



DEL MAR CAREGIVER RESOURCE CENTER

*A program of Health Projects Center*

---

## **Fact Sheet**

# **Multiple Sclerosis**

### **Definition**

Multiple Sclerosis (MS) is one of the most commonly occurring chronic neurological diseases. MS affects the central nervous system (CNS)—the brain and spinal cord—and is thought to be caused by a disorder of the immune system, or *auto-immune disorder*. About 400,000 people nationwide, and possibly 2.5 million people worldwide, have MS. The disorder affects people of all ages, but onset is most likely to occur between the ages of 20 and 40. Women are twice as likely as men to develop MS. The disease is also more common in regions with moderate climates and in people of northern European descent. The experience of people with MS varies in the extent and severity of symptoms, as well as the progression of the disease.

### **What happens when you have MS?**

It is thought that MS is caused by an inflammation in the white matter of the brain and the spinal cord. This inflammation occurs when the immune system attacks and destroys nerve cells, nerve fibers, and myelin, which is the fatty covering that surrounds nerve fibers and cells in the brain and spinal cord. Myelin is important because it separates nerve pathways from each other, allowing nerve impulses to travel from one location to another throughout the nervous system.

A nerve impulse is the body's way of communicating. When the body experiences certain sensations (e.g., eating spicy food or

touching something hot), our nerves send a signal to the brain with this information. In return, the brain evaluates the information and communicates back to the nerve the way in which our body should respond to a given stimulus. For this to happen, a nerve signal must travel from one nerve cell to another until it reaches the brain.

When damage prevents nerve signals from traveling, the symptoms of MS may develop. “Multiple” refers to the multiple sites where nerve loss, or *demyelination*, occurs. “Sclerosis” refers to scar tissue, or “sclera” which can block or obstruct the flow of messages between nerves and muscles.

Depending on the site of inflammation, these blockages can result in some of the symptoms of MS, which may include blurred vision, loss of balance, poor coordination, slurred speech, tremors, numbness and extreme fatigue. Other symptoms include problems with memory and concentration. Individuals with MS may experience some, all, or none of these symptoms.

### **Prognosis**

It is often difficult to predict the course of MS because it varies on a case-by-case basis. Current research focuses on identifying more precise indicators of disease activity.

---

**Del Mar Caregiver Resource Center**

*Serving Monterey, San Benito and Santa Cruz Counties*

831.459.6639 • Toll Free 1.800.624.8304 • [www.delmarcaregiver.org](http://www.delmarcaregiver.org)

## Symptoms

The most prominent symptoms, by group, are:

- **Visual.** The optic nerve is a common area for inflammation. Because it is responsible for carrying vision signals to the brain, visual disturbances are common. They range from haziness and blurred vision to more serious visual impairment. Often, visual symptoms lessen or disappear after a period of weeks, upon remission. Blindness in MS is rare.
- **Movement.** Difficulty in controlling the strength and precision of movements, so that holding things is a problem; balance and coordination may be impaired (also called ataxia).
- **Sensory.** Numbness, tingling and sensitivity to heat or cold.
- **Bladder.** Control problems and urinary tract infections.
- **Cognition.** Mood swings, ranging from depression to euphoria.
- **Fatigue.** Mild to severe fatigue and weakness.

### Types of MS\*

Type	Symptoms	Outlook
<b>Benign MS</b>	<ul style="list-style-type: none"> <li>• Attacks less severe at onset;</li> <li>• Symptoms are sensory or vision-related;</li> <li>• Attacks are few and much time may pass between bouts.</li> </ul>	<ul style="list-style-type: none"> <li>• Complete recovery between attacks;</li> <li>• Does not worsen with time;</li> <li>• No permanent disability.</li> </ul>
<b>Relapsing - Remitting or Exacerbating MS</b>	<ul style="list-style-type: none"> <li>• Symptoms worsen or new symptoms appear.</li> </ul>	<ul style="list-style-type: none"> <li>• Recovery may be complete or partial.</li> </ul>
<b>Progressive - Relapsing MS</b>	<ul style="list-style-type: none"> <li>• Consistent progression in disability;</li> <li>• Clear, definite flare-ups.</li> </ul>	<ul style="list-style-type: none"> <li>• May or may not experience recovery following flare-ups, or attacks.</li> </ul>

<b>Secondary-Progressive MS</b>	<ul style="list-style-type: none"> <li>• Onset similar to relapsing-remitting course;</li> <li>• After time, develops into a more progressive course.</li> </ul>	<ul style="list-style-type: none"> <li>• May or may not experience relapses;</li> <li>• Recovery may continue to occur.</li> </ul>
<b>Primary Progressive MS</b>	<ul style="list-style-type: none"> <li>• Continual progression of disease and disability from beginning;</li> <li>• Lack of obvious remission.</li> </ul>	<ul style="list-style-type: none"> <li>• Occasional stabilization of disability and minor, temporary improvement.</li> </ul>

*\*Recognized differently among national and international organizations, and physicians. Adapted from Multiple Sclerosis International Federation (2003) and National Multiple Sclerosis Society (2003).*

### **Cognitive Problems**

About 50% of people with MS will develop some cognitive problems. Symptoms include a slowed ability to think, reason, concentrate or remember. Only 10% of those who develop cognitive problems experience symptoms severe enough to interfere with daily activities. Yet, it is important to remember that for the person experiencing MS, cognitive changes may be equally or even more devastating than physical changes. Cognitive difficulties are common among people who have had the disease for a long time; however they may also appear early on, occasionally from the onset of MS. Among those individuals affected by cognitive disturbance, the most common problems are:

- Memory recall, particularly remembering recent events.
- Slowness in learning and processing new information.
- Difficulty with reasoning, such as analyzing a situation, making a plan and follow through.

- Poor judgment.
- Impaired verbal ability, such as slowed speech or difficulty coming up with a needed word during conversation.

Cognitive problems associated with MS are not related to level of physical disability and can affect people with few physical symptoms of MS. In addition, cognitive problems can develop rapidly during a flare-up of the disease. In these cases, the cognitive problems can decrease as the disease moves into remission. It is important to note that cognitive impairment in MS bears little resemblance to the intellectual decline in Alzheimer's disease. People with MS virtually never experience severe, progressive cognitive decline. Cognitive impairment in MS is typically mild and may stabilize at any time.

Individuals with MS and their families should be aware of potential cognitive problems. Recognizing and learning about certain impairments can reduce misunderstandings about a person's apparent forgetfulness, carelessness or seeming indifference. Through

open communication, families can be supportive and help the person cope with the changes that they are experiencing. Understanding symptoms related to MS can also help to reduce fears about losing one's abilities. Sometimes, it is helpful to start talking about cognitive and other changes that might occur as a result of MS before they happen, so the individual with MS and the family can be sensitive to and aware of potential changes.

Discuss suspected cognitive impairment with the person's doctor. In some cases, depression, side-effects from medications and even interactions between medications can mimic cognitive problems and can be treated separately. A neurologist can perform a brief evaluation to test for severe cognitive deficits. A neuropsychologist who has expertise in diagnosing and treating MS may be recommended to perform a more complete evaluation to test for subtle cognitive changes. If cognitive problems are found, the neuropsychologist may assist individuals and their families in coping by working on rehabilitation and strategies to help with cognitive changes.

These strategies may include memory aids such as writing down all appointments, making check lists, or using memory "tricks" (e.g., visual images or rhymes) to help remember. Practicing concentration and focus when listening will also minimize distractions and help the person retain new information.

## Diagnosis

There is no single test available to clearly identify MS. It's usually a "diagnosis of exclusion," where other conditions and diseases are systematically ruled out, leaving a diagnosis of MS. There are a few rare conditions that have similar symptoms to MS, such as Lyme disease, lupus and heavy metal poisoning. Magnetic Resonance Imaging (MRI) is currently the most sensitive diagnostic test. An MRI aids in diagnosis by producing a picture of the brain or spinal cord to show areas of inflammation and

scarring, typical in an MS-afflicted person. Periods of inflammation may or may not result in accompanying flare-ups or attacks. Diagnosis of MS usually takes a period of time and is based on overall symptoms and tests as well as analyzing a person's medical history in detail.

## Treatment

Much research is being conducted to find new approaches to the treatment of MS. Since there is no "cure," treatment tends to center on remission, or stopping the attacks from occurring. Thus, treatment focuses on:

- Helping to bring about remission of symptoms;
- Lengthening the remission period so that the flare-ups are less likely to occur;
- Changing the course of the disease so progression slows; and
- Providing symptom relief.

Clinical research suggests that it is beneficial to begin treatment for MS as early as possible, and that medications can have the most impact if they are taken as soon as the disease is diagnosed. The lack of active inflammation in the brain is seen as an indicator of successful treatment.

There are a number of medications that may reduce MS-related symptoms. Interferon beta 1-a (Avonex<sup>®</sup>), interferon beta-1b (Betaseron<sup>®</sup>), and glatiramer acetate (Copaxone<sup>®</sup>), widely known as the "ABC" drugs, can be effective in reducing the frequency and intensity of flare-ups and slowing disease progression for many people. Beta interferon 1-a agent (Rebif<sup>®</sup>) is an immunomodulating agent that has been approved for the treatment of relapsing-remitting MS. All of these medications are administered by injection, which some caregivers and individuals with MS may find difficult. Because of this, they may be less likely to stay on a medication schedule. It is important to consider method of delivery and side effects when selecting a medical intervention program that works for you and your loved one.

Other treatments are targeted to help those with MS function at their best during periods of flare-ups, or attacks. Corticosteroids such as Prednisone<sup>®</sup> were the first agents used for successful treatment of MS and remain one of the standard treatments for controlling flare-ups. Effectiveness can vary from individual to individual, however, and, due to well documented side effects, corticosteroids cannot be used on an ongoing basis. Other medications, such as antispasticity drugs, are often effective in relieving muscle spasms. Checking with organizations that specialize in MS (see resource list) is a good way to keep up-to-date on new drugs to treat MS, upcoming clinical trials and recent FDA drug approvals.

Medications are not the only ways to reduce the symptoms of MS. Physical therapy is often effective in relieving muscle spasms. Bowel and urinary distress are treated with management programs, and some people benefit from intermittent catheterization. A neurologist or urologist can help determine if this option is suitable. Rehabilitation programs or physical therapy are helpful in some cases to increase muscle strength, improve walking ability or reduce pain.

Research suggests that lifting weights and exercise can have a positive effect on individuals with MS. Results from clinical trials have suggested that individuals who exercised experienced less fatigue, greater immune function and decreased inflammation. Physical therapists can help to develop an exercise regimen.

## **The Role of Health Professionals**

When you or your loved one are being tested or receiving treatment for MS, you may seek the expertise of a number of different health professionals. Because people who have MS experience different symptoms and potentially many stages, you may interact with what might seem like a great many physicians, social workers, physical therapists and other health care providers. It can be overwhelming to

coordinate care and to find appropriate resources and professionals who are trained in MS care. Keeping a notebook, or “health journal” of the interactions with health care providers, treatments administered, and medications prescribed will help to keep appointments organized and will provide a personal record of care.

## **Getting Support**

It is important both for people with MS and their loved ones to get support when dealing with the disease. Support groups which provide safe, caring environments to share experiences and challenges are available for both individuals with MS and those who care for them. Topics discussed may include adjustment, coping, disease course, family issues, frustrations, insurance, medication, resources and more. Counseling also may be helpful for individuals, couples or families who are learning to cope with chronic illness or periodic health crises.

Family and friends who are providing assistance to a loved one with MS may feel stressed and thus be at increased risk of poor health, depression and isolation. It is important for the health of the family caregiver as well as the health of the person with MS for the caregivers to take some time off (or “respite”) from caregiving, to get enough sleep and have a support system of their own. Respite care can be arranged with the help of family members, friends, community organizations, volunteer services, independent living centers or home care agencies. Caregivers who have time for themselves give better care to their loved ones.

## Recommended Readings

**Multiple Sclerosis: The Questions You Have, the Answers You Need**, Rosalind Kalb, Second edition, 2002, Demos Vermande, 386 Park Ave. South, New York, NY 10016, (212) 683-0072.

**Mainstay: For the Well Spouse of the Chronically Ill**, Maggie Strong, 1997, Bradford Books, 160 Main Street, #9, Northampton, MA 01060-3134, (413) 584-4597.

**Symptom Management in Multiple Sclerosis**, Randall T. Schapiro, 1998, Third Edition, Demos Vermande, 386 Park Ave. South, New York, NY 10016, (212) 683-0072.

**Multiple Sclerosis: A Self-Care Guide to Wellness**, Nancy Holland and June Halper (eds.), 1998, Paralyzed Veterans of America, 801 18th St. NW, Washington, DC 20006, (202) 872-1300.

**Alternative Medicine and Multiple Sclerosis**, Allen C. Bowling, 2001, Demos Vermande, 386 Park Ave. South, New York, NY 10016, (212) 683-0072.

**The Other Victim: How Caregivers Survive a Loved One's Chronic Illness**, Alan Drattell, 1996, Seven Locks Press, P.O. Box 25689, Santa Ana, CA 92799, (714) 545-2526.

## Credits

International Journal of MS Care, 2001, Early Diagnosis and Intervention in MS.

Medscape, 2003, Fine-tuning the Management of Multiple Sclerosis.

Multiple Sclerosis International Federation, 2003, MS—The Disease.

National Multiple Sclerosis Society, 2003, Inside MS.

National Multiple Sclerosis Society, 2003, Knowledge is Power, Volume 1.

National Multiple Sclerosis Society, 2003, Research Directions in Multiple Sclerosis.

## Resources

### MONTEREY COUNTY

**Health Projects Center's  
Del Mar Caregiver Resource Center**  
(831) 424-4359

Web site: [www.delmarcaregiver.org](http://www.delmarcaregiver.org)

### SANTA CRUZ COUNTY

**Health Projects Center's  
Del Mar Caregiver Resource Center**  
(831) 459-6639

Web site: [www.delmarcaregiver.org](http://www.delmarcaregiver.org)

### SAN BENITO COUNTY

**Health Projects Center's  
Del Mar Caregiver Resource Center**  
(831) 459-6639

Web site: [www.delmarcaregiver.org](http://www.delmarcaregiver.org)

Del Mar Caregiver Resource Center supports and assists caregivers of brain-impaired adults through education, research, services and advocacy.

For residents of Central California, Monterey, Santa Cruz and San Benito Counties, Del Mar CRC provides direct family support services for caregivers of those with Alzheimer's disease, stroke, head injury, Parkinson's and other debilitating brain disorders that strike adults.

### **National Multiple Sclerosis Society**

733 Third Avenue  
New York, NY 10017  
(212) 986-3240  
(800) FIGHT-MS or (800) 344-4867  
(rings to nearest chapter office)  
[www.nationalmssociety.org](http://www.nationalmssociety.org)

The National Multiple Sclerosis Society provides information and referral, self-help or support groups, advocacy, programs for the newly diagnosed, emotional support, diversity programs and Spanish language resources, financial support and equipment loans, online programs, family programs, education and wellness programs, a chapter newsletter, and library. Services may vary by chapter, and some chapters provide additional services.

**Multiple Sclerosis International Federation**

3<sup>rd</sup> Floor Skyline House  
200 Union Street  
London SE1 OLX  
+44 (0) 20 7620 1911  
[www.msif.org](http://www.msif.org)

**Veterans Affairs (VA) MS Centers of Excellence**

East of the Mississippi  
Baltimore VA Medical Center  
MS Center of Excellence  
10 North Green Street  
Baltimore, MD 21201  
(800) 463-6295  
[www.va.gov/ms/](http://www.va.gov/ms/)

**West of the Mississippi****VA Puget Sound Health Care System**

Seattle Division  
MS Center of Excellence  
1660 South Columbian Way  
Seattle, WA 98108  
(206) 762-1010  
[www.puget-sound.med.va.gov](http://www.puget-sound.med.va.gov)

**Portland VA Medical Center**

MS Center of Excellence  
3710 SW US Veterans Hospital Road  
Portland, OR 97239  
(503)220-8262  
[www.portland.va.gov/](http://www.portland.va.gov/)

**National Council on Independent Living**

1916 Wilson Blvd, Suite 209  
Arlington, VA 22201  
(703) 525-3406  
[www.ncil.org](http://www.ncil.org)

**Independent Living Center directory by state**

[www.virtualcil.net/cils](http://www.virtualcil.net/cils)

**American Academy of Clinical Neuropsychology**

Department of Psychiatry  
c/o Linus Bielasukas  
University of Michigan Medical Center  
1500 E. Medical Center Drive  
CFOB #2954  
Ann Arbor, MI 48109-0704  
(734) 936-8269  
[www.theaacn.org](http://www.theaacn.org)

**American Academy of Physical Medicine and Rehabilitation**

IBM Plaza, Suite 2500  
Chicago, IL 60611-3604  
(312) 464-9700  
[www.aapmr.org](http://www.aapmr.org)

**American Occupational Therapy Association**

4720 Montgomery Lane  
Bethesda, MD 20824  
(301) 652-AOTA  
[www.aota.org](http://www.aota.org)

**National Association for Continence**

P.O. Box 8310  
Spartanburg, SC 29305-8310  
(800) BLADDER  
[www.nafc.org](http://www.nafc.org)

**National Institute of Neurological Disorders and Stroke**

Building 31, Room 8A-06  
31 Center Drive, MSC 2540  
Bethesda, MD 20892-2540  
(800) 352-9424  
[www.ninds.nih.gov](http://www.ninds.nih.gov)

**Well Spouse Foundation**

63 West Main Street, Suite H  
Freehold, NJ 07728  
(800) 838-0879  
[www.wellspouse.org](http://www.wellspouse.org)  
[info@wellspouse.org](mailto:info@wellspouse.org)

*Reviewed by Meche Aguirre-Sullivan, Information and Referral Coordinator, National Multiple Sclerosis Society, Northern California Chapter. Updated by the National Center on Caregiving at Family Caregiver Alliance. Funded by the Archstone Foundation. Revised September, 2003. © Family Caregiver Alliance. All rights reserved.*