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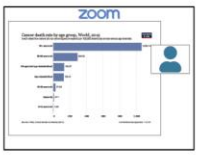

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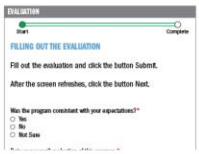

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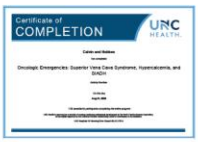

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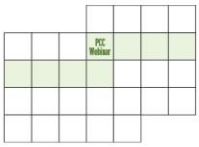

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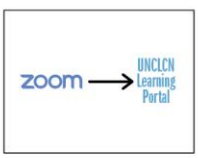

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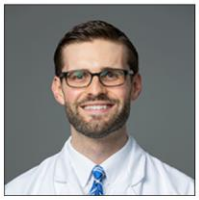
Our Presenter



Jared Lowe, MD, HMDC

Dr. Jared Lowe is an Assistant Professor in Medicine. He is board certified in Internal Medicine and is board certified in Hospice and Palliative Medicine. Dr. Lowe is an attending physician in the UNC adult palliative care program and is the Medical Director for UNC Hospice.

Dr. Lowe is a native to Cornelius, North Carolina. He completed his undergraduate degree and medical school at the University of North Carolina. He received his residency training in internal medicine at Duke University and served as chief resident, as well as completed his fellowship in Hospice and Palliative Medicine at Duke University. His clinical interests are in improving the delivery of hospice and palliative care in the community. He now lives in Pittsboro, NC and enjoys all things food related.

8

Our Presenter

9

Our Presenter

5. Jared Lowe, MD, HMDC, is currently serving as the medical director for UNC Hospice

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Our Presenter

5. Jared Lowe, MD, HMDC, is currently serving as the medical director for UNC Hospice

4. He has conducted research and implemented innovative programs to promote advance care planning for patients

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2. He finds a deep sense of connection and purpose in caring for patients at the end of life

13

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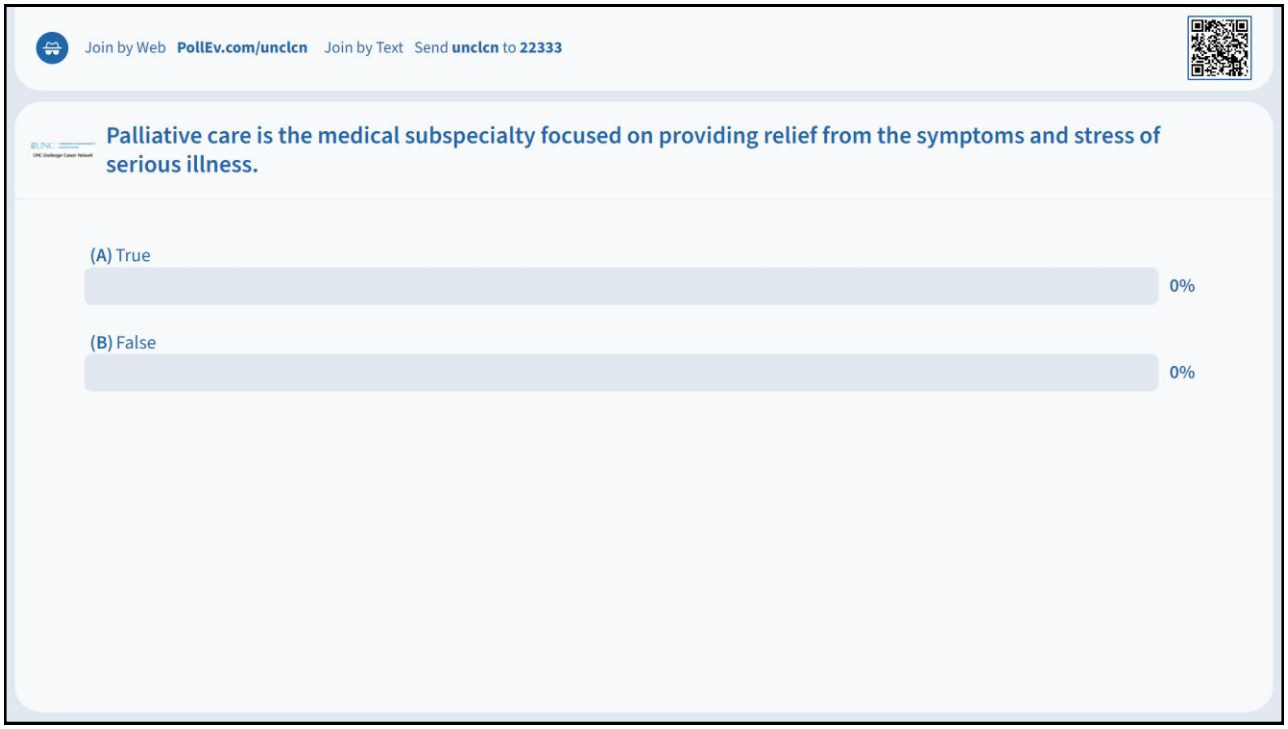
3. He has previously served as a the chief resident for internal medicine at Duke University Hospital.
2. He finds a deep sense of connection and purpose in caring for patients at the end of life
1. His work is motivated by personal experiences and loss that inspired him to improve quality for seriously ill patients

14



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Palliative care is the medical subspecialty focused on providing relief from the symptoms and stress of serious illness.

True 0%

False 0%

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Navigating Serious Illness with Palliative Care and Hospice

Jared Lowe MD HMDC

January 10, 2024

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Objectives

- Define serious illness and related terminology.
- Describe the roles of palliative care and hospice in supporting patients with serious illness.
- Review strategies for communicating with patients and families regarding serious illness and care planning.

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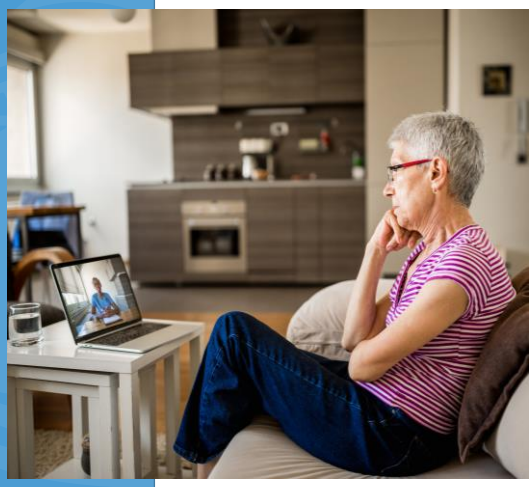
The Case of Mrs A



Mrs A is an 82 year old woman with metastatic breast cancer. She has been on treatment for her cancer over the last year. She initially responded well to chemotherapy, except she has had some side effects like trouble sleeping and nerve pain in her hands and feet.

She is a North Carolina native and has been a prominent figure in her community for decades, but now she is too tired to engage in her social activities. She lives at home with her son Kevin, who has been helping her out more. Kevin is fortunate to have a job with flexibility that allows him to take her to her doctor's appointments and treatments, but he's nervous about how frequently he's had to take off work.

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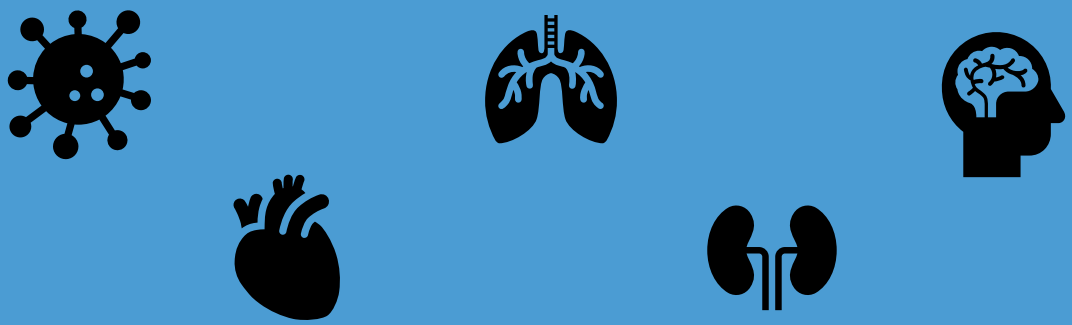
Serious illness is a health condition that:

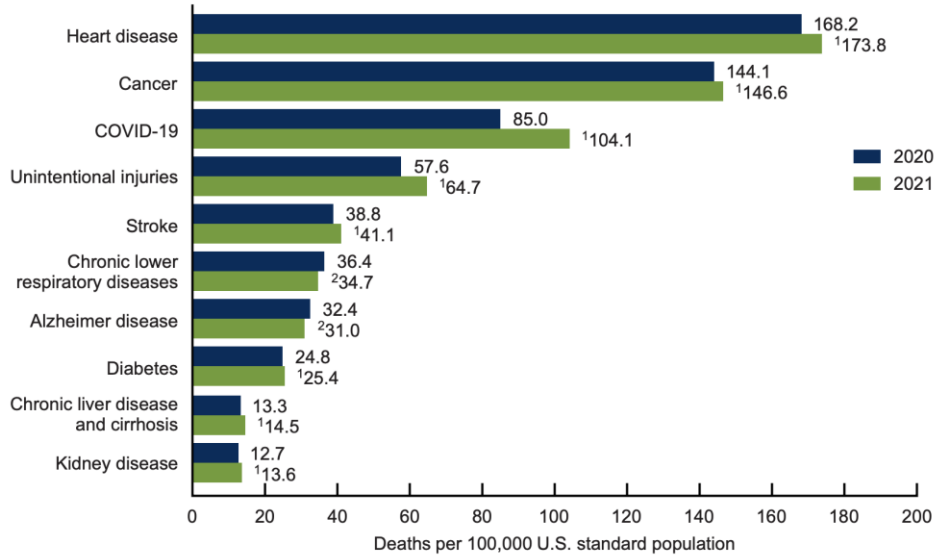
- Carries a high risk of mortality AND
- Either negatively impacts a person's daily function or quality of life, OR excessively strains their caregivers.



Kelley 2018

22

10 Leading Causes of Death – 2020, 2021



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Making the case for embracing 'serious illness':

There's more to life than just it's duration

Medical knowledge is already vast and continues to expand

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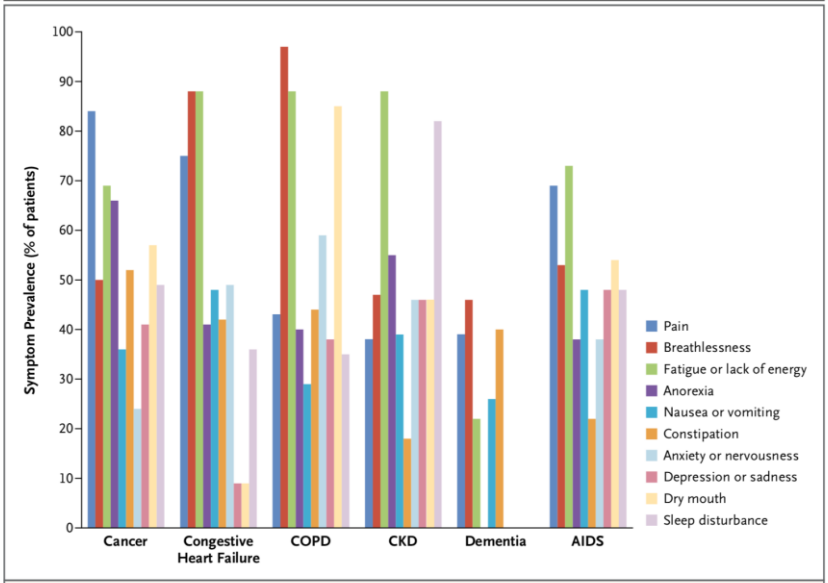

Figure 1. Symptom Prevalence in Advanced Illness.

Data are from representative studies of symptom prevalence among patients with cancer,[8-12] congestive heart failure,[13,14] chronic obstructive pulmonary disease (COPD),[15] chronic kidney disease (CKD),[13,14] or dementia[16,17] and among patients who received highly active antiretroviral therapy for the acquired immunodeficiency syndrome (AIDS).[18] Self-reported data regarding some symptoms were unavailable for patients with dementia.

NEJM 2015

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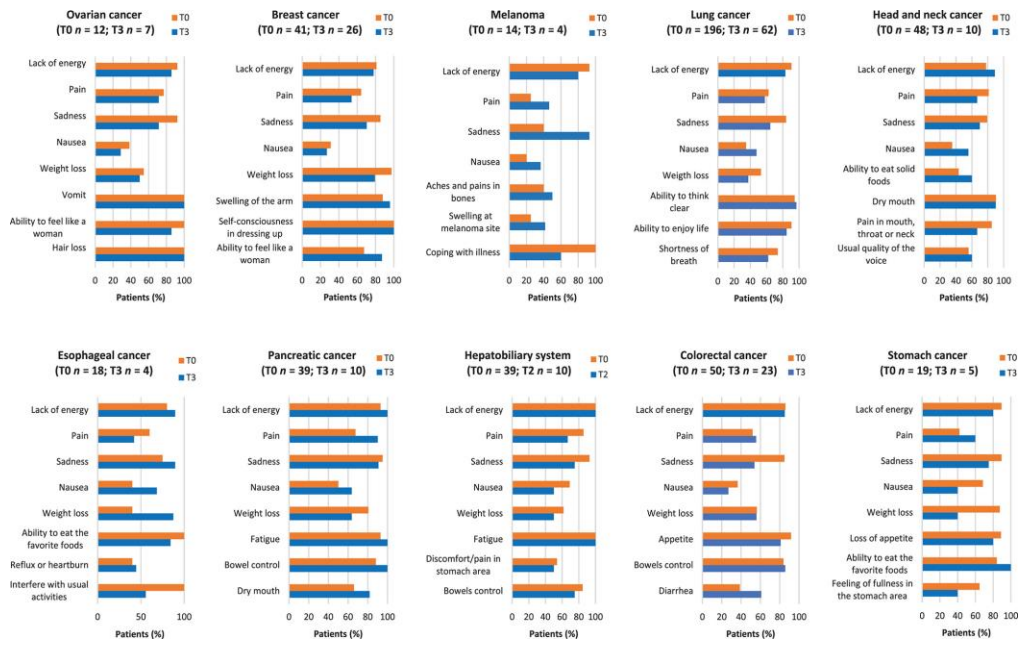
Symptom Burden and Palliative Care Needs of Patients with Incurable Cancer at Diagnosis and During the Disease Course



The Oncologist, Volume: 26, Issue: 6, Pages: e1058-e1065, First published: 09 March 2021, DOI: (10.1002/onco.13751)

26

Making the case for embracing 'serious illness':

There's more to life than just it's duration

Medical knowledge is already vast and continues to expand

Illness and death impact more than just the person who dies

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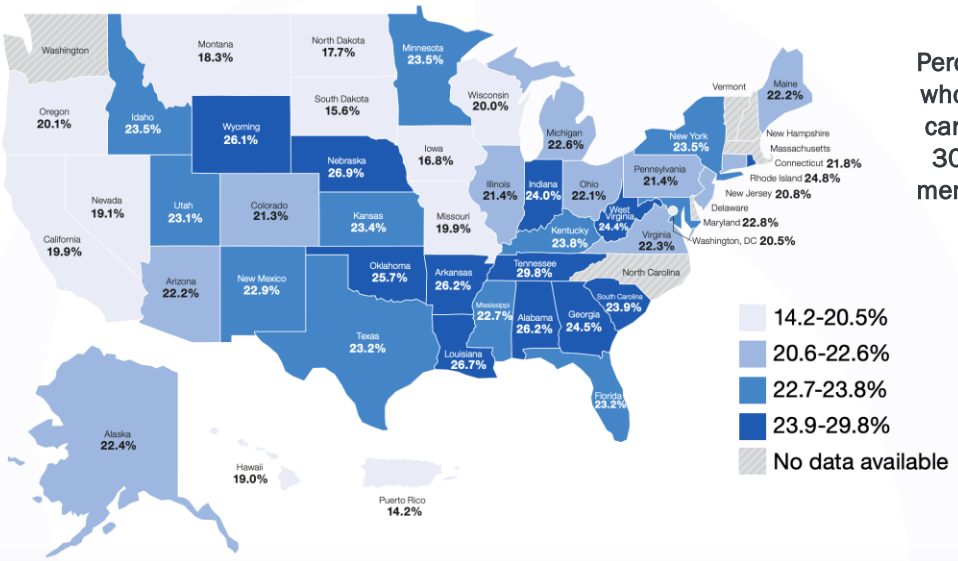
Characteristics of Caregivers and the Caregiving Situation

Figure 1: Adults aged 45 years or older who reported being a caregiver to a friend or family member



Percentage of adults over 45 who report providing regular care or assistance over last 30 days to friend or family member with health problem or disability

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CDC.Gov 2018

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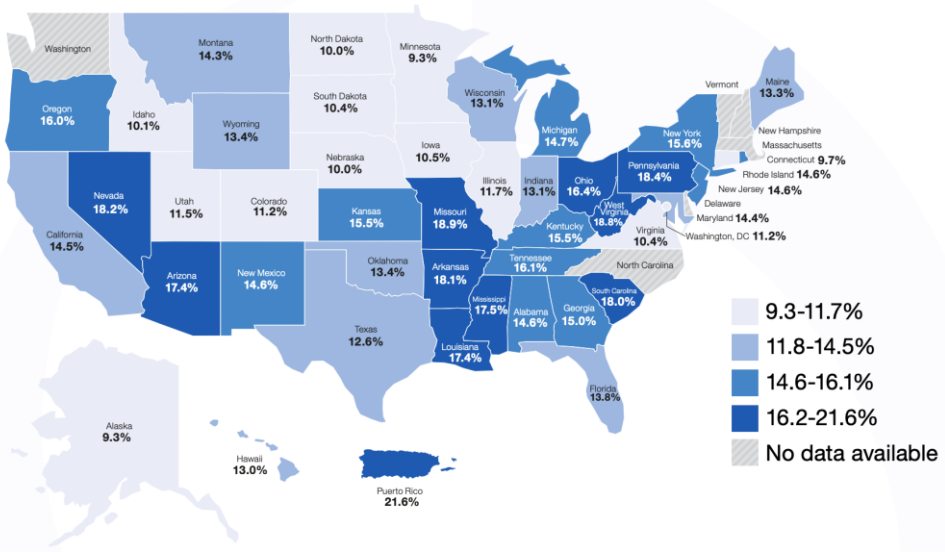
Health Status of Caregivers: Unhealthy Days and Insufficient Sleep

Figure 3: Caregivers aged 45 years or older who reported frequent mental distress

Caregivers reporting mental health was not good for >14 days in last month (including stress, depression, problems with emotions)



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CDC.Gov 2018

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Making the case for embracing 'serious illness':

There's more to life than just it's duration

Medical knowledge is already vast and continues to expand

Illness and death impact more than just the person who dies

==========

Addressing serious illness means purposefully expanding our focus to quality of life and psychosocial aspects of health

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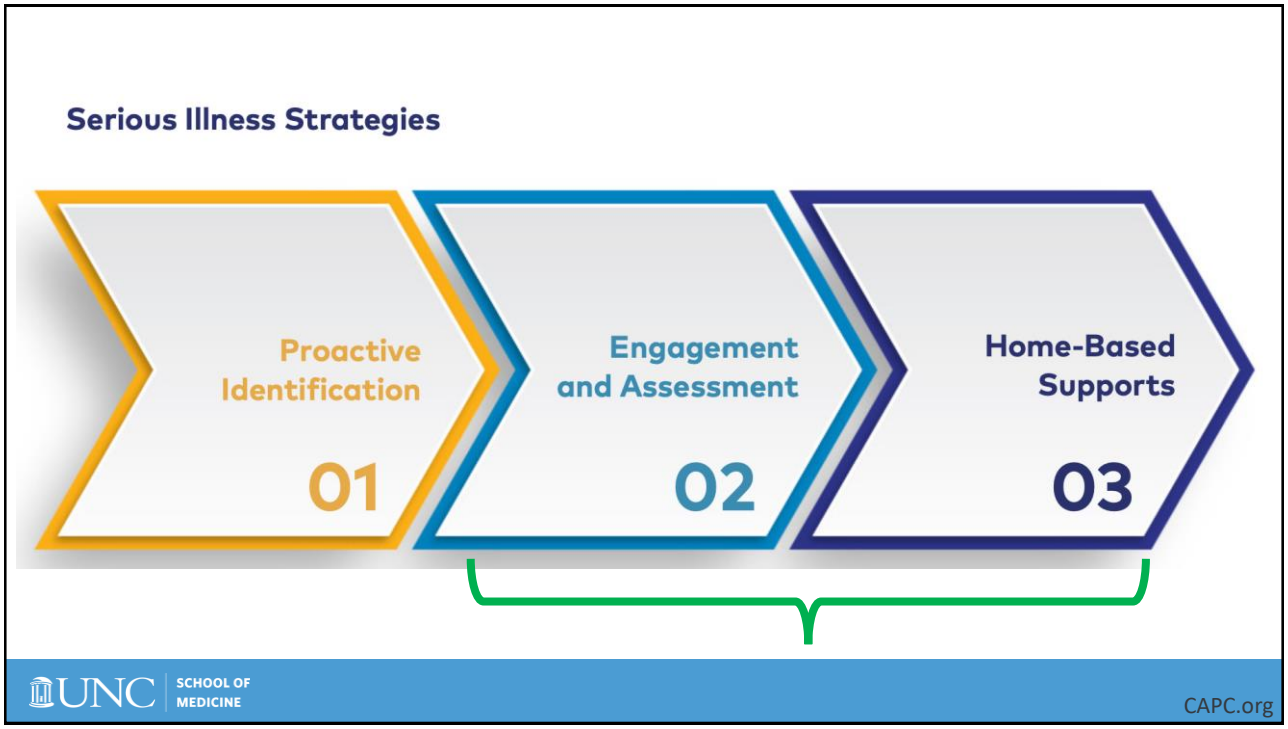
Serious Illness Strategies
Proactive Identification
01
Engagement and Assessment
02
Home-Based Supports
03
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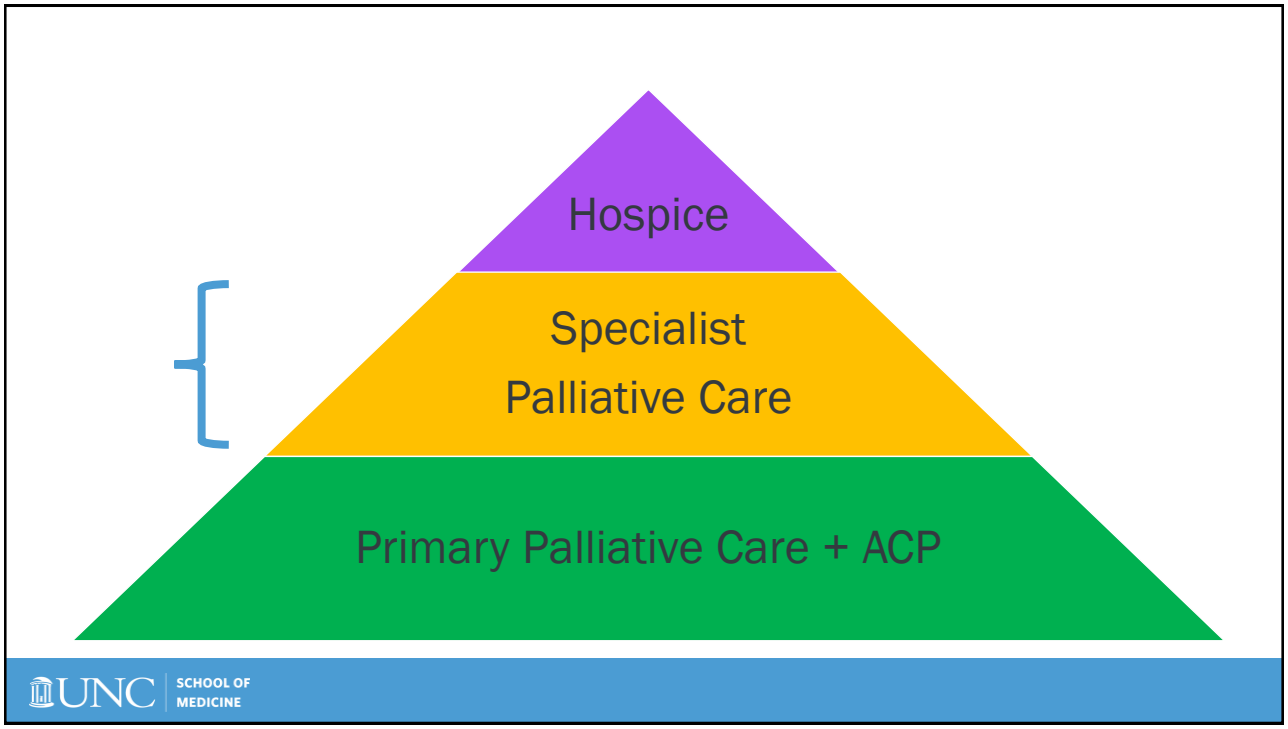
Hospice
Specialist Palliative Care
Primary Palliative Care + ACP
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Question - Palliative care is:

Only for patients in the final days of life — 0%

Only for patients who exclusively want to focus on comfort — 0%

A service available only in the hospital — 0%

None of the above — 0%

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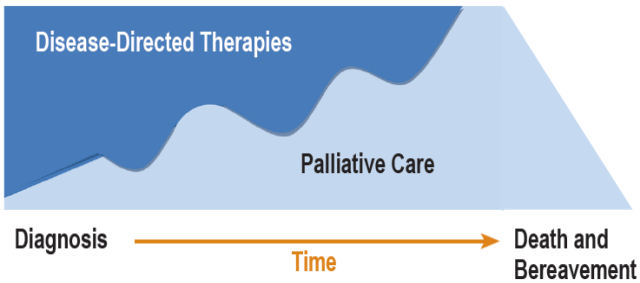
What is Palliative Care?



- Specialized **medical care** for people with serious illness
- Focuses on **improving quality of life** for patients **of any age or diagnosis** and their **families.**
- Provides **relief of symptoms, pain and stress** of a serious illness

- Provided by a **team of doctors, nurses and other specialists**
- Work together with patient's other clinicians as **an extra layer of support.**
- **Provided along with curative treatment.**

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What is Palliative Care?

Symptom Management
- Pain, shortness of breath
- Better quality of life

Decision-Making
- Sounding board
- Think through tough decisions

Advocate
- Ask about your goals so health care team works toward them

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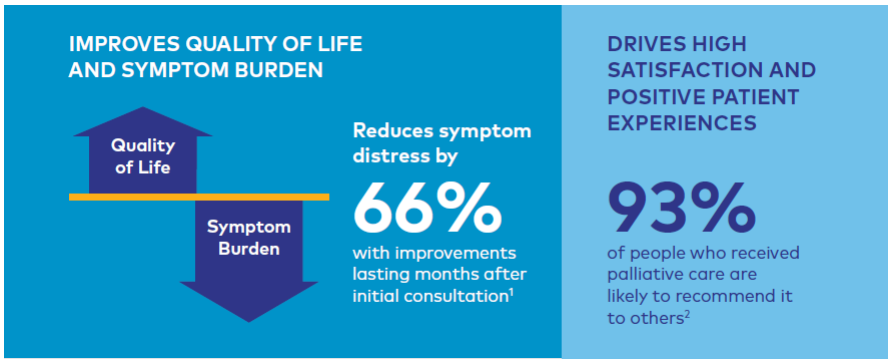
Palliative Care Drives a Positive Patient Experience and Outcomes



Evidence that palliative care is associated with longer survival in advanced cancer

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CAPC.org; Temel 2010

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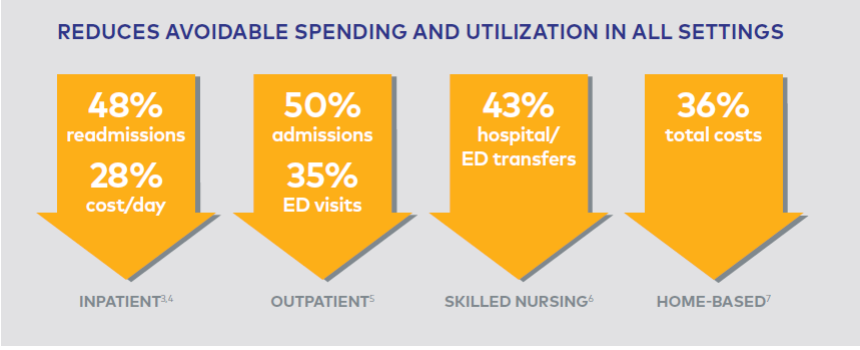
Palliative Care Improves Cost Effectiveness and Quality Scores



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Hospital-based Consultation

Clinic-Based

Community-Based

Variety of palliative care delivery models now available

Increasing number of training programs for specializing in palliative care

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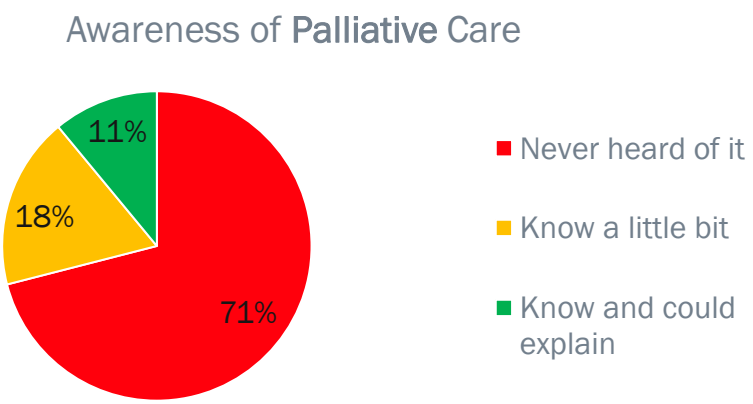
A 2019 U.S. National Survey of 3,445 adults asked "*How would you describe your level of knowledge about palliative care?*"



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Trivedi 2019

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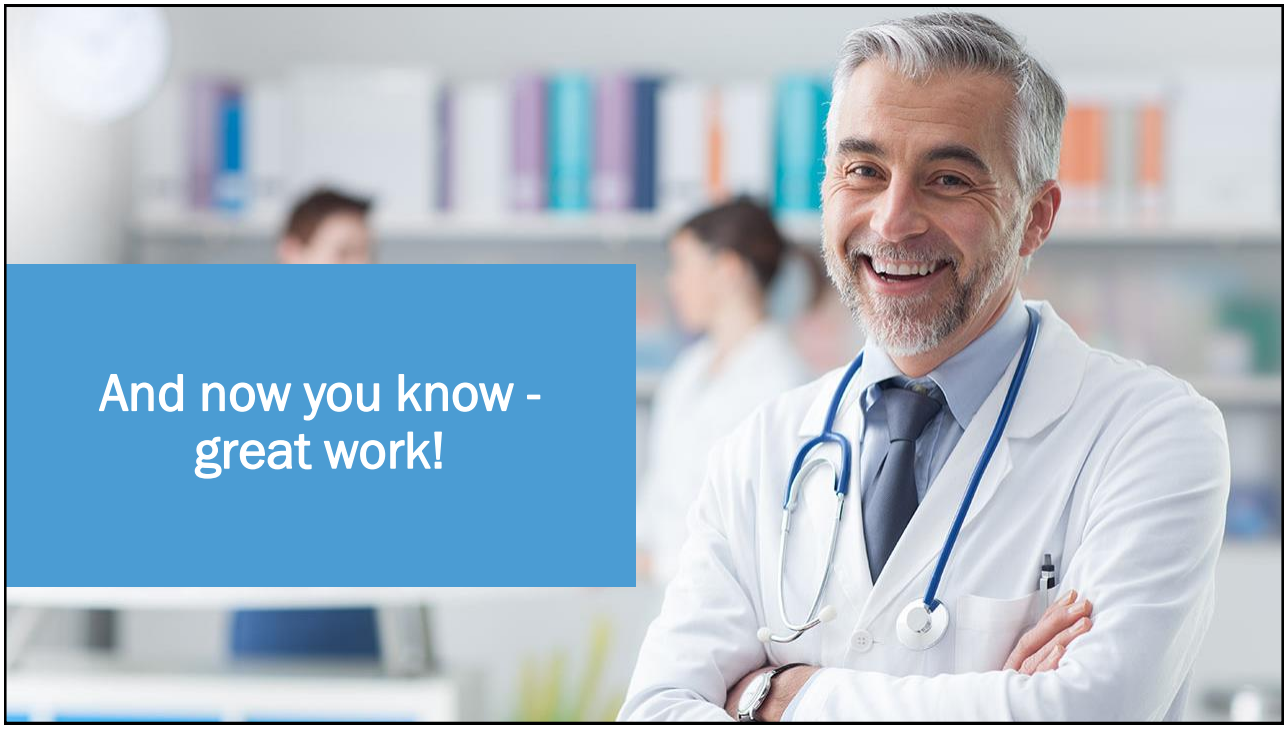

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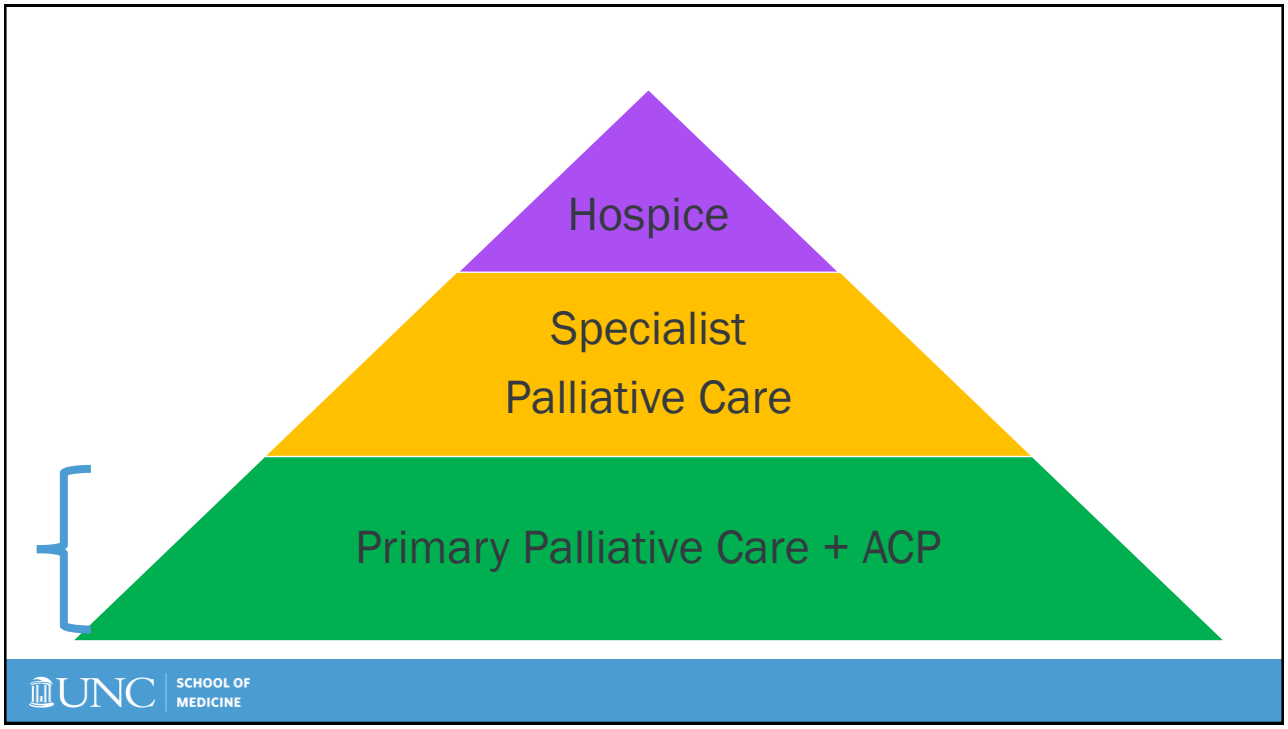

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Primary vs Specialty Palliative Care

Primary Palliative Care

- Basic management of pain and other symptoms
- Initiating and navigating straightforward discussions about:
  - Values
  - Prognosis
  - Goals of treatment
  - Stressors
  - Code Status
  - Advance Care Planning

Specialty Palliative Care

- Management of refractory pain or other symptoms
- Management of grief and existential distress
- Assistance with conflict resolution related to goals or treatment options
  - Within families
  - Between staff and families
  - Among treatment teams
- Assistance with complex goals of care discussions

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Advance Care Planning means making your healthcare decisions ahead of time before you get sick.

True 0%

False 0%

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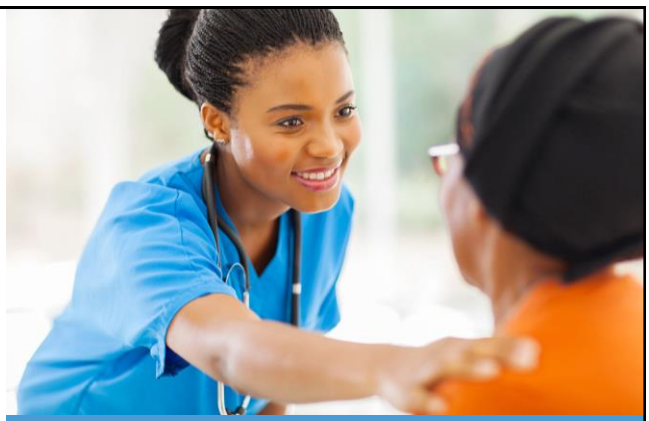
Advance care planning is a process that supports adults at any age or stage of health in understanding and sharing their personal values, life goals, and preferences regarding future medical care.



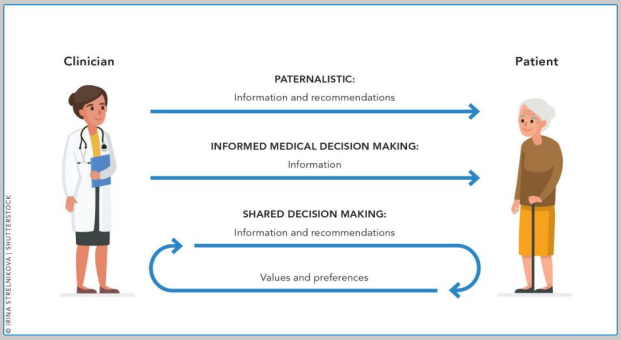
Advance Care Planning (ACP)

Sudore 2017

44

Often includes:

- Identifying a surrogate decision maker
  - HCDM
  - HCPOA
  - Next-of-kin Hierarchy
- Completing Advance Directives
  - Living Will
  - Medical Orders for Scope of Treatment
  - Code Status – Full Code vs. DNR
- <u>Education</u>



Advance Care Planning (ACP)

Sudore 2017

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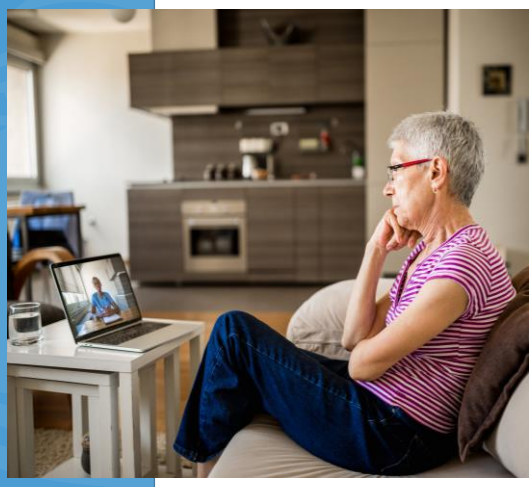
Mrs A continued -



As part of her annual wellness visit, her PCP brings up advance care planning. Mrs A identifies her son Kevin as her health care decision maker, and she takes a copy of an advance directive home to read.

Mrs A follows up with her oncologist, and she's had worsening pain in her legs despite the initial pain medication. She establishes with palliative care and starts on a new pain medication, and Kevin is connected to a caregiver support group.

Two months later, a CT can shows that her cancer has continued to progress. She is preparing to meet with her oncologist to talk about the next line of chemotherapy. She is starting to worry that any more chemotherapy will make her even more tired and sick.

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Serious Illness Strategies

Empathetic Communication and Shared Decision Making

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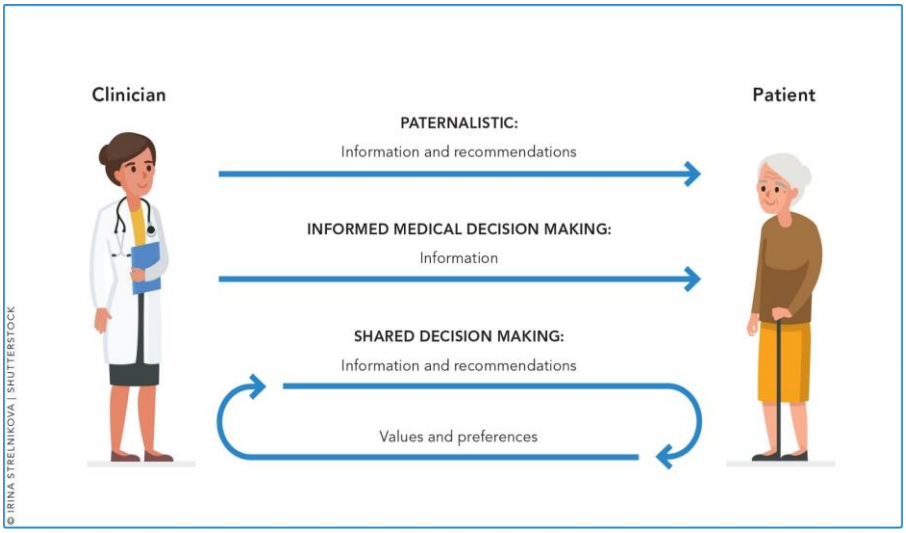
Shared Decision Making



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General Approach to Serious Illness Conversations (A Quick Look)

1. Prepare for the Meeting
2. Open the meeting
   - Introduction
   - Establish the goal for the meeting
3. Assess Family Understanding
4. Give Information
   - Illness and Treatments
   - Prognosis
5. Allow for reflection, questions and concerns
6. Learn Patient/Family Values and Goals
7. Summarize and align with values
8. Translate goals into a treatment plan
   - Making a recommendation
9. Close the meeting and document conversation in EHR

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*Adapted from Vital Talk

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Carolina Communication – Goals of Care Discussion Guide

This guide serves as a road map for goals of care communication. All steps and suggested language may not apply to every patient or discussion.

1. Set up the conversation ***-- Ask permission***	• I'm hoping we can talk about where things are with your illness and where they might be going – is this ok?
2. Assess illness understanding and information preferences	• What is your understanding of where you are now with your illness? • How much have you heard about what to expect with this illness as we look towards the future? • How much information about what is likely to be ahead with your illness would you like? • What questions do you have about your illness now and what to expect in the future?
3. Reframe when current treatment isn't working ***-- Warning shot*** ***-- Discuss prognosis***	• I have bad news to share. I think that the current treatments aren't having the desired effects. • We're in a different place now. • I'm concerned that time may be getting shorter. (Express as a range – e.g., days to weeks, weeks to months…) • I'm concerned that this may be as strong as you feel, and things are likely to get more difficult. • One to two sentences are usually enough to start – pitfalls include: too much information, medical jargon
4. Expect and respond to emotion ***-- Use of silence***	• Name the emotion: e.g., It seems like you are____; I'm sensing that you feel ____about this news. • Show understanding: I can only imagine how difficult this can be. • "I Wish" statements: I wish that the cancer had responded to the treatment. • Explore: Tell me more about that - what's going through your mind.
5. Explore goals and values ***-- Sources of strength*** ***-- Fears & worries*** ***-- Critical abilities*** ***-- Tradeoffs*** ***-- Family***	• Tell me about some of the things you enjoy doing. What gives your day quality? • Given that time may be limited, what's most important to you at this point of your life? • What gives you strength as you think about the future? What fears or worries do you have about the future? • 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 more time? • What does your family know about your priorities and wishes?
6. Summarize & align with values	• It sounds like [x,y,z] are the most important things to you at this time. Am I hearing you correctly?
7. Make recommendations & plan	• Given your goals and priorities and what we know about your illness at this stage, I recommend ___. • What do think about this plan? • We're in this together.
8. Document your discussion	• Write Advance Care Planning note so others can easily access content of your communication.

Adapted from the Ariadne Labs Serious Illness Conversation Guide (www.ariadnelabs.org) and the VitalTalk REMAP tool (vitaltalk.org) – Version 01.25.18

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ARIADNE LABS

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Serious Illness Conversation Guide

PATIENT-TESTED LANGUAGE

SET UP

"I would like to **talk together** about what's happening with your health and **what matters to you. Would this be ok?"**

ASSESS

"To make sure I share information that's helpful to you, can you tell me **your understanding** of what's happening with your health now?"

"How much **information about what might be ahead** with your health would be helpful to discuss today?"

SHARE

"Can I share my understanding of what may be ahead with your health?"

Uncertain: "It can be difficult to predict what will happen. **I hope you will feel as well as possible** for a long time, and we will work toward that goal. **It's also possible that you could get sick quickly**, and I think it is important that **we prepare** for that."

OR

Time: "I **wish** this was not the case. I am **worried** that time may be as short as *(express a range, e.g. days to weeks, weeks to months, months to a year).*"

OR

Function: "It can be difficult to predict what will happen. **I hope you will feel as well as possible** for a long time, and we will work toward that goal. **It's also possible that it may get harder to do things** because of your illness, and I think it is important that we prepare for that."

Pause: Allow silence. Validate and explore emotions.

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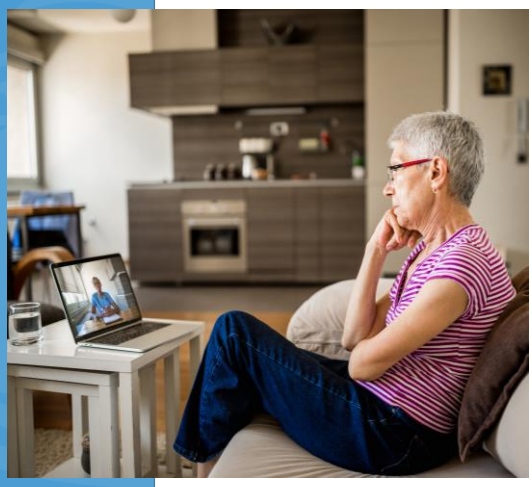
Mrs A continued -



Mrs A has a conversation with her oncologist and palliative care provider:

She feels she's spending all of her time going back and forth to clinic and hospital, and she hasn't felt well in months. She knows that time is limited no matter what she does, and she doesn't want to take the risk of feeling even sicker with chemotherapy.

She feels at peace with her life. It's most important for her now to maximize time with family and being at home, and she wants whatever help she can have to manage her pain and support her family.

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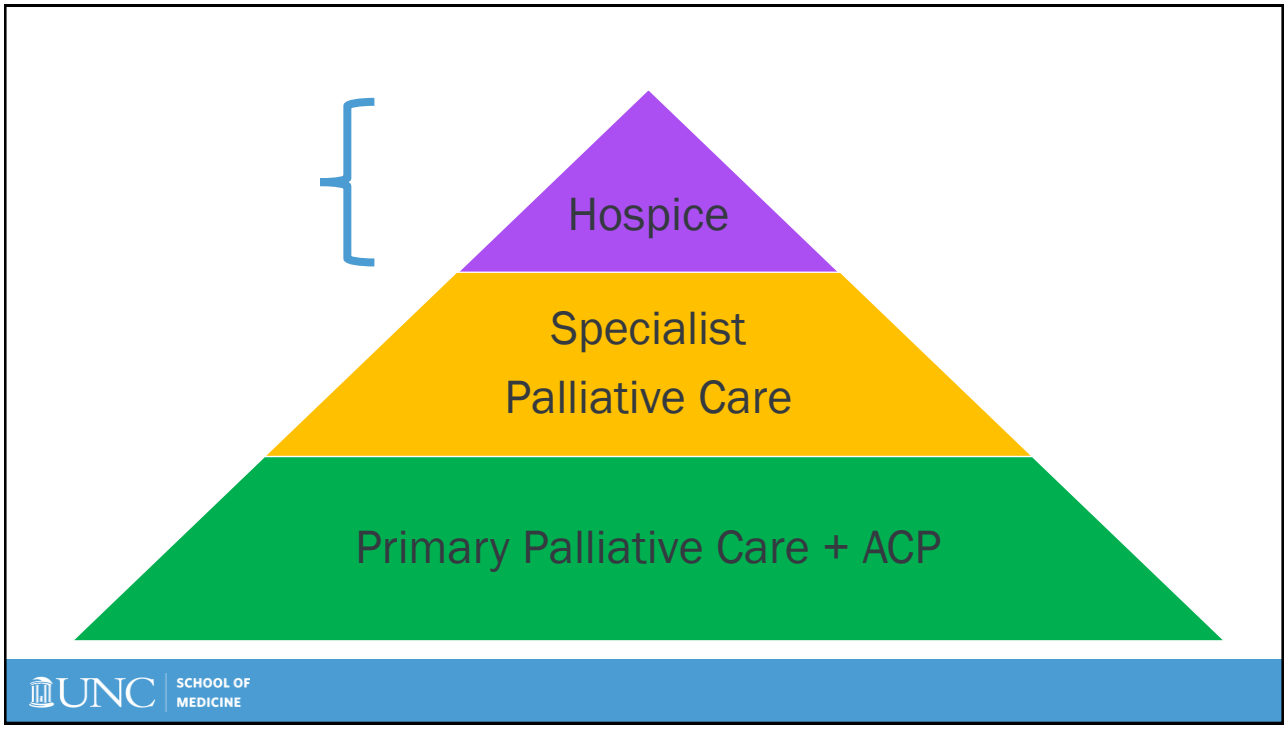
Hospice
Specialist
Palliative Care
Primary Palliative Care + ACP
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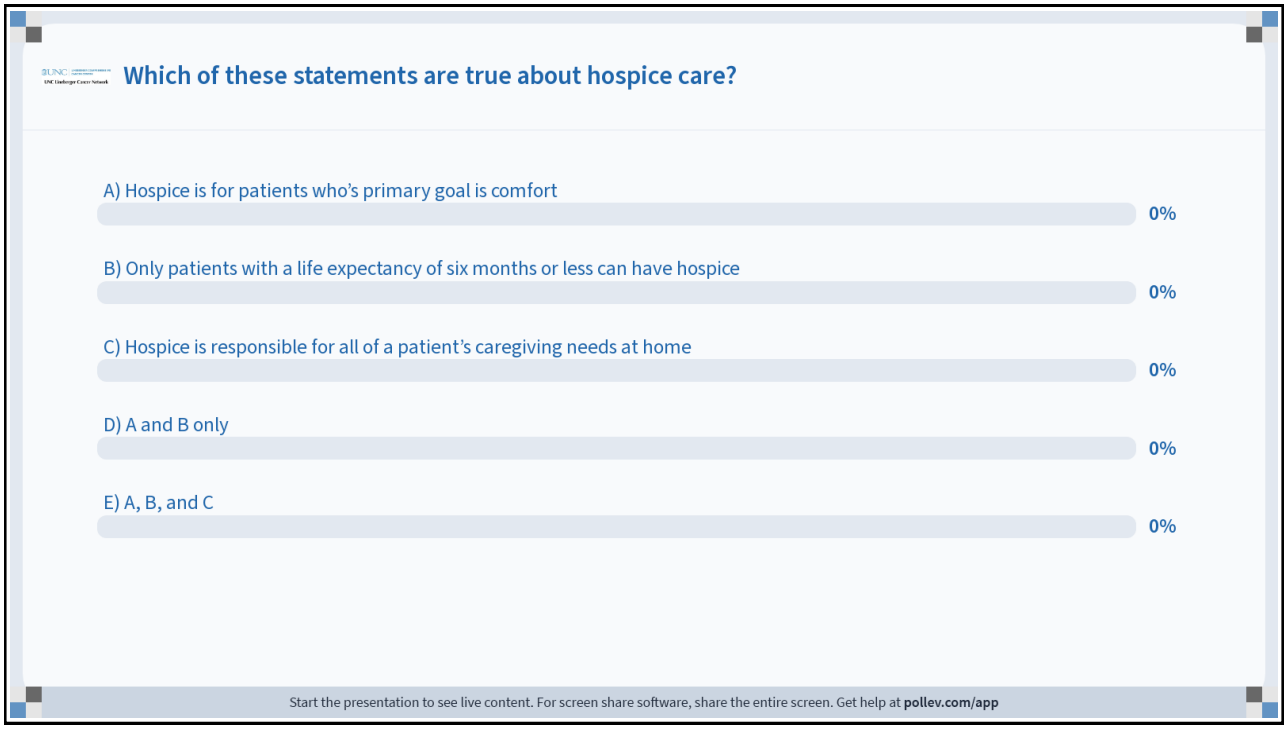
Which of these statements are true about hospice care?
A) Hospice is for patients who's primary goal is comfort
0%
B) Only patients with a life expectancy of six months or less can have hospice
0%
C) Hospice is responsible for all of a patient's caregiving needs at home
0%
D) A and B only
0%
E) A, B, and C
0%
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Hospice Care (1983 – Medicare Hospice Benefit)

A program of care and support for the terminally ill (a life expectancy of 6 months or less, if the illness runs its natural course) and their families, AND is willing to forego disease-oriented therapy

- Focuses on quality of life for patients and their caregivers
- Care delivered by an interdisciplinary team 24/7:
  - Physicians
  - APPs
  - RNs
  - NAs
  - Social Workers
  - Chaplains
- Significant contributions of volunteers and communities
- Care provided primarily in the home, also in congregate living facilities and inpatient hospice units ("hospice homes")
- Hospice is intended to provide virtually all care for the patient. It covers:
  - Hospice physician and nursing visits
  - Medical equipment and supplies
  - Prescription drugs*
  - Hospice aide services
  - Respite care
  - Inpatient care in high acuity situations

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*coverage depends on relatedness to the terminal condition

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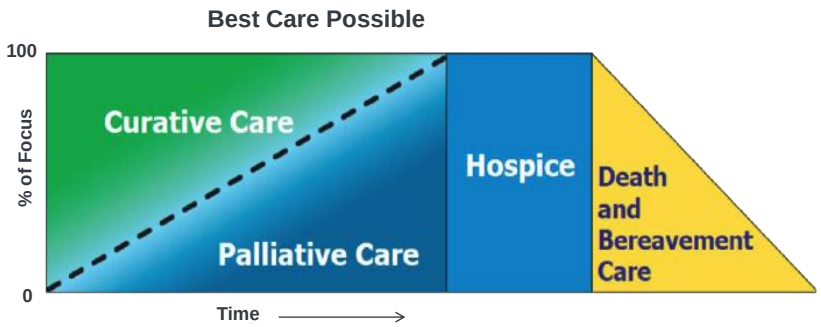
The Continuum of Care



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Adapted from: Lynn, J. (2005). "Living long in fragile health: The new demographics shape end of life care." *Hastings Cent* Rep Spec No: S14-18.

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Hospice	Palliative Care
Pain & Symptom Management	Pain & Symptom Management
Patient & Family Support	Patient & Family Support
Communication/Decision Making	Communication/Decision Making
Alternative insurance benefit: Meds/Equipment/Home supports	Component of existing health insurance, dependent on health system offerings
Prognosis < 6 months if disease follows expected course	***Independent of Prognosis***
Goal: exclusively comfort. Avoid hospitalizations	***Co-exists with*** disease-based evaluation/treatment, hospitalizations
Where: ***primarily home***, long-term care, inpatient facilitites	Where: ***primarily hospitals*** Developing in outpatient clinics, home, long-term care

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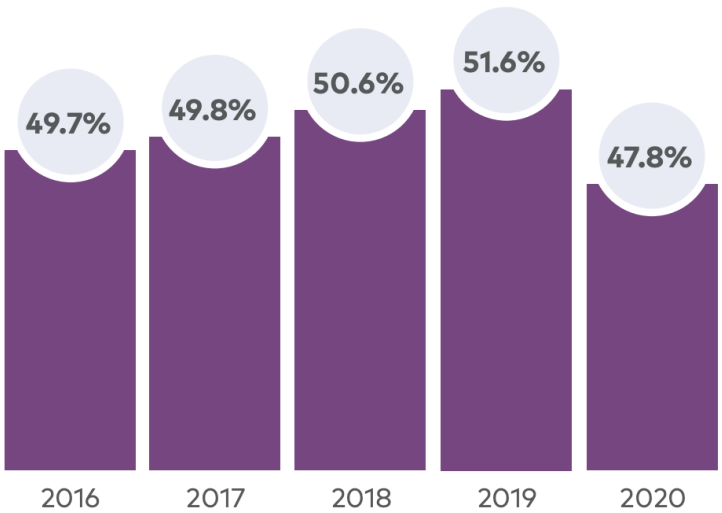
NHPCO Facts and Figures 2022

Figure 3: Share of Medicare decedents who used hospice (percentage)



Source: *MedPac March 2022 Report to Congress, Table 11-2*

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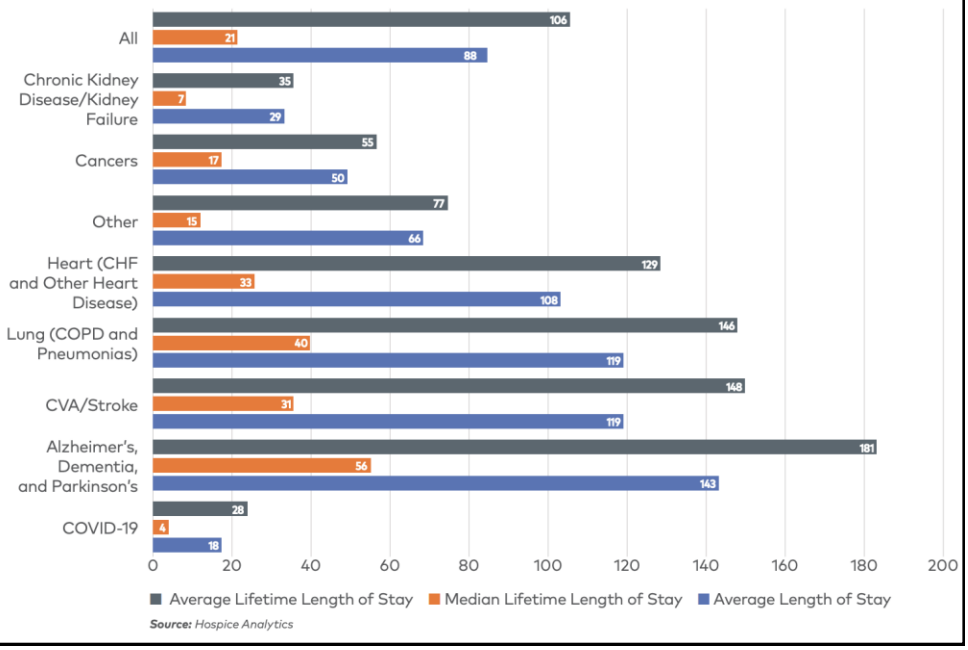
NHPCO Facts and Figures 2022

Figure 14: Average lifetime lengths of stay, median lifetime lengths of stay, and average length of Stay, 2020



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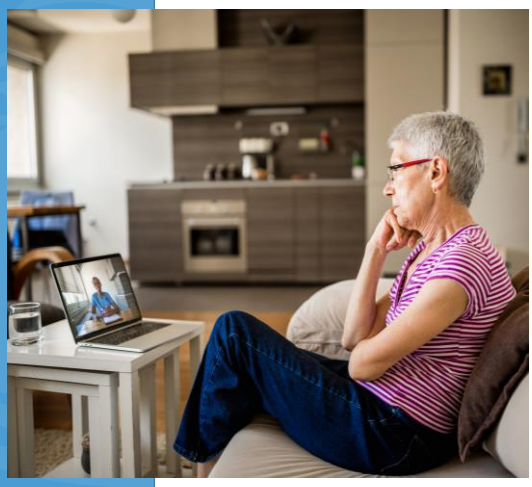
Mrs A enrolls in hospice



Mrs A starts hospice care at home. She gets help with medications and equipment in the house, and she really likes the nurse that visits her once a week. She starts to feel settled into a new routine at home, and she surprises everyone when she decides to rejoin her book club.

Three months later, she's spending all of her time in bed, has no appetite, and starts sleeping most of the day. The hospice social worker talks Kevin through preparing for death and what decisions he'll need to make.

Another month later, Mrs A dies at home. Kevin participates in the hospice's bereavement support over the next year as he prepares for the next phase of his life.

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Counseling on Palliative Care and Hospice

Determine goals of care and how they fit into available services

- For palliative care, emphasize role alongside curative treatments
- For hospice, align on a comfort-focused plan of care and the "hospice philosophy"

Critical to educate and clarify misconceptions

- Understanding benefits (and limitations) of the services, particularly lack of in-home caregiving
- Ask about prior experiences – the word 'hospice' is like the word 'hospital'

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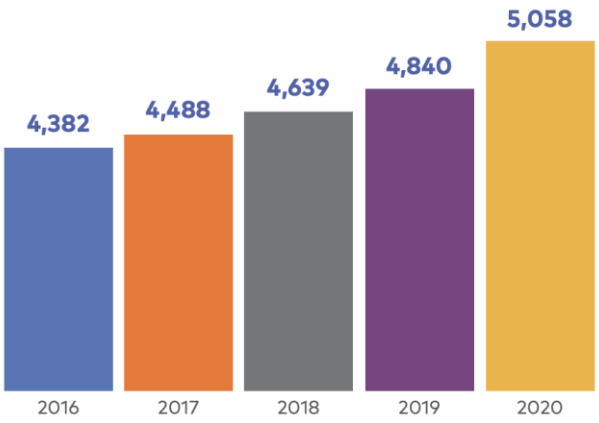
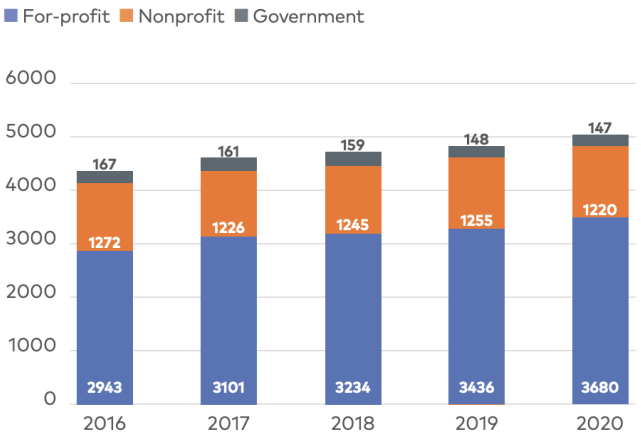
Figure 18: Number of Operating Hospices



Source: MedPAC March 2022 Report to Congress, Table 11-1; MedPAC March 2021 Report to Congress, Table 11-1

Figure 19: Providers by Type



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NHPCO Facts and Figures 2022

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Counseling on Palliative Care and Hospice

Determine goals of care and how they fit into available services

- For palliative care, emphasize role alongside curative treatments
- For hospice, align on a comfort-focused plan of care and the "hospice philosophy"

Critical to educate and clarify misconceptions

- Understanding benefits (and limitations) of the services, particularly lack of in-home caregiving
- Ask about prior experiences – the word 'hospice' is like the word 'hospital'

Provide anticipatory guidance

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Objectives

- Define serious illness and related terminology.
- Describe the roles of palliative care and hospice in supporting patients with serious illness.
- Review strategies for communicating with patients and families regarding serious illness and care planning.

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Thank you!

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Jared.lowe@unchealth.unc.edu

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References

1) Kelley AS, Bollens-Lund E. Identifying the Population with Serious Illness: "The Denominator Challenge". J Palliat Med. 2018 Mar 1; 21(Suppl 2): S-7–S-16.
2) Kelley AS, Morrison S. Palliative Care for the Seriously Ill. N Engl J Med 2015; 373:747-755
3) Vogt et al. The Oncologist, Volume: 26, Issue: 6, Pages: e1058-e1065, First published: 09 March 2021, DOI: (10.1002/onco.13751)
4) Temel et al. N Engl J Med 2010; 363:733-742
5) Trivedi et al. J Palliat Med. 2019 Dec 1; 22(12): 1578–1582.
6) Sudore et al. Defining Advance Care Planning for Adults: A Consensus Definition from a Multidisciplinary Delph Panel. J Pain Symptom Manage. 2017 May; 53(5): 821–832.e1.

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Patience & Compassion

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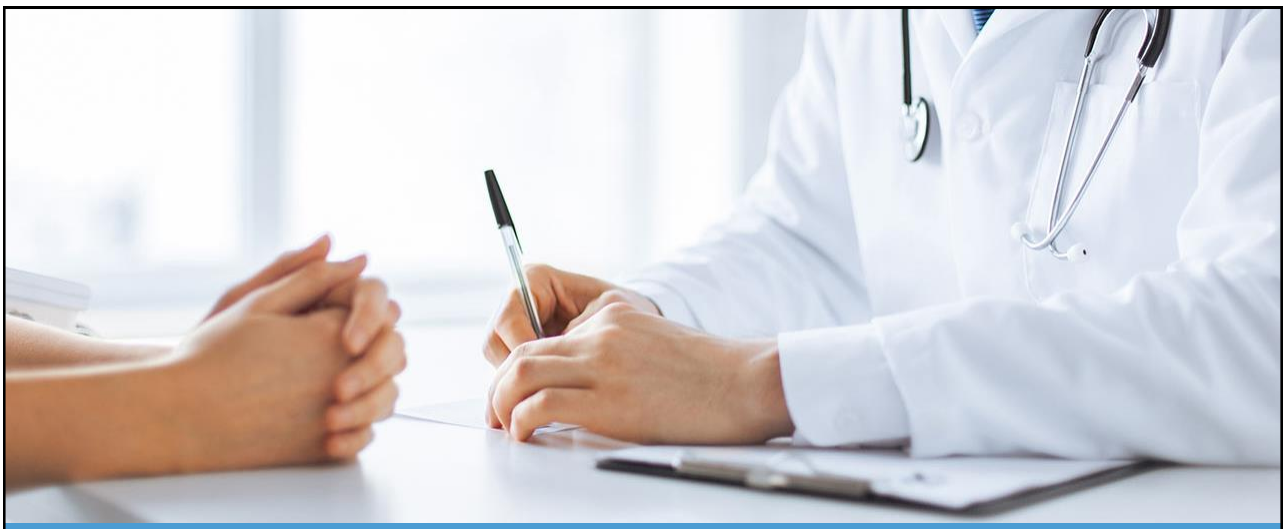

Appendix

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Carolina Communication – Goals of Care Discussion Guide

This guide serves as a road map for goals of care communication. All steps and suggested language may not apply to every patient or discussion.

1. Set up the conversation *-- Ask permission*	• I'm hoping we can talk about where things are with your illness and where they might be going – is this ok?
2. Assess illness understanding and information preferences	• What is your understanding of where you are now with your illness? • How much have you heard about what to expect with this illness as we look towards the future? • How much information about what is likely to be ahead with your illness would you like? • What questions do you have about your illness now and what to expect in the future?
3. Reframe when current treatment isn't working *-- Warning shot* *-- Discuss prognosis*	• I have bad news to share. I think that the current treatments aren't having the desired effects. • We're in a different place now. • I'm concerned that time may be getting shorter. (Express as a range – e.g., days to weeks, weeks to months…) • I'm concerned that this may be as strong as you feel, and things are likely to get more difficult. • One to two sentences are usually enough to start – pitfalls include: too much information, medical jargon
4. Expect and respond to emotion *-- Use of silence*	• Name the emotion: e.g., It seems like you are____; I'm sensing that you feel ____about this news. • Show understanding: I can only imagine how difficult this can be. • "I Wish" statements: I wish that the cancer had responded to the treatment. • Explore: Tell me more about that - what's going through your mind.
5. Explore goals and values *-- Sources of strength* *-- Fears & worries* *-- Critical abilities* *-- Tradeoffs* *-- Family*	• Tell me about some of the things you enjoy doing. What gives your day quality? • Given that time may be limited, what's most important to you at this point of your life? • What gives you strength as you think about the future? What fears or worries do you have about the future? • 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 more time? • What does your family know about your priorities and wishes?
6. Summarize & align with values	• It sounds like [x,y,z] are the most important things to you at this time. Am I hearing you correctly?
7. Make recommendations & plan	• Given your goals and priorities and what we know about your illness at this stage, I recommend ___. • What do think about this plan? • We're in this together.
8. Document your discussion	• Write Advance Care Planning note so others can easily access content of your communication.

Adapted from the Ariadne Labs Serious Illness Conversation Guide (www.ariadnelabs.org) and the VitalTalk REMAP tool (vitaltalk.org) – Version 01.25.18

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Communication Do: Respond to Emotion

NURSE Statements

Name
- "It sounds like you're worried."

Understand
- "It must be hard with how quickly this has happened."

Respect
- "I can see how hard you've worked to advocate for her."

Support
- "I will work with you to figure out the next steps."

Explore
- "Can you tell me more about how you feel about this?"

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I Wish Statements

"Can't you do more to treat my illness?"
- I wish we had a more effective treatment for your condition.

"I want to stay alive until my daughter gets married next year."
- I wish I could promise that. It sounds like it is hard to think about leaving your family.

"I want everything done to get him better."
- I wish we had treatments that could turn things around and allow him to wake up.

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Eliciting Patient Values

VALUES

- Vital Goals
- Activities
- Limits
- Uncertainties/Worries
- Experience with Illness
- Strength Supports

Substituted Judgement

- If she could speak, what do you think she would say about this?
- What would she say about what she would want to avoid?
- In terms of quality of life, what would be most important to her?
- Would she be OK with the most likely outcome of this ICU care?
- Would she be OK with undergoing these invasive treatments?

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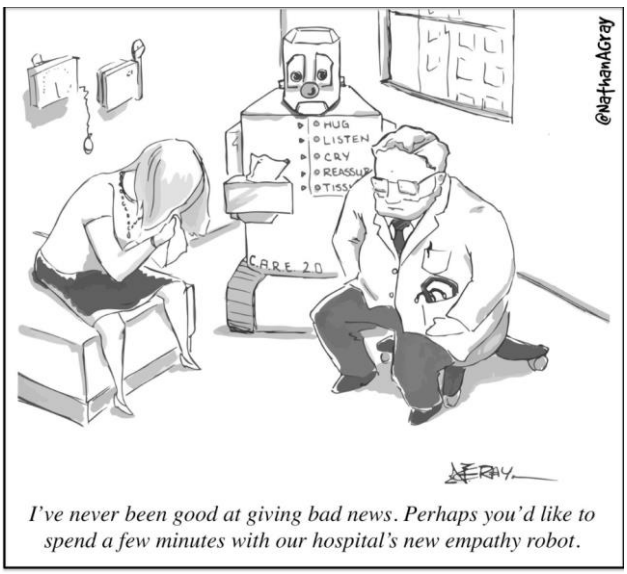

I've never been good at giving bad news. Perhaps you'd like to spend a few minutes with our hospital's new empathy robot.

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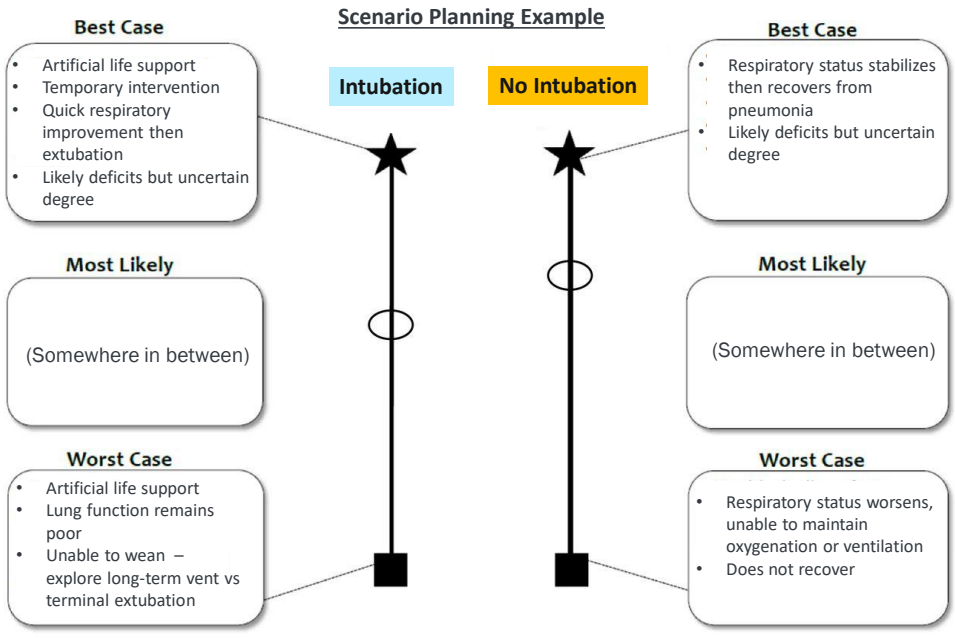

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Adapted from: Haug K, Buffington A, Zelenski A, *et al*
Best Case/Worst Case: protocol for a multisite randomised clinical trial of a scenario planning intervention for patients with kidney failure
BMJ Open 2022;**12**:e067258. doi: 10.1136/bmjopen-2022-067258

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Time-Limited Trials

Time Limited Trial acknowledges uncertainty and allows for the evolution of shared prognostic understanding over time

- Mutually agreed-upon care plans that propose the use of a treatment or procedure for a set period of time
- Clinician and patients or surrogates agree on next steps should patient improve, decline, or remain the same at the end of a trial period
- Need to outline what 'improve' and 'decline' look like, and discuss what potential next steps would be

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Additional Resources

- **Vital Talk**
- **Serious Illness Care Program by Ariadne Labs**
- **Center to Advance Palliative Care (CAPC)**

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Questions/Comments?

Nobody has responded yet.

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Thank You . . .

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Jeremiah 'Jig' Deneve, DO, FACS

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