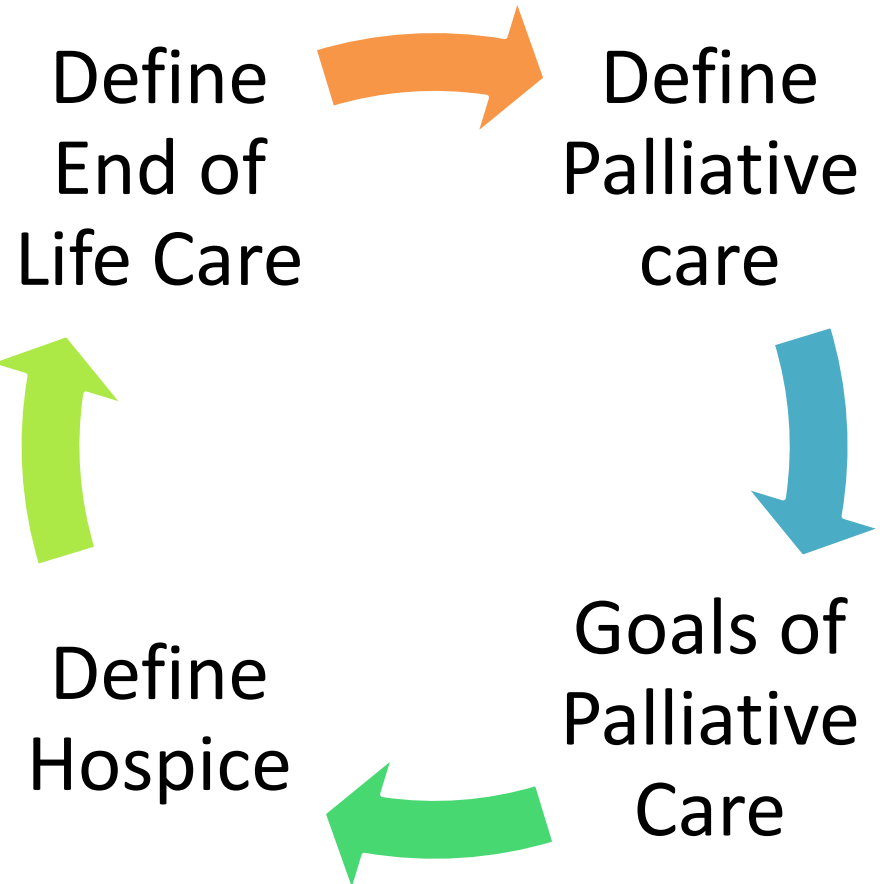




Palliative Care and End of Life

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Objectives



Palliative Care

Medical care delivered by a healthcare trained specialist that focuses primarily on symptom management to improve the patient's (with any serious, chronic, or life-threatening illnesses) quality of life.

Palliative Care

Provides relief from pain and other distressing symptoms

Affirms life and regards dying as a normal process

Intends neither to hasten or postpone death

Integrates the psychological and spiritual aspects of patient care

Offers a support system to help patients live as actively as possible until death

History of Palliative Care

Began as a hospice movement in the 19th century.

The first US hospital-based palliative care programs began in the late 1980s at a few establishments including the Cleveland Clinic

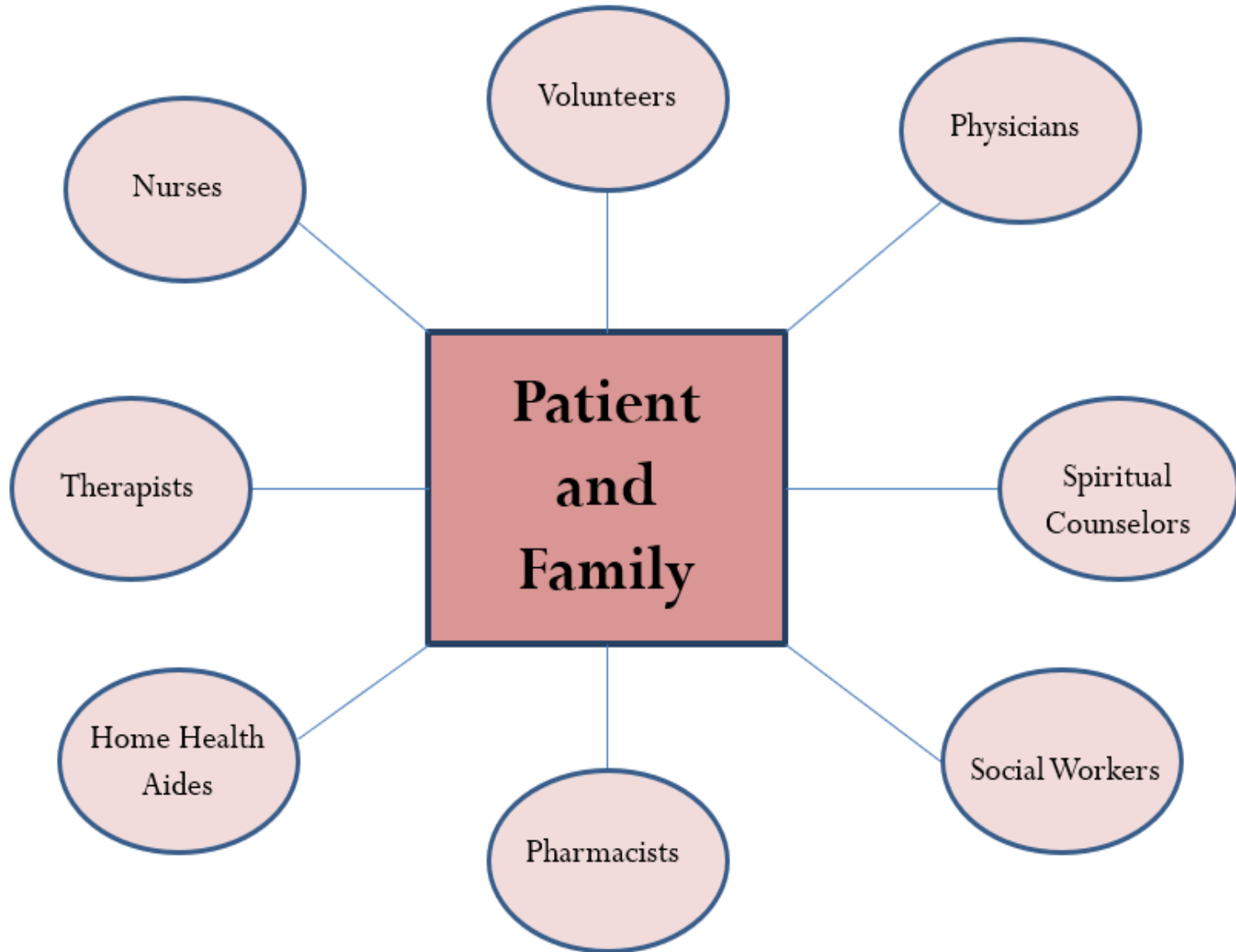
Began as a volunteer-led movement in the United States and has developed into a vital part of the health care system

Since the inception there has been a dramatic increase in hospital-based palliative care programs, now numbering more than 1400

Palliative Care Team

- Composed of a physician, and/or nurse practitioner, chaplain, social worker and nurse, to provide holistic care to patients
- The palliative care team's focus is on addressing physical, psychosocial, spiritual, and existential pain (Ferrell et. al, 2018)

Palliative Care Team



Goal of Palliative Care

To improve the quality of life for individuals who are suffering from severe diseases

Palliative care offers a diverse array of assistance and care to the patient

Importance of Early Palliative Care

As life expectancy increases and diseases become more chronic in nature

Early introduction of palliative care in leads to longer life and better quality of life in many patients

Palliative care has risen by 178 % from 2000 to 2016 (CAPC, 2018)

Dominant illnesses for which palliative care will be needed are dementia and cancer (Etkind et. al, 2017)

Effects of Early Integrated Palliative Care in Patients With Lung and GI Cancer: A Randomized Clinical Trial

- **Methods:**
 - Newly diagnosed incurable GI and Lung Cancers within 8 weeks of diagnosis
 - Sample size = 350 patients
 - Done at Massachusetts General hospital
 - Non blinded, randomized trial
 - Study conducted from May 2011 to July 2015

Effects of Early Integrated Palliative Care in Patients With Lung and GI Cancer: A Randomized Clinical Trial

- **Methods:**

- Randomly assigned to two Groups:

- Group with early integrated Palliative Care (PC) and oncology care (n = 175)
- Usual Oncology care (n = 175)

Effects of Early Integrated Palliative Care in Patients With Lung and GI Cancer: A Randomized Clinical Trial

- **Methods:**
 - Patients assigned to the intervention met with a PC clinician at least once per month until death
 - Patients who received usual care could consult a PC clinician upon request
 - Excluded patients who already had palliative care
 - Utilized the National Consensus Project for quality Palliative Care guidelines
 - Follow up assessments at 12 weeks and 24 weeks

Effects of Early Integrated Palliative Care in Patients With Lung and GI Cancer: A Randomized Clinical Trial

- **Tools:**

- Functional Assessment of Cancer Therapy General Scale (FACT-G) scale used to measure quality of life
- Patient health Questionnaire used to measure mood and anxiety
- Hospital Anxiety and Depression Scale
- Prognosis and Treatment Perceptions Questionnaire measured patient understanding of their disease and communication with oncologist

Results

- Primary end point was change in quality of life (QOL) from baseline to week 12
- Secondary end points included:-
 - Change in QOL from baseline to week 24
 - Change in depression
 - Differences in end-of-life communication

Results

- Intervention patients showed
 - Greater improvement in QOL from baseline to week 24
 - Lower rates of depression at week 24
- Intervention patients with lung cancer had improvement in QOL and depression at 12 & 24 weeks
- Usual care patients with lung cancer had poor QOL
- Patients with GI cancers in both study groups had improved QOL and mood by week 12.
- Intervention patients were more likely to discuss end of life wishes with their oncologist

Study Conclusion

- Patients with newly diagnosed incurable cancers had
 - Improved QOL and mood with early integrated PC
 - Early integrated PC may be most effective if targeted to the specific needs of each patient population.

Areas of Focus

- Two key areas of focus are
 - Early access to palliative care despite patient setting, diagnosis, age or prognosis.
 - Empowering clinicians to introduce palliative care early in the disease trajectory

Approaches to Palliative Care

Care is tailored to help the specific needs of the patient

Not a “one size fits all”

Vital for comfort to reduce patients' distress

Patients with good pain and symptom management tend to tolerate treatment better and have better quality of life

Palliative Care Patient Support Services

Psychosocial support

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Emotional and spiritual distress are extremely important as they can affect quality of life and treatment adherence as well

What does Palliative Care Provide to the Patient?

Helps patients gain the strength and peace of mind to carry on with daily life

Aids the ability to tolerate medical treatments

Helps patients to better understand their choices for care

Five Themes of Care

- Five themes include
 - Comprehensive assessment
 - Family/caregiver assessment
 - Support and education
 - Care coordination during transitions
 - Culturally inclusive care

Comprehensive assessment

- Should include physical, psychosocial, spiritual and cultural aspects of care
- Team should be interdisciplinary in nature with each focusing on their specialized area to provide holistic care
- Collaborate with patient and caregivers to develop a treatment plan focused on patients' goals, maximizing functionality and optimizing quality of life
- Continuous assess and reassess of the patients' goals are needed as the course of the disease changes

Caregiver

Care also focuses on the caregiver and family

Majority of patient care is done by caregivers

Caregivers can experience caregiver burnout if not educated appropriately (Bakitas et al, 2015)

Caregiver burnout encompasses emotional, psychological and physical stressors such as fatigue, stress, anxiety, and depression. Caregivers who suffer from these tend to have high mortality rates (Bakitas et al, 2015).

Patients and families who have early onset palliative care, have a better knowledge of symptom management at home and tend to feel more supported in caring for their loved ones (Gomes, 2015)

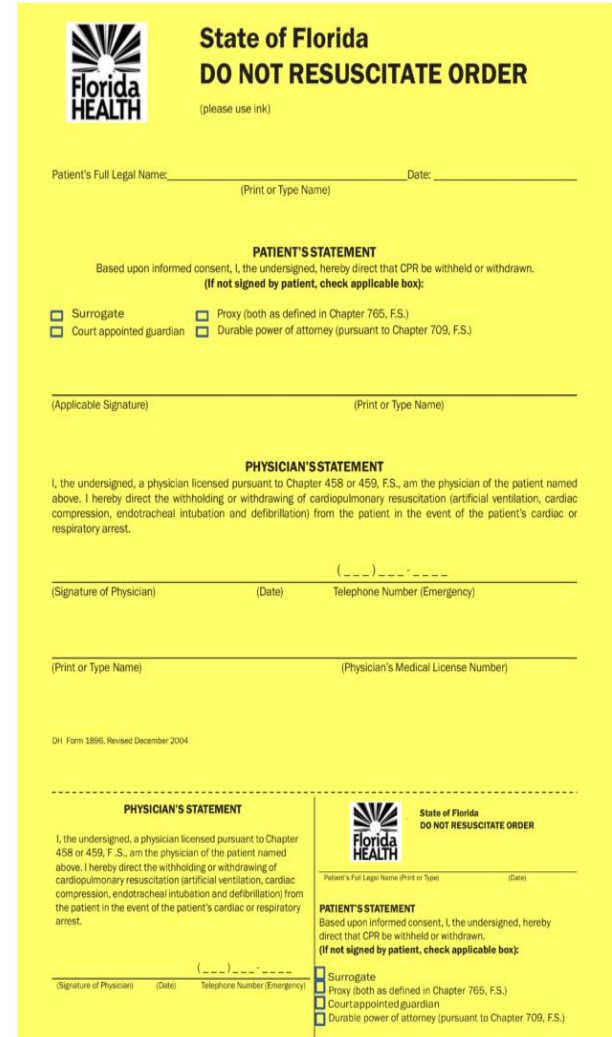
Advance care planning

- Process by which patients can delineate their wishes and preferences regarding future medical care
- Directives are only implemented when a patient loses the ability of making medical decisions on their own
- Legal documents directing medical care
- As the medical course of the patient changes, advance care planning should be readdressed with the continued focus remaining on honoring patients' preferences
- Can be revoked or changed at any time by the patient

Code Status

- Types of code statuses
 - Full Code
 - DNR– No Intubation/No ACLS (No Code)
 - DNR Comfort Measures Only (CMO)

Patients can continue treatment and still be a DNR



State of Florida
DO NOT RESUSCITATE ORDER
(please use ink)

Patient's Full Legal Name: _____ Date: _____
(Print or Type Name)

PATIENT'S STATEMENT
Based upon informed consent, I, the undersigned, hereby direct that CPR be withheld or withdrawn.
(If not signed by patient, check applicable box):

Surrogate Proxy (both as defined in Chapter 765, F.S.)
 Court appointed guardian Durable power of attorney (pursuant to Chapter 709, F.S.)

(Applicable Signature) (Print or Type Name)

PHYSICIAN'S STATEMENT
I, the undersigned, a physician licensed pursuant to Chapter 458 or 459, F.S., am the physician of the patient named above. I hereby direct the withholding or withdrawing of cardiopulmonary resuscitation (artificial ventilation, cardiac compression, endotracheal intubation and defibrillation) from the patient in the event of the patient's cardiac or respiratory arrest.

(Signature of Physician) (Date) Telephone Number (Emergency) _____

(Print or Type Name) (Physician's Medical License Number)

DH Form 1896, Revised December 2004

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Palliative Care vs Hospice

- Palliative care differs from hospice in that it does not solely focus on end of life
- Initiated at any stage of the disease and at any time during the disease trajectory
- Can be used in conjunction with curative treatment
- Focuses on a wide spectrum of disease

Hospice

- Palliative Care for patients with life-limiting illness
- Began in the United States in 1965 when Dame Cicely Saunders came to speak at Yale about the care of dying (National Hospice and Palliative Care Organization, 2016)
- Founder, Florence Wald, Hospice of Connecticut, 1974 (National Hospice and Palliative Care Organization, 2016)
- Model of care for people who are facing life-limiting illness (National Hospice and Palliative Care Organization, 2018)
- Encompasses expert medical care, pain & symptom management, and emotional and spiritual support which is personalized to the pt's wishes and goals & focuses on quality of life and living life to the fullest

Hospice Care


- Usually provided in the home but can be provided in other settings
- Care is provided by interdisciplinary team and the family/significant other(s) who serve as the primary caregiver (National Hospice and Palliative Organization, 2018)
- Services address the physical, psychosocial, and spiritual needs of the pt and their family caregivers
- Upon election of hospice care, pts forgoes all treatments with curative intent & focus on comfort

Our Culture and Reaction to Dying

- Prolonging life by using medical technology has increased with more people dying in the hospital
- Oldest and frailest citizens live in nursing homes and assisted living facilities, shielding society from the realities of aging or death
- Death denying described in 1970s as identified by Kubler-Ross

Our Culture and Reaction to Dying

Some hospices have
dropped the word
hospice from their
name to make the
concept of hospice
more palatable



Added palliative care
services



Changed name from
palliative care to
supportive care

Perceptions of Hospice

Last resort

A place to die

A method to hasten death

Denies access to life saving
treatments

“Giving up”

Policy and Payment

- Covered by Medicare, Medicaid, Veteran's Health Administration and most private insurance
- Medicare is the largest payer for hospice services through the Hospice Medicare Benefit (Institute of Medicine, 2015)
- Medicare pays a set daily rate
- To be eligible for the hospice Medicare benefit, two physicians must attest that the individual has a prognosis of six months or less
- Hospice Medicare Benefit has four levels of care to meet patients' clinical needs: routine home care, general inpatient care, and inpatient respite care
- Most hospices meet numerous regulatory standards to provide quality care and eliminate fraud

Current Trends in Hospice Care in the United States

- Hospice utilization will continue to grow
- As we grow older, our Medicare population grows
- May be influenced by the increase in the number of for-profit hospices
- Trend towards the use of experiential and alternative therapies
- Emerging trend of telemedicine in hospice care
- Regulatory issues with scrutiny of hospice compliance

Care at End of Life

Observable Physical
Changes as Death
Approaches

Common Symptoms
in Cancer at End of
Life and Their
Management

Psychosocial
Dimensions of Care

Stages of Death and Dying

- Denial – Refuses to believe
- Anger- When no longer able to deny
- Bargaining- Accepts death, but wants more time
- Depression- Determines death will come soon
- Acceptance- Understand and accepts situation

Stage I

Early Phase of Dying

- Few days to several weeks
 - Terminal Anorexia
 - Dysphagia
 - Early satiety
 - Fatigue/Drowsiness
 - Weakness

Stage II

Middle Phase of Dying

- Last few hours to several days
 - Changes in BP and HR
 - Cool Extremities and Cyanosis
 - Oliguria (< 500 mL)
 - Bedbound
 - Severe Dysphagia
 - Cheyne Stokes Respirations
 - Death Rattle/Airway Congestion
 - Near Comatose
 - Terminal Delirium
 - Respirations by Mandibular Movement

Stage III

Last Stage of Dying

- Hours
 - Increasing Cheyne Stokes with longer periods of apnea & rate decreasing
 - Chest congestion and throat rattling (Death rattle)
 - Mottling in extremities (blotchy, red-purplish marbling of the skin)
 - Neck Hyperextension with mouth breathing
 - Lack of Rectal Tone
 - Loss of Radial Pulses
 - Restlessness/Agitation

Imminent Death

- Expected within hours
- Death Rattle
- Cyanosis/Mottling
- Long shallow, irregular, apneic pauses
- Loss of Both Radial Pulses

Management

- Provide support
- Promote healthy grieving
- Ensure that the Family/Caregiver understands the signs of dying
- Consider spiritual care and social work consults
- Support cultural practices
- Ensure deactivation of implanted devices
- Ensure that caregivers understand and will honor advance directives of patient
- Offer anticipatory bereavement support

Common Symptoms in Cancer at End of Life

- Pain
 - Assess
 - Manage with Opioids which may include SL, IV, or SQ
 - Opioid doses should not be reduced for decreased bp, respiration rate, or level of consciousness
 - Opioids should be titrated aggressively to provide optimal comfort

Terminal Secretions

- Reduce parenteral and enteral fluids
- Reposition the patient
- Avoid deep suctioning
- Scopolamine 1.5 mg patch Q 72 h
- Atropine ophthalmic drops 1% 1-2 gtts SL q 4h PRN
- Glycopyrrolate 0.2-0.4 mg IV or SQ q 4h PRN
- Hyoscyamine 0.125 mg SL q 4h PRN

Dyspnea

- Most common symptom with advanced lung cancer
- Fan directed at the face
- Cooler temperatures
- Supplemental oxygen
- Treatment with:
 - Benzodiazepines
 - Lorazepam 0.25-1 mg PO/SL/IV q 4 h PRN
 - Opioids
 - Morphine 2.5-10 mg SL/PO q 2 h PRN or 1-3 mg IV q 2 h PRN

Terminal Delirium

- Hypoactive versus hyperactive
- Benzodiazepines should not be used as initial treatment of delirium
- Benzodiazepines may be effective in the setting of persistent agitation
- Haloperidol is 1st line agent for managing symptoms of delirium
- Provide family/caregiver support and education
- Decrease doses of medications dependent upon hepatic or renal function
- Consider that under-or over treatment of pain may exacerbate delirium

Terminal Delirium

- Mild to moderate delirium
 - Haloperidol, 0.5-2 mg PO BID/TID
 - Alternatives: Risperidone 0.5-1 mg PO BID; olanzapine, 5-20 mg PO daily; quetiapine fumarate, 25-200 mg PO/SL BID
- Severe delirium (agitation)
 - Haloperidol, 0.5-2 mg IV every 1 to 4h PRN
 - Alternatives: olanzapine, 2.5-7.5 mg PO/SL every 2-4h PRN (maximum = 30 mg/d); chlorpromazine, 25-100 mg PO/PR/IV q 4h PRN
- Palliative sedation
 - Midazolam, continuous infusion
 - Propofol, continuous infusion

Psychosocial Dimensions of Care

- Functional Losses
 - Unable to work / handle personal affairs
 - Loss of sense of enjoyment
 - Limited social contacts

Psychosocial Dimensions of Care

- Patient Reactions
 - Self Pity
 - Fear
 - Anger
 - Worry over not completing tasks or reaching life goals
 - Development of apathy, withdrawal, and depression

Psychosocial Dimensions of Care

- Family Relationships
 - Burdened by concern for family
 - What will happen to loved ones
 - Spouses being able to cope with finances
 - End of shared promises and experiences

Psychosocial Dimensions of Care

- Personal Dignity

Treating patient as person, not disease

Myth vs Fact

Palliative care is just for individuals with cancer

Myth vs Fact

Only people who are “very ill or dying” can complete advanced directives

Myth vs Fact

- Discussing palliative care with individuals and caregivers can “be discouraging and diminish hope”

Myth vs Fact

Palliative care can only be utilized for pain and other physical symptoms

Pearls

Be

Honest

Be

Empathetic

Be

compassionate

THANK YOU

Questions?

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