

Question & Answer (Q&A): Palliative Care for Older Adults Dually Eligible for Medicare and Medicaid

Webinar participants asked these questions during the *Palliative Care for Older Adults Dually Eligible for Medicare and Medicaid* webinar held on December 5, 2018. We have edited speakers' responses for clarity. The webinar recording, slides, and transcript can be found on the Resources for Integrated Care website:

https://resourcesforintegratedcare.com/GeriatricCompetentCare/2018_GCC_Webinar/Palliative_Care

Featured Webinar Speakers:

- Diane E. Meier, MD, Catherine Gaisman Professor of Medical Ethics and Professor of Geriatrics and Palliative Medicine, Mt. Sinai School of Medicine; Director, Center to Advance Palliative Care
- Isaac Bromberg, MD, Medical Director for Palliative Care, Commonwealth Care Alliance
- Karen Blair, BSN, Palliative Care Coordinator, Commonwealth Care Alliance
- Lisa Thompson & Linda Thompson, Family Caregivers

Q1: Can you share best practices for communicating with a client experiencing a serious illness?

Dr. Diane Meier: Begin the conversation by finding out what the individual and family understand about the illness. Some people do not like to talk about the prognosis of a serious illness, so it is best to ask permission to speak with them or another member of the family. If granted permission, discuss expectations for the next week, month, or year using simple language, not jargon. Allow silence. There may be a lot of emotion in these discussions. Let that emotion happen, be supportive, and allow time for the person and family to process the information. Once this conversation takes place, then care team members can start the discussion about making plans for how to manage the future.

It is the entire care team's job to find out what is important to the client; however, who has this discussion with the client will vary on the stage of illness and the urgency of the medical decision-making. In the early stage of a serious illness, find out who the client trusts to make decisions on their behalf if they are no longer able to make their own decisions. The care team should also ensure that the client knows what to do in the event of a medical emergency. In later stages of a disease when there is evidence of clear progression, recurrent visits to the emergency department may be actively harmful. Remember, telling an individual with serious illness to call 911 during a symptom or other crisis is not a plan. Work with the individual and their family to identify likely or predictable recurrent issues and develop a plan with them that they can activate at home (e.g., use of a hand held fan for shortness of breath in Chronic

Obstructive Pulmonary Disease (COPD); proactive implementation of respite care options for an exhausted family caregiver).

Q2: Can you elaborate on the importance of meeting the cultural needs and preferences of your members? Can you share an example?

Karen Blair: It is important for us to have some understanding about our members' origin, religion, and their cultural preferences. We look at our members in the cultural context of their ethnic background, religion, family, and neighborhood. Each of these is an aspect of their culture and is part of what makes everyone unique. It is helpful to not make assumptions and to do the research about these different backgrounds and cultures. It is also key to ask individuals what is important to them. There are many great resources which address communication, eye contact and touch, symptom management and death ritual, and other strategies. I specifically reference the book, *Culture and Clinical Care*, edited by Juliene G. Lipson and Suzanne L. Dibble, UCSF Nursing Press.

One way we meet the cultural needs and preferences of members is by connecting members with staff who speak their preferred language whenever possible and writing instructions in that language. This helps to improve understanding and comfort.

Q3: What role can aging and disability community-based organizations (e.g., Area Agencies on Aging) play in the provision of high-quality palliative care?

Dr. Diane Meier: Community organizations serving high-risk populations are a reliable source of guidance on navigating the health care system, and they understand the range of serious illness care programs in their communities. These programs serve clients with evolving functional or cognitive impairment, or those with one or more serious illnesses. To locate community organizations that offer palliative care services in your area, visit <https://www.getpalliativecare.org>.

Q4: How can interdisciplinary care teams (ICTs) identify beneficiaries who have a higher risk of hospitalization or mortality?

Dr. Diane Meier: We look at three main criteria to assess risk: the presence of one or more serious illnesses, a hospitalization or skilled nursing facility stay in the prior 12 months, and the presence of functional or cognitive impairments. The presence of all three criteria predicted 50 percent likelihood of hospitalization in the next 12 months and roughly a 25 percent risk of mortality. ICTs can review claims data to find diagnoses and hospitalizations or skilled nursing facility stays. To determine functional or cognitive impairments, consider assessments and screenings, such as the [Katz Index of Independence in Activities of Daily Living](#), [Mini-Cog](#), or the

[Clinical Frailty Scale](#). These screenings can be in the form of simple tools that ICT members can access on their phones or tablets and are effective in identifying rising risk.

Q5: Labels mean something. Do beneficiaries generally embrace the terms “palliative medicine” and “hospice care”? Should we consider other terms when speaking with our beneficiaries?

Linda Thompson: I agree that terms matter in the context of palliative care. There is an association with hospices and helping people die with dignity. Palliative care is a technical term, and it is often a new word for people. When my father was in the hospital at the end of his life, we were introduced to the term “comfort care.” Palliative teams provide comfort care by delivering and allowing individuals to access services when they need them the most.

Q6: How can we locate palliative care providers in our area?

Dr. Diane Meier: A national palliative care directory is available to the public at <https://www.getpalliativecare.org>.

Q7: What would you say was one of the most important aspects of having an interdisciplinary care team (ICT) for your mother?

Lisa Thompson: I think the most important aspect of having an ICT was the communication—that coordinated effort by a team to talk to each other about everything that is happening. Before our mother had an ICT, we would have to repeat the same information every time we would accompany her to the doctor. However, after she had an ICT, we only needed to convey information to one person, who then relayed it to the rest of the care team.

Linda Thompson: I also think that one of the most important aspects of the ICT is that they took care of us as family caregivers. My mom used to be in charge of her care, but it became very stressful for us when she began to have memory and coordination complications. During her transition of care, we needed medical professionals who were able to lay out the options and offer their help and training.

Q8: Can you elaborate more on advance care planning? What is it, and why is it important for individuals receiving palliative care?

Dr. Isaac Bromberg: Advance care planning is the process of thinking about, discussing, and documenting an individual’s preferences regarding the care they should receive in the event that they are unable to express these preferences themselves. The most basic component of an advance care plan is a Health Care Proxy document, which allows an individual to identify someone as their health care agent with the authority to make decisions on their behalf.

Expectations and requirements for Health Care Proxy documents and other advanced care planning documentation varies by state. More detailed documents, such as living wills or MOLST/POLST (Medical Orders for Life-Sustaining Treatment/Physician (or Provider) Orders for Life-Sustaining Treatment) allow for people to identify specific treatments as desirable or undesirable. Examples of these treatments include artificial nutrition or hydration, mechanical ventilation, and cardiopulmonary resuscitation (CPR). All adults regardless of health status should complete a Health Care Proxy. Individuals who have chronic progressive illnesses, or illnesses that decrease their life expectancy, should participate in the advance care planning process. This advance care planning is ideally a continuous process of tailoring the care a person receives to the current and anticipated future state of their condition.

Q9: Can you offer an example of what palliative care services look like for beneficiaries with Alzheimer’s disease and related dementias?

Karen Blair: Palliative services and support for individuals with dementia are critical. We arrange an initial visit to discuss goals of care, and if the member is still able to identify who they want caring for them, we ensure a Health Care Proxy document is completed. Generally, the intricacies of a more detailed advance directive are difficult, but one might get a sense of their wishes in conversation or from review of their past from caregivers and other loved ones. We also connect caregivers to supports and resources available on an ongoing basis, such as the [Alzheimer’s Association 24/7 Helpline and website](#). It is important to discuss with the caregiver what the disease course looks like, expectations for length of care by the caregiver, and how to care for oneself as a caregiver. We also discuss issues that are present at the time, and what one might expect next. In addition, we try to give caregivers information to understand behaviors that fit within normal range, and how to support behavior changes in their loved one. This can include conversations around when medication might be appropriate.