LIVING WELL
A GUIDE TO MANAGING MULTIPLE SCLEROSIS
FOR PATIENTS AND FAMILIES

Featuring Teri Garr
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INTRODUCTION

The first reaction many people have when they learn that they or a loved one has multiple sclerosis (MS) is: “What’s that?” In part, that’s because the word “sclerosis” is unfamiliar. Sclerosis means scar. So multiple sclerosis means many scars. But the scars of MS are invisible. In this disease, the scars form in the nervous system.

Another reason few people know about MS before they or a loved one is diagnosed is that it is not very common. Even though about 400,000 Americans have MS, and roughly 200 people in the US are diagnosed with MS every week, most people don’t know somebody who has it. As you will learn in this booklet and program, the MS community is large and very supportive. But at first it can feel strange to be told you have MS.

This booklet and DVD will explain what MS is and offer suggestions that may help you manage the disease. But right at the start, you should know these key facts:

- Although MS is a long-term and serious condition, many people live full, successful, and satisfying lives with the disorder. MS does not have to change who you are
- Everyone’s MS is different—no one can predict exactly what yours will be like
- Most people with MS have a normal or near-normal life span
- MS is not contagious
- Most people with MS do not become severely physically disabled
- Most people with MS remain able to walk, but some may require a cane or other assistive device
- Medicines today can slow the rate at which MS progresses. They can also reduce the symptoms you experience

As you are about to learn, there are many ways you can make your experience of MS more manageable and successful. The choices you make can make a big difference!

It’s something that you have—
but it doesn’t have you.

—Teri Garr
WHY ME?

It’s normal for anybody with a serious disease to wonder why they have it and others don’t. With MS, the answer is unclear. MS has been called “one of the great unsolved mysteries of modern medicine.” Genetic factors may make some people more likely to get MS, but MS is not directly inherited. There is no “MS gene” as there is for some other disorders, such as Huntington’s disease.

There are patterns in who develops MS, but they suggest only clues, not answers. For example:

- Women are twice as likely as men to develop MS
- MS is more common among whites than those of African, Asian, and Hispanic descent
- MS is less common in hot, sunny regions near the equator
- Early exposure to some types of viruses or other infections has been linked to MS, though the evidence is mixed
Although the origins of MS remain elusive, a great deal is known about the disease itself. It is thought that symptoms of MS are caused when the body’s immune system begins to attack nerves in the brain and spinal cord. Nerves are like wires carrying information from your senses to your brain, as well as from your brain out to your body. Most nerve fibers are covered with a fatty layer called myelin. Myelin acts like insulation around the nerves. It allows signals to pass rapidly from one nerve to another.

In MS, your immune system malfunctions and attacks the myelin. This weakens or blocks the signals. The symptoms you feel depend on which nerves are affected. If the nerves to your eyes are attacked, you may get blurred vision or lose your sight temporarily. If the nerves control your legs, you may have difficulty walking.

Fortunately, myelin has some natural ability to regrow. But when myelin is permanently eroded, the nerve fibers can be damaged or severed altogether. These areas of damage show up on magnetic resonance imaging (MRI) scans as spots called lesions. By taking multiple scans over time, doctors can track the progress of the disease.

**DID YOU KNOW?**

Neurologists are medical doctors who specialize in disorders of the brain and nerves. They are the specialists who most often treat people with multiple sclerosis.

**SIGNS OF MS**

MS causes a wide range of symptoms, sensations, and/or signs. For many patients, these symptoms come and go. Most people experience their first symptoms of MS between the ages of 20 and 40. Initial symptoms are often eye-related, such as blurred or double vision, red-green color distortion, or decreased vision in one eye. Some MS patients experience muscle weakness in their hands and feet, as well as difficulty with coordination and balance. Before a person is diagnosed, these signs and symptoms can seem mysterious or worrisome.

Here are some other potential signs and symptoms of MS:

- Tiredness or fatigue
- Numbness, prickling, or “pins and needles” sensations
- Muscle stiffness
- Bladder problems
- Depressed mood
- Problems with walking
HOW IS MS DIAGNOSED?

Symptoms of MS mimic those of many other types of disorders. That’s why the disease is usually diagnosed by ruling out other conditions. A neurologist (a doctor who specializes in the brain and nervous system) may do a series of tests to determine whether you have MS:

- Tests of your nerve function in different parts of your body (such as reflexes and sensitivity to touch)
- An eye examination for signs such as abnormal pupil responses or changes in the way the eye moves
- Magnetic resonance imaging (MRI) of the brain or spinal cord to look for the scars (lesions) of MS
- A spinal tap (lumbar puncture) to see if there is evidence of abnormal immune activity in the spinal fluid

Diagnosing MS can take some time, which may be frustrating. But it’s vital that the diagnosis is correct!
FORMS OF MS

MS has many forms and “looks” very different from one person to another. People feel symptoms in different parts of their bodies and at different levels of severity. Despite the unpredictability of MS, the disease progresses in one of four general patterns.

Relapsing-remitting. This is the most common type of MS. About 85% of people with MS have this form when they are initially diagnosed. People with this type of MS have times when their symptoms rapidly get worse. During relapses, immune system activity causes inflammation of the affected nerve fibers. These episodes are called “relapses,” “attacks,” or “exacerbations.” Treatments aimed at reducing inflammation, therefore, can be effective in quelling attacks. People with this form of MS experience a period of partial or complete recovery (remission) between attacks.

Primary-progressive. People with this type of MS experience a slow but continuous worsening of their disease from the onset, with no distinct relapses or remissions. This type is relatively rare: Only about 1 in 10 people with MS have the primary-progressive form. Primary-progressive MS involves much less inflammation than is common in relapsing-remitting MS. People with primary-progressive MS also tend to have fewer brain lesions than people with relapsing-remitting MS. Nonetheless, primary-progressive MS is considered to be the most serious type.

Secondary-progressive. People with this form typically have an initial period of relapsing-remitting MS, followed by a steady worsening with or without relapses. Before medicines were developed specifically for MS, about half of those with relapsing-remitting MS progressed to this form of the disease within 10 years of diagnosis.

It’s important to educate yourself about the disease—because everyone is affected differently.

—Teri Garr
**Progressive-relapsing.** Fewer than 1 in 20 people with MS have this form, which combines aspects of relapsing-remitting and primary-progressive. People with this type have a steady worsening of symptoms but also have clear relapses with or without recovery. In contrast to relapsing-remitting MS, the disease continues to get worse in the periods between relapses.

The term *clinically isolated syndrome* is used when a person who has not been previously diagnosed with MS experiences an initial symptom or attack that appears likely to be caused by MS and which puts the person at a high risk for being subsequently diagnosed.

**HOW IS MS TREATED?**

Many medicines are available today to help people with MS. Some medicines work directly to slow the progression of the disease and reduce the number and severity of relapses. Other types of medicines can be very helpful for dealing with some of the symptoms of MS, such as fatigue or mood difficulties.

A number of medicines are currently approved by the FDA for treating various forms of MS. These are called *disease-modifying therapies*. They have been shown to reduce the frequency and severity of clinical attacks (relapses) and to reduce the accumulation of lesions (damaged or active disease areas) within the brain and spinal cord. At this time, there are no FDA-approved medications for primary-progressive MS.

New treatments for MS that can be taken orally are emerging. It’s important that you speak to your neurologist about what treatment, now or in the future, is right for you.

You should tell your doctor if you are using an MS medication and you become pregnant, are breastfeeding, or are planning to become pregnant.
Approved treatments include disease-modifying therapies that are either injectable—administered by yourself or by someone at home—or must be given via a slow infusion into the blood, which is done in a health facility.

The American Academy of Neurology recommends that treatment with one of the injectable medicines be considered as quickly as possible.

Disease-modifying therapies need to be taken on a long-term basis. They are the best defense currently available to slow down the natural course of MS. They may not make you feel any better, but they are likely to keep you from getting worse. Taking a disease-modifying medicine may be an investment in your future health.

Your neurologist will work with you to find the medicine that is best for you.

PHYSICAL THERAPY

An important aspect of any MS treatment is physical therapy (PT). Because MS can affect your ability to move around, PT may be of great benefit. It isn’t a cure-all, but PT can lessen some of the symptoms of MS, such as weakness or problems with balance. In PT, you’ll learn about movement techniques, strategies, and equipment that can make daily tasks easier or safer. A physical therapist can teach you exercises to strengthen and loosen your muscles. You can do many of these exercises at home. The goal is to improve your independence and quality of life by relieving pain and improving movement and overall function.

Physical therapy can help with:

- Fatigue
- Pain
- Balance problems
- Immobility
- Lack of coordination
- Weakness

Talk to your health care provider about PT. Many hospitals offer PT services, though you may need to get an order from your doctor or neurologist to see a physical therapist.
TREATING OTHER MS SYMPTOMS

Many medicines can help people with MS deal effectively with symptoms of the disease. Steroids, for example, can reduce the duration and severity of attacks in some patients. Muscle relaxants and tranquilizers can reduce muscle spasms or stiffness. Antidepressant medicines may improve your mood. Many different medicines are available in each of these categories. Talk to your neurologist. He or she will help you find the medicines that are best for you.

ALTERNATIVE AND COMPLEMENTARY THERAPIES

Many people with MS try some kind of alternative or complementary therapy in their efforts to cope with the disease.

To date, no alternative or complementary therapy has been shown to slow the progression of MS. However, many people find that alternative or complementary therapies help them reduce stress and feel better.

Before deciding to pursue one of these therapies, investigate all potential risks, benefits, and costs, and discuss them with your neurologist.
LIFE WITH MS

As stated earlier, people with MS can expect to live as long, or nearly as long, as anybody else. That means you need to take care of yourself just as you would if you didn’t have MS.

By actively engaging in healthy behaviors, you can not only reduce your MS symptoms, but you can also improve your health, overall functioning, and mood. Here are some important things to focus on:

Avoid heat. Heat doesn’t make MS worse permanently, but many people with MS find that hot, humid weather, a hot bath or shower, or a fever temporarily makes their symptoms worse. Avoid midday heat, bathe in warm rather than hot water, and use ice packs, iced drinks, and cool baths to reduce your symptoms.

Eat a healthy diet. The recommended diet for people with MS is the same one recommended for all adults. That means plenty of vegetables and fruits, whole grains, high-fiber foods, cutting back on fat, and avoiding drinks and foods with added sugar. Special or fad diets have not been shown to impact the disease’s course. Your health care professional can help you determine a balanced diet that fits your needs.

Stop smoking. If you smoke, stop now. Although no specific link has been identified, recent studies have suggested that smokers are more likely to develop MS than nonsmokers, and smoking may make MS get worse faster.

Exercise. Exercise alone cannot alter MS, but it can improve your overall health and may prevent many complications that stem from inactivity. Exercise can also improve your sleep, mood, and general functioning. Always talk to your health care professional before starting an exercise program.

Exercise is very important, to keep moving as much as you can. Because you know what they say: If you don’t use it, you lose it!

—Teri Garr
Reduce stress. There is no clear evidence that stress makes MS worse, but nobody feels good when they’re stressed out. Learning ways to relax, accept what can’t be changed, set life priorities, and simplify life can be very helpful.

Connect with others. A wide range of groups exists for people with MS, both “live” and online. These can provide invaluable emotional support, social contacts, and helpful information (see the Resources section at the end of this booklet for places to find such groups). It’s also important to talk to your immediate family members. You can tell others about your condition when that feels comfortable for you—but there is no reason to feel ashamed that you have MS. You may be surprised at how supportive and encouraging others are when you tell them about your condition.

Get enough sleep. MS symptoms can make it hard to sleep. Ringing in the ears, needing to get up frequently to go to the bathroom, and having “restless legs” can all make getting a good night’s sleep difficult. Fortunately, there are a range of approaches that can improve sleep and reduce nighttime waking, including:

- Pain medicines
- Sleep medicines
- Regular aerobic exercise
- Avoiding caffeine
- Hypnosis
- Guided imagery
THINGS TO KEEP IN MIND

Being diagnosed with MS is a life-changing experience, but it doesn’t need to be life-diminishing. MS is serious, but there are many things you can do to make your experience with MS more manageable. You have time to think about things and talk with your health care professional before making decisions about treatments or lifestyle changes.

Remember: You are more than your MS! You’re still the same person you were before you were diagnosed, and because people with MS usually live as long as anybody else, you have to think long term and take care of yourself.

By reading this booklet and watching the DVD, you’ve already taken a key step: learning about MS. You’ve seen that you’re not alone, that there is hope, and that there are many things you can do to live an active, satisfying life despite this chronic disease.

RESOURCES

American Academy of Neurology
American Academy of Neurology Foundation
www.aan.com
800-879-1960

Neurology Now® Magazine
Free magazine for patients and caregivers, courtesy of the American Academy of Neurology.
www.neurologynow.com

National Multiple Sclerosis Society
Information available on a variety of topics relating to life with MS.
www.nationalMSSociety.org
800-344-4867

MS World
An online information and support site for people with MS, including chat rooms and bulletin boards.
www.msworld.org

MyMSMyWay
Resource for connecting people with multiple sclerosis to accessible technologies.
www.MyMSMyWay.com

Can Do Multiple Sclerosis
A nonprofit organization that offers MS programs based on the philosophy that people can have a chronic disease and also maintain their health.
www.mscando.org
800-367-3101
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American Academy of Neurology

The American Academy of Neurology (AAN), established in 1948, is an international professional association of more than 22,000 neurologists and neuroscience professionals dedicated to promoting the highest quality patient-centered neurologic care. A neurologist is a doctor with specialized training in diagnosing, treating, and managing disorders of the brain and nervous system, such as multiple sclerosis, Alzheimer’s disease, epilepsy, stroke, and Parkinson’s disease. For more information, visit www.aan.com.

American Academy of Neurology Foundation

The American Academy of Neurology Foundation (AAN Foundation) raises money to support vital research into the prevention, treatment, and cure of brain disorders, such as multiple sclerosis. The AAN Foundation is committed to improving patient care, quality of life, and public understanding of the brain and other neurologic disorders. For more information or to make a donation to the American Academy of Neurology Foundation, visit www.buyabrain.org.

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Being diagnosed with multiple sclerosis (MS) is a life-changing experience, but it doesn’t need to be life-diminishing. Today, MS is treatable with medicines and other types of therapies. That’s good news for the roughly 400,000 Americans who have MS.

MS takes many forms. Everyone’s MS is different, and no one can predict exactly what yours will be like. But the bottom line is that you are more than your MS. You’re still the same person you were before you were diagnosed. You have time to think about things and talk to other people and your health care providers before making decisions about treatments or lifestyle changes.

This booklet and DVD are a great way to start handling MS. By learning about MS, you’ll also learn that there is real hope. There are many things you can do to live an active, satisfying life despite this chronic disease.