Advanced Care Planning: Rethinking the questions

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Faculty/Presenter Disclosure

• Faculty: Leah Steinberg

• Relationships with commercial interests:
  - Grants/Research Support: NONE
  - Speaker’s Bureau: NONE
  - Consultant: NONE
Learning Objectives

• Appreciate new approaches to advanced care planning
• Go through a brief ACP exercise to help you learn about helping patients
• Learn about resources to help you advance your skills in discussing ACP
When I say:

Advanced Care Planning
Living wills?

Goals of care?

Power of attorney?

Advanced care plans?
History and context

PART 2. My Living Will
These are my wishes for my future medical care if there ever comes a time when I can't make these decisions for myself.

A. These are my wishes if I have a terminal condition
Life-sustaining treatments
____ I do not want life-sustaining treatment (including CPR) started. If life-sustaining treatments are started, I want them stopped.
____ I want the life-sustaining treatments that my doctors think are best for me.
____ Other wishes _________________________________________________________________________

Artificial nutrition and hydration
____ I do not want artificial nutrition and hydration started if they would be the main treatments keeping me alive. If artificial nutrition and hydration are started, I want them stopped.
____ I want artificial nutrition and hydration even if they are the main treatments keeping me alive.
____ Other wishes _________________________________________________________________________

Comfort care
____ I want to be kept as comfortable and free of pain as possible, even if such care prolongs my dying or shortens my life.
____ Other wishes _________________________________________________________________________

B. These are my wishes if I am ever in a persistent vegetative state
Life-sustaining treatments
____ I do not want life-sustaining treatments (including CPR) started. If life-sustaining treatments are started, I want them stopped.
____ I want the life-sustaining treatments that my doctors think are best for me.
____ Other wishes _________________________________________________________________________

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Does it work?
If this doesn’t work, then what?

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  • A. These are my wishes if I have a terminal condition
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New approaches

• More than a document
• Not simply a list
• Forms and lists are shown not to work
Advanced Care Planning
Reflection
Reflection

• Your Values

• What is important to you?
• What makes life worth living?
• What kind of living would you accept?
• What trade-offs would you make?
• What does suffering mean to you?
• What makes it good to be alive?
Conversation

• Talk with your family and health care professionals about your reflections
• Choose someone to speak on your behalf
Process over time
As your health changes

- Your values may change
- Not an epiphany -
  - Takes time, thought, conversation
So, let’s do an exercise
Question 1:

What do I value most in terms of my mental and physical health?

For example:

• being able to live independently?
• being able to recognize others?
• being able to communicate with others?
• Being able to live as long as possible?
Question 2

What would make prolonging life unacceptable for me?

For example,

• not being able to communicate with those around me?
• being kept alive with machines?
• not having control of my bodily functions?
Question 3:

When I think about death, is there anything I worry about happening to me?

For example:
• struggling to breathe,
• being in pain?
• being alone?
• losing my dignity?
Question 4:

If I were nearing death, what would I want to make the end more peaceful for me?

For example:

• Having my family and friends nearby?
• dying at home? Where is home?
• dying somewhere other than home?
• having spiritual rituals performed?
• not being a burden to my family?
Four Questions
Then, take the answer and...

1. Talk with your family
2. Choose someone to help decide if you can’t
3. Talk to them about your values, how you answered the questions
4. Write your thoughts down
Turns the way we help patients make decisions around

Instead of asking: “what treatments do you want?”
Ask her:
What she is afraid of in the end? 
What are her goals? 
What tradeoffs are acceptable?

Then I can recommend the treatments that can help
Example from last week

• Granddaughter asked my help
• Grandmother:
  - 80 yr old with CHF, worsening, many admissions
  - Wanted to know how to help her
  - Had asked her many times what she wanted re: medical care - Did she want resuscitation? Did she want IVs? Etc
Her grandmother said:

“Whatever I need”
“Whatever makes me feel better”
“Whatever the doctors think is best”

• She couldn’t engage in “medical talk”
What I suggested...

- Ask questions about what is important to her...
- How does she see the future?
- Where does she want to be cared for?
- How important is it to her to stay at home?
After our conversation...a letter came...

“I found your suggestions about what types of questions to ask especially helpful... they simplified the conversation with my grandmother...

“it helped everyone in our family get on the same page and have a conversation that it has been difficult to have.

“Actually, what it resulted in was a tear and laughter-filled, cathartic evening of conversations between my grandmother and family. I really didn’t think it was going to be possible for all of us to speak about in this way.”
My Wishes, Beliefs, and Values

1) Is there any condition or quality of life that you would consider ‘unacceptable’. For example, many people say “I would rather die than live in a nursing home where I am totally dependent on others.” Think about what health states or conditions would be unacceptable to you and write them in the space provided.

RESPONSE: If I lose my cognitive abilities (can’t think, can’t remember, can recognize family), I would rather be dead. If I had reduced physical function to the point where I was a burden on family and others (quadriplegic or dependent on others for feeding and self care), I would also rather be dead. In other conditions where the disability is not so drastic, I defer to my agent to decide if the condition is acceptable.

2) Do you have unfinished business that really want to get done before you die (assuming you are well enough)? Please describe.
RESPONSE: I would like to live long enough to see my children get married and established. After that, the answer to this question would be ‘no.’

3) If life were represented by a straight line where birth is represented on the far left of the line and death is represented on the far right of the line, place an ‘x’ on the line where you see yourself on this life line.

Birth -------------------------------------------x------------------------------------------- Death

4) It is very important for the health care team to understand how individual patients who are seriously ill would view the goals of their care. At one end of the spectrum, treatments offered are intended to reduce symptoms such as pain and shortness of breath. Symptom management treatment is not targeted to extend life and may actually shorten it. At the other end of the spectrum, treatments such as breathing machines and dialysis are offered with the primary goal of extending life. These treatments can cause additional pain and discomfort.

Please indicate on the line below where you feel would best represent your wishes regarding treatments that either extend life as much as possible or reduce symptoms (far left patient would value treatments that extend life as long as possible; far right patient would value treatments that relieve distressing symptoms, even if they hasten death).

Extending Life ← patient would value patient would value → Symptom Relief

EL_x_SSR
Decisionally-ready
Why does it matter?

Patients who have end-of-life conversations with their doctors and family members are much

• more likely to be satisfied with their care,
• will require fewer aggressive interventions at the end of life,
• place less of a strain on caregivers
• lower rate of depression in family members
What about Canadian patients?

Researchers interviewed 278 hospitalized patients over age 65 asked about ACP
Had they thought about ACP?
• 76% had thought about it
• 48% had completed ACP
Documented?

Research team then examined the charts of these patients...

30% of ACPs were documented

70% were not; many were contradictory
From: Failure to Engage Hospitalized Elderly Patients and Their Families in Advance Care Planning

Resources

• The Conversation Project

• Speak Up Campaign
Summary

• People are having these conversations - we are more afraid than our patients!
• A lot of the conversation needs to be de-medicalized to make people:
• Decisionally-ready
QUESTION #1: True or False?

- A = True
- B = False
- Advanced care planning is best thought of as a one-time discussion where patients tell us what medical treatments they want in the future.
QUESTION #2: True or False

• A = True
• B = False

• Only health care professionals should engage in these conversations with patients.
QUESTION #3: True of False?

- A = True
- B = False
- Evidence shows that patients and caregivers do not wish to talk about dying and advanced care planning.