

# Advance Care Planning Conversations: A Guide for You and Your Substitute Decision Maker

## Read this to learn about:

- How you can prepare for having Advance Care Planning Conversations
- What it means to be capable of making a healthcare decision
- Who would make decisions for you if you are not capable of making them in the future
- Preparing your substitute decision maker(s) to make the best possible decisions for you



# Advance Care Planning Conversation Guide

## How will this guide help you?

- GIVES you information about having Advance Care Planning (ACP) conversations.
- EXPLAINS how you, your substitute decision maker(s) or SDM(s) and your family can benefit from having ACP conversations.
- HELPS you understand the role of SDMs and who yours would be.
- EXPLAINS what it means to be capable of making your own healthcare decisions.
- DESCRIBES what to talk about during ACP conversations.
- SHOWS you examples of ACP through the stories of 3 people.

## What are ACP conversations?

- ACP conversations are a way for you to think about what's important to you, what you value in life and about your health.
- ACP is about knowing who your SDM(s) would be **if you are not capable** of making a healthcare decision for yourself (see side box).
- **Important:** ACP conversations are **NOT** about making decisions. Their purpose is to help SDM(s) understand the information that will guide them in making healthcare decisions on your behalf in the future.
- A person uses their values, beliefs and what they consider important in life to make many kinds of decisions.
- Communicating your healthcare wishes and how you make decisions about your healthcare can help prepare both your SDM(s) **and** you to make healthcare decisions in the future.

**If you are CAPABLE of making a healthcare decision it means you are able to both:**

1. Understand the information you need to make the decision

**AND**

2. Appreciate the likely results of making the decision (either saying yes or no)

## How will ACP conversations affect my future care?

- Right now you may be healthy but if you get sick in the future decisions about your healthcare will need to be made.
- **If you are capable**, healthcare providers will talk to you and YOU will make **your own** healthcare decisions.
- If you are **NOT capable**, healthcare providers will talk to **your SDM(s)** to make healthcare decisions.
- Any time your doctor or other health care team member suggests you should have a treatment or test, they must explain things, answer questions and get permission. **This is called consent.**
- Some examples of healthcare decisions that require consent are:
  - Receiving a blood transfusion
  - Beginning a new medication
  - Having tests done such as an x-ray, a CAT scan and a MRI
  - Being admitted to a long-term care facility
- Before providing consent, you or your SDM(s) should ask questions to make sure you understand why a treatment is being suggested and how it might help or harm you.



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- In the future, if your SDM(s) make healthcare decisions for you:
  - Having conversations now can help SDM(s) figure out how you would want decisions made.
  - They will consider things you have said and look to see if you have written anything down about your wishes for future care.
  - They will need to think about the things you have most recently said or recorded that apply to the decision that they must make for you.
  - If you haven't shared any wishes that apply to the decision, your SDM(s) will need to think about your best interests.
- Some people choose to write down details from ACP conversations, but this is not necessary. Even if your wishes have been recorded, healthcare providers must still get consent from your SDM for any care in the future.

## The two most important things about ACP conversations are for you to...

Know who your SDM(s) will be and be sure this is who you want for the role

Share your wishes, values and beliefs with your SDM(s) as these will guide making care decisions in the future

## Why have ACP conversations?

- You will be more likely to have a better quality of life.
- You will be more likely to receive the care that you identified as important to you.
- Your family and friends may be less distressed in the future and have **greater peace of mind** because they will have a better idea of the kind of care you would like.
- Your SDM(s) will understand what is important to you so they can make the best decisions for you in the future.

**Meet Althea, Tran and Bob.** They are all at different stages of their life and are ready to start having ACP conversations.



This is Althea. She is 72 years old and she is healthy other than an occasional cold and arthritis in her left knee. Althea is not married and she has two sisters.



Tran is 48 years old and she recently found a lump in her breast. She has been told that it is early stage breast cancer and is now preparing for surgery. Tran is married and has a son and daughter.



This is Bob. He is 76 years old and was admitted to the hospital for 3 days last week. He was there because he was having trouble with his breathing. Bob has been told he has heart failure. Bob's wife died 6 years ago and he has 3 children.

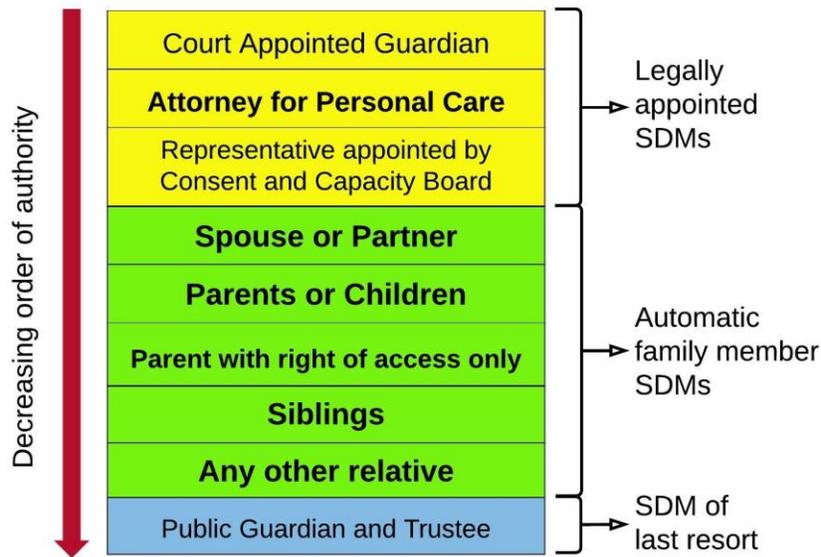


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## Who is your SDM(s)?

- In Ontario, everyone automatically has an SDM(s)...do you know who yours is?
- Your SDM(s) is your closest living family member(s) unless someone else is legally appointed.
- The rank order of people who could be your SDM(s) is shown **in the table below**.
- Green is the list of automatic family member SDM(s) and yellow are legally appointed SDM(s).
- There might be more than one person at the same level. For example, if you don't have a spouse or a partner but have one parent and two children, all three are your SDMs. In the future, if you are not capable, all three would need to agree on any healthcare decision.

### Substitute Decision Maker Hierarchy



Ontario's Health Care Consent Act, 1996

## USING THIS LIST, WHO WOULD BE YOUR SDM(s)? \_\_\_\_\_

Here are the substitute decision makers for our three individual examples:



Althea does not have a spouse or children so both of her sisters are her automatic SDMs.



Tran's husband is automatically her SDM based on the hierarchy. He has had difficulties talking about cancer since they got the news. Tran is worried he might have trouble asking questions and making decisions for her. Even though she is hopeful and positive about her diagnosis, she wants to talk about ACP to lessen any burden on her husband in the future.



All 3 of Bob's children are automatically his SDMs. If Bob loses capacity, all 3 children must agree on decisions. Bob's oldest and youngest child don't get along very well and he worries it will be difficult for them to agree on decisions. Bob decides the best person to be his SDM is his middle child. He completes the Attorney for Personal Care paperwork and now Bob's middle child is his only SDM.



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## What are important qualities of SDM(s)?

Think about who would be your automatic SDM(s):

- Can they talk to healthcare providers and make hard decisions?
- Would they be willing to talk with you to understand your wishes, values and beliefs?
- Would they be able to understand and honour your wishes as much as possible?

## What if your automatic SDM(s) is not right for the role?

- If your automatic SDM(s) is not the person or people you want in the role, you can legally appoint someone else as your Attorney for Personal Care (some call it “Power of Attorney”).
- This can be more than one person but this person or these people would become your SDM(s).

## When is the ‘right time’ to have ACP Conversations?

- **The right time is whenever you say it is.**
- It is important to have these conversations while you feel well.
- It’s like retirement planning, important to start early even if you don’t need it for many years.

ACP conversations may look different based on whether or not you are living with an illness or medical condition:

1. If you do not have a serious illness or a condition

- ACP is like 'insurance' for unexpected events

2. If you live with a serious illness or a chronic condition

- Learn about your condition
- Learn what challenges you might face in the future

3. If you live with a serious illness that is in a later stage

- Learn about what to expect if illness worsens
- Think about how things have changed or stayed the same for you as you have lived with your illness

Learn more about the stories of Althea, Tran and Bob. Which of these ACP conversations is each person likely to have?



Althea hasn’t spent much time at a hospital. During her regular check up, her family doctor asks her about ACP.



Tran has not had any illnesses before her cancer diagnosis. She has not thought much about her health care in the future. When meeting with the team before surgery, the social worker asks if she can speak with Tran about ACP.



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Bob's brother was recently admitted to the intensive care unit of the hospital and Bob visited his brother every day. Before this Bob had not thought about ACP but now has strong wishes about his care. A nurse visits Bob at home since he has come home from the hospital. He asks her about an ACP conversation.

## Tips on having ACP Conversations:

- You may not have answers to some of the questions. That's okay.
- You might be healthy and feel some questions might not apply to you at this point in your life. That's okay too.
- Remember... your SDM(s) will use this information if making decisions for you in the future.
- It can be very distressing for SDMs to make decisions. Your answers to these questions will give your SDM(s) helpful information.
- Your SDM(s) should be part of every ACP conversation you have.
- It can be helpful to also include someone from your healthcare team in an ACP conversation, although it is not required.
- Remember...your wishes, values and beliefs can be told, videotaped or written to your SDM(s).
- If you have opinions or preferences about any treatment (e.g. feeding tubes or machines to help you breathe) be sure talk to your SDM(s) about this.
- **Also, think about WHY you feel the way you do about the treatment.** This might be more important information for your SDM(s).

## ACP Conversation Guide: The Questions

These are the six questions that can make up an Advance Care Planning Conversation:

1. What do you **understand about** your health or illness if you have any? What have you been told?
2. What **information** is important for you to know?
3. What brings **quality** to your life? What do you **value**?
4. If you were critically ill or near the end of your life, what **worries** or **fears** come to mind?
5. What would you **trade** for the chance of gaining more of what you value or what's important to you?
6. If you were near the end of your life, what would make this time **meaningful**?

*Please see the last page for the ACP Conversation Guide questions*



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## A closer look at the ACP conversation questions

The following sections give you more details for each question. Talk about your thoughts and ideas with your SDM(s).

### Understanding

Think about what you have been told about your health and most importantly any illnesses that you have. If you are healthy, the Understanding and Information questions may not be as important.

- Can your illness be cured? (This means will it ever completely heal or get better)
- If it is something like cancer, can treatment take away all of the cancer?
- If it is something like heart disease, will your heart muscle get stronger?
- Will this get worse over time? If so, do you know how quickly this will happen?
- Do you think you may develop difficulty with memory, swallowing or walking?



Althea believes she is healthy other than occasional aches in her joints. She is up to date with her recommended screening tests and leads an active life.



Tran and her cancer team are hopeful she can be cured. They hope all of the cancer cells will be taken out of her body during the surgery. During the surgery the doctors will check to see if the cancer has not spread in her body.



Bob doesn't know if heart disease is something that can be cured. No one has told him whether his heart function will return back to normal. This was the first time Bob was admitted to hospital. He isn't sure if he should expect to have more admissions to hospital for his heart failure in the future.

**Tip:** If you don't understand something about your health, ask questions.

### Information

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

- **What information about your illness that you don't know would be helpful or important for you to know? Is there information about your illness that you don't want to know?**
- If you want as much information as possible, even if it is difficult or "bad news", this is a good time to let your health care team know this about you
- If you would prefer providers to share your medical information with someone else, this would be a good time to let your health care team know who this is

Some people feel it is very important to always maintain hope. This may even be when a person is very, very sick. It is possible to be hopeful and believe in miracles and at the same time think



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about, talk about and prepare for the future. Remember that ACP is about preparing your SDM(s) in the event that you are unable to make decisions for yourself.

Let your healthcare team know if it is important for you to stay hopeful through this conversation. Also, let your health care team know how you would prefer to be given “bad news”.

## Values, Beliefs & Quality of Life

- Most people have an idea of what a “good life” is.
- Take some time to think about the things that make your life good and enjoyable.
- The following **VALUES EXERCISE** is meant to help you think about what is important to you. There are three parts to the exercise.

### VALUES EXERCISE PART 1: WHAT IS IMPORTANT TO YOU?

Circle the 4 values in this list that are most important to you

(You can also write in the space any values not on this list):

Independence	Spirituality	Dignity	Courage	Loyalty
Physical strength	Happiness	Wellness	Power	Family
Clear-mindedness	Balance	Wealth	Honour	Being able to work hard
Perfection	Curiosity	Health	Respect	_____

\_\_\_\_\_

\_\_\_\_\_

### VALUES EXERCISE PART 2: WHICH ONE IS THE MOST IMPORTANT?

From the 4 values you circled, which ONE is the one MOST important to you? \_\_\_\_\_  
(Write the value here)

What comes to mind when you think of no longer having your \_\_\_\_\_?  
(Write the same value here)

Describe what you picture or what comes to your mind.

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The most important value to Althea is dignity. When Althea thinks of not having her dignity she pictures being hooked up to machines, not able to speak to her sisters.



The most important value to Tran is family. When Tran thinks of no longer having her family she pictures not being able to spend time with them. Tran is happiest when she's together with her husband and children. It's been a difficult few months with her diagnosis of cancer. To Tran, she does not need to recognize or interact with her family in any way. Just being present with her family brings her so much joy.



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The most important value to Bob is independence. When Bob thinks of no longer having his independence, he pictures his brother Jim in the intensive care unit. Bob would wait for hours to catch a few seconds of Jim waking up so Bob could ask “Do you want to be here?” Jim died in the intensive care unit and Bob still feels terrible as this is not what his brother would have wanted. For Bob, losing his independence means not being able to answer questions and not making his own decisions. Bob says “Life isn’t worth living unless I have my independence”.

## Worries & Fears

**Think about the care you might need if you have a critical illness or if near the end of your life. What worries or fears come to your mind?**

Sharing this information with your SDM(s) and your healthcare provider can be helpful:

1. To make sure you have the right information as this may lessen your fears
2. To come up with a plan to try and avoid these situations or make them better for you
3. To give important information to your SDM(s) and healthcare provider about your values and things that you would like to prevent from happening

## Trade offs

- At some point in the future, your SDM(s) may need to make difficult decisions about your care.
- There will be pros and cons to each option.
- Thinking about what is most important to you may help you.

For example:            Would it be ok to give up some of your independence and accept help with care so that you can remain at home living with your family?

For example:            The side effects of cancer treatment may be okay if you could get a lot more quality time.

The side effects may also be ok if you could live long enough to make it to an important event (e.g. someone’s wedding or graduation).

But there may be a time when comfort and quality of life becomes the most important thing to you even if it means a little less time.

**Help your SDM(s) understand what this balance would look like for you.**

## VALUES EXERCISE PART 3: WHAT IS MORE IMPORTANT TO YOU?

**What would you trade to have more \_\_\_\_\_?**  
(Write in your most important value)

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## Near the End

- **You may not be ready to think about this question yet. That's okay.**
- ACP Conversations are a process so you do not have to think about this until you are ready.
- But if you have thought about it, tell your SDM(s), family and friends:
  - What is important to you at the end of your life
  - Religious readings or ceremonies you want to have
  - Music you want to listen to
  - Books you want to read or have read to you
  - Where you might want to spend the last days of your life

As the time gets closer, it will be important to talk to your doctors and other healthcare providers about what to expect at the end of your life.

They can talk to you and your family and friends about what it would look like to spend your last days at home, in a hospice or in the hospital.

## Other people for your SDM(s) to know about

- Are there other people who know you well who might be able to tell your SDM important things about you to help your SDM(s) make decisions?
- Your SDM(s) will still be the person to make substitute decisions, these other people can support your SDM(s) and help them.
- Let your healthcare providers and SDM(s) know who they should and should not talk with.

## What's next?

- Congratulations! You have already taken an important step by taking the time to work through this guide and talk with others.
- If you have done this in preparation for meeting with your healthcare provider, it may be helpful to write a few things down. He or she may ask the same questions that you have gone through using this guide.
- Make sure you have shared this information with your SDM(s).
- Make sure you keep sharing information with your SDM(s) if your health changes.



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

Today's Date: \_\_\_\_\_  
MM DD YYYY

This document serves to record wishes, values and beliefs for future healthcare.  
It is NOT consent for treatment.

## 1. UNDERSTANDING

Based on previous discussions with healthcare providers, what do you understand about your health or illness if you have any? What have you been told about your illness? What do you expect to happen in the future? (E.g. Do you expect to get better, be cured, or is your illness expected to get worse over time? Do you think you may develop difficulty with memory, swallowing, walking or other things that are important to you?)


## 2. INFORMATION

What information about your illness that you don't know would be helpful or important for you to know? Is there information about your illness that you don't want to know?


## 3. VALUES, BELIEFS & QUALITY OF LIFE

What brings quality to your life? What do you value, or what is important in your life that gives it meaning? (E.g. being able to live independently, being able to recognize important people in your life, being able to communicate, being able to eat and taste food, spending time with friends and family etc.)




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## 4. WORRIES & 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 worries or fears come to your mind? (E.g. struggling to breathe, being in pain, being alone, losing your dignity, depending entirely on others or being a burden to your family and friends, being given up on too soon etc.)


## 5. TRADE OFFS

If you have a critical illness, life support or life extending treatments might be offered to you with the chance of gaining more time. Think about what brings quality to your life and what you value:

- What would you be willing to trade for the chance of gaining more time or more of what's important to you? (E.g. would you trade the ability to communicate, the ability to interact with others, the ability to control of your bodily functions)
- Or are the burdens of these treatments acceptable to you if there is even a slight chance of gaining more time?
- Do your thoughts or feelings change if your condition was permanent or if there was little or no chance of recovery


## 6. NEAR THE END

If you were near the end of your life, what might make the end more meaningful or peaceful for you? (E.g. family and friends nearby, dying at home, having spiritual rituals performed, listening to music etc.)