

# Multiple Sclerosis: Just the Facts



**MS**<sup>®</sup>

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 (CNS) 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. Women are at least two to three times more likely than men to develop 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) for people with relapsing forms of MS. Relapsing forms include relapsing-remitting MS as well as progressive forms of MS in people who are experiencing relapses.

One medication (a chemotherapeutic agent) is specifically approved for secondary progressive 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 (without relapses); 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, 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 early treatment important?**

Early damage in the CNS can occur even before people are experiencing any symptoms. Studies show that the best chance for reducing long-term disability is during the early relapsing phase of the disease, which is characterized by inflammation. Given

that the medications currently available all primarily target inflammation, early and ongoing treatment helps to minimize this early inflammation as well as reducing damage nerve fibers (axons) and loss of brain tissue.

## 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:

- **Clinically isolated syndrome** is a first episode of neurologic symptoms caused by inflammation and demyelination in the central nervous

system. A person who experiences clinically isolated syndrome may or may not go on to develop MS, with the chances being higher in someone who has lesions on MRI that are similar to those seen in MS.

- **Relapsing-remitting MS** is characterized by clearly defined relapses (also called attacks or exacerbations) that last from days to weeks and then subside, with full or partial recovery and no apparent disease progression between attacks. Approximately 85% of people begin with this disease course.
- **Primary progressive MS** is characterized by a gradual but steady progression of **disability** from the onset of symptoms, with few or no relapses or **remissions**. Occasional plateaus and minor, temporary improvements may occur. Approximately 15% of people are diagnosed with this disease course.
- **Secondary progressive MS** begins initially with a relapsing-remitting course that later evolves into a more consistently progressive course, with or without relapses.

# 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 services designed to help people with MS and their families move their lives forward.

## How many volunteers does the Society have?

The Society relies on the dedication of more than 500,000 volunteers across the country who help propel its mission. Society volunteers lead committees, manage projects and even recruit and train other volunteers. To learn more about volunteering opportunities, visit [nationalMSsociety.org/volunteer](https://nationalMSsociety.org/volunteer).

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

The Society offers a variety of services to facilitate education, recreation, physical and emotional wellness, connection with others affected by MS and family support. Many 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<sup>®</sup> 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](https://nationalMSsociety.org)** to learn more, call 1-800-344-4867 or email **[contactusnmss@nmss.org](mailto: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 2015 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 in pharmaceutical funding for programs that enhance the lives of people living with MS.

## 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<sup>®</sup>, Walk MS<sup>®</sup>, MuckFest<sup>®</sup> MS and Challenge Walk MS<sup>®</sup>. Key individual giving programs include Golden Circle, Circle of Distinction and Lawry Circle.

### **Bike MS<sup>®</sup>**

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 85 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 300,000 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**

## Finish MS®

Finish MS is an opportunity for cause-driven athletes to push their own personal limits and challenge

themselves physically, while working to create a world free of MS.

**finishMS.org**

### **Do It Yourself Fundraising MS**

Do It Yourself (DIY) Fundraising MS 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 raise funds in creative ways that go beyond the Society's signature fundraising events.

**doityourselfMS.org**

### **Breakthrough MS: Whatever It Takes**

Breakthrough MS is the Society's five-year campaign with the resolute goal to reach \$1 billion in funds to fuel breakthroughs that will change the world for people with MS. People affected by MS are relying on us to do whatever it takes to accelerate breakthroughs — life-changing breakthroughs that enable people to live their best lives today and research breakthroughs that will ultimately end MS.

### **Golden Circle**

Golden Circle is an annual membership program that engages donors who give \$1,000 or more.

**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](https://nationalMSsociety.org/lawrycircle)

## How does the Society allocate resources?

Approximately 75 percent of the Society's revenue is devoted to research and services that help people affected by MS move their lives forward, while the remainder is invested in support services such as fundraising and Society management. Because of dedicated volunteer support, 84 cents of every dollar raised directly supports MS research and services.

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

### Research

The 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 invested more than \$974 million — \$54 million last year alone — to advance more than 380 research projects around the world and is recognized as the catalyst for all major advancements in MS.

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 2015 to services that educate, empower, support and inform people affected by MS and connect them to the people, information and resources they need. 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 publications including lifestyle magazine **Momentum** and **MS Connection** newsletters that feature 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](https://nationalMSsociety.org/professional)** or email **[healthprof\\_info@nmss.org](mailto: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 \$40 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** 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 ask to be connected to others with MS.

**I'm so depressed. I just had an exacerbation, and I'm feeling lonely. My symptoms are odd and nobody can explain them. Can you help?**

Depression is a very common symptom of MS. Life with a recent exacerbation and unusual symptoms is challenging enough without the added weight of depression. Contact an MS Navigator for a referral to a mental health professional who can help you diagnose and manage your mood changes.

**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](https://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 (ADA), 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 counselors and community resources, and to occupational or physical therapists 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, as well other health and wellness strategies related to diet, emotional wellbeing and regular preventive healthcare, 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](http://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**<sup>®</sup> 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.









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)**.

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