



Palliative and End-of-Life Care for Persons Living with Dementia

MODULE 12

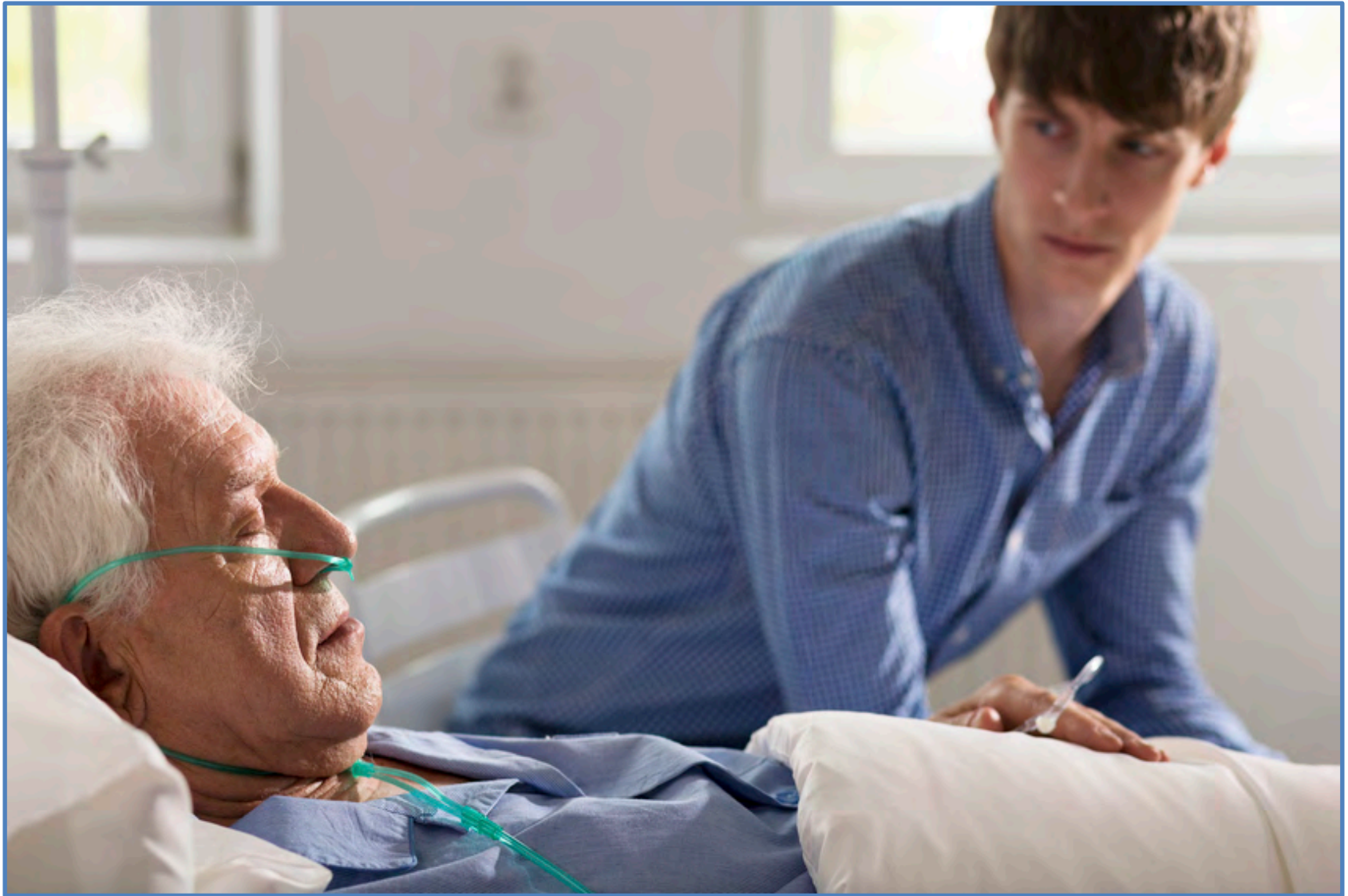


U.S. Department of Health and Human Services
Health Resources and Services Administration
December 2018



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Outline

- End-stage dementia
- Palliative care
- End-of-life issues
- Hospice care





Learning Objectives

After completing this module, participants will be able to:

- List signs and symptoms of end-stage dementia.
- Articulate how palliative care differs from hospice care.
- Explain several end-of-life goals for the persons living with dementia (PLwD).
- Describe the role of the health care team in end-of-life care.





Key Take-Home Messages

- Persons living with late stage dementia should be considered candidates for hospice care.
- Hospice care is a Medicare benefit that requires declining active aggressive therapeutic treatment.
- As dementia progresses and quality of life decreases, the value placed by the person on living longer may change.



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Introduction and Overview

- The estimated length of survival from diagnosis of dementia to death ranges from 3 to 12 years (Sekerak & Stewart, 2014; Todd et al., 2013; Wolf-Klein et al., 2007).
 - Many consider all types of dementia a terminal illness (Mitchell et al., 2009; Wolf-Klein et al., 2007).
 - Survival rates differ depending upon type of dementia.
- Family members, care partners and PLwD may have contradicting sets of goals for end-of-life care: prolong quantity of life at all costs vs. provide pain-free comfort.
 - Palliative care can be provided throughout the course of dementia.
 - Hospice care is usually provided during final 6 months of life.



Manifestations of End-Stage Dementia

- Dementias are progressive, incurable illnesses (Mitchell, 2015).
- Persons living with most types of end-stage dementia have profound memory deficits, minimal verbal abilities, cannot ambulate, are incontinent, and are dependent on others for activities of daily living (ADL) (Mitchell et al., 2009).
 - These manifestations of end-stage dementia are similar for persons diagnosed with Alzheimer's disease, Lewy body dementias, or vascular dementias.
 - Persons living with some forms of end-stage frontotemporal degeneration (FTD) have similar signs and symptoms but a faster progression to death (UCSF Memory and Aging Clinic, 2016).

Manifestations of End-Stage Dementia (continued)

- The most common clinical complications associated with advanced dementia are eating problems, febrile episodes (fevers), and aspiration pneumonia (Mitchell et al., 2009).
- Risk factors for a faster decline include greater functional disability, extrapyramidal symptoms, a history of falls, arterial coronary disease, stroke, and urinary incontinence (Schafirovits-Morillo et al., 2010).
- PLWD should undergo more frequent monitoring during the end stage, especially if they are on medications (Schafirovits-Morillo et al., 2010).

End-of-Life Goals

- End-of-life goals may differ for PLwD vs. care partners.
- Goals may be curative or comfort-based.
- It is important to educate all about terminal nature of dementia (Rose & Lopez, 2012; Sekerak & Stewart, 2014).
- End-of-life goals for PLwD encompass many issues (Mitchell et al., 2009; Mitchell, 2015).
- Need to perform risk/benefit analysis regarding value of hospitalizations in end-stage dementia (Rose & Lopez, 2012).



Behavioral and Psychological Symptoms of End-Stage Dementia

- Behavioral and psychological symptoms of dementia may become more prominent in advanced dementia (Sekerek & Stewart, 2014).
- New onset or acute behavioral problems are usually indicative of a new problem (Sekerek & Stewart, 2014).
- Agitation requires prompt attention and evaluation; management should begin with nonpharmacologic interventions.
- PLwD should be assessed for sleep problems, delirium, and pain.

Role of the Health Care Team During End-of-Life Care

- Interprofessional dementia care team responsible for helping PLwD and family/care partners understand and accept terminal nature of dementia (Hildreth & Church, 2015)
- Care team has many roles during end-of-life care, and specific responsibilities will depend upon composition of team (Hildreth & Church, 2015; Tilly & Fok, 2007)



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Continuum of Care for PLwD

- Continuum of care progresses to comfort care, end-of-life care, and bereavement counseling for family/care partners.
- There is a difference between palliative and hospice care.
- Care partners should be included in all decisions regarding end-of-life care, as appropriate (Davies et al., 2014).



Defining Palliative Care

- Palliative care provides relief from distressing symptoms, help with medical decision-making, emotional and spiritual support, and care coordination.
- The World Health Organization (WHO) defines palliative care as “an approach that improves the quality of life of patients and their families facing the problem 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” (WHO 2016).

Distinguishing Palliative Care from Hospice Care

	Palliative Care	Hospice Care
Goal of Care	Pain relief, help with medical decision-making, symptom management, emotional support	Pain relief, symptom management, emotional support
Curative Treatments	YES	NO
Eligibility Criteria	None; anyone with serious illness is eligible	PLwD must be certified by physician as having less than 6 months to live to meet Medicare and private insurance criteria
Interventions	Alleviating pain, treating infections and other symptoms	Alleviating pain and symptoms (may be more aggressive than with palliative care)

Palliative Care Addresses Quality-of-Life Issues

- Non-palliative care is common during end-stage dementia.
- It is important for PLwD and their care partners to inform providers of their requests regarding palliative care.
- Palliative care emphasizes improving quality-of-life issues and relieving suffering.
- Palliative care offers “an opportunity to provide care to patients with dementia who may not qualify for hospice until late in the disease but may have substantial unmet palliative care needs” such as for pain management (Torke et al., 2010).

Where and by Whom Palliative Care is Provided

- Palliative care can be provided in the home, in hospitals, and in skilled nursing and assisted living facilities.
- Care is provided by an interprofessional team.
- Palliative care emphasizes pain management and at least the initial management of behavior and mood issues.
- PLwD with behavioral disturbances should be assessed for delirium and pain, and empirical treatment of pain is often warranted (Merel et al., 2014).

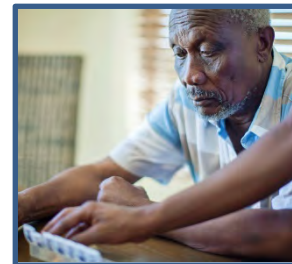
Barriers to the Use of Palliative Care

- Families may believe PLwD will improve.
- Providers and care partners may lack knowledge about palliative services.
- Barriers may involve financial concerns about payment and insurance coverage.
- PLwD may not be able to communicate symptoms (pain) that could be addressed by palliative care (Hildreth & Church, 2015; Albrecht et al., 2013).
- Palliative care may not be covered by public or private insurance.



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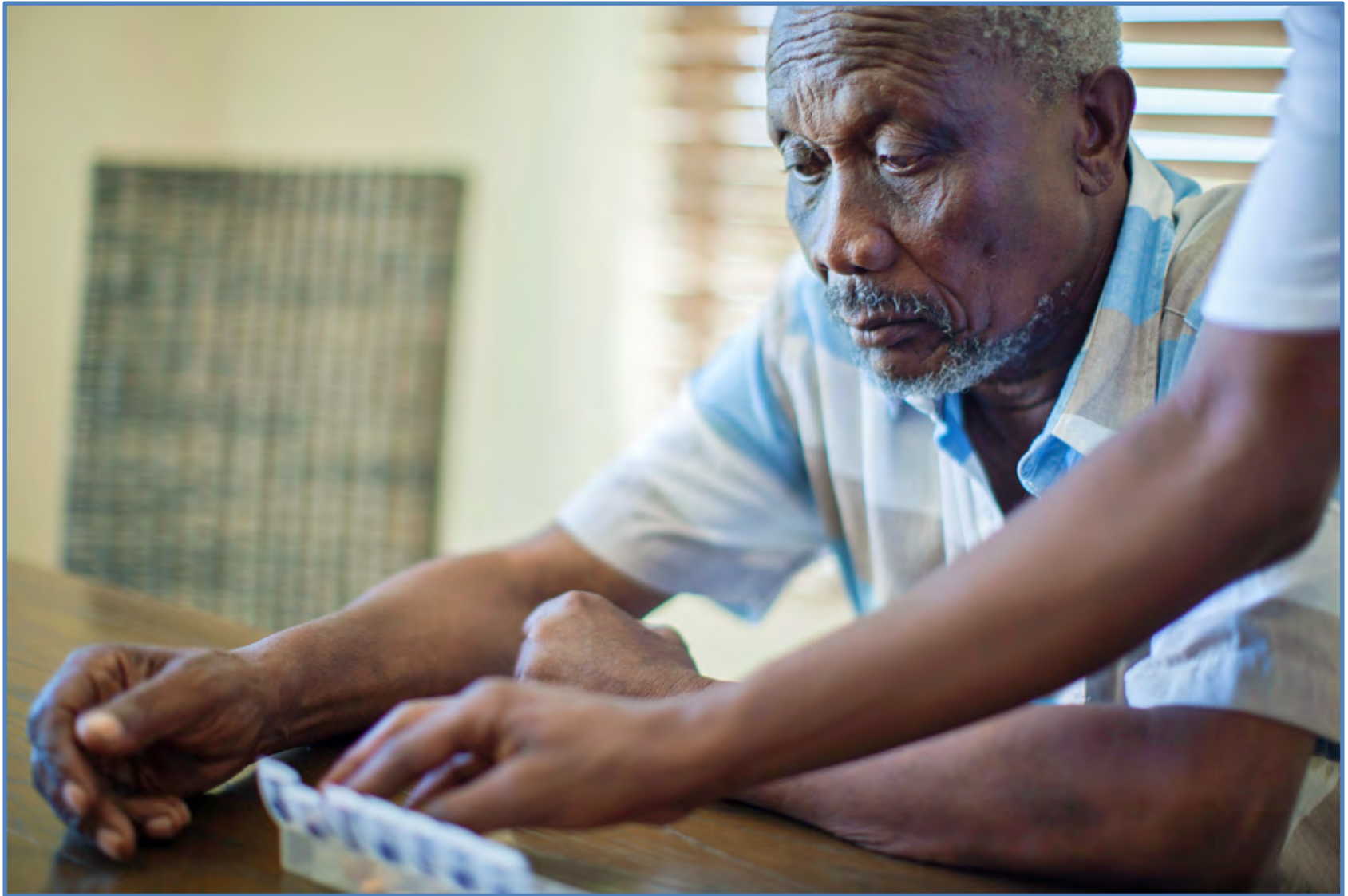


The Role of Percutaneous Endoscopic Gastrostomy Feeding Tubes in Advanced Dementia

- PLwD at end-stage have swallowing and feeding difficulties.
- One means for assisting with feeding is the use of percutaneous endoscopic gastrostomy (PEG) feeding tubes.
- Care partners require sufficient objective information to make informed decisions regarding feeding tubes.
- Providers need to understand risks and benefits of tube feeding before recommending it (Friedrich, 2013).
- There is little evidence supporting the use of feeding tubes (Peck et al., 2014).
- American Geriatrics Society (AGS) does not recommend PEG feeding tubes for older adults with advanced dementia (AGS, 2014).
- Parenteral hydration has benefits and limitations (Arcand, 2015).
- Providing objective information can reduce conflicts about these decisions (Hanson et al., 2011).
- Family members, care partners, and/or professional guardians may choose to go against provider advice (Jox et al., 2012).

Medication Management

- Medication use needs to be in accordance with the established goals of the PLwD (Mitchell, 2015) and consistent with standards of care in the absence of established goals.
 - Medications that are inappropriate or have questionable benefit should be eliminated (Mitchell, 2015; Tjia et al., 2010; Tjia et al., 2014a).
 - Many PLwD in nursing homes receive medications that are considered “never appropriate” in advanced dementia (Tjia et al., 2010).
- Statins, cholinesterase inhibitors, and memantine are inappropriate for PLwD in advanced stage (Tjia et al., 2014a; Tjia et al., 2014b).



Medical and Psychiatric Issues

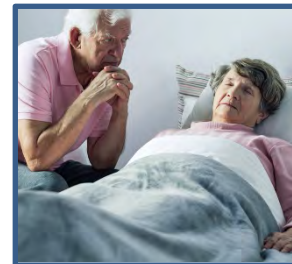
- The most common medical concerns for persons with advanced dementia involve pain, incontinence, infection, and pressure ulcers.
- Pain is common during the last weeks of life for PLwD (Hendriks et al., 2013).
 - Pain is difficult to assess.
 - PLwD often receive suboptimal dosages when treated with opioid medications for pain (Hendriks et al., 2013).
- Infections are very common (Mitchell, 2015), particularly pneumonia (Chen et al., 2006).
 - Antibiotics for infections may not be in accord with the advanced directives.
 - Providers need to follow standard of care before administering antibiotics (Chen et al., 2006; Nicolle et al., 2005).
- Antipsychotics are often administered to manage agitation, but have a black box warning for use in PLwD.
- Restraints should not be used for PLwD (Sloane et al., 2008).





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Hospice Care

- Hospice care is a type of palliative care that is instituted at the end of life.
- There are specific Medicare and/or Medicaid eligibility criteria for hospice.
- Despite many benefits of enrollment in hospice (Miller et al., 2012; Miller et al., 2001; Kiely et al., 2010; Miller et al., 2002), in 2013 only 16% of enrollees in hospice had a primary diagnosis of dementia (NHPCO, 2017).

When to Consider Hospice Care

- Hospice criteria for dementia are based on progression of Alzheimer's disease (NHPCO, 2017).
- There are many signs and symptoms of end-stage dementia that suggest consideration of hospice.
- PLWD who cannot walk, bathe, or dress independently may be closer to hospice enrollment.



When to Consider Hospice Care in Persons with End-Stage FTD

- Persons with end-stage FTD are generally younger and healthier than persons with other types of end-stage dementia.
- As with other dementias, FTD is often not recognized as a terminal diagnosis.
- End-stage FTD may “look different” than other advanced dementias (Mioshi et al., 2010; UCSF, 2016).

Barriers to Acceptance of Hospice Care

- Dementia is not always perceived as a terminal illness, so hospice is often not considered (Sloane et al., 2008).
- Many families and providers lack awareness of hospice benefits and availability (Torke et al., 2010).
- Family members whose goals are for prolonging life may be resistant to the idea of hospice (Rose & Lopez, 2012; Sekerak & Stewart, 2014).
- Some provider agencies of services to persons living with dementia and intellectual disability believe that there is a barrier to securing Medicaid-covered hospice care when the person is already receiving Medicaid covered housing and treatment services (Friedman, Helm, & Woodman, 2012).

Prognostication Difficulties Associated with Hospice Care

- Hospice care can be instituted when the person is judged to have 6 months or less left to live.
- National Hospice and Palliative Care Organization (NHPCO) criteria for hospice eligibility includes a FAST stage 7 score and at least one complication (NHPCO, 2017).
 - However, Functional Assessment Staging Tool (FAST) criteria may not be accurate in PLwD (Brown et al., 2012; Mitchell et al., 2010b).
 - Common prognostic variables involve nutrition/nourishment or eating habits, increased risk on dementia severity scales, and comorbidities (Brown et al., 2012).
 - An alternative option is the Advanced Dementia Prognostic Tool (ADEPT) tool (Mitchell et al., 2010a).
- Regardless of criteria used, it is difficult to predict 6-month mortality in PLwD (Sekerak & Stewart., 2014).



Differences in Hospice Care by Setting

- Hospice can be provided at home or in a nursing home, hospital, or freestanding hospice facility.
- Hospice care is not available in all states for persons in assisted living facilities.
- A home hospice program can work in conjunction with one or more trained family members or care partners to provide hospice care.
 - Medical care and coordination
 - Palliative but not curative medications

End-of-Life Care for PLwD from People of Color and Other Groups

- Little is known about how diverse populations approach end-of-life treatment decisions (Bonner et al., 2014).
- End-of-life care approaches are more similar than different between different ethnic groups (Connolly et al., 2012).
- Provider agencies for persons living with dementia and intellectual disability are often unaware of generally accepted practices for end-of-life care (McCarron et al., 2018).
- The American Association on Intellectual and Developmental Disabilities has a position statement on end-of-life care that should be consulted with contending with end-of-life dementia care decisions (AAIDD, 2012)

Care Partner Issues During End-Stage Dementia

- Providers can advise family members to consider bereavement counseling.
- The psychological distress of care partners for persons with end-stage dementia is equivalent to that for care partners of persons with advanced cancer (Costa-Requena et al., 2015).



Evaluation

1. **A person with end-stage dementia:**
 - a. May be able to ambulate without assistance
 - b. Has profound memory deficits
 - c. May retain bowel but not bladder continence
 - d. May be able to verbalize basic needs

2. **In which of the following ways does hospice care differ from palliative care?**
 - a. Only palliative care offers pain relief and management
 - b. Only hospice care offers pain relief and management
 - c. Only hospice care has specific eligibility requirements
 - d. Only palliative care offers emotional support



Evaluation (continued)

3. **Evidence-based care consistently recommends which of the following for persons living with end-stage dementia?**
 - a. Percutaneous endoscopic gastrostomy (PEG) feeding tubes
 - b. Antibiotics for treatment of pneumonia
 - c. Aggressive pain management
 - d. Parenteral hydration

4. **The health care team providing end-of-life care for a person with dementia should:**
 - a. Continue to recommend curative treatments for all medical concerns
 - b. Ensure medical treatments are consistent with the person's end-of-life goals
 - c. Recommend anxiolytics to help calm the person
 - d. All of the above



Acknowledgements

This module was prepared for the U.S. Department of Health and Human Services (HHS), Health Resources and Services Administration (HRSA), by The Bizzell Group, LLC, under contract number HHS25034002T/HHS250201400075I.

The dementia and education experts who served on the Dementia Expert Workgroup to guide the development of the modules included: **Alice Bonner, PhD, RN, FAAN**, Secretary Elder Affairs, Massachusetts Executive Office of Elder Affairs, Boston MA; **Laurel Coleman, MD, FACP**, Kauai Medical Clinic -Hawaii Pacific Health, Lihue, HI; **Cyndy B. Cordell, MBA**, Director, Healthcare Professional Services, Alzheimer's Association, Chicago, IL; **Dolores Gallagher Thompson, PhD, ABPP**, Professor of Research, Department of Psychiatry and Behavioral Sciences, Stanford University School of Medicine, Stanford, CA; **James Galvin, MD, MPH**, Professor of Clinical Biomedical Science and Associate Dean for Clinical Research, Florida Atlantic University, Boca Raton, FL; **Mary Guerriero Austrom, PhD**, Wesley P Martin Professor of Alzheimer's Disease Education, Department of Psychiatry, Associate Dean for Diversity Affairs, Indiana University-Purdue University Indianapolis, Indianapolis, IN; **Robert Kane, MD**, Professor and Minnesota Chair in Long-term Care & Aging, Health Policy & Management, School of Public Health, University of Minnesota; **Jason Karlawish, MD**, Professor of Medicine, Perelman School of Medicine, University of Pennsylvania; **Helen M. Matheny, MS, APR**, Director of the Alzheimer's Disease Outreach Program, Blanchette Rockefeller Neuroscience Institute, Morgantown, WV; **Darby Morhardt, PhD, LCSW**, Associate Professor, Cognitive Neurology and Alzheimer's Disease Center and Department of Preventive Medicine, Northwestern University Feinberg School of Medicine, Northwestern University, Chicago, IL; **Cecilia Rokusek, EdD, MSc, RDN**, Assistant Dean of Research and Innovation, Professor of Family Medicine, Public Health, Nutrition, and Disaster and Emergency Preparedness, College of Osteopathic Medicine, Nova Southeastern University, Fort Lauderdale, FL. Additional expertise in the development of the modules was provided by **Meg Kabat, LCSW-C, CCM**; **Eleanor S. McConnell, PhD, MSN, RN, GCNS, BC**; **Linda O. Nichols, PhD, MA, BA**; **Todd Semla, MS, PharmD, BCPS, FCCP, AGSF**; **Kenneth Shay, DDS, MS**, from the U.S. Department of Veterans Affairs and **Seth Keller, MD** and **Matthew P. Janicki, PhD**, National Task Group on Intellectual Disabilities and Dementia Practices.

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