Following the Journey of Family Caregivers



CLTC, Home Instead and Homethrive sponsored a survey to explore the journey family caregivers experience when they are supporting a loved one who needs care at home. Specifically, they were interested in understanding whether and how individuals made the decision to bring paid in-home care into the mix and how their experience differed from those who relied exclusively on family care. The survey also compared the experience of individuals juggling employment and family caregiving with those no longer working.

SURVEY HIGHLIGHTS

• What are the biggest challenges family caregivers confront?

•	Getting the emotional support they need	33%
•	Taking time off from work	32%
•	Coordinating with MDs and other providers	32%

• What were the most important reasons family caregivers cited for using paid home care?

•	Lack of expertise to provide needed care	18%
•	They are burnt out	18%
•	They are worried about their job/paying enough	15%
	attention to work	

• What was the most important reason for not using paid help?

•	Felt it was my duty to provide care	27%
•	Loved one did not want a stranger in the house	14%
•	Cost – couldn't afford it	14%

• What would have been different if you had used paid help?

•	Time to relax	48%
•	Deal with emotional stress and physical strain	44%
•	Have better self-care	30%

How does the care journey differ for family caregivers who are also working?

•	Working caregivers are significantly more likely than	56% vs. 41%	
	non-working caregivers to use paid in-home care		

 Working caregivers are more likely to say they would use paid home care if they found themselves in another caregiving situation in the future • Does the experience of being a caregiver raise awareness of the need to plan ahead for one's own future LTC needs?

•	Yes	47%
•	Yes, but I was already doing future planning	26%
•	Maybe	11%
•	No	17%

• For the small portion of family caregivers that said being a caregiver did not influence their thinking about their own future planning, they cited many different reasons:

•	Too hard to think about	29%
•	Can't afford anything except family care	25%
•	Don't see any viable planning options	18%
•	Feel family has an obligation to provide care	18%
•	Already thought about it and have done	18%
	whatever planning I can	
•	Other	6%

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Methodology: The survey was designed by ET Consulting, LLC, in collaboration with the sponsors. It was delivered using an online survey platform and took an average of 12 minutes to complete, with a 100% completion rate among respondents who qualified and began and survey. In total, 400 family caregivers were surveyed, ranging in age from 18 - 65+.

Respondents were pre-screened to fit the participant criteria:

- Current or previous (recently) family caregiver
- Caring for family member in a home-based setting
- By design, half the sample (200) included individuals who had used or were using paid home care providers and half who were not/had not
- The sample included a mix on all other demographic characteristics