



DEL MAR CAREGIVER RESOURCE CENTER

A program of Health Projects Center

Fact Sheet

Huntington's Disease

Definition

Huntington's disease is a hereditary disorder of the central nervous system. Symptoms typically appear in adult life between the ages of 30 and 50. It is most often characterized by chronic progressive chorea and dementia without remissions.

Facts

It is estimated that 30,000 persons have Huntington's disease nationwide. Another 150,000 are at a 50 percent risk of inheriting the disease from an affected parent. The age of onset can range from age two to over age 80. The disease runs a relentless degenerative course over a period of 10-25 years. The patient eventually succumbs to complications such as heart failure or aspiration pneumonia.

Symptoms

An individual with Huntington's disease often has problems in three areas: control of bodily movements, intellectual functioning and emotional control. The intensity and number of the above symptoms, however, varies with each Huntington's disease patient.

Chorea--quick, jerking, uncontrollable movements of the limbs, trunk and face are the most obvious symptoms. The patient's gait is often mistaken for that of a person who is drunk.

Poor short-term memory and judgment--

Although most patients continue to recognize their caregivers and can give feedback about their condition and care, the Huntington's disease patient suffers declining mental skills as the disease progresses.

Depression, irritability and apathy can be noted before and after the onset of chorea in a percentage of the Huntington's disease population. Some patients may exhibit schizophrenic-like behavior.

Diagnosis of Huntington's Disease

If there is a positive family history of Huntington's disease, the presence of an extrapyramidal movement disorder (when nerve impulses are not properly transferred to the muscles) is usually enough to confirm a diagnosis. Conventional neurological examinations and the presence of depression and other psychological disturbances are not enough to provide an accurate diagnosis.

The Huntington's Disease Gene and Genetic Testing

In 1993, after a ten-year search, scientists announced the discovery of the gene which causes Huntington's disease. This breakthrough has led to the development of a direct gene test for HD which can be used to predict the onset of Huntington's before symptoms develop. This test is more accurate and less complicated than the genetic marker test which has been in place since 1986.

Del Mar Caregiver Resource Center

Serving Monterey, San Benito and Santa Cruz Counties

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The gene discovery shows the Huntington's disease is caused by a "genetic stutter"--a stretch of DNA repeated over and over at one end of a gene on Chromosome four. Efforts continue to determine precisely how this genetic mutation leads to the symptoms of the disease.

Contact local chapter or HDSA National Office for a list of testing centers. Progress is being made in other areas of research, too. Clinical drug trials are being conducted at 30 sites of the Huntington Study Group around the country.

Treatment

There is no cure for Huntington's disease. Medication can help the involuntary movements and emotional disorders for some Huntington's disease patients. Because of the strong emotional impact of the diagnosis and the stress of living with the knowledge that the children in the family may be at risk, family counseling and/or participation in support groups can be very helpful.

Recommended Reading

Genes & Generations: Living With Huntington's Disease, Alison Gray, 1995, Wellington Huntington's Disease Association, Social Work Dept. (Res. 2), Wellington Hospital, Private Bag 7902, Wellington South, New Zealand. To order, send \$15.00 check payable to Wellington Huntington's Association.

A Physician's Guide to the Management of Huntington's Disease: Pharmacologic and Non-Pharmacologic Interventions, Neal Ranen, Carol Peyser, Susan Folstein, 1993, Huntington's Disease Society of America (HDSA), New York, NY.

Toward a Fuller Life: A Guide to Everyday Living with Huntington's Disease, Eileen Werbel, 1990, HDSA, New York, NY.

Huntington's Disease: A Disorder of Families, Susan E. Folstein, 1989, The Johns Hopkins University Press, Baltimore, MD.

Living With Juvenile Huntington's Disease, edited by Wendy Elliott, 1993, Huntington Society of Canada, Cambridge, Ontario.

Contact HDSA to obtain a current publications list which includes written and audiovisuals pertaining to all aspects of Huntington's disease.

Credits

Huntington's Disease Society of America, 1996, New York, NY.

Resources

MONTEREY COUNTY

**Health Projects Center's
Del Mar Caregiver Resource Center**
(831) 424-4359
Web site: www.delmarcaregiver.org

SANTA CRUZ COUNTY

**Health Projects Center's
Del Mar Caregiver Resource Center**
(831) 459-6639
Web site: www.delmarcaregiver.org

SAN BENITO COUNTY

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

Family Caregiver Alliance

180 Montgomery Street, Suite 1100
San Francisco, CA 94104
(415) 434-3388
(800) 445-8106 (in CA)
Web Site: <http://www.caregiver.org>
E-mail: info@caregiver.org

Family Caregiver Alliance supports and assists caregivers of brain-impaired adults through education, research, services and advocacy.

FCA's information Clearinghouse covers current medical, social, public policy and caregiving issues related to brain impairments.

For residents of the greater San Francisco Bay Area, FCA 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.

Huntington's Disease Society of America

140 West 22nd St., 6th Floor
New York, NY 10011-2420
(212) 242-1968
(800) 345-HDSA

The Huntington's Disease Society of America (HDSA) supports research on Huntington's disease, produces and disseminates educational materials for the public and professionals, and advocates the needs of families.

Foundation for the Care and Cure of Huntington's Disease

82681 Overseas Highway
P.O. Box 1084, IIsamorada, FL 33036
(305) 664-5044

California Resources

Regional HDSA chapters across the U.S. provide information and referrals, operate education and publicity programs, run support groups, and offer a range of services for people with Huntington's disease and their families. California chapters of HDSA are listed below:

Greater Los Angeles Chapter

9903 Santa Monica Blvd., Ste. 106
Beverly Hills, CA 90212
(213) 294-7250
Contact: Joyce Bryan, LCSW

Northern California Chapter

1212 Broadway St., Ste. 830
Oakland, CA 94612
(510) 526-3137
Contact: Jane Warren, LCSW

San Diego County Chapter

P.O. Box 152263
San Diego, CA 92195-2263
(619) 552-8585 ext. 3431
Contact: Dawn Stoll-Fernandes, MS

Genetically Handicapped Persons Program

State of California Department of Health Services
714 "P" St., Room 300
Sacramento, CA 95814
(916) 654-0503

The GHPP is a State program which provides coordination of care and helps pay for medical costs of persons with Huntington's disease.

Reviewed by the Huntington's Disease Society of America, February 1996. Prepared by Family Caregiver Alliance in cooperation with the State of California's Caregiver Resource Centers, a statewide system of resource centers serving families and caregivers of brain-impaired adults. Revised July 1996. Funded by the California Department of Mental Health. ©All rights reserved.