LIVING AT-RISK FOR HD

Do you ever wonder what living at-risk for Huntington disease (HD) means? Living at-risk is the period of time when a person's genetic status is unknown to them. Every child of a person with HD has a 50% chance of inheriting the gene that causes the illness. Living at-risk can impact multiple areas of a person's life and the decisions they make for their future. You can begin to increase your understanding of these impacts by accessing this information. The Huntington Society of Canada offers free and confidential support. You can find it by contacting your local Resource Centre Director here.

Statistics

Approximately 1 in 7000 people in Canada has HD. HD occurs in all genders, 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 that is rare and accounts for approximately 10% of all cases of HD.

Emotional Impact of Living At-Risk

Some people at-risk wonder how HD might affect their future. It is important to know that many people who are at-risk live full and active lives. Strong feelings can accompany the realization that one is at-risk. There is no right or wrong way to react. Everyone is different.

Facing HD may be particularly painful for at-risk individuals at certain times during their lives, and they may need time to process their circumstances before being ready to engage with supports. Friends, family and professionals 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.

Genetic Testing

Genetic testing for HD has been available since 1993. The decision to be tested is a complex, personal choice. It is highly recommended that every person at-risk who is considering genetic testing be referred for genetic counselling. Some potential impacts of genetic testing are:

- Reduces some uncertainty regarding the future.
- May give direction to future planning: education, career, housing, relationships, family planning, 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 impact the choice of clinical trial.
- Possible genetic discrimination by employers, insurers, landlords or others.
- Learning of a gene mutation does not provide information on time of onset or which order symptoms will appear.
- Regardless of test results, many people experience mixed emotions such as grief, loss, survivor's guilt and relief.

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There are Reasons to *HOPE*

- **H**untington 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).
- **O**verall, Huntington disease progresses slowly.
- **P**romising 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 treatments.
- **E**nvironmental enrichment: Research has shown that a healthy, balanced lifestyle, including sound nutrition, exercise, good sleep hygiene, and mental stimulus, can delay onset and slow down the progression of the disease.

Support

There is no right or wrong timeline in terms of when an individual may need to seek support. Some people find comfort in speaking to family and friends, while others find it beneficial to reach out to community groups and professionals. HSC's Family Services team is readily available to provide support to anyone impacted by Huntington disease.

If you are ready to receive supports from the Huntington Society of Canada, you can self-refer here through our website.

Resources

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

YPAHD (Young People Affected by HD) is a virtual youth chapter that is open to youth and young adults aged 14 to 35 and meets online and in-person. They also provide peer support. Learn more about YPAHD here.

HSC's Youth and Young Adult Mentorship Program is a formal program that provides one-on-one support for youth and young adults to connect with a mentor who is also from a family with HD. Learn more here.

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