

# Clarifying Goals of Care

A PATIENT CENTRED APPROACH

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# Content

- ▶ What
- ▶ When
- ▶ Why
- ▶ Who
- ▶ How



# Goals of Care – What?

- ▶ More than just ‘code status’ or ‘preference for CPR’
- ▶ How the patient wants to **LIVE**
- ▶ **“The overarching aims of medical care for a patient” used to inform current or near-future treatment decisions**
- ▶ Should involve many steps in health care decision-making: specific treatments, intensity of care, planning for future care needs (advance care planning)
- ▶ Best when they are “exploratory, conversational and longitudinal”



# Prognosis – when to discuss

- ▶ Ideally when patient is not acutely ill and is better able to process and understand information
- ▶ Should occur early and often in the course of a life-threatening illness



# GOC discussions – why?

- ▶ Allows clinician to align care with what is most important to the patient, family or loved on
- ▶ Linked with reduced hospitalisations
- ▶ Linked with less aggressive care at the end of life
- ▶ Decreased family conflict
- ▶ More likely to die in preferred place of death



# GOC conversations – who?

Long list of recommendations including:

## ► Adults with cancer

- Prognosis-related triggers:
  - “Would you be surprised if this patient died in the next year?”
- Disease-based/condition-based criteria:
  - All patients with advanced non-small cell lung cancer, nonresectable pancreatic cancer, and/or glioblastoma
  - Patients older than 70 years with acute myelogenous leukemia
- Treatment-based identification:
  - Third-line chemotherapy



- ▶ Adults with chronic obstructive pulmonary disease
  - •Lack of further treatment options
  - •Functional decline
  - •Ongoing symptom exacerbation
  - •Ongoing oxygen requirement
  - •Multiple hospitalizations
- ▶ Adults with heart failure
  - Increased symptoms
  - Reduced function
  - Hospitalizations
  - Progressive increase in diuretic need
  - Hypotension
  - Azotemia
  - Initiation of inotrope therapy
  - Not a candidate for advanced cardiac therapies
  - First or recurrent implantable cardioverter-defibrillator shock



- ▶ Adults with advanced kidney disease
  - Prognosis-related triggers:
    - -“Would you be surprised if this patient died in the next year?”
    - •Albumin level less than 3.5 g/dL
- ▶ Age (as a continuous variable)
- ▶ Dementia
- ▶ Frailty/functional status
- ▶ Peripheral vascular disease, especially if need for amputation
- ▶ General triggers:
  - Older than 80 years and hospitalized



# How?

## REMAP: A stepwise approach

Reframe

Expect Emotion

Map out the future

Align with values

Plan treatments that match values



# Reframe

- assess patient and caregivers understanding of the clinical situation and prognosis
  - “What is your understanding of what the doctors have told you about your illness?”
- Once there is shared understanding, make “reframing” statements:
  - “Given this news, it seems like a good time to talk about what to do next”
  - “We’re in a different place now. Is it okay if we talk more about next steps”

(note asking permission)



# Expect Emotion

1. Notice patient expressing emotion (verbal or non-verbal)
  2. Emotional continuer to prompt further exploration (NURSE)
    - ▶ Name
    - ▶ Understanding
    - ▶ Respecting
    - ▶ Supporting
    - ▶ Exploring
- 
- ▶ <https://www.vitaltalk.org/guides/responding-to-emotion-respecting/>



# Map out the future

“Given what you know about your illness, what’s most important to you?”

“As you think about the future, what worries you?”

“As you think about the future, are there situations or things that you want to make sure you avoid?”



# Align with values

- ▶ By aligning with the patient/caregiver's value the clinician demonstrates the patient/caregiver has been heard. This can be as simple as repeating back to you
- ▶ "I understand that you want to make sure to avoid the following things..."
- ▶ "I hear you saying that what's most important to you is ..."



# Plan treatments that match values

- ▶ Specific treatments or care plans that will help accomplish the agreed-upon goals.
- ▶ Might say:
  - “It sounds like quality of life is the most important issue for you right now. Did I get that right?”
  - “From what you’ve told me about what’s most important to you, I recommend ... How does that sound”



# Pitfalls

- ▶ Starting too late or not at all
- ▶ Expecting too much too soon
- ▶ Trying to deliver serious news and goals in one sitting
- ▶ Biasing the conversation



# Jumpstart Communication Tool

**Original Investigation** | Critical Care Medicine

April 1, 2022

## **Efficacy of a Communication-Priming Intervention on Documented Goals-of-Care Discussions in Hospitalized Patients With Serious Illness**

### **A Randomized Clinical Trial**

Robert Y. Lee, MD, MS<sup>1,2</sup>; Erin K. Kross, MD<sup>1,2</sup>; Lois Downey, MA<sup>1,2</sup>; [et al](#)

» [Author Affiliations](#) | [Article Information](#)

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Item 3: Barriers to talking about goals

|   |   |
|---|---|
| 1. I don't know what kind of care I would want if I were to get very sick.  | "Even if you aren't sure what kind of care you want in the future, it is helpful to me if we talk about the things that are important to you so that we can provide the right care."  |
| 2. I'm not ready to talk about the care I would want if I were to get very sick.  | "Some people find it hard to talk about their healthcare in the future. Would you consider giving it a try for a few minutes? At any time, you can just say, 'Ok, that's enough for today.'"  |
| 3. I don't like to talk about getting very sick.  |   |
| <del>My clinician doesn't like to talk about my getting very sick.</del>  | "Sometimes people worry that doctors don't have enough time or wouldn't agree with your thoughts. I want you to know that I consider talking about this really important."  |
| 4. My doctor never seems to have the time to talk about issues like end-of-life care.   |   |
| 5. I would rather concentrate on staying alive than talk about death.   | "Some people find it hard to talk about their healthcare in the future. Would you consider giving it a try for a few minutes? At any time, you can just say, 'Ok, that's enough for today.'"  |
| 6. I feel that talking about death can bring death closer.  |   |
| 7. I have a living will, and that means I don't need to talk with my doctor about the care I would want if I were too sick to speak for myself. | "Even though you said in the survey you have completed a living will, it is helpful for me to make sure we are on the same page about what is important to you about your care."  |
| 8. My ideas about the kind of medical care I want change at different times.  | "This is a big topic. Some people need time before they know what decisions would be best. Others worry that they might change their mind in the future. Either way, it still helps me to know something about what you think, even if it's not final." |
| 9. I have <u>not</u> felt sick enough to talk with my doctor about end-of-life care.  | "Even though you are doing pretty well, it is helpful for me if I can check my understanding about what is most important to you and the type of care that you want."   |
| 10. I'm not sure which doctor would be taking care of me if I were to get very sick.  | "Although you see a lot of doctors and it is hard to know which of us will be there if you get very sick, it is still helpful for us to talk about it and I can pass on any thoughts you have on the topic to other doctors."                           |

\*\* If there is no single "biggest / most important" barrier endorsed, we will feedback one barrier, chosen at random, of those that were endorsed.

\*\* If no barriers are endorsed, then facilitators will be included.

\*\* If no barriers OR facilitators are endorsed then use... "You didn't mention anything on your survey that makes these discussions easier or harder. Anything come to mind right now?"



|   |                | Want to discuss/discuss more?   |   |  |
|---|----------------|---|---|--|
|   |                | Yes   | No  | Don't know   |
| Previously discussed preference/goals of care | Yes            | "I'm glad you are willing to talk about the care you would want if you were to get sicker. Tell me your thoughts" | "It is helpful for me if I make sure I understand your thoughts about the care you would want if you were to get sicker"  | "It is helpful for me to make sure I understand your thoughts about the care you would want if you were to get sicker" |
|   | No             | "I'm glad you are willing to talk about the care you would want if you were to get sicker. Tel me your thoughts"  | "It is helpful for me if I make sure I understand your thoughts about the care you would want if you were to get sicker. I know this can be difficult, but it can make sure you get the care you want." | "It is helpful for me to make sure I understand your thoughts about the care you would want if you were to get sicker" |
|   | Don't remember |   | "It is helpful for me if I make sure I understand your thoughts about the care you would want if you were to get sicker. I know this can be difficult, but it can make sure you get the care you want." | "It is helpful for me to make sure I understand your thoughts about the care you would want if you were to get sicker" |
|   |                |   |   |  |

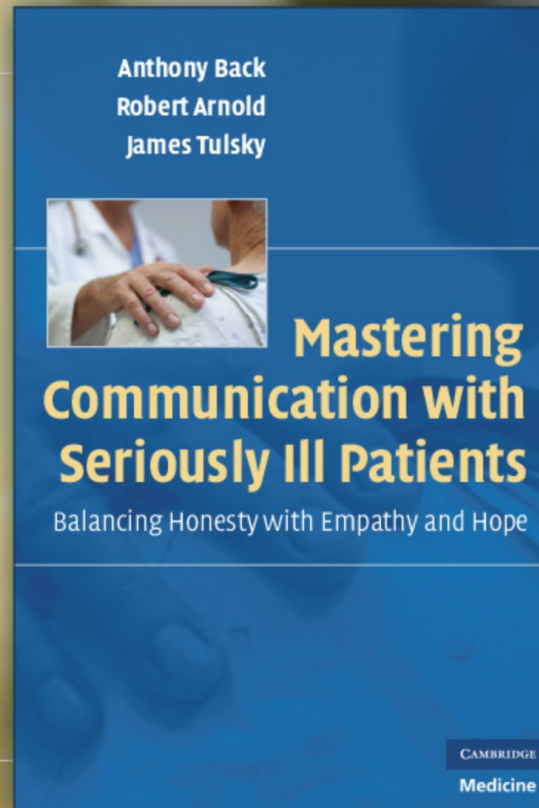


# Vital Talk

- ▶ <https://jamanetwork.com/journals/jamanetworkopen/article-abstract/2790602>
- ▶ <https://www.vitaltalk.org/guides/pause-talking-map/>



# Tips for learning communication skills



**'This useful step-by-step guide tailors the message of developing good communication to some of the most difficult conversations a physician will ever have.'**

Doody's Notes



# References

- ▶ Ariadne Labs. Serious Illness Conversation Guide. <https://www.ariadnelabs.org/wp-content/uploads/2023/05/Serious-Illness-Conversation-Guide.2023-05-18.pdf>. Accessed October 2023
- ▶ Back, A et al (2010) Mastering Communication with Seriously Ill Patients: Balancing Honesty with Empathy and Hope.
- ▶ [https://pcc4u.org.au/learning/modules/module4/m4\\_section2/m4\\_activity3/](https://pcc4u.org.au/learning/modules/module4/m4_section2/m4_activity3/) Accessed November 2023
- ▶ Lee, R.Y. et al (2022) Efficacy of a Communication-Priming Intervention on Documented Goals-of-Care Discussions in Hospitalized Patients with Serious Illness. A RCT. JAMA Open. 5(4)
- ▶ Paladino, J., Lakin, J.R., Sanders, J.J. (2019) Communication Strategies for Sharing Prognostic Information with Patients Beyond Survival Statistics. JAMA. 322(14): 1345-1346.
- ▶ Smith, A. (2016) Announcing ePrognosis: Communication – using video to teach prognosis communication. <https://genpal.org/announcing-eprognosis-communication/> Accessed October 2023
- ▶ UpToDate Discussing Goals of Care. Accessed November 2023
- ▶ UpToDate Palliative Care: Medically futile and potentially inappropriate therapies of questionable benefit. Accessed November 2023
- ▶ Vital Talk. <https://www.vitaltalk.org/guides/responding-to-emotion-respecting/> Accessed October 2023

Item 4: Preferences for CPR

|                                  |   | b. In state of dependence on others for ADLs [confined to bed]  |   |  |
|----------------------------------|---|---|---|--|
|                                  |   | DEFINITELY or PROBABLY WANTS CPR  | DEFINITELY or PROBABLY DOES <u>NOT</u> WANT CPR   | Skip   |
| a.<br>In current state of health | DEFINITELY or PROBABLY WANTS CPR                | "You indicated you would want to receive CPR if your heart were to stop beating. Is that correct? Are there treatments or situations you would not want?"   | "You indicated you would want to receive CPR if your heart were to stop beating in your current health, but not if you were to get much sicker and be dependent on others. Is that correct?"                          | "You indicated you would want to receive CPR if your heart were to stop beating. Is that correct? Are there treatments or situations you would not want?"  |
|                                  | DEFINITELY or PROBABLY DOES <u>NOT</u> WANT CPR | "You indicated you would not want to receive CPR if your heart were to stop beating in your current health, but you would want it if you were much sicker and dependent on others. Is that correct? Can you tell me more about that?" | "You indicated you would not want to receive CPR if your heart were to stop beating. Is that correct?" If yes, consider completing a DNAR order now and a POLST form prior to discharge or a Palliative Care consult. | "You indicated you would not want to receive CPR if your heart were to stop beating. Is that correct?" If yes, consider completing a DNAR order now and a POLST form prior to discharge or a Palliative Care consult.  |
|                                  | Skip  | "You indicated you would want to receive CPR if your heart were to stop beating if you were much sicker and dependent on others. Is that correct? Can you tell me more about your CPR preferences in your current health?"            | "You indicated you would not want to receive CPR if you were much sicker and dependent on others. Is that correct? Can you tell me more about your CPR preferences in your current health?"                           | <p><b>Choose either text based on question 4</b></p> <p><b>Text for comfort</b></p> <p>"Since you said you would be interested in care focused on comfort and quality of life, let's talk about whether CPR would help you achieve those goals."</p> <p>Text for longevity:</p> <p>"Since you said you would be interested in longevity, let's talk about whether CPR would help you achieve those goals."</p> |