BC Centre for Palliative Care

# Peer-facilitated Advance Care Planning public sessions

## Program Overview

**August 2017**

Prepared by the BC Centre for Palliative Care.

Special thanks to Comox Valley Hospice Society and the Community Engagement Advisory Network (CEAN) of Vancouver Coastal Health Authority for sharing your experience and wisdom around public education about Advance Care Planning in the development of the peer-facilitated public sessions program.

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# Advance Care Planning

## Evolution of Advance Care Planning definition

The definition of Advance Care Planning (ACP) has evolved over time. An updated definition was developed by a group of ACP experts and published in early 2017 as follows:

> ***Advance Care Planning*** *is a process that supports adults at any age or stage of health in understanding and sharing their personal values, life goals, and preferences regarding future medical care.*
> *The goal of Advance Care Planning is to help ensure that people receive medical care that is consistent with their values, goals and preferences during serious and chronic illness*[1].

### Key changes in Advance Care Planning definition and concept

- **Past emphasis: document completion → Current emphasis: conversation**
  ACP practice previously targeted document completion. However, it has been shown that document completion alone does not improve patient/health-care provider communication[2], or the accuracy of substitute decision making[3,4].
  The emphasis has therefore shifted from the document to the care planning process[5], where the conversation is recognized as a valuable component and an outcome in and of itself[6,7].

- **Past focus: treatment preferences → Current focus: outcomes, values and beliefs**
  Early documents focused on people outlining specific treatment preferences. However, applying these 'black and white' preferences to the nuanced circumstances that actually arise is difficult[5,7–9], and people in good health are generally unable to predict what they would want in stages of poor health[10]. This has led to the development of documents that are more focused on outcomes, values and beliefs, and can be applied to whatever circumstances that arise[7,8].

- **Past benefits: incapacity planning → Current benefits: future decisions, with or without capacity**
  Initially the cited benefits of ACP were restricted to times when a person cannot make or communicate a decision about health-care treatment (times of incapacity). However, research has also demonstrated short-term benefits to ACP, such as increased satisfaction with care, increased quality of life, and decreased depression[11–14].

- **Past relevance: people at end-of-life → Current relevance: all adults at any age or stage of health**
  While some aspects of ACP are more appropriate for people with serious illness or nearing the end of their life, other aspects are relevant for everybody, such as choice of a Substitute Decision Maker and any known wishes relating to sudden catastrophic events. Dependent on a person's stage of life and/or their illness, different ACP conversations and activities are recommended to ensure their health-care is consistent with their values, goals and preferences[15].

## BC Centre for Palliative Care definition of Advance Care Planning

The BC Centre for Palliative Care (BCCPC) has adapted the new definition of ACP for public audiences as follows:

> ***Advance Care Planning*** *is a process that supports you (a capable adult) and your family[A] to prepare to make decisions about your future health care. It involves understanding and sharing your values, beliefs and wishes regarding health and personal care.*
> *This information is used during conversations with health-care providers about the treatments and care you receive, to help you get the care that's right for you.*

## Difference between Advance Care Planning and Medical Orders for Scope of Treatment

ACP and Medical Orders for Scope of Treatment (MOST) are not the same.

Here are some key definitions:

**MOST**
These are medical orders (or forms) signed by a doctor stating the level (or scope) of medical and life-support treatments to be provided in an emergency when a person is unable to tell health-care providers directly. These treatments are often grouped into 'critical care', 'medical care' and 'comfort care'.
Ideally, these forms are completed following Goals of Care Conversations with patients, or if they are not capable their Substitute Decision Maker. Information from prior ACP conversations is used during these conversations.

**Goals of Care Conversations**
Conversations that clarify a patient's goals of care and create an individual care plan. They are between health-care provider(s) and a patient, or if the patient is not capable their Substitute Decision Maker. They include developing a shared understanding of the patient's values, beliefs and wishes, and the treatment options available.

**Goals of Care**
The outcomes a patient is hoping for from their care and treatments, based on what is most important to them.

As described above, a MOST is a possible outcome from a Goals of Care Conversation. Whereas, ACP is a process, the information from which is used during a Goals of Care Conversation.

This difference is illustrated in the diagram in Appendix A.

[A] We use family to describe anyone close to you that you see as your family. This could include close friends.

## Advance Care Planning in B.C. in numbers

**Did you know…**

76% of British Columbians agree that it's important to talk about what matters most for their future health care with those close to them and their health-care providers, but:

- Only 28% have heard of Advance Care Planning.
- Only 49% have had a conversation with family.
- Only 10% have had a conversation with a health-care provider.
- Only 27% have documented or recorded their health-care wishes.

*Source: BC public opinion poll commissioned by the BCCPC and conducted by Mustel Research Group: Advance Care Planning, 2016.*

**Together we can improve these numbers.**

BCCPC is excited to be partnering with your organization to promote ACP conversations in your communities.

# Peer-facilitated public ACP sessions program

## Background

In 2016, a B.C. public survey commissioned by BCCPC demonstrated relatively low levels of awareness and engagement in ACP among British Columbians. Differences exist between age groups, education levels, and gender. Older highly educated adults and women are more likely to engage in ACP.

The data highlighted the need for provincially coordinated efforts in B.C. to further enhance public awareness of ACP, and to empower B.C.'s adults to initiate ACP conversations with family or with their health-care providers.

To address these gaps, BCCPC launched a provincial initiative, funded by a grant from the Ministry of Health, to promote and improve conversations and documentation related to ACP. The goal of the initiative is to help British Columbians receive the care that is right for them and consistent with their values, beliefs and wishes.

## Program development

As part of the provincial ACP initiative, BCCPC partnered with two community organizations to develop a program that delivers peer-facilitated ACP sessions for the public. The two organizations, Comox Valley Hospice Society and VCH Community Engagement Advisory Network (CEAN), are pioneers in ACP public education in B.C. The program development was consulted by an advisory group of ACP experts in health authorities and members of the public.

## Program design and components

The details of the program design can be found in the program logic model (See appendix B).

**The program components are:**

- Community Organizations: Implementation and evaluation tools for community organizations who are interested in establishing their own ACP public education program;
- Peer facilitators: Training curriculum and workshop, and a guide for volunteers/staff affiliated with the community organizations to help acquire the required knowledge and skills to facilitate ACP sessions for the public.
- Public ACP Sessions: Public sessions hosted by the community organizations and facilitated by the trained peer facilitators.

## Program benefits

The program offers community organizations the opportunity to relate to the needs of their communities and engage with the public in a proactive, health-oriented way.

The program offers volunteers, who have a passion to give back to their community, the opportunity to develop their knowledge and skills and equip them with the necessary tools that support them in the ACP peer facilitator role.

The program helps communities at large to be become compassionate communities.

> **BCCPC's vision of Compassionate Communities**
> Communities in which people believe they are ready and confident to have conversations about improving the way we live and die. People in compassionate communities are motivated by empathy and kindness to offer emotional, practical and spiritual support to those who are impacted by a serious illness or experiencing a health crisis, or issues related to dying and loss.

## Program spread and recognition

BCCPC has spread the program's model through Cycles 1 and 2 of its seed grant program to more than 23 hospice societies across B.C.

Evaluation data from two volunteer training workshops and more than 40 public ACP sessions indicates that the model is effective:

- organizations experienced more partnerships, a positive image and improved connectivity with community;
- peer facilitators' knowledge, skills and confidence to facilitate public ACP sessions were improved; and
- public participants' engagement in ACP was increased.

In July 2017, the model was recognized by the Canadian Institute for Health Innovations as an innovative palliative care model worth spreading nationally.

The program components have been updated to reflect the recent evolution in the definition of ACP, and to incorporate feedback from the trained peer facilitators and from the participants of the hosted sessions.

## Partners in program delivery

1. BCCPC is the coordinating body.
2. Community organizations are the program organizers.
3. Volunteers or staff affiliated with community organizations are the facilitators of the public ACP sessions.

## Partner roles and responsibilities

### BC Centre for Palliative Care

As the program coordinating organization, BCCPC has the responsibility to provide the following support and tools:

<u>For peer facilitators:</u>

- Training in the form of in-person training workshop, access to an online training module about ACP and background reading materials.

- Resources to support session delivery, such as *Facilitator Guide*, session schematic, glossary of terms, answers to frequently asked questions and a demonstration PowerPoint.
- List of additional online resources to support the peer facilitator's knowledge of ACP and facilitation skills.
- Information tools that can be given to public participants to take home after the session.

For community organizations:

- Planning resources that outline the necessary components for hosting sessions.
- Resources to support the organization in developing its own peer facilitator ACP education program.
- Tools to support the ongoing evaluation of the sessions.
- Marketing tips and examples.

### Community organizations

The role of community organizations is to support the peer facilitators in their role, to ensure the sessions are current and accurate in content, and can be sustained.

As the organizer of the peer-facilitated ACP sessions, community organizations have the following areas of responsibility:

- **Recruitment of volunteers for the peer facilitator role as per BCCPC's criteria**
  *(see section 'The right peer facilitator', page 12)*
- **Ensure volunteers complete BCCPC's training requirements:**
  - Prior to BCCPC's training workshop:
    - Review the Program Overview document (this document).
    - Review the most current version of B.C. My Voice.
    - Complete the online ACP module Level 1 with 100% score. peer facilitators can retake the module until 100% score is reached.
  - Attend BCCPC's training workshop.
- **Ongoing support for peer facilitators, including:**
  - Encourage peer facilitators to be reflective of their work.
  - Support the collection of feedback from session participants, including collection and analysis of session evaluation data.
  - Provide peer facilitators with opportunities to debrief with peers and their supervisor following ACP sessions.
  - Provide peer facilitators with constructive feedback.
    Provide an avenue for peer facilitators to express concerns related to their roles and responsibilities.
- **Administrative support, including:**
  - Logistical support to organize the sessions, including matters such as venue, advertising, and provision of session supplies (such as participant handouts).
  - Secure necessary funds for the session either:

- through the organization's resources,
- through a minimal fee to recover costs (the sessions are not-for-profit, but may require funds 'by donation' or a nominal charge to recover costs), or
- through partnership/sponsorship with other community groups (in accordance with the organization's guidelines to avoid potential conflicts of interest).

- **Oversight**
  - Ensure evaluation is conducted on an ongoing basis, including number of sessions, number of participants, collating feedback from evaluation forms and other relevant information.
  - Consider the need for risk management policies and practices related to the sessions, for example, how any complaints about the sessions are to be resolved or how peer facilitators will be supported following a particularly challenging session.

### Peer facilitators

The role of the peer facilitator is to effectively lead the ACP session and guide interactive conversations.

Assigning two co-facilitators for the public session is recommended for large groups of participants (more than 10 participants).

The peer facilitators are provided with tools to support the content of the session.

Responsibilities of the peer facilitator:

- Provide information about ACP and guide the conversation as per the facilitator guide and Session Schematic.
- Maintain a neutral stance (provide information, not opinion).
- Share stories and examples that further explain the ACP process.
- Ensure tools and resources are made available to participants to take home after the session.
- Refer questions not covered in the ACP training or provided materials to other resources.
- Do not provide direction or advice on individual situations.
- Do not cover any topics listed as out of scope in 'About the sessions', section (Page 11)

*More detailed information can be found in the Facilitator Guide.*

# About the sessions

This section provides fundamental information about the goal and structure of the ACP public sessions.

## Goal

To help adults (those 19 and older) engage in their future health-care decision making.

## Objectives

The public ACP sessions stimulate and support thinking, talking, and planning related to ACP by:

- providing information about ACP, so that participants are aware of their options;
- increasing the comfort of participants to discuss ACP with family and their health-care providers;
- increasing awareness of resources to support participants in their ACP.

## Expected benefits for public participants

- Increased participant knowledge of ACP.
- Increased participant comfort to have ACP conversations.
- Increased participant confidence to have ACP conversations.
- Increased participant readiness to engage in ACP.

## Out of scope topics

- Discussions around personal planning related to legal and financial affairs.
- Assistance with completion of a written Advance Care Plan or the accompanying legal forms.
- Discussions about the needs of individuals with limited capability to participate in their own health-care decision making.

## Key concepts

The structure of the peer-facilitated ACP public sessions is designed based on three key concepts:

### 1. The right content

The information provided to the public through the ACP sessions was selected to serve the program's goals and outcomes. The session emphasizes the importance of **thinking**, **talking** and **planning** about ACP, especially the importance of conversations related to ACP.

The session's content addresses the following information:

- What is ACP?
- Why ACP is important.
- Who should do ACP?
- When to do ACP.

- How to do ACP:

| | |
|---|---|
| **Think** | about what matters most to you.<br>about who could be your voice if you are unable to speak for yourself (your substitute decision maker). |
| **Talk** | with those closest to you about your thoughts.<br>with your health-care provider. |
| **Plan** | by recording your wishes.<br>by sharing your plan with your family, substitute decision maker, and health-care provider. |

- Provision of resources to support the participant's on-going engagement in ACP.

*More detailed description of content can be found in the Facilitator Guide.*

### 2. The right peer facilitator

A peer facilitator could be a volunteer or a staff member at community organizations interested in establishing an ACP education program for the public. The organization selects the right individuals for this role using BCCPC's criteria for peer facilitators for ACP sessions:

- Has experience with group facilitation (provide information, present the options, encourage conversation, not try to direct people's choices);
- Familiar with ACP;
- Has interest/passion to educate others about ACP;
- Agrees to complete the required training requirements to be a peer facilitator for ACP; and
- Agrees to follow and adhere to the general content outlined in the Facilitator Guide and key messages for ACP *(see page 12).*

### 3. The right facilitation approach

To help the public engage in the conversation and enjoy the experience of attending the ACP session, the peer facilitators need to use effective engagement and facilitation techniques such as:

- have a hook - a story that will capture the interest of participants and illustrate the value of ACP;
- convey the evolving nature of ACP work; participants decide what actions to take after the session based on where they are in their lives and their ACP process;
- use a conversational tone and plain language, do not medicalize the conversation and information;
- aim to normalize conversations about values and beliefs (what matters most to people) related to future health-care decision making;
- model comfort in communicating about ACP, including comfort discussing death and dying;

- engage participants in thinking and discussing ACP by being willing to share their own (the peer facilitator's) or other's stories/experiences about ACP. Provide opportunities for participants to share their stories too;
- emphasize the positives and benefits of doing ACP
  *(Can mention problems that arise from not doing ACP and provide examples, but we should not use fear of negative consequences of failure to do ACP as the main motivator*); and
- use the session format and aids (videos, PowerPoints, handouts etc.) that work best for the participants.

## Key messaging

Public information sessions funded by the BCCPC **MUST** use the updated definition of ACP (see page 5), and emphasize and promote the following key messages based on the updated definition.

- ACP is a personal process of reflection, talking and planning (Think, Talk, Plan) that involves understanding and sharing your values, beliefs and wishes regarding health and personal care.
- ACP helps you and your family prepare to make decisions about your future health-care.
- As long you are able to understand and communicate, you will make your own health-care decisions.
- ACP is an integral part of personal planning that every adult should be doing; it is part of being a healthy citizen.
- ACP provides peace of mind to you and your family:
  - it provides reassurance to your family that they know what you would want; and
  - it provides reassurance to you that your health-care wishes are known.
- Conversations about ACP get easier the more you have.
- ACP is not just a one-time event, it is a process that you should revisit throughout your life.
- You have options for how you want to express and record your wishes. Documentation in an Advance Care Plan is helpful but not essential.
- You can change your Advance Care Plan at any time.

*For more information about the ACP process, please refer to the Facilitator Guide.*

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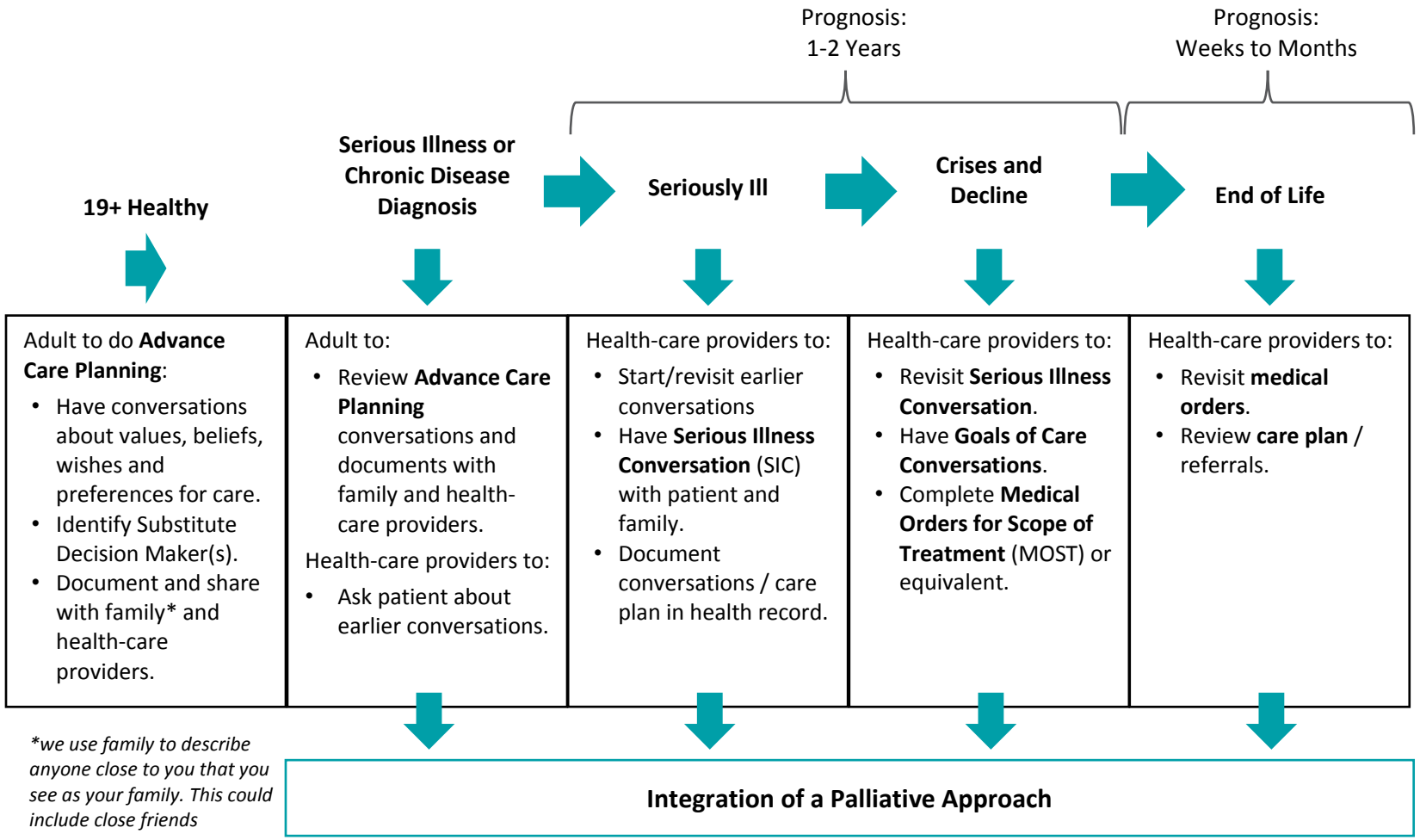
# Appendix A: Processes that facilitate person-centred care




*Revision August 2, 2017 - Draft*
*Adapted from Ariadne Labs, Serious Illness Conversation Guide*

BC Centre for Palliative Care

# Appendix B: Program Logic Model

**The Problem:**

ACP knowledge and engagement in ACP in the general population in B.C. is very low.

**Goal:**

To provide public participants with information, tools and resources to help them start or complete their own ACP after the session.

**Objectives:**

Train peer facilitators and equip them with tools and resources to help them facilitate ACP public sessions that will be organized and hosted by community organizations.

## INPUTS

### What we invest

*(Required resources)*

Coordinating body:

ACP experts.

ACP Resources/tools.

Seed Grant Funding.

Evaluation expert.

Community liaison.

Session organizers:

Project lead.

Volunteers.

Admin support.

## OUTPUTS

### Activities

*(What we plan to do)*

Coordinating body:

Train volunteers to facilitate ACP events.

Coaching to volunteers & organizations.

Process evaluation data and provide reports.

Session organizers:

Plan, publicize and host public ACP sessions

Distribution and collection of evaluation forms.

Peer facilitators

Facilitate public ACP sessions.

### Participation

*(Who we will reach)*

Public:

Capable healthy adults.

Persons with serious illness.

Family, friends and caregivers of the above.

## OUTCOMES

### Results or impact

*(In terms of learning/action/condition)*

Peer facilitators:

Increase in ACP knowledge.

Increase in level of confidence to facilitate public ACP sessions.

Public participants:

Increase in awareness and knowledge of ACP.

Increase in readiness to start or complete their own ACP.

Increased confidence to start or complete their own ACP.

Session organizers:

Better capacity to promote ACP.

Enhanced role to support the public and engage with their community.

**Evaluation Measures**

Number of peer facilitators trained.

Number and types of resources and advertising materials used and developed by program administrators for ACP sessions.

Number of ACP public sessions hosted.

Number of attendees at each ACP session.

Peer facilitators:

% increase in ACP knowledge.

% increase in level of confidence facilitating ACP public sessions.

Public participants:

% satisfaction with group session

% increase in ACP knowledge.

% increase in confidence and intent to engage in ACP following the session.

Session organizers:

Increase in capacity to support ACP public sessions.