

Talking to Patients about Living (and Dying) When They Are Dying

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Disclosures

- Nothing to disclose

Objectives

- Increase utilization of palliative care in patients with life-limiting illness, especially in the setting of a request for aid-in-dying
- Develop your own vernacular to start the conversation and have a toolkit to refer patients to after the initial conversation
- Utilize appropriate codes for both physicians and non-physician staff

Outline

- When does someone need palliative care?
 - What is palliative care?
 - What is primary (vs specialty) palliative care?
 - What are triggers for palliative care?
 - How do I determine prognosis?
- What is my role as a general internist (or non-palliative specialist)?
- How do I determine prognosis?
- How do I handle a request for medical aid-in-dying?

- Open discussion/forum

Case #1 – Ms. A

- 64 yo F recently diagnosed with ALS after presenting with leg weakness
- PMH – hypertension, hyperlipidemia, and major depression
- Medications – lisinopril/HCTZ, atorvastatin, recently started riluzole
- ROS – leg weakness with difficulty rising from seat, slow on stairs; negative for dyspnea, dysphagia, weight loss. Mood “I’m in shock”, some anxiety
- PE – 4+/5 strength in hip flexors, few fasciculations, gait slightly unsteady, speech fluent
- Studies – unremarkable, FVC 86% of predicted

Case #2 – Mr. B

- 58 yo M with multiple myeloma, relapsed after transplant, complicated by vertebral fractures and bone pain, hypercalcemia, chronic renal failure
- PMH – HTN
- Medications – oxycodone SR, oxycodone IR, losartan, lenalidomide, dexamethasone, zoledronic acid, senna
- ROS – pain lumbar spine, left hip, right shoulder; fatigue, anorexia, constipation; no weight loss; mood “depressed about being sick”
- ADL – cane or walker; wheelchair outside the house, shower bench

Do Ms. A and Mr. B need palliative care?

Do Ms. A and Mr. B need palliative care?

- Of course they do.
- All patients need and are receiving (some degree of) palliative care.
- PC offers relief from suffering and addresses and promotes QOL.
- Quality of life is part of every decision we and patient and families make.
- But the proportion differs.
- Every provider has a role in providing palliative care.

What does Palliative Care do?

What are the **GAPS**?

- **Goals of care discussions**
 - Prognosis
 - Decision-making
- **Advance directives**
 - Complex advance directive discussions
- **Psychological, emotional, and social support**
- **Symptom management**

What is my role as an internist (PCP)?

Primary vs Specialty Palliative Care (SPC)

- Symptom management - pain, nausea, dyspnea, fatigue, anorexia, etc.
 - SPC for difficult symptoms related to life-limiting illness
- Advance directives - MDPOA, MOST, resuscitation, mechanical ventilation, artificial nutrition, limits to care (e.g. trach/PEG)
 - SPC for complex issues
- Goals of care
 - SPC for complex medical cases, unrealistic expectations, differing opinions
- Psychological, social, and spiritual support



Goals of Care Discussions

- Include patients, families, decision-makers
- “What do you understand?”
 - Current state of disease
 - Treatment options and associated benefits and burdens
- “What are you hoping for?”
- “What are you worried about?”
- **What matters most?**
- Help align treatment with goals
 - Allow yourself to make recommendations based on goals

Primary Palliative Care – Goals of Care

- Assess understanding of medical issues
 - “Tell me what you understand about your lung disease.”
 - “What did Dr. Specialist tell you?”
 - “What do you understand about what may happen in the future?”
- Assess understanding of options and associated benefits and burdens
 - “What do you see as your options and how are you weighing them?”
- Assess current functional status and quality of life (QOL)
 - ADL’s, IADL’s, homebound status, etc
 - “What do you need help with to get through your day?”
- What constitutes QOL for them?

Primary Palliative Care – Advance Directives

- MDPOA
 - NOT automatically next of kin in Colorado
 - Does not require notary or witnesses
- If MDPOA not named (and pt not decisional), any “interested party” can serve as proxy decision-maker
 - Formal process for naming proxy
 - Requires consent of all interested parties
- Avoid potential risk of malpractice by getting proxy decision-maker prior to obtaining consent for any procedures, etc. in pt who lacks decision-making capacity

Consider Specialty Palliative Care referral if:

- Complex, uncontrolled symptoms (or anticipation of this)
- Complicated medical issues with uncertain outcomes or difficult decisions
- Unclear, uncertain, or unrealistic goals of care
- Complex family dynamics around decisions
- Patient or family not coping well

How do I talk about Palliative Care?

- Associated with hospice and end-of-life in the minds of many
- Can be helpful at any stage of disease along with curative or life-prolonging treatment
- Better outcomes (improved quality of life, decreased stress and depression, better coping, more hope, and, in some cases, longer life)
 - Earlier is probably better

Introducing ~~Palliative~~ Supportive Care

Specific words:

- **specialized** medical team for people and families dealing with **serious illness**
- provide an **extra layer of support**
- help with **managing symptoms** like _____
- help with **understanding your illness and your options**
- help making **complex medical decisions** figuring out **next steps**

Introducing Palliative Care

- “I’d like you to see a support team who can help be sure that you feel (live) as well as you can.
- “They can help you with decision-making and can make sure that you are getting the care that works best for you.”
- “They are called Palliative Care, but I prefer to call them Supportive Care because they are there to support you and your family.”

Other helpful phrases:

- “I’m worried...”
- “They can help you feel as well as you can. And the better you feel, the longer you are likely to live (with better QOL).”

Ms. A continued

At her first visit after with you after hearing her diagnosis from Neurology, she asks:

- How long do I have?
- What can I expect?
- How should I prepare?
- Will you help me die?

Mr. B continued

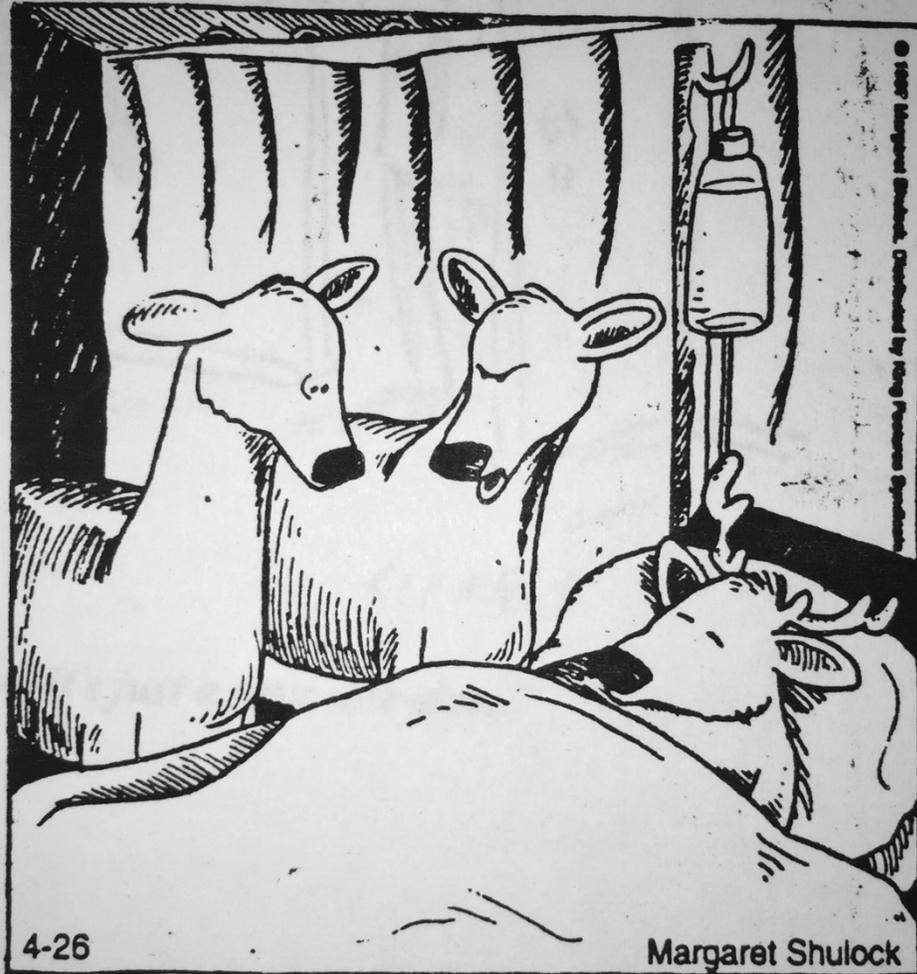
Mr. B comes to see you for help with pain and fatigue and asks:

- How long do I have?
- Will you help me die?

What can you do for Ms. A and Mr. B?

- How long do I have?
 - Assessing and communicating prognosis
- What can I expect?
 - Possible outcomes and complications
- How should I prepare?
 - Decision-maker and advance directives
- Will you help me die?

The New Breed



4-26

Margaret Shulock

“The docs don’t tell me a thing. They just say, ‘He’s out of the woods.’ Like I didn’t already know that!”

Why prognosticate?

- Patient/family decision-making
 - Medical decisions
 - Therapy – cure vs. comfort
 - Avoid burdensome therapy if not much benefit
 - Work and travel
 - Caregiving, living arrangements, financial planning
 - Relationship mending
- Referrals to palliative care and hospice

How should you respond?

- “Before I answer that, I’d like to ask you some questions.”
- “I’d like to know more about why you are asking.”
- “What have you been told?”
 - Understanding of disease, etc..
- “What are you hoping for?”
 - Realistic picture?
 - Specific goals/events/dates
- “What worries you?”

How do I determine prognosis?

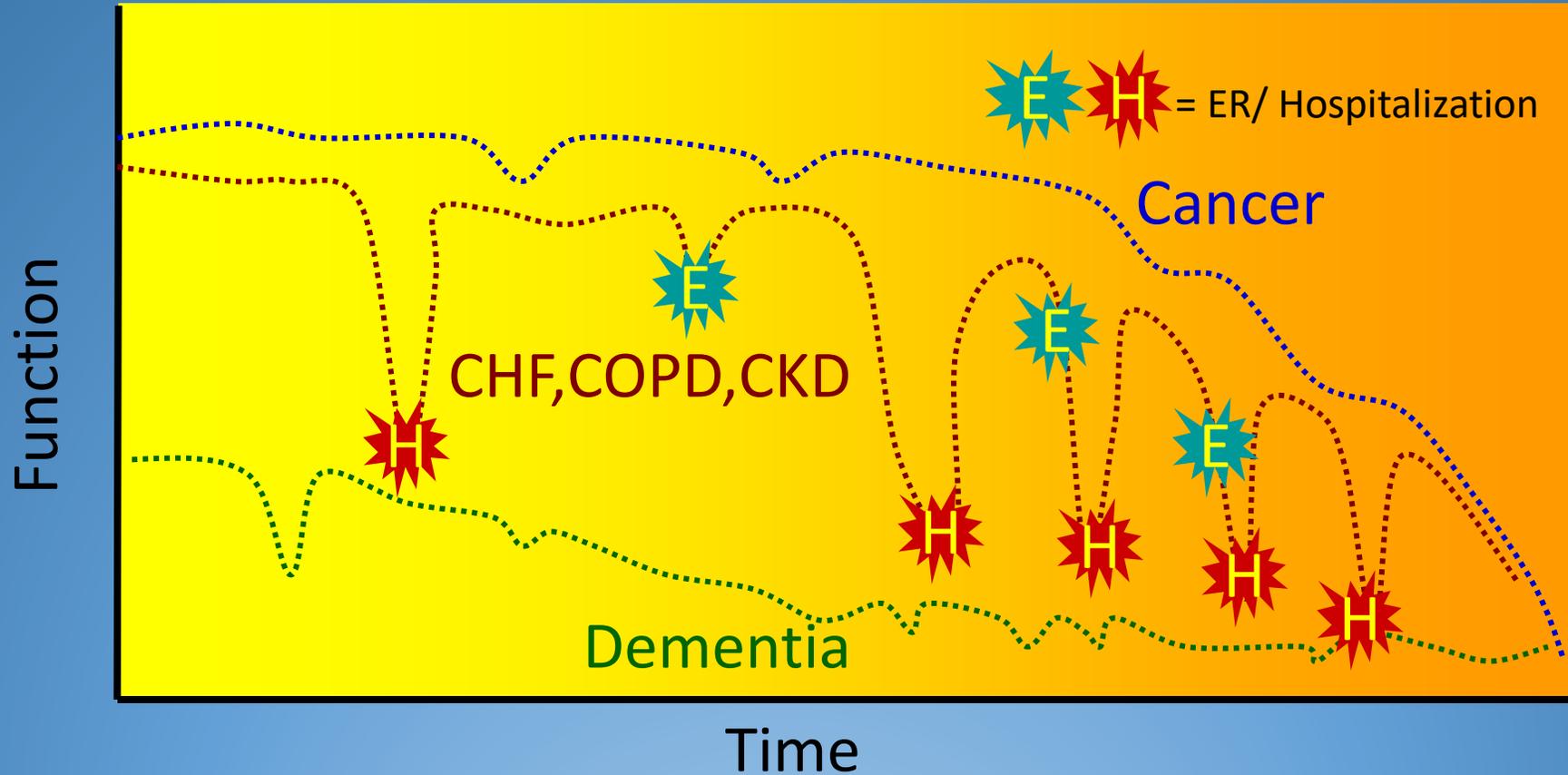
- Many different tools based on setting, disease state, etc.
- Many are cumbersome to use
- Physicians notoriously overestimate
- But it can be done reasonably



How do I determine prognosis?

- Depends on the disease state
 - Cancer
 - Organ failure
 - Neuromuscular disease
 - Dementia
- Risk of exacerbation/abrupt decline or catastrophe

Disease Trajectories

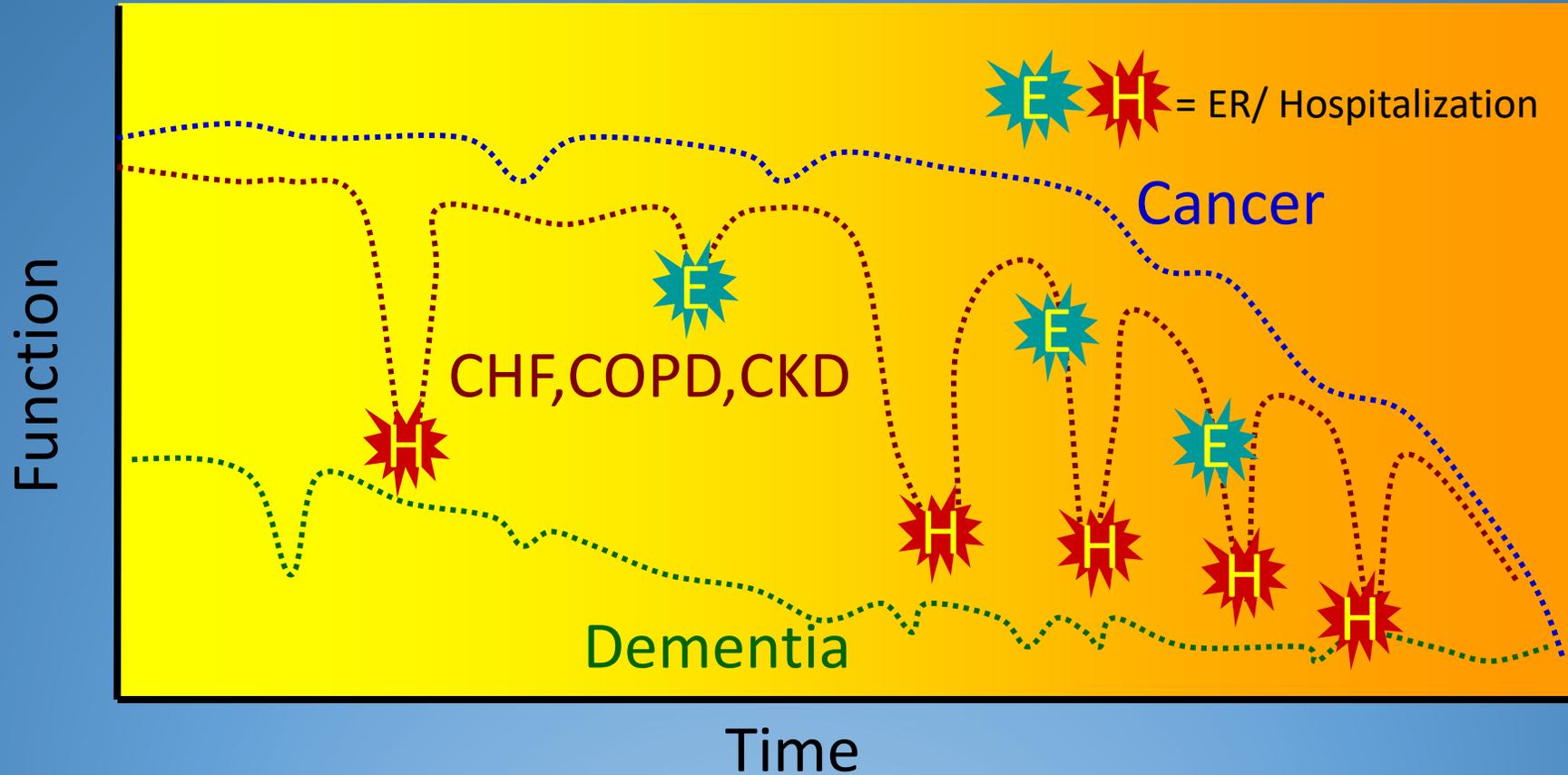


Increasing Severity of Disease

Disease Trajectories

- Cancer – increasing slope of decline with worsening performance status
 - Once someone needs help with ADL's, likely prognosis of months
- Organ failure – gradual decline with exacerbations and failure to return to previous baseline
 - Helpful to set expectations “Many people with your condition aren't able to recover as well as they would hope after a serious setback”
- Dementia – long period of decline with months to years of significant disability

Disease Trajectories



Prognostic Indicators

- Palliative Performance Scale (PPS)
- Surprise question
 - Would you be surprised if this person died in the next year?
- Online tool – eprognosis
- Hospice Eligibility Guidelines

PALLIATIVE PERFORMANCE SCALE (PPS)

%	Ambulation	Activity Level Evidence of Disease	Self-Care	Intake	Level of Consciousness	Estimated Median Survival in Days		
						(a)	(b)	(c)
100	Full	Normal <i>No Disease</i>	Full	Normal	Full	N/A	N/A	108
90	Full	Normal <i>Some Disease</i>	Full	Normal	Full			
80	Full	Normal with Effort <i>Some Disease</i>	Full	Normal or Reduced	Full			
70	Reduced	Can't do normal job or work <i>Some Disease</i>	Full	As above	Full	145		
60	Reduced	Can't do hobbies or housework <i>Significant Disease</i>	Occasional Assistance Needed	As above	Full or Confusion	29	4	
50	Mainly sit/lie	Can't do any work <i>Extensive Disease</i>	Considerable Assistance Needed	As above	Full or Confusion	30	11	41
40	Mainly in Bed	As above	Mainly Assistance	As above	Full or Drowsy or Confusion	18	8	
30	Bed Bound	As above	Total Care	Reduced	As above	8	5	
20	Bed Bound	As above	As above	Minimal	As above	4	2	6
10	Bed Bound	As above	As above	Mouth Care Only	Drowsy or Coma	1	1	
0	Death	-	-	-	-			

(a) Survival post-admission to an inpatient palliative unit, all diagnoses (Vick 2002).

(b) Days until inpatient death following admission to an acute hospice unit, diagnoses not specified (Anderson 1996).

(c) Survival post admission to an inpatient palliative unit, cancer patients only (Morita 1999).

PPS as predictor of mortality

“How much time do you spend in bed or sitting in a chair?”

- If PPS=50 (mainly sit/lie or “bed-to-chair” existence) median survival is likely weeks to months
- If PPS= 90 (full activity) median survival is more likely months to years
- Most useful for advanced cancer

The Surprise Question

- “Would you be surprised if this patient died within the next year?”
- “Yes” Survival - 93% (95%CI 91-96%)
- “No” Survival - 53%
 - Sensitivity - 59% (95%CI 49-68%)
 - Specificity - 90% (95%CI 86-93%)
 - Positive predictive value - 49% (95%CI 45-54%)
 - Negative predictive value - 93% (95%CI 90-95%).
- More predictive of death than type of cancer, age, cancer stage, or time since diagnosis

Online Tool

- <http://eprognosis.ucsf.edu/>
- Created by researchers who reviewed 16 prognosis tools
- Calculates 1 or 5 year mortality based on multiple characteristics and relevant prognosis calculators
- Utilizes objective data to stratify mortality risk
 - Physicians tend to overestimate longevity
- Based on population data, not individual circumstances
 - Most are predictive in the intermediate range 40-60%
- Not specific to all circumstances

Hospice Eligibility guidelines

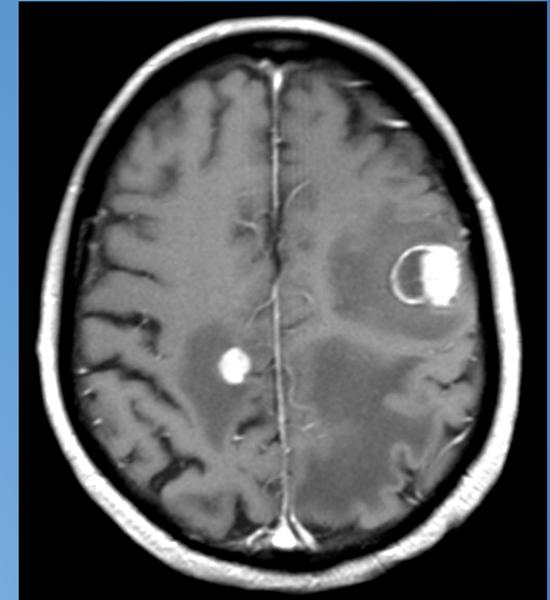
- Useful for determining eligibility for hospice support
- Do not necessarily correlate with 6-month mortality especially in non-cancer conditions
- Helpful for determining severity of disease even if not good prognostically

Hospice Eligibility – General Criteria

- Impaired functional status
 - Karnofsky Performance Status or PPS <70%
 - Cannot work, requires at least occasional assistance with personal care
 - Do NOT have to be homebound
- Dependence on assistance with 2 or more ADL's
 - Feeding, Ambulation, Continence, Transfer, Bathing, Dressing
- Disease-specific guidelines

Cancer

- Distant metastases at presentation OR
- Progression from an earlier stage of disease to metastatic disease with either:
 - A continued decline in spite of therapy
 - **Patient declines further disease-directed therapy**
- Note: Certain cancers with poor prognoses (e.g. small cell lung cancer, brain cancer and pancreatic cancer) may be hospice eligible without fulfilling the other criteria



Cardiac Disease

- Heart failure and angina most common
- Optimally treated (or declining treatment)
- NHYA Class IV symptoms
 - Discomfort (dyspnea, angina) with any physical activity
- Decreased EF not required for heart failure

Pulmonary Disease

- NYHA class IV dyspnea (at rest or with minimal exertion)
- Hypoxemia at rest
- Decreased FEV₁ not required
- Right heart failure, recurrent infections, weight loss, resting tachycardia are supportive factors

Liver Disease

- INR >1.5 AND Albumin <2.5
- AND one of the following:
 - Ascites, refractory to treatment or patient non-compliant
 - Spontaneous bacterial peritonitis
 - Hepatorenal syndrome
 - Hepatic encephalopathy, refractory to treatment or patient non-compliant
 - Recurrent variceal bleeding, despite intensive therapy
- MELD score
 - Not part of Medicare guidelines but useful prognostically

Renal Disease

- Not seeking or is discontinuing dialysis
- Not seeking transplant
- Creatinine >8.0 or low creatinine clearance
 - <10 if no comorbidity
 - <15 if DM *or* CHF
 - <20 if DM *and* CHF
- Supportive factors: volume overload, symptomatic uremia, hyperkalemia, pericarditis, hepatorenal syndrome, malnutrition

ALS

- Rate of progression is important
- Impaired breathing
 - FVC <30%, dyspnea at rest, and declines mechanical ventilation
 - Use of PAP can prolong life significantly
- Decline in functional status (progression within last 12 months)
 - From ambulating to wheelchair- or bed-bound
 - From normal to barely intelligible speech
 - From normal to pureed diet
 - From independence to needing major help with all ADL's
- Impaired nutrition
 - Oral intake insufficient to sustain life, weight loss, dehydration
 - Absence of artificial nutrition
- Aspiration pneumonia, pyelonephritis, stage 3/4 decubitus ulcers

Dementia

- FAST Stage 7A or higher*
 - No consistently meaningful verbal communication: stereotypical phrases only or the ability to speak is limited to six or fewer intelligible words
- Should have had one of the following within the past 12 months:
 - Septicemia, aspiration pneumonia, pyelonephritis or other upper urinary tract infection
 - Decubitus ulcers, multiple, stage 3-4
 - Fever, recurrent after antibiotics
 - Inability to maintain sufficient fluid and calorie intake with 10% weight loss during the previous six months or serum albumin <2.5 gm/dl.

FAST – Functional Assessment Staging of Alzheimer Disease

Stage 1 -- Normal adult - No functional decline

Stage 2 -- Normal older adult - Personal awareness of some functional decline

Stage 3 -- Early Alzheimer's - Noticeable deficits in demanding job situations

Stage 4 -- Mild - Requires assistance in complicated tasks such as handling finances, planning parties, etc.

Stage 5 -- Moderate - Requires assistance in choosing proper attire

Stage 6 -- Moderately severe - Requires assistance dressing, bathing, and toileting. Experiences urinary and fecal incontinence

FAST – Stage 7 (Hospice Eligible)

7A - No consistently meaningful verbal communication, only stereotypical phrases, or ability to speak is limited to 6 or fewer intelligible words

7B - Limited to the use of a single intelligible word which the patient may repeat over and over

7C - Ability to ambulate without personal assistance is lost

7D - Cannot sit up without assistance (patient will fall over if there are no lateral arm rests on the chair)

7E - Loss of ability to smile

7F - Loss of ability to hold head up independently

What about Failure to Thrive?

- Was an eligible hospice diagnosis up until 2014
- Now is difficult but not impossible to certify for hospice if pt has other signs of short life expectancy
 - Poor performance status
 - Malnutrition
 - Recurrent “serious” infections
 - Recurrent hospitalizations
 - Decubitus ulcers
 - Et cetera

Determining Prognosis

- Assess baseline functional status
- In non-cancer conditions, functional status may improve after exacerbations, but often not to previous level (ie new baseline)
- Ask yourself “Would I be surprised...?”
If the answer is no, you can still often be wrong.



Discussing Prognosis

- Set yourself up for success by finding out what they want to know (and what they don't)
- “How much do you want to know?”
- “What kind of information is helpful for you?”
 - Statistics?
 - Best and worst case scenarios?
- If patient doesn't want information but family does: “Is it ok if I give information to your family?”

Discussing Prognosis

- Acknowledge emotions openly
 - “It looks like this is difficult for you”
- Check your own emotions
- Allow for silence
- Balance realism and optimism
- Avoid avoidance
- Check in frequently
 - “This can be hard for people to hear, how are you doing?”

Ms. A and Mr. B

- Ms. A is able to do all ADL's and gets dyspneic after several blocks but never at rest
- She is not likely to have prognosis of 6 months or less
- Mr. B spends most of his day at home in his recliner and despite good pain management needs help with bathing and uses a walker and wheelchair
- He has PPS pf 50-60 and is eligible for hospice.
- Without chemotherapy, he has prognosis of 6 months or less

Requests for Medical Aid-In-Dying

- Questions to ask yourself
 - Am I comfortable prescribing?
- Is this patient mentally capable of making decisions?
- Are they acting voluntarily?
- Do they have 6 months or less to live?
- Questions to ask the family
 - Is this consistent with what he/she has said and valued in the past?

Is this patient able to make decisions?

- Decision-making capacity – medical determination
- Competence – legal determination
 - Words matter: use “decision-making capacity”
- Requires evaluation by 2 physicians
- If you and a consulting physician determine that the patient has decision-making capacity, no further evaluation is needed
- If you or the consultant are unsure, Psychiatric referral is indicated
- If you are sure that the patient does not have capacity, then aid-in-dying is not permitted

Can they clearly communicate a choice?

- Must have ability to communicate in some fashion
 - If impaired in any way, decisions should be “validated” by asking at different times or in different ways (e.g. rephrasing positive into negative)
 - Example: mechanical ventilation
- Better to ask open-ended questions
 - “Have you come to any decisions?”
 - “What is making it hard for you to decide?”
- Frequently changing decisions MAY be sign of lack of decision-making capacity

Can they understand relevant information?

- “Do you understand what I’ve told you?”
- “Please tell me in your own words what we’ve discussed.”
 - What is the problem (that requires a decision)?
 - What are your options?
 - What has been recommended?
 - What are the benefits and burdens of different choices as they see them?

Can they appreciate the situation and its consequences?

- Do they understand that they have illness?
 - Lack of insight into presence of illness implies lack of capacity
- Do they understand the seriousness of the situation?
 - More serious situations require higher level of decision-making capacity
- What is treatment (or not treating) likely to do for you?
- Delusions about illness or treatment effects MAY mean someone lacks decision-making capacity

Can they rationally process information?

- Ask patient to compare/contrast options and offer reasons for their decision.
- “How did you decide on this?”
- “What makes (this) better than (that) for you?”
- Process of decision-making is more important than the actual decision
 - “Unreasonable” choices do not necessarily imply lack of capacity

What should I do if I am not sure?

- Assess over time
- Ask other physicians who have seen the patient
- Ask family members and/or caregivers
 - Is this consistent with what they've expressed in the past or with their values as you understand them?
- Psychiatric consultation

When should I refer someone for further evaluation of capacity?

- Mental illness does not, in itself, mean someone lacks capacity
- Psychiatric consultation can help if mental illness is present and is uncontrolled

Why do patients ask for MAID?

- Unbearable physical suffering
- Unbearable existential suffering (emotional or spiritual)
- Loss of sense of self, control, dignity
- Burden
- Oregon:
 - 96% decreased ability to participate in enjoyable activities
 - 92% loss of autonomy
 - 75% loss of dignity

What do I do when someone requests MAID?

- Now or for the future?
- Serious request or more of a “cry for help”?
- In what ways are they suffering now or what are they anticipating?
- Is there an un- or partially-treated mental illness?
- Do they have decision-making capacity?
- Are they terminal?
- Is this consistent with long-held values?
- Are there coercive factors (family, finances, emotional or physical abuse/neglect)?

How to respond

- Ask open-ended questions
 - “Tell me more”
 - What are you experiencing? (physically, emotionally, etc.)
 - What are you most worried about?
- Respond empathically (non-judgmental)
- Treat all physical symptoms or refer for treatment
- Screen for and treat depression and anxiety
- Evaluate for spiritual suffering
- Consider Palliative Care or hospice consultation
- Complete advance directives (MDPOA, MOST)
- Discuss stopping or avoiding life-prolonging therapies (e.g. oxygen, medications, antibiotics)

Process issues

- 18 years of age or older
- 2 verbal requests 15 days apart
- 1 written request
- Confirmation of terminal prognosis
- Confirmation of decision-making capacity
- Confirmation of voluntary nature of the request
 - 2 physicians to confirm decisional, voluntary and terminal
- Ability to swallow
- Ability to self-administer
- Ability to rescind request
- Consider hospice referral

Some statistics on MAID – Oregon

- In Oregon, less than 0.5% of death are due to MAID
- 2/3 of patients who get Rx use it
- More common in older (median age 78), white, college-educated
- Cancer (72%), ALS (6%)
- 90% died at home, 92% were enrolled in hospice
- 5% were referred to Mental Health professional to assess capacity

Documentation – CMS

“Examples of appropriate documentation would include an **account of the discussion** with the beneficiary (or family members and/or surrogate) regarding the **voluntary** nature of the encounter; documentation indicating the **explanation of advance directives** (along with completion of those forms, *when performed*); **who was present**; and the **time spent** in the **face-to-face** encounter.”

Footer <https://www.cms.gov/Medicare/Medicare-Fee-for-Service-Payment/PhysicianFeeSched/Downloads/FAQ-Advance-Care-Planning.pdf>

Advance Care Planning CPT Codes

- *CPT Code 99497- Advance care planning including the explanation and discussion of advance directives such as standard forms (with completion of such forms, when performed), by the physician or other qualified health care professional; first 30 minutes, face-to-face with the patient, family member(s), and/or surrogate*
- *CPT Code 99498- each additional 30 minutes (List separately in addition to code for primary procedure)*

ACP CPT Codes

- No limit on # of times can be billed per year
 - ‘When the service is billed multiple times for a given beneficiary, we would expect to see a documented change in the beneficiary’s health status and/or wishes regarding his or her end-of-life care’
- No specific Dx code required
 - ‘It would be appropriate to report a condition for which you are counseling the beneficiary, an ICD-10-CM code to reflect an administrative examination, or a well exam diagnosis when furnished as part of the Medicare Annual Wellness Visit (AWV)’
- Can be billed in any care setting
- Can be billed by physician or NPP’s
- If <30 min spent discussing, bill for diagnosis only

Summary

- Specialty Palliative Care can help with complex issues involving goals of care, advance directives, symptom management and psychosocial and spiritual support
- Introduce Palliative Care as Supportive Care
- Use “bed-to-chair existence” and surprise question as marker for poor prognosis
- MAID is an option for terminal patients with decision-making capacity who are acting voluntarily and can self-administer
- Use functional status and other prognostic tools to assess for terminal status (and MAID eligibility)

Resources

- *Mastering Communication with Seriously Ill Patients: Balancing Honesty with Empathy and Hope.* Anthony Back et al. Cambridge University Press, 2009.
- www.vitaltalk.org
- Clinical Criteria for Physician Aid In Dying *Journal of Palliative Medicine*
- www.compassionandchoices.org/for-medical-providers/
 - Videos covering various aspects of requests for aid-in-dying ; CME credits
- *The Best Possible Day.* Atul Gawande. New York Times, 10/5/2014
http://www.nytimes.com/2014/10/05/opinion/sunday/the-best-possible-day.html?_r=0
- *Being Mortal: Medicine and What Matters in the End.* Atul Gawande. Metropolitan Books/Henry Holt and Company, 2014