



# Serious Illness Conversations

Today's Presenter

Mary Beth Billie, DNP, RN-BC, CCM



# Disclosure

**MI-CCSI, or the presenter, does not have any financial interest, relationships, or other potential conflicts, with respect to the material which will be covered in this presentation.**

# Objectives

**At the conclusion of this presentation the participant will be able to:**

1. Define a serious illness conversation.
2. State three criteria categories used to identify patients who would benefit from a serious illness conversation.
3. Define the six key components of the evidence-based serious illness conversation guide.
4. Describe three key communication skills used when exploring a patient goals relevant to their Serious Illness.

# Acknowledgements

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**VA**



**U.S. Department of Veterans Affairs**

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National Center for Ethics in Health Care



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The Conversation Project



**Institute for  
Healthcare  
Improvement**

# Let's Begin

**“In some respects,  
this century’s  
scientific and  
medical advances  
have made living  
easier and dying  
harder.”**

***Report from the field:  
Approaching Death:  
Improving Care at the End  
of Life-A Report of the  
Institute of Medicine  
(IOM, 1997)***

## Conversations are Infrequent, Late and Limited

### Infrequent

- Fewer than 1/3 of patients with end-stage diagnoses reported end-of-life (EOL) discussion with clinicians

### Late

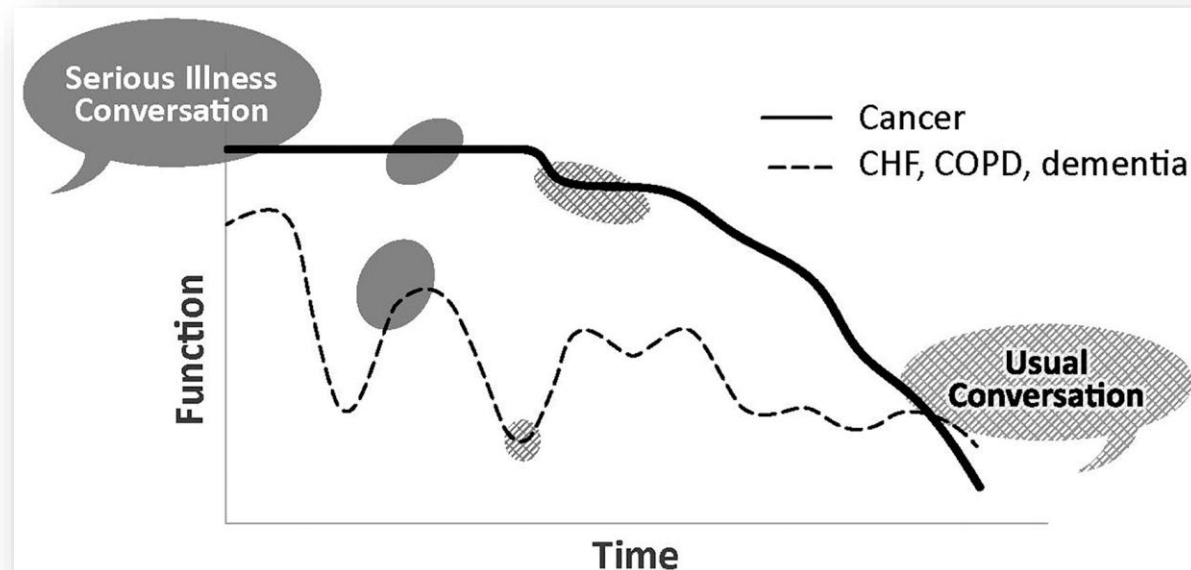
- First EOL discussion 33 days before death in patients with advanced cancer
- 55% of initial discussions occurred in hospitals

### Limited

- Conversations often fail to address key elements of quality discussions
- When conversations take place, outcomes of discussions are often not documented/difficult to retrieve or not captured accurately.

## Early conversations about patient values and goals linked to better serious illness care

- Increased goal-concordant care
- Improved quality of life / patient well-being
- Fewer hospitalizations
- More and earlier hospice care
- Better patient and family coping



Mack, 2010; Wright, 2008; Chiarchiaro, 2015; Detering, 2010; Zhang, 2009

## **Failure to recognize and honor patient's values and goals associated with harm**

- Poor quality of life and unnecessary physical and emotional suffering for patients
- Increased family distress
- Poor alignment of medical care with patient wishes
- Prolonged, undesired hospitalizations and ICU stays
- Distress among clinical staff
- Harm of not getting benefits of conversations
- Harm of getting unwanted care

Wright et al., 2008; Wright et al., 2010, Teno et al., 2007, Teno et al., 2004, Wright et al., 2016



**If we know  
earlier  
conversations  
have better  
outcomes why  
aren't we  
having them?**

# Multifactorial

- Curriculum deficits regarding End of Life care
- Lack of clinician communication skills training
- Lack of interprofessional collaboration
- Variance in chronic disease trajectories (i.e., CHF, COPD, ESRD)
  - Life expectancy increased 10 years since 1960 (69 to 79)
  - 69% will develop disabilities before they die and 35% will eventually enter a nursing home
  - 90% will live with one or more serious illnesses in the final year of their life.
- Major advances in technology and treatment options
- US healthcare system default is more care (medical model)

# Shift to Serious Illness Care Terminology

**Serious Illness (SI)**- *“disease(s) that carry a high risk of mortality and either negatively impacts a person’s daily function or quality of life, or excessively strains the caregiver.” (Kelley & Bollens-Lund, 2018)*

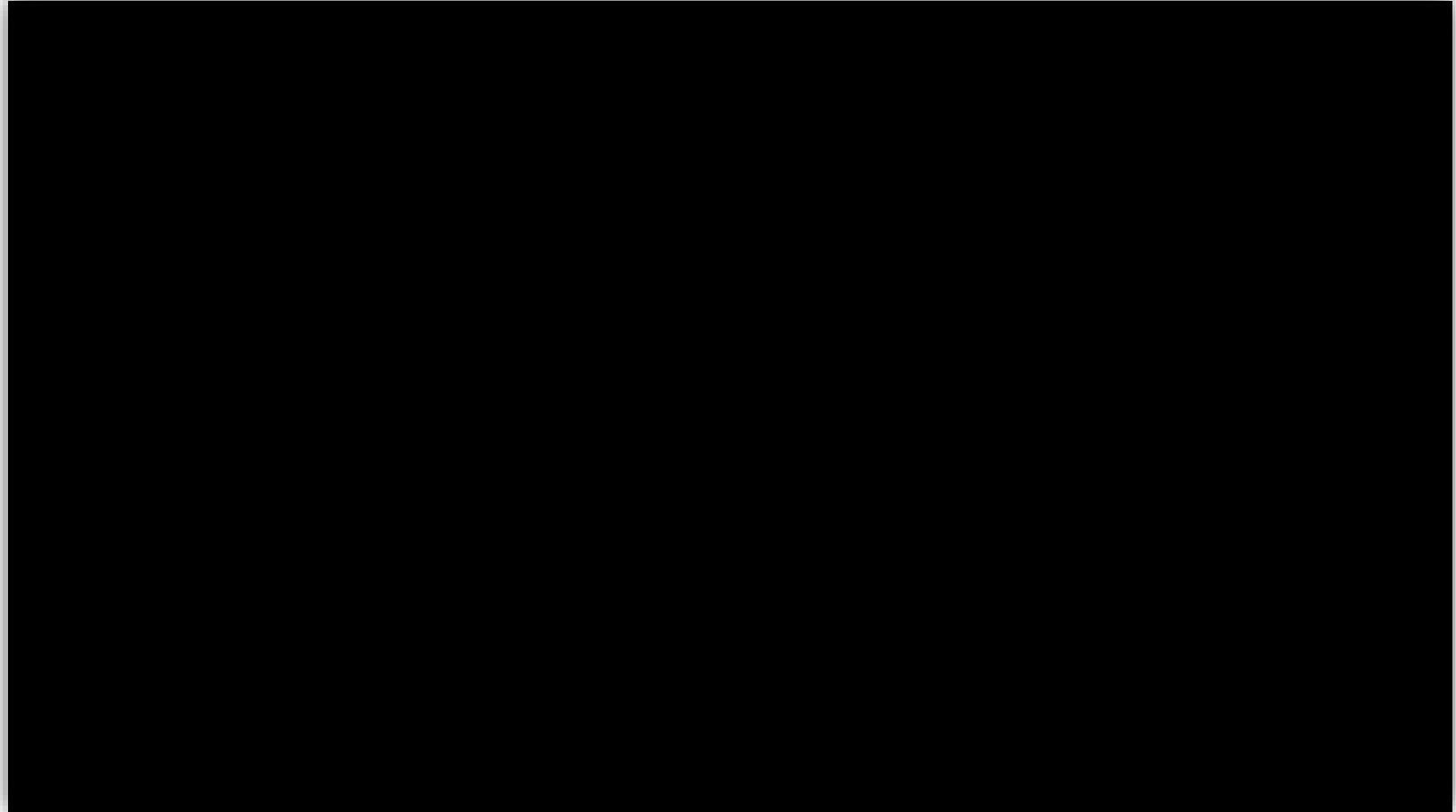
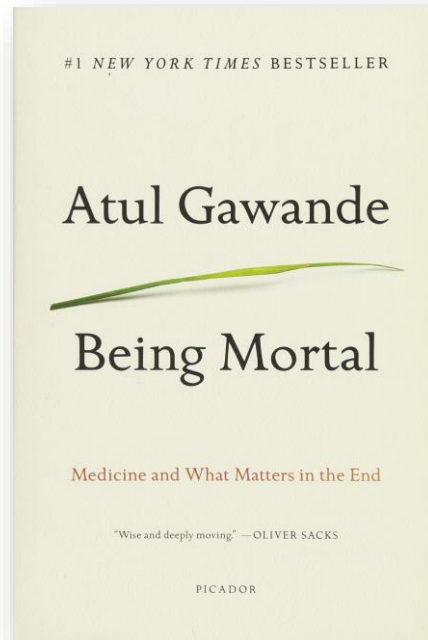
**Serious Illness Conversation**- *A clinician facilitated conversation with individuals with a serious illness to determine goals, values and preferences that then inform the serious illness plan of care.*

- *Often a series of conversations*
- *Often involves patients and families*

## **A Serious Illness Conversation is NOT:**

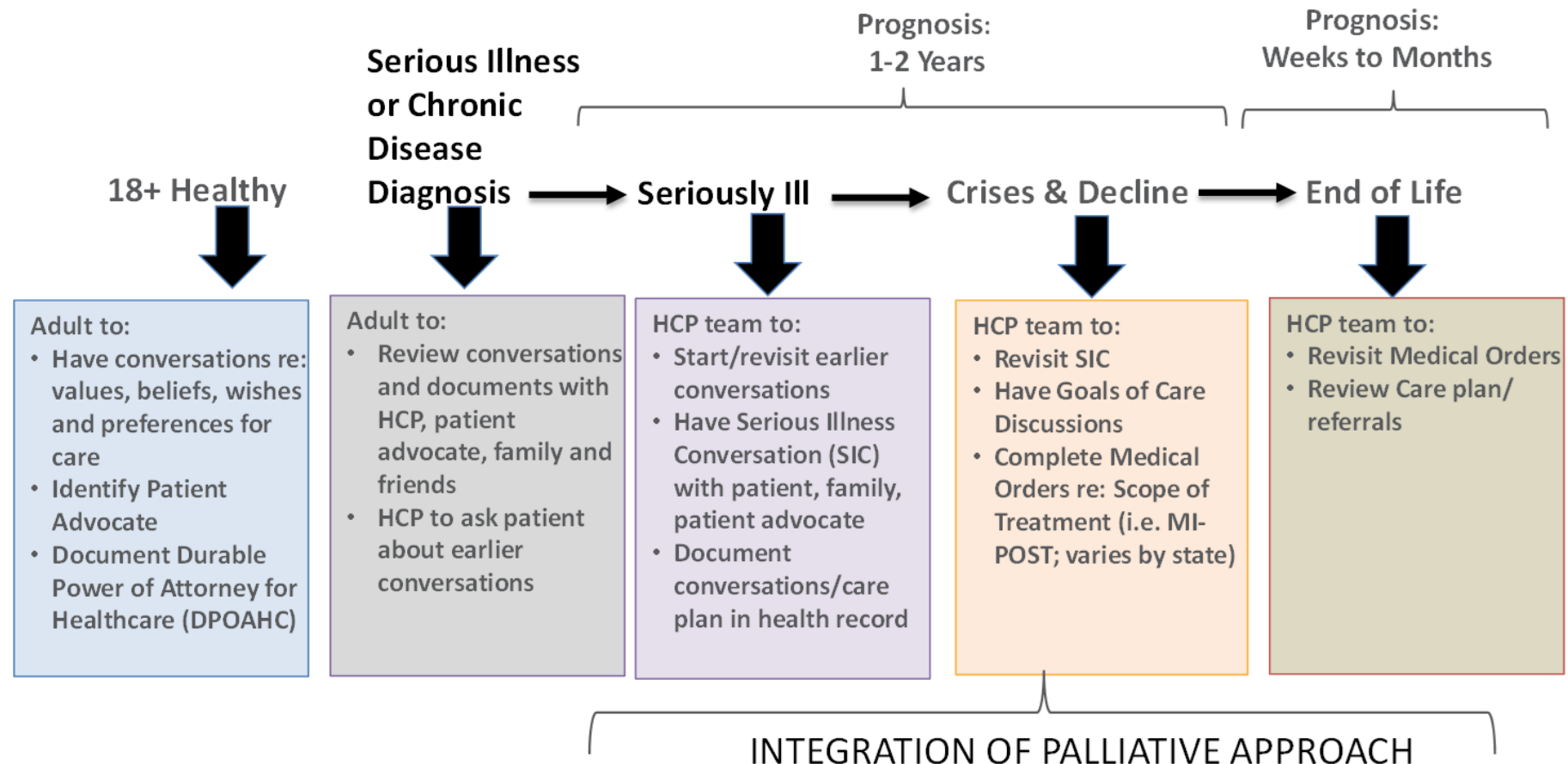
- *Discussion of medical treatments*
- *Completing Advanced Directives Forms such as HCPOA and POLST forms*
  - *CPR and DNR discussions*
- *Referrals to Palliative Care or hospice (can be an outcome of SI conversation)*

# Serious Illness Conversations



[https://www.youtube.com/watch?time\\_continue=11&v=45b2QZxDd\\_o](https://www.youtube.com/watch?time_continue=11&v=45b2QZxDd_o)

# Advance Care Planning Continuum



**Advance Care Planning** - Planning in Advance of Serious Illness

**Serious Illness Care Conversation** - Planning in the context of progression of serious illness

**Goals of Care Discussion**- Decision making in context of clinical progression/crisis/poor prognosis

# Evidence Based Intervention

Written for and Endorsed by the American College of Physician High Value Care Task Force :

## A System Approach to Serious Illness Communication

Special Communication

### Communication About Serious Illness Care Goals A Review and Synthesis of Best Practices

Rachelle E. Bernacki, MD, MS; Susan D. Block, MD; for the American College of Physicians High Value Care Task Force

1. Mechanisms to **identify patients** who would benefit from a SI conversation
2. Prompts to **remind clinicians** to engage in SI conversations at the right time
3. Use of **structured communication guide**
4. Serious Illness (SI) **communication training**
5. Patient and family **education**
6. A system for **documenting personalized patient goals and priorities** in the electronic health record

# Roles and Responsibilities

## RNs/SWs/Chaplains/MDs/APRNs/PAs

- Introduce the goals of care conversations
- Discuss role of the surrogate
- Elicit understanding of diagnosis and prognosis
- Elicit patient's values, goals
- Provide basic information about LSTs & services
- Document the conversation

## MDs/APRNs/PAs ONLY

- Deliver news about diagnosis and prognosis
- Establish a Life Sustaining Treatment plan with patient (or surrogate)
- Complete Life Sustaining Treatment ST Progress Note and Orders

# Identification - The Denominator Challenge

- Diagnosis
  - Dartmouth Atlas of Healthcare **9 serious chronic conditions accounts for 90% of death**
    - Modified above criteria to find most severely ill
- Utilization
  - Inpatient
- Measures of Need Domains: **high need if 2 or more** of following are positive
  - Functional dependence
  - Nutritional decline
  - Cognitive impairment
  - Pain limiting symptoms
  - Caregiver strain

Kelley & Bollens-Lund, 2018

1 Serious Medical Condition <sup>3</sup> (18% of total FFS population)					
↓					
Hospitalization in past 6 months (7% of total FFS pop)					
↓					
Outcomes in 1 year			% of group that is:		
Total Medicare Costs, mean	Hospital Stay	Death	Top 10% costs	2+ needs screen	ADL Impairment
\$30,489	53%	25%	37%	82%	67%

Adjusted C- statistic adjusted death within 1 year .78 (Bollens & Kelley Lund, 2018)

1 Serious Medical Condition <sup>3</sup> (18% of total FFS population)					
↓					
Hospitalization in past 6 months (7% of total FFS pop)					
↓					
Dependent for 1 or more Activities of Daily Living (4% of total FFS pop)					
↓					
Outcomes in 1 year			% of group that is:		
Total Medicare Costs, mean	Hospital Stay	Death	Top 10% costs	2+ needs screen	ADL Impairment
\$34,425	58%	30%	42%	95%	100%

Adjusted C- statistic adjusted death within 1 year .77 (Bollens & Kelley Lund, 2018)

# Serious Illness Criteria

Consider SI conversation if patient meets ANY of the following criteria:

## **Disease Based Criteria**

Inpatient admission in last 6 months & one of the following:

- Cancer with poor prognosis, metastatic or hematologic
- Chronic obstructive pulmonary disease or interstitial lung disease, only if using home oxygen or hospitalized for the condition
- End stage renal failure
- Congestive heart failure, only if hospitalized for the condition
- Advanced liver disease or cirrhosis
- Diabetes with severe complications (ischemic heart disease, peripheral vascular disease and renal disease)
- Advancing dementia with evidence of advanced disease



# Serious Illness Criteria

## Additional Criteria Categories

### Utilization/ Functional Status Criteria

- Two or more unplanned hospital admissions within past 6 months
- Resides in long term care facility
- Significant and rapid decline in ability to complete ADL's

### Surprise Question Criteria

- Would you be surprised if this patient died in the next 1-2 years?

# Why is it important to adhere to the guide?



**Dr. Susan D. Block** is a Professor of Psychiatry, Chief of Psychosocial Oncology and Palliative Care at the Dana-Farber Cancer Institute and the Co-Director of the Harvard Medical School Center for Palliative Care.

# Keys to a Successful Conversation

## Principles

- Patients have goals and priorities besides living longer; learning about them empowers you to provide better care
- You will not harm your patient by talking about end-of-life issues
- Managing your own and the patients' anxiety are key tasks in this conversation.
- Patients want the truth about prognosis
- Giving patients an opportunity to express fears and worries is therapeutic

## Practices

- Follow the guide while you are learning it
- Talk less than half the time
- Allow silence
- Acknowledge and explore emotions
- Focus on the patient's quality of life, fears, and concerns

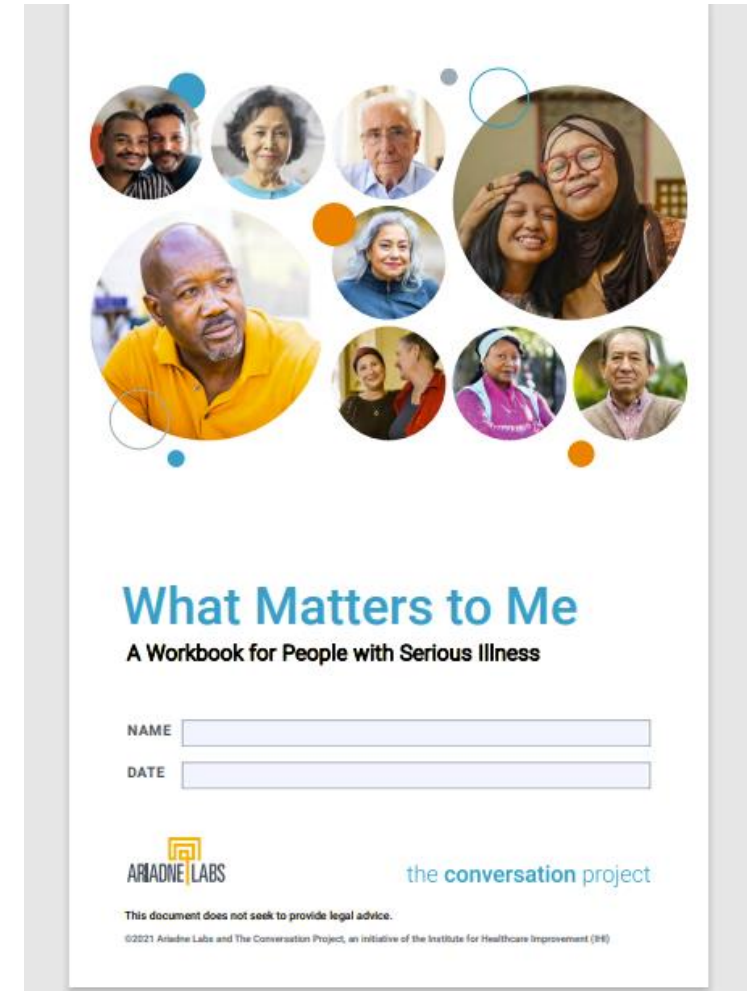
# Components of the Structured Guide

1. **Introduce** conversation and obtain permission
2. **Assess** understanding of health status and desire for information
3. **Share** prognosis within scope of practice
4. **Explore** values and goals for care
  - What is most important to you?
  - Concerns and worries?
  - Go through for the possibility of more time?
  - Critical abilities?
  - Gives you strength?
5. **Plan**
  - How much do your loved ones & doctor know about your wishes?
6. **Summarize and close**

# Prepare for Conversation

To optimize your Serious Illness Conversation with the patient provide the “What Matters to Me” workbook in advance of your conversation.

The workbook is designed to help people with a serious illness get ready to talk to their health care team (doctor, nurse, social worker, etc.) about what is most important to them.



# Introduce Conversation

*Provide purpose of the conversation and obtain patient's agreement to engage.*

“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 care with the care you want- is that okay?”

## Helpful Tips

- *Normalize the conversation ...”this is an approach that is use for all patients with serious illness”.*
- *Emphasize you prefer to do this when things are stable, so that there is more time to consider the issues.*
- *Frame the conversation as allowing the patient to be in control and relieve the burden of decision making for their loved ones.*
- *No need to make decisions today.*

## Assess Understanding

*Purpose-assess the  
extent of alignment of  
patient expectations  
and medical realities.*

“What is your understanding now of where you are with your illness?”

“How much information about with is likely to be ahead with your illness would you like from your healthcare team?”

### **Potential probes**

- *Tell me what you understand about your COPD, etc.*
- *What changes have you noticed over the past few months?*
- *Tell me more..... Can you expand on that?*

## Share Prognosis

(within scope of  
practice)

*Purpose- help patient  
prepare for what may  
be ahead.*

“I want to share with you my understanding of where things are with your illness.....”

Uncertain: “It can be difficult to predict what will happened 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 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 gets more difficult



# Physician: What if I Don't Know the Prognosis?



<https://www.youtube.com/watch?v=GC-FZ-h6qmQ>

## Nurse: Sharing a Functional Prognosis



<https://www.youtube.com/watch?v=CEUo6TzxLBE&t=11s>

## Explore Values and Goals

*Purpose- elicit values and goals to inform the current/future serious illness plan of care.*

- “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 cant imagine living without them?”
- “If you become sicker, how much are you willing to go through for the possibility of gaining more time?”

**Probe for:**

- *What is he patient worried about, with respect to their health?*
- *I want to keep going as long as I can\_\_\_\_\_?*

## Plan

*Purpose-identify and address knowledge gaps related to patient's goals and values.*

“How much do your loved ones know about your wishes?”

“How much does your doctor know about your wishes?”

**Probe for:**

- *What does the patient want their family and health care team to know about their wishes and preferences if they get sicker?*
- *What questions do you want to ask your health care team?*
- *What are the best and worst case scenario's?*

## Summarize and Close

*Purpose-ensure  
understanding of  
patient goals and  
recommend next steps  
for the plan.*

“I heard you say that \_\_\_\_\_ is really important to you. Keeping that in mind, 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?”

“Thank you for speaking with me today. I will do everything I can to help you through this”.

# Document Conversation

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- **Discussion Date: MM/DD/YYYY**
  - Patient completed a(n) in-person/telephone interaction. (Chose one)
    - The patient spoke with the nurse/ social worker to discuss goals of care and advance care planning.  
*(Choose one)*
- **Patient stated understanding of Health Condition: (use “quotes” as much as possible):**  
*i.e. I am getting sicker, I have been in the hospital more this last year, my doctors hasn’t really said anything specific but I think I am getting worse*
- **The following topics were discussed (use “quotes” as much as possible):**
  - Values/important goals if patient were to get sicker: *(from Care Goals worksheet for example, maximize function, not suffer, don’t let family be present)*
  - Biggest concerns/worries: *(i.e., suffocating from COPD, being in high levels of pain, moving into a SNF)*
- **Optional if discussed:** End of life preferences were also discussed with the patient and s/he expressed the following



# Take a Moment

- Think about an instance in which you cared for or interacted with a patient (or family member) with a serious life limiting illness.
- Reflect on what you found most challenging in having a values based conversation.
- Jot down a few key thoughts

# Key Communication Skills



1. Open Ended Questions
2. Reflective listening
3. Exploring
4. Affirmations
5. “I wish” statements



# Open-Ended Questions

- Elicit the patient's own knowledge, language, understanding and/or feelings
- Elicit details rather than one-word answers
  - “How has your health affected your day-to-day life?”
  - “You mentioned you have heart failure; what is your understanding of that disease?”



<https://youtu.be/fj5uUoNAtZU>

# Reflective Listening

The skill of listening carefully to another person and repeating back to the speaker the heard message to correct any inaccuracies or misunderstandings

## Examples of Reflective Listening

- “It sounds like ....”
- “It seems as if ....”
- “What I hear you saying ....”
- I get a sense that ....
- “It feels as though....”
- “Help me to understand. On the one hand....  
On the other hand....”

**PATIENT:** “My breathing is bad – I can’t walk as far as I used to, and I have to wear oxygen all the time now.”

**SIMPLE REFLECTION:** “Your breathing has really been giving you a hard time.”

**PATIENT:** “My doctors keep telling me there is no way to know if my cancer treatments are working. They won’t know anything until my next scan. Why do we have to wait so long?”

**Complex Refection CLINICIAN:** “It sounds like it’s really hard to live with the uncertainty.”

Are you  
listening or  
problem  
solving?



# Exploring

## Seeks more information

- Clarifies meaning
- Builds deeper understanding

“Tell me more...”

“What else?”

“What do you mean when you say live independently?”

# Affirmations

- Recognize strengths & acknowledge positive behavior
- Build rapport & patient's confidence

## **PATIENT:**

"I'm a fighter, I know I can beat this thing."

## **CLINICIAN:**

"You've been so strong through so much."

## **CLINICIAN:**

"You're saying this is difficult to talk about, and yet you came to today's appointment anyway."

"You have shown so much support for your dad."

# “I Wish” Statements

- Recognize patient's hope
- Align with the patient
  - “I wish you didn't have to deal with these lung problems.”
  - “I wish we had more effective treatments.”
  - “I hope for a miracle, too.”



<https://youtu.be/gcJE2pK4Uyg>

ambivalence

## Ambivalence

Ambivalence is having two conflicting desires

- “I don’t want to live like this. The treatment leaves me with no quality of life.”
- “My husband is not ready to let me go so I can’t stop treatment.”



## Watch for questions that are expressions of emotion

- “Isn’t there something else they can do for the cancer?”
- “Why is this happening to me?”
- Respond to the **emotion with empathy** rather than responding to the **question with facts**
  - “It must be so hard to be going through this.”

KEY SKILLS AND SAMPLE STATEMENTS				
Affirmation Acknowledging patient's strengths and abilities	Reflection		Exploring Encouraging patient exploration	"I wish" Aligning with the patient's experience
	Simple Restate or rephrase what patient says	Complex Interpretation such as naming feelings		
<i>You are such a (strong, committed, caring) person.</i>	<i>This is really important to you.</i>	<i>You can't imagine discussing this with your son, but at the same time you're worried about how this could affect him later.</i>	<i>What do you mean when you say I don't want to give up (be a vegetable/ a burden/ on life support)?</i>	<i>I, too, hope that _____ happens.</i>
<i>You (or your dad, mom, child, spouse) are such a strong person, and have been through so much.</i>	<i>You just aren't ready to discuss this yet.</i>	<i>One of the hardest things for you is all the uncertainty. On one hand, _____, and on the other, _____.</i>	<i>What else?</i>	<i>I wish things weren't so stressful for your family.</i>
<i>This is very difficult to think about, and yet you are still willing to talk to me about it.</i>	<i>So _____ has been the most difficult symptom for you to deal with.</i>	<i>This sounds frustrating (scary, overwhelming, difficult, challenging, hard).</i>	<i>Tell me more...</i>	<i>I wish the situation were different.</i>
<i>You have done so much to try to manage your illness (help your loved one with their illness).</i>	<i>Dealing with this illness has been such a big part of your life and has taken so much energy.</i>	<i>Other people in your situation have told me this feels very (name emotion).</i>	<i>Tell me more about what [a miracle, fighting, not giving up, etc.] might look like for you.</i>	<i>I hope for a miracle, too.</i>



## SAMPLE RESPONSES TO CHALLENGING STATEMENTS/QUESTIONS

These statements are examples of empathic continuers. Patients may not immediately respond to your first empathic statement. It often takes multiple successive empathic responses to help patients work through strong emotion.

<p><b>God's going to bring me a miracle.</b></p> <ul style="list-style-type: none"> <li>• I too hope that a miracle happens. <b>(Remember no buts!) ("I wish")</b></li> <li>• You have such a strong faith. <b>(affirmation)</b></li> <li>• Having faith is very important to you. <b>(reflection)</b></li> <li>• Can you share with me what a miracle might look like for you? <b>(exploring)</b></li> </ul>	<p><b>My dad is a fighter!</b></p> <ul style="list-style-type: none"> <li>• He is. He is such a strong person and he has been through so much. <b>(affirmation)</b></li> <li>• You care about your dad so much. <b>(affirmation)</b></li> <li>• It must be so <b>(name emotion)</b> to see him so sick. <b>(reflection)</b></li> <li>• Tell me more about your dad and what matters most to him. <b>(exploring)</b></li> </ul>	<p><b>Do you know something I don't know?</b></p> <ul style="list-style-type: none"> <li>• Tell me more about what you are asking. <b>(exploring)</b></li> <li>• You seem worried. <b>(reflection)</b></li> <li>• You are wondering if there is something your doctors haven't told you. <b>(reflection)</b></li> <li>• What is your understanding of where things are at with your health? <b>(open ended)</b></li> <li>• This situation must be very <b>(name emotion)</b>. <b>(reflection)</b></li> </ul>
<p><b>Why are we talking about this now?</b></p> <ul style="list-style-type: none"> <li>• You seem worried/overwhelmed/scared. <b>(reflection)</b></li> <li>• Maybe you aren't ready to discuss this right now. <b>(reflection)</b></li> <li>• That's ok if you don't want to discuss this right now. <b>(affirmation)</b></li> <li>• You don't think this is a good time to discuss this. Tell me more about what the right time would look like. <b>(exploring)</b></li> </ul>	<p><b>Are you giving up on me?</b></p> <ul style="list-style-type: none"> <li>• It sounds like you might be feeling.... <b>(name emotion)</b> <ul style="list-style-type: none"> <li>○ Alone</li> <li>○ Scared</li> <li>○ Etc.</li> </ul> </li> <li>• We will go through this together. <b>(affirmation)</b></li> <li>• No – I want to make sure we get you the best care possible to take care of what's going on for you now.</li> </ul>	<p><b>Are you telling me my dad is dying?</b></p> <p><b>These responses will affirm the question empathically – so do not use them if the patient is not dying</b></p> <ul style="list-style-type: none"> <li>• I wish the situation were different. <b>("I wish")</b></li> <li>• This must be such a shock for you. <b>(reflection)</b></li> <li>• I can't even imagine how difficult this must be. <b>(reflection)</b></li> </ul>



***Discuss:*** What communication skills could have been helpful in your discussion and why?

# Putting It All Together

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- Observe: What communication skills did you see the clinician use?
- Share other observations or reflections.



# Role Play Exercise

all progress  
takes place  
outside the  
comfort zone.

# Instructions: Break Out exercise

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- Each group has a previously assigned facilitator
- There is one Serious Illness Conversation Scenario (20 minutes)
- Facilitator role plays the patient and stops at defined points to engage in the group in discussion
- Participants will take turns playing the clinician utilizing their guide. Participants will use a round robin to move through each of the following components
  1. Introduce
  2. Assess understanding of health
  3. Share prognosis (within scope of practice)
  4. Elicit values and goals of care
  5. Make a plan (physician, family)
  6. Summarize & close
- Brief report out back to main group- what worked well? What were the challenges?



# Practice Case 1

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**SETTING:** Clinic, one month after hospitalization for COPD exacerbation.

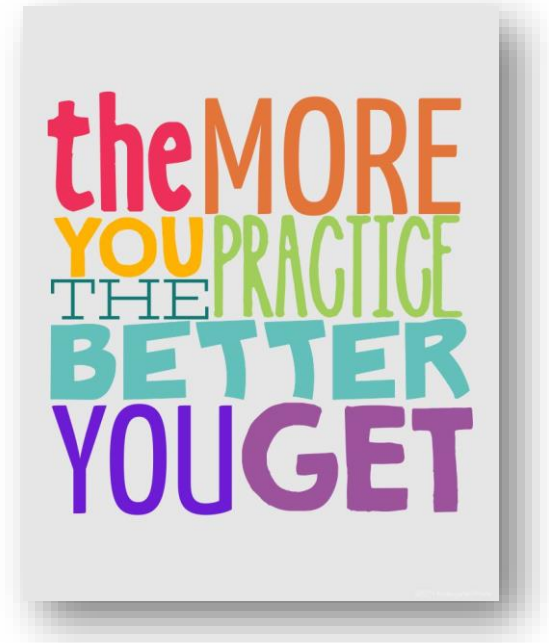
- Mr. Smith is a 68-year-old retired salesperson
- Chronic Obstructive Pulmonary Disease (COPD), on steroids and home oxygen; diabetes; chronic kidney disease; chronic hip pain
- Three hospitalizations this year (COPD exacerbations)
- Two ED visits (fall, med refill)
- Worsening shortness of breath, muscle weakness, fatigue
- Declining functional status at home, despite short stays in rehab after each hospitalization
- Spouse very involved, 28-year-old daughter lives locally



# Practice Case 1

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- The goal of the discussion today is to use the Structured Communication Guide to explore Mr. Smith's values, goals and priorities for care in the setting of illness progression.
- As you prepare to speak with Mr. Smith, you consider the following:
  - Mr. Smith has COPD and multiple co-morbidities (diabetes, kidney disease, chronic hip pain)
  - Given the hospitalizations and declining functional status, you are worried that he will have a harder time managing at home and that something serious could happen quickly, so you want to begin a conversation.



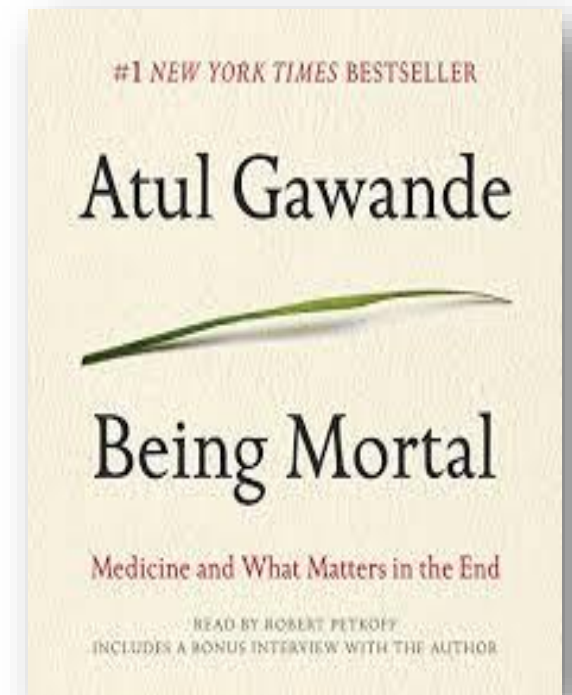
# Closing Reflection

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"If to be human is to be limited, then the role of caring professions and institutions—ought to be aiding people in their struggle with those limits. Sometimes we can offer a cure, sometimes only a salve, sometimes not even that.

But whatever we can offer, our interventions, and the risks and sacrifices they entail, are justified only if they serve the larger aims of a person's life. When we forget that, the suffering we inflict can be barbaric. When we remember it, the good we do can be breathtaking."

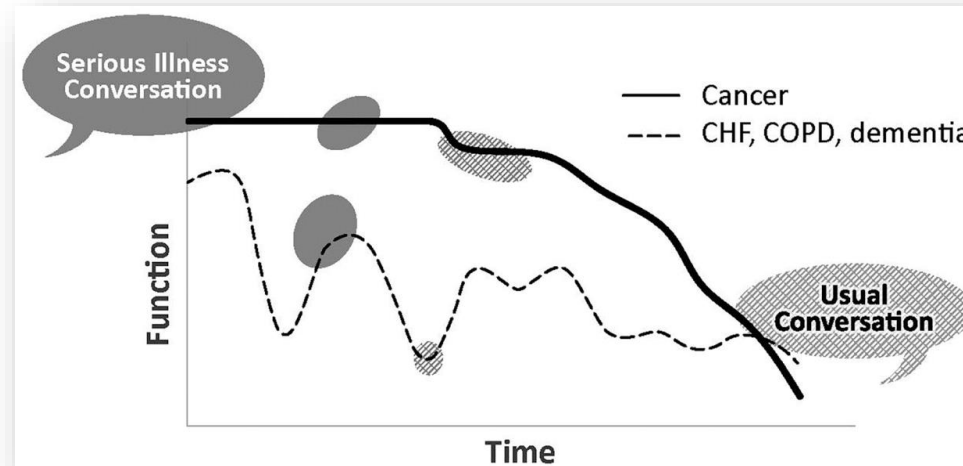
*Atul Gawande Being Mortal: Medicine and What Matters in the End.*





# Care Team Positioned to Initiate SI Conversations

- **Longitudinal relationships** with patients and families
- Ambulatory case managers – **ideal timing** – non urgent situation
- Ability to go **upstream** to help **inform** serious illness plan of care



# Recap Learning Objectives

1. Define a serious illness conversation.
2. State three criteria categories used to identify patients who would benefit from a serious illness conversation.
3. Define the six key components of the evidence-based serious illness conversation guide.
4. Describe three key communication skills used when exploring a patient goals relevant to their Serious Illness



# Questions?

# References

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