

Helping Patients at End of Life: Improving Hospice Transitions from Clinic

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Objectives

- Improve prognostication and understanding of hospice qualifications
- Learn new ways to discuss hospice with your patients and improve referral timing
- Help your patients have a successful transition to hospice

Why Hospice?

- Most benefit comes from improved communication, when the family:
 - Was regularly informed of their loved ones condition, with clear and accurate information
 - Received the right amount of emotional support
 - Identified one nurse in charge of their loved ones care, with other consistent caregivers



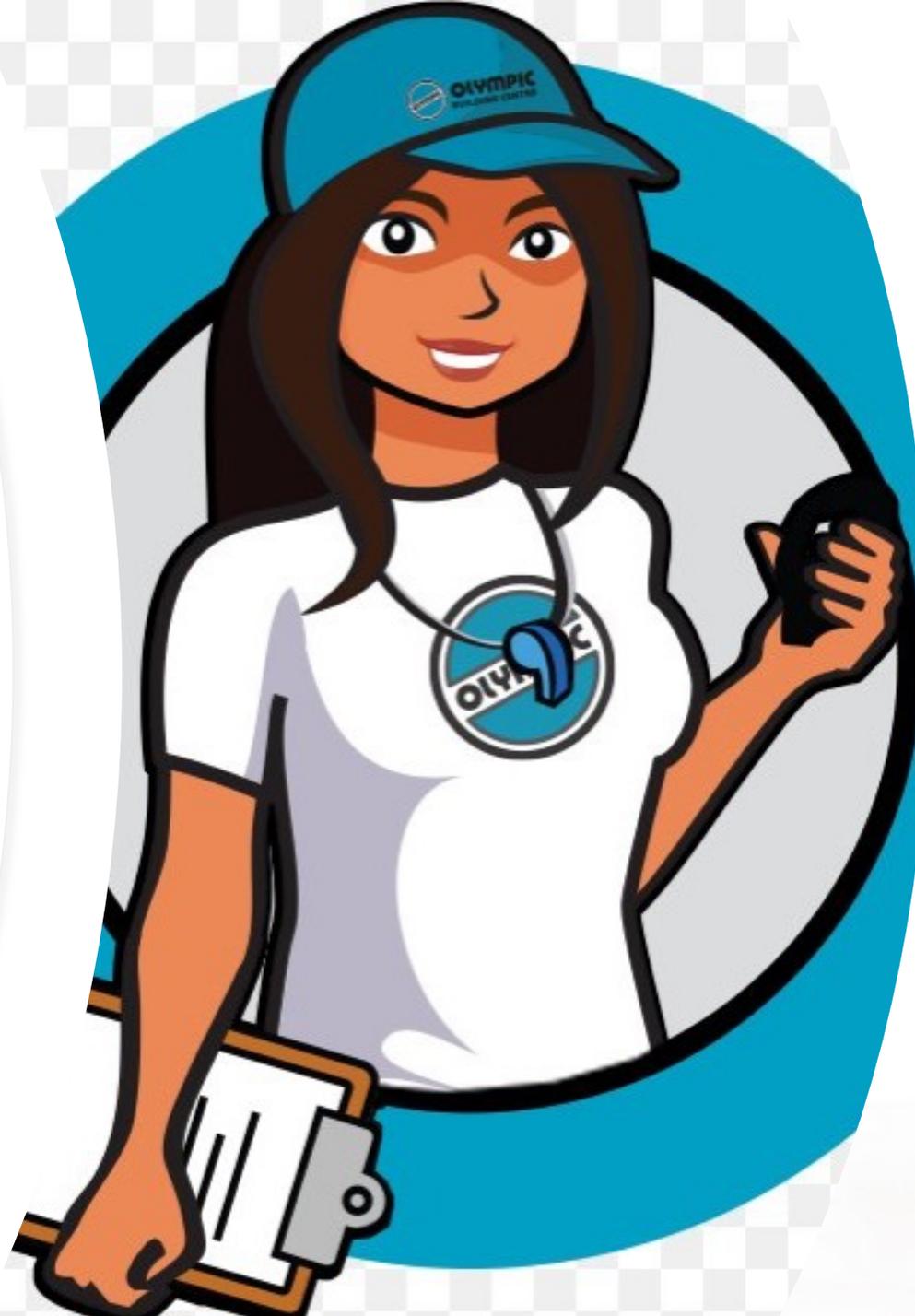
Hospice Too Late?

Hospice Myths (aka why I call it The Big “H”)

- Not “a place people go to die,” but rather a philosophy of care to keep people in their homes as comfortable as possible, as safe as possible, for as long as possible (allowing natural progression of disease)
- Not “giving up,” but transitioning to fighting and hoping for a new thing – the time spent fighting for quality time with family at home
- Some patients have had bad experience with hospice in the past (though many had good experience as well)

Physician Barriers

- Don't want to take away hope
- Limited training in serious illness communication
- Prognostication is hard!
Overestimation of prognosis, worse the longer the physician-patient relationship
- Timing of hospice referrals – too early?



Introducing the Conversation



Serious Illness Communication Guide

Serious Illness Conversation Guide

PATIENT-TESTED LANGUAGE

SET UP “I’d like to talk about what is ahead with your illness and do some thinking in advance about what is important to you so that I can make sure we provide you with the care you want — **is this okay?**”

ASSESS “What is **your understanding** now of where you are with your illness?”
“How much **information** about what is likely to be ahead with your illness would you like from me?”

SHARE “I want to share with you **my understanding** of where things are with your illness...”
Uncertain: “It can be difficult to predict what will happen with your illness. I **hope** you will continue to live well for a long time but I’m **worried** that you could get sick quickly, and I think it is important to prepare for that possibility.”
OR
Time: “I **wish** we were not in this situation, but I am **worried** that time may be as short as ____ (express as a range, e.g. days to weeks, weeks to months, months to a year).”
OR
Function: “I **hope** that this is not the case, but I’m **worried** that this may be as strong as you will feel, and things are likely to get more difficult.”

EXPLORE “What are your most important **goals** if your health situation worsens?”
“What are your biggest **fears and worries** about the future with your health?”
“What gives you **strength** as you think about the future with your illness?”
“What **abilities** are so critical to your life that you can’t imagine living without them?”
“If you become sicker, **how much are you willing to go through** for the possibility of gaining more time?”
“How much does your **family** know about your priorities and wishes?”

CLOSE “I’ve heard you say that ____ is really important to you. Keeping that in mind, and what we know about your illness, I **recommend** that we _____. This will help us make sure that your treatment plans reflect what’s important to you.”
“How does this plan seem to you?”
“I will do everything I can to help you through this.”

Introducing the Conversation (and why I am not abandoning you)

- Earlier is better – easier to address before crisis happens, and then they have the information to help plan for the future even if they are not ready for hospice
- Patients and families don't bring this up, most waiting for physicians to do it
- Not abandoning you or giving up – just shifting locus of care to home and plan for natural death at home
- Can continue to be primary care for non-terminal disease related conditions
 - Can be hospice attending if desired

Mrs. C

86yo female with CHF on diuretics, COPD, chronic hypoxic respiratory failure on 4L oxygen with 3 admissions in last year for infections (2 UTIs, one respiratory). Cognitive and functional decline: incontinence of urine, using a walker, requiring help with bathing and delirium with last hospitalization requiring 1:1 supervision.

What is the best way to introduce the idea of hospice to this patient?

- a. Discuss her recent hospitalizations and functional decline.
- b. Ask her and her family how much more medical “stuff” she wants in the future in the hope of getting just a bit more time.
- c. Assess patient and family’s current understanding of prognosis and what the future looks like.
- d. Discuss support at home and what may be needed to stay home safely.
- e. All of the above.

Benefits of hospice to patients and families

Respite care

Help with some ADLs

Education and emotional/spiritual support

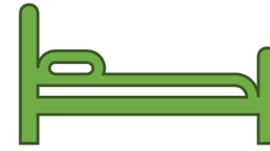
24/7 on-call provider

Medications and medical supplies delivered to the home

Bereavement support (13 months)

Hospice Pearls and Pitfalls

- What hospice provides
- What hospice does NOT provide
- LCD guidelines and how to determine eligibility
- Medications and hospice
- Can I still see my patient?
- “Graduating” from hospice



Hospice IS

- A philosophy of care that enables patients to stay at home, in familiar environments, with their symptoms managed.
- It is a nurse who visits at a minimum once every two weeks, usually once or twice a week, a social worker, a chaplain, and a physician. On-call providers are available 24/7 and can even come to the home to help manage symptoms or family concerns.
- Bereavement services (SW and chaplain) are provided to families for 13 months after the death of their loved one. SW can even help with things like funeral arrangements.
- Patients can still see their primary care physicians, and can still seek medical care for conditions other than the terminal one (ie, metastatic cancer patients can still be managed by their heart failure physicians if the HF not caused by cancer or cancer treatments).
- Hospice will pay for and deliver to the home all medications related to the terminal diagnosis, as well as all durable medical equipment.
- On-call 24/7, meaning immediate support through crises.

Hospice IS NOT

- NOT a place people go to die, but rather a philosophy of care. The aim of hospice is to keep people alive as long as possible, as comfortable as possible, and as safe as possible, preferably at home.
- It is NOT 24/7 care (except in a very few select patients who are symptomatically uncontrolled), so the majority of care is provided by families and loved ones.
- It does mean giving up life-prolonging care for the terminal condition, but it does NOT mean giving up all medical treatments. We can continue to treat infections, COPD exacerbations, and other conditions, including improved symptom management, at home.

Mr. F

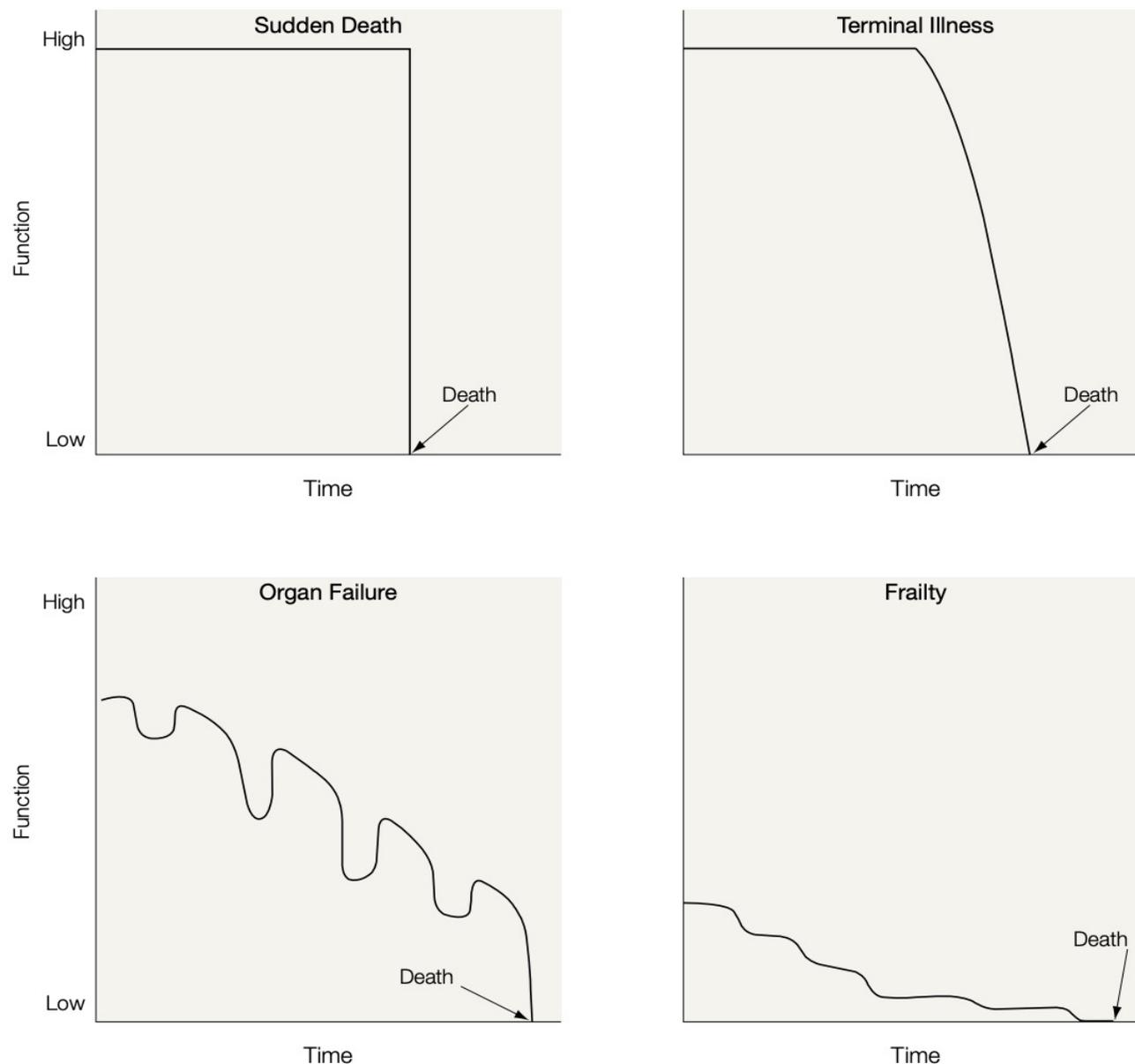
Mr. F is a 74yo male with heart failure (EF 15%, NYHA Class IV) secondary to ischemic cardiomyopathy, HTN, HLD. He was recently in the hospital for acute heart failure exacerbation and spent several days in the ICU, needing diuresis and inotropic support. He comes to see you in clinic to follow up and to make sure his new doses of medications are working. He feels like he has mostly recovered from the hospital stay though notes he is more tired and weak.

His partner has noticed a decline in Mr. F, worse over the last 2 months. Eight months ago Mr. F was still able to go out to weekly lunch with his friends, enjoy some light yard work, and take care of his personal needs. He now spends all his time either in a recliner or in bed, fatigued to the point of being unable to do more than walk to the bathroom. His appetite has dropped off and he is eating only two small meals a day. He is no longer showering due to fatigue and feeling unsafe.

What is Mr. F's prognosis? Does he qualify for hospice?

Prognosis

Figure 1. Theoretical Trajectories of Dying



JAMA. 2003;289:2387-2392

The *Surprise* Question:

Would you be surprised if this patient died in the next year?

Percentage of normal performance status	Karnofsky Performance Scale	Palliative Performance Scale					
		Ambulation	Activity	Evidence of Disease	Self Care	Intake	Consciousness Level
100	Normal, no complaints, no evidence of disease	Full	Normal	No evidence of disease	Full	Normal	Full
90	Able to carry on normal activity, minor signs or symptoms of disease	Full	Normal	Some evidence of disease	Full	Normal	Full
80	Normal activity with effort, some signs or symptoms of disease	Full	Normal activity with effort	Some evidence of disease	Full	Normal or reduced	Full
70	Cares for self, unable to carry on normal activity or do active work	Reduced	Unable to do normal job/work	Some evidence of disease	Full	Normal or reduced	Full
60	Requires occasional assistance, but is able to care for most needs	Reduced	Unable to do hobby/house work	Significant disease	Occasional assistance necessary	Normal or reduced	Full or confusion
50	Requires considerable assistance and frequent medical care	Mainly sit/lie	Unable to do any work	Extensive disease	Considerable assistance required	Normal or reduced	Full or confusion
40	Disables, requires special care and help	Mainly in bed	Unable to do most activity	Extensive disease	Mainly assistance	Normal or reduced	Full or confusion
30	Severely disabled, hospitalization is indicated although death is not imminent	Totally bed bound	Unable to do any work	Extensive disease	Total care	Reduced	Full or drowsy +/- confusion
20	Very sick, hospitalization necessary, active supportive treatment necessary	Totally bed bound	Unable to do any work	Extensive disease	Total care	Minimal to sips	Full or drowsy +/- confusion
10	Moribund, fatal process progressing rapidly	Totally bed bound	Unable to do any work	Extensive disease	Total care	Mouth care only	Drowsy or coma +/- confusion
0	Death	Dead					

Local Coverage Determinations (“LDC”) Guidelines

- General guidelines for prognosis 6 months or less:
 - Hospitalizations and ED visits
 - Infections requiring antibiotics
 - Wounds – stage III IV decubitus ulcer
 - Weight loss, loss of muscle mass (bitemporal and hypothenar wasting)
 - Incontinence, worsening incontinence
 - Decline in KPS or PPS
 - 2 or more ADL impairments
 - Comorbid conditions
- Disease-specific guidelines
 - Cancer; ALS, Dementia, Heart disease, Pulmonary disease, HIV, Liver disease, Renal disease, CVA/Coma

Heart Disease (Utah LCD)

Patients will be considered to be in the terminal stage of heart disease (life expectancy of six months or less) if they meet the following criteria. (1 and 2 should be present. Factors from 3 will add supporting documentation.):

1. At the time of initial certification or recertification for hospice, the patient is or has been already optimally treated for heart disease or is not a candidate for a surgical procedure or has declined a procedure. (Optimally treated means that patients who are not on vasodilators have a medical reason for refusing these drugs, e.g., hypotension or renal disease.)
2. The patient is classified as New York Heart Association (NYHA) Class IV and may have significant symptoms of heart failure or angina at rest. (Class IV patients with heart disease have an inability to carry on any physical activity without discomfort. Symptoms of heart failure or of the anginal syndrome may be present even at rest. If any physical activity is undertaken, discomfort is increased.) Significant congestive heart failure may be documented by an ejection fraction of $\leq 20\%$, but is not required if not already available.
3. Documentation of the following factors will support but is not required to establish eligibility for hospice care:
 - Treatment resistant symptomatic supraventricular or ventricular arrhythmias;
 - History of cardiac arrest or resuscitation;
 - History of unexplained syncope;
 - Brain embolism of cardiac origin;
 - Concomitant HIV disease.

Mr. F

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Does Mr. F qualify for hospice?

- a. Yes
- b. No



Medications and Hospice

- Goal is comfort-oriented care, so medications for pure comfort are provided by hospice (pain medication, stool softeners, antiemetics, etc)
- Medications directed towards life-prolongation or disease modification of the terminal illness (hospice diagnosis) are NOT covered by hospice
- Medications unrelated to the terminal illness continue under insurance
- Cost of medication
- Differing hospice philosophies and formularies

Medication List

Apixaban, furosemide, potassium, carvedilol, spironolactone, lisinopril, atorvastatin, tamsulosin, levothyroxine.

- Any concerns about these medications?

Hospice will work with the patient and family to deprescribe as much as possible, reducing pill burden with the goal of improved symptom management.

Making a Recommendation...

- Based on how your last hospitalization/goals/etc are, are you okay if I make a recommendation?

When to start hospice: (How to tell a patient when they will be ready)

- When hospitalizations or medical care becomes more burden than beneficial (ex, dialysis)
- When patient needs assistance with more personal cares (toileting, transferring, +/- bathing)

Follow up and Empowering Patients

Not signing in blood; if don't like hospice can revoke, if don't like company can change (in Utah), if don't like caregiver can request another one

You can continue to be primary care physician; can continue to see patient in that capacity, can even be hospice attending if desired (any physician, not just PCP)

Patient's hospice nurse best contact, a good nurse will be in close communication with providers familiar with the patients, when needed

- Under 21yo with Medicaid, certain commercial
- Veterans

- Patients in skilled nursing facility (“SNF”) – Medicare Part A

Special Situations:



All of the following patients are eligible for hospice except:

- a. 73yo female with end stage COPD wanting to just stay home and be comfortable. Expensive inhalers no longer work for her.
 - b. 41yo male with poorly controlled diabetes and kidney failure on dialysis, who wants to stop dialysis.
 - c. 87yo female with dementia who is losing weight, requiring more help with her ADLs, is incontinent, and has had 2 UTIs in the last 9 months.
 - d. 54yo male with cirrhosis, decompensated but stable for more than 2 years, no admissions or other complications. Has pain management issues and wants better at-home symptom control, but also wants to continue yearly monitoring with his hepatologist.
 - e. 62yo male with metastatic pancreatic cancer, fatigue and weight loss, who is not able to do anything beyond take care of his basic needs.
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NHPCO Facts and Figures 2021

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Utah LCD (Local Coverage Determination): <https://www.cms.gov/medicare-coverage-database/view/lcd.aspx?LCDId=34538&ver=14&contractorName=9&contractorNumber=236%7C2&lcdStatus=A&sortBy=title&bc=AAAAGAAAIAAAAA&>