

Prairie Mountain Health

advance care planning



advance care planning workbook



None of us know what tomorrow will bring, or can predict what might become of our health. But there is a way to ensure you have a say in health-care decisions that lie ahead, should there come a time when you are unable to speak for yourself. It's called advance care planning.

What is advance care planning?

Advance care planning is a way to help you think about, talk about and share your thoughts and wishes about future health care. It gives you a "voice" in decision making, helps you determine who would communicate for you if you are unable to communicate for yourself and should include conversations with your health-care team.

This workbook is a guide to help you through the process of advance care planning. It includes a number of thought provoking questions to help you explore the values and beliefs that influence your health-care decisions.

The workbook has a section with important details about terms relating to various health-care treatments. There are useful tips to consider as you develop and then share your advance care planning decisions with your family and those closest to you, as well as your health-care team.

By making your wishes known, your caregivers won't be left wondering what you might have wanted or did not want.

EVERYONE should have a say in their health care. Plan today to ensure that your wishes are known, no matter what the future holds for your family and your health.

THERE ARE SEVERAL WAYS TO MAKE YOUR FUTURE HEALTH-CARE WISHES KNOWN:

Talk to your family and trusted friends about your concerns. Let them know what care you would be willing to accept or would refuse. Talking about the kind of care you do and do not want will help reduce any anxiety that your family and friends may feel. It will also give them the confidence to make decisions for you, if that should become necessary.

You can write a Health Care Directive. This is a legal document, sometimes called a “living will”. In it, you write your instructions about the treatment you would accept or refuse. You can also name a person, known as a proxy, who will speak for you if you are unable to speak for yourself.

You can work with your health care team to complete an Advance Care Planning Goals of Care form. This should be filled out with your doctors, your nurse or other members of your health-care team. This form documents goals of care for your future health care.

Communicate and update changes. Over time, your feelings might change about the goals of care choices that you’ve made during advance care planning. That’s okay. Changes can be made any time as long as you are able to make health-care decisions. Health-care providers will also consult you directly if your health situation changes.

WHO SHOULD CONSIDER ADVANCE CARE PLANNING?

Everyone. You never know when you may face an unexpected event or illness and will be unable to make your preferences known. It is particularly important for seniors and those living with a chronic disease.

WHEN SHOULD I CONSIDER ADVANCE CARE PLANNING?

Now. It is important to take part in conversations about advance care planning before you become seriously ill. Planning will ensure that if an unexpected event occurs, your treatment wishes are known. This workbook has been created by Prairie Mountain Health to help guide you through this process.

IMAGINE

1. Imagine that without warning you are in a serious car crash. You are in a hospital intensive care unit. You are no longer able to communicate with anyone. Your heartbeat and breathing can only continue with artificial life support. Despite the best medical treatment, your physicians believe it is unlikely you will return to your previous quality of life.
2. Imagine your ability to make your own decisions is gone. You live at a residential care facility. You can feed yourself but you no longer know who you are, who your family members are, or what happens from one moment to the next. You will never regain your ability to communicate meaningfully with others. Your condition will likely become worse over time.
3. Imagine you have a progressive chronic illness. Your health care team has told you that you may lose your ability to swallow and breathe on your own.



THINK about your values & beliefs

When you plan for your future health care, you need to think about your values and beliefs, as well as your personal goals. In order to prepare yourself for advance care planning conversations, write down your thoughts to the following questions:

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What is most important to me about my physical or mental well-being?

For Example It is important for me to be able to communicate in some way, even if I cannot speak. I enjoy reading, writing and singing. It is important for me to be able to eat, drink and go to the bathroom.

What makes each day meaningful to me?

For Example Life has meaning when I spend time with my family. I can enjoy prayer and solitude.

What beliefs or values are important to me?

For Example I would like to stay home as long as it is not too hard on my family. I want to see my son graduate or my granddaughter get married next summer.

Do I have a memory of a loved one who has died, what did I learn from that experience?

For Example When someone is in pain, their family suffers too. It was important for me to be there with my grandmother, to say goodbye.

When I think about dying, what do I worry about?

For Example I worry that I will be in pain. I worry that I will be alone. I worry that my family will not know what to do. I worry that I will struggle to breathe.

When I am dying, are there things I want or do not want?

For Example I would like prayer, spiritual readings, or favourite foods. I do not want flowers. I'd like to plan my own funeral. I just want family to see me if I am in hospital.

When I am dying and if I cannot speak or be understood, are there things I would like my family and friends to know?

For Example I love you. I forgive you. Please forgive me. Thank you. Good bye.

It is important to know that the choices you may make now for health care decisions may not be ideal if you become very ill. Your health-care team will consider your wishes, but will not offer treatment that is of no benefit.



TALK about it, What's important?

Discussing your treatment wishes with loved ones may be an uncomfortable conversation, but it will help reduce pressure and stress during an already challenging time.

HEALTH CARE TREATMENTS

When you are in pain or experiencing unpleasant symptoms like dizziness or are feeling sick, your health-care team will give you medicine and treatment to relieve these symptoms. Depending on your health condition, a number of other treatments may be discussed with you.

Cardiopulmonary resuscitation (CPR) refers to medical procedures used to try to restart a person's heart and breathing when the heart and/or lungs unexpectedly stop working. CPR can range from mouth-to-mouth breathing and pumping on the chest, to electric shocks that try to restart the heart and machines that breathe for the individual.

Dialysis is a medical procedure that cleans your blood when your kidneys stop working.

End of Life/Palliative Care refers to health care provided at the end of a person's life. This type of care focuses on a person's quality of life 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 tube that carries liquid food, which is inserted through the nose or through a hole directly into the stomach.

The Intensive Care Unit is a unit in the hospital for people who are critically ill. The medical staff in the ICU try to save patients who might otherwise die. It is important to understand that the special equipment, medications and treatment in an ICU do not cure diseases. If you have a disease that can be treated, a stay in the ICU may buy you the time you need to heal.

Intravenous/Subcutaneous Lines are used to give a person medicines or fluids.

A **tracheostomy** is a surgical procedure to create an opening into your windpipe through a hole in your throat area.

A **transfusion** is when a person is given blood or blood products through an intravenous line.

A **ventilator** is a machine that helps people when they can not breathe on their own. A special machine is attached to a tube that is placed down the windpipe. A ventilated client cannot speak.

TALKING WITH FAMILY AND TRUSTED FRIENDS

The best people to talk with are your family members and/or trusted friends. The people you choose to have these conversations with should know you well.

Talking about your health and future health care may be hard. It may bring up questions, concerns, and uncomfortable feelings. You do not have to talk about your decisions all at once. Give yourself time to make your decisions and to make sure your wishes are understood.

Remember, your health-care team is an excellent source of information regarding your health and future health-care choices.

WRITING DOWN YOUR CONVERSATION

Within Prairie Mountain Health there are two ways to write your decisions around your future health care:

- Write a Health Care Directive **OR**
- Complete an Advance Care Planning Goals of Care form.

When writing your decisions, remember you have the right to accept or to refuse any health-care treatments. What is right for someone else may or may not be acceptable to you.

ADVANCED CARE PLANNING – GOALS OF CARE

PREPARING FOR A “GOALS OF CARE” DISCUSSION

Your health-care team will approach you and, if you wish, your family and trusted friends, to talk about your goals of care.

- When you are admitted to a hospital, a personal care home, or other health-care facility.
- Before you have surgery.
- When you are transferred from one health-care facility to another.

The team will talk to you about your health, your current condition, the care that would and would not help you and what you can expect from that care and treatment.

When having these discussions with your health-care team;

- Provide a copy of your Health Care Directive if you have prepared one. Your Health Care Directive will guide and inform your advance care planning conversations with your health-care team.
- Be sure to ask questions about anything that will help you make your decisions.
- Take time to think about your choices. You may need to have several discussions before coming to a decision.

Your health-care team will work with you to decide which of the following goals of care best describe your wishes for your future health care.



Which box best describes your Goals of Care?

€ COMFORT CARE

Goals of care and interventions are directed at maximal comfort, symptom control and maintenance of quality of life. Attempted cardiopulmonary resuscitation (CPR) (trying to restart the heart after it has stopped beating) will not be tried.

€ MEDICAL CARE

Goals of care and interventions are for the usual medical care that is appropriate to treat and control your condition. The consensus is that you may benefit from, and are accepting of, any appropriate investigations/interventions that can be offered. Attempted resuscitation (trying to restart the heart after it has stopped beating) will not be tried.

€ CARDIOPULMONARY RESUSCITATION (CPR)

Goals of care and interventions are for the usual medical care that is appropriate to treat and control your condition. The consensus is that you may benefit from, and are accepting of, any appropriate investigations/interventions that can be offered, including attempted resuscitation (trying to restart the heart after it has stopped beating).

Once you and your health-care team have agreed upon your goals of care, the health-care team will write these goals of care on an Advance Care Planning Goals of Care form. You will be provided with a copy of the completed form. An example of this form is included on the following page.

Remember, you can request changes to your goals of care at any time. Simply tell your health-care team you want to have further discussions. Your health-care team will also review your goals of care whenever your condition significantly changes.



ADVANCE CARE PLANNING GOALS OF CARE

PMH Advance Care Planning Policy

Client Health Record Number
 Client Surname
 Given Name
 Date of Birth
 Gender
 MHSC
 PHIN
 Address

Is there an existing Health Care Directive? No Yes
 (If yes, it shall guide further discussions as an indication of the Client's wishes at the time of writing – Please attach a copy)

Advance Care Planning (ACP) is the overall process of dialogue, knowledge sharing and informed decision making that needs to occur at any time when treatment options and goals of care are being considered or revisited. This form is used to record agreed upon goals of care reached through full and complete ACP discussions with the client and/or alternate decision maker about the nature of the individual's current condition, prognosis, treatment/procedural/investigation options, and expected benefits or burdens of those options.

GOALS OF CARE (Check the box that best describes the Client Goals of Care)

- C = Comfort Care** – Goals of care and interventions are directed at maximal comfort, symptom control and maintenance of quality of life *excluding* attempted resuscitation.
- M = Medical Care** – Goals of care and interventions are for care and control of the client's condition. The consensus is that the client may benefit from, and is accepting of, any appropriate investigations/interventions that can be offered *excluding* attempted resuscitation.
- R = Resuscitation** – Goals of care and interventions are for care and control of the client's condition. The consensus is that the client may benefit from, and is accepting of, any appropriate investigations/interventions that can be offered *including* attempted resuscitation.

If the required care is not available in the current location or setting, does the client want to be transferred to an alternate facility? No Yes

Indicate all individuals who participated in goals of care discussion(s) by checking appropriate box(es).

- Client Print Name: _____ Signature: _____
- Family Member Print Name: _____ Signature: _____
- Alternate Decision Maker Print Name: _____ Signature: _____
- Health Care Provider Print Name: _____ Signature: _____

Document other participants (i.e. family members and/or health care providers), details of the client specific instructions or wishes and/or details of discussion with the individuals indicated. (Refer to date/time of Progress Note entry if more space is required):

 Name & Designation of Health Care Provider Signature of Health Care Provider yyyy/mm/dd
 (Physician's signature is required when patient is a client of the Public Trustee)

The goals of care were reviewed with the client and/or alternate decision maker and no change to the form is required.

 Name & Designation of Health Care Provider Signature of Health Care Provider yyyy/mm/dd
 (Physician's signature is required when patient is a client of the Public Trustee)

 Name & Designation of Health Care Provider Signature of Health Care Provider yyyy/mm/dd
 (Physician's signature is required when patient is a client of the Public Trustee)

 Name & Designation of Health Care Provider Signature of Health Care Provider yyyy/mm/dd
 (Physician's signature is required when patient is a client of the Public Trustee)

If review results in any changes to the Client Goals of Care, a new form must be completed.

PROVIDE A COPY OF COMPLETED FORM TO CLIENT OR ALTERNATE DECISION MAKER

Original Effective Date:
 Revised Effective Date:

WRITING A HEALTH CARE DIRECTIVE

In Manitoba, anyone over the age of 16 can write a Health Care Directive. You have the right to accept or refuse medical treatment at any time.

The Health Care Directives Act allows you to express your wishes about the amount and type of health care and treatment you want to receive should you become unable to speak or otherwise communicate this yourself. It also allows you to give another person(s) the power to make health-care decisions for you, should you ever be unable to make them yourself.



What is a health care directive?

A Health Care Directive, sometimes called a living will, is the legal document where you write your instructions about the treatment you would accept or refuse. You can also name a proxy to speak for you when you are unable to speak for yourself.

It is strongly recommended you talk to your doctor, nurse, and health-care team before completing a Health Care Directive. This will ensure your instructions are clear and easily understood by those who provide treatment.

Manitoba Health has prepared a sample Health Care Directive and it is available at the back of this workbook. For more information please visit their website at www.gov.mb.ca/health/livingwill.html

Where should I keep my Health Care Directive?

It is wise to make several copies of your Health Care Directive to ensure that the document is easily accessible when it is needed.

You should keep one copy at home. If you have an Emergency Response Information Kit (ERIK) place it in there. If you don't have an ERIK kit, you can pick one up at any fire paramedic or ambulance station or community senior centre. Your proxy(s) should have a copy. Keep a copy in your file at your family doctor's office. Take a copy with you when you travel. Bring a copy with you when being admitted to hospital, a personal care home, and prior to surgery.

How often should I change the content of my Health Care Directive?

Review the content of your Health Care Directive once a year, or when your health condition changes. This makes sure it is still what you want now and in the future.

Your health-care provider may suggest changes to be considered.

How do I decide on my proxy?

You should consider the person who you feel is best able to carry out your wishes, if you are unable to speak for yourself. Your parents, spouse, children and their spouses, or family friends could all serve as a proxy. You can have more than one proxy, in the event one cannot be reached in case of emergency. The proxies can be listed in order, and you can decide if they must reach a consensus, or can act alone.

Is this legally binding?

Yes. The wishes you express in your Health Care Directive are binding on your friends, relatives and health care providers (unless they are not consistent with accepted health care practices) and will be honoured by the courts.

I have someone who is my Power of Attorney, and helps me with my banking. Isn't that the same thing?
No, a Power of Attorney is not the same thing as being a proxy for health care decisions, and does not enable the person to make health care decisions on your behalf. If you want your POA to make health care decisions, you must name them as your proxy on the Health Care Directive.

Health Care Directive



Please type or print legibly

This is the Health Care Directive of:

Name _____
Address _____ City _____
Province _____ Postal Code _____ Telephone (____) _____

Part 1 – Designation of a Health Care Proxy

You may name one or more persons who will have the power to make decisions about your medical treatment when you lack the ability to make those decisions yourself. If you do not wish to name a proxy, you may skip this part.

I hereby designate the following person(s) as my Health Care Proxy:

Proxy 1

Name _____
Address _____
City _____
Province _____ Postal Code _____
Telephone (____) _____

Proxy 2

Name _____
Address _____
City _____
Province _____ Postal Code _____
Telephone (____) _____

(Check one choice of "consecutively" and "jointly" please do not check both.)

If I have named more than one proxy

I wish them to act _____
 consecutively OR jointly

My Health Care Proxy may make medical decisions on my behalf when I am unable to do so for myself (check one choice only):

- With no restrictions
- With restrictions as follows:

Part 2 – Treatment Instructions

In this part, you may set out your instructions concerning medical treatment that you do or do not wish to receive and the circumstances in which you do or do not wish to receive that treatment. REMEMBER – your instructions can only be carried out if they are clear and precise. If you do not wish to provide any treatment instructions, you may skip this part.

Part 3 – Signature and Date

You must sign and date this Health Care Directive.

Signature _____
Date _____

If you are unable to sign yourself, a substitute may sign on your behalf. The substitute must sign in your presence and in the presence of a witness. The proxy or the proxy's spouse cannot be the substitute or witness.

Name of substitute: _____
Address _____
Signature _____
Date _____

Name of witness: _____
Address _____
Signature _____
Date _____

Consecutively: The second proxy would be contacted if the first is not available or is unwilling to make the required decision at the required time.
Jointly: The first proxy and second proxy would act together on your behalf.

think about it. talk about it. share it.

None of us can predict what tomorrow may bring. Make sure your health care wishes are known. Consider what's important to you and discuss it with your loved ones and your health care team to help guide future decisions about your health care. Filling out the Health Care Directive form or your Goals of Care form can prepare your loved ones, your health-care providers and yourself, ensuring your treatment wishes are known.



Dr. C. Penner

As a physician I think about it every day when treating someone with a serious illness or life threatening situation, what are their wishes. It is our job to provide the best possible care but also be mindful as to what the patient would like in terms of medical treatment. What are their expectations in terms of care as their illness progresses? Many people are scared when faced with these issues so we need to be sensitive on how we approach this discussion. For some they may have a goal in mind like being around to celebrate a wedding or birth, for others they don't want to suffer through more tests.

That is why advance care planning discussions are so important and having a health care directive in place. I have witnessed where a patient has never spoken to family members about their wishes. It is an emotional time and family often struggle making decisions over health care intervention at the end of life when someone hasn't specified their wishes.

But I have found for many patients having this type of conversation has allowed that person to still maintain a sense of control of their life at a time of such uncertainty. By laying out this path it helps not only the patient but their health care providers and family to better understand their needs and wants.

It's really a kindness to your family to be able to have said ahead time of what you want rather than having your family make that decision for you at the end. There can be a sense of relief and peace when a patient and their families have had these discussions and decisions have been made so the remainder of time is spent just being together.



Arlene Hunter, Social Worker

When I was caregiver for my Dad, I tried on several occasions to encourage him to complete a Health Care Directive, to no avail. My Dad was nearly 82 when he passed and likely was of the mindset that just let nature take its course. I can appreciate that, as many of our elders do not like to speak about death. Dad remained Full Code right up until his heart attack that took his life in hospital.

I've also experienced the loss of a younger sister at the age of 46 years to a massive heart attack. She never discussed her health or medical treatment wishes with her family. This left them very devastated when she passed away so suddenly.

As a social worker in a hospital, it is very important that patients feel they still have control as to what they want by allowing them to express their wishes on paper while they are still able to do so. This relieves a lot of burden and guilt that is otherwise put on family members to make the choices for their loved one. I have seen the relief in family members knowing they don't have to make that decision.

Advance care planning documents are very important for the entire health team to respect the patient's wishes throughout their illness. This document also allows the patient to rest assured that they will not have to keep being approached by the medical team with medical questions; instead, allowing them to focus on their own well-being and spending quality time that they have left with their loved ones.

We can just never predict when we, ourselves may be faced with our own medical dilemma and because of my own personal and professional experiences I have had those discussions with my family and have put plans into place.



Bob Ireland

Bob was diagnosed with ALS in October of 2012. Upon diagnosis he wanted to discuss a Health Care Directive and have his treatment choices documented for end of life care and support. He was a formidable planner and understood the progression and deterioration of this disease. Bob wanted this uncomfortable conversation completed in his time of wellness, so he could concentrate on making memories with family and friends. He shared his choices in discussions with family members and friends and was adamant about his care and treatment for when the time came that he could not share his thoughts. As the disease process progressed, Bob was still able to talk and he continued to remind me that it was important to follow his Health Care Directive. We had disagreements about his wishes but I understood this was something he still had control of. Being able to make his own decisions allowed him the dignity that no disease could take away from him. As a health care professional I see many families choose not to discuss the significance of a Health care directive. Often it is not discussed, and then a family member is allocated to make difficult choices. It is extremely difficult to make decisions for your loved ones in such an emotional time. I am thankful that Bob had the strength and courage to complete his directive at an early time in his disease. To the end, he was in charge of his life and in his choices of passing.

Maggie Ireland, RN BScN