Counseling Individuals With Life-Threatening Illness

Kenneth J. Doka

With a Foreword by Robert A. Neimeyer
PRAISE FOR COUNSELING INDIVIDUALS WITH LIFE-THREATENING ILLNESS

“Counseling Individuals With Life-Threatening Illness helps clinicians to push the boundaries of the need for critical psychological support when facing anticipated losses. Full of useful advice about the tasks faced in response to the many phases of loss, Doka gives insight and experienced guidance in dealing with the painful reality most of us will face when confronted with the possibility that life will end.”

—Stephen R. Connor, PhD, Vice President for Research and International Development, National Hospice and Palliative Care Organization

“Every professional counselor and other caregiver who seeks to help individuals with life-threatening illness and their family members should buy this book and consult it regularly! I gained a great deal from my first reading of this text and I intend to return to it again and again for guidance and enriched understanding of the issues involved.”

—Charles A. Corr, PhD, CT, Member of the Board of Directors, The Hospice Institute of the Florida Suncoast, Clearwater, FL

“Where was this book when I was new as a counselor, and later when new as a life-threatened patient? Fortunately, it is here now, and with all the scope, depth, resourcefulness, and balance required for such situations.”

—Robert Kastenbaum, PhD, Professor Emeritus, Hugh Downs School of Human Communication, Arizona State University

“On the cutting edge, extraordinary in detail, peerless in comprehensiveness, and making other treatments of the topic look anemic, Counseling Individuals With Life-Threatening Illness is the consummate professional resource…. Grounded in the very best of thanatological theory, philosophy, and research acumen, and integrated with the most efficacious clinical practices, this book gives new dimensions of wisdom to those who seek to serve this population.”

—Therese A. Rando, PhD, BCETS, BCBT, Author of Grief, Dying, and Death: Clinical Interventions for Caregivers
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. Dr. Doka's books include Living with Grief: Children and Adolescents; Living with Grief: Before and After Death; Death, Dying and Bereavement: Major Themes in Health and Social Welfare (a four-volume edited work); Pain Management at the End-of-Life: Bridging the Gap between Knowledge and Practice; Living with Grief: Ethical Dilemmas at the End of Life; Living with Grief: Alzheimer’s Disease; Living with Grief: Coping with Public Tragedy; Men Don’t Cry, Women Do: Transcending Gender Stereotypes of Grief; Living with Grief: Loss in Later Life; Disenfranchised Grief: Recognizing Hidden Sorrow; Living with Life-Threatening Illness; Children Mourning, Mourning Children; Death and Spirituality; Living with Grief: After Sudden Loss; Living with Grief: When Illness Is Prolonged; Living with Grief: Who We Are, How We Grieve; Living with Grief: At Work, School and Worship; Living with Grief: Children, Adolescents and Loss; Caregiving and Loss: Family Needs, Professional Responses; AIDS, Fear and Society; Aging and Developmental Disabilities; 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: The Journal of Death and Dying and Journeys: A Newsletter for the Bereaved.

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 presented him with an award for Outstanding Contributions to Thanatology and Hospice. His alma mater, Concordia College, presented him with its 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 in 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 to businesses and educational and social service agencies. Dr. Doka is an ordained Lutheran minister.
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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, tread 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 a wrong 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 described and illustrated, 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 his 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, in contrast to this occasionally abstract disciplinary rhetoric, Doka’s gift as a storyteller consistently brings these principles to life, as in accounts of his counseling with a terminally ill 12-year-old who wants to grow up to be a lawyer; in his systemic intervention with dozens of members of the family and community to secure companionship and meals for a terminally ill older woman contending with the sudden death of her husband; or in Doka’s own father’s reinvention of his life after a brush with prostate cancer. 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. The result is a readable book that covers a surprising amount of ground without leaving the reader feeling winded from slogging through intransigent 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 *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 counsel to all counselors who strive to offer guidance and understanding to persons negotiating the challenging terrain of serious illness and loss.

Robert A. Neimeyer, PhD
University of Memphis
June 2008
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. Mansell Patterson 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 Shneidman, John Stephenson, Judith Stillion, Anselm Strauss, David Sudnow, Mary Vachon, and Hannelore Wass are all apparent in these pages. Charles Corr and Therese A. Rando have had a special role; not only did their ideas and thoughts influence me, but their constant encouragement sustained me. Donald Ford, a friend and physician, was always available to answer any technical or medical questions.

My many colleagues in the Association for Death and Counseling (ADEC) and the International Work Group on Death, Dying, and Bereavement (IWG) also provided constant support. Dana Cable, Terry Martin, Neil Hefflin-Wells, Lu Redmond, Sherry Schachter, and Jane Nichols, as well as Robert Neimeyer, Britt Hysing-Dahl, Isa Jaramillo, Robert Bendiksen, Margaret Stroebe, Henk Schut, Leslie Balmer, Ron Barrett, and Stephen Fleming, to name a few, provided, over many years, encouragement, helpful criticisms, and camaraderie.

My own college has been supportive in many ways. The gift of sabbatical time provided an extended opportunity for writing. More importantly, I will always appreciate the freedom and opportunity to develop professionally that I have had at The College of New Rochelle. I hope I can provide the same to my students. I would like
to acknowledge the support of President Steve Sweeney, Senior Vice Presidents Joan Bailey and Dorothy Escribano, Dean Guy Lometti, Associate Dean Marie Ribarich, and Wendi Vescio, Director of Human Services. I also should recognize the collegiality, stimulation, and support so freely offered by my colleagues and my students throughout the College.

This book would not have been possible without the secretarial and technical help so generously provided by Vera Mezzacuella. A research assistant, Mary Ryan Garcia, assisted with editing the earlier chapters. The Division’s Administrative Assistants—first Mary Whalen and presently Diane Lewis—keep everything else operating with cheery efficiency.

Throughout the last number of years, I have had the privilege of being a consultant to the Hospice Foundation of America. 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, Amy Tucci, Lisa Veglahn, Sophie Viteri Berman, William Lamers, Norman Sherman, and the staff, past and present.

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, Don and Carol Ford, Allen and Gail Greenstein, Jim and Mary Millar, Robert and Tracey Levy, Fred and Lisa Amore, and Chris and Dirotta Fields.

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, and my grandson Kenny and granddaughter Lucy make it all seem so worthwhile. My godson, Keith Whitehead, graduates college this year—offering again a sense of vicarious pride in his accomplishments. Other members of my intimate network of family and friends, including Kathy Dillon; my sister, Dorothy; my brother, Franky; and all of their families, as well as Eric Schwarz; Dylan Rieger; Larry
Laterza; Ellie Andersen; Jim, Karen, and Greg Cassa; Linda and Russell Tellier; Jill Boyer; Lynn Miller; James Rainbolt; Scott and Lisa Carlson; Tom and Lorraine Carlson; Matt Atkins; Kurt Mulligan; Ken and Elaine Gilmore; and Don and Lucille Matthews, provide nurturing, encouragement, respite, friendship, and most importantly, laughter.

In addition, I have to acknowledge the help, encouragement, and infinite patience of my editor, Sheri Sussman, and her staff at Springer. 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.
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 two-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 learns 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 a moment of crisis, a terrible trial, a frightening encounter 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, whether the result is recovery or death, any encounter with life-threatening illness 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, to be diagnosed with any of a number of “fatal” diseases was to receive 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. The experience of serious illness today is often 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: that 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 not only affects the individual with the illness but also affects the family. Hence care must be not only holistic but also 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 publication of Elisabeth Kübler-Ross’s *On Death and Dying* (1969). My classes began to consider issues related to the diagnosis of illness, such as decisions about when to seek medical help or take diagnostic tests such as the HIV test. We also started to address issues associated with the problem 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 lists 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).

Second, my father’s bout with cancer also 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, and then lived a decade later to have 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 thirty plus years. Although 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 physicians’ 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* seemed 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” seemed awkward, unclear, artificial, and sometimes even stigmatizing.

I deliberately choose to use the term *life-threatening illness* rather than terms *catastrophic illness, fatal illness, or terminal illness* that seemed 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 avoided terms such as *fatal* or *terminal*, since these terms focus on the dying process. In this book, people are referred to as *dying* only 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 avoided the term currently in favor, *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 have had an impact on history, placing this work in its context.

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: that 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. Nor is coping with a disease an isolated process; rather, 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. These factors are described in Chapter 6.

Corr (1992) indicates that these challenges include physical ones (for example, the physical challenges caused by disease and treatment); psychological ones (for example, maintaining a sense of psychological comfort in the face of the disease); social ones (for example, negotiating relationships and the roles changed by the fact of illness); and spiritual ones (for example, 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 challenges 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 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 their own 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 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 of an illness 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*, which 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 one’s 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. Often this period is punctuated by a series of illness-related crises. Tasks in this phase (see Lubkin, 1986; Strauss, 1985) 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 feeling and fears  
11. Finding meaning in suffering, chronicity, uncertainty, and decline  

In many cases people will not experience all of these phases. Moreover, 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. Death is no longer merely possible; now it is likely. Death has become the individual’s and family’s central crisis. Tasks (see Rando 1984; Kalish 1985) here include  

1. Dealing with symptoms, discomfort, pain, and incapacitation  
2. Managing health procedures 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

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

1. Responding to the physical fact of disease
2. Taking steps to cope with the reality 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 the 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 their 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 learn that 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, while with other illnesses decline into a terminal phase will immediately follow 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 cope with all the issues and problems that they had prior to the diagnosis. The experience may affect the person's perception of these needs and ways of coping with those issues, but the needs and issues themselves continue throughout the illness. While this model
### 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></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>I. Responding to the physical fact 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>
</tr>
<tr>
<td></td>
<td>7. Ventilating feelings and fears</td>
<td>7. Preserving appropriate relationships with family and friends</td>
<td>7. Preserving appropriate relationships with family and friends</td>
</tr>
<tr>
<td></td>
<td>8. Integrating the present reality of the diagnosis with one’s past life and future plans.</td>
<td>8. Ventilating feelings and fears</td>
<td>8. Ventilating feelings and fears</td>
</tr>
<tr>
<td>IV. Dealing with affective and existential/spiritual issues created or reactivated by the disease</td>
<td>10. Ventilating feelings and fears</td>
<td>11. Finding meaning in suffering, chronicity, uncertainty, and decline</td>
<td>11. Finding meaning in suffering, chronicity, uncertainty, and decline</td>
</tr>
</tbody>
</table>
emphasizes the experience of the illness itself, it is necessary to rec-
ognize that, for the person living with life-threatening illness, all the
previous challenges of life—dealing with family and friends, coping
with work and finances, even 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, because the
life of everyone within the family is changed when one member of a
family experiences disease. Chapter 12 considers the way in which
families might be affected by the illness. It also offers suggestions
for counseling families to cope with the illness of a family member.
Chapter 12 also applies this general discussion to the special needs of
specific populations such as children, the developmentally disabled,
and older persons, as well as those of different cultures.

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 subse-
quent death. Someone asked her whether the course had helped.
She answered, “It didn’t change my feelings or situations and cri-
eses we faced. It did make them more understandable.” That really
expressed the goal of this book: to make the struggle with life-
threatening illness a little more understandable and perhaps less
lonely and frightening.

REFERENCES