

The following excerpt has been taken from the Christopher & Dana Reeve Foundation Paralysis Resource Center website.

http://www.christopherreeve.org/site/c.mtKZKgMWKwG/b.4453223/k.CA46/Multiple_Sclerosis.htm

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.msaa.com

Multiple Sclerosis Association of America (MSAA)

706 Haddonfield Road Cherry Hill, NJ 08002

Phone: 856-488-4500, 800-532-7667 (Toll-free)

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.

http://www.msfacts.org

Multiple Sclerosis Foundation (MSF)

6350 North Andrews Avenue Fort Lauderdale, FL 33309-2130

MS Helpline: 888-MSFOCUS (Toll-free)

Email: support@msfocus.org

A great source of information about MS. 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.

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.beejet.com

Beeiet

Maintained by Elizabeth and Richard Schwab, the site follows Richard's experience with MS and various therapies.

http://www.mscando.org/

Can Do Multiple Sclerosis (formerly The Heuga Center)

27 Main Street, Suite 303

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.

http://www.mscare.org

The Consortium of Multiple Sclerosis Centers (CMSC)

359 Main Street, Suite A 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 sites MS Knowledge section The 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.

http://www.clams.org

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.

http://www.msfamiliaunida.org

Familia Unida Living with Multiple Sclerosis (FULWMS)

4716 E. Cesar Chavez Avenue Los Angeles, CA 90022 Phone: 323-418-2667

Email: info@msfamiliaunida.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.

http://askjan.org/media/mult.htm

Job Accommodation Network (JAN): Accommodation Ideas for Multiple Sclerosis

Phone: 800-526-7234 (Toll-free), 877-781-9403 (TTY)

E-mail: jan@askjan.org

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.

http://www.manyfacesofms.org/

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.

http://www.momswithms.org

Moms With MS

This site offers online peer support for mothers with MS.

http://www.montelms.org/

Montel Williams MS Foundation

331 West 57th Street

PMB 420

New York, NY 10019

Phone: 888-324-2773 (Toll-free)

Email: info@montelms.org

The Foundation provides financial assistance to research organizations and institutions, raises national awarenesss about MS, and educates the public.

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.ms.neurologyreviews.com/

Multiple Sclerosis Comprehensive Care

This site sponsored by Novartis is for health care professionals who treat patients with MS.

http://www.msif.org/

Multiple Sclerosis International Federation (MSIF)

3rd Floor Skyline House 200 Union Street London SE1 0LX

Phone: +44 (0) 20 7620 1911

E-mail: <u>info@msif.org</u>

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

175 Bloor St. E., Suite 700, North Tower

Toronto ON, M4W 3R8

Phone: 416-922-6065, 800-268-7582

Email: info@mssociety.ca

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

1801 Avenue of the Stars, Suite 1400

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/

National Pediatric MS Center

Phone: 631-444-7802

Email: info@pediatricmscenter.org

The National Pediatric MS Center at Stony Brook University 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)

NARCOMS Coordinating Center

The University of Alabama at Birmingham

RPHB 507

1530 3rd Avenue South

Birmingham, AL 35294-0022

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.

http://www.tylerhamiltonfoundation.org

Tyler Hamilton Foundation

37 High Street

Marblehead, MA 01945

Phone: 303-443-8843

The Tyler Hamilton Foundation is dedicated to promoting health and personal empowerment through cycling, and supporting efforts to discover the causes of MS.

http://neurology.ucsf.edu/msc/faq.htm

UCSF Multiple Sclerosis Center

UCSF Multiple Sclerosis Clinic 400 Parnassus Avenue, 8th Floor San Francisco, CA 94117

Phone: 415-353-2069

UCSF Multiple Sclerosis Research Center

350 Parnassus Avenue, Suite 908

San Francisco, CA 94117 Phone: 415-514-1684 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.msdiscuss.com/

Multiple Sclerosis Discussion Forum

This forum sponsored by the Multiple Sclerosis Society of Canada offers a place where people can connect with others who have common experiences and concerns.

http://www.msworld.org/

MSWorld

MSWorld offers chats and message boards.

http://health.groups.yahoo.com/group/About-MS/

About MS: L.I.V.E. with MS

Living in Victory Everyday with MS is a moderated e-mail discussion group open to anyone with an interest in Multiple Sclerosis.

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*.

 Disease Modifying Therapies in Multiple Sclerosis: Evidence-Based Management Strategies for Disease Modifying Therapies in Multiple Sclerosis. Washington, DC: Paralyzed Veterans of America, 2001. Written for health care professionals.

- Fatigue: What You Should Know—A Guide for People with Multiple Sclerosis. Washington, DC: Paralyzed Veterans of America, 2000.
 Written for consumers.
- Fatigue and Multiple Sclerosis: Evidence-Based Management Strategies for Fatigue in Multiple Sclerosis (Clinical Practice Guidelines). Washington, DC: Paralyzed Veterans of America, 2000.
 Written for health care professionals.
- Immunizations and Multiple Sclerosis: Evidence-Based Management Strategies for Immunizations in Multiple Sclerosis (Clinical Practice Guidelines). Washington, DC: Paralyzed Veterans of America, 2001. Written for health care professionals.
- 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.
- Urinary Dysfunction and Multiple Sclerosis: Evidence-Based Management Strategies for Urinary Dysfunction in Multiple Sclerosis (Clinical Practice Guidelines). Washington, DC: Paralyzed Veterans of America, 1999.
 Written for health care professionals.

The following books and videos are available for free loan from the PRC library. For more information, please see www.paralysis.org and click Borrow from Our Lending Library under PRC Quick Links.

Books

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A women's fascinating journey of self-discovery and triumph over MS.

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 This guide on controlling, reducing and eliminating MS symptoms includes over 25 recipes.
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For all nurses preparing to take the examination for MS nursing given by the IOMSN.

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 Autobiography of a woman who lived with progressive MS and recovered.
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