

Comprehensive Nursing Care in Multiple Sclerosis

SECOND EDITION

June Halper, MSN, ANP, FAAN
Nancy J. Holland, RN, EdD
Editors

This page intentionally left blank

**Comprehensive Nursing
Care in Multiple Sclerosis**
2nd Edition

This page intentionally left blank

Comprehensive Nursing Care in Multiple Sclerosis

2nd Edition

*June Halper, MSN, ANP, FAAN
and Nancy J. Holland, RN, EdD, Editors*

Demos

Demos Medical Publishing, 386 Park Avenue South, New York, New York 10016

© 2002 by Demos Medical Publishing. All rights reserved. This book is protected by copyright. No part of it may be reproduced, stored in a retrieval system, or transmitted in any form or by any means, electronic, mechanical, photocopying, recording, or otherwise, without the prior written permission of the publisher.

Library of Congress Cataloging-in-Publication Data

Comprehensive nursing care in multiple sclerosis / edited by June Halper and Nancy J. Holland.

p. cm.

Includes bibliographical references and index.

ISBN 1-888799-05-6

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

[DNLM: 1. Multiple Sclerosis—nursing. 2. Multiple Sclerosis—psychology. WL 360 C737 1996]

RC377.C56 2002

610.73'69—dc21

DNLM/DLC

for Library of Congress

96-46912

CIP

Made in the United States of America

Dedication

*Pam Cavallo, MSW
1947–2001*

The second edition of our MS nursing care book is dedicated to Pamela Cavallo, MSW, former Director of the Clinical Programs Department of the National Multiple Sclerosis Society, whose entire career focused on ways to help people with MS and their families have better quality lives. Pamela supported the nurse's critical role in providing MS care, and implemented her vision of programs aimed at healthcare professionals and at families living with MS, to reduce the devastating effects of this disease.

We honor Pam for her role in advancing the MS mission within the Society, and to communities across the United States, and miss her very much.

This page intentionally left blank

Acknowledgments

This book would not have been possible without the support of our families: the Halpers, Wilsons, and Calderbanks. We also wish to thank Dr. Diana M. Schneider for her ongoing support and encouragement.

This page intentionally left blank

Contents

Foreword	xi
<i>Amy Perrin Ross</i>	
Preface	xiii
Contributors	xv
1. An Overview of Multiple Sclerosis: Implications for Nursing Practice	1
<i>June Halper, MSN, ANP, FAAN and Nancy J. Holland, R.N., Ed.D.</i>	
2. Theoretical Concepts, Current Research, and Clinical Trials in Multiple Sclerosis	15
<i>Stephen C. Reingold, PhD</i>	
3. Symptom Management in Multiple Sclerosis	31
<i>Randall T. Schapiro, MD and Diana M. Schneider, PhD</i>	
4. Management of Elimination Dysfunction	53
<i>Marie A. Namey, RN, MSN</i>	

5.	Prevention of Complications in the Severely Disabled	77
	<i>Colleen Harris, RN, MN</i>	
6.	Psychosocial Issues in Multiple Sclerosis	93
	<i>Nicholas G. LaRocca, PhD and Rosalind C. Kalb, PhD</i>	
7.	Sexuality and Family Planning	123
	<i>Rosalind C. Kalb, PhD and Nicholas G. LaRocca, PhD</i>	
8.	Women's Issues in Multiple Sclerosis	141
	<i>June Halper, MSN, ANP, FAAN</i>	
9.	Interfacing with Rehabilitation Services	147
	<i>Patricia M. Kennedy, RN, CNP</i>	
10.	Pharmacotherapeutics in Multiple Sclerosis and Nursing Implications	175
	<i>June Halper, MSN, ANP, FAAN</i>	
11.	Complementary and Alternative Therapies	183
	<i>June Halper, MSN, ANP, FAAN</i>	
12.	Patient and Family Education	191
	<i>Nancy J. Holland, EdD, RN</i>	
13.	Advocacy	205
	<i>Dorothy Northrop, MSW, ACSW</i>	
14.	Integrating the Concept of Hope into Clinical Practice	213
	<i>Linda A. Morgante, MSN, RN, CRRN</i>	
	Appendix A. Resources	223
	Appendix B. Medications Commonly Used in Multiple Sclerosis	243
	Index	329

Foreword

Multiple sclerosis (MS) is a chronic, disabling neurologic disorder that significantly impacts the lives of individuals with the disease and their families. In recent years, impressive advances have been made in the understanding of the disease particularly in the areas of immunopathology, diagnostic approaches and management. In the five years since the first edition of *Comprehensive Nursing Care in Multiple Sclerosis* was published, the role of the nurse in the management of multiple sclerosis has also changed dramatically. New treatments that modify the disease course and expanded options for symptom management have emerged. The role of the nurse has evolved from that of supportive caregiver to include educator, researcher and patient advocate. Today, patients with MS and their families have increased access to information about the disease from multiple sources. The role of the MS nurse as educator focuses on sorting out the information available, relating it to each individual and assisting patients to make informed decisions about their disease and treatment. Nurses are challenged to go beyond traditional symptom management and help the patient and family address issues such as the psychosocial impact of the disease, sexuality and family planning and the role of disease modifying agents. Multiple sclerosis nurses are increasingly involved in research on MS including issues such as the lived experience of multiple sclerosis and predictors of adherence to disease modifying therapies. Because of the tremendous advances made in the understanding and management of the disease, nurses are now in a position to integrate the concept of hope into the clinical management of a disease once thought to be hopeless.

The book begins with a comprehensive overview of MS including current information on the epidemiology, pathology and disease course. New diagnostic criteria of MS is highlighted. The use of a wellness model in MS nursing is described for use in daily practice.

Advances and increased availability of computer technology have led to increased access to information on the World Wide Web. Many clients with MS explore the Internet regularly to gain information about current research in MS. The second chapter of this text clearly describes current research and clinical trials in MS to better prepare the nurse to discuss these issues with clients and answer questions generated on the World Wide Web. Credible sites of MS information are described in other chapters.

Issues of concern to clients in everyday life, including symptom management, psychosocial issues and sexuality, are all comprehensively discussed, with a focus on how the nurse can assist in the care of MS clients facing these issues. Disease modifying agents and alternative therapies are well described to provide the nurse with the indications, rationale, and client care priorities for the person receiving these therapies. The appendixes provide a comprehensive list of various treatments along with the associated nursing care priorities.

This text differs from other books on MS because it presents issues that face the client and nurse today in the era of global uncertainty and managed care. Prevention of complications in the severely disabled, interfacing with rehabilitation services, as well as women's issues are explored with current nursing implications highlighted. Issues such as disability rights and living wills are vital for the nurse to understand in order to be able to provide truly comprehensive care for the MS client. These and other advocacy are explored.

The text concluded on a very positive note, addressing the concept of hope in MS. This reflects the current approach to the care of the MS client and family. No longer are we diagnosing and abandoning these clients. There are many opportunities for hope in MS. It is the role of the nurse to integrate this concept into daily care of the MS client and help them utilize it in their daily life.

Comprehensive Nursing Care in Multiple Sclerosis is the collaborative effort of many health care professionals edited by June Halper and Nancy Holland. It represents the most current information on the care of the MS client and family. This will be an unparalleled resource for all nurses caring for the MS client. Thank you, June and Nancy for updating this wonderful contribution to the MS literature.

Amy Perrin Ross, RN, MSN, CNRN, MSCN

Preface

Multiple sclerosis is a chronic, frequently debilitating neurologic disease that is most often diagnosed at a relatively young age. The disease lasts a lifetime, and involves a wide range of issues, some disease related and others the result of living and aging with a chronic and sometimes disabling condition.

Until recently, treatment was focused on symptomatic management rather than on disease alteration. With the advent of potentially disease modifying agents, the focus of MS care has changed from one of maintenance to a more positive outlook. The nurse has a vital role to play in the ongoing care of and interaction with patients and their families. Nursing care in multiple sclerosis is a collaboration between the patient/family and the nurse, a partnership whose goal is self-awareness and self-responsibility; whose activities involve a great deal of self-care.

There is a new vision of multiple sclerosis—one of hope and empowerment. There is now hope for disease modification in the long-term, symptom control, functional improvement, and improvement of the quality of life for both patients and families. This vision is based on a new understanding of multiple sclerosis and enhanced roles for MS nurses.

The nurse working in the field of multiple sclerosis is a care provider, facilitator, advocate, educator, counselor, and innovator. The challenges of the disease require many creative interventions in a wise variety of settings. The list of MS care needs is long and complex. Interventions range from instruction in the use of medications, both oral and injectable, to bowel and bladder management strategies, to the improvement of mobility. The

dynamic nature of the disease along with the psychosocial, economic, and physical implications of multiple sclerosis call for ongoing skill development and up-to-date information on the part of the nurse interested in MS care.

Comprehensive Nursing Care in Multiple Sclerosis is now in its second edition. Since it first was published in 1996, the world of multiple sclerosis has changed. The authors and editors of this book hope that our readers will derive both personal and professional meaning in its contents. We hope that this book, along with its companion publication, *Advanced Concepts in Multiple Sclerosis Nursing Care*, will provide nurses throughout the world with a complete resource on MS nursing.

Contributors

- June Halper, MSN, ANP, FAAN, Executive Director, Bernard W. Gimbel Multiple Sclerosis Comprehensive Care Center, Consortium of Multiple Sclerosis Center, Holy Name Hospital, 718 Teaneck Road, Teaneck, NJ 07666
- Colleen Harris, RN, MN, Calgary, Multiple Sclerosis Clinic, Foothills Hospital, 1403 29th Street NW, Calgary, Alberta T2N 2T9
- Nancy J. Holland, EdD, RN, Vice President of Clinical Programs and the Professional Resource Center, National Multiple Sclerosis Society, 733 Third Avenue, New York, NY 10017
- Rosalind C. Kalb, PhD, Director, Professional Information & Library Services, National Multiple Sclerosis Society, 733 Third Avenue, New York, NY 10017-3288
- Patricia M. Kennedy, RN, CNP, Nurse Practitioner, Rocky Mountain Multiple Sclerosis Center, 701 East Hampden Avenue, Englewood, CO 80110-2760
- Nicholas G. LaRocca, PhD, Director, Healthcare Delivery & Policy Research Programs, National Multiple Sclerosis Society, 733 Third Avenue, New York, NY 10017-3288
- Linda A. Morgante, MSN, RN, CRRN, Clinical Nurse Specialist, Division of Neurology, Maimonides Medical Center, 480 Tenth Avenue, Brooklyn, NY 11219

Marie A. Namey, RN, MSN, Mellen Center for Multiple Sclerosis Treatment and Research, The Cleveland Clinic Foundation, 9500 Euclid Avenue, Cleveland, OH

Dorothy Northrop, MSW, ACSW, National Director of Clinical Programs, National Multiple Sclerosis Society, 733 Third Avenue, New York, NY 10017-3288

Stephen C. Reingold, PhD, Vice President, Research Programs, National Multiple Sclerosis Society, 733 Third Avenue, New York, NY 10017-3288

Randall T. Schapiro, MD, the Fairview Multiple Sclerosis Center, 701 25th Avenue South, Suite 200, Minneapolis, MN 55454

Diana M. Schneider, PhD, President and Publisher, Demos Medical Publishing, 386 Park Avenue South, New York, NY 10016

CHAPTER 1

An Overview of Multiple Sclerosis: Implications for Nursing Practice

June Halper, MSN, ANP, FAAN
and Nancy J. Holland, RN, EdD

Since first thoroughly described by Charcot in 1868, multiple sclerosis (MS) has been viewed as a chronic, frequently debilitating neurologic disease that affects young adults in the prime of their lives. Diagnosis was tedious and difficult. Those affected faced a bleak future. During the latter part of the 20th century, technological advances such as diagnostic imaging (MRI) and neurophysiologic testing (evoked potentials) facilitated the diagnosis of multiple sclerosis and led to more prompt attention and treatment by healthcare 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 (Labe Scheinberg, personal communication). The treatment of MS has subsequently advanced from a focus on episodic, acute care and rudimentary symptom management, to 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 psychosocial interventions and rehabilitative services has emerged as a leitmotif of MS care throughout the world.

With its emphasis on acute patient care needs, technological and surgical advances, and primary care interventions, basic and advanced nursing education traditionally has not 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 healthcare professionals in addition to neurologists. Nurses who enter this field are often confronted with infor-

mation 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. MS care can be viewed as either predominantly difficult or as rewarding based on the information and support given to a nurse entering this specialty. From the authors' perspective, MS patient care, interaction with a variety of health-care professionals—nursing colleagues, neurologists, rehabilitation specialists, social workers, counselors, and numerous medical specialists such as urologists, orthopedists, physiatrists, and ophthalmologists—can sustain one 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 their patients with MS. We have planned this book to support and sustain nursing care of people with MS, and to support of their families.

EPIDEMIOLOGY, INCIDENCE, AND PREVALENCE

It is estimated that between 250,000 to 350,000 people in the United States are afflicted with MS (Anderson et al., 1992; Vollmer, 1999; Burks & Johnson, 2001). The disease is more common in women than in men by a ratio greater than 2:1, with the difference most marked at younger ages (Kurtzke, 1993; Ebers, 1998).

MS appears to have a higher prevalence in Caucasians than other racial groups. A study done in Hawaii (Alter et al., 1971) showed a higher prevalence in Caucasians than in Asians, native Hawaiians, or blacks living in the same geographic area. Japanese prevalence rates are the lowest of all industrialized countries (Kuroiwa et al., 1983), and the disease is very rare among African blacks (Poser, 1994). The prevalence of MS in those of Scandinavian descent is high, and Bulman and Ebers (1992) showed that the high prevalence of MS in the northern tier of the United States was closely related to the high proportion of people of Scandinavian descent who live there (Ebers, 1998).

It is now believed that MS is the result of an interaction of both genetic and environmental factors (Sadovnick, 1994). 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 multiple sclerosis (Sadovnick, 1994). 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 (Sadovnick, 1994) and remains a topic of controversy.

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 (Moffie, 1996; Dean, 1967; Alter et al., 1971) showed that they remained at high risk if they emigrated after the age of fifteen. Those who emigrated prior to age fifteen 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 (Garnieri et al., 1993; Ebers, 1998).

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” (Garnieri et al., 1993, p. S17). Garnieri 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 (Savettieri, 1983; Rosati, 1990), with similar results from studies done in Yugoslavia (Sepcic et al., 1989) and Spain (Martin et al., 1988). According to Garnieri (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 since 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, 1993) (Table 1-1).

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 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, brainstem, 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, 1985). Axonal damage has been identified in both acute and chronic MS lesions and is believed to be the cause of permanent, irreversible physical and cognitive disability (Trapp et al, 1998).

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).

TABLE 1-1. Familial Risks for MS

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

Empiric recurrence risks (age-adjusted)

- MS parent-risk for child 4%
 - MS person-risk for sibling 4–5%
 - MS twin with MS risk for co-twin (fraternal) 3–5%
 - MS twin with MS risk for co-twin (identical) 26–26%
-

Source: Vollmer, 1999; Sadovnick et al., 1993

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 or not a patient's disease will follow a specific pattern. In general, women have a better prognosis than men do (Coyle, 1996). Onset at an early age, a monoregional versus a polyregional attack, and complete recovery from an exacerbation portend a favorable prognosis (Coyle, 1996). Brainstem symptoms (such as nystagmus, tremor, ataxia, and dysarthria), poor recovery from exacerbations, and frequent attack rate are indicators of a poor prognosis (Coyle, 1996).

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 percent of MS patients have their first symptoms in their 60s (Sibley, 1990). While 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, 1990). The diagnostic criteria for MS have evolved from Schumacher et al. (1965), the Poser Committee (1983), and the McDonald consensus (2001) (Tables 1-2, 1-3, and 1-4).

TABLE 1-2. Schumacher Criteria for the Clinical Diagnosis of MS

-
- 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, stepwise progression for more than 6 months
 - No better explanation
 - Minimum routine laboratory investigation
 - Diagnosis by a physician competent in clinical neurology
-

TABLE 1-3. Poser Committee Criteria for the Diagnosis of MS

Category	Clinical				Paraclinical	
	Attacks	Evidence	Evidence		CSF	
Clinical Diagnosis:						
Definite	1	2	2		–	
	2	2	1	and	1	
Probable	1	2	1		–	
	2	1	2		–	
	3	1	1	and	1	
Laboratory-Supported Diagnosis:						
Definite	1	2	1	or	1	+
	2	1	2		–	+
	3	1	1		–	+
	Probable	1	2		–	+

TABLE 1-4. New MS Diagnostic Criteria

Clinical Attacks	Objective Lesions	Additional Requirements to Make the Diagnosis
2 or more	2 or more	None; clinical evidence will suffice (additional evidence desirable but must be consistent with MS)
2 or more	1	Dissemination in space by MRI or positive CSF and 2 or more MRI lesions consistent with MS or further clinical attack involving different site
1 (monosymptomatic)	1	Dissemination in space by MRI or positive CSF and 2 or more MRI lesions consistent with MS and Dissemination in time by MRI or second clinical attack
0		Positive CSF and
Progression from outset	1	Dissemination in space by MRI evidence of 9 or more T2 brain lesions or 2 or more cord lesions or 4–8 MRI lesions or positive VEP with less than 4 brain lesions plus 1 cord lesions and Dissemination in TIME by MRI or continued progression for 1 year

Source: McDonald et al. (2001). Recommended Diagnostic Criteria for MS. *Ann Neurol* 50,121–127.

MS is diagnosed mainly on a clinical basis due to the difficulty of obtaining appropriate tissue (Fang & Lublin, 1995). The Poser criteria for clinically definite MS require 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 somewhat controversial McDonald criteria 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.

Patients can be categorized as having either relapsing–remitting, primary progressive, secondary progressive, progressive–relapsing, benign, or malignant disease (Lublin & Reingold, 1996) (Figure 1-1).

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.

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).

DOMAINS OF MULTIPLE SCLEROSIS NURSING PRACTICE

The practice of MS nursing requires that the full range of nursing skills and practice be called into 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 (MSNICB, 2001).

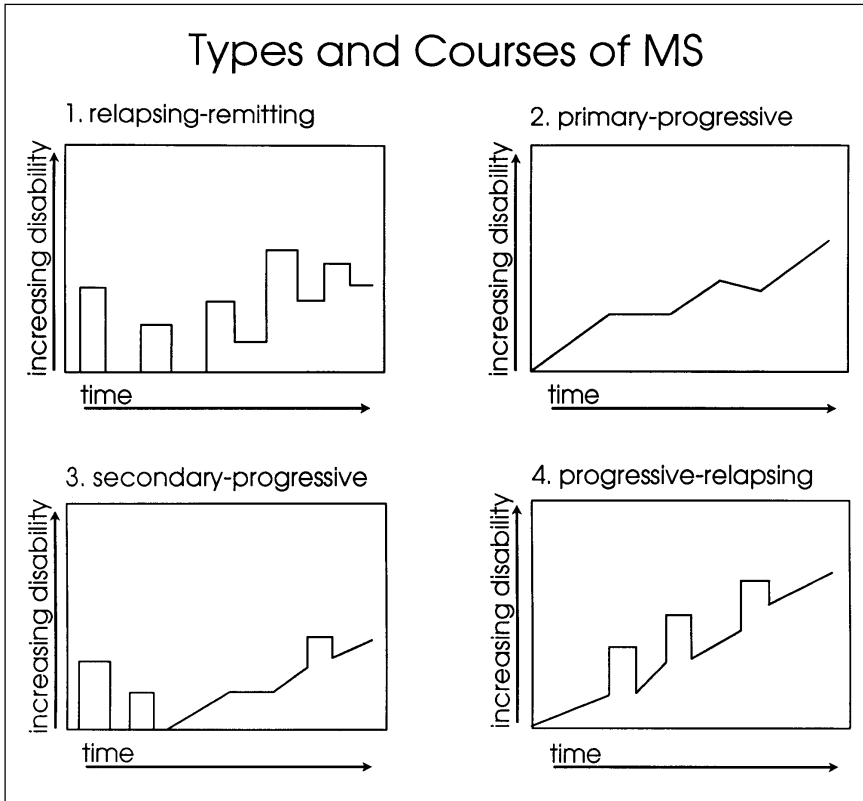


FIGURE 1-1. 1. Relapsing-remitting (RR) MS is characterized by clearly defined acute attacks with full recovery (a) or with sequelae and residual deficit upon recovery (b). Periods between disease relapses are characterized by lack of disease progression. 2. Primary progressive (PP) MS is characterized by disease showing progression of disability from onset, without plateaus or remissions (a) or with occasional plateaus and temporary minor improvements (b). 3. Secondary progressive (SP) MS begins with an initial RR course, followed by progression of variable rate (a), which may also include occasional relapses and minor remissions (b). 4. Progressive-relapsing (PR) MS shows progression from onset but with clear acute relapses, with (a) or without (b) recovery.

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) (Table 1-5). 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 thera-

TABLE 1-5. 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
Diagnose	Teach client self-assessment procedures 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, 1986.

peutic partnership and can support this relationship throughout a lifetime of coping with change and adapting to new circumstances (Halper & Holland, 1998; Halper, 2001).

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 (URI, 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 (see Chapter 3).

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 spe-

cialists, 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, 1994) and has set a standard for care of the chronically ill and disabled that one sees in disease such as HIV/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 healthcare system. The nurse in the home care setting is the link to healthcare 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 (see Chapter 5). 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 in the palliative care model.

LONG-TERM CARE

Long-term care does not necessarily imply nursing home or long-term care facility. It also may 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 (see Chapter 5).

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.

REFERENCES

- Allen, I. (1991). Pathology of multiple sclerosis. In W.B. Matthews (ed.). *McAlpine's Multiple Sclerosis*. New York: Churchill Livingstone, 298–378.
- Alter, M., Okihiro, M., Rowley, W., Morris, T. (1971). Multiple sclerosis among Orientals and Caucasians in Hawaii. *Neurology*, 21, 122–130.
- Anderson, D.W., Ellenberg, J.H., Leventhal, C.M., Reingold, S.C., Rodriguez, M., Silberberg, D.H. (1992). Revised estimate of the prevalence of multiple sclerosis in the United States. *Ann of Neuro*, 31, 333–336.
- Bulman, D.E., Ebers, G.E. (1992). The geography of multiple sclerosis reflects genetic susceptibility. *J Trop Geographic Neuro*, 2, 66–72.
- Burks, J.S. Johnson, K.P., eds. (2000) Multiple Sclerosis: Diagnosis, Medical Management, and Rehabilitation. New York: Demos.
- Clark, C.C. (1986). *Wellness Nursing*. New York: Springer.
- Cobble, N.D., Burks, J.S. (1985). The team approach to the management of multiple sclerosis. In Burks, J.S., Maloney, F., Ringel, S.R. (eds.). *Interdisciplinary Rehabilitation of Multiple Sclerosis and Neuromuscular Disorders*. Philadelphia: J.B. Lippincott, 13.
- Compson, D.A.S. (1991). Genetics and immunology. In W.B. Matthews (ed.). *McAlpine's Multiple Sclerosis*. New York: Churchill Livingstone, 298–335.
- Compson, D.A.S. Presentation on immunology of multiple sclerosis. MS Trust. Harrogate, U.K. November 2001.

- Coyle, P. Diagnosis, classification, and prognosis in multiple sclerosis. Presentation, February 2, 1996, St. Petersburg, FL.
- Dean, G. (1967). Annual incidence: Prevalence and mortality of multiple sclerosis in white South-African born and in white immigrants to South Africa. *Br Med J* 2, 724–730.
- Ebers, G.C. (1998) Introduction: A Historical Overview. Ebers, GC, Paty, DW. *Multiple Sclerosis*. (eds). Philadelphia: FA Davis.
- Fang, J.Y., Lublin, F.D. (1995). Altering the course of multiple sclerosis. *Internal Medicine*, 16 (1), 15–31.
- Garnieri, E., Casetta, I., Tola, M., et al. (1993). Multiple sclerosis: does epidemiology contribute to providing etiological clues? *Journal of the Neurological Sciences*, 115 (Suppl), S16–S23.
- Halper, J. Defining Multiple Sclerosis 2001: A New Vision. Presentation in Dallas, November 2001.
- Halper, J., Burks, J.S. (1994). Care patterns in multiple sclerosis. *Neuro Rehabilitation*, 4 (4), 67–75.
- Halper, J. Holland, NJ. Multiple Sclerosis, New Strategies, New Hope, Part 1. *AJN*, 1998. 10:27–32. Part 2. *AJN*. 1998. 11:39–46.
- Hammond, S.R., McLeod, J.G., Millingen, K.S., Stewart-Wynne, E.G., English, D., Holland, J.T., and McCall, M.G. (1988). The epidemiology of multiple sclerosis in three Australian cities: Perth, Newcastle and Hobart. *Brain*, 111, 1–25.
- Kuroiwa, Y., Shibasaki, H., Ikeda, M. (1983). Prevalence of multiple sclerosis and its north-south gradient in Japan. *Neuroepidemiology*, 2, 62–69.
- Kurtzke, J.F. (1993). Epidemiologic evidence for multiple sclerosis as an infection. *Clinical Microbiology Reviews*, 382–427.
- Kurtzke, J.F. (1985). Epidemiology of multiple sclerosis. In P.J. Vinken, G.W. Bruyn, H.L. Klawans (eds.). *Handbook of Clinical Neurology*, Revised series, Vol. 3. Demyelinating Diseases. Amsterdam: Elsevier, 259–287.
- Kurtzke, J.F., Hyllested, K. (1979). Multiple sclerosis in the Faroe Islands. I. Clinical and epidemiological features. *Annals of Neurology*, 5, 6–21.
- Lublin, F., Reingold, S. (1996). Defining the course of multiple sclerosis: Results of an international survey. *Neurology*.
- Maloni, H. Domains of Multiple Sclerosis Nursing Practice. Presentation, November 2001. Dallas, TX.
- Martin, R., Matlas-Guiu, L., Calatayud, E., J.M. Molto, J. Aranaz. (1988). Epidemiology of multiple sclerosis in Eastern Spain (Abstr.). *An Update on Multiple Sclerosis*, International MS Conference, Rome, IV/34, September 1988.
- Moffie, D. (1996). De geografische, verbreiding van multiple sclerose. *Ned Tijdschr Geneeskd*, 110, 1454–1457.
- McDonald, W.I., et al. (2001) Recommended Diagnostic Criteria for MS. *Ann Neurology* 2001; 50, 121–127.
- Multiple Sclerosis Nursing International Credentialing Board, Orlando, FL. 2001.
- Pallett, P.J., O'Brien, M.T. (1985). *Multiple Sclerosis. Textbook of Neurological Nursing*. Boston: Little, Brown, 616–619.
- Poser, C.M. (1994). The epidemiology of multiple sclerosis: A general overview. *Annals of Neurology*, 36(S2), S180–S193.

- Poser, C.M., Paty, D.W., Scheinberg, L.C., et al. (1983). New diagnostic criteria for multiple sclerosis: Guidelines for research protocols. *Ann of Neuro*, 13, 227.
- Rosati, G. (1990). Epidemiologia della sclerosi multipla. In G. Rosati, E. Garnieri (eds.). *Manual di Neuroepidemiologia Clinica*, NIS, Rome, 143–182.
- Sadovnick, A.D. (1994). Genetic epidemiology of multiple sclerosis: A survey, *Annals of Neurology*, 36 (Suppl), S194–S203.
- Sadovnick, A.D., Baird, P.A, Ward, R.H. (1988) Multiple Sclerosis: Updated risks for relatives. *Am J Med Genet*, 29, 533–541
- Sadovnick, A.D., Armstrong, H., Rice, G.P., et al. (1993). A populations-based study of multiple sclerosis in twins: Update. *Annals of Neurology*, 33: 281–285.
- Savettieri, G. (1983). Epidemiologia della sclerosi multipla in Italia. *Riv Neurol*, 52, 227–237.
- Schumacher, G.A., Beebe G., Kibler, R.F. et al. (1965) Problems of experimental trials of therapy in multiple sclerosis. Report by the panel on the evaluation of experimental trials of therapy in multiple sclerosis. *Annals of the NY Academy of Sciences*, 122, 552–568.
- Sepcic, J., Antonelli, E., Materljian, D., Rukavina, D. (1989). Multiple sclerosis cluster in Gorski otar, Croatia, Yugoslavia. In Battaglia (ed.). *Multiple Sclerosis Research*. Amsterdam: Excerpta Medica, 165–169.
- Sibley, W.A. (1990). The diagnosis and course of multiple sclerosis. *Neurobehavioral Aspects of Multiple Sclerosis*. New York: Oxford University Press, 5–14.
- Trapp, B.D., Peterson, J. Ransahoff, R.M., et al. (1998) Axonal transection in the lesions of multiple sclerosis. *NEJM*. 338, 278–283.
- Vollmer, T.L. (1999). Multiple sclerosis: The disease and its diagnosis. Van den Noort, S., Holland, N.J. (eds.). In *Multiple Sclerosis in Clinical Practice*. New York: Demos.

CHAPTER 2

Theoretical Concepts, Current Research, and Clinical Trials in Multiple Sclerosis

Stephen C. Reingold, PhD

Since its most descriptive beginnings, multiple sclerosis (MS) research has evolved into a subspecialty that incorporates virtually every discipline of modern biotechnology, ranging from the most esoteric molecular biological laboratory techniques to demographic, socioeconomic, and psychological studies. In spite of the fact that MS has been known and studied as a separate disease since the mid-1800s, its etiology remains a mystery. While many theories abound, none has been directly proven so far. However, current research is leading us closer to a true sense of what causes the disease.

THEORIES OF THE CAUSE OF MULTIPLE SCLEROSIS

Because MS presents clinically as a neurologic disease, research on its basic cause has concentrated on how nervous system pathology in MS might develop [e.g., central nervous system (CNS) inflammation, eventual loss of myelin, damage to nerve fibers and astrocytic scarring] to produce the key physiologic effect of MS: the impairment or blocking of nerve fiber conduction and the development of symptoms as the result of impaired nerve conduction.

Although many theories of the underlying cause of MS have been explored over decades, a complete understanding of causation still elludes us. Among some of the more prominent theories that seem *not* to be “the” cause of MS are:

Congenital defects in nervous system structure or function. Considerable research has claimed that CNS myelin is compositionally normal in people with MS. Thus, it has been generally believed that there is nothing intrinsically “wrong” with myelin or nerve fibers in MS that results in their damage and loss. However, the advent of magnetic resonance spectroscopy (MRS) has shown that “normal appearing white matter” in brains of individuals with MS may not in fact be normal—changes in spectrographic images characteristic of tissue damage may be seen even in areas that appear unaffected to the normal eye or in more traditional magnetic resonance imaging. It is not known whether apparent CNS tissue abnormality in people with MS is in fact a developmental abnormality that makes the person’s central nervous system tissue more disease-prone—and thus might be considered a “cause” of the disease—or if the detected abnormalities are simply a consequence of existing disease that are not (yet) grossly apparent. Studies on the genetic makeup of myelin that might provide some clues have provided conflicting results. Some studies show genetic differences in key myelin proteins in people with MS compared to healthy control subjects; other studies have failed to confirm this.

Direct damage by a virus or other infectious agent of CNS white matter. Although viral infections can damage the nervous system and cause other diseases in both humans and animal demyelinating disease models, such direct viral effects have not been shown to be relevant to MS despite detailed research in this area. Over the years, intensive searches using increasingly sophisticated techniques have led to proposals that a variety of common and uncommon viruses and bacteria, ranging from canine distemper virus to retroviruses to herpes viruses to *Chlamydia pneumoniae* (the cause of roseola), might be a “cause” of MS, or at least associated with the disease. However, none has been proven to be related to the disease. In those infectious agents that are generally believed to *not* be involved as an “MS cause,” problems of sampling, artifact, and an apparent increased immune reactivity to most or all viruses in MS patients have confounded results over the years.

Environmental toxic substances or dietary imbalance. No research has demonstrated that environmental contaminants or diet cause MS, although toxic substances and diet are known to cause other nervous system problems that may have some clinical similarities to MS. However, such theories of the cause of MS are still being explored by some scientists. One often hears of “findings” suggesting that one or the other chemical or heavy metal causes MS, sometimes associated with analysis of “clusters” of disease that may suggest a higher than expected prevalence of MS in a given community or occupational group. In spite of the attention and excitement drawn to such reports, further exploration has usually found the claims to have little scientific merit.

Similarly, there have been, over decades, many claims and anecdotal reports that specific diets can have a positive impact on MS, even though research to support such claims is lacking.

Current theories about multiple sclerosis focus on four hypotheses that, together with psychosocial, health care delivery, and experimental therapy studies, drive most of today's research efforts:

- ▷ MS is believed to be an autoimmune disorder.
- ▷ There is a genetic susceptibility that may predispose certain individuals to the disease.
- ▷ There is probably an infectious trigger, if not a cause, for the disease.
- ▷ The ultimate neurologic damage that produces the signs and symptoms of the disease results from inflammation, T-lymphocyte infiltration, myelin breakdown, nerve fiber damage and loss, and astrocytic scarring that slow or block the conduction of nerve signals in fibers of the brain, spinal cord, and optic nerves.

IMMUNOLOGY AND MULTIPLE SCLEROSIS

Significant research on the cause of MS during the past 20 years has focused on the growing understanding that MS is a disease of immune system function that is clinically apparent in signs and symptoms of the CNS. More specifically, many scientists concentrate their research efforts on the hypothesis that MS is an “autoimmune” disease, in which (primarily) cellular elements of immune function are misdirected and, instead of doing the normal job of defending our bodies against viral, bacterial, and parasitic infections, mistakenly turn against a part of our body—the white matter or myelin insulation around nerve fibers in the CNS and the nerve fibers themselves.

The evidence for immune system *involvement* in MS is fairly clear, while evidence that it is an *autoimmune disease* is more indirect. First, people with MS seem to have clear-cut abnormalities in immune function. These include, among many other factors, unusually high reactivity of immune system T-cells to proteins of myelin in the CNS (which are termed *antigens* because they can trigger immune responses); an over-representation of cells that enhance immune responses (so-called *helper T-cells* and in particular, of Th1-type cells—those that promote inflammatory responses) and a relative under-representation of cells that suppress immune responses (so-called *suppressor T-cells*); and the presence of immune system cells in MS lesions in the brain, spinal cord, and optic

nerves. While much of the focus over many years has been on T-lymphocytes, the role of B-lymphocytes—those responsible for producing antibodies—has recently been emphasized and clearly this immune component plays a role in MS pathology as well.

Direct evidence that the immune problem in MS is “autoimmune” is difficult to obtain in humans but is quite clear in a laboratory model disease of rats, mice, guinea pigs, and primates, called *experimental allergic encephalomyelitis* (EAE). In these experiments, T-lymphocytes sensitized to myelin antigens can transfer disease to healthy, syngeneic animals—the true test of autoimmunity. While this key experiment that “transfers” MS from a sick individual to a healthy one cannot be done in humans for obvious ethical and practical reasons, the similarities of CNS lesion pattern between EAE and MS and, in some regards, of the disease course and clinical signs, have led most scientists to conclude that MS must surely be autoimmune as well.

In mid-1990, for the first time, several studies on people with MS detected reactivity of specific immune cells in the blood and CNS against a protein component of normal myelin, called *myelin basic protein*, which makes up some 30 percent of all myelin proteins. Other myelin proteins, such as proteolipid protein, can also trigger specific immune system responses in MS. Even though healthy individuals may also show immune reactivity in the blood against myelin antigens (but perhaps not at the site of damage, within the nervous system), this sort of evidence enhances our belief that MS is an autoimmune disorder, involving at least T-lymphocytes apparently directed against myelin proteins in the CNS.

As a result of these studies, major focus has been brought to the nature of immune system reactivity to myelin in MS, including specificity immune responses against myelin antigens, responses of *cytokines* (soluble mediators of immune function), control of pro-inflammatory vs. anti-inflammatory immune responses (as well as efforts to shift pro- to anti-inflammatory responses), and the movement of activated immune cells from the blood to the CNS—all with the aims of better understanding of MS immune responses and of harnessing this information to develop more specific therapies.

GENETICS AND MULTIPLE SCLEROSIS

A genetic relationship in MS is borne out by a number of findings:

- Evidence from family studies has demonstrated an increased susceptibility to MS (and possibly to other known autoimmune diseases as well) in families in which MS already occurs. In fact, some 20 percent or more of individuals with MS may have another family mem-

ber with the disease. Population studies from a large clinic-based sample in Canada have demonstrated clearly that the occurrence of multiple cases of MS in families is certainly genetic in origin and not a consequence of a shared environment. Adopted siblings with their different genetic backgrounds do not share a family's overall risk for MS, even though the environment in which they are reared may be identical to that of nonadopted siblings who are genetically related to each other and may be at risk for MS. Similarly, while occasional reports surface about MS occurring in both partners in a married couple, researchers in Canada have shown that there is no increased risk among married partners—"conjugal MS" does not exist—again pointing away from any shared environmental or behavioral characteristic that might be responsible for MS.

- ▷ It has long been known that there are ethnic groups in the world that are genetically "isolated" (i.e., they rarely or never marry or bear children outside of their own group, and thus have developed a relatively restricted and unique gene pool) and rarely or never get MS. These include such religious sects as the Hutterites in Canada and such groups as Eastern European gypsies.
- ▷ There are racial differences in MS prevalence that are also most likely genetically based. The disease occurs less frequently in African Americans than among Caucasians in North America, is rarely seen in Eskimos or in pure African Bantus, and is also rarely seen—and in a form quite different from that in Caucasians—among Asians.

Even though there is a clear increased family susceptibility, the risk of disease is still quite low in families in which the disease already exists. In the United States, a little more than 1/1,000 people have MS. When a family member (parent, sibling, aunt/uncle, etc.) has the disease, the risk increases to about 1–5/100 for other family members, depending on the degree of relationship. This represents an increased susceptibility but still a relatively low risk. For twins, an important finding is that among dizygotic (nonidentical) twins, the risk resembles that for any other sibling. However, among monozygotic (identical) twins, who are genetically identical, the risk of both having MS rises dramatically to as high as 30 percent if one twin has been diagnosed—a clear indication of the importance of genetic factors in disease susceptibility (but at the same time, also a clear indication that MS is not a "genetic disease" entirely).

While genetics play a role in MS susceptibility, the nature of that genetic link is both complex and largely unknown. Importantly, given the immune focus of MS, the genes that control immune function in people

with MS may differ in one or more key ways from those of healthy individuals. By the early 1990s, molecular genetic research had identified two types of immune system genes that were thought to be involved in MS. The first type consists of genes that help the immune system differentiate between body tissues that are “self” and substances that are foreign—such as a bacteria or virus, or even a transplanted liver or kidney from a genetically different donor. This genetic “self-recognition” mechanism helps to signal the immune system to mount an effective response against foreign antigens but not against “self” antigens. Genes involved in “self-recognition” are variously called histocompatibility genes, human leukocyte antigens (HLA), or major histocompatibility complex (MHC) genes. There is evidence from population and family studies that HLA genes in people with MS differ from healthy individuals. This is not as straightforward as it seems: HLA genetic makeup can differ between MS populations, independent of health status, and thus there is no clear-cut “MS HLA gene profile” that defines the entire MS population.

A second important gene type hypothesized to be involved in immune function in MS is the gene responsible for the structure and function of receptors on T-cells of the immune system. Such receptors are essential in recognizing targets of immune attack—foreign or perhaps “auto” antigens—and consequently are essential in determining immune responses. Suspicion of a T-cell receptor genetic relationship in MS came from animal model studies and from small early MS studies, but a clear immunogenetic role related to T-cell receptors in MS has not been proven. Early claims in this regard were hampered by the fact that animal models with MS-like disease are created from highly inbred genetic animal populations. Humans, however, are very much “outbred” and it appears that the larger the MS population one examines, the more variable the T-cell receptor genetic picture becomes between individuals.

The identification of genetic factors that may underlie immune dysfunction in MS is only one step in our effort to clarify the long-known fact that there is a genetic susceptibility to the disease. By the mid-1990s, genetic molecular technology had advanced to the point that genome screening in MS was possible. Three independent studies in the United States, Canada, and Great Britain focused on understanding the specific genetic associations and links in MS, using families in which MS occurs more often than once. Data from these studies reported in 1996 were inconsistent but made it clear that MS is a complex, multigenic disease with areas of genetic “interest” on several chromosomes. Some of those chromosomes, perhaps among the most important, do relate to immune function. Others may have no apparent relationship to immune function at all. Additional attempts are underway to unravel the complex genetics of MS susceptibility via large-scale population studies, studies of selected ethnic groups and

geographic populations, and studies in which particular “candidate genes” (based on the role of the proteins or functions the genes subsume may play) are scrutinized in detail. While it may be some time before answers are in hand, it is increasingly clear that genetic answers to MS will be hard to come by.

ENVIRONMENTAL TRIGGERING FACTORS

Although genetic factors are key in MS, the fact that only 30 percent of monozygotic twins are concordant for MS means that nongenetic factors must play a major role in the development of the disease. Over decades, population studies have suggested that some triggering factor from the environment must initiate the autoimmune disease process. Epidemiologic data from migration studies suggested that some factor—most likely infectious—must be encountered before the age of 15 years in order for the disease to be triggered.

While somewhat controversial, these epidemiological data have resulted in a search over the last half century for a specific infectious agent that triggers the disease. The primary focus has been on viral pathogens. Although many common and uncommon viruses have been proposed as causative agents for MS, in each case further scientific analysis has failed to support the initial claim. This has not stopped the search for a specific MS virus, but in recent years it has made such a search somewhat unpopular and subject to skepticism.

Retroviruses have been among the most widely touted candidates as the specific viral trigger for MS, with initial findings based on serologic studies for antibodies against HTLV-1 in MS patients, followed by polymerase chain reaction (PCR) analyses looking for viral “footprints.” However, studies using the same technologies from multiple laboratories around the world were unable to confirm the initial claims. Beginning in 1995, serologic, PCR, and immunohistochemical studies pointed to a possible role of an ubiquitous human herpesvirus, HHV6—a virus more easily recognized as the cause of the childhood disease roseola. At the beginning of the new millennium a number of laboratories began investigating HHV6 in MS to determine if the virus is truly present in MS tissues and to determine if its presence is a causative factor in the disease, or a consequence of damage done by other means.

Similarly, while there have been claims of a possible bacterial infectious trigger for MS and anecdotal claims that antibiotic treatment had an impact on disease, no strong bacterial candidates were identified until recently. Claims that the ubiquitous bacterium *Chlamydia pneumoniae*, which is known as the cause of “walking pneumonia,” is associated with MS has

generated much interest. The presence of bacterium in spinal fluid demonstrated by some (but not all) laboratories, plus the claim that previously unidentified antibodies contained in oligoclonal bands of the spinal fluid can react against *C. pneumoniae*, have raised the possibility that this agent may have a triggering or causative role in disease and stimulated the initiation of a controlled antibiotic clinical trial.

In the absence of evidence for a specific viral trigger for MS, increased attention has been paid to the possibility that many viruses and bacteria—and perhaps other pathogens as well—could serve as triggers for the disease process. If so, it may well be the *manner* in which a genetically susceptible immune system reacts to such infectious challenges that determines if MS will occur. This possibility decreases the likelihood that a vaccine against a specific triggering agent could be found to prevent disease. However, it has increased research efforts to understand more about how immune responses to infectious agents might result in autoimmunity.

One attractive theory of how the autoimmune process might be triggered by infectious agents involves “molecular mimicry,” in which the immune system normally reacts to a foreign antigen but also reacts against a component of “self”—such as myelin—if the foreign antigen and myelin share some components of molecular structure. Molecular mimicry has been demonstrated to contribute to autoimmune reactions in laboratory animals with EAE and may contribute to the human disease as well. Work in 1995 showed that molecular mimicry may occur between certain viral and bacterial antigens and human myelin. Importantly, human T-cells were found that could react against the mimicking antigens as well as myelin. This lends credence to the “molecular mimicry” hypothesis of how autoimmunity may develop in MS.

DEMYELINATION: THE CAUSE OF SYMPTOMS

The damage done by an immune reaction against myelin and nerve fibers in brain and spinal cord might truly be considered the “cause” of MS since it is this process that results in symptoms. Immune system T-cells normally in the blood stream become activated against a myelin antigen and cross the blood–brain barrier, which separates the blood stream from the CNS and normally keeps such immune system cells out of the nervous system. Local inflammation in scattered places—most often around blood vessels and ventricles of the brain—results in damage to the myelin insulation around nerve fibers. Myelin is broken down and scavenged by macrophages. Lost myelin is ultimately replaced by gliotic scars produced by astrocytes, which provide a barrier to myelin regeneration.

Probably as a secondary consequence, but nonetheless occurring early in the disease, nerve fibers themselves are affected and may be damaged or severed. It is believed that while much of the “reversible” disability seen in MS may be due to inflammation and myelin loss and subsequent natural regeneration, loss of nerve fibers results in permanent, (currently) irreversible disability, and that this element becomes more prominent over time in many people with MS.

Inflammation, loss of myelin, and nerve fiber loss and scarring result in reduced conduction of nerve signals within the CNS. Conduction deficits in intact nerve fibers result from changes in membrane properties and relocation of ion channels in nerve fibers from which myelin is lost. These conduction problems produce the symptoms that characterize the disease.

Historically, oligodendrocytes that make myelin in the CNS were believed to be incapable of regenerating the insulating material in an adult once it had been lost. This may be one key difference between MS and Guillian-Barré disease, in which recovery of function after an acute episode is often seen, and in which the Schwann cells that make myelin in the peripheral nervous system are more easily capable of regeneration. However, beginning in the mid-1980s, the dogma concerning the lack of CNS remyelination after an MS attack has been challenged, even in the most advanced disease and the most serious lesions. Neuropathologic evidence from autopsy specimens shows clear but “weak” remyelination in massively demyelinated CNS lesions. An absence of necessary growth factors, an inability to “penetrate” astrocytic scars, and even immune responses that may inhibit the remyelination process, are among the theories to explain why remyelination after MS damage is difficult and incomplete. As of the 1990s, a variety of treatments—for instance, galactocerebroside and even common immunosuppressive drugs such as intravenous immunoglobulin—have been shown to enhance CNS remyelination in animal models of MS, and myelin development is being actively studied for the lessons it might teach about myelin regeneration.

Furthermore, oligodendrocyte precursor cells in the CNS have been identified that may be primed for proliferation and differentiation, and may thus be capable of forming new myelin after initial myelin damage. Finally, animal studies have demonstrated the capability of transplanted oligodendrocytes to form functional myelin insulation around nerve fibers in genetically myelin-deficient mouse strains and in experimentally induced myelin lesions. Each of these findings raises the possibility of regeneration of myelin after disease. Since proper nervous system conduction depends on functioning myelin insulation, such studies raise the hope for recovery of function in people with MS. Regeneration of myelin, however, will be of little benefit in the face of ongoing immune damage—

requiring a parallel treatment approach to control immune destruction. And, if nerve fiber damage is a significant factor, myelin repair will not be of much help. Efforts to regenerate nerve fibers themselves are a major research focus, particularly in the area of spinal cord injury, but as of 2001, little demonstrable progress has been made. As a consequence, protection against damage in the first place—*neuroprotection*—is an area of growing, cross-disciplinary research emphasis.

While not necessarily directly associated with myelin or nerve fiber damage and loss, recent attention has been drawn to loss of brain volume in MS. While apparent from relatively primitive whole-brain pathological analysis for many decades, recent efforts to assess whole brain volume with MRI have provided not only a confirmation that brain atrophy takes place in MS, but that it occurs early in this disease and also that it is progressive. Confounding factors, now being explored in detail, are the fact that the aging brain loses volume independent of MS, and that changes in water content of the brain—edema due to inflammation and loss of fluid as inflammation—resolve naturally or with steroid treatment and can confuse measures of actual tissue volume. Nonetheless, brain atrophy in MS is widely recognized and represents a negative pathologic change, and may develop as an early measure of disease progression and also of therapeutic efficacy.

RESEARCH INTO NEW TREATMENTS MULTIPLE SCLEROSIS

In the long run, all MS research—the most basic or the most applied—is directed to developing and testing new drugs or devices that can alter the disease course, prevent the disease from occurring, or improve function in people who already have MS. The ultimate research experiment, then, is the clinical trial.

A clinical trial is the scientific study of the efficacy and safety of a drug or device for a given disease on people who have that disease. As scientific studies, clinical trials are complex and must be done as carefully as any other experiment.

Clinical trials in MS are aimed at one or more of a number of desired outcomes: inducing a disease remission; maintaining that remission; altering the disease course; improving or eliminating symptoms; and prevention and cure. No one therapy is likely to satisfy all of these goals, and it is likely that management of MS will include the use of multiple treatments.

MS clinical trials are particularly difficult to undertake. First, people with MS are generally highly motivated to seek a “cure” for their disease, and a patient’s motivation can actually interfere with the objective assess-

ment of any drug or device. This often results in a *placebo effect*—the tendency for a patient to “improve” simply because of participation in a clinical trial even if no active drug is administered. Well-documented clinical studies in MS have shown that sham therapies can result in improvement in as many as 50–60 percent or more of patients. A largely psychological phenomenon, the placebo effect has a basis in the physiologic responses a person can have as a consequence of experiencing increased hope or excitement in the prospect of helping to find a useful therapy. While the true physiologic basis for placebo effects is unknown, hormonal factors surely play a role—pain research, for example, has shown that sham therapies can cause a release of endorphins and actually result in amelioration of pain if the patient is in the right psychological state. While important and potentially useful, such placebo effects are generally short term and must be carefully separated from a true therapeutic drug effect. In fact, any useful drug for MS must have an effect that is greater than the placebo effect.

The high degree of individual and unpredictable variability in MS also makes the design of clinical studies problematic. A useful drug effect must be separable from the natural variability in disease course.

Additionally, since different drugs may have different effects on various disease types, trials must be designed to answer questions about the effect on one type of disease such as relapsing-remitting or secondary progressive disease.

Finally, some drugs may seem to cause improvement but actually only have indirect effects. Understanding the true effect of any drug on the MS disease process requires a detailed knowledge of the drug’s action as well as careful clinical assessment for effects on the disease.

These and other problems associated with MS clinical trials can best be overcome by extremely rigorous experimental design for the studies. The generally accepted methods of study are time-consuming and expensive but hold the best chance of obtaining a clear-cut answer to the efficacy and safety of any agent in MS trials.

The first step, and perhaps the most essential, is that any new agent should have a strong scientific rationale for being tested for MS. Based on current knowledge about MS, immunoregulatory agents, antiviral agents, and those that may promote remyelination or improve conduction of nerve fibers or otherwise target specific disease symptoms, all have a sound rationale for possible use in MS.

Using a knowledge of the MS process, the biological action of any proposed treatment, and results from preliminary animal or human experimental studies of a drug, a physician–scientist may conclude that the drug could have a potential role in the treatment or management of MS. A drug or any other substance without a scientific rationale related to MS should not be given strong consideration for disease testing.

If there is a strong scientific rationale to proceed, human studies almost always begin with toxicity studies in a very small number of people who have the disease (called a “preliminary” or “phase I” clinical trial). In such early experiments, usually only a few, very seriously ill people, are asked to participate, since they may find the potential risk of any new agent to be worthwhile given the grave nature of their disease. If such studies demonstrate acceptable safety and risk, a physician may choose to pursue further studies to get a sense of possible efficacy.

“Pilot” or “phase II” studies usually involve larger, statistically relevant numbers of patients (often 20 to 100 or more) with a disease type and severity that seem appropriate to the hypothesized drug effect. Key objectives in such a study are: (1) obtaining additional information about toxicity and safety; (2) determining effectiveness of the drug in halting progression, reducing relapse rate, or improving function; and (3) refining knowledge about the best dose (amount and frequency of use) and route of delivery (oral, by injection, etc.). Such studies aim to be objective in obtaining the required answers. Thus, patient performance on the drug may be compared to pre-drug status. An even better approach, however, is to compare performance to an identical, matched group of patients in a control group. The most efficient and most sound type of scientific control group is a sham or placebo control group—using a treatment that looks identical to the actual drug but which is known to be therapeutically inactive. In this manner, effects of treatment with an experimental agent, in comparison with sham treatment (to control for placebo effects), can be determined. However, the ready availability of agents to treat several types of MS make use of placebo or sham control groups ethically questionable if there is a treatment of choice for the particular MS disease type. While there are certain circumstances in which placebo controls might be used ethically, fully informed consent from study subjects, including their active declination of use of available therapies, must be seen as a requirement in any placebo controlled trial where agents are available already. Alternatively, a trial might compare a new agent against a currently accepted treatment, or “historical controls” from data sets collected for other purposes. Alternatives to placebo-controlled trials are each fraught with their own problems and have not been extensively explored in MS as of 2001, but will increasingly become the preferred mode of MS clinical trials in the future.

True objectivity in assessing results of a trial is enhanced if both the patients and the physicians who periodically check for efficacy are “blind” to each individual’s treatment status in the study.

Results from such phase II studies, which can often take several years to obtain, may not show statistical benefit for people on the drug compared with people on control treatment, or acceptable levels of side effects of the drug. If there is no benefit or if there are uncontrollable or dangerous side

effects, the agent is usually abandoned as a possible therapy. On the other hand, if there is benefit and side effects are minimal and acceptable, a larger clinical trial will be undertaken to confirm and expand the studies.

Such “pivotal” or “phase III” trials are the final experimental step toward making a decision about the value of any proposed therapy. As previously, the key questions concern safety and efficacy. Statistically relevant numbers of participants are essential, as is an appropriate and relevant control group. The study is usually conducted at a number of different sites (a “multicenter” study) to ensure that the drug can be used in an equivalent fashion by many physicians. Rigorous adherence to blinding of patients and examining physicians, as well as careful random assignment of patients into treatment and control groups, is essential to ensure objectivity. In such a study, there should be sufficient information to determine if the tested agent is truly useful and safe at the conclusion of the study period, when the blinding code is broken and performance of drug-treated patients can be compared with the control group. This is the type of study that is generally required by governmental regulatory authorities in their evaluation of the safety and utility of new therapies.

While there often are variations in this outlined scheme depending on the amount of information available from use of the agent in other diseases, the elements and data described are required to determine true safety and benefit.

Once government regulator approval has been granted and the drug can be sold and advertised as a treatment for MS, a series of further studies is often done, which are called “post-market analyses” or “phase IV” studies. These are designed to test further for possible adverse reactions to the drug, to explore its use for different forms of disease (for instance, an approved drug for progressive MS might be tested in relapsing–remitting disease in a phase IV analysis), or to test the effects of the drug on related disorders (e.g., testing efficacy and safety of an MS-approved drug on rheumatoid arthritis).

FINANCING AND PARTICIPATING IN CLINICAL TRIALS

Drug studies are time-consuming and expensive. Such studies are most often supported financially by drug companies that invest significant research and development resources in these ultimate experiments. Grants from the federal government or health agencies like the National Multiple Sclerosis Society sometimes also fund part or all of the clinical trials. It is extremely rare (and often considered unethical) to require that a patient who volunteers to participate as an experimental subject pay for that privilege.

The decision by anyone with MS to participate in an experimental clinical trial is intensely personal and highly subjective. Since there is always

the potential for risk of any untested agent, a potential subject must be fully informed by the physician and must consider the risk factor in any decision-making process. A true sense of altruism—since participation in either the treatment or control group may ultimately help tens of thousands of people with MS—is often needed to volunteer. Finally, a sense of frustration and even adventure may help sway a potential study volunteer.

One of the most unfortunate dilemmas occurs when a patient has a desire to be in a clinical trial and finds that it is impossible. A frequently asked question is, “Doctor, why can’t I be in your clinical trial?” Clinical trials are limited in practice to a relatively small number of individuals who must be located geographically near the clinical center(s) where the study is undertaken. The design of trials is such that generally only one type of MS—such as relapsing–remitting disease—is involved in a study. This excludes people with any other form of disease. Further restrictions also may be enforced, such as disease limited to a certain duration, or a certain level of disability, the age of participants, based on prior or current medications, or participation in previous trials of agents where there might be dangerous or confusing effects with the experimental treatment medication. For any particular test drug, other restrictions may also apply. These practical factors often result in an eager patient being refused a place in a new clinical trial. If this is the case, a potential participant should take solace from the realization that positive findings from a clinical trial will be of eventual benefit to many more people than could ever hope to participate in the initial studies.

Increasing numbers of MS clinical trials are being completed and initiated each year. Finding out about clinical trials in MS should be a joint project of the patient and the physician. There is an ever-growing network of physicians who organize and run studies in MS. An interested patient and physician team can usually learn of pending studies nearby, often with the assistance of the National Multiple Sclerosis Society.

In summary, the ultimate research in MS is the development and testing of new therapies for use in the disease. Clinical trials designed to objectively test efficacy and safety are difficult and expensive to undertake. While people with MS are always needed to participate in such research, the decision to volunteer is often a difficult and personal one, and the practical restrictions involved in conducting clinical trials in MS often exclude many patients who would gladly participate.

HEALTH SERVICES AND REHABILITATION RESEARCH

When one thinks of research concerning particular diseases, the first assumption is that all research is aimed at understanding the basic disease process and then developing therapeutic agents that alter disease course.

The fact that diseases affect the entire person, his or her family, and even society, places focus on research aimed at improving rehabilitative care, quality of life, and access to care for people with chronic diseases like MS. Long ignored as a serious *research* enterprise in MS, rehabilitation medicine has focused instead on acute and ongoing care for disabled individuals. However, research has a critical role in bringing new methodology to the field and improving care and management. Studies of exercise programs, cognitive rehabilitation, strategies for occupational and physical therapy, among others, have become more common in comprehensive MS care groups.

The impact of chronic disease on society and the impact of society entitlements and attitudes on those with disabilities is also an area for much needed research. From questions of accessibility to delivery of services to preconceptions about disabilities that affect employment, insurance, and family and community structure, healthcare delivery research can provide hard data that can effect societal change.

CONCLUSION

Research related to multiple sclerosis is broad in scope and touches all aspects of the disease, from its basic pathology to understanding how individuals with MS cope with their disease in society today. While most focus is—and should be—aimed at understanding the disease process improving the quality of life for those with MS, and developing safe and effective treatments, the whole person is the subject of modern research in MS.

REFERENCES

- Ebers, G.C., Kukay, K., Bulman, D.E., Sadovnick, A.D., Rice, G., Anderson, C., Armstrong, H., Cousin, K., Bell, R.B., Hader, W., Paty, D.W., Hashimoto, S.D., Oger, J., Duquette, P., Warren, S., Gray, T., O'Connor, P., Nath, A., Auty, A., Metz, L., Francis, G., Paulseth, J.E., Murray, T.J., Pryse-Phillips, W., Risch, N. (1996). *Nat Genet*, 13, 472–476.
- Goodkin, D.E., Rooney, W.D., Sloan, R., Bacchetti, P., Gee, L., Vermathen, M., Waubant, E., Abundo, M., Majumdar, S., Nelson, S., Weiner, M.W. (1998). A serial study of new MS lesions and the white matter from which they arise. *Neurology*, 51, 1689–1697.
- Haines, J.L., Ter-Minassian, M., Bazyk, A., Gusella, J.F., Kim, D.J., Terwedow, H., Pericak-Vance, M.A., Rimmler, J.B., Haynes, C.S., Roses, A.D., Lee, A., Shaner, B., Menold, M., Seboun, E., Fitoussi, R.P., Gartioux, C., Reyes, C., Ribierre, F., Gypay, G., Weissenbach, J., Hauser, S.L., Goodkin, D.E., Lincoln, R., Usuku, K., Oksenberg, J.R. (1996). A complete genomic screen for multiple sclerosis a role

- for the major histocompatibility complex. The Multiple Sclerosis Study Group. *Nat Genet*, 13, 469–471.
- Johnson, R.T. (1998). *Viral Infections of the Nervous System*, 2nd edition. Philadelphia: Lippincott-Raven.
- Noseworthy, J.H., Lucchinetti, C., Rodriguez, M., Weinshenker, B.G. (2000). Multiple sclerosis. *NEJM*, 343, 938–952.
- Raine, C.S., McFarland, H.F., Tourtellotte, W.W. (1997). *Multiple Sclerosis: Clinical and Pathogenetic Basis*. London: Chapman & Hall.
- Rudick, R.A., Fischer, E., Lee, J.C., Simon, J., Jacobs, L. (1999). Use of the brain parenchymal fraction to measure whole brain atrophy in relapsing-remitting MS. Multiple sclerosis collaborative research group. *Neurology*, 53, 1698–1704.
- Trapp, B.D., Peterson, J., Ransohoff, R.M., Rudick, R., Mork, S., Bo, L. (1998). Axonal transection in the lesions of multiple sclerosis. *NEJM*, 338, 278–285.
- Trapp, B.D., Ransohoff, R., Rudick, R. (1999). Axonal pathology in multiple sclerosis: Relationship to neurologic disability. *Curr Opin Neurol*, 12, 295–302.
- Sawcer, S., Jones, H.B., Feakes, R., Gray, J., Smaldon, N., Chataway, J., Robertson, N., Clayton, D., Goodfellow, P.N., Compston, A. (1996). A genome screen in multiple sclerosis reveals susceptibility loci on chromosome 6p21 and 17q 22. *Nat Genet*, 13, 464–468.

CHAPTER 3

Symptom Management in Multiple Sclerosis*

Randall T. Schapiro, MD and Diana M. Schneider, PhD

All too often people with multiple sclerosis (MS) are told that there is little that can be done for their disease. In fact, the appropriate management of MS includes a variety of medical, rehabilitative, and psychological approaches. This chapter focuses on the management of specific symptoms that may develop as the result of the disease process in MS. For each type of problem encountered, appropriate medications and rehabilitative therapies are considered.**

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 exactly alike.

Uncertainty can be one of the major problems in dealing with MS. Studies indicate that if a person is doing reasonably well 5 to 6 years after diagnosis, he or she will likely continue to do reasonably well. The prog-

*This chapter is based on Schapiro, R.T. (1999). *Symptom Management in Multiple Sclerosis*, 2nd edition. New York: Demos.

**Appendix B, "Medications Commonly Used in Multiple Sclerosis," contains detailed information on specific medications.

nosis is better if the predominant early symptoms are sensory. If the early symptoms and findings include tremor and weakness, the prognosis is not so good and a more aggressive management program is in order. Although MS is often thought of as seriously disabling, studies indicate that the majority of patients have a relatively benign disease pattern, with over two-thirds remaining ambulatory 20 years after diagnosis. The majority of patients may be expected to live fairly 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 utilized to treat MS fall into two general categories: those used to treat the underlying disease by shortening exacerbations and slowing the progress of the disease, and those used to minimize and control specific symptoms, such as spasticity, bowel and bladder problems, or fatigue.

Some general principles have been developed for managing the disease, including minimizing fatigue, emotional stress, and increases in body temperature, all of which can magnify symptoms.

Acute attacks are generally treated with corticosteroids (prednisone, methylprednisolone, dexamethasone), which appear to shorten exacerbations, in part by reducing the amount of swelling in areas of demyelination. Studies have shown that a short course of high-dose cortisone works best to shorten the attack. High doses of methylprednisolone (intravenously) or dexamethasone (intramuscularly) are most often used. The course of therapy, which lasts from a few days to a week, is initiated at the onset of a sudden attack, often followed by tapering the oral dose over about a month. Administration in this manner minimizes many of the side effects produced by corticosteroids, including osteoporosis, cataracts, ulcers, obesity, decreased ability of the body to combat infections, and problems of salt and water balance. The goal is to decrease swelling within the CNS, thus allowing unaffected nerves to function normally.

Multiple sclerosis may involve a defect in the way the immune system “sees” myelin so that it reacts to myelin as if it were a foreign tissue. Thus, much of the focus of general management of the disease involves decreas-

ing the activity of the immune system. Corticosteroids work in part through an effect on this system. Other drugs that depress the activity of the immune system without the serious side effects of the corticosteroids are now being used in the long-term management of MS. These include a series of drugs first used to treat cancer, which also involves a defect in the immune system. Imuran® (azathioprine) or Cytoxan® (cyclophosphamide) are examples of such drugs. A new immunosuppressive medication, Novantrone® (mitoxantrone), has recently been approved for use in progressive MS. The goal in using use of these potent medications is to slow disease progression.

Immunosuppression remains somewhat controversial. Azathioprine, cyclophosphamide, mitoxanthrone, plasmapheresis (plasma exchange), and total lymphoid irradiation all remain as possible treatments for progressive MS. What *can* be said is that the trend of research for progressive MS involves modulating and redirecting the immune system. To date, the methods used have all been nonspecific. The future will involve more specific methods of immunosuppression.

Interferons are proteins made by the body in response to a foreign stimulus (e.g., a virus) and which appear to regulate or modulate the immune system. There are three broad categories of interferons: alpha, beta, and gamma. Gamma interferon appears to stimulate the immune system, worsening symptoms of MS. Beta interferon appears to “calm” the system. Three drugs have now been approved for use by the Food and Drug Administration for the treatment of MS, Betaseron® (beta interferon 1–b), Avonex® (beta interferon 1–a), slightly modified beta interferons, and Rebif® also a beta interferon 1–a, approved for use in the United States in early 2002. In recent studies in relapsing–remitting MS patients, these substances decreased the fluctuations commonly seen and also decreased the number of lesions seen on MRI when compared to placebo.

Copaxone® (glatiramer acetate) is a peptide of four amino acids which somehow attaches to components of the immune system so that the attack on the myelin in relapsing MS is slowed. This daily injection has relatively few side effects and protects the person with relapsing MS in a fashion similar to the interferons. These are the first drugs to be used for the actual demyelinating process, as opposed to symptomatic or inflammatory management and should be instituted as soon as relapsing MS is identified to allow maximal protective effect.

In addition to these general treatments, a variety of therapies is available to treat the specific symptoms that can occur during the course of the disease. The remainder of this chapter is organized around these specific problem areas. Bladder and bowel symptoms and their management are among the most common seen in MS, and are discussed separately in

Chapter 6. By no means do all or even many of these difficulties occur in every individual. Virtually all of them, however, do have management strategies that can be utilized to minimize discomfort and inconvenience.

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 and is required to perform 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, range of motion 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.

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 one minute to allow slow relaxation and to release undesired tension. With the person lying on his/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, the groin, and, after turning from the back to the stomach, stretch the muscles on the front of the thigh.

Range of motion exercises differ from stretching exercises in that the movement about the joint is not held for any specific length of time. Although range of motion 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 range of motion 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 range of motion 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 utilizing a minimum of 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 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.

Zanaflex® (tizanidine) 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. 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.

Neurontin® (gabapentin) is an anti-convulsant that has anti-spasticity properties. It is an excellent adjunctive medication when dosed up to 3600 mg each day at 4–6 hour intervals.

Another drug that is sometimes helpful in relieving spasticity is Dantrium® (dantrolene sodium), which acts directly at the level of the muscle. However, hepatotoxicity limits its use. Spasticity may also be reduced by Valium® (diazepam), which is most often used for the relief of spasms that occur at night since its calming effect also helps to induce sleep. Its strong sedative effect limits its use during the daytime. Klonopin® (clonazepam) is closely related to Valium®; 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 Valium®, it sedates and is therefore best used at night. When using Valium® and Klonopin®, 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 Flexoril® (cyclobenzaprine HCl). 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 period of 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. Tegretol® (carbamazepine) is generally used to control such spasms, although baclofen and Neurontin® 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.

Surgical Management

Occasionally spasms become so severe that no medication is effective. When this occurs, nerves controlling specific muscles of the leg may be deactivated by using a phenol motor point block. This produces decreased tone in the muscles, which may be more comfortable but usually does not increase functional mobility. Botulinum toxin (Botox®) has been approved by the FDA for managing facial spasms. Botulinum toxin causes a temporary blockage within the muscle; it is somewhat easier to control than phenol but may need more repetitive injections. This treatment is practical for small muscle spasms, especially around the eye or face. Severe spasms may be managed by surgical procedures that involve cutting nerves or tendons to decrease the contraction of specific muscles that are producing serious stiffness.

Another approach to the management of severe spasticity involves the use of a pump to deliver baclofen 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 newest 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 faithful use of an exercise program and the appropriate use of drugs when needed, significantly increase the level of function and help avoid the development of more severe problems.

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, while 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. Atarax® and Vistaril® (hydroxyzine) are antihistamines that may settle a minor tremor that has been magnified by stress. Klonopin® (clonazepam) may also decrease a tremor via its sedative effect. The anti-tremor effect must be balanced against the generally unwanted effects of sedation by carefully monitoring the dosage until the desired effect is achieved.

Inderal® (propranolol), 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 Mysoline® (primidone) may alleviate this difficult symptom. Although it is heavily sedating, low doses may be worthwhile. Diamox® (acetazolamide) is a diuretic that has some anti-tremor properties and may be of value in selected patients.

Because a component of spasm is often involved in gross tremors, baclofen 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.

High doses of INH (isoniazide), a drug used primarily for the treatment of tuberculosis, can 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.

Recent studies indicate a reasonable response to the anti-anxiety drug Buspar® (buspirone), which is nonsedating and nonaddictive.

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.

The surgical approach to decreasing tremor via deep brain stimulation and gamma knife ablation deserve exploration but have not yet been investigated. Thus, these procedures cannot be recommended at this time.

BALANCE

Vestibular stimulation involves increasing the amount of stimulation received by the “balance centers” in the brainstem, 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 central nervous system 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 in order 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, 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.

FATIGUE

Fatigue is one of the most common and annoying problems for people with MS. It is difficult for others to understand since it is not a visible symptom. There are many types of fatigue in MS. People with MS can

experience normal fatigue, the fatigue of depression, the fatigue of disuse, and the fatigue of neuromuscular overuse. The term *MS fatigue* refers to a lassitude or overwhelming fatigue that can come at any time of day and without warning. It is a sleepiness that occurs despite rest. Amantadine and Prozac® (fluoxetine) effectively manage this type of fatigue, although the manner in which they work is not yet understood. Stimulants such as Ritalin® (methylphenidate) or adderall may provide relief but they have the unwanted side effect of disrupting sleep. Some people cannot tolerate such medications and adjustment or discontinuance may be necessary. A newer approach involves a medication approved for the treatment of narcolepsy, Provigil® (modafinil). At a dose of 200 mg each day, Provigil® appears to decrease lassitude in many who have failed with previous therapy.

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. The MS Council, with administrative support from the Paralyzed Veterans of America, has developed a comprehensive *Clinical Practice Guideline for Fatigue Management in Multiple Sclerosis* that reflects a multidisciplinary point of view. This guideline may be found on the PVA website (www.pva.org).

AMBULATION

Mobility impairment is frequently associated with MS. It is fitting that the section on ambulation follows those dealing with weakness, spasticity, and tremor since 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. 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. This lightweight brace—an ankle-foot orthosis or AFO—picks up the foot and allows it to follow through in the normal heel-toe manner.

Ankle-foot orthoses 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 everting). 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 “springloaded” device that keeps the front of the foot from dropping.

If the hip muscles are also weak, the leg will swing out in front to allow the foot to clear the ground. In order 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 utilized 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 lightweight 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, 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 general overall health. It is a wholistic 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 range of motion 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

Although MS is generally considered to be a painless disease, over 50 percent of all individuals with MS find pain to be a significant problem.

There is a difference between headaches and head pains. Headaches are common in people with or without MS. They are one of the most common symptoms seen by neurologists in people who do not have MS. Head pains with sharp, stabbing qualities can be associated with the neuralgias of MS and can occur in the distribution of many of the cranial nerves. The most common is *trigeminal neuralgia* or tic douloureux.

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 Tegretol® (carbamazepine). To avoid its primary side effect of sleepiness, the drug is initially given at low doses and slowly increased to the point at which it adequately controls pain. Other drugs that may be used to control trigeminal neuralgia include Dilantin® (phenytoin), whose action is similar to but milder than Tegretol® (carbamazepine), and most commonly used for spasticity. 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 splenopalatine 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.

The predominant type of pain seen in MS is a burning, tooth-achy type of pain that occurs most commonly 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.

Electrical stimulation (TNS or transcutaneous nerve stimulation) applied over the painful area occasionally provides relief. However, it frequently has produced the opposite effect and is therefore not often recommended.

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. Since pain is a symptom that clearly increases in severity when dwelt upon, 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.* Neurontin[®] (gabapentin) and others of the newer anti-convulsant medications appear to decrease neuritic pain. Appropriate dosing is necessary, often requiring more than 2400 mg of gabapentin. This new treatment has improved pain management significantly.

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. Multiple sclerosis 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 (padlike structures that cushion the areas between the vertebrae). This stress may cause slippage of the discs, compressing one or more of the nerves as they leave the spinal cord and resulting in pain in the part of the body innervated by these nerves. Obviously, heavy lifting and inappropriate turning and bending compound the problem. Such movements irritate the spinal nerves, causing the muscles on the side of the spinal column (the paraspinous 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, including Parafon Forte[®], Flexoril[®], and Robaxin[®], 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.

SPEECH DIFFICULTIES

Speech patterns are controlled by many areas of the brain, especially the brainstem. 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 advo-

cated, they are not usually successful for this type of speech problem. Nevertheless, they may be worth trying. For example, oral motor exercises may be utilized 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 paceboard 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. A number of 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 to control its movements. Both may be affected by multiple sclerosis.

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.

A weakening of coordination and strength of the eye muscles sometimes produces double vision, which can be treated acutely with steroids. Over time, 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 various varieties of nystagmus, which is usually more of a nuisance than anything else. Klonopin® (clonazepam) and related drugs occasionally decrease 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, and double vision increases, with fatigue, increases in temperature and stress, and infection.

DIZZINESS AND VERTIGO

In MS, vertigo usually results from an irritation of brainstem 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 Benadryl® (diphenhydramine), Antivert® (meclizine), and Dramamine® (dimenhydrinate), 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 Valium® (diazepam), Klonopin® (clonazepam), and Serax® (oxazepam) 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 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 brainstem 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. Since 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.

While 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 since 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/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/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.

ADDITIONAL READINGS

- Halper, J. (2001). *Advanced Concepts in Multiple Sclerosis Nursing Care*. New York: Demos.
- Schapiro, R.T. (1998). *Symptom Management in Multiple Sclerosis*, 2nd ed. New York: Demos.
- van den Noort, S. Holland, N.J. (1999). *Multiple Sclerosis in Clinical Practice*. New York: Demos.

CHAPTER 4

Management of Elimination Dysfunction

Marie A. Namey, RN, MSN

Approximately 80 percent of patients with multiple sclerosis (MS) experience significant bladder dysfunction at some point in the course of disease. Reports of bowel problems range from 50 percent to 68 percent 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.

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 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 due to 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:

1. Maintain renal function.
2. Keep patient dry.
3. Establish normal voiding patterns.

4. Reduce symptoms and improve quality of life.
5. Motivate patient to adhere to treatment.

Bowel management issues are also of concern for the individual with MS. Although constipation is common, involuntary bowel 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 upon 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 (Figure 4-1).

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 (Figure 4-2). 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.

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

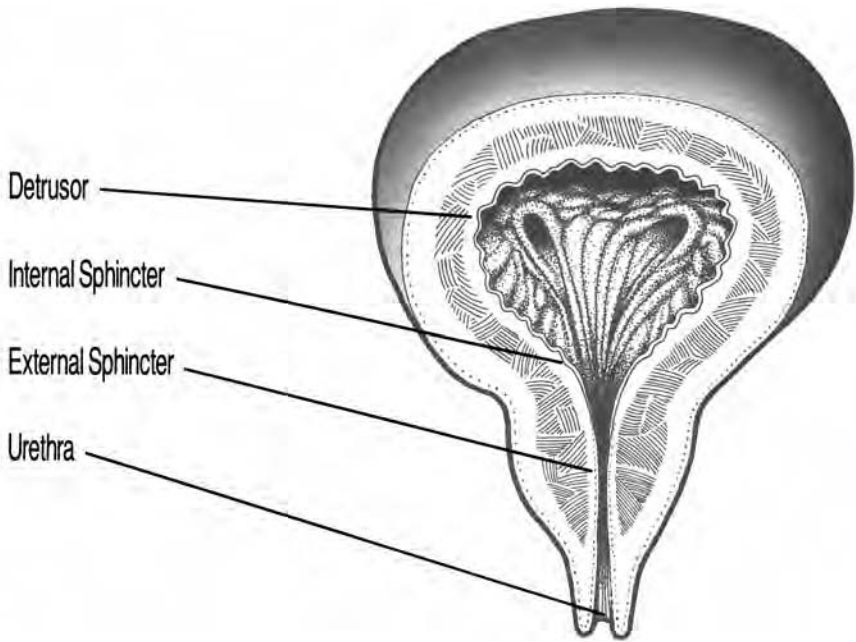


FIGURE 4-1. The bladder.

four to six times during a twenty-four hour period (depending on fluid intake, amount, and type). Generally, our bodies produce approximately 1 ml/minute of urine. Although urinary tract infections are more common in women than men, more than one urinary tract infection per year is considered abnormal.

For voiding to occur, the valve-like 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. Interruption of the spinal cord pathways may result in excessive detrusor contractions, involuntary sphincter relaxation or contraction, or detrusor areflexia with urinary retention. Bladder dys-

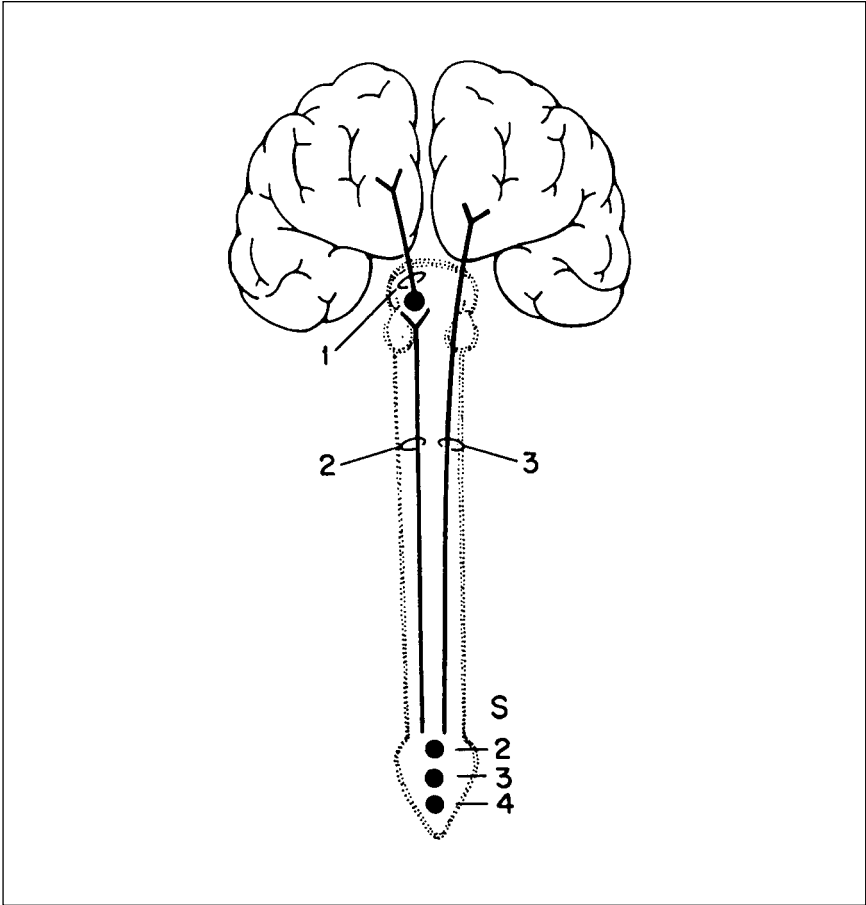


FIGURE 4-2. Supraspinal innervation of the bladder and urethra. 1. Frontal cortex to pontine-mesencephalic reticular formation. 2. Pontine-mesencephalic reticular formation to parasympathetic nucleus (reticulospinal tract). 3. Frontal cortex to pudendal nucleus (corticospinal tract).

function is referred to as neurogenic bladder and may produce a variety of symptoms:

- *Urinary urgency:* A strong sensation to urinate that cannot be controlled. Urination cannot be postponed until convenient.
- *Urinary frequency:* Having the need to urinate more often than every two to three 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.
- ⊃ *Urinary tract infections (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. Urinary tract infections can result in a temporary worsening of MS symptoms, or maybe 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 urinary tract infection.

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, and
- ⊃ incoordination of the detrusor and sphincter activity (detrusor/dyssynergia).

Simply stated, bladder dysfunction in MS can result in:

- ⊃ failure to store,
- ⊃ failure to empty, or
- ⊃ combined failure to store/failure to empty.

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 for a few days for an accurate report (see Appendixes C and D).

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

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?

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 the post-void residual urine. (It is important to note that a urinary tract infection can cause bladder symptoms and change in bladder habits.) If the urinalysis and urine culture are suggestive of a urinary tract infection (positive + nitrites; bacteria >100,000 colonies of organism), appropriate antibiotic therapy should be prescribed.

Following the patient's spontaneous void, a measurement of a post-void residual (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 post-void residual volume of < 60 ml suggest failure to store syndrome. Often a trial of anticholinergic medications is effective treatment. Reports of bladder symptoms and a post-void residual volume of < 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. Table 4-1 may be of assistance.

Commonly patients experience combined bladder dysfunction and an initial bladder assessment does not provide complete information.

TABLE 4-1.

Diagnosis	Symptoms	PVR	Interventions
Urinary tract infection (UTI)	Urgency Dysuria Frequency Hesitancy Incontinence Nocturia Change in usual pattern of voiding	Varying amounts	Treat with appropriate antibiotics
Failure to store	Urgency Frequency Incontinence Nocturia	< 60 ml	Anticholinergic medication Bladder training Protective pads
Failure to empty	Urgency Frequency Hesitancy Nocturia Incontinence Incomplete emptying UTI	> 100 ml	IC
Combined dysfunction*	Urgency Frequency Hesitancy Nocturia Incontinence Incomplete emptying UTI	Inconsistent PVR amounts	Anticholinergic medication and IC

*Can only truly be diagnosed by urodynamic testing.

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 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 liter of fluid 2 hours prior to the evaluation. The patient is then instructed to void into a commode-like 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 (Figure 4-3). The maximum or peak flow is greater than 12 ml per second and the average flow is greater than 8 ml per second. 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 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 cystometrogram, electromyography (EMG) of the striated sphincter, and pressure flow analysis.

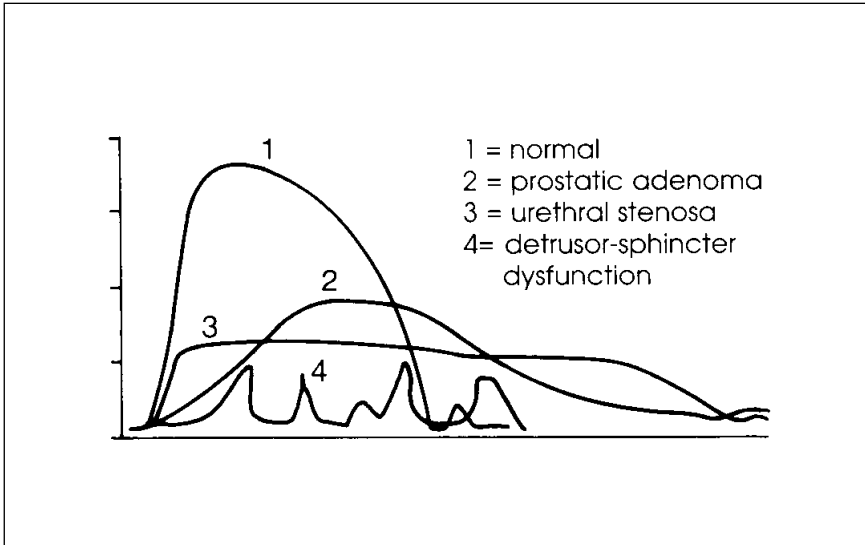


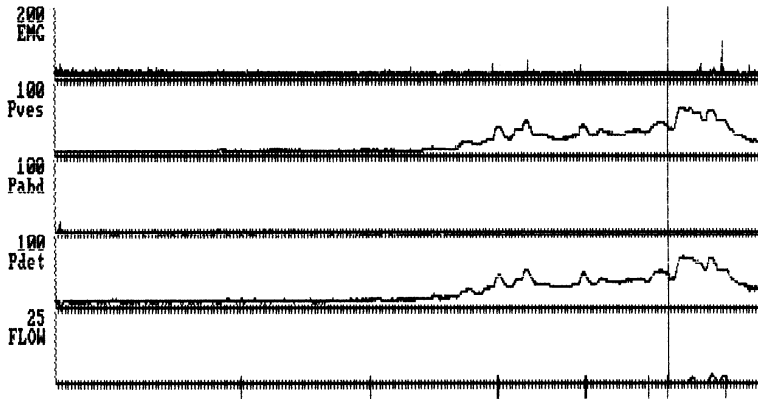
FIGURE 4-3. Uroflowmetry. 1. Normal curve. 2. Significantly decreased maximum flow-rate, prolonged flow-increase time, beginning plateau formation in cases of prostatic adenoma. 3. Severely reduced maximum flow rate and plateau formation. 4. Splash-like voiding in cases of reflex bladder detrusor-sphincter dyssynergia.

Commonly, sterile water or saline solution is used to fill the bladder through a catheter. Either a single multi-lumen catheter or two catheters are placed in the bladder. One tube measures intravesicle or total bladder pressure (VES). 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, VES (the sum of pressure placed against the bladder from the detrusor muscle and abdominal muscle), and PDET. The detrusor pressure (PDET) represents the intravesicle 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.

Urodynamic testing can yield the following type of printout:



Depending on the patient's symptoms and the initial nursing diagnosis, a variety of interventions can be recommended to the patient for improved bladder function. Common interventions can include:

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 1–1/2 to 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 these 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, diaper-like 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 a variety of 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. Common anticholinergic medications used specifically for multiple sclerosis include oxybutynin (Ditropan®), tolterodine tartrate (Detrol), hyoscyamine sulfate (Levsinex®), and propantheline bromide (Probanthine®). Tricyclic antidepressant agents (i.e., Tofranil®) can be beneficial in decreasing urgency, frequency, and incontinence.

Recently, long acting and sustained released formulations of Ditropan® and Detrol® have been developed.

Desmopressin acetate (DDAVP), an antidiuretic hormone analog, diminishes urine production at night and can reduce or eliminate episodes of involuntary bladder or nocturia.

- ⇒ 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 urinary tract infection and structural damage and other distressing bladder symptoms. The use of intermittent self-catheterization was first reported in 1972 by Lapidès as an effective therapy for individuals who experience overflow incontinence, sphincter dyssynergia, and urinary retention. This technique of catheterization is preferable to an indwelling catheter due to a lower incidence of symptomatic urinary tract infections, bladder stone formation, and social consequences. The technique of intermittent catheterization 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. Teaching guides are included in Appendixes A and B.

- An indwelling catheter may be needed for either short-term treatment or long-term use. An indwelling catheter 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 intermittent catheterization. The use of an indwelling catheter would also be suggested for an individual with chronic urinary retention that results in frequent urinary tract infections when he/she cannot perform intermittent catheterization. Individuals who have developed pressure sores of the sacral area may utilize 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 urinary tract infections. Management of indwelling catheters varies, but the usual practice is to change the catheter a minimum of 30 thirty days or prn. If the patient has a symptomatic urinary tract infection, 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 are sometimes an alternative to long-term urethral catheter use for male patients. They are also used in women who have developed severe urethral irritation secondary to an indwelling Foley catheter. The use of suprapubic catheters can create problems; consultation with a urologist is strongly 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 laporoscopic 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.

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” as a person takes a deep breath and attempts to exhale against a closed glottis, while at the same time tightening the abdominal muscles. In order 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 percent (Chia et al., 1995) to 68 percent (Hinds et al., 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 abdominal pressure 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 due to 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 upon 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:

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: (1) fluid intake of 1.5–2 liters of fluid per day; (2) high fiber diet (minimum 15 grams of fiber per day); (3) 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 non-pharmacologic interventions. Educating the patient about bowel function and the importance of adequate fluid, fiber, and exercise are important. Education about foods that are high in fiber is a first step in intervention. Surprisingly, many patients do not know what foods contain high fiber content. The best sources of fiber are cereals, fruits and vegetables (examples below).

HIGH FIBER

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. In order to be effective, bulk formers should be taken with 1 to 2 glasses of liquid. Action usually occurs within 12 to 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 to 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 utilized to provide a chemical irritant to the bowel, which increases bowel activity and aids in the passage of stool. A number of oral stimulants are available over-the-counter. Bowel movements are induced gently, usually overnight or within 8 to 12 hours. Common oral stimulants include Pericolace®, Modane®, Perdiem Granules®, Dialase®, 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 and miralax to promote osmotic catharsis 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 some time. 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.

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 due to 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 utilize 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.

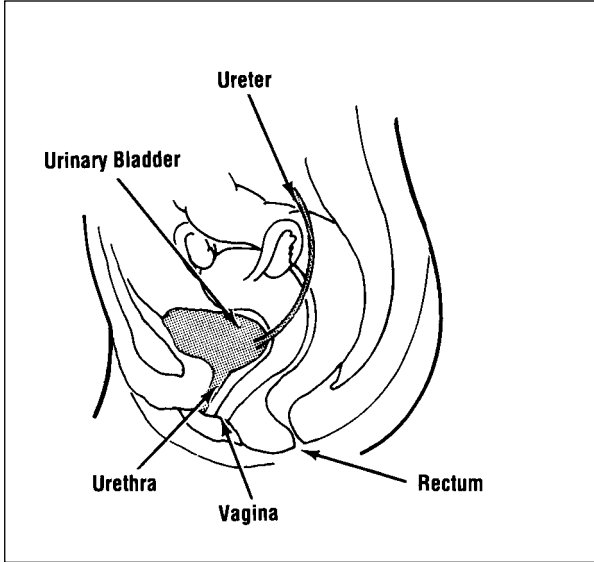
Managing bowel symptoms with an MS client is often the result of trial and error. Generally, success does not come quickly, but rather over a period of weeks or months (remember, haste does not make waste!). It is important to remember that the goal of any bowel management program is for a patient to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

Appendixes

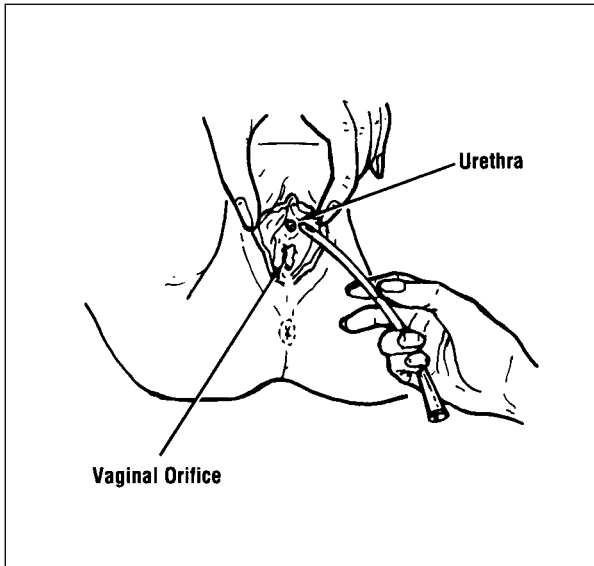
*A. Steps to Clean Intermittent Catheterization—Females**

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 and 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 inches of the catheter. (Lubricant may be optional for women.)

*Illustrations courtesy of Mentor Urology, Inc.



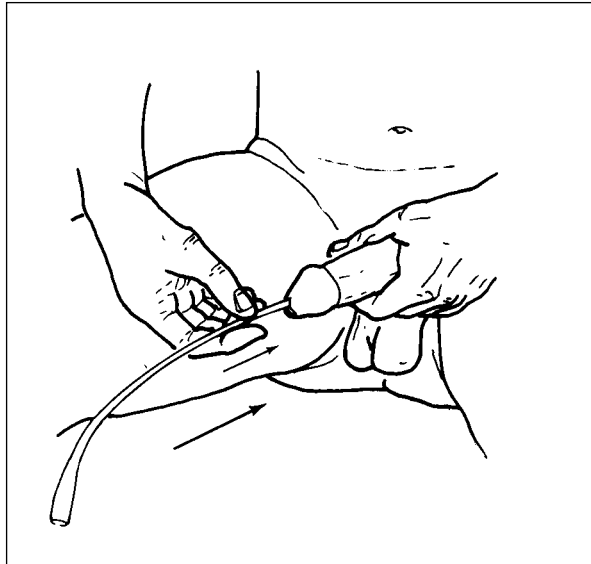
5. Slowly and gently insert the catheter into the urethra until the urine begins to flow (approximately 1–1.5 inches). Then insert the catheter about 1 inch farther and hold it there until urine stops flowing.



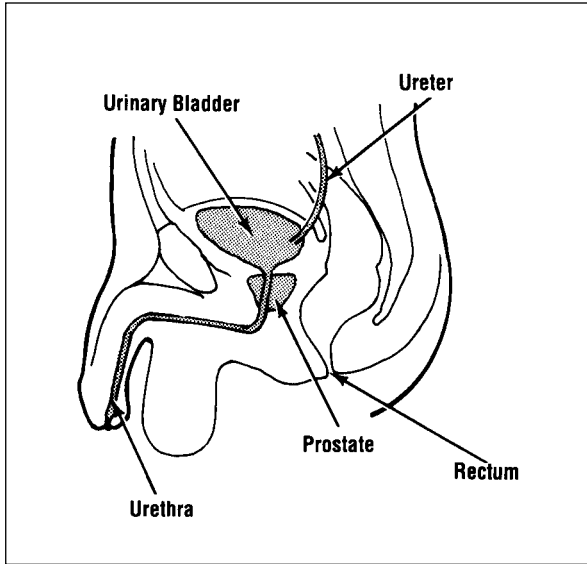
6. When urine stops, slowly begin to withdraw the catheter. It is recommended that you slightly rotate the catheter as you withdraw and stop each time more urine drains out.
7. Check the color, odor, and clarity of the urine to be aware of any changes that you may need to report to your doctor or nurse.
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.

B. 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 and 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 inches 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



**Illustration courtesy of Mentor Urology, Inc.



flow (approximately 6–8 inches). Then insert the catheter about 1 inch farther and hold it there until urine stops flowing.

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.

REFERENCES

- Blaivas, J. (1980). Management of bladder dysfunction in multiple sclerosis. *Neurology*, 30 (7), 12–18.
- Burks, J., Johnson, K., (2000). *Multiple Sclerosis: Diagnosis, Medical Management, and Rehabilitation*. (2000), New York: Demos, p. 453–460.
- Caruana, B., Wald, A., Hinds, J., Eidelman, B. (1991). Anorectal sensory and motor function in neurogenic fecal incontinence: comparison between multiple sclerosis and diabetes mellitus. *Gastroenterology*, 100 (2), 465–470.
- Catanzaro, M., O'Shaughnessy, E., Clowers, O., Brooks, G. (1982). Urinary bladder dysfunction as a remedial disability in multiple sclerosis: A sociologic perspective. *Archives of Physical Medicine & Rehabilitation*, 63, 472–473.
- Chia, Y., Fowler, C., Kamm, M., et al., (1995) Prevalence of bowel dysfunction in patients with with multiple sclerosis and bladder dysfunction. *J Neurology*, 242 (2), 105–108.
- Doughty, O. (1991). *Urinary and Fecal Incontinence: Nursing Management*. St. Louis: Mosby Yearbook.
- Edlich, R., Westwater, J., Lombardi, S., Watson, L., Howards, S. (1990). Multiple sclerosis and asymptomatic urinary tract infections. *Journal of Emergency Medicine*, 8, 25–28.
- Guyton, A. (1986). *Textbook of Medical Physiology*. Philadelphia: W.B. Saunders.
- Henderson, J. (1989). Intermittent clean self-catheterization in clients with neurogenic bladder resulting from multiple sclerosis. *Journal of Neuroscience Nursing*, 21, 160–164.
- Hinds, J., Bach, M., Wald, A. (1989). Colonic and anorectal dysfunction associated with multiple sclerosis. *American Journal of Gastroenterology*, 84 (6), 587–595.
- Hinds, J., Eidelman, B., Wald, A. (1990). Prevalence of bowel dysfunction in multiple sclerosis. *Gastroenterology*, 98, 1538–1542.
- Holland, N. (1982). Intermittent catheterization: Application in multiple sclerosis. *AUAA Journal*, 2 (3), 5–8.
- Holland, N., Wiesel-Levison, P., Madonna, M. (1985). Rehabilitation research: Pathophysiology and management of neurogenic bladder in multiple sclerosis. *Rehabilitation Nursing*, 10 (4), 31–33.
- Kelly, B., Mahon, S. (1988). Nursing care of the patient with multiple sclerosis. *Rehabilitation Nursing*, 13 (5), 238–242.
- Lapides, J., Diokno, A., Gould, F., Lowe, B. (1975). Further observations on self-catheterization. *American Association of Genitourinary Surgeons*, 67, 15–17.
- Lapides, J., Diokno, A., Silber, S., Lowe, B. (1972). Clean intermittent self catheterization in the treatment of urinary tract disease. *Journal of Urology*, 107, 458–461.
- McCourt, A. (1993). *The Specialty Practice of Rehabilitation Nursing: A Core Curriculum*, 3rd edition. Skokie, IL: Rehabilitation Nursing Foundation.
- Mohler, J., Cowen, D., Flanigan, R. (1987). Suppression and treatment of urinary tract infections in patients with an intermittently catheterized neurogenic bladder. *Journal of Urology* 1, 336–40.
- Moore, K. (1991). Intermittent catheterization: Sterile or clean? *Rehabilitation Nursing*, 16 (1), 15–18.

- Nancy, M., Halper, J. (2000). *Bowel Disturbance* in Burks, Johnson (Eds) Multiple Sclerosis. Medical Management and Rehabilitation. New York. Demos
- Namey, M., Morgante, L., Clesson, I., et al. (1994). Developing proposals for nursing research. *Journal of Neurologic Rehabilitation* 8 (3) 13–18.
- Shapiro, R. (1994). *Symptom Management in Multiple Sclerosis*, 2nd edition. New York: Demos.
- Scheinberg, L., Holland, N. (1987). *Multiple Sclerosis: A Guide for Patients and Their Families*. New York: Raven Press.
- Schoenberg, H. (1983). *Bladder Dysfunction in Multiple Sclerosis: Neurology Clinics*. Philadelphia: W.B. Saunders.
- Urinary Incontinence Guideline Panel. (1992). Urinary incontinence in adults: clinical practice guideline. HCPR publication No. 92–0038. Rockville, Maryland: Agency for Health Care Policy and Research, Public Health Service, U.S. Department of Health and Human Services.
- Urinary Dysfunction and Multiple Sclerosis (1999), Clinical Practice Guidelines, Multiple Sclerosis Council for Clinical Practice Guidelines. Paralyzed Veterans of America.

CHAPTER 5

Prevention of Complications in the Severely Disabled

Colleen Harris, RN, MN

As discussed in Chapter 1, a small percentage of people with multiple sclerosis (MS) become severely disabled and dependent on others for most or all activities of daily living. Caregivers are faced with many ongoing tasks as well as the special needs of this segment of the MS population, which include adequate nutrition and hydration, problems eating and swallowing, severe spasticity, and prevention of skin breakdown. In caring for the severely disabled, the nurse is both a caregiver and an educator of the patient, family, and other caregivers.

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).

Recommended dietary allowances (RDAs) have been developed by the U.S. Department of Agriculture (USDA) and are shown in Figure 5-1 (Welsh, 1992). Table 5-1 summarizes the USDA's latest guide to daily food choices. Major changes include increased servings in the bread and cereal group and the vegetable and fruit groups, as well as limiting fat intake.

The role of nutritional factors in the course of MS has been of considerable interest for both patients and healthcare professionals during the

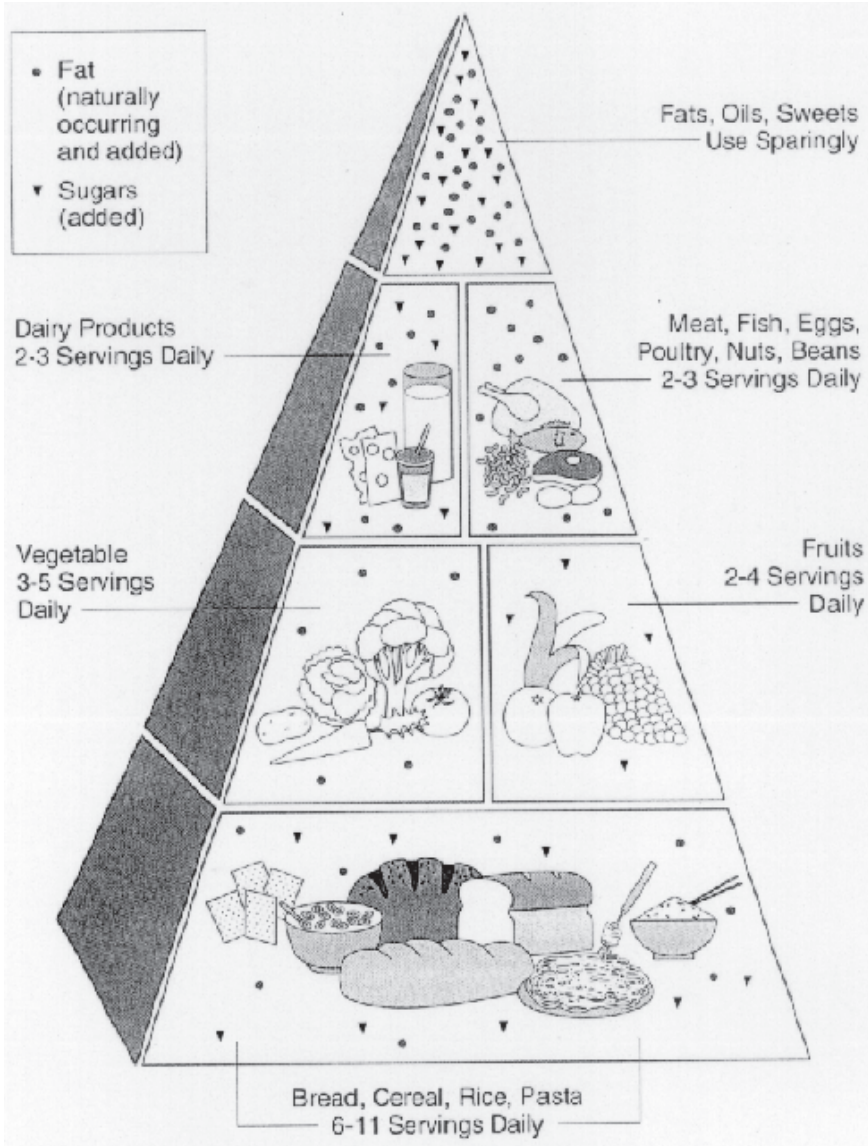


FIGURE 5-1. A guide to daily food choices.

Source: U.S. Department of Agriculture/U.S. Department of Health and Human Services (1992).

past 50 years (Wozniak-Wowk, 1993). A number of diets have received a great deal of attention, including the Swank diet and the gluten-free and other elimination diets, as has the use of supplements such as vitamins,

TABLE 5-1. The Guide to Daily Food Choices—A Summary

Food Group	Servings	Major Contributions	Foods and Serving Sizes¹
Bread, cereals, rice, pasta	6–11	Starch Thiamine Riboflavin ² Iron Niacin Folate Magnesium ³ Fiber ³ Zinc	1 slice of bread 1 oz ready-to-eat cereal $\frac{1}{2}$ – $\frac{3}{4}$ cup cooked cereal, rice, pasta
Vegetables	3–5	Vitamin A Vitamin C Folate Magnesium Fiber	$\frac{1}{2}$ cup raw or cooked vegetables 1 cup raw leafy vegetables
Fruits	2–4	Vitamin C Fiber	$\frac{1}{4}$ cup dried fruit $\frac{1}{2}$ cup cooked fruit $\frac{3}{4}$ cup juice 1 whole piece of fruit 1 melon wedge
Milk, yogurt, cheese	2 (adults ⁴) 3 (children, teens, young adults, pregnant or lactating women)	Calcium Riboflavin Protein Potassium Zinc	1 cup milk $1\frac{1}{2}$ oz cheese 2 oz processed cheese 1 cup yogurt 2 cups collage cheese 1 cup custard/pudding $1\frac{1}{2}$ cups ice cream
Meat, poultry, fish, dry beans, eggs, nuts	2–3	Protein Niacin Iron Vitamin B6 Zinc Thiamine Vitamin B12 ⁵	2–3 oz cooked meat, poultry, fish 1– $1\frac{1}{2}$ cups cooked dry beans 4 T peanut butter 2 eggs $\frac{1}{2}$ –1 cup nuts
Fats, oils, sweets	Foods from this group should not replace any from the other groups. Amounts consumed should be determined by individual energy needs.		

Source: Adapted from the U.S. Department of Agriculture, revised edition of former *Basic Four Food Groups Guide*, 1994.

¹May be reduced for child servings.

²If enriched.

³Whole grains especially.

⁴25 years of age.

⁵Only in animal food choices.

food additives, and oil of evening primrose. In addition there are many testimonials, advertisements, and anecdotal recommendations for nutritional supplements for MS. There is, however, no conclusive scientific evidence that any nutritional therapy affects the disease course (Kosich, 1998). To date, no dietary regimens have been subjected to scientifically controlled trials that have demonstrated them to be of significant therapeutic merit for MS (Wozniak-Wowk, 1993).

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. Lack of adherence to accepted regimens places the patient in a vulnerable state for inadequate nutrition and the potential development of secondary complications (Phair & Holland, 1993).

The nurse is in an excellent position to assist patients and families to recognize their nutritional needs and to teach ways to incorporate these needs 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. The underlying dysfunctions and associated symptoms in MS that impact nutrition are numerous and variable (Phair & Holland, 1993). Tremor, weakness, and paralysis may interfere with the patient's ability to eat or drink. Dysphagia, a problem frequently seen in MS, can not only 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 due to the energy required to prepare meals, cut food, chew, and swallow large portions. Depression may also contribute to poor appetite and dietary intake (Samuel & Cavello, 1999).

Whether a patient's premorbid physical characteristics are a result of reduced activity, excess body weight interferes with mobility and requires dietary intervention (Phair & Holland, 1993). The patient's weight should be monitored to determine early changes so that modifications in intake and activity can be recommended promptly. 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 require only 1,200 calories a day, while 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 positioning the patient to avoid choking. Referrals to home health programs to

relieve the caregiver should be explored, as should 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 may promote the use and fitting of these special aids (Phair & Holland, 1993). Another helpful technique is to use liquid nutritional supplements both for energy conservation and to ensure an adequate intake of basic nutrients. 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 be taken in order 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 8 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.

Nursing outcomes related to nutrition and hydration should include:

- ↳ Maintenance of optimum body weight within \pm 5 pounds
- ↳ Maintenance of fluid intake of 1500–2000 ml/24 hours
- ↳ Daily intake of basic nutritional requirements
- ↳ Utilization of appropriate assistive devices for eating (Phair & Holland, 1993).

DYSPHAGIA

Dysphagia in MS patients with and without swallowing complaints has been found to vary from 10–15 percent (Poser, 1979) to 55 percent (Daly, Code, & Anderson, 1962). In practice, it is believed that dysphagia occurs frequently, yet specific swallowing therapies have not been validated in MS

(Sorensen et al., 1993). Research has identified abnormal swallowing as being common in MS and often associated with disordered brainstem 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 every 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 (Glenn, 1995). The purpose of the swallow evaluation is to determine whether the cricopharyngeal sphincter is not opening and the epiglottis is not protecting the airway (Glenn, 1995). The modified barium swallow with videofluoroscopy allows viewing of the oral cavity, laryngopharynx, and esophagus while the patient swallows barium of various consistencies (Glenn, 1995). Videotaping of the study allows clinicians to review the procedure repeatedly and with slow-motion analysis (Glenn, 1995). An abnormal study may indicate alternatives to normal feeding methods such as positioning the head and chin, changing the consistency of food and fluid (chopping or blenderizing foods or adding thickening agents), and planning rest periods prior to mealtime to reduce fatigue (Phair & Holland, 1993). A study that reveals swallowing to be unsafe may require a surgically placed feeding tube. The most commonly used feeding tube in MS is the percutaneous endoscopic gastroscopy (PEG), which can be inserted under local anesthesia and results in fewer complications than surgical procedures (Glenn, 1995). 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, this is complicated by the variability of the disease course. Dynamic interventions are required in response to the changing needs of patients.

PULMONARY COMPLICATIONS

Respiratory muscle weakness mainly of 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 et al., 2000). Symptom management protocols should address the signs and symptoms of hypoventilation such as dyspnea, orthopnea, weak cough, hypophonia, and fatigue (Lehman & Picone, 2001). 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. 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 MS patient to overcome. Nursing outcomes should be geared to patient and family education and emphasize the following:

- Good hand washing of patient and caregiver to lower the risk of infection and avoiding other individuals with respiratory infections
- Semi-Fowlers position while in bed to assist with breathing and drainage of secretions
- Frequent ambulating from bed to wheel chair and frequent position changes while in bed with the use of assistive devices such as side rails
- For chest congestion performing deep breathing and coughing exercises with assistance of a caregiver if necessary
- Being alert to swallowing difficulties to avoid aspiration pneumonia

The influenza vaccine is strongly recommended for individuals with expiratory muscle weakness because of the association of pneumonia with many of the flu viruses (Paty & Ebers, 1998). Immunizations in MS have been linked to an increase in disease activity but recent 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 (De Keyser et al., 1998; Confavreux et al, 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, 1998). 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, 1998).

SPASTICITY

Spasticity or muscle hypertonia occurs as a result of abnormal spinal and brainstem reflexes and is a common and treatable symptom of MS. Spasticity is defined as a velocity-dependent increased resistance of muscle to stretch due to activation of tonic stretch reflexes (Lance, 1980). Lesions in several cerebrospinal or propriospinal fiber systems may contribute to this symptom (Stein et al., 1987). Spasticity occurs most frequently in the muscles that are responsible for maintaining an upright posture (see Chapter 3). Its severity varies depending on the size and location of plaques (Chan et al., 1993). The measurement of spasticity is subjective via patient report or objective using the Ashworth scale (Table 5-2) and the spasticity scale (Table 5-3) (Chan et al., 1993).

TABLE 5-2. Ashworth Scale

Score	Criteria
1	No increase in tone
2	Slight increase in tone, giving a "catch" when the affected part(s) is moved in flexion or extension
3	More marked increase in tone but affected part(s) easily flexed
4	Considerable increase in tone—passive movement difficult
5	Affected part(s) rigid in flexion or extension

TABLE 5-3. 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 but less than 10 spontaneous spasms per hour
4	More than 10 spontaneous spasms per hour

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

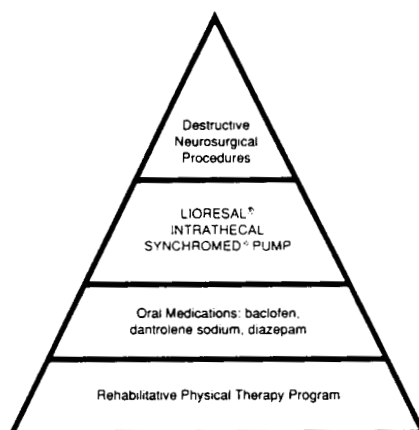


FIGURE 5-2. Pyramid approach to the management of spasticity.

pharmacologic agents such as baclofen, diazepam (Valium®), dantrolene sodium (Dantrium®), and tizanidine (Zanaflex®) (Schapiro & Schneider, 1999, pp. 44–45). Baclofen is the most commonly used antispasticity drug and doses range from 5 mg to 180 mg per day (Coyle & Halper, 2001, p.46). Diazepam (Valium®) and clonazepam (Klonopin®), both members of 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 (see Chapter 3). Dantrolene (Dantrium®) is used infrequently and patients taking this medication must be monitored closely due to the side effects of hepatotoxicity, nausea, malaise, dizziness, and weakness (Coyle & Halper, 2001). 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 (see Chapter 3). 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, using them in combination may be more effective than either one alone in treating severe spasticity (Coyle & Halper, 2001). 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, 2001). Some patients with severe spasticity may benefit with the injection of botulinum toxin (Botox®) directly into a muscle, which can offer relief of spasticity to specific large muscle groups for up to 3 months (see Chapter 3).

The use of 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 programma-



FIGURE 5-3. The SynchroMed® Infusion Pump from Medtronic, Inc., is implanted under the skin in the patient's abdomen or chest. A drug, placed in a reservoir inside the pump, is delivered to its destination in the body through a small-diameter catheter inserted into a blood vessel or the spinal space and connected to the pump.

ble pump (Penn, 1992) (Figure 5-3). 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 (i.e., activity level; 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). 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 steroid use (Halper & Murray, 1999). 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). Severely disabled individuals should be assisted in passive exercises that can promote bone rebuilding and careful attention should be taken to prevent falls. A primary care physician may initiate hormone replacement therapy for post-menopausal women after careful evaluation of risk factors. Treatment and prevention also include the dietary intake of calcium-rich foods and at least 1000 mg of calcium daily for premenopausal women and men at risk, and 1200–1500 mg for post-menopausal women. For patients who have abnormal mineral density studies the use of alendronate sodium (Fosamax[®]) or etidronate disodium (Didrocal[®]) may be indicated (Kalb, 2000). Severely disabled MS patients have been shown to have a high prevalence of vitamin D deficiency from 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

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 (Phair & Holland, 1993). The goal of

TABLE 5-4

BRADEN SCALE FOR PREDICTING PRESSURE SORE RISK		
PATIENT'S NAME _____		EVALUATOR'S NAME _____
SENSORY PERCEPTION Ability to respond meaningfully to pressure-related discomfort	1. Completely limited: Unresponsive (does not moan, flinch, or grasp) to painful stimuli, due to diminished level of consciousness or sedation or limited ability to feel pain over most of body surface.	2. Very limited: Responds only to painful stimuli. Cannot communicate discomfort except by moaning or restlessness or has a sensory impairment that limits the ability to feel pain or discomfort over half of body.
MOISTURE Degree to which skin is exposed to moisture	1. Constantly moist: Skin is kept moist almost constantly by perspiration, urine, etc. Dampness is detected every time client is moved or turned.	2. Moist: Skin is often but not always moist. Linen must be changed at least once a shift.
ACTIVITY Degree of physical activity	1. Bedfast: Confined to bed.	2. Chairfast: Ability to walk severely limited or nonexistent. Cannot bear own weight and/or must be assisted into wheelchair.
MOBILITY Ability to change and control body position	1. Completely immobile: Does not make even slight changes in body or extremity position without assistance.	2. Very limited: Makes occasional slight changes in body or extremity position but unable to make frequent or significant changes independently.
NUTRITION Usual food intake pattern	1. Very poor: Never eats a complete meal. Rarely eats more than 1/3 of any food offered. Eats 2 servings or less of protein (meat or dairy products) per day. Takes fluids poorly. Does not take a liquid dietary supplement or is NPO and/or maintained on clear liquids or IV for more than 5 days.	2. Probably inadequate: Rarely eats a complete meal and generally eats only about 1/2 of any food offered. Protein intake includes only 3 servings of meat or dairy products per day. Occasionally will take a dietary supplement or receives less than optimum amount of liquid diet or tube feeding.
FRICTION AND SHEAR	1. Problem: Requires moderate to maximum assistance in moving. Complete lifting without sliding against sheets is impossible. Frequently slides down in bed or chair, requiring frequent repositioning with maximum assistance. Spasticity, contractures, or agitation leads to almost constant friction.	2. Potential problem: Moves feebly or requires minimum assistance. During a move skin probably slides to some extent against sheets, chair, restraints, or other devices. Maintains relatively good position in chair or bed most of the time but occasionally slides down.

NPO, nothing by mouth; IV, intravenously; TPN, total parenteral nutrition.
 Source: Braden, B. Bergstrom, N. (1988). Reprinted with permission.

		DATE OF ASSESSMENT			
<p>3. Slightly limited: Responds to verbal commands but cannot always communicate discomfort or need to be turned <i>or</i> has some sensory impairment that limits ability to feel pain or discomfort in 1 or 2 extremities.</p>	<p>4. No impairment: Responds to verbal commands. Has no sensory deficit that would limit ability to feel or voice pain or discomfort.</p>				
<p>3. Occasionally moist: Skin is occasionally moist, requiring an extra linen change approximately once a day.</p>	<p>4. Rarely moist: Skin is usually dry; linen requires changing only at routine intervals.</p>				
<p>3. Walks occasionally: Walks occasionally during day but for very short distances, with or without assistance. Spends majority of each shift in bed or chair.</p>	<p>4. Walks frequently: Walks outside the room at least twice a day and inside room at least once every 2 hours during waking hours.</p>				
<p>3. Slightly limited: Makes frequent though slight changes in body or extremity position independently.</p>	<p>4. No limitations: Makes major and frequent changes without assistance.</p>				
<p>3. Adequate: Eats over 1/2 of most meals. Eats a total of 4 servings of protein (meat, dairy products) each day. Occasionally will refuse a meal but will usually take a supplement if offered <i>or</i> is on a tube feeding or TPN regimen, which probably meets most of nutritional needs.</p>	<p>4. Excellent: Eats most of every meal. Never refuses a meal. Usually eats a total of 4 or more servings of meat and dairy products. Occasionally eats between meals. Does not require supplementation.</p>				
<p>3. No apparent problem: Moves in bed and in chair independently and has sufficient muscle strength to lift up completely during move. Maintains good position in bed or chair at all times.</p>					
TOTAL SCORE					

risk assessment is to identify patients at risk of breakdown. 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 to 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, 1995). The Braden scale (Table 5-4) consists of six factors: sensory perception, moisture, activity, mobility, nutrition, and friction and shear. The subscales are rated 1 to 4. A score of 4 to 23 is possible, with 16 or below being considered at risk (LaMantia, 1995).

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 (Phair & Holland, 1993). 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 (Kalb, 2000).

Prevention is 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 (LaMantia, 1995). Additionally, reduction of spasticity is 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 (Phair & Holland, 1993). Short-term outcomes should focus on compliance and preventative treatments that involve patient and family education, professional activities, and prompt treatment. These should include:

- Identification of predisposing factors
- Patient and family demonstration of activities to relieve ongoing pressure (wheelchair push-ups, change of position in wheelchair, transfers to other seats)

- ⊃ Use of appropriate seating cushions or mattress adaptations to relieve pressure
- ⊃ 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.)
- ⊃ 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 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 healthcare system (LaMantia, 1995).

REFERENCES

- Chan, A., Hugos, G., Morrison, S., et al. (1993). Balance and spasticity; what we know and what we believe. *Journal of Neurologic Rehabilitation*, 7, 119–130.
- Confavreux, C., Suissa, S., Sadler, P., Bourdes, V., Vukusic, S. (2001) Vaccinations and the risk of relapse in multiple sclerosis. *New England Journal of Medicine*, 344 (5), 319–325.
- Coyle, P.K. & Halper J. (2001). Meeting the challenge of progressive multiple sclerosis. New York: Demos.
- Cosman, F. Komar, L., Ferrer, G., Herbert, J., Formica, C., Shen, V., Lindsay, R. (1999). Fracture history and bone loss in patients with MS. *Neurology*, 53 (2), 1161–1165.
- Daly, D., Code, C., Anderson H. (1962). Disturbances of swallowing and esophageal motility in patients with multiple sclerosis. *Neurology*, 12, 250–256.
- De Keyser, J., Zwanikken C., Boon, M. (1998). Effects of influenza vaccination and influenza illness on exacerbations in multiple sclerosis. *Journal of the Neurological Sciences*. 159 (1), 51–53.
- Glenn, N.H. (1995). Eating and swallowing. In Hoeman, S.P. (ed.). *Rehabilitation Nursing, Process and Application*. St. Louis: Mosby.
- Gosselink, R., Kovacs, L., Ketalae, P., Carton, H., Decramer, M. (2000). Respiratory muscle weakness and respiratory muscle training in severely disabled multiple sclerosis patients. *Archives of Physical Medicine and Rehabilitation*. 81 (6), 747–751.
- Halper, J., Murray T.J. (1999). Primary care needs of multiple sclerosis patients. In van den Noort, S. Holland, N. *Multiple Sclerosis in Clinical Practice* (pp. 115–116). New York: Demos.
- Kalb, R.C. (2000). Multiple sclerosis: The questions you have—the answers you need. New York: Demos.

- Katz, R.T. (1988). Management of spasticity. *American Journal of Physical Medicine and Rehabilitation*, 67 (9), 108–116.
- Kosich, D. (1998). Diet and nutrition. In Schapiro, R.T. *Symptom Management in Multiple Sclerosis*, 3rd ed. New York: Demos.
- LaMantia, J.G. (1995). Skin integrity. In Hoeman, S.P. (ed.). *Rehabilitation Nursing, Process and Application*. St. Louis: Mosby, 273–306.
- Lance, J.W. (1980). Symposia synopsis. In Feldman, R.G. Young, R.R. Koella, W. P. (eds.) *Spasticity: Disordered Motor Control* (pp. 485–495). Chicago: Year Book.
- Lehman, L., Picone, M.A. (2001). Pulmonary complications (pp. 137–148). In Halper, J. (ed.) *Advanced Concepts in Multiple Sclerosis Nursing Care*. New York: Demos.
- Paty, D.N., Ebers, G.C. (1998). *Multiple Sclerosis* (p. 433). Philadelphia: F.A. Davis.
- Penn, R.D. (1992). Intrathecal baclofen for spasticity of spinal origin; seven years of experience. *Journal of Neurosurgery*, 77, 236–240.
- Phair, L.S., Holland, N.J. (1993). Nursing outcomes in multiple sclerosis. *Journal of Neuro Rehab*, 7, 131–138.
- Poser, C. (1979). Diseases of the myelin sheath. In Marritt, H.H. (ed.). *A textbook of Neurology*, 6th edition. Philadelphia: Lea & Febiger, 767–824.
- Samuel, L. & Cavallo, P. (1999). Emotional issues. In van den Noort, S., Holland, N. *Multiple Sclerosis in Clinical Practice* (pp. 107–114). New York: Demos.
- Schapiro, R.T. (1998). Bladder symptoms. In Schapiro, R.T. *Symptom Management in Multiple Sclerosis*, 3rd ed (pp. 78–80). New York: Demos.
- Sorensen, P., Brown, S., et al. (1993). Communication disorders and dysphagia. *Journal of Neurologic Rehabilitation*, 7, 140.
- Stein, R., Nordal, H.J., et al. (1987). The treatment of spasticity in multiple sclerosis: a double-blind clinical trial of a new anti-spastic drug tizanidine compared to baclofen. *Aeta Neurologica Scandinavica*, 75, 190–194.
- Thomas F.J., Wiles C.M. (1999). Dysphasia and nutritional status in multiple sclerosis. *Journal of Neurology*, 246 (8), 677–682.
- Wiens, M.E., Reimer, M.A. (1999). Music therapy as a treatment method for improving respiratory muscle strength in patients with advanced multiple sclerosis: pilot study. *Rehabilitation Nursing* 24 (2), 74–80.
- Welsh, S.I., et al. (1992). Development of the Food Guide Pyramid. *Nutrition Today*, 27 (8), 12.
- Williams, S.R. (1995). *A Basic Nutrition and Diet Therapy*. New York: Mosby.
- Wozniak-Wowk, C.S. (1993). Nutrition intervention in the management of multiple sclerosis. *Nutrition Today*. November–December, 21–22.

CHAPTER 6

Psychosocial Issues in Multiple Sclerosis

Nicholas G. LaRocca, PhD and Rosalind C. Kalb, PhD

INTRODUCTION

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

Multiple sclerosis (MS) has wide ranging effects on individuals with the disease as well as those around them. These effects can last a lifetime and range from mild interruption in daily routine to complete disruption of everyday life. Some people with MS also report that the illness has had some positive impact. Many think it has helped them to discover new inner resources and heightened their sensitivity to others. Thus, although it is possible to see MS as a life challenge, there can be little doubt that it also represents a burdensome and often devastating intrusion in people's lives.

This chapter focuses on the psychosocial impact of 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 its vast array of symptoms, including impaired ambulation, fatigue, bladder and bowel dysfunction, tremor, spasticity, sexual dysfunction, and cognitive and emotional changes. Every facet of daily life may be invaded. 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. Individuals and families may experience the tension and distress caused by these symptoms before

they understand the role that MS has in causing these feelings. Grief, stress, conflict, and confusion can all become part of the person's daily life. The nurse can help the individual and the family to understand the effects of MS, to deal with those effects, and to rebuild damaged lives.

The Role of the Nurse

The nurse is the healthcare 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. 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 effects of MS that often go untreated. While the nurse may not be able to provide the actual treatment for many of these psychosocial problems, she or he can act as a valuable resource for information and education about a variety of 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.

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: (1) incorporate an understanding of MS psychosocial issues into their work; and (2) know what type of help is needed to begin solving these problems.

THE EMOTIONAL CHALLENGES OF MULTIPLE SCLEROSIS

Stress

There has been much speculation, many anecdotes, and some research into 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 can cite some emotionally stressful event that took place just before an MS attack. While some studies have found limited evidence to support the stress–MS link (Warren, Greenhill, & Warren, 1982; Franklin et al., 1989), many others have not (Fischer et al., 1994). 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.

There are more productive ways to look at stress. Studies that have begun to investigate the relationship between stress and the immune system (Foley et al., 1988) are finding 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 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 (Dalos et al., 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. Since no one could do anything to her satisfaction, she would loudly berate members of the family concerning their shortcomings. Gradually 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 and may be roughly divided into two types: major life events and everyday stress. The major life events are those things that require change or readjustment on the part of the individual and/or family, such as losing one's job. Everyday stress, sometimes referred to as "hassles," are the many day-to-day occurrences, that do not require major life changes but are emotionally taxing, such as being stuck in a traffic jam. 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 concept of having a degenerative illness sinks in. The person with MS wants to know his or her "prognosis" and soon discovers that predicting the course of MS is a little like picking the winner of the Kentucky Derby ten years from now. 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 a number of years at a large telecommunications company that is currently downsizing. He has been able to work out an arrangement in which he telecommutes three days per week and works at his office the other days. He feels fairly secure in his job since he has received excellent evaluations. However, the company has a number of 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 over an hour to the new job, and because of the nature of his duties he would not be able to telecommute more than one 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 soon find themselves in a state of mild shock. Most people's expectations in life do not include an incurable, degenerative disease such as MS. Some sense of disbelief is a normal and healthy reaction. Denial may be helpful because it gives the psyche time to absorb a shocking reality for which it was totally unprepared. In most instances, this initial sense of shock and disbelief gradually passes as people learn to accept and adapt to MS. Most people with MS will say that they have never really "accepted" the disease any more than one would "accept" a toothache. However, acceptance means that the person with MS is able to recognize the existence of the illness and deal with it. Once someone has accepted the existence of MS, the person can begin the work of making the adaptations that are necessitated by the disease. When healthcare 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 adaptation, it is time to consider other strategies. Here is one example:

Jennifer is a favorite customer at the auto body shops. She has had eight automobile accidents in the last three years, two of them total wrecks. She had a spotless driving record prior to being diagnosed with MS at age 34. By age 36 her physical symptoms included numbness and weakness in the legs, episodic double vision, and some memory loss. Her first serious accident occurred shortly after her 36th birthday when she took out a utility pole on a clear night when she had nothing to drink. Her family has pleaded with her either to stop driving or at least have her driving skills evaluated. She vociferously refuses, attributing her mishaps to "bad luck," "faulty brakes," or "the other guy."

Jennifer 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 not being able to walk. Jennifer needs a carefully measured combination of confrontation and under-

standing. Her need for independence should be acknowledged even as she is presented with the incontrovertible proof that something is not right. However, understanding and confrontation might not be enough. Family and friends may need to refuse to ride in a car if Jennifer is driving. Jennifer should be tested to determine if she 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. Jennifer has not injured anyone yet, but she stands a high likelihood of doing so. Her denial is standing in the way of adaptation and she 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 life. In MS, grief plays out in a slightly different way. The losses that are mourned are largely losses of self. The old, 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: (1) sadness and crying, (2) fear and denial, (3) anger and irritability, (4) asking “why me?” (5) reminiscing about the past, and (6) 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 age 37, 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. Since 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 as 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.

Sandra 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 (i.e., daily for two weeks or more) sadness and/or lack of interest or pleasure in previously enjoyable activities, along with at least three of the following: (1) loss of or increase in appetite; (2) sleep disturbance; (3) feelings of hopelessness; (4) persistent thoughts of death or suicide; (5) feelings of worthlessness, self-reproach, or guilt; (6) lassitude; (7) 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 et al., 1987). Antidepressants have also been used successfully. The tricyclic antidepressants such as Elavil® and Tofranil® were used for many years, although the SSRI antidepressants (including Paxil®, Prozac®, and Zoloft®) are now more commonly prescribed.

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 him- 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 percent 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 it may be due in part to damage to parts of the brain concerned with the regulation of emotions, such as the limbic system. In all probability, there are various causes for the clinical depression seen in MS, including demyelination, altered life circumstances, and possibly an 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 age 32. She did well for a number of years, walking with a cane and keeping close tabs on the availability of rest rooms. About two 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 improved somewhat, 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 two months ago she became 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 pounds in two 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 since 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.

Mood Swings and Personality Change

The bouts of grief and depression described so far are part of a much larger picture of emotional upheaval that occurs in MS. For want of a better term, we often refer to these collectively as “mood swings.” In reality, we all fall prey to mood swings from time to time. However, it appears that having MS makes one particularly vulnerable to emotional upheaval 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 one 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’s look at each of these in more detail.

Emotional Instability. 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. Families members may also have them in response to life pressures and their own issues. 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, i.e., the limbic system. While research on this topic is lacking, it could help to explain why many people with MS are so emotionally labile. 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.

Increased Sensitivity. Emotional sensitivity in which crying is easily provoked and difficult to stop is not confined to MS. However, it seems to be much more common in MS than in other populations. While research on this topic is sadly lacking, this sort of mood alteration is likely due in part to 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.

Emotional Release. The third and most extreme form of mood alteration was previously called pseudobulbar affect but is now referred to as emotional release. 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 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, probably in the limbic system. One small study found some success with the use of Elavil® (amitriptyline) in the treatment of this problem (Schiffer et al., 1985).

MAKING REFERRALS THAT WILL BE ACCEPTED

Referring people for help with psychosocial problems can be compared to diffusing a bomb. 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. 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 a variety of challenges and there are a variety of 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 percent 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 et al., 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. Research using brief batteries of tests have met with some success (Basso et al., 1996; Beatty & Goodkin, 1990; Beatty et al., 1995; Dent & Lincoln, 2000). However, approximately 5 to 6 hours of standardized testing may be required in order to assess the nature and severity of cognitive deficits properly.

During the last few years, numerous studies using magnetic resonance imaging (MRI) have demonstrated that the presence and severity of cognitive dysfunction is related to the overall extent of demyelination. More recent 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 et al., 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 of the ability to process information as well as any tasks that require the transfer of information between the left and right hemispheres. In contrast, lesions in the frontal lobes are often associated with memory deficits and impairments in executive functions such as planning ability.

While 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 while 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 percent 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). More recent research has suggested that many individuals with MS learn new information with greater difficulty than controls (DeLuca & Johnson, 1993; DeLuca et al., 1998). This has important implications since 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. An example serves to illustrate:

Don is a respected attorney in his early fifties. 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 a number of major slip-ups such as forgetting to pay certain bills and losing track of several 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.

While not all stories have such a happy ending, it is often the nurse who is on the front lines 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-twenties. She has built a successful career as a securities analyst. During the last two years she has noticed mild memory impairment but has been able to compensate effectively using a notebook along with liberal use of the information management capabilities of computers. During the last six months she has had increasing difficulty in her work. She analyzes companies in order 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 upon 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 she or he 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.
- Attention and concentration may be affected in MS. Deficits here can be very disabling because they are essential steps in the use of most other intellectual functions. People with attention/concentration problems may be distractible or may have trouble concentrating or keeping their mind on a task. However, we tend to see these problems manifest in more subtle ways, such as when people are called upon 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 bomber 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 bomber jacket gets shot down!
- People with MS often have problems with spatial organization, one of the skills you need in order to put together those toys that are 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, etc.

So far we have discussed the cognitive functions most 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 percent of people with MS show either no cognitive changes (50 percent) or changes that are relatively mild (40 percent), interfering with daily activities to only a limited extent. However, because MS is variable and progressive, a minority (5–10 percent) 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. There is little or no relationship between cognitive dysfunction and how long someone has had MS, or how severely disabled he or she is physically (Amato et al, 1995). 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 is some evidence to suggest that people with a progressive course are at greater risk for cognitive dysfunction, this relationship is extremely weak. 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 et al., 1997). Some studies have shown little or no measurable progression over time in cognitive impairments (Rao, 1991) or have found a mix of deterioration, stability, and improvement (Jennekens-Schinkel et al., 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, in part 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 cognitive dysfunction. An error made by many family members, friends, and even professionals is 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 \$2,000. Thus, one should not undertake this testing unless there is a good reason to do so. Sometimes a short screening battery can determine whether or not 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 et al., 1998; Foley et al., 1994; Jönsson et al., 1993; Plohmann et al., 1998; Rodgers et al., 1996; Sullivan et al., 1989). Such programs often employ two complementary approaches. In the retraining approach, the brain is viewed as almost infinitely “plastic,” 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 loose-leaf organizer book to record facts, tasks, and events

that are likely to be forgotten. Retraining may be beneficial for some deficits, e.g., attention/concentration problems. However, based on clinical experience and the scientific literature in other disorders, the compensatory approach appears to be more productive.

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 MS patients 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-modify agents include Avonex[®], Betaseron[®], Copaxone[®], Rebif[®], and Novantrone[®] among others. 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 relapsing–remitting patients from this trial were administered a battery of cognitive tests 2 years into the trial (Pliskin et al., 1996). After 2 years these patients were re-tested. Those who received Betaseron[®] performed better on a test of visual memory than patients who received placebo. In a recently completed trial of Betaferon[®] (as Betaseron[®] is called in Europe) in secondary-progressive MS, 476 patients were administered a brief battery of cognitive tests at baseline and then annually three more times (Cognition Subgroup of the European Trial of Betaferon[®] in SPMS, 2000). In this study, 193 healthy controls were administered the same cognitive tests to control for practice effects. A direct comparison of patients receiving Betaferon[®] and those receiving placebo showed no significant difference. However, the comparison with healthy controls revealed that patients receiving placebo were more likely than those receiving Betaferon[®] to be cognitively impaired by the last study visit.

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.

While much of the research examining the impact of disease-modifying agents on cognition has been disappointing, the prospects are perhaps not entirely bleak. None of the clinical trials described above were designed primarily to test the effects of treatment on cognitive function and the study periods were generally short. Moreover, the vast majority of 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 if speculative to note that those treatments that can slow the accumulation of lesions shown on MRI may help to stabilize cognitive changes over the long term, since cognitive dysfunction is greatest among those patients with the most lesions.

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 MS patients (Smits et al., 1994). Investigators found that neither amantadine nor Cylert[®] (drugs used to treat MS fatigue) had any beneficial effects on cognitive function among MS patients (Geisler et al., 1996).

There has long been 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, 1988). More recent studies have focused on Aricept[®], an acetylcholinesterase inhibitor that is used to treat mild to moderate memory disorders in Alzheimer's disease, vascular dementia, and traumatic brain injury. In one study, four MS patients receiving Aricept[®] were compared to four receiving no treatment (Krupp et al., 1999). After 6 weeks of treatment, patients receiving Aricept[®] had improved in verbal memory but no effects were observed on measures of nonverbal memory, attention span, and verbal fluency. Another study examined the effects of Aricept[®] on 17 MS patients with moderate to severe cognitive impairment (Greene et al., 2000). There was no control group in this study and treatment lasted 12 weeks. At the end of the 12 weeks, significant improvements were seen in attention, memory, and executive functions and also in several non-cognitive domains such as agitation, depression, anxiety, euphoria, apathy, inhibition, irritability, and appetite. Larger and more sophisticated clinical trials of Aricept[®] are underway and results should be available during the next few years. Another acetylcholinesterase inhibitor, known as Reminyl[®] (galantamine HBr), was recently approved by the Food and Drug Administration for the treatment of mild to moderate dementia of the Alzheimer's type (Janssen Pharmaceutica Products, L.P., 2001). While no studies of Reminyl[®] in MS have been reported to date, this new drug is likely to generate interest both on the part of MS researchers and patients, particularly since one of the ingredients in Reminyl[®], galantamine, is derived from common plants such as the snowdrop daffodil and can be purchased without a prescription as a nutritional supplement.

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.

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” (Gonzales et al., 1989). In other words, family members have to learn how to incorporate MS into their individual and communal lives without sacrificing themselves, their family life, 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. [For additional information, see Kalb (1998) and Kalb & Miller (2000).] 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 him- or herself with other things. While 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 while 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 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 house-

hold. She is dissatisfied with the way George does things around the house but doesn't 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; while 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 didn't 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. Preexisting family patterns tend to become exaggerated in times of increased stress and change, 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 in order to protect one another. The partner with MS may not want to talk about symptoms or feelings that the disease is getting worse for fear of being a burden or frightening the spouse away. The spouse is resentful and overwhelmed by the increased responsibility and workload but feels guilty expressing these feelings in light of the disabilities of the stricken partner. 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 in order 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 in order 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. In prior years 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 (Birk et al., 1988; Birk & Kalb, 1998; Birk & Werner, 2000), 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: (1) educate themselves about MS and think realistically about the problems it can pose; (2) evaluate their available economic, emotional, and family resources; (3) 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, (4) 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 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, a variety of resources are available to help mothers and fathers deal with these concerns (Crawford & Miller, 1998; Garee, 1989; Kalb & Miller, 2000). 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 MS patients, 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, while 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 who are becoming increasingly disabled. This can be particularly distressing for the young nurse who meets a newly diagnosed MS patient of similar age and sex, with whom there is more of a tendency to identify.

The Dependent and Demanding MS Patient

Nurses often find that MS patients 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 make-up, 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 patients with MS, much of the nurse's skill is directed toward teaching patients how to manage their symptoms effectively. The nurse educates the person 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 MS population, 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 MS patients. While 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, 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.

Acknowledgment. Preparation of this chapter was supported in part by grants from the National Institute on Disability and Rehabilitation Research: H133G10158; H133B80018; H133B30015.

REFERENCES

- Allen, D.N., Goldstein, G., Heyman, R.A., Rondinelli, T. (1998). Teaching memory strategies to persons with multiple sclerosis. *Journal of Rehabilitation Research and Development*, 35, 405–410.
- Amato, M.P., Ponziani, G., Pracucci, G., Bracco, L., Siracusa, G., Amaducci, L. (1995). Cognitive impairment in early-onset multiple sclerosis. *Archives of Neurology*, 52, 168–172.
- Archibald, C.J. Fisk, J.D. (2000). Information processing efficiency in patients with multiple sclerosis. *Journal of Clinical and Experimental Neuropsychology*, 22, 686–701.
- Basso, M.R., Beason-Hazen, S., Lynn, J., Rammohan, K., Bornstein, R.A. (1996). Screening for cognitive dysfunction in multiple sclerosis. *Archives of Neurology*, 53, 980–984.
- Beatty, W.W., Paul, R.H., Wilbanks, S.L., Hames, K.A., Blanco, C.R., Goodkin, D.E. (1995). Identifying multiple sclerosis patients with mild or global cognitive impairment using the Screening Examination for Cognitive Impairment (SEFCI). *Neurology*, 45, 718–723.
- Beatty, W.W., Goodkin, D.E. (1990). Screening for cognitive impairment in multiple sclerosis: An evaluation of the mini-mental state examination. *Archives of Neurology*, 47, 297–301.
- Birk, K., Kalb, R. (1998). Fertility, pregnancy, and childbirth. In Kalb, R., (ed.). *Multiple Sclerosis: A Guide for Families*. New York: Demos Vermande, 61–71.
- Birk, K., Smeltzer, S., Rudick, R. (1988). Pregnancy and multiple sclerosis. *Seminars in Neurology*, 8, 205–213.
- Birk, K., Werner, M. (2000). Fertility, pregnancy, childbirth, and gynecological care. In Kalb, R., (ed.). *Multiple Sclerosis: The Questions You Have—The Answers You Need*, (2nd ed.). New York: Demos, 311–328.

- Cognition Subgroup of the European Trial of Betaferon in SPMS. (2000). Effect of Betaferon on cognitive function: Results of the European trial on secondary progressive Multiple Sclerosis (SPMS). *Review Neurologie*, 3S115.
- Crawford, P. Miller, D. (1998). Parenting issues. In Kalb, R., (ed.). *Multiple Sclerosis: A Guide for Families*. New York: Demos Vermande, 72–87.
- Dalos, N.P., Rabins, P.V., Brooks, B.R., O'Donnell, P. (1983). Disease activity and emotional state in multiple sclerosis. *Annals of Neurology*, 13, 573–577.
- DeLuca, J., Johnson, S.K. (1993). Cognitive impairments in multiple sclerosis: Implications for rehabilitation. *Neuro Rehabilitation*, 3, 9–16.
- DeLuca, J., Gaudino, E.A., Diamond, B.J., Christodoulou, C., Engel, R.A. (1998). Acquisition and storage deficits in multiple sclerosis. *Journal of Clinical and Experimental Neuropsychology*, 20, 376–390.
- Dent, A., Lincoln, N.B. (2000). Brief report: Screening for memory problems in multiple sclerosis. *British Journal of Clinical Psychology*, 39, 311–315.
- Fischer, J.S. (1999). Assessment of neuropsychological function. In Rudick, R.A., & Goodkin, D.E. (eds.). *Multiple Sclerosis Therapeutics*. London: Martin Dunatz, Ltd.
- Fischer, J.S., Foley, F.W., Aikens, J.E., Ericson, G.D., Rao, S.M., Shindell, S. (1994). What do we really know about cognitive dysfunction, affective disorders, and stress in multiple sclerosis: A practitioner's guide. *Journal of Neurologic Rehabilitation*, 8 (3), 151–164.
- Fischer, J.S., Priore, R.L., Jacobs, L.D., and the Multiple Sclerosis Collaborative Research Group. (2000). Neuropsychological effects of interferon-beta 1a in relapsing-remitting multiple sclerosis. *Annals of Neurology*, 48, 885–892.
- Foley, F.W., Bedell, J.R., LaRocca, N.G., Scheinberg, L.C., Reznikoff, M. (1987). Efficacy of stress-inoculation training in coping with multiple sclerosis. *Journal of Consulting and Clinical Psychology*, 55, 919–922.
- Foley, F.W., Miller, A.H., Traugott, U., et al. (1988). Psychoimmunological dysregulation in multiple sclerosis. *Psychosomatics*, 29, 398–403.
- Foley, F.W., LaRocca, N.G., Kalb, R.C., Caruso, L.S., Shnek, Z. (1993). Stress, multiple sclerosis, and everyday functioning: A review of the literature with implications for intervention. *Neuro Rehabilitation*, 3, 57–66.
- Foley, F.W., Dince, W.M., LaRocca, N.G., Kalb, R.C., Caruso, L.S., Smith, C.R., Shnek, Z.M. (1994). Psychoremediation of communication skills for cognitively impaired persons with multiple sclerosis. *Journal of Neurologic Rehabilitation*, 8, 165–176.
- Foong, J., Rozewicz, L., Quaghebeur, G., Davie, C.A., Kartsounis, L.D., Thompson, A.J., Miller, D.H., Ron, M.A. (1997). Executive function in multiple sclerosis: The role of frontal lobe pathology. *Brain*, 120, 15–26.
- Franklin, G.M., Nelson, L.M., Filley, C.M., Heaton, R.K. (1989). Cognitive loss in multiple sclerosis: Case reports and review of the literature. *Archives of Neurology*, 46, 162–167.
- Garee, B.(ed.) (1989). *Parenting: Tips from parents (who happen to have a disability) on raising children*. Bloomington, IL: Accent Press.
- Geisler, M.W., Sliwinski, M., Coyle, P.K., Masur, D.M., Doscher, C., Krupp, L.B. (1996). The effects of amantadine and pemoline on cognitive functioning in multiple sclerosis. *Archives of Neurology*, 53, 185–188.
- Gonzalez, S., Steinglass, P., Reiss, D. (1989). Putting the illness in its place: discussion groups for families with chronic medical illness. *Family Process*, 28, 69–87.

- Greene, Y.M., Tariot, P., Wishart, H., Cox, C., Holdt, C., Schwid, S., Noviasky, J.A. (2000). 12-week, open trial of denepezil hydrochloride in patients with multiple sclerosis and associated cognitive impairments. *Journal of Clinical Pharmacology*, 20, 350–356.
- Janssen Pharmaceutica Products, L.P. (2001). Prescribing information for Reminyl® (galantamine HBr) tablets. Titusville, NJ: Janssen Pharmaceutica Products, L.P.
- Jennekens-Schinkel, A., Laboyrie, P.M., Lanser, J.B.K., van der Velde, E.A. (1990). Cognition in patients with multiple sclerosis after four years. *Journal of Neurological Sciences*, 99, 229–247.
- Jönsson, A., Korfitzen, E.M., Heltberg, A., Ravnborg, M.H., Byskov-Ottosen, E. (1993). Effects of neuropsychological treatment in patients with multiple sclerosis. *Acta Neurologica Scandinavica*, 88, 394–400.
- Kalb, R.C. (ed.) (1998). Multiple sclerosis: A guide for families. New York: Demos Vermande.
- Kalb, R.C., Miller, D.M. (2000). Psychosocial issues. In Kalb, R. (ed.). *Multiple Sclerosis: The Questions You Have—The Answers You Need*, (2nd ed.). New York: Demos, 221–258.
- Krupp, L.B., Elkins, L.E., Scott, S.R., Smiroldo, J., Coyle, P.K. (1999). Donepezil for the treatment of memory impairments in multiple sclerosis. Presented at the American Academy of Neurology 51st Annual Meeting, Toronto, Canada, April 17–24, A137.
- Kujala, P., Portin, R., Ruutiainen, J. (1997). The progress of cognitive decline in multiple sclerosis: A controlled 3-year follow-up. *Brain*, 120, 289–297.
- LaRocca, N.G. (1984). Psychosocial factors in multiple sclerosis and the role of stress. *Annals of the New York Academy of Sciences*, 436, 435–442.
- Leo, G.J., Rao, S.M. (1988). Effects of intravenous physostigmine and lecithin on memory loss in multiple sclerosis: Report of a pilot study. *Journal of Neurologic Rehabilitation*, 2, 123–129.
- Peysers, J.M., Edwards, K.R., Poser, C.M., Filskov, S.B. (1980). Cognitive function in patients with multiple sclerosis. *Archives of Neurology*, 37, 577–579.
- Pliskin, N.H., Hamer, D.P., Goldstein, D.S., Towle, V.L., Reder, A.T., Noronha, A., Arnason, B.G.W. (1996). Improved delayed visual reproduction test performance in multiple sclerosis patients receiving interferon- β . *Neurology*, 47, 1463–1468.
- Plohmman, A.M., Kappos, L., Ammann, W., Thordai, A., Wittwer, A., Huber, S., Bellaiche, Y., Lechner-Scott, J. (1998). Computer assisted retraining of attentional impairments in patients with multiple sclerosis. *Journal of Neurology, Neurosurgery, and Psychiatry*, 64, 455–462.
- Rao, S.M. (1986). Neuropsychology of multiple sclerosis: A critical review. *Journal of Clinical and Experimental Neuropsychology*, 8, 503–542.
- Rao, S.M., Leo, G.J., Bernardin, L., Unverzagt, F. (1991). Cognitive dysfunction in multiple sclerosis. I. Frequency, patterns, and prediction. *Neurology*, 41, 685–691.
- Rodgers, D., Khoo, K., MacEachen, M., Oven, M., Beatty, W.W. (1996). Cognitive therapy for multiple sclerosis: A preliminary study. *Alternative Therapies*, 2, 70–74.
- Ryan, L., Clark, C.M., Klonoff, H., Li, D., Paty, D. (1996). Patterns of cognitive impairment in relapsing-remitting multiple sclerosis and their relationship to neuropathology on magnetic resonance imaging. *Neuropsychology*, 10, 176–193.
- Schiffer, R.B., Herndon, R.M., Rudick, R.A. (1985). Treatment of pathologic laughing and weeping with amitriptyline. *New England Journal of Medicine*, 312, 1480–1482.

- Smits, R.C.F., Emmen, H.H., Bertelsmann, F.W., Kulig, B.M., van Loenen, A.C., Polman, C.H. (1994). The effects of 4-aminopyridine on cognitive function in patients with multiple sclerosis: A pilot study. *Neurology*, *44*, 1701–1705.
- Warren, S., Greenhill, S., Warren, K.G. (1982). Emotional stress and the development of multiple sclerosis: Case-control evidence of a relationship. *Journal of Chronic Diseases*, *35*, 821–831.
- Weinstein, A., Schwid, S.I.L., Schiffer, R.B., McDermott, M.P., Giang, D.W., Goodman, A.D. (1999). Neuropsychological status in multiple sclerosis after treatment with glatiramer. *Archives of Neurology*, *56*, 319–324.
- Warren, S., Greenhill, S., Warren, K.G. (1982). Emotional stress and the development of multiple sclerosis: Case-control evidence of a relationship. *Journal of Chronic Diseases*, *35*, 821–831.

CHAPTER 7

Sexuality and Family Planning

Rosalind C. Kalb, PhD and Nicholas G. LaRocca, PhD

INTRODUCTION

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. Yet sexuality remains one of the most difficult topics for people to discuss, with the result that neither people with multiple sclerosis (MS) nor their physicians are likely to bring up the subject. Why is sexuality such a difficult topic? In spite of 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. 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.

One purpose of this chapter is to describe the ways in which multiple sclerosis can affect a person's sexual life, ranging from the problems caused directly by neurologic impairment (primary) to those caused by the debilitating physical symptoms of MS (secondary), and those resulting

from the psychosocial sequelae of the disease (tertiary) (Holland & Cavallo, 1993; Foley, 1998; Foley & Werner, 2000). While reports of the incidence and prevalence of sexual dysfunction in MS vary considerably (Lilius et al., 1976; Lundberg, 1978; Szasz et al., 1984; Valleroy & Kraft, 1984; Zorzon et al., 1999), 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.

The goal of this discussion is to go beyond a simple description of symptoms and their management to a discussion of sexual problems within the context of each person's personality and lifestyle. The initial sections of the chapter describe the most common sexual problems and issues confronted by people with MS. The nurse is in a unique position to help people ask questions and seek appropriate solutions. 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.

Perhaps less difficult to discuss but just as emotionally loaded are the questions men and women have about the role of MS in family planning decisions. This chapter also 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.

RECOGNIZING AND MANAGING SEXUAL PROBLEMS THAT OCCUR IN THE CONTEXT OF MULTIPLE SCLEROSIS

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 unfamiliar genital sensations, decreased vaginal lubrication, and diminished orgasmic response (Lilius et al., 1976; Lundberg, 1978; Valleroy & Kraft, 1984; Schover et al., 1988; Foley, 1998; Zorzon, 1999; Foley & Werner, 2000). 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 (Lilius et al., 1976; Lundberg, 1978; Valleroy, & Kraft, 1984; Kirkeby et al., 1988; Schover et al., 1988; Zorzon, 1999; Foley & Werner, 2000). Both men and women can experience MS-related cognitive changes that affect the sexual response and/or the sexual relationship; hypersexuality, disinhibi-

tion, and sexual preoccupation have all been described in the MS population (Huws et al., 1991). 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. Since a significant number of happily married couples in the general population of healthy adults will report occasional sexual dysfunction (Frank et al., 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 healthcare professional who is knowledgeable about sexual dysfunction *and* multiple sclerosis. 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, since 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.

Treatment of Primary Sexual Dysfunction

Decreased libido in men and women can be distressing and problematic to treat. While 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 a variety of emotional states that can come and go in the course of living with any chronic, 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.

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 (Neurontin®) or carbamazepine (Tegretol®), or by an antidepressant medication such as amitriptyline (Elavil®). For some people, meditation or acupuncture may also provide relief (Bowling, 2001; Smith & Schapiro, 2000). 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, in order to discover what does and does not feel good, and to communicate that information to the partner. 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 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.

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. Sildenafil citrate (Viagra®), an oral medication for erectile dysfunction, has been shown in a placebo-controlled clinical trial in men with MS to have a positive impact on quality of life including sexual function, relationship with partner, social contacts, and overall satisfaction (presentation at the American Neurological Association meeting, Seattle, Washington, October, 1999). (Note: Preliminary, unpublished findings suggest that Viagra® may also enhance a woman's physical arousal and ability to achieve orgasm.)

Viagra® works by blocking the action of an enzyme called PDE (type 5 phosphodiesterase enzyme), thereby enhancing the action of cGMP (cyclic guanosine monophosphate). Unlike the injectable medications described below, Viagra® does not create penile erections; rather, it allows an erection to occur in the presence of adequate physical and/or erotic stimulation.

Although Viagra® has been shown to enhance erectile function in men with either organically or psychogenically based erectile dysfunction, it does not increase sexual desire. Counseling may be necessary to restore positive feelings and intimacy in a relationship with significant distress and conflict.

Viagra® typically causes a transient decrease in blood pressure. Therefore, it should be used with caution by men who are taking a nitrate-based medication, 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 pre-existing cardiovascular disease. Any man with a history of cardiovascular disease or high blood pressure should have a thorough evaluation before starting on Viagra®.

For those men who cannot take Viagra®, or derive insufficient benefit from it, there are a variety of other options (Foley & Werner, 2000). 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 (Kirkeby et al., 1988; Foley & Werner, 2000). 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. While 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.

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 (Massey & Pleet, 1978; Small, 1978; Foley & Werner, 2000). While 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.

While 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, healthcare providers can enhance the effectiveness of their interventions by teaching/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.

Secondary Sexual Dysfunction

While 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. 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/emotional enjoyment associated with sexual activity was simply not worth the day that it took her to recover her energy.

Recommended Treatments for Secondary Sexual Dysfunction

Stiffness of the lower limbs and adductor spasms of the thighs can make sexual activities awkward, uncomfortable, or even painful. Spasticity is usually managed quite effectively with baclofen and/or tizanidine (Zanaflex®). Within reasonable limits prescribed by the physician, people can self-monitor their medication dosage schedule 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, continuous rate. Chemical nerve blocks and surgery are additional treatments that can be used to relieve intractable spasticity (Smith & Schapiro, 2000).

MS-related bowel and bladder symptoms can have a significant impact on a couple's efforts to engage in stress-free, 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, honest discussion and some judicious planning and preparation.

Bladder symptoms can be managed in a variety of ways (see Chapter 4) (Multiple Sclerosis Council for Clinical Practice Guidelines, 1999; Halper, 2000). Reducing fluid intake for the previous 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 can 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, 2000). Medications for incontinence, including oxybutynin chloride (Ditropan® and DitropanXL®), tolterodine (Detrol®), propantheline bromide (Probanthine®), and imipramine hydrochloride (Tofranil®), 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. Since 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 (see Chapter 4) (Halper, 2000). 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 in MS is best managed pharmacologically with amantadine—an antiviral/antiparkinsonian agent, pemoline (Cylert®)—a mild central nervous system stimulant), or modafinil (Provigil®)—a medication most commonly used to treat narcolepsy, and with a variety of energy conservation techniques, including the use of ambulation aids and motorized carts or wheelchairs (Smith & Schapiro, 2000). 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. Since 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. Since sexual activity requires time and energy, both precious commodities for the person with MS, a certain amount of planning and prioritizing becomes important. While 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.

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 carbamazepine (Tegretol®) or phenytoin sodium (Dilantin®). Chronic, dull pain in the extremities usually responds well to the tricyclic antidepressants or to fluoxetine (Prozac®) for those individuals who cannot tolerate the tricyclics. Burning pain and other types of dysesthesias often respond well to gabapentin (Neurontin®) or carbamazepine (Tegretol®) (Smith & Schapiro, 2000).

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 due to 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, while the person with MS begins to feel pressured and resentful over the partner's lack of sensitivity.

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 a variety of problems that include memory loss, slowed information processing, attentional deficits, word-finding difficulties, visuo-spatial problems, and impaired judgment. These are discussed further under tertiary sexual dysfunction since their primary impact is on interpersonal communication. In general, however, MS-related cognitive dysfunction requires a thorough neuropsychological evaluation in order to assess the type and extent of deficits. Fortunately, remediation programs are becoming increasingly available to people with MS (Foley et al., 1994; LaRocca, Sorensen, & Fischer, 2000).

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 (Haldol®) 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 (usually the wife) is pursued incessantly—poked, stroked, and fondled—in a childlike, nagging fashion that is unpleasant and uncomfortable. Relationships with healthcare aides in the home also become complicated by this type of sexual acting out. Fortunately, this type of MS-related hypersexuality is relatively rare.

Tertiary Sexual Dysfunction

The tertiary effects of multiple sclerosis 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, societal ones about the apparent incompatibility between illness/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 disabled person continues to have all of the same sexual thoughts, feelings, and desires that he or she has always had, family members, friends, and even healthcare 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 (Holland & Cavallo, 1993; Foley, 1998; Foley & Werner, 2000). 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, satisfying sense of self. 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, gay, bisexual, or transgender. Healthcare providers must try to be alert and open to each person's need for information and support in his/her efforts to cope with these changes.

In addition to the sexual symptoms that may be occurring within the individual, a variety of changes in individual and family functioning are probably occurring that can affect 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. She or he 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—"is not the same person I married."

Recommended Treatment for 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 Multiple Sclerosis 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. 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. Multiple sclerosis 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: Should I have children? How will it affect my MS? Will I be able to be the kind of mother/father I always wanted to be? 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, or 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 MS

Based on population and family studies of MS, it is the consensus among researchers that certain people are genetically predisposed to MS (Sadovnick & Macleod, 1981; Ebers, Bulman, & Sadovnick, 1986; Sadovnick, Baird, & Ware, 1988; Ebers, 1994). This susceptibility, probably in combination with a set of other, as yet undetermined, environmental fac-

tors, results in the illness. In a population-based twin study (Ebers, Bulman, & Sadovnick, 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 percent versus 2.3 percent for dizygotic twins. In a study of 815 individuals with MS and 3,000 of their siblings and children, Sadovnick, Baird, & Ware (1988) found the relatives' risk of developing MS to be 3–5 percent, which is 30–50 times the 0.1 percent rate for the general population. While the risk is thus greatly increased for children of a parent with MS, it nevertheless remains relatively small.

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 (Birk & Werner, 2000) and should be selected on the basis of ease, comfort, and effectiveness. Oral contraceptives are safe, effective, and easy to use (Birk & Rudick, 1989). Since 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 of time should be aware that these can reduce resistance to infection, thereby compromising the safety and efficacy of an IUD (Birk & Werner, 2000).

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, 2000). Problems specific to the orgasmic phase have been reported by 44–77 percent of men with MS (Lilius, Valtonen, & Wikstrom, 1976; Minderhoud et al., 1984; Valleroy & Kraft, 1984; Schover et al., 1988; Zorzon, 1999). “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. Since these problems have been successfully treated with medication and/or electroejaculation, male patients should be encouraged to consult a urologist experienced in this area (Shaban, Seager, & Lipshultz, 1988; Birk & Werner, 2000)

Effects of MS on Pregnancy, Birth, and Lactation

Multiple sclerosis has no apparent effect on the course of pregnancy, labor, delivery, or lactation. There is no added risk of miscarriage, complications in labor or delivery, fetal malformations, or stillbirths (Cook et al., 1994; Birk, 1995; Birk & Werner, 2000). In other words, MS does not affect a woman's physiologic capability of conceiving, carrying, delivering, or nursing a healthy infant. However, it is important for women and their partners to consider the following: (1) Pregnant and lactating women must refrain from taking certain types of medications. (See Birk, 1995 and Birk & Werner, 2000, for precautions regarding the use of MS-related medications during pregnancy and lactation.) *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.* (2) Women with MS-related fatigue may find pregnancy and lactation even more than normally tiring. (3) 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. The sharing of parenting activities (particularly nighttime feedings) and utilization 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, Birth, and Lactation on MS

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 prior to 1950 did advise against women with MS becoming pregnant. More recently, research findings have altered this view. In seven retrospective studies, reviewing a total of 925 pregnancies, only 10 percent of the women experienced any disease progression during pregnancy and 29 percent experienced *temporary* worsening of the illness in the 6 months postpartum (Tillman, 1950; Sweeney, 1955; Schapira et al., 1966; Ghezzi & Caputo, 1981; Poser & Poser, 1983; Korn-Lubetzki et al., 1984; Birk, 1995). The exacerbation rate during pregnancy was actually found to be lower than the average expected rate for women (Korn-Lubetzki et al., 1984), suggesting that women with MS may be protected to some degree during pregnancy by certain immunoactive proteins and pregnancy-related hormones (Runmarker & Andersen, 1995; Birk & Werner, 2000). In a prospective study of 254 women (Confavreux et al, 1998), the rate of relapse was found to decline during pregnancy and increase during the

first 3 months postpartum before returning to the prepregnancy rate. Hence the wish expressed by some women with MS that they could stay pregnant forever because they feel so much better than they did prior to pregnancy. In another prospective study (Birk, Smeltzer, & Rudick, 1988), eight pregnant women were followed over a 2-year period. Over the course of the pregnancies, one woman reported disease worsening that was attributable to disease activity while three of the women experienced improvement in their neurologic symptoms. Six women experienced exacerbations (usually mild) during the 6-month period following delivery. In one retrospective study of 178 pregnant women (Thompson et al., 1986), no difference was found in the long-term disability levels of women with zero, one, or two or more pregnancies. The authors concluded that pregnancy does not have any long-term effect on disability level. However, the possibility that women with greater disability might have chosen to have fewer children makes the research findings somewhat difficult to interpret (Birk, Smeltzer, & Rudick, 1988).

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 percent risk of temporary worsening of the disease in the 6 months following pregnancy (even if the pregnancy ends prematurely due to spontaneous or elective abortion). Most researchers also agree that pregnancy does not affect final disease outcome or disability level (Sadovnick & Baird, 1985; Thompson et al, 1986; Sadovnick et al, 1994; Verdru et al., 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.

Multiple Sclerosis and Parenting

Men and women with MS often ask whether the disease will interfere with their parenting (Kalb & Miller, 2000). 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 in order 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.

Healthcare 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 support them in their decisions. In so doing, 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 him- 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.

REFERENCES

- Birk, K. (1995). Reproductive issues in multiple sclerosis. *Multiple Sclerosis: Clinical Issues* 2 (3), 2–5.
- Birk, K., Rudick, R. (1989). Caring for the OB patient who has multiple sclerosis. *Contemporary Ob/Gyn*, 34, 58–63.
- Birk, K., Smeltzer, S., Rudick, R. (1988). Pregnancy and multiple sclerosis. *Seminars in Neurology*, 8 (3), 205–213.
- Birk, K., Werner, M.A. (2000). Fertility, pregnancy, childbirth, and gynecological care. In R. Kalb (ed.). *Multiple Sclerosis: The Questions You Have—The Answers You Need* (2nd ed). New York: Demos Vermande.
- Confavreux, C., Hutchinson, M., Hours, M.M., Cortinovis-Tourniaire, et al. (1998) Rate of pregnancy-related relapse in multiple sclerosis. *New England Journal of Medicine* 339 (5), 285–291.

- Cook, S.D., Troiano, R., Bansil, S., Dowling, P.C. (1994). Multiple sclerosis and pregnancy. *Advances in Neurology*, 64, 83–95.
- Ebers, G., Bulman, D., Sadovnick, A. (1986). A population-based study of multiple sclerosis in twins. *New England Journal of Medicine*, 315, 1638–1642.
- Ebers, G. (1994). Genetics and multiple sclerosis: An overview. *Annals of Neurology*, 36, S12–S14.
- Foley, F.W. (1998) Sexuality and intimacy in multiple sclerosis. In Kalb, R. (ed.). *Multiple Sclerosis: A Guide for Families*. New York: Demos Vermande.
- Foley, F.W., Dince, W., Bedell, J.R., LaRocca, N.G., et al. (1994). Psychoremediation of communication skills for cognitively impaired persons with multiple sclerosis. *Journal of Neurologic Rehabilitation*, 7 (6), 165–176.
- Foley, F.W., Werner, M.A. (2000). Sexuality. In Kalb, R. (ed.). *Multiple Sclerosis: The Questions You Have—The Answers You Need* (2nd ed). New York: Demos.
- Frank, E., Anderson, C., Rubinstein, D. (1978). Frequency of sexual dysfunction in “normal couples.” *New England Journal of Medicine*, 299 (3), 111–115.
- Ghezzi, A., Caputo, D. (1981). Pregnancy: A factor influencing the course of multiple sclerosis? *European Neurology*, 20, 517–519.
- Halper, J. (2000) Nursing care to enhance wellness. In Kalb, R. (ed.) *Multiple Sclerosis: The Questions You Have—The Answers You Need* (2nd ed). New York: Demos.
- Holland, N., Cavallo, P. (1993). Sexuality and multiple sclerosis. *Neuro Rehabilitation*, 3 (4), 48–56.
- Huws, R., Shubsachs, A.P.W., Taylor, P.J. (1991). Hypersexuality, fetishism and multiple sclerosis. *British Journal of Psychiatry*, 158, 280–281.
- Kalb, R., Miller, D. (2000). Psychosocial issues. In Kalb, R. (ed.). *Multiple Sclerosis: The Questions You Have—The Answers You Need* (2nd ed.). New York: Demos.
- Kirkeby, H.J., Poulsen, E.U., Petersen, T., Dorup, J. (1988). Erectile dysfunction in multiple sclerosis. *Neurology*, 38, 1366–1371.
- Korn-Lubetzki, I., Kahana, E., Cooper, G., et al. (1984). Activity of multiple sclerosis during pregnancy and puerperium. *Annals of Neurology*, 16, 229–231.
- LaRocca, N.G., Sorensen, P., Fischer, J. (2000). Cognition. In Kalb, R. (ed.) *Multiple Sclerosis: The Questions You Have—The Answers You Need* (2nd ed.). New York: Demos.
- Lilius, H.G., Valtonen, E.J., Wikstrom, J. (1976). Sexual problems in patients suffering from multiple sclerosis. *Journal of Chronic Diseases*, 29, 643–647.
- Lundberg, P.O. (1978). Sexual dysfunction in patients with multiple sclerosis. *Sexuality and Disability*, 1 (4), 218–220.
- Massey, E.W., Pleet, A.B. (1979). Penile prosthesis for impotence in multiple sclerosis. *Annals of Neurology*, 6, 451–453.
- Minderhoud, J., Leemhuis, J., Kremer, J., Laban, E., Smits, P. (1984). Sexual disturbances arising from multiple sclerosis. *Acta Neurologica Scandinavica*, 70, 299–306.
- Multiple Sclerosis Council for Clinical Practice Guidelines (1999). Urinary Dysfunction and Multiple Sclerosis: Evidence-Based Management Strategies for Urinary Dysfunction in Multiple Sclerosis. Washington, D.C.: Paralyzed Veterans of America.
- Poser, S., Poser, W. (1983). Multiple sclerosis and gestation. *Neurology*, 33, 1422–1427.

- Runmarker, B., Andersen, O. (1995). Pregnancy is associated with a lower risk of onset and a better prognosis in multiple sclerosis. *Brain*, 118, 253–262.
- Sadovnick, A.D., Baird, P.A. (1985). Reproductive counseling for multiple sclerosis patients. *American Journal of Medical Genetics*, 20 (2), 349–354.
- Sadovnick, A.D., Baird, P.A., Ware, R.H. (1988). Multiple sclerosis: Updated risks for relatives. *American Journal of Medical Genetics*, 29, 533–541.
- Sadovnick, A.D., Macleod, P.M.J. (1981). The familial nature of multiple sclerosis: Empiric recurrence risks for first, second, and third degree relatives of patients. *Neurology*, 31, 1039–1041.
- Schover, L., Thomas, A., Lakin, M., Drogo, K., Fischer, J. (1988). Orgasm phase dysfunction in multiple sclerosis. *Journal of Sex Research*, 24 (4), 548–554.
- Shaban, S., Seager, S., Lipshultz, L. (1988). Clinical electroejaculation. *Medical Instrumentation*, 22 (2), 77–81.
- Shapira, K., Poskanzer, D.C., Newell, D.J., et al. (1966). Marriage, pregnancy, and multiple sclerosis. *Brain*, 89, 419–428.
- Small, M. P. (1976). Small-carrier penile prosthesis. *Mayo Clinic Proceedings*, 51, 336–338.
- Smith, C.R., Schapiro, R.T. (2000). Neurology. 2nd Ed. Kalb, R. (ed.). *Multiple Sclerosis: The Questions You Have—The Answers You Need*. New York: Demos.
- Sweeney, W.J. (1955). Pregnancy and multiple sclerosis. *American Journal of Obstetrics and Gynecology*, 66, 124–130.
- Szasz, G., Paty, D., Maurice, W.L. (1984). Sexual dysfunction in multiple sclerosis. *Annals of NY Academy of Science*, 436, 443–452.
- Thompson, D., Nelson, L., Burns, A., et al. (1986). The effects of pregnancy in multiple sclerosis: A retrospective study. *Neurology*, 36, 1097–1099.
- Tillman, A. (1950). The effect of pregnancy on multiple sclerosis and its management. *Res Publ Assoc Res Nerv Ment Dis*, 28, 548–582.
- Valleroy, M.L., Kraft, G.H. (1984). Sexual dysfunction in multiple sclerosis. *Archives of Physical Medicine and Rehabilitation*, 65, 125–128.
- Verdru, P., Theys, P., D'Hooghe, M.B., Carton, H. (1994). Pregnancy and multiple sclerosis: The influence on long term disability. *Clinical Neurology and Neurosurgery*, 96, 38–41.
- Zorzon, M., Zivadinov, R., Boxco, A., Monti-Bragadin, L. et al. (1999). Sexual dysfunction in multiple sclerosis: A case-control study. I. Frequency and comparison of groups. *Multiple Sclerosis*, 5 (6), 418–427.

CHAPTER 8

Women's Issues in Multiple Sclerosis

June Halper, MSN, ANP, FAAN

Although the onset of multiple sclerosis (MS) ranges from 10 to 59 years, it usually begins during the reproductive period (Sadovnick et al., 1994). Population surveys prior to 1977 showed that MS was approximately 1.4 times more common in women than in men (Matthews, 1991). Several investigations since that time suggest that this may be an underestimate, with the sex ratio ranging between 1.9 and 3.1 (Matthews, 1991). Gender differences in the incidence of disease are common but often fail to provide any strong clues about etiology. It is possible that the higher incidence of MS in women reflects a hormonal factor, but there may be many other equally possible explanations (Matthews, 1991). Many diseases with a known or alleged autoimmune etiology have an unbalanced sex distribution in which a majority of cases occur in women: Lupus erythematosus is nine times more frequent in women than in men; thyroid disease, myasthenia gravis, and rheumatoid arthritis also occur more frequently in women than in men. Sex hormones are thought to influence immune responses although there has been no research to validate this theory (Duquette et al., 1992).

Many issues in MS are unique to women and numerous questions remain unanswered. For example, why does MS disproportionately affect women? Why do hormonally mediated events such as menses, pregnancy, the postpartum period, and menopause impact disease activity? How is disease activity affected? Are primary and secondary health care and rehabilitative services available to women with MS? What are the long-term implications of ancillary services such as assistance with child care and peer

support in the course of MS? Is there a difference in the health state of women with MS who breast- or bottle-feed? The questions are many—the answers are few. Until recently there was a paucity of research on women's issues in MS, but an increased interest in women's issues both in North America and in Europe occurred in the latter part of the 20th century (Confavreux, 1998). This chapter presents an overview of emerging issues regarding women and related research.

MULTIPLE SCLEROSIS AND THE CONTEMPORARY WOMAN

The past three decades have resulted in the emergence of women in the workforce with full-time careers and roles and responsibilities within the home and the community. The diagnosis of MS can be viewed as a second or third career, almost another full-time job, which imposes alterations in lifestyles and adaptation to a changed body image. MS in and of itself can cause loss of spontaneity and sense of security about one's future, but it can also result in anxiety and insecurity for a woman juggling marriage, career, and parenting. The experiences of family planning, pregnancy, and childrearing are major life events for most couples. The diagnosis of MS makes such events more complicated (Birk & Kalb, 1992). While the disease does not appear to affect the course of pregnancy, labor, or delivery, the woman with MS faces an increased risk of an exacerbation 3 to 6 months postpartum (Davis & Maslow, 1992; Birk, Smeltzer, & Rudick, 1988). Pregnancy does not appear to alter the long-term course of the disease (Birk, Smeltzer, & Rudick, 1988).

The decision to start a family requires more than ordinary planning. Alterations in roles and responsibilities may be required for energy conservation. Parenting activities may have to be delegated or curtailed based on the mother's functional status. Spouses, care partners, family, or friends may have to be enlisted for assistance and relief during the postpartum period or during infancy or childhood. Nurses can play a vital role during the antepartum and postpartum period by assisting the patient to reassess strengths and weaknesses; prioritize their activities; identify resources within the home and the community; and facilitate the patient's ability to parent effectively while caring for herself. As any new mother, the mother with MS requires education about what bodily changes to expect, along with signs and symptoms of potential problems. She should be particularly alert for signs and symptoms of infection, such as UTI or mastitis, since these might cause a pseudoexacerbation of her MS. It is important to emphasize the need for adequate nutrition and hydration as well as rest and sleep. The new mother should be encouraged to discuss her postnatal needs with her obstetrician.

Returning to work or to other prepregnancy activities also requires a great deal of thought and planning. Child care poses an added burden to a woman with MS who is working full time. The nurse can guide the patient to identify child care options in the community. Choices of programs must include not only cost and quality but also location. Traveling great distances to day-care programs and then on to her job will tire the woman before she begins her work day. Working with both partners is desirable whenever possible to lighten the mother's responsibility. Child care and childrearing are more difficult for the single parent and occasionally community resources may be necessary. Pediatricians—and, in some areas of the country, pediatric nurse practitioners—can be helpful to new parents with parenting concerns and other worries about chronic illness and disability.

MENSES AND MENOPAUSE

While there have been a number of studies on pregnancy and MS (Sadovnick et al., 1994; Frith & McLeod, 1988; Birk, Smeltzer, & Rudick, 1988; Davis & Maslow, 1992), literature searches reveal very few studies on gender differences in the disease and even fewer on the relationship of MS to the menstrual cycle and menopause. Anecdotally, many women report changes in their symptoms related to menstruation, and two unpublished pilot studies substantiate these reports (Holland et al., 1987; Giesser et al., 1990). Many women assert that their symptoms worsen 2 to 3 days prior to the onset of their period and improve once bleeding has started. Others report that there are no changes in their condition related to their menses. This is an area that requires research in order to further understand the neuroendocrine connection.

Menopause, with its fluctuations in hormone levels and temperature swings, can cause functional problems for women in general. For women with MS, these changes can intensify symptoms or cause significant changes in functional status. Additionally, they are at greater risk for osteoporosis because of gender, potential or real immobility, and corticosteroid use (Nieves et al., 1994).

The nurse can play a vital role during the perimenopausal period by counseling the patient to seek gynecologic care about hormone replacement therapy and guarding against risks such as cardiac disease, osteoporosis, and other well-known sequelae of this period. While women with MS may be limited in weight-bearing exercises, alternatives can be explored with the patient and family to guard against bone loss. Programs such as yoga, swimming, passive standing, and stretching can be effective in maintaining function and preventing complications of altered mobility or immobility (Witmer & Sweeney, 1992).

TABLE 8-1 Gender Issues in Multiple Sclerosis**Basic Features:**

MS is very unusual prior to puberty
 MS most often affects young women of child-bearing age
 Men are predisposed to more progressive MS
 Men have a worse prognosis
 Sexual dysfunction is common in MS
 Diagnosis can be delayed in young women vs. men

Pathophysiology:

Disease activity decreases during pregnancy then temporarily increases postpartum
 Disease activity and clinical features may be affected by the menstrual cycle
 Disease activity is decreased by breast feeding
 Pregnancy may have a positive benefit in relapsing but not progressive patients

Treatment Issues:

Interferons can affect menstruation; they are recognized abortofacients
 Disease modifying therapies are not recommended in pregnant or breastfeeding patients
 Sex hormones are under evaluation for treatment of MS
 The FDA specifies pregnancy testing prior to each dose of mitoxantrone
 Targeted postpartum therapy (IVIG0) is being evaluated

General Health Issues:

Routine health maintenance/preventative medicine (PAP smear, GYN exam, bone density, mammography, PSA, guiacs) are often neglected in the disabled population
 Healthcare facilities are not always adequately accessible to the disabled

Psychosocial Issues:

Men and women face distinct parenting, spousal, vocational, and self-image issues
 Domestic violence in MS is under recognized and under reported

Source: Adapted from Coyle, 2001.

MANAGING BARRIERS

Women with physical disabilities face long-standing and substantial barriers, which may include the physical environment, the attitudes of society, and possibly abusive behavior of people close to them (Nosek et al., 1994). Women with MS must be assisted to develop a wellness perspective, and the nurse is in an ideal position to do so. Desirable outcomes are a positive self-concept, having productive relationships, managing barriers, and maintaining optimal health and physical and sexual functioning. The nurse can help the woman recognize her own vulnerability and then seek information and take action on her own behalf (Nosek et al., 1994). The nurse can help the woman with MS throughout her life span access and utilize ser-

vices and programs addressing her dynamic needs. The goals of these interactions are the development of a rich knowledge base and practices capable of promoting advancement in all aspects of physical and psychological wellness (Nosek et al., 1994).

REFERENCES

- Birk, K.A., Kalb, R. (1992). MS and planning a family: Fertility, pregnancy, childbirth, and parenting roles. In R. Kalb (ed.). *Multiple Sclerosis and the Family*. New York: Demos, 51–62.
- Birk, K., Smeltzer, S., Rudick, R. (1988). Pregnancy in multiple sclerosis. *Seminars in Neurology*, 8, (3), 205–213.
- Confavreux, C., Hutchinson, M. Hours, M.M. et al. (1998) Rate of pregnancy related relapse in MS. *NEJM*, 339, (5), 339–40.
- Coyle, P.K., *Overview: Gender Issues in MS. Gender Issues in Multiple Sclerosis*. Philadelphia: AAN Meeting. (2001).
- Davis, R.K., Maslow, A.S. (1992). Multiple sclerosis in pregnancy: A review. *Obstetrical and Gynecological Survey*, 290–296.
- Duquette, P., Pleines, J., Girard, M., et al. (1992). The increased susceptibility of women to multiple sclerosis. *Canadian Journal of Neurological Sciences*, 19, 466–471.
- Frith, J.A., McLeod, J.G. (1988). Pregnancy and multiple sclerosis. *Journal of Neurology, Neurosurgery and Psychiatry*, 51, 495–498.
- Giesser, B.G., Halper, J., Holland, N., et al. (1990). Symptoms of multiple sclerosis fluctuate during the menstrual cycle. Pilot study. Gimbel MS Center and Albert Einstein College of Medicine.
- Holland, N., Giesser, B.G., et al. (1987). The effects of the menstrual cycle on MS symptoms. Pilot study. Albert Einstein College of Medicine.
- Matthews, W.B. (1991). *McAlpine's Multiple Sclerosis*. Edinburgh: Churchill Livingstone, p. 9.
- Nieves, J., Cosman, F., Herbert, J., et al. (1994). High prevalence of vitamin D deficiency and reduced bone mass in multiple sclerosis. *Neurology*, 44, 1687–1691.
- Nosek, M.A., Howland, C.A., Young, M.E., et al. (1994). Wellness models and sexuality among women with physical disabilities. Baylor College of Medicine, Houston, TX.
- Sadovnick, A.D., Eisen, K., Hashimoto, S., et al. (1994). Pregnancy and multiple sclerosis. *Archives of Neurology*, 51, 1120–1124.
- Witmer, J.M., Sweeney, T.J. (1992). A holistic model for wellness and prevention over the life span. *Journal of Counseling and Development*. 71, (2), 140–148.

This page intentionally left blank

CHAPTER 9

Interfacing with Rehabilitation Services

Patricia M. Kennedy, RN, CNP

“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).

Larsen (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.

This chapter discusses the definitions and goals of rehabilitation, the rehabilitation team, the interdisciplinary approach to MS management, and the purpose and function of the rehabilitation team in the acute care,

home care, and outpatient settings. The role of the nurse in rehabilitation is addressed relative to case management, data collection, and both preventative and restorative care.

DEFINITION OF REHABILITATION

To rehabilitate is defined by Webster (1980) as “to restore to a condition of health or useful and constructive ability” (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 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 in order to minimize disability and handicap and maximize quality of life” (Thompson, 2000).

The American Nurses Association, Division of Medical–Surgical Nursing Practice, and the Association of Rehabilitation Nurses 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 pamphlet, *Rehabilitation Nurses Make a Difference* (2000), 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* since the latter reflects a dynamic process.

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 possi-

ble 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).

It is disheartening to realize that some nurses (and doctors) do not have a rehabilitation focus, particularly toward patients with chronic illness. Chronic illnesses are rarely cited in the rehabilitation literature. The nurse manager of a rehabilitation unit stated, "My staff and I don't like to work with multiple sclerosis patients. They usually don't improve. It's very frustrating." Nurses working with MS patients in the acute care, home care, and outpatient settings need to be cognizant 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 Association of Rehabilitation Nurses, which is now approaching 10,000.

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 rehabilitation for the patient with MS are to restore optimum function in the self-care activities of daily living, assist the patient and family to adjust to the disability, maximize the potential of each individual, and foster a wellness-oriented lifestyle.

THE REHABILITATION TEAM: AN INTERDISCIPLINARY APPROACH

Unlike many other neurologic disorders, people with MS exhibit a wide variety of symptoms, often differing over time. Classically, the patient with a spinal cord injury knows the level of impairment and a rehabilitative plan of care can be developed based on the location of the severance of the cord. Due to the variability of symptoms caused by multi-level 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 plaques, dysfunction may vary widely among patients. Indeed, an ongoing, goal-oriented program of varying intensity, rather than a one-time rehabilitation program, is

recommended by Coville (1983). Cobble and Burks (1985), Maloney (1985), and Hunter and Popp (2000) 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.

An interdisciplinary model is required by both the Joint Commission on Accreditation of Health Care Organizations (JCAHO) 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, 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, 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 (Diller, 1990; O'Toole, 1992; Cobble & Burks, 1985; Kipnis, 1993; Hunter & Popp, 2000). 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 based on open communication, establishing trust and rapport, sharing information, respect for the feelings of the patient, ability to listen, clear and concise information transferral, 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- and community-based. (These are referenced from Cobble & Burks, 1985; DeLisa, Martin, & Currie, 1993; Cobble et al., 1993; Hoeman, 1996; Schapiro, 1991; LaRocca, Kalb, & Kaplan, 1987.)

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/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, as a cooler environment will reduce the risk of elevating body temperature, which leads to fatigue. Gentle, 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, exercise 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. Studies at The Heuga Center in Vail, Colorado, and the Fairview MS Center in Minneapolis, Minnesota (Schapiro, 1995) demonstrated that individuals with MS were capable of engaging in serious exercise. The outcome of the study revealed that their MS did not worsen; indeed their general well-being improved and there was an improvement in their ability to exercise. It is clear that individuals with MS can exercise and, although their disease may not show improvement, their hearts, lungs, skin, and mental awareness can benefit with no fear of loss to their neurologic function (Schapiro, 1995).

Keep in mind that 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, while relaxation exercises such as visualization, yoga, biofeedback, and bodywork can be effective in stress reduction (Schapiro, 1995; Johnson et al., 1999).

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 (*Drug & Ther Perspect.*, 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 activities of daily living. Emphasis is on the upper extremities in such areas as maintaining and improving joint range of motion, muscle strength, coordination, endurance, and dexterity. Occupational therapists 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.

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 swallow 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 such areas 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 profes-

sional 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 (or social worker) 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 a number of 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/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/counseling groups and individual, group, and family counseling.

Recreational Therapist

The recreational therapist utilizes 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 workspace 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 and discussed in Chapter 4. According to Holland and Francabandera (1987), “urinary symptoms are common in multiple sclerosis (MS), with as many as 80 percent of individuals affected at some time during the course of the disease.” 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 patient/family members, including intermittent self-catheterization if indicated. In addition to assessing bladder function, evaluation of hand function, transfers, and sitting/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, as they represent increasing disability and may be perceived also as increasing dependence. It is important to stress that while 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 rigidity of thinking is present, intervention by a psychologist may be helpful.

Common ambulation aids include one or two canes, a quad cane, lightweight forearm crutches, ankle-foot orthoses, 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, physiatrist, nurse, psychologist, and social worker. Environmental factors—such as doorway and bathroom dimensions in the individual’s home and workplace—are a consideration (Schapiro, 1991; Hoeman, 1996).

In addition to mobility aids, there are catalogs full of available tools to assist with most activities of daily living. This 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 this equipment.

Technological advances have opened the doors for people with disabilities. Computer use is now possible with assistive devices such as modified mice, software to eliminate the mouse, voice recognition software, or screen magnification. This opens up opportunities for employment, leisure, and communication outside the home. Also available are various environmental control systems that promote greater, safer independence in the home.

THE REHABILITATION TEAM IN THE ACUTE CARE, HOME CARE, AND OUTPATIENT SETTINGS

The mission of rehabilitation is to treat the multiple needs of the individual as a whole. Ideally, rehabilitation should begin at the time of diagnosis, with evaluation early in the disease process and reevaluation as changes in condition or function warrant. Team emphasis should focus on wellness because people who perceive themselves as being well may extend themselves to a full range of activities within the rehabilitation process and gain a sense of control over their lives. The World Health Organization (WHO) defines health as “. . . the state of complete physical, mental and social well-being, and not merely the absence of disease or infirmity” (WHO Constitution, 1946). According to Holland (1992) and Francabandera (1992), the contemporary view of health is not strictly the absence of disease as this is not always a possibility. When viewed as a goal for everyone, health is the optimal level of function and well-being within possible limitations imposed by an emotional or physical impairment.

The following factors are important if rehabilitation is to succeed: a motivated patient, attainable goals, a team effort, and on-going emotional support. Keep in mind that the desired outcome of rehabilitation for the patient with MS is primarily an improved quality of life.

There is a developing shift away from inpatient settings toward the delivery of rehabilitation services in the home and other community-based settings. The current economic climate offers limited availability of financial resources for health care. This has given impetus to regulatory systems such as Diagnostic-Related Groups (DRGs) and Medicare Prospective Payment, which have resulted in intense scrutiny of the need for and length of hospitalization. At this time, inpatient rehabilitation is exempt from DRGs in some states. Increased financial incentives are being offered to hospitals to reduce costs and discharge patients more quickly. In some instances patients will receive their entire rehabilitation program in the home (Hoeman, 1996).

Medicare policies change frequently. Hospitals, home health agencies and outpatient rehabilitation facilities have to revise their care based on the new changes. HMO's are always striving to keep expenses low and have become more restrictive on allowable services. It is imperative that all care providers who order rehabilitative services or those who provide those services document need, progress, and outcomes.

Subacute units are emerging as a kind of “step-down unit” from the acute care hospital, bridging the gap before returning home. Rehabilitation can be initiated on a short-term basis in a controlled setting while allowing for more patient independence. The unit is often freestanding but connected to an acute care facility, with considerably less cost than the

acute care hospital. Medicare will generally reimburse for two to three weeks of therapy, whereas other insurance types usually will approve a 7 to 10 day stay with a review each week to ascertain realistic goals. The patient usually receives about 3 hours of therapy (PT, OT, bladder management, counseling) daily as needed, but often at a slower pace than in the acute care setting. The key to a successful program is family involvement. Upon discharge the patient often continues with home care or outpatient rehabilitation services.

RESEARCH STUDIES

A number of studies looked at the benefit of inpatient rehabilitation. Solari et al. (1999) reported that in spite of 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 et al. (1999) studied the carry over of benefits gained after a short period of inpatient rehabilitation. They found benefits were gained after discharge in spite of 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 MS patients, which was maintained in part following discharge.

Francabandera et al. (1988) examined the effects of inpatient vs. outpatient rehabilitation using comparison groups, with early reports corroborating Feigenson's findings. Initial reports at 3-month follow-up indicated that the inpatient group showed less disability on the Incapacity Status Scale (ISS) than the outpatient group. The ISS is similar to the Barthel Index and looks at activities of daily living such as mobility and self-care. However, both groups showed a gradual worsening of their disability over the next 9 months. By the 12-month evaluation, both groups were back where they had started with no difference between them. The results of the study suggested that while inpatient rehabilitation might have some initial advantage over outpatient treatment, any such advantage was short-lived. The implication of these findings is that patients with MS may need a course of rehabilitation periodically, perhaps every 12 months or so, in order for any gains to be preserved (LaRocca & Kalb, 1992).

THE FUTURE OF MULTIPLE SCLEROSIS REHABILITATION

As noted previously, the future of rehabilitation appears to lie in the outpatient setting, and inpatient rehabilitation may largely disappear except for selected cases. It is projected that the acute care setting will provide a brief rehabilitation period, almost an orientation for the outpatient arena. Increasing emphasis is on outpatient modalities that are monitored closely. Outpatient settings meet the needs of some patients and can provide a “refresher course” of skills previously learned, providing for reevaluation and perhaps a redefinition of treatments and skills. This method of rehabilitation tends to be short term, since fatigue, difficulty traveling, and limited availability of family members may be limiting factors. Frequent recertification is required with demonstrated progression toward documented goals. Insurance companies such as HMOs do not generally pay for what is considered “maintenance” therapy. Chances for reimbursement are improved when it can be reconceptualized as “preventive” therapy, with specific goals defined. Home care has the advantage of providing learning of skills in a familiar setting in which the patient is comfortable. The patient may feel more in control of his or her environment and have the support of family and friends who are willing and available to participate in the rehabilitation process. Also, skills can be directly practiced in the environment where they will be used on a long-term basis. A well-coordinated team effort with definite goals and coordination by the nurse is imperative for successful implementation. The cost of this rehabilitation setting is generally less than for the inpatient setting.

At any point in time, people with MS may need services in inpatient (acute care), home care, or outpatient settings. The best approach to rehabilitation is a system in which patients can utilize a variety of services based on their needs at that particular time, with rehabilitation concepts incorporated into the plan of care regardless of the setting. Even the obstetrical nurse needs to initiate a plan for the postpartum MS patient to resume maximal function as quickly as possible.

QUALITY IMPROVEMENT

Healthcare providers can no longer *say* that an intervention has “good outcomes” but must *prove* it to inquiring patients, families, third-party intermediaries, risk managers, and the professionals involved in the care. The processes of assessment and management of programs, and patient care problems must be looked at in an effort to demonstrate that care is effective and efficient. The health care provider must prove the efficacy of care and services provided through quality assurance activities and program evaluation (Patterson, England, & Glass, 1989).

Components of a quality improvement (QI) program should encompass activities that enhance the effectiveness of patient care, improve the delivery of health care, and result in reaching expected outcomes. External regulatory bodies such as the Joint Commission on Accreditation of Healthcare Organizations (JCAHO), the Commission on Accreditation of Rehabilitation Facilities (CARF), and nursing organizations such as the American Nurses Association (ANA) and the Association of Rehabilitation Nurses (ARN) are instrumental in setting standards for determining quality of care. JCAHO identified “quality assurance monitoring and evaluation” standards while CARF identified “program evaluation” standards. Two quality assurance models have been identified by Kipnis (1993) as being of value to nurses involved with QI at the unit level. The ANA’s conceptual model promotes quality improvement utilizing a cyclic process that is concordant with the nursing process. The JCAHO ten-step operational model is an organized process used to monitor, evaluate, and improve the appropriateness and quality of care provided to patients. Quality improvement and quality assurance depict philosophical commitments to the notion of “doing the best you can.” Quality improvement challenges health professionals to measure and monitor quality enhancing, ever-improving methods in the provision of patient care throughout the continuum of care. In an effort to prove that a health care organization can make a positive difference in the lives of the individuals it serves, the Organization demonstrates its commitment to the measurement of quality patient care services (Patterson, England, & Glass, 1989; Kipnis, 1993).

ROLE OF THE NURSE IN REHABILITATION

Case Management

In the complex world of medical care, caring for MS patients can easily become fragmented. In the 1980s, the need for case management was identified and research into 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 MS patients 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. Some examples are:

- ⊃ 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. It is a process that involves the provision of quality health care along a continuum, decreasing the fragmentation of care across settings and enhancing the patient's quality of life and containing 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. These activities 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).

While 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.

Data Collection

Case management is both a process and a system. The process of case management closely follows generic nursing process theory of assessment, planning, implementation, and evaluation. Case management involves the

identification, coordination, procurement, implementation, and evaluation of an integrated series of formal and informal services and support systems provided in a timely and cost-effective manner (McBride, 1992). In rehabilitation settings, the nurse is constantly in a position to assess the MS patient. Assessments need to identify the actual and potential needs of the patient and his/her family. Information about social situations, financial status, psychological state, and physical findings need to be documented in writing and communicated verbally at team meetings. The more the team understands about a patient's strengths and limitations, the more effective the interactions with that patient will be.

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. While sometimes considered insignificant by the patient, problems in these areas can indicate more serious neurologic/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 since 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.

When nurses obtain history indicating cognitive or behavioral dysfunction, this information needs to be shared with the rest of the team. Evaluation by a neuropsychologist is desirable if resources are available. With formal assessment, patients and families can be educated about the problems and offered strategies to lessen their impact, and nurses and other team members can use this information to modify teaching and treatment plans to be more effective. Holland (1992) and Francabandera (1992) acknowledge that family members of individuals with MS play an important role in providing support and assistance to the patient. However, their need for information regarding the disease and the rehabilitation process is frequently overlooked by the health care system.

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. In order 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, 1992; Watson, 1989).

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?

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 from 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.

While 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 an MS patient 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 an impairment before they have explored their actual abilities. When working with patients, it is important to assess 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. Check the state vocational rehabilitation office, your local chapter of the National Multiple Sclerosis Society, independent living centers, and publications

such as *Employment Issues and Multiple Sclerosis* (Rumrill, 1996) to identify services and resources for the MS patient (see Appendix A).

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. The nurse can make a referral to a therapeutic recreational therapist for assistance or to other community resources such as the National Multiple Sclerosis Society.

Educational Needs Assessment

As in any patient-education scenario, before a plan can be formulated, the nurse needs to determine the educational level of the patient, what the patient needs to know and wants to know, and the gaps in patient knowledge. Some patients self-educate about MS from a variety of sources, some of which are more accurate than others. In order to move forward with new education, corrections may need to be made to the old. When the nurse identifies areas in which education would be appropriate, the nurse can convey this to specialized team members or devise a plan of teaching to do him-/herself.

Adult Education

Holland, Wiesel-Levison, and Francabandera (1987) identify the nurse as an educator and interpreter, one who can “. . . explain the disease process and what to expect from it, as well as provide a better understanding about the various symptoms and what causes them” (p. 129).

In considering the learning process of both patients and family members, Orr (1990) believes that individuals are endowed with a natural process, the ability to learn, and a natural curiosity that allows one to view new, often difficult situations as challenges rather than as defeats. The nurse can offer support and education to patients and families in this effort to acquire essential new information.

It is important that patients and families learn that two-thirds of people with MS do not become severely disabled, that one does not die from MS but can expect to lead a reasonably normal life, and that most disabilities are usually temporary or mild to moderate in severity, with all MS-related problems being manageable to some degree. Assessment of the readiness of patients and family members to learn is an integral part of the

process since a better comprehension about MS is related to better health management (Cobble et al., 1993).

Education about MS can occur through interaction with each therapist in addition to formal education such as reading, videotapes, and classes. Another important aspect of education and communication is the participation in regular team/family conferences providing the opportunity to address past progress, time frame, and future plans in a supportive environment (Cobble & Burks, 1985).

The advent of computers has opened up a new arena for learning and communication. A large percentage of people with MS gather information from the Internet. While there are many sites that provide accurate information, there are many that do not. Information in chat rooms is frequently merely subjective and anecdotal but is taken for fact. Providing people with recommended sites is a valuable service (see Appendix).

According to Holland (1992) and Francabandera (1992), both learner- and content-centered approaches are necessary for acquiring MS-related information and skills. Certain content is considered essential for optimal adaptation to this chronic illness requiring content focus. However, the adult education principle of learner-focus is also necessary for pursuit, acquisition, and implementation of the critical learning information.

Knowles views adult education as a “process” by which the “activity” of learning takes place. Knowles (1980) describes adult education: “In its broadest sense, the term describes a process—the process of learning” (p. 25). Six principles of adult learning have been selected from *Workplace Education and the Principles and Practices of Adult Education* (Lawler, 1986), as they are relevant here.

1. *Adult education includes and builds on the experience of the participant.*
Most patients and family members do not have prior knowledge about the disease upon which to build; however, all adults have had experiences that required coping behavior.
2. *Adult education fosters critically reflective thinking.*
Issues such as self esteem and self image, which are important to people with MS and their families, 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.*
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.*

Learning that can be translated into action is important for addressing the physical, emotional, and interpersonal problems presented by MS.

5. *Adult education empowers the participant.*

Brookfield (1985a) 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. (Holland, 1992; Francabandera, 1992).

Chart Review

Because nurses work in a variety of 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 prior to 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 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.

Patient Safety

Opportunities for patient education abound in caring for individuals with MS. As mentioned in Chapter 11, an emphasis on wellness and self care is desired for this population. This is an ongoing process, and all disciplines should coordinate their recommendations with the process in mind. In the face of disabilities, however, function changes and adaptations are needed to promote safety. Patients and families must be aware of risks and know measures they can take to reduce those risks.

For patients who interact with the community through employment, volunteerism, or recreation, health and safety risks also need to be evaluated in those settings and communicated to appropriate members of the team. Problem solving by the person with MS can be done individually with therapists or by team members going to the workplace or recreation setting to evaluate adaptation needs. The team can also work directly with

employers to educate, advise, and facilitate change. The nurse should continue to encourage the patient to access this type of assistance when problems arise.

Barriers in the Community

People with any type of disability face social and physical barriers. Socially, our society continues to discriminate against people who are different. Those who are newly diagnosed often are reluctant to tell others of the diagnosis for fear of their response. Regrettably, these fears are often well-founded. Nurses are taught to advocate for their patients, but it is more important to prepare patients to advocate for themselves. As nurses, we can be supportive. We can educate patients, families, and the community. We can participate in the national advocacy efforts of the National Multiple Sclerosis Society by calling 1-800-FIGHT MS and accessing the local chapter. We can write to our representatives in Congress to educate them about issues facing the disabled and request their support on specific legislation.

The Americans with Disabilities Act of 1992 provides guidelines to the community for making adaptations for people with disabilities. It is hoped that this will lessen the physical barriers experienced by people with MS. If a nurse recognizes a noncompliant situation, she needs to make the patient and family aware of the law. Patients and families may be able to advocate for themselves or may need assistance from the legal community.

CONCLUSION

The following concepts should be inherent in the successful rehabilitation process for an individual with MS. The nurse should recognize the patient as a unique, total human being while emphasizing wellness. The nurse 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.

The author believes this excerpt from a definition of rehabilitation by McEachron, a rehabilitation nurse, has special meaning (truth) for the patient with multiple sclerosis: "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).

REFERENCES

- American Nurses Association and the Association of Rehabilitation Nurses (1988). *Rehabilitation Nursing: Scope of Practice; Process and Outcome Criteria for Selected Diagnoses*. Kansas City, MO: American Nurses Association.
- Bauer, H. (1977). *A Manual on Multiple Sclerosis*. Vienna: International Federation of Multiple Sclerosis Societies.
- Bower, K. (1992). *Case Management for Nurses*. Washington, DC: American Nurses Publishing.
- Britell, C.W., Burks, J.S., Schapiro, R.T. (2000), Introduction to Symptom and Rehabilitative Management: Disease Management Model. In Burks, J.S., Johnson, K.P. (eds.). *Multiple Sclerosis: Diagnosis, Medical Management, and Rehabilitation*. New York: Demos Medical Publishing.
- Brookfield, S.D. (1985a). A critical definition of adult education. *Adult Education Quarterly*, 36, (1), 44–49.
- Burks, K. (1999). A nursing practice model for chronic illness. *Rehabilitation Nursing*, 24 (5), 197–200.
- Cobble, N.D., Burks, J.S. (1985). The team approach to the management of multiple sclerosis. In Maloney, F.P., Burks, J.S., Ringel, S.P. (eds.). *Interdisciplinary Rehabilitation of Multiple Sclerosis and Neuromuscular Disorders*. New York: J.B. Lippincott.
- Cobble, N.D., Dietz, M.A., Grigsby, J., Kennedy, P.M. (1993). Rehabilitation of the patient with multiple sclerosis. In DeLisa, J.A. (ed.). *Rehabilitation Medicine: Principles and Practice*, 2nd ed. Philadelphia: J.B. Lippincott.
- Cohen, E., Cesta, T. (1993). *Nursing Case Management from Concept to Evaluation*. St. Louis: C.V. Mosby.
- Coville, P.L. (1983). Rehabilitation. In Hallpike, J.F., Adams, D.W.M., Tourtellotte, W.W. (eds.). *Multiple Sclerosis: Pathology, Diagnosis and Management*. Baltimore: Williams & Wilkins.
- Dean-Barr, S. (1987). Purpose and function of the rehabilitation team. In Mumma, C.M. (ed.). *Rehabilitation Nursing: Concepts and Practice*, 2nd ed. Evanston, IL: Rehabilitation Nursing Foundation.
- DeLisa, J.A. (ed.). (1993). *Rehabilitation Medicine: Principles and Practice*, 2nd ed. Philadelphia: J.B. Lippincott.
- DeLisa, J.A., Martin, G.M., Currie, D.M. (1993) Rehabilitation medicine: Past, present, and future. In DeLisa, J.A. (ed.). *Rehabilitation Medicine: Principles and Practice*, 2nd ed. Philadelphia: J.B. Lippincott.
- Diller, L. (1990). Fostering the interdisciplinary team, fostering research in a society of transition. *Archives of Physical Medicine and Rehabilitation*, 71, 275–278.
- Dittmar, S.S. (1989). *Rehabilitation Nursing: Process and Application*. Baltimore: C.V. Mosby.
- Tailored physical activity programmes beneficial for patients with MS. (2000) *Drug & Therapy Perspectives*, 15 (8), 7–9.

- Ethridge, P. (1991). A nursing HMO: Carondelet St. Mary's experience. *Nursing Management*, 22 (7), 22–27.
- Feigensohn, J.S., Scheinberg, L., Catalano, M., Polkow, L., Mantegazza, P.M., Feigensohn, W.D., LaRocca, N.G. (1981). The cost-effectiveness of multiple sclerosis rehabilitation: a model. *Neurology*, 31 (10), 1316–1322.
- Fox, N., Aisen, M.L. (1994). Predictors of outcome in multiple sclerosis rehabilitation. *Neurology*, 44 (Suppl 2), April, A313.
- Francabandera, F.L., Holland, N.J., Wiesel-Levison, P., Scheinberg, L.C. (1988). Multiple sclerosis rehabilitation: inpatient vs. outpatient. *Rehabilitation Nursing*, 13 (5), 251–253.
- Francabandera, F.L. (1992). Self-directed learning by family members of individuals with multiple sclerosis. Doctoral Dissertation, Teachers College, Columbia University, 1992. *UMI Dissertation Abstracts*, 5305, 1361.
- Frankel, D.I. (1990). Multiple sclerosis. In Umphred, D.A. (ed.). *Neurological Rehabilitation*, 2nd ed. Philadelphia: C.V. Mosby.
- Freeman, J.A., Langdon, D.W., Hobart, J.C., Thompson, A.J., (1999). Inpatient rehabilitation in multiple sclerosis. Do the benefits carry over into the community?, *Neurology*, 52 (1), 50–56.
- Hickey, J.V. (1992). *The Clinical Practice of Neurological and Neurosurgical Nursing*, 3rd ed. New York: J.B. Lippincott.
- Hoeman, S. (1992). Community-based rehabilitation. *Holistic Nursing Practice*, 6 (2), 32–1.
- Hoeman, S.P. (1996). *Rehabilitation Nursing: Process and Application*, 2nd ed. New York: C.V. Mosby.
- Holland, N.J., Francabandera, F. (1987). Bladder and bowel management. In Scheinberg, L., Holland (eds.). N.J. *Multiple Sclerosis: A Guide for Patients and Their Families*, 2nd ed. New York: Raven Press.
- Holland, N.J., Wiesel-Levison, P., Francabandera, F. (1987). Nursing care. In Scheinberg, L., Holland, N. J. (eds.). *Multiple Sclerosis: A Guide for Patients and Their Families*, 2nd ed. New York: Raven Press.
- Holland, N.J., Kaplan, S.R., Hall, H.L. (1987). Vocational issues. In Scheinberg, L., Holland, N.J. (eds.). *Multiple Sclerosis: A Guide for Patients and Their Families*, 2nd ed. New York: Raven Press.
- Holland, N.J. Self-directed learning by individuals with multiple sclerosis. Doctoral Dissertation, Teachers College, Columbia University, 1992).
- Hunter, K., Popp, N. (2000), *Home Care Management: A Model for an Interdisciplinary Approach*. In Burks, J.S. Johnson, K.P. *Multiple Sclerosis: Diagnosis, Medical Management, and Rehabilitation*. New York: Demos.
- Kipnis, N.D. (1993). The rehabilitation team: composition, models, function and issues. In McCourt, A.E. (ed.). *The Specialty Practice of Rehabilitation Nursing*, 3rd ed. Skokie, IL: Rehabilitation Nursing Foundation.
- Knowles, M. (1980). *The Modern Practice of Adult Education: From Pedagogy to Andragogy*. Chicago: Follett.
- Kraft, G.H., (1999) Rehabilitation still only way to improve function in multiple sclerosis. *The Lancet*, vol. 354, 2016–2017.

- LaRocca, N.G., Kalb, R.C., Kaplan, S.R. (1987). Psychological issues. In Scheinberg, L.C., Holland, N.J. (eds.). *Multiple Sclerosis: a Guide for Patients and Their Families*, 2nd ed. New York: Raven Press.
- LaRocca, N.G., Kalb, R.C. (1992) Efficacy of rehabilitation in multiple sclerosis. *Journal of Neurological Rehabilitation*, 6 (3), 147–155.
- Larson, P. (1995). Rehabilitation. In Lubkin, I.M. (ed.). *Chronic Illness: Impact and Interventions*, 3rd ed. Boston: Jones and Bartlett.
- Lawler, P. (1988). Workplace education and the principles and practices of adult education. Unpublished doctoral dissertation, Columbia University, Teachers College, New York.
- Lechtenberg, R. (1988). *Multiple Sclerosis Fact Book*. Philadelphia: F.A. Davis.
- Maloney, F.P. (1985). Rehabilitation of patients with progressive and remitting disorders. In Maloney, F.P., Burks, J.S., Ringel S.P. (eds.). *Interdisciplinary Rehabilitation of Multiple Sclerosis and Neuromuscular Disorders*. Philadelphia: J.B. Lippincott.
- McBride, S. (1992). Rehabilitation case managers: Ahead of their time. *Holistic Nursing Practice*, 6 (2), 67–75.
- McCourt, A.E. (1993). *The Specialty Practice of Rehabilitation Nursing: A Core Curriculum*, 3rd ed. Skokie, IL: Rehabilitation Nursing Foundation.
- Orr, R. (1990). Illness as an educational opportunity. *Patient Education and Counseling*, 15, 47–48.
- O'Toole, M.T. (1992). The interdisciplinary team: Research and education. *Holistic Nursing Practice*, 6 (2), 76–83.
- Patterson, C.H., England, B., Glass, R.M. (1989). What is quality rehabilitation? In England, B., Glass, R.M., Patterson, C.H. (eds.). *Quality Rehabilitation: Results Oriented Patient Care*. USA: AHA, American Hospital Publishing.
- Petajan, J.H., Gappmaier, E., White, A.T., Spencer, M.K., Mino, L., Hicks, R.W. (1996). Impact of aerobic training on fitness and quality of life in multiple sclerosis. *Annals of Neurology* 39 (4), 432–41.
- Petajan, J.H., White, A.T. (1999). Recommendations for physical activity in patients with multiple sclerosis. *Sports Medicine*, 27 (3), 179–191.
- Rosner, L.J., Ross, S. (1992). *Multiple Sclerosis: New Hope and Practical Advice for People with MS and Their Families*. New York: Simon & Schuster.
- Rumrill, P.D., Jr. *Employment Issues and Multiple Sclerosis*. New York: Demos Vermande, 1996.
- Solari, A., Filippini, G., Gasco, P., Colla, L., Sallimaggi, A., LaMantia, L., Farinotti, M., Eoli, M., Mendozzi, L. (1999). Physical rehabilitation has a positive effect on disability in multiple sclerosis patients. *Neurology* 59, (57) 57–62.
- Schapiro, R.T. (1991). *Multiple Sclerosis: A Rehabilitation Approach to Management*. New York: Demos.
- Schapiro, R.T. (1995). Rehabilitation. Exercise and multiple sclerosis. *MS Management*, 2 (2), 35–38.
- Scheinberg, L., Smith, C.R. (1987). Rehabilitation of patients with multiple sclerosis. Neurologic rehabilitation. *Neurologic Clinics*, 5 (4), 585–600.
- Tahan, H.A. (1999). Clarifying Case management: What is in a label?. *Nursing Case Management*, 4 (6), 268–278.

- Thompson, A.J., (1998). Multiple sclerosis: rehabilitation measures. *Seminars in Neurology*, 18 (3), 397–403.
- Thompson, A.J., (2000) The effectiveness of neurological rehabilitation in multiple sclerosis. *Journal of Rehabilitation Research and Development*, 37 (4), 455–461.
- Thompson, S., (1996). Providing a neuropsychology service for people with multiple sclerosis in an interdisciplinary rehabilitation unit. *Disability and Rehabilitation*, 18 (7), 348–353.
- Thurgood, A. (1990) Seven steps to rehabilitation. *Nursing Times*, 86 (25), 38–41.
- Watson, P. (1989). Indicators of family capacity for participating in the rehabilitation process: A report of a preliminary investigation. *Rehabilitation Nursing*, 14 (6), 318–321.
- Watson, P. (1992). Family issues in rehabilitation. *Holistic Nursing Practice*, 6 (2), 51–59.
- Woolf, H.B., et al. (eds.) (1980). *Webster's New Collegiate Dictionary*. Springfield: G. & C. Merriam.
- World Health Organization Constitution*. (1946, June 19–22). Adopted at the International Health Conference, New York, NY.

CHAPTER 10

Pharmacotherapeutics in Multiple Sclerosis and Nursing Implications

June Halper, MSN, ANP, FAAN

IMMUNOMODULATION IN MULTIPLE SCLEROSIS

During the past decade, clinical trials into effective treatments for multiple sclerosis (MS) have proliferated. Agents that can reduce central inflammatory demyelination are of particular interest (Fang & Lublin, 1995). Of the many agents that have claimed therapeutic benefit, only a handful have actually been effective in MS. As also noted in Chapter 2, spontaneous remissions of the disease along with a strong placebo effect shown to be present in MS have frequently fooled investigators (Fang & Lublin, 1995). Most disease-altering therapies in MS act by interfering with immune function. These newest treatment strategies represent an effort to alter the immune system and control the immunologic cascade that results in demyelination. The first generation of these drugs are the beta interferons, proteins that are manufactured by the body in response to a foreign stimulus (McDonald, 1995) (see Table 10-1). While three interferons (Betaseron[®], Avonex[®], and Rebif^{®*}) are currently used worldwide for relapsing forms of MS; interferon-beta-1b, only Betaseron[®], is approved in Europe (as Betaferon[®]) for secondary progressive disease. Although interferons are closely related, they differ in their mode of preparation, dosage level, and routes of administra-

*Rebif[®] is not currently approved for use in relapsing MS in the United States, but is expected to be available no later than 2003.

TABLE 10-1. Disease Altering Therapies in MS

Drug and Dosage	Route of Administration	Side Effects and Nursing Implications
Interferon beta-1a Avonex 30 mcg IM q week	IM	Fever, chills, myalgia, asthenia, depression. Patient must be taught to reduce side effects with dose titration, injection in the evening, NSAIDS. Requires blood work (CBC, LFT's) at baseline, q 3 months then q 6 months thereafter. Needs reconstitution.
Interferon beta-1-a Rebif 22 mcg 3x q week 44 mcg 3x q week	SQ	Same as above for SE and blood work Site rotation required to prevent skin reaction Has prefilled syringes with auto injector
Interferon-beta-1b Betaseron 8 ml U qod	SQ	Depression, injection site reaction, myalgia, fever, chills, menstrual irregularities. Same as above for SE management and blood work. Site rotation required. Has auto injector.
Glatiramer Acetate Copaxone 20 mg qd	SQ	Rare post-injection reaction with flushing, dyspnea, and anxiety. Injection site reaction Patient education re: side effects, need for site rotation, and reassurance about potential post-injection reaction. Has auto injector.
Aza-Thioprine Imuran Dosage range from 50–200 mg	PO	Leukopenia lymphocytopenia. Patient must have CBC LFT's. Patient education important for monitoring blood values
Mitox-antrone (Novantrone) 12 mg/m ² cumulative dose 140 mg/ m ²	IV	CBC, LFT's, echocardiogram or MUGA at baseline and regularly by Rx required. Side-effects include myelosuppression, alopecia, secondary amenorrhea, cardiotoxicity. Patient education regarding SE and avoidance of infections. Need to adhere to follow up with blood work and cardiac monitoring.
Methotrexate 7–10 mg weekly	PO	Myelosuppression, vasculitis, nausea, vomiting. Patient education required to sustain adherence.
Cyclophos-Phamide with or without seroids or ACTH	IV	Myelosuppression, alopecia, secondary amenorrhea. Blood work required. Patient and family education to avoid infection.

Source: Adapted from Keegan & Noseworthy, 2002; Paty & Ebers, 1998.

tion. Each of these regimens involves injectable medications and thus requires extensive patient and family education about drug reconstitution, self-injection (or with family assistance) with site rotation, and the need for regular laboratory testing to monitor for hematologic or hepatic side effects.

A different type of immunomodulation approved by the FDA in 1996 for relapsing MS is an injectable combination of synthetic polypeptides

called glatiramer acetate or Copaxone®. It is the first non-interferon, non-steroidal agent approved for relapsing MS. It also, is self-injected and its administration requires extensive patient and family education and support (Holland & Halper, 1999)

IMMUNOSUPPRESSION IN MULTIPLE SCLEROSIS

Immunosuppressants have a long history of use in MS. Azathioprine and methotrexate are oral preparations; cyclophosphamide is administered intravenously although it may be prescribed in a tablet form (Hauser et al., 1985). Mitoxantrone (Novantrone®) was approved by the FDA in 1999 for worsening forms of MS. It may cause myelosuppression, amenorrhea, and cardiac complications, and its use may be limited to patients with continuing clinical deterioration and poor responsive to traditional immunotherapeutic agents (Keegan & Noseworthy, 2002).

SYMPTOMATIC MANAGEMENT IN MULTIPLE SCLEROSIS

Symptom management in multiple sclerosis can be as vital as modifying the disease course. As described by Schapiro and Schneider (see Chapter 3), managing symptoms of MS may be a complex and dynamic challenge for patients and their families. Symptoms are variable and can be addressed through a variety of strategies, both pharmacotherapeutic and nonpharmacotherapeutic. In addition, patients may be asked to assume the responsibility for bowel and bladder management, rehabilitation techniques, home modification, and life planning.

EDUCATIONAL CHALLENGES IN MANAGING MULTIPLE SCLEROSIS

Nurses are confronted with a number of challenges when educating patients about treatments in MS. Unlike the insulin-dependent diabetic who is able to monitor glucose levels in blood and urine for treatment effectiveness, patients with MS cannot expect to see such dramatic results with disease modifying agents. In fact, some patients may initially feel worse with treatment because of side effects of the medications. The health care team (physicians and nurses) initially must determine who is eligible for which medication based on research data, the patient's clinical course, and his/her physical and cognitive capabilities. Since many of these medications are administered parenterally, they may or may not be covered by health insurance. Nurses may have to identify those patients who require

assistance to obtain coverage under their insurance plans. The most daunting endeavor is educating patients and their families about the proper use of the prescribed injectable product: storage, reconstitution, injection, site rotation, and monitoring for side effects. Training, education, and support—all of which promote an informed patient and family—have been shown to improve adherence to a protocol and reduce noncompliance.

In terms of symptom management, patients must be educated to the purpose of the prescribed regimen and to the proposed therapy. Bladder management may require a combination of medications, behavior modification, and/or catheterization. Bowel control may require dietary modification, medications, and environmental restructuring. Reduction of spasticity may include medications, the services of a rehabilitation team, and a home exercise program.

Managing MS requires patient and family education and support. The MS nurse is the ideal person to provide education from the perspective of ideological and practical perspectives (Leino-Kilpi & Luoto, 2001). The ideological perspective stresses the role that information plays in contributing to patient autonomy, dignity and self-respect. The practical perspective underlines the role that information plays in the patient–nurse interaction. Patients who understand more about their condition will show a stronger commitment to the success of their care. (Leino-Kilpi & Luoto, 2001).

THE PSYCHOEDUCATIONAL APPROACH

The psychoeducational approach to patient and family education differs from teaching methods that impart didactic material and then respond to the learner's needs (see Table 10-2). Psychoeducation, which is currently employed by many MS centers throughout the United States and Canada, is a rather complex procedure that has been found to be effective in promoting adherence to medication regimens and treatment protocols (Marciniak

TABLE 10-2. Psychoeducation versus Traditional Learning Model

Psychoeducation	Traditional Learning
Learner's perspective is determined before teaching is initiated.	Teaching is initiated based on material to be learned.
Goals and objectives are explained in light of learner's expectations.	Goals and objectives are predetermined by learning material.
Teaching is dynamic and individualized.	Teaching is standardized for each person.
Teaching is reinforced with additional learning material and hands-on activities.	Teaching may include other learning activities such as additional material and hands-on activities.

et al., 1991). Current literature suggests that adherence is a dynamic process that implies a partnership between the patient and the health care team, whereas compliance is a patient's unquestioning fulfillment of a physician's instructions (Brooks, 1985). Today's health care consumers, particularly patients with MS, tend to be more informed and cautious about new procedures. Therefore, innovative approaches are strongly indicated in educational activities that involve self-care and self-responsibility. Additionally, culturally sensitive interventions along with the attitude of health care providers have been shown to improve adherence (Elliott, 1994).

The psychoeducational approach begins with the health care professional determining the goals and expectations that the patient has for the prescribed treatment. By eliciting this perspective, the nurse then has the opportunity to clarify perceptions and clear up misconceptions of anticipated outcomes. For instance, if a treatment is seen as a cure rather than as a palliative intervention, the patient and family will be disappointed about outcomes and the patient is likely to discontinue therapy fairly quickly. Should the treatment bring the additional burden of side effects, disappointment will be compounded and one may expect a more abbreviated treatment program. The patient's educational and cultural background along with his or her previous experience with health care providers must be taken into consideration when providing health care education and information. Patient and family education may be enhanced with printed material, media support, such as audiotapes or videotapes, and written instructions tailored to the patient's needs. Psychoeducation is consistent with an emerging concept in chronic illness: comprehensive care that is proactive and whose goal is empowerment and patient involvement (Halper & Burks, 1994). This model has proven to be valuable for a regimen that presumes patient responsibility, self-monitoring, and accurate feedback to the health care team.

ASSESSMENT OF LEARNING STYLES

People learn in different ways: visually, through auditory stimuli, through kinesthesia, or via vicarious experiences. People have a preference in how they gather information. Visual people gesture, use pictures, use words, like to look, see and hear. Auditory people talk in strong voices, look left and right as they speak, and use words like sound, click, and hear. Kinesthetic people need to touch, feel, and both give and receive warmth. Those who learn via vicarious experiences enjoy multi-media types of tools: computers, videotapes, and other opportunities to watch others perform particular tasks (Chase, 2001).

Individuals often use multiple learning channels. A skilled nurse must remember to utilize a variety of learning tools and provide sensory input

for all preferences. Educational interventions must be designed according to a patient's previous learning styles and should incorporate these principles. Nurses who embark on patient and family education should integrate these principles into their teaching/learning activities (Leino-Kilpi & Luoto, 1999).

AN EXAMPLE: TEACHING PATIENTS COMPLEX INJECTABLE PROTOCOLS

Current disease modifying treatment options in MS are complex and can be frightening to patients since they involve self-injection. The psychoeducational design includes a care partner who can coach, assist, and occasionally substitute for the patient. The teaching program can be divided into a number of sessions to reduce information overload and allow for absorption of the new material. During the first meeting, the nurse may determine the patient's expectations of the treatment and his or her concerns about side effects, insurance coverage, self-injection, and the prior experiences of other patients. The nurse should discuss goals for treatment, expected side effects, and previous research outcomes with potential relevance to the patient. The nurse, patient, and care partner can, at this time, simulate the injection technique using an orange or another convenient device. At the end of the session, the patient should be given educational material to study prior to the next visit.

At the second visit, previous material may be reviewed and the patient's goals and objectives for treatment may be discussed once more. Technical skills may be developed at this time, including site rotation, reconstitution, and the injection itself.

The third, and most likely final teaching visit, should consist of another discussion of the patient's perceptions about the treatment. At this time, the patient will demonstrate drug reconstitution and actually inject the medication. Additional visits may or may not be required but patients should be encouraged to call regularly until they feel comfortable with the procedure. Following the initial injection, patients are usually seen every 3 months for the first year, in the case of interferons, and when interferons are used, laboratory studies are performed at each visit (usually CBC and liver profile). Glatiramer acetate (Copaxone®) does not require ongoing monitoring for liver or laboratory abnormalities. A vital part of the psychoeducational approach is clear and effective communication (see Table 10-3) (Leino-Kilpi & Luoto, 2001).

Glatiramer acetate does not require ongoing monitoring for liver or laboratory anomalies.

TABLE 10-3. Key Points for Effective Communication

-
- ▷ Be brief and succinct.
 - ▷ Ask that patients repeat instructions in their own words to clarify misunderstandings.
 - ▷ Supplement verbal instructions with written instructions.
-

COMMUNICATING AND CARING

Due to its variety of courses and unpredictable symptoms, MS imposes uncertainty into the lives of patients (Bansil, Troiano, & Dowling, 1993). Current treatment options to date have not resulted in the cure for MS that is the hope of patients and families. This painful reality can lead to disappointment and frustration unless potentially positive outcomes are pointed out at the onset of treatment. Thus, the nurse is not only faced with the challenge of technical education and development of skills, but the responsibility to clarify what patients can expect. Complicating this process is the fact that some patients have problems with cognition, as evidenced by difficulty in understanding and learning new tasks (Rao, 1986). It is important to include written material to reinforce learning. Currently, manufacturers of injectable and intravenous medications are providing both written and audiovisual support to assist with patient education and will supply them to the nurse upon request. Including a care partner in the learning process may increase the patient's comfort level and provide him or her with a backup if difficulties occur with self-injection. These strategies will assist the nurse to promote a successful integration and retention of learned material in order to achieve patient adherence to the prescribed protocol (Fraser, Hadjimichael & Vollmer, 2001).

OUTCOMES OF THE PSYCHOEDUCATIONAL MODEL

The psychoeducational approach to patient and family education has proven to be very effective in promoting patient adherence to complex procedures. Utilizing psychoeducational interventions, important skills are taught in a therapeutic rather than a didactic setting. By responding to individual needs and concerns regarding a complex injectable protocol, intermittent self-catheterization, or other self-care care activities, the nurse can realistically assess the patient's understanding of anticipated side effects and his or her skill development for the injection process. Through continuous communication regarding questions or concerns, the nurse is able to impart caring and concern and provide the support that is required for new treatment options. Helping patients to incorporate important self-

care activities related to their MS into their daily lives is thus an important outcome of this approach.

REFERENCES

- Bansil, S., Troiano, R., Dowling, P., et al. (1993). Advances in the pharmacological and neurological treatment of patients with multiple sclerosis. *Neuro Rehabilitation*, 3 (4), 1.
- Brooks, N.A. (1985). Opportunities for health promotion: Including the chronically ill and disabled. *Social Science Medicine*, 19 (405).
- Chase, TM. Learning styles and teaching strategies. Enhancing the patient's education experience. *SCI Nursing*. 18(Fall 2001): 18, 138-141.
- Elliott, W.J. (1994). Compliance strategies. *Current Opinions Nephrology Hypertension*, 3 (3), 271.
- Fang, J.Y., Lublin, F.D. (1995). Altering the course of multiple sclerosis. *Internal Medicine*, 16 (1), 13.
- Fraser, C., Hadjimichael, O., Vollmer, T. Predictors of adherence to copaxone therapy in individuals with relapsing-remitting multiple sclerosis. *Journal of Neuroscience Nursing*, 33(October 2001): 5, 231-239.
- Hauser, S.L., Dawson, D.M., Lehrich J.R. et al. Intensive immunosuppression in progressive multiple sclerosis. *NEJM* 308(1985): 173-180
- Holland, N.J., Halper, J. Primary care management of multiple sclerosis. *Advance for Nurse Practitioners* 7 (March 1999): 3, 26-34.
- Halper, J., Burks, J.S. (1994). Care patterns in multiple sclerosis. Principal care, comprehensive team care, consortium care. *Neuro Rehabilitation*, 4 (2), 67.
- Keegan, B.M., Noseworthy, J.H. *Multiple Sclerosis. Current Therapy in Neurologic Disease*. John, R, Griffin, J.W., McArthur, J.C. (eds.) St. Louis, MO: Mosby, 2002, 181-187.
- LaRocca, N.G., Kalb, R.C., Foley, F.W., et al. (1993). Psychosocial, affective, and behavior consequences of multiple sclerosis: treatment of the "whole" patient. *Neuro Rehabilitation*, 3 (4), 30.
- Leino-Kilpi, H. Luoto, E. The multiple sclerosis nurse as patient educator. *Journal of Neuroscience Nursing*. 33(April 2001):2, 83-89.
- Marciniak, M., Johnson, B., Foley, F.W., et al. (1991). The use of the Levo chair in the management of multiple sclerosis. Presented at the Consortium of Multiple Sclerosis Centers Conference. June 15-17, 1991. Halifax, NS, Canada.
- McDonald, W.I. (1995). New treatments for multiple sclerosis. *BMJ*, 310, 345-346.
- Paty, D.W., Ebers, G.C. (eds.) *Multiple Sclerosis*. Philadelphia: FA Davis, 1998.
- Platt, F.W., Tippy, P.K., Turk, D.C. (1994). Helping patients adhere to the regimen. *Patient Care*, 30-43.
- Rao, S.M. (1986). Neuropsychology of multiple sclerosis: A critical review. *J Clin Exp Neuropsychology*, 8 (5), 503-42.

CHAPTER 11

Complementary and Alternative Therapies

June Halper, MSN, ANP, FAAN

Interest in alternative medical therapies has been steadily increasing. A 1990 Harvard study revealed that of 1,539 people surveyed, one out of three had used some kind of alternative medical therapy during the past year (Eisenberg et al., 1993). Based on this survey, it was calculated that 425 million visits were made to alternative practitioners versus 388 million visits to primary care physicians (Eisenberg et al., 1993). Alternative therapy can be defined as any approach to solving a health problem that is different from approaches used by practitioners of Western medicine (Fugh-Berman, 1995). It might be more accurate to call some of these therapies *complementary*, since they are designed to complement rather than replace conventional medical practice (Fugh-Berman, 1995). This trend in health care has been given the acronym CAM—Complementary and Alternative Medicine, although this author prefers to refer to this as named in the title of this chapter. Increased interest in complementary and alternative therapies has generated many new publications; the most recent in multiple sclerosis is by Bowling (2001), and is frequently referenced in this chapter.

The percentage of patients with chronic illnesses using alternative therapies is higher than that of the general population. In a survey of 184 HIV-positive patients in Philadelphia, 40 percent reported using alternative therapies; another study found that 55 percent of Alzheimer's caregivers had tried at least one alternative therapy to improve their patient's memory (Eisenberg et al., 1993). A study conducted by the National Multiple

Sclerosis Society revealed increased utilization of alternative therapies by more educated patients with multiple sclerosis (Pignotti, 1996). Thus, it is important for nurses to be aware of issues relating to alternative or complementary therapies that may be raised by their patients with MS. Many private foundations are interested in alternative therapies and the NIH has established an Office of Alternative Medicine. The following is an overview of therapies frequently mentioned in contemporary literature (see also Table 11-1).

ACUPUNCTURE

Acupuncture is the insertion of hair-thin needles into specific points on the body to prevent or treat illness. It is one component of traditional Chinese medicine (TCM), an integrated system that has been used for over 2,000 years (Fugh-Berman, 1995). There is a great deal about this treatment that

TABLE 11-1 Complementary and Alternative Therapies or CAM

Category	Definition	Examples
Alternative systems		Theories or practices that preceded Western medicine or that evolved alongside and in addition to traditional medicine
Asian medicine		Emphasis on proper balance and the disturbance of vital energy (qi) in sickness and in health (respectively)
Acupuncture		
Herbal medicine		
Oriental massage		
Homeopathy		Unconventional Western system based on "like cures like"; i.e., the same substance in large doses produces illness; in minute doses, cures it
Mind-body interventions		A variety of techniques that facilitate mental healing (e.g., dance, music)
Biologic treatment		Natural and biologically based interventions; herbal and special diets
Manipulative/body based systems		Methods based on manipulation and/or movements of the body; chiropractic and osteopathic medicine
Energy therapies		Systems based on energy fields originating in the body; Qi gong, Reiki, therapeutic touch

Source: Adapted from Bowling (2001).

we do not clearly understand, and there have been no definitive studies of its use in MS. There have been some anecdotal reports that acupuncture may be beneficial for some symptoms of MS, particularly pain (Kraft & Catanzaro, 1996).

HYPNOTHERAPY AND IMAGERY

There are two contemporary schools of hypnosis. Traditional hypnosis works with enhanced suggestibility, which occurs in formal trances (Fugh-Berman, 1995). In the approach pioneered by Erickson, hypnosis is an altered state of mind and behavior that is affected by the everyday trances that we all experience (Fugh-Berman, 1995). Imagery is often used in hypnosis and has been shown to increase blood sugar, affect gastrointestinal activity, and alter skin temperature. Guided imagery is used with relaxation, biofeedback, hypnosis, meditation, or behavioral therapy (Fugh-Berman, 1995). Many symptomatic benefits have been attributed to hypnosis but there is no evidence that it alters the course of MS (Kraft & Catanzaro, 1996).

MAGNETS

The use of low intensity magnets is well tolerated. There is some evidence of symptomatic relief (fatigue, pain, cognition, walking) (Bowling, 2001) but further studies are warranted to further assess efficacy and safety in MS.

VITAMINS AND SUPPLEMENTS

Objective information should be obtained about vitamins, supplements, and claimed health benefits. In spite of many claims, no vitamin or supplement has been fully investigated and proven to benefit the course of the disease or the symptoms of MS. (Bowling, 2001)

EXERCISE

There are many exercise programs for people with MS. Attitudes toward exercise have changed dramatically during the past decade based on studies by Petajan et al. (1996), Scully et al. (1998), and Solari et al. (1999). There have been documented benefits in physical and emotional well-being, endurance, fatigue reduction, management of depression, and conditioning. Programs include walking, swimming, horseback riding, and

stretching. Benefits also include prevention/reduction of osteoporosis and weight control.

HERBAL THERAPY

Most herbs have not been studied as drugs. Therefore they are not well understood in terms of side effects and interactions. Caution and safety measures are very important when taking herbs and the following guidelines should be observed (see Table 11-2).

Cranberry juice has a long history of benefit in reducing the risk of urinary tract infections (UTIs) by acidifying the urine. It is bacteriostatic and is used widely in both liquid and tablet form.

Echinacea is an immune booster and should be avoided in MS (Bowling, 2001)

Garlic is sometimes recommended as a treatment for the common cold. Ginkgo biloba may increase bleeding in people taking coumadin or aspirin. This herb has had some reports of benefit in improving memory in the elderly.

Ginseng has significant side effects. It may increase fatigue and cause sedation.

Herbs should be used with caution in MS and should be discussed with healthcare providers prior to their use (Bowling, 2001) (see Table 11-2).

COOLING THERAPIES

Cooling is a unique form of CAM for people with MS. Small decreases in body temperature may lead to relief of some MS-related symptoms. The effect of heat on MS has been known for many years; cooling may lead to improvement by facilitating nerve transmission in demyelinated fibers.

TABLE 11-2 Herbal Therapies Safety Tips*

Call your healthcare provider if you experience side effects
Do not use herbs to delay traditional treatments
Follow prescribed dosages
“Natural” does not mean “harmless”
Do not ignore symptoms
Purchase from a reliable source and read labels
Tell your healthcare provider and pharmacist all medications you are taking including prescription and non-prescription

*People with MS should avoid any therapy that “boosts” the immune system since MS involves an already overactive immune response

Source: Adapted from Parkman (2001).

Different techniques may induce cooling: baths and showers, air conditioning, ice packs, and drinking cool liquids (Bowling, 2001). Cooling garments may use ice packs or ongoing circulation of coolants. Cooling strategies may make the transition from unconventional to conventional care in the near future if research continues to substantiate its benefit in MS.

DIETS AND SUPPLEMENTS

The Swank diet is an extreme approach using a low fat regime. Benefit in MS is not supported by research but it has had anecdotal reports for many years (Swank, 1987). Other diets have been purported to be of benefit but, like the Swank diet, there are no substantiated research studies to support these claims. They consist of the gluten-free diet, elimination diets, allergy-free diets, etc.

The use of fats and fatty acids is controversial. A review of the evidence concludes that a well-balanced diet with appropriate supplementation is the only nutritional claim that is accepted in traditional healthcare circles. Changes in diet or supplementation should not be used in place of conventional medicine, nursing, rehabilitation, and other supportive services (Bowling, 2001).

MASSAGE AND BODYWORK

Massage was a part of many ancient cultures, including those of China, Persia, Arabia, and Greece. In the United States, there are four major categories of bodywork, the best known of which is European massage. Swedish massage is the most popular of these (Fugh-Berman, 1995). Other types of bodywork are deep-tissue technique, which includes structural integration or rolfing; pressure-point techniques such as reflexology and acupressure (Shiatsu); and polarity therapy, including Reiki, jin shin jyutsu, and jin shin do. Therapeutic touch is a related approach to the latter therapy (Fugh-Berman, 1995). Another category, movement integration, includes Feldenkrais and Alexander techniques, which teach better ways to move one's body to reduce stress (Fugh-Berman, 1995). Some people with MS find these modalities effective, particularly for symptoms like spasticity or pain. It is more difficult to treat a global symptom such as fatigue, although patients report increased relaxation, which indeed can lessen fatigue (Kraft & Catanzaro, 1996). Massage can relieve muscle tightness and facilitate joint mobility but it has no effect on the course of MS. It has been reported to alleviate pain in some patients but not in others (Kraft & Catanzaro, 1996).

BIOFEEDBACK

Biofeedback translates skin temperature, muscle contractions, blood pressure, pulse, brain waves, or other bodily functions into audio or video signals. By learning to control the pitch of a sound, the rate of a series of beeps, or an image on a computer screen, the patient can learn to control the bodily process that is being monitored (Fugh-Berman, 1995). Biofeedback has been shown to be effective in teaching a person to reduce muscle tension associated with certain types of pain such as muscle tension headaches. Biofeedback has also been used to manage spasticity but studies have not substantiated its effectiveness in this area (Kraft & Catanzaro, 1996).

TAI CHI

Sometimes called a moving meditation, Tai Chi is a Chinese blend of exercise and energy work. Its arm movements are slow, circular, continuous, smooth, and controlled, and weight is shifted regularly from one foot to the other (Fugh-Berman, 1995). The program may provide the health benefits of more strenuous exercise without straining the heart, and may improve coordination, physical agility, and speed (Kraft & Catanzaro, 1996). Many chapters of the National Multiple Sclerosis Society have organized Tai Chi programs, which provide both physical and social benefit to participants.

CHIROPRACTIC THERAPY

Chiropractic was invented by Daniel David Palmer in the late nineteenth century. He was influenced by spiritualism during that period and performed his first spinal adjustment in September 1895. The word *chiropractic*, coined by a patient a year later, is derived from Greek and means “done by hand.” Chiropractors generally only manipulate the protruding parts of the spinal vertebrae (short lever manipulation) (Fugh-Berman, 1995).

The maintenance of health is very important. People with MS can have a variety of problems that can be treated by a variety of health care providers including chiropractors. It is important to find a practitioner who is qualified and experienced in the specific problem the patient is experiencing and who also understands MS (Kraft & Catanzaro, 1996).

CONCLUSION

Because alternative therapies are often cost effective, third-party payers are beginning to reimburse for these services. Medical education is also changing and many medical schools are incorporating alternative medicine into

their curricula. Both recognized and complementary treatment options may be the wave of the future for the twenty-first century—a new era of therapy in MS and an era of empowerment.

REFERENCES

- Bowling, A.C. (2001) *Alternative Medicine and Multiple Sclerosis*. New York: Demos.
- Eisenberg, D.M., Kessler, R.D., Foster, C., et al. (1993). Unconventional medicine in the United States: Prevalence, costs, and patterns of use. *New England Journal of Medicine*, 328, 246–52.
- Fugh-Berman, A. (1995). *Alternative Medicine: What Works*. Tucson, AZ: Odonian Press, 5.
- Kraft, G.H., Catanzaro, M. (1996). *Living with Multiple Sclerosis: A Wellness Approach*. New York: Demos Vermande.
- Parkman, C.A. (2001) Polypharmacy, herbal therapies, and elders. *The Case Manager* July/August, 32–24.
- Petajan, J.H., Gappmaier, E, White, A.T., et al. (1996) Impact of aerobic training on fitness and quality of life in multiple sclerosis. *Ann Neurol* 39, 432–441
- Pignotti, M., (1999). Treatment by persons with multiple sclerosis. *Neurorehabilitation and Neural Repair*, Vol. 13, No. 4, p. 243–254.
- Scully, D., Kremer, J., Meade M.M. et al. (1998). Physical exercise and psychological well being: A critical review. *Br J Sports Med*. 32. 111–120.
- Solari, A., Filippini, G., Gasco P., et al. (1999). Physical rehabilitation has a positive effect on disability in multiple sclerosis patients. *Neurology* 52, 57–62
- Swank, R., Dugan B.B. (1987) *The Multiple Sclerosis Diet Book*. New York: Doubleday.

RESOURCES

- HealthWorld Online – Alternative Medicine Center www.altmed.net
- Alternative Medicine www.noahhealth.org/english/alternative/alternative.html
- Whole Health MD www.wholehealthmd.com
- OnHealth Network <http://onhealth.webmd.com/alternative/home/index,5.asp>
- The Natural Pharmacist www.tnp.com
- Alternative Health News Online www.altmedicine.com
- The National Institute of Health’s Alternative and Complementary Medicine Web Site <http://nccam.nih.gov>
- A Dictionary of Alternative-Medicine Methods www.accsh.org/dictionary/index.html
- American Botanical Council www.herbalgram.org
- American Holistic Nurses Association www.ahna.org

This page intentionally left blank

CHAPTER 12

Patient and Family Education

Nancy J. Holland, RN, EdD

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 of time, chronic conditions have long-term implications for all aspects of living.

The quality of life perspective moves the person with multiple sclerosis (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 healthcare/service providers because it represents the individual’s judgments about how the illness and related interventions affect everyday life (Stuifbergen, 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 (Klemmack et al., 1974; George et al., 1985; and 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).

QUALITY OF LIFE GOALS

Through a consensus-building process, the National Multiple Sclerosis 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 disabled person 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/social support are addressed in many sections throughout this book. Independence— independent living, long-term services, employment, and accessibility—is addressed through NMSS programs and other community agencies.

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).

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 et al., 1988).

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 educa-

tion programs do encourage patients to be actively involved in decision making and care delivery.

Duchin and Brown 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, 1990, p. 255). This statement pertains to individuals with MS as well.

Education goals for individuals with MS include:

1. understanding the diagnosis and successful coping with its potential impact on one’s life;
2. planning regarding critical areas such as relationships, parenting, employment, and lifestyle; and
3. preventing potentially disabling outcomes, with specific goals related to new symptoms.

As the disease progresses, 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.

The task of assuring that people with MS have adequate information about MS and how to live most effectively with its limitations is facilitated by the desire to learn shown by many individuals with MS. A needs survey of 630 members of the National Multiple Sclerosis Society’s New York City chapter indicated that respondents ranked first the need for more information about MS, with 41 percent reporting a great or very great need for more information (Genevie, Kallos, & Struening, 1987). Orr (1990) described the perspective of viewing illness as an educational opportunity. He notes that, “it is our ability to learn that helps individuals who suffer from diseases to find innovative ways to cope with them” (p. 47).

An important learning tool utilized by people with MS is printed material, which can be absorbed at the individual’s own pace, referred to for clarification, and re-read for reinforcement. The NMSS sends a quarterly magazine called *Inside MS* to approximately 800,000 members, including 280,000 who have MS. Each of the Society’s 70 chapters throughout the United States sends a newsletter to members at least quarterly. The effectiveness of providing this type of information was demonstrated by a study conducted at the Veteran’s Administration in Buffalo, New York, which evaluated the benefit of a patient newsletter for persons with peripheral vascular disease. Sixty-five percent of respondents reported that the information obtained from reading the newsletter stimulated a positive change in their behavior (Ventura et al., 1990). Other techniques people with MS have found helpful for learning include targeted reading, experiential

learning, questioning physicians and other health professionals, and attending lectures and meetings.

THE SHIFTING PERSPECTIVES MODEL OF CHRONIC ILLNESS

This view of chronic illness was developed by Barbara Paterson through a metastudy (a metasyntesis method) of 292 research studies. The metastudy indicated that living with chronic illness is an ongoing and continually shifting process with an illness-in-the-foreground 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 (Patterson, 2001).

One aspect of a supportive environment can be the self-help group. Bonding of the group members creates an atmosphere of trust and caring, 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. Almost 2000 self-help groups are affiliated with the NMSS. People with MS and their families can obtain information about local opportunities by calling 1-800-FIGHTMS and pressing or saying 1 to be connected with their Society chapter.

There is some evidence that healthcare 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 (Paterson & 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.

Adult Education Issues

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.

Diversity is an important issue, regarding both ethnic differences and variety of learning styles. By the year 2050, minorities will account for nearly 47 percent of the overall population (U.S. Bureau of the Census, 1995). This figure reflects trends projected for the years between 2000 and 2005: The Hispanic population will account for 37.7 percent of the total population growth, Asian-Pacific Islanders about 19.5 percent, and African Americans 17 percent (Gardner, 1996). An important principle that has emerged from recent advances in communication theory is that communication should be targeted to specific populations (Windahl et al., 1992). Different strategies work better for groups of different educational, ethnic, and economic backgrounds (Institute of Medicine, 2001). Teaching techniques will need to be modified, and materials 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. Merriam & Caffarella (1999) presented a case study of a woman newly diagnosed with breast cancer which I have transposed to an MS diagnosis.

Tracey has just learned that she has multiple sclerosis. When she recovered from the shock of diagnosis, she decided to take an active role in managing her disease. With the guidance of her MS nurse, she gathered as much information as she could deal with from a number of sources: the National Multiple Sclerosis Society (Society), the Internet and a won-

derful telephone conversation with another person with MS. She feels better prepared to speak with the neurologist-MS specialist when she sees her next month. She is quite focused on her MS, distancing herself from the close interaction she normally experienced with her husband and children, but allowing her to get a handle on this new personal threat (Paterson, 2001) (illness-in-the-foreground). After a few months, she decides to join a support group for emotional support, informal learning opportunities, and comfortable socialization. Her husband and best friend have joined in Society fund raising and advocacy efforts, and all feel more appreciative of life and each other (Paterson, 2001) (wellness-in-the-foreground).

THE INTERNET

Within a short period of time, 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 five 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. Since the WWW is an open medium, some sites will contain inaccurate information. Some reliable web sites are listed below:

National Multiple Sclerosis Society <http://www.nationalmssociety.org>
 Multiple Sclerosis Society of Canada <http://www.mssoc.ca>
 Consortium of MS Centers <http://www.mscares.org>
 Eastern Paralyzed Veterans Association <http://www.epva.org>
 International Journal of MS Care <http://www.mscares.com>
 Paralyzed Veterans of America <http://www.pva.org>
 National Family Caregivers Association <http://www.nfcares.org>
 National Rehabilitation Information Center (NARIC) <http://www.naric.com>

WHAT DOES A PERSON WITH MS NEED TO KNOW?

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/psychological;
2. physical; and
3. interpersonal/social.

Emotional factors are identified first since a minimal level of acceptance must be present before information will be assimilated and acted upon. Beyond acceptance is the ongoing process of adjusting and coping which, according to LaRocca & 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 et al. (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 MS

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 (Holland, 1992; Franca-bandera, 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 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 the majority of people with MS in the early stage (five years or under 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 (six to ten years) and moderate for long-term MS (more than ten years). The majority of 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, while 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. Individual and group counseling and agencies were more utilized by those with early and intermediate MS, while people with intermediate and advanced MS used videos more often than their counterparts with early MS. This pattern may be changing due to 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 the purpose of action and to gain a sense of empowerment.

During the course of this study, three themes emerged:

1. the value of experiential learning;
2. avoidance of others more disabled; and
3. the doctor as embodiment of the MS care team.

1. *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 applied the feedback of successful vs. 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 fourteen years. What to do and what not to do for coping. If you don't know in fourteen 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 sponsored by the National Multiple Sclerosis Society, counseling groups, or self-help or other mutual support networks. Such groups are considered

homogeneous since 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 also be addressed as a potentially negative coping device. Overall, the themes that emerged will add to some unique perspectives in the MS educational program development for both clients and health professionals.

REFERENCES

- Beisecker, A.E., Kuckelman Cobb, A., & Ziegler, D.K. (1988). Patients' perspectives of the role of the care providers in amyotrophic lateral sclerosis. *Archives of Neurology*, 45.
- Brookfield, S.D. (1985). A critical definition of adult education. *Adult Education Quarterly*, 36 (1), 44–49.
- Campbell, A. (1981). *The Sense of Well-Being in America: Recent Patterns and Trends*. New York: McGraw Hill.
- Counte, M.A., Bieliauskas, L.A., Pavlau, M. (1983). Stress and personal attitudes in chronic illness. *Archives of Physical Medicine & Rehabilitation*, 64, 272–275.
- DeSouza, L.H., Ashburn, A. (1988). Knowledge of multiple sclerosis: Implications for rehabilitation. *Clinical Rehabilitation*, 2, 139–142.
- Duchin, S., Brown, S. (1990). Patients should participate in designing diabetes educational content. *Patient Education and Counseling*, 16, 155–267.
- Francabandera, F. (1992) "Self-directed Learning by Families with a Member with Multiple Sclerosis," Unpublished doctoral dissertation. Columbia University, Teachers College, New York.
- Gardner, P., (1996). Demographic and attitudinal trends: The increasing diversity of today's and tomorrow's learners. *Journal of Cooperative Education*, 31 (2–3), 58–82.
- Genevie, L., Kallos, J., Struening, E. (1987). An overview of patients' perceptions of their needs: Multiple sclerosis as a paradigm. *Journal of Neurologic Rehabilitation*, 1, (1).

- George, L., Okun, M., Landerman, R. (1985). Age as a moderator of the determinants of life satisfaction. *Research on Aging*, 7, 209–233.
- Giloth, B.E. (1990). Promoting patient involvement: Educational, organizational, and environmental strategies. *Patient Education and Counseling*, 15, 29–38.
- Holland, N. (1992). "Self-directed learning by individuals with multiple sclerosis." Unpublished doctoral dissertation, Columbia University, Teachers College, New York.
- Institute of Medicine (2001). *Multiple Sclerosis: Current Status and Strategies for the Future*, Institute of Medicine, National Academy Press, Washington, DC.
- Klemmack, D., Carlson, J., Edwards, J. (1974). Measures of well being: An empirical and critical assessment. *Journal of Health and Social Behavior*, 15, 267–270.
- Knowles, M. (1980). *The Modern Practice of Adult Education: From Pedagogy to Andragogy*. Chicago: Follett.
- Kolb, D. (1984). *Experiential Learning: Experience as the Source of Learning and Development*. New Jersey: Prentice Hall.
- LaRocca, N.G., Kalb, R.C. (1987). Psychological issues. In Scheinberg, L., Holland N. (eds.). *Multiple Sclerosis: A Guide for Patients and Their Families*, 2nd ed. New York: Raven Press.
- Lawler, P. (1986). Principles and practices of adult education. Adult Education Guided Independent Study IV Dissertation Committee, Columbia University, Teachers College, New York.
- Lawler, P. (1988). "Workplace education and the principles and practices of adult education." Unpublished doctoral dissertation, Columbia University, Teachers College, New York.
- Lechtenberg, R. (1988). *Multiple Sclerosis Fact Book*. Philadelphia: F.A. Davis.
- McDaniel, R.W., Bach, C.A. (1994). Quality of life: A concept analysis. *Rehabilitation Nursing Research*, Spring.
- Mazzuca, S.A. (1982). Does patient education in chronic disease have therapeutic value? *Journal of Chronic Diseases*, 35, 521–529.
- Merriam, S. Caffarella, R. (1999) *Learning in Adulthood*. San Francisco: Jossey-Bass.
- Mezirow, J. (1981). A critical theory of adult learning and education. *Adult Education*, 32 (1), 3–24.
- Mezirow, J., et al. (1990). *Fostering Critical Reflection in Adulthood: A Guide to Transformative and Emancipator Learning*. San Francisco: Jossey-Bass.
- Orr, R. (1990). Illness as an educational opportunity. *Patient Education and Counseling*, 15, 47–48.
- Padilla, C., Grant, M. (1985). Quality of life as a cancer nursing outcome variable. *Advances in Nursing Science*, 8, 45–54.
- Paterson, B. (2001). The shifting perspectives model of chronic illness. *Journal of Nursing Scholarship*, 33, 21–26.
- Paterson, B., Sloan, J. (1994). A Phenomenological study of the decision-making experience of individuals with long-standing diabetes. *Canadian Journal of Diabetes Care*, 18, 10–19.
- Ritvo, P., Fischer, J., Miller, D., Andrews, H., Paty, D., LaRocca, N. (1997) *Multiple Sclerosis Quality of Life Inventory*. National Multiple Sclerosis Society, New York.
- Rosner, L.J., Ross, S. (1987). *Multiple Sclerosis: New Hope and Practical Advice for People with MS and Their Families*. New York: Prentice Hall.

- Salamon, M. (1988). Clinical use of the life satisfaction in the elderly scale. *Clinical Gerontology*, 8, 45-54.
- Sheinberg, L., Holland, N. (1987). *Multiple Sclerosis: A Guide for Patients and Their Families*, 2nd ed. New York: Raven Press.
- Seligman, M. (ed.). (1982). *Group Psychotherapy and Counseling with Special Populations*. Baltimore: University Park Press.
- Stuifbergen, M. (1992). Quality of Life for Individuals with Multiple Sclerosis. Health Services Research Report, National Multiple Sclerosis Society.
- US Bureau of the Census, (1995). "Population Profiles of the United States: 1995." *Current Population Reports*, Series P23-189. Washington, DC: US Government Printing Office.
- Ventura, M.R., Todd, K., Burch, K., Grace, M.L., Crosby, F., Lohr, G. (1990). Patient newsletter: A teaching tool. *Patient Education and Counseling*, 15, 269-274.
- Whitson, D., Amstutz, D. (1997) *Accessing Information in a Technological Age*. Malabar, Fla.: Kreiger.
- Windahl, S., Signitzer, B.H., Olson, J.T. (1992). *Using Communication Theory : An Introduction to Planned Communication*. London, UK: Sage Publications LTD.
- Wolf, J.K. (1987). *Mastering Multiple Sclerosis: A Guide to Management*, 2nd ed. Rutland: Academy Books.

This page intentionally left blank

CHAPTER 13

Advocacy

Dorothy Northrup, MSW, ACSW

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 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 by either the person or by others.

In light of these challenges, the nursing profession has a pivotal role in being sensitive to the life-changing issues that the diagnosis of a chronic illness such as MS brings, and providing support to patients as they wrestle with the bewildering array of systems, bureaucracies, and environmental challenges which 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. Their training prepares them 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. However, patient advocacy

as a concept, 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. In the 1990s empowerment of patients as consumers and decision makers was supported (Mallik & Rafferty, 2000).

Nurses working with people who have 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 to the health care providers serving them as well. Issues are complex, support systems are compromised, and bureaucracies are intimidating. Within this environment, the role of the nurse as an advocate is instrumental and critical.

HEALTH INSURANCE

The current health care system of the United States continues to be based on a medical care model, focused on *curing* an illness and *restoring* a patient to prior functional status (Institute for Health & Aging, 1996). Chronic care, on the other hand, emphasizes *maintenance* of function and the *minimizing* of further deterioration. Set within the context of these contrasting agendas, the definition of the term "medical necessity" within the managed care environment has become a focus of contention and frustration.

This is particularly true when it comes to the services and treatment interventions required for a person with MS. Recommended therapies to maintain a person's health status and prevent complications may be denied, while reimbursement for treating the complications that arise as a result of that denial are approved. Short-term decisions are affecting long-term outcomes.

Education is an important part of advocacy, and the nurse is in a unique position to provide that knowledge and experience. It is important to empower patients and their families to become self-advocates. They need to 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 spokesperson and advocate in negotiating with case managers and other decision makers in the managed care organizations on behalf of their patients.

People with MS seeking new insurance coverage should spend time comparing the benefits of each plan being considered. Patients also need to be reminded not to neglect medical care and coverage for their non-MS conditions, and to continue to participate in screening procedures and preventive health care. In a recent study supported by the Agency for Health Care Policy Research, patients with disabilities were less likely than those who were not disabled to receive preventive care services. The nurse can have a vital role in ensuring that patients receive the most comprehensive medical care possible.

The system of managed care is a source of great frustration to many people with MS. Although most have some form of insurance coverage, policies are inadequate in light of the varied and specialized health care needs that this disease presents. The most frequently cited unmet needs for people with MS include medications, home care, rehabilitation services, access to specialists, counseling, and durable medical equipment. However, it has also been documented that filing appeals and grievances when denials have been issued can often be effective. It is imperative that nurses encourage patients not to take “no” for an answer, but 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 remembered 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 about the legal documents and financial options that are available, and be comfortable encouraging patients to pursue this information, whether or not they presently have significant disability.

Due to the unpredictability of MS, protecting one’s financial future is a primary concern. Not only do families lose one income if continued employment is not possible, they also 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 who are aware of these issues and encourage their patients to address them are making an invaluable contribution to assuring their patient’s financial security.

Several legal documents regarding future medical care and disposition of property upon death also need attention. MS is not considered a fatal illness. There is no way to determine the future progression or severity of the disease at the time of diagnosis. However, it is this lack of control and lack of predictability that are the very reasons that persons with MS need to take control of their futures and prepare themselves for any eventuality. The nurse is in a strategic position to encourage patients to engage in this important, albeit stressful and anxiety-provoking, process.

The following are some of the documents which people with MS 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. It establishes specific treatment guidelines. 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 his or her behalf, should the person no longer be able to do so. (A living will can often guide the proxy agent in this decision making.)

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 use 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 dis-

tribution 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 responsibility for the trust property; and
- ⊃ *Trust property*, which is held by the trustee for the beneficiary.

A trustee can be an individual or a corporation, and is required to use the utmost loyalty to control and preserve the property of the trust and meet its objectives.

ENTITLEMENTS

As families deal with a chronic illness such as MS and try to obtain the supportive services to 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 MS patients need to become educated on eligibility criteria, income guidelines and application procedures necessary for families to access financial and equipment assistance, Medicaid, home health care, homemaker services, vocational rehabilitation, veteran's benefits, special transportation, etc. Without these supportive services, 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.

Disability insurance benefits are an entitlement that 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 as to whether these benefits will be secured. Whether a patient is applying to a private disability insurer, or to Social Security, those nurses and physicians working with MS patients are

instrumental in making sure that the medical documentation they provide is comprehensive and accurate.

INTERDISCIPLINARY INTERVENTION

Due to the complex nature of MS and its chronic, unpredictable nature, many psychosocial issues can arise during a patient's struggle to live with this disease. Family relationships, financial concerns, employment difficulties, anxiety, fear, cognitive impairment, depression, or a 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 may be critical in helping a patient manage and cope with the disease. Encouraging patients to contact their local chapter of the National Multiple Sclerosis Society, or to 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 need to understand this concept and advocate for their patients to receive the interventions and supports that they need.

DISABILITY RIGHTS

No discussion of nurse advocacy would be complete without including the role that nurses and other health professionals play 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 soci-

etal and ethical responsibility to accommodate and individualize the care of patients with disabling conditions.

THE TOOLS OF ADVOCACY

Advocacy on behalf of people with MS can be effective only if the nurse is knowledgeable and informed. This includes having a full understanding of MS, including 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 local and national offices of the National Multiple Sclerosis 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.

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. Groups such as the Joint Commission of Accreditation of Health Organizations (JCAHO) 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 either an individual or a policy level. These include:

- ▷ Patient rights legislation
- ▷ Patient protection and confidentiality
- ▷ Expansion of health insurance coverage
- ▷ Broadening of Medicare and Medicaid coverage
- ▷ Pharmaceutical assistance programs
- ▷ Affordability of long-term care services
- ▷ 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.

Perhaps more than any other health care professional, nurses are aware of a patient's right to dignity and self-determination. Their profes-

sion is appreciated as a source of advice and guidance on health care reform. Nurses must recognize this 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) said in his landmark book *The Power Game: How Washington Works*, “Information and knowledge are power. Visibility is power. A sense of timing is power. Personal energy is power; so is self-confidence.” 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 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.

REFERENCES

- Agency for Health Care Policy and Research, Volume 230, October, 1999, *AHCPR Research Activities*.
- Institute for Health & Aging. (1990) *Chronic Care in America: A 21st Century Challenge*. University of California.
- Mallik, M., Rafferty, A.M. (2000). Diffusion of the concept of patient advocacy. *Journal of Nursing Scholarship*, Fourth Quarter, p. 399–403
- Parts of this chapter have been adapted with the permission of the publisher from *A Guide to Legal Rights for People with Disabilities*, by Marc D. Stolman, New York: Demos, 1994.
- Smith, H., (1988). *The Power Game: How Washington Works*. New Zealand: Random House

CHAPTER 14

Integrating the Concept of Hope into Clinical Practice

Linda A. Morgante

INTRODUCTION

Empowering hope in people with multiple sclerosis (MS) is a prime aspect of caring. Hope is a multidimensional and dynamic process that energizes people and enables healthy coping (Miller, 2000; Herth, 1991; Dufault & Mastocchio, 1985). 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 managing the disease. But MS remains incurable, and the disease has no boundaries. Symptoms of MS manifest differently in each person and are changeable 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 centers not only 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 (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 Kubler-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 a fighting spirit have all been documented as having a positive relationship to hope (Hinds & Martin, 1988; Foote et al., 1990; Barton et al., 1994; Post-White & Ceronsky, 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 & Ceronsky, 1996).

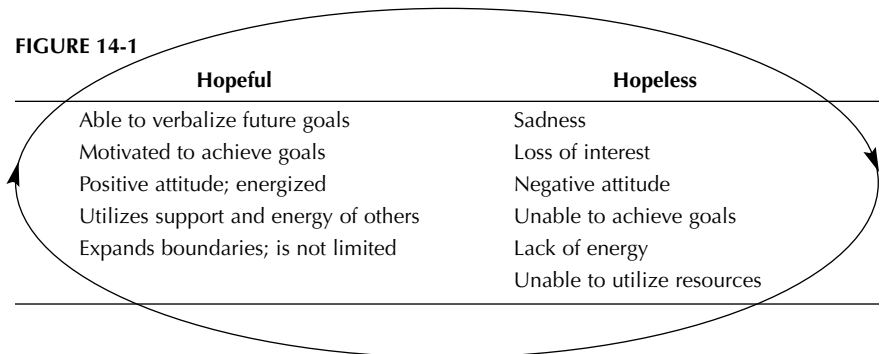
HOPE AND HOPELESSNESS

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 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 (Figure 14-1). Hope can be a 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.

FIGURE 14-1



Nursing care includes assessing behaviors that reflect hope (Table 14-1), identifying variables that make an impact on the process of hoping in order to plan care, and creating interventions for inspiring, sustaining, or restoring hope.

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. A 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 in to see the MS nurse, they are all visibly shaken. They had expected to hear “good news,” and 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 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!”

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 her 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 available for patients, has been well

TABLE 14-1. Behaviors that Reflect Hope

-
1. Verbalizes future goals
 2. Shows motivation to reach goals
 3. Expects to accomplish goals
 4. Imagines a brighter tomorrow
 5. Reminisces about past successes
 6. Sees options for self
 7. Maintains a sense of control
 8. Anticipates positive outcomes
 9. Relates to family, friends, or caregivers in supportive and reciprocal ways
 10. Feels connected to a higher being
 11. Displays humor
 12. Relaxes with imagery and visualization
-

documented over the past decade (Gilje, 1992; Easter, 2000; Dunniece & Selvin, 2000). Nurses' presence provides comfort, caring, healing, and hope for people who are acutely and 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's was to make the right decision for herself. She chose an immunomodulating therapy, and although she is not happy she has to inject herself with a needle, she is happy she is being proactive.

Mary is 15 years old and 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 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?"

Denial is a mechanism that may protect hope for those acutely ill or newly diagnosed with an illness. O'Mailley & 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, deliberately replacing negative, 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 had a relapsing-remitting course of MS when she entered a clinical trial of a new product for MS several years ago. Within two 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 or not 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 transition from a relapsing-remitting course of MS to a progressive form posed new challenges for her and her family. Together with the nurse, a plan of care was developed that included physical 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 so 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 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 twelve-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, and she is resisting. She states 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.

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. But Joan is choosing the moment, and taking things one 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 ICU because of severe pneumonia caused by aspiration, and she becomes ventilator dependent for one month. When she is weaned from the ventilator, she is told she has to have a PEG in place if she wants to go home. She now agrees 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 is an MS nurse in a busy, multi-disciplinary practice, who wears many hats: clinician, educator, administrator, researcher, and consultant. The patient mix on a day-to-day basis includes early, stable, 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.

The good news about MS nursing is that it is a *process*; patients and families are cared for over long periods of time. 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.

TABLE 14-2. Self-Care Strategies for Nurses Who Care for People with MS

-
- ☞ 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
-

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 she/he 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. Table 14-2 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.

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.

REFERENCES

- Barton, J., Magily, J., Quinn, A. (1994). Maintaining the fighting spirit: veterans living with multiple sclerosis. *Rehabilitation Nursing*, 3 (3), 86–96.
- Callan, D. (1989). Hope as a clinical issue in oncology social work. *Journal of Psychosocial Oncology*, 7 (3), 31–46.
- Dufault, K., Martocchio, B. (1985). Hope: its spheres and dimensions, *Nursing Clinics of North America*, 20, 379–91.
- Dunniece, U., Slevin, E. (2000). Nurses' experiences of being present with a patient receiving a diagnosis of cancer. *Journal of Advanced Nursing*, 32 (3), 611–618.
- Easter, A. (2000). Construct analysis of four modes of being present. *Journal of Holistic Nursing*, 18 (4), 362–377.
- Farran, C., Wilken, C., Popovich, J. (1992). Clinical assessment of hope. *Issues in Mental Health*, 13, 129–38.
- Fraser, C. (1999). The experience of transition for a daughter caregiver of a stroke survivor. *Journal of Neuroscience Nursing*, 31 (1), 9–16.
- Foote, A., et al. (1990). Hope, self-esteem and social support in persons with multiple sclerosis. *Journal of Neuroscience Nursing*, 22 (3), 155–59.
- Fromm, E. (1968). *The revolution of hope – toward a humanized technology*. New York: Harper and Row.
- Gilje, F. (1992). Being there: An analysis of the concept of presence. In Gaut, D.A. (ed), *The Presence of Caring in Nursing*. New York: National League for Nursing Press.
- Herth, K. (1991). Development and refinement of an instrument to measure hope. *Scholarly Inquiry for Nursing Practice*, 5 (1), 39–56.
- Hinds, P., Martin, J. (1988). Hopefulness and the self-sustaining process in adolescents with cancer. *Nursing Research*, 37 (6), 336–40.
- Korner, I. (1970). Hope as a method of coping. *Journal of Consulting and Clinical Psychology*, 34 (2), 134–39.
- Kubler-Ross, E. (1969). *On Death and Dying*. New York: Macmillan.
- Lynch, W. (1965). *Images of Hope*. Baltimore: Helicon Press.
- Marcel, G. (1962). *Homo Viator* (E. Craufard, trans.). New York: Harper and Row.
- McDonald, W.I., Compston, A., et. al. (2001). Recommended diagnostic criteria for multiple sclerosis: Guidelines from the international panel on the diagnosis of multiple sclerosis. *Annals of Neurology*, 50 (1), 121–127.
- McGee, R. (1984). Hope: A factor influencing crisis resolution. *Advances in Nursing Science*, 6 (4), 34–44.
- Miller, J. (1985). Inspiring hope. *American Journal of Nursing*, 85 (1), 23–25.
- Miller, J. (1989). Hope-inspiring strategies of the critically ill. *Applied Nursing Research*, 2 (1), 23–29.
- Miller, J. (2000). Inspiring hope. In Miller, J. (ed), *Coping With Chronic Illness: Overcoming Powerlessness*, 3rd ed. Philadelphia: F.A. Davis Company.
- Morgante, L. (2000). Hope in multiple sclerosis: A nursing perspective. *International Journal of MS Care*, 2, 1–7.
- Morgante, L., McCann, M.E. (1992). “The energy and power of hope.” (unpublished manuscript.)

- O'Malley, P., Menke, E. (1988). Relationship of hope and stress after myocardial infarction. *Heart and Lung*, 17 (2), 184–90.
- Poncar, P. (1994). Inspiring hope. *Journal of Psychosocial Nursing*, 32 (1), 33–38.
- Post-White, J., Ceronsky, C. (1996). Hope, spirituality, sense of coherence, and quality of life in patients with cancer. *Oncology Nurse Forum*, 23 (10), 34–42.
- Stotland, E. (1969). *The Psychology of Hope*. San Francisco: Josey-Bass.

APPENDIX A*

Resources

There is a vast array of resources available to help you in your efforts to meet the challenges of multiple sclerosis. This list is by no means a complete one; it is designed as a starting point in your efforts to identify the resources you need. Each resource that you investigate will lead you to others and they, in turn, will lead you to even more leads.

Agencies and Organizations

American Self-Help Clearinghouse (St. Clares-Riverside Medical Center, Denville, NJ 07834, tel: 201-625-7101). The Clearinghouse makes referrals to national self-help organizations as well as individual self-help groups for various problems. They also provide referrals to local self-help clearinghouses.

Beach Center on Families and Disabilities (c/o Life Span Institute, University of Kansas, 3111 Haworth Hall, Lawrence, KS 66045, tel: 785-864-7600; Internet: www.beachcenter.org). The federally funded Center conducts research and training about the functioning of families in which one member is disabled. They have a publications catalog relating to family coping, professional roles, and service delivery. They offer a free newsletter, "Families and Disability."

Consortium of Multiple Sclerosis Centers (CMSC) (c/o Bernard W. Gimbel MS Comprehensive Care Center at Holy Name Hospital, 718 Teaneck Road, Teaneck, NJ 07666, tel: 201-837-0727; Internet: www.ms-care.org). The CMSC is made up of numerous MS centers throughout the United States and Canada. The Consortium's mission is

Modified from *Multiple Sclerosis: The Questions You Have—The Answers You Need* edited by Rosalind C. Kalb. New York: Demos Vermande, 1996.

to disseminate information to clinicians, increase resources and opportunities for research, and advance the standard of care for multiple sclerosis. The CMSC is a multidisciplinary organization, bringing together health care professionals from many fields involved in MS patient care.

Department of Veterans Affairs (VA) (810 Vermont Avenue, N.W., Washington, DC 20420, tel: 202-273-5400; Internet: www.va.org). The VA provides a wide range of benefits and services to those who have served in the armed forces, their dependents, beneficiaries of deceased veterans, and dependent children of veterans with severe disabilities.

Equal Employment Opportunity Commission (EEOC) (Office of Communication and Legislative Affairs, 1801 L Street, N.W., 10th floor, Washington, DC 20507, tel: 800-669-3362 (to order publications 800-669-4000; to speak to an investigator 202-663-4900; Internet: www.eeoc.gov). The EEOC is responsible for monitoring the section of the ADA on employment regulations. Copies of the regulations are available.

Eastern Paralyzed Veterans Association (EPVA) (75-20 Astoria Boulevard, Jackson Heights, NY 11370, tel: 718-803-EPVA; Internet: www.epva.org). EPVA is a private, non-profit organization dedicated to serving the needs of its members as well as other people with disabilities. While offering a wide range of benefits to member veterans with spinal cord dysfunction (including hospital liaison, sports and recreation, wheelchair repair, adaptive architectural consultations, research and educational services, communications, and library and information services), they will also provide brochures and information on a variety of subjects, free of charge to the general public.

Health Resource Center for Women with Disabilities (Rehabilitation Institute of Chicago, 345 East Superior Street, Chicago, IL 60611; tel: 312-908-7997; Internet: www.rehabchicago.org). The Center is a project run by and for women with disabilities. It publishes a free newsletter, "Resourceful Women," and offers support groups and educational seminars addressing issues from a disabled woman's perspective. Among its many educational resources, the Center has developed a video on mothering with a disability.

International Organization of Multiple Sclerosis Nurses (IOMSN), P.O. Box 450, Teaneck, NJ 07666; tel: 201-837-9241; Internet: www.iomsn.org. The only specialty organization focusing on nurses working with MS patients and families. It is affiliated with the MS nurses international credentialing board (MSNICB), the certifying body in MS nursing.

Latin American Committee on Research and Treatment in Multiple Sclerosis (LACTRIMS), Buenos Aires, Argentina.

Learning HOW – OpportunityPlus (P.O. Box 35481, Charlotte, NC 28235, tel: 704-376-4735; Internet: www.opportunity-plus.org). Learn-

ing HOW strives to build self-esteem and confidence among disabled women by encouraging volunteer community involvement. They seek to train physically disabled people for leadership positions, job placements, resume preparation, mentoring and work in conjunction with the National Organization of Women (NOW).

Multiple Sclerosis Association of America (MSAA), (706 Haddonfield Road, Cherry Hill, NJ 08002; tel: 856-488-4500; 800-LEARN-MS; Internet: www.msaa.com). MSAA is a national, non-profit organization dedicated to enhancing the quality of life of those affected by multiple sclerosis. Programs such as equipment loan, support groups, and research grants are enhanced by a wide variety of educational publications.

Multiple Sclerosis Society of Canada (250 Bloor Street East, Suite 820, Toronto, Ontario M4W 3P9, Canada, tel: 416-922-6065; in Canada: 800-268-7582; Internet: www.mssoc.ca). A national organization that funds research, promotes public education, and produces publications in both English and French. They provide an "ASK MS Information System" database of articles on a wide variety of topics including treatment, research, and social services. Regional divisions and chapters are located throughout Canada.

National Council on Disability (NCD) (1331 F Street, N.W., Suite 1050, Washington, DC 20004; tel: 202-272-2004; Internet: www.ncd.gov). The Council is an independent federal agency whose role is to study and make recommendations about public policy for people with disabilities. Publishes a free newsletter, "Focus."

National Family Caregivers Association (NFCA) (10605 Concord Street, Kensington, MD 20895, tel: 301-942-6430; Internet: www.nfcacares.org). NFCA is dedicated to improving the quality of life of America's 18,000,000 caregivers. It publishes a quarterly newsletter, and has a resource guide, an information clearinghouse, and a toll-free hotline: 800-896-3650.

National Multiple Sclerosis Society (NMSS) (733 Third Avenue, New York, NY 10017, tel: 800-FIGHT MS; Internet: www.nationalmssociety.org). The NMSS is a nonprofit organization that supports national and international research into the prevention, cure, and treatment of MS. The NMSS funds basic, clinical, and health services 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 programs and services of the Society promote knowledge, health, and independence while providing education and emotional support. Toll-Free access to the local chapter by selecting option one at 1-800-FIGHT MS. The Internet web site listed above provides updated information about treatments, current research, programs, and services, and each chapter has a local home page.

Knowledge Programs provide information about MS and how to live with it successfully, including:

- information and referrals to local resources;
- a lending library of books and tapes;
- *MS Connection*, the Society's local newsletters;
- *Inside MS*, the Society's national lifestyle magazine;
- educational pamphlets and brochures on a variety of topics; and
- *MS Learn Online*, a regularly scheduled Internet educational program (check website for scheduling information and archived programs).
- *Keep S'myelin* newsletter for children in families affected by MS.
- *Knowledge Is Power*, an 8-week self-study program by mail for people newly diagnosed, and *Moving Forward*, a local educational program for people newly diagnosed with MS and their families.

Health and Wellness programs help keep your patients feeling as well as possible, and include swimming and other exercise programs sponsored or co-sponsored by some chapters, or referral to existing programs in the community.

Independence Programs help your patients to stay empowered as they meet the challenges of living with MS. They include:

- advocacy to increase federal funding for MS research, health insurance, and patient rights issues, and to address local access and healthcare issues;
- programs on employment, including programs for employers; and
- public awareness campaigns in local and national media.

For all who live with MS:

- referrals to healthcare professionals, MS clinics and centers, and multidisciplinary MS centers;

- referrals to wellness resources, exercise programs, and mental health professionals;
- peer support, including self-help groups and the peer support network *Someone To Listen*; and
- printed materials on a variety of topics.

National Park Service, U.S. Department of the Interior (P.O. Box 37127, Washington, D.C. 20013-7127; Internet: www.nps.gov). The service will provide you with a listing of national parks and numbers for you to call to obtain up-to-date accessibility information for the individual parks.

Office on the Americans with Disabilities Act (U.S. Department of Justice, Civil Rights Division, P.O. Box 66118, Washington, DC 20035, tel: 202-514-0301; Internet: www.usdoj.gov/crt/ada/adahom1.htm). This office is responsible for enforcing the ADA. To order copies of its regulations, call 202-514-6193.

Paralyzed Veterans of America (PVA) (801 Eighteenth Street N.W., Washington, DC 20006, tel: 800-424-8200; Internet: www.pva.org). PVA is a national information and advocacy agency working to restore function and quality of life for veterans with spinal cord dysfunction. It supports and funds education and research and has a national advocacy program that focuses on accessibility issues. PVA publishes brochures on many issues related to rehabilitation.

Rehabilitation in Multiple Sclerosis (RIMS). The Network of European MS Centers, Melsbroek, Belgium.

Social Security Administration (6401 Security Boulevard, Baltimore, MD 21235, tel: 800-772-1213; Internet: www.ssa.gov). To apply for social security benefits based on disability, call this office or visit your local social security branch office. The Office of Disability within the Social Security Administration publishes a free brochure entitled, "Social Security Regulations: Rules for Determining Disability and Blindness."

Through the Looking Glass: National Research and Training Center on Families of Adults with Disabilities (2198 Sixth Street, Suite 100, Berkeley, CA 94710; tel: 510-848-4445; 800-644-2666; Internet: www.lookingglass.org).

Well Spouse Foundation (30 East 40th Street, New York, NY 10016; tel: 212-644-1241; 800-838-0879; Internet: www.wellspouse.org). An emotional support network for people married to or living with a chronically ill partner. Advocacy for home health and long-term care and a newsletter are among the services offered.

Assistive Technology

Access to Recreation: Adaptive Recreation Equipment for the Physically Challenged (8 Sandra Court, Newbury Park, CA 91320, tel: 800-634-4351; Internet: www.accesstr.com). Products include exercise equipment and assistive devices for sports, environmental access, games, crafts, and hobbies.

Accessible Threads (1218 Central Street, Evanston, IL 60201; tel: 847-475-2183; fax: 847-475-7078; Internet: www.accessiblethreads.com). The maker of the "Oops Shirt" has other helpful innovations for patients with physical disabilities.

adaptABILITY (Department 2082, 75 Mill Street, Colchester, CT 06415, tel: 800-243-9232; Internet: www.ssw.com). A free catalog of assistive devices and self-care equipment designed to enhance independence.

Adaptive Clothing provides an online list of descriptions of web sites devoted to apparel and accessories. Internet: www.kansas.net/~cbaslock/clothint.html.

Adaptive Parenting: Idea Book I (Through the Looking Glass, 2198 Sixth Street, Suite 100, Berkeley, CA 94710; tel: 510-848-1112; 800-644-2666; Internet: www.lookingglass.org).

American Automobile Association (1712 G Street N.W., Washington, DC 20015; Internet: www.AAA.com). The AAA will provide a list of automobile hand-control manufacturers.

American Medical Alert (3265 Lawson Blvd., Oceanside, NY 11572; tel: 516-536-5850 or 800-645-3244; Internet: www.amacalert.com). Personal emergency response system that links a person living alone with a 24-hour emergency response center, as well as other services.

Enrichments (P.O. Box 5071, Bolingbrook, IL 60440, tel: 800-323-5547; Internet: www.sammonspreston.com). A free catalog of assistive devices and self-care equipment designed to enhance independence.

Finally It Fits (100-A Gilman Avenue, Campbell, CA 95008; tel: 408-866-9740; fax: 408-866-9805; Internet: www.finallyitfits.net). This company specializes in clothing for easy dressing and offers blouses, pants, skirts and dresses.

Interim In-Touch (2050 Spectrum Blvd., Fort Lauderdale, FL 33309; tel: 516-536-5850 or 800-645-3244; Internet: www.amacalert.com). Personal emergency response system that links a person living alone with a 24-hour emergency response center, as well as other services.

Life Enhancement Technologies, LLC (2682 Middlefield Road, Bldg. L, Redwood City, CA 94063; tel: 800-779-6953; Internet: www.2bcool.com).

The company manufactures a variety of cooling suits that can be used in management of heat-related symptoms in MS.

Medic Alert Foundation International (P.O. Box 1009, Turlock, CA 95380, tel: 800-344-3226; 209-668-3333; Internet: www.medicalert.org). 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.

Miscellaneous. Here is an online information list of companies that provide clothing and assistive devices for people with health impairments, their families, and for those who provide services and support – Internet: www.planetamber.com/resources/198.html.

National Rehabilitation Information Center (NARIC) (1010 Wayne Avenue, Suite 800, Silver Spring, MD 20910-5633; tel: 800-346-2742; 301-562-2400; fax: 301-562-2401; Internet: www.naric.com). 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. NARIC is committed to serving both professionals and consumers who are interested in disability and rehabilitation. Information specialists can answer simple information requests and provide referrals immediately and at no cost. More complex database searches are available at nominal cost.

ABLEDATA (8455 Colesville Road, Suite 935, Silver Spring, MD 20910; tel: 301-588-9284; 800-227-0216; fax: 301-589-3563; Internet: www.abledata.com/index.htm). ABLEDATA is a national database of information on assistive technology designed to enable persons with disabilities to identify and locate the devices that will assist them in their home, work, and leisure activities. Information specialists are available to answer questions during regular business hours. ABLE INFORM BSS is available twenty-four hours a day to customers with a computer, modem, and telecommunications software.

REHABDATA (8455 Colesville Road, Suite 935, Silver Spring, MD 20910; tel: 301-588-9284; 800-346-2742; Internet: www.naric.com/naric/search/rhab/browse.html). REHABDATA is a database containing bibliographic records with abstracts and summaries of the

materials contained in the NARIC (National Rehabilitation Information Center) library of disability rehabilitation materials. Information specialists are available to conduct a database search on any rehabilitation related topic.

RESNA: Rehabilitation, Engineering, and Assistive Technology Society of North America (1700 North Moore Street, Suite 1540, Arlington, VA 22209-1903; tel: 703-524-6686; P.O. Box 969, Etobicoke Station U, Etobicoke, Ontario M8Z 5P9; Internet: www.resna.org). RESNA is an international association for the advancement of rehabilitation technology. Their objectives are to improve the quality of life for the disabled through the application of science and technology and to influence policy relating to the delivery of technology to disabled persons. They will respond by mail to specific questions about modifying existing equipment and designing new devices.

Sears Home Health Care Catalog (P.O. Box 3123, Naperville, IL 60566, tel: 800-326-1750). The catalog includes medical equipment such as hospital beds, commodes, and wheelchairs, as well as adaptive clothing.

Sentry Detection Corporation (exclusive Westinghouse distributor) (tel: 800-695-0110). The company will install a Life Alert system (separately or as part of a total home security system) that allows a disabled person to get immediate assistance in the event of an emergency.

SOS Wireless Communication (11 W. Cooke Road, Suite 8, Columbus, OH 43214; tel: 800-259-8327; Internet: www.sosphone.com). This mobile emergency response system operates on the existing national cellular network, providing 24-hours personalized service, nationwide roadside service, and free 911 calls.

Steele, Inc. (26112 Iowa Avenue, N.E., P.O. Box 7304, Kingston, WA 98346; tel: 360-297-4555; Internet: www.steelevest.com). The company manufactures the Steele Vest® for cooling. It can be used for the management of heat-related symptoms in MS.

Electronic Information Sources

One of the most flexible ways to obtain information on multiple sclerosis is by using a computer and a modem. It is possible to dial a number of services that provide access to information about MS. These include the “big three” online services—America OnLine, CompuServe, and Prodigy (see below for customer service numbers). If you are not currently a subscriber and would like information on how to join, call one or more of these numbers. If you are a subscriber, you can access information about MS by entering one of the commands listed below.

There are also many sources of information available free through the Internet on the World Wide Web. For example, the National Multiple Sclerosis Society has a home page on the World Wide Web at: www.nmss.org. If you are an experienced “net surfer,” switch to your favorite search facility and enter the key words “MS” or “multiple sclerosis.” This will generally give you a listing of dozens of web sites that pertain to MS. Keep in mind, however, that the World Wide Web is a free and open medium; while many of the web sites have excellent and useful information, others may contain highly unusual and inaccurate information.

ABELDATA

Information on Assistive Technology

www.abledata.com

Allsup, Inc.

Assists Individuals Applying for Social Security Disability Benefits

www.allsupinc.com

Alta Vista

www.altavista.com

Apple Computer disability Resources

www.apple.com/education/k12/disability

The Ares-Serono Group/Rebif®

www.serono.com/ms/

Berlex/Betaseron®

www.betaseron.com

Biogen/Avonex®

www.biogen.com

CenterWatch Clinical Trials Listing Service™

www.centerwatch.com

CLAMS – Computer Leterate Advocates for Multiple Sclerosis

www.clams.org

The Consortium of Multiple Sclerosis Centers

www.ms-care.org

Dog Pile

www.dogpile.com

IBM Special Needs Systems

www.austin.ibm.com/sns

Immunex/Novantrone®

www.MSknowledge.com

Infosci

Selected Links on MS

www.infosci.org

International Multiple Sclerosis Federation/The World of Multiple Sclerosis

www.nmss.org

The International Journal of MS Care

www.ms-care.com

International MS Support Foundation

www.msnews.org

Internet Explorer

www.microsoft.com/windows/ie/default.htm

Metacrawler

www.metacrawler.com

Medicare Information

www.hcfa.gov/medicare/medicare.htm

Microsoft Accessibility Technology for Everyone

www.microsoft.com/enable

MS Crossroads

National Clearinghouse of Rehabilitation Training Materials (NCRTM)

www.nchrtm.okstate.edu/index3.html

National Institutes of Health's site for neurologic disease

www.ninds.nih.gov

National Rehabilitation Association

www.nationalrehab.org

National Rehabilitation Information Center

www.naric.com/naric

Personal Website of Aapo Halko, Ph.D., mathematician with MS in Finland

www.helsinki.fi/~ahalko/ms.html

President's Task Force on Employment of Adults with Disabilities

www.disability.gov/CSS/Default.asp

The Multiple Sclerosis Information Gateway

Schering AG, Berlin, Germany

www.ms-gateway.com

The Multiple Sclerosis Society of Canada

www.mssoc.ca

The Myelin Project

www.myelin.org

The National Family Caregivers Association

www.nfcacares.org

The National Institute of Neurological Disorders and Stroke
www.ninds.nih.gov

The National Library of Medicine
www.nlm.nih.gov

The National Multiple Sclerosis Society
www.nmss.org

The National Organization for Rare Disorders
www.rarediseases.org

NARIC – The National Rehabilitation Information Center
www.naric.com

Teva Neuroscience/Copaxone
www.Copaxone
www.MSWatch.com

Virtual Assistance Technology Center
www.at-center.com

Webcrawler
www.webcrawler.com

Environmental Adaptations

A Consumer's Guide to Home Adaptation (Adaptive Environments Center, 374 Congress Street, Suite 301, Boston, MA 02210, tel: 617-695-1225; Internet: www.adaptiveenvironments.org). A workbook for planning adaptive home modifications such as lowering kitchen countertops and widening doorways.

"Adapting the Home for the Physically Challenged" (A/V Health Services, P.O. Box 1622, West Sacramento, CA 95691, tel: 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.

American Institute of Architects (AIA) (1735 New York Avenue, N.W., Washington, DC 20006, tel: 202-626-7300; publications catalog and orders: 800-365-2724; Internet: www.aia.org). This organization will make referrals to architects who are familiar with the design requirements of people with disabilities.

Barrier-Free Design Centre (2075 Bayview Avenue, Toronto, Ontario M4N 3M5, Canada, tel: 416-480-6000). The Centre provides information and technical consultation in barrier-free design for Canadians with physical disabilities.

A Blueprint for Action: A Resource for Promoting Home Modifications (Center for Universal Design, North Carolina State University, Box 8613, Raleigh, NC 27695, tel: 919-515-3082; 800-647-6777; Internet: www.design.ncsu.edu/cud). This publication identifies state and local sources of financial assistance for homeowners (or tenants) who need to make modifications in their homes.

GE Answer Center (9500 Williamsburg Plaza, Louisville, KY 40222, tel: 800-626-2000; Internet: www.geappliances.com). The Center, which is open twenty-four hours a day, seven days a week, offers assistance to individuals with disabilities as well as the general public. They offer two free brochures, "Appliance Help for Those with Special Needs," and "Basic Kitchen Planning for the Physically Handicapped."

National Association of Home Builders (NAHB) (National Research Center, Economics and Policy Analysis Division, 400 Prince George's Boulevard, Upper Marlboro, MD 20774, tel: 301-249-4000; Internet: www.nahb.com). The Research Center produces publications and provides training on housing and special needs. A publication entitled "Homes for a Lifetime" includes an accessibility checklist, financing options, and recommendations for working with builders and remodelers.

National Kitchen and Bath Association (687 Willow Grove Street, Hackettstown, NJ 07840, tel: 908-852-0033; Internet: www.nkba.org). The Association produces a technical manual of barrier-free planning and has directories of certified designers and planners.

Information Sources

Canadian Rehabilitation Council for the Disabled (CRCD) (45 Shepard Avenue East, Suite 801, Toronto, Ontario M2N 5W9, Canada, tel: 416-250-7490). The Council is a federation of regional and provincial groups serving individuals with disabilities throughout Canada. It operates an information service and publishes a newsletter and a quarterly journal.

Clearinghouse on Disability Information, Communications and Information Services, Office of Special Education and Rehabilitative Services, U.S. Department of Education, Switzer Building, 330 C Street, S.W., Washington, DC 20202, tel: 202-205-8241. Internet: www.ed.gov/offices/OSER. Created by the Rehabilitation Act of 1973, the Clearinghouse responds to inquiries about federal laws, services, and programs for individuals of all ages with disabilities. Their quarterly magazine, "OSERS News in Print," is available free of charge.

Disability Rights Education and Defense Fund, Inc. (DREDF), (2212 Sixth Street, Berkeley, CA 94710; tel: 610-644-2555; 800-466-4232; Internet: www.dredf.org). DREDF is a national law and policy center dedicated to furthering the civil rights of people 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/training for legislators, policy makers, and law students.

Easter Seals/March of Dimes National Council (90 Eglinton Avenue East, Suite 511, Toronto, Ontario M4P 2Y3, Canada; tel: 416-932-8382; www.esmodnc.org). The Council is a federation of regional and provincial groups serving individuals with disabilities throughout Canada. It operates an information service and publishes a newsletter and a quarterly journal.

Eastern Paralyzed Veterans Association (EPVA), (75-20 Astoria Boulevard, Jackson Heights, NY 11370, tel: 718-803-3782; Internet: www.epva.org). EPVA is a private, non-profit organization dedicated to serving the needs of its members and people with disabilities through programs such as benefits services, hospital liaison, sports and recreation, wheelchair repair, information, and referral. EPVA also supports three professional organizations: the American Paraplegia Society, the American Association of Spinal Cord Injury Nurses, and the American Association of Spinal Cord Injury Psychologists and Social Workers. EPVA produces newsletters and journals.

HealthTalk Interactive (800-335-2500). An MS education network is available twenty-four hours a day, providing various kinds of information, including answers to commonly asked questions, a replay of a recent "Living with MS" live broadcast, and presentations on various aspects of symptom management.

Information and Resource Center, National Multiple Sclerosis Society (733 Third Avenue, New York, NY 10017, tel: 800-FIGHT MS; Internet: www.nmss.org). The Center will answer questions and send you publications of the Society as well as copies of published articles on any topics related to MS.

Inglis House (2600 Belmont Avenue, Philadelphia, PA 19131, tel: 215-878-5600; Internet: www.ign.org). A national information exchange network specializing in long-term facilities for mentally alert persons with physical disabilities.

National Health Information Center (P.O. Box 1133, Washington, DC 20013, tel: 800-336-4797; Internet: www.health.gov/nhic). The Center maintains a library and a database of health-related organizations. It

also provides referrals related to health issues for consumers and professionals.

Paralyzed Veterans of America (801 18th Street, N.W., Washington, D.C. 20006; tel: 202-USA-1300; Internet: www.pva.org.)

President's Committee on Employment of People with Disabilities (1331 F Street, N.W., Washington, D.C. 2004-1107; tel: 202-376-6200; Internet: www.info@pcepd.gov). The Committee publishes employment-related brochures for individuals with disabilities and their employers, and provides the Job Accommodation Network (tel: 800-526-7234).

Rehabilitation Research Institute (Academic Center T-605, George Washington University, Washington, DC 20502, tel: 202-676-2624). The Institute develops and disseminates materials for rehabilitation professionals and the general public. Publications include annotated bibliographies and cover topics such as attitudinal barriers, employment rights, recreation, and sexual disability.

Neurologic Organizations

American Academy of Neurology (1080 Montreal Avenue, St. Paul, MN 55116; tel: 651-695-1940; fax 651-695-2791; Internet: www.aan.com). Representing neurologists throughout North America, the AAN has recently established new membership criteria for nurses who specialize in care of the neurologically impaired patient.

American Neurologic Association (5841 Cedar Lake Road, #108, Minneapolis, MN 55416; tel: 612-545-6284). The ANA offers membership to neurologists with an academic emphasis.

European Neurological Society (Internet: www.ensinfo.com)

European Federation of Neurological Societies (EFNS) *European Journal of Neurology*, (Published by Blackwell Science, Osney Mead, Oxford, OX2 0EL, UK; tel: 011-44-0-1865-206206; fax: 011-44-0-1865-206026; Internet: www.blackwell-science.com/ene). This journal is published bi-monthly and covers all areas of clinical and basic research in neurology. The journal provides a forum for European activity in clinical neuroscience and medical practice and strengthens the links between research workers and clinicians in Europe and other parts of the world.

Newsletters and Journals

Each chapter of the National Multiple Sclerosis Society publishes its own newsletter for local distribution.

EPVA in collaboration with CMSC/NARCOMS publishes the *MS Quarterly* report, a newsletter that contains updated information about MS research, long-term, and symptomatic management of multiple sclerosis.

The MS Exchange is the official newsletter of the IOMSN and the Consortium of Multiple Sclerosis Centers.

Living Well with Multiple Sclerosis is a monthly newsletter (by paid subscription) published by Springhouse Publishing, Springhouse, PA.

Inside MS is a publication of the National Multiple Sclerosis Society distributed to society members and health professionals.

Nursing Organizations

American Academy of Nurse Practitioners, (Capitol Station LBJ Bldg., P.O. Box 12846, Austin, TX 78711, tel: 512-463-6930); American College of Nurse Practitioners (2401 Pennsylvania Avenue N.W., Suite 900, Washington, DC 20006, tel: 202-466-4825. National Alliance of Nurse Practitioners, 325 Pennsylvania Avenue S.E., Washington, DC 20003, tel: 202-675-6350.

Three national organizations representing nurse practitioners. Activities include legislative awareness, advocacy, professional education, and certification and/or recognition of advanced practice nurses.

American Association of Neuroscience Nurses (224 N. Des Plaines, Suite 60, Chicago, IL 60661, tel: 312-993-0043). This organization focuses on neurologic and neurosurgical conditions and techniques, both nursing and technological, which enhance patients' quality of life and survival. Annual meetings and a professional journal are offered to members and interested nurses.

American Association of Spinal Cord Injury Nurses (AASCIN), (75-20 Astoria Blvd), Jackson Heights, NY 11370-1177, tel: 718-803-3782). Although its focus is on spinal cord injury, this organization focuses on research and education with many common concerns of multiple sclerosis

American Nurses Association (600 Maryland Avenue S.W., Suite 100W, Washington, DC 20024-2571, tel: 800-274-4262). The national organization for nurses which offers a wide array of educational, research, and legislative services. In addition, ANCC, a branch of ANA, offers opportunities for certification in nursing specialties.

American Society of Neurorehabilitation. (2221 University Avenue S.E., Suite 360, Minneapolis, MN 55414, tel: 612-623-2405). ASNR's membership consists of physicians and non-physicians whose practice is devoted to patients with neurologic disease. ASNR publishes a jour-

nal, has an annual meeting, and holds certification courses for specialists.

Association of Rehabilitation Nurses (ARN), (5700 Old Orchard Road, first floor, Skokie, IL 60077-1057, tel: 708-966-3433). The ARN is an international organization of professional rehabilitation nurses. ARN offers a wide range of professional activities that help develop the professional skills of rehabilitation nurses. Included in these are educational conferences, seminars throughout the year, certification examinations, and support of research.

IOMSN – The International Organization of MS Nurses, (PO Box 450, Teaneck, NJ 07666 201 837-9241) The only MS nursing specialty organization with international affiliates in the United Kingdom, Australia, Italy, and the Netherlands. Internet: www.iomsn.org

Nurse Practitioner Associates for Continuing Education (NPACE), (5 Militia Drive, Lexington, MA 02173, tel: 617-861-0270). NPACE conducts educational seminars for advanced practice nurses throughout the year.

Respiratory Nursing Society (RNS) (5700 Old Orchard Road, first floor, Skokie, IL 60077-1057, tel: 708-966-3433). RNS is the professional association for nurses who care for clients with pulmonary dysfunction and who are interested in the promotion of pulmonary health.

The Society of Urologic Nurses and Associates, (E. Holly Avenue, Box 56, Pitman, NJ 08071-0056). A specialty group of nurses with a focus on urologic management problems.

Visiting Nurse Associations of America (VNAA), (3801 East Florida Avenue, Suite 900, Denver, CO 80210, tel: 800-426-2547). VNAA is a national non-profit, community-based organization of home health care providers.

Publishing Companies Specializing in Health and Disability Issues

Demos Medical Publishing (386 Park Avenue South, Suite 201, New York, NY 10016, tel: 800-532-8663, Internet: www.demosmedpub.com).

Grey House Publishing (Pocket Knife Square, P.O. Box 1866, Lakeville, CT 06039; tel: 800-562-2139; fax: 860-435-3004; Internet: www.greyhouse.com).

Resources for Rehabilitation (33 Bedford Street, Suite 19A, Lexington, MA 02173, tel: 617-862-6455; Internet: www.rfr.org).

Twin Peaks Press (P.O. Box 129, Vancouver, WA 98666, tel: 800-637-2256).

Woodbine House (Publishers of the Special-Needs Collection) (6510 Bells Mill Road, Bethesda, MD 20817, tel: 301-897-3570; 800-843-7323; Internet: www.woodbinehouse.com).

Resource Materials

Assistive Technology Sourcebook. (Written by A. Enders and M. Hall, published by Resna Press, Washington, DC 1990).

The Complete Directory for People with Disabilities. 1999-2000 (Published by Grey House Publishing, Inc., Pocket Knife Square, P.O. Box 1866, Lakeville, CT 06039; tel: 800-562-2139; fax: 860-435-3004; e-mail: www.greyhouse.com).

Complete Drug Reference. (Compiled by United States Pharmacopoeia, published by Consumer Report Books, a division of Consumers Union, Yonkers, NY). This comprehensive, readable, and easy-to-use drug reference includes almost every prescription and non-prescription medication available in the United States and Canada. A new edition is published yearly.

Complete Guide to Prescription and Non-Prescription Drugs. (Written by H. Winter Griffith, M.D., published by The Body Press/Perigee, 200 Madison Avenue, New York, NY 10016, 1995).

Directory of National Information Sources on Disabilities. (Published by the National Institute on Disability and Rehabilitation Research, Washington, DC 1994-1995. Vols. I and II).

Dressing Tips and Clothing Resources for Making Life Easier. (Written by Shelly Peterman Schwarz, c/o Real Living with MS, 1111 Bethlehem Pike, P.O. Box 908, Springhouse, PA 19477).

Exceptional Parent: Parenting Your Child or Young Adult with a Disability. A magazine for families and professionals. (Exceptional Parent, P.O. Box 3000, Dept. EP, Denville, NJ 07834, tel: 800-247-8080. A monthly magazine that celebrated its 25th anniversary by producing the 1996 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.

Guide To Catalogs for People with Disabilities, Their Families and Their Friends. (EKA Publications, Inc., 9151 Hampton Overlook, Capital Heights, MD 20743; tel: 800-386-5367).

Living with Low Vision: A Resource Guide for People with Sight Loss. (Resources for Rehabilitation, 33 Bedford Street, Suite 19A, Lexington, MA 02173, tel: 617-862-6455). The only large-print comprehen-

sive guide to services and products designed to assist individuals with vision loss throughout North America.

Parenting with a Disability. (Through the Looking Glass, 2198 Sixth Street, Suite 100, Berkeley, CA 94710; tel: 510-848-1112; 800-644-2666; Internet: www.lookingglass.org).

Resource Directory for the Disabled. (Written by R.N. Shrouf, published by Facts-on-File, 460 Park Avenue South, New York, NY 10016; 1991). A resource directory that includes associations and organizations, government agencies, libraries and research centers, publications, and products of all types for disabled individuals.

Resources for People with Disabilities and Chronic Conditions. (Resources for Rehabilitation, 33 Bedford Street, Suite 19A, Lexington, MA 02173, tel: 617-862-6455). A comprehensive resource guide covering a variety of disabling conditions as well as general information on rehabilitation services, assistive technology for independent living, and laws that affect people with disabilities.

Travel

ACCESS: The Foundation for Accessibility by the Disabled (P.O. Box 356, Malverne, NY 11565, tel: 516-887-5798). ACCESS is a clearinghouse for travel services and information on accessibility for the physically disabled. They publish monographs pertaining to travel and accessibility, and will assist in finding resources and services for individuals and corporations.

Accessible Journeys (tel: 800-846-4537 or 610-521-0339; Internet: www.disabilitytravel.com). A company that arranges travel for mobility-impaired travelers, and is affiliated with a network of offices in nine European countries.

Directory of Travel Agencies for the Disabled. (Written by Helen Hecker, published by Twin Peaks Press, P.O. Box 129, Vancouver, WA 98666-0129). This directory lists travel agents who specialize in arranging travel plans for people with disabilities.

The Disability Bookshop (P.O. Box 129, Vancouver, WA 98666, tel: 800-637-2256). The Disability Bookshop has an extensive list of books for disabled travelers, dealing with such topics as accessibility, travel agencies, accessible van rentals, medical resources, air travel, and guides to national parks.

Information for Handicapped Travelers (available free of charge from the National Library Service for the Blind and Physically Handicapped,

1291 Taylor Street, N.W., Washington, DC 20542, tel: 800-424-8567; 202-707-5100). A booklet providing information about travel agents, transportation, and information centers for individuals with disabilities.

Project Action (Internet: www.projectaction.org). Maintains a database on its web site of information about the availability of accessible transportation anywhere in the United States. Users can highlight the state and city they plan to visit and view all transportation services available to them. The database also includes travel agencies specializing in travel arrangements for people with disabilities.

Society for the Advancement of Travel for the Handicapped (SATH) (347 Fifth Avenue, Suite 610, New York, NY 10016, tel: 212-447-7284; Internet: www.sath.org). SATH is a non-profit organization that acts as a clearinghouse for accessible tourism information and is in contact with organization in many countries to promote the development of facilities for disabled people. SATH publishes a quarterly magazine, "Access to Travel."

Travel for the Disabled: A Handbook of Travel Resources and 500 Worldwide Access Guides. (Written by Helen Hecker, published by Twin Peaks Press, P.O. Box 129, Vancouver, WA 98666, tel: 800-637-2256). The handbook provides information for disabled travelers about accessibility.

Travel Industry and Disabled Exchange (TIDE) (5435 Donna Avenue, Tarzana, CA 91356, tel: 818-343-6339). The Exchange assists disabled individuals to travel throughout the world. A quarterly newsletter is available to members.

Travel Information Service (Moss Rehabilitation Hospital, 1200 West Tabor Road, Philadelphia, PA 19141, tel: 215-456-4603). The Service provides information and referrals for people with disabilities.

Travelin' Talk (P.O. Box 3534, Clarksville, TN 37043, tel: 615-552-6670). A network of more than one thousand people and organizations around the world who are willing to provide assistance to travelers with disabilities and share their knowledge about the areas in which they live. Travelin' Talk publishes a newsletter by the same name and has an extensive resource directory.

The Wheelchair Traveler (Accent on Living, P.O. Box 700, Bloomington, IL 61702, tel: 309-378-2961). A directory that provides ratings of hotels and motels in the United States.

Wilderness Inquiry (1313 5th Street, S.E., Box 84, Minneapolis, MN 55414, tel: 800-728-0719; 612-379-3858). Wilderness Inquiry sponsors trips into the wilderness for people with disabilities or chronic conditions.

Visual Impairment

Canadian National Institute for the Blind (CNIB) (1929 Bayview Avenue, Toronto, Ontario M4G 3E8, Canada, tel: 416-480-7580; Internet: www.navnet.net/~mic/cnib/index.html). The Institute provides counseling and rehabilitation services for Canadians with any degree of functional visual impairment. They offer public information literature and operate resource and technology centers. The national office has a list of provincial and local CNIB offices.

The Lighthouse Low Vision Products Consumer Catalog (36-20 Northern Boulevard, Long Island City, NY 11101, tel: 800-829-0500). This large-print catalog offers a wide range of products designed to help people with impaired vision.

The Library of Congress, Division for the Blind and Physically Handicapped (1291 Taylor Street, N.W., Washington, DC 20542, tel: 800-424-8567; 800-424-9100; for application: 202-287-5100; Internet: www.lcweb.loc.gov/nls). The Library Service provides free talking book equipment on loan as well as a full range of recorded books for individuals with disabilities or visual impairment. It also provides a variety of free library services through one hundred forty cooperating libraries.

Living with Low Vision: A Resource Guide for People with Sight Loss. (Published by Resources for Rehabilitation, 33 Bedford Street, Suite 19A, Lexington, MA 02173, tel: 617-862-6455). A comprehensive directory designed to help individuals with impaired vision to locate the products and services they need in order to remain independent.

Products for People with Vision Impairment Catalog. (American Foundation for the Blind Product Center, P.O. Box 7044, 100 Enterprise Place, Dover, DE 19903, tel: 800-829-0500). The Catalog is available in standard print and audiocassette.

APPENDIX B*

Medications Commonly Used in Multiple Sclerosis

These information sheets are intended as a patient's guide to drugs commonly used in the treatment and management of multiple sclerosis. They describe the ways in which each medication is most often prescribed in multiple sclerosis (MS) as well as precautions to be noted and the side effects that may occur with their use. Those side effects that could possibly be confused with symptoms of multiple sclerosis are marked with an asterisk.

The information contained in these sheets will help patients to be more informed about the medications they are taking and therefore more able to discuss their questions and concerns with their physician. This information should never be used as a substitute for a physician's instructions and recommendations.

The following guidelines apply to the use of any and all of the medications: and should be communicated to patients.

- Make sure that your physician knows your medical history, including all medical conditions for which you are currently being treated and any allergies you have.
- Tell your physician if you are breast-feeding, currently pregnant, or planning to become pregnant in the near future.

*Reprinted with permission of the publisher from *Multiple Sclerosis: The Questions You Have—The Answers You Need* edited by Rosalind C. Kalb. New York: Demos Medical Publishing Inc., © 2000.

- Make a list of all of the drugs you are currently taking—including both prescription and over-the-counter medications—and provide your physician with a copy for your medical chart.
- Take your medications only as your physician prescribes them for you. If you have questions about the recommended dosage, ask your physician.
- Unless otherwise instructed, store medications in a cool, dry place; exposure to heat or moisture may cause the medication to break down. Liquid medications that are stored in the refrigerator should not be allowed to freeze.
- Unless otherwise directed by your physician or pharmacist, the general instructions concerning a missed dose of medication are as follows: if you miss a dose, take it as soon as possible. However, if it is almost time for your next dose, skip the one you missed and go back to the regular dosing schedule. Do not double dose.
- Keep all medications out of the reach of children.

The following table lists all of the products described in this appendix. For each product, the table gives the generic or chemical name, the brand name, and the common usage in MS, as well as its availability in the United States and Canada. Products available without a prescription are so indicated.

- 1 Available without a prescription
- 2 Available in both US and Canada unless otherwise noted

Chemical Name: Alprostadil (al-**pross**-ta-dill); also called Prostaglandin E1

Brand Name: Prostin VR (U.S. and Canada)

Generic Available: No

Description: Alprostadil belongs to a group of medicines called vasodilators, which cause blood vessels to expand, thereby increasing blood flow. When alprostadil is injected into the penis, it produces an erection by increasing blood flow to the penis.

Proper Usage

- ⤷ Alprostadil should never be used as a sexual aid by men who are not impotent. If improperly used, this medication can cause permanent damage to the penis.
- ⤷ Alprostadil is available by prescription and should be used only as directed by your physician, who will instruct you in the proper way to give yourself an injection so that it is simple and essentially pain-free.
- ⤷ Alprostadil is sometimes used in combination with a medicine called phentolamine (Regitine—U.S.; Rogitine—Canada).

Precautions

- ⤷ Do not use more of this medicine or use it more often than it has been prescribed for you. Using too much of this medicine will result in a condition called priapism, in which the erection lasts too long and does not resolve when it should. Permanent damage to the penis can occur if blood flow to the penis is cut off for too long a period of time.

Possible Side Effects

- ⤷ Side effects that you should report to your physician so he or she can adjust the dosage or change the medication: pain at the injection site; burning or aching during erection.
- ⤷ Rare side effects that require immediate attention: erection continuing for more than four hours. If you cannot be seen immediately by your physician, you should go to the emergency room for prompt treatment.

Chemical Name: Alprostadil (al-**pross**-ta-dill); also called Prostaglandin E1

Brand Name: MUSE (U.S. and Canada) [suppository form]

Generic Available: No

Description: Alprostadil belongs to a group of medicines called vasodilators, which cause blood vessels to expand, thereby increasing blood flow. MUSE is a semisolid pellet of medication in the form of a suppository. When the suppository is inserted into the urethra, it produces an erection by increasing blood flow to the penis.

Proper Usage

- ⊃ Alprostadil should never be used as a sexual aid by men who are not impotent. If improperly used, this medication can cause permanent damage to the penis.
- ⊃ Alprostadil is available by prescription and should be used only as directed by your physician, who will instruct you in the proper way to insert the suppository.

Precautions

- ⊃ Do not use more of this medicine or use it more often than it has been prescribed for you. Using too much of this medicine will result in a condition called priapism, in which the erection lasts too long and does not resolve when it should. Permanent damage to the penis can occur if blood flow to the penis is cut off for too long a period of time.

Possible Side Effects

- ⊃ Side effects that you should report to your physician so he or she can adjust the dosage or change the medication: pain at the insertion site; burning or aching during erection.
- ⊃ Rare side effects that require immediate attention: erection continuing for more than four hours. If you cannot be seen immediately by your physician, you should go to the emergency room for prompt treatment.

Chemical Name: Amantadine (a-man-ta-deen)

Brand Name: Symmetrel (U.S. and Canada)

Generic Available: Yes (U.S.)

Description: Amantadine is an antiviral medication used to prevent or treat certain influenza infections; it is also given as an adjunct for the treatment of Parkinson's disease. It has been demonstrated that this medication, through some unknown mechanism, is sometimes effective in relieving fatigue in multiple sclerosis.

Proper Usage

- ⊃ The usual dosage for the management of fatigue in MS is 100 to 200 mg daily, taken in the earlier part of the day in order to avoid sleep disturbance. Doses in excess of 300 mg daily usually cause livedo reticularis, a blotchy discoloration of the skin of the legs.

Precautions

The precautions listed here pertain to the use of this medication as an antiviral or Parkinson's disease treatment. There are no reports at this time concerning the precautions in the use of the drug to treat fatigue in multiple sclerosis.

- ⊃ Drinking alcoholic beverages while taking this medication may cause increased side effects such as circulation problems, dizziness, lightheadedness, fainting, or confusion. Do not drink alcohol while taking this medication.
- ⊃ This medication may cause some people to become dizzy, confused, or lightheaded, or to have blurred vision or trouble concentrating.
- ⊃ Amantadine may cause dryness of the mouth and throat. If your mouth continues to feel dry for more than two weeks, check with your physician or dentist since continuing dryness may increase the risk of dental disease.
- ⊃ This medication may cause purplish red, net-like, blotchy spots on the skin. This problem occurs more often in females and usually occurs on the legs and/or feet after amantadine has been taken regularly for a month or more. The blotchy spots usually go away within two to twelve weeks after you stop taking the medication.
- ⊃ Studies of the effects of amantadine in pregnancy have not been done in humans. Studies in some animals have shown that amantadine is harmful to the fetus and causes birth defects.
- ⊃ Amantadine passes into breast milk. However, the effect of amantadine in newborn babies and infants is not known.

Possible Side Effects

The side effects listed here pertain to the use of amantadine as an antiviral or Parkinson's disease treatment. There are no reports at the present time of the side effects associated with the use of this drug in the treatment of MS-related fatigue.

- ↳ Side effects that may go away as your body adjusts to the medication and do not require medical attention unless they continue or are bothersome: difficulty concentrating; dizziness; headache; irritability; loss of appetite; nausea; nervousness; purplish red, net-like, blotchy spots on skin; trouble sleeping or nightmares; constipation*; dryness of the mouth; vomiting.
- ↳ Rare side effects that should be reported as soon as possible to your physician: blurred vision*; confusion; difficult urination*; fainting; hallucinations; convulsions; unusual difficulty in coordination*; irritation and swelling of the eye; mental depression; skin rash; swelling of feet or lower legs; unexplained shortness of breath.

*Since it may be difficult to distinguish between certain common symptoms of MS and some side effects of amantadine, be sure to consult your health care professional if an abrupt change of this type continues for more than a few days.

Chemical Name: Amitriptyline (a-mee-**trip**-ti-leen)

Brand Name: Elavil (U.S. and Canada)

Generic Available: Yes (U.S. and Canada)

Description: Amitriptyline is a tricyclic antidepressant used to treat mental depression. In multiple sclerosis, it is frequently used to treat painful paresthesias in the arms and legs (e.g., burning sensations, pins and needles, stabbing pains) caused by damage to the pain regulating pathways of the brain and spinal cord.

Note: Other tricyclic antidepressants are also used for the management of neurologic pain symptoms. Clomipramine (Anafranil—U.S. and Canada), desipramine (Norpramin—U.S. and Canada), doxepin (Sinequan—U.S. and Canada), imipramine (Tofranil—U.S. and Canada), nortriptyline (Pamelor—U.S.; Aventyl—Canada), trimipramine (U.S. and Canada). While each of these medications is given in different dosage levels, the precautions and side effects listed for amitriptyline apply to these other tricyclic medications as well.

Precautions

- ⊃ Amitriptyline adds to the effects of alcohol and other central nervous system depressants (e.g., antihistamines, sedatives, tranquilizers, prescription pain medications, seizure medications, muscle relaxants, sleeping medications), possibly causing drowsiness. Be sure that your physician knows if you are taking these or other medications.
- ⊃ This medication causes dryness of the mouth. Because continuing dryness of the mouth may increase the risk of dental disease, alert your dentist that you are taking amitriptyline.
- ⊃ This medication may cause your skin to be more sensitive to sunlight than it is normally. Even brief exposure to sunlight may cause a skin rash, itching, redness or other discoloration of the skin, or severe sunburn.
- ⊃ This medication may affect blood sugar levels of diabetic individuals. If you notice a change in the results of your blood or urine sugar tests, check with your physician.
- ⊃ Do not stop taking this medication without consulting your physician. The physician may want you to reduce the amount you are taking gradually in order to reduce the possibility of withdrawal symptoms such as headache, nausea, and/or an overall feeling of discomfort.
- ⊃ Studies of amitriptyline have not been done in pregnant women. There have been reports of newborns suffering from muscle spasms and heart, breathing, and urinary problems when their mothers had taken tricyclic antidepressants immediately before delivery. Studies in

animals have indicated the possibility of unwanted effects in the fetus.

- ⤵ Tricyclics pass into breast milk. Only doxepin (Sinequan) has been reported to cause drowsiness in the nursing baby.

Possible Side Effects

- ⤵ Side effects that may go away as your body adjusts to the medication and do not require medical attention unless they continue for more than two weeks or are bothersome: dryness of mouth; constipation*; increased appetite and weight gain; dizziness; drowsiness*; decreased sexual ability*; headache; nausea; unusual tiredness or weakness*; unpleasant taste; diarrhea; heartburn; increased sweating; vomiting.
- ⤵ Uncommon side effects that should be reported to your physician as soon as possible: blurred vision*; confusion or delirium; difficulty speaking or swallowing*; eye pain*; fainting; hallucinations; loss of balance control*; nervousness or restlessness; problems urinating*; shakiness or trembling; stiffness of arms and legs*.
- ⤵ Rare side effects that should be reported to your physician as soon as possible: anxiety; breast enlargement in males and females; hair loss; inappropriate secretion of milk in females; increased sensitivity to sunlight; irritability; muscle twitching; red or brownish spots on the skin; buzzing or other unexplained sounds in the ears; skin rash, itching; sore throat and fever; swelling of face and tongue; weakness*; yellow skin.
- ⤵ Symptoms of acute overdose: confusion; convulsions; severe drowsiness*; enlarged pupils; unusual heartbeat; fever; hallucinations; restlessness and agitation; shortness of breath; unusual tiredness or weakness; vomiting.

*Since it may be difficult to distinguish between certain common symptoms of MS and some side effects of amitriptyline, be sure to consult your health care professional if an abrupt change of this type occurs.

Chemical Name: Baclofen (**bak-loe-fen**)

Brand Name: Lioresal (no longer available in the U.S.)

Generic Available: Yes (U.S. and Canada)

Description: Baclofen acts on the central nervous system to relieve spasms, cramping, and tightness of muscles caused by spasticity in multiple sclerosis. It is usually administered orally in pill form. Recently, an intrathecal delivery system (via a surgically implanted pump) has been approved for those individuals with significant spasticity who cannot tolerate a sufficiently high dose of the oral form of the medication.

Proper Usage

- ⊃ People with MS are usually started on an initial dose of 5 mg every six to eight hours. If necessary, the amount is increased by 5 mg per dose every five days until symptoms improve. The goal of treatment is to find a dosage level that relieves spasticity without causing excessive weakness or fatigue. The effective dose may vary from 15 mg to 160 mg per day or more.

Precautions

- ⊃ If you are taking more than 30 mg daily, do not stop taking this medication suddenly. Stopping high doses of this medication abruptly can cause convulsions, hallucinations, increases in muscle spasms or cramping, mental changes, or unusual nervousness or restlessness. Consult your physician about how to reduce the dosage gradually before stopping the medication completely.
- ⊃ This drug adds to the effects of alcohol and other CNS depressants (such as antihistamines, sedatives, tranquilizers, prescription pain medications, seizure medications, other muscle relaxants), possibly causing drowsiness. Be sure that your physician knows if you are taking these or other medications.
- ⊃ Studies of birth defects with baclofen have not been done with humans. Studies in animals have shown that baclofen, when given in doses several times higher than the amount given to humans, increases the chance of hernias, incomplete or slow development of bones in the fetus, and lower birth weight.
- ⊃ Baclofen passes into the breast milk of nursing mothers but has not been reported to cause problems in nursing infants.

Possible Side Effects

- ⊃ Side effects that typically go away as your body adjusts to the medication and do not require medical attention unless they continue for several weeks or are bothersome: drowsiness or unusual tiredness*;

increased weakness*; dizziness or lightheadedness; confusion; unusual constipation*; new or unusual bladder symptoms*; trouble sleeping; unusual unsteadiness or clumsiness*.

- Unusual side effects that require immediate medical attention: fainting; hallucinations; severe mood changes; skin rash or itching.
- Symptoms of overdose: sudden onset of blurred or double vision*; convulsions; shortness of breath or troubled breathing; vomiting.

*Since it may be difficult to distinguish between certain common symptoms of MS and some side effects of baclofen, be sure to consult your health care professional if an abrupt change of this type occurs.

Chemical Name: Bisacodyl (bis-a-koe-dill)

Brand Name: Dulcolax—tablet or suppository (U.S.); Bisacolax—tablet or suppository (Canada)

Generic Available: Yes (U.S. and Canada)

Description: Bisacodyl is an over-the-counter stimulant laxative that can be used in either oral or suppository form. Stimulant laxatives encourage bowel movements by increasing the muscle contractions in the intestinal wall that propel the stool mass. Although stimulant laxatives are popular for self-treatment, they are more likely to cause side effects than other types of laxatives.

Proper Usage

- ☞ Laxatives are to be used to provide short-term relief only, unless otherwise directed by the nurse or physician who is helping you to manage your bowel symptoms. A regimen that includes a healthy diet containing roughage (whole grain breads and cereals, bran, fruit, and green, leafy vegetables), six to eight full glasses of liquids each day, and some form of daily exercise is most important in stimulating healthy bowel function.
- ☞ If your physician has recommended this laxative for management of constipation, follow his or her recommendations for its use. If you are treating yourself for constipation, follow the directions on the package insert.
- ☞ The tablet form of this laxative is usually taken on an empty stomach in order to speed results. The tablets are coated to allow them to work properly without causing stomach irritation or upset. Do not chew or crush the tablets or take them within an hour of drinking milk or taking an antacid.
- ☞ A bedtime dose usually produces results the following morning. Be sure to consult your physician if you experience problems or do not get relief within a week.

Precautions

- ☞ Do not take any laxative if you have signs of appendicitis or inflamed bowel (e.g., stomach or lower abdominal pain, cramping, bloating, soreness, nausea, or vomiting). Check with your physician as soon as possible.
- ☞ Do not take any laxative for more than one week unless you have been told to do so by your physician. Many people tend to overuse laxatives, which often leads to dependence on the laxative action to produce a bowel movement. Discuss the use of laxatives with your health care professional in order to ensure that the laxative is used

effectively as part of a comprehensive, healthy bowel management regimen.

- ⤵ Do not take any laxative within two hours of taking other medication because the desired effectiveness of the other medication may be reduced.
- ⤵ If you are pregnant, discuss with your physician the most appropriate type of laxative for you to use.
- ⤵ Some laxatives pass into breast milk. Although it is unlikely to cause problems for a nursing infant, be sure to let your physician know if you are using a laxative and breast-feeding at the same time.

Possible Side Effects

- ⤵ Side effects that may go away as your body adjusts to the medication and do not require medical attention unless they persist or are bothersome: belching; cramping; diarrhea; nausea.
- ⤵ Unusual side effects that should be reported to your physician as soon as possible: confusion; irregular heartbeat; muscle cramps; skin rash, unusual tiredness or weakness.

Chemical Name: Carbamazepine (kar-ba-maz-e-peen)

Brand Name: Tegretol (U.S. and Canada)

Generic Available: Yes (U.S.)

Description: Carbamazepine is used to relieve shock-like pain, such as the facial pain caused by trigeminal neuralgia (tic douloureux).

Proper Usage

- ⤷ It is very important that you take this medicine exactly as directed by your physician in order to obtain the best results and lessen the chance of serious side effects.
- ⤷ Carbamazepine is not an ordinary pain reliever. It should be used only when your physician prescribes it for certain types of pain. Do not take this medication for other aches or pains.
- ⤷ If you miss a dose of this medication, take it as soon as possible. If it is almost time for your next dose, skip the missed dose and go back to your regular dosing schedule. Do not double dose. If you miss more than one dose in a day, check with your physician.
- ⤷ It is very important that your physician check your progress at regular intervals. Your physician may want to have certain tests done to see if you are receiving the correct amount of medication or to check for certain side effects of which you might be unaware.

Precautions

- ⤷ Carbamazepine adds to the effects of alcohol and other central nervous system depressants that may cause drowsiness (e.g., antihistamines, sedatives, tranquilizers, prescription pain medications, seizure medications, muscle relaxants). Be sure that your physician knows if you are taking these or other medications.
- ⤷ Some people who take carbamazepine may become more sensitive to sunlight than they are normally. Exposure to sunlight, even for brief periods of time, may cause a skin rash, itching, redness or other discoloration of the skin, or severe sunburn.
- ⤷ Oral contraceptives (birth control pills) that contain estrogen may not work properly while you are taking carbamazepine. You should use an additional or alternative form of birth control while taking this drug.
- ⤷ Carbamazepine affects the urine sugar levels of diabetic patients. If you notice a change in the results of your urine sugar tests, check with your physician.

- ⊃ Before having any medical tests or any kind of surgical, dental, or emergency treatment, be sure to let the health care professional know that you are taking this medication.
- ⊃ Carbamazepine has not been studied in pregnant women. There have been reports of babies having low birth weight, small head size, skull and facial defects, underdeveloped fingernails, and delays in growth when their mothers had taken carbamazepine in high doses during pregnancy. Studies in animals have shown that carbamazepine causes birth defects when given in large doses.
- ⊃ Carbamazepine passes into breast milk, and the baby may receive enough of it to cause unwanted effects. In animal studies, carbamazepine has affected the growth and appearance of nursing babies.

Possible Side Effects

- ⊃ Side effects that typically go away as your body adjusts to the medication and do not require medical attention unless they continue for several weeks or are bothersome: clumsiness or unsteadiness*; mild dizziness*; mild drowsiness*; lightheadedness; mild nausea or vomiting; aching joints or muscles; constipation*; diarrhea; dryness of mouth; skin sensitivity to sunlight; irritation of mouth or tongue; loss of appetite; loss of hair; muscle or abdominal cramps; sexual problems in males*.
- ⊃ Check with your physician as soon as possible if any of the following side effects occur: blurred or double vision*; confusion; agitation; severe diarrhea, nausea, or vomiting; skin rash or hives; unusual drowsiness; chest pain; difficulty speaking or slurred speech*; fainting; frequent urination*; unusual heartbeat; mental depression or other mood or emotional changes; unusual numbness, tingling, pain, or weakness in hands or feet*; ringing or buzzing in ears; sudden decrease in urination; swelling of face, hands, feet, or lower legs; trembling; uncontrolled body movements; visual hallucinations.
- ⊃ Check with your physician immediately if any of the following occur: black tarry stools or blood in urine or stools; bone or joint pain; cough or hoarseness; darkening of urine; nosebleeds or other unusual bleeding or bruising; painful or difficult urination; tenderness, swelling, or bluish color in leg or foot; pale stools; pinpoint red spots on skin; shortness of breath or cough; sores, ulcers, or white spots on lips or in the mouth; sore throat, chills, and fever; swollen glands; unusual tiredness or weakness*; wheezing, tightness in chest; yellow eyes or skin.
- ⊃ Symptoms of overdose that require immediate attention: unusual clumsiness or unsteadiness*; severe dizziness or fainting; fast or irreg-

ular heartbeat; unusually high or low blood pressure; irregular or shallow breathing; severe nausea or vomiting; trembling, twitching, and abnormal body movements.

*Since it may be difficult to distinguish between certain common symptoms of MS and some side effects of carbamazepine, be sure to consult your health care professional if an abrupt change of this type occurs.

Chemical Name: Ciprofloxacin (sip-roe-flox-a-sin) combination

Brand Name: Cipro (U.S. and Canada)

Generic Available: No

Description: Ciprofloxacin is one of a group of antibiotics (fluoroquinolones) used to kill bacterial infection in many parts of the body. It is used in multiple sclerosis primarily to treat urinary tract infections.

Proper Usage

- ⤷ This medication is best taken with a full glass (eight ounces) of water. Additional water should be taken each day to help prevent some unwanted effects.
- ⤷ Ciprofloxacin may be taken with meals or on an empty stomach.
- ⤷ Finish the full course of treatment prescribed by your physician. Even if your symptoms disappear after a few days, stopping this medication prematurely may result in a return of the symptoms.
- ⤷ This medication works most effectively when it is maintained at a constant level in your blood or urine. To help keep the amount constant, do not miss a dose. It is best to take the doses at evenly spaced times during the day and night.

Precautions

- ⤷ This medication may cause some people to become dizzy, lightheaded, drowsy, or less alert.
- ⤷ If you are taking antacids that contain aluminum or magnesium, be sure to take them at least two hours before or after you take ciprofloxacin. These antacids may prevent the ciprofloxacin from working properly.
- ⤷ This medication may cause your skin to become more sensitive to sunlight. Stay out of direct sunlight during the midday hours, wear protective clothing, and apply a sun block product that has a skin protection factor (SPF) of at least 15.
- ⤷ Studies of birth defects have not been done in humans. This medication is not recommended during pregnancy since antibiotics of this type have been reported to cause bone development problems in young animals.
- ⤷ Some of the antibiotics in this group are known to pass into human breast milk. Since they have been reported to cause bone development problems in young animals, breast-feeding is not recommended during treatment with this medication.

Possible Side Effects

- ↳ Side effects that may go away as your body adjusts to the medication and do not require medical attention unless they continue or are bothersome: abdominal or stomach pain; diarrhea; dizziness; drowsiness*; headache; lightheadedness; nausea or vomiting; nervousness; trouble sleeping.
- ↳ Rare side effects that should be reported to your physician immediately: agitation; confusion; fever; hallucinations; peeling of the skin; shakiness or tremors*; shortness of breath; skin rash; itching; swelling of face or neck.

*Since it may be difficult to distinguish between certain common symptoms of MS and some side effects of ciprofloxacin, be sure to consult your health care professional if an abrupt change of this type occurs.

Chemical Name: Clonazepam (kloe-na-ze-pam)

Brand Name: Klonopin (U.S.); Rivotril; Syn-Clonazepam (Canada)

Generic Available: No

Description: Clonazepam is a benzodiazepine that belongs to the group of medications called central nervous system depressants, which slow down the nervous system. Although clonazepam is used for a variety of medical conditions, it is used in multiple sclerosis primarily for the treatment of tremor, pain, and spasticity.

Proper Usage

- ⤷ Keep this medication out of the reach of children. An overdose of this medication may be especially dangerous for children.

Precautions

- ⤷ During the first few months taking clonazepam, your physician should check your progress at regular visits to make sure that this medicine does not cause unwanted effects.
- ⤷ Take this medication only as directed by your physician; do not increase the dose without a prescription to do so.
- ⤷ Clonazepam adds to the effects of alcohol and other central nervous system depressants (e.g., antihistamines, sedatives, tranquilizers, prescription pain medications, seizure medications, muscle relaxants, sleeping medications). Consult your physician before taking any of these CNS depressants while you are taking clonazepam. Taking an overdose of this medication or taking it with alcohol or other CNS depressants may lead to unconsciousness and possibly death.
- ⤷ Stopping this medication suddenly may cause withdrawal side effects. Reduce the amount gradually before stopping completely.
- ⤷ Clonazepam frequently causes people to become drowsy, dizzy, light-headed, clumsy, or unsteady. Even if taken at bedtime, it may cause some people to feel drowsy or less alert on awakening.
- ⤷ Studies in animals have shown that clonazepam can cause birth defects or other problems, including death of the animal fetus.
- ⤷ Overuse of clonazepam during pregnancy may cause the baby to become dependent on it, leading to withdrawal side effects after birth. The use of clonazepam, especially during the last weeks of pregnancy, may cause breathing problems, muscle weakness, difficulty in feeding, and body temperature problems in the newborn infant.

- ↳ Clonazepam may pass into breast milk and cause drowsiness, slow heartbeat, shortness of breath, or troubled breathing in nursing babies.

Possible Side Effects

- ↳ Side effects that may go away during treatment as your body adjusts to the medication and do not require medical attention unless they continue for several weeks or are bothersome: drowsiness or tiredness; clumsiness or unsteadiness*; dizziness or lightheadedness; slurred speech*; abdominal cramps or pain; blurred vision or other changes in vision*; changes in sexual drive or performance*; gastrointestinal changes, including constipation* or diarrhea; dryness of mouth; fast or pounding heartbeat; muscle spasm*; trouble with urination*; trembling.
- ↳ Unusual side effects that should be discussed as soon as possible with your physician: behavior problems, including difficulty concentrating and outbursts of anger; confusion or mental depression; convulsions; hallucinations; low blood pressure; muscle weakness; skin rash or itching; sore throat, fever, chills; unusual bleeding or bruising; unusual excitement or irritability.
- ↳ Symptoms of overdose that require immediate emergency help: continuing confusion; severe drowsiness; shakiness; slowed heartbeat; shortness of breath; slow reflexes; continuing slurred speech*; staggering*; unusual severe weakness*.

*Since it may be difficult to distinguish between certain common symptoms of MS and some side effects of clonazepam, be sure to consult your health care professional if an abrupt change of this type occurs.

Chemical Name: Desmopressin (des-moe-press-in)

Brand Name: DDAVP Nasal Spray (U.S. and Canada)

Generic Available: No

Description: Desmopressin is a hormone used as a nasal spray. The hormone works on the kidneys to control frequent urination.

Proper Usage

- ⤷ Keep this medication in the refrigerator but do not allow it to freeze.

Precautions

- ⤷ Let your physician know if you have heart disease, blood vessel disease, or high blood pressure. Desmopressin can cause an increase in blood pressure.
- ⤷ Studies have not been done in pregnant women. It has been used before and during pregnancy to treat diabetes mellitus and has not been shown to cause birth defects.
- ⤷ Desmopressin passes into breast milk but has not been reported to cause problems in nursing infants.

Possible Side Effects

- ⤷ Side effects that typically go away as your body adjusts to the medication and do not require medical attention unless they continue for several weeks or are bothersome: runny or stuffy nose; abdominal or stomach cramps; flushing of the skin; headache; nausea; pain in the vulva.
- ⤷ Unusual side effects that require immediate medical attention: confusion; convulsions; unusual drowsiness*; continuing headache; rapid weight gain; markedly decreased urination.

* Since it may be difficult to distinguish between certain common symptoms of MS and some side effects of desmopressin, be sure to consult your health care professional if an abrupt change of this type occurs.

*Since it may be difficult to distinguish between certain common symptoms of MS and some side effects of desmopressin, be sure to consult your health care professional if an abrupt change of this type occurs.

Chemical Name: Diazepam (dye-az-e-pam)

Brand Name: Valium (U.S. and Canada)

Generic Available: Yes (U.S.)

Description: Diazepam is a benzodiazepine that belongs to the group of medicines called central nervous system depressants, which slow down the nervous system. Although diazepam is used for a variety of medical conditions, it is used in multiple sclerosis primarily for the relief of muscle spasms and spasticity.

Proper Usage

- ⤵ Keep this medication out of the reach of children. An overdose of this medication may be especially dangerous for children.

Precautions

- ⤵ Your physician should check your progress at regular visits to make sure that this medication does not cause unwanted effects.
- ⤵ Take diazepam only as directed by your physician; do not increase the dose without a prescription to do so.
- ⤵ Diazepam adds to the effects of alcohol and other central nervous system depressants (e.g., antihistamines, sedatives, tranquilizers, prescription pain medications, seizure medications, muscle relaxants, sleeping medications). Consult your physician before taking any of these CNS depressants while you are taking diazepam. Taking an overdose of this medication or taking it with alcohol or other CNS depressants may lead to unconsciousness and possibly death.
- ⤵ Stopping this medication suddenly may cause withdrawal side effects. Reduce the amount gradually before stopping completely.
- ⤵ Diazepam may cause some people to become drowsy, dizzy, light-headed, clumsy, or unsteady. Even if taken at bedtime, it may cause some people to feel drowsy or less alert on awakening.
- ⤵ The use of diazepam during the first three months of pregnancy has been reported to increase the chance of birth defects.
- ⤵ Overuse of diazepam during pregnancy may cause the baby to become dependent on the medicine, leading to withdrawal side effects after birth. The use of diazepam, especially during the last weeks of pregnancy, may cause breathing problems, muscle weakness, difficulty in feeding, and body temperature problems in the newborn infant. When diazepam is given in high doses (especially by injection) within fifteen hours before delivery, it may cause breathing problems, muscle weakness, difficulty in feeding, and body temperature problems in the newborn infant.

- ▷ Diazepam may pass into breast milk and cause drowsiness, slow heart-beat, shortness of breath, or troubled breathing in nursing babies.

Possible Side Effects

- ▷ Side effects that may go away during treatment as your body adjusts to the medication and do not require medical attention unless they continue for several weeks or are bothersome: clumsiness or unsteadiness*; dizziness or lightheadedness; slurred speech*; abdominal cramps or pain; blurred vision or other changes in vision*; changes in sexual drive or performance*; constipation*; diarrhea; dryness of mouth; fast or pounding heartbeat; muscle spasm*; trouble with urination*; trembling*; unusual tiredness or weakness*.
- ▷ Unusual side effects that should be discussed with your physician as soon as possible: behavior problems, including difficulty concentrating and outbursts of anger; confusion or mental depression; convulsions; hallucinations; low blood pressure; muscle weakness*; skin rash or itching; sore throat, fever, chills; unusual bleeding or bruising; unusual excitement or irritability.
- ▷ Symptoms of overdose that require immediate emergency help: continuing confusion; unusually severe drowsiness; shakiness; slowed heartbeat; shortness of breath; slow reflexes; continuing slurred speech; staggering; unusually severe weakness*.

*Since it may be difficult to distinguish between certain common symptoms of MS and some side effects of diazepam, be sure to consult your health care professional if an abrupt change of this type occurs.

Chemical Name: Docusate (**doe**-koo-sate)

Brand Name: Colace (U.S. and Canada)

Generic Available: Yes (U.S. and Canada)

Description: Docusate is an over-the-counter stool softener (emollient) that helps liquids to mix into dry, hardened stool, making the stool easier to pass.

Proper Usage

- ☞ Laxatives are to be used to provide short-term relief only, unless otherwise directed by the nurse or physician who is helping you to manage your bowel symptoms. A regimen that includes a healthy diet containing roughage (whole grain breads and cereals, bran, fruit, and green, leafy vegetables), six to eight full glasses of liquids each day, and some form of daily exercise is most important in stimulating healthy bowel function.
- ☞ If your physician has recommended this laxative for management of constipation, follow his or her recommendations for its use. If you are treating yourself for constipation, follow the directions on the package insert.
- ☞ Results usually occur one to two days after the first dose; some individuals may not get results for three to five days. Be sure to consult your physician if you experience problems or do not get relief within a week.

Precautions

- ☞ Do not take any type of laxative if you have signs of appendicitis or inflamed bowel (e.g., stomach or lower abdominal pain, cramping, bloating, soreness, nausea, or vomiting). Check with your physician as soon as possible.
- ☞ Do not take any laxative for more than one week unless you have been told to do so by your physician. Many people tend to overuse laxatives, which often leads to dependence on the laxative action to produce a bowel movement. Discuss the use of laxatives with your health care professional in order to ensure that the laxative is used effectively as part of a comprehensive, healthy bowel management regimen.
- ☞ Do not take mineral oil within two hours of taking docusate. The docusate may increase the amount of mineral oil that is absorbed by the body.
- ☞ Do not take any laxative within two hours of taking another medication because the desired effectiveness of the other medication may be reduced.

- If you are pregnant, discuss with your physician the most appropriate type of laxative for you to use.
- Some laxatives pass into breast milk. Although it is unlikely to cause problems for a nursing infant, be sure to let your physician know if you are using a laxative and breast-feeding at the same time.

Possible Side Effects

- Side effects that may go away as your body adjusts to the medication and do not require medical attention unless they persist or are bothersome: stomach and/or intestinal cramping.
- Unusual side effect that should be reported to your physician as soon as possible: skin rash.

Chemical Name: Fluoxetine (floo-ox-uh-teen)

Brand Name: Prozac (U.S. and Canada)

Generic Available: No

Description: Fluoxetine is used to treat mental depression. It is also used occasionally to treat MS fatigue.

Proper Usage

- ⤷ This medication should be taken in the morning when used to treat depression because it can interfere with sleep. If it upsets your stomach, you may take it with food.

Precautions

- ⤷ It may take four to six weeks for you to feel the beneficial effects of this medication.
- ⤷ Your physician should monitor your progress at regularly scheduled visits in order to adjust the dose and help reduce any side effects.
- ⤷ There have been suggestions that the use of fluoxetine may be related to increased thoughts about suicide in a very small number of individuals. More study is needed to determine if the medicine causes this effect. If you have concerns about this, be sure to discuss them with your physician.
- ⤷ Fluoxetine adds to the effects of alcohol and other central nervous system depressants (e.g., antihistamines, sedatives, tranquilizers, sleeping medicine, prescription pain medicine, barbiturates, seizure medication, muscle relaxants). Be sure that your physician knows if you are taking these or any other medications.
- ⤷ This medication affects the blood sugar levels of diabetic individuals. Check with your physician if you notice any changes in your blood or urine sugar tests.
- ⤷ Dizziness or lightheadedness may occur, especially when you get up from a lying or sitting position. Change positions slowly to help alleviate this problem. If the problem continues or gets worse, consult your physician.
- ⤷ Fluoxetine may cause dryness of the mouth. If your mouth continues to feel dry for more than two weeks, check with your physician or dentist. Continuing dryness of the mouth may increase the chance of dental disease.
- ⤷ Studies have not been done in pregnant women. Fluoxetine has not been shown to cause birth defects or other problems in animal studies.
- ⤷ Fluoxetine passes into breast milk and may cause unwanted effects, such as vomiting, watery stools, crying, and sleep problems in nursing

babies. You may want to discuss alternative medications with your physician.

Possible Side Effects

- Side effects that may go away as your body adjusts to the medication and do not require medical attention unless they continue for several weeks or are bothersome: decreased sexual drive or ability*; anxiety and nervousness; diarrhea; drowsiness*; headache; trouble sleeping; abnormal dreams; change in vision*; chest pain; decreased appetite; decrease in concentration; dizziness; dry mouth; fast or irregular heartbeat; frequent urination*; menstrual pain; tiredness or weakness*; tremor*; vomiting.
- Unusual side effects that should be discussed with your physician as soon as possible: chills or fever; joint or muscle pain; skin rash; hives or itching; trouble breathing.
- Symptoms of overdose that require immediate medical attention: agitation and restlessness; convulsions; severe nausea and vomiting; unusual excitement.

*Since it may be difficult to distinguish between certain common symptoms of MS and some side effects of fluoxetine, be sure to consult your health care professional if an abrupt change of this type occurs.

Chemical Name: Gabapentin (ga-ba-PEN-tin)

Brand Name: Neurontin (U.S.)

Generic Available: No

Description: Gabapentin is an antiepileptic used to control some types of seizures in epilepsy. It is used in multiple sclerosis to control dysesthesias (pain caused by MS lesions) and the pain caused by spasticity.

Proper Usage

- ⊃ Gabapentin may be taken with or without food. You must wait two hours after taking an antacid to take gabapentin.

If gabapentin is taken three times a day, do not allow more than 12 hours to elapse between any two doses.

- ⊃ If you miss a dose of this medication, take it as soon as possible. However, if it is almost time for your next dose, skip the missed dose then go back to your regular dosing schedule. Do not double dose.

Precautions

- ⊃ This medicine will add to the effects of alcohol and other central nervous system depressants that may cause drowsiness (e.g., antihistamines, sedatives, tranquilizers, prescription pain medications, seizure medications, muscle relaxants). Be sure that your physician knows if you are taking these or any other medications.
- ⊃ Before having any medical tests, or surgical, dental, or emergency treatment of any kind, be sure to let the health care professional know that you are taking this medication.
- ⊃ Consult your physician before stopping this medication because stopping abruptly may result in seizures. Depending on the dose you are taking, your physician may want you to decrease your dose gradually in order to avoid seizures.
- ⊃ Gabapentin has not been studied in pregnant women. However, animal studies have shown possible bone and kidney problems in offspring. If you are pregnant or planning to become pregnant, discuss this with your physician before starting this medication.
- ⊃ It is not known whether gabapentin passes into breast milk. Women who wish to breast-feed should consult with their physician.

Possible Side Effects

- ⊃ Side effects that typically go away as your body adjusts to the medication and do not require medical attention unless they continue for several weeks or are bothersome: blurred or double vision*; dizziness;

drowsiness, muscle ache; swelling of hands or legs; tremor*; unusual tiredness*; weakness*; diarrhea, frequent urination*; indigestion; low blood pressure; slurred speech*; sleep difficulty; weakness*.

- ↳ Check with your doctor as soon as possible if any of the following side effects occur: clumsiness or unsteadiness*; continuous, uncontrolled eye movements; depression; mood changes; memory problems*; hoarseness; lower back pain; painful or difficult urination.
- ↳ Symptoms of overdose requiring immediate medical attention: double vision*; severe diarrhea, dizziness; drowsiness; slurred speech*.

* Since it may be difficult to distinguish between certain common symptoms of MS and some side effects of gabapentin, be sure to consult your health care professional if an abrupt change of this type occurs.

Chemical Name: Glatiramer Acetate (gla-**TEER**-a-mer **ASS**-i-tate)

Brand Name: Copaxone (U.S. and Canada)

Generic Available: No

Description: Glatiramer acetate is a synthetic protein that simulates myelin basic protein, a component of the myelin that insulates nerve fibers in the brain and spinal cord. Through a mechanism that is not completely understood, this drug seems to block myelin-damaging T cells by acting as a myelin decoy. In a two-year randomized, double-blind, controlled trial involving 251 ambulatory patients with relapsing-remitting MS, those taking the drug had a 29 percent reduction in annual relapse rate compared with control subjects who were given a placebo. An extension of this two-year trial, which confirmed the ability of glatiramer acetate to reduce the frequency of relapses in patients with relapsing-remitting MS, will be continued to year 10.

Proper Usage

- ⤷ Glatiramer acetate is injected subcutaneously (between the fat layer just under the skin and the muscles beneath) once a day. A physician or nurse will instruct you in the preparation of the medication for injection and the injection procedure itself, using a specially designed set of training materials. Do not attempt to inject yourself until you are sure that you understand the procedures.

Glatiramer acetate should be kept refrigerated at all times. If refrigeration is not available, the drug may be safely stored at room temperature for up to seven days.

- ⤷ Do not reuse needles or syringes. Dispose of the syringes as directed by your physician and keep them out of the reach of children.
- ⤷ Because injection-site reactions (swelling, redness, discoloration, or pain) are relatively common, it is recommended that the sites be rotated according to a schedule provided for you by your physician. Do not use any one site more than once per week.

Before you have a Papanicolaou (Pap) test, tell your doctor or nurse that you are taking this medication. The results of the test may be affected by glatiramer acetate.

Precautions

- ⤷ Do not change the dose or dosing schedule of this medication without consulting your physician.
- ⤷ Glatiramer acetate has not been studied in pregnant women. Therefore, it should not be used during pregnancy or by a woman

who is trying to become pregnant. If you are pregnant or planning to become pregnant, discuss this with your physician before starting the medication. If you become pregnant while on the medication, inform your physician.

- It is not known whether glatiramer acetate passes into breast milk. Nursing women should discuss the use of this medication with their physician.

Possible Side Effects

- Side effects that generally resolve on their own and do not require medical attention unless they continue for several weeks or are bothersome: injection-site reactions (e.g., swelling, the development of a hardened lump, redness, tenderness, increased warmth of the skin, itching at the site of the injection); runny nose, tremor*; unusual tiredness or weakness*; weight gain.
- Unusual side effects that should be discussed as soon as possible with your doctor: hives (an itchy, blotchy swelling of the skin) or severe pain at the injection site.
- Possible immediate post-injection reaction: approximately 13 percent of individuals using glatiramer acetate will experience, at one time or another, a transient (very temporary) reaction immediately after injecting glatiramer acetate. This reaction, which usually occurs only once, includes flushing or chest tightness with heart palpitations, anxiety, and difficulty breathing. During the clinical trials, these reactions occurred very rarely, usually within minutes of an injection. They lasted approximately 15 minutes and resolved without further problem.

* Since it may be difficult to distinguish between certain common symptoms of MS and some side effects of glatiramer acetate, be sure to consult your health care professional if an abrupt change of this type occurs.

Chemical Name: Glycerin (**gli-ser-in**)

Brand Name: Sani-Supp suppository (U.S.)

Generic Available: Yes (U.S. and Canada)

Description: A glycerin suppository is a hyperosmotic laxative that draws water into the bowel from surrounding body tissues. This water helps to soften the stool mass and promote bowel action.

Proper Usage

- ⤵ Laxatives are to be used to provide short-term relief only, unless otherwise directed by the nurse or physician who is helping you to manage your bowel symptoms. A regimen that includes a healthy diet containing roughage (whole grain breads and cereals, bran, fruit, and green, leafy vegetables), six to eight full glasses of liquids each day, and some form of daily exercise is most important in stimulating healthy bowel function.
- ⤵ If your physician has recommended this laxative for management of constipation, follow his or her recommendations for its use. If you are treating yourself for constipation, follow the directions on the package insert.
- ⤵ If the suppository is too soft to insert, refrigerate it for thirty minutes or hold it under cold water before removing the foil wrapper.
- ⤵ Glycerin suppositories often produce results within fifteen minutes to one hour. Be sure to consult your physician if you experience problems or do not get relief within a week.

Precautions

- ⤵ Do not take any type of laxative if you have signs of appendicitis or inflamed bowel (e.g., stomach or lower abdominal pain, cramping, bloating, soreness, nausea, or vomiting). Check with your physician as soon as possible.
- ⤵ Do not take any laxative for more than one week unless you have been told to do so by your physician. Many people tend to overuse laxatives, which often leads to dependence on the laxative action to produce a bowel movement. Discuss the use of laxatives with your health care professional in order to ensure that the laxative is used effectively as part of a comprehensive, healthy bowel management regimen.
- ⤵ If you are pregnant, discuss with your physician the most appropriate type of laxative for you to use.
- ⤵ Use only water to moisten the suppository prior to insertion in the rectum. Do not lubricate the suppository with mineral oil or petroleum jelly, which might affect the way the suppository works.

Possible Side Effects

- Side effects that may go away as your body adjusts to the medication and do not require medical attention unless they persist or are bothersome: skin irritation around the rectal area.
- Less common side effects that should be reported to your physician as soon as possible: rectal bleeding; blistering, or itching.

Chemical Name: Imipramine (im-ip-ra-meen)

Brand Name: Tofranil (U.S. and Canada)

Generic Available: Yes (U.S. and Canada)

Description: Imipramine is a tricyclic antidepressant used to treat mental depression. Its primary use in multiple sclerosis is to treat bladder symptoms, including urinary frequency and incontinence. Imipramine is also prescribed occasionally for the management of neurologic pain in MS.

Proper Usage

- ⤷ To lessen stomach upset, take this medication with food, even for a daily bedtime dose, unless your physician has told you to take it on an empty stomach.

Precautions

- ⤷ Imipramine adds to the effects of alcohol and other central nervous system depressants (e.g., antihistamines, sedatives, tranquilizers, prescription pain medications, seizure medications, muscle relaxants, sleeping medications), possibly causing drowsiness. Be sure that your physician knows if you are taking these or any other medications.
- ⤷ This medication causes dryness of the mouth. Because continuing dryness of the mouth can increase the risk of dental disease, alert your dentist if you are taking imipramine.
- ⤷ Imipramine may cause your skin to be more sensitive to sunlight than it is normally. Even brief exposure to sunlight may cause a skin rash, itching, redness or other discoloration of the skin, or severe sunburn. Stay out of the sun during the midday hours. Wear protective clothing and a sun block that has a skin protection factor (SPF) of at least 15.
- ⤷ This medication may affect blood sugar levels of diabetic individuals. If you notice a change in the results of your blood or urine sugar tests, check with your physician.
- ⤷ Do not stop taking imipramine without consulting your physician. The physician may want you to reduce the amount you are taking gradually in order to reduce the possibility of withdrawal symptoms such as headache, nausea, and/or an overall feeling of discomfort.
- ⤷ Studies of imipramine have not been done in pregnant women. There have been reports of newborns suffering from muscle spasms and heart, breathing, and urinary problems when their mothers had taken tricyclic antidepressants immediately before delivery. Studies in animals have indicated the possibility of unwanted effects in the fetus.

- ⤵ Imipramine passes into breast milk but has not been reported to have any effect on the nursing infant.

Possible Side Effects

- ⤵ Side effects that may go away as your body adjusts to the medication and do not require medical attention unless they continue for more than two weeks or are bothersome: dizziness; drowsiness*; headache; decreased sexual ability*; increased appetite; nausea; unusual tiredness or weakness*; unpleasant taste; diarrhea; heartburn; increased sweating; vomiting.
- ⤵ Uncommon side effects that should be reported to your physician as soon as possible: blurred vision*; confusion or delirium; constipation*; difficulty speaking or swallowing; eye pain*; fainting; fast or irregular heartbeat; hallucinations; loss of balance control*; nervousness or restlessness; problems urinating*; shakiness or trembling; stiffness of arms and legs*.
- ⤵ Rare side effects that should be reported to your physician as soon as possible: anxiety; breast enlargement in males and females; hair loss; inappropriate secretion of milk in females; increased sensitivity to sunlight; irritability; muscle twitching; red or brownish spots on the skin; buzzing or other unexplained sounds in the ears; skin rash; itching; sore throat and fever; swelling of face and tongue; weakness*; yellow skin.
- ⤵ Symptoms of acute overdose: confusion; convulsions; severe drowsiness*; enlarged pupils; unusual heartbeat; fever; hallucinations; restlessness and agitation; shortness of breath; unusual tiredness or weakness*; vomiting.

*Since it may be difficult to distinguish between certain common symptoms of MS and some side effects of imipramine, be sure to consult your health care professional if an abrupt change of this type occurs.

Chemical Name: Interferon beta-1a

Brand Name: Avonex (U.S.—approval in Canada is pending)

Generic Available: No

Description: Avonex is a medication manufactured by a biotechnological process from one of the naturally occurring interferons (a type of protein). It is made up of exactly the same amino acids (major components of proteins) as the natural interferon beta found in the human body. In a clinical trial of 380 ambulatory patients with relapsing-remitting MS, those taking the currently recommended dose of the medication had a reduced risk of disability progression, experienced fewer exacerbations, and showed a reduction in number and size of active lesions in the brain (as shown on MRI) when compared with the group taking a placebo.

Proper Usage

- ⤵ Avonex is given as a once-a-week intramuscular (IM) injection, usually in the large muscles of the thigh, upper arm, or hip. If your physician decides that you or a care partner can safely administer the injection, you will be taught how to reconstitute the medication (mix the sterile powder with the sterile water that is packaged with it) and instructed in safe and proper IM injection procedures. If you are unable to self-inject, and have no family member or friend available to do the injections, the injections will be given by your physician or nurse. Do not attempt to mix the medication or inject yourself until you are sure that you understand the procedures.
- ⤵ Avonex must be kept cold. Be sure to store it in a refrigerator both before and after the medication is mixed for injection. Do not expose the medication to high temperatures (in a glove compartment or on a window sill, for example) and do not allow it to freeze. Once the medication has been mixed for use, it is recommended that you administer the injection as soon as possible; the reconstituted powder should not be used once it has been stored in the refrigerator longer than six hours.
- ⤵ Do not reuse needles or syringes. Dispose of the syringes as directed by your physician and keep them out of the reach of children.
- ⤵ Since flu-like symptoms are a fairly common side effect during the initial weeks of treatment, it is recommended that the injection be given at bedtime. Taking acetaminophen (Tylenol®) or ibuprofen (Advil®) immediately prior to each injection and during the 24 hours following the injection will also help to relieve the flu-like symptoms.

Precautions

- ⤷ Avonex should not be used during pregnancy or by any woman who is trying to become pregnant. Women taking Avonex should use birth control measures at all times. If you want to become pregnant while being treated with Avonex, discuss the matter with your physician. If you become pregnant while using Avonex, stop the treatment and contact your physician.
- ⤷ There was no increase in depression reported by people receiving Avonex in the clinical trial. However, since depression and suicidal thoughts are known to occur with some frequency in MS, and depression and suicidal thoughts have been reported with high doses of various interferon products, it is recommended that individuals with a history of severe depressive disorder be closely monitored while taking Avonex.
- ⤷ Prior to starting treatment with Avonex, alert your physician if you have any prior history of a seizure disorder.
- ⤷ Prior to starting treatment with Avonex, alert your physician if you have any history of cardiac disease, including angina, congestive heart failure, or arrhythmia.

Possible Side Effects

- ⤷ Common side effects include flu-like symptoms (fatigue, chills, fever, muscle aches, and sweating). Most of these symptoms will tend to disappear after the initial few weeks of treatment. If they continue, become more severe, or cause you significant discomfort, be sure to talk them over with your physician.
- ⤷ Symptoms of depression, including ongoing sadness, anxiety, loss of interest in daily activities, irritability, low self-esteem, guilt, poor concentration, indecisiveness, confusion, and eating and sleep disturbances, should be reported promptly to your doctor.

Avonex Support Line: 800-456-2255

Chemical Name: Interferon beta-1a

Brand Name: Rebif

Generic Available: No

Description: Rebif is a medication manufactured by a biotechnological process from one of the naturally occurring interferons (a type of protein). It is made up of exactly the same amino acids (major components of proteins) as the natural interferon beta found in the human body. In a clinical trial of 560 ambulatory patients with relapsing-remitting MS compared three groups—those receiving 66mcg per week, those receiving 132mcg three times a week, and those receiving placebo. Over the two-year study, the two experimental groups demonstrated a lower relapse rate, prolonged time to first relapse, a higher proportion of relapse-free patients, a lower number of active lesions on MRI, and delay in progression of disability, when compared to the placebo group. Rebif is available at both dosage levels in pre-fill syringes ready for subcutaneous injection. The drug is also available at both dosage levels in a sterile powder to be mixed with a diluent.

Proper Usage

- ⤷ Rebif is given three times a week subcutaneously (between the fat layer just under the skin and the muscles beneath). The physician or nurse will instruct you in the preparation of the medication for injection and/or the injection procedure itself, using a specially designed set of training materials. Do not attempt to inject yourself until you are sure that you understand the procedures.
- ⤷ When starting treatment, it is recommended that 20% of the total dose be given during the first two weeks of therapy, 50% of the total dose be given in weeks three and four, and the full dose be given from the fifth week onward, in order to reduce the severity of side effects.
- ⤷ Rebif, in both the pre-mixed and powder forms, must be kept refrigerated. Do not expose the medication to high temperatures (in a glove compartment or on a windowsill, for example) and do not allow it to freeze.
- ⤷ Do not reuse needles or syringes. Dispose of the syringes as directed by your physician and keep them out of the reach of children.
- ⤷ Since flu-like symptoms are a fairly common side effect during the initial weeks of treatment, it is recommended that the injection be given at bedtime. Taking acetaminophen (Tylenol®) or ibuprofen (Advil®) immediately prior to each injection and during the 24 hours following the injection will also help to relieve the flu-like symptoms.

Precautions

- Rebif should not be used during pregnancy or breast-feeding, or by any woman who is trying to become pregnant. Women taking Rebif should use birth control measures at all times. If you want to become pregnant while being treated with Rebif, discuss the matter with your physician. If you become pregnant while using Rebif, stop the treatment and contact your physician.
- There was no increase in depression reported by people receiving Rebif in the clinical trial. However, since depression and suicidal thoughts are known to occur with some frequency in MS, and depression and suicidal thoughts have been reported with high doses of various interferon products, it is recommended that individuals with a history of severe depressive disorder be closely monitored while taking Rebif.

Possible Side Effects

- Common side effects include flu-like symptoms (fatigue, chills, fever, muscle aches, and sweating) and injection site reactions (swelling, redness, discoloration, and pain). Most of these symptoms will tend to disappear over time. If they continue, become more severe, or cause you significant discomfort, be sure to talk them over with your physician. Contact your physician if the injection sites become inflamed, hardened, or lumpy, and do not inject into any area that has become hardened or lumpy.
- Most of these symptoms will tend to disappear after the initial few weeks of treatment. If they continue, become more severe, or cause you significant discomfort, be sure to talk them over with your physician.
- Symptoms of depression, including ongoing sadness, anxiety, loss of interest in daily activities, irritability, low self-esteem, guilt, poor concentration, indecisiveness, confusion, and eating and sleep disturbances, should be reported promptly to your doctor.

Chemical Name: Interferon beta-1b

Brand Name: Betaseron (U.S. and Canada)

Generic Available: No

Description: Betaseron is a medication manufactured by a biotechnological process from one of the naturally occurring interferons (a type of protein). In a clinical trial of 372 ambulatory patients with relapsing-remitting MS, those taking the currently recommended dose of the medication experienced fewer exacerbations, a longer time between exacerbations, and exacerbations that were generally less severe than those of patients taking a lower dose of the medication or a placebo. Additionally, patients on interferon beta-1b had no increase in total lesion area, as shown on MRI, in contrast to the placebo group, which had a significant increase.

Proper Usage

- ⊃ Betaseron is injected subcutaneously (between the fat layer just under the skin and the muscles beneath) every other day. The physician or nurse will instruct you in the preparation of the medication for injection and the injection procedure itself, using a specially designed set of training materials. Do not attempt to inject yourself until you are sure that you understand the procedures.
- ⊃ Betaseron must be kept cold. Be sure to store it in a refrigerator before and after the medication is mixed for injection.
- ⊃ Do not reuse needles or syringes. Dispose of the syringes as directed by your physician and keep them out of the reach of children.
- ⊃ Since flu-like symptoms are a common side effect associated with at least the initial weeks of taking Betaseron, it is recommended that the medication be taken at bedtime. Taking acetaminophen (Tylenol®) or ibuprofen (Advil®) thirty minutes before each injection will also help to relieve the flu-like symptoms.
- ⊃ Because injection site reactions (swelling, redness, discoloration, or pain) are relatively common, it is recommended that the sites be rotated according to a schedule provided for you by your physician.

Precautions

- ⊃ Betaseron should not be used during pregnancy or by any woman who is trying to become pregnant. Women taking Betaseron should use birth control measures at all times.
- ⊃ During the clinical trial of interferon beta-1b, there were four suicide attempts and one completed suicide among those taking interferon beta-1b. Although there is no evidence that the suicide attempts were related to the medication itself, it is recommended that individuals

with a history of severe depressive disorder be closely monitored while taking Betaseron.

Possible Side Effects

- Common side effects include flu-like symptoms (fatigue, chills, fever, muscle aches, and sweating) and injection site reactions (swelling, redness, discoloration, and pain). Most of these symptoms tend to disappear over time. If they continue, become more severe, or cause significant discomfort, be sure to talk them over with your physician. Contact your physician if the injection sites become inflamed, hardened, or lumpy, and do not inject into any area that has become hardened or lumpy.
- Depression, including suicide attempts, has been reported by patients taking Betaseron. Common symptoms of depression are sadness, anxiety, loss of interest in daily activities, irritability, low self-esteem, guilt, poor concentration, indecisiveness, confusion, and eating and sleep disturbances. If you experience any of these symptoms for longer than a day or two, contact your physician promptly.

Betaseron Customer Service: 800-788-1467

Chemical Name: Magnesium hydroxide (mag-*nee*-zhum hye-*drox*-ide)

Brand Name: Phillips' Milk of Magnesia (available in granule form in Canada, in wafer form in the U.S., and in powder or effervescent powder in the U.S. and Canada) is one of several brands of bulk-forming laxative that are available over-the-counter.

Generic Available: No

Description: Magnesium hydroxide is an over-the-counter hyperosmotic laxative of the saline type that encourages bowel movements by drawing water into the bowel from surrounding body tissue. Saline hyperosmotic laxatives (often called "salts") are used for rapid emptying of the lower intestine and bowel. They are not to be used for the long-term management of constipation.

Proper Usage

- ☞ Laxatives are to be used to provide short-term relief only, unless otherwise directed by the nurse or physician who is helping you to manage your bowel symptoms. A regimen that includes a healthy diet containing roughage (whole grain breads and cereals, bran, fruit, and green, leafy vegetables), six to eight full glasses of liquids each day, and some form of daily exercise is most important in stimulating healthy bowel function.
- ☞ If your physician has recommended this laxative for management of constipation, follow his or her recommendations for its use. If you are treating yourself for constipation, follow the directions on the package insert. Results are often obtained ninety minutes to three hours after taking a hyperosmotic laxative. Be sure to consult your physician if you experience problems or do not get relief within a week.
- ☞ Each dose should be taken with eight ounces or more of cold water or fruit juice. A second glass of water or juice with each dose is often recommended to prevent dehydration. If concerns about loss of bladder control keep you from drinking this amount of water, talk it over with the nurse or physician who is helping you manage your bowel and bladder symptoms.

Precautions

- ☞ Do not take any type of laxative if you have signs of appendicitis or inflamed bowel (e.g., stomach or lower abdominal pain, cramping, bloating, soreness, nausea, or vomiting). Check with your physician as soon as possible.
- ☞ Do not take any laxative for more than one week unless you have been told to do so by your physician. Many people tend to overuse

laxatives, which often leads to dependence on the laxative action to produce a bowel movement. Discuss the use of laxatives with your health care professional in order to ensure that the laxative is used effectively as part of a comprehensive, healthy bowel management regimen.

- ⤵ Do not take any laxative within two hours of taking another medication because the desired effectiveness of the other medication may be reduced.
- ⤵ Although laxatives are commonly used during pregnancy, some types are better than others. If you are pregnant, consult your physician about the best laxative for you to use.
- ⤵ Some laxatives pass into breast milk. Although it is unlikely to cause problems for a nursing infant, be sure to let your physician know if you are using a laxative and breast-feeding at the same time.

Possible Side Effects

- ⤵ Side effects that may go away as your body adjusts to the medication and do not require medical attention unless they continue or are bothersome: cramping; diarrhea; gas; increased thirst.
- ⤵ Unusual side effects that should be reported to your physician as soon as possible: confusion; dizziness; irregular heartbeat; muscle cramps, unusual tiredness or weakness*.

* Since it may be difficult to distinguish between certain common symptoms of MS and some side effects of magnesium hydroxide, be sure to consult your health care professional if an abrupt change of this type occurs.

Chemical Name: Meclizine (**mek-li-zeen**)

Brand Name: Antivert (U.S.); Bonamine (Canada)

Generic Available: Yes (U.S.)

Description: Meclizine is used to prevent and treat nausea, vomiting, and dizziness.

Precautions

- ⤵ This drug adds to the effects of alcohol and other central nervous system depressants (e.g., antihistamines, sedatives, tranquilizers, prescriptions pain medications, seizure medications, muscle relaxants, sleeping medications), possibly causing drowsiness. Be sure that your physician knows if you are taking these or any other medications.
- ⤵ Meclizine may cause dryness of the mouth. If dryness continues for more than two weeks, speak to your physician or dentist since continuing dryness of the mouth may increase the risk of dental disease.
- ⤵ This medication has not been shown to cause birth defects or other problems in humans. Studies in animals have shown that meclizine given in doses many times the usual human dose causes birth defects such as cleft palate.
- ⤵ Although meclizine passes into breast milk, it has not been reported to cause problems in nursing babies. However, since this medication tends to decrease bodily secretions, it is possible that the flow of breast milk may be reduced in some women.

Possible Side Effects

- ⤵ Side effects that typically go away as your body adjusts to the medication and do not require medical attention unless they continue for more than two weeks or are bothersome: drowsiness*; blurred vision*; constipation*; difficult or painful urination; dizziness; dryness of mouth, nose, and throat; fast heartbeat; headache; loss of appetite; nervousness or restlessness; trouble sleeping; skin rash; upset stomach.

* Since it may be difficult to distinguish between certain common symptoms of MS and some side effects of meclizine, be sure to consult your health care professional if an abrupt change of this type occurs.

Chemical Name: Methenamine (meth-en-a-meen)

Brand Name: Hiprex; Mandelamine (U.S.); Hip-Rex; Mandelamine (Canada)

Generic Available: No

Description: Methenamine is an anti-infective medication that is used to help prevent infections of the urinary tract. It is usually prescribed on a long-term basis for individuals with a history of repeated or chronic urinary tract infections.

Proper Usage

- ⤷ Before you start taking this medication, check your urine with phenaphthazine paper or another test to see if it is acidic. Your urine must be acidic (pH 5.5 or below) for this medicine to work properly. Consult your health care professional about possible changes in your diet if necessary to increase the acidity of your urine (e.g., avoiding citrus fruits and juices, milk and other dairy products, antacids; eating more protein and foods such as cranberries and cranberry juice with added vitamin C, prunes, or plums).

Precautions

- ⤷ The effects of methenamine in pregnancy have not been studied in either humans or animals. Individual case reports have not shown that this medication causes birth defects or other problems in humans.
- ⤷ Methenamine passes into breast milk but has not been reported to cause problems in nursing infants.

Possible Side Effects

- ⤷ Side effects that typically go away as your body adjusts to the medication and do not require medical attention unless they continue or are bothersome: nausea; vomiting.
- ⤷ Unusual side effects that should be reported immediately to your physician: skin rash.

*Since it may be difficult to distinguish between certain common symptoms of MS and some side effects of methenamine, be sure to consult your health care professional if an abrupt change of this type occurs.

Chemical Name: Methylprednisolone (meth-ill-pred-niss-oh-lone)

Brand Name: Depo-Medrol (U.S. and Canada)

Generic Available: Yes (U.S. and Canada)

Description: Methylprednisolone is one of a group of corticosteroids (cortisone-like medications) that are used to relieve inflammation in different parts of the body. Corticosteroids are used in MS for the management of acute exacerbations because they have the capacity to close the damaged blood-brain barrier and reduce inflammation in the central nervous system. Although methylprednisolone is among the most commonly used corticosteroids in MS, it is only one of several possibilities. Other commonly used corticosteroids include dexamethasone, prednisone, betamethasone, and prednisolone. The following information pertains to all of the various corticosteroids.

Proper Usage

- ⊃ Most neurologists treating MS believe that high-dose corticosteroids given intravenously are the most effective treatment for an exacerbation, although the exact protocol for the drug's use may differ somewhat from one treating physician to another. Patients generally receive a four-day course of treatment (either in the hospital or as an outpatient), with doses of the medication spread throughout the day. This high-dose, intravenous steroid treatment is then typically followed by a gradually tapering dose of an oral corticosteroid (see Prednisone).

Precautions

- ⊃ Since corticosteroids can stimulate the appetite and increase water retention, it is advisable to follow a low-salt and/or potassium-rich diet and watch your caloric intake. Your physician will make specific dietary recommendations for you.
- ⊃ Corticosteroids can lower your resistance to infection and make any infection that you get more difficult to treat. Contact your physician if you notice any sign of infection, such as sore throat, fever, coughing, or sneezing.
- ⊃ Avoid close contact with anyone who has chicken pox or measles. Tell your physician right away if you think you have been exposed to either of these illnesses. Do not have any immunizations after you stop taking this medication until you have consulted your physician. People living in your home should not have the oral polio vaccine while you are being treated with corticosteroids since they might pass the polio virus on to you.

- ⤵ Corticosteroids may affect the blood sugar levels of diabetic patients. If you notice a change in your blood or urine sugar tests, be sure to speak to your physician.
- ⤵ The risk of birth defects for women taking corticosteroids is not known. Overuse of corticosteroids during pregnancy may slow the growth of the infant after birth. Animal studies have demonstrated that corticosteroids cause birth defects.
- ⤵ Corticosteroids pass into breast milk and may slow the infant's growth. If you are nursing or plan to nurse, be sure to discuss this with your physician. It may be necessary for you to stop nursing while taking this medication.
- ⤵ Corticosteroids may produce mood changes and/or mood swings of varying intensity. These mood alterations can vary from relatively mild to extremely intense, and can vary in a single individual from one course of treatment to another. Neither the patient nor the physician can predict with any certainty whether the corticosteroids are likely to precipitate these mood alterations. If you have a history of mood disorders (depression or bipolar disorder, for example), be sure to share this information with your physician. If you begin to experience mood changes or swings that feel unmanageable, contact your physician so that a decision can be made about whether or not you need an additional medication to help you until the mood alterations subside.

Possible Side Effects

- ⤵ Side effects that may go away as your body adjusts to the medication and do not require medical attention unless they continue or are bothersome: increased appetite; indigestion; nervousness or restlessness; trouble sleeping; headache; increased sweating; unusual increase in hair growth on body or face.
- ⤵ Less common side effects that should be reported as soon as possible to your physician: severe mood changes or mood swings; decreased or blurred vision*; frequent urination*.
- ⤵ Additional side effects that can result from the prolonged use of corticosteroids and should be reported to your physician: acne or other skin problems; swelling of the face; swelling of the feet or lower legs; rapid weight gain; pain in the hips or other joints (caused by bone cell degeneration); bloody or black, tarry stools; elevated blood pressure; markedly increased thirst (with increased urination indicative of diabetes mellitus); menstrual irregularities; unusual bruising of

the skin; thin, shiny skin; hair loss; muscle cramps or pain. Once you stop this medication after taking it for a long period of time, it may take several months for your body to readjust.

* Since it may be difficult to distinguish between certain common symptoms of MS and some side effects of methylprednisolone, be sure to consult your health care professional if an abrupt change of this type occurs.

Chemical Name: Mineral oil

Mineral oil is available in a variety of brands in the U.S. and Canada.

Generic Available: Yes

Description: Mineral oil is a lubricant laxative that is taken by mouth. It encourages bowel movements by coating the bowel and the stool with a waterproof film that helps to retain moisture in the stool.

Proper Usage

- ⤷ Laxatives are to be used to provide short-term relief only, unless otherwise directed by the nurse or physician who is helping you to manage your bowel symptoms. A regimen that includes a healthy diet containing roughage (whole grain breads and cereals, bran, fruit, and green, leafy vegetables), six to eight full glasses of liquids each day, and some form of daily exercise is most important in stimulating healthy bowel function.
- ⤷ If your physician has recommended this type of laxative for management of constipation, follow his or her recommendations for its use. If you are treating yourself for constipation, follow the directions on the package insert. Mineral oil is usually taken at bedtime because it takes six to eight hours to produce results. Be sure to consult your physician if you experience problems or do not get relief within a week.
- ⤷ Mineral oil should not be taken within two hours of mealtime because the mineral oil may interfere with food digestion and the absorption of important nutrients.
- ⤷ Mineral oil should not be taken within two hours of taking a stool softener (see Docusate) because the stool softener may increase the amount of mineral oil that is absorbed by the body.

Precautions

- ⤷ Do not take any type of laxative if you have signs of appendicitis or inflamed bowel (e.g., stomach or lower abdominal pain, cramping, bloating, soreness, nausea, or vomiting). Check with your physician as soon as possible.
- ⤷ Do not take any laxative for more than one week unless you have been told to do so by your physician. Many people tend to overuse laxative products, which often leads to dependence on the laxative action to produce a bowel movement. Discuss the use of laxatives with your health care professional in order to ensure that the laxative is used effectively as part of a comprehensive, healthy bowel management regimen.

- ⤵ Mineral oil should not be used very often or for long periods of time. Its gradual build-up in body tissues can cause problems, and may interfere with the body's absorption of important nutrients and vitamins A, D, E, and K.
- ⤵ Do not take any laxative within two hours of taking another medication because the desired effectiveness of the other medication may be reduced.
- ⤵ Mineral oil should not be used during pregnancy because it may interfere with absorption of nutrients in the mother and, if used for prolonged periods, cause severe bleeding in the newborn infant.
- ⤵ Be sure to let your physician know if you are using a laxative and breast-feeding at the same time.

Possible Side Effects

- ⤵ Uncommon side effect that usually does not need medical attention: skin irritation around the rectal area.

Chemical Name: Nitrofurantoin (nye-troe-fyoor-AN-toyn)

Brand Name: Macrochantin (U.S. and Canada)

Generic Available: No

Description: Nitrofurantoin is an *anti-infective* that is used primarily to treat urinary tract infections.

Proper Usage

- ⊃ Nitrofurantoin should be taken with food or milk to lessen stomach upset and to promote your body's absorption of the medication.
- ⊃ Finish the full course of treatment prescribed by your doctor and avoid missing doses. Even if your symptoms disappear after a few days, stopping this medication prematurely may result in a return of the symptoms.
- ⊃ If you miss a dose of this medication, take it as soon as possible. If however, it is almost time for your next dose, skip the missed dose and go back to your regular dosing schedule. Do not double dose.
- ⊃ The use of nitrofurantoin may cause your urine to become rust-yellow or brownish. This change does not require medical treatment and does not need to be reported to your physician.

Precautions

- ⊃ Nitrofurantoin can interact with, or alter the action of, a variety of other medications you may be taking. It is very important to let your physician know about all the medications that you are taking so that necessary substitutions or dosage adjustments can be made.
- ⊃ If you will be taking this medication over an extended period of time, your doctor will need to check your progress at regular visits. If your symptoms do not improve within a few days, or become worse, consult your physician.
- ⊃ Individuals with diabetes may find that this medication alters the results of some urine sugar tests. Consult with your physician before changing your diet or the dose of your diabetes medicine.
- ⊃ Certain medical conditions may affect the use of nitrofurantoin. Be sure to alert your physician about any medical conditions you have, especially glucose-6-phosphate dehydrogenase (G6PD) deficiency, kidney disease, or lung disease.
- ⊃ Because nitrofurantoin may cause problems in infants, it should not be used by a woman who is within a week or two of her delivery date, or during labor and delivery.
- ⊃ Nitrofurantoin passes into breast milk in small amounts and may cause problems in nursing babies (especially those with glucose-6-phosphate dehydrogenase (G6PD) deficiency).

Possible Side Effects

- ↳ Side effects that may go away as your body adjusts to the medication and do not require medical attention unless they continue or are bothersome: abdominal or stomach pain; diarrhea, loss of appetite, nausea, or vomiting.
- ↳ Rare side effects that should be reported to your doctor immediately: chest pain; chills; cough; fever; trouble breathing; dizziness; headache; numbness, tingling, or burning of face or mouth*; unusual weakness or tiredness*; itching; joint pain; skin rash; yellow eyes or skin.

* Since it may be difficult to distinguish between certain common symptoms of MS and some side effects of nitrofurantoin, be sure to consult your health care professional if an abrupt change of this type occurs.

Chemical Name: Nortriptyline (nor-TRIP-ti-leen)

Brand Name: Pamelor (U.S.) Aventyl (Canada)

Generic Available: Yes (U.S.)

Description: Nortriptyline is a tricyclic antidepressant used to treat mental depression. In multiple sclerosis, it is frequently used to treat painful paresthesias in the arms and legs (e.g., burning sensations, pins and needles, stabbing pains) caused by damage to the pain regulating pathways of the brain and spinal cord.

Note: Other tricyclic antidepressants are also used for the management of neurologic pain symptoms: amitriptyline (Elavil—U.S. and Canada), clomipramine (Anafranil—U.S. and Canada), desipramine (Norpramin—U.S. and Canada), doxepin (Sinequan—U.S. and Canada), imipramine (Tofranil—U.S. and Canada), and trimipramine (U.S. and Canada). Although each of these medications is given in different dosage levels, the precautions and side effects listed here for nortriptyline apply to these other tricyclic medications as well.

Precautions:

- ⤷ Nortriptyline will add to the effects of alcohol and other central nervous system depressants (e.g., antihistamines, sedatives, tranquilizers, prescription pain medications, seizure medications, muscle relaxants, sleeping medications), possibly causing drowsiness. Be sure that your physician knows if you are taking these or any other medications.
- ⤷ This medication causes dryness of the mouth. Because continuing dryness of the mouth may increase the risk of dental disease, alert your dentist that you are taking nortriptyline.
- ⤷ This medication may cause your skin to be more sensitive to sunlight than it normally is. Even brief exposure to sunlight may cause a rash, itching, redness or other discoloration of the skin, or severe sunburn.
- ⤷ this medication may affect blood sugar levels of diabetic individuals. If you notice a change in the results of your blood or urine sugar tests, check with your doctor.
- ⤷ Do not stop taking this medication without consulting your doctor. The doctor may want you to reduce the amount you are taking gradually in order to reduce the possibility of withdrawal symptoms such as headache, nausea, and/or an overall feeling of discomfort.
- ⤷ Studies of nortriptyline have not been done in pregnant women. However, there have been reports of newborns suffering from muscle spasms and heart, breathing, and urinary problems when their mothers had taken tricyclic antidepressants immediately before delivery.

Studies in animals have indicated the possibility of unwanted affects on the fetus.

- ⤵ Tricyclics pass into breast milk. Only doxepin (Sinequan) has been reported to cause drowsiness in the nursing baby.

Possible Side Effects

- ⤵ Side effects that may go away as your body adjusts to the medication and do not require medical attention unless they continue for more than two weeks or are bothersome: dryness of mouth; constipation*; increased appetite and weight gain; dizziness; drowsiness*; decreased sexual ability*; headache; nausea; unusual tiredness or weakness*; unpleasant taste; diarrhea; heartburn; increased sweating; vomiting.
- ⤵ Uncommon side effects that should be reported to your doctor as soon as possible: Blurred vision*; confusion or delirium; difficulty speaking or swallowing*; eye pain*; fainting; hallucinations; loss of balance control*; nervousness or restlessness; problems urinating*; shakiness or trembling; stiffness of arms and legs*.
- ⤵ Rare side effects that should be reported to the doctor as soon as possible: anxiety; breast enlargement in males and females; hair loss; inappropriate secretion of milk in females; increased sensitivity to sunlight; irritability; muscle twitching; red or brownish spots on the skin; buzzing or other unexplained sounds in the ears; rash, itching; sore throat and fever; swelling of face and tongue; weakness*; yellow skin.
- ⤵ Symptoms of acute overdose: confusion; convulsions; severe drowsiness*; enlarged pupils; unusual heartbeat; fever; hallucinations; restlessness and agitation; shortness of breath; unusual tiredness or weakness; vomiting.

* Since it may be difficult to distinguish between certain common symptoms of MS and some side effects of nortriptyline, be sure to consult your health care professional if an abrupt change of this type occurs.

Chemical Name: Oxybutynin (ox-i-byoo-ti-nin)

Brand Name: Ditropan (U.S. and Canada)

Generic Available: Yes (U.S.)

Description: Oxybutynin is an antispasmodic that helps decrease muscle spasms of the bladder and the frequent urge to urinate caused by these spasms.

Proper Usage

- ⊃ This medication is usually taken with water on an empty stomach, but your physician may want you to take it with food or milk to lessen stomach upset.

Precautions

- ⊃ This medication adds to the effects of alcohol and other central nervous system depressants (such as antihistamines, sedatives, tranquilizers, prescription pain medications, seizure medications, muscle relaxants). Be sure that your physician knows if you are taking these or any other medications.
- ⊃ This medication may cause your eyes to become more sensitive to light.
- ⊃ Oxybutynin may cause drying of the mouth. Since continuing dryness of the mouth can increase the risk of dental disease, alert your dentist if you are taking oxybutynin.
- ⊃ Oxybutynin has not been studied in pregnant women. It has not been shown to cause birth defects or other problems in animal studies.
- ⊃ This medication has not been reported to cause problems in nursing babies. However, since it tends to decrease body secretions, oxybutynin may reduce the flow of breast milk.

Possible Side Effects

- ⊃ Side effects that typically go away as your body adjusts to the medication and do not require medical attention unless they continue for a few weeks or are bothersome: constipation*; decreased sweating; unusual drowsiness*; dryness of mouth, nose, throat; blurred vision*; decreased flow of breast milk; decreased sexual ability*; difficulty swallowing*; headache; increased light sensitivity; nausea or vomiting; trouble sleeping; unusual tiredness or weakness*.
- ⊃ Less common side effects that should be reported to your physician immediately: difficulty in urination*.

* Since it may be difficult to distinguish between certain common symptoms of MS and some side effects of oxybutynin, be sure to consult your health care professional if an abrupt change of this type occurs.

Chemical Name: Oxybutynin (ox-i-**byoo**-ti-nin) chloride – extended release

Brand Name: Ditropan XL (U.S. and Canada)

Generic Available: No

Description: This form of oxybutynin is an extended-release antispasmodic that is formulated to help decrease muscle spasms of the bladder and the frequent urge to urinate caused by these spasms.

Proper Usage

- ⊃ The tablet is to be swallowed whole, once a day, with liquids. It can be taken with or without food. Because the medication is contained within a nonabsorbable shell that is designed to release the drug at a controlled rate, the tablet should not be chewed, crushed, or divided. The shell is routinely eliminated from the body in the stool.

Precautions

- ⊃ This medication adds to the effects of alcohol and other central nervous system depressants (such as antihistamines, sedatives, tranquilizers, prescription pain medications, seizure medications, muscle relaxants). Be sure that your physician knows if you are taking these or any other medications.
- ⊃ Oxybutynin, like all anticholinergic medications, can cause heat prostration (fever and heat stroke due to decreased sweating) when taken in very hot weather.
- ⊃ Oxybutynin may cause drying of the mouth. Since continuing dryness of the mouth can increase the risk of dental disease, alert your dentist if you are taking oxybutynin.
- ⊃ Oxybutynin has not been studied in pregnant women. It has not been shown to cause birth defects or other problems in animal studies. Do not take this medication while pregnant unless specifically instructed to do so by your physician.
- ⊃ This medication has not been reported to cause problems in nursing babies. However, since it tends to decrease body secretions, oxybutynin may reduce the flow of breast milk. Do not take this medication while nursing without discussing it with your physician.

Possible Side Effects

- ⊃ Side effects that typically go away as your body adjusts to the medication and do not require medical attention unless they continue for a few weeks or are bothersome: constipation*; decreased sweating; unusual drowsiness*; dryness of mouth, nose, throat; blurred vision*;

decreased flow of breast milk; difficulty swallowing*; headache; increased light sensitivity; nausea or vomiting; trouble sleeping; unusual tiredness or weakness*.

- ⇒ Less common side effects that should be reported to your physician immediately: urinary retention*; dehydration, cardiac arrhythmia.

* Since it may be difficult to distinguish between certain common symptoms of MS and some side effects of oxybutynin, be sure to consult your health care professional if an abrupt change of this type occurs.

Chemical Name: Papaverine (pa-pav-er-een)

Brand Name: None

Generic Available: Yes (U.S. and Canada)

Description: Papaverine belongs to a group of medicines called vasodilators, which cause blood vessels to expand, thereby increasing blood flow. Papaverine is used in MS to treat erectile dysfunction. When papaverine is injected into the penis, it produces an erection by increasing blood flow to the penis.

Proper Usage

- ⤷ Papaverine should never be used as a sexual aid by men who are not impotent. If improperly used, this medication can cause permanent damage to the penis.
- ⤷ Papaverine is available by prescription and should be used only as directed by your physician, who will instruct you in the proper way to give yourself an injection so that it is simple and essentially pain-free.

Precautions

- ⤷ Do not use more of this medication or use it more often than it has been prescribed for you. Using too much of this medicine will result in a condition called priapism, in which the erection lasts too long and does not resolve when it should. Permanent damage to the penis can occur if blood flow to the penis is cut off for too long a period of time.
- ⤷ Examine your penis regularly for possible lumps near the injection sites or for curvature of the penis. These may be signs that unwanted tissue is growing (called fibrosis), which should be examined by your physician.

Possible Side Effects

- ⤷ Side effects that you should report to your physician so that he or she can adjust the dosage or change the medication: bruising at the injection site; mild burning along the penis; difficulty ejaculating; swelling at the injection site.
- ⤷ Rare side effects that require immediate treatment: erection continuing for more than four hours. If you cannot be seen immediately by your physician, you should go to the emergency room for prompt treatment.

Chemical Name: Paroxetine (pa-rox-uh-teen)

Brand Name: Paxil (U.S. and Canada)

Generic Available: No

Description: Paroxetine is used to treat mental depression.

Proper Usage

- ⊃ Paroxetine may be taken with or without food, on an empty or full stomach.

Precautions

- ⊃ It may take up to four weeks or longer for you to feel the beneficial effects of this medication.
- ⊃ Your physician should monitor your progress at regularly scheduled visits in order to adjust the dose and help reduce any side effects.
- ⊃ This medication could add to the effects of alcohol and other central nervous system depressants (e.g., antihistamines, sedatives, tranquilizers, sleeping medicine, prescription pain medicine, barbiturates, seizure medication, muscle relaxants). Be sure that your physician knows if you are taking these or any other medications.
- ⊃ Paroxetine may cause dryness of the mouth. If your mouth continues to feel dry for more than two weeks, check with your physician or dentist. Continuing dryness of the mouth may increase the risk of dental disease.
- ⊃ This medication may cause you to become drowsy.
- ⊃ Studies have not been done in pregnant women. Studies in animals have shown that paroxetine may cause miscarriages and decreased survival rates when given in doses that are many times higher than the human dose.
- ⊃ Paroxetine passes into breast milk but has not been shown to cause any problems in nursing infants.

Possible Side Effects

- ⊃ Side effects that typically go away as your body adjusts to the medication and do not require medical attention unless they continue for several weeks or are bothersome: decrease in sexual drive or ability*; headache; nausea; problems urinating*; decreased or increased appetite; unusual tiredness or weakness*; tremor*; trouble sleeping; anxiety; agitation; nervousness or restlessness; changes in vision, including blurred vision*; fast or irregular heartbeat; tingling, burning, or prickly sensations*; vomiting.

- ↳ Unusual side effects that should be discussed with your physician as soon as possible: agitation; lightheadedness or fainting; muscle pain or weakness; skin rash; mood or behavior changes.

* Since it may be difficult to distinguish between certain common symptoms of MS and some side effects of paroxetine, be sure to consult your health care professional if an abrupt change of this type occurs.

Chemical Name: Pemoline (**pem**-oh-leen)

Brand Name: Cylert (U.S. and Canada)

Generic Available: No

Description: Pemoline is a mild central nervous system stimulant that has been used primarily to treat children with attention deficit hyperactivity disorder and adults with narcolepsy. It is used in multiple sclerosis to relieve certain types of fatigue.

Proper Usage

- ⊃ The usual starting dose for the treatment of fatigue in MS is 18.75 mg each morning for one week. If necessary, in order to manage the fatigue, the dosage can be gradually increased in increments of 18.75 mg and spread out over the early part of the day. In order to maximize the medication's effectiveness and minimize sleep disturbance, it should all be taken before mid-afternoon. The maximum dose of this medication is not known. Some individuals feel jittery or uncomfortable taking more than the minimum dose; others tolerate higher doses without discomfort. Typically, the drug is not prescribed at levels over 100–140 mgs per day for MS-related fatigue.

Precautions

- ⊃ Pemoline can increase hypertension. It should not be taken if you have angina and/or known coronary artery disease.
- ⊃ If you are taking pemoline in large doses for a long time, do not stop taking it without consulting your physician. Your physician may want you to reduce the amount you are taking gradually.
- ⊃ This drug may interact with the effects of alcohol and other central nervous system depressants (e.g., antihistamines, sedatives, tranquilizers, prescription pain medications, seizure medications, muscle relaxants, sleeping medications). Be sure your physician knows if you are taking these or any other medications.
- ⊃ Pemoline may cause some people to become dizzy or less alert than they are normally.
- ⊃ If you have been using this medicine for a long time and think you may have become mentally or physically dependent on it, check with your physician. Some signs of dependence on pemoline are a strong desire or need to continue taking the medicine; a need to increase the dose to receive the effects of the medicine; withdrawal side effects such as mental depression, unusual behavior, unusual tiredness* or weakness* after the medication is stopped.
- ⊃ Pemoline has not been shown to cause birth defects or other problems in humans. Studies in animals given large doses of pemoline

have shown that it causes an increase in stillbirths and decreased survival of the offspring.

⇒ It is not known if pemoline is excreted in breast milk.

Possible Side Effects

Side effects of this medication have not been studied in adults. Side effects that have been reported by some adults in clinical practice include insomnia; elevated heart rate; nervousness; agitation; loss of appetite and weight loss; gastrointestinal upset, including constipation and diarrhea; hallucinations.

* Since it may be difficult to distinguish between certain common symptoms of MS and some side effects of pemoline, be sure to consult your health care professional if an abrupt change of this type occurs.

Chemical Name: Phenazopyridine (fen-az-oh-**peer**-i-deen)

Brand Name: Pyridium (U.S. and Canada)

Generic Available: Yes (U.S.)

Description: Phenazopyridine is used to relieve the pain, burning, and discomfort caused by urinary tract infections. It is not an antibiotic and will not cure the infection itself. This medication is available in the U.S. only with a prescription; it is available in Canada without a prescription. The medication comes in tablet form.

Precautions

- ⤷ The medication causes the urine to turn reddish orange. This effect is harmless and goes away after you stop taking phenazopyridine.
- ⤷ It is best not to wear soft contact lenses while taking this medication; phenazopyridine may cause permanent discoloration or staining of soft lenses.
- ⤷ Check with your physician if symptoms such as bloody urine, difficult or painful urination, frequent urge to urinate, or sudden decrease in the amount of urine appear or become worse while you are taking this medication.
- ⤷ Phenazopyridine has not been studied in pregnant women. It has not been shown to cause birth defects in animal studies.
- ⤷ It is not known whether this medication passes into breast milk. It has not been reported to cause problems in nursing babies.

Possible Side Effects

- ⤷ Uncommon side effects that typically go away as your body adjusts to the medication and do not require medical attention unless they continue or are bothersome: dizziness; headache; indigestion; stomach cramps or pain.
- ⤷ Unusual side effects that should be reported to your physician: blue or blue-purple color of skin; fever and confusion; shortness of breath; skin rash; sudden decrease in amount of urine; swelling of face, fingers, feet and/or lower legs; unusual weakness or tiredness*; weight gain; yellow eyes or skin.

* Since it may be difficult to distinguish between certain common symptoms of MS and some side effects of phenazopyridine, be sure to consult your health care professional if an abrupt change of this type occurs.

Chemical Name: Phenytoin (**fen-i-toyn**)

Brand Name: Dilantin (U.S. and Canada)

Generic Available: Yes (U.S.)

Description: Phenytoin is one of a group of hydantoin anticonvulsants that are used most commonly in the management of seizures in epilepsy. It is used in MS to manage painful dysesthesias (most commonly trigeminal neuralgia) caused by abnormalities in the sensory pathways in the brain and spinal cord.

Precautions

- ⤷ This drug may interact with the effects of alcohol and other central nervous system depressants (e.g., antihistamines, sedatives, tranquilizers, certain prescription pain medications, seizure medications, muscle relaxants, sleeping medications). Be sure your physician knows if you are taking these or any other medications.
- ⤷ Oral contraceptives (birth control pills) that contain estrogen may not be as effective if taken in conjunction with phenytoin. Consult with your physician about using a different or additional form of birth control to avoid unplanned pregnancies.
- ⤷ This medication may affect the blood sugar levels of diabetic individuals. Check with your physician if you notice any change in the results of your blood or urine sugar level tests while taking phenytoin.
- ⤷ Antacids or medicines for diarrhea can reduce the effectiveness of phenytoin. Do not take any of these medications within two to three hours of the phenytoin.
- ⤷ Before having any type of dental treatment or surgery, be sure to inform your physician or dentist if you are taking phenytoin. Medications commonly used during surgical and dental treatments can increase the side effects of phenytoin.
- ⤷ There have been reports of increased birth defects when hydantoin anticonvulsants were used for seizure control during pregnancy. It is not definitely known whether these medications were the cause of the problem. Be sure to tell your physician if you are pregnant or considering becoming pregnant.
- ⤷ Phenytoin passes into breast milk in small amounts.

Possible Side Effects

- ⤷ Side effects that may go away as your body adjusts to the medication and do not require medical attention unless they continue or are bothersome: constipation*; mild dizziness*; mild drowsiness*.

- ⤵ Side effects that should be reported to your physician: bleeding or enlarged gums; confusion; enlarged glands in the neck or underarms; mood or mental changes*; muscle weakness or pain*; skin rash or itching; slurred speech or stuttering; trembling; unusual nervousness or irritability.
- ⤵ Symptoms of overdose that require immediate attention: sudden blurred or double vision*; sudden severe clumsiness or unsteadiness*; sudden severe dizziness or drowsiness*; staggering walk*; severe confusion or disorientation.

* Since it may be difficult to distinguish between certain common symptoms of MS and some side effects of phenytoin, be sure to consult your health care professional if an abrupt change of this type occurs.

Chemical Name: Prednisone (**pred**-ni-sone)

Brand Name: Deltasone (U.S. and Canada)

Generic Available: Yes (U.S. and Canada)

Description: Prednisone is one of a group of corticosteroids (cortisone-like medicines) that are used to relieve inflammation in different parts of the body. Corticosteroids are used in MS for the management of acute exacerbations because they have the capacity to close the damaged blood-brain barrier and reduce inflammation in the central nervous system. Although prednisone is among the most commonly used corticosteroids in MS, it is only one of several different possibilities. Other commonly used corticosteroids include dexamethasone; methylprednisone; betamethasone; and prednisolone. The following information pertains to all of the various corticosteroids.

Proper Usage

- ⊃ Most neurologists treating MS believe that high-dose corticosteroids given intravenously are the most effective treatment for an MS exacerbation, although the exact protocol for the drug's use may differ somewhat from one treating physician to another. Patients generally receive a four-day course of treatment (either in the hospital or as an out-patient), with doses of the medication spread throughout the day (see Methylprednisolone). The high-dose, intravenous dose is typically followed by a gradually tapering dose of an oral corticosteroid (usually ranging in length from ten days to five or six weeks). Prednisone is commonly used for this oral taper. Oral prednisone may also be used instead of the high-dose, intravenous treatment if the intravenous treatment is not desired or is medically contraindicated.

Precautions

- ⊃ This medication can cause indigestion and stomach discomfort. Always take it with a meal and/or a glass of milk. Your physician may prescribe an antacid for you to take with this medication.
- ⊃ Take this medication exactly as prescribed by your physician. Do not stop taking it abruptly; your physician will give you a schedule that gradually tapers the dose before you stop it completely.
- ⊃ Since corticosteroids can stimulate the appetite and increase water retention, it is advisable to follow a low-salt and/or a potassium-rich diet and watch your caloric intake.
- ⊃ Corticosteroids can lower your resistance to infection and make any infection that you get more difficult to treat. Contact your physician if you notice any sign of infection, such as sore throat, fever, coughing, or sneezing.

- ⊃ Avoid close contact with anyone who has chicken pox or measles. Tell your physician immediately if you think you have been exposed to either of these illnesses. Do not have any immunizations after you stop taking this medication until you have consulted your physician. People living in your home should not have the oral polio vaccine while you are being treated with corticosteroids since they might pass the poliovirus on to you.
- ⊃ Corticosteroids may affect the blood sugar levels of diabetic patients. If you notice a change in your blood or urine sugar tests, be sure to discuss it with your physician.
- ⊃ The risk of birth defects in women taking corticosteroids during pregnancy has not been studied. Overuse of corticosteroids during pregnancy may slow the growth of the infant after birth. Animal studies have demonstrated that corticosteroids cause birth defects.
- ⊃ Corticosteroids pass into breast milk and may slow the infant's growth. If you are nursing or plan to nurse, be sure to discuss this with your physician. It may be necessary for you to stop nursing while taking this medication.
- ⊃ Corticosteroids can produce mood changes and/or mood swings of varying intensity. These mood alterations can vary from relatively mild to extremely intense, and can vary in a single individual from one course of treatment to another. Neither the patient nor the physician can predict with any certainty whether the corticosteroids are likely to precipitate these mood alterations. If you have a history of mood disorders (depression or bipolar disorder, for example), be sure to share this information with your physician. If you begin to experience unmanageable mood changes or swings while taking corticosteroids, contact your physician so that a decision can be made whether or not you need an additional medication to help you until the mood alterations subside.

Possible Side Effects

- ⊃ Side effects that may go away as your body adjusts to the medication and do not require medical attention unless they continue or are bothersome: increased appetite; indigestion; nervousness or restlessness; trouble sleeping; headache; increased sweating; unusual increase in hair growth on body or face.
- ⊃ Less common side effects that should be reported as soon as possible to your physician: severe mood changes or mood swings; decreased or blurred vision*; frequent urination*.
- ⊃ Additional side effects that can result from the prolonged use of corticosteroids and should be reported to your physician: acne or other skin problems; swelling of the face; swelling of the feet or lower legs;

rapid weight gain; pain in the hips or other joints (caused by bone cell degeneration); bloody or black, tarry stools; elevated blood pressure; markedly increased thirst (with increased urination indicative of diabetes mellitus); menstrual irregularities; unusual bruising of the skin; thin, shiny skin; hair loss; muscle cramps or pain. Once you stop this medication after taking it for a long period of time, it may take several months for your body to readjust.

* Since it may be difficult to distinguish between certain common symptoms of MS and some side effects of prednisone, be sure to consult your health care professional if an abrupt change of this type occurs.

Chemical Name: Propantheline (proe-pan-the-leen) bromide

Brand Name: Probanthine (U.S. and Canada)

Generic Available: Yes (U.S.)

Description: Propantheline is one of a group of antispasmodic/anticholinergic medications used to relieve cramps or spasms of the stomach, intestines, and bladder. Propantheline is used in the management of neurogenic bladder symptoms to control urination.

Proper Usage

- ☞ Take this medicine thirty minutes to one hour before meals unless otherwise directed by your physician.

Precautions

- ☞ Do not stop this medication abruptly. Stop gradually to avoid possible vomiting, sweating, and dizziness.
- ☞ Anticholinergic medications such as propantheline can cause blurred vision and light sensitivity. Make sure you know how you react to this medication before driving.
- ☞ Anticholinergic medications may cause dryness of the mouth. If your mouth continues to feel dry for more than two weeks, check with your dentist. Continuing dryness of the mouth may increase the chance of dental disease.
- ☞ No studies of the effects of this drug in pregnancy have been done in either humans or animals.
- ☞ Anticholinergic medications have not been reported to cause problems in nursing babies. The flow of breast milk may be reduced in some women.
- ☞ Be sure that your physician knows if you are taking a tricyclic antidepressant or any other anticholinergic medication. Taking propantheline with any of these may increase the anticholinergic effects, resulting in urinary retention.

Possible Side Effects

- ☞ Side effects that typically go away as your body adjusts to the medication and do not require medical attention unless they continue for several weeks or are bothersome: constipation*; decreased sweating; dryness of mouth, nose, and throat; bloated feeling; blurred vision*; difficulty swallowing.
- ☞ Unusual side effects that require immediate medical attention: inability to urinate; confusion; dizziness*; eye pain*; skin rash or hives.

- ↳ Symptoms of overdose that require immediate emergency attention: unusual blurred vision*; unusual clumsiness or unsteadiness*; unusual dizziness; unusually severe drowsiness*; seizures; hallucinations; confusion; shortness of breath; unusual slurred speech*; nervousness; unusual warmth, dryness, and flushing of skin.

* Since it may be difficult to distinguish between certain common symptoms of MS and some side effects of propantheline, be sure to consult your health care professional if an abrupt change of this type occurs.

Chemical Name: Psyllium hydrophilic mucilloid (**sill-i-yum hye-droe-fill-ik myoo-sill-oid**)

Brand Name: Metamucil (available in granule form in Canada, in wafer form in the U.S., and in powder or effervescent powder in the U.S. and Canada) is one of several available brands of bulk-forming laxative.

Generic Available: No

Description: Psyllium hydrophilic mucilloid is a bulk-forming oral laxative. The body does not digest this type of laxative; it absorbs liquids from the intestines and swells to form a soft, bulky stool. The bowel is then stimulated normally by the presence of the bulky stool.

Proper Usage

- ⤷ Laxatives are to be used to provide short-term relief only, unless otherwise directed by the nurse or physician who is helping you to manage your bowel symptoms. A regimen that includes a healthy diet containing roughage (whole grain breads and cereals, bran, fruit, and green, leafy vegetables), six to eight full glasses of liquids each day, and some form of daily exercise is most important in stimulating healthy bowel function.
- ⤷ If your physician has recommended this laxative for management of constipation, follow his or her recommendations for its use. If you are treating yourself for constipation, follow the directions on the package insert. Results are often obtained in twelve hours but may take as long as two or three days. Be sure to consult your physician if you experience problems or do not get relief within a week.
- ⤷ In order for this type of bulk-forming laxative to work effectively without causing intestinal blockage, it is advisable to drink six to eight glasses (eight ounces) of water each day. Each dose of the laxative should be taken with eight ounces of cold water or fruit juice. If concerns about loss of bladder control keep you from drinking this amount of water, discuss it with the nurse or physician who is helping you manage your bowel and bladder symptoms.

Precautions

- ⤷ Do not take any type of laxative if you have signs of appendicitis or inflamed bowel (e.g., stomach or lower abdominal pain, cramping, bloating, soreness, nausea, or vomiting). Check with your physician as soon as possible.
- ⤷ Do not take any laxative for more than one week unless you have been told to do so by your physician. Many people tend to overuse laxatives, which often leads to dependence on the laxative action to produce a bowel movement. Discuss the use of laxatives with your

health care professional in order to ensure that the laxative is used effectively as part of a comprehensive, healthy bowel management regimen.

- ⤵ Do not take any laxative within two hours of taking another medication because the desired effectiveness of the other medication may be reduced.
- ⤵ Bulk-forming laxatives are commonly used during pregnancy. Some of them contain a large amount of sodium or sugars, which may have possible unwanted effects such as increasing blood pressure or causing fluid retention. Look for those that contain lower sodium and sugar.
- ⤵ Some laxatives pass into breast milk. Although it is unlikely to cause problems for a nursing infant, be sure to let your physician know if you are using a laxative and breast-feeding at the same time.

Possible Side Effects:

- ⤵ Check with your physician as soon as possible if you experience any of the following: difficulty breathing; intestinal blockage; skin rash or itching; swallowing difficulty (feelings of lump in the throat).

Chemical Name: Sertraline (**ser**-tra-leen)

Brand Name: Zoloft (U.S. and Canada)

Generic Available: No

Description: Sertraline is used to treat mental depression.

Proper Usage

- ⊃ This medication should always be taken at the same time in relation to meals and snacks to make sure that it is absorbed in the same way. Because sertraline may be given to different individuals at different times of the day, you and your physician should discuss what to do about any missed doses.

Precautions

- ⊃ It may take four to six weeks for you to feel the beneficial effects of this medication.
- ⊃ Your physician should monitor your progress at regularly scheduled visits in order to adjust the dose and help reduce any side effects.
- ⊃ This medication could add to the effects of alcohol and other central nervous system depressants (e.g., antihistamines, sedatives, tranquilizers, sleeping medicine, prescription pain medicine, barbiturates, seizure medication, muscle relaxants). Be sure that your physician knows if you are taking these or any other medications.
- ⊃ Sertraline may cause dryness of the mouth. If your mouth continues to feel dry for more than two weeks, check with your physician or dentist. Continuing dryness of the mouth may increase the risk of dental disease.
- ⊃ This medication may cause drowsiness.
- ⊃ Studies have not been done in pregnant women. Studies in animals have shown that sertraline may cause delayed development and decreased survival rates of offspring when given in doses many times the usual human dose.
- ⊃ It is not known if sertraline passes into breast milk.

Possible Side Effects

- ⊃ Side effects that typically go away as your body adjusts to the medication and do not require medical attention unless they continue for several weeks or are bothersome: decreased appetite or weight loss; decrease sexual drive or ability*; drowsiness*; dryness of mouth; headache; nausea; stomach or abdominal cramps; tiredness or weakness*; tremor*; trouble sleeping; anxiety; agitation; nervousness or restlessness; changes in vision including blurred vision*; constipa-

tion*; fast or irregular heartbeat; flushing of skin; increased appetite; vomiting.

- Unusual side effects that should be discussed with your physician as soon as possible: fast talking and excited feelings or actions that are out of control; fever; skin rash; hives; itching.

* Since it may be difficult to distinguish between certain common symptoms of MS and some side effects of sertraline, be sure to consult your health care professional if an abrupt change of this type occurs.

Chemical Name: Sildenafil (sil-DEN-a-fil)

Brand Name: Viagra (U.S.)

Generic Available: No

Description: Sildenafil belongs to a group of medicines that delay the action of enzymes called phosphodiesterases, which may interfere with erectile function. Sildenafil is used to treat men with erectile dysfunction (also called sexual impotence) because it helps to maintain an erection that is produced when the penis is stroked. *Without physical stimulation of the penis, sildenafil will not work to cause an erection.* Sildenafil is not indicated for use in women.

Proper Usage

- ⤵ Sildenafil begins to work approximately 30 minutes after it is taken. The medication continues to work for up to four hours, although the effect is usually less after two hours.
- ⤵ Sildenafil is available by prescription and should be used only as directed by your physician. The dose of this medication will be different for different patients. Do not take more of this medication than has been prescribed for you.

Precautions

- ⤵ Sildenafil can interact with, or interfere with the action of, other medications you may be taking. Be sure to inform your physician of all other medications you are taking so that appropriate substitutions or dosage adjustments can be made. Men who are using nitrates such as nitroglycerin (e.g., Nitrostat or Transderm-Nitro) to lower their blood pressure should not use Sildenafil; sildenafil may cause the blood pressure to drop too far.
- ⤵ The presence of certain medical problems may interfere with the use of sildenafil. Be sure to inform your doctor if you have any of the following medical problems: an abnormality of the penis (including a curved penis or birth defect); bleeding problems; retinitis pigmentosa; any conditions causing thickened blood or slower blood flow (e.g., leukemia, multiple myeloma, polycythemia, sickle cell disease, or thrombocytopenia); a history of priapism (erection lasting longer than six hours); heart or blood disease; severe kidney problems; severe liver problems.
- ⤵ Sildenafil has not been studied in combination with other medications that are used in the treatment of erectile dysfunction. At the present time, it is not recommended that these drugs be used together.

Possible Side Effects

- Side effect that you should report to your physician so that he or she can adjust the dosage or change the medication: flushing; headache; nasal congestion, stomach discomfort after meals; diarrhea.
- Rare side effects that should be discussed with your physician: abnormal vision (e.g., blurred vision*, seeing shades of colors differently than before, sensitivity to light); bladder pain; cloudy or bloody urine; dizziness, increased frequency of urination; painful urination.

Note: There are a variety of other possible side effects that have not yet been definitely shown to be caused by sildenafil. Therefore, if you notice any other effects that cause you concern, be sure to talk them over with your doctor.

* Since it may be difficult to distinguish between certain common symptoms of MS and some side effects of sildenafil, be sure to consult your health care professional if an abrupt change of this type occurs.

Chemical Name: Sodium phosphate

Brand Name: Fleet Enema (U.S. and Canada)

Generic Available: No

Description: Sodium phosphate enemas are available over-the-counter.

Proper Usage

- ⊃ Rectal enemas are to be used to provide short-term relief only, unless otherwise directed by the nurse or physician who is helping you to manage your bowel symptoms. A regimen that includes a healthy diet containing roughage (whole grain breads and cereals, bran, fruit, and green, leafy vegetables), six to eight full glasses of liquids each day, and some form of daily exercise is most important in stimulating healthy bowel function.
- ⊃ If your physician has recommended this rectal laxative for management of constipation, follow his or her recommendations for its use. If you are treating yourself for constipation, follow the directions on the package insert.
- ⊃ Results usually occur within two to five minutes. Be sure to consult your physician if you notice rectal bleeding, blistering, pain, burning, itching, or other signs of irritation that was not present before you began using a sodium phosphate enema.

Precautions

- ⊃ Do not use any type of laxative if you have signs of appendicitis or inflamed bowel (e.g., stomach or lower abdominal pain, cramping, bloating, soreness, nausea, or vomiting). Check with your physician as soon as possible.
- ⊃ Do not use any laxative for more than one week unless you have been told to do so by your physician. Many people tend to overuse laxatives, which often leads to dependence on the laxative action to produce a bowel movement. Discuss the use of laxatives with your health care professional in order to ensure that the laxative is used effectively as part of a comprehensive, healthy bowel management regimen.
- ⊃ If you are pregnant, discuss with your physician the most appropriate type of laxative for you to use.

Possible Side Effects

- ⊃ Side effect that may go away as your body adjusts to the medication and does not require medical attention unless it persists or is bothersome: skin irritation in the rectal area.

- Unusual side effects that should be reported to your physician as soon as possible: rectal bleeding, blistering, burning, itching.

Chemical Name: Sulfamethoxazole (sul-fa-meth-ox-a-zole) and trimethoprim (try-meth-oh-prim) combination

Brand Name: Bactrim; Septra (U.S. and Canada)

Generic Available: Yes (U.S.)

Description: Sulfamethoxazole and trimethoprim combination is used in multiple sclerosis to treat (and sometimes to prevent) urinary tract infections.

Proper Usage

- ⤷ This medication is best taken with a full glass (eight ounces) of water. Additional water should be taken each day to help prevent unwanted effects.
- ⤷ Finish the full course of treatment prescribed by your physician. Even if your symptoms disappear after a few days, stopping this medication prematurely may result in a return of the symptoms.
- ⤷ This medication works most effectively when it is maintained at a constant level in your blood or urine. To help keep the amount constant, do not miss any doses. It is best to take the doses at evenly spaced times during the day and night. For maximum effectiveness, four doses per day would be spaced at six-hour intervals.

Precautions

- ⤷ This medication may cause dizziness.
- ⤷ If taken for a long time, sulfamethoxazole and trimethoprim combination may cause blood problems. It is very important that your physician monitor your progress at regular visits.
- ⤷ This medication can cause changes in the blood, possibly resulting in a greater chance of certain infections, slow healing, and bleeding of the gums. Be careful with the use of your toothbrush, dental floss, and toothpicks. Delay dental work until your blood counts are completely normal. Check with your dentist if you have questions about oral hygiene during treatment.
- ⤷ This medication may cause your skin to become more sensitive to sunlight. Stay out of direct sunlight during the midday hours, wear protective clothing, and apply a sun block product that has a skin protection factor (SPF) of at least 15.
- ⤷ Sulfamethoxazole and trimethoprim combination has not been reported to cause birth defects or other problems in humans. Studies in mice, rats, and rabbits have shown that some sulfonamides cause birth defects, including cleft palate and bone problems. Studies in rabbits have also shown that trimethoprim causes birth defects, as well as a decrease in the number of successful pregnancies.

- ⤵ Sulfamethoxazole and trimethoprim pass into breast milk. This medication is not recommended for use during breast-feeding. It may cause liver problems, anemia, and other problems in nursing babies.

Possible Side Effects

- ⤵ Side effects that may go away as your body adjusts to the medication and do not require medical attention unless they continue or are bothersome: diarrhea; dizziness; headache; loss of appetite; nausea or vomiting.
- ⤵ Less common side effects that should be reported to your physician immediately: itching; skin rash; aching of muscles and joints; difficulty in swallowing; pale skin; redness, blistering, peeling, or loosening of skin; sore throat and fever; unusual bleeding or bruising; unusual tiredness or weakness*; yellow eyes or skin.

* Since it may be difficult to distinguish between certain common symptoms of MS (especially in the presence of an infection) and some side effects of sulfamethoxazole and trimethoprim combination, be sure to consult your health care professional if an abrupt change of this type occurs.

Chemical Name: Tizanidine hydrochloride (tye-ZAN-i-deen)

Brand Name: Zanaflex (U.S. and Canada)

Generic Available: No

Description: Tizanidine is used in multiple sclerosis to treat the increased muscle tone associated with spasticity. Although it does not provide a cure for the problems, it is designed to relieve the spasms, cramping, and tightness of muscles.

Proper Usage

- ⊃ Tizanidine is a short-acting drug for the management of spasticity. Its peak effectiveness occurs one to two hours after dosing and is finished between three to six hours after dosing. Therefore, your physician will prescribe a dosing schedule that provides maximal relief during activities and periods of time of greatest importance to you.
- ⊃ In order to minimize unwanted side effects of this medication, your physician will start you on a low dose and gradually increase it until a well-tolerated and effective level is reached.
- ⊃ Studies of tizanidine have not been done in pregnant woman. Animal studies, using doses significantly higher than those prescribed for humans, have resulted in damage to the offspring. If you are pregnant or planning to become pregnant, discuss this with your physician before starting this medication.
- ⊃ It is not known whether tizanidine passes into the breast milk. Women should not take this medication while nursing unless told to do so by their physician.

Precautions

- ⊃ Oral contraceptives (birth control pills) may slow the release of tizanidine from the body; women using birth control pills should inform their physician so that the dose level of tizanidine can be reduced accordingly.
- ⊃ This medication may cause blurred vision*, dizziness, or drowsiness in some people.
- ⊃ This drug will add to the effects of alcohol and other central nervous system depressants (such as antihistamines, sedatives, tranquilizers, prescription pain medications, seizure medications, other muscle relaxants), possibly causing drowsiness. Be sure that your physician knows if you are taking these or any other medications.

Possible Side Effects

- ⊃ Common side effects that may go away as your body adjusts to the medication and do not require medical attention unless they contin-

ue for more than two weeks or are bothersome: dryness of mouth; sleepiness or sedation; weakness*, fatigue*, and or tiredness*; dizziness or lightheadedness, especially when getting up from a sitting or lying position; increase in muscle spasms, cramps, or tightness; back pain.

- ⇒ Common side effects that should be reported to the doctor as soon as possible: burning, prickling, or tingling sensation*; diarrhea; fainting; fever; loss of appetite; nausea; nervousness; pain or burning during urination; sores on skin; stomach pain; vomiting; yellow eyes or skin; blurred vision*.

* Since it may be difficult to distinguish between certain common symptoms of MS and some side effects of tizanidine hydrochloride, be sure to consult your health care professional if an abrupt change of this type occurs.

Chemical Name: Tolterodine (tole-TARE-oh-deen)

Brand Name: Detrol (U.S.)

Generic Available: No

Description: Tolterodine is an antispasmodic that is used to treat bladder spasms causing urinary frequency, urgency, or urge incontinence.

Proper Usage

- ⊃ Take only the amount of this medication that has been prescribed for you by your doctor; taking more than the prescribed amount may cause adverse effects.
- ⊃ If you miss a dose of this medication, take it as soon as possible. If, however, it is almost time for your next dose, skip the missed dose and go back to your regular schedule. Do not double dose.

Precautions

- ⊃ Individuals with any of the following medical problems should not take this medication: gastric retention, urinary retention, or narrow angle or uncontrolled glaucoma. Tolterodine can aggravate each of these conditions.
- ⊃ Tolterodine may cause dizziness or drowsiness; use caution when driving or doing any activities that require alertness.
- ⊃ Tolterodine may cause drying of the mouth. Because continued dryness of the mouth may increase the risk of dental disease, alert your dentist if you are taking this medication.
- ⊃ This medication may interact with fluoxetine (Prozac) in such a way as to increase the effect of tolterodine. If you are taking fluoxetine, your physician may start you at a lower dose of tolterodine, gradually raising it to the standard dose if necessary.
- ⊃ This medication has not been studied in pregnant women. However, it has been shown in animal studies to result in increased embryo deaths, reduced birth weight, and increased incidence of fetal abnormalities. If you are pregnant or planning to become pregnant, do not start this medication before you have discussed it with your physician.
- ⊃ It is not known whether tolterodine passes into breast milk. Because tolterodine is known to pass into the milk of nursing animals, causing temporary reduction in weight gain in the offspring, women should stop talking this drug as long as they are nursing.

Possible Side Effects

- ⊃ Side effects that will typically go away as your body adjusts to the medication and do not require medical attention unless they continue for

a few weeks or are bothersome: dry mouth; dizziness; headache; fatigue*; gastrointestinal symptoms, including abdominal pain, constipation*, or diarrhea; difficult urination.

- ↳ Less common side effects that should be reported to your physician immediately: abnormal vision, including difficulty adjusting to distances; urinary track infections.
- ↳ Symptoms of overdose: severe central anticholinergic effects, including blurred vision*; clumsiness or unsteadiness*; confusion; seizures; severe diarrhea, excessive watering of the mouth; increasing muscle weakness (especially in the arms, neck, shoulders, and tongue); muscle cramps or twitching; severe nausea or vomiting; shortness of breath, slow heartbeat; slurred speech*; unusual irritability, nervousness, or restlessness; unusual tiredness or weakness*.

* Since it may be difficult to distinguish between certain common symptoms of MS and some side effects of tolterodine, be sure to consult your health care professional if an abrupt change of this type occurs.

Chemical Name: Venlafaxine (ven-la-FAX-een)

Brand Name: Effexor (U.S. and Canada)

Generic Available: No

Description: Venlafaxine is used to treat mental depression.

Proper Usage

- ⊃ Unless your physician has instructed otherwise, this medication should be taken with food or on a full stomach to reduce the chances of stomach upset.
- ⊃ If you miss a dose of this medication, take it as soon as possible. If, however, it is within two hours of your next dose, skip the missed dose and go back to your regular schedule. Do not double dose.

Precautions

- ⊃ It may take 4 to 6 weeks for you to feel the beneficial effects of this medication.
- ⊃ Your physician should monitor your progress at regularly scheduled visits in order to adjust the dose and help reduce any side effects.
- ⊃ Do not stop taking this medication without consulting your physician. The doctor may want you to reduce the amount you are taking gradually in order to decrease unwanted side effects.
- ⊃ This medication could add to the effects of alcohol and other central nervous system depressants (e.g., antihistamines, sedatives, tranquilizers, sleeping medicine, prescription pain medicine, barbiturates, seizure medication, muscle relaxants). Be sure that your doctor knows if you are taking these or any other medications.
- ⊃ Venlafaxine may cause dryness of the mouth. If your mouth continues to feel dry for more than two weeks, check with your physician or dentist. Continuing dryness of the mouth may increase the risk of dental disease.
- ⊃ This medication may cause you to become drowsy or to have double vision.
- ⊃ Venlafaxine may cause dizziness, lightheadedness, or fainting, especially when you stand from a sitting or lying position. If rising slowly from a sitting or lying position does not relieve the problem, consult your physician.
- ⊃ Studies have not been done in pregnant women. However, studies in animals have shown that venlafaxine may cause decreased survival rates of offspring when given in doses that are many times the usual dose for humans. If you are pregnant or planning to become preg-

nant, do not start this medication before you have discussed it with your physician.

- It is not known whether venlafaxine passes into breast milk. Mothers who are taking this medication and wish to breast-feed should discuss this with their doctor.

Possible Side Effects

- Side effects that will typically go away as your body adjusts to the medication and do not require medical attention unless they continue for several weeks or are bothersome: abnormal dreams; anxiety or nervousness; constipation*; dizziness, drowsiness*, dryness of mouth; tingling or burning sensations*; decreased appetite; nausea, stomach or abdominal cramps; trouble sleeping; tiredness*; tremor*.
- Unusual side effects that should be discussed with the doctor as soon as possible: changes in vision or double vision*; changes in sexual desire or ability*; headache; chest pain; fast heartbeat; itching or skin rash; mood or mental changes; problems with urination*; menstrual changes; uncontrolled excitability; high blood pressure.
- Symptoms of overdose include: extreme drowsiness, tiredness, or weakness*.

* Since it may be difficult to distinguish between certain common symptoms of MS and some side effects of venlafaxine, be sure to consult your health care professional if an abrupt change of this type occurs.

This page intentionally left blank

Index

- ABLEDATA, 229
- absorbent protection for bladder dysfunction, 63
- abstract reasoning, 105–106
- accreditation, 160, 211, 150
- acetazolamide, 38, 111
- acetylcholinesterase inhibitors, 110–111
- activities of daily living (ADL), 80
- acupuncture, 45, 184–185
- acute attacks, 32
- acute care, 1, 10, 157–158
- adaptation to MS, 97–98
- adaptive devices, 155–156, 228–230, 233–234
- adderall, 41
- adult education, 166–168, 194–197
- advance directives, 208
- advocacy, 205–212
 - disability rights and, 210–211
 - entitlements and, 209–210
 - insurance issues and, 206–207
 - interdisciplinary intervention and, 210
 - legal directives and, 207–209
 - life planning issues and, 207–209
 - nurse's role in, 205–206
 - tools of, 211–212
- age at onset, 5
- agencies and organizations for MS support, 223–227
- alendronate sodium, 87
- Alexander technique, 187
- alprostadil (Prostin), 245–246
- alternative therapies (see complementary and alternative therapies)
- Alzheimer's disease, 103–104, 107, 111, 183
- amantadine (Symmetrel), 41, 110, 247–248
- ambulation and mobility, 41–42, 46, 93
 - mobility aids in, 155–156
- American Academy of Neurology, 236
- American Academy of Nurse Practitioners, 237
- American Association of Neuroscience Nurses, 237
- American Association of Spinal Cord Injury Nurses, 237
- American Neurologic Association, 236
- American Nurses Association (ANA), 148, 160, 237

- American Self Help Clearinghouse, 223
- American Society of Neurorehabilitation, 237–238
- Americans with Disabilities Act, 227
- amitriptyline (Elavil), 99, 102, 126, 249–250
- amyotrophic lateral sclerosis (ALS), 192
- animal model of MS, 18, 22, 23
- ankle edema (swollen ankles), 50–51
- ankle foot orthoses (AFO), 35, 42, 156
- antidepressants, 45
- antidiuretics, bladder dysfunction, 63
- Antivert (see meclizine)
- aphasia, 107
- areflexic bladder (see bladder dysfunction)
- Aricept (see acetylcholinesterase inhibitors)
- arthritis, 141
- Ashworth spasticity scale, 84
- aspirin, 45
- assessment of function, 8
- assistive technology, 228–230
- Association of Rehabilitation Nurses (ARN), 160, 238
- astrocytes, 17, 22
- Astroglide, 126
- Atarax (see hydroxyzine)
- ataxia, 5
- atrophy of brain, 24
- attention and concentration, 106
- autoimmune nature of MS, 17–18, 20, 22, 23–24, 32–33, 141, 175–177
- Aventyl (see nortriptyline)
- avoidance of more disabled, 200–201
- Avonex (see beta interferon)
- Axasain (see capsaic acid)
- axonal damage, 4, 103
- azathioprine, 33
- B cells, 18
- back pain, 45–46
- baclofen, 251–252
 - vs. spasticity, 35, 36–37, 85–87, **86**
 - vs. tremor, 38
- Bactrim (see sulfamethoxazole)
- balance and coordination (see also dizziness and vertigo), 31, 39–40, 48
 - ambulation and mobility and, 42
 - exercise vs., 39
 - vestibular stimulation vs., 39
- Balance Master, 39–40
- barriers, rehabilitation vs., 170
- Beach Center on Families and Disabilities, 223
- bedsores (see skin care and decubitus ulcers)
- Benadryl (see diphenhydramine)
- benign MS, 7
- beta blockers, vs. tremor, 37
- beta interferon 1a/1b (Avonex; Betaseron; Rebif), 33, 109–110, 175, 277–278, 279–280, 281–282
- biofeedback, 45, 188
- birth and MS, 136–137, 142–143
- birth control, 135
- bisacodyl (Bisacolax; Dulcolax), 68, 253–254
- bladder dysfunction, 32, 33, 54–65, 93, 178
 - absorbent protection for, 63
 - areflexic bladder in, 55
 - capacity of bladder in, 54–55
 - Crede method in, 63
 - cystometrogram (CMG) in, 60
 - detrusor action in, 55, 57
 - detrusor pressure (PDET) and, 61
 - detrusor/sphincter dyssnergia in, 61
 - diagnosis of, 58–59, **59**
 - electromyogram (EMG) for, 60
 - incomplete emptying in, 57
 - incontinence in, 57
 - indwelling catheters in, 130
 - innervation of bladder in, 54, **56**
 - intermittent catheterization and, 63–64, 69–72, **70, 71**, 83–84, 130
 - intravenous pyelogram (IVP) studies for, 60
 - intravesicle pressure (VES) in, 61
 - liquid intake and, 62
 - management of, 53–54, 62–65

- neurogenic bladder in, 56
- nocturia in, 57
- normal bladder anatomy and function vs., 54–55, **55**
- pharmacologic treatment of, 63
- postvoid residual (PVR)
 - measurement in, 59
- prevalence of, 53
- sexual dysfunction and, 129–130
- sphincter action in, 54, 55, 57
- spinal cord demyelination as cause of, 55
- surgical interventions for, 64–65
- tests and studies for, 60–62
- training programs for, 62
- ultrasound, 60
- urinary frequency in, 56
- urinary hesitancy in, 57
- urinary tract infection (UTI) or cystitis in, 57, 58, 64, 83–84, 186
- urinary urgency in, 56
- urodynamic pressure flow in, 60
- urodynamic studies for, 60, **61, 62**
- voiding diary for, **73, 74**
- blood brain barrier, 22
- Blueprint for Action, 234
- bodywork, 187
- books specializing in MS, 238–239
- botulinum toxin, 36, 85
- bowel, 32, 33, 54, 64–69, 93, 178
 - bulking laxatives and, 67
 - constipation in, 65–66, 130
 - diagnosis of, 65–69
 - diarrhea in, 68
 - enemas and, 68
 - fiber rich foods and, 66–67, **67**
 - involuntary bowel in, 68–69
 - laxatives in, 67–68
 - liquid intake and, 65, 66
 - management of, 69
 - normal function vs., 65
 - prevalence of, 53
 - rectal stimulants and, 68
 - sexual dysfunction and, 129–130
 - stool softeners and, 67
 - training in, 66, 69
- braces, 42
 - vs. pain, 46
 - skin care and decubitus ulcers in, 90
 - tremor vs., 38–39
- Braden scale for predicting risk of decubitus ulcers, **88–89, 90**
- brain, 17, 24, 31, 40
- brainstem, 4, 5, 39, 48
- breathing difficulty (see pulmonary complications), 82
- bulking laxatives, 67
- bupirone (Buspar), 38
- calcium supplements, 87
- Canadian Rehabilitation Council for the Disabled (CRCD), 234
- canes, 156
- capsaic acid/capsaicin, 45
- carbamazepine (Tegretol), 36, 44, 255–257
 - vs. pain, 131
 - vs. sexual dysfunction, 126
 - vs. spasticity, 36
 - vs. trigeminal neuralgia, 44
- care patterns in MS, 10
- caregivers, 111–118, 133
- case management in rehabilitation, 160–161
- castor oil, 68
- cataracts, 32, 48
- catheterization, bladder dysfunction, 63–64, 69–72, **70, 71**, 83–84
- cause of MS, 16–17
- Center for Independent Living, 210
- central nervous system (CNS), 4, 15, 16, 17, 22, 32, 40, 55
- cerebellum, 4, 31
- cerebrum, 4
- challenges of MS nursing, 12
- Charcot, 1
- chart review in rehabilitation, 168
- children and MS, 116–118
- chiropractic therapy, 188
- Chlamydia pneumoniae*, 16, 21–22
- chronic illness, shifting perspective model, 194–197
- ciprofloxacin (Cipro), 258–259
- Citrucel, 67, 68

- Clearinghouse on Disability Information
 Communications and Information
 Services, 234
- clinical trials, 24–27
 financing of, 27–28
 participation in, 27–28
- clinically isolated syndromes (CIS), 5
- clonazepam (Klonopin; Rivotril; Syn-
 clonazepam), 36, 260–261
 vs. dizziness and vertigo, 48
 vs. spasticity, 36, 85
 vs. tremor, 37
 vs. vision deficits, 48
- codeine, vs. pain, 45
- cognitive dysfunction, 4, 93, 103–111
 abstract reasoning and, 105–106
 Alzheimer's disease vs., 103–104, 107
 assessment of, 163
 attention and concentration deficits
 in, 106
 axonal damage and, 103
 corpus callosum demyelination and,
 103
 course of, 107
 demyelination and, 103
 frontal lobe demyelination and, 103
 interventions for, 108–111
 judgment ability and, 105–106
 magnetic resonance imaging (MRI)
 and, 103
 measurement of, 103
 memory loss and, 104–105
 neuropsychological testing in, 108
 pharmacologic treatment of, 108,
 109–111, 131–132
 reasoning ability and, 105–106
 rehabilitation and, 108–109, 153
 sexual dysfunction and, 129,
 131–132
 spatial organization problems in,
 106–107
 speech difficulties and, 107
 speed of information processing
 and, 106
 testing in, 110
 word finding problems and, 106
- Colace (see docusate)
- cold/mottled feet, 50
- Commission of Accreditation of
 Rehabilitation Facilities (CARF),
 150, 160, 211
- communication assessment, 115–117,
 165, 181, **181**
- community agency input and
 rehabilitation, 168
- complementary and alternative (CAM)
 therapies, 183–189, **184**
- complications of MS, 77–92
 nutritional support in, 77–81
 osteoporosis and, 87
 pulmonary complications and, 82–83
 skin care and decubitus ulcers in,
 87–91
 spasticity and, 84–87
 urinary tract infections (UTI) and
 cystitis in, 83–84
- comprehensive care, 10–11
- computers, as adaptive equipment, 156
- congenital defects of CNS, 16
- Consortium of Ms Centers, 197
- Consortium of Multiple Sclerosis
 Centers (CMSC), 223–224
- constipation, 65–66, 130
- cooling therapies, 186–187
- coordination (see balance and
 coordination)
- Copaxone (see glatiramer acetate)
- coping style, 112–113, 216–218
 educating the patient and family
 and, 199–200
 presence of nurse and hope,
 216–217
- corpus callosum, 103
- Correctol, 67
- corticosteroids, 32, 33, 48
- cortisone, 32
 vs. spasticity, 36
 vs. vision deficits, 47
- course of disease, 5–7, 5
- cranberry juice, 186
- Crede method, bladder dysfunction,
 63
- crutches, 42
- cure for MS, 213

- cyclobenzaprine HCl, 36, 46
 cyclophosphamide, 33
 Cylert (see pemoline)
 cystometrogram (CMG), 60
 cytokines, 18
 Cytosan (see cyclophosphamide)
- Dacomed Snap Gauge Test, 125
 dantrolene sodium (Dantrium), 36, 85
 data collection during rehabilitation, 161–162
 DDAVP (see desmopressin)
 decubitus ulcers (see skin care and decubitus ulcers)
 deep brain stimulation, 39
 Deltasone (see prednisone)
 demanding patients, 118
 demyelination, 4, 15, 16, 17, 22–24, 32, 40, 47, 55, 103, 175
 denial stage in MS, 97–98, 217
 Department of Veteran's Affairs, 224
 dependent patients, 118
 DepoMedrol (see methylprednisolone)
 depression, 96, 98–101
 - exercise vs., 185
 - fatigue and, 41
 - pharmacologic treatment of, 99
 - sexual dysfunction and, 126
- desmopressin (DDAVP), 63, 262
 Detrol (see tolterodine)
 detrusor action, 57
 detrusor pressure (PDET) and bladder dysfunction, 61
 detrusor/sphincter dyssnergia in bladder dysfunction, 61
 dexamethasone, 32
 diagnosis of MS, 1, 5, 5–6, 7
 diagnostic related groups (DRGs), rehabilitation, 157
 Dialase, 67
 Diamox (see acetazolamide)
 diarrhea, 68
 diazepam (Valium), 36, 263
 - vs. dizziness and vertigo, 48
 - vs. spasticity, 36, 85
- Didrocal (see etidronate disodium)
 dietary causes of MS, 16–17, 78
 diets, 187
 Dilantin (see phenytoin)
 - dimenhydrinate, 48
- diphenhydramine, 48
 disability insurance, 209
 disability rights, 210–211
 Disability Rights Education and Defense Fund, 235
 discharge planning and rehabilitation, 168–169
 disease altering therapies in MS, 176
 distraction thinking, 217–218
 Ditropan (see oxybutynin)
 diuretics vs. edema, 51
 diversity and patient education, 196
 dizziness and vertigo, 5, 48–49
 docusate (Colace), 67, 265–266
 Dramamine (see dimenhydrinate)
 driving, 97–98
 drugs (see pharmacologic agents)
 Dulcolax (see bisacodyl)
 durable power of attorney, 208
 dysarthria, 5, 46–47, 46
 dysphagia (see also swallowing difficulties and choking), 81–82
 dyspnea, 83
- Easter Seals, 235
 Eastern Paralyzed Veterans Association, 197, 224, 235
 echinacea, 186
 edema, 50–51
 education (see teaching and empowering patients and family)
 educational needs assessment in rehabilitation, 166
 Effexor (see venlafaxine)
 ejaculatory problems, 124, 135
 Elavil (see amitriptyline; tricyclic antidepressants)
 electrical stimulation (see also transcutaneous nerve stimulation), vs. pain, 45
 electromyogram (EMG) for bladder dysfunction, 60
 electronic information sources, 230–233

- elimination dysfunction (see also bladder dysfunction; bowel dysfunction), 53
- elimination diets, 78
- emotional factors in MS, 32, 93, 94–96, 102
and educating the patient and family, 198
- empowerment, 8, 10, 195–196, 213–222
- enemas, 68
- energy conservation techniques, sexual dysfunction, 130–131
- entitlements, 209–210
- environmental adaptation (remodeling), 233–234
- environmental factors and causes MS, 2–3, 4, 16, 21–22
- epidemiology of MS, 2–4
- Equal Employment Opportunities Commission (EEOC), 224
- erectile dysfunction, 125, 127–128, 135
- etidronate disodium, 87
- etiology of MS, 4
- European Federation of Neurological Societies, 236
- European Neurological Society, 236
- evening primrose oil, 80
- evoked potentials, 1, 7
- exacerbations, 5, 32
stress as trigger for, 94–95
- exercise, 43–44, 152–153, 178, 185–186
balance and coordination and, 39
vs. dizziness and vertigo, 49
vs. pain, 46
vs. spasticity vs., 34, 84–85
weakness vs., 40
- ExLax, 68
- experiential learning, educating the patient and family, 200
- experimental allergic encephalomyelitis (EAE), 18, 22
- family impact of MS (see also teaching and empowering patients and family), 93–94, 111–118, 177–178
- assessment of and input to rehabilitation and, 164
- children, 116–118
- communication patterns in, 115–117
- coping styles and, 112–113
- education and, 8, 166–168, 199–200
- grief and, 114–115
- parenting issues and, 117–118, 137–138
- psychoeducational approach to patient education, 178–179
- role changes and, 113–114
- fat supplements, 187
- fatigue, 32, 40–41, 93, 96
ambulation and mobility and, 42
depression and, 41
exercise vs., 185
immobility and rest vs., 43–44
mealtime and, 81
pharmacologic treatment of, 41
pulmonary complications and, 83
sexual dysfunction and, 129, 130
spasticity and, 84
- fatty acid supplements, 187
- FeenAMint, 68
- feet (see cold/mottled feet)
- Feldenkrais technique, 187
- fertility, 135
- fiber rich foods, in bowel management, 66–67, **67**
- FiberCon, 67
- Fleet (see sodium phosphate)
- Flexoril (see cyclobenzaprine HCl)
- fluoxetine (Prozac), 267–268
vs. fatigue, 41
vs. pain, 131
- food additives, 80
- food pyramid, **78**
- foot drop, 41
- footwear and shoes, 41–42
- Fosamax (see alendronate sodium)
- 4 aminopyridine, cognitive dysfunction, 110
- frontal lobes, 103
- gabapentin (Neurotin), 35, 269–270
vs. pain, 45, 131

- sexual dysfunction and, 126
- vs. spasticity, 35, 36, 85
- galactocerebroside, 23
- galantamine HBr (Reminyl), cognitive dysfunction, 111
- gamma interferon, 33
- gamma knife ablation, 39
- garlic, 186
- GE Answer Center, 234
- gender and MS, 2, 5
- genetic, 4, 16–22, 134–135
- genetics and MS, 2
- geographic region and MS, 3
- Ginkgo biloba*, 186
- glatiramer acetate (Copaxone), 33, 109, 110, 177, 180, 186, 271–272, 271
- gluten free diet, 78
- glycerin (Sani-Supp), 68, 273–274
- grief, 98–101, 114–115
- Guillian–Barre disease, 23

- haloperidol (Haldol), cognitive dysfunction, 131–132
- Halper, June*, 1, 141, 175, 183
- Harris, Colleen*, 77
- headache, 44
- health and wellness programs, 226
- health care power of attorney, 208
- health care proxy, 208
- health insurance issues, 206–207
- Health Resource Center for Women with Disabilities, 224
- HealthTalk Interactive, 235
- heat, vs. pain, 46
- helper T cells, 17
- herbal therapy, 186, **186**
- herpes virus, 16, 21
- hip, 42
- Hiprex (see methenamine)
- HIV, 183
- HMOs, rehabilitation, 157, 159
- Holland, Nancy J.*, 1, 191
- home care, 11, 157–158
- home remodeling for adaptation, 233–234
- hope in clinical practice, 213–222
- attributes supportive of, 214
- hope vs. hopelessness in, 215–220, **215**
- presence of nurse and, 216–217
- self-care strategies and, **220**
- shifting focus of, as disease progresses, 219
- hormonal factors in MS, 141–142, 143
- human leukocyte antigens (HLA), 20
- hydration, 81
- hydrotherapy and pool exercises, spasticity vs., 34–35
- hydroxyzine, 37
- hyoscyamine sulfate, 63
- hyperextension, 46
- hypersexuality and loss of inhibitions, 124–126, 132
- hypertonia (see also spasticity)
- hypnotherapy, 185
- hypophonia, 83
- hypoventilation (see pulmonary complications)
- hysteria, 96

- imagery therapy, 185
- imipramine (Tofranil), 63, 99, 130, 275–276
- immobility and rest, 43–44
- immobilization vs. tremor, 38
- immunology and MS (see also autoimmune nature of MS), 17–18, 20, 23–24, 32–33, 95, 175–177
- immunomodulation, 175–177
- immunosuppression, 23, 33
- Imodium, 68
- impact on individual and family, 111–118
- Imuran (see azathioprine)
- Incapacity Status Scale (ISS), 158
- incidence of MS, 2–4
- incomplete emptying, 57
- incontinence, 57
- independence programs, 226–227
- Inderal (see propranolol)
- indwelling catheters, 64, 130
- infections in ulcerations, 90

- infectious agents and MS, 16, 17,
21–22, 33
- inflammation, 18, 23, 24, 33, 47, 175
- influenza, 49, 83
- Information and Resource Center, 235
- information sources, 234–236
- Inglis House, 235
- INH (see isoniazide)
- injectable protocols, 180–181
- insurance issues, 206–207, 209–210
- interactive or team approach to care,
2, 10–11, 149–156
- interferon beta (see beta interferon)
- intermittent catheterization, 63–64,
69–72, **70**, **71**, 83–84, 130
- International Journal of MS Care, 197
- International Organization of Multiple
Sclerosis Nurses (IOMSN), 224, 238
- Internet as source of information on
MS, 197, 230–233
- interpersonal/social factors in MS,
educating the patient and family,
198
- intrathecal baclofen, 36–37, 85–87, **86**
- intravenous immunoglobulin, 23
- intravenous pyelogram (IVP) studies,
60
- intravesicle pressure (VES) in bladder
dysfunction, 61
- isoniazide, 38
- jin shin do, 187
- jin shin jyutsu, 187
- Joint Commission on Accreditation of
Health Care Organizations
(JCAHO), 150, 160, 211
- journals, 236–237
- judgment ability, 105–106
- Kalb, Rosalind C.*, 93, 123
- Kennedy, Patricia M.*, 147
- Klonopin (see clonazepam)
- knee, 42
- knowledge programs, 226
- L’Hermitte’s phenomenon, 5, 44
- lactation and MS, 136–137, 142–143
- lactulose, 68
- LaRocca, Nicholas G.*, 93, 123
- Latin American Committee on
Research and Treatment in MS
(LACTRIMS), 224
- laxatives, 67–68
- Learning HOW Opportunity Plus,
224–225
- learning styles and patient education,
179–180, 198–201
- legal directives, 207–209
- lesions, 4, 7, 17, 31, 103
- Levsinex (see hyosyamine sulfate)
- libido, 126
- life planning issues, 207–209
- limbic system and emotional instability,
101–102
- Lioresal (see baclofen)
- liquid intake and hydration, 81
in bladder dysfunction, 62
in bowel management, 65, 66
- living wills, 208
- Lofstrand crutches, 42
- Lomotil, 68
- long term care, 11
- low fat diets, 187
- lubricants in sexual dysfunction, 126
- lupus erythematosus, 141
- lymphocytes, 4, 17, 18
- lymphoid irradiation (see radiation
treatments)
- Macrochantin (see nitrofurantoin)
- magazines, 236–237
- magnesium hydroxide (Milk of
Magnesia), 283–284
- magnet therapy, 185
- magnetic resonance imaging (MRI), 1,
7, 103
- magnetic resonance spectroscopy
(RMS), 16
- maintenance rehabilitation, 148
- major histocompatibility complex
(MHC) genes, 20
- malignant MS, 7
- Mandelamine (see methenamine)
- Marburg’s variant (see malignant MS)

- March of Dimes, 235
 massage, 46, 187
 McDonald diagnostic criteria, 7
 mechanical devices, vs. spasticity, 35
 meclizine (Antivert), 48, 285
 Medicare, rehabilitation
 reimbursement, 157
 medication (see pharmacologic agents)
 meditation, vs. pain, 45
 memory impairment, 93, 104–105, 118–119
 men's issues
 fertility and, 135
 sexual dysfunction and, 124
 menopause, 143–144
 menstrual cycles, 143–144
 Metamucil (see psyllium hydrophil mucilloid)
 methenamine (Hiprex; Mandelamine)
 methylphenidate, 41
 methylprednisolone (Depo Medrol) 32, 287–289
 Milk of Magnesia, 67, 283–284
 mineral oil, 290–291
 miralax, 68
 mitoxantrone (Novatrone), 33, 109, 177
 mobility (see ambulation and mobility)
 mobility aids, 155–156
 modafinil (Provigil), 41, 130
 Modane, 67
 modifying course of disease, 1
 molecular mimicry, 22
 mononuclear cells, 4
 mood swings, 101–102
Morgante, Linda A., 213
 movement integration therapy, 187
 MS Council, 41
 Multiple Sclerosis Association of America (MSAA), 225
 Multiple Sclerosis Society of Canada, 197, 225
 muscle spasms, 36
 MUSE (see alprostadil)
 myasthenia gravis, 141
 myelin, 4, 15, 17, 18, 22–24
 myelin basic protein, 18
 Mysoline (see primidone)

Namey, Marie A., 53
 narcotics, vs. pain, 45
 National Association of Home Builders, 234
 National Council on Disability (NCD), 225
 National Family Caregivers Association (NFCA), 197, 225
 National Health Information Center, 235–236
 National Kitchen and Bath Association, 234
 National Multiple Sclerosis Society (NMSS), 27, 28, 133, 183–184, 197, 210, 225
 National Park Service, 227
 National Rehabilitation Information Center (NARIC), 197, 229
 nerve conduction, 15, 17, 23
 nerve fibers, 17
 neuralgia, 44–45
 neurectomy, vs. spasticity, 85
 neuritis, 47
 neurogenic bladder (see also bladder dysfunction), 56
 neurologic organizations, 236
 Neurontin (see gabapentin)
 neuroprotection, 24
 neuropsychological testing, cognitive dysfunction, 108
 newsletters, 236–237
 niacin, vs. dizziness and vertigo, 48
 nitrofurantoin (Macrofantin), 292–293
 nocturia, 57
 nonsteroidal antiinflammatory drugs (NSAIDs), vs. vision deficits, 47
Northrup, Dorothy, 205
 Norton scale for predicting risk of decubitus ulcers, 90
 nortriptyline (Aventyl; Pamelor), 294–295
 Novantrone (see mitoxantrone)
 numbness and tingling, 5, 50

- Nurse Practitioner Associates for Continuing Education (NPACE), 238
- nurse's role in rehabilitation, 160–170
- nursing homes (see also long term care), 11
- nursing organizations, 237–238
- nursing practice in MS, 7–9
- nutritional requirements, 77–81
 - calcium in, 87
 - diets, 187
 - education in, 80
 - elimination diets in, 78
 - evening primrose oil and, 80
 - fatigue and mealtimes in, 81
 - food additives in, 80
 - food pyramid for, 78, 78
 - food texture and consistency in, 82
 - gluten free diet in, 78
 - guide to daily food choices in, 79
 - hydration in, 81
 - low fat diets, 187
 - percutaneous endoscopic gastroscopy (PEG) tube for, 82
 - recommended dietary allowances (RDAs) in, 77
 - supplements, 80, 185, 187
 - swallowing difficulties and choking (dysphagia) in, 80–82
 - Swank diet in, 78, 187
 - vitamin D in, 81
 - vitamins, 185
 - weight gain and, 80
- nyelotomy, 85
- nystagmus, 5
- obesity, 32
- occupational therapist's role in rehabilitation, 153
- occupational therapy, 41, 153
- Office on the Americans with Disabilities Act, 227
- oligodendrocytes, 23
- optic nerve, 4, 17–18, 47–48
- organizations for MS support, 223–227
- orthopnea, 83
- orthoses, 35, 42, 156
- osteoporosis, 32, 87, 143
- outcomes assessment, 8
- outpatient setting for rehabilitation, 157–158
- oxazepam, 48
- oxybutynin (Ditropan), 63, 130, 296–298
- pace boards for speech problems, 39
- pacing in speech, 47
- pain, 44–46
 - massage vs., 187
 - pharmacologic management of, 45, 46, 131
 - sexual dysfunction and, 129, 131
- Palmer, Daniel D., 188
- Pameler (see nortriptyline)
- papaverine, 299
- Parafon Forte, 46
- Paralyzed Veterans of America (PVA), 41, 197, 227, 236
- parenting issues, 117–118, 137–138
- paroxetine (Paxil), 99, 300–301
- paroxysm spasms, 36
- passive stretching, 34
- Paterson, Barbara, 194
- pathology of MS, 4
- patterning techniques vs. tremor, 38
- Paxil (see paroxetine)
- pemoline (Cylert), 110, 130, 302–303
- percutaneous endoscopic gastroscopy (PEG) tube, 82
- percutaneous rhizotomy, 44
- Perdiem, 67, 68
- Pericolace, 67
- peripheral nervous system, 23
- personality changes, 101–102
- pharmacologic agents, 175–182, 243–301
 - bladder dysfunction and, 63, 130
 - cognitive dysfunction and, 108, 109–111, 131–132
 - depression and, 99
 - disease altering, 176
 - vs. dizziness and vertigo, 48
 - fatigue vs., 41, 130
 - guidelines for safe use of, 243–244

- immunomodulation, 175–177
- injectable protocols in, 180–181
- vs. pain, 45, 46, 131
- pregnancy, birth, and lactation and, 136–137, 142–143
- sexual dysfunction and, 126
- vs. spasticity, 35–36, 85
- symptom management using, 177
- vs. tremor, 37–38
- phases of clinical studies, 26–27
- phenazopyridine (Pyridium), 304
- phenol blocks, vs. spasticity, 85
- phentolamine (Regitine/Rogitine), 245
- phenytoin (Dilantin), 44, 131, 305–306
- physiatrist's role in rehabilitation, 151
- physical factors in MS, educating the patient and family, 198
- physical therapist's role in rehabilitation, 152–153
- physical therapy, 152–153
- physiologic assessment of rehabilitation, 162
- pilot studies, 26–27
- pivotal studies, 27
- placebo effect, 25, 26
- planning treatment, 8
- plaques of MS, 4, 84
- plasmaphoresis, 33
- pneumonia, 51, 83, 90
- polymerase chain reaction (PCR), 21
- pontine cerebellar micturition control areas, 55
- pools (see hydrotherapy and pool exercises)
- Poser diagnostic criteria, 7
- positive attitude (see also Wellness Model), 9–10
- post market analyses of treatments, 27
- posture, 45
- postvoid residual (PVR) measurement, 59
- potassium channel blockers, cognitive dysfunction, 110
- power of attorney, 208
- prednisone (Deltasone), 32, 307–309
- pregnancy in MS, 136–137, 142–143
- preliminary studies, 26
- presence of nurse and hope, 216–217
- President's Committee on Employment of People with Disabilities, 236
- prevalence of MS, 2–4
- preventive healthcare, 51–52
- primary MS affection (PMSA), 3
- primary progressive, 7, 8
- primidone, vs. tremor, 38
- printed material for patient education, 193–194
- prognosis, 5
- progressive relapsing, 7, 8
- propranolol (Propranolol), 63, 130, 310–311
- propranolol, 37
- prostaglandin E1 (PEG1), 127–128, 245–246
- Prostin (see alprostadil)
- Provigil (see modafinil)
- proxy, health care, 208
- Prozac (see fluoxetine)
- pseudobulbar effect, 102
- psychoeducational approach to patient education, 178–179
- psychological assessment, rehabilitation, 162–163
- psychologist's role in rehabilitation, 154
- psychosocial issues in MS, 1, 93–122
 - children and, 116–118
 - cognitive changes in, 103–111
 - communication with family and, 115–117
 - coping styles and, 112–113
 - demanding patients and, 118
 - denial and adaptation in, 97–98
 - dependent patients and, 118
 - depression and, 98–101
 - education in, 118–119
 - emotional release in, 102
 - emotional stress and, 94–96
 - grief and, 98–101, 114–115
 - impact on individual and family in, 93–94
 - memory loss and, 118–119

- psychosocial issues in MS, (*cont.*)
 mood swings and, 101–102
 nurse's role in, 94, 118–119
 parenting issues and, 117–118,
 137–138
 personality changes and, 101–102
 pharmacologic treatment of
 depression and, 99
 psychotherapy and, 99
 referrals to professional help in,
 102–103
 role changes and, 113–114
 sexual dysfunction and, 132–133
 suicidal tendencies and, 99, 100
 uncertainty and unpredictability in,
 96–97
 young, progressively disabled
 patients and, 118
 psychotherapy and depression, 99
 psyllium hydrophil mucilloid
 (Metamucil), 67, 68, 312–313
 publishing companies and books
 specializing in MS, 238
 pulmonary complications, 51, 82–83
 Pyridium (see phenazopyridine)
- quality of life, 191–194
- race and MS, 2, 19
 radiation treatments, 33
 range of motion exercises, spasticity
 vs., 34
 reasoning ability, 105–106
 Rebif (see beta interferon)
 recommended dietary allowances
 (RDAs), 77
 recreation assessment in rehabilitation,
 166
 recreational therapist's role in
 rehabilitation, 154
 rectal stimulants, 68
 reflexology, 187
 Regitine (see phentolamine)
 REHABDATA, 229–230
 rehabilitation, 1, 10, 28–29, 147–174,
 178
 acute care setting for, 157–158
 adult education and, 166–168
 barriers in community vs., 170
 case management in, 160–161
 chart review in, 168
 cognitive assessment for, 163
 cognitive dysfunction and, 108–109,
 153
 communication and trust in,
 150–151, 165
 community agency input and, 168
 course of disease vs., 147
 data collection during, 161–162
 definition of, in MS care, 148
 discharge planning and, 168–169
 educational needs assessment in, 166
 environmental adaptation and,
 233–234
 exercise and, 152–153
 family assessment and input in, 164
 future of, 159
 goals of, in MS care, 147–149, 161
 home care setting for, 157–158
 Incapacity Status Scale (ISS) to
 measure results of, 158
 information sources for, 234–236
 interactive or team approach to,
 149–156, 155
 maintenance, 148
 mobility aids and adaptive
 equipment in, 155–156
 nurse's role in, 151, 160–170
 occupational therapist's role in, 153
 outpatient setting for, 157–158
 patient and family in, 150
 physiatrist's role in, 151
 physical therapist's role in, 152–153
 physiologic assessment of, 162
 psychological assessment for,
 162–163
 psychologist's role in, 154
 quality improvement in, 159–160
 recreation assessment in, 166
 recreational therapist's role in, 154
 reluctance to pursue, in healthcare
 community, 149
 research in, 28–29, 158
 restorative, 148

- safety of patient in, 169–170
- social assessment for, 163–164
- social worker's role in, 153–154
- speech language pathologist's role in, 153
- symptom management using, 147
- vocational rehabilitation counselor's role in, 154–155
- work and productivity (vocational) assessment in, 165–166
- Rehabilitation Engineering and Assistive Technology Society of NA (RESNA), 230
- Rehabilitation Research Institute, 236
- Rehabilitation in MS (RIMS), 227
- Reiki, 187
- Reingold, Stephen C.*, 15
- relapsing remitting MS, 7, 8, 33
- Reminyl (see galantamine HBr)
- remyelination, 23, 24
- Replens, 126
- research and new treatments, 24–27, 158
- resources, 223–242
- Respiratory Nursing Society (RNS), 238
- rest (see immobility and rest)
- restorative rehabilitation, 148
- retroviruses, 21–22
- rheumatoid arthritis, 141
- rhizotomy, 44, 85
- rights of person's with disability, 210–211
- Ritalin (see methylphenidate)
- Rivotril (see clonazepam)
- Robaxin, 46
- Rogitine (see phenotlamine)
- role changes and MS, 113–114, 133
- roseola, 16, 21

- safety of patient in rehabilitation, 169–170
- salt/water balance in body, 32
- Sani-Supp (glycerin), 273–274
- scarring (see lesions; plaques)
- Schapiro, Randall T.*, 31
- Schneider, Diana M.*, 31
- Schwann cells, 23
- scooters, 42, 156
- Sears Home Health Care Catalog, 230
- secondary progressive, 7, 8
- seizures, 49
- selective serotonin reuptake inhibitors (SSRIs), vs. depression, 99
- self-care strategies, 220, 220
- self-directed patient learning, 192–193, 196, 199
- self-help groups, 194
- Sentry Detection Corporation, 230
- Septra (see sulfamethoxazole)
- Serax (see oxazepam)
- sertraline (Zoloft), 99, 314–315
- severely disabled, preventing complications, 77–92
- sexual dysfunction, 93, 123–140
 - birth control and, 135
 - Dacomed Snap Gauge Test in, 125
 - depression and, 126
 - discussion of, 125, 128–129
 - ejaculatory problems in, 124, 135
 - erectile dysfunction in, 125, 127–128, 135
 - evaluation of, 125
 - family planning and, 134–138
 - fertility and, 135
 - genetic issues and childbearing in, 134–135
 - hormonal fluctuations and MS in, 141–142, 143
 - hypersexuality and loss of inhibitions in, 124–126, 132
 - libido and, 126
 - lubricants, 126
 - men and, 124
 - parenting issues and, 137–138
 - pharmacologic treatments in, 126
 - pregnancy, birth and lactation in MS and, 136–137, 142–143
 - primary effects of MS in, 123–126
 - prostaglandin E1 (PEG1) in, 127–128
 - rehabilitation and, 154
 - secondary effects of MS and, 123–124, 129–132

- sexual dysfunction, (*cont.*)
 self concept and, 132–133
 tertiary effects of MS in, 124, 132–133
 treatment of, 126–133
 women and, 124
- shifting perspective model of chronic illness, 194–197
- shoes (see footwear and shoes)
- sick role, 194
- side effects of drugs, 33
- sildenafil citrate (Viagra), 127, 316–317
- skin care and decubitus ulcers, 87–91
 assistive devices, braces, splints, vs., 90
 Braden scale for predicting risk of ulceration in, 88–89, 90
 Norton scale for predicting risk of ulceration in, 90
 preventing ulceration in, 90–91
 secondary infection in, 90
 skin grafting in, 90
- social assessment, rehabilitation, 163–164
- social factors in MS educating the patient and family, 198
- Social Security Administration, 227
- Social Security benefits, 209–210
- social worker's role in rehabilitation, 153–154
- Society of Urologic Nurses and Associates, The, 238
- sodium phosphate (Fleet enema), 68, 318–319
- SOS Wireless Communications, 230
- spasms, 36
- spasticity, 32, 34–37, 84–87, 93
 Ashworth scale for, 84
 biofeedback vs., 188
 exercise vs., 34–35, 84–85
 fatigue and, 84
 management of, 84–85, 85
 massage vs., 187
 mechanical devices vs., 35
 pharmacologic treatment of, 35–36, 85
 scales for, 84
 sexual dysfunction and, 129
 surgical intervention in, 36–37, 85–86
 weakness and, 84
- speech difficulties (see also dysarthria), 46–47
 cognitive dysfunction and, 107
 pacing in, 47
 rehabilitation and, 153
 tremors, 47
- speech language pathologist's role in rehabilitation, 153
- speech therapy, 39
- sphincter action, 57
- spinal cord, 4, 17, 31, 40, 55
- spinal manipulation, vs. pain, 46
- splints, skin care and decubitus ulcers, 90
- Steele, Inc., 230
- steroids (see corticosteroids)
- stool softeners, 67
- stress, 32, 93, 94–96
- stretching exercises, 34
- suicide, 99, 100
- sulfamethoxazole (Bactrim; Septra), 320–321
- supplements, nutritional, 80, 185, 187
- support groups, 194
- suppressor T cells, 17
- Surfak, 67
- surgical interventions
 bladder dysfunction and, 64–65
 vs. spasticity, 36–37, 85–86
 vs. tremor, 39
- swallowing difficulties and choking (dysphagia), 47, 80–82
 videofluoroscopy for, 82
- Swank diet, 78, 187
- Swedish hyperextension cage, 42
- Swedish massage, 187
- swollen ankles (see ankle edema)
- Symmetrel (see amantadine)
- symptom management, 1, 31–52
 pharmacologic agents and, 177
- symptoms of MS, 5, 31–32
- Syn-clonazepam (see clonazepam)
- T cells, 17, 18, 20, 22
- T lymphocytes, 17
- Tai chi, 188
- tax issues, 207

- teaching and empowering patients and family, 8, 80, 166–168, 177–178, 191–203
- actions in, 195
- adult education and, 194–197
- agencies and organizations for, 223–227
- assistive technology and, 228–230
- avoidance of more disabled and, 200–201
- communicating effectively in, 181, 181
- coping and family issues in, 199
- diversity and, 196
- electronic information sources in, 230–233
- empowerment through, 195–196
- experience of participant in, 195
- experiential learning in, 200
- factors in, 192–194
- goals for, 192–193
- health and wellness programs in, 226
- hope in, 213–222
- independence programs in, 226–227
- injectable protocols in, 180–181
- Internet as source of information for, 197
- knowledge programs for, 226
- learning styles and, 179–180, 198–201
- levels of awareness and adjustment in MS and, 198
- neurologic organizations and, 236
- newsletters and journals for, 236–237
- nursing organizations for, 237–238
- principles of, 195–197
- printed material for, 193–194
- problem solving in, 195
- progression of disease and, 193
- psychoeducational approach to patient education, 178–179
- psychoeducational model outcomes in, 181–182
- publishing companies and books specializing in MS for, 238–239
- quality of life and, 191–194
- reflective thinking in, 195
- resource materials for, 223–242
- self-directed, 192–193, 196, 199
- shifting perspective model of chronic illness in, 194–197
- sick role and, 194
- support and self-help groups and, 194
- team (see interactive team approach to care)
- Tegretol (see carbamazepine)
- temperature, 32, 34, 50
- testing, 1, 5
- therapeutic touch, 187
- Therevac, 68
- Through the Looking Glass, 227
- tingling, 5
- tizanidine hydrochloride (Zanaflex), 35, 85, 322–323
- Tofranil (see imipramine; tricyclic antidepressants)
- tolterodine (Detrol), 63, 130, 324–325
- tonic spasms, 36, 84
- toxicity of treatments, 26
- toxins as cause of MS, 3, 16
- traditional Chinese medicine (TCM), 184
- tranquilizers, vs. pain, 45
- transcutaneous nerve stimulation (TENS), vs. pain, 45
- transmissibility of MS, 4
- travel and MS, 240–241
- tremor, 5, 37–39, 93
- immobilization vs., 38
- patterning techniques vs., 38
- pharmacologic management of, 37–38
- speech difficulties and, 47
- surgical treatment of, 39
- weighting vs., 38–39
- tricyclic antidepressants
- bladder dysfunction and, 63
- vs. depression, 99
- vs. pain, 131
- trigeminal neuralgia, 44
- trust funds, 207, 209
- tube feeding, 82
- twin studies of MS, 19
- U.S. Department of Agriculture (USDA), 77
- ulcers, 32

- ultrasound, 46, 60
- uncertainty and unpredictability, 96–97
- urinary frequency, 56
- urinary hesitancy, 57
- urinary tract infection (UTI) and
 - cystitis, 5, 57, 58, 64, 83–84, 186
- urinary urgency, 56
- urodynamic pressure flow, 60
- urodynamic studies, 60, **61**, **62**

- vaccinations, 51, 83
- Valium (see diazepam)
- Vaseline, 126
- venlafaxine (Effexor), 326–327
- vertigo (see dizziness and vertigo)
- vestibular stimulation, 39
- Veteran's Administration, 193
- Viagra (see sildenafil citrate)
- videofluoroscopy, 82
- virus as cause of MS, 16, 21–22, 33
- Visiting Nurse Association of American (VNAA), 238
- Vistaril (see hydroxyzine)
- visual changes, 5, 47–48, 242
- Vitamin B/niacin, vs. dizziness and vertigo, 48
- vitamin D, 87
- vitamins, 78, 185
- vocational assessment, 165–166
- vocational rehabilitation, 154–155
- vocational rehabilitation counselor's
 - role in rehabilitation, 154–155

- walkers, 156
- walking (see ambulation and mobility)
- weakness, 5, 40
 - exercise vs., 40
 - vs. spasticity and, 84

- weight gain, 49–50, 80
- weighting vs. tremor, 38–39
- Well Spouse Foundation, 227
- Wellness Model, 9–10, **9**
- wellness programs, 226
- wheelchair, 42, 49, 80, 156
- white matter, 4, 7, 16
- wills, 208–209
- women's issues, 141–145, 224
 - barriers and, 144–145
 - birth control and, 135
 - family planning and, 134–138
 - fertility and, 135
 - genetic issues and childbearing in, 134–135
 - hormonal fluctuations and MS in, 141–142, 143
 - menopause and, 143–144
 - menstrual cycles and, 143–144
 - osteoporosis and, 143
 - parenting issues and, 137–138
 - pregnancy, birth and lactation in MS and, 136–137, 142–143
 - sexual dysfunction and, 124
- work and productivity (vocational)
 - assessment, 165–166
- World Health Organization (WHO), 157
- World Wide Web as information
 - source, 197, 230–233

- young, progressively disabled patients, 118

- Zanaflex (see tizanidine hydrochloride)
- Zoloft (see sertraline)
- Zostrix HP (see capsaic acid)