Living Well, Planning Well

An Advance Care Planning Resource for Lawyers

Fall 2021

Advance Care Planning
Planification préalable des soins
CANADA

Canadian Hospice Palliative Care Association
Association canadienne de soins palliatifs

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Advance Care Planning helps ensure
a person's preferences are known,
enabling the right supports,
the right care,
the right way
and at the right time
in the right place.

Table of Contents

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Section 1

Background

What is this toolkit?

Advance care planning means thinking about how a person would like to be cared for and who to appoint to make decisions about personal care should they be incapable of making such decisions. It is about sharing thoughts on these matters with the important people in the person's life. Sometimes formal documents are created describing their wishes and/or who they would want to make decisions for them (known as a Substitute Decision Maker (SDM)). These documents make up their Advance Care Plan.

Why use this toolkit?

When a person experiences a health crisis or serious illness situation, they can be unable to indicate their treatment preferences and their SDMs may not be able to accurately predict their wishes. Advance Care Plans are used to elicit and document a person's preferences in advance so that their SDMs can make informed decisions about their care when called upon.

Advance Care Planning Conversation Starters

- How do you want to live as you age and your life changes?
- What kind of legacy do you want to leave?
- How do you want to live well and approach death?
- How do you want to be cared for and how do you want to care for those important to you?
- What personal, family and community resources and supports do we need to plan for?
- Who would you like to make personal care decisions for you if you are not able to make decisions for yourself?

You can make a significant difference in your clients' lives and their continued well-being by: encouraging them to consider their wishes and values for care when they may not be able to make decisions for themselves; helping them express their wishes and values in writing; and by legally appointing the appropriate SDMs and alternates.

How to use this toolkit?

This toolkit includes sample precedent language that you may use or edit to complement your current planning documents and client questionnaire(s). The precedent clauses are samples for your consideration and edification as may be required to reflect your clients' intentions. Review the precedent clauses carefully to ensure that they meet the requirements of the jurisdiction within which you practice.

When to use this toolkit?

Advance care planning is a process. Preferences and plans can shift as circumstances change. Checking in with clients when they meet with you for other matters is a way to ensure that their Advance Care Plan still meets their wishes and is relevant to their particular needs. The toolkit can be used to guide initial discussions and these follow up check-ins.

Did you know

Less than

1 in 5

people in Canada have completed an Advance Care Plan.

80%

of Canadians have thought about advance care planning.

66%

of people in Canada think it is important to discuss advance care planning with a lawyer; only

7%

have actually done so.

Family tensions may be greatly aggravated by a failure to discuss matters of life, death and finances prior to a health crisis or serious illness.

89%

of all Canadians could benefit from palliative care in their last year of life; yet, only

15%

of people who died in 2016–2017 received publicly funded palliative home care.

30%

of frail nursing home residents are admitted to an intensive care unit and

50%

to hospitals in their last year of life.

From 2003-2011,

7,525

Canadians died in a palliative care bed, compared to

32,217

in ICU, and

87,754

in acute care.

When offered at the right time, palliative care can help reduce stress, improve quality of life and provide relief for people living with a life limiting illness and their families.

93%

of Canadian seniors live at home and want to stay there as long as possible.

Canadians with cancer are

3x

more likely to receive palliative care than those with other conditions; people living with diseases like heart failure, dementia and chronic obstructive pulmonary disease benefit greatly from planned palliative care.

For many seniors, "old age" is accompanied by a progressively increasing number of ailments and chronic conditions, which bring a slow decline in health, frailty and a number of life-threatening episodes that occur over time

Why is Advance Care Planning important?

ADVANCE CARE PLANNING helps people and their loved ones prepare for situations where difficult decisions need to be made. Without having conversations or access to information about a person's values and wishes, it's unclear how to proceed in a way that is appropriate for that person.

Cardio-pulmonary Resuscitation (CPR) success rate

How well CPR works depends on the health of the patient. Studies have shown the chance of success with CPR.

OVERALL POPULATION

82 out of 100 will die

18 will survive CPR and leave the hospital

PEOPLE WITH SERIOUS ILLNESSES
like cancer, heart or kidney disease

90 out of 100 will die

10 will survive CPR

PEOPLE WHO HAVE CRITICAL ILLNESS
and are in the intensive care unit

98 out of 100 will die

2 will survive CPR

OVERALL POPULATION
over age 75

85 out of 100 will die

15 will survive CPR

EVIDENCE MOMENT

Benefits of Advance Care Planning (ACP)

A meta-analysis of 80 systematic reviews indicates that improved end-of-life communication, documentation of care preferences, dying in preferred place and health care savings happen when ACPs are in place. Features that make ACPs effective include repeated, iterative and interactive discussions.

(*Jimenez et al, 2018*)

The CPR Decision Aid is a helpful resource for understanding the likely outcomes of CPR and making evidence-based decisions.

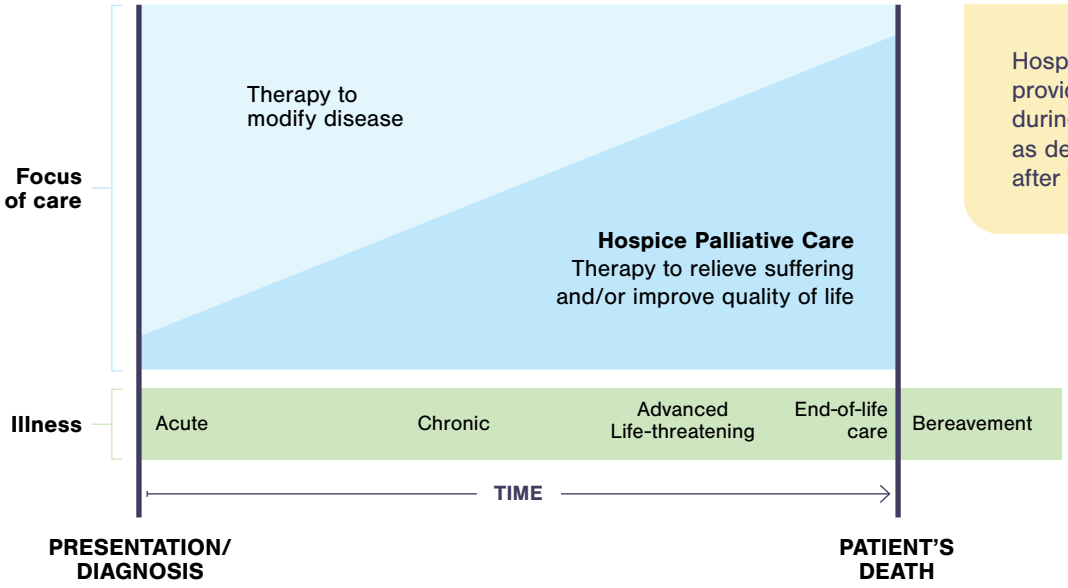
www.advancecareplanning.ca/resource/cpr-decision-aids

From CPR Decision Aid by CARENET and Speak Up

What is the role of Hospice Palliative Care during Illness?

PEOPLE DIAGNOSED with a life-limiting illness can live with that condition for many years. They may experience pain, discomfort, and other symptoms related both to the condition and to treatment (Cochrane et al., 2008). **Hospice palliative care** includes managing symptoms, relieving suffering and enhancing psychological, social, and spiritual supports to enable the best quality of life with optimal physical and mental function. Patients can gain more control over their lives, manage pain and symptoms more effectively, and access supports for their family and caregivers.

While hospice palliative care is often seen as 'giving up' it is actually complementary. Palliative care can begin when a person is diagnosed with a life limiting illness by addressing quality of life alongside therapies to treat disease. Hospice palliative care also provides support to loved ones during the person's illness, as death approaches, and after they die.



Hospice palliative care also provides support to **loved ones** during the person's illness, as death approaches, and after they die.

Section 2

Selection of Substitute Decision Maker(s)

A SUBSTITUTE DECISION MAKER (SDM) provides consent for treatment and guides health care decision-making when a person is not capable of making decisions for themselves. Various jurisdictions use different titles for this role (e.g., attorney for personal care, proxy, representative, delegate, mandatary, agent). Talk with your client to understand whether it is most appropriate to name one person to act as SDM with one or more back-up person(s), or to name multiple people to act jointly (together) or jointly and severally (each person may act on his or her own), if permitted in your jurisdiction. Consult the applicable legislation in your jurisdiction to determine what qualifications (e.g., minimum age) are required to act as a SDM, and any other requirements of a SDM.

Some questions that could help your client select a SDM are:

1. Will this person serve your best interests when you are not able to make decisions for yourself?
2. Is the person a capable adult? (adults are 18 or 19, depending on the province or territory)
3. Do you trust this person to make decisions regarding your life, comfort and well-being?
4. Are you comfortable talking to this person about sensitive and difficult issues?
5. Will this person understand your wishes and be willing to make difficult decisions on your behalf?
6. Can this person handle differing opinions of family members and health care professionals and come to a decision that reflects your wishes and discussions?
7. Is this person available and able to make the time commitment that may be required?
8. Will this person collaborate well with your attorney under your Power of Attorney? Your SDM will make your healtlh and personal care decisions, but your attorney may be called upon to exercise their powers to fund them.

Speak Up has a complementary resource for the public, ***Living Well, Planning Well: An Advance Care Planning Resource for Accessing Your Rights***. It provides information about the legal norms and requirements for advance care planning and designating SDMs. It also has information about the legislation within each of the country's provinces and territories (Nunavut excluded).

www.advancecareplanning.ca/resource/living-well-planning-well-lawyers-resource/

Section 3

Your Client's Wishes in Case of Serious illness or Injury

What's most important?

ADVANCE CARE PLANNING can be difficult as most people do not know what future situations of injury, illness or approaches to treatment and care will make the most sense at that time. That's why it is often helpful to begin advance care planning by asking people about the values that are most important to them and how they would like to be maintained or honoured in their future care.

Some questions that might help elicit people's values are:

- What makes your life meaningful?
- What matters most to you?
- What life circumstances would you find most unbearable?
- What do you worry about most when you think about your future health?
- What are your favourite activities, events, routines, or ceremonies?
- What does living well look like to you?

The **Thinking About My Wishes for Future Health Care** questionnaire can help people start reflecting on what's most important to them. It includes questions about the importance of different values and about preferences for particular situations.

www.advancecareplanning.ca/resource/primary-care-toolkit/

What Situations Might be Relevant for Advance Care Planning?

Situations where your client may not be able to make decisions for themselves or provide consent:

- Head Injury with severe brain trauma affecting cognitive understanding (e.g.: motor vehicle collision, sports injury, workplace accident).
- Medical treatments with induced coma or unconscious sedation (e.g.: mechanical ventilation, operative procedures).
- Massive heart attack with loss of consciousness.
- Stroke impacting cognitive and verbal/written abilities (e.g.: aphasia).
- Progressive chronic conditions which can impact cognitive and communication abilities (e.g.: Dementia, Huntington's Disease, Brain Tumour).
- Blood loss causing cognitive impairment or loss of consciousness (e.g.: severe internal bleeding or trauma).
- Genetic diversities or birth traumas that have long-term impacts on cognitive function.

Sample precedent language

Consider posing the following scenarios and possible actions to your client, or incorporating these scenarios in your client questionnaires or work sheets. These scenarios may help you better understand your clients' wishes. Sample precedent clauses describing wishes that you may use or edit to integrate with your current materials are described below.

Canvass with your client whether they have prepared a DNR or pronvicially specific forms (such as in BC, MOST forms) with their doctor. If they have, they should be reminded to meet with their doctor at least annually to update those and to ensure that the clauses they have included in the legal documents they prepare wtih you are consistent with those documents.

SCENARIO	SAMPLE PRECEDENT CLAUSES *(Adjust to meet your client's needs)*
If I had a sudden medical emergency, such as a massive heart attack or stroke or overwhelming infection, and I was not expected to recover to my previous level of function, independence or cognition, then I would want to be (circle all that apply): a. Allowed a natural death. b. Taken to hospital and given all possible medical interventions. c. Kept comfortable and not given antibiotics or other medications. d. Transferred to a hospital from a nursing facility but not be given CPR or taken to ICU. e. Kept in my current location of care and provided all medications and treatments possible within this location, and be kept as comfortable and pain-free as possible.	If I am suffering from a medical emergency resulting in injuries or health conditions whereby I am not expected to recover from my previous level of function, independence and cognition, and medical intervention would result in little or no quality of life given all the relevant circumstances, including my known beliefs and values, then I want to allow for a natural death and not kept alive by artificial means. I wish for medication to be administered to me, so I may be kept as comfortable and as pain-free as possible until my death, even if such medication or inaction may hasten my death. I wish to be transferred to a hospital from my nursing or long-term care facility but not be given CPR or taken to the ICU.

SCENARIO	SAMPLE PRECEDENT CLAUSES *(Adjust to meet your client's needs)*
If I could no longer safely continue living in my home on my own, or it is no longer practicable for me to do so, I would want my substitute decision maker to know I wish to (circle all that apply): a. Continue living in my home for as long as possible, together with caregivers, unless my substitute decision maker decides that another location of care will better meet my needs. b. Not be a burden on my friends and/or family. c. Move into a residence that as closely as possible will honour and reflect my beliefs, values, culture and dietary habits and preferences. d. Use my resources to ensure I am cared for at home or other residential facility. e. Transition to a long-term care facility or hospice. f. Other:_____	I wish to continue living in my home for as long as possible and hopefully until my death, and obtain in-home care services needed to do this; however, if my substitute decision maker *[insert correct terminology for your jurisdiction]* determines it is appropriate to admit me into an appropriate care facility based on my needs, then I wish to be placed in a residence near my home or close to friends and/or family members. Should it be necessary to renovate or modify my residence to accommodate me and/or my caregivers, it is my wish that such renovations or modifications be undertaken. I direct my Attorneys to act together with my attorney or attorneys for property, or if I have no validly appointed attorney for property, then with my guardian of property appointed by a court of competent jurisdiction, and to take all action necessary to give effect to my intention expressed herein. It is my wish that my long-term care facility or residence has an organizational culture that appreciates my beliefs, values, culture and dietary habits and preferences. It is important to me that I am not an emotional or financial burden for my family. I wish for my financial resources to be used to ensure that I am cared for at home, other long-term residential facility or hospice.
I wish to remain in my own home even if 24/7 care or renovations to home are required to do so.	It is my intention and strong desire to remain in my own residence as long as practicable rather than residing in a nursing home or other care facility. Should it be necessary that I require a caregiver with me at any time or times throughout the day, including for 24 hours a day, 7 days a week, I authorize my Attorneys to employ one or more caregivers to provide the care so required.
Prolonging my life would be unacceptable to me if (circle all that apply): a. I am not able to communicate with my family and friends. b. I am kept alive with machines but with no chance of survival if I am taken off the machines. c. I have no control of my bodily functions. d. I am declared brain dead and my primary organs may or may not be substantially affected. e. it is not expected that I would have the same level of function and abilities I had before this illness or injury. f. other:_____	If I am brain dead and can only be kept alive by artificial means, then I wish to be allowed to die as free of pain and suffering as possible, even if such medication or inaction may hasten my death.

SCENARIO	SAMPLE PRECEDENT CLAUSES *(Adjust to meet your client's needs)*
If I were nearing death, I would want to be as peaceful as possible by having (circle all that apply): a. A certain ceremony or ritual performed (specify). b. Particular people present. c. Particular people NOT present. d. Special music or items around me. (specify) e. other: _____	If I am nearing death, I would like to be as peaceful as possible by having _____ *(edit to meet your clients' wishes).*
If I was _____ and my health condition worsened in a way that the probability of recovery was low, I would want to receive a palliative approach to care (circle all that apply): a. Living in a long-term care home (or nursing home). b. Living at home or a residential facility. c. Admitted to an acute care facility.	If I am living in a long-term care home (or similar residence), and my health condition worsened in a way that my recovery is not expected, then I want to receive a palliative approach to care and not be transferred to an acute care facility or to a hospital. If I am admitted to an acute care facility and my health condition worsened in a way where my recovery is not expected, then I want to receive a palliative approach to care.
If I could not swallow food to obtain nutrition, I would want (circle all that apply): a. To have a feeding tube if there is some hope that Iwill recover from my illness or injury such that my quality of life is not severely compromised. b. To not have a feeding tube if two doctors involved in my care are of the view that there is no reasonable expectation of my recovery or that any recovery would result in little or no quality of life. c. My substitute decision maker to make the decision given the factors at the time after discussions with my doctors.	If I am not able to swallow food, then I wish to be fed by feeding tube if there is some hope that I will recover from my illness or injury such that my quality of life is not severely compromised. However, if two doctors involved in my care are of the view that there is no reasonable expectation of my recovery or that any recovery would result in little or no quality of life, then I do not wish to have a feeding tube and I wish for medication to be administered to me so that I may be kept as comfortable and pain-free as possible until my death.
I have other specific wishes, values, beliefs or scenarios that I would like to add in my Advance Care Plan: a. b. c. d.	Create additional clauses based on your clients' wishes and unique circumstances.

The **Speak Up : Advance Care Planning Workbook Workbook** is a helpful resource for assisting with planning. It contains tips for having conversations, common terms and questions around making a plan, different health care procedures, and a template for completing their plan.

www.advancecareplanning.ca/resource/acp-workbook/

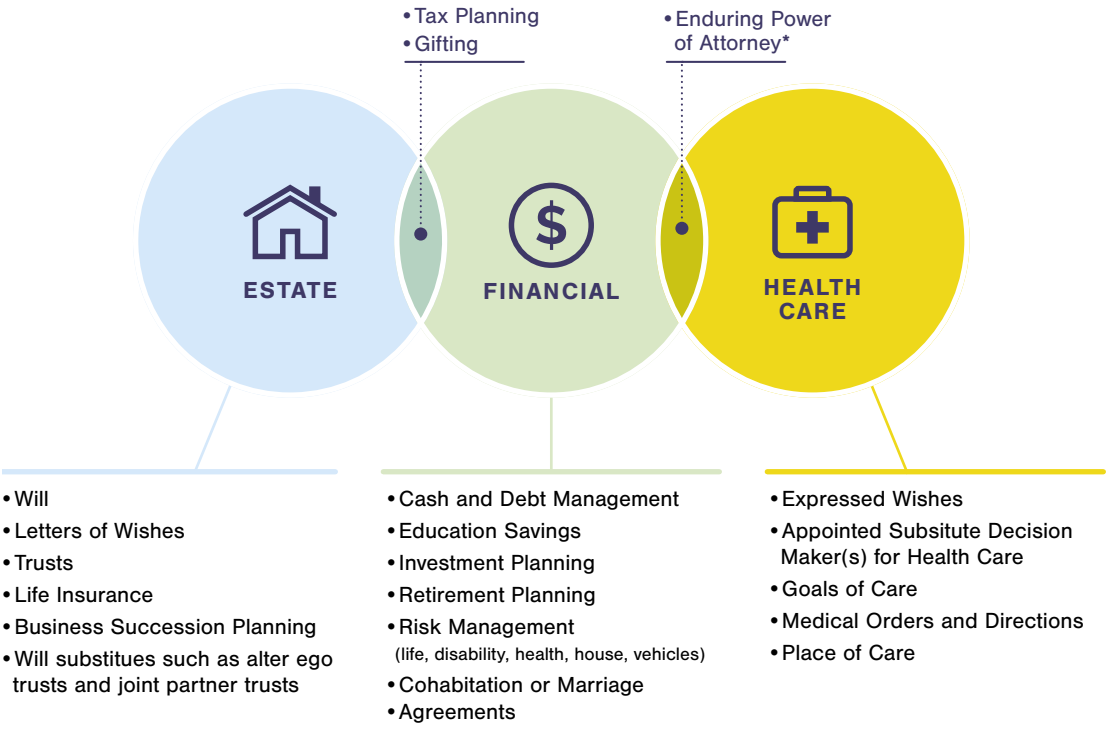
Section 4

Life Planning Model

ADVANCE CARE PLANNING is part of a larger umbrella of life planning activities that Canadians may engage in and seek the advice of legal professionals. You may have other estate, financial, and/or advance care planning discussions with your clients in accordance with the laws and services offered in your jurisdiction. The Life Planning Model places these discussions within a larger framework. As the Life Planning Model highlights, your client's needs and wishes with respect to his or her future care, estate and financial planning should be integrated and will vary in sophistication depending on your client's individual circumstances.

The Life Planning Model shows the fit of advance care planning with future planning activities. Each of these planning items may be placed somewhat differently within the model, depending on the person's situation and residence. For example, in some jurisdictions a SDM for health care may be able to make some estate and/or financial decisions. The SDMs ability to make care decisions (e.g., a move to a nursing home or long-term care) may also be limited by a person's financial resources.

The Life Planning Model



** The name of the document may vary by province; consult a legal professional for more information.*

Section 5

Next Steps

Continue conversations with your SDMs

Have you spoken to your SDMs so that they understand:

- The stage of your health condition and how it may progress?
- What your doctor or health care providers recommend that you consider and address with your SDMs?
- The health care treatments you would agree to or decline if a healthcare provider recommends them?
- That you accept or refuse life support and life-prolonging medical interventions for certain health conditions?
- The preferences you have with respect to residential care?
- The preferences you have with respect to a palliative approach to care?
- Any medical orders or health directives your SDM should be aware of?
- Their role and responsibility as your SDM?
- Where your documents are kept?

Remind your clients
An Advance Care Plan may change over time as personal circumstances change. For example, as long as one is capable, then one may change or cancel any advance care plan at any time, including legal documents appointing SDMs.

Section 6

Additional resources

Frequely Asked Questions about Advance Care Planning: **www.advancecareplanning.ca/resource/faqs**

Conversation Starters: **www.advancecareplanning.ca/resource/conversation-starters**

Provincial/Territorial ACP Resources: **www.advancecareplanning.ca/resource-library/#resource-library%7Ccategory:your-province-or-territory**

Ottawa Personal Decision Guide: **decisionaid.ohri.ca/decguide.html**

PlanWell Serious Illness Decision Guide: **planwellguide.com**

CARENET In tensive Care Unit Guide for Families: **www.myicuguide.ca**

My Voice Advance Care Planning Guide: **www.health.gov.bc.ca/library/publications/year/2013/MyVoice-AdvanceCarePlanningGuide.pdf**

Section 7

Summary Report

Brief summary the lawyer or client can provide to those accepting the role of SDM

Important Contacts

CONTACT	NAME	CONTACT INFORMATION
Subsitute Decision Maker		
Alternate Subsitute Decision Maker		
Lawyer		
Doctor		
Accountant		
Financial Planner		
Banking Information		
Safety Deposit Box		
Insurance Information		
Cultural/Spiritual Advisor		
Other		

My Other Planning Documents Relevant to My Jurisdiction

DOCUMENT	LOCATION	PERSON TO CONTACT
Specific Health Directives of Medical Orders		
Documents related to Financial Matters/Plans		
Documents related to Insurance Matters		
Documents related to Taxes		
Banking Information		
Will, Final Testament		
Personal Bequests		
Organ Donation		
Funeral Plan		
Special Wishes		
Other		

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