

My Voice

*Planning in advance for
healthcare choices*



Adapted, with permission, from the Fraser Health Authority in British Columbia.
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www.fraserhealth.ca

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This publication is intended for information purposes only and should not be relied on as providing specific healthcare or other professional advice.

If you have questions about advance care directives, please email info@saskcancer.ca or call the Allan Blair Cancer Centre at 306-766-2213 or the Saskatoon Cancer Centre at 306-655-2662 to speak with a member of your healthcare team.

Foreword

Planning for the future is important, especially when it comes to your health. Putting in place an advance care plan can give you peace of mind knowing that those who may have to make your healthcare decisions understand your treatment choices if you are unable to make or communicate your decisions at the time.

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 who are a necessary part of your future planning
- How to inform your doctor and nearest relatives of your wishes

The workbook also contains a template that you can use to complete an advance care plan. Other templates are available online, although it may be preferable to use a Saskatchewan-based site as terminology may vary between provinces.

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.

If you have any questions or need more information about advance care planning please email info@saskcancer.ca or call to speak with a member of your healthcare team:

- **Allan Blair Cancer Centre: 306-766-2213**
- **Saskatoon Cancer Centre: 306-655-2662**



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Advance Care Plan

An advance care plan (sometimes called a living will or advance directive) is the legal set of directions for your medical care should you become 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. 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 healthcare providers and others who may have to make decisions for you
- Learning about and choosing from the options available for your healthcare in a variety of situations
- Ensuring that you receive medical care that supports your values, faith or traditions
- 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 healthcare team members who may not know you.

When Should I Complete My Advance Care Plan?

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 healthcare 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.

Completing My Advance Care Plan

Advance care planning for healthcare 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 or communicate your own medical decisions

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 this, 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?

Thinking About Medical Interventions

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 crisis occurs and you can no longer speak for yourself.

This is referred to as medical interventions. Medical interventions include 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 healthcare 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 per cent of cases and can cause additional suffering.

In patients with advanced illness, one to four per cent 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.

Thinking About 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 lifesaving 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
- Result in a prolonged life not consistent with your desired quality of life

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 antibiotics have side effects that can be uncomfortable.

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

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 and the type of infection.

Thinking About Treatments

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 cancer, heart failure, COPD, and kidney failure to name a few. Care is directed toward symptom management, (i.e. pain, nausea, shortness of breath) and may include chemotherapy, radiation treatment 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 previously described in this document.

Palliative care can be provided to persons in hospitals, hospice, nursing homes or at home. Palliative care can be organized through a patient's oncologist or family doctor, however, when symptoms are difficult to control, more specialized services may be needed. The Saskatchewan Cancer Agency offers **Symptom Management Palliative Care Outpatient Clinics** (SMPCOC) where a team of specialists can assist with symptom management. A referral can be obtained from the person's care team or by contacting the SMPCOC team directly through the cancer centre.

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), naso-gastric (NG) tube, 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.

Comfort Measures Only

Comfort care provides a person with maximum comfort and control of symptoms common at the end of life (pain, confusion, anxiety, 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.

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 – you may need to talk with your healthcare team or family doctor to get the answers you need.

If you have collected some questions for your healthcare 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 or traditions.

It may be 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 at the back of this book and make some notes about what is important to you. By working through the process, you will end up with a much clearer idea of the type of future healthcare you prefer and the individuals you need to tell.

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

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 issues do you fear might affect you in the future if your disease should progress? For example: immobility, inability to adequately eat, increasing pain.
 - What frightens you most about medical treatment? Have you discussed these concerns with your healthcare team?
 - What will help you live your life well now? What about in the future?
 - 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.
 - 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?
 - 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? For example: to make amends or attend to legal matters such as completing a last will and testament.
 - 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, prayers at my bedside, 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.



Talking About Your Proxy

Choosing Your Healthcare 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 healthcare 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
- Responsible and able to respect your opinions and values
- Willing and able to explain your wishes for your medical care and end-of-life care to healthcare team members
- 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 healthcare decisions for you when you can no longer to speak for yourself

The legal order in which individuals will be approached to make healthcare decisions for you is:

- The proxy named by you in writing, signed and dated.
- A personal guardian appointed for you by the Court of Queen's Bench with power to make healthcare decisions. An advance care plan would give guidance to your personal guardian in respect of your healthcare choices.

- The person first described in the following clauses who is willing, available and has the capacity to make a healthcare 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)

If you do not want the relative who is listed first in the Act 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.



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 the end of life.

Remember 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 document aims to help your discussions with those closest to you.

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.
- Talk about what makes life meaningful for you.

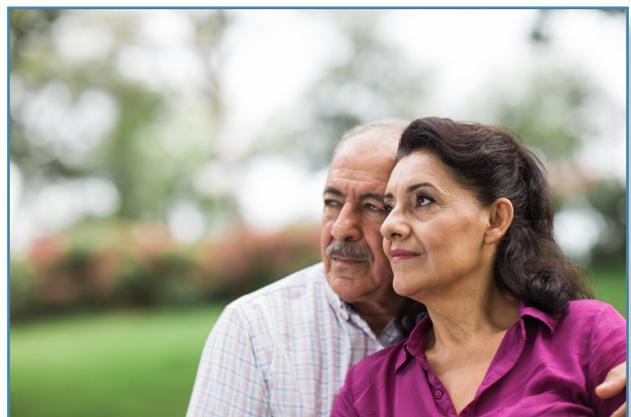
- Talk about the difference between prolonging life and allowing natural death to occur. Indicate when you might want the transition to happen for you.
- Talk about your goals for medical treatment:
 - How bad would the situation need to be for you to say, “don’t keep me alive in that state.”
 - Describe 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?
- Understand that the person you choose to be your proxy may refuse, even if he or she is the person closest to you. This is not an unusual reaction; they may prefer to be a ‘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.
- 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 lawyer, minister or priest, or a social worker if you reside in a nursing home, if you choose
 - 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.
 - Take copies with you when you travel and give a copy to your 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.



Questions and Answers

1. **Is my advance care plan legal?**

Yes. A written advance care plan gives clear direction regarding your healthcare wishes. In Saskatchewan, advance care plans are legal documents and must be signed and dated. They carry considerable weight and healthcare 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 healthcare providers legal obligations?**

There is provincial legislation that directs healthcare providers to follow advance care plans. An advance care plan is your voice when you cannot speak for yourself. Healthcare 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 healthcare 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 healthcare wishes...what now?**

If you have discussed your healthcare 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 determined 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.



Definitions

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.

Capacity means the ability to:

- Understand information relevant to a healthcare decision respecting a proposed treatment
- Appreciate the reasonably foreseeable consequences of making or not making a health care decision respecting a proposed treatment, and
- To communicate a healthcare decision on a proposed treatment.

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.

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 healthcare 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, e.g. spending more time with family and friends.

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

Healthcare professional/team member describes a person licensed, certified, or registered in Saskatchewan to provide healthcare. 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. Healthcare 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*.

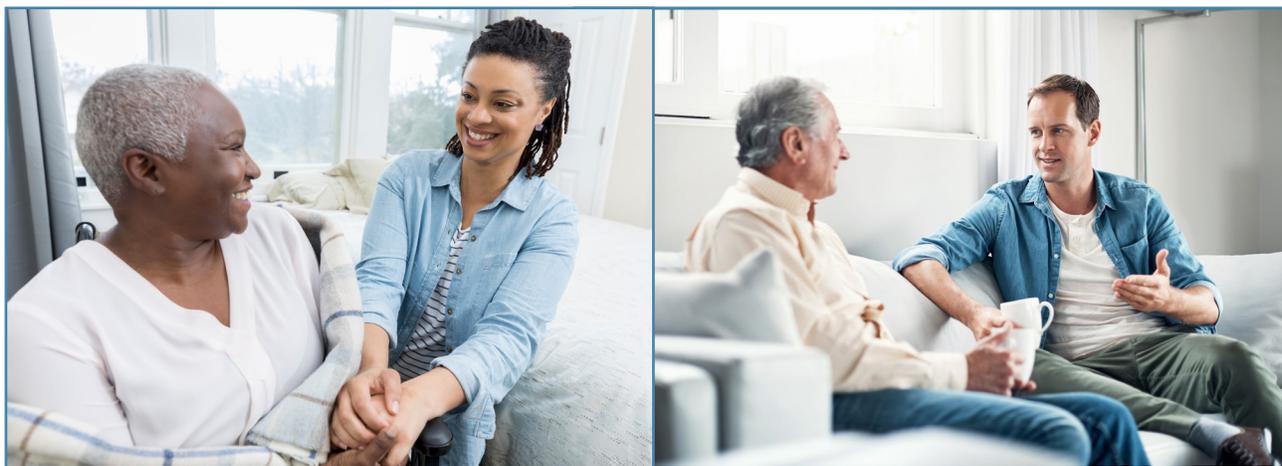
Proxy means a person appointed in a directive to make healthcare decisions for the person making the directive.

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.



Completing Your Own Advance Care Plan

You may use the forms included in this document or any other template for an advance care plan to record your healthcare wishes. It is legal in Saskatchewan, as long as it is signed and dated by you. Read each page carefully, initial, sign and witness where indicated.

- If you are using the following forms, 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 forms with you when you have a medical appointment with your oncologist or a health team member, or attend a healthcare facility.
- Keep your completed forms in a safe and accessible place in your home (not a wall safe or safety deposit box at your bank). Some people place them on their fridge, or in a coloured folder on the fridge (e.g., in a plastic sleeve).

- Take the time to discuss your advance care planning wishes with your trusted family or friends to ensure they have a copy or know where your completed forms are kept.

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 the form included in this document.



A Doctor's Story

Mr. Jones was diagnosed with advanced lung cancer at 63 years old; he was previously an active and healthy man. Having recently retired, he was looking forward to traveling and spending time with family.

When I met with him and his wife at the new patient consult, I advised them that we may not be able to cure his cancer, but could hope to control it for as long as possible.

He and his wife agreed to try the treatment, with Mr. Jones expressing he would pursue treatment only if it left him with the energy and ability to spend time with his family.

Mr. Jones began treatment, which he tolerated well, and everyone remained hopeful.

Unfortunately, seven months later, Mr. Jones' cancer progressed. During a follow-up visit, Mr. Jones stated he was feeling more short of breath and more fatigued.

We talked about other treatment options and the risks and benefits of each, as well as what to expect should he choose to not pursue any further treatment. We discussed Mr. Jones' goals of care and his strong desire to focus on quality of life so he could spend valuable time with his family.

We discussed what medical interventions Mr. Jones would accept as the cancer progressed should he need more support with his breathing. Mr. Jones decided against using a breathing machine (ventilator) and CPR.

His wife was supportive, however, he also decided to write his wishes in an advance care plan. He knew this would relieve his wife of trying to make decisions in the event of a medical crisis.

Mr. Jones accepted a referral to the Palliative Home Care team and decided against further active cancer treatment.

Two months later while visiting his son out of town, Mr. Jones went to the hospital with difficulty breathing. The doctor on duty advised that without a ventilator Mr. Jones would not survive and asked him what he wanted them to do.

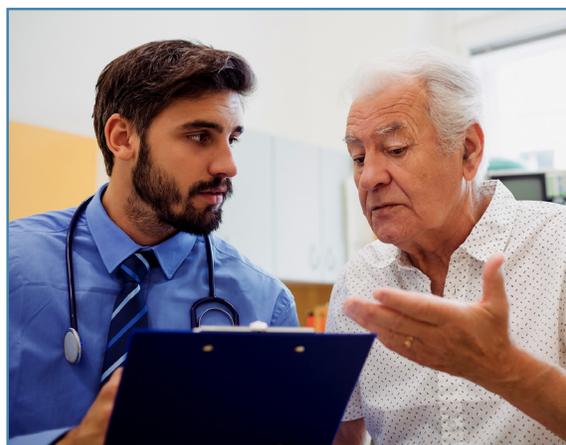
Mr. Jones explained he only wanted to be kept comfortable and did not want assistance from any machines.

The doctor, concerned if a lack of oxygen was affecting his judgment, asked Mrs. Jones. She provided the medical staff with her husband's carefully considered 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 in medical distress. The medical staff respected his choices and he died comfortably without the use of any machines.

While it was very difficult for Mrs. Jones and their son, they knew these were his wishes. Having discussed his medical care and wishes in advance, with both his family and doctor, made his final hours more peaceful.

Adapted from a story provided by Fraser Health Authority



My Advance Care Plan

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 healthcare 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 healthcare 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 healthcare 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: (____) _____ Email: _____

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)

Name: _____ Relationship: _____

Home phone: (____) _____ Cell phone: (____) _____

Work phone: (____) _____ Email: _____

Address: _____

Your name (printed)

Your name (signature)

Today's date

Health Card #

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). 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 healthcare 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 healthcare providers have a copy of your most recent wishes.

Directons

Choose and initial **one** of the four goals of care that you want.

Initial

Goal is to extend life: *Full treatment*

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

Initial

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 me/proxy, then I want these interventions stopped to allow natural death to occur. The trial period will be defined through discussions by me/proxy and the healthcare team.

Initial

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.

Initial

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

My Goals of Care

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 per cent 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 healthcare providers have a copy of your most recent wishes.

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

My Goals of Care

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 who dies in this manner may 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. I understand that age and cause of death may limit donation.

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

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

Initial

I limit donation to only the following organs, should I be deemed a suitable organ donor:
___Heart ___Lungs ___Liver ___Kidneys ___Pancreas ___Small bowel

Initial

I limit donation to only the following tissues, should I be deemed a suitable tissue donor:
___Heart for valves ___Eyes ___Pericardium ___Tendons/ligaments

Initial

___Pancreas ___Bones ___Skin ___Other

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

Initial

I wish to donate my body to the body bequeathal program. (For information contact 966-4075 or www.medicine.usask.ca/acb/department/bodybequeathal-program/forms/Body%20Bequeathal%20Form.pdf)

Initial

Signature

Print name

Date

Signing, Witnessing and Dating

Directions

If you have any additional 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 healthcare 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 cannot be a witness nor can your proxy's spouse.

I, _____ am thinking clearly, I understand
print name

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)

Your name printed

Witness's name printed (optional)

Date

Date

Thoughts I Wish to Share

Guidance

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 “practicing my faith”, or “my dog/cat”.

This is what 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, this is what I 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”.

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”.

