END OF LIFE CARE: focus on support and comfort

Ken Cearlock, MD
“Be careful if you don’t know where you are going, you might not get there.”

- Yogi Berra
Objectives

• Define palliative care, palliative medicine, palliative therapies
  • Review how “curative” and “palliative” integrate in patient care.

• Review process of creating Goals of Care

• Review symptom management, including pain management, in context of palliative medicine.

• Advanced directives

• Identify non-cancer terminal diagnoses that can be cared for in a palliative medicine model, including hospice eligibility criteria.

• Differentiate Palliative care and Hospice

• Indications for Hospice care

ENCOURAGE, ENTHUSE, MOTIVATE
What is end of life (EOL) care?

- Important part of palliative care
- Refers to the care of a person during the “last part” of their life, from the point at which it has become clear that the person is in a progressive state of decline, may be from hours to months depending on the clinical situation.
- May be referred to as terminal illness and terminal care.
What is Palliative Care?

- The World Health Organization describes palliative care as "an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other physical, psychosocial and spiritual problems."
WHO Definition of Palliative Care

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;
WHO Definition of Palliative Care (cont.)

- offers a support system to help the family cope during the patients illness and in their own bereavement;
- uses a team approach to address the needs of patients and their families, including bereavement counseling, if indicated;
- will enhance quality of life, and may also positively influence the course of illness;
- is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.
“Half of this game is 90% mental.”

- Yogi Berra
APTITUDE

ATTITUDE
“Were lost but we are making good time.”

-Yogi Berra
## Top 10 Causes of Death, United States, 2011

<table>
<thead>
<tr>
<th>Rank</th>
<th>Cause of Death</th>
<th>ICD-9 Code</th>
<th>Number</th>
<th>Death Rate</th>
<th>Age-Adjusted Death Rate</th>
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</thead>
<tbody>
<tr>
<td>1</td>
<td>Diseases of the heart</td>
<td>I00-I09, I11, I13, I20-I51</td>
<td>596,339</td>
<td>191.4</td>
<td>173.7</td>
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<tr>
<td>2</td>
<td>Malignant neoplasms</td>
<td>C00-C97</td>
<td>575,313</td>
<td>184.6</td>
<td>166.6</td>
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<tr>
<td>3</td>
<td>Chronic lower respiratory diseases</td>
<td>J40-J47</td>
<td>143,382</td>
<td>46.0</td>
<td>42.7</td>
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<td>4</td>
<td>Cerebrovascular diseases</td>
<td>I60-I69</td>
<td>128,931</td>
<td>41.4</td>
<td>37.9</td>
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<tr>
<td>5</td>
<td>Accidents (unintentional injuries)</td>
<td>V01-X59, Y85-Y86</td>
<td>122,777</td>
<td>39.4</td>
<td>38.0</td>
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<tr>
<td>6</td>
<td>Alzheimer’s disease</td>
<td>G30</td>
<td>84,691</td>
<td>27.2</td>
<td>24.6</td>
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<tr>
<td>7</td>
<td>Diabetes mellitus</td>
<td>E10-E14</td>
<td>73,282</td>
<td>23.5</td>
<td>21.5</td>
</tr>
<tr>
<td>8</td>
<td>Influenza and pneumonia</td>
<td>J09-J18</td>
<td>53,667</td>
<td>17.2</td>
<td>15.7</td>
</tr>
<tr>
<td>9</td>
<td>Nephritis, nephrotic syndrome, and nephrosis</td>
<td>N00-N07, N17-N19, N25-N27</td>
<td>45,731</td>
<td>14.7</td>
<td>13.4</td>
</tr>
<tr>
<td>10</td>
<td>Intentional self-harm (suicide)</td>
<td>U03, X50-X84, Y87.0</td>
<td>38,285</td>
<td>12.3</td>
<td>12.0</td>
</tr>
</tbody>
</table>


* Based on number of deaths

* New subcategories replaced previous ones for N18 (Chronic kidney disease) in 2011. Changes affect comparability with previous year’s data.
Chronic diseases are the leading causes of death and disability.
As of 2012:

- About half of all adults—117 million people—have one or more chronic health conditions.
- One of four adults has two or more chronic health conditions.

117 Million Adults $\geq 1$ Chronic Condition
Chronic diseases are the leading causes of death and disability.

- In 2010:
  - Seven of the top 10 causes of death were chronic diseases.
  - Two of these—heart disease and cancer—together accounted for nearly 48% of all deaths.
“We made too many wrong mistakes.”

- Yogi Berra
Demographics

- 25% of deaths occur at home - more than 70% of Americans would prefer to die at home
Vitals Stats

- 90 million Americans are living with serious illness, and this number is expected to more than double over the next twenty-five years. (1)

- By 2030, according to the Administration on Aging (AoA), there will be more than 72.1 million Americans over age sixty-five in the U.S. (20 percent of the total U.S. population). That’s more than twice the number from 2000. (2)

Gaps in Care

50% of caregivers of Americans hospitalized with a serious illness report less than optimal care: (1)

- 1 in 4 patients report inadequate treatment of pain and shortness of breath. (1)
- 1 in 3 families report inadequate emotional support. (1)
- 1 in 3 patients report that they receive no education on how to treat their pain and other symptoms following a hospital stay. (2)
- 1 in 3 patients are not provided with arrangements for follow-up care after hospital discharge. (2)

2. The Commonwealth Fund. “Care coordination.” Quality Matters. 2007 May/June;24
Not your Momma’s Palliative Care: A Conceptual Shift

Old

Life Prolonging Care

Medicare Hospice Benefit

New

Life Prolonging Care

Palliative Care

Hospice Care

Bereavement

Dx

Death
Palliative Medicine

Palliative Medicine is a medical specialty that provides comprehensive, interdisciplinary care for patients with serious illnesses (and their families) with emphasis upon the quality of life and relief of suffering. Palliative Care is provided throughout the trajectory of a disease process without regard to prognosis and can be provided in concert with curative care, as well as near end of life. The Palliative Care team works with patients in conjunction with their primary care physician to address any physical, psychosocial, emotional or spiritual issues the patient may experience.
Typical Diagnoses in Palliative Care

- Cancer
- Heart Failure
- Chronic lung disease
- Kidney failure
- Dementia/stroke
- Multi-system disease
PC Consults: When?

- When the patient is having difficult to control symptoms
- For time-intensive patients/families
- When difficult conversations become challenging
- When prognosis is known to be or may be poor
- When families are distressed and needing support
- For assistance with coordination of care
- From diagnosis throughout the disease treatment as well as at the end-of-life...ANY AGE, ANY STAGE
Good News

- From 2000-2009, PCTs increased 138% to just over 1,500 in the US
- 2011 State-by-State Report Card on Access to Palliative Care in Our Nation's Hospitals (compared to 2008 Report Card)
  - Reflects data from the American Hospital Association Annual Survey Database™ for fiscal year 2009
  - Overall prevalence of hospital (50+ beds) PCTs increased:
    - 13.3 percent in the Midwest
    - 21.7 percent in the Northeast
    - 23.7 percent in the South
    - 29.3 percent in the West
  - Cumulative national average is 63 percent (1,568 out of 2,489 study hospitals)
History of Palliative Care

- Beginning of Time: caring for each other
- Middle Ages: Convents, Hostels, Hospitality Inns
- Early years of Medicine: symptom management, comfort, sitting bedside
- Modern Era: Treatment and Cure over comfort
- Modern Hospice Movement 1970’s
  - Dame Cicely Saunders
History of Palliative Care

- Hospice in the USA
  - Volunteer Team to provide supportive care for cancer patients, in their homes: late 1970’s, early 1980’s.
  - Medicare Hospice Benefit: 1980’s
    - Non-Cancer diagnoses now more frequent than cancer diagnosis for hospice care.

- Palliative Medicine: recognized specialty for
  - physicians
  - nurse practitioners, nurses
  - Certified Nurse Assistants
“He hit from both sides of the plate, he is amphibious.”

- Yogi Berra
Curative and Palliative Model

World Health Model

Curative Model

Palliative model

Medical Condition over time

Death
Good News

- In 2008, our nation received an overall grade of C.
- In 2011, the country receives an overall grade of B.
- Seven states plus the District of Columbia now receive a grade of A, with more than 80 percent of hospitals reporting palliative care services.
- More than half of the fifty states receive a grade of B.
- Fewer than 25 percent of states now need significant improvement (C). *
- Approximately 12 percent receive non-passing grades of D or F.
“If you can’t imitate it, don’t copy it.”

- Yogi Berra
Blending the Best

Goals of Rehabilitation in Palliative Care:
- To eliminate or reduce disability by optimizing pt’s functional status and physical independence
- Improve Quality of Life
- Improve Mood
- Decrease Fatigue, Decrease Pain

J Pall Med 2003; 6:11-17, Montagnini et al
How to Introduce PC

Suggestion:

“The Palliative team will be coming to visit with you and your family. They often assist us with our patients and families who are facing serious illness and need symptom management and supportive care.”
“I wish I had an answer to that, cause I’m tired of answering that question.”

- Yogi Berra
Realistic Goals

- Distinguish “FIXABLE” from “UNFIXABLE”
- Inherent uncertainty to determine prognosis
  “Best estimate based on current condition”
- Clinicians are generally over optimistic in determining prognosis
  - The better a patient is known, the less able we are to give an accurate prognosis
- Tell the Truth
  “I can tell you on average, what I’ve seen…”
Hospice

- A philosophy of care to assist those in the end stage of life
- Model of care originated in England
- First hospice in United States was in New Haven, Conn., 1976
- Fast Growth -- currently over 3500 hospice programs in United States
Hospice Referral

- Whenever the thought enters your mind that a patient could be dying
- Ask “would I be surprised if this pt wasn’t alive in 1 year?”

Prognostication

- Physicians are uniformly overly optimistic about survival— SUPPORT study, JAMA 1995
- Consider Medicare guidelines for prognosis i.e. FAST stage 7C for dementia
Common Hospice Diagnoses

- Cancer
- End-stage Heart Disease
- End-Stage Lung Disease
- End-Stage Renal Disease
- End-Stage Liver Disease
- Stroke/coma
- HIV
- Neurological Disease – Parkinsons, Alzheimers
- General Decline in Health Status
Levels of Care

- Routine Home Care
- General Inpatient Care
  - 24 Hour Nurse for Short-term Stay
- Respite Care for Caregiver Stress
- Continuous Care
  - Expanded Level of Skilled Nursing
Major issues in End of Life Planning

- Pro-active approach
- Reduce hospitalizations
- Need for better advance care planning
  - Resuscitation directive: to have or not
  - Involvement of social work
  - Care conferencing in skilled care
“You can observe a lot by just watching.”

- Yogi Berra
Palliative Medicine Domains

- Goals of care
- Symptom management
- Resuscitation status
- Advance Directives/POA
- Psychosocial/Spiritual issues

Key components:
- Focus on quality of life
- Team approach for holistic care
- Primary “procedure”: FAMILY MEETING
Primary vs. Secondary Palliative Care

- **Primary**
  - Core skill set expected of all primary care physicians

- **Secondary**
  - Skill set and practice pattern peculiar to the new specialty
Hospice

- The subset of palliative care devoted purely to comfort care at the end of life
Hospice

- Interdisciplinary Team (IDT)
  - Physician
  - Nurse
  - Social worker
  - Home health aides
  - Spiritual care
  - Volunteers
  - Pharmacy
  - Additional therapies as needed—music, massage, PT/OT, wound care

- Any tests or treatment related to terminal condition, including meds

- Durable medical equipment
Hospice

- Criteria for hospice admission
  - Presence of disease which would result in life expectancy of < 6 months if it took its natural course
  - Pt. is willing to forgo further curative treatment for the terminal dx
- Pt elects Medicare Hospice benefit, which pays for all services related to terminal dx under Medicare Part A (payment is per diem)
- Other third party payors generally follow Medicare guidelines—sometimes they will also cover treatments such as palliative chemotherapy
“He must have made that before he died.”

- Yogi Berra
Advance Directives

- Resuscitation/life support
- Living will/POA
- IPOST
“If the world were perfect, it wouldn’t be.”

-Yogi Berra
Palliative Treatments

- All types of therapeutic measures, including very aggressive therapies, that are utilized to control pain and other distressing symptoms.
- These therapies will not change the course of the condition, the intention is to relieve the pain or symptom.
Palliative vs. Hospice Care

- Division made between these two terms in the United States
- Hospice is a “type” of palliative care for those who are at the end of their lives.

Image courtesy of http://www.ersj.org.uk/content/32/3/796.full
“We have deep depth.”

- Yogi Berra
Palliative Care Is Effective

• Successful palliative care teams require nurturing individuals who are willing to collaborate with one another.

• Researchers have studied the positive effects palliative care has on patients. Recent studies show that patients who receive palliative care report improvement in:
  • Pain and other distressing symptoms, such as nausea or shortness of breath
  • Communication with their doctors and family members
  • Emotional and psychological state
Palliative Medicine

- Specialized area of medicine that addresses care for patients whose diseases are not responsive to curative treatment measures.

- Hospice: refers to a program that uses an interdisciplinary team to provide comprehensive palliative care specifically for terminally ill patients.
“If people don’t want to come to the ballpark, how ya gonna stop them.”

- Yogi Berra
“Balancing between the appropriateness of attempts to prolong life and the vigorous palliative management of symptoms”

Chris Cassel 2004
Preserving Personhood and Dignity

- Cleanliness and odor control
- Bathing and grooming
  - Face, hands, and feet
- Mouth care, nail care
- Clothing and bedding
- Promote home-like environment
  - Pictures, bedding, personal items
“When you come to the fork in the road, take it.”

- Yogi Berra
Goals of Care

- Patient/Resident specific
- Realistic
- Related to life expectancy
- Determined by care setting
- Patient/Resident driven
- Individual
Overall Goals of Palliative Care

- To eliminate or reduce discomfort
- To improve quality of life
- To improve mood
- To decrease fatigue
- To decrease pain
Goals of Care: When to Reassess

Triggers for reassessment:
- New symptoms
- Hospitalizations
- New diagnosis
- Functional change (specific monitored status)
- Care conferences
Palliative care emphasizes

- Maximizing **quality of life**.
- Management of pain and **symptoms**.
- **Communication** among the treating physicians.
- **Coordination** of medical and supportive services.
- Assistance with **patient decision-making** about care.
- **Support** for caregivers.
- Delivery by a **team**, including interpreters.
Palliative Care

Life-prolonging therapy

Hospice Care

Pain Management

Graphic by Anne Kinderman, MD; used with permission.
“Pair up in threes.”

-Yogi Berra
Who Provides Palliative Care?

• Nurse
• Nursing Assistant
• Physician
• Social Worker
• Dietitian
• Chaplain
• Physical/Occupational Therapist
• Recreation Therapist
Cultural Considerations

• Everyone has one or more cultures
• Race, ethnicity, religion, lifestyle contribute to culture
• Culture
  • Is manifested through values, customs, behaviors & beliefs
  • Affects decision-making and views re: death and dying and palliative care
Referral to Hospice

- 2 physicians certify patient has a severely life limiting condition of 6 mos or less.
- At certification and each recertification, hospice medical director prognosticates patient’s life limiting condition.
- Avg LOS on Hospice 14-21 days, benefit covers 180 days, or more.
- Important as a service to patient, family and physician.
What is the goal of palliative care?

- The goal is 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.
Patient and Family

- Volunteers
- Physicians
- Spiritual Counselors
- Social Workers
- Pharmacists
- Therapists
- Home Health Aides
- Nurses
Spiritual Issues

- Not religion
- Common themes
  - Connectedness to things/people
  - Where strength comes from
  - Why bad things happen
  - Meaning and purpose
  - What comes after this life
- May profoundly affect decision making
“It ain’t the heat, it’s the humility.”

- Yogi Berra
“Don’t just do something, stand there.”

- Yogi Berra
Communication

- Essential to palliative medicine
- Includes:
  - Honesty
  - Willingness to talk about dying
  - Sensitive delivery of bad news
  - Encourages questions
- Identifies choices with benefits and burdens
- Assists patient/family make decisions in keeping with their goals
In a nutshell

Palliative care

- improves the quality of life
- for patients who are facing serious illness
- as well as for their family and friends.
Palliative vs. Hospice Care

- Palliative care can be provided from the time of diagnosis.
- Palliative care can be given simultaneously with curative treatment.
- Both services have foundations in the same philosophy of reducing the severity of the symptoms of a sickness or old age.
- Other countries do not make such a distinction.
Symptoms at End-of-Life

- **Pain**
  - Common, complex

- **Respiratory Symptoms**
  - Shortness of breath, coughing, wheezing

- **Gastrointestinal Symptoms**
  - Nausea, constipation

- **Psychological Symptoms**
  - Depression, delirium, anxiety
“I don’t know if they were women or men running naked across the field, they had bags on their heads”

- Yogi Berra
Care Across the Continuum

**Health Care Delivery Systems:**
- Curative Treatment
- Rehabilitative Model
- Palliative Care Model
  - Palliative Medicine
  - Hospice

**Delivery provided in:**
- Hospital systems
- Rehabilitation Centers
  - Hospital: In-pt, out-pt
  - Nursing Facilities
- Long Term Care
  - Nursing facilities
  - Assisted Living
  - Community Based with Support
PAIN MANAGEMENT IN PALLIATIVE CARE
“Take it with a GRIN of salt.”

- Yogi Berra
Types Of Pain

**NOCICEPTIVE**

Direct stimulation of intact receptors along normal nerves

- **Somatic**
  - Receptors in skin, muscles/joints
  - Easy to describe and localize

- **Visceral**
  - Receptors in hollow structures (i.e. GI, GU)
  - Difficult to describe/localize—often colicky.
Adjuvant therapy

Neuropathic pain

- **Baclofen**
  - Antispasmodic
  - Start at 5 mg bid-tid

- **Clonidine**
  - Alpha-2 adrenergic agonist
  - P.O. or transdermal
Adjuvant therapy

Neuropathic pain
(burning, tingling– paresthesia)

- Tricyclic antidepressants
- Anticonvulsants
- (SSRI’s, SSNRI’s)
Chronic pain

- May be multifactorial
- Duration indeterminate
- Maladaptive
- Patient may appear depressed rather than painful
Adjuvant therapy
Neuropathic pain

NMDA receptor antagonists

- **Dextromethorphan (Delsym)**
  - 30 mg bid up to 1 gm daily studied
- **Ketamine**
  - IV, PO
- **Lidocaine** (topical, IV infusion)
- **Capsaicin (Zostrix)**
  - Depletes substance P
Adjuvant therapy

Corticosteroids

- **Prednisone** 5 mg = **dexamethasone** .75 mg
- Antiinflammatory
- Many uses, variable doses
- Taper if longer than 10 days
- Side effects
  - Psychosis
  - Proximal myopathy
  - Hyperglycemia
  - Long term—cataracts, osteoporosis, cushingoid appearance
Adjuvant therapy

**Corticosteroids**

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“I’d give my right arm to be ambidextrous.”

-Yogi Berra
Adjuvant Therapy

Bone Pain

- Constant, worse with movement
- Metastases, compression, pathologic fractures
- Consider spinal cord lesions/compression
BONE PAIN

Treatment

- Opioids
- NSAID’s
- Steroids
- Bisphosphonates (Aredia, Fosamax)
- Calcitonin (Miacalcin)
- Radiation
TOTAL PAIN

- Depression
- Anger
- Insomnia
- Pathologic Process
- Spiritual/Existential Distress
- Anxiety
# EQUIANALGESIC DOSING

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<tr>
<th>Drug</th>
<th>IV/SQ Dose</th>
<th>PO Dose</th>
<th>Ratio PO/IV</th>
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<tr>
<td>MORPHINE SULFATE</td>
<td>10 mg</td>
<td>30 mg</td>
<td>3:1</td>
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<tr>
<td>CODEINE</td>
<td>130 mg</td>
<td>200 mg</td>
<td>1.5:1</td>
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<tr>
<td>OXICODONE</td>
<td>NA</td>
<td>30 mg</td>
<td></td>
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<tr>
<td>HYDROCODONE</td>
<td>NA</td>
<td>30-45 mg</td>
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<tr>
<td>HYRDOMORPHINE</td>
<td>1.5 mg</td>
<td>7.5 mg</td>
<td>5:1</td>
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<tr>
<td>MEPERIDINE</td>
<td>75 mg</td>
<td>300 mg</td>
<td>4:1</td>
</tr>
<tr>
<td>METHADONE (acute)</td>
<td>10 mg</td>
<td>20 mg</td>
<td>2:1</td>
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FENTANYL PATCH  
25 MCG/HR=45MG/ DAY MORPHINE

METHADONE (CHRONIC)

<table>
<thead>
<tr>
<th>MORPHINE DOSE/DAY</th>
<th>METHADONE:MORPHINE</th>
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<tbody>
<tr>
<td>&lt;90</td>
<td>1:5</td>
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<td>90-300</td>
<td>1:10</td>
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<tr>
<td>&gt;300</td>
<td>1:12-20</td>
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</table>
Transduction:
- Prostaglandin inhibitors (NSAIDs, steroids)
- Anticonvulsants
- Anesthetics
- Capsaicin, other topicals
- Opioids (when nerves “primed”)

Perception/modulation:
- Tricyclic antidepressants
- SSRIs, SSNRIs
- Alpha blockers (clonidine)

Transmission:
- NMDA receptor blockers (ketamine, methadone, dextromethorphan)
- Opioids – primary receptors are in spinal cord
Pain Ladder

**Step 1:**
- Non-Narcotic Analgesic
  - Acetaminophen
  - NSAIDs

**Step 2:**
- Mild Opioids
  - Codeine
  - Hydrocodone
  - Oxycodone

**Step 3:**
- Strong Opioids
  - Morphine
  - Fentanyl
  - Methadone
  - Hydromorphone
Opioids

Classified by interaction with receptors

- **Pure agonist**: morphine, hydromorphone, oxycodone, hydrocodone, codeine, meperidine, fentanyl
- **Mixed agonist/antagonist**: butorphanol, pentazocine, nalbuphine
- **Partial agonist**: buprenorphine
- **Pure antagonist**: naloxone, naltrexone
Opioids

- Produce analgesia by interaction with receptors in brain and spinal cord (and to lesser degree, peripheral nerves)
- *Mu* receptor is dominant
- Theoretically no ceiling dose
Management

- Begin with short-acting opioids
- Switch to long-acting drugs when 3-4 doses daily are required to control pain
- Calculate 24 hour dose
- Breakthrough: 10-20% total daily dose
Adjuvant therapy

**Tricyclic antidepressants**

- **Desipramine**— secondary amine
  - Dosing similar to amitriptyline
  - Minimal anticholinergic or sedating adverse effects

- **Nortriptyline**— secondary amine
  - Less side effects, less sedating
  - May be slightly less effective
  - Dose 10-100 mg
Adjuvant therapy

**Tricyclic antidepressants**

- **Amitriptyline**
  - Most studied—tertiary amine
  - 10-200 mg at night
  - Effect takes days
  - Caution in elderly
    - Anticholinergic side effects (orthostasis, dry mouth, blurry vision, constipation)
    - Cardiac toxicity
Adjuvant therapy

- **SSRI**’s less effective for pain
- **SSNRI**’s may be better—
  - *Cymbalta* 30-90 mg daily
  - *Effexor* 37.5-150 mg daily
Adjuvant therapy

- Medications that supplement primary analgesics
- May occasionally be used for primary therapy (ie diabetic neuropathy)
- Use at any step of WHO ladder
Adjuvant Therapy

**Nonpharmacologic Management**

- Neurostimulation (TENS, acupuncture)
- Nerve blocks (ie celiac plexus)
- Surgical (cordotomy)
- Physical therapy
Methadone

**Advantages**
- Mu/delta agonist
- NMDA antagonist
- Least expensive potent opioid
- Clearance not affected by renal/hepatic disease

**Disadvantages**
- Complex pharmacology
- Duration of action changes with prolonged use
- Dose conversions complex
- Drug interactions
- Prolongs QT interval
Adjuvant therapy

**Anticonvulsants**

Shooting, stabbing, burning neuropathic pain

- **Gabapentin**—“gold standard”
  - Structural analog of GABA
  - Inhibits excitatory neurons in CNS by affecting calcium channels
Adjuvant therapy

Gabapentin

- Begin 100 mg bid-tid
- Titrate every 1-3 days
- Usual effective dose 900-1800 mg/day
- May use 3600-4800 mg/day
- Main side effect is drowsiness, usually develop tolerance within days
- No significant drug interactions
Adjuvant therapy

Other anticonvulsants

- **Clonazepam** (Klonopin)
  - Lancinating or paroxysmal pain
  - Sedating
  - Use for restless legs/plms

- **Phenytoin** (Dilantin)
  - Uncommonly used any longer
Adverse effects

- Respiratory depression
- Nausea/vomiting
  - antiemetics
- Constipation
  - laxatives
- Sedation
  - Methylphenidate, modafinil
Adverse effects

- Neurotoxicity
  - Myoclonus
  - Renal failure leads to metabolite accumulation (ie M3G)
  - Rotate opioids
  - Clonazepam, preservative-free solutions
Adjuvant Therapy

**Nonpharmacologic management**

- Psychological
  - Cognitive therapies (relaxation, imagery, hypnosis)
  - Biofeedback
  - Behavior therapy, psychotherapy
- Complementary therapies
  - Massage
  - Art, music, aromatherapy
- Spiritual intervention
  - Pain vs suffering
Symptom Management

Pain Treatment  Non-Pharmacologic

- Exercise programs
- Acupuncture
- Transcutaneous nerve stimulation (TENS)
- Relaxation therapy, guided imagery
Symptom Management

- Agitation/Delirium
- Anxiety/Depression
- Anorexia/Cachexia
- Constipation
- Dyspnea/Shortness of Breath
- Control of Secretions
- Fatigue
- Pain
“It’s Dejavu all over again.”

- Yogi Berra
Symptom Management

Delirium

**Causes:**
- Medications
- Brain Tumor
- Metabolic abnormalities
- Organ failure
- Dehydration
- Infection
- Hypoxemia
- Fecal Impaction
- Urinary Retention
- Unfamiliar environment
Dementia in hospice

- Prognostication and hospice eligibility
  - Minimum Data Set → Advanced Dementia Prognostic Tool (ADEPT)
    - Specificity 89%, sensitivity 27% 6 month survival
  - US Medicare guidelines (spec 89%, sens 20%)
    - FAST 7c or beyond plus one of
      - Aspiration pneumonia
      - Pyelonephritis
      - Septicemia
      - Decubitus ulcers > stage 3
      - Fever after antibiotics
      - 10% weight loss in 6 months
The Clinical Course of Advanced Dementia
NEJM Mitchell 2009

- 323 NH residents with advanced dementia
- 18 months (22 NHs)
- 55% died
  - probability of death within 6 months was 25%.
  - 94% of deaths occurred in the nursing home
- 6 month mortality rate:
  - Pneumonia 47%
  - Eating problems 39%
  - Febrile illness 45%
Distressing symptoms (increased as death approached)
- Pain 40%
- Dyspnea 46%

Burdenson interventions (hospitalization, ETC visit, IV meds, tube feeding)
- 41% in last 3 months of life
- Less likely if proxies understood poor prognosis and clinical complications
Advanced Dementia

Advanced dementia in palliative care—variety of neurodegenerative diseases with ultimately common pathways of profound physical and cognitive decline

Alzheimer’s disease
- 2012—5.2 million
- 2025—est 6.7 million

Fifth leading cause of death over age 65 in 2010

Cost $157-215 billion—will double by 2040
Dementia Treatment

- **Cholinesterase inhibitors**
  - **Aricept** 5 mg daily, increase to 10 mg after 4 weeks
  - **Exelon** 1.5-6 mg bid (liquid or capsules), 4.6-9.5 mg/day (patch)
  - **Razadyne** 4 mg bid, increase to 8 mg bid after 4 weeks
- Improve cognition in dementia
- ? Benefit in neuropsych symptoms
- Well tolerated, low side effect profile (nausea/vomiting)
- Particularly beneficial in DLB
- See 1 to 1.5 pt improvement on MMSE over 6 months
- Switch based on side-effects
- Stop if no improvement or disease advancement after 3 months at max dose
- May delay NH placement (curves even out after 1-2 years)
- Do not cure the illness and may not change the overall course
- If behaviors worsen after stopping you have a 2-4 week window to restart
Dementia Treatment

- Memantine (Namenda ®)
  - Not an acetylcholinesterase inhibitor
  - Non-competitive inhibitor of NMDA receptor
  - May protect from NMDA / Glutamate-induced excitotoxicity

- Like the others, modest effects.
  - Likely does not change overall course of illness
Dementia Treatment—non-pharmacologic

- Person-centered bathing
- Aromatherapy (lemon balm, lavender oil)
- Exercise training
- Music, pet therapy—evidence of efficacy
- Massage, touch therapy—may improve oral intake, reduce agitation
Nutrition in advanced dementia

- Systematic review of 7 studies in 2009 failed to show that enteral tube feeding provided any benefit in:
  - Prolonging life
  - Preventing aspiration
  - Improving malnutrition or its consequences
  - Alleviating hunger or thirst
- No randomized trials directly comparing tube feeding with oral feeding
Unique issues and pearls with dementia in palliative care

- Parkinson’s Disease Dementia
  - Six-fold increased risk of dementia
    - 78% after 8 years
    - 90% by age 90
  - Executive function defects plus visuospatial problems (i.e., facial recognition)
    - Less memory loss
    - Rare fluctuations of cognition
  - Visual hallucinations appear late (vs LBD where they appear early)
  - Parkinson symptoms at least 1 yr before dementia
Unique issues and pearls with dementia in palliative care

- Dementia with Lewy Bodies (DLB)
  - Persistent visual hallucinations (66%)
  - Spontaneous motor features of parkinsonism (70-90%)
  - Repeated falls and/or fainting
  - Sensitivity to neuroleptic medications esp FGA
  1. Delusions of disbelief
  - REM sleep disorders
  - Depression
  - Autonomic dysfunction (early urinary incontinence)
Delirium

- **Definition (DSM-IV)**
  - Disturbance of consciousness with reduced ability to focus, sustain, or shift attention
  - Change in cognition or development of perceptual disturbance that is not better accounted for by preexisting, established or evolving dementia
  - Develops over a short period of time (hours-days) and fluctuates during the day
  - Evidence from history, exam or lab that disturbance is caused by medical condition, substance intoxication or medication side effects
Delirium—clinical presentation

- Change in cognition
  - Memory loss
  - Disorientation
  - Difficulty with speech/language
  - Perceptual disturbances
    - Delusions of harm—not usually visual/tactile hallucinations

- Temporal course
  - Develops over hours to days
  - Persists for days to months
  - Differentiates delirium from dementia
Delirium

- Associated with high mortality
  - 14% 1 month
  - 22% 6 months
  - Approx twice that of patients without delirium
  - Linked with severe physical illness and dementia, but still an independent marker for mortality at 6 and 12 months

- Subtypes
  - Hyperactive
  - Hypoactive
  - Mixed
Symptom Management

Delirium Treatment

- Treat underlying cause: correct what can be reversed.
- Symptom control: may need medications
- Medications:
  - Neuroleptics: mainstay of treatment…use with caution
  - Benzodiazepines: cautious use indicated
Symptom Management

Delirium

- Occurs in up to 85% of terminally ill pts
- Common in last 24-48 hours of life
- Disturbance in consciousness and cognition: develops in SHORT PERIOD OF TIME
- Poor attention, psychomotor agitation or psychomotor retardation, perceptual disturbances, disordered sleep-wake cycle
- Related to medical condition
Delirium– treatment

**ANTIPSYCHOTICS**

1. **Typical:**
   First Generation Antipsychotics (FGA), traditional, conventional, also major tranquilizer and neuroleptics (for the side effects).

2. **Atypical:**
   Second Generation Antipsychotics (SGA), or Serotonin-Dopamine Antagonists (SDAs)
FGA: Low vs. High Potency

- Potency = Strength

- Low-potency medications (Thorazine, Mellaril) are more likely to cause:
  - anticholinergic side effects (dry mouth, blurred vision, and urinary hesitancy)
  - sedation
  - orthostatic hypotension.

- High-potency medications (Haldol) are more likely to cause:
  - neurological side effects: Parkinsonian like symptoms (tremors, rigidity, etc)
  - Less likely to cause sedation and hypotension.
Symptom Management

Delirium Assessment:
- Know your resident
- History: important to know onset of change in condition
- Medication Review
- Physical Exam
- Identify Reversible Causes….what can we change…
Delirium—clinical presentation

- Older patients may not look sick apart from behavioral change
- May appear as depression (hypoactive)—quiet, withdrawn
- Other manifestations (nonspecific)
  - Agitation, sleep/wake reversal, irritability, anxiety, emotional lability, hypersensitivity to sound/light
Symptom Management

Delirium Treatment: Non-Pharmacologic

- Avoid over-stimulation
- Quiet room with familiar objects
- Proper lighting
- Orientation: visible clock, calendar
- Family member at bedside
- *Fall Risk*
Delirium—treatment summary

- Treat underlying cause
  - Hydrate, change opioid, treat metabolic derangement or infection

- Hyperactive delirium
  - Haldol, typically .5-5 mg p.o., p.r., or IV q6 hours prn
  - Mellaril 25-50 mg qd-qid

- Hypoactive delirium
  - Olanzapine (sedating) 2.5-5 mg bid
  - Risperidone .5-2 mg bid-tid
  - Seroquel 25-50 mg bid-tid

- Consider methylphenidate
Falls Prevention

- Team approach to determine interventions
- Safe-T alarm
- Low beds, mats
- Move resident closer to nurses station
- Toileting Program
Nausea/Vomiting

- 5 loci or centers with different receptors that can lead to symptoms, with corresponding treatment options (some overlap)
  - Vomiting center
  - Chemoreceptor trigger zone
  - Vestibular system
  - GI tract
  - Cerebral cortex
Higher centres:
- pain
- fear
- memory

D₂ receptors
- haloperidol
- 5HT₂ receptors
- 'setrons'

CTZ

H₁ receptors
- cyclizine
- Achₘ receptors
- hyoscine hydrobromide
- 5HT₂ receptors
- levomepromazine

VC

VIII nucleus

Emesis:
- nausea
- retching
- vomiting

Chemicals in blood:
- drugs
- metabolites
- toxins

Autonomic afferents

Stretch receptors in serosae and viscera:
- head and neck
- thorax
- abdomen and pelvis

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“Never answer an anonymous letter.”

- Yogi Berra
“Vomiting Center”

- Diffuse neural network in the tractus solitarius and reticular formation of the medulla
- Acts as a “clearinghouse” and “amplification center”
- Nausea may occur with or without vomiting
- Afferent input from multiple sources—cortex, thalamus/hypothalamus, vestibular system, vagus/splanchnic nerves, CTZ
- Primary receptors are H1, Ach(m), 5HT2
Chemoreceptor Trigger Zone

- Primarily sensitive to chemical irritation, especially chemotherapy and toxins/metabolites from systemic circulation
- Primary receptors are D2, 5HT3
Cerebral Cortex

- Anticipatory symptoms, affective in nature
  - Responds best to BDZ’s ie lorazepam 0.5 mg q 4 hours prn
- Increased intracranial pressure
  - Use dexamethasone 4-12 mg daily
GI tract

- Chemoreceptors and mechanoreceptors in gut
- Through Vagus to VC
- Primarily mediated through 5HT3
Medication classes and effects

- **Butyrophenones**
  - Haldol (anti-D2)

- **Prokinetics**
  - Reglan (anti-D2, anti-serotonergic)

- **Phenothiazines**
  - Thorazine, compazine (anti-D2, serotonin, Ach)

- **Antihistamamines**
  - Benadryl, promethazine (anti-H1, duh)

- **Anticholinergics**
  - Atropine, scopolamine, hyoscyamine (anti-Ach)

- **5-HT3 antagonists**
  - Zofran (anti-5-HT3!)
Favorites/Pearls

- Compazine is most versatile and can be given by multiple routes
- Reglan for decreased motility
- Zofran for chemo (also good for itching!)
- Lorazepam for anticipatory nausea
- Think of constipation in ddx
Symptom Management

Anorexia/Cachexia

Identify and treat reversible causes:

- Reversible causes:
  - Dry mouth
  - Oral yeast/Candida infection
  - Acid Reflux, affecting the esophagus
  - Nausea/vomiting, constipation
  - Pain
  - Depression
Symptom Management

Anorexia/Cachexia

- Prevalence: 24 to 80% in geriatric population
- Definition: Progressive weight loss, lipolysis, loss of organ and skeletal protein and profound loss of appetite.
Symptom Management

Anorexia/Cachexia

Education

- Part of the disease process
- Not starving
- Forced feeding can cause discomfort
- Artificial feeding usually not beneficial
- Human body can survive comfortably on very little food
Symptom Management

Anorexia/Cachexia

Dietary Changes

- Involve resident in menu planning
- Offer small portions of resident’s favorite foods
- Avoid foods with strong odors
- Offer easy-to-swallow food: semi-liquids, puddings, ice cream, soft or pureed foods.
Symptom Management

Anorexia/Cachexia  Medication Management:

Caveat:  *Nothing works for very long, all medications have side effects, and short durations of action.*

Appetite Stimulants
- Corticosteroids
- Progestational drugs
- Cannabidiols
- Thalidomide
Symptom Management

Anorexia/Cachexia

Causes

- Immune mediators
- Tumor products
- Change in taste, dry mouth, mouth sores
- Nausea, constipation
- Gastritis, Peptic ulcer disease
- Candidiasis of GI tract
- Radiation/Chemo TX
- Drugs/Medications
- Metabolic changes: dehydration
- Depression
- Pain
Non- Pharmacologic Options

- Relaxation techniques, music therapy or distraction
- Odors can be + or -
- Adjust diet (small frequent meals)
  - May consider appetite stimulant— I like Zyprexa, low dose remeron
“The towels were so thick there, I could barely close my suitcase.”

- Yogi Berra
Symptom Management

Pain

- Prevalence
  - 72% non-cancer patients experience pain in their last 6 months
  - 87% cancer patients experience pain in their last 6 months

Retrospective survey of 1472 non-cancer deaths and 202 cancer deaths in the UK. Addington-Hall and Karlsen, 1999
Symptom Management

Pain: Common Causes in Elderly

- Arthritis (approx. 70%)
- Old fractures/prosthetic joints (approx. 13%)
- Neuropathy (approx. 10%)
- Cancer related (approx. 4%)
- Other (approx. 2%)

325 Randomly selected subjects from 10 community based nursing homes. Adapted from Ferrell, et al 1995
Symptom Management

Pain

- Multi-dimensional,
  - “what the resident says it is”,
  - affects all aspects of the persons life.

- Consistent evidence that pain is under-assessed and under-treated

- Systems Barriers
  - Resident, family, staff, physician
Symptom Management

AMDA Guidelines for Pain

- Assessment
- Regularly scheduled pain medications (not prn only)
- Increased use of opioids
- Non-pharmacologic analgesia
Symptom Management

Pain Assessment

- Resident self-report, if cognitively able
  - Numeric
  - Color/ Visual Analog
  - Faces
- Behavioral tools
  - Observe breathing, behavior, body language, vocalization, consolable
- Interview
Symptom Management

Pain Treatment

- World Health Organization Step Model
  - Mild (1-3)
  - Moderate (4-6)
  - Severe (7-10)

- Use opioids when indicated: moderate to severe pain.
Symptom Management

Pain Treatment

- Barriers
- Fear of addiction
- Fear of stigma
- Fear of opioids
- Related to resident, family, staff, physician
- Under report
Symptom Management

**Pain Treatment  Non-Pharmacologic**

- “a hand to hold, a heart to touch…”
- Sensory stimulation: Presence
  - Visual: picture books
  - Auditory: music
  - Smell: aromatherapy
  - Touch: Tactile objects, massage
  - Taste: sweet
“It’s tough to make predictions, especially about the future.”

- Yogi Berra
Functional Assessment Scales

- **Karnofsky Performance Scale**
  - Developed to assess function in cancer pts.
  - 100 point scale of general function, corresponds with ability to live at home, or need for institutional care
  - Scoring predicts mortality
  - Does not address disability or rehab. potential

Dying in Old Age

- Protracted process
- Punctuated by difficult decisions at many different points in a person’s life.
- Negotiated with difficulty....
Symptom Prevalence in the Geriatric Dying Patient

- Multiple symptoms at end of life
- Symptom prevalence INCREASES with age:
  - 7.4 symptoms in pts over 85 yrs
  - 5.7 symptoms in pts under 65 yrs
- Elderly patients less likely to report their symptoms as very distressing
Symptom Prevalence in the Geriatric Dying Patient

- Most common symptoms: Fatigue, Pain, Anorexia-Cachexia, Constipation, Dyspnea, Nausea and Vomiting.

- Increased prevalence:
  - Mental confusion
  - Loss of bladder control
  - Hearing and visual loss
  - Dizziness
Reality of Death in Elderly

- Lengthy period of decline: uneven course
- Difficulty with prognostication
- Multiple chronic medical conditions
- Progressive losses: independence; control
- Heavy burden of symptoms: multifactorial
- Substantial care needs: often overwhelming for family caregivers
Causes of “Dying” in the Elderly

- Cardiovascular diseases: CHF, Stroke, MI
- Pulmonary disease: Emphysema, COPD
- Neurodegenerative diseases: Dementia, Parkinson’s, ALS
- Frailty syndrome, also known as senile cachexia, or debility
- Cancers
Dying in Nursing Facilities

- 1 in 4 will die in NF, 25% of US deaths
- 1/3 of NF residents die within 12 months of admission
- Mortality rates in NF is 25% per year
- Greater than 1000 deaths per day in NF across the USA.
Dying in Nursing Facilities

- 43% of those over 65 yr. will spend time in NF before they die.
- By 2020 nearly 1 in 2 persons predicted to die in NFs
- 60% of NF residents have cognitive impairment.
Non-Cancer Medical Conditions

- **End Stage Cardiac Disease**
  - EF less than 20 %
  - Frequent hospitalizations for exacerbations.
  - Medications maximized, and still having symptoms.
  - May be a candidate for a device, pacer, ICD, and declines intervention
  - NYHA Class 4 heart failure
Trajectory: End-Stage Cardiac Dz.

- Cardiac Disease has acute episodes that could be the patient’s last.
Non-Cancer Medical Conditions

- **End-Stage Dementia**
  - FAST scale 7C (Functional Assessment Staging)
  - Not able to walk, dress, or bathe properly
  - Incontinent of bowel and bladder
  - Ability to speak, less than 5-6 intelligible words
  - Hospitalizations for aspiration pneumonia, sepsis, infected wounds, pyleonephritis
  - Difficulty swallowing or taking in adequate nutrition, declining a tube for feeding
Non-Cancer Medical Condition

- End Stage Pulmonary disease
  - Disabling dyspnea, at rest, poorly responsive to bronchodilators, cough
  - Decreased functional ability, increased fatigue.
  - Increased visits to Emergency Dept. for exacerbations
  - Cor pulmonale
  - Hypoxemia at rest, on supplemental O2
“It Ain’t Over Til It’s Over.”

-Yogi Berra
Summary

- Define palliative care, palliative medicine, palliative therapies
  - Review how “curative” and “palliative” integrate in patient care.
- Review process of creating Goals of Care
- Review symptom management, including pain management, in context of palliative medicine.
- Identify three non-cancer terminal diagnoses that can be cared for in a palliative medicine model, including hospice eligibility criteria.
Summary

- Palliative medicine: care for the entire patient; body mind and spirit, at any time of life.
- Curative and Palliative care are **both /and**, not **either /or**…..
- If uncertain whether or not to refer for hospice care, call Medical director of hospice and discuss.
- Collaboration, collegiality benefit all, physicians, patients, family, staff  WIN:WIN
Palliative Care

- Whole person care for patients whose diseases are not responsive to curative treatment.
- Usually provided by an interdisciplinary team:
  - Nurses,
  - Certified Nurse Assistants, or home health aides
  - Social workers
  - Physicians
  - Spiritual Care Providers, (chaplains)
  - Other health care professionals.( PT, OT, Speech, Dietary)
Benefits of Palliative Care

- Honors residents’ wishes for dignity
- Provides evidence based measures for good symptom management
- Demonstrates partnering and collaboration with:
  - resident, family, staff, and palliative care team
- Provides a common platform to discuss
  - Goals of Care
  - Advanced Directives
“If you don’t attend your friends’ funerals, they won’t come to yours.”

- Yogi Berra