



**Humber River
Health** Lighting New Ways
in Healthcare™

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Advance Care Planning

WORKBOOK

Having a say in your healthcare.

Imagine...



1

Without warning, you are in a serious car crash. You are in a hospital intensive care unit. You are

no longer able to communicate with anyone. Your heartbeat and breathing can only continue with artificial life support. Despite the best medical treatment, your doctors believe it is unlikely that you will return to your previous way of life.

You are unable to make most health and personal care decisions. You live in a care facility.



2

You currently feed yourself, but you no longer recognize your family or friends and, at times, forget what your name is and where you are. You will never regain your ability to communicate meaningfully with others. Your condition will become worse over time and eventually, you will forget how to chew, swallow, and breathe on your own.



3

You have been diagnosed with lung and heart disease. Your

healthcare team has shared the typical progression of the illnesses. Together, these diseases are expected to reduce your life expectancy.

The right time to have an **Advance Care Planning** conversation is whenever you say it is.

It is important to have these conversations while you feel well. It is like retirement planning – it is important to start early even if you don't need it for many years.

Your conversations about **Advance Care Planning** may look different based on whether or not you are living with an illness or medical condition!:

If you...	You might...
Do not have a serious illness or condition	<ul style="list-style-type: none"> • Treat Advance Care Planning like insurance for unexpected events • Consider events that have happened to other family members or friends, or that you heard about through media
Live with a serious illness or chronic condition	<ul style="list-style-type: none"> • Learn about your condition • Learn about challenges you might face in the future or common healthcare decisions related to your illness/condition
Live with a serious illness that is in a later stage	<ul style="list-style-type: none"> • Learn about what to expect if the illness worsens • Think about how you have experienced your illness and what you may consider in the future

Ask Yourself...

What is Advance Care Planning?

Advance Care Planning is a process of:

- Deciding who you want to make healthcare decisions for you if you **could not** speak for yourself and making sure this person is your legal substitute decision-maker (see p. 7-8);

AND

- Communicating your **wishes, values, and beliefs** about your health and/or personal care.

Why should we have Advance Care Planning conversations?

- If you get sick or injured in the future and you cannot speak for yourself, these conversations make sure someone who knows what matters to you can make the important decisions about your healthcare needs – because everyone is different.
- When faced with a serious health issue or crisis, these conversations reduce some of the distress, anxiety, and uncertainty that you, your loved ones, and your healthcare providers may experience.
- Evidence has shown that people who plan for their healthcare are more satisfied with the care they receive.

Who should consider Advance Care Planning?

Everyone. You never know when you may face an event or illness where you will be unable to make your preferences known.

When should I consider Advance Care Planning?

Now. It is important to take part in conversations about Advance Care Planning while you still can.

How should I start having Advance Care Planning conversations?

This workbook will guide you through the Advance Care Planning process and can **help** you take the following steps:

- 1 Start thinking about what is important to you (your values, wishes, and beliefs) about your health and healthcare.
- 2 Identify your substitute decision-maker(s).
- 3 Start having Advance Care Planning conversations with others.
- 4 Write down your wishes if you choose.

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About Advance Care Planning

Advance Care Planning is different from a Goals of Care Discussion...

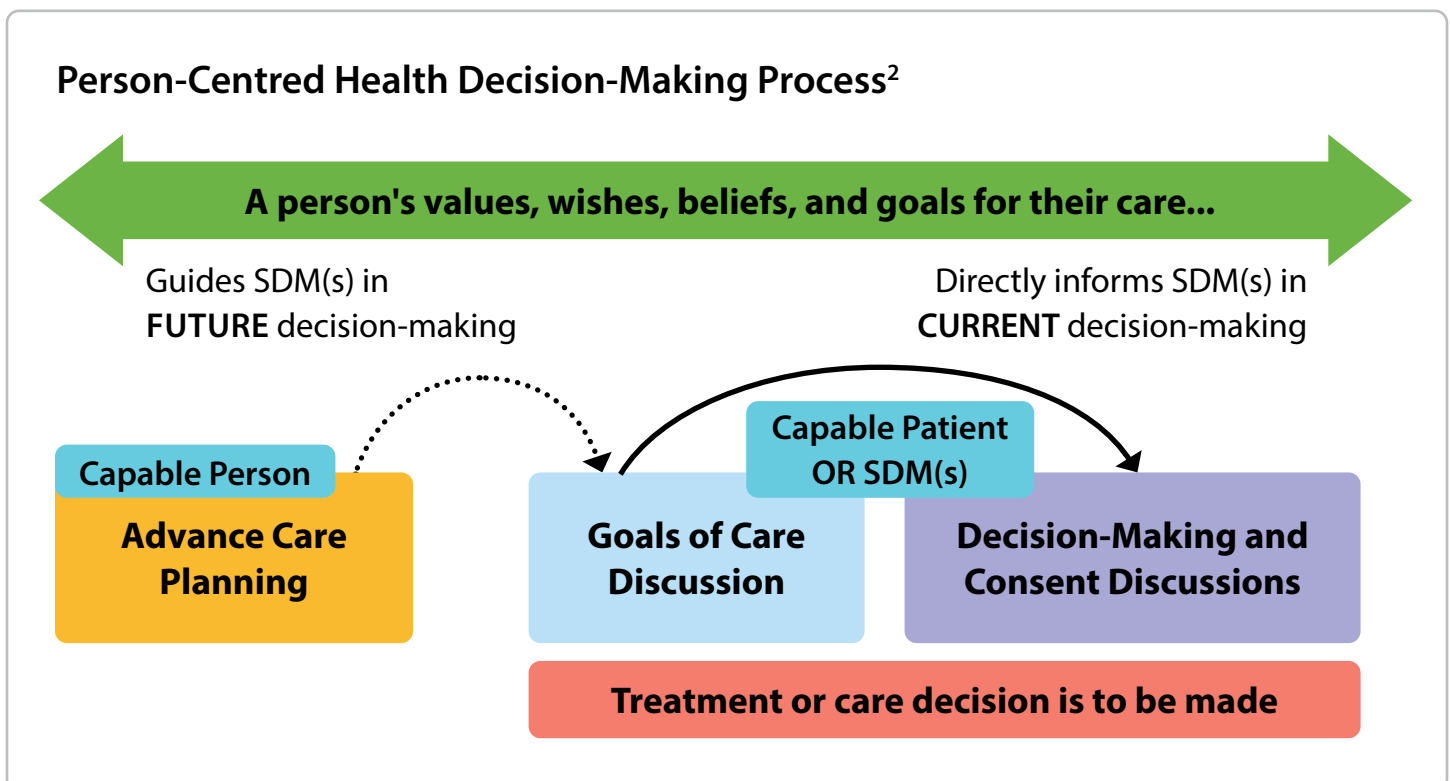
Advance Care Planning is a lifelong process. It is not about making particular decisions. Instead, it is the first step of the person-centred health decision-making process outlined in the image below.

- You can choose to start at anytime. It's best if Advance Care Planning discussions start when a person is capable of making decisions and communicating what is important to them.
- One day, you might not be capable of making treatment decisions, so it's important to learn who will make decisions for you at this time and to tell them what you want for yourself.

- Remember, values and preferences can change over time, so it's good to think about what is important to you and revisit your planning once in a while.

A **Goals of Care Discussion** is informed by, but is not the same as Advance Care Planning. Goals of Care discussions take place after a clinical event has occurred. In this discussion, your healthcare providers will try to:

- Make sure that you and/or your substitute decision-maker(s) understand your condition or illness.
- Understand who you are, what you want for yourself, and which one of your available treatment options suit you the best.



Decision-Making and Consent Discussions

Once a health event occurs, your healthcare team will need to get **informed consent** from you or your substitute decision-maker(s) before they provide a treatment or test. This involves explaining the treatment or test, reviewing the potential risks, benefits, and side effects, suggesting any alternatives (if available), answering your questions, and getting permission to proceed.

Your healthcare team may ask you or your substitute decision-maker(s) to make many kinds of decisions. Examples include decisions about:

- Having tests, surgery, or medical procedures
- Starting treatment or withdrawing life prolonging measures
- Admission to a medical facility
- Moving into in a long-term care home.

Making your own decisions about treatment is a basic patient right. If you are unable to speak for yourself, your substitute decision-maker(s) will be expected to make the kind of decisions you would make for yourself.

Your substitute decision-maker(s) **must** consider the previously expressed wishes or the values and beliefs you held while you were capable when deciding which treatment option is best for you. This is why sharing these wishes with your substitute decision-maker(s) and talking about your values and beliefs during the Advance Care Planning process is so important.



About Mental Capacity and Substitute Decision-Making

What is mental capacity?

Mental capacity is the ability to:

1. **Understand** the information that has to do with making a decision about the treatment, admission, or personal assistance service;

AND

2. **Appreciate** the likely consequences of a decision or lack of decision (saying yes or no).

You are **mentally capable** if you are able to do both of the above. The healthcare provider proposing the treatment will determine if you are mentally capable of consenting to or refusing treatment.

What happens if I am found NOT mentally capable (or mentally *incapable*)?

If your healthcare provider determines you are **mentally incapable**, they will let you know then talk with your substitute decision-maker(s) to make healthcare decisions for you. However, you have the right to ask the Consent and Capacity Board to review that finding. Your healthcare provider must tell you about that right of review.

What is a substitute decision-maker?

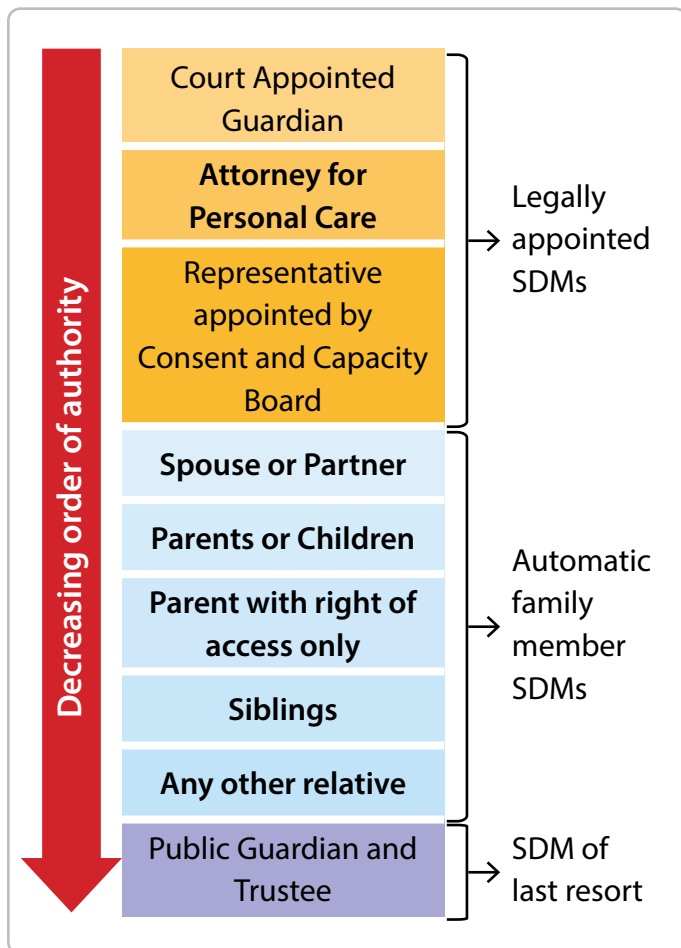
A substitute decision-maker is a person who would make health and personal care decisions on your behalf if you are unable to do so. It is a difficult role.

To make a substitute decision-maker's job easier, it's important that you share your health preferences with them while you are capable. That way, they will have a very clear idea of the choices you would make for yourself.

The first thing your substitute decision-maker has to consider when they make decisions about your healthcare are any relevant wishes you expressed while you were capable (that is, your Advance Care Planning conversations). If you never engaged in these conversations, your substitute decision-maker must try to do what is in your best interests.

How do I identify my substitute decision-maker(s)?

In Ontario, health care law makes sure that everyone automatically has at least one substitute decision-maker. Your healthcare team will use the list on the next page to find the person(s) highest up on the list who is/ are **willing** and **available** to make medical decisions or decisions about long term care for you. To make decisions, substitute decision-makers must also be over the age of 16 and mentally capable of making decisions.



To become an **Attorney for Personal Care**, the person you appoint must be:

- **Willing** to accept the role of a substitute decision-maker
- **Available** in person, by phone or electronic communication, when decisions need to be made
- **Mentally capable** of understanding the treatment/care being proposed and appreciate the consequences of consenting or refusing the treatment/care decision
- At least 16 years old (unless the parent of the incapable person), **AND**
- Free of a court order or separation agreement that prohibits them from acting as your substitute decision-maker(s).

If they meet the above criteria, you must also make sure the person you are considering is also able and willing to:

- Talk with you to understand your wishes, values, and beliefs
- Understand and honour your wishes as much as possible
- Confidentially talk to healthcare providers on your behalf in the language they are most comfortable with (HRH provides language interpretation services)
- Make hard decisions.

For more information, please see our HRH Substitute Decision-Makers brochure. To download the Power Attorney for Personal Care kit from the Ontario Attorney General, see Appendix C, p. 19.

If more than one person on the same line are willing and available to make decisions for you, they all have an equal say when it comes to your care. For example, if you do not have a spouse, but you have 3 children over the age of 16, who all want to help make decisions for you, all 3 must agree when your healthcare team presents treatment options for you.

If you are not satisfied with your automatic substitute decision-maker(s), then you can choose to name a person, or more than one person, to act as your substitute decision-maker(s) by preparing a document called a **Power of Attorney for Personal Care (POAPC)**. A person appointed this way is called an "Attorney for Personal Care."



Write down your thoughts...

Based on Ontario's Health Care Consent Act, write down the names of the people who would be considered each type of substitute decision-maker. How do you feel about the order of the people on the list? If you would like to choose someone other than the person at the top of your automatic substitute decision-maker list, you must fill out a Power of Attorney for Personal Care document (POAPC).

Type of substitute decision-maker	Name
Court Appointed Guardian	
Attorney for Personal Care	
Representative appointed by Consent and Capacity Board	
Spouse or Partner	
Parents or Children	
Parent with right of access only	
Siblings	
Any other relative	
Public Guardian and Trustee	

I would like the following people to be my substitute decision-maker(s):

Name: / Contact info:

Name: / Contact info:

Name: / Contact info:

Disclaimer: This form is not a legal Power of Attorney for Personal Care. Even though you have listed the names of people to be your substitute decision-maker in this workbook, it does NOT mean that these people have the right to act as your substitute decision-maker, unless:

- They are the highest-ranking people in your life on the hierarchy list of substitute decision-maker(s) and meet the requirements of being an substitute decision-maker, OR
- You name them your power of attorney for personal care and they meet the requirements of being an substitute decision-maker.

How to Prepare for Advance Care Planning Conversations

To prepare yourself for Advance Care Planning conversations with your substitute decision-maker(s), consider the following questions³. You may skip questions that do not matter to you.





Understanding

TIP: If you don't understand something about your health, ask questions!



Based on conversations with your healthcare providers about your health or illness, what is your understanding of it?

Do you expect to get better or get cured, or is your illness expected to get worse over time (for example, developing difficulty with memory, swallowing, breathing, walking, etc.)? If so, do you know how quickly this will happen?

Information

For people who have an illness, some like to know as much information as possible. Some people prefer to know as little as possible and prefer to have family or friends speak to healthcare teams and help make decisions.

Would you want to know everything? Would you prefer not to get bad news? If so, who should the healthcare team share bad news with? Is this the same person as your substitute decision-maker(s)? If not, you may wish to reconsider your substitute decision-maker(s).



Values, Beliefs, and Quality of Life

Most people have an idea what a “good life” is. Take time to think about the things that make you happy. Think about what are the most important values and goals for your health. Some people feel it is very important to always maintain hope, even when a person is extremely sick. It is possible to be hopeful and believe in miracles and at the same time think about, talk about, and prepare for the future.

What brings quality to your life?

Examples: Being able to live independently is most important to me. Being able to recognize and communicate with important people in my life is most important to me. Being able to make my own decisions is important to me. Being able to eat and taste food is important to me.

Worries and Fears

Think about the care you might need if you have a critical illness or if you are near the end of your life.

What are your worries or fears?

Examples: Struggling to breathe, being in pain, not being able to talk and make my own decisions, not knowing my family, losing my dignity, depending entirely on others, being alone, being a burden to your family and friends, being given up on too soon, etc.)



Acceptable Trade Offs

If you have a critical illness, your healthcare team may offer life support or life-extending treatments to you with the chance of gaining more time. Think about what brings quality to your life and what you value.

For definitions of various healthcare treatments, please refer to Appendix A, p. 17.

Would it be okay to give up some of your independence and accept help with care so that you can remain at home?

What abilities would you **not** want to lose or trade, even if it meant you might live longer or have more time?

Examples: Being able to communicate, to get out of bed and get around on my own, to interact with others, to control my bodily functions

If the burdens of treatments were significant and painful (for example, CPR), how much time would they have to provide you for them to be worth it?

During that time, what would your quality of life have to be like for the treatments to be worth it?

Are there treatments you would not want if they aren't helping you recover?



Near the End

If you were near the end of your life, what do you not want to happen?

Where might you want to spend the last days of your life? Would you want your family and/or friends present?

Are there any spiritual or cultural rituals you would like performed?

Do you want a particular type of music playing or pictures around you?

What are your wishes for organ and tissue donation when you die?

Starting Advance Care Planning Conversations with your Substitute Decision-Maker

Now that you've had a chance to identify your substitute decision-maker(s) and have thought about what's most important to you, it is time to communicate your wishes to the person you've chosen. This can be written, verbal, and/or recorded.

At some point in the future, your substitute decision-maker(s) may need to make difficult decisions about your care. Sharing what is most important to you will help them make decisions that match your values as much as possible.

Who have you had Advance Care Planning conversations with?

How did the conversations go?

If you are having a difficult time communicating your wishes to your substitute decision-maker(s), refer to Appendix B (p.18) for guidance.





Advance Care Planning Checklist

- I identified my substitute decision-maker(s).
- I was not satisfied with my automatic substitute decision-maker(s), so I completed a Power of Attorney for Personal Care (if applicable).
- I have thought about my healthcare wishes.
- I started discussions about my Advance Care Planning wishes with my chosen substitute decision-maker(s) or attorney for personal care.
- I completed this workbook.



Congratulations on beginning the process!

You have taken an important step by taking the time to work through this workbook and talking with others. Make sure to talk to your future substitute decision-maker(s) about your wishes. They may need to ask you questions to feel confident with what you may want in a situation where you are unable to speak for yourself.

Talk to your family members, friends, doctor and healthcare team. Talking about this now can reduce anxiety and help everyone understand and honour your wishes. These individuals can also help support your substitute decision-maker(s), who may have to make difficult decisions during a stressful time.

This is the greatest gift you can give to your substitute decision-maker(s)!

Appendix A. Examples of Healthcare Treatments

Cardiopulmonary resuscitation

(CPR): Medical procedures we use to try to restart a person's heart and breathing when the heart and/or lungs unexpectedly stop working. CPR can range from breathing and pumping on the chest, to electric shocks that try to restart the heart, and machines that breathe for the individual.

Dialysis: A medical procedure that cleans your blood when your kidneys no longer can.

Feeding tube: A way to feed someone who can no longer swallow food. It is a small plastic tube that carries liquid food. We insert the tube through the nose, or directly into the stomach or intestines.

Intensive care unit (ICU)/critical

care unit (CCU): A unit in a hospital that treats people who are critically ill with the anticipation of recovery. Here, we may care for patients using the following machines:

- **Ventilator:** A machine that helps people breathe when they cannot breathe on their own. We attach a machine to a tube we place down the windpipe.
- **BiPAP:** A breathing machine that helps get more air into and out of the lungs. The machine delivers the air to the patient through a mask.
- **Vasopressor:** A special intravenous medicine (a medicine given through the veins) to raise a low blood pressure.

Intravenous line (IV): A way to give a person fluids or medicine. We place a hollow narrow tube in a vein in the hand, arm or another location.

Tracheostomy: A surgical procedure to create an opening into your windpipe through your neck.

Transfusion: Giving a person blood or blood products through an intravenous line.



Appendix B. Tips on Starting the Conversation

If you would like help starting these Advance Care Planning conversations, please ask your doctor, social worker, pastor, friend, etc. If you are comfortable starting this on your own, there are many ways to get the conversation started. Remember, it may take a few tries to get things started.

Don't feel like you have to have the entire conversation at once. Advance Care Planning is a process. You may change your mind over time, so it's important for this to be an ongoing conversation.

Be straight forward:

- "I have just filled out a workbook about my wishes for future healthcare and I want to share it with you."
- "My health is good right now, but I want to talk to you about what I'd want if I was sick and needed you to make decisions for me."

Find an example from your family or friends:

- "Does anyone know how Jason's sister died? No one has ever talked about it. I wonder if she died at home or in a hospital?"
- "Do you remember my friend Frank who was in a coma for a while? I wonder if there was any argument about keeping him on that ventilator?"

Mention that others have already started the conversation with you:

- "Pastor Jones was talking about our choices for healthcare if something happened, and I realized that I haven't told you about my wishes – we should talk about that."
- "My doctor wants me to think about my future care and to make an advance care plan. Will you help me?"

Find an example from the news:

- "Remember the man who was in a coma for years? I would never want that to happen to me."
- "That story about the family fighting about their mom's care made me realize that we should talk about these things so the same thing doesn't happen to our family."

Appendix C. Useful Resources

Patient and Family Resource Centre (PFRC), Humber River Health

Telephone number: (416) 242-1000 Ext. 81200

Website address: www.hrh.ca/resources/patient-family-resource-centre

Email address: pfrc@hrh.ca

Hours: Monday to Friday, 8:00 a.m. to 4:00 p.m.

Location: Level 0, in front of the Food Court

For electronic, print, and audiovisual collection on health and wellness matters, contact the Patient & Family Resource Centre at Humber River Health. The PFRC will provide information in a language that you can understand. As well, the PFRC can connect you to community resources, including those listed below.



Advocacy Centre for the Elderly (ACE)

Telephone number: (416) 598-2656 Toll-free: 1 (855) 598-2656

Website address: www.ancelaw.ca

Consent and Capacity Board

Website address: www.ccboard.on.ca/scripts/english/common/contactus.asp

Ontario Ministry of the Attorney General (Power of Attorney Kit and FAQs)

Website address: www.ontario.ca/page/make-power-attorney

Advance Care Planning Canada

Website address: www.advancecareplanning.ca

Trillium Gift of Life

Telephone number: (416) 363-4001 Toll-free: 1 (800) 263-2833

Website address: www.giftoflife.on.ca



Special thanks to:

Humber River Health's Corporate Patient and Family Advisory Council

Hospice Palliative Care Ontario

*Winnipeg Regional Health Authority
Alberta Health Services, Calgary Zone
Fraser Health*

References:

¹Adapted from © 2016 by Sunnybrook Health Sciences Centre. *Advance Care Planning Conversations: A guide for you and your substitute decision maker*. Available from: <https://sunnybrook.ca/uploads/1/patients/resources/iii--acp-conversations--guide-for-you-and-sdm-.pdf>

²Adapted from: © 2017 by Dr. Jeff Myers, Dr. Nadia Incardona and Dr. Leah Steinberg. *Components of person-centred decision-making*. Original work is licensed under the Creative Commons AttributionNonCommercial-ShareAlike 4.0 International license. To view a copy of this license, visit: <http://creativecommons.org/licenses/by-nc-sa/4.0/>

³Adapted from © 2016 by Dr Nadia Incardona and Dr Jeff Myers. *ACP Conversation Guide – Clinician Version*. Available from: <http://acpww.ca/wp-content/uploads/2016/01/ACP-Conversation-Guide-Clinician-Version.pdf>. This work is licensed under the Creative Commons Attribution-NonCommercial-ShareAlike 4.0 International License. To view a copy of this license, visit <http://creativecommons.org/licenses/by-nc-sa/4.0/>

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English: This information is important! If you have trouble reading this, ask someone to help you.

Italian: Queste informazioni sono importanti! Se ha difficoltà a leggere questo, chieda aiuto a qualcuno.

Spanish: ¡Esta información es importante! Si tiene dificultad en leer esto, pida que alguien le ayude.