Integrating Primary Care & Palliative Care for Persons with Dementia

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Learning Objectives

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- Define Palliative Care and the types of Palliative Care
- Define when Palliative Care should be introduced in a patient with dementia
- List the most common reasons for Palliative Care consultation for a patient with dementia

What is definition of Palliative Care?

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- The Best Care Possible from the patient's perspective (Byock)
- Good Medicine for very sick people (Arnold)

Also important to know:

- Palliative Care is appropriate for persons with serious illness and with an unmet need
- PC is NOT linked to prognosis

Hospice and Palliative Care

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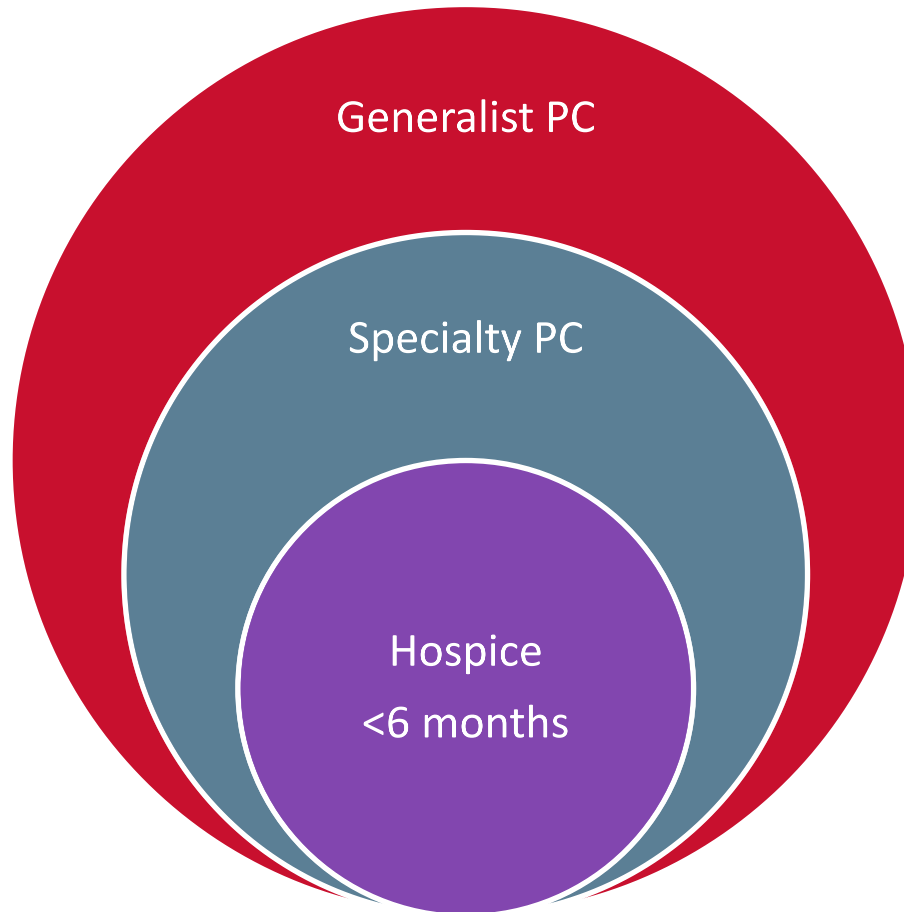
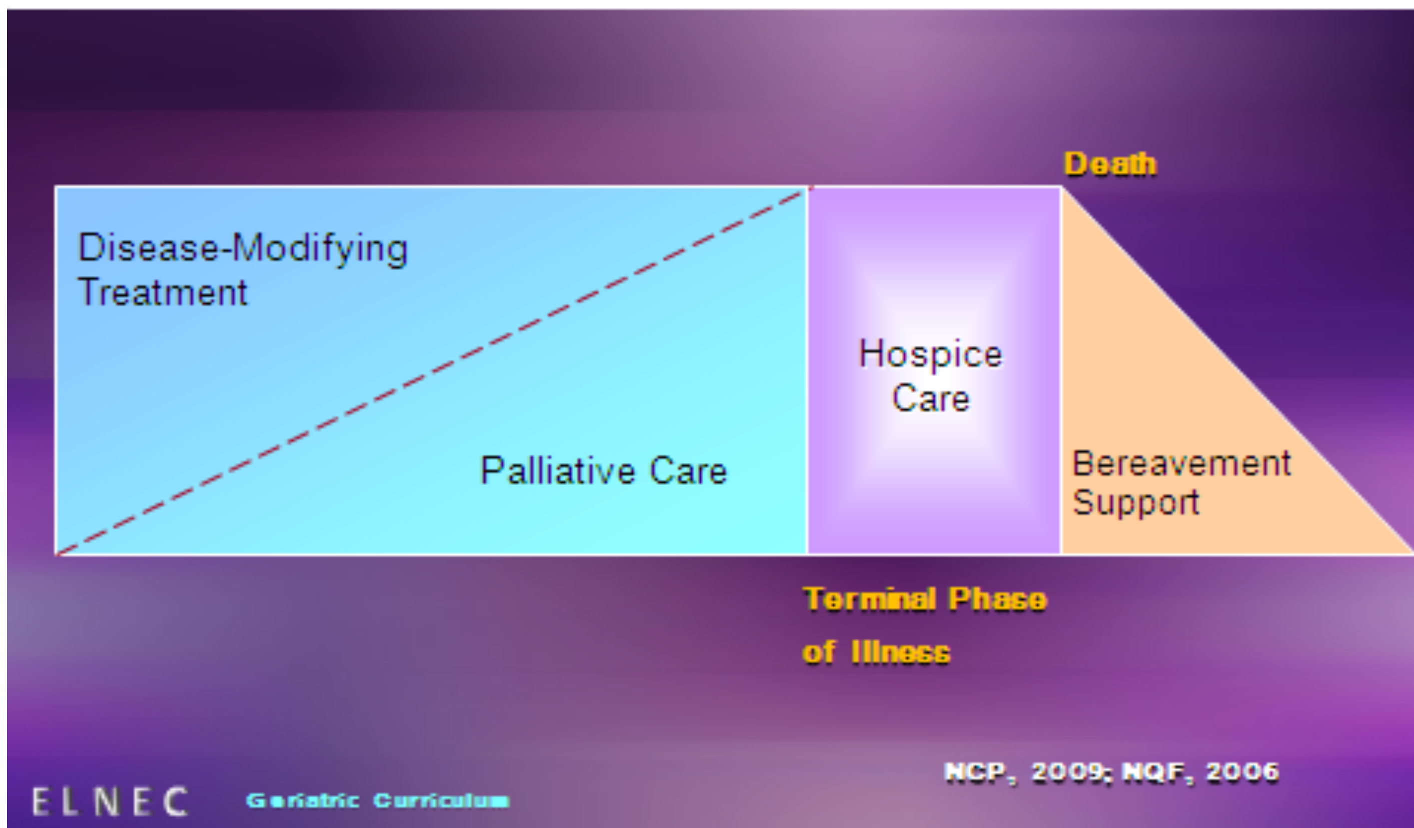


How much palliative care do you provide in your practice?

- YOU all provide Palliative Care
- Generalist vs. Specialist Palliative Care
- Palliative Care gets confused with hospice because we start it too late
- Families want to have these conversations but expect clinicians to bring it up if it is important
- We need to address the CULTURE OF SILENCE

When to start Palliative Care?

Palliative Care: continuum of Care



What's the magic?

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- Ask Before You Tell
- Respond to Emotion
- Align Intentions
- Let go of the outcome
- Make a balanced medical recommendation
- When you are recommending to limit an intervention replace it with what you are going to do upfront

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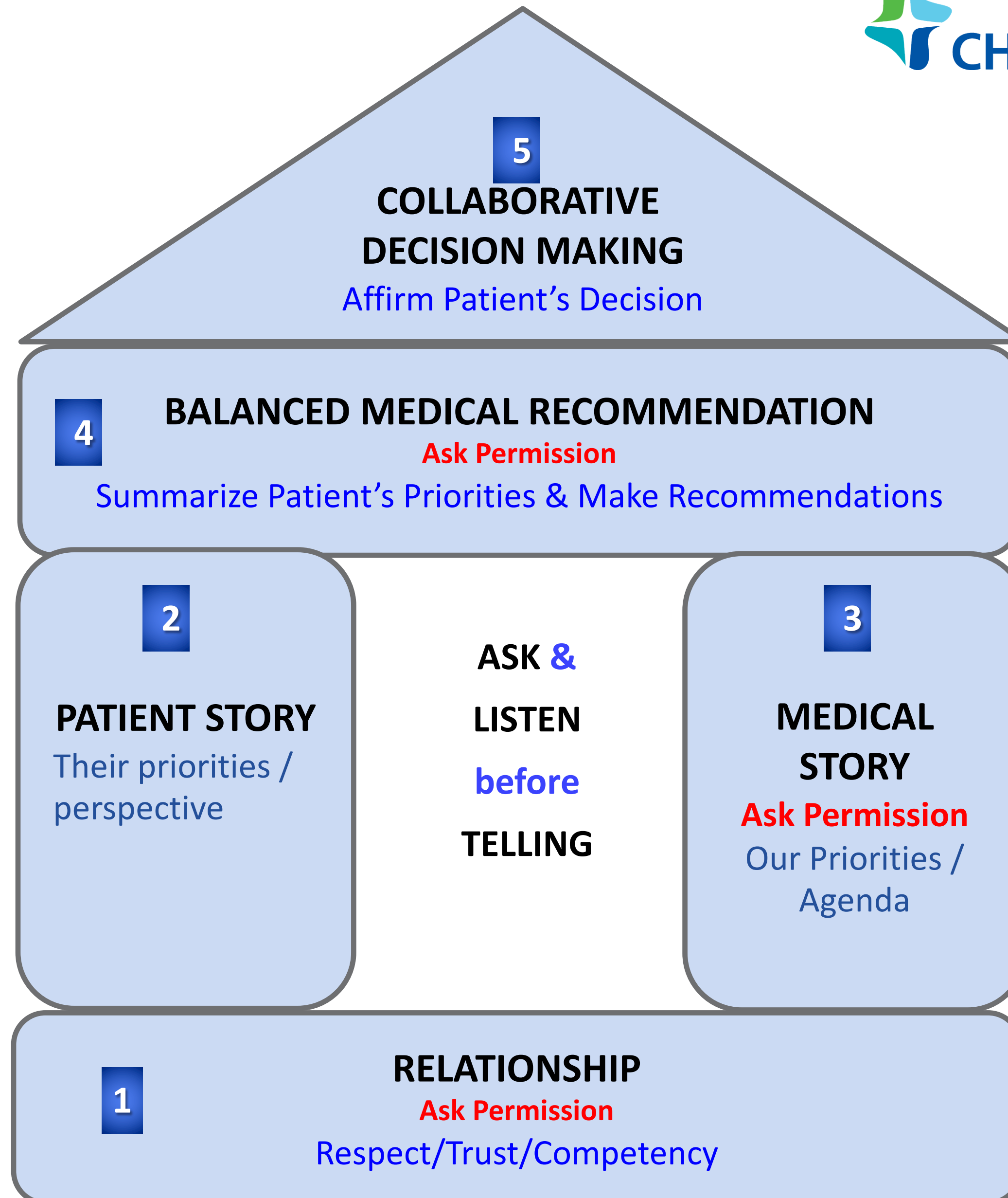

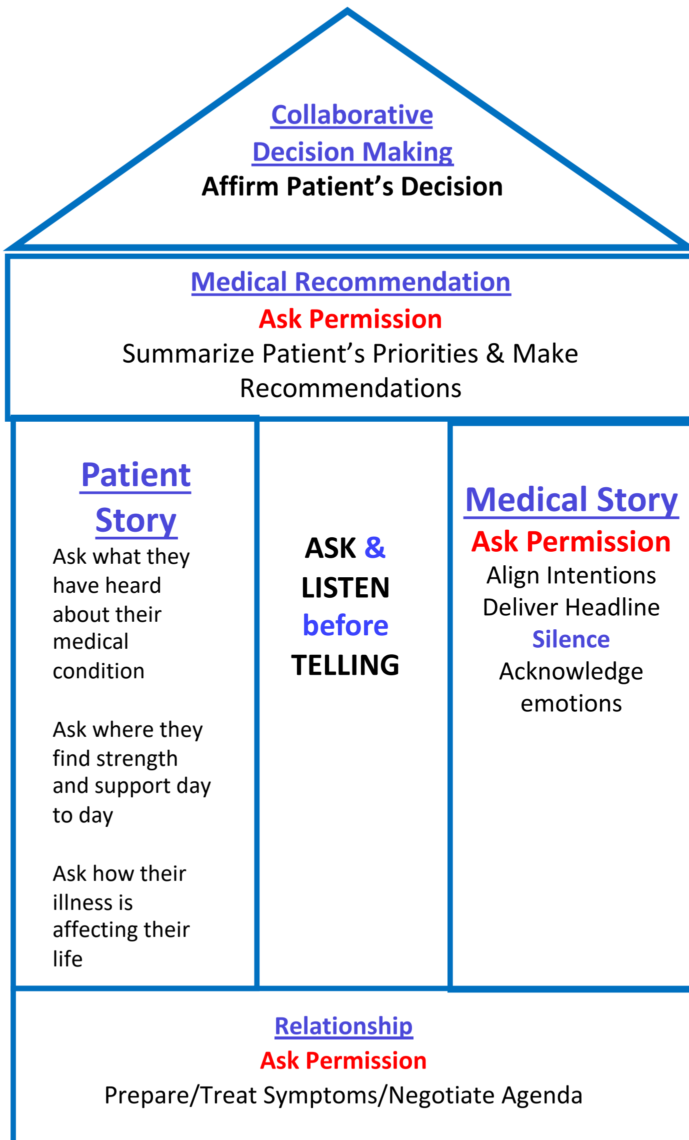

	WAYS	WORDS
Relationship	• Quiet space, silence phones and pager, request permission to enter, sit down, eye contact • Assess symptoms first • Elicit their agenda first • Review medical records, talk to rest of the team	• ***Ask permission*** ***"Is this a good time to talk?"*** • Are you comfortable enough to talk now? • What are your expectations for our conversation today? • We want to provide you the ***Best Care Possible from your perspective***. Can we talk about that?
Patient Story	• Match the pace of the patient • Listen carefully • Don't interrupt • Anticipate emotions	***Obtain Patient Story***: "can you tell me, ***in your own words***, what you have heard about your medical condition? Are you able to do the things you enjoy? Where do you get strength and support? What is your body telling you?
Medical Story	• If they do not want to talk, don't proceed • Offer only realistic hope • Deliver information in "Headlines" (15 words or less) • Avoid medical jargon	• ***Ask permission***: Would it be okay if I share medical information now? • ***Deliver headline*** & **BE SILENT (let them break silence!)** "I am worried that what we are hoping for may not happen" "The cancer has come back" • ***Name Emotion/Empathetic Statement/Align Hope*** "This is hard" "I cannot imagine" "I wish I could make this into good news, but I can't" "This is upsetting" ***Align hope/intention***: *My hope is that you/your loved one will get better. I also want us to have a plan if what we are hoping for doesn't happen.* "Given your medical situation, what is most important to you?"
Recommendation	• Make a medical recommendation that aligns patient priorities **AND** reflects what is medically possible • When you recommend limiting interventions, make sure you first offer what you WILL do	***Before Making a Recommendation:*** • This is what I hear is important to you: (list them) • Is this correct? (confirm that the list is correct) • Would it be okay if I make a recommendation? (**ASK PERMISSION**) **When making a recommendation:** "Based on what is important to you, I recommend the following" Make recommendations that match their goals. **After making a recommendation:** What do you think about this as a plan? (Obtain their opinion about your recommendations)
Collaborative	• Continue to partner with them • Consider a time limited trial w/specific goal • Protect the quality of the process rather than judging the quality of their decision	• ***Affirm their decision:*** Let me summarize what I have heard from you: *"it sounds like it is really important to you that we place a PEG/treat with Abx/ intubate / perform CPR"* • **Establish a *functional* End-Point for Time-Trial**: **Going forward, how will we know that this plan is working/not working**? (e.g. patient- "more awake/participate in PT/come off Respirator") • **Finish with Teach-Back**: "To make sure I have done a good job communicating, can you share with me what we talked about?

Hospice and Palliative Care

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Hospice

- Hospice eligibility is linked to prognosis: “Would you be surprised if this patient dies with in 6 months?” If the answer is NO, the patient most likely is hospice eligible.
- Whether patient would benefit from hospice is directly linked to goals of care and priorities—needs to be a match

Palliative Care

- Palliative Care referral linked to unmet need
- Need may be goals of care conversation, symptom management, ethical dilemma’s conflict management.
- Can be given in any setting regardless of prognosis

Common Reasons for PC Consult

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- Goals of Care/Advance Care planning
- Behavioral issues
- Feeding problems

Artificial Nutrition/Hydration in Advanced Dementia

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- Value laden and emotional conversation
- Generally not recommended
- Hand feeding has as good of outcomes of death, aspiration pneumonia, functional status and comfort
- Tube feeding associated with agitation and use of restraints

American Geriatrics Society Feeding Tubes in Advanced Dementia Position Statement JAGS 62:1590-1593, 2014

- #84
- **Swallow Studies, Tube Feeding, and the Death Spiral**
- David E Weissman MD
- Download PDF
- **Introduction** The reflex by families and doctors to provide nutrition for the patient who cannot swallow is overwhelming. It is now common practice for such patients to undergo a swallowing evaluation and if there is significant impairment to move forward with feeding tube placement (either nasogastric or gastrostomy) – see Fast Fact #128. Data suggest that in-hospital mortality for hospitalizations in which a feeding tube is places is 15-25%, and one year mortality after feeding tube placement is 60%. Predictors of early mortality include: advanced age, CNS pathology (stroke, dementia), cancer (except early stage head/neck cancer), disorientation, and low serum albumin.

Fast Facts continued

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- **The Tube Feeding Death Spiral** The clinical scenario, the tube feeding death spiral, typically goes like this:
- Hospital admission for complication of "brain failure" or other predictable end organ failure due to primary illnesses (e.g. urosepsis in setting of advanced dementia).
- Inability to swallow and/or direct evidence of aspiration and/or weight loss with little oral intake.
- Swallowing evaluation followed by a recommendation for non-oral feeding either due to aspiration or inadequate intake.
- Feeding tube placed leading to increasing "agitation" leading to patient-removal or dislodgement of feeding tube.
- Re-insertion of feeding tube; hand a

Hospice Eligibility

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Dementia due to Alzheimer's and Related Disorders

A. Patients with dementia should show all the following characteristics:
   1. FAST 7A or greater
   2. Unable to ambulate without assistance
   3. Unable to dress without assistance
   4. Unable to bathe without assistance
   5. Urinary and fecal incontinence
   6. No consistently meaningful verbal communication

B. Patients should have had one of the following in past 12 months:
   1. Aspiration pneumonia
   2. Pyelonephritis
   3. Septicemia
   4. Decubitus ulcers, multiple, stage 3-4
   5. Fever, recurrent after antibiotics
   6. Poor fluid or calorie intake with 10% wt loss last 6 mo

Usual Care vs. Palliative Care

Usual Care	Palliative Care
Bernard and Martha did not discuss care planning prior to her cognitive decline.	Martha's care team discusses what to expect as dementia progresses and asks Bernard what he thinks would be most important to Martha, if she could tell us.
Because Martha has multiple clinicians from multiple teams, none of them was identified as being responsible for discussing her care priorities when her dementia progressed.	Bernard explains to the care team that Martha is terrified of going to a nursing home and wants to stay at home. He says "Can't you do something about the pain?"
Martha has multiple emergency room visits and hospitalizations.	An alternative care plan is developed that taps into community medical and social supports, and later to hospice, to honor what is most important to Martha and Bernard.
Bernard is exhausted and overwhelmed and tearfully admits that he can no longer take care of Martha at home.	With help from house call and friendly visitor programs and later hospice, Martha is cared for at home until her death. Bernard is proud that he was able to keep her at home and honor his promise not to put her in a nursing home.

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AT EVERY POINT OF CONTACT

YOU

CAN CHANGE THE PATIENT STORY

Maya Angelou……

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