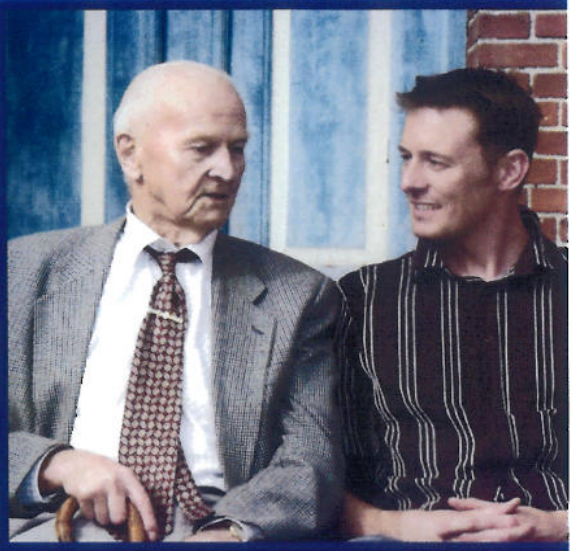
Speak Up

Start the conversation
about end-of-life care



Advance Care Planning Workbook
Ontario Edition

It's about conversations.
It's about decisions.
It's how we care for each other.

www.advancecareplanning.ca

Speak Up, c/o Canadian Hospice Palliative Care Association | Annex D, Saint Vincent Hospital, 60 Cambridge Street North, Ottawa, ON K1R 7A5

CHPCA and the Advance Care Planning project appreciate and thank their funding partners: Canadian Partnership Against Cancer and The GlaxoSmithKline Foundation.

CANADIAN PARTNERSHIP AGAINST CANCER / PARTENARIAT CANADIEN CONTRE LE CANCER

The GlaxoSmithKline Foundation

For more information about advance care planning, please visit our website at:
www.advancecareplanning.ca

e-mail: info@advancecareplanning.ca

National Advance Care Planning Task Group
c/o Canadian Hospice Palliative Care Association
Annex D, Saint-Vincent Hospital
60 Cambridge Street
Ottawa, ON K1R 7A5

Telephone: 613-241-3363
Fax: 613-241-3986

The National Advance Care Planning Task Group wishes to recognize and thank the following organizations for generously allowing us to adapt components of their publications and information for use in this workbook:

- Canadian Researchers at the End of Life Network (CARENET)
- Fraser Health Authority (British Columbia)

The Ontario Alzheimer Knowledge Exchange HCC-ACP Community of Practice adapted the original version of the Speak Up Workbook to create this Ontario edition.

Speak Up in Ontario is coordinated by Hospice Palliative Care Ontario.

HPCO
Hospice Palliative Care Ontario

Making an Advance Care Plan

Speak Up
Start the conversation about end-of-life care

Advance Care Planning is a process of reflection and communication. It is a time for you to reflect on your values and wishes, and to let others know what kind of health and personal care you would want in the future if you become incapable of consenting to or refusing treatment or other care.

Advance Care Planning means having discussions with family and friends, especially your future Substitute Decision Maker(s). A Substitute Decision Maker is the person or people who will provide consent or refusal of consent for care and treatments for you if you are not mentally capable to do so for yourself. Advance Care Planning can include choosing a Substitute Decision Maker as well as expressing your wishes about care that you want or may not want.

It can include discussions with your health care providers to ensure that you have accurate medical information on which to make decisions (consents) or to express wishes about future care and treatment. It can also include writing down your wishes, and may even involve talking with legal professionals.

It is a way to give those who will be required to provide consent for your medical treatment and care the confidence to make decisions on your behalf when you are mentally incapable to do that for yourself.

You may never need your advance care plan – but if you do, you will be glad that you have had these conversations. It is a way to make sure that your voice is heard when you cannot speak for yourself.

This workbook contains tips for having conversations with others about your wishes for care at the end of life. It also includes information about making a plan and understanding medical procedures, as well as a sample plan. You can use the workbook to help get the conversation started with a friend or family member or to express your wishes about future care.

Why plan for end-of-life care?

Speak Up
Start the conversation about end-of-life care

Life can take many twists and turns. **Imagine:**

- One day, without any warning, you find yourself in a hospital with a life-threatening illness. You are unable to speak for yourself – you do not recognize your family or friends. Your doctors do not feel that you will leave the hospital alive. Do you want to be kept alive using machines? Does anyone know your wishes? Who will make decisions for you?

  OR

- Your widowed mother has slipped into a coma. Someone needs to make some decisions about her medical care. If you have siblings, who will make those decisions? All of you? One of you? Someone else? How do you know if the decisions are the right choices for your mother?

  OR

- You are at the beginning stages of Alzheimer's and you know that at some point you will not be able to recognize people or make your own decisions. How will you make your wishes known? Who will make decisions about your care and treatment when you are no longer mentally capable of doing so yourself?

An Advance Care Plan is more than a document outlining your wishes for care at the end of life – it is also a conversation that you have with the person or people who will act for you if you cannot speak for yourself. It means thinking about what is important to you and what you value. It means talking to your loved ones about these things. Reflecting on your values and having these conversations will help you, your loved ones and anyone that will act as your Substitute Decision Maker talk to health care professionals about difficult decisions that may have to be made about your care at the end of life.

Having these conversations and making a plan are ways to give your Substitute Decision Maker(s) the confidence to make decisions on your behalf. It is how we care for each other.

Remember, this plan will only be used if you are not capable of speaking for yourself. You can also change it at any time as long as you are mentally capable.

The choices you make at the end of life – for yourself and others – are important. Make sure that your voice is heard and respected. Think about what you would want and start the conversation with others about your end-of-life care.

Let's get started:

Making an advance care plan

Speak Up

Start the conversation about end-of-life care

Advance Care Planning is a process, not just a document. In fact, in Ontario, an Advance Care Plan can be expressed orally, in written form or by any alternative means that you use to communicate, such as a picture board or computer.

Advance Care Planning includes conversations that you have with close family and friends about your values and beliefs as well as the medical procedures that you want and do not want at the end of life. It is also about the experiences and people that you want around you at the end of life.

How to begin:

1. Think about what is right for you

Begin by reflecting on your values, beliefs and understanding about end-of-life care or specific medical procedures, such as drug therapies, cardiopulmonary resuscitation (CPR) or dialysis. Think about any situations that you may have experienced with others and how it made you feel. You should also speak with your health care providers to ensure you have accurate information about your own health condition in order to express wishes about medical procedures that you may or may not want.

Ask yourself:

- If possible, would I prefer to die at home, in a hospice or in the hospital?
- What might change my mind about my choice?
- Do I want or not want certain medical interventions (e.g., resuscitation or feeding tubes) if I am unlikely to survive or live independently?
- Why would I want or not want these procedures?
- Do I have any fears about dying (e.g., I'll be in pain, I won't be able to breathe)?
- Is there someone that I can talk to about these fears, such as my doctor?
- What would be meaningful for me at the time of my death (e.g., family/friends nearby, music playing or pictures)?

2. Learn about end-of-life care options and procedures

Some individuals want to prolong life as long as possible using medical interventions. Others would not want to be hooked up to machines at the end of life if there is no chance of recovery.

We have included a list of Advance Care Planning terms and medical procedures on pages 13 and 14 to help you consider what is right for you.

3. Decide who will make medical decisions on your behalf should you become incapable of doing so

Think carefully about who you feel would understand, honour and follow your wishes, and would be most capable of making medical decisions on your behalf as your Substitute Decision Maker. This may be a spouse, an adult child, a trusted family member or a good friend.

Before you choose someone, you need to understand what the law says about what you must do to appoint someone as your Substitute Decision Maker. You also need to know what happens if you do not appoint someone to act for you through that legal process.

In Ontario, the law provides that even if you do not appoint someone to act on your behalf, you will still always have a Substitute Decision Maker that the health professional must turn to get consent or refusal of consent to any treatments for you.

Legal requirements regarding the appointment of a Substitute Decision Maker vary across the country and from country to country. You need to follow the law that is applicable in the province or territory in which you live when you appoint someone to be your Substitute Decision Maker.

What do you need to know about Ontario law regarding Substitute Decision Makers?

a. Power of Attorney for Personal Care

In Ontario, you can CHOOSE someone (or more than one person) to be your Substitute Decision Maker(s) by preparing a Power of Attorney for Personal Care.

The legal requirements for preparing a Power of Attorney for Personal Care are in the Ontario Substitute Decisions Act.

A Power of Attorney for Personal Care is a document, in writing, in which you name someone to be your "attorney." The word attorney does not mean lawyer. In this case, an attorney is a type of Substitute Decision Maker.

To be valid, the document must:

i. be signed by you voluntarily, of your own free will;
ii. be signed by you in the presence of two witnesses;
iii. be signed by the two witnesses in front of you.

Also, you must be mentally capable of understanding and appreciating what kind of document you are signing and what you are doing by signing such a document.

More information about Ontario Powers of Attorney for Personal Care can be found on the websites of the Advocacy Centre for the Elderly (www.acelaw.ca), Community Legal Education Ontario at (www.cleo.on.ca) and the Ontario Ministry for the Attorney General (http://www.attorneygeneral.jus.gov.on.ca/english/family/pgt/incapacity/poa.asp).