

# Who Will Speak for You?

## Advance Care Planning Kit Manitoba Edition

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**Special thanks to Dorothy Stephens and Cheri Frazer of the Winnipeg chapter of Dying With Dignity Canada.**

**Disclaimer:** The information provided within this workbook is included as a public service and for general reference only. Every effort is made to ensure the accuracy of the information found here. However, this information is not considered legal, medical or financial advice and does not replace the specific medical, legal or financial advice that you might receive or the need for such advice. If you have questions about your health or about medical issues, speak with a health care professional. If you have questions about your or someone else's legal rights, speak with a lawyer or contact a community legal clinic.



**Dying With Dignity Canada**  
**It's your life. It's your choice.**

Dying With Dignity Canada is the national human-rights charity committed to improving quality of dying, protecting end-of-life rights, and helping Canadians avoid unwanted suffering.

- We defend human rights by advocating for assisted dying rules that respect the Canadian Constitution and the Charter of Rights and Freedoms.
- We provide personal support to adults suffering greatly from a grievous and irremediable medical condition who wish to die on their own terms.
- We educate Canadians about all of their legal end-of-life options, including the constitutional right to medical assistance in dying (MAID), and the importance of advance care planning.
- We support healthcare practitioners who assess for and provide MAID.

Dying With Dignity Canada's charitable registration number is 11889 0086 RR0001.

### Contact Us

Our mailing address: 55 Eglinton Ave. E, Toronto, ON, M4P 1G8, Suite 802

Phone: 416-486-3998

Toll free: 1-800-495-6156

Fax: 416-486-5562

Email: [info@dyingwithdignity.ca](mailto:info@dyingwithdignity.ca)

Website : [www.dyingwithdignity.ca](http://www.dyingwithdignity.ca)

## INTRODUCTION

This **Advance Care Planning Kit** invites you to think about and express your wishes for health care and treatment at the end of life. The kit is intended to provoke thinking, conversation and planning, and to encourage communication between you, your family and your health care providers.



The kit guides you through the process of considering your personal values and asks you to imagine medical situations that could happen to you. It walks you through the steps of drafting a **Health Care Directive** and choosing a health care proxy; this is the person authorized to speak for you if you are unable to speak for yourself.

The kit contains information on medical interventions such as CPR that may be used in end-of-life situations, and explains your right to refuse resuscitation. The kit also includes a glossary of terms, a summary of your legal rights as a patient, answers to some frequently asked questions, and a section on further resources.

The best time to think about your preferences for future medical care is when you are well and able. Of course, it is hard to imagine how you may feel when you are not well. We offer various scenarios to help you to plan for the future, while reminding you that you can always change your mind. Advance care planning is the best way to ensure that your wishes are known to your family, your caregivers and health care providers. By doing it now, you ease the future burden of decisions that might have to be made, under difficult circumstances, by those who love and care for you.

## WHAT IS A HEALTH CARE DIRECTIVE?

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### **What is a Health Care Directive?**

A Health Care Directive, sometimes called an Advance Care Directive, is a document, written while you are well and able to make decisions, in which you state your wishes for medical or non-medical care, just in case you become unable to speak for yourself at some time in the future.

### **Why should you have a Health Care Directive?**

In a medical emergency or in any other circumstance that leaves you unable to communicate, for example if you have a stroke or if you are in a coma, your Health Care Directive will assert your right to choose what you want or do not want in the way of medical treatment and care. It will help those responsible for your care to decide on your treatment. It will help your family to understand and support the decisions that you would have made yourself.

There is no legal requirement for you to have a Health Care Directive. Only you can create it – no one else can do it for you. But if you do not have a Health Care Directive, others may not know your wishes and you may be subjected to aggressive or life-prolonging medical interventions that you would not want. On the other hand, you may have a specific medical condition for which you *do* want all available treatment. In Manitoba, you need to be at least 16 years of age to have an Advance Care Directive.

Start the process now of creating your Health Care Directive by thinking about your personal values and the everyday pleasures that make life worth living.



## CONSIDER YOUR PERSONAL VALUES

1. Think through a day in your life and consider what you enjoy most, what you look forward to, and what makes your life livable and workable. What gives your life purpose and meaning?

Here are some topics to get you thinking:

- |                              |                              |
|------------------------------|------------------------------|
| ▪ Independence, autonomy     | ▪ Family                     |
| ▪ Work                       | ▪ Food                       |
| ▪ Time for yourself          | ▪ Sports                     |
| ▪ Friends and colleagues     | ▪ Exercise                   |
| ▪ Hobbies                    | ▪ Reading                    |
| ▪ Holidays                   | ▪ Music                      |
| ▪ Birthdays and celebrations | ▪ Television, movies         |
| ▪ Travel                     | ▪ Keeping a journal or diary |



2. Which of the following do you fear most near the end of life?

Rank these items from 1 to 9. Think of other concerns that you may have.

- ☐ Losing your mobility
- ☐ Being in pain
- ☐ Being incontinent
- ☐ Being alone
- ☐ Losing the ability to think; being confused most of the time
- ☐ Being a burden on loved ones
- ☐ Being dependent on others for everyday activities like eating and bathing
- ☐ Being in hospital
- ☐ Losing your sight or hearing

3. If you could plan them today, imagine what the last days of your life would be like:

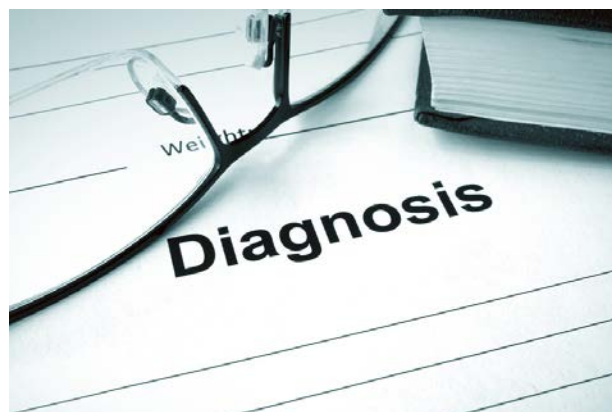
- Where would you be?
- What would you be doing?
- Who would be with you?
- What would you eat if you were able to eat?
- Would you want the comfort of spiritual support from a member of the clergy or someone who shares your religious beliefs?
- Are there people to whom you would want to write a letter or record an audio or video message, perhaps to be read, heard, or watched in the future?

4. How do you want to be remembered? If you were to write your own obituary or epitaph, what would it say?

5. What other personal values come to mind?

## CONSIDER THESE MEDICAL SITUATIONS – Copy 1

Imagine various critical conditions and think about the treatment you would accept or refuse in each case. The answers will help to make things clear in your own mind so that you are better prepared for discussions with family, caregivers and physicians.



*We have included in this kit two (2) copies of Consider These Medical Situations.*

- *Complete Copy 1.*
- *Give Copy 2 to the person(s) you are considering appointing as your health care proxy. Ask them to answer the questions as though they were you.*
- *Compare your answers to theirs. Note and discuss differences. It is important for your proxy to understand your values and your wishes for end-of-life care.*

1. You are seriously ill with cancer but your mind is still sharp. Physicians recommend chemotherapy. They explain that this treatment often has severe side effects such as pain, vomiting, and weakness. Are you willing to endure these side effects if the chances of regaining your current health are less than 25 percent?

- ☐ Yes
- ☐ Yes, on a trial basis
- ☐ No
- ☐ I am uncertain

*Note: It is your legal right to refuse or discontinue treatment. Read more about this Charter Right in Appendix 1.*

2. You are seriously ill with terminal cancer but your mind is still sharp. Physicians offer chemotherapy to 'buy time,' giving you an 80% chance of an additional six months. Do you want this treatment even though it may have severe side effects?

- ☐ Yes
- ☐ Yes, on a trial basis
- ☐ No
- ☐ I would request medical assistance in dying
- ☐ I am uncertain

## Consider These Medical Situations – Copy 1... *continued*

3. You have an advanced disease, which has progressed to the point that you can no longer feed or toilet yourself, but you are not in pain. Do you want to be spoon-fed or tube-fed?

☐ Yes  
☐ Yes, spoon-fed only  
☐ Yes, spoon-fed or tube-fed on a trial basis  
☐ No  
☐ I am uncertain

*Note: It is your legal right to refuse food or drink.  
Read more about this Charter Right in Appendix 1.*

4. You have advanced Alzheimer's disease and no longer recognize your family. You develop pneumonia, which would require massive doses of antibiotics to treat. Do you want aggressive treatment or do you prefer to be kept comfortable until death occurs naturally?

☐ I want aggressive treatment, including antibiotics, to keep me alive  
☐ I do not want treatment to keep me alive. I want comfort care at home  
☐ I am uncertain

5. You have long-standing diabetes and your mind is still sharp. Last year you developed gangrene and lost one leg to this disease. You have now developed gangrene in your other leg and amputation has been recommended.

☐ I want the surgery to amputate my second leg if this will keep me alive  
☐ I do not want the surgery. I want comfort care only, even though I may die  
☐ I would request medical assistance in dying  
☐ I am uncertain

6. You are physically very weak but your mind is sharp. You need help with most daily activities, such as dressing, bathing, eating, and going to the toilet. You develop a severe kidney infection. Dialysis is available to you. If left untreated, the infection will likely lead to organ failure that will cause your death within weeks or months.

☐ I want dialysis to keep me alive  
☐ I do not want to start dialysis. I want comfort care until I die naturally  
☐ I would request medical assistance in dying  
☐ I am uncertain



## Consider These Medical Situations – Copy 1... *continued*

7. You have congestive heart failure. You are always short of breath. Your swollen ankles make walking difficult. But your mind is still sharp and you enjoy time with family and friends. One day you have a severe heart attack and your heart stops beating. Do you want 911 called and CPR started?

☐ Yes

☐ No

☐ I am uncertain

*Note: learn more about CPR and what you can expect in Appendix 3.*

8. You are terminally ill with a condition that causes great pain. Do you want to be sedated even to the point of unconsciousness if necessary to control your pain? This is called palliative sedation. Your physician can control the level of sedation to give you occasional hours of lucidity.

☐ Yes

☐ Yes, on a trial basis

☐ No

☐ I would request medical assistance in dying

☐ I am uncertain

9. You are in a permanent coma and your body is kept alive by means such as mechanical breathing and tube feeding. Physicians say you will never recover because your brain has been severely damaged. But there are a few documented cases where people have recovered from a persistent vegetative state. Do you want to be kept alive in this way just in case you may someday recover?

☐ Yes

☐ No

☐ I am uncertain

10. Would you allow yourself to be temporarily placed on life support if your heart, kidneys or other body parts could be used in transplant operations to save other lives after you have died?

☐ Yes

☐ No

☐ I am uncertain

*Note:* Manitoba's organ and tissue registry is now **online** (paper wallet cards are no longer valid). However, it is still important to talk to your proxy and family members about your decision. Learn more at the *Sign Up for Life* website at <https://www.signupforlife.ca>.

## CONSIDER THESE MEDICAL SITUATIONS – Copy 2

**Pretend you are the person who is asking you to answer these questions.**

Imagine various critical conditions and think about the treatment that you think that person would accept or refuse in each case. Compare your answers to theirs. Note the differences; talk about them. This will help you to understand their values and wishes for medical care at the end of life.

1. You are seriously ill with cancer but your mind is still sharp.  
Physicians recommend chemotherapy. They explain that this treatment often has severe side effects such as pain, vomiting, and weakness. Are you willing to endure these side effects if the chances of regaining your current health are less than 25 percent?  
☐ Yes  
☐ Yes, on a trial basis  
☐ No  
☐ I am uncertain
2. You are seriously ill with terminal cancer but your mind is still sharp.  
Physicians offer chemotherapy to 'buy time,' giving you an 80% chance of an additional six months. Do you want this treatment even though it may have severe side effects?  
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☐ No  
☐ I would request medical assistance in dying  
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☐ I am uncertain

*Note: It is your legal right to refuse food or drink.  
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## CONSIDER THESE MEDICAL SITUATIONS – Copy 2... *continued*

4. You have advanced Alzheimer's disease and no longer recognize your family. You develop pneumonia, which would require massive doses of antibiotics to treat. Do you want aggressive treatment or do you prefer to be kept comfortable until death occurs naturally?
- ☐ I want aggressive treatment, including antibiotics, to keep me alive
  - ☐ I do not want treatment to keep me alive. I want comfort care at home
  - ☐ I am uncertain
5. You have long-standing diabetes and your mind is sharp. Last year you developed gangrene and lost one leg to this disease. You have now developed gangrene in your other leg and amputation has been recommended.
- ☐ I want the surgery to amputate my second leg if this will keep me alive
  - ☐ I do not want the surgery. I want comfort care only, even though I may die
  - ☐ I would request medical assistance in dying
  - ☐ I am uncertain
6. You are physically very weak but your mind is sharp. You need help with most daily activities, such as dressing, bathing, eating, and going to the toilet. You develop a severe kidney infection. Dialysis is available to you. If left untreated, the infection will likely lead to organ failure that will cause your death within weeks or months.
- ☐ I want dialysis to keep me alive
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  - ☐ I would request medical assistance in dying
  - ☐ I am uncertain
7. You have congestive heart failure. You are always short of breath. Your swollen ankles make walking difficult. But your mind is still sharp and you enjoy time with family and friends. One day you have a severe heart attack and your heart stops beating. Do you want 911 called and CPR started?
- ☐ Yes
  - ☐ No
  - ☐ I am uncertain

*Note: learn more about CPR and what you can expect in Appendix 3*

## CONSIDER THESE MEDICAL SITUATIONS – Copy 2... *continued*

8. You are terminally ill with a condition that causes great pain. Do you want to be sedated even to the point of unconsciousness if necessary to control your pain? This is called palliative sedation. Your physician can control the level of sedation to give you occasional hours of lucidity.
- ☐ Yes
  - ☐ Yes, on a trial basis
  - ☐ No
  - ☐ I would request medical assistance in dying
  - ☐ I am uncertain
9. You are in a permanent coma and your body is kept alive by means such as mechanical breathing and tube feeding. Physicians say you will never recover because your brain has been severely damaged. But there are a few documented cases where people have recovered from a persistent vegetative state. Do you want to be kept alive in this way just in case you may someday recover?
- ☐ Yes
  - ☐ No
  - ☐ I am uncertain
10. Would you allow yourself to be temporarily placed on life support if your heart, kidneys or other body parts could be used in transplant operations to save other lives after you have died?
- ☐ Yes
  - ☐ No
  - ☐ I am uncertain

*Note:* Manitoba's organ and tissue registry is now **online** (paper wallet cards are no longer valid). However, it is still important to talk to your proxy and family members about your decision. Learn more at the *Sign Up for Life* website at <https://www.signupforlife.ca>.

## ABOUT THE PROXY FOR HEALTH CARE DECISIONS

### What does it mean to have a proxy?

Making someone your proxy for health care decisions transfers to this person the authority to make decisions on your behalf concerning your personal care and your medical treatment in the event you are not able to make your wishes known.

Your proxy can be appointed as part of your Health Care Directive or in a separate form. In this toolkit, we have used a single form for your convenience.



### Why should I have a health care proxy?

If you are unable to communicate your wishes, your previously expressed wishes must be respected as written in your Health Care Directive or as expressed orally or in any other manner. But even if you have written a Health Care Directive, your medical condition may not be specifically addressed in your directive. Your health care proxy is authorized to make decisions on your behalf based on his or her understanding of the decisions you would have made if you were able to do so.

Your health care proxy also has the authority to make arrangements for your personal care, such as where you will live, special dietary or clothing needs, and additional help to assist you in daily living should the need arise. Your proxy is concerned with all aspects of your future personal care as well as your medical care.

### Who can I appoint?

Your proxy must be

- over 18 years of age
- mentally capable and readily available to be contacted
- legally able to have access to you

It should be someone who knows you well, who will respect your religious beliefs or spiritual values, and whom you trust to carry out your wishes.

You have the option to appoint more than one person and to decide in advance if they must act **jointly** or **consecutively**.

Under the law, if you decide they must act jointly but there is not agreement, the majority will decide. If there is not a clear majority, then the first proxy named on the list decides. A requirement for joint action may also lead to disagreements or misunderstandings that can be very time consuming.



Having your health care proxies act consecutively means that if the person you first named cannot be reached or is unable to act on your behalf, the person you named next is automatically authorized to assume the duty to decide. ***We advise that you appoint your health care proxies to act consecutively.***

### **Talking with your health care proxy**

Sharing the statements and choices you make about your life and medical situations with your health care proxy will generate a discussion of your values and wishes. By comparing the answers your health care proxy has given to your own answers, you will see if she or he understands the wishes you have expressed for your future personal care and medical treatment, and is willing to take the responsibility to act on your wishes.

### **Before completing the Proxy form**

The form is a legal document. Read it all the way through. When you are clear about its use, complete the form and have it witnessed. You must satisfy yourself that your health care proxy understands the wishes you have expressed and is willing to act on your behalf.

Power of attorney generally refers to financial and/or personal decisions. Personal decisions usually do not include a right to make health care decisions for someone but the power of attorney document can include a phrase specifically appointing the person as your proxy for health care decisions. In this case the person appointed as power of attorney is also the proxy.

If you do not have a proxy, your substitute decision maker (SDM) for health care is your nearest relative. Substitute decision maker(s) must be 18 years of age or older, willing, available and have capacity. They are required to make decisions based on your prior wishes, or in your best interests if your prior wishes are unknown or unclear.

Your nearest relative is determined by the following order: (a) the spouse or person with whom the person requiring treatment cohabits and has cohabited as a spouse in a relationship of some permanence; (b) an adult son or daughter; (c) a parent or legal custodian; (d) an adult brother or sister; (e) a grandparent; (f) an adult grandchild; (g) an adult uncle or aunt; (h) an adult nephew or niece.

### **Signing the Designation of a Proxy form.**

Your declaration must be signed and dated to be recognized. It can be a separate document or part of your Health Care Directive (as in this toolkit). 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.

## FILLING OUT THE HEALTH CARE DIRECTIVE FORM

Turn to page 17 and read the Health Care Directive form from start to finish before filling it out.

There are extra spaces for you to fill in circumstances that are not covered. For example, you may have a hereditary condition you want to add.

Pay particular attention to item 4 that pertains to the “choice to prolong” and “choice not to prolong.”



### Signing and making copies

Make copies of the form before you sign and date it so that each copy has your original signature. Give a copy to your proxy. Let your physician know that you have made a HCD. Keep a record of the people to whom you provide copies so that if you change your Health Care Directive, you can provide them with your new wishes and eliminate possible future confusion. Collecting the outdated copies will give you further assurance that your most current wishes are respected.

Keep your copy where it can be easily found in an emergency situation.

Leave a note in a prominent place, such as on the fridge, with the following information:

- a) the location of your proxy form (if it is separate from your Health Care Directive)
- b) the location of your Health Care Directive form
- c) the names and contact information of the person(s) to call in an emergency

You may consider storing a copy of your Health Care Directive on your cellular phone. Do **not** store your copy of these documents in a locked safety deposit box. It needs to be quickly accessible in case of an emergency.

### You can always change your mind

You may change your proxy and Health Care Directive forms at any time. Begin by stating that you revoke any previous Health Care Directive and then complete, sign, and date a new form. You can download it from the ELPC website or request a new form by mail.

You should regularly review your Health Care Directive at least once every five years. If you choose not to make any changes to your Health Care Directive, then sign it again, with the new date in the space at the bottom of the form. Be sure to tell everyone involved in your care if you change your Directive.

Review your HCD if your situation changes (e.g., if there are changes in your medical status or your marital status, if you move away, or if you have reconsidered any of your health care decisions). You may also need to review it if your proxy's circumstances change (e.g., if your proxy moves away, grows old or becomes ill, if the relationship between the two of you breaks down, etc.).

***Please note:*** *If you feel you have special circumstances not addressed in these forms, we suggest that you consult with your lawyer.*

## YOUR HEALTH CARE DIRECTIVE

I, \_\_\_\_\_, revoke any and all previous Health Care Directives written by me.

### *Part 1 - Designation of a Health Care Proxy*

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

#### **PROXY 1**

Name: \_\_\_\_\_

Address: \_\_\_\_\_

City: \_\_\_\_\_

Province: \_\_\_\_\_ Postal Code: \_\_\_\_\_

Telephone: \_\_\_\_\_

#### **PROXY 2 (optional)**

Name: \_\_\_\_\_

Address: \_\_\_\_\_

City: \_\_\_\_\_

Province: \_\_\_\_\_ Postal Code: \_\_\_\_\_

Telephone: \_\_\_\_\_

I have named more than one proxy:      **Yes**      **No**      (circle one)

I wish them to act:      **Consecutively**      **Jointly**      (circle one)

\_\_\_\_\_  
*Your Initials*

## Part 2 – Treatment Directions

If a time comes when I lack the capacity to give directions for my health care, this statement shall stand as an expression of my wishes and directions.

*Choose one by putting a check mark in the appropriate space.*

1. If I am sedated and unable to communicate, I would like the sedation lifted so that I can rationally consider my situation and decide for myself to accept or refuse a particular therapy.

[ ] Yes [ ] No

*When answering 2, 3, and 4 below, strike out conditions that you do not wish to be considered and add any that you do. Sign your initials in the margin next to each change.*

2. Should I be in any of the following circumstances, I **direct** that I be given only such care as will keep me comfortable and pain free until natural death occurs:
- a) [ ] An acute life-threatening illness of an irreversible nature
  - b) [ ] Chronic debilitating suffering of a permanent nature
  - c) [ ] Advanced dementia
  - d) \_\_\_\_\_
  - e) \_\_\_\_\_
3. In the circumstances set out in condition 2 above, if life-sustaining treatments have been started and they are the only treatments keeping me alive, I want them stopped. I specifically **refuse** the following life support treatments:
- a) [ ] Electrical, mechanical, or other artificial stimulation of my heart (CPR)
  - b) [ ] Respirator or ventilator
  - c) [ ] Artificial feeding such as G-tube, NG tube, or central intravenous line
  - d) [ ] Being hand-fed should I no longer be able to feed myself
  - e) [ ] Artificial hydration by intravenous line
  - f) [ ] Antibiotics
  - g) [ ] Transfer to an intensive care unit or similar facility
  - h) \_\_\_\_\_
  - i) \_\_\_\_\_
  - j) \_\_\_\_\_

*If you **do not wish** to have your life prolonged under the conditions set down in items 1, 2, and 3 above, you must **strike out 4 completely**.*

*If you wish to have your life prolonged and request all applicable treatments, you must **completely strike out 1, 2, and 3 above**, leaving only the instructions in item 4.*

---

*Your Initials*



4. ☐ I specifically **direct** that my life be prolonged and that I be provided all life-sustaining treatments applicable to my medical condition.

*Note: While this directive puts your caregivers in charge of all treatment choices, you can always change your mind. For example, you can start treatments and then discontinue them.*

I have other wishes:

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5. I would prefer to be cared for and to die:

☐ at home

☐ in a hospice or palliative care unit

6. If my healthcare provider will not follow this Health Care Directive, I ask that my care be transferred to a healthcare provider who will respect my legal rights.

7. If I am in a hospital or a resident in a healthcare or long-term care facility that will not follow this Advance Directive, I ask that I be transferred to another hospital or care facility that will.

*You have the right to be involved in all decisions about your medical care, even those not dealing with terminal conditions or persistent vegetative states. If you have wishes not covered in other parts of this document, please indicate them below:*

---

---

---

---

---

---

**Signature:** \_\_\_\_\_ **Date:** \_\_\_\_\_

**Print Name:** \_\_\_\_\_

\_\_\_\_\_  
*Your Initials*

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: \_\_\_\_\_

I have distributed this Health Care Directive to the following people. This is a reminder to myself to keep these people informed of any changes. I am aware that outdated or defunct copies of this Health Care Directive may create confusion if left in circulation.

**Name and phone number**

\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

We advise you to regularly review your Health Care Directive. After you do so, and there are no changes to be made, sign it again with the new date in the space below.

Signature \_\_\_\_\_

Date \_\_\_\_\_

Signature \_\_\_\_\_

Date \_\_\_\_\_

Signature \_\_\_\_\_

Date \_\_\_\_\_

Signature \_\_\_\_\_

Date \_\_\_\_\_

\_\_\_\_\_  
*Your Initials*

## APPENDIX 1. Your Charter Rights as a Patient

Health care laws and regulations vary slightly by province and territory, but all Canadians generally share the following rights and options:

**The right to be fully informed of all treatment options.** This is also known as the ‘right of informed consent.’ Your physician is required to inform you of the risks and benefits of each treatment option as well as the probabilities of success.

**The right to recognition of a health care proxy.** You have the right to appoint a health care proxy - someone who can represent you if and when you can no longer make your own medical decisions. Your health care proxy can speak for you with the same authority as if you were speaking for yourself.

**The right to recognition of a Health Care Directive.** Health care providers are required to follow your wishes for treatment, provided they are appropriate to your medical condition and are clearly outlined in a valid Health Care Directive. You may also have a separate Do Not Resuscitate (DNR) Order. Such requests are legally binding, so long as they are filled out properly, signed by your physician, and kept up to date. For more on DNR Orders, see Appendix 4.

**The right to a second opinion.** It is your right to consult with another physician for any reason. Most people just want the reassurance of another viewpoint and an opportunity to speak with someone who will help them to decide on the best course of treatment.

**The right to pain and symptom management.** You have the right to refuse medication, but neither the Charter of Rights and Freedoms nor health care legislation grant you the right to demand medication. However, terminally ill persons can typically expect a vigorous pain management regimen, even if it may hasten the dying process.

**The right to refuse treatment.** You have the right to refuse any treatment, even if refusal might hasten your death. You also have the right to discontinue any treatment that has already started. Ethically and legally, there is no distinction between discontinuing treatment and refusing it in the first place.

**The right to refuse food and drink.** In Canada, nutrition and hydration by tube is considered medical treatment. You have the right to refuse or stop such treatment. You also have the right to refuse food and/or drink, and the right to refuse to be fed or given drinks by others. This option is referred to as *Voluntary Stopping of Eating and Drinking* (VSED) and is supported by many palliative care providers.

## APPENDIX 1. Your Charter Rights as a Patient... *continued*

**The right to end your own life.** It is legal to end your own life in Canada and has been since suicide was removed from the *Criminal Code* in 1972.

**The right to request an assisted death.** On June 17, 2016, medical assistance in dying (MAID) became legal under some circumstances in Canada. If you are suffering from a grievous and irremediable medical condition, you can talk to your doctor or nurse practitioner about your options for treatment and care, which may include medical assistance in dying. Manitoba has a central MAID team that serves all health care regions in the province. You can contact the MAID team directly or get more information from their website, at <http://www.wrha.mb.ca/maid/index.html>.

## APPENDIX 2. Glossary of Medical Terms

**Allow natural death:** when death is about to occur from natural causes, do not delay the moment of death with medical interventions.

**Antibiotics:** drugs commonly used to treat infections. Some infections can be life-threatening for a grievously ill person. Examples would be pneumonia or an infection in the blood or brain.

**Artificial/mechanical nutrition:** feeding by a method other than by mouth if the person is unable to eat. Several methods may be used:

- Nasogastric Tube (NG tube): a tube inserted through the nose and into the stomach.
- Gastrostomy tube (G-tube or PEG tube): a tube inserted into the stomach for the long term administration of food, fluids and medications.
- Central Venous Line (TPN - total parental nutrition): a method of delivering a nutrient solution (sugar, protein, fats, electrolytes, vitamins, etc.) directly into the bloodstream via a large intravenous needle.

**Artificial/mechanical hydration:** hydration by a method other than by mouth if a person is unable to drink. Fluids are provided via a small tube inserted into a vein (IV) or into the tissue under the skin (usually in the abdomen). Patients who wish to voluntarily stop eating and drinking (VSED) and simply receive comfort care, should also request to discontinue artificial hydration by IV, as hydration prolongs the dying process.

**Cardiopulmonary resuscitation (CPR):** interventions that may include manual compressions to the chest, an electric charge to restart the heart, drug therapies, or a ventilator to assist in breathing. CPR can be life-saving, but the success rate for critically ill persons is extremely low. Read more about CPR in Appendix 3.

**Cerebrovascular accident:** see *Stroke*

**Chronic debilitating suffering of a permanent nature:** ongoing distress arising from a medical condition for which there is no cure. Examples would be Parkinson's disease or severe diabetes.

**Coma:** a profound state of unconsciousness in which a person cannot be awakened by pain, light, sound or vigorous stimulation.

**Comfort care:** services that contribute to physical and mental ease and wellbeing, often provided for a dying person when further medical intervention has been judged inappropriate or is unwanted. *See also: Palliative care.*



## APPENDIX 2. Glossary of Medical Terms... *continued*

**Dementia:** a chronic or persistent disorder of a person's mental processes caused by brain disease or injury and marked by memory disorders, personality changes and impaired reasoning. Alzheimer's disease is the most common cause of dementia.

**Do Not Resuscitate (DNR):** If your breathing or heartbeat has stopped, the emergency procedure to attempt to restore these functions is called CPR. If you do not want CPR you must have a DNR Order in hand. If you are in hospital such an order may be on your chart, but if you are anywhere else, the DNR Order or your Health Care Directive stating DNR directions must be shown to first responders to avoid being resuscitated.

**Read more about DNR in Appendix 4.**

**Heart failure:** a condition in which the heart is unable to pump sufficiently to maintain blood flow to meet the body's needs; also known as congestive heart failure.

**Hospice:** from the word "hospitality," the modern concept of hospice is a place and/or a service providing palliative care for terminally ill people in hospitals, long-term care homes or in their own home. Such care generally provides pain management and other comfort care but not medical interventions to prolong life.

**Intensive care unit (ICU):** a hospital unit with specialized staff providing constant monitoring and support for the care of those who are critically ill or injured. Also referred to as the critical care unit.

**Life support or life-sustaining treatment:** replaces or supports critical bodily functions such as breathing, cardiac function, nutrition and hydration. Such measures keep the person alive but do not cure the underlying problem. Life support may be used temporarily for a treatable condition.

**Mechanical breathing:** used to support or replace the function of the lungs. A ventilator or respirator forces air into the lungs via a tube inserted into the person's nose or mouth and into the trachea. In certain conditions, the tube is inserted through a small hole at the front of the throat.

**Medical Assistance in Dying (MAID):** also known as physician assisted dying. A person can request medical assistance in dying where a physician or nurse practitioner, at a person's request: (a) administers a substance that causes a person's death; or (b) prescribes a substance for a person to self-administer to cause their own death.

**Palliative care:** therapies given in any setting to provide comfort and to alleviate pain and distressing symptoms in order to relieve suffering and improve the quality of living and dying for those faced with a life-threatening illness or medical condition.

## APPENDIX 2. Glossary of Medical Terms... *continued*

**Personal care:** hired services providing assistance with or supervision of hygiene, washing, dressing, grooming, eating, drinking, elimination, ambulation, positioning or any other routine activity of daily living but not including medical treatments.

**Personal support worker:** hired services providing supervision and safety to clients in their homes; may include light housekeeping, laundry, and meal preparation, but not personal care.

**Stroke, also called a cerebrovascular accident:** a sudden disabling attack or loss of consciousness caused by an interruption in the flow of blood to the brain, especially through thrombosis (blood clot).

**Terminal illness:** a medical condition that has progressed to the point where death may be expected within weeks or months.

**Treatment:** any sort of procedure or action done for a health-related purpose, whether the treatment be therapeutic, preventive, palliative, diagnostic, cosmetic, etc.

**Vegetative state:** said of a person who is alive but comatose and without apparent brain activity or responsiveness. A person in a **persistent vegetative state** is completely unresponsive to psychological and physical stimuli, displays no sign of higher brain function and is being kept alive only by medical intervention.

**Withholding or withdrawing life-sustaining treatment:** If you are not capable of communicating your own wishes, the decision to discontinue treatment, when it becomes futile, may be made by your proxy or next-of-kin, in consultation with your physicians. *See also: The right to refuse treatment, page 21.*

## APPENDIX 3. About Cardiopulmonary Resuscitation (CPR)

Cardiopulmonary resuscitation (CPR) is a medical procedure used to restart someone's heartbeat and breathing when the heart and/or lungs stop working. CPR can be successful in emergency situations when the person is otherwise healthy. Imagine a young basketball player who collapses on the court, for example, and who is helped by CPR.



CPR is frequently performed on TV amid a flurry of people and machines; there are celebratory “high fives” all around when CPR is successful. This is a performance, which in real life is more fiction than fact. Only about 4-16% of CPR procedures done outside of hospital are successful.<sup>1</sup>

If someone suffers from severe illness, advanced old age or a terminal disease, the odds of a good outcome from CPR are extremely low while the odds of suffering are overwhelming. A frail person who has not been breathing even for three minutes will have brain damage. What's more, during CPR ribs may be fractured, lungs punctured or the person may slip into a vegetative state and live that way for months.

This is why it is so important to make your wishes about CPR known in advance to your health care proxy, your family, and your healthcare providers. CPR is an emergency procedure for which time is of the essence. If you wish to be resuscitated in the event of a cardiac incident, call 911 and first-line responders will automatically start that process when they arrive.

But remember that you have the right to refuse CPR. If you do not want to be resuscitated but need other help, 911 responders will do whatever else they can but must be shown a DNR Order or a Health Care Directive with explicit instructions refusing CPR when they arrive. Read more about this form in Appendix 4.

<sup>1</sup> Sasson, C., Rogers, M. A., Dahl, J., & Kellermann, A. L. (2010). Predictors of survival from out-of-hospital cardiac arrest: a systematic review and meta-analysis. *Circulation: Cardiovascular Quality and Outcomes*, 3(1), 63-81.

## APPENDIX 4. Goals of Care Form and the DNR Order

Most hospitals in Manitoba use a standard ACP - Goals of Care form. This form is completed by a health professional on admission to hospital. On this form, patients (or proxy or next of kin, if the patient is unable to communicate his/her wishes) are asked to choose between full resuscitation (including CPR), medical treatment with no CPR, and comfort care. This form is kept in your medical record at the hospital. There is a sample shown below. Note that this form does NOT replace your HCD. Make sure that your proxy knows to bring your HCD to the hospital and asks to have it placed on your medical record.

If you are in the community (not in hospital) and do not wish to undergo cardiopulmonary resuscitation (CPR) or advanced cardiac life support if your heart stops beating or you stop breathing, then you should obtain a DNR Order. This is a legal order to withhold CPR or advanced cardiac life support.

You can also specify that you do not want CPR in your HCD. However, be aware that unless the request is signed by a health care professional, it may not be recognized and followed by emergency personnel, especially in the absence of your proxy or next-of-kin.

Emergency responders prefer a clear, concise DNR Order that is separate from your HCD (so that it can be quickly found and read). If you want to make sure that your request for DNR is followed, make an appointment to see your doctor (or other primary health care professional) to discuss your wishes, and ask that he or she prepare and sign a DNR form for you. If your doctor does not have this type of form, you can print a copy of the Goals of Care form from the WRHA website <http://www.wrha.mb.ca/Professionals/acp/files/goalsOfCareForm.pdf> and take it to your doctor's office to be completed and signed.

After the DNR Order is properly completed and signed by your healthcare professional, paramedics who respond to a 911 call will respect the order shown to them and will not initiate CPR. Without a DNR Order signed by your doctor, or instructions from a proxy, first-line responders to a 911 call are bound by law to initiate resuscitation. (Contrary to popular belief, getting a tattoo on your chest that reads "DNR" is not legal / will not be accepted by emergency personnel.)

Make sure your original DNR Order (or Health Care Directive with DNR instructions) is in a clearly visible location so that no misunderstandings occur under the pressures of an emergency. We suggest keeping it with your HDC on your fridge. Put the DNR Order on top so that it will be the first form the paramedics see when they open the kit.


## APPENDIX 4. Goals of Care Form and the DNR Order...continued

Make copies of the completed DNR Order after it has been completed and make sure to give one to anyone concerned with your health care.

In the health care community, **Allow Natural Death (AND)** is a phrase that is gaining favour as it focuses on what is being done, not what is being avoided. Do Not Resuscitate (DNR) sounds to some as though life-giving treatment is being withheld. A Do Not Resuscitate Order does not affect any treatment other than that which would require intubation or CPR. People who have a DNR Order can continue to get chemotherapy, antibiotics, dialysis, or any other appropriate treatment. In other words, DNR does not mean “do not treat.”

## APPENDIX 4. Goals of Care Form and the DNR Order ...continued

Sample Goals of Care form:

 <p><b>ADVANCE CARE PLANNING GOALS OF CARE</b></p> <p>Refer to WRHA Advance Care Planning Policy # 110.000.200 prior to completing this form</p>	<p>Client Health Record # _____</p> <p>Client Surname _____</p> <p>Given Name _____</p> <p>Date of Birth _____</p> <p>Gender _____</p> <p>MFRN _____</p> <p>PHIN _____</p> <p>Address (home visits only) _____</p>
<p>Is there an existing Health Care Directive? <span style="float: right;"><input type="checkbox"/> No <input type="checkbox"/> Yes</span></p> <p><small>(If yes, it shall guide further discussions as an indication of the Patient/Client/Resident's wishes at the time of writing)</small></p>	
<p>Advance Care Planning (ACP) is the overall process of dialogue, knowledge sharing and informed decision making that needs to occur at any time when future or potential life threatening illness 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 Patient/Resident/Client and/or Substitute Decision Maker about the nature of the individual's current condition, prognosis, treatment/procedural/investigation options, and expected benefits or burdens of those options.</p>	
<p><b>GOALS OF CARE</b> (Check the box that best describes the Patient/Resident/Client Goals of Care)</p> <p><input type="checkbox"/> <b>C = Comfort Care</b> - Goals of Care and interventions are directed at maximal comfort, symptom control and maintenance of quality of life <b>excluding</b> attempted resuscitation.</p> <p><input type="checkbox"/> <b>M = Medical Care</b> - Goals of Care and interventions are for care and control of the Patient/Resident/Client condition. The Consensus is that the Patient/Resident/Client may benefit from, and is accepting of, any appropriate investigations/interventions that can be offered <b>excluding</b> attempted resuscitation.</p> <p><input type="checkbox"/> <b>R = Resuscitation</b> - Goals of Care and interventions are for care and control of the Patient/Resident/Client condition. The Consensus is that the Patient/Resident/Client may benefit from, and is accepting of, any appropriate investigations/interventions that can be offered <b>including</b> attempted resuscitation.</p>	
<p>If the required care is not available in current location or setting, does the Patient/Resident/Client want to be transferred to alternate facility? <span style="float: right;"><input type="checkbox"/> No <input type="checkbox"/> Yes</span></p>	
<p>Indicate all individuals who participated in Goals of Care discussion(s) by checking appropriate box(es).</p> <p><input type="checkbox"/> Patient/Resident/Client      Print Name: _____</p> <p><input type="checkbox"/> Family Member(s)      Print Name(s): _____</p> <p><input type="checkbox"/> Substitute Decision Maker      Print Name(s): _____</p> <p><input type="checkbox"/> Health Care Provider(s)      Print Name(s): _____</p>	
<p>Document details of the Patient/Resident/Client specific instructions or wishes and/or details of discussion with the individuals indicated above. (Refer to date/time of Progress Note entry if more space is required):</p> <p>_____</p> <p>_____</p> <p>_____</p> <p>_____</p>	
<p>Name &amp; Designation of Health Care Provider _____</p>	<p>Signature of Health Care Provider _____</p> <p><small>(Physician's signature is required when patient is a client of the Public Trustee)</small></p>
<p>The Goals of Care were reviewed with the Patient/Resident/Client and/or Substitute Decision Maker and no change to the form is required.</p>	
<p>Name &amp; Designation of Health Care Provider _____</p>	<p>Signature of Health Care Provider _____</p> <p><small>(Physician's signature is required when patient is a client of the Public Trustee)</small></p>
<p>Name &amp; Designation of Health Care Provider _____</p>	<p>Signature of Health Care Provider _____</p> <p><small>(Physician's signature is required when patient is a client of the Public Trustee)</small></p>
<p>Name &amp; Designation of Health Care Provider _____</p>	<p>Signature of Health Care Provider _____</p> <p><small>(Physician's signature is required when patient is a client of the Public Trustee)</small></p>
<p>If review results in any changes to the Patient/Resident/Client Goals of Care, a new form must be completed.</p>	
<p>PROVIDE COPY OF COMPLETED FORM TO PATIENT/RESIDENT/CLIENT OR SUBSTITUTE DECISION MAKER</p>	
<p>FORM # WCC-00018 08/11</p>	<p>HEALTH RECORD COPY - CORE DIVIDER 1 (PINK)</p>
<p>See Reverse Side for French Translation</p>	

## APPENDIX 5. Frequently Asked Questions

### **Q: Can someone else create a Health Care Directive on my behalf?**

No. But if you are unable to write, your directive may be given orally. If someone else is writing on your behalf, his/her signature must be witnessed in your presence.

### **Q: What if I have a written Health Care Directive in which I refuse a certain treatment, and then change my mind when I am in hospital?**

You can change your mind at any time. Any instructions you give orally will override previously written instructions provided you are competent when you express the new instructions.

### **Q: I am just not comfortable imagining all these medical conditions you describe. Why can't I simply say I don't want my dying to be prolonged?**

You may certainly do so. Many people do. However, if you do not set down specific instructions, a general Health Care Directive is open to interpretation—and you may be treated in ways you would not want.

### **Q: What happens if I don't appoint a health proxy?**

Under *The Health Care Directives and Substitute Health Care Decision Makers Act (the Act)*, if you have not named a specific person, then your health care proxy is your nearest relative, determined from the following list:

1. Your spouse, or the person you live with and have a relationship of some permanence with;
2. An adult son or daughter;
3. A parent or legal custodian;
4. An adult brother or sister;
5. A grandparent;
6. An adult grandchild;
7. An uncle or aunt;
8. An adult nephew or niece;
9. If you have no relatives able or willing to act on your behalf, two members of the medical team treating you will make the appropriate decisions on your care, which one member must confirm in writing.

### **Q: My son is named sole proxy in my directive. If he moves out of the country, can he delegate one of my two daughters to act instead?**

No, your son cannot decide this for you. You would have to fill out a new proxy form naming one of your daughters as your health care proxy. To prevent such a situation, name each of your two daughters as your second and third choice.



## APPENDIX 5. Frequently Asked Questions... *continued*

**Q: I have two sons and I want to give them equal rights to make decisions for me. Why should I not appoint them to act jointly?**

If two people are appointed jointly and they disagree on your care, the first person named on the proxy makes the decision.

**Q: My brother and I are not on very good terms, but I have no other relatives, so he is my health care proxy. What happens if he goes against the wishes in my Health Care Directive and makes other decisions for me?**

If your physician or anyone else who has a copy of your Health Care Directive sees that your wishes are not being followed, they can apply to the Court of Queen's Bench to have your brother ordered to comply with your directive, or to request that the Court appoint a new substitute decision maker.

**Q: My husband has a serious heart condition. He has had several medical procedures and numerous hospital stays for complications. He has told me that if he has another heart attack he wants to be left alone and I am not to call 911. I don't want to take responsibility for this decision. What should I do?**

To ensure that your husband is not resuscitated against his will, he should clearly state in his Health Care Directive that he refuses CPR, and he should have a Do Not Resuscitate Order signed by his doctor (see Appendix 4). Your husband should keep these forms where they are easily found in an emergency. In this way, the decision is his own and not your responsibility.

## APPENDIX 6. Further Resources

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### **Manitoba Health, Health Care Directives (Living Will) information**

<http://www.gov.mb.ca/health/livingwill.html>

### **Winnipeg Regional Health Care advance care planning**

<http://www.wrha.mb.ca/acp>

### **Manitoba Medical Assistance in Dying (MAID) team's website**

<http://www.wrha.mb.ca/maid>

## **Legislative Resources**

### **Manitoba Health Care Directives Act**

<https://web2.gov.mb.ca/laws/statutes/ccsm/h027e.php>

### **Manitoba Vulnerable Persons Living with a Mental Disability Act**


<https://web2.gov.mb.ca/laws/statutes/ccsm/v090e.php>

### **Bill C-14 on Medical Assistance in Dying**

<http://www.parl.ca/DocumentViewer/en/42-1/bill/C-14/royal-assent>

## APPENDIX 7. Information Wallet Card

We suggest you print this card, fill it out, and put it in your wallet. You can have it laminated at your local print shop so it lasts longer.

<div>_____ Updated</div> <div>_____ Date Signed</div> <div>_____ Signature</div> <div>_____ Tel.</div> <div>_____ Proxy</div> <div>_____ Tel.</div> <div>_____ Proxy</div>	
<b>MEDICAL DIRECTIVE ALERT</b>	
<p>I, _____ have a Health Care Directive. I have authorized the person named overleaf to act on my behalf. Copies are with my Proxies. My physician is Dr. _____ Tel. _____</p>	

