

PALLIATIVE CARE

An Integral part of Primary Care

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Palliative Care Cases

- MG was a 62 year old physician who developed Type I diabetes at the age of 12. She had experienced numerous complications of the diabetes, including peripheral vascular disease, retinopathy, and renal disease. By age 55, her renal disease progressed to the point of requiring hemodialysis. She had several A-V fistulae inserted for dialysis access, but all failed because of the vascular disease. Hemodialysis was performed via an indwelling catheter. The following year, she developed osteomyelitis of the spine, caused by skin flora, presumably from the dialysis catheter. After hospitalization for IV antibiotics, she was discharged to a rehab center and ultimately returned home. Two years later, she again developed osteomyelitis and discitis of the thoracic and lumbar spine. She was admitted to the hospital and received IV antibiotics for 6 weeks but became progressively paraplegic. Another 6 week course of antibiotics failed to reverse the paraplegia, and she was admitted to a rehab unit. After the completion of the second course of antibiotics, her pain worsened. Repeat MRI of the spine showed progressive destruction in the thoracic and lumbar regions. Another course of antibiotics failed to improve her pain and weakness.
- **What options might the physician discuss with the patient?**

- CL was an 80 year old Caucasian woman who was admitted to a skilled nursing facility with advanced dementia (Alzheimer type) and osteoporosis. She was married with 7 children, some of whom lived locally and some more distantly. She developed several episodes of aspiration pneumonia with respiratory distress, and her family requested that she be hospitalized and treated aggressively, including intubation.
- After the second episode of aspiration, the family requested the insertion of a PEG tube for feeding.
- **How should the physician respond to the family's request?**

- DYING IN AMERICA

Dying as an expected life cycle event . . .

Dying is just one of the many expected normal life cycle events

Dying can be an opportunity for personal growth.

Dying can be an opportunity for family and community growth.

But, is death a *normal* life cycle event?

- Yes ...
 - Normal in the very old;
 - Normal in patients who are chronically ill with declining function;
- No ...
 - Not normal in the young

Major causes of death in America

Chronic Diseases

- Heart disease
- Cancer
- Respiratory Disease
- Stroke

Acute Conditions

- Infections
- Trauma
- Homicide/suicide

Where Do People Die?

- Hospital – 50%
- Nursing Home – 30%
- Home – 20%

Where do People WANT to die?

- Home 1st
- Hospital 2nd
- Nursing Home Never

How do patients view what is a “Good Death”

- Dying not be prolonged
- Pain and symptoms controlled
- Not being a burden to others
- Control over decision-making
- Strengthening relationships

Dying at Home

Don't assume that all patients/families want to die at home.

Although the majority of Americans express a desire to die at home, research indicates that as a group, African-Americans and others often prefer to die in the hospital.

If people wish to die at home, why do most die in the hospital?

Forces exist in our health care delivery system together with the values related to health and illness, that propel the physician, patient, family towards aggressive, life prolonging care far longer than is medically appropriate; such care typically is provided in the hospital environment, up until shortly before death.

1. Physician Forces

- MD's personal fear of death and fear of failure
- Identification with patient
 - viewing patient as a friend pushes towards continued aggressive care
- Fear of missing a “treatable” problem
- Fear of litigation
 - Not “doing everything”
 - Fear of going against family wishes
- Personality deficiencies
 - ego, arrogance, abuse of power

2. Patient and Family Forces

- Difficulty accepting impending death
 - Expectation of miracles
 - Inability to “give up hope”
 - Fear of talking about death
 - Fear that “giving up” = personal weakness
- Fear of the impact of a death at home
- Failure to discuss advance care plans

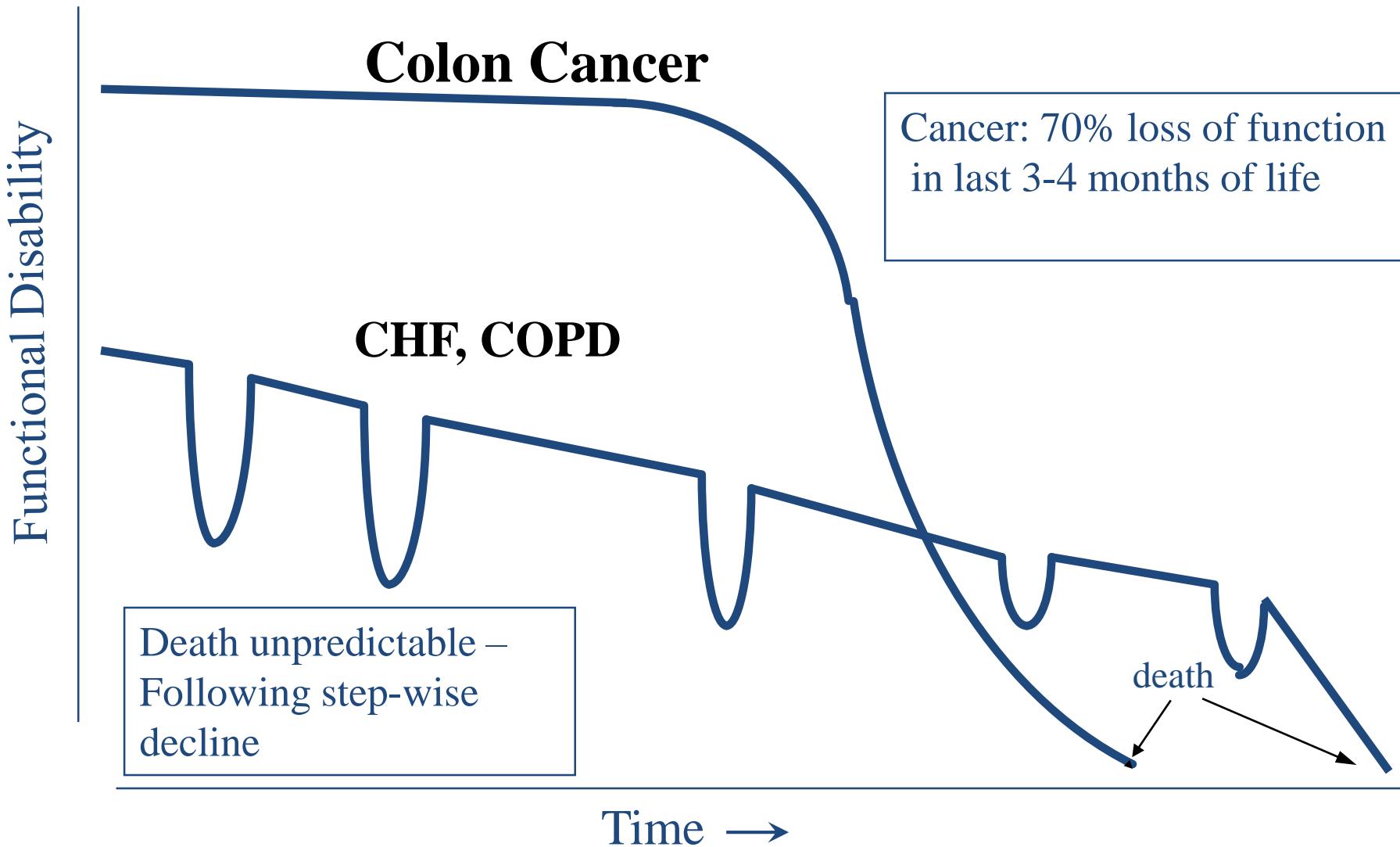
3. System Forces

- Increased number of hospital beds correlates to increased hospital deaths.
 - *“if you build it, they will come!”*
- Lack of organizational structure to support excellent end of life care in all care settings.
- Financial disincentives exist that force care toward aggressive orientation.

How can you move forward ..

- Recognize who is dying!
 - This is the single most important issue in end-of-life care—unless you can recognize and name the process, there will be no timely transition away from curative or life-prolonging care, towards palliative care.
- Understanding disease trajectories can assist in determining when someone is dying.

Illness Impact Trajectory



It is appropriate to begin using the word *dying*, when ...

The patient has: A chronic life limiting illness and

- Is progressively losing function and/or weight despite best medical therapy and/or
- Is requiring increasing medical resources with no improvement in quality of life and/or
- The patient has requested no further measures to reverse current or future medical problems (e.g. no antibiotics for the next pneumonia)

- The description of the dying patient on the previous slide has no criteria for time ... a patient may meet these criteria and live for weeks, months and even years. ***The important point is to recognize this phase of an illness in order to ensure proper communication and goal setting.***
- Patients in whom death is truly imminent, typically have a different set of findings, termed the *Syndrome of Imminent Death*, also known as *Actively Dying*.

Signs / Symptoms of Approaching Death

- Loss of mobility-bed bound
- Decreasing cognition
- Decreasing oral intake
- Loss of swallowing reflex
- Pain
- Altered respiratory pattern
- Fever
- Skin color changes

Key Aspects of Care During the Dying Process

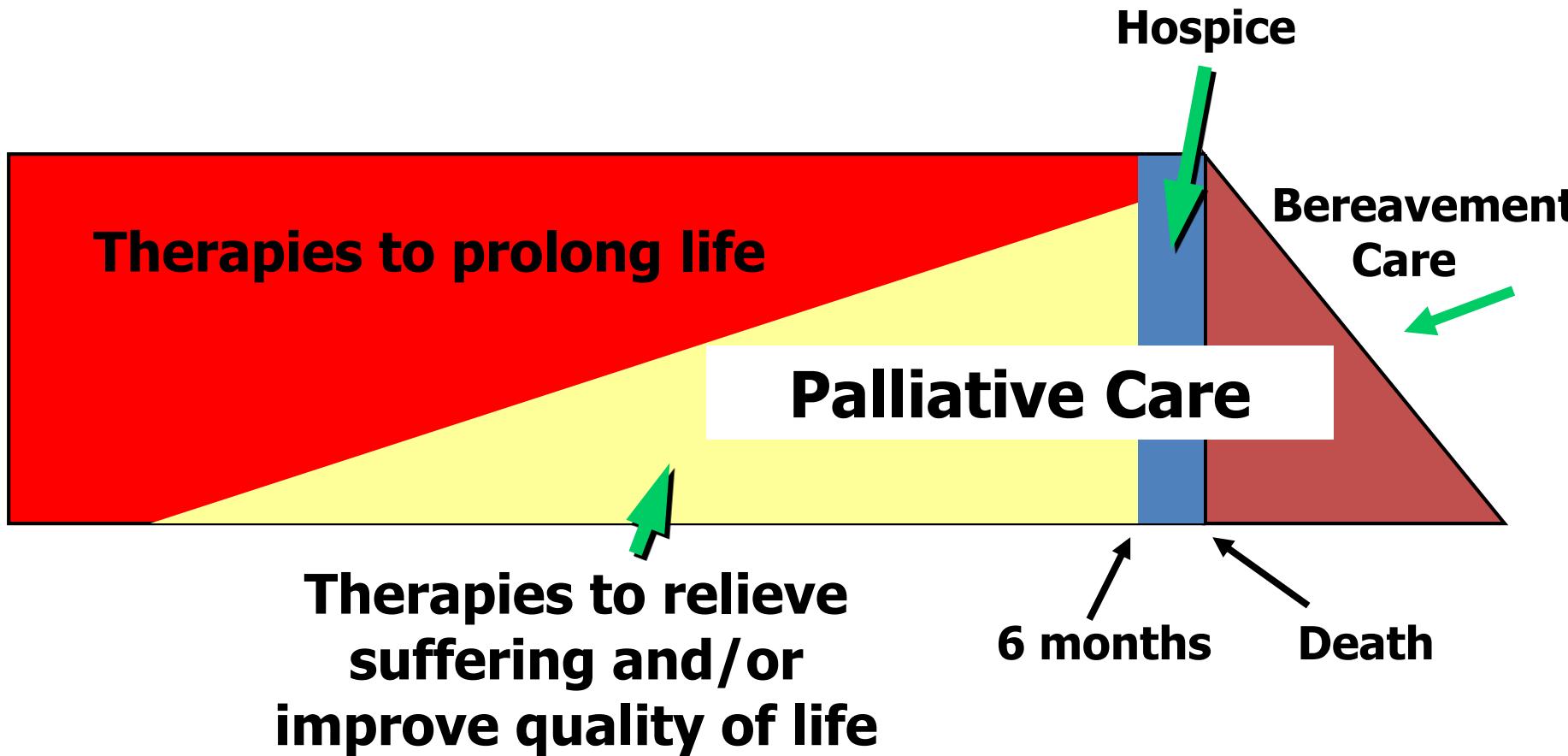
- Pain and symptom control
- Skin and mouth care
- Family and spiritual care
- Death planning
 - Funeral arrangements
 - Organ/body donation
 - Autopsy

Physicians Role in Care of the Dying

- Symptom management: control of distressing physical and psychological problems.
- Communication: shared-decision making to establish goals of care, prognostication.
- Support: patient and family psychosocial counseling, referral to specialists.
- Presence: leadership, guidance, honesty, witness to suffering.
- Self-care and team care.

The Role of Palliative Care

The course of a life-limiting illness



Palliative Care

Levels of Expertise

- Primary Palliative Care
 - Basic knowledge and skills for all physicians
- Specialist Palliative Care
 - Physicians with specialized training and experience in the care of seriously ill and dying patients

Palliative Care is ...

- Pain and Symptom Management
- Prognostication
- Communication Skills
- Application of Bioethics/Law
- Community Resources/Hospice
- Psychosocial and Family Care
- After-Death Care

What occurs in a Palliative Care Consultation?

1. What is the consult question?

- Symptom control
- Decision making-Goal Setting
- Disposition planning
- Counseling/Support

2. Chart Review

3. Staff Interview: physician, nurse, social worker, chaplain, others.

What occurs in a Palliative Care Consultation? (Cont.)

4. Patient/Family Interview

- Symptom assessment
- Psychosocial assessment
- Physical examination
- Prognostication
- Goal setting
- Disposition planning

What occurs in a Palliative Care Consultation? (Cont.)

5. Communication with primary team:
 - Symptom management plan and negotiation—define who is in charge?
 - Change care plan to meet patient-defined goals
 - Triage for additional services
6. Family Meeting—if needed for goal setting and/or information sharing
7. Transitioning if dying: where, cared for by whom?

Goals of Care *and* The Family Conference

Pause and Reflect ...

You are about to meet with the wife and two grown children of a man who had a massive stroke 4 days ago; he is obtunded, globally aphasic and hemiparetic.

The nurses have told you that the wife and one daughter are very “unrealistic”.



- What feelings go through your mind as you prepare to meet with this family?

Goals of Care

- Central to medical decision-making.
 - *If you don't know where you are going, you will end up somewhere else.* Y Berra
- Four primary goals of medicine:
 - Cure
 - Life Prolongation
 - Rehabilitation
 - Comfort until anticipated death *

***Note:** Maximizing comfort should be provided for all potential goals of care.

Meeting leadership

- Leading a Family Conference should be thought of as a ‘team sport’ to include physician, nursing, social service, and chaplains , as dictated by the clinical situation.
- Skill set necessary for successful outcome
 - Group facilitation skills
 - Counseling/emotional reactivity skills
 - Knowledge of medical and prognostic information
 - Willingness to provide leadership in decision-making

Summary of Key Steps

1. Pre-meeting planning
2. Proper environment
3. Introductions/Build relationship
4. What does the patient/family know?
5. Medical review
6. Silence, respond to emotions
7. Present options
8. Managing conflict
9. Transform goals into a medical plan
10. Summarize and document

1. Pre-Meeting Planning

- Review medical history/treatment options/prognostic information
 - Coordinate medical opinions between consultants/primary MD
 - Obtain patient/family psychosocial data from care team members
 - Review Advance Care Planning Documents:
 - Is patient decisional?*
 - Is there a Power of Attorney?
- * See Module: Ethical Constructs

Pre-Meeting Planning (cont.)

- Decide what is medically appropriate
 - Based on the current medical facts, what current and future medical interventions (tests, procedures, drugs, etc.) will improve, and which will worsen or provide no benefit to the patient's current condition, in terms of function/quality/time.

2. Environment

- Choose a Proper Environment
 - Quiet, comfortable, chairs in a circle
 - Invite participants to sit down
 - Check your personal appearance; turn off your beeper

3. Introductions - *Build Relationship*

- Introduce yourself, have participants identify themselves and their relationship to patient
- Identify the legal decision maker or family designated decision maker
- Review your goals; ask family if these are the same or different from their goals
- Establish ground rules
 - Everyone can talk
 - No interruptions



Introductions – *Building Relationship (cont.)*

- For patients with whom you have no established relationship, it is important to quickly build trust.
- For patients, or families, ask a non-medical question:
“I know about Mr. Jones’ illness, but I was wondering if you can tell me something more about him as a person, what were his hobbies?”

4. What does the patient/family know?

- Make no assumptions; Determine what the patient/family already knows
 - *What do you understand about your condition?*
 - *What have the doctors told you?*
 - *How do you feel things are going?*
- *Chronic Illness: tell me how things have been going for the past 3-6 months—what changes have you noticed?*

5. Medical Review

- Present medical information succinctly
 - Speak slowly, deliberately, clearly
 - No medical jargon
- Present the big picture

“your cancer is growing, there is no further chemotherapy which can halt the spread of cancer, based on your declining function and weight loss, I believe you are dying”.

6. Silence, Respond to Emotions

- Allow silence, give patient/family time to react and ask questions
- Acknowledge and validate reactions prior to any further discussion.
- One of two scenarios usually emerge:
 - Acceptance
 - Non-acceptance



When there is “acceptance”

- All patients/families ask, or are thinking of, these questions:
 - How much time do I have?
 - What will happen to me?
 - Will there be suffering?
 - What do I (we) do now?

When there is no or only partial “acceptance”

- *Common questions:*
 - *What are you trying to tell me?*
 - *How can you be sure?*
 - *I want a second opinion.*
 - *There must be some mistake.*
 - *I (we) will never give up.*
 - *I have a strong faith that things will get better.*

Emotional-Based Conflict

- When you hear conflict (*How can you be sure?*), think **emotion**, rather than assume a problem of factual understanding.
- Clarify any factual misunderstanding.
- Make an empathic statement ..
 - *This must be very hard.*
 - *You have fought really hard for a long time.*
 - *I can't imagine how hard this must be for you.*

7. Present Broad Care Options

- There are generally two broad care options:
 - A. Continue aggressive care aimed at restoring function or prolonging life.
 - B. Withdrawal of some or all life-sustaining treatments.
- To help patients and families arrive at a decision, the two most critical pieces of information are:
 - *Prognostic estimation*
 - *The physician's recommendation*

Prognostication

- Answering “*how long do I have*”
 - Confirm that information is desired:
“is something you would like me to address”
 - If you have a good sense of the prognosis, provide honest information using ranges.
“In general, patients with your condition live anywhere from a few weeks to 2-3 months”
“its very hard to say with your illness (COPD), but my best estimate is that you have less than one year, and death could come suddenly, with little warning”.
 - Address emotional reaction.

Prognostication (cont.)

- What if patients don't ask about their prognosis?
- It is difficult to do Goal Setting if the issue of *how much time*, is not addressed. Patients can be prompted by asking them: "*has anyone talked to you about time?*"
 - If yes—ask what they were told; if their estimate is close to yours, confirm this; if not, tell them your estimate.
 - If no—ask if they would like to discuss—see prior slide.

Making recommendations

- Patients and families want their physician to help them make decisions.
- Yet, physicians are fearful of making recommendations:
 - Fear of introducing personal bias
 - Fear of bad outcome leading to malpractice claim
 - Fear of paternalism
 - Distorted concept of patient autonomy

Making recommendations (cont.)

- Facts
 - Recommendations are considered an aspect of the professional responsibility of physician practice (AMA).
 - Doctors don't get sued for making recommendations—they get sued for failing to effectively communicate.

Read: The Boston Globe, March 5, 2007,
Longing for days when doctors still advised. by Marcia Angell

Getting at the patient's “voice”

- When the patient is not able to participate:
 - Bring a copy of their Advance Directive to the meeting if available
 - Ask the family: *“if your father were sitting here, what would he say”*

8. Managing Conflicts

- Remember, acceptance of dying is a *process*; it occurs at different times for different family members.
- Remember, a sudden illness or illness in a young person makes acceptance of dying more difficult for everyone.
- Remember, prior family conflicts, especially concerning alcohol, drugs or abusive relationships, make decisions very hard to achieve.

Common reasons for conflict?

- The Patient/Family
 - Lack of accurate information
 - Guilt/Fear/Anger
 - Grief—Time
 - Lack of trust
 - Cultural/Religious conflict
 - Dysfunctional family system

Other contributing causes

- The physician
 - Inaccurate information
 - Overly optimistic prognosis
 - Guilt-Anger-Fear
 - Fear of malpractice
 - Fear of ethical impropriety
 - Peer pressure (perceived or real)
 - Fear of mistakes
 - Prognostic Uncertainty
 - Cultural conflict between MD values and patient values

Moving forward when there is no consensus ...

- Ensure that everyone has the same medical information; information should be clear and unambiguous
- Ensure that a relationship of trust exists between the doctor and family
 - without trust, there can be no basis for shared decision making.

Moving forward when there is no consensus (cont.)

- Establish a time-limited trial
 - Let's continue full aggressive support for another 72 hours, if there is no improvement in _____, lets meet again and re-discuss the options.
 - Clearly define the elements of improvement: e.g. mentation, oxygenation, renal function, etc.
- Schedule a follow up meeting
- Other options
 - Palliative care consultation
 - Ethics consult
 - Involvement of other mediators (e.g. personal minister)

9. Translate goals into a plan

- Ask
 - *We have discussed that time is short. Knowing that, what is important to you... What do you need/want to do in the time you have left?*
- Typical responses
 - Home; Family; Comfort
 - Upcoming life events (e.g., wedding anniversary)
- Confirm Goals
 - *So what you are saying is that you want to be home, be free of pain, and would like to live beyond your next wedding anniversary in six weeks, is that correct?*

Translate goals into a plan (cont.)

- When trying to decide among the various treatment options, a good rule of thumb:
 - If the test or procedure will not help toward meeting the stated goals, then it should be discontinued, or not started.

Translate goals into a plan (cont.)

- Confirm Plan

To summarize:

- We have decided that you will not be re-intubated if your breathing gets worse
- That we will use morphine to help control your shortness of breath
- We will continue this course of antibiotics
- And if you improve, you will go home with home hospice services with the plan that you will remain at home unless new problems develop that cannot be managed in the home
- Following this hospitalization you do not want further blood tests or antibiotics

10. Summarize and Document

- **Summarize areas of consensus and disagreement**
- **Caution against unexpected outcomes—
the dying patient does not always die!**
- **Provide continuity**
- **Document in the medical record**
 - **Who was present, what was decided, what are the next steps**
- **Discuss results w/ health professionals
not present**

DNR

Pause and Reflect ...

You meet with a cachectic, bed-bound man dying of pancreatic cancer, and his wife; you discuss DNR option and the patient says "*I want you to do everything to keep me alive*".

Describe your feelings about such an encounter.

What are the indications for CPR?

- CPR was developed to reverse an acute cardio-respiratory event, in otherwise healthy individuals
 - Acute MI; arrhythmia
 - Electrocution
 - Poisoning
 - Hypothermia
 - Other acute events

Remember ...

The procedure of CPR was never intended for use in patients dying an expected death from a chronic, fatal, medical illness.

What are the contra-indications?

- Chest wall pathology
 - Myeloma, fractures
- Conditions in which the expected survival to discharge is < 10%
 - Metastatic cancer with declining function
 - Chronic renal failure on dialysis
 - Multi-organ failure
 - Sepsis

Other predictors of poor outcome

- CPR > 20 minutes
- Asystole



Survival and Complications

- Hospital patients: 15% survive to discharge
- Complications
 - Chest wall trauma, aspiration: 25-50%
 - Anoxic brain injury: 10%
- Cost to family:
 - Financial
 - Emotional cost of prolonging dying
- Cost to health care team
 - Emotional cost of prolonging dying

DNR Orders - The Law

- **QUESTION**

Fill in the blank:

Under US Federal Law, physicians are required to

regarding CPR/DNR.

- **ANSWER**

There is no Federal law or regulation concerning
CPR/DNR.

DNR Orders—The Law

- QUESTION**

True or False:

Physicians must perform CPR if requested by patient/surrogate.

Answer:

False, except in VA hospitals per National VA policy.

The AMA says ...

- DNR Orders
 - Efforts should be made to resuscitate patients who suffer cardiac or respiratory arrest except when circumstances indicate that cardiopulmonary resuscitation (CPR) would be inappropriate or not in accord with the desires or best interests of the patient.
- Futile Care
 - Physicians are not ethically obligated to deliver care that, in their best professional judgment, will not have a reasonable chance of benefiting their patients.

<http://www.ama-assn.org/ama/pub/category/2830.html>

1. Decide if CPR is medically appropriate

- Before you meet with the patient, ask yourself this question:
 - *Do you believe that CPR is an appropriate medical intervention for this patient in the event of sudden cardio-respiratory failure?*
- Remember--CPR is a medical intervention— it has:
 - Indications and Contraindications
 - Risks and Benefits
 - Patients have no autonomous right to insist that you perform CPR

The DNR Discussion (cont.)



Is CPR medically appropriate?

- If No---then plan to make a recommendation that CPR not be done
- If Yes---then plan to discuss CPR vs. no CPR options

2. Establish goals of care

A CPR/DNR discussion can only take place
following a discussion of the:

- chronic disease and expected future course
- prognosis
- available treatment options to reverse or stabilize a life-limiting treatment

Establish Goals of Care (cont.)

- Mutually decide with the patient on the steps necessary to achieve the stated goals.
- Common issues that need discussion once the end of life goals have been established include some or all of the following:
 - Future hospitalizations or ICU visits
 - Diagnostic tests
 - **DNR status**
 - Artificial Hydration/nutrition
 - Antibiotics or blood products
 - Home support (Home Hospice) or placement

3. Discuss CPR/DNR

- Once the overall goals have been established you can discuss CPR.
- If CPR is **NOT** recommended you can say:
 - *You have told me that your goals are*

XXXXXXXXXXXXXXXXXXXX

With this in mind, I do not recommend the use of artificial or heroic means to keep you alive. If you agree with this, I will write an order in the chart that when you die, no attempt to resuscitate you will be made, is this acceptable ?

Statements to Avoid

- *Do you want us to do everything?*
- *What should we do if your heart stops?*
- *If we do CPR we will break your ribs and you'll need to be on a breathing machine, do you want us to do that?*
- Avoid the term, “futility”.

Don't Forget!!!

- If you recommend DNR status:
 1. Stress positive things that will be done:
 - Pain and symptom relief
 - Continued care to achieve goals
 2. Reinforce that DNR does not mean “do not treat”



The DNR Discussion (cont.)

- When CPR outcome is not clear cut, in a patient who is not close to dying, you can say:

– We have discussed your current illness, have you given any thought to how you would like to be cared for at the time of death?

Sometimes when people die, or are near death, especially from a sudden illness, life support measures are used to try and ‘bring them back’. Alternatively, we could focus solely on keeping you comfortable. How do you feel about this?

4. Resolving DNR Conflicts

- Review overall prognosis/treatment - Clarify misconceptions. Ask:
 - *What do you know about CPR?*
 - *This decision seems very hard for you. I want to give you the best medical care possible; can you tell me more about your decision?*
 - *What do you expect will happen? What do you think would be done differently, after the resuscitation, that wasn't being done before?*

Resolving DNR Conflicts (Cont.)



- Use time as an ally
 - Ask patient advocates to be involved
- Be aware of reasons for conflict
 - Anger, guilt, dependency
 - Despair about impending loss
 - Lack of trust
 - Dysfunctional families
 - Alcohol, drug or physical abuse
- Consider palliative care or ethics consult

Resolving DNR Conflicts (Cont.)

- If you plan to honor a request for CPR, even if you believe it to be futile, you can say ...

I understand your desire for CPR, but I will need some direction if you survive, since you will almost certainly be on a breathing machine in an ICU. It is very likely that you will not be able to make decisions for yourself.

Who do you want to make decisions for you? Please give me some sense of how long we should continue life support if you are not able to make decisions and there is no improvement in your condition.

5. Summarize

- Summarize areas of consensus and disagreement
- Caution against unexpected outcomes
- Discuss results w/ other allied health professionals not present

6. Document

- Who was present?
- What information was discussed?
- What follow up is planned?

Pause and Reflect ...

You are seeing a patient with end-stage dementia—bedbound, no recognizable speech, incontinent. The patient's son is insisting that a feeding tube be placed so that Dad will not “starve to death.”

Artificial Nutrition and Hydration

Definitions

- ANH refers to any method whereby food/water is provided other than chewing/ swallowing.
 - Non-Oral Feeding
 - Provision of food by nasogastric tube (NG), gastronomy tube (G tube), Gastro-jejunostomy (G-J tube) or Total Parenteral Nutrition (TPN)
 - Artificial Hydration
 - Provision of water or electrolyte solutions by any non-oral route (Intravenous, subcutaneous, NG/G/J tube)

Dying from a chronic illness

- At some point, all dying patients lose their appetite; (see next slides on Anorexia)
- At some point, all dying patients lose their ability to take in sufficient food and water to meet basic physiologic needs
- Decisions re: ANH near the end of life often fall to families or other surrogate decision makers due to the patient's condition.

Dying from a chronic illness

(cont.)

- Anorexia
 - Lack or loss of appetite, resulting in the inability to eat and weight loss, especially as a result of disease.
 - Major contributing factor to cachexia syndrome.
 - Occurs in most cancer patients
 - Common in other chronic diseases: end-stage heart, lung, liver disease.
- Cachexia
 - State of malnutrition and wasting resulting from anorexia; advanced protein calorie malnutrition

- Primary Cachexia
 - Involuntary weight loss as a result of an illness
 - Metabolic rate exceeds caloric intake Inability to conserve protein
 - AIDS, cancer, sepsis and major trauma
- Secondary Cachexia
 - Dysphagia (head and neck cancer)
 - Oral and esophageal candidiasis
 - Poor oral hygiene
 - Gastric outlet obstruction
 - Small bowel obstruction.

Metabolic Derangements in Anorexia/Cachexia

- \uparrow metabolic rate
- \uparrow glucose consumption
- \uparrow protein breakdown
- \downarrow protein and fat synthesis
- \uparrow acute phase protein response

Assess for treatable causes

- Chronic pain
- Mouth conditions
 - Dryness; Mucositis
 - Thrush; HSV ; Aphthous ulcers
- GI motility problems
 - Constipation; Reflux esophagitis; Nausea
- Electrolyte imbalance
- Psychological distress:
 - Anxiety
 - Spiritual distress
 - Depression
- Poorly fitting dentures
- Intolerance of institutional food

Treatment-Drugs

- Available Drugs
 - Progestin (megesterol)
 - Cannabinoids (dronabinol, nabilone)
 - Glucocorticoids (dexamethasone)
- Drug Impact
 - Only modest weight gain at best
 - Little to no impact on survival duration
 - Toxicities can limit use
 - Generally not helpful in cases of massive weight loss

Treatment-Nutrition

- Oral Supplements
 - Well tolerated, high calorie/protein drinks
- Tube feeding
 - Indicated in selected patients undergoing cancer treatment (Head/Neck Ca during XRT)
 - Use in dying patient has high morbidity, no impact on survival
- Hyperal (TPN)
 - Indicated only in patients unable to tolerate enteral feeding, who have an expected prolonged survival
 - Use in dying patients has high morbidity, no impact on survival

Typical Patient Scenario

- Anorexia with early weight loss
 - Correctable conditions addressed
 - Oral supplements used with short-term weight stabilization
 - Dietary counseling
- Continued weight loss
 - Increasing family concern;
 - Family concern typically >> than patient concern
 - Questions raised about the use of enteral (G-Tube) or parenteral nutrition (TPN)

No subject provokes greater distress and uncertainty, among both families and health professionals, than issues surrounding the use of artificial feeding and hydration in the dying person.

Why?



Issues surrounding the use of artificial feeding and hydration

- Oral intake is a symbol
 - Eating represents living; the most basic of human needs.
 - Family role as protector and provider, especially true for spousal relationship.
 - *“I love him, therefore I must feed him.”*
- Confusion that withholding ANH is equal to euthanasia, assisted suicide or murder
 - Fear of legal, ethical or religious misconduct.

Questions related to ANH

1. What are the benefits and burdens of ANH?
2. What are the legal, religious and cultural issues surrounding ANH?
3. What are recommended steps in discussing ANH?

Answers



Q1: Benefits and Burdens

- A. Benefits of Art. Hydration**
 - May prolong life in selected patients
 - May improve or forestall delirium

- B. Benefits of Art. Feeding**
 - May prolong life in selected patients

C. Other “Benefits” of either Artificial Nutrition or Hydration

- Maintains appearance of life giving sustenance.
- Maintains hope for future clinical improvement.
- Avoidance of guilt by family members.

D. Unproven Benefits of Art. Hydration

- Improves quality of life
- Improves survival across a population of dying patients
- Improves symptom of thirst

E. Unproven Benefits of Art. Feeding

- Reduction in aspiration pneumonia
- Reduction in patient suffering
- Reduction in infections or skin breakdown
- Improved survival duration (in a population of similar patients)
- Improved nutritional parameters in demented nursing home residents

F. Burdens of Artificial Hydration

- Maintaining parenteral access
- Increased secretions, ascites, effusions, edema, urine output
- Fuss factor: site care, IV bag changes

G. Burdens of Artificial Feeding

- Risk of aspiration pneumonia is the same or greater with tube feeding than without
- Increased need to use restraints
- Wound infections, abdominal pain, and tube-related discomfort
- Other tube problems
- Cost; Indignity; Loss of pleasure of oral intake

Data regarding tube feeding in advanced dementia *

- In-hospital mortality: 25%
- One-year mortality: 60%
 - 10% readmission rate for complications
 - aspiration >>> other
 - Predictors of early mortality:
 - High age, CNS pathology (CVA, dementia), cancer-except Sq Cell Head/Neck, disorientation, low albumin

* Multiple retrospective cohort studies: 1995-99

* Finucance TE, et al. Tube Feeding in Patients with Advanced Dementia. JAMA 1999;282:1365-1370

H. Alternatives to Non-oral Feeding

- Allowing patient to eat/drink ad lib, even if aspiration risk is present or →
- Hand feeding or →
- No oral or non-oral food with the expectation that death will result in 14 days
 - Aggressive comfort measures will always be provided

Summary of Benefits/Burdens

- Few medical benefits
- Substantial morbidity
- Possible psychological benefits for family

Q2. Ethical and Religious Issues

- A. There is no professional mandate to provide ANH when burden/risk is greater than benefit.

The AMA says:

Life-sustaining treatment is any treatment that serves to prolong life without reversing the underlying medical condition. Life-sustaining treatment may include, but is not limited to, mechanical ventilation, renal dialysis, chemotherapy, antibiotics, and artificial nutrition and hydration. There is no ethical distinction between withdrawing and withholding life-sustaining treatment. A competent, adult patient may, in advance, formulate and provide a valid consent to the withholding or withdrawal of life-support systems in the event that injury or illness renders that individual incompetent to make such a decision. A patient may also appoint a surrogate decision maker in accordance with state law.

www.ama-assn.org; E-2.20 Withholding or Withdrawing Life-Sustaining Medical Treatment.

B. Withholding or withdrawing ANH is not:

- **Euthanasia:** the administration of a lethal agent by another person to a patient for the purpose of relieving the patient's intolerable and incurable suffering.
nor
- **Physician-assisted suicide:** when a physician facilitates a patient's death by providing the necessary means and/or information to enable the patient to perform the life-ending act
- www.ama-assn.org; Policies E-2.21 and 2.211; Euthanasia, Assisted suicide.

C. ANH is a *medical* treatment, not
ordinary care

- Ordinary care refers to oral food/water, clothing and shelter

D. When a patient cannot speak for him/herself decisions can be made on the following basis:

- Expressed wishes in a previously completed Advance Directive.
- A legal guardian **
- A Power of Attorney for Health Care **

**Note: in the absence of previously expressed desires, states have different standards for when/how a surrogate decision maker may authorize withdrawal or withholding of ANH, check your own state law.

E. Religious/Cultural Issues

- Most, but not all, religions and cultures recognize that when someone is dying, ANH may be withdrawn /withheld if the burden exceeds benefit.
- Health professionals' personal values may conflict with those of the patient/surrogate.
 - Such conflicts should not preclude the presentation of all relevant medical information and all treatment options.

Pause and Reflect ...

What cultural values do you have concerning ANH?

Do these values impact on how you present information to patients and families?

Q3: Discussing ANH

- A. Advance Care Planning; encourage patients while still well, to:
 - Discuss wishes with surrogates
 - Complete an Advance Care Planning document, including *Power of Attorney for Health Care*.
 - Some states require a written advanced directive that specifically mentions whether ANH can be stopped/withheld by a surrogate. If this is the case make sure you patients include this in their directive

B. When patients cannot make their own decision.

- Check for advance care document
- Present all medical facts and treatment options to surrogate
- Solicit input from patient's "voice"
If your ___ were sitting here, what would he/she say/want?
- Make a recommendation; Give *permission* to stop or not start ANH.
 - Families are generally looking for a recommendation to help ease their feelings of guilt.

Helpful Phrases

- *What do you know about artificial ways to provide food?*
- *All dying patients lose their interest in eating in the days to weeks leading up to death, this is the body's signal that death is coming.*
- *When people are dying, their body rejects food. They usually do not feel hungry, and eating may cause them to feel ill.*
- *I am recommending that the (tube feedings, hydration) be discontinued (or not started) as these will not improve his/her living; these treatments, if used, may only prolong his/her dying.*
- *Your (relation) will not suffer; we will do everything necessary to ensure comfort.*
- *Your (relation) is dying from (disease); he/she is not dying from dehydration or starvation.*

C. Resolving Conflicts

- Provide information
- Work to remove sense of guilt
 - Seek out the patient’s “voice” (“*what would your wife say if she could tell us her wishes*”)
 - Make a recommendation
- Use time as a ally
- Offer consultation: chaplaincy, pall care, ethics
- Consider time-limited trials of ANH based on a functional goal

Lets try the tube feeding for 2 weeks with the hope that your ___ will be more interactive; I suggest we meet again after 2 weeks and reassess how things are going.

PAIN and SYMPTOM MANAGEMENT

Pause and Reflect ...

How do you know when someone is in pain?

Pain Assessment is NOT....

- Relying on changes in vital signs
- Deciding a patient does not “look in pain”
- Knowing how much a procedure or disease “should hurt”
- Assuming a sleeping patient does not have pain
- Assuming a patient will tell you they are in pain

Remember !!

Pain occurs in the context of a person's life:

- fears and hopes for the future
- spiritual beliefs
- pressure and support from family
- social and economic realities

Thus—their report of pain will be filtered and modified by these factors.

Pain Assessment

1. Basic History

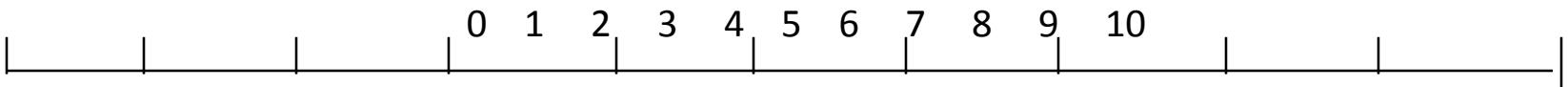
- When did it start?
- Where is it?
- What is the pain intensity?
- What does it feel like? (quality)
- What makes the pain better or worse?



Intensity

- Document the patient's self report, not your personal impression.
- Use an established rating scale; there is no single best scale; learn to use one or two scales.
- Have alternate scales available for patients unable to use your standard scale.
- Ask patient to rate pain:
 - Now
 - At worst in past 24 hours
 - At best in past 24 hours

Visual Analogue Scale



No
pain

Worst
pain
possible

Verbal Scale

No pain Mild Moderate Severe Pain

Correlation between 0-10 scale and verbal scale:

1-3 = mild pain; minimal impact on ADL's

4-6 = moderate pain; moderate impact on
ADL's

7-10 = severe pain; major impact on ADL's

Quality: Somatic pain

- **Descriptors:** *aching, deep, dull, gnawing*
- **Distribution/Examples:**
 - Well localized—patients can often point with one finger to the location of their pain
 - bone mets, strained ankle, toothache
- **Analgesics:** *NSAIDS, acetaminophen opioids*

Quality: Visceral Pain

- **Descriptors:** *cramping, squeezing, pressure*
- **Distribution/Examples:**
 - *Referred*
 - heart attack, kidney stone
 - *Colicky*
 - Bowel obstruction, gallstone
 - *Diffuse*
 - Peritonitis
- **Analgesics:** *opioids; acetaminophen*

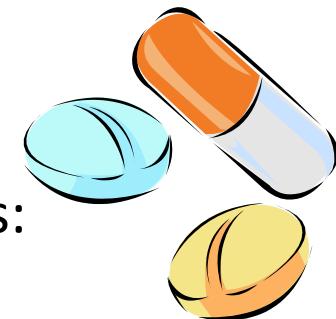
Quality: Neuropathic pain

- **Descriptors:** *burning, numb, radiating, shooting, stabbing, tingling, touch sensitive (hyperalgesia)*
- **Distribution/Examples:**
 - Radicular—single or multiple nerve roots
 - Herpes zoster; Sciatica
 - Stocking-Glove (fingers/toes)
 - Diabetic or chemotherapy neuropathy
- **Analgesics:** *opioids, adjuvants*

Pain Assessment

2. Analgesic History--Medications

- Current medications:
 - Time to onset, maximal duration of effect, change in pain intensity (quantify)
 - How does the patient use the meds: prn vs. scheduled
- Past analgesics:
 - Effect: positive/negative
 - Toxicity
- Drug phobias: is the patient fearful of ...
 - Addiction, toxicity, other



Remember the common patient related barriers to pain management

- Drugs ..
 - are addicting
 - should be saved for when it is *really* needed
 - have unpleasant or dangerous side effects
 - pills are not as effective as a shot
 - narcotics are only for dying people



Pain Assessment

3. Analgesic History: Non-Pharm

- Current or past use and effect of:
 - Heat / Cold / Massage
 - Relaxation techniques, imagery
 - Non-prescription food supplements
 - Acupuncture
 - Nerve blocks, TENS, other interventional procedures
 - Other (Aromatherapy, prayer, etc.)
- Has the patient ever been to a Pain Clinic?
- Has the patient tried anything else for the pain?

Pain Assessment

4. Impact and Meaning of Pain

- How has the pain impacted (quantify):
 - Mood, sleep, movement, diet
- Does the patient attach special meaning to the pain?
 - Punishment for past misdeeds?
 - Opportunity for spiritual growth?
 - Fear of worsening cancer?
 - Other

Pain Assessment

5. Pain Causality and Patient Goals

- Ask, “*Why do you think you are having pain?*”
- Ask, “*What is your goal for pain relief?*”
 - Numerical goal (e.g. 2-3/10) or
 - Functional goal (e.g. sleep 6 hours)

Remember!!

These groups are at especially high risk for
under-treatment of pain:

- frail elderly
- babies and children
- the mentally ill
- different language, culture, or socio-economic status
- history of substance abuse
- cognitively impaired



Pain assessment in the cognitively impaired patient

- Ask the patient—they may be able to give you some verbal information
- Rely on behavioral clues—the gold standard of assessment in this population
 - Changes in mood, appetite, movement, social interaction, time out of bed, level of consciousness

Pain assessment in the cognitively impaired patient

- Assess for clues for physical causes of worsening pain. Could there be...
 - A bladder infection or distention?
 - Worsening arthritis or new skin breakdown?
 - A history of cancer with new bone mets?
 - An occult fracture?
 - Worsening constipation?
 - Others

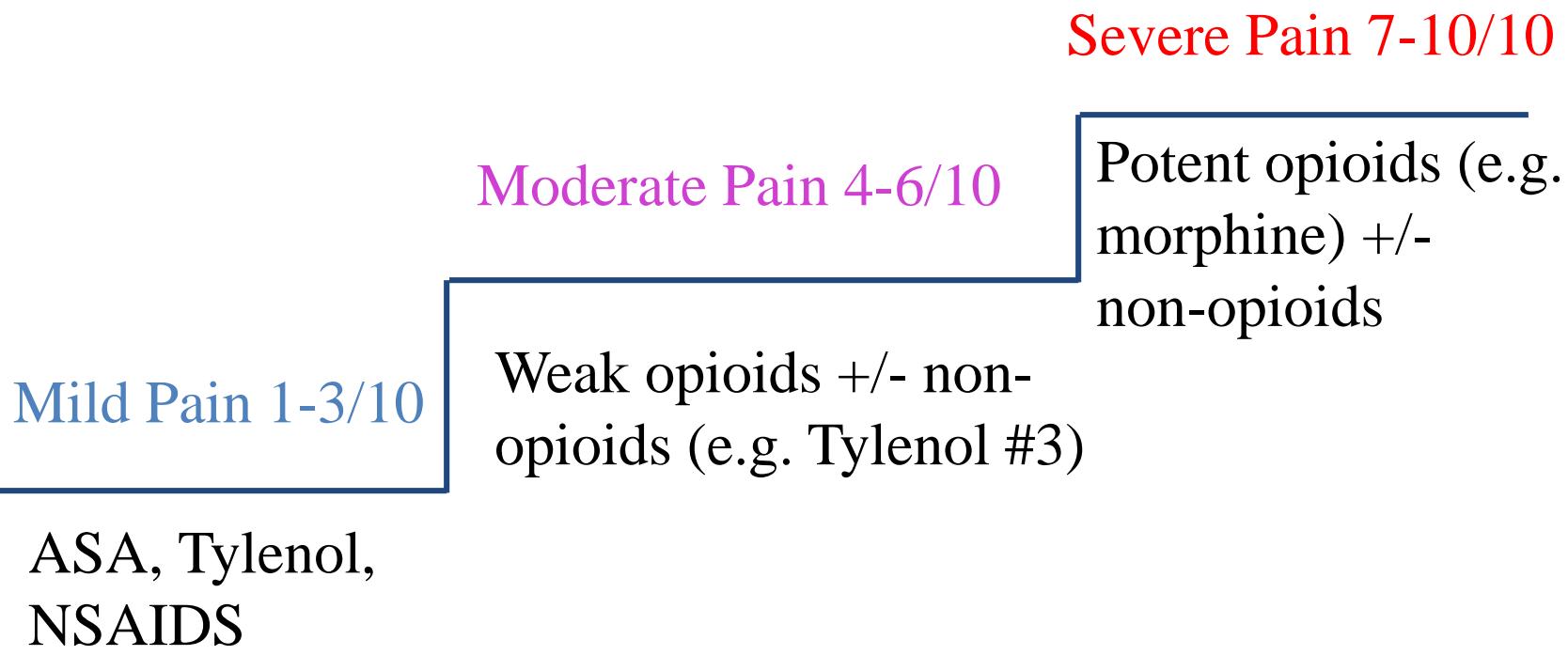
Comprehensive pain management

- Drug therapy is only one important aspect of pain treatment.
 - Non-drug therapies should always be used at the same time drug therapy is started.
- This module will only focus on drug therapy; learners are encouraged to seek other sources for reviews discussing: anesthetic, anti-neoplastic, behavioral, neurosurgical, and physical modalities to treat pain.

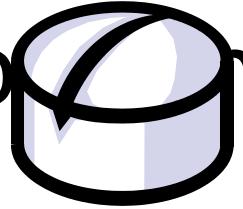
Classes of Analgesics

- Non-opioid Analgesics(NSAIDS, acetaminophen, aspirin, tramadol)
- Opioids (morphine is the prototype)
- Adjuvant Analgesics (antidepressants, anticonvulsants, steroids, others)

World Health Organization (WHO) Step Ladder Approach



Acetaminophen



Question:

Why is Tylenol the pain reliever recommended by most doctors?

Answer: Safety

It doesn't affect stomach, kidney, or platelets, *but...*

- It has no anti-inflammatory mediators
- It has a ceiling dose: 4 grams/24 hours
- It is hepatotoxic in overdose

NSAIDs

- Inhibit production of inflammatory mediators
- Synergistic analgesia with opioids
- Have significant end organ toxicity
 - Should be used with great caution in the elderly
- **Note!** No NSAID has greater analgesic efficacy compared to any other NSAID;
 - However, certain patients may report greater effect from a particular preparation

NSAID Toxicity

- Gastropathy—GI bleeding
- Renal insufficiency
- Cardiotoxicity—Worsening CHF
- Decreased platelet aggregation—Bleeding
- Hypersensitivity reactions
- CNS—Delirium
- Hepatitis

Tramadol (Ultram ®)

- A synthetic non-opioid analog of codeine with complex pharmacology: among other actions, it is a *mu*-opioid-receptor agonist
- Analgesic effect roughly equivalent to Tylenol #3 ®
 - Efficacy variable; has an analgesic ceiling
- No anti-inflammatory effects
- Side effects similar to opioids at high dose-- nausea, confusion, dizziness, constipation
- Does have an abuse potential

2. Analgesics for moderate to severe pain

- OPIOIDS
 - All opioid analgesics produce pain relief via interaction with opioid receptors in the brain/spinal cord and perhaps via peripheral opioid receptors.
 - The *mu* receptor is the dominant analgesic receptor, but other receptors play a role in analgesia for certain opioids.
 - There is no dose ceiling for opioids, only for acetaminophen in combination products.

Analgesics for moderate to severe pain (cont.)

- Opioids are classified by their interaction with the opioid receptors.
 - **pure agonist:** morphine, hydromorphone (Dilaudid ®) oxycodone, codeine, meperidine, fentanyl
 - **mixed agonist-antagonist:** butorphanol (Stadol ®), pentazocine (Talwin ®), nalbuphine (Nubain ®)
 - **partial agonist:** buprenorphine
 - **pure antagonist:** naloxone, naltrexone

OPIOIDS—Duration of Action

- A. Short
- B. Long

B. Short Acting Opioids

- Parenteral or Oral
 - morphine
 - hydromorphone (Dilaudid ®)
 - Codeine
 - fentanyl
- Oral only
 - oxycodone (Percocet ® , Tylox ®)
 - hydrocodone (Vicodin ® Lortab ®, Lorcet ®)
 - Note: hydrocodone is only available as a combination product.

- Fentanyl
 - Given IV it has 50-100 times the potency of morphine
 - Transmucosal delivery systems
 - Actiq ® (Lozenge)
 - Fentora ™ (Buccal tablet)

Short Acting Opioids (cont.)

- Duration of Action
 - All the short acting opioids should be prescribed at a dosing interval not to exceed 4 hours, as the typical duration of effect from an oral dose is 3-4 hours.

Short Acting Opioids (cont.)

- Oral dosing:
 - onset in 20-30 min;
 - peak effect in 60-90 minutes
 - duration of effect 2-4 hours
 - Can be dose escalated or re-administered every 2-4 hours for poorly controlled pain as long as the daily Acetaminophen dose stays < 4 grams.

Opioid combination products

- The following opioids are available as combination products with acetaminophen, aspirin, or ibuprofen
 - Codeine; hydrocodone; oxycodone;
 - Typically used for
 - Moderate episodic (PRN) pain
 - Breakthrough pain in addition to a long-acting opioid.
- Never prescribe more than one combination drug at any one time.

Which combination product?

Analgesic potency:

- hydrocodone and oxycodone are more potent than codeine.
- there is little difference between hydrocodone products and oxycodone products in terms of potency.

Which combination product? (cont.)

Toxicity:

- All the combination products can cause opioid toxicities: nausea, sedation, constipation, etc.
- There is little published data that supports the use of one product over another in terms of toxicity;
- however ...
 - codeine is probably the most emetogenic opioid.

Short-acting opioids for severe pain (non-combination)

- morphine
- oxycodone
- hydromorphone (Dilaudid ®)
- oxymorphone (Opana ®)

Equianalgesia

- Since all potent opioids produce analgesia by the same pharmacological mechanism, they will produce the same degree of analgesia if provided in equianalgesic doses.
- Thus, there is little basis to say, “morphine did not work, but hydromorphone did work”. Such a statement generally means that non-equianalgesic doses were used.
- There is no dose ceiling.
- Non-opioids are not included when performing equianalgesic calculations.

Equianalgesia

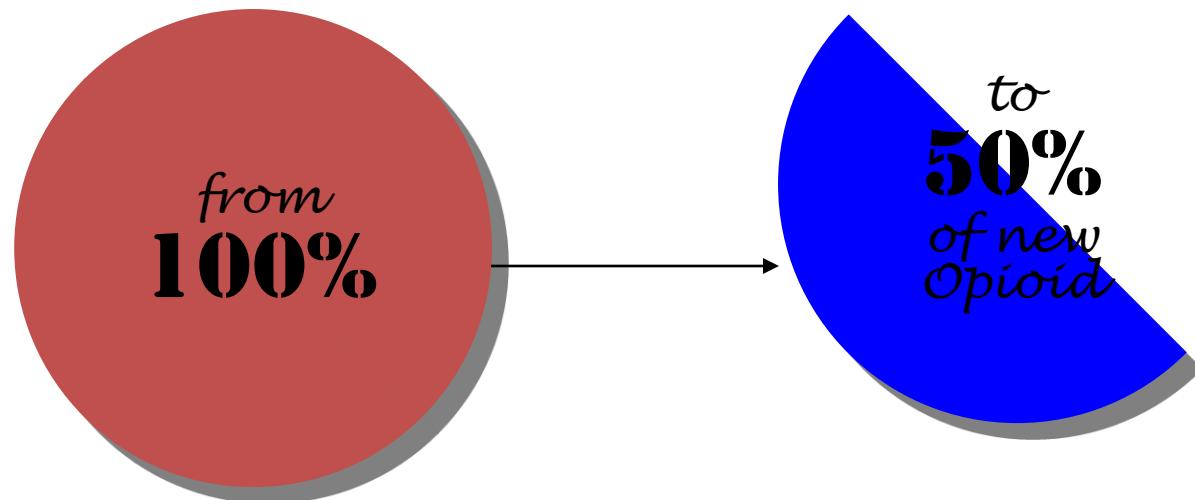
Common Conversions

- 10 mg IV MS = 30 mg po MS
- 10 mg IV MS = 1.5 mg IV Hydromorphone
- 30 mg po MS = 7.5 mg po Hydromorphone
- 30 mg po MS = 20-30 mg po Oxycodone

Note: Conversion factors are only a rough guide to approximate the correct dose.

Incomplete cross-tolerance

- If a switch is being made from one opioid to another it is recommended to **start the new opioid at ~50%** of the equianalgesic dose.
- This is because the ***tolerance*** a patient has towards one opioid, may not completely transfer (“incomplete cross-tolerance”) to the new opioid.



C. Long Acting Opioids

- Oral
 - morphine:
 - MS Contin®
 - Kadian®
 - Oramorph SR
 - oxycodone
 - Oxycontin®
 - Oxycodone SR
 - oxymorphone
 - Opana SR
 - methadone
- Transdermal
 - Fentanyl Patch (Duragesic®)

MS Contin® vs. Oxycontin®

- No clear benefit of one product over another
 - MS Contin and Oramorph contain morphine
 - Oxycontin contains oxycodone
 - No difference in toxicity; No difference in addiction potential
- Both must be taken intact—they cannot be crushed; they do not fit down GI tubes



MS Contin® vs. Oxycontin® (cont.)

- Both provide 8-12 hours of analgesia.
- Minimum dosing interval is q 8 hours.
- Both provide onset of analgesia within 2 hours.
- Both can be dose escalated every 24 hours.

Transdermal Fentanyl

- Slow onset of action: 13-24 hours
 - Duration of action: 48-72 hours
- Should only dose escalate q 3 days
 - Fentanyl stays in circulation for up to 24 hours after patch removal
- Place on hairless, non-irradiated skin
- No ceiling dose
- Absorption unpredictable in cachectic pts

Transdermal Fentanyl (Duragesic®)

Conversions

- Equianalgesic conversion formula
 - 24 hour total dose of oral morphine, divided by 2 = dose in micrograms/hour of transdermal fentanyl
 - Example:
 - MS Contin® 30 mg q 12 = 60 mg MS/24 hours
 - 60 divided by 2 = 30; rounded to one 25 mcg/hr Fentanyl Patch

Breakthrough pain

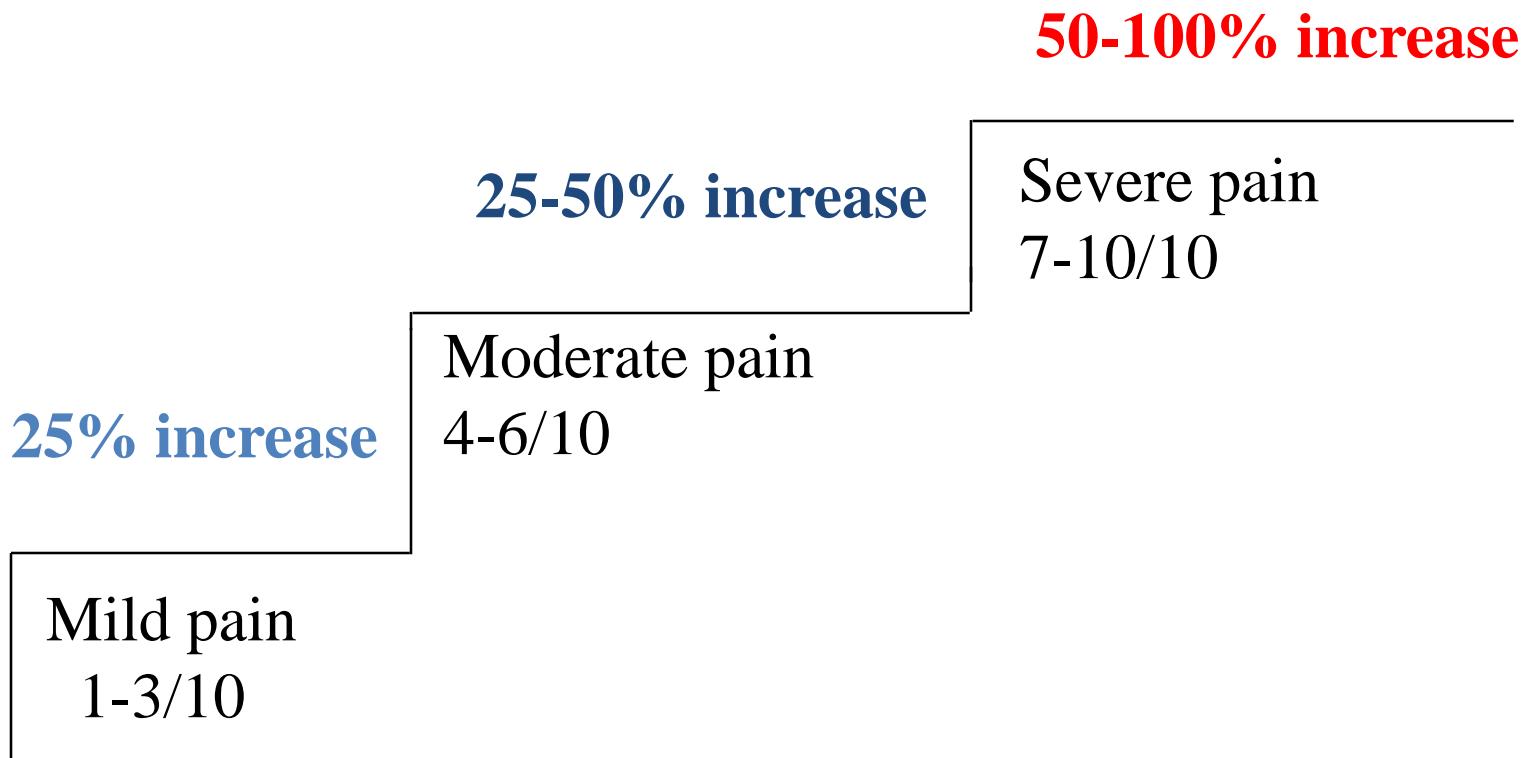
- Patients on any long-acting med always need a second, short-acting med, available for breakthrough pain; something they can take at least every 4 hours, preferably less.
- Generally, the dose of breakthrough opioid should be:
 - 10% of 24 hour dose of analgesics and made available q2 hours.
 - Example: breakthrough dose for MS Contin 60mg q12hrs should be in range of 10-15mg q2hrs of oxycodone or immediate release morphine

Methadone

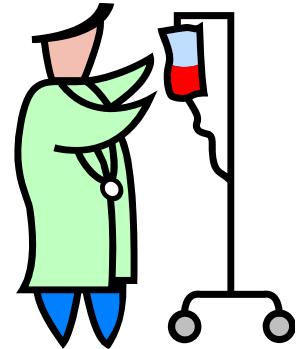
- Complex pharmacology
- Duration of action increases with prolonged use from 4 hours to as much as 12 hours.
- Dose conversions to/from other opioids are complex—seek consultation
- Least expensive potent opioid
- Does not need special DEA license to use for pain; special license only needed if used as treat for substance abuse (methadone maintenance clinic)

Opioid Dose Escalation

Always increase by a percentage of the present dose based upon patient's pain rating and current assessment



Parenteral Opioids



- IV is the route of choice if access is available.
 - There is NO indication for IM opioids (painful, no benefit over SQ route)
 - All standard opioids can be given SQ, by either bolus dose or by continuous infusion.
- PCA (basal rate plus a patient initiated dose) is an effective and well accepted modality; either IV or SQ.

Parenteral Opioids (cont.)

- IV or SQ bolus doses have a shorter duration of action than oral doses; typically 1-3 hours.
- The peak effect from an IV bolus dose is 5-15 minutes.
- Dose escalation of parenteral opioids is the same as with oral—always by a percentage of the starting dose.

Opioids Side Effects

- Sedation, confusion, respiratory depression
- Dizziness, dysphoria
- Nausea
- Constipation
- Itching, urticaria, bronchospasm
- Urinary retention
- Opioid hyperexcitability syndrome
 - Hyperesthesia, myoclonus, seizure

Respiratory Depression

- Risk Factors
 - Renal insufficiency
 - Liver failure
 - Parenteral opioids; especially rapid dose escalation in opioid naïve patients
 - Severe pulmonary disease (CO_2 retainers)
 - Sleep apnea
 - Rapid dose escalation of transdermal fentanyl or methadone

Nausea and Vomiting

- Caused by stimulation of the CTZ (chemoreceptor trigger zone) at base of 4th ventricle.
 - Nausea is not an allergy!!
- Morphine and codeine are the most emetogenic opioids
- Tolerance develops within 3-7 days for most patients
- Standard anti-emetics can reduce symptoms
 - No “best” anti-emetic

Constipation

- Multifactorial cause
- Tolerance does not develop
- Start a bowel stimulant at the time opioids are started
 - Senna (with or without docusate) is good first choice
- Add saline or osmotic laxatives as needed (e.g. MOM, sorbitol, Lactulose)
- Goal is at least one BM every other day

Itching and Urticaria

- Tolerance may or may not develop.
- Not life threatening
 - not anaphylaxis
 - does not mean that opioids can never be used
- Treatment of symptoms is not very effective (anti-histamines, steroids)
 - Trial of different opioid is indicated as some patients will itch with one product but not another.

Adjuvant Analgesics

- Adjuvant analgesics refers to drugs used to treat neuropathic pain.
 - Pain characterized by sharp, shooting, electric shocks, paresthesias, dysesthesias, cold extremities
 - Neuropathic pain often responds poorly to NSAIDs and opioids

Drugs for Neuropathic Pain

- opioids
- antidepressants
- anticonvulsants
- local anesthetics
- steroids
- other

Nausea

- The term nausea means different things to different people; a thorough assessment is key to distinguish different etiologies;
- Key questions to ask include:



Questions to Ask

1. Sensation of vertigo? → Vestibular irritation
2. Abdominal pain/ache? GERD/Ulcer
3. Early satiety or anorexia? → Squashed stomach
or liver metastases
4. Headache w/ early
morning nausea? → Brain Tumor
5. Positional vomiting
or vomiting with no
nausea → Reflux

Common causes of nausea

- Gastrointestinal Causes
 - obstruction
 - gastritis, GERD
 - gastric stasis, squashed stomach syndrome
 - GI infection
 - constipation
 - abdominal carcinomatosis, extensive liver metastases
 - acute effect of abdominal radiation or chemotherapy

Other causes of nausea

- CNS—elevated ICP, posterior fossa tumors/bleed, infectious or neoplastic meningitis
- Drugs—opioids, chemotherapy, antibiotics
- Metabolic—hypercalcemia, liver failure, renal failure, sepsis;
- Psychological—anxiety, pain, conditioned response (e.g. anticipatory nausea/vomiting).

Treatment

- Non-Drug Therapy
 - Behavioral treatments—relaxation, imagery, music, distraction, games
 - GI drainage for obstruction
 - Fluid management—a patient with obstruction may benefit from reduction in parenteral fluids to decrease GI secretions and thus limit distention

Treatment (cont.)

- Anti-emetics work via inhibition of one or more neurotransmitters active in the vomiting reflex:
 - Acetylcholine
 - Dopamine
 - Histamine
 - Serotonin
 - Substance P

Examples



Examples: Anti-emetics

- **Scopolamine**: a very potent, pure anticholinergic agent.
- **Promethazine** (Phenergan ®): antihistamine with potent anticholinergic properties, very weak antidopaminergic agent. (Poor choice for opioid related nausea.)
- **Prochlorperazine** (Compazine ®): Potent antidopaminergic, weak antihistamine, anticholinergic agent.
- **Haloperidol**: Very potent anti-dopaminergic agent.
- **Lorazepam**: weak anti-emetic, little evidence of anti-emetic activity except in anxiety

Common Agents by Drug Class

- Dopamine antagonists
 - Compazine ®, Thorazine ®, Haldol™, Inapsine ®
- Serotonin antagonists **
 - Zofran ®, Kytril ®, Anzemet ®
- Anti-Histamines / Anti-Cholinergic
 - Benedryl ®, Vistaril ® , scopolamine, Phenergan ®

**** Most expensive**

Other agents

- Pro-Motility Drug
 - Metoclopramide (Reglan ®)
- Cannabinoid
 - Marinol ®
- Glucocorticoid
 - prednisone
- Substance P receptor antagonist
 - Aprepitant (Emend ®): approved only for chemo-related nausea—no proven efficacy otherwise

Caring for the Dying Patient

An optimal care site has...

- Space for patient/family privacy
- Ready availability of medications and equipment to manage distressing symptoms
- Nursing support when needed
- Round-the-clock patient access for family/friends/caregivers

The setting for the dying patient

- The optimal place to provide care is determined by:
 - Degree of support available from family/friends
 - Physical support for patient turning, bathing
 - Psychosocial support for patient emotional distress
 - Frequency of need for skilled nursing support
 - Community resource availability
 - e.g. residential hospice
 - Insurance status

Site Options

- Home with hospice support
- Residential hospice
- Hospital: Inpatient hospice/palliative care unit
- Long-term care facility with hospice support

Progression of Symptom/Signs in the last two weeks of life

- Two semi-distinct stages over 1-14 days
- Difficult to prognosticate with precision within the last few days
- Time of high stress for family and caregivers
 - Second guessing past decisions is common
 - Most families are unfamiliar with the dying process—
not sure what is “normal”

Early Stage

- Bed bound
- Loss of interest and ability to drink/eat
- Cognitive changes
 - Increasing sedation; Lethargy
 - Delirium: Hyperactive or Hypoactive



Late Stage

- Loss of swallowing reflex
- “Death rattle”
 - Pooled oral secretions that are not cleared due to loss of swallowing reflex
- Coma
- Fever
- Altered respiratory pattern
- Skin color changes
- Death



Decreasing Oral Intake

- All dying patients lose interest in oral intake in the days preceding death.
 - Ketosis will blunt symptom of hunger
 - Bedbound patient will not experience symptoms of postural hypotension
 - No association between fluid intake and thirst in final days
 - Oral cavity needs frequent assessment to ensure good hygiene

Decreasing Oral Intake

- Caregiver Education
 - Normalize signs/symptoms
 - Do not force feed
 - Provide ice chips and small sips of liquid as tolerated
 - Mouth swabbing q1hour with baking soda mixture
 - Frequent moistening of lips with petroleum jelly to avoid cracking.

Loss of Swallowing

- The “Death Rattle” ensues when a patient is unable to swallow
 - Retained oropharyngeal secretions leads to ...
 - Loud noisy breathing—often very distressing to families.
 - Treatment
 - Discontinue artificial hydration/feedings
 - Anticholinergic drugs to dry secretions
 - Atropine, scopolamine, glycopyrrolate, others
 - Use oropharyngeal suction only if necessary

Pain

- A. The patient with significant pain, entering the final days:
 - Assume that pain will continue to be present until death
 - Do not discontinue opioids as mental status declines
 - Dose reduction may be needed due to diminished renal/hepatic function: myoclonus is a sign of opioid toxicity
 - Use physical signs of potential pain to judge analgesic need:
 - Grimacing and groaning; Tachycardia

Treatment

- Use a trial of increased analgesics for suspected pain
- Use non-pharmacologic analgesics
 - Music
 - Massage

Altered Respiratory Pattern

- In the final days, the respiratory pattern usually changes to one or more of the following:
 - Increased or decreased rate or depth
 - Cheyne-Stokes breathing
 - Periods of apnea
- Treatment is only indicated for rapid breathing, which is often quite distressing for families/caregivers
 - Careful titration of opioids can help control respiratory rate to a range of 10-20 bpm.
- Use oxygen only if it appears to reduce distressing symptoms.

Fever

- Fever is common in the 1-3 days prior to death.
 - Pneumonia due to aspiration is the most likely cause.
- Scheduled rectal acetaminophen will control many patients
 - cooling blankets, parenteral NSAIDs or steroids can be used for refractory cases.

Signs of Death

- Absence of heartbeat and respirations
- Pupils fixed
- Skin color appears yellow/waxen
- Muscles relaxed-Jaw falls open
- Eyes remain open

Death Pronouncement

- Requirements vary by hospital/state
- Physician role
 - Confirm death has occurred by absence of respirations and heartbeat
 - Comfort family
 - Complete necessary paperwork
 - Communicate with medical examiner for selected cases
 - Check with local ME office for details

Palliative Care Cases

- MG was a 62 year old physician who developed Type I diabetes at the age of 12. She had experienced numerous complications of the diabetes, including peripheral vascular disease, retinopathy, and renal disease. By age 55, her renal disease progressed to the point of requiring hemodialysis. She had several A-V fistulae inserted for dialysis access, but all failed because of the vascular disease. Hemodialysis was performed via an indwelling catheter. The following year, she developed osteomyelitis of the spine, caused by skin flora, presumably from the dialysis catheter. After hospitalization for IV antibiotics, she was discharged to a rehab center and ultimately returned home. Two years later, she again developed osteomyelitis and discitis of the thoracic and lumbar spine. She was admitted to the hospital and received IV antibiotics for 6 weeks but became progressively paraplegic. Another 6 week course of antibiotics failed to reverse the paraplegia, and she was admitted to a rehab unit. After the completion of the second course of antibiotics, her pain worsened. Repeat MRI of the spine showed progressive destruction in the thoracic and lumbar regions. Another course of antibiotics failed to improve her pain and weakness.
- **What options might the physician discuss with the patient?**

- CL was an 80 year old Caucasian woman who was admitted to a skilled nursing facility with advanced dementia (Alzheimer type) and osteoporosis. She was married with 7 children, some of whom lived locally and some more distantly. She developed several episodes of aspiration pneumonia with respiratory distress, and her family requested that she be hospitalized and treated aggressively, including intubation.
- After the second episode of aspiration, the family requested the insertion of a PEG tube for feeding.
- **How should the physician respond to the family's request?**

- THANK YOU