



## The 5 Ws of Chronic Illness Care









# The 5 Ws of Chronic Illness Care



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You're just a few years from retirement and everything is going well: the children are out of college, the mortgage is paid off, and your retirement nest egg is looking healthy. Then you receive a call in the middle of the night from your sibling who lives halfway across the country.

“ Mom has been diagnosed with Alzheimer's disease. I'm cutting back on my hours at work so I can care for her at home. Can you help out ... financially? ”

In a heartbeat we understand: our obligations to disabled relatives don't end at a milestone age of 60, 65, or the day we retire. Our obligations continue for as long as the people we love need our help.

This situation—middle-age and older people, especially women, caring for relatives who are older still—is becoming the new normal for retirees and pre-retirees. How did this happen? The answer is found in the success story of longevity.

Growth in the number and proportion of older adults in the United States is unprecedented in our nation's history. By 2050, almost 89 million Americans will be age 65 or older, which is more than double the number in 2010. Rapid aging of the population is being driven by two factors:

Americans are living longer and, given the post-World War II baby boom, there are proportionately more older adults than in prior generations.<sup>1</sup> The leading edge of the baby boomers, who were born between 1946 and 1964, reached age 65 in 2011. Since January 1, 2011, and continuing each and every day for the next 20 years, roughly 10,000 Americans will celebrate their 65th birthdays. In 2030, when the last baby boomer turns 65, one-in-five Americans—about 72 million people—will be age 65 or older.<sup>1</sup>

As we get older, many of us will develop chronic illnesses that limit our ability to care for ourselves. Chronic illness care, which is also called long-term care, is needed for two reasons: (1) inability to perform the activities of daily living, including bathing, continence, dressing, eating, toileting, and transferring in or out of a bed or a chair; and (2) needing supervision because of cognitive impairment, such as Alzheimer's disease or other causes of dementia.

The vast majority of chronic illness care is provided at home by family caregivers, including relatives, partners, friends, and neighbors.<sup>2</sup> According to AARP, “The ‘average’ caregiver is a 49-year-old woman who works outside the home and spends nearly 20 hours per week (which is equivalent to a half-time job) providing unpaid care to her mother for nearly five years.”<sup>2</sup> The importance of family caregivers

<sup>1</sup> Centers for Disease Control and Prevention. The State of Aging and Health in America 2013. Atlanta, GA: Centers for Disease Control and Prevention, US Dept of Health and Human Services. 2013.

<sup>2</sup> Feinberg L. Testimony before the Commission On Long-Term Care. “Populations in need of LTSS and service delivery issues.” AARP Public Policy Institute July 17, 2013.

is impossible to overstate, especially given the dramatic decrease in the number of elderly people who live in nursing homes today. Families provide most of the care, and much more: they perform medical and nursing tasks, coordinate services provided by health care professionals, and help loved ones stay in their homes and communities. According to AARP, “Without them, the economic cost to the U.S. health care system ... would increase astronomically.”

But there are potential problems on the horizon. Historically, chronic illness care was generally needed for short periods of time because people didn’t survive long after developing a serious illness. Families were larger, with an abundance of caregivers,

mainly women. Much has changed. Medical care has improved, people are living longer, and chronic illness care at home might last for many years. Families, the backbone of the health care system for the elderly, are smaller and often spread across the country. Daughters and daughters-in-law have less free time to provide care because they work full-time, and spouses, who have traditionally been the primary caregivers, may be less common in the future because of higher divorce rates in baby boomers.

This article will highlight major trends in chronic illness care for people age 65 and older. The principal issues will be addressed via a discussion of the 5 Ws of chronic illness care:

## 5 Ws

- **Who** will need chronic illness care?
- **Why** will chronic illness care be needed?
- **Where** will chronic illness care be provided?
- **When** will chronic illness care be needed?
- **What** duration of chronic illness care will be needed?

# 1 WHO WILL NEED CHRONIC ILLNESS CARE?

No one wants to think about being disabled during retirement. We imagine it will happen to “other people.” But the reality is much different. Seven-in-ten people who are age 65 will need chronic illness care later in life.<sup>3</sup>



**7 IN 10 WILL NEED CHRONIC ILLNESS CARE**



Many factors affect the possibility that we might need care.

### **AGE**

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The older you are, the more likely it is that you will need chronic illness care.<sup>3</sup>

### **GENDER**

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Women are more likely than men to need chronic illness care.<sup>4</sup>

### **RACE AND ETHNICITY**

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Certain racial or ethnic groups reportedly have higher rates of functional impairment<sup>5</sup> and Alzheimer's disease than older whites.<sup>6</sup> While nursing home use has declined among some racial or ethnic segments of the population, it has increased among others.<sup>5</sup>

### **EDUCATION**

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Older people with less than a high school education are more than twice as likely as those with at least a high school diploma to have difficulty performing three or more activities of daily living.<sup>7</sup> Functional limitations are more common in people with less education because they tend to work in occupations that expose them to injuries that can lead to impairment, and they are more likely to engage in risky health behaviors, such as smoking.

### **LGBT**

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Limited research suggests that some LGBT (lesbian, gay, bisexual, transgender) individuals are more likely to need chronic illness care.<sup>8,9</sup>

“ Over the next decade, the demographics of the LGBT community will change dramatically, affecting its financial health and needs. The number of lesbian, gay, bisexual and transgender parents has been growing steadily over the past decade and is expected to increase significantly with Generation Y. At the same time, Baby Boomers are and will continue to enter retirement in record numbers, which will focus the community on caring for the financial, health and housing needs of LGBT elders. ”

*Source: The 2012-2013 LGBT Financial Experience, Prudential, 2013.*

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<sup>4</sup> Smith AK, et al. “Disability during the last two years of life.” JAMA Internal Medicine. 2013;173:1506–13. Likelihood based on estimates from Figure 3, p.1510.

<sup>5</sup> Commission on Long-Term Care. Report to the Congress. September 30, 2013.

<sup>6</sup> 2013 Alzheimer's disease facts and figures. Alzheimer's Association. March 18, 2013.

<sup>7</sup> Hagen S, et al. “Rising demand for long-term services and supports for elderly people.” Congressional Budget Office. June 26, 2013, p.20.

<sup>8</sup> Hiedemann B, et al. “Increased risks of needing long-term care among older adults living with same-sex partners.” American Journal of Public Health 2013;103:e27-33.

<sup>9</sup> <http://longtermcare.gov/the-basics/lgbt/> (Accessed February 12, 2014).

## 2 WHY WILL CHRONIC ILLNESS CARE BE NEEDED?

Many illnesses require chronic illness care later in life. Some conditions that typically require short-term care include fractures, joint replacement, heart attack, heart failure, minor stroke, diabetes, and complications of cancer treatment. While these conditions are potentially life-threatening, they are less worrisome from both a financial and a chronic illness care perspective:

- Chronic illness care is usually needed for only a few days, weeks, or months.
- Medicare Part A often pays a significant portion of the costs via a post-acute care benefit that covers skilled nursing care.<sup>7</sup>
- Average length of post-acute care ranges from a high of 36 days for home health care, to a low of 13 days for inpatient rehabilitation facilities.<sup>11</sup>
- Family and friends can usually provide short-term care until recovery occurs.
- Many people have enough savings to pay for expenses not covered by Medicare or Medicare Supplement Insurance (Medigap).

In contrast, some conditions require care for long periods of time, literally “long-term care” or “chronic illness care.” These are the illnesses we all dread: Alzheimer’s disease, serious stroke, frailty at older ages, crippling arthritis, Parkinson’s disease, brain and spinal cord injury, and degenerative neurologic diseases. Unlike the illnesses that typically require short-term care, the care needed for these conditions often has a much greater impact on family finances and care dynamics.

- Chronic illness care is usually needed for many months or years, and often for the remainder of life.
- Chronic illness care is usually custodial, which means non-skilled personal care, such as assistance with the activities of daily living. Neither Medicare nor Medicare Supplement Insurance pay for custodial care.<sup>12</sup>
- Family and friends are faced with much greater demands on their time.
- Many people do not have enough savings to pay for custodial care.

“ In 2011, about 43 percent of Medicare beneficiaries discharged from prospective payment system (PPS) hospitals went to a PAC [post-acute care] setting. Of those, almost half went to SNFs [skilled nursing facilities], 39 percent received home health care, and the remainder went to other settings, including IRFs [inpatient rehabilitation facilities] and LTCHs [long-term care-hospitals]. While all or almost all beneficiaries admitted to IRFs, SNFs, and LTCHs have a prior hospital stay, two-thirds of home health episodes are admitted directly from the community.<sup>10</sup> ”

<sup>10</sup> Medicare post-acute care reforms. Statement of Mark E. Miller. Executive Director, Medicare Payment Advisory Commission. Before the Subcommittee on Health. Committee on Ways and Means. U.S. House of Representatives. June 14, 2013.

<sup>11</sup> Medicare Payment Policy. Medpac. Medicare Payment Advisory Commission. March 2013.

<sup>12</sup> Medicare and You 2014. The official U.S. Government Medicare Handbook. U.S. Department Of Health And Human Services Centers for Medicare & Medicaid Services.



In a 2013 report for the National Bureau of Economic Research, Harvard economics professor David Cutler highlighted the distinction between nursing home stays that are either short (post-acute care) or long (chronic illness care for long periods of time). Short-term stays are used to recover from acute events, such as a broken bone. These stays usually involve a considerable amount of rehabilitation, and the patient is discharged from the care facility. Medicare generally pays for many of the expenses associated with these events.

“ People with Alzheimer’s disease, Parkinson’s, and other degenerative physical and cognitive impairments are often in a nursing home for long periods of time. Medicare does not pay for these stays. Rather, payment comes from the individual, their family, or Medicaid if family funds are not sufficient. It is these stays that an individual may wish to insure against. The vast bulk of nursing home days are accounted for by long stay residents, but the share of stays will be tilted much more to the short stays.<sup>13</sup> ”

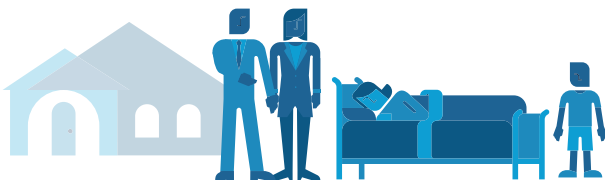
In other words, post-acute care is less worrisome because the duration of care is relatively brief, and many of the expenses are paid by Medicare. The main challenge is conditions that require chronic illness care for long periods of time.

## 3 WHERE WILL CHRONIC ILLNESS CARE BE PROVIDED?

### MOST CHRONIC ILLNESS CARE IS PROVIDED AT HOME BY FAMILIES

Chronic illness care has always been provided mainly at home by families, and this is where we want to live if care is needed later in life. “Family caregivers are more likely to listen, focus on the individual’s emotional needs, and have a level of trust and comfort with the individual.” People who receive chronic illness care at home are more satisfied with family caregivers than with paid caregivers, and happier at home than in an assisted living facility or a nursing home.<sup>14</sup>

Family care has become even more important as fewer and fewer people are cared for in nursing homes. Use of nursing homes and other institutional care facilities by people age 65 years and older peaked in 1989 at 2 million people.<sup>15</sup> Since then, the elderly nursing home population has declined dramatically, especially in people age 85 or older,<sup>16</sup> to 1.3 million people.<sup>16</sup> The trend away from nursing homes occurred despite strong growth in the number of elderly people in the United States.



<sup>13</sup> Cutler D. The problem in estimating lifetime nursing home use. Harvard University and NBER. June 13, 2013.

<sup>14</sup> Miller J, et al. “Understanding satisfaction among older adults using long-term services and supports.” SCAN Foundation. September 2013. Issue BRIEF No.1.

<sup>15</sup> Redfoot DL, et al. “More older people with disabilities living in the community: Trends from the National Long-Term Care Survey,” 1984-2004 AARP Public Policy Institute. September 2010.

<sup>16</sup> A Profile of Older Americans: 2012. Administration on Aging (AoA), Administration for Community Living, U.S. Department of Health and Human Services.

Many factors were responsible for the decreased use of nursing homes. About one-sixth of the decline can be attributed to lower disability rates in the older population.<sup>15</sup> Other factors include lower rates of widowhood and childlessness in older people, both of which increase the number of potential family caregivers; a strong preference for care at home or in assisted living facilities; and entitlement programs, such as Medicaid, that increased spending for home- and community-based services.<sup>15</sup>

**FIGURE 1. LIVING ARRANGEMENTS FOR ELDERLY PEOPLE RECEIVING CHRONIC ILLNESS CARE**

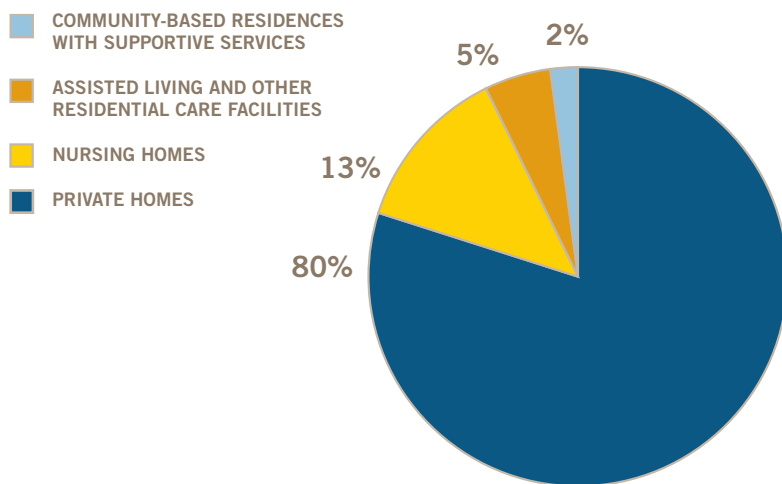


Figure 1 shows where chronic illness care is provided at older ages. The vast majority of people—four-in-five (80%)—live in private homes where about 80 percent of the care is provided by family and friends.<sup>17</sup> About one-in-eight (13%) people receiving chronic illness care live in nursing homes, one-in-twenty (5%) are in assisted living and other residential care facilities, and a small percentage (2%) live in community-based residences with supportive services.

The importance of care at home cannot be overemphasized: it delays or prevents nursing home care, thereby allowing loved ones to stay at home for as long as possible.

This is true even for Alzheimer’s disease. Seven-in-ten (70%) people with Alzheimer’s disease and other dementias live at home,<sup>18</sup> and 80 percent of the care is provided by unpaid caregivers, most often family members.<sup>6</sup>

### FAMILIES ARE PROVIDING MORE COMPLEX CARE AT HOME

The declining use of nursing homes is welcome news, but it comes with a trade-off: a significant increase in the number of very disabled people who now live in the community instead of in a nursing home.<sup>15</sup> Once again, families are on the front lines. Two-in-three (66%) disabled older people who receive chronic illness care get all of their care from family caregivers, mainly wives or adult daughters. One-quarter (26%) receive a combination of family care and paid help, and only about one-in-ten (9%) receive all of their care from paid caregivers.<sup>2</sup>



**TWO-IN-THREE (66%) DISABLED OLDER PEOPLE WHO RECEIVE CHRONIC ILLNESS CARE GET ALL OF THEIR CARE FROM FAMILY CAREGIVERS.**

<sup>17</sup> <http://longtermcare.gov/the-basics/who-will-provide-your-care/> (Accessed February 12, 2014).

<sup>18</sup> [http://www.alz.org/kyin/in\\_my\\_community\\_donate\\_use.asp](http://www.alz.org/kyin/in_my_community_donate_use.asp) (Accessed February 12, 2014).





For today’s caregivers, the level of care extends well beyond traditional assistance with bathing, dressing, eating, and moving from the bed to a chair. A survey by the AARP Public Policy Institute and the United Hospital Fund found that family caregivers perform complex tasks that were formerly provided only in hospitals:

- Managing medications, including injections and intravenous therapy (78%),
- Helping with assistive devices (canes and walkers) for mobility (43%),
- Preparing special diets (41%),
- Doing wound care (35%),

- Using meters or monitors, such as oxygen and blood pressure monitors, test kits, and telehealth equipment (32%), and
- Operating specialized medical equipment, including mechanical ventilators, tube feeding equipment, home dialysis, and suctioning (14%).

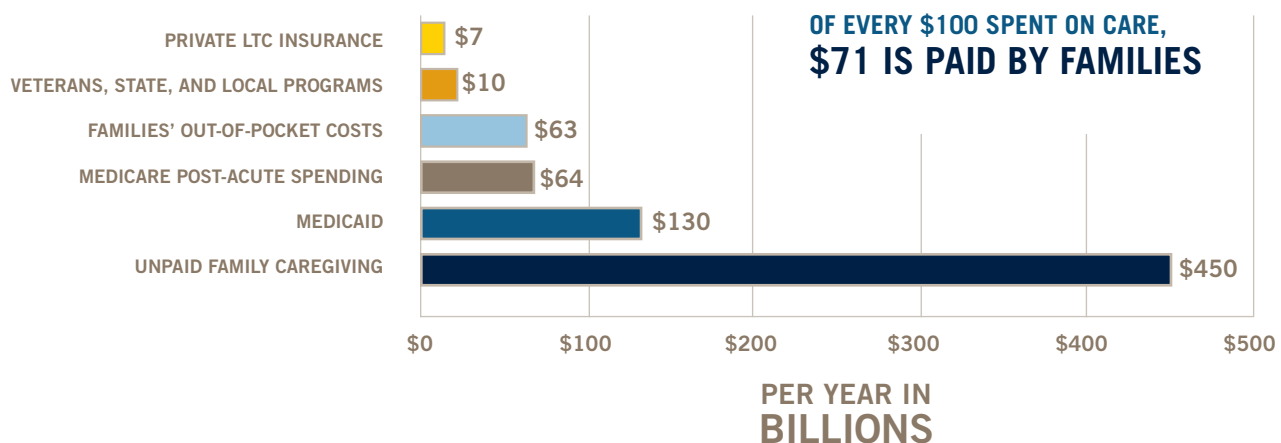
Despite the difficulty of these tasks, most people (69%) who received complex care at home did not have home visits by health care professionals.<sup>19</sup> According to AARP, “[The recipient’s] care is generally ongoing rather than intermittent, as is the contribution of family members.”<sup>19</sup> This is the new normal for today’s family caregivers.<sup>19</sup>

## FAMILIES PAY FOR MOST CHRONIC ILLNESS CARE

The United States spends nearly \$725 billion each year on chronic illness care.<sup>20</sup> Where does the money come from? Many people would guess “Medicare” or “Medicaid.” Both answers are far off the mark.

Figure 2 shows the sources of payment for chronic illness care. Each year, families contribute \$63 billion in out-of-pocket costs and \$450 billion in unpaid family caregiving. This means families pay **\$71 of every \$100** that is spent on chronic illness care.

**FIGURE 2. SOURCES OF PAYMENT FOR CHRONIC ILLNESS CARE IN THE UNITED STATES**



<sup>19</sup> America’s Growing Caregiving Crisis Spans Generations, California Health Report (August, 2013) <http://newamericamedia.org/2013/08/americas-growing-caregiving-crisis-spans-generations.php> (Accessed February 12, 2014)

<sup>20</sup> The state of long-term care financing. The SCAN Foundation. March 29, 2013.

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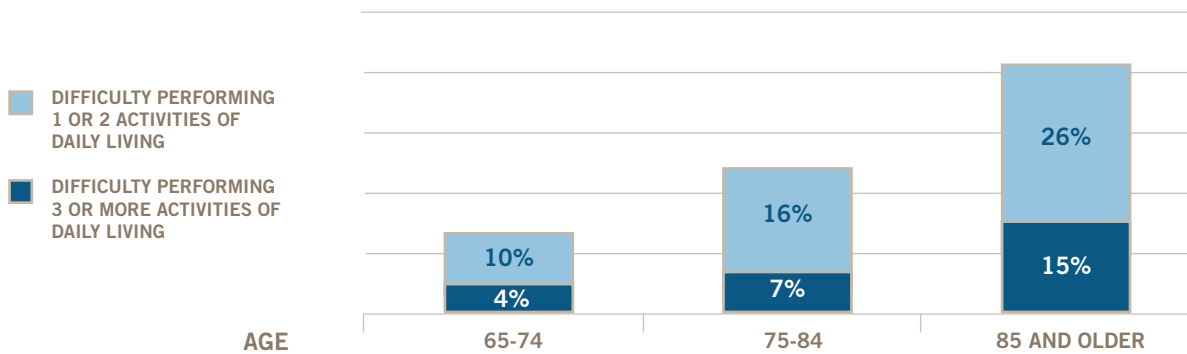
## WHEN WILL CHRONIC ILLNESS CARE BE NEEDED?

### ACTIVITIES OF DAILY LIVING

Most people know the answer to this question: at older ages. One of the main reasons is because limitations in the activities of daily living (ADLs) are much more common in older people.

At ages 65 to 74, one-in-ten (10%) people have difficulty performing one or two ADLs, and one-in-twenty-five (4%) have trouble with three or more (Figure 3). Functional limitations increase at ages 75 to 84, and by age 85 or older, one-in-four (26%) people have difficulty performing one or two ADLs, and about one-in-seven (15%) have trouble with three or more.<sup>7</sup>

**FIGURE 3. LIMITATIONS IN THE ACTIVITIES OF DAILY LIVING AMONG ELDERLY PEOPLE LIVING IN THE COMMUNITY, 2000 TO 2010**



Community refers to private homes or assisted living.

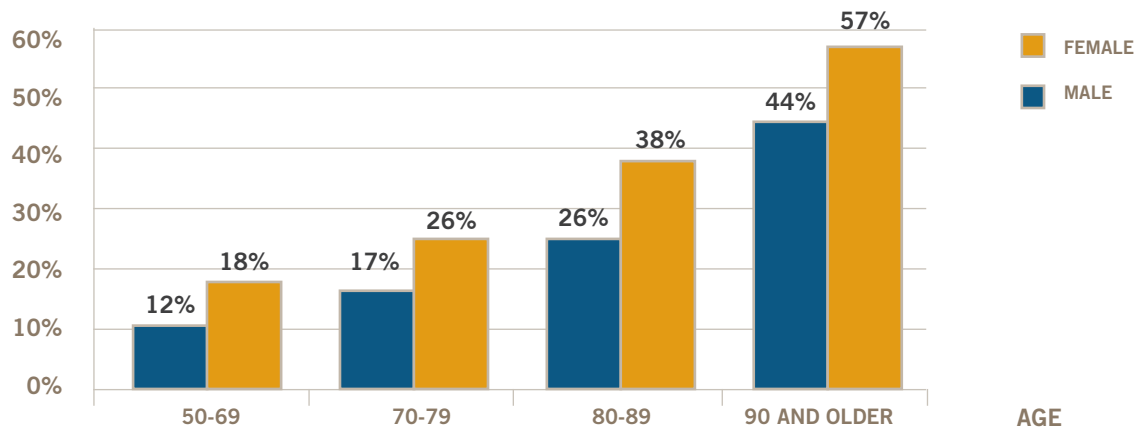
Activities of daily living include bathing, dressing, eating, walking, transferring out of a bed or chair, and using the toilet.



ADL disability is especially common during the last two years of life (Figure 4).<sup>4</sup> Male disability rates at ages 80 to 89 and ages 90 and older are 26 percent and 44 percent, respectively; for women, disability rates for these ages are considerably higher: 38 percent and 57 percent, respectively.

There are a number of reasons why women have higher rates of disability. For example, women lose bone (osteoporosis) and muscle (sarcopenia) faster than men, they're more likely to be frail and fall, and they have more fractures and serious injuries after falling.<sup>4</sup>

**FIGURE 4. LIKELIHOOD OF DISABILITY IN THE ACTIVITIES OF DAILY LIVING DURING THE LAST 2 YEARS OF LIFE**

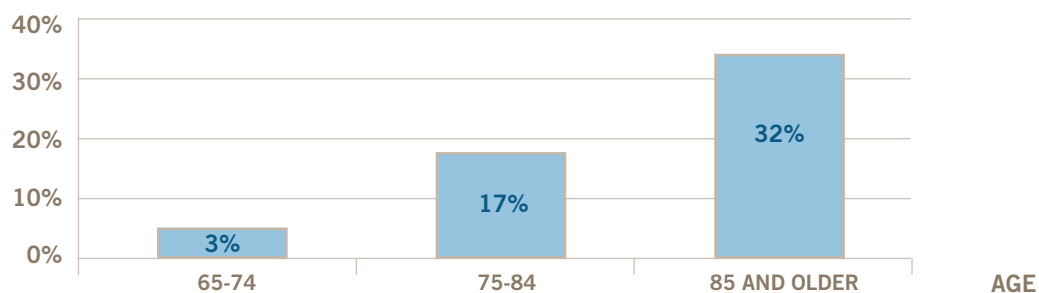


### ALZHEIMER'S DISEASE AND OTHER DEMENTIAS

The second reason why chronic illness care is needed at older ages is because Alzheimer's and other dementias are much more common in older people (Figure 5).<sup>6</sup> At ages 65 to 74, about one-in-33 (3%) people have Alzheimer's disease; at ages 75 to 84, one-in-six (17%); and at age 85 and older, one-in-three (32%).<sup>21</sup>

Within these age groups, there are differences among various segments of the population, including differences among racial and ethnic groups. The higher likelihood of these conditions in particular racial or ethnic groups may be due to health problems such as high blood pressure and diabetes that increase one's risk for cognitive impairment.<sup>6</sup>

**FIGURE 5. PERCENTAGE OF PEOPLE WITH ALZHEIMER'S DISEASE IN 2014**



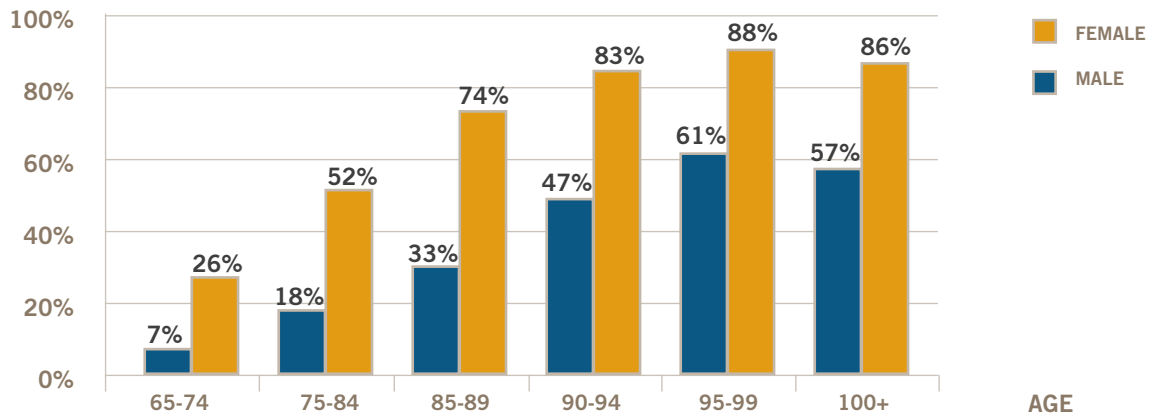
<sup>21</sup>Hebert LE, et al. Alzheimer disease in the United States (2010–2050) estimated using the 2010 census. *Neurology* 2013;80:1778-33.

## OLD AND ALONE

We know chronic illness care is often required later in life, but there's more to the story. Care is needed not only when we're old, but when we're old and alone because we've lost our spouse, who is our primary caregiver.<sup>22</sup> Women are at much higher risk. After caring for their husbands, women may find themselves alone at one of their most vulnerable times of life.

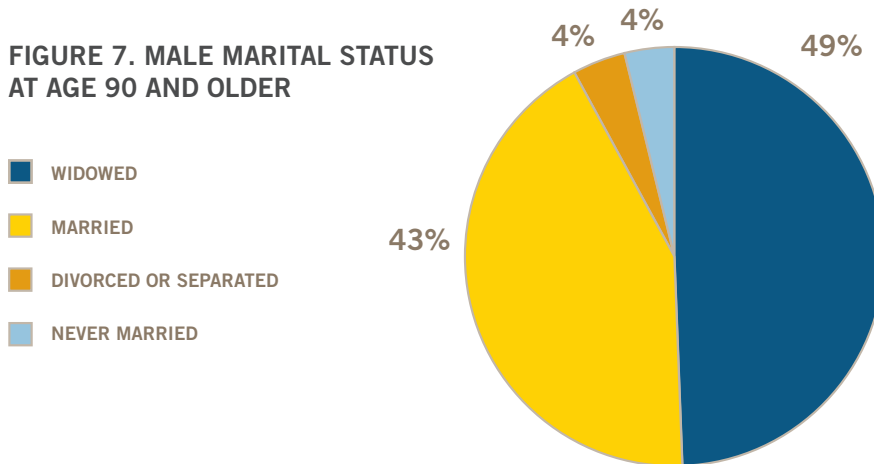
Widowhood, defined as widowed and not remarried, is much more common in women (Figure 6). At ages 85 to 89, for example, one-in-three (33%) men are widowed, compared to three-in-four (74%) women.<sup>23</sup>

**FIGURE 6. LIKELIHOOD OF BEING WIDOWED**



For people who live to age 90 and older, the differences in marital status are striking (Figures 7 and 8). Half of the men (49%) are widowers, while more than four-in-ten (43%) are married. In contrast, more than eight-in-ten (84%) women are widows, and very few (6%) are married.<sup>22</sup>

**FIGURE 7. MALE MARITAL STATUS AT AGE 90 AND OLDER**

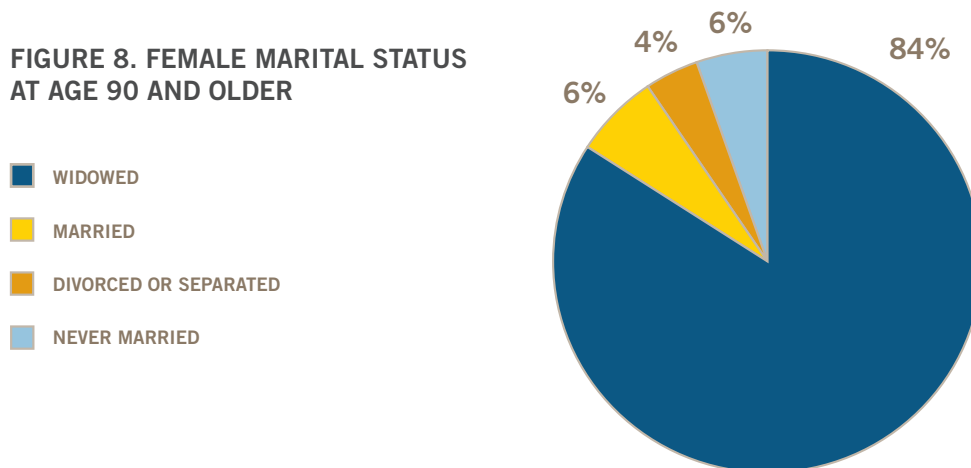


<sup>22</sup> Redfoot D, et al. The aging of the baby boom and the growing care gap: A look at future declines in the availability of family caregivers. AARP Public Policy Institute. August 2013.

<sup>23</sup> He W, et al. U.S. Census Bureau, American Community Survey Reports, ACS-17, 90+ in the United States: 2006–2008, U.S. Government Printing Office, Washington, DC, 2011.



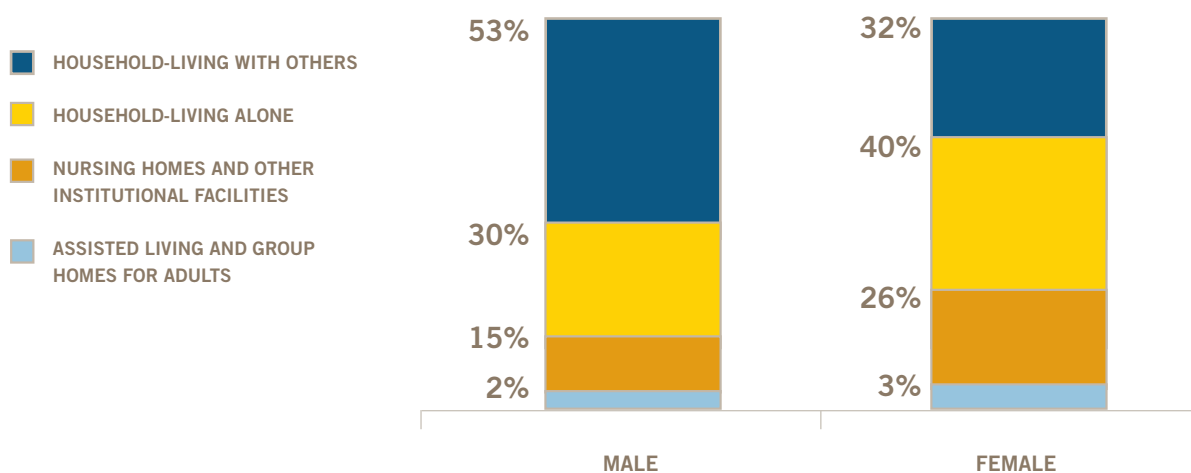
**FIGURE 8. FEMALE MARITAL STATUS AT AGE 90 AND OLDER**



Older women are not only more likely to be widowed; they are also more likely to live alone or in a nursing home (Figure 9).<sup>22</sup> At age 90 and older, more than half of men (53%) live in a household with family members and/or unrelated individuals, less than one-third live alone (30%), and about one-in-seven (15%) are in nursing homes and other institutional facilities. In contrast, only one-in-three older women (32%) live in a household with others, four-in-ten (40%) live alone, and one-in-four (26%) live in nursing homes or other institutional facilities.

**FIGURE 9. LIVING ARRANGEMENTS AT AGE 90 AND OLDER**

Percentages may total more than 100% because of rounding.



While the percentages are impressive, the absolute numbers show why widowhood takes such a toll on older women. At age 90 and older, there is one man living alone for every four women, and in institutions there is one man for every five women.<sup>22</sup>

## 5 WHAT DURATION OF CHRONIC ILLNESS CARE WILL BE NEEDED?

The duration of chronic illness care varies widely. As shown in Figure 10, more than three-in-ten (31%) 65-year-olds will never need chronic illness care, and slightly less than two-in-ten (17%) will need care for less than one year. Together, this means almost half (48%) of 65-year-olds will never need care, or they'll need it for only a short time. At the other extreme, two-in-ten (20%) people will need chronic illness care for more than five years.<sup>5</sup> Regardless of how much care is needed, the good news is that more people will receive chronic illness care at home—and for longer periods of time—than in nursing homes or other institutional settings.<sup>24</sup>

**FIGURE 10. FOR PEOPLE AGE 65, ESTIMATED FUTURE DURATION OF CHRONIC ILLNESS CARE**

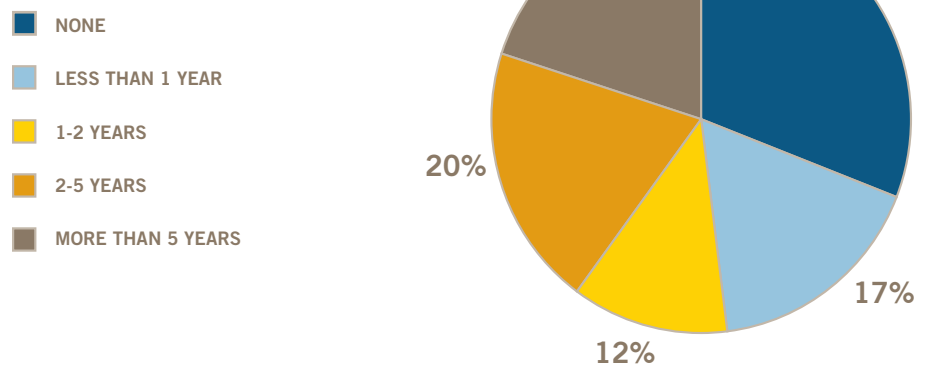
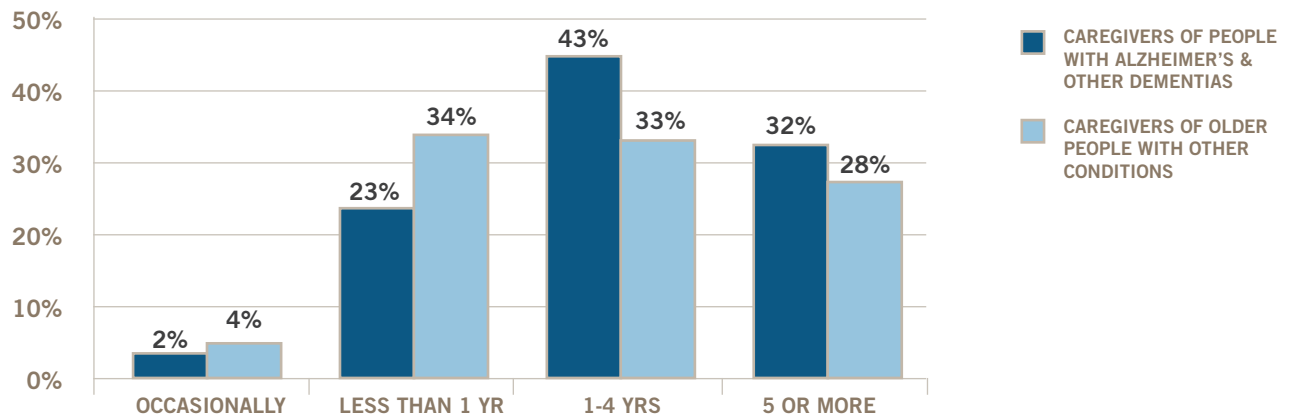


Figure 11 shows the duration of caregiving by family members and other unpaid caregivers. More than four-in-ten (43%) caregivers of people with Alzheimer's and other dementias provide care for one to four years, and more than three-in-ten (32%) are caregivers for five years or more. For other conditions that require chronic illness care, more than three-in-ten (33%) caregivers provide care for one to four years, and almost three-in-ten (28%) are caregivers for five years or more.<sup>6</sup>



Who are these caregivers? We are. Each year, 15 million Americans provide more than 17 billion hours of unpaid care for family and friends with Alzheimer’s disease and other dementias.<sup>6</sup> More than six-in-ten (62%) caregivers were women, almost one-in-four (23%) were 65 years of age and older, and three-in-ten (30%) had children under 18 years old living with them.<sup>6</sup>

**FIGURE 11. DURATION OF CARE PROVIDED BY FAMILY MEMBERS AND OTHER UNPAID CAREGIVERS**



## CAREGIVER CHALLENGES INCREASE

While families will always be the principal caregivers for elderly relatives, demographic factors and changing family structures suggest the pool of potential caregivers will be smaller. The timing couldn’t be worse: baby boomers are surging into retirement.

### SMALLER FAMILIES

Almost twenty percent of women in their early 40s are childless today, which is double the percentage in 1970.<sup>2</sup>

### HIGHER DIVORCE RATES

Divorce rates for persons aged 50 and older doubled between 1990 and 2010. Research suggests this trend will continue until 2030.<sup>2</sup>

### MORE SENIORS WITHOUT CHILDREN

The percentage of frail elders without any surviving children is expected to increase from 16 percent in 2000 to about 21 percent in 2040.<sup>2</sup>

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## **MORE WOMEN IN THE WORKFORCE**

In 2010, 47 percent of women worked outside the home, compared to only 33 percent in 1960.<sup>2</sup>

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## **FEWER POTENTIAL CAREGIVERS**

The first of the baby boomers will turn age 80 in 2026. When they do, the pool of potential caregivers will be considerably smaller than today. Because of demographic changes in future decades—relatively more older people and fewer who are middle-aged—the number of people age 45 to 64 who are potential caregivers for someone age 80 and older will fall from seven potential caregivers in 2010, to four in 2030, and to three in 2050.<sup>20</sup>

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## **NONTRADITIONAL FAMILIES**

Baby boomers have higher rates of divorce, re-marriage, and nonmarital cohabitation. When they enter old age, they will have an expanded network of potential caregivers that could include current and former spouses and partners, half-siblings, children, step-children, grandchildren, and step-grandchildren. Little is known about how these nontraditional families will view their obligation to care for older relatives, especially when the step-relationship was acquired later in life.<sup>24</sup> Two recent studies sounded a note of caution. One found that “elderly mothers with only stepchildren become disabled and institutionalized sooner, and elderly men with only stepchildren have shorter longevity relative to their counterparts with only biological children.”<sup>25</sup> Another study reported that stepchildren were less likely to be involved in caring for women with dementia.<sup>26</sup>

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## **GROWING BURDEN ON FEMALE CAREGIVERS**

Two-thirds of caregivers are women,<sup>17</sup> and they’re often widowed late in life. When their spouse dies, the responsibility for caring for them passes mainly to other women: daughters, daughters-in-law, and sisters. Female caregivers of the future might need to provide two or three decades of chronic illness care, perhaps to multiple family members.<sup>27</sup>

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## **UNBEFRIENDED ELDERLY**

Each year, tens of thousands of elderly Americans find themselves in situations where important medical decisions must be made for them, but there are no known family members or designated surrogates to help with those decisions. These individuals include “three to four percent of the 1.3 million people living in U.S. nursing homes, five percent of the 500,000 per year who die in intensive care,”<sup>28</sup> and a large but undetermined number of individuals in other care settings.<sup>29</sup> These individuals, the “unbefriended elderly,” have no one to help them make medical decisions at the end of life.<sup>30</sup> Traditional options for decision making in these situations include hospital ethics committees, court-appointed surrogate agents, and advance directives if they are available. A recently proposed solution is a “health fiduciary,” a professional who is trained and certified to act as a surrogate decision-maker. Health fiduciaries might be retired social workers or nurses, clergy, or paralegals.<sup>31</sup>

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<sup>25</sup> Pezzin L, et al. “Complex families and late-life outcomes among elderly persons: Disability, institutionalization, and longevity.” *Journal of Marriage and Family* 2-13;75:1084-97. October 2013.

<sup>26</sup> Sherman CW, et al. “Dementia caregiving in the context of late-life remarriage: Support networks, relationship quality, and well-being.” *Journal of Marriage and Family* 2013;75:1149-63.

<sup>27</sup> “Public Policy and Aging Report.” *Global Aging*, Spring 2013.



# WHAT WILL YOU WANT?

Three-in-ten Americans age 40 and older say growing older is something they “just don’t want to think about,” an attitude which is especially common in those who worry about burdening their families. Almost seven-in-ten (65%) people age 40 and older have done little or no financial planning for their older years, and barely more than half know where to go for information about chronic illness care.<sup>5</sup> But as we’ve learned from the 5 Ws of chronic illness care, this is an issue that must be addressed by older adults and their potential caregivers:

<b>WHO</b> WILL NEED CHRONIC ILLNESS CARE?	Seven-in-ten people who are age 65 will need chronic illness care later in life.
<b>WHY</b> WILL CHRONIC ILLNESS CARE BE NEEDED?	The most worrisome conditions are usually those that require care for many months or years.
<b>WHERE</b> WILL CHRONIC ILLNESS CARE BE PROVIDED?	The vast majority of people who receive chronic illness care live at home, with most care provided by and paid for by families.
<b>WHEN</b> WILL CHRONIC ILLNESS CARE BE NEEDED?	Most care is needed when we’re older, and often when we’re alone.
<b>WHAT</b> DURATION OF CHRONIC ILLNESS CARE WILL BE NEEDED?	The duration of care varies widely, but regardless of how much care is needed, more people will receive chronic illness care at home—and for longer periods of time—than in nursing homes or other institutional settings.

**How do we prepare for this challenge?** The answer can be found by asking this question:

## **IF YOU NEED CHRONIC ILLNESS CARE 20 OR 30 YEARS IN THE FUTURE, WHAT WILL YOU WANT?**

- Will you want to be cared for at home by your husband or wife, a close friend, or a neighbor? This is a good choice, unless your caregiver has already passed on or is too old and infirm to help you.
- Will you want to be cared for at home by your children and grandchildren? Another good choice, unless they’re too busy to provide all the care you need or they’ve moved across the country.
- Will you want professional care at home, in an assisted living facility, or a nursing home?

<sup>28</sup> Pope TM. “Making medical decisions for patients without surrogates.” *New England Journal of Medicine* 2013; 369:1976-8.

<sup>29</sup> Weiss BD, et al. “Medical decision-making for older adults without family.” *Journal of American Geriatric society* 2012; 60:2144-50.

<sup>30</sup> Legal briefing: The unbefriended: making healthcare decisions for patients without surrogates (Part 1). <http://www.ncbi.nlm.nih.gov/pubmed/22462389> (Accessed February 12, 2014)

<sup>31</sup> Span P. “Hiring an End-of-Life Enforcer.” *New York Times*. October 24, 2013.

**The point of the question is this:** what we will want 20 or 30 years from now depends on circumstances that are totally unknown today.

## SO WHAT CAN WE DO?

Some of the best advice is provided by the Administration on Aging, an agency of the United States Department of Health and Human Services that is charged with maximizing the independence and health of older adults and their families and caregivers.<sup>32</sup>

“ For many, a blended approach to long-term care works best. Most consumers want to remain in their homes for as long as possible and delay facility care until they need it. Plan early and look for flexible options that give you more say.<sup>33</sup> ”

A blended approach includes all of the care options that are available. Most chronic illness care will be provided at home by family and friends. Some people who live at home will also receive professional care from a nurse, therapist, or a home health or home care aide. Community support services might be needed, such as adult day care, transportation services that help us get to the doctor and do our grocery shopping, and home care agencies that provide additional services. And some people will receive care in assisted living facilities, continuing care retirement communities, and nursing homes.<sup>32</sup>

### **DETERMINING A STRATEGY FOR COSTS OF CHRONIC ILLNESS CARE**

Creating a strategy around chronic illness care costs should begin with a discussion of your concerns and priorities with your financial professional. While no product can perfectly address all of the issues of this complex problem, several considerations can help make an informed decision around which product, or products, would be suitable.

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<sup>32</sup> [http://acl.gov/About\\_ACL/Index.aspx](http://acl.gov/About_ACL/Index.aspx) (Accessed February 12, 2014).

<sup>33</sup> <http://longtermcare.gov/the-basics/where-can-you-receive-care/> (Accessed February 12, 2014).



## **COST**

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How much will the product cost? Is it a one-time payment or are they ongoing? Are the costs fixed or can they increase? If the cost is affordable now, will it still be in retirement, when income is more likely to be fixed?

## **ACCESS**

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How easily and quickly can you get access to funds?

## **PAYMENT TYPE FLEXIBILITY**

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Does the product only provide payments in the form of reimbursements for qualified medical expenses or does it provide funds that can be used for any expenses once you meet the requirements?

## **DURATION AND CONTINUITY**

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How long can the product cover you—for a lifetime or for a set time period? Is there a limit to how long you can use it once you begin payments? How long will the payments last once they have begun? Can you start and stop payments and still maintain coverage?

## **AMOUNT**

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Is the coverage based on a set amount or a time period? What happens if the amount isn't enough for an illness?

## **PRIORITIZING AND ADDING LAYERS OF PROTECTION**

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Just as there is no one product that perfectly addresses all of the issues of chronic illness care costs, there probably isn't one product on the market that is perfect for each person. Which of the considerations above are more important to you? Choose a product based on those priorities.

Additionally, you may want to have more than one layer of coverage to help address all of your priorities if one product is unable to do so, although this approach can be more costly overall.

## **CONCLUSION**

No one can be certain of their care needs in the future. What we do know, however, is that we will want the freedom, choice, and control to be cared for as we think best at the time. This means choosing caregiving and financial strategies that maximize flexibility and allow us to pivot to different options depending on future needs.



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