

How Can I Help?

You may make a tax-deductible donation to the Huntington's Disease Society of America.

Make checks out to HDSA

Mail to:

HDSA

New England Regional Office

6 Courthouse Lane, Unit 12.

Chelmsford, MA 01824

Other Ways to Give

- ◆ Through the United Way or Community Health Charities, (Please write in HDSA/NE) Mail to the address above.
- ◆ Matching Gifts Program
- ◆ The Federal Government Campaign for federal, state, school district, or city employees. (Please write in HDSA/NE)
- ◆ Tributes and Memorials
- ◆ Charitable Bequests
- ◆ Non-monetary Gifts such as marketable property, gifts in-kind, and insurance.

Huntington's Disease

Society of America

New England Regional Office

The New England Region of the National Huntington's Disease Society of America serves over 5,000 members throughout Massachusetts, Connecticut, New Hampshire, Rhode Island, Vermont and Maine. HDSA is a non-profit organization that is dedicated to finding a cure for Huntington's Disease (HD) while providing support and services to persons with HD and their families, and educating the public.

Some of Our Programs Include:

- ◆ Support Groups
- ◆ Referrals
- ◆ Education
- ◆ Advocacy
- ◆ Volunteer Program
- ◆ Newsletter (Three Editions a Year)
- ◆ Publications

For more information on our programs visit our website at www.hdsa-ne.org



Hope for
Tomorrow



Help for
Today

HDSA

New England Regional Office



*Frequently
Asked Questions about
Huntington's
Disease*



HDSA

New England Regional Office

6 Courthouse Lane, Unit 12.

Chelmsford, MA 01824

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Website: www.hdsa-ne.org

What Is Huntington's Disease? (HD)

It is a neurodegenerative disease meaning there is cell death in parts of the brain. The cell death results in an array of symptoms causing a slow deterioration of the mind and body. There is no cure for HD at this time although researchers are making great strides.

What are the symptoms?

People with Huntington's Disease slowly lose the ability to speak, swallow, and walk. They develop involuntary movements and increased difficulty with coordination. Thinking and reasoning skills become impaired. They may develop mood swings such as irritability, anxiety, and apathy. Some will develop a major depression or other types of psychiatric symptoms including: psychosis, bipolar disorder, and obsessive compulsive disorder. In the end stages of the disease, the individual is usually unable to communicate, and is totally dependent on others for care.



The Cure
Starts Here.

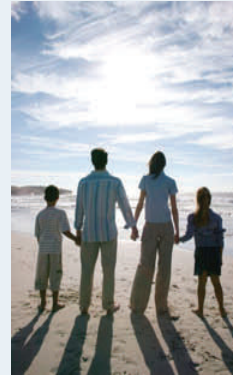


The Care
Never Ends

About Huntington's Disease

Do symptoms vary among individuals?

Symptoms vary greatly, even among affected family members. Individuals may have quite different severities of physical symptoms, emotional symptoms or cognitive symptoms. For example, one person may experience more severe and frequent involuntary movements than another. The rate of progression of the disease varies greatly as well. Symptoms in the early stages of the disease are usually mild and progress over time. For example, individuals start to have an unsteady gait, begin to fall, become weaker over time and require the use of a walker and wheelchair. Death usually occurs 15 to 20 years after symptoms begin.



How many people have HD and at what age do they develop symptoms?



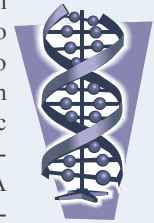
At least 30,000 people in the US have HD. The prevalence is 1 in 10,000. There are another 200,000 people at risk for developing the disease. While symptoms can begin at any age, from childhood to very late in life, most commonly symptoms begin between the ages of 30 and 50. Some individuals become symptomatic in their 20's and others are in their 60's.

Do children get Huntington's Disease?

Yes, although it is uncommon, children as young as 2 have been diagnosed with Juvenile Huntington's Disease (JHD). Although it is the same underlying disease as in adults, symptoms can differ and it can progress more rapidly.

How do you get HD and is there a test?

HD is usually inherited from a parent with HD. Every child of a parent with HD has a 50% chance of inheriting the mutated gene. If an individual inherits the mutated gene, they will develop the disease at some point in their life unless they die of some other cause before symptoms begin. There is a blood test to determine whether the genetic mutation is present. This test can be used in those who have symptoms to confirm that they are due to HD. It can also be used in those who do not yet have symptoms to determine if they will get them one day (pre symptomatic testing). This test is not performed in minors. HDSA recommends that genetic testing be performed through a certified testing center to insure sufficient counseling about the risks and benefits of testing. The test results are 99.9% accurate. The test **cannot** determine age of onset.



Is there any treatment for HD?

Although there are not yet any treatments that slow down the progression of HD, there are many treatments to help manage or lessen symptoms. These treatments may include medications, physical therapy, occupational therapy, nutrition, speech and swallowing therapy, and counseling. There are many medications to help with mood swings and behavior problems. High calorie diets keep weight on and often improve speech and the ability to walk. Exercises and adaptive equipment may help prevent falls. Many findings in the research labs are translating into clinical trials to determine their potential to delay the onset or slow progression of HD symptoms.