

ECHO IDAHO

Alzheimer's Disease and
Related Dementias

Advance Care Planning in ADRD

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University of Idaho
School of Health and Medical
Professions



Learning Objectives

- Define palliative medicine and advance care planning (ACP)
- Describe a framework to have an ACP conversation with a person with dementia and their family
- Identify other resources to develop this skill set

What is palliative medicine?

- Specialized medical care for people living with a serious illness
- Focused on providing relief from the symptoms and stress of the illness
- Improves quality of life for both the patient and the family
- Based on the needs of the patient, not on the patient's prognosis
- Appropriate at any age and at any stage in a serious illness
- Provided along with curative treatment
- getpalliativecare.org

What is advance care planning (ACP)?

- It is a process of communication about:
 - Future care and treatment preferences
 - Values and goals
- It includes the person with dementia, their family, and their health care team.
- It's an ongoing process with continued conversations and documentation
 - The process continues even when the person with dementia becomes unable to make their own decisions

Important issues to consider with ACP and dementia

- Capacity
- Family
- Engagement and communication

Serious Illness Conversation Guide

- The purpose of this document is to:
 - Talk to patients about their goals and values
 - Set up the conversation about serious illness
 - Assess the patient's illness understanding and information preferences
 - Share prognosis
 - Explore key topics
 - Document the conversation

Serious Illness Conversation Guide for Dementia (SICG-D)

Serious Illness Conversation Guide

S E T U P	“I’d like to talk about what is ahead with <i>your</i> ___’s illness and do some thinking in advance about what is important to <i>your</i> ___ so that I can make sure we provide the best care possible – is this okay?”
	“I’ll be using this Guide to help me assure I don’t miss any important information.” IF RESISTANT: Hope for best/prepare for bumps in the road; Benefit to family of planning ahead; No decisions necessary today
A S S E S S	“What is your understanding now of <i>your</i> ___’s illness?” FOLLOW-UP PROMPTS: “What is your understanding of what the future may hold with <i>your</i> ___’s illness?”
	“How much information about what may be ahead with this illness would you like from me?” FOR EXAMPLE: “Although it can be difficult to predict what will happen with <i>your</i> ___’s illness, some patients and family members have questions about time and what to expect.”
S H A R E	“I want to share with you my understanding of where things are with <i>your</i> ___’s illness...” General: “Dementia/memory loss is a brain disorder which usually progresses gradually over time, affecting people’s ability to do things for themselves like drive a car, make their own meals, use the bathroom, eat independently, and communicate effectively.”
EXPECT & RESPOND to EMOTION (see over)	
E X P L O R E	“For the next few questions, I want you to imagine what <i>your</i> ___ would say when they were able to think clearly. We are not thinking about what <i>your</i> ___ would want for you or what you would want for <i>your</i> ___, but what they would want for themselves.”
	“What are <i>your</i> ___’s most important goals if their health situation worsens?”
	“What are <i>your</i> ___’s biggest fears and worries about the future with their health?”
	“What abilities are so critical to <i>your</i> ___’s life that they couldn’t imagine living without them?” FOR EXAMPLE: “Some people need to do things for themselves, in order to say life is worth living; other people need to interact meaningfully with loved ones, and others say life is life, no matter the quality.”
	“Are there any medical treatments or types of care <i>your</i> ___ wouldn’t be willing to accept?” FOR EXAMPLE: “Would your ___ not be willing to undergo hospitalization, feeding tubes, antibiotics for infection, CPR, etc?”
	“How much does <i>your</i> ___’s <i>family/other family</i> members know about these priorities and wishes?”
	“What gives you strength as you think about the future with <i>your</i> ___’s illness?”
C L O S E	“I’ve heard you say that ___ is really important to <i>your</i> ___. Keeping that in mind, and what we know about <i>his/her</i> illness, I recommend ___. How does this plan seem to you? ” “We will do everything we can to help you and <i>your</i> ___ through this.”

DOCUMENT in the ACP NAVIGATOR

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Interstitial Skills

The Wish/Worry/Wonder framework

<p>KEY IDEAS</p> <p>“I wish” aligns with the patient</p> <p>“I worry” allows for being truthful while sensitive</p> <p>“I wonder” is a subtle way to make a recommendation</p>	<p>Align with the DPOA/patient’s hopes, acknowledge concerns, then propose a way to move forward:</p> <p>“I wish we could significantly slow down or even halt the progression of <i>your</i> ___’s cognitive decline and other symptoms, but I worry that our current tools aren’t always very effective at doing that. I wonder if we should consider how we should proceed as the disease/condition becomes more challenging.”</p>
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Responding to Emotion (N.U.R.S.E.)

EXAMPLE

<p>NAME</p> <p>name the emotion you see in front of you</p>	<p>“I can see you are frustrated”</p> <p>“This must be overwhelming”</p>
<p>UNDERSTAND</p> <p>try to put yourself in their shoes</p>	<p>“I can’t begin to understand how hard this has been”</p> <p>“I can only imagine how difficult this must be”</p> <p>“Caring for someone with dementia can be very, very challenging.”</p>
<p>RESPECT</p>	<p>“I can see what an amazing advocate you are for <i>your</i> ___”</p>
<p>SUPPORT</p>	<p>“We want to do everything we can to help you and <i>your</i> ___ with this very difficult task you are facing”</p>
<p>EXPLORE</p>	<p>“Could you share more with me about...”</p> <p>“Tell me what ___ means to you/<i>your</i> ___.”</p>

Conversation Connectors

<p>Achieve thematic saturation:</p>	<p>“Anything else?”</p>
<p>Paraphrase/Summarize:</p>	<p>“So what I’m hearing you say is _____.”</p> <p>“Sounds like we need to assure we avoid _____.”</p>
<p>Normalization of extremes/Value neutral stance</p>	<p>“Some people would choose X, others would choose Y.. and others would be in the middle. How about <i>your</i> ___?”</p>
<p>Parking lot / Bookmarking</p>	<p>“You’ve raised an important concern. Let’s bookmark that and return to it after I’ve heard all of you and <i>your</i> ___’s goals and priorities.”</p>

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Setup

- I'd like to talk about what is ahead with your _____'s illness and do some thinking in advance about what is important to your _____ so that I can make sure that we provide the best care possible – is this OK?
- I'll be using this guide to help me assure I don't miss any important information.

Assess

- What is your understanding now of your _____'s illness?
- How much information about what may be ahead with this illness would you like from me?

Share

- I want to share with you my understanding of where things are with your _____'s illness.

Explore

- For the next few questions, I want you to imagine what your ____ would say when they were able to think clearly.
 - What are their most important goals if their health situation worsens?
 - What are their biggest fears and worries about the future with their health?
 - What abilities are so critical to their life that they couldn't imagine living without them?
 - Are there any medical treatments or types of care they wouldn't be willing to accept?

Close

- I've heard you say that _____ is really important.
- Keeping that in mind, and what we know about their illness, I recommend _____. How does this plan seem to you?
- We will do everything we can to help you and your family through this.

Other Resources

- The Conversation Project
 - Theconversationproject.org
- GeriPal podcasts about communication
 - Miscommunication in medicine
 - Should we shift from advance care planning to serious illness communication?
 - Avoiding the uncanny valley in serious illness communication

Other Resources

- VitalTalk
 - Vitaltalk.org
 - Online, hybrid, and in-person modules
 - Navigating Serious Conversations
 - Best Case, Worst Case
- Empty chair framework

Dartmouth Palliative Module

- Dartmouth Health Continuing Education for Professionals
 - <https://dh.cloud-cme.com/course/onlinelisting?p=20>
 - Search for “Goals of care”

Register ▶

Details ⓘ

[EARLY Goals of Care Training: Foundational Skills using the Serious Illness Conversation Guide](#)

Wednesday, April 15, 2026, 1:30 PM - 4:30 PM

Webinar

Curriculum: Goals of Care Trainings,

Credits: AMA PRA Category 1 Credits™ (2.75 hours), CME-Designated Participation Credit (2.75 hours), ANCC Nursing Contact Hours (2.75 hours), ASWB Social Work Credit(s) (2.75 hours), CDR Dietetic CPEU(s) (2.75 hours)

This three-hour interactive, skills-based session gives healthcare professionals of any discipline a talking map for effective, efficient goals of care conversations. Led by Dartmouth Health Serious Illness Care Program faculty, the session features...

LIVE ASWBHOURS CDRHOURS GOALS OF CARE TRAININGS

Key Points

- Normalize advance care planning for all patients including those with ADRD
- Use the SICG-D framework as a guide for ACP conversations for patients with ADRD
- Feeling comfortable with these types of conversations takes time and experience

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