

Talking to your doctor about end-of-life care

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Boulder Community Health

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!

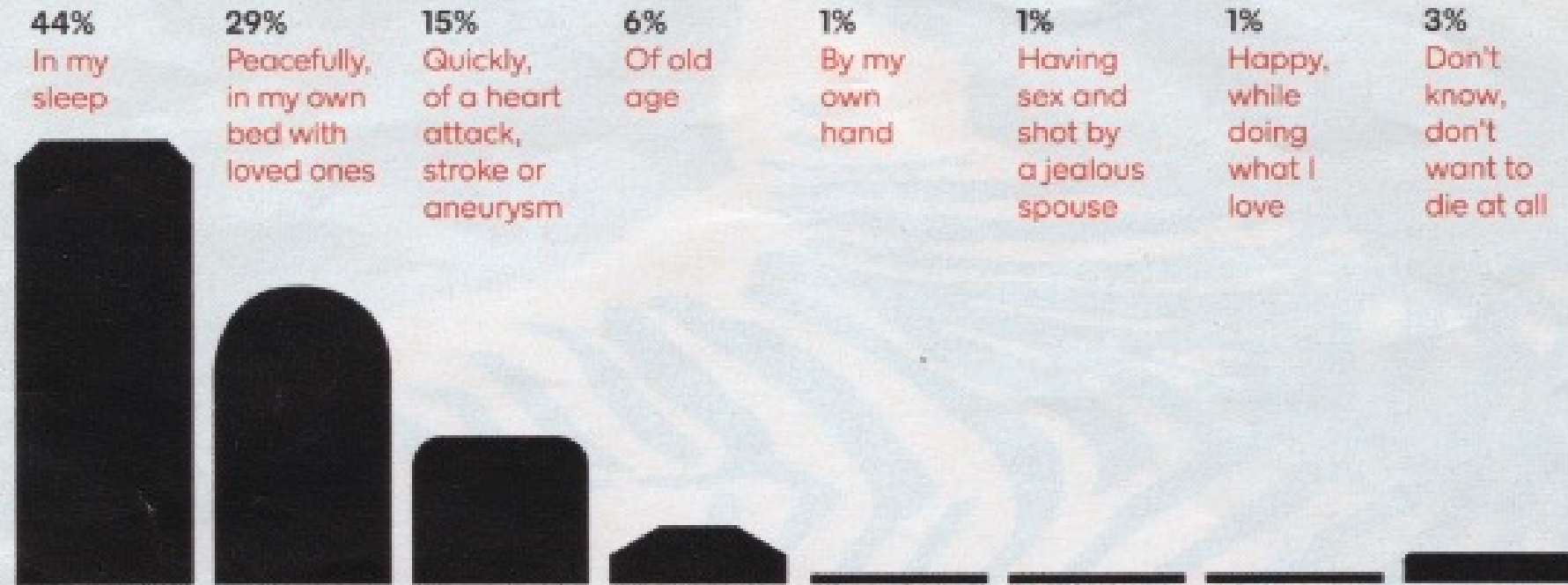
- Over half of us will not be able to participate in decisions near the end of our lives!
- In Colorado, if I don't designate the person I want to make decisions for me when I can't...

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

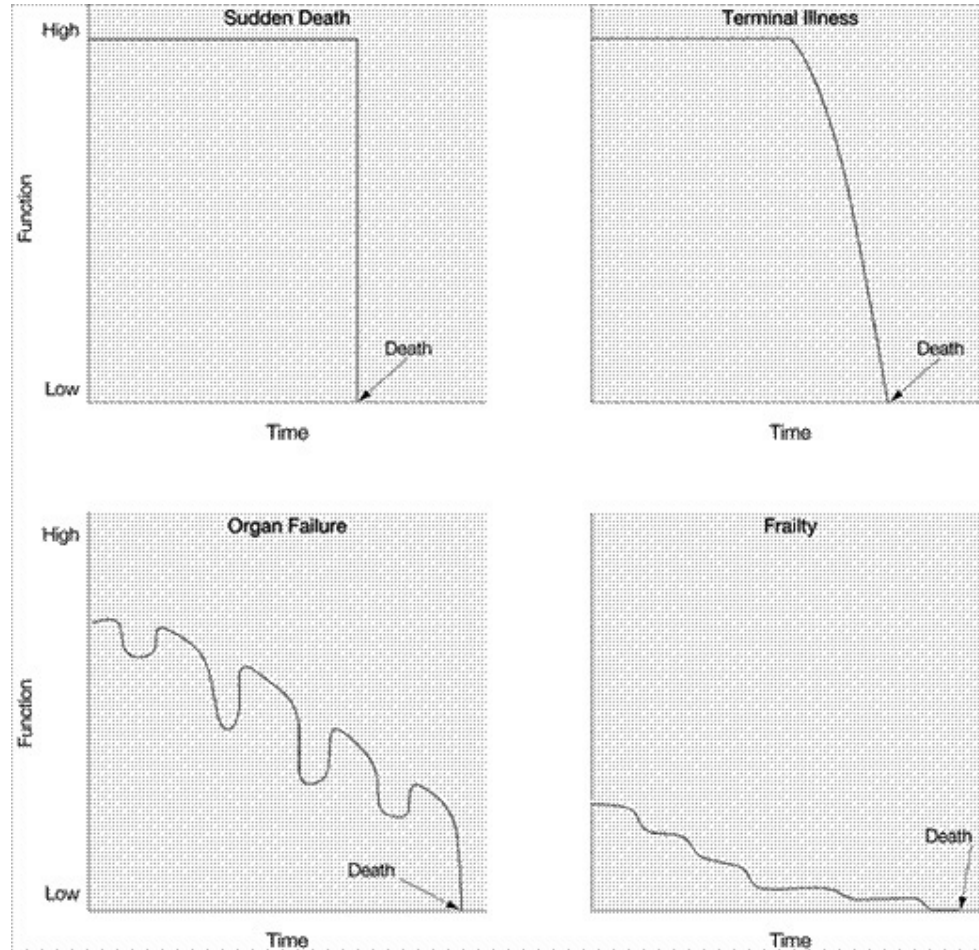
Dear Reader: How Do You Want Your Life to End?

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?*



HOW DO WE DIE?

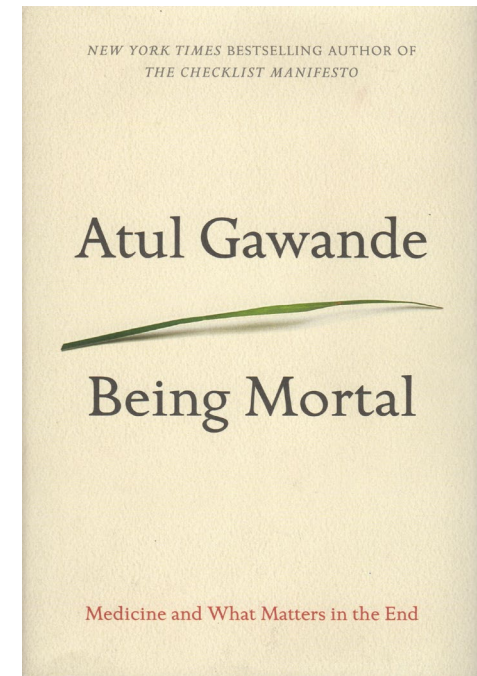
Theoretical Trajectories of Dying

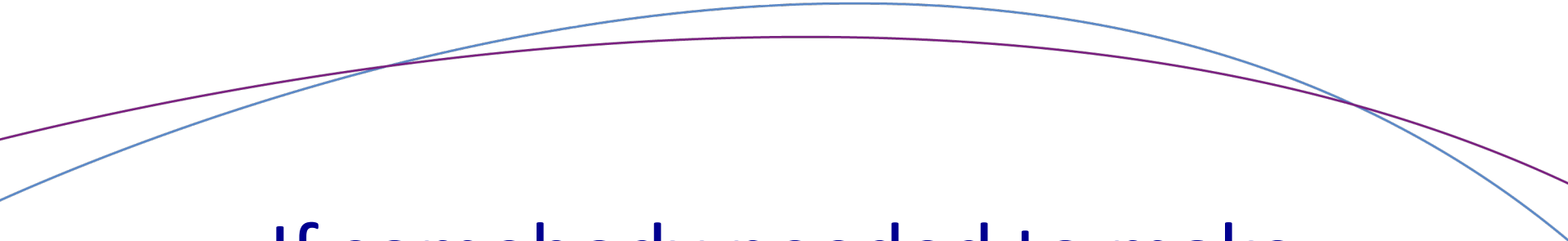


Lunney, J. R. et al. JAMA 2003;289:2387-2392.

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?*

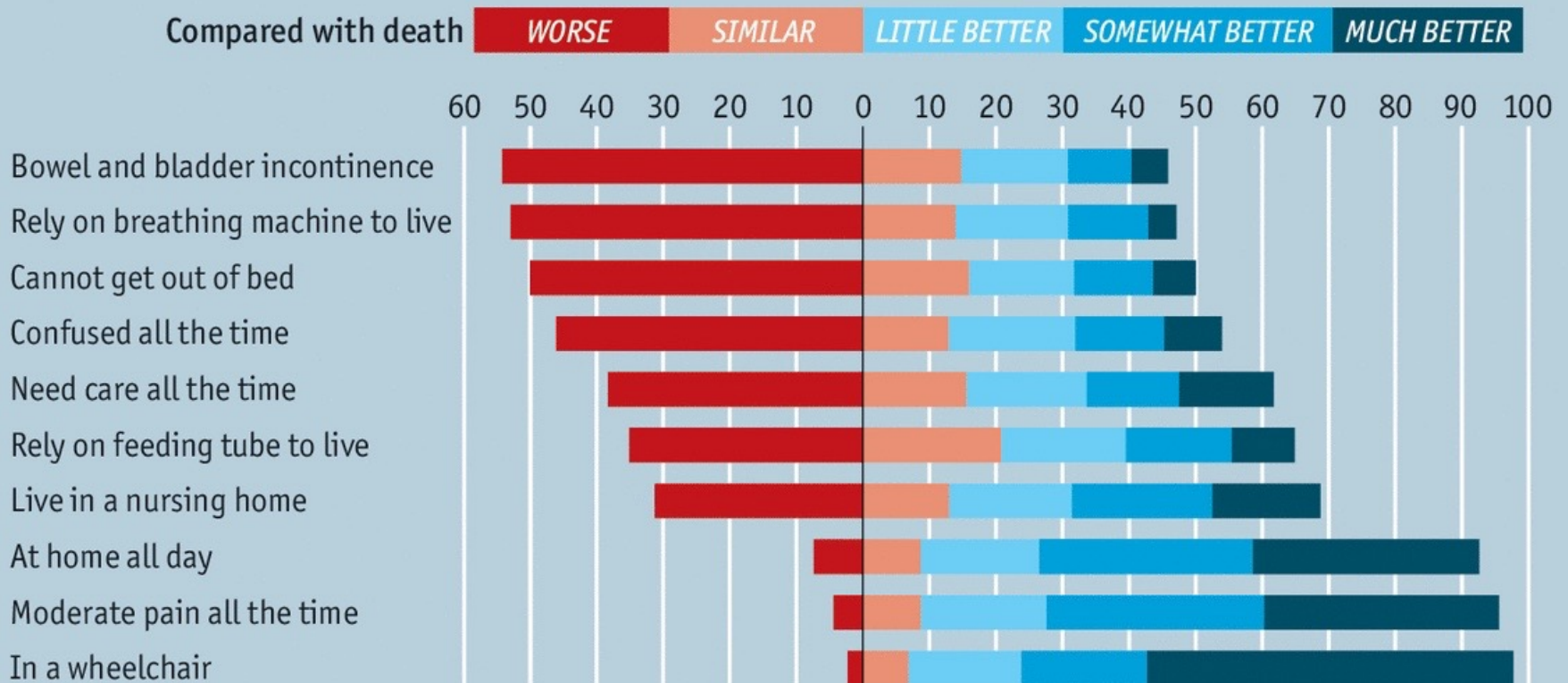


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What is an “acceptable life” varies greatly...

Where is thy sting?

Ratings of states of functional debility relative to death by patients in hospital with serious illnesses*, %

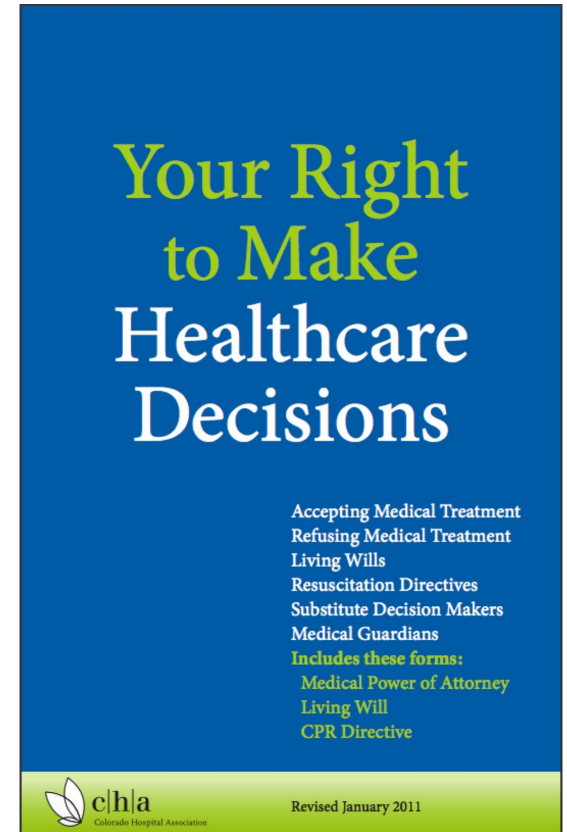


Source: *JAMA Internal Medicine*

*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.*



**Your Right
to Make
Healthcare
Decisions**

Accepting Medical Treatment
Refusing Medical Treatment
Living Wills
Resuscitation Directives
Substitute Decision Makers
Medical Guardians
Includes these forms:
Medical Power of Attorney
Living Will
CPR Directive

 **c|h|a**
Colorado Hospital Association

Revised January 2011

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

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.***

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!"



COVID-19

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*
 - ...

*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

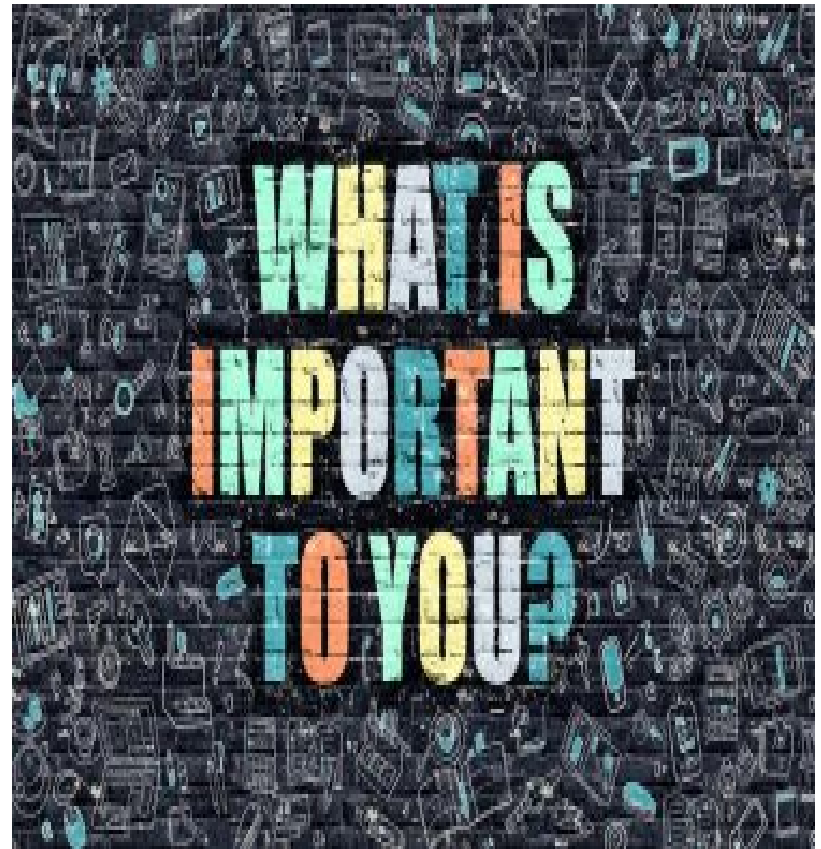




Chart Review

History Allergies Problem List Immunizations Demographics Select Encounter Place A

Chart Review

Encounters Notes Labs Imaging Cardiology Procedures Meds LDAs Media Letters E

Refresh (10:06 AM) Route Review Selected Synopsis Lifetime Preview Encounter More

Filters Hide Add'l Visits Me Family Medicine Boulder Creek Family... Admissions

Current Code Status

Assume Full

Advance Care Planning Documents

Document Type	Status	Effective Date	Expiration Date	Received On	Description
Advance Directives and Living Will	Not Received				

Code: Assume Full (no ACP docs)

Advance Care Planning

MANAGE HEALTH CARE AGENTS AND CAPACITY

Health Care Agents

Health Care Agents

Patient Capacity

ACP History

Active? Name Relationship Health Care Agent Relationship

Activation History ↑ ↓

Show: All emergency contacts

Code: DNR (has ACP docs)

Current Code Status

DNR - Set by *Andilyn Brockert* at 6/9/2020 0956 ([View report](#))

Code Status History

This patient has a current code status but no historical code status.

↑ Previous

↓ Next

Advance Care Planning Documents

Document Type	Status	Effective Date	Expiration Date	Received On	Description
Advance Directives and Living Will	Received			06/09/20	MDPOA

History ↻

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	Code Status	Order ID	Comments	User	Context
6/9/2020 0956	DNR	22666965		<i>Andilyn Brockert</i>	Outpatient

Code Status History

This patient has a current code status but no historical code status.

Advance Directives

Advance Directive Flowsheet Documentation

Most Recent Value

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:

- <https://www.bch.org/documents/medical-durable-power-of-attorney.v8.final.112116.pdf>
- <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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