

Research

The Ballooning Costs of Long-Term Care

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Executive Summary

- By 2030, 24 million Americans will need long-term care (LTC), nearly double the current need, but the supply of caregivers is shrinking rapidly relative to the demand.
- The amount and complexity of care needed per person will also increase, as a result of the increasing number of chronic conditions per person.
- An estimated \$849 billion worth of LTC was provided in 2018; this study estimates that in 2030, LTC costs will more than double and may reach as high as \$2.5 trillion, yet plans to pay for this care are woefully insufficient and primarily rely on the continued provision of unpaid care by family members.

Introduction

An estimated 14 million people in the United States currently need long-term support services.[1] According to the Department of Health and Human Services (HHS), 7 in 10 seniors reaching 65 years old are now expected to need some type of long-term care (LTC) before the end of their life. By 2030, it is estimated that 24 million Americans will need LTC.[2]

LTC is not the long-term provision of medical care. Rather, LTC typically refers to assistance with activities of daily living (ADLs), which are routine activities people do every day to live. There are six basic ADLs: eating, bathing, getting dressed, toileting, transferring (moving from one place to another, such as from bed to chair), and continence. The ease with which individuals can perform these ADLs helps determine what type of LTC they may need. Individuals may need help with these activities from birth or after a physical or mental health decline, and they may need these services for the remainder of their life or only temporarily, such as while recovering from a medical incident. Of course, an individual may need long-term help with many other types of activities, too, such as meal preparation, bill payment, and household chores (sometimes referred to as instrumental activities of daily living, or IADLs); while these types of services are typically not considered health care services, a caregiver may assist with these activities, as well.

As the population ages, the need for care and the cost of providing that care will increase significantly. Men are likely to need LTC for an average of 2.2 years and women for 3.7 years, according to HHS's Administration on Aging.[3] Unfortunately, private insurance for long-term care is hard to find, public insurance programs offer limited coverage or have restricted eligibility, and most people have not saved sufficiently for the cost of such care.

The Cost of Long-Term Care

The cost of LTC in 2018 reached an estimated \$849 billion, according to data from the Kaiser Family Foundation (KFF) and the American Association of Retired Persons (AARP), when accounting for both paid

services as well as the value of unpaid care, up from an estimated \$725 billion in 2017.[4] Changing demographics and increasing rates of chronic conditions will drive up these costs over the next few decades. Health Affairs projects that 54 percent of seniors will not have sufficient financial resources to pay for LTC, even though many people pay nothing for their care, at least at the outset. Unpaid caregivers, typically a family member, provide an estimated 80 percent of care to individuals still living at home.[5] AARP estimated in 2014 that 43.5 million people had served as an unpaid caregiver at some point in the year.[6]

Supply and demand for LTC are moving in opposite directions. Demand for long-term care will grow as the population ages. By 2050, the number of people aged 85 or older will triple and the number of people using paid LTC services in any setting will nearly double from 14 million in 2018 to 27 million. The amount and complexity of care for each person will likely increase as well because of the increasing number of chronic conditions per individual.[7] People with three to four chronic conditions are three times as likely to need help with ADLs or IADLs as people with just one or two chronic conditions.[8] The increasing demand will strain the supply of caregivers due to the caregiver demographic relatively shrinking: The population aged 64 and younger will only increase by 12 percent during this period.[9] The number of people aged 45-64 for each person aged 80 or older will be reduced to three by 2050 (down from a ratio of 7:1 currently).[10]

More than one-third of seniors will spend time in a nursing home.[11] According to Genworth's 2019 Cost of Care Survey, the median cost for a private room is now over \$100,000 per year.[12] Four out of 10 seniors will opt for paid care at home with the median annual cost for a home health aide working 40 hours per week nearing \$50,000 per year.

Median Costs of Long-Term Care in 2019

Home Health Aide	Homemaker Services	Adult Day Health Care	Assisted Living Facility	Nursing Home Care
\$47,836 (based on 40 hours/week)	\$51,480 (based on 44 hours/week)	\$19,500	\$48,612	\$90,156 for semi-private room; \$102,204 for private room

Source: Genworth 2019 Cost of Care Survey

Data from Altarum show that prices for nursing home care increased an average of 2.4 percent annually from 2012-2019, for a cumulative increase of 20.7 percent during that time; home health care prices increased 11.1 percent. According to National Health Expenditure projections, home health care spending will increase 83 percent from 2018 to 2027. Expenditures for nursing homes and other continuing care retirement communities are projected to increase 58 percent during that period.

Calculating the "Cost" of Unpaid Care

Spending would be significantly higher without the billions of hours of unpaid care provided each year. Estimates suggest that between 26 and 40 million individuals provide unpaid care annually, and that, on average, each provides between 16 and 24 hours of care per week.[13] In a study using the Panel Study of Income Dynamics (PSID), directed by faculty at the University of Michigan, researchers estimated that in 2017, 26 million family caregivers provided an average of 17.8 hours of care per week and that the average hourly wage of caregivers was \$28.[14] An estimated 70 percent of caregivers are between the ages of 50-64; according to the Bureau of Labor Statistics, the average wage for people in this age bracket is \$25 per hour. [15], [16]

This unpaid work is likely to impact these individuals' ability to work in a paid position full-time, which may lead to additional financial burdens for the family, possibly even after an individual is no longer providing care. Data in the PSID show that 25 percent of working caregivers missed work in the past year because someone else was ill.[17] A 2015 estimate found that a caregiver's lost earnings over their lifetime averaged more than \$300,000.[18]

Estimating Current Total Costs

This study estimates that the true cost of LTC in 2018—based on the cost of living in a nursing home or assisted living facility, receiving home health care, or regularly spending time at an adult day care center, as well as the "cost" of unpaid care—totaled between \$758 billion and \$1.4 trillion. This estimate is based on Genworth's annual Cost of Care Survey, utilization rates for various types of LTC based on data from AARP and the Centers for Disease Control and Prevention, and varying values placed on the time of unpaid care caregivers. This estimate does not include the costs of the various Medicaid waiver programs discussed below.

The cost of paid care is estimated to have totaled roughly \$293 billion. This assumes the following: of the nearly 1.4 million individuals estimated to live in a nursing home, half had a private room and 70 percent were there for a full year; an estimated 821,000 individuals resided in an assisted living facility with 70 percent there for the entire year; 290,000 people used adult day care services for 40 hours per week; and 4.5 million people received 30 hours of care from a home health aide each week.

The value of unpaid care provided by tens of millions of people in 2018 is estimated between \$471 billion and \$1.1 trillion. AARP estimates the value of unpaid care at \$470 billion in 2017 based on 41 million people providing 16 hours of care per week and an hourly value of that work of \$13.81. But this may significantly underestimate the value of unpaid care given other estimates of hours of care provided and the expected wage of the average caregiver.[19] Based on the PSID figures referenced above, the annual value of caregivers' time is estimated at \$673.8 billion.[20] Using an hourly rate of \$22 per hour and the high-end of the estimates for hours of care provided—24 hours per week— by 41 million individuals places the value of such care at \$1.1 trillion.

Estimating Future Costs

In 2030, an estimated 18.7 million individuals will need some type of paid LTC while millions more will likely receive unpaid care based on projected population growth. Given historical cost growth tracked by Genworth and Altarum, the total value of LTC provided in 2030 could reach between \$1.3 trillion and \$2.5 trillion. [22]

It is estimated that the cost of paid care will be roughly \$414 billion. This estimate assumes the same utilization rates described above. The cost of nursing home care is assumed to increase an average of 2.8 percent per year, for a cumulative increase of 36.4 percent by 2030; assisted living costs will increase 46.9 percent; adult day care costs will increase 45.7 percent; home health aide costs will increase 20 percent.

The value of unpaid care, increasing at a rate equal to the Social Security Trustees' estimated future increases in the national average wage index—roughly 4 percent per year—will reach between \$880.9 billion and \$2.1 trillion.

Given the likelihood that LTC utilization rates will increase as the rate of people with multiple chronic conditions increases, this estimate likely represents a lower bound.

Household Financial Burden

Most of the financial burden will fall on middle-income seniors—who are too wealthy to qualify for Medicaid but not wealthy enough to comfortably afford their expenses—and taxpayers. By 2029 there will be a projected 14.4 million middle-income seniors, 60 percent of whom will have mobility limitations and 20 percent of whom will have high health care and functional needs.

Medicare beneficiaries who live in LTC facilities spend significantly more out-of-pocket (OOP) than the average beneficiary, particularly if they do not receive Medicaid coverage: \$41,782 spent OOP on LTC for beneficiaries living in a LTC facility without Medicaid and \$19,632 for those with Medicaid coverage versus \$1,014 OOP for a temporary stay in a LTC facility.[23] According to a study by Vanguard Research and Mercer Health and Benefits, 48 percent of people now 65 and older are expected to incur no LTC costs while 15 percent of individuals will likely incur more than \$250,000 in costs.[24]

The cost of LTC has a serious impact on the effective wealth of households, as well. The average total household wealth in homes with individuals with no limitations on their ADLs is nearly twice that of households where an individual has two or more ADL limitations, according to one study. [25] Interestingly, this difference in financial wellbeing begins well before retirement and is not simply a result of having high-cost needs and having to expend one's wealth: the Urban Institute found the "median household income in 1991 among adults ages 51 to 59 who did not report any ADL limitations in 2010 (when they were ages 70 to 78) exceeded by nearly 50 percent the median income received by their counterparts who reported two or more ADL limitations in 2010" but also had no ADL limitations in their 50s. [26] This finding suggests low-income individuals are more likely to develop ADL limitations; as a result, those most likely to need LTC in the future are unlikely to be able to save enough to finance their future LTC needs.

These LTC costs are, of course, in addition to the primary health care costs individuals will likely have. Fidelity estimates that a couple reaching age 65 in 2019 will need approximately \$285,000 in savings to cover health care costs in retirement, and that figure assumes both individuals have Medicare coverage.

Paying for Long-Term Care

Despite not being medical care, most LTC is paid for through our public health insurance programs, Medicare and Medicaid, with Medicaid being the largest financier of LTC benefits. Medicare's coverage of LTC services is limited to certain types of care in certain circumstances. A small number of employers offer LTC insurance to their employees and a handful of private insurance companies offer plans for individuals to purchase.

The fact that non-medical care is primarily financed through our health insurance programs reflects the country's long-standing failure to address the need for such care. The one time Congress passed a law to establish a public LTC insurance option—the CLASS Act included in the Affordable Care Act in 2010—it ultimately had to be repealed due to an inability to find any option to make the program fiscally sustainable and affordable to potential buyers. Thus, to date, the following options are the few choices available to finance LTC besides paying wholly out-of-pocket.

Medicare Coverage

Fee-for-Service (FFS) Medicare Part A only provides facility-based LTC coverage for skilled nursing services and various types of therapy if a beneficiary 1) has had a hospital admission with an inpatient stay of at least three days, 2) is admitted to a Medicare-certified skilled nursing facility (SNF) within 30 days of that hospital admission, and 3) a doctor prescribes such services as necessary to treat an illness or injury. Medicare Part A also covers the cost of services provided in a long-term care hospital, but these hospitals are for patients with multiple serious health conditions who need long-term medical care in a hospital; they do not provide individuals with the type of custodial care that is typically referred to as LTC.

A SNF is a special facility or part of a hospital that provides medically necessary professional services from a variety of specialists to provide around-the-clock assistance with health care and ADLs. The services covered by Medicare, in addition to the cost of the room and meals at the facility, includes skilled nursing care; physical and occupational therapy; medical social services; medical supplies and medications; ambulance transportation; dietary counseling; and, sometimes, SNF-level care provided at a critical access hospital.[27] Medicare will continue to cover these services, subject to the limits discussed below, so long as they remain medically necessary and a physician reorders them after 60 days.

If the previously listed conditions are met, Medicare will pay 100 percent of costs for the first 20 days in the facility. Between days 21 through 100, Medicare requires the beneficiary to pay a daily copayment, which is \$176 in 2020.[28] By day 100, the beneficiary will have incurred costs of \$14,080. Medicare provides no coverage after 100 days; the beneficiary will be responsible for all remaining costs at this point, unless they have supplemental insurance, such as Medigap.[29]

Length of Stay	What You Pay (2020)
Days 1-20	\$0
Days 21-100	\$176 per day
Days 100+	All Costs

While Medicare covers medical services provided to someone living in a nursing home or assisted living facility, Medicare does not cover non-skilled assistance with ADLs nor any of the costs of staying in such a facility.

Medicare Parts A and B also cover some home health services, hospice, and respite care.[30] In order to qualify for home health care coverage, a doctor must develop a treatment plan for the beneficiary and certify that the patient is homebound and in need of physical or occupational therapy or speech-language pathology services. Home health care coverage includes part-time or intermittent skilled nursing care or home health services; physical or occupational therapy; speech-language pathology services; and medical social services. FFS Medicare does not cover meal delivery, custodial care, or 24-hour home health care.

Medicare Advantage plans also cover some LTC services, though, their ability to provide such benefits is relatively new: In 2018, the Centers for Medicare and Medicaid Services (CMS) amended the rules governing allowable supplemental benefits to no longer ban coverage of long-term services and supports, such as adult day

care, in-home assistance, and support for family caregivers.[31] The CHRONIC Care Act, passed in 2018 as part of the Bipartisan Budget Act, also allows for increased use of supplemental benefits, specifically for enrollees with multiple chronic conditions. In 2021, under the proposed rule, plans will be able to offer more benefits tailored to enrollees' specific needs that are *not* "primarily health related," such as structural home modifications, general supports for living (which may include subsidies for assisted living communities), and services supporting self-direction (such as financial literacy classes).[32]

Medicaid

Medicaid pays for the largest share of LTC costs, as the benefits it covers are much more comprehensive than those covered by Medicare. To qualify for Medicaid, an individual must meet income and certain other requirements, which vary from state to state. If the individual qualifies, Medicaid covers LTC services in nursing homes, intermediate care facilities, as well as at home, including custodial (non-medical) care provided by non-licensed caregivers.

More than one-fifth of Medicaid's benefit payments were for LTC provided to FFS Medicaid beneficiaries in 2016; it is unclear what share of the capitated payments for managed care went to LTC services.[33] According to the CMS Medicaid Actuarial Report from 2017, Medicaid spending on LTC is expected to grow 3.2 percent annually, on average, from 2017 through 2026, when it will reach \$158.7 billion.[34] KFF, however, estimates that in 2018, Medicaid spent \$196.9 billion on LTC.[35] Medicaid covered 36.8 percent of all freestanding home health care costs and 30.7 percent of all nursing home care (supporting 62 percent of nursing home residents) in addition to 56.7 percent of other health, personal, and residential care in 2016.[36]

There are several programs within Medicaid specifically designed for individuals in need of LTC, each aiming to increase individuals' ability to live at home where they are more comfortable rather than in an institution. A survey conducted by AARP found that 90 percent of seniors prefer staying in their homes as they age versus going to an assisted-living facility. Data suggest these programs are influencing program spending: Expenditures for home- and community-based care have been growing more quickly than expenditures for institutional-based care in recent years.[37]

PACE Programs

The Programs of All-Inclusive Care for the Elderly (PACE) covers individuals eligible for either Medicare or Medicaid who are at least 55 years old and in need of nursing-home level care but able to live safely in the community with help from PACE. Of course, the patient also must live within the service area of a PACE provider. PACE providers offer patients a team of care providers that may see patients in their home, at a PACE center, or elsewhere in the community. PACE offers patients comprehensive medical care and prescription drug coverage, as well as adult day care and other social services, such as respite care, caregiver training, nutritional counseling, and transportation to appointments. A patient's cost depends on the individual's income level: If the patient qualifies for Medicaid, he or she owes nothing other than what might otherwise be required for a minimal monthly Medicaid premium.[38] If a beneficiary does not qualify for Medicaid, the beneficiary must pay a monthly premium to cover the long-term care costs and for their Part D prescription drug coverage; no deductibles or cost-sharing are charged.

HCBS Waivers

Section 1915 of the Medicaid law, adopted in 1983, allows states to seek waivers from the standard Medicaid

rules to develop programs that allow beneficiaries to receive home and community-based services (HCBS) for the provision of their long-term care. HCBS waivers also allow states to expand financial eligibility while simultaneously capping enrollment (unlike traditional Medicaid rules which require states to cover all individuals who qualify). Most of the services offered through an HCBS waiver are benefits the states are choosing to offer beyond the program's mandatory benefits. Common service offerings include additional therapy services, meal preparation, and housekeeping; some states also cover nutrition counseling and aid at the beneficiary's work site.[39] In 2018, roughly 4.3 million people received care through an HCBS waiver program at a cost of \$92 billion; another 707,000 individuals were on state waiting lists, as of 2017.[40], [41]

Money Follows the Person Demonstration

With similar goals, Congress created the Money Follows the Person (MFP) demonstration in 2005. This program provides states with grants to transition individuals out of nursing homes and other long-term care institutions and back into their homes or other community-based residences. It also offers greater flexibility in how existing funds may be used to provide LTC in those settings. To date, more than 90,000 individuals have benefitted from the MFP program, a majority of whom had moderate to high level of care needs and moderate to severe cognitive impairment. Participants of the program have tended to be younger, male, and disproportionately minorities.

A report from HHS in 2017 found that the program had led to savings of at least 23 percent, or more than \$21,000 per individual, in the first year following their transition; individuals with intellectual disabilities who transitioned out of institutional care had reduced spending of 30 percent, or more than \$48,000, in the first year. Total first-year post-transition savings reached \$978 million by 2013. Quality of care evaluations have also found that individuals transitioning through the MFP program are less likely to be readmitted to institutional care, possibly because of the program's ability to help people stay connected to medical and social services. Quality of life surveys also indicate that individuals participating in MFP have greater satisfaction across seven different categories, and that improved quality of life continued through two years post-transition.

Other Coverage Options

Less than 1 percent of employers offered LTC insurance to their employees in 2016, and only 5 to 7 percent of employees enrolled.[42] If there is LTC coverage included in traditional employer-sponsored health insurance plans, it is typically only for skilled care provided for a limited time.

Individuals may purchase private LTC insurance plans, though there are limited choices. As of 2014, there were fewer than 15 stand-alone LTC insurance options, down from 125 in 2000.[43] The premium for these types of insurance plans are typically based on the enrollee's health status, and insurers may deny coverage if the applicant is not healthy enough. In 2019, more than half of applicants aged 75 or older and 44 percent of applicants aged 70-74 were denied coverage.[44]

The following average premium amounts offer an initial pool of lifetime benefits equal to \$164,000; when the policyholder reaches age 85, the value of benefits equals \$386,500 each.

Annual Premium					
Single Male, Age 55	\$2,050	Single Male, Age 60	\$1,925		
Single Female, Age 55	\$2,700	Single Female, Age 60	\$3,050		

Couple, Age 55 \$3,050 Couple, Age 60 \$3,400

Source: 2019 American Association for LTC Insurance Annual Price Index Survey

Federal employees, including retirees, and certain relatives are eligible to enroll in the Federal Long Term Care Insurance Program. This program offers comprehensive LTC insurance, including room and board at nursing homes and assisted living facilities and home care services. Roughly 268,000 people are currently enrolled.[45] Premiums for a 65-year-old range from \$131 per month to \$1,260 per month, and lifetime benefits range from \$109,500 to \$821,250, depending on daily benefit amounts, length of coverage, and inflation protection method. [46] A 90-day waiting period is required before coverage begins (except for hospice care); once coverage begins and a patient is receiving benefits, they are no longer required to pay premiums. If the individual recovers, has not exhausted their lifetime benefits limit, and wishes to maintain coverage, the enrollee must resume paying premiums. Patients starting coverage must also have a licensed health care professional certify within the past year that the patient is unable to perform at least two ADLs for an expected period of at least 90 days or that the patient requires substantial supervision due to severe cognitive impairment. The health care provider must then establish an approved care plan.

Workforce Problems

Aside from the financing problem, there is also a worsening shortage of LTC workers who can meet the needs of older adults. The LTC workforce is made up of licensed professionals and unlicensed direct care workers who provide care in nursing homes, assisted-living facilities, and other residential and community-based care settings as well as private in-home care. Much of the emerging crisis is driven by low wages—averaging \$12.18 an hour as of May 2018.

Turnover across the LTC sector is estimated to range from 45 to 66 percent. It is reported that one in four nursing assistants and one in five home health aides are actively looking for another job. One in two workers leave jobs in home care within 12 months. Annual certified nursing assistant turnover is at 97 percent, registered nurse turnover is at 52.5 percent, and overall staff turnover is at 69 percent. Between 2016 and 2026, more home care jobs are projected to be added than any other occupation. One study has calculated that maintaining the current ratio of paid long-term care personnel to those over 85 would require the long-term care workforce to grow by 2 percent per year from now until 2050, and ultimately adding more than four million new long-term care personnel.

The instability in the LTC workforce has caused myriad problems, including: service-access challenges for consumers; lower safety and quality of care and life; higher provider costs due to the need for constant hiring and training of new staff; and higher workloads for nurses and other staff. The result has been inadequate supervision, more accidents, and higher injury rates.

The workforce problems and resulting quality challenges may be a significant reason that family members provide so much LTC. Of course, the opposite dynamic may also be at work: Because individuals have found that they can provide the care themselves, they don't see much value in paying someone else to do it, depressing demand and wages.

Conclusion

The LTC crisis faced by the United States is significant and rapidly worsening. Millions of people—from those needing care to their families and employers—will experience hardship, and the burden on taxpayers will only

rise. Yet most are unprepared. The reality of the ballooning costs of LTC calls for a sober evaluation of the facts and clear-eved financial planning and policy formulation.

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