

October 6, 2023



American  
Society  
**on Aging**

ASA Chicagoland Roundtable

**Let's Talk About It!** End of Life and Advance Care Planning  
Discussions and Options

# Logistics

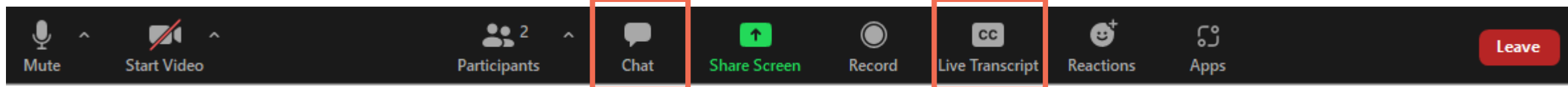
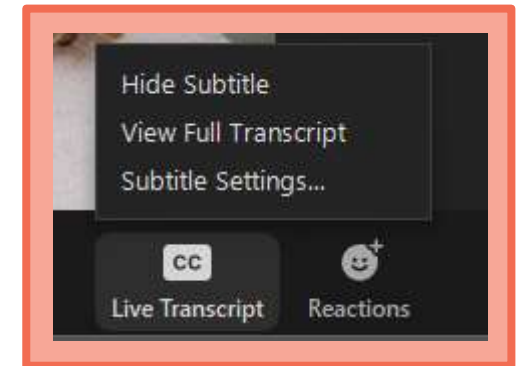
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Submit your questions into the chat box as we go

Slides and a recording will be shared with registrants

- And posted at <https://aging.rush.edu/policy/asa-chicagoland/>

Closed captioning available





**Let's Talk About It!**

**End of Life and Advance  
Care Planning  
Discussions and  
Options**



# Objectives

What is Advance Care Planning and Why is it Important?

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End of Life Care Options.  
Advance Directives How-To.

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Person and Community-Oriented Approach.

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Community Health Worker and Death Doula Roles.

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# Today's Speakers



**AMY SHERMAN,  
SHE/HER**

Compassion & Choices



**NICOLE DAIGLE,  
SHE/HER**

Winding Path Doula  
Services



**MAUREEN BURNS  
SHE/HER**

HAP Foundation




**EDITH MORAN,  
SHE/HER**

Northwestern Medicine  
Hospice

# Before We Begin...

- Take care of yourself in the space.
- Submit your questions in the “Chat” field and the speakers will address as many questions as possible throughout the session.



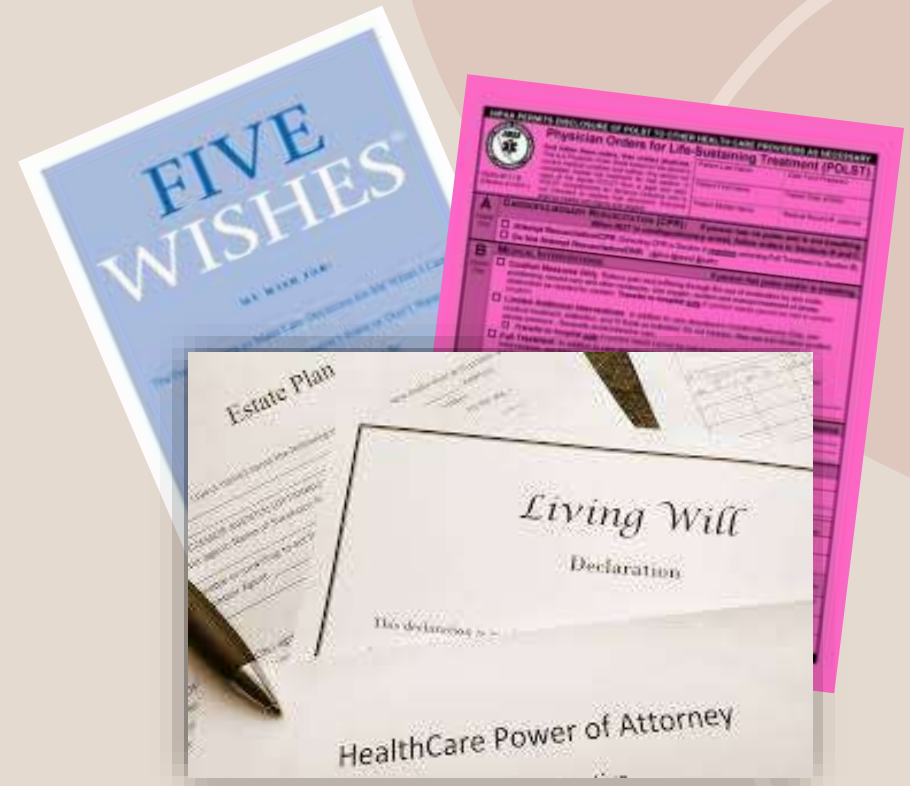
The background features a light grey base with a large, muted green organic shape in the upper right. A large, dark brown circular shape overlaps the left side, containing the text. Faint, stylized foliage patterns are visible in the top left. A white, wavy line curves across the bottom right area.

# Grounding Our Conversations

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# What is Advance Care Planning?

A process that enables individuals to make plans about their future health care. Advance care plans provide direction to healthcare professionals when a person is not able to either make and/or communicate their own healthcare decisions.





# Why is Advance Care Planning Important?

- Decreases stress and anxiety for individuals and care partners;
- Assists personal support network in making decisions that are in line with an individual's priorities and needs;
- Provides health care team with a roadmap to guide medical care decisions and the prioritization of care and support levels

# Advance Care Planning is Vital!

- 92% of people say that talking with their loved ones about end-of-life care is important.
- 32% have actually done so.
- 21% of people say they haven't had the conversation because they don't want to upset their loved ones.
- 53% say they'd be relieved if a loved one started the conversation.

*Source: The Conversation Project National Survey (2018).*

- 80% of people say that if seriously ill, they would want to talk to their doctor about wishes for medical treatment toward the end of their life.
- 18% report having had this conversation with their doctor.

*Source: Survey of Californians by the California HealthCare Foundation (2012) and Kaiser Family Foundation Serious Illness in Late Life Survey (2017)*

- 97% of people say it's important to put their wishes in writing.
- 37% have actually done it.

*Source: Kaiser Family Foundation Serious Illness in Late Life Survey (2017)*

# Main Components of Advance Directives

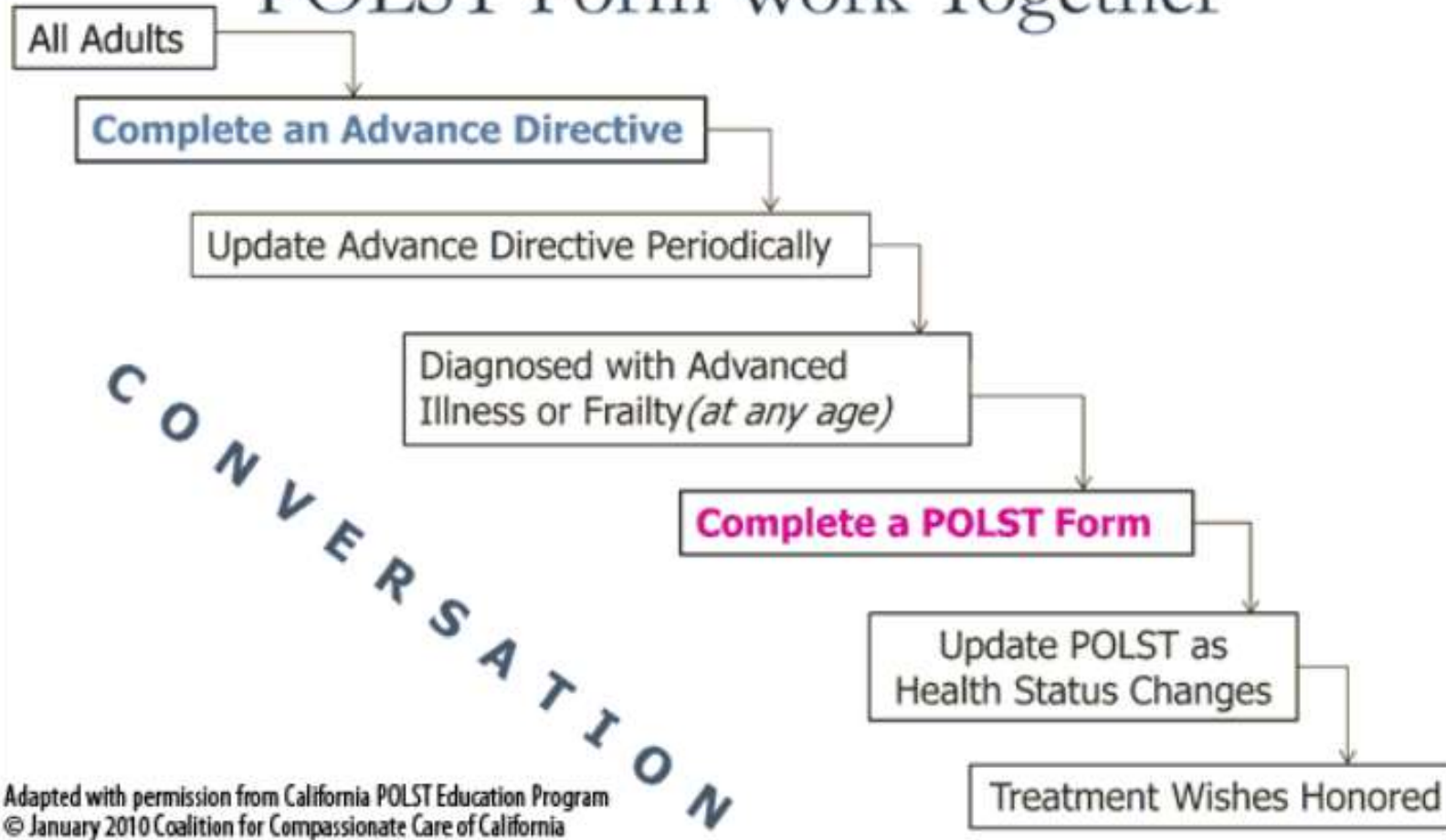
## Advance Directives (2 part):

- **Durable Power of Attorney for Healthcare**
  - Names agent to make health care decisions on your behalf
  - One witness required, no notary required
- **Living Will**
  - Written instructions that tell physicians and family members what life-sustaining treatment one wants or does not want should that person become unable to make decisions.

# Main Components of Advance Directives

- **Mental Health Treatment Preference Declaration**
  - Written preferences for treatment and hospitalization specifically for care of mental illness
  - Document expires three years from date signed.
  - Two witnesses required, no notary required
- **POLST: Practitioner's Orders for Life Sustaining Treatment**
  - Signed medical order that documents the types of treatments seriously ill individuals want at the end-of-life
  - Covers three areas: CPR, Medical Interventions, Medically Administered Nutrition
  - Requires signatures of individual, witness, and medical practitioner

# How An Advance Directive and POLST Form Work Together



# Who makes decisions when no AD in place?



## Healthcare Surrogate Act of Illinois (755 ILCS 40)

- 1) The patient's guardian of the person
- 2) Spouse
- 3) Adult child
- 4) Either parent
- 5) Adult sibling
- 6) Adult grandchild
- 7) Close friend
- 8) Guardian of the estate

# Who Will Speak For You?





# End-of-Life Options and Medical Aid in Dying

Amy Sherman  
Midwest Advocacy Director  
October 6, 2023





# About Compassion & Choices

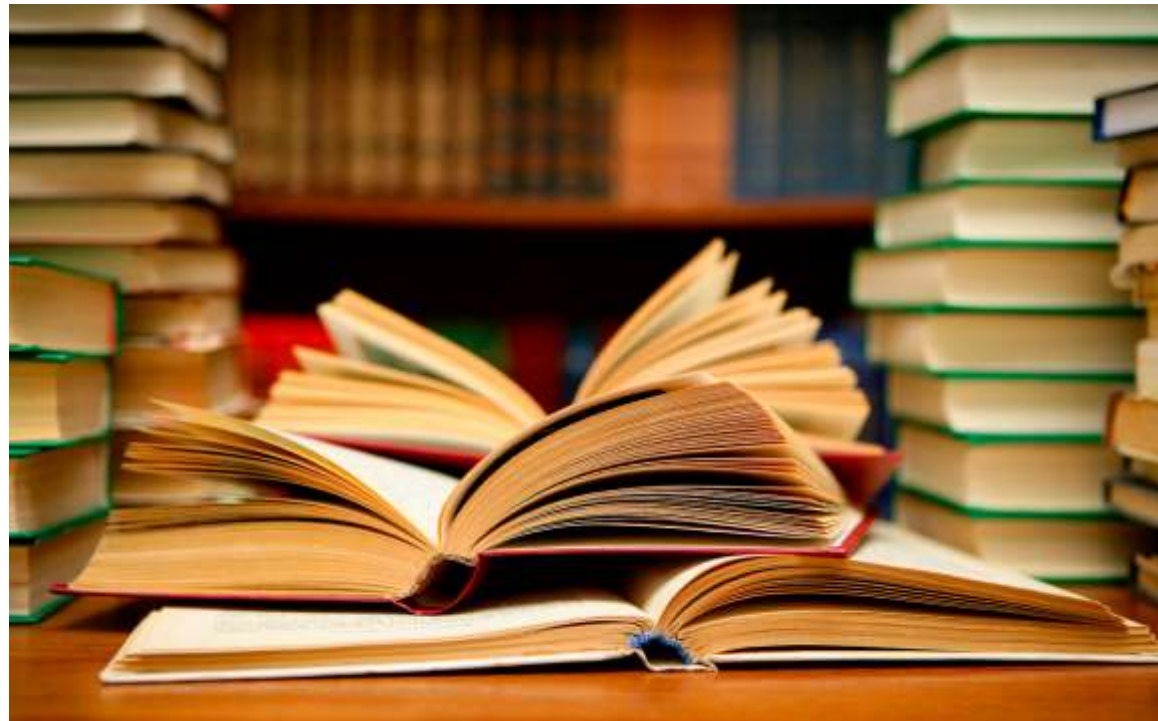
**Mission:** to improve care, expand choice and empower patients at the end of life

**Vision:** a society that affirms life, accepts the inevitability of death, and supports everyone in choosing end-of-life care that reflects their values, priorities and beliefs

**We support, empower, advocate and defend.**

*Life is meaningful because it is a story...  
and in stories, endings matter.*

- Dr. Atul Gawande, *Being Mortal*



# How We Want To Die

- At home with loved ones
- With pain and discomfort managed
- Having values respected



*Journal of the American Society on Aging, June 2015*

# End-of-Life Options

- Pursuing Life-Sustaining Treatment
- Discontinuing or Refusing Medical Treatment
- Hospice
- Voluntarily Stopping Eating and Drinking (VSED)
- Palliative Sedation
- Medical Aid in Dying

*Options are not mutually exclusive*

# Palliative Care/Hospice

- Comfort care/pain management
- Hospice limited to terminally ill
- Interdisciplinary team
- Holistic approach
- No curative treatment for hospice



# Voluntarily Stopping Eating and Drinking (VSED)

- At end stage, many lose the desire to eat or drink
- In most states, Individuals have the legal right to refuse to eat or drink.
- Should be medically supervised
- Make sure the facility will honor the wish



# Palliative Sedation

- Continuous administration of medication
- Unconscious or semi-conscious state to relieve suffering at the end of life
- Typically in conjunction with VSED



# What is Medical Aid in Dying?

Medical aid in dying is a safe and trusted practice in which a ***terminally ill, mentally capable adult with a prognosis of six months or less to live*** has the option to request from their doctor a prescription for medication which they can choose to ***self-ingest*** to bring about a peaceful death.



# Eligibility Requirements

- Adult
- Terminally ill  
(Prognosis of 6 months or less)
- Mentally capable of making informed medical decisions
- Able to self-ingest



# Safeguards

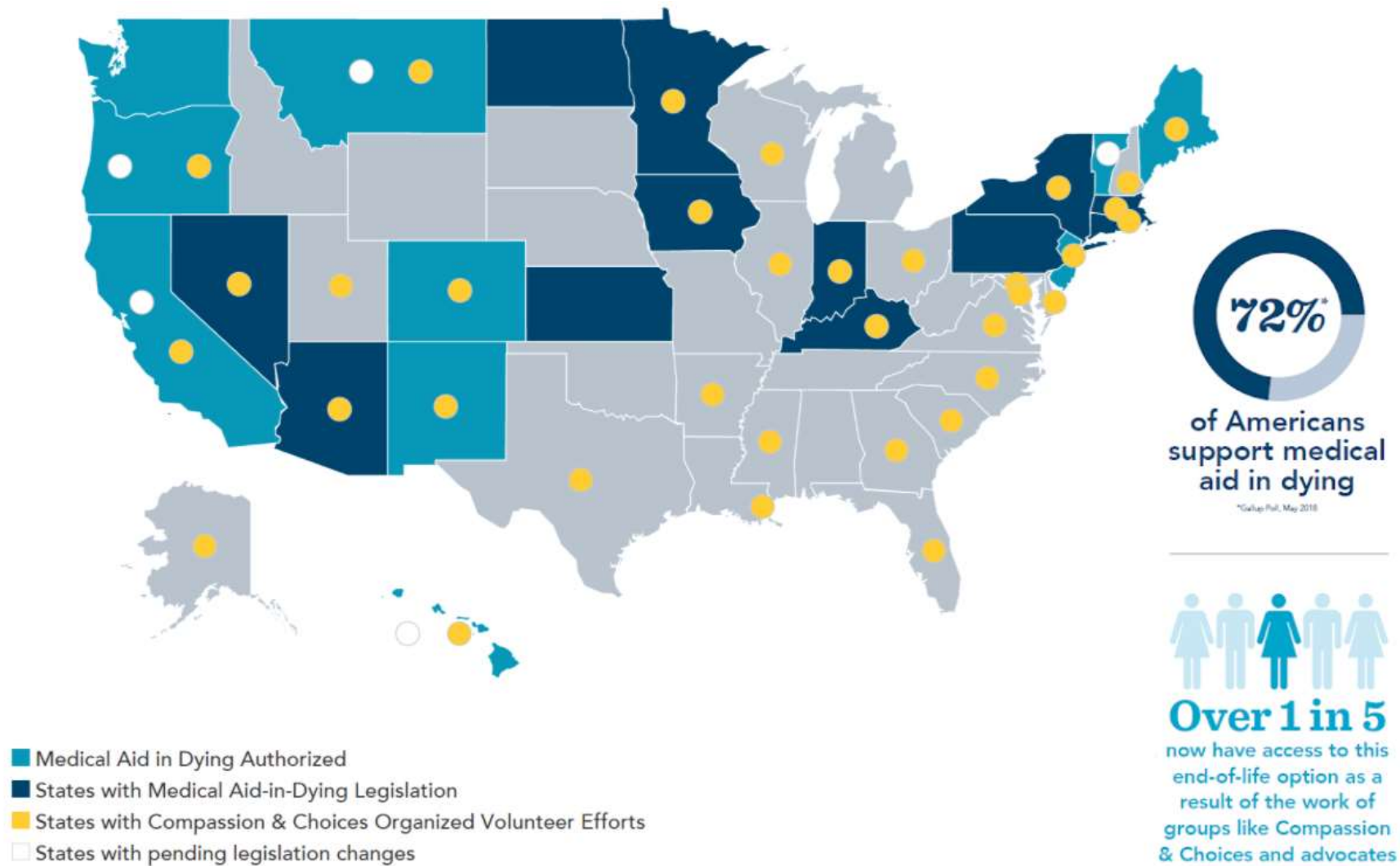
- Physician must inform person about all end-of-life care options
- Two verbal requests and one written request
- Waiting periods between requests
- Two physicians must confirm eligibility to use law
- At least one witness must attest to the voluntary nature of the individual's request

# Other Key Provisions of the Law

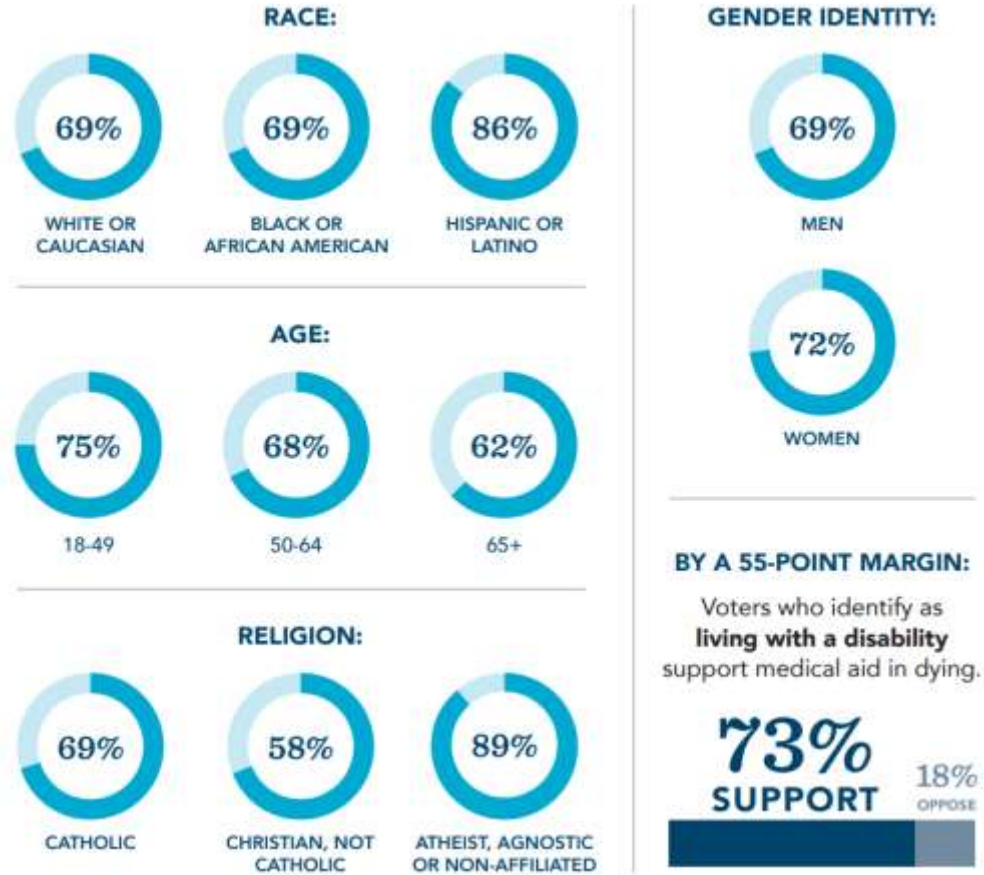
- Wills, contracts, insurance and annuity policies are not affected
- Medical aid in dying is not considered suicide or assisted suicide



# Authorized in 11 Jurisdictions

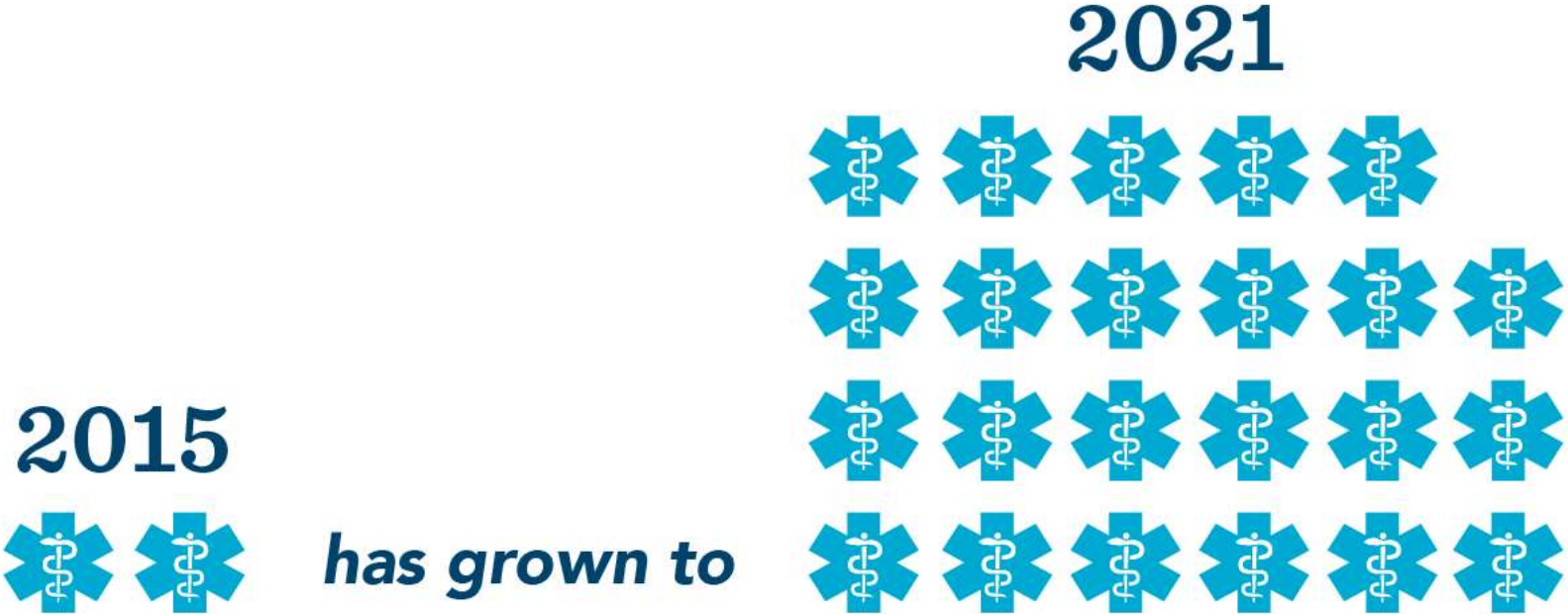


# 71% of Illinois Voters Support Medical Aid-in-Dying



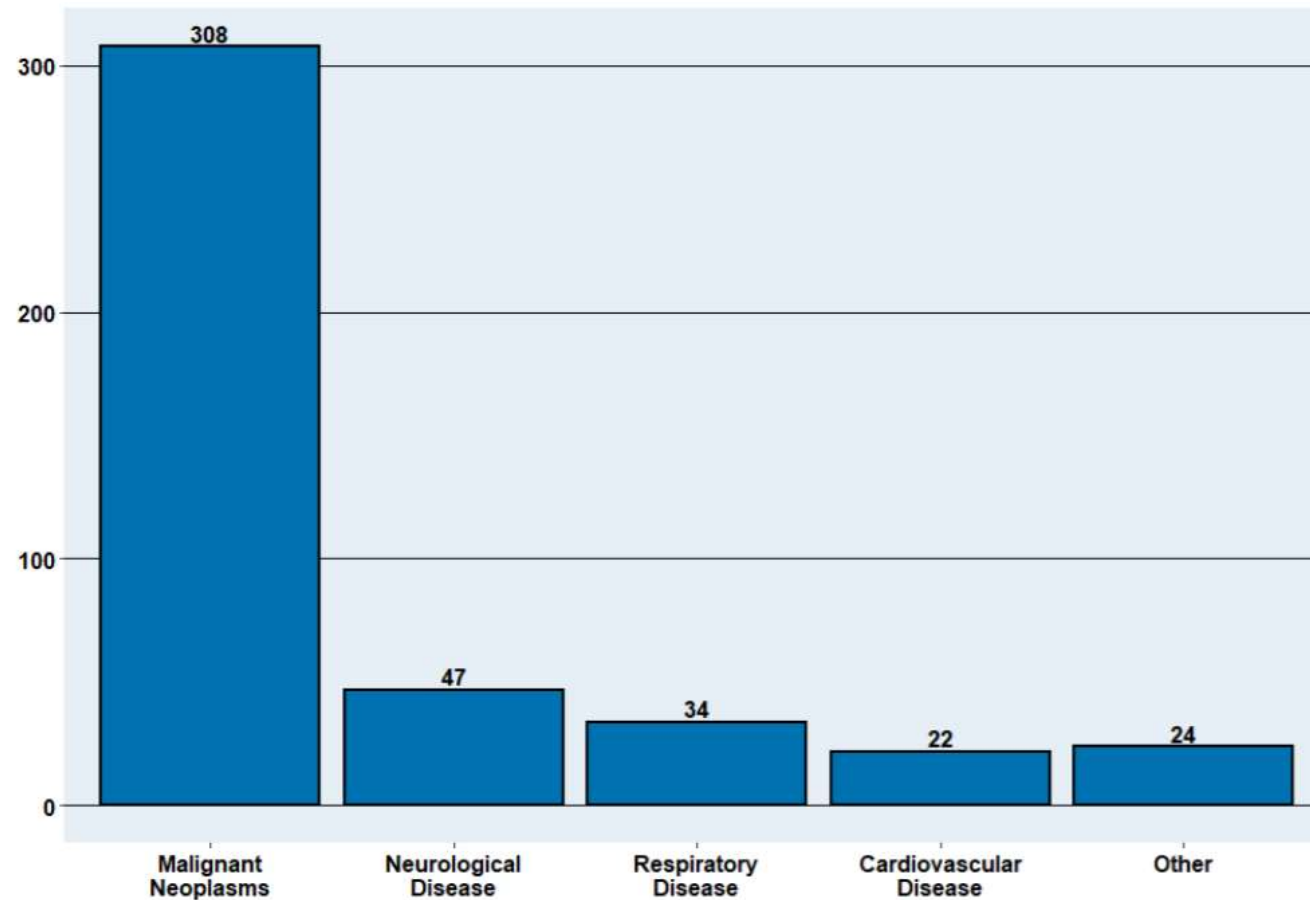
# Growing Acceptance among Medical Societies

Since 2015, 24 medical societies have dropped their opposition to medical aid in dying.



# End of Life Option Act 2020 Report

Figure 3: Major Illness Categories for EOLA Individuals in 2020



# Medical Aid In Dying Improves Care

- Medical aid in dying has been practiced without a single reported incidence of abuse or coercion in any of the authorized jurisdictions.
- Having a prescription for aid-in-dying medication is a comfort.





# Deb Robertson's Story



## What is a Community Health Worker (CHW)?

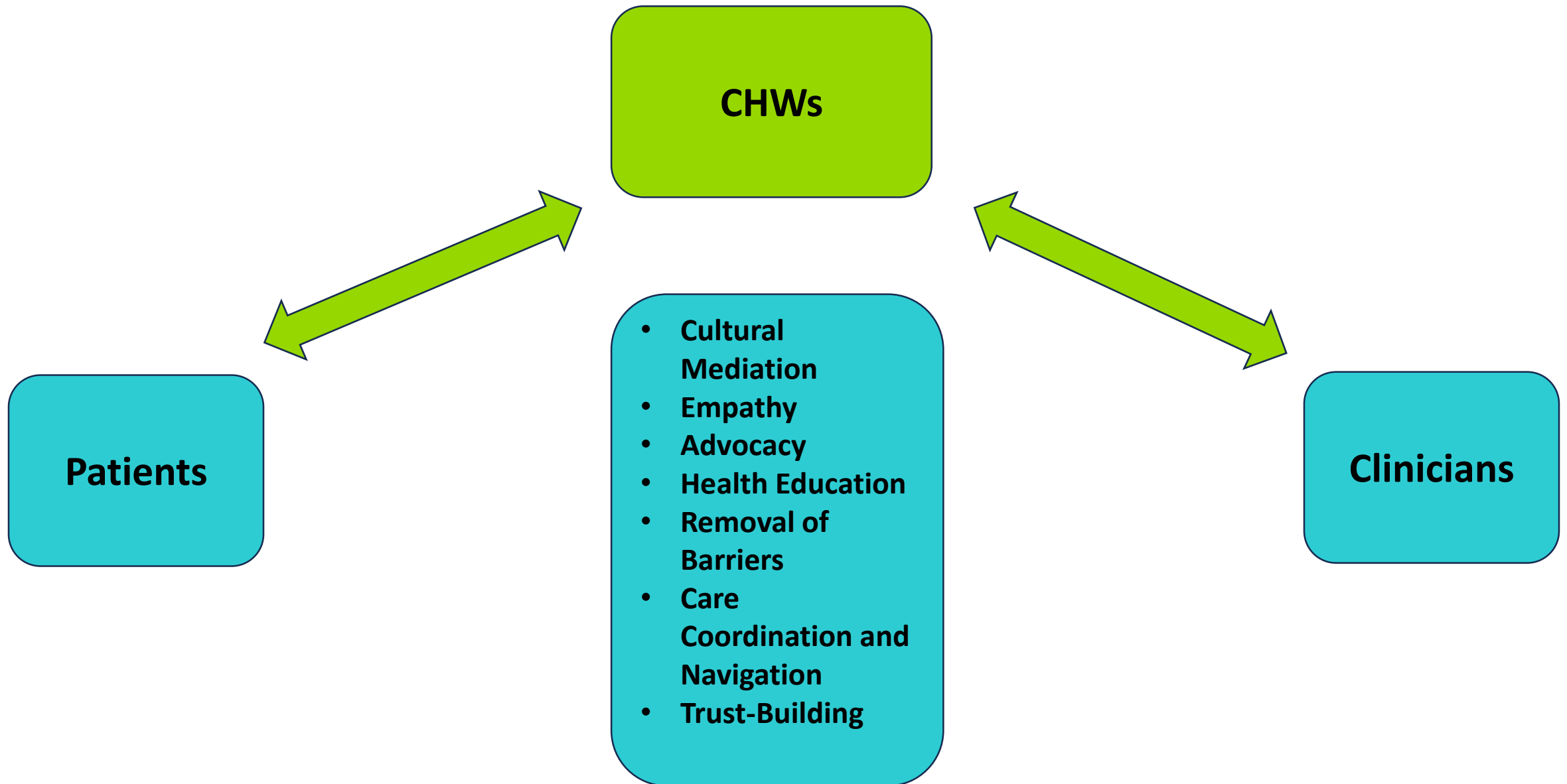
A community health worker is a **frontline public health worker** who is a **trusted member** of and/or has an unusually close understanding of the community served.

This trusting relationship enables the worker to serve as a **liaison/link/intermediary between health/social services and the community to facilitate access to services and improve the quality and cultural competence** of service delivery.

(APHA, 2023)



# What Do CHWs Bring to the ACP Process?




# What is an End of Life Doula?

End of life doulas (also known as death doulas) provide non-medical care, logistical support, and other guidance during the death process.

What do end of life doulas do?

- Provide companionship
- Create a peaceful environment
- Provide emotional and spiritual support
- Initiate conversations about the dying process
- Assist in advance care planning
- Support caregivers in self-care, reducing burnout and emotional fatigue
- Educate about health care options
- Provide vigil watches



Advance  
Care  
Planning and  
End of Life  
Roundtable

# Where Do We Go From Here?

Key Takeaways

Resources and Tools

Continuing the Conversation



# Resources and Tools

- [Prepare to Care: A Planning Guide for Caregivers in the LGBT Community](#)
- [End of Life Collective](#)
- <https://theconversationproject.org/>
- [National Resource Center on LGBT Aging](#)
- [10 Tips for Finding LGBT-Affirming Services](#)
- [The Order of the Good Death](#)
- [Death Cafe](#)
- [Death Over Dinner](#)
- [Compassion and Choices](#)
- [HAP Foundation](#)

Death in the Afternoon (The Order of the Good Death)

Em dash podcast (Kimberly Acquaviva)

Death by Design (Kimberly Paul)

The Amateur's Guide to Death and Dying:  
<http://www.theamateursguide.com/>

Acquaviva, Kimberly. (2017). LGBTQ-Inclusive Hospice and Palliative Care: A Practical Guide to Transforming Professional Practice

Gawande, Atul (2014). Being Mortal

Lee, Barbara Coombs. (2019). Finish Strong: Putting Your Priorities First at Life's End

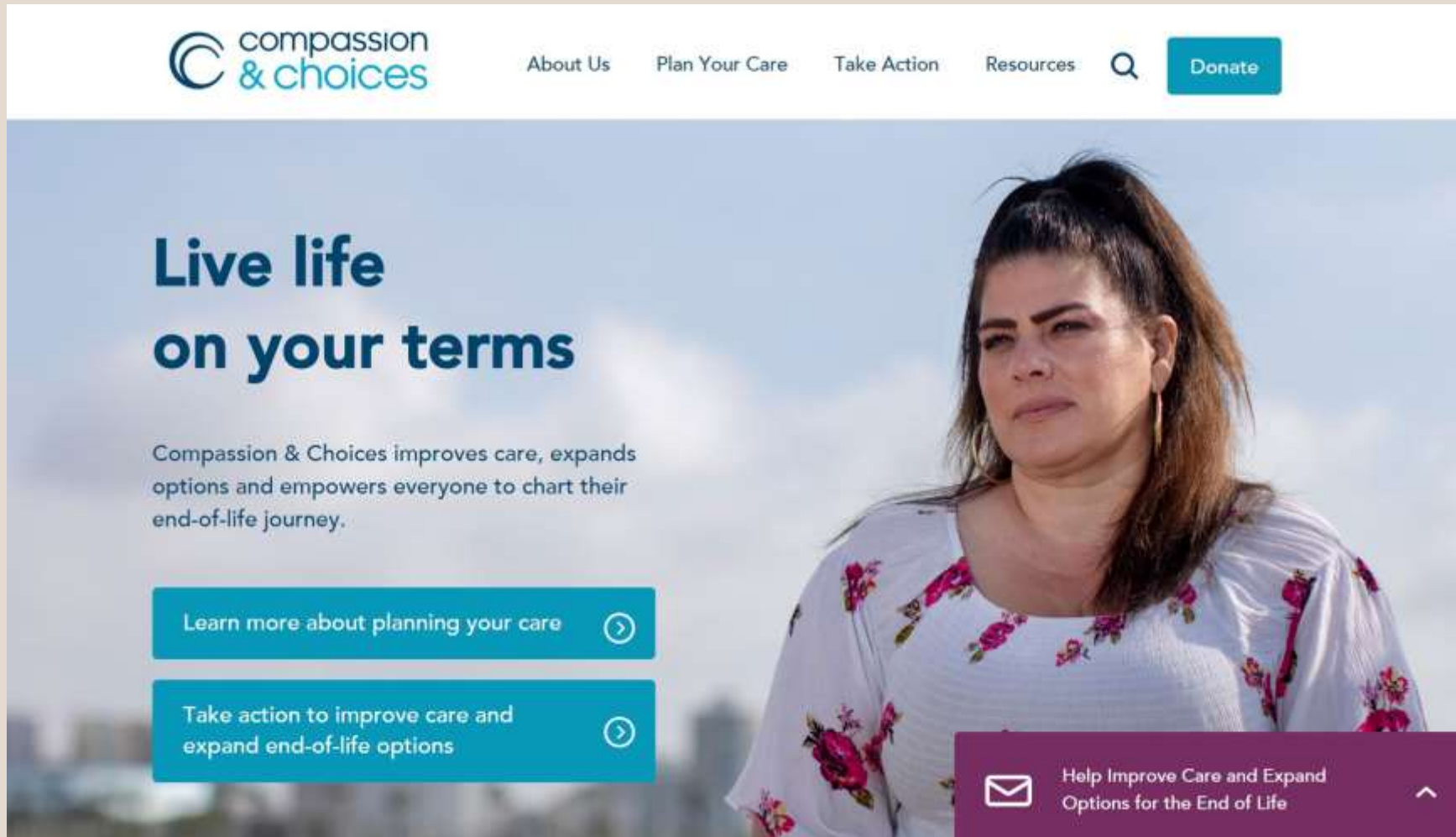
Miller, BJ and Shoshana Berger. (2019). A Beginner's Guide to the End: Practical Advice for Living Life and Facing Death

WEBSITES

PODCASTS/ BLOG


BOOKS

# CompassionAndChoices.org




The image shows the homepage of the website Compassion & Choices. The background features a woman with dark hair tied back, wearing a white top with pink floral patterns, looking thoughtfully to the side against a bright, slightly cloudy sky. The website's navigation bar is at the top, with the logo on the left and links for 'About Us', 'Plan Your Care', 'Take Action', 'Resources', a search icon, and a teal 'Donate' button on the right. The main content area has a large heading 'Live life on your terms' and a sub-headline 'Compassion & Choices improves care, expands options and empowers everyone to chart their end-of-life journey.' Below this are two teal buttons with white text and right-pointing arrows: 'Learn more about planning your care' and 'Take action to improve care and expand end-of-life options'. At the bottom right, there is a purple banner with a white envelope icon, the text 'Help Improve Care and Expand Options for the End of Life', and a white upward-pointing arrow.


compassion & choices



About Us Plan Your Care Take Action Resources  [Donate](#)

## Live life on your terms

Compassion & Choices improves care, expands options and empowers everyone to chart their end-of-life journey.

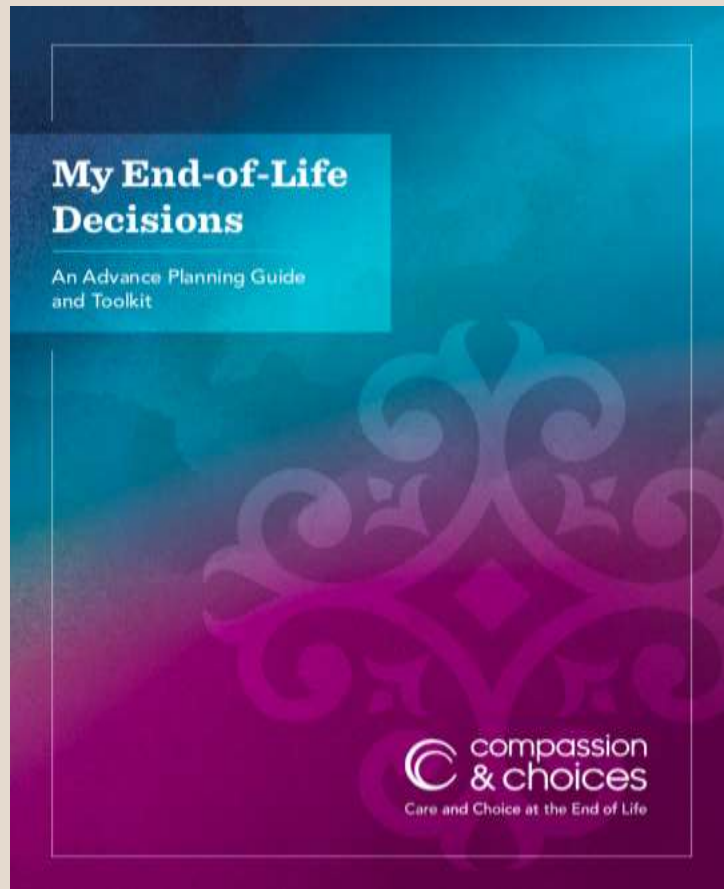
[Learn more about planning your care](#) 

[Take action to improve care and expand end-of-life options](#) 

 [Help Improve Care and Expand Options for the End of Life](#) 



# My End-of-Life Decisions: Guide & Toolkit



*“She covers all the issues we must address—from opening the conversations with our families to informing doctors about the kind of care we want at the end of our lives. Read Finish Strong and use it as a guide to consider your own final decisions.”*

- Diane Rehm, former host and executive producer of The Diane Rehm Show, and author of "On My Own"

# Dementia Resources

## Dementia Values & Priorities Tool

- Understand the disease
- Learn about your options
- Avoid unnecessary treatment
- Ensure your wishes are honored through a supplemental advance directive



## Dementia Decoder

- Prepare question list for doctors



# To Continue the Conversation

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**EDITH MORAN**

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# Thank you!

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Please share any announcements in the chat

View recordings from recent sessions at <https://aging.rush.edu/policy/asa-chicagoland/>

Please join us for our upcoming Roundtable

- Friday 12/1, 8:30-10:30am
- Registration / details will be shared in November via ASA listserv
  - *Bonnie will also share registration details in follow-up from today's event*