Advance Directives

Useful or Useless?

Kathy Kastner February 21, 2024
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Mother wouldn't want us to feel sad - she'd want us to feel guilty

Institute for Healthcare Advancement

Advancing Health Literacy toward Health Equity

Objectives

After attending this session, you will be able to:

- **Identify language that can be a barrier to Advance Care Planning conversations**
- **Make sense of recent research on effectiveness of Advance Directives**
- **Call upon tools to help initiate and navigate meaningful conversations about Advance Care Planning**

Do you know what an Advance Directive is?

Knowledge Assessment

- **No**
- **I feel like I know**
- **Yes, I know what an Advance Directive is but I’m still interested**

What is an Advance Directive

Formerly known as a Living Will

Written, legal instructions regarding your preferences for medical care if you are unable to make decisions for yourself.

Why an Advance Directive?

Medical advancements have enabled life-prolonging interventions

- Karen Ann Quinlan: New Jersey 1976
- Nancy Cruzan: Missouri 1991
- Terri Schiavo: Florida 1998-2005
- Hassan Rasouli: Toronto 2010

So many names for the same thing

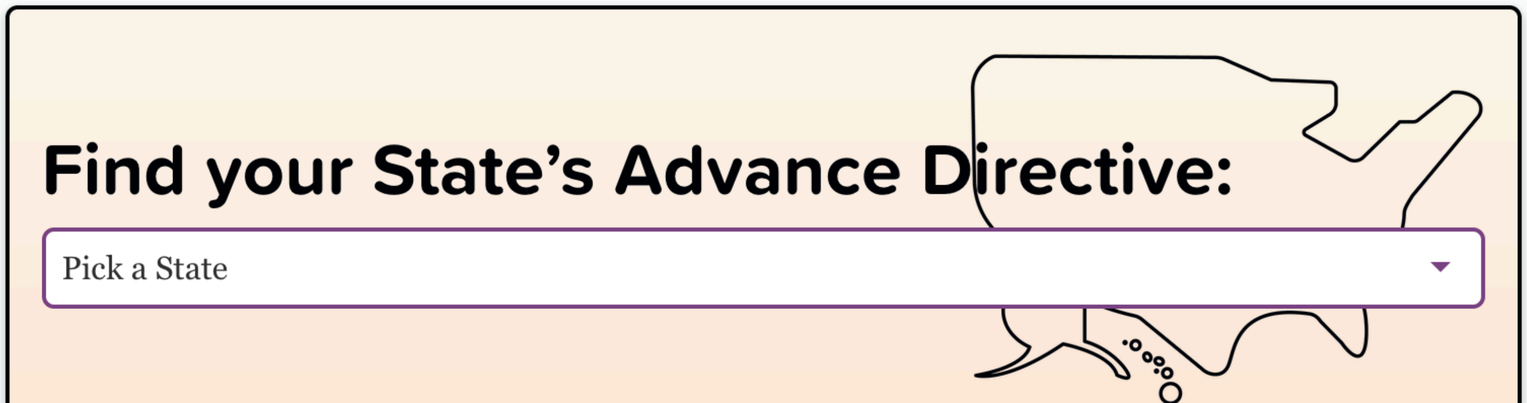
- Advance Directives
- Advance Health Care Directive
- Advance Care Planning
- POLST - Portable Medical Order
- MOLST - Medical Order for Life Sustaining Treatment

State by State Advance Directives

caringinfo.org

CaringInfo provides free advance directives and instructions for each state that can be opened as a PDF (Portable Document Format) file.

The PDF's may be filled in online. Some states allow online notarization. The forms should be saved and stored in multiple sites. They should also be printed so that they may be formalized by witness signatures or notarized if your state so requires. **The states vary in their requirements for witnesses, notarization and other specifics so review the form and its instructions carefully.**



Many decisions to consider

And many acronyms

- DNR – do not revive
- DNR:Comfort care
- DNI – do not intubate
- CPR – cardio-pulmonary resus
- Mechanical Breathing
- Feeding Tube
- Dialysis
- Organ Donation
- Tissue Donation
- Eye Donation
- Body Donation

Words that can confound

- Advance Directives
- Nothing more we can do
- Doing everything
- Palliative Care
- Withhold
- Withdraw
- Futile Measures
- Heroic Measures
- Hope
- Values
- Beliefs
- Goals of Care

So many names for the same thing:

Who’s going to speak on your behalf?

- Health care agent
- Health care proxy
- Health care surrogate
- Health care representative
- Health care attorney-in-fact
- Patient advocate

Newest Research: May 2023

Advance Care Planning: It is time to rethink our goals – results of ACP trials

Journal of American Geriatrics Society, May 2023 DOI: 10.1111/jgs.18511

- Failed to show that ACP improves goal-concordant care at the end of life.
- Failed to demonstrate the impact of ACP on improving patient quality of life.
- Inconsistent evidence that ACP improves patients' mental health, reduces health care costs, or increases home deaths.

“ACP does not seem to change patients' end of life trajectory or the care they receive at the end of life.”

Newest Research: November 2023

Adaptive Care Planning: A paradigm shift

Journal of American Geriatrics Society, November 2023 - DOI: 10.1111/jgs.18731

- Advance care planning and medical decision-making should adapt as information and condition change.
- “Adaptive Care Planning” helps clinicians engage in effective decision-making and care planning with patients and families over time.

Best Case Worst Case

https://patientpreferences.org/best-case-worst-case/

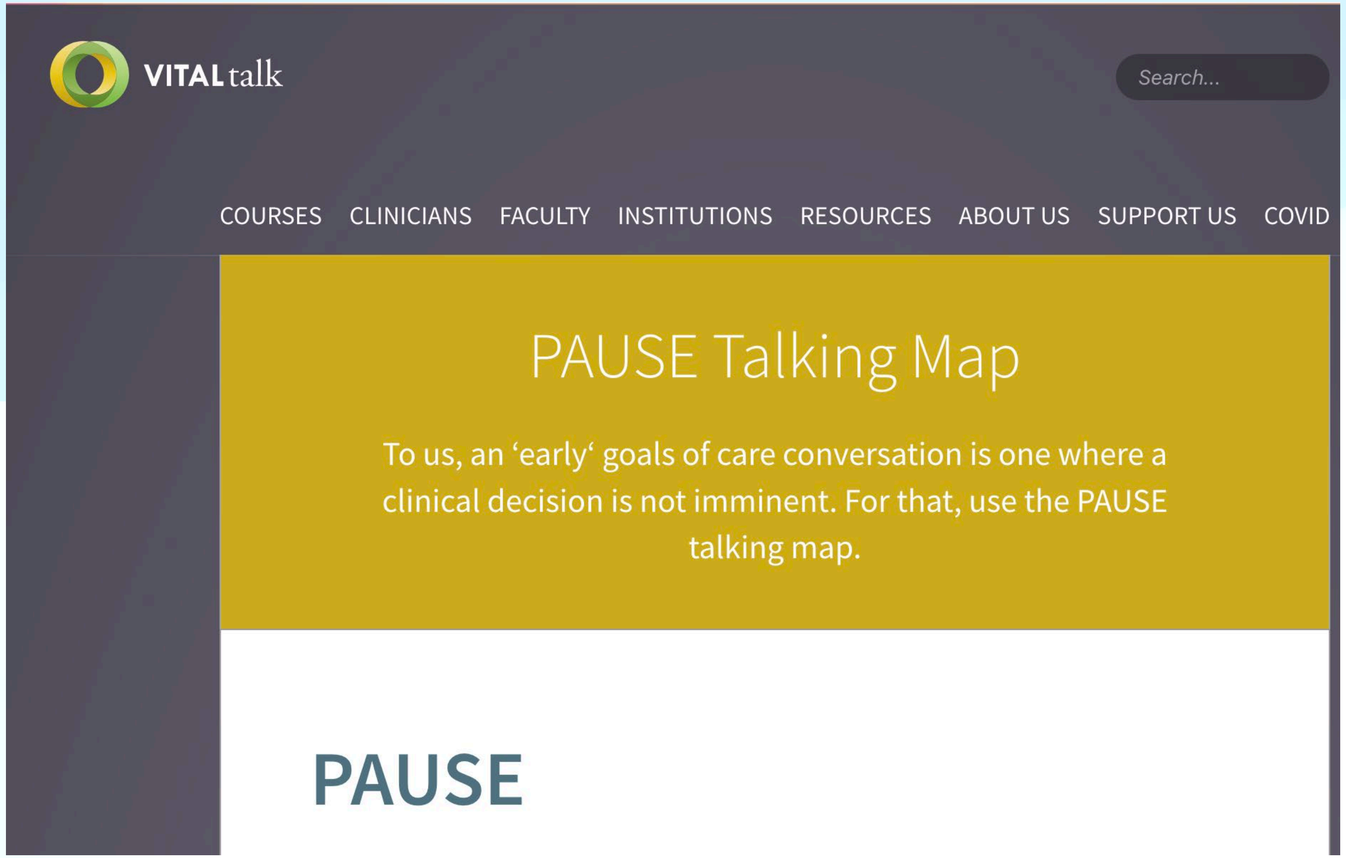
Serious Illness Conversation Guide

https://www.ariadnelabs.org/2016/03/09/redesigned-serious-illness-conversation-guide-supports-more-better-and-earlier-conversations-about-what-matters-most

Conversation flow		Patient-tested language
1. Set up the conversation • Introduce purpose • Ask permission	Set Up	*"I'd like to talk about what is ahead with your illness and do some thinking in advance about what is important to you so that I can make sure we provide you with the care you want — **is this okay?**"*
2. Assess illness understanding & information preferences	Assess	*"What is your **understanding** now of where you are with your illness?"* *"How much **information** about what is likely to be ahead with your illness would you like from me?"*
3. Share prognosis • Frame with a "wish…worry", "hope…worry" statement • Allow silence, explore emotion	Share	Prognosis: *"I want to share with you **my understanding** of where things are with your illness…"* Uncertain: *"It can be difficult to predict what will happen with your illness. I **hope** you will continue to live well for a long time but I'm **worried** that you could get sick quickly, and I think it is important to prepare for that possibility."* Time: *"I **wish** we were not in this situation, but I'm **worried** that time may be short as_ (express as a range e.g. weeks to months, months to a year)."* **OR** Function: *"I **hope** that this is not the case, but I'm **worried** that this may be as strong as you will feel"*
4. Explore key topics • Goals • Fears & worries • Sources of strength • Critical abilities • Trade-offs • Family	Explore	*"What are your most important **goals** if your health situation worsens?"* *"What are your biggest **fears and worries** about the future with your health?"* *"What gives you **strength** as you think about the future with your illness?"* *"What **abilities** are so critical to your life that you can't imagine living without them?"* *"If you become sicker, **how much are you willing to go through** for the possibility of gaining more time?" "How much does your **family** know about your priorities and wishes?"*
5. Close the conversation • Summarize what you've heard • Make a recommendation; check in with patient • Affirm your commitment to the patient	Close	*"I've heard you say that ____is really important to you. Keeping that in mind, and what we know about your illness, I **recommend** that we _____. This will help us make sure that your treatment plan reflect what's important to you"* *"How does this plan seem to you?" "I will do everything I can to help you through this."*
6. Document your conversation & 7. Communicate with key clinicians		

Vital Talk

https://www.vitaltalk.org/guides/pause-talking-map/

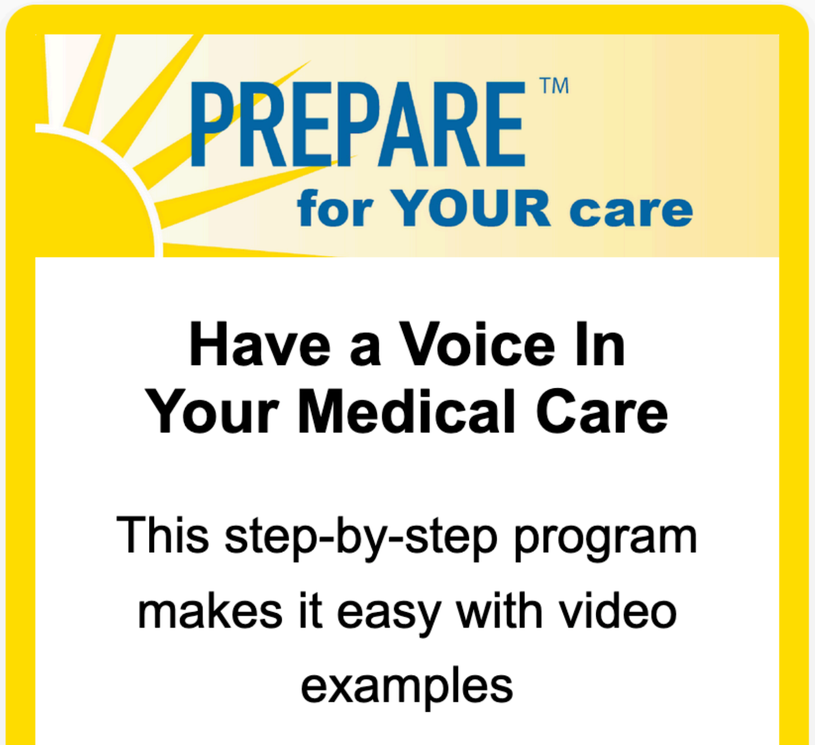


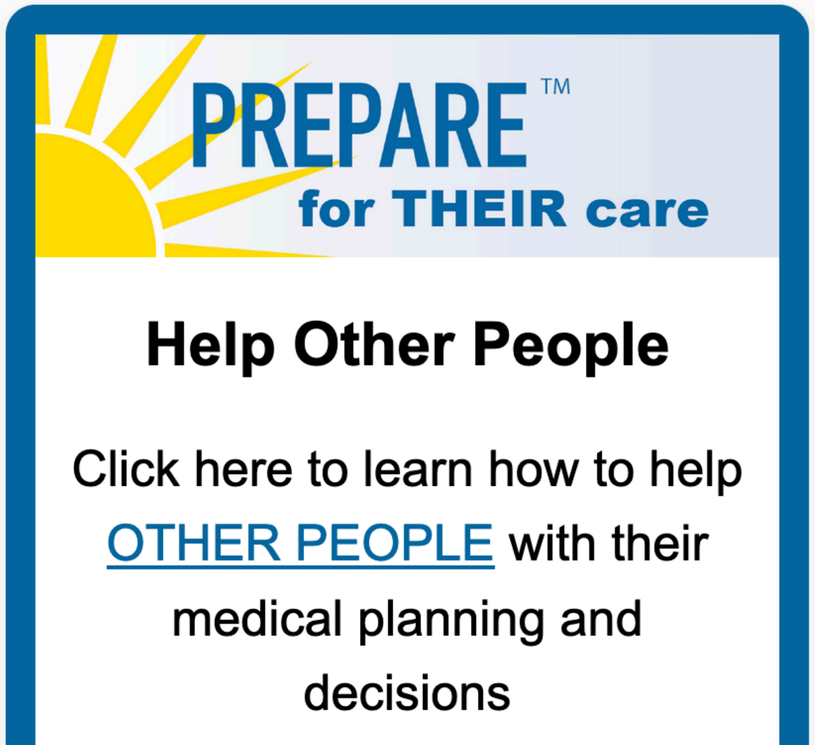
Prepare for Your Care: Rebecca Sudore

https://prepareforyourcare.org/

PREPARE has 2 programs with video stories to help you:

1. Have a voice in **YOUR OWN** medical care
2. Help **OTHER PEOPLE** with their medical planning and decisions





Which of these quotes best represent your wishes:

- ○ "Do not go gentle into that good night, Old age should burn and rage at close of day; Rage, rage against the dying of the light." – Dylan Thomas
- ○ "I've told my children that when I die, to release balloons in the sky to celebrate that I graduated: for me death is a graduation." – Elizabeth Kubler Ross
- ○ "To the organized mind, death is but the next great adventure." – JK Rowling
- ○ "Miss me, but let me go, for this is a journey we all must take" – Amy Louise Kerswell

Step 2: How's your health now?

Many people live with one or more health issues, and still consider themselves healthy. **Examples of chronic illness** diabetes, arthritis, rheumatoid disease, Crohn's disease, heart disease, mental illness, asthma, digestion, kidney disease, diabetes. **Examples of terminal or life-limiting illnes**s Dementia, Parkinson's, ALS, MS, some cancers, Kidney Failure, Lung Disease, How would you describe your current health? (check all that apply)

I describe myself as: (check all that apply)

- ☐ Healthy
- ☐ In good health
- ☐ Living with chronic illness

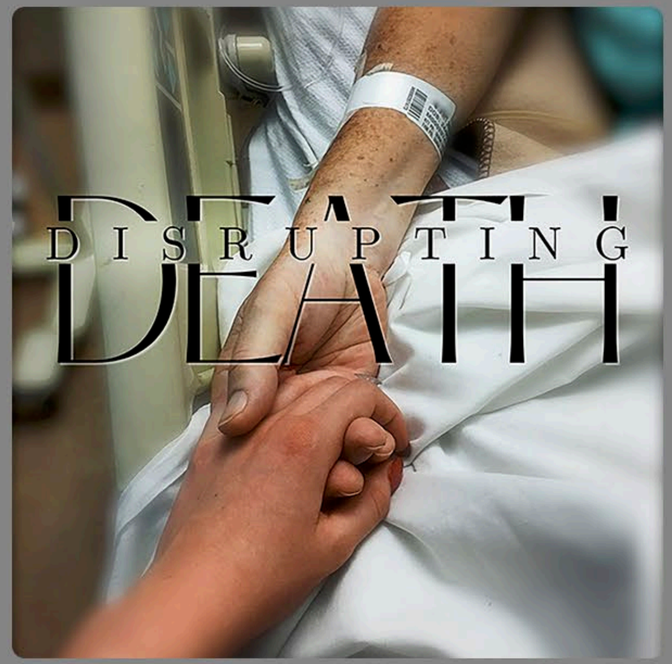
Comfort is important to me. If I can't speak for myself, I want to be as free of suffering as possible. I direct the following comfort measures: (check all that apply)

- [ ] Pain medication
- [ ] Pain medication, even if it hastens my death
- [ ] Relieve shortness of breath
- [ ] Clear my airways
- [ ] Relieve agitation (feeling uncomfortable in my own skin)
- [ ] Relieve constipation
- [ ] Relieve discomfort from infections
- [ ] Mouth care (dry mouth, mouth sores, flossing)
- [ ] Skin care (bed sores, dry skin)
- [ ] Position for comfort
- [ ] Splint for comfort
- [ ] Palliative chemotherapy (for comfort, not cure)
- [ ] Palliative radiation (for comfort, not cure)
- [ ] Palliative surgery (for comfort, not cure)

“Science tells us nothing about the individual.”

Dr. Susan Pinker

ALL EPISODES



Friday Jan 19, 2024

I want to ____ until I die: Disrupting Death with Kathy Kastner

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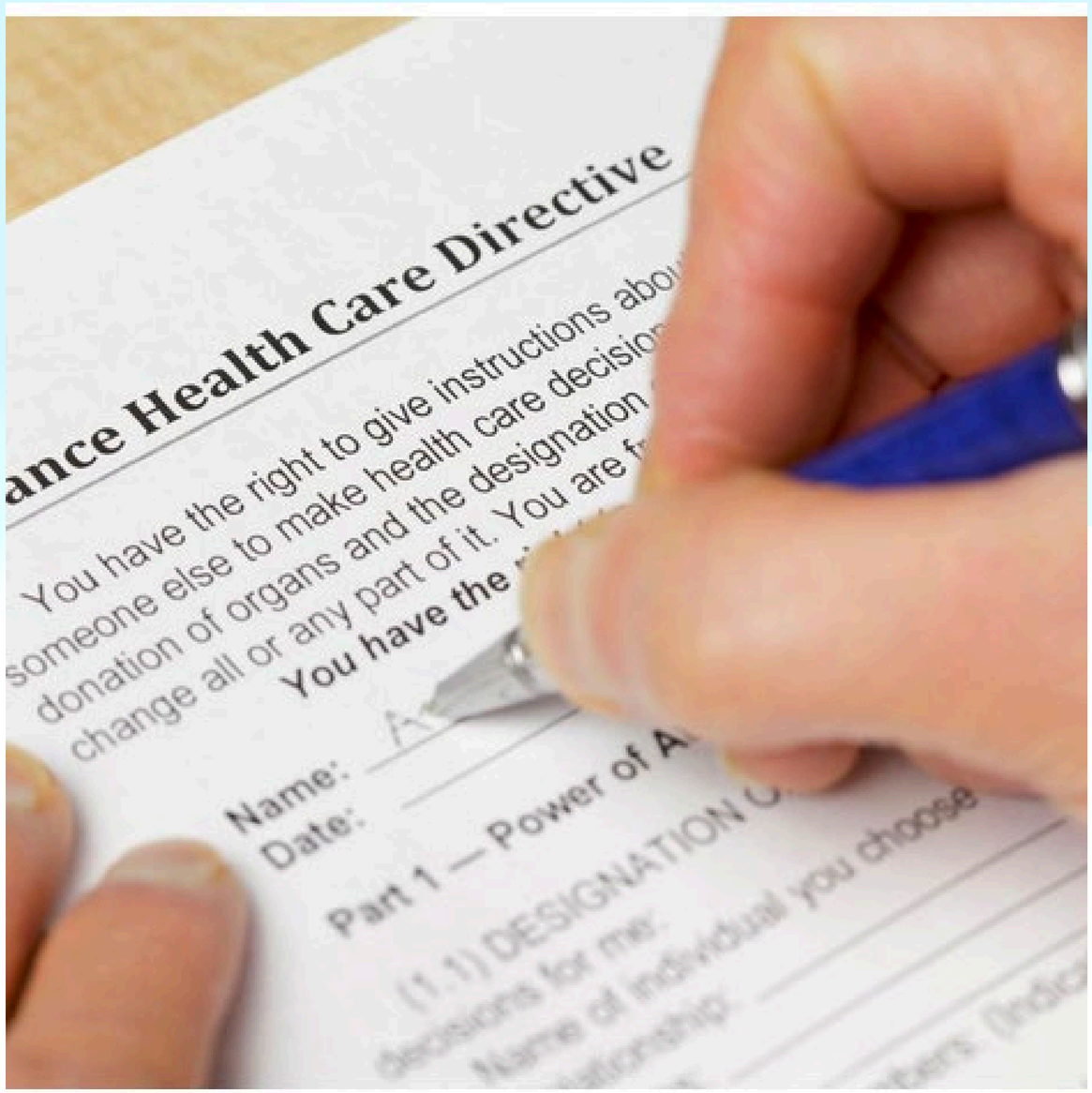
https://www.researchgate.net/publication/343068204_Eliciting_What_Matters_Most_to_People_The_Whiteboard_Initiative_Proof_of_Concept

Take Away
Advance Directives: Useful or Useless?

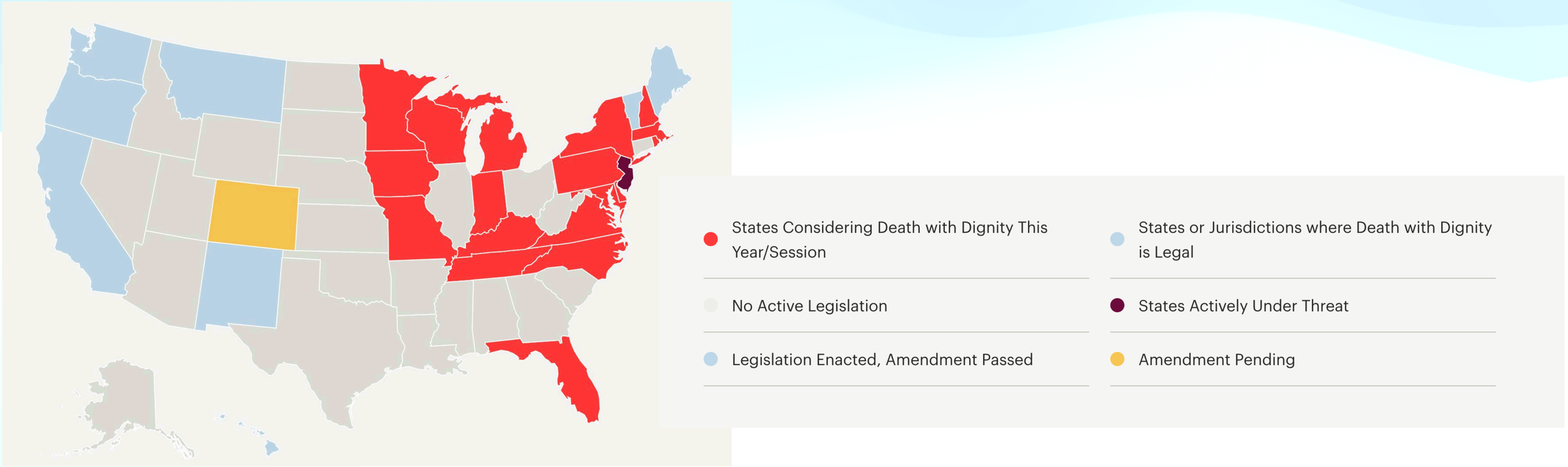
- Completing an Advance Directive doesn’t guarantee end of life wishes will be followed
- Completing an Advance Directive does not guarantee the AD will be available at time of decision
- Determining end of life wishes often requires using more than one tool and more than one conversation
- Ensuring everyone who matters understands your wishes can avoid arguments and legal action



Medical Aid in Dying in the U.S.

https://deathwithdignity.org/states/

- Find state by state status



Resources Provided

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https://www.ariadnelabs.org/2016/03/09/redesigned-serious-illness-conversation-guide-supports-more-better-and-earlier-conversations-about-what-matters-most

Also: **shorter link**

http://tinyurl.com/5n97b7uk

Vital TALK

https://www.vitaltalk.org/guides/pause-talking-map

Prepare for your care

prepareforyourcare.org

BestEndings.com

IG @MyBestEndings

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Whiteboard Initiative

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Kathy Kastner

Selected humble brags

- Created and grew The Health Television System: Patient education content broadcast in teaching hospitals across North America
- Produced: 10-second Med School YouTube Series on Medication Administration Confusion
- Created BestEndings.com first website from layman's point of view, on end of life topics
- Produced: BestEndings Video Chat about end of life
- Author: Death Kills…and other things I've learned on the internet
- TEDx: Exit Laughing
- ePatient Scholar: Stanford University Medicine X
- Presenter: North American Primary Practice Research Group
- Workshop: IHA conference
- Patient Partner: HARC, ACH Conference
- Patient Partner: PCORI study on Serious Illness Conversation Guide
- Patient Partner: Shared Decision Making and AI
- Published: Patient Journal, Canadian Medical Association Journal