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Coping with Death, Dying, and Bereavement

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John is 74 years old and six months ago he became a widower after almost 50 years of marriage. His wife Rose was ill for several years and for much of that time he did his best to care for her at home. Shortly after she was diagnosed, Rose made her wishes known in writing that she did not want any heroic measures used to keep her alive if things got to the point where she was in great pain or in a comatose state. As Rose's illness progressed, John gradually took over all the household tasks. He had always been in charge of paying bills, making household repairs, and mowing the lawn. However, he was a novice at doing laundry, cooking meals, and cleaning the house. John was astounded at the day-to-day effort involved in taking care of the things his wife always did. Toward the end of Rose's life, John was having great difficulty taking care of her needs. He was forced to find a nursing home that could provide the type of care that she required, and her last few months were spent in a hospice, where she received excellent palliative treatment. Throughout the final months of Rose's life, John had all he could do to keep things going at home but still visit Rose every single day. Now the hours he used to spend visiting Rose in the nursing home and hospice have left a big empty void in his life. Recently, one of Rose's female acquaintances, a widow, invited John to her home for dinner. Although he is flattered, he is not at all certain he is ready to become involved in a relationship. Among other things, he is concerned about what his adult children will think if he starts dating. For now, John thinks he should try to form new social connections by volunteering as a docent at one of the local museums.

Death and Dying

Human development cannot be fully understood without attention to death and bereavement (Kastenbaum, 1999), and in older adulthood many people spend time anticipating the end of their own lives (Lawton, 2001). We will discuss death and dying first, followed by bereavement, which often follows the loss of a loved one.

When does death occur? Death is the irreversible cessation of biological functioning. In the past, the moment of death was determined by signs such as lack of respiration, pulse, or response to stimulation as well as lowered body temperature. However, partly because of modern life-support technology that maintains respiration and other vital functions, it is now more difficult to detect when the exact moment of death occurs (Corr, Nabe, & Corr, 2009).

Today many life-sustaining treatments (LSTs), such as mechanical ventilation and artificial nutrition and hydration, are available. LSTs can prolong life even when patients are at death’s door (Gold, 2011). A controversial issue in both medical and religious worlds is whether the use of LSTs is a moral imperative. For example, are artificial nutrition and hydration considered to be *ordinary care*, which would be required to preserve life? Or do LSTs fall into the category of *extraordinary care*, which would be regarded as non-standard or even experimental? LSTs tend to be costly, so it is important to consider not only is the duration of LSTs that would be needed to extend a terminally ill patient’s life but also the patient’s quality of life both while LSTs are being administered and after they are terminated.

Dying is the process of physical decline that ends in death (Kastenbaum, 2007). However, with modern medical advances, people with life-threatening illnesses can sometimes live for months or years. Surgery, new medications, and improved organ donation techniques have extended the interval between the onset of some illnesses and the actual event of death. Indeed, it is often not clear whether or not a person has entered the dying process.

Thanks to improvements in public health and sanitation, relatively few young people in the United States and other developed countries die from acute infectious diseases, and we take it for granted that most of us will live long lives. Table 12.1

Table 12.1 Death rate per 100,000 population by age range in the United States (2007)

Age range (years)	Death rate
25–34	104.9
35–44	184.4
45–54	420.9
55–64	877.7
65–74	2,011.3
75–84	5,011.6
85+	12,946.5

Source: cdc/nchs/data/nvsr/nvsr_19.pdf/Table5.

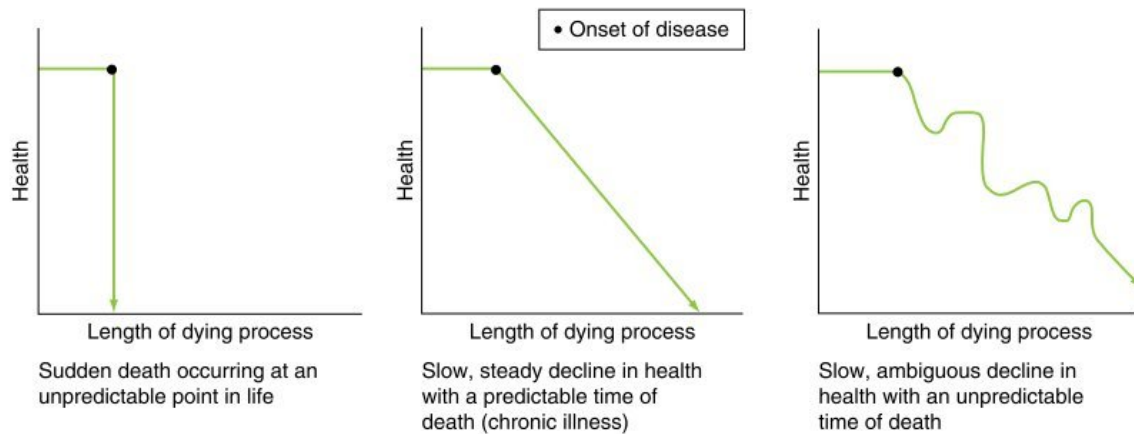


Figure 12.1 *Contrasting dying trajectories.*

Source: Corr et al. (2009, Fig. 2.2, p. 33).

shows death rates in the United States per 100,000 population in various adult age groups. Note that the rate goes up from the earlier to the later adult years. However, the increase in death rates is dramatic in the old-old (75–84) and especially the oldest-old (85+) years, illustrating that death is most likely to occur in old age. As discussed in Chapter 3, the leading causes of death among older adults in the United States are chronic illnesses such as heart disease, cancer, and stroke.

The Dying Trajectory

The rate of decline in functioning that precedes death can vary considerably (see Figure 12.1). With a sudden **dying trajectory**, death of a healthy individual occurs instantaneously, as in a fatal car accident or after a brief acute illness. At the opposite extreme is the gradual trajectory – death is certain to occur eventually but not immediately. For example, a person could be diagnosed with an illness or condition with no known cure, but medical treatments could extend life for weeks, months, or years. Gradual dying trajectories are common in modern technologically advanced societies, which means that the duration of the dying process is much longer than it once was (Gold, 2011). John's wife Rose (described at the beginning of the chapter) had a gradual dying trajectory – she was ill for several years before her life ended.

A gradual trajectory allows the dying individual time to resolve personal issues such as rifts with family members and to make decisions about the distribution of property to family members, friends, and charities. Additionally, as with Rose, the individual can make choices about medical care (Lawton, 2001). In the case of Alzheimer's disease (AD), discussed in Chapter 11, the dying trajectory is gradual because individuals may live for more than a decade after the diagnosis is made. Tragically, however, individuals with AD lose the cognitive capability that would enable them to prepare for death.

End-of-Life Decisions

Given the likelihood of a gradual dying trajectory, what kinds of decisions can people make ahead of time?

Wills

A **will** is a formal document that states how individuals want their property distributed to heirs upon their death. At the time a will is drawn up, a person must be of sound mind and not subject to undue influence. A will can be changed at any point before death as long as the person remains of sound mind. The most recent version is used to determine the disposition of the deceased individual's property.

The signing of a will must be witnessed by the specific number of people required by state law, and witnesses cannot have any personal interest in the will. Depending on the laws of the state in which a deceased person has lived, handwritten, or unwitnessed ("holographic"), wills may be accepted. However, it is highly advisable to seek professional legal assistance when making a will. A will usually names a personal representative, or executor, who will carry out the business of collecting the property of the deceased individual and notifying those who will receive it. If no executor is named, the court appoints an administrator.

Unfortunately, people often put off drawing up a will, and individuals who die without a valid will are said to have died *intestate*, or without a testament stating their wishes (Corr et al., 2009). Each state has laws governing how the property of an intestate individual will be distributed. Sadly, this may not correspond with what the deceased individual would have wanted, which is why it is important to have a will. Also, a will often specifies the type of funeral or memorial service the individual wishes to have and whether there is a preference for burial or cremation.

The living will

In addition to specifying how property should be distributed upon their death, individuals can specify what type of medical care they would choose in the event they lack the capacity to express their wishes at some time in the future. With a **living will**, a person diagnosed with a terminal illness can have a say in what, if any, medical intervention should be used to prolong life in the event he or she becomes unable to express a preference later. Living wills are also important if there is a tragic accident that results in severe injuries.

The living will is an advance directive that first appeared in 1968, opening the way for public dialogue on end-of-life issues that previously were not usually discussed (Kastenbaum, 1999). The term *advance directive* commonly refers to the individual's wishes for his or her own end-of-life care. The living will instructs physicians and family members about a patient's wishes regarding the use of medical treatments that would artificially prolong the dying process if death is determined to be inevitable (Mishkin, Mezey, & Ramsey, 1995). Theoretically, a

living will could request that life-prolonging measures be administered even if death is inevitable, but consent to withhold life-prolonging treatments is more typical. In most living wills, the preference is to withhold certain kinds of interventions (“artificial means” or “heroic measures”) so that the dying process can take its own natural course. Also, a living will may give permission for medical personnel to administer “palliative” (pain-reducing) treatments even if such treatments hasten the actual moment of death. John’s wife Rose made her wishes known in writing that no *heroic measures* be used to prolong her life.

Initially, the living will had no basis in law and many physicians and hospitals were hesitant to honor living wills, partly out of fear of malpractice lawsuits but also out of concern that if patients were able to do so, they might change their minds and would want to have LSTs. Recent years have brought greater acceptance of the idea that a competent adult has the right to refuse medical treatment. Today, each state in the United States has procedures for creating a legally valid living will (Mishkin et al., 1995). According to Gold (2011), electronic storage sites, or internet registries, where people can post living wills and other end-of-life wishes, are now available. These sites usually issue cards that individuals can carry so that this information can be accessed by family members, friends, and health care providers. Clearly, however, care must be taken to prevent any occurrence of internet fraud that could affect these registries.

In 1991, federal legislation known as the **Patient Self-Determination Act (PSDA)** was enacted. The PSDA requires that all health-care facilities (hospitals, nursing homes, health-maintenance organizations) that receive funds from Medicare and Medicaid (two government health-care programs, discussed in Chapter 3) provide patients with information on advance directives that could be used should a critical situation arise. Individuals who do not already have an advance directive must be informed about it so they can express their preference for accepting or refusing specific treatments. However, Kastenbaum (1999) points out that health-care facilities vary as to how extensively they explain a patient’s options. Some simply ask patients to endorse one of two statements such as “I want my life to be prolonged as long as possible, no matter what my quality of life” or “I do not want my life prolonged if I will be permanently unconscious.” Unfortunately, not all people are competent to make this decision at the time they enter a hospital or nursing home. It is preferable for people to execute advance directives when they are of sound mind and before they are facing a medical crisis.

Efforts to educate community-living older adults about advance directives have not been very effective in boosting the number who actually execute them. Older adults often express a preference that a family member, close friend, or even a physician, be the one to make treatment decisions for them should they become incapacitated. Cicirelli (1997) asked 388 European American and African American adults ranging from 60 to 100 years of age about the end-of-life decision they would make if they faced a situation in which their quality of life was poor. Interestingly, the majority of these older adults stated they would want

Desired Length of Life and End-of-Life Desires

In a survey conducted in Germany, Lang, Baltes, and Wagner (2007) asked men and women between the ages of 20 and 90 how long they would prefer to live (desired lifetime duration, or DLT). For the majority of the respondents, the DLT was in the mid-80s, although a small number of participants (mostly those older than 80 years of age) wanted to live into their 90s. In addition, when asked how much control they wanted to have over when and how they would die, approximately three-quarters of the respondents expressed a desire for self-determination. Surprisingly, however, only 11% of the respondents had actually completed a living will. Perhaps the internationally polarizing case of Terri Schiavo, a young woman who did not have a written living will and remained in a vegetative state for 15 years before her husband won a battle with her family to have her feeding tube removed, has served to boost people's awareness of how important a living will can be. As described earlier, John's wife Rose made her end-of-life wishes known in writing before her illness progressed.

to continue living, undergoing whatever treatments that might extend their lives. However, those who favored maintaining life were more likely to be African American, to have lower socioeconomic status (less education and lower occupational level), and to have stronger religious feelings. These individuals had less fear of dying but greater fear of destruction of the body. In contrast, those who favored ending their lives tended to be European American and to have higher socioeconomic status and weaker religious feelings. These individuals had more fear of the dying process but less fear of destruction of the body.

The durable power of attorney in health-care matters

The **durable power of attorney in health-care matters** is an advance directive that is separate from the living will. With this document, the individual designates a trusted relative or friend who can make health-care decisions on his or her behalf in the event of serious incapacitating physical illness or mental incapacity. Without this document, the medical system generally relies on relatives to make such decisions. However, a person can use this document to specify in advance which of several family members should be the final decision maker. This can be crucial when relatives disagree about what medical decision should be made (Mishkin et al., 1995), or when the individual prefers that a friend or companion rather than a relative make health-care decisions.

In sum, the will, living will, and durable power of attorney in health-care matters are all documents individuals can use to plan for a time when they themselves are unable to make important decisions about their property or medical care. It is best to give a relative or close companion the name of the lawyer who has a copy of the will. Also, a relative or good friend as well as a health-care provider should have copies of the living will and durable power of attorney in health-care matters because these documents serve no purpose if nobody knows where they are.

Anxiety About Death

It may seem paradoxical that older adults are closest to death but they express less fear of, or anxiety about, death compared to middle-aged adults (Kastenbaum, 1999; Fortner, Neimeyer, & Rybarczyk, 2000). One reason for the higher anxiety among middle-aged adults may be that many have children who are not fully launched into independent lives and they may also be helping elderly parents. Their anxiety about death could stem from concern about the well-being of those who would be left behind. In contrast, older adults probably have children who are fully grown, independent adults, so they may worry less about leaving their children to fend for themselves. Also, many older adults feel that they have had time to carry out whatever they planned to do in their lives and hopefully they consider their lives to have had purpose and meaning. However, this is not to say that older adults have no concerns. Gold (2011) describes research indicating that adults in the old-old (over 80) age group do worry about how they will die, where they will die, and whether their dying process will be a burden for their families.

According to Thorson and Powell (2000), young adults find it difficult to imagine there might not be a long future stretching out in front of them. In contrast, older adults are more aware that death is inevitable and some feel that the future does not hold as many possibilities as it did earlier in life. Also, older adults may express less anxiety about death because they have experienced the death of friends and loved ones with increasing frequency with the passing of time. In some sense, they are socialized to the possibility of death. It is not uncommon for older adults to read the obituaries in local newspapers on a daily basis. Many older adults are not so much afraid of death as they are about the circumstances of dying. They wish to die with dignity.

Clearly, however, any conclusion that older adults are less anxious than middle-aged adults about death must be qualified by their individual coping styles and social supports as well as the ethnic and religious groups to which they belong (Neimeyer & Fortner, 2006). Fortner et al. (2000) contend that older adults with strong religious beliefs (that is, intrinsic belief in God and belief in the afterlife, though not necessarily frequent church attendance) have less death anxiety than those without strong religious beliefs. However, Wink and Scott (2005) found that among educated older European American men and women (the majority of whom were raised in Protestant families), those who considered themselves moderately religious feared death more than did those either high or low in religiousness. Further study is needed to clarify which aspects of religious belief or practice, or lack thereof, may buffer people against the fear of death.

In comparing European American and African American adults over the age of 60, Cicirelli (2002) found no differences in the fear of death these two groups expressed. However, older adults with more physical problems and those living in institutional settings such as nursing homes expressed higher anxiety about death compared to those in better health who were living in the

community. Perhaps older adults who are dependent upon others feel less in control of their environment and therefore have more anxiety about the circumstances surrounding their death.

Stages of Death and Dying

In spite of its inevitability, death has been, and to some extent still is, a taboo topic in American society. In the 1960s, Elisabeth Kübler-Ross, a Swiss psychiatrist practicing at the University of Chicago Hospital, was approached by theology students who wanted to learn more about terminally ill patients. To humanize the dying process and counteract the tendency she saw in America to depersonalize dying persons, Kübler-Ross invited dying patients to share their thoughts and feelings with these students. Based on interviews with over 200 patients, many of whom were diagnosed with terminal cancer, Kübler-Ross (1969, 1974) noted five stages in the dying process (shown in Table 12.2).

The first of **Kübler-Ross’s five stages of death and dying**, denial, often occurs when the individual is initially diagnosed with a terminal illness. The individual’s initial reaction is often disbelief and a feeling that the diagnosis could not possibly be correct. According to Kübler-Ross, denial serves as a short-term buffer that allows time for the individual to take in the shocking news. As the realization begins to sink in that there is no mistake about the diagnosis, the individual may express anger and resentment that other people are healthy. Later on, some individuals may attempt to strike a bargain for more time or a second chance by promising to be on their best behavior (for example, by strictly following the doctor’s orders or by praying). Possibly related to this stage are some reports of a dip in deaths prior to birthdays and major holidays that is followed by an increase afterward. In the next stage, depression, the individual feels a great sense of loss and sadness that life is coming to an end. There is a tendency to withdraw from emotional attachments to all but a few people with whom the dying individual has the most meaningful relationships. In the final stage, acceptance, the individual reaches a state of peace that the end is near. However, an important factor to consider is whether dying individuals are sufficiently

Table 12.2 Five stages of death and dying

Stage	Example of a dying patient’s response
Denial	No, not me, it cannot be true.
Anger	Why me?
Bargaining	Maybe I will have more time if I pray and ask God nicely.
Depression	I am going to die and that is sad.
Acceptance	I am at peace and ready for death.

Source: Adapted from Kübler-Ross (1969).

Applying Research Box 12.1: Coping With Thoughts of Death

Nathan DeWall and Roy Baumeister (2007) investigated how young adults cope with thoughts about their eventual death. They asked young adult participants questions that were intended to induce thoughts either about their own eventual death or about an unpleasant but not fatal experience (a painful visit to the dentist). Thinking about death did not produce any increase in conscious negative emotions, but it did activate what these researchers consider to be unconscious emotional coping responses: Compared to the young adults induced to think about dental pain, those induced to think about mortality subsequently completed ambiguous

word stems with more emotionally positive words and also favored more positive emotional word associations. This suggests that when forced to contemplate the psychological threat of death, young adults may have an automatic psychological immune system that is outside their awareness but that searches for happy thoughts. Relatedly, researchers on aging and cognitive processes have found evidence for an automatic shift in older adulthood toward emphasizing positive, pleasant information (see Chapter 7 for discussion of the positivity effect). This may help explain how older adults cope with the imminent threat of death.

cognitively intact or at a level of consciousness that will make it possible for them to progress meaningfully through the stages.

Kübler-Ross's stages captured the attention of professionals who deal with death and dying and many adopted her ideas wholeheartedly. Eventually, however, some people leveled criticism at her ideas, contending that dying patients do not necessarily progress through the stages in an orderly manner and furthermore, that not every dying individual goes through all of the stages Kübler-Ross described. For example, not all dying patients bargain for more time, nor do all of them reach the final stage of acceptance. Such criticism was not entirely fair because Kübler-Ross never insisted on hard and fast rules for the stages. In fact, she had pointed out that some individuals remain in the stage of denial right up to the end and that reactions to dying vary considerably depending upon age, specific illness, cultural background, and the dying individual's social network. Also, there may be a series of overlapping reactions during the dying process (Wortman & Silver, 1990). In any case, Kübler-Ross's stages have been a major cornerstone in our thinking about the dying process, and it would be a mistake to underestimate her contribution to lifting some of society's taboos about death and dying.

Not only do Kübler-Ross's stages apply to dying, but they are also helpful for understanding how people deal with the loss of a loved one. An individual with a sudden dying trajectory obviously has not had time to work through the stages, but Kübler-Ross contended that loved ones left behind may go through these stages as they deal with their loss. With a lengthier trajectory, however, close friends and relatives as well as the dying individual himself or herself may experience aspects of Kübler-Ross's stages. In some instances, Kübler-Ross's stages have also been applied to loss through circumstances other than death of a loved one. For example, individuals who separate or divorce may experience feelings similar to those of someone who has lost a loved one through death.

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