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Fact Sheet: Multiple Sclerosis

Definition

Multiple Sclerosis (MS) is one of the most commonly encountered neurological diseases, yet its cause is unknown and its course unpredictable. MS is a disorder of the brain and spinal cord which results from a scattered loss of myelin, a fatty substance that surrounds the nerve cells. Myelin is considered important for separating nerve pathways from each other, so that impulses can travel from one location in the nervous system to another. "Multiple" comes from the multiple sites where demyelination occurs in the brain and spinal cord. "Sclerosis" refers to "sclera" or scar tissue which can obstruct or distort the flow of messages between nerves and to muscles.

Facts

About 350,000 people nationwide have MS. MS affects people of all ages, but is most likely to begin between the ages of 20 and 40. Women are twice as likely as men to develop MS. MS differs markedly from one patient to another.

Prognosis

It is often very difficult to predict the course of MS. The great variability of this disorder must be considered in each individual case. Some studies have shown that the degree of disability present at five years after the onset of symptoms is a good predictor of disability at 10 or 15 years after onset, and many neurologists use this "five year" rule in predicting a person's course. Other studies suggest that sensory problems (e.g., loss of feeling on the skin's surface, "pins and needles," or increased sensitivity to pain) are associated with a good prognosis, that is, a relatively benign course. Early onset of cerebellar findings, (e.g., tremor, coordination problems and slurred speech) tend to be linked to a more progressive disease course.

MS tends to take one of four clinical courses. Some people have the *benign* sensory form, where attacks are characterized by sensory symptoms and/or optic neuritis. These individuals generally do not have severe long-term disability. Many people with MS have a *relapsing/remitting* course characterized by periodic, unpredictable exacerbations where existing symptoms worsen or new symptoms appear. Remission from such flare-ups may be complete or partial. A relapsing-remitting course which later becomes steadily progressive is called *secondary-progressive*. In this course, attacks and partial recoveries may continue to occur. A minority of people with MS have a severe, *progressive* form of the disease from onset, where symptoms generally do not remit, but tend to be progressive

from the onset. Research is currently going on to try and identify more precise prognostic indicators of disease activity.

Symptoms

The most prominent symptoms are:

Visual Problems—Ranging from blurred vision
to more serious visual impairment, often a symptom which disappears later. Blindness in MS is rare.

Ataxia—Difficulties in controlling the strength
and precision of movements, so that holding things is a problem; balance and coordination may be impaired.

Sensory Problems—Numbness, tingling and sensitivity to heat or cold.

Bladder—Control problems and urinary tract
infections.

Mood Swings—Ranging from depression to
euphoria.

Fatigue—Mild to severe fatigue and weakness.

Cognitive Problems

About 50% of people with MS will develop some cognitive dysfunction. In MS, this generally means slowed ability to think, reason, concentrate, or remember. But only 10% of the group with cognitive dysfunction develop problems that are severe enough to interfere in a significant way with daily activities. While cognitive dysfunction is more common among people who have had the disease for a long time, it can be seen early on, and occasionally cognitive problems are present from the onset of the disease. Among those individuals affected by cognitive impairment, the most common problems include:

- Memory recall, particularly remembering recent events.
- Slowness in learning and processing new
  information.
- Difficulty with abstract reasoning, such as analyzing a situation, planning a course of action, and following through.
- Poor judgment.
- Impaired verbal fluency, such as slowed speech or difficulty coming up with a word during conversation.

Cognitive problems associated with MS are not related to a person's level of physical disability and can potentially affect people with few physical symptoms of MS. In addition, cognitive problems can develop rapidly during an exacerbation of the disease. In these cases, the cognitive deficits can improve as the person comes to a remission. It is important to stress 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 deficits can dispel misunderstandings about a person's apparent forgetfulness, carelessness, or seeming indifference. Families can be supportive and help the person compensate. Understanding deficits can alleviate fears about losing one's capacities. If cognitive impairment is suspected, this topic should be discussed with the person's doctor. In some cases, depression or medications can mimic cognitive problems. These can be treated separately. A neurologist can perform a brief evaluation to test for pronounced (severe) cognitive deficits. However, a neuropsychologist (preferably one with experience with MS) may be recommended to perform a more complete evaluation to test for subtle cognitive changes. If deficits are found, the neuropsychologist can follow up to help individuals and their families cope with cognitive problems and to work on
cognitive rehabilitation.

Individuals can use a number of compensatory strategies to cope with mild cognitive problems. These include memory aides 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, although Magnetic Resonance Imaging (MRI) is currently the most sensitive diagnostic test. The diagnostic process usually takes a period of time and is based on cumulative symptoms and tests and a good patient medical history.

Treatment

There are three disease-modifying treatments available to people with MS. Interferon beta-1a (Avonex), interferon beta-1b (Betaseron), and glatiramer acetate (Copaxone), widely known as the "ABC" drugs, can be effective in modifying the course of the disease and help slow disease progression for many people. While these medications are currently approved by the FDA only for people who have relapsing-remitting MS, interferon beta-1b and interferon beta-1a are being studied for treatment of secondary-progressive MS, and glatiramer acetate is being studied for treatment of primary-progressive MS.

Other treatment is targeted to help patients function at their best level on a day-to-day basis. Corticosteroids were the first agents used for successful treatment of MS and remain one of the standard treatments for controlling exacerbations. This varies, however, from individual to individual. Medications are available for symptomatic treatment. Physical therapy and antispasticity medications are often effective in relieving spasticity. Bowel and urinary distress are treated with management programs, and some people benefit from intermittent catherization. A urologist or neurologist can help determine if this option is suitable. Rehabilitation programs are helpful in some cases to increase muscle strength or improve walking ability.

Getting Support

It is important for both individuals and family members to get support when dealing with MS. Support groups are often available for both individuals and family caregivers. Counseling also may be helpful for individuals or couples learning to cope with chronic illness or periodic health crises. Caregivers with constant care responsibilities should schedule some time off from caregiving. Respite care can be arranged through family members, friends, volunteer services, independent living centers, or home
care agencies.

Recommended Readings

Multiple Sclerosis: The Questions You Have, the Answers You Need, Rosalind Kalb, 1996, 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.

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.

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

National Multiple Sclerosis Society, 1999, *Making Treatment Decisions: It's Your Call*, 1999 Teleconference.

National Multiple Sclerosis Society, 1998, *What Is Multiple Sclerosis?*

National Multiple Sclerosis Society, 1998, *Solving Cognitive Problems.*

Resources

National Multiple Sclerosis Society
733 Third Ave., 6th Floor
New York, NY 10017
(212) 986-3240
(800) FIGHT-MS (rings to nearest chapter office)
www.nmss.org

The National Multiple Sclerosis Society provides information and referral, self-help or support groups, advocacy, programs for people newly diagnosed, education programs, a chapter newsletter, and library. Some chapters provide additional services. Contact your local chapter at 1-800-FIGHT MS for more information. There are eight MS Society Chapters throughout California. The coalition of California chapters is called MS-CAN.

American Academy of Physical Medicine and Rehabilitation
IBM Plaza, Suite 2500
Chicago, IL 60611-3604
(312) 464-9700
www.aapmr.org

American Board of Clinical Neuropsychology
Department of Pychiatry
c/o Linus Bieliasukas
University of Michigan Medical Center
1500 E. Medical Center Drive
Ann Arbor, MI 48109-0704
(734) 936-8269
www.med.umich.edu/aben

American Occupational Therapy Association
4720 Montgomery Lane
Bethesda, MD 20824
(301) 652-AOTA
www.aotoa.org

Independent Living Research Utilization Program
2323 South Shepard, Suite 1000
Houston, TX 77019
(713) 520-0232
(713) 520-5136 TDD
www.ilru.org/ilru-overview.html

National Association for Continence
P.O. Box 8310
Spartanburg, SC 29305-8310
(800) BLADDER
(864) 579-7900
www.nafc.org

Well Spouse Foundation
30 East 40th Street, PH
New York, NY 10018
(212) 685-8815
(800) 838-0879

American Academy of Neurology
1080 Montreal Avenue
St. Paul, MN 55116
(612) 695-1940
www.aan.com

National Institute of Neruological Disorders and Stroke
Building 31, Room 8A-06
31 Center Drive, MSC 2540
Bethesda, MD 20892-2540
(800) 352-9424
www.ninds.nih.gov.

California Foundation for Independent Living Centers
910 K Street, Suite 350
Sacramento, CA 95814-3577
(916) 325-1690
(916) 325-1695 TDD

Reviewed by Emily Keller, Director, Information and Referral Coordinator, National Multiple Sclerosis Society, Northern California Chapter. Prepared by Family Caregiver Alliance in cooperation with California's Caregiver Resource Centers, a statewide system of resource centers serving families and caregivers of brain-impaired adults. Funded by the California Department of Mental Health. Revised September 1999.