Book 3

“Let’s Talk…”

About Making An Advance Care Plan for Personal Care

This guide takes a closer look at planning ahead for your health and medical care decisions…

London Health Sciences Centre
Regional Renal Program

Acknowledgements

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Content from Fraser Health's Advance Care Planning publications (www.fraserhealth.ca) and St. Joseph's Healthcare Hamilton used with permission.

Additional resources used in the creation of this document include:

Respecting Choices (2008) Gundersen Lutheran Medical Foundation, Inc., 1900 South Ave, ALEX, LaCrosse, WI 54601

A Guide to Advance Care Planning (2006) Government of Ontario, Queens Printer for Ontario
A free copy is available by calling: 1-800-518-7901

Powers of Attorney (2004) Ontario Ministry of the Attorney General, Office of the Public Guardian and Trustee 595 Bay St. Suite 800, Toronto, ON, M5G 2M6. Queens Printer
www.attorneygeneral.jus.gov.on.ca/english/family/pgt

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Introduction

Advance care planning is something everyone needs to think about. The time may come when you are unable to speak for yourself about your wishes for your personal care. This can happen if you become very ill or seriously injured.

Advanced Care Planning for Personal Care includes:

- Health care
- Food and Nutrition
- Living arrangements and housing
- Clothing, hygiene and safety

This book covers making decisions about your health care treatment.

It is important to have someone you trust prepared to speak on your behalf. As discussed in books 1 and 2, you must complete a Power of Attorney for Personal Care to name the person you wish to be your substitute decision maker. Otherwise, the Health Care Consent Act 1996 tells Health Care Providers who they can talk to in the event that you are incapable and a medical decision is needed. In this book you will find a Power of Attorney for Personal Care document for you to complete. If you have already completed a POA for personal care, this workbook can still be helpful in developing an advance care plan.

Each person has a different idea about what is most important to them in life. Getting an Advance Care Plan ready helps you decide:

- How much illness you are willing to live with
- The amount of medical treatment you would consent to, and how to make sure your wishes are followed
- How to make sure your wishes are followed

You can speak, record or write your thoughts and wishes that you want your Substitute Decision Maker to follow. This process is called Advance Care Planning.

Your Feelings…

When you have kidney disease, you may feel emotionally stressed, tired, sad and depressed. These feelings are caused by the many ways your illness impacts your life.

As you think about what makes life “good enough”, you may need emotional and spiritual support. There are many people and resources to help you. Talk to your doctor, nurse, social worker, chaplain or spiritual leader for support and guidance.

Steps for Advanced Care Planning for Personal Care

Here are the steps to follow. These steps take time to complete. Feel free to ask for help any time along the way.

- **Step 1**- Think about your values and beliefs
- **Step 2**- Pick your Substitute Decision-Maker
- **Step 3**- Complete the legal document naming your Substitute Decision-Maker (Power of Attorney for Personal Care)
- **Step 4**- Complete your Advance Care Plan
- **Step 5**- Make your wishes known to others

We will explain each step in this book.

Step 1 – Think about your values and beliefs

The first step starts with thinking about your own values and beliefs. For example, what sparks joy in your life? What makes life worth living for you? What spiritual/cultural beliefs are important to you? You may want to talk to friends and family members about their beliefs. This can help you think about what you believe and value about your life.

You may also want to talk to any member of your health care team such as your doctor, nurse, social worker or chaplain for more information.

∞ A Story ∞

A family had always been very helpful in supporting the health and happiness of their mother who was on dialysis. They enjoyed doing this because they loved her deeply.

The mother knew that other health problems would develop over time. She wanted to speak with her children about how much medical treatment she would be willing to accept, in case she ever became unable to speak for herself. At first the family did not want to talk about this. The mother told them that this was important to her. They agreed to get together to listen and talk.

The mother talked to her family about her wishes for her personal care. She shared her feelings and her thoughts with her children. After, the family was relieved to know what their mother wanted. They felt more prepared and peaceful. The mother also felt good about the future knowing that with her guidance her children would make decisions in her best interest.

The Gift of Health

Some people look at life as a gift. When we lose some of our health we often appreciate life more. If a time comes when sickness replaces health some people feel that life is less of a gift. At times like this, it is important to think about how far you want to go in receiving medical treatments to stay alive. These medical treatments could make you live longer, but they may not make you feel better. Some of these treatments could add to pain or make you feel very sick. These are hard but important decisions to make.

You do have choices. If a time comes when you are unable to express your choices, it is best to have a person who understands what your choices would be to speak for you.

On the next 2 pages, you will find a Self-Reflection Guide to help you with Step 1.

Self-Reflection Guide

Take some time to think about these questions. Your answers will help you decide how to guide your Substitute Decision-Maker.

What do I enjoy most in my life? Who do I enjoy most in my life?

_____

_____

_____

_____

What gives meaning to my life?

_____

_____

_____

_____

If I became seriously ill and could not do the activities I enjoy now, what and who would still give me happiness?

_____

_____

_____

_____

When I remember the deaths of people I have known, what memories stay with me?

_____

_____

_____

_____

If I think about my own death, what worries or concerns do I have?

_____

_____

_____

_____

What are my personal, religious or cultural beliefs around life and death?

_____

_____

_____

_____

What has my doctor told me about my health condition and how this will affect my future?

_____

_____

_____

_____

My thoughts about dialysis are……

_____

_____

_____

_____

∞ End of Self-Reflection Guide ∞

Step 2 – Pick your Attorney for Personal Care

Think about who knows you best, who you trust, and who would be able to follow your wishes. This person should be able to set aside his or her own personal wishes, and make choices that are in your best interest. You want this person to make the same choices that you would make if you could.

Ask this person if he or she will be your SDM. When a person agrees, arrange a time to get together to talk. Since this is a serious discussion, pick a good time and place to talk. You want to feel relaxed so you can express your wishes without worrying about time or being distracted.
When you meet, share your values and beliefs with your SDM so he or she will understand your feelings and thoughts. This will help your Substitute Decision-Maker "stand in your shoes" if ever the time arose.

If you are currently living with kidney disease, or if you are on dialysis, or you have had a kidney transplant it is difficult to predict when a complication may occur and decisions may need to be made on your behalf. If a time comes that you are incapable of making decisions for yourself, some of the questions your SDM will need to be able to answer for you are listed below:

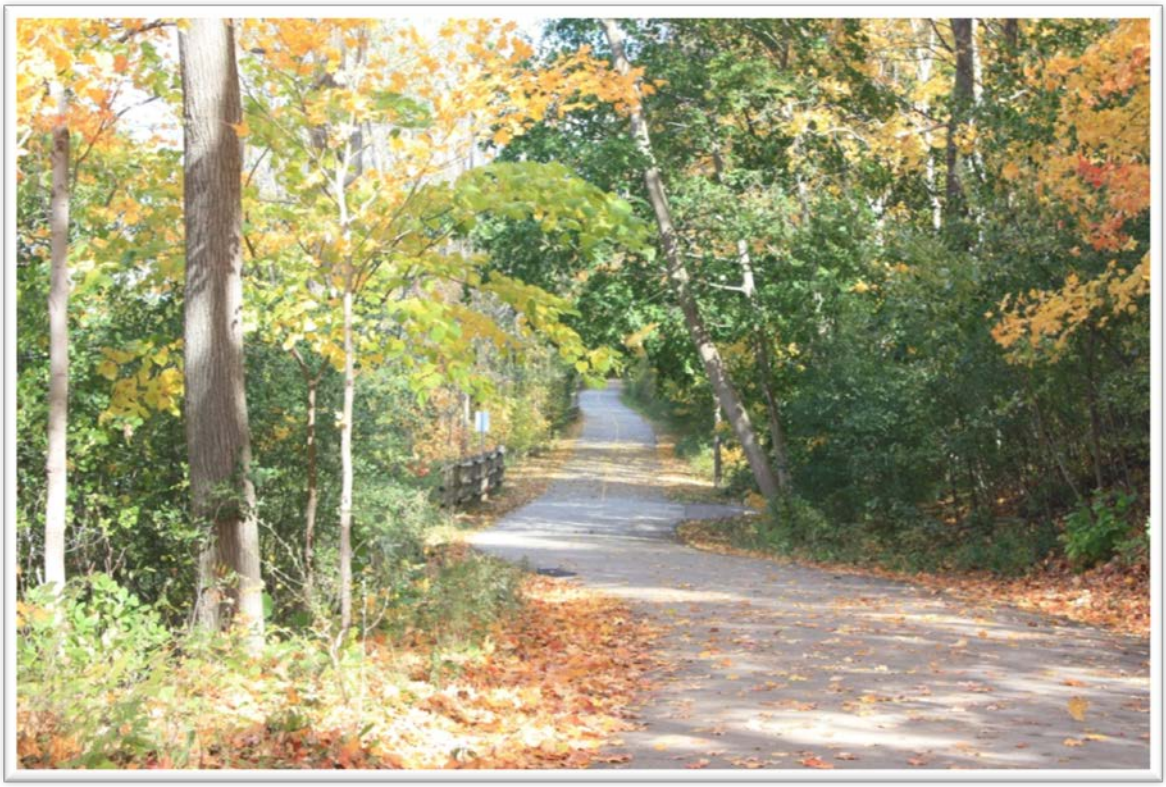
Do you want…

- To accept cardiac resuscitation if your heart or breathing unexpectedly stop? To start, continue or stop dialysis?
- To apply for long-term care, if you could no longer live in your own home?
- To have surgery no matter what?
- To be started on a feeding tube?
- To have a blood transfusion or blood product?
- To go to Intensive Care and be on a breathing machine?
- To have a breathing machine turned off and have a pain free death?

More information for your SDM is in Book 2 “Let’s Talk… About The Role of the Substitute Decision Maker”. You can ask for a copy from your renal health care team. Give it to your SDM to read before you meet to talk to them about becoming your Attorney for Personal Care.

Remember…

- If you wish, you can have more than one Substitute Decision Maker
- If there is more than one, they should get along so they can talk and support each other
- If you have more than one Substitute Decision Maker, you need to meet with each, or both together to talk about what your wishes are
- Talk to your Substitute Decision Maker if there are any changes in your health or in your health care wishes



Step 3—Complete a Power of Attorney for Personal Care

You need to complete this step for each SDM you have chosen.

The document is called "Power of Attorney for Personal Care." This legal document names your SDM:

- You must complete this document and sign it.
- You must have 2 witnesses watch you sign the form. They must sign the document as well.

You do not need a lawyer to complete a "Power of Attorney for Personal Care." However, some people talk to a lawyer to get advice and have a document that meets their specific needs.

If you do not complete a "Power of Attorney for Personal Care," the Health Care Consent Act (1996) picks your SDM for you. The order of people who can make decisions for you is:

1. Your spouse, common-law spouse or partner
2. Your child if 16 years of age or your parent
3. Your brother or sister
4. Any other relative by blood, marriage or adoption
5. The Office of Public Guardian and Trustee

You can find a copy of the "Power of Attorney for Personal Care" form on Pages 14-16.

Remember…

Any time you change your Substitute Decision Maker:

You must notify your previous SDM in writing of this change

- You need to complete a new POA for personal care, naming your new SDM
- The document with the latest date must be followed
- Ask for help from someone you trust if you do not understand parts of this document.

Ontario

Power of Attorney for Personal Care

(Made in accordance with the Substitute Decisions Act, 1992)

1. I, _____ revoke any previous power of attorney for
   (Print or type your full name here)

   personal care made by me and APPOINT:

   _____
   (Print or type the name of the person or persons you appoint here)

   to be my attorney(s) for personal care in accordance with the *Substitute Decisions Act, 1992*.

   [**Note**: *A person who provides health care, residential, social, training, or support services to the person giving this power of attorney for compensation may not act as his or her attorney unless that person is also his or her spouse, partner or relative.]*

2. If you have named more than one attorney and you want them to have the authority to act separately, write the words "jointly and severally" here:

   _____
   (This may be left blank)

3. If the person(s) I have appointed, or any one of them, cannot or will not be my attorney because of refusal, resignation, death, mental incapacity, or removal by the Court, I SUBSTITUTE:

   _____
   (This may be left blank)

   to act as my attorney for personal care in the same manner and subject to the same authority as the person he or she is replacing.

4. I give my attorney(s) the **AUTHORITY** to make any personal care decisions for me that I am mentally incapable of making for myself, including the giving or refusing of consent to any matter to which the *Health Care Consent Act, 1996* applies, subject to the *Substitute Decisions Act, 1992*, and any instructions, conditions or restrictions contained in this form.

5. **INSTRUCTIONS, CONDITIONS and RESTRICTIONS**
   Attach, sign, and date additional pages if required. *(This part may be left blank.)*

_____

_____

_____

_____

_____

_____

_____

6. **SIGNATURE:** _____ DATE: _____
   (Sign your name here in the presence of two witnesses.)

   ADDRESS:_____
   (Insert your current address here.)

7. WITNESS SIGNATURES:

*[**Note:** The following people cannot be witnesses: the attorney or his or her spouse or partner; the spouse, partner, or child of the person making the document, or someone that the person treats as his or her child; a person whose property is under guardianship or who has a guardian of the person; a person under the age of 18.]*

Witness #1: *Signature:* _____ *Print Name:* _____

Address: _____

_____ *Date:* _____

Witness #2: *Signature:* _____ *Print Name:* _____

Address: _____

_____ *Date:* _____

Continued on next page

Please complete the following information:

Power of Attorney for Personal Care
Contact Information

My Information:

First Name: _____

Middle name(s): _____

Last Name: _____

Date of Birth: _____

My Attorney for Personal Care or Substitute Decision-Maker is:

1) First Name: _____

Last Name: _____

Address: _____

_____

Home Telephone Number: _____

Work Telephone Number: _____

Cell Phone Number: _____

2) First Name: _____

Last Name: _____

Address: _____

_____

Home Telephone Number: _____

Work Telephone Number: _____

Cell Phone Number: _____

Step 4 – Complete your Advance Care Plan

It's Your Choice

Throughout your life you have been making important personal choices about where you live, your home, who you want to marry, what kind of work you do, and so on. And yet, one of the **most important personal choices** facing you is your **choice for future medical care** if you are not able to communicate your wishes. Who decides when enough is enough? You do. Or at least, you should. It is important to decide what kind of care you want while you are capable of making your own decisions.

As you get ready to complete your Advance Care Plan, consider the following scenarios……

Imagine that without warning, you come down with a life-threatening illness. You are in a hospital intensive care unit. Despite the best medical treatment, your physicians believe that it is unlikely you will return to your previous quality of life. You are no longer able to communicate with anyone. Your heartbeat and breathing can only continue with artificial life support.

Imagine your ability to make your own decisions is gone and you live at a residential care facility. You can feed yourself but you no longer know who you are, who your family members are, or what happens from one moment to the next. You will never regain your ability to communicate meaningfully with others, and will likely become worse over time.

Imagine that the progressive chronic illness you have been living with has reached a point where active treatment is keeping you alive but your quality of life is poor. The doctors have told you that there is nothing they can do to fix how you are feeling. You will continue to experience a slow, steady decline in your health and well-being. Continuing treatment is an option, but is it what you want at this time?

You can state your wishes verbally, record them (audio, video or DVD) or write them down. If you decide to state or record them, you can still use the document starting on page 16 to guide your statements.

We recommend that you write your wishes. This way, your Attorney for personal care will not have any problems telling members of the health care team and others what your true wishes are.

As you read through this form, cross out any parts of the plan you are not choosing. Make sure you sign the completed form in front of two witnesses.

You do not need a lawyer to complete an Advance Care Plan. However, some people talk to a lawyer to get advice and have a document that meets their specific needs.

You may choose to complete an Advance Care Plan (pages 19-24). Once completed attach this to your power of attorney for personal care document.

If you are currently receiving dialysis, please provide a photocopy of your POA for personal care, Advance Care Plan and contact information for your health care chart.

My Advance Care Plan for Personal Care

∞ Part 1 ∞

It is important to know that every time you come to hospital, when you start dialysis, or when your health changes, you will likely be asked what your wishes are if your heart or breathing should stop. Some people are surprised by this question, but it is asked of everyone. Therefore it is important for you to understand what the question means, and think about what is important to you, and what your wishes would be. Your doctor can give you an idea of what your prognosis for resuscitation would be based on your health. Your doctor may not recommend CPR as a treatment.

CPR refers to medical treatments used to restart a person's heart and breathing when their heart and/or lungs stop working. CPR includes bag-to-mouth breathing and pumping on the chest. It may include having electric shocks and IV drugs to get the heart pumping and a breathing machine to push air into the lungs.

CPR may work in an emergency when the heart stops and a person is otherwise healthy. However, for a person at the natural end of his or her life, or with a life-threatening injury or medical illness, attempts to restart the heart likely will not work. Your doctor may not recommend CPR as a treatment.

You have the right to refuse CPR.
If you want to refuse CPR tell your doctor:

- If you are in a hospital, health care centre, or residential care facility, your doctor must sign a doctor's order for "No CPR".
- If you are at home, your doctor must sign an Ontario-wide "No CPR" form for ambulance attendants and others to follow.

1. Read the next 2 statements about CPR.
2. Initial the choice you want.
3. Draw a line through the choice you do not want.

(…) **I want to receive** CPR if medically indicated

OR

(…) **I do not want** CPR under any circumstances. Allow my natural death to occur.

My Advance Care Plan for Personal Care

∞ Part 2 ∞

This section of your Advance Care Plan is dealing with your future wishes. It may be helpful to review the scenarios outlined on page 16, suggesting you imagine possible situations that might occur.

It is your choice to complete this section or not. It is meant to help your SDM make decisions on your behalf if you are no longer able to do so. You should talk to your SDM about these choices. If you chose not to complete this section, it is important that you have a conversation with your SDM about your wishes

This symbol (…) means that you sign your initials inside the brackets to indicate that you want this statement followed. As noted previously, it is recommended you attach your advance care plan to your POA for personal care document. Please also provide a copy for your health care chart.

1. Read the Statement.
2. Put your initials beside the choice you want.
3. Draw lines through the other choices you do not want.

∞ **Statement** ∞

"If I will not likely get well enough to do one or more of the following:

- Recognize my family and friends and/or
- Be able to communicate and/or
- Enjoy life the way I did before
- Or???

(Please use the lines below to describe what is important to your quality of life)

_____

_____

_____

_____

Initial your choice:

(…) I want to have life support with medical interventions such as a feeding tube, intravenous fluids, breathing machine or CPR, if they are medically indicated.

(…) I want a trial period of life support with medical interventions such as a feeding tube, intravenous fluids, breathing machine or CPR if they are medically indicated. If the trial period does not help me recover, then I want these interventions stopped to allow my natural death to occur.

- Please explain what "*recover*" means to you and how long you would want a trial to continue:

_____

_____

_____

_____

(…) I do not want life support with medical interventions, such as a feeding tube, intravenous fluids, a ventilator (breathing machine), or CPR, etc. If any of these interventions have been started, I want them stopped to allow a natural death."

My Advance Care Plan for Personal Care

∞ Part 3 ∞

You must have two witnesses watch you sign your Advance Care Plan. The witness then signs this document as well.

If you cannot sign, but can make your mark or direct someone to sign for you, then your mark or that person's signature must be witnessed. The following individuals may not be a witness:

- Any person(s) named as your Attorney for Personal Care, their spouse, common-law spouse, or partner
- Your spouse, common-law spouse or partner
- Your children or anyone who has legal guardianship
- Anyone who is less than 18 years of age

"**I am thinking clearly. I understand the meaning of the choices I have made. I have made and signed this Advance Care Plan voluntarily."**

My Signature or Mark: _____

Printed Name: _____

Date: _____

"As the substitute decision maker , I have read, discussed and understand the wishes of my loved one, if there comes a time when I need to make decisions on their behalf."

My Signature or Mark: _____

Printed Name: _____

Date: _____

Witness Signature: _____

Printed Name: _____

Date: _____

Witness Signature: _____

Printed Name: _____

Date: _____

∞ End of "My Advance Care Plan for Personal Care" ∞

Step 5 – Make your wishes known to others

During your appointments with your doctor and other health care providers, tell them about your Advance Care Plan. This way, your care providers will know what your wishes are. Bring a copy of your SDMs contact information. Your health care providers can file this in your health records.

Give a copy of your Advance Care Plan to your SDM and anyone who you feel would be involved in making choices for you if you were unable to. Advise them to keep this in a secure place.

Keep a list of the people who have a copy of your Advance Care Plan. If you want to make any changes to the plan, you will need to tell all of these people and give them the changes.

If you used a lawyer a copy can be stored at your lawyer's office.

Changing your Advance Care Plan

You can change your Advance Care Plan at any time. If your health condition changes, it is a good idea to review your plan to see if you want to change anything.

If you make any changes, be sure to collect the old plans and shred them. The most recent plan is the plan that must be followed.

Give a copy of your up-to-date plan to your SDM and anyone who you feel would be involved in making choices for you if you were unable to.

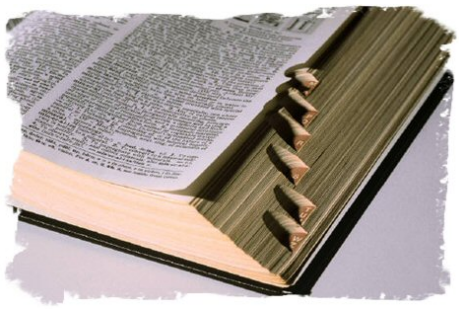
Remember…

You can change your information at any time. Be sure to update your files with everyone involved. The instructions with the latest date must be followed. Shred all old copies if you update your information.

Finally…

We hope that this guide has helped you think about your personal wishes for health care. Please feel free to talk to any member of your health care team. We are here to help you.

Words used in Health Care…



Step 1 also includes learning the words used in Health Care. Here is a list of health care terms in alphabetical order. Talk to any member of your health care team for more information.

Advance Care Plan is a set of verbal, recorded or written instructions that describe what kind of personal care you would want(or not want) if you were unable to speak for yourself. These plans are made by you, for you. You cannot make an Advance Care Plan for someone else.

Advance Directives or Living Will is a document in which you give clear instructions about what medical treatments you would want or not want in various situations. It is always done in a written document.

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

Cardiopulmonary Resuscitation (CPR) refers to medical procedures used to restart a person's heart and breathing when the heart and/or lungs stop working. CPR includes assisted breathing and pumping on the chest. It may include receiving electric shock to restart the heart and machines that breathe for the person.

Dialysis is a medical treatment that cleans the blood, balances the body's chemicals and removes extra fluid when the kidneys can no longer do so.

End-of-life care refers to health care given to a person in the final stages of life. The focus of care is providing comfort for a person nearing death.

Feeding tube is a way to feed a person who can no longer swallow food. It is a small plastic tube that gives liquid food. The feeding tube is placed through the nose to the stomach or directly through the skin of the belly into the stomach or intestine.

Informed consent is a process where a health care provider must explain the risks and benefits of a treatment. After hearing these, the person has the right to have the treatment or not. When the person agrees, he or she must give consent. This can be written or verbal. When a person is unable to make decisions and give consent, his or her Substitute Decision-Maker needs to make the decision

Intravenous is a way to give a person fluids and medications. A hollow plastic needle is put into a vein and attached to a tube that carries fluid. It is also called an IV.

Life support with intervention refers to medical or surgical treatments and procedures such as tube feeding, breathing machines, kidney dialysis, and CPR. All of these use artificial means to restore and/or continue life. Without them, the person would die.

Stopping dialysis is a decision which some people make when the burdens of health problems are felt to be greater than the benefits of continuing. Stopping dialysis means the person would die. When dialysis is stopped, the goal is to provide comfort until death.

Terminal illness means an incurable medical condition caused by injury or disease. This refers to any condition that, even with life support, would end in death within weeks or months. If life support is used, the dying process takes longer.

A ventilator is a machine that helps breathing when a person cannot breathe on his or her own. The breathing machine is attached to a tube in the person's wind-pipe.