



**Kidney and Urinary
Program**

My Advance Care Plan for Personal Care

- a guide for planning your health and medical care decisions
- the documents to complete

This book has been written by members of the Kidney and Urinary Program Advance Care Planning Committee in consultation with the Department of Nursing Practice and Education.

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Introduction

Advance care planning is something everyone needs to think about.

The time may come when you are not able to speak for yourself about your wishes for your personal care. This can happen if you become very ill or seriously injured.

Advance 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 health care treatment.

It is important to have someone you trust prepared to speak on your behalf. This person is called your Substitute-Decision-Maker or SDM.

Each person has a different idea about what a "good enough life" is. Getting an Advance Care Plan for Personal Care ready helps you decide what you want and how to make sure your wishes are followed.

You can tell, record or write the 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 emotional stress, sadness and depression. 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 Advance 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

Step 4 ~ Complete your Advance Care Plan

Step 5 ~ Make your wishes known to others

We will explain each step in this book.

After you have followed these steps you have your Advance Care Plan for Personal Care.

Step 1 ~ Think about your values and beliefs

The first step starts with thinking about your own values and beliefs. 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 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 could 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 type of thing. 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 heart 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

Good health is 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 are hard but important decisions to make.

You do have choices. If it comes to a time when you are not able 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 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?

↻ End of Self-Reflection Guide ↻

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 not able 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 shocks to restart the heart and machines that breathe for the person.

Dialysis is a medical treatment that cleans the blood 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 inserted through the nose or directly into the stomach or intestines.

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 not able 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 interventions refers to medical or surgical interventions 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.

Step 2 ~ Pick your Substitute Decision-Maker

Think about who knows you best, who you trust, and who would be able to stick to what you would want. This person should be able to set aside his or her own personal wishes, and make choices that are in your best interests. 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 heart and mind. Talk to your SDM about the medical treatments listed on page 8 and 9 and how you feel about them. This will help your Substitute Decision-Maker “stand in your shoes” if ever the time comes.

Members of the health care team in the Kidney and Urinary Program have also written a “Guide for Substitute Decision-Makers”. You can get a copy from one of your health care providers in the Kidney and Urinary Program. Give it to your SDM to read before you meet.

Remember . . .

- You can have more than one Substitute Decision-Maker.
- When there is more than one, they can talk to and support each other.
- If you have more than one SDM, you need to do the above with each SDM and keep them informed.

Step 3 ~ Complete the legal document naming your Substitute Decision-Maker(s)

You need to complete this document for each of your Substitute Decision-Makers.

The document is called a “Power of Attorney for Personal Care.” This legal document names your Substitute Decision-Maker(s):

- You must complete and sign this document for each Substitute Decision-Maker you have.
- You must also have 2 witnesses watch you sign the document(s) and then sign the document(s) themselves as well.

You do not need a lawyer to complete a “Power of Attorney for Personal Care.” However, some people consult 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 law picks your Substitute Decision-Maker 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 at least 16 years old) or your parent
3. your brother or sister
4. any other relative by blood, marriage or adoption
5. The Office of the Public Guardian and Trustee

You can find a copy of the “Power of Attorney for Personal Care” form in on pages 13 to 15.

Remember . . .

- Any time you change an SDM, you need to change this document and have 2 witnesses sign the document.
- The document with the latest date must be followed.
- Ask for help from someone you trust such as your health care provider or a lawyer if you do not understand parts of this document.

**Power of Attorney for Personal Care (..... Initials)
(Page 1)**

1. I, _____
(print or type your full name here)

revoke (take away) any previous Power of Attorney(s) for
Personal Care made by me and APPOINT:

(print or type the name of your current Power of Attorney
here)

(print or type the name of your current Power of Attorney
here)

(print or type the name of your current Power of Attorney
here)

to be my Power of 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 this person is also his or her
spouse, partner or relative.

2. If you have named more than one Substitute Decision-
Maker and you want each to have the authority to act
separately, write the words "jointly and severally" here:

(This may be left blank)

Continued on next page →

**Power of Attorney for Personal Care (..... Initials)
(Page 2)**

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

(This may be left blank)

to act as my Power of 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 Power of 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. Signature: Sign your name with 2 witnesses watching:

Signature:

Date:

Address:

Continued on next page →

**Power of Attorney for Personal Care (..... Initials)
(Page 3)**

6. Witness Signatures:

Note: The following people **cannot be witnesses:**

- your Power of Attorney or his or her spouse or partner
- your spouse, partner or child or someone you treat as your child
- any person whose property is under guardianship
- a guardian if you have one
- a person under the age of 18

Witness #1:	Signature:
	Date:
	Address:
Witness # 2:	Signature:
	Date:
	Address:

**Power of Attorney for Personal Care (..... Initials)
(Page 4)**

Note: If you plan to have more than 2 Substitute Decision-Makers make copies of this page before your start.

My information:

Full name:
Address:
Date of birth:
Doctor's name:

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

Full name:
Address:
Home telephone:
Other telephone or cell:

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

Full name:
Address:
Home telephone:
Other telephone or cell:

↪ End of "Power of Attorney for Personal Care" document ↪

Step 4 ~ Complete Your Advance Care Plan

You can state your wishes verbally, make an audio, video or DVD record or write them. If you decide to state or record them, you can still use the document starting on page 18 to guide your statements.

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

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

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

My Advance Care Plan for Personal Care

You should talk to your Substitute Decision-Maker(s) about these choices. You may want to initial your choices here or leave it up to your SDM(s) to decide what to do if the time ever comes.

This symbol (.....) means that you sign your initials inside the brackets to indicate that you want this statement followed.

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

Continued on next page →

**My Advance Care Plan for Personal Care (.....Initials)
about Life Support with Medical Interventions
and Dialysis**

I understand that I am free to accept, trial or refuse life support with medical interventions or dialysis, and that my healthcare providers will support me in my choices.

I also understand that if my life support with medical interventions or dialysis treatment is stopped, I may live for only a few days or up to several weeks, depending on my health and how much my kidneys work. I understand that I will be given the best care possible to keep me comfortable during the time leading to my death.

Continued on next page →

✎ Statement about Life Support with Medical Interventions and Dialysis ✎

“In the event that I become so ill that I likely will never again:

- recognize my family and friends and/or
- be able to communicate and/or
- enjoy the quality of life that is good enough for me, the choices I want are:

1. Life Support with Medical Interventions

(Choose one from this section and initial your choice):

(.....) **I want to have** life support with medical interventions such as a feeding tube, intravenous fluids, or a breathing machine (ventilator) etc.”

(.....) **I want a trial period** of life support with medical interventions such as a feeding tube, intravenous fluids, or a breathing machine (ventilator) etc. If the trial period does not help me recover, then I want these interventions stopped to allow my natural death to occur.”

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

Continued on next page →

2. Dialysis Treatments

(Choose one from this section and initial your choice):

(.....) **I want to have** dialysis treatments continued (or started).

(.....) **I want to have** dialysis treatments continued (or started) for a trial period. If the trial period does not help me recover, I want dialysis stopped and to be kept comfortable until my natural death occurs.

(.....) **I want to have** dialysis treatments stopped and to be kept comfortable until my natural death occurs.

(.....) **I do not want** to have dialysis treatments started. I want to be kept comfortable until my natural death occurs.

Continued on next page →

My Advance Care Plan for Personal Care about Cardiopulmonary Resuscitation (CPR)

Cardiopulmonary Resuscitation or CPR refers to medical interventions used to restart a person's heart and breathing when the heart and/or lungs stop working.

CPR includes bag-to-mouth breathing and pumping on the chest. It may include having electric shocks to get the heart pumping and a breathing machine to push air into the lungs.

CPR can help in an emergency when the heart stops and the person is otherwise healthy. However, for a person at the natural end of his or her life with a serious injury or medical illness, attempts to restart the heart may not work.

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, you will need a signed Ontario-wide 'No CPR' form for ambulance attendants and others to follow. You can get this form from your health care provider.

Continued on next page →

**My Advance Care Plan for Personal Care (.....Initials)
about Cardiopulmonary Resuscitation (CPR)**

↻ Statement about CPR ↻

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

Statement 1:

(.....) **I want** CPR attempted.

Statement 2:

(.....) **I want** CPR attempted unless:

- I have a terminal illness or injury **or**
- My heart has stopped beating and I have no reasonable chance of survival even with CPR **or**
- My heart has stopped beating and the results of CPR would cause me long-term suffering.

Statement 3:

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

Continued on next page →

My Advance Care Plan for Personal Care

You must have one witness watch you sign your Advance Care Plan. The witness then signs the same document.

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 may not be a witness:

- any person you have given "Power of Attorney for Personal Care"
- your spouse, common-law spouse or partner
- your children or anyone who has a legal guardian
- anyone who is less than 18 years old

"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:

Witness signature:

Printed name:

Date:

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

Step 5 ~ Make your wishes known to others

Fill out the Advance Care Planning wallet card at the back of this book and carry it with you.

During your next 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 page 16 that gives your Substitute Decision-Makers' contact information. Your health care providers can file this in your health records.

Give a copy of your Advance Care Plan to your Substitute Decision-Maker(s) and anyone who you feel would be involved in making choices for you if you were not able to. Advise them to keep this in a secure place.

Keep a list of the people who have 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 will 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 Substitute Decision-Maker(s) and anyone who you feel would be involved in making choices for you if you were not able to.

Remember . . . This is Your Plan

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 when you update your Advance Care Plan.

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.



Kidney and Urinary Program

PD 6113 (Rev 02-2016) File: amoulton