



FAREWELL EARTH MAGAZINE

SPRING 2025
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End of Life Guides - Stories from Hospice

*Reclaiming death care
practices that are
community focused and
environmentally-friendly.*



GUIDING THROUGH GRIEF: A HOSPICE WORKER'S JOURNEY OF COMPASSION

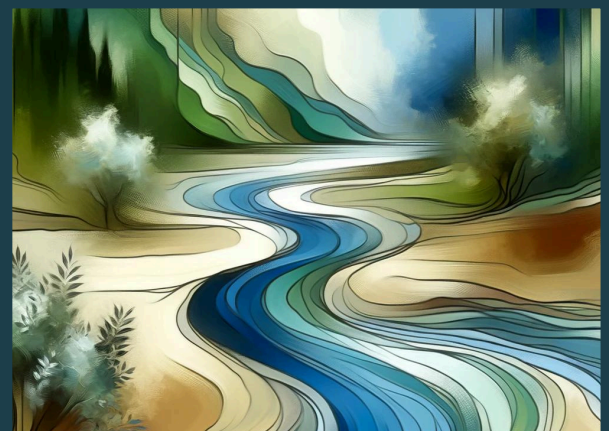
*Christie Smith, LCSW, APHSW is the
Assistant Director of Family and Volunteer
Services at Duke HomeCare and Hospice.*

Like many individuals drawn to hospice, I had a personal experience. I arrived in this work through a significant loss of a classmate when I was 11 years old. We were offered support from bereavement counselors after the death occurred. These individuals created space to answer our questions and let us process our grief. This really set a groundwork for how I continued to process grief in the future. From this experience, I knew I wanted to work with patients and families experiencing loss.

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FAREWELL EARTH IS A 501(C)(3) NONPROFIT WITH A MISSION TO FOSTER HONEST CONVERSATIONS ABOUT DEATH AND DYING, PROMOTE ECO-FRIENDLY DEATH CARE PRACTICES, AND RECLAIM THE SIGNIFICANCE OF RITUAL AND REMEMBRANCE. WE BELIEVE IN A WORLD WHERE THE END-OF-LIFE PROCESS IS NOT SHROUDED IN FEAR BUT EMBRACED AS A NATURAL, MEANINGFUL CHAPTER OF OUR JOURNEY.



BEYOND THE MYTHS: UNDERSTANDING THE HEART OF HOSPICE CARE

Hospice care is a compassionate approach to end-of-life support, but many misconceptions prevent families from fully understanding or accessing its benefits. By debunking these myths, we can help people make informed decisions. Here are five common myths about hospice care and the truth behind them.

MYTH 1. HOSPICE IS ONLY FOR THE FINAL DAYS OF LIFE.

One of the most pervasive myths about hospice is that it's only meant for the last few days of life. In reality, hospice care is intended for patients with a terminal illness and a prognosis of six months or less to live. When started early, hospice provides months of meaningful support, including symptom management, emotional care, and guidance for both patients and their families. Delaying hospice care often means missing out on the comprehensive benefits it offers.

MYTH 2. HOSPICE CARE HASTENS DEATH.

A common fear is that hospice accelerates the dying process. This is untrue. Hospice neither hastens nor prolongs death; instead, it focuses on comfort and dignity, allowing the natural process of life to unfold with less suffering. Hospice teams are trained to manage pain and symptoms, helping patients live as fully as possible during their remaining time.

MYTH 3. CHOOSING HOSPICE MEANS GIVING UP HOPE.

Many families see choosing hospice as giving up on their loved one. However, hospice shifts the focus of hope. Instead of hoping for a cure, hospice provides hope for comfort, quality of life, and meaningful moments with loved ones. Hospice care can bring peace and connection during a deeply emotional time.

MYTH 4. HOSPICE CARE IS EXPENSIVE.

Financial concerns often prevent families from considering hospice, but it is typically very affordable. Hospice care is covered by Medicare, Medicaid, and many private insurance plans. These programs often cover all or most of the costs, including medications, equipment, and professional services.

MYTH 5. HOSPICE PATIENTS HAVE NO CONTROL OVER THEIR CARE.

Some people worry that entering hospice means losing autonomy. On the contrary, hospice care is highly individualized and collaborative. Patients and families work closely with the hospice team to design a plan that reflects their values, preferences, and goals. This approach ensures that care aligns with the patient's wishes, fostering a sense of empowerment during a vulnerable time.

Hospice care is not about giving up; it's about embracing life's final chapter with dignity, comfort, and support. By understanding the realities of hospice and dispelling these common myths, families can make informed choices that honor their loved ones and provide peace of mind.



GUIDING THROUGH GRIEF

CONTINUED FROM PAGE 1.

Christie Smith at Duke HomeCare and Hospice.

HOW DID YOU ARRIVE IN THIS LINE OF WORK?

After graduate school, I began my career at a hospice in Chicago. Upon moving to North Carolina, I worked with families undergoing various transplants where loss was also a common thread. Five years ago, I found myself back in hospice field work here at Duke HomeCare and Hospice.

WHAT IS MEANINGFUL ABOUT THIS WORK?

For me, the relationships with families are the most meaningful. I enjoy providing guidance, counseling, and a sense of community during a difficult time. Hospice work recognizes the importance of helping families cope with the emotional challenges of a loved one's impending death. It recognizes the dignity of life while acknowledging that dying is a natural part of the human experience. The relationships I form with families during vulnerable and meaningful moments create bonds based on trust, empathy, and compassion. In my current role, I now have the opportunity to support the clinicians who provide the direct care. I enjoy providing education and collaborating with staff to provide the best care for our patients and families.

HOW DO YOU SUPPORT FAMILIES?

Our team addresses the whole person – addressing physical symptoms, mental health, emotional well-being, and spiritual needs – ultimately providing comprehensive care in a way that honors each individual's journey. Each family comes to us at a different place on their journey of understanding and acceptance and it's up to us to meet them there. With constant evaluation, we learn to work alongside them and support their journey no matter where it leads.

HOW HAS THIS WORK AFFECTED HOW YOU LIVE?

I think all hospice workers gain a unique perspective on life and the inevitability of death. I have done my own reflection and personal growth and have a deeper appreciation for life. I view life as a balance of future planning and living in the now. Learning to hold both of those thoughts at the same time can be challenging but important.

ADDITIONAL RESOURCES

Being Mortal: Medicine and What Matters in the End by Atul

Gawande offers a thought-provoking exploration of how modern medicine often overlooks dignity and meaning at the end of life.

The Art of Dying Well: A Practical Guide to a Good End of Life by

Katy Butler provides a compassionate and actionable guide to navigating the journey of aging and dying with intention and grace.

That Good Night: Life and Medicine in the Eleventh Hour by

Sunita Puri delivers a heartfelt blend of medical insight and personal reflection on the art and science of palliative care.

Radical Acts of Love: How We Find Hope at the End of Life by Janie

Brown shares a tender collection of stories that illuminate the power of connection and hope in the face of life's final moments.





FINDING THE RIGHT SUPPORT: PALLIATIVE CARE VS. HOSPICE CARE

Palliative care and hospice share a common goal: improving quality of life for individuals facing serious illnesses. However, they differ in timing, purpose, and scope of care.

Palliative care is available to anyone at any stage of a serious illness, whether they are pursuing curative treatments or managing chronic conditions. It focuses on relieving pain, controlling symptoms, and addressing emotional and spiritual needs alongside medical care. This type of care can be integrated into treatment plans in hospitals, clinics, or even at home, offering patients and families an added layer of support.

Hospice care, on the other hand, is specifically for individuals in the final stages of life. Typically offered to those with a prognosis of six months or less, hospice shifts the focus entirely to comfort and quality of life rather than curative treatments. It supports not only the patient but also their family, helping everyone navigate the emotional, practical, and spiritual challenges of end-of-life care. Hospice care can take place at home, in hospice facilities, or in medical centers, ensuring a peaceful and dignified transition.



COMMUNITY SPOTLIGHT: DUKE HOCK FAMILY PAVILION AND SECU JIM AND BETSY BRYAN HOSPICE HOME OF UNC HEALTH



SECU JIM AND BETSY BRYAN
HOSPICE HOME OF UNC HEALTH



DUKE HOCK FAMILY PAVILION

While many patients receive hospice care in their homes, there are situations where a dedicated hospice care facility is the best option. For individuals with complex medical needs, such as uncontrolled pain or symptoms requiring constant medical supervision, hospice care facilities such as the SECU Jim and Betsy Bryan Hospice Home of UNC Health and Duke Family Pavilion provide the specialized care and round-the-clock attention that may not be possible at home. These facilities are equipped with advanced resources and professional staff to manage even the most challenging end-of-life care needs.



NOTES FROM THE FIELD: **EMPOWERING OTHERS THROUGH EDUCATION AND LAUGHTER**

Betsy Barton, MPH, CT is the Senior Associate for Community Engagement and Learning at Transitions LifeCare in Raleigh.

I received a harsh baptism into the realities of serious illness and death at an early age. When I was about seven years old, my father began to experience symptoms of early dementia. Since this was the mid-1960s, not much was known about this illness, even at New York's finest health care facilities. It was confusing to everyone, and shame was heavy in the room. He was 50 years old at the time. At the time, there were eight kids in my family, ranging in age from 4 to 23 years old.

When I was in middle school, I tried to learn about Alzheimer's Disease by reading the proceedings of a professional conference in Switzerland - I discovered that knowing the term "neurofibrillary tangles" did not help me wade through the confusion of having a dying father for pretty much my entire childhood. I also discovered a copy of Elizabeth Kubler-Ross' first book *On Death and Dying*, and tried to read that too. Since I was only 12, I don't remember it helping much, but I do often wonder how it influenced me.

I find that the experiences I have had within my own family motivate me to do the work that I do as a community and clinical educator about serious illness care. Carl Jung said that "knowing your own darkness is the best method for dealing with the darkensses of other people." I have found this to be the case in my work. Every single day, I immerse myself in the world of death and dying ... from a certain distance. As an educator, I do not work with actively dying people every day. [Although let's face it - we are all dying, from the moment we are born!] I work with the people who work with them, or live with them, or love them.

I feel the presence of my dead parents and siblings every day when I do this work. I guarantee that my own daughter will never experience the fear and isolation that I did as a child and young person, dealing with it on my own. We talk about death all the time! I have a way to support people who experienced what I did, or some semblance of it, through education, telling stories, listening, and providing accurate information. And laughing!! Laughter is so important.

In my work life now, I create and implement educational experiences for the full range of people: young folks, elders, clinical providers, people of many diverse racial and cultural backgrounds. People often ask me "how can you do it? Isn't it so sad to think about this all day, every day?" I don't find it to be so. In fact, it is quite the opposite. By approaching my own fears head on, it dissipates them. Will I also die "early," "before my time?" Maybe so - so I had better make the best of this life, this day, this moment.

I often think of the time I spoke to a group of elders at a facility in Raleigh, NC. I said to the group "tomorrow is not guaranteed." A feisty woman in the group yelled out "Honey, for us, 2:00 today is not guaranteed!!" True enough. For all of us, actually.



BEYOND MEDICAL CARE: THE HOLISTIC WORK OF DEATH DOULAS

Death doulas, sometimes called end-of-life doulas, provide holistic, non-medical support for individuals nearing the end of life and their families. One of the reasons people turn to death doulas is their focus on legacy projects, which help individuals reflect on and preserve the essence of their lives. Whether it's creating a memory book, recording stories, or crafting letters to loved ones, these projects offer a way for the dying person to feel a sense of meaning and connection. Legacy projects are not just about preserving memories; they also provide an opportunity for the individual to express their values, gratitude, and love, leaving a tangible gift for those who remain.

In addition to legacy work, death doulas play a critical role in sitting vigil during the final hours or days of a person's life. This presence is often deeply comforting for both the individual and their family, providing a steady, calming support in an emotionally charged time. Doulas are skilled at creating sacred, peaceful environments tailored to the individual's and family's wishes. They might bring music, guided meditations, or simply sit in quiet solidarity, ensuring no one feels alone during the transition. For families who may not know how to navigate these moments, a doula provides invaluable guidance and emotional grounding.

Finally, death doulas support both the grief of the individual facing death and the grief of the family they leave behind. For the person dying, a doula offers compassionate companionship, helping them process fears, regrets, or unresolved emotions. For the family, doulas serve as a steady presence before, during, and after death, offering guidance on what to expect and holding space for their grief. They often provide resources for processing loss and support families in finding rituals or practices to honor their loved one. By addressing both the emotional and practical sides of dying, death doulas help families navigate one of life's most challenging transitions with care, clarity, and compassion.

FROM UNCERTAINTY TO UNDERSTANDING: HOW END-OF-LIFE DOULAS TRANSFORM THE DYING EXPERIENCE

Jane Dornemann is an end-of-life doula who operates Peaceful Crossings Durham.

In 2009, my mother died in a hospital room, two feet from the always-bustling nurse's station. She had been sick for a long time but we never talked about what we'd do "when." And upon admission, we didn't know then that she was dying. The days before her passing were marked by poor communication from doctors and our own inexperience with the dying process. We didn't know what questions to ask, my mother had never discussed her wishes, and we had to make big decisions quickly about things we'd never thought about. Her death didn't feel peaceful, it felt panicky. It was not the ending she would have wanted, and it wasn't the ending we wanted for her, either. And the thing about death is you don't get a do-over.



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Years later, when I gave birth to my son, I experienced the same gaps in care that I saw with my mother. Paired with my own lack of knowledge about the process, it was not the way I wanted to bring my child into the world.

I kept asking myself where things went wrong in both of those experiences. The similarities between the two made it clear that our society primarily medicalizes these significant rites of passage, and treats them as things that happen “to” us instead of “with” us. It doesn’t feel like our system treats the whole person, which includes the person’s community. Somewhere along the line, our culture had forgotten that death is a primarily social, communal, emotional, spiritual, and personal event—not something to be treated and intervened upon, or solely treated by people with medical degrees. Every person I talked to who had lost someone could tell me a similar story. I started to research what people were doing to change this, and that is when I learned about end-of-life doulas.

End-of-life doulas, or “death doulas,” are non-medical, non-legal professionals that serve as a complement to hospice, helping terminally ill people pave the way for a better death. They provide non-judgmental support, including logistical, emotional, and spiritual support that is meant to bring some control back to the patient. Think of them as death meets project management, a really good listener, and a highly informed guide. A doula’s duties can run the gamut: helping patients and their families assess and plan for care needs, coordinating visitor schedules, educating the family on the dying process, drafting advanced directives, looking at post-death options, conducting life review, creating a legacy project, advocating for the patient, designing the dying space, downsizing efforts, and writing obituaries, among many other things.

After completing my training, I started volunteering with hospice. Six years later, I have served in two states across four hospices, as well as independent clients. While I got into this to help others, it has brought me so many gifts. I have met some wonderfully interesting people with fascinating life stories. I have helped families better prepare in ways they may not have thought of, which was foundational to a more present and peaceful passing. I am always learning new things about both death and life. And in doing this work, I get to be a part of the “positive death” movement, which is improving how we die in this country.

Sometimes I tell people what I do and they say, “I wish I had known about you when [loved one] was dying.” And my goal is to have a lot fewer people say that.

We need more compassionate and personalized care at life’s most vulnerable moments. End-of-life doulas offer a path toward peace, understanding, and control in a time when those things can feel so distant. My journey as a doula has shown me that while we may not always have the power to change the outcome, we can change the experience. We can create more meaningful, peaceful transitions for those we love—and for ourselves. We all deserve a better way to say goodbye.



PRESENTATIONS AND WORKSHOPS

The following presentations and workshops will be offered in Spring 2025.

- Emerging Trends in Death Care:** Aquamation and Green Burial
- Advance Planning:** Comprehensive End of Life Planning
- Five Wishes Workshop:** Advance Planning and Go Wish Card Game
- Tips, Tricks, and Cost Saving Strategies:** Working with a Funeral Home
- End of Life Guides:** Perspectives from Death Doulas and Hospice Nurses
- Legacy Projects:** Documenting Your Life
- Estate Planning:** Putting a Plan in Place

Please contact us for dates and locations or to schedule a presentation, free of charge.



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At Farewell Earth, we are dedicated to providing information and resources on all forms of eco-friendly death care. Whether you choose a green burial, aquamation, or another sustainable method, the most important thing is to make an informed decision that aligns with your values and the wishes of your loved ones.

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