A Conversation on Dementia and Cognitive Decline
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AUTHOR

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Retirement in America is often filled with time with family and friends, hobbies and new interests, travel to places near and far, and more. But when a retiree develops dementia or cognitive decline, the picture grows less rosy. The individual, family and other loved ones must adjust to new realities where memory is fading, schedules get mixed up, housing may change, new medical providers emerge, and various unfamiliar “helpers”—as well as family “helpers”—enter the home to provide care on an increasingly regular basis.

Financial professionals as well as families and friends often become involved in this new personal reality. Whether serving as advisers or industry experts, they find themselves searching for ways to help smooth out the financial road for all concerned. In the process, they witness individuals and families becoming caught up in painful struggles never anticipated in the retirement plan. What insight can these experienced financial professionals offer on the impact on retirement, and what solutions could help?

In the fall of 2018, the Aging and Retirement Strategic Research Program of the Society of Actuaries (SOA) decided to seek some answers via an online conversation. The experts who participated in the conversation offered not only personal experiences but also professional judgments about the financial and life challenges that come with dementia and cognitive decline. They also shared compelling stories that illustrate the magnitude of the impact these conditions represent in the financial and emotional lives of those concerned.

This report provides a summary of key points made during the conversation, organized by topic. This report supplements SOA studies of Americans and Canadians aged 85 and over, and their adult children. It includes a variety of possible products and planning strategies that may help and concludes with some additional resources that may be of interest.

Due to the personal nature of some of the online commentary, this report does not show the names of online participants, the people they referenced, or unique identifiers. This was done for the sake of privacy. The commentary appearing in italics does, however, come directly from the online conversation, with only a few edits for grammar, spelling and clarity of reference.

**Highlights**

Dementia and cognitive decline can be a major problem, whether the individual has financial resources or not. One key to dealing with the challenges of dementia is strong family (or support system) communication. Yet, every situation is different. As one commenter put it, *Successful aging requires strong family communication. Spouses need to talk honestly to spouses; parents need to talk honestly with adult children, and vice versa; and adult children need to talk honestly among themselves about their parents.*

SOA research has found, however, that many families do not have conversations about such matters in advance of the time when a problem occurs. And many people do not have family available to help them, particularly as they reach the advanced ages.

The participants in the online discussion recounted several anecdotes concerning times when things went wrong. Some examples appear here with the hope that the stories will help others to do a better job of looking ahead and planning so that things do not go wrong.

A variety of support, financial, legal and other strategies can help with the management of life for individuals with dementia. Once again, implementing these strategies requires planning, and some require that legal documents be put in place or financial products be purchased in advance of developing dementia.

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1 The participants in this conversation included actuaries, retirement researchers, financial advisors, attorneys, economists and financial writers.
Individual responses to the idea of planning vary significantly. Some participants reported that certain individuals and families will not discuss the possibility of needing help or having dementia while others have clients and families who take maximum planning steps. In some cases, individuals take action that is based on planning which was done completely in advance of any signs of dementia or cognitive decline. In other cases, people take action (or try to take action) only after something has gone wrong.

In all situations, the participants stressed, it is important to look for signals that it is time to do something. If no action is taken until after an individual is deceased, the executor and family must clean up the problems left behind, an often difficult and painful experience.

The message that emerged repeatedly is that although planning does not solve all problems, it can make dealing with them when they arise a great deal easier. For that reason, it is critical to recognize problems as they occur so that solutions can be put into place.

Some signs of problems named by participants include: unpaid bills and unopened mail, check books not balanced, tax returns not signed or filed, phone calls or emails not returned, and sometimes fraudulent activities. Other examples include difficulty with driving, poor dietary habits due to difficulty shopping or making meals, and inability to manage medication properly.

Products, arrangements, and legal steps that can offer financial and legal protection regarding dementia include:

- **Use of lifetime annuities.** The funds placed in these products are managed by the insurance company and paid regularly for life without any action on the part of the individual. Another advantage is the individual can have these funds automatically deposited. Product variations sometimes used for older individuals include joint and survivor annuities and deferred income annuities.²

- **Purchase of long-term care protection.** This insurance can help finance needed care, and it can be provided in a variety of different policy types. Views do vary greatly about such insurance, so it pays to research the options first.

- **Trust arrangements.** These legal documents can transfer management of a person’s funds to a trustee, and a variety of trust structures exist to address the need.

- **Powers of attorney.** These documents delegate authority to make decisions to another person when the individual is no longer willing or able to make decisions.

- **Investment strategies that do not require ongoing choices.** One example is the use of a target date approach to investments which rebalances investments automatically, say every quarter.

- **Use of a service that provides for support with bill paying and everyday money management.** Auto-pay programs provide one common example.

Older individuals and their families need legal help with structuring and putting into place such documents as trusts and powers of attorneys. This paper does not discuss the legal issues and steps involved. The focus here is to recount observed behavior of individuals and families who are dealing with dementia and cognitive disorders, especially at the older ages. Noteworthy here is that some commenters did reflect on barriers that occur regarding completion of appropriate legal and planning steps.

² Joint and survivor annuities cover two individuals, and the income payout continues until the second dies. They may provide the same income while both are living and after one dies, or a reduced income after the first death. Deferred income annuities are also known as longevity insurance, and they normally start to pay income at an advanced age, such as 80 or 85.
Background on the Conversation

The SOA online conversation about how people approach dementia and cognitive decline started when the SOA received this emailed request from a researcher: We’re investigating strategies that older people and their families can adopt to protect themselves from financial fraud and abuse in their later years, as well as mistakes due to cognitive decline.

The researcher noted that the first immediate line of defense is to arrange your financial affairs to minimize exposure to fraud and mistakes, such as:

- Leave savings at employer-sponsored retirement plans
- Require that financial advisers adhere to fiduciary standards
- Buy an annuity
- Use low-cost index funds
- Strictly adhere to using reputable financial institutions
- Adopt internet security features for online accounts
- Automate receipt of income for all sources
- Automate payment of bills for utilities and insurance

A second line of defense is to set up “trip wires” or “warning signals” that they accept now while they are able to manage their financial affairs on their own, the researcher continued.

These trip wires essentially lay out situations in which the individuals agree that at some time in the future, when an agreed-upon event triggers, they will get a trusted, named family member involved to help with their finances. The hope is to prevent serious events and mistakes that jeopardize the older person’s financial security.

Following are some trip wires the expert cited:

- Diagnosis of specified health conditions
- Trouble balancing the checkbook
- Trouble with using computers
- Move to assisted living
- When they’ve made a specified number of financial mistakes, such as incurring late penalties on bills
- Reaching a specified age

Additional trip wires which surfaced during the subsequent online conversation include:

- When they’ve thrown away or lost bills or other important mail or documents
- When they forget to take their medication
- When they don’t remember if they took their medication

Some actions that others might take, upon noticing trip wires, could entail a family member obtaining read-only online access to the person’s bank accounts, the expert pointed out. Other actions could entail a helper serving as a...
signatory on checking and savings accounts, and even paying bills. *All of this would be voluntary*, the expert noted. *It's not intended to be forced on the older person. It's for families to plan ahead to protect the older person.*

The researcher asked the online discussion participants for input on the following questions, among others.

- *Is this a good idea?*
- *Do you have alternative suggestions?*
- *What are other trip wires you might add or remove from the above list?*
- *What are possible tasks that family members might accept?*
- *Do you have any instructive real-life examples or horror stories?*

**The Online Discussion Begins**

The SOA’s Aging and Retirement Strategic Research Program engages in online conversations about focused topics of strong interest. The above topic was no exception, so the SOA team sent the discussion group the above inquiry and invited comments.

The first question posed to the group was designed to learn if anyone had had experience with successfully convincing a resistant older person to take steps to protect themselves and the family when coping with dementia or cognitive disorder.

Within a few short hours, responses came flying in, filled with detailed and often gripping insights into the above question and related problems. The professionals weighed in on everyday experiences they had had in this area and on understandings they had developed in the course of their work and sometimes with their own family members as well.³

**Ideas for Solutions**

**Planning**

A financial planner had this to say:

> From a practical perspective, arranging financial affairs so that someone in the next generation is a trustee of a revocable trust that holds as many of the financial assets as possible allows the next generation to assist most effectively. The trustee can access and manage all accounts and assets in the trust – this is much more effective than a power of attorney. Unfortunately, this approach won’t work for retirement accounts – power of attorney is the only mechanism.

> *Doesn’t this call out for a delegation of authority in the form of a durable power of attorney?*

This points out the importance of learning about the variety of steps involved in making suitable planning and legal arrangements. These steps are beyond the scope of this paper and should be undertaken with qualified legal help.

³ The discussion comes at a time when other organizations have begun raising age-related behavioral issues as well. For instance, AARP, Genworth, and National Alliance of Caregiving, have suggested action steps such as to have a “hard talk with your parents about long-term care...” See [https://www.aarp.org/home-family/caregiving/info-04-2012/talking-parent-caregiving.html](https://www.aarp.org/home-family/caregiving/info-04-2012/talking-parent-caregiving.html) and [http://www.caregiving.org/wp-content/uploads/2014/10/Genworth_Lets_Talk.pdf](http://www.caregiving.org/wp-content/uploads/2014/10/Genworth_Lets_Talk.pdf)
But the SOA discussion and the stories shed light on a critical issue, namely that many people are unwilling to focus on these issues and seek such help.

In contrast, however, the discussion indicated that some families do plan relatively early and work together. For example:

Like many of you, I have had experiences with my own family that fit some of the methods the earlier commenters mention, including having open yearly meetings with the three kids and my parents beginning when my dad turned 79 and mom was 76. It started because Mom wanted to sell their home and move to California, where there was no family, but lots of sun. The home to be sold had been built by my grandfather in 1906, was on the water on an island, and had been my siblings’ home until they were 2, 5 and 9. Just before I was born the family moved back to the city on the mainland, but we spent every summer living at the beach.

The kids did not want to see the house go, so a series of conversations began about alternatives. Most relevant to the topic raised, these discussions led to very explicit financial and health discussions that set things up for the next 18 years.

Neither of my parents ever had any cognitive issues, and Mom handled the finances until she was 92, and then handed it to my sister because 'I just don’t want to be bothered any longer.’ My maternal grandmother had bad cognitive issues for the last 5 years of her life (88-93), so we had planned for that eventuality. My dad had many chronic health issues that all seemed to go away about age 75, and after four close shaves with death from illness, he did not get sick again, and "passed of old age" at 94. Dad happily stopped driving at 88; with mom, it was a struggle to get her to stop at 90, and she never stopped regretting the loss of freedom and mobility. Neither was ever confined to a wheel chair, and only used walkers outside for safety after about 90.

**Simplifying regular money management**

One person wrote about the bill-paying responsibility this way: Setting up as many bills as possible to be paid directly from a checking account can cut down on the need to write checks. I do this for those things that don’t change from month to month like health insurance premiums, car payment, cable, cell phone, etc.

Someone, either a family member or an outsider, could help with the following tasks:

- **Review all incoming mail to ensure bills and taxes are paid, licenses renewed, etc.**
- **Review all financial statements (either hard copy or online) to ensure that payments or transfers are appropriate and that investments allocations meet needs.**

In general, reviewing incoming mail requires that the person helping to review the mail be present. As an alternative, a log can be kept regarding mail about taxes, licenses, insurance premiums, etc. or the reviewer can use the system described elsewhere in this report when handling the mail.

**How families fit in**

The SOA’s research with individuals age 85 and over found that family help is extremely important, but few people and families do much planning ahead for it. The same research also indicated that when multiple siblings are alive and available, they often work together to help their parents.
Discussants made a variety of comments on this subject. *If the 1st generation doesn’t have a good relationship with the 2nd, said one person, and if there are not ongoing open discussions about health and financial issues, the declining years of the 1st generation are a very difficult time to improve things.*

Another said: *Ideally families can have an open discussion of these issues in advance and define an objective (maybe 3rd party) way to decide how best to manage their affairs (not sure the best approach – I realize this is a super sensitive and landmine laden area).*

### Financial products

Several discussants mentioned financial products including lifetime annuities and long-term care insurance could help with the financial aspects of dementia and cognitive decline. Another mentioned considering a deferred income annuity with a cash-refund as an option or substitute for long-term care insurance.

Many forms of long-term care insurance are available today, and they evoke different opinions of people who consider them. This is discussed in greater detail later in this report.

### Types of available help with financial matters

The online conversation and earlier SOA research highlighted several types of financial assistance that may be available to help. The key types include family members, financial advisers, legal professionals, and daily money management specialists.

According to the SOA research with individuals age 85 and over, family is the most common type of help. There is no guarantee that the available family members are well qualified and honest, however.

If a financial adviser is in the picture, family may help with that relationship. People at all ages do use financial advisers and legal help, so the individual and the family may welcome the professional assistance. Note: Financial and legal professionals do not typically help with daily money management and tasks such as paying bills, but specialists are often available to do such work. Here are a couple of comments on this subject:

> Perhaps you know about the American Association of Daily Money Managers, but if not, DMM’s are financial professionals who help older adults and others manage routine personal finances. Their tasks include reviewing mail and paying bills, communicating with creditors, banking, coordinating with other financial professionals and family members as appropriate, and preparing and filing taxes, etc.

> I have known members of this organization for many years, and they operate under a strict code of ethics, appropriate credentialing, and they are devoted to the needs of their clients. This is an excellent prospective resource for older adults who can use help keeping up with personal finances during periods of mild cognitive decline.

### Screening financial document for suspicious activity

Banks, mutual funds, and others that hold assets do screen transactions in their accounts for signs of suspicious activity. They have procedures to follow if they suspect fraud or a cognitive problem. If they encounter a problem that they are not able to address, they work with adult protective services and state regulatory agencies. In some cases, they can also freeze accounts or credit. In discussing the freezing of credit, one online commenter asked: *Shouldn’t there be a default freeze on credit at no cost to the senior that she can opt out at any time?*

The broad topic of screening did not come up in the online discussion. However, it did surface with respect to an elderly fraud detection system available to individuals, as follows.
In terms of solutions, someone I know has created an elderly fraud detection technology solution that monitors bank accounts and related financial information for suspicious activity and sends notices and updates to designated parties.

Keeping track and setting up reminders

A person with dementia or cognitive decline can find it becomes increasingly difficult to keep up with the details of everyday life. Here are a couple of examples from the online discussion:

Forgetting schedules is often a problem. One online commenter put it this way: Having just turned 86, I can easily forget to handle non-routine tasks and commitments on time. Not everything can be automated or outsourced. For other items, it helps a lot to keep a calendar and to-do list in some form that get updated often.

Mail can also be an area of difficulty. The difficulty may be after delivery but also before. Consider this extended comment on the subject:

On the topic of mail, my local neighborhood has had a lot of problems with delivery so here’s a solution I use. The post office has a free service you can sign up for called “Informed Delivery”. I get an email every morning with a picture of all the mail (other than magazines and packages) that is to be delivered that day. If something doesn’t arrive, I will know and can contact the post office. Here is more information about it: https://informeddelivery.usps.com/box/pages/intro/start.action.”

This could be one of the “trip wires” for family members of those experiencing cognitive decline; it might help them know if their loved one is not handling the mail properly.”

It could be particularly helpful if a nonresident family member could receive the notices, though it wasn’t clear on the site whether that use is permitted. But surely something could be done as a workaround if, say, a parent and child wanted to set it up.

It was not mentioned in the conversation, but some people are getting their statements and bills online from many sources. This greatly simplifies an important task that older people sometimes find onerous if not confusing. However, this practice could potentially lead to an additional set of complications if the individual forgets or cannot find a password, say, or if the person neglects to respond to certain online requests from financial or medical providers. This bears watching.

Anticipating next steps in living arrangements

Some people, and some families, do not talk about or actively plan where or how the older parent or family member will live if incapacitated long term. One discussant in the online conversation illustrated with this personal story:

Another planning act that could be helpful (based on my experience with my parents — where this was not, unfortunately, done) is to lay out “the next step” in living arrangements. This could be a transition to an attended care facility, with that facility identified, when certain wires are tripped (e.g. inability to drive).

My mom suffered from Alzheimer’s and dad cared for her. As an only child, I tried to encourage my father to plan for a transition to attended care, without (I think) realizing how big a task that would be for him (emotionally and physically). So when he fell and broke a shoulder, my wife and I had to get appropriate long term living arrangements pulled together immediately. We got it done, however my dad did not have a role in it, as he was hospitalized.
Had we had "Plan B" lined up in advance, we might have gotten the transition accomplished before his fall—and if not, at least he would have had an active role in the planning process. It would also have been less stressful—and more cost effective—for all concerned.

Comments About Long-Term Care Insurance (LTCI)

The online discussion included many comments about long-term care insurance (LTCI) including its importance, general types of coverage in the market today, and people’s feelings about why they should or should not buy such coverage. About 10% of long-term care is paid for by private insurance.

It is important to remember that LTCI is not the total answer for solving dementia or cognitive decline problems, as many problems surface before long-term care is ever needed. However, such insurance can help to finance some options in the case of a severe situation. For many households, it will open new options.

The SOA research with individuals aged 85 and over as well as the prior focus group study with individuals retired 15 years or more confirms that many families experience significant problems if a major long-term care event occurs. Even so, respondents in these studies commonly underestimated the likelihood that they will need significant long-term care. They also underestimated the cost of long term care, and they overestimated what Medicare and other insurance will pay for such care. The conclusion: If such individuals ever do need long-term care, it may be a bigger financial problem than they had predicted.

The discussion brings forward the potential for conflicting interests when extensive long-term care is needed. Much of the conflict has to do with cost. The more money that is spent for long-term care, the less there will be for the heir(s). Furthermore, the duration of a long-term care need can make a significant difference in total cost. For example, paying one or two years for care in acutely declining health situations is often manageable but paying for three or more years of decline due to cognitive issues can be unmanageable or even result in the person running out of money.

It should be noted that long periods of intensive long-term care are relatively infrequent. However, cognitive decline and dementia can occasionally lead to very long periods of care.

Here are some comments from the online discussion about some of these issues:

My experience is that an underappreciated aspect of LTC is that so many people want to stay in their homes. This is often a combination of LTC facilities not being attractive and a reluctance to leave the comfort and familiarity of the home.

People buy LTC policies not always realizing how important it will be to them to stay in their home and not realizing that the coverage for care in the home will be much less than the coverage for moving into a facility (in the couple of policies I've seen). So, people (both the elderly and their relatives) are left with a tough choice: It's cheaper and less burden for the relatives to move into the facility, but the elderly really want to stay at home.

Upon reaching the stage of thinking about LTC, the impact of the cost is arguably more important for the relatives who are probably going to get whatever is left over after the elderly person passes.

I've been impressed by a couple of friends and colleagues who spent the time and used up a lot of their potential inheritance making sure their parents were comfortable at home in the last years. It would seem heartless to do otherwise, but there are great incentives to overcome.
LTCI market challenges

The traditional LTCI market has had its share of challenges. Insurance carriers have left the market, claims for traditional LTCI have been higher than anticipated, and premiums for traditional LTCI have gone up. Still, the online commenters pointed out that the LTCI market is evolving and there are many options beyond the traditional LTCI policies. Following is a sampling of comments about the trends:

**Much variety:** Today we have 8 different ways of providing Long-Term Care Insurance Coverage and sales are more than 2 billion in premium and to over 300,000 new policyholders a year. The coverage appears in a variety of structures such as:

- Short-term care insurance
- Chronic illness riders on basic life insurance policies
- Annuity long-term care products
- Immediate needs annuities
- Long-term care insurance acceleration riders on life insurance contracts
- Long-term care insurance extension and inflation provisions within Life Insurance products
- Group and multi-life long-term care options
- Traditional long-term care insurance

Each of these product types meets a different consumer need and provides layers of protection based on other competing retirement demands. Many of these products are dual purpose retirement solutions and each offers a variety of ways to fund the coverage.

You would be surprised that more policies are sold today in products 1-7 that are sold non-cancellable and CANNOT have a rate increase! Each and every solution above covers Severe Cognitive Impairment and care in the home.

The commenter also noted that most of the products require brokers and advisers to have special licensing and meet specialized continuing education requirements.

**Specialized licensing:** Did you know that in all but 1 of the 8 insurance solutions, brokers and advisors are required to have special licensing and Continuing Education requirements (that vary by state) in order to help their clients purchase an LTC solution? No other product has such requirements.

This has severely limited the number of advisors and brokers that will even discuss the Long-Term Care risk to a retirement portfolio or retirement plans. Just like other products, that education should be included in both the Life and Health exams.

In addition, many of the advisor firms and the insurance carriers themselves have very robust CE efforts to ensure the right solution is purchased by the consumer. End this requirement and the robust insurance market can be made available to a far greater consumer audience.”

One discussant offered this observation about the overall trajectory of the LTCI market given the new variety of products, “I think the problem is still more on the demand side than the supply side. There are solutions for people who want them...making them act in advance is the hard part. People just don’t perceive the value proposition until it is too late.”
Personal reasons for buying or not buying LTCI

Some discussants weighed in on why they would and would not buy LTCI, but nearly all these comments reflected reasons to buy.

First, a caveat. Since much of the population has not purchased such insurance, the following remarks do not reflect the population as a whole. For example, the comments did not include references to the insurance being too expensive, although the earlier SOA focus groups included such comments. Then again, the SOA focus groups sampled views of people with limited resources while those contributing to the online discussion are likely to be considerably more affluent than the focus group participants. It helps to keep those factors in mind while reading this first grouping of online comments, most of which are positive about LTCI, followed by one negative comment.

Friends of mine, whose net worth will probably be $5M - $10M at retirement in a few years, recently told me that they had bought LTCI. I was a bit surprised, thinking that it wouldn’t make much financial sense for them, but didn’t say anything. After listening to how they thought about it, I ended up seeing the situation as kind of a reverse “annuity puzzle.” It just makes them feel better to have it. Without analyzing the real financial consequences too deeply, they have a general sense of having secured themselves and/or their assets against a potential big blow later in life. The premiums themselves won’t have much impact on their budget and they no longer need to worry so much about getting old. Another factor may be that their own parents are at an age where LTC might not be that far off. The list of behavioral reasons why LTC might feel good even when it doesn’t make financial sense is probably as long as the list of behavioral reasons why people don’t buy annuities.

If you have a large estate to insulate for heirs, like the previously mentioned friends, why not buy LTCI? It would be a relatively inexpensive hedge against the possibility of care for two long-term dementia patients (it happens). If I have $5 million and I’m paying a wealth manager 50 basis points a year, that’s at least $25k a year in advisory fees alone. I might be paying $50,000 a year or more in property taxes. Why would I flinch from LTCI costs?

Another view on LTCI. My brother, age 55, just purchased a hybrid product from a life insurance company (life insurance and LTC, it pays out for death and LTC) for himself and his wife. They have plenty of money and could very easily cover any LTC expenses, but he has watched friends’ families torn apart by the spouse/kids not wanting to spend their inheritance on an LTC facility. As he put it, if I need to be in an LTC facility, I want it to be one of the best and I don’t want anyone worrying about spending my money on my care.

I have another friend, 65ish, who also purchased LTCI for very similar reasons. She didn’t want the family worried about how to pay for LTC if it was needed.

Peace of mind seems to be the overriding factor even though LTC is expensive and in both cases, the individuals could self-insure.

I bought LTC. I hope it proves to be a total waste of money. Why I bought it? Because I am affluent enough to not qualify for Medicaid but not so affluent that an LTC event for me or my spouse wouldn’t impoverish the surviving spouse... If you are single, without strong legacy goals, you may as well rely on spending down your assets and accepting Medicaid, as long as you are able to pay as you enter the facility (so you can choose which facility you go to...).

I agree with the prior respondent - You are buying peace of mind and choice and control. Anyone who wants care at home and a contractual promise of what type of care they’ll get is better off with something other than Medicaid even if there are no bequest needs.
At the facility I spend time at, the issue of not having to fight with the kids about spending the money is major—and it is a big problem—and it harms the wellbeing of the person in need. Those residents who have LTC, even wealthy ones, view the contribution to the cost of the LTC to keep off some kid pressure.

Why would affluent people buy LTC insurance? If less affluent people use home equity and other assets for LTC, affluent people can do the same. Add to that all the drawbacks of insurance from the simple fact that premiums exceed actuarial value to vague clauses that deny coverage when the time comes, and adverse selection, I cannot see a reason to buy LTC. I surely would not buy it any more than I buy insurance for my home appliances, or even earthquake insurance (in California).

**Concerns about LTCI**

Some of the online discussion focused on not complaints but rather concerns that people have about LTCI and how it is managed today. But they seem to take the long view on this. For example:

> Interestingly, for all the criticism at LTC insurance, the only aspect of the contract that is NOT guaranteed is the premium (and even then, there are consumer protections and guarantees and, as previously noted, some products do have guarantees). My auto, home and health insurance doesn’t include any guarantees with regard to coverage access, benefit type, rates, renewals or anything....

> As a self-employed person in just the last two years, I’ve paid almost as much for my health insurance (and gotten almost “nothing” out of it because I didn’t get hit by a bus or have a major health event exceeding the $2000 deductible) as I’ve paid in LTC insurance premiums over the last 20 years. But if and when I need that, it will pay for at least 7 years and maybe up to 14 years’ worth of care at home or other care setting I choose.

**More About Long-Term Care Solutions**

The retirement professionals participating in the discussion had varying degrees of expertise on LTCI. The National Association of Insurance Commissioners is currently working on a new buyer’s guide that should be a great help in expanding awareness in this area.

Some noteworthy product trends mentioned by the online commenters include the following:

- **Almost all the LTCI policies sold today (and most of the in-force policies) have home care provisions.**

- **The majority of sales today are of hybrid policies, such as life insurance with LTC provisions and annuities with LTC provisions, and not traditional products.**

There are more solutions, too, according to one commenter. Not all are perfect and not all are widely known to consumers, but they share a common goal, which is to help people make their private dollars or coverage dollars go further. Examples of solutions this person cited include: …**online I&R services, fee-for-service care managers to help with long-distance caregiving, expanded and new models to provide access to in-home caregivers, services to support oversight for paid care from family and friends, renewed interest in home safety and renovation to enable people to stay at home longer, and creative use of home equity to pay for in-home care.**
Medicare Issues

The online discussion encompassed Medicare, as well. The commenters pointed out some of the health events Medicare covers as well as some things it does not cover, and embellished these accounts with related challenges, often in telling detail. Here is a short list:

I’ve heard that Medicare won’t cover home health care costs. Is that true? If so, is there a good reason, aside from the vast potential for fraud?

Medicare covers certain home care costs—but very limited and can be difficult to qualify—even just from filing, paperwork and reporting.

I’m glad Medicare came up. This is the sleeper LTC “product.”

Medicare home health and SNF coverage is picking up. Stays are shorter too. So while Medicare doesn’t cover long term stays it is increasingly a valuable way for people to get LTC for short stays. In fact, I’ve seen numbers that suggest two-thirds of payment for nursing home stays under 3 months (which are the bulk of stays) are paid by Medicare.

And the rules are getting better for folks. For instance, there was the so-called improvement standard where Medicare cut off SNF/HH unless you could show improvement. That bit the dust. Ditto the homebound rule where you could not leave the home or you’d forfeit coverage. And in February, CMS and Congress (Both! Separately!) allowed Medicare Advantage plans to add home care services as long as they would improve health outcomes. And we know such interventions work since we have experience from commercial plans and Medicaid that simple things like respite care and chore services delay or prevent people from going into the nursing home or hospital.

So the trend is definitely for greater long-term care coverage via Medicare (notwithstanding the fact it is called post-acute). Josh Wiener tracked this. In 1988, $5B of Medicare’s budget went to SNF/HH. By 2011 it was up to $75B. If I recall correctly, he was saying that was a jump from 3% to 18%.

The Medicare story is somewhat more nuanced than suggested. While the discussion is correct about the improvement standard, this new rule has still not been fully accepted by risk-averse providers, thus creating confusion for consumers. The bigger problem, however, is the growing use of observation status in hospitals. Those in observation are considered outpatients, and thus do not meet Medicare’s three-day hospital stay requirement. As a result, Medicare will not pay for their post-acute care. In 2015, more than 2 million patients were cared for in observation, in hospitals but not admitted as in-patients.

Yes, true. For those who are interested, basically a person goes into a hospital for a couple days before the doctor decides they need to stay for, say, an additional 2 more days. In the “old” days, that would have been 2+2 = 4 and the patient would have met the 3-day requirement. But CMS decided somewhere along the line to save money by saying the first 2 days (in this example) don’t count.

On the other hand, Medicare Advantage plans can waive this requirement—and will do so—if they think sending someone out of the hospital (either to home or rehab) will save them money. But that gets to the other point about it meaning even MORE confusion for consumers.

My wife’s brother learned this lesson the hard way. You need to be in a hospital for 3 days to then be eligible for Medicare to pay for a skilled nursing facility (SNF). Days in a hospital for “observation” don’t count towards the 3 days. I was able to warn them in time to change his hospital status from observation to admit.
Medicare only pays for the cost of a SNF for 20 days. Then, from day 20 to 100, there’s a $167/day copay. Nothing after 100 days. If you don’t have a Medicare Supplement or Medicare Advantage plan, the copay adds up quickly. SNFs are good for transitions from hospitals to home, but they aren’t LTC. They should be called STC — short-term care.

There’s some concern about the Medicare deduction from Social Security payments eventually consuming a much larger share of the SS benefit.

The Medicare premiums follow the Medicare costs for health. These costs have risen faster than overall inflation and earnings in the past. The indexing of benefits for beneficiaries is somewhat less than the overall inflation. Thus, one would expect that Medicare premium costs over time would increase faster than the cost of living increases to benefits. Part B premiums are paid directly to the Center for Medicare and Medicaid Services and the beneficiary receives the net amount after deducting Part B premiums. Part D premiums are not automatically deducted but can be deducted if arrangements are made with the insurer and SSA.

Medicaid Issues

Medicaid frequently becomes part of the health care picture after family funds have been exhausted. The online discussion included only one Medicaid experience. This may be expected, given that the commenters tended to be more affluent than the average American. This discussion relayed the experience of a person with health problems not centered around dementia or cognitive decline. It is included here because the commentary is equally applicable to those experiencing the financial strains of dementia/cognitive decline.

My son’s in-laws are experiencing a need for LTC in North Carolina. The father is age 68 and needs a lot of care—amputation due to diabetes, along with heart disease. Their finances are above average for Americans, but they will get wiped out by the costs of uninsured LTC. Their combined income is about $70,000—$45,000 of salary from the wife who is a 65-year-old school teacher, and $25,000 from his Social Security and a disability pension. All they own is a mortgaged home worth about $350,000, and $6,000 in savings. This amount of income and assets is above average for their area.”

They will not qualify for Medicaid’s assistance for medical expenses, which are mounting. They do not have a Medicare supplement plan, nor have they purchased LTC insurance.

They are on the cusp of qualifying for Medicaid’s assistance for LTC. Most likely they will need to spend down their modest savings. We don’t know if the wife’s salary or the value of their home will preclude eligibility for Medicaid—we’ll find out when their application is reviewed. If they do qualify for aid, most likely there will be a substantial deductible due to their financial assets. They are very intimidated by the entire process of applying for aid and need a lot of help negotiating the system. I have coached them and encouraged them to call the local Area Agency on Aging, which they have not done.

I suspect that their situation is typical of middle income Americans. They didn’t plan ahead or adopt strategies to protect themselves. They are uninformed about the issues and are intimidated by a complex system. For whatever reasons, they aren’t capable of taking the steps that people on this distribution list would take. Their burdens will fall on their kids, who are scrambling to help while raising three small children.

While I agree that Medicaid can be a safety net, in reality qualifying for it is much easier said than done for middle income Americans. That’s not to say Medicaid isn’t valuable. And it’s not to say that Medicaid should be expanded (which it won’t be, due to political considerations). It’s just that this is a big problem for middle America, and Medicaid hasn’t made it go away.
Women’s Issues and Elder Orphans

Caregivers are often women, and many more women than men reach very high ages. Women are also much more likely to be alone in old age, the so-called elder orphans. Men are more likely to have a spouse to provide them with care in old age than the other way around.

The online discussion specifically raised the issue of elder orphans, as indicted below, while the individual caregiving stories were much more about families. Here are relevant comments:

- A topic that I would like to see more discussion on is the significant population of baby boomer women who (for whatever reason) did not have children or have children who are unable to help. They may or may not have married but are alone at this point in their lives. Friends are generally in the same age group, so willingness to help is certainly there, but...

- What are your thoughts on long-term navigating financial management without family caregivers to watch for “churning” etc., if/when single individuals become cognitively impaired.

Intergenerational Issues

The tensions surfacing during caregiving events are often intergenerational, with sibling infighting, parent-child disagreements, and the like. The issues can range from the care plan, the care location, the caregiver responsibility, the money spent, the impact on the healthier spouse, and much more. Here is one example, about money issues:

- At the facility I spend time at, the issue of not having to fight with the kids about spending the money is major—and it is a big problem—and it harms the wellbeing of the person in need. Those residents who have LTC, even wealthy ones, view the contribution to the cost of the LTC is to keep off some kid pressure.

One of the stories focused primarily on the relationships between parents and children, and how tensions over care can affect outcomes. Here is one story, in full, with more stories to come later in this report:

- After many years of fighting off chronic disease, my wife entered assisted living in 2011. It is in that environment that I have seen and studied the issues raised by the discussion questions.

- The assisted living facility I am familiar with has a Resident and Family Council working with a staff attorney which interacts with community agencies on advance care planning. The most interesting aspect of the interchange is related to the rights of elders relative to children, POAs, Guardians, etc. Most of the people who need care do not have “means,” and the biggest challenges for most families and elderly are related to affordability of any care or a safe living arrangement. Only with the bulk of my life now spent in the assisted living environment, have I come to appreciate the conflict between the desires of parents and the beliefs/desires of their children. Spouses treat the spouse as a capable adult; children most often treat the parent like a child to be managed and overseen.

- Frequently it is the facility and the child gangling up against the parent, seeking to constrain their freedom and decisions, illegally (if you believe the Ombudsman lawyer). I have also been amazed by how “absent” children are once they have all too frequently moved the parent to assisted living against their will, some with no cognitive issues, some with moderate, few with severe, as they go directly to a memory care unit.

- The point made earlier about not wanting to bother the children is one that I see several times each day, as instead, they seek the help of my wife (much younger than most of the residents and younger than many of the residents’ children) and ask her to file complaints on their behalf, so that they are not seen as a trouble maker, which will upset their kids, who most often tell the parent to “get over it, you do not know how lucky
you are to live here.” Then the child disappears for days, weeks or months, depending upon how far away they live. Thus, I have become skeptical of “well meaning” children when it comes to many of these issues.

I now have a much better understanding of the “resistance” of my parents to many things that all of the children were convinced were in their best interest, and they simply did not want to do, would not, and did not.

The family member of the assisted living resident also observed the development of “Community Guidelines,” developed by the facility and intended to stifle the constitutional rights of the residents, at the request of some children.

It was observed that one of the assisted living residents has other families, both parents and children, coming to him for ‘advice’ on “how to deal with this issue with my parent/child.” The children will always want the “trigger” to be set a lot earlier than the parent will be happy with, but may agree to set because it is in the future, and they want the kids to be happy, but when the day comes, they will push for what they really wanted in the first place. Thus, listening carefully to the parent and living with their “trigger” point preference rather than “working them to agree with your view” may avoid arguments when the “trigger” is most important but was set ahead of the parents’ preference.

The cases here that have the most dire consequences are the cases of very rapid decline as opposed to the more frequent slow process in which “denial” or “failure to acknowledge” or “recognize” is more common. It was pointed out that it all needs to be kept in perspective.

**Individual Stories**

In the online discussion, a number of anecdotes came in the form of individual stories. Some are cited here, and they are linked to specific issues.

**The Big Picture**

Some comments focused on the bigger picture, as follows.

> Given my own experiences, and dozens of calls from readers, I laugh when I see the usual advice around cognitive decline and preparation. It seems to be focused around products like index funds and annuities and the expectation that the individuals have financial advisors. Most people are do-it-yourselfers….as were my parents. So there is no advisor and there may be CDs spread across many, many banks. Further, widows do not know what their husbands have set up. Many have called me crying, and I have seen advisers take advantage of them.

> Brokerage firms often lose interest in widows as they spend down what was once a profitable sum to manage. Often widows don’t want to bother their children.

**Driving issues**

One issue that surfaced several times has to do with the difficulty that some older people have with driving. Several anecdotes recounted how children dealt with concerns about their parents driving and the associated problems.

> When it became unsafe for my mother to continue driving, she resisted our pleas and we asked her doctor to intervene. The doctor asked her if she thought she should be driving. She said she was fine, and he said OK. It was clear to the doctor that she was having short-term memory issues, but he did not want to be involved.
My mother’s doctor behaved the same way as another mother’s physician cited in the conversation. He refused to intervene even when we raised the issue explicitly about cognitive impairment and driving. His response was to suggest she call the police department in Chicago and ask them if she was capable of driving. She called and spoke with “the chief of police in Chicago” who said that she was fine to drive based on a phone conversation. She still has a valid license, but we have moved her without her car, which was the only way we could stop her from driving. We tell her now that her car is coming soon, and we have hired someone to take her around in the interim, but we know her car won’t ever arrive.

A friend of mine dealt with dementia and driving by disabling their parent’s car by removing an electrical wire, knowing the parent was not able to get the car repaired.

Back to my Dad: He was able to develop strategies to avoid detection, fearing the loss of his car/house/lifestyle. One time he was driving and got completely lost and caused an accident. He was somehow successful in convincing the state not to take his license away, even though signs were there that he was slipping. A neurologist would have detected dementia but was never considered or ordered. So add that 1) people not wishing to relinquish control may be able to mask their condition out of fear of loss of control; and 2) families and friends may see the signs but either not recognize them as cognitive decline or convince themselves that the decline is real but they can still manage on their own. Both happened to us.

Refusal to recognize the need for help or to accept help

The online commenters identified the tendency to refuse as belonging to the parent, though stories do exist when adult children also refuse help for their parent. Here are a few examples from the discussion:

My mother-in-law refuses to have this discussion, even with her cognitive skills in decline.

Much of the talk about handling cognitive decline and financial matters strikes me as a bit naive. It assumes thoughtful compliant people with financial advisors. What about the aging parents who think they are fine and are not….and refuse at an early age to imagine a time of decline or trigger power of attorney documents when the time is right? I have heard from many others dealing with these issues and have experienced it myself with my parents.

My father, a sole-practitioner attorney, adamantly resisted all intrusion and inquiry into his financial affairs by his sons beginning in his 60s. By the time he died, at 83 in 2013, he left a trail of bills, an unresolved reverse mortgage from a company that had failed in the financial crisis, and a condo in Florida that was still in my long-deceased mother’s name. He hadn’t filed a tax return in three years.

My mother was a CPA and my father an executive. Both were excellent at handling financial matters into their mid-80s and had handled those matters in detail until they became very ill. Even when ill and in decline, however, they resisted help—holding onto high expectations for themselves.

Conflicts between parents and children

As noted earlier, some commenters focused on intergenerational conflict, including the adult children who don’t want to see their parents spend money on care.

But there is more to the story. SOA’s in-depth interviews with people age 85 and over indicates that many in the age 85 and over population are very frugal. In other cases, the older people (primarily parents) are very aware of their need for help and have put a good system into place. In fact, according to the SOA research, in the 85 and over segment, family members are often the first line of help. The following illustrates how things can go right when care is needed.
My mother created her own response and recognized the need for help. She asked her accountant and planner to check over her bills every few months to make sure she was paying them properly. He had a person in his office who helped with tasks like bill paying, and she moved from the periodic check to working with my mother to pay bills jointly. Ultimately when my mother moved near family, one of the children took over, and another reviewed and checked everything as well as worked with her investment advisor.

But some family stories were essentially nightmares. Here is one example:

When my mother (living 1,500 miles away from me) had a caregiver, I found out that my mother was allowing the caregiver to take credit cards and buy things such as groceries and medicine. The caregiver went alone for lengthy periods and I began to wonder if the caregiver was making personal purchases. I went to the bank to make sure there was no fraud and the bank would not talk with me because there was no paperwork allowing it.

This is an important and difficult issue. My dad is almost 92 and still lives independently in his home with his wife who is 90. He has remained very healthy physically but seemed to begin some cognitive decline after hip replacement surgery at age 85. This led to him throwing out bills in the mail as if they were junk mail, requiring my step mom to monitor and fish the bills out of the waste basket and make sure they were paid. He gets very defensive about his declining abilities, but at least he agreed to get hearing aids! Unfortunately, we did not set up any voluntary “trip wire” system, but I think it is a great idea to do so well before the need is evident. My oldest brother visits my parents every two weeks, so he can help with using the computer, but I don’t think he has direct access to their accounts and bill payment system when he is at home.

Eventually, after both parents had suffered serious physical and cognitive decline, I talked them into letting me help. They agreed when he was in the hospital and unable, for weeks, to deal with bills. By the time my parents agreed to accept help, my father was in terrible shape and the bank insisted my father physically come to the bank to sign papers. He was in a wheelchair, could not walk, had bones that broke with the slightest movement and a caregiver had to lift him in and out of the car to go to the bank. The bank would not accept a notary visiting my parents.

My dad was wise enough to have put a medical POA in place so that when he was mentally incapacitated, the POA was triggered, allowing us to take care of his affairs. At that point, we discovered he was being scammed by multiple parties that were draining his accounts in small enough increments so as to avoid detection.

Bottom line about my parents: One refuses to address the situation, and one addressed it at a minimal level and was still victimized. This can be a difficult conversation to have for various reasons, even with the best-intended and well-meaning caretakers.

One commenter focused on a situation where the problems were not addressed before the father had died, thus mixing estate complexity with grief. This is the story:

After his death, we learned that my father had been secretly borrowing money from my sister. I was the executor without an accountant or lawyer, and the process, which included me getting served with a sheriff’s notice about the sale of the reverse-mortgaged house, took a couple of years to work out. My wife’s parents left everything tidy, but it still took years to pry money (old HSA’s for instance) loose from various banks and wirehouses and the process cost five figures in legal fees. We hope to spare our children similar anxiety. Such stories come in many flavors. Our neighbor was telling us about her bitter fight over family antiques with her father’s second wife. We must keep perspective, however. These are first world problems, and the hassles are of course dwarfed by the grief.
Physicians and facilities can be a barrier

That statement may seem counterintuitive, but some discussants said it does happen. Consider the following:

I appreciate all of the commentary on cognitive decline. I’ll raise an additional issue—physicians and care facilities can sometimes have strong financial incentives to keep patients who pay their bills, even if these patients are no longer fully competent to make decisions on their own.

Here is what happened to my mother and stepfather. My stepfather spent much of his career building and running a financial planning practice with a major insurance company. We tried hard to put into place the right tools including property and health care POAs and Trust documents and had extensive conversations with them about what they wanted when they could no longer care for themselves. My mother is now suffering with significant dementia and my stepfather has advanced Parkinson’s. They had been living apart given their different needs, especially my mom’s perception that she was fine and didn’t need much care. After a hospitalization for a heart issue, my mother ended up in assisted living, which she stayed in for 3 years before we finally were able to get her out to a new facility (but not for lack of effort in trying to help). Her dementia and inability to recognize her limitations combined with her strong desire to be independent (and our desire to support her wishes) really led to problems.

Her assisted living facility, supposedly one of the best in the city of Chicago and recommended by the placement worker at the major hospital where she had been, was an enormous challenge. The facility claimed not to have seen any indicators of her inability to manage her own care over 3 years. When it was pointed out that she “forgot” to take her medication, they said that was normal for the elderly and if it only happened once or twice a month, wasn’t a big deal (they didn’t know how much it happened or not, of course). She was taking Coumadin, a medicine that requires an especially strict regimen. The facility never reached out to her physician or required that her medication be dispensed by the facility.

She was not able to open any mail or pay her bills, so my sister and I came to help and opened her mail every couple of months (neither of us lives in Chicago anymore). She could write a check if someone was standing there telling her the amount and who to write it out to for her monthly bill. Her room was filled with piles of unopened mail and she had almost 2 years of lost dividend checks that I eventually had to track down. She would repeatedly ask staff the same questions over and over. When the phone system was changed, she could not remember how to enter a new set of keystrokes to get voicemail. She had anger issues in the evening, yelling at staff and others. (As we have learned, this is so-called “sundowning.”) Apparently, none of these issues was a warning sign to either the facility or her physician of cognitive decline.

Her physician, not a geriatrician, would neither refer her to get a cognitive test, despite repeated requests by family, nor refer her to a physician knowledgeable about caring for the elderly. When we would call and give him examples of my mother’s inability to care for herself, he would either ignore them or ask my mother (just as with the driver’s license). He was a physician in one of these so-called clubs where patients pay extra for boutique care.

When we finally got her out of Chicago and to Pittsburgh and my mother was seen by geriatric professionals, they were appalled that she was allowed to drive, take her own medication, ... She has advanced dementia between stage 4 and 5. We had to invoke the POA for health care as a family, since she refused to sign forms to allow the new facility to give her medication.

We are now managing the finances for my stepfather and mom and they are getting the help they need in a facility that is understanding of their problems and has set up specific care plans for each of them working with physicians and family members. Family visits them almost every day. We live with guilt of not having acted sooner, especially if she had hurt someone while driving or gotten lost in her car. It has been very hard to get here.
Fraud and scams are a problem

Numerous financial providers, professional groups and governmental bodies have published warning signs about potential scams on the elder. Many also include suggestions on what to do should the worst happen. But fraudsters still try, as the next story illustrates.

Our health care and financial system is still not set up to help the elderly. My mother got a phone call from a scam artist before leaving Chicago. The caller wanted to get her to wire money for her grandchild to get released in a foreign country. The fact that her money is managed by a finance professional meant she could not just go into a bank and sign wiring instructions. The office that manages her money wouldn’t have wired the money without checking with relatives. But for many others, these safeguards may not be in place if the local bankers don’t know their clients.

Conclusions

This discussion about cognitive decline and finances has yielded many interesting anecdotes and stories. Said one discussant: it is fascinating that even this group of experts has fallen back on anecdotes. There are important lessons from this: There are no good data. Every dementia story is different and every person with dementia is different. Every family is different, and those complex dynamics drive very different solutions.

The SOA research with individuals as they progress through retirement does not offer data on cognitive decline, and we do not define exactly, what cognitive decline entails. The research does, however, make clear that by age 85, the majority of people need some help and the family is often central to the help. This online conversation reinforces the value and importance of strong family communication, but also reminds us that parents and children may not have the same perspectives and may not agree on how to proceed. Ideally, they will work together in a constructive way, but that does not always happen.

Open and honest communications are the start of good solutions. Spouses need to talk honestly with their spouses; parents need to talk honestly with their adult children, and vice versa; and adult children need to talk honestly among themselves about their parents. This, of course, is very often much more easily said than done. The intervention of a trusted third party may help. Where the parties can’t agree, then a new solution is needed.

The SOA conversation touched only briefly on the situation where people without family members who are available to help. This is an important topic that needs much more consideration.

As for decisions about long-term care insurance, Medicare and Medicaid, the online conversation pointed up that although all options can play a role in financing care, sometimes none can solve the problems mentioned in the stories. However, the overall takeaway was more positive—namely, that long-term care insurance, Medicare and Medicaid can increase options for older people with dementia, cognitive decline or other debilitating conditions, and these options may contribute to solutions.

Where no one is available to help, the courts may appoint a guardian. Only briefly mentioned are trusts and powers of attorney. The right legal steps are needed, and it is important to work with an attorney to put them in place. In some situations, these steps must be taken in advance of declining health or mental capacity. Some people are not willing to do that, and the legal issues will have to be dealt with as the problems emerge. That can make the situation more difficult for the individual and for concerned others. Where no one is available to help, the courts may appoint a guardian, a point that the commenters did not bring up but one that is built into the legal system.
Physicians, social workers, and health care facilities can be an important part of the solution, but they are not always helpful. The stories cited here remind us of the need to work with the right support people, and to seek other help when things do not feel right.

It is recommended that the report be read together with the SOA research on individuals age 85 and over. The in-depth interviews and surveys with individuals and their adult children offer broader perspective on the challenges faced by this group and the ways they manage their finances.

Note: Older age individuals with dementia and cognitive decline face many legal issues related to guardianship, powers of attorney, advance directives, and more. There are also many societal approaches to consider when helping people manage. These legal issues are beyond the scope of this report.
Resources

Post-Retirement Experiences of Individuals Age 85 and Over, Society of Actuaries, 2018
https://www.soa.org/research/topics/research-post-retirement-needs-and-risks/#decisions. This includes two reports—one of in-depth interviews and one of two surveys.

Family Caregiver Alliance Website https://www.caregiver.org
Introductory videos: https://www.youtube.com/user/CAREGIVERdotORG

Vernon, Steve, “Lessons from a good death,” MoneyWatch, September 12, 2013,

Rao, Anitha “A Neurologist’s Deep Dive into Insurtech”, Society of Actuaries Long-Term Care News, April 2018
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The Society of Actuaries (SOA), formed in 1949, is one of the largest actuarial professional organizations in the world dedicated to serving 30,000 actuarial members and the public in the United States, Canada and worldwide. In line with the SOA Vision Statement, actuaries act as business leaders who develop and use mathematical models to measure and manage risk in support of financial security for individuals, organizations and the public.

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