

Foreword



“Love and compassion are necessities, not luxuries.

Without them, humanity cannot survive”

—*Dalai Lama*

We are all born and begin life’s journey until “the end” – or “our passing” – or until we “move on.” All of those phrases are just expressions for death, a word that our society seems to want to avoid at all costs, as somehow it will not happen? We certainly hope it will not happen to us, or that at least we can control the death process? (We can’t.)

This book presents alternate and thought-provoking insights, yes – to death, but also on how planning with a hospice team can really make a difference in approaching the many challenges and myths about death. Perhaps, we can come to terms, or at least have a conversation, with ourselves and

those we care about. Ellen, the editor, also a contributor of this informative collection of perspectives, shares her own thoughts as well as those from hospice team members in their professional roles.

I first met Ellen when she was organizing a new LGBTQ+ ministry at the Church of Saint Ignatius Loyola in New York City. Certain things were evident, unmistakably, from the start of our friendship. The first was unequivocal love for her sons, and many family members. Second, her energy and enthusiasm were infectious. Third, she simply cares about people. Despite these qualities and her love of family, friends and the people she cared for, this love was also very much associated with Ellen's own personal and private pain. Namely, the pain of loss when several of her own family members died early, some unexpectedly. Over time, this love was transformed and shaped her life's work in hospice care, which all of us will draw solace, even if we too encounter some pain along the way. We are all human; we all have different lows and highs throughout our life journeys. Ellen would say "it's OK, just breathe – I'll be here with you."

Several years after meeting and getting to know Ellen, I reached out to her for advice concerning my then eighty-six-year-old

father. He had just said goodbye to my eighty-three-old mother, who died from a freak accident when she hit her head from a fall into the granite kitchen counter. She initially was in rehab due to the bleeding on her brain, then had brain surgery, but unfortunately, she did not recover. She entered hospice care in Pennsylvania and died three weeks later, never regaining consciousness. Soon after, my father moved to New York City, and was initially living alone near both me and one of my four brothers. However, his life had lost much of its meaning without my mother, and he rapidly began to decline, both mentally and physically. I asked Ellen for a recommendation for a home health aide who might help my father with daily walking, make sure he took his medications, and be sure he was eating properly. Ellen's network is wide, and she has since suggested not only his first home health aide when he was still somewhat independent but also another practical nurse when he moved to his current assisted living facility, now showing more signs of early dementia. Ellen's compassion, sincere interest, and uncompromising support clued me into why hospice, and people like Ellen, are so valuable.

Ellen's first book "Love Death Love" presented accounts of many different personal hospice situations with the patients and families that Ellen so gently helped to navigate the end

of their lives and leave the world without too much physical suffering or pain. This next book which you are about to read "Hospice: A Different Type of Hope: Criteria for Choosing your Hospice Team Sooner" shows that perhaps love can truly help us in planning for death. We just have to be open to others providing their expertise in the many facets of team-based hospice care.

As you turn the pages of what I trust will be an immensely helpful book, I encourage you to share some of your own feedback and comments with another person in your circle of family or friends. That action might help "start the conversation" about what many find hard to talk about. You too can be a catalyst for helping others find the help they might need, but are afraid to ask for, as many of us think we have a duty to handle this privately. (We don't and often can't.) It's OK to ask for help, we are human and the connections that others offer are often such a special gift. Say "yes" to exploring more about hospice criteria by Dr. Shahid, and the different kinds of places that hospice is offered which are shared by nurse practitioner, Christine. Don't be afraid to flip back and forth to the glossary of definitions at the end of the book. There is a terminology often used that isn't always apparent to non-medical people.

While Ellen has suggested an order of reading the chapters in this resource book, feel free to turn to any chapter that sparks your interest (in any order) but be sure to experience, and explore all the many perspectives offered. Nurse David shares one of my favorite parts of the book on the "Tree of Acceptance" which I hope you, and your loved ones, will also find very helpful. He also reviews five stages helpful to anyone facing death (from Kübler-Ross) and emphasizes that these stages often do not follow in a linear sequence. Individuals and family might experience all or only a few but not necessarily in the order presented. Social worker Ryan explains the who, what, and how social workers provide care in, and with the hospice team, while home health aide, Lena, details her own, and other home health colleagues' invaluable roles.

Overall, hospice teams are comprised of the most committed and dedicated healthcare professionals alive on earth, true heroes. Please let them help you and your family. As volunteer coordinator, James, will share with you...hospice is the only area of health care where volunteers are required. I was so honored to work with people much like James, David and Lena and the interdisciplinary team (IDT) at Bellevue where I completed my own volunteer chaplaincy internship in 2022-2023.

Lastly, physical therapist, Nelson, provides aspects of physical therapy (PT) that matter for those in hospice, while hospice chaplain/bereavement counselor, Matthew, closes your hospice "learning" journey about meaning-making. He deftly provides suggestions (and uses wonderful poetry examples) for how to assist those at end of life with thoughts, and activities. Even your presence in silence can help to companion with others gently, humbly, and lovingly towards death, and what may lie beyond.

Thank you to Ellen for her guidance and support of my own journey, and for positively influencing the journey of my father. May she, and her colleague authors and hospice experts, help you find peace.

—Rich Miller-Murphy
New York, NY

CHAPTER I

Considering Hospice: Sooner Rather than Later

Ellen Long Stilwell, RN CHPN

"Acceptance is challenging and also a new freedom"

Hospice care is supportive care given with a team-oriented approach for those with an advanced life-limiting illness, as well as their family members. This team includes a nurse, physician, social worker, home health aide, spiritual care provider, physical therapist, volunteers and bereavement counselor. Hospice care focuses on quality of life at the end of life with comfort care addressing physical, emotional, spiritual and psychosocial needs.