# Managing the Symptoms of Multiple Sclerosis

Randall T. Schapiro, M.D.

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### MANAGING THE SYMPTOMS OF MULTIPLE SCLEROSIS

FOURTH EDITION

Randall T. Schapiro, M.D. Director, Fairview Multiple Sclerosis Center Fairview University Medical Center and Clinical Professor of Neurology, University of Minnesota Minneapolis, Minnesota



New York

— To our patients —

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Randall T. Schapiro, M.D.

## CONTENTS

### Preface ix

### I. The Disease and Its Management

- 1. What is Multiple Sclerosis? 3
- 2. Managing the Disease Process 16

### II. Managing MS Symptoms

- A. Movement and Walking
  - 3. Fatigue 25
  - 4. Spasticity 33
  - 5. Weakness 43
  - 6. Tremor and Balance 46
  - 7. Paroxysmal Symptoms 52
  - 8. Mobility: Putting It All Together 54
  - 9. Pressure Sores 61

#### B. Bladder and Bowel

- 10. Bladder Symptoms 64
- 11. Bowel Symptoms 79
- C. Speech and Swallowing
  - 12. Speech Difficulties 88
  - 13. Swallowing Difficulties 91
- D. Sensory Disturbances
  - 14. Vision 94
  - 15. Pain 96

#### Contents

- 16. Dizziness and Vertigo 10017. Numbness, Cold Feet, and Swollen Ankles 102
- *E. Cognition and Memory*18. Cognitive Difficulties 105

### III. Your Total Health

- 19. Diet and Nutrition 111 Daniel Kosich, Ph.D.
- 20. Exercise 125
- 21. Sexuality 129
- 22. Adapting to Multiple Sclerosis 136

### **IV.** Appendices

- A. Glossary 145
- B. Exercises for Spasticity 163
- C. Transfers and Mobility 175
- D. Resources 191

Index 193

### Preface

We are in the age of exploding knowledge in multiple sclerosis (MS). No longer can people with MS be told there is nothing that can be done for them! The progress made during the last ten years has eclipsed that of the previous forty years. When the first edition of this book was published in 1986, disease management was only dreamed about, and the backbone of managing MS was symptom management. Now, only 16 years later, these treatments are equally important in attempting to gain control of this seemingly uncontrollable disease. As I have always emphasized, there is a person behind the MS who has needs that go beyond disease and symptom management, and these must also be addressed in any comprehensive management program.

This book remains a guide to managing the symptoms of MS, but also focuses on disease and personal management strategies. It is based on the management program developed at the oldest comprehensive MS Center in the United States, The Fairview MS Center in Minneapolis, Minnesota, USA. With all that has happened in health care delivery in the past decade, it is even more important for people with MS to take charge of their destiny as much as possible. This book provides ammunition in that fight by suggesting ways to manage the issues that accompany MS.

In this new edition, the disease management section has been expanded to reflect the growth of our knowledge in this area. Newer ways to manage complex and routine symptoms are explored. We have also reorganized the book to better reflect the three areas of management—management of the disease, management of its symptoms, and management of issues relating to lifestyle and general wellness.

It is our hope that all who use this book will be empowered to do as much as they can with what they have, and to live their lives as fully as possible.

# Part

# The Disease and Its Management

# Chapter 1

# WHAT IS MULTIPLE SCLEROSIS?

Multiple sclerosis (MS) is one of a broad category of *demyelinating* diseases that affect the central nervous system (CNS)—the brain and spinal cord. *Myelin* is a fatty material that insulates nerves, acting like the covering of an electrical wire and allowing the nerve to transmit its impulses rapidly. It is the speed and efficiency with which these impulses are conducted that permits smooth, rapid, and coordinated movements that are performed with little conscious effort. In MS the loss of myelin is accompanied by a loss of the ability to perform these movements. The sites where myelin is lost appear as hardened *sclerotic* (scarred) areas, and because there tend to be many such areas within the CNS, the term *multiple sclerosis* (literally, many scars) is appropriate.

It is well understood that the nerve—called an "axon"—is also effected by MS. Newer studies have shown even more dramatically what has been known for hundreds of years: that the axon can degenerate in MS. That degeneration may lead to more permanent damage than if the myelin only were involved. Thus, the brain functions somewhat as if it were a large computer or an electrical system that sends its messages down nerves in the nervous system. These nerves function like wires—you decide to move your right arm, and it moves. This amazing system is made efficient by the presence of myelin. To understand this process more completely, it is helpful to understand the anatomy of the nervous system.

### A WORD ABOUT ANATOMY

The anatomy of the nerves and muscles is referred to frequently throughout this book. The overview presented here is intended to provide a quick reference for the reader. More specific information is included with each topic as needed.

Three fairly distinct components make up the nervous system in the human body: the *central nervous system*, which is somewhat analogous to the main processing unit of a computer; the *peripheral nervous system* (PNS), which links the CNS to the muscles; and the *sympathetic nervous system*, which links the CNS to the internal organs (see figure). The CNS has two major parts, the brain and spinal cord, which in turn have several subdivisions, each of which plays a unique role in regulating the functions of the body.

The portion of the brain referred to as the *cerebrum* acts as a master control system and is responsible for initiating all thought and movement. Memory, personality, vision, hearing, touch, and muscle tone all are housed within the cerebrum. Behind the cerebrum is the cerebellum, which coordinates movement and "smoothes" muscle activity. The proper functioning of this region of the brain controls balance during walking and the smooth use of your hands and arms.

Beneath the cerebrum and cerebellum is the *brain stem*, which contains the nerves that control eye movements and the vital centers that are involved in functions such as breathing and heart rate. Extending downward from the brain stem is the *spinal cord*, which functions very much like a large electrical cord that carries messages between the brain centers and all other parts of the body. Although numerous biochemical reactions occur in the brain and spinal cord, their major role is to produce electrical activity that stimulates and regulates various bodily activities. These messages

<sup>4</sup> 



Nervous system

are delivered to the target structures very efficiently and effectively because the entire system is well insulated and shielded by the myelin that surrounds the conducting systems and allows the electrical nervous impulses to move through the pathways with little loss of information. The myelin in the brain and spinal cord is produced by a specific type of cell called an *oligodendrocyte* (oligo). Both oligos and myelin appear to be injured in MS. When they are injured, the nerve beneath the myelin sometimes also is injured (axonal damage). Oligos disappear as the affected myelin becomes hardened and scarred, forming what is called a *plaque* and causing a short-circuiting of electrical transmission.

The *peripheral nervous system* (PNS) is responsible for transmitting electrical messages between the spinal cord and the muscles, including those of the arms and legs. This system also contains myelin, although it is made by a different cell type than the oligo, a cell that does not appear to be affected by MS. Thus, although it is not uncommon to find leg or arm weakness in MS, the problem lies in the central conduction system (the brain and spinal cord), not in the peripheral nerves that lead from the spinal cord.

The *autonomic nervous system* has two divisions, the *sympathetic* and the *parasympathetic*. These systems are responsible for automatic types of function such as the beating of your heart, perspiration, etc. This system also contains myelin but, like the PNS, it is not directly affected by MS.

Although MS directly affects only the CNS, the disease has indirect effects on other systems and their functions because all components of the nervous system communicate with each other.

### Symptoms of Multiple Sclerosis

The most common characteristics of MS include:

- Onset most commonly is between the ages of 15 and 50 years.
- Remissions and exacerbations (improvements and flareups) are the rule.
- Scattered areas in the CNS are diseased.

Because different areas of the brain and spinal cord are responsible for different kinds of movements and sensations, the neurologic deficit that results from an area of scarring depends on the exact location of the abnormality (lesion). For example, when an area of demyelination occurs in the cerebellum, the area of the brain that is responsible for making coordinated movements, such

> No two cases of MS are exactly alike, and symptoms vary considerably from one individual to another.

coordination becomes difficult. Because symptoms depend on the location of the area of scarring, no two cases of MS are exactly alike, and symptoms vary considerably from one individual to another. In one person, the extent of MS symptoms might be mild disturbances of gait and vision, whereas another person might suffer a severe or complete sensory and motor loss.

It is relatively easy to understand that there are different types of cancer. MS may be viewed in a similar but somewhat different way. Just as some tumors are malignant and others are relatively benign, some people with MS may have severe disease, whereas others may experience only mild effects of the disease.

To better understand individual variations and to develop appropriate management plans, MS often is divided into categories. The most current classification includes:

• *Relapsing-remitting.* This form of MS is characterized by clearly defined acute attacks, with either full recovery or some remaining neurologic signs/symptoms and residual deficit upon recovery. The periods between relapses are characterized by a lack of disease progression. It is thought that about 80% of MS begins in this manner. Over time the

course may change and then the person moves into a different category. About 50% will become progressive following the relapsing start. We then call it:

- *Secondary progressive*. This form of the disease begins with an initial relapsing-remitting course, followed by progression at a variable rate that also may include occasional relapses and minor remissions. About 10% of MS worsens right from the start and is called:
- *Primary progressive.* The disease shows progression of disability from its onset, without plateaus or remissions or with occasional plateaus and temporary minor improvements. It more commonly is seen in people who develop the disease after 40 years of age. About 5% of MS starts with a progressive course and becomes more fluctuating. It is called:
- *Progressive-relapsing.* This pattern of MS shows progression from the onset but without clear acute relapses that may or may not have some recovery or remissions.

Two points should be emphasized. First, more than two thirds of all people who have MS are walking 20 years after diagnosis. The idea that MS is a progressive disease that inevitably leads to wheelchair use does not fit the most common scenario. Second, even those who have "progressive" disease usually stop progressing at some point. Many MS experts fear the potential progression of the disease so much they often overlook the fact that the disease is not always progressive. About 20% of MS appears to remain fairly stable. Just why this occurs is not known despite lengthy inquiries into diet, lifestyle, and other factors. That means that about 80% of MS will need more aggressive management.

The MS Society has continued to estimate about 300,000 to 350,000 cases with MS in the United States. This estimate is undoubtedly low, because this number has not been altered in 15 to 20 years, despite thte fact that new cases develop, and the death rate is not high—most people with MS will live to a normal age.

### Possible Causes of Multiple Sclerosis

Although a specific cause of MS has not yet been determined, several theories are plausible. MS generally is considered to be an autoimmune disease in which—for unknown reasons—the body's own immune system begins to attack normal body tissue. In the case of MS, the cells that make myelin, the myelin itself, and/or the axons are attacked.

### The Immune System

The nervous system is not the only system in the body that "talks" to other systems and to itself. Many parts of the body communicate with each other. This is especially true for the *immune system*, which is responsible for destroying foreign substances such as viruses and bacteria. Most people know about the immune system because they are familiar with the acquired immunodeficiency syndrome (AIDS), in which a virus attacks the immune system and makes it inactive. In MS the picture is different in that the immune system appears to be *too* active. It sends out "messengers" in the form of specific types of white blood cells that attack myelin as if it were a foreign substance.

The immune system is made up of many different cells that function to protect the body. These cells are made and stored in different parts of the body and make a large number of *immunomodulating* substances. The combinations of cells and substances that may be formed are essentially unlimited, which adds to the complexity of the immune system. Some cells are made in the bone marrow and are called *B cells*. Some cells are made in other parts of the body such as the thymus gland (over the heart) and in the tonsils (in the throat); these *T cells* also communicate with and regulate each other. Some cells that suppress reactions are called *T suppressor cells*; some cells that help reactions along are called *T helper cells*. Cells in the immune system that target foreign bodies for destruction are called *macrophages*. Each of these cells has an important individual function; together they create the *immune* 

9

*reaction*. These reactions usually are beneficial and often life-saving, but sometimes the system malfunctions and produces an autoimmune problem. This is what appears to happen in MS, which therefore often is referred to as an autoimmune disease. Other autoimmune diseases include systemic lupus erythematosus (SLE) and rheumatoid arthritis. All autoimmune disease involve the faulty regulation of the immune system, which appears to be overaggressive and may need to be suppressed.

Many things influence the immune system, including exposure to foreign substances, stress, and life itself. A virus may turn the system off, whereas another challenge may turn it on.

Susceptibility to autoimmune diseases appears to be at least partly genetic, so that, although MS itself is not a hereditary disease, a hereditary factor may make an individual susceptible to its development. Approximately 10 to 20% of people with MS have MS in their extended families, a higher rate than would be expected by chance. MS is not a hereditary disease in the sense that most people consider heredity. Clearly, people do not inherit MS, but they may inherit the *possibility* of developing the disease. The likelihood of developing MS in the absence of its presence in close family members is 1:2000 (0.2 percent). If a parent has MS, the probability that a daughter will develop the disease is 4:100 (4 percent), whereas a son's chances are 2:100 (2 percent). If an identical twin has MS, the likelihood of the other having it is 30%! Again, If MS was solely a hereditary disease, this figure would be 100%, but it does show that genetics plays some role in the development of the disease. Although these numbers are small, they are larger than would be expected if there were no genetic connection. Thus, it appears that one does not inherit MS, but may have a substantial chance of inheriting an immune system that may become overactive if it is stimulated in a specific way. MS is termed a multifactorial disease, which means that more than one factor is involved and that the factors must interact in a highly specific way to result in the disease process.

A distinct possibility exists that viruses may stimulate the immune system and lead to the development of MS in susceptible

individuals. Although no virus has been consistently isolated in persons with MS, many investigators believe that a virus originally is responsible for turning on the immune system and making it behave in this abnormal fashion. Because of this, much research is devoted to looking for a viral inducer of MS. Studies of populations of people who appear to be at high risk for MS fuel the idea of a viral origin. For example, the incidence of MS increased dramatically during World War II in the Faroe Islands off the coast of Scotland. Other islands off the Scottish coast, the Shetlands and Orkneys, had previously had a high prevalence of MS. The difference in prevalence between the two island groups appears to have involved British soldiers who moved to the Faroes during the war. This type of spread of MS follows the pattern of a viral transmission. However, no virus has been found, and the incidence of MS appears to have decreased in both island groups at this time.

The fact that viruses may cause demyelination is demonstrated by the viral origin of the demyelinating disease *tropical spastic paraparesis*. The search for a viral cause of MS continues. Rubeola, rubella, herpes, and human T-cell lymphotrophic, type I (HTLV-I) viruses all have been considered and eliminated. The herpes 6 virus is being closely looked at. This virus causes a childhood disease that is very common but temporary. Also being closely studied is the common bacterium *Chlamydia*, which is common in humans, but which usually does not cause symptoms. If history shows a pattern, these organisms are likely to fall by the wayside, as the others have. It is highly likely that if a virus is involved, it has disappeared from the body by the time the immune system has begun its reaction against myelin. The search for a viral cause is further stimulated by the fact that environmental factors appear to be involved in the disease.

People who spend the first 15 years or so of life in areas at a distance from the equator have a much higher risk for developing the disease than do those who spend this time closer to the equator. After the first years, there is no correlation as to where a person lives, but Caucasians appear to be at higher risks than other races. Research strategies that involve the immune system vary because it is not clear exactly where in the immune process the abnormality occurs. Thus researchers point to many different areas of the immune system in an attempt to change what happens in the MS process.

Even if a cause of MS is not found, it may be possible to halt this disease by intervening somewhere in the immune cascade and halting its progression. This does not mean that a management strategy aimed at allowing a person with MS to do as much as possible given his or her present level of function cannot be developed. This is the principle that underlies symptom management, which has advanced with time, experience, and research. That is what this book is about—making it possible for people with MS to live creative, meaningful, and enjoyable lives.

Multiple sclerosis is unique in that few diseases with the potential to cause disability appear to involve only one system in the body. Except for demyelination, oligo loss, and secondary axonal (nerve) death within the brain and spinal cord, MS leaves the indi-

> People with MS usually are quite healthy and have an almost normal life span.

vidual relatively unscathed. Thus, people with MS usually are quite healthy and have an almost normal life span.

### CHOOSING YOUR PHYSICIAN

A good relationship with your doctor is among the more important associations for a person with MS. However, finding a physician with whom you relate well may be not only difficult but also stressful.

Some basic principles should be understood when making a decision about the right doctor for you. Despite the fact that insurance companies and other health care plan administrators act as if

one physician is the same as another, this simply is untrue. Family physicians are trained to take care of general problems, but MS is not considered a general medical problem. A person with MS does need a general physician, but clearly he or she also needs someone more specialized. Internists specialize in many complicated medical problems, but most of them probably have seen few cases of MS. Physiatrists are specialists in rehabilitation and are increasingly involved as MS doctors, especially for those who have significant disability. However, neurologists—physicians who specialize in diseases of the nervous system—usually manage MS.

Not all neurologists are the same. Although neurologists are trained to make detailed and difficult diagnoses of neurologic disorders, many of them are not particularly capable of, or interested in, managing a disease after it has been diagnosed. The person with MS needs to work with a physician who will care for him or her on a long-term basis. People with MS *deserve* specialized care, but choosing a professional caregiver is not always easy.

Several factors should be considered in making your decision. Although all physicians want to be helpful, some personalities simply do not mesh. Some patients want their doctor to tell them what to do, whereas others want more choices in the process. Neither is intrinsically good or bad, but if you are with the wrong type of physician, the personal chemistry might not allow for a pleasing experience. Try to be aware of the type of person you are and try to find a physician with whom you are compatible.

Remember that a patient who wants to entirely direct his or her own care is wasting money by paying a physician for advice. A physician who takes care of himself is said to have a fool both for a patient and for a doctor. Likewise, a patient should not try to direct specialized medical care. A healthy dialogue, with the patient ultimately in control, usually works best.

Another thing to remember is that good physicians are busy. All patients would like their physician to spend a lot of time with them, and that is a fair expectation. However, just how much time is enough may be difficult to determine. Before visiting your physician, write down the specific questions that you want answered. Get right down to your questions because they may raise other important questions from the physician. It helps to have a list of all your medications and their dosages, because your physician may not be aware of all the medications that you are taking.

Do not expect your doctor to fix everything that is wrong. It is hoped that he or she will be able to help with problems, but you should not have too high an expectation.

There may be no physician in your area who is understanding, capable, and competent to meet your needs. If not, go outside your area to find a physician. Talk with other people who have MS and try to discover where your needs may be met. Although it is vitally important to have a relationship with a specialist, it may not be necessary to see that specialist more than once or twice a year. It is important to see the doctor at least once a year to develop a strong and understanding relationship. It also is important to be able to contact his or her office with questions that arise between appointments. Because you know each other, a phone call often can save a visit.

Remember that medications prescribed by your physician may or may not be helpful. Do not categorically condemn all medications as unnatural and useless. Before the advent of modern medicine, the life span of many people with MS was not much beyond 40 years of age. Medications should not be taken without a purpose, but they should not be feared if they are used properly.

MS is a highly variable disease, and no single management program fits everyone. It is difficult for people who are distant from problems to grasp the total picture. Insurance review organizations, businesses, and others who would like to manage care have an especially difficult time with MS. They often like to force patients to see physicians whom they know well but whom the patient may not know at all. In the case of a chronic disease such as MS, the physician–patient relationship should not be taken lightly. It may be important to attempt to get your managed care company to recognize your special problems and to make allowances for them. The squeaky wheel gets the oil, so keep squeaking until you get what you need.

### A WORD ABOUT COMPLEMENTARY MEDICINE

There is a lot of talk about "alternative" or "complementary" medicine as many people seek answers to the unanswerable. MS is a disease in which most people actually do well even if they do not expect to. This means that no matter what treatment one takes, a good result is likely. However, it may not be the result of the treatment, but rather of the natural history of the disease.

All of us have heard of miracle cures attributed to bee stings, lightning, cobra venom, hyperimmune cow's milk, magnets, hyperbaric oxygen, vitamins, food supplements, special shoes, calcium treatments, and other similar strategies. None of these treatments have undergone research studies that support their use. All rely solely on testimonials. Gullibility does not come with MS but it often comes with being human.

Several questions should be asked of a proposed treatment:

- Has a properly performed research study demonstrated positive results?
- Has that study been repeated in some fashion?
- Is one person or a small company making a large profit from the treatment?
- Is the treatment rational or is it "pie in the sky?"

Even if a treatment appears ridiculous, some people will swear by it. That is human nature and will persist despite significant advances in modern medical science. There always will be people who are willing to forsake science for quackery.

Having said that, there are many treatments that are not "medical" but that may have some effect on the management of some symptoms of MS. Many of these are mentioned in later chapters and include biofeedback, meditation, relaxation, acupuncture for pain, chiropractic for back pain, and others. The appropriate use of these modalities may be helpful and should not be discouraged. A good basic guide is *Alternative Medicine and Multiple Sclerosis* by Dr. Allen Bowling.

# Chapter 2

# MANAGING THE DISEASE PROCESS

The management of MS has changed dramatically in the past decade as newer agents that can actually change the course of the disease have been introduced. We recognize that we cannot predict the future with anyone, let alone those with MS, but it appears that about 20% of those with clear MS will do well with their disease no matter what we do. This figure is often debated and much data is secured on both sides of the debate, but 20% is a reasonable figure. The problem is determining who is going to be in that 20%, versus the 80% who will not do as well. Studies and now experience indicate that the medications available for altering the disease course actually make a difference. Five treatments for MS have been approved in the past decade. Interferon beta 1b (Betaseron<sup>®</sup>) was the first, followed rapidly by interferon beta 1a (Avonex<sup>®</sup>, Rebif<sup>®</sup>), glatiramer acetate (Copaxone<sup>®</sup>), and mitoxanthrone (Novantrone<sup>®</sup>).

*Interferons* are proteins that the body makes in response to a foreign substance. If one gets a cold or sore throat, the body makes interferon, which then modulates the immune system. Interferons are grouped into three broad categories: alpha, beta, and gamma. Gamma interferon appears to stimulate the immune system and

makes MS worse. Beta interferon appears to settle it, and it decreases es the attack rate, decreases the severity of attacks, increases the time between attacks, and decreases the damage to the nervous system as monitored on magnetic resonance imaging (MRI) scanning.

Glatiramer acetate is not an interferon. It is a polypeptide—a combination of four amino acids whose structure in some way fools the immune system. It also decreases the attacks and decreases MRI damage over time.

Mitoxanthrone is an immunosupressant. It is used as a chemotherapy agent (similar to that used to treat cancer) and affects all aspects of the immune system. It appears to slow progressive MS and decreases relapses.

All of these medications are expensive and all have side-effects that will be discussed, thus care must be taken in making decisions regarding their use. There is some controversy as to when in the course of the disease these should be introduced. Most MS experts believe that early intervention with an interferon or with glatiramer acetate is appropriate. The question is *how* early is early. Some feel that treatment should be initiated when the diagnosis of MS is made or even suspected. They point out that a study done on those with the suspicion of MS resulted in a delay to the actual diagnosis. Unfortunately we do not know exactly what that means for most people with the disease, because the timing of the diagnosis may or may not have anything to do with future disability. Understanding that about 20% of people with MS may not need treatment because they will do well without it also must play a role in the decision making process.

Much has been made of the fact that we can see abnormalities on the MRI and that the MRI changes in the course of MS. Some of what has been publicized is exaggerated. Clearly the MRI is an excellent tool to be used in making an early diagnosis of MS and helping to confirm the diagnosis. However little hard data allows us to prognosticate from the MRI. It is fair to assume that if there are many, many abnormalities on the initial scan, problems with function will be forthcoming. Beyond that, much is speculation. Clearly the scan changes over time, sometimes actually improving. What that means down the road is not known. Some feel that routine checking of the MRI will give information about the future course of the disease, but that is not based on reality. Some feel that the brain of those with MS will shrink if treatment is not instituted immediately. Of course, all our brains shrink with age, but it is really impossible to speculate at the front end of the diagnosis how much shrinkage will or will not occur. Thus, many unanswered questions remain that deserve an answer and undoubtedly will be answered in the next decade. In the meantime, there will be some disagreement as to when and which agent should be given and to whom. Clearly, this question must be answered by the physician who knows you and is monitoring your MS.

Treatment agents differ, even the interferons. High dose interferon (Betaseron<sup>®</sup>, Rebif<sup>®</sup>) appears to be stronger than low dose (Avonex<sup>®</sup>), which is a function of dose rather than the structure of the medication, because Avonex<sup>®</sup> and Rebif<sup>®</sup> are structurally identical. No study shows that everyone with MS needs a high dose. Clearly, many people with MS can be successfully treated with a low dose, but many will need a higher dose with time. This is no different from other diseases treated with multiple medications (high blood pressure, infections, etc). It appears that glatiramer acetate (Copaxone<sup>®</sup>) is as effective as the interferons and, in my opinion, falls between the high dose and low dose in terms of "potency." It has the fewest side-effects and is the best tolerated.

Just which treatment is given and when is a medical decision that should be made by your physician with input about to your lifestyle and desires. All symptoms do not appear to have the same prognostic meaning. Numbness, tingling, dizziness, blurred vision, and pain do not seem to indicate a bad prognosis, while weakness, clumsiness, cognitive disturbance, lots of abnormality on initial MRI, and older onset (age 55 and up) may lead to a more difficult time quickly. These factors also must play a role in the choice of medications, along with the fact that the interferons have more side-effects than glatiramer acetate and that depression can be made worse by interferon. Avonex<sup>®</sup> clearly is the most convenient because it can be given as a single intramuscular (long needle) shot. The others are subcutaneous (short needle) and require more frequent doses, thus they are less convenient.

The National Multiple Sclerosis Society (NMSS) has developed a practice guideline stating in summary that those with MS should be treated as soon as a diagnosis is made and a relapsing course (ongoing activity to the disease) is established. The Society also states that changes in medication use to fit the situation should be allowed by those paying for the treatments. None of these decisions should be casual and all need the attention of the person with MS and the medical professional involved.

For progressive MS, immune suppression appears to be a good choice. Intense modulation of the immune system with high dose beta interferon may slow the disease in the progressive phase. Immune suppression with chemotherapy agents such as mitoxanthrone (Novantrone<sup>®</sup>) also appears to slow progressive MS. Novantrone<sup>®</sup> is fairly easy to administer, because it is given every three months as an intravenous injection. Occasionally some nausea, some hair loss, and some blue discoloration to the urine and the whites of the eyes occurs. The major drawback appears to be that the medication accumulates in the body and—if it is necessary to treat for over 2.5 years—the risk of the medication permanently damaging the heart increases. Thus care must be taken. Nonetheless, if the disease is progressing to an uncomfortable degree, there is comfort in the existence of agents that can apply the brakes. As time goes by we are learning better how to apply these agents.

There are other ways to alter the immune system, and each has a scientific basis for its ability to alter the course of MS. One can remove the immune antibodies mechanically by a technique called *plasma exchange*. Unfortunately they reform and need to be removed at intervals. This is a very expensive management tool but can be utilized for refractory attacks that steroids fail to manage. One can remove the cells that attack the immune system with a process called *lymphocytapheresis*. Again, this mechanical technique has some scientific validity, but it is expensive and cumbersome and must be continually applied. Bone marrow or stem cell transplantation makes sense if one believes that the faulty immune system can be replaced and fixed. Unfortunately more studies need completion to allow appropriate analysis of this dangerous, aggressive technique; death is a potential side effect of extensive immune suppression.

### The Management of Side Effects

The use of immune modulating medication has led to a whole new topic of discussion, that of side-effect management. It should be emphasized that *none* of the immune modulators (as distinguished from immune suppressants) usually has severe side-effects. The incidence of side-effects forms a bell-shaped curve, showing some who have no side-effects while others have many. Most have some side-effects that clear over time.

Glatiramer acetate has the fewest side-effects. Its daily subcutaneous injection usually causes some redness and itching at the injection site when treatment is initiated. That usually lasts about 20 minutes and often stops after a few weeks. Occasionally increased stiffness occurs. Hives sometimes indicate an allergic reaction. One unique side-effect does occasionally occur; it is very infrequent and usually does not recur, but some people may experience a sudden warm or hot sensation throughout the body along with chest tightness, shortness of breath, and a feeling of depression. This lasts about twenty minutes and will abate. If an aggressive approach with emergency medicine is applied, increased problems occur; thus, it is recommended that if this side-effect is present, rest for twenty minutes and do not panic.

The interferons are known for their flu-like symptoms. Fever, nausea, and muscle aches are common when treatment is initiated. These are clearly dose related. At full dose Avonex<sup>®</sup> has fewer side-effects because it is given at a lower total dose each week. Knowing this, it is recommended that high dose interferon (Betaseron<sup>®</sup>, Rebif<sup>®</sup>) be initiated at a quarter of the final dose each time it is taken

until the side-effects abate. The dose then is increased to a half dose until stable, then three-quarters, then full. This is called *dose escalation*. Medication that will lower temperature is helpful (acetoaminophen, ibuprofen, etc.) given four hours before, at the time of injection, and four hours or as necessary after.

Injector guns decrease the side-effects to some degree. That is true for all the subcutaneous treatments. Small needle injections of interferon (Betaseron<sup>®</sup>, Rebif<sup>®</sup>) lead to more skin discoloration than the longer needle injection (Avonex<sup>®</sup>). These skin reactions are diminished by the injector guns. Common sense tells us that intramuscular injections are best performed by a helper. That is not true for everyone but it holds for most people who have any problems with coordination or weakness. If pain occurs with the injection, icing before and after may help. Anesthetic creams can be used to numb the area prior to injection if needed. Skin reactions may respond to cortisone cream. If one develops actual skin breakdown, a decision as to whether the treatment can be tolerated must be made. With interferon therapy, blood and liver tests should be monitored for a period of time, because sometimes significant changes can occur. Often we accept considerable abnormality to these but they need watching.

The body reacts to foreign medication by producing *antibodies*. Some of these may affect the potency of the treatment. Research continues as to the true meaning of these and how they can be altered. In the meantime, there appears to be little relevance to measuring them because they correlate poorly with effect.

Mitoxanthrone (Novantrone<sup>®</sup>) comes with the above mentioned heart concerns but it can also suppress the function of the blood and liver. Care must be taken that the i's are dotted and the t's crossed; that may be best done by a physician who is used to administering such chemotherapy agents (an oncologist or cancer doctor).

### The Treatment of Acute Attacks

The treatment of acute attacks has changed little in the past decade. Cortisone medication including methylprednisolone, dexamethasone, prednisone, and others continue to be commonly used to shorten the attack. These potent anti-inflammatory drugs diminish the swelling within the brain and spinal cord that is seen as cells of the immune system invade and attack the nervous system. They do not appear to alter the long term course of the disease. They are clearly associated with osteoporosis, cataracts, psychological changes, skin acne, weight gain, and salt and water imbalance. Thus their effect on acute attacks must be weighed against potential problems from the treatment.

General drugs that affect the immune system include azathioprine (Imuran<sup>®</sup>) and methotrexate. These usually are given by mouth for the more chronic forms of MS. These also are major medications and must be administered with expertise. Studies do not show them to be as effective for relapsing MS as the newer medications, but for some people with either relapsing or progressive MS they may help to control progression of the disease.

# 9 a r t II MANAGING MS SYMPTOMS

The new immune system medications provide true disease management for the first time. They clearly are not for everyone with MS and must be selected and used with expert advice. The backbone to MS management has been and continues to be the management of symptoms. Everyone with MS should be aware of the many ways that the symptoms of MS can be managed, with the goal of improved quality of life.

Symptoms in MS may be divided into those that are caused directly by demyelination within the brain and spinal cord and those that are not. Symptoms that are caused by the disease itself are called *primary* symptoms. If you lose myelin in the part of the brain or spinal cord that influences strength, you will develop weakness; if you lose myelin in the part that controls coordination, you will become uncoordinated; and if you lose myelin in the part that controls sensation, you will develop numbness, pain, burning, or itching. It is quite simple to understand that the number of combinations is endless. That is why no two people with MS are exactly alike.

> Symptoms in MS may be divided into those that are caused directly by demyelination within the brain and spinal cord and those that are not.

People who have primary symptoms sometimes also suffer from problems that are only indirectly caused by the disease; these are called *secondary* symptoms. For example, some people who are weak and stiff develop decreased movement at the joints, which are called contractures, and immobility can lead to osteoporosis or skin breakdown.

Chronic disease may lead to changes in how one looks at life and tackles life's stresses. It may lead to depression, frustration, or vocational and marital problems. These are called *tertiary* symptoms.

Thus, to really tackle MS, the disease process should be modified whenever it is possible to do so; the symptoms of the disease should be managed to allow better function; and the person with the disease should be helped to improve his or her quality of life.
# Chapter 3

# FATIGUE

To those who do not have MS, it may come as a surprise that fatigue is the most disabling symptom of MS. For those who have MS, this is not at all surprising. Part of the reason that fatigue is so common and potentially disabling relates to the fact that many different kinds of fatigue are experienced by people with MS, and it is possible to have none or all of the forms at the same time.

Obviously, MS does not protect you from the normal fatigue that anyone else may experience. However, a person with MS sometimes may have a "short-circuiting" type of fatigue. This occurs when a limb has weakness due to demyelination. If it is fatigued, the limb exhibits increased weakness due to demyelination. The limb will recover when the arm or leg is rested, but it may be bothersome when activities require its ongoing use. Repeatedly asking the demyelinated nerve to perform when it is repeatedly short-circuiting causes fatigue. The judicious use of aerobic exercise (see Chapter 20) may help build endurance, if not strength, and thus may decease this form of fatigue. However overexercising with weights increases both fatigue and weakness, so a careful balance must be sought.

Management strategies include the appropriate use of exercise and rest, with the understanding that "no pain, no gain" is simply wrong and that rest should come before short-circuiting fatigue becomes significant.

If a person does not remain active, muscles atrophy and *deconditioning* occurs. This is another source of fatigue. Maintaining mobility is essential! The appropriate management strategy for this type of fatigue is exercise and maintaining of mobility. Depression (see also Chapter 22) may be associated with MS and may cause significant fatigue. This may result from not eating or sleeping well, or it may be associated with a general feeling of depression. It is essential to recognize that this fatigue is related to depression. It should be managed by aggressively treating the depression with medication and counseling.

The most common fatigue seen in MS is called *lassitude*. It is sometimes referred to as "MS fatigue." Lassitude is characterized by an overwhelming sleepiness that may come on abruptly and severely at any time of day. This form of fatigue likely is biochemical in origin, and medications that modify brain chemistry may be helpful. Amantidine (Symmetrel®) is an example of a medication that affects the nervous system and also has antiviral effects. The antidepressants, including fluoxetine (Prozac<sup>®</sup>), paroxetine (Paxil<sup>®</sup>), and sertraline (Zoloft<sup>®</sup>), may be useful for this type of fatigue, even in those who are not depressed. These medications may not be interchangeable, with one working better for one person and a different one for another. Lassitude is a bothersome form of fatigue because a person may look well and yet not be able to function. A new, novel medication, modafinil (Provigil®) has been shown to decrease MS fatigue and has become a commonly used treatment for this problem. Its mode of action is not clear but it does work by altering the brain's neurochemistry. This is becoming the most popular anti-fatigue drug In MS. It has a potential side effect of agitation, which should be reported to your physician immediately.

Stimulant medications sometimes may be necessary. These include pemoline (Cylert<sup>®</sup>), methylphenidate (Ritalin<sup>®</sup>), and occasionally dextroamphetamine (Dexedrine<sup>®</sup>). These medications

26

should be used with caution because they may be habit-forming and may lead to agitation. A well-timed nap sometimes is most helpful in managing lassitude. The management strategy for this form of fatigue includes rest and the use of antidepressant and stimulant medications.

Even though fatigue is common and potentially disabling, it is clear that people who have MS are not fragile. Although rest may be helpful, the idea that fatigue leads to increased demyelination has not been proven. The idea that MS progression occurs if a person does not rest a great deal is also without merit. You need to listen to your body, but there always are times when a little extra push is necessary, and this is not a cause for fear.

In summary, the approach to fatigue in MS involves identifying the type of fatigue and treating it specifically. Removing any contributing causes is essential. These include infections, stress, and overutilization of some medications. While medications can help, rehabilitative techniques can also be valuable.

Occupational therapists may be helpful in teaching the concept of energy conservation to those who have moderate or severe fatigue of differing varieties. Efficiency in performing activities of daily living, which include dressing, grooming, toileting, eating, and so forth, may increase the energy available for other activities.

## PRINCIPLES OF ENERGY CONSERVATION

- Balance activity with rest and learn to allow time to rest when planning a day's activities. *Rest means doing nothing at all.* There is a fine line between pushing to fatigue and stopping before it sets in. Rest improves overall endurance and leaves strength for enjoyable activities.
- Plan ahead. Make a daily or weekly schedule of activities to be done and spread heavy and light tasks throughout the day.
- Pace activity. Rest before you become exhausted. Taking time out for five- or ten-minute rest periods during an activ-

ity may be difficult at first, but it may significantly increase overall functional endurance.

- Learn "activity tolerance." See if a given activity can be broken down into a series of smaller tasks or if others can assist in its performance.
- Set priorities. Focus on items that are priorities or that must be done, and learn to let go of any guilt that may be associated with not finishing tasks as the result of fatigue.

# MINIMIZING FATIGUE BY CONSERVING ENERGY

The following are some specific suggestions for common tasks and groups of tasks that most of us need to do regularly. They take advantage of the principles described previously and are designed to conserve energy expenditure.

# Kitchen and Cooking Arrangements

- Store items that are used most often on shelves or in areas where they are within easy reach, to minimize the need to stretch and bend.
- Keep pots and pans near the stove, dishes and glasses near the sink or eating area.
- Keep heavy appliances such as toasters and blenders in a permanent place on countertops.
- Have various working levels in the kitchen area to accommodate different tasks, and evaluate working heights to maintain good posture and prevent fatigue. Sit whenever possible while preparing meals or washing dishes, and use a large stool with casters that roll to eliminate at least some walking. When standing for a prolonged period, ease tension in your back by keeping one foot on a step stool or an opened lower drawer.
- Use wheeled utility carts or trays to transport numerous and/or heavy items.
- Hang utensils on pegboards to provide easier accessibility.

- Have vertical partitions placed inside storage spaces to permit upright stacking of pots and pans, lids, and baking equipment.
- If storage cabinets are deep and hard to reach, use lazy Susans or sliding drawers to bring supplies and utensils within easy reach.
- Use cookware designed for oven-to-table use to eliminate the need for extra serving pieces. Use paper towels, plastic wrap, and aluminum foil to minimize cleanup.

# Meal Preparation

- Have good lighting and ventilation in the cooking area.
- Gather items needed to prepare a meal, and then sit while doing the actual food preparation.
- Select foods that require minimal preparation such as dehydrated, frozen, canned, or packaged mixes.
- Use a cutting board with nails to hold items that are being cut.
- Prepare double recipes, and freeze half for later use.
- Use electrical appliances rather than manual ones whenever possible, including food processors, mixers, blenders, and can openers.
- Use a microwave oven or crockpot to cut down on cooking and cleanup time.
- Bake rather than fry whenever possible.
- Bake cookies as sheets of squares instead of using shaped cutters.
- Slide heavy items along the countertop rather than lifting them.
- Use a damp dishcloth or a sticky substance such as Dycem<sup>™</sup> to keep a pot or bowl in place while stirring.
- Line baking pans with foil to minimize cleanup, and soak pots and pans to eliminate scrubbing.

# Cleaning

• Spread tasks out over a period of time; do one main job each day rather than an entire week's cleaning at one time.

- Alternate heavy cleaning tasks with light ones, and either get help or break major heavy duty cleaning tasks into several steps.
- Use a pail or basket to transport cleaning supplies from room to room to save on the number of trips back and forth.
- Use adaptive equipment, such as extended handles for dusters or brushes, to avoid bending.

# Laundry

- Wash one or two loads as they accumulate rather than doing multiple loads less often.
- Collect clothes in one place, and transfer them to the laundry area in a wheeled cart if possible.
- If the laundry area is in a basement, plan to remain there until the laundry is done, and have a place to relax while you are waiting.
- If a clothesline is used, have it hung at shoulder height, and place the laundry basket on a chair while hanging laundry.
- Hang clothes promptly after they are dry to minimize ironing.
- Sit down while ironing.
- Buy clothes that require minimal maintenance.

# Shopping for Groceries

- Plan menus before going to the store, and take a shopping list with you.
- Use the same grocery store on a regular basis, and learn where various items are located for easier shopping; using a photocopied master grocery list organized to match the store layout is a simple way to minimize time and energy.
- Use home delivery whenever possible.

# Bedroom Maintenance

• Put beds on rollers if they must be moved or keep them away from walls.

- Make one side of a bed completely, then finish the other side, to minimize the amount of walking involved.
- Organize closets for easy access by making top shelves and clothing rods low enough to reach without straining.
- Use lightweight storage boxes, hanging zippered clothes bags, and plastic boxes for items that are needed daily.

### Yardwork

- Alternate tasks and incorporate short rest periods to avoid fatigue.
- Keep your garden small and easy to manage.
- Use adaptive equipment, such as handles with extensions, to minimize bending.

# Infant and Child Care

- Always use your leg and arm muscles rather than your back muscles when lifting an infant or child.
- Wash, change, and dress an infant at counter height.
- Kneel while washing a child in a bathtub.
- Use disposable diapers.
- Adapt the fasteners on a child's clothing for easier dressing.
- Have a child stand on a footstool while helping him or her dress or wash.

# Sitting and Desk Work

- Arrange your desk and chair heights to facilitate maintaining proper posture, which reduces slumping of the shoulders and neck flexion.
- Use a chair that has good back support.
- Arrange your office so that your file cabinets, computer terminal, and other equipment are easily accessible.
- Use small lazy Susans on the desktop for pens, paper clips, tape, stapler, and so on.
- Use a phone device that allows the receiver to rest on your shoulder and frees your hands during extended conversations.

# Dressing

- Lay out clothing for the next day before retiring.
- Sit while dressing whenever possible.
- When dressing, dress the weaker side first; when undressing, undress the strong side first.
- Use a long-handled shoe horn.

# Bathing

- Organize shampoo, soaps, and toiletries, and keep them together by the bathtub or shower.
- Use grab bars to assist in safely getting in and out of the bathtub.
- Use a tub bench or stool while showering or bathing.
- Always avoid hot water while bathing because it increases fatigue.

# Chapter 4

# **S**PASTICITY

Spasticity means *stiffness*. It often occurs when demyelination occurs in the nerves that regulate muscle tone. Because many of the nerves in the brain and spinal cord regulate movement and any of them may be affected by demyelination, spasticity is a common problem in MS. The stiffness often is minimal and not bothersome. In fact, a person sometimes needs the stiffness provided by spasticity to stand or pivot. At other times stiffness may become painful and may interfere with performing activities of daily living.

Spasticity tends to occur most frequently in a specific group of muscles that are responsible for maintaining upright posture. These muscles are called *antigravity* or *postural* muscles. They include the muscles of the calf (gastrocnemius), thigh (quadriceps), buttock (gluteus maximus), groin (adductor), and occasionally the back (erector spinae).

When spasticity is present, the increased stiffness in the muscles means that a great deal of energy is required to perform daily activities. Reducing spasticity produces greater freedom of movement and strength, and frequently also lessens fatigue and increases coordination. The major ways in which spasticity is reduced include stretching exercises, physical therapy, and the use of medications. If spasticity does not respond to these measures and causes discomfort, a surgical procedure may be necessary.

> Reducing spasticity produces greater freedom of movement and strength, and frequently also lessens fatigue and increases coordination.

The first management strategy is to alleviate associated problems that magnify spasticity. These include infection, pain, skin breakdown, and any similar process that may stimulate spasticity. It is interesting that pain or discomfort anywhere in the body will magnify spasticity. The following table summarizes approaches to managing spasticity.

## STRETCHING

The second management strategy is to develop a specific exercise program for stiffness. An independent stretching program based on

#### The Management of Spasticity

- Treat problems that increase spasticity—infection, pain, skin breakdown
- Develop a thorough stretching program that includes both active and passive stretching
- Use mechanical aids (orthoses) as needed
- Medications
- Surgical management used for severe spasticity that does not respond to medication

some of the principles used in physical therapy may be used at home. Appendix B describes a basic stretching program.

A thorough stretching program includes a series of exercises that are performed in certain sitting or lying positions that allow gravity to aid in stretching specific muscles. While one is in the sitting position, a towel or long belt may be used to pull on the forefoot and ankle to stretch the calf, or to stretch the thigh muscles when one is lying on the stomach. Certain muscles may be relaxed more effectively while one is lying on the stomach or side or while lying on all fours over a beach ball, rocking rhythmically forward and backward.

The simplest and often 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. After each muscle reaches its stretched position, it is held there for approximately a minute to allow it to slowly relax and release the undesired tension. This stretching program begins at the ankle to stretch the calf muscle, then proceeds upward to the muscles in the back of the thigh, the buttocks, the groin, and, after turning from the back to the stomach, 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 is essential when doing the stretches.

Exercising in a pool also may be extremely beneficial because the buoyancy of the water allows movements to be performed with less energy expenditure and more efficient use of many muscles. We recommend using the pool for both stretching and range of movement exercises. The pool temperature should be about 85 degrees; this may feel cold to some people, but warmer temperatures should be avoided because they produce fatigue. Colder temperatures can actually cause spasticity, thus the temperature of the pool is quite important.

Many people with MS have a limited range of movement 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 performed with a minimum of effort.

> The key to managing spasticity is to expand the number and kind of movements that can be performed.

Spasticity also may 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 sometimes are made for certain individuals to counteract spasticity and prevent what are termed *contractures*, in which the range of movement possible for a given joint becomes restricted as the result of spasticity. For example, a "toe spreader" or "finger spreader" is used to relax tightness in the feet and hands and to aid in mobility. Braces for the wrist, foot, and hand are used to maintain a natural position and to prevent limitations on movement and the development of deformities. These devices are called *orthoses*. An orthosis for the foot is an ankle-foot orthosis, or AFO. AFOs are made to place the foot at many different angles to the ankle. A good orthotist can make a brace to take stress off the knee. Hinges may increase flexibility. All orthoses should be customized to allow for maximal benefit.

# MEDICATIONS

Spasticity often is managed most effectively by medications (see table). Baclofen acts on the nerves that control the spastic muscles

at their site of origin in the spinal cord. It is the most common antispasticity medication used in MS, and most people 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 it interferes with the proper degree of stiffness needed for balance and erect posture. The correct dose usually is determined by starting at a low level and slowly increasing the dose until a maximal beneficial effect is obtained. The most common mistake when taking baclofen is to give up on it too soon, so that the dose never reaches the level necessary to attain proper relaxation. That dose may be as low as one half of a pill (5 mg) per day, but some people may need to take as much as 40 mg four times a day. Baclofen is only available as a generic and may be the least expensive medical treatment. Thus it is often the initial drug used.

Medication	Notes
Baclofen	May produce weakness at higher dose
Tizanidine (Zanaflex <sup>®</sup> )	Often combined with baclofen; may produce drowsiness
Sodium dantrolene (Dantrium <sup>®</sup> )	May produce weakness
Diazepam (Valium <sup>®</sup> )	Highly sedating; most often used at night; may become addictive
Clonazepam (Klonopin <sup>®</sup> )	Sedating; most often used at night
Cyproheptadine HCl	Sedating; used primarily as an
(Periactin <sup>®</sup> )	"add on" medication
Cyclobenzaprine HCl	Used for back spasms; most
(Flexeril <sup>®</sup> )	often combined with other medications
	(continued on wort word)

#### Medications for the Management of Spasticity

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Medication	Notes	
Gabapentin (Neurontin <sup>®</sup> )	May ease spasms that are diffi- cult to manage	
L-dopa (Sinemet®)	Especially useful for nighttime spasms	
Selegiline (Eldepryl <sup>®</sup> )	Especially useful for nighttime spasms	
Carbamazepine (Tegretol®)	Used for flexor spasms of the arm or leg	
Cortisone	Effective for paroxysmal spasms; should only be used on short- term basis	

#### Medications for the Management of Spasticity (continued)

Tizanidine (Zanaflex<sup>®</sup>), a newer antispasticity medication, acts on a different area of the spinal cord than baclofen. It appears to be effective in decreasing stiffness and muscle spasm, with less effect on strength than many other drugs. It must be used carefully and slowly because sleepiness inevitably results if the dose is increased too rapidly. The starting dose is 2 to 4 mg up to a maximum of 36 mg per day. It is quite effective and may be combined with baclofen in problem situations. It is especially useful for nighttime stiffness and spasms. It is not uncommon for the night to be the worst time for stiffness and spasms. This appears to have something to do with the lack of outside stimulation to the nervous system, making it more sensitive to spasm.

Another medication that sometimes is used for spasticity is sodium dantrolene (Dantrium<sup>®</sup>), which acts directly on muscles. It is a very potent medication that needs to be used carefully. It may be helpful, but it also may induce weakness, even at low doses.

Spasticity also may be reduced by diazepam (Valium<sup>®</sup>), which is most often used for the relief of spasms that occur at night. Its calming effect also helps to induce sleep, but its strong sedative effect limits its use during the daytime. Diazepam must be prescribed with caution because it may become addictive if it is used too frequently. Clonazepam (Klonopin®) is closely related to diazepam. Its main use has been to treat certain types of epilepsy. It produces significant relaxation, and thus may be used as an antispasticity medication. Like diazepam, it sedates and is best used at bedtime. When using diazepam or clonazepam, both the doctor and the person with MS must pay attention to the potential for chemical dependency. When properly used at appropriate doses, this is not a major problem. However, if the dose must be continually increased and the person is using the medication not for spasticity but as a crutch to escape the realities of the world, it should no longer be used.

Cyproheptadine (Periactin<sup>®</sup>) is an antihistamine that has antispasticity properties and may be a good add-on medication at certain times. Its sedating effect limits its use, but doses of 4 mg taken when needed may be helpful.

A drug that is commonly used for spasms in the muscles of the back is cyclobenzaprine HCl (Flexeril<sup>®</sup>). It acts quite specifically on these spasms, but also may relieve limb spasms. It usually works best in combination with one of the other antispasticity medications.

Gabapentin (Neurontin<sup>®</sup>) is a newer medication that has been approved for use in seizures. This medication also has antispasticity properties, and when it is taken in doses of over 1 gm per day often eases problematic spasms.

L-dopa (Sinemet<sup>®</sup>) is a Parkinson's disease medication that also decreases spasms, especially the painful spasms that tend to occur at night and may become especially prominent and painful. Many of the drugs available to treat Parkinson's symptoms can have similar effects on spasms and in difficult situations may be useful.

Any of these medications may become less effective when they are taken for a prolonged period (this is referred to as the development of tolerance), and it may be necessary to stop taking them for a period of time, after which they may again become effective.

# PAROXYSMAL (TONIC) SPASMS

People with MS very occasionally develop paroxysmal or tonic spasms, in which an entire arm or leg may draw up or out in a stiff, clenched, or extended position. If such spasms involve both legs, they are termed extensor or flexor spasms. These spasms may be so strong that they literally propel a person out of his or her chair. Obviously, this is disconcerting, but it also is potentially dangerous. Carbamazepine (Tegretol®), another drug used for seizures, generally is used to control such spasms, although baclofen and Zanaflex® also may be effective. In the past few years a number of newer antiseizure medications have become available. These are quite effective in managing paroxysmal spasms. They include Trileptal® and Carbitral<sup>®</sup>. Cortisone may decrease spasticity in general and is quite effective for paroxysmal spasms when it is used on a short-term basis. Its long-term use is not advocated because of numerous associated risks. The management strategy with medication is to use what works at the proper dose. Overdosing may cause increased weakness, somnolence, and decreased function.

# SURGICAL MANAGEMENT

For those who have severe *intractable* spasticity, the kind that causes problems with all functions and is not responsive to exercise or medication, a spasticity-decreasing procedure may be necessary. Nerves that control specific muscles of the leg may be destroyed with *phenol*, a chemical that is injected into the muscle. This is called a *motor point block*. It is used only for the most severe spasms that do not respond to drug therapy. It may produce flaccidity in the muscles, a profound looseness that is the opposite of spasticity. This relaxation may be more comfortable, but it usually does not increase functional mobility. It becomes progressively more difficult to repeat this procedure because of technical problems.

A better, more modern technique, is the use of *botulinum toxin* (Botox<sup>®</sup>, Myobloc<sup>TM</sup>), made by bacteria. It is a paralytic agent that causes a temporary blockage of the nerve and muscle. It is easier to control than phenol, but it may require more repetitive injections into the muscle. It is practical for treating small muscle spasms, especially those about the eye or face, but severe large muscle spasms may require too high a dose to be safe. Severe spasms also may be managed by a surgical procedure that involves cutting nerves or tendons to decrease the contraction of specific muscles that are producing stiffness.

A better approach to the management of severe spasticity involves the use of a pump (Synchromed<sup>®</sup>) that delivers baclofen directly into the spinal canal. A tube is placed in the canal and then connected (beneath the skin) to a pump implanted in the abdominal region. The pump contains baclofen, which is delivered into the spinal canal at prescribed levels. The pump may be programmed by computer via radio waves so that the dose may be changed as needed. For some patients, this technique may provide relief for intractable spasticity. Because the baclofen is delivered directly into the spinal canal and the level in blood and tissues remains low, side effects also are very low and there almost always is a significant decrease in fatigue and malaise. This treatment is aggressive and expensive and should be reserved for those who have severe spasticity that cannot be adequately managed by oral medications.

## CONTRACTURES

A *contracture* is a freezing of a joint so that it cannot bend through its full range of motion. This occurs when a joint has not been kept mobile, usually as the result of spasticity. A joint that develops a contracture becomes useless and often is painful.

All of the approaches used to treat spasticity play a role in the management of contractures. The joint must be slowly mobilized, sometimes using heat or ice applied just before stretching to ease pain and allow for more efficient stretching. Special equipment such as a tilt board may be helpful. Baclofen (taken either orally or via the pump), tizanidine, clonazepam, diazepam, or dantrolene may be used to decrease muscle tone and permit faster relief from the contracture. Occasionally, cortisone is injected directly into the joint to decrease inflammation and increase mobility. Braces may be designed to slowly stretch the joint; by changing the angle of the brace over time, a frozen joint sometimes may become mobile. Serially casting the joint (as if it were broken) by slowly stretching it with the casts may be helpful. In extreme conditions surgery may be required to release the muscle tendons to allow the joint to move.

Joints usually freeze into a contracted position, but they occasionally become fixed in the extended or straight position. Although this usually is less of a problem in terms of overall function, it is not considered an acceptable outcome, and this type of frozen joint generally is treated in a similarly aggressive manner as a contracted joint.

# Chapter 5

# WEAKNESS

Striving for increased mobility means working with whatever strengths and weaknesses you have. Muscle weakness that results from loss of strength in a muscle or group of muscles may occur for many reasons and is common to many diseases. Weakness in muscle itself is seen in muscular dystrophy; in diabetic neuropathy the problem lies in the nerve that leads to the muscle; and in MS it is caused by a problem in the transmission of electrical impulses to the muscle from within the CNS. This difficulty is the result of demyelination of the involved nerves, usually in the spinal cord but occasionally in the brain.

It is vital that the source of the weakness be understood to properly manage it. For example, if weakness is due to a lazy, weak muscle, the muscle may be strengthened by lifting weights. This is called *progressive resistive exercise*. However, 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. It is somewhat akin to a light fixture that does not work because there is a problem with the fuse. Changing the bulb or flicking the switch will not fix the problem. In MS the problem is with the fuse, and attempting to correct the problem at the muscle or nerve level will only result in frustration.

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 become weaker. Such *disuse weakness or atrophy* may have happened to anyone who has had an arm or leg placed in a cast for any length of time; when the cast is removed, your muscles have shrunk. All muscles need exercise to remain functional. It is important to determine what exercises are appropriate for the situation. This likely will require the assistance of a trained physical therapist who has knowledge of both the neuromuscular system and the specific problems involved in MS. The problems experienced by the person with MS must not be treated as they would be if they were the result of a broken bone rather than a misfiring central nervous system.

It is impossible to separate the management of weakness from that of spasticity and fatigue. If muscles are less stiff, less energy is expended for movement. Frequently, therefore, drugs or other treatments that lessen spasticity also increase strength. However, their overuse or use at too high a dose may increase weakness. Similarly, lessening fatigue also may increase strength.

*Efficiency* is the key to increasing strength in people with MS. Energy should be conserved and used wisely. This means using your muscles for practical, enjoyable activities and planning the use of time accordingly. For example, difficult activities should be done before those that are easier to perform. The appropriate use of assistive devices also may be extremely helpful in increasing overall efficiency.

As noted, an intelligent approach to strengthening exercises is necessary. Strength also may be increased with the use of an aerobic exercise machine such as an exercycle or a rowing machine. However, the principle of not becoming fatigued and exercising those muscles that can be strengthened to compensate for the weaker muscles must be applied. In general, exercise is good, but the wrong exercises may be harmful.

# Chapter 6

# TREMOR AND BALANCE

Another symptom than impairs mobility is tremor, which refers to an oscillating movement of the extremities or occasionally the head. This symptom of MS often is associated with difficulty in balance and coordination. As is true of all symptoms of MS, tremor may come and go. It is one of the most frustrating symptoms to treat. There are many different kinds of tremors; some have wide oscillations (a gross tremor), while others are barely perceptible (a fine tremor); some occur at rest, others occur only with purposeful movement; some are fast, others are slow; some involve the limbs, while others affect the head, trunk, or speech; some are disabling, but others are merely a nuisance; and some are treatable, while some are not. As with all symptoms, proper diagnosis is essential before correct management decisions can be made.

## BALANCE

Balance is necessary to perform coordinated movements, whether one is standing, sitting, or lying down. It involves the function of many neurologic centers. The *cerebellum* is the main center for balance, but the eyes, ears, and nerves to the arms and legs also contribute to balance. An impairment in any of these areas may cause balance to worsen, and it may help to compensate for others that are

#### The Management of Tremor

- Exercises for balance and coordination
  - patterning
  - vestibular stimulation
  - Swiss ball
  - computerized balance stimulation
- Medications
- Mechanical approaches
  - immobilization
  - weighting
  - stabilization with braces

not working properly. For example, a person with a balance problem caused by poor sensation in the feet may use her eyes to see the ground and avoid falling; obviously, this is a problem in the dark.

No medication is available to improve balance, so it is necessary to rely on exercises. Although there are no specific exercises for tremor, there *are* exercises for balance and coordination. *Patterning* refers to a technique that is used by physical and occupational therapists to trace and repeat basic movement patterns. It is based on the theory that certain muscles may be trained to move in a coordinated fashion by repeatedly using the nervous circuit that is 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 pattern independently. The muscles gradually appear to develop increased endurance for these learned movements and manage to retain control when the patterns are applied to functional tasks.

*Vestibular stimulation* refers to increasing the amount of stimulation received by the balance centers in the brain stem, thus allowing the brain to function more normally. The techniques used challenge your sense of balance by rocking, swinging, or spinning, using such activities as sitting on a beach ball or swinging in a hammock. Along the same lines are exercises that are performed with a Swiss ball. This large ball may become part of a balance program designed to stimulate many different balance centers within the body.

If a person is able to stand, computerized balance stimulation with a machine dubbed a "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, and this may be used to teach the person how to achieve better control of balance.

A number of medications may aid in decreasing tremor. The most common tremor seen in MS, and the most difficult to treat, occurs as a result of demyelination in the cerebellum. This area of the brain is responsible for balance and has connections throughout the brain stem (the back of the brain) and the spinal cord. Demyelination in this area often results in a gross tremor that is relatively slow and occurs during purposeful movements of the arm or leg.

This type of tremor almost always is exacerbated at times of stress and anxiety. The reason for this is not known, but exacerbation by stress is true of most of the neurologic symptoms of MS. Therefore, one mode of managing the problem is treatment with drugs that have a calming or sedative effect. For example, Hydroxyzine (Atarax<sup>®</sup>, Vistaril<sup>®</sup>) is an antihistamine whose effect is to settle a minor tremor that has been magnified by stress. Clonazepam (Klonopin<sup>®</sup>) also may decrease a tremor via its sedative effect. The antitremor effect must be balanced against the generally unwanted effects of sedation by carefully monitoring the dose until the desired effect is achieved.

Propranolol (Inderal<sup>®</sup>), a *beta blocking* agent (so-called because it blocks specific nerves, termed *beta fibers*, within the nervous system) is helpful in controlling certain inherited tremors, tremors of aging, and some tremors seen in MS. It is started at a low dose and increased over time until an effect is obtained. The effect may not be great, but even a small decrease in tremor may allow for greater function. Some people develop low blood pressure when they are

Medication	Notes
Hydroxyzine	May settle a minor tremor that
(Atarax <sup>®</sup> , Vistaril <sup>®</sup> )	has been worsened by stress
Clonazepam (Klonopin®)	May decrease tremor through
	sedative effect
Propranolol (Inderal <sup>®</sup> )	May provide modest relief
Buspirone (Buspar <sup>®</sup> )	An antianxiety agent that has
	some antitremor effect
Ondansetron (Zofran®)	May significantly decrease
	tremor with few side effects; cost
	is prohibitive
Primidone (Mysoline®)	An antiepileptic drug that may
	help tremor in low doses; highly
	sedating
Acetazolamide (Diamox®)	A diuretic that may help some
	people; may alleviate tremors
	influenced by posture
	~ *

#### Medications for the Management of Tremor

receiving beta blockers, but this is surprisingly uncommon in the MS population being treated for tremor.

Buspirone (Buspar<sup>®</sup>) is primarily a nonsedating, non-habitforming antianxiety drug. For some reason it appears to have antitremor properties in MS, at a dose of 5 to 10 mg three to four times per day. It is well tolerated and may be helpful.

Ondansetron (Zofran<sup>®</sup>) may be effective for tremor, but it is very expensive. Its primary use is for the nausea that is associated with cancer chemotherapy. In a dose of 4 to 8 mg three to four times per day, it may significantly decrease tremor with few side effects.

Some studies have shown that the antiepileptic drug primidone (Mysoline<sup>®</sup>) may help manage this difficult symptom. Although it is highly sedating, low doses may be worthwhile. Acetazolamide

(Diamox<sup>®</sup>) is a diuretic ("water pill") that has some antitremor properties and may be of value for some people.

Some medications, such as phenothiazine tranquilizers, may cause a tremor to worsen, and on occasion they may produce a *resting tremor* (a tremor that occurs only when a limb is not involved in purposeful movement) where none previously existed. Although their sedative effect may be useful in the treatment of a tremor that occurs with purposeful movement, the presence of a resting tremor must be balanced against the positive therapeutic effects of the drug.

Because a component of spasm often is 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 dose.

High doses of isoniazid (INH), a medication that primarily is used for the treatment of tuberculosis, may alleviate gross tremors that are influenced by posture. It sometimes is worth a trial if tremor is especially incapacitating, but high doses may be too toxic in a given individual to be used for this purpose.

Occasionally, a tremor seen in people who have MS is of a type called *physiologic*, also referred to as an *essential* or *familial* tremor. This is unrelated to MS itself and is treatable with propranolol (Inderal<sup>®</sup>).

Tremors sometimes may be helped by mechanical means. *Immobilization* refers to the placement of a rigid brace across a joint, fixing it in one position and alleviating 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 also may 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 is removed.

*Weighting* involves the addition of weight to a part of the body to provide increased control over its movements. The general 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 also tends to reduce tremor and to 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 or pencils, canes, walkers, and so forth.

These techniques are all used primarily for tremors that affect the limbs. The 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 setting one's arms close to the body. Adaptive equipment and/or assistive devices that are nonskid, easy to grasp, and stable are helpful and may be used for such activities as eating, writing, dressing, cooking, and homemaking.

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 voice and pronounce sounds. Speech therapy focuses on increasing the ability to communicate efficiently. It 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 paceboard, consisting of a pattern of rectangles set next to each other, may slow the person's speech and allow for improved intelligibility. The person points to each square while uttering a single syllable. A diametric increase in clarity of speech often results if he or she can slow down to keep pace with the pointing. A paceboard may be very simple, effective, and inexpensive. In some cases, tremor may make it impossible to speak, in which case alternative communication devices must be used.

None of these techniques completely eliminates the problems of tremor. The goal is continued function, which often may be accomplished by combining some of these therapies.

Chapter 7

# PAROXYSMAL SYMPTOMS

Paroxysmal symptoms or symptoms that come in waves occur relatively uniquely in MS. They can be confused with seizures such as those seen in epilepsy, but are not associated with a short circuiting of brain waves as is epilepsy. Most commonly is seen a spasm of an arm or leg which recurs every few seconds or minutes and lasts for seconds each time. Sometimes the spasm affects the muscles used to produce speech and there is a "paroxysm" of slurring. This can also occur with swallowing. Occasionally, numbness or pain occurs in a wave (see also Chapter 15 on pain).

These symptoms can be frightening and often are misdiagnosed as something else. What is important to recognize is that they are usually fairly easily treated, but do require the use of appropriate medication. The older anti-epilepsy drugs phenytoin (Dilantin<sup>®</sup>), valproate (Depakote<sup>®</sup>), and carbamazepine (Tegretol<sup>®</sup>) still are useful but now many more medications are available, including gabapentin (Neurontin<sup>®</sup>), tigabine (Gabitril<sup>®</sup>), levetiracetam (Keppra<sup>®</sup>), and oxcarbazepine (Trileptal<sup>®</sup>). There are also improved versions of older treatments, including Carbitrol<sup>®</sup> for carbamazepine and Depakote ER<sup>®</sup> for Depakote<sup>®</sup>.

The appropriate dose for each drug varies with the individual, and an experienced clinician should manage each treatment to ensure appropriate use of the agents. While the symptoms can be frightening, they are usually self limiting and will go away on their own with time; these symptoms are not likely to require a lifetime of treatment. The drugs should be tapered after the symptoms are controlled to see if they still are necessary. If the symptoms recur, the treatment should be continued.

# Chapter **8**

# Mobility: Putting It All Together

Mobility is the key to living optimally despite a disability. To function in society today one must remain mobile. To remain mobile it is essential to get the right equipment and learn how to use it. It

> To remain mobile it is essential to get the right equipment and learn how to use it.

must be stressed that using the various devices available gives you the opportunity to remain mobile. The tools to help you stay mobile have dramatically improved in the past decade. Today's walkers are not "your mother's walker." Today's power chairs are marvelous and allow for a new world to be opened to you. Your attitude toward the use of mobility devices needs to focus on the multitude of advantages they offer.

# WALKING (AMBULATION)

Movement impairment frequently is associated with MS, and difficulty in walking is a major type of such impairment. Walking is an activity that we value, perhaps far beyond its true value. Walking usually is done to get somewhere—it is a means of transportation. If walking becomes impaired, another more practical means to accomplish the same goal should be substituted, theoretically without too much emotional trauma. This is easy to say but more difficult in practice. However, understanding *why* we walk may help when selecting appropriate devices to aid in walking.

Weak foot muscles may cause a *foot drop*, in which the toes of the weak foot touch the ground before the heel, thereby disrupting balance. Because there is no way to strengthen a weakened foot, compensation techniques become essential.

It is particularly important to wear proper shoes. I recommend a leather-soled oxford. The laces gives maximum stability to the foot, and the smooth leather sole prevents the sticking that often occurs with crepe or similar types of soles that can throw you off balance. Leather soles wear with time and need to be replaced rather frequently, but their advantages far outweigh this minor problem. A plastic (polypropylene) insert often is added to the shoe to keep the foot from dropping. This lightweight brace (an anklefoot orthosis, or AFO) picks up the foot and allows it to follow through in the normal heel-foot manner.

An AFO also may be designed to decrease spasticity by tilting the foot to a specified angle and keeping it from turning in or out (inverting or everting). Its proper use decreases fatigue while increasing stability. To provide optimal support, such orthoses must be fitted by a specialist called an *orthotist*. AFOs have been improved in the past few years so that they can be hinged and placed at virtually any appropriate angle. The newer AFOs are stronger and more helpful than previous types.

A metal brace that fits outside the shoe may be needed if there is a significant increase in tone at the ankle, which is perceived as

#### PART II • Managing MS Symptoms



A rigid polypropylen ankle-foot orthosis.

stiffness. The brace is a springloaded device that keeps the toe from dropping. Fortunately, the development of new lightweight materials, including plastics and aluminum, has decreased the need to use the more cumbersome heavy metal (Klenzak<sup>™</sup>) braces.

If your hip muscles also are weak, you will swing your leg out in front to allow the foot to clear the ground. To maintain stability while doing this, the knee often is forced back farther than it should be, resulting in a condition termed *hyperextension*. This movement puts significant stress on your knee. After a while it will begin to hurt and may become swollen from arthritis. To prevent this condition from developing, a device called a *Swedish hyperextension cage* may be fashioned to prevent the knee from snapping back. A custom-made knee brace may be necessary if the knee cage cannot be fitted properly.

With the aid of such devices, walking with less fatigue may again become realistic. However, if balance also is a problem, another assistive device may be needed such as a cane. Braces, canes, and crutches should be regarded as "tools" in the same way that a hammer or a drill is a carpenter's tool. It is wrong to think that you are "giving in" by using a cane or a brace. If a carpenter wants to drill a hole, he must use the proper drill or the hole will be wrong. A person with impaired mobility who does not use the right tool cannot accomplish the job of walking. Although it may be difficult at first, try not to have negative emotional feelings about using assistive devices. They simply are tools to improve mobility.

A cane usually is carried in the hand *opposite* the weak leg. The activity of walking is reciprocal; that is, the left hand goes forward with the right foot, and vice versa. When a person walks with a cane, the cane should precede or accompany the weak leg. Walking with a cane held on the weak side may cause a noticeable limp.

If weakness is pronounced in both legs, two canes may be needed. The same reciprocal pattern applies: the left foot and right hand go forward together; the right foot and left hand go together. Walking in this fashion is slower, but there always are three points on the ground to provide increased balance and stability.

When walking stairs, the saying that applies is "up with the good, down with the bad." Step up first with the strong leg when climbing stairs, and step down first with the weak leg when descending. This pattern makes the strong leg do all the work of lifting and lowering. Again, the cane should accompany or precede the weak leg. Use a railing for support whenever possible. If a railing is on the same side as the cane, merely shift the cane to the other hand and use the stair-walking pattern described.

If balance and weakness are more severe, it may be necessary to use forearm (Lofstrand<sup>™</sup>) crutches. These crutches provide greater stability than a standard cane, and their use does not require

as much strength in the upper extremities. The patterns described for walking with a cane apply equally to walking with the aid of forearm crutches.

A walker may be the proper assistive tool if your balance is especially poor. The usual pattern to be used is as follows: walker forward at arms length, weak leg, then strong leg. Take normalsized steps, and avoid stepping past the front of the walker. Walkers come in many varieties. If your gait needs maximum stability, it is best to use a walker without wheels. Some of the newer types have larger wheels as well as seats. They can move very smoothly and allow you to take rest periods by locking the brakes and sitting.

To measure the proper height for all assistive devices, place the device six inches away from the side of the foot, and adjust the handles so that the elbow is bent approximately 25 degrees. As with any specialized tool, it is important to have the right tool, to have it fitted properly, and to know how to use it correctly. An experienced physical therapist should be helpful in ensuring a proper fit.

If walking is still extremely difficult or impossible despite the selection of excellent devices, a wheelchair may be your correct choice. You should not resist using a wheelchair; try to view it simply another mobility tool. Selecting from the many types of wheelchairs available depends on many factors, including your size and weight, strength, and level of energy. A standard manual wheelchair often does not offer people with MS sufficient independence because of the fatigue that is generated by operating the chair and the coordination that is necessary to control it.

Three-wheeled motorized scooters are a boon for people with MS because they do not carry the negative stigma with which regular wheelchairs may be inappropriately perceived. Although scooters are extremely useful, they are best used by people who have retained some means of walking, because their seating systems are not designed for sitting all day. Those who do not possess the ambulatory skills necessary to use a three-wheeler appropriately may achieve independence with one of the newer lightweight motorized wheelchairs.

#### CHAPTER 8 • Mobility: Putting It All Together



Lightweight three-wheeled scooter with tiller steering and hand brake. (Courtesy of Bruno Incorporated).

The key to choosing a chair or a scooter is *independence*. The proper device should be selected to regain control and independence in the environment. Again, help from a physical therapist, occupational therapist, or a physician who understands the use of the chair is necessary to select the most appropriate one.

There is no reason not to be mobile in today's world. The right assistive device coupled with the right attitude can make all the difference. You must remember that the idea is to get where you want to go. It really does not matter how you get there.

If you need an assistive device to maintain your mobility, transportation by car, bus, van, or other means should accommodate the



Common styles of power bases used to provide electric-powered mobility.

device. You will need proper consultation for van lifts, and it is essential to learn about local public transportation that will accommodate the devices. Working toward accessibility is in everyone's best interest and should be encouraged in every way that is appropriate to your living situation.

## **TRANSFERS**

When mobility is impaired and the use of a wheelchair is practical, it is essential that you be able to safely transfer in and out of the chair. There are many transfer techniques. These include the pivot transfer, the transfer board transfer, and the Hoyer transfer (see Appendix C).

As with all devices, the psychology of their use must be mastered. These devices provide an opportunity for mobility—they are friends not enemies. The goal must be to learn how to use them and how to transfer safely.
### PRESSURE SORES

*Decubiti*, also called *pressure sores* or *decubitus ulcers*, are breaks in the skin caused by too much pressure over a period of time. They are only an occasional problem in people with MS, but they are considered a medical emergency when they do occur. If they are managed well when they first develop, they usually resolve without problem; if they are left to increase in size, they may become life-threatening.

Decubiti most commonly occur on the buttocks and other areas that are in constant contact with the surface of a bed or wheelchair. A person with decreased skin sensation does not perceive the discomfort that normally would indicate that he or she has been in one position for too long. Pressure sores frequently appear quietly, with little or no pain, and continue to enlarge, resulting in large holes in the skin that gradually expand into the underlying muscle. Additional factors that may contribute to this process include inadequate nutrition, dependency on certain medications, stool or urine incontinence, and a lack of education regarding prevention.

When pressure is applied to an area of skin over a bony prominence, blood flow to the area is obstructed. The body produces a rebound response of redness and heat when the pressure is relieved, and the skin and muscle below can recover. The skin and muscle below can recover if the pressure does not persist. This is called *healing by first or primary intention*. People with MS should know how to avoid stressing the skin to the point that it cannot recover. Several factors affect wound healing, including age, the presence of other medical problems, and nutritional state.

The key to managing decubiti is to avoid them! Avoidance means transferring weight off contact areas at frequent intervals without using pressure, shear, or friction to accomplish the move. It

#### The key to managing decubiti is to avoid them!

means using proper equipment to disperse the weight of the body over larger surface areas, such as foam pillows, air mattresses, water mattresses, and gels. Foam rubber pads and sheepskins placed under pressure areas such as the sacrum (tail area) and heels aid in dispersing pressure during movement. These "tools," plus proper positioning, relieve shear and friction. The skin must be frequently and carefully examined for areas of pressure and breakdown.

For the bedridden person, a special mattress that takes pressure off the stressed areas may replace the standard bed. It is important to turn once every two hours to avoid continuing pressure to any one area.

*Immediate* attention is essential if an ulcerated area does form. No pressure should be applied to the area. The good skin around the affected area must be preserved and toughened. Special "skinlike" bandages may be applied. Cleaning the area (debridement) may be necessary and should be performed by someone who is trained in this technique.

If all else fails, surgical closure of the wound may be necessary. Surgery allows for *healing by secondary intention*. The ulcer cavity (opening) with its surrounding scar tissue must be completely removed, the bony edge removed, and the wound covered with healthy skin.

Proper postsurgical management is critical for a favorable outcome. It should be obvious that care must be taken not to irritate the wound until it has healed. Further attention to prevention is even more important after the wound has healed because the area remains vulnerable to re-injury.

If careful attention is paid to the preventive measures described here, the chances of a pressure sore forming will be minimized. *Prevention is the best strategy*.

## BLADDER SYMPTOMS

Many people with MS experience difficulties with bladder control and urination at some point during the course of the disease. Bladder symptoms usually can be controlled with medication or other approaches that minimize any changes in daily activities and life-style.

#### The Urinary System and Its Control

The following figure shows the urinary system, whose main function is to collect and eliminate bodily wastes in the form of urine. The urinary system includes

- the kidneys, which filter the blood to remove waste products and produce urine at a rate of approximately one ounce (30 cc) per hour
- the bladder, a muscular sac that stretches to store the urine until it is emptied by urination, a process referred to as *voiding*
- the urethra, a hollow tube through which urine passes from the body when voiding occurs
- the urethral sphincter, a valvelike muscle that opens and closes to control whether urine remains in the bladder or is voided



When 6 to 8 ounces (180 to 240 cc) of urine is present in the bladder, it becomes sufficiently stretched to stimulate nerve endings located in its wall. These nerves send a signal of fullness to an area in the spinal cord that may be thought of as a "voiding reflex center" (Figure A). This center in turn sends the signal on to the brain, and you become aware of the need to urinate. The brain then signals the spinal center, which sends two signals, one to the bladder telling it to contract and a second to the urethral sphincter muscle telling it to relax. This combination of a contracted bladder and a relaxed sphincter permits urine to flow from the bladder.

## Bladder Problems Associated with Multiple Sclerosis

The elimination of urine by conscious choice is dependent on the integrity of the spinal cord pathways that connect the brain and the

voiding reflex center. The downward command by the brain to "empty" causes relaxation and opening of the sphincter, whereas the command to wait signals the sphincter to remain closed. The pathways between the reflex center and the brain may be damaged or interrupted in MS, producing a variety of problems and/or symptoms. The specific nature of the problem depends on the location of the damage. For example, if the connections between the reflex center and the brain are severely damaged, the reflex center may assume direct control of voiding and automatically stimulate the bladder to empty whenever it fills. The most common bladder problems associated with MS are increased frequency of urination, urgency, dribbling, hesitancy, and incontinence.

*Frequency* involves an increase in the number of times urination occurs within the day. In some people, voiding may occur as often as every 15 to 20 minutes, usually in small amounts each time. The frequency of urination depends on the rate at which urine is formed and the ability of the bladder to store it.

*Urgency* is the feeling of having to empty the bladder immediately, combined with an inability to "hold" urine once the urge to void is felt. People who experience this problem have little time to reach a bathroom.

*Dribbling* is the leakage of small amounts of urine from the bladder. This may occur as the result of urgency and the inability to retain urine. In some cases, a person may only be aware of this problem when damp undergarments are noted.

*Hesitancy* involves difficulty in beginning to urinate after the urge to void is felt. This symptom may be associated with urgency, so that one is unable to urinate while the urge to do so remains.

*Incontinence* is an inability to hold urine in the bladder. It may result either from not being able to reach the toilet in time or from being unaware of the need to empty the bladder because of blockage of the pathways between the voiding reflex center and the brain. Despite the ability of the bladder to stretch as it fills, it can hold only a certain amount of urine and empties spontaneously after this limit is reached. Probably the most common type of bladder problem in MS results from a *small spastic bladder*, sometimes referred to as a "failure to store" bladder, which results from demyelination of the spinal cord pathways between the voiding reflex center and the brain (Figure B). Because the pathways to the brain are blocked, bladder emptying no longer is under voluntary control. Voiding then becomes a reflex activity, with messages to "empty" coming only from the spinal center. A small spastic bladder may produce symptoms of increased frequency, urgency, dribbling, and/or incontinence.

Symptoms	Treatment
Increased	Oxybutynin (Ditropan <sup>®</sup> ,
frequency, urgency,	Ditropan XL®)
dribbling, and/or	Hyoscyamine
incontinence	(Levsinex <sup>®</sup> , Levbid <sup>®</sup> )
	Tolterodine tartrate
	(Detrol <sup>®</sup> )
	Flavoxate HCl
	(Urispas <sup>®</sup> )
	Imipramine (Tofranil <sup>®</sup> )
	Antihistamines
Frequency, urgency,	Credé technique
dribbling, hesitancy,	Intermittent
incontinence	self-catheterization
EITHER	Alpha blockers
(a) urgency followed	
by hesitation in	
beginning to void;	
OR	
(b) dribbling or	
incontinence	
	Increased frequency, urgency, dribbling, and/or incontinence Frequency, urgency, dribbling, hesitancy, incontinence EITHER (a) urgency followed by hesitation in beginning to void; OR (b) dribbling or

#### Types of Bladder Dysfunction



A. The normal voiding process.



B. Spastic "small" bladder.



C. Flaccid "big" bladder.



D. Conflicting bladder.

When demyelination occurs in the area of the spinal voiding reflex center, messages cannot be transmitted to or from either the brain or the bladder. A *flaccid* or big bladder results (Figure C). The bladder fills with large amounts of urine, but because the spinal center cannot transmit messages on to the brain, the person is unaware of this fullness. Because the spinal center also cannot transmit messages to the bladder and sphincter, there is very little voluntary or reflex control over urination. The bladder fills and then overfills, producing symptoms of frequency, urgency, dribbling, hesitancy, and incontinence. This situation sometimes is referred to as the "failure to empty" bladder.

The third type of bladder dysfunction is the *dyssynergic* or "conflicting" bladder, in which the problem is related to coordination between bladder wall contraction and sphincter relaxation (Figure D) rather than to the size of the bladder. In the dyssynergic bladder, either (1) the bladder wall contracts while the sphincter remains closed, resulting in a sense of urgency followed by hesitancy in beginning to void; or (2) the bladder wall relaxes while the sphincter remains open, resulting in dribbling of urine or incontinence. This lack of coordination between the bladder wall and the sphincter frequently is seen in combination with either the spastic or the flaccid bladder.

It is important to remember that the bladder does not make urine—urine is made by the kidneys. Disease of the kidneys is not a routine complication of MS. It only occurs if infection of the bladder is uncontrolled, and is surprisingly uncommon in MS, which makes the routine kidney X-ray (intravenous pyelogram, or IVP) for the most part unnecessary. However, the risk of urine backing up from the bladder toward the kidney is increased in a man with a dyssynergic bladder (women usually do not experience this problem because the pressures within the female bladder are lower). This potential problem must be carefully managed by a physician.

#### Management of Bladder Problems

Bladder problems often may be managed with medications and/or other approaches. To determine the most appropriate mode of treat-

ment, it first is necessary to distinguish between the spastic (failure to store), flaccid (failure to empty), and dyssynergic bladder. This is easily done by carefully recording the frequency of urination and the amounts of fluid urinated over a 48-hour period, followed by determining how much urine remains in the bladder after voiding. The amount of this "residual" urine is measured by inserting a catheter into the bladder or by ultrasound technology after urination; a residual of less than 5 ounces (150 cc) indicates either a normal bladder or a small spastic bladder, whereas a larger amount indicates a flaccid bladder.

The small spastic bladder is best treated with medications that "slow" the bladder by decreasing transmission in the nerves to the bladder that cause it to empty. These include oxybutynin (Ditropan<sup>®</sup>, Ditropan XL<sup>®</sup>), tolterodine tartrate (Detrol<sup>®</sup>, Detrol LA<sup>®</sup>), hyoscyamine (Levsinex<sup>®</sup>, Levbid<sup>®</sup>, Cystospaz<sup>®</sup>), flavoxate hydrochloride (Urispas<sup>®</sup>), imipramine (Tofranil<sup>®</sup>), and several medications that are used for the "runny" nose of a cold. These medications lengthen the intervals between urination and decrease urgency, thus allowing for more time to reach the bathroom and avoiding dribbling and incontinence.

Treatment of the flaccid bladder is not as simple, and management frequently relies on alternative techniques for bladder emptying rather than on medication. One common method that facilitates more complete bladder emptying is the *Credé technique* of bladder massage. This technique involves applying downward pressure to the lower abdomen with both hands while bearing down after as much urine as possible has been voided naturally; it is necessary for men to sit while using the technique. This technique should not be used in the dyssynergic bladder because the urine may back up into the kidneys. This mainly is a problem in men because pressure is much lower in the female bladder.

If the bladder cannot be emptied sufficiently by the Credé technique, *intermittent self-catheterization* may be used for more complete bladder emptying. A small tube, or *catheter*, is inserted through the urethra into the bladder to allow the urine to drain out. This may seem rather complicated, but actually it is simple to learn and it poses no risk. It allows a person to empty the bladder at planned intervals, thus avoiding dribbling or incontinence. The frequency of self-catheterization varies from person to person but generally need not be done more frequently than every four to six hours. Medications such as oxybutynin frequently are used in conjunction with self-catheterization to allow the bladder to fill more completely and to decrease the need to urinate between catheterizations.

As mentioned previously, conflict or dyssynergia often is combined with either a spastic bladder or a flaccid bladder. Initial treatment based on the 48-hour diary is aimed at either spasticity or flaccidity; if the previously described techniques do not provide adequate control, it becomes apparent that the bladder wall and the sphincter are not functioning in a coordinated fashion. Occasionally, formal testing with a "bladder analysis machine" (cystometer) is needed to accurately pinpoint the source of the problem. The problem may be helped by the addition of an *alpha blocker* to the treatment regimen. Most alpha blockers were developed to aid in the treatment of high blood pressure, but they also help the bladder work in a more coordinated manner. Phenoxybenzamine (Dibenzyline<sup>®</sup>), clonidine, and terazosin (Hytrin<sup>®</sup>) are alpha blockers that improve coordination and increase bladder control.

Problems with incontinence may occur mainly at night during sleep. One approach to this problem involves the use of a medication called DDAVP (desmopressin), a hormone that slows the production of urine by the kidneys. DDAVP comes in many forms, but the most practical form is now a pill. One or two pills decrease urine formation during the night and decrease the chances of a wet bed. This helps one to get a good night's sleep, which may decrease morning fatigue. The body eliminates the stored fluid during the daytime, so the person has to be able to control his or her bladder during the day. DDAVP is very expensive.

If a bladder problem cannot be controlled with medication and/or intermittent self-catheterization, continuous (chronic) catheterization may become necessary. This is done with a permanent *Foley catheter*. This type of catheter is used only when absolutely necessary because it is associated with an increased incidence of urinary tract infection. A condom type catheter also may be used by men. The penis must be of sufficient size that the condom has enough area to adhere to the shaft. Because this area is damp and mechanical stress is involved, care must be taken not to ulcerate the penis. Unfortunately, female condom catheters are not sufficiently reliable to be used on a regular basis.

#### URINARY TRACT (BLADDER) INFECTION

Urinary tract infection (UTI) is an example of what is termed a secondary problem in MS. UTI is not a direct result of the demyelination process but occurs as the result of (secondary to) the retention of urine in the bladder. Mild infection may result only in increased frequency and urgency of urination, whereas severe infection produces fever and generalized illness.

The incidence of urinary tract infection is higher than normal in (1) those who have a flaccid bladder, because bacteria may grow in the retained urine; (2) those who need to perform intermittent self-catheterization; and (3) those who have an indwelling Foley catheter, which may provide bacteria with a direct route into the bladder. Women generally are at higher risk for the development of bladder infection than men. The diagnosis of a urinary tract infection is made by a *urine culture*, in which urine is collected in a sterile fashion and tested for the presence of bacteria. The presence of bacteria in the urine does not necessarily mean that there is an infection that requires treatment. Many people with MS have what is described as "asymptomatic bacteriuria," especially if they have an indwelling Foley catheter. If the person is asymptomatic, without pain, fever, or other signs of the spread of infection, it is appropriate simply to watch the process.

Other symptoms of a urinary tract infection may include frequent urination, urgency, burning, or discomfort when urinating, fever, or foul-smelling urine accompanied by the presence of blood or mucus. Because some of these symptoms are similar to symptoms frequently experienced by an individual with MS, treatment should not be started until the presence of infection has been confirmed. Generally, infection is suspected when symptoms occur suddenly or if fever is present. A urine specimen is cultured in the laboratory to confirm that bacteria are present before treatment is initiated with an antibiotic specific for the organism causing the infection; the antibiotic generally is taken for seven to ten days. New antibiotics are being developed constantly, and they have been very helpful in managing severe bladder infection.

Bladder infection may largely be prevented by complete bladder emptying, using self-catheterization techniques if necessary. Bacterial growth is prevented or retarded when the urine is acidic, which is best achieved by taking high doses of vitamin C. A person

Prevention is the key to avoiding bladder infections.

who has a history of urinary tract infection may be helped by substances that suppress the growth of bacteria in the urine and low doses of antibiotics, usually sulfa or nitrofurantoin. Prevention is the key to avoiding bladder infections.

- Urination should be frequent and complete, and holding urine in the bladder for long periods should be avoided.
- Women should be careful to wipe from front to back, especially after a bowel movement, and should avoid undergarments that are made of synthetic materials, which tend to trap moisture. Women who have recurrent infection should empty the bladder both before and after intercourse.
- Adequate amounts of fluid should be taken to keep the bladder "flushed." Generally six to eight glasses per day is sufficient.
- Those who are prone to the development of bladder infection should take up to 1000 mg of vitamin C four times each

day to make their urine more acidic, because higher acidity inhibits bacterial growth.

People who have an indwelling Foley catheter should be especially careful to keep the catheter, tubing, and drainage bag as clean as possible. The catheter should be changed at least once a month, using proper sterile technique.

Urinary tract infection may pose a serious threat to health if it is not properly treated, so it is very important to seek medical attention if symptoms occur.

When a urinary tract infection does occur, the key to treatment is the use of an appropriate antibiotic, as indicated by the results of the urine culture and a related test for the antibiotic sensitivity of the infect-

> Urinary tract infection may pose a serious threat to health if it is not properly treated, so it is very important to seek medical attention if symptoms occur.

ing organism. It is important that this medication be taken as directed *for the complete time period indicated* to ensure that all the invading bacteria will be destroyed. It is a mistake to stop taking an antibiotic if you are feeling better because not all the bacteria will have been destroyed; the remaining bacteria will reinvade and cause further problems.

#### BLADDER SPASMS

The bladder sometimes contracts involuntarily. The result often is pain and a squirt of urine that may lead to total emptying of the bladder. If a catheter is in place, the urine will leak out around it. This is a bladder spasm. The medications used for leg spasms (see Chapter 5) often are helpful, as are the medications used for the small, spastic bladder.

#### BLADDER PROCEDURES

Occasionally, nothing works well to control the bladder and wetness is a constant and unacceptable companion. It may then be necessary for a urologist to place an opening to the bladder in the front of the body, a procedure called a *continence viscostomy*. In women this allows for much better visualization of an entrance to the bladder and with an appropriate valve implantation selfcatheterization may be accomplished through the opening.

If the bladder is very small and shrunken, a bladder augmentation procedure sometimes may be performed by surgically taking a piece of colon and using it to enlarge the bladder. This allows for more storage room.

An indwelling Foley catheter may irritate the bladder wall, and bladder stones may form in response to this irritation. Bladder stones may increase the likelihood of infection and decrease urinary flow. The stones usually are removed by a fairly simple surgical procedure called a *cystoscopy*, which is performed through a "scope" that the urologist uses to look into the bladder.

With chronic, significant infections, the bladder wall may become so damaged that the infection cannot be cleared and the bladder must be bypassed or diverted. A piece of intestine is used to divert the urine to a bag on the body like a colostomy. This procedure is reserved for extreme situations, but it does permit infection to be controlled more easily.

#### INCONTINENCE PADS

The number of incontinence devices and pads multiplied during the last decade. There are many kinds of adult incontinence devices and diapers. The key is to prevent skin irritation, to have no specific offensive odor, and to be comfortable. It is beyond the scope of this chapter to discuss this topic in detail, but improvements are occurring constantly and must be assessed accordingly.

## BOWEL SYMPTOMS

As with the urinary tract, many people with MS have some degree of bowel complications at some point during the course of the disease. These difficulties may be effectively managed with medications and other treatments.

#### The Gastrointestinal Tract and Its Control

The gastrointestinal (GI) tract is a hollow, muscular tube that extends from the mouth to the anus and is responsible for the digestion and absorption of food followed by elimination of the waste products of the digestion process.

The *stomach* primarily acts as a storage chamber and is the first site of major digestive processes. It slowly passes food to the *small intestine*, which in turn sends it to the *large intestine* by a propulsive movement.

The large intestine is approximately five feet long and is divided into four sections: the ascending, transverse, descending, and sigmoid colon. In the sigmoid colon, stool is concentrated into a solid mass by the absorption of much of the fluid that is present in other areas of the tract. The reflex process that leads to a bowel movement (defecation) occurs when stool moves from the sigmoid colon into the rectum, the last four to six inches of the tract.

The rectum usually remains empty until just before and during defecation, when stool enters it either as a result of a mass propulsive movement or by voluntary contraction of the abdominal muscles. In a manner similar to what happens when the bladder initiates urination, filling of the rectum with stool causes nerve endings in the rectal wall to transmit a message of fullness to an area of the spinal cord that is involved in bowel function. As stool leaves the rectum, it passes through the anal canal, which contains the internal and *external sphincter* muscles. The sphincters, ring-shaped muscles that control the opening and closing of the passageway from the rectum, normally are contracted to prevent leakage. The internal sphincter is under the control of the spinal cord; its relaxation is what is termed an involuntary reflex because it is not under conscious control, and its relaxation depends only on stretching of the rectal wall by stool. In contrast, the external sphincter is under the joint control of the spinal cord and the brain, so that a bowel movement may be consciously delayed by constricting the anus if the time is not appropriate for a bowel movement. The most common bowel problems associated with MS are constipation, diarrhea, and incontinence

#### CONSTIPATION

Constipation is defined as the infrequent or difficult elimination of stool. It is by far the most common bowel problem associated with MS and may result from one or several problems that are direct or indirect consequences of the disease.

- Demyelination in the brain and/or spinal cord may interfere with the nerve transmission that is necessary for normal defecation, in a manner similar to that described in Chapter 10. A slower than normal passage of stool through the bowel results in more water being removed from it than is normal, which results in hard, constipating stool.
- A person with MS may limit fluid intake because of bladder difficulties. If fluid intake is insufficient to allow the body to

meet its basic needs, more water will be absorbed as the stool passes through the colon, which also produces hard, compacted stool that is difficult to pass.

• Weakness, spasticity, or fatigue may significantly limit physical activity, which in turn slows bowel activity and the movement of stool through the GI tract; again, excessive amounts of water will be absorbed from the stool, causing it to harden and become difficult to pass.

Some of the medications taken for other problems such as bladder frequency or depression also may slow the bowel.

#### The Development of Good Bowel Habits

#### Dietary Management

Good eating habits are important to achieving good bowel control. It is important to have a routine and to eat balanced meals at regular times and in a relaxed atmosphere. The intake of adequate amounts of liquid (8 to 12 cups daily) and the addition of fiber to the diet generally alleviates constipation. Dietary fiber is that portion of plant materials that is resistant to digestion; its addition to the diet aids in the formation of softer stool and decreases the amount of time required for stool to pass through the intestinal tract.

A high-fiber diet includes raw fruits and vegetables, nuts and seeds, and whole grain breads and cereals such as cornmeal, cracked and whole wheat, barley, graham, wild and brown rice, and bran (one of the most concentrated sources of dietary fiber).

To increase the amount of fiber in your diet, your daily intake should include:

- One serving of fruit (with the skin left on) or vegetable, served cooked, raw, or dried;
- One half to one serving of whole wheat or rye bread, or fruit juice; and
- One serving of bran (one tablespoon), bran cereal, shredded wheat, nuts or seeds; raw bran may be eaten plain; mixed

#### **Bowel Management**

- Eat a high-fiber diet of balanced meals
- Drink 8 to 12 cups of fluid daily
- Establish a bowel program
- Medications

with cereal, applesauce, soups, yogurt, or casseroles; or added to flour in cooking or baking.

Incorporating bran and other high-fiber foods into the diet too quickly may produce gas, distention, and occasionally diarrhea. These effects may be eliminated or lessened substantially if highfiber foods are incorporated in small amounts and then gradually increased.

#### ESTABLISHING A BOWEL PROGRAM

Because decreased sensation in the rectal area in MS may decrease perception of the need to have a bowel movement, stool may remain in the rectum and become hard and constipating. Although this and other factors may lead to constipation becoming a significant problem, it is manageable with a commitment to following an established elimination schedule, timing of meals, fluid intake, and the use of medications if necessary. The first step in establishing a bowel program is to select the time that is most convenient to have a bowel movement. Although this may vary depending on your job commitments, family routines, and other daily activities, the most effective time to have a bowel movement is shortly after a meal because there normally is a greater movement of contents through the bowel at that time. With this in mind, 15 to 30 minutes of uninterrupted time in which to have a bowel movement should be scheduled.

After a convenient time has been selected, it is important to adhere to this routine on a daily basis, whether or not you feel an urge to defecate. Drinking a cup of warm liquid, such as coffee, tea, or water, frequently facilitates the process. Although this schedule initially may produce little result, it is imperative that the routine be adhered to if a successful bowel program is to be established.

#### Medications

Medications may be needed if constipation cannot be corrected by changing the diet, increasing fluid intake, and/or establishing a routine. To determine the most appropriate medication, the reason for the constipation must be determined, because it may be caused by lack of bulk, hard stools, or difficulty in expelling stool.

*Bulk formers* may be prescribed if the cause of constipation is inadequate bulk in the diet and stool. These agents add substance to the stool by increasing its bulk and water content. In order to be effective, bulk formers should be taken with one or two glasses of liquid; this combination distends the GI tract, which in turn increases the passage of stool through it. Defecation usually occurs within 12 to 24 hours, although in some cases it may be delayed for up to three days. The daily use of bulk formers is necessary for maximal

Medication	Indications for Use
Bulk formers	Inadequate bulk in the diet and stool
Stool softeners	Hard stool causes constipation
Laxative	Difficulty expelling stool
(oral stimulant)	
Suppositories and	In combination with other
other rectal	medications if necessary
stimulants	
Therevac®	When lubricating stimulation is
mini-enemas	helpful
Enemas	For occasional use only, to avoid
	dependency

#### Medications for the Management of Constipation

effectiveness. They are not habit-forming, so frequent use is not a problem.

Common bulk formers include

- Metamucil<sup>®</sup>, taken in a dose of one to two teaspoons daily mixed in a glass of water or juice and followed by an extra glass of fluid. This may be increased to one teaspoon taken two or three times per day if necessary;
- Perdiem<sup>®</sup> fiber (brown container), taken in a dose of one to two rounded teaspoons daily; it should be placed in the mouth (not chewed) and swallowed with at least eight (preferably more) ounces of cool beverage;
- FiberCon<sup>®</sup>, two tablets, one to four times a day; each dose should be followed by eight ounces of liquid;
- Citrucel<sup>®</sup>, one tablespoon, one to three times daily, mixed in eight ounces of juice or water;
- Fiberall<sup>®</sup>, available in chewable tablets, wafers, or powder, may be taken one to three times a day with eight ounces of liquid.

#### Stool Softeners

If the cause of constipation is hard stool, stool softeners are used to draw increased amounts of water from body tissues into the bowel, thereby decreasing hardness and facilitating elimination. Consistent use is recommended to obtain maximal benefit; as with bulk formers, stool softeners are not habit-forming. They include

- Colace<sup>®</sup> (also known as DSS); take one pill every morning and evening;
- Surfak<sup>®</sup>; take one pill every morning; and
- Chronulac<sup>®</sup> syrup; take one ounce every evening, increasing to one ounce each morning and evening if necessary.

#### Laxatives (Oral Stimulants)

If difficulty in expelling stool is the cause of constipation, it may be corrected with laxatives, also referred to as oral stimulants. Laxatives provide a chemical irritant to the bowel. Although a number of over-the-counter laxatives are available, care should be taken to avoid the use of harsh laxatives, which may be highly habit-forming. The same results may be obtained by using the fol-

> Care should be taken to avoid the use of harsh laxatives, which may be highly habit-forming.

lowing milder laxatives, which are less harmful to the bowel and induce bowel movements gently, usually overnight or within 8 to 12 hours:

- Pericolace<sup>®</sup>; take one or two capsules at bedtime; increase to two capsules twice a day if necessary;
- Perdiem<sup>®</sup> (yellow container, not to be confused with the bulk former Perdiem Plain<sup>®</sup>), which contains the bulk former found in Perdiem Plain<sup>®</sup> plus a mild stimulant or laxative effect; take one or two teaspoons once a day, placed in the mouth and swallowed with at least eight ounces of cool liquid, preferably more; and
- Milk of Magnesia<sup>®</sup>; take one ounce at bedtime every other day.

#### Suppositories and Other Rectal Stimulants

Rectal stimulants provide both chemical stimulation and localized mechanical stimulation combined with lubrication to promote stool elimination. They may be used either occasionally when necessary or on a routine daily or every-other-day basis in conjunction with other medications already listed. Suppositories generally act within 15 minutes to an hour. They include

• Glycerin suppositories, which contain no medication and provide rectal stimulation and lubrication for easier passage of stool. Glycerin suppositories are milder and less habit-

forming than  $\mathsf{Dulcolax}^{\texttt{o}}$  and are used to help develop a bowel routine;

- Dulcolax<sup>®</sup> suppositories, which contain a medication that is absorbed by the lining of the large bowel and stimulates a strong wavelike movement of the rectal muscles that facilitates elimination; and
- Therevac<sup>®</sup> mini-enemas, which are not traditional enemas but rather lubricating stimulants in a easy-to-administer shell. This preparation is a clean way of administering a helpful medication to stimulate a bowel movement.

Enemas may be considered an occasional treatment for constipation, but *the frequent use of enemas should be avoided* because the bowel may become dependent on them when they are used routinely.

In summary, many medications are available without a prescription for the treatment of constipation, but their indiscriminate use should be avoided. A professional should be consulted to determine which medication or combination of medications is best suited to a specific problem. In attempting to control constipation, it may be necessary to begin a bowel program that includes a number of medications. This may seem rather overwhelming in the beginning, but some medications may be eliminated as a routine is established and bowel movements become more regular. *Consistency is the key to regulating constipation*.

#### DIARRHEA AND INCONTINENCE

Diarrhea is much less common than constipation in people with MS. However, it may be a significant problem because there may not be adequate warning of an impending attack and incontinence may therefore occur. The probable cause of such diarrhea is a reflex-like activity that results from the short-circuiting in MS, causing frequent emptying even though the bowel is not full.

The key to controlling diarrhea is to make the stool bulkier without producing constipation. Bulk formers such as  $Metamucil^{*}$  or

Perdiem Plus<sup>®</sup> may be helpful because they absorb water and therefore make the stool firmer. When it is used to treat diarrhea, a bulk former should be taken no more than once a day, and it should not be followed by the recommended extra fluid that is needed when a bulk former is used to treat constipation. In extreme cases, medications that slow the movement of the bowel muscles may be needed to control diarrhea, such as Kaopectate<sup>®</sup>, Imodium<sup>®</sup>, or Lomotil<sup>®</sup>.

Other causes of diarrhea must be considered. A loose stool in a person with MS most often is caused by something other than MS!

### Speech Difficulties

Speech patterns are controlled by many areas of the brain. Depending on the location of demyelinated areas, many alterations of normal speech patterns may occur as the result of MS. Most such alterations affect speech production, resulting in *dysarthria*, or slurred speech, ranging from mild difficulties to severe problems that make comprehension impossible.

Demyelination in the cerebellum, the area of the brain involved with balance, is the primary cause of speech difficulties. Speech generally becomes slow and fluency is diminished. Words may be slurred but they usually are 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 may increase both fluency and speech rhythm. Although exercises are sometimes advocated, they usually are not successful for this type of speech problem. Nevertheless, they may be worth a try.

Oral motor exercises may be used to maintain muscle coordination. The following is a list of exercises that may be done once or twice a day for 20 to 30 minutes with several repetitions:

1. Open and close the mouth slowly several times.

- 2. Pucker the lips into a big kiss, hold, then relax.
- 3. Spread the lips into a big smile, hold, then relax.
- 4. Pucker, hold, smile, hold; repeat this alternating movement.
- 5. Open the mouth, and then try to pucker with the mouth wide open; do not close the jaw, hold, relax.
- 6. Close the lips tightly and press together; relax.
- 7. Close the lips firmly, slurp all the saliva out to the top of the tongue.
- 8. Open the mouth and stick out the tongue; be sure the tongue comes straight out of the mouth and does not go off to the side; hold, then relax.
- 9. Stick out the tongue and move it slowly from corner to corner of the lips; hold in each corner, relax; be sure the tongue actually touches each corner each time.
- 10. Stick out the tongue and try to reach the chin with the tongue tip; hold at the farthest point, then relax.
- 11. Stick out the tongue and try to reach the nose with the tongue tip; do not use the bottom lip or fingers as a helper. Hold as far up as possible, then relax.
- 12. Stick out the tongue; pretend to lick a sucker, moving the tongue tip from down by the chin up to the nose; go slowly and use as much movement as possible, then relax.
- 13. Stick out the tongue and pull it back, then repeat as many times and as quickly as possible; rest.
- 14. Move the tongue from corner to corner as quickly as possible; rest.
- 15. Move the tongue all around the lips in a circle as quickly and as completely as possible; touch all of both the upper lip, corner, lower lip, corner in a circle; rest.
- 16. Open and close the mouth as quickly as possible; be sure lips close each time; rest.
- 17. Say "pa-pa-pa-pa" as quickly as possible without losing the "pa" sound; be sure there is a "p" and an "ah" each time; rest.
- 18. Say "ta-ta-ta-ta" as quickly and as accurately as possible; rest; repeat.

- 19. Say "ka-ka-ka" as quickly and as accurately as possible; rest; repeat.
- 20. Say "pataka, pataka, pataka" (or "buttercup") as quickly and as accurately as possible; rest.

Tremors of the lips, tongue, or jaw also may affect speech by interfering either with breath control for phrasing and loudness or with the ability to voice and pronounce sounds. Speech therapy focuses on increasing 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. The pausing is used between one or two words. A paceboard initially may be used to assist with this technique. Although it sounds relatively simple, it takes a lot of practice and learning to monitor yourself. Move the fingers along the board for each word produced. Exaggerating (overarticulating) speech sometimes will assist in slowing. Each sound within a word is pronounced, especially the final sounds.

Nonverbal techniques may be used in severe cases of speech intelligibility. These may include the use of a communication board (letter, word, or picture) and a variety of electronic systems. Recently a number of computerlike devices have been developed that fall under what is called "augmentative communication." These include voice synthesizers and microphones that enhance voice loudness. The world of speech has gone high tech!

## SWALLOWING DIFFICULTIES

Dysphagia, or difficulty in swallowing, may be very bothersome in MS. "Swallowing" refers to the passage of food from the mouth into the throat, down the esophagus (food tube), and into the stomach. Food may "stick" in the throat, go into the windpipe (trachea), or travel sluggishly and inefficiently, causing coughing, sputtering, and anxiety. Signs of swallowing dysfunction include:

- Gurgling sounds and sounds of congestion
- Spitting or coughing after meals
- An inability to "get the food down"
- Weight loss
- Pneumonia
- Throat clearing
- Choking
- A weak voice

A swallowing evaluation should include a speech pathologist's examination. An "x-ray in motion" (videofluoroscopy) is important to demonstrate the specific location of problems in the swallowing mechanism. After these evaluations, a management plan may be constructed.

The goal of a management plan is to improve nutritional status while making swallowing safe. This may be done by:

- Modifying food textures, because some foods may be swallowed more easily than others. The studies described previously lead to decisions about the texture of food. Sometimes a commercially available thickening agent or gelatin must be added to increase bulk. Milk products may need to be limited because they "stick" in the throat and may be irritating.
- Moistening food with broth, juice, gravy, or fat may allow for a smoother passage.
- Warming or cooling foods may help by stimulating the swallowing reflex.
- Changing the position of the head may be necessary. Tipping the chin down slows the entry of food, especially thin liquids, whereas tilting the head backwards hastens their entry.
- Alternating liquid with solid food prevents sticking in the throat.
- Reducing the size of meals and increasing their frequency so that the appropriate caloric intake is achieved, if eating is slow.
- Changing, bite size makes a big difference.

Other techniques taught by speech pathologists are important. These include:

- The "power" or "safe" swallow. The person first inhales, then holds his or her breath, which closes the airway so that whatever is being swallowed cannot cause choking. He or she then exhales, swallows again, and exhales yet again.
- Thermal stimulation. The back of the throat is stimulated with a dentist's mirror or something cold, which triggers the swallow reflex.
- Oral motor exercises. These are exercises for the tongue, lips, and soft palate that are designed to make swallowing easier.
- Laryngeal exercises. These involve closing the vocal cords while holding the breath.

Mealtimes are important because they provide social interaction as well as nourishment. It is essential that meals be served at a safe time. If swallowing is a problem, the previously described techniques may be of value. It also is important that the Heimlich maneuver be learned by those who help the person with MS. In extreme cases, it may be necessary to have a feeding tube placed directly into the stomach, which may be done under local anesthesia with minimal risk. This alternate nutritional route may help to maintain strength. The person's main nutrition may thus be given without the problems that swallowing presents, with "social chewing" being allowed for special foods.

### VISION

Seeing is very important for all of us, but in MS vision is all too often affected. Many steps are involved in actually seeing an object. The process begins in the eyes. The two major components of effective vision that involve the eye itself are the ability to correctly image what you see and the proper coordination of the muscles that surround the eye and control its movements. Either or both of these can be affected in MS.

*Optic* or *retrobulbar neuritis* is the term used when the myelinated fibers of the optic nerve are inflamed. If the inflammation can be seen with an ophthalmoscope, it is an optic neuritis. If the inflammation is behind the eye globe, it is termed *retrobulbar* and cannot be seen with the ophthalmoscope. This can be the result of MS or other conditions. The optic nerve is highly myelinated and is an out-pocketing of the brain; it is thus very prone to demyelination and inflammation. This results in an acute overall loss of vision. Many studies have shown that vision usually will return whether aggressive treatment is offered or not. However, high dose steroids will result in more rapid improvement (if it is going to improve). They are often given in form of *high dose intravenous methylprednisolone*. Oral steroids are often avoided because some studies have shown adverse effects; physicians do not want to take any chances even though this data is not firm.

Each person's optic neuritis needs to be looked at individually in terms of treatment and prognosis.

In some cases, vision remains imperfect even after inflammation has been reduced. This is especially noticeable at night when lighting is dim, although in normal light colors may appear "washed out." Leaving a light on at night may be helpful. Additionally, there sometimes may be "holes" in the vision, with part of the area one is looking at obscured. This cannot be treated with eyeglasses, which only tend to magnify these areas. It is possible to adjust to the problem over time.

Weakened coordination and strength of the eye muscles produces *double vision*. If this comes on suddenly it is considered an acute attack and may be treated with steroids. With time, the brain usually learns to compensate for double vision so that images are perceived as normal despite the weakened muscles. *This compensation will not occur if the eye is patched*. Patching should be reserved for reading, driving, or watching television. Prisms placed into eyeglasses may bring images together and provide another relatively simple way to manage this difficult problem.

Jerking eyes may occur in MS; this is called *nystagmus*. MS may be accompanied by various varieties of nystagmus. It usually is more of a nuisance than a major problem. Clonazepam (Klonopin<sup>®</sup>), gabapentin (Neurontin<sup>®</sup>), and other related drugs occasionally decrease nystagmus.

*Cataracts* (a clouding of the lens of the eye) also may decrease vision in people with MS. Because cortisone promotes the development of cataracts, they often develop at an earlier age than normal in the MS population. Surgical removal of the abnormal lens sometimes brings about a substantial improvement in vision.

As with all symptoms of MS, significant fluctuations in visual symptoms may occur. Visual acuity often falls and double vision may increase with fatigue, increases in temperature (Uthoff phenomenon), stress, and infection. Managing these symptoms may help improve vision under those conditions.

PAIN

Although MS generally is considered to be a painless disease, more than 50% of people with MS find that pain is a problem, and for 10 to 20% it is a significant problem. Pain appears to result from what might be termed *short-circuits* in the tracts that carry sensory impulses between the brain and the spinal cord.

*Trigeminal neuralgia* occasionally is seen in individuals with MS. This severe, stabbing facial pain usually is treated with carbamazepine (Tegretol<sup>®</sup>), which appears to "calm" some of the shortcircuiting in the sensory areas. To avoid its primary side effect of sleepiness, the medication initially is given at low doses and slowly increased to a point at which it adequately controls the pain. Other medications that may be used to control trigeminal neuralgia include phenytoin (Dilantin<sup>®</sup>), whose action is similar to but milder than that of carbamazepine; baclofen, which most commonly is used for spasticity; and Cytotec<sup>®</sup>, a medication that is taken for gastric distress. Newer anticonvulsants (used for epilepsy) that also can decrease neuralgic pain include Neurontin<sup>®</sup>, Trileptal<sup>®</sup>, Keppra<sup>®</sup>, and Gabitril<sup>®</sup>.

If medications fail to control pain, a surgical procedure may be performed to eliminate the pain, leaving a much less disturbing numbness in its place. This procedure, called *percutaneous rhizoto*-
*my*, is performed under local anesthesia with laser technology. Although it is not the first line of therapy, it is viable as a backup.

Occasionally, an unusual "electrical" sensation is felt down the spine and into the legs when the neck is moved. This is a momentary sensation, called *L'hermitte's sign*, which usually is surprising and disturbing. It is a signal of loss of myelin within the spinal cord in the neck region. It has no significance in terms of predicting the course of MS.

The predominant type of pain seen in MS is a burning, toothachetype pain that occurs most commonly in the extremities, although it also may occur on the trunk. The same medications that are used for trigeminal neuralgia are used for these burning "dysesthesias," but they appear to be less effective than they are for this burning pain. An antiepileptic drug, gabapentin (Neurontin<sup>®</sup>), has become a useful treatment for this type of discomfort. In doses of 1800–2400 mg per day, gabapentin significantly lessens the pain with relatively minimal side effects. Neurontin<sup>®</sup> has a very short half life of four hours which means that half of it is gone every four hours. From a practical point of view this means that the medication usually must be taken at least four times a day. It also means that enough must be taken to be effective. That amount is highly variable. Some people with MS have found that antipain cream (Zostrix<sup>®</sup>, or capsaic acid) may be helpful.

Electrical stimulation (transcutaneous nerve stimulation, or TNS) applied over the area of pain occasionally provides relief. However, it frequently has the opposite effect and therefore is not often recommended. Acupuncture may be helpful for the pain associated with MS but, unfortunately, even in the best of hands it usually fails over the long term.

Mood-altering drugs such as tranquilizers and antidepressants may be effective in some cases because they alter the interpretation of the message of pain. Several such drugs are available, and some relief may be provided with careful manipulation of the type and dose. Amitriptyline (Elavil<sup>®</sup>) is the best known of these medications.

Additionally, biofeedback, meditation, and similar techniques may be of help in specific circumstances. Because pain is a symptom that clearly increases in severity when it is dwelt on, a concerted effort to treat the reaction to pain is an important part of the overall treatment plan.

What is clear is that standard pain medications, including aspirin, codeine, and narcotic analgesics, are not effective because the source of pain is not the same as the pain that occurs with injury. *Pain medications are therefore to be avoided. They are not only ineffective but also addictive.* 

Although "MS pain" may be severe and bothersome, it usually does not lead to decreased ambulation and is not predictive of a poor prognosis. In fact, those who have these unusual sensations as the major feature of MS tend to do better than average in movement activities.

Severe pain can result from spasticity and spasms. Management strategies for these are discussed in Chapter 4.

Low back pain is one of the most common symptoms treated by the neurologist, and it therefore is not unexpected that it also is relatively common in people with MS. MS in itself rarely causes low back pain; it more commonly is the result of a pinched nerve or another problem. This situation occurs fairly frequently because of abnormal posture or an unusual MS-related walking pattern, which places stress on the discs of the spine (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 that is innervated by these nerves. Obviously, heavy lifting and inappropriate turning and bending compound the problem. These movements irritate the spinal nerves, causing the muscles on the side of the spinal column (the paraspinal muscles) to go into spasm; it is this spasm that causes low back pain. If a spinal nerve is significantly irritated, the pain may extend down to the muscles in the leg that are served (innervated) by that nerve.

If the problem is one of poor walking posture, the pattern should be corrected; if spasticity contributes to the problem, it must be lessened. Local back care with heat, massage, and ultrasound waves frequently are helpful, and exercises designed to relieve back muscle spasm may be recommended. Physical therapists and chiropractors who are sensitive to the problems associated with MS may speed healing. Drugs designed to relieve back spasms also may be used, often in conjunction with nonsteroidal antiinflammatory medications (for arthritis). If the problem is the result of a severely damaged disc, surgery may be needed to relieve the spinal irritation.

A person with MS and back pain should avoid severe spinal manipulation or spinal adjustments (rapid twisting or pushing of

A person with MS and back pain should avoid severe spinal manipulation or spinal adjustments (rapid twisting or pushing of the spinal column).

the spinal column) because they may irritate the spinal cord, increasing the neurologic problems.

It is critical that a correct diagnosis of the cause of any type of pain be made to ensure that it is properly treated. Diagnostic studies that include magnetic resonance imaging (MRI) and computed tomographic (CT) scanning may be needed to pinpoint the cause of the pain.

Other types of musculoskeletal problems of an orthopedic nature are commonly seen in MS. Ligament damage may result if there is too much knee hyperextension during walking. The knee may swell and may be very painful. Many orthopedic specialists are unfamiliar with MS and do not understand why this related problem occurs. As a result, they may recommend exercises such as "quad sets" to increase the strength of the weak leg. Unfortunately, if strength could be put back into the leg, the problem would not have happened in the first place! Exercising the leg with orthopedic exercises actually produces fatigue and increases weakness. Thus, the exercise program fails. A more appropriate approach is to take the load off the leg with an assistive device such as a cane or a crutch. A knee brace may be necessary and helpful to prevent hyperextension.

# Chapter 16

### DIZZINESS AND VERTIGO

The term *vertigo* refers to the sensation of spinning, which, when severe, may be accompanied by nausea and vomiting. There are many causes of vertigo. In MS the problem usually results from an irritation of the brain stem structures that help to maintain balance by coordinating the eyes, arms, and legs. The inner ears also play a major role in balance, and disturbances in the conduction of input to the brain from the inner ear may be very distressing. Dizziness and the sensation of lightheadedness are less severe than vertigo, but nonetheless they cause discomfort. Obviously, other diseases that involve these structures produce similar symptoms, and it should not be assumed that they are necessarily due to MS.

Antihistamines, including diphenhydramine (Benadryl<sup>®</sup>), meclizine (Antivert<sup>®</sup>), and dimenhydrinate (Dramamine<sup>®</sup>), frequently provide relief when vertigo or sensations of dizziness are relatively mild. Niacin (a component of vitamin B complex) occasionally is used to dilate blood vessels in the hope that this will reduce the problem.

Benzodiazepines, the class of medications that includes diazepam (Valium<sup>®</sup>), clonazepam (Klonopin<sup>®</sup>), and oxazepam (Serax<sup>®</sup>), directly suppress the structures of the inner ear that stimulate dizziness. They are potent antidizziness treatments but they

must be used judiciously. These medications, individually or occasionally in combination, provide sufficient relief to allow the person affected by dizziness to continue functioning reasonably well.

A physical therapist may teach effective exercises if dizziness is made worse by positional changes. The therapist determines which positions of the head make the dizziness worse. Therapy consists of holding the head in those positions for as long as is tolerated. If this is 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, and the dizziness often disappears as the flu symptoms ease.

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 these symptoms, the brain stem area at the base of the brain.

# Chapter 17

## Numbness, Cold Feet, and Swollen Ankles

This group of symptoms commonly occur with multiple sclerosis (MS), but they can be managed easily and are not major problems with the disease.

#### NUMBNESS AND TINGLING

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

Little can be done to treat numbness and, because it usually is a harmless symptom, there is no real need to do so. In some cases, steroids may improve sensation by decreasing inflammation, but their use is reserved for instances of real need. Gabapentin (Neurontin<sup>®</sup>) and/or amitriptyline (Elavil<sup>®</sup>) may be administered with an occasional decrease in feelings of numbness.

Focusing on numbress may magnify the problem and make it especially bothersome. The best approach is to realize that it is only an annoyance and does not imply a worsening of the disease. A more aggressive approach with cortisone therapy may be considered if the numbness involves the hands, impairing fine movements, or the genitalia, making sexual relations difficult. Unfortunately, no medication specifically treats numbness.

#### Cold Feet

The complaint of cold feet is common in MS, even in the milder forms of the disease. The maintenance of skin temperature is an "involuntary" process under the control of that portion of the nervous system referred to as "autonomic," which controls functions such as heart rate, sweating, and pupil dilation. Short-circuiting in the interconnections that control the diameter of blood vessels and those nerves that sense temperature appears to be responsible for the perception of cold feet.

This symptom may be annoying, but it usually is innocuous. There is nothing wrong with the blood vessels themselves in the legs or feet, and there is nothing dangerous in the slight drop in temperature that produces this sensation. It should be emphasized that cold feet do not signify a general circulatory problem. Most people who have this symptom are young and have normal blood vessels. Although they are not protected from vascular disease by MS, they are no more likely to have it than are others of a similar age. Nonetheless if the problem is severe it should be checked out by a physician.

The best way to manage the problem of cold feet is with warm socks, an electric blanket, and similar local treatments. Occasionally, niacin or medications that dilate blood vessels may be used to alleviate this symptom when it is particularly annoying.

#### SWOLLEN ANKLES

Swollen ankles result from an accumulation of *lymphatic fluid*, which helps carry nutrients and other substances to and from the organs of the body. This accumulation most often results from reduced activity of the muscles of the leg, which under normal circumstances help keep the fluid moving in the *lymphatic channels* 

and propel it upward toward the body cavity. When the fluid leaks out of its channels, gravity causes it to pool in the ankles and feet. This problem is common to many diseases in which the use of the legs is reduced. Unless the swelling is extreme, it usually is painless.

"Water pills" (diuretics) usually fail to reduce this type of swelling because they cannot move the fluid upward. If swelling is reduced, the fluid usually returns very soon, even if the medication is continued. Treatment is relatively simple and consists of keeping the feet sufficiently elevated so that gravity can begin to move the fluid toward the trunk. This means placing the feet higher than the hips for periods of time during the day and throughout the night. Support stockings may also be of assistance by helping to keep the fluid within its normal channels; these must be fitted properly to avoid pinching the muscles of the leg.

Special stockings that are worn at night during sleep actually pump the fluid back into the system by massaging the muscles of the legs. These are very effective but are expensive and should be reserved for special situations.

Despite the continued leakage of fluid, swollen ankles are essentially a nuisance, requiring looser shoes and so on, rather than a sign of a major problem. Swelling may be more noticeable in summer months because blood vessels and lymph channels dilate (swell) more when the temperature is higher. Sometimes the swelling is severe and does not go away and makes it hard to wear shoes and be comfortable. Specially trained physical therapists who are "lymphedema" specialists can be miraculous at getting the fluid mobilized.

Occasionally, extra fluid may accumulate in the body and pool in the ankles because the heart does not function properly. If a cardiac problem exists, swelling may be accompanied by shortness of breath, coughing, and a general feeling of being unwell. If swelling occurs rapidly, especially in one leg, and is accompanied by redness and pain, it is extremely important to rule out the possibility of *thrombophlebitis* (inflammation of the veins), which may lead to blood clots. This may require special testing. It is therefore important that a physician assess the cause of ankle swelling and determine proper treatment.

# Chapter 18

### COGNITIVE DIFFICULTIES

Memory, planning, foresight, and judgment are part of what makes us human. This is what we call cognition. The transmission of nerve impulses from the front of the brain to the back, from side to side and back and forth, are what make for the ability to remember and communicate. This takes highly myelinated fiber tracts working at top efficiency. It should come as no surprise that impairment happens all too often in MS. It is estimated that 50 to 55% of people with MS will have some problem with cognition. About 10 to 15% have significant problems that can lead to decreased job performance and altered social skills. Because this is often a transmission problem, there may be times when it all works well and others when it falls apart. These bad times are worse with heat, stress, and fatigue. The problem is very different from that seen in Alzheimer's disease, which involves across the board memory loss. In MS the loss can be very spotty.

Occasionally a person experiences such severe cognitive difficulties that the condition is called "cerebral MS." In cerebral MS the person often has no insight that he is experiencing a problem, which makes it more difficult to help.

The key to treatment at this time is *compensation*. It is impossible to get the nerves to start working after they have been damaged.

Testing needs to be done to determine the strengths and weaknesses, in order to build on the strengths. The testing can be extensively done by neuropsychologists or less aggressively by speech pathologists or occupational therapists.

It is important to treat aggressively any depression that may complicate the situation, to review all medication taken for MS, and other conditions, and to assess the possible effects of each on cognition.

The brain of an adult was once thought to lack what is termed *plasticity*—the ability to switch function to another brain area to allow for restoration of function normally controlled by a damaged area. We now believe that the brain has a greater degree of plasticity than was once thought. How to stimulate this is a great challenge that is being worked on diligently.

A number of compensatory techniques are used to work with the cognitive problems of MS. First, those problems need to be found and their extent measured. This is done through testing, either by a speech pathologist or more formally by a neuropsychologist. Remember that nobody's memory is perfect. Stress, anxiety, and fatigue all decrease cognition, especially memory. Poor concentration may add to the problem. Depression must be treated. A person with MS often does not recognize his or her depression but may respond to medication and therapy. Psychologic tests may be necessary to make the diagnosis of depression.

The following strategies have been found to be helpful in managing cognitive problems:

- Make lists—shopping lists, lists of things to do, and so forth.
- Use a calendar for appointments and reminders of special days.
- Establish a memory notebook to log daily events, reminders, and messages from family and friends.
- Use a tape recorder to help remember information or make up lists.
- Organize your environment so that things remain in familiar places.

- Carry on conversations in quiet places to minimize environmental distractions.
- Ask people to keep directions simple.
- Repeat information and write down important points.
- Establish good eye contact during any discussion.

Cognitive problems may be minimized if a person with such a problem can be made aware that it exists and is willing to change her mode of operation by using compensatory techniques. Part of the difficulty is perceiving this awareness without creating antagonism. This is the age of computers, and both electronic and nonelectronic organizers may be especially helpful in organizing your life.

Cognitive rehabilitation has not been well established for MS as yet, but the beginnings are taking shape. Although cognitive rehabilitation can teach people some ways to compensate, in general it has not become a practical way to counteract the losses of brain demyelination. The best strategy is to prevent the damage from occurring with aggressive earlier treatment with immune modulation.

## Part **III** Your Total Health

# Chapter 19

### DIET AND NUTRITION

Daniel Kosich, Ph.D.

Although there are many testimonials, advertisements, and anecdotal recommendations suggesting nutritional treatments for MS, no conclusive scientific evidence shows any nutritional therapy affects the course of MS.

Many of the dietary regimens that are claimed to benefit MS are not harmful, but many of them require rigorous and often stressful attention to detail without improvement in MS symptoms. Some of

> No conclusive scientific evidence shows any nutritional therapy affects the course of MS.

them may be risky, especially those that advocate meganutrient supplementation, because many nutrients may have serious side effects when they are taken in excessive amounts. In addition, regimented diets and eating plans often are quite expensive! Practicing a sensible nutritional life-style is not very difficult it is mostly common sense. It *does* take persistence and discipline, especially if a change in dietary habits is necessary. Keep in mind that, although there is no evidence to support nutritional therapy in the treatment of MS, many studies clearly show that sensible eating habits have a dramatic beneficial impact on many other aspects of health. For instance, the risks of heart disease, certain types of cancer, and obesity all can be reduced simply by following a healthy nutritional life-style.

#### BASIC CONCEPTS IN NUTRITION

Nutritional scientists have identified six general components of all life processes: proteins, carbohydrates, fats, vitamins, minerals, and water.

#### Proteins

Proteins are composed of various combinations of building blocks called *amino acids*. From approximately 22 amino acids, the body makes the many thousands of different proteins that constitute not only the major structural components of cells but also the enzymes and many of the hormones that control and regulate chemical reac-

Proteins are necessary not only for growth but also for the normal maintenance and repair of body tissues.

tions in the body. Proteins are necessary not only for growth but also for the normal maintenance and repair of body tissues. Additionally, much of the body's protection against disease is carried out by a group of proteins called *antibodies*. Although proteins also are a potential source of energy, they generally are "spared" (not used for energy) when enough carbohydrate is available. Approximately 15 to 20% of the daily caloric intake should be from proteins.

#### Fats

Fats are a primary source of energy for muscles. One gram of fat provides nine calories of energy, more than twice as much as carbohydrate or protein. Fats also are important because they help the body absorb other important nutrients, help insulate the body against heat and cold, and provide a protective cushion around vital organs.

There are two types of fat. Saturated fats, such as butter, are of animal origin and are solid at room temperature. Unsaturated fats, such as corn oil or olive oil, come from plants and are liquid at

> Fats are important because they help the body absorb other important nutrients, help insulate the body against heat and cold, and provide a protective cushion around vital organs.

room temperature. Most of our fat intake should be unsaturated fats, because saturated fats have been shown to increase the cholesterol level and risk for heart disease. Fat should provide approximately 20 to 25% of the daily caloric intake.

#### Carbohydrates

Carbohydrates provide the body with its most critical source of energy. In fact, carbohydrate must be present if muscles are to use fat for energy.

Carbohydrates come in the form of simple sugars—found in candy, soft drinks, or honey—that can link together to form long

chains called *complex carbohydrates*—such as those in vegetables, grains, and legumes (beans and peas). This complex carbohydrate is called *starch*.

Most of the recommended 60 to 65% of daily calories from carbohydrates should come from starches rather than from sim-

Carbohydrates provide the body with its most critical source of energy.

ple sugars. The body is better able to make use of the sugars in starch, which are broken down and released gradually, than of simple sugars, which cause a rapid rise and subsequent fall in blood sugar.

#### Vitamins and Minerals

Vitamins are nutrients that are needed in small amounts to play a vital role in the proper functioning of tissues such as nerves and muscles. Vitamins also play an integral role in the breakdown of carbohydrate and fat to make energy.

Vitamins are classified as *fat-soluble* (vitamins A, D, E, and K) and *water-soluble* (vitamin B complex, vitamin C). Fat-soluble vitamins are effectively absorbed from the digestive tract into the bloodstream only in the presence of fat. That is why taking a multivitamin with just a glass of water is simply a waste of money! On the other hand, because these vitamins are stored in fat tissue, it is quite possible to ingest toxic doses of the fat-soluble vitamins by megadosing on them.

Water-soluble vitamins are not stored as effectively as fat-soluble vitamins. However, recent evidence indicates that it also is possible to overdose on water-soluble vitamins.

Minerals, such as phosphorus, iodine, and magnesium, are substances that not only give strength to tissues such as bones and teeth but also play a crucial role in the body's chemistry. More than 20 different minerals, from calcium to zinc, are essential to optimum function.

Many nutritionists believe that a diet that includes a wide variety of foods eaten in the recommended percentages for carbohydrate, protein, and fat provides adequate vitamin and mineral intake, with no need for supplements. Others recommend supplements, especially for those whose low activity level suggests the need for only a modest amount of food each day.

Because some people with MS are not very active, it may be a good idea to take a daily multivitamin/mineral supplement to ensure that nutrient intake is adequate. No nutrient should be taken in excess of approximately 15% of the recommended daily allowance (RDA). Always ask your doctor about individual needs for supplementation.

#### Water

Although it is not often thought of as a nutrient, water is the "medium of life processes" (approximately 60 to 70% of the body is water). Water provides for the transportation of nutrients and hormones in

> Normally you should drink eight glasses of water per day in addition to that obtained from foods. This amount should be increased when exercising, especially in a hot environment.

the blood. It also is vital in removing waste products from cells and helping to regulate body temperature, a function that is especially important in MS because a rise in body temperature may lead to fatigue or an increase in symptoms.

Normally you should drink eight glasses of water per day in addition to that obtained from foods. This amount should be

increased when exercising, especially in a hot environment. Drink small amounts (two to three ounces) frequently rather than large amounts at longer intervals to cut down on trips to the bathroom.

#### A BALANCED DIET

In nutritional terms, 60 to 65% of daily calories should come from carbohydrates, 15 to 20% from proteins, and 20 to 25% from fats. Rather than focusing on these percentages, it is easier to simply recognize that most of your food should come from grains, vegetables, fruits, low-fat dairy foods, and legumes, with minimal amounts of lean meats, fish, and skinless poultry. This combination of foods provides nutrients in the recommended percentages. The U.S. Department of Agriculture has recently introduced the food guide pyramid to help make daily food choices.

#### Food Guide Pyramid: A Guide to Daily Food Choices

The food guide pyramid may help in deciding what and how much food to eat from each food group. It suggests adequate nutrients without excess calories, fats, cholesterol, simple sugar, or sodium. It is important to include selections from all five food groups in the diet.

The pyramid emphasizes reducing the amount of fat in the diet because most Americans eat too much fat, especially saturated fat.

The largest portion of the daily diet should come from the group at the bottom of the pyramid—grains. Choose whole grains rather than refined flour as much as possible because they have

Carrying a notebook and marking down your daily food intake may be an eye-opener.

more nutrients and more fiber. Six to eleven servings per day are appropriate. Keep in mind that a serving consists of one slice of bread or one half cup of rice.



A guide to daily food choices.

Carrying a notebook and marking down your daily food intake may be an eye-opener. At the end of three days, match the food groups and the recommended servings. Then make appropriate changes in your diet. As a complement to the food guide pyramid, the Department of Agriculture has made the following general recommendations about several aspects of nutritional life-style.

#### **Dietary Guidelines**

- 1. Eat a wide variety of foods.
  - Choose a daily selection from each of the five basic food groups in the pyramid according to servings recommended.
  - Emphasize adequate amounts of foods high in complex carbohydrate: whole grains and a wide variety of vegetables and fruits each day.
- 2. Avoid too much dietary fat (especially saturated) and cholesterol.
  - Read food labels.
  - Eat low-fat dairy foods.
  - Eat lean cuts of meat such as flank steak, lean round steak, ocean fish (except smelt), and skinless poultry. Limit meat consumption to three to four ounces per day.
  - Limit the amount of fat added to foods (butter, oils, dressings, and spreads).
  - Bake, broil, and boil instead of frying.
- 3. Reduce simple sugar intake (table sugar, molasses, honey, corn syrup, refined and processed foods, and so on).
  - Drink less canned soda and sweetened beverages.
  - DRINK MORE WATER!
  - Use these seasonings to replace sugar in recipes: vanilla extract, cinnamon, allspice, cardamom, nutmeg, mint, mace, clove, and ginger.
- 4. Avoid too much sodium.
  - Many foods provide sodium. Add less than one-half teaspoon of salt per day to your food. Eat a variety of vegetables and whole grains.
  - Use these foods to add a "salty" flavor to recipes: onion, garlic, parsley, celery, cayenne, chili powder, rosemary, sage, tarragon, oregano, and basil.

5. If you drink alcohol, do so in moderation (no more than one to two ounces per day).

#### WEIGHT CONTROL

One of the most common concerns of everyone, including those who have MS, is how to achieve and maintain a healthy body weight. In addition to good nutrition, activity is crucial.

Often, especially when the capability to exercise is limited, the choice is made to help regulate body weight by not eating very much. This may be risky because eating enough of the right kinds of foods is as important as exercise in overall weight management.

Most often, very low calorie diets do not lead to effective weight control in the long run but may actually make the body store more fat.

#### Low-Calorie Dieting

- 1. The body quickly begins to decrease its basic calorie expenditure (the basal metabolic rate) to conserve energy. Thus, fewer calories are burned, not more.
- 2. The body does not function properly without enough carbohydrate, and it begins to convert muscle protein to carbohydrate so that it can continue to make energy. Losing muscle tissue is not desirable. Of a ten-pound weight loss in two weeks, only approximately two to three pounds are fat because approximately five pounds are water and two to three pounds are lost from muscle.
- 3. While all this is going on, the body is increasing its ability to store fat when it gets enough calories sometime in the future. This is a basic survival mechanism for times of inadequate food intake, but it is not desirable when the goal is weight loss or weight maintenance.

It certainly is possible to lose weight on a low-calorie diet. However, the period of rapid weight loss typically lasts only about a week or two, and then it stops. During that period the body "readjusts" its metabolism to survive on fewer calories. When a more normal caloric intake resumes, the body takes advantage of its increased "fat-storing" ability to increase its energy reserves in stored body fat. The weight lost as water and muscle is not replaced as water and muscle; it is replaced as fat. Over time, even though total weight may not actually change significantly, the percent of body fat may increase dramatically. This clearly is not the desired goal.

Because of the associated risks and poor long-term success rate, low-calorie diets should only be attempted under the supervision of a physician. Keep in mind that in the long run success

> Because of the associated risks and poor long-term success rate, low-calorie diets should only be attempted under the supervision of a physician.

most likely will be achieved by eating enough of the right kinds of foods and by being as active as possible within the limits of your individual situation.

#### **Reading Nutrition Labels**

One of the easiest ways to keep track of the amount of fat is to read nutrition labels to determine the percentage of calories in a food item provided by fat.

To quickly read the label on a prepared food item, just remember that each gram of fat provides 9 calories.

1 gram of fat = 9 calories

Read the following label as an example:

Nutritional information per serving (2 tbsp)

Calories per serving = 210 calories Carbohydrate = 5 grams Protein = 10 grams Fat = 18 grams

To find the number of calories supplied by fat:

1. Multiply the grams of fat by 9

 $18 \times 9 = 162$  calories

2. Divide the number of calories from fat by the total calories to determine the percent of calories from fat

$$162/210 = 77$$
 percent

Linumpios of rood Lubois				
Food Item	Quantity	Calories	Fat (g)	% Fat
Milk (4%)	1 cup	150	9	54
Milk (2%)	1 cup	120	5	38
Milk (skim)	1 cup	90	1	10
Cottage cheese	1/2 cup	120	5	38
(whole milk)				
Cottage cheese	1/2 cup	90	1	10
(1% milk)				
Yogurt, plain	1 cup	160	7	31
(whole milk)				
Yogurt, plain	8 oz	140	3	15
(1% milk)				
Granola bar	1	140	7	35
(sugars are 7 out				
of 13 ingredients!)				
Candy bar	1	270	13	43
Butter	1 tbsp	100	9	99
Margarine	1 tbsp	100	9	99
"Chips"	1 oz	160	10	56

#### Examples of Food Labels

Therefore, this food item (peanut butter) is approximately 75% fat calories. Does that mean it is a "bad" food? No, it simply suggests that it should be eaten in moderation.

Remember that of all the food eaten each day approximately 20 to 25% of the calories should be from fat. Any one food item (such as peanut butter) that is high in fat should be eaten only in small quantities.

A sensible nutritional life-style is simply a question of balancing the appropriate number of servings from the pyramid. The peanut butter comes from the top of the pyramid. Put it on two slices of whole grain bread (from the bottom of the pyramid) to make a nutritious sandwich. Add a carrot, an apple, and a glass of skim milk and you have a great lunch!

Some examples of food labels are shown in the following table.

#### CUTTING FAT CALORIES

Because reducing the amount of dietary fat is important for both health and weight control, here are some reinforcements and specific suggestions on ways to reduce the amount of dietary fat:

- Decrease or omit your use of butter, margarine, spreads, mayonnaise, and salad dressings. Remember that each gram of fat eliminated also eliminates nine calories. Using one teaspoon of dressing instead of one tablespoon reduces the fat calories by 67 percent!
- Change the way foods are prepared. Deep frying greatly increases the fat content of many foods. Learn to bake, broil, boil, and microwave, and use nonstick cooking pans.
- Decrease the amount of meat you consume. Most meats, especially red meats, contain more fat calories than protein calories. For that reason, it is important to select fish, poultry, and lean cuts of beef, such as rump, round, and flank.
- Be aware that many dairy products are high in fat. For instance, whole milk (labeled as 4% milkfat) actually contains approximately 50% fat calories because of the caloric

density of fat. Cheeses made with whole milk often have 75% or more of their calories from fat. Therefore, it is important to select from low-fat dairy products, such as skim milk and 1% milk, and yogurt and cheeses made with low-fat milk. If you have lactose intolerance, ask your doctor if taking milk products with Lactaid<sup>®</sup> might allow the nutritional benefits of dairy foods.

Perhaps the most important consideration is that *you* decide what kinds of foods you eat. It is not easy to change habits, and tastes take a long time to change. Be patient; good eating is in every-one's best interest.

Any food may be eaten in moderation. Appreciate it for what it is, enjoy it, and blend it into a sensible nutritional life-style.

The key is moderation. Any food may be eaten in moderation. Appreciate it for what it is, enjoy it, and blend it into a sensible nutritional life-style.

#### Weight Gain

Weight gain may be a problem in MS if your activity level drops but your caloric intake remains constant. Very few people who are overweight do not know it; there is little point to continuous comments about it to an overweight individual. No data indicate that weight gain causes or is associated with weakness, but it is not good for your overall health and is unattractive to many people. It may make general movement more difficult than necessary, especially aided transfers.

People who are overweight usually would like to be thinner, but they often can do very little to change the situation. Decreasing caloric intake only works to a certain extent if the activity level cannot be increased. Understanding that one sometimes has to deal with a situation the way it is and not fret over what cannot be done makes for a better quality of life.

A number of exercises can be done from chairs or beds to keep limber and Increase muscle tone. It takes real ambition to stick to the exercise program but it is quite important. People who use a wheelchair often appear to have weight gain in the abdomen. This usually is unavoidable because they cannot do enough repetitions of stomach-firming exercises to change the situation.

The same basic dietary guidelines that apply to others also apply to people with MS. Appetite suppressants have little long-term effect. You must strive for a balance between exercise, calories, and

> The same basic dietary guidelines that apply to others also apply to people with MS.

fatigue. 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.

# Chapter 20

### Exercise

All too often people with MS are told to rest and not overdo, and the fear of fatigue may become almost unbearable. There is no real basis for this fear. *People with MS are not fragile!* Good clinical studies have shown that *proper* exercise increases fitness and reduces fatigue. The process is slow and begins with a carefully developed exercise prescription. Like medication, it should be prescribed by a professional, usually a physical therapist or a physician who knows how to develop exercises for a specific individual.

The exercise prescription should have four elements:

- 1. The *type* of exercise (aerobic, strengthening, balance, coordination, stretching, and so on)
- 2. The *duration* of exercise (how long you should exercise)
- 3. The *frequency* of exercise (how often you should exercise)
- 4. The *intensity* of exercise (how hard you should exercise)

The role of exercise in MS has become somewhat controversial, partly because the meaning of the term exercise is misunderstood. To many people, *exercise* is defined as stressing their bodies to the point of pain, an approach whose watchwords are "no pain, no gain." But it has become quite clear that if a person with MS exercises to the point of pain, fatigue will set in and weakness will increase. Rigorous exercise also increases the core body temperature (as opposed to superficial skin temperature). The myelin coating that

The role of exercise in MS has become somewhat controversial, partly because the meaning of the term exercise is misunderstood.

normally surrounds nerves protects them from the effects of this rise in temperature. Because of the loss of myelin in MS, a rise in core body temperature increases the amount of short-circuiting in the central nervous system, worsening existing symptoms and sometimes producing new ones. This is why exercise originally fell into bad repute with those who are 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 overall "fitness" has developed.

It is important to tailor an exercise program for each individual rather than have a set program for everyone who has the disease.

Fitness is a holistic concept that implies general overall health and whose goal is improved function of the heart, lungs, muscles, and other organs. It is attained by proper diet, not smoking, and exercising appropriately. Two major concepts underlie the term *appropriate* exercise. First, because of the wide variability of the disease, what is "good" exercise for one person may not be good exercise for another. It is important to tailor an exercise program for each individual rather than have a set program for everyone who has the disease. The second concept is that there are many kinds of exercise—"exercise" does not mean only running, jumping, or similar aerobic activities.

More work is required to move stiff muscles, resulting in early fatigue and increased weakness. Exercises that increase mobility through stretching and maintaining range of motion are discussed in Chapter 5, and a series of basic exercises is given in Appendix A. These exercises play an important part in combating weakness by reducing the stiffness that so commonly is present in MS.

Balance exercises are discussed in Chapter 7. These exercises are very different from those that are used to reduce spasticity. If balance is a problem, muscles must use more energy to maintain an upright stance, and anything that increases balance will therefore reduce weakness.

Relaxation exercises are discussed in Chapter 22. A person who is under stress will experience an increase in weakness. For this reason, techniques for learning how to relax should be part of any overall program designed to reduce weakness and fatigue.

Aerobic exercises are what most people think of as "real" exercise. They may involve using a bicycle, rowing machine, or treadmill, brisk walking or running, or a brisk self-wheel in a wheelchair. It is important to understand that the word *aerobic* implies that the body is taking in enough oxygen to meet its needs in the exercise program. This is compared with the anaerobic state that occurs when a person exercises too aggressively and starves the body of oxygen. *Endurance increases slowly but surely under aerobic conditions.* 

Specifically, you should be able to speak a sentence out loud during any aerobic exercise (except perhaps swimming). Enough air should be available to permit clear and somewhat effortless speaking. If you cannot speak in this fashion, it is likely that the type and/or extent of exercising is anaerobic and harmful. The proper exercise prescription takes into account that no exercise should cause pain. "No pain, no gain" is absolutely the wrong approach to exercise for the person with MS. The proper

"No pain, no gain" is absolutely the wrong approach to exercise for the person with MS.

exercise prescription is a balanced one that includes many different types of exercises with the goal of improving overall condition. With such an improvement, a parallel gain in strength is to be expected.

# Chapter 21

### SEXUALITY

Sexuality is a complex part of life, one that is difficult to define or measure because its expression is special and private for each individual. It has its roots in being human and adds a richness and pleasure to life that goes far beyond the sexual act. Although our society has recently become more open about sex and sexuality, many myths and negative attitudes still exist concerning the sexuality of those who have a chronic illness such as MS. Many people think that a diagnosis of MS means that their sexual life has ended, that it somehow is wrong or "inappropriate" to continue having sexual needs or to seek information about maintaining a satisfying sexual life.

Sexuality does and should continue to be an important part of life for people with MS. Sexuality affects your basic feelings of selfesteem and your views of yourself as masculine or feminine. It provides pleasure and relaxation, and it is an important aspect of relationships with a spouse or significant other because sharing a sexual life strengthens the attachment between partners.

A chronic illness such as MS may have a tremendous impact on sexuality. Sexual functioning—the actual physiology and mechanics of sex, may be affected by physical changes resulting from illnessrelated neurologic changes or by the presence of symptoms such as spasticity, bowel and bladder problems, pain, and fatigue. The psychological feelings associated with coping with an illness such as MS, including anxiety and depression, also may interfere with sexual expression and desire. Additionally, the partner of an individual who is coping with illness may experience a similar range of feelings, which may interfere with his or her sexual ability and interest.

Although there may be changes in sexuality in reaction to MS, sexual needs neither disappear nor become inappropriate. This chapter discusses both possible changes in sexuality that may occur as the result of MS and strategies to obtain information and maintain a positive sense of sexuality in the presence of the disease.

#### THE SEXUAL RESPONSE

The sexual response depends on a complicated series of reflexes that involve the neuromuscular transmissions stimulated by a wide variety of visual, tactile (touch), olfactory (smell), and emotional sensations. Sexual excitement and response begin in the brain. Electrical signals are transmitted from the brain areas involved via the spinal cord to the sexual organs or genitals, through nerves that exit near the base of the spinal cord. The pathways between the brain and the genitals are long and complex, and demyelination may "short-circuit" them.

Impulses leave the CNS from the sacral spinal cord via the autonomic nervous system, which controls bodily functions that are considered "automatic." For example, this system controls the arousal that men and women experience without external stimulation, such as that which occurs during sleep. There are two divisions to the autonomic nervous system, the *parasympathetic* and the *sympathetic*. The parasympathetic section controls the erectile response. Erections in men may be stimulated by visual stimuli. Obviously, for a visual stimulus to cause an erection, there must be an intact pathway from the brain down the spinal cord to the sexual organs. Demyelination may interfere with the connections from the "brain erection center" to the target organ, the penis. There is clear evidence of a spinal center for erection as well as the brain center. As a result, reflex erections still may occur, but even when desired, willed erections may become impossible. Stimulation of the penis by masturbation or as part of sexual foreplay may allow an erection to occur if the pathway from the penis to the spinal cord and within the spinal cord back to the penis remains intact. This stimulation may require greater intensity if there is numbness or if sensation to the stimulus is decreased. Finally, erections may occur during sleep that may or may not have to do with these centers.

The normal male sexual response has three phases: desire, lubrication-swelling (excitement, plateau phases), and orgasm. The first response to sexual stimulation is erection, which is accompanied by increases in muscle tension, heart rate, blood pressure, and respiration. This then "plateaus" with advanced lubrication and swelling and is followed by a series of contractions by which the sympathetic nervous system allows for ejaculation (emission). Finally, the body returns to its resting state during the resolution stage.

The penis has soft, spongy tissue that easily expands when it is filled with blood. The tip of the penis, the bulb, is very sensitive to stimulation and sends messages to the various centers if it is appropriately stimulated. These centers allow the parasympathetic system to be stimulated, causing blood to be trapped within the spongy tissue of the penis to produce an erection. Ejaculation, the expulsion of liquid (semen) from the penis, is handled by the sympathetic division. When the stimulus ends or ejaculation occurs, the blood flows out of the penis and the erection disappears.

The external female genitalia, or vulva, consists of the labia majora (large outer lips of the vagina), the labia minora (smaller inner lips), the clitoris, and the vestibule. Like the male penis, the clitoris contains spongy tissue and a significant number of blood vessels. Bartholin glands, which produce a lubrication fluid, lie adjacent to the vagina.

As in men, the phases of normal female sexual response include desire, lubrication-swelling (excitement and plateau phase),

and orgasm. The factors involved in the desire phase are not well understood but clearly may be affected by MS. Increased sexual excitement is accompanied by muscle tension, increased blood flow to the clitoris, and the beginning of vaginal lubrication, which then plateaus with increased lubrication and swelling. Orgasm consists of rhythmic contractions of the muscles around the vagina and uterus.

#### SEXUAL PROBLEMS IN MULTIPLE SCLEROSIS

Given the complexity of the sexual response in terms of the neuromuscular transmissions involved, it is no surprise that sexual difficulties often are encountered in MS. Such difficulties frequently are clearly physical, although a psychological component may be involved in many or most instances of difficulty.

More than 90% of all men with MS and more than 70% of all women with MS report some change in their sexual life after the onset of the disease. Men most often report impaired genital sensation, decreased sexual drive, inability or difficulty in achieving and maintaining an erection, and delayed ejaculation or decreased force of ejaculation. Women report impaired genital sensation, diminished orgasmic response, and loss of sexual interest; they also may be bothered by intense itching, diminished vaginal lubrication, weak vaginal muscles, and a reflex pulling together of the legs (adductor spasms).

#### MANAGING SEXUAL DIFFICULTIES

The diagnosis of MS may alter one's self-image, and it is common to feel sexually unattractive when one is concerned about braces, wheelchairs, and catheters. Perhaps the single most helpful approach to managing sexual difficulties is to focus on becoming comfortable with your body, a goal that requires time and commitment. It is important to identify your positive personal qualities and to put effort into feeling good about yourself by taking care of your body through exercise, diet, dress, and so forth. Feeling good about
yourself will help to defeat the myth that you must have a "perfect" body to be sexually attractive.

Communication is critical to achieving a positive, enjoyable sexual relationship, and feelings must be dealt with openly and honestly. It is important to convey information about what feels pleasurable and what does not and to experiment with different sexual positions and creative, alternative ways to give and receive pleasure. Our society emphasizes "normal" or proper ways to obtain sexual gratification, which tends to make sex goal-oriented toward intercourse and orgasm. However, many people find great physical and psychological satisfaction from activities that traditionally have been termed *foreplay*. One excellent way to decrease or completely eliminate pressures and expectations is to become less goal-oriented by renaming such activities sexplay. Sexual expression may be directed to parts of the body other than the genitals, increasing cuddling, caressing, massage, or other forms of touch, and it may involve experimenting with oral sex, masturbation, a vibrator, or other devices.

Emotional reactions may be an issue for both the person with MS and his or her partner because anxiety, guilt, anger, depression, and denial are the natural consequences of coping with any chronic illness. Again, communication between partners is the key to managing such feelings. Couples should be sensitive to the fact that some painful feelings may not improve or disappear with communication and support. In that case, it may be helpful to seek professional help in response to depression or anxiety that will not go away.

To avoid bowel, bladder, and catheter problems during intercourse, fluids should be reduced approximately two hours before sexual activity and the bladder should be emptied before lovemaking. Be prepared in case an accident occurs despite these precautions, and remember that it is not a catastrophe. If a catheter is used, it may be taped over a man's penis or to a woman's abdomen. A vaginal lubricant such as K-Y jelly should be used whether a woman uses a catheter or not.

Spasticity or leg spasms may be minimized by timing antispasticity medication so that it is maximally effective during sexual activity. Having intercourse in a side position, with the knees bent or using pillows for support, may make a difference and should be tried.

A vibrator may compensate for a loss of deep pressure sense, which is reflected as impaired sensation, numbness, and tingling. A number of different types are available, including hand-held, penisshaped, and others. They are easily obtained via the Internet. A new device called "Eros" has been approved by the FDA for sexual dysfunction in the female. It places gentle suction on the clittoral region while applying a gentle vibration. The judicious use of a frozen bag of peas rubbed gently in the vaginal area has been reported to increase sensation and decrease pain for some people. Lubrication difficulties in women may be managed by vaginal packets of lubricants that open on impact, such as Replens or Astroglide.

Several alternatives are available if a man's erections are insufficient for penetration and intercourse. The use of surgically implanted penile prostheses has decreased dramatically as nonsurgical alternatives have become popular. A solid erection may be obtained in most men with injectable prostaglandin, or Caverjet<sup>TM</sup>, which is injected using a small needle approximately 30 minutes before intercourse and almost always creates a strong erection.

An alternative involves the same prostaglandin medication administered into the opening of the penis (urethra) via an applicator. This system, which is called MUSE, is available by prescription. It usually gives an adequate erection with stimulation from one's partner. A rubber band placed at the base of the penis after erection occurs may hold the erection for a longer period of time.

There are many penile vacuum devices, which consist of a tube that is placed over the penis with a rubber band around the top of the tube. A pump removes the air from the tube, creating a vacuum that draws blood into the penis to produce an erection. When the erection is adequate, the rubber band is slid onto the base of the penis and the tube is removed. The erection produced by this method is not as firm as an erection produced by other methods, but it may be adequate for many people. No medication has been proven to stimulate ejaculation, but the antidepressant trazodone has been reported to be helpful for some people when used at a dose of 5 to 10 mg one hour before intercourse. Testosterone injections and the oriental drug yohimbine have been used with variable but not encouraging success. Sildenafil (Viagra<sup>®</sup>) often allows for a good erection, and has become a major advance in the management of erectile dysfunction. It is taken by mouth 30–60 minutes before intercourse. Absorption is faster if it is crushed and swallowed. The dose is 50–100 mg. It must be understood that foreplay is essential to its working.

Although great strides have been made in diagnosing sexual difficulties and providing alternatives, the key remains good communication between partners and between the person with MS and his or her health care team. By exploring options, requesting information, and seeking appropriate referral, a satisfying sexual life may be maintained while coping with the diagnosis of MS.

C h a p t e r ノノ

## Adapting to Multiple Sclerosis

Adapting to MS begins when the first symptom appears. It usually is vague—mild numbness, some tingling, possibly a feeling of weakness, or occasionally some urgency of urination. The initial thought is to deny the problem and ignore it. However, if the symptom persists, fear overcomes denial, often accompanied by selfdirected anger. The fear is that of "going crazy," of believing that nothing really is wrong but it is "all in my head."

Often the opinions of several physicians are sought, including family doctors, internists, and neurologists. Some physicians are vague about the problem, refraining from giving it a name, whereas others may mention MS. Stress and fear build until the tests are completed and the diagnosis is confirmed. This often is followed by a sense of relief that the problem is medical rather than psychological.

However, this relief soon disappears, and anger accompanied by grief surfaces once again. These feelings often are directed somewhat randomly, sometimes toward family, friends, or physicians as if they were responsible for the disease. A lack of understanding leads to more anger, fear, and resentment, and a "why me?" feeling tends to develop.

Some parallels may be drawn between the process of adjustment to MS and the stages of grief, as described by Elisabeth Kubler-Ross in her book *On Death and Dying*. She observed that people initially deny that death will occur. This is followed by anger, then by a bargaining stage, which in turn evolves into depression, and finally into acceptance. The order may vary but the process is fairly constant. Family and close friends also go through this adjustment process, and children may follow suit in their own way.

As grieving evolves into depression in the newly diagnosed person with MS, it may be accompanied by loss of sleep, change of appetite, and feelings of despondency. This sequence results from decreased self-esteem; changes in self-image, life plans, goals, and values; and frequently a fear of rejection by family and friends. Resolution of these feelings is hoped for at the end of the cycle, accompanied by the feeling of peace that comes with the understanding that life must go on.

Dr. David Welch (personal communication) has observed the following stages of development in understanding MS:

- 1. *Admission.* The individual allows him/herself to admit the reality of MS. This admission is private and involves no one else. Implicit in this admission is that from that moment on all relationships will in some way be altered.
- 2. *Acknowledgment*. Eventually the fact that one has MS is reluctantly disclosed. Other people need to know if they are to respond properly to the person with MS.
- 3. *Accommodation*. The disease requires the subordination of some things to the requirements of others.
- 4. *Adaptation.* The environment needs to be modified to suit the conditions. The world needs to be changed to suit the person with MS, not the reverse.

There are a number of ways to deal with all the adjustments required by MS. The element of stress is constant throughout all phases of the adjustment process. Its effect on the actual demyelination process is unclear, but in all likelihood stress does not increase demyelination. A flare-up of MS symptoms in a person under stress is not a true exacerbation caused by increasing demyelination, despite the fact that stress clearly enhances the symptoms caused by demyelination. The brain has remarkable powers to compensate for the effects

> The brain has remarkable powers to compensate for the effects of disease, but it often loses this ability when one is under stress.

of disease, but it often loses this ability when one is under stress. Symptoms that previously were compensated for will then be uncovered. The person with MS therefore will appear to have increased symptoms and problems, which may in turn lead to more stress. It is therefore important that ways of coping with stress be developed.

Under normal conditions, stress usually forces one to change and readjust one's outlook. However, the chronic stress that accompanies a disease such as MS may instead result in continued decompensation and maladaptation. This only perpetuates the stress, and the stress–illness relationship becomes quite complicated. Simply put, the stress feeds the illness, and the illness feeds the stress.

All of this results in an angry and despondent person. Anger is what shows on the outside, but depression is the internal mood. The person feels betrayed by his or her own body. The anger alienates others just when their support is most needed. This cycle has led to the perception of an "MS personality." There is *no* evidence that a specific personality exists in people with MS. Rather, a loss of self-esteem brought on by the perceived loss of physical function leads to mourning these losses, which in turn results in the development of personality traits that may be perceived as very different from those of the "predisease" state.

It is important to understand that MS is actually a disease of the central nervous system, which includes the brain. That means that the MS process by itself will change the biochemistry of the brain. This may result in what appear to be emotional changes, but that are really biochemical changes that result in a change in feelings and behavior. Because these are neurochemical they usually require neurochemical treatment with antidepressents or similar agents. They require some skill on the part of the physician to understand and use the proper medications. They require understanding by the person with MS that a problem exists and that it needs help. All to often the person does not see or feel the difference and the family has to point out how differently she is behaving.

Very occasionally, the bulk of the demyelination associated with MS occurs within the brain, and intellect ("smartness") actually decreases. Memory, planning, and foresight diminish, and the personality changes. Initially these changes are subtle, but they increase with time. Emotional lability is the hallmark of this type of disease, with inappropriate episodes of crying and/or laughing. Older memories are lost last in this type of MS, whereas remembering recent events presents the most difficulty. These changes are the result of demyelination rather than psychological causes. Thus, counseling for this problem must be focused on understanding and adjustment. Counseling family and friends can lead to better understanding. Antidepressants may help in controlling some of the emotional lability, whereas tranquilizers sometimes are necessary to control behavior. *It is important to emphasize that this type of MS is rare.* 

Most life-style stresses caused by MS are helped by appropriate counseling. Many people with MS do not want to recognize the psychological component, and counseling must be subtly offered or it will be strongly refused. Coping skills must be developed on an individual basis; they cannot be learned simply from reading a book. These skills involve learning to deal effectively with stereotypes of the disabled in the community, perceived changes in masculinity or femininity, changes in relationships, changes of roles within the family, changes in employment status, increased dependence on others, and changes in physical condition.

Some practical coping techniques include:

- Make a list of conditions required for positive self-esteem, and discipline yourself to create at least some of them
- Determine a way (small or large) to contribute to society and follow through with your plans
- Attend appropriate counseling sessions
- Learn to say no to certain requests in such a way as not to damage your self-esteem
- Make a list of people who can be relied on for various kinds of support and call on them for assistance when feelings of despair appear
- Discipline yourself to stay as healthy and as physically fit as possible
- Create opportunities to get out of the house
- Take charge of situations rather than allowing them to dictate to you, and
- Prioritize projects

### RELAXATION TECHNIQUES

Although stress usually is viewed as something to be avoided, realistically the key is to learn proper ways to manage unavoidable stress. Some stress is desirable—it energizes us, motivates us, and captivates our interest. The stress that must be managed is the "distress" that may hamper our ability to cope with the events and people in our lives.

Body and mind are linked, and stress affects both our physical and emotional well-being. Stress may produce physical signs such as "knotting" of the stomach, increased spasticity, headaches, tight or sore muscles in the neck, and an increased pulse rate. If left unchecked, more severe symptoms will appear, such as insomnia, fatigue, anxiety, poor concentration, and poor problem-solving abilities.

Although stress usually is viewed as something to be avoided, realistically the key is to learn proper ways to manage unavoidable stress.

Relaxation techniques provide a tool with which stress can be controlled, putting you in better overall control of your life and your well-being. *Relaxation takes practice!* To be successful, you must learn to keep a passive attitude and let go of thoughts that drift in and out of your mind. The following steps should be practiced until they become second nature.

- Begin by finding a quiet place where you will be undisturbed for half an hour or so.
- Sit with your arms, head, and feet supported, or lie down.
- Close your eyes. You may wish to turn on soft music.
- Focus on your breathing. The goal is deep, steady, smooth, and rhythmic breathing.
- Relax your muscles by working systematically through your body. Tell yourself to relax your feet, calf muscles, thighs, buttocks, abdomen, chest, arms, hands, neck, and head. Let your body become heavier and heavier with each breath.
- Now imagine yourself in a pleasant setting. Guide yourself on a fantasy trip to a place you always wanted to see or revisit. Explore this place with all of your senses.
- When you have spent enough time there, leave knowing that you can return at will. Slowly open your eyes and enjoy the calm.

Individual counseling is helpful when you are having difficulty making the necessary adaptations, when you have a lot of anger, when depression becomes an ongoing problem, when self-esteem fails, or when you have difficulty accepting the existence of MS.

Group counseling may be helpful when you think that no one understands your problems or if your support system is inadequate.

The person with MS need not go through life waiting for "the other shoe to drop." By understanding some of the psychological changes that accompany chronic disease, you may take an active role to achieve a healthy mental state. The physically challenged must also win the "mental/emotional" challenge. There is no simple way to do this, but it is clear that if one surrenders, one loses!

## Part IV Appendices



### GLOSSARY

Abductor muscle—A muscle used to pull a body part away from the midline of the body (e.g., the abductor leg muscles are used to spread the legs).

Adductor muscle—A muscle that pulls inward toward the midline of the body (e.g., the aductor leg muscles are used to pull the legs together).

ACTH—Adrenocorticotropic hormone; a hormone produced by the pituitary gland that stimulates the adrenal glands to produce cortisone.

Affective disorder—A disturbance of mood in an individual, such as depression.

Allergic encephalomyelitis (EAE)—A disease of animals and occasionally of humans in which an immune reaction (allergic) occurs involving the nervous system (brain and spinal cord); similar to MS in many ways.

Amino acids—Compounds composed of carbon, nitrogen, and an acid; the building blocks of proteins.

**Amyotrophic lateral sclerosis (ALS)**—A central nervous system disease of unknown etiology, almost invariably fatal.

Ankle-foot orthosis (AFO)—A brace or splint used to support the foot by stabilizing the ankle.

Antibiotic—A medication designed to kill bacteria.

Antibody—A protein made by the immune system of the body in response to a substance, usually of foreign origin, called an antigen.

Anxiety—A feeling of worry, uneasiness.

**Apraxia**—The inability to perform a purposeful movement even though the ability exists to perform the components of the movement.

Ataxia—The inability to properly coordinate movement. This usually refers to walking and to movement of the arms.

Autoimmune disease—A disease, such as rheumatoid arthritis or MS, that involves the immune system of the body, turning against a component of the body itself.

Autonomic nervous system—The portion of the peripheral nervous system that is not under voluntary control. It governs "automatic" functions such as sweating, heart rate, sexual functions, and bowel motility.

**Axons**—The nerves that carry impulses from a cell to another nerve cell or a muscle.

**B** cell—A type of white blood cell formed in the bone marrow, involved in immunologic reactions.

**Babinski sign**—An upward movement of the great toe on stimulating the sole of the foot that often occurs with abnormalities of the central nervous system.

**Bacteria**—Small organisms (germs) that can sometimes be shown to be involved in some infectious diseases and are often treated with antibiotics.

Bladder—A muscular sac that stores urine prior to urination.

**Blood-brain barrier**—The barrier that prevents entry of many substances into the brain from the blood vessels. A break in the bloodbrain barrier may underlie the disease process in MS.

**Bowel**—The lowest portion of the large intestine, involved in elimination.

**Brain stem**—The part of the central nervous system that controls breathing and the heart; it connects the cerebrum to the spinal cord.

**Bulk former**—A substance that adds bulk to the stool; frequently used in the management of constipation.

**Catheter, urinary**—A tube inserted into the bladder for drainage of urine.

**Central nervous system**—The CNS consists of the brain and spinal cord. It is where many bodily functions (such as muscle control, eyesight, breathing, memory, and so forth) are generated, processed, and signaled to the different parts of the body.

**Cerebellum**—The part of the brain responsible for coordinating motor movement.

**Certified occupational therapy assistant (COTA)**—A person trained to perform some of the duties of registered occupational therapists, usually under their supervision.

**Cerebral spinal fluid**—A clear fluid that surrounds and cushions the brain and spinal cord.

**Clonus**—Alternating contraction and relaxation of a muscle in an extremity (arm or leg), resulting in a shaking movement or spasm.

**Cognition**—The comprehension and use of speech, visual perceptions and construction, calculation ability, attention (information processing), memory, and executive functions such as planning, problem solving, and self-monitoring.

**Colon**—The lower part of the large intestine.

**Computerized tomogram (CT scan)**—A sophisticated X-ray that utilizes a computer to give a three-dimensional and internal view of an organ.

**Condom catheter**—A thin, flexible sheath connected to a tube that is worn over the penis, allowing urine to drain through the tube to a collecting system.

**Constipation**—The inability to relieve oneself of stool.

**Continence**—The ability to control urination and defecation.

**Contracture**—A decrease in the range of motion in a joint due to stiffness (spasticity) in the surrounding muscles.

Coping—Adjusting or adapting successfully to a challenge.

**Cortisone/Corticosteroid**—A hormone of the adrenal glands known to have antiinflammatory and immune system–suppressing properties.

**Credé technique**—Pushing on the bladder with a closed fist through the abdominal wall to allow more complete emptying of the bladder.

Crutch, Lofstrand—A crutch with a forearm holder used for support.

**Cystitis**—Inflammation of the bladder that often occurs with infection.

**Cystoscopy**—Examination of the bladder with a special viewing device, a cystoscope.

**Cytotoxic (killer) T cell**—A type of white blood cell formed after mature T cells interact with antigen on a foreign cell.

**Decubitus**—A break in the skin resulting from pressure on an area for a prolonged period; a pressure sore.

**Demyelination**—The abnormal process of myelin destruction that results in disruption of the normal pattern of nerve conduction.

**Depression**—Altered mood characterized by feelings of gloom.

**Dexamethasone (Decadron)**—A high-potency cortisone used to decrease swelling (inflammation) in the nervous system.

Diplopia—Double vision.

Dizziness—The sensation of light-headedness.

Dysarthria—Slurring of speech.

Dysesthesia—Pain of a burning nature along a nerve.

**Dysmetria**—The inability to control the range of a voluntary muscle movement causing over/under shoot and decreased coordination.

Dysphagia—Difficulty with swallowing.

**Dysphonia**—Disorders of voice quality caused by spasticity, weakness, and incoordination of muscles in the mouth and throat.

**Dyssynergic bladder**—A type of bladder in which the urethral sphincter and the bladder wall operate in an uncoordinated fashion.

**Dystrophy, muscular**—A familial disease of wasting and weakness of muscles.

Dysuria—Painful urination.

**Edema**—Local or generalized condition in which body tissues contain an excessive amount of fluid; swelling.

Ejaculation—The ejection of semen from the penis.

**Electrophoresis**—The movement of charged particles through a medium that has an electrical potential associated with it.

**Emotional lability**—An inability to control emotions.

Encephalomyelitis—An inflammation of the brain and spinal cord.

**Endemic**—Referring to a disease that occurs continuously in a particular population. **Energy conservation**—The careful control of energy to prevent fatigue and maximize function.

**Enterostomy**—The surgical formation of a permanent opening through the abdominal wall, usually following removal of a portion of the intestine or urinary tract.

**Epidemiology**—The study of factors in the environment that influence disease

**Etiology**—The study of all factors that may be involved in the development of a disease.

**Euphoria**—An inappropriate feeling of well-being sometimes associated with the "cerebral" form of MS.

**Evoked potentials**—The stimulation of an organ (e.g., eye, ear, skin) to elicit an electrical discharge in the brain; many diseases, including MS, alter the normal pattern by which a stimulus is transmitted to the brain.

Exacerbation—A sudden worsening of symptoms.

**Exercise, aerobic**—Performed activity designed to increase endurance and heart-lung support.

**Exercise, balance**—Performed activity designed to improve coordination.

**Exercise, relaxation**—Performed activity designed to increase relaxation.

**Experimental autoimmune encephalomyelitis (EAE)**—A disease created in animals that is autoimmune in nature and is similar in many respects to MS.

**Extensor spasm**—A symptom of spasticity in which the legs straighten suddenly into a stiff, extended position. They most commonly occur in bed at night or on arising from bed.

Fasciculation—An involuntary contraction of muscle fibers.

Fat—A substance that is broken down by digestion into fatty acid.

**Fatigue**—A feeling of tiredness; MS often is associated with a lassitude that is debilitating.

Flaccidity—Looseness and accompanying weakness in an affected muscle.

**Flexor spasm**—A spasm of legs in a knees-bent position, often occurring with minimal stimulation.

Fluency—The smoothness of speech or movement.

**Foley catheter**—A tube placed in the bladder to drain urine; held in place by an inflated balloon.

**Foot drop**—A condition of weakness in the muscles of the foot and ankle that interferes with a person's ability to flex the ankle and walk normally. The toes touch the ground before the heel does, which causes the person to trip or lose balance.

Gait—Walking pattern, often disrupted in MS.

Gastrocnemius—Muscle of the lower leg; used for normal movement of the foot.

Genetic—Pertaining to heredity.

Gluteus maximus—Muscle of the buttock.

**Hamstring**—Three muscles on the posterior aspect of the thigh that flex, adduct (pull in), and extend the thigh.

**Helper T cell**—A type of white blood cell that enhances the production of antibody-forming cells from B lymphocytes.

**Hemiplegia**—A weakness of an arm and leg on the same side of the body.

**Hereditary disease**—A disease transmitted from one generation to another.

**Hesitancy**—The inability to void on command; the urge to urinate without the process occurring on command.

**HLA typing**—The ability to type tissues in a manner analogous to blood typing.

Hot bath test—A test occasionally used to induce MS symptoms by placing a person in a tub of hot water.

**Hyperbaric oxygen**—Oxygen under greater than normal atmospheric pressure.

**Immune defect**—The general term describing a variety of malfunctions of the immune system, in which it either does not respond to a foreign substance by destroying or neutralizing it, or in which the immune system erroneously destroys normal structures of the body. Multiple sclerosis may be the result of such a defect, with myelin the specific substance attacked.

**Immune response**—The reaction of the body to substances that are foreign or are interpreted as being foreign.

**Immune system**—Consists of a number of different organs in the human body (lymph nodes, bone marrow, thymus, and so forth) that produce certain types of white blood cells and antibodies that have the ability to destroy or neutralize various germs, substances, poisons, and other harmful substances.

**Immunosuppressant drug**—A medication used to decrease the level of function of the immune system.

Impotence—The inability of a male to complete the sexual act.

**Incidence**—The number of newly occurring cases per unit of time and unit of population.

Incontinence—The inability to control the bladder or bowels.

**Incoordination**—The inability to produce a harmonious, rhythmic muscular action that is not the result of weakness.

**Interferon**—A group of immune system proteins, produced and released by cells infected by a virus, which inhibit vital multiplication and modyify the body's immune responses.

**Internuclear ophthalmoplegia (INO)**—An abnormality of eye movement caused by demyelination between the nerve cells that control the eye muscles; this finding is common in MS.

Irrigation of the bladder—Washing out of the bladder with fluid.

Joint—The joining of two bones.

Kinesiology-The study of muscles and muscular movement.

**Klenzak brace**—A brace made with metal supports connected to a shoe to prevent foot drop.

**Labia major**—The two folds lying on either side of the vaginal opening.

Labia minor—The two folds inside the opening of the vagina.

**Lassitude**—A specific type of fatigue occurring in MS; characterized by a feeling of overwhelming tiredness.

Laxative—A food or chemical substance that acts to treat constipation.

**Lesion**—A physical abnormality in the nervous system.

**L'hermitte's sign**—The feeling of an electrical sensation down the spine when the head is bent to the chest, often due to demyelination in the neck region of the spinal cord.

Linoleic acid—A component of myelin.

**Lumbar puncture**—A spinal tap, involving the insertion of a needle into the spinal canal in order to obtain spinal fluid and/or inject substances into the spinal canal.

**Lyme disease**—A recurrent inflammatory disorder characterized by distinctive skin rash, arthritis, and involvement of the heart and nervous system; caused by a spirochete, *Ixodes dammini*; tick-borne.

**Lymph**—The proteinaceous fluid that circulates through the body in distinct channels.

**Lymphocyte**—A white blood cell that is a part of the immune system; it fights foreign substances, e.g., bacteria, viruses, and so forth, and is also a prominent cell in autoimmune reactions (reactions against oneself); varieties of lymphocytes include B cells and T cells.

Lysosome—A substance in the cell that is responsible for some enzyme reactions that break down proteins.

**Macrophage**—A cell in the body that helps in cleansing the body of foreign substances.

**Magnetic resonance imaging (MRI)**—A diagnostic procedure that produces visual images of different body parts without the use of x-rays. An important diagnostic tool in MS that makes it possible to visualize and count lesions in the white matter of the brain and spinal cord.

**Metabolism**—Energy changes that occur within the cells of the body.

**Monoclonal antibody**—A specific antibody formed against a single substance by the immune system.

Monoplegia—Weakness in a single arm or leg.

**Motor**—Usually referring to the ability to carry out activities that require the use of bodily muscles.

**Multiple sclerosis**—A disorder of the CNS usually characterized by worsenings (exacerbations) and improvements (remissions) of symptoms. Multiple scars gradually form in the CNS. Most frequently encountered symptoms are loss of strength, difficulties with balance and bladder control, numbness and tingling, and blurred or double vision.

**Myelin**—A substance consisting of fat and protein, which acts as an insulator around most of the nerve fibers in the human body. It is found in the central and peripheral nervous systems.

**Myelination/myelinization**—The process of acquiring a myelin sheath.

Myelinoclasis—The destruction of the components of myelin.

Myelinolysis—The destruction of myelin sheaths.

Myelitis—Inflammation of the spinal cord.

**Myelography**—An examination of the spinal cord performed by the introduction of a dye into the spinal canal followed by X-rays.

Myelopathy—Any pathologic condition of the spinal cord.

**Myokymia**—A twitching of muscles, usually of the face, caused by increased irritability in MS.

**Natural killer cells**—Cells in the immune system that may play a role in MS.

**Nerve**—A bundle of nerve fibers (axons). The fibers are either afferent (leading toward the brain and serving in the perception of sensory stimuli of the skin, joints, muscles, and inner organs) or efferent (leading away from the brain and mediating contractions of muscles or organs).

**Neuralgia**—A sharp pain along the course of a nerve.

**Neurogenic bladder**—A condition in which urinary bladder control is disturbed, which may manifest itself by frequent urgencies for urination, a loss of sensation for urge, an inability to empty the bladder even though the urge may be present, or a complete loss of control of the urinary bladder, which then empties itself irregularly.

**Neurologist**—A physician who specializes in the diagnosis and treatment of diseases of the nervous system.

**Neuropathy**—A degeneration of the nerves to the arms, legs, or internal organs.

Nocturia—The necessity to urinate at night

Numbness—The loss of sensation in an area of the body.

**Nutrition**—The body's use of food, including ingestion, digestion, and absorption.

Olfactory—The sensation involved with smell.

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

**Oligodendrocyte**—The cell type in the central nervous system responsible for making and supporting myelin.

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

**Optic neuritis**—An inflammation of the nerve that connects the eye with the brain, which manifests itself mainly as blurring or loss of vision and occasionally pain.

Orgasm—The height of excitement at the time of sexual intercourse.

**Orthotist**—One skilled in making mechanical appliances for preservation of function.

Paraplegia—A weakness of both legs.

**Paresthesia**—A sensation of tingling or "pins and needles" in different portions of the body.

**Parasympathetic nervous system**—The part of the autonomic nervous system that is partially responsible for automatic functions, e.g., heart, blood pressure, bladder/bowel, sexual; centered in the head and lower spinal region.

**Paroxysmal spasm**—A sustained contraction of a limb that is uncontrolled and occurs intermittently.

**Passive stretching**—The movement of a person's muscles to a stretched position by someone other than the person himself.

**Patterning**—The guiding of movements over and over to allow the brain to develop repeated functions; underlies many of the physical therapies used in MS management.

**Peripheral nervous system**—Consists of numerous nerves in the body that serve the function of carrying the stimuli and information into the brain and spinal cord and, from there, back into the different parts of the body.

**Physiatrist**—A physician who specialize in physical medicine and rehabilitation; may be involved in the management of MS.

**Placebo**—An inactive substance given to group of patients in a drug study to compare with the active substance; any inactive substance given instead of an active one.

Plaque—An area of inflamed or demyelinated CNS tissue.

**Plasmapheresis**—The removal of plasma (the fluid of blood), with replacement by an approriate fluid; removes impurities in the plasma.

**Position sense**—The ability to feel slight movements of fingers or toes.

Pressure sore—See decubitus ulcer.

**Prevalence**—The algebraic product of incidence and duration (how many cases per unit of population at any one time).

**Protein**—A class of chemicals naturally occurring in plants and animals composed of nitrogen and amino acids.

**Pyuria**—Pus in the urine due to infection.

**Quadriceps**—Muscle of the upper leg involved in straightening of the leg.

Quadriplegia—Weakness of all four extremities (arms and legs).

Range of motion—The movement of a muscle about a joint.

**Ranvier's nodes**—Constrictions in the myelin sheath that allow for extremely rapid electrical transmission.

**Rectum**—The lowest part of the bowel, the part that follows the colon, which pushes the stool out during elimination.

**Reflex**—An immediate response of a certain part of the human body to a brief stimulus, which usually does not require processing of the stimulus through the conscious mind. An example is the jerking of the leg upon striking it or withdrawal from fire before conscious awareness.

**Relaxation technique**—A technique designed to calm, including biofeedback, meditation, or yoga.

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

**Retrobulbar neuritis**—Swelling or irritation of the optic nerve behind the eye secondary to inflammation.

**Romberg's sign**—An inability to maintain the body balance with the eyes shut and the feet close together.

**Schwann cell**—The cell that makes myelin in the peripheral nervous system.

**Scotoma**—A blind spot in the field of vision.

**Semen**—The thick secretion from the urethra (penis) emitted at the climax of sexual excitement.

**Sensory**—Pertaining to the ability to feel, sense, taste, smell, see, and hear.

**Sexuality**—Related to the total sexual life of a person—whether including the sexual organs themselves or not.

Sign, clinical—A physical abnormality found on examination.

**Spasticity**—The loss of normal elasticity of leg and/or arm muscles resulting from a disease process in the CNS. It is often manifested by extreme stiffness of the muscles, which results in difficulties with active and passive movements of the extremities.

**Sphincter**—A circular band of muscle fibers that tightens or closes a natural opening of the body, such as the external anal sphincter, which closes the anus, and the internal and external urinary sphincters, which close the urinary canal.

**Spinal cord**—The part of the CNS that connects the brain and its related structures to the peripheral nervous system.

Spinal tap—See Lumbar puncture.

**Steroids**—Chemicals that either mimic or are from various endocrine organs of the body (usually the adrenal gland); they are potent antiinflammatory (antiswelling) and immune-suppressing agents and often used in the management of MS.

**Suppressor T cells**—A type of lymphocyte that suppresses the production of antibody-forming cells from B lymphocytes.

**Suprapubic catheter**—A tube placed in the bladder through the skin just above the pelvic bone (pubic bone).

**Sympathetic nervous system**—That part of the autonomic (automatic) nervous system partially responsible for many automatic functions, such as sweating, heart beating, sexual activity, bowel/bladder function; centered in the chest and low back region.

**Symptom**—The subjective description of a problem as perceived by the individual.

T cell—A type of white blood cell formed in the thymus, tonsils, and other organs involved in the immunologic reaction; believed to be substantially involved in the MS process.

Tactile—Refers to the sensation involved with touch.

**Therapeutic recreation specialist**—A person trained to develop programs aimed at group or individual leisure activities (usually a bachelor's or master's training).

Tonic spasm—See Paroxysmal spasm.

**Transcutaneous nerve stimulation (TNS)**—The placing of an electrical stimulation along an area to stimulate the nerve in the same region—used for pain control.

**Transverse myelitis**—An acute attack of inflammatory demyelination in which the spinal cord loses its ability to transmit nerve impulses up and down. Paralysis and numbness are experienced in the legs and trunk below the level of the inflammation.

**Tremors**—Various involuntary movements involving arms, legs, or head, occurring in numerous illnesses and conditions and greatly varying in type and severity.

**Trigeminal neuralgia**—Severe pain in the face due to irritation of a nerve from the brain stem.

Triplegia—Weakness of three of four extremities (arms and legs)

**Ulcer**—An open sore (decubitus) in the skin or other membrane such as stomach or intestine.

Urethra—The canal for discharge of urine from the bladder.

**Urethral sphincter**—The valve controlling the flow of urine into the urethra.

**Urine culture**—The growing of bacteria (germs) from a specimen of urine to determine the presence and cause of an infection.

**Urinary tract**—The pathway involved in urination; it includes the kidneys, ureter, bladder, and urethra.

**Vertigo**—Dizziness or a spinning sensation.

**Vestibular stimulation**—The stimulation of the balance part of the ear by exercise.

**Virus**—A small organism (germ) with distinctive features consisting of either DNA or RNA, which is unaffected by most antibiotics and sometimes can be shown to be involved in some diseases.

Vision—The ability to see.

**Vitamin**—A substance essential for growth, development, and normal body processes.

Voiding—The elimination of urine or stool.

Vulva—The general term for the external female sexual organs.

Walker—A mobile device used to assist a person in walking.

Weakness—A decrease in physical strength.

**Weighting**—The use of weights placed on an extremity to decrease movement.

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

# Appendix **B**

## EXERCISES FOR SPASTICITY

RANGE OF MOTION—LOWER EXTREMITY

**CAUTION**—When doing passive exercises, do them slowly and apply pressure steadily, especially if extreme tightness is present.

## 1. Ankle dorsiflexion (calf stretch)

Bending ankle up: Back lying.

Grab the heel, placing the ball of the foot against your forearm, and bend the ankle up. (Push the toes toward the knee.)

#### 3. Hip flexion

2. Hamstring stretch

Hip flexion with straight knee: Back lying.

Knee to chest: Buttock stretch. Back lying.



4. Internal–external rotation

Rolling leg in and out: Back lying.



#### 5. Abduction-adduction

Out to side: Back lying.



#### 6. Knee flexing

Front, thigh stretch: Face lying.



#### 7. Hip extension

Leg backward at hip: Face lying.



#### 8. Trunk flexion

Back stretch: Bring both knees up to chest. Back lying.



#### INDEPENDENT STRETCHING PROGRAM

#### 1. Heel cord stretch

Sit on a mat, the floor, or the bed with your legs stretched out in front of you. (If this is difficult, sit with your back against the wall.) Take a towel and sling it around your foot, across the ball of the foot, and pull the forefoot up toward you. You should feel a stretch in your calves and up behind the knees. Hold for 60 seconds.



#### 2. Hamstring stretch

Sitting as in the first exercise, lean forward, place your hands on your calves, and slide them down toward your toes, keep your knees straight. You should feel a stretch under your thighs. Try to keep your back relatively straight. Hold for 60 seconds.



#### 3. Butterfly sit

Sit on the bed, floor, or mat with your knees and hips bent and the soles of your feet touching. Clasp your ankles with your hands so that your elbows rest on the inside of your knees. Push the knees apart with your elbows as you lean forward. Hold for 60 seconds.

#### 4. Wall stretch

Lie on your back at the base of a wall—perpendicular to it (either on the floor or on a bed if it is against the wall). Your buttocks should be all the way up against the wall and your legs stretched out and up against the wall. Let the legs slowly separate and slide out to the side as far as possible. Hold for 60 seconds.





#### 5. Kneel standing

Get your knees on a mat or the floor. Then lower your buttocks down to the right heel and come back up. Then down to the left heel and back up again. Repeat 5–7 times—progress as tolerated.



#### BALANCE AND COORDINATION

1. Kneeling



2. Sitting


#### 3. 4-point kneeling

Note equal distribution of weight over the four points of contact.



#### 4. Stand kneeling

This position develops increased balance by establishing pelvic and hip control.



#### 5. Turning to look behind

This exercise challenges the balance system.



6. Taking weight through affected arm



## STRENGTHENING EXERCISES

1. Knee extension



2. Quad set



3. Terminal knee extension



4. Elbow flexion with Theraband



5. Elbow extension with Theraband



6. Shoulder flexion-extension with Theraband



7. External rotation with Theraband



8. Shoulder abduction with Theraband



9. Shoulder adduction with Theraband









# Appendix C

# Transfers and Mobility

TRANSFER FOR LOWER LIMB WEAKNESS

Wheelchair to Bed with Sliding Board

General Tips

- Move wheelchair next to bed as close as possible.
- Remove armrest closest to bed.
- Lock wheels
- Be sure board has handles or loops on end for ease in moving.

- Place sliding board under buttocks closest to bed at angle from front of chair seat to bed.
- Push up on armrest or back of chair and slide over to bed. Establish sitting balance.

3. Bring legs up onto bed.

#### 4. Final position.

Lean away from board and move board to safe location.

Reverse this procedure to return to wheelchair.



# TRANSFER WHEELCHAIR TO BED (ASSISTED AS NEEDED)

 Remove feet from footrests, move footrests out of way, lock brakes.
Be sure feet are flat on ground and uninvolved foot is slightly forward.

(If both legs are weak, place stronger leg slightly forward.)

 Lean trunk forward and push on armrest to come to standing position. (Assist if necessary.)





3. Balance in standing position for a few seconds.



 Pivot the feet until the backs of the legs are against the bed.



 Slowly lower body onto bed while bending knees.
If possible, use arms to assist with lowering.



#### 6. Left each leg onto the bed.

(Assist if necessary.)

Reverse this procedure to return to wheelchair.



# TRANSFER WHEELCHAIR TO CAR (Assisted)

### General Tips

- Open the car door.
- Position wheelchair as close as possible (leave enough room for helper and person to stand and pivot). See picture #1.
- Remove feet from footrests, move footrests out of way, lock the brakes.
- Put feet flat on the ground. Place the uninvolved foot slightly behind the involved foot.
- If both legs are weak, put the stronger leg slightly forward.
- Be sure to explain the procedure to the person you are helping before you begin.

1. Starting position.



2. Help person to standing position.

Let person balance a few seconds.



 Help person to pivot so the backs of legs are against the seat.



4. Slowly lower person to sitting position.



5. Lift each leg into the car.

Reverse the procedure to return the person to the wheelchair.



# TRANSFER WHEELCHAIR TO CAR (UNASSISTED)

### General Tips

- Open the car door.
- Angle wheelchair as close as possible (leave enough room for person to stand and pivot). See picture #1.
- Remove feet from footrests, move footrests out of way, lock the brakes.
- Put feet flat on the ground. Place the uninvolved foot slightly behind the involved foot.
- If both legs are weak, put the stronger leg slightly forward.
- Loops or other devices may be attached to car to assist movement.

1. Starting position.



 Lean forward, push down on armrests and come to a standing position.
Balance, standing, for a few seconds.



3. Pivot on feet until the backs of the legs are against the seat.



- Slowly lower body into seat. Use the arms on the seat if possible.
- 5. Lift each leg into the car.

Reverse the following procedure to return to the wheelchair.





BED MOBILITY BASICS

How to Get up from a Lying Position (Assisted as Necessary)

1. Bend knees until feet are flat.

Helper assist as needed.



2. Lift arm closest to the side of the bed over head.

Assist as needed.



3. Roll onto side.

Assist as needed. Remind person to tighten buttocks and squeeze abdomen while rolling over.



4. Push with arms and let legs hang over side of the bed until feet are flat on floor. Tighten buttocks and squeeze abdomen.

The helper can bring legs down and place hand under the shoulder to help person lift up from the trunk.



 Sit and balance yourself. Relax buttocks and abdomen.

Helper should place both hands on shoulders until the person is stable. If unstable, do not let go.



How to Move from Sitting to Lying (For Person with Pain and Weakness)

 Tighten buttocks and squeeze abdomen throughout.



 Lean weight onto the elbow of the side on which you will lie.



Helper assist as needed.

3. Bring legs onto bed while tightening buttocks and squeezing abdomen. Slide into side lying position with knees bent.



Helper assist as needed.

#### 4. Roll onto back.

Helper assist as needed. Remind person to squeeze buttocks and tighten abdomen when beginning to roll.



 Tighten buttocks and abdomen. Let legs slide into flattened position.

Helper may need to assist person to flatten legs.



## Getting Up from the Floor

 Near a piece of furniture get onto your hands and knees.



2. Facing the furniture, push up onto your knees.



 Assist with one hand to bring your strongest leg up.



4. Place your foot flat on the floor.



5. Lean forward and using your arms and legs push up to half-stand.



6. Turn and sit on the furniture.



## HOYER TRANSFER



To place sling under patient, stand in front of patient, lean patient forward on knees, place sling behind patient and bring leg flaps alongside patient's thighs. Tuck back edge of commode opening under patient's buttocks. Lean patient back. Grasp snap hook bar in one hand, and reaching under patient's leg, grasp D ring in other and pull until front edge of sling is just behind knees. Repeat on other side. Attach snap hook on each side of D ring on other side. (Can also criss-cross flaps under one leg and over the other, or support each leg independently by connecting snap hook and D ring on the same side together.)



To lift patient from the floor, place sling under patient using "Z" fold as for bed pick up. Bring lifter behind patient and support

patient's head and neck on pillow placed over litter base. Lower cradle so that chains reach hooks of sling. Raise patient's knees and attach sling. Lift patient.

To lower patient to floor, reverse the procedure.

# Appendix D

# Resources

### Additional Reading

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### ELECTRONIC INFORMATION SOURCES

Some of the best sources of information about MS available on the Internet are:

- National Multiple Sclerosis Society: www.nmss.org
- Multiple Sclerosis Society of Canada: www.mssoc.ca
- Multiple Sclerosis Society of Canada/Société canadienne: www.mssociety.ca
- Multiple Sclerosis International Federation: www.msif.org
- Consortium of Multiple Sclerosis Centers: www.mscare.org
- Eastern Paralyzed Veterans Association: www.epva.org
- Paralyzed Veterans of America: www.pva.org
- ABLEDATA: www.abledata.com.

# INDEX

Note: Boldface numbers indicate illustrations.

accommodation stage, in understanding/ accepting MS, 137 acetazolamide (Diamox), 49-50 acknowledgment stage, in understanding/accepting MS, 137 acupuncture, 15 acute attacks of MS, 21-22 adaptation stage, in understanding/accepting MS, 137 adapting to MS, 136-142 admission stage, in understanding/accepting MS, 137 aerobic exercise, 127 alpha blockers, 74 amantidine (Symmetrel), 26 amino acids, 112 amitriptyline (Elavil), 97 anatomy of the nerves and muscles, 4-6, 5 anger, 138 ankle foot orthoses (AFO), 36, 55, 56 antibodies and drug reactions, 21, 112-113 antihistamines, 100 Antivert (See meclizine) anxiety, 48 Atarax (See hydroxyzine) atrophy of muscles, 44 autoimmune diseases, 9-12 automobiles and vans, 59-60 autonomic nervous system, 6, 130 Avonex (See interferon beta 1a) axons, 3-4 azathioprine (Imuran), 22 B cells, 9 back pain, 98-99 baclofen, 36-37, 40, 42, 96 pump delivery of, 41 balance and coordination, 7, 46-51 exercise and, 127, 166-168 bathing, 32 bed, getting in/out of, 181-185

bedroom maintenance, 30-31 Benadryl (See diphenhydramine) benzodiazepines, 100 beta blocking agents, 48-49 beta fibers, 48 Betaseron (See interferon beta 1b) biofeedback, 15, 97 bladder symptoms, 64-78 catheterization in, 73-75 conflicting (dyssynergic) bladder syndrome in, 71, 72, 74 Credé technique in, 73 cystoscopy in, 78 dribbling problems in, 66 flaccid big bladder syndrome in, 70, 72 frequency problems in, 66 hesitancy problems in, 66 incontinence pads for, 78 incontinence problems in, 66 management of, 72-75 medications for, 73, 74 permanent, indwelling, or Foley catheter in, 74-75, 77 sexual function and, 133 small spastic bladder syndrome in, 67, **69**, 70 spasms in, 77 surgical intervention, continence viscostomy, 78 tests for, 72, 73, 74, 75, 78 urgency problems in, 66 urinary system and its control in, 64-65, 65 urinary tract (bladder) infection (UTI), 75-77 voiding reflex and, 65-66, 68 blurred vision, 18 bone marrow transplants, 20 botulinum toxin (Botox, Mybloc), 41 bowel symptoms, 79-87 bowel program for, 82-84 bulk formers, 83-84

bowel symptoms (continued) constipation in, 80-81 diarrhea in, 86-87 diet and 81-82 enemas in, 86 gastrointestinal tract and its control in, 79-80 incontinence in, 86-87 laxatives (oral stimulants) in. 84-86 medications and, 83-84 sexual function and, 133 stool softeners in. 84 suppositories and rectal stimulants, 85-86 braces, 42, 50, 55-57, 99 brain, 3, 4 brain stem. 4 breathing, 4 bulk forming laxatives, 83-84, 86-87 burning pain, 24, 97 buspirone (Buspar), 49 butterfly sit, 165 canes. 57, 99 capsaic acid, 97 carbamazepine (Carbitrol; Tegretol), 38, 40, 52, 96 carbohydrates in diet, 113-114 cars, transfers to/from, 177-181 casting, 42 cataracts, 95 catheterization, 73-75 causes of MS, 9-12 Caverjet, 134 central nervous system (CNS), 3, 4 cerebellum, 7, 46, 48 cerebrum, 4 chiropractic, 15 Chlamydia bacteria, 11 choking, 93 cholesterol, 113 Chronulac. 84 Citrucel, 84 cleaning tasks, 29-30 clonazepam (Klonopin), 37, 39, 42, 48, 49, 95, 100 clonidine, 74 cognitive difficulties, 105-107, 139 Colace, 84 cold feet, 103 compensation, in cognitive difficulties, 105 complementary or alternative medicine, 15 conflicting (dyssynergic) bladder syndrome, 71, 72, 74

constipation, 80-81 continence viscostomy, 78 contractures, 24, 36, 41-42 coordination (See balance and coordination) Copaxone (See glatiramer acetate) coping skills, 139-140 cortisone. 38 cortisone medications. 21-22 cost of medications, 17 counseling, 142 Credé technique, 73 cyclobenazprine (Flexeril), 37, 39 Cylert (See pemoline) cyproheptadine (Periactin), 37, 39 cystoscopy, 78 Cystospaz (See hyoscyamine) Cytotec, 96 Dantrium (See sodium dantrolene) dantrolene, 38, 42 DDVAP (See desmopressin) deconditioning and exercise, 26 decubitus ulcers (See pressure sores) demylinating diseases, 3, 48

Depakote (See valproate) depression, 18, 24, 138-139 desk work, 31-32 desmopressin (DDAVP), 74 Detrol (See tolterodine tartrate) dexamethasone, 21-22 dextroamphetamine (Dexedrine), 26 Diamox (See acetazolamide) diarrhea, 86-87 diazepam (Valium), 37, 39, 42, 100 Dibenzyline (See phenoxybenzamine) diet, 111-124 bowel function and, 81-82 carbohydrates in, 113-114 exercise and, 123-124 fat in, 113, 122-123 food guide pyramid for, 116-118, 117 guidelines for, 118-119 low calorie weight loss, 119-120 nutritional labels on food and, 120-122, 121 protein in, 112-113 remedies using, 111 vitamins and minerals in, 114-115 water in, 115-116 weight control and, 119-124 weight gain, 123-124 Dilantin (See phenytoin) dimenhydrinate (Dramamine), 100

diphenhydramine (Benadryl), 100

disuse weakness, 44 Ditropan (See oxybutynin) diuretics, 104 dizziness and vertigo, 18, 100-101 dosage of medications, 18 dose escalation. 21 double vision, 95 Dramamine (See dimenhydrinate) dressing tasks, 32 Dulcolax, 86 dysarthria (See speech difficulties) dysesthesis, 97 dyssynergic bladder syndrome, 71, 72, 74 edema, 103-104 efficiency, 44 Elavil (See amitriptyline) Eldepryl (See selegiline) emotional changes, 139 enemas, 86 energy conservation and fatigue, 27-29, 44-45 epileptic drugs, 52, 96 essential tremor, 50 exacerbations, 6 exercise, 125-128, 161-171 aerobic, 127 balance and coordination, 127, 166-168 coordination and balance, 47 diet and, 123-124 fatigue and, 25 pain and, 128 progressive resistance, 43 putty used in, to strength fingers, 171 range of motion, 35, 161–164 relaxation, 127, 140-142 spasticity and, 34-36, 161-171 speech, 88-90 strengthening, 45, 168-171 stretching, 164-166 swallowing, 92–93 temperature and, 126 Theraband, 170-171 type, duration, frequency, intensity of, 125 weakness and, 43-45 extensor/flexor spasms, 40 falls, rising from floor, 185-186 familial tremor, 50 fat in diet, 113, 122-123 fatigue, 25-32 energy conservation and, 27-29 fear, 136

fiber in diet, 81-82 Fiberall, 84 FiberCon, 84 flaccid big bladder syndrome, 70, 72 flavoxate hydrochloride (Urispas), 73 Flexeril (See cyclobenazprine) floor, rising from, 185–186 fluid intake, 80-81, 115-116 fluoxetine (Prozac), 26 Foley catheter in, 74-75, 77 food guide pyramid, 116–118, 117 foot drop, 55 forearm (Lofstrand) crutches, 57-58 gabapentin (Neurontin), 38, 39, 95, 96, 97, 102 Gabitril (See tigabine) gastrointestinal tract and its control, 79 - 80genetics and MS, 10 geographic location and MS, 11-12 glatiramer acetate (Copaxone), 16, 17, 20 glossary of terms, 143-159 glycerin suppositories, 85-86 grief, 136-137 gross tremor, 50 group counseling, 142 hamstring stretch, 165 healing, in pressure sores (primary/ secondary intention), 62-63 hearing, 4 heart disease, 113 heart rate, 4 heel cord stretch. 164 Heimlich maneuver, 93 hereditary and MS, 10 herpes virus, 11 Hoyer transfer, 187-188 human T-cell lymphotrophic type I (HTLV) virus, 11 hydroxyzine (Atarax; Vistaril), 48, 49 hyoscyamine (Cystospaz; Levsinex; Levbid), 73 hyperextension, 56 Hytrin (See terazosin) imipramine (Tofranil), 73 immobilization vs. tremor, 50 immune system, immune response, 9-12, 16-17 immunomodulating substances, 9 Imodium, 87 Imuran (See azathioprine)

incontinence pads, 78 incontinence problems (See bladder symptoms; bowel symptoms) Inderal (See propranolol) indwelling, or Foley catheter in, 74-75, 77 infant and child care, 31 injectable medication, 21 interferon beta 1a (Avonex; Rebif), 16, 18, 19-21 interferon beta 1b (Betaseron), 16, 18, 20 - 21interferons, 16-17 Internet resources, 190 intestines, 79 isoniazid, 50 itching, 24 Kaopectate, 87 Keppra (See levetiracetam), 96 kidneys, 64 kitchen and cooking arrangements, 28 - 29Klonopin (See clonazepam) knee pain, 99 kneel standing, 166 L'hermitte's sign, 97 lassitude (See also fatigue), 26 laundry tasks, 30 laxatives (oral stimulants), 84-86 L-dopa (Sinemet), 38, 39 lesions. 7 levetiracetam (Keppra), 52 Levsinex; Levbid (See hyoscyamine) life expectancy, 8 Lofstrand (forearm) crutches, 57 - 58Lomotil, 87 low back pain, 98-99 low calorie weight loss diets, 119-120 lymphatic fluid and swollen ankles, 103-104 lymphocytaphoresis, 19-20, 19 macrophages, 9 magnetic resonance imaging (MRI), 17 - 18managing MS, 16-22, 16 meal preparation, 29 meclizine (Antivert), 100 medications, 14, 16 bladder problems and, 73, 74 bowel problems, 83-84

medications (continued) dizziness and vertigo, 100-101 fatigue, 26-27 numbness and tingling, 102 pain, 97-98 sexual function, 135 spasticity, 36-40 tremor and, 48 meditation, 15, 97 memory loss (See also cognitive difficulties), 4, 105, 139 Metamucil. 84. 86-87 methotrexate, 22 methylprednisone, 21-22, 94 methyphenidate (Ritalin), 26 Milk of Magnesia, 85 minerals in diet, 114-115 mitoxanthrone (Novantrone), 16, 17, 19, 21 mobility, 54-60 automobiles and vans, 59-60 back pain and, 98-99 canes in, 57 forearm (Lofstrand) crutches in. 57-58 motorized scooters/wheelchairs in, 58-59, 59, 60 orthoses and braces for, 55-57, 56 steps and staircases, 57 transfers and, 60 walkers in, 54, 58 walking (ambulation) in, 55-60 wheelchairs and, 58 motor point blocks, 40 motorized scooters/wheelchairs, 58-59, 59,60 MS personality, 138–139 multifactoral nature of MS, 10 muscle tone, 4 muscles and spasticity, 33-42 MUSE system, 134 myelin, 3, 6, 23 Mysoline (See primidone) natural remedies, 15 nerves, 3-4 neurologists, 13-14 Neurontin (See gabapentin) niacin, 100 Novantrone (See mitoxanthrone) numbness and tingling, 18, 52, 102-103 nutritional labels on food, 120-122, 121

oligodendrocytes, 6 ondansetron (Zofran), 49

nystagmus, 95

onset of MS, 6 optic neuritis, 94 orthoses, 36, 55-57 osteoporosis, 24 oxazepam (Serax), 100 oxcarbazepine (Trileptal), 40, 52, 96 oxybutynin (Ditropan), 73 pain, 18, 24, 52, 96-99 biofeedback, meditation, relaxation vs., 97–98 on exercise, 25-26, 128 knee, 99 L'hermitte's sign, 97 low back, 98-99 medications for, 97-98 transcutaneous nerve stimulation (TENS) vs., 97 trigeminal neuralgia, 96-97 parasympathetic nervous system, 6, 130 Parkinson's disease, 39 paroxetine (Paxil), 26 paroxysmal (tonic) spasms, 40 paroxysmal symptoms, 52-53 passive stretching, 35 patterning, in coordination exercises, 47 Paxil (See paroxetine) pemoline (Cylert), 26 percutaneous rhizotomy, 96-97 Perdiem, 84, 85, 87 Periactin (See cyproheptadine) Pericolace, 85 peripheral nervous system (PNS), 4, 6 personality, 4 phenol, 40 phenothiazines, 50 phenoxybenzamine (Dibenzyline), 74 phenytoin (Dilantin), 52, 96 physiatrists, 13 physician selection, 12-14 physiologic tremor, 50 plasma exchange, 19 plasticity of brain, in cognition, 106 prednisone, 22 pressure sores, 24, 61-63 primary progressive MS, 8 primary symptoms, 23 primidone (Mysoline), 49 progressive MS, 19 progressive relapsing MS, 8 progressive resistance exercises, 43 propranolol (Inderal), 48, 49, 50 prostaglandin, 134 proteins in diet, 112-113 Prozac (See fluoxetine)

psychological response to MS, 136 putty exercise, to strength fingers, 171 range of motion exercises, 35, 161-164 Rebif (See interferon beta 1a) relapsing remitting MS, 7-8 relaxation, 15, 127, 140-142 remissions. 6 resources for information, 189-190 resting tremor, 50 retrobulbar neuritis, 94 Ritalin (See methyphenidate) rubella virus, 11 rubeola virus, 11 saturated fats, 113 sclerotic. 3 scooters/wheelchairs, 58-59, 59, 60 secondary progressive MS, 8 secondary symptoms, 24 seizures, 52-53 selegiline (Eldepryl), 38 Serax (See oxazepam) sertraline (Zoloft), 26 sexuality, 129-135 shoes, 55 shopping, 30 side effects of medication, 18-21 sildenafil (Viagra), 135 Sinemet (See L-dopa) sitting and desk work, 31-32 skin breakdown (See pressure sores) sliding board transfers, 173-177 slings, transfers to/from, 187-188 slurred speech, 52 small spastic bladder syndrome in, 67, **69**, 70 sodium dantrolene (Dantrium), 37 spastic bladder syndrome in, 67, 69, 70 spasticity, 33-42 bladder, 77 contractures and. 41-42 exercises vs., 161-171 mechanical aides vs., 36 medications vs., 36-40 paroxysmal (tonic) spasms in, 40 sexual function and, 133-134 surgical management of, 40-41 speech difficulties, 51, 88–90 sphincter, anal, 80 spinal cord, 3, 4–6, 5 starches in diet, 114 stem cell transplants, 20 steps and staircases, 57 steroids, 94

stockings, for edema, 104 stomach, 79 stool softeners. 84 strengthening exercises, 45, 168-171 stress, 48, 136, 138, 139-141 stretching exercises, 34-36, 164-166 suppositories and rectal stimulants, 85-86 Surfak, 84 surgical intervention bladder problems, 78 pain, percutaneous rhizotomy, 96-97 pressure sores, 62-63 spasticity and, 40-41 swallowing difficulties, 91-93 Swedish hyperextension cage, 56-57 swollen ankles, 103-104 Symmetrel (See amantidine) sympathetic nervous system, 4, 6, 130 symptom management, 23-24 symptoms of MS, 6-8, 23-24 Synchromed baclofen, 41 T cells, 9 Tegretol (See carbamazepine), 38, 40 temperature and exercise, 126 terazosin (Hytrin), 74 tertiary symptoms, 24 testosterone, 135 Theraband exercises, 170-171 Therevac. 86 thrombophlebitis, 104 tigabine (Gabitril), 52 tingling, 18 tizanidine (Zanaflex), 37, 38, 40, 42 Tofranil (See imipramine) tolerance to medications, 40 tolterodine tartrate (Detrol), 73 tonic spasms, 40 touch, 4 transcutaneous nerve stimulation (TENS), 97 transfers and mobility, 60, 173-188 tremor, 46, 47, 48-51 trigeminal neuralgia, 96–97 Trileptal (See oxcarbazepine)

tropical spastic paraparesis, 11 types of MS, 7-8 unsaturated fats, 113 urethra, 64 urethral sphincter, 64 urinary tract (bladder) infection (UTI), 75-77 Uthoff phenomenon, 95 Valium (See diazepam) valproate (Depakote), 52 vehicles, 59-60 vestibular stimulation, in coordination exercises, 47-48 Viagra (See sildenafil) videofluoroscopy, 91 viruses and MS, 10-11 viscostomy, 78 vision, 4, 94-95 Vistaril (See hydroxyzine) vitamins, 114-115 voiding reflex, 64, 65-66, 68 walkers, 54, 58 walking (ambulation), 55-60 wall stretch. 165 water in diet (See also fluid intake), 115-116 water pills, 104 weakness, 43-45 web sites of interest, 190 weight control, 119-124 weighting vs. tremor, 50-51 wheelchairs, 58 transfers to/from, 173-177 car transfers to/from, 179-181 sling transfers (Hoyer transfers), 187-188 yardwork, 31 vohimbine, 135 Zanaflex (See tizanidine)

Zofran (*See* ondansetron) Zoloft (*See* sertraline) Zostrix, 97