My Voice
Planning in Advance for Health Care Choices

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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 you can use to complete an Advance Care Plan.

_Completing an Advance Care Plan is legal in Saskatchewan._ 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.

Advance Care Planning Program
Regina Qu’Appelle Health Region (RQHR)
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.

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.

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 Complete 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.

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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.

At the age of 81, Maria had had a series of strokes that robbed her of all mobility. Her husband, Henry, age 83 had been caring for Maria at home. One Saturday evening at home, Henry was holding Maria’s hand and she told Henry that she was too tired to go on. Later that evening, Maria quietly slipped into a coma. After discussion with their children, Henry felt they could no longer care for Maria at home and thought about palliative care. When they called the Emergency Department, they were advised to bring Maria in and the neurologist would evaluate her.

When the neurologist came in, he seemed surprised when Henry requested Maria be made as comfortable as possible but not to provide any aggressive treatment. The doctor asked if Maria had put anything in writing regarding her wishes. Henry said no, but during their 50 years of marriage, they had discussed it at length and he knew her wishes intimately.

Again, the doctor stressed the importance of having something in writing. Henry replied “Son, if you are in an accident tonight on your way home from this hospital, if your life is affected the way my wife’s is right now, do you have your wishes in writing? Does your wife know your feelings about being left in this state? Have you even discussed it with her? Please don’t tell me what you know. Listen to what I know”

From that point until Maria’s death, Henry and his family received care in keeping with her wishes. They believed that Maria had a good death.

Have you discussed this with those closest to you?

Shared with Advance Care Planning Program, Regina Qu'Appelle Health Region by Maria’s family, 2013

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Section 1 - Thinking

Advance Care Planning starts off with thinking about what you value in life. Your life 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?
- What does living well mean to you? 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 your current health problems, help or make it difficult for you to accomplish 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?

For more information, please call 1-(306)766-5922 or email: advancecare@rqhealth.ca.
Section 1—Thinking about medical interventions

Introduction
You have started to think on what is important and meaningful in your life. Now you can begin to think about the type of medical care you would want if a medical crisis occurs and you can no longer speak for yourself. This is referred to as medical interventions. Medical interventions includes medications, treatments, and procedures used to treat a person’s medical condition and symptoms.

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

Now, consider the medical situations that might leave you unable to make your own health care decisions. You may have a medical crisis due to an unexpected situation like an accident. Or you may have a medical condition that may result in little or no recovery, or significant loss of function. This can include:
- brain injury from an accident
- a severe stroke or heart attack.
- progressive diseases like Multiple Sclerosis or Alzheimer’s
- advanced lung or kidney disease
- end stage cancer.

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.

For more information, please call 1-(306) 766-5922 or email: advancecare@rqhealth.ca.
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 how a person functions
• 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.

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 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.

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Section 1—Thinking.....About Treatments

Comfort Measures Only
Comfort care provides a person with maximum comfort and control of symptoms common at the end of life (pain, confusion, shortness of breath).

Respectful attention is directed to your body, mind, and spirit. Comfort care may 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 focuses on helping a person live the way they choose when they have a serious life-limiting illness. This illness can include heart failure, COPD, kidney failure and cancer to name a few. Care is directed toward symptom management, (i.e. pain, nausea, shortness of breath) and may include chemotherapy or surgery. The goal of care is to improve the person’s quality of life, not to cure disease. Palliative care also includes comfort care as described above.

Palliative care can be provided to persons in hospitals, hospice, nursing homes or at home. Most palliative care is organized through a patient’s family doctor, however, when symptoms are difficult to control, more specialized services may be needed. To access specialized services from the Palliative Care Team in RQHR, contact 306-766-2674 or http://www.rqhealth.ca/departments/palliative-care.

For more information, please call 1-(306)766-5922 or email: advancecare@rqhealth.ca.
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 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 21 to 27) 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
Story and photo courtesy Fraser Health Region

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Section 2 - Talking

Talking about your medical goals of care
What kind of medical care do you want? You will need to decide what level of medical interventions you would like, including CPR and no CPR

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 you want to happen if your heart or breathing suddenly stopped?
- What would it take for you to want to be resuscitated?
- What medical conditions would make you want to change your goals of medical care from prolonging your life, to focusing on comfort measures only? 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 measures only 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.
- As your illness advances, do you have any emotional/personal goals you want to complete i.e. to make amends.
- 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.

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Section 2 - Talking  
Proxy: Choosing your health care decision maker

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 if you cannot speak for yourself. This person is called a Proxy.

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 of crisis.

If you do not have a 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 below to speak for you, or you have no relatives and want a friend to speak for you, you should appoint a Proxy.

Appointing a Proxy must be in writing, signed and dated by you. You do not need a lawyer to appoint a Proxy.

When you can no longer able to speak for yourself, 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 writing, signed and dated.
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 proxy or nearest relative 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.

Discussing his medical care in advance, with both his family and doctor, made his final hours less traumatic. Story and photo courtesy of Fraser Health Region.
Section 3 - Acting...continued

- Talk about what makes life meaningful for you.
- 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 Proxy/nearest relative 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.

For more information, please call 1-(306)766-5922 or email: advancecare@rqhealth.ca.
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.
- Your 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.

My Life Capsule
This capsule is a way to make your medical information and advance care plan available to medical personnel when an emergency occurs in your home. It looks like an empty pill bottle. It has a form for your medical information and you can put a copy of your advance care plan in it as well. The My Life Capsule goes in your fridge and the magnet goes on the front of the fridge.

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.

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“It’s okay Dad, I get it.”

Spencer was diagnosed with a chronic disease in his 20’s. He was a nice young man from a good family. He was raised by his grandmother. He had two young children and a fiancée. He also had a whole lot of denial about his disease and he was not taking his medication properly. Over time, as he became more susceptible to diseases he would end up in the Intensive Care Unit (ICU). These hospital stays would take their toll on his body but he would always recover and leave the ICU, a little weaker and thinner. Most of the time, he would leave the hospital against medical advice. This went on for years. His fiancée took their children and left him. Spencer became so weak that he moved in with his grandmother so she could care for him.

Each time he had an admission to hospital, the doctors caring for him would discuss the fact that he could not be cured and he would never regain his previous quality of life. The doctors would ask him if he wanted to “change his code status”, to be a “No CPR”. As his health care professional, he and I would talk about his pain, about yet another admission to the ICU and the invasiveness of it all. He told me he always felt as if he was being pressured to die. He told me that he could not do that to his grandmother or his kids, to just leave them.

We discussed doing an advanced directive in part because Spencer wanted to designate his grandmother as his proxy. However, given the legislation in the province, his fiancée felt she should be his decision maker whenever Spencer was incapacitated. The health care team would sift through old notes, discuss current relationships and contact the hospital’s legal team who would advise that his next of kin was his mother. Spencer did not want his mother to act on his behalf so he designated his grandmother as his decision maker. At first, Spencer did not want to complete a My Voice booklet. He felt that he would recover and return home. I left the package with him to read. We revisited the topic regularly.

He returned to the ICU after his kidney’s failed. This was his longest stay in the ICU. He went down to 65 pounds and needed dialysis. It was clear from his doctors that he would not leave the hospital. An emergency meeting was held as Spencer had begun to bleed uncontrollably and lose consciousness. The family, including his grandmother held fast to the belief Spencer would recover, even if he needed the ICU again. Spencer did not seem so sure.

A few days passed and he asked to meet with me and his spiritual advisor, privately. He had been reading the My Voice booklet. The three of us discussed the document, and Spencer felt that he should complete it now. He did not want to return to the ICU but felt that even his proxy would choose that for him if he lost capacity. He also wanted to end dialysis and stop the tube feeds. In short he had come to his end. He was clear in the fact that he did not want to disappoint his family. He was frightened to discuss this with his grandmother and his kids. He was worried that they would not understand what he had gone through in the ICU last time and what he was feeling now. We met as a group and discussed his wishes. It was a very long conversation. At first his family was upset that he had made these choices. The document was passed around the group for two days. Copies were given to his Grandmother as his proxy to show his family who could not attend the meetings.

Spencer was unable to speak for himself a few days later. He was no longer communicating. He would stare off into the distance. In his culture, it is believed that a person’s ancestors visit them at life’s end.

I was there when Spencer passed. His daughter, barely a teen asked her great-grandmother why the doctors’ were not helping her Dad anymore. Her great grandmother took out a folded, well-worn My Voice booklet. It was the one designating what Spencer wanted for his care at the end of his life. She took her great grandbaby onto her lap and read the page out loud to the group at Spencer’s bedside, and then she asked me to explain to her great granddaughter that this is what her Dad wanted, this was his dignity. I did not speak a word.

His daughter simply took her Dad’s hand in her own, and said “It’s ok Dad, I get it.”

Shared with the Advance Care Planning Program, Regina Qu’Appelle Health Region by a health care professional, 2012
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. What is the health care providers legal obligations?

There is provincial legislation that directs health care providers to follow Advance Care Plans. An Advance Care Plan is your voice when you cannot speak for yourself. Health care professionals will do their best to follow advance care plans where possible.

It is important to understand that the choices you make now for future health care may not be medically indicated if you become very ill. Your doctor will consider your wishes, but is not ethically obliged to order or perform treatments for you that are not medically indicated.

3. 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(s), this situation is less likely to occur. However, if it does, you should consider choosing someone else to speak for you. This would involve appointing someone you trust who will honour your wishes 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.

4. What happens in an emergency when my substitute decision maker (Proxy, Personal Guardian, nearest relative) 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 this is not what you wanted.

5. 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.

For more information, please call 1-(306)766-5922 or email: advancecare@rqhealth.ca.
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 procedures 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 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.

Function is a person’s ability to perform everyday activities, such as talking, thinking, breathing, eating, seeing, hearing and getting around physically.

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.

For more information, please call 1-(306)766-5922 or email: advancecare@rqhealth.ca.
Word List continued

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

**Health care professional/team member** describes a person licensed, certified, or registered in Saskatchewan to provide health care. For example: a doctor, nurse practitioner, 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.

**Medical Interventions** refers to medications, treatments and procedures used to treat a person’s medical condition and symptoms.

**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.

**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.

For more information, please call 1-(306)766-5922 or email: advancecare@rqhealth.ca.
Completing Your own Advance Care Plan (living will).

- You may use the following form or any other template for an advance care plan to record your health care wishes. It is legal in Saskatchewan, as long as it is signed and dated by you.
- If you are using the following form, you can write in any specific information pertaining to your situation. Be sure to initial any information that you write in.
- Bring a copy of your completed form with you when you have a medical appointment or attend a health care facility.
- On admission to a Regina Qu’Appelle Health Region (RQHR) facility, we routinely ask everyone, if they have an advance care plan or proxy.
- In order to ensure that we understand your wishes, a RQHR Health Care Professional (HCP) will review your wishes and help you summarize your wishes on a one page RQHR order form.
- There may be a time in your life that you have a major mental health illness. Your Advance Care Plan may not apply in this situation. It is still important to have these discussions and name a Proxy.
- If you decide not to do an advance care plan in writing at this time, we recommend that you appoint a Proxy in writing by completing page 22.
My Advance Care Plan

This section is designed to be separated from the rest of the document, photocopied, and given to your doctor, Proxy, nearest relative, and any other health or legal professionals. 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:

<table>
<thead>
<tr>
<th>Name</th>
<th>Relationship to me</th>
<th>Phone Number</th>
</tr>
</thead>
<tbody>
<tr>
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</tbody>
</table>
Appointing a Proxy

In Saskatchewan The Health Care Directives and Substitute Health Care Decision Makers Act allows you to legally appoint a person of your choice to be your health care decision maker when you no longer are able to speak for yourself. This person is called a PROXY.

The person you choose as your proxy must be over 18 years of age. Designating a PROXY must be in writing, signed and dated by you. Your PROXY must be someone you trust to,

- be able to respect your opinions and values
- be willing and able to explain your wishes for your medical care

Your health care team members are by law required to approach your nearest relatives in a specified order if you have not named a PROXY. Sometimes, this individual may not be who you would want. Naming a PROXY allows you to choose who makes decisions for you.

WHO I WANT TO SPEAK FOR ME WHEN I CAN’T

I _____________________ having attained the age of 16, have discussed my wishes for future health care with the person (s) named below and select this person(s) 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: _________________________________________________________________________

Email: ___________________________________________________________________________

YOU MAY ALSO ADD THE NAME OF ANOTHER TRUSTED RELATIVE OR FRIEND AS AN ALTERTAN E IF YOUR CHOSEN PROXY IS UNABLE TO SPEAK ON YOUR BEHALF AT ANY TIME (OPTIONAL).

Name: ________________________________ Relationship: _______________________

Home Phone: ___________________________ Cell Phone: _______________________ 

Work Phone: ___________________________

Address: _____________________________________________________________________

Email: _________________________________________________________________________

_________________________       ________________________________
PRINT YOUR NAME HERE                           YOUR SIGNATURE HERE

_____________________________            _______________________________
DATE                                         HOSPITAL SERVICES NUMBER (Provincial Hospitalization #)
What I Want Regarding My Goals of Care
Considering Life Support with Medical Interventions

Guidance
In case of a serious illness or injury, there are a number of medical interventions which can prolong life and delay the moment of death. These include ventilation, tube feeding, intravenous fluids (IV). See page 18 for the Word List. Comfort care is provided in all the options. 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 You/Proxy and your health care professionals.
- 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.

Directions: Choose and initial 1 of the 4 goals of care that you want.

Goal is to extend life: Full treatment
I want to have life support with all necessary medical interventions, such as CPR, a ventilator (breathing machine), feeding tube, intravenous fluids, or kidney dialysis. This includes all resuscitative measures as medically necessary. Includes intensive care.

Goal is to extend life for reversible conditions: Full treatment Conditional
I want a trial period of life support with all necessary medical interventions. This includes all the medical care listed in Full treatment, including CPR and intensive care. If the trial period does not help me recover to an acceptable state of health known to myself/Proxy, then I want these interventions stopped to allow natural death to occur. The trial period will be defined through discussions by myself/Proxy and the Health Care Team. Decision Maker) and the health care team.

Goal is conservative management of medical condition.
Limited Additional Interventions:
I want conservative management of my medical condition. I do not want CPR or a ventilator (breathing machine). Use medical interventions to relieve my pain and suffering, such as medication, positioning, wound care, antibiotics, and IV fluids.

Goal is comfort and symptom control at the end of life:
Comfort Measures Only
I do not want CPR, a ventilator (breathing machine), or other medical interventions, such as a feeding tube, IV fluids or kidney dialysis. If any of these interventions have been started, I want them stopped to allow natural death to occur. This does not include an intensive care setting.

__________________________  __________________________  ____________
Signature  Print Name  Date

Saskatchewan Health Authority
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.**

Directions: Considering the goal of care that you have selected on page 23, choose and initial the statement below that you want.

- [ ] I want cardiopulmonary resuscitation (CPR) attempted
  - Initial

  OR

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

  _______________________________ ___________________________ __________
  Signature Print Name Date

Saskatchewan Health Authority
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 healthcare providers have a copy of your most recent wishes.

**Directions:** If you would like to consider these options, complete the section below. Choose the statement(s) below that you want. Initial in the box beside your choice.

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:**

<table>
<thead>
<tr>
<th>Option</th>
<th>Initial</th>
</tr>
</thead>
<tbody>
<tr>
<td>I place no limitation on which of <strong>my organs or tissues</strong> may be used, should I be deemed a suitable donor.</td>
<td></td>
</tr>
<tr>
<td>I limit donation to only the <strong>following organs</strong>, should I be deemed a suitable organ donor.</td>
<td></td>
</tr>
<tr>
<td>__ Heart</td>
<td></td>
</tr>
<tr>
<td>__ Lungs</td>
<td></td>
</tr>
<tr>
<td>__ Liver</td>
<td></td>
</tr>
<tr>
<td>__ Kidneys</td>
<td></td>
</tr>
<tr>
<td>__ Pancreas</td>
<td></td>
</tr>
<tr>
<td>__ Small Bowel</td>
<td></td>
</tr>
<tr>
<td>I limit donation to only the <strong>following tissues</strong>, should I be deemed a suitable tissue donor.</td>
<td></td>
</tr>
<tr>
<td>__ Heart for Valves</td>
<td></td>
</tr>
<tr>
<td>__ Eyes</td>
<td></td>
</tr>
<tr>
<td>__ Pericardium</td>
<td></td>
</tr>
<tr>
<td>__ Tendons/Ligaments</td>
<td></td>
</tr>
<tr>
<td>__ Pancreas</td>
<td></td>
</tr>
<tr>
<td>__ Bones</td>
<td></td>
</tr>
<tr>
<td>__ Other</td>
<td></td>
</tr>
<tr>
<td>I do not wish to take part in organ or tissue donation.</td>
<td></td>
</tr>
<tr>
<td>I wish to donate my body to the body bequeathal program. (For information contact 966-4075 or <a href="https://medicine.usask.ca/department/schools-divisions/biomed/body-bequeathal-program/">https://medicine.usask.ca/department/schools-divisions/biomed/body-bequeathal-program/</a></td>
<td></td>
</tr>
</tbody>
</table>

___________________________                                ___________________  
Signature                                                     Print Name
Additional Directions: If you have any additional specific directions that are important to you, provide details here (e.g. intubation, feeding tubes, tracheotomy, dialysis, antibiotics, specific spiritual/cultural rituals etc.)

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 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 (optional)

______________________________  ______________________________
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. You can note any information you would like to share with your loved ones. The questions below are a guide. 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”.

What do I value most in terms of my mental and physical health? For example, living independently, able to recognize others, and being able to communicate with others.

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, what would I want and/or not want to make the end more peaceful for me. 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.
CEAC 1042
September 2019
Regina Area

http://www.rqhealth.ca/quality-transformation/advance-care-planning
(306) 766-5922