

## Palliative Care

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## Palliative care

- Identifying appropriate palliative consultations
- Primary vs. specialty palliative care  
(The oncology nurse as a palliative provider)
- Symptom management gems
- Communication strategies
- Coping and Self-Care

## Definition of Palliative Care

Specialized medical care for people with **serious illnesses**... focused on providing patients with relief from the symptoms, pain, and stress of a serious illness - whatever the diagnosis

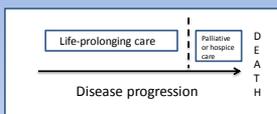
The goal is to **improve quality of life** for both the patient and family... provided by a team of doctors, nurses, and other specialists who work with a patient's other doctors to provide an **extra layer of support**

Palliative care is appropriate at any age and at any stage in a serious illness, and can be **provided together with curative treatment**

Center to Advance Palliative Care 2011



Dichotomous model of health care delivery:

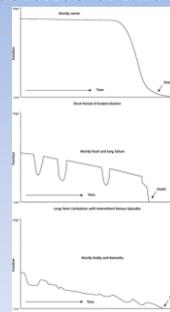


- Early models: "Life-prolonging vs. palliative care"
  - Palliative care was
    - Equated with "end-of-life" only
    - Delivered late in course of illness
    - ICU's, or uncontrolled symptoms
    - Interventions were too late, no longer desired
  - Driven by reimbursement system:
    - Regular Medicare covers curative therapies
    - Medicare hospice covers comfort care

Annals of Internal Medicine

ESTABLISHED IN 1917 BY THE AMERICAN COLLEGE OF PHYSICIANS

3 common trajectories of late-life illness:



From: Evidence for Improving Palliative Care at the End of Life: A Systematic Review. *Ann Intern Med.* 2008;148(2):147-159. doi:10.7326/0003-4819-148-2-200801150-00001. Copyright reserved.

Palliative care vs. hospice:  
Related but distinct

	Palliative Care	Hospice
Initiation	Ideally with onset of symptoms, or anywhere along disease trajectory	During the last 6 mos. or less of illness
Life-prolonging therapy?	May continue concurrently	Not allowed, per Medicare criteria
Site of care delivery	In hospitals or outpatient settings, expanding...	At home, or in long-term care or contracted facilities
Goals of care	<ul style="list-style-type: none"> <li>• Goal-setting (cure, life prolongation, QOL, function)</li> <li>• Symptom management</li> <li>• Enhance quality of life</li> <li>• Maximize function</li> <li>• Support primary care team before patient is terminally ill</li> </ul>	<ul style="list-style-type: none"> <li>• Inherently recognizes end-of-life</li> <li>• Symptom management</li> <li>• Often assumes care of the patient from primary care during the terminal phase</li> </ul>
Interdisciplinary	Yes	Yes

Goals of palliative care

- Improving quality of life
  - Comprehensive symptom management
  - Patient and family support
  - Spiritual support
- Assistance with decision-making
  - Shared decision making
  - Goals of care
  - Advance care planning
- Communication amongst all those involved in care
- Coordination across all sites of care
- Minimize invasive interventions in late stages of illness
- Staff support

## Palliative care specialists can not assume all aspects of care

- Important for Palliative Care tools and techniques to be incorporated into basic nursing skill sets and standards of practice.
- Nurses play a crucial role in communication and symptom management in patients with advanced illness.
- Nurses should have a meaningful presence in all phases of care and planning. Attend those family meetings.

## PRIMARY AND SPECIALTY PALLIATIVE CARE

- Primary palliative care
  - Care provided by all clinicians caring for patients with serious illness
- Specialty palliative care
  - Care provided by palliative care specialists including physicians, nurses, social workers, spiritual care providers and others

## Primary palliative care

- Basic management of pain and symptoms
- Basic management of depression and anxiety
- Basic discussions about
  - Prognosis
  - Goals of treatment
  - Suffering
  - Code status

Quill TE, Abernethy AP. Generalist plus specialist palliative care—creating a more sustainable model. NEJM 2013; 368(13): 1173-75

## Specialty palliative care

- Management of refractory pain or other symptoms
- Management of more complex depression, anxiety, grief, and existential distress
- Assistance with conflict resolution regarding goals or methods of treatment
  - Within families
  - Between staff and families
  - Among treatment teams
- Assistance in addressing cases of near futility

Quill TE, Abernethy AP. Generalist plus specialist palliative care—creating a more sustainable model. NEJM 2013; 368(13): 1173-75

## When to seek palliative care

- A potentially life-limiting or life-threatening condition and...
  - Primary criteria
    - The “surprise question”: You would not be surprised if the patient died within 12 months.
    - Frequent admissions (e.g. more than 1 admission for same condition within several months)
    - Complex care requirement (e.g. functional dependency; complex home support for ventilator/antibiotics/feedings)
    - Declines in function, feeding intolerance, or unintended decline in weight (e.g. failure to thrive)

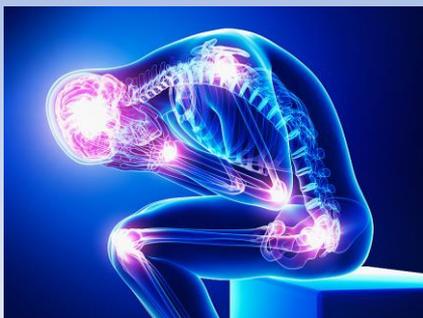
Weissman DE, Meier DE. Identifying patients in need of a palliative care assessment in the hospital setting: A consensus report from the Center to Advance Palliative Care. *Journal of Palliative Medicine* 2011; 14(1): 17-22

## Criteria for a palliative care assessment: at the time of admission

- Secondary criteria
  - Admission from long-term care facility or medical foster home
  - Elderly patient, cognitively impaired, with acute hip fracture
  - Metastatic or locally advanced incurable cancer
  - Chronic home oxygen use
  - Out-of-hospital cardiac arrest
  - Current or past hospice program enrollee
  - Limited social support (e.g. family stress, chronic mental illness)
  - No history of completing an advance care planning discussion/document

Weissman DE, Meier DE. Identifying patients in need of a palliative care assessment in the hospital setting: A consensus report from the Center to Advance Palliative Care. *Journal of Palliative Medicine* 2011; 14(1): 17-22

## Symptom Management Basics



## Oral morphine equivalents

- The “1:2:3” rule:
  - 1 mg IV MS =
  - 2 mg po oxycodone =
  - 3 mg po MS
- The “30:20:10:7.5:1.5” rule:
  - 30 mg po MS =
  - 20 mg po oxycodone =
  - 10 mg IV MS =
  - 7.5 mg po hydromorphone =
  - 1.5 mg IV hydromorphone

Example:  
Pt. taking MS Contin 60 mg q12h +  
oxycodone 10 mg q4h prn, 5x/d.  
How many oral morphine equivalents?

Ans:		
Morphine	60 x 2 =	120
Oxycodone	10 x 5 x (3/2) =	75
Oral morphine equivalents		195

## Management of opioid side effects

- Nausea
  - Usually temporary, 3-5 days
  - Antidopaminergic antiemetics (metoclopramide, prochlorperazine)
  - Refractory—try corticosteroids, or ondansetron
  - More constant drug levels helpful—change to long-acting, topical, or shorter dose intervals
- Constipation
  - stimulant (Senna or bisacodyl), or osmotic laxative (polyethylene glycol; or mag. citrate, lactulose)
  - Stool softeners alone ineffective
- Pruritus
  - Rare; caused by histamine release
  - Switch to another opioid
  - antihistamines
- Sedation
  - Dissipates as tolerance develops
  - Dose reduction or drug rotation

## Visceral pain

- Dull, colicky, poorly localized
- Caused by distention, torsion, inflammation
- Pancreatic, hepatic, renal, intestinal cancer
- Autonomic symptoms—nausea, diaphoresis
- Referred pain—liver, gallbladder -> R shoulder
- Constipation—disease, meds., immobility
- Palliative surgery to relieve obstruction
- Blockade of celiac, sympathetic or splanchnic plexuses

## Neuropathic pain

- Direct pathologic changes to central or peripheral nervous system
  - Nerve root compression, encroachment of fibers on nerve plexus
  - Burning, tingling, stabbing, shooting
- Corticosteroids
  - reduce edema and pain of obstruction; improve mood/appetite/energy
  - Lyse certain tumors, enhancing analgesic effects of pain meds.
  - Effective for:
    - malignant infiltration of brachial and lumbar plexus
    - cord compression
    - headache from brain tumors
- Peripheral neuropathy
  - Opioids
  - TCA's
  - Venlafaxine or duloxetine—for dual pain and depression
  - Gabapentin
  - Pregabalin

## Bone pain

- Bone metastases
  - XRT
  - Corticosteroids
  - Bisphosphonates
  - Interventional procedures
    - Cryoablation
    - Radiofrequency ablation

## Fatigue

- The most common symptom
- Underdiagnosed, undertreated
- Contributors
  - Cancer, cancer treatment, anemia, mood disorders, sleep, pain/anxiety, infections, deconditioning, cachexia, hypoxia, dehydration, polypharmacy, etc.
- Treatment—aimed at underlying causes
  - Pharm: steroid, megestrol, methylphenidate, antidepressants

## Dyspnea

- Causes:
  - Cardiac or pulmonary processes
  - Debilitation
  - Wasting syndromes
  - Neurodegenerative disorders
  - Progressive, chronic disease
- Potentially treatable causes
  - Pleural effusions
  - Pneumonia
  - Severe anemia
  - Ascites
- Subjective severity correlates poorly with resp. rate, ABG, SaO<sub>2</sub> %, use of accessory muscles

## Dyspnea

- Treatment:
  - **Gold standard: oral morphine**, low dose 10-20 mg/day
  - Benzodiazepines NOT consistently useful, unless treating anxiety
  - O<sub>2</sub>: useful if hypoxemic, but otherwise no better than room air
  - Nonpharmacologic
    - Breathing training, gait aids, neuroelectrical muscle stimulation, chest wall vibration
    - Music therapy, relaxation, fan use, counseling, psychotherapy

## Nausea: which treatment for which cause?

- Opioids: dopaminergic signaling (metoclopramide, prochlorperazine)
- Chemotherapy: serotonin antagonists (ondansetron)
- Increased intracranial pressure: corticosteroids
- Mechanical bowel obstruction:
  - Pharm: dexamethasone, octreotide, haloperidol
  - Non-pharm: venting gastrostomy; sleeve
- Radiation: serotonin antagonists (ondansetron)
- Motion sickness, cerebellar mets.: anticholinergic antihistamines (scopolamine, meclizine, diphenhydramine)
- If obstruction ruled out: metoclopramide + dexamethasone; glycopyrrolate (antichol.)

Common causes of nausea and vomiting in palliative care

Toxic/metabolic	Disorders of viscera	CNS causes
<b>Drugs</b>	<b>Obstruction</b>	<b>Increased intracranial pressure</b>
Cytotoxic chemotherapy	Gastric outlet	Malignancy
Opioids, tramadol	Small bowel	Hemorrhage
NSAIDs, aspirin	Biliary/pancreatic duct	Cranial irradiation
Digitalis	Constipation	<b>Abscess</b>
Iron	<b>Gastroparesis</b>	<b>Vestibular</b>
Antibiotics	<b>Inflammation/irritation</b>	Drug effects
Theophylline	NSAID	Labyrinthitis
SRIs and bupropion	Chemotherapy: (direct GI effects)	<b>Anxiety</b>
Many other drugs	Radiation	Anticipatory nausea and vomiting
<b>Organ failure</b>	Gastritis	
Liver, renal	Gastroenteritis	
<b>Metabolic</b>	Hepatitis	
Hypercalcemia	Cholecystitis	
Hyponatremia	Pancreatitis	
Ketoacidosis	<b>Tumors of the gastrointestinal tract and thorax</b>	
<b>Poisoning</b>		
<b>Substance abuse</b>		

SSRI: selective serotonin reuptake inhibitor.

UpToDate

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## Agitation, distress

- Reversible causes: pain, urinary retention, fecal impaction
- Delirium: diagnosis of exclusion
- Manifestations of distress: non-specific
  - Hyperactivity vs. apathy
  - Moaning or grunting
  - Irregular breathing and tracheal secretions (“death rattle”)
- Very distressing for families; clinician plays key role in educating re. signs of death and dying
- Prophylactic anticholinergics (scopolamine) during active dying reduce tracheal secretions

## Delirium

- Definition: acute change in mental status
- R/O treatable causes: meds., pain, urinary obstruction, bowel impaction, sensory deprivation
- Treatment:
  - Small doses haloperidol; chlorpromazine (10-25 mg po or sq; more sedating)
  - Avoid benzos: paradoxical worsening
  - Non-pharm: re-orienting; bedside sitter

## Depression

- Transiently depressed mood normal in serious, life-threatening illness
- Symptoms persisting weeks and meeting diagnostic criteria for depression are not “normal”, and should be treated
  - Grief vs. depression
- Pharmacologic treatments:
  - SSRIs
  - Methylphenidate
  - Mirtazapine (depression w/ insomnia, anorexia)
  - TCA’s, duloxetine, venlafaxine (w/ neuropathic pain)

## Anorexia

- Common in cancer and chronic disease
- Eating/enjoying food essential in social interactions
- Distressing to patients and families
  - “Giving up!”, guilt for caregivers and patients
- Educating patients and caregivers
- Appetite stimulants if death not imminent
  - Progestins
    - megestrol 400-800 mg po qd
    - Medroxyprogesterone 500 mg po bid
    - Side effects: thromboembolic, hyperglycemia, adrenal suppression, vaginal bleeding
  - Corticosteroids
    - Dexamethasone 2-4 mg po bid
  - No impact on mortality, +/- QOL

## Summary: Evidence based interventions

1. Regularly assess patients for:
  - Pain
  - Dyspnea
  - Depression
2. Use therapies of proven effectiveness to manage pain
  - NSAID's
  - Opioids
  - Bisphosphonates (bone pain in breast ca, myeloma)
3. Use therapies of proven effectiveness to manage dyspnea
  - Opioids
  - O2 for hypoxemia
  - Beta-agonists (COPD)
4. Use therapies of proven effectiveness to manage depression
  - SSRIs, TCAs
  - Psychosocial intervention
5. Ensure advance care planning occurs
  - Surrogate decision makers
  - Resuscitation and emergency treatment
  - Should occur early in course
  - Discussions about
    - Tube feedings
    - Initiate or continue cancer chemotherapy
    - Deactivate implantable defibrillators

Qaseem A, et al. Evidence-based interventions to improve the palliative care of pain, dyspnea, and depression at the end of life: A clinical practice guideline from the American College of Physicians. Ann Intern Med 2008; 148: 141-46

## Alternative Therapies

- Tesla balls, Bacon Wraps, Foldger's Crystals, copper panels, light therapy, Frankincense, photon balancing, goat testicles, Ph balancing, shredded beets in Mexico, dining on endangered species?! How do you support hope and desperation and individual choice and how do you protect vulnerable patients from con artists and hucksters.

## Issues Specific to WA

(\*Not practiced w/in VA-Federal system)

### Medical Marijuana

- Focusing on safety

### Physician Assisted Suicide

- Addressing the concerns, fears and emotions behind the question first. Educating people about all options including palliative sedation. Policy varies by facility.
- Online resources available.

## Spiritual and psychological distress

- “Are spirituality or religion important in your life?”
- “What brings purpose to your life?”
- “This sort of illness often raises significant questions...How are you dealing with this?”
- Consult your Chaplain!
- “Hoping for a Miracle”

## Miracles

- Emotional adaptation
- Avoidance mechanism
- Expression of religious beliefs
- A test of faith
- Last hope



## Belief in Miracles

- 57 % believed God could save patient even if MDs declared treatment futile
- 1 in 5 MDs & medical workers believed God could reverse a hopeless outcome
- 61 % of 1006 adults believed a person in a vegetative state could be saved by a miracle
- 20.2 % of trauma professionals believed the same

Jacobs LM, Burns K, Bennett Jacobs B. Arch Surg 2008; 143:730-35

## Factors contributing to effective coping

- Good communication
- Trust among patient, family, and clinical team
- Opportunities to share fears and concerns
- Meticulous attention to physical symptoms
- Attention to psychological and spiritual concerns

## Communication Challenges



## Communication in the acute setting

- Effective communication skills
  - To family, more important than clinical skills
  - Only ½ of families understand basic information
  - Use simple explanations
  - Use the words “dying” and “death”
  - Use a professional interpreter
- Words to avoid:
  - Withdrawal of CARE
  - There’s nothing more we can do

## Words that Work

- Ask
  - What do you understand?
  - What do you want to know?
- Tell
  - Necessary information
- Ask
  - Their understanding
- “I wish”
- “I worry”



## Guided Narrative

*Stu & Lu Farber 2013, may use for education only, all other uses require permission*

### What do you already know?

- ❖ What is your understanding of your situation?
- ❖ How do you see things?

### What is important to you right now?

- ❖ What is important to discuss today?
- ❖ What do you see as your future?

### What are your experiences?

- ❖ Have you ever cared for someone who is seriously ill?
- ❖ What are your experiences with loss?

### How do you cope with difficulties?

- ❖ Where do you draw strength to get through each day?

## Guided Narrative

Stu & Lu Farber 2013, may use for education only, all other uses require permission

### **Who are your social supports?**

- ❖ Who would speak for you if you can't?
- ❖ Who will you depend on for help?

### **What are your goals for care?**

- ❖ What are you hoping for?
- ❖ What are you concerned (worried) about?
- ❖ What do you feel is really important to do in the time left to you?

**What else do you want me to know about who you are or what you believe?**

## Allowing time



- 64% doubted prognosis
- <2% based their belief on MDs prognosis
- 32% chose life support with < 1% chance of survival

Zier LS et al. Chest 2009;126:1 Jul 2009, 110-117

## What about you?

- Self care:
  - Recognize how patient's death impacts you
  - Recognize signs of moral distress
  - Recognize signs of compassion fatigue
  - Know signs of Burnout
- Resources:
  - Chaplain
  - Preceptor / mentor
  - Co-workers
  - Manager
  - Palliative Care team
  - Employee Assistance Programs
  - Professional counseling

## Surviving in the “grey area”

- “The key to mindfulness is learning to look at the world in a more conditional way. Understanding that our perspective is merely one among alternative views requires us to embrace uncertainty. When we're uncertain and unsure, our surroundings become interesting again, like the peculiar little details we notice when we arrive in an unfamiliar place.”

## Mindfulness Technique:

(becoming less reactive)

Facing crisis or tough problem:

- Recognize you've already made unwarranted assumptions (Something is going to happen, that something will be bad)
- Give yourself 3 reasons the worrisome issue might not happen
- Give yourself 3 reasons that if it does happen and turn out bad, good things will also happen (what are the good outcomes in addition to the bad)

## What does Saving Lives Mean?

Redefining our perspective

- Physical recovery to meaningful life?
- Patient/family definition may be ok with what we ourselves perceive as "poor" quality of life
- May have alternative meanings: Peace of mind, creating meaningful living and dying experiences, closure, recognizing and validating a life well lived (or endured,) developing story or narrative about past, healing relationships, not letting people get lost in fear and loneliness, being there to hear and recognize and validate their experience.

## Learning the backstory...

- Fully understanding the patient and family experience, knowing who they are
- Motives and choices gleaned from a life story
- Eliminate assumptions and prejudice
- Read multidisciplinary notes, share the story with the entire team, develop care plan accordingly
- Pictures, "getting to know you poster," life review, and reminiscence questions

*Create an understanding of why people make specific choices, based on their own complex life experiences*

## Self Care:

- Consider grief resolution rituals/ceremonies
- Debriefing for stressful cases or loss
- Peer-supported story telling, group outings/gatherings



## Self Kindness

- Cultivate an awareness of when you are self-criticizing, blaming or condemning and **STOP**.
- Remind yourself of the good nursing practices you engaged today
- Give yourself three compliments about what you've done well
- Celebrate and share the little moments of success, humor, teamwork



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New York Times Articles:

"Achieving Mindfulness at Work, No Meditation Cushion Required" April 23, 2016 By Matthew E. May

"A Letter to the Doctors and Nurses Who Cared for My Wife" October 6, 2016 by Peter DeMarco

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- Center to Advance Palliative Care [www.capc.org](http://www.capc.org)
- American Academy of Hospice and Palliative Medicine [www.aahpm.org](http://www.aahpm.org)
- National Hospice and Palliative Care Organization [www.nhpo.org](http://www.nhpo.org)
- Caring Connections (Patient and Family Resource) [www.caringconnections.org](http://www.caringconnections.org)
- Get Palliative Care (Patient and Family Resource) [www.getpalliativecare.org](http://www.getpalliativecare.org)
- End of Life/Palliative Education Resource Center [www.eperc.mcw.edu](http://www.eperc.mcw.edu)