

Who Will Speak for You?



Advanced Care Planning Kit Alberta Edition

Revised September 26, 2016

© End of Life Planning Canada 2016
With acknowledgements to Dying with Dignity Canada for original content

TABLE OF CONTENTS

About End of Life Planning Canada	3
Introduction	4
PART 1 – Personal Directive	5
Consider Your Personal Values	6
Consider These Medical Situations	7
About the Personal Directive Form	13
Your Personal Directive	14
PART 2 – About the Authorization to Act as Agent	17
Agent Authorization Form	20
Clarifying Terms: Personal Directive and Agent Forms	22
APPENDICES	
1. Your Charter Rights as a Patient	23
2. Glossary of Medical Terms	25
3. About Cardiopulmonary Resuscitation (CPR)	28
4. Goals of Care Designation Form	29
5. Frequently Asked Questions	31
6. Further Resources	33

Disclaimer: The information provided within this workbook is included as a public service and for general reference only. Every effort is made to ensure the accuracy of the information found here. However, this information is not considered legal, medical or financial advice and does not replace the specific medical, legal or financial advice that you might receive or the need for such advice. If you have questions about your health or about medical issues, speak with a health care professional. If you have questions about your or someone else’s legal rights, speak with a lawyer or contact a community legal clinic.

ABOUT END OF LIFE PLANNING CANADA

Our Mission

End of Life Planning Canada is a national charitable organization. Our mission is to help Canadians to navigate the end-of-life experience with confidence and dignity.

Our Mandate

We promote research and provide information, education and support to help individuals and their families to plan for a gentle and dignified death, and to navigate the health care system with confidence that their rights and preferences will be respected to the very end.



We offer a broad program of information, education and support about health care rights and options at the end of life. We:

- Encourage Canadians to think about their wishes for end-of-life care, to understand their options for achieving those wishes, and to make their preferences known to their families, caregivers and health care providers in the event they should become unable to speak for themselves in the future.
- Educate Canadians about legal rights and options at the end of life, to promote informed decision-making and improve the quality of their interactions with the health care system.
- Offer personal, confidential support to individuals and/or their families who wish to discuss end-of-life rights, options and preferences in a safe and compassionate place.
- Provide resource materials such as patient rights booklets and advance care planning kits tailored to each province and territory, and conduct seminars, discussion groups and workshops to offer practical advice on how to plan for a gentle and dignified death.

Funding

End of Life Planning Canada is funded by donations from individuals, foundations and corporations that support the work that we do. Many of our services are provided by volunteers. To donate, please go to www.elplanning.ca.

Contact Us

55 Eglinton Avenue East, Suite 504, Toronto, Ontario M4P 1G8 Canada

(647) 956-3722 or 1-844-395-3640

Web: www.elplanning.ca

Email: info@elplanning.ca

INTRODUCTION

This Advance Care Planning Kit invites you to think about and express your wishes for health care and treatment at the end of life. The kit is intended to provoke thinking, conversation and planning, and to encourage communication between you, your family and your health care providers.



The kit guides you through the process of considering your personal values and asks you to imagine medical situations that could happen to you. It walks you through the steps of drafting a **Personal Directive** and choosing an Agent; this is the person authorized to speak for you if you are unable to speak for yourself.

The kit contains information on medical interventions such as CPR that may be used in end-of-life situations, and contains information on the Goals of Care Designation Form and Green Sleeve Program. The kit also includes a glossary of terms, a summary of your legal rights as a patient, answers to some frequently asked questions, and a section on further resources.

The best time to think about your preferences for future medical care is when you are well and able. Of course it is hard to imagine how you may feel when you are not well. We offer various scenarios to help you to plan for the future, while reminding you that you can always change your mind. Having a Personal Directive is the best way to ensure that your wishes are known to your family, your 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.

PART 1

Personal Directive

What is a Personal Directive?

A Personal Directive is a document written while you are well and able to make decisions, in which you state your wishes for medical or non-medical care, just in case you become unable to speak for yourself at some time in the future.



Why should you have a Personal Directive?

In a medical emergency or in any other circumstance that leaves you unable to communicate, for example if you have a stroke or if you are in a coma, your Personal Directive will assert your right to choose what you want or do not want in the way of medical treatment and care. It will help those responsible for your care to decide on your treatment. It will help your family to understand and support the decisions that you would have made yourself.

There is no legal requirement for you to have a Personal Directive but once you create one it is a legal document. Only you can create it – no one else can do it for you. If you do not have a Personal Directive, others may not know your wishes and you may be subjected to aggressive or life-prolonging medical interventions that you would not want. On the other hand, you may have a specific medical condition for which you *do* want all available treatment.

Start the process now of creating your Personal Directive by thinking about your personal values and the everyday pleasures that make life worth living.

CONSIDER YOUR PERSONAL VALUES

1. Think through a day in your life and consider what you enjoy most, what you look forward to, and what makes your life livable and workable.

What gives your life purpose and meaning?

Here are some topics to get you thinking:

- Independence, autonomy
- Work
- Time for yourself
- Friends and colleagues
- Hobbies
- Holidays
- Birthdays and celebrations
- Travel
- Family
- Food
- Sports
- Exercise
- Reading
- Music
- Television, movies
- Keeping a journal or diary



2. Which of the following do you fear most near the end of life?

Rank these items from 1 to 10. Think of other concerns that you may have.

- Losing your mobility
- Being in pain
- Being incontinent
- Being alone
- Losing the ability to think, being confused most of the time
- Being a burden on loved ones
- Being dependent on others for everyday activities like eating and bathing
- Being in hospital
- Losing your sight or hearing

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

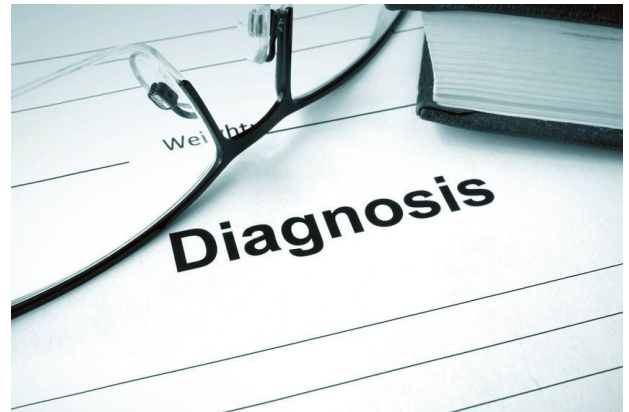
- Where would you be?
- What would you be doing?
- Who would be with you?
- What would you eat if you were able to eat?
- Would you want the comfort of spiritual support from a member of the clergy or someone who shares your religious beliefs?
- Are there people to whom you would want to write a letter or record an audio or video message, perhaps to be read, heard, or watched in the future?

4. How do you want to be remembered? If you were to write your own obituary or epitaph, what would it say?

5. What other personal values come to mind?

CONSIDER THESE MEDICAL SITUATIONS – Copy 1

Imagine various critical conditions and think about the treatment you would accept or refuse in each case. The answers will help to make things clear in your own mind so that you are better prepared for discussions with family, caregivers and physicians.



We have included in this kit two (2) copies of Consider These Medical Conditions.

- *Complete Copy 1.*
- *Give Copy 2 to the person whom you considering to be your Agent.*
Ask them to answer the questions as though they were you.
- *Compare your answers to theirs. Note and discuss differences.*
It is important for your Agent to understand your values and your wishes for end-of-life care.

1. You are seriously ill with cancer but your mind is still sharp. Physicians recommend chemotherapy. They explain that this treatment often has severe side effects such as pain, vomiting, and weakness. Are you willing to endure these side effects if the chances of regaining your current health are less than 25 per cent?

- Yes
- Yes, on a trial basis
- No
- I am uncertain

*Note: It is your legal right to refuse or discontinue treatment.
Read more about this Charter Right in Appendix 1.*

2. You are seriously ill with terminal cancer but your mind is still sharp. Physicians offer chemotherapy to 'buy time,' giving you an 80% chance of an additional six months. Do you want this treatment even though it may have severe side effects?

- Yes
- Yes, on a trial basis
- I would request medical assistance in dying
- No

Consider These Medical Situations – Copy 1... *continued*

3. You have advanced Alzheimer’s disease, which has progressed to the point that you can no longer feed or toilet yourself and you no longer recognize your family, but you are not in pain. Do you want to be spoon-fed or tube-fed?

Yes
 Yes, spoon-fed only
 Yes, spoon-fed or tube-fed on a trial basis
 No
 I am uncertain

*Note: It is your legal right to refuse food or drink.
Read more about this Charter Right in Appendix 1.*

4. You have advanced Alzheimer’s disease and no longer recognize your family. You have been hospitalized twice in the past year for pneumonia, which was cured by massive doses of antibiotics. You develop pneumonia once more. Do you want aggressive treatment in hospital again, or do you prefer to be kept comfortable at home until death occurs naturally?

I want aggressive treatment, including antibiotics, to keep me alive
 I do not want treatment to keep me alive. I want comfort care at home
 I am uncertain

5. You have long-standing diabetes and your mind is still sharp. Last year you developed gangrene and lost one leg to this disease. You have now developed gangrene in your other leg and amputation has been recommended.

I want the surgery to amputate my second leg if this will keep me alive
 I do not want the surgery. I want comfort care only, even though I may die
 I would request medical assistance in dying
 I am uncertain

6. You are physically very weak but your mind is sharp. You need help with most daily activities, such as dressing, bathing, eating, and going to the toilet. You develop a severe kidney infection. Dialysis is available to you. If left untreated, the infection will likely lead to organ failure that will cause your death within weeks or months.

I want dialysis to keep me alive
 I do not want to start dialysis. I want comfort care until I die naturally
 I would request medical assistance in dying
 I am uncertain

Consider These Medical Situations – Copy 1... *continued*

7. You have congestive heart failure. You are always short of breath. Your swollen ankles make walking difficult. But your mind is still sharp and you enjoy time with family and friends. One day you have a severe heart attack and your heart stops beating. Do you want 911 called and CPR started?

Yes

No

I am uncertain

Note: learn more about CPR and what you can expect in Appendix 3.

8. You are terminally ill with a condition that causes great pain. Do you want to be sedated even to the point of unconsciousness if necessary to control your pain? This is called palliative sedation. Your physician can control the level of sedation to give you occasional hours of lucidity.

Yes

Yes, on a trial basis

No

I would request medical assistance in dying

I am uncertain

9. You are in a permanent coma and your body is kept alive by artificial means such as mechanical breathing and tube feeding. Physicians say you will never recover because your brain has been severely damaged. But there are a few documented cases where people have recovered from a persistent vegetative state. Do you want to be kept alive in this way just in case you may someday recover?

Yes

No

I am uncertain

10. Would you allow yourself to be temporarily placed on life support if your heart, kidneys or other body parts could be used in transplant operations to save other lives after you have died?

Yes

No

I am uncertain

Note: To be considered an organ donor you should register with Service Alberta, and ideally discuss your wishes with your family and your substitute decision maker.

CONSIDER THESE MEDICAL SITUATIONS – Copy 2

Pretend you are the person who is asking you to answer these questions.

Imagine various critical conditions and think about the treatment that you think that person would accept or refuse in each case. Compare your answers to theirs.

Note the differences, talk about them. This will help you to understand their values and wishes for medical care at the end of life.

1. You are seriously ill with cancer but your mind is still sharp.

Physicians recommend chemotherapy. They explain that this treatment often has severe side effects such as pain, vomiting, and weakness. Are you willing to endure these side effects if the chances of regaining your current health are less than 25 per cent?

Yes

Yes, on a trial basis

No

I am uncertain

Note: It is your legal right to refuse or discontinue treatment.

Read more about this Charter Right in Appendix 1.

2. You are seriously ill with terminal cancer but your mind is still sharp.

Physicians offer chemotherapy to ‘buy time,’ giving you an 80% chance of an additional six months. Do you want this treatment even though it may have severe side effects?

Yes

Yes, on a trial basis

No

I would request medical assistance in dying

I am uncertain

3. You have advanced Alzheimer’s disease, which has progressed to the point that you can no longer feed or toilet yourself and you no longer recognize your family, but you are not in pain. Do you want to be spoon-fed or tube-fed?

Yes

Yes, spoon-fed only

Yes, spoon-fed or tube-fed on a trial basis

No

I am uncertain

Note: It is your legal right to refuse food or drink.

Read more about this Charter Right in Appendix 1.

CONSIDER THESE MEDICAL SITUATIONS – Copy 2... *continued*

4. You have advanced Alzheimer’s disease and no longer recognize your family. You have been hospitalized twice in the past year for pneumonia, which was cured by massive doses of antibiotics. You develop pneumonia once more. Do you want aggressive treatment in hospital again, or do you prefer to be kept comfortable at home until death occurs naturally?
- I want aggressive treatment, including antibiotics, to keep me alive
 - I do not want treatment to keep me alive. I want comfort care at home
 - I am uncertain
5. You have long-standing diabetes and your mind is sharp. Last year you developed gangrene and lost one leg to this disease. You have now developed gangrene in your other leg and amputation has been recommended.
- I want the surgery to amputate my second leg if this will keep me alive
 - I do not want the surgery. I want comfort care only, even though I may die
 - I would request medical assistance in dying
 - I am uncertain
6. You are physically very weak but your mind is sharp. You need help with most daily activities, such as dressing, bathing, eating, and going to the toilet. You develop a severe kidney infection. Dialysis is available to you. If left untreated, the infection will likely lead to organ failure that will cause your death within weeks or months.
- I want dialysis to keep me alive
 - I do not want to start dialysis. I want comfort care until I die naturally
 - I would request medical assistance in dying
 - I am uncertain
7. You have congestive heart failure. You are always short of breath. Your swollen ankles make walking difficult. But your mind is still sharp and you enjoy time with family and friends. One day you have a severe heart attack and your heart stops beating. Do you want 911 called and CPR started?
- Yes
 - No
 - I am uncertain

Note: learn more about CPR and what you can expect in Appendix 3

CONSIDER THESE MEDICAL SITUATIONS – Copy 2... *continued*

8. You are terminally ill with a condition that causes great pain. Do you want to be sedated even to the point of unconsciousness if necessary to control your pain? This is called palliative sedation. Your physician can control the level of sedation to give you occasional hours of lucidity.

Yes
 Yes, on a trial basis
 No
 I would request medical assistance in dying
 I am uncertain

9. You are in a permanent coma and your body is kept alive by artificial means such as mechanical breathing and tube feeding. Physicians say you will never recover because your brain has been severely damaged. But there are a few documented cases where people have recovered from a persistent vegetative state. Do you want to be kept alive in this way just in case you may someday recover?

Yes
 No
 I am uncertain

10. Would you allow yourself to be temporarily placed on life support if your heart, kidneys or other body parts could be used in transplant operations to save other lives after you have died?

Yes
 No
 I am uncertain

Note: To be considered an organ donor you should register with Service Alberta, and ideally discuss your wishes with your family and your Substitute Decision Maker.

ABOUT THE PERSONAL DIRECTIVE FORM

Turn to page 14 and read the Personal Directive form from start to finish before filling it out.

There are extra spaces for you to fill in circumstances that are not covered. For example, you may have a hereditary condition you want to add.

Pay particular attention to item 4 that pertains to the “choice to prolong” and “choice not to prolong.”



Signing and making copies

1. Make copies of the form before you sign and date it so that each copy has your original signature. Give a copy to your Agent. Keep a record of the people to whom you provide copies so that if you change your Personal Directive, you can provide them with your new wishes and eliminate possible future confusion.
2. Talk to your physician and ask that the directive be entered in your medical records. Keep a copy where it can easily be found in an emergency situation, such as in your Green Sleeve with your Goals of Care Designation.
3. Do not store your directive in a locked safety deposit box. It needs to be quickly accessible in case of an emergency.

You can always change your mind

Review your Personal Directive whenever your situation changes in a major way, or every year or two. If you do not make any changes, sign the directive again with the new date in the space at the top of the form.

Review your Personal Directive if you move to a new address, if your spouse dies, if you get separated/divorced/remarried, or in the case of any other major life event.

If your medical condition has changed or if you have reconsidered some of your decisions, start over with a new form. You can download it from the ELPC website or request a new form by mail.

Be sure to tell everyone involved in your care if you change your directive.

YOUR PERSONAL DIRECTIVE

We advise you to regularly review your Personal Directive. If you do not make changes, sign it again with the new date in the space below.

Signature_____

Date_____

Signature_____

Date_____

Signature_____

Date_____

Signature_____

Date_____

Signature_____

Date_____

I, _____, revoke any and all previous Personal Directives written by me.

If a time comes when I lack the capacity to give directions for my health care, this statement shall stand as an expression of my wishes and directions.

Choose one by putting a check mark in the appropriate space.

1. If I am sedated and unable to communicate, I would like the sedation lifted so that I can rationally consider my situation and decide for myself to accept or refuse a particular therapy.
 Yes No

When answering 2, 3, and 4 below, strike out conditions that you do not wish to be considered and add any that you do.

2. Should I be in any of the following circumstances, I **direct** that I be given only such care as will keep me comfortable and pain free until natural death occurs:
 - a) An acute life-threatening illness of an irreversible nature
 - b) Chronic debilitating suffering of a permanent nature
 - c) Advanced dementia
 - d) _____
 - e) _____

Your Personal Directive... *continued*

3. In the circumstances set out in condition 2 above, if life-sustaining treatments have been started and they are the only treatments keeping me alive, I want them stopped. I specifically **refuse** the following life support treatments:

a) Electrical, mechanical, or other artificial stimulation of my heart (CPR)

b) Respirator or ventilator

c) Artificial feeding such as G-tube, NG tube, or central intravenous line

d) Being hand-fed should I no longer be able to feed myself

e) Artificial hydration by intravenous line

f) Antibiotics

g) Transfer to an intensive care unit or similar facility

h) _____

i) _____

j) _____

If you do not wish to have your life prolonged under the conditions set down in 1, 2, and 3 above, you must strike out 4 completely.

If you wish to have your life prolonged and request all applicable treatments, you must completely strike out 1, 2, and 3 above, leaving only the instructions in section 4.

4. I specifically **direct** that my life be prolonged and that I be provided all life-sustaining treatments applicable to my medical condition.

Note: While this directive puts your caregivers in charge of all treatment choices, you can always change your mind. For example, you can start treatments and then discontinue them.

I have other wishes:

Your Personal Directive... *continued*

5. I would prefer to be cared for and to die:
[] at home
[] in a hospice or palliative care unit
6. If my healthcare provider will not follow this Personal Directive, I ask that my care be transferred to a healthcare provider who will respect my legal rights.
7. If I am in a hospital or a resident in a healthcare or long-term care facility that will not follow this Personal Directive, I ask that I be transferred to another hospital or care facility.

You have the right to be involved in all decisions about your medical care, even those not dealing with terminal conditions or persistent vegetative states. If you have wishes not covered in other parts of this document, please indicate them below:

Signature: _____ Date: _____

Print Name: _____

I have distributed this Personal Directive to the following people. This is a reminder to myself to keep these people informed of any changes. I am aware that outdated or defunct copies of this ACD may create confusion if left in circulation.

Name and phone number

PART 2

About the Authorization to Act as Agent

What does it mean to authorize an Agent?

An Agent is a person you have given authority to make decisions on your behalf concerning your personal care and your medical treatment in the event you are not able to make your wishes known.

Why should I have an agent?

If you are unable to communicate your wishes, your previously expressed wishes must be respected as written in your Personal Directive or as expressed orally or in any other manner. But even if you have a Personal Directive, your medical condition may not be specifically addressed in your directive. Your agent 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.

If you want to name as your agent the person who provides you with personal care services for pay. It is advisable that you speak with a lawyer if you want to complete this section.

Who can I appoint?

Your agent must be

- over 18 years of age
- mentally capable and readily available to be contacted

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

You may not appoint as your agent anyone who provides you with healthcare or support services for compensation, unless that person is also your spouse, partner or relative.



About the Authorization to Act as Agent... *continued*

You have the option to appoint more than one person and to decide in advance if they must act **jointly** or **independently**. We advise that you appoint your agents to act independently.

Under the law, if you decide they must act jointly, all must agree on all decisions before action can be taken. If one of the persons 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. But having your agents 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.

In appointing one or more agents you might want to include instructions in your Personal Directive as to whether or not your wishes for treatment must be followed even if your family and friends disagree, or, you may want your family and friends all in agreement before treatment is carried out.

Talking with your agent

Sharing the statements and choices you make about your life and medical situations with your agent will generate a discussion of your values and wishes. By comparing the answers your agent has given to your own answers, you will see if she or he understands the wishes you have expressed for your future personal care and medical treatment, and is willing to take the responsibility to act on your wishes.

Before completing the Personal directive form

The form is a legal document. Read it all the way through. When you are clear about its use, complete the form and have it witnessed. You must satisfy yourself that your agent understands the wishes you have expressed and is willing to act on your behalf.

About the Authorization to Act as Agent... *continued*

The witness to your signature must meet the criteria listed below and must be present when you sign.

Witnesses **MAY NOT** be:

1. The person you named as your agent.
2. The spouse or partner of the person you named as your agent.
3. Your own spouse/partner
4. Anyone under the age of 18

Signing and making copies

Make copies of the personal directive form before you and the witnesses sign it so that you and each of your agents have a document with the original signatures and date. Alternatively, initial each copy by your signature.

Keep your copy of your Personal Directive with your Goals of Care Designation form (see Appendix 4, page 29) in your Green Sleeve where it can be easily found in an emergency situation, such as on the fridge. Make sure it includes the names and contact information of the person(s) to call in an emergency.

Do not store your copy of these documents in a locked safety deposit box.

Remember: You may change your agent at any time.

Begin by stating that you revoke any previous Personal Directive, and then complete, sign, date, and have witnessed a completely new form.

PERSONAL DIRECTIVE (NAMING AN AGENT ONLY)

I _____, make this Personal Directive.
Name of Maker

This Personal Directive is made pursuant to the Personal Directives Act and takes effect only if I am not capable of making a decision regarding my personal care.

I have placed my initials and my witness has placed his/her initials next to the sections in this document that I want to be part of my Personal Directive.

Witness' Your
Initials Initials

1. Revoking (Cancelling) Other Directions (optional)
I revoke (cancel) all previous instructions, personal directives, and authorizations.

Witness' Your
Initials Initials

2. Authorization to Act as Agent (optional)
I authorize the following person to act as my agent to make personal care decisions on my behalf for all personal matters, of a non-financial nature, that relate to me.

Name: _____
Print Name of Agent

Address: _____
Street Address

City/Town Province

Phone: _____ Email: _____
Home Business

If my agent is unable, unwilling or unavailable to make a personal care decision, I authorize the following person to act as my alternate agent.

Name: _____
Print Name of Alternate Agent

Address: _____
Street Address

City/Town Province

Phone: _____ Email: _____

Naming an Agent Only.. *continued*

3. Signatures (mandatory)

Signed by me in the presence of my witness at _____ in the Province of
Location
Alberta, this _____ day of _____, _____.
Day Month Year

Printed Name of Witness

Printed Name of Maker

Relationship to Maker

Signature of Maker in the presence of the
the Witness

Signature of Witness in the presence of
the Maker

Address

Address

City/Town

City/Town

Province

Province

Home Phone Business Phone

Home Phone Business Phone

Email

Email

CLARIFYING TERMS

Personal Directive and Authorization to Act as Agent

	Personal Directive	Authorization of an Agent (Optional)
Purpose	Provides guidance as to what medical treatment or non-treatment you would want under the conditions specified by you, if you are unable to make your wishes known at the time.	Stipulates who you have authorized to make decisions on your behalf concerning your personal care and your medical treatment if you are unable to do so at the time.
Status of Document	Legally binding under the Personal Directives Act. Must be clearly dated and earlier versions revoked.	Legally binding under the Personal Directives Act.
Witnesses	Required because personal directives are a legally binding document. They must meet specified criteria.	One witness is required. They must meet specified criteria.

Please note: If you feel you have special circumstances not addressed in these forms, we suggest that you consult with your lawyer.

APPENDIX 1. YOUR CHARTER RIGHTS AS A PATIENT

Healthcare laws and regulations vary slightly by province and territory but all Canadians generally share the following rights and options:

The right to be fully informed of all treatment options. This is also known as the ‘right of informed consent.’ Your physician is required to inform you of the risks and benefits of each treatment option as well as the probabilities of success.

The right to recognition of a agent. You have the right to appoint a agent - someone who can represent you if and when you can no longer make your own medical decisions. Your agent can speak for you with the same authority as if you were speaking for yourself.

The right to recognition of a Personal directive. Healthcare providers are required to follow your wishes for treatment, provided they are appropriate to your medical condition and are clearly outlined in a valid Personal directive. The Directives you prepare may include a Do Not Resuscitate Order. Such forms are legally binding in provinces that offer them, so long as the documentation is filled out properly, signed by your physician, and kept up to date.

The right to a second opinion. It is your right to consult with another physician for any reason. Most people just want the reassurance of another viewpoint and an opportunity to speak with someone who will help them to decide on the best course of treatment.

The right to pain and symptom management. You have the right to refuse medication, but neither the Charter of Rights and Freedoms nor healthcare legislation grant you the right to demand medication. However, terminally ill persons can typically expect a vigorous pain management regimen, even if it may hasten the dying process.

The right to refuse treatment. You have the right to refuse any treatment, even if refusal might hasten your death. You also have the right to discontinue any treatment that has already started. Ethically and legally, there is no distinction between discontinuing treatment and refusing it in the first place.

The right to refuse food and drink. In Canada, nutrition and hydration by tube is considered medical treatment. You have the right to refuse or stop such treatment. You also have the right to refuse food and/or drink, and the right to refuse to be fed or given drinks by others. This option is referred to as *Voluntary Stopping of Eating and Drinking (VSED)* and is supported by many palliative care providers.

The right to end your own life. It is legal to end your own life in Canada and has been since suicide was removed from the *Criminal Code* in 1972.

Appendix 1. Your Charter Rights as a Patient... *continued*

The right to request an assisted death. On June 17, 2016, physician assisted death became legal under some circumstances in Canada.

For information on Medical Assistance in Dying in Alberta visit <http://www.albertahealthservices.ca/info/page13497.aspx>

APPENDIX 2. GLOSSARY OF MEDICAL TERMS

Allow natural death: when death is about to occur from natural causes, do not delay the moment of death with medical interventions.

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

Artificial nutrition: feeding by a method other than by mouth if the person is unable to swallow. Several methods may be used:

- Nasogastric Tube (NG tube): a tube inserted through the nose and into the stomach.
- Gastrostomy tube (G-tube or PEG tube): a tube inserted into the stomach for the long term administration of food, fluids and medications.

Artificial hydration: provides 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 simply receive comfort care, should also request to discontinue artificial hydration by IV, as hydration prolongs the dying process.

Cardiopulmonary resuscitation (CPR): interventions that may include manual compressions to the chest, an electric charge to restart the heart, drug therapies, or a ventilator to assist in breathing. CPR can be life-saving, but the success rate for critically ill persons is extremely low. Read more about CPR in Appendix 3.

Cerebrovascular accident: see *Stroke*

Chronic debilitating suffering of a permanent nature: ongoing distress arising from a medical condition for which there is no cure. Examples would be Parkinson's disease or severe diabetes.

Coma: a profound state of unconsciousness in which a person cannot be awakened by pain, light, sound or vigorous stimulation.

Comfort care: services that contribute to physical and mental ease and wellbeing, often provided for a dying person when further medical intervention has been judged inappropriate or is unwanted. See also *Palliative care*.

Dementia: a chronic or persistent disorder of a person's mental processes caused by brain disease or injury and marked by memory disorders, personality changes and impaired reasoning. Alzheimer's disease is the most common cause of dementia.

Appendix 2. Glossary of Medical Terms... *continued*

Do Not Resuscitate (DNR): If your breathing or heartbeat has stopped, the emergency procedure to attempt to restore these functions is called CPR. If you do not want CPR you must have a DNR Order in hand. If you are in hospital such an order may be on your chart but if you are anywhere else, the order must be shown to first responders to avoid being resuscitated.

Heart failure: a condition in which the heart is unable to pump sufficiently to maintain blood flow to meet the body's needs; also known as congestive heart failure.

Hospice: from the word “hospitality,” the modern concept of hospice is a place and/or a service providing palliative care for terminally ill people in hospitals, long-term care homes or in their own home. Such care generally provides pain management and other comfort care but not medical interventions to prolong life.

Intensive care unit (ICU): a hospital unit with specialized staff providing constant monitoring and support for the care of those who are critically ill or injured. Also referred to as the critical care unit.

Life support or life-sustaining treatment: replaces or supports critical bodily functions such as breathing, cardiac function, nutrition and hydration. Such measures keep the person alive but do not cure the underlying problem. Life support may be used temporarily for a treatable condition.

Mechanical breathing: used to support or replace the function of the lungs. A ventilator or respirator forces air into the lungs via a tube inserted into the person’s nose or mouth and into the trachea. In certain conditions, the tube is inserted through a small hole at the front of the throat.

Palliative care: therapies given in any setting to provide comfort and to alleviate pain and distressing symptoms in order to relieve suffering and improve the quality of living and dying for those faced with a life-threatening illness or medical condition.

Personal care: includes health care, nutrition, shelter, clothing, hygiene or safety. Includes both treatment and personal assistance services.

Appendix 2. Glossary of Medical Terms... *continued*

Personal support worker services: hired services providing assistance with or supervision of hygiene, washing, dressing, grooming, eating, drinking, elimination, ambulation, positioning or any other routine activity of daily living but does not include treatment.

Stroke, also called a cerebrovascular accident: a sudden disabling attack or loss of consciousness caused by an interruption in the flow of blood to the brain, especially through thrombosis (blood clot).

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

Treatment: any sort of procedure or action done for a health-related purpose, whether the treatment be therapeutic, preventative, palliative, diagnostic, cosmetic, etc.

Vegetative state: said of a person who is alive but comatose and without apparent brain activity or responsiveness. A person in a **persistent vegetative state** is completely unresponsive to psychological and physical stimuli, displays no sign of higher brain function and is being kept alive only by medical intervention.

APPENDIX 3. ABOUT CARDIOPULMONARY RESUSCITATION (CPR)

Cardiopulmonary resuscitation (CPR) is a medical procedure used to restart someone's heartbeat and breathing when the heart and/or lungs stop working. CPR can be successful in emergency situations when the person is otherwise healthy. Imagine a young basketball player who collapses on the court, for example, and who is helped by CPR.



CPR is frequently performed on TV amid a flurry of people and machines; there are celebratory “high fives” all around when CPR is successful. This is a performance, which in real life is more fiction than fact. Only about 4-16% of CPR procedures done outside of hospital are successful.¹

If someone suffers from severe illness, advanced old age or a terminal disease, the odds of a good outcome from CPR is extremely low while the odds of suffering are overwhelming. A frail person who has not been breathing even for three minutes will have brain damage. What's more, during CPR ribs may be fractured, lungs punctured or the person may slip into a vegetative state and live that way for months.

This is why it is so important to make your wishes about CPR known in advance to your agent, your family, and your healthcare providers. CPR is an emergency procedure for which time is of the essence. If you wish to be resuscitated in the event of a cardiac incident, call 911 and first-line responders will automatically start that process when they arrive.

But remember that you have the right to refuse CPR. If you do not want to be resuscitated but need other help, 911 responders will do whatever else they can but must be shown a DNRC (Do not Resuscitate Confirmation) form when they arrive. Read more about this form in Appendix 4.

¹Sassoon, C., Rogers, M. A., Dahl, J., & Kellermann, A. L. (2010). Predictors of survival from out-of-hospital cardiac arrest a systematic review and meta-analysis. *Circulation: Cardiovascular Quality and Outcomes*, 3(1), 63-81.

APPENDIX 4. GOALS OF CARE DESIGNATION

When you discuss your advance care plan with your doctor, ask to have Goals of Care fully explained. Ask which designation is appropriate for you, given your medical history, your present health condition and prognosis, and taking into account the wishes you have expressed in your directive.

Goals of Care are designations used by your health care providers to describe the aim of your health care. In a medical emergency, your Goals of Care designation will guide your healthcare team to provide the care that best reflects your health condition, and the treatments that will be of benefit to you.

R Resuscitative Care – the patient is expected to benefit from, and is accepting of, any appropriate treatment offered, including resuscitation and intensive care. (ICU)

M Medical Care – the patient is expected to benefit from, and is accepting of, any appropriate treatment offered, excluding ICU and resuscitative care. This is an appropriate approach when R therapies are unlikely to be of benefit.

C Comfort Care – this approach is appropriate when the patient has a medical condition for which a cure is no longer possible. The focus is on pain and symptom control and transfer to a hospital may be necessary.

We have included a sample Goals of Care form for you to look at, before you talk to your doctor. Having a Goals of Care designation form is a quick way for medical personnel to render appropriate care in an emergency. If you have a Goals of Care Form you should store it along with your Personal Directive in an easily found location, ideally your Green Sleeve on your refrigerator, and bring it to any medical appointments .

APPENDIX 4. GOALS OF CARE FORM - SAMPLE




Affix patient label within this box

Goals of Care Designation (GCD) Order

Date (yyyy-Mon-dd)	Time (hh:mm)	
Goals of Care Designation Order		
To order a Goals of Care Designation for this patient, check the appropriate Goals of Care Designation below and write your initials on the line below it. (See reverse side for detailed definitions)		
Check ▶	<input type="checkbox"/> R1 <input type="checkbox"/> R2 <input type="checkbox"/> R3	<input type="checkbox"/> M1 <input type="checkbox"/> M2 <input type="checkbox"/> C1 <input type="checkbox"/> C2
Initials ▶	_____	_____
Check <input checked="" type="checkbox"/> here <input type="checkbox"/> if this GCD Order is an interim Order awaiting the outcome of a Dispute Resolution Process. Document further details on the ACP/GCD Tracking Record.		
Specify here if there are specific clarifications to this GCD Order. Document these clarifications on the ACP/GCD Tracking Record as well.		

Patient's location of care where this GCD Order was ordered (Home; or clinic or facility name)		

Indicate which of the following apply regarding involvement of the Patient or alternate decision-maker (ADM)		
<input type="checkbox"/> This GCD has been ordered after relevant conversation with the patient.		
<input type="checkbox"/> This GCD has been ordered after relevant conversation with the alternate decision-maker (ADM), or others. (Names of formally appointed or informal ADM's should be noted on the ACP/GCD Tracking Record)		
<input type="checkbox"/> This is an interim GCD Order prior to conversation with patient or ADM.		
History/Current Status of GCD Order		
Indicate one of the following		
<input type="checkbox"/> This is the first GCD Order I am aware of for this patient.		
<input type="checkbox"/> This GCD Order is a revision from the most recent prior GCD (See ACP/GCD Tracking Record for details of previous GCD Order).		
<input type="checkbox"/> This GCD Order is unchanged from the most recent prior GCD.		
Name of Physician/Designated Most Responsible Health Practitioner who has ordered this GCD	Discipline	
Signature	Date (yyyy-Mon-dd)	

APPENDIX 5. FREQUENTLY ASKED QUESTIONS

Q: Can someone else create a Personal directive on my behalf?

No. But if you are unable to write, your directive may be given orally. If someone else is writing on your behalf, his/her signature must be witnessed in your presence. The witness can NOT be the person you appoint as Agent, or the spouse of your Agent.

Q: What if I have a written Personal directive in which I refuse a certain treatment, and then change my mind when I am in hospital?

You can change your mind at any time. Any instructions you give orally will override previously written instructions provided you are competent when you express the new instructions.

Q: I am just not comfortable imagining all these medical conditions you describe. Why can't I simply say I don't want my dying to be prolonged?

You may certainly do so. Many people do. However, if you do not set down specific instructions, a general Personal directive is open to interpretation—and you may be treated in ways you would not want.

Q: What happens if I have no Agent? Who will make my health care decisions?

If you choose not to name a agent and you do not provide specific instructions under section 5 of the sample personal directive form, then a statutory decision-maker will be chosen by order of hierarchy from the following list to make decisions on your behalf *:

1. Your spouse, common-law, registered domestic partners
2. Adult child
3. Your parent or person who stands in the place of a parent
4. Sibling
5. Grandparent
6. Grandchild
7. Aunt or Uncle
8. Niece or Nephew
9. Any other relative by blood, marriage, or adoption
10. Office of the Public Trustee

** If the Office of the Public Trustee has previously appointed a representative for you, then that person rather than any other is your agent.*

Q: My son is named as sole Agent in my Personal Directive. If he moves out of the country can he agent one of my 3 daughters to act instead?

No, your son cannot decide this for you. You would have to make out a new Personal directive naming one of your daughters as your agent. To prevent such a situation, name each of your two daughters as your second and third choice, and appoint them to act independently rather than jointly.

Appendix 5. Frequently Asked Questions... *continued*

Q: I have two sons and I want to give them equal rights to make decisions for me. Why should I not appoint them to act jointly?

If appointed jointly, they have to agree on every decision before any action can be taken, and situations may arise where they disagree on your care. A better solution would be to appoint one son as Personal directive and the other as your second choice if the first is not able to make decisions for you.

Q: My brother and I are not on very good terms, but I have no other relatives, so he is my agent. What happens if he goes against the wishes in my Personal directive and makes other decisions for me?

If your physician or anyone else who has a copy of your Personal Directive sees that your wishes are not being followed, they can apply to the Office of the Public Trustee to have your brother ordered to comply with your directive, or to request that the Board itself act on your behalf.

Q: My husband has a serious heart condition. He has had several medical procedures and numerous hospital stays for complications. He has told me that if he has another heart attack he wants to be left alone and I am not to call 911. I don't want to take responsibility for this decision. What should I do?

To ensure that your husband is not resuscitated against his will, he should ask his physician to complete and sign a DNR Confirmation Order. Your husband should keep the form where it is easily found in an emergency. In this way, the decision is his own and not your responsibility. You will find full details of what this document is, what it means, and how you can obtain it in Appendix 3.

APPENDIX 6. FURTHER RESOURCES

Advance Care Planning and Goals of Care Designation – Alberta Health Services
<http://www.albertahealthservices.ca/info/page12585.aspx>

Goals of Care Designations and Green Sleeve folders – Conversations Matter
<http://goals.conversationsmatter.ca/>

Advance Care Planning – My Health Alberta
<https://myhealth.alberta.ca/Alberta/Pages/advance-care-planning-topic-overview.aspx>

Registering a Personal Directive – Human Services Alberta
<http://www.humanservices.alberta.ca/guardianship-trusteeship/register-a-personal-directive.html>

Medical Assistance in Dying – Alberta Health Services
<http://www.albertahealthservices.ca/info/page13497.aspx>