



# How Caregiving Impacts Families, Communities and Society

**Beyond Dollars 2021**  
COVID-19 Pandemic Edition

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**Genworth** 

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Beyond Dollars is a periodic effort by Genworth to understand the experiences of Familial Caregivers and their loved ones who need assistance with activities of daily living. Survey participants qualify by either providing or receiving care over the last 12 months as part of an extended health care event.

# Caregiving: The Crisis for Which We Can Prepare

COVID-19 has disrupted lives. Schools and daycares are closing, and parents are juggling new caregiving responsibilities and their job requirements. Transmission concerns complicate how we transact and interact. The world is scrambling to address its needs in the face of new constraints.

COVID-19 has complicated loved ones' needs for care, too – restricting the ability to visit and assist. But needing and providing long-term care services has always been complicated. Genworth has conducted its Beyond Dollars study to examine the financial and emotional impacts of caregiving approximately every three years since 2010, and year after year the core story echoes and amplifies: [Caring for a loved one disrupts lives](#).

Even among those families that did take some steps to prepare for their loved ones' care needs, the vast majority, if they had it to do over, would take those steps sooner. It is Genworth's fervent hope that this study helps more families to consider today what is possible down the road so that action that can be taken to lessen the potential negative impacts of caregiving. After all, every day until 2030, 10,000 Baby Boomers will turn 65<sup>1</sup> and seven out of ten of them will require long-term care services and support at some point.<sup>2</sup>

The need for long-term care is a crisis for which we can prepare.



<sup>1</sup> "2020 Census Will Help Policymakers Prepare for the Incoming Wave of Aging Boomers" (census.gov), site accessed 10/11/21.

<sup>2</sup> 2021 U.S. Department of Health and Human Services (<https://acl.gov/ltc/basic-needs/how-much-care-will-you-need>). Site accessed 10/11/21.

# Caregiving in COVID-19: Key Insights

- ✓ Compared to in the Beyond Dollars 2018 Study, participants in 2021 reported **care needs are more severe and longer lasting**.
- ✓ **Fewer Care Recipients received care in a loved one's home** and Familial Caregivers reported providing less "companionship."
- ✓ **Less money was spent out-of-pocket in total, but more was spent on home modifications specifically.** And spending had a greater toll, with every potential financial impact listed – from "using savings/retirement funds" to "reducing base quality of living" – being chosen more often in 2021 compared to 2018.
- ✓ On the bright side, study participants reported the existence of **better resources, improved access to training, and more flexible work arrangements.** Employers' flexibility may have reduced the negative impact of caring for loved ones.
- ✓ **Care Recipients had prepared for their need through the purchase of insurance coverage in less than a quarter of cases.** Where Long Term Care Insurance (LTCI) was involved, parties reported less stress and lower out-of-pocket costs.





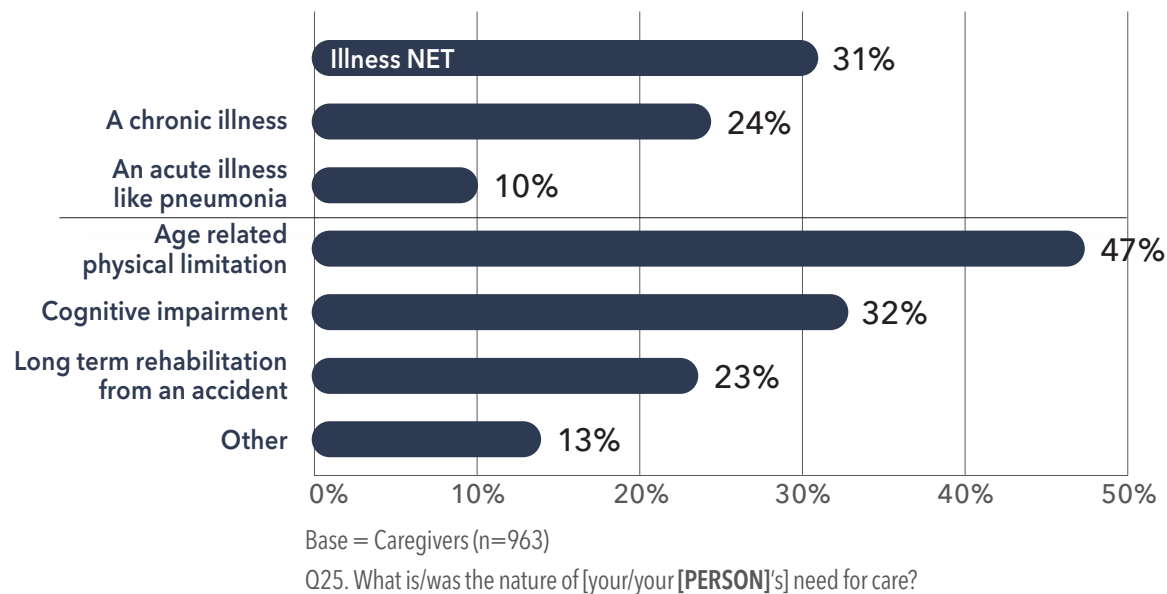
Reasons, setting and types of care vary, and needs are more severe and longer lasting.



# Care Could Be Needed for Many Reasons

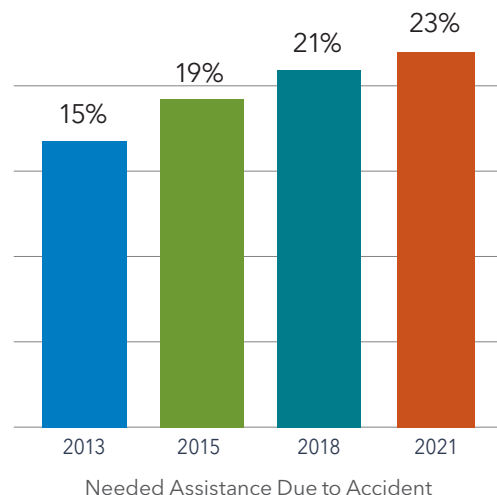
More loved ones suffered from age related physical limitations (47% from 44%), cognitive impairments (32% from 26%), and accidents requiring rehab (23% from 21%) compared to in the 2018 study.

## Causes for Care 2021



## Accident Incidence Rising

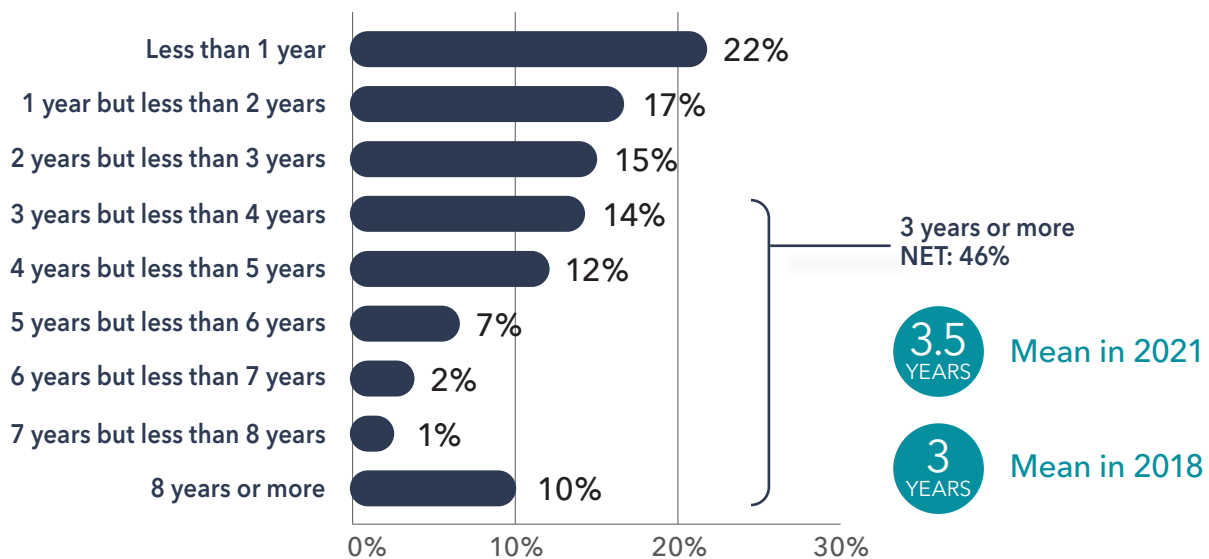
“ He fell down 3 times in a 2-month period, had a pacemaker installed, needed to go to rehabilitation home/nursing home where he passed after 5 weeks. He couldn’t rehab (walk) whatsoever, also contracted COVID there, but did not pass because of COVID. He passed from Coronary Heart Disease.”  
—Care Recipient’s Daughter



# The Need Is Lasting Longer & Is More Severe

Indicating a potentially elongating need for care, in 2018, the average duration of a care event was reported to be 3 years, while, in 2021, 3.5 years was the reported average. Also in 2021, those receiving care at home required more care than previously reported in 2018.

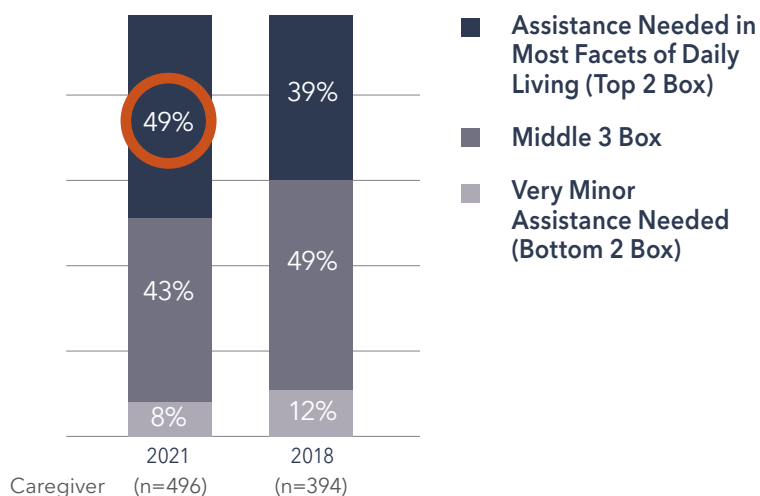
## Duration of Care Need



Base = Caregivers (n=963) / Base = Caregivers And Recipient Still Alive (n=847)^

Q23. How long did you provide care for your [PERSON]?

## Level of Care Provided



Base = Recipient Received Care At Home

Q79. What level of assistance do/did [you/they] require to continue living in [your/their] home?

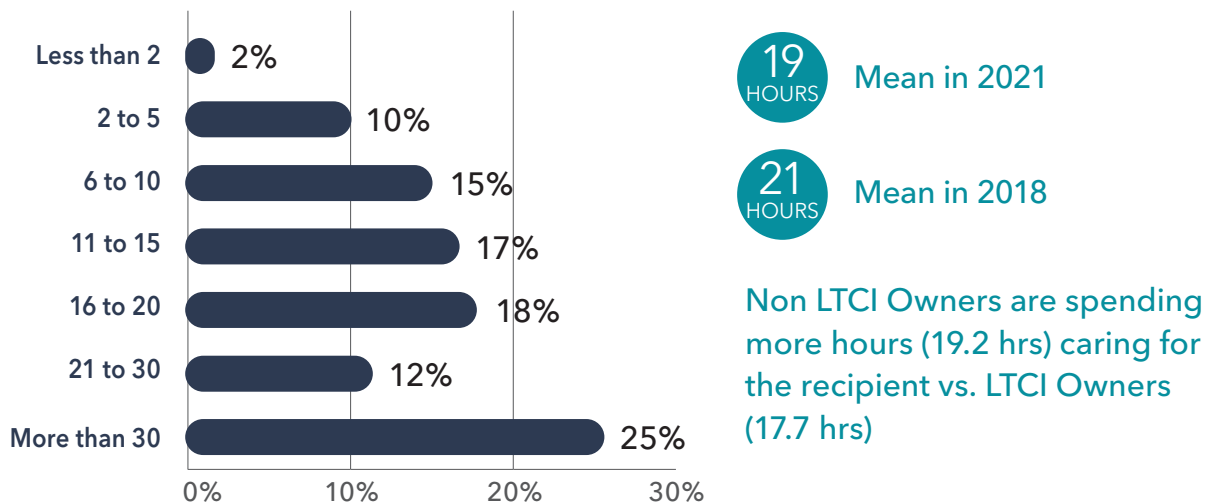
“It was difficult to make some members understand all the work involved in caring for her.”

—Care Recipient's Son

# Less Time Spent, but Less Companionship

Familial Caregivers might have spent less time providing care, but spent less “quality time.”

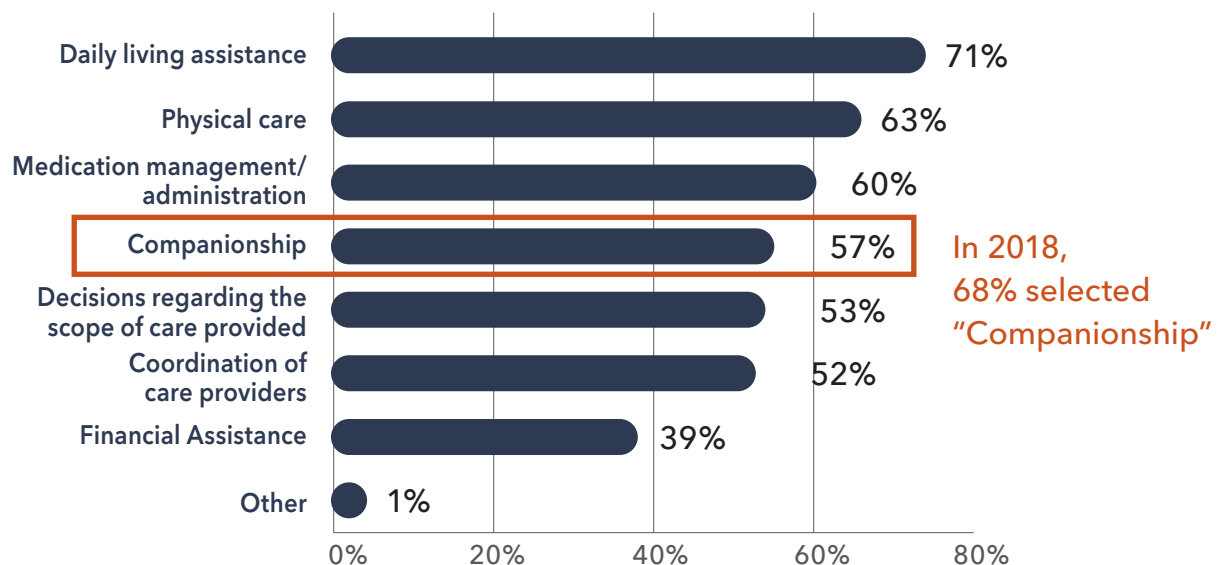
## Hours Per Week Caring



Base = Caregivers (n=963) / Base = Caregivers And Recipient Still Alive (n=764)

Q22. Approximately how many hours of your time per week on average do/did you spend in caring for your [PERSON]?

## Types of Help Caregivers Provide



Base = Caregivers (n=963)

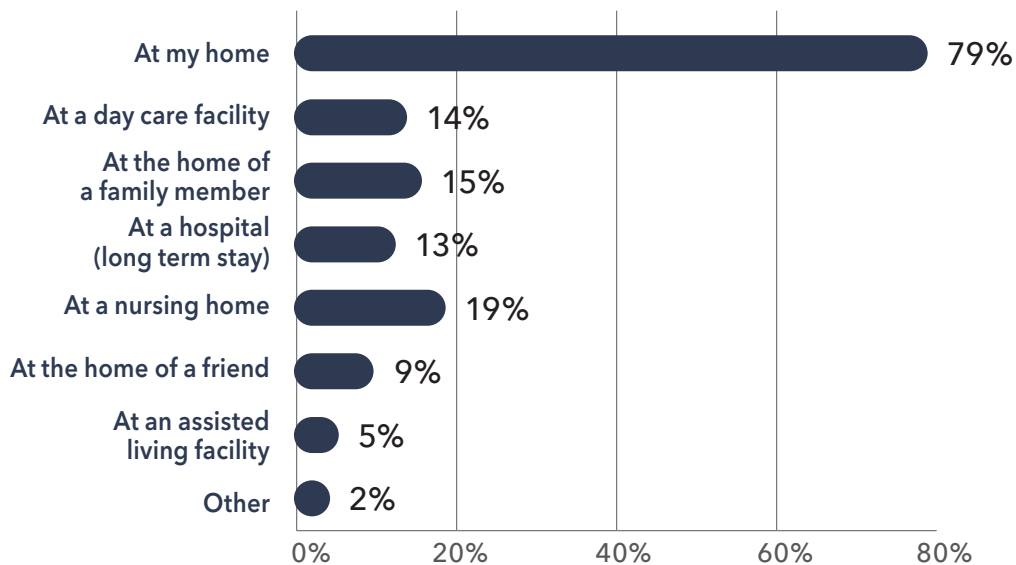
Q16. Which of the following types of help did you provide?



# Care at Home: Desired, Not Delivered

Care Recipients always say they prefer in-home care, and 2021 numbers match 2018 numbers for care at Recipients' homes. But significantly fewer Care Recipients in 2021 moved in with a loved one to receive care.

## Where Did They **Want** To Receive Care?



Base = Care Recipient (n=299) QNEW1. Where did you want to receive care?

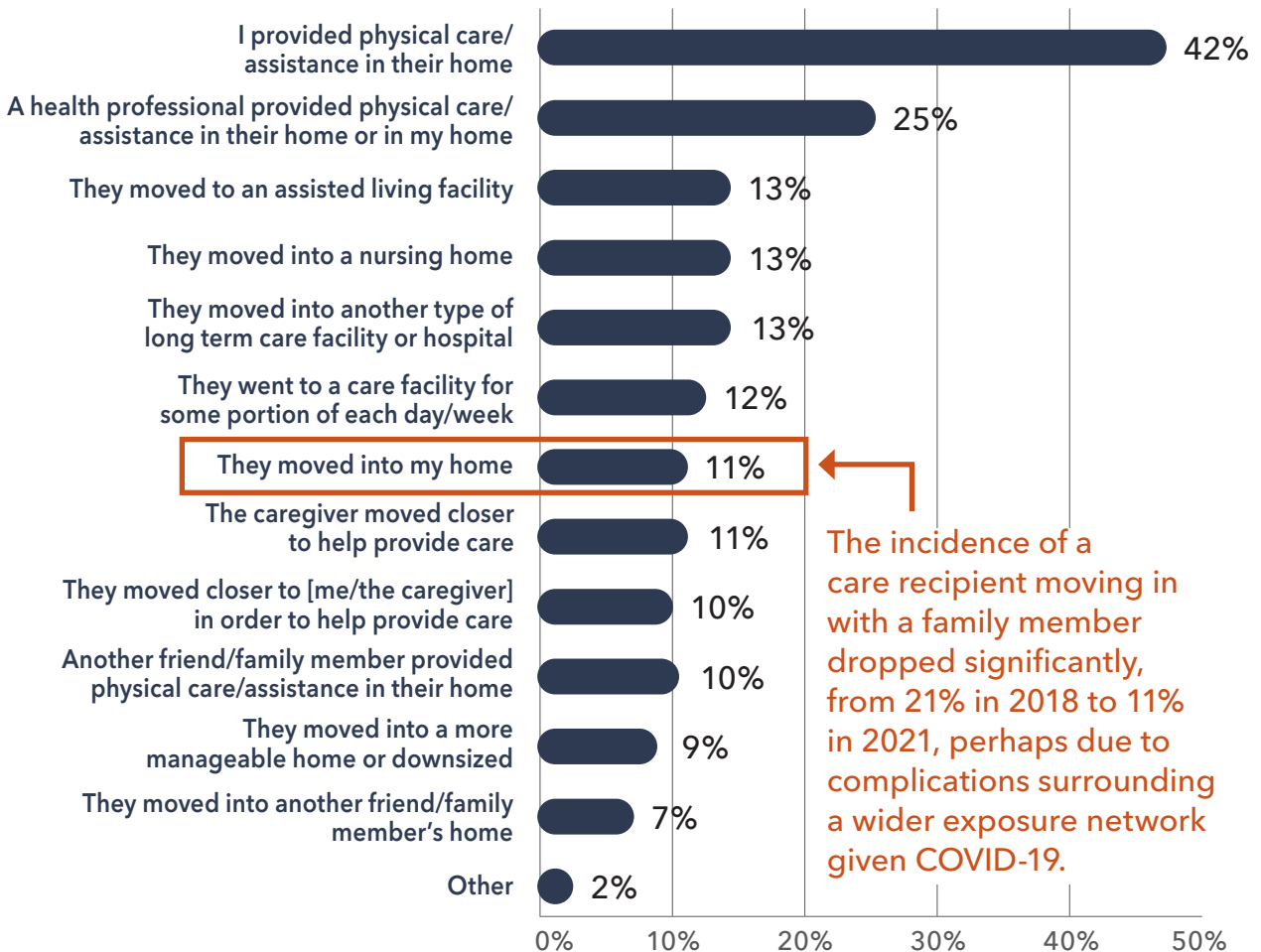
“My husband begged me not to put him in a facility.”

—Familial Caregiver



## Care at Home: Desired, Not Delivered (continued)

### Where Did They Receive Care



Base = Caregiver/Knowledgeable Family Member (n= 1,026)

Q38. Which of the following were involved in providing long term care for your [PERSON]?

# Insurance Influenced Where Care Received

LTCI Owners were more likely to go into an Assisted Living Facility<sup>1</sup> where residents may have had more space and accommodations than nursing homes typically provide.

	LTCI Owners (n=142)	LTCI Non-Owners (n=884)
I provided physical care/assistance in their home	35%	43%
A health professional provided physical care/assistance in their home or in my home	28%	24%
They moved to an assisted living facility	25%	11%
They moved into a nursing home	17%	12%
They moved into another type of long term care facility or hospital	18%	12%

Owners of Long Term Care Insurance were significantly more likely than Non-Owners to receive care in an Assisted Living Facility (25% of Owners vs 11% of Non-Owners).

Non-Owners had a Familial Caregiver provide in-home assistance 43% of the time in 2021 compared to 35% of Owners.

<sup>1</sup> in CA, Residential Care Facility

There are, of course, more feelings of “guilt” associated with moving a loved one into a facility.

	Moved Into Caregivers Home (n=66)	Received Care At Home (n=370)	Received Care at Day Care Facility (n=39)*	Moved Into Assisted Living (n=49)*	Moved Into Nursing Home (n=42)*
Guilt related to the limits of assistance you are able to provide	15%	22%	9%	35%	40%

Base = Caregiver/Knowledgeable Family Member (n=1,026); \* Denotes Comparatively Small Base Size

Q38. Which of the following were involved in providing long term care for your [PERSON]?

Caregiving can negatively impact health and well-being.



# Who are the Caregivers?



**48 / 52%**  
FEMALE MALE



**54%**  
of Caregivers are between the ages  
of 25-54 with an average age of 51



**40%**  
of Caregivers are likely an adult child  
taking care of an aging parent



**57%**  
of Caregivers have children  
under the age of 18 at home



**72%**  
of Caregivers are married  
or in long-term partnerships



**\$69,300**  
Caregivers reported an average  
annual income of \$69,300



**31%**  
of Caregivers with children said  
caregiving negatively affected their  
relationship with their children



**43%**  
of partnered Caregivers said  
caregiving negatively affected their  
relationship with their spouse/partner



**39%**  
of Caregivers provided  
financial assistance to their loved  
one who needed care

# Caregiving Affects Mental Health

Significant portions of Familial Caregivers reported experiencing stress, less time to spend on themselves or others, negative moods, sleep deprivation, insomnia, a sense of isolation, guilt and/or weight gain as a result of providing care.

	Caregivers (n=963)
Stress	48%
<b>Less Time [NET]</b>	<b>46%</b>
Less time to take care of yourself	32%
Less time with children <sup>1</sup>	19%
Less time with spouse/partner	19%
<b>Negative Mood [NET]</b>	<b>42%</b>
Depression	24%
Mood swings	20%
Resentment	16%
Sleep deprivation	30%
Insomnia	21%
Sense of isolation	19%
Guilt	18%
Weight gain	17%

While 51% of all Caregivers indicated that the experience negatively affected their personal health and well-being, Female Caregivers were more likely than Male Caregivers to report this negative impact (59% to 43%).

<sup>1</sup> Asked of those who have children

Base = Caregiver (n=963)

Q59. Looking back, do you believe you may have experienced any of the following as a result of your [PERSON]'s need for long term care?



## Caregiving Affects Mental Health (continued)

“ I don’t have a life outside of my daughter. I quit working an outside job, because of the enormous sense of guilt I felt about leaving her home all day alone and her not having a life. I gave up mine so she could have one. I’m self employed now, which is really hard. Only earn about \$750 per month (on top of her \$794 Social Security Income). It’s awful to say and feel this way, but I’m thankful for COVID, because this is the first year since 2006 we haven’t lived in poverty due to me shutting down my business and qualifying for pandemic unemployment. I’d be earning about \$60K yearly, if I could go back to work. It’s just so hard and I’m tired and I wish I could get a break sometimes. Have some time for myself. Maybe even meet people, so I can have friends. I feel so isolated and alone.”

–Familial Caregiver



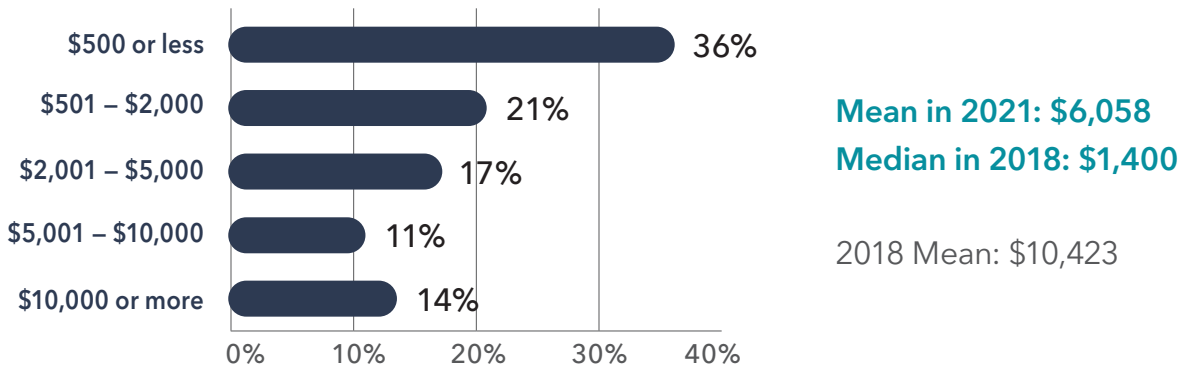
Caregivers' savings and retirement funds are at risk.



# Out-of-pocket Down; Modifications Up

Familial Caregivers might have spent less money out-of-pocket in total in 2021 compared to 2018, but spent more on home modifications specifically.

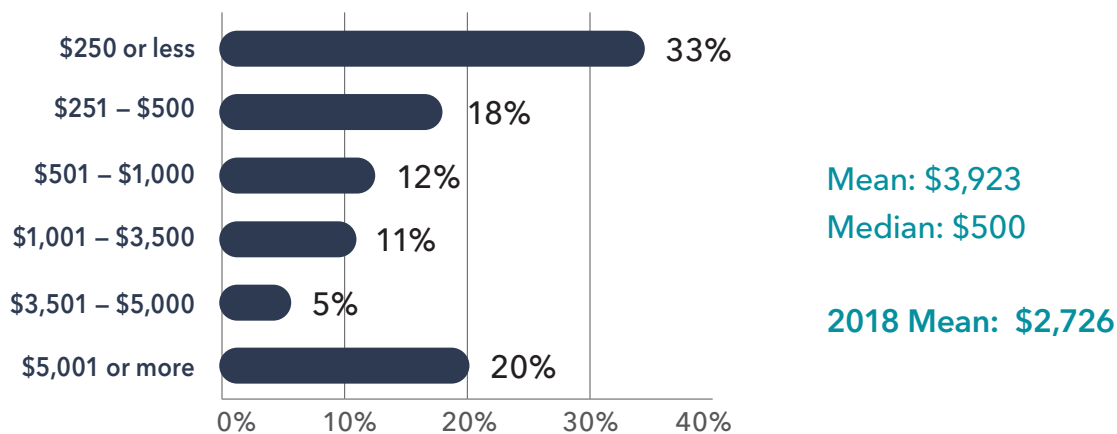
## Total Out-of-Pocket Costs



Base = Caregiver and Provided Financial Assistance or Care Recipient

Q20. Please provide a best guess estimate of the **total** out-of-pocket expenses you have incurred related to your [PERSON]'s care.

## Approximate Cost of Modifications



Base = Recipient Moved Into Caregiver's Home And Modifications (n=82)

Q73. What was the approximate cost of those modifications?

# Less Money Overall, but Greater Impact

Though, again, out-of-pocket spending to address loved ones' needs was down in 2021 compared to 2018, the reported impact of that relatively lower dollar amount was significantly more detrimental to a Familial Caregiver's overall financial health in 2021.

## Financial Actions Resulting From Need to Pay for Loved One's Care

2021	Caregivers 2021 (n=963)	2018	Caregivers 2018 (n=739)
Using savings/retirement funds	66%	Using savings/retirement funds	63%
Cutting back on luxury expenditures	63%	Cutting back on luxury expenditures	60%
Reducing contribution to savings/ retirement	54%	Reductions in base quality of living	48%
Reductions in base quality of living	53%	Reducing contribution to savings/ retirement	42%
Reducing charitable giving	52%	Reducing charitable giving	40%
Spending down funds intended for inheritance	50%	Spending down funds intended for inheritance	38%
Selling other personal possessions	43%	Selling other personal possessions	35%
Using cash value inside life insurance policies	41%	Borrowing money from a friend or family member	31%
Borrowing money from a friend or family member	40%	Taking out a loan	30%
Selling a home	39%	Selling a home	28%

**Base =Caregivers**

Q21. Please select who was responsible for the financial related items below that directly or indirectly resulted from [you/your **[PERSON]**]'s need for long term care.

Caregivers' careers and livelihoods are impacted by providing care, but flexible work arrangements and resources are making it easier.



# More and Better Resources

Compared to 2018, Caregivers were more likely to utilize professionals in 2021 when seeking support and knowledge. Many utilized resources were deemed more helpful in 2021 versus 2018, hopefully indicating an upward trend in how society is addressing the needs of its aging population.

## What Resources Were Used?

Social Workers	23% 2021	18% 2018
Financial Professionals/Companies	20% 2021	17% 2018
Attorneys/Elder Law Specialists	11% 2021	7% 2018

## Were the Resources Helpful?

Television Programs	70% 2021	42% 2018
Internet-Based Social Networks	68% 2021	50% 2018
Attorneys/Elder Law Specialists	66% 2021	51% 2018
Financial Advisors	65% 2021	52% 2018
Non-Profit/Council on Aging	61% 2021	44% 2018
Insurance Carriers	56% 2021	41% 2018
Company's Human Resources Department	56% 2021	39% 2018

**Base = Total Respondents**

Q63. Which of the following resources did you consult for the support and knowledge you needed?

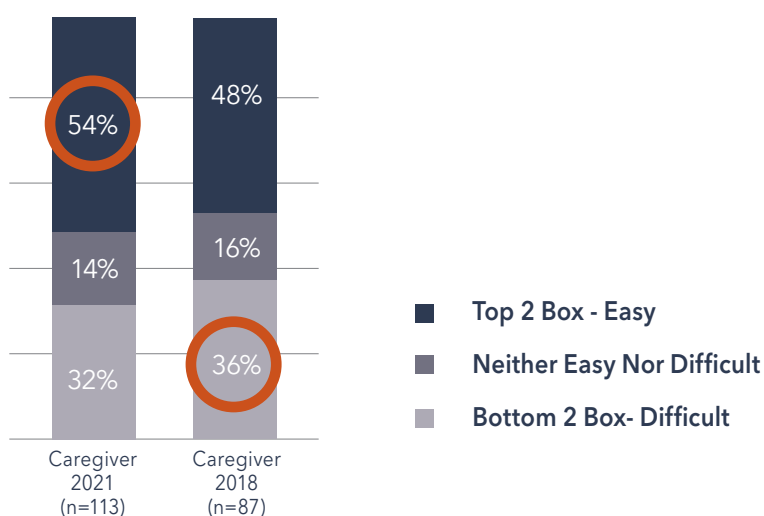
Q64. On a scale from 1 to 7 with 1 representing not at all informative/helpful and 7 representing extremely informative/helpful, please rate how informative and/or helpful the following were.



# Good Help Is Easier to Find

Finding professional care was less difficult and required less time for Familial Caregivers in 2021 vs 2018, likely due to improved online services.

## Ease of Finding Satisfactory Professional Care Providers



## How Did You Research/Evaluate Professional Care Services?



Base = Received Care From Professional Caregiver;

Base = Caregiver or Care Recipient and Received Care From Professional Caregiver

Q34. On the following scale, how easy was it to find satisfactory professional care providers?/Q35. How did you research/evaluate professional care services?

Q36. To help provide a sense of the impact of using professional care providers, please fill-in the following to the best of your ability.

# Good Help Is Easier to Find (continued)

## Average Caregiver Professionals Used & Hours Spent Researching

	Caregivers 2021 (n=113)	Caregivers 2018 (n=87)
Average Number Of Hours Spent Researching/Evaluating Professional Caregivers	6.8	7.6

“Finding a high quality facility that would seriously take care of dad wasn’t easy but we managed.”  
–Familial Caregiver

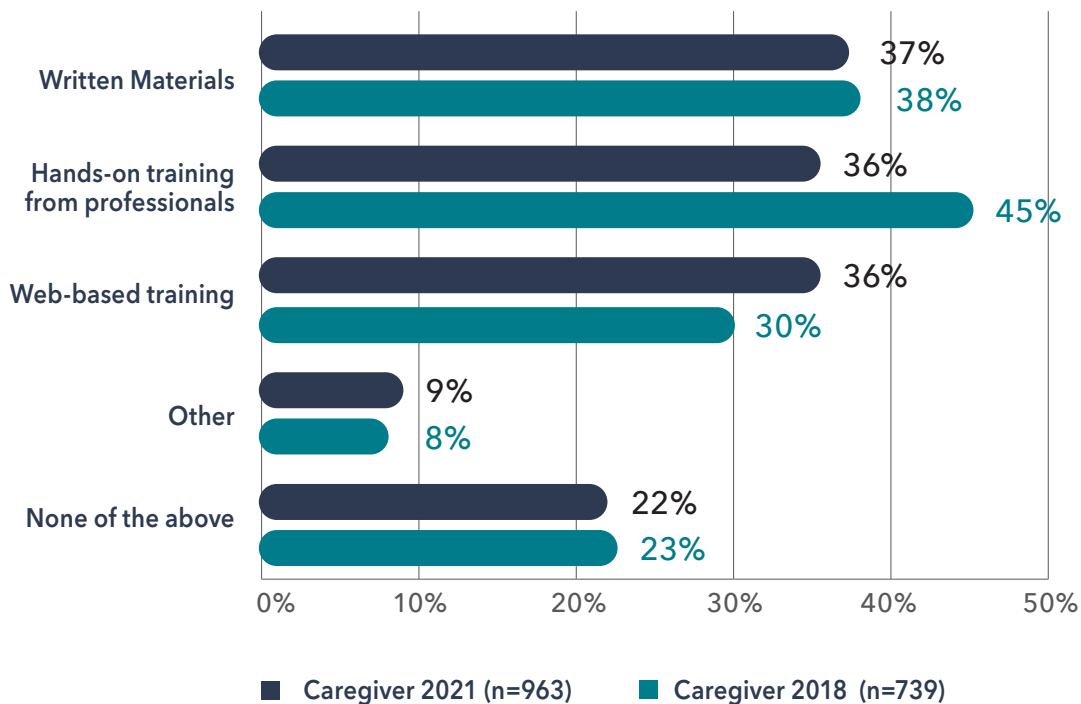


Base = Received Care From Professional Caregiver;  
Base = Caregiver or Care Recipient and Received Care From Professional Caregiver  
Q34. On the following scale, how easy was it to find satisfactory professional care providers?/Q35. How did you research/evaluate professional care services?  
Q36. To help provide a sense of the impact of using professional care providers, please fill-in the following to the best of your ability.

# Caregivers Online & Feeling Qualified

Given COVID-19, use of web-based training went up while use of hands-on training decreased, but notably, compared to 2018, Familial Caregivers were more likely to feel “qualified” to provide the care needed of them.

## Types of Training Caregiver Received



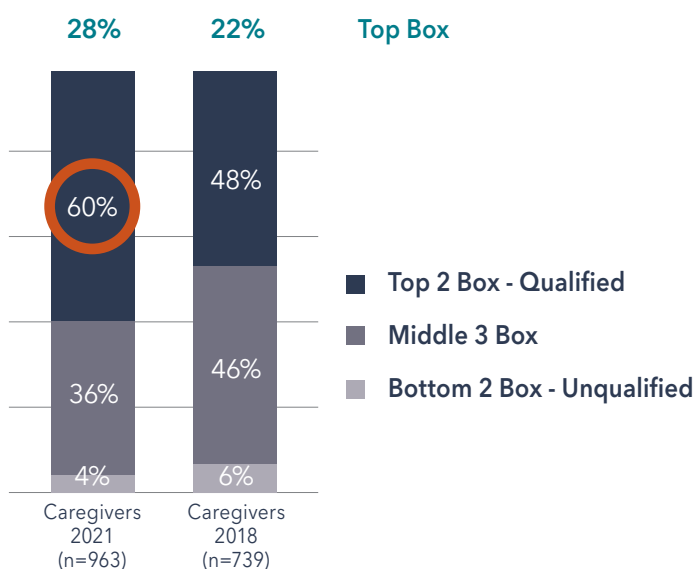
**Base = Caregiver and Provided Physical Care or Care Recipient received In-Home Care**

Q39. Which, if any, of the following ways did you receive training for the care you provided?

Q61. On a scale of 1 to 7, how qualified did/do you feel [to provide the physical care required of you/your friends and family members were that provided care for you]?

## Caregivers Online & Feeling Qualified (continued)

### How Qualified Do You Feel You Are to Provide Care?



“There’s no handbook for this, not really. And the emotion and helpless feeling isn’t something anyone can prepare you for.”

—Familial Caregiver



**Base = Caregiver and Provided Physical Care or Care Recipient received In-Home Care**

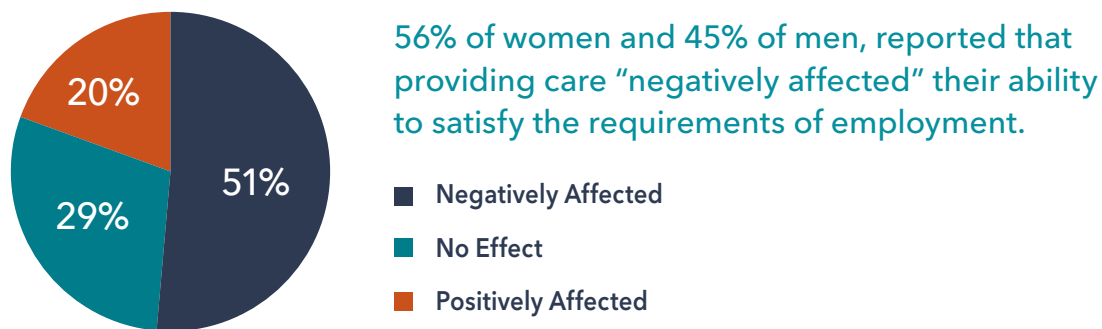
Q39. Which, if any, of the following ways did you receive training for the care you provided?

Q61. On a scale of 1 to 7, how qualified did/do you feel [to provide the physical care required of you/your friends and family members were that provided care for you]?

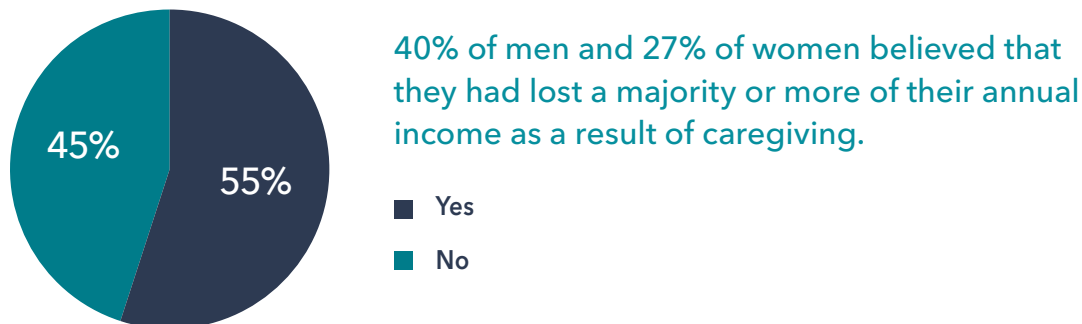
# Caregiving Negatively Affected Employment

55% of Caregivers were employed full-time when their loved one required care. 51% of these family caregivers – 56% of women and 45% of men – reported that providing care “negatively affected” their ability to satisfy the requirements of employment. Similarly, 40% of men and 27% of women believed that they had lost a majority or more of their annual income as a result of caregiving.

## Impact of Caregiving on Employment



## Was Income Lost as a Result of Caregiving?



“It was hard with work and getting appointments at times that was best for me.”

–Familial Caregiver

Base = Caregiver and Employed at time of need (n=626)

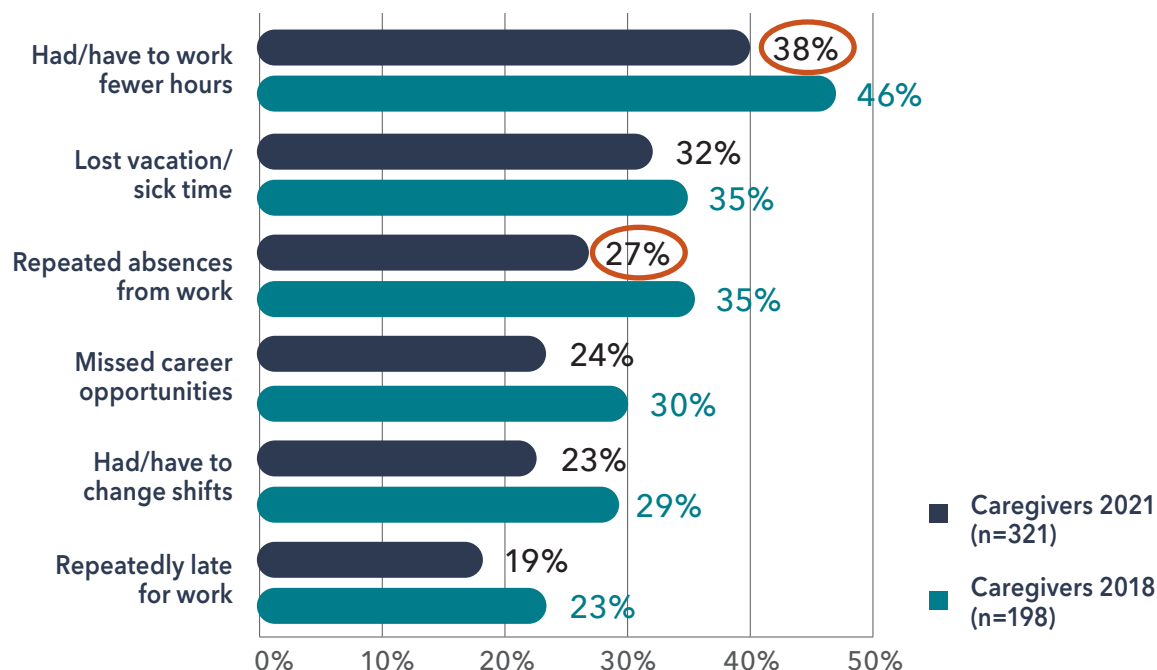
Q46. On a scale of 1 to 7 where 1 is “affected positively” and 7 is “affected negatively”, to what degree [did/does] [your long term care need/caring for your [INSERT ANSWER FROM Q5]] impact your ability to satisfy the requirements of your employment?

Q44. Do you believe you lost income due to [your long term care need /caring for your [INSERT ANSWER FROM Q5]] (working fewer hours, leaving a job, missing career opportunities, etc.)?

# But Work Flexibility Reduced Negative Impact

The flexibility of individuals' work schedules may have made it easier to be a caregiver and an employee in 2021 compared to 2018. Reduced incidence of negative effects, fewer work hours missed, and more Caregivers moved closer to their loved ones.

## Types of Training Caregiver Received



### Caregiver Hours of Work Missed (Per Week)

6 HOURS 2021 Average

7 HOURS 2018 Average

### Caregiver Moved Closer to Loved One

52% 2021 Percentage

26% 2018 Percentage

“I did have to give up my full time job and take on a part time one.”

–Familial Caregiver

Base = Caregiver And Negatively Affected Employment (n=293) / Base = Caregiver, Negatively Impacted Employment, And Missed Work Time (n=200)

Q47. Below are some work-related outcomes that can occur when a family member requires assistance and care. Please select all that were/are a result of caring for your [PERSON].

Q48. Approximately how many hours on average per week do/did you miss work because of caring for your [PERSON].

Q40B. Did any friends or family members move or relocate their home to be closer to you while you were receiving care?



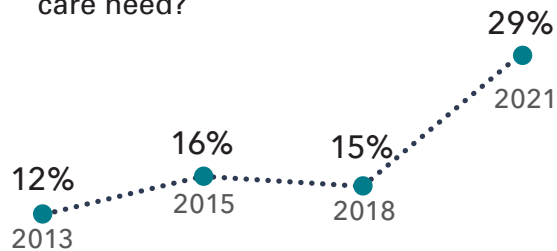
Planning helps to mitigate stress  
and negative impacts.



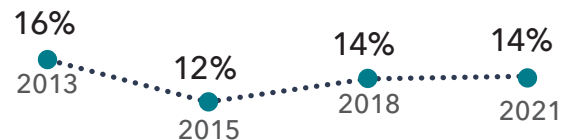
# Insurance Is Still the Step Not Taken

Belief in the importance of early planning increased during the COVID-19 pandemic, but inclination to purchase Long Term Care Insurance and utilization of its coverage has not changed.

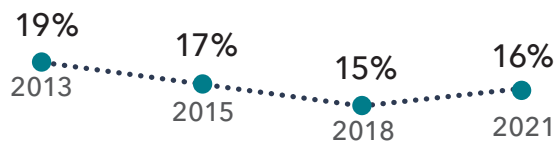
Q: Should steps have been taken sooner to prepare for the long-term care need?



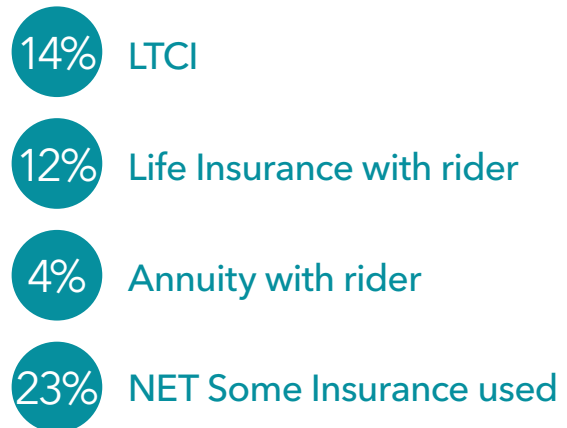
Q: Was Long Term Care Insurance utilized to pay for care services?



Q: Should you have purchased insurance to cover the potential need for long-term care?



Q: Which of the following were utilized to pay for care services? (2021)



Base = Total Respondents

Q34. Looking back, do you believe that you [or your **[PERSON]**] should have taken steps sooner to prepare for [you/your **[PERSON]**]'s long term care need?

Q65. [If you had to go through the same process all over again of providing care to your **[PERSON]**, which of the following will you want to have done/

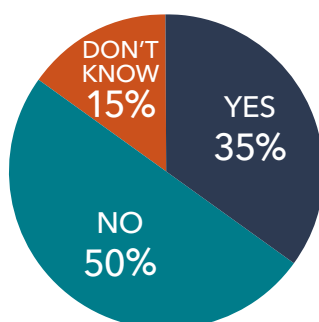
If you had to go through the same process all over again of having to receive care, which of the following will you want to have done?]

Q12. Did [you/your **[PERSON]**] utilize any of the following when [you/they] required long term care assistance?

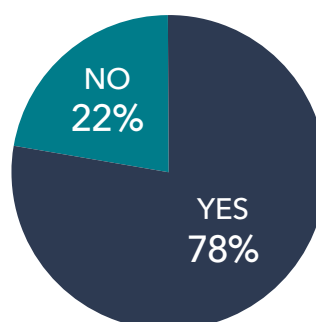
# It's Never Too Early to Plan

Even those who planned wished they'd taken steps sooner.

Planned for  
LTC Possibility



Among Those Who Made  
Plans: Should Have Taken  
Steps Sooner



“Not knowing where to start led to procrastination on doing what needed to be done.”

–Familial Caregiver

“At some point you realize that you need outside help and figuring out where this help is available & how to access it is a daunting task.”

–Familial Caregiver

“Getting in touch with the correct agencies and setting up in-home care and making sure all the schedules mesh with doctor appointments – we scrambled through all that.”

–Familial Caregiver

“I was expected to provide medical care with no knowledge including wound care, insulin shots, home IV, bathing, toileting, lifting him and carrying him, etc.”

–Familial Caregiver

Base = Total Population

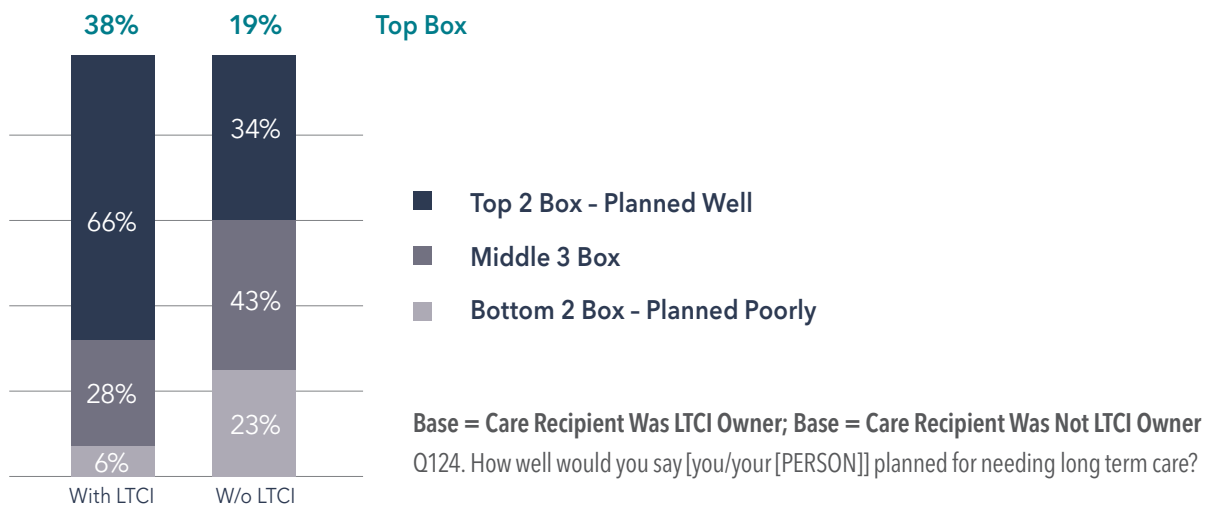
Q33. Prior to needing care, had [you/your **[PERSON]**] ever made plans to cover this type of situation?

Q34. Looking back, do you believe that you [or your **[PERSON]**] should have taken steps sooner to prepare for [you/your **[PERSON]**]'s long term care need?

# LTCI Is Associated With Better Planning

In situations where LTCI was used, Familial Caregivers credited their loved ones as having “planned well.” LTCI typically provides a benefit for respite care, a service Familial Caregivers lauded or regretted not having.

## Planning Perceptions With & W/o Long Term Care Insurance



## If You Had It to Do Over Again...

In cases where a loved one was receiving care at home, 25% of Familial Caregivers wished they'd been able to “make arrangements for someone to provide them a break.” This “respite care” is a benefit of Long Term Care Insurance.

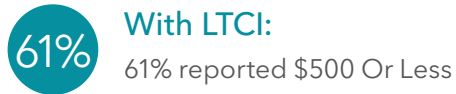
“I had regular breaks from providing care for 5 years, and that helped significantly. Without that, doing this for any length of time would have been far more mentally exhausting.”

—Familial Caregiver

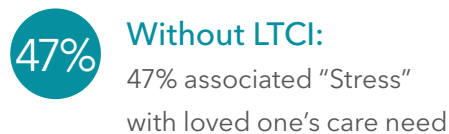
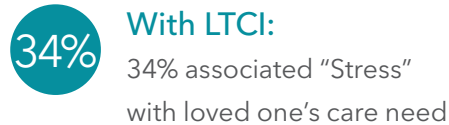
# LTCI Can Help Reduce Costs and Stress

Where LTCI was utilized survey participants reported fewer out-of-pocket costs and less stress.

## Out-of-Pocket Costs



## Emotional Effects



Care Recipients with LTCI reported that, on average, 32% of their out-of-pocket costs were reimbursed by the insurance companies.

“I’m always stressed. I don’t do things for myself or have a life of my own.”

–Familial Caregiver in situation without Long Term Care Insurance

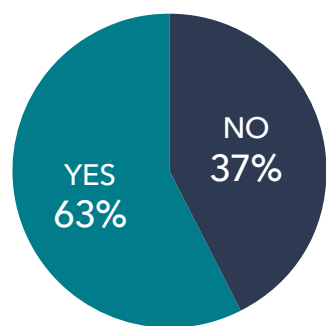
“Finding the money to pay for outside help to come in, then realizing I could no longer afford paid help. That was hard.”

–Familial Caregiver in situation without Long Term Care Insurance

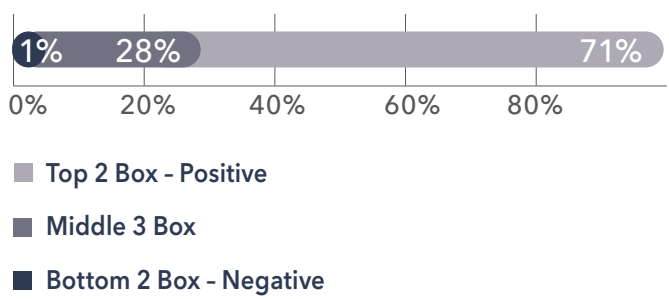
# Benefits Were Seen...

Where LTCI was used, perceptions were positive. But even where it was not, a majority of respondents believe LTCI would have improved their situation by reducing anxiety and bringing peace of mind.

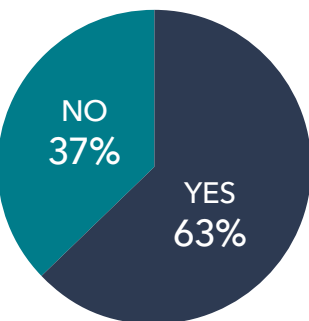
## Your Loved One Had LTCI; Do You?



## Your Loved One Had LTCI; What Is Your Impression Of LTCI?



## LTCI Would Have Benefitted Care Recipient



	Total (n=695)
Peace of mind	46%
Relief from the financial burden associated with long term care	42%
Less anxiety/More security	42%
Rest easier knowing that my care would be covered	39%
Better quality of care	38%
Relief from stress on the family	38%

Base = Care Recipient Was LTCI Owner (n=227); Base = Non-LTCi Group (n = 1,103) And Long Term Care Would Have Benefitted

Q126. [You reported earlier that you do not have Long Term Care Insurance coverage] From your perspective, would Long Term Care Insurance have benefited [you/your **[PERSON]**]?

Q127. Which of the following are ways that you feel Long Term Care Insurance coverage might have benefited [you/your **[PERSON]**]?

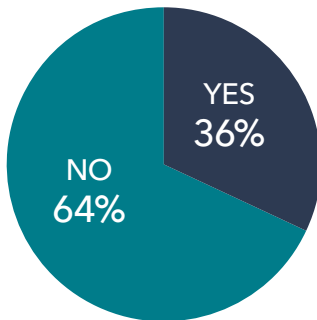
Q116. What is your overall impression of Long Term Care Insurance? Q136. What is your overall impression of Long Term Care Insurance?



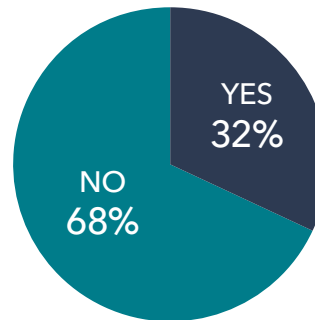
# ...But Not Seized

Caregivers in situations where Recipients did not have LTCI are unlikely to have it themselves. The number one reason why not is the perception that they “can’t afford” the coverage.

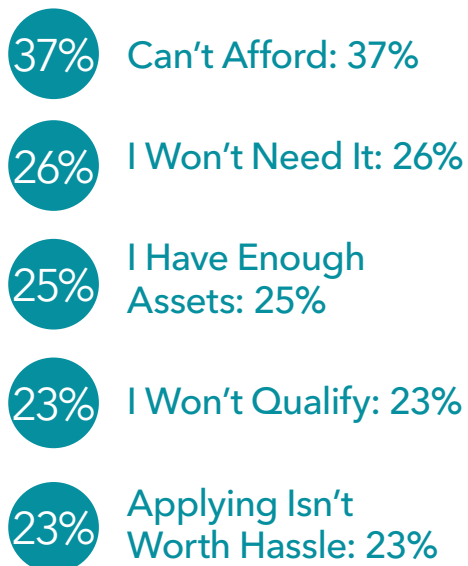
Your Loved One Did Not Have LTCI; Do You?



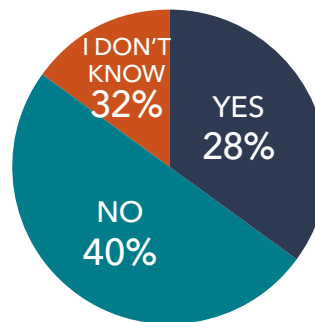
You Don't Have LTCI; Do You Have A Plan To Pay For Care?



Why Don't You Have LTCI?



Ever Look Into Purchasing LTCI?



How do you know what you can/can't afford if you haven't looked into the cost?

Base = Not LTCI Owner

Q125. Do you personally have this type of coverage?/QNew46. Do you have a plan for how you would pay for any long-term care services you could need in the future?

QNEW17. Please indicate your level of agreement with each of the following statements.

# Excuses & Advice

Breaking inaction's inertia is an obstacle. The advice from Caregivers is to hurdle it as soon as possible.

## What Those Without LTCI Say

“I haven't gotten around to it yet,”

—one Familial Caregiver said.

“I just haven't wanted to deal with it,”

—said another Family Member.

## What Familial Caregivers Who Have Benefited From LTCI Say

“Plan ahead and consider Long Term Care Insurance.”

“Prepare as early as you can and have a plan in place, if possible.”

“Open a long term care insurance policy.”

“We applied 1 year before his stroke for Long Term Care Insurance. We should have applied 10 years sooner.”

“Save money for future assisted living needs. It is difficult to try to care for elderly parents on your own. Having her in a facility to properly care for her and give her an enriching life on a daily basis is worth the cost and peace of mind.”

# About the Study

Genworth sponsored the Beyond Dollars Study in 2010, 2013, 2015, 2018 and now in 2021 to understand and share the perspectives of care recipients, familial caregivers and their wider support network.

Genworth conducted its latest Beyond Dollars Study in April 2021. The initial research population included 4,695 participants, of whom 1,325 qualified to participate based on their situations and experience. Nearly one-in-three (providing 963 completed surveys) qualified as Familial Caregivers, those individuals providing long-term care to loved ones. The study also reflects the experience and perspectives of 299 Care Recipients and 63 other Family Members with detailed knowledge of a long-term care event in their family (but not responsible for providing care).

When extrapolating to the total population of people requiring long term care services, this study looks at the responses provided by caregivers, the largest, most representative group, as opposed to the portion of survey participants qualifying as care recipients, a group that skews from the total population by nature of their physical and/or cognitive ability to participate in this online survey.

40% percent of caregivers were providing care for a parent, step-parent or parental in-law (23% for their mother, 10% for their father). 46% were caring for a spouse and 3% for a grandparent. 8% were providing long-term care for a sibling or child.

Caregivers were essentially evenly split between male and female, challenging a commonly held assumption that the caregiving role predominantly becomes women's responsibility. Their average age was 51, and 72% were married. 60% of the loved ones receiving care were women, with an average age of 61, of whom 34% were married. A dedicated effort was made to ensure the survey population was ethnically representative of the United States – resultant data shows that the experience of needing care and providing care for a loved one does not vary depending on one's ethnicity.

**For more information, visit**

[genworth.com/caregiving](https://genworth.com/caregiving)