WHAT IS AN END-OF-LIFE DOULA

Doulagivers®
What is a Doulagiver/End of Life Doula?

Doulagiver Presentation
“Doula” is a Greek word that means non-medical person that gives physical, emotional and spiritual support to someone else.
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.
An End of Life Doula can also be known as a Death Doula, Death Midwife, or End of Life Guide.

An End of Life Doula-
- Provides support and care for those in the last phases of life-limiting illness.
- Recognizes dying as part of the normal process of living.
- Focuses on quality of life for individuals and their family caregivers.
Why do we need End of Life Doulas if we have Hospice?
Due to Medicare reimbursement guidelines, the hospice team has a very limited amount of time that they are able to be with the actual patient and family. End of life is 24/7. The hospice team manages the care of the terminal patient. The hospice nurse is supposed to teach the loved ones how to do the care. These two factors are the main breakdown in the present Hospice model.
End of Life Doulas are now an intricate part of the main medical care team. EOL Doulas will be:

- Attending to the emotional, psychosocial and spiritual aspects of dying and caregiving
- Advocating for the patient and family
- Providing additional support system to patients and families with no time limitations or time restrictions
- Serving as the eyes and ears of hospice program
Other Significant Statistics:

- 78 Million people over the age of 65 in the US
- 9/10 people say that they want to be cared for at home at the end of life
- Death is the 2\textsuperscript{nd} leading fear in the US
- 20% of the 78 million elders do not have any children
End of Life Doulas are “Filling the Gap” in the end of life care team.
End of Life Doula Benefits to the terminal patient

- Provide companionship and presence – emotional support and interaction
- Earlier intervention – as they serve as they eyes and ears of hospice.
- Increased sense of autonomy
- Better coping skills and making family peace.
- Longer and more frequent visits as needed.
- Assistance with making memories, funeral arrangements, obituaries and memorials.
- Holding space and helping family members cope.
- Perform life review – validate sense of purpose
- Setting the sacred space – planning for smells, sounds, gentle touch during last days.
End of Life Doula Benefits to the family

- Continuous guidance and support with no time restrictions. Education on the natural end-of-life processes.
- Respite care – allowing and encouraging needed rest of caregivers and family.
- Reinforced family training – reviewing hospice care instructions.
- Compassionate presence throughout the dying process.
- Assistance with making memories, funeral arrangements, obituaries and memorials.
- Assistance with locating bereavement resources.
End of Life Doula Benefits to the Hospice

- **Earlier Referrals.** The median length of stay on Hospice to date is 20 days or less.

- **Increased Length of Stay.** Communities know about doulas and the EOL patient and family. This equals earlier admission = increased length of stay = increased revenue for the Hospice agency.

- **Increased Satisfaction.** Family and patient satisfaction scores increase, meaning happy families = positive word of mouth = increased revenue.

- **Increased Referrals.** Customer satisfaction and innovative programs lead to more referrals.

- **Increased Volunteer Recruitment and Retainment** – specialized training with service commitments allowing you to meet the 5% minimum

- **Enhanced Community Awareness and Interaction** – Families are requesting End of Life Doulas. Help to soften the “Hospice” death stigma. Doulagivers will bring community and hospice together.

- **Increased Employee Moral**

- **Expansion of Hospice or organizations offerings**
Doulagiver/End of Life Doula FAQ’s

• **Q:** What is the difference between a hospice nurse and a Doulagiver/End of Life Doula?

• **A:** Time and roles. The hospice nurse is the medical manager of the terminal patient, with limited time at the bedside. The Doulagiver is the non-medical professional that is the eyes and ears of the case, with no time limitations. The Doulagiver alerts the hospice team to any changes in the patient’s presentation so that the hospice nurse can assess and update the care plan for maximum daily comfort of the patient (the goal of hospice).
FAQ’s

• **Q:** What is the difference between a hospice volunteer and a Doulagiver/ End of Life Doula?

• **A:** A Doulagiver/ End of Life Doula can do everything EXCEPT give a medication and do any form of medical treatment or wound care.

• The hospice volunteer needs to follow Medicare regulations that prohibit any form of touching, moving, feeding, bathing, toileting etc. The hospice volunteer in most US states is limited to a maximum weekly bedside visit of 4 hours. The average volunteer visit is 1-2 hours a week. This does not provide the adjunct support that patients and families so desperately need at this stressful time.
FAQ’s

• **Q:** Does insurance cover the services of a Doulagiver/End of Life Doula?

• **A:** No. Doulagiver/End of Life Doulas are private pay. All “companion” services such as Home Instead, Visiting Angels, Comfort Keepers etc. are private pay. Most End of Life Doulas have a sliding scale payment option.

• **Q:** Can a Doulagiver/End of Life Doula give any medications? What about over the counter medications?

• **A:** No. A End of Life Doula never gives any medication whether prescription or over the counter.
FAQ’s

• **Q:** Can a Doulagiver/ End of Life Doula help make funeral arrangements for me?

• **A:** Yes. A Doulagiver End of Life Doula has a “scope of practice” that includes everything from the time of a terminal diagnosis to helping patients and families as the illness progresses, to the vigil, time of death, after death care, understanding and honoring grief and finally recover of life after loss.
FAQ’s

• **Q:** What services and support will hospice provide for me after my loved one has died? What does the Doulagiver provide for grief support?

• **A:** Most hospice teams leave a case after the patient has died. Many times families are feeling this as another loss. Hospice does offer bereavement services for up to a year or 15 months in most states. This is usually initiated by a call from volunteer and the living family member is told about monthly support groups that they may attend. The original hospice team that worked with the family is not part of this service.
FAQ’s

• **Q:** What can a Doulagiver/ End of Life Doula do that a Hospice home health aid can’t do?

• **A:** Time. Most hospices provide HHA services up to a maximum of 2 hours a day 5 days a week. This is based on acuity of the patient and is only available if the hospice has an available aid.

• **Q:** Is there a government licensure for End of Life Doulas?

• **A:** No. End of Life Doulas are a Non-Medical Profession, just like the establishment of Birth Doulas 40 years ago. This is not regulated by a government license.
FAQ’s

• **Q:** Are there any national organizations regulating the standards and scope of practice for the End of Life Doula Profession?

• **A.** YES! (NEDA) The National End of Life Doula Alliance has set a national practicum with Core Competencies for the practice of professional End of Life Doulas. All End of Life Doulas that pass the assessment receive the NEDA National Credential and can become members of the national membership organization.
FAQ’s

• **Q:** Does Hospice approve of End of Life Doulas?

• **A:** YES. The National Hospice and Palliative Care Organization (NHPCO) is the membership organization for all the hospices in the US. They have just put together The End of Life Doula Council 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.
“We have only one chance to have an end of life experience go well. Together, we are putting progressive holistic initiatives in place to make that happen. Thank you for being part of this positive change.”

Suzanne B. O’Brien RN
Suzanne B. O’Brien RN founder and creator of Doulagivers End of Life Doula training is a proud founding member of NEDA and the End of Life Doula Council

• The Doulagivers Certified End of Life Doula Training is a NEDA approved national training program that meets all core competencies required for passing the NEDA assessment. All students who successfully complete the Doulagivers Training are automatically eligible to take the National NEDA assessment. www.nedalliance.org