

# Just the Facts

2008-2009

GENERAL INFORMATION



# MS Facts

## 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, blindness and more. These problems may be permanent or 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 the unpredictability of the disease can present many challenges, including the possibility of facing increasing limitations.

## Who gets MS?

Anyone may develop MS but there are some patterns. At least two to three times more women than men have been diagnosed with MS. Studies suggest that genetic factors make certain individuals more susceptible than others, but there is no evidence that MS is directly inherited. MS occurs in most ethnic groups, including African-Americans, Asians and Hispanics/Latinos, but is more common in Caucasians of northern European ancestry.

## How many people have MS?

Approximately 400,000 Americans have MS, and every hour someone is newly diagnosed. Worldwide, MS affects about 2.1 million people. 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; they can 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. The majority of people with MS do not become severely physically 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, balance problems, or to assist with conserving energy.

## 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 that people consider treatment with one of the FDA-approved “disease-modifying” drugs as soon as possible following a definite diagnosis of MS with active, relapsing disease. In many instances, starting therapy is

recommended after an initial demyelinating episode (“clinically isolated syndrome”) that places a person at high risk for subsequently developing clinically definite MS. 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 U.S. Food and Drug Administration (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 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 can 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 scientists who specialize in MS research and patient care. Analysis of responses resulted in defining the following categories, which were introduced in 1996:

### 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%.

### 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%.

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

## Progressive-Relapsing

**Characteristics:** People with this type of MS experience a steadily worsening disease from the onset but subsequently 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

The National MS Society is the largest nonprofit organization in the United States supporting research for the treatment, prevention and cure of multiple sclerosis. The Society funds a wide range of research initiatives, drives change through advocacy, facilitates professional education, and collaborates with MS organizations around the world. Through its 50-state network of chapters and the combined efforts of volunteers, donors, researchers and health care professionals, the Society provides significant outreach, education and support to individuals and families who are impacted by the disease.

## How many people does the Society serve?

The Society provides assistance to over a million people every year through partnerships with the health care community, its home office and a fifty-state network of chapters.

## How many volunteers does the MS Society have?

Across the country, more than 480,000 volunteers participate in events and support programs and services and carry out daily operations to help people living with the challenges of MS.

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

Free and nominal-fee programs for people with MS are available in every chapter. These include counseling, self-help groups, help with medical equipment, information about MS and referral to professionals specializing in MS.

The Society's MS Navigator® program offers a partner to every person who lives with the challenges of MS. This free service is available to anyone who calls the Society.

## Where does the Society get its money?

The Society depends on support from members, friends, corporate partners and the public at large. The Society's total revenue in 2008 was \$234 million. This sum is a combination of all revenue including individual gifts; membership dues and contributions; legacies and bequests; special events; corporate contributions and investments. Approximately one percent of the total comes from Federal grants and four percent from pharmaceutical companies in the form of grants and sponsorships.

## How does the Society raise funds?

Each National MS Society chapter organizes a variety of special events and campaigns. Two key fund-raising events for the Society are Bike MS and Walk MS. Key individual giving programs at chapters include Golden Circle, Circle of Distinction and Lawry Circle.

### Bike MS<sup>®</sup>

With more than 100 unique rides across the nation, you can find the ride that's right for you. These fully supported rides not only connect you to more than 100,000 other cyclists, but also to a growing movement to create a world free of MS. Proceeds benefit the Society's national research programs and fund programs that help people with MS and their families. For information about Bike MS, call 1-800-FIGHT-MS (1-800-344-4867) or visit [bikems.org](http://bikems.org).

### Walk MS<sup>®</sup>

Every spring nearly 300,000 people unite across the country to participate in Walk MS. All walks have an accessible route so people of all abilities can participate. Funds raised support the Society's research and services programs. For more information about Walk MS, call 1-800-FIGHT-MS (1-800-344-4867) or visit [walkMS.org](http://walkMS.org).

### Challenge Walk MS<sup>SM</sup>

Accept the challenge to walk 30–50 miles over 2 to 3 days at any of our nine Challenge Walks across the nation. For more information about the Challenge Walk, call 1-800-FIGHT-MS (1-800-344-4867) or visit [challengewalkMS.org](http://challengewalkMS.org).

## Golden Circle and Circle of Distinction

Golden Circle is an annual membership program that engages donors in securing resources to help those living with MS move their lives forward through support for services, advocacy and research. Circle of Distinction honors the leadership of donors giving \$1 million to the Society throughout their lifetime. For information about Golden Circle and Circle of Distinction call 1-800-FIGHT-MS (1-800-344-4867) or visit [www.nationalMSSociety.org/donate/Golden\\_Circle/index.aspx](http://www.nationalMSSociety.org/donate/Golden_Circle/index.aspx).

## Lawry Circle

Lawry Circle recognizes donors who have informed their chapter of their intention to help create a better future for people with MS through a gift from their will, trust or estate plan. These forward thinking people have linked their own legacy with the MS Society mission and have embraced the quest for a world free of MS beyond their lifetime. For information about Lawry Circle and planned giving call 1-800-FIGHT-MS (1-800-344-4867) or visit [www.plan.gs/Home.do?orgId=248](http://www.plan.gs/Home.do?orgId=248).

## How does the National MS Society spend its money?

The Society's nationwide network of chapters is the lifeblood of MS research, providing major support for research programs. No less than half of all the unrestricted income that the chapters share with the national office goes to MS research.

- Approximately 83% of Society income is devoted to research and service programs that enhance the lives of people with MS and their families, while 17% is invested in support services such as fund-raising and Society management.
- It costs the Society approximately 15 cents to raise a dollar.
- At least sixty cents of every dollar stays in the chapter for local program use.

## What do donations to the Society mean to you?

### Research

The National Multiple Sclerosis Society devotes more money on MS research than any other MS organization in the world. Since its founding in 1946, the

Society has allocated more than \$650 million to MS research, a figure that has grown steadily through the years.

In 2004, the Society launched a \$35 million special targeted research campaign, Promise 2010, to fund four special initiatives.

- A nationwide MS database
- An international study to correlate MS lesions to types of disease
- The first collaborative network of MS Pediatric Centers of Excellence for children with MS
- A collaborative research network designed to speed nervous system repair and protection

More recently, the Society launched Fast Forward, a subsidiary aimed at speeding the delivery of new treatments to people with MS. Fast Forward has already made several investments into potentially promising treatments. (Read more at [www.FastForward.org](http://www.FastForward.org)).

These investments in basic and applied MS research have made possible significant advancements towards finding effective treatments and improving diagnosis, rehabilitation, and symptomatic

therapy for people with all forms of MS, as well as bringing us closer to a cure.

## Programs and Services

While the search for a cure continues, the Society helps keep families together despite the challenges of dealing with chronic illness. The Society committed \$148 million in 2008 to client programs to educate, empower, support, and inform people with MS and their families. The Society offers over 60 educational brochures, more than 1,700 support groups, and 3000 programs to over 75,000 participants.

In addition, the home office distributes several publications, including *Momentum*, the Society's lifestyle magazine, and *MSConnection*, a newsletter featuring local news and information. In addition to a monthly national e-news publication, these publications combined are circulated to more than a million individuals.

## Professional Education

Through its clinical programs, the Society offers a full complement of literature and educational training to assist

primary care physicians, neurologists, nurse practitioners and other health professionals stay current with new therapies and continuing MS research. Approximately 6,000 health professionals a month visit the Society's Professional Resource Center (PRC) on the web.

The Professional Resource Center offers library services, publications and MS specialist consultations for physicians as well as MS information for allied health care providers and a hotline for health care personnel. For information and other services, physicians can e-mail [MD\\_Info@nmss.org](mailto:MD_Info@nmss.org); other health professionals can e-mail [HealthProf\\_info@nmss.org](mailto:HealthProf_info@nmss.org).

### Advocacy

As part of the MS Action Network, MS activists are the leading voice in advocating on behalf of the approximately 400,000 people living with MS nationwide. Thousands of passionate individuals regularly take action on legislative and regulatory issues that matter to people with MS at the state and federal levels. By raising their voices together in response to tough issues, MS activists

effectively spread awareness and cultivate positive change. They do that through support from the Society's Public Policy Office, chapter Government Relations Committees, coalitions with like-minded groups, and the annual MS Public Policy Conference in Washington D.C.

## The Society in People Terms

### Life Situation:

*My wife was just diagnosed with MS, and we have many unanswered questions. Where can we go for information?*

The National MS Society offers accurate information and empowering programs. *Knowledge is Power* — a free six-week educational series 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 treatment centers, phone groups and peer support. 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.

## 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 under the Americans with Disabilities Act, information for employers, and strategies for managing symptoms and asking for accommodations.

## Life Situation:

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

Call us. A Society MS Navigator can help you determine the best course of action to advocate for your needs with your health care provider. 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. The Society also offers *Relationship Matters*, a program for couples living with MS.

## 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, *Momentum*. The Society's Web site is available 24/7. It carries breaking news, background facts, and regular "MS Learn Online" webcasts, presenting experts who help to explain MS research strategies and directions for treatment.

## 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* is available free on our Web site. The children's newsletter is also available in print from chapter offices. *When a Parent Has MS*, is a publication for teens also available online or in print.

## 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 1,700 support groups and 3,000 programs to people with MS and their families annually, many of whom stay connected via the internet. We can help you connect with others. Just let us know.

The 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.

**MS STOPS PEOPLE FROM MOVING.  
WE EXIST TO MAKE  
SURE IT DOESN'T.  
JOIN THE MOVEMENT®.**



**National  
Multiple Sclerosis  
Society**

**nationalMSsociety.org**

**For Information:**

**1 800 FIGHT MS (1 800 344 4867)**