Death Doulas, End of Life Options and Aid in Dying

Presented By: MaryKay Brady & Thalia DeWolf

End of Life Options New Mexico

March 16, 2022

Presenters

MaryKay Brady
EOLONM Board of Directors
Trained End of Life Doula

Thalia DeWolf, RN
Doula & Bedside Attendee Trainer
Director of Nursing Education, ACAMHD

Learning Objectives

• Understanding of the Doula approach to death
• Value individual autonomy and choices at the end of life and the role of the doula in supporting them.
• Awareness and understanding of the requirements of New Mexico’s new Elizabeth Whitefield End-of-Life Options Act (aka medical aid in dying).
• Appreciation of the importance of language and checklists.
• To discuss the day of dying
Birth & Death

Birth and death are the bookends of life, yet we welcome one and dread the other.

Why is it that birth is celebrated, but death is taboo?

Death History

- For most of human history, people were cared for at home
- Mid-20th century that changed due to medical advancements in technology for diagnosis and treatment
- In 1980, 60.5% of people died in hospitals
- By the mid-1980’s, this number peaked, but has now decreased

Naturalizing Death

- Studies have shown that approximately 80% of Americans would prefer to die at home, if possible.
- Despite this, 60% of Americans die in acute care hospitals, 20% in nursing homes and only 20% at home.
- There’s a movement for death to be less medicalized and more natural.
Enter the Death Doula

- A doula is Greek, meaning woman (person) who serves
- Many of you are probably familiar with birth doulas
- Death doulas serve a similar function at the other end of the life cycle

What are Death Doulas?

Doulas are non-medical companions to the dying and their loved ones. We...
- Advocate for wishes and needs of the dying person
- Complement hospice personnel
- Provide care with a wide range of holistic services, including physical, emotional, spiritual and practical support
- Coordinate support networks of loved ones and friends
- Strive to be a calming presence to all parties
End of Life Doula

- Basically, we are your personal advocate, cheerleader, companion, guide, ear, rock – whatever you need us to be
- No one who wants support at the end of life should have to go without

Doula Training

Our training gives us the ability to provide the specifics of the dying process in a calm, supportive manner.

This way the loved ones are free to spend their time together in a peaceful and meaningful way without the stress of navigating the details of dying.

Doulas Will Never...

Disrespect a client on the basis of age, race, creed, color, religion, national origin or ancestry, disability, veteran status, sexual orientation, gender/gender identity or expression, or any other factor.
**What Do Doula's Do?**
- Listen
- Hold space
- Create legacy projects
- Write letters to loved ones
- Honor wishes of the dying and loved ones
- Handle logistics

**What Does it Take to Be a Doula?**
- Ability to talk about death and dying comfortably
- Compassion
- Giving the gift of your time

**Covid 19 and the Doula Profession**
- University of Vermont Doula program began in 2017 with 200 enrolled. In 2021, that number grew to more than 600
- During the pandemic, The National End of Life Doula Alliance grew to more than 1,000 members in 2021, up from just 200 in 2019
- For instance, one Doula's business - The Dying Year - got about 6 calls a year pre-COVID and now receives 3-4 calls per month.
Medical Aid in Dying: A New Option in New Mexico

Elizabeth Whitefield End-of-Life Options Act

Medical aid in dying is the medical practice wherein a health care provider prescribes medication to a qualified individual who may self-administer that medication to bring about a peaceful death.

The law went into effect June 18, 2021

Who Qualifies To Use The NM Law?

- New Mexico residents,
- Adults, 18 years or older,
- With a terminal illness (defined as 6 months or less to live),
- Individual must voluntarily make the request for MAID,
- Must be able to self administer the drug, and
- Must have capacity to make and communicate an informed decision.
The Role of End-of-Life Doulas & Bedside Assistants in Supporting Medical Aid in Dying

Doulas and Medical Aid in Dying

The doula role in medical aid in dying can be invaluable. But traversing the landscape of a medical aid in dying death can be challenging. It involves:

1. the timing of the medication
2. the mixing of the medication
3. knowing the process of dying
4. educating about the dying process
5. making phone calls to the hospice and funeral home following death

MAID Medications

What they are:
- 3 sedatives
- 2 cardiac medications

How they work:
- Stop breathing
- Stop the heart
**Myths and Hopes of MAID**

This is easy, NO!
Unforeseen issues can develop...
Pharmacy (medications on hand)
Time to prepare
Client can change their mind

---

**Preparing For The Day**

3 things to consider:
- Guts – Swallow, Feeding tube (self administer), what doulas do not do – Rectal (self-administer)
- Brains – Mental Capacity
- Drugs – Practice swallowing ahead of time, Drug Tolerance, limiting intake prior to the day

---

**Preparing For The Day**

Red Flags:
- Drugs
- Athlete
- True complications:
  - Long time to die
  - Normal signs and symptoms of dying
  - Unpleasant for the family, not the dying
- Why a bedside attendant helps
- Loved ones must be prepared and supported
Medical Aid in Dying Checklist for Doulas

About the Client
- Check on current issues and problems
- Obtain information about loved ones and/or family and friends
- Where will the client be taking the medication?
- Who will be present?
- Personal touches (music, photos, blanket)
- Any religious or spiritual beliefs?

Get the Details
- Diagnosis
- Current medications
- Prescribing doctor name and contact information
- Hospice information and contact information
- Take photos of MAID medications
- Take a photo of MOST form, EMS/DNR
Details, continued

- Take a photo of advanced directive
- Inquire about funeral home and arrangements
- What are the parameters for doula staying on the day of ingestion – hours present?
- Discuss what will happen if something goes wrong
- Reassure client that they will be coached through the ingestion process
- Schedule the desired day and time of ingestion

Two Days Prior to Ingestion

- Check for any changes in patient’s condition
- Conduct a swallow test
- Review MAID medications and the timeline for the day of ingestion
- Inquire about sorbet, alcohol, apple juice
- Doula will be in touch the day before ingestion
- Clients last meal, early dinner the night before
- Clear liquids/no dairy/no carbonation after dinner (apple juice, clear broth, water)

Day of Ingestion

- Doula will bring a tray, apple juice, measuring cup, funnel, bowl, spoon, napkins, sorbet, paper towels, gloves, towels, note cards and colored pens
- Provide education about the dying process as it is unfolding
- Upon death, call the hospice
- If requested, doula will call the funeral home
- Document time of ingestion of MAID medication, time to unconsciousness, time to death (provide this information to prescribing doctor)
- Follow up with loved ones 2 weeks after death
Q&A

Contact information

Thalia DeWolf
Information on Medical Aid in Dying
ACAMAID@ACAMAID.org

MaryKay Brady
Information on Doulas and End of Life Options in NM
jmtranch@ymail.com
575 546 1931

A New Resource in New Mexico

End of Life Options New Mexico

EOLONM works to help...

- Individuals and families know and plan for end of life options
- The public, community leaders, and the media be informed
- Healthcare professionals access education, training and support
- Healthcare systems and hospices support their patients’ choices
- Patients and families access the new medical aid in dying law

www.endoflifeoptionsnm.org
American Clinicians Academy on Medical Aid in Dying

The Academy informs and educates about medical aid in dying,

- from clinical discussions
- to evidence-based knowledge,
- from nursing care
- to the work of volunteers at the bedside,
- from medical ethics
- to pharmacology, and more.

ACAMAID Training Resources

- Aid-in-Dying Training for End-of-Life Doulas - Part 1 (45 minutes)
- Aid-in-Dying Training for End-of-Life Doulas - Part 2 (45 minutes)
- Mock Aid in Dying video
  (on patient tab on website, under Dying Day)
  www.acamaid.org

Doula Organizations & Training Resources

International End of Life Doula Association (INELDA)
www.inelda.org
Changing the face of dying. Organizational values: advancing anti-racism, loving service, listening deeply, holding space, taking ownership, advocating courageously and fostering empathy.

National End of Life Doula Alliance (NEDA)
www.nedalliance.org
Seeks to inspire positive, creative change in American death practices by creating high standards, ethical and practical guidelines, and rich networking opportunities for all EOL Doula’s, resulting in meaningful experiences for the dying, their caregivers, and the agencies involved.