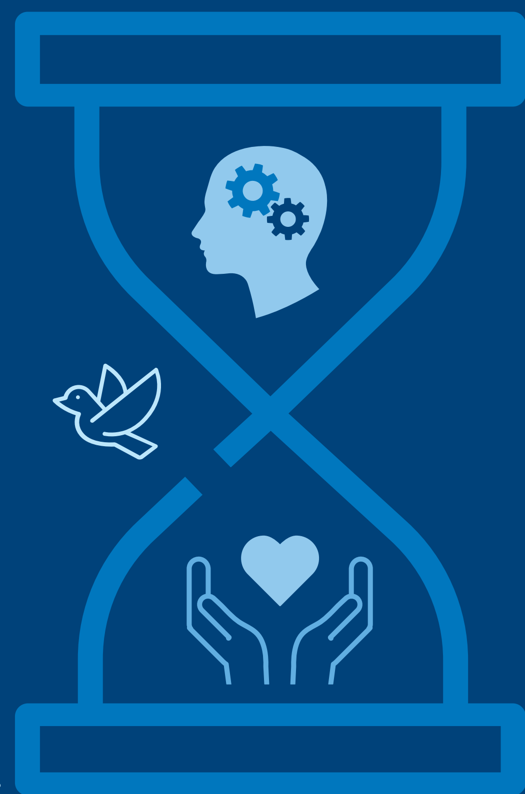
Wealth Insights

Insights into trends, forces and factors shaping the world and your wealth

Preparing for the expected

The financial impact of cognitive decline



RBC Wealth Management

Preparing for the expected

Cognitive decline can have devastating impacts not just on those diagnosed with the disease, but on their caregivers as well. These physical, emotional and financial burdens of caregiving can put individuals and families in a precarious position. In a survey conducted by RBC Wealth Management-U.S., we asked caregivers to share their experiences and how they were affected.

Of the many risks to financial well-being, it's clear that an extended long-term care event ranks at the top of the list.

Cognitive decline is a general term for some level of impaired cognitive functioning. A person with cognitive decline is at an increased risk of developing dementia or Alzheimer's disease, the most common form of dementia. A dementia-related diagnosis can be financially devastating, and the number of people affected is on the rise. Currently, cognitive decline affects 5.8 million people, and that is expected to double by 2040, according to the Alzheimer's Association. Not only is there a significant financial impact to the person affected by the disease, but on their caregivers as well. Yet few families factor this impact into their wealth plans.

To shine a spotlight on the importance of planning for the costs associated with dementia, RBC Wealth Management–U.S. commissioned a survey from Aon to better understand the financial impacts of dementia on families. The survey included responses from 1,000 current and former caregivers, who shared their insights and experiences.

Our findings confirm the expected—the high lifetime cost associated with the disease and the high risk of financial mismanagement by impacted individuals—but also exposed the unexpected, namely the massive financial burden on caregivers, particularly women.

The survey also highlighted the frustration caregivers feel with a lack of resources and guidance for both themselves and the affected person, contributing to a lack of confidence in their own financial future.

RBC Wealth Management–U.S. caregiver study The study was conducted between November and December 2019 via online survey and focused on 1,000 mass affluent and high-net-worth individuals (HNWIs) in the United States. It included current and former caregivers of family members and non-family members experiencing cognitive decline or dementia, but excluded professional caregivers. The study also included qualitative in-depth interviews with financial advisors and executives who have clients and/or family members who have dealt with, or are currently dealing with, cognitive decline or dementia.

As Americans live longer, the risk of cognitive decline increases

Advances in health care and technology have made living into one's 80s and 90s common—and for many, expected. But with longevity comes a greater risk of developing a cognitive disorder that will require long-term care—an expense that can exceed the annual cost of tuition and room and board at a private college.

At RBC Wealth Management–U.S., we stand ready to help clients plan for the expected and the unexpected.

By exploring the findings within this Wealth Insights report, we hope to help families better prepare for the future. When there is a diagnosis, we can help mitigate the many financial risks associated with the disease and provide valuable advice and resources to help you in your care journey.

Highlights of the RBC Caregiver survey

While more Americans are factoring longer life expectancies into their retirement years, most have yet to account for how a dementia diagnosis may impact those plans. The ensuing impact on their own finances—as well as the finances of their children and grandchildren—can be devastating.

- **The overall lifetime cost of care can be financially devastating,** often exceeding $750,000.
- **Financial mismanagement is a real concern,** with 80% of caregivers reporting some level of financial mismanagement by the individual they cared for. The study included both past and present caregivers.
- **Women are disproportionately providing the care** and taking the financial hit.
- **Caregivers also share the financial burden, both directly and indirectly.** 83% of caregivers surveyed shared the financial burden by contributing directly and/or indirectly, with 54% of the caregivers changing their work arrangements.
- **Surprisingly, caregiving duties are impacting younger families,** putting a further squeeze on the Sandwich Generation.

Cognitive decline is the most expensive disease in the United States.

The overall lifetime cost of care for someone diagnosed with a progressive cognitive disorder can be financially devastating, often exceeding $750,000 when you factor in the direct and indirect costs to the caregiver(s) and related financial mishaps. The price tag on the disease is escalated by the propensity of individuals with cognitive decline to make poor financial decisions that can further impair their finances.

A hefty price tag

Given the financial price tag and prevalence of this disease, it is surprising that few families have planned for the potential impact.

There's no cure for dementia at the moment, and the disease itself develops before symptoms begin.

Closely associated with a progressive dementia diagnosis like Alzheimer's is the need for daily living care, which often evolves to the need for full-time skilled nursing care in a memory care community. The duration of this disease, and the fact that most daily living expenses are not covered by Medicare, makes the total cost of care financially devastating for most families.

In 2019, the national average cost for a semi-private room in a nursing home was $247 a day or $7,513 per month, according to Genworth's Cost of Care Survey. That translates into $90,155 a year. With the average nursing home stay of five years for an individual with Alzheimer's, the price tag for skilled care exceeds $450,000.[1]

To put this figure into perspective, the average cost of undergraduate tuition, fees and room and board at a private college for the 2019–2020 academic year was $49,870, or nearly $200,000 for a four-year degree.[2]

"Families are more likely to take the costs of funding a child or grandchild's education into account than they are to prepare for the financial risk of a dementia diagnosis," says Ann Senne, head, Advice and Solutions.

Just as there are tools that can help make the high cost of college more manageable, similar financial tools exist to take the sting out of paying for long-term care, including long-term care insurance. But a proclivity for individuals to delay difficult conversations about illness or death often stands in the way of families and individuals embracing those tools.

"Putting money aside today for a future positive like college is easy," says Senne. "But putting money aside for a future negative like dementia is something that most people don't want to think or talk about."

11.6m

is the projected number of Americans who will be living with Alzheimer's, dementia and other memory disorders by the year 2040—double the amount of people living with these diseases today.

1 in 10

Americans age 65 and older has Alzheimer's dementia. 1 in 3 people who live to be 85 expect to die with a dementia-related disease.

80%

of all dementia cases are diagnosed as Alzheimer's disease, the most common form of dementia.

Understand the early warning signs

Often the early signs of decreased mental capacity are seen in the way everyday finances are handled.

Routines

Difficulty with routine financial tasks

Mail piling up, inability to organize bills and receipts

Difficulty handling money or paying bills, paying the same bill multiple times, or missing a payment

Forgetting to pay taxes

Relationships

A sudden change in a financial relationship with financial advisors or a financial institution

Unexplained changes to financial accounts, mailing address or passwords

New interest in a phone solicitor or unusual email activity

New or unusual charitable giving

Requests

Unusual requests or repeated requests for the same information

Frequent username or password resets

Inability to make basic decisions, needing repetitive explanations

Difficult to reach, has been denied access to his or her money

Risk

A sudden or escalating change in investment style or increase in credit facilities or loans

Unexplained interest in riskier investments

Sudden or increased trading or spending patterns or abrupt changes in financial assets

Sudden lack of activity, indecisiveness or disinterest

A heightened risk of financial mismanagement

Even prior to a diagnosis of cognitive decline, a person in the early stages of the disease faces a growing risk of adverse financial outcomes—a consequence of compromised decision making in addition to exploitation by others.

Another financial risk factor associated with dementia is an increasing likelihood of financial mismanagement.

According to caregivers in our study, 80% of people affected by dementia have at some point experienced financial mismanagement. In reality, these figures are likely much higher because most financial mismanagement and abuse goes unreported.

Financial missteps are often an early warning sign of dementia. Unpaid bills, unusual spending, unopened statements, or repeated calls to advisors over the same concern can all be early warning signs and even signs of financial fraud or abuse.

"It is important to understand these early warning signs," says Wally Chapman, central division director, RBC Wealth Management–U.S. "As a new caregiver, you first focus on keeping your loved one safe physically, but over time you learn that you also need to protect that person financially from mistakes that can lead to fraud, identify theft, or financial abuse."

A telling story

Consider the experiences of Nancy Carlson, author and illustrator of children's books, whose husband Barry was diagnosed with a form of dementia. A successful business owner before his diagnosis, Barry also served as Carlson's business manager. Before Carlson realized he was ill, Barry had made a series of poor financial decisions that resulted in the couple selling their home, their cars and other assets to pay off their debt.

"My husband expressed that he felt odd," says Carlson. He could never put a finger on it. "He had stopped paying taxes, which I had no idea about. Probably five years after that, it really became apparent. He was really failing on almost everything he did for my career." By the time that she had unraveled the financial knot, there was not one penny left. Her story is one that countless other spouses, children and caretakers of individuals with dementia will come to understand—and one that we strive to help clients prepare for.

In hindsight, Carlson says that her biggest mistake was putting her husband in charge of everything. "I never even asked about it," says Carlson. "He had me sign things, and I never even asked what they were. It is important to invest in understanding every aspect of your finances."

Nancy Carlson is a successful children's book author and illustrator who has published more than 60 books over the course of her career. Her life took an unexpected turn when her husband of 30 years started making a series of bad financial decisions that resulted in the couple selling off their home, their cars and other assets to pay off the debt.

LEARN MORE ABOUT NANCY'S STORY AT RBCWM.COM.

> **"Seemingly small financial missteps can have profound and lasting implications. As a caregiver, you need to protect your loved one financially from mistakes that can lead to fraud, identify theft or financial abuse."**
>
> TARA AMBROSE, MANAGER OF SENIOR AND VULNERABLE CLIENT INITIATIVES AT RBC WEALTH MANAGEMENT–U.S.

Picking up the pieces

"Caregivers often face the reality of picking up the pieces of a financial mess and having to put the pieces back together," says Angie O'Leary, head of Wealth Planning, RBC Wealth Management–U.S. "I noticed that my father-in-law, who died of dementia-related complications, usually had all his paperwork well-organized and filed away. When we saw bills and statements covering most of the open surfaces in his house, we knew something was up. Luckily there were no serious missteps, but cleaning up the mess and getting things back on track took months."

The survey also highlights the importance of having a "financial caregiver," someone who is trusted with the financial decisions and daily tasks. In fact, 88% of the caregivers who participated in the survey said they handle at least one of these financial caregiving tasks for their diagnosed loved ones:

- Keeping track of their bills and expenses
- Paying bills from the family member's accounts
- Providing financial support for family members by paying expenses from their personal accounts
- Managing their wealth and investments
- Other financial care

"Given these risks, financial advisors provide an additional layer of financial oversight," says Chapman. "They work with families to facilitate difficult or uncomfortable conversations about the possibility, the cost, care preferences as well as the demands of caregiving."

One of the best ways to lighten the cognitive load as you age is to bring others into the wealth planning process. A big part of supporting clients also centers on raising awareness around what resources are available. RBC Wealth Management–U.S. advisors work with families to build and formalize plans, conduct financial stress tests and help develop their networks. Getting the family connected to the local chapter of the Alzheimer's Association is often a first step and can be a lifeline for the family.

No matter how uncomfortable, it's always best to start thinking about the practicalities of caregiving and associated costs and risks.

Trusted contact

As the incidence of dementia rises, the risk of financial missteps or falling victim to fraud schemes targeting seniors also goes up.

As you age—or as you see early signs of capacity decline in a loved one—an important preventive step is to ask a trusted family member or close friend to review financial statements on a regular basis. It may also be a good idea to provide your financial institution with a trusted contact, which will help facilitate prompt discussions when there is suspected fraud or a decline in judgment.

The securities industry now requires financial advisors to ask all clients for a trusted contact number, a rule designed to help protect the growing number of vulnerable people as the population ages.

The financial impact to caregivers

Caring for someone with cognitive decline is a long, stressful, emotional journey. There are also significant—and unexpected—financial impacts on caregivers.

According to the RBC Wealth Management–U.S. study, 83% of caregivers make financial contributions to support their loved one's day-to-day needs. These contributions total $17,780 each year, on average, creating further financial strain for most families.

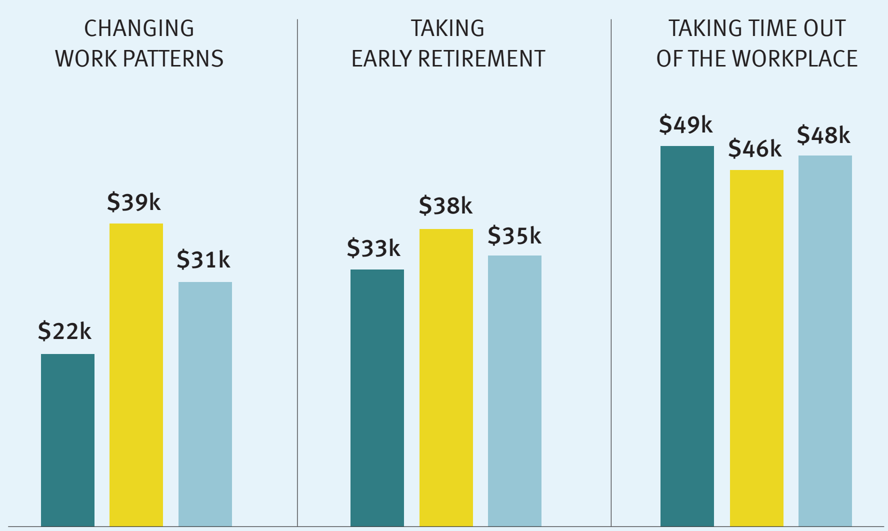
"When it comes to cognitive decline, caregiver expenses aren't just a one-time outlay. They build and increase over time," says O'Leary. "Depending on the type, cognitive decline is a journey that can last five to 15 years, on average."

That means the cumulative financial cost to caregivers, assuming the $17,780 average identified in the study, is between approximately $50,000 and $260,000. The costs caregivers incur can be both direct and indirect. Direct costs include spending on things like grocery shopping, medication, utilities, bills and other household expenses. Indirect costs include changes to employment, such as going from full- to part-time work, career pauses, or taking early retirement or a leave of absence to dedicate necessary time to caregiving duties. These unexpected expenses have a tremendous impact on families and generally require them to pull back on or give up on other financial goals and dreams, O'Leary says.

Caregivers forgo almost $38,000 of annual income as a result of their responsibilities

While most caregivers (59%) experience direct expenses only, over one-fifth (21%) are faced with both direct and/or indirect costs. Adding to this loss is often lower retirement savings, career gaps and missed career advancements, putting further stress on long-term financial wellness.

Average annual income given up as a result of:



Women: Total average annual income loss, $35,000

Men: Total average annual income loss, $41,000

All: Total average annual income loss, $38,000

83%
of caregivers contribute financially through direct and/or indirect costs to support their loved one's daily needs, totaling $17,780 annually.

80%
of caregivers contribute $11,176 annually in out-of-pocket expenses.

24%
of caregivers experience an average annual income loss of $37,992.

21%
of caregivers face both out-of-pocket expenses and income loss totaling $48,259.

Navigating financial matters

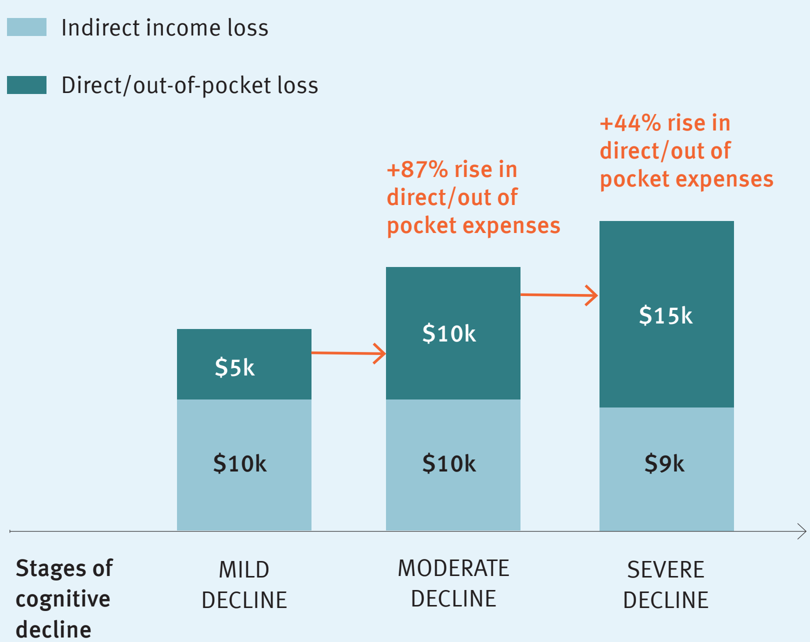
Given how quickly costs can add up, it's important to keep a budget and track expenses. Caregivers need to understand what expenses are covered by insurance and need to balance what they pick up financially versus what should be paid out of their loved one's estate. Caregivers also need a financial plan to help them understand the impact that caregiving decisions, such as taking a career break, have on their long-term plan.

Those taking care of a person with mild cognitive decline spend, on average, $452 per month. This cost increases to $846 per month when the affected person experiences moderate decline (an 87% increase), with the cost reflecting rising health care and living expenses.

Expenses soar to $1,216 per month for those caring for someone with severe cognitive decline.

The financial impact of caregiving

Costs generally increase with each stage of cognitive decline, from approximately $15,500 per year for those caring for someone with mild decline to nearly $25,000 when the affected person reaches the stage of severe decline. This increase in costs is especially true for direct expenses, which rise by 87% as the affected person advances from the mild to moderate stage.



Source: RBC Wealth Management–U.S. and Aon, 2020.

A heavy burden on her shoulders

Many female caregivers are sacrificing their own time, health, careers, finances and relationships for the sake of their loved ones.

Our survey found that women are involved earlier and provide more physical care than men, with greater impact to their careers and finances

It's long been known that the majority of caregiving for cognitive decline falls on women's shoulders. In fact, two-thirds of the primary unpaid caregivers of those with Alzheimer's are female.

Yet little research has been done to quantify the contributions of female caregivers and the impact those contributions have on their financial health and well-being.

Our study found that caregiving for cognitive decline brings more significant trade-offs for women than men in terms of career disruption and sacrificed personal time. Women typically intervene at an earlier stage of the diagnosis to support affected family members and therefore experience a longer overall journey.

For example, 64% of the caregivers assisting loved ones experiencing mild symptoms of dementia (for example, occasionally misplacing items or struggling to remember names or dates) are women.

The pressure to intervene early is unique to the disease, says O'Leary. "With most other diseases, the caregiver is in and out much more quickly. With dementia, you start with the diagnosis, which is intense. You can then go through three to four different transitions of levels of care and living arrangements. By the time your loved one is in memory care, it's very expensive and challenging for both the impacted person and the caregiver."

In contrast, male caregivers typically get involved as the affected person's condition becomes more serious and they exhibit signs of moderate to severe decline (such as wandering, memory loss or struggling with daily tasks).

These trade-offs can have lasting financial implications. Over time, female caregivers, even those in high-earning careers, experience a significant, negative impact on their income-generating capacity.

Often a full-time commitment

The intensity of women's involvement in caregiving is apparent both in the hours they dedicate and the specific tasks they undertake. Female caregivers carve out an average of 86 hours per month to accommodate their responsibilities, compared to 75 hours for men. And for 1 out of 8 female caregivers, the time commitment is significantly higher at 160 hours per month or more, which is equivalent to a full-time job, unpaid.

52%

of the female respondents were not very confident about their financial circumstances due to their extensive caregiving responsibilities.

44%

of women have changed their working patterns, including 26% who leave the workforce altogether. This can impact retirement savings, Social Security and health care insurance—and a woman's career opportunities.

42%

of women say they would like more help planning for the financial impact of caregiving and guidance on the resources available to them.

2/3

Approximately two-thirds of caregivers are women.

For 1 out of 8 female caregivers, the time commitment is 160 hours per month or more, which is equivalent to a full-time job, unpaid. These reduced hours and job leaves are costing women caregivers approximately $35,000 in annual income.

A double whammy for women: Providing more care while sacrificing their own financial security

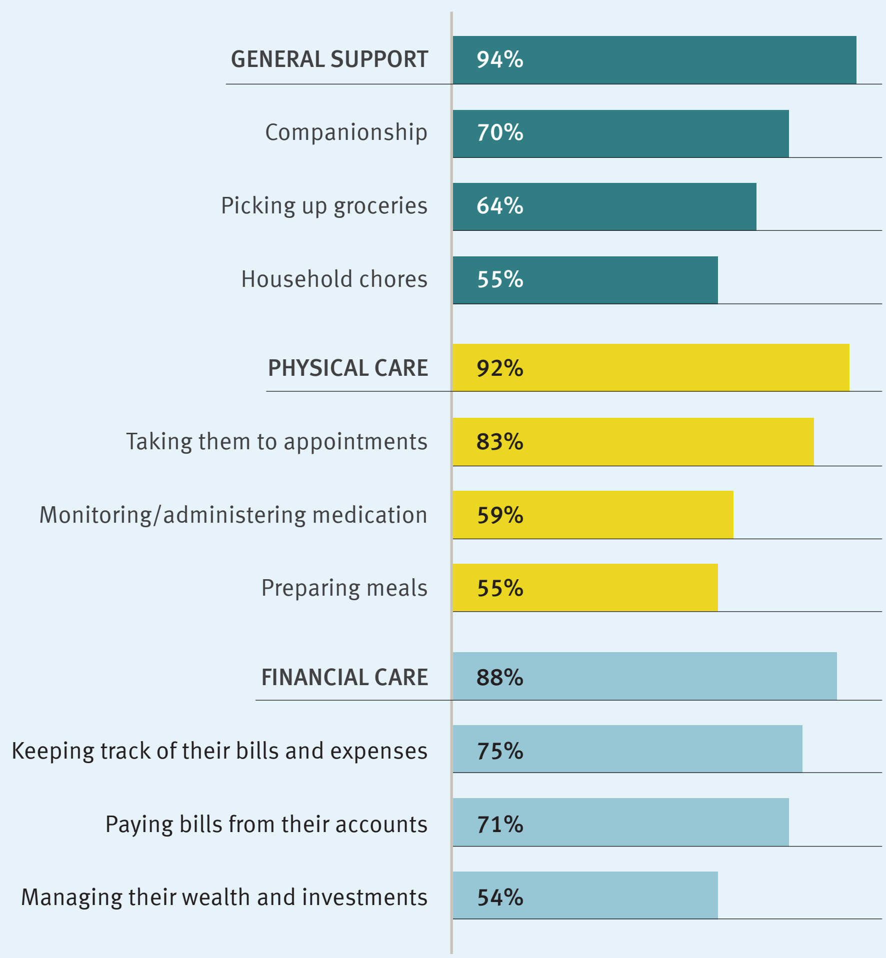
While most caregivers provide broad support to family members affected with cognitive decline, caregiving often aligns with gender stereotypes. Women primarily take charge of physical care duties that require them to be present in the home—for instance, helping with bathing and dressing, preparing meals, household chores, grocery shopping and driving. In contrast, male caregivers tend to provide more financial support and take on wealth management responsibilities.

Against this backdrop, caregivers should have a plan that addresses the reality of caring for someone with this disease, especially if they are not the spouse. Understanding both the direct and indirect costs and factoring different scenarios for the type and length of caregiving is helpful.

Advisors can help caregivers understand and plan for these costs, explore various care arrangements and make sure that the caregiver has the resources they need. Sometimes it's as simple as setting up automated bill payments or consolidating accounts. In other cases, advisors can help caregivers by confirming the proper estate documents are in place, including a power of attorney and health care directive.

Most caregivers provide multiple points of care:

Caregiving is a selfless act that takes an emotional, physical and financial toll. At first caregiving seems manageable—until it isn't. Short-term commitments often stretch into years, upending lives and careers.



The Sandwich Generation feels more of the squeeze

Just as there is a gender imbalance in caregiving, our study found a surprising new perspective on the further squeeze felt by the Sandwich Generation.

Typically between the ages of 30–59, the Sandwich Generation is so called for their role in caring for their children and older family members at the same time.

As the Baby Boomers age, it is increasingly the Sandwich Generation that assumes caregiving responsibilities for loved ones, which requires them to provide physical, emotional and financial support to multiple generations simultaneously.

"This remarkable group plays a vital role in caring for children and for older family members at the same time," says O'Leary. "In many respects, they are the linchpin that holds multigenerational families together. But their role is made infinitely more challenging when caring for a family member with cognitive decline."

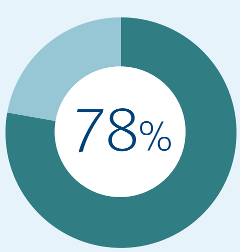
Of the 1,000 respondents to our survey, 253 were caregivers under the age of 60 who also have children and therefore fit the Sandwich Generation definition. Of those Sandwich Generation caregivers, 86% say their loved ones are in the moderate or severe stages of cognitive decline (compared with 72% of other caregivers).

"Given the myriad responsibilities the Sandwich Generation juggle in their daily lives, they are concerned about missing something—such as identity theft, fraud or financial abuse—that could have

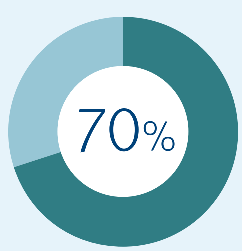
The Sandwich Generation bears greater financial responsibilities when caregiving

Not surprisingly, our survey found that caregiving in the later stages of cognitive decline requires more time and resources from caregivers. Indeed, 58% of Sandwich Generation respondents said they manage the wealth and investments of their loved one, while 47% pay their family member's bills themselves.

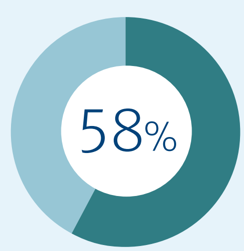
Due to the severity of the disease, and the financial commitments this generation undertakes, they face out-of-pocket costs of approximately $900 per month—31% higher than the expenses shouldered by other caregivers.



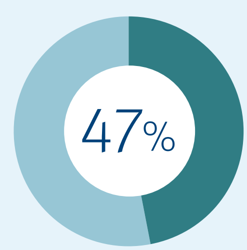
Keep track of the bills and expenses of the person they care for



Pay the person's bills from the person's accounts



Manage the person's wealth and investments



Provide financial support by paying the person's bills themselves

> **"Given the myriad responsibilities the Sandwich Generation juggle in their daily lives, they are concerned about missing something—such as identity theft, fraud or financial abuse—that could have serious repercussions on their loved ones affected by cognitive decline."**
>
> ANGIE O'LEARY, HEAD, WEALTH PLANNING AT RBC WEALTH MANAGEMENT–U.S.

serious repercussions on their loved ones affected by cognitive decline," O'Leary says.

It is for this reason members of the Sandwich Generation are raising their hands to ask for any and all types of assistance: in particular, caregiver support groups, better training or active assistance from a social worker and, of course, help with their finances.

Challenging tradeoffs

But caregivers in the Sandwich Generation are also more concerned than other caregivers about their own financial health.

Our study finds that, on average, caregivers in the Sandwich Generation dedicate 76 hours a month to caregiving. Their responsibilities force them to make significant adjustments to their professional choices—with a corresponding impact on their financial security.

Nearly one-third (30%) have changed their employment arrangements, so they can work from home more often; 17% have gone part-time and 13% have changed jobs to be more flexible. Another 13% have moved closer to their loved one.

"The pressures the Sandwich Generation face and the trade-offs they have to make when juggling their dual roles as parents and caregivers to a loved one with cognitive decline has left many in a financially precarious situation," O'Leary says.

It's no surprise that they are also more likely than other caregivers to want financial advice.

Helpful resources and tools for caregivers

According to our survey, caregivers in the Sandwich Generation are more likely than other caregivers to want financial advice.

Below, financial resources and tools are ranked by the order of their importance to the Sandwich Generation caregivers in our survey.

1. A financial advisor (47%)
2. Account-monitoring tools (42%)
3. Guidance from the Alzheimer's Association (39%)
4. Access to support from AARP Caregiving (36%)
5. Monthly budget calculator (33%)
6. Retirement planning guidance (32%)

Protect your loved ones through planning

If you haven't yet dealt with the challenge of a family member showing signs of mental decline, you likely will. Now is the time to prepare.

Take action

- ☐ **Plan ahead, especially when there is increased risk** (age, injury, gender or hereditary factors). Understand the costs and the care journey. Incorporate a long-term event scenario into your wealth plan to better understand the implications.
- ☐ **Consider supplemental insurance**, including long-term care options. There are a range of protection strategies to better prepare for unexpected health care expenses.
- ☐ **Ensure your key legal documents (power of attorney, health care directive and will) are in order**, your assets are properly titled and your beneficiary designations are current.
- ☐ **Understand the early warning signs.** If you have concerns about your own or a family member's mental capacity, contact the appropriate financial and legal professionals.
- ☐ **Consider the benefits of establishing a trust and using a professional trustee service**, especially in the absence of a competent personal executor or family member.
- ☐ **After a diagnosis, act swiftly to protect the family from financial missteps, abuse and liability.** A plan for transitioning financial and legal capacity should be put into motion.
- ☐ **Plan for the long haul** and the various stages of the disease and related levels of care.
- ☐ **For caregivers still in their career years, explore your employer benefits,** including family leave benefits and flexible working arrangements.
- ☐ **Make sure you and your caregivers have access** to valuable resources that can ease the burden of your care journey.

> **"If you or your loved one is diagnosed with dementia, the financial stakes are high. We as an industry have a responsibility to help our clients and their families navigate these tough waters."**
>
> MICHAEL ARMSTRONG, CEO OF RBC WEALTH MANAGEMENT–U.S.

Make a plan today

Every successful journey begins with a starting point, a destination and a plan to get there safely.

Your RBC Wealth Management–U.S. financial advisor offers a goals-based planning process to help you clearly see your full financial picture, with all its potential. With his or her professional expertise and the tools and resources available from RBC Wealth Management–U.S., taking action on your plan will help you prepare for the opportunities and challenges ahead—so you can enjoy clarity today and confidence for tomorrow.

If you are interested in learning more about how a quality wealth plan can help prepare you for the financial impacts of dementia, the process begins with a simple conversation.

Contact us today to get started.

About Wealth Insights

Your financial journey is enhanced by a clear understanding of where you are today and the strategic options that can guide you toward a more secure tomorrow. We are committed to delivering insights that educate, equip and engage you for that journey. Wealth Insights is a series of papers and articles focused on important wealth planning topics. Planning for the expected and the unexpected builds confidence in your plans for today and tomorrow.

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