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Final Days Symptom Management and Trajectories of Dying

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End of Life Nursing Education Consortium (ELNEC)

http://www.aacn.nche.edu/elnec

- **ELNEC-Core**
- **ELNEC-Pediatric Palliative Care**
- **ELNEC-GERIATRIC**
- **ELNEC-FOR VETERANS**
- **ELNEC-FOR PUBLIC HOSPITALS**
- **ELNEC-Advanced Practice Registered Nurses**

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Cultural attitudes have consequences

Nature exists for us to use and control

- **Daily health strategies**
- **Magic bullet mentality**
- **Deny our own mortality**
- **Psychologically unprepared for illnesses and threats to our survival that occur in old age**

Cultural attitudes have consequences

Bodily functions…losing control and shame

Palliative model not embraced in acute or LTC…poor pain control

Models of cure then palliation NOT cure and palliation

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Context: A new cohort with new values and expectations

Youth-Oriented :
Fear Disability

Marginalize Those Afflicted

Fear Death

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IGNORANT BENEVOLENCE

Closeted in our own assumptions and fears, we do not bother to find out what people really want
Begin the process of deconstructing our fears and assumptions about aging, human dignity, death and suffering
Acknowledge the limitations of the medical model
Have conversations with people about their goals of care.

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What if we feared death less?

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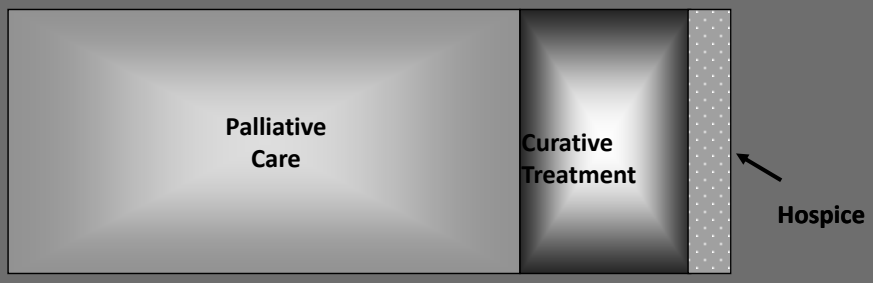
Current Practice of Hospice and Palliative Care



Illness Trajectory

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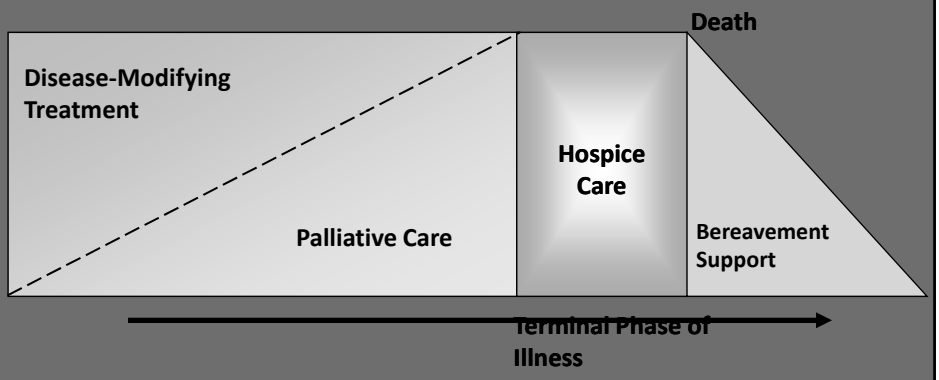
Continuum of Care



Illness Trajectory

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Cause of Death Demographic and Social Trends

	Early 1900s	Current
Medicine's Focus	Comfort	Cure
Cause of Death	Infectious Diseases Communicable Diseases	Chronic Illnesses
Death rate	1720 per 100,000 (1900)	800.8 per 100, 000 (2004)
Average Life Expectancy	50	77.8
Site of Death	Home	Institutions
Caregiver	Family	Strangers/ Health Care Providers
Disease/Dying Trajectory	Relatively Short	Prolonged

Administration on Aging, 2010; Kochanek et al., 2011; Minino, et al, 2009

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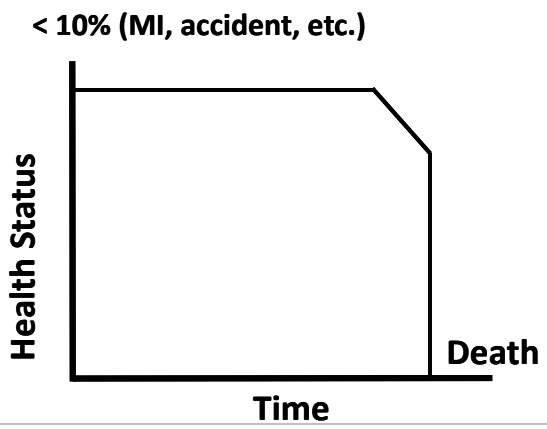
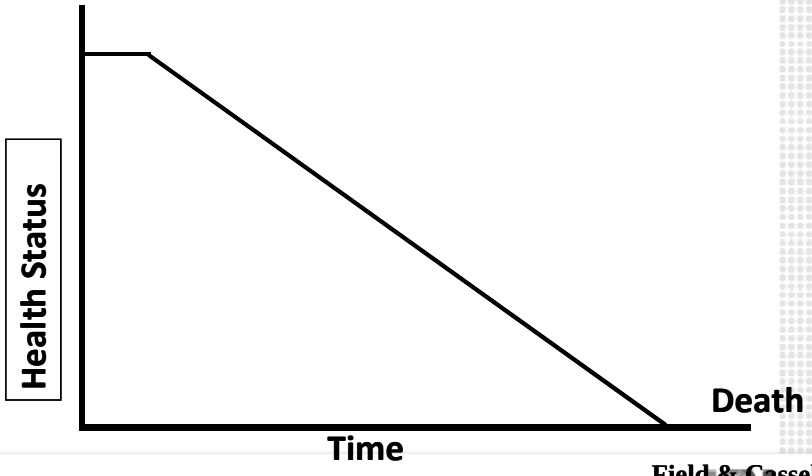
Illness/Dying Trajectories
Sudden Death, Unexpected Cause



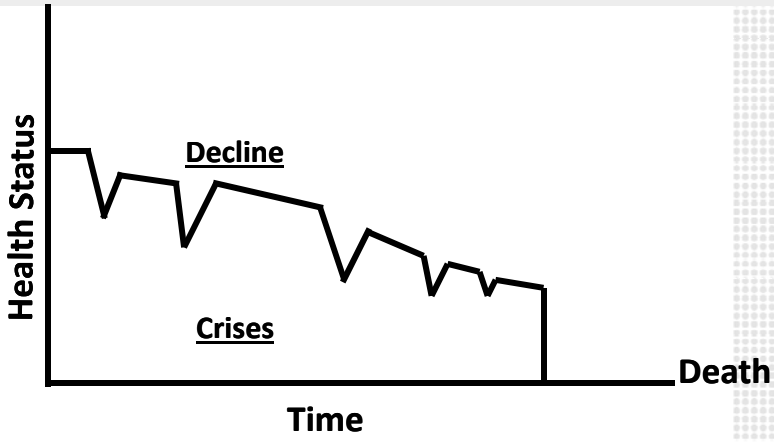
Field & Cassel, 1997

Illness/Dying Trajectories
Steady Decline, Short Terminal Phase



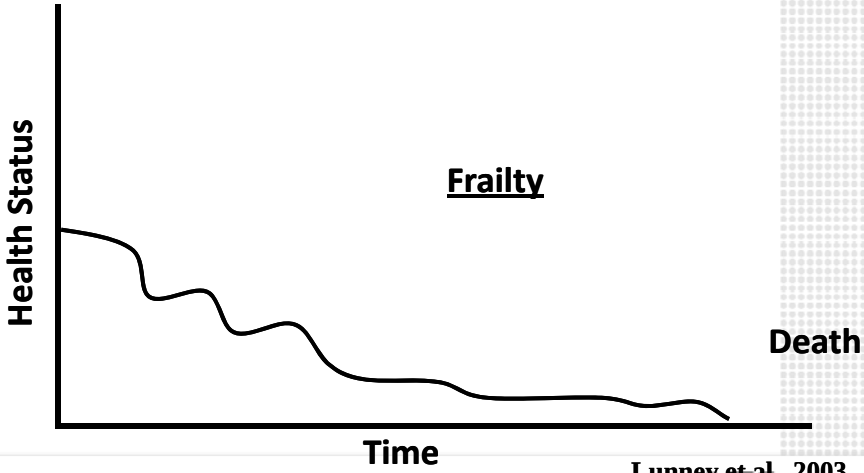
Field & Cassel, 1997

Illness/Dying Trajectories
Slow Decline, Periodic Crises, Death



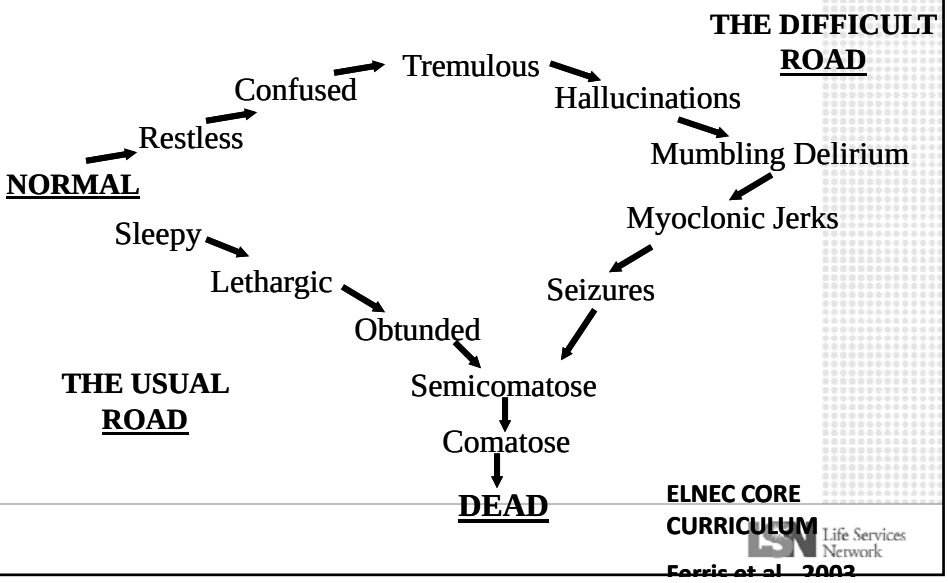
Field & Cassel, 1997

Illness/Dying Trajectories Lingering, Expected Death



Lunney et al., 2003

Two Roads to Death



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Ferris et al., 2003

Dying and Death

- Interpersonal competence
  - Empathy
  - Unconditional positive regard
  - Genuineness
- Attention to detail

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Open, Honest Communication

- Provide information in simple terms
- Patient awareness of dying
- Factors that positively impact older adults facing their own mortality
- Factors that negatively impact acceptance of death

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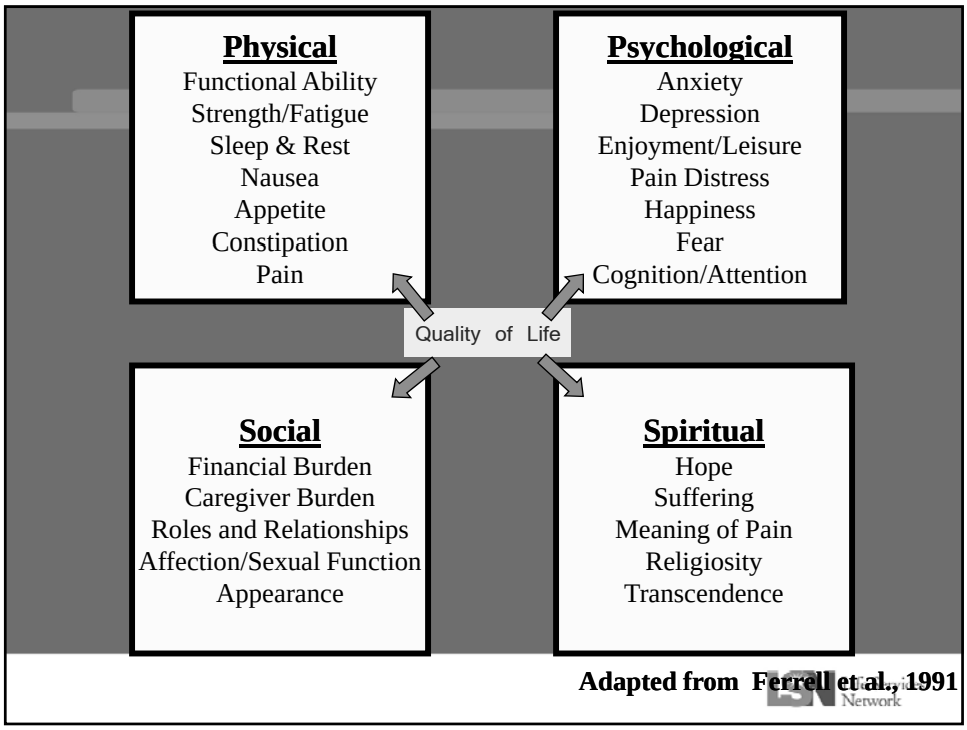

Adapted from Ferrell et al., 1991

Psychological and Emotional Considerations

- Fear of dying process
- Fear of abandonment
- Fear of unknown
- Nearing death awareness
- Withdrawal

Berry & Griffie, 2010
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Hope

Vying for a Winning Position

Cognitive strategies to

- Maintain control rather than a helpless victim
- Staying ahead of encroaching illness

1. Emphasize sustaining relationships

   Reminisce

   Work with family

   Validate relationships-you've raised good children

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Hope

2. Tell person loss of control is temporary
3. Treat as a whole person
4. Expand the patient's coping repetroire
   - Rational inquiry
   - Mutuality
   - Distraction
   - Confrontation
   - Meaningfulness in situation
   - Cooperative compliance
   - Relaxation techniques

Focus on positive strides

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Hope

5. Teach reality surveillance
   - Confirm that maintaining hope is feasible
6. Help to devise & revise goals
   - Gift of themselves to each family member
   - Make present experiences rich

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Six-Step Protocol for Breaking Bad News

1. Getting the physical context right.
2. Finding out how much the patient knows or suspects.
   - The factual content of the patient's statements.
   - The style of the patient's statements.
   - Emotional content of the patient's statements.

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Six-Step Protocol for Breaking Bad News

3. Finding out how much the patient wants to know.
4. Sharing medical information.

- Align (Using patient's words and current knowledge).
- Educate.
- Give information in small amounts.
- Use English (not medical jargon).
- Check reception frequently. (Check that message is being received.)
- Reinforce the information frequently.
- Blend concerns and anxieties with that of the patient.

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Six-Step Protocol for Breaking Bad News

5. Responding to the patient's feelings.
6. Planning and summarizing.

- Identify coping strategies of the patient and reinforce them.
- Identify other sources of support for the patient.

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Communicating prognosis

What are you expecting to happen?

How specific do you want me to be?

What experiences have you had with others with a similar illness?

What experiences have you had with others who have died?

What do you hope will happen?

What do you fear about what will happen?

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Symptoms and Suffering

- Symptoms create suffering and distress
- Psychosocial intervention is key to complement pharmacologic strategies
- Need for interdisciplinary care

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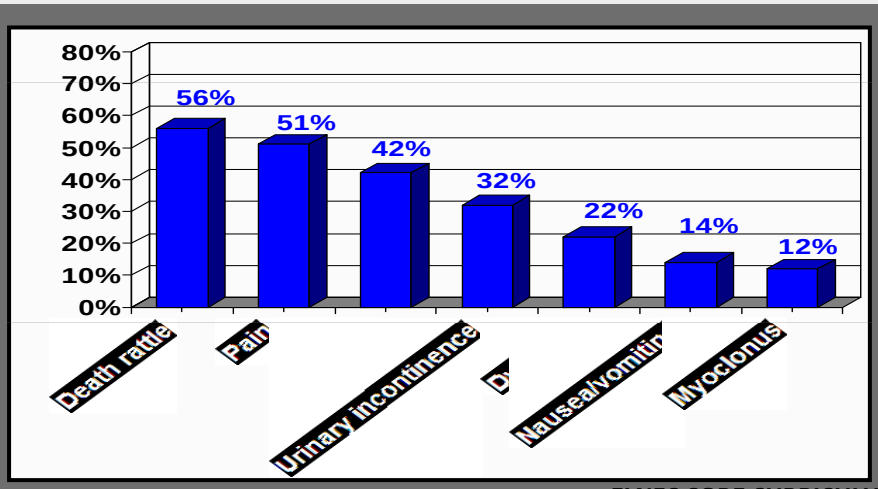
Frequency of Symptoms Last 48 Hours



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Harlos, 2010; Lunney et al., 2003

Physical Symptoms Vary

- **Confusion, disorientation, delirium vs. unconsciousness**
- **Weakness and fatigue vs. surge of energy**
- **Drowsiness, sleeping vs. restlessness/agitation**

Physical Considerations (cont.)

Fever
Bowel changes
Incontinence

Decreased intake
Pain

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Pain During the Final Hours of Life

- Assessment and management of pain is critical
- Behavioral cues
- First rule out other potential causes of distress

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Opioids

Dosing of opioids given during last hours based on appropriate assessment and reassessment.

Dose may be decreased

Consider other routes:

Oral
Rectal
Subcutaneous

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Accumulation of Metabolites

- Morphine and hydromorphine undergo glucuronidation producing M-3-G & H-3-G
- Both accumulate in renal dysfunction producing hallucinations, myoclonus and other adverse affects

Myoclonus

Review current drug regimens

Benzodiazepines can be helpful

Switching opioids

Can lead to seizures

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Intractable Pain at the End of Life

- Pain may be intractable even with aggressive treatment
- Total sedation may be the only alternative

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Rousseau, 2004

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Refractory Dyspnea

Dyspnea is difficulty in breathing of which the individual is aware. It is a subjective sensation that is difficult to measure and somewhat poorly understood.

Refractory: underlying cause cannot be reversed

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Prevalence

- Cancer-20-60%
- End-stage heart and lung disease
- HIV
- Lung, pleural and mediastinal involvements in cancer
- Low functional status

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Assessment

- Subjective 0-10
- Read aloud numbers

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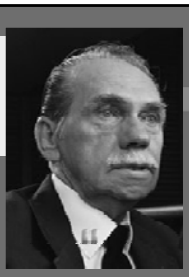
Case: John Silver (a 67 year old man with metastatic lung cancer and dyspnea)



Hx: mild hypertension, bronchial asthma

Medications

Hydrochlorothiazide 12.5mg every day

Albuterol and ipratropium inhalers prn.

Admission Exam

R 22-26, P100, **SpO2** 100% on room air. C/O breathlessness. Minimal scattered wheeze bilaterally.

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1. What are some interventions that should be considered at this point?

A. Non-breather mask with 100% oxygen
B. Morphine sulfate tablets 5mg orally every 4 hours as needed.
C. Elevate the head of the bed and place an electric fan which blows air gently on his face.
D. Albuterol and ipratropium hand held nebulizer treatment as needed.
E. Nebulized morphine in a saline solution
F. Diazepam 5 mg every 8 hours

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F. ~~Diazepam 5 mg every 8 hours~~

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Mr. Silver is DC home on hospice

- oral Morphine Sulfate sustained release 30 mg every 12 hours
- nasal prongs supplemental oxygen by a room air concentrator
- hand-held inhalers

- Exam
- Edema: mild face and neck, bilateral upper extremity edema
- distended neck and chest wall veins.
- Chest vesicular breath sounds with a few scattered rhonchi.

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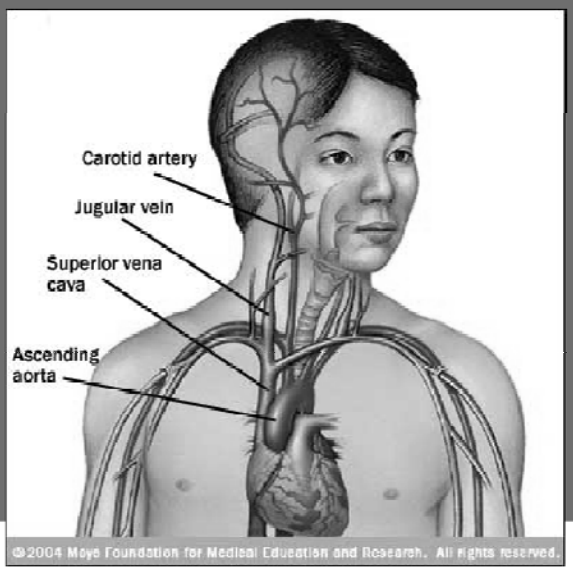
DX: **Superior Vena Cava Obstruction (SVCO)**



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The course of treatment is primarily dependent on:

A. Code Status
B. Life Expectancy
C. Presence of metastasis

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The course of treatment is primarily dependent on:

~~A. Code Status~~

B. Life Expectancy

~~C. Presence of metastasis~~

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B. Life Expectancy

Treatment depends on anticipated life expectancy:

Hours to days: These patients may be too ill to tolerate most interventions. Consider oral steroids to decrease lymphadenopathy, symptomatic management of dyspnea, headaches etc.

Days to weeks or more: Patients with lymphoma or small cell lung cancer are often treated with palliative chemotherapy. Patients with non-small cell lung cancer are palliated with radiation therapy (RT) with or without stent placement during or after RT. Patients with lymphoma and germ cell tumor may be candidates for curative RT.

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What interventions should be considered with his changed state?

A. Chest CT
B. Increase Morphine Sulfate to 45 mg q 12 hours
C. Urgent referral to radiation oncology
D. Start Decadron 8 mg every 6 hours

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Eight weeks later Mr. Silver is actively dying

- anxious and agitated
- noisy breathing due to increased secretions
- weak and unable to swallow his oral medications

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What interventions should be considered with his changed state?

A. Fentanyl transdermal patch 50 micrograms.
B. Scheduled respiratory toileting
C. Placing the patient in the left recumbent position.
D. Atropine drops orally; 2-4 drops as needed.
E. Diazepam 5 mg every 12 hours rectally.

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A. Fentanyl transdermal patch 50micrograms.

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What if Mr. Silver had severe refractory pain, edema, and breathlessness?

Should palliative sedation be considered?

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Palliative sedation remains somewhat contentious, due to:

- lack of a consistent and universal definition
- disparity in clinical use
- ethical and moral apprehensions
- confusion regarding sedative medications
- lack of well-controlled research.

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The Principle of Double Effect

1. The nature of the act must be good or morally neutral and not in a category that is absolutely prohibited or intrinsically wrong.
2. The intent of the healthcare provider must be good, and while the good effect and not the bad effect must be intended, the bad effect can before seen, tolerated, and permitted.
3. A distinction between means and effects must be envisioned, in that ***death must not be the means to the good effect.*** In other words, the good effect must be produced directly by the action, not by the bad effect. Otherwise, the agent would be using a bad means to a good end, which is never allowed
4. A proportionality between the good and bad effects must be substantiated by reason, in that the good effect must exceed or balance the bad effect (i.e. the good effect must be sufficiently desirable to compensate for the allowing of the bad effect).

Definition

Palliative sedation is the intentional administration of sedative drugs in dosages and combinations required to reduce the consciousness of a terminal patient as much as necessary to adequately relieve one or more refractory symptoms.

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Differentiating Palliative Sedation from Physician Assisted Suicide

	Palliative sedation	Physician assisted suicide (PAS)
Intent	Alleviating intractable suffering of a terminally ill patient primarily by sedation. Hastening death is **not** a primary or intended outcome.	Alleviating intractable suffering of a terminally ill patient by providing them with medication that the patient may then take to hasten their own deaths. Hastening death **is** a primary **and** intended outcome.
Informed consent	Required	Required
Where is it legal currently	All the states in USA	States are deciding: Oregan Washington Montana

Basic criteria for choosing palliative sedation

1. Presence of a terminal illness with a refractory symptom(s)
2. A do-not-resuscitate (DNR) order
3. Exhaustion of all palliative treatments, including treatment for depression, anxiety, delirium, and familial discord
4. Consideration of ethical and psychiatric consultations
5. Consideration of assessment for spiritual issues by a skilled clinician or clergy member
6. Discussion regarding the continuance of nutritional support or intravenous or subcutaneous hydration in patients receiving such treatments
7. Obtaining informed consent
8. Consideration of a trial of respite sedation in selected cases

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Once palliative sedation has been agreed upon

1. Choose appropriate agent and initiate sedation
2. Consider monitoring depth of sedation via Ramsay Sedation Scale or other instrument
3. Titrate sedative dose upward as necessary to maintain desired level of sedation
4. Administer additional bolus doses or add other agents as necessary to maintain desired level of sedation

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Palliative Sedation at End of Life

Lorazepam
Midazolam (Versed)
Ketamine
Propofol

Hanks-Bell et al., 2002; Harlos, 2010

Management of Anorexia, Cachexia

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The meaning of food

Brings People Together
Social activity
Pleasurable activity
Cultural Traditions
Foster Bonding

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Percentage with cachexia

Morley et al 2006

Disease	% with cachexia
AIDS	10-35
Cancer	30
COPD	20
Kidney failure	40
Rheumatoid arthritis	10
Heart failure	20
Nursing home	20

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Anorexia and Cachexia

- **Anorexia - loss of appetite, usually with decreased intake**
- **Cachexia - lack of nutrition and wasting**
  Kakos : bad
  Hexis : condition

Wholihan & Kemp, 2010

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Cachexia: A new definition

Evans et al. Clinical Nutrition (2008) 27, 793e799

"cachexia, is a complex metabolic syndrome associated with underlying illness and characterized by loss of muscle with or without loss of fat mass."

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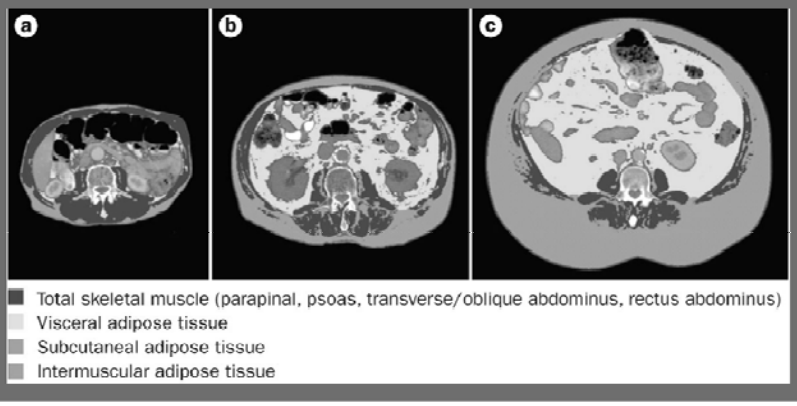
Extensive muscle wasting can be obscured by large fat mass



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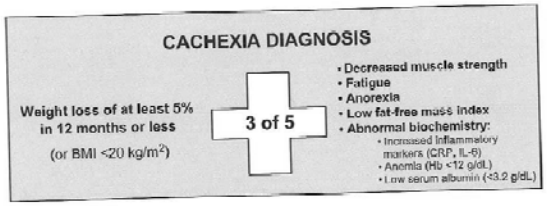

Specific illness info

Cardiac cachexia: reversal of weight loss → improved outcomes

Cancer:

Nutritional support and appetite stimulants →↑QOL but no change in mortality

anabolic hormones →↓proteolysis

Eicososopentaenoic acid →↓ muscle degradation, ↑ lean body mass, weight, QOL

Infliximab →↑ weight stability

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Treatment of Anorexia and Cachexia

- Dietary/speech consultation
- Medications
- Parenteral/enteral nutrition
- Odor control

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Earthman et al., 2002; MacDonald, 2003;
Wholihan & Kemp, 2010

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Anorexia care: Behavioral approaches

Increasing frequency of meals/snacks
Diverting attention with social activity or T.V.
Plan ahead for low energy days and take advantage of 'best' mealtimes, e.g. morning
Liquid nutritional supplements
Recipe guides

Drugs that act as cytokine antagonists

- Progestagens
- Thalidomide
- Testosterone
- Pentoxiphyline
- NSAIDs
- Eicospentaenoic acid
- Cytokine antibodies
- Soluble cytokine receptors
- Angiotensin-converting-enzyme inhibitors
- Statins

Morley et al, 2006

Anorexia: Medication: Glucocorticoids

Dexamethasone 3-6 mg/day or Prednisolone 5 mg 3x/day
effective in 60-80% of patients for 2-3 weeks of treatment
Side effects are common

Indication
- **A short course**
- **Usually used later in the course of illness when efforts to maintain muscle are no longer paramount**

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Anorexia: Medication: Progestational agents

Megestrol acetate
320-480 mg/day x 24 days to establish efficacy.
If appetite increases, then the dose can be reduced
Side effects
- **mild edema, impotence**
- **DEEP VEIN THROMBOSIS.**

Physiological effects
- **increase body mass (fat, not muscle)**
- **can be catabolic with prolonged use.**

Indication
- **should be reserved for the time when appetite is paramount and muscle function is not.**

What About Artificial Nutrition & Hydration at End of Life?

Perceptions of "starving to death"

Enteral feeding does not reduce risk of aspiration or mortality

Hydration does not decrease "dry mouth"

Patients who fasted to end their lives experienced peaceful death

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Ersek, 2003; HPNA, 2003a;

Ganzini et al., 2003; Prince-Paul & Daly, 2010

Constipation

- **Infrequent passage of stool**
- **Frequent symptom in palliative care**
- **Prevention is key**

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Causes of Constipation

- Disease related (e.g. obstruction, hypercalcemia, neurologic, inactivity)
- Treatment related (e.g. opioids, other meds)

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Causes of Diarrhea

- Disease related
- Malabsorption
- Concurrent diseases
- Psychological
- Treatment related

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Treatment of Diarrhea

- **Treat underlying cause**
- **Dietary modifications**
- **Hydration**
- **Pharmacologic agents**

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Matching Exercise

Complaint	Food Suggestion	Rationale
1. I'm not hungry	A. Ginger tea	i. Anti-emetic
2.I'm having diarrhea	B. Fresh fruit salad	ii. Stimulate taste
3. Nothing tastes good	C. BRAT-bananas, rice, applesauce, toast	iii. Quick, easy prep and intake
4. I'm constipated	D. Milkshake or fruit smoothie	iv. Appetite stimulant
5. I'm nauseated	E. Appetizer of jello and cheese	v. Bland and low-fiber foods
6. I'm too tired to eat anything	G. Cinnamon ice cream	vi. High fiber foods

Matching Exercise

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Nausea: an unpleasant subjective sensation of being about to vomit

Vomiting: the reflex expulsion of gastric contents through the mouth

Emetogenic Classes

Emetogenic Class	Medications	Incidence of Acute Nausea
I	Capecitabine, Rituximab	Minimal (<10 %)
II	Gemcitabine, Paclitaxel	Low (10-30%)
III	Doxorubicin, Carboplatin	Mild (30-60%)
IV		Moderate (80-90%)
V	Cisplatin, high-dose cyclophosphamide	High (>90%)

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Case example

Mr. Porter is a 92-year-old farmer with colon cancer metastatic to the liver. Right upper quadrant pain is well controlled with extended-release morphine, 60 mg PO bid, and dexamethasone, 4 mg PO q AM. However, he complains of constant nausea that limits his ability to eat.

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What are the cascading effects?

Fatigue/weakness → → → →

Nutritional impairment → → → →

Fluid imbalance → → → →

Electrolyte imbalance → → → →

Muscle strain → → → →

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What are the cascading effects?

Fatigue/weakness → gait and balance impaired→ fall → Fx hip →

Fatigue/weakness → stay in bed→ skin breakdown

Nutritional impairment → fatigue/weakness → → →

Fluid imbalance → dehydration→ constipation→ discomfort

Muscle strain → discomfort → ↓ expansion of lungs → atelectasis → pneumonia

Electrolyte imbalance → hypokalemia → muscle weakness & cardiac arrythmias

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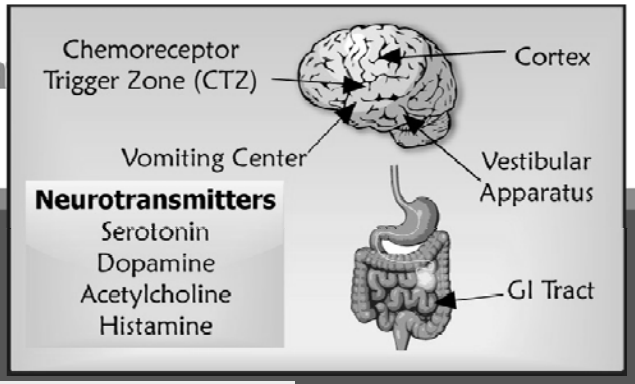

1. Chemoreceptor Trigger Zone
2. The Vestibular System
3. The Vagus Nerve
4. Vagal and Enteric Nervous System
5. The CNS

The 3 Phases of Vomiting:

1. **Nausea, sweating and salivation**
2. **Retching**
3. **Expulsion of gastric contents through the mouth**

Chemotherapy-associated nausea/vomiting

Acute nausea/vomiting occurs within the first 24 hours after chemotherapy.

Delayed nausea/vomiting occurs more than 24 hours after chemotherapy.

Anticipatory nausea/vomiting

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Classes of drugs commonly used

- **Dopamine antagonists**
- **Histamine antagonists (antihistamines)**
- **Acetylcholine antagonists (anticholinergics)**
- **Serotonin antagonists**
- **Neurokinin antagonists**
- **Prokinetic agents**
- **Antacids**

Non-Drug Treatment of Nausea and Vomiting

- **Distraction/relaxation**
- **Dietary**
- **Small/slow feeding**
- **Invasive therapies**

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Signs of Impending Death

- Blue or mottling: legs, lips, fingers
- Loss of motion, sensation reflexes
- Cold, clammy skin
- ↓ BP ↑ pulse
- Irregular respirations
  - Cheyne-Stokes
  - agonal

- Noisy breathing
- Swelling of legs (dependent area)
- ↓ bowel and bladder motility
- Bowel and bladder incontinence
- May or may not lose consciousness

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Management of Imminent Death Symptoms

- Elevate head of bed
- Begin anticholinergic drugs
- Reduce or withhold IV fluids/enteral feedings

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Matzo, 2010; Rousseau, 2007

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The Death Vigil

- Family presence
- Common fears
  - Being alone with patient
  - Painful death
  - Time of death
  - Giving "last dose"

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Cultural Considerations

- Death rites
- Rituals
- 5 tasks
  - To ask forgiveness
  - To forgive
  - To say "thank you"
  - To say "I love you"
  - To say "good-bye"

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Lipson & Dibble, 2005

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Resuscitation

No advance planning

Unrealistic beliefs regarding survival

Outcomes are usually poor

Family presence during resuscitatio

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Heyland et al., 2006;

Wallace et al., 2002

Thoughts of Patients Who Survived Resuscitation

- Felt that neither their confidentiality or their dignity had been compromised

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Signs That Death Has Occurred

- **Absence of heartbeat, respirations**
- **Pupils fixed**
- **Color**
- **Body temperature drops**
- **Muscles, sphincters relax**

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Death of a Parent … Remember the Children

- Be aware of the developmental stage of the child
- Communicate openly and honestly
- Children need opportunities to ask questions
- Questions should be answered in terms that they can comprehend

ELNEC CORE CURRICULUM
Davies & Steele, 2010

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Staff Caring for Themselves and Colleagues: Burnout Prevention

advocate educate innovate

Conclusion

Family members will always remember the last days, hours, and minutes of their loved one's life. We have a unique opportunity to be invited to spend these precious moments with them and to make those moments memorable in a positive way.

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