Planning Ahead for Possible Serious Illness and End of Life

Elizabeth Cruse, MD
Jean Abbott, MD, MH

PLANNING FOR THE FUTURE…

Boulder Community Health 100 YEARS 1922 - 2022

What You, Your Family and Your Health Care Provider Need to Know

Who are we?

Elizabeth Cruse, MD

- Internist & Medical Director, Boulder Community Health
- BCH's and Boulder Valley Care Network's medical director for ambulatory quality improvement and population health

Jean Abbott, MD, MH

- Faculty, Center for Bioethics and Humanities
- CU Anschutz Medical Campus
- University of Colorado Hospital Ethics Committee and the Ethics Consult Service

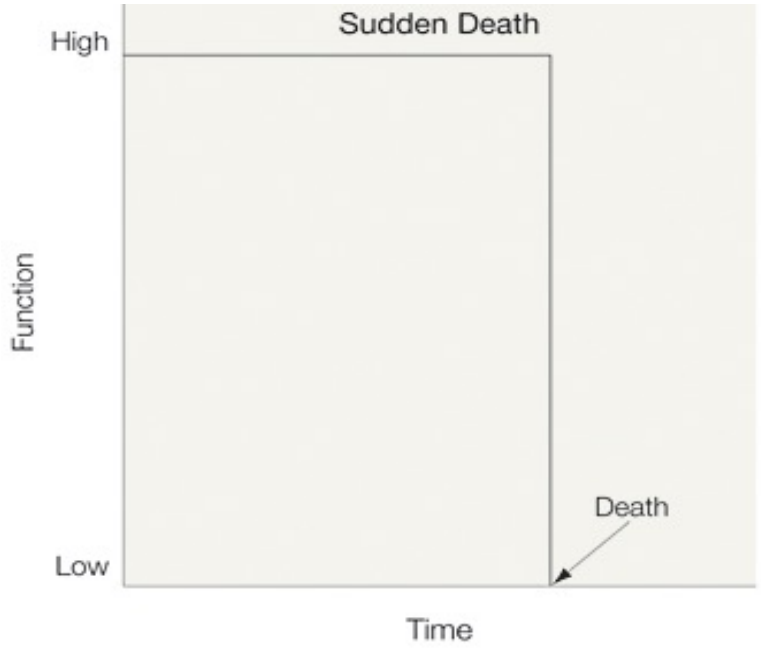
Goals for This Discussion:

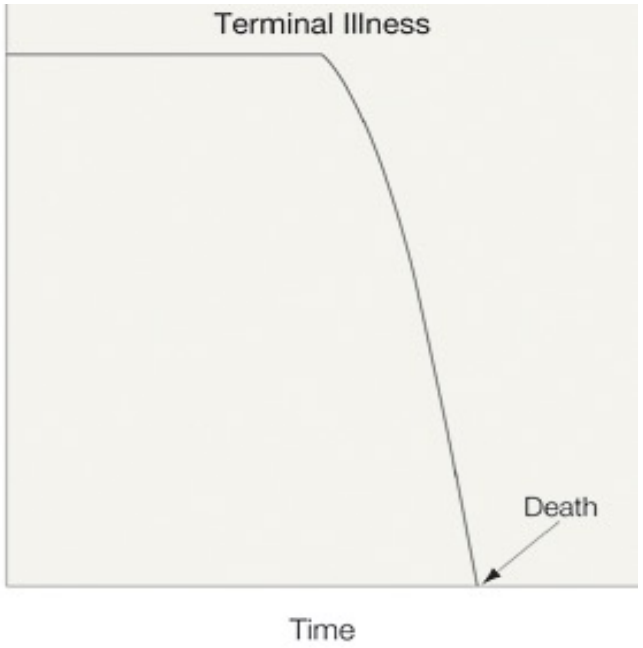
Boulder Community Health 100 YEARS 1922 - 2022

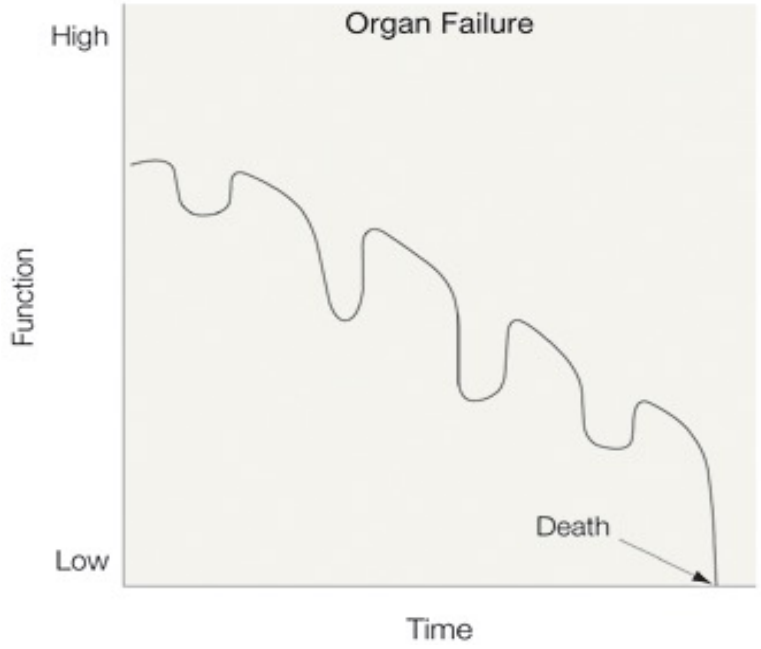
- Recognize how important it is to figure out who you would want to speak for you in a medical situation if you couldn't.
- Understand some of the important documents to help your loved ones.
- Consider why documents are only as good as your conversations with your family and HC provider.
- Know where to get more information and help.


World Mortality Rate
100%
1800
100%
1900
100%
1950
100%
2000
100%
2015
Fb/A Science Enthusiast

How Do We Die?



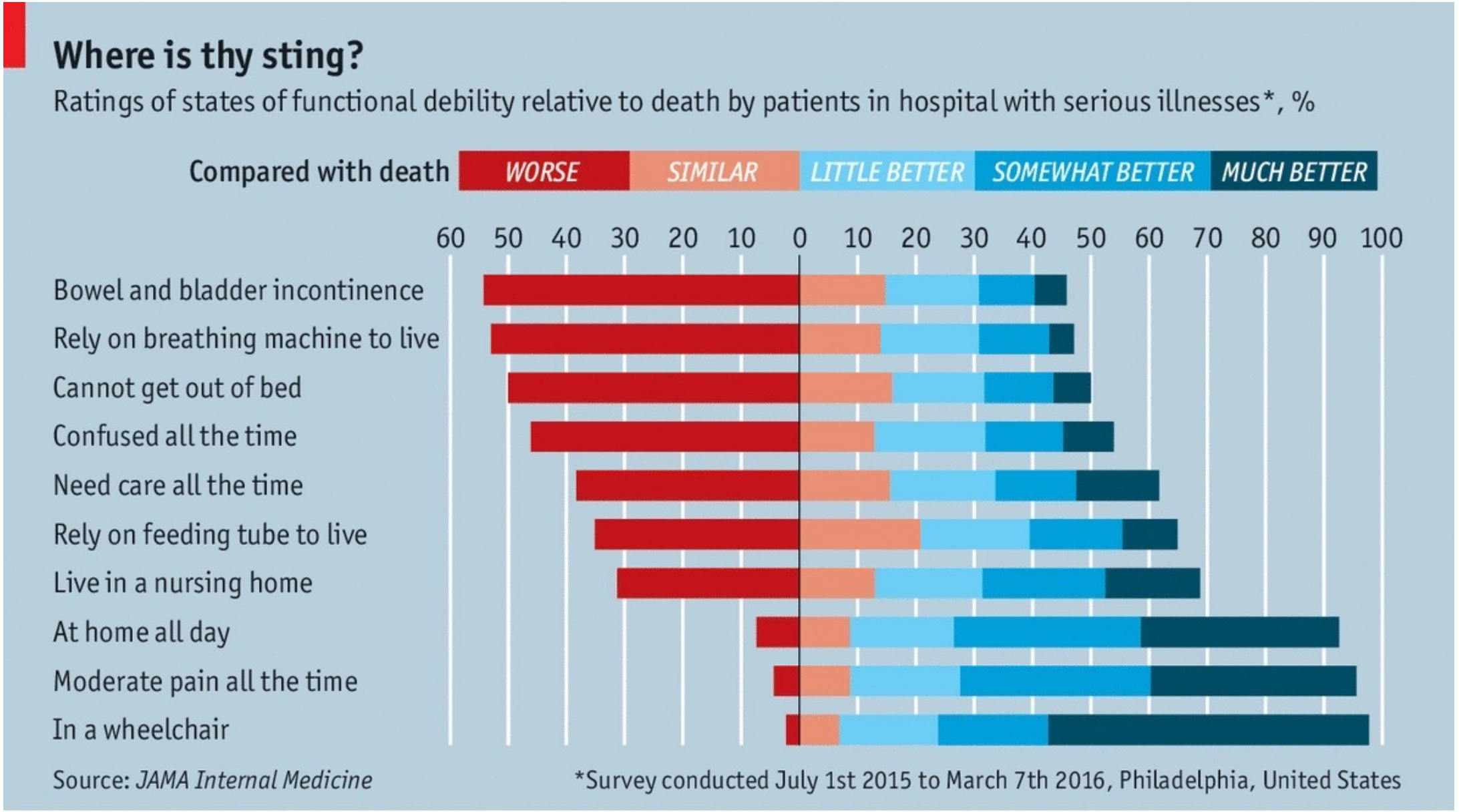




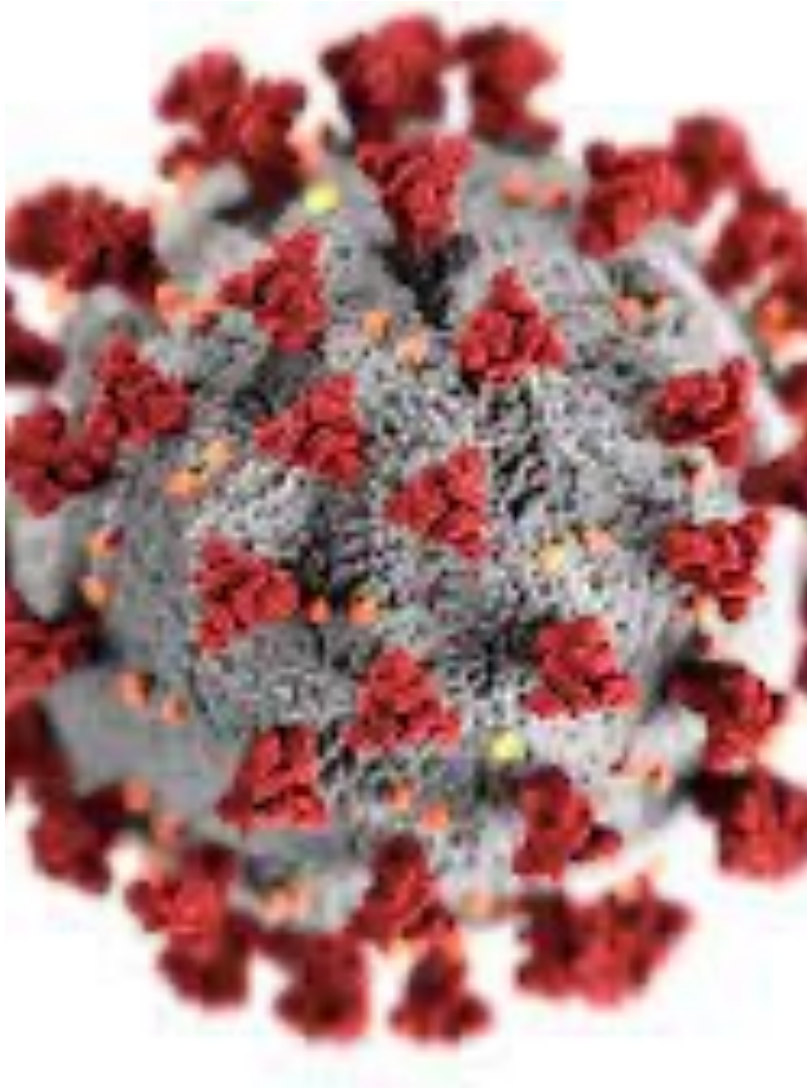
JAMA

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

What is an “acceptable life” varies greatly….



Economist.com



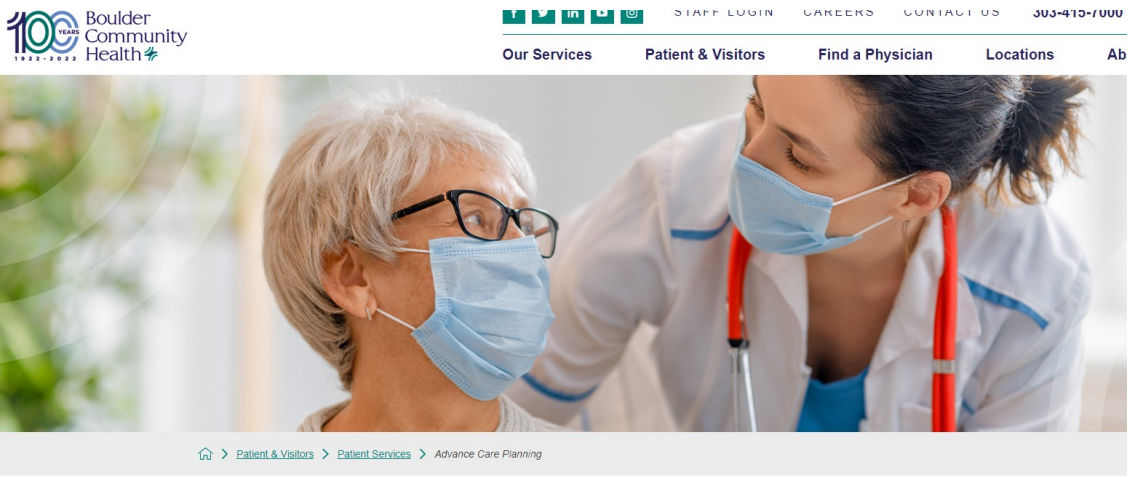
What Difference Does COVID-19 Make?

Boulder Community Health 100 YEARS 1922 - 2022

- Makes these discussions more real
- A different kind of death than you may have foreseen for yourself
- COVID-19 may be more likely to require somebody to speak for you.
- We practice talking about death, our talk about death

PLANNING FOR THE FUTURE

- Who should be “my voice” if I can’t speak for myself?
- What matters most to me?
- What needs to be documented?
- Who do I need to talk to?
- How will my wishes change over time?
- Where can I get more information and help?



Advance Care Planning

- How to Choose a Healthcare Agent
- How to Complete A Medical Durable Power of Attorney
- How to Start Advance Care Planning Conversations
- How to Talk to Your Medical Provider
- What to Know about the MOST Form
- The Living Will
- COVID-19 Advance Care Planning
- Advance Care Planning FAQ

Who Should Be My Spokesperson?

https://www.youtube.com/watch?time_continue=10&v=iTxv-20ULwQ

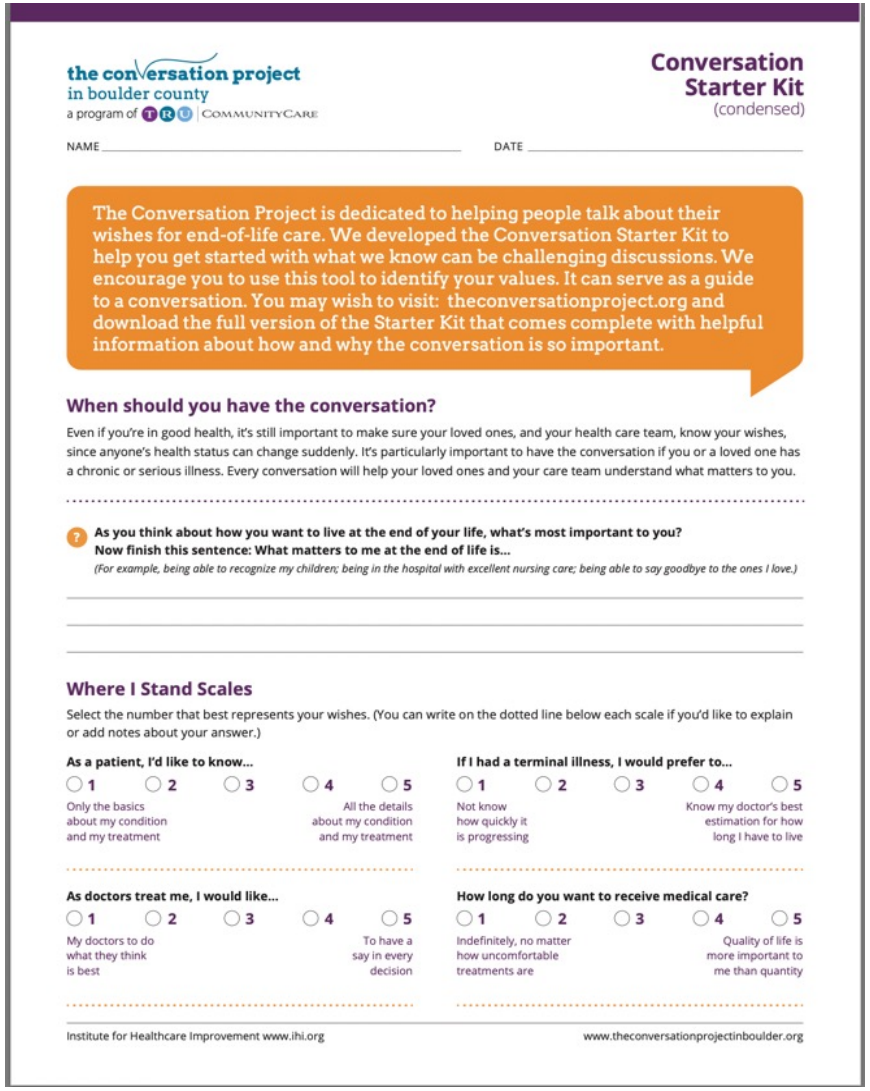
ABA Tool: How to Select your Health Care Agent or Proxy

Compare up to 3 people with this tool. The persons best suited to be your Health Care Agents or Proxies rate well on these qualifications...

	Name #1:	*Name #2:*	*Name #3:*	
				1. Meets the legal criteria in your state for acting as agent or proxy or representative? (This is a must! See next page.)
				2. Would be willing to speak on your behalf.
				3. Would be able to act on your wishes and separate his/her own feelings from yours.
				4. Lives close by or could travel to be at your side if needed.
				5. Knows you well and understands what's important to you.
				6. Is someone you trust with your life.
				7. Will talk with you now about sensitive issues and will listen to your wishes.
				8. Will likely be available long into the future.
				9. Would be able to handle conflicting opinions between family members, friends, and medical personnel.
				10. Can be a strong advocate in the face of an unresponsive doctor or institution.

What Matters Most to Me?

Boulder Community Health — 100 YEARS 1922 - 2022



the conversation project in boulder county
a program of TRU | CommunityCare

Conversation Starter Kit
(condensed)

NAME _____ DATE _____

The Conversation Project is dedicated to helping people talk about their wishes for end-of-life care. We developed the Conversation Starter Kit to help you get started with what we know can be challenging discussions. We encourage you to use this tool to identify your values. It can serve as a guide to a conversation. You may wish to visit: theconversationproject.org and download the full version of the Starter Kit that comes complete with helpful information about how and why the conversation is so important.

When should you have the conversation?

Even if you're in good health, it's still important to make sure your loved ones, and your health care team, know your wishes, since anyone's health status can change suddenly. It's particularly important to have the conversation if you or a loved one has a chronic or serious illness. Every conversation will help your loved ones and your care team understand what matters to you.

As you think about how you want to live at the end of your life, what's most important to you?
Now finish this sentence: What matters to me at the end of life is...
(For example, being able to recognize my children; being in the hospital with excellent nursing care; being able to say goodbye to the ones I love.)

Where I Stand Scales

Select the number that best represents your wishes. (You can write on the dotted line below each scale if you'd like to explain or add notes about your answer.)

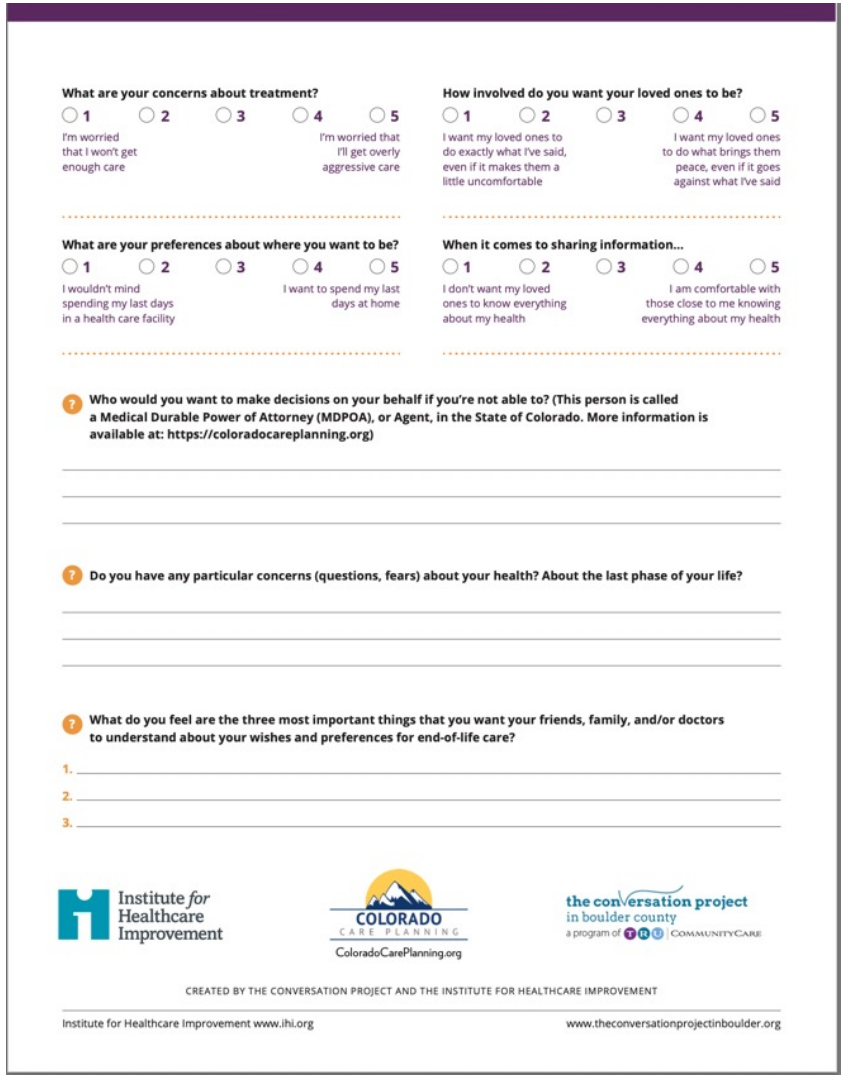
As a patient, I'd like to know...
○ 1 ○ 2 ○ 3 ○ 4 ○ 5
Only the basics about my condition and my treatment — All the details about my condition and my treatment

If I had a terminal illness, I would prefer to...
○ 1 ○ 2 ○ 3 ○ 4 ○ 5
Not know how quickly it is progressing — Know my doctor's best estimation for how long I have to live

As doctors treat me, I would like...
○ 1 ○ 2 ○ 3 ○ 4 ○ 5
My doctors to do what they think is best — To have a say in every decision

How long do you want to receive medical care?
○ 1 ○ 2 ○ 3 ○ 4 ○ 5
Indefinitely, no matter how uncomfortable treatments are — Quality of life is more important to me than quantity

Institute for Healthcare Improvement www.ihi.org — www.theconversationprojectinboulder.org



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

How involved do you want your loved ones to be?
○ 1 ○ 2 ○ 3 ○ 4 ○ 5
I want my loved ones to do exactly what I've said, even if it makes them a little uncomfortable — I want my loved ones to do what brings them peace, even if it goes against what I've said

What are your preferences about where you want to be?
○ 1 ○ 2 ○ 3 ○ 4 ○ 5
I wouldn't mind spending my last days in a health care facility — I want to spend my last days at home

When it comes to sharing information...
○ 1 ○ 2 ○ 3 ○ 4 ○ 5
I don't want my loved ones to know everything about my health — I am comfortable with those close to me knowing everything about my health

Who would you want to make decisions on your behalf if you're not able to? (This person is called a Medical Durable Power of Attorney (MDPOA), or Agent, in the State of Colorado. More information is available at: https://coloradocareplanning.org)

Do you have any particular concerns (questions, fears) about your health? About the last phase of your life?

What do you feel are the three most important things that you want your friends, family, and/or doctors to understand about your wishes and preferences for end-of-life care?

1. _____
2. _____
3. _____

Institute for Healthcare Improvement

COLORADO CARE PLANNING
ColoradoCarePlanning.org

the conversation project in boulder county
a program of TRU | CommunityCare

CREATED BY THE CONVERSATION PROJECT AND THE INSTITUTE FOR HEALTHCARE IMPROVEMENT

Institute for Healthcare Improvement www.ihi.org — www.theconversationprojectinboulder.org

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

And….

- Our wishes change over time:
  - We adapt
  - Circumstances change
- Often our values are more important than what "treatments" we get
- *If you may speak for a loved one, you can't know what to decide if you don't talk together!!*

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

What Kinds of Written Advance Directives are There?

- Medical Durable Power of Attorney
- Medical Orders for Scope of Treatment (MOST) forms
- *For late-stage translation of your wishes into orders.*
- Living Will
- CPR directive

MEDICAL DURABLE POWER OF ATTORNEY FOR HEALTHCARE DECISIONS (MDPOA)

NAME _____ DOB _____

ADDRESS _____ PHONE# _____

1. Appointment of Agent and Alternates

Declarant, hereby appoint:

_____

Name of Agent- Relationship

_____

Agent's Best Contact Telephone Number

_____

Agent's home address

State here any desires concerning life-sustaining procedures, treatment, general care and services, including any special provisions or limitations:

_____

_____

_____

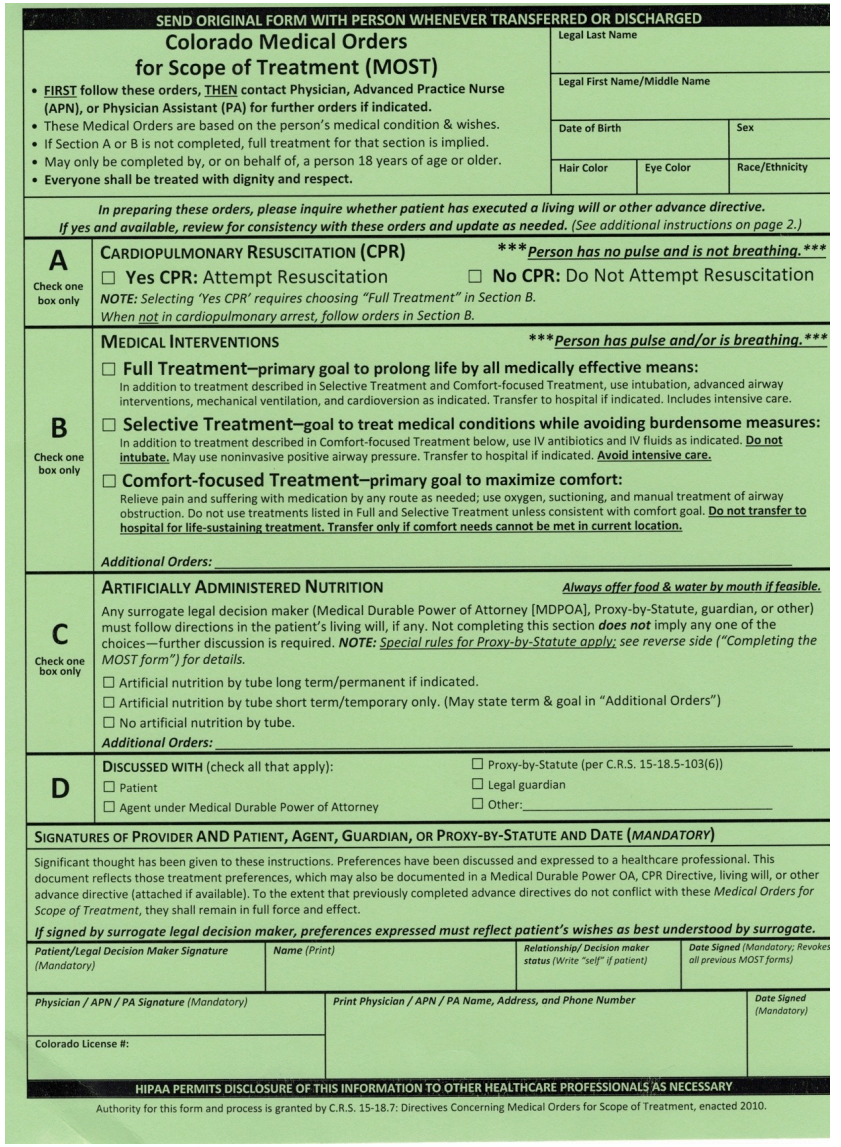
_____

_____

My signature below indicates that I understand the purpose and effect of this document. I do hereby revoke and cancel any and all prior Medical Powers of Attorney that I may have

Colorado's MOST Form

- Translates values into orders
- Near the end of life
- By patient or MDPOA and doctor
- A: CPR attempts?
- B: Ranges of treatment intensity
  - Full treatment
  - Selective treatment
  - Comfort-focused treatment



SEND ORIGINAL FORM WITH PERSON WHENEVER TRANSFERRED OR DISCHARGED

Colorado Medical Orders for Scope of Treatment (MOST)

- **FIRST follow these orders, THEN contact Physician, Advanced Practice Nurse (APN), or Physician Assistant (PA) for further orders if indicated.**
- These Medical Orders are based on the person's medical condition & wishes.
- If Section A or B is not completed, full treatment for that section is implied.
- May only be completed by, or on behalf of, a person 18 years of age or older.
- **Everyone shall be treated with dignity and respect.**

Legal Last Name | Legal First Name/Middle Name | Date of Birth | Sex | Hair Color | Eye Color | Race/Ethnicity

In preparing these orders, please inquire whether patient has executed a living will or other advance directive. If yes and available, review for consistency with these orders and update as needed. *(See additional instructions on page 2.)*

A Check one box only

CARDIOPULMONARY RESUSCITATION (CPR) ******Person has no pulse and is not breathing.******

☐ **Yes CPR:** Attempt Resuscitation ☐ **No CPR:** Do Not Attempt Resuscitation

NOTE: *Selecting 'Yes CPR' requires choosing "Full Treatment" in Section B.*
When not in cardiopulmonary arrest, follow orders in Section B.

B Check one box only

MEDICAL INTERVENTIONS ******Person has pulse and/or is breathing.******

☐ **Full Treatment–primary goal to prolong life by all medically effective means:**
In addition to treatment described in Selective Treatment and Comfort-focused Treatment, use intubation, advanced airway interventions, mechanical ventilation, and cardioversion as indicated. Transfer to hospital if indicated. Includes intensive care.

☐ **Selective Treatment–goal to treat medical conditions while avoiding burdensome measures:**
In addition to treatment described in Comfort-focused Treatment below, use IV antibiotics and IV fluids as indicated. **Do not intubate.** May use noninvasive positive airway pressure. Transfer to hospital if indicated. **Avoid intensive care.**

☐ **Comfort-focused Treatment–primary goal to maximize comfort:**
Relieve pain and suffering with medication by any route as needed; use oxygen, suctioning, and manual treatment of airway obstruction. Do not use treatments listed in Full and Selective Treatment unless consistent with comfort goal. **Do not transfer to hospital for life-sustaining treatment. Transfer only if comfort needs cannot be met in current location.**

Additional Orders: _____

C Check one box only

ARTIFICIALLY ADMINISTERED NUTRITION ***Always offer food & water by mouth if feasible.***

Any surrogate legal decision maker (Medical Durable Power of Attorney [MDPOA], Proxy-by-Statute, guardian, or other) must follow directions in the patient's living will, if any. Not completing this section ***does not*** imply any one of the choices—further discussion is required. ***NOTE:*** *Special rules for Proxy-by-Statute apply; see reverse side ("Completing the MOST form") for details.*

☐ Artificial nutrition by tube long term/permanent if indicated.
☐ Artificial nutrition by tube short term/temporary only. (May state term & goal in "Additional Orders")
☐ No artificial nutrition by tube.

Additional Orders: _____

D

DISCUSSED WITH (check all that apply):
☐ Patient
☐ Agent under Medical Durable Power of Attorney
☐ Proxy-by-Statute (per C.R.S. 15-18.5-103(6))
☐ Legal guardian
☐ Other:_____

SIGNATURES OF PROVIDER AND PATIENT, AGENT, GUARDIAN, OR PROXY-BY-STATUTE AND DATE (*MANDATORY*)

Significant thought has been given to these instructions. Preferences have been discussed and expressed to a healthcare professional. This document reflects those treatment preferences, which may also be documented in a Medical Durable Power OA, CPR Directive, living will, or other advance directive (attached if available). To the extent that previously completed advance directives do not conflict with these *Medical Orders for Scope of Treatment*, they shall remain in full force and effect.

If signed by surrogate legal decision maker, preferences expressed must reflect patient's wishes as best understood by surrogate.

Patient/Legal Decision Maker Signature (Mandatory) | *Name (Print)* | *Relationship/ Decision maker status (Write "self" if patient)* | *Date Signed (Mandatory; Revokes all previous MOST forms)*

Physician / APN / PA Signature (Mandatory) | *Print Physician / APN / PA Name, Address, and Phone Number* | *Date Signed (Mandatory)*

Colorado License #:

HIPAA PERMITS DISCLOSURE OF THIS INFORMATION TO OTHER HEALTHCARE PROFESSIONALS AS NECESSARY

Authority for this form and process is granted by C.R.S. 15-18.7: Directives Concerning Medical Orders for Scope of Treatment, enacted 2010.

Who Do I Need to Talk to?

What Do You Talk About?

https://www.youtube.com/watch?v=CgOoWU68si4]

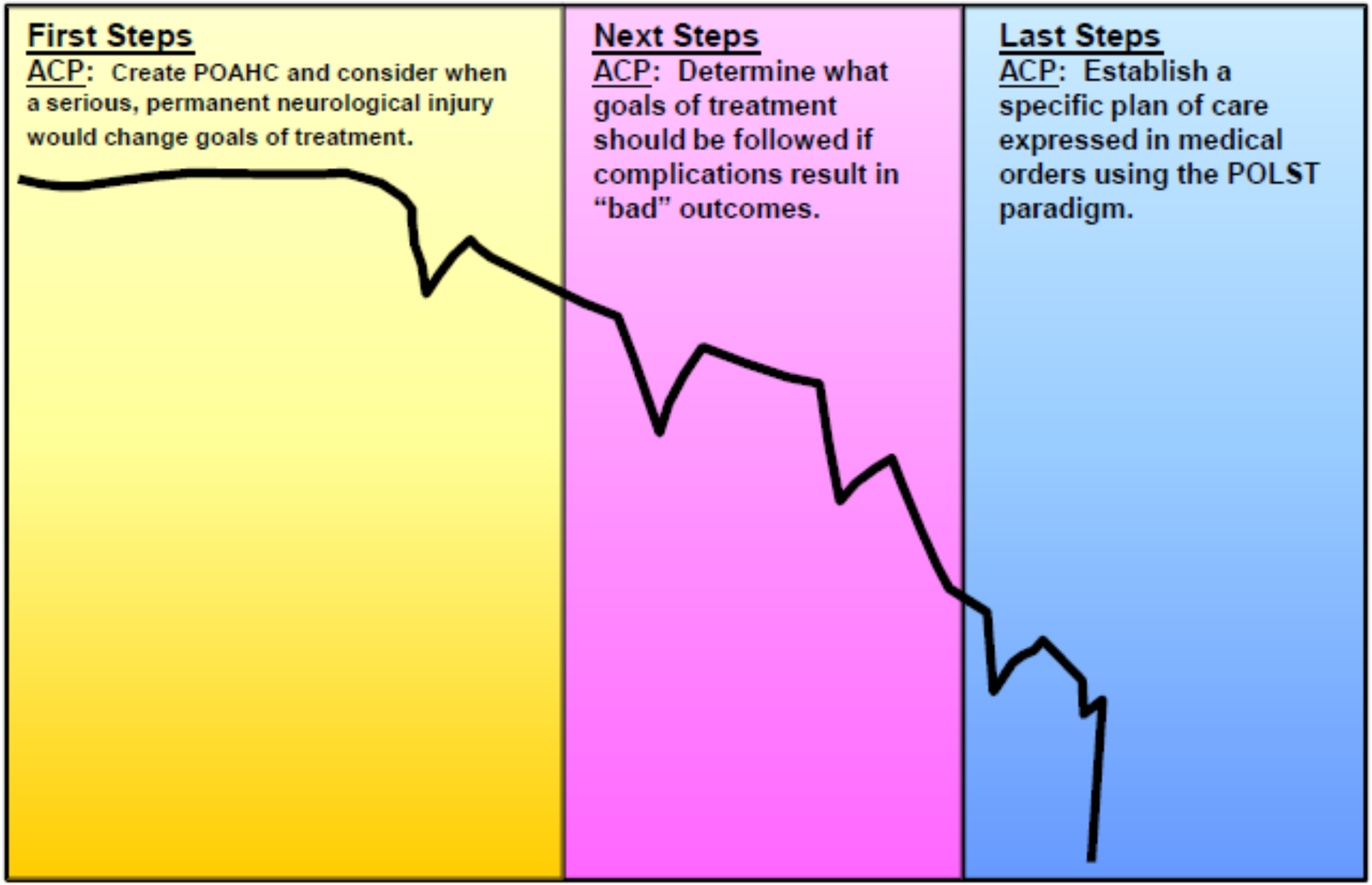
My Mother

- 85, with progressive dementia
- Wanted to “go home” to her husband
- Got a urine infection
- Should we treat it?

Talking to your Provider

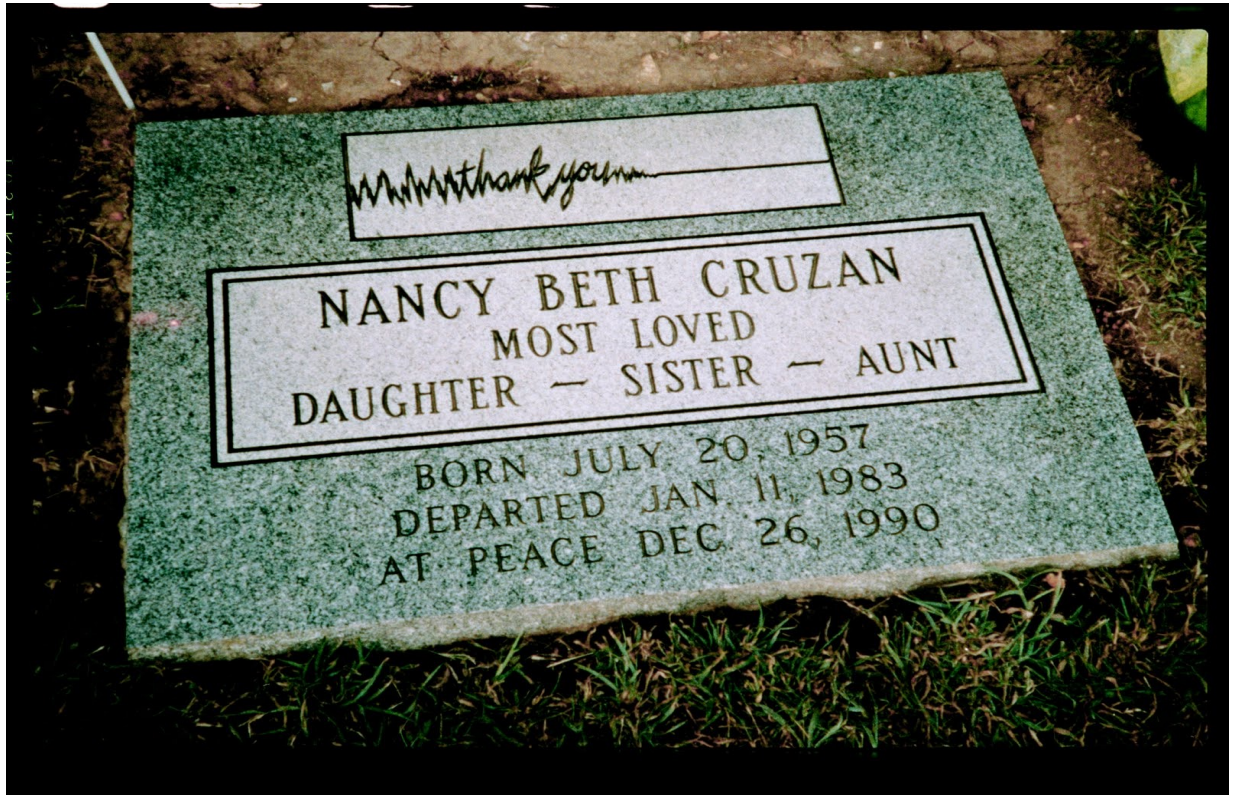
- Bring your primary care and other HCPs in on this conversation.
- Insurance, including Medicare and Medicaid, will pay your provider for the time it takes to have it!
- Make a specific appointment for this discussion, so you and your HCP have the necessary time.
- Guides are available if you are not sure what to discuss.
- How often?
  - At least update or touch base on your thoughts around advance care planning once yearly at your annual visit, and then update after any significant illness or hospitalization.

Stages of Advance Care Planning Over the Life Time of Adults



Some Final Thoughts…

Some History: Nancy Cruzan



The Spectrum:

Acts and Omissions that Lead to Death

Considered Legal, Ethical, Acceptable

Legal, Ethical, Mostly Acceptable

Illegal or, Not Acceptable or Ethical

"Because of your age, I'm going to recommend doing nothing."

Recap: Goals for This Discussion

- Recognize how important it is to figure out who you would want to speak for you in a medical situation if you couldn't.
- Understand how important documents are to help your loved ones – but how they only are as good as your conversations with your family and HC provider.
- Know where to get more information and help.

https://www.bch.org/patient-visitors/patient-services/advance-care-planning/#mdpoa

http://theconversationprojectinboulder.org/starter-kit/

What Matters Most to Me Workbook:

https://theconversationproject.org/what-matters-to-me-workbook-additional-resources/#:~:text=The%20What%20Matters%20to%20Me,get%20the%20care%20they%20want

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THANK YOU!

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