

Education

Huntington's Disease (HD)

What is Huntington's disease?

Huntington's disease (HD), also called Huntington's chorea, is a rare, fatal disease that causes nerve cells in the brain to slowly waste away. This results in chorea, which is the medical word used for jerky movements of the face, arms, neck, and trunk that you cannot control. Huntington's disease also causes dementia, which is a gradual loss of mental function.

How does it occur?

The disease is passed from parent to child by a faulty gene. If one parent has this gene, his or her children have a 50% chance of having the disease.

What are the symptoms?

The disease develops slowly and is sometimes hard to recognize. Symptoms usually affect movement, personality, and mental function.

Symptoms related to movement may include:

- clumsiness
- repeated, irregular movement of eyebrows and forehead
- facial grimaces
- rigid muscles
- loss of balance
- trouble walking
- uncontrolled jerking movements of arms, legs, and trunk
- halting speech.

Symptoms related to personality and mental function may include:

- having hallucinations (seeing or hearing things that are not really there)
- having delusions (false beliefs or ideas)
- being suspicious without cause
- neglecting personal appearance and hygiene (failing to change clothes or bathe, for example)
- neglecting duties (such as not paying bills or going to work)
- being depressed
- being irritable
- behaving irresponsibly, impulsively, or violently (such as driving recklessly, getting drunk, or starting fights)
- losing the ability to remember, think logically, or exercise judgment
- becoming unaware of person, place, and time (not knowing who or where you are or what time, date, or day it is).

How is it diagnosed?

Your health care provider will examine you and ask about your symptoms and medical and family history. A blood test may be done to check for the gene that causes the disease.

How is it treated?

There is no cure. Drugs may help lessen the movements of chorea. They can also help control behavior somewhat. You may be cared for at home until symptoms become severe. Then you may need to stay at a care facility.

How long will the effects last?

The symptoms usually begin between the ages of 35 and 50 and get worse over time. Most people live for about 15 years after symptoms begin, but some live twice that long. If symptoms begin at a young age, the disease may worsen more

quickly.

How can I help take care of myself?

It's important to try to maintain as much independence as possible. Occupational therapists are very helpful in finding ways you can stay physically independent. Also important is finding a counselor or mental health therapist who can help you sort out the usual ups and downs of life from symptoms of Huntington's disease.

Work closely with your health care provider to find the medicines that help the most with movement problems and emotional problems.

Join a Huntington's support group and encourage your family members to join also. In addition to the helpful personal relationships that can develop in these groups, they are perhaps the best way to learn of community resources for people with Huntington's and their families.

How can I prevent Huntington's disease?

Because Huntington's is a genetic disease, genetic counseling is highly recommended for all family members. The genetic counselor can tell you how the illness might be prevented in future generations.

For more information, contact:

The Huntington's Disease Society of America Phone: 800-345-4372 Web site: <http://www.hdsa.org>

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