

Multiple Sclerosis: Just the Facts

GENERAL INFORMATION



National
Multiple Sclerosis
Society

Kim, diagnosed in 1986

MS Facts

What is multiple sclerosis?

Multiple sclerosis is an unpredictable, often 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. 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 2.1 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 damage appears 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?

Most people with MS have a normal or near-normal life expectancy. In fairly rare cases, complications of MS can shorten life, including infections of various kinds. However, many of these complications are preventable or manageable. Very rare instances of MS that progress rapidly from disease onset can be terminal.

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 are helping people manage their symptoms. Advances are made every year in treating and managing MS to stop disease progression and restore lost function.

What medications and treatments are available?

Taking a disease-modifying therapy is currently the best way to reduce MS disease activity and improve quality of life. 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 those 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. Many 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.

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 (areas of damage) in the brain, and may slow the progression of disability.

In addition to therapies that address the underlying disease process, there are many medications and rehabilitation strategies to address MS symptoms such as difficulty walking, fatigue, spasticity, pain, bladder problems, sexual dysfunction, weakness and cognitive problems. People should develop a comprehensive approach to managing their MS in consultation with their physician.

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

The National MS Society addresses the challenges of each person affected by MS by funding cutting-edge research, driving change through advocacy, facilitating professional education, collaborating with MS organizations around the world, and providing programs and services designed to help people with MS and their families move forward with their lives.

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 its 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, go to nationalMSSociety.org/volunteer.

Are the National MS Society's programs free?

The Society offers a variety of community-based programs to facilitate education, recreation, physical and emotional wellness, connection with others affected by

MS, and family communication. These programs vary from one community to another; many are free or include a nominal fee.

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 toll-free 1-800-344-4867 gets partnered with a skilled professional to help provide them with the support, information and resources they need. This free service is available to anyone.

To learn more about any of the Society's programs, visit **nationalMSsociety.org**, 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 2012 was \$216.4 million,

the majority of which came from private contributions, 66 percent of which is generated through special events. Approximately 10 percent is received from corporate support or government grants, including pharmaceutical company funding and grants 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[®], Walk MS[®] and Challenge Walk MSSM. 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

Challenge Walk MSSM

People from across the nation can accept the challenge to walk 30 to 50 miles over two to three days at any of the eight Challenge Walk MS events. challengewalkMS.org

Do It Yourself Fundraising

The Society is here to help support how people choose to be part of the MS movement, with Do It Yourself Fundraising. This is an opportunity for people from across the country with a deep commitment to the MS cause to raise awareness and critical funds in new and creative ways. 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. Circle of Distinction honors the leadership of donors who give \$1 million or more to the Society throughout their lifetime.

nationalMSsociety.org/goldencircle

Lawry Circle

Lawry Circle recognizes donors who have informed the Society of their intention to help create a better future for people with MS through a gift from their will, trust or estate plan. These individuals have linked their own legacy with the Society's mission and have embraced the vision of a world free of MS beyond their lifetime. nationalMSsociety.org/lawrycircle

NOW (No Opportunity Wasted): An MS Research Revolution

The Society has made a bold commitment to fuel MS research by launching the largest and most comprehensive campaign in MS history and will direct \$250 million to the most promising MS research to stop disease progression, restore lost function, and ultimately end MS forever.

nationalMSsociety.org/NOW

How does the Society allocate resources?

Approximately 76 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 17 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 more than \$771 million – \$43.3 million in 2012 alone – to support more than 350 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.

The Society's Strategic Response to MS for 2011–2015 focuses on achieving these objectives:

- Better understanding the scientific mechanisms that lead to disease progression and accelerating the development of new therapies;
- Pursuing new avenues to discover how nerve cells are damaged and potentially repaired;
- Fostering new rehabilitation techniques and symptomatic treatments to restore neurological function and enhance quality of life;
- Identifying risk and triggering factors that cause MS, and understanding the biological interactions that lead to its development so that MS can be prevented; and
- Expanding and strengthening the quantity and quality of MS research worldwide to accelerate new discoveries and treatments for people with MS.

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 \$122.1 million

in 2012 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, more than 1,200 support groups and clubs, and **MSconnection.org**, an online community where members discover and share experiences, get tips from experts in the field, join discussions, and more. Also, a monthly e-newsletter and publications including lifestyle magazine **Momentum** and **MS Connection** newsletters that feature local news and information, and more than 60 educational brochures (online or print) and videos.

Professional Education

Through the MS Clinical Care Network, 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.

Through the Network, clinicians can access library services as well as consultations with experts in MS diagnosis and management. Access the Network at nationalMSsociety.org/MSClinicalCare or email Health-Prof_info@nmss.org.

Advocacy

We are all MS activists. 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 \$25 million for MS research.

Become an MS activist today at nationalMSsociety.org/MSactivist

Life Scenarios: 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 Society's *Knowledge is Power* — a free six-week educational series — is a good place to start. Sign up online or contact an MS Navigator at 1-800-344-4867. Local offices provide in-person educational programs specifically for people who have just been diagnosed. You can also request a packet of literature and be connected to others with MS.

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 Society can provide referrals to physicians and allied health professionals who treat MS, Centers for Comprehensive MS Care, as well as phone-based or online peer support. The Society's MS

Navigators are also available to research difficult questions and are available at 1-800-344-4867.

Life Situation:

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.

Life Situation:

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.

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 the Society's Government Relations Committee in your area.

Life Situation:

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.

Life Situation:

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.

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 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.

Life Situation:

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

The Society offers referrals to area medical and physical therapy resources. Some locations also sponsor exercise classes and aquatics programs. The Society can also make referrals to MS-friendly programs.

Life Situation:

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 at [nationalMSsociety.org](https://www.nationalmssociety.org) and request Society publications such as Momentum, MS Connection and e-newsletters.

Life Situation:

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.

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

The National MS Society is a collective of passionate individuals who want to do something about MS now — to move together toward a world free of multiple sclerosis.

We help each person address the challenges of living with MS through our 50-state network of chapters. The Society helps people affected by MS by funding cutting-edge research, driving change through advocacy, facilitating professional education, and providing programs and services that help people with MS and their families move their lives forward.

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 prescriptions. For specific information and advice, consult your physician.

The Society publishes many other pamphlets and articles about various aspects of MS. Visit [nationalMSsociety.org/brochures](https://www.nationalmssociety.org/brochures) to download them, or call your chapter at 1-800-344-4867 to have copies mailed to you.

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 [nationalMSsociety.org](https://www.nationalmssociety.org) or 1-800-344-4867 (1-800-FIGHT-MS).

**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)