CHRISTOPHER & DANA REEVE FOUNDATION
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Multiple Sclerosis

Multiple sclerosis is a disorder of the brain and spinal cord in which decreased nerve function causes varying levels of disability. Symptoms typically emerge in adults between the ages of 20 and 40, with the disorder occurring more frequently in women than men.

Q: What causes MS?

MS develops when the body's immune system mistakenly attacks the central nervous system; the resulting inflammation damages nerve fibers and leaves multiple areas of scar tissue (sclerosis) that disrupt communication between the brain, spinal cord, and the rest of the body. It is not yet known what triggers the attacks, but researchers are investigating whether environmental and lifestyle factors (smoking, obesity, Vitamin D deficiency) increase risk in people with certain genetic make-ups.

Q: What are the different types of MS?

There are four types of MS: relapsing-remitting MS, secondary-progressive MS, primary-progressive MS, and progressive-relapsing MS.

Relapsing-remitting MS is characterized by recurring attacks of symptoms and periods of inactivity called remission.

Secondary-progressive MS begins as relapsing-remitting MS and worsens over time; not everyone who has relapse-remitting MS will develop secondary-progressive MS.

Primary-progressive MS progresses gradually from onset without remission.

Progressive-relapsing MS is a rare form of MS in which the disease progresses with periods of sudden relapse.

Most people living with MS have relapsing-remitting and secondary-progressive MS.

Q: What are the symptoms of MS?

Symptoms of MS vary based on the location and severity of damage but can include fatigue, spasticity, numbness or tingling in the face or extremities, pain, loss of vision, loss of balance and coordination, incontinence, loss of memory, mood changes and difficulty with emotional control, cognitive dysfunction, weakness in muscles, and paralysis.

Q: How is MS diagnosed?

Blurred or double vision, clumsiness, and numbness or tingling in the face, arms or legs are often early symptoms of the disorder. Healthcare providers who suspect MS will review medical history, perform physical and neurological exams, and may order blood work to rule out other diseases whose symptoms are similar. A lumbar puncture that tests for proteins and inflammatory cells associated with MS, and MRI (magnetic resonance imaging) to identify lesions caused by inflammation will also help confirm diagnosis.

Q: What is the treatment for MS?

There is no cure for MS. Treatment is aimed at controlling symptoms and maintaining function to provide maximum independence and a high quality of life.

Patients with a relapsing-remitting course may be placed on immune modulating therapy to suppress inflammatory reactions; injections will be given 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 effectiveness; discuss side-effects with doctors to choose the best match for individual needs.

Steroids may help decrease the severity of an attack. 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 prescribed for fatigue.

Q: How can I manage my MS?

Physical therapy, speech therapy and occupational therapy may help preserve independence, reduce depression, maximize function, and improve coping skills. Exercise programs can help maintain muscle tone.

An MS attack can be triggered by many factors, including fatigue, stress, physical deterioration, temperature extremes, and illness; pay close attention to your health and environment to reduce risks of an attack.

Life expectancy for MS can be normal or nearly so. Most people with MS continue to walk and function at work with minimal disability for 20 or more years after diagnosis.

Q: Are there clinical trials for MS?

Yes. To find current MS trials, visit ClinicalTrials.gov (https://clinicaltrials.gov), a searchable website for publicly and privately supported clinical studies maintained by the National Library of Medicine at the National Institutes of Health (https://www.nih.gov)**.**

Sources: National Institute of Neurological Disorders and Stroke, National Multiple Sclerosis Society, Merck Manual.

Need to talk to someone?
Our Information Specialists are available to answer your questions.
Call toll-free 1-800-539-7309 Mon-Fri, 7 am-8 pm EST.
Or schedule a call or ask a question online at
https://www.ChristopherReeve.org/Ask.

Resources for MS

Multiple Sclerosis Association of America (MSAA)
http://www.mymsaa.org/

375 Kings Highway North
Cherry Hill, NJ 08034
Phone: 800-532-7667 x154
Email: MSquestions@mymsaa.org
MSAA provides information and support to individuals living with MS and their families, Services include a helpline, mobility equipment and cooling vests distribution programs, and a fund to help cover the costs of MRIs.

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

National Multiple Sclerosis Society (NMSS)
http://www.nmss.org
733 Third Avenue, 3rd Floor
New York, NY 10017
Phone: 800-344-4867 (Toll-free)
NMSS provides information on daily living, treatments and scientific progress, MS specialty centers, clinical research, and an annotated bibliography for healthcare professionals. Chapters in all 50 states and Washington, DC, provide services including employment counseling, family programs, and advocacy.

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

AboveMS
https://www.abovems.com/
Biogen
5000 Davis Drive
P.O. Box 13919
Research Triangle Park, NC 27709-3919
Phone: 800-456-2255
This website is sponsored by Biogen, a biotechnical company that has developed medications to treat MS. Topics include symptoms, diagnosis, treatment, fitness, nutrition, and travel.

Active MSers
www.activemsers.org

Email: dave@activemsers.org
Active MSers, founded by Dave Bexfield, aims to help individuals with multiple sclerosis stay as active as possible—physically, intellectually, and socially—regardless of physical limitations. The website provides information about exercising and travelling with MS and offers a forum for individuals and family members to connect and share tips.

Autoimmune Association
https://autoimmune.org/
19176 Hall Road, Suite 130
Clinton Township, MI 48038, United States
Phone: 586-776-3900
Email: hello@autoimmune.org
The Autoimmune Association is dedicated to the eradication of autoimmune diseases (including MS) and promotes collaboration in the areas of education, public awareness, research, and patient services.

Can Do Multiple Sclerosis
https://www.cando-ms.org/
100 W. Beaver Creek Blvd., Suite 200
Avon, CO 81620
Phone: 970-926-1290, 800-367-3101 (Toll-free)
Email: info@CanDo-MS.org
Founded in 1984 by alpine skier and Olympic medalist 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.

Consortium of Multiple Sclerosis Centers (CMSC)
https://www.mscare.org/
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 that offers continuing education opportunities and patient education resources. CMSC publishes the International Journal of MS Care and various clinical practice guidelines.

Familia Unida Living with Multiple Sclerosis (FULWMS)
http://www.msfamiliaunida.org
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 that provides information and services to families living with MS, including monthly support group meetings, food pantry

programs, employment services, counseling, referrals, and advocacy.

Healthline: Multiple Sclerosis Center
http://www.healthline.com/health/multiple-sclerosis
Healthline is a medical website offering news and doctor-reviewed content about disorders and diseases, including MS.

Job Accommodation Network (JAN): Accommodation Ideas for Multiple Sclerosis
https://askjan.org/disabilities/Multiple-Sclerosis.cfm
Phone: 800-526-7234 (Toll-free), 877-781-9403 (TTY)
JAN, a free service of the U.S. Department of Labor’s Office of Disability Employment Policy (https://www.dol.gov/agencies/odep), provides resources and information about job accommodations, the Americans with Disabilities Act (ADA), and employment for people with disabilities. This page, from JAN’s Accommodation and Compliance Series, lists ADA information and resources to help employers determine effective accommodations for employees with MS.

Martin MS Alliance Foundation
https://www.facebook.com/groups/2204172104/
The Foundation works to increase support, education and resources for under-represented people living with MS. The site has information on MS symptoms, types, and treatments.

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

Multiple Sclerosis International Federation (MSIF)
http://www.msif.org/
Unit A Arc House
82 Tanner St.
London SE1 3GN
United Kingdom
Phone: +44 207-620-1911
Email: info@msif.org
MSIF is a global network of MS organizations that works to increase awareness, support families living with MS, and accelerate research. Its MS Resource Hub contains information on 16 topics in more than 30 languages.

Multiple Sclerosis Society of Canada
http://www.mssociety.ca
250 Dundas St. West, Suite 500
Toronto ON, M5T 2Z5
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 advance treatment and care. The site provides information about living with MS, current research, and how to find local support groups.

National Pediatric Multiple Sclerosis Center
https://www.stonybrookchildrens.org/locations/national-pediatric-ms-center
Neurology Associates of Stony Brook
181 North Belle Meade Suite 6
East Setauket, NY 11733
Phone: 631-444-2599
Email: louriecenter@stonybrookmedicine.edu
The National Pediatric MS Center (associated with Stony Brook Children's Hospital) provides clinical care for children and adolescents with MS with a multidisciplinary team comprised of pediatric neurology, nursing, psychiatry, and neuropsychology.

North American Research Committee on Multiple Sclerosis (NARCOMS) Registry
http://narcoms.org/
NARCOMS Coordinating Center
UT Southwestern Medical Center
5323 Harry Hines Blvd.
Mail stop 8806
Dallas, TX 75390-8806
Phone: 1-214-648-4583
Email: msregistry@narcoms.org
NARCOMS is a global registry for Multiple Sclerosis research, treatment, and patient education.

PatientsLikeMe: Multiple Sclerosis
http://www.patientslikeme.com/conditions/1-ms-multiple-sclerosis
This online community platform connects individuals with medical conditions, including MS. A discussion forum allows people to share personal stories and information about their health, symptoms, and treatments; commonly experienced symptoms and management tips from the community are also featured.

Race to Erase MS
http://www.erasems.org
1875 Century Park East, Suite 280
Los Angeles, CA 90067
Phone: 310-440-4842
Race to Erase MS raises funds to support MS research at the Center without Walls, its network of interdisciplinary scientific programs across the U.S. A newsletter includes information on MS from the Center Without Walls research team, grant recipient highlights, health tips and resources.

Rocky Mountain MS Center
https://mscenter.org/
8845 Wagner St

Westminster, CO 8003
Phone: 303-788-4030
This center is committed to improving the lives of individuals and families living with MS and other neurological diseases through care, support, education, and research.

UCSF Multiple Sclerosis and Neuroinflammation Center
http://multiplesclerosis.ucsf.edu/
1651 Fourth St., suite 252
San Francisco, CA 94158
Phone: 415-353-2069
The University of California at San Francisco (UCSF) conducts MS research and treats adults and pediatric patients at its clinic. This website has information about MS, including diagnosis, treatment, and support services offered by the clinic.

U.S. Department of Veterans Affairs: Multiple Sclerosis Centers of Excellence
http://www.va.gov/ms
The VA operates two MS Centers of Excellence, one that shares sites in Baltimore and Washington D.C, 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 veterans, family members, and health care professionals.

WebMD: MS Slideshow—A Visual Guide to Multiple Sclerosis
http://www.webmd.com/multiple-sclerosis/ss/slideshow-multiple-sclerosis-overview
This slideshow has information on symptoms and treatments accompanied by pictures.

Chat Rooms and Internet Discussion Groups

NMSS: Online Chat Groups
https://www.nationalmssociety.org/resources/get-connected/online-communities

Electronic Books

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

- **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 individuals and families.

- **Fatigue: What You Should Know—A Guide for People with Multiple Sclerosis**. Washington, DC: Paralyzed Veterans of America, 2000. Written for healthcare professionals.

- **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).** Also available in Spanish. Washington, DC: Paralyzed Veterans of America, 2005. Written for health care professionals.

- **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.

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