FAMILY CAREGIVING

# ‘Death Doulas’ Serve Dying Patients at Home, in Hospice

Experienced professionals provide end-of-life caregiving assistance for patients and families

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COURTESY INELDA

Cheri Rigby always knew she wanted to work with the dying.

As a registered nurse, she was exposed to death frequently, but she believed that more support was needed for those who were facing it. Through an unfortunate circumstance, she was given the opportunity to make a difference.

“There was a tragedy — one of my very best friends,” Rigby says. “Her daughter was a special-needs child. She choked on a Fruit Roll-Up and died.

“This was a little girl who was at my house all the time; we spent a lot of time together. When Sophia died, I was sort of the closest person to that, because my friend didn’t have any immediate family,” Rigby says.

“It was a life-changing experience for me. I saw that raw emotion firsthand with my friend, and quite honestly, instead of it scaring me away, it drew me in.”

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### How death doulas assist

End-of-life doulas can provide several services to your loved ones and family:

- Accompanying clients to medical appointments
- Facilitating advance care planning
- Calming the terminally ill through guided visualization
- Providing comfort for the dying through massage
- Coordinating care
- Helping with legacy projects to memorialize the life of the soon-to-be deceased
- Offering respite care for family members
- Vigil planning and sitting

For Alua Arthur, it was meeting a stranger on a bus in Cuba, a young lady who was dying of cancer. Arthur says she engaged the woman in conversation about her inevitable death, and it sparked a fire that she says could not be contained.

"I thought, *Wow. We're all going to do this at some point. Why aren't we all talking about it now? Who are the people to support people through this?* On that bus I got super clear this was going to be my work, yet I didn't really know how."

Arthur and Rigby eventually found their way to becoming what is called an end-of-life, or death, doula — a professional who provides nonmedical caregiving services to people who are dying and to their families.

## Death doulas complement hospice

Many end-of-life doulas, also known as death midwives, say they complement the care from hospitals, senior-care facilities and hospices, as well as fill in the gaps that occur during the dying process.

"There's a lot of medical support in dying, and there's some emotional support, as well, but I find that death doulas do a great job of tying it all together and having knowledge about a vast array of subjects," says Arthur, who has been a death doula for more than a decade.

"Hospice care is wonderful. They provide a lot for the amount that they get paid by the insurance benefit," says Merilynne Rush, end-of-life doula trainer, natural death care educator and owner of The Dying Year, an end-of-life training company. "But it's not everything. The family still has to do most of the care."

End-of-life doulas bring their skills and expertise to various environments.

"I think a really important new development is that there's more awareness that for people who are living in care facilities, end-of-life doulas have a lot to offer. So more facilities are becoming aware of that," says Rush. "I have been working with a large corporation in the Detroit area [Homestead Management Group] that has many care facilities, and they are training their employees to be end-of-life doulas."

The first thing an end-of-life doula does is work with the client to determine what services are needed.

"They figure out with the family where they are at, what do they need, what's causing them to become overwhelmed, what kind of services are they looking for," says Rush. "Different doulas offer different kinds of services."

"A lot of work is done in 'legacy' — looking back at their life and creating legacy with loved ones — rituals and care planning. What do they want to happen as they're dying?" says Simpson. "One [service] that we're hoping surfaces to the top is advanced care planning — having conversations now about what you want to happen."

## Care for stressed-out families, too

A doula can see the big picture when family members might be overcome with emotion, sleep deprivation and stress, Rigby says.

"It's being present enough to know what the patient and the family need — things like hand massage, foot massage, encouraging self-care for the family," she says. Rigby completed the University of Vermont program. "It's not just about you and the dying person. You have to be able to read the situation well enough to fine-tune things."

Many end-of-life doulas find similarities between their role and the more commonly known role of doulas, aiding with childbirth.

"Doulas serve our clients where they are — wherever they call home," says Francesca Arnoldy, course developer of the University of Vermont End-of-Life Doula Professional Certificate programs, including the companion animal specialty. "Our care focuses on planning, preparing and processing. We work alongside palliative care and hospice teams as an additional, complementary layer of support."

"Where you're going to find the end-of-life doulas the most will be in individuals' homes. They're filling gaps that the hospice service can't provide or the family can't provide," says Douglas Simpson, executive director, International End-of-Life Doula Association (INELDA).

"However, there's been a shift. We are now training organizations. We're training hospice organizations. We [INELDA] have a potential training with a hospital."

"Waiting for a baby to be born and waiting for a person to die are very similar in terms of the skill set required," says Patty Brennan, an end-of-life doula with a background in birth and postpartum doula work, and owner of Lifespan Doulas. Both circumstances require the ability to be fearless, patient and calm.

End-of-life doulas have no credentialing body, but programs such as those offered by INELDA, Lifespan Doulas, The Dying Year and the University of Vermont offer training and certification.

Larner College of Medicine at the University of Vermont offers an End-of-Life Doula Professional Certificate program. "The UVM program is comprehensive. On average, people probably spend about 80 to 100 hours on this work," Arnoldy says.

INELDA's program requires 40 hours of training, but Simpson insists that a doula's education shouldn't end there: "We believe in order to see the work through, we need to be guiding and mentoring these individuals that have come out of our training for advanced learning."

While end-of-life training programs vary in their offerings and requirements, they're also seen as a valuable way for doulas to grow their skills and create a community for sharing knowledge and camaraderie.

Some doulas have private practices, while others work in connection with hospices, hospitals and community organizations.

"It's vital for aspiring doulas to know that if you're planning to launch a practice, it's really going to take initiative," Arnoldy says. "You're going to have to develop your business and your role in the community and your reputation. You're not going to look in the newspaper and find a job ad."

## 'Growth in interest and acceptance'

In addition to providing services, many practitioners are spreading the word and teaching the public more about death and the role of doulas.

The National End-of-Life Doula Alliance (NEDA) — an organization with 1,550 members that serves as a "big tent" for those who share its mission, vision and values on end-of-life doulas and end-of-life experiences — has 44 individuals and organizations in the U.S. listed as doulas/trainers in its online directory. While the directory is a resource and not an endorsement, it demonstrates the ways in which interest in the profession has grown.

Brennan says in recent years there has been "growth in interest and acceptance by the hospice industry," too.

And practitioners say the work is its own reward.

"I think focusing on death and death education helps me live life more fully and be more appreciative in the moment," says Rush.

"It's not depressing," Rigby says. "It's very powerfully motivating. It's like a wake-up call that feeds your will to live fully. This is a common thread that folks who work with the dying understand."

*Editor's note: This article was originally published on Nov. 20, 2018. It has been updated with new information.*