PART VII

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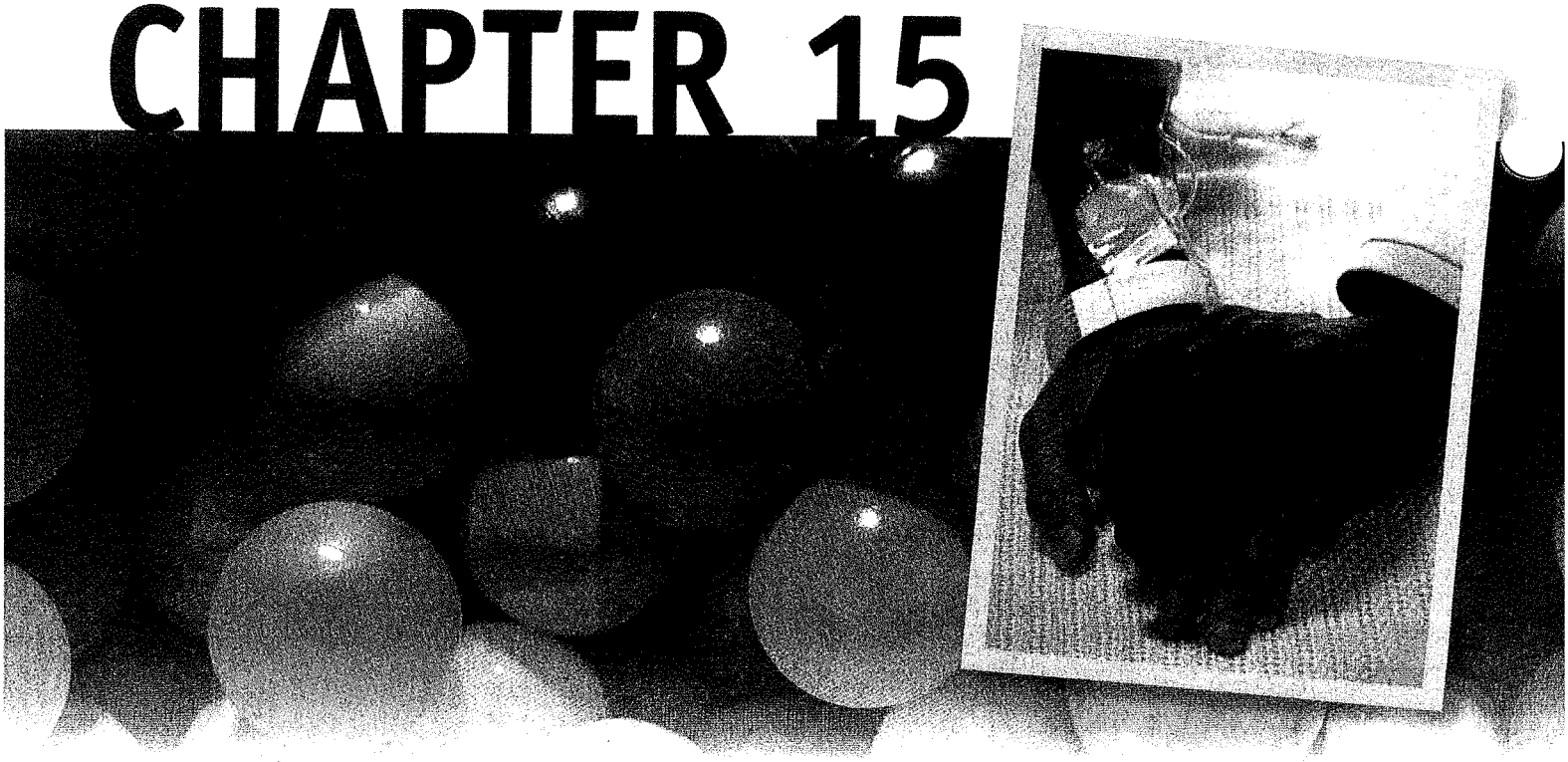
ENDINGS

Now that we have reached the end of our journey, let's focus on life's final chapter (death) and reflect on what we've learned.

Chapter 15 — Death and Dying is special because this final event embodies the strides science has made in extending our lifespan. Death showcases our human priorities. It pinpoints what gives meaning to life. How have attitudes and practices toward death changed over centuries, and what do people (and grieving loved ones) feel as they deal with this final "act"? How does the health-care system approach terminally ill people, and what are we doing to make dying humane? These topics lead me to that critical ethical issue: strategies to take control of how we die.

Final Thoughts — In this section, I'll reflect on what I've learned. What has researching this edition taught me about being human? Can I distill these insights into four nuggets of wisdom about living a full life?

CHAPTER 15



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Death and Dying

In his seventies, my father seemed immortal. While he often joked about being an "old man," he had no major infirmities. At age 81, mortality hit. For a few months, Dad had been listless—not his usual self, looking old. Then came the unforgettable call: "The doctor says that it's cancer of the liver. Jan, I'm going to die."

Because medicine never admits defeat, the plan was three rounds of chemotherapy, punctuated by "recovery" at home. The doctor said, "Maybe we can lick this thing," but the treatments were agonizing. Worse yet, recovery never happened. My father got weaker. After a few months, he could barely walk. Then, before going into the hospital for the third round, my mother called: "Last night we cried together and decided not to continue. We're calling hospice. It's time for you to come down." My father had two more weeks to live.

A day or two before you die, you slip into a coma. It's the preceding week that seems to last for years. Everyone has been summoned to bustle around a train that cannot be derailed. Yes, you can talk, but what do you say? My father was never a verbal man. Then, as if on cue, the disease picks up speed. From the wheelchair to being bedridden, the voice that mutates into a whisper, followed by waiting . . . for what? You force yourself to be at the bedside when the breathing gets slow and rattled, but you are terrified. You have never seen a person die. You don't know how things will go. You hope that things go quickly. You can't stand to see your father suffer anymore.

My father died in the "normal" late-twentieth-century way. Although we knew nothing about how people die, we had time to plan for the event. Dad's death came at the "right" time, at the end of a long life. How does death *really* happen today compared to centuries past?

CHAPTER OUTLINE

Setting the Context

Learning Outcomes

- List three pathways to death.
- Describe changes throughout history in attitudes about dying.
- Compare the Hmong approach to contemporary Western death practices.

Today, as Figure 15.1 suggests, our pathways to death take different forms (Field, 2009). Roughly 1 out of every 6 or 7 people in affluent nations dies with little warning — due to accidents, brief infectious diseases such as the coronavirus, or, most often, from a typical age-related event such as a sudden heart attack or stroke (see the red line in Figure 15.1). My father's death fits the pattern when illnesses such as cancer are discovered at an advanced stage. Here, as the blue line shows, a person is diagnosed with a fatal disease and steadily declines.

The prolonged erratic pattern, shown in yellow, is by far the most common dying pathway in our age of extended chronic disease (see Krikorian, Maldonado, & Pastrana, 2020). After developing cancer — or, like my husband, congestive heart failure (see the Experiencing the Lifespan box on page 431) — people battle that condition for years, helped by medical technology, until death occurs.

So today, deaths in affluent countries occur slowly. They are dominated by medicine. They have a protracted, uncertain course (Burg, 2018; Field, 2009; Harris and others, 2013). For most of history, people died in a different way.

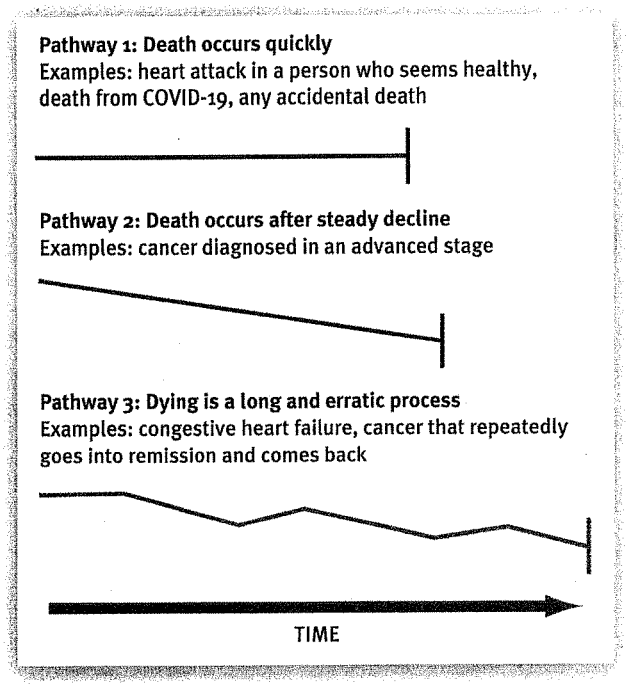


Figure 15.1: Three pathways to death Although some people die relatively quickly, the pattern in blue and especially yellow are the most common pathways by which people die today.

A Short History of Death

> She contracted a summer cholera. After four days she asked to see the village priest, who came and waited to give her the last rites. "Not yet, M. le Curé, I'll let you know when the time comes." Two days later: "Go . . . tell M. le Curé to bring . . . Extreme Unction."
>
> (reported in Walter, 2003, p. 213)

As you can see in this nineteenth-century description of the death of a French peasant woman, before modern medicine, death arrived quickly. People let nature take its course. There was nothing anyone could do. Dying was familiar, predictable, typical. It was embedded in daily life (Wood & Williamson, 2003).

According to the historian Philippe Ariès (1974, 1981), while life in the Middle Ages was horrid and "wild," death was often "tame." Famine, childbirth, and infectious disease ensured that death was an expected presence throughout the lifespan. People died, as they lived, in view of the community and were buried in the churchyard in the center of town.

During the eighteenth and nineteenth centuries, death began to move off center stage when — because of fears about disease — villagers relocated burial sites to cemeteries outside of town (Kastenbaum, 2004). Then, a more dramatic change took place during the early twentieth century, when medical science successfully waged war against disease. The conquest of many infectious illnesses moved dying toward the end of the lifespan, relocating it to old age (Zaman and others, 2017).

As modern medicine took over, the scene of death shifted to hospitals and nursing homes. So the act of dying was disconnected from life. Because hospitals billed themselves as places of recovery, death became a symptom of scientific failure. When people took their last breaths, often embedded in the recesses of intensive care, health-care workers quickly erased all signs of death's presence, as they shrouded the body and shipped it to be spruced up in the funeral home (Kastenbaum, 2004). According to one social critic, by the mid-twentieth century, death had become disgusting, abnormal, never discussed (Gorer, 1965).

A half century ago, Western society shifted course (Zaman and others, 2017). First, doctors did a total turnaround from the practice of concealing a devastating

Chronicle/Alamy

For most of human history, death was "up close and personal" and occurred in the midst of day-to-day life. Here is a nineteenth-century lithograph entitled "The Dying Request," in which a dying young woman is offering her final words to her spouse.

diagnosis — never mentioning, for instance, the "C word" — in favor of telling people, "Yes, it's cancer, and there is not much we can do." (Now that we meticulously track each symptom on the Internet, physicians foolish enough not to be upfront about a patient's prognosis could be charged with malpractice or worse!) Then, our health-care system confronted the reality that yes, people die, by developing structures to smooth our passage through the terminal phase of life and asking people to choose how they want their final act to proceed.

Cultural Variations on a Theme

While in Western nations we stress honesty and the need for planning (see Block and others, 2020), death attitudes still differ from group to group. To demonstrate this point, let's scan the practices of a culture for whom dying remains up close and personal, but where death is never openly discussed: the Hmong.

The Hmong people, persecuted for centuries in China and Southeast Asia, migrated to North America after the Vietnam War and number close to 300,000 U.S. residents today. According to Hmong tradition, mentioning dying "will unlock the gate of evil spirits" — so when a person enters the terminal phase of life, no one is permitted to discuss that fact. However, when death is imminent, the family becomes intimately involved. Relatives flock around and dress the ill person in the traditional burial garment — a black robe or suit. After death arrives, they lovingly wash and groom the body, preparing it to be viewed.

Darren Hauck/Getty Images

Even today, small pockets of the U.S. population adopt an intensely hands-on approach to death. Here, you can see phase one in the carefully orchestrated days-long Hmong funeral ceremony — the body, dressed in its traditional garments, being caressed by distraught family members.

If, contrary to Hmong custom, the person dies in a hospital, it's crucial that the body *not* be immediately sent to a morgue. The family congregates at the person's bedside to wail and caress the corpse for hours. Then, after a lavish four-day funeral ceremony, during which the body remains in view, the deceased is lovingly dressed in warm clothing to guard against the cold, and the feet are encased in special blue shoes for the journey to the next world. At the gravesite, the coffin is reopened for a final viewing before being permanently closed (Gerdner and others, 2007). Could you participate in these activities, giving your relative the hands-on care that the Hmong people and other societies provide to prepare loved ones for the grave?

In this chapter, I'll explore what dying is like in the twenty-first-century West — an age of open communications, extended chronic disease, and intense attention to providing quality end-of-life care (Zaman and others, 2017). First, I'll examine the dying person's and mourners' feelings, then turn to the health-care system, and, finally, return to the dying person to tackle controversial issues related to deciding when we die. As you just saw with the Hmong, however, remember that — just as dying pathways differ — with death and dying, diversity is the main theme. We all bring unique, *equally* valid perspectives to that ultimate event of human life (Krikorian, Maldonado, & Pastana, 2020).

Tying It All Together

1. Imagine that you were born in the seventeenth or eighteenth century. Which statement about your dying pathway is *false*?
   a. You would probably have died quickly of an infectious disease.
   b. You would have died in a hospital.
   c. You would have seen death all around you from a young age.
   d. You would probably have died at a relatively young age.

2. If you follow the typical twenty-first-century pattern, as you approach death, you can expect to decline *quickly/slowly and erratically* due to *an accident/an age-related chronic disease*. (Choose the correct options.)
3. Ella says today we live in a death-denying society. Ché argues, "That's not true. We are paying far more attention to the experience of dying than in the past." Who is most correct, and why?

Answers to the Tying It All Together questions can be found at the end of this chapter.

The Dying Person

Learning Outcomes

- Critique Kübler-Ross's theory.
- Outline the qualities involved in a good death.
- Describe typical mourning.
- Discuss how COVID-19 and a child's death affect grieving.

How do people react when they are diagnosed with a fatal illness? What are their emotions as they struggle with this devastating news? The first person to scientifically study these topics was a young psychiatrist named Elisabeth Kübler-Ross.

Kübler-Ross's Stages of Dying: Description and Critique

While working at a Chicago hospital during the 1960s, Kübler-Ross became convinced that the health-care system was neglecting the emotional needs of terminally ill people. As part of a seminar, she got permission to interview dying patients. Many, she found, were relieved to talk about their diagnosis and knew that their condition was terminal, even though the medical staff and family had tried to conceal that fact. Kübler-Ross published her discovery, that open communication was important to dying people, in a slim bestseller called *On Death and Dying*, which ushered in a revolution in the care of terminally ill patients.

Kübler-Ross (1969), in her **stage theory of dying**, originally proposed that we progress through five emotions in coming to terms with death: *denial, anger, bargaining, depression,* and *acceptance*. Let's now look at each emotional state.

Kübler-Ross's stage theory of dying The landmark theory, developed by psychiatrist Elisabeth Kübler-Ross, that people who are terminally ill progress through five stages in confronting death: denial, anger, bargaining, depression, and acceptance.

When first given some terrible diagnosis, such as "You have advanced lung cancer," a person's immediate reaction is denial. She thinks, "There must be a mistake" and consults doctor after doctor, searching for a more favorable set of tests. When these efforts fail, denial gives way to anger.

In the anger stage, people lash out, bemoaning their fate, railing at others. One patient might get enraged at physicians: "They should have diagnosed my illness earlier on!" Others direct their fury at a friend or family member: "Why did I get lung cancer at 50, while my brother, who has smoked a pack of cigarettes a day since age 20, remains in perfect health?"

Eventually, this emotion yields to a more calculating one: bargaining. Now, people plead for more time, promising to be good if they can put off death for a bit longer. Kübler-Ross (1969) gives this example of a woman who begged God to let her live long enough to attend the marriage of her oldest son:

> The day preceding the wedding she left the hospital as an elegant lady. . . . I wondered what her reaction would be when the time was up for which she had bargained. . . . [T]he moment she returned to the hospital . . . [she] said, "Now don't forget I have another son."
>
> (quoted on p. 83)

Then, once reality sinks in, the person gets depressed and, ultimately, reaches acceptance. By this time, patients are weak and beyond feeling upset, angry, or depressed. They may look forward to the end.

Kübler-Ross deserves credit for alerting us to the fact that there is a living, breathing person inside the diagnosis "terminal cancer" or "end-stage heart disease." The problem is that her ideas were embraced in a rigid, simplistic way. Here are three reasons why we *cannot* take this theory as the final word about death.

Developmental Psychology Videos

Case Studies in Accepting Death: Lucky and Dorothy

In this video, you will hear two people discuss their reactions to being diagnosed with a terminal illness.

Achieve

Terminally Ill Patients Often *Don't* Want to Fully Discuss Their Situation

Many people read into Kübler-Ross's theory the idea that ill people want to talk about impending death. This is not true! Patients and loved ones have problems broaching this touchy topic (Burg, 2018; Eun and others, 2017; Schulz and others, 2017). While it's easier to discuss death in the abstract — spelling out burial and funeral plans — mentioning the nitty gritty details of dying risks bringing the end way too near: "When I asked my mother if she'd want a breathing tube," one daughter commented, "Mom looked horrified; and quickly blurted out, 'Your brother is coming to visit at 1 P.M. today' " (adapted from Schulz and others, 2017).

Patients shy away from bringing up their feelings to protect loved ones: "I've got as much as I can cope with. So I can't get her [my sister] upset . . . and then have . . . to calm her down" (quoted in McGrath, 2004, pp. 837, 839). They avoid these discussions to protect themselves: "The reason that I don't talk to anyone about my situation is that I need to have a little hope. . . . Ah, I would just like to have hope I can extend it" (quoted in Eun and others, 2017, p. 1013).

Therefore, death discussions operate like a delicate dance. *Everyone* tries to protect everyone else. And the hope that "honest," final conversations will cure festering wounds ("Now I can tell Mom *exactly* how I felt about her preferring my brother!") doesn't pan out — and for good reason. As one daughter pointed out: "I was . . . torn . . . between wanting to get things off my chest and not wanting to upset him further, and ultimately decided not to say things" (quoted in Generous & Keeley, 2017, p. 167).

Terminally Ill Patients May Not Want to Know the "Full Truth"

Honesty from medical providers is overrated, too. People may *say* they want full disclosure — but many patients shy away from hearing very bad news. And sensitive doctors pick up on these messages:

> If I get a signal from a patient . . . that they are not ready to talk about it, I back off . . . . If . . . they don't want to hear about that, . . . well, I'm going to go where the patient is at.
>
> (quoted in Schulz and others, 2017, p. 640)

Kübler-Ross stressed full disclosure because she was railing against a late-twentieth-century death-denying culture. Now we have a more nuanced view: Yes, truth may be a *better* policy; but, above all, avoid causing people pain.

People Do Not Pass Through Stages in Adjusting to Death

The main problem, however, is that Kübler-Ross was wrong! People facing death do *not* progress in a stage-to-stage, cookie-cutter way. In fact, uncritically accepting Kübler-Ross's stages can be dangerous if it encourages us to distance ourselves from dying loved ones (Kastenbaum, 2004). Instead of realizing that depression is a reasonable reaction when facing a life-threatening illness, if friends and family see this feeling as "a phase," they might view this response as somehow not real. It's understandable for an ill person to get angry when significant others respond insensitively or don't call; but if we view this response through the lens of stage theory, we might dismiss these natural feelings of hurt as "predictable" signs of the anger stage.

Therefore, experts view Kübler-Ross's ideas with mixed emotions. Yes, she pioneered an important topic. But her theory encouraged its own insensitivity to terminally ill patients (Kastenbaum, 2004).

The More Realistic View: Many Different Emotions; Wanting Life to Go On

People who are dying *do* get angry, bargain, deny their illness, and become depressed. However, as one psychiatrist argued, it's appropriate to view these feelings as "a complicated clustering of intellectual and affective states, some fleeting, lasting for a moment, or a day" (quoted in Schneidman, 1976, p. 6).

Even when people "know" their illness is terminal, the awareness "I am dying" may not penetrate in a definitive way (Groopman, 2004; Krikorian, Maldonado, & Pastrana, 2020). This emotional state, called **middle knowledge**, is highlighted in a description of Rachel, a 17-year-old who knew she had end-stage cystic fibrosis:

middle knowledge The idea that terminally ill people can know that they are dying yet at the same time not completely grasp or come to terms emotionally with that fact.

> Rachel said . . . that when she . . . die(s), she wanted to be here [the hospice] . . . , surrounded by family. . . . And then she said "but I have another way that I'd like to die . . . sitting in a rocking chair and my husband holding my hand."
>
> (quoted in Liben, Papadatou, & Wolfe, 2008, p. 858)

Moreover, as Rachel's final heart-wrenching comment and my earlier discussion implies, when people realize that they are close to death, the emotion that often burns strong is hope (Eun and others, 2017; Schulz and others, 2017). If people are religious, hope may hinge on divine intervention: "God will provide a miraculous cure." Others pin their hope on meditation, emerging new therapies, or exercise. Another source of hope — as Kübler-Ross suggested — is the idea that medical predictions can be wrong: "True, I have that diagnosis, but I know of cases where a doctor told a person with my illness she had six months left and she has been living for 10 years."

Hope, as you can see in the Experiencing the Lifespan box, doesn't always mean hoping for a cure. It may mean wishing you survive through the summer, live to see your wife's book published, and are not bedridden before you die. It can mean hoping that your love lives on in your family, or that your life work will make a difference in the world. (Remember, that's what being generative is all about.) Contrary to what Kübler-Ross implies, even reaching acceptance has nothing to do with abandoning hope. People can understand "I'm dying" and still have future goals and plans.

Experiencing the Lifespan Hospice Hopes

It started on a trip to Washington, David's favorite city. "Something is different with my body. I got out of breath when I took a walk around the Mall." Then came the diagnosis: "You have congestive heart failure. Because your heart muscle is enlarged, fluid is accumulating around your lungs and legs. But with our medicines, you can almost certainly live — with restrictions — for some time."

During the next few years, when my husband's body became badly bloated, we periodically entered the hospital, to drain off the fluid and accumulate another cocktail of pills. Then, in May 2012, due to a side effect of the medicine, my husband went into kidney failure, and we rushed to the hospital again. Just as the frantic staff was poised to transfer David to endure another heroic intervention, our cardiologist entered the room: "I'm referring your husband to hospice," he tersely stated. "There is nothing more we can do." We left the hospital that beautiful late spring afternoon to await death.

Those last few days turned into more than 9 months. With the help of just one pill to control his symptoms, David got better. He was able to spend that summer and most of the fall walking around on his own. On the December day we finally needed to order a hospital bed, I served chili and chocolate chip cookies for dinner. Then, David just closed his eyes and died.

My husband's hope in hospice had been to live through the summer, enjoying nature and spending time sitting with me by the pool. He wanted to be alive to hold the third edition of this book, due in November, in his hands. He hated the idea of being bedridden during his final days. Hospice granted David all three of his final wishes.

Twin Design/Shutterstock

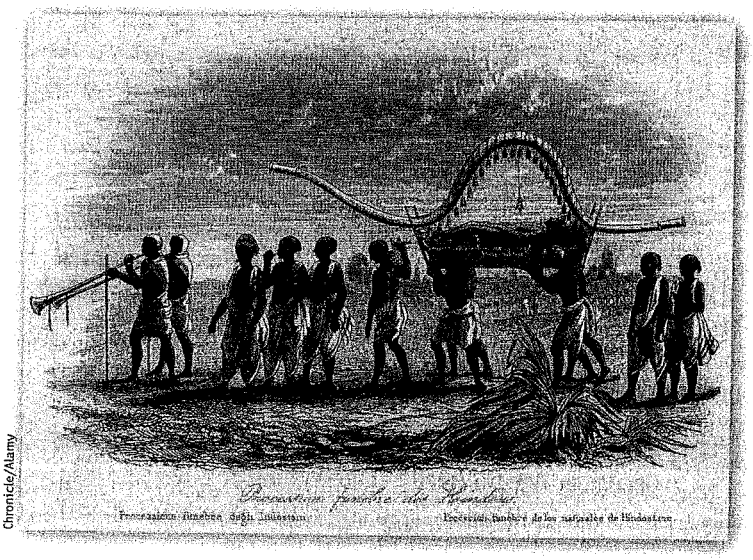
Being deprived of life as a husband and father at an off-time age seems totally "against" nature and unfair, which makes this man's death in his thirties impossibly hard for loved ones.

Heart failure epitomizes that common twenty-first-century pathway to death. People have good days and bad days. They live for years in the shadow of death. Although extended and ultimately fatal chronic illnesses can strike at any age (recall, for instance, the example relating to cystic fibrosis), most often, as with my husband, they occur *on time* in terms of our social clock, in our older years.

Drawing on Erik Erikson's theory, we might predict that facing death in our teens or early adult life is uniquely difficult. How can you reach integrity, the sense that you have fulfilled your life goals, if you have not found your identity, mastered intimacy, or discovered your generative path? Because death is appropriate at their life stage, older people don't show the classic avoidance to death-related words and phrases apparent even during middle age (De Raedt, Koster, & Ryckewaert, 2013). What do we mean by having an appropriate death?

In Search of a Good Death

Insights come from turning to religious sources. From the Old Testament (Spronk, 2004) to Hindu traditions (Gupta, 2011), religions agree that death should be celebrated after a long life. Death should be peaceful, which explains why violent deaths, like suicides or murders, are especially repellent — and why people universally reject the idea of being "tortured" by medical technology at the end of life (Enguidanos, Yonashiro-Cho, & Cote, 2013). Death is "best" when it occurs in the "homeland" (not far away), accounting for why — around the globe — people prefer to die surrounded by loved ones and reject the sanitized, impersonal dying that takes place in intensive care (Zaman and others, 2017).



Chronicle/Alamy

The principle that a good death must occur "near the homeland" is embedded in many religious traditions. This nineteenth-century depiction shows a Hindu funeral ceremony, with the deceased making his final passage surrounded by loving community members while being carried ceremoniously to the grave.

A good death came to my grandmother, one beautiful summer day. Grandma, at age 98, was just beginning to get frail. One afternoon, before preparing dinner for her visiting great-grandchildren (which she insisted on doing), she got in her car to drive to the hairdresser and — on leaving the driveway — was hit by an oncoming car. Of the eight people involved in the accident, no one was hurt but Grandma, who was killed instantly. They said she never felt any pain.

Given that our chance of being killed at our doorstep without frailties at the limit of the lifespan is almost nil, how can we expand on the previous criteria to spell out specific dimensions of a good death? Here are some guidelines adapted from one literature review (Krikorian, Maldonado, & Pastana, 2020):

1. We want to minimize physical distress and be free from debilitating pain.
2. We want to reduce fear and anxiety, and feel in control of how we die.
3. We don't want to financially and emotionally burden loved ones.
4. We want to foster our spirituality and believe there was integrity and purpose to our lives.

Although people worldwide share these core concerns, their importance varies depending on our culture and life stage. Residents of Japan (a nation with collectivist traditions) and old-old residents of the West don't care so much about personal control; they prefer to rely on loved ones and doctors to make decisions about their care. Some people worry greatly about leaving their families financially strapped. Others care less about their own suffering; their only mission is feeling close to God (Krikorian, Maldonado, & Pastana, 2020).

Yes, a strong religious faith can offer peace in one's final days (Braam, Klinkenberg, & Deeg, 2011). But it's not necessary to believe in an afterlife or religion. Actually, in one study, the main dimension that was related to feeling comfortable about dying was having a sense of purpose in life (Ardelt & Koenig, 2006).

So again, Erikson seems right in saying that the key to accepting death is fulfilling our life tasks and, especially, our generative missions. And in Erikson's (1963) poetic words, appreciating that one's "individual life is the accidental coincidence of . . . one lifecycle within . . . history" (p. 268) can be important in embracing death, too:

> Barbara [who had a day to live] turned on the lamp. . . . "Are you afraid?" I asked. "You know, . . . I have . . . comforting thoughts. . . . When fear starts to creep up . . . , I conjure up the idea that millions of people passed away before me. . . . [I]f they . . . did it, so can I."
>
> **(quoted in Groopman, 2004, pp. 137–138)**

Can many people, like Barbara in the previous quote, die at peace? One heartening study suggests that the answer is a qualified yes. Swiss researchers made meticulous records of 80 patients dying of cancer in hospital palliative care units (more about these settings later). Their several-times-per-day observations began when doctors said a patient was within one or two weeks of death.

Yes, fear and pain were not infrequent during these final days. But typically these episodes alternated with long periods of peace. Moreover (from what the researchers could tell), many patients had blissful end-of-life experiences, such as visions of angels or light as they made this transition from the world (Renz and others, 2018).

I must caution that these people were dying in places offering top-notch comfort care. But they do spell out what ideally *can* happen when we confront our final challenge of life.

What are your priorities for a good death? Table 15.1 offers an expanded checklist based on the principles in this section to help you evaluate your top-ranking death goals.

Table 15.1: Evaluating Your Priorities for a Good Death: A Checklist

When you think about dying, rank how important each of these criteria are as: (1) of utmost importance; (2) important, but not primary; or (3) relatively unimportant.

1. Not being a financial burden to my family
2. Being at peace with death—that is, not being anxious about dying
3. Not being in physical pain
4. Having control over where I die—that is, being able to choose whether to die at home or in the hospital
5. Having control over *how* I die—that is, being able to choose whether to be kept alive through medical interventions, or to end my life if I am terminally ill and in great pain
6. Feeling close to loved ones
7. Feeling close to God
8. Feeling that I have fulfilled my mission on Earth or made a difference in the world

Do your top-ranking priorities for dying tell you anything about your priorities for living?

Exploring Grieving

Death is just one chapter in survivors' life story. Although I discussed bereavement in the widowhood section of Chapter 13, let's now focus on how that universal experience should "normally" proceed (see Jordan & Litz, 2014; Penman and others, 2014).

In the first months after a loved one dies, people are absorbed in mourning, crying, perhaps having trouble eating and sleeping. They might be ruminating about their loved one, carrying around reminders, sharing stories, browsing photos, focusing on the person's last days. Some people literally sense their loved one's physical presence in the room (Keen, Murray, & Payne, 2013). Then, after about six months, we expect mourners to recover in the sense of reconnecting with the world (Jordan & Litz, 2014). People still care deeply about their loved one. The person's memory can be evoked at special times such as anniversaries. But this mental image becomes incorporated into the mourner's identity as that person travels through life.

Grief patterns, however, are shaped by each culture's unique norms (Neimeyer, Klass, & Dennis, 2014). In India, as I suggested in Chapter 13, widows were expected to mourn for life (or kill themselves!) when a spouse died. Sometimes, people do their mourning *before* a person's death, such as when the doctor refers a loved one to hospice or after a diagnosis of Alzheimer's disease. While we are tempted to accuse these people of being callous ("She went to that party right after her mother died! She hasn't even cried much!"), you might be surprised to know many bereaved adults don't feel intense distress even during the first few months after a loved one dies (Boerner, Mancini, & Bonanno, 2013).

But suppose it's been more than a year and your relative still cries continually, feels life is meaningless, and seems incapable of constructing a new life. Can grieving last *overly* long?

persistent complex bereavement-related disorder (chronic grief) Controversial diagnosis, appearing in the most recent American Psychiatric Association's *Diagnostic and Statistical Manual*, in which the bereaved person still shows intense symptoms of mourning, or an increase in symptoms, six months to a year after a loved one's death.

Very cautiously, the framers of the American Psychiatric Association's *Diagnostic and Statistical Manual* answer yes. When the person's symptoms continue unabated or become more intense after six months to a year, and that individual shows no signs of reconnecting with the world, mental-health workers can diagnose a condition labeled **persistent complex bereavement-related disorder**, or **chronic grief**.

This label is controversial, in part because it risks reclassifying mourning as a pathological state. Furthermore, aren't some deaths so "bad" that chronic grief is typical — for instance, if your loved one dies in a hospital from COVID-19, or you face the tragedy of outliving your child?

Trending in Developmental Science: Grieving COVID-19

The COVID pandemic seems tailor-made to provoke chronic grief, because this tragedy qualifies as the polar opposite of a good death: People spend their final days isolated from families; their last breaths occur with strangers in the inner recesses of intensive care. In addition, deaths from this illness often occur quickly, without time to emotionally prepare. Frantic families may be forced to make unexpected, cataclysmic end-of-life decisions—"How long should my loved one be on a ventilator?"—without being able to discuss the person's final wishes, or know what that individual wants (LeRoy and others, 2020; see also Block and others, 2020).

Worse yet, with this illness, the person's death might be inadvertently "caused" by mourners themselves. Imagine the incredible guilt if a beloved grandparent was exposed to the virus and then died because of what you did.

Will the pandemic produce an upswing in chronic grief, as some experts predict (Kokou-Kpolou, Fernández-Alcántara, & Cénat, 2020)? Can society mobilize the resources I discuss later in this chapter (such as hospice) to help survivors cope (Etkind and others, 2020)? We do not know. But because COVID often strikes people at an on-time age (old age), this trauma may be less devastating than life's worst tragedy: a child's death.

Mourning Life's Worst Trauma: A Child's Death

As with COVID survivors, a child's death may evoke powerful feelings of guilt: "I didn't protect my baby." As with COVID, parents must cope with the anger that their loved one was prematurely robbed of life: "My child could have made such a contribution to the world!" But most of all, a child's death is *destined* to produce chronic grief because this earth-shattering experience shakes our sense of life being predictable and fair (Neimeyer, Klass, & Dennis, 2014).

Listen to Joan, mired in mourning 13 years after losing her son:

> There is . . . line zero . . . before Joshua died . . . and [after]. . . . There is nothing that . . . hasn't changed.
>
> (Denhup, 2017, p. 352)

And Emma, whose daughter was killed 41 years ago, summed up why parental bereavement never fully ends:

> I'm always thinking . . ."if she were here we would do this or this" . . . you never go back to . . . normal.
>
> (Denhup, 2017, p. 353)

Given that chronic grief is normal when parents confront this intensely abnormal event, is there anything that can mute the pain?

Developmentalists find that parents tend to get (partial) closure if they discuss what is happening with their child during the final weeks — but only if a son or daughter is older and able to understand death (Kreicbergs and others, 2004). In contrast, avoiding that topic is apt to produce enduring regrets. As one anguished mother put it:

> I wish I had him back so that we could hug and kiss and say goodbye. We never said good-bye . . . there was no ending, no finish. . . . Yet he never took the lead . . . he never said, "Ma, I'm dying."
>
> (quoted in Wells-di Gregorio, 2009, p. 252)

Moreover, when a child dies, experts know the simplistic (so-called) helpful advice to "just move on" can't work. Adjusting may *depend* on mentally keeping a son or daughter alive (Albuquerque and others, 2017):

> I talk to her . . . every night. . . . I just say . . . mommy is so proud of you. I'd . . . get his ashes. . . . I'll . . . kiss his little container and say good night . . . before I go to bed.
>
> (quoted in Foster and others, 2011, pp. 427, 428, 429, 432)

> This is the way I honor Matais . . . by working as a volunteer. Matais is immortalized in the things I do, . . . in the beautiful things.
>
> (adapted from Vega, Rivera, & González, 2014, p. 171)

When people face that devastating tragedy, having a beautiful teenage child robbed of life in a school shooting, how can they cope? Listen to how Parkland dad Fred Guttenberg explains his new life mission to advocate for gun safety while *always* keeping his daughter Jaime mentally alive: "I'm certain she is on my shoulder now telling me, 'You can't put up with this. You need to be strong'" (Allen & Shapiro, 2020).

Jose A. Iglesias/El Nuevo Herald/TNS/McClatchy-Tribune/Tribune Content Agency LLC/Alamy

Actually, recovering from these most unfair deaths depends on finding new meaning in one's disrupted life story, and so restoring the idea that the universe is predictable and fair (Neimeyer, Klass, & Dennis, 2014). Grieving parents report they turned the corner when they used their tragedy as a *redemption sequence* — finding solace in adopting a son or daughter's life passion, such as working to combat climate change, devoting their life to combatting gun violence, or, as in the example above, counseling families with an ill child (Vega, Rivera, & González, 2014). One nationwide study tracking bereaved parents showed that the main predictor of adapting well was becoming active in the world

(Infurna & Luthar, 2017). But acting in the world doesn't mean leaving a beloved child behind.

The other important predictor of adjusting, this study revealed, was "social support" — meaning, having someone who understands how you feel (Albuquerque and others, 2017; Dyregrov & Dyregov, 2017; Infurna & Luthar, 2017). As one grieving mother pointed out, "There is one thing we have together. . . . I . . . understand his pain just like he . . . understands mine" (quoted in Albuquerque and others, 2017, p. 1822).

Understanding may not mean talking, but connecting in deeper ways. One wife reported that she and her husband both spent hours sitting in their deceased child's room, doing their own things: "We often understand each other without saying one word" (quoted in Hooghe, Rosenblatt, & Rober, 2017, p. 7). Because grief comes in waves, spouses use their better days to support a mate.

> Since my daughter died . . . we have never been down-hearted at the same time. There is always one of us who is . . . better and can pull the other up.
>
> (quoted in Albuquerque and others, 2017, p. 1821)

Clearly, a child's death can break a marriage and life apart. But these quotes offer lessons for how to adjust to any loss: Keep your connection to loved ones strong. Realize that the best comfort often comes from not talking, but showing you care in other ways. Draw on your memories to enrich other people's lives.

Now that we have discussed the emotions that individuals and their loved ones feel, let's explore what the health-care system is doing to provide the best possible death.

Tying It All Together

1. Sarika is arguing that Kübler-Ross's conceptions about dying are "fatally flawed." Pick the argument she should *not* use to make her case (that is, identify the false alternative):
   a. People who are dying may not want to discuss death.
   b. People who are dying do not go through "stages" in adjusting to impending death.
   c. People who are dying simply accept that fact.
2. If your cousin has recently been diagnosed with advanced lung cancer, he will feel *many different emotions/only depressed/only angry*, but, in general, he should have *hope/a lot of anger.*
3. Mauricio says he feels comforted that his beloved uncle had a good death. Which statement is *least* likely to apply to this man?
   a. Mauricio's uncle died peacefully after a long life.
   b. Mauricio's uncle was religious.
   c. Mauricio's uncle died surrounded by loving attachment figures.
   d. Mauricio's uncle felt he had achieved his missions in life.
4. Imagine you are a psychologist, and a bereaved parent comes to your office. Based on this section, describe your main treatment goals.

Answers to the Tying It All Together questions can be found at the end of this chapter.

SOMETHING TO CONSIDER: Death and Dying: Evaluating Priorities for a Good Death Achieve

The Health-Care System

Learning Outcomes

- List problems with traditional hospital care for the dying person.
- Describe end-of-life instruction and hospital-based palliative care.
- Outline the characteristics and concerns with home hospice.

How does the health-care system deal with death? Let's first take a critical look at two problems with hospital terminal care and then explore modern options designed to confront twenty-first-century death.

What's Wrong with Traditional Hospital Care for the Dying Person?

To understand exactly why hospitals are apt to treat dying patients poorly, let's turn the clock back 50 years to a study in which sociologists entered these institutions and observed how the medical staff organized "the work" of terminal care (Glaser & Strauss, 1968).

The researchers found that, when a person was admitted to the hospital, nurses and doctors set up predictions about what pattern that individual's dying was likely to follow. This implicit **dying trajectory** then governed how the staff acted.

dying trajectory The fact that hospital personnel make projections about the particular pathway to death that a seriously ill patient will take and organize care according to that assumption.

The problem was that dying trajectories could not be predicted. When someone mistakenly categorized as "having months to live" was moved to a unit in the hospital where he was not carefully monitored, this mislabeling tended, not infrequently, to hasten death. An interesting situation happened when someone was expected to die soon and then lived on. Doctors might call loved ones to the bedside to say goodbye, only to find that the person began to improve. This "final goodbye" scenario could play out time and time again. The paradox was that if dying was "off schedule," *living* might be transformed into a negative event!

> One patient who was expected to die [quickly] had no money, but started to linger indefinitely [being paid for as a charity patient in the hospital]. . . . The . . . doctor continually had to reassure [everyone] . . . that the patient [who lived for six weeks more] would soon die.
>
> (quoted in Glaser & Strauss, 1968, pp. 11–12)

The bottom line is that deaths don't occur according to a programmed timetable, yet the health-care system is structured as if they do. This brings up the first basic problem with hospital terminal care.

Dying Is Unpredictable Actually, just like forecasting the weather, with death, uncertainty is built in. In one study spanning 1996 to 2010, the odds of health-care workers accurately predicting the date of a patient's dying were only fifty-fifty (Phillips, Halcomb, & Davidson, 2011). So families and health-care providers still suffer the trauma of being caught "off guard" when faced with that event. When dying proceeds as expected, health-care personnel classify the death as "good." As one medical resident reported: "I felt good that he died in a comfortable way. . . . I just knew it would happen in 24 hours so it doesn't come as a shock" (quoted in Good and others, 2004, p. 944). Unexpected trajectories caused special pain: "She came in for a bone marrow transplant to cure her [cancer] and got pulmonary toxicity and died" (Wells-di Gregorio, 2009, p. 945).

But there is a more critical problem endemic to traditional hospital care. To approach this issue, let's briefly touch on the findings of an interview study exploring what hospitalized patients want health-care staff to provide.

People who spend days in the hospital expect nurses to respond quickly when they need physical help: "I hate . . . [when you are in pain and] pressing the button and they do not come" (quoted in Virdun and others, 2017, p. 593).

But they also want staff to pay attention to their emotional needs: "What . . . made the difference is that [the nurse listened] . . . and treated me with . . . dignity, and dignity was what made it go above and beyond" (p. 595).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Can these overworked nurses devote enough time to the terminally ill patients on their ward? Given the pressure to perform lifesaving heroic measures on people who might survive, the answer is probably no.

Are nurses equipped to fulfill these needs? The answer is probably no. As a recent interview study confirmed, in medical units, the pressure to rapidly minister to the physical body collides with the impulse to provide dignified care:

> INTERVIEWER: What are some of the challenges [of] . . . working as a nurse on this [medical] unit?
>
> NURSE: Time management.
>
> INTERVIEWER: When you have to prioritize your caseload, what happens to [terminally ill] patients?
>
> NURSE: They are usually left at the end of my priority list. . . . I always go towards the other patients — dressing changes, IVs to be put in . . . and then I get really frustrated at the end of the day.
>
> (Chan and others, 2018, p. 457)

Medicine's Focus Is to Cure the Body, Not Provide Sensitive Comfort-Care Today, medicine has remarkable tools to intervene when a body wants to die. Physicians can offer nutrition to people through a tube into the stomach, bypassing the natural metabolic tendency to stop eating in preparation for death. They can put patients on ventilators (machines that breathe for the person) after their lungs have given out. Caring doctors may agonize about using these heroic measures (Liben, Papadatou, & Wolfe, 2008), but their mission to cure makes it difficult to resist the lure of the machines:

> We were realizing that we were going to hurt him [a 40-year-old lung cancer patient who had had multiple surgeries and several strokes] if we . . . kept trying to keep a body alive. . . . And everyone figured "give it a shot."
>
> (quoted in Good and others, 2004, p. 945)

Physicians have other pressures to persist with painful, futile treatments. When people enter the hospital with some eventually fatal conditions, they may be clueless about the optimal plan of care. As one nurse confessed, "[End-stage] cancer is easy [because we know the person can't survive]. . . . But . . . with end-stage liver disease . . . [we're not] sure what's going to happen . . . if [the patient] is going to leave the hospital, or survive" (Chan and others, 2018, p. 459).

The bottom line is that hospitals are designed to promote a cure-at-all-costs approach. This pressure to save lives leaves no space to provide empathic end-of-life care (Chan and others, 2018). Therefore, to *really* help terminally ill patients, we need a different approach.

Offering Caring Terminal Care

What is the health-care system doing to promote humane deaths? Let's look at three different strategies one by one.

Educating Nurses and Doctors

end-of-life care instruction Courses in medical and nursing schools devoted to teaching health-care workers how to provide sensitive care to dying people.

End-of-life care instruction is now a common component of medical and nursing training. By the second decade of the twenty-first century, 9 in 10 medical schools offered instruction on this topic (Dickinson, 2017). Courses cover everything from the best drugs to control pain without "knocking the person out" to the ethics of withdrawing treatment. Instruction may involve assigning reflective writing to sensitize students to the moral complexities involved in prolonging life (Camp and others, 2018; Hoffman and others, 2018), or developing workshops in which student nurses share their personal experiences with death and dying (Hall, Lieto, & Martin, 2018).

Classes are also shifting to the site of much contemporary dying, nursing homes (Kataoka-Yahiro and others, 2017).

We need to do more. In one survey, nursing students reported that they craved more hands-on experiences with dying patients (Glover and others, 2017). Nurses take pride in their role as advocates, the member of the health team who best understands patients' needs. But they, too, chafe at insensitive institutional norms: "It's like, can't we keep that room vacant for just a little while [after my patients] die . . . it hurts my heart that we are not allowed to grieve" (quoted in Montgomery, Sawin, & Hendricks-Ferguson, 2017, p. 51).

Medical students report that watching doctors work with dying patients is vital. As one person said:

> I observed an attending [physician] breaking bad news about a patient who was going to die. He was very sincere and compassionate. . . . I will carry this pearl with me as my education continues.
>
> (quoted in Cripe and others, 2017, p. 81)

Fortunately, rather than relying on random experiences, we now have an entire health-care discipline devoted to providing good deaths.

Redesigning Hospitals to Offer Services for Terminally Ill Patients

A **palliative care service** is a hospital-based or home care program providing sensitive pain and symptom control. Here, certain groups of patients — for instance, old-old people with multiple chronic illnesses or people with advanced cancer — have their treatment managed by specially trained health-care workers. Patients enrolled in palliative care can still get cure-oriented interventions (Mayo Clinic, 2021). However, as their illness becomes terminal, the vigor of life-prolonging treatments shifts to providing the best possible "comfort care."

palliative care service A medical service or unit that is devoted to providing comfort care at the end of life or in the face of a serious illness.

Families give palliative care high marks, compared to traditional end-of-life care (García-Pérez and others, 2009). Doctors who work in this medical specialty are more apt to feel their job is a calling than do their peers in standard medical fields (Yoon and others, 2017). Therefore, by the first decade of the twenty-first century, most major medical centers in affluent nations provided palliative care units or services of this type (Dobbins, 2007).

Robin Nelson/Photo Edit Inc.

Palliative care workers, such as this nurse — caring for a patient who has just had a stroke — find their jobs tremendously fulfilling. In fact, health-care workers who provide palliative care rank their job satisfaction highest of all.

Still, there is a compelling need: Although the percentages vary from nation to nation, an estimated 40 million people can benefit from palliative care (World Health Organization [WHO], 2020). But sadly, these services are typically only available in rich nations. Less than 1 in 6 people worldwide has access to *any* palliative care (Tanuseputro and others, 2017; WHO, 2020).

The most damning evidence relates to global inequities in morphine use. High-income nations consume 9 in 10 morphine prescriptions — leaving 85 percent of the world's citizens locked out (Zaman and others, 2017). The dismal fact is that, as we move well into the twenty-first century, much of humanity will almost certainly continue to die in agony even though we have simple tools to control their pain (Clark, 2007).

Still, with the best hospital-based palliative service, patients and families don't have ultimate control. They must rely on that third party — health-care workers — to manage their loved one's care. So let's look at the most familiar, well-established strategy to promote dignified deaths — hospice care at home.

Unhooking Death from Traditional Health Care: Hospice at Home

The **home hospice** movement gained momentum in the 1970s, along with the natural childbirth movement (described in Chapter 2). Like birth, hospice activists argued, death is a natural process. We need to let this process occur in the most pain-free, natural way (Corr, 2007).

home hospice Providing sensitive care to dying patients outside of hospitals by giving families the support they need to care for terminally ill people at home.

Jean Pieri/Pioneer Press/AP Images

Death doulas ease people though their final passage of life. Here a person trained in this unique specialty is helping a terminally ill man plan his funeral.

Today, in addition to receiving the array of services described in the Experiencing the Lifespan box below, families caring for patients at home can increasingly rely on death doulas, who, just like traditional birth doulas, offer sensitive end-of-life care (Muthara, 2019). Death doulas are adept at using calming techniques such as visualization and massage. They offer families respite care and can coordinate funeral arrangements during this immensely stressful time (Rawlings and others, 2020).

Death doulas are the newest addition to the well-established home-based hospice teams that have existed for decades. These remarkable multidisciplinary teams swing into operation when a person is referred to hospice, offering care on a part-time, scheduled, or daily basis. They provide 24-hour help in a crisis. Their commitment does not end after the person dies: An important component of hospice care is bereavement counseling. ■

Experiencing the Lifespan Hospice Care: An Incredibly Meaningful Career

What is traditional home-based hospice care really like? For answers, here are some excerpts from an interview I conducted several decades ago with the team (nurse, social worker, and volunteer coordinator) who managed our local hospice.

Usually, we get referrals from physicians. People may have a wide community support system or be new to the area. Even when there are many people involved, there is almost always one primary caregiver, typically a spouse or adult child.

We see our role as empowering families, giving them the support to care for their loved ones at home. We go into the home as a team to make our initial assessment: What services does the family need? We provide families training in pain control, in making beds, in bathing. A critical component of our program is respite services. Volunteers come in for part of each day. They may take the children out for pizza, or give the primary caregiver time off, or just stay there to listen.

Families will say initially, "I don't think I can stand to do this." They are anxious because it's a new experience they have never been through. At the beginning, they call a lot. Then, you watch them gain confidence in themselves. We see them at the funeral and they thank us for helping them give their loved one this experience. Sometimes, the primary caregiver can't bear to keep the person at home to the end. We respect that, too.

The whole thing about hospice is choice. Some people want to talk about dying. Others just want you to visit, ask about their garden, talk about current affairs. We take people to see the autumn leaves, to see Santa Claus. Our main focus is: What are your priorities? We try to pick up on that. We had a farmer whose goal was to go to his farm one last time and say goodbye to his tractor. We got together a big tank of oxygen, and carried him down to his farm. We have one volunteer who takes a client to the mall.

We keep in close touch with the families for a year after, providing them counseling or referring them to bereavement groups in the community. Some families keep in contact with notes for years. We run a camp each summer for children who have lost a parent.

We have an unusually good support system among the staff. In addition to being with the families at 3 A.M., we call one another at all times of the night. Most of us have been working here for years. We feel we have the most meaningful job in the world.

Entering home-based hospice is simple. It requires a physician to certify that the person is within six months of death. Because Medicare fully covers this service, U.S. hospice is available to people on every economic rung (Medicare.gov, 2021).

Figure 15.2 shows how, about three decades ago, the home hospice movement took off. By 2012, roughly 1 in 2 U.S. deaths occurred in home hospice (Cagle and others, 2020). What is this experience *really* like?

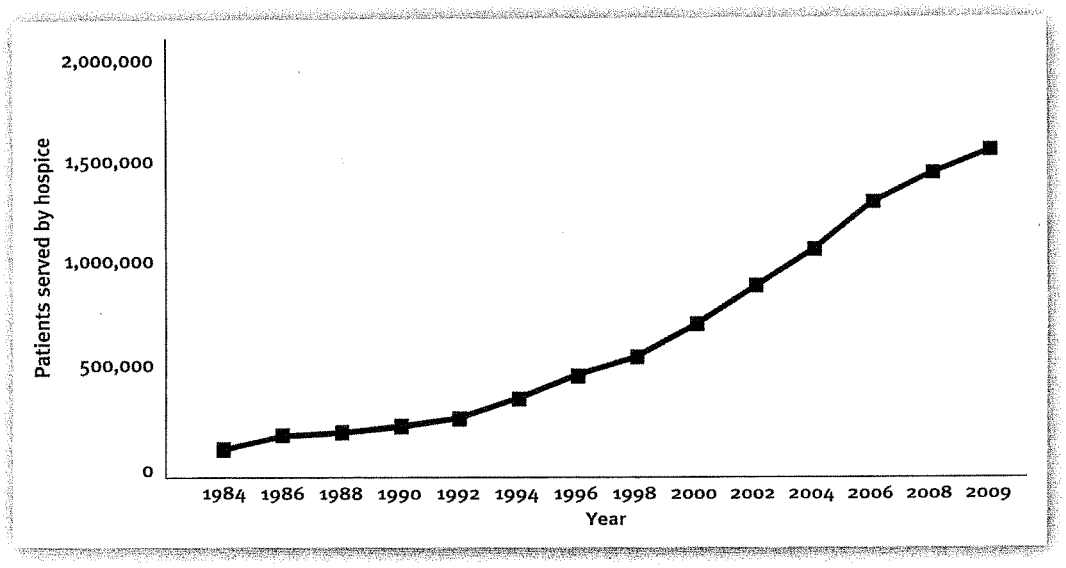


Figure 15.2: Patients served by hospice in the United States, 1984–2009

Notice that the number of people enrolling in hospice grew exponentially, especially during the first decade of the twenty-first century.

Data from National Hospice and Palliative Care Organization, 2011

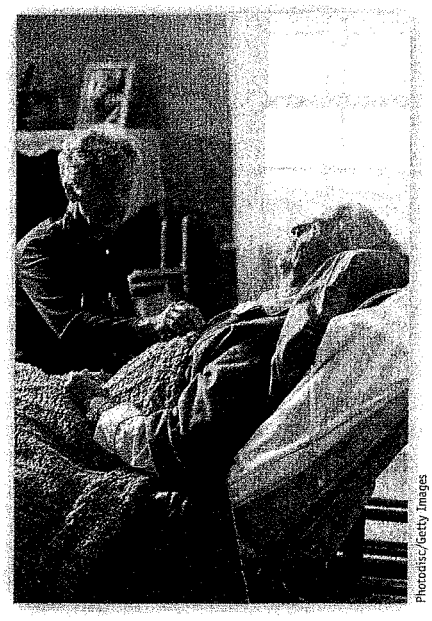
Charting the U.S. Home Hospice Experience

Imagine that your doctor has just made the pronouncement: "I'm referring your spouse or parent to hospice. There is nothing more we can do." You must deal with the shock of grieving and embark on a difficult, uncharted path. Passionate to offer your loved one this final demonstration of love, you are anxious about what lies ahead. What can you expect about the person's pathway to death?

The answer depends on the illness. If the disease is cancer, expect a more precipitous decline. With congestive heart failure or pulmonary disease, the transition to serious ADL problems is apt to be slower during the next days and weeks. Some people enter hospice bedridden and spend their final days comatose. Others, like my husband, are alert and able to perform basic ADL activities until their last moments of life (Harris and others, 2013). This variation partly explains why, although the median hospice stay is roughly three weeks (Aging in Place, 2021), 1 in 10 U.S. patients spends close to a year in hospice care (National Hospice and Palliative Care Organization, 2018).

The uncertainty is scary, but your main fear is seeing your loved one suffer. The box full of medications you just got from the hospice team is frightening. What will you do when the person is very near death (Soroka and others, 2018)? Will you be able to control your family member's pain?

Actually, issues relating to pain control rank among hospice caregivers' primary concerns: Family members worry about getting their loved one addicted (Chi & Demiris, 2017), or they fear that the final powerful opioid dose might hasten death (Kelley and others, 2013; Oliver and others, 2013). As one family caregiver reported: "She had chronic pain. The morphine was in an unusual bottle and I was afraid to give her too much or too little and the dropper wasn't working. It was very scary" (quoted in Kelley and others, 2013, p. 679).



Photodisc/Getty Images

Although caregiving partners wouldn't have it any other way, deciding on home hospice is likely to evoke scary feelings: Will I be able to control my beloved spouse's pain?

Charting the Barriers to Home Hospice

This discussion brings up the hurdles to hospice. As I mentioned earlier, hope is the main emotion people feel when facing a terminal disease. Entering hospice means confronting the reality: "I am going to die." Family members (and patients) are naturally reluctant to contemplate hospice, because there may be exciting new treatments around the corner. (And they may be right! Breakthrough advances such

as immunotherapy can now transform some previous death-sentence diagnoses into curable diseases.)

The same reluctance applies to the hospice gatekeeper — the physician. Doctors overwhelmingly tout the value of hospice (Prochaska and others, 2017). But, for the reasons discussed earlier, they find it difficult to initiate timely end-of-life discussions (Nedjat-Haiem and others, 2017) even though it's best to bring up this topic when a person is first hospitalized (Gieniusz and others, 2017).

Another issue relates to misconceptions about hospice. Even trained health-care workers may not realize that patients can still receive curative interventions after entering hospice (Chan and others, 2018) or continue to see their own doctor while using hospice care (Noh, 2019).

African Americans may be afraid that hospice will hasten death, due to a lifelong fear that traditional medicine has done them wrong (Rhodes and others, 2017). In one focus group study, Black participants expressed fears of spending their final hours with people who do not share their spiritual needs: "If I am transitioning, I am transitioning to my God. . . . And someone who doesn't believe in the living God . . . cannot go through that experience with me" (quoted in Townsend, March, & Kimball, 2017, p. 35).

Most important, hospice depends on family care. Even when patients are aware that their illness is fatal, they may be less than thrilled to have loved ones care for them during their final weeks of life. Imagine being totally taken care of by your family when you have a terminal disease. You don't have any privacy. Loved ones must bathe you and dress you; they must care for your every need. You may be embarrassed about being seen naked and incontinent; you may want time alone to vent your anguish and pain. In a hospital (or inpatient hospice), care is impersonal. At home, there is the humiliation of having to depend on the people you love most for each intimate bodily act.

Care by strangers also equals care that is free from guilt. As I described earlier in this chapter, when people are approaching death, they want to emotionally protect their loved ones — to shield them from pain. Witnessing the toll that your disease is taking on your family may multiply the pain of dying itself.

This explains why, in a rare interview study conducted with people receiving inpatient hospice care in Australia, patients' main worries centered around loved ones. Yes, people said, moving to hospice signaled a depressing step closer to death. But they were relieved to no longer be burdening their families: "My husband is . . . quiet. . . . If he feels he cannot cope, I would rather . . . give him a chance to come here, spend . . . time and then go home and get his head together," reported one woman (quoted in Broom & Kirby, 2013, p. 504). A man appreciated the privacy involved in getting care from strangers. "It's going with a little bit of dignity . . . and not in a mess" (p. 504).

This need to preserve dignity (or save face) with one's family may explain why U.S. home hospice programs are rejected among the very cultural group historically most committed to family care. When researchers polled Chinese heritage older adults living in San Francisco, people reacted with horror when they learned hospice involves care at home. One woman summed up the general feelings when she said, "If I am dying I become very grumpy; it's a good idea to send me to a nursing home" (quoted in Enguidanos, Yonashiro-Cho, & Cote, 2013, p. 996).

Table 15.2 summarizes these section points in "a pros and cons of home care" chart. Now that I have surveyed the health-care options, it's time to continue our search for a "good" twenty-first-century death by returning to the dying person.

Table 15.2: Home Deaths: Pros and Cons

The case against dying at home
1. No worries about family members not being able to control your pain
2. No fear of burdening your family with your care
3. Privacy to vent your feelings, without family members around
4. Avoiding the embarrassment of depending on loved ones for help with your intimate bodily functions
The case in favor of dying at home
1. Avoiding having life-prolonging machines used on you
2. Spending your final days surrounded by the people you care about most
3. Spending your final days in the physical setting you love best
Given these considerations, would you prefer to meet death at home?

Tying It All Together

1. List several ways traditional hospitals work against providing humane terminal care.
2. Based on this section, which statement most accurately reflects physicians' approach to dying patients in traditional health-care settings? (*Pick one.*) (a) Doctors give up too soon on using modern medical technologies. (b) Doctors may feel forced to use modern technologies that just "prolong" death.
3. A doctor has just referred Elijah's husband to hospice. If this couple lives in the United States (*pick the false statement*):
   a. Elijah will likely be caring for his spouse at home.
   b. If Elijah's spouse has heart disease, he may decline more slowly than if he has cancer.
   c. Elijah may be worried about his ability to control his husband's pain.
   d. Elijah will spend a good deal of money on hospice care.
4. Feema is arguing that there's no way she will die in a hospital. She wants to end her life at home, surrounded by her spouse and children. Using the information in this section, convince Feema of the downside to spending her final days at home.

Answers to the Tying It All Together questions can be found at the end of this chapter.

The Dying Person: Taking Control of How We Die

Learning Outcomes

- Compare different advance directives.
- Evaluate active euthanasia and physician-assisted death.
- Outline the principles of age-based rationing of care.

In this section, I'll explore two strategies people can use to control their final passage and so promote a "good death." The first is an option that our society strongly encourages: People should make their wishes known, in writing, about their treatment preferences should they become mentally incapacitated. The second approach is controversial: People should be allowed to get help if they want to end their lives.

Giving Instructions: Advance Directives

An **advance directive** is any written document spelling out instructions with regard to life-prolonging treatment when people are irretrievably ill and cannot communicate their wishes. There are four types of advance directives: two that the individual drafts

advance directive Any written document spelling out instructions for life-prolonging treatment if people become irretrievably ill and cannot communicate their wishes.

and two that other people, called *surrogates*, fill out when the ill person is severely mentally impaired.

living will A type of advance directive in which people spell out their wishes for life-sustaining treatment if they become permanently incapacitated and unable to communicate.

durable power of attorney for health care A type of advance directive in which people designate a specific surrogate to make health-care decisions if they become incapacitated and are unable to make their wishes known.

Do Not Resuscitate (DNR) order A type of advance directive filled out by surrogates (usually a doctor in consultation with family members) for impaired people, specifying that if they go into cardiac arrest efforts should not be made to revive them.

Do Not Hospitalize (DNH) order A type of advance directive inserted in the charts of impaired nursing home residents, specifying that, in a medical crisis, patients should not be transferred to a hospital for emergency care.

- In the **living will**, mentally competent individuals leave instructions about their treatment wishes for life-prolonging strategies should they become comatose or permanently incapacitated. Although people typically fill out living wills in order to refuse aggressive medical interventions, it is important to point out that this document can also specify that heroic measures be carried out.

- In a **durable power of attorney for health care**, individuals designate a specific person, such as a spouse or a child, to make end-of-life decisions "in their spirit" when they are incapable of making those choices known.

- A **Do Not Resuscitate (DNR) order** is filled out when the sick person is already mentally impaired, usually by the doctor consulting with family members. This document, most often placed in a nursing home or hospital chart, stipulates that if a cardiac arrest takes place, health-care professionals should not try to revive the patient.

- A **Do Not Hospitalize (DNH) order** is specific to nursing homes. It indicates that during a medical crisis, a mentally impaired resident should not be transferred to a hospital for emergency care.

Advance directives have an admirable goal. Ideally, the healthy person offers a road map so that family members and doctors are not forced to guess what care that individual *might* want if permanently incapacitated. However, these documents can be problematic, too.

One difficulty, as I mentioned earlier, is that people are naturally reluctant to contemplate death (Kermel-Schiffman & Werner, 2017). Do you or your parents have an advance directive? In the Netherlands, where people can choose to take their own lives, fewer than 1 in 10 people does (as reported in van Wijmen and others, 2014).

Interestingly, due to a vigorous public health push, polls show that most U.S. adults have some familiarity with advance directives (Kermel-Schiffman & Werner, 2017). An astonishing fraction (2 in 3) of elderly U.S. citizens have taken the step of filling out this kind of document. But, Hispanic and African Americans are less likely to complete advance directives (Choi and others, 2020; Peterson and others, 2019), reasoning that they will trust their future to family and rely on their faith (Boucher, 2017). But, as we learned with the COVID pandemic, advance care planning may be especially important for these very groups (see Block and others, 2020) because ethnic minorities are particularly vulnerable to dying from this disease (see Chapter 14).

Still, there are serious problems with the most well-known advance directive, the living will. Because living wills are vague, these documents are subject to misinterpretations (Cicirelli, 2007): Does "no aggressive treatments" mean not putting in the feeding tube that has allowed my aunt to survive for seven years after brain surgery? When your grandma wrote she wanted "No heroic measures," what *exactly* did she mean?

While we might think the solution would be to come up with specific checklists ("I don't want to be on a ventilator, but I do want a feeding tube"), can we expect people to make these detailed decisions? How many of you *really* know what being on a ventilator or having a feeding tube entails? A particular issue arises with the most terrifying fatal diseases (such as Alzheimer's), as some of us might vow, "If I have that illness, I'll want to end my life." But experts advise against making illness-specific documents because decisions made when you are healthy might be very different from when you are confronting any particular disease (Sulmasy, 2020). (Who knows how I will feel if I really have Alzheimer's or another incurable condition like ALS?) Therefore, the ideal strategy is to have a series of discussions with loved ones, and choose a specific family member who, in consultation with the physician, makes the final choice (van Wijmen & others, 2014; see Sulmasy, 2020).

This means the best advance directive is a durable power of attorney for health care. Granted, deciding on a single family member to carry out one's wishes can evoke jealousy ("Why did Mom choose my brother and not me?"). It doesn't ensure mistakes won't occur. Suppose after giving your so-called reliable daughter power of attorney, she elopes with a money-grubbing third husband and you realize that you made the wrong choice? Still, having a defined proxy — but making sure to sit down and regularly discuss your wishes with the family — can reduce the conflicts when you believe that Mom's suffering should not be prolonged, while your sister insists that treatment continue at all costs. These sibling disagreements are tailor-made to poison family relationships for years (or life).

By now, some readers may be feeling uneasy — not about keeping people alive too long, but about the opposite problem: letting them die too soon. Let's ratchet up the anxiety as we move to the next step in the search for death with dignity: helping people take their own lives.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Experts advise older people to regularly have frank conversations with family long before they prepare a durable power of attorney for health care.

Deciding When to Die: Active Euthanasia and Physician-Assisted Death

> Mrs. Boyles was terminally ill, in excruciating pain and begged Dr. Cox to end her life. . . . As an act of compassion, he injected potassium chloride (a fatal drug). . . . Told to "disregard the doctor's motives" a jury . . . convicted Dr. Cox [of murder].
>
> (as reported in Begley, 2008; quotes are from pp. 436, 438)

How do you feel about this doctor's decision and the jury's judgment? If you were like many people in Great Britain, you would have been outraged, believing that Dr. Cox was a hero because he acted on his mission to relieve human suffering rather than follow an unjust law.

Let's first make some distinctions. **Passive euthanasia**, or withdrawing potentially life-saving interventions such as a feeding tube, is perfectly legal. (That's what advance directives specify.) But Dr. Cox's response qualified as **active euthanasia** — taking *action* to help a person die. Active euthanasia is illegal in every nation except the Netherlands, Belgium, Luxembourg, Colombia, Canada, and Spain. However, as of this writing (2021), a variation of active euthanasia called **physician-assisted death** is legal in Switzerland, Germany, parts of Australia, California, Colorado, the District of Columbia, Hawaii, Montana, Maine, New Jersey, Oregon, Vermont, and Washington State. Under strict conditions, at a terminally ill patient's request, physicians can prescribe a medication the individual can personally take to induce death.

passive euthanasia Withholding potentially life-saving interventions that might keep a terminally ill or permanently comatose patient alive.

active euthanasia A deliberate health-care intervention that helps a patient die.

physician-assisted death A type of active euthanasia in which a physician prescribes a lethal medication to a terminally ill person who wants to die.

As the judge in the above trial spelled out, the distinction between the two types of euthanasia lies in intentions (Dickens, Boyle, & Ganzini, 2008). When we withdraw some heroic measure, we don't specifically wish for death. When doctors give a patient a lethal dose of a drug or prescribe that medicine, they *want* the individual to die.

Although active euthanasia is typically against the law, surveys suggest practices that hasten death do routinely occur (Chambaere and others, 2011; Seale, 2009). To take a classic example, doctors may sedate a dying patient beyond the point required for pain control, and so "accelerate" that person's death. Hospice workers report that some patients actively hasten their own deaths by "inadvertently" imbibing too many pain-control pills (Gerson, Preston, & Bingley, 2020).

Polls show widespread public acceptance of assisted death in Western Europe and the United States (Braverman and others, 2017). But this is not true among most clergy members (Mason and others, 2017) and in Central Europe, where most residents believe terminating a life is *never* justified (Cohen and others, 2013). Why?

One reason is that killing violates the religious dictum that only God can give or take a life. Therefore, the fact that people in nations like Poland and Hungary are more apt to be highly religious may partly explain this attitude split. Apart from religious considerations, there are other reasons to be leery about taking this step.

Critics fear that legalizing euthanasia will allow families to "pull the plug" on people who are elderly and impaired. This argument may explain why, in 2015, the U.K. parliament voted down an Assisted Dying Bill (Monteverde, 2017). Even when someone requests help to end his life, a patient might be pressured into making that decision by unscrupulous relatives who are anxious to get an inheritance. Governments might be tempted to push through euthanasia legislation to spare the expense of treating seriously disabled citizens — offering another reason why residents in authoritarian Central European nations are apt to reject assisted death (Cohen and others, 2013).

Older people may reject physician-assisted dying, based on upsetting personal encounters: "She [my niece] thought that I should be euthanized," reported one horrified woman. "And she actually said to me [when I was ill], 'If you were my dog, I would shoot you to put you out of your misery'" (quoted in Malpas and others, 2014, p. 356).

Another issue relates to where to draw the line. Should we allow people to choose death when they have a painful chronic condition, but may not be fatally ill? Suppose the person is simply chronically depressed (Blikshavn, Husum, & Magelssen, 2017)? Can permitting assisted death *ever* be an ethically acceptable choice?

There are excellent arguments on the other side. Should patients be forced to unwillingly endure the pain and humiliation of dying when physicians have the tools to mercifully end life? Knowing the agony that terminal disease can cause, is it humane to stand by and let nature take its course? Do you believe that legalizing active euthanasia or physician-assisted death is a true advance in caring for the dying person, or the beginning of a "slippery slope" that might end in sanctioning killing anyone whose quality of life is impaired?

Developmental Psychology Videos

Understanding the End of Life: Interview with Barbara Coombs-Lee

In this video, nurse practitioner and death with dignity activist Barbara Coombs-Lee summarizes the trajectory of modern death and dying and the unique experiences of terminally ill people. Achieve

A Looming Social Issue: Age-Based Rationing of Care

There obviously is an age component to the "slippery slope" of withholding care. As I suggested earlier, people with DNR or DNH orders in their charts are typically elderly, near the end of their natural lives. We already use passive euthanasia at the upper end of the lifespan, holding off from giving aggressive treatments to people we deem "too frail." Should we formally adopt the principle "don't use death-defying strategies" for everyone after they reach a certain age?

Daniel Callahan (1988), a prominent biomedical ethicist, argued that the answer must be yes. According to Callahan, there is a time when "the never-to-be-finished fight against death" must stop. Let's read Callahan's two arguments in favor of **age-based rationing of care:**

age-based rationing of care The controversial idea that society should not use expensive life-sustaining technologies on people in their old-old years.

1. After a person has lived out a natural lifespan, medical care should no longer be oriented to resisting death. While stressing that no precise cutoff age can be set, Callahan puts this marker at around the eighties. This does not mean that life at this age has no value, but rather that when people reach their old-old years, death in the near future is inevitable and this process cannot be vigorously defied.
2. The existence of medical technologies capable of extending the lives of elderly persons who have lived out a natural lifespan creates no presumption that the technologies must be used for that purpose. Callahan believes that the proper goal of medicine is to stave off premature death. We should not become slaves to our death-defying technology by blindly using each intervention on every person, no matter what that individual's age.

Age-based rationing of health care is poised to become an important affluent-world issue as the baby boomers enter advanced old age, and governments grapple with the astronomical health-care costs involved in keeping impaired elderly citizens alive for years. It may become an immediate pressing issue if another pandemic flares up and stretched-beyond-capacity ICUs must make difficult decisions about which patients most merit care.

Do you think Callahan is "telling it like it should be" from a logical, rational point of view, or do his proposals make you cringe? Should we rely on markers such as life expectancy or quality of life to allocate who does or doesn't receive medical care?

Final Thoughts: Love Across the Lifespan

Whatever your answer, notice that as we approach death, our life comes full circle, and we care only about what mattered during our first years of life — being connected to the people we most love. True, self-efficacy is important. But, when we come right down to it, attachment outweighs everything else!

Who are your special attachment figures, the significant others who made you the person you are today? Can you list these all-important people, and reach out and contact them personally to offer your gratitude and enduring love? After all, as you learned from reading this book, loving (and sharing our feelings of love) is what living is *really* all about!

Tying It All Together

1. Your mother asks you whether she should fill out an advance directive. Given what you know about these documents, what should your answer be?
   a. Go for it! But fill out a living will.
   b. Go for it! But you need to regularly discuss your preferences with each of us and complete a durable power of attorney.
   c. Avoid advance directives like the plague because your preferences will never be fulfilled.
2. Latoya and Finneas are arguing about legalizing physician-assisted death. Finneas is furious that this practice is not legal and feels that "people should have the right to die." Latoya is terribly worried about formally institutionalizing this practice. Using the points in this section, first make Finneas's case, and then support Latoya's argument.
3. Poll your class: How would your fellow students vote if they were on the jury deciding Dr. Cox's case? If you were the ward nurse, would you have reported this doctor's decision to the police?

Answers to the Tying It All Together questions can be found at the end of this chapter.

SUMMARY

Setting the Context

Today, we have three major pathways to death: (1) People die suddenly, without warning; (2) they steadily decline after being diagnosed with a fatal disease; or, (3) most often, they battle an ultimately fatal, chronic condition for a prolonged time. Before modern medicine, people died quickly and everyone had hands-on experience with death. Then, during most of the twentieth century, medical science relocated dying to hospitals, and people avoided talking or thinking about death.

During the past half century, Western attitudes changed. Doctors now openly discuss potentially fatal diagnoses, and society has health-care alternatives devoted to easing people's passage to death. We also urge everyone to discuss their end-of-life preferences, although mentioning death is still forbidden in some cultural groups.

The Dying Person

Elisabeth Kübler-Ross, in her **stage theory of dying**, proposed that people pass through *denial, anger, bargaining, depression,* and *acceptance* when learning they have a fatal disease. However, we cannot take this landmark theory as the final truth. Patients often shy away from discussing death. They may not want doctors to be totally honest about their prognosis. Dying people feel many different emotions — especially hope. Rather than emotionally approaching death in "stages," people may experience a state called **middle knowledge**, both knowing and not fully comprehending their fate. Even when they accept death, terminally ill people still have life goals.

Religious sources showcase the defining qualities of good deaths: It's best to die at peace after a long life, surrounded by our loved ones. Specifically, people want to die relatively free of pain and anxiety,

feel in control of how they die, and end their lives feeling close to their attachment figures. Believing that we have fulfilled our purpose in living and appreciating that death is part of the universal human cycle of life is also important in accepting death.

Our culture has clear conceptions about typical mourning. After an initial period spent absorbed with their loss, we expect people to recover emotionally after about a year. Mourners who still show intense symptoms after this time are diagnosed with a controversial mental health condition called **persistent complex bereavement-related disorder**, or **chronic grief**.

However, chronic grief may be typical in the face of cataclysmic events like COVID-19 and especially when parents face the death of a child. In this traumatic situation, it helps to openly discuss dying (if that child understands what is happening) and to keep the child "alive" in one's thoughts. Transforming these deaths into a redemption sequence allows grieving parents to restore a sense of life as predictable and fair. Marriages can become closer as couples seek comfort from the one person who can understand their pain: their spouse.

The Health-Care System

A classic study of **dying trajectories** showed that, since dying doesn't proceed according to a "schedule"—but medical personnel assume it does—the way hospitals manage death leaves much to be desired. Because traditional medicine is focused on cure-at-all-costs, the pressure to use futile heroic measures also impairs humane care at the end of life. Remedies include: (1) offering **end-of-life care instruction** to health-care personnel; (2) establishing **palliative care services**; and (3) relocating dying from hospitals to home-based hospices.

Home hospices in the United States offer backup services that allow families to let their loved ones spend their final months dying naturally, at home. Family caregivers can expect different trajectories to death depending on the person's illness. They confront scary issues relating to pain control. It may be hard for doctors and families to label patients as dying; also, minorities may have unique hospice concerns. Home deaths may not be the best choice when attachment-related issues, such as not wanting to burden loved ones, matter most to people facing a fatal disease.

The Dying Person: Taking Control of How We Die

Advance directives provide information about whether to use heroic measures when individuals can no longer make their treatment wishes known. These documents include the **living will** and **durable power of attorney for health care**, filled out by the individual while healthy, and **Do Not Resuscitate (DNR)** and **Do Not Hospitalize (DNH)** orders, filled out by surrogates when the person is mentally impaired. The best advance directive is the durable power of attorney, in which a person gives a specific family member decision-making power to determine end-of life care.

With **active euthanasia** and **physician-assisted death**, physicians move beyond **passive euthanasia** (withdrawing treatments) to actively help fatally ill people who want to end their lives. Paramount among the objections to legalizing active euthanasia is the idea that we may open the door to killing people who don't really want to die.

A related issue is **age-based rationing of care**, whether to hold off on using expensive death-defying technologies with people who are old-old. At this moment, age-based rationing of care is poised to move center-stage in Western nations, as the massive baby boom cohort enters their old-old years. The timeless message of this chapter—and the book—is that love (or, in developmental science terminology, our attachments) is at the core of human life.

KEY TERMS

active euthanasia, p. 445
advance directive, p. 443
age-based rationing of care, p. 446
Do Not Hospitalize (DNH) order, p. 444
Do Not Resuscitate (DNR) order, p. 444
durable power of attorney for health care, p. 444
dying trajectory, p. 437
end-of-life care instruction, p. 438
home hospice, p. 439
Kübler-Ross's stage theory of dying, p. 429
living will, p. 444
middle knowledge, p. 431
palliative care service, p. 439
passive euthanasia, p. 445
persistent complex bereavement-related disorder (chronic grief), p. 434
physician-assisted death, p. 445

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ANSWERS TO Tying It All Together QUIZZES

Setting the Context

1. (b)
2. slowly and erratically; an age-related chronic disease
3. Ché, because today we openly discuss death and are making efforts to promote dignified dying

The Dying Person

1. (c)
2. many different emotions; hope
3. (b)
4. Your goal is to restore the person's sense of meaning in life, ideally by helping that individual transform the loss into a redemption sequence; also, you might want to get the person to lean on a spouse for comfort, although partners don't need to openly discuss their mutual pain.

The Health-Care System

1. We cannot predict when people die, even though hospitals are structured as if we could. Medicine is focused on preserving life, so doctors are under pressure to persist with futile treatments, rather than focusing on providing the best comfort care. The pressure to focus on patients' physical needs makes it difficult to give dying patients the emotional attention they deserve.
2. (b)
3. (d)
4. Here's what you might say to Feema: Would you feel comfortable burdening your family 24/7 with your care or having them manage the health crises that would occur? How would you feel about having loved ones see you naked and incontinent—would you want that to be their last memory of you? Wouldn't it be better to be in a place where trained professionals could competently manage your physical pain?

The Dying Person: Taking Control of How We Die

1. (b)
2. *Finneas's case:* We are free to make decisions about how to live our lives, so it doesn't make logical sense that we can't decide when our lives should end. Plus, it's cruel to torture fatally ill people, forcing them to suffer fruitless, unwanted pain when we can easily provide a merciful death. *Latoya's argument:* I'm worried that greedy relatives might pressure ill people into deciding to die "for the good of the family" (that is, to save the family money). I believe that legalizing physician-assisted death leaves the door open to governments deciding to kill people when they think the quality of their life is not good. Furthermore, only God can take a life!
3. Here your answers may vary in interesting ways. Enjoy the discussion!

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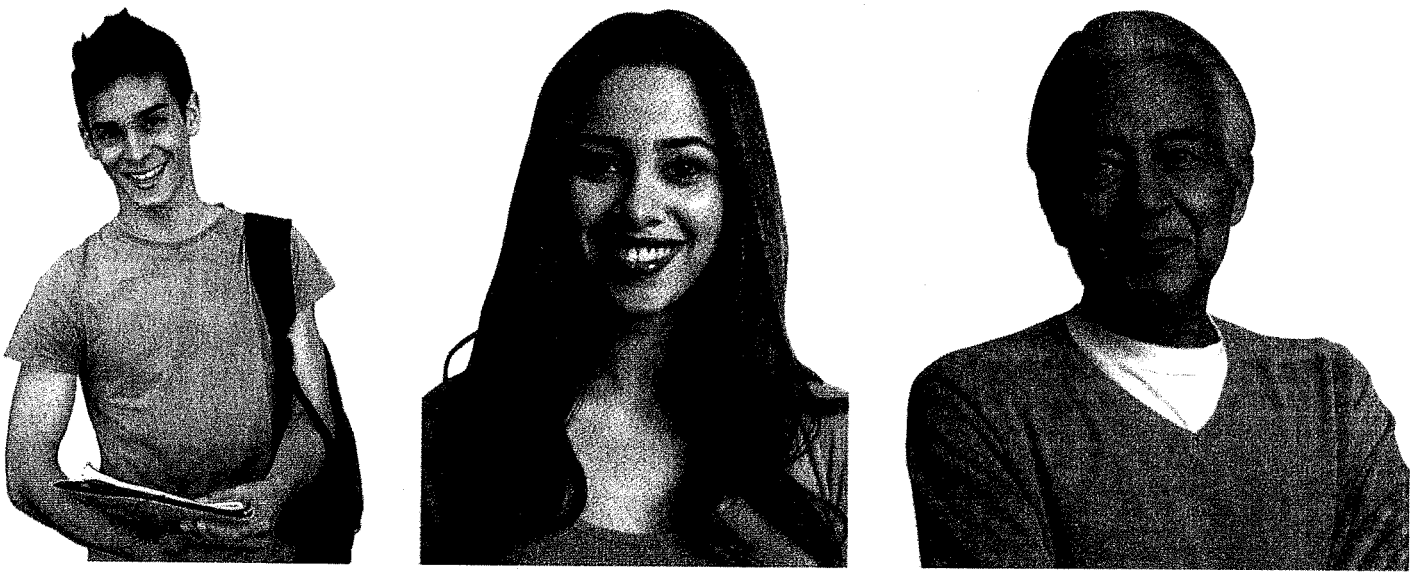

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Final Thoughts

Now that we have reached the end of our lifespan journey (whew!), it's time to step back and scan the scene. Here is how I would boil down these 400-plus pages into four top-ranking lessons about life.

Lesson 1: Attachment (Love) and Autonomy (Separation) Drive Development We can see these competing influences in infancy and toddlerhood, when babies attach to their caregivers and vigorously express their blossoming sense of self by saying "no" (Chapters 3 and 4). These forces play out during elementary school, when children bond with friends and compete to climb the status rungs (Chapter 6). They flower during adolescence and emerging adulthood, when we disengage from our parents, struggle to construct an identity, and search for adult romance (Chapters 9 and 10). They power our passion to prove ourselves at work and connect lovingly with children and grandchildren and a spouse (Chapters 11 and 12). Yes, separation, competition, and the urge to dominate our fellow humans (aka bullying) define humankind; but prosocial behavior (caring) is even more basic to our biology too.

Lesson 2: Society Shapes Development Still, the way that these passions play out depends on the wider environment. From the studies showing that efficacious neighborhoods produce competent parents and children (Chapter 7) to the power of political movements in combatting racism (Chapter 6), or the poisonous effect income inequality has on upward mobility (Chapters 7 and 10); from living in nursing homes in old age (Chapter 14) to surviving to later life (Chapter 1) — our unique culture shapes our travels through the world.

Lesson 3: Thinking Is at the Core of Development But it's really our ability to reflect on our feelings (tracked throughout childhood) that explains *how* we grow as human beings. Whether we call this trait *mind-mindedness* (Chapter 4), *theory of mind* or *concrete operations* (Chapter 5), *executive functions* (Chapter 6), or *wisdom* (Chapter 12), our capacity to step back and think about life is what makes our species unique.

Lesson 4: Development Is Complex (and Defies Generalizations!) And, of course, we can't understand each person without considering many forces—from culture to biology, from parenting to schools, from socioeconomic status to cohort, and everything else! Does personality change or stay the same as we age? What will be the impact of the social media revolution and the COVID-19 pandemic on human beings? I hope that if a friend asks you these questions, you automatically reply, "There are no simple answers." We must step back and consider the *entire* context of a person's life.

Now I'd like you to think about what you learned from this book. Can you write down four insights you found especially important? Keep a copy of your list. Perhaps you can refer to these lessons as you travel through life.

Janet Belsky