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## KNOW THE FACTS

# Older Adults and Palliative and End-of-Life Care

### WHAT IS PALLIATIVE AND END-OF-LIFE CARE?

**Palliative care** is a team-based approach to care for people with serious illness that is appropriate at any age/stage of illness. It can be provided along with curative treatment. Palliative care:

- Is focused on improving the quality of life for individuals facing serious and limiting illness, and their care partners
- Provides symptom management and relief from pain
- Includes assessment and treatment of physical, psychological, and spiritual issues
- Can also include respite care for family caregivers and bereavement care after the person dies

**End-of-life** care focuses on palliative care for terminally ill individuals who may have only very limited time to live and have elected to no longer pursue curative treatment. It is often tied to hospice care, which is defined in the United States as encompassing the final six months of life.

### WHAT ARE THE OBSTACLES TO RECEIVING PALLIATIVE AND END-OF-LIFE CARE?

Health care providers want to preserve hope for individuals with serious and life-limiting illness. For example, physicians have difficulty saying that a cure is not possible. Some health care providers are uncomfortable asking or discussing an older person's choices for care (e.g., hospital or home treatment, breathing machines or feeding tubes, curative care or comfort care). As a result, older adults and their families may not know about or understand all possible care options.

**Some health care providers are uncomfortable asking or discussing an older person's choices for care.**

Some health care providers may lack experience in managing pain and other physical symptoms (e.g., fatigue, difficulty breathing, constipation, nausea) or in providing emotional support. Some believe that they must do everything to prolong life, regardless of pain and suffering, and continue to encourage their patients to not give up hope. They fear that offering only comfort care means that they are giving up or have failed their patient.

Many older adults do not plan in advance or express their wishes for care in later life. Sometimes they are nervous to bring up the topic of palliative care with those close to them or their health care providers. Often, they don't know how to start such a discussion when they still are able. If the conversation about palliative care occurs too late—after an older adult has experienced a serious health event, or when they are too ill to express their wishes, and their families are in distress—they may not receive the care they prefer.

Mental and behavioral health care is often overlooked as an important part of both palliative and end-of-life care for older adults. Health care providers on palliative care teams may not have thorough training in managing mental health issues that are frequently present near end of life, and they may benefit from the skills of a psychologist. When not addressed, mental health issues such as depression can cause older adults to feel frustrated and hopeless about their illness. Untreated mental health issues can also make other symptoms worse. For example, anxiety can make it more difficult to breathe.

### **WHAT MENTAL HEALTH ISSUES AND CONCERNS DO SOME OLDER ADULTS FACE NEAR END OF LIFE?**

- Anxiety and depression
- Difficulty adjusting to physical and mental declines
- Agitation, restlessness, and difficulty sleeping
- Memory loss, confusion, and disorientation, which can lead to impaired decision-making
- Existential issues (e.g., concerns about what happens after death, concerns about the meaning of life)
- Previously undetected or undiagnosed Posttraumatic Stress Disorder (PTSD)
- Concerns that they will not get the care they want (e.g., dying in their preferred place/with preferred people)

- Relationship concerns (e.g., how to mend broken relationships, fear of being a burden to family members)
- Communication difficulties (e.g., not knowing how to have discussions with family members and health care providers about the care they do want)
- Concerns about family after their death

### **WHAT WORKS?**

Psychologists trained in end-of-life and palliative care are skilled in helping other health care team members understand older adults' mental health concerns, health care preferences, and personal values. They work with other professionals, such as physicians, nurses, social workers, and chaplains, who also have important roles to play in providing compassionate palliative and end-of-life care to older adults. As part of the care team, the psychologist plays a critical part in diagnosing and treating anxiety, depression, cognitive and decision-making problems, and other mental health distress that may result from serious and life-limiting illnesses.

Psychologists are skilled in helping older adults and their families. They work with older individuals with serious illness and their families to address the mental health issues described above, provide physical symptom management, and help them understand and express their personal choices related to palliative care and end-of-life options. Psychologists are experts in assessing an older adult's capacity to make decisions and then help them to identify and document their values and care preferences. This includes important decisions about feeding tubes, breathing machines, and restarting the heart (CPR). Psychologists can also help the family with bereavement and grief concerns before and after the person's death.

**Psychologists can help improve communication between older adults, their care partners, and other members of the health care team.**

Psychologists can also help improve communication between older adults, their care partners, and other members of the health care team. They can help older adults document their health care choices to share with their care partners in case they are no longer able to communicate, and they can help older adults know what questions to ask of their physicians.

## WHAT CAN YOU DO?

- Listen for complaints of pain, psychological and physical symptoms from older adults that they may need help to manage.
- Help older adults understand the importance of stating and documenting their preferences and values (using the tools listed below) and sharing this information with family members/care partners and health care providers.
- Strive to understand the important role of culture, race, ethnicity, sexual orientation, gender expression, family status and religion for each individual.
- Think about your own beliefs and possible biases related to palliative care and end-of-life care.
- Observe and respect family dynamics and interactions and offer assistance in enhancing communication when appropriate.

## SAYS WHO?

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## WHAT RESOURCES CAN HELP?

- Communication and decision-making tools for older adults and their family members
  - The Conversation Project [theconversationproject.org](http://theconversationproject.org)
  - The University of Sydney Palliative Question Prompt Lists (questions to ask your doctor) [bit.ly/2IMmyZI](http://bit.ly/2IMmyZI)
  - American Bar Association Tool Kit for Advance Care Planning [bit.ly/2kuJ5tT](http://bit.ly/2kuJ5tT)
  - Aging with Dignity *Five Wishes* (advanced care planning document) [fivewishes.org](http://fivewishes.org)
- Communication tools for providers
  - VitalTalk [www.vitaltalk.org](http://www.vitaltalk.org)
  - Tips for Breaking Bad News [palliative.stanford.edu/communication-breaking-bad-news/delivering-bad-news](http://palliative.stanford.edu/communication-breaking-bad-news/delivering-bad-news)
- National Hospice and Palliative Care Organization [www.nhpc.org](http://www.nhpc.org)
- APA Office on Aging End of Life Issues and Care web page [www.apa.org/pi/aging/programs/eol](http://www.apa.org/pi/aging/programs/eol)
- Culturally Diverse Communities and Palliative and End-of-Life Care [on.apa.org/end-of-life-diversity](http://on.apa.org/end-of-life-diversity)

This fact sheet was written by Meghan McDarby, MA, based on the work of the members of the APA Working Group on End of Life Issues and Care: Elizabeth Goy, PhD (Chair), Rebecca S. Allen, PhD, ABPP, Brian D. Carpenter, PhD, Carol J. Gill, PhD, Julia Kasl-Godley, PhD, Maureen E. Lyon, PhD, ABPP, Veronica L. Shead, PhD, & James L. Werth, Jr., PhD, ABPP.



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