How End-of-Life Doulas Fill the Gap in End-of-Life Care
I have no actual or potential conflict of interest in relation to this presentation.

Joan Bretthauer, MS, Certified End-of-Life Doula
October, 2022
Learning Objectives

• You will have an understanding of the End-of-Life Doula scope of services and benefits

• You will have an understanding of how key elements between the End-of-Life Doula, Hospice, and Palliative Care makes collaboration successful

• You will have an understanding of how an End-of-Life Doula enhances the Hospice/Palliative Care Team Operations

• You will have an understanding of how an End-of-Life Doula enhances the patient’s experience
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?

- Virginia Chang Ph.D.
Doula

Birth Doula

- A doula is a professional labor assistant who provides physical and emotional support to you and your partner during pregnancy, childbirth and the postpartum period. For instance, a doula might offer: Attention to physical comfort through techniques such as touch and massage and assistance with breathing.

End-of-Life Doula

- An End-of-Life Doula is a non-medical professional that provides holistic support for the dying and their loved ones before, during, and after death. Trained in the various end of life stages a Doula is able to assist the family with understanding the natural processes while providing comfort and support.
History & Evolution of the End-of-Life Doula (EOLD) Role in the U.S.
History & Evolution of the EOLD Role in the U.S.
First EOLD Program at Continuum Hospice, New York City, 2003

• Henry Fersko-Weiss developed this program, at Continuum Hospice

• Social worker by training

• Program was based on techniques and philosophy of birth doulas

• Henry adapted and translated that work into the end of life

• In February 2015 Henry Fersko-Weiss and Janie Rakow co-founded the International End-of-Life Doula Association (INELDA)
Quality of Life Care Certified
EOLD Program Created in 2005

- Deanna Cochran developed the first End-of-Life Doula Certificate Program in the United States
- She developed it in response to a flood of inquiries about her own professional end-of-life doula practice
- Deanna is an RN and worked in Hospice and Palliative Care
- She began to serve in this capacity after the death of her mother
- This was the first time a certificate program that included laypeople, as well as healthcare professionals, was available
History and Evolution of the EOLD Role in the U.S.

• Much has contributed to the widespread present-day acceptance of the EOLD role

• There are many people that made things happen in their own communities, calling themselves various titles, all working towards the same thing: empowering people at the end-of-life in choice of medical treatments, dying, and funeral options

• For more information click here
What is an EOLD
What is their Scope of Services & Benefits
What is an EOLD

- EOLDs are non-medical companions to the dying and their families
- EOLDs do not take the place of hospice personnel; rather, they complement other services that a dying person and their family may be receiving, including hospice or palliative care
- EOLDs provide a wide range of holistic services, including physical, emotional, spiritual, and practical support
- EOLDs may work with families from initial diagnosis through bereavement

NHPCO End-of-Life Doula Advisory Council
An EOLD can also be known as

- Death Care Educator
- Death Coach
- Death Doula
- Death Midwife
- Doulagiver Practitioner
- End-of-Life Care Doula
- End-of-Life Coach
- End-of-life Consultant
- End-of-Life Educator
- End-of-Life Guide
- End-of-Life Midwife
- End-of-Life Practitioner
- Soul Midwife
- Thanadoula
- Transition Guide
Alua Arthur

• Los Angeles based death doula Alua Arthur 3:23

• Going with Grace training

• Death has historically been a taboo topic in western culture but with the rise of the death wellness industry, the conversation is coming out of the shadows
Services & Tasks of EOLDs
Services & Specific Tasks of EOLDs

*Coordination and Navigation*

- Advance Care Planning, including organ donation
- Liaise with Hospice, Palliative Care, other health care workers, and other community services
- Facilitate legal paperwork in conjunction with relevant professionals such as estate planning, advance directives, power of attorney
- Referral to community resources - practical, emotional, spiritual
- Organize informal care networks
- Keep family members informed
- Coordinate family and friend visits
- Provide vigil planning
Emotional and Spiritual Support

- Ask questions to understand emotions
- Meaning - structured life review sessions
- Discuss values and desires - spiritual beliefs
- Legacy work - narrative work, assisting clients to write their life stories; ethical wills, write/record last messages
- Visualization, guided imagery, meditation, tapping; breath work, healing touch, and energy work (e.g. Reiki, massage)
- Music - singing, playing instruments, drumming, listening to favorite songs/music
- Generalized predeath and post-death bereavement support - talking, listening, and giving resources
Services and Specific Tasks

Death Literacy and Information Transfer

- Help explain diagnosis and treatment - help client get needed information
- Normalize end-of-life - provide practical information about what to expect - explain common signs and symptoms at the end-of-life
- Provide practical information about basic end-of-life care for family/friends
- Inform family/friends about what they can do during active dying and after death - get into bed with the person, tell stories, washing the body,
- Community work and advocacy - advance care planning workshops, death cafes, public speaking
- Informal/spontaneous conversations about end-of-life planning and care with friends, family, and community members
Companionship and Presence

- Listen - client reminiscing
- Unstructured conversations
- Read together - scripture, prayer, favorite books/poetry, newspaper, comic strip
- Hospital appointment accompaniment - if necessary
- Hospital/hospice in-patient visiting
- Vigil - being present during the active dying phase, including talking and/or singing even if unresponsive
- Create bedside rituals - lighting a candle, blessings, music
Services & Specific Tasks

Basic Practical and Personal Care

- Regular assessment of pain and symptoms
- Respite for family members
- Light massage and/or use of essential oils for pain and symptom management
- Vigil care - mouth care, repositioning in bed, changing bedsheets, applying cool compress
Services and Specific Tasks

*After-Death Care*

- Body care - instructing family on washing the body
- Instructing family on keeping the body at home after death
- Check-in with client’s family after a period of time - including bereavement support

*Describing the end-of-life doula role and practices of care: perspectives from four countries (sagepub.com)*
Limitations to an EOLD Practice

As non-medical care providers, end-of-life doulas do not perform clinical tasks (e.g., monitor vital signs, administer medication),

The doula refrains from giving medical advice or from persuading clients to follow a specific course of action or treatment,

The doula refrains from imposing his/her own values and beliefs on the client,

Doulas do not undermine their clients’ confidence in their caregiver(s). Instead, the doula uses good listening skills to support clients who initiate a discussion about dissatisfaction with a caregiver’s practice or attitudes,

Doulas do not usurp the role of other professionals and caregivers such as the nurse, social worker, chaplain, home health aide, etc.
Dementia Directive
Voluntarily Stop Eating & Drinking VSED

- Dartmouth Dementia Directive
- Dementia Directive by Dr. Barak Gaster and et al
- Compassion & Choices
- End-of-Life Choices New York
Dignity Therapy Research

The effect of dignity therapy on distress and end-of-life experience in terminally ill patients: a randomized controlled trial

Objectives

• Dignity Therapy is a unique, individualized, brief psychotherapy, developed for patients (and their families) living with life-threatening or life-limiting illness

• The purpose of this study was to determine if Dignity Therapy could mitigate distress and/or bolster end-of-life experience for patients nearing death

Interpretation from the Study

• Despite the beneficial effects of Dignity Therapy, its ability to mitigate outright distress, such as depression, desire for death or suicidality, has yet to be proven

• However, there is currently ample evidence supporting its clinical application for patients nearing death, as a means of enhancing their end-of-life experience
Client Educational Material
Training and Education
EOLD Training & Education

• There are several certifications and educational training programs across the country

• Each program is curated based on the practices and beliefs of their training center, presented using professional or expert knowledge

• Though death doulas all serve at the end-of-life, each training program may have a different set of guidelines
Who Can Become an EOLD

- Anyone who wishes to serve at the end-of-life can qualify to be a death doula. This might include caregivers, holistic practitioners, nurses, and other medical professionals
- Some courses will provide continuing education units
Do EOLDs Have To Take An Exam

- Training centers usually have a written and practical exam to receive a certificate
- You do not need to have any prior training in medical, mental health, or spiritual fields
- The only prerequisite needed is an open mind and heart
- Training program will provide you with the knowledge and tools needed
How Much Does the Training Cost

• They range from $750 to $3000+ depending on the program length

• Some of the training programs have various phases and others can be completed in 2-3 days

• Opportunities for scholarships may be available
What Will the Training Program Provide

• Each training program is different
• They all embody similar practices and principles
• You learn how to offer spiritual, emotional, and physical comfort to your clients
• The training teaches you how to be present with death and how to listen with compassion
• Learn how to help clients navigate their logistical end-of-life plans
• In some trainings you learn skills for family grief-work pre and post-death
Specific Training – Example A

- Shock Phase
- Stabilization Phase
- Transition Phase
- Most Common Medication Used at EOL

Top Ten Diseases at EOL:
- Emphysema, End-Stage COPD, Lung Cancer, Liver Cancer, Pancreatic Cancer, Dementia, Stroke, Colon Cancer, Brain Cancer, Breast Cancer, ALS

- When Science Meets the Bedside – Spiritual Wisdom
- Doula Comfort Kit
- Advance Directives

- Self-Care Practice
- EOL Planning – Obits, Eulogies, Creating Remembrances
- EOL - Options Funerals, Cremations, Green Burials/Natural Burials, Life Celebrations
- What to do when a patient dies

- The Truth about Children and Death
- Grieving and skills to Grieve
- EOLD Mission Statement and Code of Ethics
- Business information on Starting Your Doula Practice
Specific Training - Example B

- Evolution of Doulas
- Considering Culture
- Considering Your Mortality - Journaling
- Next Steps

- Life Themes
- Exploring Meaning
- Vigil Planning
- Self-Care

- Legacy Work
- Signs & Symptoms - Months to Weeks Before Dying
- Conducting Vigil - Guided Imagery, Rituals
- Early Grief & Reprocessing
Specific Training – Example C

- Introduction to EOLD Doula Work – Dying Persons Bill of Rights, Role & Scope of EOLD, Intro to Hospice & Palliative Care
- Introduction to Grief & Commonalities within EOL Experiences
- Understanding the Patients Experience
- Appropriate Professional & Personal Boundaries

- Turning toward Suffering – Dignity Therapy, Active Dying Process, Needs of the Client, Self-Care
- Religious/Cultural Beliefs & Practices
- Setting Intention, Comfort Measures, Guided Imagery, Environment, Vigil Planning & Sitting
- Doula Bag
More and more people are choosing to die in their homes instead of in hospitals. The New England Journal of Medicine reports the number is the highest it's been since the early 1900s. So families are turning to trained caregivers for support. NPR has the story.
There is nothing inherently medical about dying.
   It’s much larger than medicine.
   It is purely human.
Part of the mission is to keep all of this couched in humanity.
   Not in medical science or social science,
   but really in the full arch of humanity itself.

Dr. BJ Miller, End Game (Sidewinder Films, 2018)
National EOLD Alliance (NEDA)
National EOLD Alliance (NEDA)

• A non-profit membership organization
• Welcomes and supports all end-of-life doulas, trainers, and interested parties, regardless of background or level of experience
In order for EOLDs to provide consistent and high-quality care, NEDA has developed “Core Competencies” to inform doula training curricula. In addition, we have established **Scope of Practice** and a **Code of Ethics** for ethical, professional EOLD practice.

An individual EOLD may choose to obtain the [NEDA Proficiency Badge](#), based on [NEDA Core Competencies](#), to assess whether their knowledge and skill are comparable to other EOLDs that meet an agreed-upon standard. However, this is voluntary.
National End-of-Life Doula Alliance

Core Competencies:

Communications:
- Patient and family advocacy
- Cultivating key community relationships
- Active listening/critical thinking
- Conflict resolution/family dynamics
- Creative problem solving

Values & Ethics:
- Doula model of care
- Biopsychosocial and spiritual dimensions
- Cultural humility
- Personal integrity
- Accountability
- Boundaries and legalities

End-of-Life Doula Competencies:

Professionalism:
- Self-care
- Scope of Practice
- Confidentiality
- Professional development
- Business skills and tools
- Medicare CoPs

Knowledge:
- Patient support
- Caregiver support
- Planning needs
- Referrals and systems
- Roles and responsibilities
- Legal & medical knowledge
Midwest EOLD Collective

Mission:
Is to transform the end-of-life experience through awareness, collaboration, and advocacy.

Purpose:
Is to educate the public, health care providers, and individuals regarding end-of-life care and the role of the end-of-life doula; to expand our knowledge, to collaborate and to provide a community of support among doulas, to welcome all who care about end-of-life (inclusivity), to empower those who are dying and their loved ones.
What is the Difference Between Hospice/Palliative Care & EOLDs
Differences Between Hospice, Palliative Care & EOLDs

- EOLDs do not provide medical care
- EOLDs work in conjunction with hospice/palliative care programs to provide interpersonal, social, logistical, and spiritual guidance that complements the care they receive
- Hospice/Palliative Care is regulated by Medicare rules - limiting the time staff is allowed to spend with patients and families
## Differentiation of EOLDs from the Hospice/Palliative Care Team

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<tr>
<th>Hospice/Palliative Care Team</th>
<th>End-of-Life Doula</th>
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<td>Plan the Medical Care</td>
<td>Reinforce the Medical Care Plan</td>
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<td>A Medicare/Insurance Benefit for People</td>
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<td>Licensed Roles</td>
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<tr>
<td>Care Clearly Defined - Same State by State</td>
<td>Skillset May be Different Depending on Training</td>
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<tr>
<td>Provides Clinical Care</td>
<td>Provides Practical Non-medical Care</td>
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Overlap of EOLD with the Hospice Team

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<th>Emotional and Spiritual Support and Care</th>
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<td>Ceremony Planning</td>
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<td>Bereavement Care</td>
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Palliative Care & EOLD
Beth Patterson

- Introduce EOLD to patient/family in a clinic or primary care setting
- Have the EOLD follow up with periodic home or clinic visits
- Have EOLD continue outreach if patient is in facility
- Have the EOLD help while patient is inpatient
- Have the EOLD continue to follow through disposition, etc.
Role of the Palliative EOLD

- EOLDs can help to provide continuity across settings that may lead to patient’s wishes being verbalized, witnessed and honored more consistently.

- Beth has finished two national end-of-life doula trainings.

- Has found the perspectives, tools and preparation to be an excellent adjunct to her chaplain training, and to the palliative care fellowship she completed in 2020.

- Beth’s hope is to discern how doulas can be of more service within the palliative care domain.
Why Do We Need EOLDs

- Palliative and Hospice have a limited amount of time to be with the patient and family
- EOLD provides an additional support system to patients and families with no time limit or time restrictions
- EOLD reinforces education for better patient compliance
- EOLD serves as the eyes and ears of the Palliative/Hospice program
- EOLD can take the time to address some of the things that have been fragmented in care
- One of the biggest advantages is the continuity of care and consistent support
How Much do EOLDs Charge for Services

• Services are private pay
• EOLDs are independent contractors
• Every client is unique and so is their situation
• Costs for services vary
• Some offer packages that are tailored to the specific need and time frame
• Some may charge an hourly rate that ranges from $45 to $125+
• Some have a flat fee
• Some provide rates on a sliding scale
• Some will offer services for free
Does Hospice Approve of EOLDs
The purpose of The End-of-Life Doula Council is to be able to share with Hospices and families how the Professional End-of-Life Doula can assist and complete the hospice team to fill in “the gaps in care” and allow for the best end-of-life experience for both the patient and their loved ones.

Committees and Councils are vital components of NHPCO and its affiliate organizations, providing leadership, technical service and educational assistance to the members and the public.
Inaugural NHPCO End-of-Life Doula Council Meeting April 25, 2018
History & Importance of NHPCO EOLD Advisory Council

• February 2018, The National Hospice and Palliative Care Organization invited EOLDs to the table

• Deanna Cochran received a phone call from Director of Governance and Board Relations within the NHPCO, Beth Fells

• Inviting EOLDs to educate member hospice and palliative care organizations about what EOLDs are and how to utilize us

• John Mastrojohn, COO of NHPCO at the time, saw the potential of this new group of service providers

• Had John not been the visionary that he was, the Council may never have come into being. We owe a lot to him

• Inaugural meeting of NHPCO End-of-Life Doula Advisory Council was April 2018

• Deanna led the charge, serving as Chair of the Council for nearly 3 years

• EOLDs are now recognized by mainstream healthcare organizations, and it is only a matter of time before EOLDs are known just like the birth doulas are now
Deanna Cochran said...

It is beyond anything I could have imagined that our oldest and largest hospice trade organization would recognize EOLDs on this scale. This is one of the single most important developments in our history and the pinnacle of my career to have played a part in it.
To practice dying in our culture is not often seen as safe or advisable.

But if our culture was to recognize that death and life are inseparable, our approach to both might be quite different.

— Halifax, 2009, p. 49. Being with Dying
Benefits & Outcomes For The Hospice & Palliative Care Team
Benefits & Outcomes For The Hospice & Palliative Care Team

Problem:
- Patients are in need of care & caregivers are exhausted and emotionally drained

Situation:
- Your days are filled with multiple visits, you’re pressed for time, and you have a caregiver who needs so much more time than you can give – even though you want to stay, you can’t because the nature of your job is intermittent visits
- You feel the draw of needing to stay to support them, but your schedule is full of visits for the day
- At times you feel like you aren’t doing enough – but it’s impossible to do so

Solution:
- Imagine the peace of mind you could have using an EOLD who can reinforce your teaching and calm the family in your absence
- Having an EOLD present increases caregiver confidence because we spend a lot of time praising, educating and encouraging the caregiver
- EOLDs spend a significant amount of time seeing a problem through, allowing the caregiver to vent, and support them in this difficult time
Appropriate Referral to an EOLD

- 95-year-old patient whose wife is constantly calling the office
- Asking the staff questions about resources and advice because the wife is afraid to go it alone
- The wife is hounding the staff constantly with phone calls about menial things
- This family member needs a lot of attention
- By the staff taking these types of calls it takes away a lot of their time from doing other more productive tasks
- Wife has several questions that need individualized attention
- Appears the wife really needs more hand-holding through the end-of-life process
- Wife may have a lot of emotional fears that are not necessarily directly medically related
Referral to EOLD Con’t

• These types of calls are beyond the scope of the staff
• They don’t have time to handle that volume of calls
• This type of client is how an EOLD can make the staff’s job easier
• EOLDs are here to help
• We can fill in the gaps where patients are contacting the office and taking up all your time
• The staff could be devoting their time to their job, to other patients, or to help other staff members
• In this example the staff is spending too much time on out-of-scope responsibilities
• EOLDs do provide individualized attention for patients who really need more hand-holding through the end-of-life process
Results of this Referral to the EOLD Con’t

• Allowing the EOLD to address these uncertainties and fears with regard to the illness process, the care team ends up seeing a patient’s wife that is calmer, in a better mental state, less fearful and less chaotic.

• The care team doesn’t really have time to go in-depth into the emotional distresses of the end-of-life process,

• Having the EOLD as part of the process would help streamline seeing patients, and that allows the team to have more available time to see more patients or gear the time with patients in a way that’s more productive.

• This is how an EOLD can help your operations and help your practice to be better, more efficient, more productive, to have better interactions with your patients when the EOLD is working with them simultaneously.
How Does An EOLD Enhance The Patients Experience
How Does An EOLD Enhance The Patients Experience

An elderly man with a terminal illness is afraid to die. He fears for the family he will leave behind—his wife, children and grandchildren—and how they will cope after he is gone. He has not expressed this fear to his doctors or to his wife, who is already handling so much. I listen. I hold space for his despair and angst. He realizes the fear is based on his immense love for his family. He drinks champagne with them on his deathbed. Reconciliation with the things that are important can allow one the peace to let go.

- Virginia Chang Ph.D
Despite her wish to die at home, an elderly woman is taken to the hospital by her son, who can no longer bear to watch his mother die in excruciating pain. The hospital wants to discharge her, finding nothing wrong, and, at her age, what can be done anyhow? The family is distressed by the hospital’s response and calls me. I suggest that they ask for a palliative care consultation. Eventually, the mother is placed on a proper pain management plan and discharged to hospice care. How do you know what to ask for, if you don’t know the choices?

- Virginia Chang Ph.D
How Does An EOLD Enhance The Patients Experience

A middle-aged man lies actively dying, completely nonresponsive, in his bed. He displays “death rattle” breathing, and his body has occasional violent spasms. At his bedside, a petite woman sits, his aunt, pained to watch her nephew die this way. After creating rapport with the aunt, I seek to alleviate her distress and encourage her to speak to him. The aunt responds gratefully, awakened to the possibility of making a difference for her nephew. He dies peacefully, immersed in soft light, music and love. Sometimes all a loved one needs is permission to be an active participant in the process, to turn helplessness into empowerment.

- Virginia Chang Ph.D
Everyone is impacted differently by the process of dying and by each death.

It doesn’t matter how many times you have visited it, each journey is different.

— LeAne Austin, RN, End-of-Life Doula
Any Questions?

Thank you for participating in this conversation
Resources

• https://www.eoluniversity.com/  End of Life University Dr. Karen Wyatt

• Ethicists make case for doulas in end-of-life care for most vulnerable

• CAKE End of Life Platform Founded by MIT and Harvard Alumni (joincake.com)

• https://wingsofchangepublications.com/
• Helping others was her way of life. And for this Doula…it also meant helping others accept the end of life.

• Follow along, as an End of Life Doula explains how and why this experience should be available for everyone.