

# **483.25 Quality of Life (F309 End of Life)**

Surveyor Train the Trainer:  
Interpretive Guidance  
Investigative Protocol

## **483.25 End of Life**

**Each resident must receive and the facility must provide the necessary care and services to attain or maintain the highest practicable physical, mental, and psychosocial well-being, in accordance with the comprehensive assessment and plan of care.**



# Intent (cont'd)

The intent of this regulation is to promote the physical, mental and psychosocial well-being of residents approaching the end of life, the facility and the practitioners, to the extent possible:

The intent is operationalized by:

Identifying the resident's prognosis and the basis for it, and initiating discussions/considerations regarding advance care planning and resident choices;



# Intent (cont'd)

The intent is operationalized by:

- Recognizing and advising the resident and/or the resident's legal representative when the resident is approaching the end of life;
- Periodically review resident care, services, and support that accommodate and honor the resident's choices and rights, manage pain and other physical, mental, and psychosocial symptoms.

# Definitions

**Advance care planning** is a process used to identify and update the resident's preferences regarding care and treatment at a future time including a situation in which the resident subsequently lacks the capacity to do so; for example, when life-sustaining treatments are a potential option for care and the resident is unable to communicate (orally, in writing, through gestures or through an interpreter) his/her wishes make his or her wishes known.

# Definitions (cont'd)

**Hospice** refers to a public agency or private organization or subdivision of either of these that is primarily engaged in providing an array of care and services necessary for the palliation and management of terminal illnesses and related conditions.

**Imminently dying** indicates death is anticipated within hours to a week or two at most, because there are no treatments or interventions to prolong life or because the resident has declined to undergo treatment that could potentially prolong life.



# Definitions (cont'd)

**Palliative care** (§418.3) means patient and family-centered care that optimizes quality of life by anticipating, preventing, and treating suffering. Palliative care throughout the continuum of illness involves addressing physical, intellectual, emotional, social, and spiritual needs and to facilitate patient autonomy, access to information, and choice.

The goal of palliative care is to relieve suffering and provide the best possible quality of life for the resident and his or her family.

**Terminally ill** indicates that the resident has a life-limiting or life-threatening condition that results in a life expectancy of six months or less if the illness runs its normal course.



# Aging Population Overview

As the U.S. population ages, a greater number of older individuals may be admitted to and experience the dying process in nursing homes. It is projected that by 2030, half of the 3 million persons projected to be in a nursing home will die there. Many factors (such as a resident's age, overall condition and comorbidities, unexpected acute illness, and treatment choices) in addition to specific diagnoses influence when death may occur. However, clinical events, such as major changes in existing conditions or onset of new conditions may signal a resident is approaching the end of life.

Palliative care may be appropriate regardless of the perceived length of time to the resident's death. Palliative care focuses on symptom relief and comfort, but does not necessarily limit diagnostic, preventive, or curative interventions.





# ABCDE Mnemonic

Ask the resident or his or her legal representative about (and screen for) pain and other symptoms related to the resident's end of life status on admission and periodically thereafter;

A: Assess regularly and systematically for symptoms (such as dyspnea, fatigue, declining function, anorexia/eating difficulties/weight loss, pain, loneliness, anxiety/apprehension, depression, constipation, and delirium) and their impact on the resident;

B: Believe the resident's report of pain and other symptoms; what precipitates pain(s) and symptoms; what makes the pains(s) and symptoms worse: and what relieves the pain(s) and symptoms;



# ABCDE Mnemonic (cont'd)

C: Choose symptom control options that are appropriate for and consistent with the resident's or legal representative's wishes;

D: Deliver interventions in a timely, logical, and coordinated manner;

E: Empower the resident and the resident's legal representative to participate in defining the goals of treatment and planning the interventions to the extent possible; and evaluate the effectiveness of the chosen interventions.



# Challenges to Supporting Death with Dignity

Various challenges to supporting death with dignity have been identified.

Examples of challenges are, but are not limited to,

- Resident, staff, and physician discomfort with addressing death;
- Family expectations;
- Resident and/or family denial of the resident's condition or lack of knowledge of disease progression and inevitable outcome;
- Constraints related to limited staff time;
- Cultural and ethnic diversity; and
- Inadequate communication and coordination among practitioners and agencies providing aspects of palliative care at the end of life.



# Factors for a “Good Death” (cont’d)

Examples are, but not limited to:

- Exercising control of decision-making and selection of a decision maker;
- Adequately managing pain and other symptoms;
- Trusting one’s physician;
- Avoiding intrusive, unnecessary procedures and a prolonged death;
- Being kept clean;
- Being comfortable with the staff providing the care;
- Knowing what to expect regarding the physical condition;
- Strengthening relationships with loved ones;
- Having someone to listen and to be present; and
- Maintaining one’s dignity



# Assessment of the Resident Approaching End of Life

- History of present illness and comorbidities, medical and psychiatric disorders, and summary of current interventions;
- Physical, cognitive, and functional status (e.g., ability to communicate and activities of daily living (ADL) capacity); symptoms needing management; and whether there are potentially remediable causes of a resident's current condition that would improve the symptoms and/or prognosis or maximize his/her comfort;
- Appropriateness of and resident's desire for hospice services;
- Goals for care and treatment; resident strengths and available supports;



# Assessment of the Resident Approaching End of Life (cont'd)

- Psychological, emotional, and spiritual and environmental issues that may affect the resident's physical and/or psychological comfort (e.g., unresolved interpersonal and family issues; anxiety about dying alone and loss of independence or control; or high noise levels); and
- Other diagnostic tests and measures, as necessary [e.g., pain scales, blood tests, the Functional Alzheimer's Screening Test (FAST), or the Mini Mental Status Exam (MMSE)].



# Management of Care at End of Life

## Advance Directives

- Federal and state law provide for an individual's right to formulate an advance directive and refuse medical or surgical treatment, and offer criteria or guidelines for selecting a legal representative (also called: "Agent," "Attorney in fact," "Proxy," "Substitute decision-maker," "Surrogate decision maker").



# Management of Care at End of Life (cont'd)

- Whether or not a resident has an advance directive, the facility is responsible for giving treatment, support, and other care that is consistent with the resident's condition and medical and psychological accepted standards of care instructions.





# Management of Care at End of Life (cont'd)

## Care Planning for the Resident Approaching End of Life

- When the resident is nearing the end of life, it is important that the physician and interdisciplinary team review or update the prognosis with the resident and/or the resident's legal representative and review and revise the care plan as necessary to address the resident's situation.



# Management of Care at End of Life (cont'd)

## Activities of Daily Living (ADLs)

- Rather than restoration of a previous level of independence, care planning at this stage emphasizes support for activities of daily living to enhance the resident's comfort and dignity.



# Management of Care at End of Life (cont'd)

## Hygiene/Skin Integrity

- Ongoing, consistent oral care helps to maintain comfort and prevent complications associated with dry mucous membranes and compromised dentition. The resident receiving palliative care at the end of life may require adjustments in the frequency and intensity of measures such as turning and positioning, as well as the use of additional or alternative interventions to enhance comfort.



# Management of Care at End of Life (cont'd)

## Medical Treatment

- Diagnostic tests and monitoring may help confirm an individual's prognosis or guide treatment decisions, decisions about diagnostic tests and medical procedures should be related to the resident's prognosis, values and goals, as well as comfort and dignity.



# Management of Care at End of Life (cont'd)

## Medical Treatment

- Palliative care treatment at the end of life focuses on symptom management (e.g., controlling nausea, vomiting, uncomfortable breathing, agitation, and pain). Simple cause-specific interventions may sometimes provide effective palliation (e.g., resolving abdominal pain by reducing doses of medications with high anticholinergic properties that may lead to constipation or intestinal ileus).



# Management of Care at End of Life (cont'd)

## Medications/Drugs

- It is important that use of medications be consistent with the goals for comfort and control of symptoms and for the individual's desired level of alertness. Prescribers should review the continued need for any routine administration of medications and adjust or discontinue as may be appropriate. Routes of administration of medications may also need to be modified.



# Management of Care at End of Life (cont'd)

## Nutrition and Hydration

- Weight loss and fluid imbalance/dehydration at the end of life are common and may be a consequence, rather than a cause, of the dying process.
- End of life palliative care situations may not be compatible with maintaining normal nutritional parameters. .
- Previous dietary restrictions may be unnecessary for the resident.



# Management of Care at End of Life (cont'd)

## Activities

- As death approaches, activities that help provide comfort and symptom relief and those that require less conscious participation, rather than group or interactive activities, may be most appropriate. It is often helpful to involve the family or those with significant relationships with the resident in such activities, if possible.





# Management of Care at End of Life (cont'd)

## Psychosocial Needs

- The care plan may also identify interventions that are pertinent to the psychosocial needs of the dying resident (e.g., treatment for depression, delirium, anxiety, loneliness, restlessness or bereavement) and approaches to providing support to the resident (e.g., visits by family and others expanding visiting hours and providing desired privacy).



# Management of Care at End of Life (cont'd)

## **Monitoring the Resident Approaching End of Life**

- Areas of monitoring the quality of care at the end of life include, checking the resident's hearing aids; and recognizing a resident's condition has stabilized or improved enough to benefit from having a favorite food or drink.



# Management of Care at End of Life (cont'd)

## **Election of Hospice Benefit**

- A Medicare and/or Medicaid eligible resident with a terminal illness and a prognosis of six months or less has the right to elect the hospice benefit. If a resident requests hospice care, and a facility does not offer or contract for hospice or with the particular hospice requested, the facility must either arrange with a Medicare certified hospice to provide care to the individual resident, or help the resident and/or the resident's legal representative arrange for a transfer of the resident to a facility that provides the hospice care and/or services the resident desires.



# Management of Care at End of Life (cont'd)

## *Coordinated Plan of Care*

- When hospice services are involved, the facility and hospice are jointly responsible for developing a coordinated plan of care for the resident that guides both providers and is based upon their assessments and the resident's needs and goals.



# Management of Care at End of Life (cont'd)

## Coordinated Plan of Care

- To ensure each provider meets its responsibilities, it is essential the facility and hospice have a means to identify how the facility and the hospice determine all needed services, professionals, medical supplies, durable medical equipment, drugs and biologicals necessary for the palliation and management of pain and symptoms associated with the terminal illness and related conditions are available to the resident 24 hours a day, 7 days a week.



# Management of Care at End of Life (cont'd)

## Coordinated Plan of Care

- The hospice interdisciplinary care team is responsible for assessing the resident and identifying the physical, psychosocial, emotional, and spiritual needs related to the terminal illness that must be addressed in order to promote the resident's well-being, comfort, and dignity throughout the dying process.



# Management of Care at End of Life (cont'd)

## Coordinated Plan of Care

- The facility is responsible for notifying the hospice when the resident experiences a significant change in physical, mental, social or emotional status that it cannot manage adequately, or if the resident needs to be transferred from the facility.



# ***Resources Related to Care at End of Life***

- American Academy of Hospice and Palliative Medicine  
[www.aahpm.org](http://www.aahpm.org)
- A Guide to End-of-life Care for Seniors, (2000), Regional Geriatric Program of Toronto. Accessed November 24, 2010 from:  
<http://www.rgp.toronto.on.ca/files/File/PDFfiles/eol-english.pdf>
- Approaching Death: Improving Care at the End of Life, (1997), Institute of Medicine Consensus Report. Accessed November 30, 2010 from:  
[http://www.nap.edu/openbook.php?record\\_id=5801](http://www.nap.edu/openbook.php?record_id=5801)
- California Association of Health Facilities: Compassion and Respect toward the End of Life Recommendations, (2010). Accessed November 24, 2010 from:  
[http://www.calhospice.org/included/docs/education/8C\\_Partnering\\_With\\_Nursing\\_Homes\\_CARE\\_Recommendations.pdf](http://www.calhospice.org/included/docs/education/8C_Partnering_With_Nursing_Homes_CARE_Recommendations.pdf)





# ***Resources Related to Care at End of Life (cont'd)***

- Caring Connections: A national consumer and community engagement initiative to improve care at the end of life.  
[www.caringinfo.org](http://www.caringinfo.org)
- Center to Advance Palliative Care (CAPC): Provides health care professionals with the tools, training and technical assistance necessary to start and sustain successful palliative care programs in hospitals and other health care settings.  
[www.capc.org](http://www.capc.org)
- National Consensus Project for Quality Palliative Care, (2009), Clinical Practice Guidelines for Quality Palliative Care  
<http://www.nationalconsensusproject.org>



# ***Resources Related to Care at End of Life (cont'd)***

- *National Hospice and Palliative Care Organization*  
<http://www.nhcpo.org>
- *Robert Wood Johnson Foundation*  
[www.rwjf.org](http://www.rwjf.org)
- *Toolkit of Instruments to Measure End-of-Life Care (TIME).*  
<http://www.chcr.brown.edu/pcoc/toolkit.htm>