ADVANCE CARE PLANNING
WHAT MATTERS MOST

Lindsey Dahl MD, FACP
Marsha Nygaard, RN

OBJECTIVES
- Understand the difference between ACP, POLST, CODE status
- Realize the importance of end of life conversations, the why?
- Learn tips on navigating these conversations
- Digging deeper into aligning care with what matters
- Resources for furthering your knowledge
no heartbeat and no breathing, which is obvious enough, or no brain function, which requires an electroencephalogram.

For some of us, death is reached when all other loved ones have perished, or when we can no longer think straight, or go to the bathroom by ourselves, or have some kind of sex; when we can no longer read a book, or eat pizza; when our body can no longer live without the assistance of a machine; when there is absolutely nothing left to try. Maybe the most useful answer I ever came across was the brilliant professor who instructed his daughter that death was what happened when he could no longer take in a Red Sox game.

So, again, what is death? Talking about and around it may be the best we can do, and doing so out loud is finally welcome. Facts alone won’t get you there. We’re always left with the next biggest question, one that is answerable and more useful anyway: What is death to you? When do you know you’re done? What are you living for in the meantime?

We do have fuller ways of knowing. Who doubts that imagination and intuition and love hold power and capacity beyond what language can describe? You are a person with consciousness and emotions and ties. You live on in those you’ve touched, in hearts and minds. You affect people. Just remember those who’ve died before you. There’s your immortality. There, in you, they live. Maybe this force wanes over time, but it is never nothing.

WHAT IS DEATH: DR. MILLER


Where do Americans die?

- Studies have shown that approximately 80% of Americans would prefer to die at home, if possible.
- Despite this, 60% of Americans die in acute care hospitals, 20% in nursing homes and only 20% at home.
- A minority of dying patients use hospice care and even those patients are often referred to hospice only in the last 3-4 weeks of life.
- However, not every patient will want to die at home. Dying at home is not favored in certain cultures (due to cultural taboos) and some patients may wish not to die at home, out of concern that they might be a burden on the family.

Still, it is clear that fewer patients are dying at home than want to do so.
Many people still die in hospitals
If most people do not want to die in hospitals, why are so many deaths in this country still occurring there? There are probably a number of reasons, including:

• **Death is often unpredictable.** Many inpatient deaths occur after long admissions that begin with what seems to be a treatable problem.

• **An overestimation of the ability of medical care to cure incurable illness or reverse setbacks.**

• **A lack of alternatives.** In many parts of the country, dying patients are stuck in the hospital because they need more care than they can get at home and have nowhere else to go.

• **The “culture” of medicine and availability of medical care.** Medical training teaches doctors to diagnose and treat illness, but until recently, trainees learned little about when treatment is futile or how to de-escalate treatment. In addition, studies suggest that more aggressive, inpatient medical care tends to be offered in places where there are more specialists and more hospitals. **Doctors may encourage patients to have inpatient treatment with little chance of changing the long-term outcome, perhaps due to an overly optimistic view of the prognosis.**

• **Medical error or “misadventure.”** Critically ill individuals have limited capacity to tolerate the downsides of medical treatment, such as side effects or medical errors.

• **A healthcare system focused on the short term.** For example, Medicare will cover inpatient care for a person who has had a stroke. But if that patient preferred to stay at home, care at home would not be covered even though it would be much less costly.

---

Majority of us will spend the last 4 years of our lives requiring help with at least 1 ADL (dressing, toileting, bathing, eating)
WHY? PATIENT EXAMPLES

- Transitions of care – fragmented
- Cant make decisions when cognitive problems present
- Increased responsibility on family and caregivers
- Wishes are not honored if not documented

HOW THE DOCUMENTS DIFFER
Reflect on Your Beliefs and Values

1. If you were having a really good day, what would happen on that day? Who would you talk to? What would you do?

2. Who helps you face or overcome challenges in your life?

3. What makes life special, fun, or satisfactorily play in how you live your life?

4. If you have significant health problems, who are they and what do you fear the outcome?

5. Considering future medical treatments, what would you want to happen to you?

6. How does your opinion influence your decisions about medical care?

7. Where would you want the goal of medical treatment to reach in your efforts to preserve your quality of life as long as possible?

8. What would a "natural death" be like for you?

### ADVANCE CARE PLAN

#### My Primary Health Care Agent is:

Name: __________________________ ________________  
Relationship: __________________________

Telephone numbers: (H) _______ (C) _______ (W) _______

Full address:

If my primary agent is not willing, able, or reasonably available to make health care decisions for me, I choose an alternate Health Care Agent.

#### My Alternate Health Care Agent is:

Name: __________________________ ________________  
Relationship: __________________________

Telephone numbers: (H) _______ (C) _______ (W) _______

Full address:

### Powers of My Health Care Agent:

My Health Care Agent automatically has all the following powers when I do not have the capacity to make decisions and/or I am unable to communicate for myself:

A. Agree to, refuse, or cancel decisions about my health care. This includes tests, medications, surgery, withdrawing or starting artificial nutrition and hydration (such as tube feedings or IV (intravenous) fluids), and other decisions related to treatments. If treatment has already begun, my agent can continue it or stop it based on my instructions.

B. Interpret any instruction in this document based on her understanding of my wishes, values, and beliefs.

C. Review and release my medical records and personal files as needed for my health care, as stated in Health Insurance Portability and Accountability Act of 1996 (HIPAA).

D. Arrange for my health care and treatment in a location or by the people I think is appropriate.

E. Decide which health care providers and organizations provide my health care.

F. Make decisions about organ and tissue donation according to my instructions in Part 2 of this document.

Comments or limits on the above: __________________________
### Advance Care Plan

**Additional Powers of My Health Care Agent:**
- My initials below indicate I also authorize my Health Care Agent to:
  - Make decisions about the care of my body after death.

If I live in North Dakota or Minnesota, my initials below indicate I also authorize my Health Care Agent to:
- Make decisions about disposing of my remains if I am not able to do so for myself.

**Part 2: My Health Care Instructions**

My choices and preferences for health care are indicated below. I ask my Health Care Agent to communicate these choices, and my health care team to honor them, if I cannot communicate or make my own choices. I have indicated a box below for the option I prefer for each situation.

**NOTE:** You do not need to write instructions about treatments to extend your life, but it is helpful to do so. If you do not have written instructions, your agent will make decisions based on your spoken wishes, or if your best interest if your wishes are unknown.

**A. Cardiopulmonary Resuscitation; A Decision for the Present**

This decision refers to a treatment choice I am making today based on my current health. Item 3 below (Treatments to Prolong My Life: A Decision for the Future) indicates treatment choices I want if my health changes in the future and I cannot communicate for myself.

CPR is a treatment used to attempt to restore heart rhythm and breathing when they have stopped. CPR may include chest compressions (forceful pushing on the chest to make the blood circulate), medications, electrical shocks, a breathing tube, and hospitalization.

**B. Treatment Choices: My Health Condition**

My treatment choices for my specific health condition(s) are written here. With any treatment choice, I understand I will continue to receive pain and comfort medications, as well as food and liquids by mouth if I am able to swallow.

**C. Treatments to Prolong My Life: A Decision for the Future**

If I cannot make decisions for myself, and my health care team and agent believe I will not recover my ability to know who I am, I want (Initial One):

- To stop or withhold all treatments that may extend my life. This includes but is not limited to artificial nutrition and hydration (for example, tube feedings and IV [intravenous] fluids), resuscitation (breathing machine, cardiopulmonary resuscitation [CPR], and antibiotics.

OR

- All treatments recommended by my health care team. This includes but is not limited to artificial nutrition and hydration (for example, tube feedings and IV [intravenous] fluids), resuscitation (breathing machine, cardiopulmonary resuscitation [CPR], and antibiotics. I want treatments to continue until my health care team and agent agree such treatments are harmful or no longer helpful.

Commens or directions to my health care team:

**D. Organ Donation (Initial One):**

- I want my heart, lungs, and/or organs, if able. My Health Care Agent may start and continue treatments or interventions needed to maintain my organs, lungs, and eyes until donation has been completed. My specific wishes (if any) are:

- I do not want to donate my eyes, tissues and/or organs.

OR

- My Health Care Agent can decide.

**E. Religious Affiliation:**

- I am of the (religion) faith, and am a member of (faith community or city). I would like my Health Care Agent to notify the faith community of my death and arrange for them to provide my funeral/memorial/burial.

- I would like my funeral to include, if possible, the following (people, music, rituals, etc.).

**Other wishes and instructions:**

- My initials here indicate additional documents are attached.
TIPS FOR CONVERSATIONS STARTERS

- What matters most to you?
- What makes life worth living?
- What brings you joy each day?
- What are you willing to live without, and still feel life is worth living?
- What are your biggest fears and concerns?
- What is your understanding of the current situation, and potential outcomes?
- What goals are most important to you?
- What tradeoffs are you willing to make, and which are you not?

PATIENT EXAMPLES

- Pt is 85y/o wm with h/o chf, copd, gi bleeds..
  - What matters: to live for 2 years when my grandson gets back from Japan
  - Still DNR/no invasive procedures but willing to push medications/treatment and not feel good now in effort to live

- Pt is 86y/o wm with h/o chf, copd, dm...
  - What matters: to have energy to play cards with my buddies 2 days a week
  - Weaned medications in effort to feel the best today even if may decrease length of life
RESOURCES

- [http://www.ihi.org/resources/Pages/Tools/Conversation-Ready-Toolkit-for-Clinicians.aspx](http://www.ihi.org/resources/Pages/Tools/Conversation-Ready-Toolkit-for-Clinicians.aspx)
- [https://www.youtube.com/watch?v=apbSsLlh28](https://www.youtube.com/watch?v=apbSsLlh28)
- [https://theconversationproject.org/](https://theconversationproject.org/)
- Netflix: Documentaries Extremis and End Game