Living At-Risk for HD

Living At-Risk For Huntington Disease

Huntington Society of Canada
Société Huntington du Canada

Huntington disease (HD) is a hereditary, neurodegenerative illness with physical, cognitive and psychiatric symptoms. To date, there is no cure for Huntington disease; however, there are drugs available to reduce some of the symptoms, and some very promising research is underway.

Huntington disease is a progressive disease with symptoms increasing in severity over time. Every child of a person with HD has a 50% chance of inheriting the gene which causes the illness. As a result, Huntington disease can affect family members in successive generations.

People who might have inherited the mutated HD gene are said to be at-risk. While it is obvious that people who have HD face difficulties in living with their illness, people who are at-risk for the illness experience serious challenges as well. This fact sheet provides information to those who are at-risk for HD.

STATISTICS

Approximately **1 in 7000** people in Canada has HD.

Approximately **1 in 5500** is at-risk of inheriting the disease.

Approximately **1 in 1000** is affected by HD (e.g. spouses, other friends and relatives).

Males and females have the same risk of inheriting the disease. HD occurs in all races and ethnicities and is found in all parts of the world. Symptoms usually start to appear between the ages of 35 and 55; however, those who are younger or older can become symptomatic with HD. There is also a childhood form of HD, called Juvenile HD, which is quite rare and accounts for approximately 10% of all cases of HD.

EMOTIONAL IMPACT OF LIVING AT-RISK

Whether HD has been in the family for a long time or it is a new diagnosis, there are strong feelings that come with the diagnosis of a loved one. There are also strong feelings accompanying the realization that one is at-risk. For many, the question becomes, "What does it mean for me?" There is no right or wrong way to react. Everyone is different.

Some people at-risk for HD may pull back from interaction with people who have HD, or from activities related to HD. Facing HD may be particularly painful for at-risk individuals at certain times during their lives, and they may need time away to come to grips with their situation before being ready to re-engage. Professionals and others who interact with someone at-risk need to keep in mind the particularly difficult situation at-risk individuals face when looking to the future and the future of loved ones.

Some people at-risk wonder how HD might affect their future relationships. It is important to know that many people who are at-risk have tremendously supportive friendships and find partners who are committed to a loving relationship.

It is beneficial for young people at-risk to learn about HD. The Huntington Society of Canada (HSC) can provide information and guidance to help parents engage in conversation about HD with children and youth in a way that is appropriate for their age and situation.

GENETIC TESTING

Genetic testing for HD has been available since 1993. A person who is 18 years of age or older, who is at-risk for HD, can request predictive testing. Diagnostic testing can also be requested when a person is showing symptoms of HD. The decision to be tested is a complex, personal choice. It is highly recommended for every person at-risk for HD who is considering genetic testing to be referred for genetic counselling. Ideally, each person will meet with the geneticist and genetic counsellor at least once to ensure that all up-to-date information is available, open questions are addressed and an informed decision can be made about whether getting tested is the right step at this point in time.

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IMPACTS OF GENETIC TESTING

- Possibly removes some uncertainty regarding the future.
- May give direction to future planning: career, marriage, children, and lifestyle choices. Knowing one's gene status may help a person focus on setting goals and living for today.
- Knowing if one carries the gene with the HD mutation may allow a person to participate in the appropriate clinical trials.
- Possible genetic discrimination by employers, insurers, landlords or others.
- Coping with the emotional roller coaster (anxiety, waiting for symptoms, grief, guilt) after learning of a positive or negative test result.
- Uncertainty associated with an indeterminate result: intermediate or reduced penetrance.
- Effect on relationships.
- Results do not provide information on time of onset or when first symptoms will appear.

CONSIDERATIONS

There are a number of important life decisions that a person who is at-risk may want to consider: education and employment, family planning and housing, financial (employment benefits, various types of insurance - life, disability, mortgage).

THERE ARE REASONS TO HOPE

Huntington disease is very individual in its presentation; the symptoms and progression of the disease that are seen in one person with HD will not necessarily be the same for another person with HD (even within the same family).

Overall, Huntington disease progresses slowly.

Promising research has progressed significantly and now includes the earliest stages of clinical trials involving humans and potential treatments for people with HD. There are a number of clinical trials in progress across the globe. Even discontinued trials help narrow the search for a cure and for treatments of symptoms. Please visit the HD Clinical Trial Research section of our website (under the Research tab).

Environmental enrichment: Research has shown that a healthy, balanced lifestyle, including sound nutrition, exercise and mental stimulus, can delay onset and slow down the progression of the disease.

SUPPORT

One of the best ways of dealing with worry and anxiety is to talk with others. There are many with whom one can talk: family members and friends, members of a faith community, like-minded people including those in HSC support groups and chapters and health professionals, especially those who are particularly knowledgeable about HD such as the Huntington Society of Canada Family Services team members.

RESOURCES

For further information regarding genetic testing, speak with a genetic counsellor, connect with the local Family Services team member, and consult the HSC website's fact sheets on genetic testing and on genetic discrimination.

Ongoing support, education and information is available from the Huntington Society of Canada (HSC). You can find a listing of our Family Services team members at www.huntingtonsociety.ca/family-services-team.

YPAHD (Young People Affected by HD) is a virtual youth chapter that is open to all youth and meets online and in-person. They also provide peer support. Learn more at www.ypahd.ca.

HSC's Mentorship Program is a formal program that provides one-on-one support for youth to connect with a mentor who is also from a family with HD. Learn more at www.huntingtonsociety.ca/learn-about-hd/youth/youth-mentorship-program.

Other reliable sources for information on HD:

Huntington Disease Youth Organization (HDYO) at http://en.hdyo.org/you
HDBuzz at http://en.hdbuzz.net

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