Palliative Care and Hospice for Persons with Dementia

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Virginia Mason Franciscan Health™

Learning Objectives

- List the most important difference between Hospice and Palliative Care
- List Hospice Eligibility criteria for the diagnosis of dementia
- Discuss common occurrences in the trajectory of dementia requiring the most preparatory guidance

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Why is Hospice care so important?

"How people die remains in the memory of those who live on."

– Dame Cicely Saunders (1918-2005)
Founder of the Modern Hospice Movement

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In the context of quality…..

When we fail to provide care that matches patients preferences, we commit a medical error, no less urgent than any other harmful error.

Sanders, Curtis, Tulsky, Journal of Palliative Medicine, Vol 21 No S2, 2018

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Definition of Palliative Care

Palliative Care is specialized medical care for people with serious illnesses.

It is focused on providing patients with relief from symptoms, pain, and stress of a serious illness-whatever the diagnosis.

The goal is to improve **quality of life** for both the patient and the family. Palliative care is provided by a team of doctors, nurses, and other specialists together with patient's other doctors to provide an extra layer of support, appropriate at any age and at any stage in a serious illness and can be given with curative treatment. *CAPC March 2012*

HEADLINE DEFINITION

The Best Care Possible from the Patient perspective

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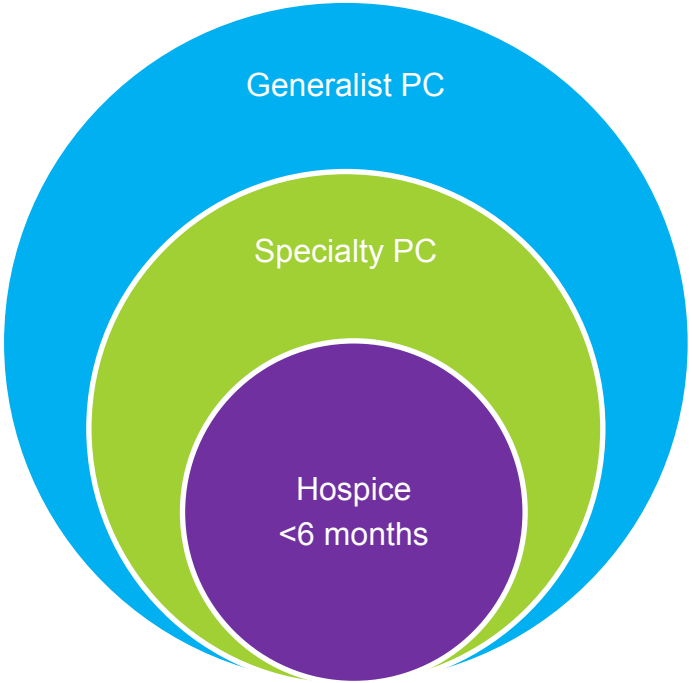

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Does every person with dementia need Palliative Care?

It depends

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Hospice Care

Specialized care for persons in the last 6 months of life

- Insurance Benefit
- Specialized team
- Done in homes–wherever the person living

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No Surprises…No Regrets

Areas of focus in ACP

- Appointing DPOA
- Caregiving
- Nutrition and hydration
- Treating Infections
- Time for Hospice

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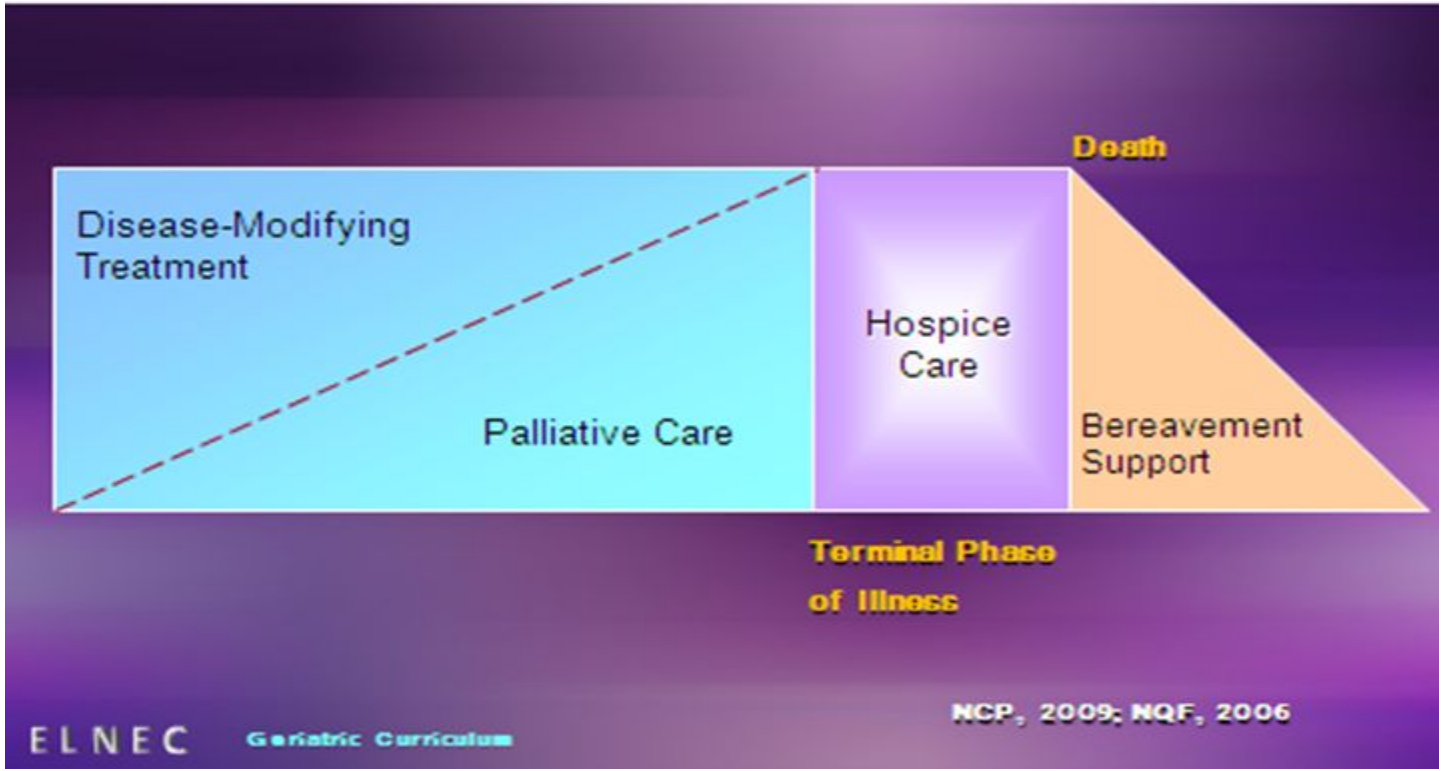
Palliative Care: continuum of Care



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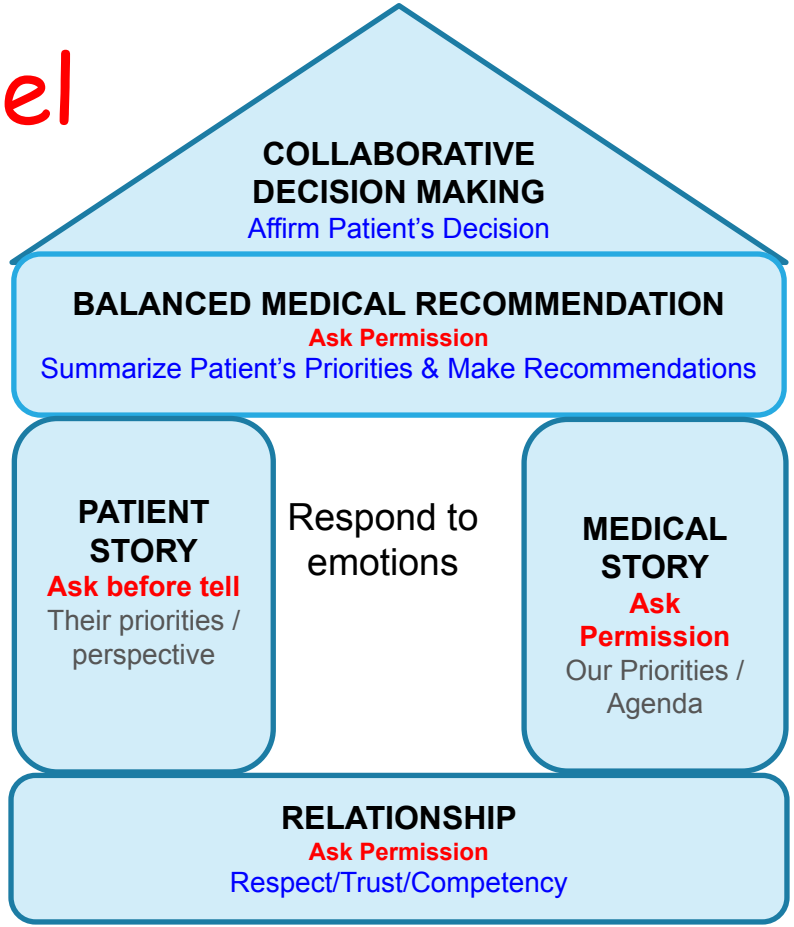
The House Model



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Alzheimer's Disease Eligibility Criteria

The patient has both 1 and 2.

1. Stage VII FAST
   Inability to ambulate without assistance
   Inability to dress without assistance
   Urinary and fecal incontinence
   No consistent meaningful/reality based verbal communication

2. Has had one of the following in the last 12 months

- Aspiration pneumonia
- Pyelonephritis
- Septicemia
- Decubitus ulcers, Multiple and /or Stage 3-4
- Fever , recurrent after antibiotics
- Inability to maintain sufficient fluid and caloric intake demonstrated by 10% weight loss in previous 6 months or serum albumin <2.5 gm/dl

For Hospice care- must meet eligibility requirements
and show evidence of decline

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When should I refer a person with dementia to hospice?

When you would NOT be surprised if the person dies in the next 6 months!

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Hospice Myths

- A hospice patient can no longer see their own doctor
- After Hospice care is started people die
- Caregiving is paid for
- A person can only be on hospice for 6 months
- Most medications are stopped when hospice care started
- Persons with Dementia don’t really experience pain

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Pain Assessment

ITEMS*	0	1	2	Score
Breathing independent of vocalization	Normal	Occasional labored breathing. Short period of hyperventilation	Noisy labored breathing. Long period of hyperventilation. Cheyne-Stokes respirations	
Negative vocalization	None	Occasional moan or groan. Low-level speech with a negative or disapproving quality.	Repeated troubled calling out. Loud moaning or groaning. Crying.	
Facial expression	Smiling or inexpressive	Sad. Frightened. Frown.	Facial grimacing.	
Body language	Relaxed	Tense. Distressed pacing. Fidgeting.	Rigid. Fists clenched. Knees pulled up. Pulling or pushing away. Striking out.	
Consolability	No need to console	Distracted or reassured by voice or touch.	Unable to console, distract or reassure.	
			TOTAL¶:	

This pain assessment score can be used to assess pain in patients with dementia. Patients should be observed for 5 minutes prior to performing the assessment. Total scores range from 0 to 10, with 10 representing severe pain.
*5-item observational tool.
¶ Total scores range from 0 to 10 (based on a scale of 0 to 2 for 5 items), with a higher score indicating more severe pain (0 = "no pain" to 10 = "severe pain").

Original figure modified for this publication. Warden V, Hurley AC, Volicer L. Development and psychometric evaluation of the pain assessment in advanced dementia (PAINAD) scale. J Am Med Dir Assoc 2003; 4:9.

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Pain AD Resource

http://www.amda.com/caring/may2004/painad.htm

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Margaret’s Story

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Thank You

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