

**Understanding and Managing Post-Retirement Risks**

A series of reports presenting highlights from the Society of Actuaries' extensive body of research on post-retirement risks and issues.



Aging and Retirement

# Long-Term Care, Caregiving and Related Housing Issues: The Perspective of the Individual

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# Introduction and Overview

This report is one of a series of summary reports focusing on a variety of Society of Actuaries Research Institute research on a single topic area related to retirement security. Managing retirement security in the U.S. has been increasingly challenging for all stakeholders. Major factors contributing to these general challenges include people living longer than did prior generations, an increasing older-age population, changes during retirement, inflation, the shift from defined benefit to defined contribution plans, and significant gaps in financial literacy. In recent years, behavioral changes during the COVID-19 pandemic and climate change created a new set of challenges and uncertainties. These factors contribute to growing concern about how well Americans will fare in old age and the adequacy of their retirement security.

The Society of Actuaries (SOA) Research Institute's Aging and Retirement Strategic Research Program (the SOA program) established in 2018 builds on nearly 20 years of post-retirement-focused research designed to identify and understand the ways Americans prepare for and manage their finances post-retirement. This research work includes a wide-ranging exploration of post-retirement risks through surveys of the public; focus groups and interviews; and collections of essays, research papers and other research reports covering related topics. The research and individual projects have been designed to build a body of knowledge on particular topics and much of the work has been supplemented by the publication of consumer education materials.

This summary report focuses on findings about personal planning and perspectives about long-term care and caregiving, and the links to housing. The content is based on the Institute's work and related outside research and provides guidance about where to find more information. This report focuses on several aspects of long-term care, primarily from the point of view of the individual planning for or providing long-term care. The intended audience for this report includes retirement experts, plan developers and service providers, and those who serve individuals, including employee benefit plan sponsors, advisors and financial services organizations.

Key aspects of long-term care include recognizing and dealing with limitations, the settings for and providers of support and care, and financing of such care. All of these aspects should be considered as part of retirement and general financial planning.

**Dealing with limitations** – Individuals as they age may have a variety of physical and cognitive limitations. Physical limitations may include hearing loss, sight loss, mobility limitations and more. Some are related to chronic diseases. Usually, health care refers to services provided for acute care and prevention, while long-term care consists of on-going services to assist a person who needs help. Some commenters refer to long-term services and supports rather than long-term care. Long-term care can also include assistance with cognitive limitations including financial management, often referenced as financial caregiving. Planning and managing long-term care focuses on identifying the needs, finances, where support will be provided, and how support will be provided.

**Settings** - Traditionally, long-term care was most commonly associated with care that occurred in a nursing home. However, long-term care may occur in other settings as well and can be understood as a continuum of care with personal, home-based care with minimal assistance at one end and nursing home care on the other end. Settings include home health care, adult day care centers, continuing care retirement communities, assisted living facilities, memory care facilities, and nursing homes. The extent of care provided may vary in any of these settings. In addition, needed care may be provided primarily by family and friends, depending on the setting. This report deals with the settings for long-term care in the sections linking housing to long-term care.

**Financing** – Long-term care can be financed through several different sources or a combination of them:

- Private, out-of-pocket financing – For those with sufficient means, long-term care could be financed entirely out of pocket from personal savings and resources. Given its potential cost, many are not in a position to finance long-term care solely in this manner.
- Private, long-term care insurance – Insurance coverage may be obtained through an employer or individual policy. Although policies vary widely, most benefits are triggered by needs related to what are known as “activities of daily living (ADLs)”: bathing, dressing, eating, transferring, and toileting. Policies typically pay a weekly or daily benefit after a waiting period and for a maximum period of time. Many of the policies sold in recent years combine long-term care coverage with life insurance or an annuity. It has been estimated that only about 10% of individuals have purchased a long-term care insurance policy.

Note that private insurance is subject to underwriting, and this may impact the availability of private long-term care insurance to those with certain limitations or health problems.

- Public financing – Those with limited means may qualify for long-term care benefits under Medicaid. Coverage varies from state to state. Medicare does provide some in-home health care and hospice services, but generally does not pay long-term care benefits, yet many individuals have the misperception that it does.
- Housing – Private homes can be sold to provide financing for long-term care or converted to income with a reverse mortgage. A reverse mortgage can also be used to help pay premiums for long-term care insurance.

# Consumer Awareness: Long-Term Care and Expected Limitations

The Institute's Retirement Risk Survey series started in 2001 and it is the core of the Institute's consumer research program. The Retirement Risk Survey series is a series of biennial surveys of retirees and pre-retirees including some long-term care content in every survey and a special emphasis on long-term care in several of the surveys. It consistently shows relatively high general awareness of long-term care, but less belief that it will happen to the respondent, poor understanding about what care costs and how it will be paid for, and relatively little planning for long-term care. Key findings are:

**General awareness of long-term care** - Risk concerns and awareness are the core repeated questions in the Institute's Risk Survey series. Long-term care has been among the top three risks consistently. Both pre-retirees and retirees are aware of this issue and place a high priority on it.

**Expectations about levels of incapacity** - The 2007 Retirement Risk Survey report, *Key Findings and Issues: Health and Long-Term Care Risks in Retirement* observes that pre-retirees are more likely than retirees to expect a period of no limitations during retirement. Six in ten pre-retirees expect to have an active stage of retirement (60%), compared to 52% of retirees. Pre-retirees are also more likely than retirees to expect some level of limitations. Over eight in ten pre-retirees expect to be somewhat limited and less active during retirement (84%), versus 72% of retirees. Pre-retirees and retirees have similar expectations for experiencing greater incapacity. About two-thirds of pre-retirees (68%) and retirees (65%) expect to be severely limited and much less active.

**Expectations about changes during retirement** - The 2013 Retirement Risk Survey report, *Key Findings and Issues: Experiencing Change in Retirement* explores a variety of changes during retirement. It asks respondents about physical limitations and when they expect that they will be less able to perform a variety of functions including ability to work, ability to serve as a caregiver, ability to perform household chores and mobility. Thirty-three percent of retirees expect they will be less able to do caregiving within 20 years, 37% after twenty years, and 30% say they will never have such limitations. It also asks about cognitive issues and when they will be mentally unable to work, unable to drive, and less able to manage money.

**Expectations for Medicare help** - Medicare covers acute medical care for age 65 and over, but very little long-term care. The 2017 Retirement Risk Survey report, *Key Findings and Issues: Planning for Long-Term Care Risks* indicates that respondents over-estimate what Medicare will pay for major long-term care expenses. When asked, "If you or your spouse required extensive long-term care in a nursing home, how would you pay for it?", 33% of pre-retirees, 50% of retirees and 55% of retired widows responded Medicare. A different public program, Medicaid, pays for such care, but primarily for people with limited financial resources. Twenty-one percent of pre-retirees, 23% of retirees and 20% of retired widows responded Medicaid, which is also an over-estimate. Medicaid pays for considerable amounts of nursing home care, but it will pay only when certain individual financial requirements are met. The report also indicates that respondents are quite optimistic about having the resources to pay for long-term care, which points to likely gaps in knowledge about both the costs of care and the methods of financing.

**Preparedness for long-term care costs** - The 2021 Retirement Risk Survey included planning and dealing with change, and 41% of married or partnered pre-retirees and 59% of such retirees said they were very or somewhat prepared for significant long-term care expenses. For singles living alone, 32% of pre-retirees and 41% of retirees said they were somewhat or very prepared for such expenses. The author observes that these respondents may be overly optimistic.

**Expectations about family caregiving** - The 2021 Retirement Risk Survey included a focus on health and caregiving. The survey indicated that most respondents were not currently caregivers. While family and friends can play a critical role in care situations, most pre-retirees and retirees, especially wealthier ones, were not counting on care from family or friends. Most respondents (70% of pre-retirees and 77% of retirees) are not currently giving or receiving support to or from family or friends based on a list of possible types of assistance. Among those who say support is provided, the most common types of support are assistance with technology, running errands, and providing transportation.

**Recognition of diversity** - Note that the Institute has focused on diversity and related retirement issues on a number of topics. The most recent Institute consumer surveys used oversampling to study race and ethnicity. There have also been essay calls focusing on both race and ethnicity and LGBTQ+ issues and retirement planning. These topics are beyond the scope of this report, and they will be considered for future research.

# Planning for Long-Term Care

There is relatively high awareness of but little planning for future long-term care needs. This may be partly a result of shorter term and cash flow linked planning. The Institute research shows relatively little planning is done for longer-term risks other than acute health care. There is also probably an “it will happen to someone else” feeling on the part of many people.

There are gender differences with regard to planning for long-term care. Some key issues include:

- Women are more likely to serve as a family caregiver. Women are less likely to have a family caregiver.
- Women have a longer expected period of disability and need for support.
- Women have a longer expected lifespan.
- Women are less likely to be married at older ages. They are more likely to be widowed and less likely to remarry.

The Institute report, *Women and Retirement Risks* (2018) summarizes the situation with regard to women and retirement. It focuses on women as caregivers and as individuals who are receiving care.

The following key points should be kept in mind:

- Although the majority of the population need only some support, there are still people who have long-term high cost needs for care. As a result, planning involves consideration of tail risk. Alzheimer's is an example of a disease where extensive care can be required for years.
- Family members are major providers of long-term care, but often they are not involved in planning for it, so the need can be disruptive to them.
- When families are regularly involved in helping older individuals who need care, it is important to live reasonably close together. Some older individuals and some younger family members who will be helpers move to be nearer family members as part of their planning for the needs of an aging family member.
- Planning earlier is focused on financing; later-in-life or after an emergency, the focus is on how and where care will be provided which can include considerations of how it will be paid for.
- As limitations arise, issues include assessing needs, overseeing care and finding caregivers.
- As stated earlier, it has been estimated that 10% of Americans have long-term care insurance. Long-term care insurance includes a variety of products, and the industry has faced challenges, leading to changes in coverage, premium adjustments, and companies no longer offering coverage.
- Some employers secure group long-term care insurance to provide to employees, but this is not common. These group products may be priced – and available more easily via underwriting – on a more favorable basis than the individual market.
- Long-term care insurance generally requires applicants to undergo an underwriting review at the time of purchase. The requirements differ by company and plan, and sometimes state of residence, and policies sold to individuals generally have more stringent requirements than the policies sold to groups.

A variety of Institute reports and publications provide insights with regard to long-term care planning.

**Recent retirees and long-term care planning** - The Institute conducted focus groups with recently retired retirees, *The Decision to Retire and Post-Retirement Financial Strategies: A Report on Eight Focus Groups* (2013). The report examines what people think about with regard to retirement planning and provides important information about the short-term nature of planning, the focus on cash flows, and the failure to focus on risks. Many of the participants had the attitude when it came to dealing with risks that “we will deal with them when it happens.” Subsequent focus groups with people retired 15 years or more, and in-depth interviews with individuals age 85 and over reinforced these points. The age 85+ research is a series of six studies with separate reports and it is also summarized in a summary report, *Retirement Experiences of People Age 85 and Over*.

**What people think about long-term care planning** - Findings from the Retirement Risk Surveys and other consumer research.

The Retirement Risk Survey special report, *Key Finding and Issues: Health and Long-Term Risks in Retirement* (2007) includes expectations about family and community support, and as mentioned above, expectations about limitations. Pre-retirees and retirees have similar expectations for needed services in the somewhat limited, less active stage of retirement, with one exception. Pre-retirees are more likely to expect to rely on family or community services (59%) than are retirees (46%). Pre-retirees are more likely than retirees to expect they will need family or community assistance, paid assistance, home modifications, and nursing care by the time they reach the least active, most limited stage.

The 2007 report also includes expectations about whether limitations will increase or reduce financial needs. Travel and activities will decline with limitations reducing spending, but if paid care is needed, that will increase financial needs. Some of the key findings from that report include:

- Shorter-term cash-flow-based planning that works satisfactorily for many people during retirement no longer works effectively when people need assisted living, extensive paid long-term care at home, or nursing home care.
- Americans overestimate how much of their long-term care costs will be covered by Medicare and supplemental insurance. However, they underestimate the potential burden that may be placed on those who will help them.
- Medicaid is a significant and important payor of long-term care costs for lower-income individuals in the United States.

The Retirement Risk Survey report, *Planning for Personal Long-Term Care Risk* (2017) integrates the 2017 Retirement Risk Survey findings with findings from the Age 85+ research. Some of the key findings from that report include:

- A high level of confidence in adequate household resources to cover a major medical event, long-term care or the death of a spouse. Of the elderly, 69% were somewhat or very confident of having such resources. Of the adult children surveyed, 74% were somewhat or very confident that their parent had such resources. The report expresses concern that the responses indicate over-confidence rather than reality.
- The 2017 Retirement Risk Survey respondents are much more likely than the 85+ respondents to feel that long-term care expenses will be a major burden. Of the Retirement Risk Survey respondents, 79% of pre-retirees and 73% of retirees think costs of a major long-term event would be a major burden or worse. This compares to 27% of the individuals 85+ surveyed, and 47% of the adult children of people 85+ who were surveyed.
- The 2017 Retirement Risk Survey respondents say they are more familiar with the provisions of Medicare, Medicaid, and long-term care insurance than they probably are based on other responses. The respondents seem to

overestimate what Medicare will pay. Sixty-five percent of pre-retirees and 83% of retirees say they are very or somewhat familiar with the provisions of Medicare. The biggest sources of payment for a major long-term care event were cited in the Retirement Risk Survey as out-of-pocket and Medicare, followed by health insurance and Medicaid.

**Late-in-Life Decisions Guide** - The guide provides practical information about where to get support, and about planning for and managing care and support, and focuses on decisions needed by life stage. Each of the sections of the report are focused on helping people when they need long-term care and support. Life stage during retirement is defined by degree of limitations: no limitations, moderate limitations and major limitations. Four domains of retirement planning are considered, and they are intertwined. The four domains are managing finances, health, housing and transportation, and support. Support during the periods with limitations includes long-term care but also different forms of day-to-day life support, often not considered in discussions about long-term care. Such life support includes activities like driving someone to appointments, help with errands, help with housework, etc.

# Integrating Long-Term Care into Retirement Planning

Providing for risks is a major part of retirement planning, and long-term care is a major risk area for which most people do not have insurance. The potential for changing circumstances including decline in physical and mental capability is an important life factor in retirement planning. Planning for long-term care involves different types of issues at different times during the life-cycle and in different circumstances.

Earlier in life planning for long-term care is generally about financing and providing adequate resources if long-term care is needed at some point later in life.

Planning later-in-life (or after one starts to have limitations) is about how and where one will get support and/or care and who will provide it. It is also about assembling a support system. Support may be needed as soon as there are limitations, but insurance benefits are not payable until certain requirements of capability are met.

A significant part of retirement planning is also deciding where to live. Some types of living arrangements are compatible with limitations and others are not. Some include support integrated into the living arrangements. Location determines access to family and/or friends who will help and some people move to be near the people who can help them or the people they plan to help.

**Comprehensive awareness of risks** - The Institute publication, *Managing Post-Retirement Risks* (Risk Chart) brings together the range of retirement risks and provides an overview about how to manage them. The fourth edition is divided into three broad categories: economic risks, personal planning considerations, and unexpected (or unpredictable) events. Long-term care needs are primarily covered in personal planning considerations under Changes in Housing and Support Needs: Suitability and Affordability. They are also related to unexpected events including public policy changes, health care needs, and unforeseen needs of family members.

**A focus on changes and shocks** - The Retirement Risk Survey topic reports on Phases of Retirement (2007), Changes During Retirement (2013) and Shocks (2015) all focus on changes during retirement including the development of limitations. The shocks report makes clear that a major long-term care event can create very difficult situations for a retiree. Many retirees experience physical and mental limitations. Phases of retirement can be defined in terms of the extent of limitations – with moderate limitations defining the second phase, and major limitations the third phase. The 2021 Retirement Risk Survey also focused on changes during retirement and shocks.

**Planning for and financing long-term care** - The report *Retirement Adequacy in the United States: Should We Be Concerned?* (2018) is one of several Institute studies of benefit adequacy that indicate the importance of long-term care as an element in retirement planning. While few people have a major long-term care expense, it can be very costly and a reason for not having enough money in retirement. These studies offer a focus on the impact of large amount risks with different frequencies.

The paper *The Impact of Long-Term Care Costs on Retirement Wealth Needs* by Vickie Bajtelsmit and Anna Rappaport (2014) from the Institute monograph on long-term care and retirement provides an overview of how long-term care is financed in the US and how it affects retirement finances. It provides a simulation analysis to show how long-term care costs affect families in different situations under different financing strategies. A major conclusion of this analysis is the importance of considering and measuring tail risk in planning. This analysis is connected to the Institute's *Retirement Adequacy* study. Key conclusions reached in this paper include the following:

- Retirement strategies that focus on making small adjustments to spending or retirement age are insufficient to outweigh the tail risks associated with health, long-term care and longevity. Households with greater financial resources may be able to pay for long-term care costs directly, although this may require sacrificing other goals such as bequests to family or philanthropic objectives. However, low- and middle-income households in the United States are more likely to experience long-term care related financial difficulties because most have not purchased insurance or set aside sufficient funds prior to retirement. The purchase of long-term care insurance at later ages is quite expensive and may not be feasible for those with limited retirement wealth and/or poor health. Without insurance, any period of extended long-term care provided in a facility will rapidly deplete household funds for households with middle level financial status.
- An important takeaway from simulation models in general, and this one specifically, is that it is dangerous to focus on average outcomes. The amount of wealth needed to be highly certain of having sufficient funds to meet retirement needs is much greater than the amount needed on average. The primary reason for this is that retirees are subject to significant tail risk from shocks, such as an unexpected longevity, extended long-term care, or steep declines in asset values during retirement. Although relatively uncommon, when they do occur, these events can rapidly deplete retirement wealth, making it more likely that an individual will run short of assets. This is perhaps most pronounced for long-term care risk, where the majority of households have near zero out-of-pocket costs and a small percentage have extremely large costs. Using an average estimate for retirement planning results in significant errors in estimates for both groups.

The paper also includes a comparison of four methods of private funding for long-term care (Table 3 from the paper). The comparison chart is shown below. This paper does not focus on caregiver issues.

## COMPARISON OF PRIVATE FINANCING OPTIONS FOR LONG-TERM CARE

|                                                           | Insurance                                                                                                             | Savings                                                                                                                                     | CCRCs with a life care contract                                                                                                                                  | Housing Equity                                                                                                                              |
|-----------------------------------------------------------|-----------------------------------------------------------------------------------------------------------------------|---------------------------------------------------------------------------------------------------------------------------------------------|------------------------------------------------------------------------------------------------------------------------------------------------------------------|---------------------------------------------------------------------------------------------------------------------------------------------|
| Prevalence                                                | Less than 10% of care is paid for by private long term care insurance.                                                | About 15% of long-term care is paid for out of pocket. On average, older households have insufficient funds to cover the cost.              | Low; limited to higher wealth households.                                                                                                                        | Low prevalence of reverse mortgages to pay for LTC                                                                                          |
| When to do it                                             | While still healthy enough to qualify for lower rates.                                                                | Throughout life                                                                                                                             | Payment at time of entry and ongoing payments thereafter                                                                                                         | When funds are needed                                                                                                                       |
| Constraints                                               | Limited access after health deteriorates. LTC insurance may not cover all costs.                                      | Requires long period of saving to accumulate sufficient savings.                                                                            | Limited access after health deteriorates.                                                                                                                        | Insufficient home equity to finance care; illiquidity may make selling difficult                                                            |
| Match of solution to care needs                           | Depends on contract terms, e.g., qualification for benefits, type of care covered, waiting periods, maximums.         | Does not provide or finance care directly; difficult to estimate needs; savings may be insufficient; flexibility to use funds as needed     | Depends on contract terms and care available at CCRC chosen                                                                                                      | Does not provide or finance care directly; no guarantee that home equity will be sufficient to meet needs.                                  |
| Risks                                                     | Insurance premiums may increase over time; expenses may exceed policy maximums if care required for extended periods. | Investment risk; potential for shortfall; difficulty of managing assets; savings may be depleted prior to needing care                      | Monthly costs are likely to increase; CCRC could change management or go bankrupt; don't know if all needs will be covered.                                      | Housing equity may be inadequate to meet needs, housing market risk, interest rate environment impact on reverse mortgage payouts           |
| Which household type should use this method of financing? | Middle and upper middle income because they can afford premiums                                                       | Higher income and net worth households; need to start early and be willing to take investment risk.                                         | Higher net worth only because of the cost of buy in and regular payments.                                                                                        | Any households that own their home; lower risk for singles.                                                                                 |
| If no LTC costs incurred, what cost has been incurred?    | Insurance premiums from date of purchase to death                                                                     | Nothing. All savings can be accessed for other purposes.                                                                                    | CCRC buy-in price, higher monthly living cost to cover premium for long term care                                                                                | Nothing. Housing equity is still available to use for other purposes.                                                                       |
| Issues for surviving spouse                               | Reduces risk of asset depletion; insurance can be cheaper if bought for both spouses.                                 | Healthy spouse may incur personal and financial costs to delay accessing paid care; survivor may have insufficient assets to meet own needs | Security of being in the CCRC and of receiving care if needed; monthly charges higher than alternative housing; high cost for relocation if it becomes necessary | Healthy spouse may incur personal and financial costs to delay accessing paid care; survivor may have insufficient assets to meet own needs |
| Tax issues                                                | Some long-term care insurance has tax advantages                                                                      | Most retirement saving is tax-deferred; wealth will be taxed on withdrawal                                                                  | Part of the buy-in price and monthly cost are deductible as insurance                                                                                            | Gain on the sale of the house usually tax free                                                                                              |

\* Continuing care retirement community

Source: *The Impact of Long-Term Care Costs on Retirement Wealth Needs* by Vickie Bajtelsmit and Anna Rappaport (2014)

Current and future financing issues were also discussed in the 2014 Institute paper, *How American Society will Address Long-Term Care Risk, Financing and Retirement* by John Cutler and in a variety of other projects. Late-in-life deferred annuities (QLACs) have also been identified as a way for individuals to finance long-term-care, but at present they are very rarely used in that way. The future structuring of the long-term care delivery system is beyond the scope of this paper.

# Consumer Education

Personal management of finances, health care, and day-to-day living can be a complex task and especially once an individual starts to experience limitations. Family members are the most common source of help but there may not be any available family members. The Institute offers several consumer guides that help identify the issues and means of management. It also offers a series of decision briefs on important retirement planning issues.

**Late-in-Life Decisions Guide** - As mentioned earlier, this publication offers a guide to late-in-life decisions and management. It focuses on practical real-life complexities. It focuses on three limitation stages during retirement: no limitations, moderate limitations, and major limitations. Limitations may be physical and/or cognitive and they can occur in any combination. It focuses on four areas of retirement management: finances, health and long-term-care, housing and transportation and support. The guide provides information about steps in managing each area, complexities and it offers information about resources and sources of detailed information. The guide provides insight into the need to build a support system and offers suggestions for doing this. Building a support system and planning ahead provide the means for an individual to have more control of their own life. Another often overlooked area is the need for a health advocate to manage the complexities of dealing with the health care system and caregivers where there are multiple health problems and some decline in capabilities. This is a common situation.

**Thinking Ahead Roadmap: A Guide to Keeping Your Money Safe as You Age** - This project focuses on the management of money when one is no longer able to do this. It focuses on simplifying money management while one is able to do so, documenting information to make it easier for helpers, and securing help. This is a two-phase project. The Institute sponsored the research underlying this project. The AARP sponsored the implementation and there is a consumer website with information and tools. The project team was from the University of Minnesota and the Stanford Center on Longevity.

**Financing Long-Term Care Needs** - One of the Institute Decision Briefs reviews a variety of means of financing long-term care focused on the consumer. This publication is designed for individuals who are nearing or at retirement. It reviews different types of insurance products in the market today and their pros and cons. (Note that there are a variety of different types of long-term care insurance products with differences in provisions. The insurance offerings have changed over time and are continuing to change. Specialized knowledge is recommended when a household is evaluating or buying long-term care insurance. Some insurance advisors specialize in this area.)

**Managing Post-Retirement Risks (Risk Chart)** - This publication brings together the range of retirement risks and provides an overview about how to manage them.

## How Housing Fits In

One of the major decisions about retirement is where to live and in what kind of housing to live in. Most people say they prefer to stay in their own homes as they age. This can include moving to a different independent home. A large private home with substantial land may require a lot of work and expense to maintain the home and property. Apartments generally come with maintenance provided and no responsibility for yards. Some specialized senior housing includes some care and support. Continuing care retirement communities (CCRCs) offer a range of housing options starting with independent living and progressing to skilled nursing, so that an individual can receive more support as needed. Some local areas are more age friendly and have a variety of support services in the community.

Location also defines the access to health and support services, family and friends, transportation, climate, museums, theatres, and much more.

Housing choices and desirable design are linked to capability and care needs.

Issues include:

- Preference for staying in one's home.
- Who does maintenance and lawn care – this can be solved by hiring people or moving to an apartment or condo where the organization does this.
- Accessibility in conventional home – depending on the home, this may not be an issue, it may require modifications, or it may leave open the possibility that a move will be necessary.
- When support is needed – family often provides support and care, caregivers can be hired and brought into the home, or one can move to housing that includes care.
- Financial issues. Note that reverse mortgages are a means of converting home equity to regular income while still living in the house. These financing methods are used by a small minority of retirees.

The 2007 Retirement Risk Survey report, *Key Findings and Issues: Phases of Retirement* introduces the issue of integration of care and housing in the third phase of retirement (the major limitations phase).

While most individuals prefer to stay in their own home, the feasibility of doing so after limitations arise depends on the configuration of the house and modifications to fit the need of the person with limitations, availability of support services in the community and the availability of family or friends to help. Village-to-village organizations offer a way for seniors in a neighborhood to connect and find support, and age friendly communities look at design of the community as well as individual homes. The preference to stay in one's home and the related issues were discussed repeatedly through the Institute's 2023 Living to 100 Symposium. A summary of the discussion is provided in the SOA's July 2023 Retirement Section News article, *Highlights of 2023 Living to 100 Symposium*.

There are several types of housing that integrate support and/or care directly into the housing. The housing types include:

- CCRCs, also known as life care communities – these communities offer multiple levels of care and many services.
- Assisted living – these communities serve individuals with moderate limitations and provide assistance to people who need support with activities of daily living.
- Skilled nursing care – include both short-term rehab and long-term nursing home care.
- Memory care – higher level of care than assisted living specifically focused on individuals with Alzheimer's and substantial dementia.

The Institute issued a call for papers on long-term care in 2014 and several of the papers focused on housing options. The monograph, *Managing the Impact of Long-Term Care Needs and Expense on Retirement Security* includes the following papers related to housing:

- *Home Equity: A Strategic Resource for Long-Term Services and Supports* by Barbara Stucki
- *Improving Retirement by Integrating Family, Friends, Housing and Support: Lessons Learned from Personal Experience* by Anna Rappaport
- *Home Equity and At-Need Annuities—A Dynamic Long-Term Care Funding Duo* by Steve Cooperstein

The Stucki paper focuses on home equity as a means of financing long-term care. The Rappaport paper offers stories and shows various types of change over time and discusses decisions that were made about housing. It also includes comparisons of different types of housing options and discussions of their pros and cons. The Cooperstein paper integrates a financial product with home equity.

The Institute has included CCRCs in its long-term care options, focused on home values and their potential use to fund long-term care. Both options are shown on the financing exhibit above.

There is an additional essay on CCRCs in the Institute COVID and Retirement Essays, *Are CCRCs and Senior Housing Communities a Good Choice? COVID-19 and Risk in Arrangements for Senior Housing and Support* by Anna Rappaport.

The 2021 Retirement Risk Survey asked about living in multi-generational households. Fewer than one in ten respondents lived in such households. Those who did agreed that it would be easier to care for elderly family members in multi-generational households.

Housing is also related to considerations about emerging risks. See the discussion below.

Note: It should also be noted that housing is the largest item of expense for retirees and that housing is the largest asset for many retired households. In addition to being related to care and support, choice of house is important for life in general. Discussion of these issues is included in other Institute publications, but is not part of this topic.

# Help Needed at Ages over 85

The Institute, as part of its post-retirement risk work, examined the situation of retirees at different points during retirement. A series of research projects focused on individuals aged 85 and over is summarized in *Retirement Experiences of Individuals Aged 85 and Over* (2019). The separate studies summarized in that report include on-line conversations with experts, interviews with people who remain independent and families of those in assisted living, a telephone survey of individuals over age 85, an online survey of adult children of individuals over age 85 and a special report on cognitive decline. The family is a very important part of this research, and a separate report, *Family is Important for Retirement Security* (2020) summarizes the Institute research on family as a part of retirement security and management.

**Highlights of findings** - Many people reported needing help at older ages, with the need often seeming to increase with age. Wide variations exist in whether help is needed, what help is needed, how much, when and for how long, especially since the person's situation can change dramatically and frequently.

The situation is very different depending on household and family situations. Variations include:

- Couples, with at least one well-functioning person, with or without children or other family members who can help.
- Couples, both of whom need help, with or without children or other family members who can help.
- Singles, with children or other family members who can help.
- Singles, without a family member to help.

Note: Many couples with children may also be in blended families.

Changes in health status often lead to declines in capability and the need for more help. Cognitive and physical changes can require the need for different types of help. Changes in health can easily dominate the situation, especially when they occur suddenly and unexpectedly.

People who live independently, and do not have significant cognitive difficulty, did not appear to change the way they managed their money as they aged. However, once people experienced cognitive decline, everything changed. These individuals often needed help with money management, driving and taking medication, and other aspects of life.

For some families, long-term care and health costs are a huge issue. Health coverage usually does not pay for much long-term care, and the cost of long-term care can be devastating. Insurance generally does not pay for vision, dental care and hearing aids. Some situations involve other uncovered expenses.

People who reside in assisted living facilities very often get help with money management. Family members, especially children or other younger adults, often find themselves in the role of helpers, and they appear to be used more often than financial advisors. This happens even though family members are not always the best qualified to help (some may not be competent and diligent, and some may not be honest).

The money management help that people need includes help with daily tasks like bill paying, as well as advice in making decisions and managing investments. Some professionals specialize in daily money management and bill paying, and some focus primarily on working with elders. By comparison, financial advisors generally do not provide this type of service.

Even if not disabled, the older population also often needs help with other important tasks. These include making doctor's appointments, visiting doctors, keeping track of drugs and medical history, running errands and performing some household tasks.

For people with chronic health conditions, many prescription drugs and/or multiple medical issues, personal management of health care becomes increasingly complex. The helper needs to also serve as a health advocate.

Family help is not available to substantial numbers of people and this number is likely to grow. They are often referred to as solo agers. Those with no available family members may find it difficult to find a suitable person to help. They can sometimes engage fee-based services or individuals to provide or manage people who provide these hands-on services. In addition, they may find assistance through churches and senior community groups, such as Village-to-Village organizations. Locating and vetting such support can be challenging.

Family members are common helpers, but the relationships and situations are not always smooth. When multiple children or family members are in the picture, the potential for conflict and resentment exists concerning management of the older family members' finances, living arrangements, and/or health care. This can be a thorny issue, particularly for family members who are playing primary roles in helping relatives.

The role of family - The research found that people 85 and over plan to remain independent, but when they need help and there is no spouse or partner to provide it, many turn to family members. Family members often provide a variety of help for as long as they can. The 85 and over interviews emphasized the role of family, and the survey data provided additional insights, such as:

- In the telephone survey, about half of these elderly (49%) reported the need to be driven places, women (58%) more so than men (33%).
- The need for driving help is far more common among those with less than \$50,000 in assets (55%) than it is with those with greater assets (33%).
- Only about a third (35%) need support in taking care of their residence or assistance in shopping.
- Less than a quarter (23%) require assistance with housekeeping activities.

The online survey found that parents of the adult children who were surveyed received more help, including paid help, than the individuals aged 85 and over who participated in the telephone survey, as follows:

- Many adult children said they provide transportation to and from places (62%) or shopping (61%) for their elderly parents, especially widowed parents (68% and 66%, respectively).
- Nearly half (44%) of adult children said they manage medications or medical care for their parents, and many help clean their parents' residence (40%), do laundry (38%), or prepare meals (37%).
- More than a third (38%) of adult children said their parents have paid help to clean their residence, and nearly a third of the parents have paid help to prepare meals (32%), assist with personal care (31%) or do laundry (28%).

**If help from family or friends is not enough** - When the need for help exceeds what the family and friends can handle, alternatives include seeking help from paid helpers and caregivers, an assisted living facility or a nursing home. For solo agers, the questions arise: What are the best routes for people with no family or no nearby family? Who will make health care and end-of-life decisions when the older adult can no longer do so?

The next steps are to address several questions: What are the triggers that indicate it is time to move to the next step? Who will approach the topic with the elder loved one? How will the next step be funded and by whom?

**Blended family issues:** For blended families, the questions may be different from that of other families. Will adult children in these families maintain a relationship with stepparents once their natural parent is no longer in the picture? More research is needed to understand blended family issues related to late-in-life family members.

**Acting on the Age 85 and over research** - The Institute Late-in-Life Decisions Guide and the Thinking Ahead materials offer information on how to deal with the issues raised in this research.

# Caregiving Impact on the Caregiver

When individuals need help, it affects two parties: the individual receiving the help and the individual providing the help. Caregiving demands have a big impact on careers, retirement decisions, life in retirement; it affects a very large number of people.

Some caregiving can be planned based on a schedule, but in other cases, it must be responsive to need. A caregiver taking someone to the doctor knows in advance when the appointment is, but there may not be many options for making the appointment. However, there are no choices about when to respond to an emergency. Likewise, the caregiver may be able to control when they do the laundry, but not when they help the individual they are caring for go to the bathroom. Caregiving often means that individuals must take time off from work – a mix of predictable and unpredictable time. Depending on the situation, it may mean an occasional short absence, a reduction in work schedule, or a leave of absence.

**Overview of caregiving issues** - The 2014 Institute call for long-term care papers, *Managing the Impact of Long-Term Care Needs and Expense on Retirement Security*, included *The 65 Plus Age Wave and the Caregiving Conundrum: The Often Forgotten Piece of the Long-Term Care Puzzle* by Sandra Timmermann. The paper provides an overview of the challenges of caregiving. These forces remain in effect today. The following is an excerpt from the paper:

“Caregiving and what it entails are often the forgotten links in the LTC discussion, and the issues surrounding them need more attention. One reason why caregiving is so important is that it is an integral part of the LTC delivery and financing puzzle and needs to be incorporated into any proposed LTC solution. Several intertwined factors are now bringing these issues to the forefront, and four trends stand out:

1. Families provide the [majority of caregiving], but they are stretched as a result of the care they provide, not only physically and emotionally but also financially. Family members juggle work and caregiving, figuring out the best path for their loved ones and providing care while holding down a job. Many spend money out of their own pocket, or leave the workforce prematurely, impacting their own retirement security.
2. The aging-in-place movement, based on the premise that most people would prefer to [age] in their homes and communities rather than move into nursing homes or other facilities, has gained traction and will create a greater need for caregivers. Aging at home and receiving care there are not only preferred by the public, but also have gained support from the aging field, backed and promoted by the government. The expectation (perhaps a false assumption) is that it will allow a better quality of life for older people and, at the same time, will reduce government expenditures previously directed to nursing home occupancy. However, the infrastructure and funding on the community level aren't there to provide the LTC and social support that would alleviate the burden on family caregivers, create caregiver jobs, and make this idea fully operational.
3. There is a shortage of paid caregivers—the personal care assistants, the CNAs, the home health aides, the LPNs and others who do the difficult daily work of custodial and semi-skilled care—and the situation is projected to worsen in the near future. The jobs are low-paying, rarely have a career ladder, and are physically and emotionally exhausting. While many of those who do this work are compassionate and caring, the turnover is high and the potential for elder abuse and fraud is always present. Family members often have to step in due to the difficulties of finding adequate paid care for their loved ones.
4. LTC costs continue to rise at a steady rate, but families have not prepared sufficiently for the possibility that they may need care. LTC insurance penetration continues to be low, leaving many in the middle market with little choice but to spend down assets and cobble together a care plan, and rely on their family to finance their care out-of-pocket.

The convergence of these four factors is creating a perfect storm, not only for the care recipient, but also for the families who do their best to care for the ones they love. The patchwork caregiving situation is symptomatic of bigger LTC issues ahead. Boomers are now in their [late 50s to late 70s], caring for their parents. It won't be long before they move into old age and find themselves caring for a spouse or partner, or needing care themselves.”

The Institute 2023 research report, *Informal Caregiving: Measuring the Cost and Reducing the Burden* provides a literature search and discussion about caregiving. It examines the perspective of the individual and family, the business community as an employer of caregivers, and financial services companies. It covers care and support for older family members, and care for disabled persons at all ages. It does not include childcare for healthy children.

The report offers insights into the definitions of caregiving: “As discussed earlier in this paper, there is no single definition of a “caregiver”; in addition to the sources discussed above, there are many resources that have laid out various tasks and situations classified as “caregiving”. For instance, the National Business Group on Health noted that common tasks performed by caregivers include transportation, bathing, feeding, dressing, and help getting around the house. But caregiving can also involve going to appointments, spending time on the phone, or coordinating and scheduling appointments online. These tasks can almost feel like a part-time job.”

**Impact of caregiving on personal health** - The report offers insights into the impact of caregiving on personal health and well-being: “According to a recent NBGH [National Business Group on Health] survey, 88% of caregivers reported that their responsibilities had a negative impact on their personal health and well-being.

In the NBGH study:

- Caregivers were twice as likely to develop chronic illness
- They were twice as likely to develop depression
- 92% reported that caregiving impacted their stress levels, with 48% saying “a lot”
- 49% reported exhaustion
- 27% reported stress on their marriage or relationships
- 25% reported missing their own doctor’s appointments
- 16% reported that not covering what was wanted or needed caused additional stress
- They spent on average \$7,000 of their own money annually on caregiving expenses“

**Impact of caregiving on work and careers** - The report also offers insights into the impact of caregiving on work and careers: “Beyond the physical and mental detriments of caregiving discussed above, there can be substantial additional costs on caregivers’ careers and earning potential.

The NBGH study also found:

- 75% reported calling in sick or taking paid time off
- 52% reported missing or being late to work due to caregiving responsibilities
- 33% reported higher leave incidence and duration
- 20% reported a decrease in productivity due to caregiving duties

These costs can increase significantly for informal caregivers providing more intense levels of care, as measured by the weekly hours of care as well as the Activities of Daily Living (ADLs) and Instrumental Activities of Daily Living (IADLs) assisted with.

Work accommodations for caregiving can lead to lower earnings, lower benefits, lower retirement income, and lower social security income. Needed employment accommodations can also impose costs on employers.”

**Consumer research and the caregiver** - Some of the Institute Consumer Research – the 2017 Retirement Risk Survey and the age 85 and over research - offer insights about the caregiver in a consolidated report, *Caregiving for Older Individuals: Perspectives of the Caregiver and the Care Recipient*.

Key findings from this report and supplemented from other work include the following:

**Prevalence and impact of caregiving**

- Caregiving is a part of retirement for many Americans, and it can have a significant impact for them. Roughly half of pre-retirees and retirees said they have been a caregiver for someone near or in retirement who has a serious disability or illness. Caregiving is more common among retired widows: nearly three in four said they have been a caregiver, though fewer indicated they are currently spending time as a caregiver. (The author's experience is that many people between ages 50 and 70 seem to be increasingly involved in helping or caring for parents.)
- Survey respondents say the impact is greater emotionally than financially or physically.

**More help is need at higher ages**

- People aged 85 and older more often rely on informal support, often provided by family, rather than formal support from institutions and organizations. Individuals without a support system have a gap to fill in their planning. Further research is needed to understand and develop alternatives for people without family.
- Overall, people aged 85 and older need much more help than younger cohorts and, often, people need more help as they age.
- By age 85, most women are alone, many of them widowed. Women alone are much more likely than couples to need help from others.
- When people aged 85 and older need help and have multiple children, the children often share responsibility.
- A large majority of elderly participants, over four in five, said they have at least one close family member who lives within 50 miles of them.
- About one in three people aged 85 and over stated that they rely on family or others to help them manage their daily activities. However, adult children were more likely than the elderly surveyed to say their elderly parents are receiving familial support.

**Planning for the economic impact on the caregiver** - The Informal Caregiving report offers a variety of different statistics that provide evidence that caregiving is costly to the caregiver and their family, but it does estimate a lifetime cost to the caregiver. It would be helpful to have a model and a tool to enable family to do an estimate of this cost. Things to be considered would be length of time caregiving, out-of-pocket expenses spent on caregiving, wages lost, value of benefits lost, etc. One of the difficulties in making estimates in advance is the caregiver often will have no idea how long the responsibilities will last. In addition, it is common for the duties of the caregiver to gradually increase, so that the reduction in work schedule that applies initially may change. The Timmermann paper referenced above had a lifetime estimate of \$325,000 included in the paper. This was an estimate of average lost wages and retirement benefits plus additional costs and may need updating since it was calculated a number of years ago.

The other approach to this issue would be for the caregiver to think about the inputs into a financial planning tool and vary them based on reducing pay and/or years of work as a result of caregiving and also increasing expenses (or reducing savings)

# Interaction with Emerging Risks

The Institute annually conducts a survey of emerging risks, identifying the risks which are of the most concern to corporate risk managers. These risks also affect retirees and have some links to long-term care, caregiving and housing.

**Climate risk and retirement** - There was discussion of this topic at the 2022 SOA ImpACT Meeting (annual meeting) and the 2023 Living to 100 Symposium. An article in the April 2023 Retirement Section News, *Climate Change, Emerging Risks and Retirement Security*, offers an overview of issues, many of which are linked to housing. The issues are particularly dramatic when individuals need support and/or for caregivers. A climate event may make delivery of care difficult, and the caregiver may not be able to get to the person needing care. If power is out for a long period, that may disrupt care. If there is a major storm or event, and evacuation is required, this can be very difficult (or impossible) for individuals with limitations. There are questions about where they will go, how will they manage when they get there, and how will they get there. Some areas expect more frequent evacuations and are more vulnerable to climate events. If an individual is in senior housing offering support, there are questions about how well the housing can deal with emergencies. These are a consideration in choice of housing community. The Institute issued a call for essays linking climate and retirement and published the first group of essays in 2023.

**Pandemics and retirement** – COVID-19 affected the lives of most people. A series of Institute reports focused on the link between COVID-19 and retirement. Two of these reports focused on long-term care, and the interaction of COVID-19 issues with housing and support.

The Institute report *Impact of COVID-19 on Senior Housing and Support Choices* (2020) focuses on how COVID-19 impacted housing that includes care, including nursing homes, and on caregivers. One of the open questions is whether more people will choose to live in multi-generational housing. COVID-19 was particularly troublesome for families needing caregivers. Paid caregivers often were not available during COVID-19, and some of them got COVID-19. This increased the burden on family members and made it much more difficult to get help. Families were not allowed to visit their loved ones who were in nursing homes and assisted living facilities. Many talked with them by phone, ZOOM or other similar computer programs.

Some facilities had many COVID-19 cases and an increase in deaths. Great care was taken to manage the spread of COVID-19. Sometimes it worked and sometimes it did not.

A second Institute report, *COVID Aging and Retirement Research: What's Been Done and What's to Come* (2022) also includes a section on housing and support issues. One of the uncertainties is the impact of long COVID and the extent to which it may increase the need for support at later ages and increase the length of time support is needed.

The Institute is continuing to monitor emerging risks. To the extent that they affect all of retirement, they are likely to interact with the need for long-term care and affect caregiving.

# Areas for Future Research

## Areas where more research would be helpful

- There are an increasing number of blended families. The research does not provide any insights about how things are different for blended families. However, anecdotal evidence provides information about stepchildren who do not continue relationships with stepparents after the spouse dies.
- How people can manage if they have no available family members who can help. People without available family, i.e., solo agers, also need help, and they may have difficulty finding it. The challenges increase substantially when solo agers experience cognitive decline. The SOA Research Institute is currently working on a decision guide for solo agers.
- Diversity and long-term care, considering both race and ethnicity and LGBTQ+ groups. Different groups have different issues accessing and getting the most appropriate medical care. They likely have differences in family patterns and the prevalence of multi-generational households. More research on whether there are different issues and why with regard to long-term care and caregiving would be helpful.
- Housing is the largest expense and asset for many families. Housing choices link to support when needed, and housing assets can contribute to financing support. Further research on these decisions and processes for evaluating them would be helpful.
- Multi-generational households are more prevalent in some cultures than others. They seem to be disappearing in some cultures but may be growing more common in others.
- Technology and its use to support people with limitations and ease the burdens on caregivers. Such research should consider the use of Artificial Intelligence, sensors, and robots. It should also consider the potential to distribute medical testing through small devices and wearables.

## Conclusions

The need for long-term care is a major retirement risk, but one where the costs can vary widely depending on care needs. Managing the risk needs to consider this distribution of care needs and not just averages. The Institute's consumer research on retirement risks shows that concern about long-term care is consistently one of the top three retirement risks, but this may not translate into advance planning. For many individuals, planning is short-term, cash flow focused and not risk focused.

Knowledge and action gaps around long-term care risk are part of a larger group of gaps in knowledge and planning. Many people overestimate what Medicare will cover when care is needed, and they may underestimate the cost and burden of care. A small minority buy private long-term care insurance, and that market has challenges. Family and friends are the major caregivers, but they are usually not included in planning. Family help can be supplemented by paid help, but there is a shortage of caregivers, and it is growing.

A study of changing needs and the support usually needed late-in-life indicates the need for more planning and a support system which will be needed as an individual develops limitations. Most individuals prefer to age at home, but "home" can be a variety of different places. Some senior housing has support built in. There are important links between housing choices and how well they work for people with limitations.

An often-overlooked impact of long-term care is the impact on the caregiver. Increased attention has been paid to this issue recently and the Institute has increased its focus on this issue as well. The caregiver who supports a spouse, parent or other family member over a period of years often pays a heavy price in lost wages, retirement benefits, impact on health, and out-of-pocket spending.

The issues related to long-term care can be viewed from the perspective of the care recipient, the caregiver, public policy, the financial services industry, the health care delivery system, the housing industry, etc. This report focused on SOA Research Institute research and the individual. It also pointed out diverse needs in different situations and some areas for further research.

## Related Issues and the Future

This report deals with the perspective of the individual. The SOA also does a considerable amount of work on long-term care insurance and on the future of long-term care in U.S. society.

The long-term care insurance market faces challenges with a number of insurance companies having left this market and other issues. Discussion of these issues is beyond the scope of this report. The SOA Long-Term Care Insurance Section regularly addresses these issues and the Institute has sponsored experience studies on long-term care and two Think Tanks to focus on the future of the system. These materials are available on the SOA website.

Government plays a role in long-term care funding. Medicaid is a substantial funder of long-term care today. This is a government program, operated by the states and partially funded by Federal dollars. It provides payment for nursing home care and for some additional long-term care for low asset and income individuals. These programs are under financial pressure and are likely to change. Several states are exploring alternative methods of funding modest amounts of long-term care, and some states have had partnership programs with private insurance in the past. These issues are beyond the scope of this report. They were also discussed in two recent reports: *Informal Caregiving: Measuring the Cost and Reducing the Burden* (2023) and *Long-Term Care Coverage: Stakeholder Opinions on State Based Catastrophic Coverage* (2023).

Caregiving is also being recognized as a business issue because employers have found that caregiving over a long period affects performance at work and business results. This is beyond the scope of this report, but it was discussed in *Informal Caregiving: Measuring the Cost and Reducing the Burden* (2023) as well as in the essay by Sandra Timmermann. EBRI has also recognized this as an important issue.

Future issues related to long-term care financing were discussed in the 2014 Institute paper, *How American Society Will Address Long-Term Care Risk, Financing and Retirement* by John Cutler. The future structuring of the long-term care delivery system is beyond the scope of this paper.

Technology has changed the way many jobs are performed, the way financial service companies deal with customers, the way individuals communicate with each other, the way health care is delivered and much more. There is growing technology for use at home. Wearables allow people to monitor some of their behaviors related to health and to do some diagnostic testing remotely. Sensors help keep track of individuals' movements. Robots are gradually doing an increasing number of tasks. Artificial intelligence is changing an increasing number of tasks. Technology offers the potential to support caregivers and change the job of caregiving. Technology is beyond the scope of this paper, but it is one of the areas that will affect long-term care and caregivers.

There are a number of reasons why change can be expected in the overall long-term care system. More people will need support, existing financing vehicles are not aligned for many individuals, government support has challenges, and shortages of caregivers are expected to grow. Technology will offer new opportunities. The SOA Research Institute's Aging and Retirement Strategic Research Program, the Long-Term Care Insurance Section and the Retirement Section will all likely provide research that continues to examine these issues.

This report is primarily focused on SOA Research Institute resources. Note that the Women's Institute for a Secure Retirement sponsors a webpage for financial caregivers, which offers substantial resources to individual caregivers and employers. The Institute report *Informal Caregiving: Measuring the Cost and Reducing the Burden* includes a literature search and mentions a number of organizations and sources that focus on caregiving and caregivers. Some of the resources are local. The Institute *Late-in-Life Decisions Guide* also offers information about finding local resources and pathways to consider. Generally, Area Agencies on Aging are a good place to start.

# Appendix: List of SOA Research Institute Research and References:

## BIENNIAL RISK SURVEYS AND OTHER CONSUMER SURVEY RESEARCH

The entire Risk Survey series includes long-term care as a regularly recurring key risk question. Several surveys have topics that provide insight into the incorporation of long-term care into retirement planning.

Reports focusing on long-term care as a special topic: 2007 and 2017 Risks and Process of Retirement Survey. The 2017 survey also focuses on caregiving. The two reports on long-term care and caregiving combine the results of the Risk Surveys with the results of special research on age 85+.

The 2021 Retirement Risk Survey includes topics related to long-term care and caregiving. The two topics included in the survey are planning and dealing with change, health and caregiving.

The age 85+ research includes a telephone survey of individuals age 85+ and an on-line survey of adult children of individuals age 85+. Limitations, needs for support, place of support and the role of the family are important topics in this research.

## FOCUS GROUPS AND IN-DEPTH INTERVIEWS

### ***Focus groups include:***

- *Post-Retirement Experiences of Individuals Retired for 15 Years or More* (2015). This study includes a combination of focus groups as well as some in-depth interviews to reflect on the situation of individuals unable to participate in focus groups.
- *The Decision to Retire and Post-Retirement Financial Strategies: A Report on Eight Focus Groups* (2013)
- *Post-Retirement Experiences of Individuals 85+ Years Old* (2018). This research includes focus groups and in-depth interviews.

## ESSAYS AND PAPERS

*Managing the Impact of Long-Term Care Needs and Expense on Retirement Security Monograph* (2014). This monograph includes several papers relevant to home equity and long-term care planning:

- *Home Equity: A Strategic Resource for Long-Term Services and Supports* by Barbara Stucki
- *Improving Retirement by Integrating Family, Friends, Housing and Support: Lessons Learned from Personal Experience* by Anna Rappaport
- *Home Equity and At-Need Annuities—A Dynamic Long-Term Care Funding Duo* by Steve Cooperstein
- *The Impact of Long-Term Care Costs on Retirement Wealth Needs* by Vickie Bajtelsmit and Anna Rappaport
- *The 65 Plus Age Wave and the Caregiving Conundrum: The Often Forgotten Piece of the Long-Term Care Puzzle* by Sandra Timmermann.

## IMPACT OF COVID-19 ON AGING AND RETIREMENT ESSAY COLLECTION (2021):

- *Are CCRCs and Senior Housing Communities a Good Choice? COVID-19 and Risk in Arrangements for Senior Housing and Support* by Anna Rappaport

In addition, other materials are referenced in this report.

## RESEARCH AND RELATED REPORTS

- *Informal Caregiving: Measuring the Cost and Reducing the Burden* (2023)
- *Understanding and Managing Post-Retirement Risks: Retirement Experiences of People Age 85 and Over* (2019)
- *A Conversation on Dementia and Cognitive Decline*

## EMERGING RISKS

### ***Covid-19 and long-term care planning:***

- *Impact of COVID-19 on Senior Housing and Support Choices* (2020)
- *Aging and Retirement Research: What's Been Done and What's to Come* (2022)

### ***Climate change and retirement planning:***

- *Article in Retirement Section News: Climate Change, Emerging Risks and Retirement Security* (2023)

## INFORMATION FOR CONSUMERS

### ***Decision Briefs (for individuals nearing or in retirement):***

- *Financing Long-Term Care Needs*
- *Where to Live in Retirement*

### ***For individuals later in life and caregivers:***

- *Late-in-Life Decisions Guide*

### ***For an overview of the big risk picture:***

- *Managing Post-Retirement Risks*

Note: The content of this research brief is a combination of the author's own ideas and findings drawn from the research described in the brief. The ideas are not the opinions of the Society of Actuaries Research Institute or any committee thereof.

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