



Advance Care Planning Workshop



# Advance Care Planning – and Understanding Grief Along the Way

Starting the Conversation



# Objectives

- Engage you in thinking about advance care planning
- Talk about grief
- Explain the how – the five steps – of advance care planning
- Help you plan how to start conversations about advance care planning with the people who matter most to you
- Help you start to think about choosing a substitute decision maker

# Why We Need to Talk About Grief

- Advance care planning often brings up **grief** – for the person planning, families, friends, and caregivers
- Grief is a **natural response** to changes in health, identity, independence, or relationships
- You do not need to be seriously ill to experience grief
- Ignoring grief can make planning harder – acknowledging it helps people feel seen and supported
- **Talking about grief creates space for empathy and clarity** in decision-making

# What Could Grief Look Like in Advance Care Planning?

## Type of Grief

## Examples

Anticipatory grief

Sadness or loss about the future —  
e.g., changes in health, aging, or  
ability

Ambiguous loss

Grieving someone who is physically  
present but emotionally or mentally  
changed

Disenfranchised grief

Grief that feels unacknowledged or  
unsupported — due to stigma or  
silence

Cumulative grief

Grief from multiple or ongoing  
losses over time

# What Helps?

- **Naming and normalizing grief** – letting people know their feelings are valid
- **Making space for emotions** – it's okay to feel sad, uncertain, or overwhelmed during these conversations
- **Connecting with support** – through grief counselors, spiritual care, peer groups, or trusted individuals
- **Recognizing the emotional weight of planning** – preparing for future care often brings up deep reflection, concern, and care for others

# What is Advance Care Planning?

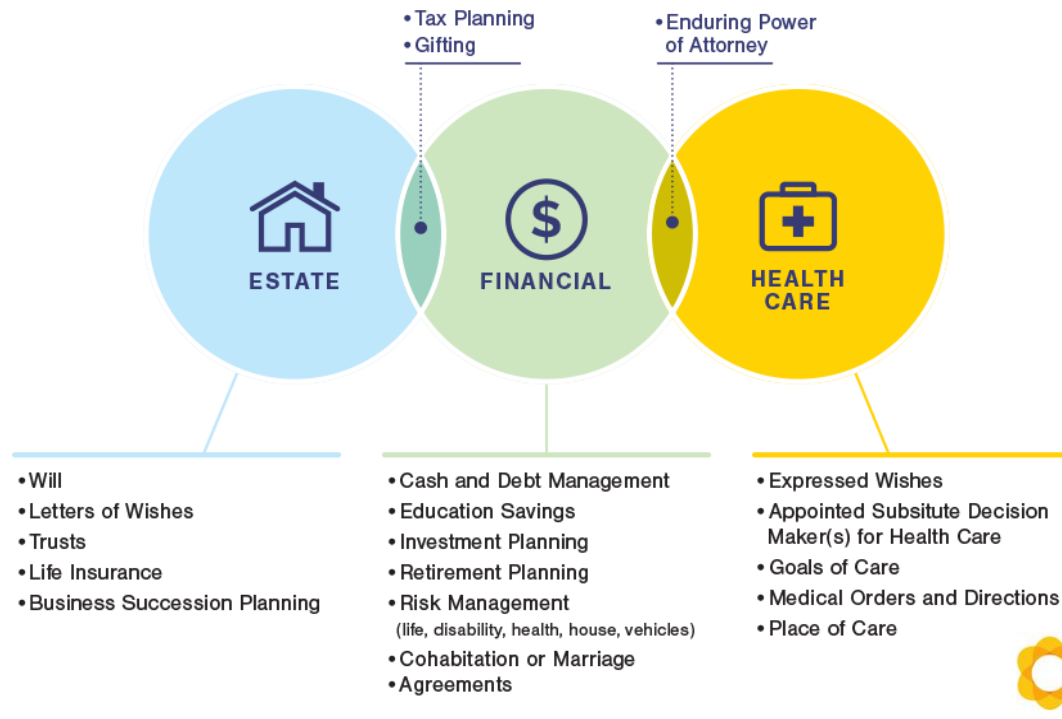


Advance Care Planning (ACP) is a lifelong process of thinking about what matters to you — your values, goals and preferences — and the care you would like to receive at any age/stage of your adult life.

ACP is also about talking to the people who matter most to you — and to your health care professionals — about your wishes.

# ACP is Part of Life Planning

## The Life Planning Model



# When Choosing a Substitute Decision Maker



Try to choose someone who:

- Is a capable adult
- Will honour your wishes even if they are different from their own —
- Is calm in a crisis
- Is able to handle conflict or disagreement
- Is accessible and able to commit the time that might be required

# Why is ACP Important?

- Life can change at any moment.
- The more people know about your values, goals and wishes ... the more they can help you get the care you want.
- The earlier people have conversations about their wishes, the less anxious they are if they experience a health crisis.



# Activity

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- Do you have any stories about the impact of having – or not having – engaged in ACP on anyone you know?
- What lessons did you learn from that experience?

# Who Should do ACP?



Everyone!

ACP may be more urgent for:

- People who think their family may have different views or beliefs than their own
- People who have been diagnosed with a chronic condition that could affect their ability to communicate

# When is the Right Time to do ACP?

## Life's milestones

- Getting married
- Buying a *house*
- *Having children*
- Changes in personal relationships
- Changes in living situations

## Health Events

- Upcoming surgery
- Being diagnosed with heart disease
- Becoming increasingly frail

# How to do ACP?



ACP is not a one-time event.

It is an ongoing process of thinking, talking, planning and reviewing your plan

 Here are the Five Steps of ACP

# The Five Steps of ACP

## Advance Care Planning in 5 Steps



### Think

About my values, wishes, beliefs, and my understanding of my care and treatment.



### Learn

About different medical procedures and what they can and can't do.



### Decide

Who will be your substitute decision maker. Someone who is willing and able to speak for you if you can't speak for yourself.



### Talk

About your wishes with your substitute decision maker, loved ones, and your doctor.



### Record

Your wishes. It's a good idea to write down or make a recording of your wishes.

# Step One: Think

What makes life worth living?

What does a great day look for you?

What would you be doing?

What do quality of life and comfort mean to you?

“I’m willing to undergo almost anything as long as I can watch football on television and eat chocolate ice cream.”

*Being Mortal,  
Atul Gawande.*



## Step Two: Learn

ACP is NOT about making a laundry list of treatments you would or would not want some time in the future.

ACP is about thinking about what's important to you and using that information to inform the health decisions you may make throughout your life.



## Step Three: Decide

If you are unable to make a decision for yourself, you need someone to speak and decide for you.

That person is your substitute decision maker.



## Step Four: Talk

Think about the people who matter most to you. How well do they know you?

It's important to talk about your wishes so they know what's important to you and because your wishes might change over time.

Normalize talking about it



# Step Four: Conversation Starters

**The hardest part is starting the conversation.**

- I need your help with something ...
- I was thinking about what happened to (name) and it made me realize ...
- Right now, I'm living with (name of condition) and I expect (prognosis). Is that what you understand too?



## Step 4: Talk - Activity

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1. How many of you have had conversations with people who matter to you about your wishes for your care?
2. What was the hardest part about having those conversations?
3. How did you prepare? What are some ideas for starting the conversation?
4. How did it go? What, if anything, would you do differently?

# Step 5: Record

## Why?

There is no legal requirement to write down or record your wishes but recording can help:

- you remember what you thought and said
- your substitute decision maker remember the details of the discussion
- provide evidence of your wishes if there is disagreement about your care.

# Review

Remember: ACP is not a one-time event! It's important to review your ACP regularly.

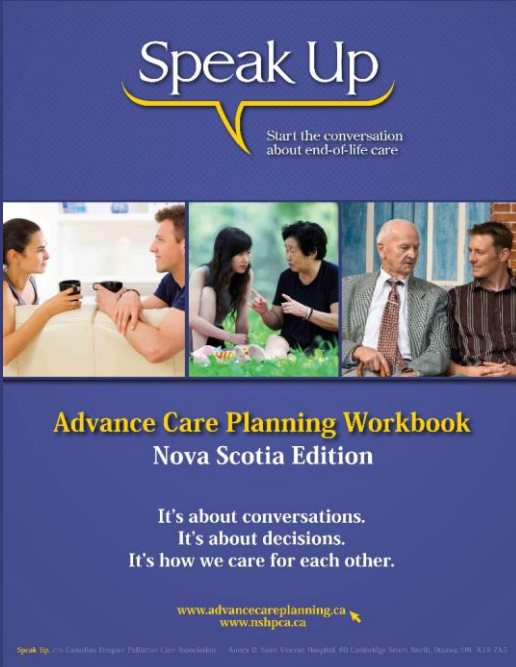
**Why?** Your understanding of your health and treatment options can change over time, as can your values and goals.

**When?** Whenever your life, health or circumstances change.


**How?** Use the same five-step process. If anything changes, tell your substitute decision maker and the people close to you.



# For more information:



**Speak Up**  
Start the conversation  
about end-of-life care



**Advance Care Planning Workbook**  
Nova Scotia Edition

It's about conversations.  
It's about decisions.  
It's how we care for each other.

[www.advancecareplanning.ca](http://www.advancecareplanning.ca)  
[www.nshpca.ca](http://www.nshpca.ca)

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