

# Multiple Sclerosis & Your Emotions

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Cherish (front cover), diagnosed in 2002.

# Multiple Sclerosis & Your Emotions

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People living with multiple sclerosis (MS) experience many different emotions and mood changes over the course of the disease. Some of these are reactions to the stresses and challenges created by this chronic, unpredictable illness, while others seem to be symptoms of MS itself. This booklet describes the range of emotional reactions and changes that can occur and provides information for individuals with MS and their families on how to recognize, talk about, manage and learn from these feelings.

## Common Emotional Reactions

No two people or families living with MS react to the disease in exactly the same way or face exactly the same challenges. Nevertheless, there are certain reactions that seem to be very common.

### Initial Reactions to the Diagnosis

The diagnosis of multiple sclerosis may produce shock, anger, fear, relief and denial — all of which are normal, predictable reactions to this kind of difficult news.

- **Shock:** For some people the news is so startling and puzzling that they simply cannot absorb it. It may take several days or weeks for them to be able to think about next steps for dealing with this unwelcome intrusion in their lives.
- **Fear:** For those people who know very little about MS — or those who have known someone with very progressive, disabling MS — the first reaction may be fear or even panic. They may be quick to assume the worst about their health, their life, and their future.
- **Anger:** It isn't at all unusual for people to feel angry and frustrated by their diagnosis. Certainly no one asks to get MS, and many react with resentment to the unfairness of being diagnosed. "Why me?" is the first question on many people's minds.
- **Relief:** For anyone who has had to wait months or even years for an explanation of puzzling, uncomfortable symptoms, getting the diagnosis can be a relief. Particularly for those people who were worried about having a brain tumor or some other potentially fatal disease, the diagnosis of MS can feel like welcome news. The news may also provide validation for anyone who has been told, "There's nothing wrong with you — it's all in your head."
- **Denial:** Some people react to the diagnosis by shoving it under the rug — telling themselves that it couldn't possibly be true or that the doctor has made a mistake. Denial can be a very useful and effective coping strategy during the early days of a chronic illness — allowing a person to take a brief "time out" before beginning to deal with the realities of MS. However, denial that goes on for weeks or months can also get in the way of important treatment decisions and self-care strategies. [For information about the importance of early treatment with one of the approved disease-modifying medications, read the Society publication, *The Disease-Modifying Medications*, at [nationalMSSociety.org/dmd](http://nationalMSSociety.org/dmd) or call your chapter for a print-out if you don't have access to the Internet.]

Although physicians will generally provide their newly-diagnosed patients with information about treatment options, they recognize that some people want and need the time until their follow-up appointment to get used to the idea of starting treatment — particularly if their symptoms have disappeared and they feel like themselves again. Since most people are diagnosed with the relapsing-remitting form of MS, denial is common during early periods of remission, when symptoms partially or completely disappear.

It is important to remember that any and all of these reactions are normal. Each person is going to react in his or her own way to the diagnosis of MS. Keep in mind, however, that there is help available if any of the feelings become unmanageable or too uncomfortable. The National MS Society offers a variety of information and support services — in person, by phone, and online. (See the Resource List on p. 21.)

## Longer-Term Reactions

Like people's initial reactions to the diagnosis, their longer-term reactions will vary considerably as well. Since everyone's MS is different, there are no predetermined stages of adjustment and no right or wrong ways to feel about it. However, there are some very common reactions that most people will experience at one time or another over the course of the disease. And people often find these feelings recurring as the disease goes through its characteristic ups and downs of attacks and remissions or causes new or worsening symptoms.

- **Grief:** This unique kind of sadness is a normal reaction to change and loss. Although most people associate grief with the loss of a loved one, it's also a common, healthy reaction to any change that threatens one's sense of self. In other words, people with MS may find themselves grieving initially over the diagnosis of a chronic illness, and then experiencing those feelings again any time that MS causes a new symptom, moves to a new place in the body, or interferes with their ability to do something that's important to them.

Grieving is an important first step in any person's efforts to cope with a chronic illness. As the pain of grieving gradually eases over time, the person is able to begin making positive adaptations to whatever changes have occurred. The cycle of grief and adaptation will continue to repeat itself whenever significant change or loss occurs.

- **Anxiety:** Feelings of anxiety are very common in MS. Whether people are concerned about getting to the bathroom on time, holding on to their job, keeping up with their kids, or becoming severely disabled, they tend to feel anxious when they can't be sure what's going to happen next. Learning how to live with the unpredictable ups and downs of MS is a significant challenge for anyone affected by this disease. Anxiety may be even more of an issue if a person tended to worry excessively before MS.
- **Anger:** As the disease runs its course, people may find themselves feeling very angry about all the changes MS brings to their lives. Although anger is a common and normal response to changes and losses that feel unfair, many people find it difficult to know what to do with it — how to handle and express their anger in ways that are effective and won't spill over onto family members, friends, and colleagues.

The goal is to find ways to put that angry energy to good use — to channel it into effective planning and problem-solving. Healthy anger can fuel a lot of productive change.

- **Guilt:** If and when the disease begins to interfere with activities at home or at work, people may feel that they are letting others down. They may worry that their loved ones or colleagues are taking on extra responsibilities. They may worry about not contributing to the family income or worse, being a drain on family resources. They may feel that their children aren't getting as much attention as they need. If the disease progresses in spite of their best efforts to manage it, they may feel guilty about that too, as if the disease were their fault or that they could have made a difference by trying harder.

While each of these reactions is a natural response to the upheavals caused by MS, they can begin to feel unmanageable. Grief can feel so overwhelming that it becomes difficult to distinguish from depression. (See page 8 for information about the diagnosis and treatment of clinical depression.) People can become so anxious about the future that they can't deal with how things are at the moment. Anger can drain a person's energy and interfere with important relationships. And the guilt can rob a person of the confidence and self-esteem needed to deal with the challenges of the disease.

Whenever these common reactions start to feel unmanageable or overwhelming, it's important to know that help and support are available. For many people, the opportunity to talk about these feelings in a supportive setting (on the phone

with a peer counselor, in a self-help group, in an online chat room, or with a knowledgeable mental health professional) can bring some relief and help channel overwhelming feelings into productive problem-solving.

## Family Members Have Feelings Too

Just as the person with MS is learning how to deal with all of these feelings, family members are experiencing a similar set of emotions. Everyone who loves someone with MS, and whose life is affected in one way or another by the presence of MS, needs to figure out how to respond to it. Since no two people handle feelings in exactly the same way, the result can be a household full of strong emotions that are being expressed in different ways at different times. It's like a symphony orchestra without a conductor — everyone is playing his or her own tune, not necessarily in sync with anyone else. Here are some points to consider:

- It's important for family members to acknowledge that they are all affected in one way or another by MS. Like a pebble thrown into the water, the disease creates its own ripple effect on the whole family's everyday life.
- Family members need to acknowledge and respect each other's coping styles and strategies. People tend to react to stress, express feelings, and problem-solve in very different ways — and one person's style isn't necessarily any better or more effective than another person's style. While acknowledging these differences, family members will benefit from learning how to communicate comfortably and respectfully in spite

of them. Talking comes more easily to some people than others; the challenge lies in making sure that everyone's feelings are recognized.

- Parents with MS are often reluctant to talk about the disease with their children because they don't want the children to be frightened or upset. However, children (even very young ones) are highly sensitive to their parents' moods. They know when mom and dad are upset or not feeling well — even when the MS symptoms are mostly invisible. And they worry about what might be wrong. It's important to give children age-appropriate information about MS so that they have the opportunity to ask questions and express their own feelings about whatever is going on.
- Teamwork makes everything easier. By making MS the “common enemy,” family members can focus their frustrations on the disease rather than each other, and work together to figure how best to handle the changes in their lives. This kind of teamwork can also help to reduce the guilt spouses and partners often feel about not being able to “fix” the problems their loved ones are experiencing.

## Common Emotional Changes

The previous section talked about common reactions people have to the challenges of living with MS. This section describes emotional changes that are thought to result, at least in part, from the damage to the nervous system caused by MS. In

other words, these changes are considered by MS experts to be part of the disease process itself rather than a reaction to the challenges it poses.

### Moodiness & Irritability

People with MS report feeling more sensitive and moody, and family members may find their loved ones to be quick on the emotional trigger, cranky, irritable, or unpredictable in their emotional responses to things. Knowing that this moodiness can be part of the disease as well as a reaction to it may make it easier for everyone to understand and tolerate it. But the moodiness isn't comfortable for anyone, so it's important to let the health care team know about it, particularly since irritability may be a symptom of depression (see next section). A health care professional with expertise in MS can teach strategies for managing uncomfortable mood changes, and recommend an appropriate medication, if needed.

### Depression

While everyone has occasional days of feeling blue or down-in-the-dumps, major depressive episodes (also known as *clinical depression*) are different. For reasons that are not yet fully understood, clinical depression is more common in MS than in the general population or in other chronic illnesses. In fact, more than half of people with MS will experience a major depressive episode at some point over the course of the disease. And milder forms of depression are even more common.

MS experts believe that depression is a symptom of MS as well as a response to it. Researchers have found evidence that immune system changes and damage in specific areas of brain may contribute to depression in MS. Further support comes from the fact that depressive episodes can occur early or late in the disease, regardless of a person's other symptoms or their level of disability. But it's important to know, that people who are in the midst of an exacerbation (also called a relapse or attack), or who have a personal or family history of depression, are at greater risk for a depressive episode.

Depression is not a sign of weakness — it is a medical condition that can and should be treated because it interferes with just about everything including a person's ability to function comfortably in daily life. Living with MS can be challenging enough without the added burden of a depressed mood.

Depression continues to be under-diagnosed and under-treated in people with MS. There are four primary reasons why this is so:

1. Several of the symptoms (listed in box on page 11 and marked with an \*) overlap with common symptoms of MS. Therefore, it may take a psychiatrist or psychologist with expertise in MS to sort out the various symptoms and confirm the diagnosis.

2. People with MS who are depressed may appear more irritable or moody than tearful or sad, so it may not be obvious to them or to others that they are depressed.
3. Many people are too embarrassed or ashamed to admit these kinds of feelings to their doctors, as though they are a sign of weakness.
4. There is a common, but incorrect, assumption that anyone with a chronic, unpredictable illness like MS would or should be depressed — and this is definitely not the case. While everyone with MS needs to grieve over whatever losses the MS may cause, and everyone has days of feeling down or discouraged, not everyone experiences five or more of the symptoms listed for days or weeks at a time.

The good news is that depression is a treatable problem. Most experts agree that a combination of psychotherapy and anti-depressant medication is the most effective treatment strategy. Research has also demonstrated that regular exercise, geared to the person's abilities and limitations, has a positive impact on depression. For more detailed information about depression and its management, see the brochure entitled *Depression & Multiple Sclerosis* online at [nationalMSSociety.org/brochures](http://nationalMSSociety.org/brochures) or call your chapter for a printed copy.

## DIAGNOSING DEPRESSION

The diagnosis of depression can be made if a person experiences five or more of the following symptoms most or all of every day for at least two weeks:

- Ongoing feelings of sadness or emptiness, irritability, or tearfulness
- Loss of interest or pleasure in most activities
- Significant weight loss or gain or a decrease or increase in appetite
- Sleeping too much or inability to sleep
- Physical restlessness or slowed movement observed by others\*
- Ongoing fatigue or loss of energy\*
- Feelings of personal worthlessness or guilt without appropriate cause\*
- Diminished ability to concentrate or make decisions\*
- Recurrent thoughts of death or suicide, or planning suicide

At least one of the first two symptoms must be present for the diagnosis of a major depressive episode to be made.

## Anxiety

Anxiety is at least as common among people with MS as depression. The assumption that anyone living with a chronic, unpredictable illness is going to experience anxiety may prevent people from discussing these feelings with their health care providers. When feelings of anxiety become overwhelming, interfere with everyday activities, or prevent a person from enjoying life, they need to be properly diagnosed and treated. Like depression, severe anxiety responds well to treatment involving a combination of psychotherapy and medication. In fact, several of the medications used to treat depression are also effective for treating anxiety.

## Uncontrollable Laughing and Crying

Episodes of uncontrollable laughing or crying (also called *pseudobulbar affect* or PBA) are another symptom that can be caused by MS. These episodes occur independently of how the person is feeling emotionally, and they start and stop unpredictably. In other words, a person may find him- or herself laughing inappropriately at a funeral, while actually feeling sadness and loss, or unable to stop crying while watching a comedy. Individuals with MS and their family members understandably find these episodes frustrating and embarrassing, and employers may find them unacceptable. Fortunately, uncontrollable laughing and crying affects only 10 percent of people with MS. It can usually be managed with medication, so it's important to bring this problem to the attention of

the health care team. In addition to the anti-depressant medications that have been used successfully in the past, a medication called Neudexta™ was approved by the U.S. Food and Drug Administration (FDA) in 2010 specifically to treat pseudobulbar affect.

## A Word about MS Medications and Mood

A number of medications that people take to manage MS or its symptoms can also affect mood.

- **Steroids and mood swings:** The corticosteroids that are sometimes prescribed to treat MS exacerbations cause some people to experience fairly significant mood swings — from bubbly, energetic “highs” while on the medication to irritable, depressing “lows” as it is being tapered or stopped. While not everyone experiences these mood changes with corticosteroids, and not everyone has the same experience each time they are prescribed, the mood changes can be very uncomfortable. For people who experience significant mood changes, the physician can prescribe a short course of a mood-stabilizing medication.
- **Interferons and depression:** All four of the beta interferon medications (Avonex®, Betaseron®, Extavia®, and Rebif®) that are used to treat MS carry an FDA warning about depression. Although studies have failed to show a clear connection between these medications and depression in people with MS, there have been reports of people experiencing significant depressive episodes. Therefore, anyone who has a history of depression should discuss it with the doctor before starting

one of these medications. And any person who experiences a significant mood change while taking an interferon should alert the doctor immediately.

## The Role of Stress

### What We Know — and Don't Know — about Stress and MS

A common question on people's minds is whether stress — or the emotions that accompany it — can cause MS or make it worse. We still don't know what causes MS, but there is little evidence to suggest that life stresses are the primary culprit. MS experts believe that the disease occurs in those individuals who are genetically predisposed to respond to some environmental trigger, such as a virus or bacterium, which alters the functioning of the immune system.

Research has shown that stress interacts in complex ways with the body's immune system, but the relationship between stress and MS activity or progression is unclear. The difficulty in sorting this out seems to come from the fact that not all stress is the same. For example, studies have shown that acute, traumatic stress may have no effect on the disease course, or may even be associated with reduced risk of exacerbation, while chronic stress/distress may be associated with an increased risk of exacerbation. Whatever the relationship turns out to be between stressful life events and the course of MS, it is also likely to differ from one individual to another.

There is ample evidence to suggest that coping strategies differ markedly from one person to another, and that some people are more resilient to life stresses than others.

This means that trying to manage or control MS by reducing the stresses in one's life is not the best strategy — for several reasons:

- The impact of stress on the course of MS is unclear.
- Everyday life is filled with stressful events, most of which are out of an individual's control. Trying to eliminate them can only lead to feelings of frustration and failure. And then people may feel guilty or inadequate if their MS progresses in spite of their best efforts to reduce their stress levels.
- The stressful events of everyday life are both negative and positive. Work, for example, involves the stresses of deadlines and year-end evaluations, as well as the stresses associated with a promotion or new, exciting job. Family life may be stressful because of arguments or illness, but also because of the arrival of a new baby or an upcoming holiday. Eliminating all stress from everyday life would rob it of things that make life exciting, challenging, and worthwhile.
- While there is little or no evidence to suggest that controlling stress can reduce disease activity, there is ample evidence to show that the disease-modifying medications do reduce MS activity. Regular use can limit both the risk of relapses and the development of new lesions as shown on magnetic resonance imaging (MRI). By far the best strategy for managing one's MS is to begin treatment early and stay with it.

## Strategies for Managing Stress

Everyone — with or without MS — may feel and function less well under stress. The best way to deal with the stresses of everyday life is to learn how to manage them more effectively — by eliminating those that aren't essential and finding more effective ways to deal with those that are. A good place to start is by carefully tracking one's activities for a week or two to see how much time and energy are being taken up by things that don't really matter. By figuring out what's most important and meaningful, it becomes easier to establish some priorities and decide what to keep doing and what to let go. A tidy house or a perfectly tended lawn, for example, may just not be as important as quality time with the kids.

The next step is to find stress management techniques that fit one's tastes and lifestyle. Options may include exercise, meditation, prayer, listening to music, or getting together with a friend, among many others. What works for one person may be very different from what works for someone else. The point is to find whatever healthful strategies provide relief from the pressures of everyday life — and then make time for them on a regular basis. For a detailed discussion of stress management strategies, see the brochure entitled *Taming Stress in Multiple Sclerosis* online at [nationalMS-society.org/brochures](https://www.nationalmssociety.org/brochures) or call your chapter for a printed copy.

# Some Helpful Tips

MS is a complex, unpredictable disease that can pose significant emotional challenges for even the strongest, most resilient people. It will probably take time to find the coping strategies that work best for you. These basic suggestions may serve as a good starting point:

- **Be an active partner in your own health care:** Seek out good information about MS and its management — the more you know, the more prepared you'll feel to make the treatment and lifestyle choices that work for you. Try to find a physician with whom you are comfortable. 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. Multi-disciplinary MS clinical centers have much to offer both individuals and families. National MS Society chapters can refer callers to a range of local health care providers who have experience in MS and to clinical facilities where people with MS can find the quality medical care they need.
- **Appraise your MS with realism and flexibility:** Allow yourself to grieve over whatever changes or losses the MS brings your way. In time this will free you to create new options for yourself. Some people stubbornly try to do all the things they did before — in exactly the same way — regardless of their symptoms. A realistic approach means letting go

of some activities (or learning how to do them differently) and/or taking on new ones that are more feasible — and thus more enjoyable and rewarding.

- **Maintain strong bonds with family and friends:** Strong connections with others are an important ingredient in a fulfilling life whether one has MS or not. Most of us need to know we are loved and cared for, and we also need to love and care for others who are important to us. Although MS may alter some of the things you're able to do, it's important to maintain meaningful relationships in which you're on both the giving and the receiving end.
- **Keep a sense of purpose by setting goals:** Personal goals help point you in the direction you want to go and provide a feeling of accomplishment and pride when you get there. An unpredictable disease that saps your energy and alters your ability to get things done can make progress towards your goals more difficult. It may even make it necessary for you to re-think previous goals and develop new goals over time. Whatever course your MS takes, it's important to set your sights on things that are important to you. And working toward your personal goals — whatever they may be — will help you maintain your self-confidence and self-esteem, and feel more in control.
- **Talk about your concerns and feelings:** It's important for people with MS to have at least one trusted individual to talk with about how MS is affecting their life. While this may be a relative or friend, many people find it helpful to have someone — perhaps a counselor or spiritual advisor — who is less personally involved and therefore more objective.

The National MS Society, a doctor, nurse, social worker, or other professional can provide referrals. Most people find that talking with someone from time to time lets off steam, motivates them to generate options, and helps them develop perspective.

Most people also talk to themselves, and how they do it can affect their feelings in a positive or negative way. For example, a shift from saying to oneself that “This situation is impossible” to saying “This is difficult but I think I can handle it” is a major step toward a healthier, more satisfying life.

- **Find an exercise regimen that’s right for you:** A regular exercise program is a key strategy for maintaining emotional health. Many studies have shown a positive link between exercise and improved moods. And 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.

Exercise (geared to a person’s level of ability) improves fitness and muscle strength, and reduces depression and fatigue in people with MS. Participants in exercise programs not only enjoy an improved sense of well-being, but experience improvements in bowel and bladder function as well. For more information about the role of exercise in MS, look at the brochure entitled *Exercise as Part of Everyday Life* online at [nationalMSSociety.org/brochures](http://nationalMSSociety.org/brochures) or call your chapter for a printed copy. And talk with your doctor about what kinds of exercise would be best for you.

- **Build relaxation into your schedule:** Together with aerobic exercise, programs to enhance physical and mental relaxation — such as yoga, Tai chi, or meditation, can be extremely helpful. Other techniques, such as massage, progressive relaxation, and using a mantra (“slow down” is a good one), help establish a sense of well-being. All of these are proven tools for reducing daily tensions.
- **Avoid the negative cycle:** Fatigue and depression can prompt people to stop doing things they once enjoyed and reduce their contacts with friends and colleagues. What begins as feeling tired and blue easily becomes a negative cycle, in which reduced activity reduces physical well-being, which in turn leads to less energy for activity and more fatigue and depression. Medication to relieve fatigue or depression may be needed to break the cycle once it is established. But awareness of the cycle is the first step toward dealing with it.
- **Don’t underestimate the value of your spiritual beliefs:** Faith is a very important part of many people’s lives. Studies of people with chronic illnesses have found that those who have a strong religious or philosophical belief system do better than those without such a source of support. Even the simple act of regular attendance at spiritual gatherings appears to improve coping, perhaps because it gives those individuals a feeling of belonging and a sense of group support. And for those who choose not to attend meetings of this kind, support groups and other social networks may meet the same need.

- **Plan on having some fun:** Recreation is often the first thing people eliminate when they need to cut back on regular activities because of fatigue or a too-busy schedule. Putting responsibilities at the top of one's priority list is understandable, but recreation and taking part in social activities can reduce stress, refresh spirits, and contribute to overall health and well-being. People who are able to laugh and enjoy humor generally feel better about themselves and manage their lives more effectively. Humor goes a long way toward taking the sting out of some of the more challenging aspects of life with MS.

## Resources

### Books

- *300 Tips for Making Life with Multiple Sclerosis Easier, (2nd Ed.)* by Shelley Peterman Schwarz. New York. Demos Press, 2006. 128 pp. ([demosmedpub.com](http://demosmedpub.com))
- *MS and Your Feelings: Handling the Ups and Downs of MS*, Allison Shadday, LCSW. Hunter House, 2006. 256 pp. 800-266-5592 or email: [ordering@hunterhouse.com](mailto:ordering@hunterhouse.com).
- *Multiple Sclerosis: A Guide for Families, (3rd Ed.)*, Rosalind Kalb, PhD, ed. Demos Medical Publishing, 2006. 256 pp. 800-532-8663 ([demosmedpub.com](http://demosmedpub.com))
- *Multiple Sclerosis for Dummies*, by Rosalind Kalb, PhD; Nancy Holland, EdD, RN, MSCN; and Barbara Giesser, MD. Wiley Publishing, Inc., 2007. 362 pp.

### Chat

In collaboration with MS World Inc., MS World is the official online chat and message board site for the National MS Society. Here you have an opportunity to network with others whose lives are affected by MS. [msworld.org](http://msworld.org)

### 24/7 Telephone Helpline

MS Friends provides a 24-hour-a-day telephone helpline to people living with MS, their families, friends and caregivers. Every trained volunteer who answers the helpline is living with MS — offering support, information and crisis intervention. 1-866-673-7436. [msfriends.org](http://msfriends.org)

### Webcasts, Podcasts and Transcripts

MS and Emotions: Parts I & II. Go to [nationalMSSociety.org/MSLearnOnline](http://nationalMSSociety.org/MSLearnOnline). Click on Symptom Management in the green side bar. Then go to Feature Presentation (center of page) and scroll down to the MS and Emotions presentation. Click the title to view the webcast. Transcripts and Podcasts are also available by clicking on the links.

### Referrals

Contact your chapter for a range of health care providers in your area. [nationalMSSociety.org](http://nationalMSSociety.org) Tel: 1-800-344-4867

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The National Multiple Sclerosis Society is proud to be a source of information about multiple sclerosis. Our comments are based on professional advice, published experience and expert opinion, but do not represent individual therapeutic recommendations or prescriptions. For specific information and advice, consult your physician.

The Society publishes many other pamphlets and articles about various aspects of MS. Visit [nationalMSSociety.org/brochures](http://nationalMSSociety.org/brochures) to download them, or call your chapter at 1-800-344-4867 to have copies mailed to you.

Early and ongoing treatment with an FDA-approved therapy can make a difference for people with multiple sclerosis. Learn about your options by talking to your health care professional and contacting the National MS Society at [nationalMSSociety.org](http://nationalMSSociety.org) or 1-800-344-4867 (1-800-FIGHT-MS).

### Some of our popular pamphlets include:

- Depression and Multiple Sclerosis
- The Disease-Modifying Medications
- Exercise as Part of Everyday Life
- MS and the Mind
- MS and Intimacy
- Plaintalk: A Booklet for Families
- Solving Cognitive Problems
- Someone You Know Has MS
- Taming Stress in MS

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