



Advance Care Planning for People Living with Dementia

Environmental Scan

Executive Summary

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ACP Dementia Initiative – Environmental Scan – Executive Summary

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Background

Advance care planning (ACP) is a component of palliative care that enables individuals to retain control of decisions about health care when they can no longer speak for themselves. ACP is the process of conversations between an individual, their family caregiver, and health-care provider about the person's personal values, life goals, and preferences regarding future health care.

ACP is a key component of person-centred care for persons living with dementia. The progressive decline in capacity to formulate and communicate decisions about care in advanced stages of dementia presents significant challenges to assuring quality end of life and a dignified and respectful death. Best practice indicates that ACP in the early stage of dementia, or even earlier, will help facilitate care and decision making by families that is in keeping with the person's wishes and end-of-life preferences.

Dementia is distinctive in that loss of decision-making capacity in advanced stages is more certain than in other illnesses. In the early stage of dementia, the patient has a window of time to talk with family and health-care providers about their preferences and develop a formal plan of care if desired. Without these discussions, persons living with dementia (LWD) may be subjected to unwanted treatments and unsuitable end-of-life care. Persons with dementia and their family caregivers are not always well informed of the course of dementia, planning and options for end-of-life care, and the importance of early ACP.



Purpose

The purpose of this environmental scan was to gather information that can inform the adaptation of existing resources developed by BC Centre for Palliative Care (BCCPC) to support community-based organizations promote awareness and education of ACP for persons living with dementia (LWD) and their family caregivers.

Methods

The environmental scan consisted of the following three components:

- 1. Literature Review:** Published and grey literature relating to ACP best practices, education, tools and resources for persons with dementia and family caregivers was reviewed for information that could inform the adaptation of ACP resources. Education resources and tools were identified as potential resources.
- 2. Online Survey of B.C. Organizations:** The purpose of the survey was to gather information on current ACP activities for persons with early dementia and family caregivers. The questions were designed to elicit information about populations served, existing ACP activities and resources used, and barriers and strategies around early conversations between persons LWD and family caregivers and with health-care providers. An email that provided the link to the online survey was sent to 100 organizations drawn from BCCPC's distribution list, inviting them to complete the survey and to send to organizations that may have been missed by BCCPC. The survey was conducted over a two-week period from February 17th to 28th, 2020.
- 3. Key Informant Interviews:** Survey participants were asked if BCCPC could contact them for a short follow-up interview. Eighty percent of survey respondents agreed and provided their name and contact information. Thirteen (13) representatives of provincial and community-based organizations were interviewed during the weeks of March 9th and 16th. Questions were aimed at gathering more detailed information on ACP activities conducted in B.C. and the barriers and strategies for engagement of persons LWD and family caregivers.

Findings from these components are synthesized into key themes and are also discussed individually.

Findings: Themes Common across Components of the Environmental Scan

The three environmental scans showed us that individuals with dementia and family caregivers recognize the importance of ACP for quality end-of-life and want to know how to develop an advance care plan. Knowledge about the course of dementia, care decisions and ACP is important, but even more critical is the shared understanding that arises from conversations about values and wishes.

Individuals with dementia and family caregivers who participated in ACP conversation-based interventions found those conversations to be very beneficial in reducing concern about future care. ACP conversations helped reassure persons LWD that others knew their preferences and wishes. Family caregivers are more confident that they made the “right” decision.

The environmental scans also showed a pattern of common barriers and facilitators of ACP which are listed in Table 1. The table also includes recommendations for delivering ACP activities to persons LWD and family caregivers.



Table 1. Key Barriers and Facilitators to ACP for Dementia

Barriers Related to Persons Living with Dementia	Barriers Related to Caregivers/Family
<p>Lack of early diagnosis Stigma and fear Not informed about early ACP and dementia Lack of appropriate resources Delay in initiating ACP conversations</p>	<p>Not informed about early ACP and dementia Presumption of mental incapacity of person LWD Fear of hurting/distressing person LWD Overwhelmed with caregiving responsibilities Unable to get out to ACP events Delay in initiating ACP conversations</p>
Barriers Related to Health-care Providers	Barriers Related to Community Organizations
<p>Missed and delayed diagnosis Presumption of mental incapacity Lack of knowledge about ACP and resources Not comfortable initiating ACP conversations Lack of time Focused on Rep. Agreement/Advance Directive Lack of support to persons with dementia in ACP</p>	<p>No services/ACP for persons LWD Lack of referrals Engagement challenges Lack of funding for programs Lack of appropriate resources for ACP dementia</p>
Facilitators to Engagement in ACP	Recommendations for Delivering ACP Activities
<p>Promote early ACP to normalize conversations Use storytelling and other formats Emphasize conversations, not forms Provide a step-by-step approach Offer ways to start the conversation Provide practical and emotional support Respect capability, strengths and culture Make it fun</p>	<p>Provide information about advanced and terminal stages of dementia Assume capability; support active engagement in discussions Focus on exploring goals of living, values Provide core list of resources on dementia Use clear understandable language Offer examples of how to start ACP conversations Provide resources for Rep Agreement and Advance Directive Discuss role and responsibilities of Substitute Decision Maker</p>

Literature Review Findings

There is immense interest in ACP as an intervention that contributes to quality of care consistent with patients' goals, reduction in family caregiver decision-maker burden, and meaningful use of health care by older adults with dementia. The literature leans heavily towards a medical model of ACP as a process between patient and health-care provider and the desired outcome of an advance directive. There is increasing recognition that this model is not aligned with the preferences of individuals LWD and is not reflective of actual practices in dementia care. The findings from this review offer some insights into a more person-centred approach to ACP.

Person-centred ACP

People with mild to moderate dementia have the mental capacity to make their own decisions, including health decisions. Individuals stay involved in decisions about their care through a shared process with family caregivers.

- Inclusion of family caregivers in models of ACP is essential to person-centred care for patients with dementia.
- Family caregivers reported feeling unprepared and unsupported in end-of-life care decisions. Knowing values and preferences of the person increased confidence in decisions.
- People with dementia often prefer informal planning through conversations with family. This preference is a general pattern observed among older adults.
- Conversations between the person LWD and their caregiver/family about values, goals of living, and preferences may be one of the most important targets of ACP interventions.

Motivators: Reasons and Prompts to ACP

Planning future care for some individuals can be a means to ensure they have a “natural death” rather than an artificially prolonged life. Self-interests are not the only motivators; ACP can be important for other reasons or triggered by an event in the person's life.

Reasons for ACP

- To reduce the burden placed on their caregivers/families.
- To prevent potential conflict in decision making between family members who have different opinions.
- Encouragement from family or others. Person LWD and family caregiver developed their individual plans together.
- Past experience witnessing/providing end-of-life care for a relative or friend.

Event Triggers of ACP Conversations

- Decline in health or a major change in life.
- Recent illness or death of a relative or friend.
- Other planning activities e.g., finances, will, etc.

Barriers to ACP for Dementia

The ACP literature on barriers covers a wide range of issues, from problems in early diagnosis to actual end-of-life care decisions. Barriers may prevent individuals from engaging in ACP, initiating ACP conversation, writing an advance directive, and/or the use of advance care plans in actual care decisions. The focus of the review was on barriers that may prevent an individual from engaging in early ACP conversations. These include:

- Lack of awareness and knowledge about ACP and advanced stages of dementia.
- Dementia is not viewed as a life-limiting illness.
- Lack of clarity about when to start ACP and difficulty finding an opportune time.
- Individuals LWD or family caregivers may refuse to engage in ACP conversations for any number of reasons, including denial of illness, needing time to adjust, fear of the future, or stigma.
- Conversations may not be initiated because of fear of distressing a person or from assumptions the person is not capable or that preferences are already known.
- Health-care providers' discomfort initiating conversations with patients and lack of time are common barriers to ACP.
- Preference for informal planning, cultural traditions, or delegating decisions to medical experts are viewed as barriers rather than choices.

Formal ACP - Advance Directives

An advance directive (AD) can effectively assist in treatment decisions when the goals of care are clearly established and translated into directions on treatments relevant to dementia, and a substitute decision maker is appointed for the person. AD can still be valuable for individuals without any close relatives or who are unable to appoint a substitute decision maker.

- Individuals LWD see AD as too constraining and would prefer to give some leeway to their decision makers.
- Advance directive forms require a high literacy level and medical knowledge; assistance may not be available in all communities. Research has found that standard ADs frequently do not address treatment decisions that are common in dementia end-of-life care.
- There is growing interest in dementia-specific ADs that enable individuals LWD to state specific goals of care (palliative care, treatments to prolong life). The Dementia Advance Directive was developed in the US and can be found here: www.dementia-directive.org

Dementia Interventions and Recommended Practices

Evidence-based programs are limited to the Structured Conversation intervention, a professional facilitated process for developing an advance care plan.

- Recommended practices include using a psychosocial approach that aligns with the value older adults place on conversation and relationships. Face-to-face and interactive dialogue are essential components.
- Engagement may be easier when future care planning is embedded in personal values, preferences and goals for living with dementia.
- People LWD and family caregivers want information about the course of dementia, especially the later stages of dementia and options for care.
- Decision-aid tools may help with specific decisions around care, as well as strategies such as minimizing distractions, reducing load on short term memory, etc. These measures can enhance decision-making capacity.

Education for Informed ACP

Individuals LWD and family caregivers are often not well informed about ACP and dementia.

- Knowledge of commonly used life-prolonging measures and associated benefits and harms can help enable persons with dementia to choose the care they wish to have.
- Information and support for individuals who want to write an advance directive is clearly needed.
- Learning capacity is an important consideration and can be enhanced by using different mediums (e.g., written, video), and strategies that facilitate understanding and retaining information (e.g., handouts, video recordings of workshop).
- Discussions and materials need to be sensitive to and respectful of different views and beliefs.
- Information about terminal stage dementia and end-of-life care decisions enables family caregivers to plan ahead.
- Resources on a variety of ACP-related topics available online are listed in Appendix A.

Educational Resource for Family Caregivers

- *Comfort Care at the End of Life for Persons with Alzheimer's Disease or Other Degenerative Diseases of the Brain* is a Canadian evidence-based guide for caregivers and is available in French and English. It is based on the consensus that comfort/palliative care is best practice and that life-prolonging interventions may be futile and prolong suffering.

Decision Aid Tools

Decision Aids provide information about a specific decision and options, along with associated benefits and risks.

- They guide individuals to consider and express their own personal values.
- Existing decision aids for dementia cover three topics: 1) goals of care, 2) place of care, and 3) support with eating/feeding options.

Training for Delivering ACP Dementia Interventions

Communication and interpersonal skills are viewed as essential to working with people LWD and family caregivers.

- *Respecting Choices* is a well-known program that focuses on training facilitators to communicate effectively with patients, including persons with dementia.
- No studies were found that addressed peer-led education on ACP for persons with dementia.
- Evaluation of a peer-led workshop on ACP for older adults supports recommended practices.

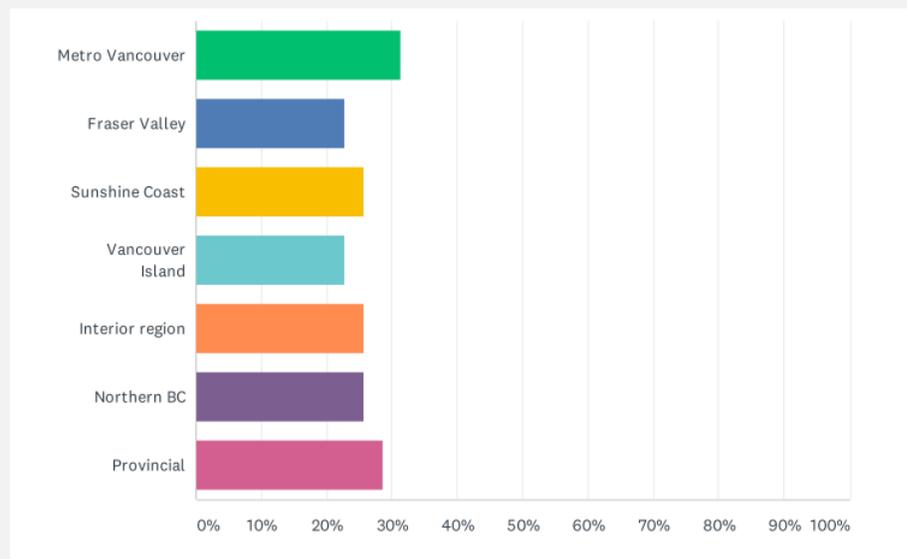
The literature review report is available [here](#)

Online Survey of B.C. Organizations

A total of 35 participants completed the survey (response rate was 30%). Respondents represented 28 different organizations and seniors' services. Organizations included hospice societies, organizations serving seniors, provincial and community-based organizations that provide education, recreational programs, housing, home care, and support to family caregivers, health authorities, and health clinics. One third of the organizations were hospice societies. Survey respondents had a wide range of roles, including executive/senior management positions, volunteer, ACP educator, program coordinator, health-care provider, and board member. Forty-three percent (43%) were in director and senior management positions.

All participant organizations served persons over the age of 65, with the majority also serving persons with mild cognitive impairments and/or dementia and family caregivers. Provincial and community-based organizations from all areas of B.C. were represented in the survey.

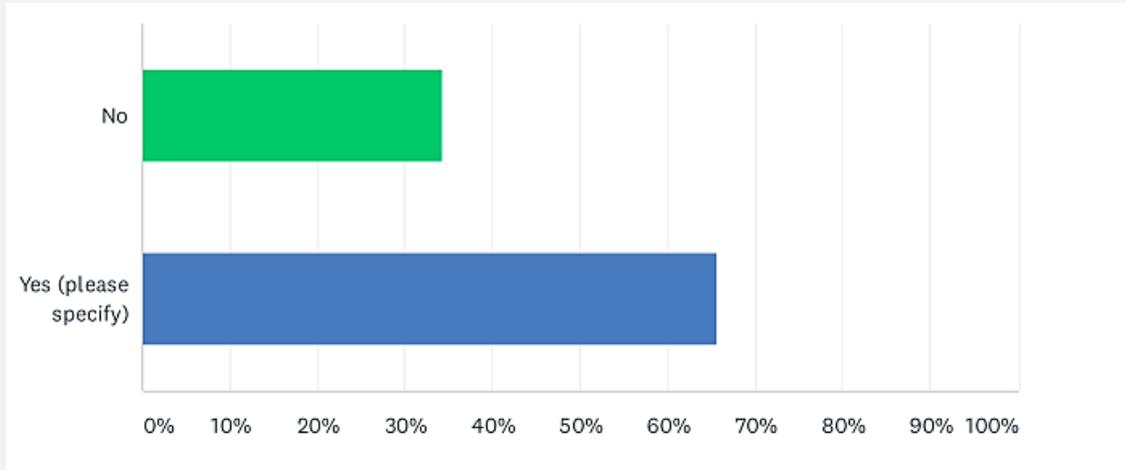
Areas of British Columbia Served by Organizations



Findings

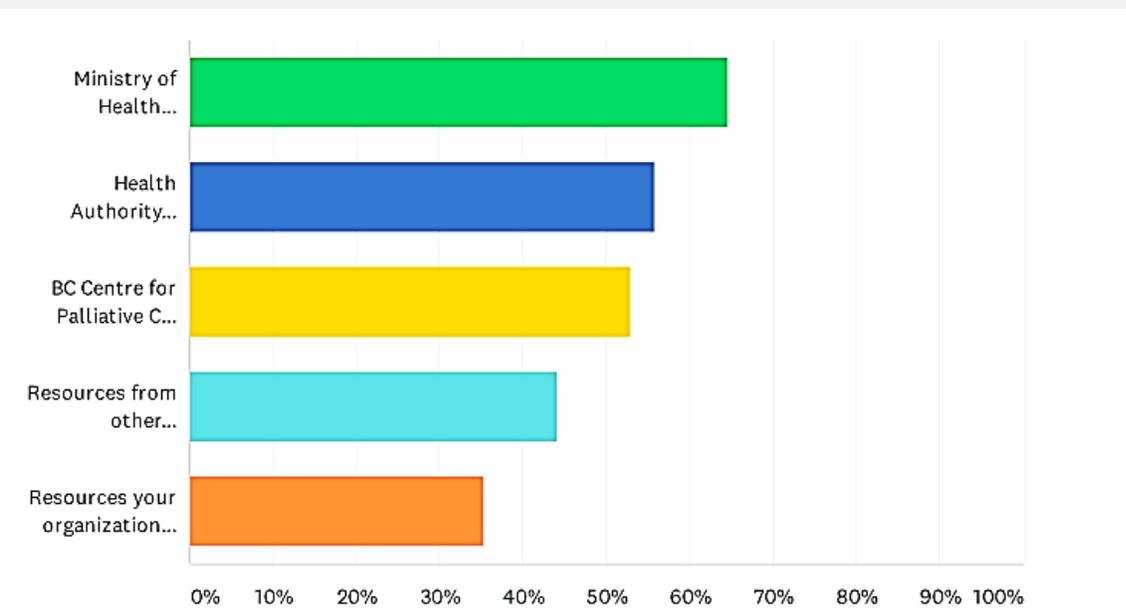
Two-thirds (66%) of the organizations were engaged in ACP activities, largely aimed at increasing general public awareness and knowledge of ACP.

Provision of ACP Activities



Organizations were using ACP resources developed by the B.C. government, Health Authorities, and BC Centre for Palliative Care. Forty-five percent (45%) of the respondents indicated they were using resources from other sources (e.g., NIDUS, Canadian Hospice Palliative Care Association, Community Resources information), and one-third (34%) were using resources developed in-house (e.g., handouts).

ACP Resources Currently Used by Organizations





Fifteen percent (15%) of the organizations offered dementia-specific ACP activities, mostly for family caregivers. About one-quarter (25%) provided dementia-specific ACP resources. The Alzheimer Society of B.C. was the primary source of resources.

Reaching family caregivers was the most frequently mentioned barrier to delivering ACP activities to individuals LWD and family caregivers. Existing tools are confusing for some people and there is a lack of resources that provide practical information.

Survey respondents identified a wide range of barriers to early ACP conversations with family caregivers and with health-care providers. Lack of knowledge about ACP for dementia and fears about distressing the individual were barriers common to both caregiver and health-care provider conversations. Education for persons LWD, family caregivers, and health-care providers was an overall strategy for facilitating early ACP conversations. Barriers to early conversations with family caregivers included difficulty accepting the diagnosis, stigma and family caregivers feeling overwhelmed. Strategies included promoting public awareness of ACP for dementia and providing education/training for family caregivers.

Health-care provider reluctance, lack of skills, and lack of time were identified as barriers to early conversations with health-care providers. In addition to ACP training, building a relationship with patients and ongoing conversations was a common theme in suggested strategies. In general, there was a strong belief that providers should take responsibility for initiating ACP conversations.

Overall, the findings demonstrate the respondents' and their organizations' recognition of the importance of ACP and commitment to supporting persons with dementia. The survey respondents' answers indicated significant awareness of barriers to ACP for dementia and provided insightful strategies for increasing engagement of persons LWD and their family caregivers in ACP conversations.

The survey results report is available [here](#)

Key Informant Interviews

Interviews were held with 13 respondents who completed the online survey for the project and had agreed to a follow-up interview. Key informants represented both provincial (3) and community-based organizations (4 hospice) from all areas of B.C. All organizations provided ACP support to people LWD and family caregivers through general ACP activities such as public education workshops (75%) and/or on an individual basis (50%), and/or providing information and links to resources (42%). The primary ACP resources used by organizations were from Ministry of Health, BCCPC and Nidus. ACP activities are promoted to people LWD and family caregivers through education events for the general public, by partnering with local business or health organizations, and through media, posters, websites, and Facebook.

Informants described how individuals LWD and family caregivers want to plan for future care but encounter challenges in accessing information, completing the legal documents, and trying to have conversations with unwilling persons. On the whole, it appears that the health care system is not providing the supports and services that facilitate ACP. Many of the barriers identified are ones that have appeared in the literature review and survey. Information requests included resources for caregivers, step-by-step ACP, dementia resources and culturally appropriate resources.

Strategies that informants have found to be helpful for engaging people LWD in ACP discussions revolved around framing ACP in a non-threatening way (e.g., talking about wishes), attending to the needs and goals of individuals, and providing practical support. Training for facilitators included education on dementia, communication skills, core resources, online or group training, representation agreements and advance directives.

Fifty percent (50%) of informants indicated they were interested or might be interested in being a pilot or evaluation site for the new resources. Many informants suggested organizations and key persons from their network that could help inform the project.

The key informant interviews report is available [here](#)



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Appendix A: Educational Resources and Decision-aid Tools for Persons Living with Dementia and Family Caregivers

Websites

Alzheimer Society of B.C.

<https://alzheimer.ca/en/bc>

Alzheimer Society of Canada

<https://alzheimer.ca>

Dementia Dialogue

<https://www.dementiadialogue.ca>

First Nations ACP Resources

<https://www.advancecareplanning.ca/resource/first-nations-acp-resources/>

Webinar

Dementia and End of Life Care

<https://vimeo.com/121378821>

Advance Care Planning

Personal Planning Along the Dementia Journey

<https://alzheimer.ca/en/bc/Living-with-dementia/Caring-for-someone/Personal-planning>

Shaping the Journey: Living with Dementia. Section 5: Planning Ahead

<https://alzheimer.ca/en/bc/Living-with-dementia/Caring-for-someone/Personal-planning>

A Road Map: Guiding Ethical and Legal Planning for Persons with Alzheimer’s Disease or Another Dementia and Their Families

<https://alzheimer.ca/en/bc/Living-with-dementia/Caring-for-someone/Personal-planning>

Advance Care Planning – Myth Busting

<http://www.rethinkdementia.ca/#section-what-is-dementia>

Alzheimer’s disease What to expect

www.alzheimer.ca

Care Planning Checklist for Caregivers The Dementia Society, Ottawa and Renfrew County.

<https://dementiahelp.ca/download/care-planning-checklist-caregivers/>

When your loved one has dementia: A Dementia Roadmap for Families. Division of Family Practice, Kootenay Boundary

<https://www.divisionsbc.ca/kootenay-boundary/our-impact/team-based-care/residential-care>

ACP Conversations

Tips for Talking About End-of-Life

<https://alzheimer.ca/en/bc/Living-with-dementia/Caring-for-someone/End-of-life-care/Advance-care-planning/Tips-for-talking-about-end-of-life>

Actually Having the Conversations

<http://www.rethinkdementia.ca/#section-what-is-dementia>

Decision Making

Appointing Substitute Decision Makers

<https://alzheimer.ca/en/bc/Living-with-dementia/Caring-for-someone/End-of-life-care/Appointing-substitute-decision-makers>

Part I: What decisions do I need to make? Dementia and End-of-Life Care Alzheimer Society of Canada

<https://alzheimer.ca/en/Home/Living-with-dementia/Caring-for-someone/End-of-life-care>

Making Decisions: Respecting Individual Choice

<https://alzheimer.ca/en/cornwall/Living-with-dementia/Caring-for-someone/Making-decisions>

Guides for Family Caregivers

Comfort Care at the End of Life for Persons with Alzheimer's Disease or Other Degenerative Diseases of the Brain

<https://www.expertise-sante.com/produit/comfort-care-at-the-end-of-life-for-persons-with-alzheimers-disease-or-other-degenerative-diseases-of-the-brain-a-guide-for-caregivers/>

Advanced Dementia. A Guide for Families

<https://www.divisionsbc.ca/victoria/resources/rci-resources/dementia#presentations>

The Palliative Approach for Advanced Dementia in Long Term Care: A Resource for Residents, Family and Friends

<https://www.chpca.ca/knowledge/strengthening-a-palliative-approach-in-long-term-care-spa-ltc-project/>

Medical Decisions and Feeding Choices

Medical Care Decisions

<https://alzheimer.ca/en/bc/Living-with-dementia/Caring-for-someone/End-of-life-care/Medical-care-decisions>

Feeding Choices for Patients with Advanced Dementia University Health Network.

<https://www.uhn.ca>

Making Choices: Feeding Options for Patients with Dementia

https://ohri.ca/docs/Fdas/Feeding_Options.pdf&usg=AOvVaw1d3ZZr3UALiPIONdyQzk1

Decision Aids

Goals of Care Video Decision Aid for Caregivers

<https://www.med.unc.edu/pcare/resources/goals-of-care/>

Tube Feeding Decision Aid & Tube Feeding Narration

decisionaid.ohri.ca

Training Resources (International)

Serious Illness Conversation Guide: Conversation Flow

<http://www.bccancer.bc.ca/other-phsa-sites-search-results?k=serious%20illness%20conversation>

Respecting Choices® Advance Care Planning. Facilitator Certification Manual. A Guide to Person-Centered Conversations.

www.learnrc.org

End-Of-Life Decisions Honoring the Wishes of a Person with Alzheimer's Disease.

https://www.alz.org/national/documents/brochure_endoflifedecisions.pdf

