

## our **STORY**

Family is at the heart of our community. Our families and volunteers tell a powerful story of caring people who pull together to improve the quality of life for Canadians impacted by HD. Huntington disease (HD) is a fatal hereditary brain disorder with devastating effects on both the mind and body. It is like having Alzheimer's, Parkinson's and Schizophrenia all at the same time.

The good news is, with recent medical breakthroughs many researchers and scientists believe that once we are successful in stopping the progression of HD we may also find the answers to many other neurological diseases. Your valued support will bring us one step closer to this goal.

## 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



FOR MORE INFORMATION, OR TO DONATE

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Huntington Society of Canada

# FAMILY SERVICES



## **FAMILY** is at the heart of our **COMMUNITY.**

At the Huntington Society of Canada (HSC), we understand what you're going through, whether you have the disease yourself, are caring for someone with HD, are gene positive or are at-risk of inheriting HD. 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 Huntington disease?

Huntington disease (HD) is an inherited brain disorder. About one in every 7,000 Canadians has HD, but one in every 1,000 are touched by HD whether at-risk, as a caregiver, family member or friend.

## **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 30 and 45, but the disease can first appear in children as young as 5, or in adults in their 70s.

## **SYMPTOMS** of HD include:

- 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)

The disease leads to complete incapacitation and, eventually, death (generally due to other health complications).

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.

## **WHAT** the Huntington Society of Canada offers:

The HSC Family Services Program provides support to individuals, families, and professionals as they face 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, Resource Centre Directors, and Family Services Workers. The Director of Family Services manages the program across Canada. Resource Centre Directors are full or part-time permanent staff that provide a range of services within large geographic regions that include highly populated areas. Family Service Workers are contract staff that provide priority services of the program within specific geographical areas.

The Family Services program includes:

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

## Support Services

Direct support services are available to anyone who is affected by Huntington disease:

- Persons with HD
- Persons at-risk
- Persons who are gene-positive
- Caregivers and family members
- Community members, friends and neighbours

### **Information & Education**

Information is provided about the nature and progression of HD and care strategies.

### **Short-term Counselling**

Counselling is available to address emotional and practical adjustments to the changes one may experience while living with HD.

### **Resource Counselling & Referral**

Information is provided about community resources available to help meet specific individual needs.

### **Individual Advocacy**

Support is available to work with service providers and individuals to help ensure access to the necessary services.

### **Mutual Support**

Provide opportunities for individuals with HD and family members to connect with others i.e. support groups and therapeutic retreats.

### **Partnerships**

The Family Services team works in partnership with local HD Clinics, Movement Disorder Clinics and Genetics Clinics to enhance service delivery.

## Education and Support to Health, Social Service and Community Workers

Education and support is available to health and social service workers involved in the care of an HD family member.

- Staff at hospitals, mental health centres, long-term care facilities
- Home care staff, counsellors, physicians and other health and social service workers
- Community support groups or agencies
- Community workers such as lawyers, police, staff involved in the justice system

Education and support to health, social service and community workers includes:

- Information and education
- Individual consultation
- Links to other professionals

## Community Development

Community development activities include:

- Foster an awareness and understanding of Huntington disease
- Liaise with other professionals and organizations to improve the services
- Collaborate with other service providers and government to expand existing services
- Develop new services

## National Advocacy

The Family Services team supports HSC's participation in activities that focus on systemic change to enhance the social, political, and environmental conditions that contribute to the well-being of individuals with HD and their families.

