

Promoting Engagement of People Living with Dementia and Family/Friend Caregivers in Advance Care Planning through Community-led Programs

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The presentation will provide an overview of learnings from, and resources developed as a part of a two-year project aimed to promote the engagement of people living with dementia and their family/friend caregivers in Advance Care Planning (ACP). Despite universal recognition of its importance for people with dementia, who gradually lose decision-making capability, informing literature identified that ACP happens infrequently. The project was built on the proven success of an existing sustainable, evidence-based, community-led education model co-developed by BC Centre for Palliative Care to support community organizations facilitate in-person ACP sessions for the public.

Two complementary programs were adapted for people living with early stages of dementia and 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 ACP.

Each program comprises of a training curriculum and a toolkit of resources for organizers, trained facilitators, and public participants. The programs 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 family/friend caregivers. The programs were subsequently adapted for online delivery due to COVID-19.

In partnership with community organizations, the programs were piloted then implemented in communities across British Columbia. Evaluation data was collected from organizers, facilitators, and public participants through surveys and focus groups to inform refinement of the programs. The project will be entering the knowledge translation and dissemination phase in fall/winter 2021.