MULTIPLE SCLEROSIS

A GUIDE FOR PATIENTS, FAMILIES, AND CAREGIVERS

Featuring Danelle D’Aquanni Umstead
Alpine Ski Racer with Multiple Sclerosis
The enclosed 28-minute DVD, *Multiple Sclerosis: A Guide for Patients, Families, and Caregivers* includes expert commentary from neurologists Drs. Fred D. Lublin and Dr. Aaron E. Miller. Three of their patients with MS are profiled, together with the MS story of award-winning Alpine ski racer Danelle D’Aquanni Umstead.

This video may also be viewed on the American Academy of Neurology’s YouTube channel.
INTRODUCTION

Learning you have been diagnosed with multiple sclerosis (MS) can be difficult, even overwhelming. So it’s important to keep a few key ideas in mind right from the start:

• **You are not alone**—many people have coped successfully with this condition, and many caring professionals are standing by to help. About 400,000 Americans now have MS, and every week about 200 people are newly diagnosed.

• **There is hope**—medicines today can help reduce disease activity of MS.

• **Take a breath**—you don’t have to learn everything today! Take time to read, think, and talk.

• **It’s OK to ask questions**—even *lots* of questions! Your neurologist and other health care providers with specialized training in neurology want to help, and they want you to understand as much as you can.

Everyone’s MS experience is different: no one can predict exactly what yours will be. Most people with MS have a normal or near-normal life span. Most people with MS remain able to walk, although they may require a cane or other assistive device. It’s important to know that treating MS early may help to reduce relapses and slow the accumulation of disability.

This booklet and DVD are a great way to start learning about MS—and what *you* can do to live an active, satisfying life despite this chronic disease.

About 400,000 Americans now have MS, and every week about 200 people are newly diagnosed.
WHAT IS MS?

MS is a chronic disorder of the central nervous system. This means it affects the nerves in the brain and spinal cord. To understand what happens in MS, you need to know a little about your nerves. Nerves are like wires carrying information between cells in your brain and spinal cord. To work well, the major “cable” of a neuron, called the axon, is insulated with a fatty layer called myelin. Myelin allows nerve signals to pass rapidly from one nerve to the next.

In people with MS, the body’s immune system begins to attack the myelin of the nerves. This weakens or blocks the signals. The symptoms you feel depend on which nerves are affected. If the nerves involved in vision are attacked, things may look blurry, or you may lose sight temporarily. If the nerves that control your legs are attacked, you may have difficulty walking.

Sometimes damaged myelin can recover. This is why some people with MS have symptoms that come and go. But, over time, nerve fibers themselves can be damaged. This may lead to a gradual decline in function.
WHAT CAUSES MS?

Scientists still do not know exactly what triggers MS. 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.

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

- MS affects women much more than men: roughly 4 women have MS for every 1 man who has MS.
- MS is more common among whites than those of African, Asian, and Hispanic backgrounds.
- Smoking is a clear risk factor. Smoking is associated with more rapid disease progression, while quitting smoking lowers the risk.
- Early exposure to some types of viruses or other infections has been linked to MS, though the evidence is mixed.

SIGNS AND SYMPTOMS 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 pain when the eyes are moved, dimmed vision, or distortion of colors. 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
- Problems thinking clearly, or being able to concentrate and remember things
- Bladder problems
- Problems with walking
- Depressed mood

DID YOU KNOW?

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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 may do a series of tests to determine if you have MS:

• Tests of the 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 signs of increased immune system activity are present in the spinal fluid

Sometimes diagnosing MS can be frustrating, because it may take a long time. But that time may be needed to obtain a correct diagnosis.

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.
MS has several forms and appears differently from one person to another. People have symptoms in different parts of their bodies, and at different levels of severity. There are three general patterns of MS:

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 suddenly get worse. These times are called “relapses,” but may also be called “attacks” or “exacerbations.” During relapses, immune system activity causes inflammation of the affected nerve fibers. Treatments aimed at reducing inflammation may be effective in suppressing relapses. People with this form of MS experience a period of partial or complete recovery (remission) between relapses.

Primary-progressive. People with this type of MS experience a steady worsening of their disease from the start, with no distinct flare-ups or remissions. This type is relatively uncommon: only about 1 in 10 people with MS have this form. Primary-progressive MS involves much less inflammation than usually occurs in relapsing-remitting MS. Although people with this type of MS tend to have fewer areas of actual damage in the brain than people with relapsing MS, this form of MS is considered to be the most serious type. Sometimes people with primary-progressive MS also have relapses. This used to be called “progressive-relapsing MS,” but it is now called “primary-progressive MS with activity.”

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.

Another term you may hear is “clinically isolated syndrome.” This refers to an initial symptom, or attack, in a person not previously diagnosed with MS. Having clinically isolated syndrome puts you at risk for being diagnosed later with MS.
HOW IS MS TREATED?

Today, there are many medical options to help people with MS. Some medicines work directly to slow the progression of the disease, and to reduce the number and severity of relapses. It’s important to understand that treating MS early may delay the onset of symptoms and reduce symptom severity. In addition, neurologists may use a variety of treatments to help patients with some of the symptoms related to their MS.

Many medicines are currently FDA-approved for treating relapsing-remitting forms of MS. These are called disease-modifying therapies (DMTs). As a class, they have been shown to reduce clinical attacks, reduce the risk of further disability, and to reduce the extent of new lesions in the brain and spinal cord. These medicines are taken in various ways:

- Oral therapies (pills or capsules)
- Injections
- Intravenous (IV) infusions

Disease-modifying therapies need to be taken on a long-term basis. They offer the best chance for slowing the natural course of MS. Even though disease-modifying therapies may not make you feel better right away, they can be looked upon as an investment in your future.

Your neurologist will work with you to find the medicine that is best for you. Each person’s body or disease can respond to these medicines in different ways. Women who are pregnant, or who want to have a child, and men who wish to father a child, should talk to their health care provider about family planning decisions related to their treatment.

DID YOU KNOW?
When considering therapy, remember that your therapy won’t work if you don’t take it as prescribed!
STARTING OR CHANGING MS THERAPY

When you are considering your options for treating MS, or changing an existing treatment, you’ll need to consider the following:

- The possible benefits and side effects of a medicine
- Dosing and administration of the medicine
- What other medical conditions you have
- Cost

Talk to your neurologist if you have any concerns about sticking to your treatment plan, how your medicine is working, or about any side effects you may be having.

TREATING OTHER SYMPTOMS

Many kinds of medicines and therapies can help you deal effectively with your symptoms, or the side effects of your medicines. For example, some medicines may help reduce muscle spasms or stiffness. Other medicines may help improve a depressed mood or boost energy. Physical therapy may help improve strength or balance. Your neurologist and other health care providers can help you decide if any of these medicines or therapies might be helpful for you.

DID YOU KNOW?
If you use an MS medication, be sure to tell your neurologist if you become pregnant, are breastfeeding, or are planning to become pregnant.
By actively engaging in healthy behaviors, you may be able to reduce your MS symptoms and improve your overall health and mood. Here are some important things to focus on:

**Stop smoking.** If you smoke, talk to your neurologist or other health care providers about quitting. 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.

**Avoid heat.** Many people with MS find that hot, humid weather, a hot bath or shower, or a fever temporarily makes their symptoms worse. However, heat does not affect everyone with MS in the same way. If heat seems to be a trigger for you, 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 grain, high fiber foods, cutting back on fat, and avoiding drinks and foods with added sugar. No specific types of foods have been proven to affect MS one way or the other. Your neurologist or other health care providers can help you create a balanced diet that fits your needs. There is no specific “MS diet.”

**Exercise.** Exercise alone cannot alter MS, but it can improve your overall health and may prevent problems related to being inactive. Exercise can also improve your sleep, mood, and overall level of fitness. Always talk to your health care provider before starting an exercise program.

**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 find ways to simplify life can be very helpful.

**Get enough sleep.** MS symptoms can make this challenging! Muscle stiffness or needing to get up frequently to go to the bathroom can make getting a good night’s sleep difficult. Fortunately, there are a range of approaches that can improve sleep and reduce nighttime waking, including:

- Avoiding caffeine
- Regular exercise
- Pain medicines
- Sleep medicines

**Connect with others.** There is a wide range of groups for people with MS, both “live” and online. These may provide emotional support, social contacts, and helpful information (see the Resources section later in this booklet for information on finding support groups). You can wait to share that you have MS until it feels comfortable. You may be surprised at how supportive and encouraging others are when you tell them about your condition.
TIPS FOR CAREGIVERS

People with MS may need some help with everyday tasks. They may need more help as the disease gets worse. Spouses and other family members or friends often provide this help. But caring for a person with MS can be tiring or stressful. Caregivers should talk to others about any frustrations they are experiencing. Talk to friends or family members, or join a support group for caregivers. (Use the Resources section to find a support group in your area.)

Caregivers also need to take care of themselves, and make sure their own needs are being met. You don’t want to “burn out” or develop your own physical or emotional problems! You need to stay healthy, so you can best care for a loved one with MS.

Watch for signs of depression, confusion, memory problems, or other mental problems in the person with MS. Report any concerns promptly to your loved one’s neurologist or other health care providers, to determine the best way to help the person with MS. The sooner a problem is identified, the better.
THINGS TO KEEP IN MIND

It can take time to adjust to learning you have a long-term condition like MS. Remember, you don’t have to do everything at once! You have time to think about your situation and talk with others—including your neurologist and other health care providers—before making decisions about treatments or lifestyle changes.

Also, remember that you are more than your MS! You’re still the same person you were before you were diagnosed—you just have more to handle now. By reading this booklet and watching the DVD, you’ve taken an important step: learning about MS and the many things you can do to manage this disease.

RESOURCES

American Academy of Neurology
AAN.com

American Brain Foundation
AmericanBrainFoundation.org

Accelerated Cure Project for Multiple Sclerosis
AcceleratedCure.org

Can Do Multiple Sclerosis
Mscando.org

Neurology Now™ Books
“Navigating Life with Multiple Sclerosis”
AAN.com/view/NeurologyNowBooks

Neurology Now® Magazine
NeurologyNow.com

Multiple Sclerosis Association of America
MSAssociation.org

Multiple Sclerosis Foundation
MSFocus.org

National MS Society
NationalMSSociety.org
Try to be as open and honest as possible with your neurologist. Tell him or her about any physical or emotional issues you might be dealing with. It’s also OK to ask questions—even lots of questions! Your neurologist and other health care providers want to help.

And if you or a loved one does not speak English, or are not comfortable with English, ask if an interpreter is available.

Here are some questions you might want to ask during a visit. It’s important to write down questions in advance, and note the answers. Make notes about any information the neurologist and other health care providers give you, as well.

1. Once multiple sclerosis has been diagnosed, what types of tests might I need to have on a regular basis?

2. What type of MS do I have?

3. How severe is my current condition?

4. What is the usual prognosis for people who have this type of MS?

5. How do you expect my condition to progress?

6. How might MS affect my daily life?

7. What type of treatment do you recommend?

8. Why do you recommend this particular course of treatment?

9. Should I seek a second opinion? Why or why not?
10. **Might lifestyle changes, such as diet and exercise, help slow or stop the progression of my multiple sclerosis? If so, what changes do you recommend?**

11. **What support resources are available to help me change my lifestyle?**

12. **What are the benefits, risks, and possible side effects from my medications?**

13. **What should I do if I experience side effects?**

14. **About how long might it take for my MS treatments to begin working?**

15. **How will my condition be monitored? Are there any warning signs I should look for?**

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**SELECTED REFERENCES**


National Multiple Sclerosis Society. The MS Disease-Modifying Medications, General Information. 2014.


American Academy of Neurology

The American Academy of Neurology (AAN), established in 1948, is an international professional association of more than 28,000 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, AAN.com.

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Credits

Multiple Sclerosis: A Guide for Patients, Families, and Caregivers was made possible through the expertise, time, and efforts of many contributors. Special gratitude to:

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...and the three patients with MS who so generously share their personal stories.
Multiple sclerosis (MS) is a long-term disease of the nervous system. Treatments available today may help slow the progression of MS, and reduce relapses you may experience. Your neurologist, and other health care providers with specialized training in neurology, may prescribe other treatments or therapies to treat your symptoms or any side effects you might have. That’s good news for the roughly 400,000 Americans who have MS.

Everyone’s MS experience is different, and no one can predict exactly what yours will be. But you don’t have to make any quick decisions. You have time to think about your situation and talk with others—including your neurologist and other health care providers—before making decisions about treatments or lifestyle changes.

This booklet and DVD are a great way to start! By learning more, you’re in a stronger position to make good choices about treatment and lifestyle changes that can help manage your MS, and improve your overall health.