Caregiving for Older Individuals: Perspectives of the Caregiver and the Care Recipient

2017 Risks and Process of Retirement Survey Report
ACKNOWLEDGMENTS

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The views and opinions expressed in this report are those of the authors and do not necessarily reflect those of the Project Oversight Group nor the SOA as a whole.

TO OBTAIN A COPY OF THE COMPLETE SURVEY REPORT

The 2017 Risks and Process of Retirement Survey report may be obtained from the website of the Society of Actuaries at www.soa.org.
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Introduction

The Society of Actuaries (SOA) has sponsored a number of studies to learn about how Americans are faring in retirement, what they are doing to manage post-retirement risks, how their situation changes during retirement and how shocks have impacted them.

Starting in the year 2001, the SOA began researching Americans’ assessments of post-retirement risks and views on the management of those risks. The 2017 Risks and Process of Retirement Survey (the 2017 Risks Survey), conducted on the SOA’s behalf by Greenwald & Associates, is our ninth biennial study in this area.

The SOA has also conducted a series of focus groups and in-depth interviews to gain insight into how people fared at different stages of retirement. This additional research has included studies of people age 85 and older in 2017, people retired 15 years or more in 2015, and people retired under 10 years in 2013.

Caregiving and intergenerational care support, as this relates to long-term care needs in the post-retirement years, is one of several major topics raised in the 2017 Risks Survey. The subject is also addressed in the other research in 2017, 2015 and 2013. In addition, the topic has been examined in earlier SOA studies. Now, this new report pulls together the various findings from this growing body of caregiving research, the purpose being to illuminate what people are experiencing and thinking about such care today.

This comprehensive report begins with a general discussion of the key findings along with relevant quotes from individuals that help flesh out the issues and experiences of people involved in caregiving and intergenerational care support. Following is an exploration of several detailed survey results, including questions selected from the 2017 Risks Survey and from SOA’s two age 85 and older surveys. The 2017 Risks Survey provided insights into what people are expecting and how they are planning, whereas the age 85 and older research provided insights into what has actually happened to people who need caregiving and care support.
Key Findings and Perspective

Long-term care has been continuously recognized as a key post-retirement issue throughout the 20 years of the SOA’s research on public perceptions and knowledge about post-retirement risks. What is less often recognized is that long-term care has great impact on both the individuals needing care and the caregivers. However, the SOA Project Oversight Group for this effort recognized a little-explored issue. Caregivers and support people who assist those who need a variety of support as they age find that it requires a lot of attention and has a substantial impact in their lives. They need to be thoughtful about how to make the support work well for both parties. Further, the SOA committee saw that caregiving for frail or disabled family members can become a major driver of retirement behavior and decisions, and that this can impact what retirement resources are needed and available.

As noted earlier, this report focuses on caregiving during retirement and draws results from several different studies. Key findings include the following:

• Caregiving is a part of retirement for many Americans, and it can have a significant impact for them. Survey respondents say the impact is greater emotionally than financially.

• Several studies show that Americans underestimate the amount of long-term care they may need, and they are overly optimistic about having resources to pay for it. They overestimate the costs that Medicare and supplemental insurance will pay. They also underestimate the amount of help they may need and the potential burden this may create for those who will help them.

• People age 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 age 85 and older need much more help than younger cohorts and people need more help as they age.

• Family is often willing to step up to help when care is needed. However, families frequently do not plan for this in advance, and few families have advance discussions about expected help needed and long-term care.

• Parents do express concern about not burdening their children, but the children often provide help when needed. Family support provides an important cushion for many older people.

• Family help often includes driving, household tasks, daily money management, taking people to the doctor, etc. When the person needs help with activities of daily living, however, professional help becomes more likely.

• Children are more involved in helping with tasks than in providing financial support to parents, although many children do provide some financial support. Parents are more likely to provide financial support to adult children than vice versa.

• Experiences with parents influence some people in their own retirement expectations.

• 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 age 85 and older need help and have multiple children, the children often share responsibility.

• The research does not provide any insights about how things are different for blended families or how people manage if they have no available family members who can help.
About the Research

THE SOA 2017 RISKS SURVEY

The 2017 Risks Survey was designed to evaluate Americans’ awareness of retirement risks and how these perceptions affect feelings of financial security. From June 20 through June 30, 2017, the researchers completed a total of 2,258 online interviews (1,030 pre-retirees, 1,025 retirees and an additional 203 interviews among retired widows). The interviews lasted an average of 20 minutes. Topics emphasized included not only long-term care but also financial wellness, housing, and the burden of caregiving.

The researchers selected individuals for participation using Research Now's nationwide online consumer panel. Respondents were classified as retired if they described their employment status as retired, or retired from a previous or primary career, or were not currently employed and were either age 65 or older or had a retired spouse. All other respondents were classified as pre-retirees.

The sample data were weighted by age, sex, education and household income to match targets obtained from the March 2016 Current Population Survey (CPS).

Note: This was the ninth in a series of biannual surveys. These surveys were conducted by telephone from 2001 to 2011 and online subsequently.

THE SOA 2015 AND 2017/2018 LATER IN RETIREMENT STUDIES

Other research in 2015 and 2017 also produced insights into caregiving issues. Here is a little about these studies:

THE 2015 RESEARCH

- In 2015, Greenwald & Associates conducted 15 in-depth interviews with relatives who provide assistance to someone who requires long-term care. Research Now conducted the recruitment for the interviews. The resulting report is *Post-Retirement Experiences of Individuals Retired for 15 Years or More: A Report on Twelve Focus Groups and Fifteen In-depth Interviews in the United States and Canada* (2015 15 year+ Retirees).

Those who participated in the in-depth interviews were spouses or children of the person in need of long-term care. The participants had to have knowledge of their loved one's finances and also be involved with long-term care decisions. Those interviewed also had to be caring for someone who received less than $2,000 in pension or annuity income and have less than $700,000 in total assets (not including the value of their home). All participants must have served in their role at some point during the past five years.

THE 2017 RESEARCH

- In 2017, the SOA focused on the age 85 and older population. It commissioned 36 one-hour, in-depth interviews in the United States and 26 in Canada, conducted in March and April of 2017. Interviewees represented a mix of elderly participants, children of elderly parents or in-laws, and dyads (two-person groups) consisting of elderly participants and their adult children. The resulting report is *Post-Retirement Experiences of Individuals 85+ Years Old: A Report on Sixty-Two In-depth Interviews in the United States and Canada* (85+ In-depth Interviews).

To qualify for this research, the elderly participants or parents needed to be age 85 or over, with one-third over age 90. The participants represented a combination of married and unmarried individuals and those with financial assets of more and less than $50,000. All had less than $400,000 in assets, and no more than two per location had more than $400,000 of equity in their houses. Participants could not have pension income of more than $2,500 per month.
Also in 2017, the SOA conducted two surveys focused on the age 85 and older population. These were a telephone survey of age 85 and older individuals and an online survey of adult children of individuals age 85 and older. Greenwald & Associates, in cooperation with the SOA's Project Oversight Group, designed the questionnaires. All together, 202 adult children with elderly parents and 201 elderly individuals completed these interviews. The SOA published this research in 2018 in a report titled *2018 SOA Report Post-retirement Experiences of Individuals over 85 Years Old: A Report of Surveys of Individuals Ages 85 and Over and Adult Children with Parents 85 and Over (85+ Surveys: Individuals 85+ and Adult Children)*.

The telephone interviews with age 85 and over respondents were conducted in October 2017 and averaged 23 minutes. To qualify for the survey, potential respondents needed to be at least 85 years old with under $400,000 in assets; at least 45% had to have incomes of less than $50,000.

The online interviews were conducted in December 2017 with adult children of 85 and over parents and averaged 19 minutes. The adult children needed to have at least one living parent or stepparent who was age 85 or older and to be close enough to that person to have some knowledge of the parent's finances, health status, and cognitive ability. Forty percent of the online sample had to have a living parent or stepparent age 90 or over. The parent or step-parent had to have less than $400,000 in financial assets with at least 40% having under $50,000.

### DIFFERENCES IN POPULATION STUDIED

- The 2017 Risks Survey included people at all income levels and at ages 45 to 80. There was no reason to expect that the distribution was skewed to any particular income level.

- All of the focus groups, in-depth interview studies, and the age 85 and older surveys were with resource-constrained retirees.

- The adult children of people retired 15 years or more who were interviewed in 2015 had parents who were relatively unhealthy. The purpose of these interviews was to add information into a broader study to represent people who could not participate in a focus group study of retirees retired 15 years or more. The interviews were limited to people with less than $700,000 in total assets (not including the value of the home).

- The people interviewed in 2017 for the age 85 and older study included a mix of individuals, adult children, and a combination of parents and adult children. Assets were limited to less than $400,000.

- The sample for the survey of adults age 85 and over was likely healthier than the total population at these ages. This was likely because the respondents needed to be healthy enough to respond to a telephone interview.

- The parents of the adult children sample were probably less healthy. This is because half or more of the latter sample reported that their parents had limitations that required assistance with personal care (56%) or hearing issues (49%) and four in 10 (42%) had parents with moderate to severe cognitive decline. These issues would likely have precluded participation in a telephone study for many in this age group. Also, the study required that children be knowledgeable about their parents’ financial situation; this might not have been the case for children of many of the parents living independently without their support.

- For all of the surveys, some questions were asked of the entire population and some of a subpopulation. The page showing the question indicated the basis for that question.
An examination of the results for the telephone survey of people age 85 and older confirmed some characteristics of this age group. Less than 10% of the telephone sample required a great deal of assistance in daily living. Also, because of the advanced age of the sample, most were female, and most were widowed. Due to these demographic characteristics, these results differed from the results for the adult children surveyed.
Report Overview

This section of the report groups results by major topic. Later on, this report details survey results on a question-by-question basis and identifies the research report where the questions appear. The order of discussion approximates the topics summarized here.

**IMPORTANT NOTE ABOUT REFERENCES IN THIS SECTION**

This section of the report includes qualitative comments, or quotes, from various research respondents. These quotes, as well as other references in the material here, refer to the studies shown in the following list with their abbreviated titles. The full titles are introduced earlier and also appear in the Appendix.

- 85+ Survey: Individuals 85+ and Adult Children
- 85+ In-depth Interviews
- 2015 15 year+ Retirees
- 2017 Risks Survey

**ASPECTS OF CAREGIVING AND INTERGENERATIONAL CARE**

**1. Caregiving Experience**

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. Among pre-retirees, a slim majority of respondents predicted they will likely spend time providing care during retirement.

Though retirees and retired widows are more inclined to have provided care at some point, they are less likely than pre-retirees to believe they will provide care again in the future. As caregivers age, those they provide care to changes. Pre-retirees providing care are most likely caring for a parent or an in-law, while caregivers who are retired are more likely to be caring for their spouse and adult relatives or children.

A large majority of elderly participants, over four in five, said they have at least one close family member that lives within 50 miles of them. About one in three people age 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, especially with transportation and shopping. This may reflect the differences in the survey samples, or differences in the perceptions of parents and children.

The differential shows up in the financial area as well. For instance, a larger share of adult children (20%) said they provide financial assistance compared to the smaller percentage of elderly (6%) who said they have received financial assistance from their family.

The matter of finances is important to the elders. The SOA 2017 Risks Survey found that running out of assets, cognitive decline, chronic illness and needing long-term care are prevalent reasons why parents require financial support from their families. However, very few pre-retirees and retirees have contributed significantly to their parents’ long-term care costs, although sizable minorities (37% pre-retirees, 29% retirees) said they did pay for at least a part of it. The research indicates that those providing care tend to view the burden of caregiving as more emotional than physical or financial.
The SOA 2017 Risks Survey suggests that parents’ retirement experience clearly influences their children’s views about retirement, especially among those whose parents required long-term care. Overall, more than half of pre-retirees (56%) and four in 10 retirees (43%) stated that their parents’ experiences in retirement had made them more concerned about their own financial security in retirement.

The SOA’s 85+ In-depth Interviews study underscored these themes. The report made clear that more people have needed help later in life than anticipated they would need and that family played a very major role in providing care. The study did not provide insight into what older people without available family do when they need care; this is an area for further study.

**QUALITATIVE QUOTES ON CAREGIVING EXPERIENCE**

“I think I’m fairly involved. She physically needs a little help. She’s 93, but she is just starting to get a little bit more confused. She can still make a lot of her decisions on her own. That’s what I mean. I am trying not to bulldoze her into decisions, I guess. I just keep making suggestions until she makes up her mind.” —Woman assisting mother in Canada (2015 15 year+ Retirees)

“It was more mobility issues more than anything. She wasn’t up to getting her own groceries. She couldn’t drive herself, because she couldn’t see well enough, and she just wasn’t really up to traveling through stores and stuff like that by herself.” —Woman assisting mother in Canada (2015 15 year+ Retirees)

“She has no idea where her finances are at the moment or the fact that actually I am paying a partial amount to keep her in there. She has no idea.” —Woman assisting mother in Canada (2015 15 year+ Retirees)

“I’m the one that does it all. When she’s had any unexpected, I’m the one that drives people to the hospital, picks them up. I’m that caregiver. She’s never had to pay for anything.” —Dyad, low-asset, elderly female (85+ In-depth Interviews)

“He depends on us. Honestly, even if he didn’t bring a single penny here still he’s not a problem for us. He is still living with us . . . . First thing because he knows English, but it’s not like he can’t manage if he goes to bank. It’s like different. Like he can’t do anything on his own here, so he needs our opinion and our advice what to do here.” —Dyad, low-asset, male (85+ In-depth Interviews)

### 2. Parents’ Experiences

A majority of pre-retirees and retirees in the various studies reported that at least one parent experienced an illness or disability that limited the elder’s ability to care for self. Furthermore, many retirees said their parents needed not only care from family and friends but also professional care.

Prevalent reasons for parents losing their ability to care for themselves included chronic or debilitating illness, physical frailty and cognitive decline. The surveyed elderly and those whose parents required care in retirement said that driving to and from places, household chores and shopping were the top daily living activities for which the elderly required help. Although there were differences in the populations studied, compared to the elderly surveyed in the 85+ Surveys: Individuals 85+ and Adult Children, pre-retirees and retirees in the 2017 Risks Survey reported higher instances of their parents needing assistance with household chores and daily living activities.
QUALITATIVE QUOTES ON FAMILY DISCUSSIONS ABOUT LONG TERM CARE

“He has some balance issues, and he has very limited short-term memory. His short-term memory, he almost has none. He can ask a question, you can answer it, and 30 seconds later he will ask it again.” —Woman assisting father in the United States (2015 15 Year+ Retirees)

“I think she is doing well for her age. But, at that age, they are a little frailer. She is at a greater risk for falls. Seeing and hearing even worse than she was four years ago. But it has been a gradual decline as opposed to something happened.” —Woman assisting mother in Canada (2015 15 Year+ Retirees)

“She completely lost ability to do the simplest things. She actually could no longer feed herself and needed help going to the bathroom. She couldn’t take a shower or bath by herself. It got to be so that it was a full-time job watching her. So that is when we all decided it was time for her to go into an Alzheimer’s unit full time.” —Man assisting wife in the United States (2015 15 Year+ Retirees)

“She’s always talking about [moving to a center], which I probably should have said, she would like somewhere where she could go to have three meals a day and be taken care of. She gets lonely in the house . . . . So when she’s at home she’s pretty much by herself.” —High-asset, elderly female (85+ In-depth Interviews)

“I do have care workers come in twice a week to help me with my shower. I have those. And to help me with making, changing the bed and things like that.” —High-asset, elderly female (85+ In-depth Interviews)

“She is virtually totally dependent other than feeding herself. She is on diapers. Incontinent. Immobile. Depends on the use of the wheelchair.” —Dyad, high-asset, elderly female (85+ In-depth Interviews)

3. Family Discussions about Long-Term Care

Most family members do not discuss long-term care issues in advance of the need for such care. About one in 10 elderly, defined as those 85 years and older, said they have had a great deal of family discussion about their desired lifestyle in retirement and how long their assets will last in retirement (85+ Surveys: Individuals 85+ and Adult Children). A third of the elderly said their family has discussed how long-term care will be provided and paid for. The SOA 2017 Risks Survey echoed these findings. Only one in 10 pre-retirees and one in six retirees said they have discussed with their families how they would pay for a nursing home or home health aide. Among retired widows, the numbers reporting having had such conversations with their families were a little higher, but the percentage was just one in four. The SOA 2017 Risks Survey also suggested that despite having infrequent conversations on this topic, children end up heavily involved in their parents’ long-term care decisions.

QUALITATIVE QUOTES ON FAMILY DISCUSSIONS ABOUT LONG-TERM CARE

“Sometimes we [with daughter] discuss how I am doing financially. That is a concern of both daughters.” —Higher-asset, elderly male (85+ In-depth Interviews)

“Before mother went into the nursing home and before father died, they shared very little about their finances.” —Dyad, low-asset, elderly female (85+ In-depth Interviews)
“It’s private really, isn’t it? I never ask her about her financial situation. I mean, I have like a power of attorney in case she can’t do something, or she was in the hospital for a number of months, so I was able to pay her bills. She just takes care of all of that herself.” —Dyad, higher-asset, elderly female (85+ In-depth Interviews)

“Not that I am aware of. He is terrified about being put into a home. We have had this conversation many times. He wants to stay in his house for as long as possible. We were together this past Sunday and we had this conversation about even a retirement home, but he is terrified about being put into some sort of institution.” —Dyad, higher-asset, elderly male (85+ In-depth Interviews)

4. How Children Share Responsibility

Half of the surveyed adult children of individuals age 85 and older said they do not provide any financial support to an elderly parent; however, three in 10 say they subsidize a parent’s finances at least to some extent, with one in 10 providing a great deal of support.

Those who provide financial support to parents do so for significant periods of time. Nearly half of adult children providing financial support to parents have done so for longer than five years. Among adult children whose elderly parent’s finances are subsidized, nearly all said they help provide that support. A significant portion of adult children who reported helping their parent financially said they did so in combination with one or more of their siblings.

Among adult children with a parent requiring hands-on help, a plurality said the need for support began between three and five years ago, and one-third said the need for help was more recent. Though providing hands-on help is mostly shared among siblings, adult daughters are more likely than adult sons to say they provide hands-on help to their elderly parent.

Siblings generally reported cooperating with one another when providing financial and hands-on support to elderly parents. Nearly half of adult children say they cooperate with their siblings a great deal to provide their parents with support.

QUALITATIVE QUOTES ON HOW CHILDREN SHARE RESPONSIBILITY

“I’m quite involved. I have two sisters, and three of us have power of attorney over all of her affairs. We share the responsibility equally, and no one does anything without consulting the other two.” —Woman assisting mother in Canada (2015 15 year+ Retirees)

“Between me and all my brothers, we would all sit down and take care of it one way or another. Everybody would be there. Their part in finding out the best way to handle it financially . . . . I think it would according to what we think would be best for her.” —Dyad, high-asset, elderly female (85+ In-depth Interviews)

Pre-retirees and retirees are moderately concerned about burdening their children in retirement by having to live with them. When compared to retirees, more retired widows (35%) expressed these concerns than retirees (25%). Unsurprisingly, very few pre-retirees and retirees plan to move in with their families, but a significant minority of pre-retirees and retirees are not sure if they will live with family in retirement. (2017 Risks Survey)
Despite their reluctance to live with family and the concerns they have about becoming a burden, both retirees and pre-retirees indicated that they plan to turn to family members, especially spouses and daughters, before looking to professional aides if they required long-term care. The research in the 85+ studies confirmed that this is what happens. (2017 Risks Survey)

**QUALITATIVE QUOTES ON ACCEPTING CARE FROM CHILDREN**

“So I tell our children what’s going on, but I am totally responsible” — Man assisting wife in the United States (2015 15+ Retirees)

“For my in-laws, I chose not to get involved because it is always complicated when you get into finances. Family structure always makes things difficult.” — Dyad, low-asset, elderly male (85+ In-depth Interviews)

“I’ve never been holding back on anything. They always knew what I had. I would ask them if there was a problem, if I should proceed that way or do something else and they were very helpful.” — High-asset, elderly female (85+ In-depth Interviews)

“It may come to that. My family is fine. She takes me to doctors and treatments when I have to go. And my son pitches in when he can. He does all the marketing you know. I took care of them, but they’re taking better care of me.” — Dyad, low-asset, elderly female (85+ In-depth Interviews)

“No, because if we ever needed any help like that, the kids would. We would turn to the kids. We know we can go to them for just about, you know, both the daughter-in-law and son-in-law, you know, all four of them are really dependable kids.” — High-asset, elderly female (85+ In-depth Interviews)

5. **Differences between Long-Term Care Expectations and Realities**

Both adult children and elderly parents report that having a full-time in-home aide to provide care and moving in with family are their top expectations for meeting future long-term care needs. In reality, long-term care is provided differently. Among elderly whose spouse required long-term care and adult children with a parent who required care, very few said care was provided by a full-time in-home aide (elderly 3%, and adult children 7%) or family (elderly 8%, and adult children 7%). The most common care arrangement cited by adult children (46%) and the elderly (31%) was a 24/7 nursing home. (85+ Surveys: Individuals 85+ and Adult Children)

Although prevalent, nursing home care is not a popular option. Very few people, less than one in 10, said they find nursing homes attractive. However, people are more receptive to an assisted living arrangement and continuing care communities as roughly two in three and three in five, respectively, said these housing types are attractive.

1 Note that only a small minority of people need major long-term care for a longer period, but as indicated in the adult children report, when such care is needed, it is commonly in a nursing home. People who enter nursing homes very often received care at home or in another setting first.
QUALITATIVE QUOTES ON LONG-TERM CARE EXPECTATIONS VERSUS REALITY

“Essentially when it became clear that she needed to go into assisted living, we had her purchase long-term care insurance and she . . . well, we certainly helped to find an appropriate place for her to live. When it was time for her to then move to nursing care, similarly we did a lot of work to identify the best setting for her.” - Man assisting Mother in the United States (2015 15 year+ Retirees)

“It really makes you think about how much all these things can cost. So, it’s really, seeing what is going on with my in-laws, it’s really made me realize that you need a lot of stuff in place and a lot of extra funds to get through a situation like this.” - Woman assisting Father in the United States (2015 15 year+ Retirees)

“You really need to make sure that you’ve got coverage. Whether it’s savings; whether it’s insurance.” - Woman assisting Father in the United States (2015 15 year+ Retirees)

“For example, if I cannot take care of myself and I need to go into, say, assisted living, I don’t think I can afford to go into an assisted living at this point.” - Low-asset, elderly female (85+ In-depth Interviews)

Q: Do you have any plans for if you need nursing care or care? “I don’t expect to go that route.”
Q: But in the future. Not tomorrow, but I’m saying ... “Yeah. When I have to go, I have to go.”
Q: How would you pay for that? “How does that work? You have to pay to go to a nursing home? Doesn’t your insurance take care of that?”
Q: No, it doesn’t. Medicaid might, if you have no assets.
   “I better stay healthy!” - Higher-asset, elderly female (85+ In-depth Interviews)

“I said to myself that I do keep myself healthy, and I am hopeful I won’t have any problem like that. But with three wonderful kids, if anything came up, they would probably help me. That is all I am going to worry about. So I don’t have insurance.” - Higher-asset, elderly male (85+ In-depth Interviews)

“I think it depends on what her status is that she needs because ultimately we want her to stay in the home as long as she can. And if it just means somebody comes a couple times a week, that’s ultimately what we would want.” - Dyad, higher-asset, elderly female (85+ In-depth Interviews)

“[Looking at long-term facilities] I played in those places with the band, and I’m very familiar with them. Not for me. I’d rather stay in my home and read my books.” - Higher-asset, elderly female (85+ In-depth Interviews)

“She just moved to long-term care in January . . . . Right now it’s $12,000 a month. It was like $6,000. So it’s doubled.” - Dyad, higher-asset, elderly female (85+ In-depth Interviews)
Detailed Findings

This section includes results of selected questions from the surveys, as indicated in parenthesis.

THE CAREGIVING EXPERIENCE

Chart 1: Experience as a Caretaker (2017 Risks Survey)

QUESTION: HAVE YOU EVER SPENT TIME CARING FOR SOMEONE?

Survey findings
Roughly half of pre-retirees and retirees said they have spent time caregiving. Caregiving was more common among retired widows, with nearly three in four saying they have been a caregiver. In addition, substantially more women, both retired and pre-retired, reported providing caregiving services than did their male counterparts (pre-retired women 56% versus pre-retired men 35%, and retired women 63% versus retired men 43%).

Discussion
Caregiving is an important part of life for many Americans as they near and enter retirement. Unfortunately, retirement planning often does not anticipate and provide for this service. The SOA surveys do not address issues of time spent on caregiving, the duration of caregiving and the extent of caregiving, but anecdotal evidence indicates these caregiving elements vary greatly.
Chart 2: Currently Spending Time Caregiving (2017 Risks Survey)
QUESTION: ARE YOU CURRENTLY SPENDING ANY TIME CARING FOR SOMEONE? (Asked among those who have ever spent time caregiving)

Survey findings
Only a third of pre-retirees and a quarter of retirees who have ever provided care said they are currently spending time caregiving. Relatively few retired widows were currently providing care.

Discussion
This question, when considered together with the prior question, demonstrates that caregiving often occurs over a limited period. Needs change over time. But retired widows are very likely to have been caregivers before their spouse was deceased.
Chart 3: Likelihood to Provide Care in the Future (2017 Risks Survey)

QUESTION: HOW LIKELY DO YOU THINK IT IS THAT YOU WILL SPEND ANY TIME CAREGIVING AGAIN DURING YOUR RETIREMENT? (Asked among those who are not currently caregiving)

Survey findings
Among pre-retirees who are not currently caregiving, a slim majority of pre-retirees said it is likely that they will spend time caregiving in retirement. Though retirees and retired widows more often reported providing care at some point, when compared to pre-retirees, a smaller percentage of these demographics said it is likely they will provide care again in the future. Interestingly, only about one in nine pre-retirees or retirees said it is very likely they will become caregivers in the future.

Discussion
Although most survey respondents recognize that they may have caregiving responsibilities in the future, they may be underestimating the likelihood and the potential burden.
**Chart 4: Person Currently Receiving Care  (2017 Risks Survey)**

**QUESTION: WHO ARE YOU CURRENTLY PROVIDING CARE FOR? (Asked among current caregivers)**

<table>
<thead>
<tr>
<th>Category</th>
<th>Pre-retirees (n=163)</th>
<th>Retirees (n=125)</th>
<th>Retired Widows (n=37)*</th>
</tr>
</thead>
<tbody>
<tr>
<td>Parent/In-law</td>
<td>30%</td>
<td>45%</td>
<td>71%</td>
</tr>
<tr>
<td>Minor child</td>
<td>10%</td>
<td>2%</td>
<td>5%</td>
</tr>
<tr>
<td>Spouse/partner</td>
<td>5%</td>
<td>5%</td>
<td>0%</td>
</tr>
<tr>
<td>Adult non-relative</td>
<td>10%</td>
<td>24%</td>
<td>0%</td>
</tr>
<tr>
<td>Other adult relative</td>
<td>14%</td>
<td>19%</td>
<td>0%</td>
</tr>
<tr>
<td>Adult child</td>
<td>8%</td>
<td>14%</td>
<td>0%</td>
</tr>
<tr>
<td>Other minor child relative</td>
<td>2%</td>
<td>3%</td>
<td>8%</td>
</tr>
<tr>
<td>Grandparent/In-law</td>
<td>1%</td>
<td>1%</td>
<td>0%</td>
</tr>
</tbody>
</table>

*Caution low base size

**Survey findings**
Most caregivers were caring for a parent or an in-law. However, those for whom they provide care varied by the caregiver’s retirement status. Pre-retirees providing care overwhelmingly reported caring for a parent or an in-law, while caregivers who had retired more often reported caring for their spouse and adult relatives or children.

**Discussion**
The survey focuses primarily on family members, although it does have a category for nonrelatives. More research is needed to understand the options for elder orphans, those without available family members to help. Neighbors are also a source of help, and some people have businesses offering various forms of help to others. Arrangements to secure help can be formal or informal.
QUESTION: TO WHAT EXTENT DO YOU RELY ON THE ASSISTANCE OF OTHERS TO HELP YOU MANAGE YOUR DAILY LIFE?

<table>
<thead>
<tr>
<th>extent of assistance</th>
<th>count</th>
<th>percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>To a great extent</td>
<td>8</td>
<td>8%</td>
</tr>
<tr>
<td>To some extent</td>
<td>20</td>
<td>20%</td>
</tr>
<tr>
<td>To a minor extent</td>
<td>34</td>
<td>34%</td>
</tr>
<tr>
<td>Not at all</td>
<td>37</td>
<td>37%</td>
</tr>
<tr>
<td>Don't know</td>
<td>1</td>
<td>1%</td>
</tr>
</tbody>
</table>

Survey findings
Nearly two-thirds of elderly people rely on the assistance of others to at least a minor extent. Only one in 12 said they rely on others to a great extent.

Discussion
By age 85, a majority of the population (probably more than two-thirds) get at least some assistance with their daily activities. How much help they need, and what types, vary greatly. Some of this age group lives fully or mostly independently while others get a lot of help on a regular basis. The choice of housing influences how much help people need. People remaining in their own homes may need help with yard work, changing lightbulbs, and maybe home maintenance tasks. Those who move into condos or elderly housing have many of these tasks taken care of for all residents. Getting a modest amount of help enables many people to remain independent.
Survey findings
A large majority of elderly have at least one close family member who lives within 50 miles of them. However, one in seven elderly participants is fairly isolated, meaning they do not have a family member who lives nearby.

Discussion
It would be interesting to know how often these families interact compared to families where the distance is more than 50 miles. It would also be interesting to learn to what extent the 85 and older population or a family member moved to be near family or considered the location of family in choosing where to live.
Survey findings
While one-third (32%) of the elderly said they count on their family for a significant amount of support with physical activities, just 24% said they rely on their family at least a little.

Discussion
The survey responses show that although half of the very old do depend on their families for help with physical activities, nearly half said they don’t rely on family for such help at all. At first glance, this may look as if nearly half the families just don’t care. However, the reality is that some people do not need help, some people do not have families, some families live far away from parents, some do not have good relationships with their family members, some family members who live nearby may be physically or mentally disabled or even deceased, and some may have jobs that make physical support impossible (though they may be able to provide financial support). It will take further research to understand what is happening in total.
Chart 8: Help Received with Daily Activities  (85+ Surveys: Individuals 85+ and Adult Children)

QUESTION: [DOES YOUR [ELDERLY REFERENCE] / DO EITHER OF THEM] RECEIVE HELP FROM ANY COMBINATION OF FAMILY, FRIENDS OR PAID HELP TO DO EACH OF THE FOLLOWING:

<table>
<thead>
<tr>
<th>Daily Activities</th>
<th>Family</th>
<th>Friends</th>
<th>Paid help</th>
<th>Don’t know</th>
</tr>
</thead>
<tbody>
<tr>
<td>Transportation to and from places</td>
<td>62%</td>
<td>8%</td>
<td>16%</td>
<td>25%</td>
</tr>
<tr>
<td>Shopping</td>
<td>61%</td>
<td>7%</td>
<td>11%</td>
<td>29%</td>
</tr>
<tr>
<td>Management of medications and medical care</td>
<td>44%</td>
<td>26%</td>
<td>32%</td>
<td></td>
</tr>
<tr>
<td>General upkeep and cleaning of their residence</td>
<td>40%</td>
<td>38%</td>
<td>26%</td>
<td></td>
</tr>
<tr>
<td>Doing laundry</td>
<td>38%</td>
<td>28%</td>
<td>37%</td>
<td></td>
</tr>
<tr>
<td>Preparing meals</td>
<td>37%</td>
<td>32%</td>
<td>35%</td>
<td></td>
</tr>
<tr>
<td>Personal care*</td>
<td>25%</td>
<td>31%</td>
<td>49%</td>
<td></td>
</tr>
</tbody>
</table>

Survey findings
Over three in five adult children say family members said they help their elderly parents with transportation and shopping. Other common daily activities they said they help with include management of medications, general upkeep and cleaning of their residence, doing laundry, and preparing meals.

Discussion
This question is very interesting because it provides insights into some of the most common types of help that the elderly receive and which ones are more prevalent. It also provides insights into the mix of family and paid help. It shows very little help from friends, but this could reflect issues with underreporting. This is interesting data and is in an area where more could be done to enhance understanding.

Interestingly, when compared to elderly data, the adult children research showed that the children reported familial support as more prevalent than do the elderly parents. This is partly due to differences in the health status of the elders reflected in the two surveys. In addition, this may also indicate that adult children assist with activities that the elderly do not define as “help.”

A point to keep in mind: The parents of the adult children surveyed reflected a sample that is more likely to need help than the population at large or the telephone survey.
Chart 9: Financial Support Elderly Receive from Family  
(85+ Surveys: Individuals 85+ and Adult Children)

QUESTION: TO WHAT EXTENT DO YOU RELY ON YOUR FAMILY TO SUPPORT YOU FINANCIALLY TODAY?

Survey findings
A large majority of elderly surveyed age 85 years and older said they do not rely on their family for any financial support. One in seven say they receive at least a little financial support.

Discussion
These results are consistent with research using the Health and Retirement Study; this study found that many more seniors financially help adult children than vice versa. There may be underreporting in the data because elderly respondents may not have answered yes when asked about children driving them places, buying them groceries, etc. These activities require outlay of money, but they may not seem like financial support in the eyes of elders.
Survey findings

Three in 10 adult children said they subsidize their parents’ finances at least to some extent with one in 10 providing a great deal of support. Half of adult children said they do not provide any financial support to their elderly parents. A greater percentage of adult sons than adult daughters said they provide financially for their parents at least to some extent (36% versus 23%).

Discussion

Two groups were surveyed: individuals over age 85 and adult children of individuals over age 85. Half of the adult children reported they were providing at least some financial support, whereas 86% of individuals over age 85 reported that they were not getting any financial support.

As indicated earlier, the health status, living arrangements, and other aspects of the two samples are different, with the survey of children reflecting elders who are in poorer health and who are getting more help. This question, when combined with the somewhat similar question asked of the age 85 and over respondents, serves to illustrate the effect of the differences in the samples in the two surveys.
Survey findings
Compared to the elderly surveyed, a larger share of adult children said their elderly parents rely on financial support from their family. Although a little over half said their parents receive no additional money from family, one in five adult children said their elderly parents rely on at least some financial support.

Discussion
This question, when combined with the somewhat similar question asked of age 85 and over respondents, serves to illustrate the differences between the samples in the two surveys. The question remains, how do the two demographic groups define financial support from family?
Survey findings
Running out of assets, cognitive decline and chronic illness were prevalent reasons why parents said they required financial support from their families. Compared to retirees, a larger percentage of pre-retirees said they provided financial support to their parents because of significant medical expenses, running out of assets, and financial mistakes.

Discussion
Unlike the special surveys of the age 85 and older population, this survey had respondents ages 45 to 80, so parents may have been from a wide range of ages. For this sample, illness or frailty were clearly major reasons that parents needed help. Some needed help because of their financial situation, but illness seems to be a bigger reason.
Survey findings
Very few adult children reported having contributed significantly to paying for their parents’ long-term care. However, sizable minorities of pre-retirees and retirees said they paid for at least a little of their parents’ care, with a larger percentage of pre-retirees doing so than retirees.

Discussion
These findings track with the financial pressures that the three generations are known to experience. The parents must find a way to pay for care they need, while the retirees who pay for a little of their parent’s care are grappling with how to balance these contributions with their own expenses and possibly those of their own children.

The pre-retirees who contribute a little more still have income from work and so more of them may be better able to contribute—and still cover other expenses and savings goals—than retirees. The pre-retirees may be anticipating that they will be able to continue working to compensate for the parental care expenses. Some may anticipate receiving a bequest later on when the elder dies. Whatever the situation, each generation in the family may feel financial pressure when an elder parent needs long-term care.
Survey findings
Pre-retirees and retirees see the burden of providing care as more emotional than physical or financial. Over one-third of pre-retirees and one in four retirees and retired widows said being a care provider is a catastrophic or major emotional burden. Roughly one in 10 pre-retirees and one in seven retirees said they consider caregiving a catastrophic or major financial burden.

Discussion
Caregiving is a major commitment on the part of caregivers and can interfere with their working and complicate other family commitments. Caregiving can go on for a very long time. Comparing the percentage of people who said that caregiving was a financial burden to the percentage of costs they said they paid in the previous question, it is clear that even paying for a little of the cost can be a burden. This is an area that deserves further exploration.
Chart 15: Level of Financial Concern Based on Parents’ Experiences  
(SOA 2017 Risks Survey)

QUESTION: ON THE WHOLE, DO YOU THINK YOUR PARENTS’ EXPERIENCES HAVE MADE YOU MORE OR LESS CONCERNED ABOUT - YOUR FINANCIAL SECURITY IN RETIREMENT? (Asked among those whose parents lived to retirement)

Survey findings
The retirement experiences of parents clearly influence their children’s views, especially among children whose parents required long-term care. Overall, more than half of pre-retirees (56%) and four in 10 retirees (43%) stated that their parents’ experiences in retirement have made them more concerned about their own financial security in retirement.

Moreover, among those whose parents required long-term care, 67% of pre-retirees and 46% of retirees said their parents’ experience made them more concerned about their own financial security. This was a far higher level of concern than among children whose parents did not require care (41% pre-retirees and 32% retirees).

Discussion
The research overall shows that many people are not planning for long-term care costs. Even when they believe that long-term care is likely, they tend to underestimate its financial impact and often do not provide for meeting these costs. It may be possible to increase planning for long-term care costs with more education about the costs, options and likelihood of long-term care.
**PARENTS’ CAREGIVING EXPERIENCES**

**Chart 16: Parents’ Experiences Needing Care** *(SOA 2017 Risks Survey)*

**QUESTION:** TO THE BEST OF YOUR KNOWLEDGE, DID EITHER OF YOUR PARENTS EXPERIENCE ANY OF THE FOLLOWING DURING RETIREMENT? *(Asked among those whose parents lived to retirement)*

<table>
<thead>
<tr>
<th>Experience</th>
<th>Pre-retirees (n=896)</th>
<th>Retirees (n=757)</th>
<th>Retired Widows (n=298)</th>
</tr>
</thead>
<tbody>
<tr>
<td>An illness or disability that limited their ability to care for themselves</td>
<td>36%</td>
<td>43%</td>
<td>52%</td>
</tr>
<tr>
<td>The need for family or friends to provide care or support because they were unable to care for themselves</td>
<td>32%</td>
<td>48%</td>
<td>61%</td>
</tr>
<tr>
<td>The need for professional care or support because they were unable to care for themselves</td>
<td>21%</td>
<td>32%</td>
<td>74%</td>
</tr>
<tr>
<td>Loss of capacity requiring someone outside the household to manage their finances</td>
<td>32%</td>
<td>55%</td>
<td>67%</td>
</tr>
</tbody>
</table>

**Survey findings**

A majority of pre-retirees and retirees reported that their parents experienced an illness or disability that limited their self-care abilities. Furthermore, many retirees said their parents needed not only care from family and friends, but also from professionals. More retirees than pre-retirees noted that their parents required care from family or friends, professionals, or from someone outside the household who could manage the finances.

**Discussion**

The retiree’s pronounced recognition of their parents’ need for care support likely reflects the fact that the parents of retirees are older than parents of pre-retirees and have already reached the later life phase when illness and disability is more commonplace. It is important to think about how these findings can be better reflected in retirement planning.
**Chart 17: Reasons Parents Required Care (SOA 2017 Risks Survey)**

**QUESTION:** WHAT TRIGGERED YOUR PARENT’S NEED FOR CARE OR SUPPORT? SELECT ALL THAT APPLY. (Asked among those whose parents required care in retirement)

<table>
<thead>
<tr>
<th>Reason</th>
<th>Pre-retirees (n=519)</th>
<th>Retirees (n=575)</th>
<th>Retired Widows (n=238)</th>
</tr>
</thead>
<tbody>
<tr>
<td>A chronic or debilitating illness</td>
<td>49%</td>
<td>48%</td>
<td>42%</td>
</tr>
<tr>
<td>General physical frailty</td>
<td>39%</td>
<td>32%</td>
<td>34%</td>
</tr>
<tr>
<td>Cognitive decline, Alzheimer’s, dementia or other mental confusion</td>
<td>12%</td>
<td>14%</td>
<td>15%</td>
</tr>
<tr>
<td>Loneliness depression or other emotional/mental health issue</td>
<td>11%</td>
<td>9%</td>
<td>11%</td>
</tr>
<tr>
<td>Something else</td>
<td>8%</td>
<td>7%</td>
<td>7%</td>
</tr>
</tbody>
</table>

**Survey findings**

Roughly half of pre-retirees and retirees said their parents required care because of a chronic or debilitating illness. Other prevalent reasons for needing care included physical frailty and cognitive decline.

**Discussion**

The top triggers for care seem to be very similar among parents of both pre-retirees and retirees. This could be useful information for anyone working with adult children of aging parents, so the children can better see the trends. In addition, knowing what triggered other people to enter care arrangements may help adult children of pre-retirees understand what may lay ahead for their own parents—and what might need to be done now, before care is needed.
Chart 18: Elderly Daily Activities that Require Assistance (85+ Surveys: Individuals 85+ and Adult Children)

QUESTION: DO YOU CURRENTLY REQUIRE ANY OF THE FOLLOWING?

- The need to be driven places: 49%
- Support with taking care of your residence: 35%
- Assistance with shopping: 34%
- Support with daily or weekly household activities such as cooking or laundry: 23%
- Daily living such as getting in and out of bed, getting dressed, toileting, bathing or feeding*: 8%
- None: 36%

*Response text has been abridged

Survey findings
Nearly two-thirds of the elderly reported that they needed help with at least one important activity, but far fewer needed help with an “activity of daily living.” About half said they need to be driven places, and one-third said they need assistance with maintaining their residence and shopping.

On a current basis, fewer than one in 10 elderly said they require assistance with getting in and out of bed, getting dressed, toileting, bathing or feeding.

Discussion
It is interesting to note that by age 85, many people who can still answer telephone surveys and still get around do need help with certain aspects of living. People move from needing help with one or two tasks to needing help with more and more tasks.
**Chart 19: Support Parents Needed in Retirement**  
*(SOA 2017 Risks Survey)*

**QUESTION:** WHAT TYPE OF SUPPORT DID YOUR PARENT(S) NEED? PLEASE SELECT ALL THAT APPLY. *(Asked among those whose parents required care in retirement)*

<table>
<thead>
<tr>
<th>Type of Support</th>
<th>Pre-retirees (n=519)</th>
<th>Retirees (n=575)</th>
<th>Retired Widows (n=238)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Household chores, such as cleaning or doing laundry</td>
<td>65%</td>
<td>68%</td>
<td>76%</td>
</tr>
<tr>
<td>Help with activities of daily living (i.e. getting out of bed, toileting and bathing)</td>
<td>56%</td>
<td>52%</td>
<td>61%</td>
</tr>
<tr>
<td>Transportation</td>
<td>55%</td>
<td>67%</td>
<td>71%</td>
</tr>
<tr>
<td>Coordinating medical care</td>
<td>53%</td>
<td>53%</td>
<td>63%</td>
</tr>
<tr>
<td>Medical/nursing care (i.e. tube feedings, wound care, administering medicine)</td>
<td>53%</td>
<td>48%</td>
<td>46%</td>
</tr>
<tr>
<td>Managing finances</td>
<td>38%</td>
<td>44%</td>
<td>45%</td>
</tr>
</tbody>
</table>

Survey findings

Adult children said that when their parents required support or assistance in retirement the most common types of support desired were help with household chores, daily activities and transportation. More retirees than pre-retirees had a parent that required help with transportation, a not surprising finding given the older age of retirees’ parents. Interestingly, compared to the elderly surveyed in the SOA’s 2018 85+ Study, pre-retirees and retirees in the SOA 2017 Risks Survey reported higher instances of elderly parents needing assistance with household chores and daily living activities.

Discussion

The parents of the survey respondents overall are younger than the age 85 and over population studied, and they should reflect the spread of the total population with regard to health status. This demographic will include some people who are in nursing homes and assisted living, however.

The responses seen here also reflect the types of things about which children are aware with regard to their parents support needs.
FAMILY DISCUSSIONS ABOUT LONG-TERM CARE

Chart 20: Extent of Thought and Discussion about Lifestyle and Longevity Risk (85+ Surveys: Individuals 85+ and Adult Children)

QUESTION: HOW MUCH THOUGHT OR FAMILY DISCUSSION HAVE YOU HAD ABOUT EACH OF THE FOLLOWING?

<table>
<thead>
<tr>
<th>Topic</th>
<th>Elderly (n=201)</th>
<th>Elderly with at least $25k in assets (n=77)</th>
</tr>
</thead>
<tbody>
<tr>
<td>How long your assets will last in retirement</td>
<td>13%</td>
<td>18%</td>
</tr>
<tr>
<td>The type of lifestyle you want for the rest of your life</td>
<td>11%</td>
<td>22%</td>
</tr>
</tbody>
</table>

Survey findings
About half of the elderly said they have discussed with their family, at least a little, their desired lifestyle and how long they think their assets will last in retirement. However, only one in 10 reported discussing these topics a great deal. Furthermore, significant proportions admitted that they have given these topics no thought or discussion.

Discussion
It appears that children start helping parents when they need help but with little preparation. And help often starts with minor needs and grows over time as the parent needs more and different types of help. More discussion of retirement planning would be desirable, but many seniors may resist such conversations. The family needs the right relationships for this to work.
Survey findings
Only one-third of the elderly said their family has discussed how long-term care will be provided and paid for. Roughly half indicated they have not had this discussion and do not intend to have it. More elderly participants with monthly incomes in excess of $2,000 said they have discussed this with family than did those with monthly incomes of less than $2,000 (57% vs. 41%).

Discussion
The fact that half of the elderly haven’t discussed their plans for obtaining and paying for long-term care, and don’t plan to, suggests that this may be a touchy subject for some elderly people. Of course, some do not do much longer-term planning and may not have a plan. But since 34% reported having had such a discussion, and 11% said they plan to, that makes for 46% who are, or plan to be, proactive on the subject.

It may be that this subject is touchy for some in the more proactive group as well, but it is worth reflecting on the fact that these elderly people are moving forward on the discussion all the same.

It may be that those with greater financial means find more reason to broach the topic, or that they have been in contact with care professionals who have suggested such conversations. Perhaps the proactive group has seen the value of such conversations in other family matters or seen the impact on friends and others who did, and did not, have such discussions.
**Chart 22: Discussions about Long-Term Care** (85+ Surveys: Individuals 85+ and Adult Children)

**QUESTION:** [HAS/HAVE] YOUR [ELDERLY REFERENCE] DONE, OR PLAN TO DO, ANY OF THE FOLLOWING TO HELP PREPARE FOR THE COST OF NURSING HOME CARE OR HAVING A HOME AIDE? - HAVE A FAMILY DISCUSSION ABOUT HOW LONG-TERM CARE WILL BE PROVIDED AND PAID FOR.

<table>
<thead>
<tr>
<th>Already done</th>
<th>Intend to do</th>
<th>Haven’t done, don’t intend to do</th>
</tr>
</thead>
<tbody>
<tr>
<td>42%</td>
<td>16%</td>
<td>42%</td>
</tr>
</tbody>
</table>

**Survey findings**

More than two in five adult children of elderly parents say they have not had a conversation with their parent about how long-term care will be provided and paid for and they do not intend to have one. An additional two in five adult children have already had a discussion with their parent on the topic and one in six intend to do so.

**Discussion**

This is another question that points out the differences in the samples between the age 85 and older adults surveyed and the survey of adult children.
Chart 23: Involvement in Parents’ Long-Term Care Decisions  *(SOA 2017 Risks Survey)*

How involved were you in the decision about how and where your parent(s) would receive the care or support they needed? (Asked among those whose parents required care in retirement)

<table>
<thead>
<tr>
<th>Group</th>
<th>Very involved</th>
<th>Somewhat involved</th>
<th>Not too involved</th>
<th>Not at all involved</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pre-retirees</td>
<td>73%</td>
<td>18%</td>
<td>9%</td>
<td>9%</td>
</tr>
<tr>
<td>Retirees</td>
<td>67%</td>
<td>30%</td>
<td>19%</td>
<td>14%</td>
</tr>
<tr>
<td>Retired Widows</td>
<td>69%</td>
<td>24%</td>
<td>18%</td>
<td>13%</td>
</tr>
</tbody>
</table>

Survey findings

Active involvement in making long-term care decisions for parents is common. Over two-thirds of pre-retirees and retirees were at least somewhat involved in their parents’ care decisions, with roughly two in five saying they were very involved.

Discussion

This question provides insight into the difference between what happens when the time comes for a decision and what is planned for. It further demonstrates the gap in planning for future long-term care. It also shows that despite the failure to involve the family early, the family often becomes heavily involved in helping their elders when needed.
Chart 24: Discussions about Long-Term Care (SOA 2017 Risks Survey)

QUESTION: HAVE YOU DONE OR DO YOU PLAN TO PREPARE FOR THE COSTS OF NURSING HOME CARE OR HAVING A HOME AIDE IN THE FOLLOWING WAY? - DISCUSSED HOW YOU WILL PAY FOR LONG-TERM CARE WITH YOUR FAMILY.

Survey findings
Few pre-retirees and retirees said they had discussed the realities of paying for long-term care with their families. Only one in 10 pre-retirees and one in six retirees said they had already discussed the topic with family members.
HOW CHILDREN SHARE RESPONSIBILITY

Chart 25: Length of time Elderly Parents’ Finances Have Been Subsidized (85+ Surveys: Individuals 85+ and Adult Children)

QUESTION: FOR HOW LONG HAVE YOU [OR YOUR SIBLINGS] BEEN DOING THAT? (Asked among those whose parents’ finances are subsidized)

Survey findings
Close to half of adult children providing financial support to their parents said they have done so for longer than five years. Additionally, about one in five have been subsidizing their parents’ finances for longer than 10 years. When looked at by income, 56% of adult children of parents whose monthly income was less than $2,000 reported having provided their parents with financial support for longer than five years. By comparison, just 30% of adult children of parents with monthly income in excess of $2,000 per month said the same.

Discussion
It would be helpful to learn more about the circumstances under which children are subsidizing parents.
Survey findings
A plurality of adult children who subsidize their parents’ finances do so in combination with one or more of their siblings. Only one in eight of adult children surveyed in families where children are subsidizing parents’ finances are not involved in providing financial support to their parents.
Chart 27: Siblings Providing Financial Support (85+ Surveys: Individuals 85+ and Adult Children)

QUESTION: ARE THE SIBLINGS THAT PROVIDE FINANCIAL HELP YOUR...? (Asked among those with siblings who subsidize their parents’ finances)

Survey findings
Regardless of gender, when siblings provide support, in a plurality of cases, both brothers/stepbrothers and sisters/stepsisters step in.

Discussion
This may be something that families would like to know. Such information is not always easy to obtain by talking with friends, but it could help guide the adult children as they decide how to proceed if they are financially able to contribute. Of interest is that the question included not only siblings but also stepsiblings.
Survey findings
Among adult children who subsidize their parents’ finances, half say they provide the most financial support to their parents, while one in three say their sibling provides the most.

Discussion
This divergence in financial support to an ailing parent is not surprising, especially when the personal assets of the children differ, sometimes substantially, when some children have very different family situations and needs, when some children have different perspectives on their obligation to parents, and when some siblings are located elsewhere, involved in military service or otherwise unable to participate in a meaningful way. It is here where long-term care planning, financial planning and estate planning intersect. Families are challenged when they need to work things out to fit everyone’s needs.
**Survey findings**

A plurality of adult children whose elderly parents require hands-on help said the need for help began between three and five years ago. Over one-third said the need for help is fairly recent, within the past one to two years.

**Discussion**

It appears that an elder’s need for support does not arrive abruptly in many cases, but neither does it take decades, typically not even one decade. This suggests that many older persons and their families do have time to plan, but often not a lot of time. This is helpful to know, for all concerned.
Chart 30: Family Members Providing Hands-on Help (85+ Surveys: Individuals 85+ and Adult Children)

**QUESTION:** WHO PROVIDES THE HANDS-ON HELP (YOUR [ELDERLY REFERENCE] RECEIVES / ONE OR BOTH RECEIVE)? (Asked among those whose parents receive hands-on help from family)

<table>
<thead>
<tr>
<th>Family Member</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>You</td>
<td>55%</td>
</tr>
<tr>
<td>One or more of your siblings</td>
<td>49%</td>
</tr>
<tr>
<td>Your spouse/partner</td>
<td>28%</td>
</tr>
<tr>
<td>Grandchildren</td>
<td>18%</td>
</tr>
<tr>
<td>Your siblings’ spouse/partner</td>
<td>11%</td>
</tr>
<tr>
<td>Other relatives</td>
<td>13%</td>
</tr>
</tbody>
</table>

**Survey findings**
Providing hands-on help is mostly shared among siblings. To a lesser extent, the responsibility of caregiving is shared among spouses, grandchildren and other relatives. More adult daughters said they provide hands-on help to their elderly parent than do adult sons (67% vs. 42%).

**Discussion**
This is another illustration of women being more involved in caregiving than men and is consistent with some other studies. The National Caregiving Alliance also shows that women represent a larger percentage of caregivers than men, and women also spend more time providing care than do men.
Survey findings
Over one-third of adult children whose parents receive hands-on help from family said they are the primary caregiver to their elderly parent. The data showed that more women provide hands-on care than men. According to adult children, more sisters or stepsisters provide care to their elderly parents when compared to brothers and stepbrothers. Furthermore, more adult daughters reported that they were a primary caregiver to their elders than did adult sons (50% versus 23%).

Discussion
This provides additional confirmation of the preceding findings showing women (adult daughters) taking on caregiving roles more frequently than men (adult sons).
**Survey findings**

Cooperation among siblings to provide financial and hands-on support for elderly parents is common. Three in four adult children said they cooperate with their siblings at least somewhat, with nearly half saying they cooperate a great deal.

**Discussion**

Parents, especially elderly parents, should be gratified to learn that 75% of adult children report cooperating with their siblings when it comes to providing either financial or hands-on help to their elderly parents.
ACCEPTING CARE FROM CHILDREN

Chart 33: Concern about Burdening Children by Having to Live with Them in Retirement (SOA 2017 Risks Survey)

QUESTION: HOW CONCERNED ARE YOU ABOUT EACH OF THE FOLLOWING (IN RETIREMENT)? - BURDENING YOUR CHILDREN BY HAVING TO LIVE WITH THEM. (Asked among homeowners)

Survey findings
Pre-retirees and retirees voiced moderate concern about needing to live with their adult children during retirement and about burdening their children in the process. This concern was more pronounced among retired widows than among all retirees, with more than one-third of the widows saying they are at least somewhat concerned compared to about one-fourth of all retirees.

Discussion
As indicated, many people do not want to burden their children and are concerned about doing so by living with them. But when elderly parents need help, many children who are available do tend to offer help. This report provides a variety of different insights about receiving—and giving—such help.
Survey findings
Although the data revealed a moderate level of concern among parents about having to move in with their adult children, very few pre-retirees and retirees currently plan to move in with family during retirement. A notable amount of uncertainty does exist. Nearly one in five retired widows and pre-retirees and one in six retirees are unsure if they would have to live with family in retirement.

Discussion
Most people want to remain independent. The age 85 and over research found that by the time people reach that age, most need some sort of help, and some ultimately do move in with family. Others look for alternatives such as condos and senior living communities, in-home care, adult day care and several forms of skilled and nursing home care.
Chart 35: Likely Primary Caregiver (SOA 2017 Risks Survey)

QUESTION: WHO IS OR WOULD BE YOUR PRIMARY CAREGIVER IF YOU NEED LONG-TERM CARE SUPPORT? (Asked among those needing and likely to need long-term care)

(Top responses shown)

- **Spouse/partner**: 41% (Pre-retirees: 33%, Retirees: 11%, Retired Widows: <0.5%)
- **Daughter or daughter-in-law**: 13% (Pre-retirees: 30%, Retirees: 11%, Retired Widows: 9%)
- **Professional aides**: 7% (Pre-retirees: 12%, Retirees: 7%, Retired Widows: 6%)
- **Care provided in a long-term care facility**: 8% (Pre-retirees: 14%, Retirees: 20%, Retired Widows: 7%)
- **Son or son-in-law**: 6% (Pre-retirees: 15%, Retirees: 7%, Retired Widows: 7%)
- **Not sure**: 18% (Pre-retirees: 22%, Retirees: 19%, Retired Widows: 15%)

**Survey findings**

In the event long-term care support is needed, two in five pre-retirees and one in three retirees said they would turn to their spouse for care. Retired widows, more so than pre-retirees and retirees, said they plan to rely on their children or a facility for care. Meanwhile, a significant amount of uncertainty existed regarding planning for a long-term care provider, and about one in five pre-retirees and retirees were not sure who they would rely on for support.

**Discussion**

When looked at together, all the SOA research on caregiving suggests that family is the first source of support. Family is more likely to provide support with tasks such as transportation, shopping and household help than to provide hands-on care for those needing help with activities of daily living. 2 As people need an increasing amount of help, paid caregivers will likely become more involved, or assisted living or a nursing home care may be needed.

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2 Activities of Daily Living (ADLs) include basic requirements for daily life such as bathing, getting in and out of bed, using the toilet, etc. Insurance companies and government programs use ADL assessments to determine eligibility for benefits, but exact designations and definitions vary.
Chart 36: Comfort Accepting Help from Non-biological Children (85+ Surveys: Individuals 85+ and Adult Children)

QUESTION: WOULD YOU BE LESS COMFORTABLE SEEKING HELP, EITHER FINANCIAL OR OTHERWISE, FROM ADULT CHILDREN WITH WHOM YOU ARE NOT BIOLOGICALLY RELATED? (Asked among those in a blended family)

<table>
<thead>
<tr>
<th>Total Definitely/Probably less comfortable: 52%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Definitely yes: 30%</td>
</tr>
<tr>
<td>Probably yes: 22%</td>
</tr>
<tr>
<td>Probably no: 15%</td>
</tr>
<tr>
<td>Definitely no: 30%</td>
</tr>
<tr>
<td>Don’t know: 4%</td>
</tr>
</tbody>
</table>

Elderly (n=27*)

*Caution: small base size

Survey findings

Over half of the elderly from blended families say they would be less comfortable seeking support from adult children with whom they are not biologically related. Three in 10 say they would not be less comfortable.

Discussion

The SOA research has clearly documented the importance of help from family, particularly at the high ages. More and more families are blended families. However, it is unclear to what extent blended family members will respond in the same way as children from first marriages. Some questions to be considered include: Is there a difference in the way blended families will respond to a call for help from parents? Will the stepchild respond to a need for help from a surviving spouse once their natural parent is deceased or if their natural parent is divorced from the spouse? More research is needed to understand the issues of blended families.
### Differences Between Long-Term Care Plans and Realities

#### Chart 37: Attractiveness of Long-Term Care Facilities (SOA 2017 Risks Survey)

**Question:** If you needed assistance and it met your care needs, how attractive would the following types of senior communities and long-term care facilities be to you?

<table>
<thead>
<tr>
<th>Housing Type</th>
<th>Pre-retirees (n=1,030)</th>
<th>Retirees (n=1,025)</th>
<th>Retired Widows (n=421)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Independent living</td>
<td>Very attractive</td>
<td>53%</td>
<td>52%</td>
</tr>
<tr>
<td></td>
<td>Somewhat attractive</td>
<td>37%</td>
<td>37%</td>
</tr>
<tr>
<td>Assisted living</td>
<td>Very attractive</td>
<td>15%</td>
<td>15%</td>
</tr>
<tr>
<td></td>
<td>Somewhat attractive</td>
<td>67%</td>
<td>63%</td>
</tr>
<tr>
<td>Continuing care communities (which provide an increasing amount of care depending on needs all in the same location/facility)</td>
<td>Very attractive</td>
<td>14%</td>
<td>16%</td>
</tr>
<tr>
<td></td>
<td>Somewhat attractive</td>
<td>60%</td>
<td>58%</td>
</tr>
<tr>
<td>Nursing home</td>
<td>Very attractive</td>
<td>7%</td>
<td>8%</td>
</tr>
<tr>
<td></td>
<td>Somewhat attractive</td>
<td>10%</td>
<td>10%</td>
</tr>
</tbody>
</table>

**Survey findings**

Not surprisingly, independent living was much more attractive than the other housing types, especially nursing homes. Half of pre-retirees and retirees said they believe independent living is very attractive, but only about one in six found assisted living very attractive and similar proportions feel that way about continuing care retirement communities (CCRCs). However, roughly six in 10 pre-retirees and retirees said that assisted living and CCRCs are at least somewhat attractive. Very few said nursing homes were attractive.

**Discussion**

Most people want to remain independent. They often do not think very much about how they will manage if they need help. Nursing homes are a last resort for almost everyone, and people who go to nursing homes usually have exhausted their other options.

Assisted living and CCRCs offer alternatives to independent living for people needing varied degrees of help. They tend to be costly. They may be preferable to having help at home for many people, depending on the situation. These facilities offer a combination of housing, limited transportation to special events and shopping, meals and social engagement. They generally offer activities on the premises. For people who prefer social engagement and are limited in their ability to get around, they can be a preferable choice.
Chart 38: Expectations of Long-Term Care (85+ Surveys: Individuals 85+ and Adult Children)
QUESTION: IF YOU (OR YOUR SPOUSE/PARTNER) WERE TO REQUIRE CARE FOR THE ACTIVITIES OF DAILY LIVING, WHICH OF THE FOLLOWING WOULD YOU BE MOST LIKELY TO DO? (Activities of daily living (ADLs) can include getting in and out of bed, getting dressed, toileting, bathing, or eating.) (Asked among those who do not currently require care)

<table>
<thead>
<tr>
<th>Option</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Have an aide and/or support in your home</td>
<td>25%</td>
</tr>
<tr>
<td>Move to a nursing home</td>
<td>14%</td>
</tr>
<tr>
<td>Move in with family</td>
<td>14%</td>
</tr>
<tr>
<td>Have a family member move in with you</td>
<td>13%</td>
</tr>
<tr>
<td>Move in with family and have a home aide come in to that home</td>
<td>3%</td>
</tr>
<tr>
<td>Would stay in house, not sure of arrangement</td>
<td>3%</td>
</tr>
<tr>
<td>Move to assisted living</td>
<td>3%</td>
</tr>
<tr>
<td>Move in with family and have a home aide come in to that home</td>
<td>3%</td>
</tr>
<tr>
<td>Don't know/Refused</td>
<td>26%</td>
</tr>
</tbody>
</table>

Survey Findings
A little over one in four elderly said that if they required care they would either move in with family or have family move in with them. An additional one in four said that if they required care, an aide would provide support to them in their home. Only one in seven said they plan to move to a nursing home.

Discussion
The responses to this question indicate preferences without exploring the detailed situation. The choices in each individual situation depend on details. For example, someone with limited mobility, but who can get in and out of bed and use a walker within the house, is in an entirely different situation from someone who is wheelchair-bound and must be lifted to get in and out of the wheelchair and bed. In between is someone who is mostly in a wheelchair but who can get in and out of bed and a chair with help. Major differences in cognitive function, hearing and vision also exist and need to be factored into the decision of where to live when a person needs care.
**Chart 39: How Long-Term Care was Provided to Spouse** (85+ Surveys: Individuals 85+ and Adult Children)

**QUESTION:** HOW IS/WAS THE CARE PRIMARILY PROVIDED TO YOUR SPOUSE? (Asked among those whose spouse requires/required long-term care)

<table>
<thead>
<tr>
<th>Care Arrangement</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>24/7 care in a nursing home</td>
<td>31%</td>
</tr>
<tr>
<td>You provide the care</td>
<td>30%</td>
</tr>
<tr>
<td>Part-time aides come to the home</td>
<td>26%</td>
</tr>
<tr>
<td>Family or friends provide the care</td>
<td>8%</td>
</tr>
<tr>
<td>Full-time aides come to the home</td>
<td>3%</td>
</tr>
<tr>
<td>Don’t know/Refused</td>
<td>2%</td>
</tr>
</tbody>
</table>

**Survey findings**

Although having a full-time aide come to the home is the care arrangement the elderly commonly anticipate turning to if they require care, very few said their spouse received care this way. One in three said their spouse received care at a nursing home. An additional three in 10 said they provided their spouse’s care.

**Discussion**

This question provides further indication of the complexities involved in situations where individuals need major care. When care at home requires an aide to come into the home, for example, a variety of challenges arise. It may be difficult to find a suitable person to provide care, and this type of care is likely to be more costly than anticipated. In addition, the person needing care may not like the caregiver. Sometimes the ailing person will fire the caregiver, leaving a troublesome situation behind.

Reliability is a further challenge. If the caregiver is unavailable on a given day, for example, this may create a very difficult situation. The person needing care may be left with no help for a long period, and the emergency contact may need to leave work or other activities to make time to find a solution. If a home care agency is in the picture, the agency may step in and provide a substitute as part of its service, but sometimes they are unable to find a suitable person on short notice.
Chart 40: Adult Child’s Expectation of Parents’ Future Care (85+ Surveys: Individuals 85+ and Adult Children)

**QUESTION:** IF YOUR [ELDERLY REFERENCE] WERE TO REQUIRE CARE FOR THE ACTIVITIES OF DAILY LIVING, WHICH OF THE FOLLOWING WOULD THEY BE MOST LIKELY TO DO? (Asked among those whose parent is not currently receiving care)

<table>
<thead>
<tr>
<th>Option</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Have an aide and/or support in your home</td>
<td>33%</td>
</tr>
<tr>
<td>Move to a nursing home</td>
<td>26%</td>
</tr>
<tr>
<td>Move in with family</td>
<td>17%</td>
</tr>
<tr>
<td>Have a family member move in with them</td>
<td>13%</td>
</tr>
<tr>
<td>Move in with family and have a home aide come in to that home</td>
<td>6%</td>
</tr>
<tr>
<td>Other</td>
<td>4%</td>
</tr>
</tbody>
</table>

**Survey findings**
The elderly and adult children have similar expectations for future long-term care. Having an aide come to the home was the top expected care arrangement among adult children. Roughly an additional one in three said they expect care for their parent to be provided by a family member, and one in four said they expect their parent to move to a nursing home.

**Discussion**
As the two questions preceding this one indicate, expectations and realities do not always match. The elderly and their adult children may want in-home care and they may expect it to happen, but they may run into roadblocks, making in-home care impractical. How people adjust their expectations to meet everyday realities is part of the hard work of establishing and implementing an effective long-term care plan. In many cases, those plans would benefit from a plan B for just such situations.
Chart 41: Current Care Arrangement for Elderly Parents (85+ Surveys: Individuals 85+ and Adult Children)

**QUESTION:** HOW IS THE CARE PRIMARILY PROVIDED TO YOUR [ELDERLY REFERENCE REQUIRING CARE]? (Asked among those whose parent currently requires care)

<table>
<thead>
<tr>
<th>Care Arrangement</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>24/7 care in a nursing home</td>
<td>46%</td>
</tr>
<tr>
<td>24/7 care in an assisted living facility</td>
<td>28%</td>
</tr>
<tr>
<td>Part-time aides come to the home</td>
<td>11%</td>
</tr>
<tr>
<td>Family or friends provide the care</td>
<td>7%</td>
</tr>
<tr>
<td>Full-time aides come to the home</td>
<td>7%</td>
</tr>
</tbody>
</table>

Survey findings

Nearly half of adult children whose parents required long-term care said their parent’s care was provided by a nursing home. Although many adult children expect their parent’s care to be provided by in-home aides or family, far fewer said this was the current care arrangement.

Discussion

Fifty-four of the 202 adult children responding to the survey had parents currently needing long-term care. For this group, care was most often provided in a nursing home or assisting living, as shown in the chart. It is worth noting that many more than 54 of the 202 respondents had parents who needed assistance, but often they did not need long-term care. They may have needed assistance with transportation, shopping, household chores and so on. In these situations, the children were much more likely to be providing the care. The chart covers only those getting long-term care, and not those getting other types of help.
Conclusion

The SOA has conducted many research studies on post-retirement risks, which focused on the topic from the perspective of the individual. Long-term care also emerges as an important risk, and usually as one that is not well planned for. But the discussion frequently stops with financing, rather than focusing on the facts that there are big impacts for helpers and caregivers, many issues surrounding the provision of care, and issues surrounding the relationship between those who need help and those who get help. Long-term care has been a topic of emphasis in several SOA studies, and more recently where long-term care is considered, the issues surrounding caregiving are also considered. As the research teams have learned more, they have expanded their focus on how caregiving and support needs impact both the long-term care recipients and those who help and support the recipients. This SOA report is a summary of several studies of what the public says about this issue. The groups studied include retirees up to age 80, those nearing retirement, individuals ages 85 and over, adult children supporting groups ages 85 and over, and individuals providing support to people retired at least 15 years.

The studies provide a compelling examination of how pre-retirees, retirees, elders and their families, friends and caring others deal with their respective care needs and how they arrange for help.

The research makes clear that not only do many people experience the need for care as they age in retirement but that the affected families and close others need to learn where and how to provide such care or arrange for it. One way or another, those involved in caregiving and support pay a cost, in money, time and emotion. Furthermore, the cost increases when the amount and types of care increase.

The research shows that, currently, only a small percentage of surveyed respondents have talked about caregiving and care support with their families. Neither have many established plans for “what happens if.” Some of this silence may reflect the obvious—that people are busy living their lives now and have no idea of what care needs will be in the future or who, or what, will be around to help with that care. Some may not even know what long-term care planning is, or how to start the process if they do know. Some of it may reflect the fact that some retirees prefer to deal with risks when they happen, rather than planning in advance.

But a few people are planning and maybe this research will encourage more to do so. In this study about 10 percent of pre-retirees and nearly 17 percent of retirees said they already have had family discussions about how they would pay for a nursing home or home health aide. That’s a good place to start. More research and education about long-term care realities may help expand awareness and trigger more people to have more talks about care planning. Such planning may not alleviate all the stress associated with caregiving and support but at least it can help provide a track to run on, injecting more certainty about “what happens if.”
Appendix

ADDITIONAL INFORMATION AND RESOURCES FROM THE SOCIETY OF ACTUARIES

Managing the Impact of Long-Term Care Needs and Expense on Retirement Security—2014.
- This SOA “call for papers” includes a variety of papers on long-term care and caregiving and their relationship to retirement.

- This is the full report of the 2017 Risks and Process of Retirement Survey. It includes more detail about questions raised in this caregiving report, including breakouts by gender and age.

- This SOA research report summarizes 62 interviews of individuals 85 years and older. The study seeks to understand how the habits and behaviors from earlier in life played out in the later years of retirement.

- This is a follow-up report to the preceding research on people who are very old.

Post-Retirement Experiences of Individuals Retired for 15 Years or More—January 2016.
- This SOA study seeks to understand how middle-income market retired Americans and Canadians manage their assets and spending decisions over the long term.

- This SOA report examines the decision process people go through when retiring and includes views on managing assets after retirement. The respondents are those who were not forced to retire due to ill health or disability.

- Based on studies and additional research, this paper seeks to clarify the financial situations and experiences of older Americans. It discusses financial management and planning.

SOA Retirement Section News (formerly Pension Section News):
