

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 is looking healthy. Then you receive a call in the middle of the night from a 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 elderly 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.**

As we get older, many of us will develop chronic illnesses that limit our ability to care for ourselves. Chronic illness refers to a disability that meets criteria set in the Health Insurance Portability and Accountability Act (HIPAA):¹ A person is considered to be disabled if he/she has been certified by a licensed health care practitioner as:

1. Being unable to perform (without substantial assistance from another individual) at least two activities of daily living (bathing, continence, dressing, eating, toileting, and transferring) for a period of at least 90 days due to a loss of functional capacity; or
2. Requiring substantial supervision to protect such individual from threats to health and safety due to severe cognitive impairment.

Severe cognitive impairment is most commonly due to Alzheimer's disease.

This article will highlight 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:

1. **Who will need chronic illness care?**
2. **Why will chronic illness care be needed?**
3. **Where will chronic illness care be provided?**
4. **When will chronic illness care be needed?**
5. **What duration of chronic illness care will be needed?**

¹Drabek J, et al. Measuring the Need for Long-Term Services and Supports. ASPE Research Brief. Department of Health and Human Services. July 2015.



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. For men and women combined, about half (52%) of today’s 65-year-olds will need chronic illness care later in life.²

Many factors affect the possibility that we might need care.

GENDER

Slightly less than half (47%) of 65-year-old men will need care, compared with almost 3 in 5 (58%) women (Figure 1).²

Figure 1.

Chart View

Table View

LIKELIHOOD THAT A 65-YEAR-OLD WILL NEED CHRONIC ILLNESS CARE LATER IN LIFE	
MALE	47%
FEMALE	58%

AGE

The older you are, the more likely it is you will need care.¹

INCOME

The need for chronic illness care is greater in 65-year-olds who have lower incomes.²

MARITAL STATUS

Unmarried people are at slightly higher risk of needing chronic illness care than those who are married.²

² Favreault M, et al. Long-term Services and Supports for Older Americans: Risks and Financing. ASPE Issue Brief. Department of Health and Human Services. July 2015.

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WHY WILL CHRONIC ILLNESS CARE BE NEEDED?

Chronic illness care may be needed for short or long periods of time.

SHORT-TERM CARE

Short-term care generally refers to short-term services for conditions that are expected to improve, such as physical therapy to help regain function after a fall or stroke. Conditions where care is usually limited in duration include cancer, heart attack, heart failure, minor stroke, joint replacement, fractures (including hip fracture), and accidents and hospitalizations where recovery occurs.

While these conditions are serious and potentially life-threatening, they are less worrisome from a financial and a care perspective:

- Short-term care is usually needed for only a few days, weeks, or months.
- Out-of-pocket costs are generally limited. After a hospital stay of at least three days, Medicare and Medicare Supplement Insurance (Medigap) will pay many of the expenses for up to 100 days for skilled nursing care in a rehabilitation facility, at home, or for hospice care.^{3,4}
- Many people have enough savings to pay for expenses not covered by insurance.
- Family and friends can usually provide short-term care until recovery occurs.

“Can you stop your life to care for me for the rest of my life?”



LONG-TERM CARE

In contrast, some conditions require care for long periods of time. These are the illnesses we all dread: Alzheimer’s disease and other types of dementia, serious stroke, crippling arthritis, brain and spinal cord injuries, and degenerative neurologic diseases like Parkinson’s disease. Unlike illnesses that typically require short-term care, care for these conditions can have a much greater impact on family finances and care dynamics.

- Long-term care is usually needed for many months or years, and often for the remainder of life.
- Medicare and Medicare Supplement Insurance do not pay for the largest part of long-term care because it is custodial, which means non-skilled personal care, such as assistance with the activities of daily living.^{3,4}
- Many people do not have enough savings to pay for long-term care.
- Family and friends are faced with much greater demands on their time because the need for care is much longer compared with short-term care. For example, after a diagnosis of Alzheimer’s disease or a serious stroke where recovery is unlikely, we may need to ask family and friends this question: *Can you stop your life to care for me for the rest of my life?*

³ LongTermCare.gov. U.S. Department of Health and Human Services. <http://longtermcare.gov/medicare-medicaid-more/medicare> (accessed July 19, 2016).

⁴ Medicare.gov. U.S. Department of Health and Human Services. <https://www.medicare.gov/supplement-other-insurance/medigap/whats-medigap.html> (accessed July 19, 2016).

WHERE WILL CHRONIC ILLNESS CARE BE NEEDED?

3

Chronic illness care has always been provided mainly at home by families; this is where we want to live if care is needed later in life. Three in four (75%) people are cared for at home, about one in seven (15%) is in an assisted living facility, and one in ten (10%) is in a nursing home (Figure 2).⁵

Figure 2.

Chart View

Table View

LOCATION WHERE CHRONIC ILLNESS CARE IS PROVIDED FOR PEOPLE AGE 65 AND OLDER	
At Home	75%
Assisted living and other supportive care settings	15%
Nursing home	10%

WHEN WILL CHRONIC ILLNESS CARE BE NEEDED?

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The need for chronic illness care increases rapidly with age, from about one in sixteen (6%) people age 65 to 69, to slightly more than half (52%) at age 90 and older (Figure 3).¹

Figure 3.

Chart View

Table View

LIKELIHOOD THAT CHRONIC ILLNESS CARE WILL BE NEEDED, BY AGE	
65 to 69	6%
70 to 74	8%
75 to 79	15%
80 to 84	22%
85 to 89	36%
90 +	52%

⁵ Freedman VA, et al. Disability and Care Needs among Older Americans. The Milbank Quarterly. Vol.92, No.3, August 26, 2014, p.517.

Many of us will need chronic illness care late in life, but there's more to the story. **Care will be needed not only when we're old, but when we're old and living alone.**

The likelihood of living alone increases with age, mainly because people outlive their spouses or partners. This is especially true for women. For people late in retirement who are age 85 and older, about three in ten (29%) men live alone compared with more than half (52%) the women (Figure 4).⁶ The absolute numbers paint an even more vivid picture of life at older ages. Because women generally live longer than men and are less likely to live with a spouse or partner, there are more than three women living alone at age 85 and older for every one man living alone.

Chart View Table View

Figure 4.

LIVING ARRANGEMENTS OF COMMUNITY-DWELLING PEOPLE AGE 65 AND OLDER			
	Lives alone	Lives with spouse	Lives with children/others
65 – 74 Men	18%	72%	11%
65 – 74 Women	30%	52%	18%
75 – 84 Men	22%	68%	10%
75 – 84 Women	40%	37%	23%
85+ Men	29%	52%	19%
85+ Women	52%	15%	33%

Values in chart may not total 100% due to rounding.



There are more than three women living alone at age 85 and older for every one man living alone.

⁶ Medicare Current Beneficiary Survey. Demographic and Socioeconomic Characteristics of Noninstitutionalized Male and Female Medicare Beneficiaries, by Living Arrangement and Age, 2013. October 30, 2015. Table 1.4b, p.46; Table 1.4c, p.48.

WHAT

DURATION OF CHRONIC ILLNESS CARE WILL BE NEEDED?

5

The duration of chronic illness care is similar for men and women for short and medium durations (Figure 5). About one in six people (18% of men, 19% of women) will need care for less than one year, one in fourteen (7% of men, 8% of women) will need care for 1 to 1.9 years, and about one in nine (11% of men, 12% of women) will need care for 2 to 4.9 years. However, important gender differences occur for longer care durations. One in ten (10%) men and about one in six (18%) women will need chronic illness care for five years or more.²

[Chart View](#)
[Table View](#)

Figure 5.

PROJECTED DURATION OF CHRONIC ILLNESS CARE FOR PEOPLE TURNING AGE 65 BETWEEN 2015 AND 2019		
	Male	Female
Less than 1 year	18%	19%
1 to 1.9 years	7%	8%
2 to 4.9 years	11%	12%
5 years or more	10%	18%

For those who need care, the average duration of care is projected to be 3.2 years for men and 4.4 years for women. In other words, women will need care for more than a year longer than men.



For people who need care, women will need care for more than a year longer than men.

OTHER CONCERNS

COST OF CARE

Many people are surprised to learn that the primary source for chronic illness care for people age 65 and older is informal, unpaid care provided by family and friends. This care is valued at \$234 billion and represents more than half (53%) of total expenditures (Figure 6).⁷ Medicaid is the second largest source of payment for chronic illness care (30%), followed by out-of-pocket (10%) and other private (5%) and public (2%) sources. In total, 63% of expenditures for chronic illness care (informal care, 53%, plus out-of-pocket, 10%) for people age 65 and older, or \$63 of every \$100, is provided by family and friends.

[Chart View](#)
[Table View](#)

Figure 6.

SOURCES OF PAYMENT FOR CHRONIC ILLNESS CARE FOR ADULTS AGE 65 AND OLDER, 2011	
Other public sources (\$10 billion)	2%
Other private sources (\$24 billion)	5%
Out-of-pocket (\$46 billion)	10%
Medicaid (\$134 billion)	30%
Informal care (\$234 billion)*	53%

*The dollar amount for informal care was determined by multiplying \$21 per hour (the average wage of a home health aide in 2011) by the approximately 11.2 billion hours of informal care provided by family and friends in 2011.⁸ 2011 is the last year for which complete government data were available.



\$63 of every \$100 for chronic illness care for people age 65 and older is provided by family and friends

⁷ 2015 White House Conference on Aging: Final Report. December 29, 2015, p.5–6.

⁸ Hagen S, et al. Rising Demand for Long-Term Services and Supports for Elderly People. Congressional Budget Office. June 26, 2013, p.2.

Medicaid primarily serves individuals with lower incomes. About one in three people in the lowest income quintile (the lowest fifth) at age 65 will have some of their future chronic illness care expenses paid by Medicaid, compared to only one in twenty in the highest income quintile (the highest fifth). People with higher incomes who eventually qualify for Medicaid are usually individuals who exhaust their assets after living into their mid-to-late 90s.²

One in twenty adults in the highest income quintile group at age 65 will spend down their assets and eventually qualify for Medicaid. These are usually individuals who exhaust their assets after living into their mid- to late 90s.

Out-of-pocket expenses are concentrated in upper income groups. One in five people in the highest income quintile at age 65 will spend \$50,000 (in 2015 dollars) or more out-of-pocket for chronic illness care. One in twenty will spend more than \$250,000 (in 2015 dollars).²

Out-of-pocket expenses are concentrated in upper income groups. One in twenty will spend more than \$250,000 (in 2015 dollars).

Women generally have higher out-of-pocket costs for chronic illness care than men, largely because they need care for longer periods of time. For those who need chronic illness care, costs are projected to be (in 2015 dollars) \$56,000 for men and \$81,000 for men (Figure 7).²

Figure 7.

Chart View

Table View

FOR THOSE WHO WILL NEED CHRONIC ILLNESS CARE, PROJECTED AVERAGE LIFETIME OUT-OF-POCKET COSTS FOR PEOPLE TURNING 65 IN 2015 – 2019 (IN 2015 DOLLARS)	
Men	\$56,000
Women	\$81,000

WHO WILL CARE FOR THE ELDERLY OF TOMORROW?

A strong majority (70%) of people age 40 or older expect to rely on family members to provide much of their chronic illness care. The reality may be much different due to a combination of medical, societal, and demographic changes.

More people will need care

- The number of severely disabled adults age 65 and older who need care is expected to increase from 6.3 million in 2015 to 15.7 million in 2065.⁹

There will be fewer caregivers

- Families, the backbone of our health care system for the elderly, are smaller and often spread across the country. In 1976, women had an average of three children, compared with two children in 2012. About one in seven (15%) women never have a child.¹⁰
- More women, who are the traditional caregivers, are employed, which means fewer will be available to provide care.
- Fewer people marry, many divorce and remarry, and non-marital cohabitation is more common than in the past.^{11,12,13,14} Americans 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 the caregivers of tomorrow will view their obligation to care for older relatives, especially when informal and step-relationships were acquired later in life.
- Because of demographic changes in future decades—relatively more older people and fewer who are middle-aged—there will be fewer people age 45 to 64 who are potential caregivers for someone age 80 and older.¹⁵ The implications are profound: Instead of seven potential caregivers for seniors who turned 80 in 2010, people age 67 in 2017 will have only four potential caregivers when they turn 80 in 2030, and people age 47 in 2017 will have only three potential caregivers when they reach age 80 in 2050.

People age 67 in 2017 will have only four potential caregivers when they turn 80 in 2030, and people age 47 in 2017 will have only three potential caregivers when they reach age 80 in 2050.

⁹ Iglehart JK. Future of Long-Term Care and the Expanding Role of Medicaid Managed Care. *New England Journal of Medicine*. January 14, 2016, p.184.

¹⁰ Monte LM, et al. Fertility of Women in the United States: June 2012. *Current Population Reports*, P20-575, U.S. Census Bureau. July 1, 2014, p.1,5.

¹¹ Lamidi E. Marriage in the U.S. Twenty-five Years of Change, 1989-2014. *National Center for Family & Marriage Research*. October 2015.

¹² Yau N. Divorce Rates for Different Groups. *FlowingData*. March 30, 2016.

¹³ Lewis JM, et al. Remarriage in the United States. *American Community Survey Reports*, ACS-30, U.S. Census Bureau, Table 1, p.3, March 2015.

¹⁴ Lamidi E. Trends in Cohabitation. The Never Married and Previously Married. 1995-2014 (FP-15-21). *National Center for Marriage & Family Research*. 2015.

¹⁵ 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.

Families may be overwhelmed by the demands of caregiving

- Many older adults age 65 and older require substantial assistance with self-care, mobility, and complex medical care at home. Almost three in four (73%) of their caregivers provide all of the care themselves, while only about one in four (27%) caregivers use formal (paid) care services (Figure 8).¹⁶
- Family members provide almost all (97%) of the informal care in these situations (Figure 9). More than half of the care (54%) is provided by adult children, followed by a spouse (26%), other relative (17%), and a nonrelative (3%).¹⁶
- Long periods of caregiving for older relatives are the rule, not the exception. More than four in ten (44%) family caregivers provide care for one to four years and half (50%) provide care for more than four years (Figure 10).¹⁶

Figure 8.[Chart View](#)[Table View](#)

UNPAID CAREGIVERS PROVIDE THE GREAT MAJORITY OF CARE FOR ADULTS AGE 65 AND OLDER WHO NEED SUBSTANTIAL CARE	
FORMAL (PAID) CARE	27%
INFORMAL (UNPAID) CARE	73%

Figure 9.[Chart View](#)[Table View](#)

RELATIONSHIP OF FAMILY CAREGIVERS WHO PROVIDE SUBSTANTIAL HELP TO RELATIVES AGE 65 AND OLDER	
Other Relative	17%
Non Relative	3%
Spouse	26%
Adult Child	54%

¹⁶Wolff JL, et al. A National Profile of Family and Unpaid Caregivers Who Assist Older Adults with Health Care Activities. JAMA Internal Medicine. March 2016.

Chart View

Table View

Figure 10.

DURATION OF FAMILY CAREGIVING FOR RELATIVES AGE 65 AND OLDER WHO NEED SUBSTANTIAL HELP	
Less than 1 year	5%
1 – 4 years	44%
More than 4 years	50%

Values in chart do not total 100% due to rounding.

Among family caregivers of older relatives who need substantial care:¹⁶

- One in six (18%) caregivers is also caring for a child.
- Almost four in ten (39%) family caregivers are still working.
- Almost half (46%) of these caregivers are helping an older adult with dementia.
- Family caregivers often report physical, emotional, and financial difficulties, and they spend less time on valued activities, such as visiting friends and relatives and going out for entertainment.

WOMEN CARRY A HEAVY BURDEN AS CAREGIVERS

- When a woman's spouse or partner dies, the responsibility for caring for her passes mainly to other women: daughters, daughters-in-law, and sisters. As a result, female caregivers sometimes care for multiple family members over long periods of time.
- Almost seven in ten (69%) family caregivers of people age 65 and older who need substantial help are women.¹⁶
- A strong majority (70%) of family caregivers for people with Alzheimer's disease are also women.⁷
- Indirect costs are one of the biggest expenses incurred by family members who care for loved ones with Alzheimer's disease (Figure 11). A female family member of a male with Alzheimer's disease will incur far higher indirect costs for providing care (\$54,956) compared with a male family member caring for a female with Alzheimer's disease (\$8,659). The reason is because females care for males at home and in the community for longer periods of time.¹⁷

¹⁷Yang Z, et al. Gender Differences: A Lifetime Analysis of the Economic Burden of Alzheimer's Disease. Women's Health Issues. Sept-Oct 2015, p.437.

Figure 11.

Chart View

Table View

INFORMAL COSTS FOR PROVIDING CHRONIC ILLNESS CARE AT HOME AND IN THE COMMUNITY FOR MEN AND WOMEN WITH ALZHEIMER'S DISEASE	
Men	\$8,659
Women	\$54,956

The monetary value of informal care is based on replacement costs (the cost of an equivalent service provided by a home health agency) or forgone wages (income lost because of time spent providing care).¹⁸ For Alzheimer's disease, the cost of informal care is estimated from the duration of time the person with Alzheimer's disease lives in the community, the probability of being a caregiver by gender, and the average annual cost of informal care, which is estimated at \$27,789 per year.

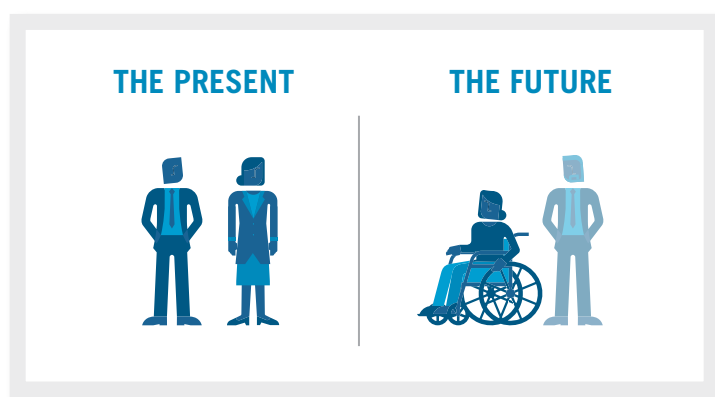
“... the fact that daughters are the most likely caregivers for individuals with dementia is alarming in light of shrinking family sizes and the growing numbers of women in the labor force: These changes suggest that, in the future, this source of care for people with dementia may be less available.”¹⁹

¹⁸Hurd MD, et al. Monetary Costs of Dementia in the United States. The New England Journal of Medicine. April 4, 2013, p.1328.

¹⁹Friedman EM, et al. US Prevalence and Predictors of Informal Caregiving for Dementia. Health Affairs. October 2015, p.1640.

WHAT WILL YOU WANT?

As pre-retirees and recent retirees, we find it difficult to imagine a time in life when chronic illness care might be needed. We're still feeling young and strong, we're as rich as we'll ever be because of the size of our retirement savings, and we usually have a spouse or partner. Our idea of "old age" is someone who looks much like we do today, except we have more gray hair and a bit of arthritis, and we're walking a step slower. However, for most of us, this won't be the situation when care is needed years or decades in the future. We will no longer be young or strong, we may not be rich because we've spent much of our savings, and we're often alone because we've lost our spouse or partner.



The 5 Ws of Chronic Illness Care addresses challenges faced by older adults and their potential caregivers:

- **WHO will need chronic illness care?** About half (52%) of today's 65-year-olds will need chronic illness care later in life.
- **WHY will chronic illness care be needed?** The most worrisome conditions are usually those that require care for many months or years.
- **WHERE 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.
- **WHEN will chronic illness care be needed?** Most care is needed when we're older, and often when we're alone.
- **WHAT 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 these challenges? 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 spouse or partner, a close friend, or a neighbor? This is a good choice, unless your chosen 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 in a nursing home?

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.

STRATEGY FOR DEALING WITH THE 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 you make an informed decision around which product, or products, would be suitable.