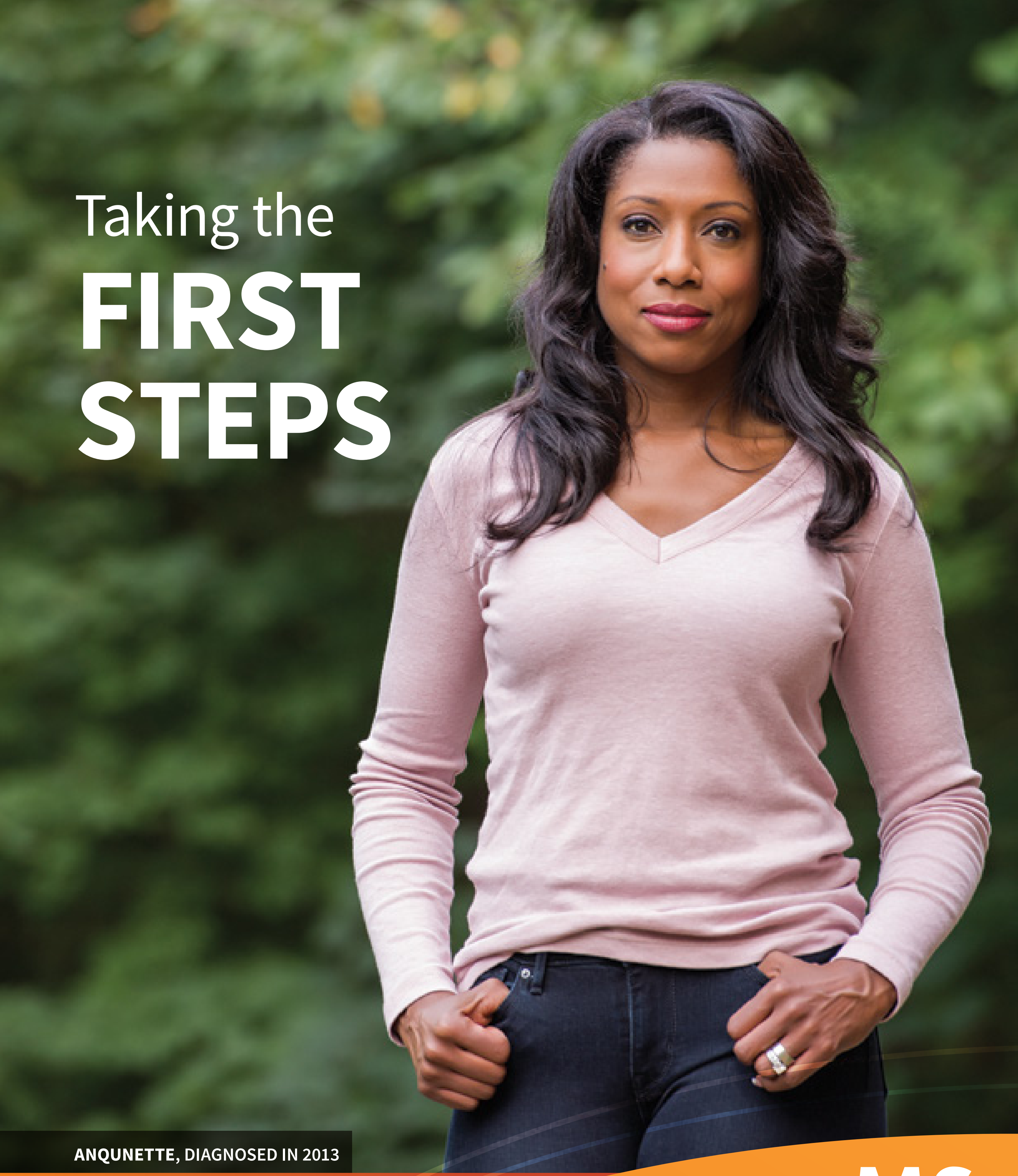


Taking the FIRST STEPS

ANQUNETTE, DIAGNOSED IN 2013

National
Multiple Sclerosis
Society

Chances are you are reading this because you have recently been told you have multiple sclerosis (MS). A new MS diagnosis can be frightening and overwhelming, and taking the first steps to deal with it is challenging for everyone. Many people find it helpful to start by gathering the facts — learning as much as they can about MS and getting basic answers to the most common questions people have when faced with a new diagnosis. This chapter offers information about the disease — what happens, why it happens, why it varies so much from one person to another — and provides some suggestions for how to begin adapting to a life with MS.

Information about multiple sclerosis

Who gets MS?

MS is a chronic, sometimes disabling disease for which we do not yet know the cause or the cure. While most people are diagnosed between the ages of 20 and 50, MS is also seen in children and older adults. The diagnosis most often occurs in early adulthood, when young men and women are actively building careers and starting families of their own. An estimated 2.3 million individuals are reported to have MS worldwide. The disease is two-to-three times more common in women than men. MS occurs in most ethnic groups — including African Americans, Asians, and Hispanics — but is more common in Caucasians of northern European ancestry. MS is also more common in cooler areas away from the equator, such as the northern United States, Canada, and northern Europe, and less common in warmer climates such as the southern United States, the area around the Mediterranean, or the tropics.

What causes MS?

While MS is not directly inherited, people who develop the disease seem to be genetically predisposed, and therefore more susceptible to whatever stimulus or agent in the environment causes the MS to become active. Although we have not yet identified any specific stimulus or agent, large research studies have identified a number of risk factors that appear to increase a person's risk of developing MS. These include infection with Epstein Barr virus, cigarette smoking, childhood obesity, and low levels of Vitamin D. So while no one of these factors causes MS, they seem to play a role in increasing the risk in those individuals with a genetic predisposition to develop the disease. The vast majority of people with these common risk factors do not develop MS — which means that, for some reason we still do not understand, —

genetic factors and risk factors combine in some individuals to create "the perfect storm," causing MS to happen.

So for people who wonder why this happened to them, or what they could have done to prevent it, the answer is that we still do not know. The more helpful question is what can be done today and in the days ahead to deal with MS in the most comfortable and effective way — which is what **Knowledge Is Power** is all about.

What happens in MS?

MS is thought to be an immune-mediated disease in which the body's immune system mistakenly attacks normal tissue in the body. In MS, this attack is aimed at the myelin coating around nerve fibers (axons) in the central nervous system (CNS), as well as the axons themselves and the cells that make myelin, which are called oligodendrocytes. The CNS includes the brain, optic nerves and spinal cord, which are made up of nerves that act as the body's messenger system. The myelin coating around each nerve fiber in the white matter (so-called because of the whitish color of myelin) of the CNS serves as insulation, much like the plastic coating on an electrical wire. This insulation helps to ensure the efficient transmission of nerve impulses (messages) between the brain and other parts of the body.

In MS, damage from inflammation and demyelination causes scar tissue or sclerotic plaques (lesions) to form along the myelin sheath. These plaques interfere with the conduction of nerve impulses within the CNS, which in turn causes the symptoms that people experience over the course of the illness. The name "multiple sclerosis" comes from the multiple locations of scarring or sclerosis in the white matter of the CNS. In addition to the damage that occurs in CNS white matter, recent research has confirmed that damage also occurs in the cortex (gray matter) of the brain.

Since demyelination occurs randomly throughout the CNS, a wide range of symptoms can occur, including:

- unusual fatigue
- blurred or double vision
- problems with walking caused by stiffness, weakness or imbalance
- sensory problems like numbness, tingling and pain
- problems with bladder and bowel control
- changes in sexual function
- depression and other emotional changes
- problems with memory, attention and other cognitive functions

While some individuals will experience only one or two of these symptoms as a result of MS, others may experience several of them at one time or another. A more detailed discussion of these symptoms and their management can be found in the chapter on **Treating Yourself Well**.

The type and number of symptoms vary with each individual, depending on where demyelination occurs in the CNS.

How is MS diagnosed?

By now you are probably aware that MS is not easily diagnosed. This is because there is currently no single test to determine whether a person has the disease. Rather, a clinical diagnosis is made on the basis of a person's medical history, an assessment of symptoms reported by the person, and the presence of abnormalities detected by the physician (but not always noticeable to the person) during the comprehensive neurologic examination.

At the present time, a physician can make a definite MS diagnosis only if the following criteria are met:

- There must be evidence of plaques (lesions) in at least two separate areas of the CNS.
- It must be clear that the plaques have formed at different points in time or progressively over six months' time.
- And, most importantly, there must be no other reasonable explanation for the plaque formation or the person's symptoms.

Therefore, a definite diagnosis of MS is made only when other explanations of the signs and symptoms can be ruled out.

This helps to explain why it takes some people such a long time to get a definitive explanation for their puzzling and uncomfortable symptoms. Fortunately, increasingly sophisticated technology has helped speed the diagnostic process.

What tests may be used to confirm the diagnosis?

While for many people the medical history and neurologic examination will provide sufficient information to support an MS diagnosis, other tests are generally used to help confirm it.

- **MRI** — The most common test in use today is called magnetic resonance imaging (MRI). The MRI, which can produce pictures of the brain and spinal cord without the use of x-rays, is used to identify lesions in the CNS that are consistent with MS. Specific MRI findings are part the criteria used to diagnose MS.

- **VEP** — Another test that can help confirm a diagnosis of MS is the visual evoked potential (VEP) which measures the speed and efficiency of nerve conduction along visual pathways in the CNS. This test is noninvasive and well tolerated by most people.
- **Spinal tap (lumbar puncture)** — In some instances it is necessary to examine the person's cerebrospinal fluid (fluid that bathes the brain and spinal cord) for evidence of abnormalities in the immune system. The fluid is collected via a needle inserted into a space in the lumbar region of the spinal column, and chemically analyzed. While the results of this test are not specific to MS, they can help distinguish MS from other diseases that may look like MS. Since this test is somewhat uncomfortable, it is not done as frequently as MRI.

Again, these tests by themselves cannot diagnose MS because MS is only one of many conditions that can cause their results to be positive. Your medical history, and the symptoms and signs of CNS demyelination that you and your doctor will piece together, serve as the clearest evidence for the MS diagnosis.

What can you expect?

While there is no way to predict with any certainty how a person's MS will progress, four basic disease courses have been defined:

- **Clinically isolated syndrome** is a first episode of neurologic symptoms caused by inflammation and demyelination in the central nervous system. A person who experiences clinically isolated syndrome may or may not go on to develop MS, with the chances being higher in someone who has lesions on MRI that are similar to those seen in MS.
- **Relapsing-remitting MS** is characterized by clearly defined relapses (also called attacks or exacerbations) that last from days to weeks and then subside, with full or partial recovery and no apparent disease progression between attacks. Approximately 85 percent of people begin with this disease course.
- **Primary progressive MS** is characterized by a gradual but steady progression of disability from the onset of symptoms, with few or no relapses or remissions. Occasional plateaus and minor, temporary improvements may occur. Approximately 15 percent of people are diagnosed with this disease course.

- **Secondary progressive MS** begins initially with a relapsing-remitting course that later evolves into a more consistently progressive course, with or without relapses.

Additional details about the disease courses can be found at **nationalMSsociety.org/types**.

> “It is easy to become so overwhelmed by what ‘might be,’ that one loses out on ‘what is.’”

One of the greatest challenges presented by MS is the unpredictability and uncertainty of what is to come. It is virtually impossible to predict what symptoms a person will experience or how the MS will progress over time. In addition, remissions can occur at any time in someone with relapsing-remitting MS, and last anywhere from months to years.

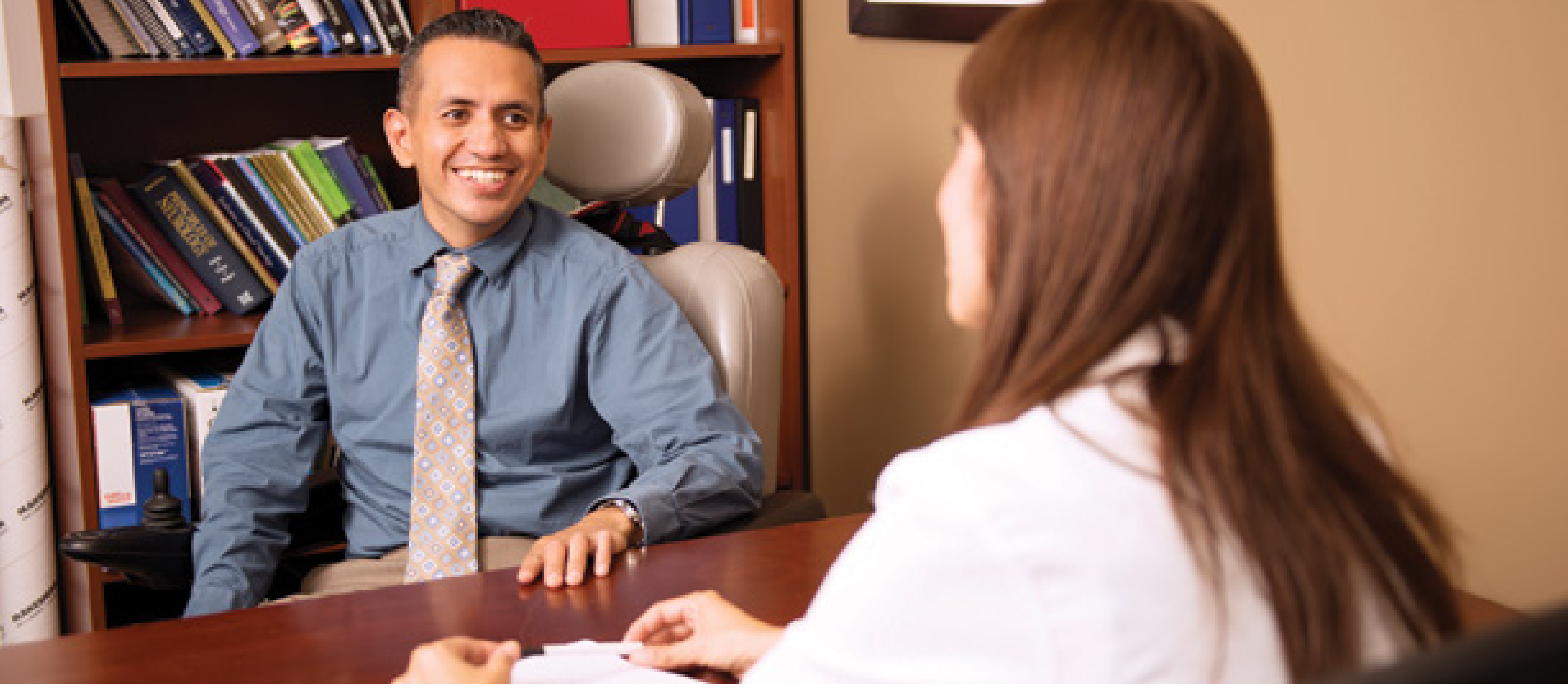
This unpredictability can make life difficult, particularly in terms of planning for the distant and not-so-distant future. A good strategy for dealing with the future involves:

- educating yourself about the possible changes brought on by MS
- working with your doctor and other healthcare professionals to manage your symptoms as effectively as possible
- communicating openly with family members whose daily lives will also be touched by this disease
- developing a support system of family members and friends, knowledgeable healthcare professionals and community resources
- optimizing your general well-being by pursuing a wellness-focused lifestyle and adhering to recommended preventive health strategies
- protecting your financial security by planning early for the unpredictability of the future
- keeping your life as full and satisfying as you would like it to be

It is easy to become so overwhelmed by what “might be,” that one loses out on “what is.” Subsequent chapters talk about various aspects of life with MS and provide suggestions for meeting the challenges ahead.

What are the treatments for MS?

Although a cure for MS has not yet been discovered, several medications have been shown to be effective in reducing the number of MS relapses



Carlos, diagnosed in 2001

and slowing the progression of the disease. In addition, the symptoms of MS can be managed with a range of medications, rehabilitation techniques and lifestyle management strategies. With the help of your healthcare team, you will learn to manage whatever symptoms the MS brings, and take whatever steps you can to slow disease progression and enhance your quality of life. All of these interventions are discussed in some detail in subsequent chapters: **Disease-Modifying Treatments for MS** and **Treating Yourself Well**.

What kinds of research are being done?

Large-scale studies (clinical trials) have demonstrated the effectiveness and safety of the treatments for MS that are available today. More trials of potential treatments are underway around the world and additional trials are in the planning stages. Because the course of MS is so unpredictable, and so many of the symptoms may spontaneously improve over time, it takes a fairly large, lengthy and carefully controlled study to prove that a proposed treatment is both effective and safe. It is for this reason that your doctor will discourage you from trying each and every one of the so-called “cures” that well-meaning friends and relatives may pressure you to consider. Over the years, a great variety of medical and non-medical treatments have been held out as “cures” for MS. Obviously, none of them has stood up to the rigors of controlled research. Today, as we continue to look for the cause(s) and cure for MS, research efforts also focus on trying to slow or halt disease progression and identify ways to repair damage that has already occurred. Individuals with MS are invited and encouraged to participate in clinical trials so answers can be found. Information about current and future trials is available from the National MS Society.

With this initial introduction to what we know — and don't know — about MS, it is time to talk about coping strategies to manage this life change.

Dealing with your diagnosis

The recent weeks or months of living with symptoms, medical tests and finally a diagnosis have probably been stressful. You may feel a bit overwhelmed by all the emotions and questions that are going through your mind. And you may be wondering how to begin dealing with the stress and uncertainty that this new diagnosis has introduced into your life. It is often helpful to start by understanding the feelings you are having; this is an important first step in learning to live with MS.

> "This is so overwhelming. I'm not even sure what I'm supposed to feel right now."

Common reactions to the diagnosis

Immediate reactions

People often ask what they "should" be feeling or what other people feel in a difficult situation like this. The answer, of course, is that there is no one right way to feel. Initial reactions to being diagnosed with MS usually include some combination of disbelief, shock, fear and possibly even relief.

Some people simply do not believe the diagnosis and continue to search for an explanation for their symptoms that is less difficult to accept. Others may feel so shocked that they find it difficult to feel anything at all. For people who have heard only about the most disabling cases of MS, the initial reaction may be fear. Anyone who has lived for months or years with unexplained symptoms or has been told that the problems were all emotional or psychological may actually feel relieved to finally have an answer. Others may be relieved that their illness isn't a brain tumor or some other type of cancer.

Longer-term reactions

Other reactions to MS will gradually emerge as the realities of the illness begin to make themselves known to you. These reactions are determined, in part, by the kinds of symptoms you are having and the degree to which these symptoms interfere with your daily life. Thus, for someone who works as a store manager or loves to dance, problems with walking might be the most distressing, while for an author or a teacher, walking problems might seem less frightening than cognitive changes involving memory or problem-solving. In general, however, there are some feelings that everyone with MS tends to experience at one time or another — namely anxiety, sadness or grief, anger, and guilt. Remember that there is no particular order or progression to these feelings. You will not "graduate" from one of these to another. Instead, these feelings are likely to come and go as the disease ebbs and flows.

- **Anxiety** — One of the hallmarks of MS is its unpredictability. People tend to feel anxious or nervous when they do not know what is going to happen next. "If someone could just promise me that it's not going to get any worse, I could handle this. It's not knowing what's going to happen next that makes this so difficult ..." is a common refrain among people with MS. Feeling out of control also makes people anxious. Neurologic changes that affect vision, bladder and bowel control, and ability to walk can feel threatening to any person's sense of control and autonomy.
- **Sadness and grief** — Similar to creating a lifetime jigsaw puzzle, a person gradually pieces together a self-image. Being diagnosed with a chronic illness requires one to think a bit differently about him or herself. MS is a new, awkwardly-shaped puzzle piece that somehow needs to fit in. This kind of change makes people feel sad, and grieving over the lost sense of self is a normal, necessary and important part of building a new self-image that includes MS. Any time that a symptom interferes with your ability to do something that is important to you, some of this grieving will take place.
- **Anger and resentment** — These are also common and normal reactions to a chronic, unpredictable illness. People resent the intrusion into their lives of something over which they have so little control. Some wonder what they could have done to deserve this; others find themselves angry at the doctor, and even at God, for letting this happen. They may feel anger at people around them whom they perceive as healthy and having few problems. They may also feel angry at themselves when they cannot do something that they used to do with ease.
- **Guilt** — If MS interferes with the ability to meet various work or family obligations, people may also experience guilt. They don't want to let down family members or colleagues who are depending on them. One of the ongoing challenges

of life with MS is finding a comfortable balance between caring for oneself and meeting the needs of others.

Beginning the coping process

Becoming educated

Coping with this unexpected complication in your life begins with learning as much as you can about MS. **Knowledge Is Power** was developed out of a firm belief that knowledge can give you a greater feeling of security and control even in the face of change and uncertainty. Knowledge helps you sort out your fears about the disease from its realities. Information can come from a variety of sources — some more reliable than others. Your own physician and the National MS Society are two of your best resources for accurate, up-to-date and unbiased information about the most effective ways to treat MS and manage your symptoms.

Communicating with others

As you are learning about MS, begin sharing your feelings about it with the important people in your life. Try to remember that each of these people will also have his or her own reactions to this change in your life. Sharing the feelings with one another can make them feel less overwhelming for all of you. This kind of open communication can also lead to more effective problem-solving strategies. Some thoughts on how and when you might want to talk to other people about your diagnosis are provided later in this chapter.

Building a support system

Talking about your MS with others is a crucial step toward creating a valuable support system. In addition to selected relatives and friends, your support network will come to include some or all of the following: a physician and other healthcare professionals with whom you can work comfortably; the National MS Society; MS self-help groups; and the growing array of agencies, organizations, and companies that specialize in meeting the needs of people with a chronic illness or disability.

Establishing realistic goals and expectations

Many people with MS wonder how long it will take them to “accept” that they have MS. Asking yourself to accept this unexpected and complicated change in your life is probably not realistic. Instead, find ways to adapt to its presence, first by learning what you need to know about its potential impact on your life, and then by making use of all the tools that are available to help keep your life as enjoyable, full and productive as you would like it to be.

The diagnosis of a chronic, unpredictable illness can feel frightening and overwhelming. Many people respond with a determination that they are going to “beat this disease.” They feel that if they try hard enough, they can keep the illness from getting worse or even make it go away. Wanting to "beat the disease" is certainly understandable, but it may not be the most realistic or productive goal.

> "Flexibility and creativity are the key to effective problem-solving in your daily life."

A person is usually better off putting that strength and determination into problem-solving. Rather than trying to do battle with the disease itself, try to identify the individual problems it is causing in your life and do battle with them one by one. Breaking down the big problem into smaller, more manageable ones can enhance your feelings of success and control and minimize feelings of failure or guilt if the disease progresses in spite of your best efforts. Flexibility and creativity are the keys to effective problem-solving in your daily life. While MS may sometimes prevent you from doing things exactly the way you have done them in the past, your willingness to explore new strategies and tools will ensure that you still achieve your goals.

Managing stress

Many people are concerned about the effects of stress on their MS. Believing that stress could worsen their MS, some people try to rid themselves of stress in an effort to control the disease. They may even go so far as to quit their jobs to avoid job-related stress, withdraw from leisure or social activities, or make significant relationship changes. Giving up important roles and relationships, however, generally amounts to exchanging old stresses for new ones.

Although many studies have been conducted in an effort to identify a link between stress and MS, the findings are inconclusive. Whatever conclusion is finally reached about the impact of stress on MS, remember that modern-day life is stressful for all of us, and trying to remove the stresses from your life would not only prove to be impossible, but might also remove much of what is most interesting and fulfilling. In addition, the effort to rid one's life of stress in order to control MS becomes a stress in itself; people who experience a worsening of their MS in spite of efforts to control stress tend to feel guilt and anxiety over having failed.

Give yourself time to learn about your MS and the ways that it affects your life's activities. Learning effective stress-management techniques to deal with the challenges of daily life will prove far more satisfying in the long run than giving up things that are meaningful to you. The goal is for your life to remain satisfying, productive and enjoyable in spite of MS-related challenges.

Recognizing your strengths and resources

As you begin to deal with the intrusion of MS into your life, remember to take stock of your own inner strengths and resources. Although MS may seem like a bigger or more frightening problem than you have previously encountered, many of the same strengths and coping strategies that you have relied on in the past to deal with challenges in your life will serve you well now. At the same time, however, keep in mind that "going it alone" isn't necessary or even expected. Just as you would consult a lawyer or an accountant to educate and advise you about dealing with complex legal or financial issues in your life, you can rely on healthcare professionals to help you in your efforts to adapt to life with MS. Counseling and education about MS are important coping tools and no one should ever feel uncomfortable about seeking out this kind of support.

Making disclosure decisions

When you first learned of your MS diagnosis, you may have felt like sharing the information with loved ones, friends, colleagues and even total strangers — or you may have felt like sharing it with no one at all. With the passage of time, it is unlikely that either of these extremes will prove workable. Now that you have been living with this unwelcome news for a little while, you have probably given the question of disclosure a bit more thought.

You may be wondering who needs to know about your MS and who does not. You may be concerned how others will react to your news and how they will feel about you once they know. And, you are probably worried about what the consequences of disclosure might be for your relationships and your career. There are several factors you might want to take into consideration as you come to your own conclusions about discussing your diagnosis with others.

> "Sometimes I want everybody to know about my MS, and sometimes I don't want anybody to know."

Telling the people who are closest to you can benefit you and them

As a person newly diagnosed with MS, you will probably find that the support of people closest to you is extremely helpful. Your spouse or partner, your parents, a brother or sister, or your close friend are all people with whom you might want to share the information. Begin with those individuals whose lives are involved with yours on a daily and intimate basis, for these are the people who know and love you enough to sense when something is wrong anyway. The sooner you and they can begin to talk openly about this unexpected intrusion into your lives, the sooner you can share each other's concerns and begin to cope and problem-solve together.

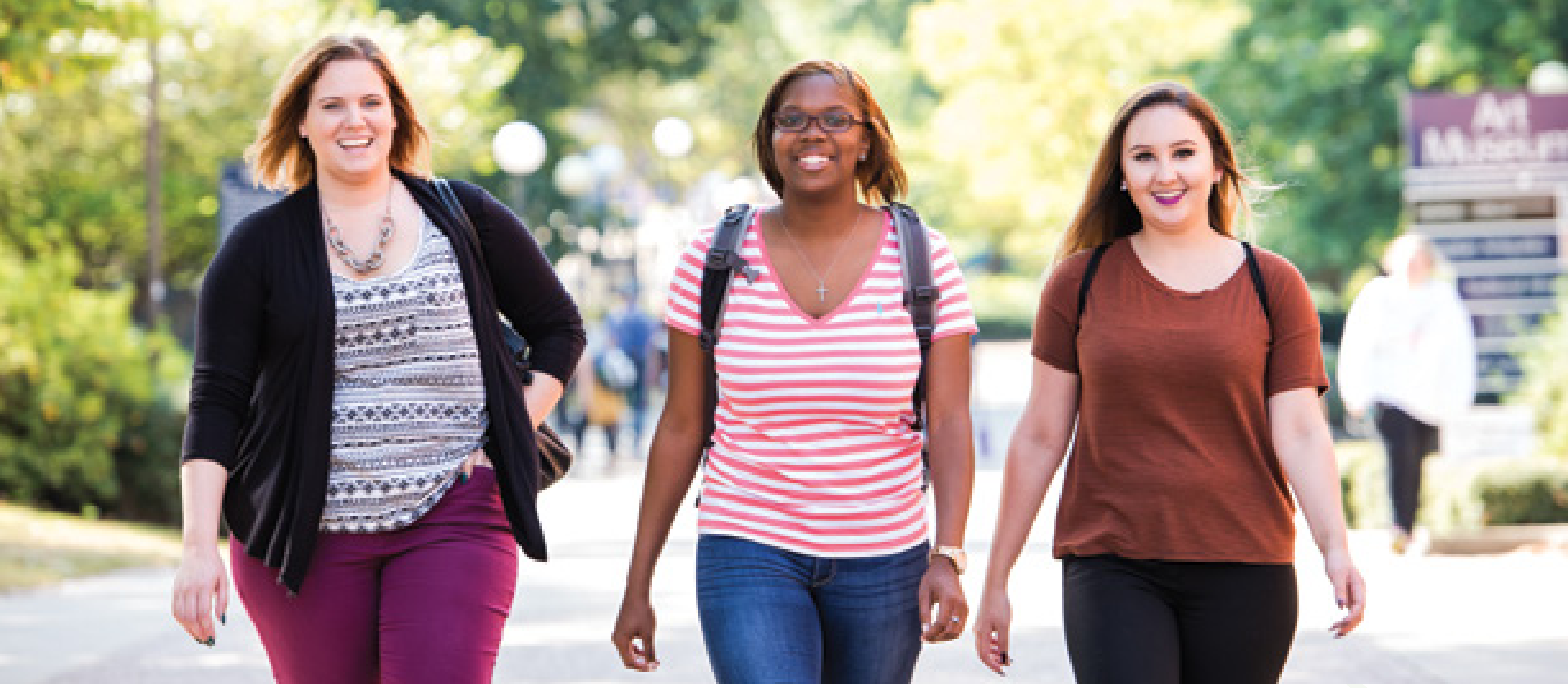
Adults are sometimes hesitant to talk about the diagnosis with elderly parents, for fear that the news will be harmful to the parents' health and peace of mind. Since families tend to have different habits or "rules" about the sharing of health-related or other personal information, your parents may be accustomed to sharing a lot with you, or very little. As you are thinking about your own needs and theirs, keep in mind that the withholding of significant information can tend to create an atmosphere of secrecy that is easily misinterpreted.

If you find that "keeping mum" about the MS is causing you to talk less to your parents, or avoid them altogether, the end result will probably be more stressful to them than the news itself.

People will react differently to your MS

You may be quite surprised at the variety of responses you get from different people in your life. While some will want to ask you a lot of questions, others may ask none at all. Some will immediately begin trying to take care of you, while others will need you to reassure them that you are going to be all right. And some will hover protectively while others will seem to pull away.

As you make the decision to tell one or another person in your life, try to anticipate what you think that person's response might be. This will help you to feel a bit more prepared. Be ready to answer some questions and provide some explanation (either in your own words or with one of the many pamphlets and books that are available) since many people may not understand what MS is. Be ready, as well, to hear about other people they have known with MS or about the miracle "cures" they have read about in a magazine or on the internet. And remember that people who can't think of what to say or what to ask may say



Crystal (center), diagnosed in 2010

very little — or nothing at all. This doesn't mean that they don't care, but rather that they need some time to react to this startling information.

Most people will also need some cue from you on how they should respond. You can let them know if you are comfortable talking about MS or if you would prefer not to discuss it right now. You can talk about it in a more lighthearted, joking manner, if that is your style, or you can invite the person to go with you to a lecture about MS. In other words, feel free to use whatever style of disclosure feels most comfortable for you, while remembering that others will look to you to tell them how they should respond. You can also let them know what you want or need from them, whether it's someone to talk to, a shoulder to cry on, some help with some of your activities or simply a hug.

The chapter on **Maintaining Healthy Relationships** addresses some of these relationship issues in greater depth.

Once you have told someone, you can't take it back

The point is not that your MS should be kept secret, but that you may want to take some time to think through when and how you choose to share the information — particularly if your initial inclination is to tell everyone about your recent diagnosis. Over the next few months, as you experience a variety of reactions to this unexpected upheaval in your life, you may find that your feelings about disclosure tend to shift or fluctuate. As some of your initial anxiety and distress begin to subside, you may feel less of a need to talk about it. Or, you may find talking about the MS becomes more comfortable for you. Taking time to think it through will help you avoid the awkward situation of telling a particular friend or business associate about your MS and then regretting that you have done so.

When the time feels right, think about your reasons for wanting a particular person to know and what you hope to achieve by disclosing your MS.

> "I know that once I talk about my diagnosis, it's not private anymore, so I need to think carefully about whom I tell and when."

Try to evaluate how the information might affect your personal or professional relationship with the other person. Sometimes a person's emotional need to share the information conflicts with some very practical considerations — in a job situation, for example. Before talking about your MS with colleagues or supervisors, even those who are also close friends, learn about disability-related employment issues. These are discussed in some detail in the chapter on **Maximizing Your Employment Options and Financial Security**.

If you are currently experiencing symptoms that interfere with your work and feel the need to request on-the-job accommodations from your employer, be sure to seek professional advice about disclosure and accommodation issues before you do so. The National MS Society can guide you in this process and refer you to appropriate resources for learning about the Americans with Disabilities Act (ADA). If you are not experiencing any work-related difficulties at this time, and have no visible symptoms, it is generally advised that you delay disclosing your MS at the workplace until you have had time to consider the matter very carefully. While some employers are understanding and supportive, others may not be.

Secrecy can make a shaky foundation for a growing relationship

Single people often wonder when they should share their diagnosis with someone they are dating. Again, while there is no strategy that is right for everyone, some general guidelines may prove useful. The first date is generally a time to get acquainted and find out if this is a person with whom you would like to spend more time. There is certainly no need to launch into a detailed description of your medical history. If you are experiencing noticeable symptoms, you might feel comfortable making a comment about being clumsy or having a problem with your leg without going into greater detail.

Once you have decided that you would like to develop a relationship with this person, the time for greater openness is at hand. Secrets and half-truths can only hamper the growth of a trusting and intimate relationship. A reasonable strategy may be to ask yourself when **you** would want to know significant personal information about the other person; don't wait too long to talk about this particular aspect of your life.

While many people assume that talking about their MS will get easier with time — "when we know each other better" — this is seldom the case. The more involved and invested you become in a relationship, the more painful the potential loss.

The risk of rejection is part of any dating situation, and MS can certainly create an additional stress on a developing relationship. While some people will be put off or frightened by the MS, others will take it in stride. You may even find that talking about your MS encourages the other person to share health information that he or she might have been hesitant to mention. You will also have freed yourself of the burden of a secret that grows heavier with the passage of time.

Children shouldn't be the last to know

Parents often wonder when and how they should talk with their children about MS. They may be reluctant to approach the subject for several reasons: they do not want to frighten the children unnecessarily, they do not want the children to talk about the MS outside the family, or they find it too emotionally painful to discuss. This subject is covered in some detail in the chapter on **Parenting with MS**. There are, however, certain guidelines to keep in mind as you think about talking with your own children about MS:

- First, the type and amount of information you give to your children should be guided by their age and ability to understand, as well as by your own feelings and needs. These factors will obviously change over time, and your discussion of the disease will change and grow accordingly.
- Second, it is important for your children to hear this kind of sensitive, personal information from one or both parents rather than from an outsider who inadvertently "spills the beans." This is true not

only because you want to decide how and what to tell them, but also because hearing it from you gives your children a greater feeling of confidence and security — and children do not like being the last to hear family news.

- Third, children are acutely aware of things going on around them. They may not know the words “multiple sclerosis,” but they will certainly be sensitive to changes in their parent’s physical and emotional state, as well as the general emotional climate in the household. When children are not given the information they need to explain the changes they sense, their imaginations simply fill in the gaps — usually with less-than-accurate information.
- Fourth, by talking openly and honestly with your children about MS, you set the stage for effective parent-child communication about other issues that may arise in your life or theirs.

Disclosure is a multi-stage process involving people in all the different areas of your life

The decision to disclose your diagnosis is not a simple one. In general, you will base disclosure decisions on your own needs and priorities while also taking into account the needs and priorities of others. Consider what is to be gained — and lost — in your various personal and professional relationships by sharing this information. To help you think through your decisions around disclosure, the Society offers a disclosure worksheet included in the back of this KIP book if you received KIP by mail, or it is available online at **nationalMSsociety.org/DisclosureDecision**.

Keep in mind, as you begin to talk with others about MS, that people will generally look to you to guide them in their response to your MS. Your ability to educate them about the disease and reassure them that MS is now a part of your life, but not the whole of it, will tend to minimize the impact of this new information about you.

Things to think about

- While each person with MS has a chronic, neurologic disease, no one person’s MS is exactly like anyone else’s.
- Over the course of your MS, you may experience some of the symptoms described and not others. Being knowledgeable about MS is your best strategy for dealing with the unpredictable nature of this disease.
- As you experience new or changing symptoms, take time to educate yourself about them — what they are, how they affect your life — and management strategies for dealing with them.

- Learn about your MS, not everyone else's.
- Keep in mind that your reaction is just that — your reaction. It may differ not only from what was discussed in this chapter, but from the reactions of others around you. And it may well change over time.
- Flexibility and creativity are your keys to managing the day-to-day challenges of MS. When MS interferes with your ability to do something when and how you want to do it, look for alternative strategies and tools to get the job done.
- There are no set "stages" to a person's reactions to MS. Your feelings will reflect the changing ways in which MS affects your life and the lives of people close to you.
- Remember that you do not have to handle your feelings alone; there are a variety of resources available to help you.
- In making the decision(s) to disclose your diagnosis, think about:
  - » **Whom** you are telling
  - » **What** you are going to tell them
  - » **Why** you are telling them and what you expect in the way of a response
- You need to be prepared to educate people about your MS, and be ready to hear different responses.
- In general, people will look to you to let them know how to respond to your news.
- It's never too early to consult a financial planner about how to plan for an unpredictable disease like MS. Free financial information and advice is available through Financial Education Partners (the National MS Society's collaborative program with the Society of Financial Service Professionals). Call 1-800-344-4867.

Resources

From the National MS Society

Thousands of resources, pieces of information and shared experiences about MS are available in print and on the internet. Some of the information you come across may be strictly experiential, anecdotal, unsupported or even inaccurate. Always consider the source; ask your healthcare provider or the National MS Society to help you identify credible resources.

For answers to questions about MS and its management, contact the National MS Society at 1-800-344-4867 or visit **nationalMSsociety.org** or the following topic-specific pages:

- **nationalMSsociety.org/newlydiagnosed**
- **nationalMSsociety.org/aboutMS**
- **nationalMSsociety.org/exacerbation**
- **nationalMSsociety.org/treatments**

- **nationalMSsociety.org/research**
- **nationalMSsociety.org/clinicaltrials**
- **nationalMSsociety.org/FAQs**
- **nationalMSsociety.org/firststeps**

The Society produces many other resources about various aspects of MS. These resources are available online or call 1-800-344-4867 to request.

- **nationalMSsociety.org/educationalvideos** (also at youtube.com/nationalMSsociety)
- **nationalMSsociety.org/brochures** (or see the Catalog of Informational Resources mailed with this book if you received it by mail)

Books

Books may be available at bookstores and/or online booksellers.

- Bowling AC. **Optimal Health with Multiple Sclerosis** (2014) (NY:DemosHealth)
- Kalb R (ed.). **Multiple Sclerosis: A Guide for Families** (3rd ed.) (2006) (NY:DemosHealth)
- Kalb R (ed.). **Multiple Sclerosis: The Questions You Have; The Answers You Need** (5th ed.) (2012). (NY:DemosHealth)
- Kalb R, Giesser B, Costello K. **Multiple Sclerosis for Dummies** (2nd Ed). (NJ:Wiley) (2012)
- Murray TJ, Saunders C, Holland N. **Multiple Sclerosis: A Guide for the Newly Diagnosed** (4th ed.) (2012). (NY:DemosHealth)
- Schwarz SP. **300 Tips for Making Life with Multiple Sclerosis Easier** (2nd ed.) (2006). (NY:DemosHealth)

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The National MS Society's mission is for people affected by MS to live their best lives as we stop MS in its tracks, restore what has been lost and end MS forever. To fulfill this mission, the Society funds cutting-edge research, drives change through advocacy, facilitates professional education, collaborates with MS organizations around the world, and provides services designed to help people with MS and their families move their lives forward.

The National Multiple Sclerosis Society ("Society") is proud to be a source of information on multiple sclerosis related topics. The information provided is based on professional advice, published experience, and expert opinion, but does not constitute medical or legal advice. For specific medical advice, consult a qualified physician. For specific legal advice, consult a qualified attorney.

The Society does not endorse products, services or manufacturers. Such names appear here solely because they are considered helpful information. The Society assumes no liability for the recipient's use of any product or service mentioned. The Society does not independently verify whether the information provided by each service provider is accurate. The Society undertakes no responsibility to verify whether the service provider is appropriately licensed and certified and has applicable insurance coverage.

Early and ongoing treatment with an FDA-approved therapy can make a difference for people with multiple sclerosis. Learn about your options by talking to your healthcare professional and contacting the National MS Society at **nationalMSsociety.org** or 1-800-344-4867.

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