April 4, 2025

ASA Chicagoland Roundtable

An ASA Chicagoland Roundtable on Medical Aid in Dying Legislation

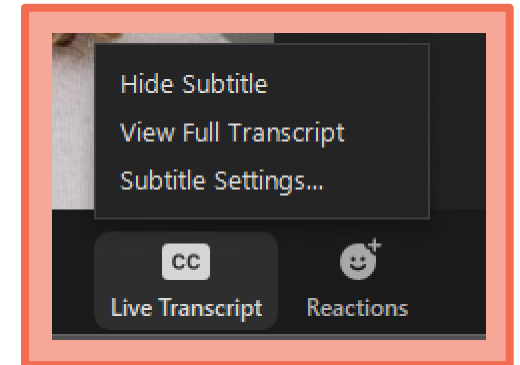
Welcome to the ASA Chicagoland Roundtable

- **Longstanding series of bimonthly educational gatherings with professionals in aging in the greater Chicago area**
  - Hosted by RUSH University Medical Center – Center for Excellence in Aging
  - Organized by local volunteer planning committee
  - Communications support from the American Society on Aging
- **Virtual sessions since 2020 available at https://aging.rush.edu/policy/asa-chicagoland/**

Logistics

Slides and a recording will be shared with registrants

Submit your <u>questions for panelists to address into the Q&A box</u> and <u>general resources or comments</u> into the chat box as we go



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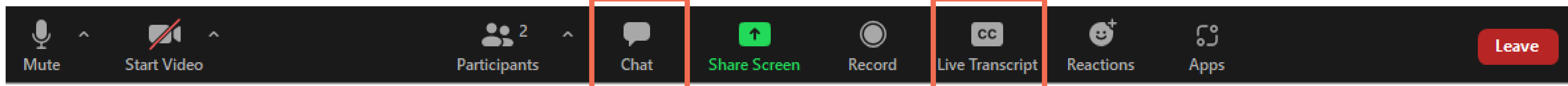


Today’s panelists

- **Susan Hedlund, LCSW, FAOSW -** Oncology social work leader and member of Oregon's Death with Dignity taskforce
- **Chloë “Izzy” King -** Senior Campaign Organizer, Compassion & Choices Action Network
- **Representative Robyn Gabel (18th) -** Illinois State Representative and Chief sponsor of the Illinois End-of-Life Options Act
- **Khadine Bennett -** Advocacy and Intergovernmental Affairs Director, ACLU of Illinois
- **Moderated by: Ellen S. Byrne, MPP -** Director of Policy & Government Affairs, Illinois Hospice & Palliative Care Organization

Ellen S. Byrne, MPP

DIRECTOR OF POLICY & GOVERNMENT AFFAIRS,
ILLINOIS HOSPICE & PALLIATIVE CARE ORGANIZATION

Palliative care including hospice intends to neither hasten nor postpone death.

- Trade organization supporting Illinois hospice providers
- Committed to promoting and enhancing end-of-life care in Illinois
- Neutral position on medical aid in dying as a policy matter for the state
- Highly engaged in supporting our providers and their patients if the End-of-Life Options for Terminally Ill Patients Act becomes law

Susan Hedlund, LCSW, FAOSW

ONCOLOGY SOCIAL WORK LEADER AND
MEMBER, OREGON'S DEATH WITH DIGNITY TASKFORCE

Oregon’s Death with Dignity Law

Susan Hedlund, LCSW, FAOSW

Director, Supportive Care Initiatives-Biller Family Foundation

Faculty and Senior Scholar, Center for Ethics, School of Medicine, Oregon Health & Sciences University

Defining the terms

- Euthanasia- is defined as the "painless killing of a patient suffering from an incurable disease, or an irreversible coma". The practice is illegal in most countries, including the U.S.

- Medical Aid in Dying- is a practice in which a physician (or in some states, other medical provider) provides a competent adult with a terminal illness with a prescription for a lethal dose of a drug-at the request of the patient- which the patient intends to use to end his or her life.
  - Pub Med.ncbi.nim.nih.gov
  - Providers can choose not to participate in MAID and some are prohibited from participating by their employers
  - Legal in 10 US States and the District of Columbia- 2025

History of Physician Aid in Dying in U.S.

- First effort (by ballot) Washington 1991 -defeated
- California (by ballot)– 1992- defeated

- Oregon (by ballot) 1994- approved, repeal defeated in 1997
- Washington (by ballot)-2008-approved
- Montana Supreme Court legalized in 2009
- Vermont legislature, 2013 approved
- California-End of Life Option Act signed into law –Oct. 2015
- Colorado-End of Life Options Act-2016
- District of Columbia-DC Death with Dignity Act -2017*
- Hawaii-Our Care, Our Choice Act-2018, signed into law, April 5, 2018
- Maine Ballot-2019
- New Jersey-2019
- New Mexico Elizabeth Whitefield End-of Life Options Act (legislation)
- Massachusetts and New York have proposed several times

- 23 States and the District of Columbia have sought to codify the practice of physician aid in dying

  - * Federal Budget will not support this

A bit about language…

- Oregon’s law was called “death with dignity”
- Some states refer to it as “medically-assisted suicide” or ”provider assisted death”
- Over time the field has moved away from the term “suicide”

- Cause of death on the death certificate is the underlying disease

Provision of ODWDA

- Allows terminally-ill resident prescription for self-administered medication to end life
- Ending life under the Act is not considered suicide
- Prohibits euthanasia
- “physician-assisted suicide” has been replaced with “physician aid in dying” or “medically assisted death”

Patient Requirements

- Oregon resident* As of 2023 no longer required
- 18 years of age
- “Capable” (able to make and communicate health care decisions)
- Terminal illness with 6 months or less to live
  - (if the patient has a terminal or chronic illness, but their life expectancy cannot be predicted within reasonable medical judgment to be less than 6 months, then he/she is not eligible to use the Act).
- Request must be voluntary

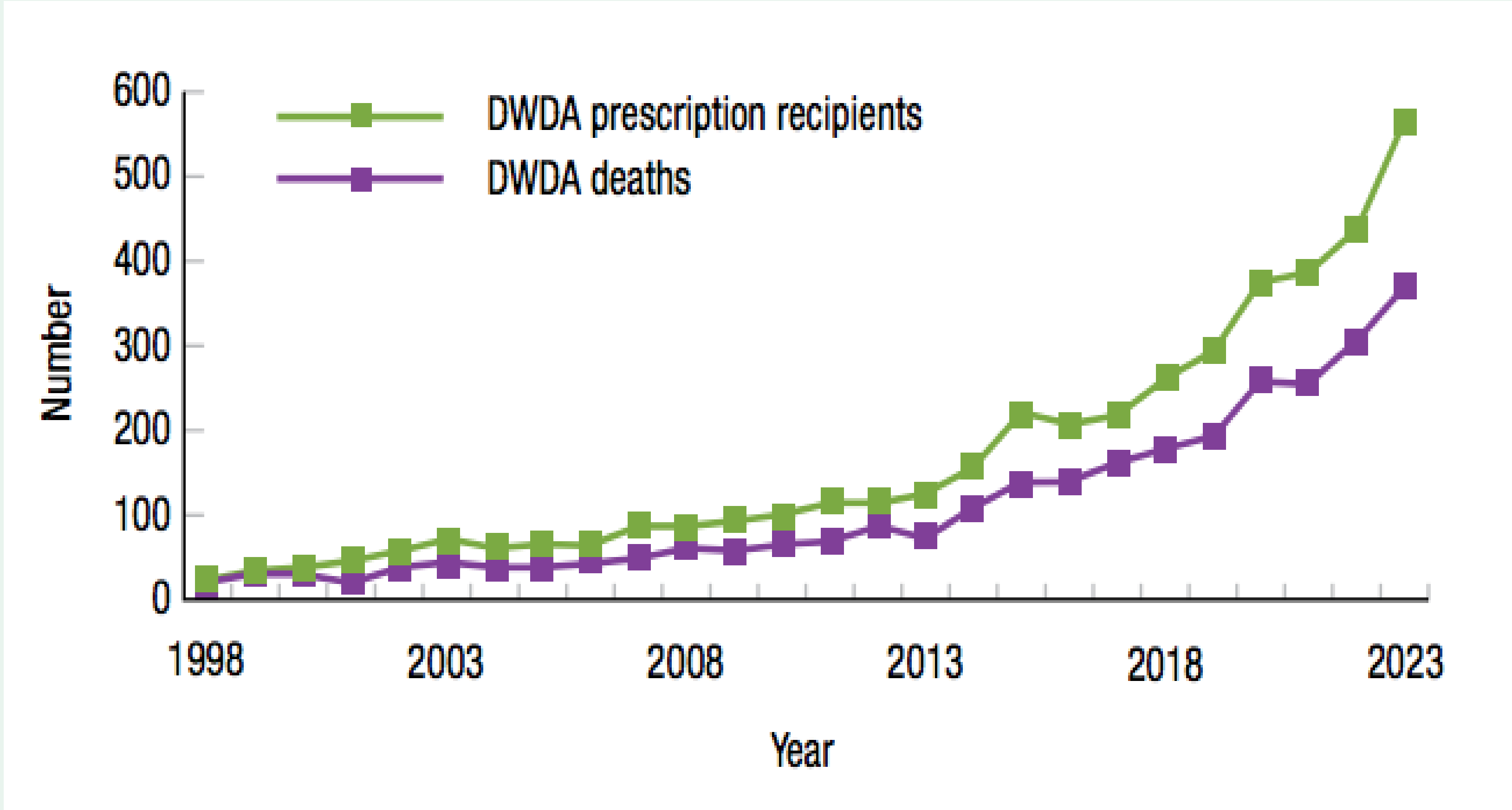
Prescription Requirements

- 1 written request, 2 witnesses
- 2 verbal requests, 15 day waiting period *
- Prescribing & consulting physicians must confirm diagnosis/prognosis, determine patient capability, consider mental health referral
- Patient informed of alternatives (ie: palliative, hospice care)
- Legal protections for patient, MD's, pharmacist
  - * As of January, 2020, patient is exempt from waiting period if it exceeds their life expectancy

What is prescribed?

- Previously Seconal. (Secobarbital). Discontinued and no longer available.
- Currently, a compounded mixture of medications is utilized, including pain medication, a sedative, anti-anxiety, antiarrhythmic, in some cases, a beta blocker may be included in the compound
- Usually capsules are emptied of the powdered drug and stirred into a liquid. Patients must ingest it quickly to avoid falling asleep before all is ingested.

25 years of data



Oregon Health Division Data

- Since the law was passed in 1997, total of 4,274 people have had DWDA prescriptions written and 2,847 have died from ingesting medications prescribed under the DWDA
- During 2023, the rate of DWDA deaths was .8% of total Oregon deaths
- In 2023, 560 lethal prescriptions were written, 367 patients took the medication

Patient characteristics

- Of the DWDA deaths during 2023, most patients (82%) were aged 65 years or older. The median death was 73 years. As in previous years, decedents were commonly white (94%) and well-educated (50.0% had at least a baccalaureate degree).

- Patient's underlying illnesses were similar to those of previous years. Most had cancer (66%), followed by heart disease (10%) and neurological diseases (ALS-11%).

Oregon Health Division Data

- Most died at home (88%) and most (87%) were enrolled in hospice
- Excluding unknown cases, all had some form of health insurance
- Similar to previous years, the three most frequently mentioned end-of-life concerns were:
  - Decreasing ability to participate in activities that made life enjoyable (92%)
  - Loss of autonomy (89.5%)
  - Loss of dignity (64%)

End of Life Concerns

Oregon Public Health Division (1998-2023 N: 4,274)

- Losing Autonomy 91.5 %
- Less able to engage in activities making life enjoyable 88.9%
- Loss of dignity 80.6%
- Losing control of bodily functions 50.1%
- Burden on family, friends/caregivers 40%
- Inadequate pain control or concerns about it 23.7%
- Financial implications of treatment 2.9%

Existential Challenges

- Many people experiencing terminal disease, face numerous existential challenges

- It is not uncommon to think about death in this situation, though these thoughts are not necessarily indicative of suicidal ideation

Conclusions..

- Patient advocates, concerned citizens, medical providers should continue to evaluate the concerns of people who consider this option
- Aggressive symptom management and referral to hospice should always be provided
- More study is needed. The data from Oregon represents its population and may not be easily generalizable to more diverse states.

Chloë "Izzy" King

SENIOR CAMPAIGN ORGANIZER,
COMPASSION & CHOICES ACTION NETWORK

RobynGabel
STATE REPRESENTATIVE, 18TH DISTRICT

Representative Robyn Gabel (18th)

ILLINOIS STATE REPRESENTATIVE AND
CHIEF SPONSOR OF THE ILLINOIS END-OF-LIFE OPTIONS ACT

Biography

- **Represented the 18th House District since 2010**
  - The 18th District includes Evanston, Wilmette, Kennilworth, Winnetka, and part of Chicago's Rogers Park neighborhood
- **Appointed House Majority Leader by House Speaker Emmanual "Chris" Welch in 2023**
- **Chair of the Rules Committee, lead negotiator of the House budget team, and co-chair of the Energy Working Group. Former chair of Medicaid Working Group.**
- **Prior to being elected, was the Executive Director of Illinois Maternal and Child Health Coalition, now EverThrive, from 1988-2010.**

Medical Aid in Dying - Illinois Legislative History

- **1997 - First Death with Dignity Act introduced in Illinois in the 90th General Assembly. Neither HB0691 nor SB0948 advanced**
- **February 2024 - SB3499, End-of-Life Options for Terminally Ill Patients Act introduced by Senator Linda Holmes**
  - The bill passed first reading and was referred to the Senate Subcommittee on End-of-Life Issues, where it does not advance.
- **January 2025 - End-of-Life Options for Terminally Ill Patients Act introduced in the Senate by Senator Holmes (SB0009) and in the House by Leader Gabel (HB1328)**

Current status

- SB0009 assigned to Executive Committee and had a public hearing on March 5
- HB1328 re-referred to Rules Committee

General Intent

- **Authorizes a qualified patient with a terminal disease to request that a physician prescribe aid-in-dying medication that will allow the patient to end the patient's life in a peaceful manner.**
- **Allows terminally ill patients to choose their own end-of-life care. Medical aid in dying is but one of the full range of end-of-life options from which terminally ill patients can choose.**
- **As someone who has spent my entire career advocating for better health care and human services, I view medical aid in dying as a compassionate choice for people who are suffering to end their own lives with dignity**

"Qualified patient" means an adult Illinois resident with the mental capacity to make medical decisions who has satisfied the requirements of the Act in order to obtain a prescription for medication to bring about a peaceful death.

- No person will be considered a qualified patient under this Act solely because of advanced age, disability or a mental health condition, including depression.

"Terminal disease" means an incurable and irreversible disease that will, within reasonable medical judgment, result in death within 6 months.

Guardrails

There are significant safeguards for patients and their families written into the law, some of which include:

- Nothing in the law requires terminally ill patients to use aid in dying care.
- Qualified individuals must be able to self-administer (i.e., self-ingest) the medication.
- There must be two verbal requests for the medication directly from the patient, with a 5-day waiting period between the first and second request.
- The law includes multiple protections to prevent coercion including strict eligibility requirements, two separate physician assessments, and mandatory counseling on all treatment options.
  - *The law makes it a felony to coerce someone to request the medication or to forge a request.*

There are adequate guardrails for the medical profession.

- Health care professionals and entities are not required to provide aid-in-dying care *(consistent with the Healthcare Rights of Conscience Act HCRCA).*
- Healthcare providers who participate and comply with all aspects of the law are given civil and criminal immunity.

Khadine Bennett

ADVOCACY AND INTERGOVERNMENTAL AFFAIRS DIRECTOR,
ACLU OF ILLINOIS

Moderated discussion

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Thank you!

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 June 6, 2025, 8:30-10:30am
- Registration / details will be shared in May via ASA listserv
  - *Rush team will also share registration details in follow-up from today's event*

And, we hope to see you soon at ASA's On Aging conference in Orlando!

- April 21-24, 2025