



# How caregiving impacts families, communities and society

# The issues of aging impact us all.

The physical and financial challenges that come with growing older don't just affect individuals over a certain age. They affect everyone those individuals know and love. Spouses, children, grandchildren, siblings, coworkers and friends are all impacted when someone needs care. The effects of the need for long term care ripple far beyond the individual and can have an emotional, financial and physical toll on not just family, but the community at large.

In fact, with the world's population aging at a faster rate than ever, the need for long term care will soon impact the entire nation. Every day until 2030, 10,000 Baby Boomers a day will turn 65 and seven out of ten of them will require long term care at some point.<sup>1,2</sup>

In the following pages, we share the latest findings from our Beyond Dollars research. They reveal the true impact of the need for care, focusing on 5 key insights:

- Most people are in denial about the potential need for care.
- Caregiving can negatively impact health and well-being
- Caregivers' savings and retirement funds are at risk
- Caregivers' careers and livelihoods are impacted by providing care
- Planning helps to mitigate stress and negative impacts

**These findings provide important insights on ways to mitigate the impact on all of us. By planning together today for what may lie ahead tomorrow.**

<sup>1</sup>Cohn, D., & Taylor, P. (2010, December 20). Baby Boomers Approach 65- Glumly. Retrieved from <http://www.pewsocialtrends.org/2010/12/20/baby-boomers-approach-65-glumly/>, Accessed on October 10, 2017

<sup>2</sup>2018 U.S. Department of Health and Human Services, <https://longtermcare.acl.gov/the-basics/how-much-care-will-you-need.html>, Accessed on October 10, 2017

# The Ripple Effect

The financial, physical and emotional demands of providing care for a loved one often exceed what a single caregiver can handle. In fact, multiple people generally contribute time, energy and money toward caregiving for a family member or friend. As the cost of care continues to rise, the good news is that more family members are helping provide care. Our research has shown that a “Circle of Care” often forms around the care recipient, involving people who provide different levels and types of support. As the impact of long term care is felt across the lives of many, not just one, the opportunity to plan for the likelihood of needing care before a crisis situation occurs remains large.

The reality is that challenges of aging don't ever affect just one person. They affect that person's spouse, siblings, children, grandchildren, friends, neighbors, co-workers and employers in ways most of us don't think of.

## The Circle of Care

### Care Recipient

An individual who requires short or long term care because of a physical, mental or medical need.

### Primary Caregiver

The person who is responsible for providing assistance to the Care Recipient. This person often provides hands-on care and/or financial assistance.

### Secondary Caregiver

This person contributes financially and/or physically to a lesser degree than the Primary Caregiver.

### Community Support

Additional support may come from friends, neighbors, religious organizations, non-profits and other community service groups.

# Most people are in denial about the potential need for care.

Seven out of ten people will need long term care at some point.<sup>3</sup> Yet six out of ten are convinced the need for care will never happen to them.<sup>4</sup> In fact, 63% of Care Recipients and 61% of Caregivers report that, prior to the moment care was needed, they'd never considered that the need for long term care at some point was a very real possibility.

Among the minority that DID consider the need for care, fewer than a quarter had made any plans to cover this type of situation.

Why not? Most people reported they "didn't want to talk about it" or "admit care was needed." But many simply also "thought [they] had more time."

## Caregivers

The characteristics of the people in the Circle of Care have changed. While their roles remain the same, here's what the research revealed about today's caregivers:

**58%** of caregivers are between age 25-54, with an average age of 47 vs. 53 in 2010

**51%** are more likely to be the adult child of the care recipient



Caregivers are more evenly split between men and women

**50 / 50%**  
FEMALE MALE



<sup>3</sup>2018 U.S. Department of Health and Human Services, <https://longtermcare.acl.gov/the-basics/how-much-care-will-you-need.html>, Accessed on October 10, 2017

<sup>4</sup>Genworth Cost of Care Companion Study, Conducted September 1-4, 2017

## Care Recipients

Long term care recipients are getting younger. More care recipients are below the age of 65 in 2018 as compared to 2010.

**81%** of care recipients were age 65 or older in 2010

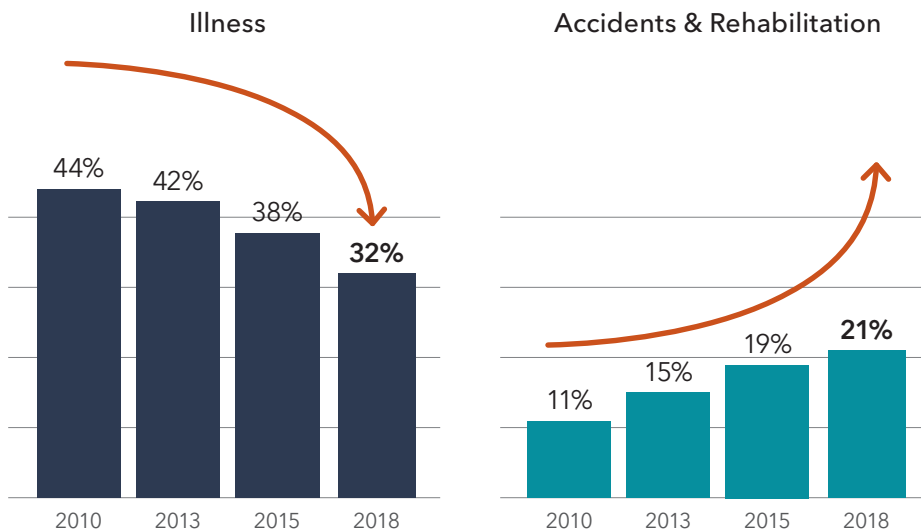
**57%** of care recipients were 65 or older in 2018

20%

About one-in-five indicate they or a close relative (over the age of 25) have experienced an extended healthcare event in the past 12 months.

### Reasons for needing care: fewer illnesses, more accidents

Today, a smaller percentage of recipients need care because of an illness while an increasing percentage require care because of an accident. It's important to remember that the need for long term care takes a significant toll on the emotional, physical and financial lives of the families and friends of every care recipient, not just those who require care due to the challenges of aging.



# Caregiving can negatively impact health & well-being.

Most of our survey respondents said that they appreciated the opportunity to care for their loved one and were proud to be able to do so. In fact, 82% of caregivers experienced some positive feelings.

However, their personal health and well-being are often negatively affected, and the stresses of the situation can impact their relationships with family and friends. It's no surprise that spending time caregiving requires attention, energy and resources that detract from the ability of caregivers to care for themselves and their own immediate families.



“ I definitely have less energy and patience when it comes to interacting with my children and my husband, I get overwhelmed more easily, but I am trying my best.”

–Caregiver, Daughter

**60%**

Of caregivers report having to cut back on luxury expenditures.

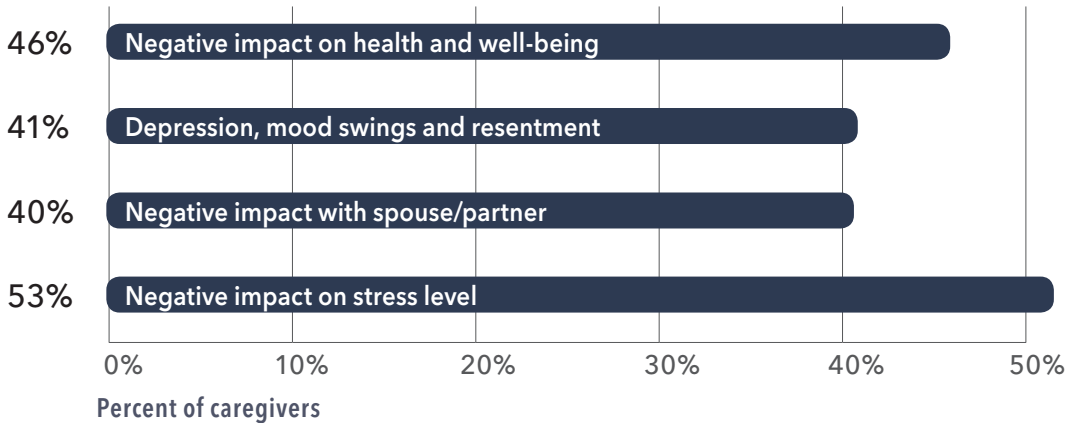
**46%**

Of caregivers said the long term care event negatively affected their health and well-being.

**50%**

Of caregivers report having less time for their spouse/partner, their children and themselves.

## Caregiving can cause negative health and emotional impacts



70%

In most cases, caregiving is done out of necessity, not out of choice, because older family members have no other means to care for themselves. 70% of care recipients only have family to rely on.<sup>5</sup>

More than half of those family members providing care don't feel highly qualified for the job. **They feel they are lacking a firm foundation for their decision making and are facing a sea of confusion** when it comes to caring for aging loved ones.



41%

Of caregivers experienced feelings like depression and resentment.

53%

Of caregivers reported feeling a high level of stress.

52%

Of caregivers did not feel qualified to provide physical care.

<sup>5</sup>Genworth Cost of Care Companion Study, Conducted September 1-4, 2017

# Caregivers' savings and retirement funds are at risk.

Caregivers who help provide financial assistance for the care of their loved ones estimate that they pay, on average, a total of about \$10,400 in out-of-pocket expenses.

Care needs and thus costs can vary widely:

- Average of \$9,651 on care facilities alone (nursing homes, assisted living facilities, etc.)
- Average of \$6,399 on hospitals and physicians
- Average of \$4,670 on professional care providers (homecare nurses, etc.)

Most caregivers did not anticipate or plan for this expenditure. In many cases, they are cutting back on personal spending and savings. More significantly, some may be jeopardizing their own financial futures.



“We are having financial problems now and that keeps us from enjoying vacations, movies, etc.”

—Caregiver, Spouse/Partner

**70%**

Of caregivers report purchasing items for their loved one's daily living.

**61%**

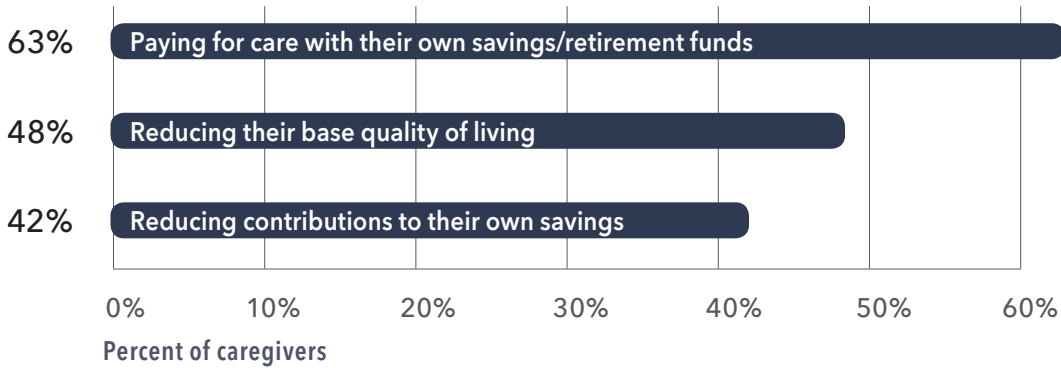
Of families are helping to cover the cost for situations where professional care is received at home.

**53%**

Of caregivers reported making household modifications for their loved one.



## Caregivers often provide out-of-pocket financial assistance



29%

Caregivers' reported out-of-pocket expenses have increased almost 29% since 2013.

On average, most long term care events require three years of care. During that time, **familial caregivers spend up to 21 hours a week providing care. That's over three thousand hours total.** Because the average caregiver is married and age 47 with a 56% chance of having children under the age of 18, **that means three thousand hours not spent helping a child with homework, connecting with a spouse, or working to further a career.**



**60%**

Of caregivers report having to cut back on luxury expenditures.

**48%**

Of caregivers report a reduction in their quality of living in order to pay for care.

**35%**

Report having to sell personal possessions to pay for care recipients' needs.

# Caregivers' careers and livelihoods are impacted.

**The news is not all bad.** As the population ages, many companies are changing the way they respond to the needs of employees who are also caregivers.

While caregivers are still spending as much time providing care (21 hours on average in 2018; 20 in 2015), the percentage of caregivers reporting negative impacts on their careers as a result of caregiving have gone down. While current numbers don't indicate all is well, they do indicate that companies' efforts to implement flexible work hour policies are making a positive difference. Compared to 2015, fewer caregivers reported having to miss work (70% vs 2015's 77%) and fewer reported cutting back their hours (46% vs 2015's 52%).

Companies understand that absences, reduced hours and chronic tardiness affect productivity, which in turn affects their bottom line.



“ I can't get a good nights sleep. I'm exhausted and struggling at my job.”

–Caregiver, Daughter

**70%**

Of caregivers missed time from work.

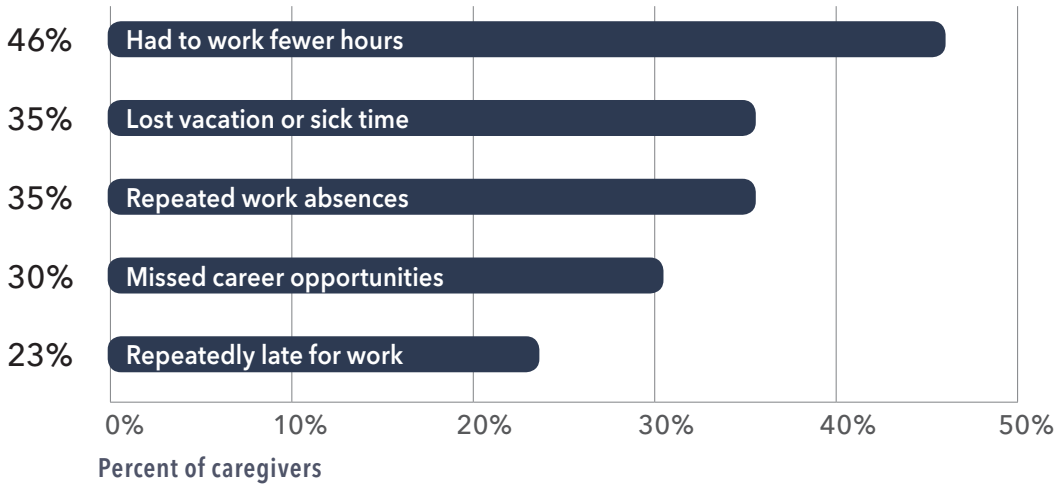
**46%**

Of caregivers had to work fewer hours.

**9%**

Of caregivers lost their job due to providing care.

## Impact of caregiving on work/career



1 in 5 caregivers reported missing 10 or more hours of work per week

For caregivers employed by companies without more flexible policies, caregiving provides an even greater financial challenge. **62% of caregivers believe they lost income as a result of caregiving. These caregivers estimate losing a third of their annual income on average.** If a long term care event lasts an average of 3 years, that's potentially a full year's worth of income lost in the course of a single care event.



**50%**

Of caregivers surveyed felt their career was negatively impacted by the situation.

**21%**

Of caregivers missed 10 or more hours of work per week.

**30%**

Of caregivers felt they missed career opportunities.

# Planning helps to mitigate stress and negative impacts.

The Beyond Dollars research offers insights into the real life situations and challenges that caregivers, care recipients, their families and communities face every day.

Some of these challenges included:

- Finding relief from the emotional stress associated with providing care for a loved one
- Planning to cover the responsibilities that could jeopardize the caregiver's job or career
- Easing financial pressures that strain a family's budget

Many of those stresses can be alleviated by having options like additional caregivers, alternate sources of funds and respite care for the primary caregiver.

The best way to have those options when they're needed is to plan ahead.





“ Talk soon, talk often and then talk again! ”

—Caregiver, Son



“ Start looking years before you have the need—know what is available—know when the move is appropriate—know all the financial help available. ”

—Caregiver, Daughter



“ Ask for help when you feel you need it. Don't try to handle everything yourself. Get family involved. ”

—Caregiver, Son

# Planning early brought benefits for all when the need arose later.

Our research has shown that having a long term care plan, whether it was a long term care insurance policy or simply a plan to handle care if needed, could have helped alleviate some of the emotional, financial and physical stress of what can often be a difficult situation.

Even among those who had prepared, two out of three people wish they had taken steps sooner. In hindsight, 84% of caregivers and 75% of recipients would have done things differently.

The old adage says that “people don’t plan to fail, they fail to plan.” That’s as true for long term care planning as it is for anything else. According to our survey, the top reasons people fail to plan are:

- Didn’t want to admit care was needed
- Timing of long term care need was unforeseen/unexpected
- Didn’t want to talk about it
- Thought they had more time
- Hoped the issue would resolve itself

51%

If they could do things differently, more than half of care recipients would have planned better.



# Long term care planning—a checklist:

The thought of formulating a long term care plan might seem daunting, but it doesn't have to be. Whether you're preparing a plan for yourself or a loved one, it should reflect your thoughts and feelings about where and how care would be provided, who would provide it and how it would be funded.

Of course, a long term care plan should not be developed in a vacuum. Anyone who might be involved in any aspect of caregiving—emotionally, physically or financially—should be included in the process. Talk to your spouse, children, grandchildren, friends, neighbors and coworkers. Research should also be a part of planning, including consulting knowledgeable professionals who can provide insight and guidance.

## Choose where and how you'd like to receive care:

- Research home and facility care options prior to the need for care
- Use the [Genworth Cost of Care tool](#) to assess costs in your area
- Discuss with family members

## Discuss your plans with your family:

- Make sure roles and responsibilities are clearly defined and that those responsible are committed to performing that role
- At a distance: delegate and divide responsibilities, time available and ability of the individual. Leverage the expertise of each individual.

## Determine how to pay for care:

- Explore and evaluate the financial options for care: out of pocket, contributions from family members, Medicare/Medicaid, long term care insurance
- Take into consideration the increasing cost of care. Think about adding a cost of living adjustment to your annual costs as you identify ongoing funding sources.

## Consult knowledgeable professionals:

- Seek financial advisors, attorneys and long term care professionals for guidance with Powers of Attorney, medical directives, wills, financial and estate planning, etc.

## Put it in writing:

- Write down your goals and wishes
- Inform everyone that it might affect
- Update the plan if your situation changes

# Long term care insurance helped some caregivers.

Our Beyond Dollars research reveals that long term care insurance helped to mitigate the negative emotional and financial impacts on both caregivers and recipients.

Caregivers whose loved ones had long term care insurance contributed more towards reimbursable long term care expenses, including medical equipment, professional care providers, long term care facilities and residential alterations to accommodate care, as compared to caregivers whose loved ones did not have long term care insurance.

Long Term Care Insurance policy owners were significantly less likely than those without these policies to report:

- Stress (40% v 52%)
- Depression (25% v 32%)
- Sense of Isolation (16% v 21%)

65%

Nearly 65% of those whose loved ones did not have long term care insurance felt those loved ones would have benefited from it.

## Long term care insurance helped relieve some stress

Our survey respondents said that long term care insurance helped in these different ways:

- ✓ Relief from the financial, emotional, and physical burden associated with long term care
- ✓ Less strain on family situation
- ✓ Relief in knowing that someone would provide care, should it be required
- ✓ Relief from the guilt or emotional burden of depending on family for care
- ✓ Maintained care recipient's ability to leave family a financial legacy or property





“ My wife has become more distant and feels overwhelmed by my need for care. She is fearful that we will go broke paying for the care I need to remain at home. ”

—Care Recipient



“ Our adult children did not want to visit my mother-in-law and my husband felt bad about it. I constantly have to travel and spend money on traveling to care for my mother-in-law. ”

—Caregiver, Daughter-in-law

# Take control of the future.

Loss of control is one of the most difficult things for a long term care recipient to deal with. Often, other people are making decisions that affect every aspect of their lives and they have very little say.

Caregivers also have to deal with a loss of control—over their emotional well-being, their jobs and, in many cases, their financial situations.

The families, friends and communities of caregivers also lose control over the amount of time, attention and energy caregivers have to share with them.

Formulating a plan and communicating wishes in advance to loved ones can help care recipients return a degree of control to all parties. Our research reveals that those who have been through a long term care event wish they had started planning earlier and believe that planning financially for a long term care event could have saved them thousands of dollars. The finding also confirm the value of long term care insurance to those who have been through a long term care event.

## Here's the challenge:

It's not always easy to broach the topic of long term care with the people you love. And it can be even more difficult to put plans in place. Meet the challenge with action—start the conversation today, not someday and meet with a financial professional. The price of not doing so goes beyond dollars.



# About the Research

In February of 2018, Genworth conducted the Beyond Dollars study. The initial research population included 7,421 participants and was narrowed down to 1,200 qualified individuals. The final represents responses from 739 people providing long term care to loved ones (caregivers), 351 care recipients and 110 family members with detailed knowledge of a long term care event in their family (but not responsible for providing care). Genworth has sponsored the Beyond Dollars survey in 2010, 2013, 2015 and now in 2018 to understand and share the perspectives of Care Recipients, Familial Caregivers and their wider support network.

These results represent statistically significant findings tested at 95% and 90% confidence intervals. 51% of respondents were providing care for a parent (34% for their mother, 17% for their father). 30% were caring for a spouse and 8% for a grandparent. 8% were providing long term care for a sibling or child.

Caregivers were evenly split between male and female, challenging a commonly-held assumption that women are the predominant caregivers. Their average age was 47 and 60% were married.

Care recipients were predominantly women at 63% with an average age of 66 and 36% of them were married.

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