

Staying Well

Multiple Sclerosis and Your Emotions



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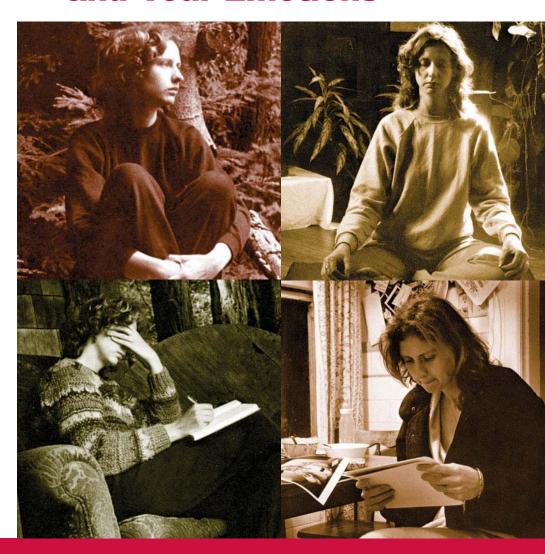
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The Society publishes many other pamphlets and articles about various aspects of MS. To ask for these, or for other information, call the National MS Society at 1-800-FIGHT-MS (1-800-344-4867).

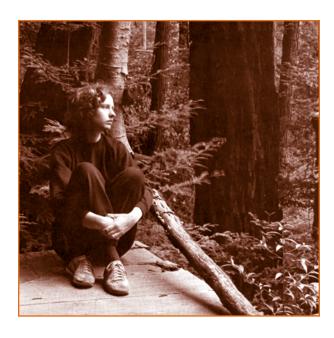
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Some of our popular pamphlets include:

- * MS and the Mind
- ❖ Depression and Multiple Sclerosis
- ❖ Taming Stress in MS
- MS and Intimacy

We welcome your comments by mail or to editor@nmss.org.

Multiple Sclerosis and Your Emotions



by Mary Eve Sanford, PhD, and Jack H. Petajan, MD

INTRODUCTION

What is multiple sclerosis?

Multiple sclerosis is a chronic disease of the central nervous system (the brain and spinal cord). It affects about 400,000 people in the United States today. MS causes breakdown of the myelin sheath that normally surrounds and protects nerve fibers in the central nervous system (or CNS). The underlying nerve fiber can also be damaged. Symptoms of MS range from occasional numbness and tingling to fatigue, muscle spasms, poor bladder control, poor vision, paralysis, and more. MS can also affect the ability to remember, solve problems, or concentrate. MS symptoms may come and go, or become permanent.

Commonly, MS is a "relapsing-remitting" disease. There are **flare-ups**, also called **exacerbations** or **relapses**, when symptoms become much worse, followed by **remissions** or **recovery** when symptoms lessen. Recovery may be partial or complete.

Relapses happen most frequently at the begin-

ning of the disease and then the rate declines. For most people a more steadily progressive form of the disease with fewer or no relapses eventually begins. The progression or worsening usually occurs slowly over months or years. All forms of MS may stabilize at any time.

Today, there are "disease-modifying" medications that can put the brakes on relapsing forms of MS and slow down its progress. But none of them cure MS. These drugs are the first medications ever shown to affect the underlying disease process. In most cases, the sooner MS is treated with one of these disease-modifying drugs, the better.

Be sure to ask your physician and the National MS Society for information about all current treatments for MS and for any symptoms you may be experiencing.

COMMON EMOTIONAL REACTIONS



Regardless of the kind of MS a person develops, emotional reactions are likely to be similar. People feel disbelief, fear, anger, depression, and guilt.

Many self-help books about chronic illness place a strong emphasis upon regaining control of one's life, but a battle with MS must not become a battle against oneself.

If a person's sense of self-worth hinges on being able to control all changes, then his or her ability to adapt to changes will be blunted. Sometimes the best way to improve a situation is to practice letting go of the need to control.

This work is part of a process, and not a single one-time challenge. Success probably lies in gradually redefining family, social, and work roles and relationships, and learning to exchange some areas of responsibility for others.

Fear or apprehension

Fear is a very common reaction to chronic illness. The diagnosis of MS implies an unpredictable lifelong condition and long-term adjustments. It is reasonable to fear pain, disability, and the unknown. For many people, the greatest fear is losing control over their lives. Loss of self-esteem may be intense. These are not easy issues to work through.

Denial

Recent studies of people with chronic illnesses have concluded that denial can be a positive coping strategy as long as it doesn't interfere with proper treatment and self-care. Denial is a normal reaction, particularly at the time the initial diagnosis is made, or later, when MS has been quiet for a period of time.

To the extent that denial allows people to set worries aside, it can be a positive "time out". At the same time, a decision to use one of the disease-modifying drugs should be made early on. Scientists know that significant and irreversible neurologic damage can occur early in the disease while the person looks and feels fine. If a disease-modifying drug is recommended, it's important for the person to work on making it a normal part of life. Taking a regular injection does not have to be a constant reminder of illness. Instead it is a positive and hopeful action.

Grieving

It is essential for people with MS to mourn their losses. Mourning can actually help people adjust. Grieving needs to be accepted with patience and compassion by both the individual with MS and friends and family.

The pain of grieving eases over time and is gradually replaced by sadness and by positive accommodations to the loss. This adjustment is ongoing and does not follow any calendar or set of stages. Moreover, a period of grieving can be expected to follow every major loss.

Depression

The changes imposed by a chronic illness may lead to bouts of clinical depression. For reasons that aren't yet understood, depression is more common in MS than in other chronic illnesses. About half of all people with MS must deal with a serious, or clinical, depression at some point during their lifetimes.

If the person with MS has a personal or family history of depression, she or he will be especially vulnerable. In some people, depression is thought to be caused by damage MS has done within the central nervous system. Or it can be a side effect of some MS medications. On the other hand, many people without MS also struggle with depression.

Most people who are grieving have feelings of sadness or unhappiness—but these feelings can lift. In a clinical depression, a person loses interest and pleasure in activities that were once satisfying, and these feelings persist for weeks. Other symptoms may include changes in appetite, sleep problems, fatigue or loss of energy, inability to concentrate or make decisions, uncommon restlessness or uncommon sluggishness, feelings of personal worthless-

ness or guilt, or recurrent thoughts of violence, death, or suicide.

Severe depression often goes unrecognized in our culture because there is a taboo against expressing negative feelings and an inclination to define emotional problems as weaknesses.

Serious or clinical depression is a disorder that can be treated. After evaluation by a professional, antidepressant medication and/ or psychotherapy are generally recommended and are generally effective over time.

Despite the likelihood of a bout with depression, a recent study of a large group of people with MS showed that after the initial adjustment phase, most individuals were able to achieve a positive sense of self-worth that continued throughout their lives.

Guilt

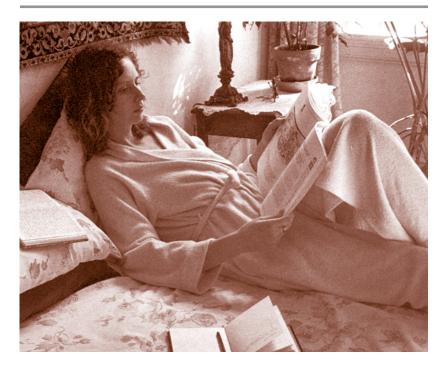
Feelings of letting down family and friends or of somehow being responsible for developing this disease may envelop a person with MS. Young mothers with growing families, the most commonly diagnosed group, are particularly vulnerable to guilt about not being able to accomplish their usual tasks. Children easily amplify a parent's guilt feelings. Their anger and frustration—which stems mainly from their fear of abandonment—increase parental distress. Children or a spouse may not express fear or anger verbally but the anger and fear may be there. Both are normal; they reflect the importance of family attachments. But if they are kept secret, these feelings can become destructive.

Everyone in the family will need a basic understanding of what the disease can do. It is important to define the real enemy as MS. No one is to blame for the problems MS has produced. Pick a calm time to talk this through.

Feelings of guilt or shame may be heightened when friends or relatives are short-tempered or resentful. This is more likely to happen when the person has **invisible** symptoms such as fatigue or pain. The reactions are normal; family and friends are also affected by the stresses of living with MS.

On the positive side, MS in a family sometimes encourages compassion and helpfulness, especially in children. Many people say closer family ties develop in time.

THE SPECIAL EMOTIONAL STRESSES OF MS



In addition to the emotional stresses that apply to anyone with a chronic illness, there are some characteristics of MS that create special emotional burdens.

Lack of a definite diagnosis

The diagnosis of MS may be a lengthy process. Physicians may not have enough information to make a definitive diagnosis, even when MS is a very real possibility. This is due to the erratic nature of the illness and the fact that no single specific medical test exists to confirm or rule out MS.

For some people, a diagnosis after months or years of symptoms is a relief: "At last I know what I have." For others, it comes as a terrible shock. Both reactions are entirely normal.

The unpredictability factor

Even when a diagnosis is made, uncertainty isn't over. The course of MS is always unpredictable: People living with MS are aware that their symptoms can improve or suddenly get worse at any time. Unpredictability may be somewhat easier to deal with if it is anticipated—if people make alternative plans, "just in case." Discussing one's individual prognosis or expected future with a neurologist may also help ease some fears.

When chronic illness is diagnosed, some people think of the future in statistical terms, saying, for example, "I have a 50 percent chance of this or that." In one's mind, such predictions soon become fact. But only the

present is real. No one can truly predict the future. Furthermore, new treatments for MS make past experience unreliable. The future is unknown and today it is full of hopeful signs.

The invisible symptom factor

Symptoms such as fatigue and weakness are invisible. They can occur without a person showing obvious signs of illness. When this happens, family and friends often expect too much from the person with MS. MS fatigue is frequently perceived as laziness or lack of initiative. Under such pressures, it is not uncommon for people with MS to doubt themselves.

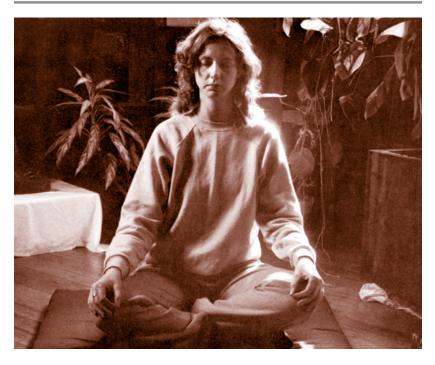
Sharing these feelings with others who have MS and learning their coping strategies can be very helpful. As one person with MS said, "Don't let others 'should' on you."

Making decisions about treatment

A number of "disease-modifying" drugs have been shown to limit the number of relapses, or attacks, to limit the number of lesions, or areas of damage, seen by MRI within the central nervous system, and may slow the progression of MS. The National MS Society
Medical Advisory Board has issued a Disease
Management Consensus Statement advising
that most people who have a definite diagnosis
of a relapsing form of MS should begin treatment with one of these drugs as soon as possible. The Consensus Statement is available
from Society chapter offices or online at:
www.nationalmssociety.org/SourcebookEarly.asp.

This good news about treatment options poses a new challenge to people with MS. The benefits of these medications are sometimes hard to see as the drugs may have little effect on the way people experience daily MS symptoms. But people who stay with their treatment will be doing all they can to minimize the long-term progression of their disease.

MS AND THE MIND



Cognitive effects of MS

At least half of all people with MS notice some changes in their mental abilities or cognitive function. These might include problems with memory and problem solving, as well as difficulties processing information quickly and using language. A person may have trouble comprehending information that is presented too rapidly. These changes can interfere with work, social life, and everyday activities.

There are many ways to cope with these problems. Some people make lists of things to be done or remembered. They allow more time for demanding tasks. They accept some help from others. Some people find it helpful to visualize what's on tomorrow's agenda. Most of all, people learn a sense of proportion about daily life. In other words, they don't sweat the small stuff.

Sometimes medication can reduce fatigue and increase attentiveness. A neuropsychologist can test cognitive functioning to determine where the problems lie and suggest specific strategies for coping more effectively.

Mood swings and MS

People with MS sometimes express emotions in an exaggerated manner. A person may laugh or cry more easily than before. A sad comment may cause tears. A joke may induce uncontrolled laughter. These exaggerated emotions can occur because of MS changes in the brain. The medical term is "pseudobulbar effect".

People with MS may also experience abrupt mood changes. They may go from calm and happy to upset and angry on a hair trigger. These rapid mood swings, sometimes called "emotional lability", can also be traced to MS changes or they can be triggered by medications, such as high-dose steroids.

It's important to recognize that abrupt changes in mood or inappropriate emotional responses are very likely to be MS problems. Medications can be effective for some people. For others, counseling and coping strategies prove useful. An open discussion with health-care professionals and family members may also calm some of the stress such reactions can cause.

People who have a history of clinical depression or bipolar disorder (in which there are swings from depression to excitement and back) should discuss this with their physicians even if the disorders appear to be under control. The symptoms of these disorders can be exaggerated by MS or its treatment and it may be necessary to avoid or modify some MS medications.

SEXUALITY AND MS



Individuals bring their own values and personal histories along with them when they develop a chronic illness. Accommodation to changes in areas of sexuality may be more difficult than changes in any other area of daily living.

Sexuality can be easier to discuss when it is seen as an integral part of human relations. It is important to recognize that work pressures, stress, and fatigue can reduce interest in sex among people who are totally free of any illness. It is quite normal for fatigue to have an effect on a person's interest in sex—and fatigue is one of the most common symptoms of MS.

Other MS symptoms, such as numbness or spasticity, may actually change one's capacity to experience sexual pleasure. But sometimes problems are out of proportion to the change in function caused by MS. For example, one embarrassing experience of losing bladder control during sexual intercourse may discourage a woman from all future affectionate expression, even though her partner did not regard the problem as serious. One embarrassing experience in which a man fails to achieve an erection can lead him to think any display of affection is a potential challenge to his sexuality, and he may choose to avoid that risk.

Such reactions do more than reduce exchanges of affection. They also interfere with communication, and create additional problems in relationships. To avoid a negative cycle of failure and withdrawal, people need to work at sharing their feelings, learning to be flexible about patterns of sexual behavior, and, above all, seeking professional help if change is not forthcoming. But first, some relatively simple steps can help.

- 1. Physical exhaustion, lack of sleep, emotional turmoil, too much heat, over-eating, or heavy use of alcohol are common distractions that interfere with sexual enjoyment for anyone. A bit of planning can help make romantic encounters romantic.
- 2. A soak in a tepid-to-cool bath may improve sexual performance just as it improves other physical functions for many people with MS.
- 3. Medications to reduce muscle spasms and stiffness can, in many instances, be timed to enhance sexual activity. Whenever possible, avoid taking muscle relaxants, sedatives, or antianxiety drugs just before sex. Antidepressants may also interfere with sexual function. Discuss dosage, timing, and medication type with your physician.
- 4. Reduced genital sensation concerns many people. But erotic sensations can be produced in many parts of the body. The thrill of that first touch can be recaptured with patience and skill.
- 5. Erectile dysfunction—the inability to produce a firm erection—affects many men with MS. There are new medications for

- improving erectile dysfunction which can be explored with a knowledgeable urologist.
- 6. An indwelling catheter need not stand in the way of sexual enjoyment if both partners desire each other. It can simply be moved aside.
- 7. Always empty the bladder just before sex. However, if there is some leaking, remember that urine is sterile and no real damage is done.
- 8. Medications for fatigue and improvements in fitness from a regular exercise program can both reduce fatigue, which may, in turn, improve sexual function.

And finally, there are virtually limitless variations of sexual technique and expression. Imagination and ingenuity are essential for a successful sexual relationship in the face of physical changes that may be imposed by MS.

Chapters of the National MS Society have information and resource lists and can make referrals to qualified professionals.

THE FAMILY AND MS



A bad case of flu or a broken leg may temporarily disorient a family, but most people adjust when the changes mean short-term shifting of roles and responsibilities. Multiple sclerosis is far more complex.

The diagnosis affects everyone in the family. Not only will each member have individual emotions, their feelings will often be out of synch with one another. While one family member is overwhelmed with anger, another may be cushioned in calm denial. Even in lov-

ing families, it's easy for communication to break down.

In addition, family roles may be turned upside down. People unprepared for caregiving may find themselves thrust into that position. A spouse may suddenly feel more like a parent than a partner.

At times, family members try to do so much for the individual with MS that they make the person feel even more helpless. Having too much care can discourage a person with MS from coping independently.

Some families handle their issues at special family meetings where everyone is allowed his or her say. Others do better one-on-one, perhaps in a neutral place, such as a parked car away from home. Family and spiritual advisors may be important resources. And mental health professionals are trained to help people work through their feelings about MS and talk more openly about difficult subjects.

Children in families with MS feel anger, frustration, and grief, just as their elders do. They may also feel neglected. A parent who listens, who acknowledges the child's feelings and provides encouragement can meet the child's emotional needs.

All children in a family with MS will probably shoulder new housekeeping responsibilities, a situation that is not necessarily bad. But in some homes, children end up as major caregivers. In doing so, they lose their roles as children. In such situations, people need to call on all possible sources of support—the extended family, social agencies, religious organizations, clubs, and the National MS Society.

IS THERE AN MS PSYCHOLOGICAL PROFILE?

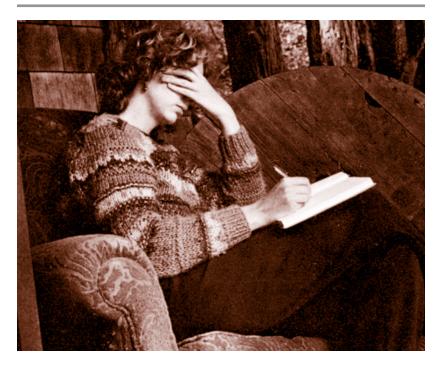
What can we say about the emotional makeup of people who have MS? How do most people react? Dr. Nicholas LaRocca, an MS researcher, arrived at these conclusions after reviewing major studies:

No MS personality profile has ever been demonstrated.

- People with MS are as normal psychologically and as diverse as any other random group. They can be expected to be distressed when diagnosed, and to be under additional stress when they experience attacks of symptoms or losses of ability.
- Emotions such as depression, grief, and anxiety often fluctuate with the ups and downs of the illness.
- An individual's sense of self-esteem may be seriously challenged by MS, but most people bounce back and maintain a positive sense of self-worth over the long term, even when their MS symptoms worsen.
- Most people find information about MS helpful and would prefer to understand as much as possible about the disease.
- There are many factors beyond the physical symptoms involved in adjusting to MS.

In short, while we can mention common disturbing emotions and common problems, no two people with MS have exactly the same psychological profile.

HOW TO LIVE MORE SUCCESSFULLY WITH MS



What does it take to be reasonably happy with a chronic illness? There are a number of common misunderstandings about this. A landmark study by the researchers Sobel and Worden in 1982 identified common misconceptions among a group of cancer patients that tend to make successful living almost impossible. The ideas included feeling that one should be completely free of symptoms; people should treat you just as they did before you became

ill; you should be able to do everything you did before you became ill; your family shouldn't be inconvenienced or made to worry about your condition; and your doctor always knows best.

Most of these will be rare for anyone with a chronic illness. Moreover, none of them are automatic obstacles to happiness or achievement.

Research has identified a number of characteristics common to people who live successfully with chronic illness:

- They are actively involved in their own care, as well as in other aspects of their lives.
- They are flexible, resourceful, optimistic, and positive.
- They have a practical approach to problem-solving.

It is interesting to note that these people maintain positive attitudes despite physical and cognitive symptoms, prejudicial treatment by others, limited activity, family problems, and doctors who don't have all the answers. Here are some points that contribute to successful living with MS:

Stay involved

People with many different chronic illnesses have demonstrated that when they are actively involved in the world around them—especially in their own health care—their outlook improves. Joining a support group often provides emotional connections. Seeking good information and learning about MS treatment may be especially helpful.

Appraise your MS with realism and flexibility

Some people stubbornly try to do all the things they always did regardless of their symptoms. A realistic approach means discarding some activities and taking on new ones that are more feasible—and thus more enjoyable and rewarding.

Maintain strong bonds with family and friends

This is an important ingredient in a good life whether one has MS or not. Most of us need to know we are loved and cared for. We also need to love and care for others who are important to us. The limitations of MS may change how this is done but not the need.

The person with MS is not the only person in the family and circle of friends who must adjust to a changed situation. Each person adjusts at different rates and in different ways, and the process cannot be forced. Nevertheless, relationships have the best chance to remain strong if everyone relaxes and engages in open conversation.

The person with MS needs to take the initiative in opening up discussions. By taking the lead and bringing up MS and what it does, the person with MS reassures friends and relatives and puts them at ease.

Talk sessions to air feelings will often reveal anger, frustration, and fear, as well as the positive emotions of love, concern, and the desire to provide support. These negative reactions shouldn't be discouraged. They can be handled appropriately. It's often true that someone who is overly cheerful is actually suppressing fears and worry—and possibly anger and resentment.

Keep a sense of purpose by setting goals

Having a goal—however modest—provides something to work toward and puts some structure into life. A large study showed that many people with MS coped better when they carried on their daily activities with a real sense of movement toward a goal.

It's important for people with MS to have at least one trusted individual to talk with about what MS is doing to their lives. If this would be a burden to relatives or friends, then a counselor, a spiritual advisor, or another person with MS may become that valuable confidant. The National MS Society chapter, a doctor, nurse, social worker, or other professional may provide referrals. Most people find that talking with someone from time to time lets off steam and helps them develop perspective.

Most people also talk to themselves and this affects their feelings. A shift in "self talk" from "This situation is impossible" to "I think I can handle this" is a major step toward a healthier life.

Find an exercise regimen that's right for you

Exercise is well known to be crucial to staying emotionally healthy. Many studies have shown a positive link between exercise and improved moods. The long-term benefits of exercise on the heart, lungs, bones, nerves,

and muscles apply to people with MS just as much as they do to the general population.

But MS symptoms may temporarily worsen during exercise and the period of fatigue afterwards may be somewhat long. In the past many people with MS were advised not to exercise.

More recent studies of vigorous training by people with MS who were able to walk showed training improved fitness and muscle strength and reduced depression and fatigue. People in exercise programs not only enjoyed an improved sense of wellbeing but many found their bowel and bladder control also improved.

Most people with MS can participate in comfortable exercise. It is essential to obtain an exercise prescription from a physician if disability or other health problems influence performance. And there are a few other guidelines.

The exercise must be mild to moderate with warm-up and cool-down periods. Exercise sessions should be brief at first and lengthened as fitness improves. It is very helpful to "feel" the exercise level and not to push too hard too soon. It should take about an hour to get over fatigue after exercise and the person should feel well the rest of the day.

Both exercise ability and recovery time are usually improved by keeping cool. It is best to exercise in a cool environment or to use cooling baths before and after sessions. One effective technique is to sit in a tub of tepid water and slowly add cooler water until the lower half of the body is noticeably cooled. There are also special cooling vests, neck wraps, and headbands to be worn during exercise that may help.

Relax

Together with exercise, programs for relaxing physically and mentally, such as yoga or meditation, are of great importance. Other techniques, such as massage, progressive relaxation, tai chi, and using a mantra ("slow down" is a good one), help establish a sense of well-being. They are proven tools for reducing life's daily tensions. Meditation and other relaxation techniques require practice and should be learned when stress is at a minimum.

■ Avoid the negative cycle Fatigue and depression both prompt people

to stop doing things they once enjoyed and to have fewer contacts with friends and colleagues.

What begins as feeling tired and blue easily becomes a negative cycle. Reduced activity further erodes physical well-being which leads to less strength for activity, more fatigue and depression, and even less physical activity. Medication to relieve fatigue or depression may be needed to break the cycle once it is established. But the person with MS can understand the nature of this cycle and take action to break away early on.

Don't underestimate the value of your spiritual beliefs

Faith is a very important part of most people's lives. Studies of people with chronic illnesses find that those who had a strong religious or philosophical belief system did better than those without such a source of support. Even the simple act of regular attendance at spiritual gatherings appeared to improve coping, perhaps because it gave those individuals a feeling of belonging and a sense of group support.

Any doctor you feel comfortable with Any doctor can prescribe medication and provide periodic examinations. Having a physician who can discuss personal matters and explain complex issues is another matter.

It is legitimate to shop for a doctor who is knowledgeable about MS and able to spend time listening and educating patients.

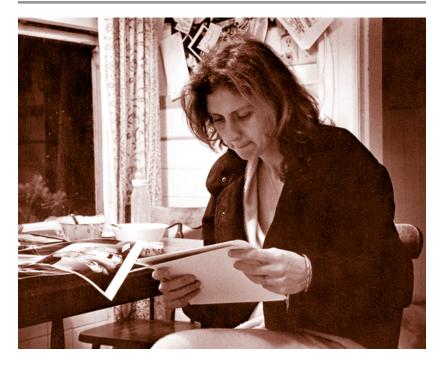
Multi-disciplinary MS clinics have much to offer both families and individuals.

National MS Society chapters can refer callers to a range of local health-care providers who understand MS and to clinics where people with MS find the quality medical care they need.

Plan on having some fun

Recreation is often the first thing people cut out when they pare down regular activities. It's understandable, but the fact remains that playing and taking part in social activities can reduce stress and refresh spirits. The people who are able to laugh and enjoy humor generally feel better about themselves and manage their lives more effectively.

COMMON QUESTIONS



Could my MS be caused by emotional upset or nervousness?

No. MS is a disease of the nervous system, but it is not caused by nervousness or tension. Studies of people with MS undergoing severe stress, such as injury, surgical operations, or personal losses show they do not experience any more attacks or exacerbations than people with MS who are leading more tranquil lives.

Could emotional factors affect my day-to-day functioning with MS?
Probably. Many people with MS report that

when they're upset or nervous, their legs won't work well, their speech is more of a problem, or their fatigue seems worse. MS specialists believe that these difficulties may simply be normal responses to tension. These increases in symptoms are only temporary and will disappear on a better day. They do not represent progression of the disease or a true relapse (also called an exacerbation or attack) of MS.

Should I try to minimize stress in my life? It's not possible to be alive and avoid stress. Stress is a natural part of life. A better question to ask is what daily stresses affect me negatively and how can I manage them better? Most people can handle considerable stress quite well. Most people get along from day to day on about half of their potential psychological strength. Living with MS may require more. Learning good stress management techniques is a sensible response.

What do we know about stress and MS?

Research continues to examine the relationships of emotional stress, family conflict, job stress, other major life stressors, and the course of MS. People with MS have often observed that their symptoms are worse when stress is greatest. We also know that worsening of the disease can compromise a person's ability to cope with stress. For example, reduced ability to process

information may require slowing down the pace of work. This may be hard to do, in practical terms. Work "overload" can easily occur, leading to frustration, anger, and feeling overwhelmed.

Despite our lack of understanding of the precise relationship between stress and MS, it is essential to be aware that MS can affect thinking and emotions. Education of family and friends, and appropriate treatment can help a person with MS achieve a balance in life.

Now that I've read this—what's next?

Simply reading this material is not enough. You may want to share this booklet with family members. We believe people with MS do better if they are able to develop an active, optimistic attitude. This involves communicating with others, and perhaps becoming involved with a group. The ultimate goal is to live a full life despite having the chronic condition of MS. Adapting to this illness does not mean living life as a sick person. It involves adjusting to various unpredictable limitations. It takes courage to do it, but it is certainly possible.