

Just the Facts

2006-2007

General Information

Frequently asked questions about
multiple sclerosis and
the National MS Society

MSTM

National
Multiple Sclerosis
Society

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 they may struggle to live as productively as they desire, often facing 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. People of African, Asian, and Hispanic backgrounds are also diagnosed with MS, however, the incidence is much lower.

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. 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. 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, 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 treatment with one of the FDA-approved “disease-modifying” drugs as soon as possible following a definite diagnosis of MS with active or relapsing 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 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 scientists 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

Founded in 1946, the National Multiple Sclerosis Society supports more MS research, offers more services for people with MS, provides more professional education programs, and furthers more MS advocacy efforts than any other MS organization in the world.

We do this through the extensive research we support to find the cause, cure and improved treatments of the disease, the comprehensive services we provide to people with MS and their families, the professional education programs we offer to assist health care providers better serve their MS patients, and through our advocacy efforts on state and federal levels to encourage public policies supportive of the needs of people with multiple sclerosis.

**MS stops people from moving.
We exist to make sure it doesn't.**

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, over 460,000 volunteers participate in events, and support programs and services to help people with 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 2006 was \$219 million, up \$12 million from last year. This is a combination of all revenue including individual gifts; membership dues and contributions; legacies and bequests; special events; corporate contributions and investments; about one percent comes from Federal grants. The Society receives less than three percent of its income from pharmaceutical companies and those funds are contributed in the form of grants.

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 the MS 150 Bike Tour[®], and the MS Walk[®].

MS 150 Bike Tour[®]

The Society's MS Bike Rides are the country's largest organized cycling series. There are over 100 bike rides

offered coast to coast from April through November. Proceeds benefit the Society's national research programs and fund programs that help people with MS and their families. For information about the MS 150 Tour[®], call 1-800-344-4867 or visit nationalmssociety.org.

MS Walk[®]

Every spring about 200,000 people unite at over 600 sites across the country to participate in The MS Walk[®]. All walks have an accessible route so people of all abilities can participate. Funds raised support the Society's research and services programs. The Society also offers in select areas The MS Challenge Walk[®], a 3-day, life-changing journey across 50 miles to raise funds to fight MS, increase public awareness and promote health and fitness. For more information about the MS Walk[®], call 1-800-344-4867 or visit nationalmssociety.org.

How does the National MS Society spend its money?

The Society's nationwide network of chapters are 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.

- 79 percent of Society expenses are devoted to research and service programs that help people with MS and their families, and to public and professional education.
- 21 percent is invested in support services such as fund-raising and Society management.
- Sixty cents of every dollar stay in the chapter for local program use.

What do donations to the Society mean to you?

RESEARCH

The National Multiple Sclerosis Society spends more money on MS research than any other MS organization in the world. Since its founding in 1946, the Society has allocated more than \$500 million to MS research. These figures have increased steadily over the years.

In 2004, the Society launched a \$30 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 MS Pediatric Centers of Excellence for children with MS
- A collaborative research designed to speed nervous system repair and protection.

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

While the search for a cure continues, the Society helps keep families together despite the challenges of dealing with chronic illness. The Society funds more service programs for people with MS than any other MS organization in the world. It committed \$125 million in 2006 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, 1000

family programs, and 2,000 chapter-based educational programs to over 75,000 participants.

In addition, the home office publishes *InsideMS*[®], the Society's lifestyle magazine, and *Teen InsideMS*[®] for young adults. These publications are circulated to more than a half million readers.

The Society funds more professional education programs than any other MS organization. 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 specially designated Web site.

PROFESSIONAL EDUCATION

The Society offers a Professional Resource Center with library services and MS specialist consultations for physicians as well as MS information for allied health care providers. The Resource Center offers a hotline for health-care personnel. For targeted information, call toll-free: 1-866-MS-TREAT. Physicians can e-mail

MD_Info@nmss.org; other health professionals can e-mail 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: *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 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 clinical 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 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 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 1-800-344-4867.

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SURE IT DOESN'T.**

JOIN THE MOVEMENT.



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