



My Voice

Planning in Advance for Health Care Choices



Advance Care Planning

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Foreword

Planning for future health care choices is a wise thing for all capable adults to do. Life threatening illness or injury can happen at any time and it's important that those who may have to make decisions for your care, if you are unable to do so, are clear about your wishes and know that they are supporting you in the choices you have made.

The purpose of this workbook is to provide you with the information you need to make informed choices about your future health care - ahead of time.

This workbook contains useful information on how to make the decisions that are right for you: how to hold the discussions with your loved ones that are a necessary part of the preparation of your plan for the future, and how to inform your doctor and nearest relatives of your wishes.

This workbook also contains an “**Advance Care Plan**” template that will enable the Regina Qu'Appelle Health Region to “hear” your wishes if a time comes when you are too ill to communicate for yourself.

All Saskatchewan residents who are **16 years of age and older** can complete an **Advance Care Plan**, and can change or revoke the plan at any time if mentally capable of doing so.

Regina Qu'Appelle Health Region (RQHR)
Advance Care Planning Steering Committee

What is an Advance Care Plan?

Many people lose the ability to express what they want when they are very ill, seriously injured, or close to death.

An Advance Care Plan (sometimes called a living will or advance directive) is the legal set of directions you develop for your medical care if you are too ill or injured to communicate or make decisions.

The instructions and information in the plan would only be used to give direction for your treatment if you were not capable of speaking for yourself.

Preparing a written Advance Care Plan is always voluntary.

What are the Benefits of Having an Advance Care Plan?

The benefits of preparing an Advance Care Plan vary from person to person. For you, some benefits may include:

- Giving the gift of guidance, confidence, and strength to those closest to you in the event that you become ill and they have to speak for you.
- Reducing the emotional distress on those closest to you.
- Providing clear instructions for health care providers and others who may have to make decisions for you.
- Learning about and choosing from the options available for your health care in a variety of situations.

- Ensuring that you receive medical care that supports your values and/or faith tradition.

- Preventing the use of medical procedures that may prolong your life unnecessarily.

- Increasing the likelihood of a peaceful, dignified death in a location you prefer.

You may prefer to communicate your wishes verbally rather than in writing. However, a written plan helps people accurately remember what you want. It makes it easier for you, your family, or a friend to communicate your wishes to health care team members who may not know you.

When Should I Prepare My Advance Care Plan?

As soon as you can.

Making the decision to complete an Advance Care Plan is not something that should be done in the middle of a health crisis – the process is best done ahead of time in a non stressful environment.

You must be at **least 16 years old** to make an Advance Care Plan in Saskatchewan.

You must be able to understand the kind of health care choices you are making and what they mean.

You can change or revoke your plan at any time while you are mentally capable of doing so.

What is the Process of Completing My Advance Care Plan?

Advance Care Planning for health care choices is a process of thinking and talking about complex and sensitive issues, and then sharing.

The process includes:

Thinking

- Reflecting and considering what makes life meaningful for you.

Talking

- Learning about possible medical treatments for the very ill or injured and their complications.

Acting

- Discussing your choices and wishes with those closest to you so they know what you would want in a variety of situations.
- Choosing an individual (**Proxy**) to speak for you if the time comes when you cannot make your own medical decisions.

A gift for your children



My mother gave me a very loving and insightful gift – namely, careful direction about what to do if she became irreversibly ill and unable to make her own decisions.

Within a few years, she was the victim of Alzheimer's disease. My mother was unable to understand her health care or make any decisions because of her impaired judgment and the complexity of her situation. I became her advocate and relied on the direction she had given me earlier. My first experience in decision-making occurred when the doctor discussed the "Do Not Resuscitate" issue with me. He asked, "We need

to know what your mother's choice would be if her heart should stop." Mom had prepared me for this – the answer was not to resuscitate. Few illnesses along the way required much decision making, which was fortunate for us. But I do think I would have known what she wanted and acted accordingly. When my mother died, amidst the sadness, there was peace. Peace in knowing that she had said many times to me, "No medical intervention when there's nothing that can be done for me." I am grateful that I didn't have to struggle with decisions during that time.

A daughter's story

Section 1 - Thinking

Advance Care Planning starts off with thinking about what you value in life. Your previous experiences shape who you are, what you believe, and what you value. Faith, family traditions, jobs and friends play a part in your life and affect you deeply. Take a moment to think about the following questions:

Reflecting

- Has anything happened in your past that shaped your feelings about medical treatments?
- Think about an experience you may have had when someone close to you was very ill or dying:
 - What was positive about the event?
 - What do you wish had been done differently?

Here and Now

- What brings you pleasure and joy?
- Who do you like to spend time with?
- What role does spirituality play in your life?
- How important is faith or religion to you?
- What or who would you miss most if you were unable to function as you do now? (“function” refers to a person’s ability to speak, think, or walk.)
- Would being unable to participate in these activities or be with these individuals make life meaningless for you? If so, at what point?
- What are your goals for your life from now on?
- Do you have any significant health problems at present? What are they? Might they get worse? How will they affect the rest of your life?
- How might medical treatments for the above help or make it difficult for you in accomplishing your personal goals

Considering the above, here are some questions to think about

- Would **you** want your life prolonged if there was little chance of recovery or return of abilities such as speech, walking, or thinking?
- When would it make sense **to you** to continue certain treatments in an effort to prolong your life and seek recovery?
- When would it make sense **to you** to stop or withhold certain treatments and accept death when it comes?

Section 1—Thinking.....About Treatments

Introduction

When you are in pain or experiencing other unpleasant symptoms (such as dizziness, nausea, or fever), health care team members will give you medicines and treatments to control these symptoms. When you reach the point when you no longer want life saving care, medical treatments and nursing care are always given to keep you comfortable.

Examples of such treatments/care include:

- surgery to control pain (such as the repair of a broken hip)
- pain-relieving medicine and treatments
- medication to ease breathing difficulties.

Now, you need to consider the life threatening or end of life situations that might cause you to be unable to make your own health care decisions. These include illnesses or injuries that could result in little or no recovery such as:

- advanced lung or kidney disease
- end stage cancer.

Conditions that can cause significant loss of function (speech, mental ability, or mobility):

- brain injury from an accident
- progressive diseases like Multiple Sclerosis or Alzheimer's
- a severe stroke or heart attack.



Cardiopulmonary Resuscitation (CPR)

CPR refers to medical interventions used to restart a person's heart and breathing when the heart and/or lungs stop working unexpectedly. CPR can range from mouth to mouth breathing and pumping on the chest to more aggressive treatments.

CPR can be successful in emergency situations when the heart stops and the person is otherwise healthy.

However, for individuals at the natural end of their lives or who have a serious injury or medical illness, restarting the heart is not effective in over 96% of cases and can cause additional suffering.

In patients with advanced illness, 1 to 4% survive CPR and go home – and half of those will need significant support to carry on their lives. In this case, doctors may not offer CPR. Instead they will discuss choices for achieving a natural and comfortable death.

Section 1—Thinking.....About Treatments

Medical Treatments

In case of a serious illness or injury, there are a number of medical treatments, often known as **life support**, which can prolong life and delay the moment of death. These include CPR, artificial breathing using a machine, tube feeding, artificial hydration (intravenous), and kidney dialysis. These treatments can sometimes be both life saving and hurtful.

Life prolonging treatments might be viewed as **helpful** if they can:

- prolong life so you can return to the lifestyle you enjoyed before the hospitalization or one you would be happy with
- restore function (ability to walk, to hear, to speak)
- relieve pain and suffering
- be consistent with your religious or cultural beliefs.

Life prolonging treatments might be viewed as **harmful** if they:

- result in more pain and suffering
- damage your body or function
- are psychologically damaging.

Often treatments provide a measure of both help and harm. For example: it might be possible to prolong biological life, but not restore consciousness; functions like walking might be restored, but with considerable pain. You need to think through the helpful and harmful aspects of life prolonging interventions and measure them against your values and personal goals.

All individuals have the right to receive full life support treatments, should they be offered, or to refuse them under any circumstances.

Antibiotics

Antibiotics are drugs used to treat infections caused by bacteria or other organisms.

Antibiotics kill bacteria or prevent it from growing. Depending on the type of infection, treatment with antibiotics can result in a decrease in fever, pain, or other symptoms, and can also prevent the spread of the infection to other areas of the body.

While antibiotics are useful, there are risks associated with their use. For example, some infections go away on their own and may not need to be treated with antibiotics.

Over use of antibiotics can lead to resistance (meaning the antibiotics are no longer able to destroy bacteria). In addition, antibiotics can cure the initial infection but another infection can occur from bacteria that are resistant to the antibiotic.

Some antibiotics have side effects that can be uncomfortable.

When a person is dying, antibiotics may or may not prolong life. The ability of antibiotics to make a difference varies from person to person.

Section 1—Thinking.....About Treatments

Comfort Care

Comfort care provides a person with a comfortable and dignified death without the use of medical treatments to prolong life. Care is directed towards control of symptoms common at the end of life (pain, confusion, shortness of breath).

This type of treatment focuses on your wishes and those of your loved ones. Respectful attention is directed to your body, mind, and spirit. Comfort care can take place in your home, nursing homes, hospices, and hospitals.

Artificially Administered Nutrition

Artificially administered nutrition is the provision of liquids and food through the use of tubes such as intravenous (IV) which may include fluids only or Total Parenteral Nutrition (TPN), and/or a feeding tube in the stomach.

Tube feeding is a way of giving food and fluids when a person cannot eat in the usual way.

Tube feeding may be provided in two ways. One is by a tube through the nose which goes to the stomach (a “naso-gastric” or “NG” tube). The other is by a tube which goes through the abdominal wall into the stomach or small intestine (a “PEG” tube). This requires a minor surgical operation.

When a person is dying, artificially administered nutrition is usually discontinued. The dying person will not feel the thirst and hunger that would be expected from not eating and drinking. At this stage, artificial feeding does not improve a person’s quality of life and in many cases causes discomfort.

Palliative Care

Palliative care refers to treatment provided to a person who is believed to be in the last months or days of life. “Palliative care services are helpful not only when a person is approaching death but also at earlier stages in their illness.” “Canadian Hospice Palliative Care Association”

Palliative care focuses on the person living the way they choose when they have an illness at an advanced stage. This may include treatments like pain and symptom management, chemotherapy or surgery aimed at improving the person’s quality of life, not curing the disease.

Palliative care, with the support of the Palliative Care Team, can be provided in the hospital, hospice or at home. Nursing homes also provide palliative care.

Section 2 - Talking

Decision Making

Some people think and work out their answers alone and others find discussing the questions with another person helpful. It is natural to have questions as you work through this process and you should seek answers – you may need to talk with your health care provider, family doctor, or get in touch with the RQHR Advance Care Planning health educators.

If you have collected some questions for your doctor(s), health care providers, or your lawyer, now is the time to meet with them to clarify the areas you either do not understand or need more information about. Perhaps you also want to consult your clergy member regarding the suitability of your choices in light of your faith tradition.

It is preferable to do this before you hold the necessary conversations with those close to you. It is a good idea to have read the sample Advance Care Plan form at the back of this book (pages 20 to 26) or at least filled it out in pencil.

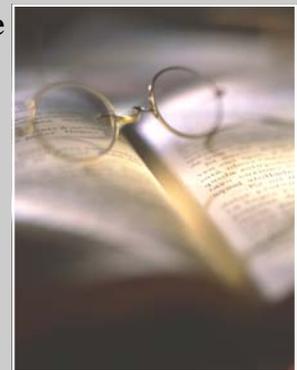
By working through the process, you will end up with a much clearer idea of the type of future health care you prefer and the individuals you need to tell.

The process can take a while to complete – take as much time as you need.

Life is like a book...

Rose had a strong relationship with her family, and expressed what she wanted for end of life care. We talked about...how she felt about living in a nursing home. When we discussed CPR and care choices when she couldn't speak for herself, she was very clear that she did not want interventions. She wanted only to be kept comfortable. Her daughter listened to the conversation...but couldn't entirely accept her Mom's wish to accept death so readily. Rose was unable to explain to her daughter why she felt as she did. Hesitantly, I described that our lives are like a book and some people die before they have "completed" their book. I asked Rose if she had finished writing her book, or if there were more chapters to write. She looked at me, smiled and said, "Yes, I have finished my book, and I am content with that." I could see that her daughter felt comfortable with that explanation.

A residential care nurse, 2006



Section 2 - Talking

CPR or No CPR? - Medical Intervention or Comfort Care?

This section will help you decide under what circumstances you would want to change the medical goal from prolonging your life (including resuscitation and life support) to allowing a natural death to occur.

Consider these questions:

- What medical problems do you fear might affect you in the future?
- What frightens you most about medical treatment?
- What will help you live your life well from now on?
- How do you feel about having to go into a nursing home?
- Who could speak for you, if you could not?
- What would an ideal death look like to you?
- What would you want to happen if your heart or breathing suddenly stopped?
- What would it take for you to want to be resuscitated?
- Under what circumstances would you want the goal of medical care to switch from attempting to prolong your life, to focusing on comfort care? Describe the circumstances in as much detail as you can.
- When you think about death, what situations worry you? For example: I worry about being alone or I worry about struggling to breathe.
- What does **comfort care** mean to you? When thinking of death, many people say, “Just keep me comfortable.” But what exactly does that mean for you – everyone has a different view of what they would want at that time. Often called a person’s “last wishes”, you need to consider what would matter most to you at this time in the areas of personal comfort, environment, and your spiritual needs.
- What do you need to do before you die? For example: Make amends to certain individuals or re-establish communications (or a relationship) with...
- Where would you prefer to spend your last few weeks or days? What would be your ideal surroundings at this time?
- Who do you want with you at the end of your life?
- When you are nearing your death, what do you want or NOT want? For example: I want soft music playing or I don’t want to be fed if I’m not hungry.
- What kind of spiritual care do you want at the end of your life? For example: my minister present, or prayers at my beside, or none ...
- When you are nearing your death and cannot communicate, what important things would you like your family and friends to know and remember? For example: I love you....I forgive you..... please forgive me.....thank you.....and goodbye.

Section 2 - Talking

Proxy

Subject to your express written wishes as documented in your Advance Care Plan, *The Health Care Directives and Substitute Health Care Decision Makers Act* allows you to legally appoint the person of your choice to be your health care decision maker. This person is called a Proxy and must be an adult who is willing to make health care decisions for you, based on your expressed wishes when you cannot speak for yourself.

The person you choose as your Proxy must be over 18 years of age. Your Proxy must be someone you trust:

- Be responsible and able to respect your opinions and values.
- Be willing and able to explain your wishes for your medical care and end-of-life care to health care team members.

- Be willing and able to explain your wishes in a complex medical situation or in a time or crisis.
- Be named in your Advance Care Plan, if you choose to appoint a Proxy.

If you have no Proxy, *The Health Care Directives and Substitute Health Care Decision Makers Act* identifies who can make health care decisions for you. Your health care team members are by law required to approach your nearest relatives in a specified order.

If you do not want the relative who is listed first in the chart to speak for you, or you have no relatives and want a friend to speak for you, you should appoint a Proxy.

The legal order in which individuals will be approached to make health care decisions for you is outlined in *The Health Care Directives and Substitute Decision Makers Act* as follows:

1. The Proxy named by you in your Advance Care Plan.
2. A personal guardian appointed for you by the Court of Queen's Bench with power to make health care decisions. An Advance Care Plan would give guidance to your personal guardian in respect of your health care choices.
3. "The person first described in the following clauses who is willing, available and has the capacity to make a health care decision:
 - (a) the spouse or person with whom the person requiring treatment cohabits and has cohabited as a spouse in a relationship of some permanence;
 - (b) an adult son or daughter;
 - (c) a parent or legal custodian;
 - (d) an adult brother or sister;
 - (e) a grandparent;
 - (f) an adult grandchild;
 - (g) an adult uncle or aunt;
 - (h) an adult nephew or niece

(Source: *The Health Care Directives and Substitute Health Care Decision Makers Act*, 1997)

Section 3 - Acting

Discussing Your Choices

You will want to discuss your desire to complete an Advance Care Plan and to explain your wishes to the individuals who are most likely to be involved in decision making if you become too ill to speak for yourself.

An important component of Advance Care Plans which makes them different from Living Wills is that you name an individual who will speak for you and make decisions on your behalf if you cannot. This person is called a Proxy.

As these discussions can involve complex and sensitive issues, they can take several sessions. Talking about these issues may not be easy; you may face resistance, even denial, because those closest to you may be uncomfortable talking about living at the end of life.

Remember always, that your nearest relative, family and/or proxy do want to respect your wishes even though the conversation may get emotional.

Asking those closest to you to make decisions on your behalf, if you cannot, can be difficult for them too, but discussing your choices with them will reassure them. This book aims to help your discussions with those closest to you by providing the words to say and questions to ask.

Start by explaining that you are planning ahead for the day that you might be seriously ill or injured, and/or dying, and unable to communicate what kind of medical care you want.

Tell your nearest relative or proxy that you want them to know what you have chosen so they will not have to guess what you want at a difficult time.

A doctor's story.....

I had a patient with a serious lung disease that made him very short of breath and unable to walk. We talked about what he would want us to do if his lungs failed. He decided against using a breathing machine (ventilator) in this situation. His wife supported his choice and my patient stated his wishes in a written Advance Care Plan, which he knew would relieve his wife of trying to guess what he would want in an inevitable medical crisis. Six months later, he came to the hospital hardly able to



breathe. Without a ventilator, he would die. The doctor on duty did not know him and asked him what he wanted them to do. He repeated he only wanted to be kept comfortable and didn't want assistance from a breathing machine. The doctor wondered if lack of oxygen was affecting his judgment. Then my patient's wife showed the hospital staff her husband's carefully considered, written Advance Care Plan. Even though he was still able to speak for himself, the plans he had made ahead of time supported the decision he made when he was very ill. The medical staff respected his choices and he died comfortably without the use of a machine.

Section 3 - Acting...continued

- Talk about what makes life meaningful for you and what would make it pointless
- Talk about the difference between prolonging life and allowing natural death to occur. Indicate when you might want the transition to happen for you.
- Talk about your goals for medical treatment:
 - How bad would the situation need to be for you to say, "Don't keep me alive in that state."
 - Describe what being a "vegetable" (vegetative state) means to you.
 - Explain the circumstances that might make you want certain treatments.
- Some situations for discussion include:
 - When to begin life support treatments (CPR, ventilation, feeding tubes,).
 - When to withhold or withdraw life support treatments.
- Talk about CPR and life support measures.
- Ask your nearest relative/Proxy what they think about your views. Give them time to ask you questions.
- Tell them what frightens you about certain medical treatments and why.
- Tell them exactly what you want. You can show them the Advance Care Plan form, if it is helpful.
- Discuss who would make your medical decisions if you cannot (**Proxy**). Talk about who might be most capable and/or knowledgeable. Identify who you think could do this for you? Does everyone agree? Does the main decision maker want a supporter? Who could that be?
- Allow the person you choose to be your Proxy to refuse, even if he or she is the person closest to you. This is not an unusual reaction; perhaps they would prefer to be the 'supporter' rather than the individual on whom the main responsibility will fall.
- Describe what you want at the end of your life. Ideally, where you would like your natural death to take place, and with whom.
- Encourage those closest to you, especially the individual who agrees to speak for you if you cannot, to find out about new medical treatments if you fall seriously ill or are injured. New procedures and drugs may become available and might be suitable for you if they honour the values and goals you have developed for such situations. Your Proxy should be willing to gather new information on your behalf and use it in selecting medical care for you if you cannot.

Section 3 - Acting...continued

Once the discussions are over, you can finish your Advance Care Plan in writing by completing the template **in ink**. Then you must sign it . You may have someone witness you signing the forms.

Give copies to:

- Your Proxy:
- The person who is willing to support your Proxy.
- Other members of your family, and/or friends.
- You may choose to give it to your lawyer, minister or priest, or a social worker if you reside in a nursing home.

In Addition:

- Tell your doctor(s), including your family doctor and specialists who you see regularly, that you have completed your Advance Care Plan. You may give him/her a copy for your medical file; this is not essential, but recommended.
- Many individuals take copies with them when they travel and give a copy to a traveling companion.

This is a lot to talk about.

Remember, although it is difficult to know the details of any future illness you have, talking about your beliefs, values, and goals for living well at the end of life will help those closest to you to make medical decisions for you when you can not.

Do not try to do it all at once and give those closest to you time to think it over if they wish. Many people need time to process this much information. Allowing thinking time is especially important for the person you have asked to act as your Proxy.

Section 3 - Acting...continued

Jean's Story.....

Jean was only 35 when she was diagnosed with a severe and chronic illness. As a result of this illness, Jean's family could not care for her at home. She went to live in a nursing home where she stayed for five years, receiving excellent care. Unfortunately, Jean's marriage came to an end during her stay in the nursing home and her husband moved to another province with her only child. Jean was devastated, but she learned to cope and enjoyed the regular visits of her younger brother. As Jean's condition worsened, she started to worry more and more. "What if I die alone? What if I have a hard time breathing and can't let anyone know how I'm feeling? What if they want to take me to the hospital and I don't want to go?" A nurse offered to sit with Jean and her brother as they talked about Jean's worries and wishes. Jean asked her brother to write her wishes down. As a result of several conversations, Jean was able to make a written Advance Care Plan and share it with her brother and those who cared for her in the nursing home. Jean spent her last few days in the nursing home, surrounded by caring nursing staff and her devoted brother. Her Advance Care Plan had let every one know what she wanted, and every wish was honoured. She was not left alone during her final hours and her brother was able to communicate a final message to Jean's teenaged child. A week after Jean died, her brother came to the nursing home to thank the staff for all the loving care they had given Jean over the years. He held tightly to Jean's Advance Care Plan and told them how powerful it was for him. "This," he said "is Jean. Her Advance Care Plan has been my strength. I've had to deal with a lot over the past few weeks, but this plan reminds me that I did everything Jean wanted. I'm keeping it forever."

A family story



Answers to Other Questions that You May Have

1. Is my Advance Care Plan legal?

Yes. A written Advance Care Plan gives clear direction regarding your health care wishes. In Saskatchewan, Advance Care Plans are legal documents and must be written and signed. They carry considerable weight and health care providers must honour it in all but exceptional circumstances. (see *The Health Care Directives and Substitute Health Care Decision Makers Act*).

2. Are health care providers legally obliged to follow Advance Care Plans?

Yes. There is provincial legislation that directs health care providers to follow Advance Care Plans. An Advance Care Plan allows health care providers to “hear” your wishes clearly when you cannot speak for yourself. Doctors, nurses, and other health care team members will do their best to follow advance care plans where possible; however, it is important to understand that the choices you make now for future health care may not be ideal if you become very ill. Your doctor will consider your wishes, but is not ethically obliged to order or perform treatments to you that are of no benefit.

3. What if I leave Saskatchewan? Will other provinces or other countries honour my Advance Care Plan?

As Advance Care Plans are recognized by common law in Canada, you have every reason to expect that your Advance Care Plan will be honoured anywhere in this country. Other countries, certainly those in the developed world, should honour your wishes. The best way to ensure that you receive the type of care you want is to take a copy of your Advance Care Plan with you whenever you travel and give one to your traveling companion.

4. My children/spouse do not agree with my carefully chosen health care wishes...what now?

If you have discussed your health care choices and last wishes with your doctor and nearest relative, this situation is unlikely to occur. However, if it does, you should consider choosing someone else to speak for you. In Saskatchewan, this would involve appointing someone as your Proxy. In this case, Saskatchewan law requires that this legally appointed substitute decision maker follow your wishes and others cannot have your instructions changed.

Specific Advance Care Plans that clearly anticipate and give directions relating to treatment for the specific circumstances that exist must be followed unless certain exceptional circumstances exist.

5. What happens in an emergency when my substitute decision maker is not available?

In emergencies, there may not be time to locate and consult the detailed instructions in your Advance Care Plan. Life saving treatments may be started, but can be stopped if it is learned that they are not what you want.

Word List

Here is a list of the words used in this booklet that you may want to know more about:

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

Advance Care Plans (sometimes called advance directives, living wills) are verbal or written instructions made while you are still capable. They describe what kind of care you would want (or not want) if you were unable to speak for yourself. These plans are made by you, for you. You cannot make an Advance Care Plan for someone else.

Antibiotics are drugs that are used to fight bacterial infections, such as pneumonia.

Artificial nutrition refers to giving food through tubes to a person who cannot eat/swallow; tubes can be used permanently or for a short time.

Cardiopulmonary resuscitation (CPR) refers to medical interventions 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 on the chest, to electric shocks that restart the heart and machines that breathe for the individual.

Capacity means the ability:

- (i) to understand information relevant to a health care decision respecting a proposed treatment
- (ii) to appreciate the reasonably foreseeable consequences of making or not making a health care decision respecting a proposed treatment, and
- (iii) to communicate a health care decision on a proposed treatment.

Comfort Care includes treatment to relieve pain and other unpleasant symptoms at the end of life.

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

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.

A feeding tube is a way to feed someone who can no longer swallow food. It is a small plastic tube that carries liquid food, which is inserted through the nose or directly into the stomach or intestines.

Goals refer to your personal goals at the time you complete this form. For example: spending more time with family and friends.

Health care decision means a consent, refusal of consent or withdrawal of consent to treatment.

Word List continued

Here is a list of the words used in this booklet that you may want to know more about:

Health care provider /team

member describes a person licensed, certified, or registered in Saskatchewan to provide health care. For example: a doctor, nurse, social worker, or physiotherapist.

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

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

Nearest relative means nearest relative as described in Section 15 of: *The Health Care Directives and Substitute Health Care Decision Makers Act*.

Proxy means a person appointed in a directive to make health care decisions for the person making the directive.

Symptoms are what you tell your care provider about how you are feeling or what you are experiencing. Symptoms are largely subjective in nature. For example: pain, dizziness, or feeling exhausted.

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.

Vegetative state describes a condition where the basic bodily functions continue, but the person is unconscious, unaware of their surroundings, and unable to feel pain.

Ventilator is a machine that helps people breathe when they cannot breathe on their own. A special machine is attached to a tube that is placed down the windpipe.

My Advance Care Plan

Respect

Trust

Caring

This section is designed to be separated from the rest of the document, photocopied, and given to your doctor, Proxy, nearest relative, and/or trusted friends. Please read each page carefully, initial, sign, and witness where indicated.

This is the Advance Care Plan of:

My first name: _____ Middle initial(s): _____

Last name: _____

My date of birth: _____

My Saskatchewan Hospitalization #: _____

My address: _____

My home phone number: _____

My cell phone number: _____

My work phone number: _____

My e-mail address: _____

The following people have copies of this Advance Care Plan:

Name	Relationship to me	Phone Number
		()
		()
		()
		()
		()
		()

Proxy - Who I Want to Speak for me When I Can't

1. I have discussed my wishes for future health care with the person named below and select this person to be my Proxy and speak for me if I am unable to communicate for myself or am unable to understand what the care providers are saying to me.

Name: _____ Relationship: _____

Home phone: _____ Cell phone: _____

Work phone: _____

Address: _____

E-mail address: _____

You may also add the name of another trusted relative or friend as an alternate if your chosen Proxy is unable to speak on your behalf at any time (optional).

2. I have discussed my wishes for future health care with the person named below. I trust this person to speak for me if my Proxy is unable to do so or requires support.

Name: _____ Relationship: _____

Home phone: _____ Cell phone: _____

Work phone: _____

Address: _____

E-mail address: _____

Signature

Print Name

Date

Witness Signature (Optional)

Print Witness Name (Optional)

What I Want – Considering Cardiopulmonary Resuscitation (CPR)

Guidance

CPR refers to medical interventions used to restart a person's heart and breathing when the heart and/or lungs stop working unexpectedly. CPR can range from mouth to mouth breathing and pumping on the chest to more aggressive treatments.

CPR can be successful in emergency situations when the heart stops and the person is otherwise healthy. However, for individuals at the natural end of their lives or who have a serious injury or medical illness, restarting the heart is not effective in over 96% of cases. Therefore, doctors may not offer CPR. Instead, they will discuss choices for achieving a natural and comfortable death.

You have the right to refuse CPR. If this is your wish, you need to tell your doctor.

Remember you can change your wishes at any time, however, you must ensure that your Proxy/nearest relatives and health care providers have a copy of your most recent wishes.

Choose the statement below that you want. Initial in the box beside your choice. Draw a line through the statement you do not want.

I want cardiopulmonary resuscitation (CPR) attempted **unless my doctor determines one of the following:**

Initial

- I have a terminal illness or injury.
- My heart has stopped beating and I have no reasonable chance of survival even with CPR.
- My heart has stopped beating and the results of CPR would cause me significant suffering.

OR

I do not want cardiopulmonary resuscitation (CPR) under any circumstance. Please allow natural death to occur.

Initial

Signature

Print Name

What I Want –

Considering Life Support with Medical Interventions

Guidance

In case of a serious illness or injury, there are a number of medical interventions called interventions, which can prolong life and delay the moment of death. These include ventilation, tube feeding, intravenous fluids (see page for the Word List). It is important to think about and choose what you want from the following:

- Have full life support with medical interventions.
- Have a trial period of life support with medical interventions and, if unsuccessful, allow natural death to occur. The trial period could last several days or weeks and would be the result of a discussion between your substitute decision maker and your health care providers.
- Limit the use of life support with medical interventions and allow natural death to occur.

Remember you can change your wishes at any time, however, you must ensure that your proxy/nearest relatives and health care providers have a copy of your most recent wishes.

Choose the statement below that you want. Initial in the box beside your choice. Draw a line through the statement you do not want.

Even if I would be unlikely to recover my ability to recognize my nearest relatives and friends, and/or I would not be able to communicate with them, and/or I would not be able to enjoy life the way I did before,

Initial

Full Treatment

I want to have life support with all necessary medical interventions, such as a feeding tube, intravenous fluids, a ventilator (breathing machine), CPR, or kidney dialysis.

OR

If life support would delay the moment of my death, and/or I would be unlikely to recover my ability to recognize my nearest relatives and friends and/or communicate with them, and/or I would not be able to enjoy life the way I wish, then,

Initial

Conditional Full Treatment

I want a trial period of life support with medical interventions, such as feeding tube, intravenous fluids, a ventilator (breathing machine), CPR, or kidney dialysis. If the trial period does not help me recover, then I want these interventions stopped to allow natural death to occur.

OR

Initial

Comfort Measures Only

I do not want life support with medical interventions, such as a feeding tube, intravenous fluids, a ventilator (breathing machine), CPR, or kidney dialysis. If any of these interventions have been started, I want them stopped to allow natural death to occur.

Signature

Print Name

What I Want – Considering Organ and Tissue Donation Options

Guidance

The Human Tissue Gift Act provides that organ and tissue donation can only happen after death. **Organs** can only be retrieved from someone who has died because of a brain injury causing blood flow to the brain to stop. The heart and lungs are functioning only with the aid of the ventilator machine and medication. Anyone that dies in this manner will be considered for organ donation. There are medical and social concerns that may limit donation; this will be discussed at the time of referral to the transplant program.

Tissue donation occurs only after death, after the heart has stopped beating. There are restrictions of age and cause of death that may limit what tissues can be retrieved. There are also medical and social factors that may limit donation; this will be discussed at the time of referral to the transplant program.

Remember you can change your wishes at any time, however, you must ensure that your proxy/nearest relatives and health care providers have a copy of your most recent wishes.

Choose the statement(s) below that you want. Initial in the box beside your choice and draw a line through the statement you do not want.

At the time of my death I have the option to decide what may be done with my body. I understand that age and cause of death may limit donation.

My wishes at time of death in regards to donation are:

I place no limitation on which of my organs may be used, should I be deemed a suitable organ donor.

Initial

I limit donation to only the following organs, should I be deemed a suitable organ donor.

Initial

Heart Lungs Liver
 Kidneys Pancreas Small Bowel

I limit donation to only the following tissues, should I be deemed a suitable tissue donor.

Initial

Heart for Valves Eyes Pericardium
 Tendons/Ligaments Pancreas Bones
 Skin

Initial

I do not wish to take part in organ or tissue donation.

Signature

Print Name

Signing, Witnessing, and Dating

1. You must sign and date this Advance Care Plan to indicate to your health care providers and those close to you that you are in agreement with the wishes you have expressed.
2. You may have someone witness this plan, if available.
3. If you cannot sign, but can make your mark or direct someone to sign for you, then your mark or that person's signature **must be witnessed**. Under these circumstances your Proxy named in this directive **can not** be a witness nor can your Proxy's spouse.

I, _____ am thinking clearly, I understand the
insert name
meaning of the questions and the choices I have made, and I have made this Advance Care Plan voluntarily.

My signature or mark

Witness's signature

Print your name here

Print witness's name here

Date

Date

Thoughts I Wish to Share

This page does not have to be filled in or attached to your Advance Care Plan unless you choose to do so. If there is not enough space, please write on the back of this page or add additional pages.

This is what makes life meaningful for me: For example: “Spending time with my family and friends”, or “Fresh air”, or “Practising my faith”, or “My dog/cat”.

When I think about death, I worry about the following possible situations: For example: “I worry I will struggle to breathe”, or “I worry that I will be alone”.

If I am nearing my death, I want (and/or do not want) the following: For example: “I want soft music playing”, or “I want someone to hold my hand”, or “I want my minister or priest to perform the necessary religious rituals”, etc.

When I am nearing my death and cannot communicate I would like my nearest relatives and friends to know and remember these things: For example: “I love you”, or “I forgive you”, etc.

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