



My Wishes, My Care

Community-led
Advance Care Planning
sessions for the public

Facilitator
Guide





Prepared by the BC Centre for Palliative Care

Citation: BC Centre for Palliative Care. My Wishes, My Care: Community-led Advance Care Planning sessions for the public: Facilitator Guide – v2.0 October 2020.



This work is licensed under a [Creative Commons Attribution-NonCommercial-NoDerivatives 4.0 International License](https://creativecommons.org/licenses/by-nc-nd/4.0/).

Production of earlier versions of this document have been made possible with thanks to funding from the BC Ministry of Health and the Canadian Frailty Network (for the original version for the public); Health Canada’s Health Care Policy and Contribution Program (for the adaptation for cultural groups); and Public Health Agency of Canada and Health Canada (for the adaptation for people living with early stages of dementia and their family and friends).

Production of this updated document for the public has been made possible through a financial contribution from BC Ministry of Health.

How to use this interactive document:

Click on the topics listed in the **Table of Contents** to navigate directly to that topic and page. To return to the table of contents from any page, click on **“Table of Contents”** link on the bottom left corner of each page.

Table of Contents

Introduction	5
About this guide	5
Desired outcomes	5
Out-of-Scope Topics	6
Your role as facilitator	6
Advance Care Planning Session Schematic	11
Starting the Session	12
During the session - Topics to cover	15
What is Advance Care Planning?	15
Why is ACP important?	18
Who should do Advance Care Planning?	21
When to do Advance Care Planning?	21
How to do ACP?	22
THINK: What matters most to you?	23
THINK: Who could make health-care decisions for you if you cannot?	25
TALK: to the people you trust	28
TALK: to your health-care providers	31
PLAN: Prepare an Advance Care Plan	37
Temporary Substitute Decision Makers	40
Representation Agreement	43
Advance Directive	47
PLAN: Share your Advance Care Plan	49
REVIEW: Your plan	49
Closing the session	52
After the Session	53
Appendix A: Glossary	54
Appendix B: Frequently Asked Questions	58
Appendix C: Resources for Facilitators	65

Introduction

Congratulations on volunteering to facilitate Advance Care Planning (ACP) sessions for members of the public. Once you have finished the training, you will be ready to help your community engage in Advance Care Planning, so they can make health-care decisions aligned with their wishes and values.

About this guide

This guide is designed to help you facilitate a 2-hour session in person or via an online platform. Shorter sessions are not recommended, but if necessary, we encourage you to decide in advance what you need to change so you don't lose the main message.

The guide provides:

- The topics to be covered in the session. It walks you through what the session looks like from beginning to end.
 - Please note: this guide is more in depth than the PowerPoint slides and the accompanying notes to provide you with enough background information to facilitate the session and feel prepared for questions from participants.
- Checklists to help you prepare for, conduct, and close a session.
- Suggestions for engaging participants in conversation.
- Helpful tips from experienced facilitators.
- Resources for facilitators (see Appendix C) – stories, videos, example advance care plans you can incorporate into your sessions, and resources to further your learning.
- Glossary of terms.

Other key resources included in the toolkit:

- **Program Overview**
 - Program history, curriculum development, roles and responsibilities of organizers and facilitators.
- **Community Partner Guide**
 - Program evaluation, venue and remote platform selection, email templates.
- **PowerPoint slides**
- **Public participant handouts**

Desired outcomes

The Advance Care Planning session aims to:

- Increase participant knowledge of Advance Care Planning and its importance and benefits
- Increase participant readiness to engage in Advance Care Planning
- Motivate participants to engage in Advance Care Planning conversations

Out-of-Scope Topics

- Assistance with completing an Advance Care Plan or the accompanying legal forms
- Advice about a participant’s personal situation
- Detailed information about capability & consent for health care

Your role as facilitator

- Create a comfortable and safe space for participants to talk about Advance Care Planning.
- Ensure the session covers the key information about Advance Care Planning: what, why, who, when and how.
- Balance conversations and participant engagement with covering the key topics to meet the desired outcomes for the sessions.
- Present the information in a neutral manner. Share information, not opinions.
- Share examples, stories, and videos that illustrate the importance of Advance Care Planning and the process of Advance Care Planning.
- Provide participants with tools and resources that can help them engage in Advance Care Planning after the session.
- Aim to model comfort in having conversations about:
 - values and beliefs (what matters most to people) related to future health-care decision making.
 - Advance Care Planning, including comfort discussing death and dying.

Tips to overcome feeling nervous

- Take a deep breath.
- Tell yourself “I am enough.”
- Tell yourself “You don’t need to be perfect. Just be yourself.”
- Stay in the moment.
- Enjoy the experience.
- Remind yourself why Advance Care Planning is important to you.
- Prepare well for the sessions. Refer to the checklists in the next section of this guide.

Tip for successful facilitation

- Be genuine. Be friendly.
- Draw on your passion to engage with your audience.
- Demonstrate compassion and sensitivity, recognizing the impact that discussing ACP may have on participants (see [page 8](#) for ‘Tips for addressing emotional conversations’).
- Use a conversational tone and plain language (do not medicalize the conversation or information).
- Maintain a relaxed pace. Check in with your audience on the pacing during the session.
- Use a ‘hook,’ or a story that will capture the interest of participants and illustrate the value of Advance Care Planning.
- Engage participants in thinking and discussing Advance Care Planning by being willing to share your own or others’ stories/experiences about Advance Care Planning and providing opportunities for participants to share their stories too.
- Emphasize the benefits of doing Advance Care Planning - you can mention problems that arise from not doing Advance Care Planning and provide examples, but should not use fear of the negative consequences of failure to do Advance Care Planning as the main motivator.
- Use the session format and aids (videos, PowerPoints, handouts, etc.) that work best for the participants.
- Be prepared to re-focus when needed. You could say, for example:

“I hear you say ____, but I wonder what you think about ____.” Or,

“That is a great question! I will make note of it to address later on in the session.”

Tips for addressing questions and out-of-scope topics

Keep the information simple and within your scope as a facilitator.

- It's okay to say 'I don't know', as you can follow it up with 'I will find out and let you know'.
- Refer questions not covered in your training and the toolkit to other resources. Be familiar with the Resources for Facilitators in [Appendix C](#) so you can refer participants to the resources listed.

Tips for addressing emotional conversations

At times, a participant may share something that is especially intimate or may become emotional.

- Be prepared to gently acknowledge, and perhaps allow a brief silence, before moving on. E.g., "What a tough decision. That is really hard. Thank you for trusting us with that." Or "These are hard things to think about and they bring up a lot of emotions."
- Suggest that the participant may take a moment, if they wish, to step away from the group by leaving the room or by turning off their camera and muting the microphone.
- Have a plan for follow up after an event, as needed:
 - Check in with the person after the event to be sure they are okay.
 - The host organization may have counselling or peer support services to connect the person with.
 - There may be other counselling services in the community to refer the person to.

Preparing for in-person sessions

- Check the registration list so you know how many participants to expect.
- Plan the room layout (theatre style, one circle, smaller groups at tables, etc.).
- Plan any refreshments that will be served.
- If needed, arrange for additional facilitator(s) or assistant(s) to be present to help greet participants or to facilitate at tables.
 - Recommend: minimum 1 facilitator for up to 12 participants. Sessions with over 12 participants should have minimum 2 facilitators.
- Plan how you will conduct the session:
 - Review this guide
 - Prepare any videos, stories, etc.
 - Have equipment ready if you plan to use the PowerPoint slides
 - If you will be co-facilitating, agree on how you will divide the facilitation
- **Rehearse a session** with others from your organization to become familiar with the content and flow of the event.
- Prepare handout materials for the participants in advance.
- Prepare supplies:
 - Name tags
 - Pens, sticky notes, flip charts, felt pens, etc.
 - Extra paper for those who may want to take notes.
- Ensure you have evaluation forms ready to distribute at the end of the session. Encourage participants to complete the evaluation forms prior to leaving the session.
- Arrive at the venue at least 30 minutes before the session starts.
 - Prepare to welcome people as they arrive.

Preparing for online sessions

- Check the registration list so you know how many participants to expect.
 - Recommend minimum 6 and up to 20 participants per session
- Plan how you will conduct the session:
 - Review this guide
 - Prepare any videos, stories, etc.
 - Have equipment ready if you plan to use the PowerPoint slides
 - If you will be co-facilitating, agree on how you will divide the facilitation
- Ensure you are aware of who will be providing tech support during the session and monitoring participation (hand raises, chat rooms).
- **Rehearse a session** with others from your organizations to become familiar with the content, flow of the event and the online platform functions, including using the PowerPoint and any videos.
- Prepare handout materials and how you will distribute them in advance.
- Ensure you have evaluation forms ready to distribute at the end of the session.
- Login to the online platform at least 20 minutes before the session starts.
 - Welcome participants as they arrive.

You may want to offer to provide tech support to participants ahead of the session.

Advance Care Planning Session Schematic

Facilitating Public Advance Care Planning Sessions

Welcome. Introductions

Assemble:
a comfortable
and safe space
to meet

Acknowledge:
the conversation
to your
audience



Engage: use
stories. Aids:
videos, letters,
quotes, images

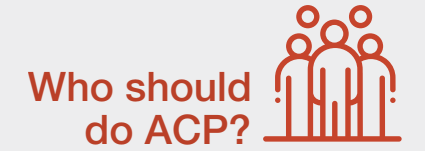
Adapt: your
conversation
to your
audience



What is ACP?

ACP helps you
to **Think, Talk
and Plan**

How to do ACP?



Who should do ACP?

Everybody!

Why is ACP important?

For you, for your
family and for your
health-care provider



When to do ACP?

- Life's milestones
- Changes in health
- Final months/years



Wrap Up

- Express appreciation for the conversation
- Summarize



Starting the Session

▶ Welcome participants

▶ Acknowledge the Indigenous land/territory that you meet on

Here is a script you can use:

“I would like to acknowledge with respect the history, customs and culture of the [Insert First Nation name], on whose traditional territory and home we meet.”

To find this:

- <https://www.whose.land/>
- First Nations A-Z Listing: <https://www2.gov.bc.ca/gov/content/environment/natural-resource-stewardship/consulting-with-first-nations/first-nations-negotiations/first-nations-a-z-listing>
- Pronunciation guide: https://www2.gov.bc.ca/assets/gov/british-columbians-our-governments/indigenous-people/aboriginal-peoples-documents/a_guide_to_pronunciation_of_bc_first_nations_-_oct_29_2018.pdf

▶ Introductions

- Introduce yourself, any co-facilitators, and tech support person if delivering the session online.
- Provide brief information about the organization hosting the session.
- Review housekeeping items:
 - **In-person delivery:** Emergency exits, washrooms, parking, refreshments, cell phone use (silent mode), etc.
 - **Online delivery:** functions of online platform (camera, mute, raise hand, chat, breakout rooms, etc.)
 - o To minimize distractions, recommend participants only turn on cameras (optional) and unmute microphones during discussions.
 - **Breaks:**
 - o minimum one (1) 10-minute break per session - A brief check-in about pacing and technology prior to the break(s) is recommended.
 - o If a participant needs to take a break or step away, ask that they signal their intention to the facilitator (in-person or via chat box) and return when they are able.
 - ◇ *In person: leave room*
 - ◇ *Online: turn off camera and mute*

- At the end of the session:
 - **Handouts:** Reassure participants that handouts summarizing the information and resources will be provided at the end of the session.
 - **Evaluation surveys:** Inform participants that evaluation surveys will be distributed at the end of the session. Encourage participants to complete the surveys before they leave the session.

▶ Explain what the session will cover

Here is a script you can use:

Today's session is about Advance Care Planning in British Columbia, a process to help you get the kind of health care you want throughout your life. You will learn:

- the what, why, who, when and how of planning for your care.
- to think about what is important to you. This will help you decide what kind of care fits with your goals, values, and wishes.
- the importance of talking to others so they know what matters most to you.
- how to talk to others.
- how decisions are made when you aren't able to make them for yourself.
- how to choose the best person to speak on your behalf if you are not able to speak for yourself.

Please note that this session will not cover:

- advice specific to your own situation
- assistance with completing an advance care plan or filling out any forms or documents

▶ Introduce guidelines for discussion

This helps participants know what to expect, and it can help you guide the conversation.

Here is a script you can use:

Before we start our session today, I would like to remind us all that we need to:

- **Respect other’s opinions.** We will be talking about things that are very personal. We may not all agree with each other, but everyone has a right to their own opinions.
- **Respect other’s privacy.** Please do not share other’s stories or personal information.
- **You don’t have to talk in the group if you don’t want to.** I understand that some of us don’t feel comfortable talking in a group.
- **Be sure to ask questions if you need more information.** If I am not able to answer any of your questions in the session, I will try to tell you where you can find answers after the session.

Additional Guidelines for Online Sessions:

Here is a script you can use:

If you wish to participate in the conversation or have a question, you can:

- Use raise-hand function,
- Physically raise hand on camera;
- Write your comment or question in the chat box, which will be monitored by <name of co-facilitator/assistant> and shared verbally with the group.

Also explain how to use the breakout rooms or polls if you decide to use these features.

▶ Explain your role as facilitator

Here is a script you can use:

My job as the facilitator today is:

- To provide information and resources about ACP, and to share examples.
- Answer your questions or help you know where you can find answers after the session.
- Ensure we all follow the guidelines for discussion.

During the session- Topics to cover

What is Advance Care Planning?

Discussion Break: Invite discussion to find out how familiar participants are with Advance Care Planning

Ask: Before signing up for this session, had you heard of the term “Advance Care Planning”?

▶ Introduce Advance Care Planning

Here is a script you can use:

Advance Care Planning is a process of thinking about your values, beliefs, and wishes for future health and personal care, and sharing them with the people you trust. It can include choosing who would make care decisions for you if you cannot. Advance Care Planning can help you get the care that’s right for you, even if you’re unable to speak for yourself.

ACP is part of life planning

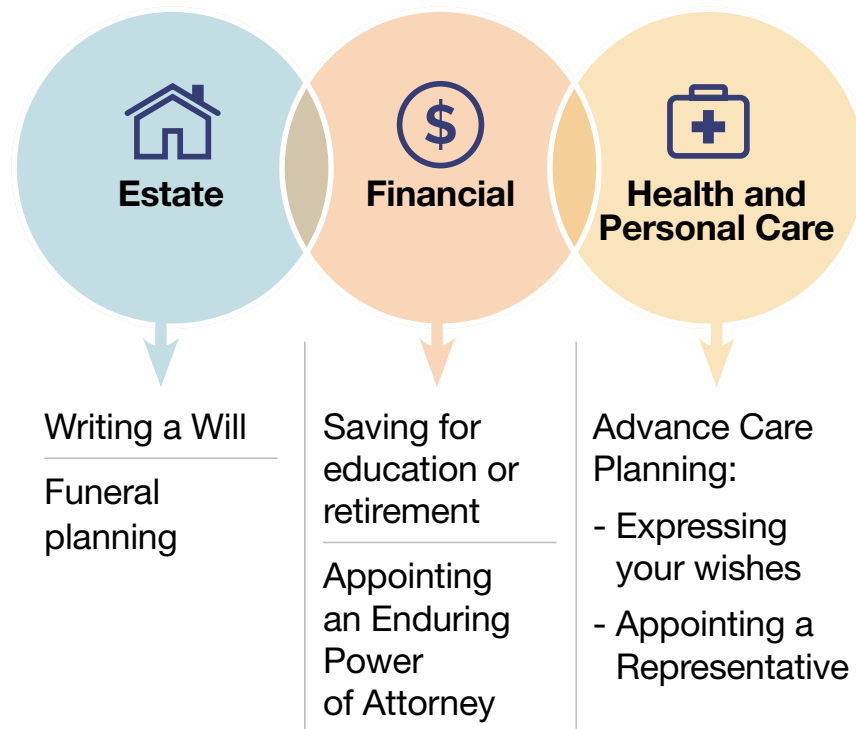
▶ Present questions to help participants recognize they have done some planning already.

Here are some questions you can use. Do not expect participants to answer – these are for reflection only:

Here are some questions to think about:

- Have you made a will?
- Have you saved money for your children's or grandchildren’s education?
- Have you decided who would be guardians for your children?
- Have you made a plan for retirement?
- Have you needed to make a difficult health-care decision?
- Have you helped someone else go to medical appointments and helped them understand what was said?

► **Explain that health-care planning is just as important as financial and estate planning.**



You can use the diagram of the Life Planning Model to show how the three types of planning are related.

Here is a script you can use while showing the Life Planning Model:

Life is a complicated journey full of ups and downs. To make life easier, most people do some form of life planning for themselves and their families. They plan for tomorrow so they can live for today. Each type of planning includes thinking, talking, and planning to make sure we can have the life we want. Planning can also include recording our choices in forms or documents.

Estate planning:

People make wills to say what they want done with their assets when they die, and if needed, to appoint guardians to look after their children.

Financial planning:

People save money for school, major purchases and retirement. They buy insurance in case something happens to their house, car or themselves.

Personal-care planning:

People make preparations for day-to-day life decisions such as:

- Living arrangements
- Diet and dress, and other day-to-day decisions
- Exercising
- Driving
- Working
- Deciding who you have contact with
- Any cultural traditions that are important to you
- Types of clothing for special occasions
- Foods that are nourishing

Health-care planning:

People prepare for changes in their health, so they are ready to make decisions. They also prepare for situations where they cannot speak for themselves, and who will speak for them if this happens.

Just like you change your financial and legal plans for each stage of your life journey, your health-care plans should be updated, too.

Why is ACP important?

Discussion Break: Have a discussion about why Advance Care Planning is important.

Ask: Why do you think Advance Care Planning is important?

Summarize what people have shared before moving forward.

► Explain the importance of doing ACP

Importance of ACP in Canada

Here is a script you can use:

In Canada, when you are ill and need health care, you can choose whether you say yes or no to the tests, examinations, and treatments your health-care provider recommends. Your health-care provider can only provide care that you want and agree to.

Before you make any decisions, your health-care provider will explain to you the risks and benefits of the health care options. When deciding, it helps to think about what difference it will make in your life.

It's important that the health care we receive matches our goals, values, and preferences.

Advance Care Planning can help make that happen.

► Discussion Break: Discuss why people might do ACP

Use stories to create “the hook” to engage people in the discussion about why ACP is important for everyone, in all stages of life. Use a compelling video or story about ACP (even yours) - ensure the story reinforces the message about the importance of conversations on health care.

Facilitate a discussion to allow sharing of the impact that having an ACP (or lack of) had on their family or friends

Acknowledge how life can change at any moment!

Here is a script you can use:

- **Mrs. Smith didn't do any Advance Care Planning and was in a serious car accident** resulting in a brain injury that left her unconscious and a spinal cord injury that may leave her paralyzed from the neck down. The hospital could not find anyone who could make decisions according to her wishes.
- **Pam needed someone to make decisions for her for a short time after undergoing heart surgery.** After a few days of recovery, she was able to go back to making her own decisions.
- **Henry had a stroke and could not make his own decisions.** He didn't have any written plans, but his spouse was with him and knew what his wishes were.
- **Mr. Johnson has late-stage dementia and didn't do any Advance Care Planning.** His family and friends have different ideas about what his wishes for health and personal care are from previous conversations but cannot come to a consensus and do not know who they should be listening to.

Benefits of ACP

► Explain the benefits of Advance Care Planning to everyone, family and friends, and health care providers

Here is a script you can use:

Advance Care Planning can benefit everyone, regardless of health and stage of life. You may not have any health concerns, but being ready in case a health crisis happens will ease the burden on everyone. It is especially important for people living with serious illnesses such as dementia, cancer, heart disease, or kidney disease to begin the process as soon as possible. Advance Care Planning helps people diagnosed with serious illnesses prepare themselves and the people important to them for the future.

For you:

- It's an important part of your life planning.
- It can help you get the care that is right for you and aligned with your values, preferences and wishes.
- It allows you to know yourself better and to understand what's important to you.
- It can bring you peace of mind, knowing that people you trust know your health care wishes in case you aren't well enough to speak for yourself.

For your family and friends:

- It's a gift you give your family. It lets those who care about you know what care you would (or would not) want.
- It makes it clear to everyone in your family and friend circle who you want to make care decisions for you if you can't.
- It reduces family disputes and confusion about your health-care wishes.
- It helps your decision maker communicate better with your health-care team

For your health-care providers:

- It lets your health-care providers know what kinds of things in life are important to you.
- It helps your health-care providers know more about your culture and beliefs and how they affect your care decisions.
- It helps your health-care providers know what life support or care options you would refuse to receive if needed.
- It lets your health-care providers know who will make decisions for you if you cannot make them for yourself.

Who should do Advance Care Planning?

Discussion Break

Ask: **Who do you think should do Advance Care Planning?**

Invite: participants to share their thoughts.

Explain: **Advance Care Planning is for everyone!**

All adults, 19 years and older, who are capable of making decisions should do Advance Care Planning, especially people who:

- have a serious illness;
- think their family may have different views or beliefs from their own;
- have family members who don't know, understand, or support their health-care choices; or
- have a condition, such as dementia, that will lead to a loss of capacity to make decisions.

When to do Advance Care Planning?

Discussion Break:

Ask: **when should we do Advance Care Planning?**

Invite: participants to share their thoughts.

Explain: **The sooner you start the better.** You can do Advance Care Planning at any stage of life, as things can change at any time.

You should consider doing Advance Care Planning at these times:

- When you experience a significant change or major event in your life, such as:
 - Changes in health
 - Changes in your relationship (including common law, marriage, divorce)
 - Having children/grandchildren
 - Retirement
 - Buying/selling property
 - Upcoming surgery
 - Moving
- When a serious illness happens:
 - On diagnosis
 - If your health declines
 - On diagnosis of terminal illness

► **Before moving on, summarize the information shared so far**

Emphasize these key messages:

- **What:** Advance Care Planning is a process of thinking about your values, beliefs, and wishes for future health and personal care, and sharing them with the people you trust. It can include choosing who would make care decisions for you if you cannot. **It is a part of life planning.**
- **Why:** Advance Care Planning helps you get the care that is right for you and aligned with your values, beliefs and wishes, even if you're unable to speak for yourself.
- **Who:** It's for every adult, not just for people who are old or ill.
- **When:** The sooner you start your ACP, the better!
- **When:** Advance Care Planning is not a one-time event. It's recommended that you review your plans at key times in your life, like when there are changes to your health or close relationships.

How to do Advance Care Planning?

► **Explain the three simple steps of Advance Care Planning: Think, Talk, Plan**



THINK: What matters most to you?

► **Explain what they should Think about**

Here is a script you can use:

THINK: what matters most to you?

Think about:

- your personal values: the things that are important to you and that you would want to continue even if you became seriously ill.
- your personal wishes: who you like to be with, where you would want to live and be cared for if you were ill, things you would like to have with you.
- your personal beliefs: the spiritual or cultural practices that are important to you, or spiritual beliefs that will influence the options of care to be considered for you.



Thinking about what matters to you informs your future care decisions.

Discussion Break

Here are some conversation starter questions you can use to facilitate discussion:

- What is something that always makes you smile?
- What activities or routines make your day more enjoyable?
- What does 'quality of life' look like for you? What does it include?

Allow for time to reflect as each question is presented and encourage participants to write down their thoughts.

Facilitate a discussion to allow sharing of the participants' thoughts.

If you have a large group, allow for discussion in pairs or break out groups/rooms, then share in the larger group the highlights of each small group. Ask for volunteers to share their responses before going on to the next question.

Remember, what matters most can depend on the stage of life you are in:Everyone should think about:

- Who would make decisions for you if you were in a critical accident or experienced a sudden health crisis?
- What life support options, like receiving blood transfusions or CPR, would you accept or refuse in case of emergencies, and with what considerations?
- Do you wish to donate your organs after death?

In addition to the above, people who are older, frail, or living with a serious illness should think about:

- What is important to you to maintain your quality of life? For example: hobbies, religious/spiritual practices and beliefs, preferences for food/music/art, specific routines for personal care, etc.
- How do you want to be involved in your health-care and personal-care decision-making processes? For example, would you want to be fully involved in every decision or only the major ones?
- What are your thoughts about the importance of having a long life compared to the importance of feeling well and being able to do what is important to you?

As you approach end of life, also think about:

- How you would like your end-of-life experience to be for you and those important to you,
- What comfort means to you,
- What suffering means to you,
- What abilities or comfort you would be willing to give up to live longer.

Figuring out the things that matter most to you takes time and energy. It is easier to do it now than when urgent decisions are needed.

THINK: Who could make health-care decisions for you if you cannot?

Capability and Consent

► Explain capability and consent

Here is a script you can use:

When we talk about health-care decisions, you will hear some important terms come up: consent, informed consent, and capability/capable.

Consent for health care is agreeing to or refusing a test or treatment.

Informed consent is agreeing to a treatment when you understand its purpose, benefits and risks.

You can only provide informed consent when you are capable.

Capable means you can:

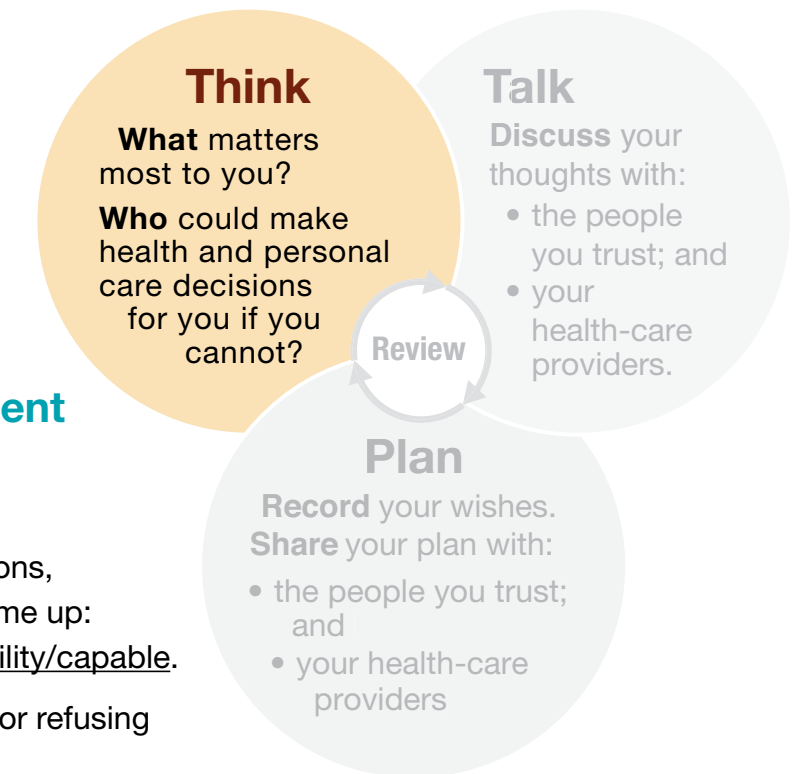
- understand the information provided about the treatment offered, its purpose, benefits and risks,
- make a decision to receive (consent to) or refuse that treatment, and
- communicate your consent or refusal.

As a capable individual, your health-care decision-making rights include the right to:

- agree to treatment (give informed consent),
- refuse treatment,
- stop treatment that is already started, and
- choose whether to participate in research.

You can say no to health care recommended by your doctor.

You are entitled to information that will help you make a decision.



Substitute Decision Makers

Discussion Break: about Substitute Decision Makers

Ask: Have you heard of the term “Substitute Decision Maker”?

► Explain what Substitute Decision Makers are

Here is a script you can use:

If you need medical treatment but cannot make a decision and provide consent yourself, you will need someone to express your wishes and speak for you. **This person is called your substitute decision maker.**

Appointing a person to be your substitute decision maker is part of Advance Care Planning. Being unable to speak for yourself is a common situation. There may be many reasons why you may not be able to speak for yourself:

- Before or after surgery
- Memory loss due to progression of dementia
- After an accident or brain injury
- If your health declines rapidly due to a serious illness

► What is the role of substitute decision makers?

Here is a script you can use:

The role of your substitute decision maker(s) is to make health and personal care decisions on your behalf if you are not able to make them for yourself. These include:

- health care decisions such as providing consent on medical treatments according to your wishes and instructions
- personal care decisions such as place of care, nutrition, clothing, and hygiene.

To help your substitute decision makers make the right care decisions for you, you need to share with them:

- Your values, beliefs and wishes
- Your health and treatment preferences
- Your health conditions
- Your medical and treatment options

► Describe what makes a good Substitute Decision Maker

Your substitute decision maker(s) will speak and advocate for you. They will provide consent for medical care or treatments according to your wishes. Their role is to make sure your wishes are known when you are unable to speak for yourself. They must honour your wishes and instructions.

A good substitute decision maker is someone who:

- knows you well
- will honour your wishes and instructions (this is their legal role), even if they are different from their own;
- is calm in a crisis;
- can communicate with health-care providers and not be pressured into accepting treatment that they know you wouldn't want; and
- can handle conflict or disagreement.

Engagement break: selecting a substitute decision maker

Recommend that participants write down who comes to mind when they think of these questions.

- Who knows what gives your life meaning, joy and purpose?
- Who helps you with your health care? Who helps you with your personal care?
- Who do you trust to respect your wishes and make decisions the way you would make them for yourself?

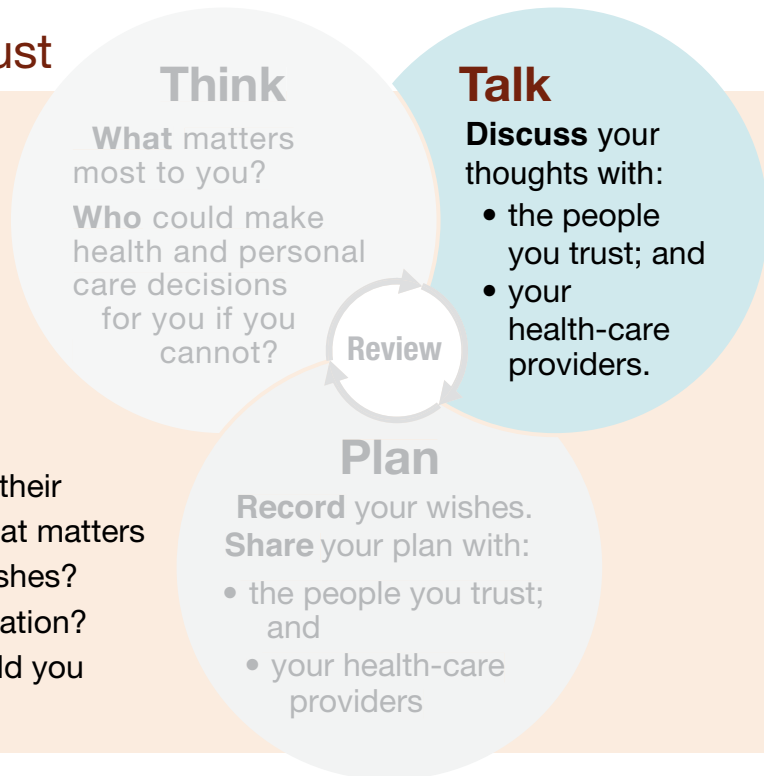
Let participants know that we will be talking more about substitute decision makers later.

TALK: To the people you trust

Discussion Break: talking to the people you trust

These questions will help you facilitate the discussion:

- Why it is important to share what matters most to you with the people you trust?
- Has anyone had a conversation with their family members and friends about what matters most to them and their health care wishes? How did you prepare for this conversation? How did it go? What (if anything) would you do differently?



Who should you talk to

- The person or people you choose to be your substitute decision maker.
- Other members of your family or your close friends.

Why should you talk to them

- To help them understand the care you would want.
- To help them make decisions that match your wishes if you are not able to speak for yourself.

What you should talk about

- Share your thoughts about the things that are important to you (your values, beliefs, preferences).
- Talk about your fears and concerns about your future health and illness.
- Talk about any specific treatments or health-care decisions you already know you want/do not want.
- Discuss who will make health-care decisions for you, if you cannot make these decisions yourself.
- Explain to your other family members and friends that you would like them to support the person chosen to represent you when decisions are made.

How to have these conversations

► Share some suggestions for starting the conversation

Discussion Break: starting conversations with people you trust

Ask: How might you prepare for and start a conversation about what matters most to you with your family and friends?

► Add to the previous discussion and share how to prepare for this conversation

- **Prepare ahead of time.** Write down the topics you want to talk about. Think about:
 - What matters most to you.
 - Who do you want to talk to? Who would you choose to make health care decisions for you when you cannot?
 - Reasons why it is important for you to have the conversation.
 - What you would like to accomplish by having it.
- **Pick a time** when you and the person you would like to talk to feel relaxed and have time to talk.
- **Choose a place** that is free of distractions and where you all feel comfortable.
- **Be gentle and go slowly.** These conversations touch upon vulnerable and intimate topics, which can be difficult to talk about.
- **Be open to learning and hearing what each person has to say.** Each person is entitled to hold their own values, beliefs and preferences.
- **Be open to having the conversation in smaller sections.** It may take a few pre-conversations to even begin to talk about Advance Care Planning.
- Using ACP aids, such as websites, leaflets or videos, may help.
- It may help to talk about health care situations that have happened to people you know and compare their situations to what you would want.
- Start by discussing the present, don't go straight to end-of-life. Emphasize that living well includes planning well.

► Share some suggestions for starting the conversation

- “Right now, I’m healthy, but I want to think ahead and be prepared if something unexpected should happen... and how we might want to handle that situation...”
- “I was thinking about what happened to ____, and it made me realize...”
- “Even though I’m okay right now, I’m worried that _____, and I want to be prepared.”
- “Right now, I’m at a point where I’m still able to discuss my health-care wishes. I want to use this time to prepare for the future and make sure we can work together so that my needs and wishes are understood and respected.”
- “I just answered some important questions about my health-care wishes. I want you to see my answers. And I’m wondering if we can talk about them.”
- “I’m living with dementia/heart disease/kidney failure/cancer, and I expect_____. Is this what you understand too?”
- “I know that my health condition/illness is only going to get worse and I want you to feel prepared and confident when you have to make health-care decisions on my behalf. Can we talk more about it?”
- “I think it’s really important our family and people we trust know what’s important to me about my health-care wishes as I live with this illness.”

TALK: To your health-care providers



► Discussion Break: what to talk about with health-care providers

Ask: What might you talk about with your health-care provider?

Explain why they should talk to their health-care provider(s)

Everyone should let their health-care providers know

- who their substitute decision maker is, (TSDM list and a copy of your Representation Agreement, if you have one) and
- any clear health care instructions they may have currently (e.g. refusing blood transfusions).

For those who have a health condition or serious illness:▶ **Describe who they should talk to**

You should talk to all of your health-care providers: doctors, specialists, nurse practitioners, etc.

▶ **Explain why they should talk to their health-care provider(s)**

- To get information about your health that can help you when thinking about what matters most to you.
- To share information about you, so they can understand what matters most to you when making their recommendations.

▶ **Explain what they should talk about with their health-care provider(s)**

Here is a script you can use:

1) Book a time with your health-care provider to understand your health.

Some questions you can ask include:

- How do you expect my illness will progress over time?
- How will my abilities and my life overall be affected by this progression?
- What kind of health-care treatments may be involved as my illness progresses? What are the benefits and risks?
- Will life support treatments be considered for me during this progression? For example, will I need to be fed through a tube, hooked to a ventilator or any means of life support to keep me alive?

2) Take your time to reflect on their answers. What you learn from them will help you think about what matters most and who you would want to speak for you if you cannot.

3) Book a time with your health-care providers to share what they need to know about you.

This includes:

- **What matters most to you** - your values, beliefs and wishes for health and personal care as we previously discussed. This will help them consider the care options that are aligned with your preferences.
- **Who can speak for you** when you are not capable of making health-care decisions for yourself. In other words, who are your substitute decision makers.

Talking to your health-care providers is an ongoing process. The questions you ask and the answers you receive may change as your health changes and illness progresses.

Share a story about someone living with a serious illness whose experience with their illness and treatment changed their decisions. For example, someone who:

- decided at a certain age or stage of illness that they would not want cardio-pulmonary resuscitation
- started dialysis but decided to withdraw as the burden of illness increased
- had chemotherapy for cancer and changed their mind about further chemotherapy

Discussion Break: starting conversations with health-care providers

Ask: How might you prepare for and start a conversation about what is important to you with your health-care providers?

► Share tips on how to prepare for a conversation with your health-care providers

Here are some tips that can help you have conversations with your health-care providers:

- Prepare ahead of time. Write down the questions and topics you want to talk about. Also think about:
 - Reasons why it is important for you to have the conversation.
 - What you would like to accomplish by having it.
 - Which health-care providers you would like to talk to (e.g., doctors, specialists, nurses, etc.).
- Make an appointment with the health-care providers you want to talk to.
 - Select times when you are feeling most capable of understanding information (i.e. not stressed, exhausted)
 - Inform the health-care provider of the topics of discussion and the amount of time you may need to talk about them.
 - Make several appointments if needed.
- Invite someone you trust to participate in the conversations.
 - Ideally, this person should be someone you would choose to be your substitute decision maker so they can learn your preferences for health care.
 - They can help you with note taking and recording the conversation.
- Other strategies, if needed:
 - Ask for a quiet room that is free of distractions.
 - Work with a language interpreter.

Additional Information for Facilitators:

Below is general information on types of health-care treatments to help you answer questions that may arise during the session:

- **Life-prolonging treatments**, which prolong your life after failure of one or more organs or diagnosis of a serious illness, but does not involve resuscitation or life support. These include:
 - Radiation and chemotherapy for cancer
 - Dialysis for kidney disease
 - Feeding tubes
 - Antibiotics to treat infections
- **Life-supporting treatments**, which focus on resuscitation and life support to keep you alive. These include:
 - **Cardiopulmonary resuscitation (CPR)**: CPR is an emergency procedure used if you stop breathing or your heart stops beating. It can involve pressing forcefully on your chest, breathing into your mouth, and electrical shock and drugs to try and start your heart. CPR can cause injuries such as broken ribs or bruised lungs. Very few people of all ages survive CPR in hospital and about half of the people who survive CPR are left with brain damage and ongoing serious health issues.
 - **Ventilator**: A machine that helps you breathe when you are sedated and need to undergo surgery or are unable to breath on your own. Ventilation can lead to pneumonia and other infections, lung injury and damage as well as permanent decline in health and lung function. People who are really sick, have pre-existing serious illnesses and those who have to be on a ventilator for a long time are more likely to experience these effects.
- **Comfort care**, which involves treatments that focuses on making you comfortable by controlling symptoms. Comfort care is always provided but can become the only focus towards end of life. Treatments include:
 - Pain medications to reduce pain,
 - Medications to reduce anxiety,
 - Bowel medications for constipation.

Summarize the key messages to this point in the session

Emphasize these key messages:

- **Advance Care Planning is a part of life planning.** It is for every adult and not just for people who are old or sick.
- **The sooner you start your Advance Care Planning, the better.**
- **Advance Care Planning is voluntary.** But given the many benefits of Advance Care Planning, people should prepare an Advance Care Plan to make sure they get the care that is aligned with their wishes and beliefs.
- **Conversations are key!** Advance Care Planning involves communicating your values and beliefs with those who might be involved in your health or personal care. This allows them to make the right decisions for you if you cannot make decisions yourself.
- **The more conversations you have, the easier they get.**
- **There are three simple steps to Advance Care Planning: Think, Talk, Plan.** So far, we have covered:
 - Think about matters to you (your values, beliefs, and wishes)
 - Think who would you choose to be your substitute decision makers
 - Talk with the people you trust about what matters most to you
 - Talk with your health-care providers to understand your health conditions and share what they should know about you.

Remember! As long as you are capable, your health-care provider will always ask you to make decisions about your own care.

Next, we will talk about the third step to Advance Care Planning – the Plan.

PLAN: Prepare an Advance Care Plan

Explain what an Advance Care Plan is

Here is a script you can use:

Once you THINK and TALK, you should record this information in an Advance Care PLAN.

An **advance care plan is a record of:**

- **your values, beliefs, and wishes** about your future health and personal care – what matters most. This information can be written down, audio/video recorded or spoken.
- **contact information for the persons on your Temporary Substitute Decision Maker List,** determined by BC law.

Your advance care plan could also include any of the following legal documents:

- **Representation Agreement** - a legal document that you can use to appoint one or more people, also known as your Representatives, to act as your substitute decision makers.
- **Advance Directive** - a legal document that you can use to record instructions from you to health care providers about the treatments and care options you consent to and refuse.

We are going to talk more about substitute decision makers and the legal documents now.



Why is making an advance care plan important?

Discussion break: about making an advance care plan

Ask: Why do you think making an advance care plan is helpful?

Here would be a good place to share a video of a substitute decision maker talking about their experiences (see *Resources for Facilitators in Appendix C*).

► **Add to the discussion by explaining how having an advance care plan can inform health-care decision making**

Here is a script you can use:

- If you are capable of making decisions, an advance care plan will help you remember what you thought and spoke about.
- If you are incapable of making decisions, an advance care plan will help those involved in your care, including your substitute decision maker by:
 - reminding them what your wishes are;
 - helping guide decision making; and
 - providing evidence of your wishes if there is disagreement.

Facilitator Tip

- Share 1-2 examples of Advance Care Plans (see *Resources for Facilitators in Appendix C*)

► **Emphasize this:**

Remember that as long as you can still make your own decisions, your advance care plan won't be used but can still be useful to remind you about your wishes and preferences for care. The documents only come into play when you become incapable of making decisions about your care.

► **Explain Substitute Decision Making Options in Health Care**

Provide an initial review of the options for substitute decision making in health care by sharing this chart:



The above was adapted from People's Law School: <https://www.peopleslawschool.ca/everyday-legal-problems/planning-your-future/health-personal-care/list-potential-temporary>

- Emphasize that the above information is ONLY for health-care decisions.
- For legal and financial decisions, they can use an Enduring Power of Attorney. Advise them to consult a lawyer or financial advisor.
- An Enduring Power of Attorney is not for health-care or personal-care decisions.

Note to facilitators: Committeeship - if needed, refer to the Glossary for an expanded definition and to consult a lawyer for assistance.

Refer to the public guardian and trustee website or People's Law School websites for further information about legal and financial decisions.

Temporary Substitute Decision Makers

► Explain the Temporary Substitute Decision Maker list

Here is a script you can use:

If you have not legally named someone (a representative), BC law provides a list that defines who is chosen to make **health care decisions** for you when you are incapable of making them for yourself. A Temporary Substitute Decision Maker is selected by a health-care provider if:

- you need health care, and
- you are not capable to make the decision, and
- you do not have a Representation Agreement or an Advance Directive that speaks to the situation.

The authority of a Temporary Substitute Decision Maker only applies to the specific health-care decision at hand. If another decision is needed and you are still not capable of making the decision, your health-care provider will use the list again to identify a Temporary Substitute Decision Maker.

To qualify to be a TSDM the person must:

- be least 19 years of age or older
- be capable
- have no dispute with you
- have been in contact with you in the past 12 months, and
- be willing to comply with their duties as a TSDM

Your health-care provider will work down the following list that is defined in law.

1. Your spouse, including common-law, same sex (the length of time living together doesn't matter)
2. One of your children (equally ranked)
3. A parent (equally ranked)
4. A sibling (equally ranked)
5. A grandparent (equally ranked)
6. A grandchild (equally ranked)
7. Anyone else related by birth or adoption
8. Close friend
9. Person immediately related by marriage

If no one can be reached or qualifies, someone authorized by the Public Guardian and Trustee will be chosen. This person may be an employee of the Public Guardian and Trustee.

Limitations of a Temporary Substitute Decision Maker

- **A Temporary Substitute Decision Maker can only make health-care decisions** for you. They cannot make personal care decisions.
 - Personal care decisions are about your daily life, such as:
 - o Living arrangements (including admission to a care facility)
 - o Diet and dress, and other day to day decisions
 - o Participation in educational, vocational or social activities
 - o Who you have contact with
 - o Access to personal information
 - o Restraint issues.
- A Temporary Substitute Decision Maker is only appointed for one decision (or set of decisions).
- You do not get to decide the order of the Temporary Substitute Decision Maker list
- You do not get to decide who your health-care provider selects as your Temporary Substitute Decision Maker if more than one person qualifies within a category of the list (for example if you have more than one child, the health-care provider can choose which to select).
- The person selected to be your Temporary Substitute Decision Maker may not be someone you would trust to make health-care decisions for you.
- The person selected to be your Temporary Substitute Decision Maker may not be the same person every time. Depending on the eligibility and availability of people on the list the person selected may change for different decisions.

► Discussion Break: TSDM List & preferred SDMs

Ask:

“Are you aware of this B.C. legislation?”

“Who would be on your Temporary Substitute Decision Maker list? How do you feel about that?”

Suggest they use the list to write down the names and contact information of the people who would potentially qualify to be their Temporary Substitute Decision Maker.

“Is there anyone on your list that does not qualify, for example because of a dispute?”

Let them know that they can indicate this on their contact information for TSDM.

Inform participants that if the TSDM list does not work for them, they should consider appointing a Representative using the Rep 9 form, which is for capable people.

Many of the limitations of a Temporary Substitute Decision Maker do not apply for a Representative.

- **A Representative can also make personal-care decisions for you.**
- You get to choose exactly who your Representative(s) is, and who are your Alternate Representative(s).
- Appointing a Representative gives the best chance of the person(s) making decisions for you being the same person(s) over time.

Legal Documents

► Introduce the legal documents

Here is a script you can use:

Legal documents are specific to each legal jurisdiction - we will be discussing options for BC only. There are different legal documents to help you plan for the future.

Documents requiring FULL capability:

- Representation Agreement Section 9 – Enhanced (RA9)
- Advance Directive

Document that can be made with REDUCED capability:

- Representation Agreement Section 7 – Standard (RA7)

Representation Agreement

► Explain Representation Agreement as a Planning Option

Here is a script you can use:

- A Representation Agreement (RA) is a legal document in which you name a capable adult, called a Representative, to make **personal-care and health-care** decisions for you, if you cannot make these decisions on your own.
- You can name more than one person to act as your Representative.
- You can also specify which decisions they can make, for example, you can appoint someone to make personal-care decisions for you and someone else to make health-care decisions for you in the same agreement.
- You can specify how they may act. Unless they have different areas of authority, your representatives must act together (act unanimously) unless your RA says otherwise.
 - ¹**Caution:** If you appoint two or more representatives in an RA and one is no longer able to act for any reason, the remaining representative cannot continue to act unless the RA says otherwise. This may or may not be what you want. If you want one representative to be able to continue, your RA must address this.
- You do not need a lawyer or notary to prepare a Representation Agreement, but you may wish to involve one.

You can also appoint an alternate representative.

- This is someone who can step in if your first representative is no longer willing or able to act for you.
- If you appoint an alternate representative, **you must specify in the agreement when they can act in place of the representative.**

There are two types of Representation Agreements:

- **Section 9 (Enhanced)** – can be used by a capable person to name a Representative to make personal-care and health-care decisions, including decisions about life support and life prolonging treatments.
- **Section 7 (Standard)** – can be used by a person with lessened capability (e.g. with progression of dementia) to appoint a Representative who can make personal care and minor and major health care decisions, as well as provide routine management of the person’s financial affairs and legal affairs.

¹ Public Guardian and Trustee of British Columbia. It’s Your Choice: Personal Planning Tools. September 2019, [www.trustee.bc.ca/documents/STA/It%27s Your Choice-Personal Planning Tools.pdf](http://www.trustee.bc.ca/documents/STA/It%27s%20Your%20Choice-Personal%20Planning%20Tools.pdf)

Additional Information for Facilitators:

A **monitor** can also be appointed to oversee the activities of Representative(s) to make sure they follow what is in the agreement.

- A monitor is mandatory in a Section 7 agreement that allows the Representative(s) to make routine financial decisions unless:
 - the Representative is the spouse, the Public Guardian and Trustee, a trust company, a credit union, or
 - two Representatives are appointed to act unanimously.

The key differences between the two types of Representation Agreements:

- To make a Section 9 agreement, a person must have full capacity. A person with diminished capacity can make a Section 7 agreement.
- A Section 9 Representative can make more health-related decisions than a Section 7 Representative. A Section 7 Representative cannot make decisions to refuse life support treatments, but a Section 9 Representative can.
- A Section 7 Representative can make routine financial decisions. A Section 9 Representative cannot make financial decisions - a capable person can make an Enduring Power of Attorney for this.

Standard Powers [s.7]	Enhanced Powers [s.9]
<p>Minor and major health care</p> <p>Minor health care includes examinations, immunizations, medications.</p> <p>Major health care includes:</p> <ul style="list-style-type: none"> • major surgery, anything with general anesthetic • major diagnostic or investigative procedures • radiation • kidney dialysis • chemotherapy • laser surgery <p>Note: you cannot authorize your section 7 Representative to refuse life support on your behalf in an Agreement with only standard powers, however, they will be included in life support decisions for you.</p>	<p>Minor and major health care</p> <p>Minor + Major health care matters from column 1 plus:</p> <ul style="list-style-type: none"> + Refuse consent for specific kinds of health care, including life-supporting care or treatment + Consent (must be specifically (listed) to specific prescribed kinds of health care: abortion; electroconvulsive therapy (ECT); psycho-surgery; aversive stimuli for behaviour modifications; tissue donation; experimental health care and research + Give consent, to specific kinds of health care, even if adult refusing to give consent at the time the health care is provided; for situations where an illness or condition affects adult's judgement or perception (e.g. - mood disorder, dementia, anorexia, addiction).

Source (and for more information):

<http://seniorsfirstbc.ca/for-professionals/representation-agreements/>

<https://www.peopleslawschool.ca/everyday-legal-problems/planning-your-future/health-personal-care/understand-representation>

For further information about Representation Agreements see Public Guardian & Trustee and People’s Law School websites.

► Describe examples of when a Representation Agreement (Section 9) might be helpful

Here are some examples:

- When you may need someone to help you with personal care decisions. **Appointing a Representative is the only way in the law that someone you choose can make these decisions for you.**
- if you have an early diagnosis of dementia and are still capable of making decisions for yourself, but know the time will come when you will not be able to do so;
- for consistency in care and decision-making (with only one person making decisions on your behalf);
- when the person on the TSDM list is not who you wish your SDM to be; or
- in cases of family conflict.

► Emphasize that:

- If you decide to appoint one or more Representatives, it is important to TALK to your Representatives beforehand to make sure they agree to this and that they know your wishes, values and preferences for health and personal care.
- It is recommended that people with a diagnosis of dementia involve a lawyer or notary public in making a Representation Agreement, especially if:
 - There are any concerns about capability, such as with progression of dementia.
 - They anticipate family dispute or confusion over the health-care decision making.
 - Their requirements don't fit in the standard templates (for example, would like to appoint multiple Representatives with each making a specific set of decisions, an alternate and/or a monitor).

Advance Directive

► Explain Advance Directive as a Planning Option

Here is a script you can use:

An Advance Directive is a legal document that records your instructions for **accepting or refusing specific health-care treatments**. You must be capable to make an Advance Directive.

An Advance Directive only covers health-care decisions, not personal-care, financial or legal decisions.

An Advance Directive gives instructions to your health-care provider at a time when you need health care but aren't capable of providing consent.

It must be:

- clear about the specific treatment(s) you would want or refuse;
- in writing; and
- signed, witnessed and dated.

► Describe some examples of when you might want to make an Advance Directive:

Here are some examples

you do not have anyone you want making health-care decisions for you,

“I do not have any family to make my health-care decisions. I have lived with kidney disease for 10 years. I want to prepare for a time when dialysis is not working so I made an Advance Directive to provide for refusal of dialysis if I am not able to provide consent and dialysis is prolonging my suffering rather than promoting my health.”

you have certain instructions you want to be legally binding, or you want to spare your decision maker from making certain decisions.

“I have lung disease and have been on a breathing machine four times. I know I'm not well and have decided that I want to be free of pain but don't want a breathing machine again. I want the doctor to talk about my care with my friends and family but I don't want the doctor to ask them to make this decision for me. It's not easy but it's right for me. I've decided to make an Advance Directive.”

► Emphasize this:

It is very important to **TALK** with your health-care provider before making an Advance Directive to ensure:

- You understand the treatment options,
- The directive is clear and specific, and
- You understand how what you write would be interpreted.

It's hard to cover every possible decision in an Advance Directive, so **it is still important to have a Representative to be your voice when you are unable to speak for yourself.**

Because the Advance Directive is a legal document, your substitute decision maker(s) and health-care providers must honour its instructions, as long as what is written is current, relevant and addresses the specific treatment you need at the time. Your health-care providers will ask your substitute decision makers to make any treatment decisions that are not clearly specified in your Advance Directive.

► Explain what happens if you have both a Representation Agreement and an Advance Directive

If you have both a Representation Agreement and an Advance Directive

Your Representative will still be asked about all decisions, unless you state in your Representation Agreement that they should not be asked about decisions covered by your Advance Directive.

Your Representative should use your Advance Directive to guide them in making decisions on your behalf.

► Summarize what to include in an Advance Care Plan

Here is a script you can use:

What to include in your Plan?

- Written record or video/audio recording of what matters most to you: your values, beliefs and wishes for health care and personal care;
- A contact list of your eligible Temporary Substitute Decision Makers, with notes about who on the list is ineligible;
- Any legal document(s) you choose to make:
 - a Representation Agreement
 - an Advance Directive

Remember: having conversations about what matters most with the people you trust is key!

PLAN: Share your Advance Care Plan

► Explain what to do with an Advance Care Plan

Here is a script you can use:

What to do with your Advance Care Plan?

- Keep all documents together in a safe place where it can easily be found if needed. Be sure to tell your family where this is.
- First responders know to check on or near the fridge for health-care planning documents
- Share copies with your Substitute Decision Maker, close family and health-care provider(s).
- Bring the documents with you if you go to hospital.

REVIEW: Your plan



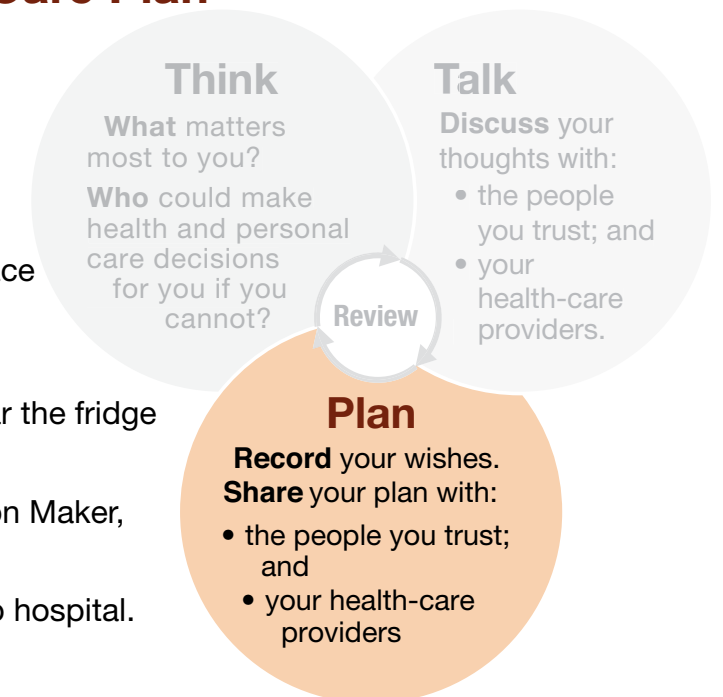
► Emphasize that Advance Care Planning is not a one-time thing

► Explain the importance of reviewing your Advance Care Planning

Here is a script you can use:

Why?

- Our health, our illnesses, and our treatment choices change over time.
- As our health changes, so do our decisions about what we consider to be tolerable and intolerable.
- What might seem like an intolerable quality of life when we look down the road, may look more tolerable when we get there.
- It's necessary to keep thinking about what is important to you based on your current health and life situation, and share your thoughts with the people closest to you.
- As your health and life circumstances change, you may want to document your wishes using legal documents, such as Advance Directives or Representation Agreements.
- If your relationship with your chosen Substitute Decision Maker changes, you may wish to choose someone else.



► Discussion Break: when to review your Advance Care Planning

Here is a script you can use:

When?

It's recommended to review your Advance Care Plan and all accompanying legal documents at least once a year.

You should also review your Advance Care Plan:

- When there is a change in your health (for example, new diagnosis of a serious illness, decline in health).
- If your life circumstances change (for example, if you move).
- If your relationship with your Substitute Decision Maker changes (for example, you get married divorced, or widowed).

How?

Think

Revisit the same questions as before, in light of any new circumstances. See whether your thoughts have changed.

- THINK again about what matters most to you
- THINK again about who could make decisions for you if you cannot

Talk

If your wishes have changed:

- TALK to the people you trust, including your Representative(s) and any Alternate Representative(s) if you have them.
- TALK to your health-care providers.

If nothing has changed:

- Remind the people you trust, including your Representative(s) and Alternate Representative(s) if you have them.

Review with the people you trust where your most up-to-date Advance Care Plan is located.

Plan

If you would like to make changes to any of your Advance Care Planning documents, do not make changes to the original copy.

- **Documents of what matters most to you:** record any changes after talking to people you trust, including your Representative(s) and Alternate Representative(s) if you have them.
- **Legal Documents: Representation Agreement:**
 - You can end your Representation Agreement by writing a notice of revocation. This must be signed and dated. You need to give a copy to your Representative(s), and any Alternate Representatives.
 - If you make a new Representation Agreement you should refer to the old agreement in the new one stating that it's revoked. This will provide certainty who has authority to act for you. For example, "I have revoked my prior representation agreement dated_____."
- **Advance Directive:**
 - It's best to put in writing that you intend to revoke the Advance Directive. You can write this in a new advance directive, or in a separate document. However, you can revoke your Advance Directive by destroying it with the intention of revoking it.

If you update any documents, make sure to give copies to anybody who had copies of the old documents. Ask them to destroy copies of the old documents. others updated copies and let them know where the documents are stored.

Closing the session

▶ Summarize the key messages about Advance Care Planning

Key Advance Care Planning messages

- **Advance Care Planning is a part of life planning.** It is for every adult and not just for people who are old or sick.
- **The sooner you start your Advance Care Planning, the better!**
- **Advance Care Planning is voluntary.** But given the many benefits of Advance Care Planning, you should prepare an advance care plan to help you get the care that is aligned with your wishes and beliefs.
- **Making Advance Care Planning legal documents is not mandatory but can give you more control** over who can speak for you and the decisions they can make. E.g., a Representative can make personal-care and health-care decisions for you; a Temporary Substitute Decision Maker can only make health care decisions.
- **There are three simple steps to Advance Care Planning: Think, Talk, Plan.**
 - Think about matters to you (your values, beliefs, and wishes).
 - Think who would you choose to be your substitute decision makers.
 - Talk with the people you trust about what matters most to you.
 - Talk with your health-care providers to understand your health conditions and share what they should know about you.
 - Plan by recording your wishes, preparing any legal documents, and sharing them with the people you trust.
- **Conversations are key!** An important step of Advance Care Planning is talking about your values and beliefs with those who might be involved in your health or personal care. This allows them to make the right decisions for you if you cannot make decisions yourself.
- **The more conversations you have, the easier they get.**
- **Advance Care Planning is not a one-time event.** It is recommended that you review your plan at key times in your life, like when there are changes to your health or close relationships.
- **As long as you are capable, your health-care provider will always ask you to make decisions** about your own care, regardless of whether or not you have an advance care plan in place.

▶ Ask for final questions

▶ Share the take-home resources

Review the content of the handout(s) you will be sharing with participants.

▶ Encourage participants to complete their Advance Care Planning over the next month.

Here is a script you can use:

Thank you for joining us over this Advance Care Planning session and sharing your stories. We encourage you to take what you have learned and use the resources we provide to get started on your advance care plan over the next month by:

- 1) Recording what matters most to you: your wishes, values, preferences for health and personal care. You may wish to talk to your health-care providers to gain a better understanding of your health conditions and treatment options.
- 2) Writing down a contact list of the eligible Temporary Substitute Decision Makers in your life and making notes of who is not eligible.
- 3) Deciding if you want to appoint your substitute decision maker with a Representation Agreement and who that will be.
- 4) Sharing and having conversations about what matters most with your substitute decision makers, your health-care providers, and others you trust.

▶ Distribute evaluation survey

Encourage each person to complete the survey prior to leaving the session.

See the *Community Partner Guide* for evaluation instructions.

After the Session

Reflect on the learnings from today

- What do I feel worked well?
- Is there anything I would do differently?
- Debrief with co-facilitator.
- Report back to your host organization, including:
 - any recommendations for the future, in particular if you have suggestions for other facilitators who will be offering the ACP session, and
 - if you have referred any participants back to the organization for follow up from the session.

Appendix A: Glossary

Term	Definition
Advance Care Planning	A process of thinking and talking about your future health-care wishes with the people you trust. The goal is for you to get the care that's right for you, even if you're unable to speak for yourself.
Advance Care Plan	A record of your values, beliefs, wishes and instructions about your future health and personal care, for use when you are not able to make decisions. Your plan can be written down, audio/video recorded or spoken. You may also include written legal documents such as an Advance Directive and Representation Agreement.
Advance Directive	A legal document that records your instructions for accepting or refusing specific health-care treatments. An Advance Directive gives instructions to your health-care provider at a time when you need health care but aren't capable of providing consent.
Capable	In health care, being capable means you can: <ul style="list-style-type: none"> • understand the information provided about the treatment offered, its purpose, benefits, and risks; • make a decision to receive (consent to) or refuse that treatment; and • communicate your consent or refusal. <p>You may become incapable at points in your life due to illness, disability or accident. Being capable or not is often assessed by your health-care provider.</p>
Cardio-pulmonary resuscitation (CPR)	A procedure used in an emergency if you stop breathing or your heart has stopped. Somebody presses on your chest and may blow air into your lungs to try and restore the flow of oxygen in your body.
Consent	In health care, consent is agreeing to or refusing a test or treatment.
Comfort care	Comfort care involves health care treatments that focuses on making you comfortable by controlling symptoms. Comfort care is always provided, but can become the only focus towards end of life. Examples include using medications treat reduce pain, anxiety, and constipation.

Term	Definition
Committee-ship	A person or persons appointed by the B.C. Supreme Court to make personal, medical, legal or financial decisions on your behalf if you become mentally incapable of making decisions for yourself. A committee-ship serves people who have not already designated someone to be their decision maker.
Enduring Power of Attorney	A legal document that you can use to appoint someone to make decisions about your financial and legal affairs. Unlike a Power of Attorney, an Enduring Power of Attorney remains active even if you are not mentally Capable.
Family and friends	We use family and friends to describe the people who matter most to you and whom you trust.
Health care	Tests, examinations, treatments and procedures related to your health.
Health-care provider	A trained professional who can legally provide health care. Examples of a health-care provider include a doctor, nurse practitioner, nurse or social worker.
Informed consent	In health care, informed consent is agreeing to a treatment when you understand its purpose, benefits, and risks.
Life-prolonging treatments	Life-prolonging treatments prolong your life after failure of one or more organs or diagnosis of a serious illness, but does not involve resuscitation or life support to keep you alive. Examples include radiation and chemotherapy for cancer, dialysis for kidney disease, feeding tubes.
Life-supporting treatments	Life-supporting treatments focuses on resuscitation and life support to keep you alive after failure of one or more vital organs. Examples include CPR and using ventilators.
Medical Assistance in Dying (MAiD)	Medical Assistance in Dying (MAiD) is a medical procedure available to eligible patients who wish to voluntarily end their life with the assistance of a doctor or nurse practitioner.

Term	Definition
Medical Orders for Scope of Treatment (MOST)	A MOST form is an optional medical order completed with your doctor or nurse practitioner to document your preferences regarding treatments you may receive in hospital or in a care home. A MOST form is signed by a doctor but can be changed or cancelled at any time. It is a useful tool to have in place in case of emergency but it does not replace informed medical consent.
Natural death	When used in Advance Care Planning, the phrase “allow a natural death” refers to decisions 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, such as age, health condition or illness.
No CPR Form	A No Cardiopulmonary Resuscitation (CPR) order can be put in place by a capable person or their substitute decision maker to refuse CPR in the event of cardiac or respiratory arrest. The form must be signed by you or your decision maker and your doctor or nurse practitioner.
Notice of Revocation	A legal document that allows you to annul permissions previously given by you to someone else to act on your behalf. For example, in Advance Care Planning you can use a Notice of Revocation to cancel a Representation Agreement.
Organ donation	Removing healthy organs and tissues from one person and placing these organs and/or tissues into another person.
Personal-care decisions	Choices about your daily life, such as where you live, your diet, clothing, hygiene, and activities.
Power of Attorney	A legal document that allows you to appoint someone to make decisions about your financial and legal affairs on your behalf. You must be mentally capable to sign a Power of Attorney. Unlike an Enduring Power of Attorney, the Power of Attorney becomes invalid once you are no longer mentally capable.

Term	Definition
Representation Agreement	A legal document in which you name someone, called a Representative, to make personal-care and health-care decisions for you if you cannot make these decisions on your own. There are two types of Representation Agreements: <ul style="list-style-type: none"> • Section 9 (Enhanced) – can be used by a capable person to name a Representative to make personal-care and health-care decisions, including decisions about life support and life prolonging treatments. • Section 7 (Standard) – can be used by a person with lessened capability to appoint a Representative who can provide routine management of the person’s financial affairs, legal affairs, personal care, and health care.
Representative	The person appointed by you in a Representation Agreement.
Spouse	Your husband or wife, or someone you are living with in a marriage-like relationship. For health-care decisions, it does not matter how long you and your spouse have been living together.
Substitute Decision Maker (SDM)	Someone who makes your health-care decisions when you cannot provide consent. In B.C., a Substitute Decision Maker can be appointed by you (a Representative), by the court (committee) or identified by your health-care provider from a list (Temporary Substitute Decision Maker).
Temporary Substitute Decision Maker (TSDM)	Someone identified by your health-care provider to make health-care decisions for you if you are not capable and do not have a Representative or personal guardian. British Columbia law provides a list that defines who your health-care provider must choose to make health-care decisions for you.

Appendix B: Frequently Asked Questions

Below are frequently asked questions about Advance Care Planning you may encounter while facilitating the sessions and scripts you can use to answer these questions.

1. What is the difference between a Representation Agreement, an advance care plan and an Advance Directive?	59
2. What is the difference between a Substitute Decision Maker (SDM) and Temporary Substitute Decision Maker (TSDM)?	59
3. Who should complete an Advance Directive (AD)?	60
4. What are the main components that need to be in my advance care plan?	60
5. Who should I talk to about my advance care plan?	60
6. How do I talk about my advance care plan?	61
7. Does a lawyer need to be involved in preparing and signing a Representation Agreement?	61
8. What is a 'living will'?	61
9. What is a No CPR Form?	61
10. What is a MOST?	62
11. What Advance Care Planning documents must ambulance attendants/paramedics comply with?	62
12. What Advance Care Planning information/documents do I need to have with me at all times?	62
13. Can I change my advance care plan?	63
14. Where should I keep my advance care plan?	63
15. Is my Advance Care Planning information attached to my health care number (PHN/Personal Health Number)?	63
16. What is MAiD?	63
17. What about the Bentley case?	64
18. What is an Enduring Power of Attorney and what is the difference from a Power of Attorney?	64

1. What is the difference between a Representation Agreement, an advance care plan and an Advance Directive?

An **advance care plan** is a record of your values, beliefs, wishes and preferences about your future health and personal care and who your substitute decision makers are, for use when you are not capable of making decisions. Your plan can be written down, audio/video recorded or spoken. An advance care plan can also include any legal documents you make, such as an **Advance Directive** and a **Representation Agreement**.

An **Advance Directive** is very specific and is a legally binding instruction related to health-care treatments.

A **Representation Agreement** is a legal document that nominates someone to speak for you.

2. What is the difference between a Substitute Decision Maker (SDM) and Temporary Substitute Decision Maker (TSDM)?

A **Substitute Decision Maker (SDM)** is someone who makes your health-care decisions when you are not capable of providing consent. In BC a Substitute Decision Maker can be appointed by you (a Representative through your Representation Agreement) or for you (a Temporary Substitute Decision Maker or a Committee).

A **Temporary Substitute Decision Maker (Temporary Substitute Decision Maker)** is one type of Substitute Decision Maker that is chosen by your health-care provider to make health-care decisions for you if you are not capable. BC law provides a ranked list that defines who your health-care provider must choose. A Temporary Substitute Decision Maker will be selected for you if you do not have any other Substitute Decision Makers, if your appointed Substitute Decision Makers are not available, or if for any reason they are not able to make the decision. The person can only temporarily make health-care decisions for you while you are not capable and only for the specific treatment that requires a decision. The selection process is restarted for every new health-care treatment that requires consent so the person who is selected one time to be your Temporary Substitute Decision Maker may not be the same person selected again depending on their availability and eligibility.

3. Who should complete an Advance Directive (AD)?

We highly encourage you to involve your doctor when make an Advance Directive. An Advance Directive must be very clear and specific to be legally binding.

An Advance Directive may be helpful for you if you:

- know you want or do not want a specific health care treatment, such as a blood transfusion or CPR
- have a disease, such as cancer, heart, lung or kidney disease, and have decided that there are specific treatments you don't want again (for example, chemotherapy, dialysis).
- do not have or want to appoint anyone to act as your Representative to make decisions about health care treatments.
- would like your health-care providers to refer to your Advance Directive rather than ask your Substitute Decision Maker regarding specific health-care treatments.

4. What are the main components that need to be in my advance care plan?

In BC your advance care plan should consist of the following:

- A written record, audio recording, or video of your values, wishes, and preferences for health and personal care and any conversations you have had regarding them with family, friends and health-care providers.
- A list containing the contact information of people in your life based on the Temporary Substitute Decision Maker list in BC law. You can also include notes about people who are on the list in the law but are not eligible (e.g. you have not been in contact with them for the past 12 months or you have had a dispute with them).
- Any legal documents you make: such as a Representation Agreement or an Advance Directive

5. Who should I talk to about my advance care plan?

- The people in your life who are on the Temporary Substitute Decision Makers list in BC law
- If you appointed them: your Representative(s), any alternate Representative(s), any Monitor(s)
- Other family and close friends
- Your health-care providers (doctors, nurses)

6. How do I talk about my advance care plan?

Starting to talk about Advance Care Planning can be challenging. Consider using the handouts outlining some conversation starters and talking points about Advance Care Planning. First, think about your values, beliefs and preferences for health and personal care, and then prepare how you will start talking with your Substitute Decision Makers, family, friends, and health-care providers about them.

7. Does a lawyer need to be involved in preparing and signing a Representation Agreement?

No, you can make a Representation Agreement without the help of a lawyer or notary public. You may choose to involve a lawyer or notary public if:

- there is the potential for conflict (for example, between family members).
- your requirements don't fit in the standard templates (for example, appointing multiple Representatives, choosing when your alternate representative can act)
- if there are any concerns about capability, such as with progression of dementia.

8. What is a 'living will'?

The term 'living will' is not in BC's health-care consent legislation (or anywhere in Canada).

The term 'living will' is a term from the United States that has been adopted into everyday language, and typically refers to any kind of Advance Care Planning document. The documents defined by BC law are Representation Agreements (Rep 7 or Rep 9) and Advance Directives. These, and other documents can form part of an advance care plan.

9. What is a No CPR Form?

In BC, the No Cardiopulmonary Resuscitation (No CPR) Form is a medical order that provides you and your physician or nurse practitioner with a legal option to order that no CPR be provided to you by health-care providers and first responders.

For the form to be valid, it must be signed by a capable adult, which is either you or your Substitute Decision Maker, and your physician or nurse practitioner.

If you have a No CPR order that is visible and signed, you will not be given CPR by first responders or other health care providers. People often put the form on their fridge so it can be easily seen.

You can also sign up to receive a No CPR MedicAlert® bracelet or necklet that you can wear to visibly indicate to first responders that you have an active No CPR order in place.

10. What is a MOST?

Medical Orders for Scope of Treatment (MOST) is a medical order that is completed based on conversations between a doctor or nurse practitioner and a capable person or their Substitute Decision Makers about goals of care and desired treatments. It is most commonly used in hospitals and care homes to help health care providers understand what kind of treatments a person prefers. The MOST form must be signed by a doctor or nurse practitioner after they have had a conversation with you or your Substitute Decision Makers about your preferences for health care treatments. The MOST form must be revisited and resigned every year.

11. What Advance Care Planning documents must ambulance attendants/paramedics comply with?

In emergency situations, ambulance attendants/paramedics will ask a substitute decision maker for consent or refusal of emergency treatments if the substitute decision maker is available immediately to answer. If not, they will look for any of these documents to give them directions:

- Advance Directive
- Provincial No CPR form and/or MedicAlert® No CPR bracelet or necklet
- MOST form (Medical Order for Scope of Treatment) provided that it is dated within one year.

If none of the above is readily available, the emergency health-care worker will follow normal procedure.

12. What Advance Care Planning information/documents do I need to have with me at all times?

It is recommended to carry with you information about your Substitute Decision Makers (the contact information for your Temporary Substitute Decision Maker list and your Representatives, if you appointed them). You can do this by:

- Using the wallet card available in the back of My Voice
- Entering their information under the contact “ICE” (In Case of Emergency) on your mobile phone.

Other legal documents and medical orders, if you have them:

- Advance Directive
- Provincial No CPR form and/or MedicAlert® No CPR bracelet or necklet
- MOST form (Medical Order for Scope of Treatment) provided that it is dated within one year.

13. Can I change my advance care plan?

You can change your Advance Care Planning as often as you wish. It is recommended to revisit your plan at minimum once a year and more frequently if there is a change in your health or if your life circumstances change.

If you have legal documents in place, such as a Representation Agreement and Advance Directive, there are specific requirements when making changes. You may need to talk to a lawyer.

14. Where should I keep my advance care plan?

It is recommended to keep the documents in an envelope or plastic sleeve on the front of your fridge; this is where emergency medical assistants/paramedics will know to check.

15. Is my Advance Care Planning information attached to my health care number (PHN/Personal Health Number)?

Unfortunately, BC does not yet have a provincial registry for Advance Care Planning information. However, in some health authorities, such as Fraser Health, you can ask your health care provider to add your Advance Care Planning information to your hospital health care records.

16. What is MAiD?

“MAiD” or Medical Assistance in Dying is a medical procedure available to eligible patients who wish to voluntarily end their life with the assistance of a doctor or nurse practitioner. MAiD is legal in Canada for a person meeting specific eligibility criteria:

- Are capable of making decisions about their health,
- Have given informed consent, and
- Have a serious and incurable medical condition, which means they are in an advanced state of decline, experiencing enduring and intolerable physical or psychological suffering, and their natural death has become reasonably foreseeable.

The government sets out procedural safeguards for protecting people, and the process by which MAiD can be provided.

► Emphasize this:

Medical Assistance in Dying cannot be requested in advance through an advance care plan or an Advance Directive. It also cannot be requested through a substitute decision maker on your behalf.

17. What about the Bentley case?

Mrs. Bentley was an elderly woman with advanced dementia living in a nursing home in Abbotsford. Because of earlier documents stating that she did not want artificial food or fluids the family asked that she not be spoon fed. This went to supreme court in BC twice.

The court ruled that health-care providers and families must provide necessary basic personal care to vulnerable adults and that the previous documents did not apply to being fed or being offered food and fluids. In the Supreme Court decision Judge Grevall stated: “Withdrawing oral nutrition and hydration [food and fluids] for an adult that is not capable of making that decision would constitute neglect within the meaning of the Adult Guardianship Act.” “Even if Mrs. Bentley was found incapable of making the decision to accept oral nutrition and hydration, I am not satisfied that the British Columbia legislature intended to allow reference to previously expressed wishes or Substitute Decision Makers to be relied on to refuse basic personal care that is necessary to preserve life.”

(<http://eol.law.dal.ca/wp-content/uploads/2014/02/Bentley-v.-Maplewood-Seniors-Care-Society-2014-BCSC-165.pdf>)

Health care and personal care are not considered the same under the law.

Health care consent legislation allows you to refuse health care in advance. However, withholding personal care such as oral food and fluids may constitute neglect.

18. What is an Enduring Power of Attorney and what is the difference from a Power of Attorney?

An Enduring Power of Attorney is a legal document that allows you to assign someone you trust to manage your legal and financial affairs right away AND when you are no longer capable of doing so. Without this document in place, no one can automatically step in make these decisions for you. At the time you create the Enduring Power of Attorney you must be capable of making decisions for yourself. An Enduring Power of Attorney is not for health-care or personal-care decisions so is not a legal document used in Advance Care Planning.

The main difference between an Enduring Power of Attorney and a Power of Attorney is that the effects of the Power of Attorney ends when a person is no longer capable of making decisions for themselves. An Enduring Power of Attorney has effect when a person is capable and continues to have effect when they are no longer capable.

Talk to a lawyer or financial advisor for more information.

Appendix C: Resources for Facilitators

You can refer to these resources to supplement your learning and the topics addressed in the facilitator guide. There are also videos and personal stories you can use during the sessions, as well as booklets, brochures, and handouts you may wish to provide to participants to take home (in addition to the handouts in the toolkit).

It would be helpful to be familiar with this list so you can refer participants to any relevant resources as needed.

Videos and Personal Stories You Can Use in Your Sessions	66
Advance Care Planning Videos - English	66
Advance Care Planning Videos – Other Languages	67
Personal Advance Care Planning Stories	68
Information on Capability and Consent	68
Overview of Advance Care Planning (Think/Talk/Plan)	69
Information on the Planning Options & Legal Documents	70
Other Advance Care Planning Topics	72
Advance Care Planning Step-by-step Guides & Workbooks	72
Advance Care Planning Conversation Guides	73
First Nations Resources	73
Legal Help	74
Example Advance Care Plans & Documents	74

Videos and Personal Stories You can Use in Your Sessions

Advance Care Planning Videos - English

Resources	Details	Link
SPEAK UP Video (Speak Up)	3.5-minute video explains why ACP is important for you and your family.	https://www.youtube.com/watch?v=nnsYlfioTpo&feature=youtu.be
Advance Care Planning – Conversations (Speak Up)	4.5-minute video featuring real-life stories and thoughts from researchers, health professionals and family members about having Advance Care Planning conversations.	https://www.youtube.com/watch?v=6gFzCiMnlq
Walter Gretzky Speaking up! About Advance Care Planning (Speak Up)	1.5-minute video: Walter Gretzky and his daughter talks about their experience with Advance Care Planning and how it helped his family members know about his wishes and values.	https://www.youtube.com/watch?v=0ZXvgpkW-34&list=PLypGbhyn1zsl92pKnocdXjlvEpAU8qUP1
Importance of ACP (Canadian Virtual Hospice)	6-minute by Dr. Doris Barwich talking about the importance of ACP.	https://www.youtube.com/watch?v=0PUhEoGWC08
Health care consent (Doctors of BC)	6-minute video by Dr. Doris Barwich answering questions about advance directives, role of a substitute decision maker, role of physicians in ACP and health-care consent.	https://www.youtube.com/watch?v=a-HFLkL5IRk
Advance Care Planning: Our Patients' Stories (Tomorrow's Medicine)	2.5-minute video of people of Asian origin speak about importance of ACP	https://www.youtube.com/watch?v=FDxVxo33A0w
ACP Conversations (ABC World News)	5-minute video: 15 years old talks about his cancer with his family	https://www.youtube.com/watch?v=J1r0Xbh0UVo&feature=youtu.be
ACP Conversations (Common Practice)	5-minute video: 15 years old talks about his cancer with his family with help from nurse and a conversation game	https://vimeo.com/126962214

Resources	Details	Link
ACP Conversations (Irish Hospice)	6-minute video: Mother and daughter speak of wishes and goals	https://www.youtube.com/watch?v=oB-acZRUOo4&feature=emb_title
Living.My.Culture.ca (Canadian Virtual Hospice)	People from various cultures share their stories and wisdom about living with serious illness, Advance Care Planning, end of life and grief to support others. Videos are available in various languages.	https://livingmyculture.ca/culture/

Advance Care Planning Videos – Other Languages

Resources	Details	Link
Advance Care Planning for Everyone (Speak Up)	Youtube playlist of 1 to 1.5-minute videos on Advance Care Planning in the following languages: <ul style="list-style-type: none"> • French • Chinese (Traditional) • Chinese (Simplified) • Punjabi • Italian • Tagalog • German • Korean • Spanish • Portuguese 	https://www.youtube.com/c/AdvanceCarePlanning/playlists?view=50&sort=dd&shelf_id=3 Punjabi speakers: https://www.youtube.com/watch?v=0lq9ITUuz4Q&list=PLypGbhyn1zsJUwH3MMfbTcPlzvFVv2N8b

Personal Advance Care Planning Stories

Resources	Details	Link
Advance Care Planning Personal Stories (ehospice)	4 personal stories about ACP from individuals, including one from a person living with dementia (Marjorie Goodfellow).	https://ehospice.com/canada/english_posts/read-advance-care-planning-personal-stories/
Five Moving Stories From The Conversation Project (The Conversation Project)	Five stories from individuals highlighting importance of Advance Care Planning (ACP) conversations and their experiences with having ACP conversations with their family members.	https://theconversationproject.org/tcp-blog/five-moving-stories-from-the-conversation-project/
Choosing Life (The Conversation Project)	Conversation with a sibling diagnosed with cancer.	http://theconversationproject.org/your-stories/choosing-life/
Dying With Dignity (Beijing Review)	News article about Advance Care Planning in Chinese culture and the taboos associated with the topic of death and end of life. Contains several personal stories.	http://www.bjreview.com/nation/txt/2013-10/07/content_570289.htm

Information on Capability and Consent

Resources	Details	Link
Health Care Consent (Seniors First BC)	Information on health care consent and the hierarchy of consent as outlined in BC legislation.	http://seniorsfirstbc.ca/for-professionals/adult-guardianship/health-care-consent/

Resources	Details	Link
Health Care Decision-Making: Legal Rights of People Living with Dementia (Canadian Centre for Elder Law)	Information for the public on the decision-making rights of people living with dementia developed by the Canadian Centre for Elder Law in collaboration with the Alzheimer Society of BC: <ul style="list-style-type: none"> • Three short animated videos (3-min long Youtube videos) • Links at the bottom of the page to booklets available in English, French, Traditional Chinese and Punjabi 	https://www.bcli.org/project/health-care-decision-making-legal-rights-of-people-living-with-dementia

Overview of Advance Care Planning (Think/Talk/Plan)

Resources	Details	Link
Advance Care Planning Resources (BC Centre for Palliative Care)	BCCPC's webpage on Advance Care Planning (ACP) for the public, which include: <ul style="list-style-type: none"> • Information on ACP: The What, Who, When and How (Think/Talk/Plan) • Conversations starter with your family and friends • How to Talk to Your Health-Care Provider • Who can make care decisions for you (about Substitute Decision Makers) • Links to other guides and workbooks for Advance Care Planning in B.C. 	https://bc-cpc.ca/cpc/all-resources/individuals/acp-resources/

Resources	Details	Link
Be Prepared in the Time of COVID-19 (BC Centre for Palliative Care)	An interactive online webpage for the public with printable documents. <ul style="list-style-type: none"> Information about COVID-19 and its impacts on health Information about ventilators and cardiopulmonary resuscitation (CPR) Summary of the steps for Advance Care Planning 	https://bc-cpc.ca/cpc/all-resources/individuals/covid19/#1588374602503-c7657d43-fff5

Information on the Planning Options & Legal Documents

Resources	Details	Link
Planning for Your Future (People's Law School)	People's Law School is a non-profit society in British Columbia, dedicated to making the law accessible to everyone. Their Work It Out pages provide information on Advance Care Planning and the associated legal documents (MOST forms, Representation Agreements, etc.) as well as other types of planning (financial, legal).	https://www.peopleslawschool.ca/everyday-legal-problems/planning-your-future/start-your-planning-here
Personal Planning (Dial-A-Law)	Dial-A-Law is a service of People's Law School (see above). This webpage provides information on: <ul style="list-style-type: none"> Committeeship Representation agreements Power of Attorney (for financial and legal planning, not of Advance Care Planning) 	https://dialalaw.peopleslawschool.ca/category/life/wills-planning-estates/personal-planning/

Resources	Details	Link
Representation Agreements (Seniors First BC)	This webpages provides a detailed information on and comparison of Section 7 and Section 9 Representation Agreements. The comparison charts are referenced in the Facilitator Guide.	http://seniorsfirstbc.ca/for-professionals/representation-agreements/
Nidus – Personal Planning Resource Centre and Registry	B.C. based non-profit organization that provides the following Advance Care Planning services: <ul style="list-style-type: none"> Information on the planning options and associated legal documents, specializing in Representation Agreements Example legal documents for planning (eg. Representation Agreements) Free live webinars Personal help by phone and email Online registry to store your advance care plan 	https://www.nidus.ca/
MOST Form (People's Law School)	Information the Medical Orders for Scope of Treatment (MOST) form.	https://www.peopleslawschool.ca/everyday-legal-problems/planning-your-future/health-personal-care/understand-most-forms-medical
No CPR Form (HealthLinkBC)	Information the No Cardiopulmonary Resuscitation (CPR) Form and associated MedicAlert bracelet.	https://www.healthlinkbc.ca/health-feature/no-cpr-form

Other Advance Care Planning Topics

Resources	Details	Link
Organ Donation	For information on organ donation in BC.	http://www.transplant.bc.ca/ You can register to be an organ donor in BC online or by calling 1-800-663-6189 to get a registration form in the mail.
Medical Assistance in Dying (MAiD)	For the most up-to-date information on Medical Assistance in Dying in BC.	https://www2.gov.bc.ca/gov/content/health/accessing-health-care/home-community-care/care-options-and-cost/end-of-life-care/medical-assistance-in-dying

Advance Care Planning Step-by-step Guides & Workbooks

Resources	Details	Link
My Voice – Advance Care Planning Guide (Ministry of Health)	A comprehensive, printable guide to Advance Care Planning: <ul style="list-style-type: none"> Includes example legal documents for planning (Advance Directive, Representation Agreements) Available in English, Punjabi and Simplified Chinese 	https://www2.gov.bc.ca/gov/content/family-social-supports/seniors/health-safety/advance-care-planning
Speak Up - B.C. (Canadian Hospice Palliative Care Association)	An online, interactive Advance Care Planning guide and workbook. This workbook will help individuals make an advance care plan and prepare to make any legal documents.	http://www.speak-upinbc.ca/

Advance Care Planning Conversation Guides

Resources	Details	Link
How Well Do You Know Me? (BC Centre for Palliative Care)	A brochure on how to start a conversation with your family and friends about what matters to you and your goals of care.	https://www.bc-cpc.ca/cpc/wp-content/uploads/2019/05/ConversationStarter.png
Serious Illness Conversations Initiative in British Columbia (BC Centre for Palliative Care)	A brochure on how to prepare for a conversation with your health-care providers about your serious illness, risk of getting sick with COVID-19, fears, preferred treatments and goals of care.	http://www.bccancer.bc.ca/new-patients-site/Documents/SIC%20Initiative%20BCCPC%20Brochure.pdf

First Nations Resources

Resources	Details	Link
Advance Care Planning (Lakehead University)	Brochure providing an overview of Advance Care Planning	https://www.advancecareplanning.ca/wp-content/uploads/2020/06/acp_pdf.pdf
Why Advance Care Plan (Lakehead University)	Poster explaining why you should do Advance Care Planning.	https://www.advancecareplanning.ca/wp-content/uploads/2020/06/advancecareplanposter.pdf
Your Care, Your Choices – Planning in Advance for Medical Care (First Nations Health Authority)	A guide to Advance Care Planning for First Nations peoples, including the legal forms.	https://www.advancecareplanning.ca/wp-content/uploads/2020/05/FNHA-Your-Care-Your-Choices-Planning-in-Advance-for-Medical-Care.pdf

Legal Help

Resources	Details	Link
Legal Advocacy Program (Senior's First BC)	The Legal Advocacy Program provides legal advice, advocacy and representation to people aged 55+ on legal issues	http://seniorsfirstbc.ca/programs/legal-programs/ Phone Number: 604-437-1940 Toll-free Number: 1-866-437-1940
Access Pro Bono	Volunteer lawyers who provide free legal services for eligible British Columbians.	http://accessprobono.ca/ Phone Number: 604-878-7400 Toll-free Number: 1-877-762-6664

Example Advance Care Plans & Documents

Resources	Details	Link
Letter From Mom (Conversation Project)	A simple example of an advance care plan written as a letter to family.	https://bc-cpc.ca/cpc/wp-content/uploads/2020/09/Letter-from-Mom.pdf
Advance Care Plan Example by CL (Comox Valley Advance Care Planning)	The advance care plan of CL, a 55-year-old grandmother.	https://bc-cpc.ca/cpc/wp-content/uploads/2020/09/CLs-Advance-Care-Plan.pdf
Advance Care Plan Example by JK (Comox Valley Advance Care Planning)	The advance care plan of JK is a 58-year-old RN who worked most of her 35-year nursing career in critical care/intensive care Units.	https://bc-cpc.ca/cpc/wp-content/uploads/2020/09/Jks-Advance-Care-Plan.pdf
Advance Care Plan Example by Mr. Zhang	The advance care plan of Mr. Zhang, a retired 65-year-old who is taking care of his parents at home.	https://bc-cpc.ca/cpc/wp-content/uploads/2020/09/PLAN-Example-by-Mr.-Zhang-English-Traditional-Chinese.pdf
For examples of forms to make Representation	Refer to resources listed above: <ul style="list-style-type: none"> • My Voice – Advance Care Planning Guide (see page...) 	

Resources	Details	Link
Agreements and Advance Directive	<ul style="list-style-type: none"> • Nidus – Personal Planning Resource Centre and Registry (see page...) 	
Example of a MOST form (Interior Health)	This a medical order that must be completed by a doctor. Different health authorities may use different forms (see Other Advance Care Planning Topics section for more information).	https://www.interiorhealth.ca/YourCare/PalliativeCare/ToughDecisions/Documents/MOST-Orders%20for%20scope%20of%20treatment.pdf
No CPR Form	This a medical order that must be completed by a doctor (see Other Advance Care Planning Topics section for more information).	https://www2.gov.bc.ca/assets/gov/health/forms/302fil.pdf



*All British Columbians affected by serious illness
will have equitable access to compassionate,
person-centred care and resources.*