

advance care planning

HAVE A SAY IN YOUR HEALTH CARE.



Winnipeg Regional
Health Authority
Office régional de la
santé de Winnipeg



think about it. talk about it. share it.

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. And 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.



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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 the Winnipeg Health Region to help guide you through this process.

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. This is also a good time to discuss your wishes around organ and tissue donation.


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 doctor, 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 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.

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:

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 taste and touch.

What makes each day meaningful to me?

FOR EXAMPLE Life has meaning when I communicate with my friends and loved ones, when I can enjoy nature and when I can practice my faith. I need to know I am making a difference to the well-being of others. Creative activities are important to my daily routine.

What beliefs or values do I think will help my family, trusted friends or health-care providers know what is important to me?

FOR EXAMPLE I would like to stay home as long as it is not too hard on my family or caregivers. Do everything possible to keep me alive until I can say goodbye to family who are coming to see me. It does not matter if I live until my next birthday.

Have I registered my organ and tissue donor intention at www.signupforlife.ca? Have I discussed my wishes with my family, friends or proxy? Yes No

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

When I think about death, 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 nearing death, are there things I would wish for (or do not wish for)?

FOR EXAMPLE I would like music, prayer, religious or spiritual rituals/readings in my own language. I do not want music or flowers in my room. I would value my privacy.

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

FOR EXAMPLE I love you. I forgive you. Please forgive me. Thank you.

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

Write down how you feel about health-care treatments. Definitions are found under the blue heading "Health Care Treatments" on the following 2 pages.



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 can no longer do so.

End of life care refers to health care provided at the end of a person's life. This type of care focuses on 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 small plastic tube that carries liquid food, which is inserted through the nose or directly into the stomach or intestines.

An **intensive care unit (ICU)** is a unit in a hospital where people are kept alive using machines (such as a breathing machine or ventilator) and special intravenous medications to support the heart. It is important to understand that the special equipment and medications used in an ICU do not cure diseases. If you have a potentially curable or treatable disease, the machines and special intravenous medications used in the ICU may provide you with more time to heal so that hopefully you can resume your life without machines or special intravenous medications.

An **intravenous line (IV)** is a way to give a person fluids or medicine. A hollow needle, attached to a narrow tube, is placed in a vein in the hand, arm or another location.

A **tracheostomy** is a surgical procedure to create an opening into your windpipe through your neck.

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.

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 the Winnipeg Health Region, there are two ways to write your decisions around your future health-care:

- Write a Health Care Directive OR
- Develop 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.



SHARE your plans.
WRITE it down.



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.



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 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 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 Winnipeg Fire Paramedic 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, 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?

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. A Power of Attorney addresses financial issues only.

Source: Manitoba Health

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 and future health-care treatment:

- When you are admitted to a hospital or a personal care home.
- Before you have surgery.
- When you are transferred from one health-care facility to another.
- If you come to an emergency department or urgent care centre.

They 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, you need to:

- 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.



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 of 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).

You can also write any special instructions or wishes you feel are important for your health-care team to know.

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 at the back of this workbook.

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 about your goals of care. Your health-care team will also review your goals of care whenever your condition significantly changes.

INCLUDING ORGAN AND TISSUE DONATION IN YOUR FINAL WISHES



Donating organs, tissues and eyes after your death can help save up to eight lives and greatly enhance the quality of life for up to 100 people.

Advance care planning is a good time to talk with your family about your decisions around organ, tissue and eye donation. If being an organ and tissue donor is important to you, tell your family about your decision so they will know how to honour your wishes. The best way to indicate your wish to be an organ and tissue donor is to signal your intentions by registering online at www.signupforlife.ca, and speak with family about your choices.

Common questions and concerns:

WHAT IS ORGAN, TISSUE AND EYE DONATION?

Donation is the process of surgically removing organs after brain death or tissues after death. If you have questions about organ donation, please visit www.transplantmanitoba.ca or call 204-787-1897, for questions concerning tissue donation visit www.sharedhealth.ca or call 204-940-1750.

WHO CAN BE A DONOR?

Nearly everyone has the potential to be an organ, tissue and eye donor. The health of the donor, not the age, is the most important consideration. Your family will be required to provide consent on your behalf so it is important that you discuss your wishes.

I AM LIVING WITH MANY DIFFERENT MEDICAL CONDITIONS. I DON'T THINK I CAN BE A DONOR.

Should the situation arise and donation becomes a possibility, the medical team will assess whether you could be a donor.

I'M NOT SURE IF MY RELIGION SUPPORTS DONATION.

Having a conversation with your faith leader can help you develop your advance care plan. Religions practiced in Canada support organ, tissue and eye donation because it is an act that can save the life or improve the quality of life of another.

I HAVE INDICATED MY WISHES IN MY WILL.

Unfortunately by the time your will is read, the opportunity to donate will have already passed.

I HAVE SIGNED A DONOR CARD. WHY DO I NEED TO REGISTER?

Donor cards are no longer an option. Registering online means your decision is always available to the medical team and your family. That card might not be.

WHOLE BODY DONATIONS

Whole body donations are not handled by Transplant Manitoba – Gift of Life. If you wish to donate your whole body to science, please contact the University of Manitoba's Department of Anatomy at 204-789-3652 for more information.

Register Today

Manitoba's online organ and tissue donor registry, www.signupforlife.ca, has been recording decisions of Manitobans since 2012. It takes two minutes and three pieces of information to register – name, birthdate and nine-digit number on your Manitoba Health card.

Care Directive

it legibly

Health Care Directive of:

_____ 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 **only**.) For an explanation of “consecutively” and “jointly” please see the reverse side of this form).*

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 lack the capacity 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 set out clearly and precisely. 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. No witness is required.

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 _____



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.

SPECIAL THANKS TO :

*Alberta Health Services
Fraser Health Region*

Aussi disponible en français.

www.winnipeghealthregion.ca/acp