



## **Just the Facts**

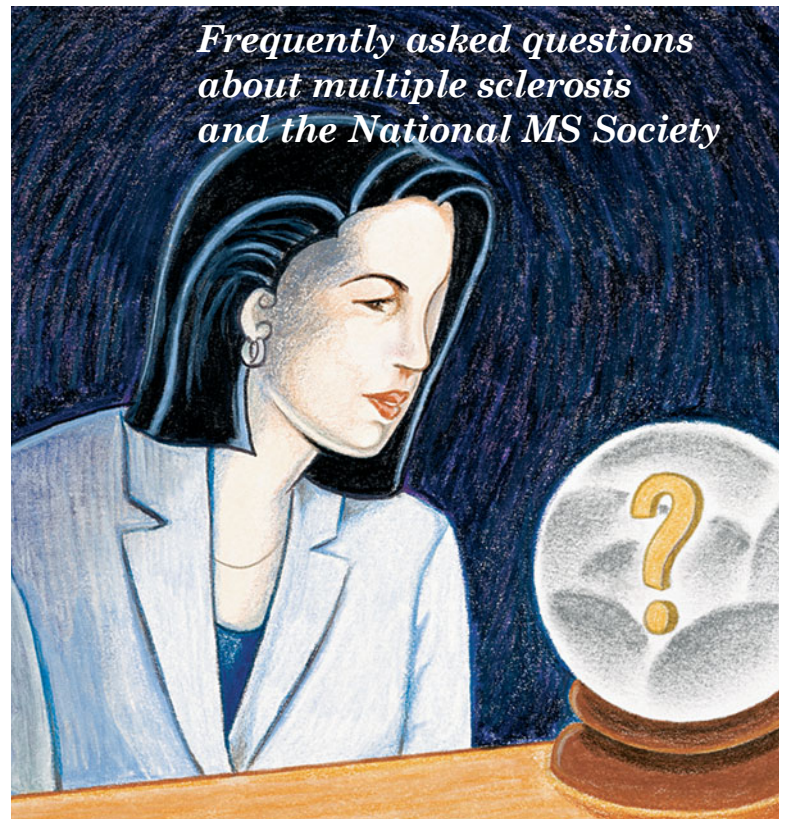
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**2005-2006**

**The National Multiple Sclerosis Society is dedicated to ending the devastating effects of multiple sclerosis.**



**National Multiple  
Sclerosis Society**

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*Frequently asked questions  
about multiple sclerosis  
and the National MS Society*

## I. MS FACTS

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### What is multiple sclerosis?

Multiple sclerosis is a chronic, unpredictable disease of the central nervous system (the brain, optic nerves, and spinal cord). It is thought to be an autoimmune disorder. This means the immune system incorrectly attacks the person's healthy tissue.

MS can cause blurred vision, loss of balance, poor coordination, slurred speech, tremors, numbness, extreme fatigue, problems with memory and concentration, paralysis, and blindness. These problems may be permanent, or they may come and go.

Most people are diagnosed between the ages of 20 and 50, although individuals as young as 2 and as old as 75 have developed it. MS is not considered a fatal disease as the vast majority of people with it live a normal life-span. But they may face a struggle to live productively, often with increasing limitations.

### Who gets MS?

Anyone may develop MS but there are some patterns. Twice as many

women as men have MS. Studies suggest that genetic factors make certain individuals more susceptible than others, but there is no evidence that MS is directly inherited. It occurs more commonly among people with northern European ancestry, but people of African, Asian, and Hispanic backgrounds are not immune.

### How many people have MS?

Approximately 400,000 Americans have MS, and every week about 200 people are diagnosed. Worldwide, MS affects about 2.5 million people. Because the Centers for Disease Control and Prevention (CDC) does not require U.S. physicians to report new cases, and because symptoms can be completely invisible, the numbers can only be estimated.

### What are the typical symptoms of MS?

Symptoms of MS are unpredictable, vary from person to person, and from time to time in the same person. For example: One person may experience abnormal fatigue and episodes of numbness and tingling. Another could have loss of balance

and muscle coordination making walking difficult. Still another could have slurred speech, tremors, stiffness, and bladder problems.

Sometimes major symptoms disappear completely, and the person regains lost functions. In severe MS, people have symptoms on a permanent basis including partial or complete paralysis, and difficulties with vision, cognition, speech, and elimination.

## **What causes the symptoms?**

MS symptoms result when an immune-system attack affects myelin, the protective insulation surrounding nerve fibers of the central nervous system (the brain and spinal cord). Myelin is destroyed and replaced by scars of hardened “sclerotic” tissue. Some underlying nerve fibers are permanently severed. The damage appears in multiple places within the central nervous system.

Myelin is often compared to insulating material around an electrical wire; loss of myelin interferes with the transmission of nerve signals.

## **Is MS fatal?**

In rare cases MS is so malignantly progressive it is terminal, but most people with MS have a normal or near-normal life expectancy. Severe MS can shorten life.

## **Does MS always cause paralysis?**

No. Moreover, the majority of people with MS do not become severely disabled. Two-thirds of people who have MS remain able to walk, though many will need an aid, such as a cane or crutches, and some will use a scooter or wheelchair, because of fatigue, weakness, or balance problems.

## **Is MS contagious or inherited?**

No. MS is not contagious and is not directly inherited. Studies do indicate that genetic factors may make certain individuals susceptible to the disease.

## **Can MS be cured?**

Not yet. There are now FDA-approved medications that have been shown to “modify” or slow

down the underlying course of MS. In addition, many therapeutic and technological advances are helping people manage symptoms. Advances in treating and understanding MS are made every year, and progress in research to find a cure is very encouraging.

## **What medications and treatments are available?**

The National Multiple Sclerosis Society recommends treatment with one of the FDA-approved “disease-modifying” drugs as soon as possible following a definite diagnosis of MS with active disease. These drugs help to lessen the frequency and severity of MS attacks, reduce the accumulation of lesions (areas of damage) in the brain, and may slow the progression of disability.

The FDA has also approved a disease-modifying drug for reducing disability and/or the frequency of attacks in patients with secondary-progressive, progressive-relapsing or worsening relapsing-remitting MS. This drug is a chemotherapeutic agent. The lifetime dose is limited to prevent heart damage.

In addition to drugs that address the basic disease, there are many therapies for MS symptoms such as spasticity, pain, bladder problems, fatigue, sexual dysfunction, weakness, and cognitive problems. People should consult a knowledgeable physician to develop a comprehensive approach to managing their MS.

## **Why is MS so difficult to diagnose?**

In early MS, symptoms that might indicate any number of possible disorders come and go. Some people have symptoms that are very difficult for physicians to interpret, and these people must “wait and see.” While no single laboratory test is yet available to prove or rule out MS, magnetic resonance imaging (MRI) is a great help in reaching a definitive diagnosis.

## **What are the different types of MS?**

In an effort to develop a common language for evaluating and researching MS, an international survey was conducted among scien-

tists who specialize in MS research and patient care. Analysis of responses resulted in defining the following categories, which were introduced in 1996.

**1 Relapsing-Remitting**

Characteristics: People with this type of MS experience clearly defined flare-ups (also called relapses, attacks, or exacerbations). These are episodes of acute worsening of neurologic function. They are followed by partial or complete recovery periods (remissions) free of disease progression.

Frequency: The most common form of MS at time of initial diagnosis. Approximately 85%.

**2 Primary-Progressive**

Characteristics: People with this type of MS experience a slow but nearly continuous worsening of their disease from the onset, with no distinct relapses or remissions. However, there are variations in rates of progression over time, occasional plateaus, and temporary minor improvements.

Frequency: Relatively rare. Approximately 10%.

**3 Secondary-Progressive**

Characteristics: People with this type of MS experience an initial period of relapsing-remitting MS, followed by a steadily worsening disease course with or without occasional flare-ups, minor recoveries (remissions), or plateaus.

Frequency: 50% of people with relapsing-remitting MS developed this form of the disease within 10 years of their initial diagnosis, before introduction of the “disease-modifying” drugs. Long-term data are not yet available to demonstrate if this is significantly delayed by treatment.

**4 Progressive-Relapsing**

Characteristics: People with this type of MS experience a steadily worsening disease from the onset but also have clear acute relapses (attacks or exacerbations), with or without recovery. In contrast to relapsing-remitting MS, the periods *between* relapses are characterized by continuing disease progression.

Frequency: Relatively rare. Approximately 5%.

# NATIONAL MS SOCIETY FACTS

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## What is special about the National MS Society?

The mission of the National Multiple Sclerosis Society is to end the devastating effects of MS.

We do this through the research we support to find the cause, cure, and improved treatments of the disease; the services we provide to people with MS and their families; the professional education programs we offer to health-care providers; and our advocacy efforts to encourage public policies supportive of the needs of people with multiple sclerosis. This is why the National MS Society is here.

The National MS Society meets all the standards of the agencies that rate not-for-profit groups in the United States.

## How many people does the Society serve?

Through the Society's fifty-state network of chapters, assistance is provided to over a million people

annually, including people with MS, their family members, employers, and caregivers.

## How many people support the Society?

An estimated two million people contribute funds, time and expertise to carry out our mission to end the devastating effects of MS. Over 400,000 volunteers contribute to leadership, fund raising, advocacy, client programs, or clinical services for chapter and national programs.

## How many people are members of the Society?

In 2005, the Society had an estimated 599,000 general members; 351,000 of them indicate that they have MS.

## Are the National MS Society's programs free?

Every chapter offers a free equipment loan closet, a library, an information service, and many opportunities to volunteer. Information about MS and referrals to area health-care professionals and resources, and to chapter-affiliated self-help groups, are free to all. Free and nominal-fee

programs may include education, counseling, and recreational events.

## How do I reach the Society?

Call toll-free, **1-800-FIGHT-MS (1-800-344-4867)** for automatic connection. Direct line telephone numbers can be found in local phone books under Multiple Sclerosis. Our Web site is [nationalmssociety.org](http://nationalmssociety.org).

## How much does it cost the National MS Society to raise a dollar?

It costs the Society approximately 16 cents to raise a dollar. General guidelines for nonprofit organizations require that fund-raising costs not exceed 35% of related contributions, and that total fund-raising and administration costs not exceed 25% of total income. The National Charities Information Bureau requires an organization to spend at least 60% of annual expenses for program activities. The Society more than meets these requirements.

## How does the Society raise funds?

The Society depends on support from members, friends, corporate partners, businesses, religious and civic groups, private and public federated campaigns, and the public at large.

The Society's total support in 2004 was over \$184.5 million. This is a combination of individual gifts, membership dues and contributions, legacies, trusts, and bequests, proceeds from special events, corporate contributions, and investments. Gifts from individuals are made with cash, securities, or other property, and include tributes and memorial gifts. The Society has a charitable gift annuity program. Annuities provide payments to the donor as well as future support for the National MS Society.

The Society receives grants from pharmaceutical companies and other corporations for educational projects, under strict guidelines to ensure impartial content. It leases exhibition space at national meetings and earns revenue from the sale of advertising space in our national magazine, also under strict guidelines.

## Special events

Each National MS Society chapter organizes a variety of special events to raise funds and awareness. The top nationwide events are the MS Bike Tours, and the MS Walk. More than 300,000 people participate each year. Many participants join teams formed at their workplace or by family and friends of people with MS.

### ■ MS 150 BIKE TOUR

The Society's MS 150 Bike Tour and its one-day cycling events comprise the country's largest organized cycling series. Avid or occasional cyclists can choose a suitable ride. There are more than 100 bike rides coast to coast from April through November. Proceeds support MS research and chapter programs for people with MS and their families. For information, call **1-800-FIGHT-MS** or visit [nationalmssociety.org](http://nationalmssociety.org).

### ■ THE MS WALK

Every spring people across the country participate in the MS Walk near them. There are some 600 sites. All walks have an accessible route so people of all

abilities can take part. Funds raised support MS research and chapter programs for people with MS and their families. For information about the nearest MS Walk, call **1-800-FIGHT-MS** or visit [nationalmssociety.org](http://nationalmssociety.org).

## How does the National Multiple Sclerosis Society spend its money?

Approximately 78% of the Society's combined expenses are devoted to research, programs that actively help people with MS and their families, and to public and professional education; 22% is invested in Society management and the expenses of fund raising. Seventy cents of every unrestricted dollar stays in the community where it was raised.

## What do Society expenditures mean to you?

The National Multiple Sclerosis Society spends more money on MS **research** than any other voluntary agency in the world. By the end of 2004, the Society had invested \$420 million in research since it was founded in 1946. This support has

resulted in improved diagnosis, important new treatments, and improved rehabilitation and symptomatic therapy for all forms of MS. The Society supports more than 300 research projects in the U.S. and abroad every year. Research is bringing us closer to a cure.

The Society is equally committed to helping people deal with the strain of MS. While research presses forward, the Society spends money on **programs** to educate, empower, support, and inform people with MS and their families. Society programs address issues from the trauma of diagnosis to maintaining personal productivity, to meeting the challenges of old age with a chronic disabling disease.

The Society is a catalyst for **advocacy** on local, state, or federal public policies that affect people with MS. Through chapter Government Relations committees, the “MS Action Network” on the national Web site, coalitions with like-minded groups, and an annual visit to Washington, D.C., the Society's volunteer advocates are a voice for all Americans affected directly or indirectly by MS.

The Society works to improve medical care for people with MS by improving professional understanding of **clinical issues**. The Society sponsors professional meetings, teleconferences, and accredited continuing medical education courses in collaboration with major medical centers. The Professional Resource Center offers a hotline for health-care personnel. For targeted information, call toll-free: **1-866-MS-TREAT**. Physicians may e-mail [MD\\_info@nmss.org](mailto:MD_info@nmss.org); other health professionals may e-mail [HealthProf\\_info@nmss.org](mailto:HealthProf_info@nmss.org).

Linking all these efforts is a wide-ranging **communications** program, which includes the locally edited chapter newsletters, **MSConnection**; an award-winning national magazine, **InsideMS**; a comprehensive Web site, which includes individual chapter sites. There are professional bulletins, white papers, and other publications for the health-care community; publications for people with MS (including many in Spanish)—and award-winning quarterly newsletters: **Keep S'myelin** for children and **Teen InsideMS** for young adults.

## THE SOCIETY IN PEOPLE TERMS

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***LIFE SITUATION:*** We're very confused. My wife was just diagnosed with MS and we have many unanswered questions.

The National MS Society offers accurate information and empowering programs. “Knowledge is Power”—a free nine-week home study program is a good way to begin. Sign up on our Web site or contact your chapter. Your chapter has a face-to-face educational program specifically for people who have just been diagnosed. They will also send you a packet of literature. If you ask, they will help you find another person with MS to talk to.

***LIFE SITUATION:*** I'm so depressed. I'm at home with a newborn baby and I just had an exacerbation. My symptoms are odd and nobody can explain them. Can you help?

The National MS Society offers referrals to physicians and allied health professionals, MS clinical centers, phone groups, and peer counseling. Chapters have access to

our national Information Resource Center, where specialists research difficult questions. Professionals in MS care can access our Professional Resource Center by e-mail or a toll-free telephone call.

***LIFE SITUATION:*** My MS has worsened and I'm finding it increasingly difficult to get around the office.

The National MS Society offers information about your rights in the workplace, work site consultations, information for employers, and support of guidelines set forth in the Americans with Disabilities Act (ADA).

***LIFE SITUATION:*** I am unable to see an appropriate specialist quickly in my managed care health group.

Legal referrals are available at your chapter. In addition, organized volunteer advocates are working with state and federal legislators to achieve quality health care. You are invited to join.

***LIFE SITUATION:*** I can't cross the street in my neighborhood because there are no curb cuts.

National MS Society volunteers

work to secure accessibility in our communities. Talk to your chapter's Government Relations Committee.

***LIFE SITUATION: My mother is having some memory problems and I'm afraid that she is going to get worse.***

The National MS Society offers reassuring information, self-help groups, and referrals to experts familiar with these problems.

***LIFE SITUATION: Help! My scooter is being repaired and I have no way of getting around until it's fixed.***

The National MS Society offers emergency equipment loans and equipment assistance.

***LIFE SITUATION: I am so tired and my husband doesn't understand that I'm fighting fatigue. He wonders why I don't try harder.***

The National MS Society offers education about MS, referral to family counselors and community resources, and to occupational or physical therapists who may help. Many chapters have family programs that combine recreation and education.

***LIFE SITUATION: I want to start an exercise program but I'm not sure what to do or not do.***

The National MS Society offers referrals to area medical and physical therapy resources. Some chapters sponsor exercise classes and aquatics programs. Others can refer callers to MS-friendly programs.

***LIFE SITUATION: I want to keep up-to-date on advances in MS research and treatments.***

The National MS Society supplies information on the telephone, in chapter newsletters, in brochures and pamphlets, and in the national magazine, **InsideMS**. The Society's Web site is available 24/7. It carries breaking news, background facts, and regular "MS Learn Online" Webcasts, presenting experts who discuss specific topics such as wellness, mobility, or sexuality.

***LIFE SITUATION: My dad is in a wheelchair and the kids at school think that's weird.***

The National MS Society offers family programs that combine education, disability awareness, counseling,

and fun. Some chapters have special programs for children or teens. Our award-winning children's newsletter, **Keep S'myelin** and the exciting new **Teen InsideMS** are available free on our Web site. The children's newsletter is also available in print from chapter offices.

***LIFE SITUATION: My best friend saw an MS cure on the Internet. Why don't you tell people about this?***

We rely on an international board of scientific and medical experts in MS for advice about safe and effective treatments. The home page on our Web site always lists breaking news and your chapter will be able to answer questions.

***LIFE SITUATION: I am in search of an understanding neurologist who knows MS.***

The National MS Society offers physician referrals and information about nearby MS centers and clinics.

***LIFE SITUATION: Sometimes I feel so alone and would like to talk to other people who have MS.***

National MS Society chapters offer more than 1,800 support groups, 250 client education programs, and many family programs every year. Peer counseling and telephone support are available on the spot in most chapters. Just pick up the phone.

The National Multiple Sclerosis Society is proud to be a source of information about multiple sclerosis. Our comments are based on professional advice, published experience, and expert opinion, but do not represent individual therapeutic recommendations or prescription. For specific information and advice, consult your personal physician.

The Society publishes many other pamphlets and articles about various aspects of MS. To ask for these, or for other information, call the National MS Society at 1-800-FIGHT-MS (1-800-344-4867).