HUNTINGTON SOCIETY OF CANADA
EDUCATIONAL MODULES

Huntington Society of Canada
HUNTINGTON
Société Huntington du Canada

EDUCATIONAL MODULES

The Huntington Society of Canada is pleased to offer educational modules providing information about Huntington disease (HD). The educational modules are delivered through the Society's Family Services team as presentations for individuals, families, long-term care facilities and to the medical community. They have been designed to address the multi-facets of this complex disease and are divided by specific topics.

If you are interested in having one of the Family Services team members present an educational module, please contact the Huntington Society of Canada at 1.800.998.7398 or email info@huntingtonsociety.ca.

AVAILABLE MODULES

1. **Introduction to Huntington Disease**
   An overview of Huntington disease (including its origin, five stages, and areas of impact) genetic testing and predictive testing.
2. **Huntington Society of Canada – The Origins**
   An introduction to the only Canadian organization dedicated to families and individuals living with Huntington disease. Founded by Ralph and Ariel Walker in 1973.
3. **Huntington Disease**
   a. **The Diagnosis**
      Information includes advance care planning, power of attorney, financial planning, accessing resources, living at-risk and talking to children about HD.
   b. **Living with a Chronic Illness**
      How to cope with the emotional, physical and social effects of a chronic disease, home safety suggestions.
4. **Juvenile Huntington Disease**
   An overview of early onset Huntington disease, (now known as juvenile Huntington disease or JHD), the differences between JHD and HD, and the five stages of JHD.
5. **Caregivers**
   a. **Caregivers Guide – General Overview**
      A guide for families and health professionals about living with HD including strategies for communication and responsive behaviours.
   b. **Caregivers Guide – Movement**
      A step-by-step guide on the physical symptoms of HD (including involuntary movements).
   c. **Caregivers Guide – Emotions**
      An overview of common emotional reactions and psychiatric symptoms of HD.
   d. **Caregivers Guide – Thinking**
      A guide to understand the cognitive changes, losses and strategies to address them.
   e. **Caregivers Guide - Swallowing**
      An overview of swallowing and strategies to help with swallowing difficulties, feeding aids.
6. **End of Life Care in Huntington Disease**
   Learn about end-of-life care symptoms, considerations and strategies to enhance quality of life.
7. **Huntington Disease and Law Enforcement**
   Strategies and considerations for law enforcement and families when someone with HD is in conflict with the law.
8. **Huntington Disease and Clinical Trials**
   An introduction to clinical trials in Canada, types of clinical studies, and which HD trials are currently in progress.

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FAMILY is at the heart of our COMMUNITY

At the Huntington Society of Canada (HSC), we have a solid understanding of Huntington disease (HD). Whether you have the disease yourself, are caring for someone who does, or are at-risk of inheriting HD, we are here to support you. We are a not-for-profit charitable organization which raises funds to deliver counselling and other support services to individuals and families living with Huntington disease (HD). The Society works with health and social services professionals to enable them to better serve people living with HD. We also fund medical research leading to treatments that will delay or stop the progression of the disease.

WHAT is HD?

Huntington disease is an inherited brain disorder that causes cells in specific parts of the brain to die. About one in every 7,000 Canadians has HD, but one in every 1,000 is touched by HD whether at-risk, as a caregiver, family member or friend.

SYMPTOMS of HD Include:

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

The disease leads to complete incapacitation and eventually death. At the moment, there are no treatments that will slow down or stop the disease in humans, but hope for a meaningful treatment has never been more real. In recent years, basic research has dramatically increased our knowledge of HD. Various promising treatment strategies are now in the drug discovery pipeline.

WHO Does HD Affect?

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 and HD occurs in all races. Primarily, HD affects adults. Symptoms usually appear between the ages of 35 and 55, but the disease can first appear in children as young as five, or in adults in their 70s.

What the Huntington Society of Canada offers:

The HSC Family Services program provides support to individuals, families, and professionals as they face the many challenges encountered throughout the progressive course of Huntington disease (HD). We also support caregivers and those living at-risk. The Family Services Program strives to maximize quality of life and to assist with meeting urgent needs.

Services are provided through a Director of Family Services, Family Services Coordinator, Resource Centre Directors, and Family Services Workers. The Director of Family Services manages the program across Canada and provides support to HSC's national advocacy initiatives. The Family Services Coordinator is often the first point of contact for individuals and families calling into the national office. Resource Centre Directors and Family Services Workers provide priority services of the program within specific geographic areas.

The Family Services program includes:

- Direct support services
- Education and support
- Local community development
- Support to HSC's national advocacy efforts

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