

## Promoting engagement of People Living with Dementia and their Family/Friend Caregivers in Advance Care Planning through Community-led Planning Interventions.

### Learning Objective

By the end of this session, participants will be able to describe the barriers and facilitating factors to engaging people living with early stages of dementia and their family/friend caregivers in Advance Care Planning.

### Context

The initiative aims to promote the engagement of people living with dementia and their family/friend caregivers in Advance Care Planning to help them get care consistent with their wishes. Despite universal recognition of its importance for people with dementia, who gradually lose their ability to make care decisions for themselves, informing literature identified that Advance Care Planning happens infrequently. The intervention builds on the proven success of an existing sustainable, community-led education program co-developed by BC Centre for Palliative Care to support community organizations facilitate in-person Advance Care Planning sessions for the public.

### Interventions

Two complementary interventions were developed for people with early stages of dementia and their family/friend caregivers.

1. **Guided group conversation event** to help participants reflect on their values, beliefs and wishes for care.
2. **Advance Care Planning information sessions** to share information and resources about Advance Care Planning.

Each intervention comprises of a training curriculum and a toolkit of resources for organizers, trained facilitators, and public participants. The interventions were developed with an Expert Task Group, informed by an environmental scan, Advisory Committee and Participatory Action Research activities all involving people living with dementia and their family caregivers. The interventions were subsequently adapted for online delivery due to COVID-19.

## Measurement

The interventions are being piloted with community organizations across BC using a mixed-methods approach. Data are collected from trained facilitators and public participants through surveys and focus groups. Results will be available in early 2021.

## Lessons

Stigma associated with dementia requires special attention to terminology use and promotional strategies. To encourage engagement in Advance Care Planning, clear information supplemented with personal stories and step-by-step guides are needed. Adaptation of the original program included addition of the guided conversation event and changes in materials' design to better suit the learning needs of people with early dementia.