



Living Our Best Life
Includes Talking About
the End Journey
Advance Care Planning
Workbook

Dr. Bob Kemp Hospice ACP Workbook

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Introduction

When we take the time to reflect on what makes our lives comfortable, satisfying, and worthwhile, we can begin to integrate these simple things into our everyday existence. This takes effort. Without effort, we leave things up to chance. By giving thought to our future health care needs, we gain control of how our life unfolds and ensure that what is important to us continues to be part of our everyday life experience.

We understand that thinking and talking about living and dying can be a difficult and emotional process. These conversations are not easy, but they are essential. Yet if we do not go through the process of Advance Care Planning then it will be difficult for our family members and loved ones to carry out our wishes if we are unable to speak for ourselves.

We are here to help support you through this process. We hope you will find this Advance Care Planning Workbook helpful in your journey of self-reflection, in opening the conversations with those who matter most to you and in making your end of life wishes a reality.

OUR MISSION

Inspired by the vision of Dr. Bob Kemp, we compassionately service the emotional, physical, social, and spiritual needs of individuals living with a progressive, life-limiting illness until the end of life. We support them, their bereaved and our community through our residential, outreach and bereavement programs.

WHAT MATTERS TO US...

- Dignity and Quality of Living
- End of Life Care
- Compassion, Kindness, and Respect Diversity
- Continuous Enquiry and Learning

HOW TO USE THIS WORKBOOK

This workbook can help you work through the steps of planning for your future health, known as Advance Care Planning or ACP

It will help you start to use your own plan after you have learned about what advance care planning is. You can learn about Advance Care Planning by:

Visiting the Speak-up Canada, Plan Well or Quality Life Planning websites

Talking with your health care professionals

Attending an Advance Care Planning workshop

Working through the 5-step check list (page 7)

This workbook (based off of the work done by Advance Care Planning Canada) is for you to work through as part of the Dr. Bob Kemp Hospice Advance Care Planning workshop. You can also work through this workbook by yourself or with the people that matter to you. It might not answer every question, but it will help you get your thoughts together.

Writing things down does not replace speaking to the people who are close to you. Once your Advance Care Plan is put together you will want to share your thoughts with the people who matter to you, as well as your doctor, nurse, social worker, or other health care providers who help you. Take your time completing this workbook. It is meant to be a process that will assist you to plan well for your future health care needs and will likely change over time as things change in your life.

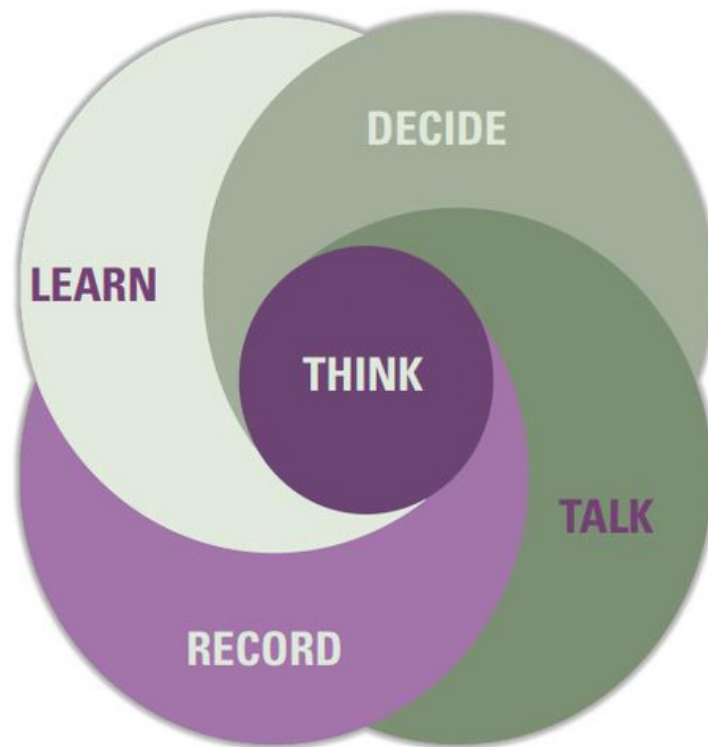
What is Advance Care Planning?

Advance Care Planning is a process of reflection and communication, a time for you to reflect on your values and wishes, and to let others know your future health and personal care preferences if you are unable to consent or refuse treatment or other care. Advance Care Planning is also thinking about options around housing and residency that may work into your health and lifestyle in later years.

Advance Care Planning may include thinking about information about specific treatments that you do or do not want to have (such as cardiac resuscitation or mechanical ventilation), as well as other information about your care at the end of life (for example, religious or spiritual rituals, being able to see a family member, dying at home or hospice).

It is important to have discussions with family and friends, especially your *Substitute Decision Maker* – the person who will speak for you when you cannot. This may include writing down your wishes and may even involve talking with healthcare providers and financial and legal professionals. A written advance care plan may also be called an Advance Health Care Directive, a Medical Directive or a Living Will that can be an addendum to your Power of Attorney for Personal Care.

Think, Learn, Decide, Talk, and Record



Key Steps in Advance Care Planning

1. **Think** about what matters most to you; your values and wishes and how they influence your health preferences, specific rituals around your end of life care.
2. **Learn** about specific medical treatments, options of care, and future housing options that fit into your lifestyle in later years.
3. **Decide** on who will speak for you if you cannot speak for yourself.
4. **Talk** with others about your future health priorities and personal care.
5. **Record** and share your wishes so others will be confident to make decisions on your behalf when you are not able to.

My Advance Care Planning Checklist

Preparing for the “what ifs” in life will ensure I received the care I want and that I have prepared those who may be in a position to make decisions on my behalf.

Think

- I have thought about my wishes and values and how they may influence my future health care decisions
- I have considered any current health issues and decisions that may need to be made.
- I have reflected on previous experiences with my own health or of others and how this may impact a future health care choice for myself.

Learn

- I have sourced out information on advance care planning terms and medical procedures (such as resuscitation and feeding tubes).
- I have contemplated what quality of living means to me.

Decide

- I have chosen who will make medical, shelter and personal decisions on my behalf if I am not able to make these decisions from myself. (Substitute Decision Maker).
- I have identified an alternate person in case my first choice is unable to fulfill this role.

Staring the Conversation

- I have discussed my health, shelter, and personal care preferences with my Substitute Decision Maker and those closest to me including my health care professionals.

Documenting/Recording

- I have documented my health preferences in an Advance Health Care Directive, a video or some other format that my Substitute Decision Maker can draw upon to understand my wishes.
- I have completed Power of Attorney for Personal Care documents and provided my Power of Attorney for Personal Care a copy of my Advance Health Care Directive.
- I have provided a copy of my AHCD and discussed who will be making decisions on my behalf with my family and doctors.

Step 1: Think

Beliefs, Values, and Wishes

What matters most to me? What or who influences my life?

Thinking about your beliefs, values, and wishes may seem hard to do at first. However, as you work through the questions below, you will see that we are asking you to think about your personal values. We all live our lives within unique values, whether we know it or not. We show our values through our daily actions. Our daily actions are how we express what is important in our lives. Reflecting on your personal values, and their importance, helps you to make decisions related to your health care.

What makes my life meaningful?

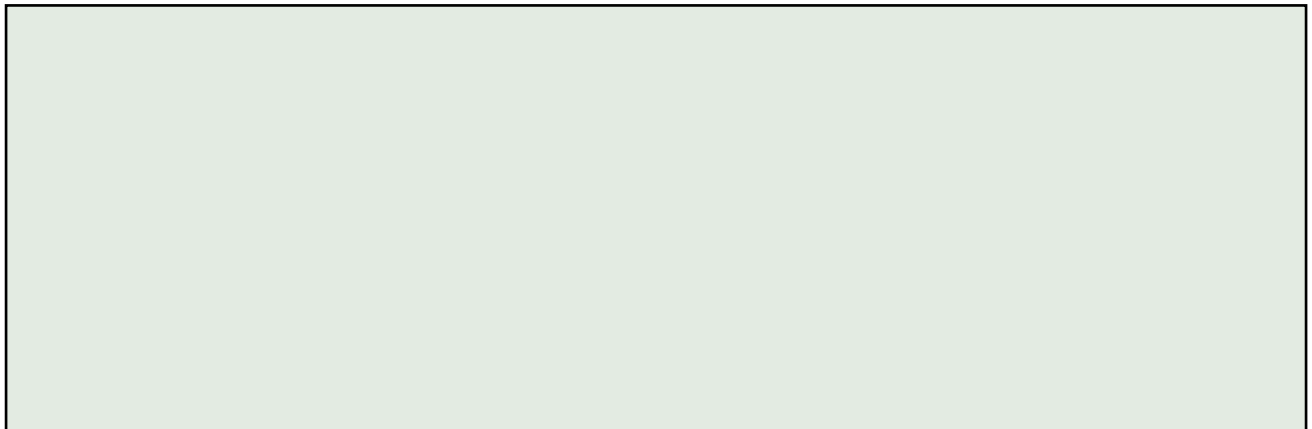
Think about what a good day would look like for you. What do you do for fun? What makes you smile and feel good? How do you spend your time and with who?

Examples could include:

I prefer being active outdoors or I prefer doing indoor activities

Rituals or spiritual practices that give me strength

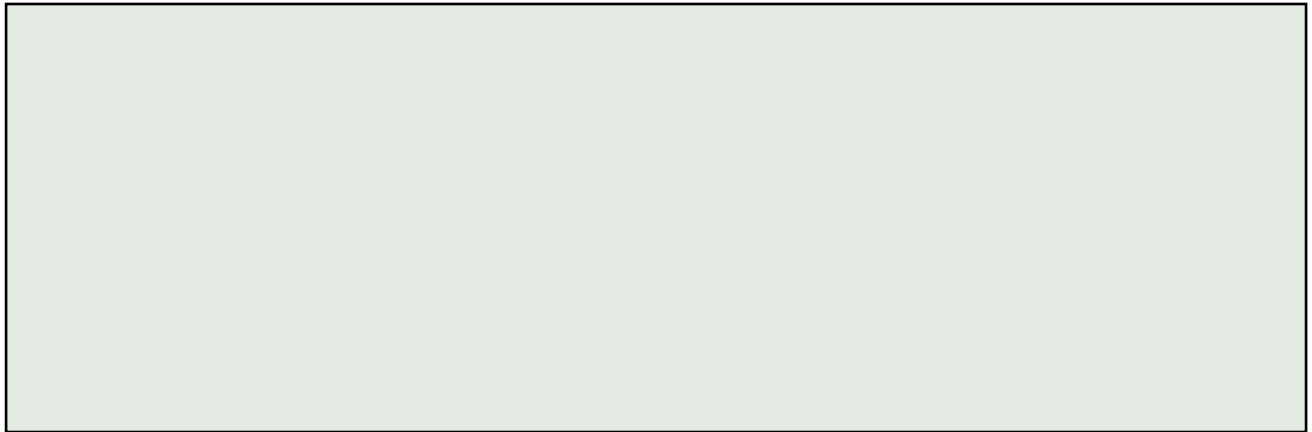
In the past week, most of my time was spent doing...



What do I value most about my mental and physical health?

Examples could include:

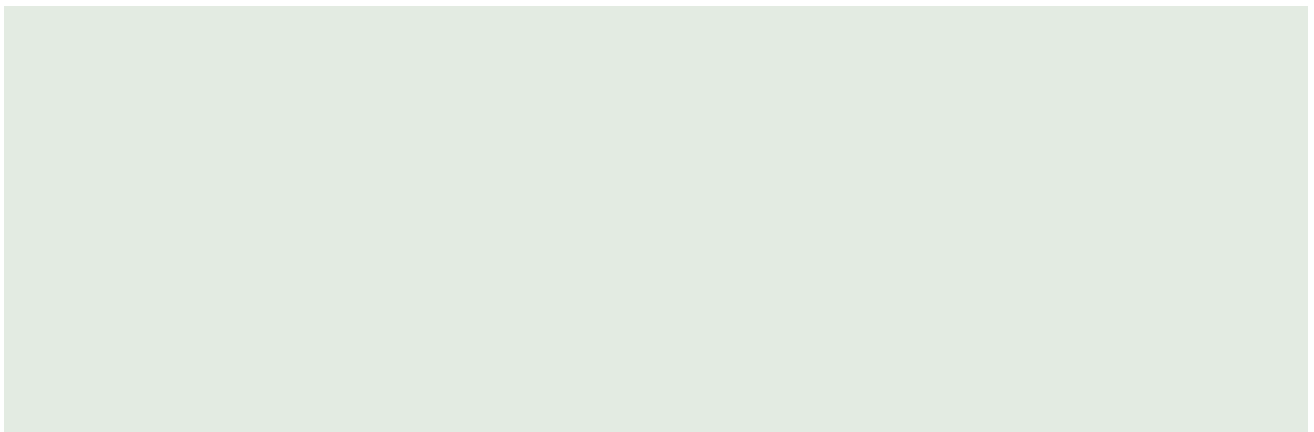
- Living life with some help or without help
- Having my privacy or being around people
- Having those who matter to me nearby



I would find the following situations or conditions difficult:

Examples could include:

- Staying in bed and needing help with getting around
- Not being able to talk with others
- Being in pain
- Leaving things undone that I have not had a chance to do
- Coping with my emotions and those of my family/friends



Step 2: Learn

My Health

What do I need to know about my health?

As a patient, I'd like to know....

<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
I do not like to know anything		I like to know a little at a time		I like to know everything

When there is a medical decision to be made, I would like...

- to make decisions on my own
- to involve others who matter such as my family
- for my health care team to decide for me

Other: _____

Here is a summary of my current health situation?

Issue/problem	Current treatment

How much do I need to know about my health conditions?

<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
I do not need more information		I need a little more information		I need a lot more information

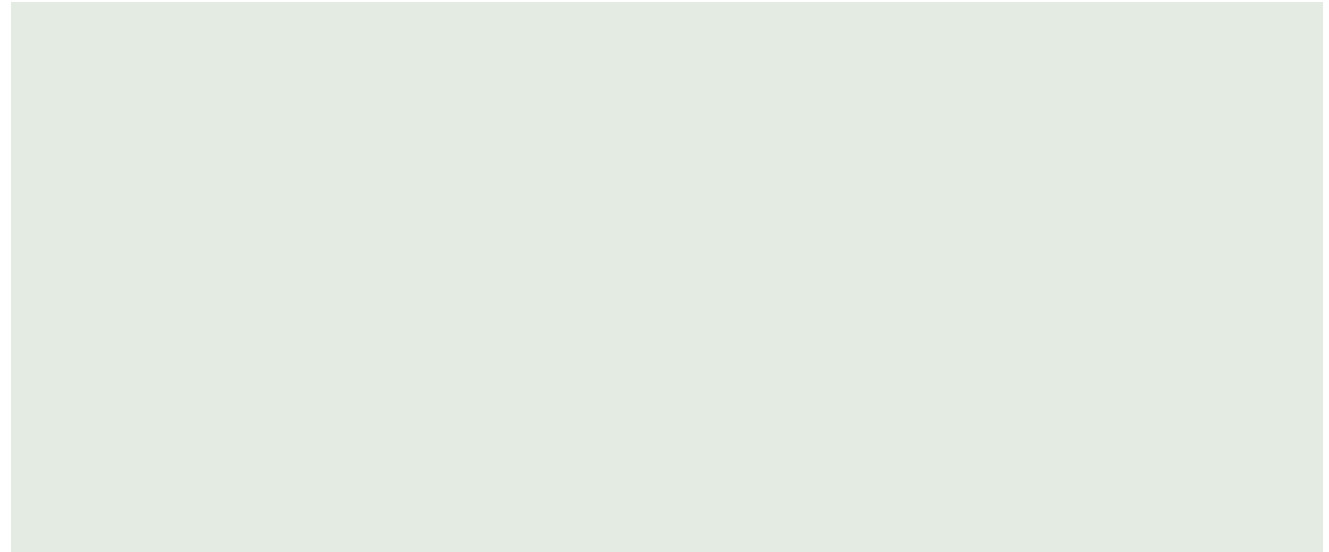
How much do I know about what is likely ahead with my health conditions?

<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
I do not need more information		I need a little more information		I need a lot more information

I have thought about medical treatments I might want or not want. I have thought about:

It is important to talk this over with your doctor, nurse, or other health care providers. You may still need more information.

Some questions I have about my health condition or different treatments include:



If you are currently facing a serious illness here are some questions you may want to ask your health care provider:

- What health conditions do I have?
- What does my health conditions mean for me?
- What will my health conditions look like in the future?
- What are possible treatments?
- What possible problems might I face down the road?
- What do you think may lead to the end of my life?

•

Thinking ahead about treatment is important but there may come a time when the care you want is not right for you. Some wishes many not be possible to follow. Some values may need to be traded off to meet other demands of your situation or wishes you may have. For example, changes in your health may mean a treatment you wanted before may no longer help you or may harm you. Talk to your health care providers and find out what would be of benefit for you.

Health Care Decision Tool: B.R.A.I.N

If you are currently facing a health care decision, below is a tool to help when you need to make health care choices.

First, find out what treatment is being suggested from your health care team then ask yourself...

B	Benefits	What are the benefits of this procedure/treatment?
R	Risk	What are the risks of this procedure? How might this negatively affect me and/or those who matter to me?
A	Alternatives	Are there alternatives to this procedure or treatment? Are there other options?
I	Intuition	What is my gut feeling about this?
N	Need Time or Nothing	Can I delay this procedure or treatment and take some time to think about it? Can I discuss it with the people who matter to me? What will happen if I choose to do nothing from now?

Regardless of the medical treatments that you get or do not get, your health care team will always provide medicine and treatments to help you feel better.

For example, when you are in pain or are feeling dizzy or sick, health care providers will always offer you:

- Pills or medicine to help reduce pain
- Medicines or treatment to help with breathing
- Surgery to control pain or other issues
- Medicine to help you from feeling sick to your stomach

Step 3: Decide

Substitute Decision Makers (SDMs)

Who will speak for me if I could not speak for myself?

If you cannot make your own health care decisions (not capable) and a medical treatment or shelter decision is offered, someone will be needed to speak on your behalf. A ranking order of the people who qualify to speak on your behalf is set out in the Ontario Health Care Consent Act. If you appoint a Power of Attorney for Personal Care they will be at the top of the ranking list.

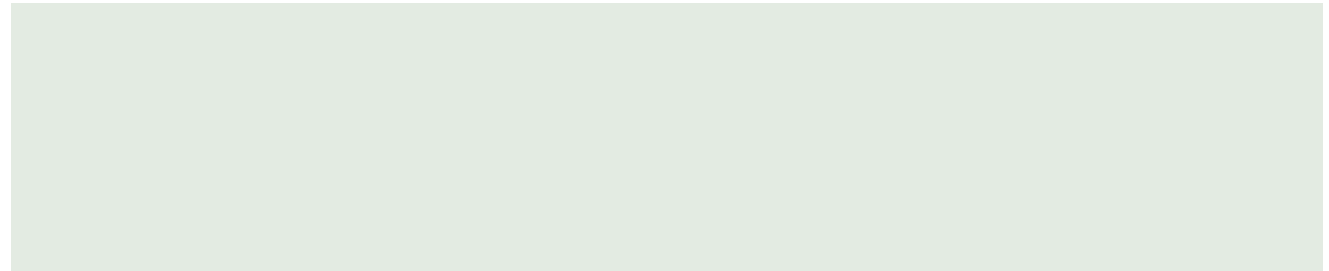
If you were unable to speak for yourself and someone was going to make a medical decision on your behalf...

What kind of person would I want them to be?

Examples could include:

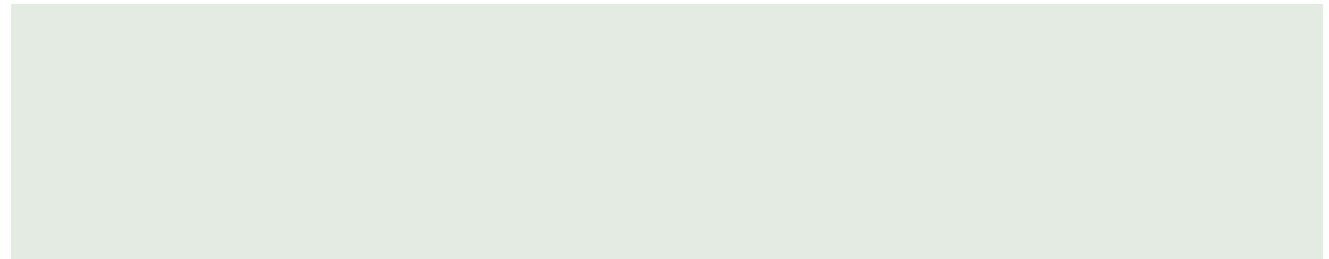
- Someone I can trust and will be comfortable carrying out my wishes
- Someone who can make themselves available to speak with my health care professionals
- Someone who has a good relationship with those I love and care about
- Someone who is not afraid to make tough choices for me that may or may not align with their own values
- Someone who is willing to spend time understanding my health preferences and their role

Who do I talk with about important things? Who knows me the best?



Could this person set aside their own values and honour my wishes?

Yes or No? Why Not?

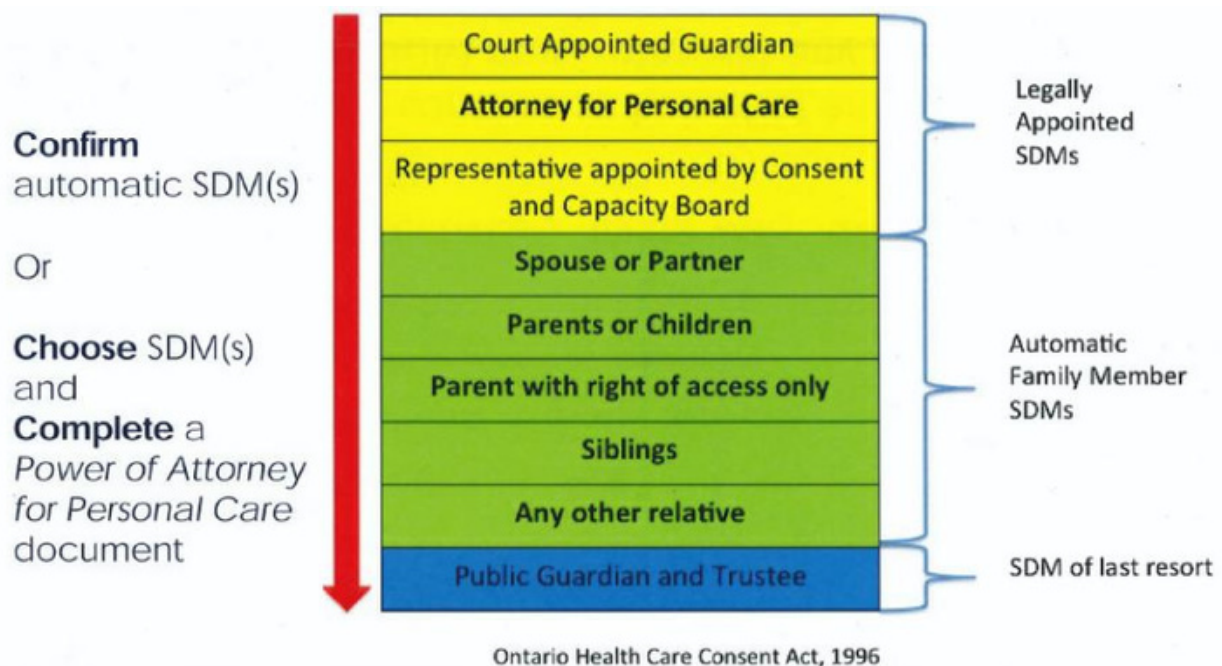


A Substitute Decision Maker will be responsible for:

- making medical decisions on your behalf when you are unable to make your own health care decisions
- Deciding on care facilities should you require assistance
- ensure your personal care needs are met (clothing, food, transportation etc.)
- fostering previous relationships you have had with others
- can refer to written documents/plans, such as your Advance Health Care Directive, to communicate, advocate and make decisions on your behalf
- should understand your wishes and have a copy of your most recent directives
- they may need help or support from your family and friends when deciding on your behalf if they are unclear what you would want

Who will be my Substitute Decision Maker?

- Every person in Ontario has a SDM according to a ranking list laid out in the Ontario Health Care Consent Act.
- A Power of Attorney for Personal Care (POA) is a person you appoint to be your SDM.
- A POA is the highest-ranking SDM unless the courts have appointed a SDM.
- If you do not appoint a SDM one will be appointed for you according to a ranking list.
- **Ontario ranking order for determining who will be your SDM**



If there are two or more people who rank equally they will all be entitled to act as your SDM . (i.e. 3 children or 1 child and 1 parent, 5 cousins, 2 siblings etc.)

If you have more than one Substitute Decision Maker they must:

- Make decisions jointly.
- Come to an agreement on your care needs (it must be by consensus, NOT majority).
- If they cannot agree the default is the Public Guardian and Trustee

It is wise to clearly make your wishes know to your SDMs to avoid conflict and disagreement.

Substitute Decision Maker List

Power of Attorney for Personal Care

(the person you have legally appointed to be your SDM)

Name	Phone Number

Spouse / Common Law Partner of at least 1 year

Name	Phone Number

Adult Children over the age of 18 (birth order does not matter)

Name	Phone Number

Parents (may include adoptive)

Name	Phone Number

Brothers or sisters (birth order does not matter)

Name	Phone Number

Anyone else related to me by birth or adoption

Name	Phone Number

Step 4: Talk

Start the conversation

One conversation can make all the difference. Imagine how easy ongoing conversations will be once you begin the first one.

Now that I have started to think about this, who do I want to talk to about my wishes?

Is there someone I may be asked to make decisions on their behalf?

When is a good time to talk to them?

Think about when you might approach those who matter to you.
For example, at a social gathering, before your next big trip etc.

Where is a good place to talk?

Think about where you might have the conversations.
For example, at the kitchen table, at a restaurant, during a walk etc.

Conversation Starters

Conversations about future health care wishes can be difficult to start. Below are questions created to get the conversation going. Once you start talking, you will be surprised at how easy the discussion flows.

To describe your wishes to others:

- My doctor and I talked today about my future health care needs and I realized that I haven't told you about my wishes – we should talk about that.
- I have just completed a document outlining my future health care wishes and I want to share it with you.
- That story about the woman fighting with the doctors to keep her husband alive on machines made me realize that we should talk about these things so we both understand what each other would want.
- Remember our neighbor who died after being in the hospital for such a long time? I would never want that to happen to me.
- Do you remember when Auntie Kay was in a coma for a while? She did not talk to her daughters about her wishes so I want to make sure I talk to you about what I would want.

To ask others what their wishes are:

- I am happy you asked me to be your Power of Attorney, I would really like to know your wishes and health preferences so that I can make good decisions for you.
- You seem to really be struggling (tired, sad etc.), and I am worried for you. I am wondering if you would find it helpful to talk with me about your day-to-day challenges and what the future might look like for you.
- I did not realize there are so many choices a person could make about health care and housing as they age. I am interested in getting your thoughts about optional housing.
- I know I might be in the position of having to make decisions for you. We have not really talked about what you would want for yourself. I would feel better and more prepared if we did.
- It seems many people around me are becoming frail and burdened by illness as they age. I think it would be helpful for us to talk about the "what ifs" in life, just in case one of us gets sick, quick.

Step 5: Record

Write down your plan

...or make a video, or an audio recording

Now you are ready for the final step in Advance Care Planning; ensure your SDM and loved ones have material to refer to in case they need to make a treatment decision on your behalf.

Planning papers to keep in my ACP binder:

My Advance Care Planning workbook

Power of Attorney from Personal Care legal papers

Advance Health Care Directive (addendum to my POA papers)

Do Not Resuscitate Confirmation Form (if applicable)

Funeral Arrangements

Will (estate planning after death)

Power of Attorney for Property

Life Insurance Policies

Are you an organ and tissue donor?

Yes

No

Further details: _____

Additional Important Information

Proper Name: _____

Current Residence E-mail address		
Past and Current Medical Conditions *List any medical conditions you have been diagnosed with. If none, indicate Not Applicable.		
Future Shelter / Residence: List any arrangements made for future residence if you can no longer reside in your current residence.		
Funeral Arrangements (if not complete, indicate N/A)	Location	Specific details
Important Information and Contacts	CONTACT NAME	CONTACT INFORMATION
Substitute Decision Maker		
Alternate SDM		
Other family members		
Lawyer		
Family Doctor		
Religious affiliations		
Cultural/Spiritual Advisor		

Definitions

Allow Natural Death

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

Advance Care Planning

Advance Care Planning is a process of reflection and communication, a time for you to reflect on your values and wishes, and to let others know your future health and personal care preferences if you become incapable of consenting to or refusing treatment or other care. Advance Care Planning means having discussions with family and friends, especially your Substitute Decision Maker, the person who will speak for you when you cannot. It may also include writing down your wishes and may even involve talking with healthcare providers and financial and legal professionals.

Advance Health Care Directive

This is a written summary of a capable adult's wishes or instructions about the kind of care they want or do not want if they cannot speak for themselves. It can guide a substitute decision maker if that person is asked by a health care provider to make treatment decisions on behalf of the person. Directives often accompany formal Power of Attorney for Personal Care papers completed during estate planning with a lawyer.

Cardiopulmonary resuscitation (CPR)

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

Comfort Measures

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

Dialysis

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

End-of-life Care

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

Feeding Tube

A feeding tube is a way to feed someone who can no longer swallow food. This can be a permanent or temporary measure to provide nutritional requirements.

Health Care Provider

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

Hospice Care

Hospice care is a special kind of care that focuses on the quality of life for people and their caregivers who are experiencing an advanced, life limiting illness. Hospice care providers compassionate care for people in the last phase of an incurable disease so that they may live as fully and comfortably as possible.

Incapable

Incapacity is determined by a health care provider who must base their decisions on whether the adult demonstrate they understand:

1. The information given to them about their health condition.
2. The nature of the proposed health care including risks, benefits, alternative options and consequences of not receiving care or proposed treatment
3. They demonstrate an understanding of how the illness impacts them.

Informed Consent

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

Intravenous line

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

Life Limiting Illness

A life limiting illness refers to an incurable medical condition caused by an injury or illness.

Life Support with Medical Interventions

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

Palliative Care

Care provided for people who have a life-limiting illness that focuses on providing good quality of life, in other words, keeping the patient as comfortable and free of pain as possible. Palliative care may involve medicines, treatments, physical care, psychological/social services, and spiritual support, both for the patient and for those who are helping to care for them. A palliative approach to care can be provided anywhere, at any stage of any illness along with care and treatment aimed at cure or prolonging life.

Power of Attorney for Personal Care

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

Public Guardian and Trustee

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

Substitute Decision Maker (SDM)

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

Symptoms

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

Terminal Illness

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

Ventilator

A ventilator is a machine that helps people breathe when they cannot breathe on their own.

References & Additional Resources

Canadian Hospice Palliative Care Association: Speak Up Canada Individuals and Families, Resources and Tools. www.advancecareplanning.ca

Fraser Health. My Advance Care Plan. My Voice in Action: A Supportive Workbook to My Voice. www.fraserhealth.ca/acp

Plan Well. Advance Serious Illness Planning. Dr. Daren Heyland
www.planwellguide.com

Quality Life Planning. Living our Best Life Until our Last Breath: Planning for Your Future Health Care Needs. Sandra Andreychuk www.qualitylifeplanning.com

My End of Life Plan. Michael Williams www.myendoflifeplan.ca

