# DOULAGIVERS DEATH DOULA GUIDE



# **Doulagivers** Institute<sup>™</sup>

"Death Doulas are the answer to 'filling the gap' in the mainstream end of life care system." – Suzanne B. O'Brien RN

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### What You'll Learn in This Guide

- What is a Death Doula?
- The Death Doula Movement
- What do Death Doulas Do?
- Why Do We Need Death Doulas if We Have Hospice Care?
- Does Hospice Approve of Death Doulas?
- What Type of Holistic Support do Death Doulas Provide?
- How to Know if Being a Death Doula is Right for You?
- How to Pick The Best Training for You When Becoming a Death Doula?
- Where Do Death Doulas Work?
- How Do Death Doulas Get Paid?
- How to Choose the Right Death Doula to Care for Your Family
- Free Death Doula Training and Additional Resources

#### "There is no greater fulfillment and joy in this world than finding your calling and being of service to others."

- Suzanne B. O'Brien RN

# WELCOME TO DOULAGIVERS INSTITUTE!

I am so grateful and honored that you've downloaded our Death Doula Guide! This means that you are interested in **learning how to be a Death Doula** and be of service to patients and families at this often frightening and feared time in their lives **or how to find the** *right* **Death Doula** to care for someone you love at the end of life. Or maybe you're just curious about this profession that is starting to gain mainstream recognition. Whatever the reason you are here for, **this guide will provide the answers you need!** 

I have been doing this work for a long time. It is my life's purpose. I have worked directly at the bedside of over a thousand end of life patients as a hospice and oncology nurse and am a founding member of The National Hospice and Palliative Care Organization's (NHPCO) End of Life Doula Council. I am also the former Vice President and founding member of The National End of Life Doula Alliance (NEDA).

I can assure you that myself and The Doulagivers Team have been working non-stop to make this profession and movement the best it can possibly be for everyone around the world who requires these services.

#### We only have one opportunity to have the end of life go well for people. We cannot do it over.

In Love & Service,

Suzanne B. O'Brien RN and The Doulagivers Team

### What is a Death Doula?

A Death Doula is a non-medical person trained to care for someone holistically (*physically, mentally, emotionally, & spiritually*) at the end of life. It is a non-medical profession that recognizes death as a natural, accepted, and honored part of life. One might say that death doulas are to hospice palliative care as birthing doulas are to obstetrics. Death Doulas are also known around the world as: end of life coaches, transition guides, death coaches, doulas to the dying, end of life doulas, and end of life guides.

# The Death Doula Movement

**Death is having a rebirth!** We have been dying for thousands of years. However, it is only in the last century that we have completely removed the natural life experience of death from our awareness. **Death is not a medical experience - it is a human one.** Hospice is a beautiful model of care, but unfortunately the present model of hospice has many "gaps" and is not working well for most patients and families. **There is a need for additional support from trained and knowledgeable professionals in this space of end of life care.** 



The Hospice "Gap" **C** 

A recent Medicare study showed that a hospice worker is in the home on average only 30 minutes a day - but the end of life is 24/7. The hospice nurse "manages" the care of the dying person and is supposed to teach the family members how to do the actual hands-on care. This model is not working well, as the hospice RN is only required to make a visit once every **14 days**. On average, a registered nurse makes a visit to the home of a hospice patient once a week for one hour. The average number of days that a patient is on hospice services is between 14 to 16 days. That means a patient and family usually only sees a hospice nurse once or twice during the entirety of their end of life journey. Meanwhile, death is the biggest fear in the world and most families do not know the first thing about how to care for someone who is dying. This is all contributing to extremely difficult end of life experiences and heartbreaking outcomes for most people.

What is desperately needed right now is the addition of non-medical practitioners who can have a functional impact within the home and who understand what matters most to the patient. People who can develop a plan around the wishes and values of the dying person, advocate on behalf of the patient, attend to and manage their symptoms, conduct life reviews, and help to resolve unresolved issues. Having this supportive presence working collaboratively with patients, family caregivers, and the hospice care team is what's best for the patient's journey and overall experience. Enter the Death Doula, the non-medical practitioner that has no time restrictions. Death Doulas are "filling the gap" in Hospice Care.

The Death Doula movement has not only brought forth an industry of practitioners to support patients and families in one of the most stressful times in their lives, it has brought back the conversations, questions and fundamental teachings about death. Caring for someone who is dying was a skill that a hundred years ago was handed down from a grandmother to a grandchild. We've all but lost the skill of caring for the dying in our modern day society... but there is some good news - we are starting to bring it back! By doing so, we are helping to create beautiful, sacred end-of-life experiences that families will remember forever. After a century or so of medicalizing and outsourcing end of life care, I'm happy to say that death is having a rebirth and end of life care is beginning to return to its holistic roots.

# What Do Death Doulas Do?

Death Doulas are people who support people in the end-of-life process, much like a birthing doula with the birthing process. It is a "new", nonmedical profession that recognizes death as a natural, accepted, and sacred part of life. One might say that death doulas are to hospice palliative care as birth doulas are to obstetrics.

### **Death Doulas...**

• Help create positive and empowering end of life plans.

- Provide spiritual, psychological and social support.
  - **Suggest** ideas for optimal physical comfort.
    - ••• Help **plan** home vigils.

 Educate patients and families on the new and progressive options of home wakes, water cremations and natural burials.

# Why do we *Need* Death Doulas if we have Hospice Care?

Due to Medicare reimbursement structure, the hospice teams have a limited amount of time that they are actually able to be with the patient and family. A recent Medicare study states that **a member of the hospice team is only in the home of a dying patient an average of 30 minutes per day.** The 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. Hospice nurses on average make a one hour visit once a week to patients. There is insufficient time to teach the loved ones how to care for their dying family member and offer optimal support. Lack of adequate education and support for patients and families are the leading factors contributing to poor end of life outcomes for most people today.

# Does Hospice Approve of Death Doulas?

### YES!

How Death Doulas Work with Hospice:

(Provided by The NHPCO End-of-Life Doula Advisory Council)

**Definition**: End-of-Life Doulas (EOLDs) are non-medical companions to the dying and their families. Doulas 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.** They provide a wide range of holistic services, including physical, emotional, spiritual and practical support. EOLDs may work with families from initial diagnosis through bereavement.

**Typical Tasks of an EOLD**: Doulas spend time with families, reinforcing palliative care concepts and providing emotional support. They may assist in advance care planning, coordinating family caregiving, life review, vigil planning, respite care and bereavement support. They are most useful in providing the additional support of holding space with the family during imminent dying, as well as during high need situations.

#### How Hospices Work with Doulas

There are several ways hospices may incorporate EOLDs:

Help **educate the public** about the availability of EOLDs in the community, for those who are not (*yet*) receiving hospice services.

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**Refer families** to a community EOLD for additional care and practical support services alongside hospice care.

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Incorporate EOLDs within **hospice volunteer services** (*this would entail additional training for hospice volunteers*).

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**Collaborate** with an EOLD Independent Contractor in the community.

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Hire an EOLD as a staff member.

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# Does Hospice Approve of Death Doulas?

continued...

**EOLD Training:** Most EOLDs have completed in-person or online training where they learn fundamental knowledge and skills. There are a growing number of organizations and individual trainers who conduct these courses. Some EOLDs come to this work with a background as a healthcare provider, with or without a history of working with the dying and their families. EOLD trainers offer their expertise to hospice and palliative care programs interested in developing volunteer doula programs or enhancing existing vigil programs.



**Conclusion:** Whether doulas work in a hospice or palliative care program or are hired directly by a dying individual or caregiver, they work collaboratively with other services and care providers involved - including palliative care and/or hospice teams. Doulas do not usurp the role of any other care provider; rather, they follow and reinforce established plans of care. EOLDs bring added support and peace of mind to overwhelmed families caring for their dying loved ones in whatever setting they call home. In many ways, EOLDs act as an extension of both the patient's support network and their professional care team. EOLDs are becoming a vital part of forming Compassionate Care Practitices at End-of-Life.

#### "As long as they go through a training process, I think Death Doulas can complement the work of the hospice team really well. The more people there to help a patient and family the better."

~ John Mastrojohn III,

Executive Vice President of The National Hospice and Palliative Care Organization (NHPCO)

# What Type of Holistic Support do Death Doulas Provide?

Death Doulas care for the whole person, taking into account the emotional, mental, spiritual, and physical well-being of the patient and their family. They provide invaluable assistance in these notable areas of holistic support:

#### They Act as the "Eyes and Ears" for Hospice by Identifying Acute Issues:

Death Doulas identify all acute issues and suggest interventions to provide tight symptom management leading to the highest quality of daily living for both the patient and their loved ones. Achieving optimal comfort and quality of life is our goal every single day!

#### Legacy:

We are all born, and we all die too. It's what we do in the middle that creates our legacy. What we leave behind is far more than simply wealth and possessions. We can share our story or give wisdom, advice, love, and support even after we have passed. In doing so, we give those left behind and those in the future a glimpse of our essence – who you were, how you saw the world, and what gave your life purpose. Death Doulas can help patients with the powerful and uplifting process of conducting a life review and developing a legacy project.

#### **Presence:**

The topic of death can produce fear and anxiety as we each face our end-of-life. This is simply because we have not walked this path before. Having someone present with a wealth of experience and proper training at such a tender time can bring a sense of comfort to the otherwise unfamiliar. Death Doulas provide holistic and informational support as they accompany individuals and their families through the entire end of life journey.

#### **Dignity:**

Everyone wants to have a positive passing where they maintain their dignity and honor as they exit this life. We all have our own values, traditions, and belief systems that influence our vision and expectations of what that would look like. Creating an environment that represents that vision and is authentic to the individual is important. Death Doulas help patients and families develop a plan around the wishes and values of the dying person and always advocate on their behalf.

# How do I Know if Being a Death Doula is Right for Me?

You only have to ask yourself one simple question... Is this my calling and do I feel like I am meant to do this work in every cell of my body?

If the answer is no - then you have your answer. This is probably not the right fit for you.

#### If you answered YES! - then keep reading!

Being an End of Life Doula/Doulagiver is the hardest thing I have ever done, but it is also the **MOST REWARDING!!!** This is so much more than just an occupation - it is a calling. It is a life's purpose. This is not something that you think may be a good career - *it chooses you*.



### Why Do We Need Death Doulas? Why Now?

### We are Facing a Global Elder Care Crisis

In the United States, we are facing the largest elder care crisis we have ever seen. In 2034, adults aged 65 and older will outnumber children aged 18 and younger for the first time in this nation's history - and it's not just a problem in America. This trend is occurring in practically every developed nation on earth. This trend is expected to continue until at least the year 2060, when those 65 and up are expected to outnumber children 94.7 million to 80.1 million according to the U.S. Census Bureau. Who is going to care for that staggering number of people? How do we ensure quality of life and a dignified death for each of them?

As an RN working within mainstream medical for over the past 20 years, I have seen this crisis only intensify every single year.

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Read more about the Elder Care Crisis Here



### How did this happen?

This is what I call the "Perfect Storm." We have an increasing elderly population and at the same time we have a nursing and physician shortage. As the number of patients is increasing the number of our healthcare professionals is decreasing. The projection for this trend is also expected to continue for the next several decades. We're simultaneously heading towards a scenario when many more people will be requiring care from trained professionals and there may be less people qualified to care for them.

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# \Lambda Alarming Statistics 🕂

- There are **76.4 million people that are over the age of 65** in the United States at this time.
- **20%** of those 76.4 million people **do not have children** to care for them as they age.
- 9/10 people polled say they want to be cared for at home if terminally ill.
- Death is the #1 fear in the world.
- In the last 100 years, **life expectancy has gone from 46 to 79**. People are living much longer, but not necessarily more independently.
- By the year 2030, **19.6% of the U.S. population will be over 65** years old.

### The Mainstream Medical Shortage

- The US could see a shortage of up to 120,000 physicians by 2030. Source: The Complexities of Physician Supply and Demand - AAMC (Association of American Medical Colleges)
- By 2030, the U.S. will need 12 million new nurses. In the coming years there will be more jobs available for registered nurses than any other profession.

Source: ANA (American Nurses Association)

### End of Life Care Requires Time and Presence

When a person is experiencing the end of life, time and presence can be your most valuable healing modalities. In our present medical system, most end of life healthcare professionals are allowed only one hour at the bedside per visit (if they're lucky) with much of that time spent documenting rather than providing care. End of Life Care does not work this way. End of Life requires time. Time that is all but absent in our modern medical system - with no signs of that changing any time soon.



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### The Answer: The Future of Healthcare will be Non-Medical

In 2014, the National Institutes of Health released a report called Dying in America in which they discussed the future of end of life care. This report declared that there is a need to move towards:

Person-centered, family-oriented end of life care models.

An increase in education and higher standards for Advance

Care Planning.

Better trained end of life care providers.

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Revamped policies and payment systems designed to

support high quality end of life care and services.

Many End of Life Care experts are in agreement that over the course of the next decade there is going to be a necessity to expand and enhance alternative care services in order to accommodate the aging Baby Boomer generation and keep people at home during end of life (rather than residential care facilities).

# How to Pick The Best Death Doula Training for YOU

<u>Death Doulas have no government licensure</u> and therefore Death Doulas practice many different ways with varying degrees of education and expertise. With so many different Death Doula trainings available and with most of them containing wildly varying curriculums, <u>it is important to know what to look</u> <u>for.</u>

There are many great trainings and wonderful trainers out in the world. At the same time, the unregulated Death Doula profession has become a global movement and as with all rapidly growing trends, there are those that want to capitalize on it for the wrong reasons. Many Death Doula trainings have "popped up" with little substance, depth or credibility behind them. Potential students must do their homework before paying for training. The one thing that is critical to note is that there can be several trainings with the title "Death Doula Training" and they can be entirely different curriculums, and usually are.

\*\*\*\*Picking a Death Doula training is a financial commitment and a time commitment. **Do your research!** Find out what the curriculum of the program is before enrolling. Make sure the curriculum matches what you want to learn as there are no government licenses for End of Life Doulas and all training programs have their own teaching styles, perspectives, and focal points.\*\*\*\*

#### There are two questions that you should always ask:

- 1. What is the curriculum and does it match what I want to learn?
  - 2. Who is the teacher and what is their background?

This oftentimes will let you know what type of focus the training will have and whether it aligns with your personal interests. You also want to like your teacher as you will be spending lots of time learning from them! **This is an incredibly transformative experience and should be an enjoyable one also!** 



# How to Pick **The Best** Death Doula Training for **YOU**

#### Where Do Death Doulas Work?

Death Doulas are now working in Nursing Homes, Senior Living Centers, Oncology Care Units, Hospice Houses, Home Health Agencies and private practice. The adoption of Death Doulas by mainstream medical agencies has catapulted the profession into a new level of legitimacy as it continues to grow year over year.



### How Do Death Doulas Get Paid?

Below is an excerpt from the Cake Library Article "**How to Become a Death Doula: Training, Salary & FAQs**" by Erin Coriell, originally published 7/8/2021

Most Death Doulas work as independent contractors and they charge an hourly or flat rate. This role is not currently covered under medicare.

Some hospices budget for these services and hire contractors for a set number of hours.

### How to Pick **The Best** Death Doula Training for **YOU** continued...

#### FAQs: Death Doula Jobs:

#### How much does a Death Doula get paid?

The pay of a Death Doula will depend upon the agreed-upon amount between you and your client or the organization/company that hires you. This is usually presented at an hourly rate. Some Death Doulas may decide to charge a flat fee or have packages of hours to assist the person in their dying process.

### The hourly rate can range from \$25 to over \$100 an hour depending on the needs of the client.

For our Doulagiver Graduates, there is a pricing model we use based on geographical location for in-person visits. The Doulagivers Certified Death Doula hourly salary is anywhere from \$20-\$85 an hour.

We also encourage Certified Doulagivers to have packages of hours available, as well as to offer their services on a sliding scale basis and do pro bono work where appropriate to ensure that no one is ever turned away during their time of need due to financial reasons.

#### <u>Click Here to Join our next Free</u> <u>Webinar!</u>



### How to Choose the Right Death Doula to Care for Your Family:

#### The Top 7 Questions to Ask *BEFORE* Hiring a Death Doula!

When someone you love is dying, it is one of the most stressful, scary and vulnerable times for everyone involved. Allowing someone you do not know into your home is a big decision and one that should be made with great caution and care.

Below are the top 7 questions you should ask a potential Death Doula before hiring them:

## **Do you have professional Death Doula Training?** Through what organization/trainer?

**How many years of experience** do you have as a Death Doula?

**How many deaths** have you been a Death Doula for?

Do you carry professional Liability Insurance for being a Death Doula?

Do you have a list of services you provide as a Death Doula?

**V** Do you have a **price list** for your services?

**V**Do you have at least **3 references** I can check? *Check references!!!* 



### What is My Next Step?

If you're interested in becoming a Death Doula and want to learn more about this profession, I welcome you to join our **FREE Doulagivers Level 1 End of Life Doula Live Webinar Training**.

#### What will you learn in this training?

In this *free webinar*, you will learn how to care for someone who is dying from the time of a terminal diagnosis all the way through until the end-of-life. You will learn the **3 Phases of End of Life Care Model** that we use at **Doulagivers Institute** and the interventions you can use to provide comfort and support to both patients and their families in each phase.

#### Suzanne B. O'Brien RN will show you how to:

- 1) Identify **the Shock Phase** and what suggestions for comfort can be given.
- <sup>2</sup> Identify **the Stabilization Phase** and what suggestions for comfort can be given.
- <sup>3</sup> Identify **the Transition Phase** and what suggestions for comfort can be given.
- A **Reduce the fear of death** and **heal grief** from past experiences with death.
- **Empower and inspire yourself** to start living fully with compassion and presence TODAY.

Infused with real bedside stories, the training empowers people with the skills to care for their loved ones at the end of life, help heal grief from past experiences with death, and reduce the fear of death in general. It also aims to provide insightful and priceless wisdom from those ready to leave this world about how to live fully and make the most out of life's journey!



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## What is My Next Step?

Do you have the calling to become a Doulagiver Death Doula and serve end of life patients and their families as a professional?

#### **Click Here to Join our Next Free Webinar!**

During this LIVE Discovery Webinar, you will find out if becoming a Doulagivers Holistic Non-Medical End of Life Practitioner is right for you!

There will also be a Q&A session following the webinar where you can ask Suzanne any questions you have directly!

Showing up for someone at the end of life is one of the most important things we will ever be called to do.

If you have the calling, Suzanne and the Doulagivers Team will teach you EVERYTHING you need to know!

Register Now for the FREE Doulagivers Institute Discovery Webinar for End of Life Practitioners to find your calling, be of service, and align with your life's purpose!

#### **Click Here to Join!**