

End-of-Life Care: A Framework for Advance Care Planning Conversations

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 - Research focus: ethics, professionalism, advance care planning, quality of care, artificial intelligence, generative AI

Disclosures

- Employee of Verily
- Former Google employee

Key Learning Objectives

- Clarify the benefits of advance care planning (ACP)
- Provide guidance on effective communication about goals of care and values
- Provide an actionable framework for ACP conversations

What is Advance Care Planning (ACP)?

- A *process* of making decisions about the care patients would want if they become unable to speak for themselves
 - An advance directive is one outcome of process
- Based on personal values, preferences, & discussions with their loved ones and doctors



Clinical Indications for Advance Care Planning

- **Routine indications**

- Reviewing health care maintenance with patient
- Hospitalized patient
- Discussing poor prognosis
- Discussing treatment with a low probability of success
- ***MD would not be surprised if the patient died in 6-12 months***
- Machine learning identifies patients at high risk of death

- **Urgent indications**

- Imminent death
- The patient talks about wanting to die
- Recently hospitalized for severe progressive illness
- Severe suffering and poor prognosis

Benefits of Advance Care Planning

- Promotes patient autonomy
 - Gives voice to patients' preferences even when they cannot speak
 - Higher rates of care concordant with patients' wishes
 - Gives patients peace of mind that their preferences will be respected
- Benefits for healthcare providers
 - Avoids future confusion and conflict
- Benefits for family
 - Decreases family angst about end-of-life decisions
 - Diminishes family guilt if treatment is limited

Clinical Outcomes & Advance Care Planning

- Decreased ICU admission
- Improved quality of life
- Increased hospice use
- Improves family bereavement outcomes
 - Reduced stress, anxiety, and depression among surviving relatives
- Does not hurt the therapeutic relationship

-Wright AA et al. [JAMA](#). 2008;300(14):1665-7.
-Temel JS et al. N Engl J Med 2010;363:733-42.
-Wright AA et al. JAMA. 2016;315(3):284-292.
-Fenton JJ, et al. JCO. 2018;36(3):225-230

Key Principles for ACP Conversations:

Expect Emotion and Respond with Empathy

Ask – Tell – Ask

ASK

- Would it be okay if I asked?
- Would it be okay if I shared.....?
- What are your concerns?

TELL

- Succinct and non-medical language

ASK

- Given that, what is important?
- What are you thinking now?
- Was that different than you expected?

Respond to Emotion (NURSE)

NAME EMOTION

- It sounds like you are very worried

UNDERSTAND

- I cannot imagine how difficult this is

RESPECT

- I'm so impressed with how hard you've worked through these treatments

SUPPORT

- We'll be here to help you throughout

EXPLORE EMOTION FURTHER

- Tell me what you mean when you say, "I have to fight no matter what."

A Structured Framework for ACP

1. Ask permission to discuss advance care planning and explain why you think it is important
2. Solicit the patient's understanding of his/her illness
3. Assess if the patient has a healthcare agent
 - Encourage communication between patient and agent
4. Elicit the patient's goals and values
5. Offer a prognosis
 - Share information on outcomes
6. Make a recommendation based on goals & values
7. Summarize and affirm commitment to care
8. Document the conversation and goals and values
9. Apply the directives when indication arises

Discussing Goals of Care: Priorities for Medical Care

PRIORITIES FOR MEDICAL CARE		
LIVING LONGER	MAINTAINING CURRENT HEALTH	COMFORT
<ul style="list-style-type: none">• Live as long as possible, even if I do not know who I am or who I am with• Be in the hospital and receive all care my doctors think will help me, even if it means relying on machines to keep me alive	<ul style="list-style-type: none">• Live longer, if quality of life and comfort can be achieved• Be in the hospital, if needed, for effective care• Stop treatment that does not work or makes me feel worse• Allow a natural death if my heart or breathing stops	<ul style="list-style-type: none">• Live the rest of my life focusing on my comfort and quality of life• Avoid the hospital and being on machines• Allow a natural death if my heart or breathing stops

Questions to Elicit Goals of Care

- What are your goals for treatment?
 - Living longer, maintain current health, comfort
- What do you want to accomplish with your healthcare?
- Are there certain health situations you would find unacceptable?
 - Unable to care for yourself, unable to interact, etc.

-Gehlbach et al *Chest* 2011; Bernacki et al 2012

Questions to Elicit Patient's Values

- Is there anything I should know about your beliefs or wishes that would help me be sure you get the care you want?
- When you think about the future, what do you hope for? Is there anything you want to avoid?
- When you think about the possibility that you may get sicker, what worries you the most?
- If your health gets worse, what are the most important things to you?

Prognosis: Survival to Hospital Discharge after CPR in the Elderly

- Medicare data on 433,985 patients who underwent in-hospital CPR
- Patients >65 years
- Overall survival 18.3%

-Ehlenbach WJ, et al. NEJM 2009; 361:22-31.

Prognosis: Survival in Cancer Patients After In-Hospital Cardiac Arrest (Total N=47,157)

Outcome	No Cancer	Cancer	RR (95% CI)	P
Survival to discharge				
Unadjusted, % (No.)	19.2 (7,796)	9.6 (635)	0.50 (0.45-0.54)	<.001
Adjusted %, (95%CI)	13.4 (12.1-14.8)	7.4 (6.6 to 8.4)	0.55 (0.51-0.60)	<.001

- Adults with and without a metastatic or hematologic malignancy
- 369 US hospitals between April 2006-June 2010

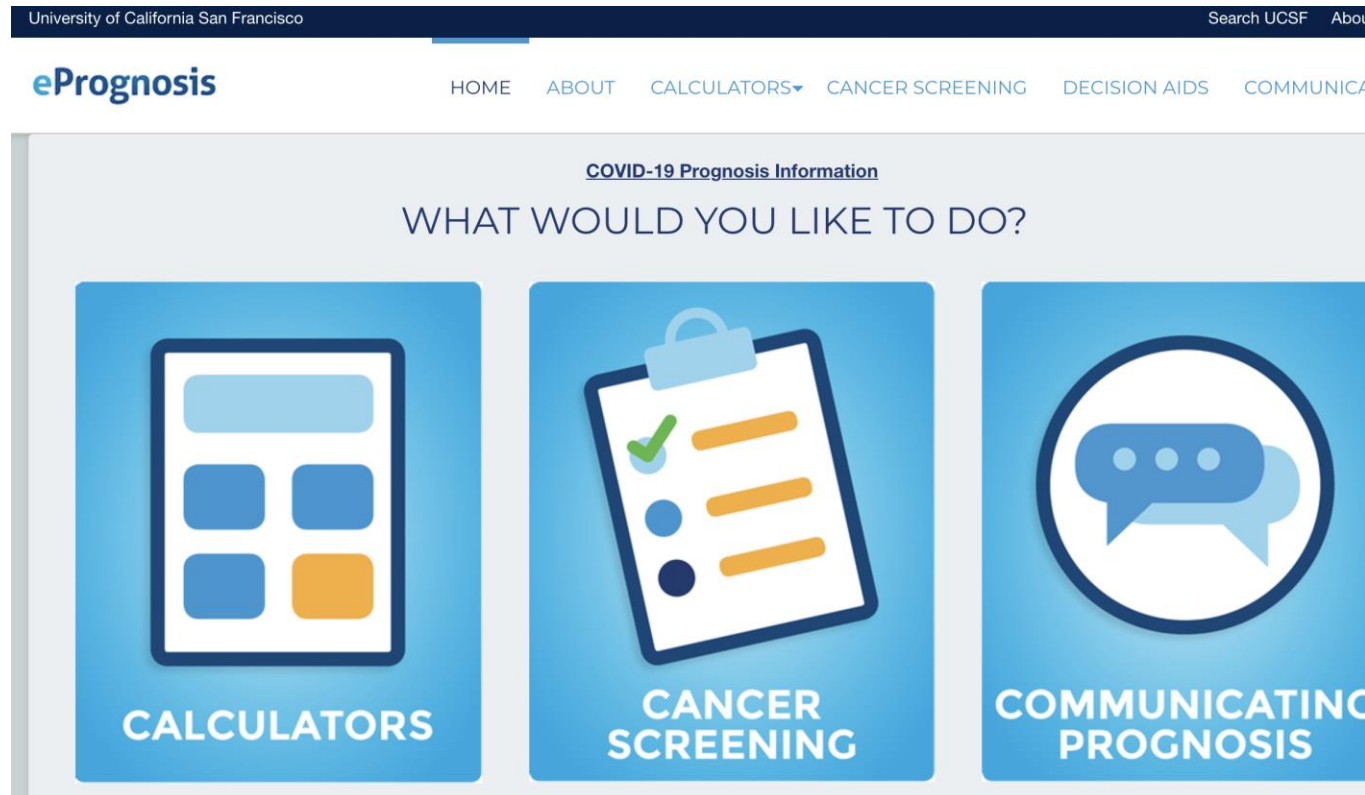
-Bruckel JT et al *JOP* 2017

Outcomes of In-hospital CPR United States 2000-2009

- All patients > 18 years of age
- Survival increased from 20% to 29%
- Discharge home decreased 36% to 24%
- Discharge to hospice or long-term care increased
 - Hospice 0.4% to 7%
 - Long term care 1% to 9%
- Neurologic compromise increased by 38%
- Feeding tube use increased by 28%
- Ventilator use increased by 58%

-Kazaure, Roman, and Sosa. *Resuscitation*. 2013

Prognosis Tools



- RESPECT
 - Risk Evaluation for Support: Predictions for Elder-Life in Community Tool
- Personalized mortality risk and survival
 - Predicts 6-month mortality
- Derivation cohort 435,009
- Validation cohort 139,388
- Algorithm c-statistic 0.753
- www.projectbiglife.ca/elder-life-calculator
- Hsu AT, et al., CMAJ 2021

Make a Recommendation

- Does not undermine patient autonomy
- Based on clinical situation, goals of care, & patient values
 - "I am hearing that what is most important to you is..."
- Offers guidance and relieves patients & families of some of the burden of decision-making



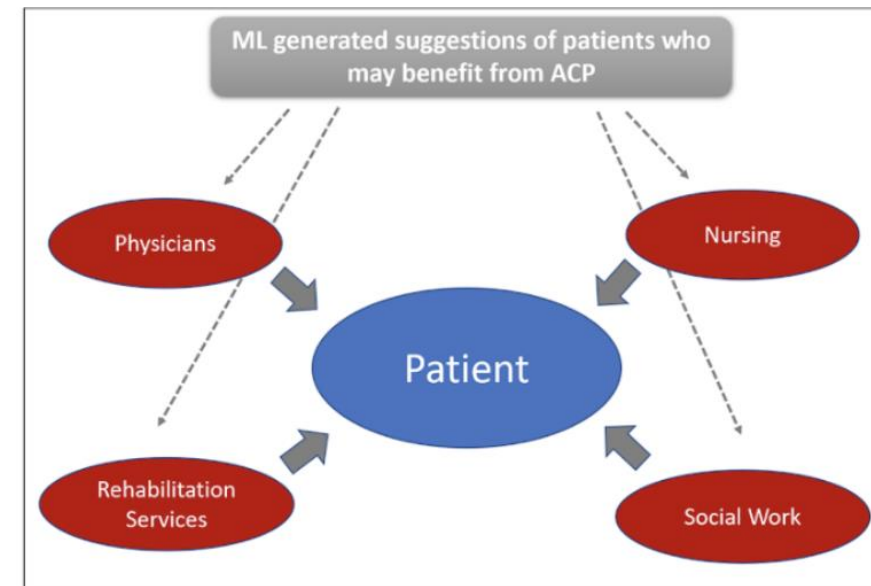
Questions to Guide Conversation

1. What is your understanding of your illness?
2. How much information do you want about what is likely to happen in the future with your illness?
3. Who would you want to make decisions for you if you cannot communicate?
4. What are your goals for medical care?
5. What are your biggest fears and worries?
6. If you become sicker, how much are you willing to go through to have the possibility of more time?
7. Are there certain health situations you would find unacceptable or make your life not worth living? E.g., feeding tube, unable to care for self, etc.
8. Have you discussed your preferences with your family?

Artificial Intelligence to Improve ACP

- Chat GPT to assist with conversation skills and empathy
- Machine learning (ML) model that identifies patients at high risk of dying (mortality >25%) within 3-12 months of hospitalization
 - i.e., patients who would benefit from ACP with clinician nudge
 - Empowered **all** team members to address ACP
 - Nursing, social work, rehabilitation, physicians
- Chatbots for patients to clarify values & goals
 - Increased knowledge and readiness for ACP
- Can AI improve the quality and compassion of care?
 - An empathic conversation is crucial

Li, R. C., Smith, M., Lu, J., et al. (2022). [Using AI to Empower Collaborative Team Workflows: Two Implementations for Advance Care Planning and Care Escalation](#). *NEJM Catalyst Innovations in Care Delivery*, 3(4), CAT-21.



Take Home Messages

- Advance care planning is more than just filling out a form
 - It is a process of understanding values and goals
 - It is fundamentally a communication process
- Begin with what the patient understands
- Listen more and talk less
- Share prognostic information & data on CPR outcomes
- Include family in conversations
- Make a recommendation & document it in the medical record

Question 1

You have a patient with advanced multiple sclerosis who has developed renal failure secondary to diabetes. The patient is DNR. She presents to the ED unconscious with a K of 8 meq/L.

Which is the most appropriate next step?

- a. No intervention because she is DNR
- b. Discuss a reversal of the DNR order and dialyze
- c. Proceed with dialysis
- d. Give Patiromer or Zirconium cyclosilicate (ZS-9) to bind potassium until you can find the health care agent to discuss dialysis

Question 1

You have a patient with severe advanced multiple sclerosis who has developed renal failure secondary to diabetes. The patient is DNR. She presents to the ED unconscious with a K of 8 meq/L.

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- a. No intervention because she is DNR
- b. Discuss a reversal of the DNR order and dialyze
- c. *Proceed with dialysis***
- d. Give Patiromer or Zirconium cyclosilicate (ZS-9) to bind potassium until you can find the health care agent to discuss dialysis

Question 1

Correct answer is proceed with dialysis.

- “Do-Not-Resuscitate” (DNR) is specifically defined as refraining from cardiopulmonary resuscitative efforts
- A DNR order should prompt a conversation about the patient’s goals of care and raise the question of whether she intended comfort care only
- DNR does not mean do not treat
- Hyperkalemia is life threatening. Patiromer or Zirconium cyclosilicate (ZS-9) is an inferior therapy for the long-term management of renal failure

Question 2

A 29-year-old man sustained a C1 and C2 spinal fracture during a boxing championship 3 months ago. He is paralyzed from the neck down and is ventilator dependent. He is fully alert and understands his condition. He requests removal from the ventilator and understands that he will die as a result.

The most appropriate next step is:

- a. Assess for depression and if no evidence remove the ventilator as requested
- b. Obtain a court order to continue the ventilator
- c. Seek family consensus on removing the ventilator
- d. Seek approval of the health care agent

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Question 2

Correct answer is assess for depression and remove the ventilator.

- Any adult patient with the mental capacity to understand his medical condition and the implications of withdrawal of treatment has the right to do what he wants to his own body
- There is no ethical distinction between withholding and withdrawing life sustaining treatment
- Patients are frequently depressed following a high c-spine injury
- The patient is alert, so no consent of the family or health care agent is necessary

Resources: Tools for Effective Conversations and Documentation

- PREPARE for Your Care: <https://www.prepareforyourcare.org>
- Making Your Wishes Known: www.makingyourwishesknown.com
- Digital Advance Directive: MyDirectives.com
- Respecting Choices: <https://respectingchoices.org/>
- Know Your Wishes: www.knowyourwishes.com
- Center to Advance Palliative Care: <https://www.capc.org/>
- The Conversation Project: theconversationproject.org

References

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6. VitalTalk, Addressing Goals of Care: “REMAP”
<https://www.vitaltalk.org/resources/quick-guides/>