

**Volume 1**

What is Multiple Sclerosis?



Introduction

You have recently received the unwelcome news that you have multiple sclerosis (MS). You may know very little about the disease, or you may know just enough to feel overwhelmed and frightened by this new development in your life. A series called *Knowledge Is Power* has been developed to help you deal with some of the implications of your recent diagnosis. The series will provide you with current and accurate information about MS, address many of your initial questions and concerns, and start you on the road to coping with this significant life change. In this volume, some of the medical aspects of MS will be explained.

Epidemiology

MS is a chronic, sometimes disabling, neurologic disease for which we do not yet know the cause or the cure. While 70% of people are diagnosed between the ages of 20 and 50, MS may also be seen in very young 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 400,000 individuals are reported to have MS in the United States. The disease is two-to-three times more common in women than men. MS occurs more commonly among Caucasians (particularly those of Northern European

ancestry) but people of African, Asian, and Hispanic backgrounds are not immune. MS is also more common in temperate 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.

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While MS is not directly inherited, those who develop the disease seem to be genetically predisposed, and therefore more susceptible to whatever stimulus or agent causes the MS to become active. While we have not yet identified the specific stimulus or agent, it is currently thought that the development of MS is stimulated by one or more viruses or bacteria.

Neurology

MS is described as an autoimmune disease in which the body's immune system mistakenly attacks normal tissue in the body. In MS, this attack is aimed at myelin, an important substance in the central nervous system (CNS). The CNS includes the brain, optic nerve, and spinal cord, which are made up of nerves that act as the body's messenger system. Each nerve fiber in the CNS has a fatty covering of myelin sheath (white matter) that 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, a process called demyelination causes scar tissue or sclerotic plaques (lesions) to form along the myelin sheaths. 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 CNS white matter. Damage also occurs to the nerve fibers (axons) themselves.

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Since demyelination occurs randomly throughout the CNS, a wide range of symptoms can occur, including: blurred or double vision; unusual fatigue; 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; and emotional changes and intellectual impairment. While some individuals will experience only one or two of these symptoms as a result of MS, others may experience most or all of them at one time or another. A more detailed discussion of these symptoms and their management will be found in another volume of the *Knowledge Is Power* series.

The type and number of symptoms vary with each individual, depending on where demyelination occurs in the CNS. It is not known why this demyelinating process occurs, or why some people get more or different symptoms than others. We do know, however, that the person who develops MS has done nothing to cause the disease or its symptoms, and could not have prevented it from occurring.

discussion about a possible relationship between stress in people's lives and the onset or worsening of MS. Although a variety of research studies have been conducted in an effort to identify a possible link between stress and MS, no conclusive evidence of such a link has been demonstrated. Whatever conclusion is finally reached about the impact of stress on MS, the important thing to remember is that modern-day life is challenging and stressful for all of us. 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. Learning to manage life's stresses comfortably and effectively is a far more realistic goal.

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Diagnosis

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: 1) There must be evidence of plaques (lesions) in at least two separate areas of the CNS. 2) It must be clear that the plaques have formed at different points in time or progressively over six months' time. 3) 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 will be 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. With the advent of increasingly sophisticated technology, MS experts have recently embarked on the task of developing a new, more efficient, set of diagnostic criteria for MS.

While for many people the medical history and neurologic examination will provide sufficient information to support an MS diagnosis, other tests may be

needed to confirm it. 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. Other tests used to confirm a diagnosis of MS are the visual evoked potential (VEP), brain stem auditory evoked potential (BAEP), and the somatosensory evoked potential (SSEP). These tests, which measure the speed and efficiency of nerve conduction along different pathways in the CNS, are noninvasive and well tolerated by most patients.

In some instances it is necessary for a person to have a lumbar puncture (spinal tap) in order to rule out other medical conditions and support the MS diagnosis. In this test, cerebrospinal fluid (fluid that bathes the brain and spinal cord) is collected via a needle inserted into a space in the spinal column, and chemically analyzed. The physician is looking for certain indications of abnormality in the immune system. 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 or VEP.

Again, these tests are used to confirm a diagnosis of MS because MS is only one of many conditions that can cause them 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 to Expect

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

- **Relapsing-remitting MS** is characterized by clearly defined attacks (relapses) that last from days to weeks and then subside, with full or partial recovery and no disease progression between attacks.
- **Primary-progressive MS** is characterized by a gradual but steady progression of disability from the onset, with no obvious plateaus or remissions, or only occasional plateaus and minor, temporary improvements.
- **Secondary-progressive MS** begins initially with a relapsing-remitting course that later evolves into a more consistently progressive course, with or without relapses.
- **Progressive-relapsing MS** shows a steady progression in disability from the onset of the disease, but with clear, acute relapses (attacks) that may or may not have some recovery following the acute episode.

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symptoms a person will experience, or how the MS will progress over time. In addition, remissions can occur at any time over the course of the illness, and last anywhere from months to years. This unpredictability can make life very difficult, particularly in terms of planning for the distant and not-so-distant future. A good strategy for dealing with the

future seems to involve educating yourself about the possible changes brought on by MS, working with your doctor and other health care professionals to manage your symptoms as comfortably and effectively as possible, communicating openly with family members whose daily lives will also be touched by this disease, and 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." A future volume of this series will talk about various aspects of life with MS and provide suggestions for meeting the challenges ahead.

Treatments

We have entered into an exciting new era in MS care. While there is no known cure for MS, there are a variety of treatments that help to manage symptoms, as well as several new medications that have been shown to be effective in altering the progression of the disease. With the help of your doctor, 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 the volume on treatments in MS.

Research

Large-scale studies (clinical trials) of potential treatments for MS 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 remit over time, it takes a fairly large, lengthy, and carefully controlled investigation 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 interventions have been held out as "cures" for MS. Obviously, none of them has stood up to the rigors of

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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. Individuals with MS are invited and encouraged to participate in clinical trials so that these important answers can be found. Information about current and future trials is available from the National MS Society.

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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 in this segment 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.
- It is very important that you learn about your MS, not everyone else's.

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For additional information contact your National Multiple Sclerosis Society chapter by dialing 1-800-FIGHT MS (1-800-344-4867).