

# Living With the End in Mind

Author Barbara Becker '89 explores life, love, and loss. **By Anne Stein**

**E**arly on in life, **Barbara Becker '89** was curious about what she calls “those big questions.” Why are we here? What are we supposed to do with our lives? What happens after we die?

Coming from a family of doctors (her grandfather, father, and a brother) and nurses (her grandmother and mother), it wasn't surprising that the northern New Jersey native would think about life and death. At age eight, she learned that her father had previously been married to a British woman who died in an accident shortly after their honeymoon. In her young mind, “someone had to die for me to live,” explains Becker, who became even more fascinated by the role of love and loss in our lives.

She continues exploring those big questions in her recently published book, *Heartwood: The Art of Living With the End in Mind*. It's both a tribute to patients she cared for during her three years as a hospice volunteer in New York City's Bellevue Hospital and a memoir about mentors, friends, and relatives—living and dead—who have had a significant impact on her life.

*Heartwood* grew out of an earlier piece Becker wrote about a childhood friend's final year of life. “When Marisa was diagnosed with cancer, she made the most of the time left, exploring the world, getting married, and spending time with her friends,” explains Becker. “It made me think about how we can more fully live life with the end in mind. It's learning to be present to everything in life, the good and the bad, the light and the darkness.” An editor saw the essay and asked her to expand it to a book, which took nearly a decade to write.

Married and the mother of two sons—one chapter discusses the “taboo” topic of pregnancy loss and her own two miscarriages—Becker spent 25 years in strategic communications and international human rights before turning to writing and hospice work. “I started thinking of my own parents who I loved so much, and realized I was really afraid of them dying,” she explains. “I knew I had to face this somehow.” Becker trained with two Zen monks in New York City who prepared volunteer hospice caregivers.

In one chapter of *Heartwood* she tells the story of Mr. K, one of her toughest hospice patients, who yelled at her and kicked her out of his room after

he had a difficult phone conversation with his wife. “He'd lost the ultimate control, and he couldn't take it out on his doctor, so he took it out on me,” she says. “I learned that our interactions with the dying don't all have to look perfect. And that our job is to love others, as the theologian Thomas Merton said, without stopping to inquire whether or not they are worthy.”

Becker sat with hospice patients who are Muslim, Hindu, Jewish, Christian, and Maori. “Our worldview can look really different, and to me it was important to learn the language and stories that would give

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*Barbara Becker writes about her work as a hospice volunteer as well as her own losses in her book Heartwood.*



PHOTO: JAYNE RIEW

me context for being fully there at the bedside with them,” she writes. But the best advice on how to talk to the dying came from the Zen monks who trained her.

“We put so much thought into the idea that people who are dying want to talk about the big questions, but sometimes, you go into the room and the person just wants to watch *Jeopardy!*. Your job is to meet them where they are, pull up a chair, and watch *Jeopardy!*. If they want to talk about their children, talk about their children. And if they want to talk about the Mets, talk about the Mets.”

An important aim of the book was to tell diverse stories about loss, Becker says. One chapter is about a Rwandan genocide survivor who lost her father and three young brothers, was sexually assaulted, and is HIV-positive; she has emerged from that trauma and grief and today helps other survivors.

Another chapter tells about a Muskogee Native elder named Generous Bear, who lives in Becker’s Lower East Side neighborhood. She writes about the visit they made to a site near their homes where more than 120 men, women, and children were slaughtered in 1643 by the Dutch. “He taught me the importance of creating rituals around loss,” Becker says. “We went through a ceremony to honor the people who had died there. It felt like such a healing act. I really believe in the power of ritual to help right wrongs.”

In *Heartwood*’s final chapter, Becker describes her decision to become an interfaith minister; she was ordained in 2017. She’s since been certified as a

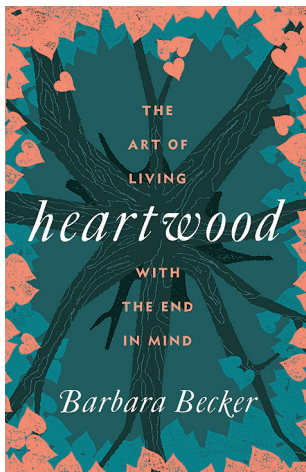
disaster chaplain with the American Red Cross. The book’s postscript takes up life during the COVID-19 pandemic, when Becker participated in memorial services at Hart Island—New York City’s ‘potter’s field’ for the unclaimed dead. “It’s often said that death is the great equalizer, but the pandemic disabused me of the notion that all deaths are equal,” she says.

She cites a New York City minister who lost 44 congregants to COVID, mainly frontline workers “who didn’t have the luxury of working safely from home. There’s nothing equal about a death like that.” And she recounts the loss of her beloved Aunt Bev to COVID, and their final goodbye over the phone.

Since the release of the book, Becker has heard from readers, some who have lost loved ones and others who are themselves dying. They’ve found comfort in her stories. “I think there’s a sense of release and surrender for them,” says Becker. “We never tell these stories to one another, so we feel isolated. We don’t know what it looks like to die, or talk about who should be in the room. Do we want music playing? What are our wishes for our bodies? Those topics aren’t regularly discussed. So when someone goes out on a limb and tells some of the stories, it gives people permission to think about how they want to see their final days.”

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*Anne Stein is a Chicago-based journalist and regular contributor to Haverford magazine. Her features and profiles have appeared in the Chicago Tribune, Christian Science Monitor, LA Times, and ESPN magazine, among other places. She has huge admiration for those who wrestle with end-of-life issues on a regular basis.*



*In our culture, we are told that death is the last and greatest taboo—as welcome as a skunk at a garden party. Yet most often when I spoke of my experiences with loss, people opened up about their own. Death truly is a great equalizer, it turns out. As I sat with stories of grief and suffering, I began to hear an undercurrent of the inner resources people drew upon when their lives got hard. How people evolve and grow, even as the body withers. How we fare better when our sense of meaning is big enough to hold the things that don’t make sense. Every person, whether they defined themselves as religious, spiritual, agnostic, or atheist, made me even more curious about the ways in which we seek comfort and purpose, especially when we find ourselves in the crucible of our lives. Aren’t we, to borrow from William Faulkner, not meant to merely endure but to prevail?*

—Barbara Becker, *Heartwood: The Art of Living with the End in Mind*

# Talking About Living With Those Who Are Dying

*Palliative care physician Justin Sanders '00 brings compassion and clarity to the seriously ill.*

**A**t age 21, during midterms at Haverford, **Justin Sanders '00** received a call that changed his life. A childhood friend who had been suffering from a serious illness was close to death. He flew across the country and was with her for the final hours of her life. Sanders, who already had planned on going to medical school, became fairly certain he would specialize in palliative care.

He traveled the world after graduating, including time at a hospice in Calcutta, helping feed, bathe, and give medicines to patients. “It was very routine in some ways and taught me that caring for the dying is like caring for the living,” says the art history major. “You’re trying to help them get as much out of life as possible.”

Now married and the father of two, Sanders earned his medical degree at the University of Vermont, followed by a master’s in medical anthropology, and completed a palliative care fellowship at Harvard. Formerly an attending physician in the Psychosocial Oncology and Palliative Care department at Boston’s Dana-Farber Cancer Institute and the Brigham and Women’s Hospital, he recently accepted a position in Montreal, as chair of Palliative Care McGill, an interdisciplinary network of clinicians, educators, researchers, allied-health professionals, volunteers, and support staff working together across five teaching hospitals. Sanders spoke with journalist Anne Stein about palliative care’s open-hearted, human-centered approach to terminal illness and death.

## **Anne Stein: What is palliative care?**

**Justin Sanders:** It’s specialized medical care focused on quality of life for people with serious illness. It’s appropriate for people at all stages of serious illness. Serious illness is a health condition that carries a high risk of mortality and either negatively impacts daily functioning and quality of life or excessively

strains caregivers. [Palliative care] grew out of the late 1960s hospice movement that started in the United Kingdom.

## **AS: Is palliative care’s main focus on death and dying?**

**JS:** People have this strong association between palliative care and dying, but it’s really about enhancing the quality of life throughout the course of a serious illness. It’s a subtle but important distinction. Palliative care strives to ensure that the treatments people get align with what matters most to them. We’ll ask, “What are your most important goals?”

Palliative care reflects the notion that people have priorities in life besides living longer. Medical care typically operates as if that’s not the case. Medicine doesn’t generally act that way, so, in some sense, palliative care is about humanizing medical care. Palliative care aims to help people live the lives they want to live. If someone wants to be with their grandchildren, for example, we may get them out of the hospital and home with hospice care.

## **AS: What do you say to patients when you’re first called in to talk about palliative care?**

**JS:** All of our focus is on how we can improve their life, managing symptoms and anxieties, up to the very end. We ask the patient what they know and understand about their prognosis. We talk about what we expect to happen over the course of their illness, including—if it’s important to them to know—how much time they might have.

We ask, “What abilities are so important that you can’t imagine living without them?” “What are you willing or not willing to go through to live longer?” If clinicians model these serious conversations well, families can go home and carry on those conversations with their loved ones in a way that makes a real difference in their care.

We ask what they are most worried about. A lot



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*“Palliative care reflects the notion that people have priorities in life besides living longer,” says Justin Sanders.*

of physicians are afraid to ask that because often they can't address those worries, but to be able to say out loud what you are worried about is profoundly therapeutic. If you are able to engage in difficult conversations with people, if you are able to sit with that and respond to their emotion and sit in silence, it sends a message about what you are willing to do as a doctor, which is to go to difficult places with them. They are worried about being abandoned. Our field shows people that we will be caring for them until the very end. As a result, we develop strong relationships quickly with patients and families.

**AS: Do you experience grief or sadness when a patient dies?**

**JS:** Oh yes, absolutely! I was always resistant to this idea about never getting emotionally involved with patients. I've never believed that, not before medical school and not now. Our willingness to connect and engage with families gives my work so much meaning. It's an antidote to burnout, and it makes me more effective as a healer.

**AS: How do you process grief?**

**JS:** The palliative care team does a weekly "remembrance." Someone reads a poem or book passage that has meaning to them, then we read the names of the people who died in the last week or two. That can be 10 to 20 patients. Then we reminisce, tell stories

about what it was like to work with family. We cry. We grieve openly, and it's an incredibly healing and very powerful thing to be a part of. It's something all of medicine could benefit from.

**AS: Is there a particular personality that goes into palliative care?**

**JS:** We have a reputation for walking calmly into a crisis. Comfort with uncertainty would also describe people who do our work. You need to make decisions, even when you don't know the outcome. And you have to help other people cope with uncertainty.

**AS: How has the pandemic affected your palliative care team and healthcare workers in general?**

**JS:** We are at risk of a tsunami of grief in medicine because of the pandemic. The hardest thing for all of us is that we rely on families very much to be present with people in the hospital. That was impossible during the pandemic, and we all experienced a lot of moral distress about that. Holding up an iPad with a person who's going to die while their family members erupt in tears and you feel helpless to do anything about it is not an easy experience. God bless the nurses who do it all the time. The isolation for families and patients was profound. That's what a lot of us will wrestle with.

—A. S.

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## My Death

*During Labor Day weekend in 1995, **Tem Horwitz '66** went into anaphylactic shock in the middle of the night. As his panicked wife, Susan, drove him to the hospital from their remote home in the dunes above Lake Michigan, ten miles from the nearest town, Horwitz had a near-death experience.*

*After it happened, when what he had felt and witnessed was still fresh in his mind, Horwitz wrote down an account of the experience and its aftermath and eventually turned his notes into a short book, titled *My Death: Reflections on My Journey Into Non-Being*, published in 1996. Here are some excerpts from the book.*

**A**s I sat there, my body struggling to breathe, I watched the dashboard in front of me lose its definition. The lights lost their brightness. Everything turned a dark gray, and then black. My body began to feel very heavy. I could feel the weight in the middle of my back. I let everything settle down into my center, not struggling with this feeling of heaviness. I responded weakly to Susan, partly because of the physical state that I was in but largely

because I was totally absorbed in the process of dying. My head felt huge and heavy, like a boulder. I felt my body toppling. I could not tell in which direction I was falling.

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Sounds. There was only one sound component of this experience. At what I take to have been one of the stages of my biological death, there was a tremendous roar that came out of nowhere. It felt like I was hearing my body from the inside,