

**FACULTY GUIDE**

**Core Module 12:**

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

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**Slide 1:**

- Providing optimal end-of-life care for persons living with dementia is challenging for providers as well as the care partners and family. This module will address how to identify when persons living with dementia are in end-stage dementia and will address the medical concerns that arise during this final stage. In addition, the module will explain the difference between palliative and hospice care.

**Slide 4:**

- In this module (12), we will be examining the issues surrounding advanced dementia and end-of-life care. We continue to focus on persons living with dementia who reside at home.

**Slide 5:**

- 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 persons living with dementia (PLwD).
- Describe the role of the health care team in end-of-life care.

**Slide 7:**

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

**Slide 8:**

- We begin with a brief discussion of end-stage, or advanced, dementia. We note that the literature uses the terms “late-stage,” “end-stage,” and “advanced” dementia interchangeably to describe the final phase of dementia characterized by profound cognitive and physical disability.

**Slide 9:**

- The estimated length of survival from diagnosis of dementia to death ranges from 3 to 12 years:
  - For many investigators, researchers, and providers, dementia can be considered a terminal illness.
  - Survival rates differ depending upon the type of dementia. Also, disease severity does not always dictate survival rates.
- There are two opposing sets of goals that persons living with dementia and their care partners and loved ones often express regarding end-of-life care: (1) do everything possible to prolong quantity of life versus do what is possible to minimize pain, and (2) provide comfort at the end of life.

- Palliative care provides relief from distressing symptoms and helps with medical decision-making, emotional and spiritual support, and care coordination. It plays an important role in dementia care at all stages of dementia, not just at the late stage.
- Hospice care is a type of palliative care that is often invoked at the end of life (typically final 6 months).

**Slide 11:**

- Dementias are progressive, incurable illnesses.
- Persons living with end-stage dementia typically have profound memory deficits, minimal verbal abilities, difficulties ambulating independently, inability to independently perform any activities of daily living, and urinary and/or fecal incontinence. This is true of persons diagnosed with most types of dementia—including Alzheimer’s disease, Lewy body dementias, and vascular dementias.
- As with Alzheimer’s disease and other dementias, persons with end-stage frontotemporal degeneration (FTD)—which is also known as frontotemporal disorder, frontotemporal dementia, or frontotemporal lobar degeneration—may have trouble with ambulation and require a wheelchair. The person with end-stage FTD may have difficulty swallowing, chewing, and moving, along with bowel and/or bladder incontinence. The time from diagnosis to death is typically about 5 years, although it can vary widely depending upon the type of FTD.

**Slide 12:**

- The most common clinical complications associated with advanced dementia are eating problems, febrile episodes (fevers), and aspiration pneumonia:
  - Results from the Choices, Attitudes, and Strategies for Care of Advanced Dementia at the End-of-Life (CASCADE) study demonstrate that after adjusting for age, sex, and disease duration, the 6-month mortality rate for nursing home residents who had pneumonia was approximately 47 percent, 45 percent for persons with febrile episodes, and 39 percent for persons with dementia with eating problems.
  - In addition, distressing symptoms such as dyspnea (46 percent) and pain (39 percent) were common in this population.
- Risk factors for a faster decline include greater functional disability, extrapyramidal symptoms, a history of falls, arterial coronary disease, stroke, and urinary incontinence.
- Persons living with dementia should undergo more frequent monitoring during the end stage, especially if they are on medications.

**Slide 13:**

- The persons living with dementia and the care partners may have disparate end-of-life care goals. The goals may be curative or comfort-based:
  - Although dementia is incurable, persons living with dementia and/or the care partners may not understand or accept this prognosis. In these cases, their goals may be curative—to agree to any treatment for any concomitant disease or condition. Comfort-based goals recognize the terminal nature of dementias and limit treatments to those that minimize discomfort.

- It can be challenging for a provider to manage cases where the goals of the persons living with dementia are not in concordance with those of the care partners.
- As we discussed in Modules 4 and 11, the importance of having advance planning discussions and directives in place soon after the diagnosis cannot be underestimated. In the absence of advance planning documents, educating the care partner, proxy decision-maker, and/or family members about the terminal nature of a dementia diagnosis becomes especially important.
- End-of-life issues facing persons living with dementia may include:
- Management of eating and swallowing problems—up to 90 percent of persons living with end-stage dementia will have eating problems
  - Management of infections
  - Management of incontinence
  - Pain relief
  - Relief from agitation, hallucinations, delusions, depression, and delirium
  - Reducing potential for pressure ulcers
  - Medication management, which can include:
    - Discontinuing medications that do not contribute to quality of life
    - Relying on standard of care for determining whether a medication is deemed appropriate for an older person with dementia
    - Changing the method of administration to improve a person’s ability to take medication
- Another issue surrounding care for persons living with end-stage dementia concerns a risk-benefit analysis of whether or not to hospitalize for care for acute medical issues (such as pneumonia and other infections). For many persons, the risks and disadvantages often outweigh the benefits for persons with end-stage dementia. We address this issue shortly.

**Slide 15:**

- Behavioral and psychological symptoms of dementia may become even more prominent in advanced dementia:
  - Behavioral problems generally abate during the last few months of life.
  - At this point, persons living with dementia may demonstrate more passivity, lethargy, and apathy instead of agitation, with fewer delusions and hallucinations.
  - However, there may be greater resistance to care.
- New onset or acute behavioral problems are usually indicative of a new problem, such as an injury, infection, or illness.
- Agitation is predominantly a sign of distress, which requires prompt attention. It may represent fear, pain, discomfort (such as constipation), or infection. By end-stage dementia, many—if not most—persons living with dementia are non-verbal but will demonstrate agitation in other ways.
- Physical touch or hands-on care may be overwhelming to the person living with end-stage dementia. As such, it may be preferable to limit their showers to every other day, and reschedule bathing routines until times when they are more relaxed and tolerant.
- Nonpharmacologic interventions to manage agitation are preferable, but not always feasible. We discussed many of these approaches in Modules 5 and 6. Pharmacotherapy—such as neuroleptics—may be necessary to manage fearfulness or agitation in some instances. In such

cases, providers are often instructed to start slow and titrate gradually, but to avoid dosages that are too sedating.

- Sleep issues may worsen but may respond to sleep hygiene measures.
- Delirium may be a source of many acute behavioral changes. Care partners and providers need to ensure treatment decisions are consistent with the pre-established goals of care.
- Pain is a common complaint. Studies show that persons living with dementia receive less analgesic medications than those without dementia, even if they have a similar pain condition. If pain medication is warranted, it should be administered on a schedule as many persons living with end-stage dementia are unable to ask for as-needed medications.

**Slide 16:**

- The interprofessional dementia care team is responsible for preparing the care partners and family members for the eventual need for hospice care for persons living with dementia. In many cases, the care team must be prepared to help the care partner and family members understand and accept the terminal nature of dementia.
- There are many aspects to providing end-of-life care, and the division of responsibility will depend upon the specific members of the person's health care team. In general, the roles of the health care team include the following:
  - Help find quality hospice care or palliative care in a timely fashion.
  - Certify or recertify a terminal diagnosis or a prognosis of 6 months or less for Medicare hospice eligibility.
  - Meet with hospice team and family to create an individualized care plan.
  - Establish, review, or revisit goals of care, in conjunction with a recent assessment of the patient's health and functional status.
  - Be aware of how persons living with dementia may use behaviors to communicate nonverbally.
  - Provide evidence-based guidance regarding the risks and benefits of specific medical interventions, taking into consideration the person's end-of-life goals:
    - Tube feeding
    - Antibiotics
    - Laboratory tests
    - Respirator use
    - Intravenous (IV) hydration
    - Cardiopulmonary resuscitation (CPR)
    - Hospital transfers
  - Explain the process of active dying to the care partner and family.

**Slide 17:**

- We now focus on the role of palliative care.

**Slide 18:**

- Comfort care, end-of-life care, and bereavement counseling are important parts of the continuum of care.

- Palliative care, which we will be discussing next, may be appropriate at any point during the course of treating persons living with dementia.
- Hospice care, which we discuss later, is only available for individuals with end-stage dementia (or other conditions) who are determined to have less than 6 months to live.
- The health care team has an important role to play in helping family members make informed end-of-life decisions for persons living with dementia.
- The care partner(s) should be included in all decisions, and providers need to be aware of the additional burdens of end-stage dementia on care partners.

**Slide 20:**

- 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”.
- Palliative care:
  - Provides relief from pain and other distressing symptoms
  - Affirms life and regards dying as a normal process
  - Intends neither to hasten nor postpone death
  - Integrates the psychological and spiritual aspects of patient care
  - Offers a support system to help patients live as actively as possible until death
  - Offers a support system to help the family cope during the patient’s illness and in their own bereavement
  - Uses a team approach to address the needs of patients and their families, including bereavement counseling, if indicated
  - Will enhance quality of life, and may also positively influence the course of illness
  - Is applicable early in the course of any serious illness

**Slide 21:**

- Palliative care differs from hospice care.
- Palliative care is an option for anyone with a serious illness, regardless of life expectancy.
- Curative treatment for concomitant medical concerns may continue while palliative care is being provided for persons living with dementia.
- Hospice is for individuals in the final stage of a disease for whom curative treatment is no longer provided.

**Slide 22:**

- Non-palliative care is quite common in persons in the late stages of dementia:
  - This generally includes the use of medications or treatments that aim to cure a concomitant illness (dialysis, antibiotics, statins) or prolong quantity of life (such as with feeding tubes). We discuss this shortly.

- Preplanning and communication among members of the care team and the care partners can ensure that palliative care is provided when needed.
- Palliative care emphasizes improving quality of life and relieving suffering. It involves:
  - Having pain aggressively treated
  - Spending time with loved ones
  - Desires related to feeding and hydration
  - Desires related to treatment of illnesses such as infections or pneumonia
  - Staying in a preferred location (home vs. in the hospital)
  - 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.

**Slide 23:**

- 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 that typically includes a palliative care doctor, a nurse, and a social worker, along with other providers as needed, such as a pharmacist, therapist, or dietitian:
  - Some palliative care treatments, medications, and services may be covered by Medicare, Medicaid, or private insurance programs.
  - Providers can help persons living with dementia and/or the care partners find out what services and treatments are covered or not covered by their specific plan.
- Primary care providers should be proficient in basic discussions surrounding prognosis and goals of care, and advance care planning.
- Palliative care emphasizes avoidance of polypharmacy (when possible), pain management, and at least the initial management of behavior and mood issues.
- Persons living with dementia with behavioral disturbances should be assessed for delirium and pain, and empirical treatment of pain is often warranted.

**Slide 24:**

- Some families believe that persons living with dementia can and will improve.
- Providers and care partners may lack knowledge about palliative services.
- Barriers to the use of palliative care can be financial—specifically associated with insurance reimbursement issues.
- A full interprofessional palliative care team may not be available, especially in rural and medically underserved areas.
- Persons living with dementia may lack the ability to communicate about their symptoms (such as pain) and treatment effects:
  - Providers can assess for pain using validated behavioral observational scales.

### Slide 25:

- End-of-life issues for persons living with dementia focus predominantly on feeding issues, medication management—particularly for infections and psychiatric concerns, management of delirium and of pain.
- Providers should approach these issues from an evidence-based perspective.
- Providers need to be aware that the choices around tube feeding, lab tests, and restraints can be particularly difficult and emotional for care partners:
  - For example, tube feeding in advanced dementia generally does not prolong life and, in fact, promotes infections and restraints.
  - Another example is that physical and chemical restraints are considered to be not good care, except in rare emergency situations.
  - Also, at a certain point antibiotics do NOT prolong life. Further, for many persons living with end-stage dementia, prolonging life may not be the desired goal.

### Slide 26:

- Persons with end-stage dementia have swallowing and feeding difficulties that can predispose them to weight loss, malnutrition and aspiration pneumonia. There are both physiologic reasons underlying this, as well as the challenges associated with feeding themselves.
- One means for assisting with feeding is the use of percutaneous endoscopic gastrostomy (PEG) feeding tubes.
- Many care partners are not provided with sufficient information to make informed decisions regarding insertion of PEG tubes for persons living with end-stage dementia.
- Providers need to understand the risks and benefits of PEG tube feeding before recommending it.
- There is little evidence supporting the use of nasogastric or PEG tubes for persons with advanced dementia.
- The American Geriatrics Society (AGS) 2014 position statement notes that PEG tubes are not recommended for older adults with advanced dementia:
  - Tube feeding is associated with agitation, increased use of physical and chemical restraints, and worsening pressure ulcers.
  - Hand feeding is preferred.
  - Studies have shown tube feeding is associated with medical and other patient burdens. It has not been shown to prevent aspiration, improve nutritional status, or decrease mortality in persons with advanced-stage dementia.
- Parenteral hydration may help during end-stage dementia, but may also contribute to discomfort. Withholding or withdrawing artificial nutrition and hydration is generally not associated with manifestations of discomfort for persons with adequate oral care.
- Providing objective information about feeding problems and potential solutions has been shown to reduce conflict about decisions, but evidence suggests there may be differences between family and professional guardians in making the decisions—with families far less likely to provide consent. Providers need to recognize that this can be a highly emotionally charged issue for families who believe that PEG is the only available option to keeping the person alive, but the provider has a responsibility for strongly advising against the PEG option in most cases.



**Slide 27:**

- Medication use needs to be in accordance with the established goals of persons living with dementia (Mitchell, 2015), and consistent with standards of care in the absence of established goals:
  - Medications that afford questionable benefit should be eliminated.
  - Inappropriate medications include cholinesterase inhibitors, memantine, and statins.
  - As discussed in Module 8, other medications that may not be appropriate for persons living with end-stage dementia include antibiotics and antipsychotics.
  - Providers can check the 2015 AGS Updated Beers Criteria for Potentially Inappropriate Medication Use in Older Adults for additional guidance.
- There are few studies on appropriate and inappropriate use of medications among persons living with end-stage dementia residing at home. Consequently, we must rely on information on persons living with end-stage dementia in long-term care facilities.
- A study on persons residing in nursing homes with dementia found that more than one in three residents received at least one medication considered “never appropriate” in advanced dementia:
  - Acetylcholinesterase inhibitors (16 percent) and lipid-lowering agents (12 percent) were the most common inappropriate drugs.
  - More than one in four residents took antipsychotics daily.
  - Many persons with dementia remain on drugs long past their original indications.
- Another study noted that although statin use neither prolongs life nor promotes comfort, 17 percent of more than 10,200 nursing home residents with advanced dementia were receiving statin drugs.

**Slide 29:**

- The most common medical concerns for persons with advanced dementia involve pain, incontinence, infection, and pressure ulcers. We have covered this in greater detail in Module 7 and Module 8.
- Pain is the most common symptom during the last weeks of life for persons living with end-stage dementia:
  - However, pain is difficult to assess.
  - Other common complaints are agitation and shortness of breath.
  - Pain and shortness of breath are predominantly treated with opioids, and agitation with anxiolytics.
  - Evidence suggests that many persons with end-stage dementia who have pain receive suboptimal (or too low) dosages of opioid medications and thus remain symptomatic during their last days.
- Infections are very common in persons with advanced dementia:
  - Persons with end-stage dementia are frequently treated with antibiotics, even though it is often contradictory to their stated preferences.
  - Many persons living with end-stage dementia are treated with antibiotics for asymptomatic bacteriuria, although this is not standard of care. According to the Infectious Diseases Society of America (IDSA) guidelines, treatment of asymptomatic

bacteriuria has not been shown to improve outcomes or decrease the frequency of symptomatic infection, and antibiotic treatment is discouraged in older adults.

- Agitation is often treated with antipsychotics, although (as mentioned in Module 8) there is a black box warning regarding the use of atypical (second-generation) antipsychotics in persons with dementia because of increased risk of death. A boxed warning, often called a “black box” warning, is issued by the Food and Drug Administration and placed on the first page of the package insert for specific prescription drugs identifying potential safety concerns.
- Physical restraints should be avoided. Care partners are recommended to use nonpharmacologic interventions, discussed in Modules 5 and 6, whenever possible; as noted in Modules 7 and 8, medications may be necessary in some instances.

**Slide 31:**

- We end this module with a discussion of hospice.

**Slide 32:**

- Hospice care is a type of palliative care that is often invoked at the end of life. It is not a place but a type of medical care given to terminally ill persons facing end-of-life events.
- In order to be eligible to elect hospice care under Medicare, an individual must be entitled to Part A of Medicare and be certified as being terminally ill by a physician and having a prognosis of 6 months or less if the disease runs its normal course.
  - Medicare covers hospice care for patients with a prognosis of  $\leq 6$  months, but the person can remain for longer than 6 months if the physician recertifies that the person is terminally ill:
  - Medicare hospice benefits cover all services, medications, and equipment related to the illness, including physician and nursing services, home health aides, medical appliances/medications/supplies, spiritual, dietary, and other counseling.
  - Continuous home care or inpatient care is provided during crisis periods, as are trained volunteers, bereavement services, social work services, inpatient respite, and 24/7 on-call support.
  - Medicaid also covers hospice in almost all states and the District of Columbia (DC), as does the military Tricare program.
- Persons who were enrolled in hospice had:
  - Lower risk of dying in hospital
  - Lower risk of being hospitalized in the final 30 days of life
  - Higher frequency of treatment for pain and dyspnea
- In 2013, only 16 percent of enrollees in hospice had a primary diagnosis of dementia.

**Slide 33:**

- Hospice criteria for dementia are based on progression of Alzheimer’s disease.
- For persons to be eligible for hospice under Medicare, they must be entitled to Part A of Medicare and be certified as terminally ill by a physician and have a prognosis of 6 months or less if the disease runs its normal course.
- Signs and symptoms of end-stage dementia that suggest consideration of hospice include:
  - Recurrent aspiration pneumonia

- Recurrent urinary tract infection
- Dysphagia
- Immobility
- Cachexia
- Agitation
- Incontinence of bowel and bladder
- Once certified, hospice should also be considered if persons living with dementia are unable to walk, bathe, or dress independently.

**Slide 35:**

- As we discuss shortly, it is very difficult to prognosticate end-of-life for any type of dementia.
- Persons with frontotemporal degeneration (FTD) have additional barriers for hospice admission, in that they are generally younger persons with fewer comorbid conditions. In addition, FTD (along with other dementias) is not recognized as a terminal diagnosis.
- Persons with FTD are not likely to have prominent memory impairments during end-stage disease. Some may be able to ambulate, and therefore do not necessarily “look like” they are in end-stage disease. However, many will require a wheelchair, and at some point all will likely have bowel and bladder incontinence and difficulty swallowing and chewing.

**Slide 36:**

- Because dementia is not always perceived as a terminal illness, families, care partners, and providers do not seek hospice care as early as they might with other terminal illnesses.
- A major barrier to use of hospice care is lack of awareness of the option by families and referring providers.
- Many hospice programs for persons living with dementia are underutilized, or are utilized very late in the process.
- Family members may have prolonging life as the primary goal. In some cases, providers might suggest a compromise intervention—such as treating the persons living with dementia for pneumonia but not hospitalizing the person, or hand feeding the person living with end-stage dementia instead of tube feeding.

**Slide 37:**

- 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 include:
  - FAST (Functional Assessment Staging Tool) stage 7 (dependence in all ADLs, incontinence, minimal speech), **and**
  - One or more of following complications:
    - Aspiration pneumonia
    - Upper urinary tract infection (UTI)
    - Recurrent fever or infection after course of antibiotics
    - Sepsis
    - Stage 3 or 4 pressure ulcers
    - Weight loss >10 percent in prior 6 months
    - Albumin <2.5 g/dL

- However, FAST criteria have been criticized as being limited in persons with dementia:
  - Majority of studies concur that the FAST 7 criterion is not a reliable predictor of 6-month mortality for elderly people with advanced dementia
  - Most common prognostic variables involve nutrition/nourishment or eating habits, followed by increased risk on dementia severity scales, and comorbidities
- The Advanced Dementia Prognostic Tool (ADEPT) tool uses length of stay, age, male gender, dyspnea, pressure ulcers, total functional dependence, bedfast, insufficient food intake, bowel incontinence, body mass index (BMI), weight loss, and congestive heart failure to predict 6-month survival based on a retrospective study examining variables that predicted survival in nursing homes.
- Regardless of the criteria, it is challenging to predict 6-month mortality in persons living with dementia.
- Care planning strategies—talking with person and care partners early, after diagnosis about end-of-life issues and decisions—can minimize risk of overly aggressive interventions. Many persons and/or care partners never even discuss prognosis with their physician.

**Slide 39:**

- Hospice can be provided in the home or in a nursing home, hospital, or freestanding hospice facility. It can also be provided in some, but not all, assisted living facilities:
  - Hospice care is not available in all states for persons in assisted living facilities, and some assisted living facilities will not allow a person to remain there at the end of life—the person will have to be transferred elsewhere to die.
  - Some nursing homes have a dedicated hospice unit.
  - Providers should be aware of any cost factors associated with hospice care.
- Home:
  - One or more trained family members or friends provide most of the hospice care.
  - The hospice program handles:
    - Home visits to provide medical care and additional services, including help with personal care
    - 24/7 emergency phone consultations
    - Medication (palliative but not curative)

**Slide 40:**

- Little is known about how diverse populations approach end-of-life treatment decisions.
- End-of-life care approaches are more similar than different between different ethnic groups:
  - There may be differences in approaches to life-sustaining treatments.

**Slide 41:**

- Providers can advise family members to investigate if their hospice provider offers bereavement counseling; many hospice providers do.
- Research has shown that the psychological distress of care partners for persons with end-stage dementia is equivalent to that for persons with advanced cancer. Both sets of care partners experience similarly high levels of distress and burden symptoms. It is important for providers to

ensure that the care partners are receiving appropriate support to continue being able to provide care for persons living with end-stage dementia.

- If bereavement services are not available through the hospice program, care partners can be directed towards other bereavement or grief counseling support services listed in the resource section of this module.

**Slide 42:**

These items are provided to allow faculty to evaluate what students have learned. The items can be used in several ways including given at the end of the lecture to assess knowledge or as a pre posttest to assess knowledge gain. These items have face validity. Psychometric testing was not conducted on these items.

Answers:

1. b. Has profound memory deficits
2. c. Only hospice care has specific eligibility requirements

**Slide 43:**

Answers:

3. c. Aggressive pain management
4. b. Ensure medical treatments are consistent with the person's end-of-life goals