



Advance Care Planning Kit



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INTRODUCTION

This Advance Care Planning Kit invites you to think about and express your wishes for health care and treatment. It is intended to provoke thinking, conversation, and planning, and to encourage communication between you, your loved ones, and your health care providers.

This toolkit provides important background information on Advance Directives and appointing a Substitute Decision-Maker (SDM). It focuses largely on medical and end-of-life care scenarios, and contains information on interventions such as Cardiopulmonary Resuscitation (CPR) that may be used in end-of-life situations.

When you have finished working through this kit, you can find the province-specific forms for creating an Advance Directive and appointing a Substitute Decision-Maker for Health on Dying With Dignity Canada's (DWDC) website at:

www.dyingwithdignity.ca

[/download your advance care planning kit](#)



Alternatively, you can call DWDC toll free at **1-800-495-6156**, and a member of the team will mail you a copy.

The best time to think about your end-of-life care options is when you are well and able. It is important to keep in mind that when you are unwell and mentally incapable, you will not be able to plan and sign the appropriate forms to legally appoint your desired SDM. We offer various scenarios to help you plan for the future, while reminding you that you can always change your mind. Advance Care Planning is the best way to ensure that your wishes are known to your SDMs, family, caregivers, and health care providers. By doing it now, you ease the future burden of decisions that might have to be made under difficult circumstances by those who love and care for you.

Once completed, this kit and the forms provided by DWDC may not constitute a legally valid Advance Directive or appointment of an SDM in your jurisdiction. Consult a lawyer to be sure. DWDC is not responsible for the information contained in the websites included in this kit, or the decisions that you make regarding your Advance Care Plan. These are important decisions, and we encourage you to seek the advice of professionals as required.

ADVANCE CARE PLANNING

Advance Care Planning (ACP) is at the heart of being an empowered patient or caregiver and is important for all adults, at all ages and stages of life. Think of ACP as an umbrella of planning documents that allows you to plan for serious injury, illness, and end of life.



Estate planning*

- Will and executor
- Life insurance
- Business succession planning
- Trusts
- Letter of wishes

*It is recommended that you seek professional assistance for estate planning.

Financial preparation*

- Health insurance: short- and long-term disability, critical illness, and long-term care
- Getting and keeping financial documents in order
- Enduring Power of Attorney agreements
- Investment and retirement planning
- Liquid assets to pay for unforeseen costs of loss of income, medical equipment, and private home care and private residential care

*It is recommended that you seek professional assistance for financial planning.

Values, beliefs, and preferences for future health care

- Think about what's important in your life now and at the time of serious injury, illness, and end of life
- Determine where you are in your health journey

Have ongoing conversations

- With SDMs, loved ones and future caregivers about your values, beliefs, and future wishes for health care
- With the health care team about your health journey, values, and beliefs

Health documentation

- Formalize your SDM in writing (see part 2)
 - Please note that, by law, every person in Ontario already has an SDM by default. If you would like to choose someone else, please see part 2
- Complete your Advance Directive (stating your values, beliefs and preferences for care when you cannot make decisions for yourself)
- Consider other end-of-life documents, as applicable to your health circumstances
- Sign your No CPR or Do-Not-Resuscitate (DNR) orders and/or Hospital medical orders stating your level of resuscitation and care, if desired

- Complete your organ donation documentation, if any

Note: More information on medical assistance in dying (MAID) is provided below on page 18.

THE ADVANCE CARE PLANNING PROCESS

| | |
|-----------------|---|
| CONSIDER | Your values, beliefs, and preferences for future health care |
| DECIDE | <ul style="list-style-type: none"> • Who you would like as your SDM • What you would like your end of life to be like |
| DOCUMENT | <ul style="list-style-type: none"> • Your values, beliefs, and preferences for future health care in an Advance Directive • Who you appoint as Substitute Decision-Maker for Health and Finances (Separate documents may be required and the documents used vary between the provinces and territories) |
| REVIEW | Review all documents regularly to make sure they still accurately reflect your wishes and ensure others are notified of any changes |

STRATEGIES TO ASSIST IN COMPLETING YOUR ADVANCE CARE PLAN

You already know how important it is to have an Advance Care Plan. Now it's time to start on putting yours together. Below are some tips on how to achieve your goal of getting your ACP completed and ready in case you need it.

Prioritize

Once you determine the components of your ACP, decide which are most important to you. If something unexpected were to happen tomorrow, what would you want to have done? What are your biggest risks? Prioritize this part of your ACP first!

Buddy System

Working with someone else creates mutual accountability and is a good way to motivate you to keep going on your Advance Care Plan. If you participate in an ACP workshop, consider who in the group you may get along with, and propose the idea of working together. When you meet your “buddy,” set some milestone goals and dates by which you want to achieve them. Or choose a friend, family member, or neighbour who shares your interest in making an Advance Care Plan. As always, exercise your best judgement when sharing sensitive health or financial information with others.

Bite-Sized Pieces

Being realistic about what you can do will keep you motivated as you see your successes accumulating. Breaking down the ACP into distinct sections and tasks can make a daunting task seem much more manageable.

Reward Yourself

Once you have set your goals, plan to do something to celebrate the completion of each milestone. It doesn't need to be anything grand, just something to mark that you have met your goal. This recognition builds momentum and confidence — you can get this done! — as you get closer to obtaining the peace of mind that comes with having your ACP finished.

PART 1: ADVANCE DIRECTIVES

A. BACKGROUND

What is an Advance Directive?

An Advance Directive is most often a document, written while you are well and able to make decisions, in which you state your wishes for medical or non-medical care. It is intended to ensure that your end-of-life wishes are respected in the event that you become unable to make decisions for yourself. The name of the document is different depending on the province or territory in which you live. See Table 1 below to determine what an Advance Directive is called where you live.

Table 1.

| Province / Territory | Province-Specific Term Used for an Advance Directive |
|---------------------------|--|
| Alberta | Personal Directive |
| British Columbia | Advance Directive |
| Manitoba | Health Care Directive |
| New Brunswick | Advance Care Directive |
| Newfoundland and Labrador | Advance Health Care Directive |
| Northwest Territories | Personal Directive |
| Nova Scotia | Personal Directive |
| Nunavut | No specific term |
| Ontario* | Wishes* |
| Prince Edward Island | Health Care Directive |
| Quebec | Advance Medical Directive |
| Saskatchewan | Health Care Directive |
| Yukon | Directive |

*A special note about Advance Directives and “Power of Attorney for Personal Care (POAPC)” in Ontario:

In Ontario, an Advance Directive is not a legal document and there is no reference to it in the province’s health care legislation. This means that if you choose to document your preferences for future care, they will be treated as “wishes” that must be considered by your SDM when they make decisions or provide consent on your behalf. In Ontario, health care professionals must get consent from you or your SDM at the time of treatment. Your wishes, written or spoken in advance, are not consent. Any document that expresses your future wishes for care is meant to advise your SDM (or attorney appointed through a POAPC) and health professionals in making decisions on your behalf. Making your wishes known does not necessarily mean that they will be followed exactly. We advise that you write an Advance Directive to communicate your wishes clearly, but you should also understand that there are many factors that weigh in a health care decision that may lead to different outcomes in certain situations.

Why have an Advance Directive?

In a medical emergency or in any other circumstance that leaves you unable to make decisions for yourself – for example, if you have a stroke or if you are in a coma – your Advance Directive will assert your right to choose what you want (or do not want) in the way of medical treatment and care. It will assist those responsible for your care in selecting your treatment(s) and help family members understand and support the decisions you would have made for yourself.

You are not legally required to have an Advance Directive. Only you can create it – no one else can do it for you. But if you do not have an Advance Directive, others may not know your wishes and you may be subjected to aggressive or life-prolonging medical interventions that you would not have wanted. On the other hand, you may have a specific medical condition for which you do want all available treatments. Start the process now of creating your Advance Directive by thinking about where you are on your personal health journey.

B. WHERE ARE YOU ON YOUR HEALTH JOURNEY?

What is the state of your health? It sounds like a simple question, but most of us can't answer it accurately. We may think we are healthier than we really are because change often comes slowly, and we adapt.

We may not get all the information we need to make informed decisions. For example, a patient may be told: "Your kidneys are not functioning quite as they should. We'll just keep an eye on that." This does not tell you what level of kidney function you have.

If your health care provider has raised some concerns about anything in your health, ask more questions and educate yourself on available treatments and your prognosis. Some health issues seem minor because you feel you are managing them well with medical treatments. However, health issues can worsen over time and become more urgent quickly, so it is important to ask yourself where you are on your health journey on a regular basis.

i. Health journey questionnaire

Take the time to go through this questionnaire – it may help you to determine how critical your Advance Directive is at this stage in your life. When you don't know the answers to questions about your health, it's a clue to speak with your health care providers or specialists.

Be honest with yourself while doing this exercise. Checkmark which category you are in:

You are under 65 and in good health and fitness

Serious illness and injury can happen at any age. You likely will want any and all treatment for conditions that develop, but it's not too early to think about what your values, beliefs and preferences for care would be if you were in a serious accident, you had a major stroke, or developed any other condition that might render you incapable making decisions for yourself, and to share your thoughts with your loved ones.

You have one or more *chronic* conditions, at any age

The most common chronic health conditions are:

- Diabetes (insulin dependent or non-insulin dependent) – even if well-controlled
- High blood pressure (hypertension) – even if well-controlled
- Organ Diseases:
 - Kidney disease (your health care provider may or may not use the word 'failure')
 - Heart disease such as: abnormal rhythm, angina, heart attack, congestive heart failure (CHF), cardiomyopathy (heart enlargement)
 - Lung disease (COPD or other)
 - Liver disease
- Neurological Diseases such as Parkinson's, ALS, Huntington's, and Multiple Sclerosis
- Vascular disease
- Autoimmune disease
- Early to moderate dementia

You have a life-threatening illness and your life-expectancy is less than one to two years, at any age

Receiving a life-threatening diagnosis can be destabilizing, but you can still take control of your own end-of-life plans. The choices are yours to make. Think about doing your Advance Care Planning early in your diagnosis so it is done, and then revisit and revise your Advance Directive as your health changes. If you don't know how to talk about your Advance Care Plan with your loved ones, we've got a few suggestions in Section D: "Having conversations."

You are over 65 and relatively healthy

Your body is getting older, a little less resilient and progressively more fragile. As we age, it is important to think a little deeper and more often about what we do and do not want should we become seriously ill or injured. It also becomes more important to talk to those who will be making health care decisions for you if you become unable to do so for yourself so that they are not blindsided by any sudden health changes and decisions they may have to make, and are prepared by knowing what you want.

You are over 65 and having trouble managing your day-to-day affairs and the activities of daily living. This is referred to as a "frail elder"

We all age differently. Mild frailty occurs when people need help with their day-to-day care and affairs, such as meal preparation and housework. As people become increasingly frail, it becomes more and more important to think about Advance Care Planning. See below to determine where you fit on the frailty scale (Section ii).

You are over 75, no matter your state of health

This is considered the age where everyone, no matter their apparent health, is more vulnerable and less resilient to disease and injury. Advance Care Planning should be an urgent call to action at this point in your life.

ii. What is frailty?

When people hear the word “frail,” it is often associated with being “sickly” or “weak.” This is generally not correct. Frailty is a spectrum, ranging from very fit to terminally ill, and everyone lands somewhere on the spectrum.

“People are considered frail when they have multiple interacting health problems that are often made worse by social vulnerability (food insecurity, income that is inadequate for need, inadequate shelter, not feeling safe in one’s environment, or feeling lonely).”










– Dr. Kenneth Rockwood, Division of Geriatric Medicine, Dalhousie University

Frailty is associated with several factors which may be reversible or preventable to improve or delay serious outcomes:

- **Advancing age**
- **Vulnerability (such as poverty and/or isolation)**
- **A decline in the ability to function on your own or to be active**
- **Poor nutrition or weight loss (sometimes called ‘failure to thrive’)**
- **Taking several medications (polypharmacy)**
- **More than one medical and/or mental health issue, including dementia**
- **Falls**

Use the Clinical Frailty Scale below to determine where you fit on the spectrum. It will help you create an Advance Directive that suits your needs.

Figure 1. The Clinical Frailty Scale (CFS) version 2.0

| CLINICAL FRAILTY SCALE | | |
|---|----------|--|
|  | 1 | VERY FIT People who are robust, active, energetic and motivated. They tend to exercise regularly and are among the fittest for their age. |
|  | 2 | FIT People who have no active disease symptoms but are less fit than category 1. Often, they exercise or are very active occasionally , e.g., seasonally. |
|  | 3 | MANAGING WELL People whose medical problems are well controlled , even if occasionally symptomatic, but often are not regularly active beyond routine walking. |
|  | 4 | LIVING WITH VERY MILD FRAILITY Previously “vulnerable,” this category marks early transition from complete independence. While not dependent on others for daily help, often symptoms limit activities . A common complaint is being “slowed up” and/or being tired during the day. |
|  | 5 | LIVING WITH MILD FRAILITY People who often have more evident slowing , and need help with high order instrumental activities of daily living (finances, transportation, heavy housework). Typically, mild frailty progressively impairs shopping and walking outside alone, meal preparation, medications and begins to restrict light housework. |
|  | 6 | LIVING WITH MODERATE FRAILITY People who need help with all outside activities and with keeping house . Inside, they often have problems with stairs and need help with bathing and might need minimal assistance (cuing, standby) with dressing. |
|  | 7 | LIVING WITH SEVERE FRAILITY Completely dependent for personal care , from whatever cause (physical or cognitive). Even so, they seem stable and not at high risk of dying (within ~6 months). |
|  | 8 | LIVING WITH VERY SEVERE FRAILITY Completely dependent for personal care and approaching end of life. Typically, they could not recover even from a minor illness. |
|  | 9 | TERMINALLY ILL Approaching the end of life. This category applies to people with a life expectancy <6 months , who are not otherwise living with severe frailty . (Many terminally ill people can still exercise until very close to death.) |

SCORING FRAILITY IN PEOPLE WITH DEMENTIA

The degree of frailty generally corresponds to the degree of dementia. Common **symptoms in mild dementia** include forgetting the details of a recent event, though still remembering the event itself, repeating the same question/story and social withdrawal.

In **moderate dementia**, recent memory is very impaired, even though they seemingly can remember their past life events well. They can do personal care with prompting. In **severe dementia**, they cannot do personal care without help. In **very severe dementia** they are often bedfast. Many are virtually mute.

 **DALHOUSIE UNIVERSITY**
www.geriatricmedicineresearch.ca

Clinical Frailty Scale ©2005–2020 Rockwood, Version 2.0 (EN). All rights reserved. For permission: www.geriatricmedicineresearch.ca Rockwood K et al. A global clinical measure of fitness and frailty in elderly people. CMAJ 2005;173:489–495.

¹ The Clinical Frailty Scale is used with permission from its author, Dr. Kenneth Rockwood, Division of Geriatric Medicine, Dalhousie University

It's time to pause and do some homework.

After an honest assessment, where are you in your health journey? If you don't know, it's time to ask your health care provider for their honest assessment, and possibly get more testing and referrals, if needed.

Based on what you determined, write down where you are in your life health journey.

For example, "I am over 65 and relatively healthy. I would classify myself as Managing Well on the Clinical Frailty Scale. While I am not dependent on others for daily help, I am starting to consider my end-of-life wishes should I get into an accident or become ill."

C. DETERMINE YOUR PERSONAL VALUES AND BELIEFS

Use the following tables and questions to help you think about and identify your personal values and beliefs.

| What do you fear most near the end of life? | Not Important | Somewhat Important | Very Important | | |
|---|---------------|--------------------|----------------|---|---|
| Losing control over my own decisions | 1 | 2 | 3 | 4 | 5 |
| Losing my mobility | 1 | 2 | 3 | 4 | 5 |
| Being in uncontrollable pain | 1 | 2 | 3 | 4 | 5 |
| Lingering rather than dying quickly | 1 | 2 | 3 | 4 | 5 |
| Being incontinent | 1 | 2 | 3 | 4 | 5 |
| Being alone | 1 | 2 | 3 | 4 | 5 |
| Being confused most of the time | 1 | 2 | 3 | 4 | 5 |
| Being a burden on loved ones | 1 | 2 | 3 | 4 | 5 |
| Being dependent on others for everyday activities like eating and bathing | 1 | 2 | 3 | 4 | 5 |
| Losing my sight or hearing | 1 | 2 | 3 | 4 | 5 |

Other things that you fear:

| Rate how important the following are to you: | Not Important | Somewhat Important | Very Important | | |
|---|---------------|--------------------|----------------|---|---|
| Quality of life over quantity | 1 | 2 | 3 | 4 | 5 |
| Living as long as possible, regardless of quality | 1 | 2 | 3 | 4 | 5 |
| My spiritual beliefs and traditions | 1 | 2 | 3 | 4 | 5 |
| Independence, autonomy, control | 1 | 2 | 3 | 4 | 5 |
| Being mentally alert and competent | 1 | 2 | 3 | 4 | 5 |
| Time with family and friends | 1 | 2 | 3 | 4 | 5 |
| Time in nature (fresh air and sunlight) | 1 | 2 | 3 | 4 | 5 |
| My work or volunteering | 1 | 2 | 3 | 4 | 5 |
| Time with my pets | 1 | 2 | 3 | 4 | 5 |
| Care that meets my needs | 1 | 2 | 3 | 4 | 5 |
| Watching my favourite TV shows and movies | 1 | 2 | 3 | 4 | 5 |
| Birthdays and celebrations | 1 | 2 | 3 | 4 | 5 |
| Preparing, eating and sharing food | 1 | 2 | 3 | 4 | 5 |
| Playing or listening to music | 1 | 2 | 3 | 4 | 5 |
| Vacations/travel | 1 | 2 | 3 | 4 | 5 |
| Writing: keeping a journal or writing letters | 1 | 2 | 3 | 4 | 5 |
| My hobbies or reading | 1 | 2 | 3 | 4 | 5 |
| Quiet time | 1 | 2 | 3 | 4 | 5 |

Other things that are important to you:

End-of-life wishes:

If you could plan them today, imagine what the last days of your life would be like:

- Where would I like to be?
- What would I be doing?
- Who would I want with me?
- What would I eat if I am able to eat?
- Would I want the comfort of spiritual support from a member of the clergy or someone who shares my religious beliefs?
- Are there people to whom I would want to write a letter or record an audio or video message, perhaps to be read, heard, or watched in the future?
- How do I want to be remembered? What would I write for my own obituary or epitaph?
— Examples: where I was born and grew up; where I have lived; my major life moments; what I'm most proud of in my life.

On your Advance Directive you will be asked to pick ONE of the following:

If possible and reasonable, I would like to die:

- At home
- In hospice
- In hospital

At the end of my life it's important to me (write down the details of your answer to the questions above):

It's time to pause and put this all together (You may need some extra paper):

My most important personal values and beliefs:

My feelings and wishes about spiritual ceremonies being performed before or after my death:

My most important cultural beliefs:

Other important values and beliefs:

Can a request for medical assistance in dying be included in my Advance Directive?

In Canada, it is legal under certain circumstances for a person to end their lives with the help of a physician or nurse practitioner. Medical assistance in dying (MAID) is provided by a physician or nurse practitioner to a consenting, capable adult earlier than when a natural death would occur. Ultimately, it is always the patient's decision whether to request and – if eligible – go through with MAID.

The current laws of Canada do not allow people to make an advance request for MAID in their Advance Directive. [You can learn more about MAID on the DWDC website.](#)

D. HAVING CONVERSATIONS

i. Talk to your Substitute Decision-Makers, Loved Ones, and Medical Team

While it's important to talk about end-of-life care at all stages of life, it's critical to have these discussions if and when:

- You have been diagnosed with cancer, especially if your cancer has metastasized beyond its place of origin and even if you are still receiving treatment
- You have moderate to advanced organ failure of any kind: heart, lung, kidney, liver – even if you are on a transplant list
- You have a progressive neurological disease of any type (MS, ALS, Parkinson's, Huntington's, etc.)
- You have more than one chronic condition, moderate to end-stage
- You are over 65 years of age and consider yourself Stage 5 on the Clinical Frailty Scale

Talking about end-of-life care is not easy, but if you want your wishes for future care to be known, you need to talk to your loved ones, SDMs and anyone else involved in your care. Not only will this ensure that they know your preferences for care, but it can also lead to more in-depth conversations about what is important to you.

Being simple, direct and specific allows others to really hear what you are saying. Let the people in your life know that you want to talk about end-of-life care and that this is important to you.

A bit of strategic planning to make the situation as comfortable as possible will go a long way to having a good conversation. Ask yourself, “Who do I want to talk to? When would be a good time? Where? What do I want to be sure to say?” Do I want to talk to them as a group or individually? Do I need a support person to help me feel comfortable?”

Starting the conversation can be the hardest part. Here are some suggestions to help you start:

- I attended a workshop yesterday on Advance Care Planning. I was encouraged to talk to you today about my values and beliefs. I would like to talk to you now while things are still fresh...
- What I’m asking to talk to you about today might be tough, but I need to talk to you now about what I want the end of my life to look like...
- Remember how [someone you both know] died? Talk about what you think of that situation
- I was thinking about what happened to [someone who died], and it made me realize...
- I want to talk to you about something that is really important to me
- I need to plan for the future. Will you help me?
- I’m okay now but I want to be prepared and I am concerned that...
- I’ve been reading a [book, article or blog] that I’d really like you to read so we can talk about it
- I know it’s really tough for you to think about me dying but if we talk about it now, I’m still here to help you through it
- I know that you don’t see eye-to-eye with me about my decisions about dying and the way I see my last days unfolding, but this is my life, and it would mean the world to me if you’d hear my position and try and step into my shoes

Letting the people who may need to make care decisions for you in the future know what your preferences are is a tremendous gift to them. If they are not sure of what you want, they may end up feeling guilt or questioning their decisions. It can also help reduce conflict among your loved ones.

It's time to pause and write out what you want to talk about, and what you need to say to your loved ones or person in charge of your care (you may need extra paper):

ii. Talk to your health care providers

Q: Who do I want to talk to?

A: Your health care provider, or specialist/surgeon

Q: When do I want to talk to my health care providers, and in what situation? During a routine office visit, urgent care, emergency room, hospital admission, or at the time of a new diagnosis?

A: It makes most sense to have the discussion in a calm and less rushed environment than an emergency room or during urgent care, but you should not hesitate to talk to your health care providers about end-of-life care.

Individuals who talked with their health care providers or families about their preferences for end-of-life care:

- Had less fear and anxiety
- Felt they had more ability to influence and direct their medical care
- Believed their health care providers had a better understanding of their wishes
- Indicated a greater understanding and comfort level than they had before the discussion²

It can be challenging to know how to bring up the subject of dying and end of life with your health care provider. But it is an important conversation that deserves careful planning. Do not wait for them to ask about your wishes. Chances are they are waiting for you to start the conversation.

² "Planning Ahead." Delaware Hospice. June 25, 2020. Accessed August 05, 2020. <http://www.delawarehospice.org/planning-ahead>.

You may want to let your health care provider know in advance that you want to talk about end-of-life wishes during your next appointment. Let them or their team know that this is the purpose of your visit, so that they are ready for the conversation. Health care providers can allot extra time when having these discussions with patients.

If end of life happens to come up in a consultation but there is not enough time for a full conversation, ask for an appointment to specifically discuss this topic. In hospital, ask your nurse to speak to the unit social worker – they are specially trained for these kinds of conversations.

Before you talk to your health care provider, it might be helpful to prepare what you want to say. Prepare a list in advance of what you absolutely need your health care provider to know. For example, “For an acceptable quality of life, if I am no longer able to [fill in your values and beliefs], I am prepared for my life to end.”

Think about how to start the conversation:

- Be direct: “I want to talk about my wishes for end-of-life care”
- Bring in your written beliefs, values, and preferences and highlight the top ones that will be in your Advance Directive. Show the document to your health care provider. “I’ve written down my thoughts about end of life and would like you to see them”
- Share thoughts on someone else’s death you have witnessed. “My father died a prolonged death from dementia, and I would want something different for myself”

TIP: Consider having your Substitute Decision-Maker for Health attend the appointment with you for emotional support, assistance in listening, and to reinforce their own understanding of your wishes. If you have not reached that point in your planning, take along a trusted friend for moral support and to take notes.

Ask your health care providers the tough questions about treatment and prognosis:

- What is my diagnosis and what stage am I at currently?
- Is my condition curable, chronic but manageable, or life-ending?
- Who is the health care provider who will be leading my treatment team?

- Will I need a specialist?
- What information will I need and where can I get it?
- What are the most important steps for me to take now?
- What do I tell friends, family, children, and co-workers about my illness?

Talk about pain control and symptom management options and let them know your preference between relief of pain or alertness.

Share your thoughts on what is important to you. If you choose quality over quantity of life, let them know.

NOTE: Give your health care provider a copy of your completed Advance Directive and the contact information of your Substitute Decision-Maker for Health to include in your medical records.

It's time to pause and write out what you want to talk about, and what you need to say, to your health care providers:



PART 2: SUBSTITUTE DECISION-MAKER FOR HEALTH AND FINANCES

A. Background

If you lose the capacity to make decisions about your own personal care and/or finances, you can appoint someone to make decisions on your behalf. Each province has its own term for an SDM. See Table 2 for the term used in your province.

Table 2.

| Province | Health | | Financial |
|---------------------------|-------------------------------------|-------------------------------|--------------------------------|
| | Term Used | Document Name | Term Used |
| Alberta | Agent | Personal Directive | Enduring Power of Attorney |
| British Columbia | Representative | Advance Directive | Enduring Power of Attorney |
| Manitoba | Proxy | Health Care Directive | Enduring Power of Attorney |
| New Brunswick | Attorney for Personal Care | Advance Care Directive | Attorney for Property |
| Newfoundland and Labrador | Substitute Decision-Maker | Advance Health Care Directive | Enduring Power of Attorney |
| Northwest Territories | Agent | Personal Directive | Enduring Power of Attorney |
| Nova Scotia | Delegate | Personal Directive | Enduring Power of Attorney |
| Nunavut* | Guardian | N/A | Enduring Power of Attorney |
| Ontario** | Power of Attorney for Personal Care | Advance Care Directive | Power of Attorney for Property |
| Prince Edward Island | Proxy | Health Care Directive | Enduring Power of Attorney |
| Quebec | Mandatary | Advance Medical Directive | Power of Attorney |
| Saskatchewan | Proxy | Health Care Directive | Enduring Power of Attorney |
| Yukon | Proxy | Directive | Enduring Power of Attorney |

*In Nunavut, there is no legislation that allows a person to appoint an SDM for health, or “Guardian”, before they become unable to make their own decisions. Any person can apply to become your Guardian, but the court will consider several factors, including your prior expressed wishes about who should be your Guardian.

**By law, every person in Ontario already has an SDM, but you can also specify who you want as your SDM by completing a Power of Attorney for Personal Care document through which you can appoint an attorney, who will be your SDM.

Why have a Substitute Decision-Maker for Health?

If you are unable to communicate your wishes, your previously expressed wishes should be respected as written in your Advance Directive or as expressed orally. Even if you have written an Advance Directive, you may not have addressed the specific medical condition or scenario that your SDM or health care providers need to make decisions about. Also, the legal framework for Advance Directives varies across Canada, and Advance Directives are not legally binding documents in all provinces or territories.

Ultimately, the decision will be made by your SDM (or health care provider in an emergency). Your SDM is authorized to make decisions on your behalf based on his or her understanding of the decisions you would have made if you were able to do so.

Why have a Substitute Decision-Maker for Finances?

It is recommended that you also appoint an SDM for Finances if:

- You own real property (like land or a house)
- You have investments or money that need to be managed
- Money is needed from your accounts to pay for living expenses and regular bills

You can appoint an SDM for Finances for free at the following website:* <https://www.lawdepot.com/contracts/power-of-attorney-form/?loc=CA&s=QSgeneral&g=QGFinalDetails>

*Use at your own risk. Please note that in some provinces, you cannot appoint a Substitute Decision-Maker to deal with real property (Land Title Office) without a lawyer or notary as a witness.

Most provinces and territories in Canada have a standard power of attorney form created by the government that you can fill in (for example, the Ontario government provides a free kit for creating your own power of attorney at <http://www.attorneygeneral.jus.gov.on.ca/english/family/pgt/poa.pdf>).

Some commercial websites also offer free templates (for example, you can appoint an SDM for Finances for free at the following website:* <https://www.lawdepot.com/contracts/power-of-attorney-form/?loc=CA&s=QSgeneral&g=QGFinalDetails>)

If your financial affairs are complicated, it is recommended that you consult a lawyer.

Who can I appoint?

Your SDM must be:

- Of the legal age in the province or territory where you live (see Table 3)
- Mentally capable and readily available to be contacted
- Not prohibited by court order or separation agreement from acting as SDM
- Someone you trust to carry out your wishes

For Health: It should be someone who knows you well, who will respect your beliefs or values, and whom you trust to carry out your wishes.

For Finances: Whomever you appoint as your SDM for Finances will have access to all your financial and legal affairs. This gives them an extraordinary amount of power over your life (for example, they may be able to sell your home). Your SDM for Finances should be someone that you trust and who will put your interests and wishes first. Carefully consider who you choose and include details about the types of decisions you want your SDM for Finances to make for you in your power-of-attorney documents.

If you do not completely trust someone while you are alive and capable, then this person should not be appointed as your SDM for Finances. If no one in your life can take on the role, you may want to consider consulting a lawyer and appointing a trust company. Click here for more information on what happens if you do not appoint an SDM.

*Use at your own risk. Please note that in some provinces, you cannot appoint a Substitute Decision-Maker to deal with real property (Land Title Office) without a lawyer or notary as a witness.

Table 3.

| Province | Age of Majority |
|---|-----------------|
| Prince Edward Island, Ontario* | 16 |
| Alberta, Saskatchewan, Manitoba, Quebec, Nunavut** | 18 |
| Newfoundland and Labrador, New Brunswick, Nova Scotia, British Columbia, Northwest Territories, Yukon | 19 |

*In Ontario, a person must be 16 years or older to be appointed as an SDM for Health or “attorney for personal care” but a person must be 18 years or older to be appointed as an SDM for finances or an “attorney for property”.

**In Nunavut, a person must be 18 years or older to be appointed as an SDM for Health or a “Guardian”, but a person must be 19 to be appointed (or appoint someone else) as an SDM for Finances.

Appointing two SDMs jointly:

In most provinces and territories, you can appoint more than one person as your SDM and decide in advance if they must act jointly or independently. You can find out more about the rules where you live by looking at our Advance Directive Forms and instructions at: www.dyingwithdignity.ca/download_your_advance_care_planning_kit

We suggest that you appoint your SDMs to act independently. Under the law, if you decide they must act jointly, they both must agree on all decisions before action can be taken. If one of the SDM’s cannot be reached, important decisions about your care may be delayed. A requirement for joint action may also lead to disagreements or misunderstandings that can be very time consuming. However, having your SDMs act independently means that if the person you first named cannot be reached or is unable to act on your behalf, the person you named next is automatically authorized to assume the duty to decide.

Talking with your Substitute Decision-Maker(s):

Sharing the statements and choices you make about your life and medical situations with your SDM may help encourage a discussion of your values and wishes. You can refer to sections 1-C “Determine your personal values and beliefs” and 1-D “Having conversations” above for ideas about how to talk to your SDM. You may even try reviewing these sections together, or ask them what they think your answers would be.

By comparing the answers they have given with your own answers, you will see if these people know you well, understand the wishes you have expressed for your future personal care and medical treatment, and are willing to take the responsibility to act on your wishes.

What if I don't appoint a Substitute Decision-Maker?

If you do not appoint an SDM for Health and do not have a legal guardian, in most of Canada, you will be automatically assigned an SDM based on the hierarchy below. When a person becomes unable to make decisions for themselves and has no legally appointed SDM, the health care practitioner will move down the list until they find someone qualified to make decisions on the person's behalf.

1. Spouse or partner
2. Child or parent
3. Parent with right of access
4. Brother or sister
5. Any other relative or close friend
6. Office of the Public Guardian and Trustee

Even where the above hierarchy is not in place (such as in Nunavut), health care providers will usually look to your spouse or partner and family for insight into what you would want in a given situation.

WHAT'S NEXT?

The hard part is done! Now that you have some of the background information on Advance Care Planning for Health Care Decisions and have thought about your own personal beliefs, wishes, and values, the types of care you would like to receive should you become incapacitated, and selected and discussed with someone you trust to appoint as an SDM, you are now ready to create your Advance Directive. Please go to the DWDC website where you found this toolkit and click on the province in which you live. This will provide you with the province-specific documents needed to create an Advance Directive and appoint your SDM for Health, if possible.

If you also wish to appoint an SDM for Finances (Enduring/Continuing Power of Attorney), there are free resources that you can use if your financial affairs are not too complicated. If your financial affairs are complicated, it is recommended that you consult a lawyer.

Most provinces and territories in Canada have a standard form power of attorney form created by the government that you can fill in (for example, the Ontario government provides a free kit for creating your own power of attorney at: <http://www.attorneygeneral.jus.gov.on.ca/english/family/pgt/poa.pdf>).

Some commercial websites also offer free templates (for example, you can appoint an SDM for Finances for free at the following website:* <https://www.lawdepot.com/contracts/power-of-attorney-form/?loc=CA&s=QSgeneral&g=QGFinalDetails>)



*Use at your own risk. Please also note that in some provinces, you cannot appoint an SDM to deal with real property (Land Title Office and other authorities) without a lawyer or notary as a witness.

APPENDIX: GLOSSARY OF TERMS

Advance Directive: A document, written while you are well and able to make decisions, in which you state your wishes for medical or non-medical care.

Antibiotics: Drugs commonly used to successfully treat infections. Some of these infections can be life-threatening for a grievously ill person. Examples would be pneumonia or an infection in the blood or brain.

Artificial nutrition: Being fed by a method other than by mouth. This would apply if you were in a coma or otherwise unable to swallow, and may be administered by:

- Nasogastric tube (NG tube) - A tube inserted through the nose and into the stomach. The tube may also be used to suction excess acids from the stomach.
- Gastrostomy tube (G-tube or PEG tube) – A tube placed directly into the stomach for the long-term administration of food, fluids and medications.

Artificial hydration: Being given fluids via a small tube inserted into a vein (venous catheter or IV). Terminal patients who wish to voluntarily stop eating and drinking (VSED) and to simply receive comfort care, should also request to discontinue artificial hydration by IV, as artificial hydration prolongs the dying process.

Cardio-Pulmonary Resuscitation (CPR): Applying pressure to the chest, or an electric charge to re-start the heart, and sending air directly into the lungs to assist in breathing. CPR can be lifesaving, but the success rate for critically ill patients is extremely low.

Cerebrovascular Accident (CVA): See Stroke

Coma: A profound state of unconsciousness in which a person cannot be awakened by pain, light, sound or vigorous stimulation. There may be some movements, but these are not conscious acts. A patient in a coma state which is of short duration can recover. Over four weeks in coma, the patient may progress to a vegetative state.

Comfort care: Care of a dying patient to make them more comfortable when further medical intervention is rejected or has been judged of no further value in treating the patient's condition.

Dementia: A condition that impacts a person's ability to perform everyday functions. Examples would be Alzheimer's disease, or loss of thinking skills and memory following a major stroke.

Electrical, mechanical or other artificial stimulation of my heart: See CPR

Heart failure: A condition where the heart is damaged and fails to pump enough blood to the critical organs in your body.

Hospice care: Care for terminal patients where the emphasis is on pain and symptom control for the dying patient, and there is normally no aggressive medical treatment. The care may be given in the home or in a hospital or care facility.

Intensive Care Unit (ICU): Sometimes referred to as the Critical Care Unit is a hospital ward with highly specialized staff. It is for the patient with a life-threatening illness or injury, including major surgery with a threat of complications, which needs constant monitoring and the support of specialized equipment.

Life-sustaining treatment: Treatment that replaces or supports defective bodily functions. It may be used temporarily for a treatable condition until the patient is stabilized. If there is no hope of the body regaining the ability to function normally, life support may simply prolong the dying process without the benefit of increased quality of life.

Mechanical breathing: Used to support or replace the function of the lungs. The ventilator or respirator is a machine attached to a tube inserted into the patient's nose or mouth and down into the windpipe in order to force air into the lungs. It helps people with a short-term medical problem. People with irreversible respiratory failure such as that caused by injury to the spinal cord or a progressive neurological disease will require long term ventilation; and in this case, the tube is inserted through a small hole at the front of the throat into the trachea (tracheostomy tube).

Palliative care: Care where the emphasis is on pain and symptom control and the management of side effects of the treatment, such as weakness and nausea. Most often this care is provided in a hospital setting and may be given in conjunction with medical treatment such as chemotherapy or radiation.

Stroke: Damage to the brain caused by a blockage of blood flow, or bleeding into the brain. The degree of disability resulting depends on the location and severity of the initial cause.

Substitute Decision-Maker: Someone you appoint to make decisions on your behalf if you lose capacity to make decisions about your own personal care and/or finances.

Terminal illness: A medical condition which has progressed to the point where death may be expected within weeks or months.

Vegetative state: A persistent unresponsive state resulting from damage to the parts of the brain that control thinking, memory, consciousness and speech. The patient may have no damage to the part of the brain that controls breathing and heart rate and may continue to survive in an unresponsive state with medical interventions in place.



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