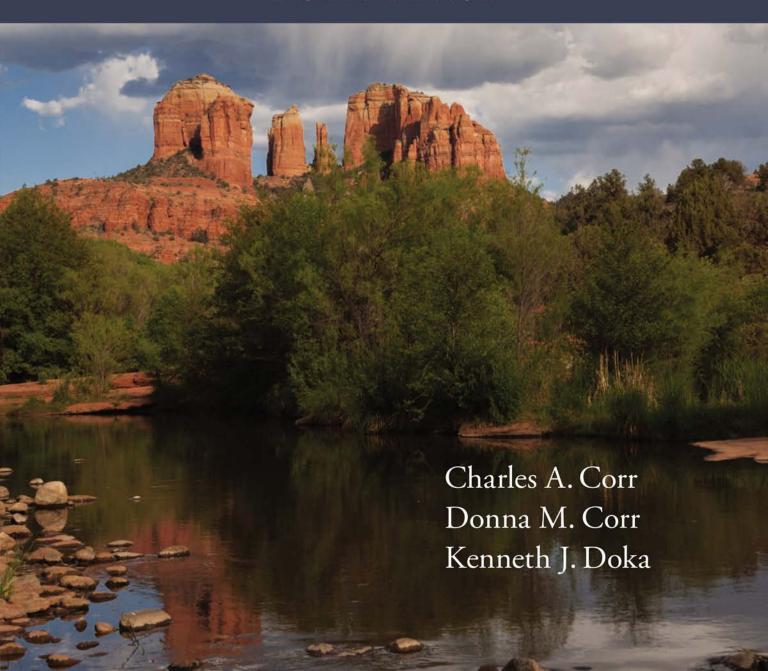
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DEATH DYING, LIFE LIVING

eighth edition

Charles A. Corr Donna M. Corr Kenneth J. Doka



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Printed in the United States of America Print Number: 01 Print Year: 2017 We dedicate this eighth edition of *Death & Dying*, *Life & Living* to our colleagues in the Association for Death Education and Counseling and in the International Work Group on Death, Dying, and Bereavement, as a small token of our thanks for the insights and support they have shared with us over many years

The days of our lives, for all of us, are numbered. We know that. And yes, there are certainly times when we aren't able to muster as much strength and patience as we would like. It's called being human. But I have found that in the simple act of living with hope, and in the daily effort to have a positive impact in the world, the days I do have are made all the more meaningful and precious. And for that I am grateful.

-Elizabeth Edwards (1949-2010)

Death is no enemy of life; it restores our sense of the value of living. Illness restores the sense of proportion that is lost when we take life for granted. To learn about value and proportion, we need to honor illness, and ultimately to honor death.

—A. W. Frank, *At the Will of the Body* (1991, p. 120)

# About the Authors



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**CHARLES A. CORR,** PhD, is a long-time member of the Association for Death Education and Counseling (ADEC; Board of Directors, 1980–1983), the National Hospice and Palliative Care Organization (NHPCO), and the International Work Group on Death, Dying, and Bereavement (IWG; Chairperson, 1989-1993). Currently, he is Senior Editor of a quarterly e-journal for NHP-CO's Children's Project on Palliative/ Hospice Services (ChiPPS). His publications include 35 books and booklets, such as Helping Children Cope with Death: Guidelines and Resources (1982; 2nd ed., 1984), Childhood and

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Attitudes Commonly Associated with Alzheimer's Disease



In his allegory, "The Horse on the Dining-Room Table" (our Prologue in this book), Richard Kalish wrote that we cannot magically make death disappear from our lives nor can we erase completely the anxiety and other forms of distress often associated with death-related issues. However, we can talk about encounters and attitudes, share insights and practices, learn from each other, and strive together to cope more effectively with dying, death, and bereavement. It is in that spirit that we offer the eighth edition of *Death & Dying*, *Life & Living* as a new contribution to ongoing conversations about dying, death, and bereavement. Our hope is that constructive interactions related to these subjects will help all of us lead richer and more productive lives. We are particularly pleased that Professor Kenneth J. Doka, one of the best known and most productive workers in this field, has agreed to join us as coauthor of this new edition and as a contributor to the discussions undertaken here.

It has sometimes been suggested that there really is nothing new to teach about in this field. In fact, in the interval since the seventh edition of this book was published, new encounters with death have occurred, new issues have come to the fore, new insights and attitudes have emerged, and much that is of enduring value has evolved and matured. We have worked diligently to incorporate these and other death-related developments as will be seen in the text itself and in the section of this Preface that identifies new materials in this eighth edition.

#### **FEATURES**

This book can be used as a primary textbook for undergraduate and graduate courses in death, dying, and bereavement; as a supplementary text in related courses; and as a general resource in this field. Individual instructors and other readers can easily adapt the contents of this book to their own needs and preferences. In particular, different Parts of the book can be studied in any order, and most chapters within a specific Part can be read on their own. On this book's Instructor Resource Center, instructors can download the following supplementary materials to support teaching and learning:

- Instructor's Manual, which provides suggestions about how to use this book, educational resources (from organizations, printed materials, guest speakers, and audiovisuals), and detailed guides with extensive activities for each chapter.
- Test bank questions, including LMS-ready versions, for each chapter.
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Each of the seven Parts in this book opens with a short introduction, and every chapter begins with a bulleted list of Objectives and a representative vignette or case study. Each chapter closes with a brief Summary, a Glossary, some Questions for Review and Discussion, a list of Suggested Readings, and Selected Web Resources, which include some useful search terms along with organizational and Internet sites. In addition to the text, three Appendices identify and provide annotated descriptions of books on death-related topics for children and adolescents.

The following features distinguish our work in this book:

- 1. A careful exploration of the main features of death-related experiences in our society examined in terms of changing encounters with death, changing attitudes toward death, and changing practices associated with death within the American death system
- 2. An emphasis on *coping with death-related experiences*—instead of merely reporting how individuals react to death-related encounters, we highlight responses that individuals make in the form of efforts to manage those encounters and to integrate their implications into ongoing living
- 3. The use of a *task-based approach* to explain coping—by individuals and by communities—with life-threatening illness and dying, with loss and grief, with funeral and memorial rituals, and as bereaved children, adolescents, or adults of different ages
- 4. Sensitivity to a developmental perspective, which considers death-related issues in ways that emphasize experiences of individuals within four different eras in the human life course: as children; as adolescents; as young and middle-aged adults; and as older adults
- 5. An emphasis on *cultural patterns within American society* that recognizes distinctive modes of death-related encounters, attitudes, and practices typically found in Americans of Hispanic, African, Asian or Pacific Island, and American-Indian or Alaskan Native backgrounds, as well as other examples of diversity in our society
- 6. A practical orientation that highlights *helping with death-related experiences* helping others; helping oneself; and helping through families, social groups, institutions, and communities
- 7. An appreciation of moral, ethical, legal, religious, and spiritual values not only in debates about controversial issues such as aided death or in accounts of organ and tissue donation, but also throughout the book as an essential framework for such topics as care of the dying, support for the bereaved, and helping children and adolescents
- 8. Recognition of *important lessons about life and living*—lessons about limitation and control, individuality and community, vulnerability and resilience, and quality in living and the search for meaning—that can be learned from the study of death, dying, and bereavement

#### **NEW TO THIS EDITION**

Several instructors who have used this book as a basis for classroom or distance learning courses have asked us not to change its fundamental structure. We have accepted that advice and have retained the basic organizational structure and substance of the book for this edition. However, as appropriate, we have thoroughly revised the internal contents of the text. For example, in Chapter 1 there is a new vignette on the Death Cafe movement, an expanded account of the endings of the Little Red Riding Hood story, and an example of a personal death-related encounter involving one of the coauthors of this book.

In Part Two, Chapter 2 offers new information on how lifestyle factors impact encounters with death and an updated comparison of mortality data between the United States and Canada, noting how death-related encounters differ in significant ways between these two countries and asking why those differences appear to be generally more favorable to Canadians. Chapter 3 includes a new section on Terror Management Theory, Chapter 4 adds information on the Ebola epidemic in West Africa and new examples of mass murders in the United States, and Chapter 5 sharpens our efforts to challenge ethnocentrism, avoid cultural and racial stereotyping, and appreciate the value of cultural conscientiousness in understanding and helping others

Concerning coping with dying in Part Three, Chapters 6–8 add information on the primary regrets of the dying; a new box on active listening techniques; reflections on differences between being a pastor and a chaplain (with implications for all who seek to help dying persons); and additional research studies evaluating hospice care. As well, the section on pediatric palliative and hospice care is significantly rewritten, and the World Health Organization's definition of palliative care is added.

In Part Four, the structure of Chapter 9 is completely revised to reflect Doka's schema of new understandings of bereavement, grief, and mourning. In addition, there are new sections on attachments, absent grief, and Catherine Sanders' theory of six phases in mourning, plus new comments on the DSM-5 in the section on complicated grief reactions. In Chapter 11, a new figure graphically illustrates roles of digital and social media in coping with loss and achieving digital immortality.

In Part Five, we devote four full chapters to developmental perspectives, more than any other comparable book in our field. Here, Chapters 12–15 are enriched with new statistical data and supported by three Appendices that identify and briefly describe an updated selection of books on death-related topics for young readers. We believe these Appendices are the most thorough and helpful sources of information about death-related literature for young readers available from any textbook (and perhaps from any other book-length source) in our field. Further, Chapter 12 adds information on The Conversation Project, while Chapter 13 includes an updated account of adolescent involvements in the digital universe, a new description of an adolescent girl's bereavement after the death of her father, and a report on the death of an adolescent who was "skitching."

In Part Six, Chapter 16 now includes a new section on conversations about death-related matters, new information about Physician Orders for Life-Sustaining Treatment (POLST), and revised data on recent numbers of transplant candidates, organ transplants, and organ donors (both living and deceased). Chapter 17 adds new information on firearm laws and suicide, while Chapter 18 is reframed to focus on aided death, a new perspective that permits a better account of aid in dying, new information on the Death with Dignity Act in Oregon, and reports on aided death developments elsewhere in the United States and in other countries. A section in Chapter 19 sharpens our account of violence and security.

In Part Seven, Chapter 20 stands alone to clarify that its goal is to use one specific disease context to illustrate the basic themes and underlying structural features of this book. To that end, the descriptions of Alzheimer's disease and related disorders are refined to incorporate new data on encounters with these diseases, their staging, and the dying trajectories and deaths that follow from them. There also are a new section on communicating diagnoses and new examples from the lives and deaths of Robin Williams and Glen Campbell.

Attention to the digital universe appears throughout this new edition, but especially among the Questions for Review and Discussion at the end of each chapter, where Selected Web Resources and greatly updated and expanded Suggested Readings can also be found.

Throughout this eighth edition we report the most recent statistical data currently available from the National Center for Health Statistics (NCHS) and other sources. This includes final data for 2014 on numbers of deaths, death rates, and causes of death for the population as a whole in Chapter 2; for four selected cultural and racial subgroups in Chapter 5; for children, adolescents, young and middle-aged adults, and older adults in Chapters 12–15; and for Alzheimer's disease and related disorders in Chapter 20. We also provide the most recent NCHS data available on average life expectancy and place of death in Chapter 2, as well as on accidental deaths and homicide in Chapter 4. In addition, in Chapter 2 we include a newly updated figure on cancer-related deaths from the American Cancer Society.

Beyond that, we draw on the most recent data available from the U.S. Census Bureau concerning selected cultural and racial groups in Chapter 5, and concerning hospitals, long-term care facilities, and home health care programs in Chapter 8. Chapter 8 also reports the most recent data available on hospice programs from the National Hospice and Palliative Care Organization—including the striking fact that hospice programs cared for more than 1.6 million Americans in 2014. Chapters 8 and 12 also describe recent developments in pediatric palliative/hospice care.

Further, we provide recent data from: the Centers for Disease Control and Prevention in Chapter 2 concerning HIV and AIDS in the United States; UNAIDS concerning experiences with HIV and AIDS around the world; Statistics Canada concerning mortality data in Canada; the American Association of Suicidology in Chapters 13 (concerning adolescents), 15 (concerning older adults), and 17 (concerning the American population as a whole); the United Network for Organ Sharing in Chapter 16 concerning organ and tissue donation and transplantation; the Oregon Department of Human Services in Chapter 18 on aided death under the Oregon Death with Dignity Act; and the Alzheimer's Association in Chapter 20.

Among many other distinctive features in this eighth edition of *Death & Dying*, *Life & Living* there are new or significantly revised boxes, figures, tables, photos, and drawings, plus approximately 600 new references in a total of nearly 2,600 entries. Once again, most boxes have been divided into two primary types: "PERSONAL INSIGHTS" that report significant perspectives from individuals and "FOCUS ON" pieces that explore a specific subject or set of resources. Other boxes, in a distinctive format, appear as "ISSUES FOR CRITICAL REFLECTION," designed to stimulate discussion on 17 critical topics. We have also again worked diligently to simplify and clarify the text of this eighth edition, to make its tone even more personal, and to update its factual base.

#### **ACKNOWLEDGMENTS**

We are grateful to all who shared personal and/or professional life experiences with us, including our students and colleagues, thereby teaching us many of the important lessons about death, dying, and bereavement that are described in this book. We thank all who helped in the preparation of this eighth edition, in particular those who are credited in the text for the boxes, photos, and images that they helped us obtain and that are such important features of this book. Professors Mary Alice Varga of West Georgia University and Carla Sofka of Sienna College offered important guidance about the digital universe.

We are indebted to all of the many reviewers who helped us on previous editions of this book. For this new edition, we owe a particular debt of gratitude to seven experienced classroom instructors who took part anonymously in early review processes. It is extremely helpful to receive insightful and constructive comments from knowledgeable educators who teach courses in this field in a variety of institutions and contexts. We greatly appreciate their willingness to share insights and ideas to help strengthen this new edition. At our publisher, we appreciate the help and guidance we have received from Kassi Radomski, Nedah Rose, and their colleagues.

Although we have worked diligently to provide accurate, up-to-date knowledge about death, dying, and bereavement, neither we nor anyone else could claim to have completely covered every aspect of this extraordinarily broad field of study. For that reason, we encourage readers to pursue additional opportunities available to them for further study and research on these subjects. We welcome comments and suggestions for improvements that might be made in this book, because we know that imperfections are inevitable in as large and sweeping an enterprise as this project and in a field that changes rapidly and has many ramifications. Such comments or suggestions—along with outlines or syllabi for courses in which this book has been used, as well as references and other supplementary materials—can be sent to us by e-mail at ccorr32@tampabay.rr.com.

> Charles A. Corr Donna M. Corr Kenneth J. Doka



## The Horse on the Dining-Room Table

by Richard A. Kalish

I struggled up the slope of Mount Evmandu to meet the famous guru of Nepsim, an ancient sage whose name I was forbidden to place in print. I was much younger then, but the long and arduous hike exhausted me, and, despite the cold, I was perspiring heavily when I reached the plateau where he made his home. He viewed me with a patient, almost amused, look, and I smiled wanly at him between attempts to gulp the thin air into my lungs. I made my way across the remaining hundred meters and slowly sat down on the ground—propping myself up against a large rock just outside his abode. We were both silent for several minutes, and I felt the tension in me rise, then subside until I was calm. Perspiration prickled my skin, but the slight breeze was pleasantly cool, and soon I was relaxed. Finally I turned my head to look directly into the clear brown eyes, which were bright within his lined face. I realized that I would need to speak.

"Father," I said, "I need to understand something about what it means to die, before I can continue my studies." He continued to gaze at me with his open, bemused expression. "Father," I went on, "I want to know what a dying person feels when no one will speak with him, nor be open enough to permit him to speak, about his dying."

He was silent for three, perhaps four, minutes. I felt at peace because I knew he would answer. Finally, as though in the middle of a sentence, he said, "It is the horse on the dining-room table." We continued to gaze at each other for several minutes. I began to feel sleepy after my long journey, and I must have dozed off. When I woke up, he was gone, and the only activity was my own breathing.

I retraced my steps down the mountain—still feeling calm, knowing that his answer made me feel good, but not knowing why. I returned to my studies and gave no further thought to the event, not wishing to dwell upon it, yet secure that someday I should understand.

Many years later I was invited to the home of a casual friend for dinner. It was a modest house in a typical California development. The eight or ten other guests, people I did not know well, and I sat in the living room—drinking Safeway Scotch and bourbon and dipping celery sticks and raw cauliflower into a watery cheese dip. The conversation, initially halting, became more animated as we got to know each other and developed points of contact. The drinks undoubtedly also affected us.

Eventually the hostess appeared and invited us into the dining room for a buffet dinner. As I entered the room, I noticed with astonishment that a brown horse was sitting quietly on the dining-room table. Although it was small for a horse, it filled

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much of the large table. I caught my breath, but didn't say anything. I was the first one to enter, so I was able to turn to watch the other guests. They responded much as I did—they entered, saw the horse, gasped or stared, but said nothing.

The host was the last to enter. He let out a silent shriek—looking rapidly from the horse to each of his guests with a wild stare. His mouth formed soundless words. Then in a voice choked with confusion he invited us to fill our plates from the buffet. His wife, equally disconcerted by what was clearly an unexpected horse, pointed to the name cards, which indicated where each of us was to sit.

The hostess led me to the buffet and handed me a plate. Others lined up behind me—each of us quiet. I filled my plate with rice and chicken and sat in my place. The others followed suit.

It was cramped, sitting there, trying to avoid getting too close to the horse, while pretending that no horse was there. My dish overlapped the edge of the table. Others found other ways to avoid physical contact with the horse. The host and hostess seemed as ill at ease as the rest of us. The conversation lagged. Every once in a while, someone would say something in an attempt to revive the earlier pleasant and innocuous discussion, but the overwhelming presence of the horse so filled our thoughts that talk of taxes or politics or the lack of rain seemed inconsequential.

Dinner ended, and the hostess brought coffee. I can recall everything on my plate and yet have no memory of having eaten. We drank in silence—all of us trying not to look at the horse, yet unable to keep our eyes or thoughts anywhere else.

I thought several times of saying, "Hey, there's a horse on the dining-room table." But I hardly knew the host, and I didn't wish to embarrass him by mentioning something that obviously discomforted him at least as much as it discomforted me. After all, it was his house. And what do you say to a man with a horse on his dining-room table? I could have said that I did not mind, but that was not true—its presence upset me so much that I enjoyed neither the dinner nor the company. I could have said that I knew how difficult it was to have a horse on one's dining-room table, but that wasn't true either; I had no idea. I could have said something like, "How do you feel about having a horse on your dining-room table?", but I didn't want to sound like a psychologist. Perhaps, I thought, if I ignore it, it will go away. Of course I knew that it wouldn't. It didn't.

I later learned that the host and hostess were hoping the dinner would be a success in spite of the horse. They felt that to mention it would make us so uncomfortable that we wouldn't enjoy our visit—of course we didn't enjoy the evening anyway. They were fearful that we would try to offer them sympathy, which they didn't want, or understanding, which they needed but could not accept. They wanted the party to be a success, so they decided to try to make the evening as enjoyable as possible. But it was apparent that they—like their guests—could think of little else than the horse.

I excused myself shortly after dinner and went home. The evening had been terrible. I never wanted to see the host and hostess again, although I was eager to seek out the other guests and learn what they felt about the occasion. I felt confused about what had happened and extremely tense. The evening had been grotesque. I was careful to avoid the host and hostess after that, and I did my best to stay away altogether from the neighborhood.

Recently I visited Nepsim again. I decided to seek out the guru once more. He was still alive, although nearing death, and he would speak only to a few. I repeated my journey and eventually found myself sitting across from him.

Once again I asked, "Father, I want to know what a dying person feels when no one will speak with him, nor be open enough to permit him to speak, about his dying."

The old man was quiet, and we sat without speaking for nearly an hour. Since he did not bid me leave, I remained. Although I was content, I feared he would not share his wisdom, but he finally spoke. The words came slowly.

"My son, it is the horse on the dining-room table. It is a horse that visits every house and sits on every dining-room table—the tables of the rich and of the poor, of the simple and of the wise. This horse just sits there, but its presence makes you wish to leave without speaking of it. If you leave, you will always fear the presence of the horse. When it sits on your table, you will wish to speak of it, but you may not be able to.

"However, if you speak about the horse, then you will find that others can also speak about the horse—most others, at least, if you are gentle and kind as you speak. The horse will remain on the dining-room table, but you will not be so distraught. You will enjoy your repast, and you will enjoy the company of the host and hostess. Or, if it is your table, you will enjoy the presence of your guests. You cannot make magic to have the horse disappear, but you can speak of the horse and thereby render it less powerful."

The old man then rose and, motioning me to follow, walked slowly to his hut. "Now we shall eat," he said quietly. I entered the hut and had difficulty adjusting to the dark. The guru walked to a cupboard in the corner and took out some bread and some cheese, which he placed on a mat. He motioned to me to sit and share his food. I saw a small horse sitting quietly in the center of the mat. He noticed this and said, "That horse need not disturb us." I thoroughly enjoyed the meal. Our discussion lasted far into the night, while the horse sat there quietly throughout our time together.

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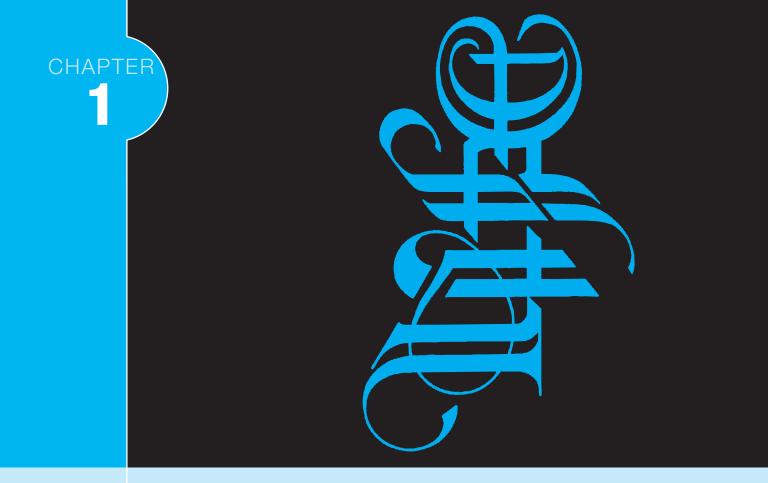
PART One

# LEARNING ABOUT DEATH, DYING, AND BEREAVEMENT

ife and death are two aspects of the same reality. To see this fact represented in graphic form, look at the image on page 2 of this book. You can decipher its meaning by rotating the image one-quarter turn clockwise and then one-quarter turn counterclockwise from its original position. Clearly, one could not properly understand one aspect of this image ("life") without also grasping something about its second aspect ("death"). In other words, we believe that learning about death, dying, and bereavement is an important way of learning about life and living. Just as every human being is inevitably involved in learning about life and living, we suggest that each person is also engaged in a process of learning about death, dying, and bereavement. In this book, we pursue that process in a deliberate and explicit way.

Our Prologue, Richard Kalish's allegory, "The Horse on the Dining-Room Table," teaches us that it is desirable to talk about death together, to share insights and attitudes, to try to learn from each other, and to strive to cope more effectively in the face of death (see Corr, 2015d). But how do we begin?

One good place to start is with some preliminary remarks about education in the field of death, dying, and bereavement. Thus, in Chapter 1 we examine some concerns that lead people to study death-related subjects, how this type of education is conducted, its four principal dimensions, its six central goals, and some things we can learn about life and living by engaging in these studies. These introductory remarks are a kind of warm-up for the main event that follows in the remainder of this book. Some readers might prefer to bypass this warm-up by jumping directly to the central work of this book and returning later to Chapter 1. Others will benefit from these preparatory comments about certain aspects of the project ahead.



# Education about Death, Dying, and Bereavement

## **Objectives** of this **Chapter**

- To explore the *nature* and *role* of education about death, dying, and bereavement (often called "*death education*")
- To examine *concerns* that lead people to discuss and study death-related subjects
- To look briefly at how education about death, dying, and bereavement is conducted
- To describe *four dimensions* of education *about death, dying, and bereavement*
- To identify six main goals of education about death, dying, and bereavement
- To indicate *lessons we can learn about four central* themes in life and living by studying death, dying, and bereavement

Death and life: two dimensions of the same reality. To interpret the meaning of this drawing, rotate the image one-quarter turn clockwise, then one-quarter turn counterclockwise from its original position.

#### **DEATH CAFE**

The phrase Death Cafe identifies both a movement and the individual gatherings that occur as part of that movement. The movement began in Switzerland when Bernard Crettaz held his first Café Mortel on March 23, 2004. Later, a review of a book by Crettaz (2010) led a British web designer, Jon Underwood, to host a Death Cafe gathering at his home in London in September, 2011 and to establish a website for the movement. The website stipulates that Death Cafe events are always offered on a not-for-profit basis; in an accessible, respectful, and confidential space; with no intention of leading people to any conclusion, product, or course of action; and alongside refreshing drinks and nourishing food. The overall objective of Death Cafe gatherings is "to increase awareness of death with a view to helping people make the most of their (finite) lives."

The Death Cafe movement was brought to the United States by Lizzy Miles and Maria Johnson, who hosted the first gathering in a suburb of Columbus, Ohio, on July 19, 2012. Their promotion for this gathering described it as "a pop-up event where people get together to talk about death and have tea and delicious cake" (Miles, 2013). The phrase "pop-up event" indicated that this was to be a gathering, not a physical space like a restaurant, and signified that these events are not planned or scheduled on a regular basis. The word "people" suggested that attendees may come with friends or be unknown to each other before joining the gathering. Mention of "tea and delicious cake" signified that these events are warm and inviting, with no preset agenda.

According to the website, as of August 3, 2017, there have been 4954 Death Cafe gatherings in 51 countries around the world. Death Cafe gatherings are not intended to be grief support groups, lecture or educational sessions, or avenues for promoting a business or cause. Both hosts and other attendees have typically commented that the gatherings are "safe" and "interesting" forums in which people can talk about whatever is on their minds related to death, dying, and bereavement. Karen Van Dyke, who hosts Death Cafe gatherings in San Diego, has been quoted as saying, "When you talk about sex you don't get pregnant, when you talk about death you do not die" (Accomando & McVicker, 2014).

People choose to take part in Death Cafe gatherings for many different reasons, but it is worth noting that the Death Cafe movement and its gatherings have arisen spontaneously, appear to be meeting a felt need, and demonstrate that at least some people in our society and elsewhere are willing and able to talk openly about death-related subjects (Miles & Corr, 2017). (Note: What seems to be a more directive approach is offered by Death Over Dinner.)

#### A TABOO TOPIC? A DEATH-DENYING SOCIETY?

In times past, it was often said that death was a *taboo topic* in American society, a subject that was somehow not acceptable for scholarly research, education, or public discussion (Feifel, 1963a, 1963b). If that was true, it was as if death needed to be quarantined in order not to infect the way in which people wished to think about and live out their lives. That has led some people to claim, even today, that ours is a "death-denying society." But although some people do not want to talk about death-related subjects and may comment that a course on death and dying must be

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depressing or "morbid," how can it be claimed that there is complete denial here? After all, isn't there evidence to the contrary in the very existence of multiple courses across North America on various aspects of death, dying, and bereavement, the reality of this book you are reading, and the people who take part in Death Cafe gatherings? (Since you are reading a book about death, dying, and bereavement, and discussing education in this field, these topics must no longer seem to you to be taboo or forbidden. If so, see Issues for Critical Reflection #1).

Many years ago, Dumont and Foss (1972) analyzed conflicting claims about acceptance and denial of death. They concluded that: (1) "[A]vailable evidence strongly suggests that it is quite untenable to assume that there exists an 'American' attitude toward death" (p. 85) and (2) "[T]here is substantial evidence to indicate that the culture of the United States and the individuals in this society both accept and deny death, simultaneously" (p. 95). Earlier, Talcott Parsons (1963), an American sociologist, suggested Americans have an active orientation toward death. Parsons meant that Americans value efforts to control death by strongly trying to regulate to prevent accidental ("unnecessary") and "out of order" deaths (such as that of a child), minimizing pain in dying, and curtailing the toll of death by preparing the bodies of the deceased at funerals so they look as life-like as possible. Parsons felt that Americans choose to avoid aspects of death that cannot be controlled.

The argument for acknowledging the role of death in our society has been supported over many years by pioneers like Herman Feifel (1959, 1977a), Cicely Saunders (1967), and Elisabeth Kübler-Ross (1969), who encouraged behavioral scientists, clinicians, and humanists to pay attention to death-related topics. As a

## #1 Teaching about Death, Dying, and Bereavement

Before you read the rest of this chapter, you might ask yourself what you would do if you were asked to take part in teaching about these subjects. How would you respond to questions like the following?

- Who should be taught about these subjects? Children, adolescents, adults of various ages?
- Who should be involved along with you in teaching about these subjects? Individuals who have had death-related experiences, persons who are formally trained or certified in these subjects, parents or religious leaders, anyone at all?
- What topics should be part of this teaching program? Loss and grief, life-threatening illnesses and dying, suicide, aided death, how to cope effectively with death-related challenges, and views about life, death, and the possibility of an afterlife?

- Where should this teaching take place? In the home, in religious institutions, in public or private schools, in colleges or universities, in programs of professional education?
- When should this teaching be offered? Before people are forced to confront a death-related encounter? After a public tragedy, such as a suicide, mass death, or natural disaster? As part of general preparation for living? As an element in vocational training programs?
- How should this type of education be offered? Informally as part of education about life? As a formal component of some other subject like biology, nursing, philosophy, psychology, religious studies, or sociology? As a separate subject in its own right?
- Why, if at all, should we engage in this type of education in the first place?

result, in recent years, new programs have been developed on care of the dying, support for the bereaved, and research about death-related attitudes. These developments are part of what has been called the *death-awareness* movement or *thanatology* (from *thanatos*, the Greek word for *death*, + *ology* = a science or organized body of knowledge) (Doka, 2003; see also Stillion & Attig, 2015). As indicated in the title of this book and the calligraphy on page 2, we believe that death and life are so intertwined that the body of knowledge in this book is focused on life and living considered from the perspective of death and dying. In this, we follow Kastenbaum (2012, p. xv) who defined "thanatology" as "the study of life—with death left in" and the guru's advice in the last three paragraphs of the Prologue to this book (on p. xxviii).

#### CONCERNS LEADING PEOPLE TO STUDY DEATH-RELATED SUBJECTS

Let's think about this subject in more specific ways. Why did instructors begin to offer courses on what has come to be called **death education** (a popular phrase in this field, but one that may not be a very good name for the study of life and living from the standpoint of death and dying; see Corr & Corr, 2003c)? And why did people want to talk about and study death-related issues (Bucklea, 2013)? We think that some of the concerns that help this type of education thrive include the following:

- Some people become interested in these subjects because of *work they are already doing or are preparing to do in a profession or vocation in which they expect to be asked to help people who are coping with death-related issues.* These include students or those working in fields like counseling, education, funeral service, medicine, the ministry, nursing, and social work, as well as individuals who volunteer in hospice organizations.
- Many people have pressing personal concerns because they want to learn how to cope more effectively with a current encounter with someone who is dying or with their own grief and mourning after their significant other has died.
- Others say they want to prepare for personal experiences that might or could be expected to arise in the future. For example, some say: "No important person in my life has yet died, but I know it can't continue this way as my grandparents are getting pretty old." These people don't want to wait until events demand a response under pressure; they prefer to be proactive by preparing themselves and others (as much as possible) to cope with death-related challenges.
- Finally, some people are simply curious about some death-related topic or issue
  in this field, such as debates about assisted suicide or how one might talk to children about death and loss.

Do any of the above apply to you? If so, death-related education programs should try to help you meet your interests by developing a special sensitivity to and compassion for your concerns. That is especially true if participants in these educational programs include people who have experienced the death of a loved one in the recent past, whose close relative or friend is presently trying to meet the challenges of a terminal illness, or who may themselves be living with a life-threatening condition.

Of course, education is different from counseling, and a classroom or an online course is not really an appropriate context for individual therapy. So, we need to offer this caution: Education alone may not be sufficient to address your needs if you are unable to cope with difficult personal experiences by yourself. If you are in such a

situation, it may be desirable to seek personal counseling or therapy. Also, if you have recently experienced a major loss in your life and are not comfortable with a dispassionate, educational approach to death-related topics, you might choose to postpone enrolling in a course in this field until some later time. In short, a formal course may not meet all needs at all times.

## HOW IS EDUCATION ABOUT DEATH, DYING, AND BEREAVEMENT CONDUCTED?

This type of education may be conducted formally or informally. Formal or planned education about death, dying, and bereavement is usually associated with organized instructional programs of the type found in schools, colleges and universities, graduate education, professional workshops, and volunteer training programs (Berman, 2011; Corr, 2015a; Dickinson, 2012; Hayasaki, 2014; Loerzel & Conner, 2016; Noppe, 2007). These formal programs can be of many types. Some are taught in traditional classrooms, but lately many are taught online, whether as credit-bearing offerings for degrees in various fields or thanatology-related programs, or as part of continuing education or certification programs.

One imaginative example designed to be used as a basis for formal education in the community is *Lessons from Lions: Using Children's Media to Teach about Grief and Mourning* (Adams, 2006), a resource that can be used to teach children (and adults) about grief and mourning in primary school classrooms or grief support groups. This slim booklet provides an outline and ten slides from the Disney movie, *The Lion King*, to encourage discussion about three common but unhelpful reactions following a loss: (1) running away from the problem, the pain, and those who know and love you best; (2) pretending the bad thing never happened; and (3) never telling anyone about your grief reactions.



Students learn during a planned visit to a funeral home.

astin Brinkley

Early examples of formal education about death, dying, and bereavement in secondary schools typically focused directly on death, dying, and bereavement (Stevenson, 2004). Examples of such courses can still be found (e.g., Campbell, 2016), although many recent courses are more likely to emphasize topics like: coping with loss (including bereavement and grief, but in which "death" is a secondary element); suicide and suicide prevention (aimed more directly at students than earlier programs developed for faculty, staff, and parents); violence and violence prevention (in which loss and grief are typically addressed as factors contributing to violence); or crisis counseling courses for school counselors and teachers, as well as agency-based counselors (R. W. Stevenson, personal communication, February 9, 2007). One of the main goals of this book is to support formal educational programs however they may be organized.

Informal or unplanned education about death, dying, and bereavement is more typical and more widespread, although it may not always be recognized for what it truly is. Most human beings first learn about loss, sadness, and coping from a parent or guardian and through interactions within a family or similar social group (Gilbert & Murray, 2007). They also learn about these topics from their own experiences, the people they meet in their lives, and events in which they take part. The media (notably television and videos) and many other sources contribute raw materials and insights to a lifelong process of informal education that may take place almost without one's notice. Also, Death Cafe gatherings, the Internet, and various self-education activities (e.g., Straub, 2015) can contribute to this type of informal education. (For an example of how death has been (mis)treated in one well-known children's story, see Issues for Critical Reflection #2.)

## ISSUES FOR CRITICAL REFLECTION #2 Do You Know What Really Happened to Little Red Riding Hood?

Which, if any, of the following excerpts from the Little Red Riding Hood story is familiar to you?

#### Example 1

The Wolf, seeing her come in, said to her, hiding himself under the bedclothes:

"Put the custard and the little pot of butter upon the stool, and come and lie down with me."

Little Red Riding Hood undressed herself and went into bed, where, being greatly amazed to see how her grandmother looked in her night-clothes, she said to her:

"Grandmamma, what great arms you have got!"

- "That is the better to hug thee, my dear."
- "Grandmamma, what great teeth you have got!"
- "That is to eat thee up."

And, saying these words, this wicked wolf fell upon Little Red Riding Hood, and ate her up.

Source: From Lang, 1904, p. 66.

#### Example 2

"The better to EAT you with," said the wolf. And he sprang from the bed and ate Little Red Riding Hood up.

A passing woodsman stepped into the house to see how Little Red Riding Hood's grandmother was feeling. And when he saw the wolf, he said, "Ah ha! I've found you at last, you wicked old rascal!" He lifted his ax, and with one blow, killed him. Then he cut the wolf open and out stepped Little Red Riding Hood and her grandmother.

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## ISSUES FOR CRITICAL REFLECTION (continued) #2 Do You Know What Really Happened to Little Red Riding Hood?

They thanked the woodsman for what he had done. Then all three sat down and ate the cake and the butter and drank of the grape juice, which Little Red Riding Hood had brought.

Source: From Jones, 1948.

#### Example 3

"THE BETTER TO EAT YOU WITH, MY DEAR," cried the wolf. He pushed back the covers, and jumped out of the bed. Then Little Red Riding Hood saw that it was the big wolf pretending to be her grandmother!

At that moment a hunter passed the house. He heard the wolf's wicked voice and Little Red Riding Hood's frightened scream. He burst open the door. Before the wolf could reach Little Red Riding Hood, the hunter lifted his gun to his shoulder and killed the wicked wolf. Little Red Riding Hood was very happy and she thanked the kind hunter.

Grandmother unlocked the door and came out of the closet, where she had been hiding. She kissed Little Red Riding Hood again and again. And she thanked the hunter for saving them both from the big wolf. They were all so happy that they decided to have a party right then and there. ... And they all lived happily ever after.

Source: From Anonymous, 1957.

#### Example 4

"All the better to EAT you with!" cried the wolf.

With that, Little Red Riding Hood let out a scream and ran from the room. The wolf gave chase with hunger in his eyes.

"Stop!" cried a loud voice.

Little Red Riding Hood looked up to see a woodcutter holding his ax in the air. He reached for the wolf and grabbed him by the tail. Then the woodcutter carried the wolf into the forest.

Grandmother came running up to Little Red Riding Hood. She had been hiding in the garden shed. [After she had run out of the front door when frightened by the first sight of the wolf.]

"Grandmother! I am so glad you are safe!" cried Little Red Riding Hood. "I was worried that the wolf had eaten you."

Grandmother gave Little Red Riding Hood a great big hug as the woodcutter came out of the woods.

"I do not think that wolf will trouble you again," he said, adjusting his cap.

Source: From Anonymous, 2013, pp. 35–37. Note the changes from Example 1 in which both Grandmother and Little Red are eaten by the wolf and presumably they die—which reinforces the basic moral of the original story; to Example 2 in which they are eaten but then experience a type of instant reappearance (resurrection?) when the woodsman cuts the wolf's stomach open (and apparently the wolf dies); to Example 3 in which a hunter kills the wolf before he can eat Little Red and Grandmother emerges from a closet where she had been hiding; to Example 4 in which both Little Red and Grandmother escape from the wolf, no one is eaten, and even the assumed death of the wolf occurs offstage.

Why do you think people made these changes to the end of this beloved story?

Opportunities for informal education also emerge naturally from teachable moments. These are the unanticipated events in life that offer important occasions for developing useful educational insights and lessons, as well as for personal growth (see Personal Insights 1.1 for an unexpected encounter on the part of one of our coauthors that was for him also a teachable moment). For example, a natural disaster, an act of violence like the horrific events of September 11, 2001, barely avoiding an auto accident, the death of a pet, the funeral of a loved one, or a visit to a cemetery are only a few of the many instances in which teachable moments thrust themselves into the middle of life and offer important opportunities for informal education about death, dying, and bereavement for both children and adults.

Visiting a cemetery with a child can provide a "teachable moment."



Courtesy of Kevin A. Corr

#### PERSONAL INSIGHTS 1.1

#### **A Personal Vignette and a Teachable Moment**

For several years, an elderly couple in their 80s (let's call them Mike and Maggie) came to Florida from Michigan to rent the house next door to us during the months of January and February. Although they were not married, they had known each other since grade school and had been together for 14 years after each was widowed earlier.

Late one evening immediately after they had arrived, Mike had a massive heart attack. I was in bed, but was woken by the sound of loud engines, which turned out to be several fire rescue and ambulance vehicles parked along the street with lights flashing. Fearing that bad things were happening, I threw on some clothes and went outside to join two neighbors standing across the street.

Soon, Mike was taken out on a gurney into an ambulance and driven away. Some minutes later, Maggie was escorted from the house by a police officer and also driven away.

I wish I had reached out to her at that point, but I soon realized she would be alone in the emergency department of our local hospital with no other family or friends in this area. I thought someone should go to be with her and one of our neighbors (a nurse who did not know this couple) encouraged me to do so.

When I arrived at the emergency department, I found Maggie sitting in an exterior waiting area. She said she was pleased I had come. Soon, a staff person invited her to come in to an interior family waiting area and Maggie asked me to accompany her. She said she was glad to have some company so that she

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