

# 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 who does, 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 HD?**

Huntington disease (HD) 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 are 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 and recall, 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 30 and 50, 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, 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. 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:

- person with HD
- family members
- caregiver
- others such as friends, neighbours
- person at-risk

## Direct support services to individuals and families include:

### 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 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

**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 of 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 activities include:**

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

## National Advocacy

The Family Services team supports the Huntington Society of Canada's participation in activities that focus on systemic change by aiming to affect laws, policies, practices or attitudes that will serve to enhance the social, political, and environmental conditions that contribute to the well-being of individuals with HD and their families.