# Adult Foster Home Provider Alert

**Policy updates, rule clarifications and announcements**

**Date:** October 29, 2019

**To:** APD Adult Foster Home Providers

**From:** Safety, Oversight and Quality Unit

**Topic:** **Palliative Care Toolkit Webinar Training – 1.5 CEUs**

The Oregon Partnership to Improve Dementia Care has developed a Palliative Care Toolkit for Oregon's long-term care setting. This toolkit:

- Describes the difference between palliative care and hospice care what person-centered palliative care looks like;
- Explains the benefits of palliative care, especially for people living with dementia;
- Provides instructions on how to conduct a palliative care conference;
- Lists resources and tools in developing a palliative care program; and
- Is approved for 1.5 CEUs

To introduce this resource a webinar, *"What, When & How: Palliative Care Meetings for People Living with Dementia"* will be held on November 6, 2019, 1:00 – 2:30 pm. This webinar will feature Maureen Nash, MD and Harry Krulewitch, MD. To register, please click on the link above or visit:
https://healthinsight.zoom.us/webinar/register/WN_WeitIESaSEyW4IB7LTX8VQ

*The Oregon Partnership to Improve Dementia Care Presents*

# What, When, & How:
# Palliative Care Meetings for People Living with Dementia

A webinar featuring **Maureen Nash, MD, FAPA, FACP** & **Harry Krulewitch, MD, MPH**

**When**: Wednesday, November 6, 2019
1:00—2:30 p.m.

The Oregon Partnership to Improve Dementia Care is proud to present a new resource for long-term care staff:

**What is Palliative Care?**

**Tools & resources to help focus discussions with individuals living with dementia and their loved ones about how they want to live**

Click here to view or download the toolkit
http://bit.ly/palliativecaretoolkit

Please join us for a webinar to introduce and discuss this free resource. Participants will learn:

- The importance of recognizing and decreasing suffering among persons living with dementia
- What it means to provide palliative care
- How to conduct a palliative care conference with individuals and their loved ones

**Click here to register!**
http://bit.ly/Nov6palliativewebinar

## Who should attend this event?

Long-term care staff across all settings, including nursing homes, assisted living communities, residential care communities, and adult foster homes

### Who is the Oregon Partnership to Improve Dementia Care?

The Partnership's mission has been to promote the use of nonpharmacological approaches and person-centered practices in the care of older adults, and to guide quality initiatives specific to the needs of older adults in Oregon, especially those living with dementia. OPIDC includes representatives from Alzheimer's Association, DHS Aging and People with Disabilities, Consonus Pharmacy Services, Comagine Health, LeadingAge Oregon, Making Oregon Vital for Elders, Oregon Geriatric Society, Oregon Health Authority, Oregon Health Care Association, Oregon State University School of Pharmacy, Providence ElderPlace, and Regence BlueCross BlueShield of Oregon.

**Questions?**

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# What is Palliative Care?

Tools & resources to help focus discussions with individuals living with dementia and their loved ones about how they want to live

REVISED 9/24/19

## Purpose & objectives

The purpose of this collection of tools and resources is to help long-term care staff understand what palliative care is and increase their skills and comfort providing palliative care, particularly for individuals living with dementia.

The tools and resources provided are intended to support:

- Decreased suffering through appropriate screening, assessment, and use of palliative care practices
- Increased staff knowledge and comfort with conversations about palliative care with individuals and their loved ones
- Decreased use of inappropriate medications in older adults, especially those living with dementia

## Audience for this guide

Long-term care staff across all settings, including nursing homes, assisted living communities, residential care communities, and adult foster homes.

## Who is the Oregon Partnership to Improve Dementia Care (OPIDC)?

In 2012, the Centers for Medicare and Medicaid Services launched a national campaign to improve quality of life for people living with dementia living in nursing homes. The campaign was based on emerging evidence of potential serious side effects associated with off-label use of antipsychotic medications. While the initial goal was to reduce the use of antipsychotics among those persons living with dementia, the Partnership's larger mission has been to promote the use of nonpharmacological approaches and person-centered practices in the care of older adults, and to guide quality initiatives specific to the needs of older adults in Oregon. OPIDC includes representatives from Alzheimer's Association, DHS Aging and People with Disabilities, Consonus Pharmacy Services, Comagine Health, LeadingAge Oregon, Making Oregon Vital for Elders, Oregon Geriatric Society, Oregon Health Authority, Oregon Health Care Association, Oregon State University School of Pharmacy, Providence ElderPlace, and Regence BlueCross BlueShield of Oregon.

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**Download this toolkit**: https://www.oregon.gov/DHS/PROVIDERS-PARTNERS/LICENSING/CBC/Pages/resources.aspx

# What is palliative care?

The World Health Organization defines palliative care as "an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual."

## Palliative care:

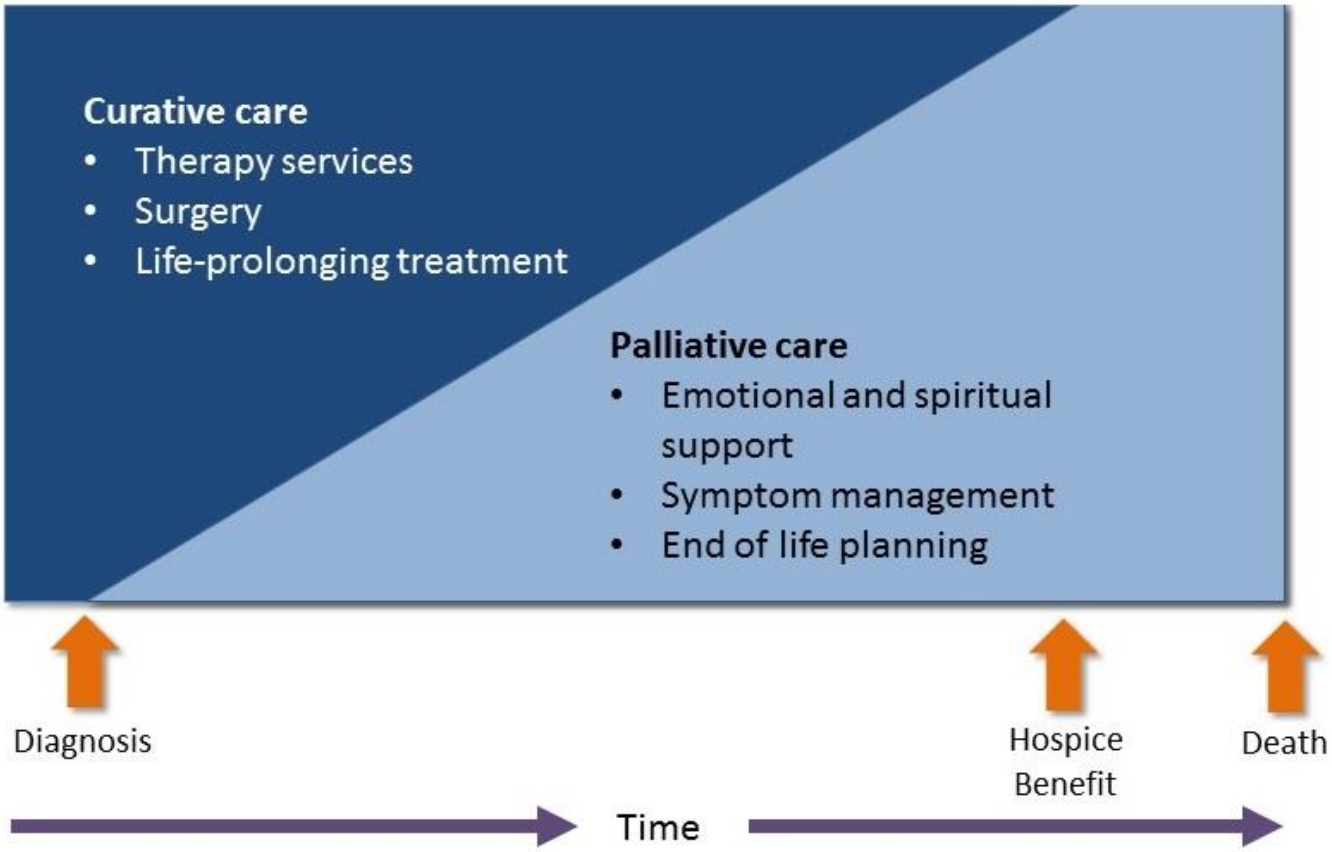
- Is appropriate early in the course of illness
- Enhances quality of life
- May positively influence the course of illness
- Provides relief from pain and other distressing symptoms
- Integrates the psychological and spiritual aspects of patient care
- Affirms life and regards dying as a normal process
- Uses a team approach to address the needs of patients and their loved ones
- Offers a support system to help the family cope during the patient's illness
- Offers a support system to help patients live as actively as possible until death

Source: https://www.who.int/cancer/palliative/definition/en/

# What's the difference between palliative care and hospice?

Simply put, all hospice care is palliative, but **not all palliative care is hospice**. As you can see in the figure below, a person may receive curative treatments, such as chemotherapy, while also receiving palliative care. Hospice care is an optional care benefit that a person may choose to use when nearing the end of their life; it does not include curative treatments.

## Continuum of care



# Who could benefit from palliative care?

Palliative care provides relief from symptoms and stress of a life-limiting illness along with the goal to improve quality of life for both the person and their caregivers. There are many factors that may contribute to a decision to include palliative care in an individual's care plan, but it's important to consult with an interdisciplinary team to identify and address distressing symptoms. Some specific indicators and potentially distressing symptoms to consider include:

Diagnosis of a life-limiting illness, including:

- Alzheimer's disease or other dementia
- Congestive heart failure
- Chronic Obstructive Pulmonary Disorder (COPD)
- Cancer

Multiple hospitalizations in the previous 6 months to one year

Decline in function, i.e., less ability to do tasks of daily living

Pain that is difficult to control

Chronic, debilitating bowel issues

Weight loss

Skin breakdown

Delirium

Nausea

Shortness of breath

## Decision support screening tools related to palliative care

| | |
|---|---|
| **INTERACT**<br>**Advance care planning & decision support tools** | INTERACT (Interventions to Reduce Acute Care Transfers) is a program designed for long-term care professionals. It includes clinical and educational resources, tools, and strategies to recognize and treat acute change in resident condition. |
| **Mini Suffering State Exam (MSSE)** | A short and simple scale designed to measure quality of life; especially useful when trying to assess suffering in a person who may not be able to speak for themselves, such as a person living with dementia. May be administered by nurses and physicians, but also involves the opinions of loved ones and/or caregivers. |
| **Pain Assessment in Advanced Dementia (PAINAD)** | This pain behavior tool is used to assess pain in older adults who have cognitive impairment and/or are unable to reliably communicate their pain. |

## How do I talk to an individual and/or their loved ones about introducing palliative care?

Even when it seems clear that palliative care is needed, having a conversation with the individual and their loved ones can be difficult for everyone involved. Whenever possible, it is best practice to have these conversations before serious symptoms and suffering occurs. The following checklist and communication prompts are intended to support and facilitate conversations about palliative care. This conversation can be conducted by anyone from the care team, with the individual and at least one family member or loved one. The best way to become comfortable and skilled at these conversations is to practice as much as possible.

### Conducting a Palliative Care Conference: Checklist

1. **Choose an appropriate setting for the conference.**
   - ☐ Use a quiet, private space that is large enough to comfortably accommodate all attendees.
   - ☐ Stock the room with water for everyone and have tissues available.
   - ☐ Limit the number of team members in the room; too many people can be overwhelming.
   - ☐ Choose one person to lead the discussion.
2. **Make sure everyone is comfortable and on the same page.**
   - ☐ Arrive prepared. Review the chart, consult with the care team, and clarify what the team hopes will come from the meeting ahead of time.
   - ☐ Begin with introductions for everyone present.
   - ☐ Establish expectations, goals, and ground rules for the meeting.
   - ☐ Understand and be sensitive to the ethnic, cultural, and spiritual influences on communication, family relationships, and concepts of illness and death.
3. **Explore knowledge, beliefs, and attitudes about the illness, prognosis, and end of life.**
   - ☐ Assess what they know about the current clinical situation.
   - ☐ Assess how much information they want to be given.
4. **Offer knowledge about the individual's condition.**
   - ☐ Focus on the current clinical situation and treatments.
   - ☐ Be clear about the prognosis, potential recovery, and ongoing quality of life.
   - ☐ Be open about uncertainty.
   - ☐ Avoid medical jargon and check in frequently to make sure everyone understands what is being discussed.
   - ☐ Determine the goals of care before discussing specific therapies.
5. **Clarify goals of care moving forward and plan next steps.**
   - ☐ Explore the goals of the person and attitudes toward critical illness. What care decisions would be in their best interest?
   - ☐ Listen to the goals from everyone in the room but maintain focus on the individual's perspective.
   - ☐ Check with family members to hear their thoughts and validate their feelings.
6. **Offer clear recommendations based on the goals discussed during the conference and summarize the conversation.**
   - ☐ Discuss appropriate therapy or treatment to be implemented.
   - ☐ Review what will be done to achieve the goals discussed and what will indicate whether the person is better or worse.
   - ☐ Briefly summarize what was discussed during the conference.
   - ☐ Assess their understanding of the discussion and all decisions made during the conference.
   - ☐ Make a clear follow-up plan, including when the next communication or care conference will be, and document the meeting.

# Conducting a Palliative Care Conference: Communication Prompts

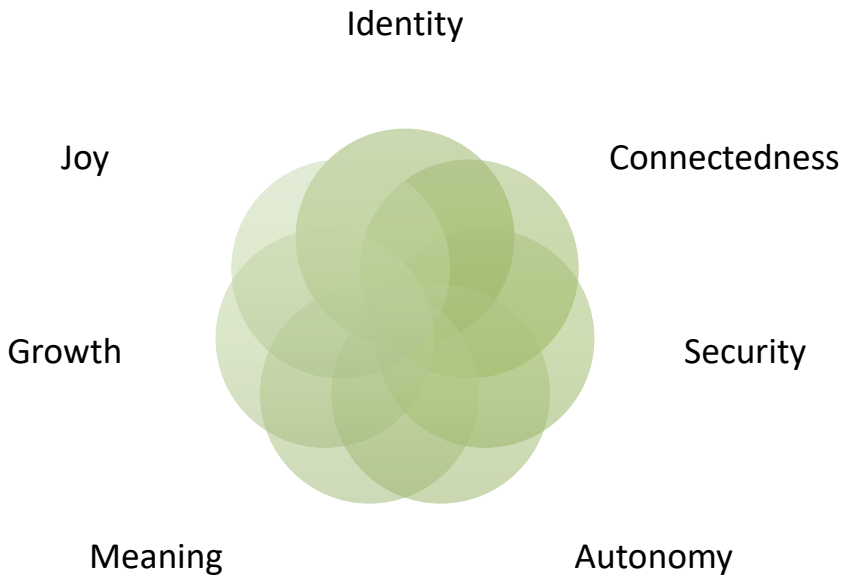
| Checklist Section | Examples of what to say |
|---|---|
| **Make sure everyone is comfortable and on the same page.** | *We have 45 minutes for this discussion. I want to review how your loved one is doing and try to answer all your questions. If possible, let's try to have only one person speaking at a time.*<br><br>*Can you help me understand what I need to know about your/your loved one's beliefs and practices so we can take the best care of you/them?* |
| **Explore knowledge, beliefs, and attitudes about the illness, prognosis, and end of life.** | *I want to make sure we all understand what is happening medically.*<br><br>*What is your understanding of your medical situation?*<br><br>*Would you be surprised if you/your loved one was not alive in a year?*<br><br>*Have you thought about what is important to you for the rest of your/your loved one's life?*<br><br>*Do you feel like you are getting enough information about your/your loved one's health status?*<br><br>*I don't want to overload you with details, but I want to keep you informed.* |
| **Offer knowledge about the individual's condition.** | *Would you like me to talk about what we think is going to happen?*<br><br>*I wish I could be clearer about what will happen.*<br><br>*What questions do you have about what I just said?* |
| **Clarify goals of care moving forward and plan next steps.** | *We are doing everything we can in hopes your loved one will get better. I wonder, though, if you have been able to think about what if things do not go well?*<br><br>*What kinds of things are important to you/your loved one? Did this conversation or situation ever come up in your family?* |
| **Offer clear recommendations based on the goals discussed during the conference and summarize the conversation.** | *It sounds like your loved one's primary goal was to be able to be stay independent. And if that could not happen, he wanted to avoid being on a breathing machine?*<br><br>*It sounds like we should try the treatment for a week or two and see if you/your loved one is better.* |

**Additional Resources:** Center to Advance Palliative Care: https://www.capc.org/ VitalTalk: https://www.vitaltalk.org/

*7 Steps to a Successful Family Conference*. Education in Palliative and End-of-Life Care (EPEC). Feinberg School of Medicine, Northwestern University.
*A Guide for Conducting a Family Meeting Modified "SPIKES" (original by Baile & Buckman).* Cerceo, E. Society of Hospital Medicine.

# What does person-centered palliative care look like?

People with dementia and other chronic diseases have the right to remain engaged in life to the fullest extent possible. Consider what living well looks like to the person in this moment of their life. Below are the seven Eden Alternative® Domains of Well-Being:




| | |
|---|---|
| Identity | What defined this person's identity in their earlier life? How can the care team support and help them maintain their identity? |
| Connectedness | What helps this person feel connected to others? What connections are important to them? |
| Security | What gives this person a sense of security and trust? |
| Autonomy | Is this person allowed to participate in day-to-day decisions that are meaningful to them? |
| Meaning | What gives their life meaning? Do they have a belief system that gives their life purpose? |
| Growth | How are the strengths, dreams and goals of this person captured and shared? |
| Joy | What brings joy to this person? Are they encouraged to participate in activities that bring them joy? |

It is crucial to regularly meet with the interdisciplinary team—individual, family, nurses, care staff, life enrichment staff, dietary staff, clinician—to discuss what everyone knows about the person and craft a care or service plan that provides meaningful engagement and care for the individual. This will need to be monitored and updated as their condition and preferences change.

The Eden Alternative® Domains of Well-Being adapted by G. Allen Power *in Dementia Beyond Disease: Enhancing Well-Being* published in 2014 by Health Professions Press.

# Other tools & resources

**Additional resources for providing person-centered care**

- Making Oregon Vital for Elders (MOVE) (orculturechange.org)
  A statewide coalition of dedicated organizations and individuals united in changing the way Oregonians approach health and long-term care for older adults.
- Familias en Accion (familiasenaccion.org)
  A culturally specific organization to promote health for the Latinx community, including free online palliative care training for health care professionals.

**Advance care planning resources**

- Oregon Advance Directive
  (oregon.gov/oha/PH/ABOUT/Pages/AdvanceDirectiveAdoptionCommittee.aspx)
  A link to the Oregon Advance Directive Adoption Committee page on the State of Oregon website. The most current Advance Directive forms can be downloaded for free in English and Spanish.
- Oregon POLST® (Portable Orders for Life-Sustaining Treatment®) (oregonpolst.org)
  Designed to improve the quality of care people receive near the end-of-life, the Oregon POLST® Program is based on effective communication of patient wishes, documentation of portable orders for life-sustaining treatments and promise by a health care professional to honor these wishes.
- Oregon Health Decisions (oregonhealthdecisions.org)
  An organization whose mission is to educate and empower Oregonians to understand their options and plan for health care at the end of life. The website contains materials and education to help people make better-informed decisions about their future health care needs and wishes.

**End-of-life and dementia-specific resources**

- The Conversation Project (theconversationproject.org)
  An organization dedicated to helping people talk about their wishes for end-of-life care. The website includes resources for individuals, families, and health care professionals, including a free online course to help health care professionals develop skills for having conversations about end-of-life care.
- National Institute on Aging: End-of-life care for people with dementia
  (nia.nih.gov/health/end-life-care-people-dementia)
  A website that provides information about dementia and its progression, as well as resources and support for legal, financial, and advance care planning.
- Advanced Dementia: A Guide for Families
  (marcusinstituteforaging.org/sites/default/files/files/DementiaGuideForFamilies.pdf)
  A free guide for families about what to expect when they have a loved one with advanced dementia.
- Alzheimer's Association (alz.org)
  An organization that works to improve care and provide support and resources for all who are affected by Alzheimer's disease, as well as advance research to find a cure, and promote brain health to reduce the risk of developing dementia.
- Music and Memory® (musicandmemory.org)
  An organization dedicated to helping people who struggle with cognitive and/or physical challenges in long-term care find renewed connection and meaning through the gift of personalized music.
- Positive Approach to Care® (teepasnow.org)
  An organization founded by Teepa Snow that is dedicated to enhancing the life and relationships of those living with dementia by supporting families and professionals with training and skills development.
- Best Friends Approach™ (bestfriendsapproach.com)
  An organization that has designed training for both family and professional care partners to improve and support the care and the lives of individuals living with dementia.