THE PSYCHOLOGICAL AND SPIRITUAL CHALLENGES INHERENT IN DYING WELL

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The individual dying in an ancient or pre-industrial culture is equipped with a religious or philosophical system that transcends death, and is likely to have had considerable experiential training in altered states of consciousness, including symbolic confrontations with death. The approach of death is faced in the nourishing context of the extended family, clan, or tribe, and with its support—sometimes even with specific and expert guidance through the successive stages of dying. . . . The situation of an average Westerner facing death is in sharp contrast to the above in every respect.

—Stanislav and Christina Grof
Beyond Death

When death approaches, the health care professional is—ready or not—often the default manager of complex psychological, interpersonal, and spiritual challenges. As the Grofs suggest above, however, our culture has not been particularly adept in cultivating the high art of supporting a person through life’s final passage. And, as a product of that culture, the attending professional often lacks the perspective and training for ministering to the opportunities and completing the tasks that beckon at the close of a life. The opportunities are significant, often casting into new light the life that has been lived.

This chapter offers health care professionals, as well as anyone confronted with these challenges, perspectives and techniques for navigating their way through end-of-life issues in a manner that completes what needs to be completed; seizes the profound and precious opportunities that inevitably present themselves; and meets fear, pain, and uncertainty with love and acceptance. A series of structured exercises throughout the chapter may be used by the professional or the client for exploring various issues involved in coming to a “good death.” “A good death,” counseled the fourteenth-century founder of humanism, Francesco Petrarca, “does honor to a whole life” (cited in Grooves & Klauser, 2005, p. 13).

Many cultures have “books of the dead”—texts that teach about the journey into the afterlife and how to assist another with the process of dying. Scholars find these to be amongst the most profound spiritual literature generated by the culture. Based on a survey of these texts, Grooves and Klauser (2005) provide a summary of the principles that show up consistently. “The
common ground of our collective human experience at the end of life” (pp. 35-36) includes, in their analysis, that:

1. The passage through the stages of dying can be enriched profoundly by ordinary people trained to assist in this process.
2. Certain universal patterns or stages in the life-to-death transition process are predictable.
3. There is a clear relationship between physical and spiritual pain.
4. It is necessary to accurately assess spiritual pain before it is likely to be responded to effectively.
5. A “good death” involves maintaining a sense of clear knowing or consciousness at the end of life.
6. Some form of consciousness survives the death of the physical body.
7. The way one lives sets the stage for the way one will die.

This seventh principle underlies a core observation about life and death found in a myriad of cultures: “The sacred art of dying is the sacred art of living” (cited in Groves & Klauser, 2005, p. 16). These words (Ars sacra moriendi, ars sacra vivendi) have been inscribed in the rafters of one of the oldest standing hospices, in the medieval town of Beaune in southeastern France, for more than 500 years. Built with a glass floor over a river so patients and caregivers were continually serenaded with the soothing sound of water, the building is a stunning relic from Europe’s original hospice movement. Its founder, Nicholas of Rolin, believed “the only measure of a society’s greatness depends on how it cares for the poorest of its poor at the end of life” (Groves & Klauser, 2005, p. 14). The European hospice movement has its roots in ancient Celtic practices for relieving both physical and spiritual pain at the end of a person’s life, which were exported throughout the Mediterranean world between the ninth and eleventh centuries A.D. The Celtic “midwife to the dying” was called the anamcara (soul friend) who used “harp music and special prescriptive poetry together with a wide range of complementary healing modalities . . . addressing everything from regulating a person’s breath and diet to the content of their dreams” (Groves & Klauser, 2005, p. 24).

Every culture and every era of human history has had its own beliefs, customs, and rituals regarding death. Because our culture tends to regard death as a failure of the medical system and a defeat in our quest to dominate nature, we often approach death with greater fear and apprehension than many other societies. But no society has trumped death’s unequivocal power over human preferences and fears. Nor has any society fully understood death. “Death,” as Hamlet famously ruminated, is that “undiscovered country from whose bourn no traveler returns,” leaving us to our own speculations about a Larger Story—about, in fact, the spiritual foundations of our existence. Neither science nor medicine has been able to penetrate the mysteries shrouded in the miracle of a human birth or the journey back into the unknown. Yet no questions are more fundamental.
Your Personal Philosophy of Death

What beliefs and assumptions do you hold about death? The topics in this chapter contain vital questions worthy of deep reflection. You can delve more fully and personally into these topics by simply journaling about your underlying thoughts, images, and intuitions—exploring key assumptions, feelings, and beliefs in each area. Journaling instructions will be provided from time to time, for you to at least mentally consider specific questions and, if you wish, to deepen your inquiries with stream-of-consciousness writing. To experiment here, place the heading "My Philosophy of Death" on the top of a page of a journal, notebook, or word processing file. You will be recording your stream-of-consciousness as you reflect upon your beliefs, attitudes, and feelings regarding death. Place the following under the heading, where you can glance at it easily. Begin to ponder the question:

• What is death?

Then, for 10 uninterrupted minutes (it is best to set an alarm clock or timer so you don’t even need to look at the clock), write non-stop in your journal or computer, producing an uncensored flow of thoughts and feelings.

In stream-of-consciousness journaling (also sometimes called “automatic writing” because the conscious mind lets go and more intuitive levels of the mind are freed to express themselves), the only rule is that you never stop writing during the suggested time period. You can write gibberish or “I don’t know what to write,” but you keep writing. After you have completed this process with the question “What is death?” you might read what you have written and underline or highlight or summarize in another section of your journal the points that are most meaningful to you. An alternative approach is to speak, for at least 10 minutes, your stream-of-consciousness regarding these questions to another person or into a tape recorder, and then to summarize your thoughts and feelings in your journal.

If you wish, you may take this further with additional questions, still under the heading of “My Philosophy of Death.” Consider the following, or devise questions you would prefer to explore. The list is provided solely to stimulate your thoughts, feelings, and philosophy about death.

• Why do people die?
• How do I feel about my own death?
• What happens after a person dies?

The Consequences of What We Believe

Surveys consistently show that more than 70 percent of Americans believe in some form of afterlife. Such beliefs and visions have consequences. They shape a person’s core values and many of the key choices people make. If life is a series of tests through which you earn your way into Everlasting Peace, you had better find out what your spiritual mentors have to say about
how to pass those tests. If life is a school in which the soul evolves, from one life time to the next, as many Eastern religions teach, the person is prompted to learn well the lessons life presents. If death is the final curtain, the end of the story, all meaning and purpose must be found during this lifetime.

Death not only provides the context for life, it holds at least three fundamental challenges, beyond facing the moment of our own death, that each of us must confront during our lifetimes. First, what do we do with the fact that we are the only creatures on the planet that possess an ability to reflect upon our ultimate demise? Live in denial? In fear? In rage? Find comfort in some spiritual framework? Second, each of us will probably be called upon to be present in the dying process of someone we love, and there are many ways to answer that call. And, third, each of us will almost inevitably carry the grief of losing a loved one. While science and scientific psychology have much to say in each of these areas, some of the issues regarding death extend, by their nature, beyond the reach of science. This chapter explores how to confront these three deep challenges in ways that are informed by science, psychology, and clinical experience from those who work with death and dying, as well as by your own personal spiritual perspective.

A Life Enriched by the Inevitability of Death

“The dark background which death supplies brings out the tender colors of life in all their purity.”

—George Santayana

Robert Jay Lifton, a psychiatrist and pioneer in bringing a psychological perspective to the study of history, believes “the quest for symbolic immortality is an aspect of being human” (1983, p. 35). Symbolic immortality refers to the biological, psychological, social, and spiritual strategies people use to transcend the reality of death. Whether you take great comfort in knowing you will spend eternity in Heaven (or hold another idyllic vision of an afterlife), whether you expect to one day return to Earth in another body, or whether you are quite certain that there is no afterlife, the quest for symbolic immortality is a motivating force in most people’s lives. While death “does indeed bring about biological and psychic annihilation,” Lifton observes that human “life includes symbolic perceptions of connections that precede and outlast that annihilation” (p. 18).

Lifton describes five modes for attempting to transcend death by achieving symbolic immortality. The first is biological immortality, epitomized by family continuity and imagery of an endless biological chain linked to one’s sons and daughters, their offspring, and on and on into eternity. A second mode for attaining symbolic immortality is through one’s creative contributions, which may live on “through great works of art, literature, or science, or through more humble influences on people around us” (p. 21). Here we take comfort in the knowledge that our best efforts may become part of human continuity. A third mode of symbolic immortality involves an identity with nature, a knowledge that the natural world will survive our physical demise, and that we, from dust to dust, will be returned to that natural world.
A fourth mode of transcending death involves a belief in "a specific concept of life after death, not only as a form of 'survival,' but even as a release from the profane burdens of life into a higher plane of existence" (Lifton, 1983, p. 20). Lifton believes that the common thread in all great religions is the spiritual quest and realization of the hero-founder that enables him to confront and transcend death and to provide a model for generations of believers to do the same. . . . One is offered the opportunity to be reborn into a timeless realm of ultimate, death-transcending truths. (p. 20)

Lifton's fifth mode, "experiential transcendence," is based on an inner experience that is "so intense and all-encompassing that space and time disappear [and there is] a sense of extraordinary psychic unity, and perceptual intensity, and of ineffable illumination and insight" (pp. 24–25). In his classic, The Varieties of Religious Experience, William James examined the impact of such experiences and reported that "mystical states of a well-pronounced and emphatic sort are usually authoritative over those who have them. . . . Mystical experiences are as direct perceptions of fact for those who have them as any sensations ever were for us" (James, 1902/1961, p. 332).

Write as a second major heading in your journal “My Experiences with ‘Symbolic Immortality.’” Write five subheadings corresponding with Lifton’s list and record your thoughts and feelings about your relationship to each:

1. Do you have sons or daughters who will carry your biological inheritance from your parents into the future?
2. What will live on in the world in terms of your accomplishments or influence on others?
3. In what ways are you able to take comfort in your connection with the natural world and your knowledge that the natural world will continue after your physical being has reunited with it?
4. What beliefs or concepts, religious or otherwise, do you hold that give comfort or meaning regarding death and what follows death?
5. Have you had experiences that suddenly elevated your understanding and acceptance regarding your limited time here on Earth?

After reflecting on these five questions, consider another uninterrupted 10-minute stream-of-consciousness session on the core question regarding symbolic immortality:

• What gives me peace regarding my eventual inevitable death?

Again, it is best to use a timer or alarm clock so you don’t need to keep checking the time, and the only rule is still that you do not stop writing for the entire 10 minutes. When you have completed your stream-of-consciousness writing, go back and underline, highlight, or summarize the most meaningful ideas.
Embracing the Preciousness of the Moment

Elisabeth Kübler-Ross, the physician who in the 1970s did much to dignify death as a topic for public and professional discourse, said the central message she hoped to convey is that death does not have to be feared as a catastrophic, destructive force; that it can, in fact, “be viewed as one of the most constructive, positive, and creative elements of culture and life” (Kübler-Ross, 1975, p. 2). This is not how most Westerners are raised. Even if we accept a vision of an afterlife based on religious or other teachings, more fundamental in our psyches is our culture’s scientific/materialistic world-view, which does not provide a framework for understanding death in any terms but annihilation (Templer, 1972).

One of life’s ironies, however, is that people who have a close encounter with death often begin to participate more fully in living. A shift in attention occurs as the preciousness of each moment is recognized and savored. Often the change is no less than a spiritual transformation. There is both an opening to one’s deeper nature and to qualities of existence that transcend one’s individual identity. Regardless of whether traditional religious concepts are used to explain the experience, a deepened sense of purpose and a more profound sense of connection with other people and with the universe are often reported. Higher passions are stimulated; love, beauty, truth, and justice are savored anew.

Two years after a near-fatal heart attack, Abraham Maslow, one of the twentieth century’s most innovative psychologists, spoke of the intervening period as "the postmortem life" (Hoffman, 1988, p. 325). Reflecting on how these years were a kind of bonus, an extra gift, he noted that

if you're reconciled with death or even if you are pretty well assured that you will have a good death, a dignified one, then every single moment of every single day is transformed because the pervasive undercurrent -- the fear of death—is removed.

In the postmortem life:

Everything gets doubly precious, gets piercingly important. You get stabbed by things, by flowers and by babies and by beautiful things -- just the very act of living, of walking and breathing and eating and having friends and chatting. Everything seems to look more beautiful rather than less, and one gets the much-intensified sense of miracles. . . . The confrontation with death -- and the reprieve from it -- makes everything look so precious, so sacred, so beautiful that I feel more strongly than ever the impulse to love it, to embrace it, and to let myself be overwhelmed by it. (p. 325)

Those who have seen someone come into such peace and enhanced perception after a near-death encounter may wonder why we must wait until the final season to attain such grace. Perhaps we do not.

We will be exploring ways of intentionally shifting consciousness to find natural sources of inner wisdom and grace, but we can also do things that add meaning and richness to our lives. In your journal, write a heading:
• “If Today Were My Last Day.”

With 10 minutes of uninterrupted stream-of-consciousness writing, unleash your pen or keyboard to find out what you would do if you knew you were to die tomorrow. Often, people identify actions that could immediately enhance their lives but that they don’t seem to get around to doing. Circle the actions you commit to carrying out this week.

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**Shifting Consciousness, Shifting Perspectives**

People in every culture throughout time have sought altered states of consciousness. Technologies for inducing these states range from religious rituals to ecstatic drumming, from meditative states to trance dances, from shamanic journeys to elaborate rites of passage, from rhythmic chants to the ingestion of sacred plants. These interventions change brain chemistry in highly specific ways (Austin, 1999). They tend to open what William Blake called the “doors of perception,” sometimes sensory perception, sometimes the perception of inner realities (Huxley, 1970). People often emerge from powerful altered states with their perceptions expanded regarding life, nature, and their place in it all. “If the doors of perception were cleansed, every thing would appear,” according to Blake, “as it is, infinite.” From this expanded perspective, the terror of impending death often dissolves into peaceful acceptance.

Although major shifts of consciousness can be induced, they can also be spontaneous. Known variously as religious experiences, mystical experiences, peak experiences, and ecstatic states, people who go deeply into these states often return with a richer understanding about their life. Some of these experiences also have a direct and lasting influence on their relationship to death. Near death experiences (NDEs) are particularly powerful in this regard. Best known for the “white light” and “life review” that are widely reported, these are often profound, ecstatic, life-changing events.

Like many men born in the first quarter of the 20th century, Fred was a stern, hard working husband and father. Having grown up desperate for work in the rural South during the Depression, he treated life as serious business. He believed "you get what you earn and you earn what you get. It is best not to be too positive lest you set up expectations that will result in disappointment." For Fred, there was little room for emotion because "feelings keep you from what is important and make you look weak." Unlike many of his peers, he had no use for religion. He was bitter about his early church experiences, and he found no assurance in promises of an afterlife.

At age 55, Fred had a heart attack and was hospitalized. In the hospital, he had another massive coronary. His vital signs indicated that he was clinically dead, but he was revived. Fred had never heard of strange or poignant "near-death" experiences, and he was about the last person on the planet likely to invent one. Yet he reported:

“First I was up near the ceiling and I could see the medical team trying to resuscitate me. I heard a doctor say, ‘He's had it!’ I yelled back, ‘Whatever it is, I
don't want it!' but nobody heard me. Suddenly, I was walking over a bridge with a dry wash underneath. On the other side was an open green field. Walking to greet me was Bart [a childhood friend who had died in his early twenties]. I was overjoyed to see Bart. He greeted me warmly and told me to observe everything. But he said that I had to go back. ‘Why?’ I asked. ‘Because you haven't learned a damned thing, Fred. You haven't learned how to love.’"

As Fred became aware of being back in the hospital room, he opened his eyes and met the gaze of a shocked nurse who was putting a sheet over his head. The words "I love you" came out of his mouth. He said "I love you" to each nurse and doctor from the resuscitation team, who were still in the room. One doctor, according to family legend, uncomfortably replied, "That really isn't necessary." His family was amazed. His daughter explained that Fred did not find it easy to say "I love you" to anyone. He would sometimes walk out of the room with a disgusted look on his face when a song on the radio or a program on television got "too mushy."

For the remaining 16 years of Fred's life, he seemed to be making up for lost time—cultivating an ability to listen, taking an intense interest in the lives of others, traveling extensively to various parts of the world to try to understand people from different cultures, making amends for the past with his intimates, and enjoying the company of his grandchildren. At his memorial service, the theme most dwelt upon was the loving spirit Fred brought into his life. (Feinstein & Krippner, 2006, pp. 11-12)

Is this an isolated case? A study published in Lancet of 344 cardiac patients who were resuscitated after clinical death showed that 18 percent reported having had NDEs (von Lommel, van Wees, Meyers, & Elfferich, 2001), and thousands of people have been systematically interviewed following such experiences (Moody, 2001). They report—and observations from friends and family confirm—changes in their values, their behavior, and sometimes their personalities. Kenneth Ring, who has been one of the most ardent researchers of this surprising finding, summarizes that, after returning from a near-death experience, “individuals tend to show greater appreciation for life and more concern and love for their fellow humans while their interest in personal status and material possessions wanes. Most NDErs also state that they live afterward with a heightened sense of spiritual purpose and . . . these self-reports tend to be corroborated by others in a position to observe the behaviors of NDErs” (Ring, 1985, p. 141). In addition to these radical changes in a person’s values, in some cases, the NDE is followed by the individual making radical life changes, as if the person has “come into a new and more authentic sense of self” and is able to develop newly appreciated potentials, sometimes to an “astonishing degree” (p. 120).

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**Inner Journeys**

In addition to spontaneous experiences such as NDEs, profound inner experiences that impact one’s personality, values, and behavior can be generated with specific interventions.
Work with cancer patients at the Chicago Medical School in the early 1960s, using LSD to help control pain, led to the unexpected finding that the treatment also resulted in a range of psychological benefits. A series of clinical trials at the Maryland Psychiatric Research Center confirmed these observations (Grof, 2006) and was apparently leading to new dimensions in end-of-life care until the political climate put an end to such exploration. In one extreme, dramatic, eminently humane program, 31 terminal cancer patients who were experiencing substantial physical and psychological suffering were administered a single session using LSD (Grof, Goodman, Richards, & Kurland, 1973). Twenty-two of the patients showed substantial to dramatic improvements in the alleviation of various emotional symptoms, including depression, anxiety, general tension, sleep disturbances, and psychological withdrawal; a pronounced reduction of physical pain in the weeks or months following the session; and a marked increase in the sense of peace about dying. No significant adverse reactions resulted from the treatment, including in the nine patients who did not show substantial improvement.

Are there pathways to such experience that do not wait for them to occur spontaneously, as in NDEs, and that do not utilize drugs? There are. Stanislav Grof, for instance, one of the investigators in the study just described, surveyed the ways altered states have been induced throughout history. With his wife, Christina, he developed a non-drug approach, called holotropic breathwork, which utilizes sustained dynamic breathing for evoking powerful internal experiences in a manner that impacts one’s sense of self. He claims, in fact, that this method yields positive psychological changes that are similar in scope and impact to those produced by his earlier use of LSD-assisted therapy (Grof, 1990), including the “ego deaths” that lead to self-transcendence. In many cultural traditions, experiences that bring an experiential death to one’s ego and identity are seen as preparation and training for dying well.

The embrace by modern psychotherapy of ancient meditation practices (Walsh & Shapiro, 2006) should be of interest to anyone concerned with issues involving healthy living and conscious dying. Meditation has been shown to cultivate positive emotions such as love, joy, and a sense of peace. It helps reduce problematic emotions such as anxiety, fear, depression, and anger. It measurably strengthens desirable personality traits such as emotional stability, agreeableness, and openness to experience. It improves relationships. Meditators score higher on measures of empathy, interpersonal functioning, and marital satisfaction. Meditation also seems to enhance overall maturation, with meditators scoring higher on measures of ego development, moral development, cognitive development, coping skills, and stage of consciousness (Walsh & Shapiro, 2006).

The practice of meditation seems to produce some outcomes that are similar to those of a spontaneous near-death experience. In a way, meditation training offers practice in dying. One of the phenomena associated with meditation is a “death of the ego” and an awakening into a larger sense of self. According to Ken Wilber,

If one progresses fairly well in any meditation system, one eventually comes to a point of having so exhaustively ‘witnessed’ the mind and body that one actually rises above or transcends the mind and body, thus ‘dying’ to them, and to the ego.” (Wilber, 1990, p. 188)

This ego death may be frightening, but what ultimately dies is the sense of being a separate self, and what is born is a higher identity, an experiential identification with the larger forces of nature and of creation. The death of the ego may seem a far cry from physical death,
but it is a death that people nonetheless struggle valiantly in their busy outward-directed lives to avoid. Some meditators, however, open themselves to the interior death and rebirth inherent in an ego death. Certain forms of meditation, in fact, serve as an active rehearsal of death. These practices, Wilber elaborates, “contain very precise meditations that mimic or induce the various stages of the dying process very closely—including stopping the breath, the body becoming cold, the heart slowing” (p. 189). Kenneth Kramer (1988), in an examination of “the three faces of death” (biological, psychological, and spiritual) in both Western and Eastern spiritual traditions, observed that practices that result in a spiritual death lead to “self-transcendence,” where awareness moves beyond the “prior confines of the self” (p. 24).

Is it necessary to go to these extremes—to seek faux death encounters—in order to live more fully and in a right relationship with death’s inevitable call? Meditation, the time-honored approach for transforming consciousness and cultivating a more wholesome relationship with life and death, can be done in many ways and many places. It is available to everyone. And it is free. Some forms of meditation involve focused concentration on an object, on the breath, or on an inner sound. Others cultivate a more open awareness, aiming for “fluid attention to multiple or successively chosen objects” (Walsh & Shapiro, 2006, p. 229). Some forms of meditation simply observe the thoughts and images that arise while others attempt to modify them. Some practices seek to develop general well-being and consciousness expansion while others “focus primarily on developing specific mental qualities, such as concentration, love, or wisdom” (p. 229). Some forms require that the meditator maintain a rigid posture, others are more lax; some involve stretching, and there are even eyes-open “walking meditations.”

Meditation may focus on the body, the breath, a sound, an image, or on products of the mind. Some cultures and spiritual disciplines place meditation in about the same relationship to the mind as bathing is to the body. Western culture has not, but as Western psychotherapy is discovering the value and power of meditation for overcoming psychological problems and enhancing mental health, meditation practice is being elevated from a quaint New Age pastime to a viable form of personal development. It is a technology for following the teachings of many wisdom traditions for the person who is in the last stages of dying: “simply, rest in the power of the present” (Groves & Klauser, 2005, p. 27).

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**Dedicated Time and Sacred Space**

Dedicated time and sacred space are terms borrowed from Peg Elliott Mayo, the author’s first clinical supervisor circa 1968: they are a way of taking a pause from one’s daily routines and responsibilities to engage in quiet, uplifting experiences. Setting aside dedicated time in sacred space is a way to attain, in Peg’s words, “relief from ordinariness.” The term *dedicated time* emphasizes that this is a choice. We have the option of devoting committed time and attention to knowing, enjoying, and cultivating our inner life. *Sacred space* supports us in the process. It need not be an elaborate temple or altar. A woman who lived in a tiny apartment with her husband and three young sons claimed a dresser drawer and put into it things she treasured and that had strong positive associations for her (drawings she had made in her late teens of her mother and her father, photos of her sons in infancy and at various stages since, a seashell from her honeymoon, a few favorite poems, Gibran’s *The Prophet*, a candle, and a walkman with
spirited CDs). After the boys were in bed and her husband was watching sports on TV, she regularly took the drawer from the dresser, set it on a table, spread the contents, lit the candle, put on the headphones, and browsed the treasures or went within. She looked forward to these make-shift ceremonies, which took her outside her ordinary routines, refreshed her, and provided a route to simple contemplative reveries.

Whether journaling, meditating, engaging in breath work, reveling in nature, creating art, performing personal spiritual rituals, conducting dresser-drawer ceremonies, or doing other forms of inner work, activities that bring us to the edge of our ordinary consciousness and daily routines enhance our appreciation of life. Peg recommends finding or creating a sacred space that you want to enter and visiting regularly. In a new area of your journal, place the heading:

- “Dedicated Time, Sacred Space”

and write for 10 uninterrupted stream-of-consciousness minutes. When finished, go back and underline, highlight, or summarize the most meaningful ideas.

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**Helping a Loved One Pass through the Final Gateway**

There is no greater gift of charity you can give than helping a person to die well.

—Sogyal Rinpoche

_The Tibetan Book of Living and Dying_

The social context of dying with an incurable disease in the United States today not only fails to support the psychological tasks and spiritual opportunities that arise at the end of a life, it breeds unnecessary suffering in the patient and the patient’s family (Byock, 1997). Health care providers have rarely had more than a few hours of coursework in caring for persons as they die. Realistic fears hover about untreated pain, abandonment, loss of dignity, and financial hardship. Physical comfort, psychological needs, and quality of life are secondary to aggressive medical strategies involving “ever more toxic regimens and all-out efforts to forestall death” (Byock, 1997, p. 243). Attention stays focused on heroically prolonging life even after circumstances dictate a shift to the challenges of providing effective, enlightened end-of-life care. Meanwhile, the attendant costs are increasingly placed on the patient’s family. Nearly a third of families caring for a loved one with a prolonged illness lose most or all of their savings. Tragically, a dying father who feels that he is a drain on his family, physically and financially, will experience being a burden every moment of every day; that will be what his life has come to mean. Though his wife and children may affectionately acknowledge his years of love and selfless devotion, he will fret, feel worthless, and suffer. (Byock, 1997, p. 242)

Ira Byock, a physician and former president of the American Academy of Hospice and Palliative Medicine, after vividly describing the untenable situations faced by many people who are dying, observes:

The root cause underlying the mistreatment and needless misery of the dying is that America has no positive vision and no sense of direction with regard to life’s
end. Without a position on the compass pointing the way, the health care profession’s and society’s approach to care for the dying has been confused, inconsistent, and frequently ill-considered (1997, 244)

Byock calls for communities to, as in earlier times, assume coordinated responsibility to see that the physical, social, and spiritual needs of dying persons are met.

Of the fundamental needs of persons as they die, only the need to control physical symptoms is uniquely medical. Their more basic needs are broader than the scope of medicine . . . In recognizing these needs, we can say to the dying person with our words and, more importantly with our actions: “We will keep you warm and we will keep you dry. We will keep you clean. We will help you with elimination, with your bowels and your bladder function. We will always offer you food and fluid. We will be with you. We will bear witness to your pain and your sorrows, your disappointment and your triumphs; we will listen to the stories of your life and will remember the story of your passing. (Byock, 1997, p. 247)

The physical, legal, and medical needs involved in caring for a person who is dying have been identified, studied, and ably described (Tobin, 1998). Effective protocols exist even for the most overwhelming physical pain and distress.

Pain and other symptoms causing physical distress can be alleviated, even when they are severe. It is not always easy, but by being careful and comprehensive, and by being absolutely committed to do whatever is necessary to control physical distress, it can always be done. (Byock, 1997, p. 245)

Less tangible or predictable are the unique psychological, interpersonal, and spiritual needs that emerge during the final phase of life.

Maggie Callanan and Patricia Kelley are hospice nurses who, after many years of working with people who are dying, identified the recurring themes in the communications that are of special significance during the final phase of life. They observe that these communications fall into two categories: “attempts to describe what someone is experiencing while dying and requests for something that a person needs for a peaceful death” (Callanan & Kelley, 1997, p. 14). Accurately discerning such messages can be the difference between knowing or not knowing how to alleviate anxiety and suffering, how to provide the most effective care at any moment, how to elevate good intentions into empathy and rapport, and how to join the dying person on a journey that reviews a life that is ending, completes what is emotionally unfinished, and moves peacefully into the unfamiliar and unknown.

While it is almost too obvious to say that communication is important, a depth and quality of listening may be required that goes far beyond normal discourse. Callanan and Kelley (1997) observe that many dying people are lonely, not only because people don’t visit, but also because of what happens when people do visit. Visitors may spend their time with
the person wrapped up in idle talk about the weather, sports, or politics. . . . A
dying person’s world shrinks, narrowing to a few important relationships and the
progress of [the] illness. When dying people aren’t allowed to talk about what’s
happening to them, they become lonely, even amid loving concerned people.” (p.
59)

People who are dying often have experiences unlike any they have ever previously
encountered, and they may not have the language, or even the concepts, for communicating
about them. Caregivers frequently discount the attempts to express these unfamiliar experiences
as stemming from confusion, physical deterioration, or medication, missing the nuance and
symbolic language being presented. Callanan and Kelley (1997) observe that “bewilderment or
disorientation may stem from the unfamiliar, unexpected experiences of dying [and] too often,
the responses of those caring for dying people only add to that bewilderment” (p. 17). Yet a
dying person’s attempts to describe uncommon phenomena “offer unique opportunities to enter
that landscape, to participate by responding to their needs and wishes, and to learn what death is
like for them—and, perhaps, what it will be like for us” (p. 16).

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**Territory Dying People Are Likely To Encounter**

Researchers have noted remarkable similarities of deathbed visions in radically different
cultures (Osis & Haraldsson, 1977). Dying people often have the sense of being two places at
once: in the room and in another realm. They may have glimpses or lucid visions of another
world with deceased relatives waiting to greet them, of spiritual beings, or of religious figures.
These may include precise communications about “the other side” that bring feelings of peace
and understanding. In fact, most of the elements associated with “near-death experiences”—such
as seeing a bright light, sensing the presence of a greater intelligence, visits with loved ones who
have died, or experiencing a life review that brings profound insight and meaning—are
frequently reported during the last days of life. People who have such encounters may not,
however, have the words to describe them, and if the caregiver lacks a framework for making
sense of the attempts, they may easily be missed or dismissed. The dying person’s most
subjectively meaningful experiences may become a source of isolation.

Beyond the need of the dying person to speak about unexpected experiences that may
emerge as a natural part of the dying process, Callanan and Kelley’s second category of
communication involves requests about the dying person’s emerging sense of what needs to be
completed before a peaceful death can occur. This may include a desire to reconcile personal
relationships or to remove other barriers to achieving peace. Because this is delicate,
emotionally-laden psychological terrain, these requests may be vague or indirect and, again, they
may easily be missed or ignored if the caregiver is not alert.

The five stages of dying elaborated by Elisabeth Kübler-Ross (1995) provide a map for
some of the psychological territory a dying person will traverse. Although clinical experience has
shown that dying people do not necessarily experience each phase or progress through the phases
in an orderly sequence—and may in fact shift back and forth among these phases (Callanan &
Kelley, 1997)—familiarity with Kübler-Ross’s observations about denial, anger, bargaining,
depression, and acceptance helps prepare the caregiver for understanding the deeper dynamics of a dying person’s experience.

Denial, a refusal to accept reality, is sometimes a healthy coping mechanism that gives people time to integrate difficult news. The fine line for the caregiver is that, while it is not useful or appropriate to try to dismantle a coping mechanism such as denial, neither is it helpful to encourage a refusal to face reality or enter into a conspiracy of denial where the patient, the family, and the caregivers all pretend a terminal patient is going to recover. Callanan and Kelley (1997) discuss this dilemma:

If you should neither challenge nor encourage denial, what should you do? You should recognize the wish or desire behind it. When your dying friend talks about getting better and going camping again, you could say, “Wouldn’t that be fun!” or “I bet you’d like that!” These responses acknowledge your friend’s hopes and wishes without reinforcing denial. (p. 40)

Most dying people move beyond denial about their medical situation. Some do not. Gentle exploration and unfaltering support rather than a direct assault on any coping mechanism is part of the challenge facing the caregiver.

Anger is generally oriented toward a real or supposed grievance. When people realize that an illness that seems arbitrary and unfair is probably going to take their lives, anger is one of the strong emotions likely to follow. The anger may be at God, at society and its carcinogens, at others who get to go on living oblivious to the dying person’s suffering, at the medical system and caregivers that are treating the patient, or at other parts of the patient’s physical and interpersonal surroundings. Wherever it may be focused, it is in the safety of the patient’s closest relationships that the anger is most likely to be expressed, and often the vehemence is directed toward family, friends, or caring professionals. At such times it is difficult to avoid feeling hurt or defensive. The least useful responses are to attempt to talk the patient out of the anger or to strike back with your own unprocessed anger. Rather, Callanan and Kelley (1997) suggest: “Look for the cause. Think of anger as a feeling that develops from another emotion. In people who are terminally ill, the roots of anger often are frustration, resentment, or fear” (p. 42). Add loss, helplessness, humiliation, and the inability to care for one’s most basic needs.

When these emotions can be raised and explored within the container of a caring and knowledgeable relationship, the energy bound in anger can be directed to addressing its causes more effectively. Frustration does not have to create isolation. Resentments can be expressed, dealt with, and discharged. Losses can be discussed and mourned. Examining the sense of helplessness, humiliation, and the inability to care for oneself can lead to more effective strategies for keeping the patient in control and for accepting that the patient’s situation is a natural and inevitable part of the life cycle. Fear can be particularly challenging, because the dying person’s fears may intersect with the caregiver’s fears and anxieties.

Fear may arise around the progressive symptoms of the illness. Fear may permeate thoughts about the process of dying or, as Woody Allen quipped, “I’m not afraid of dying, I just don’t want to be there when it happens.” Fears about what occurs after death are also common. One of the best ways to help a person deal with and counter fear is with accurate information. Consultations with doctors, nurses, hospice workers, or clergy that focus specifically on the fears and concerns that have emerged can be extremely helpful in curbing escalating fear.
Nonetheless, the prospect of death brings us to the edge of everything we know and know how to control. Engaging one’s fears is not just a psychological challenge; it can push us into an encounter with the foundations of our spiritual beliefs. One of the most effective tools for engaging this territory is mindfulness meditation, discussed below. Stephen Levine, a meditation instructor and one of the modern pioneers in teaching people to die consciously and well, once advised a woman who was going through the agony of watching her daughter die, “Let her death be surrounded by your care for her and a willingness to go beyond your fear” (Levine, 1989, p. 5). Procedures such as mindfulness meditation and acupressure for the emotions (also discussed below) can be invaluable resources for dealing with fear and anxiety.

The **bargaining** phase of coping with a terminal diagnosis involves attempts to postpone the inevitable. Whether with God, through heroic but unlikely medical interventions, an embrace of a healthy diet, or a promise to be a better person if given more time, these “deals” are typically not discussed and often go unnoticed. They have been likened to the way a child at bedtime may bargain for another goodnight kiss, another song, another drink of water. But they should not be discounted. Callanan and Kelley describe how people with AIDS often make deals to spend the time they have left working to stop the epidemic. “I’ll get involved,” they may think. “I’ll take care of others. I’ll teach people how not to get infected. But, God, if I do this you have to let me live longer.” Amazingly, such bargains often seem to work. (p. 50)

**Depression** is a natural reaction to loss and a fundamental emotional component of grief. For a dying person, loss has many faces. The illness may already have extracted the ability to hold a job, to continue roles in the family and community that had always been taken for granted, to care for oneself, or a thousand other insults to one’s sense of self. Meanwhile, even greater losses approach: further physical debilitation, never again seeing loved ones and, finally, the loss of life itself. Mourning is the process of emotionally working through such losses, and depression keeps the mind from focusing on much else. In this way, it serves an adaptive function. Reactive depression helps the person cope with losses that have already occurred; preparatory depression helps the person emotionally prepare for coming losses. For the caregiver, the dying person’s depression may be extremely difficult to encounter. As adaptive as grief and depression may be in theory, they usually do not appear to be serving a constructive purpose. Yet you cannot talk a person out of depression, and the depression itself can be contagious. Asking the person to cheer up in one way or another (e.g., “Hey, it’s been a good life”) discounts the emotional pain and further isolates the individual. Callanan and Kelley (1997) counsel that, presented with a dying person’s expressions of sadness and depression, “All you can do when they voice these feelings is listen. Often, no answer is needed—only the attempt to understand” (p. 50). Describing work with the father of two small children who was dying of cancer, they conclude:

He didn’t need cheering up. He didn’t need someone to say, “I’ll help raise your children,” or “I’ll try to be there for Joyce after you’re gone.” . . . What Mark needed was to have someone listen to his pain, empathize with his sadness, and share his tears.” (p. 51)

**Acceptance**, according to Callanan and Kelley (1997)

is a feeling of peaceful resignation that usually doesn’t come to stay until death is very close. It’s common for patients to experience interludes of acceptance and
then, in one day, in one conversation, on one sentence, slip into another emotional stage. But eventually death nears, at which time permanent acceptance may arrive. When this occurs—provided a dying person is comfortable—she needs little except the presence of one or two important people. . . . If you are one of these people, you may experience mixed emotions. The peace of another’s acceptance of death can be comforting, but with acceptance comes detachment, a drawing away from others no matter how close they have been. This can be painful for those being left behind. (pp. 51 - 52)

Interlaced with these five emotional states that people regularly encounter during the dying process—denial, anger and the feelings that underlie it, bargaining, depression, and acceptance—is the need to complete or abandon various unfinished physical and emotional tasks. Books and screenplays have been completed in the last days of life, sometimes with a feeble body prolonging life beyond what seems imaginable in order to get to the final word. Sometimes life extends itself to allow the person to attend an event, such as the marriage of a son or daughter, or experience the arrival of a loved one from far away. Other times, projects that had been central in a person’s existence have been abandoned as no longer possible or as having never really been worthy of the person’s life force. Such decisions may be met with grief or relief. In many instances, the unfinished business seems to be more about core life lessons, such as how to live more fully or with a more open heart, than about completing specific projects. Not infrequently, when a major longstanding issue is resolved, or a core life lesson learned—even if it is not until the person’s last few weeks, or even days—the entire life may take on “retrospective meaning,” accompanied by a greater sense of peace about dying. A literary depiction of this process is Tolstoy’s Ivan Ilych who, after an existential crisis in the last days of his life, “transformed himself and was able to flood, retrospectively, his entire life with meaning” (Yalom, 1980, p. 208).

The area of unfinished business that frequently becomes the most complex involves other individuals. Sometimes this can be as expressing an intimate feeling that has never been stated. Sometimes it involves a long-held resentment or unresolved conflict. Often it entails asking for or rendering forgiveness. The issue of forgiveness may be complicated by confusion between forgiving and condoning an intolerable action. Complex family dynamics may emerge. When the caregiver is able to maintain and model an open heart, the interpersonal atmosphere can change in beautiful ways, a process gracefully described in a classic series of books by Stephen Levine (1982, 1987, 1989) and in an enlightening audio program, Being with Dying, by Joan Halifax (1997).

Although a quick, unexpected death may relieve a person of having to face frightening trials, dying with an illness over time provides opportunity for being able to complete what has not been completed. Byock (1997) observes that when Americans have been asked how they want to die, they sometimes respond with flippant quips about wishing for a sudden death, such as “I want to be struck by lightning after sinking a birdie on the eighteenth hole” or “I want to be a hundred and be shot in the back by a jealous husband.” But he notes that while sudden deaths are attractive among the healthy, in reality, they leave many things undone, and they are often the hardest deaths for families to accept. In contrast to an abrupt, easy death, dying of a progressive illness offers precious opportunities to complete the most important of life’s relationships. This includes the chance to reconcile strained relationships, perhaps between previous spouses,
or between a parent and an estranged adult child. When the story of two people ends well, a warm light is shone on all that has preceded. Even at the very end of life, healing a relationship can transform the history of a family. . . . When a dying person and a loved one come to feel complete between themselves, time together tends to be as full of joy and loving affection as sadness.” (p. 53)

**Mindfulness Meditation and Acupressure for the Emotions**

Skills in deep, open-hearted listening and responsiveness are the first pillar for assisting a person who is dying to more effectively confront the psychological and spiritual challenges that will emerge, and skills in meeting emotions in ways that open awareness and provide a sense of command form a second pillar. Two procedures from Eastern spiritual and healing traditions that are being adopted increasingly by Western psychotherapists can be invaluable for helping the dying person as well as the caregiver. Each can be self-administered outside the clinical context. Each may be enormously empowering, giving a person a measure of control and a sense of mastery over the ebb and flow of feelings that may run wild in the face of a terminal diagnosis for oneself or a loved one. Each teaches a person to encounter and manage difficult emotions in ways that are generally unfamiliar to individuals brought up in our culture.

**Mindfulness Meditation**

The stream-of-consciousness writing exercises in the previous section can be training wheels for mindfulness meditation. They can be used for any of the issues discussed in this section as well. You might experiment with this now, using headings such as “My Sadness about Jim’s Illness,” “My Terror of Losing Jim,” “My Helplessness,” “Jim’s Pain,” “My Anger with Jim,” “Not Knowing What to Say to Jim,” “The Unfairness.” Again, focusing on a single topic, write without pausing for 10 uninterrupted minutes, and then review.

Like stream-of-consciousness writing, mindfulness meditation involves turning inward and keeping one’s attention on the present moment. Mindfulness meditation, however, is a more subtle art that offers an alternative way of being with pain, anxiety, depression, and stress (Segal, Williams, & Teasdale, 2002). In mindfulness meditation, one pays attention, non-judgmentally, to the unfolding of experience, moment by moment. You learn to witness the emergence of your inner landscape as an ongoing process rather than a fixed state. The result is that you become less attached to your thoughts and emotions, recognizing how they rise and fall, and this starts to free you from the tyranny of your thoughts (a bumper sticker instructs that “Meditation is not what you think”). You learn how your thoughts change with your mood and discover that thoughts are not facts. You become a witness of rather than a slave to habitual, automatic thought patterns. And by turning toward rather than turning away from difficult feelings, you are able to notice and identify negative thought patterns that keep you trapped (Lau & McMain, 2005).

Mindfulness involves a “deep, penetrative non-conceptual seeing into the nature of mind and world” (Kabat-Zinn, 2003, p. 146) that can be cultivated through the types of attention and concentration that are developed in the practice of meditation. Mindfulness and other forms of meditation were originally “nested within a larger conceptual and practice-based ethical framework” (p. 146). The management of one’s emotions may be a more modest aspiration than Buddha-like compassion or the liberation from “the wheel of life and death,” but it is still a
practice that can lead to a skillful understanding of how unexamined thoughts, emotions, and behaviors “contribute directly to human suffering, one’s own and that of others” (p. 146). Meditation is far more than a mind game. Because “mind” and “heart” are conveyed by the same word in Asian languages, mindfulness implies attending to the moment with “an affectionate, compassionate quality . . . a sense of openhearted, friendly presence and interest” (p. 145).

Books such as Jon Kabit-Zinn’s Wherever You Go, There You Are (1994) and classes (eight two-hour weekly sessions are typical when mindfulness meditation is introduced into a person’s psychotherapy) can teach the basic principles. But there is no way around regular practice to keep the principles alive and active in one’s awareness. A daily practice of mindfulness meditation for a person who is faced with a life-threatening illness can significantly enhance the quality of the final days. To experiment, one of the most immediate ways to move into a space of mindfulness, as taught by Stephen Levine, is to simply, one breath at a time, “Soften belly. Notice breath. Open heart.” Over and over. Try it.

Acupressure for Emotions

Reviewing a major text in the field of energy psychology for the prestigious online book review journal of the American Psychological Association, Ilene Serlin notes: “Energy psychology is a new discipline that has been receiving attention due to its speed and effectiveness with difficult cases” (Serlin, 2005). Energy psychology, also sometimes called “acupressure for the emotions,” is an approach for emotional self-management and therapeutic change that draws from both Traditional Chinese Medicine and modern cognitive-behavioral therapies. It combines the stimulation of specified acupuncture points on the skin with a variety of mental strategies in a manner that seems to quickly change the way the brain organizes specific emotional response patterns (Feinstein, 2006a). Among the emotions that seem to readily respond are excessive anxiety, fear, anger, guilt, jealousy, and shame, as well as mild depression.

Although the psychotherapy establishment has been slow to embrace the methods of and explanations about moving energy, an e-newsletter that provides instruction on how to utilize energy psychology techniques on a professional as well as self-help basis had 318,000 active subscribers at the time of this writing, and this number was increasing at a rate of about 5,000 to 10,000 per month. People seem to find the approach effective for emotional self-management. Growing numbers of psychotherapists are incorporating it into their practices. Reports of its effectiveness in the extreme challenge of treating postdisaster trauma have come out of more than a dozen countries (Feinstein, 2006b). Most relevant for the context of a person dying at home is that the method can be readily learned and self-applied (Feinstein, Eden, & Craig, 2005).

Tools that can help a person place difficult feelings into a larger context, or even subdue intense and sometimes extreme emotional reactions, would have obvious value in helping a person move through the psychological challenges as life’s final passage draws near. Such tools are readily available. Family members and caregivers must, however, remain very sensitive to not badgering the dying person with the availability of such aids. Fear, anger, depression, and grief all have constructive purposes within the economy of the psyche. Although an onlooker might be tempted to encourage a person to transcend such feelings, it is for each individual to navigate his or her way through complex internal landscapes. Still, experience among energy psychology practitioners suggests that reducing overwhelming emotional intensity does not rob
the person of the lesson life is trying to provide. Rather, it allows the entire situation to be received, evaluated, and traversed with greater clarity and equanimity.

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**Individually Tailored Rituals that Bring a Fullness of Meaning**

If deep, compassionate listening and responsiveness comprise the first pillar of being a presence in helping a person die well and introducing emotional self-management techniques the second, the third pillar involves introducing rituals that move a person forward on the journey with greater resolution, peace, and awareness. Groves and Klauser (2005) note that “Death is a mystery so deep that sometimes only sacred ritual can express the fullness of its meaning for both the dying person and the caregivers” (p. 268).

Rituals, according to Megory Anderson (2003), “transform one state of being into another. They carry us from childhood into adulthood, or from membership in our family of birth to the creation of a new family through marriage” (p. 33). They have the ability to bring people an experience of something greater. They create a safe space and time in which we can touch the deeper issues of our existence. They have the power to bring to the surface and resolve very deep feelings and unnamed blocks that have been buried in our unconscious. (p. 35)

Rituals may be highly elaborate or exquisitely simple, planned or spontaneous. Anderson, a specialist in creating rituals for people who are about to cross over and their families, tells the story of walking by a hospital room where a man was being taken off of life support. A situation had arisen with the man’s adult daughter, and Anderson, who was known to the hospital staff, stepped in to help:

The woman, who was witnessing her father’s death, was weeping uncontrollably. She was so distraught that one of the nurses had to hold her back. She was the only family member there, and I was sure she felt horribly guilty about making the decision to stop his life support.

I asked the nurses to hold everything for just a few minutes while I took the woman into the hallway. I took her by the shoulders and spoke to her very firmly.

“I know this is a horrible experience for you, but let’s think for a moment about your father. He’s hearing everything going on around him. Do you really want the last thing he hears to be a hysterical daughter? Why don’t you talk to him as this is happening? Tell him how much you love him. You might even sing to him!”

Her eyes grew round in amazement.

“I never thought about it that way,” she said through tears and hiccups.

The woman took a deep breath and marched back in. She took his hand and said, “Daddy, I’m sorry I behaved that way. I was thinking about me more than I was thinking about you.”

She sniffled, wiped her eyes with the back of her hand, and then began singing in the most extraordinary voice.

Amazing Grace! How sweet the sound
That saved a wretch like me!
I once was lost, but now am found
Was blind, but now I see.

I stared at the woman. Five minutes before, she was hysterical, almost having to be restrained, and now she was sitting here with a beautiful glow on her face. Her voice was pure and exquisite. The nurses were transformed as they listened to her sing. I watched people from the hallway stop and then come to the door of the room, listening.

The nurse at the machines had tears in her eyes as she sang softly with the daughter. Then, quiet. We let the echoes stay with us a bit longer, and the nurse came over to the bed and unhooked tubes and monitors. She looked at the daughter and nodded, without saying anything. We both left the room allowing privacy for father and daughter. (pp. 217-218)

Ritual provides structure for helping what wants to happen at the deepest levels to be able to happen. They may or may not be rooted in religious or spiritual symbolism. Many rituals are highly attuned to the psychological needs of the dying person and the family. The themes of the rituals Anderson performs most frequently involve (1) letting go of the body, of loved ones, of life; (2) rituals for unresolved issues such as anger, remorse, sadness, fear, and relationships; (3) rituals for physical, emotional, and spiritual purification; and (4) rituals of transition from the state of living to the state of existence in the afterlife. She usually begins by creating “sacred space”: devoid of clutter, contained for privacy and intimacy, and adorned with objects of beauty, candles, music, incense, or other devices that shift awareness through the senses. Symbols of personal, spiritual, or religious significance are brought, each ritualistically imbued with sacred intention. Sacred space can be created anywhere, from the person’s bedroom to an antiseptic, machine-strewn room in a critical care unit. The rituals Anderson creates are based on an astute assessment of the emotional and spiritual needs the situation presents. She listens intently to all involved and pays close attention to the deep desires of the dying person in particular. She learns about the person’s religious and cultural background and builds upon symbols and rituals that were meaningful to the person in their past.

While Anderson’s Sacred Dying: Creating Rituals for Embracing the End of Life (2003) is perhaps the best practical overview of the subject, Groves and Klauser’s The American Book of Dying (2005) provides a toolkit that also can be enormously useful. It includes rituals for the bedside, rituals for release, vigil rituals, rituals for remembering, meditation practices, religious rites, journaling and sacred writing exercises, life review exercises, forgiveness exercises, breathwork, dream work, guided visualizations, the use of artistic expression, the use of music, the use of prayer, the use of energy therapies, ways of working with people in a coma, and ways of invoking the help and spiritual guidance of one’s ancestors. A beautiful and poignant account of the way rituals can be created and can evolve to illuminate the journey of each family member during the illness and death of a young father is also highly instructive (Mayo, 1990a).

Through these three pillars—the power of deep listening, techniques for emotional self-management, and wisely-crafted rituals—the process of dying can be transformed. Byock (1997) summarizes:

Without adequate medical care, dying can be horrible. With skillful medical care and attention to the personal experience of the patient and the patient’s family,
dying can be made bearable. When the human dimension of dying is nurtured, for
many the transition from life can become as profound, intimate, and precious as
the miracle of birth. (p. 57)

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**Expressive Grief Work**

Death is that curse that makes sweet love our anguish.

– The Buddha

“The terrible fire of grief,” writes Peg Elliott Mayo, “is an energetic furnace, refining
cracter, personality, intellect, and soul. It is a catalyst for creation. What is created may be
dreadful—a distorted, unapproachable monument to despair—or a distillation of experience that
is wholesome, useful, bright, and even wise (Mayo, 1990b, p. 121). Mayo coined the term
expressive grief work to describe the importance of emotional expression, psychological
discharge, ventilation, and catharsis in the process of “conscious, ritualized grieving” (p. 128).
Most cultures have memorials, services, and other practices that allow time where the family and
other bereaved “are supported, expected, and encouraged to experience and express their
anguish” (p. 128). She guides the reader through a series of internal “rituals for transmuting grief
to creativity,” including visualization, meditation, movement, sounding, auditory drawing,
internal dialogues, reframing, and rituals for saying good-bye (Mayo, 1990b, 2001). One ritual
for saying good-bye, after appropriate preparation, involves invoking the one being grieved,
making the person present in one’s imagination, placing the person in an “empty chair,” and very
consciously working through (perhaps in numerous sessions) the four stages associated “with the
final phase of transmuting grief to creativity in expressive grief work” (Mayo, 1990b, p. 168):

First, we express the resentment and anger associated with the loss.

Second, we dredge our memories and recall the person we’ve lost and our
associations about the person. Making a long list of “I remembers” is very useful
and often primes the pump for the last two stages.

Third, we do well to express our appreciations. Speaking or listing these brings
balance and gives a sense of legacy from our absent loved one.

Finally, and with much resolution, we give a benediction and say good-bye.

The presentation of Mayo’s rituals for expressive grief work is imbued with enormously
moving and instructive accounts of her personal struggles and steps toward resolution following
the suicide of her son Patrick not long after his graduation from Yale. In addition to the deeply
personal rituals Mayo describes, the essential principles of heartfelt listening discussed in the
previous section apply to grief as well. In another moving account about losing a child, Bachu
(1997) notes how important it was to talk, in a bereavement support group, with other grieving
parents:

I think it was the sharing of stories that saved my life. There were stories of
confession, of regrets, of laments, of fury. . . . We let it all spill out into the
collective pool of tears. Compassion filled our hearts. We held each other,
remembered other times, and eventually we dared to begin to dream new dreams.
(p. 208)

The same three pillars for helping a person die well (deep expression and witnessing, internal and shared rituals, and emotional self-management tools) can also help transform the anguish of grief into the wisdom, compassion, and treasured memories of a life well lived. Each can be useful with the emotional issues that are part of grieving, including sorrow, anger, depression, anxiety, denial, emptiness, longing, loneliness, loss of meaning and identity, withdrawal, thoughts of suicide, and pessimism about the future. Any of these topics can, in fact, be a focus for stream-of-consciousness journaling or mindfulness meditation. For journaling, again, put the topic at the top of the page, write without pausing for 10 minutes, and reflect. In mindfulness meditation, one turns toward rather than away from difficult feelings, going deeper and deeper into the feeling of, say, inconsolable sorrow. Watching its ebb and flow, watching the thoughts one’s mind creates around it, can itself be healing.

The elements of effective therapeutic approaches to grief are also instructive. In the first phase of a promising method called traumatic grief therapy (Shear, Frank, Houck, & Reynolds 2005), the therapist provides information about normal grief and unresolved, protracted, complicated grief. A model of coping is introduced in which focus alternates between adjusting to the loss and restoring a satisfying life. The process addresses both the loss and goals for the future. One way of focusing on the loss is through memories. For instance, the person’s death may be revisited, told as a story, with eyes closed, and tape recorded. At various points, the person may be asked to describe the amount of distress being experienced. At the moments of greatest distress, techniques to promote a sense of connection with the deceased are used, such as imaginal conversations, concentrating on both positive and negative memories. The person might be asked to imagine that the one who has died is able to hear and respond and is then encouraged to engage in a dialogue with the deceased. A technique that focuses on restoring a satisfying life is to have the person consider what would be desirable at this time if the grief were not so intense. These desirable visions become goals. Other goals might also be identified, such as finding ways of stepping into one’s new role in life without the loved one, resolving existing interpersonal difficulties that interfere with moving forward, and reengaging in meaningful relationships. Concrete plans for putting envisioned goals into action are discussed, along with ways of identifying progress toward them.

Conclusion

In each of the areas discussed in this chapter—using an awareness of the inevitability of death to enhance one’s life, being the “soul friend” with someone who is dying, and moving forward creatively after losing a loved one—the three pillars of deep listening and responsiveness, emotional self-management, and transformative rituals can help guide the way. Although U.S. culture is known for its denial of death, caregivers can draw from the rich traditions and rituals from societies throughout recorded history. Such a multicultural perspective on death is not only enormously empowering, culturally sensitive practices regarding death have, with the increased mobility of the world’s population, become essential training for health care professionals.
**Tool Kit for Change**

**Perspective of the Health Care Professional**

1. The patient will provide the cues about the care that is needed.

2. Denial, anger, fear, bargaining, and depression all have important psychological functions. Listen well.

3. The dying process includes unusual internal experiences and the need to complete unfinished business.

4. Powerful palliative care methods for reducing pain and increasing physical comfort are available, as are methods for effectively engaging difficult emotions. Ensure that they are used.

5. Rituals bring structure that helps what wants and needs to occur—psychologically and spiritually—to occur.

**Perspective of the Dying Person**

1. This is a time to express what you feel and what you need.

2. This is a time to come to resolution about what is not completed.

3. This is a time to accept where you are on the wheel of life. Do not waste your energies or quality time with loved ones mired in shame or guilt.

4. You will go through a myriad of emotions—engage them in a “soften belly, notice breath, open heart” manner.

5. Spiritual and religious questions, and questions about what happens after death, will occur to you. Request visits from people with whom you would like to discuss them.

**The Larger Perspective**

1. While every culture has its own beliefs and practices regarding death and dying, universal principles found in all cultures help us map what is required in caring for a dying person.

2. The spiritual dimensions of the dying process frequently become important even for people who have not considered themselves religious or spiritual.
References


