

Beyond Dollars

The True Impact of Long Term Caring

Published:
9/30/2010

Research findings
on the circle of care
and the impact on
the many people
within it.



Survey Reveals the True Costs of Providing Care

Since 2003, Genworth has published its annual Cost of Care Survey to help people realize the financial cost of long term care services across the country. The 2010 report features data collected from nearly 13,000 long term care providers – home care providers, adult day care facilities, assisted living facilities and nursing homes – revealing the costs of differing levels of care in more than 436 regions throughout the U.S.

In April of 2010, Genworth conducted a survey to arrive at an assessment of the true impact of long term care for recipients, their caregivers and their families. Genworth has now published *Beyond Dollars: The True Impact of Long Term Caring*. *Beyond Dollars* reports the results of the survey of more than 800 consumers with personal involvement in a long term care event lasting more than 30 days. See page 26 for the full methodology.

On these pages are the quantitative data, along with the compelling stories, thoughts and perspectives of the individuals who participated in this survey, provided in their own words. Photos are illustrative only and do not represent actual participants.

Beyond Dollars

Each of us has defining relationships in our lives. With our parents. Our siblings. Our spouses. Our children. Our colleagues.

We even have relationships of sorts with our accomplishments. Our achievements. Our successes. And we have relationships with our own futures. We think of them as relationships because they mean something to us – and we are committed to them.

And all these relationships can be affected when we take an active role in someone else's care.

The Ripple Effect

We may understand that there is a financial impact to helping provide care, but there is more to the equation, and it goes far beyond dollars.

There is a ripple that can touch a primary caregiver, a secondary caregiver, their families and their futures. While a loving and selfless act, accepting or taking responsibility for another individual's care can have a dramatic impact on our own lives, and on our families' lives.

No matter how willing we are, no matter how heartfelt our promises are, our caregiving commitments can affect marriages, family dynamics, work commitments, financial stability and other building blocks of our own futures.

Will You Have a Role in Someone's Care?

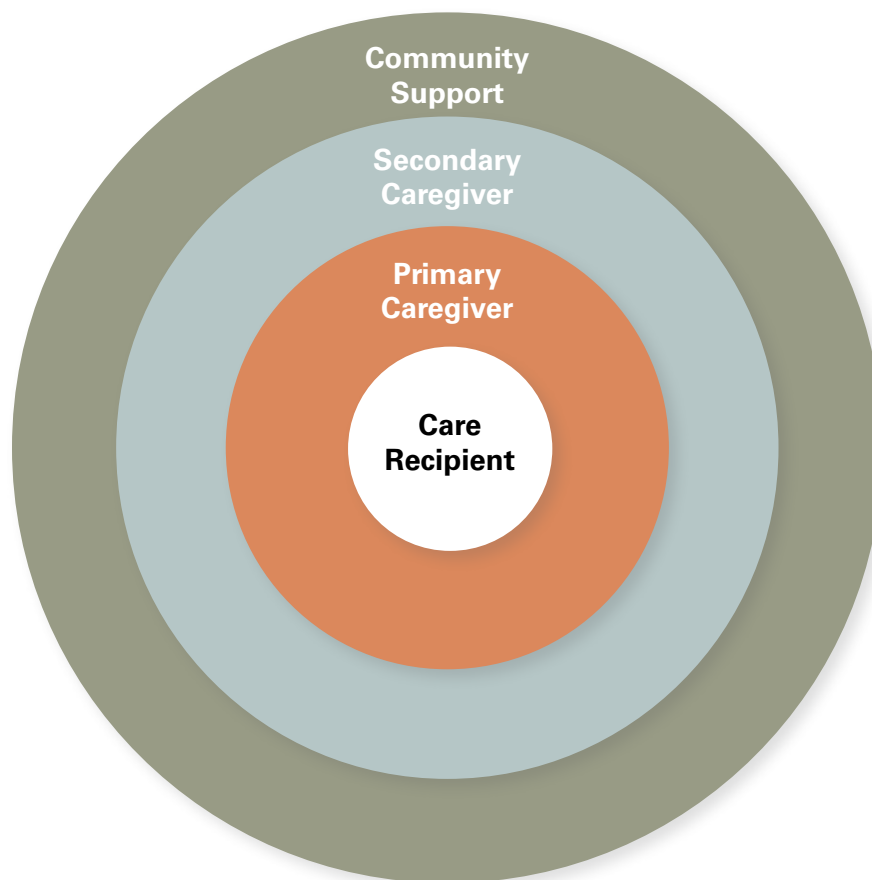
Thinking through the impact of your responsibilities as a caregiver is a first and important step.

Whether you are a primary or hands-on caregiver, or someone who orchestrates the care provided by others – whether you provide some financial support or weigh in on important decisions – it's important to recognize the potential impact of caregiving on all aspects of your life.

Planning ahead for ways to mitigate costs or share caregiving responsibilities is worthy of every family's consideration.



The Circle of Care - *definitions*



Care Recipient

An individual who requires care on a short-term or long-term basis based on physical, mental or medical needs.

Primary Caregiver

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

Secondary Caregiver

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

Community Support

Additional support services that may provide assistance. These often include friends, neighbors, religious organizations, non-profits and other community service groups.

Care is often provided by and impacts a wide contingency of people who are important to us.

When someone has a short-term or long-term care event, there are often people within a “circle of care” who jump in to help out. At the center of this circle is the **care recipient**, the individual who is in need of assistance.

Surrounding that person is an evolving circle of care that includes a **primary caregiver**, who most often provides the majority of hands-on care. In addition, they often contribute significant financial support. Primary caregivers and their families are the most directly impacted by their involvement in providing care.

The **secondary caregiver** is involved in care to a lesser degree. Whatever the level of engagement, this person fully understands all the dynamics of the care the recipient receives.

Even though they are not at the forefront of care, the financial and emotional impacts of a long term care event can be surprisingly similar to those that affect the primary caregiver and should not be underestimated or overlooked.

Also impacted are the **primary and secondary caregivers’ families** – siblings, spouses, children and in-laws.

The **broader community** also provides care through religious organizations, community non-profits, friends and neighbors, and others.

Let’s look at the impacts – financial and emotional – on caregivers and families in the **Circle of Care**.

The *Care Recipient* Perspective



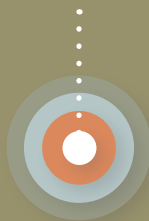
“ It’s just hard between us. My wife still has to work to keep up insurance. We thought this would be a time in our lives that we could sit back and travel, spend more time with the grandkids, but it’s not to be.”

“I think my son and daughter worried that I would want to move in with them so they could take care of me. Fact is, I didn’t. It was the elephant in the room for the longest time. I have always valued my independence. That doesn’t change with age. But I inevitably ended up needing their help. I am grateful and don’t know what I would have done without them, but it definitely altered their way of living and mine.”

“My wife had to be available 24/7. She also became my chauffeur and needed to help me shower and dress – to help me move at all, really. It impacted her freedom and her lifestyle.”

“My husband had to take time off from his job to help me, more than we expected. And he was frustrated that I had so much pain and felt like he wasn’t helping enough. I hated asking for so much assistance.”

Care Recipient



The Care *Recipient*

When someone experiences a debilitating health event – short-term or long-term – that may require them to be dependent on others, to dip into savings or stop working, the effects can be significant. There are obvious consequences and new circumstances; other impacts are unseen, but real nonetheless.

About Care Recipients:

34%	Are mothers receiving care from their children
12%	Are fathers receiving care from their children
9%	Are spouses receiving care from their spouse

Financial Impact

88%	Said their household income was reduced by an average 34% due to their long term care event
60%	Reported a need to cut back on family expenses after a long term care event
63%	Reduced their savings by an average 61%

Emotional Impact

42%	Felt stress with their spouse
35%	Reported stress with their children



Care Arrangements

49%	Of care recipients had not considered the possibility of needing long term care
29%	Of care recipients required care for 3 years or more
37%	Of care recipients were moved into a family member's home for a period of time

The dollars to pay for care must come from somewhere. Most often, savings and retirement contributions are hardest hit, threatening families' ability to live comfortably in the future. There are four primary areas of financial strain upon care recipients and caregivers associated with providing care for an individual:

1

Out-of-pocket expenses for care, medications, transportation, etc.

2

Home modifications such as ramps, railings, bathroom modifications and other adaptations needed to allow the care recipient to live more comfortably at home

3

Facility care for those who can no longer reside at home or who need a place to go during the day when the primary caregiver is not available

4

Income lost due to missed work or inability to work

Out-of-Pocket Costs

\$14,000	Average amount care recipients spent out-of-pocket for their own care (excludes cost of facility care)
\$8,000	Average amount family members spent for out-of-pocket expenses (excludes cost of facility care)



The *Primary Caregiver* Perspective



“ If my sister could take Mom in for just one month, perhaps she would be more understanding of the day-to-day responsibility. I want to take care of her and wouldn't have it any other way. But sometimes I just get burned out and feel spread too thin. I wish my sister could simply give me a little relief from time to time, just for me to take a breather.”

“Anger at my brother and sister for not helping more with our dad... Stress with my wife over how much of ‘our time’ this was taking up.”

“Since my mom lives with us, we now have someone else in the house, plus caregivers 12 hours a day. For the first 38 years of our marriage, it was just my husband and I... This has required a change for both of us.”

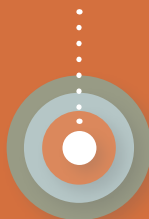
“We expected things to change... But the reality of caring for someone 24/7 changes life the way you know it. It’s nothing like I imagined.”

“It has changed my life and all routine in my life entirely... It’s difficult to attend normal social and professional meetings, and I am now limited to how many I can participate in.”.

“We have absolutely no time alone in the house to be intimate... I tend to let my daily grooming slip and look scruffy – which can kill romance.”

“My children were resentful that I had siblings who did not help me.”

Primary Caregiver



The *Primary Caregiver*

“Taking care of someone can be very expensive and time consuming. It changes your whole life when you care for someone 24 hours a day.”

Being the main caregiver has significant effects on the emotional and financial well-being of an individual and their family. Juggling time, career, family and finances are the most prevalent stress points, but they are only part of the personal and emotional issues that make providing long term care (LTC) “expensive” on many levels for the Primary Caregiver and their family.

About Primary Caregivers:

53	Average age
42%	Care for a mother
14%	Care for a father
13%	Care for a spouse

Length of time they provided care in their home:

32%	Less than 1 year
26%	1 - 2 years
18%	3 - 7 years
24%	8+ years

42% reported that the care recipient resided in their home for a period of 3 years or more.

Financial Impact to Primary Caregivers

83%	Contributed financially – an average \$8,800 for out-of-pocket care expenses (excludes cost of facility care)
57%	Had to dip into their own retirement funds and/or savings
29%	Borrowed money, took out a reverse mortgage and/or sold their home
63%	Reported lost income – an average of 23% of household income
61%	Reduced their savings by an average of 63%
40%	Reduced family vacations
45%	Cut back on their own family expenses

57% 57% of primary caregivers provide care for more than 16 hours each week

31% 31% of primary caregivers provide care for more than 30 hours each week

Career Impact

A career is usually more than simply how we pay our bills. In many instances, our careers are tied to our self esteem and help define who we are socially as well as financially.

Over a third of surveyed caregivers reported direct negative consequences to their own careers resulting from their responsibilities to a care recipient. Many of these family members worked fewer hours with repeated absences. And nearly 20% reported a direct loss of career opportunities.

44%	Had to work fewer hours
48%	Lost a job, changed shifts and/or missed career opportunities
38%	Incurred repeated absences from work
17%	Found themselves repeatedly late for work

Savings and Retirement Contributions Impact

On average, among those reporting a reduction in their savings plans...

Contributions to savings accounts were reduced by 73%
401(k) contributions were reduced by 65%
Retirement contributions were reduced by 80%

"Caring for my mother has left me with much less time to spend with my son. With three generations living together, there's a whole new set of rules to live by and a new set of frustrations for everyone."

Family and Relationships Impact

Experienced an increase in stress with their spouse	44%
Reported stress with siblings	27%
Experienced an increase in stress with their children	23%
Reported reduced time with children	20%
Reduced savings for college education by	58%

"My husband did not show much compassion, which I did not understand. I still think about it to this day."

42%

42% reported that the care recipient resided in their home for a period of 3 years or more

44%

44% experienced increased stress with their spouse

63%

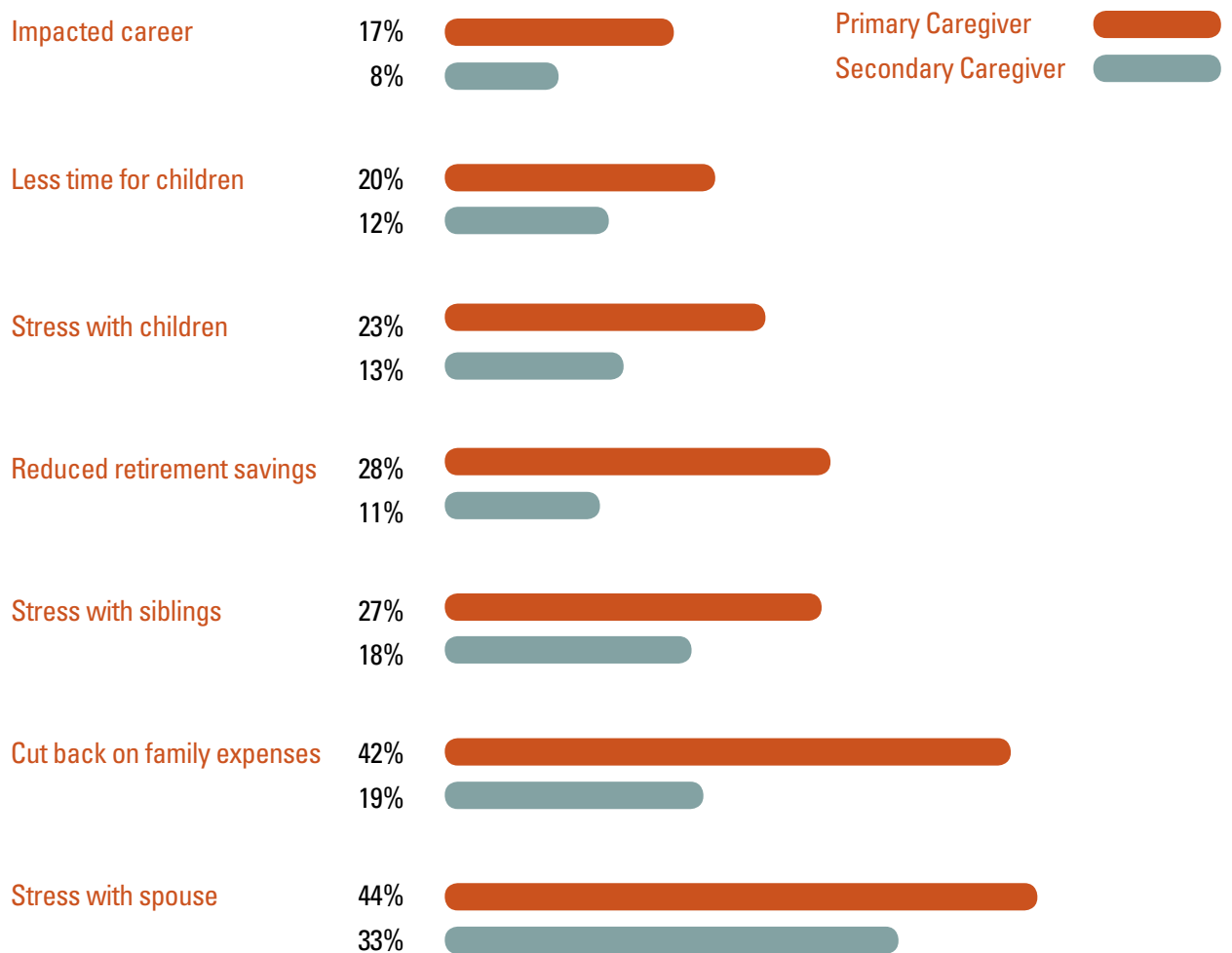
63% reported lost income – an average decrease of 23% of household income

Comparing the Impact to the *Primary* and *Secondary Caregivers*



“ In theory, I believed I could take care of my Mom, keep up with her home, and take care of my family, my kids and myself. In reality, I’m running Mom to her doctor appointments and my kids to school and sporting events or sleepovers. I am constantly torn, feeling guilty that I’m not doing enough for anyone, including taking care of myself these days.”

While the impact to the primary caregiver is widely recognized, the effect on the secondary caregiver(s) is not often acknowledged, but still significant.



The *Secondary Caregiver* Perspective



“ It is difficult to explain the money I lost due to the fact that I was employed as an airline pilot. I had to call in sick, drop trips and adjust my schedule to be at home with my father. Eventually, I retired early so I could be at home with him full time to provide for his care. When I was no longer physically or mentally able to provide care for him, I had to move him into a long term care facility.”

“It’s what you do (take care of family). But I have found myself somewhat isolated... Friends don’t call as often because I have to decline or change plans if something with Dan’s mom comes up... And sometimes I think they just don’t know what to say, so they avoid having to deal with my new way of living.”

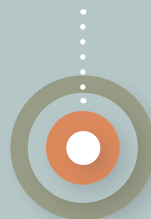
“The entire family contributed money so one person wasn’t hit so hard... So we all pitched in to to help.”

“There’s just more tension in our house – now that my husband and my stepson are helping take care of my parents.”

“My husband is her son, but he can’t take care of her... He does help with housework and the lawn work.”

“I will have to work more hours to put more funds into my 401(k)... I will have to retire at a later date than expected... I will have to work additional hours to put more money into my personal savings.”

Secondary Caregiver



The *Secondary Caregiver*

The secondary caregiver is impacted when a long term care event affects someone close to them.

About Secondary Caregivers:

53	Average age
29%	Care for a mother
16%	Care for a father
9%	Care for their in-laws

Financial Impact to Secondary Caregivers:

36%	Of secondary caregivers contributed financially – an average \$2,600 for out-of-pocket care expenses (excludes cost of facility care)
42%	Dipped into their own retirement funds and/or savings
15%	Borrowed money or sold their home
33%	Lost up to 20% of their household income
19%	Reduced vacation spending
19%	Cut back on their own family expenses



36% of secondary caregivers contribute financially – an average \$2,600 for out-of-pocket care expenses (excludes cost of facility care)

Career Impact

One-fifth of those secondary caregivers surveyed reported direct negative consequences to their careers resulting from their responsibilities for a care recipient, and of these...

29%	had to work fewer hours
42%	lost a job, changed shifts and/or missed career opportunities
33%	lost vacation/sick time
33%	incurred repeated absences from work

Care commitments cost caregivers wages and caused issues with bosses and co-workers.

Savings and Retirement Contributions Impact

On average, among those reporting a reduction in their savings plans...

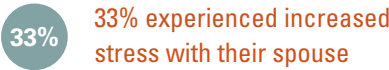
Contributions to savings accounts were reduced by	40%
401(k) contributions were reduced by	22%
Retirement contributions were reduced by	55%
Family vacation savings were reduced by	71%
Savings for college education were reduced by	76%

While stress with a spouse always ranks at the top of the list, family members are also likely to report stress with siblings over tough decisions.

Family and Relationships Impact

Experienced an increase in stress with their spouse	33%
Reported stress with siblings	18%
Experienced an increase in stress with their children	13%
Reported reduced time with children	12%

“Disagreements about mother’s cognitive abilities – how to handle siblings... We worked through them, but they caused added stress... It was hard to find good caregivers, too, and we would argue about who we wanted to care for her.”



The *Caregiver's Family*



“ I have less time to spend with my husband and my kids.
I have less time to spend with friends. I miss being home at nights
because I’m having to stay day and night with my parents.
It wears me out physically and mentally.”

“My wife did not bargain for such a long stay and is angry at biological family members for not stepping up to offer aid.”

“It’s a struggle for the whole family, as we are losing a big chunk of all our incomes to see that my father is taken care of.”

“I sold my house and moved 500 miles from my adult children and grandchildren to care for my stepfather.”

“My children would take up for their grandma and make a lot of excuses for her bad behavior... They certainly wouldn’t take her into their homes and certainly wouldn’t contribute to any expenses she might have... Getting them to transport her to a doctor’s appointment wasn’t happening, either... They certainly criticized how she was being cared for, but NEVER wanted to be involved in helping with the situation.”

“My mother was putting my children down and disrespecting them somewhat at first, but not too much now, after they (grandparents) realize that they need their help more and more.”

“I have to leave on weekends to see her – not there for sports games or other school-related events for them.”

Family



The *Family*

Spouses and children – even in-laws or other extended family members – of primary and secondary caregivers can be affected by a long term caregiving situation. Consider these facts for family members:

The Kinds of Assistance the Family Provides

The immediate family is more likely to contribute financially, but not significantly more than step-family, in-laws and extended family.

	Care	Financial Assistance
For an immediate family member	87%	77%
For a step-family member/in-law	74%	71%
For an extended family member	74%	71%

“The family has to sacrifice so that I have time, energy, and resources to care for my brother.”

“I see them less. I have not been able to go visit my grandkids as often as I’d like... I have given my children and grandchildren less in terms of birthday, Christmas, etc. gifts.”

“Children are happy for Grandma... She also lives much closer and in a better place.”

Where the Money Comes From

As a result of caring for a family member, they reported:

	Immediate Family	Step/ In-law	Extended Family
Dipping into savings/retirement plans	55%	57%	50%
Selling other possessions	13%	12%	13%
Selling a home	11%	17%	18%
Borrowing money from a friend/family member	12%	6%	13%
Taking out a loan	6%	3%	6%
Acquiring a reverse mortgage on a home	2%	3%	4%

Career and Workplace Pressures

Among those family members reporting adverse effects of the long term care event on their careers, data show that:

	Immediate Family	Step/ In-law	Extended Family
Had to work fewer hours	44%	39%	32%
Lost a job, changed shifts/missed career opportunities	49%	36%	48%
Had repeated absences from work	40%	32%	32%
Were repeatedly late for work	19%	7%	8%

Family Stress & Pressure

As a result of caring for a family member

	Immediate Family	Step/ In-law	Extended Family
Experienced an increase in stress with their spouse	40%	63%	30%
Cut back on family expenses	43%	35%	32%
Reported more stress with siblings	29%	16%	19%
Had an increase in stress with their children	22%	23%	14%
Reported reduced time with children	17%	20%	25%
Ability to save for children's education was hindered	10%	9%	8%
Ability to save for retirement was diminished	27%	24%	13%

Supporting a care recipient requires time, commitment and care beyond physical needs. A spouse may resent the intrusion and withdrawal of attention they are used to receiving.

"I can't attend to my children like I used to do anymore because of the care I have to give to my mother... The kids seem to act up more in school or their grades are not as good as they once were."

"Less time for activities. Homework is stressful if there are things going on with Mom, Dad or Grandmother, and we have to hurry sometimes."

Children

Children need at least as much attention as care recipients over the long term. Diverting resources from children to the care recipient often causes regret, guilt, resentment and confusion for children and their adult family members. Some children bond with their parents' efforts and pull together as a family. Commonly, however, children may not understand and may feel resentful.

Top 7 Stress Points on Marriages

As a result of caring for a family member

40%	Tension/stress/frustration
12%	Less time for spouse
12%	Caring took up too much time to be and do anything together
11%	Conflicts/arguments/communication breakdowns
11%	Less time for family
8%	Money issues
8%	Not home enough

74%

74% of step-families or in-laws provide or contribute to care

71%

71% of step-families and in-laws report providing financial contributions

Beyond Dollars. *Minimize The Impact*

A Care Event in Your Family Can Be a Challenge, But You Can Lessen Its Impact

The impact of long term care events on families is well documented. We have learned through our assessment that there are other financial and emotional costs that may not be as readily apparent. Specifically, there are costs to the long term care recipient, caregivers and extended family.

All of the people in the Circle of Care may experience an impact on:

- Stress levels from demands on time and serving the needs of others
- Jobs and careers
- Relationships with spouses, siblings, children, step-families and in-laws
- Their incomes and finances

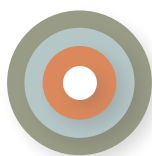
Perception and Reality

With medical advances and healthier lifestyles, people are living longer these days – often 20 or even 30 years into retirement. As we're doing a better job at living longer, the likelihood of needing care, companionship or help later in life is greater than ever.

Consider the statistics around the potential need for long term care:

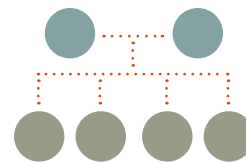
Nearly two-thirds of Americans over age 65 will need long term care at home, through adult day health care, or in an assisted living facility or nursing home.*

* AARP Public Policy Institute (2007). "Long - Term Care Trends"



The Double Whammy

For younger couples with two sets of parents, the chances of being affected by a long term care event are high if any of their parents lacks the financial resources for their own care. And if care for one parent significantly impacted a couples' finances, would they be able to contribute to the care needed for the other parents?



Survey Reveals Top Concerns

A January 2010 Age Wave/Harris Interactive survey sponsored by the Genworth Financial companies revealed that “medical expenses not covered by insurance” is the top retirement concern of people age 55 and older.

More than half of all respondents (55%) reported that their greatest fear regarding a long term care illness or event was being a burden on their family. In fact, they reported being five times more concerned about being a burden than dying.

Although the issue is a top concern, many are still not engaging in open conversations about potential long term care expenses, the costs or the types of care they would prefer or may need in the future. More than 90% surveyed have not talked about critical long term care issues with their spouse/partner, aging parents or adult children.

The First Step In Planning is to Talk to Your Family

Figuring out how to address a long term care need is stressful, but having a direction before there's a need can help immensely. Having no plan can be overwhelming. When people have to make emotional and financial decisions unexpectedly, judgment and decisions can be less than optimal. And not having the conversation means you don't have direction from the person needing care. People can find themselves writing on-the-spot checks for care. Spending money for care on a moment's notice is something no one wants to do, and the quality of those decisions may be compromised.

The broad impact – to finances, emotions, jobs and careers, immediate and extended families – adds urgency to the need for these important conversations – before the need for care arises.

“We all wish we had done it (talked) a year before. We thought the problem would go away, but it just got worse... Making specific plans when you are younger and healthier would benefit any caregiver.”

Additional 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 cover and ways to think and plan ahead for the best outcomes for you and your loved ones.



Other Valuable Resources:

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.

MyLifeMyFamily.com

nfcacares.org

National Family of Caregivers Association

caregiving.org

National Alliance for Caregiving

Methodology

In the spring of 2010, Genworth Financial sought to determine the true cost of long term care services shouldered by care recipients and their support networks. To do this, Genworth contracted with Rockhopper Research, a national third-party research firm, to develop and launch an online blinded survey aimed at care recipients and caregivers. The survey was 15 minutes in length, contained close-ended and open-ended questions, and was placed in field for a duration of two weeks. Additional information regarding survey design is detailed below.

The *Beyond Dollars: The True Cost of Long Term Caring* survey garnered 818 completed surveys from across the spectrum of those affected by a caregiving situation, whether short-term or long-term.

The results of this survey enable Genworth to expand the definition of long term care and build upon the long term care cost index, which the company has been publishing for eight years in its annual Cost of Care Survey. Broadening the index beyond strictly monetary costs, the resultant data includes impacts on relationships, jobs, and levels of stress and anxiety.

To qualify for participation in the survey, participants must have been over 25 years of age and must have been affected by a long term care event either directly, as a care recipient, or indirectly, as a caregiver or knowledgeable family member. Specifically, participants had to answer Yes to the following question:

In the past 12 months, have you or any member of your family over 25 years of age experienced an extended health care event that required either (1) a change in living structure, such as moving in with a family member or moving to a care facility, or (2) daily assistance in your or your family member's home for 30 days or longer?

The survey methodology called for 800 completed surveys. Of the 818 surveys completed, 125 were completed by care recipients. Participants classified as primary caregivers completed 575 surveys, and secondary caregivers accounted for the remaining 118. Special care was taken to make sure the sample population fell within national demographic profiles. Resultant survey findings were tested at 95% and 90% confidence levels. Significance testing was based on z-Test for percentages and Independent t-Test for means.

In the words of caregivers



“ Very difficult... Had to split my time between the family, work and caring for my mother. Husband did not always understand... A few notches were carved in our marriage, but we survived it. My husband’s parents are getting older now. He may be more understanding of what I went through when he faces it himself.”



“ My mom would call my boss every half-hour looking for me... He was understanding for a short time. This also put a strain on me physically and emotionally... Once I got home from work for the day, she started calling the house, which upset my girlfriend.”



“ Caring for my dad has left me with much less time to spend with my own daughter... With three generations living together, there’s a whole new set of rules to live by and a new set of frustrations for everyone.”



“ I am an only child, and my mother’s plan was to have me care for her. She became ill during the worst financial crisis of our lifetime... She is better now, after 11 months. But I am broke.”



“ Tension within sibling relationships... No parity in amount of individuals’ time or financial care contributions. Siblings in denial as to our mother’s need for admission to a nursing home with regard to wanting to keep mom happy and friends judging placement in elder care.”



“ I spent so much time doing it, my husband started to act neglected. I mean, he didn’t technically resent it, and he wanted me to do it. But it took me away from him for weeks at a time, and when I came home, I was tired and crabby... He understood, but even though you can understand something in your head doesn’t mean you like it in your heart. Although he never exactly said it, I feel like he felt a bit neglected.”

Plan ahead.

A Letter from Grant

I had to write and let you know how “spot on” you were in exploring the true costs of a caregiving situation. I probably have a fairly unique perspective on this because I am a claims manager in Genworth Financial’s long term care insurance business and my wife has been on claim with our company for several years now.

Due to my wife’s advancing Multiple Sclerosis (MS), I have seen her care needs grow to the point that she now needs help with 5 out of 6 ADLs (activities of daily living). That’s about as functionally impaired as a person can get.

It has been a tremendous burden on our family, emotionally and financially. My message for everyone is that without planning, we could not afford care now. I am a full-time employee and the primary caregiver and I could not be at work because I would need to be home providing that care.

Beyond the financial aspects, I can tell you firsthand that trying to be the primary caregiver for my spouse is probably the most difficult challenge I’ve ever faced in life. Without the break I get from our paid caregivers, I don’t think I could function at work.

So my message is: Whatever you can do to help people realize the importance of planning is worth the time and effort.

Grant

A handwritten signature in black ink that reads "Grant". The script is cursive and fluid, with the 'G' being particularly large and stylized.



The Value of Planning Ahead

“...it does allow me to orchestrate his care rather than administer it. Having a skilled caregiver there to help lift and bathe him provides the care he needs and lets me spend my time best visiting him, doing things that mean more to him and to me.”



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