Talking to your doctor about end-of-life care

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Objectives

• Think about what matters to YOU
• Decide who would best speak for you if you couldn’t
• Nudge you to think about this, discuss it and document it
• How to talk with your physician/PCP
• Document it in your medical record
Do you...

- Have a medical decision-maker for yourself?
- Does that person know they are your decision-maker?
- *Have you talked to your doctor about your end-of-life wishes?*
- Has COVID 19 impacted the way you think about advance care planning?

- *Other pressing questions you have?*
What does our future look like?

*Some facts for you to know!*

- Over half of us will not be able to participate in decisions near the end of our lives!
- In Colorado, if I don’t designate the person I want to make decisions for me when I can’t...
So WHO Should You Choose?

- Somebody who knows what matters to you
- Somebody who can speak (to medical team)
- A person who can speak for YOUR interests (rather than their own, perhaps)
- Close and available
Dear Reader: How Do You Want Your Life to End?

Every week the magazine publishes the results of a study conducted online in January by The New York Times’s research-and-analytics department, reflecting the opinions of 3,244 subscribers who chose to participate. This week’s question: *How would you like to die?*

- **44%** In my sleep
- **29%** Peacefully, in my own bed with loved ones
- **15%** Quickly, of a heart attack, stroke or aneurysm
- **6%** Of old age
- **1%** By my own hand
- **1%** Having sex and shot by a jealous spouse
- **1%** Happy, while doing what I love
- **3%** Don’t know, don’t want to die at all
HOW DO WE DIE?
Theoretical Trajectories of Dying

Atul Gawande: Being Mortal

- People are unprepared for the final stage.
- “Our system of technological medical care has utterly failed to meet [people’s top concerns], and the cost of this failure is measured in far more than dollars.”
- Often the medical system emphasizes safety and survival...
If somebody needed to make decisions for you, **how** would you want them to decide?

*Would they know what is important to you?*
What is an “acceptable life” varies greatly...

<table>
<thead>
<tr>
<th>Where is thy sting?</th>
<th>WORSE</th>
<th>SIMILAR</th>
<th>LITTLE BETTER</th>
<th>SOMEWHAT BETTER</th>
<th>MUCH BETTER</th>
</tr>
</thead>
<tbody>
<tr>
<td>Bowel and bladder incontinence</td>
<td>60</td>
<td>50</td>
<td>40</td>
<td>30</td>
<td>20</td>
</tr>
<tr>
<td>Rely on breathing machine to live</td>
<td>60</td>
<td>50</td>
<td>40</td>
<td>30</td>
<td>20</td>
</tr>
<tr>
<td>Cannot get out of bed</td>
<td>60</td>
<td>50</td>
<td>40</td>
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<td>20</td>
</tr>
<tr>
<td>Confused all the time</td>
<td>60</td>
<td>50</td>
<td>40</td>
<td>30</td>
<td>20</td>
</tr>
<tr>
<td>Need care all the time</td>
<td>60</td>
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<td>40</td>
<td>30</td>
<td>20</td>
</tr>
<tr>
<td>Rely on feeding tube to live</td>
<td>60</td>
<td>50</td>
<td>40</td>
<td>30</td>
<td>20</td>
</tr>
<tr>
<td>Live in a nursing home</td>
<td>60</td>
<td>50</td>
<td>40</td>
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<td>20</td>
</tr>
<tr>
<td>At home all day</td>
<td>60</td>
<td>50</td>
<td>40</td>
<td>30</td>
<td>20</td>
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<tr>
<td>Moderate pain all the time</td>
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<td>40</td>
<td>30</td>
<td>20</td>
</tr>
<tr>
<td>In a wheelchair</td>
<td>60</td>
<td>50</td>
<td>40</td>
<td>30</td>
<td>20</td>
</tr>
</tbody>
</table>

Source: *JAMA Internal Medicine*

*Survey conducted July 1st 2015 to March 7th 2016, Philadelphia, United States*
What kinds of Written Advance Directives are there?

- CPR directive
- Living Will
- Medical Durable Power of Attorney***
- Medical Orders for Scope of Treatment (MOST) forms
  - For late stage translation of your wishes into orders.
What I’ve seen in ethics consults...

- Written directives not completed
- “We don’t know what they would want!”
- Haven’t seen documents before
- Disagreeing family members
- Difficulty interpreting in light of acute situation
- Prior wishes may differ from current “best interests”
The forms can be useful... But why do you need more than forms?

- We aren’t good at **Predicting** what we might want in the abstract future.
- We often **Adapt** more than we think we will!
- It’s not clear how people should **Extrapolate** from the specific wishes we write down.
What are your concerns about treatment?

1. I’m worried that I won’t get enough care

2. 

3. 

4. I’m worried that I’ll get overly aggressive care

5. 
What do people say they want?

• To not be a burden.
• To maintain some control.
• Avoid suffering.
• To have time to strengthen relationships, share and reach closure.

• *Family peace of mind may be more important to some people as they are dying than the details of what treatments they get or don’t get.*
This concept of “leeway”

- Surrogates may need to make decisions that conflict with your prior preferences.
- They do better with permission to consider factors with your doctors other than your prior wishes during actual decision-making situations.
And...

• Our wishes change over time:
  – We adapt
  – Circumstances change

• Your family can’t know if you don’t talk together!!

• Your doctor can’t know if you don’t talk to them!!

“I eat right, I exercise, I don’t drink or smoke...but I’m still going to die someday? That changes everything!”
How do I talk to my Provider?

• Explain!! -- so they have a feel for:
  – Who you chose as your agent.
  – Understand the “why” of your written wishes.
  – What is important to you.

• Strategize jointly about how to “break the ice.”

• Ask for a special appointment for this important work if you wish.

• We HAVE THE TIME.
First Steps in Advance Care Planning

• Think about what matters to YOU
• Decide who would best speak for you if you couldn’t
• Share your values with your loved ones and write it down
• Review your wishes with your physician/PCP
• Document it in your medical records

• Updating:
  – Anniversaries
  – Change in health care status
  – ...

Boulder Community Health
IT’S ALWAYS TOO SOON TO START THE CONVERSATION… UNTIL IT’S TOO LATE.

- Ellen Goodman
BCH’s role

• We want to have these conversations
• Clear documentation of ACP wishes in EPIC
• Dedicated time to discuss this
Advance Care Planning

Current Code Status
DNR - Set by Andelyn Brecken at 6/9/2020 0956 (View report)

Code Status History
This patient has a current code status but no historical code status.

Advance Care Planning Documents

<table>
<thead>
<tr>
<th>Document Type</th>
<th>Status</th>
<th>Effective Date</th>
<th>Expiration Date</th>
<th>Received On</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Advance Directives and Living Will</td>
<td>Received</td>
<td></td>
<td>06/09/20</td>
<td>MDPOA</td>
<td></td>
</tr>
</tbody>
</table>

Advance Care Planning History

History of Patient Capacity Status Changes
The patient has full capacity. There is no history of patient status change.

History of Health Care Agent Status Changes
None

Code Status
Current Code Status
- Date Active: 6/9/2020 0956
- Code Status: DNR
- Order ID: 22666965
- Comments
- User: [redacted]
- Context: Outpatient

Code Status History
This patient has a current code status but no historical code status.
What do I need to do now?

• Our goal today:
  – Understand WHAT matters to you
  – Nudge you to think about this, discuss it and document it
  – Be sure you have your agent chosen

• Review with your physician/PCP

• Document in medical chart

• BCH.org  Search Advanced Care Planning
Resources:

• http://theconversationprojectinboulder.org
• Cute video on deciding on a proxy:
  https://www.youtube.com/watch?time_continue=10&v=iTxv-20ULwQ
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