

## Talking to your doctor about end-of-life care

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Boulder Community Health

- You/family member/loved one with serious illness?
- Family member with a good death or a challenging one?
- Caregiver?
- Decision-maker designated by friend/family member?
- Just curious?

## Who are you?

## Where we're headed...

- Who we are here today?
- What is in our future?
- How do we make choices near the end of our lives?
- How would we want others to choose for us?
- How do we share this with our health care providers?

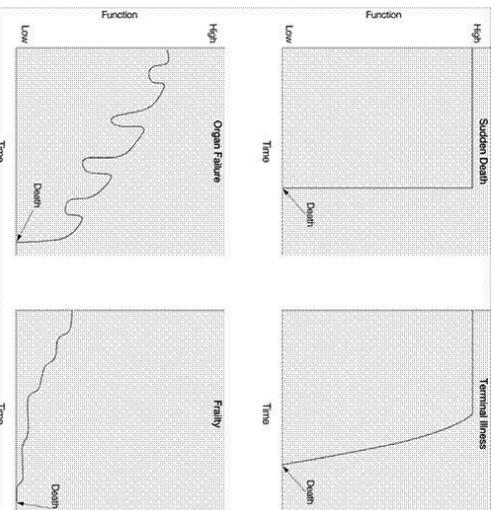
## Do you...

- 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?***
- ***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...

### HOW DO WE DIE? Theoretical Trajectories of Dying



Lunney, J. R. et al. JAMA 2003;289:2387-2392.

### 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?*



## 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...

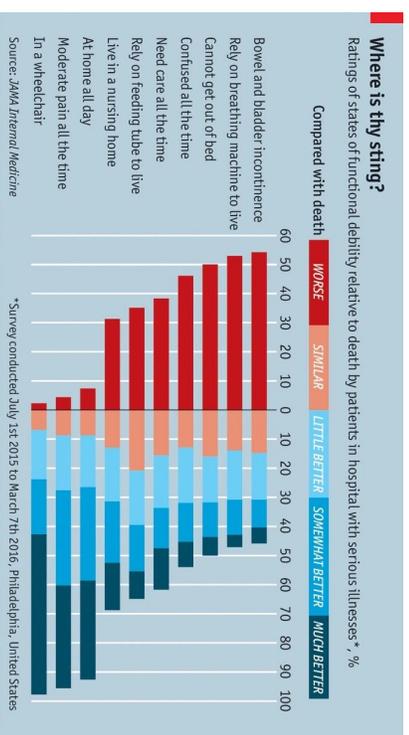


If somebody needed to make decisions for you, how would you want them to decide?

*Would they know what is important to you?*

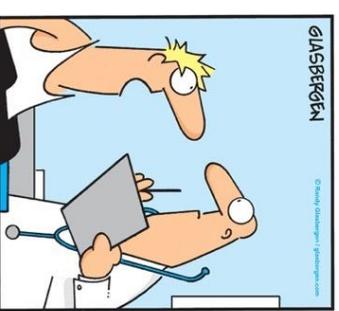


What is an “acceptable life” varies greatly...



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 her



"I eat right, I exercise, I don't drink or smoke...but I'm still going to die someday? That changes everything!"

What are your concerns about treatment?

- 1     2     3     4     5  
 I'm worried that I won't get enough care    I'm worried that I'll get overly aggressive care

## What do people say they want?

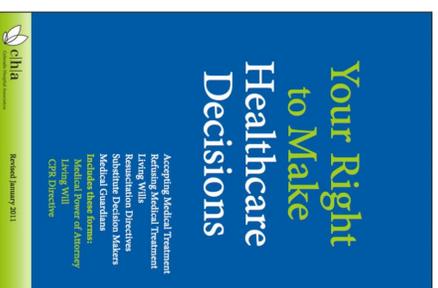
- To not be a burden.
- To maintain some control.
- Avoid suffering.
- To have time to strengthen relationships, share and reach closure.
- ***Family peace of mind may be more important to some people as they are dying than the details of what treatments they get or don't get.***

## WHAT MATTERS MOST TO YOU?

## 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.

Thinking upstream!

This concept of “leeway”

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

First steps in

Advance Care Planning

- Understanding what is important for yourself
- Writing it down
- SHARING it with extended family/friends
  - Not JUST agent
- SHARING it with your physician
- Making it accessible
- Updating:
  - Anniversaries
  - Change in health care status
  - ...

**IT'S ALWAYS TOO SOON TO START THE CONVERSATION... UNTIL IT'S TOO LATE.**  
-Ellen Goodman



## The BCH Initiative:

- Medicare has recognized the need for better end of life conversations and care.
- BCH is committed to partnering with our community to help address this opportunity.
- We have trained staff to help.

## How do I talk to my Provider?...

- Explain!! -- so s/he has 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.

## What do I need to do now?

- Choose a Proxy
- Discuss your values with your doctor
  - Bring your proxy (agent) if possible
- Use a coach if you want
- **What we have for you today:**
  - **Colorado Forms** – esp. **MDPOA!!**
  - **Starter Kit to help you think about values**
  - **How to choose a decision-maker**
  - **Coaching volunteer referral**

## Conclusions

- You need to think about your values, wishes
  - Understand that they may change
- Deciding on somebody who can speak for you is vital!
- You need to share what is important with your “community”
  - Talking is a gift to your family
- Your provider wants/needs to be part of your team
- Written ADs are just part of helping you get the care you want

## **Questions and Answers**

### **10 Questions for you to ask your Doctor in Regard to End-of-life Care**

1. What is this treatment for?
2. How will it help?
3. What are the physical risks or discomforts?
4. What are the emotional risks or discomforts?
5. Does the treatment match what I (or the person I am deciding for) would want?
6. Are we doing all we can to maintain (my) dignity?
7. Are we doing all we can to give me (or the person I am speaking for) the best quality of life?
8. Will this cause pain? (Or is he or she in pain)?
9. What can be done to ease my pain or other symptoms?
10. When is the best time to ask for a palliative care consult or hospice care?

*These questions are useful for yourself, or if you are making decisions for another with a serious illness.*

*(Originally suggested by Alzheimer Association.)*

### **8 Questions the Doctor may ask You in Regard to End-of-life Care**

1. Who would make decisions for you if you are fuzzy or unable to?
2. How much does your family know about your priorities and wishes?
3. What is your understanding now of where you are with your illness?
4. How much information about what is likely to be ahead with your illness would you like from me? (And how do decisions get made in your family?)
5. If your health situation worsens, what are your most important goals?
6. What are your biggest fears and worries about the future with your health?
7. What abilities are so critical to your life that you can't imagine living without them?
8. If you become sicker, how much are you willing to go through for the possibility of gaining more time?

*From Bernacki, Block and Ariadne Labs in Boston.*