

What is Palliative Care?

- Specialized medical care for people with serious illnesses
- Focus - relief from the symptoms, pain, and stress
- Goal - improve quality of life for both patient and family
- Provided by - team of doctors, nurses, and other specialists who work with a patient's other providers as an extra layer of support.
- Appropriate at any age and at any stage in a serious illness, and can be provided together with curative treatment.

Center for Advancement of Palliative Care

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What is Hospice Care?

- Hospice care is palliative care for people in the final phases of life-limiting illness
- Focus- relief from the symptoms, pain, and stress of a terminal condition
- Goal - improve quality of life for both patient and family
- Provided by a team of doctors, nurses, and other specialists
- Appropriate in the final stages of illness when aggressive life-saving interventions no longer work or are wanted
- Recognizes dying as part of the normal process of living. It affirms life and neither hastens nor postpones death.

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Hospice Range of Services

- Skilled interdisciplinary case management
- Pharmaceuticals
- Durable medical equipment
- Supplies
- Trained volunteers
- Bereavement support for 13 months
- Inpatient hospice care
- Complementary therapies
- Care-partner training classes

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Benefits of Hospice for Patients & Families

- Increase comfort, quality of life and dignity for patient *and* family
- Decrease hospitalization & use of unhelpful services
- Higher perceived quality of care and quality of dying

Mitchell et al., 2007; Teno et al., 2011

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FAQ

- Who can initiate referral to hospice?
 - › Anyone can make the initial call
- Where is hospice provided?
 - Wherever the person lives
- Who pays for services?
 - › Medicare, many private insurances & non-profits like HOV will not turn anyone away for lack of ability to pay

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Eligibility Criteria for Hospice Challenges

- Difficult to accurately prognosticate final 6 months of life for certain conditions
- More challenging to determine for people living with PSP, CBS, MSA
- Some Medicare criteria are based on Alzheimer's disease

* Services can be renewed for more than 6 months
as long as criteria are met

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But for people with PSP, certain signs and symptoms may serve as “red flags” of final decline...

- Significant speech/ swallowing / chewing difficulties triggering more coughing / choking episodes
 - › Aspiration pneumonia is most common cause of death
- Frequent falls that pose risks for head injuries and fractures
- Severity of dementia
- Bedbound status- Immobility poses risks for blood clots & further complications
- Incontinence & recurrent urinary tract infections may lead to sepsis

AFTD Expert Consensus

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