END-OF-LIFE OPTIONS FOR PEOPLE WITH HD

Huntington Society of Canada
HUNTINGTON
Société Huntington du Canada

There are a number of options to consider when thinking about end-of-life. Individuals are encouraged to consult their medical team and local health authority for more information.

What Options Are Available?

Palliative Care: The goal of palliative care is to provide high quality of life to people with a life-threatening illness. It can be provided in addition to treatment. This level of care:

- Provides comfort to the person with the illness
- Supports the family
- Respects chosen traditions
- Manages symptoms

Hospice Care: Provides holistic comfort care for a person and their family at the end stages of an illness.

Medical Assistance in Dying (MAiD): MAiD is a legal option assessed and provided by a doctor or nurse practitioner to provide medication to cause death at the person's voluntary request.

The criteria to access MAiD are:

1. An individual must be eligible for federal health services
2. Age requirement of 18 years old and deemed mentally competent
3. Diagnosed with a grievous and irremediable medical condition
4. The individual must have made a voluntary request and provide informed consent

Please discuss questions with your medical team/HD Clinic team.

Having the Conversation

It is important to have sensitive conversations about end-of-life. They may bring up a variety of emotions. End-of-life is a deeply personal experience, and there is no right or wrong way to have these conversations.

Things to consider

- Choose a time and place that feels comfortable. Family and friends may be at different stages when thinking about death. We can't predict how others will feel; however, starting end-of-life conversations early on can be helpful.
- Reflect on personal preferences, wishes, important traditions and values around quality of life.

Starting the conversation

1. **Think about it:** It is never too early to explore and identify personal beliefs and values around end-of-life.
2. **Talk about it:** Encourage an open conversation about treatment options, limitations of treatment, and expected outcomes. Talk about your choices with your family and medical team. It may be helpful to have more than one conversation to allow time to consider options. Identify a substitute decision maker whom you trust to carry out those wishes.
3. **Document it:** Write down your choices and wishes. Changes can be made as needed. Verify provincial guidelines regarding the proper documentation, as each province may have their own requirements.

RESOURCES

Advance Care Planning Canada | www.advancecareplanning.ca

Canadian Virtual Hospice | www.virtualhospice.ca

Dying with Dignity | www.dyingwithdignity.ca

If you are ready to receive individual or group support from the Huntington Society of Canada, you can self-refer here: https://contactme.cloud/form/huntingtonsociety

Reach out to your local Resource Centre Director (RCD) of the Family Services Program at HSC for ongoing support and education at www.huntingtonsociety.ca/family-services-team-list/

Informational fact sheets for family and friends impacted by HD are available to view, print and download at www.hdfactsheets.ca

Healthcare professionals and caregivers needing a more in depth understanding on caring for someone with HD can find guides at www.huntingtonsociety.ca/hd-booklets-and-publications/, on:

- A Physician’s Guide to the Management of Huntington Disease
- Understanding Behaviour in Huntington Disease: A Guide for Professionals.
- A Carer’s Guide for Huntington Disease