Chapter 1 Meeting MS Face to Face

In This Chapter

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Because you've picked up this book, we're assuming that your doctor has delivered the news that you have multiple sclerosis (MS). Or, perhaps he or she said that you *may* have this disease, or that you *probably* have this disease (which makes you wonder why you can't get a clear answer). Whether you got the news yesterday or several months ago, you're probably trying to figure out what it means for you, for your future, and for your family. In other words, you have about a zillion questions about what's in store.

Chances are, the answers you've received so far haven't been all that satisfying — mostly because MS still can't be cured, no one knows what causes it, and no doctor can predict with any certainty how your MS is going to behave in the future. However, the good news is that the treatment options are expanding, and people with MS are busy getting on with their lives — and you will too.

In this chapter, which is an introduction to MS and an overview of what we cover in the rest of the book, we fill you in on the available MS info including what scientists have been able to discover about the workings of this disease and what questions remain to be answered. We explain why your MS is different from everyone else's, and we introduce you to the treatment strategies that can help you manage your MS. Finally, we glance at the ways that MS can affect life at home and at work, and we show you what you can do to ensure the best possible quality of life for you and the people you love.

Introducing the Roles Your Immune and Nervous Systems Play in MS

Surprise! Even though MS is described as the most common *neurologic* disorder diagnosed in young adults, the problem doesn't appear to originate with the nervous system. Instead, decades of research have pointed to the body's immune system as the culprit. Some kind of malfunction in the immune system interferes with the functioning of the body's nervous system, resulting in the symptoms commonly associated with MS. The current thinking is that the glitch is an *autoimmune* problem, which basically means that your body is mistakenly destroying some of its own healthy tissues and cells. But, this thinking has yet to be proven. We explain the autoimmune process in the section "What happens in MS" later in the chapter, but for now, it's important to understand how the immune system is supposed to work when it's healthy.

The immune system: Your body's frontline defender

The *immune system* — which is a complex network of glands, tissues, and circulating cells — is your body's frontline defense in the fight against infection by viruses, bacteria, and other bad guys. When confronted with an infection, the immune system gears up to neutralize the foreign invader and make you healthy again.



In order for your immune system to do its job properly, it has to be able to distinguish between the good guys (the cells, tissues, and organs that make up your body) and the bad guys (any foreign invader, such as a virus or bacteria that doesn't share your genes). And get this: The immune system is so powerful that it would reject a pregnant woman's developing fetus (which shares only some of her genes) if the hormones of pregnancy didn't suppress her immune system. (Check out Chapter 16 to read more about how pregnancy hormones appear to affect MS.)

The nervous system: Your body's CEO

The *nervous system*, which controls all bodily functions, is made up of *neurons*, each of which consists of a cell body and its long extension — the *axon*. And each axon is covered by a protective or insulating coating called *myelin*. The neurons are gathered into small- and large-sized bundles called *nerves*.

The system is basically divided into two parts: The *central nervous system* (CNS), which consists of the brain, spinal cord, and optic nerves, is the target of the damage done in MS. The *peripheral nervous system* (PNS) includes the branching network of nerves and axons that connects the CNS to muscles, sensory organs, and glands in the rest of the body.



The nervous system conducts three basic kinds of electrical signals throughout the body:

- ✓ Motor signals: These signals, which move from the CNS, through the PNS, and to muscles and other organs, control movement, strength, and other bodily functions.
- Sensory signals: These signals go back to the CNS from the eyes, ears, skin, and other sensory organs, and they provide information about the environment from those organs.
- ✓ Integrative signals: These signals travel from nerve cell to nerve cell within the nervous system and are thought to be responsible for many cognitive functions, such as thinking and memory (check out Chapter 9 for information about cognitive changes in MS).

These electrical signals are like the current in an electrical wire: When everything is working fine, they travel long distances along the myelin-covered axons in the CNS, jumping from one axon to another as needed. The myelin (like the rubber or plastic insulation around an electrical wire), is what helps speed the electrical signals on their journey and smoothes out any bumps along the way.

What happens in MS

After you understand the role of the immune system and the nervous system, you can begin to understand how MS affects them. In autoimmune diseases like MS (and rheumatoid arthritis, myasthenia gravis, and Type I diabetes, among others), the immune system loses the ability to distinguish the good guys from the bad guys, and so it starts attacking the normal tissues in the body. In MS, this autoimmune response targets the myelin coating around the axons in the CNS as well as the axons themselves.



The autoimmune attack happens because of a breakdown in the *blood-brain barrier* (BBB), which allows immune cells that have been living harmlessly in your blood to travel into your CNS to attack the myelin and axons, resulting in the symptoms associated with MS. The autoimmune process in MS follows these steps (see Figure 1-1):

1. The inflammation that occurs during an MS *relapse* (also called an attack or exacerbation) damages the BBB, allowing the movement of immune cells into the CNS. (Skip to Chapter 6 for more info about MS relapses.)

- 2. Toxic substances are released into the CNS, which can increase inflammation and result in the breakdown of myelin (in a process called *demyelination*) and the axons.
- 3. Nervous system cells called *astrocytes* move into the locations where the damage has occurred and they form scar tissue (giving rise to the name *multiple sclerosis,* which means multiple scars).



Demyelination disrupts transmission of impulses along the nerve fiber...

AND...

Figure 1-1: A view of the autoimmune process.



Astrocytes are attracted to demyelinated areas on nerve fibers where they form scar tissue. Multiple sclerosis means "multiple scars."



The results of the autoimmune process aren't all that pretty: The inflammation can cause swelling, which interferes with the conduction of signals in the nervous system. The demyelination results in a loss of insulation around the neurons' axons, which slows or interrupts nervous system conduction. And finally, the axons can be broken (a process referred to as *axonal loss*), which breaks the connections between the nervous system and parts of the body. (Figure 1-2 shows the steps involved in demyelination and axonal loss.) This whole process results in the symptoms that we describe in Chapters 7, 8, and 9. (Flip to Chapter 6 to read about the treatments that can reduce the inflammation and slow the destructive process.)



Taking advantage of the body's natural healing process

The body has a natural capacity to heal some of the damage caused by MS. For example, partial healing occurs following each MS relapse. Here's how it works: The inflammation that occurs during an MS relapse causes *edema* — the accumulation of fluids at the site of the damaged myelin (picture what happens when you sprain your ankle). Edema results in swelling that compresses the myelin-coated axons and interferes with the transmission of nerve signals. As the inflammation and swelling disappear, and the relapse comes to an end, some of the axons begin to decompress and are able to function normally again. The reduction of inflammation can happen through a natural healing process, or can sometimes be prodded along with steroid medications (which you can read about in Chapter 6).

In addition, the myelin coating that has been damaged by the inflammation has some ability — but not a whole lot — to heal or regenerate. As long as the axon itself remains intact, the natural regeneration of myelin can smooth

out the conduction of nerve impulses and result in some amount of improvement of symptoms over time. Check out the National MS Society Web site at www.nationalmssociety.org/myelin for more information on myelin and current research efforts to stimulate this natural healing process.



After the nerve fiber itself has been damaged or severed, and scar tissue has formed, healing is much more difficult. Unfortunately, doctors haven't yet found a way to repair damaged axons or to remove the scars. Researchers are focusing a lot of attention on how to promote this kind of repair — and this is precisely where stem cell research may be most relevant in MS. To read about stems cells and their potential value in the treatment of MS, go to www.nationalmssociety.org/stemcell.

Exploring Possible MS Triggers

Assuming that MS is, in fact, an autoimmune disease, it's important to figure out what actually triggers the immune system's attack on the nervous system. Most scientists agree that no single virus or bacterium causes MS all by itself. They have also concluded that no single thing in the environment or in a person's diet is directly responsible for the disease.



Currently, scientists believe that the disease is caused by a combination of several factors — including gender, racial or ethnic, geographic, genetic, and lifestyle factors that interact with an infectious trigger of some kind (for example, one or more viruses or bacteria) to stimulate the autoimmune process. This means that when a person with a genetic susceptibility to MS meets up with the environmental trigger or triggers, his or her immune system overreacts in a way that sets off the abnormal autoimmune process.

This sounds simple enough, but the question of why some people get MS and others don't remains one of the great mysteries of this disease. Solving this mystery is important because identifying the factors that make some people susceptible to MS and others not would help scientists figure out the cause of MS. And, identifying the cause would make it a whole lot easier to find more effective treatment and, eventually, a cure.

Gender clues

The fact that MS doesn't occur equally in women and men has long piqued the curiosity of scientists and physicians. It turns out that some interesting differences exist between the sexes (in regard to MS, that is) that may provide important clues to the cause of MS:

- ✓ MS is two to three times more common in women than in men. However, prior to the onset of puberty, boys are as likely to get MS as girls (check out Chapter 15 for more info about MS in kids).
- Men tend to develop MS at a later age than women do, and they're more likely than women to be diagnosed with primary-progressive MS. (You can read more about the disease courses in the section "Distinguishing the four disease types" later in the chapter.)

Ethnic or racial clues

MS isn't unique to one racial or ethnic group, but certain groups are much more susceptible than others. Scientists are using the following clues to help themselves understand the genetic and environmental factors that may be causing these group differences:

- MS is most common among Caucasians of northern European ancestry.
- ✓ African-Americans and Hispanics develop MS half as often as Caucasians.
- ✓ Asians develop MS less frequently than Caucasians and generally have different types of symptoms.
- ✓ MS is rare (or unheard of) in pure Africans, Inuits, and some isolated populations around the world that have never mingled with other groups.

Geographical clues

The geographical distribution of MS has been known for a long time: In general, the further you live from the equator, the greater your chances are of developing MS. Like a lot of other aspects of MS, no one knows why this is true, but here are some possible explanations:

- ✓ Genetic/ethnic: Residents in the temperate areas of the world (except certain groups like the Inuits) tend to be of northern European descent.
- Climatatic/meteorologic: Residents of the tropics have greater exposure to the sun and vitamin D, which may offer some protection against MS.
- ✓ Infectious: Certain types of infectious agents may be more common in temperate areas of the world.

Each of these possible explanations is the subject of intensive study in the MS research community.



An interesting wrinkle in the geographical data — which no one can yet explain — suggests that timing may be the key. Data, particularly from Israel and South Africa, suggest that people who migrate from their birthplace *before* puberty take on the MS risk factor of their new home, whereas people who migrate *after* puberty maintain the risk level associated with their birthplace. Just remember that these are statistical statements that characterize large groups of people, not single people within that group. This means that these statements provide no kind of guarantee for you or your children. So, there's no need to pack your bags and relocate to the tropics.

Genetic clues

MS isn't an inherited disease. However, the evidence is quite strong that a genetic factor contributes to a person's risk of developing MS. The following facts point to a genetic component:

- ✓ Approximately 20 percent of people with MS have a close or distant relative with MS.
- ✓ The risk for someone who has one close relative with MS is 3 to 5 percent (compared to less than 1 percent in people without a relative with MS). For a person in a *multiplex family* which has several members with MS the risk of developing MS is even higher. Keep in mind, however, that even within the same family, close relatives can experience very different disease courses, symptoms, and levels of disability.
- ✓ If one identical twin develops MS, the risk for the other twin is about 30 percent proving that the disease isn't directly inherited. Because identical twins share identical genetic traits, the risk would be would be 100 percent if genetics told the whole story.

Lifestyle clues

You've probably asked yourself (and your doctor) a hundred times what you did — or didn't do — to cause your MS. Just remember that it's clear from the study of geography, ethnicity, and genetics that the cause of MS — whatever it turns out to be — isn't anything simple or direct. You didn't *do* anything to cause MS to happen.

However, here are some intriguing findings related to lifestyle:

Even though exposure to sunlight and vitamin D is primarily determined by how close to the equator a person lives, it may also be related to time spent outdoors. One study also found that people who got extra vitamin D from a daily multivitamin were at a lower risk for MS.

- Some studies have suggested that dietary factors may play a role in determining a person's susceptibility to MS. For example, it has been suggested that Inuits don't get MS because of their fish-heavy diet.
- ✓ A few studies have suggested that smoking may increase a person's risk of developing MS as well as the risk for disease progression, but no one has a clue why this may be true. So, if you're looking for yet another reason to quit smoking, its possible relationship to MS is a good one.



It's difficult to separate out these lifestyle findings from other factors because none of them happen in isolation. Genetics and geography are also operating regardless of one's smoking, sunning, or eating habits. So, in the meantime, flip to Chapter 11 for more info about diet and general wellness.

Understanding Why Your MS is as Unique as Your Fingerprint

Here's something to think about: If you went to a large gathering of people with MS, chances are high that you wouldn't meet anyone whose MS was just like yours. MS is so variable from one person to the next that your experience with MS will be totally unique.

Even though the cause of this variability isn't clear, it probably has to do with the genetic and geographic factors we talk about in the section "Exploring Possible MS Triggers" earlier in the chapter. In addition, the inflammatory process that damages myelin and axons can happen just about anywhere in the central nervous system, with the random targets resulting in different kinds of symptoms (check out the section "Scanning the possible symptoms" later in the chapter).

Distinguishing the four disease types

A little over a decade ago, a group of MS specialists — researchers and clinicians — got together to develop a common language for talking about MS. The group identified the following four disease types or courses:

Relapsing-remitting MS (RRMS): MS begins as a relapsing-remitting disease about 85 percent of the time. RRMS is characterized by unpredictable periods of worsening (called *relapses, exacerbations,* or *attacks*) followed by remissions. A *remission* may be complete, meaning that the person returns to his or her pre-relapse level of functioning, or partial, meaning that some of the symptoms are likely to be permanent.

- Secondary-progressive MS (SPMS): Within about 10 years, approximately 50 percent of those who are diagnosed with RRMS transition to SPMS, which is characterized by a steady (but not necessarily rapid) progression of disability without any remissions. These folks generally have fewer or no relapses as time goes on.
- ✓ Primary-progressive MS (PPMS): For about 10 percent of people, MS progresses right from the beginning, without any relapses or remissions. PPMS seems to differ from RRMS and SPMS in terms of its underlying disease process it has less inflammatory action going on in the brain and spinal cord and more tissue degeneration and destruction early on. These differences may be the reason that the current treatments for MS (check them out in Chapter 6) which mainly target the inflammation work much better in relapsing forms of MS than they do in PPMS.
- ✓ Progressive-relapsing MS (PRMS): A very small number of people (less than 5 percent) are diagnosed initially with a progressive form of the disease, but then experience some relapses down the road.

Check out Figure 1-3 for a quick glance at the four disease types.





Even though these categories may seem nice and neat, they really aren't. Within each of the groups is a tremendous variability, so don't be surprised if your MS doesn't quite fit any of the descriptions outlined here.

For example, regardless of their disease type, some folks may experience a course that's mild and relatively stable for many years, while others (more often those with PPMS or severe SPMS) may have a rapidly disabling course (see Chapter 13 for more on dealing with advanced disease). Unfortunately, no one can predict with any certainty whose MS is going to do what, which has led most MS specialists to conclude that early treatment with one of the available medications (refer to Chapter 6) is the best way to hedge your bets.

Scanning the possible symptoms

MS symptoms can involve virtually any sensory or motor function that's controlled by the central nervous system. This means that the list of possible symptoms is long — including fatigue (by far the most common), visual changes, walking problems, and tremor (Chapter 7); bladder and bowel problems, sexual difficulties, sensory changes, and speech and swallowing problems (Chapter 8); and mood changes and problems with thinking and memory (Chapter 9).

Most symptoms tend to come and go, but some may come and stay. And they can range from mild to quite severe. The good news is that most people don't develop *all* of these symptoms, and most of the symptoms are treatable.



MS symptoms don't show up in any particular order. Often, however, visual changes are what bring someone to the doctor. Then, once in the doctor's office, it's pretty common for someone to remember an episode of one or more of these symptoms during high school or college that came and went without anyone paying much mind. That's why your doctor asks you so many questions and takes such a careful medical history when trying to arrive at a diagnosis. (Flip to Chapter 2 for information about the diagnostic process.)

Perusing the MS Treatment Menu

Reading about all the MS symptoms can definitely be an eye-opening experience. In fact, both your eyes and your mouth may be hanging wide open when you do. But try not to panic. With the help of your treatment team (flip to Chapter 4 for details), you can figure out how to manage your symptoms and take the necessary steps to control the disease as much as possible. Because MS is so complex, treatment involves several different strategies, all of which are discussed in detail in Part II. However, for now, here are snapshots of several steps you can take to feel and function up to snuff:

- ✓ Use disease-modifying therapy. Your doctor will discuss with you whether you're a candidate for treatment with one of the disease-modifying therapies (flip to Chapter 6 for details). For example, if you have relapsing-remitting MS or secondary-progressive MS and are having periodic relapses, you're probably a candidate. These medications don't cure MS, but they do reduce the frequency and severity of relapses. And, they probably slow the progression of the disease to some degree.
- ✓ Manage your relapses. Relapses (also called attacks or exacerbations) can be treated with corticosteroids if necessary. Even though the corticosteroids don't have any long-term impact on the disease, they're often effective in reducing the inflammation and bringing the relapse to an end more quickly. When you have a relapse, you and your doctor will decide whether the symptoms are interfering enough with your everyday activities to warrant treatment. (Check out Chapter 6 for more on managing your relapses.)
- ✓ Manage your symptoms. You and your healthcare team will work together to manage your symptoms effectively (see Chapters 7, 8, and 9). Successful symptom management relies on effective teamwork — with you being a key player on your team. Your job is to report symptoms promptly, follow through with the treatment plan, and provide feedback on what treatments do and don't work for you. And, remember, as your symptoms change, so will the strategies you use to manage them.
- ✓ Work with the rehabilitation team: Like the mechanics that keep your car finely tuned and road-ready, the rehab team helps you get in gear (check out Chapter 4 for more on this team). Physical and occupational therapists can help you do what you want to do, comfortably and safely, and prevent yucky complications. They're the experts when it comes to finding the right tools to solve problems with walking, seeing, holding on to stuff, or anything else you're having trouble with.
- ✓ Promote your overall health and wellness. Feeling your best involves more than just managing your MS. So, it's important that you not focus on your MS to the exclusion of your general health. Unfortunately, being diagnosed with MS doesn't protect you from the health problems that plague all mortals. This means that you have to get the proper nutrition, exercise, and preventive healthcare (Chapter 11) and you have to manage the stresses of your everyday life (Chapter 12).

✓ Seek out emotional support. Living with MS isn't a piece of cake. Even for those whose symptoms remain mild and manageable, the unpredictability alone is enough to stress people out. So, Chapter 3 shows you how to deal with your new diagnosis and come to grips with a chronic illness. The fact is that adjusting to this intrusion in your life — and your family's life — is an ongoing process that begins with your first symptoms and continues through all the changes that MS can bring.



Fortunately, you don't have to cope with this alone. Throughout this book, we suggest ways to get the support you need — from your health-care team, from the National MS Society and other organizations, and from those close to you. Check out Part IV for suggestions on how to communicate with others about your MS and about how to deal with the emotional stresses that MS can cause for you and the people you love.

Recognizing How Your MS Affects Your Loved Ones

When you throw a pebble into a lake or stream, there's always a ripple effect. Getting diagnosed with MS is similar because when one person in a family is diagnosed with MS, the entire family is affected by it. To help you adjust, we devote Chapter 15 to making MS a part of your family. Even though the symptoms are yours, your loved ones share everything from the impact of those symptoms on daily life to the financial pressures caused by MS. And like you, each family member is going to react to all of these challenges.

Talking about the tough stuff

One of the first hurdles for family members is figuring out how to talk comfortably — and honestly — with one another about the intrusion of MS in their lives. No one asked for MS, and no one likes it, so all of you are likely to feel sad, anxious, and maybe even a little resentful about the whole thing. Talking about these heavy-duty feelings can be difficult, particularly when you're all worried about creating more upset or worry for people you love.



Family members also tend to have different ways of dealing with tough stuff. For example, you may be a talker while your partner is the strong, silent type. These different — and sometimes conflicting — coping styles are another barrier to communication. So Chapter 15 offers you strategies for starting and continuing — the tough conversations.

Keeping daily life on track

As you may have noticed, MS symptoms can disrupt the rhythms of daily life. You may find that you can't do some things as well or as fast as you used to do them, and that you need to swap some chores and responsibilities with other family members. If you and your family members are finding that plans — especially outings and trips — are disrupted by pesky symptoms or unexpected relapses, check out Chapter 15 for ideas on how to keep the good times rolling, and Chapter 23 for ten traveling tips to keep in mind.



Because MS symptoms are so unpredictable, you may all need to be a lot more flexible and creative than you have ever been before. Your goal as a family is to make sure that MS doesn't interfere with your plans and priorities any more than absolutely necessary.

Maintaining healthy partnerships

Couples generally don't know what they're getting into with that "in sickness and in health" line. So chances are, you're probably learning from scratch how to adapt your partnership to the challenges of MS. In Chapter 15, we provide strategies to help you keep your partnership feeling comfortable and balanced. And in Chapter 8, we tell you how to manage the symptoms that can interfere with your sexual relationship. Regardless of the path your MS takes, the goal is to maintain a healthy, mutually satisfying partnership.

If you aren't already in a committed relationship, you're probably in the dating scene, which is challenging enough without MS symptoms getting in the way. If this sounds like your situation, turn to Chapter 14 for tips on how to talk about your MS with a prospective partner.

Becoming confident parents

When young adults are diagnosed with MS, some of the first questions they ask are about having kids. Young women want to know how a pregnancy will affect their MS and whether their MS will harm the baby. Men and women both have questions about how MS will affect their ability to be good parents.

Although Chapter 16 gives you all the details about conception, pregnancy, childbirth, and breastfeeding, here's a sneak preview: Women and men with MS can be terrific parents of healthy, happy children. We suggest some important

stuff to keep in mind when making your family plans — such as the unpredictability of MS, the depth of your financial resources, and the strength of your support system. And, we recommend some strategies to help you and your partner come to the decisions that are right for both of you.

But, we don't stop with childbirth, because that's over in a jiffy. Chapter 17 is full of parenting tips, including how to talk to your kids about MS, how to keep your MS symptoms from getting in the way of quality time with your kids, and how to keep MS from being the center of everyone's attention.

Minimizing the Impact of MS on Work and Play

MS is generally a relapsing-remitting disease, which means that symptoms come and go in an unpredictable way. So, don't make big decisions about any major life activities in the middle of a relapse or a particularly stressful week. Too many people end up leaving the workforce when they're first diagnosed or during a subsequent relapse, only to discover a few weeks or months down the road that they're feeling fine — but now they're unemployed. (If stress is getting you down, flip to Chapter 12 for ways to manage it.)

If you're considering leaving your job because of your MS, be sure to take advantage of all the legal protections that are available to you before thinking about disability retirement. The Americans with Disabilities Act (ADA) and other statutes are in place to help you stay employed as long as you want and are able to. Chapter 18 describes the provisions of the ADA, gives you pointers on how and when to disclose your MS at the workplace, and walks you through the steps for requesting accommodations from your employer.



Fun and recreation are just as important as work. Too often, people begin to give up activities they can no longer do easily or well. Before they know it, they've given up a lot of the things that make their life fun, full, and interesting. We talk a lot in this book about getting comfortable with doing things differently. After you decide that it's okay to be creative, you'll find a way to do just about everything that's important to you. People with MS swim, ski, sail, play golf, go camping, and travel all over the world. Chapter 7 describes the tools and strategies that can help you get around some of your symptoms, and Chapter 23 gives you ten tips for travel.

Taking Steps to Protect Your Quality of Life

Given the unpredictability of MS, you're probably wondering what you can do to safeguard your quality of life. The short answer is: You have to be a master at thoughtful planning and decision-making. We know that most folks don't enjoy second-guessing the future, but the best way to ensure your comfort and security down the road is to get all your ducks in a row now. So, check out Chapter 19 for info on how to ensure that your insurance coverage is the best that it can be, and Chapter 20, which gives you tips on how to plan for an unpredictable future. In the meantime, here's the shorthand prescription for protecting your quality of life: *Hope for the best, but plan for the worst*.



You aren't alone. Lots of people are with you on your MS path, including the scientists who continue to look for answers, the health professionals who want to partner with you in your care, and the voluntary health organizations, such as the National MS Society, that offer information and support. We offer this book as a friendly guide through the process.