Palliative Care — An Opportunity To Make A Difference At The End of Life

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Learning Objectives

- Define the terms “palliative care,” “hospice,” and “the Medicare Hospice Benefit.”
- Recognize patients who are eligible for hospice/palliative care services.
- Apply predictive models to determine prognosis in patients with a life-limiting illness.
- Identify and address barriers to hospice and palliative care services.

Case #1

An otherwise healthy 37 year old woman presents for discussion of her recently diagnosed amyotrophic lateral sclerosis. Her neurologist advises that she has slowly advancing disease, and may live for many months to a year or more. Her expressed goal of care is to manage the symptoms of her illness proactively, as she has twin teenage daughters who live at home. The best choice for meeting her goal is

A. Hospice referral.

B. Physical and occupational therapy referrals.

C. Palliative care referral.

D. Mental health referral (she just doesn't get it).

Terms

- Palliative care
  - A form of medical treatment that manages the pain, symptoms and side-effects of chronic illness
  - Available at any stage of a serious illness and can be combined with aggressive treatments
  - It's not hospice!
  - Many insurance companies cover the cost of palliative care services

Terms

- Hospice
  - A form of palliative care for patients who are terminally ill
  - Terminally ill - life expectancy is 6 months or less if the disease runs its normal course
  - The Medicare Hospice Benefit governs the delivery of hospice services

Terms

- The Medicare Hospice Benefit
  - Replaces Medicare Part A in Medicare-eligible patients
  - Patients “elect” the benefit, and have the right to revoke their election at any time
  - Medicare will pay for services related to a terminal diagnosis on a daily captitated rate

Who Is Eligible For Hospice?

- The beneficiary must be “entitled to Part A of Medicare”

AND

- “Certified as being terminally ill in accordance with §418.22”
- “The certification must specify that the individual’s prognosis is for a life expectancy of 6 months or less if the terminal illness runs its normal course” §418.22(b)(1)

IMPORTANT: this terminology applies to the Medicare Hospice benefit. However, Medicaid and many private insurers follow very similar guidelines

The Medicare Hospice Benefit

- Duration of hospice care coverage
  - A patient who elects the hospice benefit can receive care in the following order
    - An initial 90 day benefit period
    - A subsequent 90 day benefit period (total of two 90 day benefit periods)
    - An unlimited number of subsequent 60 day benefit periods

The Medicare Hospice Benefit

- Core Services
  - Physician services
  - Nursing services
  - Medical social services
  - Counseling services

The Medicare Hospice Benefit

- Non-Core Services
  - PT/OT
  - Hospice aide/homemaker services
  - Volunteer services (a minimum of 5% of patient-care hours must be provided by volunteers)
  - Drugs and biologicals

Determining Eligibility for Palliative Care Services

- Any patient with a chronic illness (any chronic illness)
  - Patients can receive care during other treatments, even if the treatment is curative in nature
- At any time during that illness
- Goal is management of symptoms and improvement in quality of life

Determining Eligibility for Hospice Services

- Any patient with a terminal diagnosis
- At any time during the terminal illness
- Requires two physicians to certify that the patient is terminally ill
  - Not an NP or PA…DO/MD only!!!
  - Requires determination of prognosis

Prognosis vs Eligibility

- Determining prognosis is the practice of medicine
- Coverage determination involves eligibility for the terminal diagnosis; but this is grounded in prognosis
- Eligibility governs coverage (payment for hospice services)

Great! So How Do I Know Who's Eligible for Hospice?

- Determine prognosis
- Discuss options with patient/family
- Evaluate with hospice - review chart and speak with medical director

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“Would you be surprised if your patient died within a year?”

Challenges to Determining Prognosis

- It's the practice of medicine, but we really weren't trained to do it
- I can generally spot someone who's dying
- Maybe it isn't as bad as I think
- "…not quite dead yet…"

Challenges to Determining Prognosis

Christakis, *Annals Int Med*, 2001

- 326 patients with cancer in five Chicago area hospices
- 20% oncologist's accuracy in predicting prognosis
- 63% overestimate, 17% underestimate
- Only 37% would give frank and honest disclosure, even when patient requested survival estimate
- Average survival was 26 days; average communicated survival time was 90 days

The Coming Storm…

- Nearly 1 in 2 Americans has a chronic disease
- Projected to increase - 157 million Americans by 2020, 171 million by 2030
- 90% of patients > 65 have at least one chronic disease; 77% have two or more
- 24% of retirees have some form of disability

The Benefits of Accurate Prognostication

- Gives a good framework in making informed decisions
- Provides opportunity for life-care planning
  - Spiritual
  - Financial
  - Psychosocial (relationships/forgiveness)
  - Opportunity to say “good-bye”
  - Life closure and legacy giving

Prognostication Assessment

- Clinical signs
- Performance status
- Disease trajectory
- Tools

Clinical Signs

- Progressive weight loss
- Decline in neurocognition
- Increasing dyspnea or fatigue with effort
- Longer periods of rest needed
- Dependence in activities of daily living (ADLs)
- Loss of independence

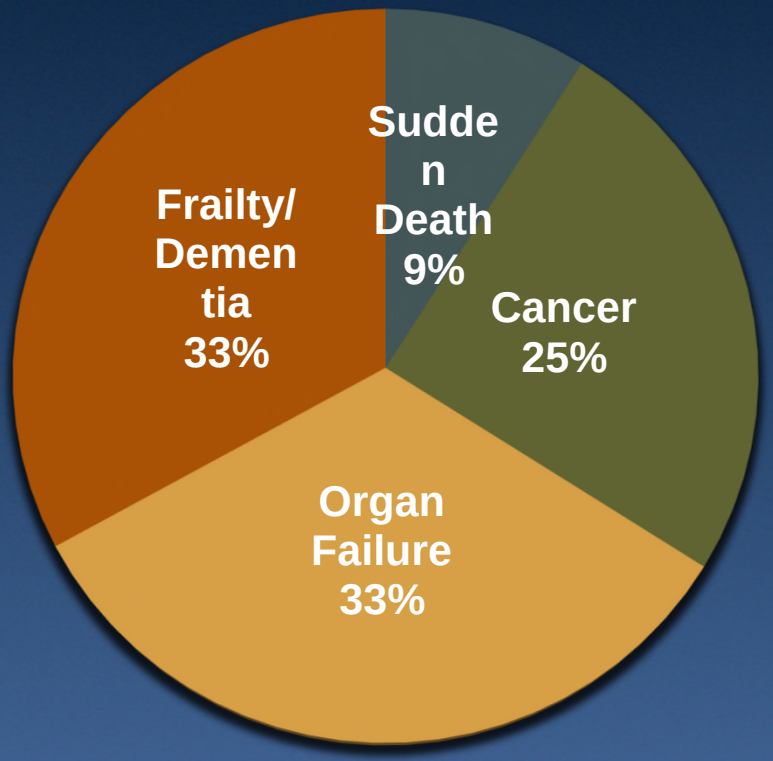
…these are major features of performance status

Activites of Daily Living (ADLs)

- Functional mobility: ability to walk, transfers out of bed or chair
- Personal hygiene: showering/bathing, oral care, grooming (hair, nails, makeup)
- Toileting: getting on/off the toilet, managing toileting tasks
- Dressing
- Self-feeding

Disease Trajectory

- Major diseases causing death in the United States
- Organ failure…heart disease, kidney disease, liver disease, lung disease, cerebrovascular disease, etc.



Sudden Death

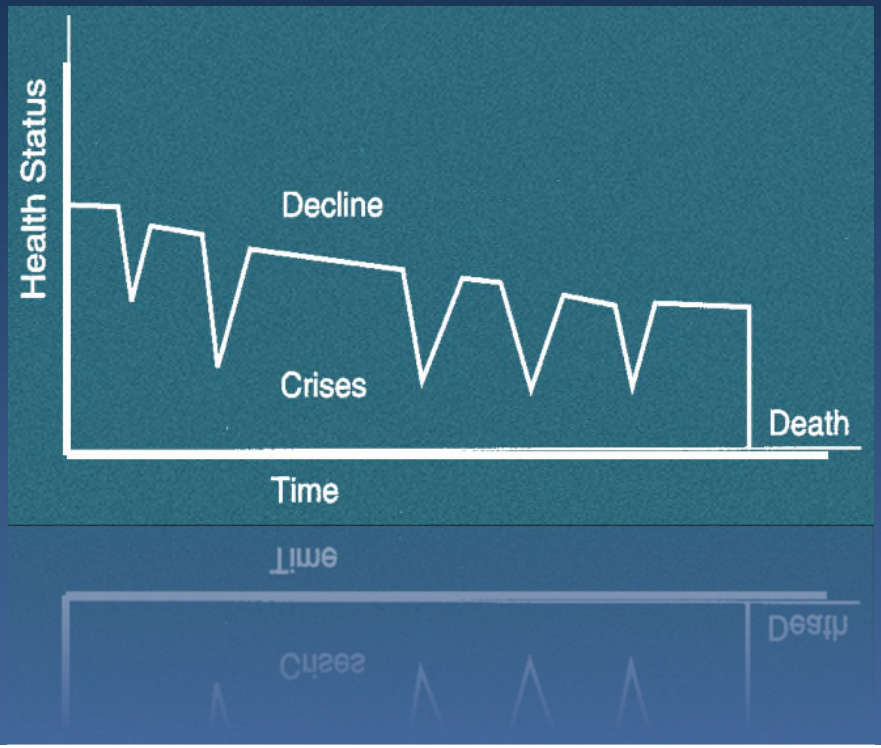
- 8-11% of deaths annually
- Examples: acute myocardial infarction, pulmonary embolus, CVA
- Patients are often highly functional prior to death
- Dependence
  - 1 year prior to death: 0.69 ADLs
  - 1 month prior to death: 1.22 ADLs

Cancer

- Accounts for 30-35% of all deaths
- Patients are usually highly functional early on with slow decline 3 months prior to death
- Dependence
  - 1 year prior to death: 0.77 ADLs
  - 3 months prior to death: 4.09 ADLs

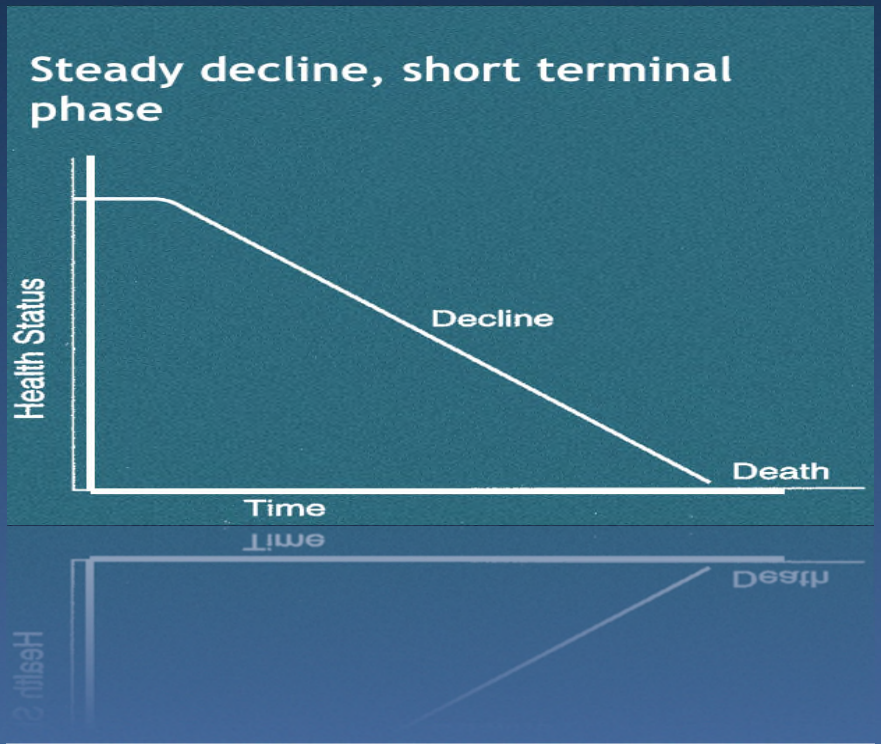
Organ Failure

- Accounts for 35-40% of all deaths
- Multiple exacerbations, often requiring hospitalizations
- Generally die during exacerbations
- Renal, liver, cardiac, pulmonary
- Dependence
  - 1 year prior to death: 2.1 ADLs
  - 3 months prior to death: 3.66 ADLs



Frailty

- 20-30% of all deaths
- Elderly women with multiple co-morbidities
- Dementia often is present
- Very slow rate of decline, with early functional decline
- Dependence
  - 1 year prior to death: 2.92 ADLs
  - 1 month prior to death: 5.84 ADLs



Depression and Social Isolation

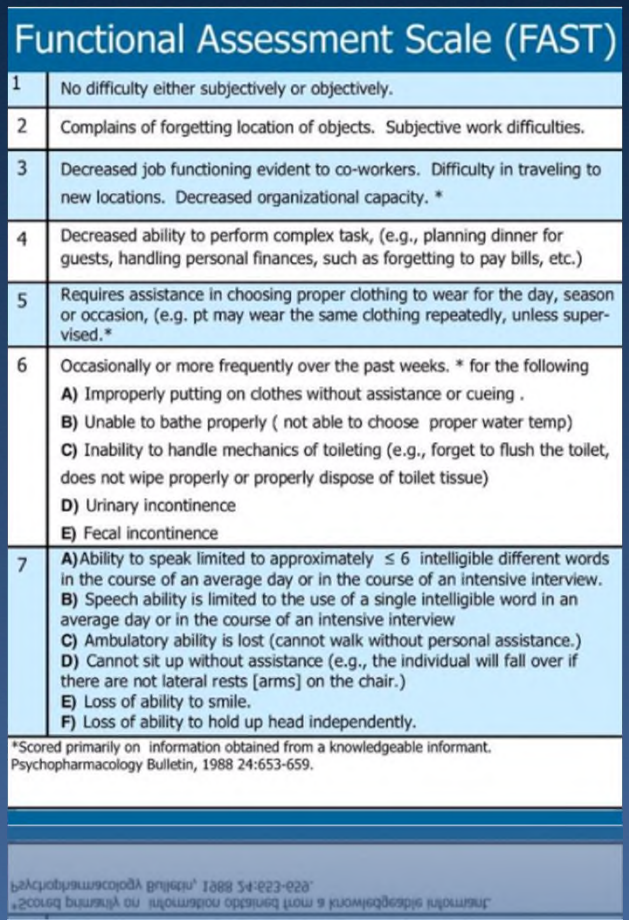
- Higher rates of hospitalization
- Increased mortality post-MI
- Increased mortality from cancer
- Overall higher mortality rates from all diseases
- Lowered immune function
- Depression and social isolation are independent risk factors

Prognostication Tools

- Prognostic indicators - LCDs from MACs
- Disease-specific tools (FAST, MRI, BODE, MELD, NYHA, Albumin, CrCl, others)
- BMI
- ADLs and dependence
- PPS, ECOG/Karnofsky performance status
- Rapidity of decline (trajectory)
- Co-morbidities

FAST

- FAST = the Reisberg Functional Assessment STaging scale
- 16 item scale designed to parallel progressive activity limitations in Alzheimer dementia
- Only evidence-based for Alzheimer dementia, but used in dementias of all types



Functional Assessment Scale (FAST)	
1	No difficulty either subjectively or objectively.
2	Complains of forgetting location of objects. Subjective work difficulties.
3	Decreased job functioning evident to co-workers. Difficulty in traveling to new locations. Decreased organizational capacity. *
4	Decreased ability to perform complex task, (e.g., planning dinner for guests, handling personal finances, such as forgetting to pay bills, etc.)
5	Requires assistance in choosing proper clothing to wear for the day, season or occasion, (e.g. pt may wear the same clothing repeatedly, unless supervised.*
6	Occasionally or more frequently over the past weeks. * for the following **A)** Improperly putting on clothes without assistance or cueing . **B)** Unable to bathe properly (not able to choose proper water temp) **C)** Inability to handle mechanics of toileting (e.g., forget to flush the toilet, does not wipe properly or properly dispose of toilet tissue) **D)** Urinary incontinence **E)** Fecal incontinence
7	**A)** Ability to speak limited to approximately ≤ 6 intelligible different words in the course of an average day or in the course of an intensive interview. **B)** Speech ability is limited to the use of a single intelligible word in an average day or in the course of an intensive interview **C)** Ambulatory ability is lost (cannot walk without personal assistance.) **D)** Cannot sit up without assistance (e.g., the individual will fall over if there are not lateral rests [arms] on the chair.) **E)** Loss of ability to smile. **F)** Loss of ability to hold up head independently.

*Scored primarily on information obtained from a knowledgeable informant.
Psychopharmacology Bulletin, 1988 24:653-659.

Performance Status Tools

Karnofsky Performance Scale (KPS)		Eastern Cooperative Oncology Group (ECOG, Zubrod) Performance Scale	
Normal, no evidence of disease Able to perform normal activity with only minor simptoms	100 90	Normal Activity	0
Normal activity with effort, some symptoms Able to care for self but unable to do normal activities	80 70	Symptomatic and ambulatory Cares for self	1
Requires occasional assistance, cares for most needs Requires considerable assistance	60 50	Ambulatory > 50% of the time Occasional assistance	2
Disabled, requires special assistance Severely disabled	40 30	Ambulatory $\leq$ 50% of the time Nursing care needed	3
Very sick, requires supportive treatment Moribund	20 10	Bedridden	4

Performance Status Tools

Performance Status: ECOG, Karnofsky, others

Better

Working
Cares for self
Ambulatory, out of bed most of the day

Not working
Cannot care for self
Confined to bed most of the day

Worse

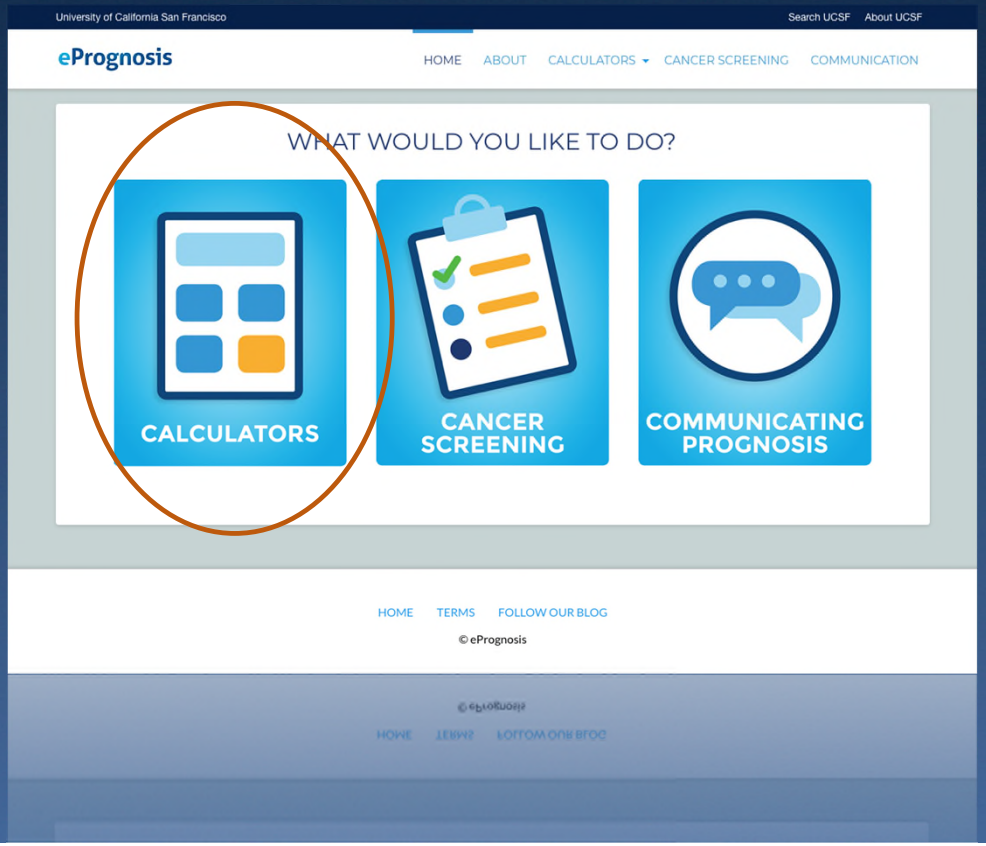
MELD Score

- MELD = Model End-Stage Liver Disease
  - INR
  - Bilirubin
  - Creatinine
- Parameters are graded and scored along with presence of ascites and encephalopathy

MELD Score	% Mortality Rate (90 days)
≤9	4
10-19	27
20-29	76
30-39	83
≥40	100

Prognostication Tools

- Online
  - ePrognosis
  - https://eprognosis.ucsf.edu
  - A number of useful tools
  - My favorite is the "Calculators" section



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“Would you be surprised if your patient died within a year?”

Barriers to Palliative Care/Hospice

- Unaccepting professionals
  - May cause dissent between patient and team or between other professionals
  - If there are questions of ethics, the concern should be taken to an ethics committee
  - The patient decides who will be involved in care, and if professionals are not able to reconsider a position, they should sign off the case or be dismissed from care

Barriers to Palliative Care/Hospice

- Focus of care too narrow
  - Goals of care should be broad enough to encompass the totality of concerns for the patient and family
  - Team-based approaches allow for a more complete strategy
  - The focus should be dynamic and adaptable to a changing patient situation

Barriers to Palliative Care/Hospice

- Failure to acknowledge the diverse nature of American culture
  - Cultural awareness: appreciative of the different backgrounds of Americans and the contributions of those backgrounds to American society
  - Cultural competence: willingness to address different backgrounds of patients and their families, sensitivity to their unique needs, and the ability to meet those needs

Cultural competence is what the patient says it is. It means that we have to ask specific questions and address specific needs!

Barriers to Palliative Care/Hospice

- Missed Opportunities
  - American Cancer Society Survey 2014: Over 90% of surveyed respondents indicate a desire to discuss end-of-life care issues and incorporate them into a patient-focused plan of care
  - As of 2015, ACoS requires multidisciplinary palliative care service availability for its accredited programs
  - Newer data demonstrating a lower cost of care for patients with life threatening chronic conditions and terminal care will likely drive the market toward increased utilization of palliative care services

Case #2

- A 75 year-old patient presents with rapid weight loss of 20# in 6 weeks and the onset of Type II diabetes mellitus requiring insulin. The patient's family indicates that she spends over half her time in bed, has no appetite, and complains of back and abdominal pain. CT scan reveals a large mass in the head of the pancreas and multiple hepatic metastases. The best approach for this patient is

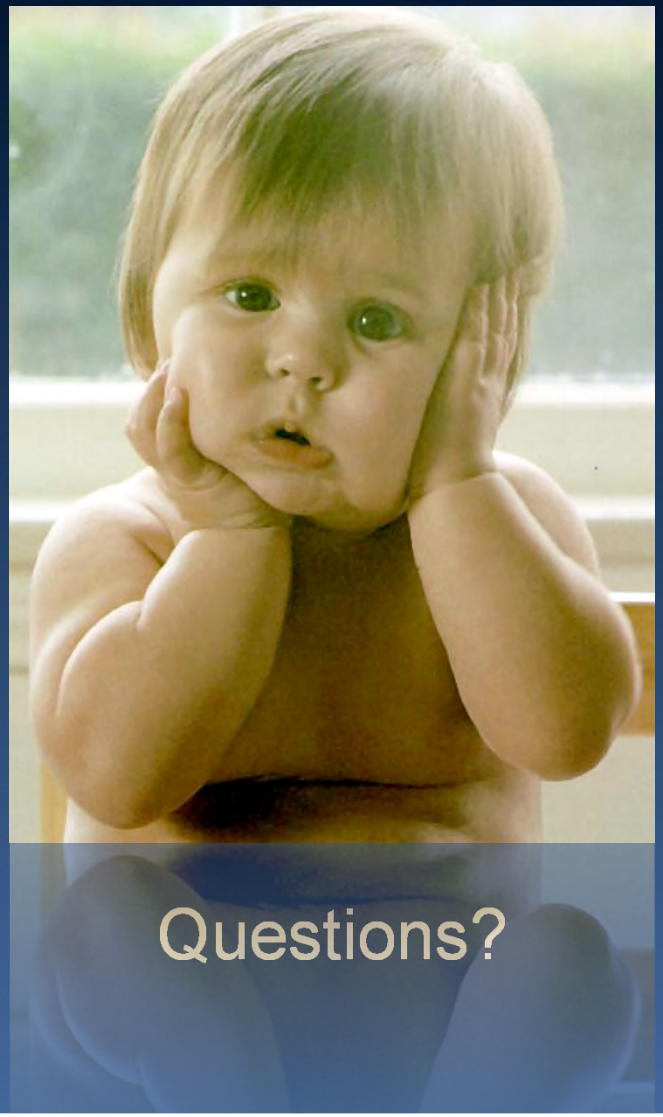
A. Multiagent chemotherapy.

B. Single agent chemotherapy.

C. Gastrojejunostomy to avoid obstruction.

D. Radiation therapy.

E. Supportive care with hospice referral.


Questions?