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This Advance Care Planning Kit was created within Treaty 13, the traditional home of the Mississaugas of the Credit, the Anishnabeg, the Chippewa, the Haudenosaunee, and the Wendat peoples. We thank the individuals across Canada who provided expertise and consultation on the development of this resource.



# STEPS IN THE PROCESS

Step 1: **THINK** (Section B)

Step 2: **ASSESS** (Section C)

Step 3: **CONSIDER** (Section D)

Step 4: **DETERMINE** (Section E)

Step 5: **DOCUMENT** (Section F)

Step 6: **APPOINT** (Section G)

This Advance Care Planning (ACP) Kit provides general information and resources to help you explore your values, beliefs, and preferences regarding your future health care and treatment.

The information provided is not the same as receiving legal advice or any other kind of professional advice.

The accompanying Advance Directive forms are each tailored for their respective province or territory, so be sure to use the right form for your jurisdiction and to read the instructions carefully.

If you still have questions or concerns after working through the ACP Kit and the Advance Directive form for where you live, we encourage you to consult a lawyer in your jurisdiction who is familiar with health law or estate planning.



# A. INTRODUCTION

## A1 Advance Care Planning is a process where you:

- Think about your values, beliefs, and preferences for your future health care.
- Write down (or “document”) your directions in an Advance Directive.
- Share these directions with a Substitute Decision-Maker that you choose.

A2 **Everyone should have an Advance Care Plan**, no matter their age or current health status. It can help ensure you receive care that aligns with your values and provides peace of mind for you and your loved ones.

**A3 IMAGINE YOU HAD A CAR ACCIDENT OR OTHER MEDICAL EMERGENCY THAT RESULTED IN YOU BEING IN A COMA.**

**A4 IMAGINE THAT YOU HAD A CONDITION THAT CHANGED YOUR ABILITY TO MAKE DECISIONS OR COMMUNICATE YOUR CARE NEEDS.**

A5 Would your loved ones know what help or care you would want – or not want? Would they know how to speak on your behalf? These are just two of many scenarios which highlight the importance of Advance Care Planning.

A6 Think about these difficult scenarios ahead of time. Have sensitive conversations with those closest to you. Use this guide to help you prepare for those important conversations.



## LEARN ABOUT YOUR PATIENT RIGHTS

It is important to be aware of your rights as a patient in Canada. Especially before writing down your directions for future health care. Ask for information, weigh the risks and benefits, and then decide what is right for you. Dying With Dignity Canada has a Patient Rights Guide available for free online at [dyingwithdignity.ca/patient-rights-guide](https://dyingwithdignity.ca/patient-rights-guide)

**A7** The best time to think about your end-of-life care options is when you are well and able. Do not wait until you are unwell or mentally incapable. You may not be able to plan for your health care and complete the forms needed. By doing it now, you ease the future responsibility of decision-making that might fall on others. Only **YOU** can create an Advance Directive for yourself. No one else can do it for you.

**A8** There are different words for an “**Advance Directive**” (such as “Health Care Directive,” “Directive,” “Personal Directive,” “Advance Health Care Directive,” or “Advance Care Directive”) and “**Substitute Decision-Maker**” (such as “Attorney for Personal Care,” “Proxy,” “Delegate,” “Representative,” or “Agent”) in each province and territory. For the purposes of this Advance Care Planning Kit, we will be using these generic terms. Once you have finished working through this Kit, you can then create your Advance Directive and appoint one or more Substitute Decision-Makers.

## IMPORTANT NOTE

This Advance Care Planning Kit **DOES NOT** address estate planning, wills, and executors. It also **DOES NOT** address the appointment of enduring powers of attorney for finances. Please consult a lawyer for any financial planning.











# C. ASSESS YOUR HEALTH STATUS

**C1 Advance Care Planning is important for all adults, no matter your age or health status.**

Accidents can happen unexpectedly, and one's health can change from one day to the next.

However, it may be helpful for you to consider your current health status when making decisions about your future treatment or care.

## WHERE ARE YOU ON THE CLINICAL FRAILITY SCALE?

**C2** Frailty refers to decreased function and health, which could look like:

- **Unintentional weight loss**
- **Muscle weakness**
- **Slowed movement**
- **Fatigue, and/or**
- **Reduced physical activity levels**

**C3** Frailty ranges from “**very fit**” to “**terminally ill.**” Everyone falls somewhere in this range. There are many factors that contribute to frailty, including:

- **Old age**
- **Poverty**
- **Isolation**
- **Poor nutrition**
- **Weight loss**
- **Weight gain**
- **Medication use**
- **Physical and/or mental health diagnoses**





C4 Take a moment to consider your health status **right now**. Place a checkmark in the list below next to the words that best describe you. If you place your checkmark further down on the list, then it is more urgent that you complete your Advance Directive.

### C5 EXERCISE 1

At the time of completing this Advance Care Plan, I consider myself:

- Very fit:** I am robust, active, energetic, and motivated. I exercise regularly (at least three to five times per week).
- Fit:** I have no active disease symptoms. I only exercise occasionally (e.g., once a week).
- Managing well:** My medical problems are well controlled. I have occasional symptoms. I am not active beyond regular walking (e.g., daily or every other day).
- Living with very mild frailty:** My symptoms limit my activity. However, I am not dependent on others for daily help. I am slower than I used to be. I may be frequently tired throughout the day.
- Living with mild frailty:** I need help in my day-to-day life. I might need help with finances, transportation, housework, shopping, walking outside alone, preparing meals, and/or taking medications.
- Living with moderate frailty:** I need help with all outside activities and maintaining my household. I have problems with the stairs and need help bathing and dressing.
- Living with severe frailty:** I am completely dependent on others for personal care but am not at risk of dying within the next six months.
- Living with very severe frailty:** I am completely dependent on others for personal care. I am approaching the end of my life. I likely would not recover even from a minor illness.
- Terminally ill:** My life expectancy is less than six months, BUT I am not otherwise living with severe frailty. For example, I can still exercise.

**Other:** (please elaborate) \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_





# D. CONSIDER MEDICAL SCENARIOS

**D1** The next step is to consider various medical conditions that you may experience and outcomes that you would accept or refuse. You can use the prompts below to help you. The answers you provide will help clarify your preferences. It will make it easier to discuss them with loved ones, health care providers, and your Substitute Decision-Maker(s).

**D2 Note:** If you select “No,” in the prompts below, you may wish to speak with your health care provider about your options. These may include palliative or end-of-life comfort care (such as pain medications and symptom management, physical therapy, counselling and emotional support, and/or spiritual care) or medical assistance in dying (MAID), if advance requests for MAID become legal in the future. Use the space after each prompt to explain your selections.

**D3 As long as you are mentally able to make your own decisions and are physically able to communicate them, you have the right to:**

- Accept, refuse, or stop any medical treatments, and to change your mind at any time
- Refuse nutrition (food) and hydration (water), either by mouth or ‘artificial means’ such as a tube
- Decline cardiopulmonary resuscitation (CPR), ensuring you obtain a do-not-resuscitate (DNR) order from your health care provider, in accordance with local requirements

Read more about your rights as a patient in Dying With Dignity Canada’s Patient Rights Guide at [dyingwithdignity.ca/patient-rights-guide](https://dyingwithdignity.ca/patient-rights-guide)



#### D4 **SCENARIO 1**

You suffer a sudden stroke. This causes permanent problems with thinking, memory, speech, mobility, and swallowing. Doctors say you will need assistance with basic self-care like feeding, bathing, and toileting, and that you will need to be tube-fed for the rest of your life. Would you accept this quality of life for yourself? Please mark your preference and explain your answer below.

- Yes
- Yes, on a trial basis (explain below what “trial basis” would look like for you)
- No
- I am uncertain

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#### D5 **SCENARIO 2**

You have advanced dementia. You can no longer feed or toilet yourself, but you are not in pain. Would you want to be spoon-fed or tube-fed? Please mark your preference and explain your answer below.

- Spoon-fed ONLY (no tube feedings)
- Either spoon-fed or tube-fed
- I don't want to be fed
- I am uncertain

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★ Attach this worksheet to your Advance Directive. An Advance Directive is a document in which you state your directions for future health care, including your values and beliefs.



## D6 SCENARIO 3

You have a cardiac arrest (heart attack) when you are not at home. Emergency responders successfully perform CPR. You are admitted to the intensive care unit (ICU) on life support. A few days later, after running some tests, doctors give your family an update: You have suffered serious brain damage. You will never fully recover or be able to live independently again. Would you:

**a.** Want to continue treatment in the ICU hoping your condition will improve over time?

**OR**

**b.** Want life support discontinued and receive palliative or end-of-life comfort care (such as pain medications and symptom management, physical therapy, counselling and emotional support, and/or spiritual care)?

Please mark your preference and explain your answer below.

- I would want to continue treatment
- I would want to continue treatment on a trial basis (explain below what “trial basis” would look like for you)
- I would want comfort care
- I am uncertain

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## D7 SCENARIO 4

You have an advanced chronic or worsening disease. You develop a serious infection (such as pneumonia). Your doctor advises that there is no cure for the underlying illness, but that the infection may be treatable, and presents the following two options:

**a.** To be treated with antibiotics (although they may not be effective, without them the infection will likely cause your condition to decline more quickly)

**OR**

**b.** To receive palliative or end-of-life comfort care (such as pain medications and symptom management, physical therapy, counselling and emotional support, and/or spiritual care) until death occurs naturally

Which would you prefer? Please mark your preference and explain your answer below.

- I would want antibiotics to try to keep me alive
- I would want palliative or end-of-life comfort care
- I am uncertain (explain below)

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# E. DETERMINE YOUR END-OF-LIFE PREFERENCES

**E1** If you could choose, how and where would you prefer to spend your final days or weeks? For example, at home, in hospital, or in a hospice. Consider the following questions to help you decide:

- a) **Is my preferred location wheelchair accessible?**
- b) **Is my preferred location able to accommodate medical equipment?**  
Examples include hospital beds, mechanical lifts, and commode chairs (a type of chair used by someone with an illness, injury, or disability to make it easier to go to the toilet).
- c) **Could my medical needs be properly met in my preferred location?**
- d) **If I want to be at home, are home care services available and reliable in my area?**
- e) **Do I have family or close friends who are willing and able to help with my care?**

## NOW, IMAGINE THE FINAL DAYS OF YOUR LIFE AND ANSWER THE FOLLOWING QUESTIONS:

### **E2 EXERCISE 1**

**Where am I?**

For example, at home, in a favourite place like a park, or in a hospice setting.

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★ **Attach this worksheet to your Advance Directive. An Advance Directive is a document in which you state your directions for future health care, including your values and beliefs.**



### E3 EXERCISE 2

#### Who is with me?

For example, specific family members, friends, spiritual and/or religious leaders, pets.  
If you would prefer complete privacy or very few visitors, write that here.

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### E4 EXERCISE 3

#### How am I spending my time?

For example, visitors, music, old photos, favourite foods.

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### E5 EXERCISE 4

#### What other end-of-life preferences are important to me?

For example, spiritual, cultural, or religious practices, or “bucket-list” items (a list of experiences, achievements, or activities you hope to accomplish before you die).

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★ Attach this worksheet to your Advance Directive. An Advance Directive is a document in which you state your directions for future health care, including your values and beliefs.

## HAVE CONVERSATIONS ABOUT YOUR END-OF-LIFE PREFERENCES

**E6** Before you continue, it is important to talk about your values, beliefs, and preferences with loved ones, health care providers, and anyone else involved in your care. These conversations are not necessarily about consulting others on your choices. Instead, they should focus on informing those closest to you about what you want in the future.

### TALKING TO LOVED ONES

(Family, friends, or anyone else who is close to you and whose opinion you value)

**E7** It can be hard to talk about end-of-life preferences with loved ones. Here are some suggested conversation starters:

- a) **I attended a workshop yesterday on Advance Care Planning. The speakers encouraged me to talk to you about my values and beliefs at end of life. Is now a good time?**
- b) **This conversation might be hard, but it's important that you understand what I want the end of my life to look like.**
- c) **When [Insert name] died, it made me think about my own end of life. I'd really like to discuss my thoughts with you.**
- d) **I've been reading a [book, article, or blog] about end of life. I'd really like you to read it so we can talk about it.**
- e) **I know it's tough for you to think about me dying. If we talk about it now, I can help you through it.**
- f) **I saw/read something in the news about death and dying that really worries/upsets me. What do you think?**

### TALKING TO HEALTH CARE PROVIDERS

**E8** Where possible, it is also important that you speak about your end-of-life preferences with a health care provider that you see regularly and who knows you well. Especially if you already have a chronic or worsening disease or condition. This health care provider is usually a nurse practitioner or physician, but they could also be a home care nurse or coordinator, or a nurse at a facility you regularly attend (such as a cancer clinic or dialysis center).





# F. DOCUMENT YOUR DIRECTIONS IN AN ADVANCE DIRECTIVE

**F1 An Advance Directive is a document in which you state your directions for future health care.** You write it while you are well and able to make decisions to be used when you are not able to make decisions for yourself. An Advance Directive informs others of your end-of-life preferences and helps those who are responsible for your care to understand and support the decisions that you have made.

**F2 You are not legally required to have an Advance Directive. However, if you do not have one, others may not know what you want.** You may be given treatments or care that you would not have chosen. Or you might be denied treatments that you would have selected for yourself.

**F3** There is a different form for completing an Advance Directive in each province and territory. We have prepared instructions and forms to help you complete an Advance Directive and appoint a Substitute Decision-Maker where you live. A link to those forms is included at the end of this Kit.

**F4** Here is a general overview of what you will need to do:

- a) **Provide your name, date of birth, address, and phone number.**
- b) **Revoke (cancel) any previous Advance Directives. Doing so will confirm that this document reflects your current choices.**
- c) **Designate one or more Substitute Decision-Makers. See page 23.**
- d) **Provide directions for your future health care.**



F5 Things to consider when providing directions for health care:

- a) **What if you could not communicate because of medication(s) that cause sedation? Would you be willing to tolerate some pain or other discomfort to have the sedation lifted so you could decide for yourself to accept or refuse a particular treatment?**
- b) **Would you want to prolong your life and be provided with all life-sustaining treatments applicable to your medical condition? OR are there circumstances in which you would want to receive only palliative or end-of-life comfort care (such as pain medications and symptom management, physical therapy, counselling and emotional support, and/or spiritual care)?**
- c) **Are there any treatments you would specifically refuse? For example, artificial heart stimulation (CPR), a respirator or ventilator, artificial feeding, artificial hydration, antibiotics, etc.**
- d) **If you were in a health care facility or under the care of a health care provider that would not respect your directions, would you want to be transferred to another facility or provider?**

F6 These decisions are very personal and require you to consider your values, beliefs, and preferences carefully. Review what you have written in this Advance Care Planning Kit. Use that information to have conversations with loved ones and health care providers who may be involved in your end-of-life care. Create an Advance Directive that communicates your values, beliefs, and preferences clearly.

F7 Remember: Only **YOU** can create an Advance Directive for yourself – no one else can do it for you.

Download the forms to create an Advance Directive and appoint a Substitute Decision-Maker in your province/territory at [dyingwithdignity.ca/advance-care-planning](https://dyingwithdignity.ca/advance-care-planning). You can also call Dying With Dignity Canada (DWDC) toll free at **1-800-495-6156** to receive a copy in the mail.



# G. APPOINT A SUBSTITUTE DECISION-MAKER

**G1** A Substitute Decision-Maker is a person you choose to communicate your health care decisions, or who is appointed by law to make decisions on your behalf if and when you become unable to do so yourself.

**G2** Generally, your Substitute Decision-Maker must:

- **Meet the age requirement for being a Substitute Decision-Maker in the province or territory where you live**
- **Be mentally capable (meaning they are able to understand information, evaluate options, and communicate decisions effectively)**
- **Be available and willing to accept the role of Substitute Decision-Maker**

**G3** Never appoint someone to be your Substitute Decision-Maker without talking to them first, since they must agree to accept the responsibility.

**G4** Some things to consider when choosing your Substitute Decision-Maker:

- **Are they a person that you trust to carry out your directions and make decisions for you?**
- **Do they have the time to dedicate to this role?**
- **Are they emotionally capable of handling difficult conversations and making tough decisions?**
- **Are they healthy enough to handle the responsibility whenever you may require it?**
- **Do they have any experience dealing with the health care system?**
- **Do they live in your area? Your Substitute Decision-Maker can carry out the role long distance, but it is easier in person.**

All these factors can play a role in your choice.



**G5** We recommend that you appoint **ONE** primary person to be your Substitute Decision-Maker. It is also ideal to appoint an **ALTERNATE**. This is in case your first choice is unable or unwilling to act on your behalf at the time needed.

**G6** You can require your Substitute Decision-Maker to consult with specific others (such as siblings or children) if time permits. If you would like your Substitute Decision-Makers to make decisions jointly, they must agree on decisions about your care before action is taken. This can create logistical problems and disagreements.

**G7** The specific requirements for appointing a Substitute Decision-Maker where you live are explained in more detail in our forms.

Download the forms to create an Advance Directive and appoint a Substitute Decision-Maker in your province/territory at [dyingwithdignity.ca/advance-care-planning](https://dyingwithdignity.ca/advance-care-planning). You can also call Dying With Dignity Canada (DWDC) toll free at **1-800-495-6156** to receive a copy in the mail.

**G8** We recommend that you also consider appointing someone to look after your financial and legal affairs when you are not able to do so for yourself. The forms that we provide do not address financial matters or property. Please consult your lawyer or financial advisor to assist you with this aspect of your planning.





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If you found this resource helpful, please consider making a donation to help us continue our work. Donations can be made online at [dyingwithdignity.ca/donate](https://dyingwithdignity.ca/donate) or over the phone by calling **1-800-495-6156** and selecting option 2.

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IT'S YOUR LIFE. IT'S YOUR CHOICE.



For more information about Advance Care Planning, or any other questions about end-of-life rights and choice, please visit [www.dyingwithdignity.ca](http://www.dyingwithdignity.ca), contact us at [support@dyingwithdignity.ca](mailto:support@dyingwithdignity.ca) or call us toll free at **1-844-395-3640**.



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