Optum Health Education™

# Incorporating Palliative Care into your Primary Care Practice

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# DISCLOSURE STATEMENT

**Caroline DeFilippo, MD, MPH, FACP and Kristofer Smith, MD, MPP have no financial relationships to disclose.**

# Objectives

By the end of this session, the learner will be able to:

- Define palliative care and the impact it has on quality of life for patients and their families
- Describe the characteristics of patients who can benefit from palliative care
- Identify specific actions primary care providers can take to provide primary palliative care
- Review tools and strategies to engage patients in palliative discussions
- Identify when additional resources are needed for both patients and providers that require a higher level of care

# Who is Caroline?

- Medical Director Adult Primary Care and Population Health, Tristate
- Started Serious Illness Conversation Training program
  - Trained over 200 providers
  - Over 1000 conversations
- Practicing Internal Medicine physician
- Culture champion
- “Words Matter”

# Who is Kris?

- Chief Medical Officer of Landmark Health and Senior Physician for Home & Community Care
- Internal Medicine as well as Hospice and Palliative Care boarded
- More than 10 years experience as a home-based medical care physician providing primary and palliative care in New York City and Long Island
- 15 years building clinical programs for complex and high-risk patients at Mount Sinai Health System, Northwell Health, naviHealth and Prospero.

# What is palliative care?

**Palliative care** is specialized medical care for people with serious illnesses. This type of care is focused on providing patients with relief from the symptoms, pain, and stress of a serious illness - whatever the diagnosis.

**The goal** is to improve quality of life for both the patient and the family. Palliative care is provided by a team of doctors, nurses, and other specialists who work with a patient's other doctors to provide an extra layer of support. Palliative care is appropriate at any age and at any stage in a serious illness, and can be provided together with curative treatment.

https://www.capc.org/

# Palliative Care: An Extra Layer of Support

- Improves quality of life
- Reduces symptom burden
- Reduces depression
- Increases patient and family satisfaction with care
- May improve length of survival
- May decrease burnout among other providers

# What about Hospice?

## Palliative Care

- Can be offered at any time during the course of illness regardless of the prognosis
- Patients still have access to any treatment modality including chemotherapy, surgery, radiotherapy

## Hospice

- Insurance benefit only available when physician certifies life expectancy less than 6 months
- Patients much forego further life prolonging therapy

# Primary vs. Specialty Palliative Care?

## Primary Palliative Care

- Basic management of pain and symptoms
- Basic management of depression and anxiety
- Basic discussions about
  - Prognosis
  - Goals of Treatment
  - Code status

## Specialty Palliative Care

- Management of refractory pain or other complex symptoms
- Management of complex anxiety, depression or existential stress
- Assistance with conflict resolution regarding goals or treatments
  - Within families
  - Between staff and families
  - Among treatment teams
- Assistance in addressing cases of near futility

Adapted from Abernethy, AP et al. Generalist plus Specialist Palliative Care – Creating a more sustainable model. NEJM 2013; 368:1173-1175

# Models of Palliative Care

# Multiple randomized trial support early palliative care?

### Temel, NEJM 2010 (MGH)

- Metastatic NSCLC patients at diagnosis randomized to early palliative care versus standard care
- 151 patients (101 evaluable)
- Significant improvements in quality of life and mood, overall survival benefit (11.6 vs 8.9 months), less aggressive care at end of life

### Zimmerman, Lancet 2014 (Princess Margaret)

- Lung, GI, GU, breast, GYN cancer patients randomized to early palliative care consultation and follow-up versus standard care
- 461 patients randomized, 393 evaluable
- Significant improvements in symptoms, quality of life, satisfaction with care, spiritual well-being

### Bakitas, JAMA 2009, Project ENABLE II (UAB)

- Advanced Practice Nurse-led intervention, randomized to intervention or usual care
- 322 patients with metastatic GI, lung, GU, or breast cancer
- Significant improvements in mood, quality of life, not symptoms, hospital days or ICU days compared with usual care

### Bakitas, JCO, Project ENABLE III (UAB)

- Randomized nurse-led intervention of early versus delayed palliative care, similar intervention to ENABLE II
- 207 patients randomized to early versus delayed intervention (3 months later)
- No differences in symptoms, QOL, hospital days, ICU days, but statistically significant improvement in 1-year survival (63% vs 48%, p= 0.38)

# Which patients need palliative care?

**Frank** is a long-time patient who is 85 with systolic heart failure, CAD s/p PCA, arthritis, CKD, and frailty.

In the past  two years he has had one visit to the emergency room for weakness and one hospitalization for COVID requiring 2 days in the ICU.

Since his hospitalization he uses a walker, has a good appetite, limited exercise tolerance due to knee pain and deconditioning, and is mostly homebound.

He often comments that he is lucky to still be alive and he doesn't want to return to the hospital again. He is full code.

**Alma** is a long-time patient who is 82 with moderate dementia, first diagnosed 4 years ago, Fast stage 6, hypothyroid, hypertension, and moderate obesity.

In the past two years, she has had no hospitalizations and one episode of wandering but was found by a neighbor.

She is always pleasant, mobile but unsteady on her feet, has lost ~10lbs in the last year as her appetite has decreased, she needs help with 4 of 6 ADLs.

Her other chronic conditions are well controlled.  Her daughter-in-law is her caregiver. She is full code.

**Sasha** is a long-time patient, aged 73 who was diagnosed with stage 4 colon cancer.

2 years prior, she had a resection and is on her second round of immunotherapy, she initially responded well but has been told that her cancer is once again progressing.

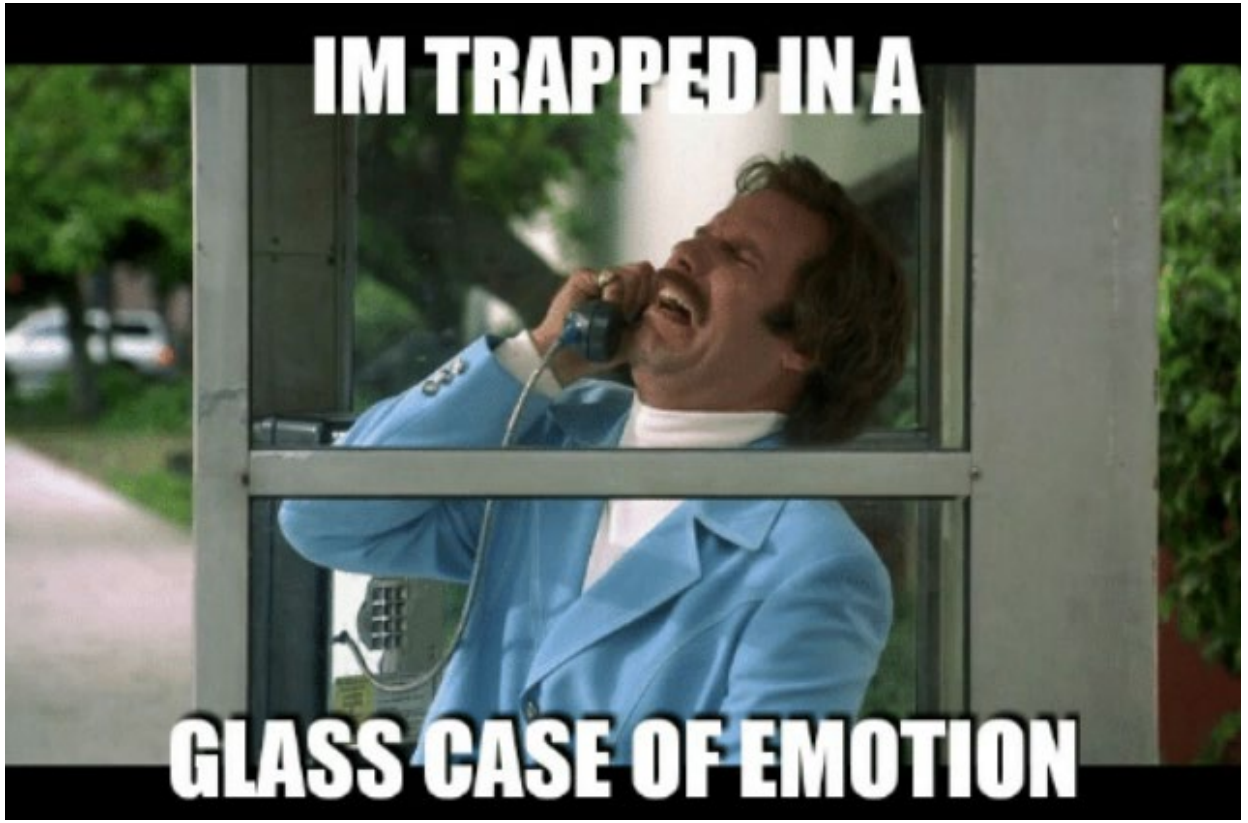
She is depressed.  She has lost a substantial amount of weight.  She can still perform all of her ADLS. She enjoys being with her family but wishes she had more energy.

Her oncologist does not have a palliative clinician as part of the care team. She is full code.

# Primary Palliative Care for the PCP

# Palliative Care Communication Skills

# Feelings First




*Dreamworks Pictures*

# Feelings First

Difficult conversations are worthwhile, even if they raise anxiety in the moment

Avoiding difficult conversations or talking "around" issues can raise anxiety

Feeling connected reduces anxiety

Give patients as much control as possible over the conversation

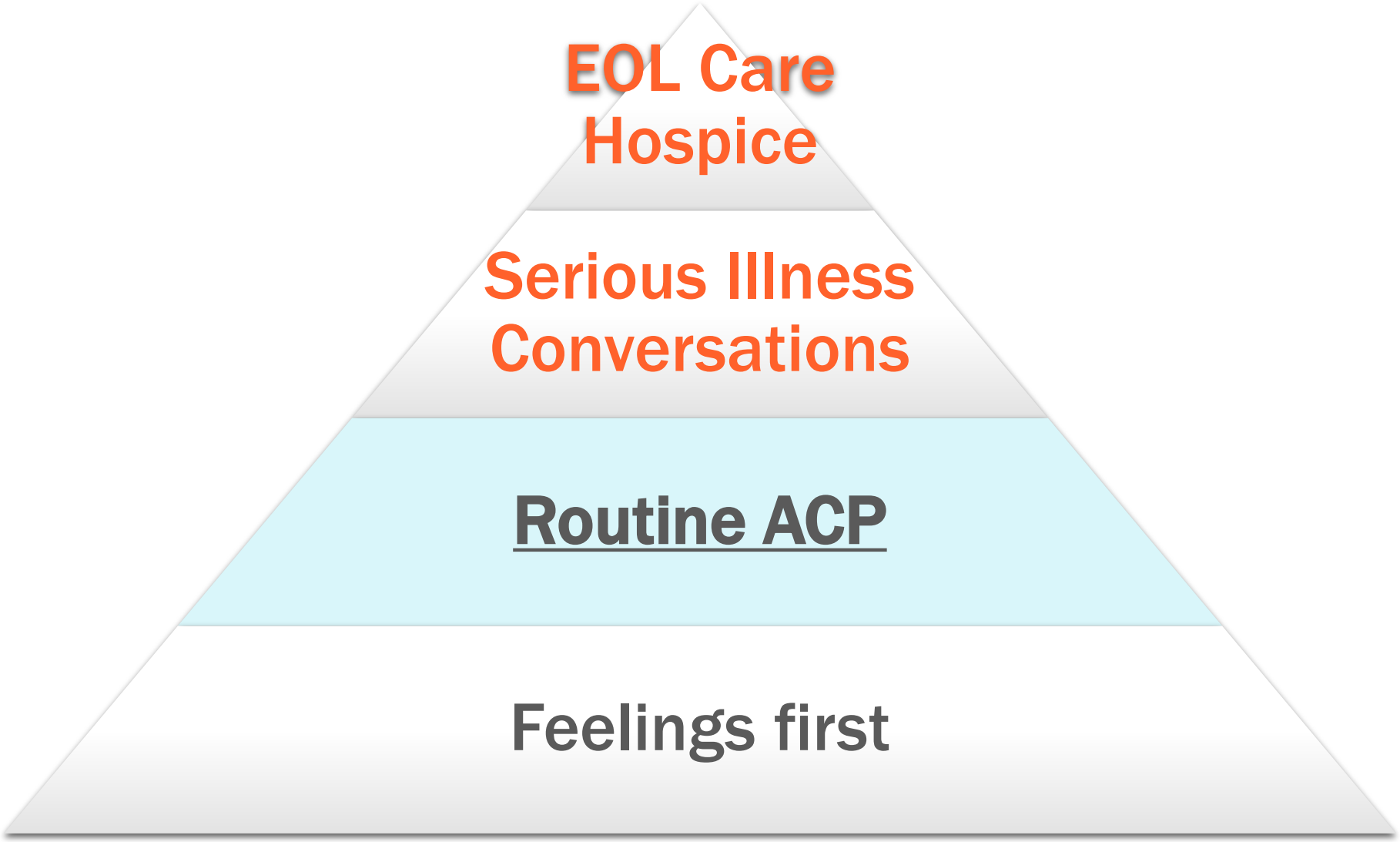
Titrate your language and responses to keep anxiety at a manageable level

Pay attention to and manage your own emotions

# Feelings First

- **N**ame the feeling (and dial it down)
  - ✓ *"This is bringing up a lot of frustration."*
- **U**nderstand
  - ✓ *"I can understand why this might feel overwhelming."*
- **R**espect
  - ✓ *"You have really shown courage through this process."*
- **S**upport
  - ✓ *"I'm going to be there for you through this."*
- **E**xplore
  - ✓ *"Can you tell me more about how this is affecting you?"*

# Palliative Care Communication Skills



# Advanced Care Planning (ACP)

- The purpose of ACP is to ensure goal concordant care near end of life for patients who lack decisional capacity.
- Does it work? 30+ years, 80 systemic reviews, 1600 original articles found no evidence ACP associated with concordance or quality of care received.
- PCORI funded > 750 studies, spent over $300M taxpayer money and most people still don't have an advance directive.

*"For every complex problem there is an answer that is clear, simple and wrong."*
*– H.L. Mencken*

Morrison. *J Palliat Med.* 2020.

# What's Wrong with Advanced Care Planning?

1. Need sophisticated knowledge of prognosis/treatment
2. Providers often focus on easy conversation and shy away from or lack competency with complex situations
3. Hypotheticals vs in-the-moment reality
4. People struggle to anticipate what they'd want in the future
5. Good advanced care planning is longitudinal
6. Healthcare driven by financial incentives which don't always align with good care

# Routine ACP: What to Say

- **Ask permission**
  - ✓ *"I'd like to take a few minutes to learn about your values and how they relate to your health. Would that be ok?"*
- **Explore values**
  - ✓ *"I'm thinking about a situation where someone gets very sick unexpectedly and can't speak for themselves. If that happened to you, what would be most important to you?"*
- **Identify a surrogate**
  - ✓ *"In a situation like that, who would you want to speak for you and help make decisions?"*
- **Offer support**
  - ✓ *"I know this is hard to think about. But it can help us take the best possible care of you."*
- **Update advance directives, care plan, and EMR**
  - ✓ *"Let's talk about how to capture in writing what you just told me."*

# Routine ACP: Advance Directives

***What is an Advance Directive?***

A legal document describing a person's medical wishes if they can't speak for themselves

***Who should speak for me if I can't speak for myself?***

- May be known as healthcare proxy, agent, representative, power of attorney, or surrogate decision-maker
- Without a legal document, decision-making falls to legal next of kin, as defined by each state

***What do I want that person to say on my behalf?***

- Captured through a living will, advance directive, healthcare directive, or Five Wishes
- Advance directives are legally-binding documents

***What about POLST/MOLST forms?***

- POLSTs are portable medical orders intended to protect the medical wishes of frail or seriously ill patients
- Without a POLST, EMTs are required to provide CPR and full resuscitative efforts
- POLSTs are medical orders, not advance directives

# Routine ACP: Five Wishes

Five Wishes is recommended advance directive
Patients in Kansas, Ohio, Oregon, and Texas also need to fill out their state-specific advance directive


https://www.fivewishes.org/

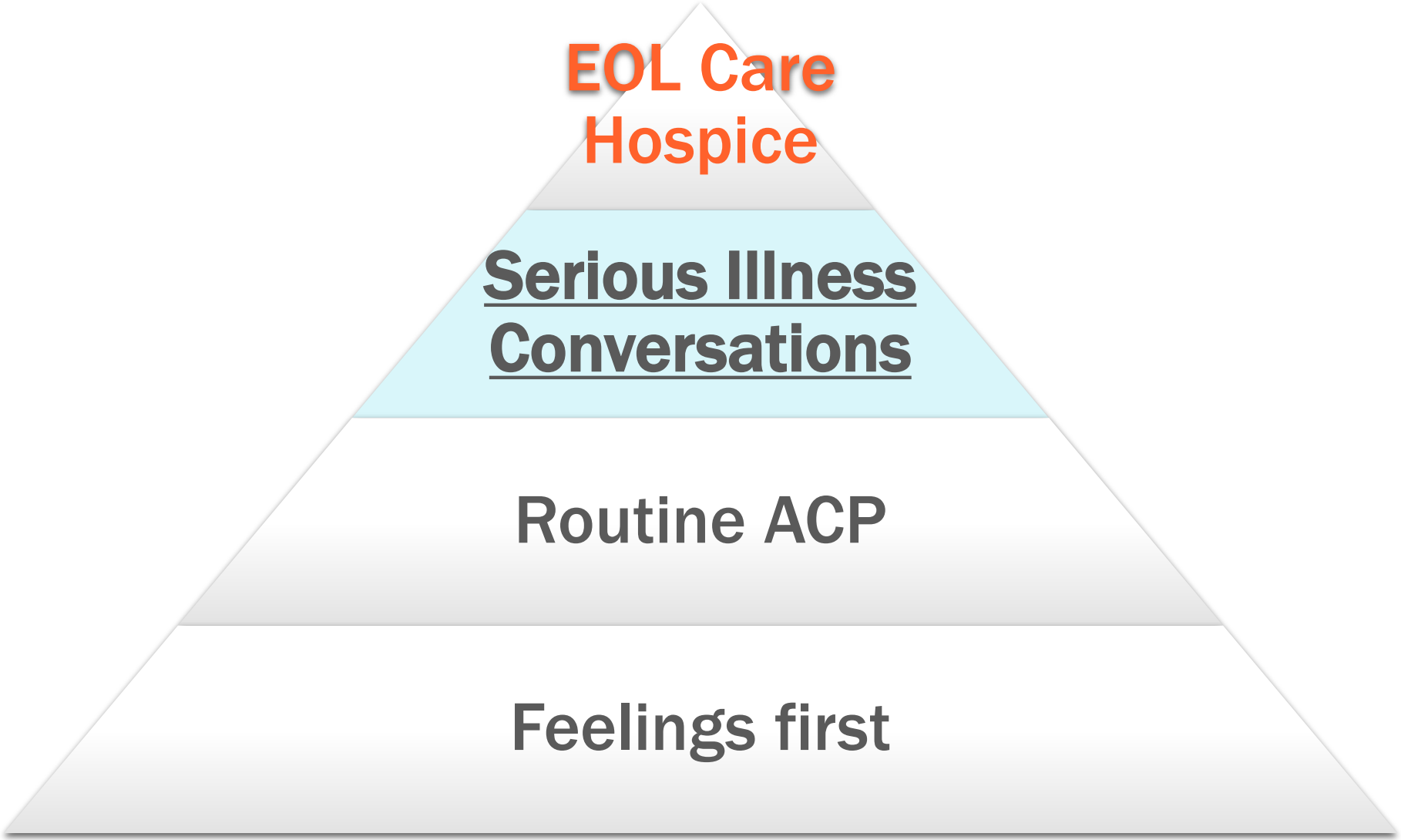
## Why use the Five Wishes?

- DIY guidebook for ACP, prompting patients to share what matters most to them
- Patient-friendly everyday language
- Patient defines what life support means
- Clinically relevant
- Addresses medical, emotional, and spiritual wishes

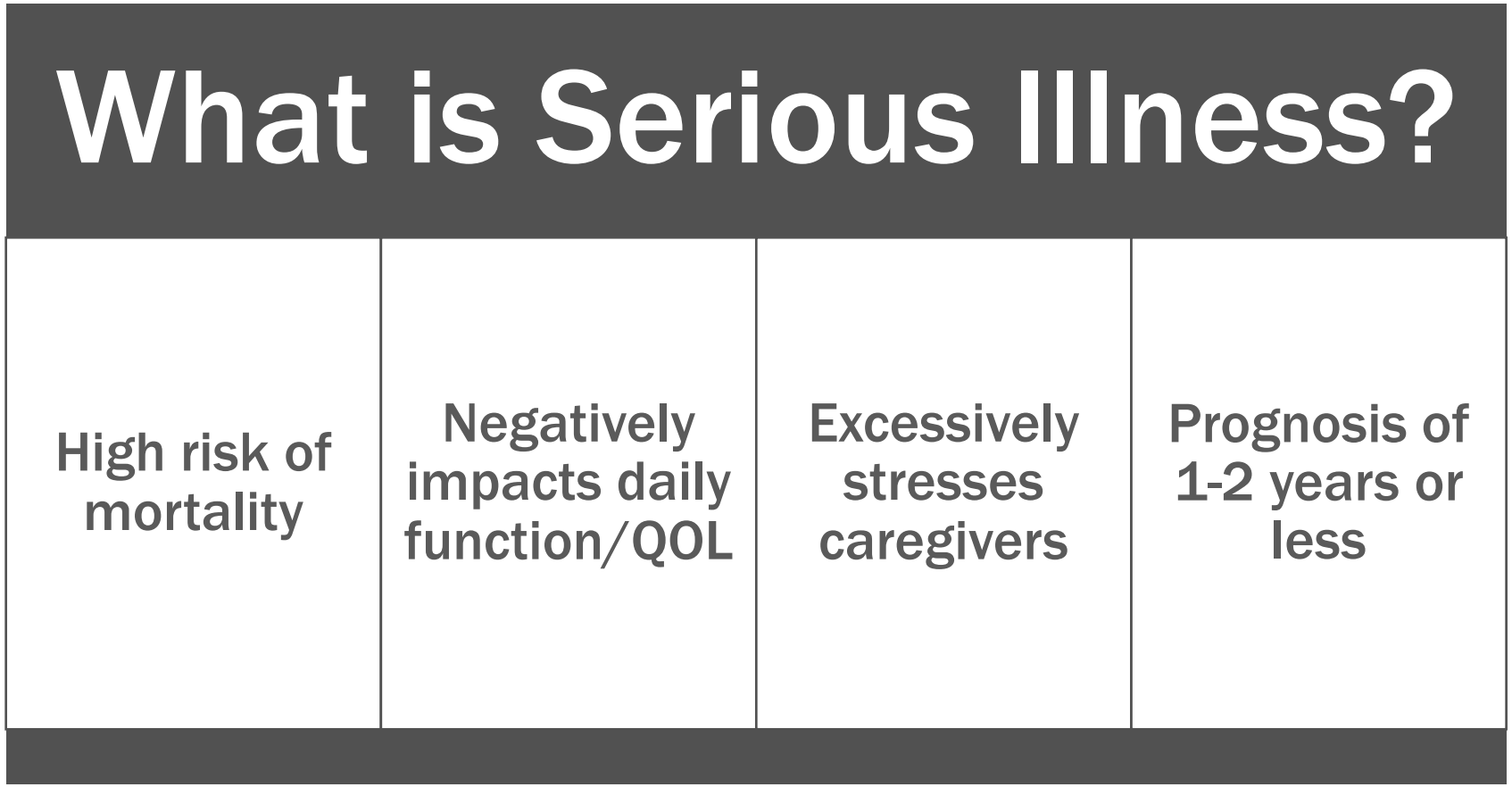
## What are the Five Wishes?

1. "The person I want to make care decisions for me when I can't."
2. "The kind of medical treatment I want or don't want."
3. "How comfortable I want to be."
4. "How I want people to treat me."
5. "What I want my loved ones to know."

# Palliative Care Communication Skills

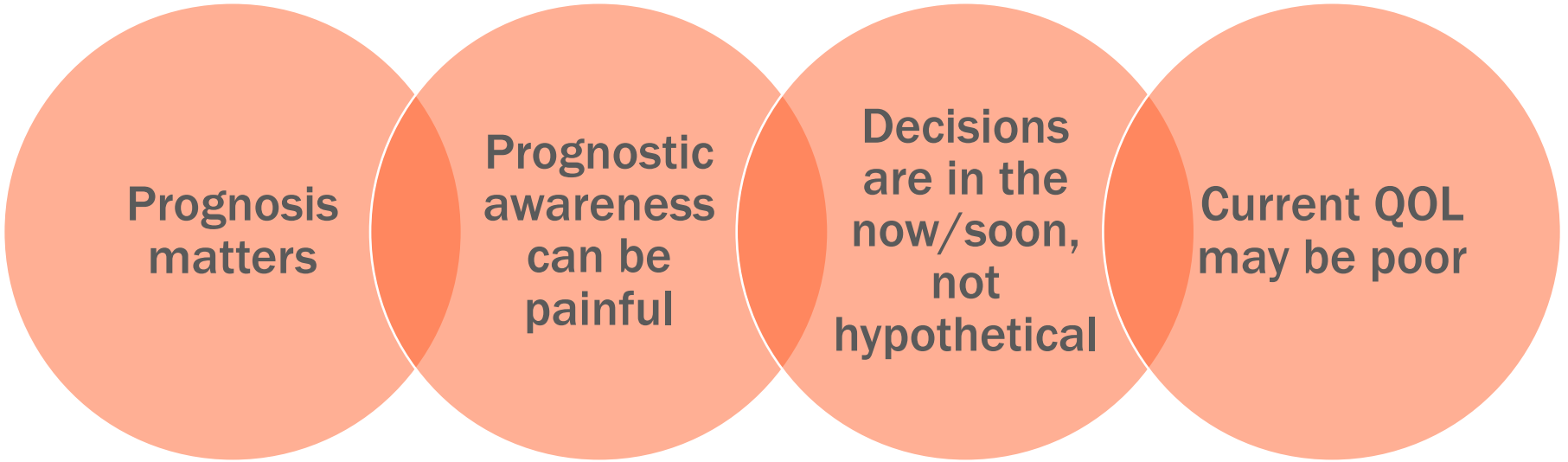


# Serious Illness: Definitions



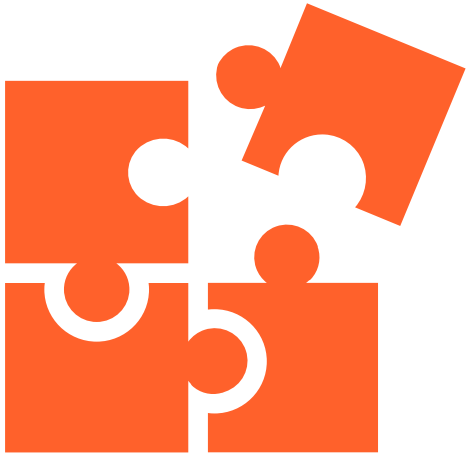
# Serious illness: Prognostic Awareness

## How are Serious Illness Conversations different?



# Why is prognostication important?

Patients with serious illness make different care decisions as prognosis changes



Honors the ethical and legal principles of a patient's right to self-determination

Helps patients make informed treatment decisions that align with their goals and values

Gives people time to prepare physically, emotionally, spiritually for the dying process

Allows for planning of supportive services, palliative care, and timely hospice transitions

# Prognostication

Why do we avoid prognostication?

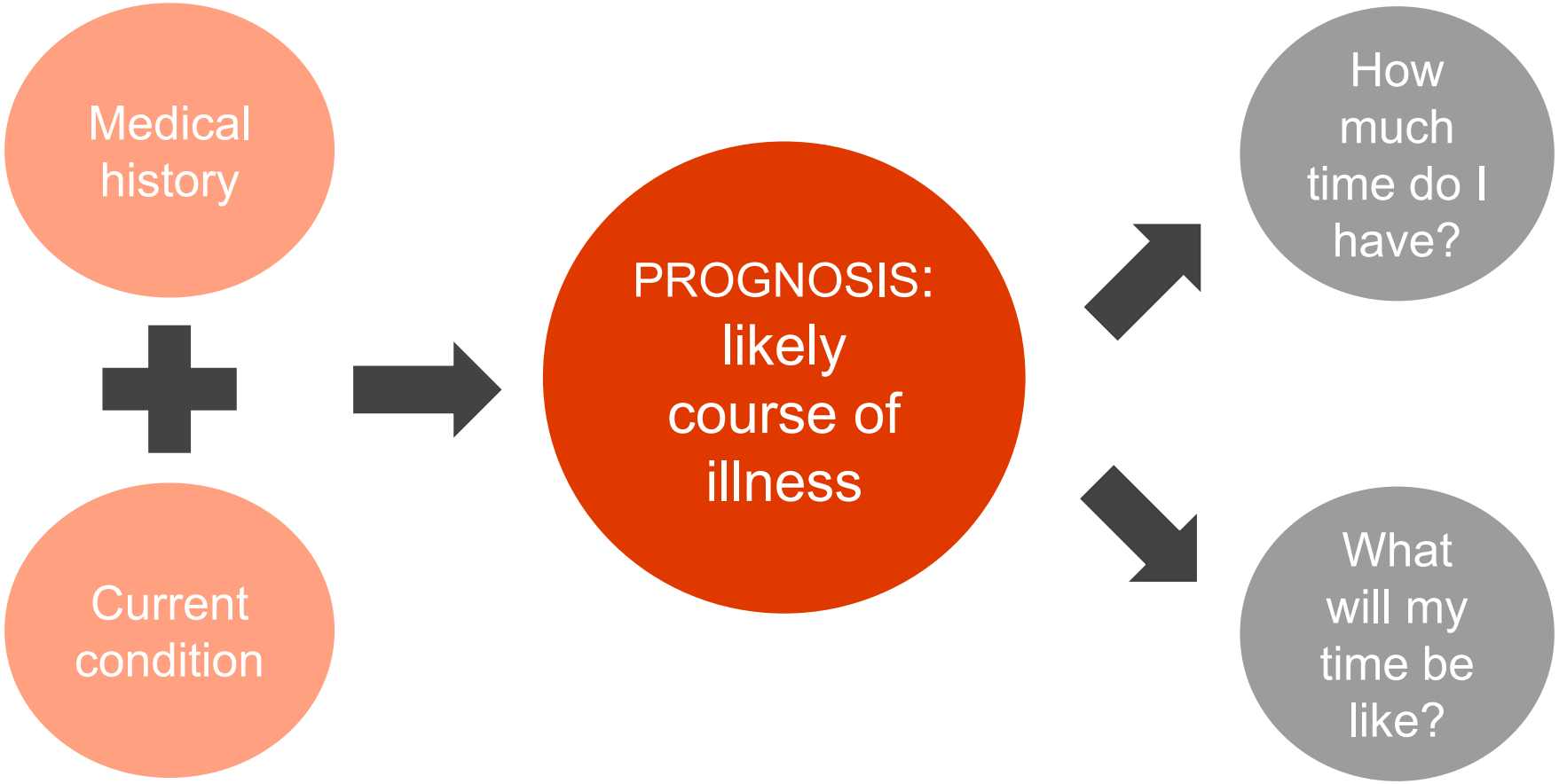
- Physicians overestimate life expectancy, and the longer you've known your patient, the more optimistic you'll be
- "Ritualized optimism"
- Probability rather than individual estimate

(Christakis et al, 2000; Gramling et al, 2013)

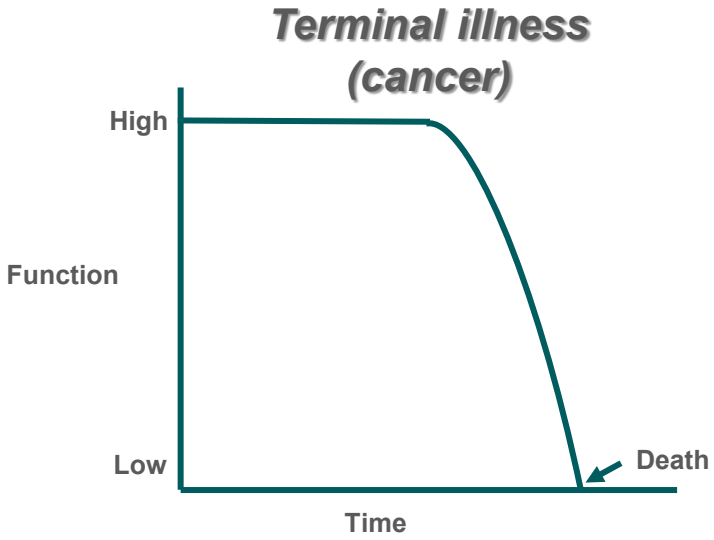
- What else makes it challenging?
  - Difficult to balance maintaining hope while offering a realistic picture
  - Requires humility and openness to cultural differences
  - Probabilities can be difficult to understand for both patients and clinicians

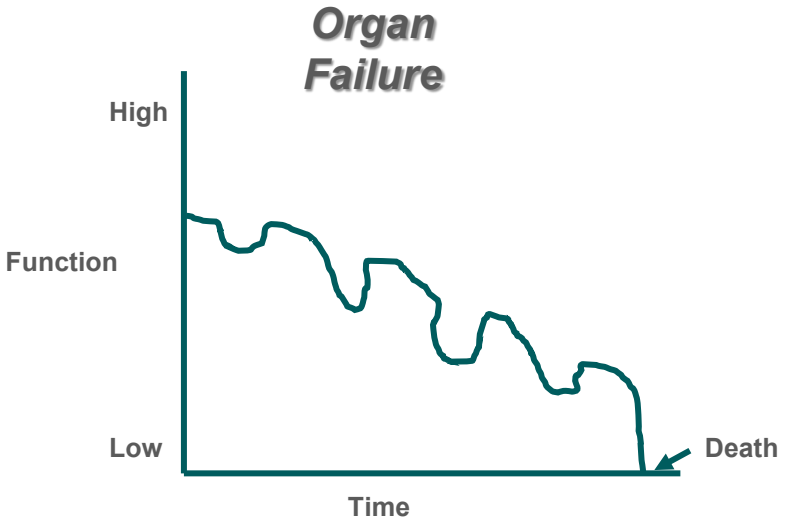
(Kwok, 2011; Cartwright, 2014)

# Prognostication

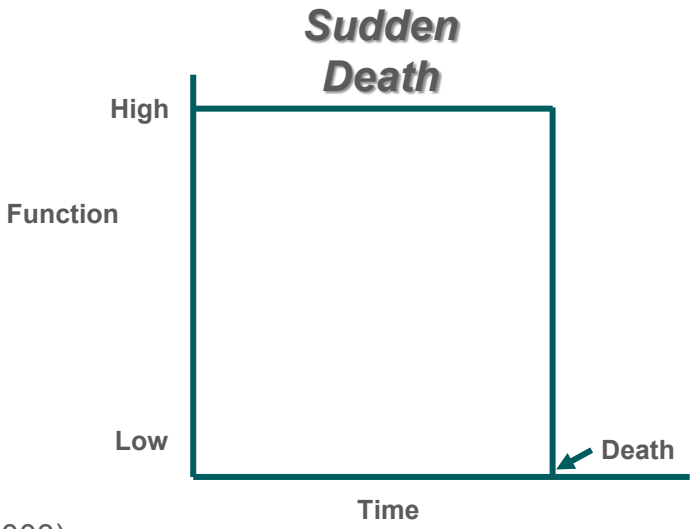


# Prognostication








(Lunney et al, 2003)

# Prognostication: How to do it

## The surprise question:

- Would you be surprised if this patient died within the next year?
- How about 6 months?

**Uncertain**: It can be difficult to predict what will happen with your illness. I hope you will continue to live well for along time but I'm worried that you could get sick quickly, and I think it is important to prepare for that possibility.

**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.

**Time**: I wish we were not in this situation, but I am worried that time may be as short as ___ (express as a range of e.g. days to weeks, weeks to months, months to a year.

# Drivers of Prognosis

- Karnofsky Performance Status
- Palliative Performance Status
- Modification of KPS with ambulatory status, activity and evidence of disease, self-care, intake and level of consciousness
- Symptoms
- Laboratory values (LDH, CRP, Cr, Alb, WBC)
- Histology, stage, extent of metastatic disease
- Molecular markers

# Do we have an in-house predictive performance tool?

| REFERRAL_PATHWAY | HCE_LEVEL | Mortality Potential Category |
|---|---|---|
| PALLIATIVE | LEVEL 4 | HIGH |
| PALLIATIVE | LEVEL 4 | HIGH |
| PALLIATIVE | LEVEL 4 | HIGH |
| PALLIATIVE | LEVEL 5 | HIGH |
| PALLIATIVE | LEVEL 5 | HIGH |
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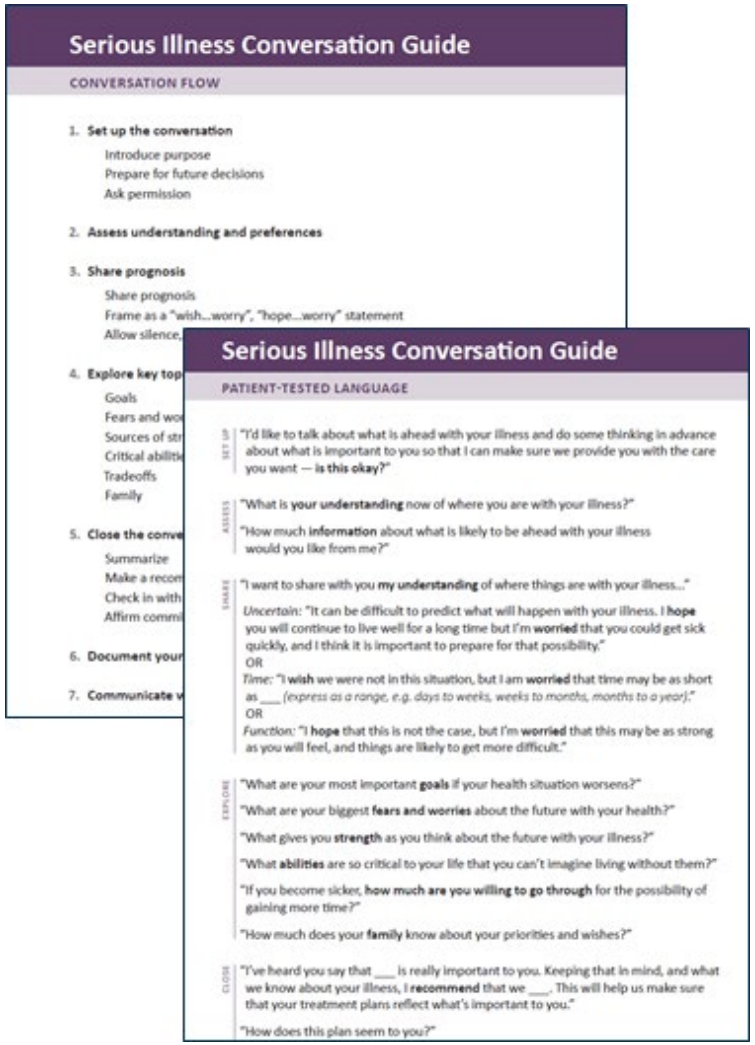
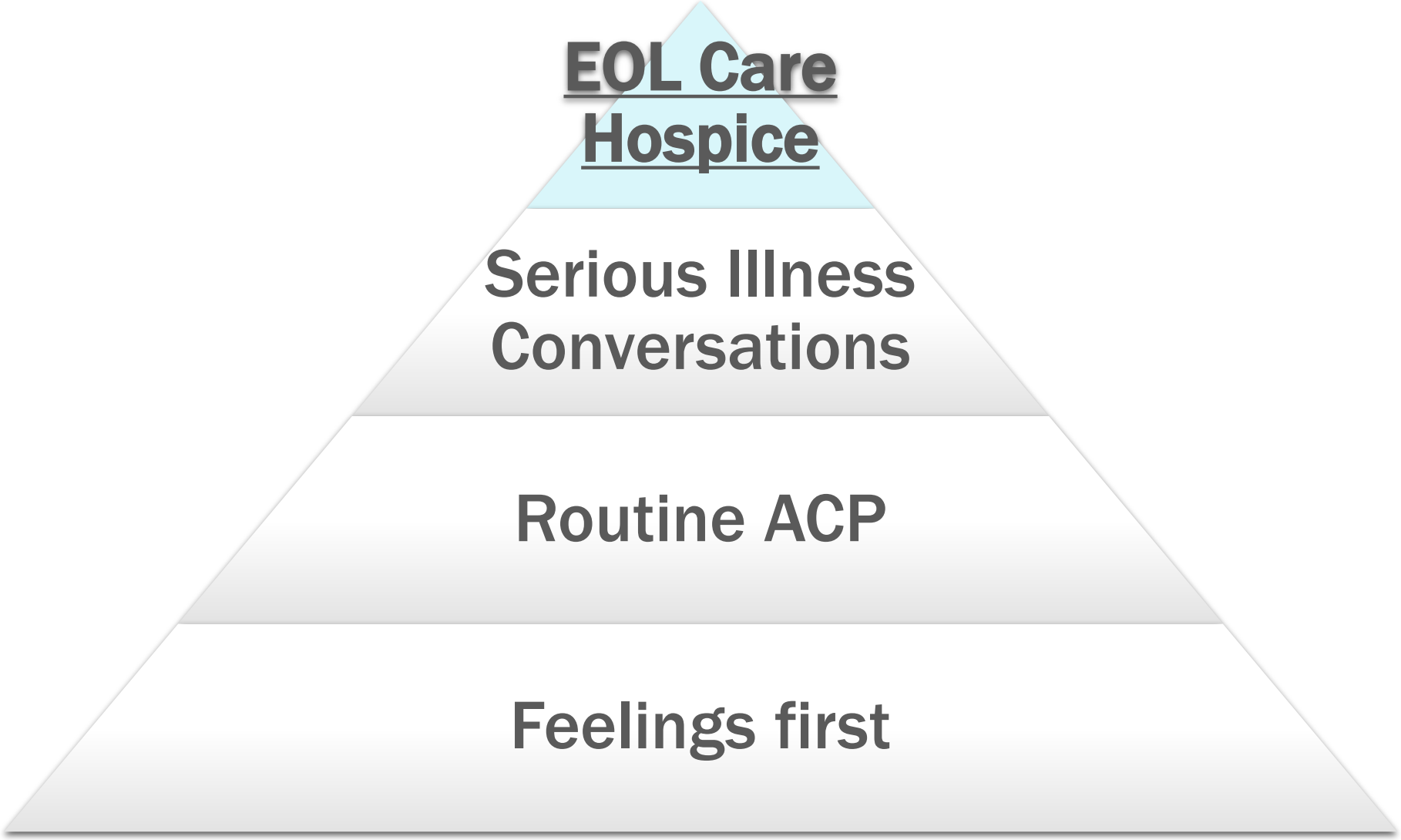
# Serious Illness Conversation Guide




https://www.ariadnelabs.org

- The Serious Illness Conversation Guide is an approach to communicating with our patients with serious illness
- Developed by palliative care experts at Ariadne Labs
- Scripted checklist of questions to share prognosis and explore patients' values, goals, and preferences
- Using the SICG results in more, better, and earlier Serious Illness Conversations, positive impact on patients, and cost reductions in the last six months of life

# Palliative Care Communication Skills



# 5 Fs of Hospice Eligibility

## Feeding
- Weight loss, dysphagia

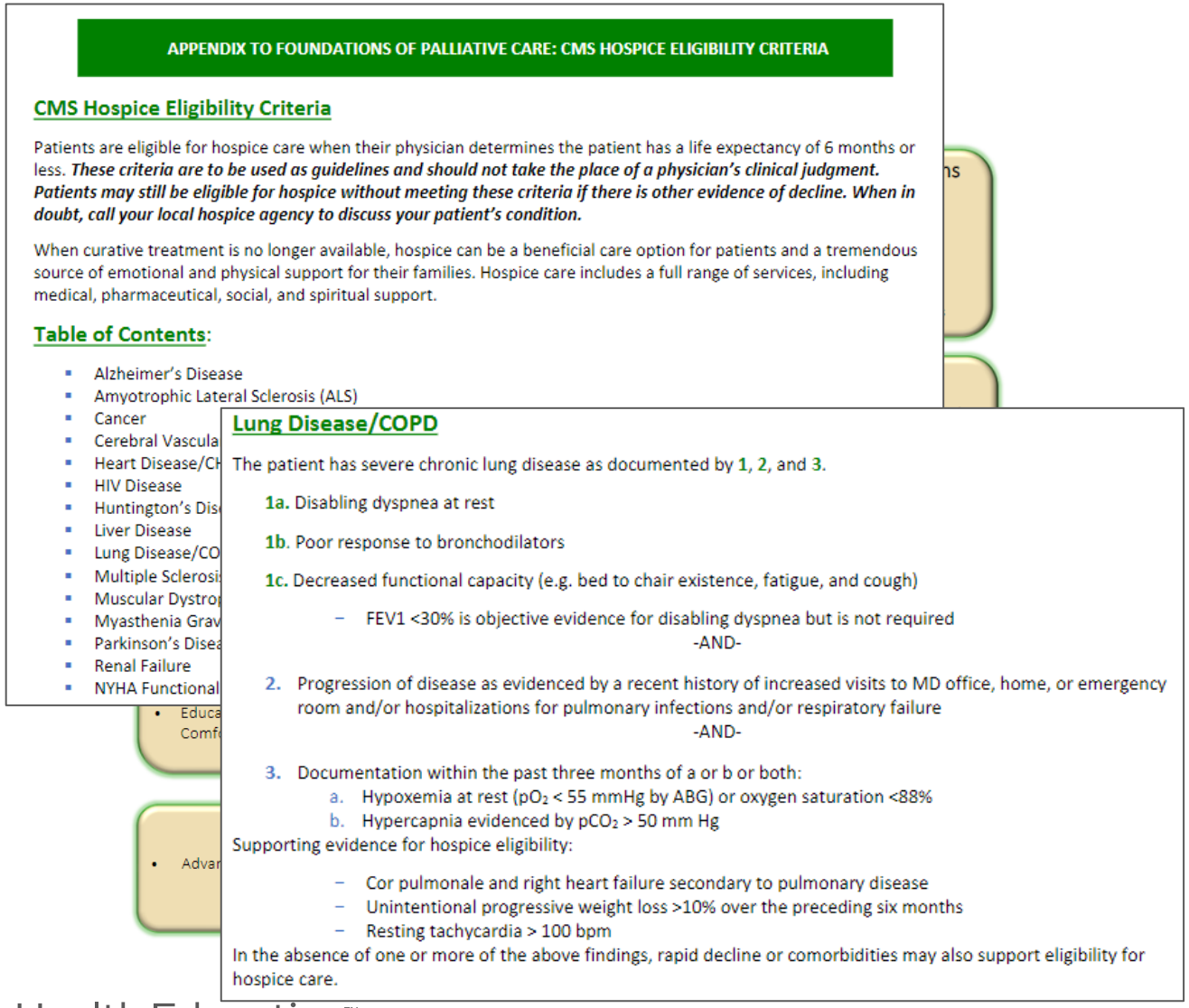
## Function
- Falls, decline in function documented over time

## Frequent events
- Hospital readmissions, ER visits, infections, aspiration pneumonia

## Failing systems
- Wounds, multiple advanced comorbidities with symptom burden

## Feeling
- Would you, the patient, the treating physician or caregiver be surprised if this patient died in the next year.

# Hospice Medical Eligibility



**APPENDIX TO FOUNDATIONS OF PALLIATIVE CARE: CMS HOSPICE ELIGIBILITY CRITERIA**

**CMS Hospice Eligibility Criteria**

Patients are eligible for hospice care when their physician determines the patient has a life expectancy of 6 months or less. ***These criteria are to be used as guidelines and should not take the place of a physician's clinical judgment. Patients may still be eligible for hospice without meeting these criteria if there is other evidence of decline. When in doubt, call your local hospice agency to discuss your patient's condition.***

When curative treatment is no longer available, hospice can be a beneficial care option for patients and a tremendous source of emotional and physical support for their families. Hospice care includes a full range of services, including medical, pharmaceutical, social, and spiritual support.

**Table of Contents:**

- Alzheimer's Disease
- Amyotrophic Lateral Sclerosis (ALS)
- Cancer
- Cerebral Vascula
- Heart Disease/CH
- HIV Disease
- Huntington's Dis
- Liver Disease
- Lung Disease/CO
- Multiple Sclerosi
- Muscular Dystro
- Myasthenia Grav
- Parkinson's Disea
- Renal Failure
- NYHA Functional

**Lung Disease/COPD**

The patient has severe chronic lung disease as documented by **1**, **2**, and **3**.

**1a.** Disabling dyspnea at rest

**1b**. Poor response to bronchodilators

**1c.** Decreased functional capacity (e.g. bed to chair existence, fatigue, and cough)

- FEV1 <30% is objective evidence for disabling dyspnea but is not required

-AND-

2. Progression of disease as evidenced by a recent history of increased visits to MD office, home, or emergency room and/or hospitalizations for pulmonary infections and/or respiratory failure

-AND-

3. Documentation within the past three months of a or b or both:
   a. Hypoxemia at rest ($pO_2$ < 55 mmHg by ABG) or oxygen saturation <88%
   b. Hypercapnia evidenced by $pCO_2$ > 50 mm Hg

Supporting evidence for hospice eligibility:

- Cor pulmonale and right heart failure secondary to pulmonary disease
- Unintentional progressive weight loss >10% over the preceding six months
- Resting tachycardia > 100 bpm

In the absence of one or more of the above findings, rapid decline or comorbidities may also support eligibility for hospice care.

Prognosis of < 6 months

Specific disease criteria are in CRB

Don't forget about generalized decline:

- *weight loss*
- *functional losses*
- *recurrent infections*
- *decreased po intake*
- *dysphagia*

*multiple comorbidities*

# Talking about Hospice

**Feelings come first**

- NURSE: Name, Understand, Respect, Support, Explore
- Acknowledge fear, sadness, disbelief, anger

W**hat's most important, given the prognosis?**

- Use your Serious Illness Conversation skills

**Offer a recommendation**

- Describe how hospice can help

# Revisiting Frank, Alma and Satima

- Should each of these patients have an advanced care plan?
  - What would it include? HCP? MOLST/POLST? DNR form?
- Should a PCP have a serious illness conversation with each of these patients?
- Are any of the three hospices eligible?

# Where to go when patients require specialist palliative care?

- Clinic based palliative care
- Virtual palliative care
- Home-based palliative care