



# My Wishes, My Care

## Community-led Advance Care Planning Programs

For **people living with  
early stages of dementia** and  
their family and friends

## Program Overview





Institute for Health System  
Transformation & Sustainability



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# How to use this interactive document:

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## Introduction

### Program Materials

This Program Overview forms one piece of the toolkit for the *My Wishes, My Care: Community-led Advance Care Planning Programs* for people living with early stages of dementia and their family and friends, and it should be reviewed by organizers and facilitators of the programs.

This guide shares important background information on Advance Care Planning (ACP), history of the community-led model ([page 11](#)), and an overview of the two programs developed for people living with early stages of dementia and their family members and friends ([page 12](#)):

1. *My Wishes, My Care: Starting the Conversation* (a guided conversation event)
2. *My Wishes, My Care: Advance Care Planning Information Sessions*

Other components of the toolkit include:

- **Community Partner Guide** – information for organizers on promotion, planning, and evaluation.
- **Facilitator Guides** – information on how to effectively facilitate each program.
- **Materials for public participants** – handouts, worksheets, example advance care plans, etc.

### Evolution of Advance Care Planning Concept

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:

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**“** *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.*<sup>1</sup>

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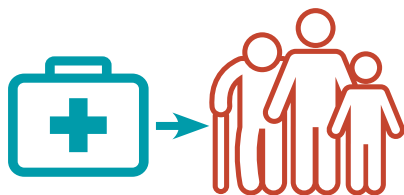
### Benefits of Advance Care Planning

Research has demonstrated many benefits of ACP. Benefits include:

- Increased likelihood the person’s wishes will be known,<sup>2</sup> and the care they receive matches their wishes.<sup>2-4</sup>
- Increased satisfaction with care by the person and their family.<sup>2,5</sup>
- Decreased depression,<sup>2,6</sup> anxiety,<sup>7</sup> decisional conflict,<sup>4,6</sup> and higher mood,<sup>8,9</sup> all contributing to higher quality of life.<sup>6,9,10</sup>
- For people at the end of life, earlier hospice referrals,<sup>10</sup> increased palliative care,<sup>3,11,12</sup> and less aggressive care at the end of life,<sup>9,10,13</sup> all contributing to better quality of death.<sup>14</sup>

## Advance Care Planning has changed

The focus of ACP has evolved over time. These changes have expanded the benefits and relevance of ACP. Research has led to a number of changes in our approach:



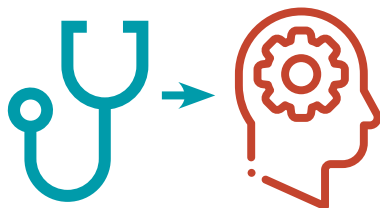
**Past emphasis: health-care specific** → **Current emphasis: part of life planning.**<sup>15</sup> Advance Care Planning is a part of life planning and is just as important as financial and estate planning. All adults, 19 years and older, who are capable of making health-care decisions should do Advance Care Planning.

The vision: *All people in Canada will have regular opportunities to express their wishes and, if they can't speak for themselves, their substitute decision makers are ready to speak confidently on their behalf.*



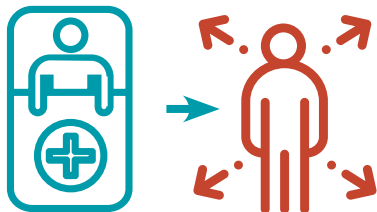
**Past emphasis: document completion** → **Current emphasis: conversation.** ACP practice previously targeted document completion, but it has been shown that document completion alone does not improve patient/health-care provider communication<sup>16</sup>, or the accuracy of substitute decision making.<sup>17,18</sup>

Therefore, current ACP practice focuses on the importance of having conversations about what matters most with family, close friends and health-care providers.<sup>19</sup> Conversation is recognized as a valuable component and an outcome in and of itself.<sup>20,21</sup> It prepares people for making health-care choices and ultimately get care consistent with their goals and wishes.



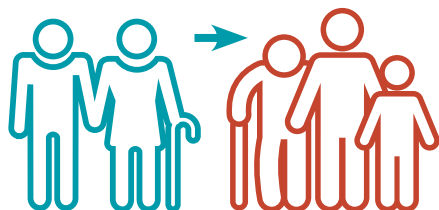
**Past focus: treatment preferences** → **Current focus: values, beliefs and wishes.** Early documents focused on outlining specific treatment preferences. However, applying these 'black and white' preferences to the nuanced circumstances that actually arise is difficult,<sup>19,21-23</sup> and people in good health are generally unable to predict what they would want in stages of poor health.<sup>24</sup>

Therefore, more recently developed documents are more centred on values, beliefs and wishes as these can be applied to whatever circumstances that arise.<sup>21,22</sup>



**Past focus: incapacity planning** → **Current focus: future decisions, with or without capacity.** In the past the focus of ACP was on preparing for times when a person cannot make or communicate a decision about health-care treatment (times of incapacity).

More recently it has been recognized that expressing their values, beliefs and wishes during ACP can help a person with future decisions they themselves make. Instead of considering things for the first time when the conversation is required, they can draw on the earlier thoughts and conversations from their ACP.



**Past relevance: people at end of life** → **Current relevance: all adults at any age stage of health.** 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.

Depending on a person's stage of life and/or their illness, different ACP conversations and activities are recommended.<sup>25</sup> As an example, when a person is diagnosed with a serious illness, it may be relevant for them to learn about and discuss their wishes about circumstances and treatments that are common for their illness.



## Advance Care Planning Definition in Plain Language

BC Centre for Palliative Care (BCCPC) uses the following description to explain to the public the meaning of the term “Advance Care Planning”:

### “ 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. The goal is for you to get the care that's right for you, even if you're unable to speak for yourself.*

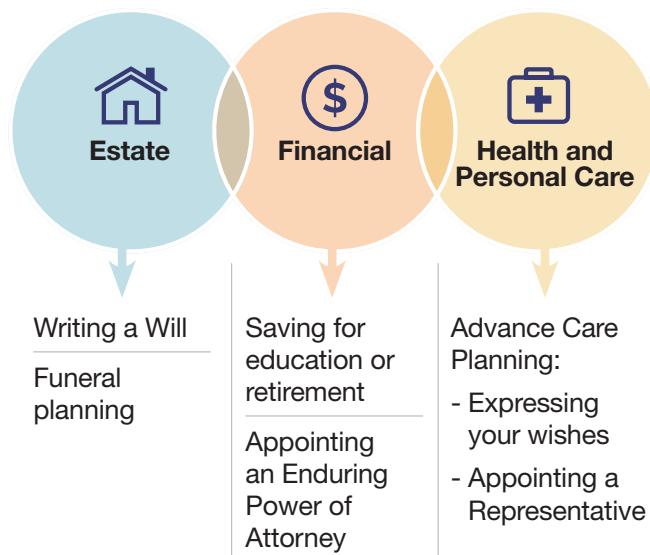
## Pan-Canadian Framework for Advance Care Planning

In 2019, a Pan-Canadian framework on Advance Care Planning was released.<sup>15</sup> The framework envisions a Canada where:

- Advance Care Planning is a normal part of the life journey;
- Advance Care Planning is part of life planning. Like financial and estate planning, care planning is an equally important life-long process (see Figure 1);
- All people in Canada have regular opportunities to express their wishes for their future care;
- The care they receive reflects their wishes; and,
- If they can't speak for themselves, their Substitute Decision Makers are ready to speak confidently on their behalf.

An integral part of the framework is respect for diversity. Culture plays a strong role in how people view health-care decisions, particularly those made near the end of life. Advance Care Planning is open to, respects, and supports the cultural, ethnic, sexual, gender, religious, socio-economic, geographic, and ability diversity of Canada, including the wide range of beliefs and practices related to life, health and well-being, individual and collective decision making, and death and dying.<sup>15</sup>

Figure 1: Advance Care Planning as part of life planning<sup>15</sup>



Adapted from the Pan-Canadian Framework for Advance Care Planning.

Care planning may be a new concept for many people, especially for newcomers and recent immigrants who may find that Canadian healthcare system operates quite differently than they are used to. ACP is an effective process that opens up lines of communication with health care professionals to ensure that patients get the care that is best for them and that respects their traditional culture and values.

## 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 33%** have heard of Advance Care Planning



**Only 48%** have had a conversation with family



**Only 14%** have had a conversation with a health-care provider



**Only 28%** have documented or recorded their health-care wishes

*Source: B.C. public opinion poll commissioned by the BCCPC and conducted by Mustel Research Group: Advance Care Planning, 2020.*

## Community-led Advance Care Planning Model

The community-led ACP model is a culmination of many years of work undertaken by both the BC Centre for Palliative Care and a large network of community partners who participated in the development, adoption, and evaluation of the model's curriculum and toolkit.

**The model is designed to empower community-based organizations** to stimulate ACP conversations in the community and support British Columbians in having their wishes for health and personal care known to their circle of family and friends and health-care providers.

**The goal is to help British Columbians get the care that's right for them** and is aligned with their values, beliefs, and wishes.



## Model Components



The original version of the community-led Advance Care Planning information sessions program was developed in 2016 for the general public and subsequently adapted and translated in 2019 for British Columbians with a Chinese or South Asian background. Refer to [Appendix A](#) for the history of the community-led ACP information sessions.

*My Wishes, My Care: Community-led Advance Care Planning* builds upon a culturally adapted curriculum and toolkit to better meet the needs of people living with early stages of dementia and their family and friends. Furthermore, a guided conversation event was developed and added as an introductory event to complement the information sessions. Refer to [Appendix B](#) for the adaptation and development process.

## Nationally Recognized Model

The BCCPC's community-led ACP education model for the general public received national recognition by both the Canadian Foundation for Health Improvement (2017)<sup>26</sup> and the Canadian Frailty Network (2018)<sup>27</sup> as an innovation that should be spread nationally.

# My Wishes, My Care: Community-led Advance Care Planning Programs

For people living with early stages of dementia and their family and friends

## Introduction

Advance Care Planning (ACP) is a key component of person-centred care for people living with dementia. Dementia is distinctive in that loss of decision-making capability in advanced stages is more certain than in other illnesses and best practice indicates that ACP in the early stage of dementia, or even earlier, will help facilitate care and decision making that is in keeping with the person's wishes, values and beliefs. Individuals can stay involved in decisions about their care through a shared and supported decision-making process with family and friends.

Supported by funding from the Public Health Agency of Canada's Dementia Community Investment, the community-led ACP program was adapted and enhanced to meet the specific needs of people living with early stages of dementia and family and friends of people living with dementia. Two programs were developed and designed to complement each other. For best outcomes, they should be experienced sequentially.

### 1. My Wishes, My Care: Starting the Conversation (New program added in 2020)

A guided group conversation event to help people living with early stages of dementia and family/friend caregivers explore their wishes, values, and preferences for health care and personal care.

### 2. My Wishes, My Care: Advance Care Planning Information Sessions

An interactive, two-part series adapted from the curriculum developed for the general public and cultural groups to share information on ACP and how to make an advance care plan.

## Benefits

Together, the programs aim to:

**Empower people living with early stages of dementia** to advocate for care that is aligned with their wishes and help them get the care that is right for them.

**Prepare family and friends of people living with dementia** for their potential role as a substitute decision maker.

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

**Offer 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 facilitator role.

***The program helps communities at large become Compassionate Communities.***

## Components

- Online and in-person facilitator training provided by BCCPC
- Toolkit of resources for community organizations, trained facilitators and public participants
- Ongoing coaching and mentoring by BCCPC

## Toolkit Components

- Program Overview (this document)
- Community Partner Guide – an event/session planning guide
- Marketing poster templates
- Facilitator Guides – step-by-step guides on how to facilitate ACP conversation events and information sessions from start to finish
- PowerPoint slides and scripts for use during the event/sessions
- Public participant handouts

## Partners in Program Delivery

1. BC Centre for Palliative Care – provincial program coordinator
2. Community organizations – organizers of ACP event and sessions.
3. Volunteers or staff affiliated with community organizations-- facilitators of ACP event and sessions.

**A Compassionate Community is a** community of people who are passionate and committed to improving the experiences of those living with a serious illness, caregiving, dying, or grieving. A Compassionate Community takes an active role in caring for people affected by these experiences, connects people to supports, raises awareness about end-of-life issues, and builds supportive networks.

## Partner Roles and Responsibilities

### Role of BC Centre for Palliative Care

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

#### For community organizations:

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

#### For trained facilitators:

- Training in the form of an in-person or online workshop, an online training module about ACP and background reading materials
- Resources to support program delivery online and in-person
- List of additional online resources to support the facilitator's knowledge of ACP and facilitation skills
- Information tools that can be given to participants to take home after the session

### Role of Community Organizations

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

As the organizer of the ACP Programs, community organizations have the following areas of responsibility:

- **Recruitment of volunteers or staff for the facilitator role as per BCCPC's criteria** (see 'The Right Facilitator' on [page 17](#) and [20](#))
  - **Conversation event:** one (1) lead facilitator who has attended training, and additional support facilitators to read out the questions at each breakout group/table if needed. For online delivery, an additional assistant/volunteer is recommended to provide technical support.
  - **ACP information sessions:** minimum one (1) facilitator for each session of no more than 12 participants (2 or more facilitators for sessions with over 12 participants). An additional assistant/volunteer is recommended for online delivery.
- **Ensure facilitators complete BCCPC's training requirements** (see training plan in [Appendix C](#))
- **Ongoing support for facilitators, including:**
  - Encourage facilitators to be reflective of their work.
  - Support the collection of feedback from session participants, including collection and analysis of session evaluation data, and sharing the results (see *Community Partner Guide*).
  - Provide facilitators with opportunities to debrief and receive constructive feedback.
  - Provide an avenue for 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 program supplies such as participant handouts (see *Community Partner Guide* for program planning information).
- Secure necessary funds for the session through:
  - o the organization's resources,
  - o 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
  - o 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 (see *Community Partner Guide* for more information).
- Consider the need for risk management policies and practices related to the sessions; for example, how any complaints about the sessions will be resolved or how facilitators will be supported following a particularly challenging session.

## **Role of Program Facilitators**

In general, the role of facilitators is to lead the public participants through the core content of the ACP conversation events and information sessions in an engaging, safe, and respectful manner. Information pertaining to the role of the facilitator in each program is in the 'About' sections on [page 17](#) and [20](#). Details can be found in each *Facilitator Guide*.

## About My Wishes, My Care: Starting the Conversation

This section provides information about the goal and structure of the guided conversation event as well as the role of facilitators.

### Goal

To help people living with early stages of dementia and one accompanying family member or friend explore their own wishes, values, and beliefs as a crucial first step to planning for their future health and personal care.

### Objectives

To support thinking and talking about wishes, values, and preferences for health care and personal care by guiding participants through a list of questions. This event prepares participants for ACP and making an advance care plan (covered in the ACP information sessions).

### Expected Benefits for Public Participants

All participants will:

- Gain the knowledge and skills they need to start thinking and talking about what matters most to them when it comes to their personal and health care.
- Feel motivated to think more about their future health-care wishes.
- Feel motivated to talk more about their future health-care wishes with people who are important to them.

Family and friends will:

- Begin learning about the values, beliefs and wishes of the person living with dementia. This will help prepare them for their role of supporter or substitute decision maker, or both.

### Out-of-scope topics

- Information about dementia
- Information on the steps of Advance Care Planning and how to make an advance care plan (*the ACP Information Sessions cover these topics*)

### Operations

The 90 to 120-minute conversation event can be delivered in person, online, or via conference call. More information is provided in the *Community Partner Guide* and *Facilitator Guide*.



## Key concepts

### 1. The right content

A list of questions for in-person delivery and a narrowed list questions for online and conference call delivery were developed to encourage participants to explore the following key themes:

- 1) Personal views on quality of life
- 2) Personal values, beliefs and preferences
- 3) Beliefs, values and preferences for health care and personal care
- 4) Making decisions
- 5) Starting conversations

For the lists of questions, see the *Facilitator Guide*. To see how the questions were developed, see [Appendix B](#).

### 2. The right facilitator(s)

A facilitator could be a volunteer or a staff member from 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 the conversation event:

- Has experience with group facilitation (ideally a conversation-style event)
- Has experience working with people living with dementia and their family/friend caregivers
- Has experience and training in supporting people living with serious illness and having conversations about serious illness and end of life
- Basic knowledge of dementia and facilitating events for people living with early stages of dementia (training provided )
- Basic understanding of Advance Care Planning (training provided)
- Agrees to complete the training requirements to become a facilitator (see [Appendix C](#) for the training plan)

### 3. The role of facilitator(s)

The role of the facilitator(s) is to guide the participants through the pre-determined list of questions. Responsibilities include:

- Creating a comfortable and safe space for participants to share their values, beliefs and wishes for health and personal care.
- Maintaining group focus.
- Making sure the discussion guidelines are followed:
  - Ensure that everyone has an opportunity to reflect on and respond to each question.
  - Ensure that any judgment or criticism of a person's response is quickly interrupted, and the group is gently reminded this conversation event is an opportunity to explore personal thoughts and accept differences.

More detailed information and tips for facilitators can be found in the *Facilitator Guide*.

## About My Wishes, My Care: Advance Care Planning Information Sessions

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

### Goal

To help people living with early stages of dementia and their family and friends engage in their health-care decision making.

### Objectives

To stimulate and support thinking, talking, and planning related to ACP by:

- providing information about ACP so participants are aware of their options
- increasing the comfort level of participants in discussing ACP with family, friends and health-care providers
- increasing awareness of resources to support participants in their ACP

### Expected benefits for public participants

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

### Out-of-scope topics

- Information about dementia
- Personal assistance with completing of an advance care plan or the accompanying legal documents
- Advice about a participant's personal situation.
- Detailed information about capability and consent for health care

### Operations

The two-part series, with each session being 90-minutes long, can be delivered in person or via an online platform.

More information is provided in the *Community Partner Guide and Facilitator Guide*.

## Key concepts

### 1. The right content

The information provided to the public through the two-part series was selected to serve the goals and outcomes of the sessions. The sessions emphasize the importance of **thinking, talking** and **planning** about ACP (see Figure 2) , especially the importance of conversations related to ACP.

The session content includes the following information:

- What is ACP
- Why is ACP important
- Who should do ACP
- When to do ACP
- How to do ACP (Think/Talk/Plan/Review)
- Resources to support the participant’s on-going engagement in ACP

A more detailed description of content can be found in the Facilitator Guide.

*Figure 2: ACP is an on-going cycle of thinking, talking and planning*



## 2. The right facilitator(s)

**Please note that the programs and training sessions are designed for experienced facilitators.**

Inexperienced facilitators may find the materials challenging. A facilitator could be a volunteer or a staff member from 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 (i.e. the ability to provide information, educate, present options, encourage conversation, but not direct people's choices)
- Has experience with health education
- Has experience working with people living with dementia and their family/friend caregivers
- Has experience and training in supporting people living with serious illness and having conversations about serious illness and end of life
- Has interest and passion to educate others about ACP
- Solid understanding of key components of ACP and the associated legal documents (training provided; content covered in the *Facilitator Guide*)
- Basic knowledge of dementia and facilitating events for people living with early stages of dementia (training provided)
- Agrees to complete the training requirements to become a facilitator (see [Appendix C](#) for the training plan)

## 3. The role of facilitator(s)

The role of the facilitator(s) is to effectively lead the information sessions and guide interactive conversations and discussions. Responsibilities include:

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

More detailed information and tips for facilitators can be found in the *Facilitator Guide*.

## Key messaging

Public information sessions funded by BCCPC **MUST** use the updated definition of ACP (see [page 9](#)), and emphasize and promote the following key messages based on the updated definition:

- ACP is an integral part of personal planning that every adult should do.
- People living with dementia can make their own health-care decisions—even as dementia progresses—through ACP and supported decision making with the people they trust.
- ACP is a process of reflection, talking and planning (Think, Talk, Plan, Review) that involves understanding and sharing your values, beliefs and wishes regarding health and personal care and deciding who can make care decisions for you if you cannot do so.
- The sooner you start the process of ACP, the better.
- ACP helps you and your family prepare to make decisions about your health and personal care.
- 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 them.
- ACP is not just a one-time event, it is a process that you should revisit throughout your life.
- You can change your Advance Care Plan at any time.
- You have options for how you want to express and record your wishes. Legal documentation in an advance care plan is helpful but not essential.
- As long you are able to understand and communicate, you will make your own health-care decisions and your advance care plan will not be used.

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

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## Appendix A: History of the Community-led Advance Care Planning Information Sessions

### Recognizing the Need

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 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 was to help British Columbians receive the care that is right for them and consistent with their values, beliefs and wishes.

### Initial Development

As part of the provincial ACP initiative, in 2016 BCCPC partnered with two community organizations to develop a program that delivers community-led ACP information 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.

Program development was led by Terry Webber, with essential support from working group members, and advice from an advisory group of ACP experts in health authorities and members of the public.

#### Working Group members:

- Barbara Colwell, Comox Valley Hospice Society
- Barb Warren, Comox Valley Hospice Society
- Joyce Kuhn, Comox Valley Hospice Society
- Karen Sanderson, CEAN
- Pat Porterfield, CEAN
- Terry Webber, BCCPC
- Sue Grant, BCCPC
- Rachel Carter, BCCPC
- Laura Spencer, BCCPC



## Testing and Evaluation

Between 2016 and 2019, BCCPC supported the development and delivery of public ACP information sessions delivered by trained facilitators who volunteer with 68 community-based organizations (the initial adopters of the program). In addition to training and access to coaching and the toolkit, the initial adopters of the program received seed funding from BCCPC.

In 2017, a research study of the initial implementation, funded by the Canadian Frailty Network, demonstrated it to be an effective and sustainable way to increase ACP engagement. Findings include:

Findings include:

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

The toolkit was updated in 2020 based on learnings from the culturally adapted and dementia-tailored toolkits (see below and [Appendix B](#)). Training using the updated toolkit was provided in fall 2020 to twenty-one community organizations and seed grant recipients across BC. Program evaluation of this spread has continued to support the positive outcomes demonstrated by the research project.

Research project investigators:

- Doris Barwich, Division of Palliative Care, University of British Columbia
- Jennifer Kryworuchko, Department of Nursing, University of British Columbia
- Arminee Kazanjian, School of Population and Public Health, University of British Columbia
- Eman Hassan, Director Public Health Initiatives, BCCPC
- Shima Soheilipour, School of Population and Public Health, University of British Columbia
- Jessica Simon, Division of Palliative Medicine, The University of Calgary
- Richard Sawatzky, School of Nursing, Trinity Western University
- Kelli Stajduhar, School of Nursing, University of Victoria
- Pippa Hawley, Division of Palliative Care, University of British Columbia

Research project sites:

- Comox Valley Hospice Society,
- CEAN,
- Cowichan Valley Hospice Society,
- Kamloops Hospice Society,
- Nanaimo Hospice Society,
- Pacific Rim Hospice Society,
- Seniors 411 Centre,
- Sunshine Coast Hospice Society,
- Terrace Hospice Society

Research team:

- Rachel Carter, Project Manager
- Amber Husband, Research Assistant
- Larry Mroz, Research Coordinator

Seed grant spread and evaluation:

- Eman Hassan, Director Public Health Initiatives, BCCPC
- Kathy Kennedy, Community Development Specialist, BCCPC
- Melody Jobse, Community Engagement Specialist, BCCPC
- Neerjah Skantharajah, Research and Project Assistant, BCCPC

## **Cultural Adaptation and Translation**

Despite further spread of public ACP sessions, they were largely attended by older, well-educated Caucasians. Feedback from our partners, stakeholders, and session participants has identified that the model did not address the specific needs of various cultural, religious, or language groups. Given our multicultural society, this is a substantial gap.

Supported by funding from Health Canada's Health Care Policy Contribution Program, in 2019/2020 the program was reviewed and updated to consider cultural adaptations for the Chinese and South Asian communities. Key materials have been translated into Simplified Chinese and Punjabi. This work was completed by working groups comprising individuals who serve and support these communities, with advice from an Advisory Committee, and with input from end-users throughout the process.

Working Group Members, Chinese Subproject:

- Katherine Tam, Volunteer Facilitator, CEAN
- Marisa Ku, Volunteer Facilitator, CEAN
- Bonnie Leung, Palliative Care Nurse
- Betty Chan, Public Partner

Working Group Members, South Asian Subproject:

- Jas Cheema, Surrey Hospice Society
- Joti Gill, ACP Facilitator, Patient Pathways
- Tara Shushtarian, Public Partner
- Pat Porterfield, Volunteer Facilitator, CEAN

Project Team:

- Eman Hassan, Project Director
- Rachel Carter, Project Manager
- Vicki Lee, Curriculum Development Specialist
- Thomas Shajan, Project Officer
- Jing Xu, Chinese Project Coordinator
- Gagan Kurrha, South Asian Project Coordinator
- Cynthia Ng, Chinese Community Liaison
- Nitin Kumar, South Asian Community Liaison
- Pam Martin, Evaluation Consultant
- Chibuzo Ottih, Performance Measurement Specialist

Advisory Committee:

- Jas Cheema, Surrey Hospice Society
- Saori Yamamoto, CEAN
- Khairun Jivani, Canadian Cancer Society
- Janine Sam, VCH, Richmond (co-chair)
- Arun Garg , Canada India Network Society / South Asian Health Institute
- Rani Mangat (for Yvonne Chiu), Multicultural Health Brokers Cooperative
- Gloria Gutman, Department of Gerontology, Simon Fraser University
- Cari Hoffmann, Fraser Health
- Wallace Robinson, Providence Healthcare
- Pat Porterfield, BCCPC public awareness and education committee, co-chair
- Margaret Young, Public Partner
- Saroj Ludhera, Public Partner
- Kathy Kennedy, Community Development Specialist, BCCPC

## Appendix B: Program Development for People Living with Early Stages of Dementia

Supported by funding from Public Health Agency of Canada's Dementia Community Investment and in-kind contributions from project partners, in 2020 the community-led ACP information session was adapted to meet the specific needs of people living with early stages of dementia and family and friends of people living with dementia. A guided conversation event was developed to complement the ACP information session.

In spring of 2021, a pilot of both programs was completed in partnership with four community-based organizations in B.C. from the Lower Mainland, Vancouver Island, and the Interior. Evaluation data was collected from public participants, facilitators, and organizers to inform ways to improve the programs.

Curriculum development and improvement was completed in collaboration with a Task Group of Experts, with advice from an Advisory Committee, and with input from end-users throughout the process.

### Project Partners

- Alzheimer Society of B.C.
- Diversity Access Team for iCAN study on ACP (iCAN-ACP)
- Family Caregivers of B.C.
- Hospice Palliative Care Ontario
- United Way of the Lower Mainland - Healthy Aging
- Pat Porterfield, ACP facilitator, CEAN (Community Engagement Advisory Network), Vancouver Coastal Health

### Task Group of Experts

- Carol Anderson, Public Partner, Instructor, UBC Health
- Marissa Stalman (Co-Chair), Dementia-Friendly Community Task Group Member, Maple Ridge Seniors Network
- Myrna Norman, Public Partner, Executive Member, Dementia Advocacy Canada
- Pat Porterfield, ACP facilitator, CEAN (Community Engagement Advisory Network), Vancouver Coastal Health
- Stephen Holliday, Instructor, North Shore Elder College Society

### Advisory Committee

- Angela Brooks, Program and Operations Coordinator – Population Health, United Way of the Lower Mainland
- Anthony Kupferschmidt, Executive Director, West End Seniors' Network
- Avery Milne, Provincial Coordinator- Knowledge Mobilization, Alzheimer Society of B.C.
- Barbara Lindsay, Director - Advocacy & Education, Alzheimer Society of B.C.
- Barbara MacLean, Executive Director, Family Caregivers of B.C.
- Carol Anderson, Public Partner, Instructor, UBC Health
- Cathy Almost, Engagement Leader – Patient & Public Engagement, BC Patient Safety & Quality Council
- Gloria Gutman, Principal Investigator, iCAN-ACP, Simon Fraser University
- Heather Cook, Seniors Services Advisor, Ministry of Health
- Julie Darney, Director - Education & Strategic Partnerships, Hospice Palliative Care Ontario
- Laurel Gillespie, Director – ACP in Canada Initiative, Canadian Hospice Palliative Care Association
- Marissa Stalman (Co-Chair), Dementia-Friendly Community Task Group Member, Maple Ridge Seniors Network
- Myrna Norman, Public Partner, Executive Member, Dementia Advocacy Canada
- Pat Porterfield, ACP facilitator, CEAN (Community Engagement Advisory Network), Vancouver Coastal Health
- Rachel Carter, Research Manager, Cultural Adaptations Project Manager, BCCPC
- Stephen Holliday, Instructor, North Shore Elder College

### Project Team:

- Eman Hassan, Project Director
- Kathy Sheng, Project Manager
- Kathy Kennedy, Project Lead, Community Development Specialist, Master Trainer
- Neerjah Skantharajah, Research and Project Assistant
- Vicki Lee, Curriculum Development Specialist
- Melody Jobse, Community Engagement
- Pam Martin, Evaluation Consultant
- Chibuzo Ottih, Performance Measurement Specialist
- Pam Warkentin, Communications Consultant
- Nicole Chovil, Research Consultant
- Vi Ho, Research/Project Assistant
- Leslie Ste. Marie, Writer/Editor
- David Jung, Graphic Designer

## Information Gathering and Research

To inform the curriculum development process and ensure that the community-led ACP programs reflect the perspectives, rights, needs, and preferences of people living with early stage dementia and family/friend caregivers, the following methods and processes were used:

1) **Environmental scan** – comprised of three (3) components:

- **Literature review** of published literature, tools, and resources relating to ACP best practices for people living with dementia and family/friend caregivers
- **Online survey of B.C. organizations** to gather information on current ACP activities for people living with early stages of dementia and family/friend caregivers
- **Key informant interviews** of online survey participants to provide more detailed information on ACP activities and the barriers and facilitating factors to ACP for people living with dementia and family/friend caregivers

The executive summary of the environmental scan is available here:

[https://bc-cpc.ca/cpc/wp-content/uploads/2020/06/2020-May\\_Executive-Summary-Environmental-Scan\\_ACP-Dementia-Project\\_For-Website-PHAC-approved.pdf](https://bc-cpc.ca/cpc/wp-content/uploads/2020/06/2020-May_Executive-Summary-Environmental-Scan_ACP-Dementia-Project_For-Website-PHAC-approved.pdf)

2) **Additional key informant interviews** were conducted with:

- People living with early stages of dementia
- Family and friend caregivers of people living with dementia
- Alzheimer Society of B.C.
- Members of the Task Group of Experts

## Program Development – Guided Group Conversation Event

Curriculum development was informed by:

- Information gathering and research findings
- Key features of existing conversation-style ACP activities
- Learnings from a trial run of an online conversation-style event
- Learnings from piloting the event with four (4) community-based organizations in B.C.

### Question selection process:

Five (5) key themes for the questions were first identified:

1. Personal views on quality of life
2. Personal values, beliefs and preferences
3. Beliefs, values and preferences for health care and personal care
4. Making decisions
5. Starting conversations

With consideration of the themes, the following research-based criteria were used to formulate an initial selection of 37 questions:

- Open ended to stimulate conversation
- Direct and clear
- Include an introduction and/or example to help clarify, when needed
- Avoid “most”, “best”, “only”
- As concrete as possible; abstraction may be difficult
- Avoid multiple choice or choosing from a list of more than 2 to 3 options
- Avoid questions requiring specific recall, especially short-term memory
- Have more questions than are likely to be needed. The flow of the events may differ depending on the number of participants, engagement of participants, and conversations that arise.

To pilot the event, twelve (12) questions were selected for the online events and 19 questions were selected for the in-person events. Fewer questions were selected for the online events due to barriers associated with using an online platform (e.g., technical difficulties, “Zoom fatigue”) and a shorter duration for the online event. Learnings and feedback from the pilot informed additional changes to the questions, which included:

- Reducing the length of questions
- Reducing the total number of questions for online events
- Reducing the scope of questions to make them more concrete
- Expanding on the event’s introduction and conclusion to provide participants with a better understanding of the event’s purpose and how it relates to ACP

The questions were ordered in such a way so that events begin with conversation starters, move on to address heavier topics, and end with a positive, light-hearted question.

The finalized questions (see *Facilitator Guide*) were reviewed by a writer/editor and communication consultant for language and clarity.

## **Program Adaptation – Advance Care Planning Information Sessions**

The sessions build on the culturally adapted version of the community-led ACP information session for the general public.

Curriculum development was informed by:

- Information gathering and research findings.
- Learnings from a trial run of an online ACP information session conducted by the cultural adaptation project team.
- Learnings from piloting the sessions with four (4) community-based organizations in B.C.

## Appendix C: Facilitator Training Plan

### My Wishes, My Care: Starting the Conversation

A guided conversation event for for people living with early stages of dementia and their family and friends.

	Actions	Resource
1.	<b>Review</b>	<input type="checkbox"/> “Informational Materials on Dementia” (see table below) <input type="checkbox"/> <i>Advance Care Planning Information Booklet</i> from BCCPC
2.	<b>Review key toolkit components</b>	<input type="checkbox"/> <i>Program Overview</i> <ul style="list-style-type: none"> <li>- To gain an understanding of the evolution of Advance Care Planning and the history of the community-led programs.</li> </ul> <input type="checkbox"/> <i>Community Partner Guide</i> <ul style="list-style-type: none"> <li>- An event planning and promotion guide for facilitators who will be helping to organize the event.</li> </ul>
3.	<b>Please inform your <u>organization</u> once you have completed actions 1 and 2.</b>	
4.	<b>Attend a training session hosted by BCCPC</b> (online or in-person)	<input type="checkbox"/> 2.5-hour training session covering the curriculum and a summary of the pre-reading materials. Facilitators will experience the event as a participant.
5.	<b>Post-training Actions</b>	<input type="checkbox"/> Review the full toolkit. <input type="checkbox"/> Rehearse a session with your peers. <input type="checkbox"/> Follow up on questions with BCCPC.



## My Wishes, My Care: Advance Care Planning Information Sessions

An two-part information session series for for people living with early stages of dementia and their family and friends.

	Actions	Resource
1.	<b>Review</b>	<ul style="list-style-type: none"> <li><input type="checkbox"/> “Informational Materials on Dementia” (see table below)</li> <li><input type="checkbox"/> <i>Advance Care Planning Information Booklet</i> from BCCPC</li> <li><input type="checkbox"/> <i>My Voice– Advance Care Planning Guide</i> (Ministry of Health)</li> <li>- <a href="https://www.health.gov.bc.ca/library/publications/year/2013/MyVoice-AdvanceCarePlanningGuide.pdf">https://www.health.gov.bc.ca/library/publications/year/2013/MyVoice-AdvanceCarePlanningGuide.pdf</a></li> <li>- It is important for you to be familiar with this resource because it:                             <ul style="list-style-type: none"> <li>o is the primary Advance Care Planning resource developed by the B.C. government;</li> <li>o is well known and frequently referenced, so you may be asked questions about it;</li> <li>o contains example legal forms; and</li> <li>o is available in multiple languages.</li> </ul> </li> </ul>
2.	<b>Review key toolkit components</b>	<ul style="list-style-type: none"> <li><input type="checkbox"/> <i>Program Overview</i> <ul style="list-style-type: none"> <li>- To gain an understanding of the evolution of Advance Care Planning and the history of the community-led programs.</li> </ul> </li> <li><input type="checkbox"/> <i>Community Partner Guide</i> <ul style="list-style-type: none"> <li>- An event planning and promotion guide for facilitators who will be helping to organize the event.</li> </ul> </li> </ul>
3.	<b>Please inform your <u>organization</u> once you have completed actions 1 and 2.</b>	
4.	<b>Attend training session(s) hosted by BCCPC</b> (online or in-person)	<ul style="list-style-type: none"> <li><input type="checkbox"/> A one-day in-person training session covering the curriculum and a summary of the pre-reading materials. If delivered online, training will be divided into multiple 2.5-hour sessions.</li> </ul>
5.	<b>Post-training Actions</b>	<ul style="list-style-type: none"> <li><input type="checkbox"/> Review the full toolkit.</li> <li><input type="checkbox"/> Rehearse the sessions with your peers.</li> <li><input type="checkbox"/> Follow up on questions with BCCPC.</li> </ul>

## Informational Materials on Dementia

The dementia-specific informational materials listed below were developed in collaboration with Alzheimer Society of B.C.

	<b>Actions</b>	<b>Resource</b>
1.	<p><b>Jim’s Story Dementia Friendly Communities</b> (Alzheimer Society BC)</p> <p><a href="https://www.youtube.com/watch?v=_ynYNKMTkhs&amp;feature=youtu.be">https://www.youtube.com/watch?v=_ynYNKMTkhs&amp;feature=youtu.be</a></p>	<p>6-minute Youtube video: Alzheimer’s Advocate Jim Mann, who was diagnosed with Alzheimer’s disease in 2007, has his story told in a new video called “Jim’s Story” about Dementia-Friendly Communities and what his experience has been like living with early stage dementia.</p>
2.	<p><b>What is dementia?</b> (Alzheimer Society)</p> <p><a href="https://alzheimer.ca/en/Home/About-dementia/What-is-dementia">https://alzheimer.ca/en/Home/About-dementia/What-is-dementia</a></p>	<p>Webpage providing introductory information on dementia.</p> <p>Review these topics:</p> <ul style="list-style-type: none"> <li>• What is dementia</li> <li>• Difference between Alzheimer’s Disease and dementia</li> <li>• Normal aging vs. dementia</li> <li>• Stigma</li> <li>• Shattering the myths</li> </ul>
3.	<p><b>Communication – Day to Day Series</b> (Alzheimer Society)</p> <p><a href="https://alzheimer.ca/sites/default/files/files/national/brochures-day-to-day/day-to-day-series-communication.pdf">https://alzheimer.ca/sites/default/files/files/national/brochures-day-to-day/day-to-day-series-communication.pdf</a></p>	<p>A 6-page brochure on communication considerations.</p> <p>Review these topics:</p> <ul style="list-style-type: none"> <li>• How do we communicate?</li> <li>• How does dementia affect communication?</li> <li>• What else could cause communication difficulties?</li> <li>• What is a person-centred approach to communication?</li> <li>• Strategies for a person-centred approach</li> <li>• Communication tips and strategies (a checklist)</li> </ul>
4.	<p><b>Person Centred Language</b> (Alzheimer Society)</p> <p><a href="https://alzheimer.ca/sites/default/files/files/national/other/person-centred-language-guidelines_one-pager.pdf">https://alzheimer.ca/sites/default/files/files/national/other/person-centred-language-guidelines_one-pager.pdf</a></p>	<p>A 2-page brochure on person centred guidelines.</p> <p>Review these topics:</p> <ul style="list-style-type: none"> <li>• The power of words</li> <li>• Human rights</li> <li>• Language and behaviours</li> <li>• Cultural awareness</li> <li>• Preferred/non-preferred terminology and rationale</li> </ul>

## Additional Resources on Dementia (Optional – For Interest Only)

Resource	Description
<p><b>Recorded videos/webinars</b> (Alzheimer Society of B.C.) <a href="https://alzheimer.ca/en/bc/We-can-help/Dementia-education/webinars/recorded-videos">https://alzheimer.ca/en/bc/We-can-help/Dementia-education/webinars/recorded-videos</a></p>	<ul style="list-style-type: none"> <li>• Recorded webinars on:                             <ul style="list-style-type: none"> <li>- Foundational topics on living with dementia</li> <li>- Caring for someone with dementia</li> <li>- Dementia-friendly communities</li> </ul> </li> <li>• Information on upcoming, live webinars hosted by ASBC</li> </ul>
<p><b>What to expect as the person's dementia progresses</b> (Alzheimer Society) <a href="https://alzheimer.ca/en/help-support/im-caring-person-living-dementia/what-expect-persons-dementia-progresses">https://alzheimer.ca/en/help-support/im-caring-person-living-dementia/what-expect-persons-dementia-progresses</a></p>	<ul style="list-style-type: none"> <li>• Review the webpage for general information on early, middle, and late stage dementia.</li> <li>• Review the linked “early stage information sheet”.</li> </ul> <p>[FYI only: other linked info sheets]</p>
<p><b>Living with dementia</b> (Alzheimer Society of B.C.) <a href="https://alzheimer.ca/en/bc/Living-with-dementia">https://alzheimer.ca/en/bc/Living-with-dementia</a></p>	<p>Introductory information and resources for people newly diagnosed with dementia and their family and friends. Some of the topics are covered in the required pre-reading list (eg. “Ways to communicate” and “Grieving”).</p>
<p><b>Understanding Behaviour</b> (Alzheimer Society) <a href="https://alzheimer.ca/en/Home/Living-with-dementia/Understanding-behaviour">https://alzheimer.ca/en/Home/Living-with-dementia/Understanding-behaviour</a></p>	<p>Information on the behavioural changes that can occur with progression of dementia.</p>

Resource	Description
<p><b>Alzheimer’s Disease: Signs, Symptoms, and Stages</b> (HelpGuide.org) <a href="https://www.helpguide.org/articles/alzheimers-dementia-aging/alzheimers-disease.htm">https://www.helpguide.org/articles/alzheimers-dementia-aging/alzheimers-disease.htm</a></p>	<p>Online study guide recommended for all volunteer support group facilitators of Alzheimer Society of B.C.</p>
<p><b>Tips for Alzheimer’s and Dementia Caregivers</b> (HelpGuide.org) <a href="https://www.helpguide.org/articles/alzheimers-dementia-aging/tips-for-alzheimers-caregivers.htm">https://www.helpguide.org/articles/alzheimers-dementia-aging/tips-for-alzheimers-caregivers.htm</a></p>	<p>Online study guide recommended for all volunteer support group facilitators of Alzheimer Society of B.C.</p>
<p><b>Dementia Friends Webinar</b> (Alzheimer Society of B.C.) <a href="https://www.youtube.com/watch?v=m-f3-W5D30&amp;feature=youtu.be">https://www.youtube.com/watch?v=m-f3-W5D30&amp;feature=youtu.be</a></p>	<p>24-minute YouTube video: Learn how you can build a community that is supportive of people living with dementia.</p> <ul style="list-style-type: none"> <li>• What a dementia-friendly community is</li> <li>• What a dementia friend is</li> <li>• What dementia is</li> <li>• How to communicate in an effective and appropriate way</li> <li>• Where you can go for more help</li> </ul> <p>[FYI only: for more information on dementia-friendly communities, visit: <a href="https://alzheimer.ca/en/bc/Get-involved/dementia-friendly-communities">https://alzheimer.ca/en/bc/Get-involved/dementia-friendly-communities</a>]</p>
<p><b>Other dementias</b> (Alzheimer Society) <a href="https://alzheimer.ca/en/Home/About-dementia/Dementias">https://alzheimer.ca/en/Home/About-dementia/Dementias</a></p>	<p>Review the webpages of the following 4 types of dementia for an introductory understanding of the types of dementia, other than Alzheimer’s disease, a person can be diagnosed with.</p> <ul style="list-style-type: none"> <li>• Young onset dementia</li> <li>• Mild Cognitive Impairment</li> <li>• Vascular dementia</li> <li>• Mixed dementia</li> </ul> <p>[FYI only: other types of dementia listed and linked information sheets on any of the webpages]</p>

Resource	Description
<p><b>Communication challenges and helpful strategies for the person with dementia</b> (Alzheimer Society) <a href="https://alzheimer.ca/sites/default/files/files/national/brochures-day-to-day/day-to-day-series_communication-challenges.pdf">https://alzheimer.ca/sites/default/files/files/national/brochures-day-to-day/day-to-day-series_communication-challenges.pdf</a></p>	<p>A 4-page brochure developed for people living with early stages of dementia that summarizes the following topics:</p> <ul style="list-style-type: none"> <li>• Talking about your wishes and plans for the future</li> <li>• Learn about the disease and being open about it</li> <li>• Communication challenges when in social situations</li> <li>• Using non-verbal communication</li> <li>• Communicating with your doctor or another healthcare provider</li> </ul>
<p><b>Person-centered language guidelines</b> <a href="https://alzheimer.ca/en/take-action/become-dementia-friendly/using-person-centred-language">https://alzheimer.ca/en/take-action/become-dementia-friendly/using-person-centred-language</a></p>	<p>Review the “Person-centred language guidelines” linked on the webpage. A 7-page brochure that covers the following topics:</p> <ul style="list-style-type: none"> <li>• Principles of person-centred language</li> <li>• Human rights for people living with dementia</li> <li>• Language and behaviours</li> <li>• Cultural Awareness</li> <li>• Terminology to use when talking with and about people living with dementia</li> </ul>
<p><b>Grieving</b> (Alzheimer Society of B.C.) <a href="https://alzheimer.ca/en/bc/Living-with-dementia/Grieving">https://alzheimer.ca/en/bc/Living-with-dementia/Grieving</a></p>	<p>Review the webpages “Grieving” and “What is ambiguous loss?”. As a facilitator you will not be providing grief counselling for participants but you should be aware of grief in the context of dementia for people living with dementia and their family and friends.</p> <p>You should also be prepared with any counselling resources that you can refer participants to in your community. You can always recommend for participants to phone the First Link Dementia Helpline.</p>



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