



Physician's Guide

HSC has published the 3rd edition of A Physician's Guide to the Management of Huntington Disease, with the assistance of HDSA.

For a copy please contact us at info@huntingtonsociety.ca or 1-800-998-7398.



HUNTINGTON'S DISEASE
YOUTH ORGANIZATION

WHAT DOES IT MEAN TO BE CAPABLE OR INCAPABLE OF MAKING DECISIONS?

In order to make advanced care plans, you must be 'capable' or 'of capacity.' Under Canadian law, each person is considered 'of capacity' unless determined otherwise. Each province has its own protocol for assessing an individual's ability to make decisions on their own behalf. Capacity relates to soundness of mind and to an intelligent understanding and perception of the risks, benefits and consequences of one's actions and ability to communicate these. The progression of HD – or other factors – may lead to loss of capacity and being deemed no longer capable of making decisions on your own. In this case, the power to make these decisions will go to a 'substitute decision maker.'

Future Planning

We all make decisions every day: what to eat, what to wear, etc. Many of these decisions require very little thought or consideration. However, in preparation for health changes or times of emergency, it is important to discuss our thoughts and feelings about issues of significance with our family and friends. Starting conversations well in advance helps to ensure that our wishes are heard and can also reduce stress and anxiety. Planning in advance will not only put you in control of major life decisions, it will save those close to you from having to make difficult decisions without your input. Everyone should think about and plan for their future, but it is particularly important if you are facing a major health challenge such as Huntington disease.

What is Advanced Care Planning?

Advanced care planning is an approach taken to ensure that your family, friends, physician and substitute decision makers are aware of your preferences and are equipped to make decisions for your future care. Discussions on this topic may be difficult to initiate, but are essential. Whether you work through this process with people close to you or do it on your own, professionals such as social workers, nurses, family physicians, lawyers and others are available to help guide the conversation.

What should I consider?

There are key areas of planning that need to be considered:

1) Finding the Right Person

Who will make decisions for you and how will they make these decisions? It is important that this person knows you well and is aware of your values, beliefs and wishes.

2) Evaluating Your Options

What are your choices and preferences regarding health care decisions that you may face (tube feeding, resuscitation, etc.)? These major health care decisions are often complex. It is important for you to be aware of the many positive and negative aspects of the choices you make. This may involve research and talking with friends, family and professionals.

3) Financial and Property Planning

What is your financial plan for yourself and for your family? Do plans need to be put in place to ensure that future financial decisions are made according to your wishes? Who will make those decisions on your behalf? Also, if you have children, who will act as legal guardian if needed?

What is a Personal Directive for Advanced Care?

Personal Directive/Living Will: This document is referred to by different names in different provinces and territories. Essentially, it must be written while you are of capacity. It may not be legally binding, but is a statement reflecting your values, beliefs and wishes with regard to your health care and living arrangements. This plan provides a guide to assist in future decisions. In addition, you will need to identify a substitute decision maker/agent who will make decisions along with your medical or care team should you not be capable of doing so yourself. Be sure that your doctors, other medical professionals and spiritual advisors are aware of your wishes and your Personal Directive. Although it is not required, you may want to have your plan reviewed by a lawyer.

What are the other alternatives for a trusted person to act for me when I can no longer handle my own affairs or make health care decisions?

Legally binding documents that could come into effect as needed in the future include: Enduring Power of Attorney (for health care and for finances), Guardianship or Trusteeship.

The names and rules associated with these documents vary between provinces and territories. For information specific to the part of Canada in which you live, consult your local Huntington Society of Canada Resource Centre Director or Family Services Worker. Once a discussion has begun, and you have an understanding of what you want, it is important to complete legal documents, usually with the assistance of a lawyer or appropriate legal advisor.

Power of Attorney

Legal Documents – often referred to as Power of Attorney – need to be set up, allowing you to decide who will manage your health and financial affairs should you become mentally or physically incapacitated. You may select the same person or different persons for each area of care. You must be of sound mind; alert and able to make decisions at the time of drawing up this document. Generally, the services of a lawyer are required. This process allows you to select the person(s) you want to act on your behalf – a person you are confident will act with your wishes and values in mind. The order ends at the time of death.

Note: In some provinces Health/Personal Care and Property/Financial Care Power of Attorney are separate legal documents and they may also have other names.

Guardianship and Trusteeship

If Power of Attorney was not established prior to loss of capacity, alternative decision makers may be established without your input through the court system and may be an individual or a Public Guardian.

Guardianship is an order granted by a court appointing a ‘guardian’ to make decisions related to health care, living arrangements and your daily needs when you are no longer deemed mentally competent (or ‘of capacity’). The guardian is generally a government individual and is expected to operate in your best interest, encouraging independence and acting in the least restrictive manner possible. A guardianship order ends at the time of death.

Trusteeship is also court appointed. When you are no longer able to manage your financial affairs, a ‘trustee’ (person submitting the request i.e. next of kin) is appointed by the court. Their role includes managing, handling, administering, selling and disposing of assets. A trusteeship order ends at the time of death.

Will

In addition to planning for decision making while you are alive, it is important to also plan for your death. A will is the key legal document to ensure your wishes are respected beyond your lifetime.

A will that is up to date is an important gift you can give your family. A will outlines the distribution of your assets and provisions for care of your children and family upon your death and must be written when you are competent (of capacity). Generally, legal assistance is used to prepare a will.

Future planning is a difficult process that people tend to delay. However, it is critical to your well-being in the future and to ensure that your substitute decision makers are able to act according to your perspective, values and wishes. To gather additional information about future planning and the systems in your province or territory, contact your local HSC Resource Centre Director or Family Services Worker for support and assistance.

RESOURCES

- Advance Care Planning Speak Up Campaign
www.advancecareplanning.ca (English) or
La planification préalable des soins
www.planificationprealable.ca/accrueil.aspx (Français)
- College of Family Physicians of Canada:
Advanced Care Planning
www.cfpc.ca/ACP/ (English) www.cfpc.ca/PPS/ (Français)
- What every older Canadian should know about: Power of Attorney (for financial matters and property) and Joint Bank Accounts
www.seniors.gov.on.ca/en/moneymatters/poa_and_ja.php
(Also available on other provincial government seniors resource pages.)
- Ce que tous les Canadiens âgés devraient savoir au sujet des Procurations (pour la gestion des finances et des biens) et comptes conjoints
www.seniors.gov.on.ca/en/moneymatters/poa_and_ja.php

