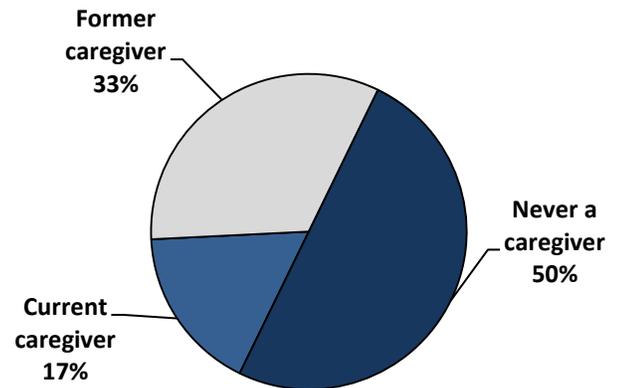


# 2018 AARP Illinois Caregiving Survey: The Family Caregiver Profile

Exactly half of registered voters age 40 and older in Illinois (50%) are currently providing care to an adult loved one or have previously provided such care.

**In our survey, a family caregiver in Illinois, currently caring for an adult loved one – most likely a parent – is a woman (53%), who is married (73%), is 61 years of age, has at least a two-year degree (64%), and lives in a household with income under \$100,000 (62%).** While almost half are currently working (49%), more had been employed at some point during their caregiving journey (62%).

Caregiver Status of Registered Voters Age 40-plus in Illinois (N=1100)



In addition to providing care to their loved ones, one in three current caregivers (34%) are also caring for their children. One in ten (12%) are caring for children 18 and younger who live with them, one in seven are also (15%) caring for children 19 and over living with them, and seven percent are caring for both younger and older children living with them.

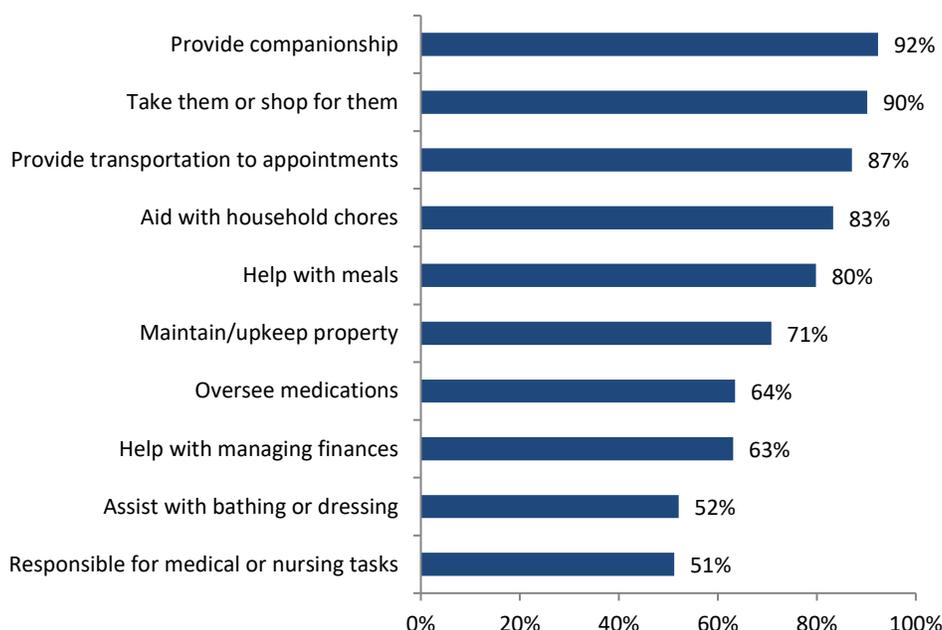
Current caregivers are providing care to loved ones who are most likely over 70 years of age. In fact, the median age of the person they are caring for is 82 years old. Most current caregivers rate their health as excellent, very good, or good (85%), and just over one in ten rates it as fair or poor (13%).

Age of Loved Ones	
18-49	6%
50-69	19%
70+	73%

## Care Family Caregivers Provide

Current and former caregivers provide significant amounts of care to their loved ones. Many caregivers help their loved ones by assisting with activities of daily living. About two in three oversee medications; and over half assist with bathing and dressing or have responsibility for other medical or nursing tasks.

Care Provided by Current and Former Caregivers (n=546)



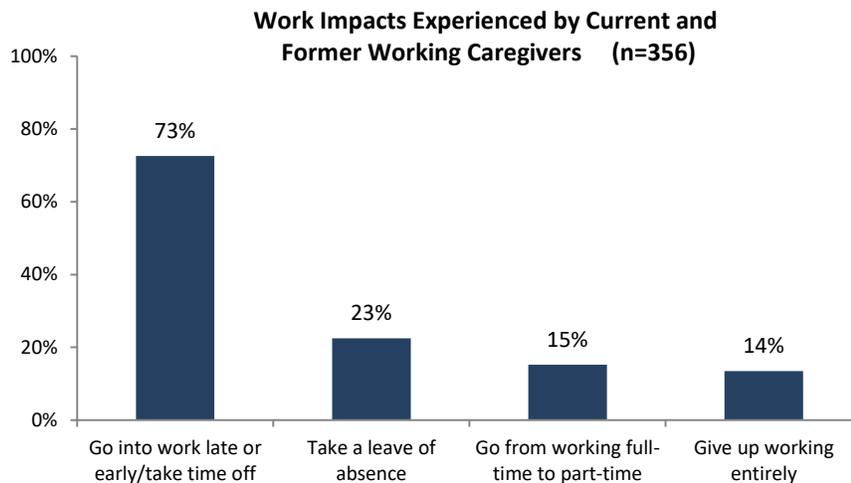
About nine in ten caregivers provide companionship for their loved ones, take them shopping, or provide transportation to appointments.

About eight in ten caregivers help their loved ones with meals or other household chores, and seven in ten help to maintain property.

Many caregivers perform this care **every day**. At least half of current caregivers help with meals (69%), oversee medications (63%), help with household chores (63%), or assist with bathing and dressing (59%) every day.

## Most Family Caregivers Have Worked When Caring

Balancing work and family can be challenging, and adding caregiving responsibilities to the mix can drastically amplify this challenge. **About two in three current and former family caregivers (65%) have been employed either full- or part-time while they provided care to a loved one.** When this balance between work and caregiving becomes difficult, caregivers may need to make changes to their work situation. Many working caregivers have had to adjust their work schedules to provide care – over seven in ten say they have gone into work late or early or taken time off to provide care, and about one in seven say they have gone from working full-time to part-time to provide care.



Some working caregivers have stopped working to provide care – either by taking a leave of absence or by giving up work entirely to provide care. In fact, over three in four (78%) working caregivers say they have taken at least one of these four actions while providing care.

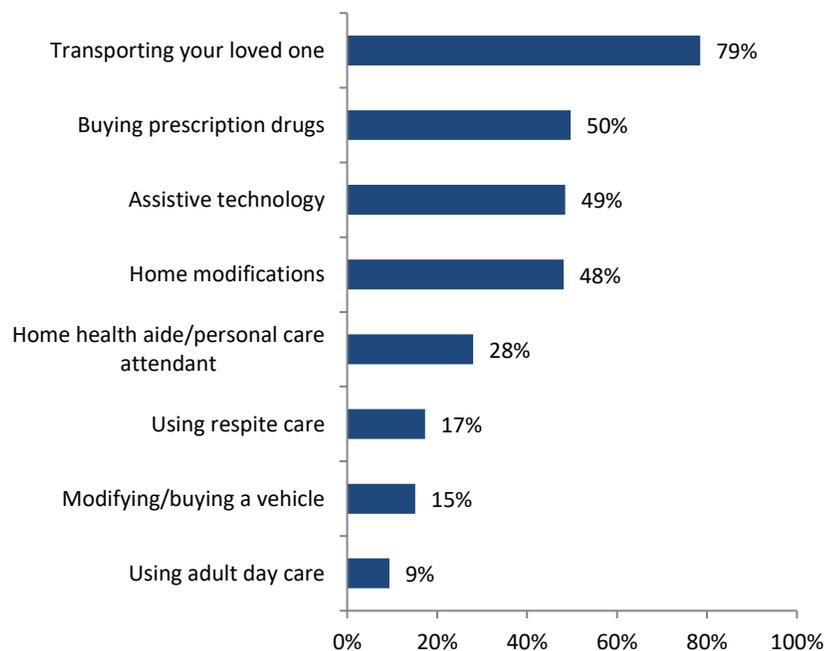
## Caregivers Spend Their Own Money to Care

**Over six in ten current and former caregivers (62%) have used their own money to care for their loved ones.** Of these caregivers, most have spent money transporting their loved ones where they need to go. Exactly half have spent money buying prescription drugs, and just under half have spent money modifying homes, or on assistive technology, such as a wheelchair, or hearing, vision, or other wearable devices.

About three in ten have spent money hiring aides to help them care for their loved ones. And, fewer caregivers have spent money getting a break from their caregiving responsibilities by using respite care or adult day care services.

One in five of these caregivers who have spent their own money to provide care (21%) live in households with income under \$50,000.

**Things Caregivers Spent Their Money On While Caring (n=339 – Current and Former Caregivers Who Use Own Money to Care)**



Staying at home and out of costly institutions appears to be highly valued by caregivers as 91 percent of them say it is extremely or very important to provide care so their loved ones can live independently at home. In fact, if caregivers needed help, most would prefer to receive that help at home with caregiver assistance (83%).

## Caregivers Feel Emotional Stress

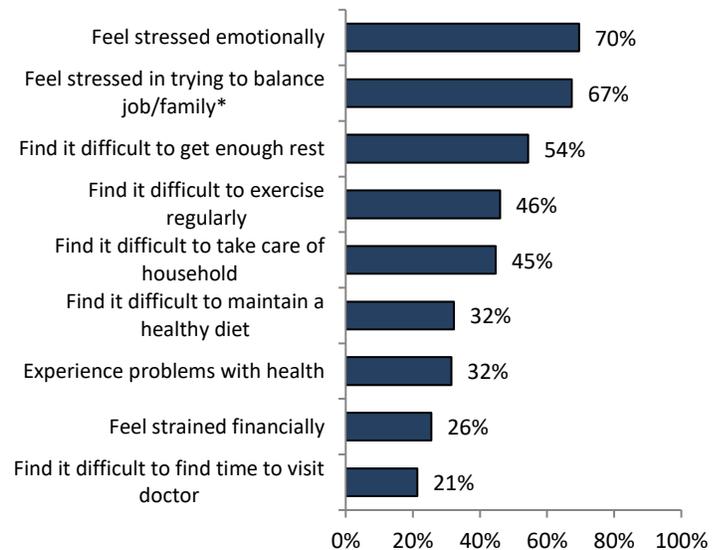
Over eight in ten current and former caregivers (86%) reported feeling at least one of the nine stressors asked about in this survey.

Seven in ten current and former caregivers felt stressed out emotionally due to caregiving, and two in three **working** caregivers admitted to feeling stressed in trying to balance their job and their family.

Over half have found it difficult to get enough rest. Over four in ten found it difficult to take care of their household or to exercise regularly. About a third found it difficult to eat well or have experienced problems with their own health. And, over two in ten have felt strained financially or found it difficult to visit their own doctor.

*\*Asked only of working caregivers*

**The Emotional Stress of Caregiving  
(Current and Former Caregivers; n=546)**



## Action Needed by Illinois' Elected Officials

**Two in three** caregivers (67%) say that **funding services** that support family caregivers, such as home- and community-based services, adult day programs, and transportation services should be a **top or high priority** for elected officials in Illinois.

In 2015, 39 percent of nursing homes in Illinois received a low quality rating (one or two stars out of five) from the Centers for Medicaid and Medicare Services (Kaiser Family Foundation Issue Brief: Reading the Stars: Nursing Home Quality Star Ratings, Nationally and by State, May 2015). **Nine in ten** caregivers (89%) say it is **extremely or very important** that elected officials in Illinois take action to **increase the quality of care in nursing homes**.

## Support for Respite Care

Given all the stressors that caregivers face, it is not surprising that nearly **nine in ten current and former caregivers (88%) support the provision of respite care** – or short-term help from a home health aide so that they can get a break from their caregiving duties. Seven in ten caregivers (70%) also say that respite care is an extremely or very important service to have available in their communities.



## Importance for Caregiving Resources and Training

Three in four current and former caregivers 40-plus say that it is extremely or very important to have more resources and training for family caregivers (75%). Less than one in ten say it is not very or not at all important (7%). This demand for training may be high as three in four family caregivers (77%) say that information about available resources for caregivers in their community would be extremely, very, or somewhat helpful to them. And, many current caregivers are providing daily, hands-on care, like bathing and dressing, medication management, and other medical or nursing tasks.

## METHODOLOGY

AARP Illinois commissioned a telephone survey among 1,100 registered voters age 40-plus in Illinois to learn about their experiences with family caregiving. The sample utilized an age-targeted registered voter landline and cell phone list. The sample was obtained from Aristotle International. The sample database consisted of 5,147,744 registered voters age 40-plus in the State of Illinois. There are approximately 979,547 residents of Illinois age 40-plus who are not registered to vote, and there are approximately 1,886,194 registered voters age 40-plus who did not have a phone number on file that were not included in the sampling of this study. Quotas were used in this study based on age and gender and were filled based on responses to questions in the questionnaire. They were designed to yield a proportional representation of the Illinois age 40-plus registered voter population. The sample also included oversamples of Illinois voters 40-plus who identified their race or ethnicity as African-American/Black and Hispanic/Latino.

Voter files were selected at random from the voter list to be dialed. American Directions asked to speak with the registered voter listed on the file. If that person was unavailable, American Directions asked to speak with another member of the household aged 40-plus who was a registered voter. The interviews averaged 26 minutes in length and were conducted in English and Spanish. The survey has a margin of sampling error of  $\pm 2.95$  percent.

This report highlights results from 1,100 residents interviewed from October 17 to November 14, 2018. The data collection and weighting were performed by American Directions. The data is weighted by age, gender, race, and ethnicity to reflect registered voters in Illinois age 40-plus, based on the population of registered voters 40-plus from the sample source.

Percentages reported are rounded. For more information about the methodology, contact Terri Guengerich, AARP Research, [tguengerich@aarp.org](mailto:tguengerich@aarp.org), (202)434-6306.

AARP is the nation's largest nonprofit, nonpartisan organization dedicated to empowering Americans 50 and older to choose how they live as they age. With nearly 38 million members and offices in every state, the District of Columbia, Puerto Rico, and the U.S. Virgin Islands, AARP works to strengthen communities and advocate for what matters most to families with a focus on health security, financial stability, and personal fulfillment. AARP also works for individuals in the marketplace by sparking new solutions and allowing carefully chosen, high-quality products and services to carry the AARP name. As a trusted source for news and information, AARP produces the nation's largest circulation publications, *AARP The Magazine* and *AARP Bulletin*. To learn more, visit [www.aarp.org](http://www.aarp.org) or follow @AARP and @AARPadvocates on social media.

AARP staff from the Illinois State Office, Campaigns, State Advocacy and Strategy Integration (SASI), and AARP Research contributed to the design, implementation, and reporting of this study. Special thanks go to AARP staff including Bob Gallo, Ryan Gruenenfelder, Lori Hendren, Vikki Ortiz, and Dina Anderson – AARP Illinois State Office; William F. Brown, III, Priscilla Hume, and Ruben Hernandez – Campaigns; James McSpadden – SASI; and Terry Keenan and Kate Bridges – AARP Research. Please contact Terri Guengerich, the author of this report, at 202.434.6306 for more information regarding this survey.

**AARP Research | For more information about this survey,  
please contact Terri Guengerich at:**

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