

Frequently Asked Questions:

END-OF-LIFE DOULAS

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Compassion & Choices is the nation's oldest, largest and most active nonprofit working to improve care and expand options for the end of life. For more than 40 years we have sought to change attitudes, practices and policies so that everyone can access the information and care they need. Compassion & Choices is committed to collaborating with legislators from every state and political party who seek to honor their constituents by engaging in this mission with us.

Frequently Asked Questions

Terms used

This resource uses the terms end-of-life doula, death doula, and doula interchangeably to refer to non-medical professionals who provide comprehensive emotional, spiritual, and practical support for individuals and loved ones during the dying process, or who are planning ahead for the end of life.

Death doulas are growing in popularity, as they provide a powerful service to people seeking to explore their end-of-life care options. Compassion & Choices values the role they serve as a part of an individual's care team, and the work they do on an even larger scale — advancing death literacy and awareness in our society.

We receive many questions about the role of end-of-life doulas, and we know you may have some as well. We created this resource to help you learn more about their work and how to find a doula to support yourself or your loved one. Doulas from our community have responded to the questions below, sharing resources and more information to help you explore your options.

What is an end-of-life doula? What do they do?

End-of-life doulas are a complement to medical, spiritual, and community-based supports and serve as part of a comprehensive and knowledgeable care team for a person planning for the end of life. Many end-of-life doulas are educators seeking to demystify issues around death and dying, and it is common to find us offering both virtual and in-person support and education. Some of us may call ourselves death doulas, end-of-life midwives, psychopomps, or end-of-life guides.

What services does a doula provide (and not provide)?

End-of-life doula services often incorporate spiritual, emotional, and practical support for the person and their loved ones. We offer a grounded presence during advance care planning discussions, provide respite care for loved ones, facilitate legacy or memory projects, identify resources, complete practical and household tasks, and offer bedside

support for those in the final weeks and days of life. This work is non-medical, but is a wonderful compliment to someone's care team.

It should be noted that some doulas may have additional training as a nurse, massage therapist, chaplain, or other provider — which could influence the kind of services they provide. In these situations, most doulas refer to the <u>doula scope of practice</u> (from the National End-of-Life Doula Alliance) when serving in that role, while some of us may choose to incorporate other expertise into our doula work. If this is the case, a doula's expertise and certification should be clearly outlined through marketing materials or in conversation.



When people ask me what a death doula is, the first thing I tell them is: service. The main goal is to serve your client and their families — whatever that looks like.

David Copeland, death doula in Cincinnati, OH

What kind of training do end-of-life doulas complete?

There is no universal training, or single professional group for doulas, but there are dozens of end-of-life doula training programs across the country with varying environments (in-person for many weeks, weekend intensives, virtual, hybrid), focuses (some may be created by people with healthcare or legal backgrounds, others may have a focus on spiritual support), and levels of accessibility.

Though there is no standard educational route for end-of-life doulas, you have the opportunity to decide what kind of training matters to you when you are hiring a doula to support you.

Is formal training important to you in a doula? If so, what kind of training and experience would you like them to have? Do you want to work with someone who brings a specific kind of background or spiritual practice? A doula who engages in ongoing training or has expertise in a certain area? Asking about training when meeting with a potential doula is highly encouraged, and we have included that on our questions to discuss with a potential doula below!

How do I find a doula in my area?

You can find information about end-of-life doula organizations, groups, and private practitioners in your area a few different ways.

- You can start by accessing a list of providers through the <u>National End-of-Life</u> Doula Alliance (NEDA). They are passionate about equitable access to end-of-life care and options, and are a trusted partner of Compassion & Choices.
- Additionally, we suggest the International End-of-Life Doula Alliance (INELDA), a trusted training and resource organization.
- Finally, you can attempt a Google search using "end-of-life doula" + "[Your City]" (or "[Virtual]") and see some doulas who may have websites linking them to your area, or you may find a group or collective of providers. Please note that some of the websites or services could be outdated, so cross-checking these individuals through NEDA or INELDA can be helpful.

We suggest checking these platforms, but also reaching out to your community for any connections they may have — such as your social groups, faith community, or online message boards. With the rise in awareness around this work it is becoming easier to find an end-of-life doula aligned with you, your values, and your needs just by voicing it to those around you!



A big part of my doula practice is to provide practical resources, to provide spiritual care, and to also be an advocate for improvements in healthcare and end-of-life care for everyone.

Isabella Carr, founder of DeathFat Doula

What does it cost to hire an end-of-life doula? Is it ever covered by insurance?

This varies widely, which is challenging. Doulas are generally hired privately (no insurance coverage) and typically charge a flat fee for certain services such as advance care planning or general discussion about end-of-life. Some of us may have hourly or package fees for ongoing support, ongoing assistance with legacy projects, or care for the final weeks of life. Some doulas offer their services on a sliding scale, and others offer these services for

free. Discussing pricing structure early on when meeting with a potential end-of-life doula is critical, so understanding what you are comfortable with will help you determine if they are the right fit for you.

You may hear about instances where hospices include death doulas as part of the care team, but it should be noted that this support is *not* included in the Medicare hospice benefit, and very rare among hospice programs. But we would love to see this become more common in the future.

Can a doula help with documenting final wishes prior to the end of life?

Yes! Some of us specialize in advance care planning for any adult regardless of health but all doulas should be able to identify needed documentation for your state. However, there are other types of paperwork that will require direct discussion with a clinician — such as a POLST/MOLST form. Any adult over the age of 18 is encouraged to consider having their end-of-life wishes documented, whether through an end-of-life doula, or with the help of another care provider.

Do doulas support people accessing options such as Medical Aid in Dying or Voluntarily Stopping Eating and Drinking (VSED)?

It varies from doula to doula. Many of us are passionate about supporting various end-of-life options, and openly discuss them on our website or in marketing materials. If you are interested in particular options, make sure you share that in any discussions you have with a potential end-of-life doula, so they can let you know if they are the right fit.

Other end-of-life doulas may have personal experiences, or professional boundaries, that leave us unable to comfortably provide support for someone exploring these options. If that is the case, an end-of-life doula should be able to let you know that, and recommend another doula. The bottom of this document includes questions you can ask when meeting with a potential doula, which can help identify any of these boundaries they may have.

Do doulas have written contracts with clients, and do they hold insurance?

The answer to both is: some do! When it comes to contracts, many doulas have formal contracts available, while others use less formal email agreements or conversations to establish the support they provide. Some doulas have established their services under an LLC, and retain end-of-life doula insurance (which does exist), while others offer support on a volunteer basis. Anyone pursuing the support of a doula should consider if these elements are important to them in choosing someone.

How many hours do doulas spend with someone they are supporting?

It depends on how much support someone needs! Everyone's needs are different; some folks may want to meet for an hour each week to go over paperwork, and once that is complete they may not need us for some time. Other people may have more urgent needs and require additional hours as they are closer to the end of life. Our job as your doula is to help you identify your needs if you are uncertain. Anyone working with a doula should feel comfortable asking about time when meeting with them!



Anybody and everybody can hire an end-of-life doula. Just as we are born, we shall pass away. We will die. A doula is someone that will be able to walk with you, as well as hold your loved one's hands, each and every step of this journey.

> Ashley Johnson, death doula in Orlando, FL, and President of the National End-of-Life Doula Alliance

What should I be asking a potential doula?

Ask questions, like those below, to potential end-of-life doulas to help discern who is a good fit for you. Remember that many doulas offer free consultations to talk about these things — so feel free to ask anything!

- What is your goal with your practice?
- How did you get into this work?
- Have you been trained and do you engage in ongoing professional development?
- What is your level of bedside/care experience?
- How many deaths have you supported/been present for?
- What are your available hours for contact?
- What is the scope of your services?
- What is your pricing structure?
- Do you have a sample contract I can view?
- Do you have back-up doulas or associates you work with in case you are unavailable?
- Are there any end-of-life options (such as medical aid in dying) or particular situations that you are unable to support your clients through?