MANAGING YOUR HUNTINGTON DISEASE

What Is Huntington Disease?

Huntington disease (or Huntington chorea) involves degeneration of certain parts of the brain. These parts control movement, thinking, memory, perception, and intelligence. About 30,000 people have this disease in the US. At least 150,000 others have a 50% chance of getting the disease.

Today, genetic testing can confirm the diagnosis.

What Causes Huntington Disease?

This inherited disorder is passed from parents to children. The specific cause is a mutation of a gene on chromosome 4. A mutation means that an error was made in building blocks that make up the DNA (deoxyribonucleic acid). DNA carries genetic information. The mutation leads to too much protein called huntingtin being made. This protein may cause a loss of brain cells and symptoms of the disease.

What Are the Symptoms of Huntington Disease?

This disease can occur between the ages of 2 and 70 years but is usually diagnosed in early adulthood, at age 30 to 40. Uncontrolled movements called chorea, unsteadiness, clumsiness, loss of balance, slurred speech, and trouble swallowing and eating are symptoms. Chorea is a twisting dance-like motion, usually starting in the feet, fingers, face, or upper chest. Anger, mood swings, irritability, loss of memory, and poor judgment can also occur. Not all people have these exact symptoms. Some may appear rigid, with little movement, or have fine twitching with tremors.

The disease is progressive, meaning slow loss of motor and thinking skills continues. Death can result, most often from pneumonia or complications from injuries.

How Is Huntington Disease Diagnosed?

The health care provider will make a diagnosis from the medical history, physical examination, and laboratory tests. Other tests such as computed tomography (CT) and magnetic resonance imaging (MRI) will be done to exclude other illnesses that may cause similar symptoms.

A neurologist (specialist in nervous system diseases) and other specialists may help with diagnosis and treatment.

How Is Huntington Disease Treated?

No treatment is available that will reverse Huntington disease.

Antidepressant medicines can be used for depression. Antipsychotic drugs (haloperidol) or benzodiazepines (e.g., diazepam or clonazepam) may help the problems with movement.

DOs and DON'Ts in Managing Huntington Disease

- ✔ **DO** understand that this disease is inherited. When a family member is diagnosed with Huntington disease, you may have overwhelming anxiety about knowing or not knowing whether you have the Huntington disease gene. Children of a person with the disease have a 50% chance of inheriting the disease gene.
- ✔ **DO** remember that genetic markers or tests can be done to find out whether you carry the Huntington gene. The decision to have this test won’t be easy. Refer to guidelines of the Huntington’s Disease Society of America (HDSA).
- ✔ **DO** call your health care provider if a family member has been diagnosed with Huntington disease.

⊗ **DON'T** forget that people with this disease need a team of caregivers. The best person to see for advice is the neurologist. Physical therapists, occupational therapists, psychiatrists, and social workers can all help with treatment.

⊗ **DON'T** be afraid to ask for more information. If you are thinking of being tested for Huntington disease, it is important to have pre- and post-test counseling.

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FOR MORE INFORMATION

Contact the following source:

- Huntington's Disease Society of America: Tel: (800) 345-4372; Website: http://www.hdsa.org
- American Academy of Neurology: Website: http://www.neurology.org