With characteristic clarity, Doka draws on the classic and contemporary literature as well as his own pedagogy and practice in death and dying to offer orienting concepts for the whole spectrum of care people may require when illness intrudes into their lives. For each phase of the illness trajectory... he offers intelligent attention to the problems and prospects people confront, and in countless examples of actual clinical situations he brings to life the concepts that inform compassionate care.

From the Foreword by Robert A. Neimeyer, PhD, University of Memphis

This holistic, family-centered guide to counseling individuals with life-threatening illness considers not only the physical manifestations of the illness, but its psychological, social, economic, and spiritual implications. Revised and updated to reflect the most current research and enhanced theoretical development, this second edition encompasses new therapies that enhance meaning-making at life's end, and offers expanded sections on counseling families during the illness and as they grieve. One of the book's most significant changes involves the adaptation of a model of concurrent care. This model of care has great implications for end-of-life care, bridging the divide between treatment that is primarily palliative and treatment that seeks to cure or extend life.

Comprehensive and practical, the book discusses such social and psychological factors as gender, race, ethnicity, social class, education, and intelligence, and how they inform the experience of gravely ill people. The initial crisis of diagnosis is addressed along with unique considerations for those who live with chronic illness, those who are terminally ill, and those who recover.

New to This Edition:
- Generational differences as a source of diversity
- Expanded sections involving meaning-making strategies (dignity-enhancement therapy, living eulogies, reminiscence therapy, life review, meaning-centered therapy, moral/ethical issues, and heart wills)
- Discussion of end-of-life phenomena and ways to assist patient and family in interpreting and responding to them
- Enhanced coverage of caregiver issues
- Expanded discussion of spirituality
- Additional behavioral strategies to assist pain management
- Anticipatory mourning
- Post-death grief for family members
- Chronic care and rehabilitation
- Incorporates Rand Study on Concurrent Care and other new models

Kenneth J. Doka, PhD
Counseling Individuals With Life-Threatening Illness
Kenneth J. Doka, PhD, is a Professor of Gerontology at the Graduate School of The College of New Rochelle and Senior Consultant to the Hospice Foundation of America. A prolific author, Dr. Doka’s 27 books include Grieving Beyond Gender: Understanding the Ways Men and Woman Mourn; Counseling Individuals With Life-Threatening Illness; Living With Grief: Ethical Dilemmas at the End of Life; Living With Grief: Alzheimer’s Disease; Living With Grief: Coping With Public Tragedy; and Disenfranchised Grief: New Directions, Challenges, and Strategies for Practice. In addition to these books, he has published over 100 articles and book chapters. Dr. Doka is editor of both Omega: Journal of Death and Dying and Journeys: A Newsletter to Help in Bereavement.

Dr. Doka was elected President of the Association for Death Education and Counseling in 1993. In 1995, he was elected to the Board of Directors of the International Work Group on Dying, Death and Bereavement and served as chair from 1997 to 1999. The Association for Death Education and Counseling presented him with an award for Outstanding Contributions in the Field of Death Education in 1998. In 2000, Scott and White Healthcare presented him with an award for Outstanding Contributions to Thanatology and Hospice. His alma mater, Concordia College, presented him with their first Distinguished Alumnus Award. In 2006, Dr. Doka was grandfathered in as a mental health counselor under New York State’s first licensure of counselors.

Dr. Doka has keynoted conferences throughout North America as well as Europe, Asia, Australia, and New Zealand. He participates in the annual Hospice Foundation of America Teleconference and has appeared on CNN and Nightline. In addition, he has served as a consultant to medical, nursing, funeral service and hospice organizations, as well as businesses and educational and social service agencies. Dr. Doka is an ordained Lutheran minister.
Counseling Individuals With Life-Threatening Illness

Second Edition

Kenneth J. Doka, PhD
To My Grandchildren,
Kenny and Lucy
Who Each Day Bring New Joy in Living
And To Their Parents, My Son and Daughter-in-Law,
Michael and Angelina
For the Gifts of Grandparenthood
And Parental Pride

And

In Memory of Mary Lou Millar
And In Honor of Jim Millar
Neighbors, Friends, and Surrogate Parents for a Quarter of a Century
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Anyone who has provided companionship, counseling, or care to persons who are coping with serious illness knows how diverse the landscape of loss can be, with some itineraries through this terrain climbing to vistas of hope while others descend into valleys of despair. But most, perhaps, thread through a variegated terrain of threat, uncertainty, helplessness, action, isolation, acceptance, and connection, with too few markers to signal the way forward. Worse, those touched by the illness as well as those who help them may be presented with presumptive markers of a standardized, stepwise journey that departs substantially from the journey on which this patient, in this family, struggling with these issues, in this cultural frame, at this point in the progression of his or her illness, is embarked. Trying to find the way forward with an erroneous map can be still more disorienting than having no map at all.

In this compact volume, anchored as it is in a deep history of personal and professional acquaintance with the topic, Ken Doka provides an authoritative and appropriately individualized guidebook for professionals who willingly accept the role of fellow travelers for patients and families contending with this unfamiliar terrain. With characteristic clarity, Doka draws on the classic and contemporary literature as well as his own pedagogy and practice in death and dying to offer orienting concepts for the whole spectrum of care people may require when illness intrudes into their lives. For each phase of the illness trajectory,
from prediagnosis through acute, chronic, and recovery/remission periods to the terminal phase, he offers intelligent attention to the problems and prospects people confront, and in countless examples of actual clinical situations he brings to life the concepts that inform compassionate care. What struck me was not only the simple practicality of the principles and interventions he describes and illustrates, but also their comprehensiveness and sweep, encompassing concern with the physical, medical, psychosocial, and existential aspects of life-threatening illness. Implicit in this nuanced and multidimensional treatment of the topic is Doka’s advocacy of interdisciplinary contributions to caring for people with life-altering conditions, as well as encouragement for all of us who do this work to recognize its complexity and be willing to transcend sometimes-artificial disciplinary divisions to provide treatment to the whole person. In this respect I found this book to accord fully with recent developments in hospice and palliative care, which emphasize the importance of recognizing the integrity and diversity of patients in their own unique family and cultural contexts. However, even as he integrates in this new edition the latest work on meaning making, dignity therapy, and moral wills, Doka brings to bear his gift as a storyteller to bring these concepts to life. In other words, as a skilled pedagogue, Doka tacks back and forth between abstract conceptualization and concrete experience, giving the reader useful models and methods for counseling in this challenging context but also illustrating their application to real people facing real problems. Moreover, orienting as he does to the tasks of coping with illness in all its varied challenges, he casts patients as protagonists empowered by choice, characterized by individuality, and animated by activity as they and their families negotiate their own pathway through the terrain of illness and treatment. The result is a readable book that covers a surprising amount of ground without leaving the reader feeling winded from slogging through interminable theories or being bogged down with technicalities. As usual, Doka seems to have gotten the balance just right.

Although I am no stranger to this literature, I readily acknowledge that I learned a good deal myself from the perusal of these pages, and I am certain this will be the case for other readers, whatever their level of expertise. In consequence, I will find myself adding the second edition of Counseling Individuals With Life-Threatening Illness to the recommended readings I use in classes with students as well as those I offer.
in workshops with professionals who work in end-of-life care. And I recommend it to you as well, confident that it provides practical guidance to all counselors who strive to offer support and understanding to persons finding their way through the often daunting landscape of serious illness and loss.

Robert A. Neimeyer, PhD
Professor, Clinical Psychotherapy
University of Memphis
Acknowledgments

This work has been influenced and nurtured by many sources. Thus, it is both fitting and pleasurable to acknowledge these diverse contributions. The contributions of Avery Weisman and E. Mansel Pattison are clearly evident in these pages. Others, too, through their writing or teaching influenced my thinking about life-threatening illness. The ideas of Myra Bluebond-Langer, Herman Feifel, Robert Fulton, Barney Glaser, and the late Richard Kalish, Robert Kastenbaum, Nat Kollar, Elisabeth Kübler-Ross, Ilene Lubkin, Bruce Jennings, Victor Marshall, Rudolph Moos, Catherine Sanders, Edwin Schneidman, John Stephenson, Judith Stillion, Anselm Strauss, David Sudnow, Mary Vachon, and Hannelore Wass are all apparent in these pages. Charles Corr and Theresa A. Rando have had a special role; not only did their ideas and thoughts influence me, but their constant encouragement sustained me. Richard Cohen and the late Don Ford, friends and physicians, were always available to answer any technical or medical questions.

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This book would not have been possible without the secretarial and technical help so generously provided by Vera Mezzacuella. The division’s Administrative Assistant Diane Lewis keeps everything else operating with cheery efficiency.

Throughout the past number of years, I have had the privilege of being a consultant to the Hospice Foundation of America (HFA). This has helped me professionally in so many ways. Each year, preparation for a new teleconference and accompanying book continues to make me stretch my professional knowledge, moving me, for example, to study pain management or end-of-life ethics in a much deeper way. In addition, I have enjoyed the professional stimulation and personal friendships of the many wonderful people I have met there including the late Jack Gordon, Myra MacPherson, David Abrams, Lisa Veglahn, Norman Sherman, and the staff, past and present. I have to give special thanks and mention to my often collaborator and co-editor, and always friend—HFA’s CEO, Amy Tucci.

Then there are all those in my own environment who, I like to think, keep me grounded. I am fortunate to live in a community that really is one. For that I thank my neighbors Paul Kimbal, Allen and Gail Greenstein, Jim Millar, Robert and Tracey Levy, Fred and Lisa Amore, Chris and Dorota Fields, and all my friends on Alda Drive.

I, of course, need to acknowledge all those in my personal life who are always a source of joy. My son, Michael, and his wife, Angelina, my grandson Kenny, and granddaughter Lucy make it all seem so worthwhile.

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Franky; and all of their families, as well as Eric Schwarz; Dylan Rieger; Larry Laterza; Ellie Andersen; Jim, Karen, and Greg Cassa; Linda, Russell and Ryan Tellier; Jill Boyer; Lynn Miller; Kim Rainbolt; Lisa, Cody, and Ciarra Carlson; Tom and Lorraine Carlson; Adrianna Whitehead; Matt Atkins; Kurt Mulligan; Ken and Elaine Gilmore; Don and Lucille Matthews; and Liz Galindo provide nurturing, encouragement, respite, friendship, and most importantly, laughter. The Internet has allowed contact with long-lost friends, often allowing new recognitions of commonalities. To that technology, I owe renewed ties to S. E. Hodges, Alice Hum, and Kathy Nacey.

In addition, I have to acknowledge the help, encouragement, and infinite patience of my editor, Sheri W. Sussman and the staff at Springer Publishing Company. And finally, I need to acknowledge all those people who in their own struggle with life-threatening illness and grief taught me much about dying and living.
Introduction: Counseling Individuals With Life-Threatening Illness

• A 36-year-old mother learns that the tingling in her arm has been diagnosed as multiple sclerosis.
• A 64-year-old man, experiencing chest pains, is told he is having a heart attack.
• The parents of a 2-year-old boy sit anxiously in a doctor’s office, waiting to learn why their son has experienced continuous fevers and bruises so easily.
• A 28-year-old architect finds that he is HIV positive.
• During a routine examination a 69-year-old man is informed that he has a spot on his lung.
• A 41-year-old physician finds a lump in her breast.

In all these cases, individuals and their families are facing moments of crisis, terrible trials, and frightening encounters with mortality. Each must decide upon a course of action—when to seek medical help, how to choose the best treatment. The experiences of all these people may be very different. Some may find their worst fears are not realized. The lump may turn out to be merely a cyst; the spot on the lung may be benign. Some may undergo surgery or chemotherapy and eventually recover but be forever changed by the experience of the illness. Others may struggle with chronic illness. And still others may face impending death.
The experience of life-threatening illness is one of the most difficult situations that individuals and their families ever have to face. From the first mounting suspicions about dangerous symptoms through the crisis of diagnosis and long periods of chronic illness, any encounter with life-threatening illness—whether the result is recovery or death—leaves an indelible mark on ill individuals, their families, and even the people who care for them.

This book is meant to be a guide for anyone counseling or offering professional care to persons with life-threatening illness. Its very title, *Counseling Individuals With Life-Threatening Illness*, recognizes the medical revolution that has so radically changed the experience of illness. A few decades ago an individual diagnosed with any of a number of “fatal” diseases received a virtual death sentence. A person with such a serious disease could expect to live but a short time; indeed, he or she might never leave the hospital.

Often now, the experience of serious illness is dramatically different. Individuals can live a long time with life-threatening illness. Some, and these numbers continue to increase, will fully recover. Most will leave hospitals even as they carry on treatment. Many will resume their former lives, going back to work or school even as they continue to struggle with disease. Only at the very end of this process, often years after the initial diagnosis, will some finally reach the terminal phase of their illness. Living with life-threatening illness is the theme of this book as it describes the particular challenges that individuals, families, and caregivers face at varying points during serious illness.

In the last 50 years there has been another revolution in medical care, evidenced by the growth of hospice and palliative care. Behind both is a simple yet critical premise—care in life-threatening illness must be holistic. Life-threatening illness is not only a medical crisis; it is a social, psychological, and spiritual crisis as well. It does not only affect the individual with the illness but also affects the family. Hence, care must not only be holistic, it also must be family centered. Both premises underlie this book.

Every book has its own biography. This book really arises from three sources. For the past 30 or so years I have taught courses on dying and death. In that teaching, particularly in a graduate seminar for nurses and other caregivers, I began to incorporate additional material that reflected the changed reality of illness, dying, and death that has occurred since the 1969 publication of Kübler-Ross’s epochal *On Death and Dying*. My
classes began to consider issues related to the diagnosis of illness, including decisions about when to seek medical help or take diagnostic tests such as that for HIV. We also started to address issues associated with the problem of living with chronic illness.

In short, we began to look at the dying process in the larger context of life-threatening illness. We studied the writings of E. Mansell Pattison (1969, 1978) and Avery Weisman (1980), two pioneering clinical researchers who emphasized the idea that life-threatening illness is a long process, best viewed as a series of phases, each with its own unique issues and problems. This book owes a heavy debt to their insights as well as to the work of many writers, researchers, and clinicians who are mentioned in the references.

The references comprise all the sources I have found helpful while writing this book, but I wish to acknowledge my special debts to the classic work of Corr (1992), Kalish (1985), Moos (1977, 1984), Rando (1984), and Strauss (1975) among others, and the more recent insights of individuals such as Byock (1997, 2004) and Chochinov (2012).

Yet the field and the course I teach continue to change. In the 5 years since the publication of the first edition of this book, it seemed wise to do a second edition to incorporate new material that reflects advances in the care of persons with life-threatening illnesses.

One of the most significant changes involves the adoption of models of concurrent care. These models have significant implications for end-of-life care since they blur the sharp divide between treatment that is primarily palliative and treatment that seeks to cure or extend life. In addition, a number of newer therapies have been developed that seek to enhance meaning-making at life’s end. There are a number of other areas such as spirituality, pain management, anticipatory mourning, and caregiving that have benefitted from both research and enhanced theoretical development. Finally, the revised book includes expanded sections on counseling families both throughout the illness and as they grieve.

A second influence on this book was personal experience, specifically my father’s bout with cancer, which helped me to organize my own thoughts about the ways we look at life-threatening illness. It reminded me of the uncertainty we often face as we struggle with illness. Diagnosis can be an uncertain process, a roller coaster of good and bad news. Prognosis is rarely certain and time frames can only be expressed as probabilities. The struggle is draining, not just for the ill individuals, but also
for their families and caregivers. My father recovered, then lived a decade before having a second, terminal bout with the disease.

This work draws from a third critical source, the experiences and responses that so many people have shared with me throughout these past 40 years. While their names are not listed in any of the references, they too have taught me much about living with life-threatening illness.

Throughout my career I have resisted the term patient. I have always found the term patient to be inaccurate because it suggests that the ill individual is totally passive. For much of the struggle with life-threatening illness, individuals are rarely patients in the sense that they are spending much of their time in hospitals or physician’s offices. The root of the word patient actually means “someone being acted upon.” That idea, too, was objectionable, for I have always stressed that individuals respond best to life-threatening illness when they are participants in their own treatment.

One colleague, Claire Kowalski, who once struggled herself with life-threatening illness, liked to call herself a protagonist. Drawn from Greek drama, the term protagonist refers to the central character around which all action revolves. It is the protagonist who sets the pace and direction for the ensuing drama. I have often felt that her perception of her role was admirable. Her demand to be the pivotal character in her own life struggle was the key factor in her own survival. I hope we come to the time soon when all persons with life-threatening illness will define themselves as protagonists.

Given my strong negative feelings about the word patient, I tried to avoid its use as much as possible in this book, often using the term client as more suitable to counselors. At times, though, patient seems the best and clearest way to refer to individuals with an illness. Also, in certain contexts, such as a hospital, other terms such as person with illness, victim, or client seem awkward, unclear, artificial, and sometimes even stigmatizing.

I deliberately choose to use the term life-threatening illness rather than terms such as catastrophic illness, fatal illness, or terminal illness that seem to overemphasize the crisis nature of the illness. Though there are times of crisis, and a diagnosis can be truly catastrophic, the term catastrophic illness tends to underemphasize the reality that many people strive to maintain a normal life even when faced with impending death. For similar reasons, I avoid terms such as fatal or terminal, since these terms focus on the dying process. In this book, people are only referred to as dying
when they are in the final, terminal phase of life-threatening illness. In the terminal phase the illness has progressed to such a point that recovery or remission is highly improbable, health has declined, and death is likely to occur within a specific time frame. I also avoid the term currently in favor of life-limiting illness, since many people do recover from such illnesses and go on to lead normal lives. Not every life-threatening illness is life limiting.

As stated earlier, this work follows a long history of others who have contributed much to the care of persons with life-threatening illness. Chapter 2 reviews those that impacted history, placing this work in its context as well as highlighting newer developments such as concurrent care.

Chapters 3 and 4 address the particular ethical and systematic stresses that those persons who counsel or care for individuals with life-threatening illness may experience, causing moral distress. These chapters also recognize the special sense of loss that is part of that role as well as the critical skills and attributes needed of caregivers who are privileged to work with persons with life-threatening illness and their families. While emphasizing the importance of self-care at both individual and organizational levels, the chapters affirm a central paradoxical message of work in hospice and palliative care—few other jobs are as exhausting or as rewarding.

One of the central lessons that I have learned is that every experience of life-threatening illness is distinct, and individual responses are therefore very different. Chapter 5 explores and emphasizes that individuality. People respond to life-threatening illness in a variety of ways. A wise instructor once told me that she could predict the way I would die. When I asked, “How?” she answered, “The same way you respond to any life crisis.” Chapter 5, then, considers the range of responses to life-threatening illness that individuals, their families, and their caregivers may experience.

Responses to illness are affected by many factors. No two experiences of illness are alike. Each disease creates its own special issues and particular problems. Coping with a disease is not an isolated process, it is a part of the continuing process of life, influenced by all the developmental, psychological, and social factors that influence response to any life crisis. In addition, generational differences are a significant but often unrecognized factor that will affect the ways that an individual responds to life-threatening illness. These factors are described in Chapter 6.
Corr (1992) indicates that these challenges include physical ones (e.g., the physical challenges caused by disease and treatment); psychological ones (e.g., maintaining a sense of psychological comfort in the face of the disease); social ones (e.g., negotiating relationships and the roles changed by the fact of illness); and spiritual ones (e.g., finding meaning and value in the midst of illness). All dimensions of our lives are affected by an encounter with illness and death.

Chapters 7 through 11 describe particular issues that arise at different points during the experience of life-threatening illness. Underlying this book is a perspective or model that views life-threatening illness as a series of phases, each with its particular challenges or tasks (see Figure 1.1).

I use the term *task* since that word does not imply any order or sequence. Each task simply refers to a challenge posed by the illness, so that people might face a given task at different points in life-threatening illness. As Corr (1992) notes, the use of the term *task* also reinforces a personal sense of freedom in meeting each challenge. Just as any individual can decide on any day that he or she will choose to do or not to do particular chores, so too individuals struggling with life-threatening illness can also choose to confront or not to confront particular challenges or tasks presented by the illness. Moreover, the term *task* emphasizes individuality. Just as different individuals may do even the same chore in a somewhat unique manner, persons with life-threatening illness will find their own individual and idiosyncratic ways to complete their tasks. And as with any set of tasks, persons will vary in how quickly and competently they can tackle

![The Phases of Life-Threatening Illness](image_url)

*Figure 1.1 The phases of life-threatening illness.*
these tasks. These tasks in life-threatening illness can be outlined in the following ways:

A prediagnostic phase, discussed in Chapter 7, often precedes diagnosis. Here, someone recognizes symptoms or risk factors that make him or her prone to the illness. That person now needs to select strategies to cope with this threat. The tasks here include:

1. Recognizing possible danger or risk.
2. Coping with anxiety and uncertainty.
3. Developing and following through on a health-seeking strategy.

Chapter 8 considers the acute phase that centers on the crisis of diagnosis. At this point an individual is faced with a diagnosis of life-threatening illness and must make a series of decisions—medical, psychological, interpersonal, and so on—about how, at least initially, to cope with the crisis. Here the tasks include:

1. Understanding the disease
2. Examining and maximizing health and lifestyle
3. Maximizing one’s coping strengths and limiting weaknesses
4. Examining internal and external resources and liabilities
5. Developing strategies to deal with issues created by disease (disclosure, coping with professionals, treatment options, life contingencies)
6. Exploring the effect of illness on one’s sense of self and relationships with others
7. Ventilating feelings and fears
8. Integrating the present reality of the diagnosis with one’s past life and future plans

Chapter 9 describes the chronic phase. During this period the individual is struggling with the disease and its treatment. Many people in this phase may be attempting, with varying degrees of success, to live a reasonably normal life within the confines of the disease. In this phase, rehabilitation therapies may significantly enhance the quality of life and facilitate adjustment. In addition, this period is punctuated by a series of illness-related crises. Tasks in this phase (see Lubkin, 1986; Strauss, 1975) include:

1. Managing symptoms and side effects
2. Carrying out health regimens
3. Preventing and managing health crises
4. Managing stress and examining coping
5. Maximizing social support and minimizing social isolation
6. Normalizing life in the face of disease
7. Dealing with financial concerns
8. Preserving self-concept
9. Redefining relationships with others throughout the course of the disease
10. Ventilating feelings and fears
11. Finding meaning in suffering, chronicity, uncertainty, and decline

In many cases, people will not experience all of these phases. Sometimes in the acute or chronic phase, or even rarely in the terminal phase, a person may experience recovery. This recovery/remission phase is described in Chapter 10. Even here, however, people may have to cope with certain tasks such as:

1. Dealing with psychological, social, spiritual, and financial aftereffects of illness
2. Coping with fears and anxieties about recurrence
3. Examining life and lifestyle issues and reconstructing one’s life
4. Redefining relationships with caregivers

Chapter 11 reviews the terminal phase. This describes the situation in which the disease has progressed to a point where death is inevitable. It is no longer merely possible. Death has become the individual’s and family’s central crisis. Tasks (see Kalish, 1985; Rando, 1984) here include:

1. Dealing with symptoms, discomfort, pain, and incapacitation
2. Managing health and institutional procedures
3. Managing stress and examining coping
4. Dealing effectively with caregivers
5. Preparing for death and saying good-bye
6. Preserving self-concept
7. Preserving appropriate relationships with family and friends
8. Ventilating feelings and fears
9. Finding meaning in life and death
This chapter now includes a significant section on meaning-making strategies such as dignity-enhancement therapy, living eulogies, reminiscence and life-review therapies, and ethical or moral wills. In addition, this chapter contains a discussion of end-of-life phenomena such as near-death experiences, nearing death experiences, transpersonal end-of-life experiences, and premonitions as well as ways to assist patients and families in interpreting and responding to such phenomena. Finally, there is enhanced material on pain management incorporating both assessment and advocacy strategies.

To summarize, this model holds that in any experience with life-threatening illness one is faced with four major tasks:

1. Responding to physical facts of disease
2. Taking steps to cope with realities of disease
3. Preserving self-concept and relationships with others in the face of disease
4. Dealing with the affective and existential/spiritual issues created or reactivated by disease

At each phase of the illness, these basic tasks may raise different issues, concerns, and challenges (see Table 1.1). There is one additional advantage to the term task. It reminds counselors that they are facilitators—their role is not to do task work for clients but to assist clients as they assess and complete necessary tasks.

It is important to remember that while this model can be useful, at best it offers a general description of a complicated and highly individual process. Not every individual will experience the same situations and reactions I describe here. Nor will every life-threatening illness proceed methodically or precisely through these phases. In many cases an individual will seek medical treatment, fearing the worst, and happily find the symptom is minor and the condition itself easily treated. Even a diagnosis of life-threatening illness can result in successful surgeries or other interventions that minimize or eliminate any further risk. In many illnesses, such as multiple sclerosis, a chronic phase can last indefinitely, but other illnesses may decline into a terminal phase immediately following diagnosis.

There is another limitation to this model. We need to remember that life-threatening illness is only a part of life. Throughout the time of illness, at whatever phase, individuals continue to meet many needs and to
### Table 1.1 TASKS IN LIFE-THREATENING ILLNESS

<table>
<thead>
<tr>
<th>generic tasks</th>
<th>acute phase</th>
<th>chronic phase</th>
<th>terminal phase</th>
</tr>
</thead>
<tbody>
<tr>
<td>I. Responding to the physical fact of disease</td>
<td>1. Understanding the disease</td>
<td>1. Managing symptoms and side effects</td>
<td>1. Dealing with symptoms, discomfort, pain, and incapacitation</td>
</tr>
<tr>
<td>II. Taking steps to cope with the reality of disease</td>
<td>2. Examining and maximizing health and lifestyle</td>
<td>2. Carrying out health regimens</td>
<td>2. Managing health procedures and institutional procedures</td>
</tr>
<tr>
<td></td>
<td>5. Developing strategies to deal with issues created by disease (disclosure, coping with professionals, treatment options, life contingencies)</td>
<td>5. Maximizing social support and minimizing social isolation</td>
<td>5. Preparing for death and saying good-bye (if necessary)</td>
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<td></td>
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<td>9. Redefining relationships with others throughout the course of the disease</td>
<td>7. Preserving appropriate relationships with family and friends</td>
</tr>
<tr>
<td>IV. Dealing with affective and existential/spiritual issues created or reactivated by the disease</td>
<td>7. Ventilating feelings and fears</td>
<td>10. Ventilating feelings and fears</td>
<td>8. Ventilating feelings and fears</td>
</tr>
</tbody>
</table>
cope with all the issues and problems that they had prior to the diagnosis. Naturally clients’ prior experiences will influence both how they perceive their needs and how they respond to the issues and challenges posed by the illness. In short, these earlier needs and issues, however, continue throughout the illness. This model recognizes that all the previous challenges of life—dealing with family and friends, coping with work and finances, and keeping up with the demands of a home or apartment—remain an ongoing part of that larger struggle.

Life-threatening illness is inevitably a family illness, for the life of everyone within the family is changed when one member of a family experiences disease. Chapter 12 considers the ways in which families might be affected by the illness and offers suggestions for counseling families that are coping with the illness of a family member. Chapter 12 also applies this general discussion to the special needs of specific populations such as children, persons with developmental disabilities, and older persons, as well as those of different cultures. Since one of the major roles of the family involves caregiving, there is discussion of factors that affect caregiver stress and burden as well as suggestions of strategies to assess and to assist caregivers. Since the family is the unit of care, families need support in their grief should the patient die. This concluding chapter synthesizes current research and theory, offering a link to task theories of grief such as Worden’s Task Model (Worden, 2009).

A number of years ago, one of my students, soon after taking my Dying and Death course, found that her brother, with whom she was very close, had cancer. She nursed him, helped her parents, and struggled with her own emotions. One day she came to class to talk about her experiences in coping with his illness and subsequent death. Someone asked her if the course had helped. She answered, “It didn’t change my feelings or situations or the crises we faced. It did make them more understandable.” That really expresses the goal of this book: to make the struggle with life-threatening illness a little more understandable, and perhaps less lonely and frightening.