Family SERVICES

The Huntington Society of Canada (HSC) has a Family Services team composed of registered social workers and professionals who provide support to individuals and families affected by HD. Family Services team members are located across Canada.

The Family Services team offers support and services to persons with HD, persons at-risk, persons who have the genetic mutation or do not, caregivers and family members, community members, friends and neighbours. Some of the services offered include information and education, referrals to community resources and individual advocacy.

In addition, the Family Services team offers education and support to health, social service and community workers. The team also collaborates with other service providers to improve and expand existing services as well as increase awareness and understanding of Huntington disease and support for advocacy.

HSC supports CLINICAL TRIALS and CRITICAL RESEARCH

The universal goal for the international HD research focus is to find treatments that reverse, slow or prevent the progression of HD. Canada's strategic research funding has helped to develop a critical mass of research in Canada. For more information on HSC research visit www.huntingtonsociety.ca/research.

Clinical trials depend on the participation of individuals and families affected by HD. HSC plays a key role in bridging the relationship between researchers and individuals by educating Canadians on the importance of the clinical trial process, how they can get involved, and why their participation is crucial.

HSC will continue to build a strong foundation for clinical trials in Canada and work in partnership with our HD community to find answers.

The HUNTINGTON SOCIETY of Canada

Founded by Ralph and Ariel Walker in 1973, the Huntington Society of Canada is a not-for-profit charitable organization which is governed by a volunteer Board of Directors.

HSC is self-funded and dedicates those funds to Family Services and Research efforts.

HSC raises funds with the following objectives:

- Maximize the quality of life of people living with HD by delivering services to individuals and families, and by providing education to healthcare professionals
- Advance medical research to slow progression of the disease and to prevent HD
- Enable others to better understand the disease

Huntington Society of Canada
HUNTINGTON
Société Huntington du Canada

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What is HUNTINGTON DISEASE?

Huntington Society of Canada
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WHAT is Huntington disease?

Huntington disease (HD) is a hereditary, neurodegenerative illness with physical, cognitive and emotional symptoms.

HD is caused by a mutation in the gene that makes the protein called huntingtin. In people with HD, the CAG sequence is repeated too many times at the beginning of the gene. That causes cells to manufacture a harmful protein called mutant huntingtin. The mutant huntingtin protein causes certain parts of the brain to die - specifically the caudate, the putamen and, as the disease progresses, the cerebral cortex.

As the brain cells die, physical, cognitive and emotional symptoms will appear.

To date, there are no drugs to slow or stop the progression of Huntington disease; however, there are specific drugs available to reduce some of the symptoms.

Research is being conducted in Canada and globally to find promising treatments and approaches to treating HD.

WHO gets HD?

Huntington disease is a genetic disorder. The HD gene is dominant, which means that each child of a parent with HD has a 50% chance of inheriting the disease and is said to be "at-risk".

Males and females have the same risk of inheriting the disease. HD occurs in all races.

Symptoms usually appear between the ages of 35 and 55, but the disease can appear in youth (Juvenile HD) or older adults (Late Onset HD).

WHAT are the symptoms?

Symptoms vary from person to person and at different stages of the disease.

- Physical symptoms: weight loss, involuntary movements (chorea), diminished coordination, difficulty walking, talking and swallowing
- Cognitive symptoms: difficulty with focus, planning, recall of information and making decisions; impaired insight
- Emotional symptoms: depression, apathy, irritability, anxiety, obsessive behaviour

There are early, intermediate and advanced stages of HD – which will have more severe symptoms as the disease progresses. For more detailed information on the symptoms of each stage, please visit: www.whatishd.ca.

Juvenile HD

About 10% of people diagnosed with Huntington disease have the juvenile form. In Juvenile Huntington Disease (JHD), the symptoms occur in childhood or adolescence (before the age of 20) and tend to follow a more rapid course. Symptoms differ from HD and may include slow and stiff movement (rigidity), difficulty learning in school and attention deficits, increase in responsive behaviours and seizures.

Late Onset HD

There is a wide range in the age of disease onset for people with HD. If a diagnosis is received after age 60, it is considered Late Onset HD.

Knowledge of the typical age of onset (ages 35 to 55) sometimes leads physicians to miss the diagnosis, because doctors incorrectly believe the person is too old to develop HD. Late onset consists of about 10% of all HD diagnoses.

Genetic TESTING/DIAGNOSIS

Predictive genetic testing may be done to confirm if a person (who has a parent with HD) has the genetic mutation. A person who has the genetic mutation will develop HD at some point in his/her lifetime, but it will not be known when symptoms will appear and which symptoms will appear first. Predictive genetic testing involves the examination of an individual's DNA, which is obtained from a blood sample.

Predictive testing is an individual choice that needs to be considered carefully. If one chooses to be tested, it is important to learn more about genetic discrimination. See Genetic Discrimination (below) for more information. It is also recommended that individuals meet first with a genetics counsellor and/or geneticist (when possible) in order to fully understand what it means for an individual and the family. Genetic testing takes time and test results for HD can be complex, so consulting with professionals is very important.

Diagnostic testing is done by a physician who looks at an individual's family history of HD (if it's known) and observes involuntary movements as well as other changes in function and/or mood disturbances.

Genetic DISCRIMINATION

It is critical to create a safe environment for people with hereditary diseases like Huntington disease to feel free to come forward, get the help they need and participate in clinical trials without any concern about genetic discrimination. The Huntington Society of Canada (HSC) and Canadian Coalition for Genetic Fairness (CCGF) have worked very hard to advocate for genetic fairness and to protect genetic test information for all Canadians.

Learn more about genetic discrimination and the protection currently in place by referring to www.ccgf-cceg.ca or asking your HSC Family Services team member and healthcare professionals.