CHAPTER 10

Very Late Adulthood

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Chapter Outline
Opening Questions
Key Ideas
Case Study 10.1: Margaret Davis Stays at Home
Case Study 10.2: Pete Mullin Loses His Sister’s Support
Case Study 10.3: Marie Cipriani Is Losing Her Life Partner
Very Late Adulthood: Charting New Territory
Very Late Adulthood in Historical and Cultural Perspective
What We Can Learn From Centenarians
Functional Capacity in Very Late Adulthood
Relationships in Very Late Adulthood
Relationships With Family and Friends
Intimacy and Sexuality in Very Late Adulthood
Relationships With Organizations and Community
The Use of Technology
The Housing Continuum
Spirituality in Very Late Adulthood
The Dying Process
Advance Directives
Care of People Who Are Dying
End-of-Life Signs and Symptoms
Loss, Grief, and Bereavement
Theories and Models of Loss
Culture and Bereavement
The Life Course Completed
Implications for Social Work Practice
Key Terms
Active Learning
Web Resources
Opening Questions

- What are some of the reasons for the fast growth and increased diversity among very-late-life adults, and what are some of the main challenges associated with increased longevity?
- What are some of the implications for intimacy among very-late-life adults as their families and peers die and they become less mobile and independent?
- When working with clients in very late adulthood, what do social workers need to know about how people respond to crises such as severe illness, acquired disability, and loss?

Key Ideas

As you read this chapter, take note of these central ideas:

1. People 85 and older are the fastest-growing segment of the older adult population. Never have so many people lived so long.
2. Among very-late-life adults, women outnumber men 2 to 1, and 4 out of 5 centenarians are women.
3. Because the more frail individuals die sooner, those surviving to very late adulthood tend to be a relatively robust group, but they face an increased incidence of chronic disease and disability.
4. In very late adulthood, individuals continue to desire and need connections to other people.
5. In very late adulthood, spirituality is often associated with making meaning of loss and finding a way to stay connected to others.
6. Very late adulthood is the one life course phase when dying is considered “on time,” and very-late-life adults seem to have less denial about the reality of death than those in other age groups.
7. Theoreticians and researchers continue to try to understand the multidimensional process of grief.

CASE STUDY 10.1

Margaret Davis Stays at Home

Margaret Davis has lived in her small, rural community in southern West Virginia for all of her 85 years. It is in this Appalachian mountain town that she married her grade school sweetheart, packed his pail for long shifts in the mine, and raised their four children. It has been more than 30 years since she answered the door to receive the news that her husband had perished in an accident at the mine. She remains in that same house by herself, with her daughter living in a trailer on the same property and one of her sons living just down the road. Her other son recently moved to Cleveland to find work, and her other daughter lives in the same town but has been estranged from the family for several years.

Mrs. Davis has hypertension and was recently diagnosed with type 2 diabetes. The nurse from the home health agency is assisting her and her daughter with learning to give insulin injections. It is the nurse who asks for a social work consult for Mrs. Davis. The nurse and Mrs. Davis’s daughter are concerned that she is becoming increasingly forgetful with her medications and often neglects her insulin regime. They also suspect that she is experiencing
some incontinence, as her living room couch and carpet smell of urine. Mrs. Davis and her daughter Judy greet the social worker at her home. They have been baking this morning and offer a slice of peanut butter pie. Judy excuses herself to go to her trailer to make a phone call. The social worker asks Mrs. Davis about how her insulin regime has been going and if she feels that she could keep up with the injections. She responds that she has learned to give herself the shots and “feels pretty fair.” The social worker conveys the concern that she may be missing some of the injections and other medications as well. To this she replies, “Oh, don’t worry about me, I’m fine.” The social worker proceeds to ask the sensitive question as to whether she has been having trouble with her bladder or getting to the bathroom. This causes Mrs. Davis to become very quiet. Looking up at the social worker she shares that witches have been visiting her house late at night and have been urinating in her living room. The witches are very “devious,” but because she is a very religious person, she does not feel that they will harm her.

Judy returns to the home and joins her mother and the social worker. Judy voices her concern about her mother’s safety, noting the problems with medications and with general forgetfulness. Judy is able to prepare meals, dispense the medications, and give insulin injections in the morning because she works evenings at a factory. Judy’s daughter, Tiffany, has been staying overnight in the home but complains of her grandmother’s wandering and confusion late at night. As a result, she is often exhausted during her day shifts at a nursing home in the next county and in caring for her small children. When asked about Mrs. Davis’s son’s involvement in her care, Judy responds, “He works and is in the Guard some weekends. He handles mom’s money mostly, and his wife, well, she has her own problems.” Judy also reported that her mother has Medicare, but she was not sure if that would be sufficient to pay for all her mother’s care long-term. Judy is also worried because her old car has been giving her problems lately, and the repairs are becoming expensive. She concludes by stating, “We promised Mom that she would never go to a home . . . we take care of our own.”

—Kristina Hash

—Meenakshi Venkataraman

**CASE STUDY 10.2**

Pete Mullin Loses His Sister’s Support

Pete Mullin and Lucy Rauso, brother and sister, ages 96 and 92, have lived together since the death of Lucy’s husband, Tony, 25 years ago. Pete and Lucy are second-generation Irish Catholic Americans, and Tony Rauso was Italian American. Pete was married in his 30s but had lived alone since his divorce at age 55. Pete and Lucy were both in their early 70s when they decided to pool their limited savings and retirement income to buy a small home in a rural retirement community in central Florida. The promise of a lower cost of living and milder winters, and the fact that many of their friends had moved or died, made it easier for Lucy and Pete to leave the community in Massachusetts where they had spent their entire lives.

Pete has been estranged from his one daughter since his divorce but is in touch with a granddaughter who “found” him when she moved to Florida a few years ago. Lucy has one surviving son in New Jersey and several grandchildren who provide limited financial support and some social support via phone calls and an occasional visit. Pete has enjoyed his life and, despite some difficulty with his vision and hearing, manages to get around well in his familiar surroundings. He is especially fond of tending his orchids in the back porch.

(Continued)
Lucy has just been hospitalized with chronic heart failure and is not expected to make it through the night. A neighbor has brought Pete to the intensive care unit to be with Lucy. Pete states that together he and Lucy managed to provide for each other and served as each other’s durable power of attorney and health care surrogate and in general made it possible for each of them to remain in their home. He wonders what will happen to him after Lucy’s death. He knows that many people his age live in nursing homes, but he prefers to stay in his own home. He wonders if the Meals on Wheels will still come to the home, because their eligibility was based on Lucy’s diagnosis of chronic heart failure. He hopes he will die soon and quickly like Lucy.

The social worker employed for the Meals on Wheels program has been asked to make a home visit within the week following Lucy’s death to reassess Pete’s eligibility for services. The social worker had not realized how much her job would involve working with people who have experienced a major loss, whether death of a loved one as in Pete’s case or the accompanying losses that come with illness, disability, and aging.

CASE STUDY 10.3
Marie Cipriani Is Losing Her Life Partner

Marie Cipriani was born in a small apartment house on the Lower East Side of Manhattan 86 years ago. Just one year before Marie’s birth, her mother passed through Ellis Island with Marie’s three older siblings. Her father and two brothers, already established in the states, eagerly awaited their arrival. Later, when Marie was an adolescent, the family moved to Long Island. Today Marie lives in a modest two-bedroom home that she shares with Irene Wright, her partner of 42 years. Irene, a petite 79-year-old African American woman, has recently been diagnosed with stage IV lung cancer. The disease has progressed rapidly, hastening Irene’s decision to transition to hospice service.

Jessica, the hospice social worker, met with Irene and Marie at their home this Friday afternoon. Marie was making soup while Irene reclined in the warmth of the backyard sun when Jessica arrived. She immediately put the soup on simmer and accompanied Jessica out back to meet Irene. Marie was initially apprehensive as she was not sure how this stranger felt about two women sharing their lives together. However, when Jessica asked them how long they had lived in their home and complimented them on the length of their relationship, Marie began to feel at ease. Jessica worked from a family systems perspective and considered both Irene and Marie her clients. She discovered that Marie’s siblings died years earlier. And, although Marie had one son from a previous marriage, he had died of congestive heart failure last June at age 64. Marie has no other close relatives. Irene, however, has two younger sisters who never understood Irene’s relationship with Marie. “They generally do not visit when I am around,” Marie said, hinting to Jessica that the relationship is rocky. “I don’t know what they will do now because I am not leaving Irene’s side.”

Jessica was concerned about what would happen to Marie after Irene died. Although Marie appeared to be in good physical shape, going through the grieving process might impact Marie’s mental and physical health. Should Marie decline, who will she rely on for help? Moreover, even though New York had marriage equality, they were not married. If they did not have all the proper paperwork in place, Marie could find herself at risk for eviction.
At 85, 86, 92, and 96, respectively, Margaret Davis, Marie Cipriani, Lucy Rauso, and Pete Mullin are charting new territory. They are a part of the rapidly growing population older than age 85, many of whom are surprised they are living so long.

In the first edition of this book (1999), the chapter on late adulthood covered all persons 65 and older. The fact that subsequent editions present this content in two chapters (“Late Adulthood” and “Very Late Adulthood”) indicates the scope and rapidity of the demographic changes taking place in the United States and other late-industrial societies. Within the past 20 to 25 years, some researchers have begun to more methodically consider age distinctions after age 65 or 75, given the population growth in this age group.

This chapter summarizes some of the emerging literature on very late adulthood, including those who reach 100—our centenarians. (Much of what appears in the previous chapter on late adulthood applies as well.) The current knowledge about very late adulthood is growing as the population and related interest increase each year. However, given the scarcity of longitudinal studies that have followed a cohort from early adulthood deep into very late adulthood, it is difficult to tease out the cohort effects in the available cross-sectional research.

One issue that comes up at all adult stages is the ages included in the stage. As you have seen throughout this book, chronological markers of age are arbitrary at best and influenced by biological age, psychological age, social age, and spiritual age. But it is fairly standard to think of 85 and older as old old, oldest old, or very late adulthood. The category of the very old, those older than 80, is also referred to by some as the “fourth age” (Hazan, 2011, p. 11). This is more about circumstances in one’s life than about age; for example, the “third age” refers to being older and still remaining independent, and the “fourth age” refers to a time when people are more dependent and in need of care (MacKinlay, 2006). This is less a chronological distinction than a reflection of changes in life circumstances that often happen as one approaches age 80. For the most part, we use “very late adulthood” to describe people in this life course phase, but we also use “old old” and “oldest old” when citing work where those terms are used. However, keep in mind that chronological age may not be the best marker for categorizing very late-life adults (Agronin, 2011). Loss of health might be a better criterion for categorization as very late adulthood or old old. Nevertheless, in keeping with the other chapters in the book, this chapter uses a chronological distinction.

The drawback to using a chronological marker for entry into very late adulthood is that the path through very late adulthood is quite diverse, and for many people older than 85, ill health is not a central theme of their lives. In his book Aging Well, George Vaillant (2002) reminds us that

- Frank Lloyd Wright designed the Guggenheim Museum at age 90.
- Dr. Michael DeBakey obtained a patent for a surgical innovation when he was 90.
- Grandma Moses was still painting at 100.
- Sarah and Elizabeth Delany (1993) published their book Having Our Say: Our First 100 Years when Sarah (Sadie) was 103 and Elizabeth (Bessie) was 101.
- Daniel Schorr was heard weekly on National Public Radio as the senior news analyst until the age of 93, having served as a news journalist for more than 60 years.
- Anna Halprin continues to teach and inspire at age 93. A pioneer in the experimental post-modern dance world and expressive arts healing movement, after a cancer diagnosis in 1972,
she continues to write and teach about dance/movement as an expressive therapy.

- Business owner Samuel Myers actively worked at his dry cleaning business until 3 months before he died at age 97.
- Golfer Pauline Whitacre, 85, of Canton, Ohio, not only continues to golf but shoots better than her age.
- Betty White, 92, hosts her own TV show while starring in another. Since turning 85, she has won a Grammy, an Emmy, and three SAG awards.
- Angie MacLean, 98, from Bridgeport, Connecticut, has been bartending for 81 years.

So, there is much variation in the age at which health issues take on great importance. Margaret Davis has reached this stage in her mid-80s. Marie Cipriani remains healthy at 86 while she cares for a younger life partner who is on hospice service at age 79. Lucy Rauso reached it in her early 90s, and it does not yet seem to have overtaken Pete Mullin in his mid-90s. But sooner or later in very late adulthood, health issues and impending death become paramount.

With our current ways of living, such as busy and pressured work schedules and families geographically scattered, late-industrial societies pose challenges as one ages. That portion of the physical environment attributable solely to human efforts was designed, in the main, by and for those in young and middle adulthood, not for children, persons with various types of physical disabilities, or older adults. However, increasingly, the current cohort of very-late-life adults is charting new territory, and some aspects of society are preparing for the growth in this age group. What can we learn from people who reach 85 and beyond, and what do social work practitioners need to know to provide meaningful and relevant interventions?

As Erik Erikson suggested, we have one and only one life cycle (at least in this incarnation). For some of us, death will come quickly, but for others, death will come after a protracted period of disease and disability. One of the life tasks we face in late adulthood is to come to terms with our one and only life cycle, and the evidence suggests that most very-late-life adults do that remarkably well. We began this book with a discussion of conception, pregnancy, and birth, the starting line of the life course, and in this chapter we end the book with a discussion of death and dying, the finish line of the life course. While this might sound linear, Erikson noted in relation to his life cycle chart that it “becomes really meaningful only when you have observed it as a weaving or, even better, have undertaken to weave it yourself” (Erikson & Erikson, 1997, p. 2). Our challenge as social workers is to be open to the uniqueness of each person’s tapestry.

**VERY LATE ADULTHOOD IN HISTORICAL AND CULTURAL PERSPECTIVE**

There have always been those who outlive their cohort group, but greater numbers of people are surpassing the average life expectancy. Overall, the 85-and-older population is the fastest-growing segment of the population both in the United States and worldwide. This age group is projected to grow from 5.9 million in 2012 to nearly 18 million by 2050 in the United States (U.S. Census Bureau, 2012b, 2013b) and from 46.9 million to 224.1 million worldwide (U.S. Census Bureau, 2013c). This growth is due to advances in medical technology; the prevention and control of childhood diseases; improved nutrition, housing, and hygiene; and greater access to medical care (Crimmins, Preston, & Cohen, 2011).

The phenomenon of the baby boom generation helps explain the current growth in the midlife age groups as well as these projections for future growth in the older-than-85 population. But what else accounts for the fact that persons 85 and older are the fastest-growing segment of the older adult population? Several contributing factors include the following: better health care in early and middle years; earlier diagnosis and improved technology for treatment and overall health care;
improved health habits, including less smoking, less consumption of alcohol and saturated fats; and increased exercise in some groups. In addition, fewer people die of infectious diseases (Hooyman & Kiyak, 2011).

Because both group-based and individual differences within this age group are great, one is cautioned against stereotyping very-late-life adults in an attempt to describe them (Innes, 2009; Poon & Cohen-Mansfield, 2011). For instance, gender and racial or ethnic differences are embedded within these overall statistics. Life expectancy at birth in the United States in 2010 was about 81.1 years for non-Hispanic White females, 77.7 years for non-Hispanic Black females, 76.4 years for non-Hispanic White males, and 71.4 years for non-Hispanic Black males. Hispanic females born in that same period have an estimated life expectancy of 83.8 years and Hispanic males an estimated life expectancy of 78.5 years (National Center for Health Statistics, 2013). Life expectancy has not been uniformly calculated for other ethnic groups, but estimates do exist. Accordingly, an American Indian/Alaska Native (Census Bureau language) born in 2010 has a life expectancy of 75.1 years (no gender breakdown confirmed) (Lewis & Burd-Sharps, 2010). The estimated life expectancy of Asian females born in that period is 85.8 years, and for Asian males it is 84.5 years (Office of Minority Health, 2014). Among very-late-life adults, women outnumber men 2 to 1, and 4 out of 5 centenarians are women (U.S. Census Bureau, 2011a, 2012b). As the data show, very late adulthood is largely a woman's territory. Pete Mullin is an exception to this trend. Culturally, the most significant fact is that very-late-life adults, like other age groups, are becoming more diverse. It is projected that from 2012 to 2050, the racial and ethnic breakdown of the U.S. population of adults age 85 and older will change in the following way: the percentage of this population that is non-Hispanic White will decline from 84.5% to 67.5%; the percentage that is non-Hispanic Black will grow from 6.8% to 9.9%; the percentage that is Hispanic will grow from 5.8% to 15.1%; the percentage that is Asian will grow from 2.1% to 5.9%; and the percentage of all other racial and ethnic groups, including mixed race, will grow from 0.5% to 1.0% (U.S. Census Bureau, 2012b). These trends indicate an increased diversity among the old old.

Census data such as these are of interest to researchers studying ethnogerontology, the study of the causes, processes, and consequences of race, national origin, and culture on individual and population aging (Hooyman & Kiyak, 2011). Innes (2009) refers to the cross-cutting interplay of gender, class, and age on aging experiences. Poverty is another indicator of interest with the older population, given decreased earning power and increased health-related expenses. Older women (13%) were almost twice as likely to be poor as older men (7%) in 2010. Overall, the poverty rate increased with age, with 8.1% of people aged 65 to 74, 9.2% of people aged 75 to 84, and 12.3% of those 85 and older living in poverty. Race and ethnicity are also related to poverty among older adults, with older African Americans (20.7%), Hispanics (19%), Asian Americans (16.7%), and non-Hispanic Whites (7.9%) living in poverty (Tarver, 2013).

Chapter 1 suggests that one of the themes of the life course perspective is that individual and family development must be understood in historical context. It is particularly important when we interact with very-late-life adults to be aware of the historical worlds in which their life journeys have taken place. Inquiring about this will help social workers better understand a person’s resilience, responses to life challenges, and personal goals. For example, one’s experience with the Holocaust, the Depression, war, or other personal trauma may help contextualize current stressors, resilience, and other responses to life.

Chapter 1 also discusses the concept of cohort effects, which suggests that a historical event affects one cohort differently than it affects subsequent cohorts because of the life phase in which
it occurred. Let’s look, for example, at the wide use of the computerized worldwide network (the Internet). It was experienced

- By the current cohort of 85-year-olds when they were in their 60s
- By the current cohort of 65-year-olds when they were in their 40s
- By the current cohort of 45-year-olds when they were in their 20s

For the current cohort of 25-year-olds and those younger, it may be hard to remember when social media and other aspects of the Internet were not part of their lives.

Individuals’ cultural backgrounds also play a role in their perceptions of very late adulthood. Margaret Davis has spent her entire life in an impoverished small Appalachian town where families are expected to “take care of their own.” In contrast, Pete Mullin and Lucy Rauso relocated from Massachusetts to Florida in their 70s, moving away from family and friends. Marie Cipriani grew up in New York in an Italian immigrant family. For the past 42 years, she has lived on Long Island with her female partner. Social workers need to try to understand clients’ years in their previous homes and any important historical markers in those settings. They also need to know something about migration experiences as well.

WHAT WE CAN LEARN FROM CENTENARIANS

“Forget about Generation X and Generation Y. Today, the nation’s most intriguing demographic is Generation Roman numeral C—folks age 100 and over” (Harvard Health Letter, 2002, p. 1). This seems to be a time of both resilience and ongoing development and vulnerability (Poon & Cohen-Mansfield, 2011).

Although very few 100-year-old people were known to exist in the United States in 1900, there were 53,364 of them in 2010. The majority of these centenarians were women (82.8%) and were ages 100 to 104 (92%) (U.S. Census Bureau, 2012d). By 2050, it is estimated that more than 442,000 people in the United States will reach the century mark (U.S. Census Bureau, 2013a). Worldwide, more than 6 million are expected to reach age 100 by 2050 (U.S. Census Bureau, 2013b).

A small number of these centenarians, those aged 110 and older, are considered supercentenarians. As of January 2013, there were 63 validated supercentenarians throughout the United States, 58 women and 5 men (Coles, 2013). The Gerontology Research Group (2013) estimates that...
there are approximately 300 to 400 supercentenarians throughout the world. However, more than counting numbers, researchers want to know the answers to fundamental questions about human health and longevity, such as the following:

- What does it take to live a long life?
- How much do diet, exercise, and other lifestyle factors matter compared with “good” genes and other genetic factors?
- What is the quality of life among very-late-life adults?
- What role do individual characteristics such as gender, race or ethnicity, personality, and socioeconomic status play in longevity?
- What is the role of social support, religion and spirituality, and social environment in longevity?

Much of what is known about centenarians in the United States comes from the work of Leonard Poon and his colleagues (Poon et al., 2007; Poon & Cohen-Mansfield, 2011) in the Georgia Centenarian Study and from the New England Centenarian Study (Terry, Sebastiani, Andersen, & Perls, 2008). These and other centenarian studies are trying to understand the interrelationship between multiple variables such as family longevity, gender, personality, environmental support, adaptational skills, individual traits, life satisfaction, and health.

These studies reveal that because the more frail individuals die sooner, those remaining are a relatively robust group. Although these “extra” years are for the most part healthy years, several studies report high levels of dementia (66% in one study and 51% in another), cardiovascular disease (72%), urinary incontinence (60%), and osteoarthritis (54%) (Hall, 2008). What is more notable, however, is that the period of serious illness and disability for those who make it to 100 tends to be brief. Some factors thought to contribute to centenarians’ robustness in U.S. studies are physical activity, such as walking, biking, golfing, and swimming, and mental exercise such as reading, painting, and playing a musical instrument. The Okinawa Centenarian Study notes the importance of the traditional lifestyle that includes high physical activity, social integration at all ages, a deep spirituality, adaptability, and optimistic attitudes (cited in Hooyman & Kiyak, 2011). A cluster of personality traits—low neuroticism (reflecting emotional stability), high competence, and high extroversion—were found among centenarians in the Georgia study (Martin, da Rosa, & Poon, 2011).

However, 100 is still old, and life expectancy is short at 100, with most only living 1 to 2 more years. In the New England study, 75% of the people were still living at home and taking care of themselves at 95. By age 102, this number had dropped to 30%—which is still quite remarkable (Terry et al., 2008).

The gender gap in very late adulthood widens further past the age of 100, with female centenarians outnumbering males 4 to 1. However, men who reach their 100th birthday are, on the whole, more healthy than their female counterparts, reporting lower incidence of dementia and other serious medical problems. Estrogen may give women an edge in longevity. Another possibility is that there may be some protective genes in the X chromosome, of which women have two but men only one. Others theorize that menstruation and systems related to childbirth better equip women to eliminate toxins from the body. Another hypothesis is that genetics are relatively neutral, but women tend to be more social, and these connections are thought to be critical in weathering old age (Margrett et al., 2011).

In general, findings point to a life course of healthy lifestyles among centenarians: they didn’t smoke, or if they did, not for long; didn’t overeat, and their diet included many fruits and vegetables; didn’t drink heavily; got regular physical exercise for as long as they were able; challenged their minds; had a positive outlook and were able to “shed stress easily”; and maintained close ties with family and friends (Harvard Health Letter, 2002). Future cross-cultural studies in which differences in diet, physical activity, and other lifestyle factors can be compared will be important in helping researchers better understand the influence...
of these multiple contributing variables. Overall, Poon and Cohen-Mansfield (2011) remind us it is important to focus on emotional as well as physical health and not to assume that physical decline necessarily means a decline in emotional well-being.

Critical Thinking Questions 10.1
Imagine that you are having lunch with Fred Hale Sr. (from Photo 10.1). How do you imagine the conversation going? What questions would you like to ask him? How do you think life will be different for centenarians in 2050?

FUNCTIONAL CAPACITY IN VERY LATE ADULTHOOD

Although persons who reach 85 years of age and older demonstrate resilience in the simple fact of their longevity, they continue to face an increased incidence of chronic illness and debilitation with age. Chapter 9 provides a good overview of changes in physiology and mental functioning that begin to occur in late adulthood and only become more prevalent with advancing age. Unfortunately, much of the available information does not distinguish the 85-and-older cohort group from the larger 65-and-older group. We do know that the likelihood of living in a nursing home increases with age. Among nursing home residents, about 14.6% are 65 to 74 years old, 27.5% are 75 to 84, and 42.9% are 85 and older (Centers for Medicare and Medicaid Services, 2012b). U.S. Census (2012a) data show that 37.5% of female centenarians and 23.3% of male centenarians were living in a nursing or group residence compared with 20.8% of females and 11.9% of males ages 90 to 94. Many late-life adults enter a nursing home for a period of convalescence after hospitalization and then return to home or another setting. The prevalence of older adults with a disability and those needing assistance with instrumental activities of daily living (IADLs), activities that are not necessary for fundamental functioning but do allow an individual to live independently, increases steadily with age. Of those ages 65 to 69, 35% report a disability with 6.9% needing assistance; of those ages 70 to 74, 42.6% report a disability with 10.8% needing assistance; of those 75 to 79, 53.6% report a disability with 15.4% needing assistance; and of those age 80 and older, 70.5% report a disability with 30.2% needing assistance (Brault, 2012). Limitations in activities of daily living (ADLs), basic care activities, also increase with age; 1.6% of those ages 65 to 74, 3.5% of those ages 75 to 84, and 9.7% of those age 85 and older need assistance with three or more activities (National Center for Health Statistics, 2009). (Exhibit 10.1 lists common ADLs and IADLs.)

In general, all persons experience primary aging, or changes that are a normal part of the aging process. There is a recognized slowing with age—slowing of motor responses, sensory responses, and intellectual functioning. For example, the percentage of older adults in the United
States with significant visual loss increases during late and very late adulthood: 12.2% among the 65- to 75-year-olds and 15.5% among those older than 75 (American Foundation for the Blind, 2013). Similarly, 37% of 61- to 70-year-olds, 60% of 71- to 80-year-olds, and 80% of persons 85 and older experience hearing loss of 25 dB (Walling & Dickson, 2012).

In addition, many experience secondary aging caused by health-compromising behaviors such as smoking or environmental factors such as pollution (Bjorklund, 2011). Access to health care, ample and nutritious food, safe and affordable housing, safe working conditions, and other factors that influence the quality of life also affect longevity.

Although late adulthood is a time of loss of efficiency in body systems and functioning, the body is an organism that repairs and restores itself as damage occurs. Those persons who live to be 85 and older may be fortunate enough to have a favorable genetic makeup. But they may also have found ways to compensate, to prevent, to restore, and to maintain other health-promoting behaviors. Most very-late-life adults come to think of themselves in ways that fit their circumstances. They narrow the scope of their activities to those that are most cherished, and they carefully schedule their activities to make the best use of their energy and talents.

Sooner or later, however, most very-late-life adults come to need some assistance with ADLs and IADLs. As a society, we must grapple with the question of who will provide that assistance. Currently, most of the assistance is provided by family members. But as families grow smaller, fewer adult children exist to provide such care. A number of family theorists have begun to wonder how multigenerational families might adjust their relationships and better meet long-distance caregiving needs (Cagle, 2008; Harrigan & Koerin, 2007).

Chapter 9 provides an overview of dementia and more specifically Alzheimer’s disease (AD). Additional content here emphasizes the importance of ongoing and longitudinal research and needs of families and other caregivers and also some interesting perspectives about the medicalization of dementia.

To better understand the progression of AD in the oldest old and compare it with the progression among younger older adults, functional ADLs and cognitive Mini Mental Status Evaluations, or MMSEs, were studied in a cohort of adults who were older than 85 and a cohort of adults who were younger than 85, all living in a community in France (Nourhashemi et al., 2009). The progression of cognitive impairment was the same across groups; however, after adjusting for age and dependency (help with ADLs), the progression of dependence occurred more quickly for the older group. In sum, even among the oldest old, dementia shortened life, especially among women. Studies such as this have important public health consequences, helping us better prepare for the type of care some of our oldest citizens, and our most rapidly growing age group, may need.

Innes (2009) summarizes some thought-provoking theories and commentaries about our current approach to understanding dementia, suggesting that we tend to medicalize dementia so as to then seek a cure for aging and death. Vincent (2006, cited in Innes, p. 22) writes of an anti-aging science that tends to perceive “old age as a problem to be resolved rather than a stage of life to be embraced and accepted.” Gilleard and Higgs (2000, cited in Hazan, 2011, p. 18) warn against the “fear-riddled attitude” we have toward increasing dementia described as the “Alzheimerization of society.” When aging and dementia become problems to fix or perhaps hide away, what are the implications for the persons living with this life challenge?

RELATIONSHIPS IN VERY LATE ADULTHOOD

Much of what is presented in Chapter 9 under the Families in Later Life section applies also to very late adulthood. Research that looks
specifically at relationship patterns among very-late-life adults notes the following themes (Litwin, 2011; Mayo Foundation for Medical Education and Research, 2012):

1. Individuals continue to desire and need connections to other people throughout life.
2. In very late adulthood, people interact with others less frequently, but old-old adults make thoughtful selections about the persons with whom they will interact.
3. Age per se doesn’t account for diminishing social networks; rather it is the combination of older age and limitations related to increased disability.

**Relationships With Family and Friends**

Social isolation is considered to be a powerful risk factor not only for the development of cognitive and intellectual decline in very late adulthood but also for physical illness (McInnis-Dittrich, 2009; Steptoe, Shankar, Demakakos, & Wardle, 2013). A sense of connectedness with family and friends can be achieved in person, on the phone, and more recently via e-mail, Facebook, chat rooms, blogs, Skype, and other social networking technology. The focus in this section is on relationships with people; however, remember that pets, plants, and other connections with nature bring comfort to any age group, including older adults.

Pertinent to very-late-life adults is the increased likelihood that one will have lost a spouse or partner, friends, an adult child, or other family members to death, illness, debilitation, or relocation. Loss is more prevalent during this stage than at other times of life, but there is also greater opportunity for intergenerational family contact as 4-, 5-, and 6-generation families become more common.

Siblings often provide companionship and caregiving for each other, as Pete Mullin and Lucy Rauso did in the case study. Siblings are comforting because they are part of one’s cohort and also have experienced many of the same family events. In addition, siblings tend to be the most long-standing relationships in a person’s life (Hooyman & Kiyak, 2011). However, as we see with Marie Cipriani and Irene Wright, this is not always the case. Irene’s relationship with her siblings is strained due to their nonacceptance of her life partner. Marie’s siblings, who might have been able to provide support, have all died.

Obviously, sibling relationships may range from loving and close to ambivalent, distant, or even hostile. Sharing responsibility for aging parents may create greater closeness between siblings or increase tension. There is some evidence that sibling relationships are especially important sources of support among members of lower socioeconomic groups. Close relationships especially with sisters in very late adulthood have been found to be positively related to positive mental health (McGoldrick & Watson, 2011). Relationships with adult children are another important part of the social networks of very-late-life adults, as is the case with Margaret Davis. Very-late-life adults in the United States are in fact institutionalized more often for social reasons than for medical reasons (Hooyman & Kiyak, 2011). One reason for this is that approximately 1 in 5 women 80 and older has been childless throughout her life or, like Marie Cipriani, has outlived her children. In addition, baby boomers and their children tended to have more divorces and fewer children, decreasing the caregiving options for their parents and grandparents (Hooyman & Kiyak, 2011). Racial and ethnic variations exist, however. The proportion of multigenerational relationships that involve parents living with adult children tends to be higher among some families of color, especially African Americans (Hooyman & Kiyak, 2011), as well as there being more grandparents raising grandchildren, especially in African American and Latino families (Richardson & Barusch, 2006). Also, families with a collectivist heritage prefer to have elderly parents reside with their grown children. It is important to understand and honor historical and cultural expectations of each family when
addressing the caregiving and health care needs of aging members. Geographic separation, most often because of the adult child’s mobility, tends to interfere with intergenerational interaction among family members, although many manage “intimacy at a distance” (Hooyman & Kiyak, 2011, p. 359) or strong emotional ties despite the separation.

Agencies serving older adults and children often seek opportunities for contact across generations. Whether referred to as inter-, multi-, or cross-generational, many programs recognize the benefits of activities that bring older adults, young parents, teens, and/or children and infants together. Each has something to offer and something to receive. Some examples include elders providing tutoring, telephone support, or assistance in day care and school settings or serving as surrogate grandparents; adolescents providing assistance around the yards and homes of older adults, helping to write life reviews, or being pen or computer pals; and children and elders interacting around crafts, music, gardening, storytelling, or other activities that create ways of being together (Hooyman & Kiyak, 2011).

Relationships with friends remain important in very late adulthood. In general, women have fewer economic resources but more social resources and richer, more intimate relationships than do older men (Hooyman & Kiyak, 2011). But over time, women tend to outlive partners, friends, and other key members of their social support system, often being left to deal with end-of-life decisions at an advanced age, without the social and perhaps financial support of earlier life.
Relationships with a domestic partner become much less likely in very late adulthood than in earlier phases of life. Very-late-life adults have the potential to have shared 60 to 70 years with a spouse or partner. Such long-term relationships, where they do exist, present the risk of tremendous loss when one member of the relationship dies. (Widowhood is presented in more detail in Chapter 9.) Because women outnumber men 2 to 1 after the age of 85, heterosexual men stand a greater chance of starting a new relationship than heterosexual women. With women living longer than men, lesbian domestic partnerships may have the greatest opportunity for continued long-term relationships in very late adulthood. However, this is not the case for Marie Cipriani and Irene Wright.

**Intimacy and Sexuality in Very Late Adulthood**

Given the scarcity of men and the fact that many partners and friends have died, many persons 85 and older, especially women, are more alone in this life stage than at other times in their lives. The implications for intimacy and sexuality for heterosexual women are significant. Although limited research has been conducted specifically about intimacy and sexuality with this age group, some tentative conclusions can be drawn from literature on aging. In particular, a summer 2001 issue of *Generations* focused on “Intimacy and Aging,” including the expressions of intimacy in a variety of relationships, challenges related to physical and mental illness, gay and lesbian relationships, and separation of couples because of institutionalization.

A greater understanding of intimacy may help people “navigate between current binary discourses of asexual old age and ‘sexy seniors’” (Sandberg, 2013, p. 261). Intimacy can be seen as much broader than sexuality, which has been identified as only one of five major components of intimacy (Moss & Schwobel, 1993, cited in Blieszner & deVries, 2001). The five major components of intimacy in this view are the following:

1. **Commitment.** Feeling of cohesion and connection
2. **Affective intimacy.** A deep sense of caring, compassion, and positive regard and the opportunities to express the same
3. **Cognitive intimacy.** Thinking about and awareness of another, sharing values and goals
4. **Physical intimacy.** Sharing physical encounters ranging from proximity to sexuality
5. **Mutuality.** A process of exchange or interdependence

Closeness is inherent in cognitive, affective, and physical intimacy. Communication, or self-disclosure, facilitates intimacy. In sum, intimacy is about connection, closeness, and trust, whether it is physical, sexual, emotional, or spiritual intimacy (Mayo Foundation for Medical Education and Research, 2012). Guided by culturally informed practice and a belief that older adults are continuing to grow and develop, how might social workers work to help older adults minimize barriers to intimacy in their lives?

Although sexuality is only one aspect of intimacy, it deserves additional attention; it should not be neglected, as it often is in our interaction with older adults. A study aimed at preparing health care professionals to engage with older adults about emotional and physical intimacy concluded that “regular sexual activity is a normal finding in advanced age” (Lochlainn & Kenny, 2013). However, there may be barriers to meeting one’s needs. The lack of a sexual partner because of divorce, death, or illness is one of the most common reasons for an older adult reporting low interest in sex and little sexual activity. However, there are other physical and psychosocial conditions that impact the level of sexual interest, satisfaction, and performance of older adults, and social workers need to be comfortable addressing this important aspect of quality of life. Medical conditions such as heart disease, diabetes, arthritis, chronic pain, depression, and medications prescribed to address these and other conditions may reduce or restrict movement or sexual function as...
well as impact pleasure (Hooyman & Kiyak, 2011). Some of the more common psychosocial factors associated with reduced sexual desire or sexual dysfunction include restrictive beliefs about sexuality and aging, role changes because of illness or disability in one or both of the partners, anxiety about sexual function, and psychological disorders (Lochlainn & Kenny, 2013). Depression and substance abuse are more prevalent in older adults with sexual dysfunction. Also, cultural ideals about body image, perceived sexual attractiveness, and expression of emotions that may influence capacity for intimacy make it more difficult for some older adults to embrace age-related changes (Mayo Foundation for Medical Education and Research, 2012).

Relationships With Organizations and Community

Relationships with the wider world peak in young and middle adulthood. They grow more constricted as access to social, occupational, recreational, and religious activities becomes more difficult due to decreased mobility and independence and as the physical and cognitive impairments associated with age increase. As mobility declines, community-based programs such as Meals on Wheels can become important resources to people like Pete Mullin and Lucy Rauso, not only providing them with essential resources such as food but serving also as a connection to the community.

One organizational relationship becomes more likely with advancing age, however. As people live longer and need greater assistance, many move into some form of institutional care. When reading the upcoming discussion about the housing continuum, consider the benefits and the challenges each option presents.

The Use of Technology

The use of computer technology and the Internet has steadily increased over the past 20 years. However, although adults age 85 and older access the Internet, the percentage of those who do is small (Choi & DiNitto, 2013a, 2013b). Those more likely to use the Internet generally have a higher socioeconomic status, are actively involved in the community, have a social network that encourages Internet usage, and are “computer ripened” (Choi & DiNitto, 2013a, 2013b; Richter, Bannier, Gliott, Marquard, & Schwarze, 2013). Conversely, those less likely to use the Internet are less likely to have the resources to obtain computers or other devices for accessing the Internet and/or are more likely to have cognitive, perceptual, or motor skill deficits; vision impairment; or difficulty with ADLs and IADLs (Choi & DiNitto, 2013a).

Like any other age group, older adults have used the Internet for online banking and to pay bills, for shopping, to refill prescriptions, to contact medical providers, to participate in online forums and support groups, to communicate with family and friends, and to search for health-related and nonhealth-related information. However, those 85 and older most often use the Internet for e-mail or text messages (Choi & DiNitto, 2013b).

Internet usage does have its benefits for those age 85 and older. Although the findings are mixed, it has been suggested that Internet usage increases communication within social groups, allows the maintenance of long-distance relationships, increases access to health information and resources, allows those who are mobility challenged to participate in online health self-management programs and support groups, and enables access to community, church, and organization websites (Choi & DiNitto, 2013b).

In addition to the Internet, robots are being developed for improving the sociophysical environment for older adults (Kidd, Taggart, & Turkle, 2006; Kolling et al., 2013). Currently, robots can be used to assist with everyday tasks and activities as well as to increase social interactions for those who are mobility or cognitively challenged. The development of robotics is still in the early stages. Maintenance of the robots may require a team approach to turn the machine on and off and to keep it clean. Additionally, as this is a new field, ethical issues must be considered.
Critical Thinking Questions 10.2

What have you observed about the functional capacity of the very old adults that you know? How much assistance have they needed with ADLs and IADLs? How did they react to needing assistance? Who provided the assistance? How have you seen very old adults cope with the reality that many of their relatives and friends die while they still live? How have you seen very old adults make use of technology to create and maintain relationships?

THE HOUSING CONTINUUM

As people live longer, the likelihood of illness and disability increases; spouses, partners, and friends die, and the chance of needing more support than is available to the very-late-life adults in their own home increases. Review the section on informal and formal resources in Chapter 9 for a description of the variety of options along the continuum as need for assistance increases.

Other than skilled nursing care reimbursed by Medicare and other health insurance, the majority of assistance people need must be paid for privately. Financing is a major problem for low-income and even many middle-income people. Women, especially women of color, are overrepresented in lower socioeconomic categories, and in very-late adulthood, safe, affordable housing options are a serious concern. But even Pete Mullin and Lucy Rauso found housing a problem until they moved in together and pooled their resources. Margaret Davis’s daughter, Judy, is determined that Margaret won’t go “to a home,” but she is also worried about how costly Margaret’s care will become in the future. What if Marie Cipriani needs to leave her home? Will she find living arrangements that welcome a lesbian woman?

Current trends indicate that in the future, the following housing options will be in greater demand and hopefully more readily available (Hogstel, 2001; Office of Citizen Services and Innovative Technologies, 2013):

- Shared housing, shared expenses, and support by family members and friends
- Options for care and assistance in the home with education and support available to family and other informal caregivers, home health skilled services, reverse mortgages, home equity loans
- Independent living facilities, including retirement villages and naturally occurring retirement communities such as inner-city high-rise retirement communities close to medical, cultural, and recreational activities
- Assisted-living facilities that provide 24-hour assistance, continuing-care retirement communities that offer a range of services
- Nursing homes providing custodial care only (The number of skilled nursing facilities that also provide custodial care is likely to decrease, with their role taken over by assisted-living facilities)

Access and receptivity to this continuum of options are influenced by several factors: geographic location, including urban and rural location; socioeconomic status; race; ethnicity; gender; sexual orientation; family support; and health care status. Specifically, a substantial disparity in nursing home admissions of non-Hispanic White and minority late-life adults continues to exist, particularly among women (Mudrazija & Thomeer, 2012). Moreover, African American men and women more often report a need for help with their ADLs and are less likely to receive the appropriate level of care than White men and women (Hooyman & Kiyak, 2011). Obtaining assistance with ADLs and IADLs can be expensive. Some of the current cohort of very-late-life adults have arrived at that stage without any expectation that they would live so long or any preparation for such a prolonged life. And some arrive there after a full life course of limited resources, as is the situation with Margaret Davis.
SPIRITUALITY IN VERY LATE ADULTHOOD

When the first author, Pam, called her 85-year-old aunt to wish her a happy birthday, Pam’s uncle said, “She has been thinking a lot more about the hereafter.” Curious about what sounded like a connection to aging and spirituality, Pam asked her aunt to tell her more. Her aunt added with a chuckle, “Yes, I go into a room and I wonder ‘What am I here after?’” On one hand, Pam’s aunt was trying to make light of some short-term memory loss. But Pam also knew that increasingly her aunt had been questioning the meaning of her life and wondering about her own death, especially since the recent death of her 58-year-old son to cancer.

There is often a conceptual division when describing religion and spirituality, with religion connected to an institution and spirituality being a more personal experience. Bishop (2011) cautions against this binary conceptualization, suggesting that the two are more often related than independent of each other, and some longitudinal research indicates that the two are highly correlated in late-life adults (Vaillant, 2012). More simply, spirituality represents the way in which people seek meaning and purpose in their lives (Nelson-Becker & Canda, 2008; Sheridan, 2011). Our role as social workers is to understand what role, if any, religion and spirituality play in the unique lives of our clients. Given possible barriers related to mobility, vision, hearing, and other access issues, older adults may feel disenfranchised and less connected to religious institutions that had once been a meaningful source of social support (Bishop & Martin, 2011).

Photo 10.3 Although those who reach 85 and older demonstrate resilience by surviving, they continue to face increased incidence of chronic illness and debilitation with increased age.

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The following discussion about spirituality refers to aging in general, not specifically to very late-life adults, but is included in this chapter because of the connection among aging, loss, spirituality, and meaning making. Often when faced with crises—particularly those of severe illness, disability, and/or loss—one tends to reexamine the meaning of life. And although illness, disability, and loss occur throughout life, these challenges tend to accumulate and come at a faster pace during very late adulthood. Dalby (2006) notes that some aspects of spirituality pertain across the life course; however, the following tasks, needs, or changes become more relevant with aging: integrity, humanistic concern, changing relationships with others and greater concern for younger generations, relationship with a transcendent being or power, self-transcendence, and coming to terms with death.

Spirituality late in life is often associated with loss (Armatowski, 2001). Over time, losses accumulate in the following areas:

- **Relationships**: to children, spouses and partners, friends, and others
- **Status and role**: in family, work, and society
- **Health**: stamina, mobility, hearing, vision, and other physical and cognitive functions
- **Control and independence**: finances, housing, health care, and other decision-making arenas

Whether incremental or sudden, these losses can be difficult for members of a society where personal autonomy, independence, and sense of control are highly valued. Ironically, this increased focus on spirituality often coincides with decreased mobility and independence and diminishing social contact, limiting access to religious services and other opportunities for spiritual fulfillment and social support (Watkins, 2001).

The search for meaning is a central element of Erik Erikson's (1963) eighth developmental task, referred to as maturity. It involves the challenge of *ego integrity versus ego despair* and centers on one's ability to process what has happened in life and accept these experiences as integral to the meaning of life. As Erik and Joan Erikson (1997) moved into their 8th decade, they began writing about a ninth stage. Joan published this previously unfinished work in 1997 following Erik's death in 1994 at the age of 92. She revisits the meaning of wisdom and integrity in light of the losses that occur with time and, despite the challenges, declares that “to grow is a great privilege” (p. 128). When describing this ninth stage, she refers to “gerotranscendence” and the work of Lars Torstam of Sweden, who coined the word as a possible path toward wisdom as we age. Joan Erikson, a dancer, played with the concept, calling it “gerotranscendence” to note the room for creativity as we move through the “process towards maturation and wisdom” (p. 123).

Other important spiritual challenges facing elders include transcendence beyond oneself and a sense of connectedness to others (McInnis-Dittrich, 2009). An elderly person’s struggle to maintain independence and the ability to make choices in the face of multiple challenges, versus becoming dependent on others, is both psychosocial and spiritual, calling for a social work response addressing both. It is important to remember that culture, race, religious upbringing, and other life experiences may influence each person’s spiritual journey.

This is often a time for slowing down, looking back, and reaching out—steps that make sense developmentally as one nears the end of life. Over time, people tend to review their lives, some informally and others more formally. The more formal life review involves helping people shape their memories and experiences for others, usually family and loved ones, whether shared orally or in writing. Social workers, family members, or others who share a closeness with a person often help facilitate this process of reflection and meaning making (Hooyman & Kiyak, 2011).

The subject of spirituality is separated in this chapter from the subject of dying to emphasize the point that spirituality is not just about preparing for death. Rather, it is about making meaning of one’s life (Bishop, 2011; Gordon, 2013; Jenkinson, 2013), transcending oneself, and remaining connected to others (McInnis-Dittrich, 2009).
Critical Thinking Questions 10.3

Why do you think it is important to people like Margaret Davis to stay in their own homes? The majority of very old adults today are women. What are the implications of this for housing policy and programs for this age group? How have you observed the very old adults in your family cope with the accumulation of loss? What role did religion and spirituality play in their coping?

THE DYING PROCESS

The topic of death and dying is almost always in the last chapter of a human behavior textbook, reflecting the hope that death will come as late as possible in life. Obviously, people die in all stages of life, but very late adulthood is the time when dying is considered “on time.”

Despite our strong cultural predisposition toward denial of the topic, and perhaps in response to this, there have been a plethora of efforts to talk about death, starting most notably with Elisabeth Kübler-Ross’s book On Death and Dying in 1969. Beginning in the late 1990s, initiatives such as the Project on Death in America (PDIA) funded by the Soros Foundation and end-of-life initiatives funded by the Robert Wood Johnson Foundation set out to change mainstream attitudes. The mission of PDIA was to understand and transform the culture and experience of dying and bereavement. It promoted initiatives in research, scholarship, the humanities, and the arts, and fostered innovations in the provision of care, education, and policy. Television programs such as the Public Broadcasting Service’s On Our Own Terms: Moyers on Dying have facilitated public education and community dialogue (Moyers, Mannes, Pellet, O’Neill, & Moyers, 2000). Additionally, TV series, such as Desperate Housewives, have begun to integrate death and dying into a beloved character’s storyline (Cherry, 2012).

On a more individual level, many factors influence the ways in which a person adjusts to death and dying, including one’s religion and philosophy of life, personality, culture, and other personal traits. Adjustment may also be affected by the conditions of dying. A person with a prolonged terminal illness has more time and opportunity to accept and prepare for his or her own death, or that of a loved one, than someone with an acute and fatal illness or sudden death.

The following adjectives used to describe death are found in both the professional and popular literature: good, meaningful, appropriate, timely, peaceful, sudden, and natural. One can be said to die well, on time, before one’s time, and in a variety of ways and places. This terminology reflects an attempt to embrace, acknowledge, tame, and integrate death into one’s life. Other language is more indirect, using euphemisms, metaphors, medical terms, and slang, reflecting a need to avoid directly talking about death—suggesting that the person is “lost,” has “passed away,” or has “expired” (DeSpelder & Strickland, 2005). It is important for a social worker to be attentive to words that individuals and families choose because they often reflect one’s culture and/or religious background and comfort level (Bullock, 2011).

As with life, the richness and complexity of death are best understood from a multidimensional framework involving the biological, psychological, social, and spiritual dimensions (Bern-Klug, 2004). The following conceptualizations of the dying process help capture the notion that dying and other losses, and the accompanying bereavement, are processes that differ for each unique situation, yet share some common aspects.

In On Death and Dying, Kübler-Ross (1969) described stages that people tend to go through in accepting their own inevitable death or that of others, summarized in Exhibit 10.2. Although these stages were written with death in mind, they have application to other loss-related experiences, including the aging process. Given time, most individuals experience these five reactions, although not necessarily in this order. People often shift back and forth between the reactions rather than experience them in a linear way, get stuck in a stage, and/or skip over others. Kübler-Ross suggests that,
on some level, hope of survival persists through all stages.

Although these reactions may fit people in general, very-late-life adults appear to experience far less denial about the reality of death than other age groups (McInnis-Dittrich, 2009). As they confront their limitations of physical health and become socialized to death with each passing friend and family member, most very-late-life adults become less fearful of death. Unfortunately, some professionals and family members may not be as comfortable expressing their feelings related to death and dying, which may leave the elder feeling isolated.

In addition to expressing feelings about death, some very-late-life adults have other needs related to dying. A fear of prolonged physical pain or discomfort, as well as fear of losing a sense of control and mastery, trouble very-late-life adults most. Some have suggested that older adults who are dying need a safe and accepting relationship in which to express the fear, sadness, anger, resentment, or other feelings related to the pending loss of life and opportunity, especially separation from loved ones (Agronin, 2011; Bowlby, 1980).

### Advance Directives

On a more concrete level, social workers can help patients and families discuss, prepare, and enact health care advance directives, or documents that give instructions about desired health care if, in the future, individuals cannot speak for themselves. Such discussions can provide an opportunity to clarify values and wishes regarding end-of-life treatment. Ideally, this conversation has been started prior to very late adulthood (see Chapter 9 regarding a power of attorney and other health care decision-making processes). If not, helping people to communicate their wishes regarding life-sustaining measures, who they want to act on their behalf when they are no longer competent to make these decisions, and other end-of-life concerns helps some people feel empowered.

Since the passage of the Patient Self-Determination Act in 1990, hospitals and other health care institutions receiving Medicare or Medical Assistance funds are required to inform patients that should their condition become

### Denial

The person denies that death will occur: “This is not true. It can’t be me.” This denial is succeeded by temporary isolation from social interactions.

### Anger

The individual asks, “Why me?” The person projects his or her resentment and envy onto others and often directs the anger toward a supreme being, medical caregivers, family members, and friends. (Older adults may be less apt to raise this question and instead reflect on how fortunate they have been to live so long.)

### Bargaining

The individual starts bargaining in an attempt to postpone death, proposing a series of deals with God, self, or others: “Yes, me, but I will do . . . in exchange for a few more months.”

### Depression

A sense of loss follows. Individuals grieve about their own end of life and about the ones that will be left behind. A frequent reaction is withdrawal from close and loved persons: “I just want to be left alone.”

### Acceptance

The person accepts that the end is near and the struggle is over: “It’s okay. My life has been . . .”

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**Exhibit 10.2 Stages of Accepting Impending Death**

**Denial:** The person denies that death will occur: “This is not true. It can’t be me.” This denial is succeeded by temporary isolation from social interactions.

**Anger:** The individual asks, “Why me?” The person projects his or her resentment and envy onto others and often directs the anger toward a supreme being, medical caregivers, family members, and friends. (Older adults may be less apt to raise this question and instead reflect on how fortunate they have been to live so long.)

**Bargaining:** The individual starts bargaining in an attempt to postpone death, proposing a series of deals with God, self, or others: “Yes, me, but I will do . . . in exchange for a few more months.”

**Depression:** A sense of loss follows. Individuals grieve about their own end of life and about the ones that will be left behind. A frequent reaction is withdrawal from close and loved persons: “I just want to be left alone.”

**Acceptance:** The person accepts that the end is near and the struggle is over: “It’s okay. My life has been . . .”

**SOURCE:** Based on Kübler-Ross, 1969

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life-threatening, they have a right to make decisions about what medical care they wish to receive (McInnis-Dittrich, 2009). The two primary forms of advance directives are the living will and the durable power of attorney for health care.

A **living will** describes the medical procedures, drugs, and types of treatment that one would choose for oneself if able to do so in certain situations. It also describes the situations for which the patient would want treatment withheld. For example, one may instruct medical personnel not to use any artificial means or heroic measures to keep one alive if the condition is such that there is no hope for recovery. Although a living will allows an individual to speak for oneself in advance, a durable power of attorney designates someone else to speak for the individual.

The promotion of patient rights as just described has helped many patients feel empowered and comforted some family members, but this
topic is not without controversy. Because the laws vary from state to state, laypersons and professionals must inquire about the process if one relocates. Also, rather than feeling comforted by knowing a dying person’s wishes, some family members experience the burden of difficult decision making that once was handled by the physician. Advance directives are not accepted or considered moral by some ethnic, racial, and religious groups. Because of historical distrust of the White medical establishment, some African American and Hispanic families have preferred life-sustaining treatment to the refusal of treatment inherent in advance directives. Among some religious groups, the personal control represented in advance directives is seen to interfere with a divine plan and is considered a form of passive suicide. As discussed shortly, social workers must approach each patient and family with an openness to learn about their values and wishes. Volker (2005) cautions health care providers to consider the relevancy of Western values, such as personal control over one’s future, in the lives of non-Western patient groups.

Care of People Who Are Dying

Although some associate hospice and palliative care with “giving up” and there being “nothing left to do,” in fact hospices provide palliative care—a form of care focusing on pain and symptom management as opposed to curing disease. The focus is on “caring, not curing” (National Hospice and Palliative Care Organization [NHPCO], 2012), when curative focused treatment is no longer available or desired. Palliative care attends to the psychological, social, and spiritual issues in addition to the physical needs. The goal of palliative care is achievement of the best possible quality of life for patients and their families.

Hospice is one model of palliative care, borrowed from the British, that began in the United States in the mid-1970s to address the needs of dying persons and their loved ones. It is more a philosophy of care than a place, with the majority of persons receiving hospice services where they live, whether that is their private residence (41.6%), a nursing or residential facility (24.9%), or inpatient hospice facility (26.1%) (NHPCO, 2012). Marie Cipriani’s partner, Irene Wright, receives hospice services in their home. Hospice services are typically available to persons who have received a prognosis of 6 months or less and who are no longer receiving care directed toward a cure. Exhibit 10.3 summarizes the key ideas that distinguish hospice care from more traditional care of the dying.

The National Hospice and Palliative Care Organization (2012) estimates that the United States had 5,300 hospice programs in 2011 serving most rural, suburban, and urban communities in all 50 states. In 2011, approximately 1.65 million

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Exhibit 10.3  Key Ideas of Hospice Care

| The patient and the family (as defined by the patient) are the unit of care. |
| Care is provided by an interdisciplinary team composed of physician, nurse, nurse’s aide, social worker, clergy, volunteer, and other support staff who attend to the spectrum of biopsychosocial and spiritual needs of the patient and family. |
| The patient and family have chosen hospice services and are no longer pursuing aggressive, curative care but selecting palliative care for symptom management. |
| Bereavement follow-up is part of the continuum of care available to family members after the patient’s death. |

SOURCES: McInnis-Dittrich, 2009; NHPCO, 2012
patients, representing approximately 46.6% of all deaths in the United States, received hospice services. Four out of five hospice patients are 65 years of age or older, and about 39.3% are 85 and older. When hospice care was first established in the United States in the 1970s, cancer patients accounted for the majority of hospice admissions. Over time, hospices responded to the needs of others with end-stage disease (e.g., AIDS, dementia, heart disease, lung disease, and stroke as well as others), and in 2011, cancer accounted for less than half (37.7%) of all admissions (NHPCO, 2012).

Health disparities have been noted in hospice care, as in other health care settings, with persons of color historically being underserved. Initiatives through NHPCO, the Soros Foundation's Faculty Scholar program, and the Robert Wood Johnson Foundation's Promoting Excellence in End-of-Life Care have focused on program development specific to the needs of patients and families in African American, Hispanic, Native American, and other communities that have been underserved by more traditional hospice programs (Crawley et al., 2000; NHPCO, 2012).

Palliative care programs are emerging in hospital settings to address pain and symptom management in patients who might not fit the hospice criteria. Some hospitals have palliative care units specializing in management of short-term, acute symptoms; others have palliative care consultative services that bring their expertise to medical, oncology, pediatric, and other units throughout the hospital (Reith & Payne, 2009).

End-of-Life Signs and Symptoms

Family members and others caring for a person who is dying often experience a great deal of anxiety when they do not have adequate information about the dying process. Most families appreciate knowing what to expect, and honest, factual information can help allay their fears of the unknown (Cagle & Kovacs, 2009; Proot et al., 2004). Pete Mullin, for instance, might benefit by knowing what to expect as his sister is dying. Likewise for Marie Cipriani, who is caring for her dying partner. Many hospice services provide written information about symptoms of death for those families anticipating the death of a loved one at home. Exploring how much information people have and want is an important part of the social worker’s assessment.

Obviously, each individual situation will differ, but the following general information about symptoms of impending death, summarized in Exhibit 10.4, helps people prepare (Lamers, 2013; Reith & Payne, 2009):

- **Temperature and circulation changes.** The patient’s arms and legs may become cool to the touch, and the underside of the body may darken in color as peripheral circulation slows down. Despite feeling cool to touch, the patient is usually not aware of feeling cold, and light bed coverings usually provide sufficient warmth.

- **Sleeping.** The dying patient will gradually spend more time sleeping and at times may be difficult to arouse as metabolism decreases. The patient will gradually retreat from the surroundings. It is best to spend more time with the patient during the most alert times.

Exhibit 10.4 Signs and Symptoms of Impending Death

<table>
<thead>
<tr>
<th>Symptoms</th>
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<tbody>
<tr>
<td>Lowered temperature and slowed circulation</td>
</tr>
<tr>
<td>Deeper and longer periods of sleep</td>
</tr>
<tr>
<td>Decreased acuity of vision and hearing</td>
</tr>
<tr>
<td>Increased secretions in the mouth and congestion</td>
</tr>
<tr>
<td>Incontinence</td>
</tr>
<tr>
<td>Restlessness and confusion</td>
</tr>
<tr>
<td>Reduced need for eating and drinking and difficulty swallowing</td>
</tr>
<tr>
<td>Irregular and interrupted breathing</td>
</tr>
<tr>
<td>Increased signs of pain</td>
</tr>
</tbody>
</table>

SOURCES: Lamers, 2013; Reith & Payne, 2009
• **Vision and hearing.** Clarity of vision and hearing may decrease. The patient may want the lights on as vision decreases. Hearing is the last of the five senses to be lost, so it should not be assumed that an unresponsive patient cannot hear. Speech should be soft and clear but not louder than necessary. Many patients talk until minutes before death and are reassured by the exchange of words between loved ones.

• **Secretions in the mouth and congestion.** Oral secretions may become more profuse and collect in the back of the throat. Most people are familiar with the term *death rattle*, a result of a decrease in the body’s intake of fluids and inability to cough up normal saliva. Tilting the head to the side and elevating the head of the bed will ease breathing. Swabbing the mouth and lips also provides comfort.

• **Incontinence.** Loss of bowel and bladder function may occur around the time of death or as death is imminent, as the muscles begin to relax. The urine will become very dark in color. If needed, pads should be used to keep skin clean and dry.

• **Restlessness and confusion.** The patient may become restless or have visions of people or things that do not exist. These symptoms may be a result of a decrease in the oxygen circulation to the brain and a change in the body’s metabolism. Someone should stay with the patient, reassuring the person in a calm voice, telling the person it is okay to let go, and using oxygen as instructed. Soft music, back rubs, and gentle touch may help soothe the patient. The patient should not be interfered with or restrained, yet should be prevented from falling.

• **Eating, drinking, and swallowing.** Patients will have decreased need for food and drink. It may be helpful to explain that feeding will not improve the condition and in fact may exacerbate symptoms. Slight dehydration may be beneficial in reducing pulmonary secretions and easing breathing. Dehydration also generally results in mild renal insufficiency that is mildly sedating. To withhold food and water feels counterintuitive, however, because food and water are usually equated with comfort and sustaining life. Ice chips, small sips of water, and small amounts of food that have meaning to the patient and family are more helpful than forcing food or liquids.

• **Breathing changes.** Breathing may become irregular, with periods of 10 to 30 seconds of no breathing. This symptom is very common and indicates a decrease in circulation and buildup of body waste products. Elevating the head of the bed and turning the patient on his or her side often helps relieve irregular breathing patterns.

• **Pain.** Frequent observation will help determine if the patient is experiencing pain. Signs of discomfort include moaning, restlessness, and a furrowed brow. Medication should be given as instructed, or the nurse or physician should be contacted if pain persists.

Dying may take hours or days; no one can predict the time of death even when the person is exhibiting signs and symptoms of dying. The following are signs that death has occurred:

- Breathing stops
- Heart stops beating
- Bowel or bladder control is lost
- No response to verbal commands or shaking
- Eyelids may be slightly open with eyes fixed on a certain spot
- Mouth may fall open slightly as the jaw relaxes

Such explicit discussion of death with those attending a dying family member or close friend may seem upsetting, but this knowledge is also comforting and can help ease the anxiety related to the fear of the unknown. Dying persons are also comforted knowing that their family members have the informational, medical, and social support they need to help them in their caregiving role. It is also helpful to have funeral plans in place so that one phone call to the mortuary facilitates the process, rather than facing difficult and emotional decision making at the time of death.
LOSS, GRIEF, AND BEREAVEMENT

Loss is a common human experience. There is a great deal of evidence that people of all cultures have strong, painful reactions to the death of the people to whom they are emotionally attached (Doka & Tucci, 2009). Sadness, loneliness, disbelief, and anxiety are only a few of the feelings a person may experience in times of bereavement. The challenge is to refrain from making grief the problem, thereby pathologizing someone's experience, and to understand the complexities related to death in a society that has grown increasingly old-age and death avoidant (Jenkinson, 2012). So we offer the following, cautioning against turning someone's grief into a problem and encouraging readers to help others understand grief as a normal part of life, perhaps even a skill that we need to learn (Jenkinson, 2012).

Grief, bereavement, and mourning are words that are often used interchangeably, perhaps because no one word “reflects the fullness of what a death introduces into the life of an individual, family or community” (Silverman, 2004, p. 226). The following definitions help distinguish the various aspects of this process:

- **Loss.** The severing of an attachment an individual has with a loved one, a loved object (such as a pet, home, or country), or an aspect of one's self or identity (such as a body part or function, physical or mental capacity, or role or position in family, society, or other context) (Stroebe, Stroebe, & Hansson, 1993). Silverman (2004) suggests that loss doesn't happen to us; rather it is “something we must make sense out of, give meaning to, and respond to” (p. 226).

- **Bereavement.** The state of having suffered a loss.

- **Grief.** The normal internal reaction of an individual experiencing a loss. Grief is a complex coping process, is highly individualized (Stroebe et al., 1993), and is an expected period of transition (Silverman, 2004).

- **Mourning.** The external expression of grief (Stroebe et al., 1993); the “mental work following the loss of a loved one . . . social process including the cultural traditions and rituals that guide behavior after a death” (Silverman, 2004, p. 226).

The rituals associated with death vary in historical and cross-cultural context (Bullock, 2011; Doka & Tucci, 2009). In some cultures, the dead are buried; in other cultures, the dead are burned and the ashes are spread. In some places and times, a surviving wife might have been burned together with her husband. In the United States, death rituals can be as different as a traditional New Orleans funeral, with street music and mourners dressed in white, or a somber and serene funeral with hushed mourners dressed in black. Some cultures prescribe more emotional expression than others. Some cultures build ritual for the expression of anger, and some do not.

Throughout life, we are faced with many losses, some that occur by death but many that occur in other ways as well. For example, Margaret
Davis lost her husband to death, but she has also lost a daughter through estrangement and faced much loss of independence and privacy as she increasingly needed assistance from her children and grandchildren. Pete Mullin lived through the losses related to divorce and retirement. Marie Cipriani has experienced similar losses, as well as the loss of her siblings and her adult child. Recently, the burgeoning literature on loss, grief, and bereavement has recognized that there may be similar processes for grieving all losses, including those that occur for reasons other than death. Loss is one of the most important themes in our work as social workers. For example, we encounter loss caused by foster care placement, divorce, disease and disability, migration and immigration, forced retirement, and so on. Disenfranchised grief occurs when a loss is not honored or recognized by individuals and/or society because of the nature of one’s relationship, such as often occurs with same-sex couples, like Marie Cipriani and Irene Wright.

**Critical Thinking Questions 10.4**

What does death mean to you? Is it the final process of life, the beginning of life after death, a joining of the spirit with a cosmic consciousness, rest and peace, a continuation of the spirit? How has culture influenced your understanding of the meaning of death? How has religion influenced your understanding of the meaning of death? How might your understanding of the meaning of death affect your work with someone who is dying? What does it mean to live a good life?

**Theories and Models of Loss**

A variety of theorists have sought to make sense of the complex experience of loss. Much of the literature on grief and bereavement for the past century has been influenced by Sigmund Freud’s (1917/1957) classic article “Mourning and Melancholia.” Freud described the “work of mourning” as a process of severing a relationship with a lost person, object, or ideal. He suggested that this happens over time as the bereaved person is repeatedly faced with situations that remind him or her that the loved person (object or ideal) has, indeed, been lost. From this classic work came the idea of a necessary period of grief work to sever the attachment bond, an idea that has been the cornerstone of a number of stage models of the grief process.

In the United States, Erich Lindemann (1944) was a pioneer in grief research. Through his classic study of survivors of a fire at the Cocoanut Grove Lounge in Boston, he conceptualized grief work as both a biological and a psychological necessity. The common reactions to loss that he identified included the following:

- Somatic distress, occurring in waves lasting from 20 minutes to an hour, including tightness in throat, choking and shortness of breath, need for sighing, empty feeling in abdomen, lack of muscular power, and intense subjective distress
- Preoccupation with image of deceased, yearning for the lost one to return, wanting to see pictures of the deceased or touch items associated with the deceased
- Guilt
- Hostile reactions, toward the deceased as well as toward others
- Loss of patterns of conduct, where the ability to carry out routine behaviors is lost

Lindemann proposed that grief work occurs in stages, an idea that has been popular with other theorists and researchers since the 1960s. A number of stage models of grief have been proposed, and four are presented in Exhibit 10.5. As you can see, although the number and names of stages vary somewhat among theorists and researchers, in general the stage models all agree that grief work progresses from disbelief and feelings of unreality, to painful and disorganizing reactions, to a kind of “coming to terms” with the loss. Stages or phases run the risk of being misused when taken too literally; however, they have served to remind us that grief is a process with different parts that...
people experience in their own time (Winokuer & Harris, 2012).

J. William Worden (2009) took a somewhat different approach, writing about the “tasks of mourning” rather than stages of mourning. He considered task to be more consistent with Freud’s concept of grief work given that the mourner needs to take action and do something rather than passively move through grief. Worden suggests that the following four tasks of mourning are important when a person is adapting to a loss:

Task I: to accept the reality of the loss. Working through denial takes time, because this involves both an intellectual and an emotional acceptance. Some people have traditional rituals that help with this process.

Task II: to work through the pain of grief. Because people are often uncomfortable with the outward displays of grief, our society often interferes with this task. People often seek a geographic cure or quickly replace the lost person in a new relationship but often still have this task to complete.

Task III: to adjust to an environment in which the deceased is missing. This includes filling roles previously filled by the deceased and making appropriate adjustments in daily activities. In terms of roles, many widows report being thrown the first time they have to cope with a major home repair. Regarding adjustments in daily activities, many bereaved persons report that they find themselves automatically putting the favorite foods of the deceased in their grocery carts.

Task IV: to emotionally relocate the deceased and move on with life. This task was best described by Sadie Delany after the loss of her beloved sister, Bessie: “I don’t want to get over you. I just want to find a way to live without you” (Delany, 1997).

In the past few decades, there has been a critique of the idea of grief work. A highly influential article, “The Myths of Coping With Loss” (Wortman & Silver, 1989), disputed two major themes of the traditional view of grief work: distress is an inevitable response to loss, and the failure to experience distress is a sign of improper grieving. In fact, a number of researchers have found that those who show the highest levels of distress immediately following a loss are more likely than those who show little distress to be depressed several years later. In another vein, Silverman (2004) challenges the notion of “tasks,” which suggests something can be completed, recommending that we focus instead on “issues and processes” (p. 237).

Given the tremendous diversity among individuals based on gender, culture, personality style, and life experience, as well as the various circumstances surrounding a loss, the grieving process is not easily defined, but theorists and practitioners continue to try to provide some framework for
understanding the process. Camille Wortman and Roxanne Silver (1990) proposed that at least four patterns of grieving are possible: normal, chronic, delayed, and absent. Worden (2009) elaborated on these patterns:

1. **Normal or uncomplicated grief.** Relatively high level of distress soon after the loss encompassing a broad range of feelings and behaviors, followed by a relatively rapid recovery.

2. **Chronic or prolonged grief.** High level of distress continuing over a number of years without coming to a satisfactory conclusion.

3. **Delayed grief (or inhibited, suppressed, or postponed grief).** Little distress in the first few months after the loss, but high levels of distress at some later point.

4. **Absent grief.** No notable level of distress either soon after the loss or at some later time. Some question this notion and wonder if it is not absent, but masked or delayed; observation over time is important.

In their research, Wortman and Silver (1990) found absent grief in 26% of their bereaved participants, as well as a high rate (more than 30%) of chronic grief.

Given these critiques of traditional models of grief, theorists and researchers have looked for other ways to understand the complex reactions to loss. The study of bereavement has been influenced by developments in the study of stress and trauma reactions. Research on loss and grief has produced the following findings (Bonanno & Kaltman, 1999):

- It is the evaluation of the nature of the loss by the bereaved survivor that determines how stressful the loss is.
- How well a coping strategy works for dealing with loss depends on the context and the nature of the person-environment encounter.
- Maintaining some type of continued bond with the deceased, a strong sense of the continued presence of the deceased, may be adaptive.
- The capacity to minimize negative emotions after a loss allows the bereaved to continue to function in areas of personal importance.
- Humor can aid in the grief process by allowing the bereaved to approach the enormity of the loss without maximizing psychic pain or alienating social support.
- In situations of traumatic loss, there is a need to talk about the loss, but not all interpersonal relationships can tolerate such talk.

Martin and Doka (2000) propose an approach to adult bereavement that explores the role of gender, culture, and other characteristics that influence a person’s grieving style. This approach includes two aspects of adaptive grieving: the internal experience of loss and the outward expression relating to the loss. Martin and Doka (2000) suggest that adaptive grieving styles exist on a continuum with intuitive grievers at one end and instrumental grievers at the other end. Intuitive grievers experience and express their grief primarily through emotion, and instrumental grievers experience and express their grief primarily through a cognitive, behavioral, problem-solving approach. They suggest that few people tend to be at either extreme of the continuum, but rather most tend to have a blended style of grieving, using both intuitive and instrumental strategies (Doughty, 2009). They assert that the difficulty may arise when an individual for whatever reason uses a grieving style that is in conflict with their more natural adaptive style. Doughty (2009) sought more empirical feedback about this model, in addition to the strong anecdotal evidence from practitioners. She surveyed 20 experts in the field of thanatology to examine their opinions about this model. Consensus was found on the following items: the uniqueness of the griever; recognition of multiple factors influencing the grief process; the use of both cognitive and affective strategies in adapting to bereavement; and both internal and external pressures to grieve in certain ways.

In summary, grief is a multidimensional process—a normal life experience—that theorists and practitioners continue to try to understand (Gordon, 2013). There seems to be general agreement that culture, past experience, gender, age, and other personal characteristics influence how one copes with loss.
Culture and Bereavement

Some suggest that all people feel the same pain with grief but that cultural differences shape our mourning rituals, traditions, and behavioral expressions of grief (Walsh, 2012). While there are good sources for exploring ethnic variations related to death and grief (see Irish, Lundquist, & Nelson, 1993), we hesitate to provide overviews of various cultural groups, because of the diversity within groups, as well an increasing cultural diversity in most communities. So instead we suggest you come to each encounter with an openness and curiosity, acknowledging people as the experts about what has been helpful in the past and inquiring about what you need to know to best work with them now. Hooyman and Kramer (2006) provide detailed suggestions for conducting a good cross-cultural assessment and communication (see pp. 174–178), some of which include the following:

- Do your homework before talking to members of the group.
- Begin by listening to their story using open-ended questions.
- Approach them with humility and caution, recognizing them as “insiders” who have the more immediate and critical knowledge of their experience.
- Never judge or have predetermined ideas of what they should feel or do.
- Recognize potential cultural conflicts and respect their decisions and choices.
- Use and train qualified interpreters, understanding the benefits and limitations of doing so.

Important components of an assessment include reactions to loss; mourning style; level of acculturation; cultural history; the role and presence of religion and/or spirituality; grieving rituals; family dynamics, including intergenerational relationships; and other components of any good multidimensional assessment such as social support, financial resources, strengths, and personality. Inquire more specifically about the following:

- Their interpretation of the illness and/or death (asking what they call it, think caused it, think will help, fear most)
- Questions relevant to the care of the body after the death and related beliefs and rituals
- How people in their family and culture commonly express grief (i.e., who, when, how long)

Knowledge about beliefs, values, and customs puts certain behaviors in a context that will help guide you in your work.

A few examples of important components of some cultural norms that may be helpful to consider include the following:

- In the United States, the dominant culture tends to psychologize grief, understanding it in terms of sadness, depression, anger, and other emotions.
- In China and other Eastern societies, grief is often somatized, or expressed in terms of physical pain, weakness, and other physical discomfort (Walsh, 2012).
- Gender differences exist in many cultures, including the dominant U.S. culture, where men have learned to be less demonstrative with emotions of grief and sadness than women (Walsh, 2012).

Mourning and funeral customs also differ a great deal even within groups. For example, among African Americans, customs vary depending on whether the family is Southern Baptist, Catholic, Unitarian Universalist, Muslim, or Pentecostal; in fact “religion may be a stronger determining factor than race alone” (Barrett, 2009, p. 85). Perhaps because of some vestiges of traditional African culture and slavery and a strong desire to celebrate the person’s life and build up a sense of community, funerals are important external expressions of mourning in many Black communities.

Tremendous diversity exists within the Latino cultures in the United States, depending on country of origin and degree of acculturation; however, for the most part these subgroups share Latino values, language, religion, and traditional family structure. Some Latino cultural themes that can influence care at the end of life include familismo (emphasis of family over individual), personalismo

Why is it important for social workers to learn about cultural variations in grief and bereavement?
(trust building over time based on mutual respect), jerarquismo (respect for authority and hierarchy), presentismo (focus on present more than past or future), espiritismo (belief that good and evil spirits can impact health), and fatalism (fate determines life outcomes) (Sandoval-Cros, 2009).

Given approximately 350 distinct Native American tribes in the United States and more than 596 bands among the First Nations in Canada, and because of the differing degrees of acculturation and religious practices from one group to another, it is difficult to provide useful generalizations about this cultural group (Brokenleg & Middleton, 1993). Most understand death as a natural end of life, not fearing it, and although it may be a painful separation for the living who are left behind, rituals exist to help with the transition (Cox, 2009).

A good source of more specific information about rituals and practices is websites on particular cultural/ethnic groups such as Hmong Americans: Dying and Death Rituals (http://sfsuyellowjournal.wordpress.com/2011/11/17/hmong-americans-dying-and-death-ritual). Sites such as these are often written by members of the respective community, and they too remind you of the great diversity among their members. The complex and at times impersonal health care system in the United States can be inadvertently insensitive to important cultural traditions. For example, in some cultures, proper handling of the body, time to sit with the deceased, and other traditions are valued. For one specific example, the Hmong believe that proper burial and worship of ancestors directly influence the safety and health of the surviving family members. They believe that the spiritual world coexists with the physical world and that each person has several souls that must be appropriately sent back to the spiritual world.

These are only a few examples of the rich diversity and complexity you will face in working in our increasingly multiethnic society. You cannot possibly know all the specific traditions, so start by knowing you do not know, and do your homework on their world, including being open to their story and teachings. It is exciting to think of how much there is to learn about how others make sense of these mysterious times of life.

Critical Thinking Questions 10.5

Think of your first experience of a human loss due to death. What do you remember observing the adults in your life do? How did the adults explain what was happening to you? What do you recall thinking and feeling at the time? What death rituals were used to acknowledge the loss? How do you think your current attitudes and beliefs about loss and grief are influenced by this early experience?

THE LIFE COURSE COMPLETED

In this book, we have explored the seasons of the life course. These seasons have been and will be altered by changing demographics. Current demographic trends have led to the following predictions about the future of the life course (Hogstel, 2001):

- The size and inevitable aging of the baby boom generation will continue to drive public policy debate and improve services for very-late-life adults.
- Women will continue to live longer than men.
- Educational attainment levels of the very-late-life adult will increase, with more women having been in the labor force long enough to have their own retirement income.
- Six-generation families will be common, although the generations will live in geographically dispersed settings, making care for very-late-life adults difficult.
- Fewer family caregivers will be available for very-late-life adults because the baby boomers and their children tended to marry later and have fewer children. At the same time, the need for informal or family caregiving to supplement formal care will increase.
- Assessment and management of health care, as well as health care education, will increasingly be available via telephone, the Internet, and television, providing greater access in remote areas but running the risk of rendering the service more impersonal.
As a society, we have a challenge ahead of us to see that newborns begin the life course on a positive foot and that everyone reaches the end of life with the opportunity to see his or her life course as a meaningful whole. As social workers, we have a responsibility to take a look at our social institutions and evaluate how well they guarantee the opportunity for each individual to meet basic needs during each season of life, as well as whether they guarantee the opportunity for interdependence and connectedness appropriate to the season of life. We close this section with a quote by Socrates about how we would do well to learn from our elders (Agronin, 2011, p. 279): “I enjoy talking with very old people. They have gone before us on a road by which we, too, may have to travel, and I think we do well to learn from them what it is like.”

**Implications for Social Work Practice**

All the implications for practice listed in Chapter 9 on late adulthood apply in very late adulthood as well. See the following resources for additional information about social work practice and end-of-life-related patient and family care: Csikai and Jones (2007); Hooyman and Kramer (2006); Kashushin and Egan (2008); Kovacs, Bellin, and Fauri (2006); and Walsh (2012). In addition, the following practice principles focus on the topics of spirituality, relationships, the dying process, and loss, grief, and bereavement.

- Given the links among aging, disability, loss, and spirituality, consider doing a spiritual assessment to find ways to help very-late-life adults address increasing spiritual concerns.
- Assess the impact of loss in the lives of your very-late-life clients—loss of partners, friends, children, and other relationships but also loss of role, status, and physical and mental capacities.
- Recognize and be delighted when very-late-life adults are grateful for their “extra time.”
- Assess the loneliness and isolation that may result from cumulative loss.
- Be informed about available formal and informal resources to help minimize isolation for older adults.
- Be aware of your own feelings about death and dying so that you may become more comfortable being physically and emotionally present with clients and their loved ones.
- Identify literature, websites, cultural experiences, key informants, and other vehicles for ongoing education about your clients’ cultural, ethnic, and religious and spiritual practices that are different from your own. Remember, the client may be your best teacher.
- Assume that the very-late-life adult continues to have needs for intimacy. Stretch your conceptualization of intimacy to include any relationship the person might have, wish for, or grieve, including a spouse or partner, friends, children, self, and community.

**Key Terms**

- activities of daily living (ADLs)
- advance directives
- bereavement
- centenarian
- grief
- grief work
- hospice
- instrumental activities of daily living (IADLs)
- living will
- loss
- mourning
- palliative care
- primary aging
- secondary aging
Active Learning

1. Take an inventory of your assumptions about what it is like to be 85 and older. What are your biggest fears? What do you think would be the best part of reaching that age? Think about how these assumptions might influence your feelings about working with clients in very late adulthood.

2. You have recently been hired as the social worker at an assisted-living facility, and Margaret Davis, Pete Mullin, and Marie Cipriani have all recently moved in. All three are unhappy to be there, preferring their prior living arrangements. Pete’s sister and Marie’s partner recently died. You want to help them share some of their recent experiences related to loss but want to be sensitive to the diversity in life experience that they bring with them. What barriers might you face in accomplishing your goal? What are some ways you might begin to help them?

3. Think about possible relationships among poverty, gender, sexual orientation, and race as one ages in the United States today. Identify ways that social workers can influence policies that affect housing, health care, and other essential services directly related to quality of life in very-late-life adulthood.

Web Resources

Administration for Community Living: www.acl.gov

Site of U.S. Department of Health and Human Services Administration for Community Living contains help and resources, information about programs and activities, a newsroom, and funding opportunities.

American Society on Aging: www.asaging.org

Site provides general information about aging-related services, including a link to LGBT Aging Issues Network (LAIN) and LGBT Aging Resources Clearinghouse (LARC) and information on older adults, alcohol, medication, and other drugs.

Generations United: www.gu.org

Site maintained by Generations United (GU), the national membership organization focused solely on improving the lives of children, youth, and older people through intergenerational strategies, programs, and public policies. See site for links to resources, bibliographies, and so on.

Hospice Foundation of America: www.hospice-foundation.org

Site contains information for locating hospice programs, a newsletter, and links to resources.

National Association of Social Workers: www.naswdc.org/aging.asp

Site provides access to resources related to aging and social work practice, including some online courses.

National Caregivers Library: www.caregiverslibrary.org

Site created and maintained by FamilyCare America contains information and tools for caregivers, seniors, and employers.

National Center for Gerontological Social Work Education: www.cswe.org/CenterInitiatives/GeroEdCenter.aspx

Site maintained by the Council on Social Work Education Gero-Ed Center (National Center for
Gerontological Social Work Education) provides resources for aging and end-of-life care.

**National Hospice and Palliative Care Organization: www.nhpco.org**

Site maintained by the National Hospice and Palliative Care Organization contains information on the history and current development of hospice and palliative care programs, advance directives, grief and bereavement, caregiving, and other related topics.

**National Resource Center on LGBT Aging: www.lgbtaginingcenter.org**

Site of the National Resource Center on LGBT Aging formed in 2010 provides education, training, and critical resources to providers, organizations, and consumers.

**Office on Aging: www.apa.org/pi/aging**

Site presented by the Office on Aging of the American Psychological Association contains news briefs, publications, and links to aging organizations.

**The Retirement Research Foundation: www.rff.org/aging-related-websites**

Site provides links to many age-related websites.

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