focus strengthens and sustains the therapeutic partnership and can support this relationship throughout a lifetime of coping with change and adapting to new circumstances (Halper & Holland, 1998a, 1998b; Halper, 2001).

TABLE 1.3 Comparison of the Traditional Nursing and Wellness Nursing Processes

Traditional Nursing Process	Wellness Nursing Process
Assess client	Model integrates whole person wellness for the client Teach client self-assessment procedures
Diagnose	Assess unique learning needs based on client belief systems
Set goals	Teach client to set meaningful wellness goals
Develop nursing care plan	Develop plan of action with client and help client take responsibility for carrying it out
Carry out nursing interventions	Teach client self-care and self-healing measures consistent with client beliefs
Evaluate results	Teach client to self-evaluate results

Source: Clark, C. C. (1986). *Wellness nursing*. New York: Springer.

CARE PATTERNS IN MULTIPLE SCLEROSIS: WHERE NURSES DO NURSING

Acute Care Settings

Patients with MS often experience exacerbations of their illness and require acute interventions with corticosteroids, rehabilitation services, and assistance with the acquisition of community services. Care during this time is usually limited to the period of clinical worsening and may be provided in a hospital setting, rehabilitation facility, or at home. Treatment of an acute exacerbation usually begins with screening for an underlying infection (upper respiratory infection [URI], urinary tract infection [UTI]) or an environmental trigger (heat, humidity). The nurse's role at this time is one of direct patient care, education, counseling, reassurance, and support.

Rehabilitative Care

Rehabilitation in MS can be provided in an outpatient setting, an inpatient unit, or at home. During this period, nurses provide education and counseling to promote adaptation to a new level of function. In addition, nursing may involve functions, such as wound care; pulmonary care; toilet, bowel, and bladder management; and discharge planning. Physical, occupational, speech and language therapy and vocational rehabilitation are designed to help patients regain lost function, perform at a maximal and safe level, and accept and adjust to periods of dependence and interdependence as the disease waxes and wanes.

Comprehensive Care

Comprehensive care in MS is an organized system of health care designed to address the medical, social, vocational, emotional, and educational needs of patients and their families (Halper & Burks, 1994). Comprehensive care embraces a philosophy of empowerment—a wellness approach in which the patient takes an active role in planning and implementing health care and self-care activities and acts as a consultant to the team, which may consist of physicians, nurses, rehabilitation specialists, counselors (social workers, psychologists, neuropsychologists), educators, and clergy. Patients must learn to adapt and change in response to alterations in their physical and cognitive functioning. This implies a total commitment by the health care team and the patient to a clearly defined program of “wellness” that looks beyond impairments to each person’s potential (Cobble & Burks, 1985). Comprehensive care centers have proliferated throughout the United States and Canada since the early 1980s. The team approach to MS care has become universally accepted (Halper & Burks) and has set a standard for care of the chronically ill and disabled that one sees in disease such as HIV or AIDS, cancer, and coronary artery disease. A team leader, a case manager, or a case coordinator (Ignatavicius & Hausman, 1995) may coordinate patient care services provided by the interdisciplinary team. A nurse frequently assumes this role.

Home Care

Patients with more advanced disease are frequently cared for in their homes. Many families are faced with day-to-day challenges of caring for loved ones who require total care, including personal hygiene, nutrition, transfers, and access to the health care system. The nurse in the home care setting is the link to health care providers in the community and is often faced with challenges such as advocacy on behalf of the patient to increase services available in the home and to guarantee a basic level of medical attention. Patients, who may be severely disabled with no hope of any improvement, may also face medical complications, such as pneumonia, skin breakdown, and pulmonary compromise. These patients may request and receive comfort measures as in the palliative care model.

Long-Term Care

Long-term care does not necessarily imply nursing home or long-term care facility. It may also mean residing in housing for the disabled, participation in adult day programs, and sustained care within the

community. Nurses have a vital role in the long-term care of people with MS: in nursing homes as care providers and supervisors of bedside care; in assisted living programs as monitors of health, function, wellness, and safety; in adult day programs, as part of the team supporting day-to-day activities; and in community centers as educators and advocates for patients and families.

MEETING THE CHALLENGES OF MULTIPLE SCLEROSIS NURSING

The challenge of nursing care in MS impels the nurse to answer the following questions when entering into the therapeutic partnership:

- What is the patient's disease course?
- What treatment(s) have been prescribed?
- How has MS affected the patient's quality of life?
- What is the patient's history of adherence?
- How are symptoms interfering with the patient's functional status?
- How has MS impacted the patient and the family?
- What are the available resources?
- How can I help?

We hope that this book will assist nurses in this wide variety of nursing settings to develop their own philosophy of care, to sustain themselves as MS nurses, and to transfer this model of nursing to other chronic illnesses requiring similar types of interventions.

The MS nurse met with Janet on two occasions, first to explain MS in a personal context, relating her symptoms to MS, and then explaining the usual picture of the disease. She used visual aids and printed materials provided by local MS organizations, the International Organization of MS Nurses, and from the nurse's personal files. She advised Janet that she would be available to talk to her as needed. During the subsequent visit, Janet brought her husband and the couple asked many more questions about treatment options, potential implications for their future, and the possibility of their children acquiring MS. The nurse answered their many questions and offered to meet with them again. She also gave them information about support groups, online chat rooms, and various Web sites that contained reliable information. Janet has begun MS therapy and continues to contact the nurse intermittently when she is concerned.

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Integrating the Concept of Hope Into Clinical Practice

Linda A. Morgante[†]

Editors' Note: This chapter was written for the first and second editions of *Comprehensive Nursing Care in Multiple Sclerosis*. The late Linda A. Morgante inspired thousands of her patients along with her nursing colleagues with her model of care that incorporated patient and family education, sustaining self-efficacy, counseling, and skills development. This model helped patients, families, and her nursing colleagues sustain hope for the future through positive actions, involvement with others, and knowledge. In this third edition, your authors have developed an algorithm that we feel embodies the Linda Morgante conceptual framework of hope in which the challenges of multiple sclerosis (MS) can be met with a therapeutic partnership with a nurse. This partnership can be altered to include other health care professionals, such as physicians, therapists, counselors, and advocates. Integral to this model is culturally competent care, a focus on wellness rather than illness, addressing the physical and emotional needs of the disease, and empowering the patient with education, skills development, and resource utilization. The leitmotif of this model is wellness rather than illness and a positive outlook leading to hope and empowerment.

INTRODUCTION

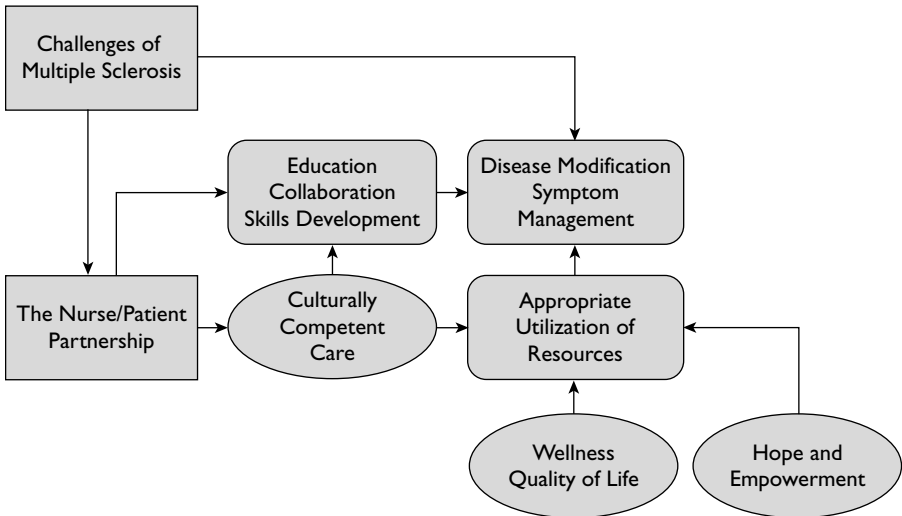
Empowering hope in people with MS is a prime aspect of caring (see Figure 2.1). Hope is a multidimensional and dynamic process that energizes people and enables healthy coping (Dufault & Martocchio, 1985; Herth, 1991; Miller, 2000). Hope is experiencing a sense of unlimited possibility and potential. It is a resource within each person that can be illuminated to promote healing.

New drug treatments that can alter the course of the disease in a positive way have given people with MS and their families options for

[†]Deceased.

FIGURE 2.1 Linda Morgante Conceptual Framework of HOPE

This conceptual framework was developed by June Halper in memory of the late Linda A. Morgante to honor her contribution to MS nursing. Linda always believed in the value of the nurse–patient relationship: the comfort and care that this provided. She always emphasized the importance of collaborative activities that promoted skills and knowledge that enabled patients to overcome the challenges of the disease. With the advent of disease-modifying therapies, this model was enlarged to embrace the complex addition of these treatments. Underlying this framework was Linda’s belief in wellness and the importance of recognizing each individual’s definition of quality of life, a fluid, and self-defined concept unique to each person.



managing the disease. However, MS remains incurable, and the disease has no boundaries. Symptoms of MS manifest differently in each person and may change over time. People who have MS experience its variability on a day-to-day basis and have difficulty living with uncertainty.

People with MS cling to hope. They hope for a cure, hope that their condition will stabilize or improve, hope that they will not be abandoned, and hope that they will be able to endure the physical, emotional, and spiritual distress that accompanies MS. The experience of hope is limitless. Redirecting people’s attention to a fuller meaning for hope in their lives offers “greater flexibility in maintaining an authentic, reality-based hope despite changing circumstances” (Callan, 1989, p. 42). Hope then not only centers on tangibles like “a cure,” but also taps previously unexplored dimensions of the self. Weaving a tapestry of hope while untangling a web of false hope becomes a nursing challenge in caring for those with MS and their families.

This chapter presents several vignettes that demonstrate the use of hope in practice. The behavioral cues for assessing hope will be reviewed, and the nursing interventions, which nurture hope, will be highlighted. The final vignette will illustrate ways in which nurses can replenish their own wellspring of hope when the stress of MS care becomes depleting.

BACKGROUND

The study of hope by theologians, philosophers, sociologists, and psychologists provides underpinnings for the use of the concept in nursing (McGee, 1984). The Old Testament is filled with passages that reveal anticipation and hope for the coming of the Messiah. The New Testament reflects the teachings of Jesus, which promise a glorious life after death for those who follow His path. The contemporary philosopher Marcel (1951/1962) viewed a person as having unending potential to be expansive and to transcend boundaries to become a fuller being. This implies the presence of hope within all of us.

Sociological evidence of hope can be found in Martin Luther King's famous "I have a dream" speech, which expressed his vision of equal rights for African Americans and the preservation of civil liberties for all. The existence of hope can also be found in our own ancestors and in the anticipation of a better life for every immigrant. Ellis Island is a moving tribute to those ideals and reminds us of past and present dreams that exist for those seeking a new home in America.

Psychologists documented hope in their studies of prisoners of war. They found that the idea of getting out and being reunited with loved ones sustained many of the prisoners (Korner, 1970). In her work with the terminally ill, Elisabeth Kübler-Ross (1969) found that hope for a cure or remission of illness helped people through difficult times. She noted that it was a sign of imminent death when people stopped expressing hopeful ideas.

ATTRIBUTES THAT SUPPORT HOPE

Several personal attributes have been shown to contribute to an optimistic and hopeful attitude. A strong sense of self, the ability to feel competent and in control of one's life, resiliency, hardiness, and fighting spirit have all been documented as having a positive relationship with hope (Barton, Magilvy, & Quinn, 1994; Foote, Piazza, Holcombe, Paul, & Daffin, 1990; Hinds & Martin, 1988; Post-White et al., 1996). A person's beliefs, values, and faith, whether expressed as traditional religious faith or simply feeling connected to a higher being, have also been found to have a positive impact on a patient's hopefulness (Post-White et al., 1996).

HOPE AND HOPELESSNESS

Lynch (1965) defined hope as a sense of the possible, “the best resource of man, always there in the inside making everything possible when he is in action, or waiting to be illuminated when he is ill. It is [our] most inward possession and is rightly thought of according to the Pandora story, as still there when everything else has gone” (p. 31). Other definitions contrast hope to hopelessness or despair; when hope is lost, one becomes despondent and loses energy necessary for hopefulness. Fromm (1968) identified the loss of the ability to dream as a response of one who is hopeless. Dreaming not only takes place in sleep but is also an important part of wakefulness and being able to imagine better times. Talking about dreams can be comforting psychologically and emotionally. Disruption of sleep is a clue to possible hopelessness.

Lynch (1965) defined hopelessness as not having the energy for either imagining or wishing. It is deeply passive, not in any of the good sense of the work, but in its most unhappy sense. Its only fundamental wish is the wish to give up. In a particular situation it cannot imagine anything that can be done or that is worth doing. It does not imagine beyond the limits of what is presently happening. (p. 50)

Although hope is often seen as the absence of hopelessness, no experience is static. It is only our language that limits our vision to an either-or situation. A person moves from hope to hopelessness from moment to moment, and recognition of this ever-changing process can inspire hope even in moments of despair (see Figure 2.2). Hope can be a

FIGURE 2.2 Hope in Despair

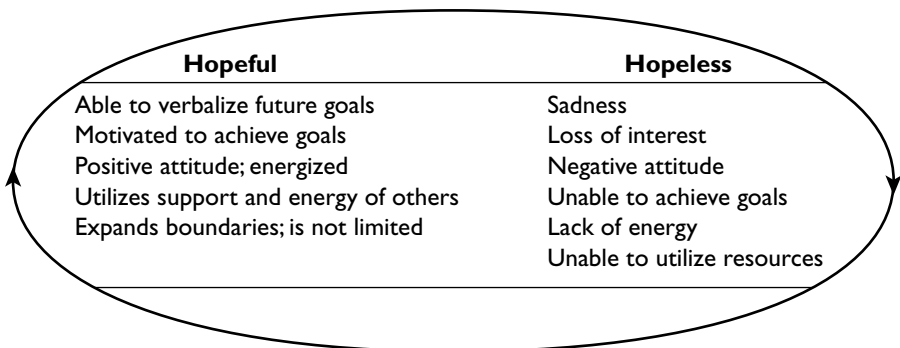


EXHIBIT 2.1 ■ Behaviors That Reflect Hope

- Verbalizes future goals
- Shows motivation to reach goals
- Expects to accomplish goals
- Imagines a brighter tomorrow
- Reminisces about past successes
- Sees options for self
- Maintains a sense of control
- Anticipates positive outcomes
- Relates to family, friends, or caregivers in supportive and reciprocal ways
- Feels connected to a higher being
- Displays humor
- Relaxes with imagery and visualization

song, a poem, a painting, a flower arrangement, a smile, or a joke. Hope is the smallest or largest expression of the spirit of optimism (Morgante & McCann, 1992). Nurses who care for people with MS and their families are in a position to provide the resources needed to promote hope and prevent hopelessness.

Nursing care includes assessing behaviors that reflect hope (see Exhibit 2.1), identifying variables that make an impact on the process of hoping to plan care, and creating interventions for inspiring, sustaining, or restoring hope.

CASE STUDIES**Lisa**

Lisa is a 26-year-old woman who was undergoing routine evaluation for migraine headaches. She is an associate at a major New York City law firm, and engaged to be married. An MRI reveals multiple white matter lesions typical of MS. She has never experienced an exacerbation of MS and feels fine. She is referred to a neurologist who specializes in MS care and is presented with information regarding the likelihood of developing MS, along with options for treatment. When Lisa and her parents come to see the MS nurse, they are all visibly shaken. They had expected to hear good news, but instead they were told Lisa most likely has MS. They are each overwhelmed, crying, and confused. Lisa's disbelief centers around the fact that she feels fine and has never experienced an

(Continued)

(Continued)

MS flare-up. "I don't know what to do, but I need time to absorb all of this information. I mean, why should I take medicine I have to inject, and which could make me feel sick!"

Lisa's Study Analysis

MRI has become a useful diagnostic and prognostic tool in MS. The new criteria for diagnosing MS have presented many more people with the possibility that they have MS (McDonald et al., 2001). This is a new area for exploring the meaning of hope, and Lisa presented the nurse with a challenge: How to support a young women's sense of confidence about her body and health without frightening her about the consequences of having MS?

In Lisa's case, the nurse's presence became her anchor. The concept of "being there," of being present, and being available for patients has been well documented over the past decade (Dunniece & Slevin, 2000; Easter, 2000; Gilje, 1992). Nurses' presence provides comfort, caring, healing, and hope for people who are acutely or chronically ill.

In several in-person sessions with Lisa, the nurse explored the reality of the "pictures" of the brain as belonging to her, and the potential meaning of the "spots" to her future health and well-being. The biological, physical, emotional, and spiritual aspects of the self were brought into play to help Lisa realize the implications of the disease in the present, as opposed to the threat it could possibly pose for her future. During several phone conversations, she struggled with the choices for treatment versus doing nothing, and the nurse nurtured her right to self-determination while supporting her thinking with the latest information and findings. Lisa was to make the right decision for herself. She chose an immunomodulating therapy, and although she is not happy because she has to inject herself with a needle, she is happy because she is being proactive.

Mary

Mary is a 15-year-old girl who was newly diagnosed with MS. She and her parents were brought in together to see the nurse after an obviously upsetting session with the doctor, who had just explained the treatment options and plan of care. The father would not sit down and continued to pace the room while using his cellular phone in an attempt to reach the pediatrician who awaited news of the confirmation of the MS diagnosis. Mary's mother was anxious, tearful, and could not stop talking. She fired questions to the nurse and challenged her to make a decision for them regarding therapy. Mary sat quietly as her anxious parents processed what was clearly surprising and upsetting information. Finally, the nurse asked Mary if she had any questions, and she responded, "How old do you think I should be before I think about getting married?"

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Mary's Study Analysis

Denial is a mechanism that may protect hope for those acutely ill or newly diagnosed with an illness. O'Malley & Menke (1988) determined that denial during the initial phase of an acute event protects people from perceptions that are hopeless in nature (such as the long-term threat of severe illness). Miller (1989) also suggested that denial plays a role in maintaining a person's sense of hope during a crisis. Denial helps a person process upsetting information, such as learning that one has MS. Mary clearly demonstrated how useful denial can be. She was not ready to incorporate the MS diagnosis into her life. She was anxious and fearful and needed time to learn.

Adolescents practice distraction-based thinking to maintain internal equilibrium, which deliberately replaces negative and despairing thoughts with cognitive clutter, such as thoughts of marriage. They also comfort themselves by engaging in physical activities or socializing to keep busy. Their coping is often more emotionally focused, especially when they feel that nothing can be done to change the threat (Hinds & Martin, 1988). Mary and her family were counseled over several visits, and immunomodulating therapy was initiated. The plan of care included ensuring that Mary would continue to be socially active and maintain a sense of normalcy. A support group for teenagers with MS was organized through the local chapter of the National MS Society, and Mary and her parents have found solace in this ongoing process.

Barbara

Barbara had a relapsing–remitting course of MS when she entered a clinical trial of a new product for MS several years ago. Within 2 years, she transitioned to a secondary progressive course of the disease, demonstrating weakness in her legs, urinary urgency and incontinence, and cognitive changes. She was taken out of the relapsing–remitting trial to become eligible for a trial for secondary progressive MS. Participating in clinical trials gives people renewed hope, not only for their personal health, but also for the good of others with MS. When recruiting people with MS, the nurse can incorporate hope into the conversation and use it as a tactic to help people decide on whether to participate in the study. The investigator can present the positive aspects of the drug under study while dispelling any false hopes a person may have about how the product will affect his or her disease.

Barbara's Study Analysis

Barbara's transition from a relapsing–remitting course of MS to a progressive form posed new challenges for her and her family. Together with the nurse, her family developed a plan of care that included physical

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therapy, the use of assistive devices and equipment, occupational therapy, and speech and cognitive retraining. Home renovations were also suggested to improve Barbara's independence and enhance her quality of life. Education and counseling sessions over the course of a month helped give Barbara and her family insight and direction to move ahead with their lives.

On the last visit, Barbara brought in a gift for the nurse, a jar with "HOPE" embossed on it. She said that she greatly appreciated the hope the nurse had given her, and she wanted to leave a symbol of the good work achieved together. Today, the jar holds notes from patients who want to write something hopeful for others to read. Often a new patient will take out a note and find comfort in the words of someone in the same situation. In this way, people with MS are sharing healing messages with one another in an anonymous, but thoughtful way.

Joan

Joan has advanced MS. She is quadriplegic, has severe ataxia and a head tremor, and is incontinent. Joan lives at home with her husband and two 12-hour home attendants. She has two grown sons, one of whom is engaged to be married. She is competent to make her own decisions. Joan has been referred by the nurse for a speech and swallowing evaluation, but she is resisting. She states that she does not want a feeding tube in place because eating and shopping are her only pleasures in life. She does not keep the appointment.

Joan's Study Analysis

In situations such as this, the nurse is faced with a dilemma. Strategies to reinforce hope in this patient would include education and counseling regarding safety and the prevention of serious complications. However, Joan is choosing the moment and taking things 1 day at a time. Her family is supporting her decision. Fraser (1999) found that hoping in the moment may be appropriate for people like Joan because they fear the future and the uncertainties that surround the illness. Hopes and dreams of recovering at some point in the future undergo a transition to focusing on the present. Reframing the experience promotes a sense of self-control, and this in and of itself renews hope.

Three months later, Joan is admitted to the intensive care unit (ICU) because of severe pneumonia caused by aspiration, and she becomes ventilator dependent for 1 month. When she is weaned from the ventilator, she is told she has to have a percutaneous endoscopic gastrostomy (PEG) in place if she wants to go home. She now agrees

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because she wants to “live to see my son get married.” This behavior supports Fraser’s (1999) notion that hope shifts as people move through an experience for long periods of time. Joan is now able to look ahead and plan for the future because she has a goal and something to look forward to.

Kando

Kando is an MS nurse in a busy multidisciplinary practice, who wears many hats: clinician, educator, administrator, researcher, and consultant. The patient mix on a day-to-day basis includes early, stable, and uncomplicated patients with MS, those who have “collected” disability over time and are progressing, and those who are severely disabled and arrive at the center on stretchers. Each patient has multiple needs and wants, which draws energy and vitality from the nurse. The nurse’s challenge becomes how to maintain a balance between providing the necessary patient care, while preserving what is needed for the self.

Kando’s Study Analysis

The good news about MS nursing is that it is a process; patients and families are cared for over long periods. The nurse can deal with priorities at the time of the visit, plan for follow-up care, and implement various nursing measures over time. In this way, the nurse maintains a sense of control, making a sometimes overwhelming situation much easier to manage.

Inspiring, sustaining, and restoring hope must be integrated into gestures, tone of voice, smiles, touch, and words of wisdom. The nurse can only inspire hope when he or she has a sense of personal hope. Each day, each experience must take on some meaning, which enriches the spirit and keeps the nurse wanting more. The evolution of the nursing experience becomes a hopeful means of merely getting through each day. Having something to look forward to each day is an important and helpful way to keep hope alive, even during moments of stress.

MS nurses have one another; nurses who care for people with MS are keenly aware of what another MS nurse’s day is like. The sense of empathy and compassion among MS nurses is a vital resource within the field. The peer support and nurturing provides a mechanism for inspiring, sustaining, and restoring hope for ourselves.

Self-care is vital to fostering personal hope. Exhibit 2.2 lists several important strategies for caring for the self. A healthy, harmonious, and happy nurse is the key to a successful career and personal life. Let hope always be a guide.

EXHIBIT 2.2 ■ Self-Care Strategies for Nurses Who Care for People With Multiple Sclerosis

- Savor each moment.
- Exercise regularly.
- Eat nutritiously.
- Network with peers.
- Rely on others for guidance when in doubt.
- Use your confidante.
- Nurture supportive and reciprocal relationships.
- Know your limitations.
- Expand your knowledge base.
- Be inventive.
- Share your expertise.
- Pamper yourself (massage, facials, manicures, pedicures, etc.).
- Try deep breathing, relaxation, yoga, and meditation.
- Give yourself something to look forward to each day.
- Take vacations.

CONCLUSION

Hope is a powerful resource for coping. Nursing care directed toward helping people with MS to hope can make a significant difference in the healing process. Keeping hope alive within the self is essential to practicing the art and science of MS nursing.

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Educating the Patient and Family

June Halper and Nancy Joyce Holland

*J*udy was diagnosed with multiple sclerosis (MS) 2 years ago. She is a 25-year-old single woman who graduated with a law degree but is currently not working. She has not returned for care for more than a year, and when she does, she appears quite upset. When questioned by the MS nurse, she relates that she does not understand why she needs to be seen. She will eventually end up in a wheelchair no matter what she does. Her great-aunt had MS and she sees nothing but disability in her future. She has no reason to seek treatment; she sees no quality of life ahead for her.

INTRODUCTION

Nurses are increasingly emphasizing wellness and quality of life over disease orientation. This is especially important for individuals with a chronic disease or disability, who face a lifetime of dealing with its ramifications. Unlike acute illness leading to either recovery or death within a brief period, chronic conditions have long-term implications for all aspects of living (Nortvedt, 1999; Rudick, 1992).

The quality of life perspective moves the person with MS out of the patient role, which identifies the medical team as leader and expert, and into the decision-maker role, which identifies the individual as the controlling force of his or her life. This gives the individual with MS the ultimate decision-making power over proposed health-related and life-planning strategies. Quality of life is important to individuals with chronic disease, their families, and health care or service providers because it represents the individual's judgments about how the illness and related interventions affect everyday life (Rudick, 2008; Stuijbergen, 1992).

The quality of life construct has been interpreted as having several different but related meanings by various authors. Life satisfaction and well-being are prominent concepts (George, Okun, & Landerman, 1985; Klemmack, Carlson, & Edwards, 1974; Padilla & Grant, 1985). Salamon (1988) contends that there is universal acceptance of life satisfaction as a valid

measurement of quality of life. A recent concept analysis of quality of life identified a positive view as encompassing satisfaction with one's life and acceptance of one's life circumstances (McDaniel & Bach, 1994). Several instruments are available to assess quality of life in people with MS, including the "Multiple Sclerosis Quality of Life Inventory" (Ritvo et al., 1997).

Consistent with the theme (the Morgante conceptual framework of hope) that has been integrated into this work, patient and family education should be designed with quality of life in mind. The purpose of patient and family education should not only increase knowledge but also contribute to each person's vision of how he or she would like to live a life with the "unwelcome visitor" MS with which to cope.

Through a consensus-building process, the National MS Society (NMSS) identified three main areas that contribute to quality of life: MS knowledge, health, and independence. These categories extend thinking beyond the physical and emotional well-being of the person to also encompass changes that might be necessary in the environment. An MS employment specialist may be needed to perform a job analysis and partner with the employer and employee with MS to make job accommodations essential for continued employment. Legal assistance may be needed in this area or to facilitate removal of environmental barriers in the community. The Disability Community criticizes the "medical model" for only working to "fix" what is wrong with the person, not realizing that the missing piece is "fixing" the environment and attempting to impact the societal attitudes that prevent full functioning of the person with disability outside the medical or rehabilitation setting.

Acquisition of the MS knowledge base needed to deal effectively with the disease is the focus of this section. Health issues related to physical management, emotional needs, and family relationships or social support are addressed in many sections throughout this book. Independence— independent living, long-term services, employment, and accessibility—is addressed through programs offered by the many organizations serving the MS patient community who have formed the multiple sclerosis coalition (www.multiplesclerosiscoalition.org).

PATIENT EDUCATION FACTORS

The need for factual information about MS is the most basic element for enhancing quality of life for the person with MS and is crucial to the success of all other quality of life goals. The dissemination of information through educational programs can often have a major impact on the person with MS and his or her family. Such programs can effect the desired behaviors

that will support health and minimize the negative features of a chronic, potentially disabling disease (Mazzuca, 1982). Nurses play key roles in this effort because they develop individualized and dynamic nursing plans during each patient encounter (Leino-Kilpi & Luoto, 2001).

In the dissemination of such knowledge, the nurse often has the primary role with patients and family members. A survey of people with amyotrophic lateral sclerosis (ALS) at the University of Kansas Medical Center demonstrated that patients saw the role of information provider as one of the major functions expected of a nurse (Beisecker, Cobb, & Ziegler, 1988). It has also been determined that educational aids must fit patient needs based on age, diagnosis, developmental stage, culture, and educational preparation (Murphy, Chesson, Berman, Arnold, & Galloway, 2001).

To ensure that the patient will continue to acquire necessary information and skills on a lifelong basis, the nurse needs to facilitate an independent learning orientation, which can be achieved through self-directed learning techniques. Self-directed learning emphasizes empowerment and suggests fairly independent activity. Giloth (1990) notes that although the process is not well-defined, most patient education programs do encourage patients to be actively involved in decision making and care delivery.

Duchin and Brown (1990) note that “patients with diabetes are ultimately responsible for their disease management, but many patients with diabetes do not have the necessary knowledge or skill” (Duchin & Brown, p. 255). This statement pertains to individuals with MS as well.

Education goals for individuals with MS include:

1. Understanding the diagnosis;
2. Successful coping with its potential impact on one’s life;
3. Integrating treatment regimens into one’s lifestyle;
4. Planning regarding critical areas such as relationships, parenting, employment, and lifestyle; and
5. Preventing potentially disabling outcomes with specific goals related to new symptoms.

Should the disease progress, the process needs to be adjusted so that appropriate goals are developed relative to the person’s changing condition. DeSouza and Ashburn (1988) note that planning, which begins at diagnosis, must be consistently followed throughout the course of the disease.

An internationally recognized thought leader in adult education has stated that “learning is an elusive phenomenon” (Knowles, Holton, & Swanson, 2005). Knowles defined education as an activity undertaken

or initiated to effect changes in the knowledge, skills, or attitudes of individuals, groups, or communities. In contrast, Knowles has stated that learning emphasizes the person in whom the change is expected to occur and is the act or process by which knowledge, skills, and attitudes are acquired (Knowles et al.).

C. B. Easterling (personal communication, 2008–2009) has asserted that the roles and activities of MS nursing are well suited to patient and family education. The bond that is created between the MS nurse and the patient and family is based on mutual trust, respect, and acceptance in that the ethos of MS nursing:

- Respects patient and family individually
- Respects and accepts the patient's right to choose
- Considers health beliefs, values, ethnic and cultural backgrounds
- Promotes empowerment and well-being.

Knowles (1980) has differentiated adult learning (andragogy) from childhood learning (pedagogy), and these definitions are important considerations when nurses are developing educational programs or tools for their patients. He states that andragogy is a theory of adult learning in which the adult assumes responsibility for what is learned and adults learn better when the material directly relates to their lives. Pedagogy is based on the art and science of teaching children where the teacher has full responsibility for making all decisions about what is learned (Knowles pp. 1, 60).

C. B. Easterling (personal communication, 2008–2009) has stated that learning is successful when the learner feels the need to learn; the learning environment is characterized by acceptance; the learner participates actively in the learning process; and the learner feels that there has been progress toward his or her goals.

When providing information to the person with MS, principles applicable to adult education can facilitate the learning experience (Lawler, 1986). Six principles that have relevance to working with people with MS are:

1. *Adult education includes and builds on the experience of the participant.* Most people with MS do not have prior knowledge about the disease. However, all adults have had experience that required coping behavior. These existing styles should be considered in learning activities relative to coping with MS. According to Knowles (1980), “. . . adults have a richer foundation of experience to which to relate new experiences (and new learnings tend to take on meaning as we are able to relate them to our past experience)” (p. 50).

2. *Adult education fosters critically reflective thinking.* Critical reflection, according to Mezirow (1990), is an “assessment of the validity of the presuppositions of one’s meaning perspectives, and examination of their sources and consequences” (p. xvi). A component of this, self-reflection, describes one of the three domains of learning (Mezirow, 1981). Critical self-reflection is defined as “assessment of the way one has posed problems and of one’s own meaning perspectives” (Mezirow, 1990, p. xvi). Issues such as self-esteem and self-image, which are particularly important to people with MS, can be addressed by the process of critical self-reflection, leading to critical analysis of assumptions (attitudes, values, beliefs, orientations).
3. *Problem posing and problem solving are fundamental aspects of adult education.* According to Lawler (1988), problem posing and problem solving refer to “learning which involves examination of issues and concerns, transforms content into problem situations and necessitates analysis and development of solutions” (p. 48). In relation to adult education, Knowles (1980) points out that the motivation of most people who seek out adult education comes from the desire to improve their ability to cope with the problems they currently face in life. Therefore, their frame of mind is problem or performance centered.

MS can present problems in all aspects of daily living. Therefore, the process of looking at problems, analyzing their components, and deriving solutions is crucial for people with MS and their families, and is relevant to the self-directed learning process.

4. *Learning for action is valued in adult education.* Action is often a direct consequence of problem solving and, therefore, closely related to the preceding principle. Learning that can be translated into action is important to address the physical, emotional, and interpersonal problems presented by MS.
5. *Adult education empowers the participant.* Lawler (1988) stated that adult education designed to empower the participant is “learning which facilitates an awareness that one possesses the means to influence or change his or her environment” (p. 50). Brookfield (1985) defined “genuine” adult education as including activities that assist adults in their efforts to establish a sense of control over their lives, within their interpersonal relationships, and societal roles.
6. *Self-directed learning is encouraged and enhanced in adult education.* Encouragement of independence in action and thought is believed by some to be a crucial component of adult learning activities (Lawler, 1986).

Some view these adult education principles as having greater application within a more formal classroom setting with a facilitator present. However, in the education of persons with MS, the health professional

often fulfills the role of a facilitator. An understanding of these principles by the patient can also help shape subsequent educational activities, particularly self-directed learning efforts.

LIFE SPAN ROLE DEVELOPMENT PERSPECTIVE

Effective adult learning is also dependent on the age of the patient and his or her stage of growth and development. Knowles et al. (2005) describe the stages of life development that have been identified by other researchers. These include early adulthood (17–45 years old), middle adulthood (40–60 years old), and late adulthood after the age of 60. By understanding the changes and transitions in adults' lives, MS nurses can tailor their educational strategies to meet the needs of their patients and families. Knowles et al. has stated that adult education must be designed to:

- Anticipate learning needs that arise at various life points
- Understand how life events facilitate or inhibit learning during a particular situation
- Prepare patients for life changes
- Capitalize on “teachable moments” to accommodate learning
- Plan learning experiences that are meaningful and relevant to each person (p. 223)

THE SHIFTING PERSPECTIVES MODEL OF CHRONIC ILLNESS

This view of chronic illness was developed by Barbara Paterson (2001) through a metastudy (a metasynthesis method) of 292 research studies. The metastudy indicated that living with chronic illness is an ongoing and continually shifting process with an illness- or wellness-in-the-foreground perspective, each having usefulness at the appropriate time. The “illness” orientation focuses on the sick role, suffering, and loss, and creates a barrier to the individual's ability to meet the needs of significant others. However, at the time of diagnosis or appearance of new symptoms, the illness focus helps the person to learn what is needed to deal with the disease, and to adjust to the associated losses. With the “wellness” focus, the self, not the body with its impairments, is the basis of identity. This perspective is attained by learning about the disease, creating a supportive environment, and emphasizing the emotional, spiritual, and social aspects of life, rather than the disease (Paterson, 2001).

One aspect of a supportive environment can be the self-help group. Bonding of the group members creates an atmosphere of trust and car-

ing, as well as a useful forum to learn about products, techniques, and interventions that have worked for other people, and how to best make them successful. Most groups have a strong social component, with members extending some relationships beyond the group experience. This helps keep wellness in the foreground.

There is some evidence that health care professionals and others can facilitate the shift from an illness to a wellness perspective. In one study, people with diabetes deliberately selected clinicians whose focus was wellness, or who had a wellness-in-the-foreground perspective (Patterson & Sloan, 1994). Nurses who are aware of this model can support the appropriate perspective that will facilitate learning at each stage of the individual's illness.

THE INTERNET

Within a short period, electronic communication and information technologies have changed society in general, including how people learn. There has been an "information explosion," and one projection is that information will soon double every 20 months (Whitson & Amstutz, 1997). Others have speculated that half of what professionals know when they finish their formal training will be outdated in less than 5 years (Merriam & Caffarella, 1999). Professionals clearly need to escalate their efforts to stay current. For people with MS, their families, and those connected with other chronic diseases, the Internet is a comprehensive and private means of gathering very specific disease-related information.

We need to understand that the Internet is just one of many ways to acquire MS information but an increasingly important information resource.

There are many sources of information available free through the Internet on the World Wide Web (WWW). Dozens of sites regarding MS can be reached by entering the key words "MS" or "multiple sclerosis" on the search engine. Because the WWW is an open medium, some sites will contain inaccurate information. Some reliable Web sites are listed here:

- National MS Society (<http://www.nationalmssociety.org>)
- Multiple Sclerosis Society of Canada (<http://www.mssociety.ca>)
- Consortium of MS Centers (<http://www.ms-care.org>)
- United Spinal Association (<http://www.unitedspinal.org>)
- International Journal of MS Care (<http://www.ms-care.org>)
- Paralyzed Veterans of America (<http://www.pva.org>)

- National Family Caregivers Association (<http://www.nfcares.org>)
- National Rehabilitation Information Center (<http://www.naric.com>)
- Multiple Sclerosis Association of America (<http://www.msassociation.org>)
- Multiple Sclerosis Foundation (<http://www.MSFoundation.org>)
- Multiple Sclerosis International Federation (<http://www.msif.org>)
- Multiple Sclerosis Coalition (<http://www.multiplesclerosiscoalition.org>)
- International Organization of MS Nurses (<http://www.iomsn.org>)

In addition, social networking sites such as Facebook, Twitter, and Plaxo, to name a few, are helpful in networking patients and families throughout the continent and, frequently, throughout the world.

Living “optimally” with a chronic illness, such as MS, involves several levels of awareness and adjustment, both for the person diagnosed with the condition and for the family members who experience the illness as part of the family unit. These levels include:

1. Emotional or psychological
2. Physical
3. Interpersonal or social

Emotional factors are identified first because a minimal level of acceptance must be present before information will be assimilated and acted on. Beyond acceptance is the ongoing process of adjusting and coping, which, according to LaRocca and Kalb (1987), “. . . is not a simple, one-time event. For each individual, adjustment gradually evolves during the course of the disease” (p. 210).

Successful adjusting or coping permits the individual to explore additional areas of information or pursue new skills that will support psychological growth, reduce symptoms, prevent disabling and/or life-threatening complications, and continue to develop satisfying interpersonal and social relationships and activities.

To reach emotional, physical, and interpersonal levels of awareness involves learning by the individual. According to Mezirow (1990), “learning may be defined as the process of making a new or revised interpretation of the meaning of an experience, which guides subsequent understanding, appreciation, and action” (p. 1).

Understanding certain underlying concepts is key in the ability to learn needed behaviors and skills. Such concepts include the disease process, symptoms and therapies, prevention of complications, nonmedical therapies, coping strategies, family issues, work issues, equipment and services, community resources, financial aid, and arresting disease progression.

A STUDY OF LEARNING AND MULTIPLE SCLEROSIS

Two small studies were done to see if there was any relationship between stages of MS, degree of disability, what topics the participants' learning included (one study assessed people with MS, the other family members), and what areas they thought were most important (Francabandera, 1992; Holland, 1992). The patient sample consisted of 18 women and 8 men who were clients at an MS clinic in New York City. The purpose of the study was to identify possible trends, realizing that the sample was not a representative of people with MS in the general population. There was some difference in areas addressed at different time frames in the disease process. The topics pursued by most people with MS in the early stage (5 years or less since diagnosis) included the disease process, symptoms and therapies, prevention of complications, coping strategies, and community resources. Interest in the disease process remained high for intermediate duration (6–10 years) and moderate for long-term MS (more than 10 years). Most subjects in the intermediate and long-term stages sought to learn about halting disease progression, and almost all sought information about symptoms and therapies and the prevention of complications. Coping and community resources were high in the early stages, and coping again was high in long-term MS.

Questioning health professionals and reading were by far the most frequently used modes of learning, regardless of the stage of MS. Self-directed learning about the disease process was mostly accomplished by reading, whereas arresting disease progression was pursued with health professionals. Information about coping strategies and family issues was obtained mainly through informal (experiential) learning and individual and group counseling. People with early and intermediate MS used individual and group counseling and agencies more, whereas people with intermediate and advanced MS used videos more often than their counterparts with early MS. This pattern may be changing because of increased use of videos by all groups, as home video viewing continues to increase in the population at large.

Coping and family issues were most notably pursued by those with severe disability. Otherwise, little difference was found in learning content as a function of degree of disability. This highlights the need to promote coping and family content areas with those newly diagnosed, at a time when this information might guide efforts in these areas rather than later in the disease course, when potentially avoidable problems may already have developed. Another area of concern is the low amount of self-directed learning in the areas of equipment and services by people with moderate disability. Again, the nurse must be especially attentive

to the patient's knowledge and pursuit of information about appropriate assistive equipment and techniques.

Successful coping was identified more frequently as MS advanced, suggesting a greater understanding of coping as the duration of MS increased. Regardless of the stage of MS or the degree of disability, people engaged in self-directed learning for action and to gain a sense of empowerment.

During the course of this study, three themes emerged:

1. *Value of experiential learning.* While experiential learning can refer to planned classroom activities, for the purposes of this study, it was defined as learning from experience, through sometimes unintentional but most often intentional trial and error activities. Study participants spoke about trial and error, relying on oneself to understand or master necessary concepts, and being an expert on the personal experience of living and coping with MS. Participants alluded to trial and error as an important way of experiencing a sense of control over the learning activities. This kind of informal learning involves learning from mistakes, learning by doing, and learning from interpersonal interactions, all of which were reported by participants in the study.

Kolb's (1984) model of experiential learning has two factors: emphasis on here-and-now concrete experience to test abstract concepts and the role of feedback. These features were reflected in the statements of the subjects who applied actual experience to the abstract concepts of coping and symptomatic management and statements of the subjects who applied the feedback of successful versus unsuccessful measures.

Linda explained that much of her coping came from a personal decision to be more independent. She explored various routes of public transportation to select the most accessible.

Fran was discouraged from pursuing exercise by her previous physician: "He said I shouldn't. 'It makes you get tired. It will make you get worse.' And I kind of disagreed with that so I started doing it on my own."

Norma speaks about her own experience relative to coping: "So it's just been a gradual learning over the past 14 years. What to do and what not to do for coping. If you don't know in 14 years what MS is all about, you'll never know."

In a discussion of coping and independence, Henry stated, "I try to be as creative as possible."

Sue gave an example of her self-learning coping: "This is a very simple thing, I just learned it. When you go shopping, you don't go to

the supermarket and then bring everything in. I learned that I just take in the stuff for the refrigerator . . . leave the rest in the car and the next day just bring it in.”

Experiential learning is an important component of the coping scheme for people with MS. The trial and error aspect of experiential learning is a practical approach to problem solving and empowers the individual to perform an activity or function in a more effective or efficient manner.

2. *Avoidance of others who are more disabled.* A popular method of providing information and support for people with MS throughout the course of their illness is the group format. This may take the form of lectures, counseling groups, or self-help or other mutual support networks. Such groups are considered homogeneous because members share a common problem or diagnosis (Seligman, 1982). The benefits of such group experiences are well-documented. People feel less isolated and have the opportunity to develop mutual support networks with others going through a similar distressing experience. However, when questioned about the various learning modes that use a group format, a surprising number of people interviewed for the study were totally opposed to any kind of group interactive experience with others who have MS.

The themes that emerged from the NMSS study on quality of life goals—MS knowledge, health, and independence—add to an understanding of the self-directed learning process used by people with MS to learn about their disease and about ways to deal with it most effectively. Experiential learning strongly enhances empowerment but can limit access to important information if it is used as the exclusive learning mode. Avoidance of others who are more disabled needs to be considered by programmers during the planning process and should be addressed as a potentially negative coping device. Overall, the themes that emerged will add to some unique perspectives in the MS educational program that may be designed for individuals, groups, or entire communities. With advanced technology, learning experiences may extend into homes, facilities located at great distances, and may be archived for long-term use (Caffarella, 2002).

3. *Doctor as embodiment of the MS care team.*

The MS nurse working with Judy spent some time with the patient to determine how she was told about her diagnosis and what contact she has had with the health care system. It appeared that she was told that she had MS over the telephone and did not schedule a follow-up appointment

for quite some time. She feels socially isolated and feels that no one cares about her. Her MS nurse reached out to her several times before she agreed to come to the office to discuss her MS. She has participated in three educational sessions with her MS nurse and has agreed to join a support group with people of her own age. She is now considering initiating self-injection therapy but feels she will need more time to make her decision.

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Providing Advocacy for the Patient With Multiple Sclerosis

Dorothy E. Northrop

Carol V. is 40 years old and lives with her husband and two teenagers in a suburb of a large metropolitan area. Carol was diagnosed with multiple sclerosis (MS) 10 years ago and immediately started on disease modifying therapy. Initially, she felt that she had her life under control and that MS would just be something she had to learn to live with. However, after only a few years she began to transition into a more progressive course. Now she is struggling with significant physical and cognitive issues and knows that she will not be able to remain employed much longer. This reality has created considerable stress for Carol and for her family as they have depended on her income to make ends meet. She is concerned about her insurance coverage, the high out-of-pocket costs she is already facing, and the fact that down the road she may need more care than her family will be able to give. She is depressed, fearful, overwhelmed, and feeling very pessimistic about the future.

INTRODUCTION

A person receiving the diagnosis of multiple sclerosis (MS) is immediately thrust into a new reality—living with chronic illness. Chronic medical conditions require permanent changes in how life is lived, often necessitating accommodation to increased functional limitations and disability. Concerns about health insurance arise. Accessibility may become a paramount issue, determining not only where one can go, but also what health care facilities one can access. Independence can be seriously threatened, both in terms of realistic limitations, as well as limitations that are perceived either by the person or by others.

In light of these challenges, the nursing profession plays a pivotal role in being sensitive to the life-changing issues that the diagnosis of a chronic illness such as MS brings and in providing support to patients as they wrestle with the bewildering array of systems, bureaucracies, and

environmental challenges that confront them. We call this awareness and willingness to support patients and become engaged with them in confronting these realities advocacy.

THE NURSE AS ADVOCATE

Nurses have always been patient advocates. Training prepares nurses to understand health care needs and secure the interventions and supports that their patients require. Enabling, negotiating, mediating, and educating are roles familiar to the nursing profession. Patient advocacy as a concept, however, was not identified in the nursing literature until the mid 1970s. At that time the focus was on protecting and guaranteeing the individual's rights to privacy, information, and refusal of treatment. In the 1980s emphasis was placed on patient rights in health care. Since the 1990s, a primary focus has been the empowerment of patients as consumers and decision-makers (Mallik & Rafferty, 2000).

Nurses working with people with MS frequently find themselves in the role of patient advocate. The unpredictability and variability of this disease, its onset in young adulthood, and the devastating impact it can have emotionally, socially, and financially present enormous challenges, not only to the person with MS but also to the health providers who serve them. Issues are complex, support systems are compromised, and bureaucracies are intimidating. Within this environment, the role of the nurse as advocate is instrumental and critical.

One nurse describes the advocacy role of nurses this way:

Nurses advocate for all patients. We take those in need under our wings, we steer them in the right direction, and sometimes we carry them every step of the way through pain, fear and hopelessness of illness. We do this better than anybody else in the health care system. (Nettina, 2005)

The International Organization of MS Nurses (IOMSN) formally identifies patient advocacy as an organizational responsibility. It considers advocacy a fundamental role of the MS nurse and a commitment that must be shared by all health care providers involved in helping patients along their MS journey. "Health care professionals, and particularly nurses, are in a key position to advocate and to make life easier for people with MS and their families." Nurses must "represent people with MS to help secure their human, legal and service rights" (Namey, 2009, p. 5).

HEALTH INSURANCE

The current health care system of the United States is based primarily on a medical model of care, *curing* illness and *restoring* a patient to functional status (Institute for Health & Aging, 1996). Chronic care has a different focus, emphasizing *maintenance* of function and *minimizing* further deterioration. Set within the context of these contrasting models, the definition of the term *medical necessity* has become a frequent cause of contention and frustration. Therapies and specialized equipment aimed at maintaining health status and preventing or delaying complications have routinely been denied to people with MS, whereas reimbursement for treating complications that arise as a result of those denials are approved. Short-term decisions have affected long-term outcomes.

One would think that with the increasing attention given to disease management in today's health care world, people with MS would benefit from such a philosophical shift that focuses on prevention and the implementation of treatment protocols to reduce complications and health care costs. For conditions such as diabetes and heart disease, disease management strategies work well and established treatment protocols can produce impressive cost savings. But for people with MS, the picture is not as clear and results are not as predictable. MS can progress regardless of what actions are taken. Disease modifying drugs have not been proved effective for everyone. Therefore to argue the financial advantage of expensive medications and interventions in the short run to avoid high costs in the long run can be problematic.

This challenging situation means that people with MS must be empowered to become self-advocates, and nurses are in a unique position to help patients do this. Patients must be encouraged to study their insurance policies and know in detail the specifics of their health care coverage. When necessary, they must know when and how to frame an appeal, and how to engage health care providers in that process. Nurses who have experience with insurance company procedures can often assist patients in the process of challenging a denial. A nurse can also serve as a powerful advocate and spokesperson in negotiating with health plan case managers and other decision makers within the health care system.

People with MS may also need guidance and support in dealing with a change in their health coverage, whether evaluating employee health plan options at open enrollment, changing employment, purchasing an individual policy, or retiring into the Medicare system. It is not easy to compare health plan benefits and calculate the cost of premiums versus potential out-of-pocket costs. Nurses can be very helpful to patients as they struggle with these very difficult decisions.

Patients also need to be reminded about their primary medical care needs and how important it is to make sure they have adequate health coverage for their non-MS conditions. Sometimes focus can be so much on MS that screening procedures and preventive health care for other conditions are neglected. In a study supported by the Agency for Health Care Policy and Research, patients with disabilities were less likely than those not disabled to receive preventive care services (Agency for Health Care Policy and Research, 1999). The nurse can have a vital role in ensuring that patients receive the most comprehensive medical care possible.

The system of health care today is a source of great frustration to many people with MS. Although most have some form of insurance coverage, most are underinsured and their policies are inadequate to meet the varied and specialized health care needs that MS presents. The most frequently cited unmet needs for people with MS include medications, home care, rehabilitation services, and coverage for specialists, counseling, and durable medical equipment.

It is often perseverance alone that will make a difference in whether a particular therapy or intervention is covered. It is well documented that filing appeals and grievances is effective in reversing denials. But people with MS are tired and discouraged. It is often the nurse who can encourage patients not to take “no” for an answer and to pursue all of their options and opportunities for reconsideration.

LIFE PLANNING AND LEGAL DIRECTIVES

Chronic illness requires long-term planning. Financial advisors and attorneys specializing in estate planning and elder law are important resources to people with MS and should be considered as part of the team of professionals addressing patient issues. It is important that nurses recognize that patients need to develop plans and strategies for the future. Nurses must become knowledgeable of the legal documents and financial options available and be comfortable encouraging patients to pursue this information, whether or not they presently have significant disability.

Because of the unpredictability of MS, protecting one’s financial future is of primary concern. Not only do families lose one income if continued employment is not possible, but also they face numerous additional expenses, medical and otherwise, for which there is no reimbursement. It is critical that families maximize and protect their assets. Tax options must be exercised and entitlements secured. Insurance coverage for all family members needs to be reviewed. Trusts may need to be established. Nurses, aware of these various financial options, can encourage patients to use these strategies and can connect them to the National MS Society

where they can receive appropriate referrals. Taking these steps can be so important in assuring a patient's financial security.

There are several legal documents regarding future medical care decisions and disposition of property upon death that also need attention. MS is not considered a fatal illness but the time may come when a person with MS is unable to make an important medical care decision. There is no way to determine at the time of diagnosis the progression or severity of the disease, nor the eventuality of acquiring any other serious medical condition. Because of this lack of control and lack of predictability, it is very important that people with MS prepare themselves for any eventuality. Nurses are in a strategic position to encourage patients to engage in this important, albeit stressful and anxiety-provoking, planning process.

The following are some of the documents which patients should be encouraged to secure.

Advance Directives

Advance directives are documents such as a living will or health care power of attorney that allow a person to state preferences regarding future medical treatment in the event of incapacitation and inability to communicate. These documents remove questions and doubt from family members and the health care community with regard to the treatment wishes of an individual.

A living will gives specific instructions to health care providers and establishes specific treatment guidelines regarding life sustaining medical treatment. A health care power of attorney or health care proxy designates and entrusts another person, sympathetic to a person's desires, to make medical decisions on a person's behalf, should that person no longer be able to do so. (A living will can often guide the proxy agent in this decision making.). This responsibility includes all medical decisions, not just those that are life-sustaining. A third directive, the do-not-resuscitate (DNR) order, allows a patient or proxy to advise health care providers not to administer cardiopulmonary resuscitation (CPR) should the patient's heart stop.

Power of Attorney

A power of attorney is a written document that appoints another person to act in place of the person who signs the document. This document becomes invalid, however, if the person who signs it later becomes unable to care for his or her welfare. A durable power of attorney, on the other hand, is effective *after* the person who signs the document becomes

incapacitated and gives that designee the power to make decisions in financial or health matters.

Wills

A will is the most common device that people have to control the disposition of their property after death. It outlines how property (an estate) is to be distributed and appoints a person known as an executor to govern the distribution of that property. If a person dies intestate (without a valid will), state laws will determine the division of property.

Trusts

Trusts are another common device used for estate planning. They are more complicated than a will and generally cost more to create. A trust has three components:

- A trustee, who holds the trust property and manages it for the benefit of another
- A beneficiary, for whose benefit the trustee has the responsibility to deal with the trust property
- Trust property, which is held by the trustee for the beneficiary

For those younger than 65 years old with permanent disability, supplemental needs trusts provide a way to maintain assets such as real estate, stocks, or bequests without jeopardizing eligibility for supplemental security income (SSI) and/or Medicaid. Third party trusts allow a family member or friend to create a trust fund to enhance the quality of life of a person with disabilities of any age. People with MS need to be aware of these kinds of financial options.

ENTITLEMENTS

As families dealing with a chronic illness such as MS try to obtain supportive services and benefits for which they are entitled, either in their local community or from state and federal agencies, they are thrust into a complex maze of bureaucracies and regulations that can be totally overwhelming. The fact that MS is an adult-onset disease means that these families are embarking on a road with which they have little familiarity. Nurses working with patients with MS need to become educated on eli-

gibility criteria, income guidelines, and application procedures necessary for families to access a range of services—financial and equipment assistance, Medicaid, home health care, homemaker services, vocational rehabilitation, veteran’s benefits, special transportation, and so forth. Without these supports, many people with MS cannot be maintained in the community. Many times these services are required just to get a person to a physician’s office or clinic for a medical appointment.

In some states there are programs available to protect a spouse from becoming impoverished if their loved one requires long-term care services and must “spend down” to meet Medicaid eligibility. In these situations, the spouse is allowed to retain a basic amount of income and resources to meet ongoing living expenses. This is a very important protection for families, and nurses need to know whether spousal protections are available in their particular state.

Disability insurance benefits are an entitlement, which many people with MS need to access as their disease progresses and they accrue functional deficits. The documentation provided by health care professionals is often the most important determinant whether these benefits will be secured. Whether a patient is applying for Social Security Disability Insurance, or to a private disability insurer, nurses and physicians working with MS patients are instrumental in making sure that the medical documentation that is provided is comprehensive and accurate. The National MS Society has two publications that can assist health care providers in their documentation of disability claims: *Social Security Disability Benefits for People Living with Multiple Sclerosis: A Guide for Professionals* and *Supporting MS-Related Disability Claims to Private Insurers: The Physician’s Role*. Both are available on the society’s Web site (www.nationalmssociety.org).

INTERDISCIPLINARY INTERVENTION

Because of the complex nature of MS and its chronic and unpredictable nature, many psychosocial issues arise during the struggle to live with this disease. Family relationships, financial concerns, employment difficulties, anxiety, fear, cognitive impairment, depression, and the shifting of home responsibilities can all impact a patient’s sense of self and ability to cope. It is often the nurse who is the one to identify these issues and recognize the need for professional intervention and support.

Nurses must be proactive in referring patients to other health care professionals when such intervention seems appropriate. Mental health professionals, vocational counselors, rehabilitation specialists, counseling

groups, and neuropsychologists can be critical in helping a patient manage and cope with his or her disease. Encouraging patients to contact their local chapter of the National MS Society or become involved in their local Center for Independent Living can also help link them to invaluable information and support. In the treatment of MS, quality care means collaborative care. Nurses understand this concept and can advocate for their patients to receive the interventions and supports that they need.

MAKING A DIFFERENCE

Advocacy in behalf of people with MS can be effective only if the nurse is knowledgeable and informed. This includes having a full understanding of MS, its physical, emotional, psychosocial, and financial impact, as well as the medical, health, personal, and social implications of the disease. Knowledge of available community resources, including services and programs available from the chapter and national offices of the National MS Society, is important, as well as the recognition of where gaps in community services exist. There also needs to be an understanding of the function of federal, state, and local government, and how to address legislative and regulatory issues.

In looking back to the story of Carol V., which introduced this chapter, having a nurse as advocate can make a significant difference in how Carol deals with her disease and views her future. Whether it is making sure she is receiving all of the treatments and interventions necessary to manage her symptoms, supporting her through her disease transitions, or helping her to access the entitlements and services available to her, Carol will receive the message that she is not alone, that there are options and decisions available to her, and that she can still exert control over her future and prepare herself for any challenge that might come along.

ADVOCACY IN THE PUBLIC POLICY ARENA

No discussion of nurse advocacy would be complete without including the role of nurses and other health professionals in supporting the rights of people with disabilities. Reaching beyond the medical needs of the individual, disability rights extends into the areas of accessibility, accommodations in the workplace, and access to full participation in the community. It includes access to retail stores, restaurants, movie theaters, religious institutions, and the voting booth. It supports the right of those with chronic illness to have adequate, affordable health insurance coverage and to receive appropriate long-term care services.

Nurses must advocate for the removal of obstacles that limit independence for people with disabilities. This can include obstacles that interfere with receiving adequate medical care such as inaccessible physician offices, high examining tables, narrow doorways, rigid appointment schedules, or lack of knowledge in treating patients with physical disabilities. Nurses can be a powerful voice in reminding all health care professionals of their societal and ethical responsibility to accommodate and individualize the care of patients with disabling conditions.

All of today's health care standards stress patient advocacy, empowerment, and consumerism. Nurses' associations and practice guidelines clearly define the role of nurses as advocating for the health and social needs of the public, and groups such as the The Joint Commission and the Commission on Accreditation of Rehabilitation Facilities (CARF) place emphasis on patient rights. Several major issues facing people with MS are fertile ground for nursing advocacy on a policy level. These include:

- Patient rights legislation
- Patient protections and confidentiality
- Expansion of health insurance coverage
- Broadening of Medicare and Medicaid
- Pharmaceutical assistance programs
- Affordability of long-term care services
- Age-appropriate long-term care services that promote quality of life
- Caregiver tax credits
- Promotion of MS research funding

When advocating for a particular issue, facts are the key. The process is the same, whether one is testifying before a legislative committee or challenging a denial of insurance coverage. State the purpose at the outset, specify the incident, policy, or program being addressed, and provide information on MS and the impact of that incident, policy or program on the patient.

Nurses, perhaps more than any other health care professional, are aware of a patient's right to dignity and self-determination. Their profession is appreciated as a source of advice and guidance on health care reform. Nurses must recognize the unique position that they hold, the power that they possess, and the significant impact that they can have on health care delivery.

Hedrick Smith (1988), in his landmark book *The Power Game: How Washington Works*, said, "Information and knowledge are power. Visibility is power. A sense of timing is power. Personal energy is power; so is self-confidence" (Smith). He could just as easily have been speaking to the

nursing profession. Nurses work not only in offices, clinics, hospitals, and health care facilities, but also throughout the community in governmental agencies, corporations, health organizations, and academic institutions. They function in positions that influence societal change and can impact the future of health care. The nurse is a powerful voice of advocacy.

Nancy met with her clinic nurse and shared her concerns about the future. The nurse listened carefully and made notes summarizing the major issues that were causing anxiety for the future. She asked Nancy to return for a subsequent visit and at that time she provided Nancy with a list of community agencies, Web sites, and printed material for her review. Nancy began to make follow-up appointments with various agencies and individuals to begin realistic planning. She and her husband are working together toward a future that considers her MS, their financial status, and potential resources that would support them in the transition.

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Part II: Managing the Disease and Its Symptoms and Promoting Healthy Coping

CHAPTER 5

Providing Culturally Competent Care

June Halper

Carl S. is a 45-year-old African American man diagnosed with multiple sclerosis (MS) 2 years ago. He has weakness in both lower extremities, diminished truncal sensation, mild clumsiness in both hands, and an ataxic gait. He was told 2 years ago that he had primary progressive disease and was not offered any treatment. He calls your office complaining of severe fatigue; he is sure he is having a relapse. Neurologic examination is without change from his previous examination. His laboratory work is within normal limits. He speaks loudly and is restless in his chair. He states he is going to get worse but feels that he has flu and wants treatment. He states that “no one cares about anything else but MS” and he is not getting treatment for this woman’s disease anyway.

INTRODUCTION

As described in the Morgante conceptual framework of hope, the changing epidemiology of multiple sclerosis (MS) has resulted in the need for MS nurses to develop knowledge and skills to provide culturally competent care to patients from diverse backgrounds. The nature of MS, its wide range of impact (pediatric to adult to older population), its variable courses, its spectrum of symptoms, and its broad reach into diverse populations calls for skills and knowledge throughout the patient’s lifetime with the disease. The challenge for MS nurses is to be aware and prepared for the variety and possibility of the disease.

Each person presents with a different personal and medical history and has a different set of symptoms, nature of onset, and disease course. Ethnocultural considerations should be included in our assessments along

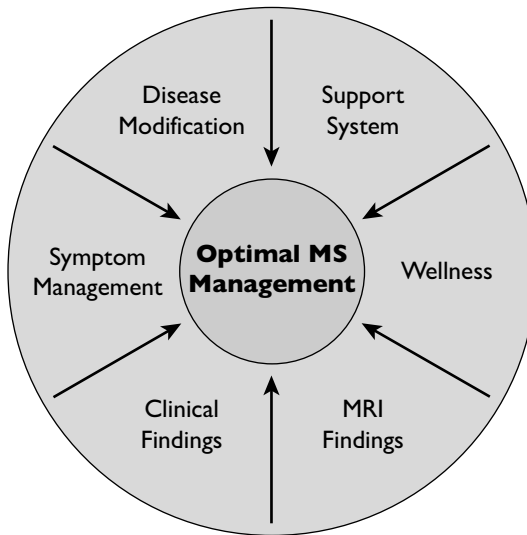
with socioeconomic factors. Patients' needs range from clinical care, to education, to counseling, to rehabilitation, to advocacy, and to culturally sensitive care. There is a need to assess each patient's health literacy; MS may not be in his or her vocabulary. Nurses need dynamic and flexible tools to empower himself or herself to individualize care for each patient. New models of care and new concepts are required to address these needs along with creative ways of intervening. Included in these concepts are the medical home, the need for culturally competent care, and familiarity with the mores of the population with disability.

THE CONCEPT OF A MEDICAL HOME

The comprehensive needs in MS may call for new models of care, one of which is the concept of the medical home. First conceived in 1967 by the American Academy of Pediatrics' (AAP) Council on Pediatrics, it was originally used to define a place, a single source of all medical information about a patient. It actually refers to health care that is accessible, family centered, coordinated, comprehensive, continuous, compassionate, and culturally effective (Sia, Tonniges, Osterhus, & Taba, 2004). Principles of the patient-centered medical home include the following:

- Each patient has an ongoing relationship with a health care team trained to provide first contact, continuous, and comprehensive care
- The team of individuals collectively takes responsibility for ongoing care of the patient
- There is a whole person orientation including all stages of life and all stages of illness and wellness
- Care is coordinated and integrated across all elements of the complex health care system
- Care is facilitated by registries, information technology, health information exchange, and all means to ensure culturally sensitive interventions
- Quality and safety are the hallmarks of the medical home (American Academy of Family Physicians, American Academy of Pediatrics, American College of Physicians, & American Osteopathic Association, 2007)

This concept is very consistent with the comprehensive MS care model that has been emerging worldwide since the mid-20th century. Comprehensive MS care seeks to provide optimal services in a cost-effective and coordinated fashion, individualized to each person, and avoiding duplication and overlap of care (see Figure 5.1).

FIGURE 5.1 Optimal Multiple Sclerosis Management

Developed by Kathleen Costello, RN, MSCN, NPC

CULTURALLY COMPETENT CARE

How does one define culture? It has been defined as learned beliefs, values, behaviors, attitudes, and customs shared by a group. Culture implies the integrated pattern of human behavior: thought, communication, customs, beliefs, values, and institutions of a racial minority or social group. Competence implies having the capacity of function effectively.

Teaching techniques will need to be modified, and materials will need to be created, to target the specific ethnic entities. Cultural sensitivity courses and seminars that address adult education issues are available for professionals. The variety of learning styles is also important. Consider one-to-one in person, print, videotape, audiotape, group program, and Internet as an array of choices. Today, topics are covered in an assortment of modalities, and options often exist regarding various MS-related topics. Professional practices must also consider cultural beliefs of the patient along with cultural practices of each person when drugs or therapies are prescribed to patients of different backgrounds (Dawson & Lighthouse, 2010).

Easterling (2008–2009) has described a model that recognizes cultural diversity in MS that she has described as the transcultural assessment

model that recognizes and respects cultural and health care literacy. Principles implicit in this model include that the MS nurses:

- Recognize every individual as unique
- Identify literacy level and those “at risk”
- Identify cultural health practices and beliefs
- Plan culturally based learning experiences
- Use materials using different languages when appropriate
- Use visual aids
- Use concrete rather than abstract words
- Invite questions
- Avoid the use of complex medical terminology when possible

Nursing strategies to facilitate learning under this model include that the nurse must validate brief information in writing and use humor cautiously. Nurses should avoid the use of slang words. One should not assume that smiles or nods mean learning understanding. It is important to include the family, when possible, in planning and learning sessions. Finally, it may be appropriate to use interpreters to improve the patient’s and family’s understanding when language causes a barrier to communication.

Purnell developed the Purnell model for cultural competence with the following precepts:

- All cultures share similarities
- One culture is not better; they are just different
- Cultures change slowly over time
- Difference exists within, between, and among cultures
- Culture has a powerful influence on patients’ reactions to illness and interactions with the health care system (Purnell & Paulanka, 2005)

Purnell defines cultural competence as understanding biological variations and effects of medications and disease processes in different ethnic groups (Purnell & Paulanka, 2005). It is also the ability to perform cultural assessments that lead to the development of individualized and holistic care that is sensitive and respectful with awareness of the differences between cultures. Domains of culturally competent care are cultural awareness, cultural knowledge, cultural skills, cultural encounter, and cultural desire (Campinha-Bacote, 1998).

Key practice points for MS nurses in developing cultural competence, in addition to exploring the background of each patient, is to

conduct self-examination of one's own biases toward other cultures and ethnic groups in the process of self-awareness. It is equally important to explore one's own cultural heritage and upbringing as well as one's professional background in the context of dealing with people from other races, religions, and other countries (Nathenson, 2009).

Huber (2009) has developed an acronym that will assist the MS nurse to assess personal cultural competence: **ASKED**.

- **Awareness**—Am I aware of my biases and prejudices?
- **Skill**—Do I have the skill to conduct a culturally based physical assessment sensitively?
- **Knowledge**—Do I have knowledge of the patient's worldview?
- **Encounters**—How many encounters?
- **Desire**—Is my desire genuine?

Huber (2009) goes on to describe key questions to ask while doing a cultural assessment. Queries such as "What do you think caused your problem?," "What do you think made it start?," "What does your sickness do to you?," "How long do you expect it to last?," "What kind of treatment do you expect?," and "What results to you hope to see from your treatment?" will assist the nurse to identify the patient's perceptions of his or her illness and expectations from this and future encounters. This knowledge and sensitivity will allow the MS nurse to realistically plan and implement current and future interventions.

It is equally important to acknowledge cultural dissonance, a sense of discomfort brought on by the patient's mores and beliefs. This is very difficult to negotiate and may cause interference with therapeutic relationships. Cultural dissonance can cause a nurse to impose his or her own values on others with what has been defined as "cultural blindness" and result in misunderstood expectations (Huber, 2009).

The question is, how can one overcome this problem? Several strategies have been suggested by Huber. These are:

- **Cultural preservation**—supporting the use of scientifically sound, cultural practices (acupuncture for pain management)
- **Cultural accommodation**—supporting the use of cultural practices that have not proven harmful (yoga, meditation, worry beads)
- **Cultural repatterning**—working with a patient to help change habits that are harmful (e.g., herbal therapies contraindicated with prescription medications) (Huber, 2009)

In 2009, the National Quality Forum endorsed 45 practices to guide health care systems toward better patient outcomes. These included culturally appropriate care, patient-centered care, enhanced communication, community engagement, workforce training, and practices appropriate to each diagnosis. They endorsed the national voluntary consensus standards that included that one should determine and document the linguistic needs of patients at the first point of contact and periodically. There was also consensus on the need to implement workforce training to address patients' cultural needs along with maintenance of demographic, cultural, and epidemiological profiles of the patient community to plan for appropriate services. The aim of these standards is to reduce disparities in care, create more patient-centered and culturally competent care, and directly align with the goals of the National Priorities Partnership, a diverse coalition of 28 national organizations representing those who pay for, receive, provide, and evaluate health care. These guidelines can be viewed in their entirety at <http://www.qualityforum.org/>.

THE CULTURE OF DISABILITY

It is important that MS nurses are aware of the mores of the community with disability, which has grown and organized since the late 1960s. Many individuals with MS have joined with this community and have become more vocal about their needs and entitlements. The American With Disabilities Act of 1990 (ADA) has made a significant change in the lives of both the physically and mentally challenged and nurses and all health care professionals must be sensitive to actions and terms that may be offensive to patients and their families. For example, terms such as handicapped, wheelchair bound, MS victim, and mentally retarded are not acceptable whereas disabled, wheelchair user, visually impaired, and someone with cognitive changes do not offend. It is important to avoid the use of labels such as diagnosis rather than the person (MS in Room 1). Patients are not victims or are not their diagnosis; they are experiencing problems because of their MS. ADA etiquette requires that a nurse waits for the person to ask for assistance and uses language that reflects positive views of disability. It is vital that we respect personal space, allow people with speech impairment adequate time to express themselves, and verify that your communication with a cognitively impaired patient is understood. Remember to use simple language with visual aids to explain complex concepts.

CONCLUSION

Successful individualized treatment of special populations in MS calls for ongoing self-awareness, knowledge, and sensitivity about differences, accepting and respecting those differences, evaluating the concordance of your personal beliefs and those of your patients, resisting judgmental attitudes, and being open and comfortable with cultural encounters. This variability in MS patients and their families adds to the daily challenges faced by MS nurses as they strive to meet their patients' needs throughout the spectrum of the disease.

There are important aspects that the nurse should recognize in a man of African American background. Most individuals are comfortable with close personal space. Health care providers should be aware that maintaining direct eye contact may be misinterpreted as aggressive behavior. Most of the younger people are present oriented and relaxed about keeping appointments. Generally, they prefer being addressed by their family name as a sign of respect.

The MS nurse working with Carl S. sat down with him to discuss why he believes he has flu. He explained that he is weak, tired all the time, and walking is getting more difficult. His cousin had flu and was treated. Now his cousin is feeling better. The nurse then asked Mr. S. what his understanding about his MS is. He was unable to describe his disease and was convinced that it was "all in his head" because no one had any treatment for him. The nurse then used pamphlets and charts to define MS in user-friendly terms and then discussed treatments that might help Mr. S's fatigue and walking difficulty. She also made another appointment to go over community resources including support groups that might help Mr. S. Mr. S. is now having physical therapy; he is taking an oral medication for his fatigue with "mixed results," and he is seen regularly at the MS practice. The nurse is hoping to enroll Mr. S. in a clinical trial for progressive MS and she is watching the Internet for notice of such a study.

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Managing and Minimizing Symptoms

Randall T. Schapiro and Diana M. Schneider

Beth is a 45-year-old neonatal intensive care nurse who has had multiple sclerosis (MS) for 25 years. She has done fairly well with her MS and, after several attacks early, on has settled down on immune modulating therapy over the past 16 years. Her neurologic examination shows mild spasticity that does not get in the way of functioning and had not required treatment other than a stretching program. She does have significant urgency and frequency of urination with preserved bowel function. Fatigue has been her major disabling symptom. She fits the adage of “but you look so good” very well. Many people have commented on how well she does, but she is exhausted and her quality of life is suffering.

She does not admit much at appointments but, when the fatigue got to an unbearable level, she finally admitted to it. On further questioning, it turns out that Beth not only is an intensive care nurse, the mother of two teenagers, and the wife of a very busy businessman, but she also works at a greeting card shop 3 nights a week.

INTRODUCTION

Multiple sclerosis (MS) may be associated with various symptoms that can occur in almost any combination and vary widely among individuals. These symptoms are managed with both rehabilitation strategies—including physical and occupational therapy—and a range of pharmacologic agents. This chapter focuses on the management of specific symptoms that may develop as the result of the disease process in MS.¹ For each type of problem encountered, appropriate medications and rehabilitative therapies are considered.

¹This chapter is based on Schapiro, R. T. (2007). *Managing the symptoms of multiple sclerosis* (5th ed.). New York: Demos Medical Publishing; and on Schneider, D. M. (Winter 2009). Symptom Management Update. *The Motivator*.

SYMPTOMS OF MULTIPLE SCLEROSIS

Because different areas of the brain and spinal cord are responsible for different movements and sensations, the neurologic symptoms and signs (deficits) are dependent on the location of the lesion (scar). For example, coordination is affected when demyelination occurs in the cerebellum.

Because of the variability of scarring, no two cases of MS are alike. Uncertainty can be one of the major problems in dealing with MS. Studies indicate that if a person is doing reasonably well 5–6 years after diagnosis, he or she will likely continue to do reasonably well. The prognosis is better if the predominant early symptoms are sensory. If the early symptoms and findings include tremor and weakness, the prognosis is not as good and a more aggressive disease management program is in order. Although MS is often thought of as seriously disabling, studies indicate that many patients may have a relatively benign disease pattern, with more than two thirds remaining ambulatory 20 years after diagnosis. Thus, many people with MS may be expected to live relatively normal lives, and some may have only one or two attacks of neurologic deficit.

A specific characteristic of the disease is the presence of clinical symptoms that affect several sensory or motor functions in the central nervous system (CNS), reflecting the existence of multiple sites of damage. Symptoms may fluctuate or steadily progress in severity. Many patients have periods of stability for years, and even those who ultimately progress to severe disability often have long periods of more moderate symptoms.

THE MANAGEMENT OF MULTIPLE SCLEROSIS

Management strategies used to treat MS fall into three general categories: those used to treat the underlying disease by shortening exacerbations and slowing the progress of the disease; those used to minimize and control specific symptoms, such as spasticity, bowel and bladder problems, or fatigue; and those used to address the many nonmedical issues associated with MS. This chapter focuses on the many effective treatments available to manage the wide range of symptoms associated with the disease. It is organized around specific problem areas. By no means do all or even many of the symptoms discussed in this chapter occur in every individual. Virtually all of them, however, do have management strategies that can be used to minimize discomfort and inconvenience.

Many people with MS take multiple medications, and it is important that any health care professional prescribing any new drug know *all* of the medications a patient is currently taking. This is especially important

for those drugs that have either a depressant or stimulant effect on the CNS. Additionally, some drugs are used to manage more than one symptom. For example, some antidepressants are also effective in managing fatigue, and several agents that are originally developed as antiseizure medications are helpful in managing pain and spasticity. It is important to note that many, even most, of the medications used to manage the symptoms of MS were first developed for use in other conditions or for the same symptom in people who do not have MS. As a result, these drugs are often used on an off-label basis.

SPASTICITY

Increased tone and resistance to movement produce spasticity in MS. In the extreme, spasms become prominent and are often quite uncomfortable. Spasticity tends to occur most frequently in the muscles responsible for maintaining upright posture, the antigravity or postural muscles.

Increased muscle tone may require a great amount of energy to be expended on performing everyday activities such as walking, transferring, and performing other activities of daily living. Reducing spasticity can produce greater freedom of movement and strength, frequently accompanied by less fatigue and increased coordination. The major ways in which spasticity is reduced include stretching, ROM exercise, aerobic exercise, and the use of medications. When spasticity does not respond to these measures and is clearly uncomfortable, a surgical procedure may be necessary.

Because spasticity may be worsened by a variety of other MS symptoms and non-MS-related conditions, it is important that spasticity be managed as part of a comprehensive strategy. Common MS symptoms that contribute to an increase in spasticity include fatigue, stress, heat, urinary tract and other infections, and pain. Therapies designed to relieve these symptoms may result in significant improvement in spasticity.

Stretching and Range of Motion Exercises

The simplest and often the most effective way to reduce spasticity is *passive stretching*, in which each affected joint is slowly moved into a position that stretches the spastic muscles. Once the muscles reach their stretched position, they are held there for about 1 minute to allow slow relaxation and to release undesired tension. With the person lying on his or her back, begin stretching at the ankle to stretch the calf muscle, then proceed upward to the muscles in the back of the thigh, the buttocks, and the groin and, after

turning from the back to the stomach, stretch the muscles on the front of the thigh.

Range of motion (ROM) exercises differ from stretching exercises in that the movement about the joint is not held for any specific length of time. Although ROM is important, holding the stretch is significant, and patience in doing the stretches is essential. An independent stretching program based on some of the same principles used in physical therapy can be used at home.

Exercising in a pool may also be beneficial because the buoyancy of water allows movements to be performed with less energy expenditure and with more efficient use of many muscles. We recommend using the pool for both stretching and ROM exercises, which consist of easy, slow, rhythmic, and flowing calisthenics that allow most of the joints of the body to move through their full stretching range. The pool temperature should be cool to lukewarm, about 85°F; this may feel cold to some, but warmer temperatures produce fatigue and cooler temperatures may result in shivering.

Many people with MS have limited ROM in at least some joints and muscles, and the key to managing spasticity is to expand the number and kind of movements that can be performed. The exercises should be done using minimum effort.

Spasticity may also be reduced by the use of relaxation techniques that involve a combination of progressive tensing and relaxing of individual muscles, accompanied by deep breathing techniques and imagery.

Mechanical Aids

Specific devices can be made for individual patients to counteract spasticity and prevent contractures. For example, a toe spreader or finger spreader can be used to relax tightness in the feet and hands and to aid mobility. Braces (orthoses) for the wrist, foot, and hand can be made to maintain a natural position and to prevent limitations on movement and deformities. For example, an ankle-foot orthosis (AFO) can be made to place the foot at many different angles to the ankle. A good orthotist can make the brace alleviate stress on the knee with hinges in the material to add to its flexibility. All orthoses should be customized to allow for maximal benefit.

Medications

Baclofen (Lioresal) is the most common antispasticity agent used in MS, and most patients respond well to it. The dose must be carefully determined for each individual; too little will be ineffective, whereas too

much produces fatigue and a feeling of weakness because the drug interferes with the proper degree of stiffness needed for balance and erect posture. The correct dose is usually determined by starting at a low level and slowly increasing the amount until a maximum beneficial effect is achieved. The most common error when taking baclofen is to abandon it before it has reached the dose necessary to obtain proper relaxation. That dose may be as low as 5 mg per day, but as much as 40 mg four times a day may be necessary in some patients.

Tizanidine hydrochloride (Zanaflex, Zanaflex TM), available in capsule form, has effects on spasticity that are similar to those of baclofen. It produces greater sedation than baclofen but less weakness, and may therefore be a useful medication for those in whom sedation is less of a concern than weakness. The starting dose is usually 2–4 mg daily, but dosages of up to 36 mg each day may be necessary to achieve the desired effect. The half-life is such that spreading the dose out is important to gain the maximum activity.

Gabapentin (Neurontin) is an anticonvulsant that has antispasticity properties. It is an excellent adjunctive medication when dosed up to 3,600 mg each day at 4–6 hour intervals. Several other anticonvulsant medications may also be effective, including carbamazepine (Tegretol), at a dose that normally ranges from 400–1,000 mg per day, and levetiracetam (Keppra).

Another drug that is sometimes helpful in relieving spasticity is dantrolene sodium (Dantrium), which acts directly at the level of the muscle. However, hepatotoxicity limits its use. Spasticity may also be reduced by diazepam (Valium), which is most often used for the relief of spasms that occur at night because its calming effect also helps to induce sleep. Its strong sedative effect limits its use during the daytime. Clonazepam (Klonopin) is closely related to diazepam; its main use has been to treat certain types of epilepsy. It produces significant relaxation and thus may be used as an antispasticity medication. Like diazepam, it sedates and is therefore best used at night. When using diazepam and clonazepam, both the physician and the person with MS must keep in mind the potential for chemical dependency.

Another drug commonly used for spasms in the muscles of the back is cyclobenzaprine hydrochloride (Flexeril). This medication acts quite specifically on such spasms, but may settle limb spasms as well. It usually works best when used in combination with another spasticity medication. Any of these drugs may become less effective when taken for a prolonged period as tolerance may develop; it may be necessary to stop taking them for a time, after which they may again become effective.

People with MS occasionally develop paroxysmal or tonic spasms, in which an entire arm or leg may draw up (flexor) or out in a stiff, clenched, or extended (extensor) position. Carbamazepine is generally used to control such spasms, although baclofen and gabapentin may also be effective. Cortisone may decrease spasticity in general and is effective for paroxysmal spasms when used on a short-term basis; its long-term use is not advocated because of numerous risks.

Painful nighttime spasticity may also be treated with dopaminergic agonists, ropinirole (Requip), pramipexole (Mirapex), and carbidopa/levodopa (Sinemet), originally developed for use in Parkinson's disease and also used to treat restless leg syndrome.

Physical Interventions

Botox and Myobloc (Botulinum Toxin)

Botulinum toxin type A (Botox, Myobloc) is administered by injection into a muscle (or muscles) that is involved in severe spasticity and has almost completely replaced the phenol blocks used earlier for spasticity. It temporarily blocks the nerves that lead to specific muscles, for a period of months. The drug should only be administered by an experienced physician or other health care provider. Side effects may include unexpected weakness.

Baclofen Pump (Intrathecal Baclofen)

Another approach to the management of severe spasticity involves the use of a pump to deliver baclofen (Lioresal) directly into the spinal canal. A tube is placed in the canal, then connected (underneath the skin) to the pump placed in the abdominal region, through which the drug is delivered into the spinal canal at prescribed levels. The pumps can be programmed by computer via radio waves so that the dose can be changed as needed. For some patients, this technique may provide relief of intractable spasticity. Because the doses of baclofen needed with this approach are so low (micrograms), side effects are also low and there is almost always a significant decrease in fatigue and malaise. This treatment is aggressive and expensive, and it should be reserved for those with severe spasticity that cannot be adequately managed by oral medications.

The most frequent complications of this therapy are catheter malfunction and infections, with weakness being a problem in people who are ambulatory.

Surgical Procedures

In rare instances, spasticity that does not respond to standard pharmacologic management strategies requires irreversible surgical procedures, which involve cutting nerves to specific muscles that do not respond to the procedures discussed previously.

TREMOR

Tremor is one of the most frustrating symptoms to treat in MS. There are many different kinds of tremors: Some have gross oscillations, others are fine; some occur at rest, others occur only with purposeful movement. Some tremors are fast, others are slow; some affect the limbs, whereas others may involve the head, trunk, or speech. Some tremors are disabling, others are merely a nuisance; some are treatable, but unfortunately others are not. As with all symptoms, because of this wide variation, proper diagnosis is essential before correct management decisions can be made.

The Pharmacologic Management of Tremor

The most common tremor seen in MS, and also the most difficult to treat, occurs as the result of demyelination in the cerebellum, which results in a slow gross tremor (intention tremor) and occurs with purposeful movement of the arm or leg.

This type of tremor is almost always exaggerated during times of stress and anxiety, so one approach is treatment with drugs that have a calming or sedative effect. Hydroxyzine hydrochloride (Atarax) and hydroxyzine pamoate (Vistaril) are antihistamines that may settle a minor tremor that has been magnified by stress. Clonazepam (Klonopin) and buspirone (Buspar) may also decrease a tremor via their sedative effects. The antitremor effect must be balanced against the generally unwanted effects of sedation by carefully monitoring the dosage until the desired effect is achieved. Gabapentin (Neurontin) may be effective.

Propranolol (Inderal), a beta blocker, is helpful in controlling some tremors seen in MS. The effect may not be great but even a small decrease in tremor may allow greater function.

Some studies have shown that the anticonvulsant primidone (Mysoline) may alleviate this difficult symptom. Although it is heavily sedating, low doses may be worthwhile. Acetazolamide (Diamox) is a diuretic that has some antitremor properties and may be of value in selected patients.

Because a component of spasm is often involved in gross tremors, baclofen (Lioresal) may provide some relief. The potential but reversible side effect of weakness must be balanced against the tremor-reducing effect of the drug, again by careful adjustment of the dosage.

Ondansetron (Zofran), originally developed as an anti-nausea drug, may decrease tremor in some patients. Isoniazid (Laniazid, Nydrasid), originally developed to prevent or treat tuberculosis, may be effective; its mechanism of action is unknown. It may alleviate gross tremors that are influenced by posture. It is sometimes worth a trial if tremor is especially incapacitating, but toxicity to the liver must be monitored.

Other Treatments for the Management of Tremor

Drugs are not the complete solution to the management of tremor. Physical techniques provide another approach. Physical treatments fall into three general categories.

Patterning is a technique used by physical and occupational therapists to trace and repeat basic movement patterns. It is based on the theory that certain muscles can be trained to move in a coordinated fashion by repeatedly using the nervous circuit involved in a movement. These normal movements are guided and assisted by the therapist until they become automatic. Minor resistance is then added and removed while the patient repeats the patterns independently. The muscles appear to gradually develop increased endurance for these learned movements and manage to retain control when the patterns are applied to functional tasks.

Immobilization is the placement of a rigid brace across a joint, fixing it in one position and dampening the severity of a tremor by reducing random movement in the joint. Bracing is most helpful in the ankle and foot, providing a stable base for standing and walking. It may also be used for the arm and hand. The desired position of function is defined by the tasks that are to be facilitated, such as writing, eating, or knitting; the brace is used to immobilize the arm or hand for these tasks and then removed.

Weighting involves the addition of weight to a part of the body to provide increased control over its movements. The underlying theory behind this approach is that more muscles will be used to stabilize a distant point in the body (hands, wrists, feet, ankles) when a heavier object is involved. This stabilizing action tends to reduce tremor and provide greater sensory feedback to the brain. In practical terms, either the limb itself may be weighted or the object being used may be made heavier, including utensils, pens and pencils, canes, or walkers.

These techniques are used primarily for tremors that affect the limbs. Their goal is to teach the person with MS to compensate for tremor

by providing as much stability for the limbs as possible. It may be important to develop postural adjustments, such as using one's arms close to the body. Adaptive equipment and/or assistive devices that are nonskid, easy to grasp, and stable are helpful and can be used for many activities.

Tremors of the head, neck, and upper torso are more difficult to manage than those of the limbs. Stabilizing the neck with a brace may be helpful.

Tremors of the lips, tongue, or jaw may affect speech by interfering either with breath control for phrasing and loudness or with the ability to form and pronounce sounds. Speech therapy may involve changing the rate of speaking or the phrasing of sentences. Suggestions may be made as to the placement of the lips, tongue, or jaw for the best possible sound production. A simple pace board, a pattern of rectangles set next to each other, may slow the person down and allow for improved understanding. The person points to each square while uttering a single syllable. If he or she can slow down to keep pace with the pointing, a dramatic increase in clarity of speech often results. Pace boards may be simple and effective at virtually no cost. In some instances, tremor may make it impossible to speak, in which case alternative communication devices must be used.

None of these techniques completely eliminates the problem of tremor. The goal of continued function can often be managed by combining some of these therapies.

Because tremor results from damage to axons in the thalamus, it is sometimes treated by thalamotomy, in which a section of this area is destroyed.

Deep brain stimulation, a technique originally developed to treat the tremor associated with Parkinson's disease, has been used in a small study of approximately 40 people with MS but has not yet been approved by the Food and Drug Administration (FDA) for use in MS. It involves implanting an electrode in the thalamus that connects to a wire lead and then to a control device implanted under the skin. Activating the device sends impulses into the thalamus that disrupt the signals that cause tremor.

BALANCE

Balance difficulties are common in MS and can result from a combination of MS lesions in various areas of the brain that are involved in the control of movement; the presence of weakness, tremor, and fatigue in the muscles involved in walking; as well as by symptoms such as visual problems and numbness. It is possible to improve poor balance by improving

the other symptoms that contribute to it, as well as by various exercise strategies.

Vestibular stimulation involves increasing the amount of stimulation received by the “balance centers” in the brain stem, thus allowing the brain to function more normally. The techniques, which challenge the patient’s sense of balance by rocking, swinging, or spinning, use activities such as sitting on a beach ball or swinging in a hammock.

Along the same lines are exercises performed with a Swiss ball. This large ball may become part of a balance program designed to stimulate the different balance centers within the body.

If a person can stand, computerized balance stimulation via a machine called the Balance Master may be helpful. The person stands on a platform that is in contact with a video screen via a computer. Movements of the feet influence the screen much like a video game, teaching people how to achieve better control of balance.

WEAKNESS

Weakness results from difficulties in transmitting electrical impulses from within the CNS to the muscles as a result of demyelination, usually in the spinal cord but occasionally in the brain.

It is vital that the source of weakness be understood to properly manage it. If weakness is caused by weak muscles, they may be strengthened by lifting weights (progressive resistive exercise). When weakness is the result of poor transmission of electrical impulses, lifting weights may only fatigue the nerve and further increase muscle weakness. For people with MS, it is important to realize that exercises that involve lifting weights or repetitive movements of muscles to the point of fatigue do not increase strength; they increase weakness.

A weak muscle that is not stimulated at all will atrophy. It is important to determine what exercises are appropriate, which will likely require the assistance of a trained physical therapist who has knowledge of both the neuromuscular system and the specific problems involved in MS.

It is impossible to separate the management of weakness from that of spasticity and fatigue. If muscles are less stiff, less energy is expended in movement. Drugs or other treatments that lessen spasticity also frequently increase strength. Similarly, lessening fatigue may also increase strength.

Efficiency is the key to increasing strength in patients with MS. Energy should be conserved and wisely used. This means using one’s muscles for practical and enjoyable activities and planning the use of time

accordingly; difficult activities should therefore be done before those that are easier to perform. The wise use of assistive devices may also be helpful in increasing overall efficiency.

Strength may also be increased with an aerobic exercise machine such as an Exercycle or a rowing machine. The principle of not becoming fatigued and exercising those muscles that can be strengthened to compensate for the weaker muscles must be applied. Exercise in general is good, but the wrong exercise may be harmful.

Although drugs have generally been ineffective at treating weakness, long-acting fampridine, 4-aminopyridine (Ampyra) has been approved by the FDA to improve walking and lower extremity weakness and will be taken at a dose of 10 mg once to twice per day. It is a potassium channel blocker that is believed to improve nerve conduction in demyelinated nerves.

FATIGUE

Fatigue is one of the most common and annoying problems for people with MS. People with MS can experience normal fatigue, the fatigue of depression, the fatigue of disuse, and the fatigue of neuromuscular overuse. However, the term *MS fatigue* refers to a lassitude or overwhelming fatigue that often comes on suddenly can come at any time of day and without warning. It is difficult for others to understand because it is not a visible symptom. Several strategies and medications may be helpful.

Because fatigue can result from various metabolic and hormonal conditions, sleep deprivation, depression and anxiety, and various medications—both those used to manage other symptoms of MS and those used for non-MS-related problems—a comprehensive evaluation should be the first step in addressing this issue and developing a management plan. Occupational therapists are in many ways efficiency experts, and their advice on planning, work simplification, and performing activities in the most efficient manner can help relieve fatigue. Allowing for frequent rest periods is also helpful for rejuvenating the mind and body to enhance overall performance. Stress management techniques and an appropriate exercise program—especially aerobic exercise in moderation—also may be helpful.

Many people see a pattern to their fatigue; for example, it is often experienced most in the afternoon. They can learn to plan their activities to take advantage of those times when they tend to have the most energy and to pace their activities to allow for rest periods. An occupational

therapist can help individuals learn energy conservation strategies that will allow them to balance activity and rest, so that they can enjoy those things that matter the most to them.

Because many people with MS are heat sensitive and find that their fatigue is increased in hot weather or in warm indoor environments, various cooling techniques may be useful. These include swimming in cool water, taking cool drinks on warm days, using air conditioning, and using a cooling vest.

Several drugs have been used effectively to manage fatigue. Many of them were first developed to treat other disorders such as alertness or depression.

Modafinil (Provigil) and armodafinil (Nuvigil) may be effective in the management of fatigue. It promotes wakefulness and was originally developed to treat *narcolepsy*, a neurologic condition associated with uncontrollable daytime sleepiness. Amantadine, a generic medication previously available as Symmetrel, is an antiviral medication used to prevent or treat influenza that has also been used in Parkinson's disease. Its mechanism for relieving fatigue in some individuals with MS is unknown, although it may increase brain levels of dopamine.

Methylphenidate (Ritalin), originally developed as a treatment for attention deficit disorder, has also been used to manage narcolepsy. It has proven useful for managing fatigue in some people with MS. Because it may cause difficulty sleeping, the last dose should be taken before 6 p.m. Dextroamphetamine (Dexedrine) is also used to improve wakefulness, boost energy, and decrease fatigue. The side effects of these drugs are similar and include nausea, dizziness, insomnia, constipation, high blood pressure, and rapid heart rate.

Selective serotonin reuptake inhibitors (SSRIs) including sertraline (Zoloft), paroxetine (Paxil), and fluoxetine (Prozac) may alleviate symptoms of fatigue as they relieve depression.

Caffeine, taken as coffee, tea, or caffeinated soda, also can be helpful in managing fatigue.

AMBULATION

Mobility impairment is frequently associated with MS. It is fitting that the section on ambulation follows those dealing with weakness, spasticity, and tremor because walking becomes difficult as the result of these impairments.

If walking becomes impaired, a practical means to accomplish the same goal should be substituted, hopefully without too much emotional

trauma. People value being ambulatory far beyond its true value and often believe that it is “giving in” to the disease when they are unable to walk without help. They must be encouraged to consider the positive aspect of having their ability to participate in daily activities restored to them through the use of a mobility aid.

When foot muscles are weak, foot drop results, in which the toes of the weak foot touch the ground before the heel, thereby disrupting balance. As discussed in the section dealing with weakness, there is no way to strengthen a weakened foot, and compensation techniques become essential.

It is particularly important to wear proper shoes. A leather-soled oxford is recommended. The tie gives maximum stability to the foot, and the smooth leather sole prevents the sticking that can occur with crepe soles that throw the walker off balance. A plastic (polypropylene) insert is often added to the shoe to keep the foot from dropping. The lightweight brace, an AFO, picks up the foot and allows it to follow through in the normal heel-toe manner.

AFOs can also be designed to decrease spasticity by tilting the foot to a specified angle and keeping it from turning in or out (inverting or evert-ing). The proper use of AFOs decreases fatigue while increasing stability.

A metal brace that fits outside the shoe may be needed if there is a significant increase in tone (stiffness) at the ankle. This is a spring-loaded device that keeps the front of the foot from dropping. Newer electrical stimulators of the peripheral nerves of the leg may be appropriate for specific individuals who have foot drop without hip weakness.

If the hip muscles are also weak, the leg will swing out in front to allow the foot to clear the ground. To maintain stability, the knee is often forced back into hyperextension, which puts significant stress on the knee. After a period of time, the knee begins to hurt and may become swollen as the result of arthritis. To prevent this condition, a metal device called a *Swedish hyperextension cage* can prevent the knee from snapping back. Alternatively, a custom-made knee brace may be necessary.

Walking with less fatigue may again become realistic with the aid of such devices. If balance is also a problem, another assistive device such as a cane may be needed. Two canes may be needed if weakness is pronounced in both legs.

If balance and weakness are more severe, it may be necessary to use forearm (Lofstrand) crutches. Forearm crutches provide greater stability than a standard cane, and their use does not require as much strength in the upper extremities.

If walking is still difficult or impossible, a wheelchair may be the correct choice. A three-wheeled scooter chair can be a boon for people

with MS because it does not carry the stigma associated with a regular wheelchair. Although extremely useful, a scooter is best used by those who have retained some means of walking, as the seating system of a scooter is not designed for all-day sitting.

Those who do not possess the ambulatory skills necessary to use a three-wheeler appropriately may achieve independence using a light-weight motorized wheelchair. A standard manual wheelchair often does not offer the person with MS sufficient independence because of the fatigue generated by operating the chair and the coordination necessary to control it. The key in choosing a chair or scooter is *independence*. The proper device should be selected to regain control and independence in the environment. Help from a physical therapist or a physician who understands the use of the chair is necessary to select the most appropriate one.

PREVENTING IMMOBILITY

People with MS are too often told to rest and not overdo, and the fear of fatigue becomes almost unbearable. There is no real basis for this fear. People with MS are not fragile! Proper exercise leads to increased fitness and less fatigue. The process is slow, and it begins with a carefully developed exercise prescription. Like medicine, it should be prescribed by a professional, usually a physical therapist or a physician, who knows how to tailor the exercises to the individual.

The exercise prescription should have four elements:

1. The type of exercise (aerobic, strengthening, balance, and stretching)
2. The duration of exercise (how long to exercise)
3. The frequency of exercise (how often to exercise)
4. The intensity of exercise (how hard to exercise)

The role of exercise in MS has become somewhat controversial, partly because the meaning of exercise is misunderstood. To many, exercise is defined as stressing one's body to the point of pain, an approach whose watchwords are "no pain, no gain." But in MS it has become quite clear that if one exercises to the point of pain, fatigue sets in and weakness increases.

Rigorous exercise also increases core body temperature. Because the protective shielding of the nerves has been destroyed in MS, this rise in temperature increases short-circuiting in the CNS and further increases weakness. This is undoubtedly why exercise originally fell into bad repute with those knowledgeable about MS.

Our understanding of what is good exercise for people with MS and how they should train has increased considerably in the past few years as the concept of *fitness* has developed. Fitness implies overall health. It is a holistic concept that strives for improvement in the function of the heart, lungs, muscles, and other organs and is attained by adhering to a proper diet, not smoking, and exercising appropriately.

Two major concepts underlie the term *appropriate*. First, because of the wide variability of the disease, what is good exercise for one person may not be good for another. It is important to tailor an exercise program for each individual rather than to have a set program for everyone who has MS. The second factor is that there are many kinds of exercise—not just those that involve running, jumping, or similar activities.

Exercises that increase mobility through stretching and maintaining ROM play an important part in combating weakness by reducing the stiffness that is so common in MS. As discussed previously, balance exercises are helpful in managing tremor. Relaxation exercises are particularly helpful in reducing stress, which can increase weakness; relaxation techniques must be considered a part of any overall program designed to reduce weakness and fatigue.

Moderate aerobic exercises, which may involve a bicycle, rowing machine, or treadmill, or brisk walking, running, or use of a self-wheel in a wheelchair, will all result in a slow but definite increase in endurance.

The proper exercise prescription takes into account that each exercise should not bring on pain. “No pain, no gain” is absolutely the wrong approach to exercise for the person with MS. The proper exercise prescription is a balanced one that includes many different types of exercises with the goal of improving overall condition.

PAIN

MS may be associated with various symptoms characterized as pain, and more than half of all people with MS will experience pain in one form or another during the course of their disease. In addition to the types of pain experienced by everyone—with or without MS—some types of pain are directly related to the MS process itself, whereas others are secondary to the physical effects of MS, such as the stress on joints produced by problems such as imbalances associated with walking difficulties.

Dysesthesias are the most common types of pain seen in MS. They are experienced as a burning or aching sensation. The most common drugs used to treat this type of pain include the antiseizure medications gabapentin, carbamazepine, levetiracetam, and phenytoin (Dilantin); antianxiety agents such as duloxetine hydrochloride (Cymbalta), diazepam, and

clonazepam; tricyclic antidepressants such as amitriptyline (Elavil) or nortriptyline (Pamelor); and pregabalin (Lyrica).

Trigeminal neuralgia is a sharp pain in the facial area, often brought on by touch or movement of the face. It can be treated with antiepileptic agents such as gabapentin (Neurontin), carbamazepine (Tegretol), or phenytoin (Dilantin). If drugs fail, a surgical procedure can usually be performed to eliminate pain, leaving a less disturbing numbness in its place. This procedure, percutaneous rhizotomy, can now be performed under local anesthesia with laser technology. Although not the first line of therapy, it is a viable backup. Other neuralgias may affect the glossopharyngeal and sphenopalatine nerves.

Occasionally an unusual electrical sensation is felt down the spine and into the legs when the head is nodded. This momentary sensation, called *L'Hermite's sign*, is usually surprising and disturbing. It is a signal of loss of myelin within the spinal cord in the cervical region but has no significance in predicting the course of the MS. A soft neck collar is often used to prevent the forward movement that triggers the pain.

A common type of pain seen in MS is a burning, toothachy type of pain that occurs most often in the extremities, although it may also occur in the trunk. The same medications used for trigeminal neuralgia are used for these burning dysesthesias, but they appear to be less effective than they are for facial pain. Capsaic acid (Axsain, Zostrix HP) was recently made available; it is safe and can be of value for this type of pain. The cream is applied sparingly three times per day and has few side effects. It creates a different type of burning sensation as it soothes the irritant feeling.

Mood-altering drugs such as tranquilizers and antidepressants may be effective in some cases because they alter the interpretation of the message of pain. A number of such drugs are available, and some relief may be provided with careful manipulation of the type and dosage. Biofeedback, meditation, acupuncture, and similar techniques may help in specific circumstances. Because pain is a symptom that clearly increases in severity when dwelt on, a concerted effort to treat the reaction to pain is an important part of the overall treatment plan.

What *is* clear is that standard pain medications, including aspirin, codeine, and narcotic analgesics, are not effective because the source of pain is not the typical one that occurs with injury. Pain medications are therefore to be avoided; they are ineffective and can be addictive. Pregabalin (Lyrica) and others of the newer anticonvulsant medications appear to decrease neuritic pain. Appropriate dosing is necessary to result in improved pain management significantly.

Various nontraditional therapies may be helpful in managing pain associated with MS. These include acupuncture and acupressure, guided imagery, biofeedback, and yoga or tai chi.

Although MS pain may be severe and bothersome, it usually does not lead to decreased ambulation and is not a predictor of a poor prognosis. Studies have shown that people who have these sensations as the major feature of MS do better than average in movement activities.

Low back pain is one of the most common symptoms treated by the neurologist, so it is therefore not unexpected that it is also relatively common in people with MS. MS itself rarely causes low back pain; it is more commonly caused by a pinched nerve or other problem. This situation occurs fairly frequently because abnormal posture or an unusual walking pattern resulting from MS places stress on the discs of the spinal cord, causing slippage of the discs and compression of one or more of the nerves as they leave the spinal cord.

Obviously, heavy lifting and inappropriate turning and bending may compound the problem. Such movements irritate the spinal nerves, causing the muscles on the side of the spinal column (the paraspinal muscles) to go into spasm; it is this spasm that causes low back pain. If a spinal nerve is significantly irritated, the pain may extend down a leg to the muscles in the leg that are innervated by that nerve.

If the problem is one of poor walking posture, the pattern needs to be corrected; if spasticity contributes to the problem, it must be lessened. Local back care with heat, massage, and ultrasound waves are frequently helpful, and exercises designed to relieve back muscle spasm may be recommended. Drugs designed to relieve back spasms may also be used, and some arthritis medications are frequently useful. If the problem is the result of a faulty disc, surgery may be needed to relieve the spinal irritation.

Spinal manipulation (rapid twisting or pushing of the spinal column) is not recommended for the person with MS because it can irritate the spinal cord and increase neurologic problems.

It is critical that a correct diagnosis of the cause of any type of pain be made to ensure proper treatment. Diagnostic x-rays, including CT scanning, may be needed to pinpoint the cause of pain, after which the appropriate mode(s) of treatment can be prescribed.

Other types of musculoskeletal problems of an orthopedic nature are commonly seen in MS. Ligament damage may result if there is significant hyperextension of the knee while walking. The knee may swell and become painful. Many orthopedic specialists are unfamiliar with MS and do not understand why this occurs. As a result, they may recommend

exercises to increase the strength of the weak leg. Exercising the leg with orthopedic exercises produces fatigue and increased weakness. A more appropriate approach is to take weight off the leg with an assistive device (cane or crutch). A knee brace may be necessary and helpful to prevent hyperextension.

SLEEP DISTURBANCES

Sleep problems are common in MS. They may be the result of various symptoms such as spasms, urinary frequency, depression, or anxiety, as well as medications used to manage various symptoms associated with the disease. This can lead to the proverbial “vicious cycle” in which symptoms disturb sleep, and the lack of needed sleep in turn worsens various symptoms, such as fatigue.

Various strategies can help manage sleep problems. The following include some fairly simple changes can be very effective in ensuring a good night’s sleep:

- Keeping a regular schedule, even on weekends, can help the body adjust to a normal sleep pattern. People with MS should go to bed and get up at the same time every day
- Fluids should be kept to a minimum in the evening to minimize nighttime trips to the bathroom
- The bedroom should be used only for sleeping and sex, *not* for watching TV or reading
- Exercise should be avoided in the evening; any regular exercise program should be done earlier in the day

Because many MS symptoms can affect sleep—including spasticity, pain, depression or anxiety, and bladder and bowel issues—managing these symptoms can be extremely helpful in achieving better sleep and reducing attendant fatigue.

There are many meditation tapes and other relaxation-oriented approaches to improving the amount and quality of sleep. These can be very effective, especially when combined with better sleep habits and symptom management.

Although the occasional use of sleep medications may be helpful, people with MS should avoid prescription sleep medications, because they lose their effectiveness quickly, are potentially addictive, and do not provide a normal night’s sleep. Over-the-counter diphenhydramine (Benadryl) and diphenhydramine-containing products may be helpful, but should not be used on a regular basis.

SPEECH AND SWALLOWING DIFFICULTIES

Speech patterns are controlled by many areas of the brain, especially the brain stem. Depending on the location of demyelinated areas, many different alterations of normal speech patterns are possible. Most affect speech production and result in *dysarthria*, ranging from mild difficulties to severe problems that make comprehension impossible.

If the cerebellum is primarily involved in speech difficulties, speech generally becomes slow and fluency is diminished. Words may be slurred, but they are usually understandable. If the tongue, lips, teeth, cheeks, palate, or respiratory muscles become involved, the speech pattern becomes even more slurred (dysarthric). In either case, speech therapy can increase both fluency and rhythm. Although exercises are sometimes advocated, they are not usually successful for this type of speech problem. Nevertheless, they may be worth trying. For example, oral motor exercises may be used to maintain muscle coordination.

Tremors of the lips, tongue, or jaw may affect speech by interfering either with breath control for phrasing and volume or with the ability to voice and pronounce sounds. Speech therapy focuses on changes that increase the ability to communicate efficiently. It may involve making changes in the rate of speaking or in the phrasing of sentences.

Pacing and pausing techniques may be helpful if speech is slurred and rapid. Pausing is used between one or two words. As discussed previously, a pace board may be used to initially assist with this technique.

Swallowing problems also fall within the expertise of the speech language pathologist. Bedside assessment substantiated by video swallowing studies may reveal specific problems that have specific treatments. Several compensatory techniques are available to allow more efficient swallowing with less aspiration. The speech pathologist in conjunction with the radiologist can determine the extent of difficulties with various textures of swallowing materials. Trials of swallowing can be visualized to ensure improved function.

VISION

The two major components of effective vision are the ability to correctly image what one sees via proper coordination and strength of the muscles that surround the eye and the ability to control its movements. Both may be affected by MS.

Inflammation and demyelination in the optic nerve produce optic or retrobulbar neuritis, resulting in an acute overall loss of vision with accompanying pain in the eye. This is often managed simply by waiting for the

inflammation to abate, after which function returns. If the problem is sufficiently disabling, cortisone may be given to reduce inflammation. Recent studies indicate that if cortisone is used, it should be administered in relatively high doses. The end results are no better than without treatment but the time needed for a return to usual clarity may be reduced. Nonsteroidal anti-inflammatory drugs may alleviate the pain. It is becoming increasingly clear that not all optic or retrobulbar neuritis requires treatment.

In some cases, vision remains imperfect even after inflammation has been reduced. This is especially noticeable at night when light is dim, although colors may appear washed-out in normal lighting. Leaving a lamp on at night may be helpful. Additionally, there may sometimes be "holes" in the vision, with part of the visual field obscured. This cannot be treated with eyeglasses, which only tend to magnify these areas. The patient can adjust to this problem with time. If visual problems persist, an ophthalmologist who specializes in low vision can help provide low-vision devices that include magnification and computer modifications and also help design various helpful strategies for managing daily activities.

A weakening of coordination and strength of the eye muscles sometimes produces double vision, which can be treated acutely with steroids. Eventually, the brain usually learns to compensate for double vision so that images are perceived as normal despite the weakened muscles. This compensation does not occur if the eye is patched. Patching should be reserved for reading, situations in which there is fatigue, or while driving or performing other essential tasks. Prisms placed into eyeglasses may bring the images together and provide another relatively simple way to manage this difficult problem.

MS can be accompanied by varieties of nystagmus, which is usually more of a nuisance than anything else. Clonazepam and related drugs occasionally decrease nystagmus. Memantine (Namenda) has also been recommended for some with nystagmus.

Cataracts often develop at a younger age in the MS population because cortisone promotes their development. The surgical removal of the abnormal lens sometimes brings about a substantial improvement in vision.

As with all symptoms of MS, significant fluctuations can occur in visual symptoms. Visual acuity often falls whereas double vision increases, with fatigue, increases in temperature and stress, and infection.

DIZZINESS AND VERTIGO

In MS, vertigo usually results from an irritation of brain stem structures that are involved in maintaining balance. The inner ears also play a major role in balance. Disturbance in the conduction of inputs to the

brain from the inner ear may be distressing. Dizziness and the sensation of lightheadedness are less severe than vertigo but nonetheless are uncomfortable. Other diseases that involve these structures produce similar symptoms, so it should not be assumed that they are necessarily caused by MS.

Antihistamines, including diphenhydramine (Benadryl), meclizine (Antivert), and dimenhydrinate (Dramamine), frequently provide relief when vertigo or sensations of dizziness are relatively mild. Vitamin B (niacin) is occasionally used to dilate blood vessels in the hopes that this will reduce the problem. The class of medications that include diazepam (Valium), clonazepam (Klonopin), and oxazepam (Serax) are direct suppressants of the structures of the inner ear that stimulate dizziness. They are potent treatments that should be used judiciously. These medications—used individually or occasionally in combination—provide relief sufficient to allow the patient to continue functioning reasonably well. A scopolamine transdermal patch most often used to treat motion sickness and its associated vertigo may be helpful.

A physical therapist can teach exercises that are effective if dizziness is worsened by positional changes. The therapist determines which positions of the head make the dizziness worse. Therapy consists of holding the head in these positions as long as can be tolerated. If done successfully, tolerance develops and comfort results.

Dizziness frequently accompanies an attack of influenza. When flu and its accompanying fever and muscle aches occur, the symptoms are managed with aspirin or other medication; dizziness often disappears as the flu symptoms abate.

If vertigo is severe and vomiting prevents the use of oral medications, intravenous fluids are administered in combination with high doses of cortisone to decrease inflammation in the region that produces the symptoms—the brain stem area at the base of the brain.

SEIZURES

Seizures occur twice as often in people with MS as in the general population. No studies have attempted to predict which person with MS is more likely to have a seizure, but cerebral involvement may be an indicator. Because MS is a disease that involves the subcortical transmission systems of the brain, patients with significant cognitive disturbances quite possibly are at increased risk for seizures. Febrile seizures also occur when a patient has an infection that is inadequately treated.

Although seizure management in MS is similar to the management of seizures that result from other causes, it often is more difficult to control seizures in these individuals. Treatment may necessitate the use of higher doses or various combinations of anticonvulsant medication.

WEIGHT GAIN

Weight gain can be a problem in MS if a person's activity level decreases but caloric intake remains constant. There are no data indicating that weight gain causes weakness, but it is not good for one's overall health and is unattractive. It can make general movement and aided transfers more difficult than necessary. People who are overweight usually know they are overweight; it does little good to point that out on a continuous basis.

People who use a wheelchair show weight gain first in the abdominal area. Although stomach firming exercises may be of some benefit, it is not usually possible to perform enough repetitions to cause an effective redistribution of weight, and the problem is practically unavoidable.

The same basic dietary guidelines that apply to others apply to people with MS. A balance between exercise, calories, and fatigue must be achieved. This starts with eating smaller meals. Many people find that eating small but frequent meals results in both lower overall caloric intake and greater satisfaction.

NUMBNESS

Numbness and tingling are among the most common complaints in MS, usually as an annoyance rather than as a disabling symptom. Numbness and tingling occur when the nerves that transmit sensation do not conduct information properly, so that one is unable to feel sensations from that area.

Little can be done to treat these sensations, and there is no real need to do so because they are usually harmless. Steroids may improve sensation by decreasing inflammation, but use is reserved for instances of real need.

Focusing on numbness can magnify the problem and make it especially bothersome. The best approach is the realization that it does not indicate a worsening of the disease. A more aggressive approach with cortisone treatments may be considered if numbness involves the hands, impairing fine movements, or the genitalia, making sexual relations difficult. No medications are available that specifically treat numbness.

COLD AND MOTTLED FEET

The complaint of cold feet is common in MS, even in the milder forms of the disease. The maintenance of skin temperature is under the control of the autonomic nervous system; a short-circuiting in the connections that control the diameter of blood vessels and those nerves that sense temperature is responsible for the perception of cold feet.

This symptom can be annoying, but it is innocuous; there is nothing wrong with the circulatory system itself in the legs or feet, and there is nothing dangerous in the slight drop in temperature that produces this sensation. Warm socks, electric blankets, and similar devices are the best way to manage the problem. Niacin or medications that dilate blood vessels may be used to alleviate the symptom when it is particularly annoying.

ANKLE EDEMA

Swollen ankles result from an accumulation of lymphatic fluid, which most often results from reduced activity of the leg muscles. Unless the swelling is extreme, it is usually painless.

Diuretics usually fail to reduce this type of swelling because they cannot stimulate upward movement of fluid. Treatment is relatively simple and consists of keeping the feet sufficiently elevated so that gravity can begin to move the fluid toward the trunk. Support hosiery may help by keeping the lymphatic fluid within normal channels; elastic stockings must be properly fitted to avoid pinching the muscles of the leg. Special stockings are now available that literally pump the muscles, allowing the fluid to be mobilized and carried away; they are expensive and should be reserved for special situations.

Despite continued leakage of fluid, swollen ankles are essentially only a nuisance and not a symptom of a major problem. Swelling may be more noticeable in summer because blood vessels and lymph channels dilate (swell) more when the temperature is higher.

If a cardiac problem exists, swelling may be accompanied by shortness of breath, coughing, and a general feeling of unwellness. If swelling occurs rapidly, especially in one leg, and is accompanied by redness and pain, it is important to rule out the possibility of thrombophlebitis.

PULMONARY PROBLEMS

It is not uncommon for decreased respiration of air to occur with increasing disability. Sometimes this is very subtle, only occurring at night during sleep. It can lead to frequent awakenings and increasing fatigue during

the next day. Because of its subtleness, it is often difficult to identify and a trial of positive pressure breathing may be warranted despite a lack of clear evidence of a specific difficulty. People prone to pulmonary infections should receive pneumonia vaccine as a preventive measure.

GOOD HEALTH

All too frequently, people with a chronic condition ignore the other things that go along with good health. It is important for everyone with MS to have regular physicals and, if female, gynecologic and breast examinations. Everyone with MS should have a primary care physician as well as a neurologist. There is controversy regarding vaccinations and it is recommended that each patient check with her or his neurologist in that regard. Some feel that stimulating the immune system with vaccinations that may not be effective is damaging. Others vehemently disagree with this premise. Despite attempts to study this, no accurate conclusion has been reached.

What *is* clear is that people with MS can and should live relatively healthy and productive lives. MS management has changed dramatically in the recent past and people need to take advantage of these changes in improving their lives.

In discussing her fatigue it appeared obvious to suggest that Beth needed to do some energy planning. It really did not take an occupational therapist to suggest her changing her schedule. However, Beth would not agree to a change at all. She demanded that she continue her full-time nursing, full-time homemaking, and part-time side job. She understood that she was not fragile just because she had MS, but still wanted more energy for a better quality of life.

Further discussion with her husband led to the discovery that she moved about in bed so much that he often had to move to the guest room to avoid being kicked throughout the night. It also turned out that she was up to the bathroom frequently. Beth had tried to avoid any unnecessary medication and had restricted her fluids after dinner but not to the effect necessary to get through the night.

The nurse suggested that she review her schedule and try to accommodate energy saving strategies that she would find acceptable. She was placed on a dopaminergic agonist medication to calm her "restless legs," significantly allowing for better marital relations, and she was placed on an anticholinergic bladder medication, which calmed the frequency down significantly. A bladder ultrasound revealed a small, low residual, and failure to store bladder, which responded so well during the night that she

agreed to take the treatment during the day as well. Her fatigue lessened significantly as her sleep improved and her quality of life improved. Energizing medication was offered for daytime fatigue but held in abeyance for the present.

Many mistakenly believe that most of the MS appointment is spent discussing immune modulation. The reality is that successful MS practitioners are especially good at symptomatic management as that is usually the rate limiting step in the quality of life of an individual.

ADDITIONAL READING

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Managing Elimination Dysfunction

Marie A. Namey

A 39-year-old woman was diagnosed with active relapsing–remitting multiple sclerosis (MS) in 2001. She had been treated with disease-modifying therapies (DMA) but continued to experience breakthrough disease with active magnetic resonance imaging (MRI) scans. She is currently being treated with natalizumab with stabilization of her disease.

She is a wife and a mother of two young children. She works for a rehabilitation service. She has reported an increase in fatigue.

She reports bladder symptoms of “possible incomplete emptying.” She wakes up twice at night to void. She takes a daily anticholinergic medication prescribed by her primary care provider. She performs intermittent self-catheterization (see Exhibit 7.1 and Exhibit 7.2) on occasion. She has not experienced any recent urinary tract infection. She has daily bowel movements.

She admits that her bladder disturbance is affecting her quality of life.

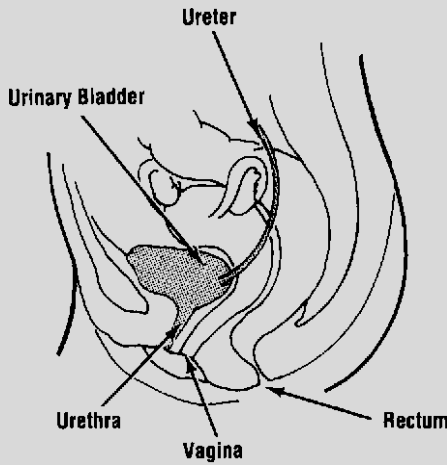
INTRODUCTION

Approximately 80% of patients with multiple sclerosis (MS) experience significant bladder dysfunction at some point in the course of the disease. Reports of bowel problems range from 50–68% of the MS population. Bladder and bowel symptoms can be distressing and may interfere with personal, social, and vocational activities; sleep may also be disrupted. Alteration in elimination patterns can create feelings of loss of control, embarrassment, dependency, and isolation (Nortvedt et al., 2007).

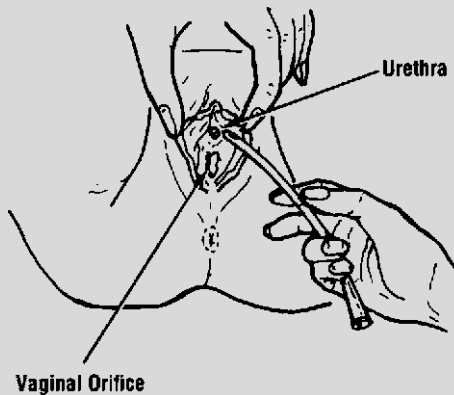
Nursing plays a major role in the assessment and treatment of bladder and bowel conditions. Nursing interventions focus on helping the individual to achieve a predictable and effective elimination plan and to minimize complications. Most bladder and bowel symptoms are

EXHIBIT 7.1 ■ Steps to Clean Intermittent Catheterization: Females

1. Assemble equipment and place in an accessible area. Equipment needed: catheter, water-soluble lubricant, moist towelette or soap and water, and dry hand towel.
2. Wash hands thoroughly with soap and water, then dry.
3. Position yourself comfortably with thighs spread apart. Many women prefer to sit on the toilet or in a chair across from the toilet.
4. Lubricate the catheter end that will go into the urethra. Use Lubri-Wipe or a similar water-soluble lubricant and lubricate the tip and approximately 2 in. of the catheter (lubricant may be optional for women).



5. Slowly and gently insert the catheter into the urethra until the urine begins to flow (approximately 1–1.5 in.). Then insert the catheter about 1 in. farther and hold it there until urine stops flowing.



(Continued)

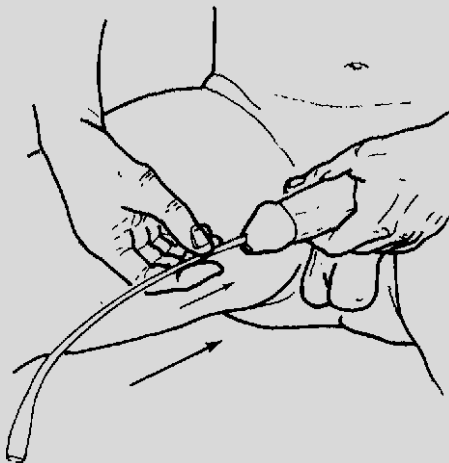
EXHIBIT 7.1 ■ Steps to Clean Intermittent Catheterization: Females (Continued)

6. When urine stops, slowly begin to withdraw the catheter. It is recommended that you slightly rotate the catheter as you withdraw and stop each time more urine drains out.
7. Check the color, odor, and clarity of the urine to be aware of any changes that you may need to report to your doctor or nurse.
8. Never reuse a catheter that appears rough, stiff, worn, discolored, or damaged in any way. Consult with your physician or nurse as to how frequently a new catheter should be used.

Note. Illustrations courtesy of Mentor Urology, Inc.

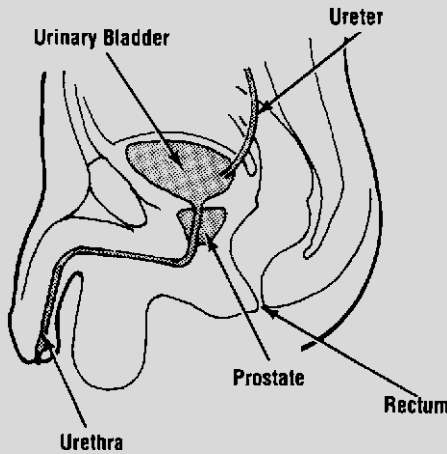
EXHIBIT 7.2 ■ Steps to Clean Intermittent Catheterization: Men

1. Assemble equipment and place in an accessible area. Equipment needed: catheter, water-soluble lubricant, moist towelette or soap and water, and dry hand towel.
2. Wash hands thoroughly with soap and water, then dry.
3. Position yourself in front of the toilet or in a chair across from the toilet. Men may prefer to stand during the catheterization process.
4. Lubricate the catheter end that will go into the urethra. Use Lubri-Wipe or a similar water-soluble lubricant and lubricate the tip and the first 6 in. of the catheter.
5. Hold the penis straight up from the body at a 60°–70° angle from the body. Slowly and gently insert the catheter into the urethra until the urine begins to flow (approximately 6–8 in.). Then insert the catheter about 1 in. farther and hold it there until urine stops flowing.



(Continued)

EXHIBIT 7.2 ■ Steps to Clean Intermittent Catheterization: Men (Continued)



6. When urine stops, slowly begin to withdraw the catheter. It is recommended that you slowly rotate the catheter as you withdraw it and stop each time more urine drains out.
7. Check the color, odor, and clarity of the urine to be aware of any changes that you may need to report to your doctor or nurse.
8. Never reuse a catheter that appears rough, stiff, worn, discolored, or damaged in any way. Consult with your physician or nurse as to how frequently a new catheter should be used.

Note. Illustrations courtesy of Mentor Urology, Inc.

manageable for most patients after proper assessment and intervention. Although nursing research is limited in the areas of bladder and bowel for the individual with MS, a significant amount of information is available from practice.

Normal bladder function and changes caused by MS will be detailed in this chapter. The three common types of bladder dysfunction will be discussed: failure to store, failure to empty, or a combination of these. A step-by-step assessment leading to appropriate intervention will be reviewed. Treatment goals include the following:

- Maintain renal function
- Keep patient dry
- Establish normal voiding patterns

- Reduce symptoms and improve quality of life
- Motivate patient to adhere to treatment

Bowel management issues are also of concern for the individual with MS. Although constipation is common, involuntary bowel movement is particularly distressing. Techniques for assessment and intervention will be reviewed.

BLADDER MANAGEMENT

Normal Bladder Anatomy and Function

The main function of the urinary bladder is to store and expel urine. Urine is continuously produced by the kidneys and carried to the bladder through the ureters. The bladder is a hollow muscular organ and is supported anteriorly and anterolaterally by loose connective tissue attachments to the pubic symphysis and pelvic diaphragm. The trigone and lower portion of the base of the bladder rest on the anterior vaginal wall. The wall of the bladder consists of an inner mucous membrane, with transitional cell lining and underlying lamina propria; a layer of smooth muscle, the detrusor; and an outer adventitial layer of connective tissue.

The urethra has an internal and external sphincter mechanism. The internal sphincter has three components (urethral mucosa, periurethral connective tissue, and periurethral vascular plexus), and each is responsible for one third of the urethral closure pressure. The internal sphincter is composed of small muscle bundles and is not under voluntary control. The external sphincter has those components of the internal sphincter and is augmented by striated muscle fibers that are under voluntary control.

The bladder is innervated by sympathetic fibers from the hypogastric nerve at T-10 through L-2 and parasympathetic fibers from the pelvic nerve at S-2 through S-4. As the bladder distends with urine, its fundus rises into the lower abdominal cavity. To initiate voiding, the urethra relaxes first, then the bladder contracts and expels the urine through the relaxed sphincter. These functions occur automatically (de Sèze et al., 2007; Fowler, Griffiths, & de Groat, 2008).

Average bladder capacity for an adult is 300–500 ml. Initial urge occurs when approximately 200 ml has accumulated in the bladder. Contractions of the bladder are inhibited by the nervous system until at least 300 ml has collected. An individual can sense bladder fullness

and can initiate or postpone emptying as it is convenient. Normally, a person urinates four to six times during a 24-hour period (depending on fluid intake, amount, and type). Generally, our bodies produce approximately 1 ml/min of urine. Although urinary tract infections (UTIs) are more common in women than men, more than one UTI per year is considered abnormal.

For voiding to occur, the valvelike muscle (sphincter) and the urethra relax so urine can pass easily; then the bladder detrusor muscles contract to expel urine through the urethra. As bladder fullness is sensed by the individual, emptying can be postponed by voluntarily contracting the external sphincter until there is a convenient time for voiding.

Problems Occurring With Multiple Sclerosis

Bladder dysfunction in MS is primarily associated with demyelination in the spinal cord, the pontine cerebellar micturition control areas, or other CNS points in between (Andersen & Bradley, 1976; Smith & McDonald, 1999). Interruption of the spinal cord pathways may result in excessive detrusor contractions, involuntary sphincter relaxation or contraction, or detrusor areflexia with urinary retention.

Bladder dysfunction is referred to as *neurogenic bladder* and may produce various symptoms including:

- Urinary urgency: a strong sensation to urinate that cannot be controlled; urination that cannot be postponed until convenient
- Urinary frequency: having the need to urinate more often than every 2–3 hours
- Urinary hesitancy: difficulty initiating the flow of urine; although a person may experience an urge to void, urination may not be easily initiated
- Nocturia: waking up more than once at night to urinate
- Incontinence: losing control of urine; this may be leaking, dribbling, or loss of a larger amount of urine prior to reaching the toilet
- Incomplete emptying: feeling that some urine is left in the bladder after urinating
- UTIs (or cystitis): resulting in classic symptoms of burning or pain upon urination, itching, change in odor or color of urine, pain in the lower back or abdomen, chills, and fever; UTIs can result in a temporary worsening of MS symptoms, or may be the first sign that a person is experiencing a change in the usual bladder pattern; increased lower extremity stiffness or spasticity is often associated with a UTI

The presence of one or more of these symptoms is suggestive of a neurogenic bladder. However, the specific abnormality cannot be identified by the reported symptoms alone.

The three common types of bladder dysfunction in MS are the result of:

- Hypercontractility of the detrusor muscle of the bladder
- Inability of the sphincter to relax and open or detrusor areflexia
- Incoordination of the detrusor and sphincter activity (detrusor or dyssynergia)

Simply stated, bladder dysfunction in MS can result in:

- Failure to store
- Failure to empty
- Combined failure to store or failure to empty (Di Benedetto, Giorgini, Delneri, & Biasutti, 2006)

Similar symptoms may be present in all three types of bladder dysfunction. A patient may report symptoms of urgency, frequency, and incontinence as a result of inability to store or inability to completely empty. In fact, combined bladder dysfunction commonly presents with a mix of symptoms that can be confusing to the practitioner.

Diagnosis of Bladder Dysfunction

A key to accurate diagnosis of bladder dysfunction is obtaining a complete history of bladder symptoms from the patient. Often, it is helpful for the patient to keep a diary of bladder function and voiding for a few days for an accurate report (see Exhibit 7.3 and Exhibit 7.4).

Critical questions to ask to assess if bladder dysfunction is neurogenic or related to other causes include the following:

1. What is your chief concern about bladder function? What bothers you the most about how your bladder is currently working?
2. How often do you void during the waking hours (including voluntary versus involuntary voiding)?
3. How often do you awake at night to void (nocturia)?
4. Do you leak urine when you cough, sneeze, or laugh?
5. Do you experience a strong urge to void that sometimes results in an accident? How often does this occur?
6. Do you feel you completely empty your bladder when you void?
7. Do you find it hard to begin urinating?

8. Do you wear pads or protection? How often?
9. Have you had bladder, urine, or kidney infections? If so, how often and when was the most recent infection?
10. Do you experience pain or discomfort when you urinate?
11. Have you had blood in your urine?
12. What medications are you currently taking?
13. Have you had your bladder function evaluated before? If so, what tests were done?
14. For women: How many pregnancies have you experienced? How many births?
15. Have you had abdominal surgery? If so, what type of surgery, and when? (Abrams & Cardozo, 2002)

After a complete history is obtained, it is important to have the patient spontaneously void and measure the amount of urine voided. A urine specimen for urinalysis and culture and sensitivity should be obtained, either from the spontaneous void or from the postvoid residual (PVR) urine. (It is important to note that a UTI can cause bladder symptoms and change in bladder habits.) If the urinalysis and urine culture are suggestive of a UTI (positive + nitrites; bacteria more than 100,000 colonies of organism), appropriate antibiotic therapy should be prescribed.

Following the patient's spontaneous void, a measurement of a PVR amount is obtained by catheterization or bladder ultrasound. Based on the results of the initial history and bladder assessment, assumptions can be made regarding bladder function and a probable diagnosis and possible interventions can be entertained. Reports of bladder symptoms and a PVR volume of less than 60 ml suggest failure to store syndrome. Often a trial of anticholinergic medications is effective treatment. Reports of bladder symptoms and a PVR volume of less than 100 ml suggest failure to empty. Intermittent catheterization (IC) is a first step in treatment. If symptoms persist with performance of IC, addition of anticholinergic medication may be considered (Fowler & Kalsi, 2006).

It is common that patients experience combined bladder dysfunction and an initial bladder assessment does not provide complete information (see Table 7.1).

Additional Bladder Studies

An ultrasound of the bladder and kidneys can yield useful findings to rule out any structural abnormalities causing bladder symptoms. An intravenous pyelogram (IVP) is a method of outlining the urinary passages

TABLE 7.1 Spectrum of MS Bladder Dysfunction

Diagnosis	Symptoms	PVR	Interventions
UTI	Urgency Dysuria Frequency	Varying amounts	Treat with appropriate antibiotics
Failure to store	Urgency Frequency	<60 ml	Anticholinergic medication
Failure to empty	Urgency Frequency Hesitancy	>100 ml	IC
Combined dysfunction ^a	Urgency Frequency Hesitancy	Inconsistent PVR amounts	Anticholinergic medication and IC

IC = intermittent catheterization; PVR = postvoid residual; UTI = urinary tract infection.

^aCan only truly be diagnosed by urodynamic testing.

and also a test of kidney function. The position of the ureters and kidneys is studied following injection of a radiopaque solution. The ultrasound and IVP are common tests of upper urinary tract function to determine diagnosis or rule out other abnormalities.

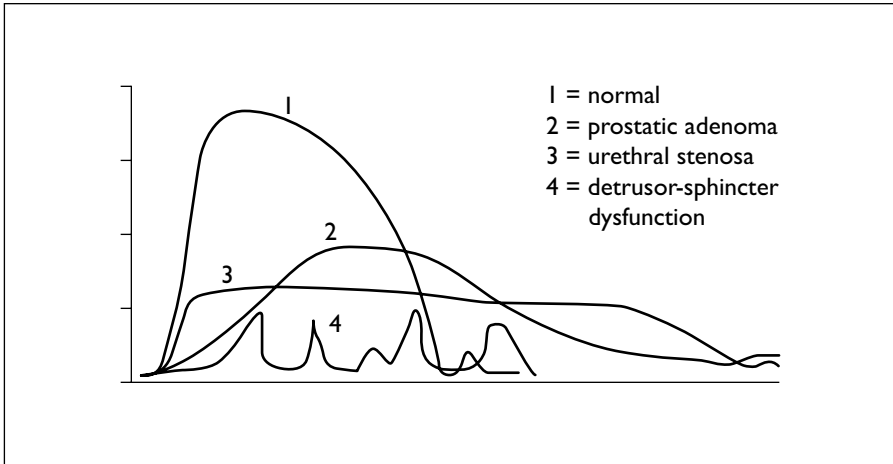
Urodynamic studies clarify the functional process of the lower urinary tract, specifically focusing on bladder function. Urodynamic testing helps to qualify and quantify bladder function. Complete urodynamic testing includes uroflowmetry, the quantitative and qualitative analysis of urinary stream. Uroflowmetry is a measurement of the rate of urination and force of the bladder's expulsive ability. It is the first test of the detailed urodynamic studies, is not invasive, and is easily performed in an outpatient setting.

The patient should be instructed to drink approximately 1 L of fluid 2 hours prior to the evaluation. The patient is then instructed to void into a commodelike device that funnels the urine into a container on a sensor pad. The urine flow rate is measured in milliliters per second and a flow pattern is obtained. Uroflowmetry serves as a "baseline" of the patient's voiding patterns.

A normal flow pattern is represented as a bell curve (see Figure 7.1). The maximum or peak flow is greater than 12 ml/s and the average flow is greater than 8 ml/s. Poor flow pattern, intermittent flow pattern, or explosive pattern are represented.

Generally, poor flow pattern indicates bladder outlet obstruction or deficient detrusor function. Intermittent flow rate indicates deficient

FIGURE 7.1 Uroflowmetry. 1 = normal curve; 2 = significantly decreased maximum flow rate, prolonged flow-increase time, beginning plateau formation in cases of prostatic adenoma; 3 = severely reduced maximum flow rate and plateau formation; 4 = splashlike voiding in cases of reflex bladder detrusor–sphincter dyssynergia.



detrusor function or bladder outlet obstruction caused by anatomic or functional factors. Stress urinary incontinence is a common cause of explosive flow pattern.

The urodynamic pressure flow parameters in the study include bladder pressure, rectal pressure, differential pressure, urethral pressure, flow rate, volume, as well as electromyogram (EMG) sphincter activity. The goals of urodynamic studies are to define the pathophysiology of the bladder and urethra in patients, suggest therapy, and provide a prognosis. Ideally, urodynamic evaluation can be carried out in a setting that reproduces that of the patient’s naturally occurring symptoms. Urodynamic studies are likely to include a filling cystometrogram (CMG), voiding CMG, EMG of the striated sphincter, and pressure flow analysis.

Commonly, sterile water or saline solution is used to fill the bladder through a catheter. Either a single multilumen catheter or two catheters are placed in the bladder. One tube measures intravesical or total bladder pressure (Pves). Additionally, a rectal tube is inserted to provide simultaneous measurement of abdominal pressure (Pabd) evacuation. During filling, the patient is asked to report sensation of filling, initial urge to void, and strong urgency.

A computer recording of cystometric results provides the measurements from the CMG, Pves (the sum of pressure placed against the bladder

from the detrusor muscle and abdominal muscle), and detrusor pressure (PDET). The PDET represents the intravesical pressure produced by detrusor contractions during bladder filling and evacuation.

The filling CMG is accompanied by an EMG of the sphincter muscles. As the bladder fills, muscles are recruited; the EMG sweeps more vigorously as the bladder approaches capacity. Both needle and surface EMG in conjunction with the CMG are helpful in diagnosing detrusor-sphincter dyssynergia (Ciancio, Mutchnik, Rivera, & Boone, 2001).

Depending on the patient's symptoms and the initial nursing diagnosis, various interventions can be recommended to the patient for improved bladder function. The following sections discuss some common interventions.

Bladder Management Interventions

Bladder training, timed voiding, and prompted voiding are behavioral techniques that are often suggested to improve bladder functioning. Bladder training generally consists of education, scheduled voiding, and positive reinforcement. A bladder retraining program requires that the participant resist or inhibit the sensation of urgency to postpone voiding and to urinate according to a timetable, rather than according to the urge to void. Bladder training may also involve tactics that allow the bladder to hold more volume. Initially, the interval goal is set at 1.5–2 hours (this voiding schedule is not generally enforced during sleep). Drinking an adequate amount of fluid at one sitting will generally result in an urge to void within the retraining time frame. Patients need to know that certain fluids, especially those containing caffeine, NutraSweet, and alcohol, are bladder irritants and cause additional urgency with frequency. Eliminating these products or limiting intake can relieve bladder symptoms. For an individual who has MS, the functional difficulty of getting to the bathroom and removing clothes can also cause problems. A voiding schedule can help deter the effects of these functional problems. Absorbent products have proliferated for individuals with incontinence. Protective pads, either disposable or reusable, are worn to absorb involuntary urine flow. These absorbent products include minipads, maxipads, diaperlike garments, shields, undergarment pads, and absorbent chair or bed pads. Absorbent products provide protection and can be a useful and rational way to manage bladder problems. Male external catheters (condom catheters) are available in various sizes and styles. Most external catheters are disposable and indicated for one-time use. Individuals may have a preference for brand types.

Medications have been beneficial in treating bladder problems, including urgency, frequency, and incontinence. Specifically, anticholinergic medications are helpful to block contraction of the detrusor muscle

of the bladder. Various anticholinergic medications have been used to treat bladder symptoms of urgency and frequency. These medications commonly have typical anticholinergic side effects of dry mouth and thirst and constipation.

Desmopressin acetate (DDAVP), an antidiuretic hormone analog, diminishes urine production at night and can reduce or eliminate episodes of involuntary bladder or nocturia (Cardozo et al., 2008; Karram et al., 2009).

Using a Credé method is contraindicated with sphincter hyperreflexia or detrusor–sphincter dyssynergia because of the potential danger to create increased pressure and damage the upper tract. Instead, intermittent self-catheterization allows an individual to empty the bladder at regular intervals and thereby reduce the risk of UTI and structural damage and other distressing bladder symptoms. The use of intermittent self-catheterization was first reported in 1972 by Lapides as an effective therapy for individuals who experience overflow incontinence, sphincter dyssynergia, and urinary retention (Lapides, Diokno, Silber, & Lowe, 1972). This technique of catheterization is preferable to an indwelling catheter because of a lower incidence of symptomatic UTIs, bladder stone formation, and social consequences. The technique of IC has been widely supported in the literature for bladder management in individuals with MS. Basically, an individual is taught to catheterize using a clean technique.

An indwelling catheter may be needed for a short-term treatment. It allows for continual bladder drainage by gravity. Indwelling catheter use should be restricted to individuals whose incontinence cannot be managed effectively by combining the use of anticholinergic medications and IC. The use of an indwelling catheter would also be suggested for an individual with chronic urinary retention that results in frequent UTIs when he or she cannot perform IC. Individuals who have developed pressure sores of the sacral area may use indwelling catheters to eliminate urinary incontinence that may complicate healing of decubitus.

Long-term use of indwelling catheters is a significant source of bacteriuria and UTIs. Management of indwelling catheters varies, but the usual practice is to change the catheter a minimum of 30 days or as needed. If the patient has a symptomatic UTI, the entire system (catheter and bag) must be changed and a urine culture obtained when the new catheter is inserted.

A person with MS may still experience urinary incontinence with an indwelling catheter. In this instance, the indication is not to increase the size of the catheter or balloon but to suggest the use of an anticholinergic medication to decrease spasms of the detrusor muscle of the bladder.

Surgical Procedures

1. Suprapubic catheters have emerged as an alternative to long-term urethral catheter use for female and male patients. The suprapubic catheter is inserted through the abdominal wall just above the pubic bone and into the bladder. This is a minor surgical procedure and involves giving a local anesthetic injected around the area before the insertion. Suprapubic catheters eliminate urethral irritation and carry a lower risk of infection and complications than intraurethral catheters. Consultation with a urologist is recommended before this procedure is undertaken.
2. Sphincterectomy may be recommended for very disabled male patients who experience intractable hesitancy and retention. The use of anticholinergic medications and an external condom catheter can be combined to manage bladder activity.
3. Some female patients with small capacity bladder may benefit from a laparoscopic procedure that includes bladder augmentation with continent diversion. Patients can then catheterize a stoma at the naval or abdomen.
4. Diversion procedures including cystostomy (performed for obstruction of bladder outlet or for males needing long-term indwelling catheter) or transurethral resection (removal of excess tissue of the area where the bladder connects with the urethra) provide a clear passageway for the urine to flow freely. This procedure is used rarely and generally as a treatment for male patients.
5. Another treatment for bladder instability is injection of botulinum, a toxin, into the detrusor muscle. This intervention can help restore continence with few side effects. The improvement of bladder function can last up to 9 months; injection of botulinum is repeated at intervals to maintain bladder control.

BOWEL MANAGEMENT

Normal Bowel Function

Normally, communication from the brain through the parasympathetic nerve center located at S2–S4 to the rectum and anal sphincter results in defecation. When sensory nerves are stimulated because of a bowel filled with stool, the message sent to the brain is interpreted as an urge to defecate. If it is convenient to do so, the internal anal sphincter is voluntarily relaxed and stool is allowed to pass. However, if it is not an appropriate time to defecate, the external anal sphincter is kept tonically contracted until the defecation reflex is suppressed and the reflex disappears for several hours. Then, at an appropriate time, the person can stimulate the

defecation reflex by abdominal straining. However, abdominal straining is not usually as effective as a natural reflex.

Elimination of stool is actually accomplished by the aid of the Valsalva maneuver. This action may be described as “bearing down” because a person takes a deep breath and attempts to exhale against a closed glottis, while tightening the abdominal muscles. To accomplish this maneuver, intact innervation to the lower thoracic cord (T6–T12) is required.

Most people with MS gave little thought to bowel function before the onset of their illness, and many continue without bowel dysfunction throughout the course of the disease. Estimates of bowel dysfunction in MS patients range from 52% (Chia et al., 1995) to 68% (Hinds & Wald, 1989).

The most common bowel complaint from a person with MS is constipation, but the most distressing bowel complaint is probably that of involuntary bowel.

Diagnoses of Altered Elimination

Constipation

Factors related to constipation in the individual with MS include correlating pathophysiology (described in the following), inadequate fluid intake, inadequate bulk in the diet, decreased physical activity or immobility, and/or medications such as anticholinergics used for bladder control. Constipation may result directly from MS involvement of that portion of the nervous system that controls the bowel function, the sacral area. This produces a slow bowel, in which waste moves slowly through the digestive system. Another indirect MS influence on bowel movements is weakened abdominal muscles, making it difficult to “bear down” strongly enough to create sufficient Pabd for easy evacuation of stool.

Additionally, decreased physical activity because of impaired walking or easy fatigability is a common secondary cause of slow bowel syndrome. Constipation also results when the amount of fluid a person drinks is voluntarily limited because of bladder problems. Often, individuals decrease fluid to “manage” bladder problems, and then, in addition, develop bowel problems. For better bowel habits, it is therefore important to improve bladder function so that individuals can tolerate adequate fluid intake.

Usually an individual reports decreased frequency of defecation, less than the usual pattern. It is important to remember that “normal” frequency of bowel movements is dependent on the individual and not necessarily a daily activity. Individuals usually complain of straining on defecation, difficulty evacuating stool, and hardened fecal matter. Other symptoms related to constipation include severe flatus, feeling of rectal

fullness, distended abdomen, headache, anorexia, nausea or vomiting, diarrhea (related to fecal impaction), and increased fatigue.

Commonly, the nurse would observe distended abdomen, decreased bowel sounds, or oozing of stool around fecal impaction.

Specific nursing interventions for constipation include the following:

1. Determine premorbid pattern of elimination, including frequency and time of day, and factors that facilitate elimination.
2. Assess current pattern of elimination.
3. Palpate abdomen for distention or abdominal mass and auscultate abdomen for bowel sounds.
4. Identify related factors contributing to the problem, including issues of privacy, ability to get to a bathroom facility, or inadequate fluid or fiber in diet.
5. Implement interventions to promote normalization of bowel function based on assessment.

Initial interventions to relieve constipation include (a) fluid intake of 1.5–2 L of fluid per day, (b) high-fiber diet (minimum 15 g of fiber per day), and (c) routinize bowel schedule and encourage patient to evacuate at the same time each day. (The best time to attempt defecation is about one-half hour after mealtime, when the gastrocolic reflex is the strongest.)

Constipation should first be treated by nonpharmacologic interventions. Educating the patient about bowel function and the importance of adequate fluid, fiber, and exercise is important. Education about foods that are high in fiber is a first step in intervention. Surprisingly, many patients do not know what foods have high-fiber content. The best sources of fiber are cereals, fruits, and vegetables (see Table 7.2).

TABLE 7.2 High-Fiber Examples

Type	Amount	Grams of Fiber
Fiber-One cereal	1/3 cup	12
All-Bran cereal	1/3 cup	9
100% Bran cereal	1/2 cup	8
Baked beans (navy, kidney, lima)	1/2 cup	9
Corn	2/3 cup	4
Prunes	3	4.5
Raisins	1/2 cup	5
Raspberries	1/2 cup	5

The next line of defense includes bulk formers, which add substance to the stool by increasing bulk and water content. To be effective, bulk formers should be taken with one to two glasses of liquid. Action usually occurs within 12–24 hours, but results may be delayed in some individuals. Daily use is recommended for maximum effectiveness. (Bulk formers are not habit-forming.) Common bulk formers include Metamucil, Perdiem, FiberCon, and Citrucel.

Stool softeners can also be helpful to draw increased amounts of water from body tissues into the bowel, thereby decreasing the hardness of stool and facilitating elimination. Stool softeners usually act within 24–48 hours. Consistent use is recommended to achieve the most benefit. (As with bulk formers, stool softeners are not habit-forming.) Common stool softeners include Colace, Surfak, and Correctol syrup.

Oral stimulants are used to provide a chemical irritant to the bowel, which increases bowel activity and aids in the passage of stool. Several oral stimulants are available over-the-counter. Bowel movements are induced gently, usually overnight or within 8–12 hours. Common oral stimulants include Peri-Colace, Modane, Perdiem Granules, Dialose, and milk of magnesia. Harsher laxatives such as Ex-lax, Feen-A-Mint, Dulcolax tablets, and castor oil have a high potential of becoming habit-forming. The use of daily lactulose or polyethylene glycol (MiraLAX) to promote osmotic catharsis and to increase the amount of water in the stools has gained popularity to help restore regular bowel habits.

Rectal stimulants provide chemical stimulation combined with localized mechanical stimulation and lubrication to promote elimination of stool. These may be used only as needed or on a routine basis (every other day) in conjunction with other bowel regimens included in this chapter. Suppositories usually act within 15 minutes to 1 hour. Glycerine or Dulcolax suppositories are most commonly used.

Frequent use of enemas should be avoided because the bowel will become dependent on them if used routinely to stimulate the elimination of stool. The Therevac mini-enema is a stool softener evacuant that can be used for relief of chronic constipation. Other enemas include Fleet oil retention, saline, and soapsuds.

Developing a bowel routine may take weeks or months. Consistency and reevaluation of the bowel management program is key to success.

Diarrhea

Diarrhea may occur secondary to fecal impaction, diet or irritating foods, inflammation or irritation of the bowel, stress or anxiety, medications (antacids or antibiotics), and overuse of laxatives or stool softeners. Diarrhea

may result from a gastrointestinal virus or influenza. Usually, the patient complains of abdominal cramping or pain with urgency of bowel.

Chronic diarrhea is a worrisome symptom and not likely caused by MS directly. It may be advised for a patient to consult with a gastroenterologist.

Nursing interventions include basic assessment including characteristics of stool (color, odor, amount, frequency), bowel sounds, signs and symptoms of dehydration, medication, and anxiety or stress factors. If diarrhea has been persistent, monitoring electrolytes, client weight, and intake and output are helpful parameters, as are monitoring dietary habits and discontinuing the intake of irritating foods (high-fiber bran, fruits, or vegetables).

An additional complication of diarrhea is alteration in skin integrity. Scrupulous skin care is important when diarrhea occurs. Certain medications can be helpful to decrease gastrointestinal mobility and fluid loss (Lomotil, Imodium). Bulk-forming fiber supplements (Metamucil, Citrucel, Perdiem) might improve consistency of stool.

Involuntary Bowel

Uninhibited bowel elimination can result because of loss of or diminished sphincter control or hyperreflexic bowel. The patient reports involuntary stools, urgency, or a lack of awareness of need to defecate. Nursing interventions include complete assessment of normal bowel patterns or habits, including frequency, time of day, color, consistency, amount of stool, and use of laxatives or enemas. Nutritional patterns or habits may contribute to this problem.

A structured daily plan for bowel management can lead to more predictable bowel habits. Patients should be encouraged to use the gastrocolic reflex by establishing a consistent daily time for bowel elimination within 30 minutes of a meal. They should select a time of day that is most convenient for their home schedule. The use of a suppository may be helpful to structure a daily bowel movement. Anticholinergic medication can relieve bowel hyperreflexia when this is a causative or contributing factor.

Managing bowel symptoms with an MS client is often the result of trial and error. Generally, success does not come quickly but rather over a period of weeks or months (remember, haste does not make waste!). It is important to remember that the goal of any bowel management program is for a patient to move his or her bowels comfortably in an appropriate setting.

Bladder evaluation for the 39-year-old woman revealed adequate daily fluid intake. History revealed three pregnancies, three uncomplicated deliveries, and no other abdominal surgery. She was able to void 240 cc with 70 cc postvoid residual (measured by bladder scan). Urine sample was sent for urinalysis.

Most likely, diagnosis is inability to empty completely (or possible detrusor–sphincter dyssynergia but urodynamic testing was not completed).

It was suggested to the patient to stop the anticholinergic medication and employ behavior modification techniques for bladder management (drink fluids at once, void 1.5 hours later). She was advised to stop drinking fluids 2 hours before bedtime and void right before sleep. It was also discussed with her that she may need to catheterize on occasion.

Urinalysis and culture were negative.

The patient called a few weeks later to say that she had done everything suggested and it has “changed her life.” She can sleep through the night, does not dribble urine, and has marked improvement of bladder control.

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Addressing Risk Factors Across the Disease Spectrum

Colleen Harris

Holly is a 40-year-old woman with long-standing multiple sclerosis (MS). She started interferon beta 1-b late in her disease and did not obtain clinical benefit before reaching a progressive course. During the course of her therapy, she experienced a site reaction that evolved into a necrotic lesion that required surgical intervention. She stopped her injections following surgery and, since that time, her disease has followed a slowly progressive course. During her time on her interferon beta, she maintained close follow-up with her MS health team but, since stopping her medication, she has had only sporadic contact with the clinic.

Holly is on a disability pension and is now confined to a wheelchair. She moved in with her mother 4 years ago because she could no longer function independently in her apartment. She has the services of a home help aide but her mother assists her with her feeding and wheelchair to bed transfers. She has an indwelling catheter and current medications include baclofen, tizanidine, and an antidepressant medication. Holly has had two hospitalizations over the past 6 months for pneumonia as well as a urinary tract infection. She is currently on bed rest because of a red area thought to be the start of a bed sore. She has grown very thin, frequently cries, and does not see the purpose in life. Her mother is very concerned and expresses feelings of guilt because of failure to meet Holly's health needs. They have reached out to their MS nurse for help.

INTRODUCTION

Even with the introduction of new and promising therapies, there are individuals with multiple sclerosis (MS) who, like Holly, accumulate disability throughout the spectrum of the disease. We are in an era of disease management and control since the introduction of the disease modifying therapies, but there is still no cure. There are unique

challenges faced by individuals affected by MS and their care providers as they strive to live with wellness in the presence of a chronic and often disabling illness. These special needs can pose health risks if not addressed through a model of day-to-day wellness focused living. Areas of concern include adequate nutrition and hydration, eating problems and swallowing complaints, severe spasticity, and complications of immobility such as skin breakdown.

NUTRITION IN MULTIPLE SCLEROSIS

Adequate nutrition has traditionally been recognized as a key factor in health maintenance both for people in good health and for those with altered health states. Good nutrition is characterized by a well-developed body, ideal weight for body composition (ratio of muscle mass to fat), healthy hair and skin, and mental alertness (Williams, 1995).

To ensure adequate dietary intake, many governments and agencies regularly update dietary recommendations to ensure nutritional recommendations are in keeping with current research and evidence. Food guides are designed to help people follow a healthy diet with essential vitamins and nutrients. They embody sophisticated dietary analysis and merge national nutrition goals, data from food consumption surveys, and issues of food supply and production (Health Canada, 2007). They translate the science of nutrient requirements into a practical pattern of food choices, incorporating variety and flexibility. In the United States these recommendations are referred to as the Dietary Guidelines for Americans and in Canada are known as Canada's Food Guide. Such recommendations are structured to promote health and to reduce risk for major chronic diseases through diet and physical activity (Health Canada; United States Department of Agriculture, 2005). Embracing the current trends in healthy dietary requirements is important to all people but even more vital when living with a lifelong chronic illness such as MS.

The role of nutritional factors in the course of MS has been of considerable interest for both patients and health care professionals for some time (Wozniak-Wowk, 1993). Several diets have received a great deal of attention, including the Swank diet, the gluten-free diet, and other elimination diets, along with the use of supplements such as vitamins, food additives, and oil of evening primrose. The wide use of supplements in the past decade has prompted closer appraisal of potential risks and benefits (Bowling & Stewart, 2004). In addition there are many testimonials, advertisements, and anecdotal recommendations suggesting nutritional supplements for MS. There is a growing body of evidence pointing to vitamin D deficiency and its impact on many aspects of health. There is,

however, no conclusive scientific evidence that any nutritional therapy affects the course of MS, and no dietary regimens have, to date, been subjected to scientifically controlled trials that have demonstrated significant therapeutic merit for MS (Kosich, 1998).

It is essential to recognize the educational needs of people with MS and to support them by providing information about the value of good nutrition as well as the pitfalls of fad diets or undocumented therapeutic claims. Poor or inadequate dietary intake increases many of the risks factors that those living with MS are exposed to such as skin breakdown, bowel and bladder complications, and osteoporosis.

The nurse is in an excellent position to assist patients and families to recognize their nutritional needs and teach ways to incorporate them into their lifestyle. These needs do not differ greatly from those of the general population, but they should be individually evaluated based on the patient's disease course, functional status, activity level, and age. Various symptoms specific to MS can impact an individual's ability to maintain an adequate nutritional status and can often be overlooked when managing the overall illness. Tremor, weakness, and paralysis may interfere with the patient's ability to eat or drink. Dysphagia, a problem frequently seen in MS, not only can compromise adequate nutrition but can also result in pneumonia secondary to aspiration of either liquid or solid food. Fatigue may result in inadequate dietary intake because of the energy required to prepare meals, cut food, chew, and swallow large portions. Depression may also contribute to poor appetite and dietary intake (Samuel & Cavallo, 1999).

The role of obesity in MS is a current area of interest. In a study of adolescent women, obesity at the age of 18 was associated with a greater than twofold risk of developing MS (Munger, Chitnis, & Ascherio, 2009). Other research has suggested that obesity in MS aggravates symptoms and contributes to poor health outcomes such as cognitive and physical fatigue, and increased levels of depression, pain, and stress (McMullen, Bamer, Johnson, & Amtmann, 2009). The patient's weight should be monitored to determine early changes so that modifications in intake and activity can be recommended promptly. Obesity in an individual with altered mobility is very difficult to overcome.

A registered dietitian or nutritionist can help determine individual caloric needs based on an in-depth interview that takes individual preferences into consideration. For example, someone with limited mobility (a person using a wheelchair or a walker) might function on 1,200 calories a day whereas a person with mild disease might continue on his or her usual intake. A patient who is in bed all or most of the day and is dependent on others for activities of daily living (ADLs) will require restricted calories with an adequate intake of nutrients and fluid.

A patient with skin breakdown will require additional intake of calories and protein to promote healing and replace loss of nutrients and fluid through wound drainage.

If the person is totally dependent, his or her family will need assistance in learning feeding techniques and may need information about proper positioning of the patient to avoid choking. Referrals to home health programs to relieve the caregiver should be explored, as well as information about community programs such as food stamps and meals-on-wheels for those with fixed and limited incomes.

The person with decreased energy should be encouraged to adopt techniques such as precooking and freezing meals, using a microwave to heat food, eating small portions frequently rather than having large meals, and purchasing frozen foods for use when tired. Assistive devices such as weighted utensils and elongated straws can be helpful for patients with tremor or weakness. A consultation with an occupational therapist or other members of the rehabilitation team can be helpful for individuals who may require specialized strategies and aides to help with meal preparation and feeding. Liquid nutritional supplements both for energy conservation and to ensure an adequate intake of basic nutrients are also helpful in maintaining adequate nutritional intake. These supplements are available in pudding form for patients who have difficulty swallowing liquids or prefer a solid form of supplementation.

HYDRATION

It is extremely important that adequate fluids are taken to maintain all bodily functions at the highest level. Food without fluid is akin to a car without oil. Fluid is the lubrication needed to assist in swallowing, the hydration for body tissues, the liquid needed to form waste products and body fluids (blood, lymph, perspiration), and the moisture for skin, hair, and nails. Inadequate fluid intake contributes to constipation, urinary tract infections, and skin breakdown. A minimum of eight glasses of fluids should be ingested daily. People with frequent urinary tract infections can reduce their risk by drinking cranberry or prune juice to acidify their urine. Fluids can also be obtained indirectly through gelatin and other desserts made from liquids.

DYSPHAGIA

Dysphagia or difficulty with swallowing is often reported by patients and their care providers. Symptoms of swallowing problems include not only choking but also gurgling, sounds of congestion, sore throat,

spitting, or coughing after meals (O'Connor, 2009, p. 84). Undetected swallowing problems could result in weight loss and pneumonia (Leslie, Carding, & Wilson, 2003). Research has identified abnormal swallowing as being common in MS and often associated with disordered brain stem and cerebellar function, overall high disability, depressed mood, and low respiratory vital capacity (Thomas & Wiles, 1999). This problem must be identified by the nurse by asking questions such as: "Do you have difficulty swallowing? Are you having problems with liquids? Solids? Do you ever have choking episodes? Have you ever had pneumonia? Have you maintained your current weight or have you experienced weight loss?" Once the problem is identified, referral to a speech-language pathologist is indicated, usually followed by testing. The most commonly used diagnostic tests for evaluating dysphagia include the bedside swallow examination, a modified barium swallow with videofluoroscopy, or other endoscopic procedures (Leslie et al.). The purpose of the swallow evaluation is to determine whether the cricopharyngeal sphincter is not opening and the epiglottis is not protecting the airway. The modified barium swallow with videofluoroscopy allows viewing of the oral cavity, laryngopharynx, and esophagus while the patient swallows barium of various consistencies (Leslie et al.). Videotaping of the study allows clinicians to review the procedure repeatedly and with slow-motion analysis. An abnormal result of the study may indicate alternatives to normal feeding methods such as positioning the head and chin, changing consistency of food and fluid (chopping or blenderizing foods or adding thickening agents), and planning rest periods prior to mealtime to reduce fatigue. Percutaneous endoscopic gastrostomy has increasingly replaced surgical gastrostomy as the preferred procedure for the long-term nutrition of patients with swallowing disorders due to lower post procedure complication rates (Ljungdahl & Sundbom, 2006). Patient and family education is required for tube feeding at home, and the discharge planner must make arrangements to supply the appropriate equipment.

Although maintenance of adequate nutrition is an inherent principle of nursing care, nutrition in MS is complicated by the variability of the disease course. Dynamic interventions are required in response to the changing needs of patients with MS.

PULMONARY COMPLICATIONS

Respiratory muscle weakness of mainly the expiratory muscles is characteristic of individuals with advanced MS and can result in difficulty clearing secretions and repeated episodes of pneumonia (Wiens & Reimer, 1999). Pulmonary dysfunction secondary to MS is the leading cause of

morbidity and mortality in this patient population (Lehman & Picone, 2001). It has been shown that expiratory muscle weakness and poor cough efficacy is related to impaired functional status in MS (Gosselink, Kovacs, Ketelaer, Carton, & Decramer, 2000). Symptom management protocols should address the signs and symptoms of hypoventilation such as dyspnea, orthopnea, weak cough, hypophonia, and fatigue (Lehman & Picone). It is vital that nurses involved in caring for individuals with significant disability be alert to respiratory changes that can lead to life-threatening complications such as pneumonia. Respiratory weakness should be suspected in any individual with MS who has significant upper limb weakness as this is accompanied by chest wall weakness as well. Pulmonary assessment is simple and inexpensive and should be performed to avoid complications when pulmonary dysfunction is suspected. A respiratory infection or aspiration can be very difficult for a severely disabled patient with MS to overcome. Nursing outcomes should be geared to patient and family education and emphasize the following:

- Avoid respiratory infections by good hand washing of patient and caregiver and by avoiding other individuals with respiratory infections
- Semi-Fowler's position while in bed to assist with breathing and drainage of secretions
- Frequent ambulating from bed to wheelchair and frequent position changes while in bed with the use of assistive devices such as side rails
- For chest congestion, perform deep breathing and coughing exercises with assistance of a caregiver if necessary
- Avoid aspiration pneumonia by being alert to swallowing difficulties

The influenza vaccine is strongly recommended for individuals with expiratory muscle weakness because of the association of pneumonia with many of the flu viruses (O'Connor, 2009, p. 41). Immunizations in MS have been linked to an increase in disease activity but evidence has shown that influenza vaccination does not lead to an increase in relapses or disease activity and is less of a health risk than contacting influenza (Confavreux, Suissa, Saddier, Bourdès, & Vukisic, 2001). Avoiding an episode of pneumonia can be life saving to individuals with advanced MS.

URINARY TRACT INFECTIONS

Urinary tract infections are common in the severely disabled individual with MS because of incomplete emptying of the bladder or the need for an indwelling Foley catheter in the case of incontinence. Urinary tract infections may pose a serious threat to the health of an individual with MS

if appropriate antibiotic treatment is not initiated when symptoms occur (Schapiro, 2003, p. 76). To minimize the risk of urinary tract infections, intermittent catheterization by the patient or caregiver should be performed on a regular basis. For people with indwelling Foley catheters, attention should be focused on keeping tubing and drainage bags as clean as possible and changing the catheter at least once a month, using proper sterile technique (Schapiro, p. 77).

SPASTICITY

Spasticity or muscle hypertonia occurs as a result of abnormal spinal and brain stem reflexes and is a common and treatable symptom of MS. Spasticity is defined as a velocity-dependent increased resistance of muscle to stretch because of activation of tonic stretch reflexes (Lance, 1980). Lesions in several cerebrospinal or propriospinal fiber systems may contribute to this symptom (Stein, Nordal, Oftedal, & Slettebø, 1987). Spasticity usually occurs in the larger stronger muscles responsible for maintaining an upright posture and/or moving against gravity (O'Connor, 2009). Its severity varies depending on the size and location of plaques (Chan, Hugos, Morrison, & Theriot, 1993). The measurement of spasticity is subjective via patient report or objective using the Ashworth scale (see Table 8.1) and the spasticity scale (see Table 8.2; Chan et al.).

The management of spasticity in MS is a challenge because of intercurrent symptoms such as weakness and fatigue. The primary management of spasticity consists of regular stretching programs and pharmacologic agents such as baclofen (Lioresal), diazepam (Valium), dantrolene sodium (Dantrium), and tizanidine (Zanaflex; Schapiro, 2003, p. 37). Baclofen is the most common antispasticity drug used and doses range from 5–180 mg a day (Coyle & Halper, 2001, p. 46). Diazepam (Valium) and clonazepam (Klonopin), both members of

TABLE 8.1 Ashworth Scale

Score	Criteria
1	No increase in muscle tone
2	Slight increase in tone giving a “catch” when affected part is moved in flexion or extension
3	More marked increase in tone but affected part is easily flexed
4	Considerable increase in tone; passive movement difficult
5	Affected part is rigid in flexion or extension

TABLE 8.2 Spasticity Scale

Score	Criteria
0	No spasms
1	No spontaneous spasms (except with vigorous motor stimulation)
2	Occasional spontaneous spasms and easily induced spasms
3	More than 1, less than 10 spontaneous spasms per hour
4	More than 10 spontaneous spasms per hour

the benzodiazepine family, have been used successfully in reducing spasticity during the night but are inappropriate for daytime use because of their sedative side effects (Schapiro, p. 39). Dantrolene sodium (Dantrium) is used infrequently and patients taking this medication must be monitored closely because of the side effects of hepatotoxicity, nausea, malaise, dizziness, and weakness (Coyle & Halper, p. 47). Tizanidine (Zanaflex) is taken in doses up to 36 mg a day and although it produces more sedation than baclofen, it is also known to produce less weakness (Schapiro, p. 38). Tizanidine inhibits the polysynaptic reflexes whereas baclofen inhibits monosynaptically (Stein et al., 1987). Because baclofen and tizanidine act on different sites in the nervous system, use of them in combination may be more effective than either one alone in treating severe spasticity (Coyle & Halper, p. 46). Gabapentin has also been used to treat spasticity both alone and in combination with baclofen, but its effects have not been well studied (Coyle & Halper, p. 47). Some patients with severe spasticity may benefit with the injection of botulinum (Botox) toxin right into a muscle, which can offer relief of spasticity to specific large muscle groups for up to 3 months (O'Connor, 2009, p. 76).

Phenol blocks and surgical techniques such as neurectomy, rhizotomy, and myelotomy have been greatly reduced with the advent of intrathecal baclofen, which is delivered by an implantable and programmable pump (Penn, 1992). After test dosing via lumbar puncture to evaluate efficacy, the pump is inserted under the skin of the abdomen and connected to a catheter in the spinal canal. Baclofen is delivered continuously throughout the day and may be titrated to deliver variable doses depending on the patient's needs (activity level and the need for some spasticity to transfer, sit, etc., and for rest and sleep at night). Up to 10 doses can be delivered throughout a 24-hour period. Maintenance of the pump is relatively simple and refilling is performed with a computerized programmer either via a home care nursing service or in the physician's office.

A wide variety of treatment options are available for managing spasticity in MS. Management of this symptom can promote improved patient and family function and facilitate improved quality of life. If this symptom is not managed well, complications such as contractures, skin breakdown, and pain can occur.

OSTEOPOROSIS

Osteoporosis is a progressive disorder of bone mass loss that can lead to deformity, pain, and low-impact fractures (Coyle & Halper, 2001, p. 104). Osteoporosis is a common problem in older women but the risk is increased in both men and women with severe advanced MS because of immobility and past steroid use (Halper & Murray, 1999, p. 120). Mineral density testing for diagnosis should be done where possible in these patients and other risk factors such as tobacco and alcohol use and poor dietary intake of calcium should be eliminated (Coyle & Halper, 2001, p. 104). Severely disabled individuals with MS should be assisted in passive exercises that can promote bone rebuilding and careful attention should be taken to prevent falls. Treatment and prevention also includes the dietary intake of calcium-rich foods and at least 1,000 mg of calcium daily for premenopausal women and men at risk and 1,200–1,500 mg for postmenopausal women. For patients who have abnormal mineral density studies, the use of alendronate sodium (Fosamax) or etidronate disodium (Didrocal) may be indicated (Kalb, 2000, pp. 325–326). Severely disabled MS patients have been shown to have a high prevalence of vitamin D deficiency because of poor dietary intake and reduced exposure to the sun, which can lead to an increase of bone loss (Cosman et al., 1999). To avoid osteoporosis it is also imperative that there is adequate supplementation of vitamin D to promote calcium absorption.

SKIN CARE

Attention to skin care is an intervention that starts very early in the disease course. The first generation of disease modifying therapies are all injectable medications that require appropriate skin preparation, injection technique, and injection site rotation. Injection site reactions are common and complications such as skin infection and necrosis can occur. The role of the MS nurse in the education of patients and care providers in maintaining appropriate injection practices and monitoring for skin complications has been significant since the introduction of these medications.

The importance of skin care in the prevention of decubitus ulcers is widely accepted in MS. The economic and emotional costs of prolonged hospital and home management of decubiti are obvious. Prevention of skin breakdown has traditionally been viewed as part of nursing practice and is essential in caring for the MS patient. The goal of risk assessment is to identify patients at risk of breakdown. The three main factors implicated in pressure ulcers and skin breakdown are interface pressure from lack of repositioning, shear friction, which is generated by the motion of the bone and subcutaneous tissue relative to the skin, and moisture from body fluids (Grey, Stuart, & Harding, 2006). Both the patient and care providers require ongoing education to assess for and minimize or prevent risk factors.

The Braden and Norton Scales have been tested and validated in many settings (LaMantia, 1995). The Norton Scale consists of five factors: physical condition, mental condition, activity, mobility, and incontinence. Each factor is rated 1–4; a score of 14 indicates onset of risk and a score of 12 and below indicates a high risk of pressure ulcer formation (LaMantia). The Braden Scale consists of six factors: sensory perception, moisture, activity, mobility, nutrition, and friction and shear. The subscales are rated 1–4. A score of 4–23 is possible, with 16 or below being considered at risk (LaMantia).

There is significant potential for impaired skin integrity in MS patients, especially those who have alterations in mobility. Several factors predispose the MS patient to this problem, including the use of assistive devices such as braces or splints, which could increase friction or pressure; decreased sensation or paresthesias, which may interfere with the perception of irritation or pain; urinary or bowel incontinence, which can chemically irritate the skin; nutritional deficiencies; and cognitive impairment, which may alter judgment regarding self-care activities. A pressure sore can develop in a few hours but takes several months to heal. Healing a pressure sore requires long periods of immobility, which can lead to secondary problems such as pneumonia. In some cases surgical skin grafting may be necessary when circulation to the area of skin breakdown is severely impaired (Srivastava, Gupta, Taly, & Murali, 2009).

Prevention is the key to the treatment of skin impairment. The nursing assessment will provide areas of concern, and a comprehensive management plan can then be developed to reduce pressure. Pressure reduction encompasses all activities and modalities from bed to wheelchair, transfer activities, clothing fit, and mobility. Additionally, reduction of spasticity is the key to the prevention of skin breakdown of the lower extremities, the

sacrum, and other areas with bony prominences. Maintenance of desired weight and promotion of maximum health all contribute to the prevention of skin breakdown.

Long-term outcomes of skin care should include freedom from skin breakdown and its complications starting early in the disease trajectory with appropriate injection care practice and later with careful attention to the hazards of immobility. Short-term outcomes should focus on compliance and preventative treatments that involve patient and family education, professional activities, and prompt treatment. These should include:

- The identification of predisposing factors
- Adherence to good injection practices and skin reaction management with the use of disease modifying therapies
- The maintenance of adequate nutrition
- Patient and family demonstration of activities to relieve ongoing pressure (wheelchair push-ups, change of position in wheelchair, transfers to other seats)
- The use of appropriate seating cushions or mattress adaptations to relieve pressure
- The use of assistive devices to facilitate changes in bed lying positions (side rails, trapeze)
- Inspection of the skin by patient, family, home health aides, or the nurse to identify early signs of skin impairment (redness, excoriation, blanching, etc.)
- The provision of early intervention and treatment
- Maintenance of bowel and bladder continence or frequent cleansing and changes for those who are incontinent of urine and stool

The nurse, in conjunction with the patient and family, is often the primary team member in the prevention and treatment of skin impairment. The appropriate use of modalities and patient and family education provide for decreased emotional and monetary cost to the patient, family, and the health care system.

Throughout the spectrum of MS, health promotion and prevention of complications remains the optimal goal for disease management. With the increased attention being given to the disease there is renewed hope for a cure. Hope itself is a powerful coping tool for patients, family, and care providers. Until that cure comes, all members of the MS care team need to facilitate both emotional and physical health in the presence of a chronic illness.

Through interaction with Holly and her mother, the MS nurse was able to provide some successful strategies that helped both Holly and her mother deal with their current crisis. Holly admitted to avoiding MS care professionals following her surgery for skin necrosis because she believed there was nothing else that could be done for her. She freely admitted to feeling hopeless about her future. Her mother also expressed feelings of failure as both a mother and care provider.

Initially, the nurse spent time reestablishing a trusting care partnership. Holly's failure on a disease modifying therapy and resulting serious skin complication did make her feel like life had let her down. The nurse acknowledged these feelings and introduced the concept of symptom management and wellness focused behaviors as other potential disease management options. Many of Holly's symptoms were not optimally managed and her depression had not improved since initiating antidepressant therapy. Her mother was not well informed about issues around nutrition and potential swallowing problems, catheter care, or risk factors for skin breakdown. This presented an excellent educational opportunity for the nurse.

Through the ongoing involvement with the MS care team, both Holly and her mother developed skills that positively impacted their quality of life. They received education on appropriate dietary requirements and eating habits after an abnormal swallowing assessment that most likely led to her recent bout of pneumonia. This allowed Holly to gain back some much needed weight. It was discovered that she did qualify for more home health services and this eliminated much of the caregiver burden and feelings of guilt that her mother was experiencing. A change in antidepressant therapy did improve Holly's moods and, following a seating adjustment to her wheelchair, she once again pursued outside interests.

Holly is now very active with her local MS society and both volunteers and attends the yoga program. Her mother has gone back to doing some of her own activities with her church group. They remain connected with their MS care team.

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Incorporating Complementary and Alternative Medicine in Symptom Management

Patricia M. Kennedy

S.M. is a 40-year-old woman who was diagnosed with multiple sclerosis (MS) at the age of 32 after the birth of her second child. Her neurologist recommended treatment with a disease modifying agent to slow the progression of her disease. She refused his recommendation and chose to “go the natural way.” Her family and others in her support system had rarely used medical services out of a belief that they could get through whatever they experienced. They also believed that vitamins, minerals, and herbs should be taken to both maintain health as well as improve health. They also believed that medical professionals charged too much and medications were too expensive.

She decided to follow a lactose and sugar-free diet, to take a large amount of various vitamins, and to take a supplement to boost her immune system. Her neurologist told her that none of these treatments would help but gave her no reasons why he felt that way. She was symptom free at that time and perceived her provider was not engaged with her and her beliefs so did not return to see him for 18 months. At this time, she was more symptomatic with both motor and sensory involvement.

A new MRI scan revealed an increased lesion load with enhancing lesions. Her neurologic examination indicated muscle weakness, spasticity, sensory loss, and indications of cognitive dysfunction.

Her provider inferred that her choices of treatment had been foolish and she should take a disease modifying therapy.

At this point, she felt unhappy with herself and with her provider and was feeling that she had no power over MS or choices in its treatment.

COMPLEMENTARY AND ALTERNATIVE THERAPIES AND MULTIPLE SCLEROSIS

Globally, the use of alternative therapies has been increasing. People with chronic diseases such as multiple sclerosis (MS) are higher users. In May 2008, the National Center for Complementary and Alternative Medicine (NCCAM) of the National Institutes of Health (NIH) launched a “Time to Talk” campaign to encourage patients and care providers to encourage patients and care providers to discuss the use of alternative therapies whether used alone or with conventional therapies. The concern was the potential for drug interactions and lack of coordinated care (Bowling, 2007).

Complementary and alternative medicine (CAM) is the combination of products and therapies found outside the medical treatments commonly taught in medical schools or found in traditional hospitals (alternative) and therapies that are found there (conventional). CAM today is more commonly used in conventional treatment. Medical schools are developing “Integrated Medicine” departments. Many conditions and diseases are being treated by medical care providers using products and practices previously outside the realm of conventional therapy such as folic acid in pregnancy, acupuncture for pain relief, and diet and exercise for cardiac conditions.

Usage of CAM is becoming commonplace. A Norwegian study of 9,000 people found that 48% of those surveyed had received CAM from either alternative practitioners or medical health care providers. Those interviewed did not feel they were choosing one system over another but were combining systems to design their own health care (Bowling, 2007). A German survey of 1,500 people with MS from a chapter of the German MS Society found more patients were positive toward CAM (44%) versus conventional therapy alone (38%). More than 70% had used CAM in a lifetime. Use of CAM was associated with religious beliefs, functional independence, the female sex, white-collar jobs, and higher education. Of the people surveyed, 52% reported low levels of satisfaction with conventional treatments as well as brief patient–physician contacts (Fønnebø & Launsø, 2009). A review of the literature to evaluate patients with MS use of CAM reported use of CAM from 27–100%. Reasons cited were lack of effectiveness of conventional treatment, anecdotal reports of CAM benefits, and provider referral. Types of CAM reported were exercise, vitamins, herbal and mineral supplements, relaxation techniques, acupuncture, cannabis, and massage. Symptoms reported in the literature for which CAM is used are pain, fatigue, and stress (Olsen, 2009).

Patients with MS, a disease without certain cause or cure, are apt to look at any treatment that they perceive will help them. Beliefs may come from their culture, support system, or society in general, but mostly from hope that they can gain some control over this disease.

Medical providers are divided on CAM. Some, based on their education and practice, see little value. Others are poorly informed and do not ask patients if they use CAM or discuss use with them. More providers are becoming aware of the benefits of CAM and are having discussions with their patients. Alternative health care providers are also divided. Some work closely with the patient incorporating conventional therapy into the total health care plan. They encourage patients to discuss CAM use with medical providers. Other providers reflect negative feelings and beliefs about conventional treatment and encourage their patients to only use alternative management.

Regardless of the reasons for considering a CAM therapy, patients need information. They need to learn how to evaluate the evidence and to evaluate their own response to risks, costs, and availability.

Talking to patients about the types of evidence about which they should be aware is critical for their decision making. Evidence evaluation should include:

- Anecdotal evidence
- Laboratory evidence
- Animal evidence
- Experimental clinical evidence (Schwarz, Knorr, Geiger, & Flache-necker, 2008)

Resources for reliable information should be provided. Common sources used by patients seeking information include public libraries, retail health stores, and the Internet. Information about alternative therapies is variable, making patient decisions difficult. Reasonable suggestions to give them are listed at the back of this chapter.

When a patient is inquiring about or has chosen a CAM therapy, providers should provide information about known benefits and risks and advise whether use is advisable or not. This advice would apply to alternative and conventional treatments. Providers need to be mindful of a patient's belief system in this discussion, being careful not to discourage hope they might derive from some treatments. There may be positive placebo responses to some therapy with little risk. Providers, regardless of their opinions, may want to support that treatment.

When evaluating CAM use with a patient, determine what they desire to treat. When treating the disease of MS, conventional therapies

are biologically based and have shown, through clinical trials, to be strong in their effectiveness. Although some CAM therapies have some biologic effect, none are as strong. If symptoms are being treated, CAM therapies may have strong benefit in nonbiologic areas (Stewart & Bowling, 2006).

The NIH has established five types of CAM therapy:

- Biologically based therapies: diet, dietary supplements
- Mind–body medicine: meditation, hypnosis, spirituality
- Manipulative and body-based systems: massage, chiropractic medicine
- Alternative medical systems: traditional Chinese medicine, ayurveda
- Energy therapies: magnets, therapeutic touch

Biologically based therapies have more interest for disease management. They carry more risk and may cause serious complications or interactions. Patient education is most needed on this topic. Patients need to be taught that no CAM therapy is felt to be equal to or better than conventional therapy for the treatment of the disease process of MS.

Diet

Although there is no diet that appears overwhelmingly beneficial for MS, there is evidence from small studies that a diet that is relatively low in saturated fats and enriched with polyunsaturated fats (omega-3 and omega-6 fatty acids) may have mild disease modifying effects in MS (NCCAM, 2008).

“What diet should I follow?” is often one of the first questions patients ask. There are many diets recommended for individuals with MS. Many of these are elimination diets. If someone has allergies to certain foods, they should be avoided. There is little evidence, however, that eliminating foods as a treatment for MS is beneficial. Elimination diets, without allergies or sensitivities, may deplete the body of essential nutrients needed for good health.

Herbs and Supplements

In the literature available about managing MS alternatively, there is little agreement about what may be beneficial or harmful. When speaking to employees in a vitamin store or to others who have a strong belief in alternative therapy, there is also little agreement. Patients need to be encouraged to research any recommendation they are given prior to using

it. References to suggest to patients are at the end of this chapter. Generally, there are some supplements that may benefit some symptoms, some that may be beneficial to the immune system, especially experimental autoimmune encephalomyelitis (EAE) in the animal model, and many that may be immune stimulating or harmful to the system in some other way. Patients need to be informed to let their care provider know of any alternative therapies they may be using to avoid the risk of interactions with medications he or she might prescribe.

Vitamins and Minerals

It is common practice to include testing for vitamin B levels during the diagnostic process as deficiency can produce neurologic symptoms. If deficient, supplementation is indicated. There is little evidence that large amounts of other vitamins are beneficial for MS in general. Calcium, however, plays a role in bone health and vitamin D also plays a role in bone health as well as in MS itself and health in general.

The incidence of osteoporosis in MS is higher for men and women. Both vitamin C and D play a strong role. Calcium is readily available in the diet and can be supplemented if not consumed in adequate amounts. Patients need to discuss their risk of osteoporosis with their care providers as it tends to be underdiagnosed and undertreated. Vitamin D needs to be taken with vitamin C to maintain bone density.

Evidence is accumulating that vitamin D may also play a role in MS as well as other diseases. Vitamin D levels tend to be lower in patients with MS. If low, supplementation is often recommended. Evidence at this time is not clear on how much to supplement, how long or how often. Research continues. The cause of low levels is not known but may be related to sunscreen, skin pigment, obesity, aging, as well as medications such as seizure medications and steroids. Vitamin D may have implications in other autoimmune diseases, heart disease, some cancers, lung disease, and psychiatric conditions. In MS, it may play a role in altering disease progression.

Nonbiologic Therapies

Many of the nonbiologic therapies may have positive benefits for managing symptoms in people with MS. Generally, they carry less risk. When combined with traditional biologic therapies, they may provide a more complete relief of MS symptoms. Not all of these therapies have undergone rigorous clinical trials. Their lower risk profile and

potential for benefit may make that less relevant. The following are some examples:

- Yoga
- Tai Chi
- Massage
- Meditation
- Spirituality
- Music Therapy
- Therapeutic Touch
- Healing Touch
- Reiki

It is important to expand our thinking when managing MS. Although treating illnesses with a medicine is common in our culture, other management tools such as CAM play a role in:

- Empowerment
- Improved self-efficacy
- Management of general health

Using CAM can help some patients enhance their lifestyle, improve their quality of life, and manage many of the symptoms of MS.

See Exhibit 9.1 for suggested book and Web site resources.

EXHIBIT 9.1 ■ Suggested Resources

Books

- Bourdette, D., Yadav, V., & Shinto, L. (2004). Multiple sclerosis. In B. S. Oken (Ed.), *Complementary therapies in neurology: An evidence-based approach* (pp. 291–302). New York: Parthenon Publishing Group
- Bowling, A. C. (2006). *Alternative medicine and multiple sclerosis* (2nd ed.). New York: Demos Medical Publishing
- Cassileth, B. R. (1998). *The alternative medicine handbook*. New York: W.W. Norton
- Ernst, E. (Ed.). (2001). *The desktop guide to complementary and alternative medicine: An evidence-based approach*. Edinburgh: Mosby
- Foster, S., & Tyler, V. (1999). *Tyler's honest herbal: A sensible guide to the use of herbs and related remedies*. Binghamton, NY: Haworth Press

(Continued)

EXHIBIT 9.1 ■ Suggested Resources (Continued)

- Freeman, L. (2004). *Complementary and alternative medicine: A research-based approach*. St. Louis, MO: Mosby
- Hendler, S. S., & Rorvik, D. (Eds.). (2001). *PDR for nutritional supplements*. New York: Thomson Healthcare
- Medical Economics. (2004). *PDR for herbal medicines* (3rd ed.). New York: Thomson Healthcare

Web sites

- CAM Web site of the Rocky Mountain MS Center (www.ms-cam.org)
- Oregon Center for Complementary and Alternative Medication in Neurological Disorders (www.ohsu.edu/orccamind/)
- Quackwatch is a nonprofit corporation whose purpose is to combat health-related frauds, myths, fads, and fallacies (www.quackwatch.com)
- Federal Trade Commission investigates false advertising (www.ftc.gov)
- National Center for Complementary and Alternative Medicine. The federal government's lead agency for scientific research on CAM (www.nccam.nih.gov)

A friend recommended to S.M. that she should see a new neurologist; one with whom she could form a relationship and who might offer her more options. The neurologist she chose worked with an MS nurse who was able to answer many of her CAM questions. The nurse discussed dietary changes such as inclusion of omega-3 and omega-6 fatty acids and suggested she slowly reintroduce lactose and sugar into her diet if she chose to. She also looked at S.M.'s list of vitamins and minerals and supplements. Reviewing the list with her, they were able to eliminate many items and the nurse explained why some of them might be harmful. She gave credit to S.M. for her choices but then discussed treatments that might be more helpful at this time.

The new neurologist also recommended a disease modifying therapy and provided her information on expectations of therapy. He did not discourage her combining some CAM therapies. He did ask her to let him know any time she thought about a new CAM therapy so he could be sure there were no interactions.

Over the next few months, S.M. talked with the nurse about her symptoms and how she was managing them. She had joined a hydrotherapy class and yoga class and was seeing a physical therapist. She became involved in a group at her church and also volunteered there a few hours a week.

S.M. is not atypical. We all try to do what is best for us. Nurses play a large role in being resources for our patients on CAM therapies. What we do not know is that we can either look up or give our patients the resources to do their own research. We need to understand our patients' culture and previous experience. We also must be nonjudgmental but yet encourage choices we know to be better and why we think so, using evidence wherever we can.

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Addressing Psychosocial Issues

Nicholas G. LaRocca and Rosalind C. Kalb

Melinda is a 43-year-old married mother of two who was diagnosed with relapsing multiple sclerosis (MS) 9 years ago. After an initial period of shock and sadness over the diagnosis, she found that she was able to settle back into her regular routines at home and work. Although she experienced three episodes of optic neuritis, significant fatigue that seemed to wax and wane, and some problems with urinary urgency and frequency, Melinda was able to manage her roles as a wife, mother, and part-time administrative assistant.

Over the past several months, however, Melinda has found herself struggling more and more to stay on top of things. Once a very organized person—someone, in fact, who always prided herself on being able to multitask, manage the finances at home and at the office, and keep everyone else’s schedule straight for them—Melinda is feeling out of control. She forgets appointments, misplaces things, and finds it hard to prioritize and organize the many tasks in her day.

All these changes have shaken her self-confidence and left her feeling discouraged and frightened. She finds herself snapping at her husband and children and wishing she could hide away from everyone. She knows she is very lucky in a lot of ways, but worries that her world is crashing around her. Melinda wonders what will be left for her if MS takes away the abilities that enable her to do the things that are important to her.

INTRODUCTION

The Impact of Multiple Sclerosis on the Individual and on Family Life

This chapter focuses on the psychosocial impact of multiple sclerosis (MS) and describes how it affects the thoughts, feelings, and relationships of the people it touches. The broad sweep of MS derives in part from the array of variable and unpredictable symptoms it can cause, including impaired

ambulation, fatigue, bladder and bowel dysfunction, tremor, spasticity, sexual dysfunction, and cognitive and emotional changes. Every facet of daily life may be altered. Difficulty in walking can interfere with important activities of daily living and perhaps lead to unemployment, loss of self-esteem, and a dramatic erosion in the lifestyle of the family. Memory impairment can make basic activities, such as reading a book or learning a new skill difficult or impossible. Bladder and bowel changes can threaten people's feelings of control. And depression can make even the simplest activities feel overwhelming. Individuals and families may experience intense feelings of loss in the face of changes brought about by the disease, anxiety about the unpredictable future, and tension and resentment about changes over which they feel little if any control.

The Role of the Nurse

The nurse is the health care provider with whom many people have the most regular and extensive contact. The nurse can play a pivotal role in facilitating individual and family adjustment to the illness and promoting hope in the face of uncertainty. Early signs of new or worsening symptoms may first come to the attention of the nurse, thus providing opportunities for early intervention and education. In particular, the nurse can recognize the signs of cognitive, emotional, and family problems—those effects of MS that often go untreated. Although the nurse may not be in a position to provide treatment for many of these psychosocial problems, he or she can act as a valuable resource for information and education about various MS-related problems. The nurse will often be the one who makes the referral that will get things back on track. The psychologist, psychiatrist, social worker, and vocational counselor often rely on the nurse to act as an “early warning system” for new symptoms.

The Goal of This Chapter

This chapter delineates some of the cognitive, emotional, and family problems that result from MS, describing them in terms of their various signs and symptoms. It also discusses the challenges facing nurses who work with people who have MS and how they can be met. Additionally, attention is paid to the effect that MS problems may have on the work of the nurse. For example, memory loss can make the nurse's patient education efforts seem fruitless at times. Readers of this chapter will acquire a basic understanding of the psychosocial problems that arise in MS and how to respond to them. The goal is to assist nurses to (a) incorporate

an understanding of MS psychosocial issues into their work; (b) know what type of help is needed to begin solving these problems; and (c) learn ways to promote optimism and hope in the face of significant emotional and/or cognitive challenges.

THE EMOTIONAL CHALLENGES OF MULTIPLE SCLEROSIS

Stress

There has been much speculation, many anecdotes, and considerable research in the question of the impact of emotional stress on MS. Many believe that stress can precipitate the onset of the disease or trigger exacerbations. Almost everyone with MS can cite some emotionally stressful event that took place just before an attack. Some studies have found evidence to support the stress–MS link (Franklin, Nelson, Filley, & Heaton, 1989; Golan, Somer, Dishon, Cuzin-Disegni, & Miller, 2008; Li et al., 2004; Potagas et al., 2008; Warren, Greenhill, & Warren, 1982), whereas others have not (Fischer et al., 1994; Nisipeanu & Korczyn, 1993). Most recent studies appear to be finding a link between stress and exacerbations of MS (Mohr, Hart, Julian, Cox, & Pelletier, 2004).

Many of the stress studies have used methods that were scientifically weak. As a result, the question of the stress–MS link remains cloudy and controversial. However, there is little doubt that the belief in this link can cause much unnecessary heartache. Family members may express guilt because they think they caused emotional stress that worsened their loved one’s MS. Many people with MS have quit their jobs because a misguided physician told them that they needed to avoid “occupational stress” to keep their MS from worsening. Such ideas have no scientific basis whatsoever. People with MS should be discouraged from making major life changes based on “avoiding stress.” Most sources of stress are beyond our control in any case. The key is to learn how to deal with stress in one’s life, not to try to escape it.

Mohr (2008) provides some useful insights concerning this complex issue, which are worth quoting in detail:

- A feeling of distress may be an early sign of disease activity. We know that changes in brain tissue begin many months before the appearance of gadolinium enhancing lesions; such changes may somehow precipitate feelings of distress
- Stressful life events may be one factor among many that determine if early pathogenic disease processes progress to become gadolinium enhancing brain lesions or full exacerbations

- Chronic stress may cause alterations in levels of endogenous glucocorticoids, thereby altering the body's ability to regulate inflammatory pressure
- If there is a real relationship between stressful life events and MS exacerbation, it is likely quite variable across patients; some patients may be resilient, whereas others may be more vulnerable
- The evidence regarding stress and disease progression, or sustained progression, is contradictory; no conclusions can be drawn at this time

Studies that have investigated the relationship between stress and the immune system (Foley et al., 1988; Mohr et al., 2000; Heesen et al., 2007) have found that the relationship between stress and illness is not a simple one and may vary depending on how long the person has had MS. Other studies have long shown what is self-evident, that MS is a tremendous source of stress and can lead to emotional distress (LaRocca, 1984). There is evidence that psychological distress is likely to increase when an exacerbation occurs and to abate as remission ensues (Brown et al., 2006; Dalos, Rabins, Brooks, & O'Donnell, 1983). We need to be particularly sensitive to a person's emotional state and potentially increased need for help when he or she is dealing with an exacerbation. Because MS can disrupt a person's physical and social life and undermine self-esteem, it may aggravate preexisting personality problems. Here is an example:

Mary has always been a person who needed to be in control. Some would have described her as bossy or picky. She had an opinion about everything and was generally critical about the way people in the family did things. Nothing was ever good enough for her. After she developed MS, Mary was no longer able to walk and had to rely more and more on other family members to do things around the house. Gradually, she progressed from picky to petulant. Because no one could do anything to her satisfaction, she would loudly berate members of the family concerning their shortcomings. Eventually, everyone in the household began to avoid her and Mary became increasingly isolated and lonely within her own family.

The individual described here has become a caricature of her former self. She and her family need the help of a psychotherapist to sort out the feelings that MS has engendered. Mary will probably always be somewhat perfectionistic. However, at present she has become impossible to live with—even for herself—and some intervention is needed.

Many stresses accompany MS; they may be roughly divided into two types: major life events and everyday stress. The major life events are

those things such as losing one's job that require change or readjustment on the part of the individual and/or family. Everyday stress, sometimes referred to as "hassles," are the many day-to-day occurrences, such as being stuck in a traffic jam, that do not require major life changes but are emotionally taxing. Let us look at some of the psychosocial issues in MS that are sources of stress and how we can respond to them. Each is illustrated with a vignette. Although these vignettes have been prepared so that in their details they do not resemble any real person, each situation is drawn from actual clinical experience and exemplifies the real-life challenges of MS.

Uncertainty and Unpredictability

Uncertainty is probably the first of the stresses that MS places on the individual. Fleeting and ambiguous symptoms, such as numbness or blurred vision, may be the first signs of MS. It may take months or years to establish a definite diagnosis, during which time these symptoms may be attributed to fatigue, depression, hysteria, or any of a host of other causes. Shock and disbelief may ensue once the diagnosis of a chronic, degenerative illness sinks in. The person with MS wants to know his or her prognosis—"What is going to happen? . . . Am I going to end up in a wheelchair?"—and is frustrated to learn that no one can predict the disease course or outcome with any certainty. Building a sense of security and stability in the face of such uncertainty is a significant challenge that carries with it the potential for significant emotional turmoil. Here is an example:

Tom walks with difficulty using a cane. He has worked for several years at a large telecommunications company that is currently downsizing. He has been able to work out an arrangement in which he telecommutes 3 days per week and works at his office the other days. He feels fairly secure in his job because he has received excellent evaluations. However, the company has several employees with disabilities, and no one is exempt from downsizing. Tom has another job offer from a different company. The new company has a reputation as a good employer and has made him a good offer. However, he would have to travel more than an hour to the new job, and because of the nature of his duties, he would not be able to telecommute more than 1 day a week. Tom thinks that he could handle the new job so long as his MS does not get worse. However, if driving became more difficult or fatigue became a problem, he would probably not be able to do it. When he comes in for a medical visit, he discusses how his uncertainty about his illness is making it hard for him to make a decision.

Tom needs to express some of his feelings of anxiety about the unpredictability and uncertainty of his illness. A psychotherapist could help him to do this. Tom might also find it helpful to talk to an employment specialist and/or an attorney to make sure that he understands his rights and options. He cannot escape the uncertainty of MS. His challenge in the face of uncertainty is to make an informed decision that is neither overly optimistic nor pessimistic.

Denial and Adaptation

When the diagnosis of MS is established, a sense of relief may follow because at least some of the initial sense of uncertainty has been resolved. However, many may then find themselves in a state of mild shock. Because most people's expectations in life do not include an incurable, progressive disease such as MS, some sense of disbelief is a normal and healthy reaction. Denial can be helpful in that it gives the individual time to absorb a shocking reality for which he or she was totally unprepared. In most instances, this initial sense of shock and disbelief gradually passes as people begin to acknowledge the diagnosis and find ways to incorporate the realities of the illness into their lives. Most people with MS will say that they never fully accept the disease any more than they would accept a perpetual earthquake shaking the ground under their feet. However, they do begin the work of making the adaptations that are necessitated by the disease. When health care providers find that such changes are not being made, it is often because denial has persisted long after it has outlived its usefulness. When denial begins to get in the way of effective planning and decision making, particularly in terms of initiating or adhering to treatment, disclosure, accommodation requests in the workplace, and safety issues, it is time to consider other strategies. Here are a couple of examples:

Following her recent diagnosis with relapsing–remitting MS, Ellen's neurologist recommended that she begin treatment with one of the disease-modifying therapies. He told Ellen that although her initial symptoms had remitted, her MRI showed signs of significant disease activity. He explained the benefits of early treatment, referring to it as an important investment in her future. Nonetheless, Ellen decided not to start treatment at this time because she is feeling fine right now and does not want to take a medication that may make her feel worse than the disease. And, she is finding it hard to believe that she really has a chronic, potentially disabling illness when she is so healthy. Ellen wants to wait

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and see what happens because, after all, the doctor may have made a mistake about her diagnosis.

William is a favorite customer at the auto body shops. He has had four automobile accidents in the last 3 years, two of them quite serious wrecks. He had a spotless driving record prior to being diagnosed with MS at age 34. By age 36, William's physical symptoms included numbness and weakness in the legs, episodic double vision, and some memory loss. His first serious accident occurred shortly after his 36th birthday when he hit a utility pole on a clear night when he had nothing to drink. William's wife has pleaded with him to either stop driving or at least have his driving skills evaluated. He loudly refuses, attributing his mishaps to "bad luck," "faulty brakes," or "the other guy."

Ellen's reluctance to accept the reality of her diagnosis is interfering with her ability to make sound decisions. Education and support will be needed to enhance Ellen's readiness to accept the reality of her diagnosis and initiate disease-modifying therapy, but it may take the occurrence of another relapse for her to feel ready to contemplate treatment (Holland et al., 2001a, 2001b).

William appears to be engaging in a particularly dangerous form of denial. Unfortunately, denial is often hard to break through because, by its very nature, it shuts out ideas. Driving is a major bulwark of independence and, for many people, giving it up is worse than being unable to walk. William needs a carefully measured combination of confrontation and understanding. His need for independence should be acknowledged even as he is presented with the incontrovertible proof that something is not right. However, understanding and confrontation might not be enough. Family and friends may have to refuse to ride in a car if William is driving. He should be tested to determine if he has any specific visual or spatial deficits. In some states, such evidence of impaired ability to drive must be reported to the state motor vehicle agency. William has not injured anyone yet, but stands a high likelihood of doing so. His denial is standing in the way of adaptation and he will need a lot of help to break through it.

Grief and Depression

The shock and denial that can occur at some points in MS are akin to what people feel when they first hear of the sudden and unexpected death of a loved one. Shock and denial normally give way to grief as people mourn

the loss of someone who was an important part of their lives. In MS, grief plays out in a slightly different way. The losses that are mourned are largely losses of self. The old and able-bodied self is no more and needs to be mourned. Long-held expectations concerning the future may have to be abandoned. Valued physical abilities, such as running or skiing, may be lost and need to be mourned.

Family and friends do not always have an easy time with MS-related grieving. It is sometimes hard for them to understand why the person with MS is down in the dumps when his or her symptoms are “not so bad.” However, grief is a normal reaction to the types of changes that occur in MS. Grieving can encompass several reactions and may include (a) sadness and crying, (b) fear and denial, (c) anger and irritability, (d) asking “why me?,” (e) reminiscing about the past, and (f) longing for happier times. At times, feelings of anger and resentment borne of the person’s feelings of loss may be directed against others, adding to family strain and confusion. Here is an example:

Before she developed MS at the age of 37 years, Sandra had been a successful account representative for a major office technology company. Although her cognitive abilities are intact, she is no longer able to walk. She had been in a competitive field and her inability to get around to her accounts spelled the end of her career. Her company had excellent disability insurance but was planning to scale it back along with other costly parts of the benefit package. Sandra agonized over whether to go out on disability or try to transfer to a lower paying position in the company. Because she has a family—a husband and two daughters—she opted for the financial security that disability payments based on her old salary would provide. The first few weeks of retirement went fine because she caught up on reading, saw friends whom she had not seen for a long time, and worked on long-neglected hobbies. However, after several months went by, Sandra became increasingly moody, alternating between periods of somber withdrawal and extreme irritability. Formerly a mellow and loving wife and mother, she now seems to find fault with everything. Unknown to her husband, she cries every morning when he leaves for work. She spends a lot of time thinking and talking about her old job. Her husband cannot understand what is going on. She has a nice pension and lots of time to do whatever she wants. He wishes he had it so easy. He urges her to stop thinking about the old days and try to enjoy the present. She has always been good with people and once considered going to school to become a social worker. However, she simply cannot face the prospect of starting over again.

Saundra is grieving. She needs space to engage in this process and live through the feelings that go with it. If her husband can develop a better understanding of the process of grieving, he can be helpful in allowing her to give vent to her emotions. In time, she will probably be ready to build a new life for herself, perhaps even getting her degree in social work.

When we encounter someone who is grieving, we are likely to say that he or she is “depressed.” What is the difference between grief and depression? Grief is often focused on a specific event or set of events and is generally time limited. The individual who is grieving may be sad but is usually able to engage in stimulating activities and enjoy the company of others. In contrast to grief, clinical depression is generally more severe, pervasive, and persistent. Clinical depression is typically diagnosed in the form of a major depressive episode. Such an episode consists of persistent (daily for 2 weeks or more) sadness and/or lack of interest or pleasure in previously enjoyable activities, along with at least three of the following: (a) loss of or increase in appetite, (b) sleep disturbance, (c) feelings of hopelessness, (d) persistent thoughts of death or suicide, (e) feelings of worthlessness, self-reproach, or guilt, (f) lassitude, and (g) inability to concentrate.

In practice, it is often difficult to distinguish between severe grief and clinical depression. Professional help may be *useful* in both instances; it is *essential* in clinical depression. There is evidence that psychotherapy can relieve some of the symptoms of depression in MS (Foley, Bedell, LaRocca, Scheinberg, & Reznikoff, 1987; Mohr, Boudewyn, Goodkin, Bostrom, & Epstein, 2001). Antidepressants have also been used successfully. The tricyclic antidepressants such as amitriptyline (Elavil) and imipramine (Tofranil) were used for many years, although in the last few years, the selective serotonin reuptake inhibitor (SSRI) antidepressants (including paroxetine [Paxil], fluoxetine [Prozac], and sertraline [Zoloft]) are more commonly prescribed and there is evidence for the effectiveness of sertraline (Mohr et al., 2001).

The term *depression* is a potential source of confusion in MS because it is used in so many different ways. When used as defined previously, it refers to a specific set of conditions that, taken together, constitute a particular psychiatric diagnosis: major depressive episode. However, the term is often used to refer to a less specific and less severe state of dysphoria (sadness) and generalized psychological distress. Thus, a person who is having a bad day in which everything goes wrong may describe himself or herself as “depressed.” Because MS has such wide-ranging effects, people with MS frequently experience some emotional distress, especially when they have an exacerbation.

Both clinical depression and less severe emotional distress are common in MS. It has been estimated that 50% of people with MS experience a major depressive episode at some time during the course of their illness, a rate much higher than in the general population or in other conditions with similar disabilities (e.g., spinal cord injury). In fact, the very high frequency of depression in MS has led many to theorize that some of the clinical depression seen in MS may be the direct result of damage to parts of the brain concerned with the regulation of emotions and research has confirmed this to some extent (Feinstein et al., 2004; Zorzon et al., 2001). In all probability, there are various causes for the clinical depression seen in MS, including demyelination, altered life circumstances, and possibly inherited susceptibility to affective disorders. Whatever the cause, clinical depression should be taken seriously and treated. The rate of suicide is much higher in people with MS than in the general population and is one of the leading causes of death in MS. If you recognize the signs of clinical depression, you should strongly recommend evaluation by a psychiatrist. Here is an example:

Margaret has had MS for 16 years, having been diagnosed at the age of 32 years old. She did well for several years, walking with a cane and keeping close tabs on the availability of rest rooms. About 2 years ago, however, she experienced a severe flare-up that required hospitalization for the administration of high-dose intravenous steroids followed by inpatient rehabilitation. Although Margaret somewhat improved, she never regained the ability to walk and now must use a wheelchair. She seemed to be making a good adjustment and had a lot of friends, numerous interests, and a part-time job doing computer work at home. About 2 months ago she began to become increasingly withdrawn, stopped seeing friends, and lost interest in her hobbies. She had been an avid reader but now rarely picks up a book, saying that she cannot concentrate. Food had always been important to her, but she only eats if reminded to do so and then picks at her food. She has lost 15 lbs in 2 months. She has one son who is away at college. Her husband tries to engage her in conversation, but she seems listless and uninterested. In occasional moments of intimacy, she confides to him that she feels completely useless and that her life has no purpose. Margaret fantasizes about being dead so that she can escape her pain and cease being a burden to her husband. She has not received treatment for depression but her internist has given her a prescription for sleeping pills because she has been having trouble falling asleep. One day Margaret's husband found a plastic bag containing about 30 of the sleeping pills hidden in her night table.

Margaret has progressed well beyond grief or simple emotional distress. She is clinically depressed and has at least a rough plan to take her own life. This represents an abrupt and recent change for her. She had been enjoying life, work, and friends until recently. She needs professional help quickly, probably a combination of medication and psychotherapy. With such help, she should be able to resume her former activities and will likely see things in a more positive light.

Emotional Instability and Personality Change

The bouts of grief and depression described so far are part of a much larger picture of emotional instability that occurs in MS. For want of a better term, people often refer to these collectively as *mood swings*. In reality, we all fall prey to emotional instability from time to time. However, it appears that having MS makes one particularly vulnerable to emotional instability of many types. The possible exacerbations and remissions of MS can create their own emotional instability. Mood swings may also occur on an hour-to-hour or minute-to-minute basis. Families often mention that the person with MS may be cheerful and loving 1 minute and angry and critical the next. Other families describe a different phenomenon in which the person with MS is extremely sensitive, cries easily, and finds it difficult to stop crying once having begun. A third type of emotional instability involves fits of laughing and crying that seem unrelated in any obvious way to what is happening in the environment. Let us look at each of these in more detail.

Mood Swings

Most people experience some emotional instability when they are placed under tremendous stress. It may manifest itself as irritability, hypersensitivity, and fragility of mood. A good mood may be toppled easily, like a house of cards, and replaced by darker thoughts and a pessimistic outlook. These mood swings may not be confined to the person with MS. Family members, responding to life pressures and their own issues, may also have them. However, the ups and downs sometimes experienced by people with MS may also be fueled in part by demyelination in those parts of the brain responsible for the regulation of emotion. Although research on this topic is lacking, it could help to explain why many people with MS are so emotionally unstable at times. Whatever the cause, dealing with mood swings can be challenging. Brief family therapy can help everyone understand the phenomenon. Therapy can also help to clarify

and resolve some of the psychosocial issues that may contribute to the mood swings. Sometimes several members of the family are experiencing the same pain and concerns but are unable to share them effectively with one another. Through therapy, family members can be helped to air some of their concerns and work toward solutions.

Emotional Lability

Emotional lability in which crying, laughing, anger, or other strong emotions are easily provoked (“at the drop of a hat”) and difficult to stop is not confined to MS. However, it seems to be much more common in MS than in other populations. Although research on this topic is sadly lacking, this sort of mood alteration is likely caused, in part, by demyelination. Once people become aware of this problem, it is possible for them to handle it constructively. Being aware of the situations that are likely to provoke a strong reaction may help people prepare for the rush of emotions that may result. Taking a few deep breaths or pausing for several moments before saying anything in response can help the person control the strong emotions. Finally, trying to see individual events in a larger context may be helpful. Sometimes each event is treated as if it were a life or death situation. Trying to see the larger picture can have a calming effect.

Pseudobulbar Affect

The third and most extreme form of mood alteration is called *pseudobulbar affect*. This is a classic symptom of MS in which the individual has fits of laughing or crying that seem to be out of his or her control. Additionally, these episodes of laughing or crying may have little or no precipitant or the precipitant, if any, may have little or nothing to do with the emotion being expressed. The person having a crying jag may report later that he or she did not really feel sad and cannot say why the crying started. There is little doubt that such episodes are a direct result of demyelination in the brain. Studies have shown some success in treating pseudobulbar affect with Elavil (amitriptyline; Schiffer, Heldon, & Rudick, 1985) and fluoxetine (Seliger, Hornstein, Flax, Herbert, & Schroeder, 1992).

MAKING REFERRALS THAT WILL BE ACCEPTED

Referring people for help with emotional issues requires care and sensitivity. When it is done carefully, you may be successful. When it is done carelessly, not only are you not successful but you might not get a second

chance. People who confide private problems are likely to “clam up” in the future if they find that these confidences are handled clumsily or abruptly. A person may reveal psychosocial problems yet feel ambivalent about discussing family and emotional problems with physicians and nurses who deal primarily with physical problems.

Many people become incensed when you suggest that they see a therapist or a psychiatrist. They have barely gotten accustomed to the idea that their body is not working properly and may misinterpret a referral to a therapist as an indication that they are “crazy” or have “mental” problems as well as physical ones, or that they are too “weak” to handle their problems on their own. Psychosocial interventions need to be presented as another facet of comprehensive medical care. Showing people that psychiatry, psychology, and social work are routine components of the team, just like the nurse, physical therapist, and speech pathologist, can help diffuse some of the anxiety. MS presents various challenges and there are various tools available to help people in dealing with it. Psychosocial interventions are important additional tools.

Cognitive Changes

MS is a disease that produces demyelination and axonal damage in the brain and spinal cord. It is, thus, not surprising that upward of 50% of people with the disease show some cognitive deficits when properly evaluated. The frequency of cognitive changes was grossly underestimated in the past. This underestimate occurred because people relied on the brief mental status exam performed by a physician (Peyser, Edwards, Poser, & Filskov, 1980). The so-called bedside mental status can readily detect only major and obvious traumas to the brain. More subtle insults to the brain may require a more sophisticated assessment using standardized tests such as those administered by a psychologist or speech pathologist. There has been research using brief batteries of tests (Basso, Beason-Hazen, Lynn, Rammohan, & Bornstein, 1996; Beatty & Goodkin, 1990; Beatty et al., 1995; Dent & Lincoln, 2000; Rao, Leo, Bernardin, & Unverzagt, 1991) or batteries of moderate length (Benedict, Fischer, et al., 2002). However, approximately 5–6 hours of standardized testing may be required to assess the nature and severity of cognitive deficits properly. Other innovative assessment techniques that have been developed in recent years include self-report measures (Benedict et al., 2003, 2004) and computerized assessments (Wilken et al., 2003).

During the last few years, numerous studies using MRI have demonstrated that the presence and severity of cognitive dysfunction is related to the overall extent of demyelination. More studies have shown

that lesions clustering in particular areas of the brain are likely to be associated with specific functional deficits (Foong et al., 1997; Ryan, Clark, Klonoff, Li, & Paty, 1996). For example, the corpus callosum is the heavily myelinated structure that connects the right and left halves of the brain. Lesions in this area tend to be associated with slowing in the ability to process information as well as any tasks that require the transfer of information between the left and right hemisphere. In contrast, lesions in the frontal lobes are often associated with memory deficits and impairments in executive functions such as planning ability. Studies have also shown a relationship between cognitive impairment in MS and axonal transection, cerebral atrophy, biochemical changes in the brain, and abnormal brain activation patterns (Amato, Zipoli, & Portaccio, 2008; Benedict, Bakshi, et al., 2002; Mainero et al., 2004; Stone et al., 1995; Trapp et al., 1998;).

Although debate continues concerning the exact cognitive functions affected, consensus has been building over the years. In contrast to conditions such as Alzheimer's disease, in which most intellectual functions are severely affected in the space of just a few years, the deficits seen in MS tend to be circumscribed and more limited in severity. Typically, MS affects some cognitive functions whereas leaving others intact. This preservation of functions is important because it gives the person valuable assets with which to compensate for more compromised functions. Only about 5–10% of people with MS experience cognitive changes severe enough to interfere seriously with daily activities. Let us examine some of the cognitive functions that can be affected in MS and what can be done about them.

Memory

Memory loss is the most commonly cited cognitive dysfunction in MS. It has generally been thought that people with MS are able to learn new material adequately but then have trouble recalling or retrieving that information (Rao, 1986). Some researches have suggested that many individuals with MS learn new information with greater difficulty than controls but can recall that information well as long as learning was adequate in the first place (DeLuca, Gaudino, Diamond, Christodoulou, & Engel, 1998; DeLuca & Johnson, 1993). This has important implications because those who are attempting to teach new skills to people with MS may find it a frustrating experience. MS memory problems impinge on everyday life in myriad other ways. Those affected may find that they forget appointments, misplace things, have trouble following the plot of a book or movie, and cannot remember family social events. Families are

often unaware that MS may be causing memory problems. A person with MS may forget to do important things, angering other family members. Here is an example:

Don is a respected attorney in his early 50s. He has had MS for about 15 years. He walks with a cane and works full time. He and his wife, a guidance counselor, have two children in college. Don has always handled the family finances, including the taxes, financial aid applications, and refinancing the mortgage. During the past few months, he has made several major slip-ups, such as forgetting to pay certain bills and losing track of a couple of important documents. Recently he and his wife had a major blow-up because he forgot to submit the annual financial aid form for their younger son. They were able to get an extension but his wife was furious. She accuses him of being “all wrapped up in himself,” careless, and lazy. She is also irritated at him because he often forgets things that she has told him. When he was diagnosed with MS, he was reassured that cognitive changes rarely occur and then only in very debilitated, end-stage patients. When Don’s wife calls his doctor’s office to renew a prescription for baclofen, she mentions off-handedly that she and Don are getting old, as shown by his failing memory. The nurse explains that although there are cognitive changes associated with age, people with MS frequently have memory problems even if they have only mild physical disability. Given this new information, Don and his wife decide to pursue the issue. Don’s memory loss is confirmed through neuropsychological testing. He works for several weeks with an occupational therapist who helps him to learn compensatory strategies.

Although not all stories have such a happy ending, it is often the nurse who is on the front line and who may hear or see things that escape the notice of others. Sensitivity and quick action can often help people with MS get the intervention they need sooner rather than later.

Reasoning and Judgment

Abstract reasoning involves the internal manipulation of ideas, particularly symbolic representation of things existing in the real world. For example, “love” is an abstraction, a symbol that represents for the lover an entire set of thoughts and feelings. Mathematics is replete with abstractions such as “square root,” something we cannot see or touch but which has an existence in our minds. Abstract reasoning can be impaired by MS but, because of its subtlety, impaired abstract reasoning may not be recognized as quickly as memory loss. At times,

the first sign of a problem with abstract reasoning may be a lapse in judgment. Anyone who engages in any sort of analysis or decision making may find that deficits in abstract reasoning get in the way. Here is an example:

Judy is 44 years old and has had MS since her mid-20s. She has built a successful career as a securities analyst. During the last 2 years, she has noticed mild memory impairment but has been able to compensate effectively using a personal digital assistant (PDA) along with liberal use of the information management capabilities of computers. During the last 6 months, she has had increasing difficulty in her work. She analyzes companies to develop recommendations concerning their investment potential. She now finds that she has trouble keeping straight the many facts that she must take into account in performing her analysis. Even worse, long known for having a sixth sense about investments, she now finds it hard to sort the more important from the less important factors in her analyses. Things came to a head recently when she submitted a positive report on a European telecommunications firm that the rest of the investment community had written off. About a week after she submitted her report, the company announced massive layoffs, huge fourth-quarter losses, and the closure of several divisions. Fortunately, her report was still under internal review and had not been distributed to clients.

Judy is in a real bind. If MS has indeed affected her analytic skills to the extent suggested by this vignette, she will be confronting the need for a career shift. In addition to a good evaluation of her deficits, she is likely to need a lot of support as she goes through the process of accepting these new limitations, grieving for her loss, and adapting to the changes.

Other Cognitive Changes

Space does not permit a full discussion of all the ways in which cognitive functioning can be affected by MS. Memory and abstract reasoning were highlighted because they are often the initial cause of problems in work and family life. Here are some others:

- *Speed of information processing* can be impaired in MS and is often mentioned by those affected (Archibald & Fisk, 2000). A typical description might be, "I can still do everything I used to do, but now it takes longer. It's like my head is filled with molasses." This problem can be particularly acute when people are called on to process information

that is coming at them quickly from many different directions (e.g., in a busy office or hectic household).

- *Word-finding* problems may be the most socially mortifying of the MS cognitive changes. This refers to the “tip of the tongue” phenomenon in which the individual gets stuck in mid-sentence because he or she cannot think of a particular word. Unlike most other cognitive changes, this one is hard to hide and it occurs right where everyone can see it.
- *Complex attention* (sometimes referred to as *multitasking*) may be affected in MS. Deficits here can be very disabling because complex attention is essential for many functions in daily life and helps to facilitate the use of other intellectual functions. People with complex attention problems may have trouble with distracting environments and switching between tasks. We tend to see these problems manifest in subtle ways, such as when people are called on to divide their attention. Much of life involves doing two things at once (e.g., preparing dinner while your 12-year-old tells you why she needs a new jacket). People with MS sometimes find that they need to slow the flow of information and focus on only one channel at a time—otherwise dinner gets burned and the jacket gets lost.
- People with MS often have problems with visual–perceptual skills, one of the skills you need to put together furniture labeled “some assembly required.” An experienced auto mechanic who developed MS mentioned that he now has to think twice about which way to turn the wrench. This can be more devastating than memory loss for someone in a job that requires spatial skills. Many leisure activities also are dependent on these same skills—woodworking, sewing, and so forth.
- *Executive functions* are frequently affected in MS. These include planning, prioritizing, and organizing. These functions come into play when we have to implement a project and bring it to fruition. This could be a small project such as paying the bills or a large project, such as one might encounter as part of one’s job as a construction manager. Initiation of a project is often affected and the individual so affected that he or she just cannot seem to get started. Disorganization and inability to logically set priorities, timelines, and goals are other signs of problems in this area. Needless to say, impairment of executive functions can have serious consequences not only in the workplace but in the family as well.

So far we have discussed the cognitive functions more frequently affected in MS. The cognitive effects of MS, like its physical symptoms, can vary tremendously from person to person (Fischer, 1999). Most language functions are preserved, so it is rare to find someone with MS having an

expressive aphasia. Perhaps 90% of people with MS show either no cognitive changes (50%) or changes that are relatively mild (40%), interfering with daily activities to only a limited extent. However, because MS is variable and progressive, a minority (5–10%) may develop a severe global dementia, which in its most severe manifestations can resemble Alzheimer's disease. In such instances, most cognitive functions are severely affected and the person may be unable to care for himself or herself or manage personal and financial affairs. When this happens, constant supervision will be needed as well as assistance with even simple tasks such as dressing, even if the person is physically able to perform them.

The Course of Cognitive Dysfunction

The cognitive symptoms of MS do not seem to relate very closely to the physical symptoms. Although it is clear that cognitive impairment is likely to progress over time, there is little or no relationship between how long someone has had MS, or how severely disabled they are physically, and cognitive dysfunction (Amato, Ponziani, Siracusa, & Sorbi, 2001; Amato et al., 2006). People with few physical symptoms may have fairly severe cognitive ones. Conversely, individuals who are unable to walk and have a host of physical symptoms may be cognitively intact. Although there are some evidence to suggest that people with a progressive course are at greater risk for cognitive dysfunction, this relationship is extremely weak and probably based on the fact that patients with a progressive course are likely to have more extensive lesion area. Once they appear, cognitive deficits rarely disappear completely. However, cognitive symptoms can worsen during an exacerbation and gradually abate as the person goes into remission. Sometimes these changes can be dramatic, but it is more common for cognitive symptoms to progress gradually (Kujala, Portin, & Ruutiainen, 1997). Some studies have shown little or no measurable progression over time in cognitive impairments (Rao et al., 1991) or have found a mix of deterioration, stability, and improvement (Amato et al., 2001; Jennekens-Schinkel, Laboyrie, Lanser, & van der Velde, 1990). Given the generally mild severity of these symptoms and their slow progression, and the fact that many functions are intact, people with MS are generally excellent candidates for cognitive rehabilitation.

Intervention

At one time, cognitive dysfunction was a taboo topic in MS, partly because the problem had no solution. We still do not have a cure, but many investigators and clinicians around the world are trying to address cogni-

tive dysfunction. An error made by many family members, friends, and even professionals was to ignore these problems or try to dismiss them. Well-meaning but misguided people reassure the person with MS that “everyone is forgetful from time to time” or “I lose things all the time myself.” The cognitive problems of the person with MS are generally not the same as the everyday forgetfulness experienced by others.

As discussed previously, the first step is recognition of the problem, followed by a thorough assessment. A good neuropsychological evaluation may cost close to \$4,000. Thus, one should not undertake this testing unless there is a good reason to do so. Sometimes a short screening battery (Strober et al., 2009) can determine whether something is wrong. However, the full-length battery will be needed to properly delineate the exact nature and severity of the deficits. People are naturally sensitive about these deficits. They may be afraid that others will consider them crazy or stupid. Having cognitive changes does not mean that a person is stupid or has lost his or her intellectual abilities. Cognitive changes are generally specific, and the individual usually retains a good portion of his or her abilities and can use them in a rehabilitation program. Cognitive changes are neurologic manifestations of the disease, just like spasticity or optic neuritis, and do not imply craziness, stupidity, laziness, or any other misconstrued causes.

Treatment of cognitive dysfunction in MS has generated increasing interest and research in recent years. The two most important treatment options include cognitive rehabilitation and pharmacologic treatment. Perhaps the most exciting development in this area has been the growth of cognitive rehabilitation for MS. In many parts of the world, psychologists, speech pathologists, and occupational therapists are working with people who have MS-related cognitive dysfunction (Allen, Goldstein, Heyman, & Rondinelli, 1998; Brenk, Laun, & Haase, 2008; Foley et al., 1994; Jönsson, Korfitzen, Heltberg, Ravnborg, & Byskov-Ottosen, 1993; Khan, Pallant, Brand, & Kilpatrick, 2008; Plohmann et al., 1998; Rodgers, Khoo, MacEachen, Oven, & Beatty, 1996; Sullivan, Edgley, & Dehoux, 1990; Tesar, Bandion, & Baumhackl, 2005). Such programs often employ two complementary approaches. In the retraining approach, the brain is viewed as having “plasticity,” and progressively more challenging exercises are used to strengthen impaired cognitive functions. The retraining approach to memory deficits, for example, might involve drills in which word lists of increasing length are memorized. In the compensatory approach, the permanence of the impairment is taken as a given and the individual is taught how to perform specific functions in new ways using various aids and substitutions. The compensatory approach to memory deficits might involve use of a PDA to record facts, tasks, and events that

are likely to be forgotten. Retraining may be beneficial for some deficits (e.g., attention or concentration problems). However, based on clinical experience and the scientific literature in other disorders, the compensatory approach appears to be more productive and recent research suggests that simple compensatory measures, such as use of a PDA, can achieve real benefits in patients' everyday lives (Gentry, 2008).

Cognitive rehabilitation is routine in head injury but, at this writing, it remains something of a novelty in MS. Many people with MS are excellent candidates for cognitive rehabilitation: their deficits are usually mild to moderate, many abilities are intact, and their symptoms are not likely to progress rapidly. It thus seems likely that this area of treatment will grow rapidly during the next few years. In the meantime, nurses who work with patients with MS may find it useful to adapt some of the compensatory techniques developed by rehabilitation specialists. Here are some strategies that may prove useful:

- Try to provide instructions to patients in written form or, if possible, on video or audio tape.
- Give patients printed medication schedules with explicit instructions.
- Keep instructions as simple as possible.
- Repeat instructions, many times if needed.
- Verify that the patient understands the instructions.
- Consider using compensatory aids such as blister packs or pill boxes for medications.
- Train patients to use clocks or timers with multiple alarms to improve adherence to medication schedules.
- Enlist the assistance of a helper, such as a family member, to improve adherence to medication regimens.

Research on pharmacologic interventions is focused on two types of treatments: disease-modifying agents and symptomatic therapies. Disease-modifying agents include interferon beta-1a (Avonex), interferon beta-1b (Betaseron), glatiramer acetate (Copaxone), mitoxantrone (Novantrone), interferon beta-1a (Rebif), and natalizumab (Tysabri). Research examining the potential beneficial effects of these agents on cognitive function has had mixed results. In the pivotal clinical trial that led to the approval of Avonex, 166 patients with relapsing–remitting MS were given a comprehensive battery of cognitive tests at entry and at the end of 2 years. A shorter battery of cognitive tests was administered every 6 months (Fischer et al., 2000). Compared to those receiving placebo, the patients who received Avonex performed better on tests of learning, memory, and information processing. In addition,

beneficial effects were observed on tests of executive functions and visuospatial abilities.

The pivotal clinical trial of Betaseron was not originally designed to include measures of cognitive function. However, a subset of 30 patients with relapsing–remitting MS from this trial were administered a battery of cognitive tests 2 years in the trial (Pliskin et al., 1996). After 2 years, these patients were retested. Those who received Betaseron performed better on a test of visual memory than patients who received placebo. In another study, patients receiving Betaseron were compared to controls who were not receiving treatment over a 1-year period (Barak & Achiron, 2002). Patients in the treatment group improved in complex attention, concentration, and visual learning and recall whereas controls deteriorated in complex attention, verbal fluency, and visual learning and recall.

A brief battery of cognitive tests was administered to 248 patients with relapsing–remitting MS enrolled in the pivotal clinical trial of Copaxone (Weinstein et al., 1999). Patients were tested at baseline and at 12 and 24 months. There was no difference between the Copaxone and the placebo groups at baseline, 12, or 24 months on any of the cognitive tests.

Stephenson, Kamat, Rajagopalan, Agarwal, and Singer (2009) examined the impact of Tysabri on a self-report measure of the impact of cognitive changes. After three infusions, patients reported modest improvement in perceived impact of cognitive deficits as well as fatigue and quality of life. No actual cognitive tests were administered in the study. In an earlier Atrial Fibrillation Follow-Up Investigation of Rhythm Management (AFFIRM) study, Tysabri was shown to reduce the likelihood of progression in cognitive impairment by 43% compared to placebo as measured by the Paced Auditory Serial Addition Test (Fisher et al., 2006).

Although the research examining the impact of disease-modifying agents on cognition has been limited and, at times, disappointing, the prospects are perhaps more positive than the results would suggest. None of the clinical trials described previously were designed primarily to test the effects of treatment on cognitive function and the study periods were generally short. Moreover, most patients in all of these studies had little or no cognitive dysfunction. Improvements in study design, better selection of tests, and more sophisticated statistical analyses should help investigators to achieve greater sensitivity and precision in this area of research. It is also encouraging to note that those treatments that can slow the accumulation of lesions and cerebral atrophy shown on MRI should help to stabilize cognitive changes over the long

term because cognitive dysfunction has been shown to be associated with these changes.

Symptomatic pharmacologic interventions do not attempt to modify the course of the underlying disease but to improve one or more manifestations of MS, such as cognitive dysfunction. A study of 4-aminopyridine (a potassium channel blocker that speeds nerve conduction) found no effects on cognitive dysfunction among patients with MS (Smits et al., 1994). Investigators found that neither amantadine nor pemoline (Cylert; drugs used to treat MS fatigue) had any beneficial effects on cognitive function among patients with MS (Geisler et al., 1996). Other agents that have not been shown to benefit cognitive function in MS include ginkgo biloba (Lovera et al., 2007) and memantine, which actually produced reversible worsening (Villoslada, Arrondo, Sepulcre, Alegre, & Artieda, 2009).

Positive results have been found with methylphenidate (Harel, Appleboim, Lavie, & Achiron, 2009) and L-amphetamine sulfate (Morrow et al., 2009) and anecdotal reports suggest that many physicians are prescribing attention-enhancing drugs to their patients with MS with cognitive impairment. Mixed results in terms of both positive and negative impacts have been found with corticosteroids (Oliveri et al., 1998; Patzold, Schwengelbeck, Ossege, Malin, & Sindern, 2002). Several other agents are in early stages of study but have shown some promise in small trials including testosterone gel, monthly treatments with cyclophosphamide and corticosteroids, and erythropoietin.

There has been long interest in the possible benefits of a class of drugs known as acetylcholinesterase inhibitors (Leo & Rao, 1988). These drugs are used to treat memory dysfunction in Alzheimer's and other disorders. They increase the available supply of a neurotransmitter called acetylcholine, which is thought to play a crucial role in memory. Early studies with one of the acetylcholinesterase inhibitors using small numbers of patients showed some benefits on verbal memory (Leo & Rao). Some studies have focused on donepezil HCl (Aricept), an acetylcholinesterase inhibitor that is used to treat mild-to-moderate memory disorders in Alzheimer's disease, vascular dementia, and traumatic brain injury (Greene et al., 2000; Krupp, Elkins, Scott, Smiroldo, & Coyle, 1999). In the largest study completed to date, Krupp et al. (2004) showed that Aricept produced modest improvements in verbal memory among patients with MS with memory deficits and that this improvement had some practical significance for everyday life. Another acetylcholinesterase inhibitor, known as (galantamine HBr) Razadyne, formerly known as Reminyl, is approved by the Food and Drug Administration for the treatment of mild-to-moderate dementia of the Alzheimer's type (Ortho-McNeil-Janssen Pharmaceuticals,

Inc., 2008). Although no studies of Razadyne in MS have been reported to date, this new drug is likely to generate interest on both the part of MS researchers and the patients, particularly because one of the ingredients, galantamine HBr, is derived from common plants, such as the snowdrop daffodil.

Considerable research remains to be done before we will have clear answers concerning the pharmacologic treatment of MS-related cognitive dysfunction. However, looking optimistically toward the future, it seems possible that these problems could be addressed through a combination of disease-modifying agents that help reduce or stabilize cognitive changes, symptomatic treatments that improve specific abilities, and rehabilitation strategies that help people to function more effectively in daily life.

THE IMPACT OF MULTIPLE SCLEROSIS ON THE FAMILY

When one member of a family is diagnosed with MS, it is almost as though a stranger has moved into the household and everyone must adjust or reorganize to make room. The central challenge facing the family is “to find a place for the illness while keeping the illness in its place” (Gonzalez, Steinglass, & Reiss, 1989). In other words, family members have to learn how to incorporate MS into their individual and communal lives without sacrificing themselves, their family lives, their interests and activities, and all of their energy to its demands. Clinical experience tells us that the family’s adjustment to the intrusion of MS into their lives is an ongoing one that ebbs and flows over the course of the illness.

The impact of MS on the family is too pervasive and complex to describe in any detail within this chapter (Kalb, 2006; Miller & Kalb, 2008). Therefore, we highlight some of the major challenges to family life, including conflicting coping styles, role changes, the shared grieving process, family communication patterns, and parenting issues.

Conflicting Coping Styles

Even within a single family, people differ significantly in how they approach problems, deal with stress, and express feelings. Once MS is part of the household, each family member must try to understand and accommodate the changes brought about by the disease. One person may want to research MS and talk about it with others as a way of dealing with the stress and uncertainty associated with the disease. Another may be unable to talk or read about MS, and try to cope by busying himself or herself with other things. Although there is no single “correct” coping

style, family members with different or conflicting coping styles may misunderstand or misinterpret each other's behaviors.

Susan was recently diagnosed with MS following several months of mysterious but fleeting symptoms. Although she has experienced some blurred vision, sensory changes, and occasional bouts of clumsiness, she is essentially symptom free at the present time. She has called the National MS Society to request literature and has checked out more than a dozen books from the library. She keeps trying to get her husband to talk and read with her about the disease and attend a support group meeting, but Jim does not seem interested. He has told her that he does not see any reason to spend a lot of time talking about MS because all of her symptoms have gone away. Susan is hurt by his lack of interest and has begun to worry that Jim may not be able to handle her MS.

Susan and Jim have different styles of dealing with their feelings. It is easy for Susan to interpret Jim's unwillingness to talk or read about MS as being insensitive to her feelings or uncaring about what is happening to her. Frequently, however, a spouse's reluctance to become educated about the disease has to do with fear of the unknown. Jim may also have concerns about his ability to deal with Susan's chronic illness and be afraid to learn what it might entail. Susan's anxiety about the diagnosis may be causing her to become overly focused on the disease to the exclusion of other things in her life, including her husband and their shared interests and activities.

Susan should be encouraged to invite Jim to visit the physician with her. This will help to ensure that they are both hearing accurate information about Susan's MS and have the opportunity to ask any questions they might have. The nurse is often in an ideal position to observe a couple's conflicting coping styles and determine if they might benefit from family counseling sessions to help them talk to one another about their concerns.

Role Changes

MS-related disability may gradually necessitate role changes within the family. If a man who has been the primary wage earner becomes too disabled to continue working, his wife may need to take on the role of breadwinner whereas he remains at home to care for the children and manage the household. A woman who has previously handled most of the housework may require the assistance of other family members for tasks she can no longer do. The teenage child of a severely disabled parent

may suddenly be required to assist not only with household chores but also with the parent's personal care. These role changes within the family are always stressful and sometimes problematic. Some happen gradually and others occur in response to an abrupt deterioration of symptoms. In either case, the changes disrupt the commonly accepted roles and rhythms of everyday life that gradually develop in every family.

Because these changes typically occur in response to disease-related disabilities, most family members find them difficult to discuss. The family member with MS may feel guilty about being unable to fulfill his or her former role(s); other family members may be resentful about the changes that are required and then be guilt-ridden about their resentments.

George has always prided himself on working hard and providing for his family. When he was forced to retire on disability a few months ago, his wife took a job at a local department store. George now has primary responsibility for running the household. He feels guilty that his wife, Ellen, has to work, having always believed that it was his job to support the family. He enjoys seeing his children more but cannot resign himself to doing chores that he always considered "women's work." He is embarrassed about his new role and has become moody and short-tempered with Ellen and the children. Ellen always kept a clean and orderly household. She is dissatisfied with the way George does things around the house but does not have the heart to criticize him, or the energy after a long day on her feet to do any housework herself.

George and Ellen had always felt good about their chosen roles within the family and proud of their relative contributions to family life. When George's disability forced them to change these roles, they made the necessary adjustments but never found a comfortable way to share their feelings about them. A family therapist could help them support each other through these changes in their lives, perhaps focusing on their success as a team; although each has had to make a major role change, their effective teamwork has enabled them to run the household and take care of their children.

Shared Grief

Feelings of loss and grief accompany the family through each new symptom and change in functional ability. Each progression in the illness requires that the individual and family members adjust to the loss and redefine themselves accordingly. "Who are we as a family now that our roles have

changed and our relationships to each other and the larger community are changing?" The family that once defined itself as "outdoorsy, athletic" may need to find a new identity. A family whose resources are being strained by medical costs or job changes may need to give up activities that once formed a core of their recreational time together and provided important connections with other members of the larger community.

The Jones family was always very active. Sid coached the kids' soccer and baseball teams and Sid and Mary belonged to a neighborhood tennis club. The whole family enjoyed hiking together during the summer. As Sid developed balance problems and severe fatigue, the family gradually started doing fewer and fewer of their sports activities. Sid felt like a burden, slowing everyone down all the time, and Mary and the children felt uncomfortable doing things that Sid once enjoyed so much. Both Mary and Sid stopped seeing their friends from the tennis club; they were worried about the club costs and Mary felt that Sid resented her playing tennis without him. The children, who previously had their dad with them at all their sporting events, found that they just did not see him as much anymore. No one was happy—but no one knew what to do about it.

Although most people are familiar with the concept of grieving over the death of a loved one, many people do not realize that grief is a normal response to the loss of anyone or anything that is significant in their lives. When families are forced to give up activities that are important to them, they need to grieve over the loss before they can begin to find satisfying and meaningful alternatives. Sid and Mary need to talk with the children about the changes the family has experienced so that they can share the feelings of loss with one another. The children can encourage Sid to watch the games even if he is no longer able to coach. Sid might look into a mobility aid that would enable him to accompany the family on certain types of hikes. Sid and Mary might decide to learn to play bridge as an alternative way to meet other couples. Sid might encourage Mary to continue playing tennis even though he can no longer play with her. Many families need the help of a family therapist to recognize the grieving process and begin this type of problem-solving discussion.

Family Communication Patterns

Family communication patterns are complex under the best of circumstances. In times of increased stress and change, preexisting family patterns tend to become exaggerated. A family that has tended to talk

little about their thoughts and feelings, either with each other or with others outside the family, may find it even more difficult to share their private fears and concerns about MS. Each lives with his or her own experience of the disease without attempting to share it with one another or with outside resources.

Another family that has been more comfortable with shared expressions of feelings and opinions may rely on this as their primary coping strategy when faced with the diagnosis of MS. As with conflicting coping styles, the family's communications become even more complex when individuals within the same family have different communication needs and styles.

Richard had already been diagnosed with MS by the time he and Joan got married. He was relatively symptom free and MS was never a major topic of conversation. Richard was the quieter member of the couple. He enjoyed solitary activities like carpentry and gardening and never talked much with Joan or anyone else about MS or his feelings about it. Joan was the social member of the couple. She enjoyed being with people and talking with family or friends about anything and everything. As Richard's MS became more disabling, their lack of communication became more and more of an issue. Even when he was forced to give up his job, Richard felt no need to discuss the major changes confronting the family. In response to Joan's efforts to talk to him about the changes in their lives, Richard would respond, "What's to talk about? This is the way it is." Joan became increasingly resentful of her husband's inability or unwillingness to talk about their situation and finally mentioned her difficulty to Richard's neurologist, who referred them for family counseling.

A second communication issue that is frequently observed in families learning to live with MS involves a conspiracy of silence. Family members feel the need to keep their feelings and concerns to themselves to protect one another. The partner with MS may not want to talk about his symptoms or his feeling that the disease is getting worse for fear of being a burden to his spouse or frightening her away. His spouse is resentful and overwhelmed by the increased responsibility and workload but feels guilty expressing these feelings in light of her husband's disability. Each is carrying a heavy emotional burden that could more easily be handled if they could learn how to share their feelings and support one another.

Couples locked in this type of silence may benefit from a couples' support group. In this setting, they may find it easier to share what they

are feeling and ask for what they need from one another because each member of the couple has the support of the other group members facing similar issues. It is sometimes easier for people to understand and accept feelings expressed by their spouses when they realize that other spouses are expressing similar feelings.

A third communication issue has to do with talking about MS with children. Parents tend to tell their children about MS on a need-to-know basis, and the parents' assessment of the child's need to know is frequently based on the severity or visibility of the physical symptoms of the parent with MS. The parent who needs an ambulation aid is more likely to tell the children than is a parent who has no apparent symptoms. However, recent studies involving children who have a parent with MS have strongly suggested that children are at least as concerned about, and affected by, the psychological changes in their parents—including both cognitive and emotional changes—as they are about balance or ambulation problems. In fact, children seem to be more affected by the emotional climate within the household than by the parent's physical limitations. Thus, children are aware that something is going on to cause a parent to be more upset, tearful, cranky, or forgetful than usual but do not have the information they need to be able to understand and deal with the behavioral changes they are witnessing.

Parents are also hesitant to talk with children about the MS diagnosis if that diagnosis has not been shared with the parent's employer or other family and friends. They may think (correctly) that the children would not be able to keep this "secret." This is a complex problem with no simple solution. On the one hand, adults sometimes need to protect their privacy to avoid employment problems. Or a parent may not be ready to have people in the community know about the disease. On the other hand, the parent's need for secrecy interferes with important parent-child communication about MS-related issues in the household that might help everyone live more comfortably with MS. The notion that the MS is a secret cannot help but give the child some feeling that there is something shameful or bad going on in the household.

Parenting Issues

MS is often diagnosed during that period of a person's life when important career and family decisions are being made. Prior to 1950, women diagnosed with MS were often told not to have children. In light of more recent evidence indicating no long-term risk of disease progression associated with pregnancy and childbirth, couples are generally being

encouraged to proceed with their families. This means that couples in which one partner has MS are faced with a decision that is essentially nonmedical. Today the issue is seldom whether it is “safe” to begin a family, but whether it will be manageable in the face of MS-related impairments.

The nurse is in a unique position to help couples think through this important decision. Couples need to be encouraged to (a) educate themselves about MS and think realistically about the problems it can pose; (b) evaluate their available economic, emotional, and family resources; (c) assess their ability to be flexible in their family and societal roles in the event that progressive disability requires a sharing or switching of anticipated parenting and breadwinning activities; and, perhaps most importantly, (d) think beyond the initial months of infancy to the big picture of parenting. Many prospective parents focus so intently on how they will hold, change, or carry a newborn that they forget how brief the period of placid immobility actually is.

Most adults begin parenthood with many preconceived ideas about what it means to be a “good” parent. Men frequently envision playing ball or coaching a soccer team as prototypical “father” activities. Women may picture themselves chauffeuring to lessons or play dates, baking cookies, and being a room mother or active in the Parent-Teacher Association (PTA). Physical impairments that interfere with these activities shake a parent’s confidence. The person wonders how he or she can be a good parent if these activities are not possible.

Fortunately, various resources are available to help mothers and fathers deal with these concerns (Crawford & Miller, 2006; Garee, 1989; Miller & Kalb, 2008). Family therapists experienced in disability issues, support groups, and parenting literature can help men and women think through their attitudes and preconceptions about parenting. People can be helped to redefine their parenting priorities, identify alternative ways of doing the things they want to do with their children and, perhaps most importantly, talk with their spouse and their children about their feelings and concerns. In recent studies, children have indicated quite clearly that open communication, emotional closeness, and shared time are more important than any particular parent–child activity.

CHALLENGES FOR NURSES

Nurses are involved in the care of people with MS in hospital inpatient services, outpatient treatment settings, and through community nursing services. Regardless of the setting in which the nursing activities take

place, there are certain challenges that, although not unique to the care of patients with MS, seem to be particularly common for health care professionals working with relatively young, chronically ill people.

Emotional Reactions to Working With Young, Progressively Disabled Patients

Most health care professionals view their work as a way to help people recover from illness and feel better. Nurses working with people who have MS are faced with the reality that their work, although necessary and important for maintaining a patient's optimal functioning and preventing unnecessary complications, will not help the person "get well." In fact, nurses in hospital settings and MS centers frequently encounter patients with MS who are becoming increasingly disabled. This can be particularly distressing for the young nurse who meets a newly diagnosed patient with MS of similar age and sex, with whom there is more of a tendency to identify.

The Dependent and Demanding Patient With Multiple Sclerosis

Nurses often find that patients with MS can be demanding and manipulative. Examples might include the person who packs a suitcase full of clothes for a 4-day admission for high-dose corticosteroids and demands nursing help for dressing and putting on makeup, or the person who calls the doctor's office every day with an endless list of questions and requests. In most cases, the patient is reacting either to the multiple losses imposed by the disease or to the anticipated loss of control and independence that can result from progressive disability. So many things in the person's life are out of his or her control that the effort to control the details of daily life becomes exaggerated.

Teaching Self-Care Skills to the Memory-Impaired Patient

In caring for people with MS, much of the nurse's skill is directed toward teaching patients how to manage their symptoms effectively. The nurse educates the patient about medications, bladder and bowel management, skin care, and important community resources. Given that some degree of cognitive impairment occurs in more than half of the population with MS, it is not surprising that nurses often feel frustrated in their teaching efforts. Patients who ask the same questions repeatedly or fail to follow

through with specific procedures may need written instructions to help them remember what they have been told.

These are just a few of the challenges facing nurses who work with patients with MS. Although it is important to keep them in mind, it is equally important to remember that it is precisely because of these challenges that the nurse's work in MS is so vital. Individuals living with a chronic and progressive illness need a unique and ongoing kind of support for their efforts to manage the disease effectively and live full, productive, and comfortable lives.

Melinda's self-confidence and self-esteem have been threatened by changes in her ability to carry out her roles and responsibilities at home and at work. She is experiencing a deep sense of loss compounded by anxiety about the future. When Melinda shares these feelings with the neurologist and nurse during her 6-month visit, they take several steps to help Melinda regain her confidence and rebuild her hopes for the future:

- 1. The neurologist explains the relationship between MS and cognition and suggests a neuropsychological evaluation to identify Melinda's cognitive deficits and strengths. Using this information, the neuropsychologist will be able to recommend compensatory strategies that Melinda can use to address the challenges she has been experiencing. As Melinda begins to use these strategies, the nurse helps her incorporate these same strategies into her own MS management and wellness activities.*
- 2. To address the mood changes Melinda has been experiencing, the nurse also helps her connect with a social worker in the community who is familiar with MS. The opportunity to talk over her feelings of loss and concerns about letting down the people around her provides Melinda with a deep sense of relief. A psychiatric consultation determines that Melinda is responding well to the supportive therapy and does not need medication or other treatment at this time.*
- 3. The nurse continues to help Melinda manage her urinary symptoms and connects her with an occupational therapist for assistance with energy management.*

With the help of the doctor and nurse, Melinda has now taken steps to address her major challenges. Armed with strategies to deal with her cognitive problems, a supportive therapist with whom she can discuss her feelings of loss and anxiety and a plan to manage her fatigue and urinary symptoms, Melinda feels less vulnerable, more in control, and more optimistic about her future. She has gained confidence in her ability to face the future and any new challenges that might come along.

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Acknowledging Sexuality and Implementing Family Planning

Rosalind C. Kalb

Nancy W. is a 27-year-old married woman who was recently diagnosed with multiple sclerosis (MS). Nancy and her husband, Alan, share a wish to have children but had planned to spend some time enjoying each other and their careers before trying to get pregnant. Then symptoms of fatigue, blurred vision, and some weakness in her left leg brought Nancy to the doctor. A careful medical history alerted the neurologist to some prior neurologic symptoms during Nancy's teenage years and those, coupled with MRI findings, were sufficient to make the diagnosis of MS. Nancy and Alan were shocked but not surprised, because Nancy's mother has been living with MS for more than 40 years.

Nancy's vision has returned to normal, but she continues to experience bouts of fatigue and leg weakness. With her doctor's encouragement, she started a disease-modifying therapy. Now, Nancy is eager to start a family "before it's too late," but Alan has several concerns: how a pregnancy would affect his already-exhausted wife; what the impact would be on her MS; what the risks would be for their child; and what the unpredictable future might bring—particularly because he knows the impact MS has had on his mother-in-law. And both have joked a bit awkwardly about how hard it will be to get pregnant if Nancy does not start to get interested in sex again. For the last several months, she has noticed that she is too tired by the end of the day to care much one way or the other, and her sexual response, including orgasm, just does not feel the same. Alan wonders if he is doing something wrong or if Nancy is finding him less attractive, but Nancy knows that the MS is affecting both her feelings as well as her body.

INTRODUCTION

Sexuality and decisions about parenthood are important issues for most young adults—and each can be significantly impacted by multiple sclerosis (MS). Changes in a man's or woman's sexual activity and responses, fears about the impact of pregnancy and delivery on a woman's MS or about the impact of a parent's MS on the child, and concerns about future disability and the ability to care for and support a child or children are the focus of this chapter. The initial sections describe the most common sexual problems and issues confronted by people with MS. The remaining sections of the chapter focus on family-planning decisions—a subject that may be less difficult to discuss but is just as emotionally loaded as concerns about sexuality. The discussion addresses the most common concerns pertaining to childbearing and the early parenting role: the genetic risk for one's children; impact of MS symptoms on pregnancy, childbirth, and nursing; and the relationship between pregnancy and disease progression.

The time spent with the nurse discussing general symptom management or bowel and bladder problems may be more relaxed and less pressured than the appointment with the physician—and therefore more conducive to discussion of sensitive topics. This places nurses in a unique position to help people articulate their questions and concerns, seek appropriate solutions, and maintain hope in the face of MS-related challenges and changes.

RECOGNIZING AND MANAGING MULTIPLE SCLEROSIS-RELATED SEXUAL PROBLEMS

Sexual feelings and behavior are an important aspect of everyday life. Our culture bombards us with sexual stimuli and encourages us to be sexually active and open. However, sexuality remains one of the most difficult topics for people to discuss, with the result that neither people with MS nor their physicians are likely to bring up the subject. Why is sexuality such a difficult topic? Despite the modern emphasis on openness and sexual freedom, many people still feel that sex is too private, too mysterious, or even too shameful to discuss with anyone. The current emphasis on sexual performance or prowess makes it uncomfortable for men and women with MS to talk about the problems or changes they are experiencing. People frequently have no idea that these changes have anything to do with the disease and may be embarrassed to share their concerns for fear that the doctor or nurse will think less of them. These barriers are even greater for gays and lesbians and those who are single.

If such questions and concerns are ignored in the early stages of the disease, it becomes less likely that they will be addressed as the MS progresses; the more disabled people become, the less likely it is that health care providers, caregivers, and even partners will think of them as sexual beings with sexual feelings or concerns.

Research and clinical experience have clearly demonstrated that MS can affect a person's sexual life in various ways, ranging from the problems caused directly by neurologic impairment (*primary*) to those caused by the debilitating physical symptoms of MS and medications used to treat them (*secondary*), and those resulting from the psychosocial sequelae of the disease (*tertiary*; Fletcher et al., 2009; Foley & Werner, 2008; Mattson, Petrie, Srivastava, & McDermott, 1995). Although reports of the incidence and prevalence of sexual dysfunction in MS vary considerably (Lilius, Valtonen, & Wikström, 1976; Lundberg, 1978; Szasz, Paty, & Maurice, 1984; Valleroy & Kraft, 1984; Zorzon et al., 2001), the consensus is that MS-related sexual problems are common in both men and women, and that these problems are in need of far greater clinical attention than they have received in the past.

Defining Primary Sexual Dysfunction

Neurologic changes caused by MS can directly alter sexual feelings and responses. In women, neurologic changes can result in decreased libido, reduced or uncomfortable genital sensations, decreased vaginal lubrication, and diminished orgasmic response (Foley, 2006; Lilius et al., 1976; Lundberg, 1978; Schover, Thomas, Lakin, Drogo, & Fischer, 1988; Valleroy & Kraft, 1984; Zorzon et al., 1999; Zorzon et al., 2001). Men may experience diminished libido, changes or reduction in genital sensitivity, problems in achieving or maintaining an erection, and reduced ejaculatory force or inability to ejaculate (Kirkeby, Poulsen, Petersen, & Dorup, 1988; Lilius et al.; Lundberg; Schover et al.; Valleroy & Kraft; Zorzon et al., 1999; Zorzon et al., 2001). Both men and women can experience MS-related cognitive changes that affect the sexual response and/or the sexual relationship; hypersexuality, disinhibition, and sexual preoccupation have all been described in the MS population (Huws, Shubsachs, & Taylor, 1991). According to one longitudinal study (Zorzon et al., 2001), symptoms of sexual dysfunction increase over time and are independently related to urinary dysfunction in both women and men.

From the time of diagnosis onward, it is important to give patients the opportunity during routine office visits to talk about changes in their sexual functioning. One should never assume that a person with MS has

no problems simply because he or she does not mention them to the physician or the nurse. Because a significant number of happily married couples in the general population of healthy adults will report occasional sexual dysfunction (Frank, Anderson, & Rubenstein, 1978), problems or changes in neurologically impaired individuals are probably more the rule than the exception. Patients should be asked on a regular basis about any changes in their sexual feelings and responses. This matter-of-fact approach to the subject accomplishes two things: First, it alerts people with MS and their partners to the fact that changes they may be experiencing could be related to MS; second, the ease and regularity with which the subject is broached by the physician or nurse sends the message that sex is safe to talk about. Sometimes people need encouragement to bring up this difficult topic. Thus, for example, if a person denies any difficulties but is experiencing significant bowel and bladder problems of the type often seen in tandem with sexual changes, it is appropriate to let him or her know that these types of problems often coexist and that there is help for both.

Once the person with MS has expressed questions or concerns, it is appropriate to recommend a thorough evaluation by a health care professional who is knowledgeable about sexual dysfunction and MS. This may be a neurologist, urologist, nurse, sex therapist, psychologist, or some combination thereof. Evaluation and accurate diagnosis of the problem are essential to the formulation of an adequate treatment plan. This process should include a detailed medical evaluation, complete with a review of all medications being taken, because sexual functioning can be affected by many of the medications used to manage MS symptoms (e.g., anticholinergics for bladder management) as well as those used for other common health problems (e.g., high blood pressure, depression). Specific tests of sexual function may be used. For example, the Dacomed Snap Gauge Test, which provides a simple, at-home assessment of the frequency and rigidity of nocturnal erections, helps to determine whether erectile dysfunction is the result of neurologic impairment.

The evaluation must also include a detailed sexual history of the individual and, if the person is married or has a sexual partner, of the sexual relationship as well. The information elicited during this kind of detailed discussion is the best indicator of both the problems to be targeted and the individual's and couple's ability to talk freely in a mutually supportive way and to engage in sexual problem solving. Individuals or couples who have never been able to discuss sexual feelings and/or behavior in the past, or who have always been somewhat inhibited in their lovemaking, will not suddenly find it easy to explore and experiment with new sexual behaviors.

Treating Primary Sexual Dysfunction

Changes in Libido

Decreased libido in men and women can be distressing and problematic to treat. Although there is no doubt that a person's interest in sexual activity and sexual responsiveness can be affected by the neurologic changes in MS, it is also true that they can be affected by various emotional states that can come and go in the course of living with any chronic and progressive illness, including anxiety, grief, depression, and anger. Careful evaluation can determine the cause of the change in libido. Changes resulting from transient emotional states often respond well to individual and couple's counseling in which feelings can be explored and expressed in a supportive environment. Decreased libido resulting from a clinical depression is somewhat more complex because the antidepressants used may lift the depression and restore the libido while simultaneously interfering with the orgasmic response. When decreased libido seems to be the direct result of neurologic change, counseling can provide individuals and couples with ways to talk about the change and its effect on their relationship while also helping them explore ways to heighten the sexual mood and enhance intimacy.

Sensory Changes

Changes in sensation for men and women can be confusing and frightening. Something that once felt good may now feel bad—even painful—or may hardly be felt at all. Painful dysesthesias may be relieved by antiepileptic medications such as gabapentin, carbamazepine, or pregabalin, or by an antidepressant medication such as amitriptyline or duloxetine hydrochloride. For some people, acupuncture may also provide relief (Bowling, 2007). Treatment also involves a series of sensate focus exercises in which the person is encouraged to explore his or her own body, alone or with a partner, to discover what does and does not feel good, and to communicate that information to the partner (Foley, 2006; Foley & Werner, 2008). For many, the hardest part of the treatment is becoming comfortable with the idea of asking for what they want and need from their partner. Decreased genital sensation in both sexes often requires different, more intense stimulation; however, the introduction of oral stimulation, lubricants, or vibrators may initially be threatening to those who have never used them.

Decreased Vaginal Lubrication

Decreased vaginal lubrication is managed most effectively with any one of a number of water-soluble lubricants (e.g., Replens or Astroglide).

Non-water-soluble products such as Vaseline can cause urinary tract infections and should be avoided.

Erectile Dysfunction

Several options are currently available for the treatment of erectile dysfunction. The choice of treatment should be guided by the nature and severity of the problem, medical history, potential side effects, and personal preference.

- Three oral phosphodiesterase type 5 inhibitors (sildenafil citrate, tadalafil, and vardenafil) block the action of an enzyme called PDE (phosphodiesterase), which allows the chemical compound cGMP (cyclic guanosine monophosphate) to remain at higher levels in the erectile tissues of the penis. Of the three medications, only sildenafil has been tested in men with MS, but all have been used clinically with approximately equal effectiveness. In one placebo-controlled clinical trial in men with MS, sildenafil was shown to have a positive impact on quality of life including sexual function, relationship with partner, social contacts, and overall satisfaction (Fowler et al., 2005). In a recent, randomized, placebo-controlled, double-blind study, however, sildenafil was found to be no more effective than placebo in treating MS-related erectile dysfunction (Safarinejad, 2009). Clinical experience has indicated that PDE-5 inhibitors work well with some individuals but not with others, and that a man should try each of the medications to determine which provides the most benefit.

Although the PDE-5 inhibitors have been shown to enhance erectile function in men in the general population with either organically or psychogenically based erectile dysfunction, they do not increase sexual desire. Unlike the injectable medications described later, these oral medications do not create penile erections; rather, they allow an erection to occur in the presence of adequate physical and/or erotic stimulation. Counseling may be necessary to restore positive feelings and intimacy in a relationship with significant distress and conflict.

All three medications typically cause a transient decrease in blood pressure. Therefore, they should not be used by men who are taking a nitrate-based medication, even on an infrequent basis, because the combination can cause a sudden and potentially dangerous drop in blood pressure. The additional cardiovascular stress of intercourse may increase the risk of heart attack or stroke for men with preexisting cardiovascular disease. Any man with a history of cardiovascular disease or high blood pressure should have a thorough evaluation before starting on a PDE-5 inhibitor.

- For those men who cannot take any of the oral mediations, or derive insufficient benefit from them, there are a variety of other options (Foley & Werner, 2008). Some men can achieve a reflex erection by stroking the penis or putting on a tightly fitting condom. A reflex erection, which may be only partial or of short duration, makes intercourse possible but seldom leads to ejaculation. The reflex erection will not restore sensations in the genital area once they have been reduced or lost, but it is a reasonable option for men who derive pleasure and satisfaction from pleasuring their partner and achieving the intimacy of intercourse. The same is true of vacuum suction devices, which induce blood flow into the penis. Once an erection has been achieved, a band is placed at the base of the penis to prevent venous return during intercourse.
- Injections for the management of erectile dysfunction have been available for about 15 years (Foley & Werner, 2008; Kirkeby et al., 1988). Three medications are commonly prescribed at this time. Prostaglandin E1 is the newest of the medications and the only one that has been approved for this use by the Food and Drug Administration (FDA). The original drug used for this purpose, papaverine, is a safe and effective alternative for any man who has a problem using prostaglandin E1. The third drug, regitine, is never used alone but may be combined with either prostaglandin E1 or papaverine to enhance their effectiveness. The penile injection produces a fully turgid erection that lasts for several hours. Men who retain their ability to ejaculate report natural and satisfying results. Although this pharmacologic approach is safe, effective, and inexpensive, careful counseling and medical follow-up are required. Although men occasionally experience scarring at the injection site or slight discomfort, the most significant potential complication with these drugs is priapism. It is important for the man to be carefully instructed in the injection procedures and to use only the dosage prescribed for him.

Of equal concern is the fact that individuals and couples vary considerably in their reactions to the injection process. Some are happy to find this relatively simple solution to a difficult problem; others find the use of a needle so threatening and unpleasant that it interferes with the expression of intimate sexual feelings. Careful discussion and supportive counseling are particularly useful when a man and his partner react in opposite ways. As in all areas of sexual expression and sharing, pressure to participate in behaviors that are threatening or uncomfortable reduces the intimacy and mars the pleasure.

- Surgical implants are also available to treat erectile dysfunction (Foley & Werner, 2008; Massey & Pleet, 1979; Small, 1976). Although they do nothing to address sensory or ejaculatory problems, they do make intercourse possible. The noninflatable rod prosthesis consists of a sponge-filled rod

that is implanted into the corpus cavernosum and produces a permanent semi-erection. A flexible version of this device allows for the penis to be bent upward to simulate an erection and downward for easier concealment. The simulated erection is smaller than normal and sometimes awkward in its omnipresence, but the implant procedure is relatively simple.

The inflatable prosthesis mimics the natural erection process by allowing the normally flaccid penis to become erect through the manipulation of a pump or pressure transducer inserted in the scrotum. A fluid-filled reservoir is implanted in the abdomen; when an erection is desired, the man or his partner “pumps” the fluid from the reservoir into expandable cylinders implanted in the penis. The surgical procedure for this device is somewhat more complex and involves more potential complications. Manipulation of the pump requires a certain degree of manual dexterity and sensitivity.

Although various interventions and strategies are available to address primary sexual dysfunction in MS, they are effective only to the extent that individuals and couples are comfortable and competent with them. Health care providers can maximize this comfort and competence in several ways: first, by acknowledging the deep feelings of loss and embarrassment that can accompany changes in sexual function. It is not enough simply to hand someone a booklet about medication, penile injections, or implants. The loss of libido or genital sensations, changes in sexual responsiveness, and the inability to achieve or enjoy orgasm threaten a person’s sense of self and sexual identity. The recognition of this loss is a necessary preamble to any efforts to provide solutions.

Second, health care providers can enhance the effectiveness of their interventions by teaching or modeling important communication skills. The interventions will prove satisfactory only if the people using them are able to communicate comfortably and effectively with one another. An integral part of any therapeutic intervention is communication skills training to ensure that sexual partners are talking and listening to each other in meaningful ways (Foley et al., 1994).

Defining Secondary Sexual Dysfunction

A person living with MS may experience various symptoms over the course of the disease, many of which can interfere with sexual activity and pleasure. A person who is severely fatigued may lack the interest or the energy to be sexual. Someone who experiences significant sensory changes may find sexual activity uncomfortable or even painful. And someone who is severely constipated or worried about urinary incontinence may put sex at

the very bottom of the priority list. In other words, MS symptoms create significant barriers to sexual expression. And commonly used medications contribute to these barriers.

Treating Secondary Sexual Dysfunction

Although primary sexual dysfunction in MS is the direct result of neurologic impairment, secondary dysfunction follows from the various physical symptoms that can be part of the picture—including fatigue, spasticity, bladder and bowel problems, pain, and cognitive impairment—as well as the medications used to treat them. People with MS often report that they are simply too fatigued or uncomfortable to feel sexual or engage in physically exhausting sexual activities. One woman reported that the relatively short period of physical or emotional enjoyment associated with sexual activity was simply not worth the day that it took her to recover her energy.

Spasticity

Stiffness of the lower limbs and adductor spasms of the hips can make sexual activities awkward, uncomfortable, or even painful. Spasticity is usually managed quite effectively with baclofen and/or tizanidine. Within reasonable limits prescribed by the physician, people can self-monitor their medication regimen to maximize comfort and flexibility during sex. Individuals with intractable spasticity and those who cannot tolerate the oral medication can be treated with a surgically implanted pump that releases baclofen into the subarachnoid space at a slow and continuous rate. Chemical nerve blocks and surgery are additional treatments that can be used to relieve intractable spasticity (Schapiro, 2007, 2008).

Bowel and Bladder Dysfunction

MS-related bowel and bladder symptoms can have a significant impact on a couple's efforts to engage in stress-free and spontaneous sex. Concerns about loss of bladder or bowel control and the discomfort of constipation interfere with sexual activities and enjoyment. The presence of a urinary catheter or diaper does little to enhance feelings of sexual attractiveness or interest. Aggressive symptom management will help considerably when combined with open and honest discussion and some judicious planning and preparation.

Bladder symptoms can be managed in various ways (Halper, 2008). Reducing fluid intake for the preceding several hours and urinating just prior to intercourse may enhance bladder control and alleviate anxiety

about urinary incontinence. Those who manage their bladder by intermittent self-catheterization should be encouraged to catheterize just prior to intercourse. Women who use an indwelling catheter will need to hold or anchor the catheter to one side in any way that is least cumbersome and most comfortable for them (Foley & Werner, 2008). Medications for incontinence, including oxybutynin chloride, tolterodine, trospium chloride, and solifenacin succinate, among others, relax the bladder so that it can fill up before the urge to urinate occurs, thus alleviating symptoms of urgency and frequency. Medication schedules can sometimes be arranged to enhance comfort during sexual activity. Because medications might also increase vaginal dryness, the use of a water-soluble lubricant is advised.

Constipation is best managed with a careful dietary regimen and adequate fluid intake. Obviously, the need to increase fluid intake to reduce constipation can work at cross-purposes with the desire to control urinary incontinence; each individual needs to experiment and arrive at the management techniques best suited to his or her own needs. For those with little or no control or predictability of their bowel functions, a regular schedule can be artificially imposed via the carefully prescribed use of laxatives, enemas, and/or routine disimpaction. This schedule can be established in such a way as to create relatively stress-free times for sexual activity.

Fatigue

Fatigue in MS is best managed pharmacologically with amantadine, an antiviral/antiparkinsonian agent, or modafinil, a medication most commonly used to treat narcolepsy, and with various energy conservation techniques, including the use of ambulation aids and motorized carts or wheelchairs (Schapiro, 2007, 2008). Unfortunately, most people with MS miss out on the valuable energy-saving benefits of these aids because they resist their use until ambulation is no longer possible. So much time and energy is consumed in the struggle to walk that little energy is left for anything else, including sex. Short naps or rest periods at different times during the day can also provide relief for most people. Because fatigue tends to build over the course of the day, many people find that sexual feelings are at their lowest ebb by evening. Again, a short nap late in the day may be helpful, but many find that sexual activity can be enjoyed more fully in the early morning before all their energy has been used up by the daily routine. Because sexual activity requires time and energy, both precious commodities for the person with MS, a certain amount of planning and prioritizing becomes important. Although it necessarily

involves some loss of spontaneity, planning for sexual activity allows a couple to give it the time, attention, and energy required to make it an enjoyable, relaxing, and intimate experience.

Pain

Various types of MS-related pain can also interfere with sexual interest and pleasure. Sharp, stabbing pains of the type experienced in trigeminal neuralgia are best treated with antiepileptic medications, including carbamazepine, gabapentin, pregabalin, or topiramate. Chronic neurogenic pain, typically described as burning, tingling, aching, or bandlike, responds to the tricyclic antidepressants (e.g., amitriptyline or nortriptyline) or a combination of antidepressants and antiepileptics (Maloni, 2008).

Unlike spasticity and incontinence, which can be obvious and visible, the symptoms of fatigue and pain are much less apparent to a sexual partner. Clear and open communication becomes more important than ever when the lack of sexual interest or responsiveness is the result of causes that cannot be seen or felt. Neither partner can read the other's mind. In the absence of open discussion, the partner may feel frustrated and rejected, whereas the person with MS begins to feel pressured and resentful over the partner's lack of sensitivity.

Cognitive Impairment

Providers must also be aware of the role played by MS-related cognitive impairment in sexual dysfunction and its potential impact on treatment interventions. Cognitive impairment of the type often found in MS involves various problems that include memory loss, slowed information processing, attentional deficits, word-finding difficulties, visuospatial problems, and impaired judgment. These are discussed further under tertiary sexual dysfunction because their primary impact is on interpersonal communication. In general, however, MS-related cognitive dysfunction requires a thorough neuropsychological evaluation to assess the type and extent of deficits. Fortunately, remediation programs are becoming increasingly available to people with MS (Foley et al., 1994; LaRocca & Miller, 2008).

Another facet of MS-related cognitive impairment involves hypersexuality, sexual preoccupation, and inappropriate sexual acting out, which are best managed psychiatrically with small amounts of haloperidol and a great deal of structure and limit-setting. The effects of this type of hypersexuality are devastating on a marital relationship because it completely removes sexual expression from the realm of emotional intimacy.

The spouse is pursued incessantly—poked, stroked, and fondled—in a childlike, nagging fashion that is unpleasant and uncomfortable. Relationships with health care aides in the home also become complicated by this type of sexual acting out. Fortunately, this type of MS-related hypersexuality is relatively rare (Huws et al., 1991).

Medication Side Effects

Most people with MS take various medications to modify the course of MS and to manage their symptoms and many of these medications have side effects that may interfere with sexual interest or activity. For example, the interferon medications used to reduce relapses and slow progression commonly cause flulike symptoms that may last as long as a day or more. The anticholinergic and antimuscarinic medications used to treat urinary symptoms can increase vaginal dryness and increase cognitive symptoms. Antispasticity and anticonvulsant medications can cause additional fatigue, and most antidepressant medications interfere with arousal and/or orgasm. Unfortunately, this issue is seldom raised during hurried doctor visits. It is important for people with MS to be aware of these potential side effects and for clinicians to take into account their potential impact on sexual feelings and activities when prescribing these medications so that appropriate adjustments or substitutions can be offered.

Defining Tertiary Sexual Dysfunction

The tertiary effects of MS on sexual functioning encompass all of the complex feelings and attitudes people have about sexuality and its expression. The feelings and attitudes range from the more general and societal ones about the apparent incompatibility between illness or disability and sexuality to the more personal feelings and attitudes of individuals struggling to deal with the changes MS brings to their daily lives and personal relationships. We live in a culture that associates sexuality and sexual attractiveness with youth, vigor, and good health. Even if a person with disability continues to have all of the same sexual thoughts, feelings, and desires that he or she has always had, family members, friends, and even health care providers may cease to see the person as a sexual being. Not only is this a devastating blow to self-esteem, but it also affects efforts to relate in a sexual way and to gain needed help and information concerning sexual problems.

On a more personal level, each individual must reformulate his or her self-concept to incorporate whatever changes in sexual feelings or

functioning have occurred. Our sexual roles and behaviors play an integral part in the way we define ourselves (Foley, 2006; Foley & Werner, 2008; Holland & Cavallo, 1993). As with all of the losses and changes caused by MS, these changes must be acknowledged and grieved over before the person can begin to reestablish a meaningful and satisfying sense of self (Kalb & Miller, 2008). The same struggle to redefine oneself that follows the loss of ambulation or the termination of gainful employment can follow the change in sexual response. This cycle of loss-grief-redefinition is experienced to some degree by everyone going through these changes—whether married or single, heterosexual, lesbian, or gay. Health care providers must try to be alert and open to everyone's need for information and support in their efforts to cope with these changes.

In addition to the sexual symptoms that may be occurring within the individual, various changes in individual and family functioning can affect also a sexual relationship. Primary among these are the changes in roles that family members undertake in response to the demands of the illness. The balance of partnership within a couple may shift periodically as the roles of wage earner, houseperson, or caregiver are hampered by worsening symptoms. As the partnership gradually shifts away from the familiar, agreed-upon role relationships, partners may find their sexual feelings changing as well.

A spouse who begins to feel more like a nurse than a husband or wife, or who is trying to juggle several roles and responsibilities at once, may feel too angry, tired, or resentful to be interested in sex. A spouse may find it difficult to feel sexually aroused by a partner with symptoms such as tremor, spasticity, or incontinence. As one husband described his situation, "I love my wife dearly, but it isn't very stimulating to hug someone whose body feels like a board." Similarly, the spouse may be afraid of hurting or tiring a partner who must cope with debilitating and uncomfortable symptoms. The partner with MS may find that dependency needs, fears of abandonment, or feelings of sexual inadequacy interfere with open communication about sexual feelings or problems. He or she may be afraid that discussion of physical symptoms or sexual problems will "turn off" the partner or drive the partner away completely. Or the person with MS may simply be less interested in sexual activity.

Partners also report that the cognitive and personality changes that can occur with MS interfere with sexual relationships. The person with MS may have problems with memory, attention, word-finding, or logical thinking, any of which can interfere with empathic communication. A husband or wife may find that the partner with MS thinks, behaves, or relates very differently—"not the same person I married."

Treating Tertiary Sexual Dysfunction

Given all of the possible stresses that MS can bring to bear on a person's sexuality and sexual relationships—physical, emotional, and social—the need for adequate information and support is clear. Nurses can provide the link between people with MS and the resources they need, whether it be a medical evaluation, reading material, individual or couple's counseling, cognitive remediation, or communication skills training. Written materials about MS and sexuality are available from the National MS Society. Individuals and couples can derive important benefits from this kind of reading, such as feeling less alone as they read that others share similar problems, becoming more familiar and therefore more comfortable with the vocabulary used to describe their difficulties, and learning how to get help with the problems they are experiencing. By providing people with appropriate reading materials and offering to answer any questions that they might have, nurses and other professionals convey the message that it is just as appropriate and important to talk about sexual problems as it is to talk about any other MS-related symptoms.

Individuals and couples often find the relaxed atmosphere of an ongoing counseling relationship the most conducive to discussion of sexual questions or problems. The group therapy setting—whether it be for persons with MS, spouses of persons with MS, or couples—is also ideal for discussion of the impact of MS on sexual feelings and intimate relationships. By sharing with one another in a psychotherapy or support group, people can share the feelings of loss, strengthen the sense of self and adulthood that can be threatened by sexual changes, and exchange suggestions and ideas.

Family Planning

Questions about family planning are very much on the minds of young men and women with MS (Sadovnick & Baird, 1985). People have concerns about the effects of pregnancy and childbearing on a woman's disease progression and about the impact of MS on a couple's ability to conceive, deliver, and ultimately nurture and raise children. MS typically has its onset in the young adult years when people are trying to make plans and decisions about the future. The unpredictability of the illness can make planning for the future difficult and stressful, particularly regarding emotionally charged issues like childbearing and parenting. People with MS often look to their doctors and nurses to answer the unanswerable questions: "Can I have children, or should I?," "How will it affect my MS?," "Will I be able to be the kind of mother/father I always wanted to be?,"

or “Will my children develop MS?” The following discussion describes the current thinking about these issues. However, it is important for patients and professionals to bear in mind that current opinion is based on research findings, which yield nothing more than probability statements about outcomes. Thus, we can say to a young couple that most women with MS have no long-term effects of pregnancy, that the risk of their child developing MS is very small, or that most people with MS do not end up in a wheelchair, but these are only statements of probability. There are no guarantees. Each individual and each couple must be encouraged to make these decisions based on careful consideration of all possible outcomes.

The Genetic Factor in Multiple Sclerosis

Based on population and family studies of MS, it is the consensus among researchers that certain people are genetically predisposed to MS (Ebers, 1994; Ebers et al., 1986; Sadovnick, Baird, & Ware, 1988; Sadovnick & Macleod, 1981). This susceptibility, probably in combination with a set of other, as yet undetermined, environmental factors, results in the illness. In a population-based twin study (Ebers et al., 1986), monozygotic twins, who share identical genetic material, demonstrated a significantly higher concordance rate for MS (i.e., both members of the pair having the disease) than dizygotic twins, who have in common only one half of their genetic material. The concordance rate for monozygotic twins was 25.9% versus 2.3% for dizygotic twins. In a study of 815 individuals with MS and 3,000 of their siblings and children, Sadovnick and colleagues found the relatives’ risk of developing MS to be 3–5%, which is 30–50 times the 0.01% rate for the general population. Although the risk is greatly increased for children if one parent has MS, it nevertheless remains relatively small. The risk rises to approximately 30% if both parents have MS.

Fertility

Because neither male nor female fertility is generally affected by MS, couples must make the same decisions and take the same precautions as anyone else. Any form of birth control is medically acceptable for someone with MS (Giesser, Benedetto, & Werner, 2008) and should be selected on the basis of ease, comfort, and effectiveness. Oral contraceptives are safe, effective, and easy to use (Birk & Rudick, 1989). Because condoms and diaphragms require a certain amount of manual dexterity, significant hand tremor or weakness might make either of these methods unmanageable. However, couples can be encouraged to make the insertion of the diaphragm or fitting of a condom part of sexual foreplay, with

the partner “doing the work.” Women who have used antibiotics and/or immunosuppressive drugs for long periods should be aware that these can reduce resistance to infection, thereby compromising the safety and efficacy of an IUD (Giesser et al.).

The erectile and orgasmic difficulties experienced at one time or another by most men with MS can interfere with fertility. Couples need to be aware that these difficulties are not necessarily related to a person’s age or the duration or severity of his illness. They can occur at any time (even as an initial symptom of MS) and depend solely on the location of MS plaques (Foley & Werner, 2008). Problems specific to the orgasmic phase have been reported by 44–77% of men with MS (Lilius et al., 1976; Minderhoud, Leemhuis, Kremer, Laban, & Smits, 1984; Schover et al., 1988; Valleroy & Kraft, 1984; Zorzon et al., 1999; Zorzon et al., 2001). Dry orgasms are caused by the failure of seminal emission or by retrograde ejaculation into the bladder. Dry orgasms of either type can obviously impair fertility. Because these problems have been successfully treated with medication and/or electroejaculation, male patients should be encouraged to consult a urologist who is experienced in this area (Giesser et al., 2008; Shaban, Seager, & Lipshultz, 1988).

Effects of Multiple Sclerosis on Pregnancy, Birth, and Lactation

Research since the 1950s has indicated no apparent effect of MS on the course of pregnancy, labor, delivery, or lactation. The studies in this area have demonstrated no added risk of miscarriage, complications in labor or delivery, fetal malformations, or stillbirths (Birk, 1995; Cook, Troiano, Bansil, & Dowling, 1994; Giesser et al., 2008). There is some recent evidence, however, that infants of women with MS may be small for their gestational age. Using a nationwide population-based dataset in Taiwan, Chen and colleagues (Chen, Lin, & Lin, 2009) found that mothers with MS had an increased risk of preterm births, lower weight infants, and cesarean deliveries compared to mothers without MS. Dahl and colleagues (Dahl, Myhr, Daltveit, & Gilhus, 2008) also found slightly lower birth weights among infants of mothers with MS but found no difference in the rate of birth complications or medical interventions between births that occurred prior to the onset of MS, between MS onset and diagnosis, and after the diagnosis of MS. Pending further research in this area, most MS clinicians remain confident that MS does not affect a woman’s physiologic capability of conceiving, carrying, delivering, or nursing a healthy infant.

Nevertheless, it is important for women and their partners to consider the following: (a) Pregnant and lactating women must refrain from

taking certain types of medications (Birk, 1995; Giesser et al., 2008). In general, women of childbearing age should routinely be advised to alert their physicians as soon as they are considering becoming pregnant so that the doctor can make recommendations about discontinuing or substituting medications. (b) Women with MS-related fatigue may find pregnancy and lactation even more than normally tiring. (c) Various MS symptoms (e.g., impaired ambulation, weakness, sensory changes, loss of coordination or balance) can make pregnancy, delivery, and infant care more than normally challenging. (d) Urinary tract infections, which are common in pregnancy, occur in greater frequency in women with a neurogenic bladder (Lee & O'Brien, 2008). The sharing of parenting activities (particularly nighttime feedings) and use of all available resources (primarily helpful friends and relatives) will greatly reduce a woman's stress and fatigue in pregnancy and the postpartum period.

Effects of Pregnancy and Childbirth on Multiple Sclerosis

Of equal concern to couples are the effects of pregnancy and childbirth on the mother's MS. Many women with MS have read or heard from well-meaning friends or relatives (and even some physicians) that they should not have children because pregnancy causes the disease to worsen. Indeed, medical opinion before 1950 did advise against women with MS becoming pregnant. Recently, research findings have altered this view. In seven retrospective studies, reviewing 925 pregnancies, only 10% of the women experienced any disease progression during pregnancy and 29% experienced temporary worsening of the illness in the 6 months postpartum (Birk, 1995; Ghezzi & Caputo, 1981; Korn-Lubetzki, Kahana, Cooper, & Abramsky, 1984; Poser & Poser, 1983; Shapira, Poskanzer, Newell, & Miller, 1966; Sweeney, 1953; Tillman, 1950). The exacerbation rate during pregnancy was actually found to be lower than the average expected rate (Korn-Lubetzki et al.), suggesting that women with MS may be protected to some degree during pregnancy by certain immunoactive proteins and pregnancy-related hormones (Giesser et al., 2008; Runmarker & Andersen, 1995). In the prospective Pregnancy in Multiple Sclerosis (PRIMS) study of 254 women (Confavreux, Hutchinson, Hours, Cortinovis-Tourniaire, & Moreau, 1998; Vukusic & Confavreux, 2006), the rate of relapse was found to decline during pregnancy (particularly during the last trimester) and increase during the first 3 months postpartum before returning to the prepregnancy rate. Women with greater disease activity in the year before and during pregnancy had a higher risk of relapse in the first 3 months postpartum. About one third of the women in the study group experienced a post-partum relapse.

In communicating these findings to concerned couples, one can say that a woman's condition is likely to remain stable or even improve during the 9 months of pregnancy but that there is a 20–75% risk of temporary worsening of the disease in the 6 months following pregnancy (even if the pregnancy ends prematurely because of spontaneous or elective abortion). Most researchers also agree that pregnancy does not affect final disease outcome or disability level (Sadovnick & Baird, 1985; Sadovnick et al., 1988; Thompson, Nelson, Burns, Burks, & Franklin, 1986; Verdrue, Theys, D'Hooghe, & Carton, 1994). Once again, however, it is important to make sure that a couple understands the meaning and implications of these statements of statistical probability. They need to think through their family planning decisions with an open mind, considering not only the probable (positive) outcomes but also the possible (negative) ones.

Effect of Breastfeeding on Multiple Sclerosis

Given the increased risk of relapse following delivery, many physicians recommend that women whose disease was active during pregnancy or the year prior to pregnancy start or resume treatment with a disease-modifying therapy immediately following delivery. Because it is not known whether the beta-interferons or glatiramer acetate pass into the breast milk, this means that women with active disease are discouraged from breastfeeding their babies to gain the benefits of immunomodulatory therapy as quickly as possible—a painful decision for many women.

In the PRIMS study (Confavreux et al., 1998) women who chose to breastfeed had fewer relapses and lower disability scores in the year prior to pregnancy and during the pregnancy itself than women who chose not to breastfeed. The PRIMS investigators interpreted their data to mean that the women with MS who chose to breastfeed had a milder form of MS during the months leading up to the study, whereas those with more active disease opted not to breastfeed. They concluded that their data did not support a protective effect of breastfeeding on the postpartum relapses rate.

In a recent pilot study, Langer-Gould et al. (2009) followed 32 pregnancy women with MS, assessing their disease and breastfeeding status for 12 months after delivery. They found that women who breastfed *exclusively* (without supplemental formula) for at least 2 months (thereby suppressing the resumption of the menstrual cycle) were approximately five times less likely to have a relapse than those who chose not to breastfeed or who combined breastfeeding with formula feeding. This protective effect occurred regardless of a woman's prepregnancy relapse rate or treatment with a disease-modifying therapy. The authors of this small

study concluded that breastfeeding exclusively significantly reduced the risk of a postpartum relapse but recommended further research to confirm the protective effect.

Multiple Sclerosis and Parenting

Men and women with MS often ask whether the disease will interfere with parenting activities (Crawford & Miller, 2005; Miller & Kalb, 2008). For the most part, they tend to focus their concerns on the early days and months of infant care. Like all other couples making family planning decisions, they need to consider their ability to provide long-term emotional and financial security for their children. If one or the other parent could no longer work at a salaried job, if one or the other parent could no longer provide the necessary hands-on child care, or if the parent with MS were to require costly medical treatment, would they be willing and able to make the adjustments necessary for coping with these changes? Because there is no accurate way to predict disease course or outcome, couples need to be helped and encouraged to think through these questions so that they will not be caught unaware and unprepared several years down the road. It is particularly important for a husband and wife to discuss these issues openly with each other to lessen future resentment and recriminations.

At one time or another, most fathers and mothers with MS need to modify their parenting behaviors to meet the demands of the illness. Fatigue or any of a variety of other physical limitations can interfere with parenting activities. They should be encouraged to approach their roles with an open mind and a certain degree of flexibility. To the extent that a parent feels there is only one right way to do the job, he or she will feel frustrated, inadequate, and guilty. Playing catch and being a soccer coach are not the only ways to be a father; there is more to being a mom than baking cookies and sewing Halloween costumes.

CONCLUSION

Health care providers have an important role in helping couples with the decisions and adjustments that MS forces on them. The uncertain and unpredictable nature of MS prevents us from giving people many of the answers they seek. Nevertheless, we can help them to ask the right questions, explore their options and resources, and support them in their decisions. In doing so, we must recognize that any adjustment or compromise in one's sexual life, family planning decisions, or parenting roles involves a kind of loss. Whether it be a change in sexual interest or activity level, a decision to have no children or fewer children than one had anticipated,

or a need to let go of certain parenting activities—any of these kinds of adaptations require the person to redefine himself or herself in accordance with the demands imposed by the illness. The process of redefinition can be slow and painful. Nurses and other care providers accompany people with MS through this process, supporting them as they grieve over their losses and work to identify satisfying options and alternatives.

So what does all of this mean for Nancy W.? How do we provide her and her husband with the information they need to make their personal decisions while promoting hope and optimism for the future?

If we can agree that hope needs to be grounded in accurate information, the starting point is education. The information contained in this chapter can help Nancy and her husband sort out realistic concerns from needless worry. They can be reassured that having children is not likely to affect the course of her MS or its long-term outcome. She may, in fact, feel better during her pregnancy because of the immunosuppressant effect of the pregnancy hormones. They can also feel confident that her MS is not likely to impact her ability to become pregnant or deliver a healthy baby. There is even some data to suggest that nursing her baby will reduce her risk of a postdelivery relapse. However, they need to recognize that there are no guarantees—that some women do experience significant relapses following delivery and the risks of developing MS for their children are higher than they would be if no one in their families had MS. They also need to recognize that Nancy's MS may worsen over time, interfering with her ability carry out some aspects of her parenting, work, or household activities.

As clinicians, we need to be sensitive to the fact that Nancy and her husband may not share similar reactions to this information; one might wish to proceed with baby-making whereas the other is reluctant to take on any additional risks or uncertainties. Our role is to help them sort through the available information, answer questions, and refer them for any counseling they may need to facilitate their conversations and decision making.

The same recommendations hold true for their sexual relationship. Accurate information about the ways in which MS can affect sexual feelings and responses can lay the groundwork for effective communication and problem-solving around this issue. The most important thing for both Nancy and her husband to understand is that there is no fault or blame here—sexual feelings and responses are likely to ebb and flow with the disease. By encouraging them to share their concerns openly with each other and with their health care providers, every effort can be made to manage any symptoms and/or medications that may be interfering with their sexual relationship.

Thus, being informed makes it possible for people to engage in effective planning and problem-solving—strategies that allow them to feel more prepared, confident, and hopeful no matter what the future brings.

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Working With the Pediatric Patient Diagnosed With Multiple Sclerosis

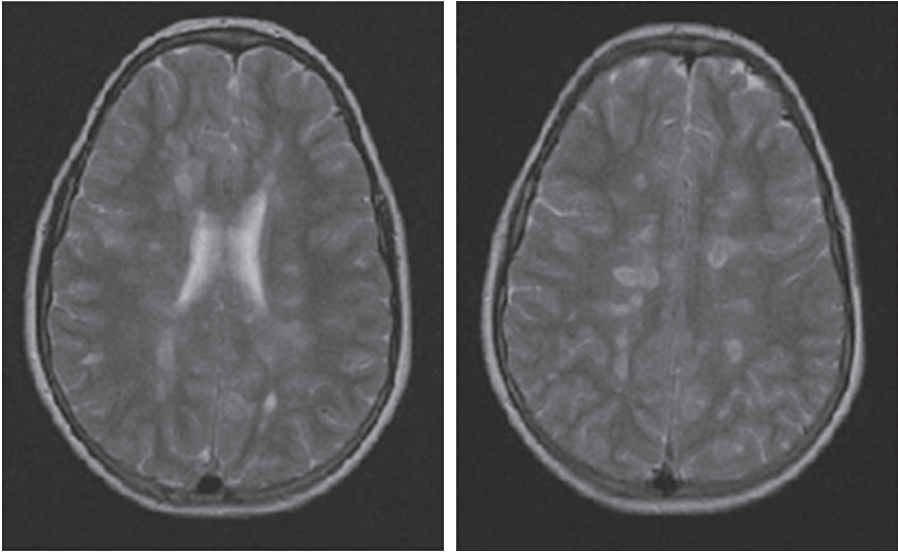
Jennifer R. Boyd and Maria C. Milazzo

Alex is a 10-year-old boy who, in March 2003, presented to his local pediatrician with a 1-day history of diplopia. He had a history of fever, dizziness, and gastrointestinal (GI) illness about 1 month before. The pediatrician referred him to a local neurologist who found a sixth nerve palsy. An MRI revealed 30–40 multiple white matter lesions (see Figure 12.1). The lesions were juxtacortical, infratentorial, and corpus callosal, more than 3 were periventricular and at least 20 were gadolinium enhancing. Alex was admitted to the hospital with a request for consultation from the pediatric multiple sclerosis (MS) team. A lumbar puncture showed cerebrospinal fluid (CSF) pleocytosis with 9 white blood cells, 100% lymphocytes, normal protein, and 5 oligoclonal bands. Immunoglobulin G (IgG) index was elevated at 0.78 (normal to 0.70). Serum Lyme titer was elevated, but CSF was negative. Varicella, Epstein-Barr virus (EBV), and mycoplasma titers showed evidence of previous infection.

Alex was treated with a 5-day course of intravenous (IV) methylprednisolone followed by a 5-day oral prednisone taper. By Day 2 of his admission, his neurologic exam had returned to normal. He was discharged home with a plan for repeat MRI and neurologic exam in 1 month. The differential diagnoses included acute disseminated encephalomyelitis (ADEM) and pediatric MS. At follow-up, Alex had a normal examination. The MRI showed fewer enhancing lesions and no new lesions, but remained markedly abnormal. Repeat Lyme, mycoplasma, and EBV testing showed no evidence of current infection.

In July, a repeat MRI revealed at least two new lesions, both enhancing. Consequently, the diagnosis of pediatric MS was made. Alex's health care team at the Pediatric MS Center recommended close monitoring, including another MRI in 3 months. They also initiated discussion about various treatment options. Shortly after this visit, Alex developed headache and pain with eye movements. Visual acuity was decreased in his left eye and his Expanded Disability Status Scale (EDSS) score was 1. His parents

FIGURE 12.1 Neuroimaging at Onset



considered the treatment options and planned to begin therapy at the end of the summer after traveling to Portugal to visit family.

During their visit to Portugal, the family obtained second and third opinions that concurred with the diagnosis and options for treatment. While away, Alex experienced a third clinical event, with left-sided weakness and diplopia. EDSS score was 2. Upon his return home, he began treatment with daily injections of glatiramer acetate (GA). He was pretreated with eutectic mixture of local anesthetic (EMLA) cream for injection site discomfort. Because Alex was very anxious about self-administering, his mother and older sister received training on injection administration.

INTRODUCTION

About 5% of people living with multiple sclerosis (MS) are diagnosed before 18 years of age and are considered to have pediatric- or childhood-onset MS (Brett, 1995; Cole & Stuart, 1995; Ghezzi et al., 1997; Iannetti et al., 1996; Sindern, Haas, Stark, & Wurster, 1992). Although very rare, children as young as 2 years old have developed this disease. While pediatric-onset MS remains uncommon, increased awareness, improved diagnostic capabilities, and the impetus to diagnose and implement treatment early in the

disease process is leading to the diagnosis of a rising number of pediatric patients (Ness et al., 2007). As a result, more and more MS nurses and pediatric nurses now care for children and adolescents with MS.

With a growing number of children and adolescents requiring MS care, nurses must consider the needs of this special group of patients. Caring for children and adolescents creates unique challenges and requires understanding of developmental factors, differing psychosocial needs, parental involvement in care, issues with schooling, and resources specific to the pediatric population. As well, diagnosis and treatment is often more complex in young patients. Transition from pediatric to adult care is another concern that requires nursing support and facilitation. This chapter will focus on these issues specific to children and adolescents living with MS and their families and describe strategies to enable nurses to provide optimal care when working with the pediatric patient diagnosed with MS.

DIAGNOSTIC CHALLENGES IN PEDIATRIC MULTIPLE SCLEROSIS

Compared to adults, children are not as readily diagnosed with MS. They may have difficulty describing the transient symptoms associated with MS, especially sensory and visual symptoms (Ness et al., 2007). Although the presenting symptoms of MS are similar in both children and adults, children are more likely than adults to be systemically unwell with malaise, irritability, and low-grade fever at the time of disease onset (Renoux et al., 2007). They are also more likely to have seizures and brain stem and cerebellar symptoms with the first event and are less likely to have oligoclonal bands or elevated immunoglobulin G (IgG) index in their cerebral spinal fluid (Waubant & Chabas, 2009). The typical diagnostic markers of MS, such as MRI findings, may be different in children (Callen et al., 2009). Acute neurologic problems with white matter changes on a MRI may result from a wide variety of disorders in the pediatric population including mitochondrial disorders, acute disseminated encephalomyelitis (ADEM), lymphoma, leukodystrophies, and vasculopathies (Hahn, Pohl, Rensel, & Rao, 2007). In the recent past, MS was rarely considered a potential diagnosis in children, yet many people diagnosed with MS as adults report experiencing symptoms as a child or adolescent that were likely the initial manifestations of the disease (Ness et al., 2007). This supports the notion that MS has been underdiagnosed in the pediatric population for many years. The large array of differential diagnoses at initial presentation can make diagnosis challenging.

DEVELOPMENTAL CONSIDERATIONS

A major consideration when caring for children and adolescents is growth and developmental factors. Especially in the context of a chronic illness, a child's ongoing growth and development need to be recognized and fostered. In pediatrics, the dosing of medication is typically determined by weight, therefore, weight changes influence the amount of medication required at any given time. As well, certain medications impact children's physical growth. For example, corticosteroids suppress growth and can lead to permanent short stature with prolonged use.

In addition to growth in height and weight, children also grow developmentally with respect to their physical, cognitive, and social abilities. As young people move through and reach different developmental stages, approaches to care change (Kieckhefer & Trahms, 2000). Younger children are concrete thinkers who rely on their parents for care and support. They gradually transition to adolescence and adulthood and increasingly become abstract thinkers who progress toward independence from parents and greater influence from peers (Erikson, 1963). Childhood and adolescence are key periods in life for learning, establishing self-identity, building self-esteem, and developing social skills. Adolescents in particular focus on developing a sense of independent identity, achieving peer acceptance, planning for the future, and developing romantic and intimate relationships (Taylor, Gibson, & Franck, 2008). The needs, abilities, and points of view of the pediatric patient constantly change necessitating adjustments to education and support strategies.

Although most youth with MS are developmentally normal, those who are physically, socially, or cognitively impacted by the disease process may not meet the developmental stages by the anticipated chronological age. Nurses need to identify each child's stage of physical, cognitive, and social development and adapt care accordingly. For those less familiar with caring for the pediatric population, collaboration with pediatric professionals is suggested in an effort to best address their developmental needs.

TREATMENT CHALLENGES

Treatment in pediatric MS is similar to the adult patient, but there are additional challenges with respect to dosing, initiating treatment, and addressing adherence issues with pediatric patients. These treatment challenges apply to treating relapses, disease-modifying therapies (DMTs), and symptom management.

Treatment of Relapses

No therapeutic trials have explored relapse treatment in the child and adolescent population with MS. As with adults, relapses are treated with intravenous (IV) methylprednisolone. Dosing is based on weight and is 20–30 mg/kg daily in the morning for 3–5 days, to a maximum dose of 1 g daily for 5 days. Irritability, sleep disturbance, and stomach upset are common and the child and family should be prepared for these possible side effects. Gastric protection given concurrently is recommended. During the infusion, many children complain of a strong metallic taste in their mouths and some find a Popsicle or freezie helpful to “numb” the taste. Long-term complications of corticosteroid use include adrenal suppression, growth suppression, and steroid dependence. Shorter courses of therapy with short tapers can reduce this risk.

Plasmapheresis is used for severe relapses in adult MS and Devic’s disease (Chabas, Green, & Waubant, 2006). Anecdotally, plasmapheresis is also used for treatment of severe relapses in pediatric MS. When steroids are contraindicated or ineffective, IV immunoglobulin (IVIG) is an alternative treatment choice often used in pediatrics (Chabas et al.).

Disease-Modifying Therapies

Although the DMTs are not Food and Drug Administration (FDA) approved in children, they are used in pediatric MS with good results. To date, they appear to be well tolerated in this age group with a side effect profile similar to adults (Chabas et al., 2006). Although placebo-controlled trials have never been done, several studies have shown a decrease in pretreatment relapse rate after treatment initiation (Ghezzi, Ruggieri, Trojano, Filippi, & the ITEMS Study Group, 2004; Pohl et al., 2007). In studies where treated patients were compared to those not treated, a relative decrease in relapse frequency was noted (Makhani et al., 2009; Mikaeloff, Caridade, Tardieu, Suissa, & KIDSEP Study Group of the French Neuropediatric Society, 2008; Pohl et al., 2007). Initiating treatment early appears to be beneficial in adults and is increasingly the approach with children, particularly those in the adolescent age group. Recommending early treatment for children and adolescents is becoming a common practice (Chabas et al., 2006; Makhani et al., 2009).

In pediatric MS care, beta-interferons are typically started at one-quarter dose, and increased every 2–4 weeks to the full adult dose. Very young children may remain at half the adult dose, though children as young as 7 years of age have tolerated the full dose well. Monthly monitoring of complete blood count (CBC), aspartate transaminase (AST),

and alanine transaminase (ALT) is indicated during dose escalation and should continue every 3–6 months or more frequently as needed. Thyroid function should be checked annually. Side effects commonly experienced with the beta-interferons involve fatigue and flulike symptoms and can be managed with the nonsteroidal anti-inflammatory drugs (NSAIDs) such as ibuprofen or naproxen (Naprosyn) before and after dosing. Increased hydration can also reduce side effects.

Glatiramer acetate (GA) is usually started at the full adult dose. The experience of children on GA is less well documented than for the beta-interferons. As with adults, the most common side effects are injection site reactions and pain and, occasionally, a postinjection reaction of vasodilation, shortness of breath, chest pain, asthenia, anxiety, and nausea.

Contraceptive counseling should be initiated for any adolescent female initiating DMT treatment and at other times as appropriate. Discussion can begin in broad terms to the younger adolescent and become more detailed and specific with age.

Initiating Disease-Modifying Therapies

After discussion about treatment options, side effects, injection specifics, and laboratory monitoring, the choice of DMT should be made jointly among the youngster, family members, and health care team. To promote adherence, the adolescent in particular needs to be actively involved in the decision-making process. Parents know their child best and will know family strengths and coping styles. This input is important in choosing the best treatment option for each child.

The parents of younger children usually administer the injections, although the child can play a major role in preparation, site selection, and recording information on a calendar or in a journal. As children mature, they should be encouraged to take on more responsibility for disease management. Adherence to therapy requires ongoing discussion with the child or adolescent as well as family members.

Initiating an injectable treatment is stressful for anyone at any age. Children fear the discomfort of injections themselves, whereas parents are anxious about causing their child pain. Techniques we have found helpful when initiating treatment in children include:

- Discussing the rationale for the therapy in terms that are age appropriate.
- Teaching the whole family the injection process.
- Arranging for younger children to obtain shorter needles for intramuscular injections and suggesting shorter injection depths for subcutaneous injections.

- Suggesting the application of topical anesthetics such as eutectic mixture of local anesthetic (EMLA) cream to decrease discomfort of injections.
- Offering children choices such as choosing the injection site or opting for a Band-Aid.
- Recommending the family build medication time into the family routine.
- Offering a small treat after the injection to make the process more positive.
- Proposing the development of comfort rituals.
- Allowing the older child and teen more autonomy in the process, while still offering supportive monitoring.

Second-Line Therapy

There is limited experience in the treatment of poorly controlled disease with second-line therapies such as cyclophosphamide (Krupp & MacAllister, 2005) or the monoclonal antibody natalizumab (Borriello, Prosperini, Luchetti, & Pozzilli, 2008; Huppke, Stark, Zürcher, Huppke, Brück, & Gärtner, 2008), but they have been used in pediatric patients who are unresponsive to DMTs. Other options for treating aggressive disease include regular IVIG infusions. Several studies in the adult population have shown a beneficial effect. Dosing for children at 0.4 g/kg for 3–5 days can be repeated monthly to every 3 months (Chabas et al., 2006). There are some reports of immunosuppressive therapy use in children (Krupp & MacAllister; Makhani et al., 2009), but none are approved for use in pediatric MS and all have the risk of serious side effects including secondary malignancy, infertility, and infection. Cyclophosphamide, azathioprine, methotrexate, and mitoxantrone are used to treat severe MS that is refractory to DMTs but must be used with extreme caution in the pediatric population (Chabas et al., 2006; Makhani et al., 2009; Pohl et al., 2007).

Symptomatic Management

As with adults, symptomatic management is specific to individual need and varies with time. A careful review of symptoms is needed at every visit. Exploring persistent symptoms with both the youth and parent in an open-ended fashion offers optimal efficacy. Open and frank discussion about topics including sexuality should be initiated. Pharmacologic and nonpharmacologic symptom management is recommended as detailed elsewhere in this book. Specific recommendations for concerns with cognition and fatigue are described later in this chapter under “Schooling.”

Treatment Adherence

Adherence to a treatment regimen is based on the assumption that the child and family acknowledge the diagnosis and accept the treatment plan. Possible causes of adherence issues include injection site reactions, medication side effects, perceived lack of treatment efficacy, poor family functioning, lack of disease-specific education, and lack of resources (Clerico, Barbero, Contessa, Ferrero, & Durelli, 2007; Thannhauser, Mah, & Metz, 2009). In the adolescent population, one can anticipate poor adherence because of normal maturational factors (Geist, Grdisa, & Otley, 2003). Taking medication is a constant reminder to teens that they are different from their peers. A lack of understanding or appreciation of the disease process may cause children and teens to be more concerned about impact on school and social life, rather than the neurologic consequences of the disease (Weisbrot et al., 2010). Nonadherence may result from psychosocial dysfunction, a perceived loss of control, anger at the diagnosis, and concerns about the future. For the adolescent, treatment adherence signifies recognition and acceptance of the illness. Furthermore, adhering to treatment may produce untoward adverse effects. The fact that the DMTs involve needles leads to adherence difficulties among many children and teens.

Experience with other childhood chronic disorders finds that children with greater parental involvement have higher rates of adherence (Anderson, Ho, Brackett, Finkelstein, & Laffel, 1997). In one small study of adherence in pediatric MS, strategies to maximize adherence include educational programs for families and children regarding the DMTs, access to a trained MS nurse specialist to deal with side effects and reactions, referral to support systems, and funding for medication and supplies as necessary (Thannhauser et al., 2009). Providing opportunities for youth with MS to interact with each other improves adherence and a sense of well-being for both youth and families (MacAllister, Boyd, Holland, Milazzo, & Krupp, 2007). By promoting the adolescent's autonomy and decision making, while guiding care, treatment adherence may be maximized (Geist et al., 2003).

PSYCHOSOCIAL ISSUES

MS creates many stressors for children and adolescents that affect their ability to cope. The unpredictability of MS, persistent symptoms such as fatigue and cognitive difficulties, the perception of being different from peers, and ongoing treatment with injectable therapies are just some of these stressors (Boyd & MacMillan, 2005). At diagnosis, most children

and teens do not know what MS is and feel scared or sad (Boyd & MacMillan). Many younger children fear dying, believing they have a brain tumor or a rare terminal illness. Because of the rarity of MS in those younger than age 18, children and teens can feel isolated and alone with their diagnosis. Usually, they do not know anyone their own age with MS and have difficulty relating to adults with MS. They often feel misunderstood by others (Boyd & MacMillan). As many as 50% of children and teens with MS experience depression, anxiety, or adjustment issues (MacAllister et al., 2005).

When dealing with the pediatric MS population, the psychosocial issues of parents also require consideration. An important part of children's lives is their parents who are their main sources of support and act as their advocates and decision makers (Coffey, 2006; Stewart, 2003). When a child is diagnosed with MS, the parents tend to be the most burdened by the knowledge that their child has a potentially disabling chronic disease and faces an uncertain future. As with all parents who have been given the news that their child has a chronic condition, they may experience a gamut of grief reactions including denial, fear, anxiety, guilt, anger, and sadness (Johnson et al., 1995). They continue to live with worry about their child's future and the uncertainty of the illness, become extra vigilant about their child's health, and struggle to maintain a normal family life (Coffey). Addressing the psychosocial needs of both children and parents is essential.

Awareness and sensitivity to cultural differences is also important when considering the psychosocial needs of this population. Compared to adult-onset MS in which patients are mostly Caucasian and of European ancestry, there is greater racial and cultural diversity in pediatric MS (Boster et al., 2009; Chitnis, Glanz, Jaffin, & Healy, 2009; Kennedy et al., 2006). Unlike their adult counterparts, those with pediatric-onset MS are much more likely to be of African, Hispanic, Asian, or Middle Eastern descent. The cultural and religious background of the family needs to be taken into account and explored with respect to understanding health beliefs and family values, recognizing and addressing their unique psychosocial needs, and supporting their coping strategies.

Supporting Children and Adolescents

The age and developmental stage of children and adolescents influences not only their response to the diagnosis of MS and how they cope living with the disease but also the type of information and support they need (Stewart, 2003). Adolescents in their late teens are likely to respond to the diagnosis in a similar fashion to young adults and their needs are

probably comparable. In contrast, children and younger teens who think concretely are focused on the present and have a greater dependence on their parents require a different approach.

Informational Support

It is common for children and many adolescents to ask few questions about their disease and some will state that they do not want to talk about it. Most inquiries tend to relate to their immediate situation. They are often quite comfortable letting their parents be the information seekers. Answering their questions in a simple and honest manner, discussing only necessary and requested details, and periodically offering additional education as they mature is the best way to address the information concerns of this age group. Providing basic written material they can read when they are ready may also be helpful. Children and teens report that the preferred methods of gaining information about MS are talking to someone or reading about it (Boyd & MacMillan, 2005). Because younger children in particular fear dying, they need reassurance that they do not have a brain tumor and that they are not going to die. They often worry about this possibility but hesitate to ask. Adolescents, on the other hand, worry about how to manage health threats (Stewart, 2003). Note that children often feel more comfortable asking their parents questions rather than health care professionals, therefore, parents should be encouraged to capitalize on the opportunity to provide education when their children ask spontaneous questions. In contrast, teens may want the opportunity to ask questions to health care professionals without their parents' presence and benefit from a private meeting.

Emotional Support

Parents remain the main sources of support for most aspects of their children's lives and to support children emotionally, the most effective approach is to support their parents. Children have a strong sense of their parents' emotions and will often assimilate these feelings to themselves. A child's attitude to their illness is strongly dependent on their parent's attitude and behavior toward the illness (Taylor et al., 2008). When parents successfully come to terms with the diagnosis and learn to adapt to the uncertainties of MS, they are better able to support their children (Clawson, 1996). Consequently, their children more readily learn to cope with the issues inherent with the disease.

Although parents and professionals alike believe linking a child or teen with MS with another for mutual support is beneficial, many firmly decline this offer. Older teens may be more receptive to this idea and

consider e-mail communication as an initial approach. More recently, camps, family retreats, chat rooms, and e-mail groups offer opportunities for children and teens with MS to connect with each other (see “Family Resources” later in this chapter).

Despite facing additional stressors because of their disease, most children with MS cope quite well and feel supported by family and friends (Boyd & MacMillan, 2005; Kalb et al., 1999). Coping strategies used by children and teens with MS include:

- Maintaining a positive outlook
- Striving for goals and dreams
- Making downward comparisons
- Identifying positive role models
- Normalizing, adapting lifestyle
- Seeking support
- Participating in distractions
- Accepting treatment

They also use other coping mechanisms such as denial, manipulation, relying on others to deal with the stressors (e.g., parents), avoidance, and hiding differences (Boyd & MacMillan, 2005).

Research has found that maintaining a sense of normalcy is associated with positive adjustment to chronic illness in children (Stewart, 2003). Markers of normalcy include school participation, defining oneself as an ordinary person, minimizing one’s sense of difference from peers, focusing on routine and the ordinary rather than the illness, and accepting responsibility for illness self-care. Therefore, supporting children to achieve a sense of normalcy is recommended. Additional strategies for supporting coping include optimally managing physical symptoms, limiting the severity of medication side effects, and involving them in health care decision making (MacAllister et al., 2007). Nursing behaviors that adolescents identify as supportive are caring involvement and the use of humor (Stewart). They want to feel understood and respected by the health care team and be offered flexible treatment plans (Taylor et al., 2008).

Studies have found that children and teens with MS often do not view themselves as being different from their peers and show little or no awareness of the potential impact of MS on their lives (Boyd & MacMillan, 2005; Kalb et al., 1999). Children who experience difficulties coping may benefit from professional counseling from a social worker, psychologist, or psychiatrist with pediatric expertise. Like adults with MS, depression is not uncommon in patients with pediatric-onset MS and needs to be recognized and treated.

Supporting Parents

As suggested, the most effective approach to supporting children is to support their parents. Nurses can assist parents in the process of adaptation using several strategies (Boyd, 2001):

- Provide current and accurate information (both verbal and written)
- Direct them to additional sources of information
- Offer hope
- Encourage them to access their personal sources of emotional support (e.g., family, friends, clergy)
- Refer them to a social worker, psychologist, or psychiatrist, as appropriate
- Link them with other parents who have a child with MS
- Identify community resources

Facilitating the adaptation of parents will in turn assist the children in their own adaptation process.

Disclosing the Diagnosis to Others

When children are diagnosed with MS, it is important to discuss with them and their parents the disclosure of the diagnosis to others. Adolescents, in particular, prefer to remain selective about whom to disclose their diagnosis (Boyd & MacMillan, 2005; Stewart, 2003). Those diagnosed in their childhood years frequently recall “everyone” knowing they had MS, which was a source of embarrassment at times and left them vulnerable to possible teasing, pity, or ostracism. However, most recognize that certain people such as their family, close friends, teachers, employers, and coaches need to know about their diagnosis because they believe these people are in the position to be understanding and supportive of their needs and provide assistance when required. Nurses should discuss with the child and parents the potential ramifications of full disclosure, encourage them to identify key individuals who need to know about the diagnosis, and discuss the type of information to be shared and approaches to disclosure.

SCHOOLING

School participation is a significant aspect of life for youth. Efforts to support their academic achievement and maximize their attendance and involvement in school activities aid their cognitive, physical, and emotional development and support their sense of normalcy. Frequent school

absenteeism because of relapses and medical appointments and persistent symptoms such as fatigue and depression are all potential problems for children and teens with MS that impact school performance and participation (Boyd & MacMillan, 2005). These problems can be minimized by advocating for use of treatment that will reduce the number of relapses and by adequately treating fatigue, depression, and other ongoing symptoms.

Cognitive Issues

Many adults with MS experience cognitive issues, and children with MS are no exception. Children and adolescents can experience cognitive deficits affecting memory, attention, and cognitive processing speed that lead to poor school achievement or the need for added academic supports (MacAllister et al., 2007). Studies examining the neurocognitive effects of MS in children and teens found that many scored below age-matched normative data in at least one cognitive domain and that the longer the child had the disease the greater the deficits (Banwell & Anderson, 2005; Kalb et al., 1999; MacAllister et al., 2005; Montiel-Nava, Peña, González-Pernía, & Mora-La Cruz, 2009). Deficits in perceptual motor skills, memory, naming, visual motor skills, executive functions, and processing speed are reported (Amato et al., 2008; Kalb et al., 1999; MacAllister et al., 2007; Montiel-Nava et al.). Children may be particularly vulnerable to cognitive impairment because the neuropathologic processes of MS occur while the brain is still developing (MacAllister et al., 2007).

Although those with more profound or global cognitive deficits experience academic performance issues, others are high-achieving students who overcome their deficits. Not all children with MS have cognitive dysfunction but those who experience school performance issues or those who demonstrate short-term memory and concentration difficulties warrant neuropsychological testing. Neuropsychologists can provide strategies to both the student and the teacher on overcoming or adapting to cognitive deficits with the goal of helping the child with MS reach his or her maximum potential. Nurses are in the position to advocate for appropriate assessment and implementation of required services.

School Program Adaptations

Some parents choose not to inform the school administration of their child's MS diagnosis either because they do not want him or her to be labeled as having special needs or because their child prefers the school

not to know. However, it may become necessary if the child presents with mobility impairments, visual disturbances, bladder dysfunction, profound fatigue, or cognitive deficits that impact school attendance, academic performance, or participation consistent with their peers. Having the child formally identified as a student with special needs will lead to the development of an Individualized Educational Plan (IEP) that supports the addition of resources and implementation of adaptations and accommodations that promote achievement and integration in school life. For example, preferential seating in the classroom, reduced workload, extended time for tests or completion of assignments, and assistive technologies such as voice recognition software for a personal computer are just some of the strategies used to assist students with cognitive deficits or physical limitations (MacAllister, et al., 2007). As well, interventions to improve memory or compensate for impaired memory are often required. For children who experience heat sensitivity or exercise intolerance, alerting teachers is essential so that the child can be permitted to stay indoors and be offered cold fluids on a hot day or be allowed frequent rest periods during physical exercise.

Nurses may need to advocate for children to receive the necessary support and appropriate modifications that help them function at their optimum level. With the parents' consent and the child's assent, writing a letter or making personal contact with the school confirming the needs of the child and supporting the suitability of requested services and accommodations may be all that is needed to initiate change. The neuropsychologist's report should be provided to the school for implementation of recommendations. Note that some young people with MS are reluctant to have modifications at school that draw attention to their disabilities or make them feel different. It is important to remain sensitive to the views of the child and include them in decision making about changes that will be put in place.

Fatigue is a common issue for children and teens with MS. Profound fatigue can influence academic performance, interfere with social involvement with peers, and prevent or limit participation in physical exercise. It causes poor concentration and attention in the classroom and limits the student's ability to study and complete assignments. If necessary, refer to a pediatric physiotherapist for suggestions around energy conservation strategies and adaptations to a physical education program. Suggestions for reducing activities that increase fatigue in the school setting include (a) accessing the school elevator rather than using the stairs; (b) arranging transportation to school rather than walking; and (c) obtaining two sets of textbooks (one for home and one for school) rather than being burdened with carrying heavy books to and

from school. A reduced course load is sometimes recommended. In some cases, prescribing medication that reduces fatigue such as modafinil is effective.

PROMOTING A HEALTHY LIFESTYLE

Although some young people with MS report major changes to their lifestyle after diagnosis, others perceive little change (Boyd & Mac-Millan, 2005). They often participate in the same activities as their peers, but some modify their activities such as decreasing participation in competitive sports or not going out as often. Some indicate that they are now more careful, take fewer risks, and do not push themselves as much. Continued involvement in recreational, sports, and social activities outside school should be highly encouraged, as these are conducive to healthy growth and development. If fatigue or depression prevents these activities, appropriate interventions must be offered. Nurses can address lifestyle changes by providing anticipatory guidance, facilitating necessary adaptations, supporting lifestyle modifications, and encouraging a balance between school and extracurricular activities.

TRANSITIONING TO ADULTHOOD

Transition in pediatric health care is the process of moving from childhood to adulthood care and includes medical, educational, vocational, and social domains. It is recommended that planning for transition begin early.

In the health care arena, a plan for transitioning care from a pediatric to adult-centered model should be developed. In some cases, care is transferred from a pediatric MS center to an adult MS center. For other individuals, the medical team may follow both pediatric and adult patients. As the teen matures, the responsibility for care begins to shift from the parent toward the young person. Allowing the young person time alone with the health care team fosters independence and gives them an opportunity to discuss topics that might be difficult in the presence of parents. When relapse symptoms develop and the parent calls to report the issue, asking to speak to the adolescent to obtain more information increases their involvement in self-care. Providing both the teen and parent with contact information also encourages direct participation.

Transition is a dynamic and ongoing process. The goal is to provide high-quality, uninterrupted health care that is patient centered and

developmentally appropriate. Promoting skills in communication, decision making, and self-advocacy enhances a sense of control in health care and maximizes lifelong function and potential as children make the transition to adulthood (McDonagh & Kelly, 2003). Tools such as a personal medical record that the young person can use to record and collate medical history, treatment history, lab and MRI results, and a list of health care providers with contact information can be reviewed and updated at each visit.

Transitioning in the education domain begins by middle adolescence, with discussion of goals for the future. A plan for higher education, either academic or vocational, needs development. For some individuals, referral to a regional independent living organization may be indicated for support. Meeting with personnel in the office of disabilities at the vocational school or college can ensure a smooth transition for those furthering their education.

Financial planning and planning for future health care needs are important for children with chronic illness. Maintaining access to medication is a priority. Young adults eventually become too old to qualify under their parent's medical coverage and need to determine alternative coverage.

As teens begin to explore the world and themselves, the health care team should provide a safe, supportive environment in which the teen can grow and mature. Adolescents need frank discussion about the real-world experiences that teens face, such as dating, sexuality, alcohol, smoking, substance use, attitudes from nonaffected peers, and overprotective parents.

FAMILY RESOURCES

There are many resources available to support families living with pediatric MS. Referral to support services can be made early in the diagnostic process. Although some families benefit from the support of other parents who have had a similar experience, others may take longer periods to become involved with these programs. A common concern among families of newly diagnosed children is a fear of what is to come. Ultimately, after making connections, parents report that they are pleased that they have "met."

Because of the relatively small number of youth with MS, many support programs are "virtual" support groups offered online or via telephone. *Children and Teens with MS: A Network for Families* facilitated by the National MS Society and the MS Society of Canada offers educational

and psychosocial support for families. The network currently provides the following resources:

- *Kids Get MS Too: A Handbook for Parents Whose Child or Teen Has MS*
- *Mighty Special Kids*—activity book for children (ages 5–12) with MS
- Moderated e-mail groups for parents and teens to share their questions and concerns
- Information and referral

A handbook for school personnel working with children affected by MS and a booklet for teens with MS are also in development. For information call 1-866-KIDS W MS or e-mail childhoodms@nationalMSSociety.org. In Canada, call 1-866-922-6065 or e-mail kidswithms@mssociety.ca.

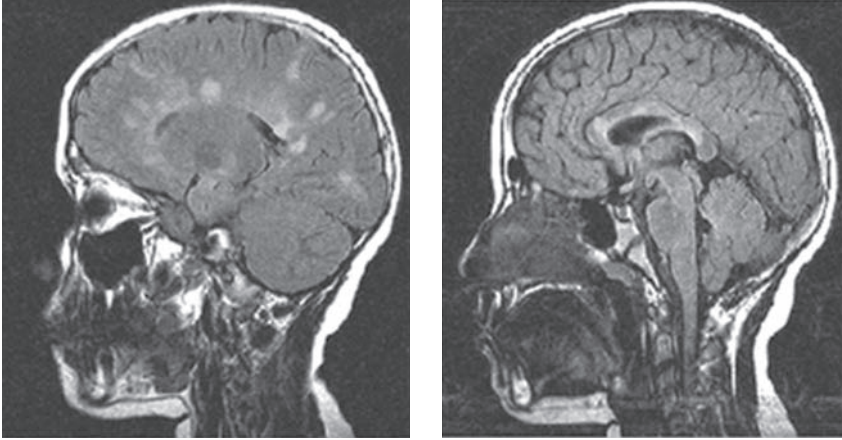
Other support networks include camp programs that bring youth together from great distances for an opportunity to meet others with MS. For example, the Pediatric MS Center of Excellence at Stony Brook, NY, runs an annual teen adventure program and the MS Society of Canada runs a camp for children and teens with MS each summer. In recent years, we have found that teens have connected online, developed relationships, and then finally meet in person at a camp program. Support networks developed online or at camp maintain the youth through the year, knowing that there are “people out there who know how I feel.”

Over the past 10 years, several pediatric MS centers and clinics have been created across the United States, Canada, and now Europe to optimally support and meet the needs of young people with MS and their families. For example, in 2006, the National MS Society established six Pediatric MS Centers of Excellence. Each center offers comprehensive services by multidisciplinary teams of pediatric and adult MS experts including staff who evaluate and address school and other psychosocial issues, and support families. Referral to a center with expertise in pediatric MS may be helpful to families.

Over the course of the first year, Alex experienced four relapses. He was treated with an IV of methylprednisolone with full recovery each time. His medication was changed from GA to a beta-interferon. He then had one relapse a year for the next 4 years. His highest EDSS score was 2. Despite treatment, his MRI continued to show evolution of new enhancing lesions (see Figure 12.2). Consequently, 2 years ago, he began treatment with natalizumab and has been relapse since that time.

Alex is now a senior in high school. He does well in the classroom, but in the first 3 years after his diagnosis, he showed a decline in his annual

FIGURE 12.2 Neuroimaging 1 Year Later, on Treatment 6 Months



neurocognitive assessment, particularly in areas of memory. An individualized education program (IEP) was developed for him in order to provide accommodations such as extended testing times, and 2-day testing for standardized exams, to maximize his potential and accommodate for fatigue.

He is active in organized sports and plays for the school soccer and lacrosse teams. Shortly after his diagnosis, he took a break from competitive soccer for a few years, but is back in the game now.

The family continues to be a strong support for Alex. They advocate for his needs and try to maintain a “normal” lifestyle. He is active in the community of young people with MS, attending the Teen Adventure Camp program for kids with MS, and is involved with chat rooms for teens with MS. He describes some of his online friends as the “best friends I have never met.”

Now 16 years old, Alex is planning for his future. He is more involved in his own health care and maintenance, calling for appointments and with questions. He is planning to attend a local university with the goal of becoming a physical education teacher or, perhaps, an architect. The future is wide-open for Alex.

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Collaborating With the Rehabilitation Team

Patricia M. Kennedy

J. H. is a 68-year-old woman with secondary progressive multiple sclerosis (MS) who was diagnosed in 1982. Three years ago, after continuing to walk poorly with a walker at home, she developed severe pain and deformity in her right knee. She had a knee replacement but was not sent to an inpatient rehab facility to help in her recovery of function. She developed a deep venous thrombosis and then a decubitus ulcer. She was discharged to a skilled facility for wound care for 6 months. After wound healing, she was discharged to a skilled nursing facility. At this facility, she received no active physical therapy except for “restorative therapy” for 15 minutes, 3 times a week. She was being transferred with a 1- or 2-person assist or was using a lift. She had a Roho cushion to prevent further decubitus ulcers but could not shift her weight independently. Her upper extremities, although weak, were functional enough to allow her to do most activities of daily function. Her old wheelchair was heavy and bulky and she could not propel it independently. Being a resident of a nursing facility, she was unable to receive a power wheelchair or even a manual chair that was more appropriate for her needs.

At this point, she and her husband expressed their goal of having her return home. She thought she would need to walk as she could not manage the wheelchair at home. The skilled nursing facility refused to assist her in meeting her goal as they felt it was unreasonable. The MS nurse, when presented with this goal in her office, discussed it and the barriers she might face with them. She was referred to a physiatrist for evaluation.

A power lift was installed to assist in transfers. She now has daily assistance from the agency as well as other community care providers. She is receiving physical therapy and occupational therapy services at home and is becoming more independent. The palliative care team meets with the original physiatrist monthly and revises the care plan.

INTRODUCTION

“Go home and live with it—there is nothing we can do.” All too often, people with multiple sclerosis (MS) have heard these words. However, experts in the field of MS know that providing rehabilitation as well as symptomatic treatment for existing problems can assist the person with MS to remain as independent as possible in an environment of his or her choosing (Rosner & Ross, 1992; Scheinberg & Smith, 1987). Although research has not demonstrated that rehabilitation has an impact on the pathologic process in MS, rehabilitation techniques are often highly effective in treating its symptoms. According to Lechtenberg (1988), “during remission, much of the weakness, speech difficulty, or incoordination that developed with the flare-up can be compensated for with physical or occupational therapy” (p. 187).

Larson (1995) states, “rehabilitation is an approach to care, a philosophy, and an attitude, as much as it is a set of specialized techniques” (p. 536). It may also be defined as “an active process of change by which a person who has become disabled acquires and uses the knowledge and skills necessary for optimal physical, psychological and social functioning” (Thompson, 1998, p. 397). Although there is no cure for MS, much can be done to alleviate its symptoms and assist the client to lead a relatively normal life to the optimum level possible within the limitations of the disease and within the least restrictive environment possible (Corbin, 1998; Liu, Playford, & Thompson, 2003).

DEFINITION OF REHABILITATION

To rehabilitate is defined by Webster as “to restore to a condition of health or useful and constructive ability” (Woolf, 1980, pp. 966–967). According to Hickey (1992), rehabilitation is “... a dynamic process through which a person achieves optimal physical, emotional, psychological, social, and vocational potential and maintains dignity and self-respect in a life that is as independent and self-fulfilling as possible” (p. 178). Thompson (2000) writes that “the philosophy of rehabilitation, which addresses the needs of the whole patient and emphasizes patient management, is ideally suited to the needs of patients with such a complex and progressive disorder. It aims to improve independence and coping to minimize disability and handicap and maximize quality of life.”

The American Nurses Association (ANA), Division on Medical–Surgical Nursing Practice, and the Association of Rehabilitation Nurses (ARN) define rehabilitation nursing practice as “the diagnosis and treatment of human responses of individuals and groups to actual or potential

health problems stemming from altered functional ability and altered style” (ANA & ARN, 1988, p. 4). In the ARN (2000) pamphlet, *Rehabilitation Nurses Make a Difference*, they state that “rehabilitation nursing is a philosophy of care, not a work setting or a phase of treatment.” McEachron states, “rehabilitation is teaching, learning. It is discovering teaching is good, learning better, but applying is best of all” (Dittmar, 1989, p. 10).

There are two types of rehabilitation, both of which are implemented in the care of MS clients. *Restorative rehabilitation* attempts to reestablish function that has been lost during an exacerbation. *Maintenance rehabilitation*, although not well compensated for by most insurance companies, is an effort to keep a progressive disease process from causing unnecessary functional deterioration. The term *maintenance* has been mostly replaced by *preventive* because the latter reflects a dynamic process.

THE GOALS OF REHABILITATION

In *A Manual on Multiple Sclerosis*, Bauer (1977) identifies significant guidelines in setting goals:

In every rehabilitation program, the patient must be treated as a whole, the best physical and psychological condition under the circumstances must be achieved, complications eliminated as far as possible and realistic motivations exploited. This can only be accomplished by the well-coordinated teamwork of doctors, nurses, physiotherapists, occupational therapists, clinical psychologists, social workers, the patient and his family and friends, and organizations with a genuine interest and sense of responsibility for him. (p. 34)

Based on educational preparation and prior experiences, many nurses (and physicians) do not have a rehabilitation focus, particularly toward patients with chronic illness. Chronic illnesses are rarely cited in the rehabilitation literature. Nurses working with patients with MS in the acute care, home care, and outpatient settings should be aware of the benefits of rehabilitation and identify the need for rehabilitation protocols to improve function and quality of life for their patients. Many schools of nursing have incorporated well-defined rehabilitation content in their curriculum, preparing nurses to specialize in this area. Exposure of nursing students to rehabilitation concepts and practices fosters incorporation of a rehabilitation perspective across all specialty areas, focusing attention on maximizing function in all areas of daily life. Growth in the field of rehabilitation is escalating, as evidenced by the increased membership of nurses in such organizations as the ARN, which has now well more than 10,000 members.

The goals of rehabilitation, as expressed by Dittmar (1989), are “... to prevent further disability, maintain existing ability, and restore maximum levels of function within the limits of the client’s impairment” (p. ix).

The goals of MS rehabilitation are to improve mobility, improve activities of daily living (ADL), improve and sustain a desired quality of life, prevent complications, reduce health care use because of injury, and promote safety and independence (Easterling, personal communication, 2008–2009; Patti et al., 2002).

THE REHABILITATION TEAM: AN INTERDISCIPLINARY APPROACH

Unlike with many other neurologic disorders, people with MS exhibit a wide variety of symptoms, often differing over time. Typically, the patient with a spinal cord injury knows the level of his or her impairment and a rehabilitative plan of care can be developed based on the location of the severance of the cord. Because of the variability of symptoms caused by multilevel lesions, there can be no set rehabilitation plan of care or regimen for the person with MS. Each is unique and, depending on the location of lesions, dysfunction may vary widely among patients. An ongoing and goal-oriented program of varying intensity, rather than a one-time rehabilitation program, is recommended by Coville (1983). Cobble and Burks (1985), Maloney (1985), Hunter and Popp (2000), and Solari et al. (1999) stress that rehabilitation goals in MS must be developed from careful functional assessment and the patient’s ongoing response to treatment, taking into account past, current, and expected disease activity (Kesselring & Beer, 2005; Patti et al., 2002).

An interdisciplinary model is required by both The Joint Commission and the Commission on Accreditation of Rehabilitation Facilities (CARF). In this model, the patient is viewed as the center or core of the team, which may offer the patient control over his or her illness (i.e., the experience of living with the disease). This model encompasses professionals from various fields working together to achieve a desired outcome. Inherent in this concept is a comprehensive, nonfragmented, and consistent approach that fosters optimal client outcomes and provides the team with a holistic view of client needs while reducing health care costs and improving client outcomes (Kipnis & Emick-Herring, 1993; O’Toole, 1992). This is in contrast to multidisciplinary approach, which includes the same professionals working individually toward a desired outcome.

Members of the interdisciplinary team include health professionals who meet regularly and engage in problem solving beyond the confines of their own discipline to reach a common goal (Diller, 1990). Weekly or

biweekly team meetings afford the opportunity to share information and discuss progress toward goals. A key component of the interdisciplinary model is the concept of working together to unify individual treatments into a comprehensive plan (Cobble & Burks, 1985; Diller; Hunter & Popp, 2000; Kipnis & Emick-Herring, 1993; O'Toole, 1992). According to Frankel (1990), "... the overriding principle in setting rehabilitation goals [for the patient with MS] is to maximize independence, self-determination, and quality of life within the context of the individual's life-style and abilities" (p. 544). The team works together to meet the physical, emotional, social, economic, and vocational needs of people with MS and their families.

The person with MS and his or her family are an integral part of the rehabilitation team and must be active participants in the rehabilitation process. They need to attend team meetings and must be included in identifying goals and developing a plan of care. According to Dittmar (1989), "the client and family are the core members of the rehabilitation team and the reasons for its existence" (p. 31).

Inherent in the effectiveness of the rehabilitation team is the relationship between the person with MS and the health care provider that is based on open communication, establishing trust and rapport, sharing information, respect for the feelings of the patient, ability to listen, clear and concise information transfer, freedom to ask questions, providing available resources, realistic goal setting, and periodic evaluation. Sometimes it is most appropriate to have the team step back and allow the patient to make his or her own decisions based on the information provided in concert with personal beliefs. At times, team members may identify with patients as peers (e.g., age, educational background). Consequently, feelings of identification could surface, such as "this could be me or my daughter," as well as discomfort and/or frustration. Such feelings should be addressed openly by the team with support from its members or, if indicated, from outside. Conflict within the team is a normal part of the process. An atmosphere in which members are permitted to agree to disagree can be a stepping-stone to growth.

The following disciplines are most commonly represented on the MS rehabilitation team, both facility based and community based (Cobble & Burks, 1985; Cobble, Dietz, Grigsby, & Kennedy, 1993; DeLisa, Martin, & Currie, 1988; Hoeman, 1996; LaRocca, Kalb, & Kaplan, 1987; Schapiro, 1991; Storr, Sørensen, & Ravnborg, 2006).

Nurse

The nurse involved in rehabilitation of the person with MS functions as a "change agent" and patient advocate, empowering a patient and family to know, envision, and evaluate options and to work together

formulating problem-solving strategies and behaviors to achieve outcomes. The complexity of MS and “its interacting disabilities result in changing patterns of need over the continuum. If the person with MS is to be involved in his or her own management, they require an understanding of the condition and the strategies that will help to cope with and manage it” (Thompson, 1998, p. 398). In addition to providing direct physical care, the nurse evaluates the health status of the patient, helps determine short- and long-term goals, interprets medical terms, acts as a resource for community services, and provides education for the patient and family. Often the nurse can provide fellow team members with valuable insights regarding the patient’s motivation, problem-solving skills, and family process. The nurse effectively functions as a coordinator of care or case manager, overseeing cost-effective, efficient, and beneficial coordination of therapies.

Physiatrist

The physiatrist has special skills in the evaluation of functional issues and symptom management. These include neuromuscular, musculoskeletal, cognition, bowel, bladder, and skin symptoms, sexual function, and rehabilitative aids. The physiatrist usually leads the team and may work with the nurse in coordinating and integrating the often complicated rehabilitation program.

Physical Therapist

The physical therapist assists the patient to achieve or maintain functional restoration and predominately concentrates on the lower extremities. A person with lower extremity weakness or other difficulty with mobility may benefit from exercise to maintain general conditioning and reverse or prevent disuse atrophy. Consideration needs to be given to the temperature of the environment in which physical therapy takes place, because a cooler environment will reduce the risk of elevating body temperature, which leads to fatigue. Gentle and sustained stretching exercises are beneficial in the management of spasticity.

Historically, the role of exercise in MS has not been clear. Schapiro (1995) reminds us that numerous research studies have demonstrated that exercise, when performed regularly, is beneficial for the heart, lungs, skin, bones, and psyche. Exercise helps to increase an individual’s general health, with or without MS. Petajan et al. (1996) reported that individuals with MS participating in 15 weeks of aerobic training

achieved a substantial increase of maximal aerobic capacity independent of the level of neurologic impairment. In addition to improved fitness, aerobic training had a positive impact on factors related to quality of life. Significant reductions in fatigue, anger, and depression, and improved ambulation, mobility, and body care and movement were reported. A sense of control over one's destiny, which fosters empowerment, can be created through exercise. When properly performed, exercise should alleviate fatigue rather than increase it.

There are different kinds of exercises and that the choice of type selected depends on the desired goal. Types of exercise include aerobic exercises such as swimming and running, which build endurance. Stretching and range of motion exercises are helpful in the management of spasticity and the prevention of contractures, whereas relaxation exercises such as visualization, yoga, biofeedback, and bodywork can be effective in stress reduction (Schapiro, 1995).

Benefits derived from various types of exercise include improved fitness, improved ability to perform everyday tasks, reduced depression and anxiety, improved measures of well-being, reduced fatigue and increased strength. In addition, it may reduce morbidity resulting from cardiovascular disease and other problems arising from immobility ("Tailored physical activity programmes," 2000).

Occupational Therapist

The occupational therapist (OT) focuses more specifically on functional activities and is concerned with how one is "occupied" in life, particularly with respect to ADL. Emphasis is on the upper extremities in such areas as maintaining and improving joint range of motion, muscle strength, coordination, endurance, and dexterity. OTs also work with people with MS on issues of fatigue management and energy conservation. They can assess cognitive status and recommend compensatory techniques. They are sometimes asked to do workplace evaluations, offering strategies and suggesting changes that will keep a person with MS employed longer, more productively, and in appropriate occupations.

Speech-Language Pathologist

The speech-language pathologist evaluates and treats patients with neurogenic disorders such as dysarthria (speech difficulties) and dysphagia (swallowing difficulties) that may occur in MS. Dysarthria may vary from a slight slur to a more severe condition such as scanning

speech, in which understanding speech may be difficult. Therapy is ideally initiated when symptoms first appear and focuses on teaching and training techniques that compensate for reduced neuromuscular function, such as the use of pauses between one or two words and exaggeration in articulation.

When a person experiences dysphagia, speech-language pathologists evaluate the swallowing pattern to identify the areas of dysfunction. They then instruct individuals and caregivers how to perform the swallow more safely and efficiently. Cognition is important in communication and, as such, falls into the realm of therapists who are trained in its evaluation and treatment. They use the information from their diagnostic testing to assist individuals with MS to improve organization, regulate the speed of information, and work on memory strategies.

Social Worker

The social worker assesses the patient and the family's total living situation and assists in areas such as financial arrangements, community resources, and alternative living situations, as well as facilitating discharge planning. In many settings the social worker is also the primary counseling professional for both the person with MS as well as the family. Social workers also serve as case managers in some health systems.

Psychologist

The psychologist assists the patient and family to prepare psychologically for active participation in rehabilitation. In an MS care center, as well as in some other settings, the psychologist can be involved in several activities that include assessment of psychological status, coping styles, problem-solving skills, testing of cognitive function in areas such as intelligence, memory and perceptual functioning, and clinical research. Through counseling, the psychologist assists the patient with MS to develop or strengthen the tools necessary for coping with periods of extra stress and turmoil. Counseling in the following areas may be needed: dealing with the diagnosis, adjustment to body changes, development of problem-solving skills, anxiety or uncertainty about the future, loss of self-esteem, secondary problems caused by the disease and its disability, adjustment to changes in sexual functioning and viable alternatives, and family upheaval. This support may come in various forms based on the needs of the patient (e.g., orientation or counseling groups and individual, group, and family counseling).

Recreational Therapist

The recreational therapist uses recreation as an intervention to bring about a desired change in physical, emotional, or social behavior while promoting the growth and development of the patient. Therapeutic activities include the assessment of the patient's capabilities and interests, and development of a program plan based on the patient's needs. These activities include leisure activities, increased concentration or maintenance of physical strength, social skills and motivation, as well as assisting in adjustment to disability and increasing independence.

Vocational Rehabilitation Counselor

The vocational counselor assists the patient with MS to identify, develop, and attain realistic vocational goals. Efforts should focus on continuing work activities with whatever modifications are needed, as maintenance of employment is much more easily achieved than reemployment. Modifications might include staggered work hours, lunchtime naps, locating the work space closer to restrooms, or providing enlarging capacity for the computer screen. For those who are unable to work or choose not to work, the vocational counselor will help identify other activities, such as volunteer work or homemaking, to support the need for productivity.

Other Team Members

Depending on individual patient needs, other professional team members may include an orthotist, neurologist, respiratory therapist, urologist, chaplain, ophthalmologist, driver education specialist, dietician, and durable medical equipment vendors.

Team Interaction

The following is an example of how the rehabilitation team might function interactively when dealing with bladder dysfunction, a problem common in MS. Although bowel problems frequently occur, it is important to treat bladder problems first because of the risk of urinary tract infections and the potential for kidney damage. Also, the necessary high fluid intake needed to treat constipation is unlikely to occur when urinary symptoms are present. The physician, urologist, nurse, and occupational and physical therapists will collectively work toward a mutual goal for

the patient to be free from infection and incontinence. The plan should include assessment, evaluation, medication, if indicated, and teaching a bladder program to the patient or family members, including intermittent self-catheterization if indicated. In addition to assessing bladder function, evaluation of hand function, transfers, sitting or standing, and balance might need to be done by the occupational and physical therapist. A critical health need is determining and treating the underlying pathology, as well as treating urinary infections and creating an overall intervention plan for management of urinary symptoms. Evaluation on an ongoing basis is inherent in this process.

Mobility Aids and Other Adaptive Equipment

Mobility aids are not useful in all instances. When the patient is disabled primarily because of fatigue rather than from weakness or spasticity, other measures need to be introduced. Ambulation aids may assist the patient to improve function and remain walking as long as possible. The appropriate use of an aid, specific to the needs of the patient, can increase endurance, decrease energy cost, and improve safety while ambulating. The nurse needs to be aware that the use of assistive devices may raise complicated emotional issues for the person with MS, because they represent increasing disability and may be perceived also as increasing dependence. It is important to stress that although use of a wheelchair for mobility may feel like a threat to self-esteem, the conservation of energy and increase in access permit more diverse activities that outweigh the psychological need to ambulate. Keep in mind that the goal is to improve function and that whatever tools it takes to improve the quality of life for the patient is paramount. Some people with MS may be presented with overwhelming evidence as to why an assistive device would be beneficial but will be unable to make the decision to use the device. If a patient is reluctant to initiate change, education and short-term counseling may be helpful in promoting adaptation to his or her new functional status.

Common ambulation aids include one or two canes, a quad cane, lightweight forearm crutches, ankle-foot orthoses, newer technology to reduce foot drop, and walkers. Proper fit of the aid to the patient, teaching safe and efficient use, and subsequent evaluation of the method of use are of vital importance. Using a wheelchair, often on an as needed basis, can be effective for the patient who tires easily. The nurse needs to be cognizant of the fact that impaired walking is not always the primary consideration in determining the need for a wheelchair or scooter, but that fatigue may be the main factor driving this

decision. For example, a wheelchair allowed a woman with MS and her husband to take a long-anticipated trip to London, successfully taking in all the sights and the theater. Motorized wheelchairs and/or scooters can also increase a patient's independence, sense of freedom, and mobility. Ideally, wheelchair design and use will be evaluated by the team, including occupational and physical therapists, rehabilitation engineer, psychiatrist, nurse, psychologist, and social worker. Environmental factors—such as doorways and bathroom dimensions in the individual's home and workplace—are a consideration (Hoeman, 1996; Schapiro, 1991).

In addition to mobility aids, there are catalogs full of available tools to assist with most ADL. These equipment can help with eating, bathing, dressing, and grooming. Some aids are energy saving and some promote independence. People with MS should be encouraged to become informed about and to use these equipment. Technological advances have opened the doors for people with disabilities; computer use with assistive devices such as modified mouses, software to eliminate the mouse, voice recognition software, or screen magnification. This opens up opportunities for employment, leisure, and communication outside the home. Various environmental control systems can promote greater and safer independence in the home.

RESEARCH STUDIES

Several studies looked at the benefit of inpatient rehabilitation. Solari et al. (1999) reported that despite unchanging impairment, physical rehabilitation resulted in an improvement in disability and had a positive impact on mental components of health-related quality of life perception at 3 and 9 weeks. Freeman, Langdon, Hobart, and Thompson (1999) studied the carryover of benefits gained after a brief inpatient rehabilitation. They found benefits were gained after discharge despite worsening neurologic status. These benefits diminished over time, reinforcing the need for continuity of care between inpatient setting and community. Feigenson et al. (1981) reported that patients who have not responded to outpatient rehabilitation benefit functionally from intense inpatient therapies, usually requiring a longer commitment. However, an untreated control group was not used in the study.

Fox and Aisen (1994) also conducted an uncontrolled study composed of a retrospective chart review with follow-up phone calls. Results again suggested that inpatient rehabilitation was associated with significant functional improvement for patients with MS, which was maintained in part following discharge.

ROLE OF THE NURSE IN REHABILITATION

Case Management

In the complex world of medical care, caring for patients with MS can easily become fragmented. In the 1980s, the need for case management was identified and research to various models was instituted, resulting in its now widespread use by facilities, governmental agencies, insurance carriers, and health care programs. Third-party payers also retain case managers to coordinate services provided to clients (McBride, 1992). Health care reforms that began in the 1990s and continue today mandate efficiency and quality in health care delivery, as well as the prudent use of health care resources. Nurses who deal with patients with MS in rehabilitation settings, both inpatient and outpatient, are in an ideal position to serve as case managers for their care.

Many definitions of case management appear in the nursing literature. The following are some of the examples:

- A set of goal-oriented activities that organize, coordinate, and monitor health care delivery based on measurable objectives designed to meet the needs of chronically ill patients. It is a process that involves the provision of quality health care along a continuum, which decreases the fragmentation of care across settings and enhances the patient's quality of life and contains cost.
- A multidisciplinary care process method, which aims, by case-type, to achieve a purposeful and controlled connection between quality of care and cost of that care by standardizing appropriate use of resources (services and treatments), promoting collaborative team practice coordinated, continuity of care over the course of illness ... and minimization of cost.
- The nursing activities of coordination, advocacy, and referral involve facilitating services delivery on behalf of the client, communicating with health and human services providers, promoting assertive client communication, and guiding clients toward use of appropriate community resources (Tahan, 1999).

Although definitions vary, it is clear that case management is best suited for patients classified as high risk or high cost (McBride, 1992). Regardless of the model, case management is a way to systematically organize care. In MS, it provides a system to identify areas that need coordination, helps provide a framework to define unmet needs, and guides the selection of providers to meet those needs. It organizes the formulation of specific treatment plans to

improve the quality and efficiency of services provided. This in turn serves as a framework to measure outcomes and quality of care.

Through case management, nurses can identify when treatment approaches become so complex that they increase frustration or confusion in the patient. Nurses also communicate and clarify the plan to other providers as well as to the patient and family. Nurses can assist the patient in gathering information from all involved providers and participating in a comprehensive treatment plan.

Physiologic Assessment

The physiologic status of patients entering or returning to a rehabilitation system must be evaluated by the nurse. Attention must be paid to all systems, not just the neurologic. Problems are often missed if they are not directly related to MS. A thorough history should be taken about current problems related to neurologic function as well as a review of systems. In specialty care, less attention is paid to general physiologic status, and the nurse is frequently the one who identifies other problems. Particular attention should be directed to subtle changes in bladder, bowel, sexual function, swallowing, speech, vision, and skin. Although sometimes considered insignificant by the patient, problems in these areas can indicate more serious neurologic or physiologic problems. Patients may fail to mention these subtle changes because they are unaware of their importance or the fact that they are related to MS.

Reporting these changes to the other members of the rehabilitation team will be helpful in their assessments. Nurses can use this information to formulate their teaching plans and expected outcomes of performance by the patient. No information or finding is too trivial, nor should it be assumed that someone else is aware of it. As the professional who spends the most time with the patient, the nurse can observe a great deal. Careful attention to written documentation of the nursing assessment is critical to the team process.

Psychological Assessment

In some settings, the rehabilitation team has a psychological professional who can perform a formal assessment; in other settings this resource is not readily available. All members of a rehabilitation team are constantly observing psychological status. The nurse needs to assess on an ongoing basis for symptoms of clinical depression or anxiety, observing or obtaining a history of significant changes in behavior, and obtaining a history of suicidal

thoughts. Being sensitive to expressions of helplessness, hopelessness, anger, sadness, and lack of motivation will help in assessing the emotional state. Nurses need to be critical observers and hear what patients are really saying, not what they want the medical staff to hear. Family input is vital in evaluating emotional status because patients often deny or are unaware of emotional changes in themselves. Attention should be paid when there are discrepancies between a patient's self-assessment and that of the family.

Cognitive Assessment

Patients and families may not always be aware of cognitive changes resulting from MS. These changes may be misinterpreted as stubbornness, acting out, not listening, not paying attention, or irritability. Nurses can perform a bedside mental status exam but unless changes are significant, patients tend to do well with this testing. It is the subtle changes that are the most telling. Patients who do not concentrate well, have difficulty following directions, have short-term memory problems, or make poor or impulsive decisions or experience confusion if doing more than one task at a time may be manifesting symptoms of cognitive dysfunction. When people with MS express fear of losing their job, it may be related to a diminishing ability to cognitively perform the work that may not even be recognized by the person himself or herself. Patients who are concerned because they are more irritable, struggle in relating to family, or are withdrawing may be demonstrating behavior changes related to cognitive status or reflecting a psychological response to the illness.

When performing physical assessment, the unspoken observations are as important as the historical data collected. Patients with MS may demonstrate difficulty in recall, staying on a topic, following directions, or selecting words or ideas.

Social Assessment

Part of the nursing assessment may be obtaining a thorough social history, particularly if a social worker is not part of the team. In other settings, team members who identify social needs communicate this information to the social worker as part of the referral process. The nurse continues ongoing social assessment for feedback to the team. To implement plans, social supports must be identified. Financial resources need to be explored for food, housing, equipment, help in the home, and transportation to appointments. Patients who live alone need to be evaluated for safety, ability to perform personal and household tasks, and access to help in the home. When a patient lives with family or friends, the entire support

system needs to be evaluated to determine how it can be integrated into the plan of care. A patient's geographic location is important in determining what services are available in the community. It is important to evaluate the educational level of both the patient and the family to tailor education or treatment plans. Determining their level of understanding and belief system and communicating that information to the team will help establish realistic goals. Cultural needs and mores should be recognized and included in any goal setting to increase adherence to those goals.

Family Assessment and Input

Patients who are in close contact with their families have a greater chance of positive outcome from rehabilitation measures. Rehabilitation teams have a better chance of making inroads when there is family involvement in providing information as well as formulating the treatment plan. Nurses can assist the team by gathering information about the family and from the family. Close alliances are often formed among patients, families, and nurses. Information that no one else can elicit may be shared with nurses. It is often this information that cements an intervention or treatment plan (Watson, 1989, 1992).

Nurses should question patients about their families. Are they supportive? Do they help too much or too little? Who has the primary financial responsibility, and is this a change? How does the patient feel about that? What is expected of the patient at home? What does the patient expect of his or her family? Who is the primary care provider for the children? What do the children understand about MS? How often does the extended family visit? Does the extended family provide financial help? Who does the majority of the household tasks?

Nurses should question the families about existing roles. What is their perception of the patient? Do they think the patient has the ability to do more than he or she does? Do they think the patient does activities that are unsafe? Are they experiencing burnout? Do they need respite? What is their understanding of MS? How willing are they to learn or do more? Are they willing to change roles or tasks?

Communication Assessment

Speech and language encompass a broad area. People with MS can have limitations because of dysarthria that make intelligible speech difficult. This includes articulation disorders, voice disorders, vocal tremor, and loudness control. Those with cognitive impairment also demonstrate problems with word finding, tangential speech, loss of ability to complete

verbalization of ideas, and/or paraphasic errors. Some patients experience problems with verbosity and have difficulty interacting with others. Patients are sometimes easily distracted and struggle with interactions if they are in a busy or noisy area.

If MS has caused significant weakness that affects respiratory function, the ability to produce and sustain enough airflow to speak effectively will be impaired. Weakness may also decrease the ability to communicate in writing, push a call light, dial a phone, or call for help.

Although the speech-language pathologist on the rehabilitation team will do a formal assessment, information gathered by the nurse can be used to initiate interventions that will enhance communication among patient, family, and staff, and thus, decrease frustration. Speech-language pathologists often use information from the nursing assessment to direct their work-up.

Work and Productivity (Vocational) Assessment

Whether you are dealing with a patient with MS in the clinic, home, or rehabilitation facility, the subject of “work” usually comes up. Work can be a paid position, a volunteer task, or a role in the family. In our society, many people believe they “are what they do.” When a disease such as MS threatens their usual activities, they experience problems with self-esteem, fear of economic hardship, role reversals, and grief over what they have lost. It is not uncommon for patients to set unrealistic goals regarding their ability to work safely and effectively at their usual employment. Others prematurely make a decision that they cannot perform their usual activities when they experience impairment before they have explored their actual abilities. When working with patients, it is important to assess their work history, attitudes about work, perception of what their work is, and educational level. Using this information, various members of the rehabilitation team can be alerted to further evaluate any identified problems. The rehabilitation counselor is the primary professional relating to vocational issues, but often many disciplines are involved, such as occupational therapy, physical therapy, social work, speech-language pathology, and psychology.

Recreation Assessment

It is also important to assess recreational interests. Knowing what a patient enjoyed doing previously may help set goals for what can be done with remaining abilities or with adaptations. Any patient facing loss of employment or change in role can be encouraged by the nurse to develop new interests or rediscover old ones.

Chart Review

Because nurses work in various settings, the type and availability of records may vary. Whenever possible, they should obtain prior records that provide historical information including past assessments and indicate functional changes that may be more objective than those provided by the patient and family. Previous goals set by the patient may contribute to current goal setting, as well as response to previous medications and interventions.

Input From Community Agencies

If a patient receives help in the home from a home health agency, any information obtained from the staff about how they view the patient in that setting can be exceedingly helpful to others in outpatient or inpatient settings. The nurse can request, compile, and communicate that information to the team. Communication from the rehabilitation team to the home health staff about proposed plans and goals can be facilitated by nurses.

Data can also be collected from other community agencies such as vocational rehabilitation agencies, social services, and community mental health agencies if the patient signs a release to do so. At times, it is appropriate to contact an employer (if requested to do so) to enable the team to address pertinent issues in the workplace.

Discharge Planning

Discharge planning is an integral component of rehabilitation and should occur as a parallel process, with ongoing coordination and reassessment. Modifications may be needed in the home or place of employment, new equipment may be appropriate, and community agencies may become essential to successful functioning of the patient and family. Excellent rehabilitative care will have less impact if patients are sent home or discharged from home services without support systems in place.

Help in the home is often needed when leaving an inpatient setting. It should be arranged before discharge and should be in place when the patient arrives home. Family education should have occurred throughout hospitalization. The patient and family should be able to demonstrate understanding of discharge instructions. Because of cognitive impairments or the stress of hospitalization, patients and families may indicate understanding of information but may not fully comprehend it, so succinct written plans for follow-up should be in place. A home health

nurse often will make follow-up visits and report the patient's status to the primary care provider. Medications should be clearly explained and instructions written. Ideally, the team has fostered independence when appropriate, but patients and families need to be encouraged to call a contact person with questions and concerns. Going through a rehabilitation stay with all of its help, support, and structure is different from being home alone or with a family member.

As an outpatient involved with a team or is part of a team, the patient is discharged when goals are met or measurable improvement has plateaued. Planning is directed at individual issues and needs. A nurse functioning as the case manager will coordinate efforts and plan follow-up.

Patients who receive care in the home are sometimes discharged from this care. The home health nurse is charged with educating the patient and family in self-care and providing clear plans for follow-up. Discharge plans need to be coordinated with the primary care provider to facilitate continuity of care.

CONCLUSION

The nurse should recognize the patient as a unique, total human being while emphasizing wellness and should foster the inquisitiveness of the patient and his or her family while striving for improved quality of life.

These suggestions are made to assist the experienced nurse to work successfully with a patient who has MS. Unless nurses work with many patients with this disease, the nuances may be missed. Whether he or she works in a setting with an existing team of rehabilitation specialists or works independently and has to network to create a team, the quality will be enhanced by teamwork.

Rehabilitation is a dynamic process of planned adaptive change in lifestyle in response to unplanned change imposed on the individual by disease or traumatic incident. The focus is not cure, but on living with as much freedom and autonomy as possible at every stage and in whichever direction the disability progresses. (Dittmar, 1989, p. 8)

The physiatrist saw J. H. in a small MS rehabilitation clinic with a physical therapist, occupational therapist, speech-language therapist and a social worker. The team began the process of reframing her goals to be more realistic and evaluating the barriers to allow her goals to be realized.

J. H., her husband, and the team decided that her goal of ambulation was not realistic but that the use of a power chair in the home might be possible.

Barriers identified were:

- *No access to the home or levels in the home for a power chair*
- *No access to the bathroom and other rooms in the home*
- *No available help in the home during the day while her husband still worked outside the home*
- *No ability to get a home evaluation while residing at the care facility*
- *No ability to purchase a power chair while residing at the care facility*

The outpatient rehabilitation team assisted in the following:

- *The family paid out of pocket for a home visit to evaluate for the appropriateness of ramps and to measure for a potential power chair. The ramp was built. The patient was not present for that visit.*
- *A team of caregivers was formed to care for her while her husband worked.*
- *She was discharged from the facility, against their advice, and returned to her home.*
- *Another home visit was made to evaluate J. H., her ADL needs, and other structural changes that needed to be made.*

A home health agency that provided palliative care was engaged and they began addressing the other barriers. The social worker was able to help with funding and support. A wheelchair specialist measured her for a power chair. J. H. and her husband are happy that she is at home. Her problems are still present but, with assistance, are manageable. The “system” is not set up to assist people like J. H. Persistence from her care providers initially and interaction with the rehabilitation specialists along the way, helped her reach her goal.

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Maximizing the Effectiveness of Pharmacotherapeutics

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Ms. Kerry Smith is a 35-year-old woman who has presented with unilateral OS (left eye) optic neuritis (ON) with remarkable recovery without treatment of intravenous steroids for the acute attack. Upon discussion of her history, she recalled numbness and tingling in her lower extremities a few years ago. These paresthesias have resolved within 7 days and therefore she has not gone to see her clinicians. An MRI of the brain has demonstrated four periventricular lesions, one enhancing lesion, and a few juxtacortical lesions. A cervical spine MRI has shown an intramedullary lesion at C4, which did not enhance. Ms. Smith had a current episode of ON and a history of myelitis. Her presentation and MRI findings confirm the diagnosis of multiple sclerosis and do not support a diagnosis of neuromyelitis optica (NMO), which is an aggressive relapsing disease affecting mainly the optic nerve and the spinal cord. Ms. Smith has recovered well from both initial episodes and she questioned any decisions regarding initiating a disease-modifying agent (DMA). Her clinicians, the neurologist and the nurse, have explained to Ms. Smith about the importance of initiating a DMA. The discussion entailed a description of all the available DMAs, which are all injectable medications, the potential side effects profile, and the unpredictable course of multiple sclerosis. Furthermore, the discussion included potential future research options and hope into better treatments and optional cure of the disease. Ms. Smith has opted to follow up with the clinicians but not starting any of the DMAs.

INTRODUCTION

Multiple sclerosis (MS) is an inflammatory demyelinating neurodegenerative disease, which gained increased insight into its potential etiology, pathophysiology, and immunology within the last 2 decades. The increased knowledge of the variability and pathology of the disease,

including the involvement of white matter, grey matter, T cells, and B cells, has helped in the development of new treatments for the disease along with therapies to increase conduction of demyelinated axons (Ben-Zacharia & Del Bene, 2008; Costello, 2008). The last 2 decades have shown an emergence of new pharmacotherapeutics for the disease and its symptoms. The importance of early and long-term treatment has captured the practice of clinicians maximizing the effectiveness of the different therapies. The multiple choices of therapeutics have changed the faces of the disease (see Exhibit 14.1), halting its progression and improving quality of life along the life span of the disease. New era of treatments in MS have mastered hope among patients, their caregivers, family members, and professionals.

The pharmacotherapeutics available in MS is partially effective and mostly well tolerated. These treatments are termed *disease-modifying agents* (DMAs) or immunomodulatory as compared to immunosuppressive agents. The mechanism of action of the DMAs hypothesized on basic science and in vitro experiments. These agents include the three interferons (IFNs): interferon β -1a intramuscularly (IM; Avonex), interferon β -1a subcutaneously (SQ; Rebif), interferon β -1b (Betaseron), and glatiramer acetate (GA; Copaxone). The exact mechanisms of action are not completely known. The IFNs inhibit proliferation of leukocytes and antigen presentation, increase anti-inflammatory cytokines, and inhibit T-cell movement across the blood-brain barrier (BBB; see Table 14.1).

EXHIBIT 14.1 ■ Maximizing Therapeutic Options

Early treatment; clinically isolated syndrome (CIS trials: CHAMPS, ETOMS, BENEFIT, PreCISe, StAyCIS), diagnosis of CDMS

Long-term treatment, adherence

Switching treatments in suboptimal responders

Combination of disease-modifying treatments

Treating the disease while improving quality of life through realistic expectations

Maximizing symptom management in MS using nonpharmacologic and pharmacologic agents

TABLE 14.1 The Multiple Sclerosis Approved Disease-Modifying Agents

	Mechanism of Action	Delivery Method	Dose	Frequency	Side Effects	Education
β interferon-1a (Avonex)	Inhibits proliferation of leukocytes and antigen presentation, increases anti-inflammatory cytokines; inhibits T-cell movement across BBB	IM injection	30 μ g	Q week	Fever, chills, HIAs, mild flulike symptoms, muscle aches, anemia, depression	Training about dose titration to reduce side effects, CBC and LFTs periodically, injections done nightly, and use of NSAIDs
β interferon-1a (Rebif)	Same as previous	SC injection	44 μ g	TIW	Injection-site reactions, mild flulike symptoms, muscle aches, anemia, depression	Same as previous site rotation required to minimize skin reactions, may use an Autoject
β interferon-1b (Betaseron)	Same as previous	SC injection	250 μ g	QOD	Injection-site reactions, flulike symptoms, menstrual disorders, headaches, mild neutropenia, anemia, or thrombocytopenia, depression	Same as previous; nonrefrigerated needs reconstitution
Glatiramer acetate (Copaxone)	Designed to mimic myelin basic protein and promote production of anti-inflammatory cytokines	SC injection	20 mg	QD	Injection-site reactions, IPIR, rarely lymphadenopathy	Site rotation to minimize skin reactions including lipoatrophy, report IPIR cases to providers

(continued)

TABLE 14.1 The Multiple Sclerosis Approved Disease-Modifying Agents (Continued)

	Mechanism of Action	Delivery Method	Dose	Frequency	Side Effects	Education
Natalizumab (Tysabri)	Natalizumab is a humanized monoclonal antibody against the cellular adhesion molecule $\alpha 4$ -integrin	IV infusion	300 mg	Every 28 days	Allergic reactions especially after second dose, infections, progressive multifocal leukoencephalopathy, liver abnormality, questionable related melanoma	Recognition of changes and notification of providers, labs for CBC and LFTs, skin checks, periodic brain MRIs
Miroxantrone (Novantrone)	Disrupts DNA synthesis and DNA repair in both healthy cells and unhealthy cells	IV infusion	Based on body surface area	Every 3 months with total lifetime dosage based on body surface area	Myelosuppression, alopecia, secondary amenorrhea, cardiotoxicity, leukemia	CBC, LFTs, echocardiogram or MUGA cardiac scan at baseline and annually for lifetime for cardiac monitoring and monitoring for potential infections

Note: BBB = blood-brain barrier; CBC = complete blood count; HA = headache; IM = intramuscular; IPIR = immediate postinjection reaction; IV = intravenous; LFT = liver function test; MRI = magnetic resonance imaging; MUGA = multigated acquisition scan; NSAID = nonsteroidal anti-inflammatory drug; Q = every; QD = once a day; QOD = every other day; SC = subcutaneous; TIW = three times a week.

GA is designed to mimic myelin basic protein and promote production of anti-inflammatory cytokines. Most MS patients will have a reasonable response to IFN or to GA with a change in the pattern of their disease. Mitoxantrone (Novantrone) and natalizumab (Tysabri) are considered immunomodulatory and immunosuppressive agents. Mitoxantrone is an antineoplastic agent, which disrupts DNA synthesis and DNA repair in both healthy cells and unhealthy cells. Major adverse events related to mitoxantrone therapy include cardiotoxicity and leukemia. Natalizumab is a humanized monoclonal antibody against the cellular adhesion molecule $\alpha 4$ -integrin. The drug is believed to work by reducing the ability of inflammatory immune cells to attach to and pass through the cell layers lining the intestines and BBB. As of June 2009, 10 cases of progressive multifocal leukoencephalopathy (PML), which is a fatal central nervous viral infection, had been reported in natalizumab monotherapy patients since its reintroduction.

**THE CONCEPT OF EARLY TREATMENT:
CLINICALLY ISOLATED SYNDROME,
RADIOLOGICALLY ISOLATED SYNDROME,
AND CLINICALLY DEFINITE MULTIPLE SCLEROSIS**

Early treatment of MS has been shown to minimize neurologic damage. Clinically isolated syndrome (CIS) treatment reduces the conversion to clinically definite MS by high percentage as compared to placebo. In addition, early treatment reduces relapse rate and slows progression of disability in diagnosed MS patients. The completed CIS clinical trials (Controlled High Risk Avonex Multiple Sclerosis Study [CHAMPS], Belatacept Evaluation of Nephroprotection and Efficacy as First-line Immunosuppression Trial [BENEFIT], Early Treatment of Multiple Sclerosis [ETOMS], and Prediction of Regulatory CIS-acting Elements [PreCISe]) have shown a significant reduction in conversion to clinically definite MS (CDMS) based on a second clinical episode (Poser criteria) or based on MRI changes (McDonald criteria; see chapter 1 for these criteria).

STAYCIS and REbif FLEXible Dosing in Early Multiple Sclerosis (REFLEX) are currently ongoing trials evaluating the efficacy of atorvastatin (Lipitor) and interferon β -1a SQ (Rebif) in CIS patients. Neurologic irreversible damage occurs early in the disease and therefore it is imperative to treat early. The DMAs have shown significant effectiveness in reducing relapses, slowing disease progression and disability in patients who have met the diagnostic criteria for CDMS. Furthermore, these medications have demonstrated a reduction in new or active MRI lesions and improving quality of life (Coyle, 2008a).

The most common form of MS is the relapsing–remitting MS (RRMS) form and the first clinical presentation of RRMS is the CIS. CIS is the initial relapse highly suspicious of MS, which does not meet the criteria for CDMS consisting of dissemination in time and space. That is two different clinical episodes separated by at least 30 days or second episode as characterized by an active lesion on MRI and presentation of the symptoms on exam and on MRI at different places in the central nervous system (CNS). Careful evaluation identifying any potential red flags has to take place in purpose to minimize possibility of misdiagnosis. The CIS trials CHAMPS, ETOMS, and BENEFIT where patients were randomized to either interferon β or placebo showed a benefit in delaying the occurrence of a second attack and MRI activity. The CHAMPS trial studied patients with monofocal events treated once weekly with Avonex 30 μg IM or placebo over 3 years. CIS patients treated with Avonex were found to be 15% less likely to have a second neurologic episode. The 2-year ETOMS trial showed that patients who were treated with Rebif 22 μg once weekly were less likely to experience a second episode as compared with placebo. The BENEFIT trial using Beta-son 250 μg every other day in patients with monofocal and multifocal events versus placebo showed a 46% reduction in converting to CDMS at 3 years. The PreCISe trial randomized CIS patients with monofocal events to Copaxone 20 mg SQ or placebo. CIS patients who received Copaxone were less likely to convert to CDMS. These studies demonstrated a remarkable effectiveness in treating patients after the first clinical episode without even reaching a diagnosis of MS. Clinicians have to educate patients and their significant others regarding the importance of early treatment (Coyle, 2008a; Mowry et al., 2009; Pandey & Lublin, 2009; Thrower, 2007).

Radiologically isolated syndrome (RIS) includes changes on MRIs without any history of clinical episodes. In the last year, there has been a lot of discussion about these typical MS changes on MRIs without a typical history of MS or findings on exam. The main question that clinicians face is whether to treat “dots on MRIs” or monitor patients clinically. Our history as clinicians supported a clinical diagnosis based on the Poser criteria including support of paraclinical studies. In a few recent studies, preclinical MS has been investigated and its risk of conversion to CIS. The latest data showed that patients with typical radiologic changes on MRIs and who have positive spinal fluid for inflammatory disease (i.e., increased oligoclonal bands, increased immunoglobulin [IgG] index, and increased IgG synthetic rate) have a higher risk to convert into CIS. However, Lebrun and colleagues (2009) found that positive spinal fluid (elevated IgG index or oligoclonal bands) was not a predictive factor for CIS. Early treatment raises a debate about the definition of *early* and when therapy initiation is justified. Most commonly, when patients initiate a DMA, it is

unlikely for clinicians to discontinue the medication. Therefore, it is of utmost importance to gather all historic findings and paraclinical studies through questioning of the patient and his or her family or significant other and to reach an accurate RIS preclinical diagnosis.

A CDMS diagnosis necessitates an immediate initiation of DMA treatment. The pivotal trials of interferon β -1b, interferon β -1a, and GA showed a significant reduction in relapse rate and disability in patients diagnosed with MS (Ebers, 1998; "Interferon beta-1b in the treatment of MS," 1995; Jacobs et al., 1996; Paty & Li, 1993; The IFNB Multiple Sclerosis Study Group, 1993). The outcome measures used in MS clinical trials are short-term outcomes calculating efficacy and, to a lesser effect, long-term disability. The multicenter Betaseron randomized, double-blind placebo-controlled trial (class I evidence) showed that interferon β -1b reduced the relapse rate and reduction in burden of disease as measured by T2 lesions (Goodin et al., 2002). The available treatments for RRMS or relapsing forms of MS have grown in the last 2 decades but there are still no proven treatments for progressive forms of MS. The European interferon beta-1b trial has shown a significant reduction in disability in secondary progressive MS (SPMS) in contrast to placebo but the North American trial in SPMS could not replicate the same results (Goodkin & the North American SPMS Study Group, 2000; Kappos, 1998). There are no therapies approved for primary progressive MS (PPMS); unfortunately, rituximab has failed to show efficacy in PPMS. Rituximab appeared to have efficacy only in younger patients with signs of inflammation, suggesting that parameters such as age and MRI findings might be more useful for directing therapy than clinical designations. The main results of the trial's primary end point showed no statistical difference in the time to confirm disease progression with rituximab versus placebo in patients with PPMS over 96 weeks (Palkhivala, 2008). In addition, GA (the PROMiSe trial) has not been proved efficacious in PPMS but post hoc analysis of this study showed that GA might have a favorable gender effect and might be effective in men with PPMS (Wolinsky et al., 2009).

The dosage of the IFNs and GA seems to be at its maximum effective dose. The trial studying a higher dose of GA (40 mg) compared to 20 mg has not shown any significant differences between the two groups. In addition, the recent Israeli trial and Omar Kahn's trial did not show significant differences between every-other-day GA and daily injections. Furthermore, the Beyond trial did not show any significant differences between the Betaseron 500- μ g dose and 250 μ g. The dosage of each DMA, the route of administration, and the frequency of injections are all critical in maximizing the effects of these medications. However, higher dosages than the commonly used dosages have not shown to improve outcomes (Kieseier, Wiendl, Leussink, & Stüve, 2008; Vollmer, 2008b).

LONG-TERM TREATMENT AND THE CONCEPT OF ADHERENCE

Long-term efficacy of the IFNs and GA has been shown in a few studies. Ford and colleagues (2006) reported the results of 15 years of GA treatment in RRMS. Patients who maintained on GA treatment showed a relatively stable disease with little change in their disability scores. Most patients that continued GA therapy (mean disease duration of 15 years) remained ambulatory and the safety profile of GA therapy was maintained for long-term use (Ford et al., 2006). As in any long-term study, the dropout rate was high in the GA long-term prospective follow-up assuming that these patients have had poor outcomes and therefore switching therapies or discontinuing therapies. The missing data may skew the results in favor of GA (Vollmer, 2008a).

The IFNs' long-term observational trials have shown positive results for 8–16 years of use. The interferon β -1a (Avonex) long-term 15-year follow-up study of patients with MS showed similar results. Patients who remained on IFN therapy had a relatively stable disease and decreased rate of relapses. This study also had a high dropout rate, which led to overstatements of the benefit of the DMA (Vollmer, 2008a). The 8-year interferon β -1a (Rebif) long-term follow-up demonstrated that patients who originally randomized to the 44- μ g arm had a lower score on the Expanded Disability Status Scale (EDSS), low relapse rate, and low T2 burden of disease in comparison to the late-treatment group (Kappos et al., 2006). The 16-year long-term follow-up study of interferon β -1b therapy showed that patients who remained on treatment had a slower progression to EDSS score of 6 compared with those that were treated for a short period. The study showed that early treatment can delay progression to significant disability and supports the concept that improving early disability has long lasting effects (Carroll, 2009).

In summary, a long-term study that has been tracking individuals for more than 20 years provides information enabling clinicians to predict the clinical course of the disease. The United Kingdom investigators reported that patients with MS with relatively rapid increases in brain lesion volume during the first 5 years were more likely to develop long-term disability than those with slower rates of lesion accumulation (Fisniku et al., 2008).

Adherence to the DMAs is associated and directly linked to effective long-term therapy. Adherence is mainly affected by lack of efficacy and adverse effects. Studies of patients treated with IFNs or GA demonstrated that 22–51% have stopped treatment because of adverse effects (Ross, 2008b). Adverse events and unrealistic expectations of patients can be anticipated and managed with nursing support and education (Ross, 2008a).

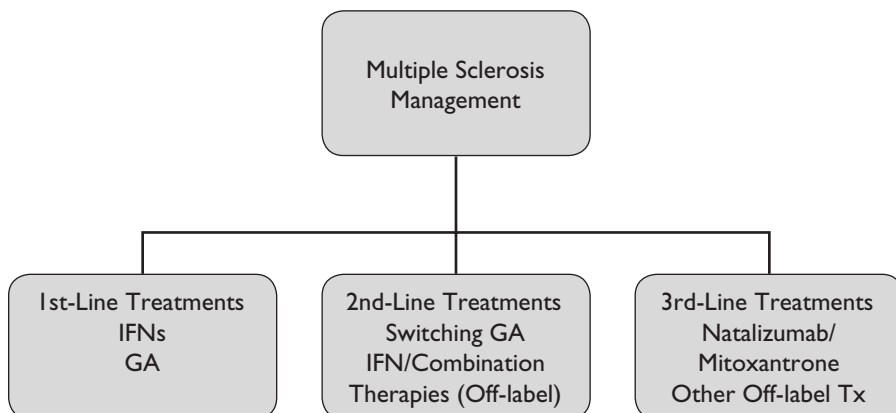
SWITCHING DISEASE-MODIFYING AGENTS

The available treatments in MS have been used in clinical practice in the different courses of disease. There is no consensus as far as first-, second-, and third-line treatments in MS; however, many clinicians see the IFNs and GA as first-line treatments in MS because of their efficacy and safety profile (see Figure 14.1 and Figure 14.2). Unfortunately, these drugs do not provide complete control of the disease.

The rationales for switching therapies in MS are usually suboptimal response including developing neutralizing antibodies to the IFNs and major adverse effects to the current regime. Clinicians face a few options of treatments in patients who reached a suboptimal response. The potential strategies include switching to a different DMA, combining treatments, or initiating a short-term induction therapy prior to the DMA (Caon, 2009; Coyle, 2008b). Portaccio and his colleagues studied the long-term validity of the main clinical outcomes of response (relapse rate and disability) after 1–2 years of interferon β in patients with RRMS. In their study, 26 patients out of 147 RRMS patients had reached suboptimal response and were switched to intravenous immunosuppressive therapy. They concluded that disability progression, as measured by the EDSS, and high number of relapses in the first 2 years of therapy were related to long-term suboptimal response (Portaccio, Zipoli, Siracusa, Sorbi, & Amato, 2009).

FIGURE 14.1 Summary of First-, Second-, and Third-Line Therapies in Multiple Sclerosis

GA = glatiramer acetate; IFN = interferon; Tx = treatment.

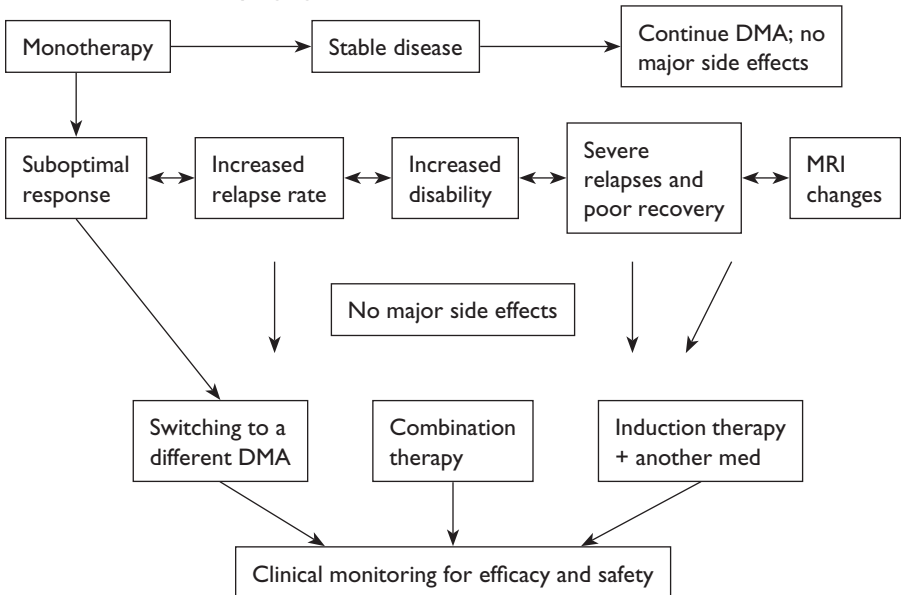


COMBINATIONS OF DISEASE-MODIFYING AGENTS

Combination therapies have been instituted in multiple clinical practices. Clinicians have treated the disease aggressively with different combinations, other immunomodulators or chemotherapeutic agents, and selective and nonselective immunosuppressive agents in managing the disease. The efficacy and safety of most combination therapies has not been proven. Combination therapy may be a solution in patients with aggressive disease but it can lead to major safety issues. Therefore, the common discussion between clinician, patient, and family is about the potential risk versus benefit. The goal is to optimize use of monotherapy and if inefficacious to add on other medications or using conservative methods (Figure 14.2).

Combinations of IFN and GA have been contemplated in clinical practice. IFN and GA have different mechanism of actions and may synergistically increase the efficacy of their treatment or might negate each other's effects. The phase III Combi-Rx trial is testing the efficacy of the combination of interferon β -1a (Avonex) and GA (Copaxone). The National Institute of Health (NIH) has completed patient enrollment in 2008

FIGURE 14.2 Therapeutic Options Algorithm
DMA = disease-modifying agents.



and the results of this study will be available in a few years. The phase II Combi-Rx trial did not show any major adverse events or any increased burden of disease as measured by brain MRIs.

The combination of pulse methylprednisolone and a DMA have often exemplified a better control of the disease. Pulse therapy is often used as a single-day or multiday treatment every few months, or as an add-on to disease-modifying therapies. In practice, it is used most often for people who are developing secondary progressive disease, for people who have failed other therapies, and before using mitoxantrone (Zivadinov et al., 2001). Steroids are general immune suppressants and they produce anti-inflammatory effect. High-dose methylprednisolone administered monthly in addition to the DMA often provide a synergic effect. Ravnborg (Ravnborg et al., 2010) has studied the effect of monthly 500 mg of oral methylprednisolone in monthly pulses in addition to interferon β -1a IM weekly injection in comparison to a group of patients that received interferon β -1a IM and a placebo. This study showed that the combination of pulse steroids and IFN reduced the relapse rate by 38%. In addition, patients who received both treatments have demonstrated improvement in their overall function (Stump, 2009). Steroids have multiple potential side effects and therefore patients should be monitored cautiously. Zivadinov and colleagues (2001) randomized 81 patients with relapsing–remitting disease either to receive 5 days of methylprednisolone with a prednisone taper every 4–6 months, or to receive the same steroid regimen for relapses only. The group that received regular pulse steroid infusions had a 32% reduction in the probability of disability progression compared with the group that received treatment only for relapses ($P \leq .0001$) and a reduction in active lesions in Then Bergh’s study (Then Bergh et al., 2006; Zivadinov et al., 2001). In summary, pulse steroids may be helpful in treating patients with MS.

Combination treatments can pose increased efficacy and increased safety challenges. The Glatiramer Acetate and Natalizumab Combination Evaluation (GLANCE) trial evaluated the safety and tolerability of natalizumab when added to GA in patients with RRMS. The primary outcome assessed was the development of new active lesions seen on MRI. The results showed significant reduction ($p = .031$) in number of T2 lesions in the combination group. The combination of natalizumab and GA seemed safe and well tolerated during 6 months of treatment (Goodman et al., 2009). In contrast, the combination of natalizumab and beta IFNs has resulted in major risks: infections and mainly PML, which is a fatal viral infection. Therefore, the Food and Drug Administration (FDA) has approved natalizumab as monotherapy.

Many clinicians used an immunosuppressive agent (e.g., mitoxantrone) with a DMA, whereas others used a chemotherapeutic agent as an induction therapy, which is an immunosuppressant, followed by immunomodulation therapy. These therapeutic options may aggressively suppress the disease initially prior to initiating a long-term DMA to hopefully control the disease effectively (Boggild, 2009; Le Page & Edan, 2009). Other unfavorable combinations include statins (Lipitor) and beta IFNs, which caused worsening of the disease. In summary, combination therapies should be used cautiously in patients with MS, especially those treatments that do not have proven efficacy and safety data.

TREATING THE DISEASE WHILE IMPROVING QUALITY OF LIFE THROUGH REALISTIC EXPECTATIONS

Quality of life is a valuable concept that has recently been studied in chronic illnesses including MS. Patients ought to be educated to set reasonable expectations regarding their response to therapy and their future disease progression and prognosis. Education, disease control, symptom management, and targeted side effects therapies promote quality of life and better adjustment to the disease.

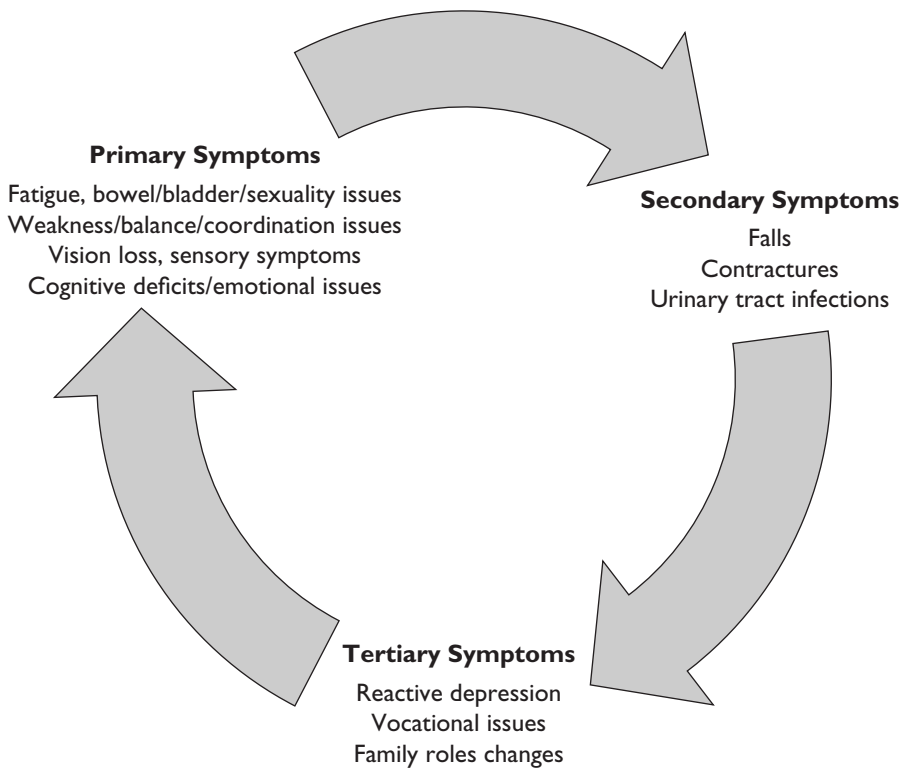
MAXIMIZING SYMPTOM MANAGEMENT IN MULTIPLE SCLEROSIS

The focus in symptoms management is toward identifying the primary, secondary, and tertiary symptoms (see Figure 14.3), while prioritizing the management and devising a treatment plan promoting the least number of interventions for a few symptoms through nonpharmacologic and pharmacologic therapies, rehabilitation, and psychosocial support (see Figure 14.4).

Identification, causation, alleviation, and prevention of complications (ICAP) are an approach to symptom and disability management in MS proposed by Dr. Bruce Cohen (see Figure 14.5). This model can be applied to all symptoms management while optimizing function and improving quality of life (Cohen, 2008).

SUMMARY

Maximizing the effectiveness of pharmacotherapeutics is critical in the early and long-term management of MS, especially because there are no

FIGURE 14.3 Category of Multiple Sclerosis Symptoms

available therapies for neurologic repair yet. The ongoing debate in clinical practice is how aggressive we should be when treating and how early should we be initiating treatment for patients with MS. The benefit–risk ratio should guide us through our decision making with our patients and deciding on the best individual options for patients with the different courses of MS. Many controversial discussions have entered the world of MS care. Recently a few clinicians have started treating naïve MS patients with natalizumab despite the safety concerns including PML and other potential infections. In contrast, during the last few years, MS clinicians have been using less mitoxantrone because of the increased risk of cardiotoxicity and leukemia. Treating a chronic illness such as MS is an art more than medicine and the ultimate goal is treating and controlling the disease while optimizing quality of life and hope for better treatments or cure of the disease.

FIGURE 14.4 Pyramidal Symptomatic Management in Multiple Sclerosis

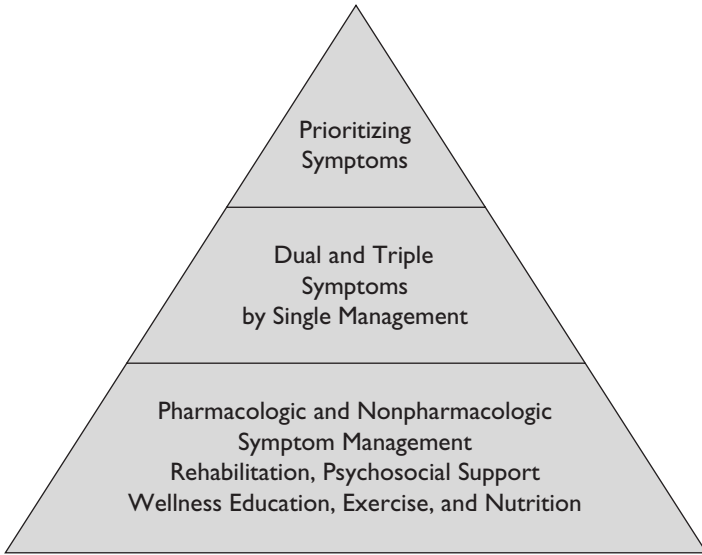
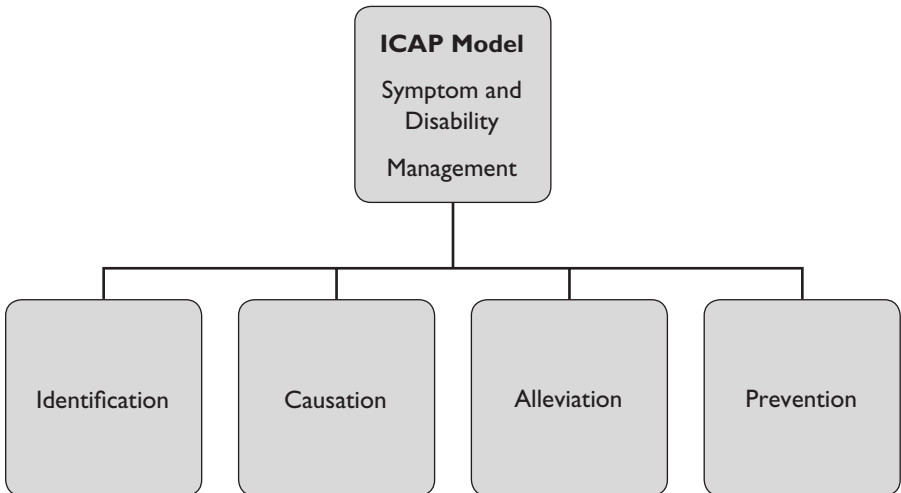


FIGURE 14.5 ICAP Model Adapted From Bruce Cohen



Ms. Kerry Smith has had a few follow-up appointments with her clinicians discussing her ongoing intermittent symptoms and her sensitivity to increased body temperature. Ms. Smith has decided not to initiate the injectable treatment. Patients are always a part of the decision-making process but they need to be knowledgeable regarding the risks of not going on any treatment versus the benefits of early treatment. Nurses are at a position to explore with patients and their families their health beliefs and their future goals including quality of life issues (Morgante et al., 2006). Ms. Smith has realized the tremendous unpredictability of the disease while learning about CIS, CDMS, and long-term disease management during her discussions with her clinicians: nurse, physician assistant, and physician. She has decided after experiencing a change on her subsequent brain MRI to initiate a DMA. She was trained by the nurse how to self-inject. The injection training and MS education included explanation of realistic expectation from the treatment, potential side effects, rotation and injection techniques, and use of Autoject if available. The thorough education and support increases the likelihood of adherence to the medication. Ms. Smith was scheduled for frequent follow-up appointments to monitor her clinically, to address adherence issues, and to treat any adverse events related to the DMA.

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Part IV: Targeted Resources

APPENDIX **A**

Managing Resources

Nancy Clayton Reitman

Carlotta G. is a 32-year-old woman who has just learned that her husband has been transferred to a small town in the Southwestern part of the country to open a branch of his software company. Carlotta was diagnosed with relapsing–remitting multiple sclerosis (MS) 5 years ago. Carlotta has been taking glatiramer acetate since her diagnosis. Her MS symptoms are few, consisting mostly of fatigue and occasional numbness in her legs. She also has a history of mild anxiety, which has been successfully treated with a mild anxiolytic.

Carlotta, who has no siblings, is close to her widowed mother, and is fearful of missing her because of the move. She would also like to start a family and feels she will be “stranded” when she needs her mother the most should she become pregnant.

A graphic artist by occupation, Carlotta plans to do volunteer work until she finds a part-time job in her new location. She and her husband enjoy a close, healthy relationship and spend free time exploring the large city in which they currently live. They would also like to travel more, before Carlotta either gets pregnant or starts to experience more disabling symptoms of her MS.

But for now, Carlotta has the move on her mind, and a great deal of uncertainty about the future.

INTRODUCTION

The Internet has expanded the volume of resources available to people seeking help with all kinds of challenges. However, it is important to use good sense when accessing assistance online. Keep in mind that the Internet is a free and open medium; although many of the Web sites have excellent and useful information, others may contain highly unusual and inaccurate information.

Organizations and Services

American Institute of Architects (AIA; www.aia.org). Tel: 1-202-626-7300. Publications catalog and orders: 1-800-365-2724. This organization will make referrals to architects who are familiar with the design requirements of people with disabilities.

American Self-Help Groups Clearinghouse (www.selfhelpgroups.org). Tel: 1-201-625-7101. A keyword-searchable database of over 1,100 national, international, model, and online self-help support groups for addictions, bereavement, health, mental health, disabilities, abuse, parenting, caregiver concerns, and other stressful life situations. Also lists local self-help clearinghouses worldwide, research studies, information on starting face-to-face and online groups, and a registry for persons interested in starting national or international self-help.

Beach Center on Families and Disabilities (www.beachcenter.org). Tel: 1-785-864-7600. Conducts research and training about the functioning of families in which one member is disabled.

CenterWatch Clinical Trials Listing Service (www.centerwatch.com). Ongoing clinical research, including both industry- and government-sponsored trials.

Clearinghouse on Disability Information, Communications and Information Services (www.ed.gov/offices/OSER). Tel: 1-202-245-7307, 1-202-205-5637 (teletypewriter [TTY]). Created by the Rehabilitation Act of 1973, the Clearinghouse responds to inquiries about federal laws, services, federal funding and programs for individuals of all ages with disabilities.

Consortium of Multiple Sclerosis Centers (CMSC; www.ms-care.org). Tel: 1-201-487-1050. One of the preeminent professional organization for multiple sclerosis (MS) health care providers and researchers in North America and a valued partner in the global MS community. The core purpose is to maximize the ability of MS health care providers to impact care.

The Disability Bookshop. P.O. Box 129, Vancouver, WA 98666. Tel: 1-800-637-2256. The Disability Bookshop has an extensive list of books for travelers with disabilities, dealing with such topics as accessibility, travel agencies, accessible van rentals, medical resources, air travel, and guides to national parks.

Department of Veteran Affairs (www.va.gov). Tel: 1-800-827-1000. Provides a wide range of benefits and services to those who have served in the armed forces, their dependents, beneficiaries of deceased veterans, and dependent children of veterans with severe disabilities.

Disabled Rights Advocate (DRA; www.dralegal.org). Tel: 1-510-665-8644. Nonprofit law firm dedicated to securing the civil rights of people with disabilities.

Disability Rights Education and Defense Fund Inc. (DREDF; www.dredf.org). Tel: 1-800-466-4232. DREDF is a national law and policy center dedicated to furthering the civil rights of people with disabilities. The center provides assistance, information, and referrals on disability rights laws; legal representation in cases involving civil rights; and education or training for legislators, policy makers, and law students.

Disaboom (www.disaboom.com). Founded by a physician who is quadriplegic, Disaboom stresses the power of community advice from medical experts and from “peers” and comprehensive solutions to the difficulties faced by the more than 100 million adults worldwide living with disabilities.

Equal Employment Opportunity Commission (EEOC; www.eeoc.gov). Tel: 1-202-663-4900, 1-202-663-4494 (TTY). Monitors employment sections of the Americans with Disabilities Act.

GE Answer Center (www.geappliances.com). Tel: 1-800-626-2000. The center, which is open 24 hours a day, 7 days a week, offers assistance to individuals with disabilities as well as the general public.

Health Resource Center for Women With Disabilities (www.rehabchicago.org). Tel: 1-312-908-7997. Provides reproductive and gynecological services; peer support education; advocacy and research services that enable women with disabilities to become self-determining in achieving physical and psychosocial well-being. Center is run by and for women with disabilities in partnership with staff of a renowned rehabilitation hospital—the first comprehensive center established by women with disabilities nationally.

The Can Do Multiple Sclerosis (www.mscondo.org). Provides programs and services designed to enable people with physical disabilities to enjoy life with the greatest amount of independence and mobility. Services include an adult day program, affordable and wheelchair-accessible housing, care management, and community employment.

Institute for Human Centered Design (www.adaptiveenvironments.org). Tel: 1-617-695-1225. Offers workbooks for planning adaptive home modifications such as lowering kitchen countertops and widening doorways.

International Organization of Multiple Sclerosis Nurses (IOMSN; www.iomsn.org). Tel: 1-201-487-1050. Specialty organization focusing on nurses working with clients with MS and families. Affiliated with the MS Nurses International Credentialing Board (MSNICB), the certifying body in MS nursing.

Multiple Sclerosis Association of America (MSAA; www.msaa.com). Tel: 1-800-LEARN-MS. MSAA is a national, nonprofit organization dedicated to enhancing the quality of life of those affected by MS. Programs such as equipment loan, support groups, and research grants are enhanced by various educational publications.

Multiple Sclerosis Foundation (www.msfacts.org). Multimedia library and other activities including a cruise.

Multiple Sclerosis International Federation (www.msif.org). Information about MS in foreign languages. Lists contact information about MS societies around the world.

Multiple Sclerosis Society of Canada (www.mssoc.ca). Tel: 1-416-922-6065, in Canada: 1-800-268-7582. A national organization that funds research, promotes public education, and produces publications in both English and French. They provide an "ASK MS Information System" database of articles on various topics including treatment, research, and social services. Regional divisions and chapters are located throughout Canada.

National Association of Home Builders (NAHB; www.nahb.com). Tel: 1-301-249-4000. Produces publications and provides training on housing and special needs. Includes information on an accessibility checklist, financing options, and recommendations for working with builders and remodelers.

National Council on Disability (NCD; www.ncd.gov). Tel: 1-202-272-2004. Provides advice to the president, congress, and executive branch agencies to promote policies, programs, practices, and procedures that guarantee equal opportunity for all individuals with disabilities, regardless of the nature or severity of the disability and to empower individuals with disabilities to achieve economic self-sufficiency, independent living, and inclusion and integration into all aspects of society.

National Council on Independent Living (NCIL; www.ncil.org). Tel: 1-877-525-3400, 1-202-207-0340 (TTY). Advances independent living philosophy, and advocates for rights of people with disabilities.

National Easter Seal Society (www.easterseals.com). Tel: 1-800-221-6827. Wide variety of information on rehabilitation.

National Family Caregivers Association (NFCA; www.nfcacares.org). Tel: 1-800-896-3650. NFCA is dedicated to improving the quality of life of America's 18,000,000 caregivers. It publishes a quarterly newsletter, has a resource guide, and an information clearinghouse.

National Health Information Center (www.health.gov/nhic). Tel: 1-800-336-4797. The center maintains a library and a database of health-related organizations. Puts health professionals and consumers who have health questions in touch with those organizations that are best able to provide answers.

National Institutes of Health for Neurologic Disorders and Stroke (www.ninds.nih.gov). Reliable information regarding MS.

National Multiple Sclerosis Society (NMSS; www.nationalmssociety.org). Tel: 1-800-344-4867. The NMSS is a nonprofit organization that supports national and international research in the prevention, cure, and treatment of MS. The NMSS funds health services and clinical research. Chapters and branches of the society provide direct services to people with MS and their families, including information and referral, counseling, equipment loan, and social and recreational support programs. The society's goals include provision of nationwide services to assist people with MS and their families and provision of information to those with MS, their families, professionals, and the public. The society promotes knowledge, health, and independence while providing education and emotional support. Numerous publications are available to clients and health care professionals, and Spanish materials are available as well. Access local chapters by calling 1-800-344-4867.

National Rehabilitation Information Center (NARIC; www.naric.com). Tel: 1-800-346-2742, 1-301-562-2400. NARIC is a library and information center on disability and rehabilitation, funded by the National Institute on Disability and Rehabilitation Research (NIDRR). NARIC operates two databases—ABLEDATA and REHABDATA. NARIC collects and disseminates the results of federally funded research projects and has a collection that includes commercially published books, journal articles, and audiovisual materials.

Paralyzed Veterans of America (PVA; www.pva.org). Tel: 1-800-555-9140, 1-800-424-8200. PVA is a national information and advocacy agency working to restore function and quality of life for veterans with spinal cord dysfunction. It supports and funds education and research and has a national advocacy program that focuses on accessibility issues. PVA publishes brochures on many issues related to rehabilitation.

Social Security Administration (www.socialsecurity.gov). Tel: 1-800-772-1213. To apply for social security benefits based on disability, call this office or visit your local social security branch office. The Office of Disability within the Social Security Administration publishes a free brochure entitled, "Social Security Regulations: Rules for Determining Disability and Blindness."

U.S. Department of Justice Americans With Disabilities Act (ADA; www.ada.gov). Tel: 1-800-514-0301. This office is responsible for enforcing the ADA. Standards for assessable design, civic access, job accommodations network, and e-mail updates.

United Spinal Association (formerly Eastern Paralyzed Veterans Association; www.unitedspinal.org). Tel: 1-800-404-2898. Commits energy and talent to improve the lives of individuals with a spinal cord injury or disease. Initiatives are to promote inclusion, improve access, foster independence, enhance mobility, and demand equality; along with the commitment of improving the quality of life for all people with spinal cord injuries or disorders.

Well Spouse Foundation (www.wellspouse.org). Tel: 1-212-644-1241, 1-800-838-0879. Organization focusing exclusively on the needs of all spouses caring for a husband, wife, or partner who is chronically or and/or with a disability. Advocacy for home health and long-term care and a newsletter are among the services offered.

Lifestyle Resources

adaptABILITY (www.ssw.com). Tel: 1-800-288-9941. A free catalog of assistive devices and self-care equipment designed to enhance independence.

Adaptive Clothing (www.disability-resource.com/adaptive-clothing). Provides an online list of descriptions of Web sites devoted to apparel and accessories.

American Automobile Association (AAA; www.AAA.com). The AAA provides a list of automobile hand-control manufacturers.

Canine Partners for Life (CPL; www.k94life.org). Tel: 1-610-869-4902. Trains and places assistance dogs with individuals with mobility impairments to help increase their independence and quality of life.

Enrichments (www.sammonspreston.com). Tel: 1-800-323-5547. A free catalog of assistive devices and self-care equipment designed to enhance independence.

Interim In-Touch (www.amacalert.com). Tel: 1-800-286-2622. Personal emergency system that links a person living alone with a 24-hour emergency response center.

Library of Congress, Division for the Blind and Physically Handicapped (www.loc.gov/index.html). Tel: 1-888-NLS-READ. Provides free talking books and equipment on loan for people with disabilities.

Life Enhancement Technologies, LLC (www.2bcool.com). Tel: 1-800-779-6953. Offers a line of personal cooling products.

Lighthouse International (www.lighthouse.org). Tel: 1-212-821-9200, 1-800-829-0500. Provides information and resources for people with visual challenges.

Medic Alert Foundation International (www.medicalert.org). Tel: 1-800-344-3226; 1-209-668-3333. A medical identification tag worn to identify a person's medical condition, medications, and any other important information that might be needed in case of an emergency. A file of the person's health data is maintained in a central database to be accessed by a physician or other emergency personnel who need to know the person's pertinent medical information.

Assistive Technology Sites

ABLEDATA (www.abledata.com). Tel: 1-800-227-0216. Information about assistive technology and rehabilitation products and devices that will assist at home, work, and recreational activities.

Allsup, Inc. (www.allsup.com). Assists individuals applying for social security disability benefits.

Apple Computer Disability Resources (www.apple.com/accessibility). Provides new and innovative solutions for people with disabilities.

Computer Literate Advocates for Multiple Sclerosis (CLAMS; www.clams.org). Offers computer communication and support.

Disabled Online (www.disabledonline.com). A wide variety of resources for people with disabilities.

Dogpile (www.dogpile.com). Internet assistance.

MouseCage (www.mousecage.org). Software designed to help people with hand tremor control their computer mouse.

IBM Accessibility Center (www-03.ibm.com/able/). Makes Web sites available to those with disabilities.

Family Issues

Disability, Pregnancy & Parenthood International (DPPI; www.dppi.org.uk). A UK-based registered charity that is controlled by parents with disabilities and provides information on pregnancy and baby care equipment. Promotes awareness for health care professionals as well.

Exceptional Parent: Parenting Your Child or Young Adult with a Disability. Tel: 1-800-247-8080. A monthly magazine for families and professionals that produces the *Resource Guide*, which includes 10 directories with more than 1,000 resources in the United States and Canada. This is a very useful directory for adults with disabilities as well.

Lamaze International (www.lamaze.org). Tel: 1-800-368-4404. Provides referrals to local Lamaze teachers.

La Leche League International (LLLI; www.llli.org). Tel: 1-800-LALECHE. Encourages breastfeeding and offers lactation support.

Method for Birthing Better (www.birthingbetter.com). Support for prospective parents with disabilities.

Parents With Disabilities Online (www.disabledparents.net). Products and solutions for making independent parenting more possible for people with disabilities.

Planned Parenthood (www.plannedparenthood.org). Tel: 1-800-230-PLAN. Provides family planning, fertility information, and referrals to local service providers.

Teratogenic Society (OTIS; www.teratology.org). Tel: 1-703-438-3104. Promotes research that reveals the causes, improves the diagnoses and treatments, and prevents the occurrence of abnormal development and birth defects. Checks medications and interactions with pregnancy.

Through the Looking Glass: National Research and Training Center on Families of Adults With Disabilities (www.lookingglass.org). Tel: 1-510-848-4445, 1-800-644-2666. Has pioneered research, training, and services for families in which a child, parent, or grandparent has a disability or medical issue. Encourages nonpathological and empowering resources and early intervention services for families.

Rehabilitation Engineering and Assistive Technology Society of North America (RESNA; www.resna.org). Tel: 1-703-524-6686, 1-703-524-6639 (TTY). Improves the potential of people with disabilities through the use of technology. Can adapt baby care equipment.

Travel Assistance

Accessible Journeys (www.disabilitytravel.com). Tel: 1-800-846-4537. Arranges travel for mobility-impaired travelers.

Access to Recreation: Adaptive Recreation Equipment for the Physically Challenged (www.accesstr.com). Tel: 1-800-634-4351. Products include exercise equipment and assistive devices for sports, environmental access, games, crafts, and hobbies. Goal is to provide products that provide ability to enjoy activities that once were thought impossible. Wide range of products from fishing aids to crochet aids.

International Association for Medical Assistance to Travelers (IAMAT; www.iamat.org). Makes available competent medical care available to travelers by Western-trained doctors who speak English.

National Park Service, U.S. Department of the Interior (www.nps.gov). Committed to ensure that all information is accessible to people with disabilities, including both employees and customers. This includes providing the information in an alternate format. The service will provide a listing of national parks and numbers to obtain up-to-date accessibility information for the individual parks.

Society for the Advancement of Travel for the Handicapped (SATH; www.sath.org). Tel: 1-212-447-7284. Nonprofit organization that acts as a clearinghouse for accessible tourism information. In contact with organizations in many countries to promote development of facilities for people with disabilities.

Travelin' Talk (www.travelintalk.net). Global network of persons with disabilities who have formed a unique family of friends around the world and are willing to provide assistance to travelers with disabilities.

Resource Materials

Adapting the Home for the Physically Challenged. Tel: 1-540-389-4339. A 22-minute videotape that describes home modifications for individuals who use walkers or wheelchairs. Ramp construction and room modification specifications are included.

The Disabled Woman's Guide to Pregnancy and Birth, by Judith Rogers. Published by Demos Medical Publishing, New York, 2005. A "bible" for those pursuing motherhood with a disability. Delves into planning pregnancy and the postpartum period.

The Lighthouse Low Vision Products Consumer Catalog (www.lighthouse-sf.org). Tel: 1-800-829-0500. This large-print catalog offers a wide range of products designed to help people with impaired vision.

Living With Low Vision: A Resource Guide for People with Sight Loss. Published by Resources for Rehabilitation (www.rfr.org). Tel: 1-617-862-6455. A directory designed for individuals with impaired vision to find products and services needed to remain independent.

Multiple Sclerosis for Dummies, by Rosalind Kalb, Nancy Holland, and Barbara Giesser. Published by Wiley Publishing, Inc., 2007. Easy to read format and extremely helpful reference material about MS.

Multiple Sclerosis: A Guide for Families, 3rd ed., by Rosalind Kalb. Published by Demos Medical Publishing, New York, 2005. Practical and highly readable information addressing the many family issues that are caused by the presence of MS in the family.

Multiple Sclerosis: A Guide for the Newly Diagnosed, 3rd ed., by Nancy Holland, T. Jock Murray, and Stephen C. Reingold. Published by Demos Medical Publishing, New York, 2007. Designed for people new to MS and their friends and families. Answers early questions and helps to resolve life-altering issues.

Multiple Sclerosis: A Self-Care Guide to Wellness, 2nd ed., by Nancy Holland and June Halper. Published by Demos Medical Publishing, New York, 2005. Covers a wide segment of topics related to self-care in MS. Designed to promote independence.

Multiple Sclerosis: The Questions You Have—The Answers You Need, 4th ed., by Rosalind Kalb. Published by Demos Medical Publishing, New York, 2008. Written in a question and answer format, it deals with physical and emotional aspects of MS.

Multiple Sclerosis: 300 Tips for Making Life Easier, 2nd ed., by Shelley Peterman Schwartz. Published by Demos Medical Publishing, New York, 2006.

Products for People With Vision Impairment Catalog. American Foundation for the Blind Product Center (www.axistive.com/american-foundation-for-the-blind). Tel: 1-800-829-0500. The catalog is available in standard print and audiocassette.

Resource Guide for Clinicians, National Multiple Sclerosis Society (www.nationalMSSociety.org), 2009.

Travel for the Disabled: A Handbook of Travel Resources and 500 Worldwide Access Guides, 6th ed., by Helen Hecker. Published by Twin Peaks Press, available at www.Amazon.com. The handbook provides information for travelers with disabilities about accessibility.

One Step Ahead Special Report, A Guide to Catalogs for People With Disabilities, Their Families and Their Friends. Published by Gale Group, Farmington Hills, MI, 1994 (www.eric.ed.gov/ERICWebPortal/Home.portal). Tel: 1-800-386-5367.

It is time now to check back with Carlotta.

Carlotta and her husband have moved into their new home. They have installed several safety-related items such as grab bars in the bathrooms. They were able to find information through the American Institute of Architects (AIA). Carlotta has connected with her new local MS chapter and has started going to a support group where she is making new friends. Before she moved, she asked the chapter for a list of MS specialists and has an appointment to see one of the doctors.

The fatigue she generally experiences was amplified by the exertion needed to pack and move, so she has modified her daily routine. She has contacted a company to order a cooling garment because she is now living in a hotter climate and is anxious about the impending summer season and her tendency toward heat intolerance.

Carlotta used the Internet to find some travel ideas for individuals with disabilities because she occasionally uses a cane. She is aware that assistive equipment is available for people with MS who use computers and who have progressive diseases. Until she gets her new home organized and finds a part-time job, Carlotta will search the Web for more information for people with MS and will keep in touch with her mother, who is now some distance away.

And, most important of all to Carlotta and her husband, they are planning to start a family. They are using information they found on the Web site of the National MS Society and other sources that are friendly to women and men who have thought out the decision to get pregnant and raise a child while possibly being disabled.

The several challenges that a long-distance move and the uncertainties of life held for Carlotta were eased by her ability to find assistance and resources and enhanced her life and her relationship with her husband.

Managing Multiple Sclerosis Relapses and Symptoms: Pharmacology Overview

MS Symptom	Generic Name	Brand Name	Usual Dosage
MS relapse	ACTH	Acthar gel	80–100 U/d × 2 weeks IM IV
	Methylprednisolone	Solu-Medrol	1 g IV × 3–5 days
	Dexamethasone	Decadron	160–180 mg/d × 3–5 days (PO) or 30 mg tapered × 10 days (PO)
	Prednisone	Deltasone	Given initially in high doses and tapered per prescriber preference (PO)
MS fatigue	Modafinil	Provigil	100–200 mg/d (PO)
	Armodafinil	Nuvigil	150 mg or 250 mg/d (PO)
	Methylphenidate	Ritalin	6–20 mg BID or TID (PO)
	Dextroamphetamine	Dexedrine	5–60 mg TID (PO)
	Amantadine	Symmetrel	100 mg BID–TID (PO)
Depression	Fluoxetine	Prozac	20–80 mg/d (PO)
	Paroxetine	Paxil/Paxil CR	20–50 mg/25–62.5 mg (PO)
	Sertraline	Zoloft	100–200 mg/d (PO)
	Citalopram	Celexa	20–60 mg/d (PO)
	Escitalopram	Lexapro	10–20 mg/d (PO)
	Fluvoxamine	Luvox	100–300 mg/d (PO)
	Venlafaxine	Effexor XR	50–375 mg/d (PO)
	Duloxetine	Cymbalta	40–60 mg/d (PO)
	Amitriptyline	Elavil	100–300 mg/d (PO)
	Desipramine	Norpramin	100–300 mg/d (PO)
	Imipramine	Tofranil	100–300 mg/d (PO)
	Nortriptyline	Pamelor	50–150 mg/d (PO)
	Doxepin	Sinequan, Adapin	100–300 mg/d (PO)
	Bupropion	Wellbutrin and Wellbutrin XL	75–100 mg/150–300 mg XL (PO)

(Continued)

MS Symptom	Generic Name	Brand Name	Usual Dosage
Urinary dysfunction	Antimicrobials		
	SMZ + TMP Sulfonamide		SMZ + TMP BID × 10–14 days (PO)
	Cephalosporin	Keflex	Per prescriber preference PO (250–500 mg) or IV
	Quinolones		
	Ciprofloxacin	Cipro	Per prescriber preference
	Levofloxacin	Levaquin	
	Ofloxacin	Floxin	
	Norfloxacin	Noroxin	
	Gatifloxacin	Tequin	
	Gemifloxacin	Factive	
	Moxifloxacin	Avelox	
	Urinary antiseptics		
	Methenamine	Hiprex, Mandelamine	Hiprex 1 g BID Mandelamine 500 mg (both PO)
	Urinary urgency/frequency		
	Oxybutynin	Ditropan, Ditropan XL	5–30 mg QID/XL 30 mg/d (PO)
	Oxybutynin patch	Oxytrol	
	Fesoterodine	Toviaz	3.9 mg twice weekly
	Tolterodine	Detrol LA	4 or 8 mg/d (PO)
	Darifenacin	Enablex	1–2 mg BID; LA 2–4 mg/d (PO)
	Solifenacin	VESIcare	7.5–15 mg/d (PO)
Trospium	Sanctura	5–10 mg/d (PO)	
Hyoscyamine sulfate	Levsin, Levsinex	20 mg BID (PO) 0.125–0.25 mg QID/ 0.375–0.75 mg BID (PO)	
Urinary hesitancy/retention			
Tamsulosin	Flomax	0.4–0.8 mg after meals	
Terazosin	Hytrin	1–5 mg HS (PO)	
Bowel dysfunction	Fecal urgency or incontinence		
	Imipramine	Tofranil	10, 25, 50 mg/d (PO)
	Propantheline	ProBanthine	15 mg BID (PO)

(Continued)

MS Symptom	Generic Name	Brand Name	Usual Dosage
Bowel dysfunction (cont.)	Agents for constipation		
	Docusate	Colace	Over the counter products
	Psyllium hydrophilic mucilloid	Metamucil, Konsyl	
	Methylcellulose	Citrucel	
	Glycerin suppository		
	Lactulose	MiraLAX, Kristalose	
	Polyethylene glycol	GlycoLax, GoLYTELY	By prescription by prescriber
		Colytel, NuLyteLy	
	Fleet enema stimulants	Peri-colace, Bisacodyl	Over the counter products
		Senokot, Cascara Sagrada	
	Erectile dysfunction		
Sexual dysfunction	Sildenafil citrate	Viagra	25–100 mg/d (PO)
	Tadalafil	Cialis	5–20 mg/d (PO)
	Vardenafil	Levitra	2.5–20 mg/d (PO)
Spasticity	Baclofen	Lioresal	20–80 mg/d (PO)
	Intrathecal baclofen		25–750 µg/d intrathecally
	Tizanidine	Zanaflex	4–32 mg/d (slow titration)
	Diazepam	Valium	2–10 mg/d or up to QID (PO)
	Clonazepam	Klonopin	0.5 mg TID (PO)
	Gabapentin	Neurontin	100–900 mg/d (PO)
	Botulinum toxin A	Botox	IM small muscle groups
Pain	Salicylate	Aspirin	1600 mg BID max (PO)
	Acetaminophen	Tylenol	up to 2–4 g/d (PO)
	NSAIDs		
	Ibuprofen	Motrin, Nuprin, Advil	
	Naproxen	Aleve	
	Celecoxib	Celebrex	

(Continued)

MS Symptom	Generic Name	Brand Name	Usual Dosage
Pain (cont.)	Antiepileptic drugs used for pain (dosages per prescriber)		
	Carbamazepine	Tegretol	
	Phenytoin	Dilantin	
	Gabapentin	Neurontin	
	Lamotrigine	Lamictal	
	Topiramate	Topamax	
	Pregabalin	Lyrica	
Walking difficulty/ weakness	Ampyra	Fampridine SR	10 mg BID (PO)

Note. ACTH = adrenocorticotropic hormone; BID = twice daily; CR = controlled release; HS = at bed time; IM = intramuscular; IV = intravenous; LA = long acting; max = maximum; MS = multiple sclerosis; PO = by mouth or orally; Q = every; QID = four times a day; SMZ = sulfamethoxazole; SR = sustained release; TID = three times a day; TMP = trimethoprim; XL = extended release; XR = extended release.

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