

## Advance Care Planning Reference Guide

Of all the choices you make in life, among the most important could be the choices you make now about your future personal care

## **Advance Care Planning**

#### It is important...

to take the steps now, while you are capable, to ensure **your** wishes guide the decisions made for your care and medical treatment if you ever become unable to make such decisions yourself.

This is what **Advance Care Planning** is about: making it clear how you wish to be cared for, and giving someone you trust the authority to act on those wishes for you, if the need arises in the future.

Advance Care Planning is different from, but just as important as making plans for your finances, property, estate, will or funeral arrangements.

Let the Dorothy Ley Hospice staff offer guidance to start the conversation on Advance Care Planning.

## Five Steps in Advance Care Planning

#### **Advance Care Planning means...**

Thinking about your values and wishes for future health and personal care and sharing your wishes with others. It also means deciding who will speak for you if you can't speak for yourself. It's a way to give loved ones the confidence to make decisions for you during a difficult time.

#### There are 5 Steps to Advance Care Planning:

#### Step 1: Think

**Think** about what's right for you. What's most important to you about your end-of-life care?

#### Step 5: Record

Record your end-oflife wishes – write them down, record them, or make a video.

# Think Record Learn

#### Step 2: Learn

Learn about the different medical procedures that can be offered at the end of life.

Refer to the *glossary* in this package.

#### Step 4: Talk

Talk about your wishes with your Substitute Decision Maker, loved ones and health care providers.

#### Talk Decide

#### Step 3: Decide

Decide upon your Substitute Decision Maker. Choose someone who is willing and able to speak for you if you can't speak for yourself.

## **Conversation Starters**

#### **Be Straight Forward**

"I have just filled out a workbook about my wishes for future health care and I want to share it with you."

"My health is good right now, but I want to talk to you about what I'd want if I was sick and needed you to make decisions for me."

#### Find an example from Friends & Family

"Does anyone know how Jason's sister died? No one ever talked about it. I wonder if she died at home or in a hospital."

"Do you remember my friend Frank who was in a coma for a while? I wonder if there was any argument about keeping him on that ventilator."

#### Utilize your community network

"Pastor Jones was talking about our choices for health care if something happened, and I realized that I haven't told you about my wishes – we should talk about that."

"My doctor wants me to think about my future care and to make an advance care plan. Will you help me?"

#### Individuals I may want to discuss my wishes with:

Name	Relationship to me

## **Personal Reflection**

What do I value most in terms of my mental and physical health? (For Example: being able to live independently, being able to recognize others, being able to communicate)
What would make prolonging life unacceptable for me? (For Example: not being able to communicate, being kept alive with machines with no chance of recovery, no control over bodily functions)
If I were nearing death, what would I want to make the end more peaceful for me? (For Example: family and friends nearby, dying at home, having spiritual rituals performed)
<b>When I think about death, I worry about certain things happening.</b> (For Example: struggling to breath, being in pain, being alone, losing dignity)



## Glossary

Allow Natural Death: refers to decisions NOT to have any treatment or procedure that will delay the moment of death. It applies only when death is about to happen from natural causes.

Cardiopulmonary resuscitation (CPR): refers to medical procedures used to restart a patients heart and breathing when the heart and/or lungs stop working unexpectedly. CPR can range from mouth-to-mouth breathing and pumping of the chest, to electric shocks that restart the heart and machines that breathe for the individual.

Comfort measures: treatments to keep you comfortable (e.g. pain relievers, psychological support, physical care, oxygen, etc.) but not to keep you artificially alive or cure any illnesses.

Dialysis: a medical procedure that cleans your blood when your kidneys can no longer do so.

End-of-life care: refers to health care provided at the end of a persons life. This type of care focuses on patients living the way they choose during their last weeks and on comfort care until the time of death.

Feeding tube: a way to feed someone who can no longer swallow food.

Health care provider: describes a person licensed, certified, or registered in their province/territory to provide health care. For example: a doctor, nurse or social worker.

Informed consent: refers to the permission patients give to health care providers that allows medical investigations and/or treatments. Health care providers give detailed explanations of the investigations/treatments and their risks before you give verbal consent or sign the consent form.

Intravenous (IV): is a way to give a person fluids or medicine, i.e. through a vein in your hand.

Life support with medical interventions: refers to medical or surgical procedures such as tube feeding, breathing machines, kidney dialysis, some medications, and CPR. All of these use artificial means to restore and/or continue life. Without them, the patient would die.

Palliative care: care provided for people who have a life-limiting illness that focuses on providing good quality of life in other words, keeping the patient as comfortable and free of pain as possible. Palliative care may involve medicines, treatments, physical care, psychological/social services and spiritual support, both for the patient and for those who are helping to care for them.

Power of Attorney/Power of Personal Care: These terms usually indicate someone who is legally appointed to speak on your behalf. Typically, you would have a witnessed document naming your Power of Attorney / Power of Personal Care and outlining their responsibilities. Terms and responsibilities differ across the provinces/territories.

Public Guardian and Trustee: If you are incapacitated and have not designated a Substitute Decision Maker or if family members disagree about your care, a provincial or territorial Public Guardian or Trustee may be assigned to make decisions about your care.

Substitute Decision Maker: A person who makes medical decisions and provides consent for treatment or withdrawal of treatment on behalf of another person when they are incapable of communicating their wishes on their own. This person might also be known as a medical proxy, a health representative or agent or a Power of Attorney for Personal Care. Terms differ across the provinces/territories

Symptoms: signs that you are unwell. For example: pain, vomiting, loss of appetite, or high fever.

Terminal illness: an incurable medical condition caused by injury or disease. These are conditions that, even with life support, would end in death within weeks or months. If life support is used, the dying process takes longer.









## Resources

#### Advance Care Planning: Speak Up!

Website: http://www.advancecareplanning.ca

Workbooks: http://www.advancecareplanning.ca/resource/acp-workbook/

#### **Ontario Seniors' Secretariat (OSS)**

Website: www.gov.on.ca/mczcr/seniors

Toll free: 1-888-910-1999 Local calls: 416-314-7511

#### **Alzheimer Society of Ontario (ASO)**

Website: www.alzheimer.ca Telephone: 416-967-5900

#### **Local Health Integration Network (LHIN)**

Website: http://www.lhins.on.ca/

Contact your local LHIN for more information in your region

#### Office of the Public Guardian and Trustee

Website: www.attorneygeneral.jus.gov.on.ca

(Click on "Office of the Public Guardian and Trustee")

Telephone: 1-800-366-0335 Toronto: 416-314-2800

#### **Advocacy Centre for the Elderly (ACE)**

Website: www.advocacycentreelderly.org

Telephone: 416-598-2656

#### **Consent and Capacity Board**

Website: www.ccboard.on.ca

Telephone: 416-327-4142



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