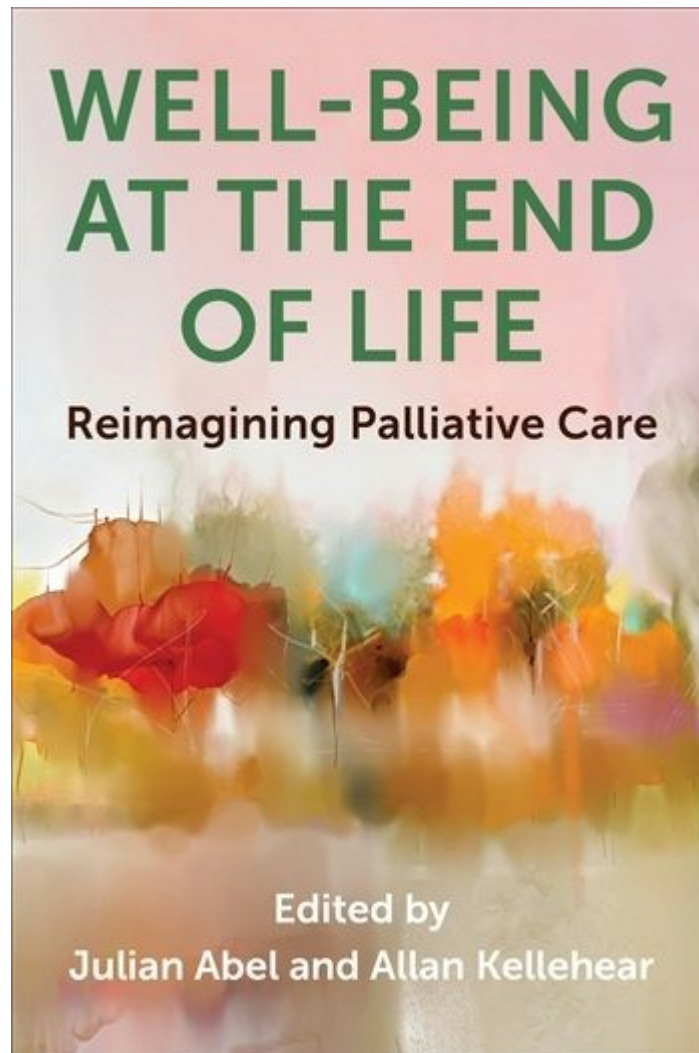




Reviewed by Nancy Eichhorn, PhD

“Death, dying, loss and caregiving are facts of life” (pg. 211)

Reviewing a book that involves an entirely new field of knowledge feels like enrolling in an intensive graduate seminar—at a minimum, it’s a semester long commitment, if not paving a path for continuing education. The time and research dedicated to grappling with new concepts extend far beyond what is contained between the front and back covers. The result is not a simple arc of learning but an oscillation: starting to get it, getting confused, gaining ground, stalling out, moving deeper into the content. Eventually, I experience a change in perspective as my understanding deepens one page at a time.

Reading *Well-Being at the End of Life: Reimagining Palliative Care* brought me into new knowing, including what the words palliative care even meant. Abel and Kellehear want readers to see palliative care not as a medical specialty but as a broader social, civic, and compassionate response to serious illness, dying, grief, and caregiving. Their anthology broadened my conception of end-of-life care and challenged me to consider a pertinent question repeated within the chapters of this book: what would it mean for communities, families, clinicians, and institutions to share responsibility for well-being until the end of life?



My Experience of End-of-Life Care

When I first received the invitation to review this book, I focused on three words: end of life. I immediately thought, oh, it's about 'hospice'.

Our family cared for Mom at home. Her decline started with a stage four cancer diagnosis in 2011, then three recurrences with medical treatments triggering the Alzheimer's that eroded her memory and left a widening gap between what she knew and what she could still recall. She would say, "I can't be here now," referring to the classes she and my dad attended at Spirit Rock, a spiritual and educational center immersed in mindfulness practices. Over time she stopped eating solid foods and then refused liquids. After a decade of fighting

various symptoms and treatments, my mom's soul decided it was time to return home to the God of her belief. She welcomed death as the entrance into Heaven and what came next didn't scare her.

At one point, her primary care doctor recommended hospice. Our family disagreed. One member felt that hospice meant death, On top of that, my dad could not face the reality that his wife, partner, and best friend of seventy years was leaving him. The hospice team came shortly before Mom died. Their purpose was to help her die with dignity and less pain. The nurse explained that dehydration had triggered a survival response: high cortisol and adrenaline resulted in rapid shallow breathing, moaning, flailing arms, restless legs. Mom needed medication to quiet the physical friction of dying so her body could settle into sleep. Mom died at 1 a.m., asleep in Dad's arms. Without hospice, her death would have been harder because we lacked knowledge about what happens when someone is dying.

What still surprises me is that no one mentioned palliative care during her decades-long struggle with cancer—four recurrences, chemotherapy, clinical trials, experimental drugs—or during the years Alzheimer's took her short-term and eventually long-term memories. We were lucky: she knew who we were until the moment she died.

Back to Basics

Memories aside, this book taught me that palliative care is not the same as hospice. Palliative care can begin at any stage after a serious, long-term disease has been diagnosed—cancer, Parkinson's disease, Alzheimer's disease—while hospice usually begins when curative treatment is no longer the focus and death is expected. The mutual vision of hospice and palliative care is to minimize suffering so that we can "live until we die." The purpose is to address distress and ease discomfort while supporting well-being and honoring the living until death comes (pg. xiii).

Hospice and palliative care both attend to the needs of the individual and family, but they vary in timing, scope, and sequence. Abel and Kellehear trace hospice's roots through religious-based histories of care for people on pilgrimages: the ill, injured, hungry, and dying, with care centered on cleanliness, protection, safety, and companionship. Gradually it became focused on medical and nursing care. Today, both hospice and palliative care are expanding in new directions because of thinkers and practitioners like Abel and Kellehear.



End of Life Re-Visioned

My understanding of end of life care, started from experience rather than specialized training or a global view of the field. So to explore the treasures contained in this text, I needed to define palliative care and then use that definition as a guidepost to guide my reading.

According to Abel and Kellehear: *"The World Health Organization defines palliative care as 'an approach that improves the quality*

of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual'" (61).

Got it. So I was reading about an approach that involved various stages of involvement by the medical community. So I thought.

Starting to read the book, the words 'dying is not a disease' on page 3 caught my eye because of my work with another book I was blessed to read: *The Nature of Being Human: How Body and Consciousness Change Together* authored by Jeanne Denney. I felt Denney, Abel and Kellehear wanted to let people know that death and dying, grieving and loss are part of living. These experiences, and the symptoms that accompany them, do not define us as healthy or sick. They are part of what it means to be living, breathing human beings until we stop breathing.

After many conversations with Denney and now reading this book, I have a sense that most people/therapists don't talk about dying in our cultural or clinical settings. We talk about disease, symptoms, cures. We discuss death in terms of wills, medical releases, Power of Attorney etc. But, we do not talk about death as an emotional and spiritual experience that impacts not just the person dying but their family, friends, and members of their community. Simply stated: this is wrong. And authors like Denney and Abel and Kellehear are writing to bring change to this injustice.

Abel and Kellehear have written about palliative care for decades. Julian Abel is a professor and director of Compassionate Communities UK, and he has spent more than 20 years working as a palliative medicine specialist in southwest England. He has co-authored numerous books and articles on palliative care. Allan Kellehear is a professor of end-of-life care at Northumbria University in Newcastle-upon-Tyne in the UK. He co-founded Compassionate Communities with Abel, taught internationally, and has co-authored books and articles with Abel.

The chapters in this book, originally part of The Reimagined Series, address apparent shortcomings in end-of-life care. Abel and Kellehear's work focuses on policy and practice, cultivates alternative ideas, and argues for changes that strengthen what already works while dealing with what needs attention.

Their vision of palliative care and public health is multidisciplinary, interprofessional, and explicitly oriented toward change and advocacy. They want to academically critique and revise education, training, and curricula, and rethink access to palliative care and our clinical response to grief and bereavement (xv).

Death as a Public-Health Question

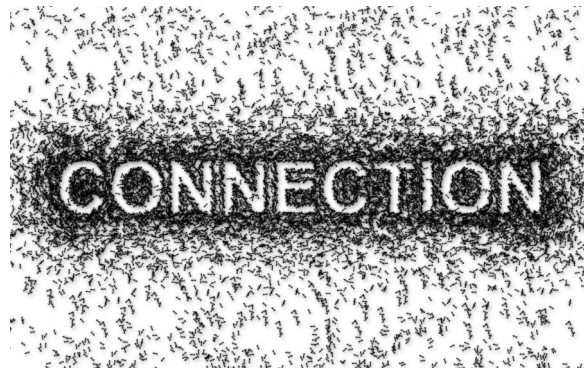
Framing death as a social event and a human experience, not an exclusively medical event, Abel and Kellehear argue that if dying affects families, friends, neighbors, workplaces, faith communities, and civic institutions, then end-of-life care cannot belong only to professionals.

The authors examine what has been happening in palliative care and invite readers to imagine how it could improve. They identify six shifts that move end-of-life care away from an exclusively institutional, professional model and toward active participation and mutual responsibility (pg. 21). In their terms, this means civic participation at the end of life, as well as a more equitable level of care across diagnoses and a broader range of nonmedical support in a time of diminishing resources (pg. 46).

Their proposed answer is a model that integrates four components: specialist palliative care, generalist palliative care, compassionate communities, and civic end-of-life care (65). Together, these categories widen the field from professional service delivery to shared social responsibility.

Should You Read This Book?

One of the book's many contributions is its stance that care is not only a clinical service but a mutual social practice. By the end, *Well-Being at the End of Life* reads less like an academic anthology (though the reference citations could create a course of their own) and more like an invitation to reconsider who is responsible for care when cure is no longer the central question. Abel and Kellehear ask readers professionally involved in end of life care to imagine systems in which dying people and their families are not cared for only by hospitals, specialists, or hospice teams, but by communities willing to acknowledge death as part of life and caregiving as a shared civic duty.



References:

Abel, J. & Kellehear, A. (Eds). (2026). *Well-being at the end of life: Reimagining palliative care*. Columbia University Press.

Denney, J. (2026). *The nature of being human: How body and consciousness change together*. Self Publisher.

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