



At The Ready: How End-of-Life Doulas Can Support Hospices

Overview

- End-of-Life Doulas (EOLDs) provide non-medical, holistic support and comfort to the dying person and their family, which may include education and guidance as well as emotional, spiritual or practical care
- EOLDs provide valuable complementary services to patients and their families during life-limiting illness and the dying process in partnership with hospice personnel and other medical teams
- EOLDs are not eligible for certification by a governmental, third-party, or academic agency or board at this time; certificates of course completion are often awarded by training entities; a proficiency assessment is available through the National End-of-Life Doula Alliance that measures general knowledge in four areas of core competency



The Current State of Dying in America

In a groundbreaking fifteen-year research study published by the Journal of American Medical Association in July of 2018¹, we learned that more terminally ill people are dying at home on hospice service, or receiving palliative care in facilities, than noted prior to 2000. Since then, the emphasis on defining and actualizing a 'good death' has begun to preempt the focus on invasive, expensive 'heroic' measures, resulting in greater awareness by medical personnel of the unspoken needs of the dying.

Already walking the talk of aligning patient needs and values with end-of-life care options, hospice and palliative care has risen in use and stature within the medical community.

¹Site of Death, Place of Care, and Health Care Transitions Among US Medicare Beneficiaries, 2000-2015, by Joan M. Teno, MD, MS; Pedro Gozalo, PhD; Amal N. Trivedi, MD, MPH; et al, July 17, 2018, Journal of the American Medical Association *JamaNetwork*
<https://jamanetwork.com/journals/jama/article-abstract/2686318> Accessed July 26, 2018

Statistical evidence in the study points to more patients receiving in-home and in-facility care that aims to relieve suffering, improve quality of life, and keep costs and distractions to a minimum over ICU admissions, ventilation, or other forms of life-extending care.

While this is good news for hospices seeking to serve the dying in their communities, it also presents a potential problem—and a creative solution. Where there may be increased demand for in-home services that exceed hospice offerings and stretch providers' demands on time and services, there are now trained end-of-life doulas available to provide families with complementary, personalized, non-medical support, making it even more possible—and beneficial—for patients to return or stay home on hospice service, surrounded by family and friends, in comfort and dignity.

Answering the Call to Action

Anyone who has experienced care of a dying loved one can probably recall a moment when the prospect seemed overwhelming. Sometimes this is small things—wondering when to squeeze in a quick trip to the store, or to simply take a shower. Other times it is much bigger. Am I doing the right thing? Are we tending to what's important or just getting by? How can I balance all my roles as caregiver, mate, parent, worker, partner?

Imagine being the patient who may be grappling with fears of all sorts—fear of being in pain, being a burden, being unable or afraid to express needs that go beyond those being met by medical personnel. Or the patient who wishes for a conscious, intentional experience, who seeks companionship and guidance on the journey. To them, and to all of us, it becomes not just about the fact that we die, but *how* that matters.

There is a rapidly growing movement made up of specially trained non-medical providers whose vocation is to provide guidance and assistance to the patient, family, and wider community during the dying period. For the purposes of our work here, we will use the term End-of-Life Doula. The National Home Funeral Alliance has conducted a study of terminology used by various people when referring to themselves in their roles at the end of life and beyond (*Figure 1, End-of-Life Doula Terminology*).

What is the Role of an End-of-Life Doula?

These dedicated companions to the dying provide a wide range of frontline caregiving services, from physical, emotional and spiritual support and comfort to practical needs, such as organizing household details, coordinating visitors, respite care, and facilitation when problem solving. EOLDS may be called upon to witness, to guide, to facilitate family meetings, manage inside and outside communications, work through tough decisions, or simply lend a listening ear.

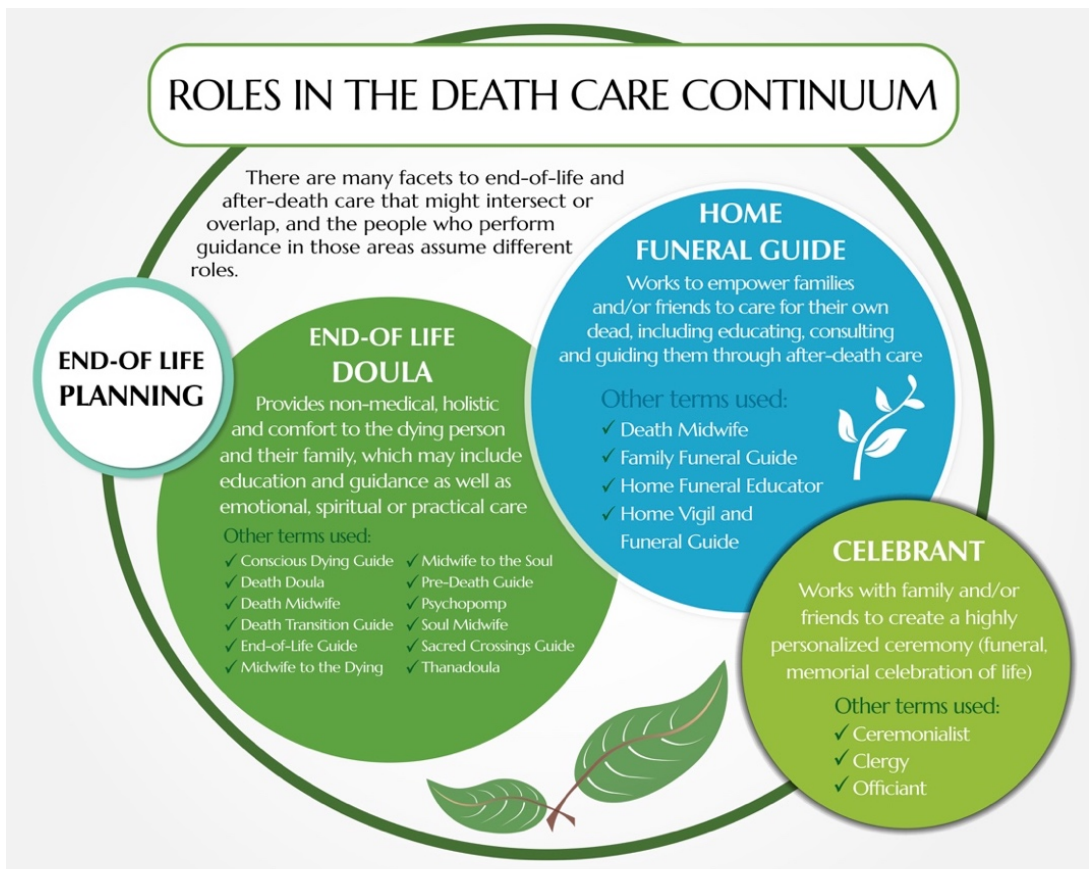


Figure 1: National Home Funeral Alliance Roles in the Death Care Continuum²

End-of-life doulas are rigorously trained in holistic care modalities for the express purpose of bringing comfort and peace to those at the end of life and their families. They bring a wealth of knowledge about local resources, people, and professionals to save the family the time and stress of trying to locate services that fall outside the realm of hospice or other medical team management.

Given the vagaries of family dynamics and disease progression timelines, it can be difficult to navigate the death of a loved one. When doulas are brought into the care team early enough in the process, relationships may be strengthened between family members. Sometimes doulas may be asked to take on the role of advocate for the dying person’s beliefs and values when patients are no longer able to advocate for themselves. This service alone has the ability to bring great peace to patients and to smooth the way for other relationships to grow.

²Figure 1: National Home Funeral Alliance, *Roles in the Death Care Continuum* diagram, homefuneralalliance.org, <https://www.homefuneralalliance.org/what-we-call-ourselves.html>, accessed June 16, 2018

A major aspect of doula work is organizing bedside vigils, a vital service that supplements hospice volunteer programs. Doulas coordinate 4-8 hour shifts of people willing to sit vigil, in addition to hospice volunteers if available, tailored to integrate with the family's care plan. Sharing local resources is another forte of doulas who make a point to invest time and energy in relationship building and making beneficial connections for all involved in preparation for what may arise.

EOLDs are:

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| <ul style="list-style-type: none">▪ skilled communicators▪ companions and witnesses▪ organizers▪ practical and personal helpers▪ good listeners▪ resource point people▪ frontline caregivers▪ care plan facilitators | <ul style="list-style-type: none">▪ patient advocates▪ team members/collaborators▪ vigil coordinators▪ caring and healing presence▪ knowledgeable about the dying process▪ providers of hands-on nonmedical support |
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Most importantly, doulas are a calm and grounding presence in what can be an indefinite period of constantly shifting circumstances and needs. They are knowledgeable, experienced, and ready to support and guide in ways that meet the patient and family where they are. They are there to offer options and ideas, new perspectives, and enriching approaches to death and dying, meeting each member of the patient's constellation wherever they may be coming from.

"The presence of an end-of-life doula at bedside assures families and loved ones that they can focus on what is most important throughout the dying time. End-of-life doulas may assist in working with grief, forgiveness, creating ceremony or ritual, and bring healing practices to the sacred process of dying before during and after death." — Tarron Estes, Conscious Dying Institute

What does doula service look like?

It is vitally important for patients and families to research what particular experiences and talents a prospective doula has to encourage a helping relationship and positive outcome. Doulas have different interests and skill areas in end-of-life work, and it behooves clients to endeavor to match need to service.

Here are some activities that doulas may specialize in³:

- Elder/Senior care—offering companion and practical services (e.g., errands for elderly, support for frail individuals who are not at the end of life)

- Dementia care—hired by the family for companionship and stimulation
- Palliative care/Pre-Hospice—supportive care for the seriously ill
- Vigil care—supportive care in the active dying phase
- Full end of life care—physical, emotional and spiritual support from diagnosis till death
- Advance care planning, or Life Prep—for advance directives, ethical wills, spiritual directives
- Legacy—supportive guidance through life review and legacy projects **Although there is no such thing as an average case, and the process from diagnosis to death cannot be predicted, a general progression of steps may include⁴:**
- Initial meeting with the patient and/or family members
- Assessing the reasons for hire (overwhelm, fear, need practical help, advocacy, etc., or combo)
- Understanding family/patient vision for the relationship by identifying goals, interests, needs, wishes of all parties who will be central to the patient
- Identifying and addressing any opposing family dynamics that may interfere with ability to offer service
- Translating vision into service package or offering (what services, responsibilities of each party, payment); formally contracting for services, whether volunteer or for hire
- Determining logistical and technical guidelines for the relationship (how contact is made, expectations of time and service, communication, boundaries)
- Planning for how the last days and hours should look and feel to the dying person and the family (things as basic as lighting, sounds, smells, and the kinds of interactions desired with friends, family and health care staff)
- Meeting with outside service providers who are supporting the patient/family (introduction to the hospice team, key people in faith community, and other significant people in the sphere of the patient/family's world)
- Coordinating the remaining communication and navigating of various working relationships within the hospice team in a spirit of cooperation and collegial exchange
- Check-ins with the patient and/or family at intervals to make sure that all are on the same page, and work can continue as agreed
- Adjusting expectations and work flow, based on need, disease trajectory, external influences
- If necessary, introducing trusted back-up doulas before needed and closer to death for seamless entry into family home and dynamic (all under the guidance of the primary doula)
- Referring to professionals and outside resources as needed
- Coordinating and carrying out to the best of abilities the wishes, and potentially changing needs, of the patient and family; plan in place
- Following up for the stated period in the service package, after the death and coordinating bereavement services with hospice if involved, necessary and appropriate
- Referring to funeral professionals or providing home funeral guide services within the bounds of state and federal laws; negotiating separate contract for post-death funeral services

^{3,4} Patty Burgess, *Doing Death Differently*

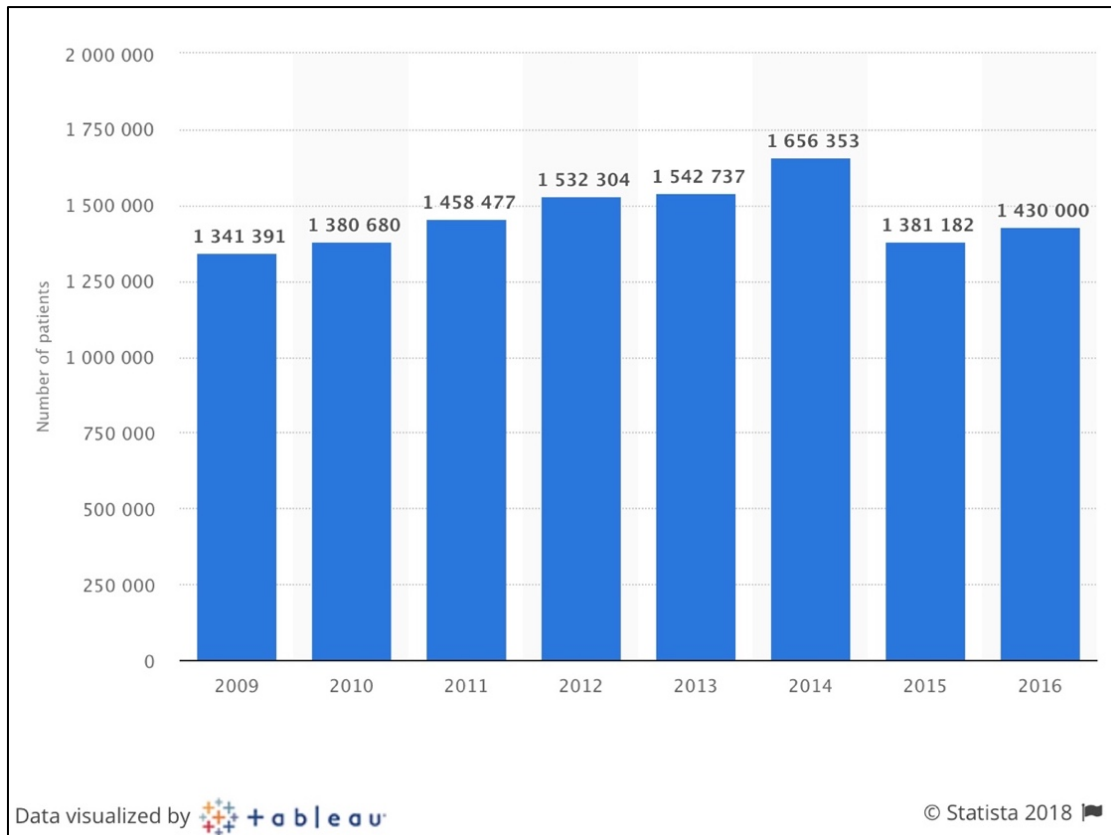


Figure 2: Total hospice patients served in the US⁵

What is the relationship between doulas and hospice?

The growth of hospice service has been up and down, but the trend is essentially upward in terms of patient numbers (NHPCO Facts and Figures: Hospice Care in America⁶), in-home care, and complexity of services. This trajectory represents creative opportunities for hospices to address financial restraints and maximize patient care.

In 2016, according to the NHPCO⁶:

- 54.2% of patients were enrolled in hospice for 30 days or less
- 27.9% were on service for less than 7 days
- 55.6% received some care in the home
- 44% of patients died at home

⁵Figure 2: Total Number of Hospice Patients Served in the U.S. From 2009 to 2016, Statista, <https://www.statista.com/statistics/339851/number-of-hospice-patients-in-the-us-per-year/>, accessed June 15, 2018

⁶NHPCO Facts and Figures: Hospice Care in America, Revised April 2018, https://www.nhpc.org/sites/default/files/public/Statistics_Research/2017_Facts_Figures.pdf, accessed June 15, 2018

We often hear talk about gaps in insurance coverage, gaps in availability of hospice service in underserved populations and remote areas, temporary or long term gaps in hiring and retaining appropriately trained hospice staff. While these are critically important to address, doulas are acutely aware of a different set of gaps in palliative and hospice care.

In addition to other care providers, doulas help patients and families adjust to their ever-changing 'new normal'. Doulas actively seek to identify and address concerns that may be just outside everyone's grasp, such as gaps in knowledge-based communication between patients and healthcare professionals, or gaps in the difference between recommended treatments and what actually happens in the home or facility once the prescribing physician has finished rounds or the hospice nurse heads off to her next appointment.

Hospice and the medical team bring enormous support and relief to patients and families. However, they are neither intended nor funded to provide care around the clock; doulas, however, may contract with the family to be present at specific times of need, sometimes for hours, days, and nights at a time.

"End-of-life doulas are the mesh between professionals and families, between what is and what can be—they are the connectors, the ones who have the time and expertise and intuition to assure the dying, relatives, friends, and all the people in their precious world that they are loved and cared for with dignity and respect. It is a sacred trust." — Deanna Cochran, Quality of Life Care

What happens when caregivers have questions and concerns that fall outside hospice care and time constraints that are nonetheless crucial to the wellbeing of both patients and families? Doulas will help families develop a list of questions to be brought to the appropriate person or professional in the moment when needed, reducing anxiety and ensuring the highest level of care.

EOLDs aren't there to supplant hospice personnel or volunteers; they seek to provide support of hospice services in a nonmedical, nonjudgmental way, and to address other needs of the dying and their family that arise off the hospice clock or radar. Ideally, the doula should be an extension of the hospice team, providing services that are complementary, cooperative and collaborative.

A doula has the potential for supporting the hospice team by being another set of eyes and ears, spending additional quality time with the patient and family in other capacities that allows for keen observation. Patients and families may trust their doula to speak for them

about things that are especially difficult to share with others, requiring an intimate relationship that can only develop when there is sufficient time and opportunity.

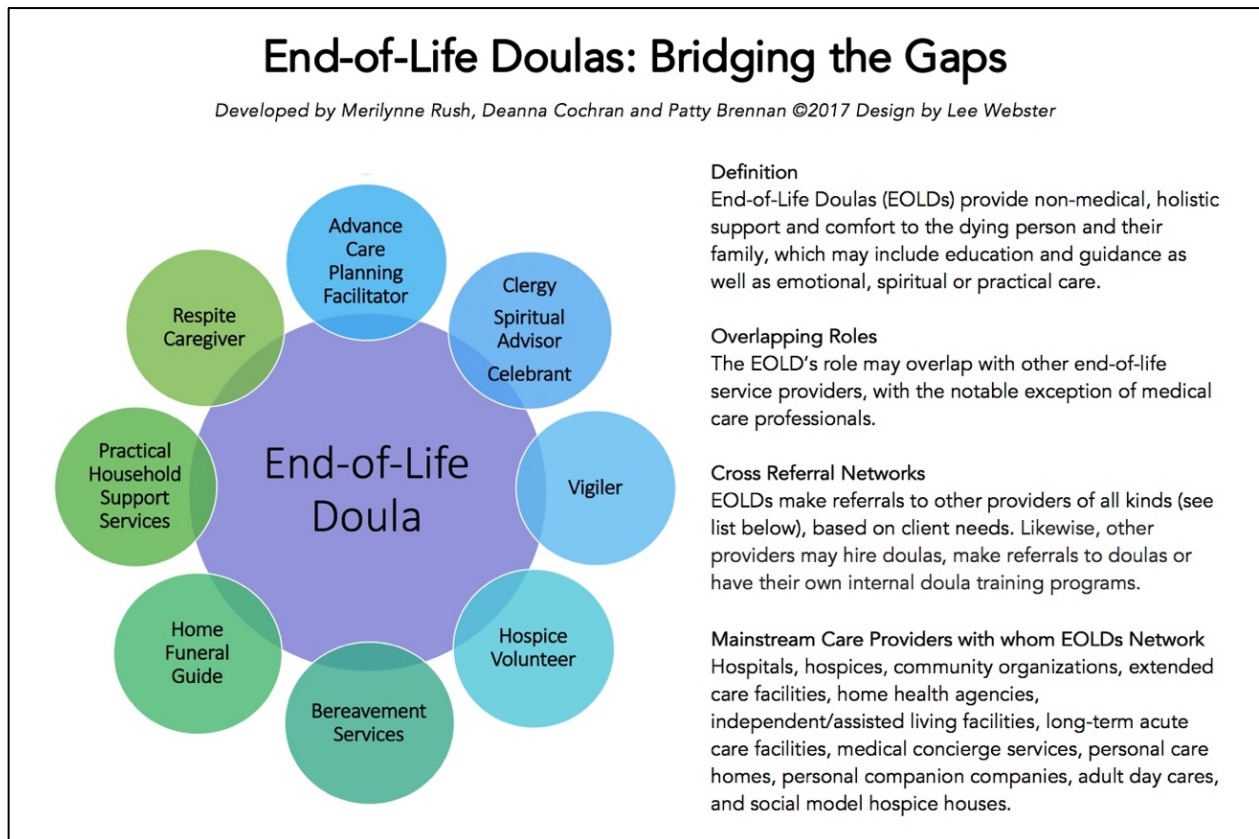


Figure 3: End-of-Life Doulas: Bridging the Gaps⁷

It is important to remember that doulas may or may not have a medical background, though many have previous training in related fields. And it is equally important for doulas to actively engage with the visiting hospice team members by asking how they can support each discipline, and then endeavor to interact appropriately. Doulas can play an active role in bridging the gaps and ensuring continuity of care from pre-death to bereavement, deepening the hospice presence.

Doulas can also benefit hospice in ways that are not as obvious. They can provide background services during the final week prior to death to enable registered nurses and social workers to maximize opportunities for claiming Service Intensity Add-on (SIA) benefits.

⁷Figure 3: National End-of-Life Doula Alliance End-of-Life Doulas: Bridging the Gaps, <http://www.nedalliance.org/scope-of-practice.html>, accessed June 15, 2018

In addition, doulas can aid in increasing participation in the Medicare mandated Consumer Assessment of Healthcare Providers and Systems Hospice Survey (CAHPS) that seeks information from hospice families in the following areas in their post-service questionnaire:

Hospices' average performance on CAHPS survey	
Category	Score* ▼
Treating patient with respect	90.6%
Getting emotional and religious support	89.5%
Willingness to recommend hospice	84.5%
Rating of hospice care	80.4%
Hospice team communication	80.3%
Getting timely care	78%
Getting hospice care training	75.2%
Getting help for symptoms	75.1%

*Percentage of those surveyed who gave positive responses
Sources: CMS

⁸Figure 4 Hospice's average performance on CAHPS survey

The results of these surveys are in debate due to the voluntary aspect of gathering data, which skews the results which could cause potentially false readings. Many of these areas—communication, timely care, training, symptom relief, emotional and religious support—are also squarely in the doula's wheelhouse. Including doulas in hospice care makes it likely that these scores may actually improve, and more importantly, be more accurate when doulas add survey completion compliance to their to-do list with families after the death occurs.

What types of doulas are there?

Doulas have long been known under different names, and active in related professions and avocations, across history, cultures, socioeconomic levels, and circumstances. But more historically, they have been everyday people who have simply and effectively supported members of their community in times of need, paid or unpaid.

⁸Hospice providers got high marks on CMS satisfaction surveys, but do they reflect reality? by Maria Castellucci, March 31, 2018, Modern Healthcare, <http://www.modernhealthcare.com/article/20180331/NEWS/180339993>, accessed June 16, 2018

These people may have been affiliated with local churches, civic groups, or even self-designed and operated neighborhood care groups. The bottom line is that they have years of experience in accompanying the dying and working within community systems to form an irrefutable, trusted web of compassion, connection, comfort, and skill.

Some EOLDs are hospice volunteers who have completed in-house trainings that meet the Medicare Conditions of Participation. They may wish to extend their time and energy by continuing to support the family after-hours in either volunteer or paid roles.

With the changing landscape of healthcare pointing to the need for more creative, interconnected models, some doulas now choose to train with recognized instructors whose specialty is preparing doulas for service, particularly in partnership with existing systems, such as hospice. Regardless of their orientation to the work, end-of-life doulas bring an added dimension of care to patients and families.

What training and credentials must doulas have?

There is no formal certifying body in the US for end-of-life doulas, so what does it mean when a doula claims to be certified? How are patients, families, hospice and medical personnel to know who is fit for the role?

To be clear, the US Bureau of Labor Statistics⁹ states that certification

- Is awarded by a professional organization or other nongovernmental body
- Is not legally required in order to work in an occupation
- Requires demonstrating competency to do a specific job, often through an examination process

Many trainers offer an in-house 'certificate of completion' for their course and may call it certification. Technically, these certificates attest to the presence and interest of the student but may or may not meet the bar for certification of demonstrated proficiencies or skill sets, the universally recognized prerequisite for professional certification.

Doulas have increasingly expressed interest in a credential that will help them to earn the trust of their clients and the agencies with which they work, as have the agencies themselves. To meet this demand, the National End-of-Life Doula Alliance has developed core competencies for teachers (*Figure 5, Core Competencies for End-of-Life Doulas*) that identify the

⁹US Bureau of Labor Statistics *Will I need a license or certification for my job?* by Elka Torpey, September 2016, <https://www.bls.gov/careeroutlook/2016/article/will-i-need-a-license-or-certification.htm>, accessed June 18, 2018

fundamental areas of proficiency for students wishing to formalize their association with healthcare professionals, especially hospice. They may even choose to sit for an assessment to earn a proficiency micro credential that is designed to inform hospices and other medical agencies of their successful completion and proven competence through advanced training.



Figure 5: NEDA Core Competencies for End-of-Life Doulas¹⁰

¹⁰Figure 5: NEDA Core Competencies for End-of-Life Doulas, by Merilynne Rush and Lee Webster for the National End-of-Life Doula Alliance, <http://www.nedalliance.org/proficiency-assessment.html>, accessed September 1, 2018

Training that specifies readiness for healthcare system compatible service often includes standard information regarding understanding of the hospice philosophy of care, hospice culture, applicable Medicare Conditions of Participation, myths and misconceptions, benefits, eligibility, hospice team approach, HIPAA, patients' rights, along with communication and other 'soft' skills.

*"The reason we need to include doulas in American healthcare today is because too many needs go unmet. Families still wait too long to get into hospice. Doulas can advocate for hospice, help clear up misunderstandings, and encourage people to enter into hospice sooner. And doulas have the time to listen and engage in genuine dialog. When we say, "Doulas fill in the gaps" this is what we mean: it's about time." — Marilynne Rush, *The Dying Year**

This track is entirely elective, and in no way diminishes the work community doulas already do. Many choose to take training to bolster their experience, and some begin with training and then seek internship opportunities. Some simply enjoy learning more about care of the dying and have no intention of practicing outside of their own circles. And while doulas are expected to behave professionally, however that is defined by individuals, there is no assumption that any currently available certificates indicate professional status at the level of medical personnel.

Are doulas paid?

Since doula services are not covered by private insurance or Medicare, doulas currently contract directly with patients and their families. Some may charge by the hour or the day; others may charge for specific services by line item, or bundle packaged services into a one-time, comprehensive fee. Many offer a sliding scale, and most will not turn anyone away regardless of ability to pay. Still others choose to remain free from financial expectations, seeing their work as a heart-centered vocation that is entirely voluntary.

Some hospices are becoming aware of the advantages of hiring doulas as part of their own program offerings, and even hiring them on staff. This may be on a per diem basis, contracted by the agency to meet identified times and services for a family on service, or they may serve in this capacity full time. If possible, a pool of funds, preferably raised through designated donations from several healthcare organizations, may be raised to cover these services, or to lead programs within the system, such as vigil managers who assist volunteer coordinators or supplemental grief and bereavement programs.

In the end, what doulas will be paid or whether they will be paid at all will depend on what the local market will bear, what level of education and experience a doula has, and how doula service is valued.

What about post-death services?

These fall into two distinct categories: bereavement and physical care of the deceased body. Bereavement and grief work as part of the hospice 13-month program addresses follow-up support. Doulas are an extra set of eyes with time to recognize complications and needs for referrals to appropriate programs and services. Doulas whose contracts include bereavement support may have more access than hospice personnel after the death occurs, which could open the door for observation, and for outreach by family and community members who are struggling.

Often doulas will continue serving families after the death occurs in the capacity of a home funeral guide. Though doulas and guides share the same goal of providing a seamless continuum of high quality care, in practice there is a legal cut-off point between what doulas and home funeral guides can and cannot do, specifically how and what they can be paid for doing it, and that is when the patient draws a final breath.

Doulas do not take the place of anyone else—they are providing unique services and are not regulated in any way by an established industry or entity. Home funeral guides, on the other hand, are subject to state laws enforced by mortuary boards that oversee the regulated funeral industry.

“There needs to be a familiarity and fearlessness with dying and death. Many of us come to end of life work by learning from family experiences (I was taught by my grandmother and aunts), some from professional experience (hospice workers or medical workers or church workers or social agency workers). We all need to pay it forward until we are no longer needed and we all once again can explore our attitudes, beliefs and tender spots around death with loving kindness and confidence.” — Suzanne O’Brien, DoulaGivers International

Hands-on care for pay is considered practicing funeral directing without a license in every state and, as such, can incur heavy fines and penalties. In some states, the very act of discussing funeral plans with a family could result in charges for violating statutes forbidding the act of “making funeral arrangements” by anyone other than a funeral director. Furthermore, the US government, through the Federal Trade Commission, determines what constitutes funeral service, setting forth detailed directives for funeral service practices and pricing.

Doulas engaging in after-death service may do so voluntarily, and may assist the family who has retained custody and control of their loved one at their express invitation, but no money may change hands, either specifically or under the guise of their pre-death doula contract. This

is not to say that doulas may not discuss funerals as part of the patient care plan or casually during the course of their service, or that they may not be paid for educational or consultative services; it means that they may not do certain very specific things for a family for pay.

“When friends and neighbors and relatives came by to say goodbye...I could see what happen[ed] to the people when they step[ped] through the threshold of fear...and how quickly and beautifully that transformed and the person was able to relax and to be present to the dead body with awe and amazement... I was determined to help other families break through their fear and resistance and begin to embrace their dead, and in so doing, embrace their own dying in a different way.” — Olivia Bareham, Sacred Crossing¹¹

Specialized training in state and federal funeral laws and home funeral technical skills and knowledge is recommended for those wishing to change hats at the moment of a patient’s death from doula to home funeral guide. For more information about home funerals and home funeral guide training, go to the National Home Funeral Alliance.¹²

Despite the limitations on doulas and home funeral guides, hospice patients are in dire need of being educated to all of their options, not just the conventional ones. Doulas and home funeral guides can help alleviate stress caused by rising costs and misunderstandings around post-death care and practices, offering alternative suggestions and information, potentially saving families money, time, and anguish, while continuing their vital work in supporting and guiding choices that are in keeping with the patient’s desires and the family’s capabilities.

The future for end-of-life doulas

For more than thirty years, healthcare for those suffering from life-limiting illness and for those reaching the end of their lifespan has been in constant flux, with steady improvements to quality of care, largely due to the acceptance and validation of hospice.

What comes next in the evolution of end-of-life healthcare is unknown, but one thing is certain: end-of-life doulas will play a significant role in pushing the boundaries further toward meaningful, holistic care of the terminally ill, the dying, and their families and communities.

¹¹Interview with Olivia Bareham, Business Innovators Radio Network, May 9, 2016, YouTube <https://www.youtube.com/watch?v=cHFTFSIPRJE>, accessed June 14, 2018

¹²National Home Funeral Alliance, homefuneralalliance.org

There is a rapidly growing social and cultural imperative that is sweeping end-of-life and funeral reform into the mainstream, in no small part due to the synergy of baby boomers and millennials who express frustration with hiding death, mystifying its processes, and obscuring or excusing its outcomes. The blossoming of a death positive consciousness, the resurgence of family-led home funerals, the return to understanding the human need for ritual and connection, the environmental crises of our current disposition methods—all these movements are driving us to embrace a different way of coping with death.

End-of-life doulas are a steadfast presence in the dying arena who are equipped to offer vital services that cross all cultural boundaries, bringing comfort to all, regardless of race, gender, economic means, urban or rural settings, or other factors that may inhibit delivery of services in other sectors.

They represent a unique opportunity for egalitarian, socially just service, one dying person, one family, one community at a time. Doulas are at the forefront of social change in America that will have far-reaching, positive impacts on those who are served.

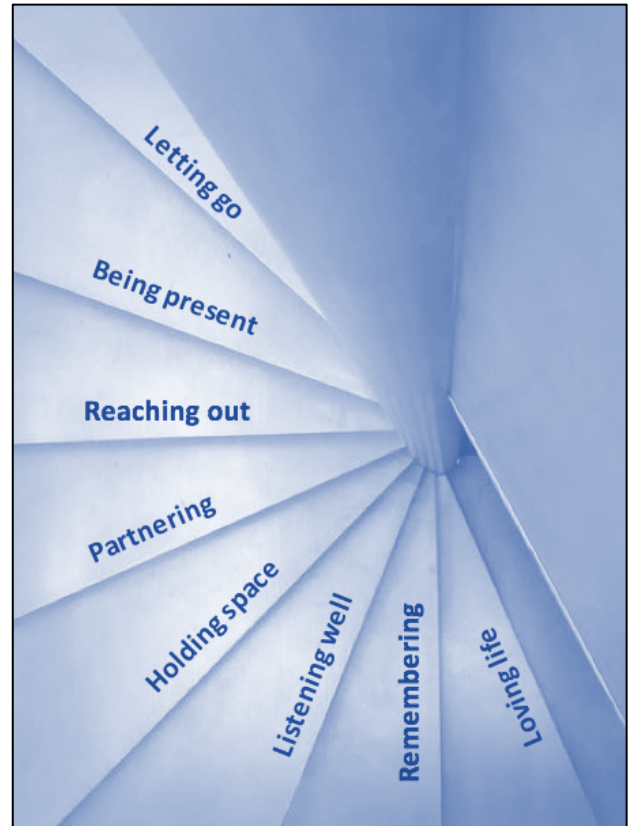


Figure 6: Core Attributes and Activities of End-of-Life Doulas¹³

“There was a time when we took care of our own dying and dead, because there weren’t really other options, and it was a part of the rhythm and cycle of life. Out of each community emerged the one who was the healer, the caregiver, the communicator, the death worker. End-of-Life Doulas are the natural extension of that, of living in community and caring for one another.

— Patty Burgess, *Doing Death Differently*

¹³Figure 6: Core Attributes and Activities of End-of-Life-Doulas by Lee Webster, New Hampshire Funeral Resources, Education & Advocacy, nhfuneral.org

Final thoughts

Here's what end-of-life doulas say about why they choose to work in this field:

- *"It's what I would want for myself."*
- *"I can inspire a re-frame of the death experience from overwhelm, sadness, and fear to one of connection and meaning by being a compassionate presence."*
- *"I am my best self in the presence of death."*
- *"Being able to help another suffer less and be present to 'what is', with all its beauty, heartbreak and possibility."*
- *"I have found a doula helpful to me personally."*
- *"I feel most connected and alive at the bedside of those who are dying—death is the best connector, leveler and equalizer, as it happens to all of us, the one place where we have the opportunity to all consciously come together, if we choose to."*
- *"It's an area of life I understand, and a very needed service."*
- *"I can't NOT do it."*
- *"My main passion for this is that I know people are suffering and they don't need to be."*
- *"Working with the dying and those in grief is a calling to me."*
- *"I can make a list and know it will get done, and that has value to the family."*
- *"I get to practice not having an agenda, listening to others, experiencing differences, helping to facilitate wishes, all while modeling a kind of comfort with the death and dying process that may offer some comfort to loved ones/caregivers—this might reframe their experience from one of only sadness, overwhelm and fear, to one of meaning, connection, and maybe a bit of awe."*