

The Expanding Circle of Care

Beyond Dollars 2015

Executive Summary



Addressing the need for long term care

Like many of life's realities, the issues surrounding long term care (LTC) – and the need to be prepared to deal with them – are often something people prefer not to think about. Having a plan in place to address the possibility can go a long way toward easing some of the related concerns.

Sometimes an event that warrants long term care is unexpected, and sometimes it is gradual. No matter the circumstances, a loved one's need for long term care can create emotional, financial and career impacts that extend far beyond the immediate situation.

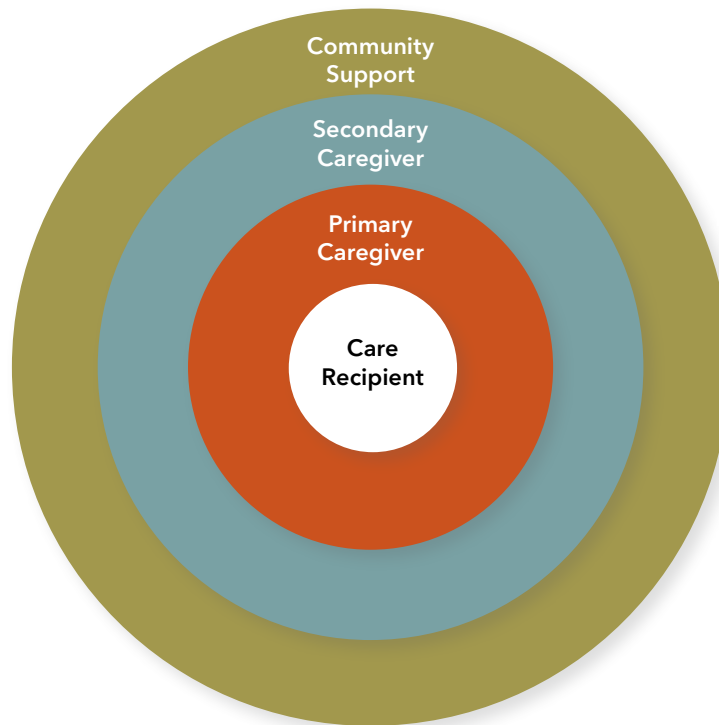
In the following pages, we share the findings from our Beyond Dollars research that reveal the true impacts of long term care, focusing on 5 key insights:

1. The changing face of long term care
2. Caregiving can negatively impact health and well-being
3. Caregivers' savings and retirement funds are at risk
4. Caregivers' careers and livelihoods are impacted by providing care
5. Planning mitigates stress and negative impacts

More importantly, we provide insights on ways to mitigate those impacts by planning for what may lie ahead.

The Circle of Care

The financial, physical and emotional demands of providing care for a loved one can sometimes be more than a single caregiver can handle. The good news is that more family members are helping provide care. The opportunity to plan for the likelihood of needing long term care before a crisis situation occurs remains large. 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.



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.

FIVE YEAR TRENDS

1 The changing face of long term care

Comparing the 2015 research with research from five years ago has uncovered two notable trends. Both caregivers and care recipients are skewing younger. One possible explanation for this is the fact that the number of people needing care due to accidents – as opposed to illnesses – is also increasing. Additionally, more family members, and younger family members are often getting involved. Millennials today are not strangers to long term care – and the perception that it's “nursing home care” for the elderly is diminishing.

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:

62%	of caregivers are between 25-54 – younger compared to 2010
52%	are more likely to be the adult child of the care recipient
50%	caregivers are evenly split between men and women
24%	are other family members, more than in prior years

Caregivers are no longer primarily female



Caregivers are more evenly split between men and women

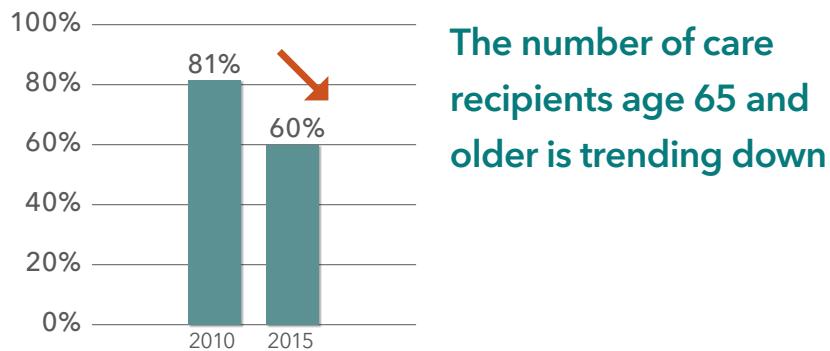
50% | 50%
MALE | FEMALE

Care Recipients

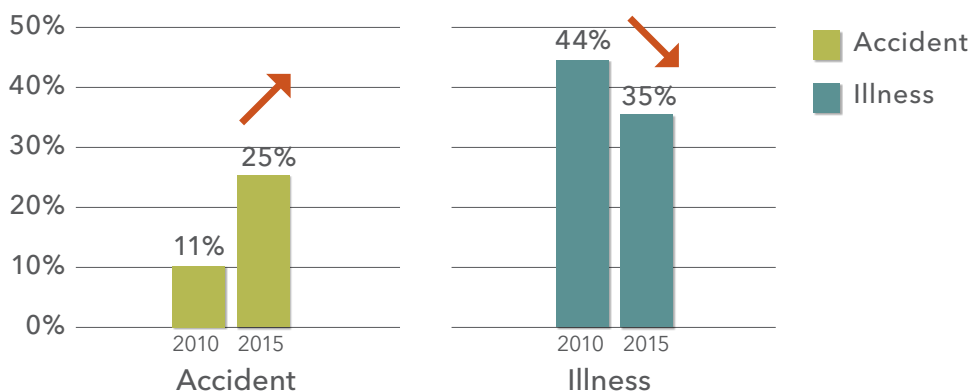
Long term care recipients are getting younger. More care recipients are below the age of 65 in 2015 as compared to 2010.

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

60% of care recipients were 65 or older in 2015



Reasons for needing care: less illness, more accidents



Today, a smaller percentage of recipients need care because of an illness while an increasing percentage require care because of an accident.

HEALTH AND WELL-BEING

2 Caregiving can negatively impact health & well-being

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, 83% 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.

- 43% of caregivers said the LTC event negatively affected their personal health and well-being
- 44% of caregivers experienced negative feelings such as depression
- 33% nearly 33% of caregivers reported an extremely high level of stress
- 55% of caregivers did not feel qualified to provide physical care



54%

Of caregivers experience negative feelings as a result of caregiving.

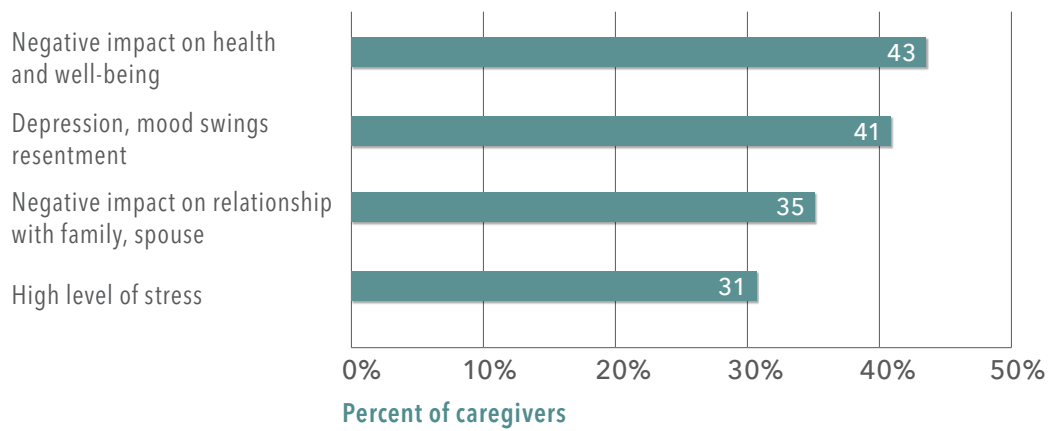
43%

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

51%

Of caregivers worry about the lack of time for themselves and their families as a result of caregiving.

Caregiving can cause negative health and emotional impacts



44% Of caregivers experienced feelings like depression and resentment.

33% Of caregivers reported feeling a high level of stress.

32% Of care recipients reported feeling a high level of stress.

FINANCIAL IMPACTS

3 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, about \$10,000 in out-of-pocket expenses annually.

That's up from an average of \$7,285 in 2010. Those financial expenses can include everything from household expenses, personal items, or transportation services, to payment of informal caregivers or long term care facilities.

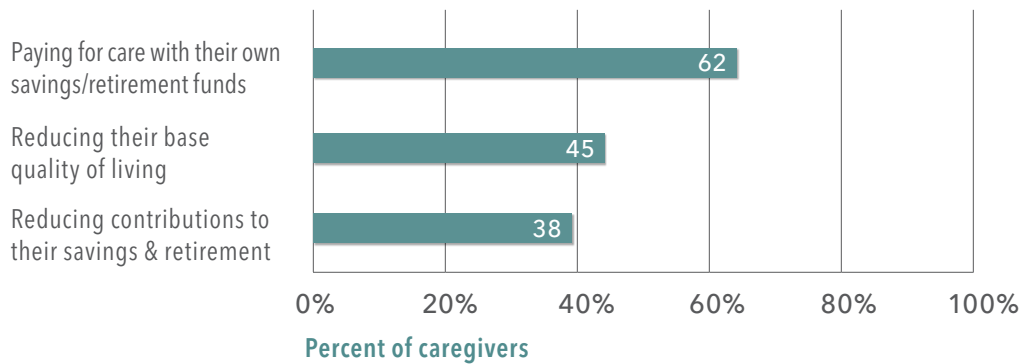
Most caregivers did not anticipate or plan for this expenditure. In many cases, they are cutting back on personal spending and savings. More significantly, some may be jeopardizing their own financial futures.

"I had to change jobs and I made less money. I spent less time with my family and we had less money to do activities."

—Caregiver, Daughter



Caregivers often provide out-of-pocket financial assistance



20%

Caregivers' out of pocket expenses have increased almost 20% since 2010



62%

Of caregivers used their own savings and retirement funds.

45%

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

27%

Report a negative impact on their relationship with the care recipient.

CAREER IMPACTS

4 Caregivers' careers and livelihoods are impacted by providing care

Caregivers report spending about 20 hours a week providing care for their loved one. If they work full-time, that's almost half of what they would normally spend at work. In fact, 77% percent of caregivers indicated that they had missed work in order to provide care for a loved one.

Absences, reduced hours and chronic tardiness can translate into a significant reduction in a caregiver's paycheck. Approximately one-third of caregivers provide 30 hours – or more – of care per week. Half of those who do so estimate that they lost around one-third of their income. If a long term care event lasts an average of three years, that's potentially a full year's worth of income lost in the course of a single long term care event.

"It is hard to hold down a full time job and help take care of the one you love."

—Caregiver, Spouse/Partner



77%

Of caregivers missed time from work.

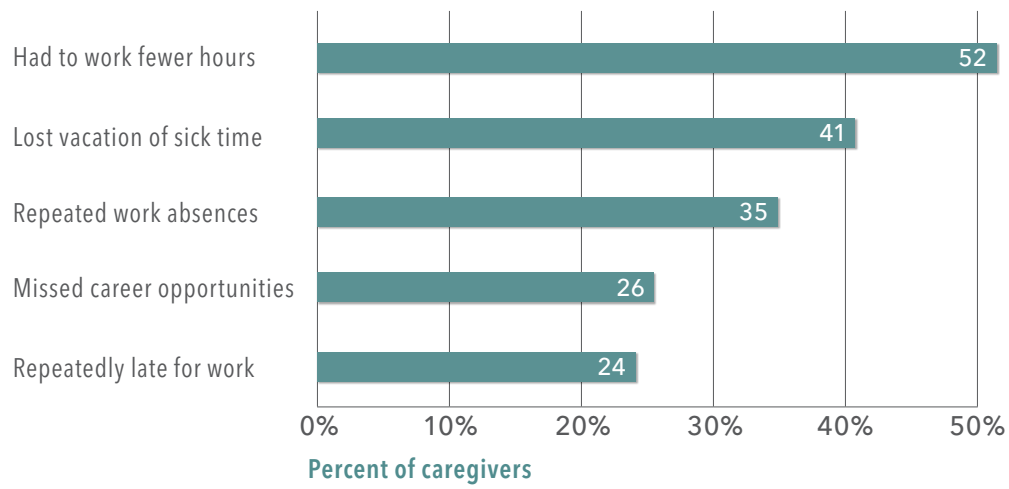
52%

Of caregivers had to work fewer hours.

11%

Of caregivers lost their job due to providing care.

Impact of caregiving on work/career



-7

HOURS/WK

Caregivers miss an average of 7 hours of work per week – almost 18% of a 40 hour work week.



51%

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

19%

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

55%

Of care recipients had to leave their job as the result of a long term care situation.

THE BENEFITS OF PLANNING

5 Planning mitigates stress and negative impacts

The Beyond Dollars research offers insights into the real life situations and challenges that caregivers – and care recipients – 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: Additional caregivers; alternate sources of funds; respite care for the caregiver.

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



"The advice I could give is to have a plan in place!"

–Caregiver, Son

"Research what you need to know before taking on this big responsibility. Don't feel bad asking the doctor about questions that you have. Stay on top of appointments and medical bills."

–Caregiver, Mother

"My husband is frustrated that I do go out there so often and that I'm gone so often."

–Caregiver, Mother

"Be prepared financially for the unexpected, and make sure you have an emotional support system... focus more on cherishing every moment with your loved one, rather than on your own personal losses from the work. It is worth it."

–Caregiver, Mother

"Realize that if family doesn't help as much as they should, you may need to get professional care to complement your care, You shouldn't push yourself to the limit or feel guilty for looking out for yourself "

–Caregiver, Mother

"It is exhausting physically and emotionally for me since we had a very good life together before his stroke. We did a lot of outdoor activities together and he was very active."

–Caregiver, Spouse/Partner

THE BENEFITS OF PLANNING

Planning early brought benefits for caregivers and recipients 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 most often can be a difficult situation.

In fact, the majority of those who had prepared for a long term care need said they wished that they had taken steps sooner. And, given the benefit of hindsight, 53% of caregivers and 59% 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

Avoiding the subject won’t make it go away. According to the Centers for Medicare and Medicaid Services, at least 70% of people over 65 will need long term care services and support at some point.*

50% Over 50% of caregivers and care recipients feel that planning better would be something they would do differently if they could.

80% Respondents who thought action should have been taken sooner estimated that \$8,000 of the \$10,000 of out-of-pocket expenses could have been saved.

*2015 Medicare & You, National Medicare Handbook, Centers for Medicare and Medicaid Services, September 2014.

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 to pay for it**.

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. Research should also be a part of it, along with consulting knowledgeable professionals who can provide insight and guidance.

Where and how care would be provided

- ☐ Research the options available for long term care in your area: in the home, an assisted living facility or skilled care facility prior to your need
- ☐ Estimate the cost of the care options in your area ([Genworth Cost of Care](#))
- ☐ If family members will be involved in caregiving, discuss it with them in advance

How to pay for care

- ☐ Explore and evaluate the financial options for paying for care: out of pocket, contributions from family members pitching in, Medicare/Medicaid, long term care insurance
- ☐ Take into consideration the increasing costs 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 who can provide guidance in their areas of expertise (Powers of Attorney, medical directives, wills, etc.)
- ☐ Be prepared to ask questions, investigate and weigh your options

Discuss your plans with your family

- ☐ Are there family members who are natural caregivers and who can afford to give the time and emotional energy to caregiving?
- ☐ Are other family members better able to oversee finances?
- ☐ 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.

Put it in writing

- ☐ A written long term care plan should articulate your goals and wishes
- ☐ Inform everyone that it might affect
- ☐ Update the plan if your situation changes

THE ROLE OF LONG TERM CARE INSURANCE

How long term care insurance helped some caregivers

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

Caregivers whose loved ones had LTCI 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.

59% of caregivers and 49% of care recipients who had long term care insurance reported feeling significantly less stress than non-owners

47% of caregivers of recipients who had long term care insurance felt much better prepared to deal with the situation

63% nearly 63% of survey participants whose loved ones did not have long term care insurance felt that having long term care insurance would have benefited their care recipient

Long term care insurance helped relieve some stress

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

1. Relief from the financial, emotional, and physical burden associated with long term care
2. Less strain on family situation
3. A higher level of care
4. Relief in knowing that someone would provide care, should it be required
5. Relief from the guilt or emotional burden of depending on family for care
6. Maintained care recipient's ability to leave family a financial legacy or property



"If you really love someone,
I don't feel that caring for them
is any burden at all. But you
have to make sure you are
happy to make others happy.
So take care of you and you will
be able to take care of others."

—Caregiver, Spouse/Partner

"The hardest part was giving up
a job search. When a job offer was
made, I had to turn it down due to
caring for my stepfather."

—Caregiver, Stepdaughter

"Some of the family members
could not or did not contribute
financially or assist with help
personally. The family had
several feuds about her care
and money situation."

—Caregiver, Mother

"I was lucky enough to be able
to retire so that I could help my
mother as needed."

—Caregiver, Mother

"Plan in advance, we're all
going to get old, it should not
come as a big surprise!"

—Caregiver, Spouse/Partner

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 them but in which they have 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. Care recipients who formulate a plan and communicate their wishes to their loved ones in advance help to return a degree of control to both 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 findings 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 – speak with your loved ones and meet with a financial professional.



The price of not doing so goes beyond dollars.



About the Research

In the first half of 2015, Genworth conducted the **Beyond Dollars** study. The survey included **822 people** providing long term care to loved ones (caregivers), **281 care recipients**, and **97 family members** with detailed knowledge of a long term care event in their family (but not responsible for providing care).

These results represent statistically significant findings tested at 95% and 90% confidence intervals. 52% of respondents were **providing care for a parent** (28% for their mother, 24% for their father). 27% were **caring for a spouse**, and 10% 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 46**, and **62% were married**.

57% of care recipients were male, while **43% were female**. Care recipients were age **67 on average**, and **50% of them were married**.

For more information visit:

genworth.com/lets-talk

For help getting your important conversations started, visit genworth.com/lets-talk to get your free guide. You'll find tips and valuable information on what to discuss and ways to think and plan ahead for the best outcomes for you and your loved ones

genworth.com/costofcare

To see how much different levels of care cost in your specific area or any other areas of interest within the United States, visit genworth.com/costofcare.

longtermcareinsurance.org

National Advisory Center for long term care information- sponsored by Genworth. You'll have access to relevant and helpful information on all key topics related to long term care to help you and your family make long term care plans.

MyLifeMyFamily.com

Get more information about long term care insurance and how it works from America's Health Insurance Plans. Hear other peoples' stories or share your own.

caregiveraction.org National Family Caregivers Association

caregiving.org National Alliance for Caregiving

