In addition to conventional medicine, many people with MS also use some form of alternative medicine, and there is growing evidence and interest in the effects of lifestyle factors, such as diet and exercise, on MS. Yet, until now, it has been difficult to obtain unbiased information about the MS-relevant aspects of these nonmedication approaches. Optimal Health With Multiple Sclerosis provides the accurate information people with MS, their friends and family, health care professionals, and educators need to make responsible decisions and achieve the very best outcomes.

• Find other options that may provide symptomatic relief when conventional therapies are limited.
• Learn about potentially dangerous interactions between alternative therapies and medical treatments used in the management of MS.
• Identify alternative and lifestyle therapies that are effective, low risk, and inexpensive.
• Recognize ineffective, dangerous, or costly alternative therapies.

“A valuable resource….Dr. Bowling’s new book takes us all further in our management decisions. We can think in a more global sense that includes conventional approaches as well as a broader utilization of lifestyle management and unconventional therapies which may improve symptoms.”
—Pat Kennedy, RN, CNP, MSCN, Can Do Multiple Sclerosis and Past President, International Organization of MS Nurses

“The ever expanding knowledge base about MS demands the integration of traditional allopathic medicine, complementary, and alternative strategies, and lifestyle considerations into a coordinated approach to treat the whole patient….This book will be an indispensable aid to health care providers and persons with MS as they partner to achieve ‘optimal health.’”
—Barbara Giesser, MD, Professor of Neurology, Clinical Director, UCLA Multiple Sclerosis Program, David Geffen UCLA School of Medicine

Allen C. Bowling, MD, PhD, is Physician Associate at the Colorado Neurological Institute (CNI). He is also Clinical Professor of Neurology at the University of Colorado. Dr. Bowling has more than 100 lay and professional publications, including five books on MS. He has provided consultation or authored publications for many MS and neurological organizations, including the American Academy of Neurology (AAN), the National MS Society (NMSS), and the MS International Federation (MSIF). Dr. Bowling incorporates the approaches outlined in Optimal Health With Multiple Sclerosis in his clinical practice, Neurology Care (www.neurologycare.net), in Englewood, Colorado.
Optimal Health With Multiple Sclerosis
Also by Allen C. Bowling, MD, PhD

*Complementary and Alternative Medicine and Multiple Sclerosis*, Second Edition

*Dietary Supplements and Multiple Sclerosis: A Health Professional’s Guide*  
with Thomas M. Stewart, JD, PA-C, MS

*Multiple Sclerosis: The Guide to Treatment and Management*, Sixth Edition  
with Chris Polman, MD, PhD; Alan Thompson, MD, FRCP, FRCPI; T. Jock Murray, MS,  
and John Noseworthy, MD
Optimal Health With Multiple Sclerosis

A Guide to Integrating Lifestyle, Alternative, and Conventional Medicine

Allen C. Bowling, MD, PhD
Physician Associate
Colorado Neurological Institute
Englewood, Colorado
and
Clinical Professor of Neurology
University of Colorado
Aurora, Colorado
To my wife, Diana
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Foreword

Let me start by sharing my personal bias. As a psychologist providing individual, group and family therapy for people living with MS, I always recommended Dr. Bowling’s previous, very valuable book, *Complementary and Alternative Medicine and Multiple Sclerosis* to my patients as the go-to, comprehensive and objective resource for their questions about the role of complementary and alternative strategies in managing their multiple sclerosis (MS). And when my husband and I recently down-sized to a new home, Dr. Bowling’s book was one that I was determined to make room for on my MS shelf.

With this new book, Dr. Bowling has gone far beyond his earlier effort to explain what is known and not known about the wide variety of treatment strategies that lie outside the realm of conventional medicine. He provides an evidence-based roadmap for fully integrating lifestyle and unconventional medicine strategies into MS management so that readers can knowledgeably attend to their physical, emotional, and spiritual well-being while utilizing a comprehensive approach to disease and symptom management.

The layout of the book allows readers to delve deeply into the current knowledge about more than 50 different lifestyle and unconventional approaches and hundreds of dietary supplements and herbs, while also providing quick-reference summaries—complete with helpful icons—indicating approaches that are safe and effective for use by everyone, those for which we have insufficient data regarding their safety and effectiveness, and those for which the risks clearly outweigh any possible benefits. If only all our roadmaps could be this clear!

To live fully and well with a chronic, unpredictable disease like MS requires a comprehensive and integrated approach to managing the “whole you.” I can think of no better reference tool to guide you. Dr. Bowling brings to bear his years of training and experience as an MS specialist neurologist, his passion for promoting health and well-being, his determination to support informed and collaborative decision-making by people with MS and their health care providers,
and his endless curiosity about the potential benefits and risks of the wide range of conventional and unconventional approaches to disease and symptom management. Keep this book handy just as I do.

Rosalind Kalb, PhD
Vice President, Clinical Care
Advocacy, Services and Research Department
National Multiple Sclerosis Society
Preface

This book provides objective and practical information and guidance about using lifestyle approaches, unconventional medicine, and conventional medicine to optimize health in those with MS. Medical care of MS typically involves the use of conventional medical approaches to slow down the disease course and treat the symptoms of MS. In its most narrowed form, MS care focuses exclusively on administering and monitoring the safety and effectiveness of FDA-approved disease-modifying medications. However, there is much evidence that many other treatment strategies, which generally are not components of MS care, have significant health effects on those with MS. For example, lifestyle approaches, such as nutrition, tobacco smoking, and physical activity, may have beneficial, as well as harmful, effects on MS. Similarly, among unconventional medical approaches, some may be beneficial and others may be harmful. This book aims to fill these gaps in MS care by providing information and guidance on incorporating lifestyle and unconventional medicine into a broad-based treatment plan for people with MS.

Objective information about conventional MS therapies is readily available. However, it is difficult to find evidence-based information about the safety and effectiveness of lifestyle strategies and unconventional medicine approaches in MS. Also, there are currently no objective, comprehensive guides on how to use these lifestyle and unconventional approaches in combination with conventional medicine in treating MS. To address these needs, this book provides objective, MS-specific information about more than 50 different lifestyle and unconventional medicine approaches and hundreds of dietary supplements and herbs. This information is based on reviews of dozens of books and thousands of scientific and clinical research studies. These books and studies are referenced throughout the text and are also provided as Additional Readings at the end of each chapter. In addition to providing objective information about specific
lifestyle and unconventional strategies, this book transforms this information into a practical treatment approach. The Seven-Step Approach that is presented integrates lifestyle and unconventional medicine with conventional medicine to provide a multidimensional treatment strategy that is designed to optimize health in those with MS.
How to Use This Book

This book was written so that it would be accessible and useful for nearly everyone in the MS community. It is written in lay language, but, for those who are interested, references are provided to the relevant studies in the scientific and medical literature. Thus, this book may be used by people with MS and their family and friends as well as by health professionals. Indeed, a goal for this book is to have it serve as a common ground for people with MS and health professionals to explore and use treatment approaches that may be beneficial but are underutilized and also to avoid approaches that are ineffective or harmful.

This book is divided into five main sections, each of which has a specific purpose:

- **Part 1: Introduction**
  
  This section lays the foundation for the remainder of the book by providing broad overviews of MS, lifestyle and unconventional medicine, placebos, and precautions about using lifestyle and unconventional medicine.

- **Part 2: Optimal Health With Multiple Sclerosis: A Seven-Step Guide to Integrating Lifestyle, Alternative, and Conventional Medicine**
  
  In many ways, this is the heart of the book. It distills the vast information about MS and lifestyle, unconventional, and conventional medicine. The Seven-Step Approach that is provided may be used as a practical treatment guide for people with MS and health professionals.

- **Part 3: Types of Lifestyle and Unconventional Medicine**
  
  This part of the book is an A-to-Z compendium of MS-relevant information about more than 50 different lifestyle and unconventional medicine approaches. This section may be used to find detailed information about a specific approach, including a general overview, details of the treatment method, relevant studies in MS and other conditions, side effects, practical
information about using the therapy, a concise MS-relevant conclusion about the therapy, and additional readings.

• Appendices

Appendix 1 provides a listing of the overall ratings of the effectiveness and safety (see below) of all of the lifestyle and unconventional approaches that are discussed in Part 3. Appendix 2 provides an alphabetical listing of dietary supplements and herbs that may produce MS-relevant side effects or drug interactions. These two appendices serve as quick references to therapies that may be helpful and those that may be harmful.

• Index

The index of this book is extremely detailed because it may not be apparent from the Table of Contents where to find information on particular therapies, such as uncommon dietary supplements and herbs. Like the Appendices, the Index may be used to quickly find information on specific therapies.

Icons are used throughout this book to indicate the relative effectiveness and safety of specific lifestyle and unconventional approaches. The use of any of the therapies that are in this book, even those with the highest rating, should be discussed with health professionals. The icons in this book are designed to provide a visual indicator of the overall rating of specific strategies:

✴

“Essential”—This is the “highest rating” and indicates that these approaches have benefits that far outweigh risks. With rare exceptions, approaches in this category should be used by everyone with MS.

✔

“Worth Considering”—These approaches have some indication of beneficial effects in MS and have little or no risk. These approaches may be worth consideration by many people with MS.

❓

“Uncertainties”—A question mark indicates that there are uncertainties about safety or effectiveness. If these therapies are considered, one should be aware of the uncertainties and carefully weigh the risks and benefits.

❗

“Caution”—Therapies in this category have significant safety concerns or the risks significantly outweigh the benefits. These approaches should be avoided or used with caution.
Acknowledgments

Many individuals and organizations made this book possible. First, I would like to thank my wife, Diana, who is a clinical psychologist. Much of her clinical acumen and life wisdom is woven into this book. She provided valuable thoughts about challenging topics as well as formatting and design features. Also, she tolerated the ridiculously early morning risings that allowed me to have writing time in my daily schedule. Our two daughters, Elizabeth and Sarah, provided much inspiration—they continually motivate me to search for what constitutes a healthy, happy, and meaningful life.

I am thankful for the thousands of people with MS who, over the past few decades, have had the openness and courage to share their personal experiences and perspectives with me. These interactions have shaped me as a clinician and greatly influenced the general approach of this book as well as many of its specific details.

Several decades ago, Dr. David Jenkins was kind enough to take me in and mentor me in ways that still influence my career, including some of the underlying concepts of this book. More recently, Dr. Rosalind Kalb provided a critical “push” that motivated me to undertake this project. Nola Nielsen made it possible for me to have “protected” time to write. Sharon Martin, Nancy Peterson, and the Dorsey Medical Library provided efficient and high quality library services that were essential.

I am grateful for my ongoing involvement with the Colorado Neurological Institute (CNI) and appreciate the support for this project by Tami Lack, MA, Executive Director of CNI. Hugh “Monty” Loud and his family provided financial support and inspiration.

Finally, I am thankful for my long-term relationship with Demos Medical Publishing. In the past, Dr. Diana M. Schneider heartily supported books about controversial, but clinically important, topics. More recently, Julia Pastore expertly facilitated the writing of this book at all stages and provided outstanding editorial input.
PART 1

Introduction
Alternative Medicine and Lifestyle Medicine

Multiple sclerosis (MS) is a common disease of the nervous system. Most people with MS use some form of conventional medical therapy, and there are well-established approaches for using these therapies to treat those with MS. In addition to conventional medicine, many people with MS also use some form of complementary and alternative medicine (CAM) and there is growing evidence and interest in the effects of lifestyle factors, such as diet and exercise, on MS. In fact, there is now evidence that various CAM therapies and lifestyle factors have beneficial—as well as harmful—effects on MS. Unfortunately, although CAM and lifestyle factors may have a significant impact on MS, they are often not included in the formal treatment plans that are developed by MS health professionals. It may even be difficult for people with MS—as well as health professionals—to obtain unbiased and practical information about the MS-relevant aspects of these nonmedication approaches. To improve this situation, this book provides evidence-based, MS-relevant information about CAM and lifestyle medicine and also provides guidance on how to safely and thoughtfully develop an MS treatment approach that utilizes CAM and lifestyle medicine alongside conventional medicine.

Before considering the relevance of CAM and lifestyle medicine to MS, it is important to understand the approach of conventional medicine to this disease. Dramatic advances have occurred recently in the field of MS research. Through scientific studies, we now have a significantly increased understanding of the disease process itself. Also, clinical studies using experimental medications have yielded a remarkable array of therapies that slow the disease process and alleviate MS-related symptoms.
Who Develops MS?

MS is a common neurologic disease that affects 350,000 to 400,000 people in the United States. Women are diagnosed with the disease about twice as frequently as are men. Although MS may affect people in all age groups, it is typically diagnosed between the ages of 20 and 40 years. A striking relationship exists between the prevalence of MS and the geographic area in which an individual lived during childhood. In general, an individual has a higher risk of developing MS if he or she grew up in an area that is far from the equator and a lower risk if the childhood years were spent near the equator.

How Does MS Affect the Nervous System?

In contrast to many diseases that affect a single part of the human body, MS affects two different body systems: the immune system and the nervous system. The immune system is not a distinct organ like the brain or liver. Instead, it is composed of many different types of molecules and cells (known as white blood cells) that travel through the bloodstream. The immune cells use chemical messages to protect the body from attack by bacteria, viruses, and cancers. MS is believed to be an autoimmune condition in which the immune system is excessively active and actually attacks the nervous system.

The central nervous system (CNS) is the part of the nervous system involved in MS. The CNS includes the brain, spinal cord, and optic nerves. The nerves in the CNS communicate with each other through long, wire-like processes that have a central fiber (axon) surrounded by an insulating material (myelin). In MS, the immune system cells produce inflammation that injures the myelin. In addition, damage occurs to the axon and the nerve cell itself. This damage is known as degeneration, which is the process that occurs in aging-related neurological diseases such as Alzheimer’s disease and Parkinson’s disease. The injury to the myelin and axons results in a slowing or blocking of nerve impulses that prevents the affected parts of the nervous system from functioning normally.

The cause of MS is not entirely clear. It is believed that two important factors are involved in developing the disease, one of which is environmental and the other genetic. The characteristic geographic distribution of MS indicates that an environmental factor is present. Many recent studies indicate that an important environmental factor is vitamin D, which mildly suppresses the immune system and thus could be protective against MS. Because vitamin D becomes active with sunlight exposure, those who live farther from the equator (with less-direct sunlight exposure) may have lower levels of vitamin D and higher risks of developing MS. Other environmental factors that appear to increase
the risk of MS include infectious mononucleosis ("mono") as a teenager and cigarette smoking.

The presence of a genetic factor is indicated by family studies that demonstrate a hereditary predisposition to MS. Some genetic diseases are “dominant” and are clearly passed down through generations. MS is not passed on in such a well-defined pattern. Rather, there may exist an inherited predisposition to the disease that must be present in addition to an environmental agent to cause disease. Recent genetic studies indicate that multiple genes, many of which are related to immune system function, play a role in increasing the risk of developing MS. Ongoing, intensive research efforts are aimed at identifying specific genes that increase the risk of developing MS or affect the severity of the disease.

What Symptoms Do People With MS Experience?

The symptoms of MS depend on which areas of the brain and spinal cord develop MS lesions. For example, if the nerve that is involved in vision (the optic nerve) develops a lesion, blurring of vision occurs. This is referred to as optic neuritis. If a lesion develops in the part of the brain that produces movement on the left side of the body, left-sided weakness develops. In addition to visual blurring and weakness, other common MS symptoms include fatigue, depression, urinary difficulties, walking unsteadiness, stiffness in the arms or legs, tingling, and numbness.

The time course over which MS lesions develop and the number and location of lesions is different for each individual. Consequently, the time frame in which symptoms occur and the specific types of symptoms experienced are unique for each person. Also, as a result of the large variability of lesions between individuals, MS varies greatly in severity. Some people may have rare, mild attacks over their lifetime and may not experience any permanent symptoms, whereas others may develop severe, permanent symptoms over a relatively short period.

MS symptoms may occur episodically or may progress continuously. Episodes of symptoms are known as relapses, attacks, or exacerbations. Usually, some improvement in symptoms occurs after an attack. This improvement is referred to as a remission. In contrast to these relapsing-remitting symptoms, some people have symptoms that develop slowly and then progressively worsen over time with no clear remissions. These symptoms are referred to as progressive.

Specific combinations of relapsing-remitting and progressive symptoms are the basis for classifying MS. People who experience attacks and then improve
have relapsing-remitting MS. This is the most common type of MS. At the time of diagnosis, about 85% of people with MS are classified as having relapsing-remitting MS. Some people who initially have relapsing-remitting disease may subsequently develop progressive symptoms. This is known as secondary-progressive MS. Those who have exclusively progressive symptoms from the onset of the disease, which constitutes only about 10% of people at the time of diagnosis, have primary-progressive MS, whereas those with progressive-relapsing MS, which make up about 5% of those with MS, have progressive symptoms from the onset (as occurs with primary-progressive MS), but also experience intermittent relapses. Some people who have experienced only one relapse may be diagnosed with clinically isolated syndrome (CIS) instead of MS. CIS is a condition that has a high risk of developing into MS.

### Conventional Medical Therapy for MS

Dramatic breakthroughs have been made recently in the treatment of MS. In the past, no particularly effective therapies were available to change the course of disease. Since 1993, remarkable advances have led to Food and Drug Administration (FDA) approval of 10 medications for slowing down the disease course of MS. These drugs are referred to as disease-modifying therapies. In addition to these therapies, there is a long and diverse pipeline of MS drugs in development.

The currently available disease-modifying medications may be given by pill, injection, or intravenous administration:

- **Pills**
  - Fingolimod (Gilenya)
  - Teriflunomide (Aubagio)
  - Dimethyl fumarate (Tecfidera)

- **Injections:**
  - Interferons: interferon beta-1b (Betaseron and Extavia), interferon beta-1a once-weekly (Avonex), and interferon beta-1a three-times-weekly (Rebif)
  - Glatiramer acetate (Copaxone)

- **Intravenous**
  - Natalizumab (Tysabri)
  - Mitoxantrone (Novantrone)

These drugs decrease the number and severity of relapses, slow the progression of the disease, and decrease the development of new brain lesions. All of these medications have side effects, some of which are serious. Thus, it has become
increasingly important in MS treatment to monitor closely for side effects and carefully balance the risks and benefits of therapies.

Because of the therapeutic effects of the FDA-approved medications, all people with MS should be strongly considered for treatment with one of these drugs. A 2008 statement by the National Multiple Sclerosis Society emphasizes the importance of treatment. The statement recommends treatment with these medications should be considered in all people with relapsing forms of MS and also in those with a CIS, the condition that has a high risk of developing into MS.

In addition to these medications, several other medications are used to treat MS. Steroid-based approaches are used for exacerbations. Steroids may be taken orally (prednisone, dexamethasone) or intravenously (methylprednisolone or Solu-Medrol). Also, a drug that increases the body’s own production of steroids may be taken by injection (corticocortropin injection or Acthar) at the time of an attack. Some chemotherapy medications that are not FDA-approved for MS, including methotrexate, azathioprine (Imuran), and cyclophosphamide (Cytoxan), are used occasionally in an attempt to slow disease progression.

Given the wide range of symptoms caused by MS, multiple treatment approaches are possible. Therapies for symptoms include medications and non-medication-based approaches, such as physical therapy, occupational therapy, speech therapy, and psychotherapy. Common MS symptoms that are treated using these therapies include fatigue, depression, weakness, incoordination, walking difficulties, stiffness, bowel and bladder disorders, and sexual difficulties. Recent FDA-approved symptomatic therapies for MS include dalfampridine (Ampyra), which may improve walking, and dextromethorphan/quinidine (Nuedexta), which may alleviate uncontrollable laughing or crying.

(For more information on conventional approaches to MS, see the other, more extensive texts in this area in the “Additional Readings” section at the end of this chapter.)

**Complementary, Alternative, Lifestyle, and Integrative Medicine**

Beyond conventional medicine, there are many, many other approaches that may provide benefit—as well as harm—to those living with MS. These other approaches may be broadly categorized as CAM and lifestyle medicine. A term that is inclusive of all of these diverse healing methods is *integrative medicine*.

**Complementary and Alternative Medicine**

There are many different terms that are used in this area. The most general term is *unconventional medicine*, which refers to therapies that are not widely taught
in medical schools or generally available in hospitals. The term *complementary medicine* refers to unconventional therapies that are used *in addition* to conventional medicine, while the term *alternative medicine* is used to describe unconventional treatments that are used *instead* of conventional medicine. The more inclusive term for both of these approaches is CAM. An even more inclusive term is *integrative medicine*, which refers generally to the combined use of unconventional medicine and conventional medicine.

CAM includes a vast array of therapies. To categorize these diverse and often unrelated therapies, multiple schemes have been proposed, several of which have been developed by the National Institutes of Health (NIH). This is one NIH scheme, with representative examples of therapies:

- Biologically based therapies—Dietary supplements, diets, bee venom therapy, hyperbaric oxygen
- Mind-body therapies—Guided imagery, hypnosis, meditation
- Alternative medical systems—Traditional Chinese medicine, Ayurveda, homeopathy
- Manipulative and body-based therapies—Chiropractic, reflexology, massage
- Energy therapies—Therapeutic touch, magnets

**Lifestyle Medicine**

As with CAM, there are many different definitions of lifestyle medicine. Generally, lifestyle medicine refers to daily habits and practices, such as diet and exercise, that are incorporated into conventional medical care in order to lower the risk for disease or, if disease is already present, to assist in the treatment of disease. Thus, lifestyle medicine aims to prevent and treat disease and also, more generally, to promote good health. Importantly, lifestyle factors are often two-edged swords—adhering to healthy lifestyle approaches, such as proper nutrition, exerts positive health effects, but leading an unhealthy lifestyle, such as poor nutrition, causes and worsens diseases.

Many different lifestyle approaches may be used. Commonly used strategies include:

- Nutrition
- Exercise
- Stress management
- Smoking cessation

While medications are often thought to be the best approach to treating a disease, it has been increasingly recognized that healthy lifestyle approaches are also very important—and perhaps the most important—strategy in treating, as well as preventing, multiple diseases. Hundreds of studies demonstrate that
lifestyle practices play an important role in many diseases, including diabetes, obesity, high blood pressure, and heart disease.

Evidence is growing that a long list of other diseases, including MS, are also significantly impacted by daily habits and practices. For example, lack of physical activity, smoking, and some dietary factors, such as high salt intake and low vitamin D levels, may increase the risk of developing MS or increase the severity of the disease. Furthermore, in those with MS, the presence of other lifestyle-associated diseases, such as diabetes, high blood pressure, and heart disease, may lead to more rapid progression of neurological disability and lower quality of life.

Which Approach Belongs in Which Category?
In spite of these formal definitions, the distinction between CAM, lifestyle medicine, and conventional medicine is not always clear. For example, physical activity is often a component of conventional medicine, yet may also be categorized as lifestyle medicine and CAM. Similarly, some dietary interventions, such as vitamin D supplementation, may be classified as CAM, lifestyle medicine, or conventional medicine. An excessive focus on classifying and compartmentalizing therapies is not helpful—putting specific therapies in different treatment “turfs” with different practitioners and specialists may “disintegrate” care and ultimately detract from bringing all of the many potentially beneficial MS therapies together into an integrated, broad-based approach that is readily accessible to people with MS.

Integrative Medicine
The term integrative medicine refers to an approach that aims to optimize health and healing by decompartmentalizing all of the various therapeutic approaches. Integrative medicine is sometimes defined as the combination of CAM and conventional medicine. Actually, integrative medicine is much broader. It emphasizes health and wellness of the whole person through the use of conventional medicine, CAM, and lifestyle strategies within a supportive clinician-patient relationship.

CAM Is Popular in the General Population and in MS
Many studies have documented that CAM is used frequently in the general population in the United States. One well-known large study was conducted in 1997 and was reported in the medical literature in 1998 by Dr. David Eisenberg (1). In this landmark study of more than 2,000 people, approximately 42% used some form of CAM. It was estimated that 629 million visits were made to practitioners of alternative medicine; this was greater than the number of visits to all
primary care physicians in that year. Nearly half of the people were using CAM without the advice of a physician or a CAM practitioner, which demonstrates the need for increased communication in this area between patients and health care providers.

More recent U.S. studies indicate that the use of CAM continues at a similar level and will continue in the future. In several large studies, approximately 40% of Americans were found to use some form of CAM (2–5). Another U.S. study found that CAM use is not a short-lived fad (6). In this report, CAM use by the age of 33 was evaluated relative to birth date. For those born before 1945, about 30% of respondents used CAM. The percentage of CAM users rose to about 50% for those born between 1945 and 1964, and was even higher, about 70%, for those born between 1965 and 1979. This study also found that nearly one-half of people who tried a specific form of CAM continued to use that CAM therapy more than 20 years later. Overall, this study indicates that CAM is not a short-lived phenomenon because some CAM therapies are used long-term and CAM use in general is higher among younger people.

Many studies have evaluated CAM use specifically in those with MS. One of the earliest studies in this area was conducted in Massachusetts and California in the 1990s (7). Approximately 60% of people had used CAM, and, on average, people used two to three different types of CAM. Subsequent studies have investigated CAM use in people with MS in the United States and have produced extremely variable results. CAM use among people with MS has ranged from 30% to 100%. As a whole, these studies indicate that at least 50% of people with MS use some form of CAM (8–16).

The use of CAM among people with MS is not simply an American phenomenon. Studies in other countries indicate similar results for the percentage of people with MS who use CAM: 65% to 80% in Australia, 70% in Canada, 27% to 55% in Denmark, 45% to 60% in Nordic countries, 41% in Spain, and 70% in Germany (17–24).

In surveys of people with MS and of the general population, a consistent finding is that CAM usually is used in conjunction with conventional medical therapy. Approximately 80% to 90% of people who use CAM also use conventional medicine. This leaves a relatively small fraction of people who use CAM in a truly alternative manner. These findings indicate that CAM usually is used in a complementary way.

People with MS use a wide range of CAM therapies. Those that appear to be especially popular include massage, dietary supplements, diets, chiropractic medicine, acupuncture, meditation and guided imagery, and yoga.

The reasons why people with MS pursue CAM are as varied as the different CAM modalities used. “Curing MS” is not a frequently cited reason for using CAM. Common reasons include decreasing the severity of MS-associated symptoms, increasing control, improving health, and using a method that accounts for the
interrelation of mind, body, and spirit. Some people are drawn to CAM because of the lack of effectiveness of conventional medications and anecdotal reports of benefits or recommendations from friends, relatives, or physicians. One study of CAM use in people with MS and other chronic diseases concluded that CAM was an important component for self-care and was not generally embraced as a rejection of conventional medicine or an unrealistic search for a cure (25).

Underutilized Tools in the Toolbox

CAM and lifestyle approaches are often underutilized tools in the “MS toolbox.” It is recognized that they are important factors to address in treating the disease. CAM is of high interest, and is used widely, in those with MS. In addition, both CAM and lifestyle approaches have beneficial as well as harmful effects on the disease. Despite the recognized importance of these “nonmedication” strategies, multiple barriers significantly limit their use.

Books and Other Written Material

For CAM in particular, the information available to the general public in books, magazines, and the Internet is vast but of variable quality. For CAM that is relevant to MS, the amount of information is limited and the quality also is variable. To attempt to understand the type of information that is available on CAM and MS, we conducted an informal survey of the popular literature on CAM several years ago. At two local bookstores, we found 50 CAM books written for a lay audience. In some books, MS was incorrectly defined as a form of muscular dystrophy. Other books made the erroneous—and potentially dangerous—statement that, because MS is an immune disorder, it is important to take supplements that stimulate the immune system. In fact, MS is an immune disorder, but it is characterized by an excessively active immune system; thus, immune-stimulating supplements actually may be harmful. On average, the CAM books recommended five or six therapies for MS. In 20% of them, 10 or more therapies were recommended. It was rare for books to discourage the use of any CAM treatment. Interestingly, none had the same recommended therapies.

Products and CAM/Lifestyle Practitioners

In addition to books, information about CAM and lifestyle strategies may be obtained from vendors of products, CAM practitioners, and others such as nutritionists and physical trainers. Unfortunately, product vendors, such as people who sell supplements, often exaggerate claims about their products. Practitioners of CAM and lifestyle approaches (as well as product vendors) sometimes have limited experience with MS and are not certain how their therapy relates to a complex disease process such as MS.
Physicians and Other Mainstream Health Care Providers

Physicians and other conventional medicine providers are potential sources of information and could play a valuable role in developing a treatment plan that utilizes CAM and lifestyle medicine in combination with conventional medicine. However, there are multiple barriers and challenges in this area. First, in the area of CAM, most conventional health providers have little or no training or experience. As a result, they may have little or no MS-relevant CAM information. In addition, for various reasons, some conventional health providers may find CAM unappealing or even repulsive. With lifestyle medicine, conventional health providers may also feel challenged. Many may find lifestyle medicine more palatable than CAM but, as with CAM, they may have little or no formal training, experience, or information. Further, they may feel that they lack the skills, time, or appropriate clinician–patient relationship to produce long-lasting changes in lifestyle, such as diet or physical activity. Indeed, producing changes in lifestyle may be extremely difficult and time-consuming, and it requires skills that are very different from those used to prescribe or administer medications and other conventional therapies. Paradoxically, the remarkable advances in conventional medical therapy for MS may actually prevent well-intentioned conventional health providers from using or discussing CAM and lifestyle medicine. The intensive safety and effectiveness monitoring and complex decision making that are required for using these drugs may consume all of the time that is available for a standard medical appointment. In addition, staying up-to-date and well-informed about all of the various conventional MS therapies may be an enormous challenge on its own for health care providers—to then also stay well-informed about the vast number of MS-relevant CAM and lifestyle approaches may simply not be possible for many.

Evidence for Safety and Effectiveness: Differences in Perspective

An additional challenge in this area is that conventional health providers and people with MS may have very different views about information on conventional therapies, CAM therapies, and lifestyle strategies. Physicians view the use of basic science and rigorous clinical trial methods as a powerful tool to develop new disease understanding and new therapies. In contrast, people with MS may agree that this process is powerful, but that it is also slow and thus may yield limited advances during their lifetimes. Also, they may believe the complexity of these studies is excessively rigorous, especially for many CAM and lifestyle strategies that have little or no risk and are known to provide general health benefits.

The “gold standard” for developing new therapies is a randomized, controlled clinical trial. This clinical testing employs specific and rigorous methods, including the use of a placebo-treated group, “blinding” of patients and investigators (so that neither patients nor investigators know who has received placebo and...
who has received active medication), and randomly selecting those who will receive placebo or active medication. Physicians and other mainstream health care providers generally use therapies only after they have been found to be effective in these well-designed clinical trials. FDA approval generally requires two randomized, controlled trials that are of the highest quality (“Class I”) and show that the benefit outweighs the risk. Through the rigorous clinical trial methods, a black-and-white distinction exists between those therapies that have been proven effective and those that have not.

For CAM therapies and many lifestyle approaches, there may not be such a black-and-white distinction, but rather shades of gray. For example, some CAM and lifestyle approaches have not undergone definitive and rigorous large-scale clinical testing, but scientific studies in animals or limited clinical studies in people have produced promising results. These types of therapies generally are not incorporated into mainstream medicine and are not thought to be the “standard of care.” However, people with a disease may have significant interest in such promising therapies, especially if they are relatively safe and inexpensive. In addition, some of these promising CAM and lifestyle approaches may provide other health benefits, which may make them even more appealing to people with a disease. An example of this situation in MS is vitamin D supplementation and other dietary strategies—these approaches have possible, but not definite, effectiveness in MS but they do have definite general health benefits.

Another difference in patient–physician perspective occurs with proven mainstream therapies. Conventional medications that are 30% to 60% effective at slowing down the disease process may represent a major advance for physicians and other health care providers but, for people with MS, these therapies may be seen as 40% to 70% away from a cure (which would be 100% effective).

In some areas of CAM, the same set of facts is viewed negatively by conventional medicine and positively by some people with MS. This emphasizes the importance of first establishing the facts about a therapy and then realizing that these facts may be interpreted differently by mainstream health care providers and people with MS. Under some circumstances, it is as if two different cultures exist: that of the health care provider and that of the person who has the disease. These two cultures may have strikingly different belief systems.

The difference in perspective becomes especially apparent when a physician develops a disease. In this situation, a dramatic shift may occur in an individual’s attitudes about what constitutes an appropriate medical therapy. In MS, there have been several published examples of this shift in perspective.

Dr. George Jelinek is an Australian physician who has MS. Although he was not trained as a neurologist, he has devoted some of his career to MS-related writing and research. Much of his MS work actually highlights the differences between patient and physician perspectives and aims to study, and increase the use of, appropriate lifestyle and CAM approaches in MS treatment.
He writes: “Although a specialist emergency physician with typically conservative medical background, I have also experienced MS from a patient’s perspective… Studies which have not ‘proven’ the treatment to be beneficial but which suggest a major benefit look much more interesting when you actually have the disease, especially when the treatment has other health benefits as well… Despite [its] effectiveness, lifestyle change is often not promoted” (26).

Two English physicians with MS have also written on this topic. With reference to evening primrose oil, a fatty acid dietary supplement, Dr. Alexander Burnfield states: “I started taking it before the research was published and, being only human, take it just in case I get worse if I stop. This is, I know, an unscientific and emotional response, and the logical—doctor part of me is quite shocked” (27).

Dr. Elizabeth Forsythe writes whimsically about diet and MS: “It is what you feel in your own body and mind that is the most important thing, and it is very easy for doctors and patients to forget that. I believe that a little of what you fancy does do you good!” (28).

**Transforming Challenge into Opportunity**

There are challenges with incorporating CAM and lifestyle medicine into MS care. However, addressing these challenges and overcoming them provides a great opportunity to improve the quality of care for those with MS.

An encouraging aspect of the current situation is that a plethora of MS-relevant CAM and lifestyle information already exists but is underutilized or inappropriately utilized. Thus, one of the greatest challenges now is *not* to “start from scratch” and develop new therapies—that can be a long, expensive, and uncertain path. Rather, the challenge is to take currently available information about existing approaches and thoughtfully incorporate this information into MS therapy. This book aims to do this by providing MS-relevant, objective information about the safety and effectiveness of CAM and lifestyle approaches (Part 3) and also by providing guidelines on integrating these approaches with conventional medicine (Part 2). Having all of this information in one resource that is objective and easily accessible to people with MS as well as health professionals creates common ground upon which people with MS and their health care providers may communicate openly and work together to develop broad-based, safe, and effective treatment plans.

**Additional Readings**

**Websites**

www.neurologycare.net—CAM website that is maintained by Dr. Allen Bowling

www.nationalmssociety.org—website of the National MS Society of the United States
Books


**Journal Articles**


