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HospiceCare | PalliaHealth | Grief Support Center | Age at Home

End-Of-Life Conversations: Bringing the elephant in the room down to size

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Objectives

- Understand the difference between palliative care and hospice, and establish when each type of care may be appropriate.
- Learn approaches to having difficult conversations, especially as a resident's condition is changing.
- Be aware of resources related to palliative and end-of-life care.

Palliative Care vs. Hospice

Palliative Care	Hospice
• Can be helpful for anyone at ANY stage of serious illness • May be provided throughout course of illness	• Life-limiting prognosis of 6 months or less
• May utilize life-prolonging treatments	• Typically focused on comfort care
• Do not waive any benefits to seek palliative care services	• Medicare/Medicaid patients waive their traditional Medicare benefit to pursue hospice

Similarities

Palliative Care AND Hospice
• Focus is on symptom management, goals of care and Quality of Life
• May be provided where a patient lives (i.e. private residence, assisted living facility, skilled nursing facility)
• May be covered by Medicare, Medicaid or private insurance
• Not intended to serve as an around-the-clock caregiver

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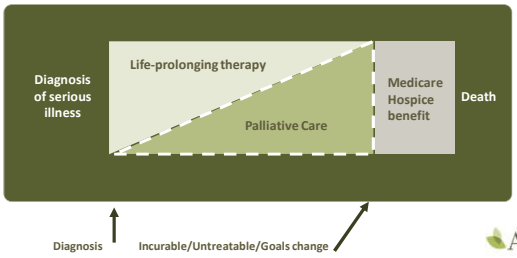
Palliative Care and Hospice in the Continuum of Care



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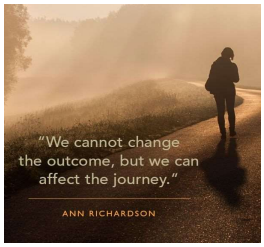
Palliative Care

- Goals of Palliative Care
  - Advance Care Planning
    - Creation of advanced directives
  - Symptom Management
    - Active Treatment
    - Chronic Disease
  - Improved Quality of Life



The Medicare Hospice Benefit[1]

CMS
CENTERS for MEDICARE & MEDICAID SERVICES

- Established in 1983
- For patients enrolled in Medicare, Part A
- Patients must elect the Benefit and in turn forgo traditional Medicare coverage
  - Informed Consent
    - Role of the Hospice Attending

The Medicare Hospice Benefit (continued)

- For patients with a prognosis of 6 months or less should the illness run its normal course
  - Focus is on comfort
- Patient must be certified as 'terminally ill'
- 'Per Diem' payment is provided
- Hospice is responsible to cover all things related to the patient's terminal prognosis
  - Supplies
  - Durable Medical Equipment
  - Hospitalizations
  - Physician Visits
  - Medications

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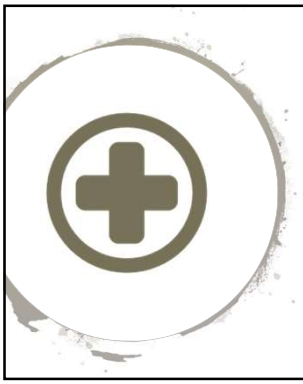
The Hospice Interdisciplinary Team (IDT)

Levels of Care

- Routine Home Care
- Respite Care
- Continuous Care
- General Inpatient Care

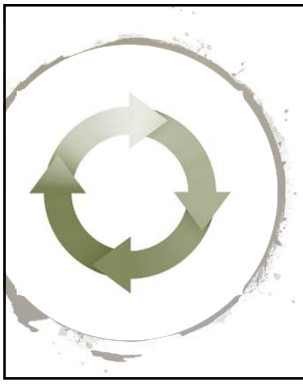
Routine Home Care(3)

- The patient receives care in their own home:
  - Private residence
  - Assisted Living Facility (ALF)
  - Skilled Nursing Facility (SNF)/Nursing Facility (NF)
  - Adult Family Home
- Most common level of care provided by hospice with approximately 96.5% of beneficiaries receiving this level



Respite(3)

- A temporary rest (respite) for caregivers
- Up to 5 consecutive days
- Must be provided in a hospital, hospice facility or long-term care facility with 24-hour nursing presence on all shifts



Continuous Care (3)

- Intended to maintain the patient in their own residence for periods of crisis
  - Not meant to be long-term

Inpatient Care (3)

- Acute care
- Must have Registered Nurse on premises 24-hours/day
- Short-term
- Purpose is to provide symptom relief that cannot be managed in another level of care
- How about 'actively dying?'

The Agrace (Madison) Inpatient Unit

A Room on the Agrace Inpatient Unit

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Hospice Eligibility

- It can be challenging to recognize when a patient could benefit from hospice services.
- Hospices must follow specific clinical guidelines to determine when a patient is eligible (and continues to be eligible) for the Medicare Hospice Benefit

Hospice Eligibility Guidelines(2)

A. Progression of disease as documented by worsening clinical status, symptoms, signs and laboratory results

B. Decline in Karnofsky Performance Status (KPS) or Palliative Performance Score (PPS) due to progression of disease.

C. Progressive decline in Functional Assessment Staging (FAST) for dementia (from 7A on the FAST).

D. Progression to dependence on assistance with additional activities of daily living

E. Progressive stage 3-4 pressure ulcers in spite of optimal care.

F. History of increasing ER visits, hospitalizations, or physician visits related to the hospice primary diagnosis prior to election of the hospice benefit.

Guidelines-- Dementia

- Stage 7 or beyond according to the Functional Assessment Staging Scale (FAST) with all of the following:
  - Inability to ambulate without assistance
  - Inability to dress without assistance
  - Urinary and fecal incontinence, intermittent or constant
  - No consistent meaningful/reality-based verbal communication, or the ability to speak is limited to a few intelligible words

AND

- Has had at least one of the following conditions within the past 12 months:
  - Aspiration pneumonia
  - Pyelonephritis or other upper urinary tract infection
  - Septicemia
  - Pressure ulcers, multiple and/or Stage 3 or Stage 4
  - Fever, recurrent after antibiotics
  - Inability to maintain sufficient fluid and caloric intake demonstrated by either of the following:
    - 10% weight loss during the previous six months

    OR
    - Serum albumin <2.5 gm/dl

In the absence of one of more of these findings, rapid decline or comorbidities may also support eligibility for hospice care.

Guidelines—Heart Disease

- The patient has 1 or 2 and 3:
  - Poor response to (or patient's choice is not to pursue) optimal treatment with diuretics, vasodilators and/or angiotensin converting enzyme (ACE) inhibitors
- OR
  - The patient has chest pain at rest resistant to standard nitrate therapy and is not a candidate for invasive procedures and/or has declined revascularization procedures
- AND
  - New York Heart Association (NYHA) Class IV symptoms with both of the following:
    - The present of significant Congestive Heart Failure (CHF) symptoms at rest (chest pain, shortness of breath)
    - Inability to carry out even minimal physical activity with symptoms of heart failure (shortness of breath and/or chest pain)

In the absence of one of more of these findings, rapid decline or comorbidities may also support eligibility for hospice care.

Guidelines—Lung Disease

The patient has severe chronic lung disease as documented by 1, 2 and 3:

1a. Disabling dyspnea at rest
1b. Poor response to bronchodilators
1c. Decreased functional capacity, e.g. bed to chair existence, fatigue and cough

AND

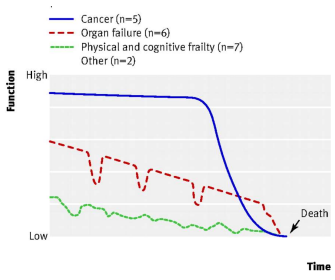
2. Progression of disease as evidenced by a recent history of increased visits to MD office, home or emergency room and/or hospitalizations for pulmonary infections and/or respiratory failure

AND

3. Documentation within the past three months of a or b:
   a. Hypoxemia at rest—O2 saturation < 88%
   b. Hypercapnia evidenced by pCO_2>50 mm Hg

In the absence of one of more of these findings, rapid decline or comorbidities may also support eligibility for hospice care.

Disease Trajectory (4)



How Do You Talk about Hospice and Palliative Care?

Initiating Difficult Conversations

- SPIKES was initially created to deliver 'bad news' to oncology patients,[5] however there is application in other areas of healthcare
- 6 steps
  - S — SETTING up the interview
  - P — Assessing the Patient's PERCEPTION
  - I — Obtaining the Patient's INVITATION
  - K — Giving KNOWLEDGE and Information to the Patient
  - E — Addressing the Patient's EMOTIONS with Empathic Responses
  - S — STRATEGY and SUMMARY

Step 1: SETTING up the interview

- Mental preparation (for the person delivering the news)
- Arranging for privacy — Setting matters!
- Include key players — Family, friends, etc
- Sit down — Ensure there are no barriers between you and the resident/family
- Make a connection — Eye contact; Hold hands (if appropriate)
- Minimize interruptions

Step 2: Assessing the Resident's PERCEPTION

- Understand what the resident (or family) comprehends about their illness, prognosis, etc.
  - Can be helpful to understand if denial is present.
  - May outline if the resident has unrealistic expectations
- Ensures that everyone is on the same page

Step 3: Obtaining the Resident's INVITATION

- Is the Resident/Family ready to receive the information?
- Does the Resident want all of the information or would they prefer it go to someone else?

Step 4: Giving KNOWLEDGE and information to the Resident

- Inform the Resident/family that unfortunate news may be coming
- Stick to the facts; Make it succinct
- Use non-technical words

Step 5: Addressing EMOTIONS with empathic responses

- Observe for any emotion (i.e. tearfulness, a look of sadness, or silence)
- Identify the emotion — Ask what emotions people are thinking/feeling
- Verify the reason for the emotion — Typically connected to the news you just shared, but not always!
- Give the resident/family a moment to respond
- Until a reaction/emotion is addressed, it will be difficult to discuss other matters

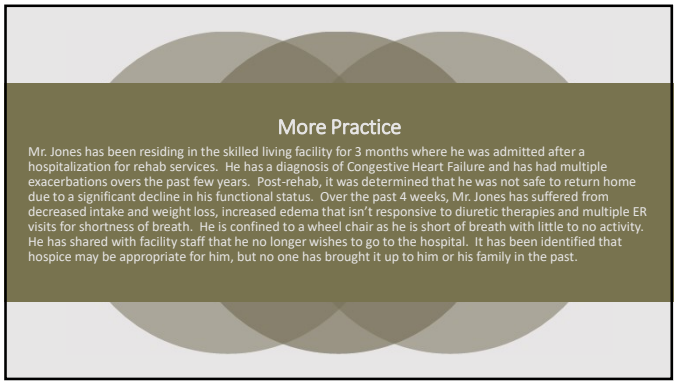
Step 6: STRATEGY and SUMMARY

- Establish a plan
- What are the next steps?

Let's Practice

You are the Director of an Assisted Living Facility where Ann has been residing for several years. Over the past few months Ann has required increased care and it is now apparent that her medical needs are increasing. It is recommended that the resident transition to a different level of care.


Practice #1:
1. SET it up
2. Resident/family PERCEPTION
3. Obtaining the INVITATION
4. Giving KNOWLEDGE and information
5. Addressing EMOTIONS with empathic responses
6. STRATEGY and SUMMARY


More Practice
Mr. Jones has been residing in the skilled living facility for 3 months where he was admitted after a hospitalization for rehab services. He has a diagnosis of Congestive Heart Failure and has had multiple exacerbations overs the past few years. Post-rehab, it was determined that he was not safe to return home due to a significant decline in his functional status. Over the past 4 weeks, Mr. Jones has suffered from decreased intake and weight loss, increased edema that isn't responsive to diuretic therapies and multiple ER visits for shortness of breath. He is confined to a wheel chair as he is short of breath with little to no activity. He has shared with facility staff that he no longer wishes to go to the hospital. It has been identified that hospice may be appropriate for him, but no one has brought it up to him or his family in the past.


Practice #2:
1. SET it up
2. Resident/family PERCEPTION
3. Obtaining the INVITATION
4. Giving KNOWLEDGE and information
5. Addressing EMOTIONS with empathic responses
6. STRATEGY and SUMMARY

Hospice and Palliative Care Resources

FAST Facts (https://www.mypcnow.org/fast-facts/)

Hundreds of documents regarding palliative care concepts

Include case studies, information regarding best practice and references

National Hospice and Palliative Care Organization (NHPCO)

https://getpalliativecare.org

Identifies palliative care resources by area

Hospice Compare (https://www.medicare.gov/hospiceCompare/)

Compare hospices by area based on the quality of care they provide

Vital Talk (https://www.vitaltalk.org)

Resources related to:

Addressing goals of care

Conducting a family conference

Questions?

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References

1. U.S. Department of Health and Human Services, Centers for Medicare and Medicaid Services. (2018). Medicare Hospice Benefits. Retrieved from https://www.medicare.gov/Pubs/pdf/02154-Medicare-Hospice-Benefits.PDF
2. Local Coverage Determinations (LCDs). National Government Services (NGS). (2010). Retrieved from https://www.ngsmedicare.com
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4. Murray, S.A. et al. Care For All At the End of Life. (2008).
5. Baile, W., Buckman, R., Lenzi, R., Glober, G., Beale, E., & Kudelka, A. (2000). SPIKES—A Six-Step Protocol for Delivering Bad News: Application to the Patient with Cancer. *The Oncologist.*