

[Serving the Dying: End-of-Life Doulas](#)

Western society has grown increasingly fearful of aging and death. But an increasing number of people are stepping forward to love and comfort the dying.

By [Helen Avery](#)

They call themselves death doulas, or death midwives. Some prefer the term ‘end-of-life doula’ or ‘soul midwife.’ And some, like me, are simply hospice volunteers. The roles vary, as do the titles. Some are paid, but most are not. Nevertheless these people are connected by a common thread—they are all drawn towards serving the dying. And whatever the moniker, a growing number of individuals, many with a background in yoga and meditation, are joining them.

Compassion for the dying is in our bones, as revealed in the fossils of our distant ancestors... In the Republic of Georgia, the remains of an individual with just one tooth were found several years back. This *Homo erectus* lived around 1.8 million years ago to the incredibly then-ripe age of 40. With a sole tooth remaining in his final years, it would have been almost impossible for this creature to have survived, and so, [paleoanthropologists believe he must have been cared for](#). His last meal was quite likely fed to him by another. Similarly there is evidence from Neanderthal skeletons that indicate clans 40,000 years ago cared for the sick and dying right up until their final breath.

The Lonely Death

But, fast forward to the 21st century, and our role as community caretakers and witnesses to the dying seems to have devolved. In Western countries, thousands of elderly will die alone this year—some within the institutions that care for them, but many in their own homes. In Japan, where one in four of its 127 million inhabitants are over the age of 65, it has become such a common occurrence—where the dead are not found for many weeks—it even has a name: [kodokushi](#), lonely death.

In some part, the increase of the “lonely death” is the result of an aging global population where people are outliving relatives and friends—12.5 million Americans over the age of 65 live alone. And with more than 50 percent of the world now living in urban areas, the anonymous and transient culture that cities foster adds to our collective unawareness of who might be dying next door.

But we must also take personal responsibility. Our society has become increasingly fearful and intolerant of aging and dying. It is as if we would rather be immortal machines than face the rite of passage that comes with being part of nature.

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The introduction of hospice care in the last century has sought to ease the final days of the living, but it serves just a tiny fraction of the population. Now end-of-life volunteer programs are stepping in. The volunteer-led [No One Dies Alone \(NODA\) program](#) was introduced by a nurse in Oregon in 2001. It involves volunteers holding “vigil shifts” for the dying in hospitals, and has been adopted in hundreds of institutions across the U.S., Singapore, and Japan. In the last 10 years, the efforts of NODA have been taken one step further with the introduction of tailored end-of-life volunteer training programs held beyond hospital wards.

The Deeper Lessons

Deanna Cochran, a former hospice nurse, founded [Accompanying the Dying](#), an end-of-life doula training program, in 2010. An end-of-life doula herself since 2005, Deanna says that most of the inquiries she received were not from the dying, but rather from those who wanted to serve them, which led her to set up the program. Hers is one-year long, as are most program commitments for end-of-life volunteer work.

In a hospice training program, like those of the doulas, practical advice is shared: Don’t tell grieving family members that their loved ones are ‘in a better place’ after passing. And *don’t* discuss the patient with anyone. But *do* take the patient’s hand and ask them questions.

These programs can also be introspective, discussing: [How can we provide comfort for those in fear?](#) How can we listen with love? As well as intense: What are the clues that a patient may soon be passing? (Mentions of past relatives, talk of serene vistas.) And how can you know if you are the one holding the patient back from moving on?

Primarily, Deanna says her aim is to empower individuals to find their own expression of service for the dying. “It’s not for me to say ‘I now appoint you a doula,’” says Deanna. “It’s very personal how people want to serve, and I believe people are called to it.”

You become acutely aware of the fragility of life, but also the strength and purpose of the spirit that the body encases.

This appears to be an apt belief as an increasing number of people are being called to serve. Juliet Sternberg, manager at [The Doula Program to Accompany and Comfort](#) in New York—which also trains volunteers—says they receive more than 300 applications a year, and choose only 12 to 15. The slots in next year’s training are already filled. Funding is their biggest drawback, she says, *not* lack of volunteers.

End-of-Life Companions

While relatively new, the role of the end-of-life doula has been found to be helpful to the one dying. “So often the only contact the dying have is with someone who is looking at them over a clipboard, or asking about their bowel movements,” my own mentor says. With volunteers and doulas, patients feel more comfortable sharing their celebrations on life, and their trepidations around death. It can help them process their situation. Patients are also more likely to talk to volunteers about what music they like or what religion they adhere to—this is all useful knowledge which can help a hospice team provide an art therapist, or a chaplain.

The role of the volunteer and the service they provide vary from individual volunteer to individual patient, as one may expect. Some may provide aromatherapy, meditation, or reiki. Others may help with chores at home. “Yes, volunteers may be serving individuals who are dying, but really they are providing a service for the living,” says Juliet. Some become traveling partners for “bucket list” activities. One volunteer within my hospice discovered her patient had never seen the Statue of Liberty, so she took him there.

Above all, it’s a healing role, says Deanna. “End-of-life companions can help relax a traumatic situation by allowing those involved to feel loved, and heard.”

Letting Go of Expectations

While training can offer some preparation, ultimately the most learning is done while in service. Learning firsthand to: Be an empty vessel. Let the person in front of you fill you up. Remember, [this is a gift to you, not just from you](#). Listen.

No death is quite the same, after all.

Indeed, Deanna says mentoring is as much preparing an end-of-life doula on to what to expect, as it is teaching them to let go of expectations. One story shared with me was of a volunteer who was sitting silent vigil—breathing with the patient’s breath—when she noticed that her next breath she took alone, and the next, and the next... The patient had passed without warning, and without fanfare. We often expect life-shaking moments around death. It can be alarming how passing can almost go unnoticed.

And while we want everyone to have a beautiful death, Deanna says we have to let that go too. “Deaths are different. And they are not always beautiful,” says Deanna. “It doesn’t mean the experience is a failure.” In real life, not all conflicts get resolved, nor do all life reviews get finished. And sometimes, hospice nurses say, people *do* choose to die alone.

The Aha Moments

These are the “aha” moments that you have when you serve the dying. You are let into a brief, but intimate moment of an individual’s world as they straddle the here and the there. [You become acutely aware of the](#)

[fragility of life](#), but also the strength, purpose, and mystery of the spirit that the body encases. There are relationships formed that are complex, beautiful, and heart-breaking.

For Juliet, the volunteers themselves cause her aha moments. “When I see the integrity of those who want to give—who believe in being part of something greater than their own lives—it gives me hope about the future of society. In spite of what we see on the news, it is comforting to know the world has good people.”

There was no fear of death, no judgment of a life, no religiosity, or even spiritual wordiness—just kindness, gentleness, and incredible gratitude and humility...

I felt similarly when I first interviewed with hospice. My trainers spoke of death as a transition. They spoke of the volunteer as “holding space” for a person as they take the next step in their journey. There was no fear of death, no judgment of a life, no religiosity, or even spiritual wordiness—just kindness, gentleness, and incredible gratitude and humility for those who they serve. Like Juliet, I find it deeply comforting to know these people, these kind volunteers, are here on Earth. I don’t feel I was “called,” I just knew this was a community I wanted to join. I wanted to learn what they had learned, and serve as they had served.

A Shift in Mindset

Deanna finds the increasing number of people wanting to serve encouraging. She is hopeful that a shift in our collective mindset towards death is occurring. She has just returned from a retreat with Sogyal Rinpoche, a Tibetan master and author of the bestseller [The Tibetan Book of Living and Dying](#), who, she says, advises us that death is not to be feared. Death is our friend, for it teaches us to love life more. And so we would do well to form an intimate relationship with the dying, rather than averting our gaze. Some Tibetan monks hold a skull every day. Deanna suggests weekly visits to graveyards, and daily meditations on our own mortality.

“In the Middle Ages, the Christian monks bent over and whispered in each other’s ears—*memento mori*—remember death,” says Zen Buddhist and end-of-life care pioneer, [Joan Halifax Roshji](#), in an interview with [School of Lost Borders](#). “It’s an extraordinary opportunity for each of us to observe those who are dying in order to not just help them, but to liberate ourselves from the continuum of suffering.”

She references poet Rainer Maria Rilke: *Love and death are the greatest gifts given to us, but mostly they are passed on unopened.*

“The fact is, love and death are about fully letting go,” says Joan. And by choosing to hold hands with the dying, we open both gifts.

[Helen Avery](#) is a Section Editor at Wanderlust Media, working on the Vitality and Wisdom channels on Wanderlust.com. She is a journalist, writer, yoga teacher, minister-in-training, and full-time dog walker of Millie.