

# ***MAKING A WILL TO LIVE:***

***A workbook for you, your proxy, and your  
physician about your values and preferences  
in critical healthcare situations***

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This workbook was first published by the Manitoba  
League of Persons with Disabilities in April 2003.

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Persons New Emerging Teams (VP-NET) Ethics Theme research,  
Community Health Sciences, University of Manitoba in June 2005

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## **Acknowledgements**

The first edition of this document was the third in a series undertaken by the Manitoba League of Persons with Disabilities (MLPD) that addressed issues people face concerning decision-making about possible end-of-life situations. Although this workbook is intended for anyone regardless of ability, persons with disabilities have historically experienced de-valuing of their lives, especially in critical medical circumstances. It is for this reason that special attention is devoted to providing opportunities for workbook users to describe in their own words why their lives, despite some limitations, are worth saving.

Many individuals and organizations have been supportive of this ongoing exploration throughout its previous phases. Gratitude is extended to members of the 2003 MLPD Ethics Committee – April D’Aubin, Clare Simpson, Joe Kaufert, and Barbara Beauchamp, the MLPD Provincial Council, and each MLPD staff members.

A revision of “Making a Will to Live” was used as a research document for the ethics theme, led by Dr. Joseph Kaufert of the Vulnerable Persons New Emerging Team (VP-NET) in 2005. Focus groups consisting of approximately forty lawyers, chaplains, ethicists, physicians, palliative care and acute care nurses, and persons living with disabilities examined the workbook and provided helpful feedback. Their recommendations were incorporated into a third revision which was then republished by the MLPD in 2015,

Thanks are extended to Menno Wiebe in 2003 and April D’Aubin in 2015 for consenting to be external readers. Special acknowledgement goes to Jim Derksen who first coined the phrase, “Will to live,” in the fall of 2000.

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## 1. Introduction

Making personal choices is basic to our sense of identity and well-being. This is especially true of decisions about our health, our personal care and our safety. If illness or an accident prevents us from making decisions about what really matters to us, who will make those decisions for us? How will we make our preferences known?

This workbook is designed to help you state your preferences if you are in a critical medical situation and unable to speak for yourself. Most importantly, it can help you declare that living with a disability is *still living*, and that you want rights to the same quality of health care as persons without disabilities. Access to that health care, therefore, is essential.

Historically, the Manitoba League of Persons with Disabilities has had a long-standing involvement in dealing with end-of-life issues as they concerned persons with disabilities. In the past, the League has undertaken research exploring legal, policy and societal perspectives of the placement of DNR (Do Not Resuscitate) Orders and their impact on the lives of the people they affect. The first phase of this research was presented to the MLPD membership in October 2000. It was here that the concept of a “Will to Live” was recommended as one way to help people specify to health care providers the level and type of care they want in critical medical circumstances.

The law in Manitoba states it is up to the attending physician alone to decide whether or not a person can receive life-sustaining treatment, including resuscitative measures and such basic health care as administering antibiotics, food and hydration. Therefore, a doctor can place a DNR Order on a patient’s chart *without acquiring the consent* of the patient or the patient’s substitute decision-maker or proxy. Perhaps most alarming, a DNR Order can be placed *without even informing* the patient, the patient’s family/support circle, or those who are making decisions on the patient’s behalf. According to the Manitoba Court of Appeal:

*The Court holds it is for the doctor to determine whether or not heroic measures are to be used to maintain the life of a patient in an irreversible condition. Neither consent nor a court order in*

*lieu is required for a medical doctor to issue a non-resuscitation direction... The wishes of patient's family or guardians should be taken into account, but neither their consent nor the approval of the courts is required.*<sup>1</sup>

A Will to Live workbook was suggested as a way to giving voice to people with disabilities concerning some prevailing medical assumptions that is better to be dead than to live with a disability. It also provides an opportunity for people to express appreciation for the value of life. People can articulate and reinforce their convictions that life, despite some limited capacities, is still worth living.

Included in this workbook are:

- ✓ Some preparatory materials that help you begin completing your Will to Live;
- ✓ Questions to help develop a Life Statement;
- ✓ A guide to help you list your preferences concerning medical actions, personal care and support;
- ✓ An Advance HealthCare Directive from the Government of Manitoba.

Along the way are tips that help you with communication skills, self-assertion and choosing a proxy or substitute decision-maker.

These are complicated and serious ideas to consider. Hopefully this workbook will ease the task of creating a Will to Live and will empower each user to make their voice heard in critical health care situations.

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<sup>1</sup> As cited in the Dominion Law Reports (1997.) 154 DLR (4<sup>th</sup>) 409.

## 2. How this workbook works

*This workbook is a guide, not a rule book!* Suggestions are here to help you create your Will to Live, but do this in whatever way is most useful for you. You do not need to complete all the sections in the workbook to make your Will to Live. Choose those sections most relevant to you, and design your document according to your own needs.

The workbook is designed to help you say what is most important to you about:

- ✓ The life you lead now;
- ✓ The effects additional physical &/or mental restrictions might have on your future;
- ✓ Actions you would or would not want taken in crucial medical situations.

**It is very important for you to remember that this is *not going to produce a legal document for you!*** The only legally binding part you will have on record is the Advance Health Care Directive found in Section 9. The intention of this workbook is to give you an opportunity to make your preferences known so that you can discuss them with your doctor, the person you choose to speak on your behalf if you are unable in the future, and your support circle (family or other loved ones). There is no “one-size-fits-all” formula for advance planning, so choose what parts of this workbook are best for you.

One issue that has been prominent in the media and in health care concerns the dilemma doctors and loved ones face when they don't know what a patient would want to have happen in a critical medical situation because the patient is unable to communicate. This leaves some very agonizing decisions up to people who haven't been given direction as to preferences for actions taken. Often this ambiguity, along with prevailing attitudes among some health care providers, has led to the devaluing of the lives of people with disabilities. Previous research has documented medical viewpoints that consistently view life as being too pitiable, too difficult and too

expensive when disabilities requiring assistive support are involved.<sup>2</sup> Discussing how you find fulfillment in your life and how you overcome barriers despite some limitations may be a real eye-opener to the people around you, including your health care provider!

These are complicated and serious ideas to consider. It is our hope that having questions to get you started will make this task easier.

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<sup>2</sup> Abramson, N. 2000. *Quality of Life: Who Can Make the Judgment?* Journal of Medical Ethics, January.  
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### 3. What is a “Living Will?” What is a “Will to Live?”

Before going further, it is very important to establish the differences between the terms “Living Will” and a “Will to Live.”

An **Advance Health Care Directive** (sometimes called a living will) is a legally binding document set out by a competent person that indicates your health care preferences should you become critically ill and unable to speak for yourself. The Advance Care Directive can be found in Section 8 of this workbook.

It is important to know that patients **have the right to refuse, but not to demand, treatment.** The **Advance Health Care Directive** gives you the opportunity to state you want no further measures to sustain life. On the other hand, a **Will to Live** emphasizes that **you want the right to secure rather than refuse treatment.** This workbook gives you the opportunity to make your preferences known to your physician so that he/she can work with you in coming up with a treatment plan. It provides you the chance to express who you are and what you value as a whole person, not just what you want to have done to your physical body when you are ill.

The document you will have made upon completions of this workbook contains a **Will to Live** consisting of a:

- ✓ “My Life” Statement;
- ✓ List of preferences regarding medical treatment, personal care and support; and,
- ✓ Advance Health Care Directive
- ✓ Proxy Directive

You can choose to complete some or all of the parts in this book for your Will to Live.



## 4. Getting Started

### 4.1 What do I need to begin a Will to Live?

- ✓ Recording tools – some suggestions are a recorder device, a notepad for jotting down ideas, or a computer. Or, you could sit with a friend who could fill out the workbook as you talk.
- ✓ A file or binder for collecting articles that express your point of view. Sometimes a poem, story or picture helps stimulate your own thoughts.
- ✓ A quiet space to think.
- ✓ Ways to reflect your thoughts and gain feedback. It might be helpful to do a few questions at a time and then review them privately after a few hours. You might also want to discuss what you've decided with a trusted friend or support circle. It is important to remember that this is about **your** life, and what **you** want to have happen.
- ✓ Reliable, up-to-date information about any pre-existing medical conditions you may have. Knowledge is power, and living in a state of denial will not help you take measures that enable you to live as full a life as possible. However, take caution! **Clinical medical information is valuable, but doesn't necessarily take into account all the other parts of you** – your character, your interests, your passions, your experiences, your social circle and your convictions. It might help to think about plugging medical information into a much larger holistic framework which is the canvas of your life!
- ✓ Start with the **My Life** section first. This gives you a chance to recognize what your priorities are and what you appreciate about your life. It provides a positive framework – from there you can move into the more difficult questions about your preferences in critical medical situations.

## 4.2 What if making a Will to Live feels overwhelming?

Thinking about being in a vulnerable situation such as a critical medical emergency is difficult for most people to imagine, and many avoid it all together. Some people are far less reluctant to make a will for their worldly possessions than to think about what they want to have happen to themselves in an end-of-life situation. You're being brave by undertaking this step! But it's not easy... if you find working on your Will to Live overwhelming, try these suggestions:

- ❖ Focus on the importance of this task. You are empowering yourself and those who may speak for you by taking the guesswork out of a tough situation AND you are exploring what gives your life quality and meaning.
- ❖ Keep a journal to record any difficulties you experience while pondering potential end-of-life questions. Noticing similar issues that come up repeatedly can help you explore and overcome emotional blocks that keep you from going further.
- ❖ Talk about the difficulties of certain questions or the concept as a whole with someone you trust.
- ❖ Search for something – a song, a poem or anything else inspiring that captures the ways you feel about your life, your future dreams and your aspirations.
- ❖ Take a break! BUT, make a promise to yourself to consider working at your Will to Live another time.
- ❖ Remind yourself how rewarding it will be to complete your Will to Live. You will have created something that may alleviate considerable hardship for yourself and those close to you. You are also taking the time to appreciate and reflect on what is most important to you – and that's something many people intend to do and never get around to doing!

## 5. Starting with the good stuff – the “My Life Statement”

### 5.1 BEING: Who I Am

- 1) I am someone in (*circle one*)  
excellent  
good  
fair  
poor health the majority of the time

- 2) My strongest characteristics are
- 
- 
- 

*(Examples might be stamina, determination, strength in a certain part of my body, sense of humour, sensory ability, appearance, or whatever is most appropriate for you.)*

- 3) I like to be:
- \_\_\_ Very physically active;
- \_\_\_ Somewhat physically active;
- \_\_\_ Not very physically active.

- 4) When I am with other people, I feel happy and relaxed when:  
*(check all that apply)*
- \_\_\_ People ask me about myself;

\_\_\_ People show an interest in what I have to say;

\_\_\_ I can choose to do the activities others are doing;

\_\_\_ I have a say in discussions and decisions that affect me;

\_\_\_ I am respected;

\_\_\_ People check with me before they make assumptions about what I can and cannot do.

5) When I am with other people, I can feel upset and anxious when this happens to me:

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6) These are the changes I would like other people to make about their attitudes towards about me:

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7) Making my own decisions about my goals and directions is:

\_\_\_ Very important to me;

\_\_\_ Somewhat important to me;

\_\_\_ Not very important to me.

8) Being independent is:

\_\_\_ Very important to me;

\_\_\_ Somewhat important to me;

\_\_\_ Not very important to me.

9) When I say I want to “live independently,” this is what I mean:

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10) I find my life most stressful when \_\_\_\_\_

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11) When my life changes unexpectedly, this is how I cope: (*check all that apply*):

I improve whatever skills I need to help me with the change;

I get new information to help me with the change;

I talk with others to get new ideas about problems;

I look at the change from a new perspective;

I ignore my problems associated with the change;

I get very depressed;

I get angry at others;

I get angry with myself;

I just want to be by myself;

I cope with unexpected changes very well;

I don't cope well at all with unexpected changes;

other \_\_\_\_\_

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12) Some things that give my life meaning are: \_\_\_\_\_

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*(Some examples might be relationships, religious beliefs, creative expressions – feel free to be general or specific).*

13) I find helping others to be:

\_\_\_ Very important to me;

\_\_\_ Somewhat important to me;

\_\_\_ Not very important to me.

14) My ideas about my own spirituality are:

\_\_\_ Very important to me

\_\_\_ Moderately important to me

\_\_\_ Not very important to me.

15) My sense of hope for the future is:

\_\_\_ Strong;

\_\_\_ I'm not very sure how I feel about it;

\_\_\_ I'm worried about it;

\_\_\_ I don't think about it.

## 5.2 BELONGING: My Place in the World

16) Having a place to call my own like a house or apartment or my own room in a healthcare facility is:

\_\_\_ Very important to me:

\_\_\_ Somewhat important to me;

\_\_\_ Not very important to me.

17) Living in my current neighbourhood is:

\_\_\_ Very important to me;

\_\_\_ Somewhat important to me;

\_\_\_ Not very important to me.

18) My heritage and the traditions of my family

\_\_\_ Make a big difference in what I do every day;

\_\_\_ Sometimes make a difference in what I do;

\_\_\_ Are not very important to me.

19) My support circle includes the following people:

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20) Going to places in my community like shopping centres, restaurants, places of worship, concerts, movies, etc. is:

\_\_\_ Very important to me;

\_\_\_ Somewhat important to me;

\_\_\_ Not very important to me.

21) Doing activities that are interesting and meaningful is:

\_\_\_ Very important to me;

\_\_\_ Somewhat important to me;

\_\_\_ Not very important to me.

22) Learning more about my work or other interests is:

\_\_\_ Very important to me;

\_\_\_ Somewhat important to me;

\_\_\_ Not very important to me.

23) When I think of the social groups to which I belong like clubs, online groups or other activity groups, the ones that mean the most to me are \_\_\_\_\_

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### **5.3 BECOMING: What I Want to Do, What I Want to Be**

24) Skills I don't have but I still want to learn include:

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25) Places I love to visit are:

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26) If I could go anywhere, I would like to see \_\_\_\_\_

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27) If I could choose five words that really describe me, they would be: \_\_\_\_\_

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28) The things I still really want to do or learn include:

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## 6. Treatment preferences

Determining the kinds of treatment you want to receive in critical medical situations can be complicated. It is important to gather reliable information about any pre-existing medical conditions you have. It is also very important to discuss the effects of various treatments with a doctor that you trust. *However, it is impossible to predict all the potential unforeseen circumstances that could occur in a medical emergency; for this reason it is important to communicate clearly about situations in which you want life-sustaining and life-enhancing medical actions taken.*

You may think of yourself as being on a continuum or a journey with several steps along the way. You may or may not prefer different medical actions depending on where you are in that journey. This journey may feel like a circle, with times where you feel sick and other times where you feel very well. In other words, your journey isn't necessarily one where you start out healthy and just keep getting more ill. You may zigzag back and forth.

One way to begin a discussion concerning medical actions is to gather information about medical procedures and treatments and then decide what you would like to have happen. Using the Internet for research can be helpful. There are community access computers at local libraries or other locations where you can go online free of charge.

A critically important person to include in your discussion is your doctor. Asking what each procedure involves for you and the impact it will have on your personal medical situation is key to your decision-making. Different medical procedures affect you at different points in your health journey.

## 6.1 Healthcare preferences

What are your treatment preferences concerning:

*Transfusion of blood and blood products?* \_\_\_\_\_

\_\_\_\_\_

*Cardio-pulmonary resuscitation?* \_\_\_\_\_

\_\_\_\_\_

*Diagnostic tests?* \_\_\_\_\_

\_\_\_\_\_

*Dialysis?* \_\_\_\_\_

\_\_\_\_\_

*Prescription drugs?* \_\_\_\_\_

\_\_\_\_\_

*Feeding or hydration by tube?* \_\_\_\_\_

\_\_\_\_\_

*Mechanical Respirator?* \_\_\_\_\_

\_\_\_\_\_

*Surgery?* \_\_\_\_\_

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*Pain Management?* \_\_\_\_\_

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*Organ transplants?* \_\_\_\_\_

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*Have you had previous experiences with medical technology (using a mechanical respirator, dialysis, tube feeding, intravenous tubes, transfusions, etc.) and if so, is there anything you learned from that experience that you feel a healthcare provider should know? If so, please record it here:* \_\_\_\_\_

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## **6.2 Personal care preferences**

Summarize below what kind of personal care you prefer if you are in a critical medical situation. This can include bathing, dressing, feeding, bathroom routines, teeth, hair or any other kinds of personal care.

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### 6.3 Personal support

- Who do you want to have with you when you are in a critical medical situation?
- What kinds of emotional support will you need?
- Do you want someone with you at all times?
- Are there people you do **not** want to have around you?
- Who should look after your pets and/or your children?
- How do you want your illness explained to others?
- Should someone inform the place where you work (including where you volunteer?)
- Do you want someone designated as a main contact person with whom others in your community can communicate in order to know how you're doing?
- Do you want to see a rabbi, priest, chaplain or other religious leader?
- If you have children, how do you want them to be told of your condition?
- Are there poems, spiritual readings or songs that you want someone to read, even if you are not conscious?
- Do you want a photograph of a special place or a loved one nearby?
- What kinds of actions or times would be offensive to you that others may not necessarily know about?

These are all questions to think about in terms of personal support. Summarize your preferences on the next two pages.

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## 7. Communicating preferences

### 7.1 With your physician

When discussing your Will to Live document with your physician, it might be a good idea to tell the receptionist when you make your appointment that you want to discuss a Health Care Directive and other materials with your doctor, and will need more than a ten minute visit as your time slot.

*Here are some things to remember when visiting your doctor.<sup>3</sup>*

- √ Write down ahead of time what you want to say, including any questions you might have;
- √ Bring a pen and paper to jot down notes during your discussion. You can also ask to bring in a tape recorder if writing is difficult for you or if you think you won't get everything down. Just remember to always ask permission before taping anyone;
- √ Bring someone with you. This serves several purposes. A friend can help you relax - you are having an important discussion, after all – and a friend can remind you of concerns you may have forgotten. You may want to consider bringing an advocate with you who can help you say what you need to say in a clear way and can help you recall what was said afterwards.
- √ Speak up! Be sure to ask questions if there is anything you don't understand. Be sure they are answered to your satisfaction before you leave.
- √ Inform your doctor if there are other health care providers are also involved in your care.

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<sup>3</sup> Creating a Balance in Chronic Disease Partnership. 2002. *A Roadmap for Living Well with Chronic Disease in Manitoba*.

## **7.2 Communicating preferences with your support circle**

Sometimes it is easier to talk about sensitive issues like possible end-of-life situations with a professional like a doctor than it is to discuss it with your friends and family. Illness and dying are often very uncomfortable topics for people who are close to each other – it can remind people about their own mortality or of losses they've experienced in the past.

Here are some suggestions for communicating the contents of your Will to Live document with people you trust.

- Explain that creating a Will to Live isn't a morbid exercise you've done because you want to die. Rather, a Will to Live is about empowerment – you want to be prepared if you find yourself in a critical medical situation. A Will to Live is a tool that helps you communicate important information!
- Explain that a Will to Live is beneficial to your support circle. It will take the guesswork out of a very stressful situation. None of them will have to make decisions on your behalf without clear knowledge of what you want to have happen;
- Inform your support circle regarding the location of your Will to Live document, the name of your doctor, and the name of your substitute decision-maker. Promise to keep them “in the loop” if there are any changes.
- Reinforce that preparing for emergencies is a good exercise for everyone to do, and encourage your friends to complete a Will to Live document for themselves.

## **8. Choosing a Proxy or Substitute Decision-Maker**

One of the most frightening things to consider is a situation where you may be very hurt or ill and you are unable to communicate. Most times we don't even want to think about this because it sounds like a nightmare, but much like fire drills and emergency exit plans, it's more empowering to be prepared than to avoid dealing with situations because they are so upsetting. There are ways to plan for this ahead of time, and part of the work done by the Vulnerable Persons New Emerging Team (VP-NET) Ethics research was to find out effective ways people can make their wishes known if they should become unable to speak for themselves.

### **8.1 Appointing someone to speak on your behalf**

A Proxy is someone you choose and name in your directive to act for you in the event you are not able to make such judgments and speak on your own behalf. Because it is not possible to anticipate every set of circumstances, your Proxy has the power to make health care decisions for you based on what you have told your Proxy about your wishes and the information in your directive.

This definition of a Proxy is used by Manitoba Health, and can be found on their website called "Health Directives in Manitoba." If you live in another province, territory or state, check your legislation because laws about proxies and directives may change from place to place.

Another word for Proxy that is sometimes used is a *Substitute Decision-Maker*.

### **8.2 How to choose a proxy**

It may be an unpleasant thing to do, but imagine who you know that could explain to healthcare providers what they believe would be your choices if you could not speak for yourself. Proxies need to be calm

in a crisis, and firm and clear communicators. Proxies must be reliable and willing to accept the responsibility of acting in your best interest. Proxies may have to make decisions that you never discussed with them, so they need to understand your beliefs, values and wishes. Some people choose family members as their Proxies, but you can choose whoever you think would best communicate your health care choices. Legally, Proxies in Manitoba must be considered mentally competent and at least eighteen years of age.

**It is often recommended that you choose more than one Proxy in case that person is unavailable in an emergency or other situation where you can't speak for yourself.** If you choose two or more Proxies, you must decide how you want them to work together. One option is to list them in order so that health care providers would contact the first one, and if that person is unavailable or unable to make the required decision within the required time, the health team would move on to the next Proxy on your list. Your other choice is to have your Proxies work as a team. If you decide two (or more) Proxies should act jointly, they will act together on your behalf. **It is important to make sure that your Proxy (or Proxies) understands what is expected and is willing to speak and act for you.** Your Proxy must try to make the same health care choices that you would make in that situation, and follow any instructions you have given. Your Proxy only acts for you when you are unable to make decisions for yourself.

Four very important things to remember when you choose your Proxy or Proxies are:

**1. You do not need to hire a lawyer to legally appoint your Proxy or Proxies. However, it is a good idea to make your lawyer and your doctor aware that you have named your Proxies, and to leave a copy of your Health Care Directive with them.**

**2. Make sure you write the name of your Proxy or Proxies on your Health Care Directive so that your choice is legally documented.** Some people make the assumption that family members are automatically the ones health care providers turn to if a patient is unable to communicate. This may often be the practice, but

it is not legally binding. If you legally appoint a Proxy or Proxies by writing their names down on your Healthcare Directive, **you have made the decision as to who speaks for you, and that must be respected by health care providers.**

**3. *Make sure you discuss the values and beliefs that affect your health care decisions openly and in detail with your Proxy or Proxies.*** It is impossible to predict every possible healthcare problem you might face in the future, but with the help of some of the questions found throughout this series, you can discuss with your Proxy or Proxies what is important to you in terms of the quality of your life.

**4. *Stay in touch with your Proxy or proxies.*** Keep all information about yourself current and up-to-date. This means that each of your Proxies must have the most recent copy of your Health Care Directive with the document that names your Proxy or Proxies. Anytime your health condition changes in ways that could have an impact on decisions about your care, your Proxy needs to know.

### **8.3 What should I discuss with my proxy?**

You need to stay in touch with your proxy or proxies, but they also need to keep in contact with you. If they have a change in telephone number, address or other contact information, they need to let you know so you can keep your Health Care Directive up to date.

Discuss all relevant information about your health care, including prescriptions and other treatments you currently use.

Explain as much as you can about what you want to have happen concerning any decisions regarding your health care. You might want to give specific instructions about certain decisions. Your Proxy or Proxies need to know enough about your values and beliefs that they can make decisions based on what they believe to be in your best interest.

If you have regular care routines, like using a catheter, tube feeding or massage for circulation, your Proxy or Proxies should know enough about these routines to explain them to a health care provider.

We have included a sample of a memorandum that shows how you can record the names of your Proxy or Proxies in a Health Care Directive on the next page.

## 9. Legal documents

### ***Memorandum re proxy(s)***

To: My Health Care Providers

From:

Subject: My Health Care Directive

Date:

Attached please find a copy of my ***Health Care Directive***.

You will note that, as provided by Manitoba's ***Health Care Directives and Consequential Amendments Act***, I have opted to execute a ***Proxy Directive***.

Although not required by Manitoba's legislation, I have asked that my Proxies indicate their willingness to act in this capacity by initialing the form in the space next to their names. I appreciate that at the point when this Directive takes effect (i.e. when I am unable to make decisions for myself), circumstances may prevent one or more of them from acting as my Proxy.

I have taken an opportunity to talk with them about my feelings and wishes regarding my health care. I am confident that they appreciate what I consider to be "appropriate" health care in various circumstances.

Because I recognize that it is impossible to predict every possible eventuality, it is my wish that my Proxies undertake, to the best of their ability, to communicate my actual preferences and, if that is not possible, to faithfully represent what they believe to be my interests.

As well, although not required by Manitoba's legislation, I have asked \_\_\_\_ (# of proxies) individuals to witness my signature on the original copy of the ***Health Care Directive***. Neither of these individuals is one of my Proxies or a spouse of same.



## Advance Health Care Directive

***Note: This form is taken from the Manitoba Health Website. See <http://www.gov.mb.ca/health/livingwill.html>***

### Health Care Directives in Manitoba

#### **What is the purpose of a Health Care Directive?**

As a Manitoba citizen 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 the power to make medical decisions for you should you ever be unable to make them yourself.

#### **Why should I fill out a form?**

Due to accident or illness, you may become unable to say or show what treatment you would like, and under what conditions. If you have signed a directive, those close to you and the health care professionals treating you are relieved of the burden of guessing what your wishes might be.

#### **How do I make a Health Care Directive?**

The Manitoba government has prepared a form for your convenience (see following pages.) The form serves as a guide for providing the appropriate information. However, **any paper that is signed, dated and provides the same information may be used.** A directive may be made by anyone capable of making a health care decision and understanding the consequences of that decision.

#### **Who do I talk to about these decisions?**

It is strongly recommended you talk to your doctor before completing the directive. This will ensure your instructions are clear and easily understood by those who provide treatment. Your choices should then be clearly typed or printed.

#### **What is a proxy?**

A proxy is someone you choose and name in your directive to act for you in the event you are not able to make such judgments and speak on your own behalf. Because it is not possible to anticipate every set of circumstances, your proxy has the power to make health care decisions for you based on what you have told your proxy about your wishes and the information in your directive.

### **Who do I choose as my proxy?**

The choices you make in a directive are very personal. The person(s) you choose to represent you should be close friends or relatives who are willing to accept this responsibility. You should discuss your wishes openly and in detail with them. It is wise to name more than one proxy in case one is not available when needed.

If you designate two proxies, you must decide how you want them to work, either independently or together as a team. If you decide the two proxies should act **jointly**, they will act together on your behalf. If you decide they should work **consecutively**, the second proxy will be contacted if the first is not available or unwilling to make the required decisions at the required time.

It is important to make sure that your proxy (or proxies) understand(s) what is expected and is willing to speak and act for you.

### **Can I change my mind about my directive?**

A Health Care Directive should be a record of your current wishes. If at any time you wish to change the content or the proxies you have listed, all copies of your old directive should be destroyed and a new directive written.

### **What is the effect of a Health Care Directive?**

The wishes you express in your directive are binding on your friends, relatives and health care professionals *unless they are not consistent with accepted health care practices* and will be honoured by the courts. However, health care professionals treating you are not obliged to search for or ask about a signed directive. It is important to be sure that family, friends, your doctor and your proxy know you have a directive and know where it can be found.

For more information contact: **your regional health authority.**

**Manitoba Health Care Directive** (Please type or print legibly)  
**This is the Health Care Directive of**

Name \_\_\_\_\_  
Address \_\_\_\_\_ City \_\_\_\_\_  
Province \_\_\_\_\_ Postal Code \_\_\_\_\_  
Tel (\_\_\_\_) \_\_\_\_\_

**PART 1 – Designation of a Health Care Proxy**

You may name one or more persons who will have the power to make decisions concerning 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.

**Proxy 1**

Name \_\_\_\_\_  
Address \_\_\_\_\_  
City \_\_\_\_\_  
Province \_\_\_\_\_ Postal Code \_\_\_\_\_  
Telephone (\_\_\_\_) \_\_\_\_\_

**Proxy 2**

Name \_\_\_\_\_  
Address \_\_\_\_\_  
City \_\_\_\_\_  
Province \_\_\_\_\_ Postal Code \_\_\_\_\_  
Telephone (\_\_\_\_) \_\_\_\_\_

*(check  $\surd$  one choice **only**.) For an explanation of “consecutively” and “jointly” please see the previous page 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  $\surd$  one choice **only***).

- With **no** restrictions  
 With **restrictions as follows:**

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**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 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.

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**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 \_\_\_\_\_

## 10. Conclusion

Congratulations! You've done some extraordinary and important work! There are only a few tasks left for you to do. Here is a check list:

- \_\_\_ Fill out your wallet sized Will to Live card in *Section 10* of the workbook.
- \_\_\_ Find a safe place for your Will to Live document, and inform your substitute decision-maker and another designated person as to its whereabouts.
- \_\_\_ Make an appointment to discuss your Will to Live with your doctor. Make a copy for her/him. If you have more than one doctor, inform them as well.
- \_\_\_ Choose your substitute decision-maker and give that individual a copy.
- \_\_\_ Provide copies to any other designated persons (a second proxy, your attorney, or other appropriate persons.)
- \_\_\_ Inform your support circle of the existence of your document.

## 10.1 A few self-assertion tips

It can be difficult to stand up for yourself. Asking questions and being persistent in getting answers can be very intimidating, especially when you're dealing with busy professionals. Talking about end-of-life care decisions with friends or family members can be hard work – and it's even harder when they are uncomfortable with illness, disability or the thought of you facing a critical medical circumstance.

Situations where you need to assert yourself are often easier if you have the support of like-minded persons or a group with an understanding of the issues you face. It's also important to stand strong when others aren't really listening to you or are trying to pressure you to do something that isn't in your own best interest. Here are a few self-assertion tips:

- Use assertive body language
  - Maintain direct eye contact
  - Maintain as erect a body posture as possible
  - Maintain a firm tone of voice
  
- If you need to say “no” in a situation that you believe is not good for you, don't make your “no” sound like an apology. Be direct and clear. Saying the word “No!” has far more power than phrases like, “I really don't know,” or, “Well, I don't think so.”
  
- When you need to advocate for yourself with health care professionals, it is important to:
  - Educate yourself about your medical condition, symptoms, and treatment;
  - Get the facts;
  - Decide what you want (even if all you want is help in understanding your options);
  - Gather your support from people who understand the issues
  - Express yourself clearly and simply, and assert yourself calmly;
  - Be firm and consistent;
  - Follow up so that you're sure you understand what was discussed.

# ASSERTIVENESS RIGHTS

You have the right to...

- **Say, “No!”**
- **Be proud of what you do**
- **Change a situation**
- **Say, “I don’t understand – tell me again.”**
- **Say, “I don’t agree.”**
- **Be treated with respect**
- **Express your needs, opinions, thoughts, ideas and feelings**
- **Have a support system**
- **Take pride in your body and define attractiveness in your own terms**
- **Be yourself and have a separate identity**
- **Ask for help and receive information**
- **Have privacy**
- **Say, “I’m not willing to accept that.”**
- **Grow, learn, change and value your experiences**
- **Recognize YOUR needs as important.**

## 10.2 Wallet sized Will to Live notice

Name _____	If I can't communicate call my proxy immediately
Address _____	Proxy _____
MB Health # _____	Phone # _____
ATTN: I have directives for medical care on file.	Alternate _____
These are located _____	Phone # _____
_____	

*Instructions:*

Remove card and fold in half to fit into wallet