What are the Symptoms of HD?

Huntington Society of Canada
HUNTINGTON
Société Huntington du Canada

What are the Symptoms?

- Emotional turmoil (depression, apathy, irritability, anxiety, obsessive behaviour)
- Cognitive loss (inability to focus, plan, recall or make decisions; impaired insight)
- Physical deterioration (weight loss, involuntary movements, diminished coordination, difficulty walking, talking, swallowing)

There are significant variations in symptoms, and not every person will have all the symptoms to the same degree. Symptoms also vary with each stage of the disease.

Early Stages

Early symptoms of the disease often include subtle cognitive changes.

- May have difficulty organizing routine matters or coping effectively with new situations
- May have difficulty recalling information; may appear forgetful
- Work activities may become more time-consuming
- Decision making and attention to detail may be impaired
- May include irritability

Slight physical changes may also develop at this stage. There can be involuntary movements which may initially consist of "nervous" activity, fidgeting, twitching of the hands or feet, or excessive restlessness. Individuals may also notice a little awkwardness, changes in handwriting, or difficulty with daily tasks such as driving. At this stage, people with Huntington's can function quite well at work and at home. As the disease progresses, the symptoms become worse.

Intermediate Stages

As the disease progresses, the symptoms become worse. The initial physical symptoms will gradually develop into more obvious involuntary movements such as jerking and twitching of the head, neck and arms and legs. These movements may interfere with walking, speaking and swallowing. People at this stage of Huntington's often stagger when they walk and their speech may become slurred. They may have increasing difficulty working or managing a household, but can still deal with most activities of daily living.

Advanced Stages

The advanced stages of Huntington's typically involve fewer involuntary movements and more rigidity. People in these stages of HD can no longer manage the activities of daily living and usually require professional nursing. Difficulties with swallowing, communication, and weight loss are common. Death usually occurs 15 to 25 years after the onset of the disease. People do not die from Huntington's itself, but from complications such as choking, heart failure, infection or aspiration pneumonia.

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What is Juvenile HD

Close to 10 percent of Huntington disease cases are considered "juvenile" – that is, the symptoms occur in childhood or adolescence. Symptoms of juvenile HD are somewhat different from the adult disease.

- Children with HD move slowly and stiffly
- Increased difficulty learning
- May have convulsions or epileptic seizures
- Some children have severe behavioural problems

Because these symptoms can be very different from those in adults, it can be difficult to diagnose. Neurologists, psychologists, genetic counsellors and social workers can play an important role in helping individuals or families deal with the disease. Physical therapists, occupational therapists and speech therapists can also help people with Huntington's cope better with some of the symptoms. And because people with HD often lose a lot of weight, a nutritionist can be very helpful. It is important that all of these professionals work together to help manage the most effective treatment for each individual, since the disease often develops differently in different people.

Genetic Testing

Since 1986, genetic testing for HD has been available; however, a direct test for the disease was developed in 1993. This means people who are at-risk for Huntington's or who believe they have the symptoms can take a blood test to determine whether they have the gene that causes HD. Many people at-risk choose not to take the test. It is a personal decision and varies from person to person as there is still no treatment to prevent HD from developing if the gene is present. Others make the decision to be tested so they can make arrangements as far as careers, family planning, and other issues are concerned. Anyone considering taking the test should have genetic counselling. This will ensure that the person understands what the possible outcomes could be, and whether the decision to be tested is the right one for them at that time.

Genetic Discrimination

It is critical to create a safe environment for people with hereditary diseases, like Huntington's, and ensure they are free to come forward, get the help they need and participate in clinical trials. This is why HSC advocates on behalf of genetic fairness. Canada is the only G7 country that does not have protection over the use of its citizens' genetic information. As the leading organization of the Canadian Coalition for Genetic Fairness (CCGF), HSC is dedicated to establishing protection over the use of personal DNA information for all Canadians.

Huntington Disease Facts

- HD is a fatal hereditary brain disorder
- A child born to a parent with HD has a 50% chance of sharing the same fate
- 1 in every 1,000 Canadians is directly or indirectly impacted by HD
- Currently there is no cure for HD

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