Multiple Sclerosis

Multiple Sclerosis (MS) is a disorder of the brain and spinal cord involving decreased nerve function associated with scar formation on the covering of nerve cells. In many cases, MS symptoms include various stages of paralysis.

Multiple sclerosis involves repeated episodes of inflammation that destroy the myelin sheath that covers nerve fibers, leaving multiple areas of scar tissue (sclerosis) along the covering of the nerve cells. This results in slowing or blockage of nerve impulse transmission in that area.

MS often progresses with episodes that last days, weeks, or months alternating with times of reduced or no symptoms (remission). Recurrence (relapse) is common.

The exact cause of MS is unknown. Studies indicate an environmental factor may be involved. There is a higher incidence in northern Europe, northern United States, southern Australia, and New Zealand than in other areas of the world. There may also be a familial tendency toward the disorder.

MS is believed to be a type an abnormal immune response directed against the central nervous system (CNS). The exact antigen -- the target the immune cells are sensitized to attack -- remains unknown. In recent years, researchers have identified which immune cells are mounting the attack, how they are activated to attack, and some of the sites, or receptors, on the attacking cells that appear to be attracted to the myelin to begin the destructive process.
Theories about the cause of MS include the role of a virus-type organism, an abnormality of the genes responsible for control of the immune system, or a combination of both.

MS affects approximately 1 out of 1,000 people. Women are affected more commonly than men. The disorder most commonly begins between 20 to 40 years old but can happen at any age.

MS symptoms include weakness of one or more extremities, paralysis of one or more extremities, tremor of one or more extremities, muscle spasticity (uncontrollable spasm of muscle groups), movement dysfunction, numbness, tingling, pain, loss of vision, loss or coordination and balance, incontinence, loss of memory or judgment and fatigue.

Symptoms may vary with each attack. Fever can trigger or worsen attacks, as can hot baths, sun exposure, and stress.

MS varies greatly from person to person and in the severity and the course of the disease. Some people have few attacks and little disability. Others have "relapsing-remitting" MS which means they have a series of attacks (exacerbations) followed by periods of recovery (remissions).

Some have what is called "progressive" disease that can be "primary" or "secondary." People with primary-progressive MS have steady worsening (or progression) from onset with only minor recovery. Secondary-progressive MS begins with a series of relapses and recovery but becomes steadily progressive over time with continued worsening. Most people with MS have the relapsing-remitting or secondary-progressive forms.

There is no known cure for multiple sclerosis. There are promising new therapies that may decrease exacerbations and delay progression of the disease. Treatment is aimed at controlling symptoms and maintaining function to give the maximum quality of life.

Patients with a relapsing-remitting course are now placed on immune modulating therapy that requires injection under the skin or in the muscle once or several times a week. This may be in the form of interferon (such as Avonex or Betaseron) or another drug called glatiramer acetate (Copaxone). They are all similar in their effectiveness and the decision on which to use depends on one’s side-effect profile.

Steroids are often given to decrease the severity of an attack. Other common MS medicines include baclofen, tizanidine or diazepam may be used to reduce muscle spasticity. Cholinergic medications may be helpful to reduce urinary problems. Antidepressant medications may be helpful for mood or behavior symptoms. Amantadine may be given for fatigue.

Physical therapy, speech therapy or occupational therapy may improve the person’s outlook, reduce depression, maximize function, and improve coping skills. A planned exercise program early in the course of MS helps to maintain muscle tone.
Attempts should be made to avoid fatigue, stress, physical deterioration, temperature extremes, and illness to reduce factors that may trigger an MS attack.

The expected outcome is variable and unpredictable. Although the disorder is chronic and incurable, life expectancy can be normal or nearly so, with a life span of 35 or more years after diagnosis occurring commonly. Most people with MS continue to walk and function at work with minimal disability for 20 or more years.

Sources: National Institute of Neurological Disorders and Stroke (NINDS), National Multiple Sclerosis Society, Consortium of MS Centers

Web Sites

http://www.mysa.org/
Multiple Sclerosis Association of America (MSAA)
375 Kings Highway North
Cherry Hill, NJ 08034
Phone: 856-488-4500,
Toll-free Helpline 800-532-7667 x154
Email: MSquestions@mymsaa.org
MSAA’s site features news, information and community connections. There is also contact information for the association’s six regional offices which offer awareness events as well as networking and social events. MSAA also lends equipment, cooling vests and accessories, and books through their lending library. They also have an MRI Fund to assist people who can’t afford their MRIs. Please contact MSAA about qualifications for any of these programs. They also offer a Helpline that people with MS can call for help with MS-related questions.

http://www.msfocus.org/
Multiple Sclerosis Foundation (MSF)
6520 North Andrews Avenue
Fort Lauderdale, FL 33309-2130
MS Helpline: 888-MSFOCUS (Toll-free)
Email: support@msfocus.org
This site has an interactive, multimedia MS library and online forum. MSF publishes MSFocus, a complimentary quarterly magazine, and the MS Foundation newsletter.

http://www.nmss.org
National Multiple Sclerosis Society (NMSS)
733 Third Avenue, 3rd Floor
New York, NY 10017
Phone: 800-344-4867 (Toll-free)
Provides information on living with MS, MS treatments, scientific progress, MS specialty centers, clinical research, local chapters and an annotated bibliography for healthcare professionals. NMSS has developed several programs to give needed information and
support to those recently diagnosed. The Society has chapters in all 50 states and Washington, DC, that encourage personal empowerment with employment counseling, family programs, volunteer opportunities, and advocacy issues.

http://www.nationalmssociety.org/for-professionals/healthcare-professionals/index.aspx
National Multiple Sclerosis Society: Professional Resource Center
The Society’s Professional Resource Center houses a comprehensive library of MS information and provides a variety of information and consultation services.

www.activemzers.org
Active MSers
Founder: Dave Bexfield
Email: dave@activemzers.org
Active MSers is designed to help, motivate, and inspire those with multiple sclerosis to stay as active as possible—physically, intellectually, and socially—regardless of physical limitations.

https://www.affordablecollegesonline.org/college-resource-center/students-with-multiple-sclerosis/
Affordable Colleges Online: College Students with MS: A Guide to Campus Resources and Support
This website offers tips for college students with MS as well as educational scholarships for those with MS.

http://www.mult-sclerosis.org
All About Multiple Sclerosis
This site aims to provide accurate and comprehensive medical information about multiple sclerosis written in plain English by people living with the disease and its symptoms.

http://www.autoimmunemom.com/
Autoimmune Mom
Autoimmune Mom offers an online community for mothers with autoimmune disorders such as MS and others. It also has info on multiple autoimmune disorders for people who have more than one.

http://www.mscando.org/
Can Do Multiple Sclerosis (formerly The Heuga Center)
100 W. Beaver Creek Blvd., Suite 200
PO Box 5860
Edwards, CO 81632
Phone: 970-926-1290, 800-367-3101 (Toll-free)
E-mail: info@mscando.org
Founded in 1984 by Jimmie Heuga as a sports and exercise program for people with MS. The Center is a non-profit organization dedicated to improving the lives of people with MS through educational and wellness programs and on-going research.
The Consortium of Multiple Sclerosis Centers (CMSC)
3 University Plaza Drive, Suite 116
Hackensack, NJ 07601
Phone: 201-487-1050
Email: info@mscare.org
CMSC is a professional organization for multiple sclerosis (MS) health care providers and researchers in North America. The site’s MS Knowledge section covers MS resources such as book reviews, articles, Powerpoint and video presentations, podcasts, and DVDs. The Consortium publishes the International Journal of MS Care, the Multiple Sclerosis Quarterly Report, and various clinical practice guidelines.

Computer Literate Advocates for MS (CLAMS)
CLAMS is a web site bringing those with MS out of isolation and into a web community for support, companionship and information. CLAMS offers live chat and discussion forums and has many links to other sites.

Familia Unida Living with Multiple Sclerosis (FULWMS)
4716 E. Cesar Chavez Avenue, Bldg. A
Los Angeles, CA 90022
Phone: 323-418-2667
Email: info@familia-unida.org
FULWMS is a bilingual non-profit organization with information and services related to MS. Programs include a monthly support group meeting, employment services, counseling, referrals and advocacy.

Healthline: Multiple Sclerosis Center
Healthline offers an educational tutorial on understanding, diagnosing, and treatment of MS. They also offer news and doctor-reviewed content.

Job Accommodation Network (JAN): Accommodation Ideas for Multiple Sclerosis
Phone: 800-526-7234 (Toll-free), 877-781-9403 (TTY)
JAN is a free consulting service that provides information about job accommodations, the Americans with Disabilities Act (ADA), and the employability of people with disabilities. This page, from JAN’s Accommodation and Compliance Series, provides information about MS, ADA information, and resources for additional information to help employers determine effective accommodations for employees with MS.

Martin MS Alliance Foundation
Phone: 877-890-6287 (Toll-free)
Email: KamilahProctor@gmail.com
The Foundation serves under-represented people, including racial and ethnic minorities, the elderly, young people, and people with limited English proficiency. The site has information on MS symptoms, types, and treatments.

https://www.facebook.com/MomsWithMS.StrongerTogether/
Moms With MS
This Facebook page offers online peer support for mothers with MS.

http://www.MSActiveSource.com
MS Active Source
Biogen Idec
5000 Davis Drive
P.O. Box 13919
Research Triangle Park, NC 27709-3919
Phone: 800-456-2255 (Toll-free)
This site sponsored by Biogen Idec is a comprehensive resource that provides a range of services and support for anyone whose life is affected by MS.

http://www.msawareness.org
MS Awareness Foundation
Phone: 888-336-6723 (Toll-free)
E-mail: info@msawareness.org
The Foundation’s goal is to promote self-awareness and educate the public at large about the health and lifestyle challenges facing those affected with MS.

http://www.mscrossroads.org
MS Crossroads
This site offers information, news, and links to other resources.

http://www.msif.org/
Multiple Sclerosis International Federation (MSIF)
3rd Floor Skyline House
200 Union Street
London
SE1 0LX
Phone: +44 207-620-1911
E-mail: info@msif.org
MSIF works to support better understanding and treatment of MS by facilitating international cooperation between MS societies, the international research community and other stakeholders. The site is available in 15 languages.

http://www.mssociety.ca
Multiple Sclerosis Society of Canada
The MS Society provides services to people with multiple sclerosis and their families and funds research to find the cause and cure for this disease. The Society has over 120 local chapters. The site has information on living with MS, research, and treatments.

http://www.erasems.org

Nancy Davis Foundation for Multiple Sclerosis
1875 Century Park East, Suite 980
Los Angeles, CA 90067
Phone: 310-440-4842
The Nancy Davis Foundation for Multiple Sclerosis is dedicated to the treatment and ultimate cure of MS. Funding research is the core focus of the Foundation and all funds raised support the Center Without Walls program, a selected network of the nation’s top MS research centers.

http://www.pediatricmscenter.org/

The National Pediatric Multiple Sclerosis Center
Neurology Associates of Stony Brook
179 North Belle Meade Suite 3
East Setauket, NY 11733
Phone: 631-689-8333
Email: louriecenter@stonybrookmedicine.edu
The National Pediatric MS Center (associated with Stony Brook Children’s Hospital) in New York is dedicated to the clinical care and scientific research of children and adolescents with MS. The center has assembled a unique multidisciplinary team of experts in MS, pediatric neurology, nursing, psychiatry, and neuropsychology.

http://narcoms.org/

North American Research Committee on Multiple Sclerosis (NARCOMS) Registry
NARCOMS Coordinating Center
Washington University School of Medicine
Campus Box 8067
600 S. Euclid Ave.
St. Louis, MO 63110
Phone: 800-253-7884 (Toll-free)
E-mail: msregistry@narcoms.org
NARCOMS is a global registry for Multiple Sclerosis research, treatment, and patient education.

http://www.patientslikeme.com/conditions/1-ms-multiple-sclerosis

PatientsLikeMe: Multiple Sclerosis
This site has statistics on MS symptoms and treatments from registered patients with MS. There is also a discussion forum.
www.ThePreJaxFoundation.com

PreJax Foundation
1741 Travertine Terrace
Sanford, FL 32771
Phone: 407-734-3114
Email: info@ThePreJaxFoundation.com
A non-profit organization that gives college scholarships to people with MS or to children whose parents have MS.

http://multiplesclerosis.ucsf.edu/

UCSF Multiple Sclerosis Center
Pediatric Clinic
1825 4th Street, 5th Floor, Reception 5A
San Francisco, CA 94143
Phone: 415-353-2069

Adult Clinic
1500 Owens Street, Suite 320
San Francisco, CA 94158
Phone: 415-353-3939

The University of California at San Francisco (UCSF) conducts MS research and treats adults and pediatric patients at its clinic. This site has information on MS, including causes, diagnosis, and treatments.

http://www.va.gov/ms

U.S. Department of Veterans Affairs: Multiple Sclerosis Center of Excellence
The VA operates two MS Centers of Excellence, one in Baltimore and one that shares sites in Seattle and Portland. The website has information on diagnosis, symptom management, and therapies (including alternative and complementary medicine) for the general public, veterans, and health care professionals.

http://www.webmd.com/multiple-sclerosis/ss/slideshow-multiple-sclerosis-overview

WebMD: MS Slideshow—A Visual Guide to Multiple Sclerosis
This slideshow has information on symptoms and treatments accompanied by pictures.

Chat Rooms and Internet Discussion Groups

http://www.clams.org
Computer Literate Advocates for MS (CLAMS)
CLAMS offers live chat and discussion forums.

http://www.msworld.org/
MSWorld
MSWorld offers chats and message boards.

Electronic Books
The following booklets are available for free download from Paralyzed Veterans of America (PVA). Go to www.pva.org, click on Publications at the top, then click on Guidelines and Publications on the left, then click Multiple Sclerosis Publications.


- **Multiple Sclerosis Council for Clinical Practice Guidelines. Spasticity Management in Multiple Sclerosis: Evidence-Based Management Strategies for Spasticity Treatment in Multiple Sclerosis (Clinical Practice Guidelines).** Written for health care professionals. Also available in Spanish.


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