

Multiple Sclerosis: Just the Facts



MS[®]

National
Multiple Sclerosis
Society

LISA
DIAGNOSED IN 1998

MS Facts

What is multiple sclerosis?

Multiple sclerosis is an unpredictable and potentially disabling disease of the central nervous system, which interrupts the flow of information within the brain, and between the brain and body. The disease is thought to be triggered in a genetically susceptible individual by a combination of one or more environmental factors. In MS, the immune system attacks tissue and cells within the central nervous system and causes damage to nerve connections resulting in neurological symptoms. Although MS is thought by some scientists to be an autoimmune disease, others disagree because the specific target of the immune attack in MS has not yet been identified. For this reason, MS is referred to as an immune-mediated disease.

Who gets MS?

Anyone may develop MS but there are some patterns. Two to three times more women than men have been diagnosed with MS. Most people are diagnosed between the ages of 20 and 50, although an estimated 8,000–10,000 children

under the age of 18 also live with MS, and people as old as 75 have developed it. Studies suggest that genetic factors may 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?

An estimated 2.3 million people live with MS worldwide. These numbers can only be estimated — in the absence of formally reported data — because MS disease activity can occur without a person being aware of it and symptoms may be completely invisible. At the present time, MS incidence and prevalence are not consistently tracked and reported in the U.S. as there is no government requirement to do so.

What are the typical symptoms of MS?

MS can cause extreme fatigue, impaired vision, problems with balance and walking, numbness or pain and other sensory changes, bladder and bowel

symptoms, tremors, problems with memory and concentration, mood changes, and more.

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, while another could experience loss of balance and muscle coordination making walking difficult. Still another could experience slurred speech, tremors, stiffness and bladder problems.

These problems may be permanent or may come and go. Major symptoms sometimes disappear completely, and the person regains lost function. In severe MS, people have permanent symptoms that might include partial or complete paralysis and difficulties with vision, cognition, speech, and bowel and bladder function.

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. Myelin is often compared to

insulating material around an electrical wire; loss of myelin interferes with the transmission of nerve signals.

Myelin is destroyed and replaced by scars of hardened “sclerotic” tissue. Some underlying nerve fibers are permanently damaged or severed as well. The scars (or lesions) appear in multiple places within the central nervous system, giving the disease its name. When any part of the myelin sheath or nerve fiber is damaged, nerve impulses traveling to and from the brain and spinal cord are distorted or interrupted, producing the variety of symptoms that can occur.

Is MS fatal?

Life expectancy for people with MS has increased over time. We believe this is due to treatment breakthroughs, improved healthcare and lifestyle changes. Recent research, however, indicates that people with MS may live an average of about seven years less than the general population because of disease complications or other medical conditions. Many of these complications are preventable or manageable. Attention to overall health and wellness can help reduce the risk of

other medical conditions, such as heart disease and stroke, that can contribute to a shortened life expectancy. In some rare instances, there are cases of MS that progress rapidly from disease onset and can be fatal.

Does MS always cause paralysis?

No. The majority of people with MS do not become severely physically disabled, although the unpredictability of the disease can present many challenges, including the possibility of facing increasing limitations. Two-thirds of people living with 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 help conserve 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.

What can be done about MS now?

There is much one can do to manage the disease and the symptoms it can cause. A number of medications that have been shown to “modify” or slow the course of MS have been approved by the U.S. Food and Drug Administration (FDA). In addition, many therapeutic and technological options help people manage their symptoms. Advances are made every year in treating and managing MS to stop disease progression and restore lost function. On a day-to-day basis, striving for personal wellness — a healthy diet, regular exercise, attention to emotional, intellectual and spiritual wellbeing, and adherence to recommended preventive care strategies — can help people lead their best lives.

What medications and treatments are available?

Abundant evidence shows that taking a disease-modifying therapy is the best way to reduce MS disease activity. Studies (comparing people in clinical trials who started therapy earlier than those on inactive placebo) suggest that early treatment offered important

benefits against the accumulation of disability, which were generally not experienced to the same degree by people who started treatment later. These studies suggest that one should consider treatment with one of the FDA-approved therapies as soon as possible following a definite diagnosis of MS with active, relapsing disease. Most of the available therapies are approved for people with all relapsing forms of MS, which includes relapsing-remitting, secondary-progressive, and progressive-relapsing with relapses. One medication (a chemotherapeutic agent) is specifically approved for secondary-progressive, progressive-relapsing and worsening relapsing-remitting MS. Another medication is approved for people with relapsing MS who have not had an adequate response to at least two other disease-modifying therapies.

Some of these medications are also approved for people who have experienced an initial demyelinating episode (clinically isolated syndrome) and are therefore at high risk of developing MS. These medications have been shown to be effective in delaying the onset of the disease.

All of these medications help to lessen the frequency and severity of MS attacks, reduce the accumulation of lesions in the brain, and may slow the progression of disability.

Unfortunately, there are currently no therapies available to treat primary-progressive MS; however, research efforts are underway to identify effective treatment options for this form of MS as well.

While the disease-modifying therapies are an important component to MS management, equally important are treatments and strategies that address MS symptoms such as difficulty walking, fatigue, spasticity, pain, bladder problems, fatigue, sexual dysfunction, weakness and cognitive problems. People need a comprehensive approach to managing their MS, which is best developed in consultation with their MS healthcare provider.

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, so they must often “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?

While there is no way to predict with any certainty how a person’s MS will progress, four basic disease courses have been defined:

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) that are 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: Many people whose MS begins with a relapsing-remitting course eventually transition to this form of MS. It is not yet certain whether and to what extent this transition to secondary-progressive MS is delayed by the available disease-modifying therapies.

Progressive-Relapsing

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

Our vision: a world free of MS.

Our mission: people affected by MS can live their best lives as we stop MS in its tracks, restore what has been lost and end MS forever.

To fulfill this mission, the Society funds cutting-edge research, drives change through advocacy, facilitates professional education, collaborates with MS organizations around the world, and provides programs and services designed to help people with MS and their families move their lives forward.

How many people does the Society serve?

The Society provides resources, support, programs and services to more than one million people every year through

partnerships with the healthcare community and our 50-state network of chapters.

How many volunteers does the MS Society have?

The Society relies on the dedication of more than 500,000 volunteers across the country who provide support for people living with MS and their families. Society volunteers lead committees, manage projects and even recruit and train other volunteers. To learn more about volunteering opportunities, visit nationalMSSociety.org/volunteer.

Are the National MS Society's programs free?

The Society offers a variety of programs to facilitate education, recreation, physical and emotional wellness, connection with others affected by MS and family support. Many programs are free and available throughout the country.

The Society can offer guidance and resources to help manage the financial impact of MS with a range of initiatives that support independence, safety, health and quality of life for people living with MS, as well as their families.

In addition, through the Society's MS Navigator® program, any person who calls 1-800-344-4867 is partnered with a skilled professional to provide them with the support, information and resources they need. This free service is available to anyone.

Visit **nationalMSsociety.org** to learn more about the Society's programs, call 1-800-344-4867 or email **contactusnmss@nmss.org**.

What are the Society's sources of support?

The Society depends on support from members, friends, corporate partners and the public at large. Nationwide income in 2014 was \$232.7 million, the majority of which came from private contributions, 63 percent of which is generated through special events. Approximately 10 percent of overall funding is received from corporate support or government grants, including approximately 4 percent from the pharmaceutical industry that supports Society program and services.

How does the Society raise funds?

The Society organizes a variety of special events and campaigns around the nation. Key fundraising events for the Society include Bike MS®, Walk MS®, MuckFest® MS and Challenge Walk MS®. Key individual giving programs include Golden Circle, Circle of Distinction and Lawry Circle.

Bike MS®

For cyclists and all those seeking a personal challenge and a world free of MS, Bike MS is the premier fundraising cycling series in the nation. With a choice of more than 100 extraordinary rides, the Bike MS experience is the ride of your life.

bikeMS.org

Walk MS®

Walk MS connects people living with MS and those who care about them. Each year, more than 330,000 people unite across the country to participate in Walk MS.

walkMS.org

MuckFest® MS

MuckFest MS is the fun mud and obstacle 5K for everyone. If you can laugh, you can do it. No special training required. Have a blast on mountains of mud and 18+ outrageous obstacles that will spin, swing, and fling you and your teammates up, down, and sideways.

muckfestMS.org

Challenge Walk MS®

Challenge Walk MS is the perfect way to embrace a personal challenge of spirit and strength, while making an important difference in the lives of people living with MS. Walk during a two- or three-day, 30-50 mile event in one of several exciting destinations.

challengewalkMS.org

Do It Yourself Fundraising

Do It Yourself (DIY) Fundraising speaks to the growing trend in the nonprofit world where donors and event participants want a customized fundraising experience to match their lifestyle and passion. Each year, thousands of people come to the Society with creative ideas to raise funds that go far beyond the Society's signature fundraising events.

doityourselfMS.org

Golden Circle and Circle of Distinction

Golden Circle is an annual membership program that engages donors who give \$1,000 or more for resources that help those living with MS move their lives forward.

nationalMSsociety.org/goldencircle

Lawry Circle

Lawry Circle recognizes donors who have informed the Society of a deferred gift through their will, trust or estate plan. Through their generosity, Lawry Circle members offer a lasting legacy of support to all people affected by MS.

nationalMSsociety.org/lawrycircle

NOW (No Opportunity Wasted): An MS Research Revolution

NOW is the Society's groundbreaking \$250 million commitment to drive MS research forward faster. Launched in 2011, NOW has fueled more promising MS research and has driven more progress towards life-changing solutions for people with MS than any other time in history. NOW marks a significant milestone on the Society's relentless journey to stop disease progression, restore lost function, and ultimately end MS forever.

How does the Society allocate resources?

Approximately 75 percent of the Society's revenue is devoted to research and programs and services that help people affected by MS move forward, while the remainder is invested in support services such as fundraising and Society management. It costs the Society about 16 cents to raise a dollar.

What do donations to the Society mean to you?

Research

The MS Society is committed to a world free of MS, advancing a comprehensive strategy of promising research aimed at stopping the progression of the disease, restoring function for those living with the disease, and ultimately ending MS forever. Since our founding in 1946, the Society has propelled research forward into many of the currently available therapies and treatments by allocating nearly \$868 million — \$50.2 million in 2014 alone — to support more than 380 research projects around the world.

We support a unique, comprehensive approach that funds activities spanning all types and stages of research, ensuring all promising paths are not overlooked.

Programs and Services

The Society helps people living with MS and those who care for them address the challenges of chronic illness. The Society committed \$122.2 million in 2014 to programs and services that educate, empower, support and inform people affected by MS. The Society connects people with their communities, information, resources, programs and services, and each other, offering more than 4,000 programs to almost 190,000 participants annually. These include in-person self-help groups, the MSFriends peer support phone helpline, and one-on-one connections. The Society hosts **MSconnection.org**, an online community where members discover and share experiences, get tips from experts in the field, join discussions, and more. Additionally, the Society provides a monthly e-newsletter and publications including lifestyle magazine **Momentum** and **MS Connection** newsletters that feature local news and information, and more than 60 informational publications (online or print) and videos.

Professional Education

The Society offers a full complement of publications, training materials and clinical resources and tools to support the work of physicians, nurses, rehabilitation specialists and mental health professionals, and help them stay current with new therapies and continuing MS research.

Clinicians can access library services as well as consultations with experts in MS diagnosis and management. Visit nationalMSsociety.org/professional or email healthprof_info@nmss.org.

Advocacy

As MS activists, we are on the frontline, moving together and speaking with one clear voice to create legislative and regulatory changes that benefit people living with MS and their families.

MS activists raise awareness about MS by sharing personal stories with public officials and legislators at the federal, state and local levels and educating them about how proposed legislation or funding will impact the MS community. By raising our collective voice, MS activists drive change and achieve real world results. For example, MS activists helped establish a new

federal funding avenue that thus far, has yielded nearly \$33 million for MS research.

nationalMSsociety.org/MSactivist

In people terms, how can the Society help you?

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

The Society's **Knowledge Is Power** — a free six-week informational series — is a good place to start. Sign up at nationalMSsociety.org/knowledge or call **1-800-344-4867**. You can also request a packet of literature and be connected to others with MS. Many offices provide in-person programs specifically for people who have just been diagnosed.

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 Society offers information about your rights in the workplace under the Americans with Disabilities Act (ADA), information for employers, and

strategies for managing symptoms and asking for accommodations.

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

The Society can help you determine the best course of action to advocate for your needs with your healthcare provider. In addition, organized volunteer activists are working with state and federal legislators to achieve quality healthcare. Join at nationalMSSociety.org/MSactivist.

My MS has worsened, and I'm finding it increasingly difficult to get around the office.

The 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.

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 the Society's Government Relations Committee in your area.

My mother is having some memory problems, and I'm afraid that she is going to get worse.

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

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

The Society offers assistance with durable medical equipment such as purchase or repair, equipment loans, or referral to related resources.

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

The Society offers education about MS, referral to family counselor and community resources, and to occupational or physical therapist who may help. There are also family programs that combine recreation and education.

I want to start an exercise program, but I'm not sure what to do or not do.

Information about the role of exercise in managing MS can be found on the Society's website and in various Society publications. The Society also offers referrals to area medical and physical

therapy resources as well as to local exercise and yoga classes and aquatics programs.

I want to keep up-to-date on advances in MS research and treatments.

Access breaking news, facts, videos and live webcasts featuring experts who explain research strategies and directions for treatment and request Society publications such as **Momentum**, **MS Connection** and e-newsletters at **nationalMSsociety.org**

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 Society's home page always lists breaking news. Contact us with questions.

My dad is in a wheelchair, and the kids at school think that's weird.

The Society offers family programs that combine education, disability awareness, counseling and fun, including some locations that also offer special programs for children or teens. The award-winning children's newsletter **Keep S'myelin**[®] is available free of charge in print or online).

When a Parent Has MS, a free publication for teens, is also available in print or online.

Notes

The National Multiple Sclerosis Society (“Society”) is proud to be a source of information on multiple sclerosis related topics. The information provided is based on professional advice, published experience, and expert opinion, but does not constitute medical or legal advice. For specific medical advice, consult a qualified physician. For specific legal advice, consult a qualified attorney.

The Society does not endorse products, services or manufacturers. Such names appear here solely because they are considered helpful information. The Society assumes no liability for the recipient’s use of any product or service mentioned. The Society does not independently verify whether the information provided by each service provider is accurate. The Society undertakes no responsibility to verify whether the service provider is appropriately licensed and certified and has applicable insurance coverage.

Early and ongoing treatment with an FDA-approved therapy can make a difference for people with multiple sclerosis. Learn about your options by talking to your health care professional and contacting the National MS Society at 1-800-344-4867 or [nationalMSSociety.org](https://www.nationalMSSociety.org).

The National MS Society mobilizes people and resources so people affected by MS can live their best lives as we stop MS in its tracks, restore what has been lost and end MS forever. To fulfill this mission, the Society funds cutting-edge research, drives change through advocacy, facilitates professional education, and provides programs and services designed to help people with MS and their families move their lives forward.



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