
MY VOICE

Planning in Advance for Future Healthcare Choices



Health Care Directives

For more information please call 1-888-425-1111

Adapted, with permission, from:

Regina Qu'Appelle Health Region
2180-23rd Ave
Regina SK S4S 0A5
306-766-5922
www.rghealth.ca

Fraser Health Authority
10334-152nd A St
Surrey BC V3R 7P8
www.fraserhealth.ca

Cypress Health Region
429-4th Ave NE
Swift Current SK S9H 2J9
www.cypresshealth.ca

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

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FOREWARD

We plan in advance for all kinds of events such as birthday parties, anniversary celebrations and vacations. We plan for our education and we plan for our retirement. In spite of the fact that planning in advance is something we do every day, we often don't plan in advance for our healthcare.

Planning for future healthcare 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 healthcare – ahead of time.

The workbook contains useful information on how to make the decisions 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.

The workbook also contains a **Health Care Directive** template that you can use to complete a **Health Care Directive**.

Completing a Health Care Directive is legal in Saskatchewan. All Saskatchewan residents who are **16 and older** can complete a **Health Care Directive** and can change or revoke the plan at any time if mentally capable of doing so.

INTRODUCTIONS

WHAT IS A HEALTH CARE DIRECTIVE?

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

A **Health Care Directive** (sometimes called a living will, advance directive or advanced care plan) is the set of instructions and guidelines you develop for your medical care in the event 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. For example, if you were unconscious, had suffered a severe stroke or suffered a progressive mental condition like Alzheimer's disease that caused you to lose your ability to understand and make decisions.

Preparing a written Health Care Directive is always voluntary.

See page 19 of this booklet for more answers to questions you may have.

WHAT ARE THE BENEFITS OF HAVING A HEALTH CARE DIRECTIVE?

The benefits of preparing a Health Care Directive 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;
- 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;
- Learning about and choosing from the options available for your future healthcare in a variety of situations;
- Identifying those people and activities that improve your quality of life;
- Providing clear instructions for healthcare providers and others who may have to make decisions for you; and/or
- Reducing the emotional distress on those closest to you.

You may feel that you prefer to communicate your wishes verbally rather than in writing; however, a written plan helps people accurately remember what you want and makes it easier for you, your family or a friend to communicate your wishes to healthcare providers who may not know you.

WHEN SHOULD I PREPARE MY HEALTH CARE DIRECTIVE?

As soon as you can.

Making the decision to complete a Health Care Directive 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 a Health Care Directive in Saskatchewan. You must also 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.

WHAT DO I DO WITH MY HEALTH CARE DIRECTIVE?

You will give a copy to your Proxy (named representative) if you have one. You can also give it to your partner, children and other relatives, or a trusted friend. It is important that you or your representative bring your Health Care Directive to the hospital with you.

WHAT IS THE PROCESS OF COMPLETING MY HEALTH CARE DIRECTIVE?

Health Care Directive planning for healthcare choices is a process of thinking and talking about complex and sensitive issues, then sharing and acting:

Thinking

Reflecting and considering what makes life meaningful to you

Talking

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

Sharing

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

Acting

Putting your **Health Care Directive** in writing.

A Gift for Your Children

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

Within a few years, she was the victim of Alzheimer’s disease. My mother was unable to understand her healthcare or make any decisions because of her impaired judgment and the complexity of her situation. I became her advocate and relied on the direction she had given me earlier.



My first experience in decision-making occurred when the doctor discussed the “Do Not Resuscitate” issue with me. He asked, “We need to know what your mother’s choice would be if her heart should stop”. Mom had prepared me for this – the answer was not to resuscitate. Few illnesses along the way required much decision-making,

which was fortunate for us. But I do think I would have known what she wanted and acted accordingly.

When my mother died, amidst the sadness, there was peace. Peace in knowing that she had said many times to me, “no medical intervention when there’s nothing that can be done for me”. I am grateful that I didn’t have to struggle with decisions during that time.

Story and photo courtesy of Fraser Health Region

SECTION 1 – THINKING ABOUT MEDICAL INTERVENTIONS

Health Care Directive planning starts off with thinking about what you value in life. Your previous experiences shape who you are, what you believe and what you value. Faith, family traditions, jobs and friends play a part in your life and affect you deeply. Take a moment to reflect on 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 roles does spirituality play in your life?
- How important is faith and 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?



THINKING ABOUT MEDICAL INTERVENTIONS, CONTINUED...

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 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 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)

Cardiopulmonary Resuscitation (CPR) refers to medical procedures used to restart a patient's heart and breathing when the heart and/or lungs stop working unexpectedly. CPR can range from mouth-to-mouth breathing and pumping 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, 1-4% 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.

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

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

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

ANTIBIOTICS

Antibiotics are drugs used to treat infections caused by bacteria or other organisms. Antibiotics kill bacteria to prevent them 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, some infections go away on their own and may not need to be treated with antibiotics. In cases where antibiotics are needed, there are risks associated with their use. For example, overuse 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.

COMFORT CARE

Comfort care, also called palliative care, concentrates on providing the person with a comfortable and dignified death without the use of medical treatments to prolong life. When comfort becomes the main medical goal, the care includes relief of your pain and other unpleasant symptoms, as well as caring support of you and your family.

This type of treatment also involves following your wishes and those of your loved ones, as well as respectful attention to your body, mind and spirit. Comfort care can take place in your home (and may be supported by a palliative care team), nursing homes, 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 “nasogastric” or “NG” tube). The other is by a tube which goes through the abdominal wall into 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 or 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, chronic obstructive pulmonary disease (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, 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.

SECTION 2 – TALKING

DECISION MAKING

Some people think and work out their answers alone, and others find discussing the question 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 or family doctor.

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 at least read the sample Health Care Directive Form at the back of this book or perhaps fill 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 interacted well with her family and ably 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" the 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, story and photo courtesy of Fraser Health Region



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 to 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 spiritual needs.

- As your illness advances, do you have any emotional/personal goals you want to complete? For example: 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 bedside, 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...



PROXY: CHOOSING YOUR HEALTH CARE DECISION MAKER

The Health Care Directives and Substitute Health Care Decision Makers Act, 1997 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 18 years of age or over. Your Proxy must be someone you trust to:

- 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, 1997* 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 are 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, 1997* 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. A Health Care Directive 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. The eldest is preferred in each section:
 - a. The spouse, or person whom the person requiring treatment cohabits and 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 – SHARING

DISCUSSING YOUR CHOICES

You will want to discuss your desire to complete a Health Care Directive 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 Health Care Directives is that you are able to 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 conversations can involve complex and sensitive issues, they can take several sessions. Talking about these issues may not be easy; you may face resistance, even denial, because those closest to you may be uncomfortable talking about living at the end of life.

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

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

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

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

- 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 Health Care Directive 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.



There is a lot to talk about. Remember, although it is difficult to know the details of any future illness you may 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't. Don't try to do it all at once and give those closest to you time to think it over if they wish. Many people need time to process this much information. Allowing thinking time is especially important for the person you have asked to act as your proxy.

SECTION 4 – ACTING

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

Give copies to:

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

In addition:

- Also, tell your doctor(s), including your family doctor and specialists who you see regularly, that you have completed your Health Care Directive. You may also 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.

Jean's Story

Jean was only 35 when she was diagnosed with a severe and chronic illness. Because of this illness, Jean's family could not care for her at home. She went to live in a nursing home where she stayed for 5 years, receiving excellent care. Unfortunately, Jean's marriage came to an end during her stay in the nursing home and her husband moved to another province with her only child. Jean was devastated, but she leaned to cope and enjoyed the regular visits of her younger brother.

As Jean's condition worsened, she started to worry more and more. "What if I die alone? What if I have a hard time breathing and can't let anyone know how I'm feeling? What if they want to take me to the hospital and I don't want to go? A nurse offered to sit with Jean and her brother as they talked about Jean's worries and wishes. Jean asked her brother to write her wishes down.

As a result of several conversations, Jean was able to make a written advance care plan and share it with her brother and those who cared for her in the nursing home.

Jean spent her last few days in the nursing home, surrounded by caring nursing staff and her devoted brother. Her advance care plan had let everyone know what she wanted, and every wish was honoured. She was not left alone during her final hours and her brother was able to communicate a final message to Jean's teenaged child. A week after Jean died; her brother came to the nursing home to thank the staff for all the loving care they had given Jean over the years. He held tightly to Jean's Advance Care Plan and told them how powerful it was for him.

"This", he said, "is Jean. Her Advance Care Plan has been my strength. I've had to deal with a lot over the past few weeks, but this plan reminds me that I did everything Jean wanted. I'm keeping it forever."

Story courtesy of Fraser Health Region

ANSWERS TO OTHER QUESTIONS YOU MAY HAVE

Is My Health Care Directive Legal?

Yes. A written Health Care Directive gives clear direction regarding your healthcare wishes. In Saskatchewan, Health Care Directives are legal documents and must be written and signed. 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, 1997*).

Are healthcare providers legally obliged to follow Health Care Directives?

Yes. There is provincial legislation that directs healthcare providers to follow Health Care Directives. A Health Care Directive is your voice when you cannot speak for yourself. Health care professionals will do their best to follow 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.

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

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

What if I leave the Province of Saskatchewan? Will other provinces in Canada or other countries honour my Health Care Directive?

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

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, this situation is unlikely to occur. However, if it does, you should consider choosing someone to speak for you when you are unable to. In Saskatchewan, this would involve designating someone as your Proxy. In this case, Saskatchewan law requires that this legally-appointed substitute decision-maker follow your wishes and others cannot have your instructions changed.

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

A Doctor's Story

I had a patient with a serious lung disease that made him very short of breath and immobile. 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

WORD LIST

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

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

Health Care Directives (sometimes called living wills or advance care plans) 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 a Health Care Directive 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 patient's heart and breathing when the heart and/or lungs stop working unexpectedly. CPR can range from mouth-to-mouth breathing and pumping on the chest, to electric shocks that restart the heart and machines that breathe for the individual.

Capacity means the ability:

- (a) to understand information relevant to a healthcare decision respecting a proposed treatment;
- (b) to appreciate the reasonably foreseeable consequences of making or not making a health care decision respecting a proposed treatment; and
- (c) 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 procedure that cleans your blood when your kidneys can no longer do so.

End-of-life 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. For example: spending more time with family and friends.

Health Care Decision means a consent, refusal of consent or withdrawal of consent to treatment.

Healthcare provider describes a person licensed, certified, or registered in Saskatchewan to provide healthcare. For example a doctor, nurse, social worker, or physiotherapist, etc.

Informed consent refers to the permission patients give to healthcare providers that allow medical investigation and/or treatments. Healthcare providers give detailed explanations of the investigations/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, 1997*.

Palliative Care is the active total care of patients whose disease is not responsive to curative treatments. Control of pain, other symptoms, and of psychological, social, and spiritual problems is paramount. The goal of palliative care is achievement of the best possible quality of life for patients and their families.

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 with 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 HEALTH CARE DIRECTIVE

- You may use the following form or any other template for a health care directive 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 the Five Hills Health Region (FHHR) facility, we routinely ask everyone if they have a Health Care Directive or Proxy.
- In order to ensure that we understand your wishes, a FHHR Health Care professional will review your wishes and help you summarize your wishes on a one page FHHR order form.
- There may be a time in your life that you have a major mental health illness. Your Health Care Directive may not apply in this situation. It is still important to have these discussions and name a Proxy.
- If you decide not to do a Health Care Directive in writing at this time, we recommend that you appoint a Proxy in writing by completing the Appointing a Proxy form in this booklet.



HEALTH CARE DIRECTIVE – GUIDANCE



This section is designed to be separated from the rest of the document, photocopied and given to your doctor, Proxy, nearest relative and/or trusted friend.

There are 6 parts for you to complete:

- Your contact information and contact information of Health Care Directive holders
- Contact information for your Proxy
- Your wishes for cardiopulmonary resuscitation treatment
- Your wishes for life support and/or medical interventions
- Your wishes for organ and/or tissue donation
- Your signed declaration

There is 1 additional part you may wish to complete:

- Your thoughts and feelings you would like to pass on to those you leave behind.

Please note: if you are admitted to a Five Hills Health Region facility, this Health Care Directive will be reviewed with you, with a view to completing a “Health Care Directive Goals of Care” order.



My Health Care Directive

Respect

This section is designed to be separated from the rest of the document, photocopied, and given to your Proxy, nearest relative, any other health or legal professionals. Please read each page carefully, initial, sign, and witness where indicated.

Trust

This is the Health Care Directive of:

My first name: _____ Middle initial(s) _____

Last name: _____

My date of birth: _____

My Saskatchewan Hospitalization #: _____

My address: _____

My phone number: _____

My cell phone number: _____

My email address: _____

Caring

The following people have copies of this Health Care Directive:

Name	Relationship to Me	Phone Number
		()
		()
		()
		()
		()
		()

APPOINTING A PROXY

In Saskatchewan, *The Health Care Directives and Substitute Health Care Decision Makers Act, 1997* 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 18 years of age or over. 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, _____, have discussed my wishes for future health care with the person named below and select this person to be my Proxy and speak for me if I am unable to communicate for myself or am unable to understand what the care providers are saying to me.

Name: _____ Relationship: _____

Telephone: _____ Cell phone: _____

Address: _____

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).

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

Name: _____ Relationship: _____

Telephone: _____ Cell phone: _____

Address: _____

Email address: _____

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 22 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.

WHAT I WANT

Considering Life Support with Medical Interventions

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.

MY HEALTH CARE DIRECTIVE

Directions: Choose and initial **1 of the 4 goals of care** that you want. Then draw a line through any section(s) that does not apply to you. If you have further directions please add to 'Additional Directions' box on page 30.

Goal is to extend life: *Full treatment*

_____ I want full treatment.

Initial 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 including intensive care.

CPR will be attempted

_____ **Goal is to extend life for reversible conditions: *Full treatment Conditional***

Initial 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.

Attempt CPR (Initial one) _____ **Yes** _____ **No**

_____ **Goal is conservative management of medical condition: *Limited Additional Interventions***

Initial 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.

CPR will NOT be attempted

_____ **Goal is comfort and symptom control at the end of life: *Comfort Measures Only***

Initial **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.

CPR will Not be attempted

Signature

Print Name

Date

WHAT I WANT

Considering Life Support with Medical Interventions

Guidance

The Human Tissue Gift Act provides that organ and tissue donation can only happen after death.

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

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

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

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 have the option to decide what may be done with my body at the time of my death. I understand that age and cause of death may limit donation. **My wishes at time of death in regards to donation are:**

(____) I place no limitations on which of my organs may be used, should I be deemed a suitable organ donor.

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

- | | | | |
|--------------------------|----------|--------------------------|-------------|
| <input type="checkbox"/> | Heart | <input type="checkbox"/> | Lungs |
| <input type="checkbox"/> | Liver | <input type="checkbox"/> | Kidneys |
| <input type="checkbox"/> | Pancreas | <input type="checkbox"/> | Small Bowel |

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

- | | | | |
|--------------------------|------------------|--------------------------|-------------------|
| <input type="checkbox"/> | Heart for Valves | <input type="checkbox"/> | Eyes |
| <input type="checkbox"/> | Pericardium | <input type="checkbox"/> | Tendons/Ligaments |
| <input type="checkbox"/> | Pancreas | <input type="checkbox"/> | Bones |
| <input type="checkbox"/> | Skin | | |

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

SIGNING, WITNESSING AND DATING

Additional Directions

If you have any additional specific directions that are important to you, provide details here (i.e. intubation, feeding tubes, tracheotomy, dialysis, antibiotics, specific spiritual/cultural rituals, acceptable state of health etc.):

1. You must sign and date this Health Care Directive 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 cannot be witness nor can your Proxy's spouse.

I, _____ *(insert name)* am thinking clearly, I understand the meaning of the questions and the choices I have made, and I have made this Health Care Directive voluntarily.

My signature or mark

Witness's signature

Print your name here

Print witness's name here

Date

Date

THOUGHTS I WISH TO SHARE

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

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

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”, etc.*

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

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

My Name: _____ Date: _____