

The Financial Impact of Dementia

A family strives to return to financial health
following a dementia diagnosis



Wealth
Management

The financial impact of dementia

By the time doctors diagnosed Nancy Carlson's husband with frontotemporal degeneration (FTD), a little-known form of dementia that most commonly strikes people under age 60, the damage—both physical and financial—had already been done.

Once affable and organized, Carlson's husband Barry McCool had become irritable and erratic. He had taken out tens of thousands of dollars in loans that he could not pay back, racked up astronomical credit card debt and owed years in back taxes to the IRS.

"It wasn't him," Carlson says, "It was the disease. I had no worries before the disease hit. He was so on top of things. But then it spiraled."

Today, more than seven years after Barry's diagnosis and a year after his death, Carlson, a well-known author and illustrator of children's books, is trying to put her financial life back together.

"There is basically not one penny left," she says.

Carlson's story is one that countless other spouses, children and caretakers of individuals with dementia know all too well—and one that many more still will come to understand. Dementia-related diagnoses are rising sharply. According to the Alzheimer's Association, the number of Americans living with dementia may nearly triple by 2050. Because age is the primary risk factor with Alzheimer's, baby boomers, the first wave of whom are now in their early 70s, are a driving force behind this trend.

"The odds are that you are likely to have some experience with this disease either directly or as a close family member," says Angie O'Leary, Head of Wealth Planning for RBC Wealth Management-U.S.

The increasing rate of dementia diagnoses will clearly impact the health care system. What is not as obvious, but of critical importance, is the negative financial impact the disease will have on a generation of Americans and their families.

"Financially, a dementia diagnosis is one of the most devastating," says Michael Armstrong, CEO of RBC Wealth Management-U.S. "For many families the implications are not visible until they look in the rearview mirror."

For those facing dementia at a young age, the circumstances can be particularly dire. A study funded by the Association for Frontotemporal Degeneration (AFTD) and published in November 2017 in the journal *Neurology* found that young-onset dementia—and specifically, FTD—



Nancy Carlson is a successful children's book author and illustrator who has published more than 60 books over the course of her career.

can cost \$119,654 annually, nearly two times the average annual costs associated with Alzheimer's.

"Nancy and other FTD caregivers have reported to us firsthand the uniquely devastating financial impact of young-onset dementias," says AFTD CEO Susan L-J Dickinson. "This study gives us numbers to go along with the anecdotes—and the financial toll of this disease is even more devastating than we imagined."

"If you or your loved one is diagnosed with any form of dementia, the financial stakes are high," Armstrong says. "We as an industry have a responsibility to help our clients and their families navigate these tough waters. Planning ahead



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MICHAEL ARMSTRONG, CEO OF RBC WEALTH MANAGEMENT-U.S.

People with dementia are living longer, and the costs are escalating. Some of that cost is unpaid work by family and friends. There's no cure for dementia at the moment, and the disease itself develops before symptoms begin.

for the unexpected and having a ready action plan designed to safely transition financial and legal capacity can help manage the financial implications.”

DEMENTIA'S TOLL ON FINANCIAL DECISION MAKING

One of the early warning signs of Alzheimer's and other forms of dementia is decreased or poor judgment and decision making. This may become particularly noticeable in how someone is handling money.

Difficulty organizing and paying bills was the first visual sign O'Leary noticed in her father-in-law, who died of dementia-related complications. “Usually, he had everything 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 unraveling the mess and getting things back on track took months.”

But many families do not realize what is happening until it is too late.

That was the case for Carlson. Since the very start of her career, Barry had served as her business manager. He handled her book contracts, arranged her

speaking engagements and managed the couple's finances.

But around 2008 to 2009, the book contracts and speaking engagements started to dry up. Carlson first chalked it up to the recession, but soon she began to discover it was a series of bad financial decisions that were impacting not only her business but the couple's financial stability.

Unbeknownst to either Carlson or her husband, Barry was suffering from frontotemporal degeneration, a form of younger-onset dementia that, according to AFTD, can cause profound

Diagnosing Alzheimer's requires a careful and comprehensive medical evaluation.

changes in personality, behavior, language and/or movement. For Carlson, Barry's diagnosis was a relief; an explanation for the uncharacteristic behavior he had exhibited for years leading up to his diagnosis.

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About dementia

Dementia is not a specific disease. It's an overall term that describes a wide range of symptoms associated with a decline in memory or other thinking skills severe enough to reduce a person's ability to perform everyday activities.

While there are many forms of dementia, Alzheimer's is the most common and accounts for 60 to 80 percent of dementia cases. **One in 10 people 65 and older have Alzheimer's, and one in three over age 85 have the disease.** While the greatest known risk factor is increasing age, Alzheimer's is not a normal part of aging.

In addition, **approximately 200,000 Americans under the age of 65 have younger-onset Alzheimer's disease** (also known as early-onset Alzheimer's).

And for people under 60, the most common form of dementia is frontotemporal degeneration (FTD), representing **more than 60,000 cases** in the United States.

There is no one test to determine whether someone has dementia. A diagnosis is made through a complete assessment that considers all possible symptoms. If you or a loved one has concerns about memory loss or other symptoms of Alzheimer's or another form of dementia, it is important to be evaluated by a physician.

A conversation with Nancy Carlson



Nancy was a successful artist and illustrator.

But her life—as well as her career and business—took an unexpected turn when Barry McCool, her husband of 30 years, started making a series of bad financial decisions that resulted in the couple selling their home, their cars and other assets to pay off the debt McCool incurred. Eventually, McCool was diagnosed with frontotemporal degeneration (FTD), a form of early dementia that causes profound personality changes. For Carlson, McCool's diagnosis was a relief; an explanation for the uncharacteristic behavior he had exhibited for years leading up to his diagnosis.

Today, in addition to continuing her work as a children's author, Nancy devotes her time to telling her

story in the hope her wisdom from years of dealing with FTD may help others.

Q: Tell me a little about your life before Barry's diagnosis.

A: Barry had a successful design firm and made good money. Before FTD, he was so organized. Every t was crossed and i dotted. He really had a head for numbers. He looked ahead and planned; he knew where we were financially.

Q: What were the first signs that something was wrong?

A: One thing about FTD, this particular form he had, which is behavioral, is that they don't know they have anything. They never do. He expressed that he felt odd. He never could put his finger on it. He stopped paying taxes in 2006, 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. He was in charge of all my speaking and book

contracts, and he was doing a bad job. It was the perfect storm because it was also the recession (2008-2009), so everyone was having a hard time getting contracts. I was about to divorce him. I met with my lawyer friend. She asked, "Well, what is he doing? Why are you so irritated?" He was hiding things, taking batteries out of the phone, borrowing money from people. She said, "It sure sounds like my dad, who has dementia." She suggested I bring him to a neurology clinic. I took him, and he was diagnosed immediately with FTD (in 2011).

Q: After the diagnosis, what steps did you take to protect yourself financially?

A: The first thing the doctor did when Barry was diagnosed was give me the number for the Alzheimer's Association 24/7 Helpline (800-272-3900). FTD and Alzheimer's are different diseases, but the advice was relevant for both, and the steps you need to take are exactly the same: go to the Social Security office, go to the county, get his driver's license taken away.

Always get their license taken away. You can fall into huge debt if they get into an accident. A license is the hardest thing to take away. It was the only thing Barry showed emotion over.



Barry McCool and Nancy Carlson during better times.

I also filed Barry for bankruptcy when he was first diagnosed. That really good divorce attorney friend gave me that advice. She also gave me power of attorney papers and told me to get him to sign it ASAP and get it notarized. That's the first thing everyone should do, because people suffering from dementia lose the ability to write. Barry could write initially, but six months later he couldn't. That piece of paper saved me so much time and headache. No matter where I went, I had that piece of paper that said I had power of attorney.

Q: What advice do you have for others with loved ones suffering from dementia?

A: My biggest mistake was putting him in charge of everything. I never even asked about it. He had me sign things, and I never even asked what they were. Be aware of every part of your finances. Don't be afraid to confront them. Listen to friends. Friends can see things that you don't see. Barry was hired for two days to sell suits at Nordstrom's, and his boss said, "I have a bad feeling about you; you aren't going to work out." What did she see that I didn't see?

Q: How did you care for yourself during this process? What advice do you have for other caregivers?

A: It's really the hardest job you'll ever do. You have to take care of yourself. It sounds selfish, but it's not. I've met so many people whose health declines because of their partner's FTD. You can't do anything if you're not healthy.

Take it one step at a time. It's so overwhelming, especially for people like me. I am an artist; I am not mathematically gifted by any stretch of the imagination. You can do it; just don't get overwhelmed.

For me, therapy became hiking, travel, writing, reaching out to friends. It's really easy to become isolated when you have somebody you are taking care of.

The Association for Frontotemporal Degeneration (AFTD) was another great resource. I joined one of their support groups. There you are with people who have the same problem, and it can get overwhelming, but the advice you get from others who have been there is really great.

Lastly, if you can afford help, you should of course get it.

Q: What did you learn about the financial impact of dementia that might surprise people?

A: Even if you catch it early, the nursing home care and day care costs are off the charts. If you haven't taken time to put away money for care in the future, nursing home care will take every penny. Medicare pays for some services, but Barry was diagnosed in his early 60s. When he turned 65, that's when Medicare kicked in.

I got really good at using those check cashing places, payday loans. Before Barry's diagnosis ... I had just deposited a big royalty check. I went to the bank later that day, and it was gone. They (the bank) took it to pay back credit card debts. I realized then that I had to learn how to live [on cash] ... and I hid it. I could not even remotely have him find it and go buy something.

Q: People often talk about their dreams for retirement. What dreams did you have that changed as a result of FTD, and what new ones have you created?

A: In terms of my work, we never thought I'd retire. I'd write books until I couldn't anymore. But we had plans when the kids were done with college; that we wanted to downsize. We were going to get a van and travel around for the winters, but I would still work. We thought maybe we'd buy a cabin someday.

This isn't the future I thought I'd have, but it's OK. Had we continued as we were [before FTD], maybe we could have bought our kids a house or gone to Europe. We have different things we do now, and they are just as fun.

Q: So what's next for you? Will you keep writing?

A: I'm writing a book about the whole experience with FTD. I'm on my fifth draft. The working title is *Losing Him, Finding Me*. I did a lot of hiking when Barry was first diagnosed, and I was always lost, and I was lost with this disease. But as things progressed, I stopped getting lost in the woods. I started to find myself through this journey. But while I was finding myself, I was losing him.

Alzheimer's Association
www.alz.org/

Association for
Frontotemporal
Degeneration
www.theaftd.org/

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THE REAL COST OF CARE

The diagnosis also resulted in a plan of action and a need for services and care that ushered in a new mountain of additional expenses and financial hurdles Carlson never imagined she'd face.

The Alzheimer's Association 2017 Alzheimer's Disease Facts and Figures report indicates that people age 65 or older with Alzheimer's dementia on average survive four to eight years after diagnosis, with some living as long as 20 years. Families typically step in as the caregivers or coordinators, especially early in the diagnosis.

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—one preventive step is to ask a trusted family member or close friend to review financial statements on a regular basis. It also includes providing 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 odds are that you are likely to have some experience with this disease either directly or as a close family member. If a loved one is diagnosed with Alzheimer's, it's important to act quickly to protect assets."

ANGIE O'LEARY

HEAD OF WEALTH PLANNING, RBC WEALTH MANAGEMENT-U.S.

Caregivers initially help with routine activities like shopping and medical appointments, but those duties often evolve to assisting with bathing and dressing. For many families, this adds to the financial burden in the form of lost wages, career disruptions and out-of-pocket expenses.

As the disease advances, the care needs become more than any family member can handle, eventually requiring home and transition care and generally culminating in a residential skilled memory care facility. In fact, most people with dementia spend 40 percent of their time after diagnosis in a skilled memory care facility.

"Even for those with supplemental insurance, the costs can be significant, and for many, they're so great that they lead to financial ruin," O'Leary says.

Most of the nonmedical care costs associated with dementia are not covered by Medicare or traditional health insurance.

The good news, O'Leary says, is that there are more options today than ever before. Hybrid insurance policies as well as some life insurance sometimes provide financial relief. But the key is to have the insurance in place before the diagnosis, particularly if there is a family history of dementia.

The care and the financial implications will hit families hard. This is especially important if there is a hereditary link or suspicion of dementia (including but not limited to memory decline), no matter the cause.

Recognize the four early financial warning signs of diminished capacity:

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



Requests

- Unusual requests or repeat requests for the same information
- Frequent user name or password resets
- Inability to make basic decisions, needing repetitive explanations
- Difficult to reach, has been denied access to his or her money



Relationships

- A sudden change in a financial relationship with financial advisors or a financial institution
- Unexplained changes to the account, mailing address or password
- New interest in a phone solicitor or unusual email activity
- New or unusual charitable giving



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

Given the devastating impact dementia can have on the financial health and future of families, RBC Wealth Management is committing additional time and energy to educating financial advisors and clients about the disease.

TAKE ACTION:

- Plan ahead, especially when there is increased risk (age, injury, gender or hereditary). This should include having key legal documents (power of attorney, health care directive and will) in place as well as having assets properly titled and beneficiary designations 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 a trust and professional executor services, especially in the absence of a trusted and competent personal executor or family member.
- Consider supplemental insurance including long-term care options. There are a variety of ways to prepare for unexpected health care expenses.
- 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.

ADDITIONAL RESOURCES

Your financial journey is enhanced by a clear understanding of both where you are today and the strategic options that can help fund your tomorrows. We are committed to delivering insights that educate, equip and engage you for that journey. Thus we created Wealth Insights, a series of papers and articles focused on important wealth planning topics.

This article on the financial impact of dementia as well as the paper *Taking control of health care in retirement* are part of the Wealth Insights series. If you are interested in reading more or want to share this information with a loved one or friend, contact your RBC Wealth Management financial advisor for additional information.

MAKE A PLAN TODAY

Your RBC Wealth Management financial advisor offers a proven 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, 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.](#)

Illustrations courtesy of Nancy Carlson Studios.



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