



## *Practical Guidelines for Living with Multiple Sclerosis*

**T**here are many things you can do to stay as healthy as possible, take control of your life, and cope with the challenges that multiple sclerosis (MS) may bring. The disease should not be in control—*you* are in control of your life, your attitudes, your relationships, your approach to problems, your interests, and your activities. The best way to take control is to obtain information and learn more about MS.

This chapter discusses some things you should do and some things you should not do. For example, you should get more information about MS; you should make sure you have an opportunity to ask questions about the disease; you should exercise; you should try to live a normal, active life, adapting to any limitations; you should work to improve your relationships; you should express a positive attitude; and you should have regular medical assessments.

The things you should not do are actually fewer in number. For example, do not withdraw from life and friends; do not stop exercising;

do not expose yourself to a hot environment; do not try every drug, herb, therapy, and procedure that you hear about without first getting reliable information about the scientific evidence, possible benefits, and side effects; and do not feel ashamed or diminished because you have MS.

### *Should I Learn More About Multiple Sclerosis?*

MS is a disorder of the central nervous system. Many things are known about MS, and many advances are being made. There still are a great deal of unanswered questions, but it is important to learn more about the questions that are being asked by researchers and the theories that are being tested.

The best initial source of information is the MS Society. In the United States, call 800-FIGHT-MS to reach the National MS Society, and in Canada call 800-268-7582 (see Chapter 12 for the number of the nearest office of the MS Society of Canada).

### *What Should Others Know About Multiple Sclerosis?*

It is important for your family, friends, and coworkers to understand MS. Initially you may feel that you do not want anyone to know that you have MS. That is understandable, but it is essential to tell the people you love, and others when necessary, so that they can understand and help you deal with the disease. Most people with MS are pleased and surprised at how supportive and understanding others are when they are informed. Many people may have guessed that something was wrong but did not know what to do or say. Until they know the truth (see Chapter 7), employers may not understand your need to take time off or to rest, and they may think you are not working well. Decisions to inform should be made on an individual basis, but, in general, disclosure is a good idea.

Once family and friends are aware of your diagnosis, they might benefit from literature that would allow them to better understand MS. In particular, your family should understand your symptoms and problems so they can be helpful and supportive. This is not possible if they are unaware of your MS and how it makes you feel.

### *Who Can Answer My Questions?*

It is important to have your concerns addressed and your questions answered. Sometimes people are afraid that they might ask too many questions or that their questions might not be clear. Make a list of the questions you want to ask. Call the MS Society or bring the questions to your physician or nurse on your next visit. You probably will find that they are questions most people ask and that they are not new to the staff. If there is no clear answer to a question, it is important to find that out as well. Each new piece of information will add to your overall understanding of MS.

### *What Can I Learn from Other People Who Have Multiple Sclerosis?*

People with MS soon learn that it is a common neurologic disorder and that there are many others in their community who have the same disease. It often helps to talk to others who share the challenges and problems of coping with MS, but there are some cautions. *You cannot compare yourself with others in terms of the type of disease, the course, or the symptoms. Multiple sclerosis is an individual disease,* and you probably will find that the features of your MS are quite different from those of the next person. It may seem puzzling that there are so many individual patterns for the disease, but that is actually fairly common in other diseases as well. The variety of symptoms of MS is great, so the apparent variations in individuals are great as well.

One way that people with MS can benefit from each other is in self-help or support groups. These take various forms, but they usually are small groups that meet in homes or in community facilities to talk about and better understand MS. The object is always to take a positive approach and to take control over everything that you can manage so that you can help yourself and others. The MS Society has information on support groups, including how to join one or how to start one.

### *When Is Information Not Helpful?*

Misinformation is not helpful and can cause much trouble and distress, not to mention wasted time and money. If someone says that mercury in dental fillings causes MS, check it out from those who know—staff at the MS Society, someone in the MS clinic in your area, or your physician—but do not go to the dentist and have your fillings removed. If someone tells you that ginseng cures MS, check it out. If someone says there is a doctor in a clinic somewhere who has a cure for MS, call the MS Society, not your travel agent.

### *What About My Activities?*

People with MS should lead normal and active lives within the limitations of their symptoms. This means that we encourage activity more than rest and staying active and involved rather than withdrawing and dropping out. We want people to remain productive and working. It is understandable that symptoms and problems may make this harder for you, that doing things may take more time and energy, but it is still better to do it than not to do it.

People with MS are happiest and at their best when they live normally and carry out the activities they enjoy. There are no absolute limitations—if you feel like climbing a mountain and do not have symptoms and problems that limit you, go for it! Unfortunately, MS does cause symptoms that may limit activities to some extent.

It requires adjustment so that you can continue to do as much as you can, in the time you need, and in the way you can manage. If you work at managing your problems, coping with any limitations, and keeping a positive attitude, not only can you do many of the things in life you want to do, but also you may accomplish much more than others without MS, as they often do not use these positive skills to deal with life.

### *What About Exercise?*

Simply put, exercise is good for everyone. When the diagnosis of MS is made, you should set about getting yourself in the best shape that you can, both mentally and physically, in order to manage any challenges that come with the disease. We all benefit from regular exercise, and it is even more important for the person with MS. If fatigue is a problem, you should arrange your exercise for times when fatigue is less bothersome, schedule it in periods with breaks, or redesign the type and pattern of exercise so that you can still do it.

In general, the best exercise is one that you enjoy so that you will still be doing it in 6 months and in 6 years. Exercise should be a lifetime habit for all of us, including people with MS, even if the exercise program needs to be modified at times. Decide what you like to do and would enjoy doing almost every day. Try to involve others in exercise as well. Exercise programs in the community have a tendency to motivate you to participate regularly; they also have an enjoyable social aspect.

### *Can I Overdo It?*

It would seem logical to be concerned that overdoing things might cause attacks of MS and worsen the disease and that we should rest and avoid strain and work. This is *not* good advice. *There is no*

*evidence that doing a lot, exercising, or even overdoing activities or physical exercise has any deleterious effect on MS.* True, it may make you tired for the next day or so, but there is no evidence that it worsens your MS. Some people “push through” their fatigue, which also may make them tired the next day but does no harm.

It might be tempting to blame overactivity for the development of a new attack of MS or a new symptom, especially if it happened a day or a few days later, but a careful accounting of strenuous events, stressful events, and the occurrence of attacks would show that this probably is coincidental. Do not worry about activity; be reasonable, keep active, and do what you can.

### *How Much Should I Rest?*

Because fatigue is a major problem for many people with MS, a reasonable balance between maintaining your normal activities and taking brief rests is appropriate. People usually find their own balance of activity and rest, and in this way they keep up their activity, work, and other responsibilities.

It is important to recognize that the fatigue in MS is not “normal” tiredness that follows too little sleep or a long, hard day. The fatigue in MS is often an abnormal sensation; it is unrelated to the amount of sleep and activity and it feels different. It can occur in waves and may seem overwhelming at times. Adapting the level of activities is often successful, and some medications also may be helpful (see Chapter 3).

Do not rest too much. *Activity* is a more important watchword than rest in MS.

### *What About Stress?*

Everyone experiences stress in their lives, and being given a diagnosis of MS is certainly stressful. Having to see yourself and

your life in a different light, with greater uncertainty, is stressful. But marriage, raising children, doing our jobs, and the “daily-ness” of life also bring stress. The central point is not whether stress is present in your life (it almost always is), but your response to it. People can, and do, react differently. Some see stress as a problem to be solved. Some respond emotionally, collapsing in tears, becoming depressed, or lashing out angrily at others. Some are initially upset, but then set about overcoming or dealing with the stress. Others do not believe it is possible to deal with it and give up. It is not the stress; it is our reaction to it that makes the difference.

When people react to stress in a nonproductive way, they often state that anyone would react the same way. That actually is not true, but some people are unable to see any other way of reacting. Fortunately, by analyzing such events, you can learn how to react more positively. It is not easy and sometimes requires counseling, but a person who reacts ineffectively to stress can learn how to respond better. It does mean that you must recognize that your responses could be more productive before you can work at it or seek help.

### *Can I Develop Better Coping Skills?*

We all have certain patterns of coping. Some of us react more intellectually to problems and stresses, while others react more emotionally. Most of us have a combination of the two; it is the balance of intellectual problem-solving responses and emotional responses that is important.

It is natural to feel upset when something stressful happens. However, it is not normal for that to be the only response. There is a point at which we must think clearly and objectively about what the stress is all about, how we can analyze it, and how we can most effectively deal with it. That combines the appropriate emotional and problem-solving aspect. You can improve these coping skills by improving their components. When a stressful event has passed,

you can analyze how well you responded: whether your emotional response was appropriate and balanced, and whether the steps you took were the most effective and efficient ones for solving or dealing with the problem. Such analysis often gives you a different perspective, particularly if it is done in an honest fashion and enables you to see how you could respond more effectively the next time.

### *How Can I Maintain a Positive Attitude?*

The most important factor in dealing with MS—or any challenge in life—is a mature, positive, and good-humored attitude whenever possible.

Some people struggle harder than others. There is no question that a positive attitude is of great importance because a negative person cannot tolerate very much adversity. Multiple sclerosis does not make you positive or negative; you already had an approach to life before you developed the disease. Multiple sclerosis can challenge your approach, your positivity, and your good humor, however, so it is important to make an even greater effort to overcome difficulties in a way that makes you feel good and improves your relationships. People like to be around those who are positive and good humored. We can understand those who are negative and turn their frustration on others, but they do not manage well, are more unhappy, and do not learn to take control of the things they can manage.

### *What About My Relationships?*

Good relationships are helpful to all of us, and they become even more important when we have difficult challenges to deal with and overcome. One important aspect of taking control of your health and your future is to strengthen your relationships. It may seem simplistic, but it actually is one of the most important things you can do. It has a positive effect on you when you do everything you can

to improve your relationships with your spouse, your children, your family, your friends, and everyone with whom you come in contact. Our relationships with others are central to our happiness and state of well-being, and it is rewarding to continue to improve them.

### *Should I Tell People I Have Multiple Sclerosis?*

It is natural that you may have felt uncertain about telling people—even your family or close friends—when you first were told that you have MS. It is hard to recognize that something about yourself has changed, and it is worrisome to think that it may change relationships and how people regard you. Eventually you will come to recognize that you are still the same person, that the people who love you will continue to love you and support you, and that others generally are understanding and helpful. Sometimes they may try to be too helpful, as most people do not want the relationship to be altered or to be treated differently. All of these feelings, plus some embarrassment about “having an illness,” make many people want to hide the diagnosis. They think “maybe if I pretend the problem doesn’t exist, it won’t exist.”

It is a good rule to be honest and open in our relationships and interactions. Of course, like all health matters, the fact that you have MS is a private and confidential matter, so who you confide in is a personal choice. It is common to keep the information within a small circle initially, especially because everything may be calm and stable for many years. A problem begins to develop when symptoms cause difficulties that are visible to others, but they have not been made aware that you have a health problem. At that point, others may wonder, worry, and speculate about what is happening, and their speculation can be more harmful than the truth.

It also is worth considering that people feel excluded and not trusted when they are kept in the dark yet know that something is being kept secret. There are some instances when keeping a medical problem a secret can be a serious offense or can cause serious problems.

For example, you cannot lie about having a medical problem when answering questions on insurance forms or other official documents. There are only a few instances when it is proper to ask such questions, but in such instances you must answer truthfully.

### *What Happens When It Is Hot?*

Most, but not all, people with MS find that they are heat sensitive. They notice that they become weak or dizzy, or even feel sick, in a hot bath, on a hot humid day, or in a warm environment. They also notice the opposite—they feel better and function better when it is cooler, when they are swimming in cool water, or when they move from a warm room to a cool room.

Remyelinated and partially damaged nerve fibers may function less well when body temperature is elevated and, conversely, the nerves function better when temperature is lowered. This tends to be a transient phenomenon that does not produce a lasting effect. However, it can produce marked weakness, and people often describe themselves as feeling like a “dishrag” or “wiped out” on a hot day. This response to heat was once the basis of the *hot bath test*, which was used as a test for MS before modern diagnostic tests were available. Although it is suggestive of MS, it is not accurate enough to be an important test.

You may wonder whether becoming weak in a hot environment will make the disease worse, but the phenomenon is transient and disappears as soon as you cool off. We do recommend that you avoid a warm environment whenever possible because you will feel less well, function less well, and have more symptoms when it is very warm. Air conditioning often is required in summer months to maintain reasonable temperature control and is considered medically necessary for tax purposes (a letter from your physician is needed). Cool drinks are also helpful—get in the habit of carrying one with you. The fluids will help your bladder and bowel function as well! Avoiding sunbathing, saunas, and hot tubs is strongly advised.

### *Should I Change My Diet?*

The dietary approach to the management of MS has a long history. It is difficult to perform clinical trials on diets, but there was interest and some suggestion of a positive response from studies of diets that are low in animal fats (essentially a low-cholesterol diet) and with a supplement of a vegetable oil such as sunflower seed oil or evening primrose oil. A few of these studies showed some positive benefit; one large study showed no benefit. There also was some suggestion that people with early and mild disease benefit the most. Many people use the simple approach to diet of lowering the amount of animal fat and supplementing it with a vegetable oil because it is a healthy diet and everyone in the family can potentially benefit from it. Many more complex diets have been recommended in MS, which have little logic or justification and are so complicated that people give them up after a short time.

The most important points are to stick to a balanced, healthy diet, maintain normal weight, and limit your intake of animal fat. This is a good dietary recommendation for everyone.

### *Should I Sleep More?*

How much sleep you need is based on your own normal pattern. Some people require 8 or 9 hours a night, whereas others require only 5 or 6 hours. The average is 7½ hours of sleep, and the measure of effectiveness is how rested you feel in the morning. You should not change your sleep pattern because you have MS. Since fatigue is a major problem for many people, there is a tendency to think that you will be less fatigued if you sleep more. However, even with normal or greater sleep hours, you will still tend to feel tired during the day if fatigue is due to MS. Surprisingly, oversleeping often makes people feel more tired. It is worth remembering that many factors can decrease the quality of sleep, including alcohol and many drugs.

### *What If I Need Surgery?*

The answer to this question is simple. If you need surgery and there are good indications for surgery, you should have it. If you do not need surgery, you should not have it. This is a good rule whether you have MS or not. There does not appear to be any increased risk to people with MS who undergo surgery. In the past, there was concern that the stress of surgery might precipitate MS attacks, but the number of attacks of MS that occur in those circumstances is the same as that which would be expected in an average population of people with the disease, and no more. This relates to the previous point that there is little evidence that stressful events precipitate attacks of MS, whether they involve surgery, anesthesia, trauma, or major life events. The most important rule is to be assured that surgery is truly indicated and necessary.

### *Is Pregnancy a Risk?*

The relationship between MS and pregnancy is now fairly well understood. Pregnancy does not appear to increase the incidence of attacks of MS; in fact, some data suggest that the likelihood of an attack of MS decreases by up to 70 percent during this period. However, there is an increased number of episodes of symptoms or attacks in the 6 months following delivery than would be expected in a 6-month period. Those episodes should be treated and managed like any other episode of MS. Pregnancy has no long-term effects on disability or disease progression.

Two other aspects of pregnancy and child rearing must be considered. First, there is a small, but real, genetic risk for MS in a family—in the range of 2 to 5 percent for a first-degree relative. This is greater than the risk in the normal population, but it clearly is low. More significantly, raising a child is a life-long responsibility, and people with MS must recognize that their health during the time that

they will need to carry out this responsibility may be uncertain. For example, one cannot predict health status in 10 years. This probably is the major factor that governs the decision about having a child. Recognizing the risks and problems, each couple must determine for themselves this very personal decision. An excellent resource on this topic is the book *The Disabled Woman's Guide to Pregnancy and Birth* (see Additional Readings).

### *Will Multiple Sclerosis Affect My Sex Life?*

Because MS affects the central nervous system and the nerves that control various functions in the body, the complex and sensitive control system for sexual function also can be affected. Early in the disease there may be no physical effect on sexual function, but the enjoyment of sex may be affected by your emotional state. Worries, depression, or altered feelings about yourself can affect your relationship with others and the normal emotions associated with sexuality. Thus, sexual function may be affected by psychologic factors, and this possibility needs to be considered. More often there is a physiologic basis for the difficulties, which often are seen in conjunction with bladder and bowel symptoms. For men, the most common problem is achieving or maintaining an erection, which can be helped by medication such as sildenafil citrate (Viagra®). Women may experience decreased vaginal lubrication, which can be accommodated by synthetic lubricating products, such as Astroglide®.

### *What About Driving?*

Driving is only a problem when symptoms or limitations make it risky or unacceptably difficult. Vertigo, double vision, or a temporary loss of vision would not permit you to drive safely. Problems with leg weakness or incoordination limit rapid and accurate use

of brake and accelerator pedals and make driving unsafe. It may be possible to return to driving when symptoms improve, but it is wise to depend on the assessment of your physician when there is any question about this. Most rehabilitation facilities can assess whether a person can drive safely.

When a problem is more long standing and renders driving unsafe, it may be possible to adapt the controls on the vehicle to allow a person to drive. The most common adaptation is that foot pedals are converted to manual control.

Although a person may be anxious to continue driving and willing to take some chances, feeling that they are “all right to drive,” greater consideration must be given to others who may be at risk, including passengers and pedestrians.

### *Should I Move?*

Some people with MS ask if it would be helpful if they moved to another area because they have read that the incidence of MS varies in different parts of the world, that it is more common in temperate climates, and that it is rare in very hot climates, such as near the equator. The answer is no. In fact, they might find the heat a problem because it tends to make people with MS feel worse. We also believe that the geographic patterns of MS incidence probably have other explanations, and there is no evidence that moving to another area once you have the disease will help.

### *Will I Be Different?*

It is natural to wonder how MS will change you. Young people see themselves as healthy and do not visualize themselves with a serious disease. When you are given a diagnosis of a medical condition, it is natural to begin to think of yourself differently, and you may have to readjust your self-concept. You are still *you*, but it requires you to see that a different element has entered your life.

Many things change as you go through life—some good, some not so good. What is necessary is a positive approach to challenges and determination to move ahead.

*What About Other Questions I May Have?*

We could not possibly anticipate all the questions you may have about what to do and not to do, but we have tried to anticipate the most common questions. You will have many more, and they should be asked of your physician, other health-care professionals, or staff at the MS Society. It is always better to ask a question even if you are uncertain about exactly how to ask it or if you think it sounds “silly” than to wonder or worry in silence.

We recommend the book *Multiple Sclerosis: The Questions You Have—The Answers You Need* as a more detailed guide to many of your questions (see Additional Readings).