HAVING MS: AN EMOTIONAL ROLLER COASTER

Living with multiple sclerosis (MS) can be very stressful. MS not only affects your physical health, it may also affect your emotional health. This disability may cause changes in your routines, your abilities, your goals, and your lifestyle. MS also can be unpredictable, which can make adapting to its changes particularly challenging. When living with MS, it is normal to feel any of a variety of emotions. At times you may feel overwhelmed, sad, angry, nervous, or worried. You may feel depressed. You may question your ability to deal with all of the changes that this disability and the treatments for it may require. At other times, you may surprise yourself and feel happy, calm, confident, and fully in control of your life. You may feel capable of handling whatever challenges MS presents you with; you may even feel grateful for some of the aspects of your life that have been changed by MS. And these are just a few of the many emotions you may feel as a result of living with MS.

In this chapter, you will learn about the various ways that MS can impact how you feel. You'll learn something about the most common emotional experiences that result from living with MS, including depression. We’ll describe what depression is—and what it isn’t—as it commonly appears in people with MS. You’ll learn to recognize when your own emotional reactions are interfering with your life. More importantly, you’ll learn skills to help you feel better and to meet the emotional challenges of MS.
Because many people not only survive but thrive following a diagnosis of MS, we will also discuss the process of bouncing back, also known as resilience, and we’ll discuss how to build or maintain your resilience. You will have opportunities in this chapter to practice specific techniques for managing your emotional challenges.

We also want to acknowledge the fact that you may not have significant problems with your mood or emotions. Certainly, not everyone with MS experiences depression or the other emotional challenges discussed in this chapter. In fact, many individuals with MS adapt quite well to living with the chronic condition. Nonetheless, the information and skills presented in this chapter will help you to maintain your emotional health and improve your skills for managing the stress of living with MS.

It may be helpful for you to know what we mean by a few of the terms used in this chapter. When we use the word emotions, we are simply referring to feelings. Sadness, fear, happiness, anger, anxiety, contentment are all examples of emotions. Emotions can be transient, that is, temporary, or more persistent. When an emotion is all-encompassing and persistent, it is often referred to as a person’s mood. If your mood is a persistent, negative one, you may want to change it.

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**COMMON EMOTIONAL EXPERIENCES**

**Gloria.** When Gloria was diagnosed with MS, she felt very fearful. She was worried about how MS would affect her, her ability to care for her family, and her ability to work. She was afraid of what the future might hold. At times, she also felt angry that she had MS. She was also hopeful, however, that the treatments prescribed by her healthcare provider would reduce any progression of the disease and help her to keep doing everything she enjoyed doing: raising her children, nurturing her other relationships, and working.

**Dan.** After living with MS for more than twenty years, Dan found himself becoming moodier than usual. He noticed that he became irritated easily and was quick to lose his temper, sometimes saying things to others he later regretted. He often felt guilty after an irritable outburst or losing his temper. His family and friends were quite surprised by his outbursts because he had been known for his calm, relaxed demeanor.

**Donna.** It seemed that Donna was at the height of her career when she was diagnosed with MS. As the CEO of a large company, she had many responsibilities, worked long hours, and traveled a lot. She loved her job and everything that went with it. She approached her diagnosis in the same way that she approached challenges at work: with a vigorous optimism that she would meet the challenges of the disease. Sometimes she felt nervous or sad about the changes in her life, but these feelings never lasted too long and were often followed by a renewed sense of hope and optimism.

It’s likely that you’ve experienced a number of different emotions about living with MS. You may recognize in yourself some of the feelings experienced by Gloria, Dan, and Donna. Some of the emotions may be “negative,” that is, uncomfortable feelings, and some may be “positive,” that is, pleasant feelings. Now, take a few minutes to think about how you’ve been affected by living with MS. Specifically, think about some of the emotions you’ve experienced and then complete the checklist that follows.
Checklist 6: Emotional Inventory

Circle the emotions that you recall feeling when you were first diagnosed with MS:

- Aggravated
- Angry
- Annoyed
- Anxious
- Ashamed
- Caring
- Compassionate
- Competent
- Courageous
- Dejected

Circle the emotions that you have felt recently:

- Aggravated
- Amusement
- Angry
- Annoyed
- Anxious
- Ashamed
- Caring
- Cheerful
- Compassionate
- Competent
- Content
- Courageous

As always, the emotions you are currently feeling are the most important. Please take some time to describe your current emotional state as a function of the emotions you’ve circled. We often don’t take the time to do this. This will be a kind of emotional inventory for you.

There are several important points to understand about the emotional experiences of people with multiple sclerosis:

- Emotions can vary from person to person
- Not everyone with MS will have the same set of emotions
Your emotions may change over time

Emotions are neither “right” nor “wrong,” and there is no “right” way to feel

Negative emotions are not necessarily bad or destructive

Having MS doesn’t sentence you to a life of unhappiness

People don’t necessarily experience emotions in stages

Many people with MS live happy, satisfying lives without experiencing significant depression or anxiety

You may not be aware of “how extreme” an emotional reaction may appear to others

Other people may project their emotional responses to MS on you

**Donna.** One day Donna ran into an old friend from college, Jan. Over coffee, she informed Jan about the recent events in her life, including her diagnosis of MS. After hearing of this, Jan said, “How awful! You must feel so much sadness at having that disease! You are very brave to be continuing on with your life as you are doing.” Donna felt misunderstood by her friend, as well as irritated, because, in fact, she felt neither depressed nor particularly courageous. When she tried to explain this to her friend, Jan replied, “It sounds to me like you are in emotional denial about your disease. You must accept it if you are to move on with your life.” This, too, irritated Donna, as she knew that she was managing her MS successfully and was living her life just the way she wanted to live.

It’s important to recognize that other people in your life may expect you to have certain emotional reactions to MS. For example, when some people learn of your disease, they may assume that you feel depressed or sad about having it, regardless of how you actually feel. They may express surprise when you tell them you don’t feel that way. They may overestimate the suffering caused by MS. Some may even go so far as to say you are “in denial” of your feelings.

Conversely, some people may feel very uncomfortable if you express strong emotions such as anger about having MS. They may encourage you to “always look on the bright side” and warn you that a “negative attitude” can cause you to worsen. Or they may put you on a pedestal, praising you for being “brave” or “courageous.” These are just a few of the reactions you may get from others about how you are feeling about having MS. It is common for humans to make assumptions about how one should feel in response to a loss or to the presence of a disability, such as MS.

Even if such a response is well-intended, be careful not to assume that you should feel what others tell you to feel. If you are uncertain after some of these interactions as to what to do, it can be helpful to talk about them with a trusted friend, family member, or therapist. It may also be helpful to discuss this with others who have MS.

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**WHAT IS DEPRESSION?**

Depression is the most commonly discussed emotional reaction in the MS literature. However, there can be a lot of confusion about what is meant by the term. Sometimes, the word “depression” is used to describe a temporary emotion, such as feeling sad for a couple of hours when you are having a bad day or not feeling well. Other times, the term is used to mean a pervasive mood that significantly interferes with
living. This is technically called major depressive disorder (MDD), which is also sometimes referred to as “clinical depression” or simply “depression.” People with MS may or may not experience depression or MDD. However, when they do, it often negatively affects all aspects of their lives. Thus, it is important to educate yourself about what MDD is, so that you can recognize it if it is present, or prevent it, in the future.

Major depression is not just feeling blue or down in the dumps. It is also more than feeling sad or experiencing grief after a loss. Major depression is a medical condition (just like diabetes, high blood pressure, obesity, or heart disease) that day after day affects your thoughts, feelings, physical health, and how you act. Major depression is not your fault, nor caused by personal weakness or lack of willpower. Most importantly, there are effective treatments for major depression, which will be described later in this chapter.

**Facts About Major Depression**

Major depression is defined as a period of two weeks or longer in which a person experiences depressed mood or loss of pleasure most of the time, on most days, along with several other symptoms, such as significant weight changes, changes in sleep, changes in activity (either slowness or agitation), fatigue, feeling worthless or guilty, difficulty concentrating or making decisions, or thoughts of death or suicide.

Technically, to receive a diagnosis of a depressive disorder, you must have these symptoms most of the day, nearly every day, and the symptoms would need to cause significant interference with living your life. In addition to these primary symptoms, depression may cause irritability and moodiness, which can make the depressed person hard to be around. Some people who are depressed tend to want to be alone and to stay away from others. Persons who are depressed may feel hopeless and alone.

Major depressive disorder doesn’t affect only those with MS. Indeed, MDD is common in the general population, affecting about one in twenty Americans each year (more than 11 million people). Almost one in four women will go through an episode of major depression sometime in her life.

People with MS are at greater risk for major depression than the general population. Approximately 25 percent of those with MS will have suffered from MDD at some point in the last year, and as many as 54 percent will suffer from it at some point in their life (Ehde and Bombardier 2005). What causes depression to occur in some, but not all, people with MS is not completely understood.

A variety of factors may contribute to the development of MDD in some people with MS. Major depressive disorder may be associated with genetics, immune dysregulation, or certain brain lesions caused by MS. Those people who have been recently diagnosed with MS, those with more severe MS disease, and those with fewer friends or social supports are more at risk for major depression (Chwastiak et al. 2002).

However, how much someone is disabled by MS doesn’t necessarily determine whether that person will become depressed. For example, some people who are severely disabled by their MS do not get depressed, whereas others with MS without any disability may become depressed. Our individual capacity to deal with depression is a function of several factors, including genetics, our emotional reserves at the onset of the disability, and so forth.

Major depression may be difficult to detect because depression and MS share a number of symptoms, including fatigue, problems with concentration or memory, and changes in sleep and eating. It is also difficult to tell major depression from the normal distress associated with having a chronic, possibly progressive, illness.
The Impact of Depression

Depression is significant because it affects your ability to function in your daily life. People who are depressed may have difficulties getting things done; for example, finishing work commitments or keeping appointments. At least one study has suggested that those who are depressed are not as good at taking their MS medications as those who are not depressed (Mohr, Classen and Barrera, Jr. 2004). Depression also amplifies pain and other physical symptoms in people with chronic illnesses. Sleep problems and poor energy are characteristic of MDD and can make fatigue, already a problem for many with MS, worse. Untreated depression can last a long time, for example, from six to twelve months or more.

Josh. Josh had lived with MS for more than ten years when he suddenly began feeling very depressed, lethargic, irritable, and disinterested in life. He was quite moody, and others told him he was difficult to be around. He had difficulties falling asleep at night, and found himself not wanting to get out of bed in the morning after a night of turning and tossing and fitful sleep. Sometimes, he was so fatigued he chose to skip work and stay in bed most of the day. He didn’t have much of an appetite and noticed, for the first time in his life, that he was losing weight even though he wasn’t dieting. He quit swimming, which he had previously enjoyed doing. Although he had never had problems with his cognition, he began noticing he was forgetful and had difficulties concentrating when reading or working. At times, he missed his MS medications because of his forgetfulness. At other times, he chose not to take them, thinking, “Why bother?” He also observed that he was feeling more pain than usual, and he felt helpless in dealing with it. These difficulties went on for a couple months and, over time, Josh became very worried that his MS was progressing.

The first step to dealing with MDD is to recognize it. Take the self-test below as a way to determine whether any mood changes you might be experiencing may meet the criteria for MDD.

Checklist 7: The Depression Self-Test

<table>
<thead>
<tr>
<th>Over the last two weeks, how often have you been bothered by any of the following problems?</th>
<th>Not at all</th>
<th>Several days</th>
<th>More than half the days</th>
<th>Nearly every day</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Little interest or pleasure in doing things.</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>2. Feeling down, depressed, or hopeless.</td>
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<tr>
<td>3. Trouble falling or staying asleep, or sleeping too much.</td>
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<td>4. Feeling tired or having little energy.</td>
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<td></td>
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<tr>
<td>5. Poor appetite or overeating.</td>
<td></td>
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</table>
6. Feeling bad about yourself—or that you are a failure or have let yourself or your family down.

7. Trouble concentrating on things, such as reading the newspaper or watching television.

8. Moving or speaking so slowly that other people could have noticed. Or the opposite—being so fidgety or restless that you have been moving around a lot more than usual.

9. Thoughts that you would be better off dead or of hurting yourself in some way.

From the Patient Health Questionnaire, ©Pfizer Inc., used with permission.

**Scoring**: If you checked five or more symptoms as occurring several days or more, you should probably check with your healthcare provider about whether your symptoms are due to MDD, your health, medications, or other life issues. If you checked five or more symptoms in the shaded area, your symptoms are consistent with MDD and medical attention is definitely advised. If you are experiencing thoughts of death or suicide you should notify your healthcare provider immediately, as well as others who know or care about you. The intense feelings of depression, hopelessness, or loss often leading to suicidal thoughts or actions are not permanent. These feelings and situations can be helped with medications or psychotherapy.

It’s also important to point out that there are other health conditions that can cause similar symptoms. For example, if you have a thyroid problem, you may have symptoms of depression. Also, some medications can cause symptoms of depression. For example, some people who take steroids for an MS exacerbation may feel depressed. That’s why it’s important to talk with your healthcare provider about your symptoms, so the two of you can work together to determine what is going on and what to do.

**Josh.** At his family's insistence, Josh made an appointment to see his doctor about his symptoms. He was very worried his doctor would tell him that his MS was progressing. During his meeting with his doctor, they talked at length about Josh's symptoms and their impact on his life. The doctor asked Josh the same questions from the self-test you just took. After some additional questions and some medical tests to rule out any other causes, Josh’s physician diagnosed Josh with MDD and recommended treatment specifically for that.

**Proven Treatments for MDD**

The good news is that MDD is treatable. Below, we review some of the most common treatments for MDD, mostly focusing on those that have demonstrated their effectiveness in published papers in the
scientific literature. Typically, depression is treated most successfully when several strategies (pharmacologic and nonpharmacologic) are employed.

**Exercise**

Exercise is one of the most accessible and effective ways available to improve the quality of your life and to help with depression. Exercise is safe for people with MS and improves their fitness and strength. It is known to produce widespread positive effects in mood, quality of life, sexual functioning, recreation, pain, fatigue, and psychosocial functioning. Finally, research indicates that exercise is as effective as standard medications and psychotherapy for treating depression. Those people who exercise to treat their depression also are more likely to continue treatment and less likely to relapse into depression.

If you want to consider exercising to help your mood, it would be wise to take into account several factors. Do you have any health problems, other than MS, that might be affected by increased exercise? It would be prudent to discuss your plans to exercise with your healthcare provider before beginning any exercise program. Next, think about the types of exercise you would enjoy now or have enjoyed in the past. Common sense indicates that you’ll stick with a form of exercise that you enjoy longer than you will with something not as enjoyable. Also, enjoyment may be part of the reason that makes exercise a good antidepressant for some. Finally, the type of exercise you do and even its intensity may be less important than doing something regularly; that is, doing it several times a week. So if you really like walking or Pilates but don’t like aerobics classes, go with what you like.

What fits into your life and your budget? Can you fit in time to go to the gym in the morning, at lunch, after work? Would it be better to use yoga or aerobics videotapes at home? Consider “lifestyle exercise” in which you incorporate exercise into your daily life; for example, walking to work or to the store, walking up the stairs rather than taking the elevator, or even turning regular chores like vacuuming or mowing the lawn into a purposeful exercise session.

There are many good options for exercise: jogging, rowing, mall walking, swimming, treadmill training, water aerobics, Tai Chi, weight lifting, stationary biking, and martial arts. Of course, you’ll want to consider individual factors such as the best time of day for you to exercise, how to keep cool during exercise, and whether you want to exercise in classes, with friends, or alone.

**A measured beginning.** It is usually best to start an exercise program at the low end in terms of time and intensity, and then to build yourself up gradually. For example, measure how long or far you can walk now, before you get tired. Then, set that time or distance as your initial goal. Increase the time or distance by 5 to 10 percent at each exercise outing. The principles of a classic begin-to-jog program are illustrative of a good gradual buildup for exercise. In this program, you begin jogging for only two minutes; then you walk for four minutes; repeating that cycle five times for a total of thirty minutes of exercise. You do that every other day for a week. The second week, you jog for three minutes and walk for three minutes, five times every other day. The program increases the ratio of jogging to walking gradually, until you are jogging for thirty minutes straight within ten weeks.

However you choose to begin exercising, start low, set your goals low enough so that you have a 90 percent chance of succeeding, build up gradually, and enjoy your progress. For more tips on how to start an exercise program, see chapter 4 in this workbook.
Psychotherapy

Psychotherapy can be very effective for treating depression. In fact, research suggests that psychotherapy combined with other forms of treatment, including medications, is likely the best form of treatment for MDD (Mohr, Goodkin, and Donald 1999). Psychotherapy appears to be helpful in treating depression in persons with MS, too. Cognitive behavioral therapy, as described in chapter 3, is particularly useful in treating depression. However, other psychotherapeutic approaches also can be quite effective. Whatever approach you prefer, it is important to find a therapist with whom you feel comfortable and with whom you can develop a collaborative relationship. See chapter 3 for ideas on finding a good therapist.

Medications

As evidenced by the numerous advertisements for antidepressants in today’s magazines, newspapers, and commercials, there are a number of antidepressant medications that are used for treating depression. Antidepressants are thought to treat depression by altering the chemical pathways in the brain that are related to mood. Only a few studies have examined the effectiveness of antidepressant medications in treating depression in persons with MS, however. So far, it looks as if people with MS are likely to benefit from antidepressant medications, although there is no clear indication that one antidepressant is better than another for treating MS-related depression. Thus, our conclusions about medications have been drawn from what we know about treating depression in those who do not have MS.

Common antidepressants. The most common antidepressants prescribed are the selective serotonin reuptake inhibitors (SSRIs). Others include the newer antidepressants, such as the alpha-2 antagonists, selective norepinephrine reuptake inhibitors (SNRIs) and aminoketones, and the tricyclic antidepressants (TCAs). An older class of antidepressants, the monoamine oxidase inhibitors (MAOIs), are less commonly prescribed today.

Typically, antidepressant medications work gradually and require several weeks or more for their full benefit to take effect. For many antidepressants, to receive the full benefit may take six to eight weeks of treatment. Note: This is important because antidepressants generally will not be that quick a fix. If little or no improvement is seen after several weeks, your healthcare provider may alter the dosage of the medication, change the type of medication, or add another medication.

Typically, you will be encouraged to continue taking the medication for five months or longer, even after your depression has lifted. Some people can then discontinue the medication without experiencing any further depressive symptoms, while others who have chronic depression often benefit from staying on the medication to prevent or decrease future episodes.

Regardless of which medication you try, it’s important for your health provider to closely monitor how well you are doing after you start an antidepressant course of treatment. The reason for this is that antidepressants sometimes don’t work for some people, or they may not be prescribed at the right dosage, or it may not be the precisely right medication for you. It’s important to inform your healthcare provider about how your depressive symptoms respond to the medication, as well as reporting any side effects. Also be sure to tell your doctor of all other medications you are taking, including any for your MS, as well as any herbal or complementary treatments, because you don’t want to experience any complications that might arise because of any drug interactions.
**Alternative or complementary medicines.** What about the effectiveness of herbal medicines such as Saint-John’s-wort and S-Adenosyl Methionine (SAM-e)? Both have received a lot of attention for their antidepressant properties. First, we recommend that you talk with your primary care physician before using other herbal or alternative medications because they can have both positive and negative effects and can interact badly with other medications you may be taking. Saint-John’s-wort has been studied extensively with some studies suggesting it is helpful for mild depression; however, the best studies done so far demonstrate that it is no better than a sugar pill for people suffering from major depression (Shelton et al. 2001).

SAM-e has been studied less, but it, too, seems to improve mild depressive symptoms. SAM-e tends to improve depressive symptoms less than standard antidepressants, however (Agency for Healthcare Research and Quality 2002). When considering alternative therapies, see chapter 6 for a decision-making framework. Unfortunately, many alternative therapies that have been subjected to scientific study are of no or minimal value.

**Self-Help Books**

There are a number of excellent self-help books for depression. They are written primarily for people who do not have MS but they can be helpful nonetheless. *Feeling Good* by David Burns (1999) is a classic text on helping yourself overcome depression by changing how you think and act. There is also *Mind over Mood* by Dennis Greenberger and Christine Padesky (1995). Reading autobiographies of people who have struggled with depression can also be helpful. Best-selling books on this topic include *Darkness Visible* by William Styron (1990) and *The Noonday Demon* by Andrew Solomon (2001).

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**WHAT ABOUT ANXIETY?**

Most of us have experienced anxiety at some point in our lives. For example, you may recall the feeling of butterflies in your stomach before you gave a speech, or the tension and jumpiness you felt while waiting for the results of a medical test, or the way your heart pounded after you narrowly missed being in a car accident. When anxious about an upcoming situation, you might worry, think about your concerns frequently, and have difficulties concentrating. You might have problems falling asleep the night before a big event, such as getting married or starting a new job.

In the short run, anxiety can be a normal and helpful response to situations that require us to act. It can prepare you to face a challenging or threatening situation. For example, if you are nervous before giving a speech or taking an exam, you can deal with your anxiety by practicing your speech or studying. It can be helpful to take stock of both the physical and psychological symptoms of anxiety that you’re feeling by using checklist 8.

**Checklist 8: Assessing Your Anxiety**

Anxiety can include physical and psychological symptoms; please check (✓) those symptoms that apply to you.
Take a few minutes to summarize the anxiety symptoms you might be feeling after you’ve reviewed this checklist and any others that you observe. Write a description of how you experience anxiety in the space provided below. This summary can then be discussed with your primary care physician or therapist if needed.

____________________________________________________________________________________

____________________________________________________________________________________

____________________________________________________________________________________

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When you’re anxious, your behavior is also affected. You may have difficulties getting things done or staying on task. Sleep can be disrupted. It is common to want to avoid whatever is making you anxious. For example, if you are really anxious about a final exam, you might decide to skip studying and go to a movie as a way to avoid your anxiety. Or you might notice that you feel detached from your relationships, tending to be preoccupied with your thoughts and worries rather than listening to others. You might find that you get irritated, anger easily, or just feel generally overwhelmed.

Melinda. On the day Melinda had an appointment with a neurologist to learn the results of her medical tests, including an MRI, she felt very nervous. Her physician had told her that she might have multiple sclerosis. She didn’t know much about MS and worried it might shorten her life. She felt queasy, had difficulties sleeping the night before, and couldn’t focus well enough to get any work done before her appointment. She also felt “jumpy.”

Because she felt so anxious, she called a friend to ask him to accompany her to the appointment, in case the news was bad. She also went to the Internet to look up information on MS. She was relieved to see there is quite a lot of information about MS online, including some Web sites that indicate it is possible to live a happy, satisfying life even with MS. She was surprised at how much support and
information there is, both on the Web and in her community to help people with MS, including the newly diagnosed. After absorbing all the new information and talking with her friend, she felt much better prepared for the news she might get from her doctor that day.

Melinda had a normal response to her situation: anxiety. It is very common to feel anxiety at the possibility of a diagnosis of MS. Many people with MS feel anxious when they learn they have it, experience exacerbations, or have to deal with the uncertainties of the disease.

*Useful and Harmful Anxiety*

With a new diagnosis of MS, you may worry about how much your health, your family and friends, and your ability to do what you want to do will be affected. Anxiety is an understandable and normal response to uncertain or challenging events. When anxiety prompts you to obtain help—make positive changes or fortify your coping skills and resources—it actually can be helpful. In Melinda’s case, her anxiety caused her to seek information. In that way, her anxiety helped her to be better prepared for the possibility of being diagnosed with MS. When time-limited and not too intense, mild anxiety can be useful, even adaptive for everyone.

When anxiety is difficult to control, excessive, long-lasting, or disruptive to your life, it is not helpful; it may even be harmful. If you feel overwhelmed by anxiety, have many anxiety symptoms that last longer than a few weeks, or find that your anxiety is interfering with your life, you may have an anxiety disorder. Anxiety disorders, like MDD, are disorders that are likely to have a number of causes, including biological.

**Anxiety disorders.** Several types of anxiety disorders exist, ranging from one type in which anxiety arises only in response to a specific situation (e.g., a phobia for a needle injection) to another type, in which the anxiety is more generalized and not connected with any particular situation (free-floating anxiety). Anxiety disorders may make you feel nervous most of the time, without any apparent cause. To avoid feeling anxiety, you may stop doing certain activities.

You might even feel immobilized or terrified by your anxiety. A description of the specific types of anxiety disorders is beyond the scope of this chapter. However, for more information about the types of anxieties, as well as strategies for how to manage them, you may wish to read *The Anxiety and Phobia Workbook* by Edmund J. Bourne (2005).

Anxiety disorders are the most common of all mental disorders experienced by the general public. However, when compared to depression, less is known about the specific rates of anxiety and anxiety disorders among those with MS. Similar to depression, not everyone who has MS develops an anxiety disorder. Feelings of significant anxiety are especially common for the person with MS as well as her or his partner immediately preceding and shortly after the diagnosis of MS is made.

For those of you who are newly diagnosed, this anxiety will decrease with time. It may even motivate you to learn more about the disease, make positive changes that promote your health, fortify your resources, and plan for the future. However, if the anxiety persists or interferes with your life’s activities, it may be a signal that you need to do something about it.

**Injection anxiety and phobia.** You may be anxious about injecting yourself with a disease-modifying medication. For some people with MS, their anxiety about self-injection causes them to avoid taking their medication or makes them unable to inject themselves. Fortunately, this type of anxiety is very responsive to a brief course of cognitive behavioral psychotherapy. If you find that you are unable to self-inject as a
result of anxiety, you may wish to talk with your healthcare provider about referring you to a psychotherapist who can help you to overcome your anxiety and avoidance of self-injection.

Whether you have a full-blown anxiety disorder or more transitory anxiety, there are a number of things you can do to counter it. Occasionally, medications cause anxiety, so if you are unusually anxious, you should talk with your healthcare provider about it. Health-promoting activities such as exercise, described in this chapter as well as in chapter 4, can be useful. The other strategies described above under depression, as well as those described later in this chapter in the section on promoting resilience, are often effective in decreasing, eliminating, or managing anxiety. If you think you have a full-blown anxiety disorder, you may wish to see a therapist. (See chapter 3 for tips on finding a therapist.)

Psychotherapy, particularly cognitive behavioral psychotherapy, is an effective treatment for anxiety disorders. In addition, a number of medications can be useful in treating anxiety. You may wish to talk with your healthcare provider or a psychiatrist about medications for anxiety. In most cases, mild anxiety can be addressed through the strategies described in this chapter as well as through psychotherapy. For moderate to severe anxiety disorders, a combination of medication and psychotherapy may be indicated. For a few types of anxiety, including phobias, psychotherapy (often cognitive behavioral) is the first line of approach to treatment.

IRRITABILITY AND MOODINESS

People with MS sometimes describe feeling irritable, cranky, or easily frustrated more often than they were before being diagnosed with MS. Irritability can be a symptom of other emotional challenges, such as depression, anxiety, or stress. It also can be caused by other difficulties such as sleep problems, pain, fatigue, or cognitive difficulties. For some, changes in how the brain regulates moods also can contribute to irritability.

If you find yourself feeling cranky or irritable more than you like, notice when you start feeling irritable. You may wish to write down what is going on at the time you are feeling irritable. You may notice patterns to your irritability that will help you figure out what to do.

For example, have you noticed that you get irritable at the end of the day, when you are feeling tired? You might also be irritable when you are anxious or simply when you are overstimulated. If you don’t notice a pattern to your irritability but do notice that you feel irritable much of the time, you should consider talking with a healthcare provider. Your irritability may be the result of a major depressive disorder, for example, or a side effect of one of your steroid medications. Psychotherapy can be helpful in recognizing contributors to irritability and in learning ways to manage it.

Brain changes. Sometimes, changes in the brain associated with MS also can lead to difficulty in controlling your emotions, for example, controlling your mood or visible displays of your emotions. In such instances, a person may be perceived as moody or as showing emotions that seem out of character or unsuitable for the situation. For example, if you have this syndrome, you may cry more easily, or be quick to become angry or upset. You may laugh at a time that seems inappropriate for the situation.

If you notice these difficulties in controlling your emotions, or others have described observing such emotions in you, this may be due to your MS. If such emotional changes interfere with your relationships, your activities, your work, or your self-esteem, you should consider learning more about them as well as finding ways to decrease such emotional control challenges.

Talk with your healthcare provider, as well as to others with MS. They may help you better understand how your emotions sometimes can be dysregulated by neurological changes. They may also
recommend psychotherapy or medications that can help to regulate your moods better. When the
difficulty in controlling emotions is extreme, sometimes certain medications can be helpful.

BUILDING RESILIENCE

As mentioned earlier in this chapter, not every emotion experienced in MS is negative. In fact, many
people find that they are able to meet the challenges of living with MS successfully, and to live happy,
satisfying lives. People who “bounce back” from difficulties are sometimes described as having “resilience.”
This topic is just as important, if not more, than knowing about depression, because it holds the key to
managing the challenges and emotions that can accompany MS.

Before we describe what we mean by resilience, please do the following exercise as it can help to
better ground this concept for you.

WORKSHEET 13: INVENTORY OF YOUR PERSONAL STRENGTHS

What do you know about your own abilities to cope with the challenges of MS? Please take a few minutes
to think about the personal strengths that aid you in managing your emotions. Then, write them down in
the space provided below. Answering the following questions will help you to identify some of the
strengths and strategies you already possess.

What are some things you have accomplished while living with MS? Examples: Successfully raised
children, developed a new hobby, worked part-time at the local bookstore, and so on.

____________________________________________________________________________________
____________________________________________________________________________________
____________________________________________________________________________________

What has helped you meet the challenges of life, including MS? These might be personal characteristics,
such as qualities or skills you have, or they may be things you do (your own actions). Examples: Am a
positive thinker, maintain my sense of humor, or listen to upbeat music, and so on.

____________________________________________________________________________________
____________________________________________________________________________________
____________________________________________________________________________________

List people you can turn to for assistance or support, emotional or practical. Examples: My spouse, my MS
support group, my friends with whom I volunteer at the food bank, and so on.

____________________________________________________________________________________
____________________________________________________________________________________
____________________________________________________________________________________
What other strengths or support do you have that you can tap? **Examples:** My faith, my church or temple, my next-door neighbor, and so on.

____________________________________________________________________________________

____________________________________________________________________________________

____________________________________________________________________________________

What did you learn from doing this exercise? Hopefully, this helped you to see some of the strengths you have more clearly. Sometimes, we tend to focus on the problems or challenges of MS. We lose sight of all the good things that we experience or become “in spite of” or sometimes even “because of” the challenges of living with MS.

This process of adapting well to or bouncing back from significant challenges is known as **resilience.** Being resilient doesn’t mean that you don’t experience discouragement or emotional distress. Such experiences are common and may be part of the resilience process itself.

When you are resilient, you experience such feelings but you don’t let those feelings define who you are or how you respond to challenges.

The remainder of this chapter will focus on how to learn, nurture, and practice resilience. The skills that follow will not only help you build or maintain resilience, they will also help you to decrease stress, anxiety, and other negative emotions that you may experience.

**Strategies to Cultivate Resilience and Manage Your Emotions**

Research in the fields of health and psychology has shown that a number of skills are very useful for building resilience and positive mood, reducing stress, treating depression, and promoting health. These skills include some of the matters discussed in other chapters, including chapter 4 on health promotion and chapter 13 on spirituality. The main skills for cultivating resilience and promoting healthy emotions fall into the following categories:

1. Nurturing positive emotions. Look for them, focus on them, create them.

2. Getting active, physically and socially.

3. Practicing relaxation skills.

4. Thinking differently about challenges.

5. Using support from others.
Nurturing Positive Emotions

Positive emotions play a very important role in our health. By “positive emotions” we mean experiencing feelings that make you feel good; for example, feeling joy, happiness, laughter, playful. So, when we say “positive emotions,” we are talking about “feeling good” emotionally.

As you probably know from your own life, positive emotions such as joy, laughter, and contentment can and do occur even in the face of difficulties, such as a recent loss, disability, or adversity. For example, after a difficult board meeting, a “frazzled” businesswoman looks forward joyfully to spending the evening at home with her spouse and family. And it is common at memorial services to laugh when recalling humorous events that involved the deceased.

It is a good idea to try to have positive emotions on a daily basis. Experiencing positive emotions during a stressful or difficult time can be particularly helpful, for a number of reasons. Positive emotions can:

- Increase creativity
- Decrease distress
- Increase flexibility of attitude and thinking
- Prevent depression, chronic stress, and anxiety
- Help with problem solving
- Serve as a break from stress
- Improve physical health

So, how can you increase positive emotions in your daily life when you need to? You may not realize it, but you probably do things every day that cause you to feel good, even if for just a few minutes. For example, do you read the comics? Listen to certain CDs? Watch sit-coms? Snuggle with your cat? Share jokes with your child? Laugh with the counterperson at the coffee shop or grocery store? There are many things we can do to help us feel good emotionally.

Now, turn to worksheet 14 on building positive experiences. Take a few minutes to list some things you have found help you feel good (emotionally).

**WORKSHEET 14: BUILDING POSITIVE EXPERIENCES**

Things I currently do that make me feel good (emotionally):

____________________________________________________________________________________
____________________________________________________________________________________

Now, take a few moments to write down some things you really want to do to build more positive emotions into your life. This can be a combination of things you are doing already and things you haven’t tried. They may be simple things that don’t take a lot of time, like singing in the shower, listening to your favorite music in the car, or spending a few minutes cuddling with your pet. They may be things that require a little more time, such as hobbies, recreational pursuits, exercise, relaxation exercises, or other activities. They may involve other people, such as talking to a friend, volunteering, or spending more time with a family member.
If you have a hard time coming up with ideas, talk to a friend or family member for their ideas. You already may be doing or using some things that make you feel more positive without realizing it. If you are at a loss for ideas, review the entertainment section of your newspaper for amusing and inexpensive activities or cultural events, or call the closest tourist office in your area. These “pleasant events” can take planning and involve more of your time. But the investment in time and planning will be worth it.

Things I can do to make me feel good in the future (may require some planning):

____________________________________________________________________________________
____________________________________________________________________________________
____________________________________________________________________________________

Get Active

One of the best ways for you to improve or maintain your health, physical and emotional, is to exercise. Take a moment to focus on exercise. Exercise is certainly an important part of being active and healthy. It is an important potential treatment for people with MS. Physical activity may include a number of things. Please check those that you’d like to consider learning and those that you know and continue to do:

___ Aerobic classes  ___ Climbing stairs  ___ Hiking
___ Strength training  ___ Gardening  ___ Household chores
___ Water aerobics/exercise  ___ Floor exercises  ___ Stretching
___ Swimming  ___ Jogging or jog/walk  ___ Sedentary exercises
___ Yoga  ___ Weight training  ___ Horseback riding
___ Cycling  ___ Parking further from the store to walk
___ Racquet sports (tennis, racquetball, badminton)  ___ Other

An important point to remember is to exercise within your tolerance limits. Your doctor and physical therapist can help you to figure out what your limits are and which of your desired exercises might be best for you. Exercise, however, will build tolerance. Exercise within a group context is physically positive while also providing a social, “mood-elevating” experience.

You can use the information in chapter 4 to help you set realistic goals for incorporating more physical activity into your life. If you think that you could benefit from more activity, set a goal of increasing your activity in the next week. You may wish to set reasonable exercise goals (e.g., beginning with just a few minutes a day), increasing gradually, from week to week or month to month. You also may get ideas on exercising with MS from national or local MS organizations as well as from the Internet.

Relax

Relaxation strategies are techniques that can promote feelings of well-being, relaxation, and calmness. There are a number of ways you can try to achieve the “relaxation response,” which is a
physical state of deep comfort and rest that has a number of positive physiological changes associated with it, including decreased blood pressure and muscle tension. Learning to relax your body and mind can have positive effects for your physical and emotional health. Some of these strategies involve deep breathing or imagining peaceful images or scenery.

Whatever the technique, regular use of relaxation strategies are likely to help you feel better and may also benefit other MS symptoms, such as pain or fatigue. If you are interested in learning specific relaxation techniques, you may wish to obtain the Relaxation and Stress Reduction Workbook (Davis, Eschelman, and McKay 2000). There are also a number of useful tapes or CDs available that can teach you how to relax. You may wish to check out the relaxation tapes available through the Mind/Body Medical Institute (see the Web site address in the Resources section at the back of the book).

Think Differently

The way we talk to ourselves is called self-talk. When we refer to “self-talk,” we are referring to how we think or the things that we say to ourselves. Our self-talk influences how we feel, including our moods and our pain, both physical and emotional. Holding an internal dialogue is quite normal. It can be helpful, if your self-talk is positive, or unhelpful, if it is negative. Your inner conversations have a powerful impact on how you feel.

For example, let’s take a look at a common situation: being stuck in traffic. Let’s say you get stuck in traffic on your way to a doctor’s appointment. If you think to yourself, “This is terrible. I’m stuck and going to be really late! I’ll never get to my appointment on time! My doctor will be angry with me! What an idiot I am for picking this route. I should have known there would be traffic!,” what do you think you might feel while you are saying these things to yourself? You are right. You are likely to feel bad: anxious, stressed, angry, frustrated, and so forth.

Now, let’s say you are in the same situation, stuck in traffic, and you say to yourself: “They must be working on the road. Sometimes things don’t work as planned. Oh well, it looks like I’m going to be here for a while, so I might as well call ahead and let them know I will be late. Guess it gives me some time to listen to my new CD, or a radio show, or simply to be quiet.” What do you think you might feel if you said this to yourself? You still will be late and you might feel mildly anxious or annoyed, but you won’t be so worked up about it, and your feelings will be more in accord with the situation.

If you think negative or alarming thoughts, you tend to feel bad. If you think positive or reassuring thoughts, you tend to feel good or, in difficult situations, better. When you feel bad, which can mean angry, depressed, irritable, anxious, and so forth, it is usually because you’ve had negative or alarming thoughts, like cognitive “sinkholes.” So what can you do to feel better? Basically, change how you think. If you change your thought, you’ll change your feeling. It sounds simple, but it can take some practice. In fact, there are a few steps to help you change the thought.

**Step 1: Become aware of your negative self-talk.** Becoming aware of exactly what you are saying to yourself can help you understand why you react the way you do to events and people in your life. Self-talk is so automatic and subtle that often you don’t notice it or the effect it has on your mood. You react without noticing what you told yourself right before you reacted.

It’s important to step back and see the connection between what you say to yourself and how you react to situations. One way to become more aware of self-talk is to work backwards. When you notice yourself experiencing a strong emotion (e.g., anger, depression, guilt, joy), ask yourself what is occurring. What is the situation? And then ask yourself what you are saying to yourself about the situation. What
thoughts are running through your head? Identify your negative self-talk. What do you say to yourself when you are sad, angry, or depressed?

Look at the table below and read the example. Then, in the space provided below the example, try to come up with three examples of your own negative self-talk.

<table>
<thead>
<tr>
<th>Emotions</th>
<th>What is occurring</th>
<th>My self-talk</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Example:</strong> Guilt</td>
<td>Not able to go to my daughter’s ballgame due to fatigue</td>
<td>“I am a lousy parent.” “I should go to her game, even if I am fatigued.” “Why won’t I push myself?”</td>
</tr>
</tbody>
</table>

Step 2: Change your negative self-talk. The most effective way to change negative self-talk is to get rid of it. When you catch yourself thinking negatively, just stop it. You may find it helpful to imagine a stop sign, which can serve to remind you to “stop” your negative thinking. Reframe your thoughts with more helpful, realistic self-talk. Countering involves writing down and rehearsing more accurate and functional thoughts. It’s a form of mental reprogramming. Sometimes this comes easily; other times it takes some practice.

One more thing you can do to change how you think is to fill your mind with positive, reassuring, and humorous thoughts as much as possible. What are some things you can tell yourself to help you feel better and manage the challenges of living with MS (or living, in general, for that matter)? In the space provided in the table below, write down some of your common negative thoughts on the left side, and then write down your positive thoughts to counteract your negative thoughts on the right side.

<table>
<thead>
<tr>
<th>My negative self-talk</th>
<th>More positive self-talk</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Example:</strong> “I am useless. I can’t work as hard or as long as I used to.”</td>
<td>“I am doing the best I can do.” “I may not work as many hours, but I have a lot of useful experience to contribute to the success of the mission.”</td>
</tr>
</tbody>
</table>
If you find that you tend to think negatively a lot of the time, you may wish to read more on this topic. See the section Talking Yourself Through Challenges below for more ideas. You may want to use another workbook that discusses in greater detail how to change negative thinking; *Thoughts & Feelings: Taking Control of Your Moods and Your Life* is an excellent workbook (McKay, Davis, Fanning 1997). You may also find it helpful to talk to a therapist, especially one who specializes in cognitive behavioral treatment, as this approach specifically targets the negative thoughts that make you feel bad.

You can also try to experience and look for more humor in your life. Humor can be an effective strategy for dealing with stressful life events.

Humor helps us to:

- avoid jumping to negative conclusions
- avoid blowing things out of proportion
- make more balanced and reasonable assessments of our problems
- enjoy positive moments
- have a favorable impact on those around us
- increase our support and cooperation from others

**Talking Yourself Through Challenges**

We all have the ability to talk to ourselves. In fact, we often carry on a running conversation with ourselves throughout the day. Whether we talk to ourselves aloud or silently, we can use this ability to coach ourselves through difficult challenges. Although you already talk to yourself during difficult situations, you may not always be aware of this process. That's why many of the internal conversations we have with ourselves are referred to as “automatic self-talk.” It occurs automatically, without much awareness on our part.

Here are some steps to help you talk yourself through difficult challenges.

**Prepare for the challenge.** You can prepare for a challenge by talking to yourself in a way that will increase your feelings of control over the situation. You need to think in terms of how you'll deal with it, and what you'll gain from this experience, even though it may be stressful. You need to stop yourself from blowing things out of proportion and suffering before the challenge really takes place.

It often helps to make a list of useful statements to say to yourself when you are preparing for the challenge. You can say things like:

- “It won’t help matters to sit and worry about it.” “It might not be fun, but I can handle it.”
- “I'll use my problem-solving skills to make a plan.” “Some anxiety helps performance.”

You can also prepare for a challenge by going over what it will be like in your mind. Visualize yourself going through the situation while using your problem-solving skills when things become stressful.

**Confront the challenge.** Tell yourself that you are someone who knows how to use coping skills effectively. Learn how to talk yourself through the challenge. Use your creativity to think of things you
can say to yourself when you are confronted by challenging situations. Be willing to make mistakes. Don’t force yourself to be perfect. Say to yourself statements like these:

“This is tough, but I will survive.” “Relax, I must concentrate on what I have to do.”

“Stick to my plan. Don’t get negative.” “If I act as if I’m in control, I will feel that way.”

**Reflect on what you’ve learned.** When the challenge is over, you should take some time to reflect on what you learned. It’s okay to notice your mistakes and ask yourself how you can improve, so long as you are not too critical. You need to be willing to look at new ways of doing things. But you must also be sure to look at what you did right. When the challenge has ended, say to yourself things like this:

“It wasn’t as bad as I expected.” “I did pretty well and I can do even better next time.”

“Life is full of difficult challenges. I might as well learn how to cope with them.”

**Seek Support from Others**

Another strategy to build resilience and cope with difficult emotions is to seek support from others. There are a number of ways you can do this. It can be as simple as talking to a supportive family member or friend. You can also seek out more formal support, through MS support group meetings, telephone networks, Web-based discussion groups, church groups, or therapy. You can join a social group, such as a book club, hobby association, historical or arts group, or a volunteer organization as ways to find and receive more informal support.

**Conclusion**

So, how can you put all of this together to help yourself feel better? You might try thinking about your life as if it were a car. Sometimes, when your car breaks down because of the stress and strain of doing what cars do, you just need one part to fix it and get it running again. Other times, you may need a mechanic and several new parts before it can be fixed.

The same is true for using the skills we’ve been discussing in this chapter. Sometimes, when we are in stressful situations, using one skill (“part”), for example, thinking differently, relaxing, or exercising can do the trick to get us bouncing back and feeling better. Other times, it may take several kinds of techniques to feel better. If you are feeling really sad, depressed, anxious, or angry, you may wish to consult a mental health “mechanic”; that is, a therapist or your physician (see chapter 3). Whatever your situation, we hope that you recognize you have many strengths and tools to assist you in managing any emotional challenges presented by your MS.