Delivers the collective wisdom of foremost scholars and practitioners in the death and dying movement from its inception to the present. Written by luminaries who have shaped the field, this capstone book distills the collective wisdom of foremost scholars and practitioners who together have nearly a millennium of experience in the death and dying movement. The book bears witness to the evolution of the movement and presents the insights of its pioneers, eyewitnesses, and major contributors past and present. Its chapters address contemporary intellectual, institutional, and practice developments in thanatology: hospice and palliative care; funeral practice; death education; and caring of the dying, suicidal, bereaved, and traumatized. With a breadth and depth found in no other text on death, dying, and bereavement, the book disseminates the thinking of prominent authors William Worden, David Clark, Tony Walter, Robert Neimeyer, Charles Corr, Phyllis Silverman, Betty Davies, Therese A. Rando, Colin Murray Parkes, Kenneth Doka, Allan Kellehear, Sandra Bertman, Stephen Connor, Linda Goldman, Mary Vachon, and others. Their chapters discuss the most significant facets of early development, review important current work, and assess major challenges and hopes for the future in the areas of their expertise. A substantial chronology of important milestones in the contemporary movement introduces the book, frames the chapters to follow, and provides guidance for further, in-depth reading. The book first focuses on the interdisciplinary intellectual achievements that have formed the foundation of the field of thanatology. The section on institutional innovations encompasses contributions in hospice and palliative care of the dying and their families; funeral service; and death education. The section on practices addresses approaches to counseling and providing support for individuals, families, and communities on issues related to dying, bereavement, suicide, trauma, disaster, and caregiving. An Afterword identifies challenges and looks toward future developments that promise to sustain, further enrich, and strengthen the movement.
Death, Dying, and Bereavement
Judith M. Stillion, PhD, CT, is professor emerita of psychology and currently serves as a consultant on a variety of issues, including end-of-life issues, meaningful aging, positive psychology applied to grieving and dying, and strategic planning and facilitation of grief groups. Her varied career includes teaching and counseling in the public schools and at the university level. She began teaching the psychology of death and dying in 1975 and continued for more than 20 years. She also served as associate and vice chancellor for academic affairs at Western Carolina University, associate vice president for academic affairs in the University of North Carolina system, and founding director of the Institute for Leadership, Ethics & Character at Kennesaw State University. She is a past president of the Association for Death Education and Counseling and recipient of both their Death Educator and Contributions to the Field awards. She has written three books and numerous chapters and articles in her field of expertise, which includes suicide across the life span, aging, positive psychology applied to grief groups, and gender issues in death and grief.

Thomas Attig, PhD, is the author of Catching Your Breath in Grief . . . and Grace Will Lead You Home (2012), The Heart of Grief: Death and the Search for Lasting Love (2000), How We Grieve: Relearning the World (2011), and numerous articles and reviews on grief and loss, care of the dying, suicide intervention, death education, expert witnessing in wrongful death cases, the ethics of interactions with the dying, and the nature of applied philosophy. He spent the greater part of his career (1972–1995) as professor of philosophy (now emeritus) at Bowling Green State University, where he served as department chair for 11 years and established the first PhD in applied philosophy in the world in 1987. A past president of the Association for Death Education and Counseling, he has also served as vice chair of the board of directors of the International Work Group on Death, Dying, and Bereavement. He holds degrees in philosophy from Northwestern University (BA) and Washington University in St. Louis (MA and PhD). He currently resides in Victoria, British Columbia, Canada, and devotes his time to writing and speaking. He invites you to visit his web site at www.griefsheart.com.
For Glenn, John William, Bethany Dawn, and Daniel James, who form the core of meaning in my life; and for all those who are courageous enough to serve the dying and bereaved.

—JMS

For Betty, Julie, Ty, Jamie, Sher, Skyler, and Dan, the loves of my life, and for all who take seriously the stories of love and sorrow the dying and bereaved have to tell.

—TWA
# CONTENTS

Preface xvii

*Introduction: Chronology of Developments in the Movement*

Thomas Attig xix

## PART I: INTELLECTUAL DEVELOPMENTS

1. Seeking Wisdom About Mortality, Dying, and Bereavement 1
   *Thomas Attig*
   
   Personal History 1
   Philosophy as Love of Wisdom 2
   Existential Phenomenology 3
   Facing Personal Mortality 4
   Living While Dying 7
   Bereavement and Grieving 10
   Looking to the Future 13
   References 14

2. Know Thyself: Psychology’s Contributions to Thanatology 17
   *Judith M. Stillion*
   
   My Entry Into the Field 17
   Early Psychology 18
   The Psychoanalytic Movement 18
   Humanistic/Existential Psychology 21
   Cognitive Psychology and Cognitive Behaviorism 22
   Positive Psychology 24
   Eclectic Thinkers 26
   Facing the Future 27
   References 28

3. Sociological Perspectives on Death, Dying, and Bereavement 31
   *Tony Walter*
   
   What Draws a Sociologist to Study Death? 31
   Foundations 32
   Current Themes 35
   Contemporary Challenges 39
   References 41

4. Science and Practice: Contributions of Nurses to End-of-Life and Palliative Care 45
   *Diana J. Wilkie and Inge B. Corless*
## Contents

**Palliative and End-of-Life Care Journeys**
- Uncovering and Combating the Conspiracy of Silence About Death and Dying
- Making Meaning: Living With the Chronicity of Life-Threatening Illnesses
- Promoting Team-Based Collaborative Approaches to Care
- Managing Pain and Symptoms of Children and Adults
- Integrating Bereavement Within Patient-Centered and Family-Focused Dying Care
- Conducting Research With People at the End of Life
- Educating Nurses to Improve Care of People at the End of Life
- Summary: Impact of Nurses on Palliative and End-of-Life Care

**References**

**5. Legal Issues in End-of-Life Decision Making**

*James L. Werth Jr.*
- Background
- 1970s and 1980s
- 1990s
- 2000s
- 2010–Present
- Conclusion

**References**

**6. The Ethics of Caring for the Dying and the Bereaved**

*Thomas Attig*
- My Involvement in End-of-Life Ethics
- The History of Medical/Health Care Ethics
- Respect for Persons
- The Turn to Narrative Ethics
- Looking to the Future

**References**

**7. Theoretical Perspectives on Loss and Grief**

*J. William Worden*
- Sigmund Freud
- Erich Lindemann
- John Bowlby
- Colin Parkes
- Elisabeth Kübler-Ross
- William Worden
- Therese Rando
- Simon Rubin
- Thomas Attig
- Stroebe and Colleagues
- Continuing Bonds
- Robert Neimeyer and Janice Nadeau
- The Elephant Needs a Pedicure: Similarities, Differences, Directions for the Future

**References**

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Contents

8. The Psychologization of Grief and Its Depictions Within Mainstream North American Media 105  
Leeat Granek  
Grief as a Psychological Object of Study in a Modernist Context 106  
The Pathologization/Psychologization of Grief 107  
Depictions of Pathological/Psychological Grief in Mainstream Media 110  
Discussion 116  
Looking Ahead 117  
References 118

9. Developmental Perspectives on Death and Dying, and Maturational Losses 121  
Judith L. M. McCoyd and Carolyn A. Walter  
Our Stories 121  
Our Developmental Perspective 122  
Perinatal Period and Infancy 123  
Toddlerhood Through Preschool-Aged Children 124  
Elementary School-Aged Children 125  
Tweens and Teens 126  
Young Adults 127  
Middle Adulthood 128  
Retirement/Reinvention 129  
Older Adults 130  
New Directions and Developments 131  
References 131

PART II: INSTITUTIONAL DEVELOPMENTS

10. Hospice Care of the Dying 135  
David Clark  
Attractions of Hospice 135  
Foundational Strands of Early Development 136  
Hospice Care Today: Evaluation and Controversy 142  
Challenges and Hopes for the Future of Hospice Care for the Dying 148  
References 148

11. Hospital-Based Palliative Care 151  
Bernard J. Lapointe and Dawn Allen  
Where We Began and How We Have Changed—A Brief History of Hospital-based Palliative Care 153  
Cornerstones and Foundations of Hospital-Based Palliative Care 157  
Current Challenges in Hospital-Based Palliative Care 159  
Looking Ahead: Protecting the Future of Hospital-Based Palliative Care 161  
References 162

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Contents

12. Palliative Care for Children 165
   Betty Davies
   My Entry Into the Field 165
   Early Work in the Field 166
   The 1970s and 1980s 167
   The 1990s 169
   Definition of Pediatric Palliative Care 170
   Current Developments in PPC (2000–the Present) 172
   Challenges 175
   References 178

13. The Global Spread of Hospice and Palliative Care 181
   Stephen Connor
   Personal Reflection 181
   Foundational Work on the Global Development of Palliative Care 182
   Current Work on Development of Palliative Care 185
   Challenges and Hopes for the Future 189
   References 191

14. Death and Funeral Service 193
   Vanderlyn R. Pine
   Historical Antecedents to Post–World War II Funeral Directing 194
   The Changing Role of Funeral Directors Following World War II 195
   Scholarship About Funerals, Death, Grief, and Bereavement 196
   Research Focused on Funeral Directing 198
   Criticism of Funeral Directors and Funeral Practices 202
   The Impact of the Baby Boom on the Funeral Industry 203
   The Future 204
   References 205

15. Death Education at the College and University Level in North America 207
   Charles A. Corr
   My Involvement in This Field 207
   Early Initiatives 209
   Early Pedagogical Resources 210
   More Recent Developments: Survey Courses on Death, Dying, and Bereavement 211
   More Recent Developments: Other Death-Related Courses 214
   More Recent Developments: Thanatology Programs 215
   What Have We Learned From and About Death Education? 216
   References 217

16. Death Education as a Public Health Issue 221
   Allan Kellehear
   The Case for Death Education as a Public Health Issue 222
   Two Current International Examples 228
   Future Challenges 230
   References 232
PART III: PRACTICE DEVELOPMENTS

17. Spirituality: Quo Vadis? 233
   Kenneth J. Doka
   Religion, Spirituality, Health, and Grief 234
   Spiritual Tasks in Life-Threatening Illness 235
   Spirituality and Grief: After the Death 237
   Assisting Individuals and Families at the End of Life:
     Using Spirituality 237
     The Power and Use of Rituals 239
     The Challenge of Spiritual Support 241
   Quo Vadis 242
   References 242

18. Using the Arts and Humanities With the Dying, Bereaved, . . .
    and Ourselves 245
   Sandra Bertman
   Where and How It All Began 245
   The Equinox Institute (1969–1971) 247
   Failproof Techniques for All Ages 248
   Fast Forward: From Dissection to Palliative Care—Soul Pain,
    Aesthetic Distance, and the Training of Physicians 251
   Changing Ideas About Health Care 254
   Where We Are Going 257
   References 257

19. Family Support for the Dying and Bereaved 261
    David W. Kissane
    The Development of Family-Centered Care 261
    The Foundations of Family-Centered Care 263
    Clinical Organization of Family-Centered Care Today 265
    Challenges for the Future of Family-Centered Care 268
    Conclusion 270
    References 271

20. Supporting Grieving Children 275
    Linda Goldman
    My Early Years in the Field 275
    Children’s Concepts of Death 276
    Resources for Children 278
    Children’s Grief and the Digital Age 280
    Grief Work With Children 282
    Grief Education for Adults 284
    Basic Understandings for Adults 285
    Joining as a Global Grief Community for Children 289
    References 290

21. Helping Each Other: Building Community 293
    Phyllis R. Silverman
    Background 293
    The Widow-to-Widow Program 295

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Contents

Widows Who Accepted Help  296
Widows Who Refused Help  297
The Widowed Service Line  298
Other Programs  298
A View of Grief  299
Mutual Help  300
Current Programs and Practices  302
Conclusion  303
References  303

22. Treating Complicated Bereavement: The Development of Grief Therapy  307
Robert A. Neimeyer
A Backward Glance  307
The Contemporary Landscape of Loss  309
A Scientific Coda  316
Notes  317
References  317

23. When Trauma and Loss Collide: The Evolution of Intervention for Traumatic Bereavement  321
Therese A. Rando
Definitions and Conceptual Clarifications  323
From Two Disparate Areas to One: Pivotal Steps in the Development of Traumatic Bereavement  324
The “Classics” in the Field: Six Foundational Concepts Associated With the Treatment of Traumatic Bereavement up to 2000  327
Someday to Be “Classics” in the Field: Five of the Newest, Most Valuable Areas of Contribution to the Treatment of Traumatic Bereavement Since 2000  328
Future Concerns Regarding Traumatic Bereavement and Its Treatment  330
References  331

24. To Be or Not to Be: Suicide Then and Now  335
Judith M. Stillion
A Little History  335
Dimensions of the Problem  337
Myths About Suicide  338
Understanding and Preventing Suicide  338
Patterns of Suicide  341
Suicide Prevention  342
Society’s Role in Suicide Prevention Intervention  345
A Look Ahead  346
References  346

25. Grief After Suicide: The Evolution of Suicide Postvention  349
John R. Jordan
Personal Evolution  349
Evolution of the Response to a Public Health Problem Interventions for Survivors—History  351
Contents

Interventions for Survivors—Current Standing 352
Interventions for Survivors—Future Directions 357
Conclusion 359
Notes 359
References 359

26. Responding to Grief and Trauma in the Aftermath of Disaster 363
Colin Murray Parkes

Preparation for Disasters 366
The Impact Phase—Psychological First Aid 367
Recoil—Planning and Implementation—Posttraumatic Reactions 370
Aftermath—Community Care and Recovery 373
Recovery—Withdrawal of External Services 374
Implications for Future Developments 376
References 377

27. Care of the Caregiver: Professionals and Family Members 379
Mary L. S. Vachon

Professional History 379
Overview 380
Stress and Distress 380
Burnout and Job Engagement 382
Compassion Fatigue, Empathy, and Compassion Satisfaction 383
What Are Caregivers Already Doing That Works? 383
Current Interventions 386
Major Challenges and Hopes for the Future 390
References 391

Afterword 395
Judith M. Stillion and Thomas Attig

Index 399
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The two of us met in 1979 at one of the early conferences sponsored by the then newly formed Forum for Death Education and Counseling, each having already devoted several years to work in the emerging contemporary death, dying, and bereavement movement. It was so good to gather with others from such diverse backgrounds in teaching, research, health care, counseling professions, and volunteer service. We were not alone in sensing the excitement of meeting others who were passionate about learning from one another and about changing ways of understanding, living with, and caring for others facing death, dying, and bereavement.

We were privileged then, and have been in the years since, to learn from, work with, and in many cases befriend pioneers and major contributors in the field. Two years ago, while looking back at how remarkably far the movement has come, we realized how many leading figures and friends have died. We saw an opportunity to capture the collective wisdom of living pioneers, major contributors, and participant witnesses to the founding and evolution of the movement before more voices were lost. We would bring those voices together in a book that would be a testament to and celebration of the work of all those who have led us to where we are today. We are excited to have gathered together an extraordinary team of 28 authors with nearly a millennium of experience in the field to tell stories that only they can tell about unprecedented changes that have been unfolding since the movement began in the middle of the 20th century. We are grateful that our editor at Springer Publishing Company, Sheri W. Sussman, endorsed our idea enthusiastically and helped us so ably to bring it into reality. We are also so grateful for the opportunity to work together again on this volume, work that has deepened both our knowledge and friendship.

We asked all of our authors to describe what drew them into the field, discuss the most important strands of early development in the area of their chapters that they consider to be foundational and not to be forgotten, review the most valuable current work in the area, and assess major challenges and hopes for future developments. Although we hope that all will live long and continue to prosper, we wanted to harvest the insights of these seminal figures before it became too late to do so.

We are amazed and enormously grateful for the foundational and revolutionary efforts of the thought leaders, institutional innovators, imaginative practitioners, and concerned citizens whose stories our authors tell. As their informative and often provocative chapters came flooding in and we began the editorial review and polishing process, we realized how collectively they were expanding our own understanding and appreciation of how rich and varied the contributions of the death, dying, and bereavement movement are. Taken together, we believe these writers have created a unique and lasting contribution to the growing body of work that is defining a new discipline: thanatology.
We bring this book to you out of the following shared convictions. First, we pay too high a price individually and collectively in missing what matters most in life if we persistently turn away from and remain silent about the realities of mortality that are so intimately interwoven in the fabric of our being. Everyone can benefit from development and dissemination of better understanding the meanings of death, dying, and bereavement for individuals, families, and communities and of their implications for how we live. We do well to counter tendencies to isolate the dying and bereaved that increase their dependence on professionals. We believe there is a deep human need to come together as family and community while loved ones are dying, grieving, traumatized, or contemplating suicide to hear their stories, bear witness to their suffering, and offer support and compassion. We endorse efforts to reach past the limitations of disease-focused medical care and pathology-focused bereavement support to recognize and respond more effectively to the multidimensional needs of whole persons living with disease and relearning the world in grief. We affirm and call for increased understanding and support of the resilience and capacities for overcoming suffering and finding healing that are inherent in the human spirit. We heartily support revival of the art of medicine as at least coequal with the science and value team-based and volunteer-based approaches to end-of-life care. We applaud resistance to professional paternalism in favor of informed consent; respect for human dignity; attunement through dialogue to the particularities of individual, family, and community experiences and needs; and affirmation of their freedom to shape their own experiences. We seek to enable families and communities to reclaim responsibilities for death education and care and support of those who are dying, bereaved, traumatized, or suicidal. We eagerly await the day when death education will be integrated into schooling at all levels to prepare citizens for those responsibilities, for scholars to deepen their understanding, and professional caregivers to use the best of what is known wisely.

We intend this book for all who have been interested or actively engaged in the movement through the years, and especially for those relatively new to the field as students or practitioners who share these convictions and passions and will carry on, extend, and creatively transform the efforts discussed here. Our authors trace the development of thanatology as an interdisciplinary field of study (in Part I) and organizational and practice developments in response to the diverse needs of dying, bereaved, suicidal, and traumatized individuals, families, and communities (in Parts II and III). A unique feature of this book is a detailed chronology that includes many, though of course not all, of the most important milestones of the last 60 years. It is intended to serve as an overview as well as the foundation for understanding this burgeoning field and as a guide for readers who wish to understand in detail its short, but rich, history.

Robert Kastenbaum often casually defined the emerging academic field of thanatology as “the study of life with death left in.” Clearly, we have in this book stretched beyond the study of death, dying, and bereavement to encompass institutional and practice developments in response to these universal human experiences. Gandhi charged us to “be the change you want to see in the world.” The pioneers and major contributors to the movement (including our authors) have done that and in so doing crafted better, more humane ways to conceptualize and cope with the many faces of death, dying, and bereavement in our times. We invite you to join them and learn from them as we move forward together.

Judith M. Stillion and Thomas Attig
Thomas Attig

INTRODUCTION: CHRONOLOGY OF DEVELOPMENTS IN THE MOVEMENT

It is impossible to capture all of the events, strains of thought, organizational developments, and changes in practice that have shaped the study of death, dying, and bereavement and transformed contemporary responses to them. However, this chronology captures many of the most important influences on and milestones in the evolution of contemporary responses to death, dying, and bereavement as we, after consultation with our authors, see them. We know of nothing else like it in the literature.

We invite you to peruse this chronology (1) as a broadly based introduction to work in the death-and-dying field; (2) as an organizing framework for reading the chapters that follow, enabling you to see where the works described in them fit in this larger context; (3) as a review to return to when you’ve finished reading the book; and (4) as a detailed guide to further, in-depth reading in the field.

1955  Robert W. Habenstein and William Lamers author The History of American Funeral Directing, helping to solidify understanding of the role of the funeral director as a professional.
* Geoffrey Gorer publishes “The Pornography of Death,” an early study of reasons why society at that time tended to ignore or deny death.
* Edwin Shneidman, Norman Farberow, and Robert Litman found the Los Angeles Suicide Prevention Center, the first of its kind.
1959  Herman Feifel publishes The Meaning of Death, promoting establishment of death studies as an interdisciplinary academic field.
* Renée C. Fox writes Experiment Perilous: Physicians and Patients Facing the Unknown on conflicting responsibilities of caring for incurably ill men and conducting research on them.
* Margaret Torrie founds Cruse Clubs for Widows, subsequently developed by Colin M. Parkes and Derek Nuttall into Cruse Bereavement Care, for all bereaved persons in the United Kingdom.
1960  Robert Habenstein and William Lamers publish Funeral Customs the World Over, a comprehensive overview of ritual responses to death.
1961  Robert Fulton writes “The Clergyman and the Funeral Director: A Study in Role Conflict,” about the two primary functionaries associated with burial of the dead.
Introduction: Chronology of Developments in the Movement

*C. S. Lewis’s A Grief Observed appears, a singularly memorable grief journal by a leading religious thinker describing his spiritual struggles after the death of his wife.


1963 Jessica Mitford authors The American Way of Death, raising public awareness of ethical issues surrounding American funeral practices.

* Jeanne Quint Benoliel’s report, “The Impact of Mastectomy,” in American Journal of Nursing, is the first in nursing to focus on issues of dying and catapults her research in death and dying.

1965 Barney Glaser and Anselm Strauss write Awareness of Dying about communication patterns between the dying and their caregivers.

* Robert Fulton edits Death and Identity, calling for the scientific study of attitudes and reactions toward grief, bereavement, and human mortality.

1967 Dame Cicely Saunders founds the first modern hospice, St Christopher’s in London, England, marking a revolutionary turn in care of the dying and their families.

* Jeanne Quint Benoliel authors The Nurse and the Dying Patient, the first systematic study of the role of nurses in caring for the dying.

* David Sudnow writes Passing On: The Social Organization of Dying on how presumed social value of dying patients determined treatment and information exchange in hospitals.

* Phyllis Silverman begins the Widow-to-Widow Project through Harvard Medical School, which has served as a basis for mutual-help programs for widows in the United States and other countries.

* The Euthanasia Society of America (Concern for Dying after 1978) introduces the “Living Will” to specify desires concerning cessation of end-of-life treatment.

* Robert Fulton establishes the Center for Thanatological Studies at the University of Minnesota (the Center for Death Education and Research in 1969), sponsor of early conferences bringing together scholars from many fields.

* Austin Kutscher founds the Foundation of Thanatology, sponsor of multidisciplinary symposia and publisher of the first journal in the field, The Journal of Thanatology. This work continues in the Columbia University Seminar on Death.

* John Bowlby releases Attachment, followed by Separation (1973) and Loss (1980), a cornerstone trilogy in contemporary thinking about grief and loss.

* John Fryer founds Ars Moriendi, publishing a newsletter and bibliographies and sponsoring symposia.

1968 Edwin Shneidman founds the American Association of Suicidology and the first American journal in the study of suicide, Suicide and Life Threatening Behavior.

1969 Elizabeth Kübler-Ross publishes On Death and Dying, bringing death out of the shadows into public discourse, urging acceptance of the reality of death.

* Robert Kastenbaum establishes the Center for Dying, Death, Suicide and Lethal Behavior at Wayne State University.

1970 Richard Kalish, Robert Kastenbaum, and Robert Fulton found Omega: Journal of Death and Dying, which continues to publish thinking and research in death, dying, and bereavement.

* Colin Murray Parkes starts the first hospice-based bereavement service using carefully selected, trained, and supervised volunteers at St Christopher’s Hospice.
1971  The Hastings Center Report begins publication, a journal devoted to ethical, legal, and social issues in medicine, including end-of-life ethics.
1972  Colin Murray Parkes authors Bereavement: Studies of Grief in Adult Life on potentially detrimental effects of bereavement and typical manifestations of grief.
* Avery Weisman publishes On Dying and Denying, a psychiatric study of living with terminality and introducing the idea of “appropriate death,” a death one would choose.
* Robert Kastenbaum and Ruth Eisenberg release The Psychology of Death, a treatment of our construction of death from a developmental perspective.
* A. Alvarez authors The Savage God, a review of attitudes toward suicide and death through history and literature.
* Albert Cain writes Survivors of Suicide, the first clinically oriented volume to describe problematic reactions to a suicide experienced by many survivors.
1974  Florence Wald (Dean of the Yale School of Nursing) and her colleagues co-founded the first hospice in North America in Branford, Connecticut.
* Ars Moriendi sponsors the International Convocation of Leaders in the Field of Death and Dying, centering on dialogue rather than paper presentations, prefiguring the International Work Group on Death, Dying, and Bereavement.
* The first hospital-based hospice programs are established at the Royal Victoria Hospital in Montreal and St. Boniface General Hospital in Winnipeg. Dr. Balfour Mount first uses the term “palliative care” in the name of the Royal Victoria program.
* Ernest Becker publishes The Denial of Death, a sustained reflection on how human refusal to face mortality shapes culture in wide-ranging and unexpected ways.
* Lily Pincus authors Death and the Family, a social worker’s perspective on understanding and working therapeutically with grieving families.
1975  Hannelore Wass convenes the first American conference that brings together academics and practitioners in Orlando, Florida, inspiring the founding of the Forum on Death Education and Counseling.
* Karen Ann Quinlan falls into a permanent vegetative state. Her parents’ request that she be removed from life support rouses controversy that leads to establishment of hospital, hospice, and nursing home ethics committees and wider use of advanced directives.
* Raymond Moody publishes Life After Life, the first book devoted to the modern study of near-death experiences.
1976  The Forum on Death Education and Counseling (now the Association for Death Education and Counseling: The Thanatology Association [ADEC]) first meets in Washington, DC. The original name is retained in ADEC’s publication, The Forum.
* The Royal Victoria Hospital in Montreal sponsors the first biennial International Congress on Care of the Terminally Ill (later the International Congress on Palliative Care), bringing together clinicians and scholars from around the world.
* William Worden authors PDA: Personal Death Awareness on the fear of death.
1977  The National Hospice Organization (NHO) is founded to support the spread of hospice in the United States (The National Hospice and Palliative Care Organization [NHPCO] since 2000).
* Herman Feifel publishes New Meanings of Death, a second interdisciplinary anthology featuring many of the early thinkers in the field.
Phillipe Aries authors *L'Homme devant la mort*, an amateur social-historian’s review of a thousand years of Western responses to death, translated as *The Hour of Our Death* in 1981.

Hannelore Wass founds *The Journal of Death Education*, dedicated to death education in schools and universities. As *Death Studies*, it is a major outlet for researchers and theorists.

The International Work Group on Death, Dying, and Bereavement (IWG) incorporates, fostering interdisciplinary group discussion and occasional publications.

1978

The Society for Compassionate Friends, a support group providing friendship, understanding, and hope for bereaved parents, incorporates.


The International Symposium on the Dying Human, held in Tel Aviv, Israel, brings together scholars and practitioners from around the world.

1979

Robert Fulton coordinates Courses by Newspaper: Death & Dying, a 15-part series on death in American culture, published in more than 400 newspapers with a readership of 12 million and offered in more than 300 colleges and universities, with a student enrollment of more than 12,000.

Robert Lifton publishes *The Broken Connection*, about immortality (literal and symbolic) in an era of declining traditional belief and possible nuclear annihilation.

1980

Dr. Josefina Magno founds the International Association of Hospice and Palliative Care (IAHPC), initially as the International Hospice Institute, later the American Academy of Hospice and Palliative Medicine and the International Hospice Institute and College (IHIC).

Ida Martinson demonstrates that it is possible to care for children dying of cancer at home.

1981

Simon Shimshon Rubin introduces his two-track model of bereavement in the *American Journal of Orthopsychiatry*.

Harold Kushner authors *When Bad Things Happen to Good People*, reflecting compassionately on spiritual doubts and fears that surface when loved ones die.

1982

William Worden writes *Grief Counseling and Grief Therapy*, urging that grieving is not only reactive but also actively responsive, and providing guidance for grief counselors and therapists.

Beverly Chappell founds the Dougy Center for Grieving Children in Portland, Oregon.

The Hospice Foundation of America is established to raise funds for South Florida hospices but later to provide leadership on a broad spectrum of end-of-life issues.

The Medicare hospice benefit is approved by Congress, providing coverage for hospice care for the elderly and the poor in the United States.

Sister Francis Dominica and her colleagues open Helen House, the world’s first free-standing hospice for children in Oxford, England.

The journal *Bereavement Care* begins, edited by Colin Murray Parkes and Dora Black.

Lynne DeSpelder and Albert Strickland publish *The Last Dance: Encountering Death and Dying*, destined to become the best-selling textbook in the field.

1983

Ann Armstrong-Dailey starts Children’s Hospice International (CHI), with the objective of providing education, legislation, and support for families of children with terminal illness.
* The first annual King’s College International Conference on Death and Bereavement is held in London, Ontario (in LaCrosse, Wisconsin since 2006).
* Colin Murray Parkes and Robert Weiss author *Recovery From Bereavement*, the main account of the *Harvard Bereavement Project*, a study that facilitated bereavement risk assessment.

1984

Beverley Raphael offers *The Anatomy of Bereavement*, showing how the dynamics of grief and recovery vary from infancy through old age.

1985

The first triennial International Conference on Grief and Bereavement in Contemporary Society is held in Jerusalem, Israel, bringing together scholars, researchers, and clinicians.

* *The Journal of Palliative Care*, edited by David Roy, begins publication.
* Thomas Beauchamp and James Childress write *Principles of Biomedical Ethics* on core principles of beneficence, nonmaleficence, personal autonomy, and justice in medical ethics.
* Therese Rando edits *Loss and Anticipatory Grief*, followed in 2000 by *Clinical Dimensions of Anticipatory Mourning* on grieving as death approaches.
* Betty Rollin releases *Last Wish*, a poignant account of her response to her mother’s plea for assistance in killing herself while facing terminal illness.

1986

The Hospice and Palliative Nurses Association is founded, dedicated to promoting excellence in hospice and palliative care nursing.

* Beverley Raphael writes *When Disaster Strikes: How Individuals and Communities Cope With Catastrophe*, on the psychological consequences of disasters.
* Judith M. Stillion authors *Death and the Sexes*, the first book on gender issues in death and grief.

1987

The Royal College of Physicians (Great Britain) is the first to recognize palliative care as an official subspecialty in medicine.

* Mary Vachon writes *Occupational Stress in the Care of the Critically Ill, Dying and Bereaved*, a international interview study of 581 professional caregivers.
* Randy Shilts authors *And the Band Played On*, a searing critique of institutional failure in response to the early stages of the AIDS epidemic.

1988

The Academy of Hospice Physicians is founded (later the American Academy of Hospice and Palliative Medicine).

* The European Association for Palliative Care (EAPC) is founded. EAPC now consists of 55 associations in 32 countries.
* Dennis Klass writes *Parental Grief: Solace and Resolution* on the basis of his work with bereaved parents in Compassionate Friends.

1989

Kenneth J. Doka edits *Disenfranchised Grief: Recognizing Hidden Sorrow* on the range of loss experiences not acknowledged by the larger society (followed in 2002 by *Disenfranchised Grief: New Directions, Challenges and Strategies for Practice*).

* Judith M. Stillion and Eugene McDowell author *Suicide Across the Lifespan: Premature Exits*, offering a developmental perspective on suicide.
* Michael Kearl writes *Endings: A Sociology of Death and Dying*, arguing that death is the central force shaping our social life and order.

1991

The Association for Children With Life Threatening or Terminal Conditions and Their Families (ACT), now known as Together for Short Lives, is formed in the United Kingdom.
* The Canadian Palliative Care Association is established (now the Canadian Hospice and Palliative Care Association [CHPCA]).
* The journal *Illness, Crisis & Loss* is established, a reflective forum for practitioners, researchers, leaders, and students, linking theory, research, and practice.
* Eric Cassell authors *The Nature of Suffering and the Goals of Medicine*, describing how persons suffer in all dimensions of their being, not just physically.
* Sandra Bertman writes *Facing Death: Images, Insights and Interventions*, sensitizing readers via the arts to universal issues confronting the dying and those who care for them.
* Derek Humphry publishes *Final Exit*, a how-to guide to suicide at the end of life, arousing great controversy about issues in end-of-life ethics.

1992

Ronnie Janoff-Bulman authors *Shattered Assumptions: Towards a New Psychology of Trauma*, focusing on the loss of the assumptive world in bereavement.

1993


* Timothy Quill writes *Death and Dignity*, for physicians and their terminally ill patients about the active role the dying should take in end-of-life decisions.
* Edwin Shneidman publishes *Suicide as Psychache*, a collection and reworking of his seminal papers on suicide from 1971 to 1993.
* Therese Rando authors *Treatment of Complicated Mourning* about working therapeutically with individuals for whom standard counseling techniques do not suffice.
* Margaret Stroebe, Wolfgang Stroebe, and Robert Hannson edit the *Handbook of Bereavement*, featuring essays covering a broad range of research and clinical practice.

1994

Genocide kills about 700,000 in Rwanda. Leila Gupta, assisted by Colin Murray Parkes, sets up a Trauma Recovery Program for UNICEF.

* The Hospice Foundation of America broadcasts its first teleconference, an event that has become the single largest annual death education experience in the United States.
* The Project on Death in America begins funding initiatives in education, the arts, research, clinical care, and public policy to transform the culture of dying and bereavement.
* Robert Neimeyer edits the *Death Anxiety Handbook: Research, Instrumentation & Application*, a comprehensive treatment of research on its subject.

1995

Sherwin Nuland writes *How We Die*, about the biological and clinical realities of dying from cancer, heart attack, AIDS, Alzheimer’s disease, trauma, and old age.

* Brian L. Mishara writes *The Impact of Suicide*, examining the impact of suicide on individuals, families, helping professionals, and society as a whole.
* Betty Davies, Brenda Eng, and their colleagues cofound Canuck Place, the first free-standing hospice for children in North America in Vancouver, British Columbia.
1996  Thomas Attig authors *How We Grieve*, an all-encompassing phenomenology of grieving as a process of relearning how to be and act in a world transformed by loss.
* Dennis Klass, Phyllis Silverman, and Steven Nickman publish *Continuing Bonds*, reporting on research indicating that grievers maintain connections with the dead.
* William Worden releases *Children & Grief: When a Parent Dies* on the basis of his work with Phyllis Silverman on the Harvard Child Bereavement Study.
* Colin Murray Parkes, Pittu Laungani, and Bill Young edit *Death and Bereavement Across Cultures*, about major world systems of belief and ritual and their practical implications.

1997  The Education in Palliative Care and End-of-Life Care (EPEC) program, sited within the American Medical Association and sponsored by the Robert Wood Johnson Foundation, begins training trainers of national and international physicians in palliative care.
* Oregon enacts its Death with Dignity Act, authorizing physician-assisted suicide for the first time in the United States.
* *Mortality*, an English publication (now the official journal of the Association for the Study of Death and Society), is first published and is devoted to the interdisciplinary study of death and dying.
* Mitch Albom authors *Tuesdays With Morrie: An Old Man, A Young Man, and Life’s Greatest Lesson*, a memoir of sessions with his former professor, who is dying of ALS.

1998  Ira Byock writes *Dying Well*, containing poignant and instructive accounts of a hospice team attending to the whole person of those in their care.
* Janice Winchester Nadeau publishes *Families Making Sense of Death*, an exploration of meaning reconstruction from a familial perspective.
* Kathleen Dowling Singh authors *The Grace of Dying*, an account of psychological and spiritual transformation as we surrender our egos and bodies to death.

1999  Margaret Stroebe and Henk Schut introduce the dual-process model of coping with bereavement in *Death Studies*.
* Pauline Boss writes *Ambiguous Loss* on grieving when there is no direct confirmation of death—used widely after the 9/11 terrorist attacks.
* Betty Davies authors *Shadows in the Sun: The Experience of Sibling Bereavement in Childhood*, about childhood experiences of and lifelong consequences of sibling loss.
* Tony Walter writes *On Bereavement: The Culture of Grief*, a study of the sociological and cultural dimensions of and influences on grieving.

2000  The End-of-Life Nursing Education Consortium (ELNEC), a train-the-trainer initiative sponsored by the Robert Wood Johnson Foundation and administered by the American Association of Colleges of Nursing and the City of Hope, begin training nurses and other health care providers the world over.
Phyllis Silverman publishes *Never Too Young to Know: Death in Children’s Lives*, based on her work with William Worden on the Harvard Child Bereavement Study.

*On Our Own Terms: Moyers on Dying*, a four-part series on efforts to improve how we die, produced by Public Affairs Television, airs on PBS, reaching millions.

2001

Terrorist attacks kill 2,981 in the United States on 9/11, sparking the “War on Terror.”

* The Latin American Association for Palliative Care is founded (Asociación Latino Americana de Cuidado Paliativo [ALCP]).
* The Asia Pacific Hospice Palliative Care Network (APHN) is founded.
* Robert Neimeyer edits *Meaning Reconstruction and the Experience of Loss*, underscoring the place of meaning-making in grieving.
* Edward Rynearson authors *Retelling Violent Death*, for those bereaved through suicide, homicide, or accident and those who work with them.
* Routledge publishes *The Encyclopedia of Death and Dying*, the first volume of its kind.
* *Finding Our Way: Living and Dying in America*, a 15-part newspaper series is published in 161 newspapers, reaching an audience of more than 7 million.

2002

Susan Roos writes *Chronic Sorrow: A Living Loss*, sensitizing counselors to issues that arise when individuals cope with ongoing loss.

* David Kissane and Sidney Bloch publish *Family Focused Grief Therapy: A Model of Family-Centred Care During Palliative Care and Bereavement*.

2003

Kathleen Nicholson Hull, Barbara Beach, and their colleagues cofound George Mark House, the first free-standing children’s hospice in the United States in San Leandro, California.

2004

The African Palliative Care Association (APCA) is founded.

2005

The International Children’s Palliative Care Network (ICPCN) is founded to achieve the best quality in living with life-threatening conditions for children and young people, their families, and carers worldwide.

* Oxford University Press releases the *Oxford Textbook on Palliative Nursing*, the first comprehensive textbook on the subject, now in its third edition.
* Allan Kellehear authors *Compassionate Cities: Public Health and End-of-Life Care*, a vision of whole communities adopting a compassionate approach to dying, death, and loss.
* Sharon Kaufman writes *And a Time to Die: How American Hospitals Shape the End of Life*, an anthropological examination of dying within the medical culture in American hospitals.

2006

The posthumous publication of *Cicely Saunders: Selected Writings 1958–2004* provides key references for historians and Dame Cicely’s personal influence on hospice/palliative care.

* Oxford University Press releases the *Oxford Textbook on Palliative Care for Children*, the first comprehensive textbook on the subject, now in its second edition.
* Edward Rynearson edits *Violent Death: Resilience and Intervention Beyond the Crisis* for those planning clinical and spiritual services following violent death.
* Lawrence Calhoun and Richard Tedeschi author the *Handbook of Post-traumatic Growth: Research and Practice* about possible growth following bereavement.
2007  Alan Horwitz and Jerome Wakefield write *The Loss of Sadness: How Psychiatry Transformed Normal Sorrow Into Depressive Behavior*, distinguishing abnormal reactions due to internal dysfunction and normal sadness brought on by external circumstances.
*  ADEC publishes the *Handbook of Thanatology: The Essential Body of Knowledge for the Study of Death, Dying, and Bereavement*, edited by David Balk.
*  Allan Kellehear writes *A Social History of Dying*, a historical review of the human and clinical sciences literature about human dying through the ages.

2008  Rita Charon publishes *Narrative Medicine: Honoring the Stories of Illness* on using techniques of literary interpretation to understand the stories the ill and dying have to tell.
*  Irvin Yalom writes *Staring at the Sun: Overcoming the Terror of Death*, an existentialist interpretation of the fear of death.
*  The Worldwide Palliative Care Alliance is incorporated in the United Kingdom as a global alliance of all the hospice and palliative care associations to advocate for palliative care.

2009  SAGE publishes the *Encyclopedia of Death and the Human Experience*.
*  Carolyn Walter and Judith McCoyd author *Grief and Loss Across the Lifespan: A Biopsychosocial Perspective* about maturational losses and losses through death.
*  George Bonanno writes *The Other Side of Sadness* about our resilience and innate ability to thrive in life after loss.

2011  Robert Neimeyer, Darcy Harris, Howard Winokuer, and Gordon Thornton edit *Grief and Bereavement in Contemporary Society: Bridging Research and Practice*, pairing pieces by researchers and clinicians who use the research in their counseling practice.
*  Jack Jordan and John McIntosh edit *Grief After Suicide: Understanding the Consequences and Caring for the Survivors*, covering impacts on survivors, helping survivors, and support programs in the United States and internationally.

2012  Harvey Chochinov writes *Dignity Therapy: Final Words for Final Days* about a program to help the dying say what they need to say.
*  Robert Neimeyer edits *Techniques of Grief Therapy: Creative Practices for Counseling the Bereaved*, featuring a broad range of case studies and useful counseling techniques.


*  David Kissane and Francine Parnes edit *Bereavement Care for Families*, covering conceptual frameworks, practical approaches, and particularly challenging circumstances.
SEEKING WISDOM ABOUT MORTALITY, DYING, AND BEREAVEMENT

Philosophy means, literally, the “love of wisdom.” The disciplines of the philosopher are thought to be worth cultivating because, as Socrates said, “The unexamined life is not worth living.” Philosophy takes root in this conviction that living wisely is preferable to not doing so. This chapter begins with a brief description of my being attracted to philosophy by a hunger for wisdom. It then expands on the nature of wisdom and its value for guiding (a) a search for truth and understanding and (b) the pursuit of living well or meaningfully. It is not possible in a single chapter to cover the full history of what philosophers have said about death and dying across several millennia (Chapter 6 is devoted to philosophical perspectives on ethics at the end of life). Hence, this chapter focuses on the contributions of phenomenology and existentialism to recent developments in the death and dying field: Phenomenology calls for descriptive and interpretive analyses of experiences of facing mortality, dying, and grieving as foundations for all theories about them. Existentialism stresses the importance for caregiving of attuning to the singularities of the lived experiences of unique individuals living near the boundaries of life and death. Together these perspectives provide means for evaluating representative theories in these areas in (a) enriching general understanding of lived experience or (b) providing caregivers with entrée into effective dialogue with those in their care to learn about and respond appropriately to their unique needs and experiences.

PERSONAL HISTORY

When my Dad died more than 40 years ago, my young head filled with wonder. Where had the forces that animated his life gone? Where had they come from? What was it like for him to realize that his life would soon end? What did the flow of life through his 73 years mean to him, at the peaks and in the valleys? Why was I still alive and he not? How had sharing 24 years changed us? What would my life mean to me without his presence? What would carry me through sorrow and crisis? What would dying be like for me one day? Why do any of us ever come to life? Where does any single life fit in the vastness of the universe?

I knew I was not alone in wondering about such matters. We humans have been wondering about them since we first began to care about and love one another; experience brokenness and sorrow coming over us; express ourselves in tears, gestures, words, actions, art, and ritual; struggle to overcome suffering; and engage with the mysteries of life. It is said that the search for wisdom begins in wonder, and when my father died, I longed for wisdom in the depth of my being. I have carried such wonder and longing with me ever since.
As I was returning to graduate school after Dad’s funeral, I wanted to share my wondering with and seek wisdom from my graduate school philosophy professors. But sadly (and possibly quite mistakenly) I did not feel confident in approaching any of them about matters then so vital to me. Silently, I vowed to myself that I would do my best to become the kind of philosopher that others would want to approach with wonder and invite to join them in seeking wisdom about such things as the meanings of life, love, death, and suffering.

Eventually, my wondering moved me to introduce a course on death and dying for students entering helping professions. I knew they would want wisdom about being with and supporting the dying and the bereaved and about coming to terms with their own mortality. I knew I did not have such wisdom, but I knew we could search together.

Over years of reflecting on my own experiences, hearing and reading stories of literally thousands of others, and wondering with so many students, survivors, family members, friends, teachers, researchers, and caregivers, I’ve become well acquainted with the contour and depth, poignancy and power of the challenges in facing personal mortality, living while dying, and living meaningfully in the aftermath of loss.

PHILOSOPHY AS LOVE OF WISDOM

It is easy to read Socrates’s call for the examined life as an affirmation of the value of wisdom. Plato’s dialogues portray Socrates as regularly undermining pretension in knowing and affirming the wisdom of (1) recognizing the limits of one’s knowing and (2) reflecting carefully about the challenges of living virtuously and meaningfully, especially in the shadows of uncertainty.

Wise persons weigh ideas mindfully, concerning themselves with their truth value and applicability to the realities they encounter. They cultivate understanding of how to refine and adapt ideas to changing experiences that call them into question. They acknowledge the limits of their perspectives and ways of knowing, what they know, and what they can know. Wise persons also evaluate ways of living mindfully, concerning themselves with their practical value and appropriateness in their particular embodied, social, and cultural life circumstances. They cultivate understanding of how to adapt and refine ways of living to changing experiences that call them into question. They acknowledge the limits of (1) their habitual ways of living, (2) their control in the responsible exercise of freedom, and (3) what they’ve learned about how to live. Wise persons remain ever aware of the limits of the application of static ideas, plans, and principles to flowing experiences of dynamic realities. Ultimately, wisdom is a virtue of humility, discernment, imagination, and adaptability in making claims to truth and seeking value and meaning in living.

There is nothing boastful in claiming to be a seeker of wisdom. It is a noble aspiration. Most who so aspire sense that growth in wisdom is incremental, hard-won, worth the trouble, and never finished. Few, if any, are consummately wise, and none would ever claim to be so. Seeking wisdom is not the exclusive province of professional philosophers. Many across the broad spectrum of other disciplines and professions have been driven in wonder to seek wisdom. Because wonder and the impulse to seek wisdom are common human experiences, it is no stretch to say that all conscious and mindful persons are philosophical to some degree.
EXISTENTIAL PHENOMENOLOGY

Life can only be understood backwards; but it must be lived forwards.
—Søren Kierkegaard

Existential philosophers (including Friedrich Nietzsche, Søren Kierkegaard, Martin Heidegger, Karl Jaspers, Jean-Paul Sartre, Simone deBeauvoir, Albert Camus, Gabriel Marcel, Maurice Merleau-Ponty) wonder about what it is to exist as a singular and irreplaceable human being. They seek wisdom about how to live given that each of us is a conscious subject at the center of a unique world of experience. We are born into unique life circumstances not of our own choosing. We are grounded in, consciously aware of, and engaged with the world in and through our bodies. We are historical and temporal beings who exist in time, emerging from the past, through the present, and into the future. We find and make meaning in our lives (lived meaning) in practical, caring interactions with the world, including our physical surroundings, social surroundings, and selves. We find our identities in the particularities of our unique daily life patterns and life histories of caring interaction with the world. We are social beings, challenged to live meaningfully and with integrity through the responsible exercise of our freedom in the world around us, especially, but not only, with our fellow humans. We are multidimensional beings, at once biological, cognitive, emotional, psychological, behavioral, social, soulful, and spiritual. We are finite beings: small, transitory, vulnerable, uncertain, and fallible. We first learn how to live in the world prereflectively, as we seek what we need and desire, acquire abilities, form habits and dispositions, shape life patterns, and move through the days of our lives. Typically, we purposefully reflect, seek knowledge about the world, develop theories, make plans, and the like only in extraordinary experiences or when life proves challenging. Most of the time we live unselfconsciously in straightforward engagement with the world.

Phenomenological philosophers, beginning with Edmund Husserl (Spiegelberg, 1960), wonder about the essential features of the experiences within which we encounter and interact with the world. They seek wisdom about how, within experiences appropriate to their objects, we come to know about the world and all that is in it, including logical relationships, mathematics, the physical world, the biosphere, our selves, other persons and the social world, relationships, systems, histories, and cultures. In his call, “to the things themselves,” Husserl urges that good thinking about anything requires a firm understanding of just what the thing is. Because it is through experiences that we come to know anything, describing and analyzing experiences is crucial for understanding and building the foundations of knowledge, the evidential ground of theory in experience. Intent on capturing the subtlety and nuance of experiences and the richness of what they are about, phenomenologists resist reductionism, or thinking that any experiencing process has to unfold in a certain way or that anything experienced amounts to nothing more than but one aspect of what it is, or even something else entirely. Phenomenologists would insist that theories about death, dying, and bereavement must be grounded in understanding of the distinctive combinations of experiences within which we become familiar with them. They view the stories of those who have the experiences as the heart of the matter in building such theories.

Existential phenomenologists (prominently Heidegger, Sartre, deBeauvoir, Merleau-Ponty, and Paul Ricoeur) add to accurate description and analysis the
element of interpretation of the lived meanings of experiences. Less interested in experiences of coming to know about the world for their own sake, they wonder about experiences of coming to know how to live in the world. They extend the use of phenomenological methods to exploration of not only cognitive experiences but also the full ranges of our physical, emotional, psychological, behavioral, social, soulful, and spiritual experiences. They pay special attention to how experiences come to have meaning for us as they shape our daily life patterns, affect the unfolding of our life histories, and contribute to our becoming the individuals we are. Existential phenomenologists seek wisdom about how to live with personal mortality, dying, and bereavement. They would insist that counseling with persons facing mortality, dying, or grieving requires attending to the singularities of their experiences and the meanings they find and make in them. The stories they tell, then, are the heart of the matter in fostering self-discovery and mutual understanding among the story-tellers, their caregivers, and members of their families and friendship circles.

FACING PERSONAL MORTALITY

Without death men would scarcely philosophize.
— Arthur Schopenhauer

Experiences of Death and Mortality

We do not experience our own deaths directly. One of my professors, William Earle, described our situation with regard to death as like standing in a small pool of light surrounded by vast darkness. If someone were to call attention to the darkness and we to turn flashlights onto it, we would not see darkness but rather more illuminated areas. We know the dark only as the limit of, or background condition of, our light; we cannot see it, but we are aware that it is there. We know death itself only as the limit of life as we know it. Those among us who have near-death experiences (Moody, 2001), by no means only in clinical contexts, or extraordinary encounters with those who have died (LaGrand, 1999), experience and interpret them as experiences of a possible afterlife beyond life as we know it rather than as experiences of death or being dead.

We are more directly aware of our own mortality, our vulnerability to dying. We may be immediately aware in, for example, experiences of life-threatening illness, serious accidents, disasters, armed conflict, or life under oppressive regimes. Less directly, we may be reminded of our mortality in midlife crises, witnessing the dying and deaths of loved ones, or caring for the dying and bereaved. Such encounters remind us of how attached we are to our bodies, how small and vulnerable we are, and how short our time on Earth is.

Existentialists on Mortality

Jaspers, Kierkegaard, and Heidegger wonder and seek wisdom about death, viewing it as an irreducible limit to our possibilities in living. Jaspers (1969) writes of death as one of the “boundary situations” that define life in the human condition, along with such things as chance and suffering. Although other animals are also mortal, only we humans are capable of knowing our mortality and taking it into account as we exercise our freedom and shape and direct our lives.

Kierkegaard stresses the vital difference between objective and subjective experiences of human mortality (Kierkegaard, 1941). In objective experience, we
remain at an intellectually safe distance from mortality, focusing on facts, ideas, and theories about it in general. We can recognize that all persons are mortal but not grasp that this means, “I must one day die.” In a subjective experience, we appropriate the truth of our personal mortality, allowing it to inform our self-understanding, values, and decisions about how to live. Mortality is a defining feature of personal existence that we can either accept and affirm or treat with indifference. Not merely a biological fact about us, its significance permeates all dimensions of our experience. We are not safe and distant from our mortality, even if we ignore it. It is in us as a condition of our existence, part of our present reality. Kierkegaard holds that the seeker of wisdom will attend to how awareness of mortality can affect and transform an entire life as it confers seriousness, urgency, and passion on choice among possible ways of living.

Heidegger (1962) distinguishes between inauthentic and authentic experiences of mortality. In inauthentic experience, I remain at a safe, objective distance from death, as if it happens to everyone but has no particular significance for me or for how I live my life. He observes that many of us live in retreat from acknowledging death as something that involves us personally until the end of life is clearly approaching, distracting ourselves in diversions, keeping busy, or investing in unexamined efforts. In authentic experiences of mortality, we understand our being as a being-unto-death and acknowledge and accept responsibility for achieving honesty, genuineness, integrity, individuality, and meaning in life in the finite time available.

Heidegger describes five signature characteristics of authentic experience of mortality: (1) It is unique among all of the possibilities in living. Authentically embracing this singular possibility grounds and focuses our concern, or care, about all other possibilities, our purpose in living, our individual destiny. (2) It is nonrelative. Acknowledging it brings us back to appreciation of how irreplaceable our individual life is. We cannot transfer to another responsibility for living and dying the uniquely mortal life that is ours alone to live. (3) It cannot be outstripped. Unlike other possibilities, it is permanent. In authentic experience, facing the possibility of dying frees us for it and the possibility of affirming the whole of our existence before it ends. (4) It is certain. In authentic experience, we courageously face the certainty of personal death and recognize its relevance in every moment of life-altering decision. (5) Its timing is indefinite. In authentic experience, we are aware that as soon as we are born, we are old enough to die. This awareness awakens in us a constructive anxiety about losing all other possibilities for being in the world. Authentically embracing mortality frees us to evaluate and decide with the whole of our being what matters most to us in living a finite life.

Existential Suffering

Each of us is susceptible to existential suffering that may be defined as “the distress and anguish we experience when limitation, change, loss, brokenness, and sorrow lead us to question our very existence, the value and meaning of our lives” (Attig, 2011a). We may suffer existentially as we wonder what mortality means for who we are and can become, why we are living, what our lives mean or might mean, and whether it is worth continuing to live.

We may recoil in fear before the prospect of dying. Ernest Becker writes as if we can only flee in terror in response to personal mortality and interprets virtually all individual and cultural efforts and achievements as nothing but expressions or manifestations of the fear of death (Becker, 1973). Although there may be elements of fear in what motivates some effort and achievement, this interpretation is decidedly reductionist as it flies in the face of experiences of nearly all of
these as affirmations of the value and meaning of living. William Worden writes of the possibility of taking the measure of whatever fear of death may come over us, cautioning against both (1) overestimating the extent to which mortality threatens living meaningfully and allowing fear to grip and paralyze us and (2) underestimating the threat and allowing ourselves to live carelessly, without due caution (Worden, 1976). I have described how we struggle to come to terms with the meaning of our own mortality in all dimensions of our being at once, not simply in fear (Attig, 1989). Rachel Naomi Remen writes of mortality and suffering as mysteries rather than everyday problems. As constants in living, we cannot change, control, manage, eliminate them from our experience, or fully understand their meanings. We can only change how we live in response to them. Instead of facing mortality alone, she urges that:

> Perhaps real wisdom lies in not seeking answers at all. Any answer we find will not be true for long. An answer is a place where we can fall asleep as life moves past us to its next question. After all these years I have begun to wonder if the secret of living well is not in having all the answers but in pursuing unanswerable questions in good company. (Remen, 2000, p. 338)

Frankl (1959), writing out of his suffering in Auschwitz says, “Everything can be taken from a man but one thing; the last of human freedoms—to choose one’s attitude in any given circumstance, to choose one’s own way” (p. 86). This is the freedom the existentialists say comes to light as we suffer existentially and authentically embrace our mortality.

**Existentialism Versus Stoicism**

Stoicism, ancient and contemporary, promotes one form of authentic response to personal mortality. It recognizes that human life is finite, that all beginnings have endings, all attachments bring eventual separations, and all commitments come with attendant risks. Finding these human limitations to be tragic flaws, stoicism advises that we rein in our passions and hold back from entanglements that will inevitably bring us pain and unhappiness. It sees wisdom in resolving to begin little, minimize attachment, and avoid commitment. Such emotional disengagement from the world leads to peace of mind and a tempered human happiness.

Existentialism promotes an alternative authentic response to personal mortality. It urges acceptance of the finiteness and fragility of human existence and embraces limited opportunities for meaning and fulfillment as fortuitous and precious. It advises persevering in our vulnerability and accepting the hurts and disappointments that come with mortality as the price of realizing the values that beginnings, attachments, and commitments can bring. It sees wisdom in embracing the possibilities of living a finite life meaningfully with the whole of our freedom and passion.

We can see this existential wisdom in response to mortality in Kierkegaard’s description of three ways of living in the world: (1) aesthetic investment in what interests us; (2) ethical adherence to moral principles, making commitments, and taking on responsibilities; and (3) religious appreciation of wonder and awe before the mystery, presence, and transcendence of eternal meanings that cannot be touched by death in others, nature, and the divine (Kierkegaard, 1940). We see this wisdom in
Nietzsche’s (1999) urging that we should live our lives creatively, as works of art. We see it in deBeauvoir’s (2000) urging that we embrace the potential of living ethically and politically with integrity in the face of ineradicable uncertainty and ambiguity.

LIVING WHILE DYING

In my first death and dying classes, I invited a university colleague, Dorothy Hamilton, to come to discuss her experiences of living with terminal cancer. She invariably came around to saying the equivalent of, “I wish I could look each of you in the eye and tell you that we are not so very different. I’m living with cancer, but we are all going to die some day. The only difference is that someone has told me that I am likely to die before you do. But he could be wrong.” She reminded us that we are all eligible to die from the moment of birth whether we make that truth our own or not. She urged us not to wait for terminal illness to awaken from indifference to, or avoidance of, mortality and begin living now in terms of what matters most to us.

Coming to Know That We Are Dying

Phenomenologically, the inherent indefiniteness of the time of our dying makes it difficult for anyone to know when death is approaching. Dying most often begins to show itself in our bodies. At first, we may mistake physical changes and symptoms for signs that we are ill, as we have been before and recovered. As they persist or worsen, and often as we experience companion emotional, behavioral, social, or spiritual distress, we commonly turn to physicians. Few of us know enough to tell that we are seriously ill or even dying without expert opinion. If our primary physician cannot, or will not, tell us we may be dying, we will be sent to a specialist.

Nuland (1993, pp. 248–261) describes how the primary focus of specialized medicine falls on the dual challenges in “The Riddle” of (1) coming to a correct diagnosis of life-threatening illness and (2) discerning the most effective ways to cure it. Knowing what is happening in our bodies is often difficult for experts. Diagnosis is often tentative and prognosis more difficult, given wide variation in individual responses to illness, treatments, and procedures. On the way to our physician’s solving (or not solving) The Riddle, we may come to know all too well the unpredictable progression of our illness or life-threatening condition, its implications for the quality of our living, medical personnel and institutions, invasive and physically challenging procedures, and their independent serious consequences for our bodies and overall well-being. Doka (1993) describes prediagnostic, diagnostic, chronic, and terminal phases of living with life-threatening illness with uncertainty a near constant companion in all but the last, terminal phase. Glaser and Strauss (1966) describe how, even when others know “the truth” about our dying, we may be kept in uncertainty or not acknowledge it openly as others withhold it, decline to confirm our suspicions, or join us in mutually pretending that matters are not as serious as they are.

In the most well-known account of living while dying, Kübler-Ross (1969) describes it as unfolding in five stages. They are most aptly read as aspects of resistance to recognizing the growing certainty that we are dying, a struggle that often continues long after a serious diagnosis is given. She describes ego fight/flight defenses against the harshness of realities of dying as in denial we retreat from
persistent reality, with anger we try to control the uncontrollable, or in bargaining we attempt to negotiate the nonnegotiable. In depression we concede the futility of these efforts. We can die at any time before reaching the last stage, acceptance, when we acknowledge that we are dying. It is a reductionist mistake to claim that these stages are the sum of “how we cope with dying.” Coming to know that we are dying is by no means the same as, but can only be the beginning of, learning how to live while dying.

When we acknowledge that we are dying, we realize that our physical distress, the progress of our illness or condition, and whatever emotional, behavioral, social, and spiritual distress have arisen from it, are all aspects of living while dying. We experience our dying against the horizon of memories of prior illnesses and brushes with mortality, experiences of others that we have witnessed, and social and cultural expectations and understandings that shape and color our present experiences. We also experience our dying against the horizon of often uncertain anticipations of possible challenges and difficulties ahead, approaching the end of life, letting go of goals and aspirations, and parting from those we love.

Meanings in Living While Dying

Meanings in what happens to us

Existential phenomenologists are interested in what dying means, how we live while dying. Many experiences of living while dying are passive. Physically, taken-for-granted health maintenance and immune systems in our bodies begin to give way beneath our awareness and beyond our control. Others too often treat us as if we are the disease or condition we have rather than the whole persons we are living with the disease or condition. Both Cicely Saunders, founder of the modern hospice movement, and Balfour Mount, founder of hospital-based palliative care, devoted their lives to countering this tendency and wisely promoting whole-person care. Frank (1991) reminds us that we cannot simply drop off our bodies for repairs. Our whole conscious being is embodied; we live “at the will of the body.” We are consciously aware of and engage with the world through our bodies. Things that happen in our bodies limit what we can do and experience in the rest of our lives. Intense physical suffering makes it nearly impossible to attend to or care about anything else. The progress of disease or a life-limiting condition, treatments and procedures, or their consequences can affect our access to and abilities to move about within our environment, limit our interactions with familiar things and places, undermine our abilities to do things or enjoy doing them, reduce the range and variety of our experiences and activities, compromise our acting on our decisions, distort or undermine our abilities to express ourselves, alter our interactions with others, make us increasingly dependent, distort our awareness of the world around us, and even undermine our capacities to orient ourselves cognitively in reality.

Eric Cassell writes of how we suffer in living while dying as the whole persons we are, from both disease and its treatment (Cassell, 1991). We can define suffering as the experiences of loss of wholeness (brokenness) and pain and anguish that come over us. Our suffering may include helplessness before what we cannot control, fear of being overwhelmed, shame in dependence or loss of appearance, longing for life as it was, sensing we do not belong where we are, anguish over connections with those we hold dear, feeling distant from the ground of our being in the divine or the sacred, fear that the world is chaotic or unfair, feeling deserted by faith, doubting our abilities to persevere, fear that joy and laughter are no longer possible, longing for hope and courage to face and venture into the unknown, anguish over what
is to become of our loved ones, or doubting the value and meaning of our lives as already lived or as they remain to be lived. Rando’s works on “anticipatory mourning” (Rando, 1985, 2000) vividly describe experiences of loss and grief reactions to them as well as the suffering that accompanies anticipation of leaving behind everyone and everything we have cared about in the finite life we know.

We are often gripped, even stopped, by emotions as we live while dying. As the etymology of the word “emotion” (attachment of the prefix “e” to “motion”) tells us that it literally means “without motion,” it captures this aspect of our emotional experiences. It is a mistake to interpret emotions as nothing but the physical sensations we associate with them. Judgments about reality and some of our deepest desires and needs are inherent in them (Solomon, 1983). Many interpret emotions as crying for expression to dissipate their energy and power. I prefer to read them (Attig, 2012, p. 40) as like physical pains calling us to attend to things that give rise to them and have serious implications for how we live. Like physical pains, they persist and intensify until we give them and their underlying causes appropriate attention.

**Meanings in what we do**

Many experiences of living while dying are active. As life-threatening illness and life-limiting conditions come into our lives, much of what we do in their shadows involves learning how to live within a changing life environment, in relationships with others, and within our own skins, as we reshape our daily life patterns, learn to carry elements of brokenness and sorrow, and focus on what is most important to us in what may be the last chapter or chapters of our life stories. These engagements with major change are active aspects of anticipatory mourning strongly analogous to my interpretation below of grieving response as the active aspect of relearning the world.

How much more valuable and urgent is the existentialist wisdom in authentically facing our mortality when we see that our life possibilities are rapidly diminishing! Tragically, many of us become caught up in increasingly futile attempts to find a cure, experience suffering that spirals out of control, or die suddenly without realizing genuine possibilities for living meaningfully while dying. As Weisman and Worden describe the possibility of dying an appropriate death (Worden, 2000) and Corr (1992) writes of task work in actively coping with dying, they focus of how we can do what matters most to us while dying.

Frankl (1959) describes three possible sources of meaning in living. We can reach for meaning in achievement values as we attend to unfinished business, contribute in small ways at home or in community, or put our affairs in order. We can teach others important lessons in how to live through telling or showing the way in what we do (Albom, 1997; Kübler-Ross, 1969). We can help loved ones prepare for living in separation from us (Attig, 2000b); write ethical wills to pass on values, beliefs, and blessings (Baines, 2006); or, in dignity therapy, say what we need to before we die (Chochinov, 2012).

We can reach for meaning in experiential values as we savor happenings and encounters in everyday life we may have taken for granted or reach for joy, excitement, awe, and wonder in the extraordinary in events we do not want to miss: nature, the arts, or items on a “bucket list.” Many of us treasure experiences in loving relationships most of all.

Finally, we can reach for meaning in suffering and attempts to overcome or transcend it. Balfour Mount speaks often of the possibility of healing when physical healing is no longer possible, asserting boldly that “a person can die healed.”
Defining “healing” as turning from suffering toward experiences of integrity, wholeness, and inner peace, he believes that deep within we all tend, in hope, toward healing in connections with our deep selves, others, the world perceived through our senses (in nature or music), and ultimate meaning as variously conceived.

Byock (2004) describes how we and our survivors can complete or heal our relationships as we express our love for one another, say thank-you for what we treasure most about each other and our lives together, forgive and ask for forgiveness, and find meaningful ways to say good-bye. He tells compelling stories of interactions among his dying patients and their families that vividly illustrate these healing possibilities (Byock, 1997).

Singh (1998) describes engagement with mystery at the end of life unfolding in three stages. Chaos includes letting go of ego defenses and dread of being engulfed or overwhelmed. We sense we are entering unknown depths that appear at first to be dark, mysterious, and “other.” In surrender we can open to and find healing connection with deeper aspects of ourselves (soul and spirit); review our whole lives with forgiveness, gratitude, and compassion; let go of our sense of separateness; begin to sense that the power our ego had been resisting is a higher power within us; and come to a deep stillness. In transcendence we can experience ourselves expanding into a spiritual connection with the most subtle and sacred dimensions of being, the divine or the surrounding mystery that holds us all, and experience the ground of our being as love itself. Singh reports that many dying persons say they have never felt so truly alive; have tears of joy, awe, and gratitude; feel spirit pouring into them; sense the presence of God; and feel that they are “entering into something vast.”

BEREAVEMENT AND GRIEVING

Her absence is like the sky, spread over everything.

—C. S. Lewis

Experiences of bereavement and grieving, like C. S. Lewis’s when his wife died, are about matters of the heart. They invariably include losing an irreplaceable loved one through death (bereavement); reacting to loss in brokenness and sorrow (suffering); and responding to loss and suffering in a process I have called relearning the world that includes learning how to live in a world transformed by loss, carry the pain of missing our loved one, and love in separation.

As perhaps the only existential phenomenologist work in the field, I wrote How We Grieve: Relearning the World (Attig, 1996) to capture what I had learned about the general contours and singularities of bereavement and grieving. I describe grieving as relearning how to live in the world, including our physical and social surroundings, spiritual place in the world, selves, and ties with the deceased. Where others have described, more or less well, particular dimensions of bereavement and grieving (organic/biological, psychological, cognitive, familial, and social), to my knowledge How We Grieve remains the only comprehensive phenomenology of these experiences. The Introduction to the revised edition (Attig, 2011b) explores extensively the view in relation to other writings that I cannot repeat here in detail.

I wrote The Heart of Grief: Death and the Search for Lasting Love (Attig, 2000a) to describe more of what I had learned about how love in separation is both possible and desirable and to discuss what I found missing in descriptions of love and lasting connection in other works (Klass, Silverman, & Nickman, 1996). Too
often authors, following John Bowlby, write as if attachment were *all there is* to love. Attachment involves holding on to relationships for the security and safety in them. Although there may be elements of attachment in many relationships, it is central in few mature ones, and rarely their most valued aspect. Attachment may sometimes provide a means of staying alive, but rarely if ever a reason for living. Love includes experiences of mutual respect, valuing, caring, generosity, receptivity, and reciprocity. In love we commit to a different way of being with and for others, as we let go of attempts to hold or control and instead engage in soul and spirit with the vitality, depths, and mystery of another.

**Coming to Know That a Loved One Has Died**

Usually we come to *know that* we have lost a loved one far more directly than we come to know that we are mortal or dying. Most of our loved ones die anticipated deaths from illness. We have contacted or visited them in hospitals, nursing homes, hospices, or at home. Some die suddenly from acute illness, in accidents or disasters, or at the hands of others. Often we see for ourselves that they have died, though if death has been horrible and away from home, some may try to prevent our doing so. In rare and excruciating instances, we do not know with certainty that a loved one has died because their body has not been or cannot be recovered.

**Meanings in Bereavement and Grieving**

*Meanings in what happens to us*

Existential phenomenologists are interested in what bereavement and grieving mean in the living of them. Many experiences of loss and grief are **passive**. Deaths of our loved ones happen, and we find ourselves in *bereavement*, a state of having lost, or deprivation. Loss brings unwelcome changes into the world of our experience, undermining the rhythm and disrupting the momentum of the flow of our lives. It takes our breath away (Attig, 2012).

In *grief reactions*, brokenness and sorrow *come over us* as we experience the emotional, psychological, physical, behavioral, social, cognitive, soulful, and spiritual impacts of bereavement. We *relearn the world* in reaction as we absorb, or take in, the realities of loss in our individual, family, and community experiences. We experience *brokenness* in shattered illusions of control, invulnerability, and separateness; unraveled individual, familial, and communal daily life patterns; and disrupted individual and collective life stories taken into unanticipated next chapters. Bereavement leaves us still poised in needs, wants, emotions, motivations, habits, dispositions, interaction patterns, expectations, and hopes that shaped *how* we lived when our loved ones were alive that now may no longer find their objects in a world where they have died. Bereavement renders useless all of what we and our families and communities have assumed, or taken for granted, about *how to live* in the presence of our loved one. It undermines our egos’ practical functioning and self-confidence, uproots our souls, and shakes our spirits. It often undermines beliefs about the world as being more or less safe and just and our place in it secure (Janoff-Bulman, 1992). For most of us this cognitive disenchantment, painful though it may be, is not the most important aspect of the loss of the assumptive world in bereavement. The visceral unsettling losses of the sense that we are safe, the feeling that there is a place where we belong in the great scheme of things, and so much of what we have taken for granted about *how to live* are far more daunting (Attig, 2002).
Our sorrows (Attig, 2001b) may include pain that comes when we meet with something that reminds us of separation, or as memories spontaneously surface from within or in conversation among us. This is only rarely the pain of separation anxiety (as attachment theory would have it) but rather the pain of missing someone we love. We may experience ego pain in helplessness, frustration, disillusionment about fight/flight defenses, or fear of being overwhelmed. We may feel soul pain in sadness; longing for the presence of our loved one and all it made possible; homesickness for the familiar, guilt or anger about ties with the deceased; isolation or alienation from others; doubt about caring deeply again; or abandonment by, or loss of trust in, God. We may experience spirit pain in despair, discouragement, fear that life is meaningless or joyless, or doubt that we can overcome suffering, face unwelcome change, or open to an unknown future. We may feel family and community pain in missing an irreplaceable character in our lives, feeling for others’ grieving, or dread for our futures together.

**Meanings in what we do**

Many experiences in bereavement and grieving are active. In grieving responses, we invest time and effort in coming to terms with what happens to us in bereavement and grief reactions. We relearn the world not by cognitively mastering information but instead by learning how to live in all dimensions of our being with our brokenness and sorrow, in our physical surroundings, with those who survive with us, in our place in the great scheme of things, within ourselves, and in our relationship with the one who died.

The labors of relearning the world (labors of love; Attig, 2001a, 2012) are as richly varied as are those of learning how to live from birth. Most often without thinking and in styles uniquely our own, we straightforwardly engage in ways of living we already know well. Sometimes, we self-consciously solve problems. Often we complete relatively small bits of work, or tasks properly so-called. We undertake life long projects of adapting our understandings (sometimes deliberately changing our life narratives), emotions, behavior patterns, and relationships as we meet with new aspects and implications of our losses, what Worden (2009) calls “tasks.” In encounters with mysteries of finiteness, change, uncertainty, life, love, suffering, and death inherent in our human condition, we change ourselves and how we live. We do these things in contexts in which we are vulnerable (Attig, 1996) to anguish over unfinished business with the deceased, trauma, disenfranchised grieving (Attig, 2004; Doka, 2002), other challenging social circumstances, and limits of our coping capacities.

We relearn the world as we engage with our sorrows. Sometimes from past experience we sense what our reactions and the needs reflected in them are, are guided in usual ways by them, and feel no need to dwell in or express them. It is only human to experience sorrowful emotions as things we would like to avoid or overcome quickly if possible. So we may respond to them in ego fight/flight defenses (Kübler-Ross & Kessler, 2007) in attempts to control reactions we may experience as threats, failings, or weaknesses (Greenspan, 2003). As they persist and grip us more tightly, we can experience our grief reactions as crying more for attention and understanding than expression. We can reflect on them self-consciously alone or with others. We can use sorrow-friendly practices to befriend our sorrows: to make ourselves at home in our deep selves, dwell compassionately with our suffering, and venture beneath life’s surface to discover our deepest needs and capacities to meet them (Attig, 2012). Attending to and learning from sorrows loosens their grip. We can learn to carry sorrow as, through our tears, we meet with and welcome our loved one’s soul and spirit in the world around or within us in lasting differences he
or she has made. Experiencing the pain of missing them after they’ve died can then become more and more like the pain of missing them in separation when they lived.

We relearn the world as we draw on our resilience, or what is not broken within us (Attig, 2012). Our breath animates our bodies. Our egos, humbled by mysteries, return to practical functioning, dealing with threats, controlling appropriately, solving problems, and fixing when possible. Our souls find sustenance in our surroundings, draw from roots in family and community, and still care and love deeply. Our spirits find hope and courage to rise above suffering, venture into the new, change and grow, know joy again, and seek transcendent understanding. Our love cherishes precious memories and legacies, revives connections with fellow survivors, and opens to new relationships. As we do these things, we revive ourselves, weave a web of old and new cares and loves into our daily lives, and give new direction and meaning to our life stories.

We relearn the world as we learn how to love in separation (Attig, 2000a, 2012). We continue loving while apart in ways familiar from when we were apart when our loved ones lived. We find renewed wholeness as we weave threads of enduring connection into our daily life patterns, develop themes of lasting love in next chapters of our lives, and sustain movements of loving and being loved in next figures of the dances of our lives. We “let go” of the living presence of our loved ones and all it made possible and of troubles in ties with them that may cause separation anxiety, anger, or guilt. We forgive our loved ones or ourselves in order to reach through trouble to enduring value and meaning. When we meet with painful reminders of separation, we can reach through the hurt and attend to how the reminders also hold something touched by our loved ones or from our lives together. In such experiences, and through deliberately remembering, we reconnect with some of the best in life (not “inner representations” as some in the field would have it), attend to and are moved by our loved ones here and now, feel the warmth of our love for them, sense their love for us, and enjoy them again in praise and gratitude. We embrace their legacies: material things and genetic inheritances; interests and ways of doing things; ways of making ourselves at home in the familiar, caring, and loving; and ways of reaching for the extraordinary, changing, growing, striving, overcoming, and searching for understanding. We appreciate how our families, our communities, and we are indelibly different because they lived and how we have become, in part, their living legacies.

As we relearn the world in these ways, we can sense that we are returning home in the universe (Attig, 2012). We can draw on belief, trust, and loyalty to life; engage in spiritual practices; pour our souls and spirits into living well again; make ourselves at home in the world around us; give places in our hearts to all of our loved ones as well as to the full range of cares, loves, hopes, and aspirations that make us who we are; acknowledge our good fortune in loving and being loved by the deceased; sense that, in the end, courage, hope, and joy outweigh fear, despair, and sorrow; and live more fully when we are grateful.

LOOKING TO THE FUTURE

The phenomenologist in me appreciates the wonder in efforts to learn about all aspects (physical, emotional, psychological, cognitive, behavioral, social, or spiritual) of lived experiences of facing mortality, living while dying, and grieving. When done well they enable us to be more mindful of these ongoing, primarily prereflective experiences and of the hazards of imposing inapt conceptual frameworks on them. We experience mortality, dying, and grieving in all dimensions of our being at once. It can be useful, but it is inevitably limiting and can be distorting to focus on
only one dimension of any of these experiences for research purposes. Good studies have and will continue to shed light on particular aspects of them, but it is wise to be clear about their limited scope. I worry about all-too-prevalent reductionist tendencies to read facing mortality as nothing but fear or terror, to overly medicalize dying, and to pathologize or overly intellectualize grieving. I hope for broader recognition that “the things themselves” to be studied here are the experiences themselves and that the best available evidence, or foundation, for theories about them is in the stories those having them have to tell. Pressures to study only what can be counted or measured should be resisted and more qualitative studies undertaken.

The existentialist in me appreciates the wisdom of recognizing the limited usefulness of generalizations of even the most acutely sensitive phenomenologist in meaningfully informing the singular experiences of individuals in facing mortality, living while dying, or grieving. Although it is safe to say that the generalizations offered here are not irrelevant to the experiences of individuals, we must be clear that they do not, and can never in principle, capture all that is important in their singular experiences. It can be wise to cultivate such insights so we can know what it is reasonable to expect in interacting with or counseling persons having the experiences and become more empathetic. Rather than expressing the insights all too knowingly in interactions with persons caught up in the experiences, it would be wiser to use the insights as mind frames for attuning to the specific details of the lives of the individuals having them. It turns out, paradoxically, that they want both reassurance that their experiences are not outliers, that they are not alone in having them, and empathy and full appreciation of how fresh and unprecedented the experiences are in their lives.

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