A Calling To Care-
End of Life Doulas

An Evolution in End of Life Care
Lisa Kaufman, CMC, CTRS, EOLD
Owner, SeniorCare Options
Aging Life Care Management™
About Lisa Kaufman, CMC, CTRS, C-EOLD

- Lisa has owned and operated her Aging Life Care Management practice since 2001. Her role as a Care Manager has provided her the privilege of working with clients during their final chapters, and into the last days of their lives.

- This intense compassion and caring at the most tender of times has been a part of her intrinsic gifts. It prompted Lisa to seek a more specific means to provide for better care at this sacred time for her clients. Her journey as an End of Life Doula has launched in earnest.
What is a “Death Doula”?

• The term *doula* is an ancient Greek word that means a servant or slave.

• For the ancient Greeks, the doula was usually a female servant who helped the other women in the household perform all duties seen as “women’s work”.

• With the emergence of death doulas, the definition is changing to include both women and men.
What is a “Death Doula”?

- Throughout history, women have played a major role in handling the affairs of the deceased.

- Across cultures and religious traditions, women have been instrumental in the rites and procedures for preparing loved ones for the final repose.

- One possible explanation is that this role was seen as an extension of the women’s caregiving role for the members of the household.
What is a “Death Doula”?

- End of Life Doulas are people, both men and women, who help the dying and their families as death approaches.
- Doulas are used to give education, guidance, and support to the patient and their family during the end-of-life process.
- The Doulas are there to provide comfort, support and advocacy for the client and ensure that he or she doesn’t die alone.
What is a “Death Doula”?

- Similarities between Birth Doulas and Death Doulas are not accidental.

- Just as laboring mothers can benefit from a doula who is there to comfort and support them through labor, dying patients need support and comfort during their “labors” or the work of dying.

- Doulas have traditionally been companions and guides for those coming in to this world, and now do so for those leaving this world.
What is a “Death Doula”?

Death Doulas are also known by several other terms:

- End-of-Life Doula
- End-of-Life Companion
- Soul Midwife
- Transition Coach
- Death Midwife (However, there has been pushback in the community when using this term in the aspect of death.)
History

• In the US, the tradition of women’s roles for death preparation changed during the civil war.

• During this time, embalming became the standard method for preparing the body for burial. As embalming became more accepted, bodies were sent to professional embalmers to care for the deceased, thus taking the family and friends out of the process of caring for the deceased.

• Lately, there has been renewed interest in other, home-based medical services, and people looking to age in the home. This has helped give rise to the End-of-Life Doula movement.
Video: “Let Joy Flow – A Dying Woman’s Wish”
Duties

• End of life Doulas may not necessarily be medically trained, and they are NOT there to take place of nurses, social workers, homecare aids, hospice care, etc.

• The primary duty of the End of Life Doula is to offer support, education, and comfort to the patient and the family.
Duties

Typical doula duties may include:

• Allowing the patient the time and space for Life Review – and to examine regrets, unfinished business, grief and shame

• Creating a Legacy Project that has meaning for the patient, such as an Ethical Will or scrapbook

• Creating a “Vigil Plan” much like a birth plan for the bedside wishes of the patient. How do they want to be cared for at the time they need it most?

• Guided Imagery for pain and anxiety management

• Mediation and advocacy for the patient’s wishes to be carried out

• Sitting Vigil

• Attending to the needs of the patient and family

• Emotional support

• Providing education and resources to the family

• After death care and guidance, as well as bereavement support
Duties

- In-home doulas may have more flexibility in the amount of physical support provided versus hospital / hospice doulas.

- Examples of care that an in-home doula might provide include:
  - Light massage
  - Helping the primary caregiver change patient clothing or bedding

- Arrangements for the level of care by the doula are typically made with the family prior to the start of service.
Duties

Doulas DO NOT:

• Inject their own personal beliefs or traditions

• Provide medical services or degrade the quality of care provided by medical partners

• Take steps to actively hasten death (assisted suicide)

• Prescribe or suggest specific medical treatment plans
Life Review

- Life story
- People of profound impact
- Significant accomplishments
- RUGS
  - Regrets
  - Unfinished Business
  - Grief
  - Shame

I regret not listening to you. I never gave you any space. I didn’t respect you. I... I was afraid of you. I see now how stupid I was. I’m so sorry. Will you forgive me?
Legacy Projects

Highly personal “project” for the dying to create a lasting memory for family and friends. To impart wisdom, values, personality, and a lasting impression for the generations to come.

Can give a sense of purpose during the final months or weeks of a person’s life.
Case Study – Legacy Project

Mary B. – Artist. 86 y/o. Dx: COPD, Dementia, Impaired Hearing.
Mary B.
Mary B.
Vigil Planning

• What would you like your bedside and final days to look like?
  • Non-Medical Comfort Measures
  • Music
  • Aromas
  • Visitors
  • Pets
  • Readings
Sitting Vigil

• In the effort that no one “dies alone.”
  • Filling in when Hospice cannot provide CC
  • Create vigil shifts
  • Holding space
  • Educating family
  • Guiding how to say Goodbye
Grief Support

- Offers grief support after the death of a loved one.
- Can begin several days after the death
- Check-ins after one month, 6 weeks, and so forth to make sure the surviving family is getting their needs met. Refer out for Counseling as needed.
Training

- Social Worker Henry Fersko-Weiss pioneered the End of Life Doula model in 2003. It was based on his experiences as a birth doula and with hospice care.

- 2015 he founded the International End of Life Doula Association (INELDA)

- Still in its infancy, there are currently no local, state, national or international licensures available for End of Life Doulas

- However, there are a number of companies that provide End of Life Doulas training and program certifications, including, but not limited to: INELDA, Quality of Life Care, Doulagivers, Lifespan
• Hospitals, hospices and homecare providers are beginning to offer End of Life Doula volunteers and professional services to patients and their families.

• Since the profession is currently unlicensed, there is no clear number of End of Life Doulas in the US. The general agreement is the numbers are quickly rising. Some of the associations do provide a directory of those doulas trained in their program.
• Some doulas volunteer and donate their time and energy.

• Others are in private practice and charge a fee for their services.

• Medicare does not reimburse for End of Life Doula services.
Steps to become an End of Life Doula

- End of Life Doulas come from all walks of life – the medical community, corporate world, retired, etc.

- Look for volunteer opportunities, especially in hospitals or hospices

- Attend a training program – training companies have individual training programs and some hospital / hospices may have doula training programs

- Get certified by one of the End of Life Doula training companies (certifications are given by the training company and are not licensed by any government agency

- Get Liability Insurance
Lessons Learned

• This opportunity to serve as an EOLD has given me gifts just as much as what I strive to give my clients.

• What we all want...