

Carewell

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# Supporting Family Caregivers

Identifying the Gaps in Support for  
America's Hidden Workforce



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# Supporting Family Caregivers

## Identifying the Gaps in Support for America's Hidden Workforce

### EXECUTIVE SUMMARY

Care is essential to the very fabric of society. Without it, communities would fail to thrive, and entire countries would collapse. Everyone requires care at some point in their lives. Either as a child, after an injury or illness, or as we age. In any case, caregivers provide support and nurturing to prepare us for the world, get us back on our feet, or help us enjoy our days later in life.

Family caregivers – any relative, partner, or friend that provides unpaid care – are historically underappreciated and unsupported, although they provide an invaluable service. The pandemic highlighted the plight of caregivers as they took on additional responsibilities, and the isolation brought on by quarantine significantly impacted their mental and physical health. As the pandemic winds down, the push to return to the office and other shifts puts additional pressure on caregivers, and their needs continue to be ignored.

The demand for unpaid family caregivers will increase as the aging population's need for care grows. This will have far-reaching consequences for the U.S. across various systems and industries. However, without identifying the gaps in support and taking action to mitigate them, caregivers will not be able to sustain the level of care needed without compromising their health.

# Introduction

There is little support and assistance provided for family caregivers. However, they play a significant role in our society as they care for those in need. Understanding their critical needs is crucial in supporting the aging population that will soon need care. This paper aims to explore the areas in which caregivers need support and highlight how society, employers, the government, and family units can step up for those that care for us.

## The paper covers the following:

- 1. Who Are Family Caregivers:** An overview of the family caregiver population, their roles, and responsibilities
- 2. The Needs of Caregivers:** Findings from Carewell's survey exploring the type of support that caregivers need from the institutions in their lives
- 3. How to Support Caregivers:** A breakdown of solutions to help caregivers feel more supported and less overwhelmed by their caregiver duties

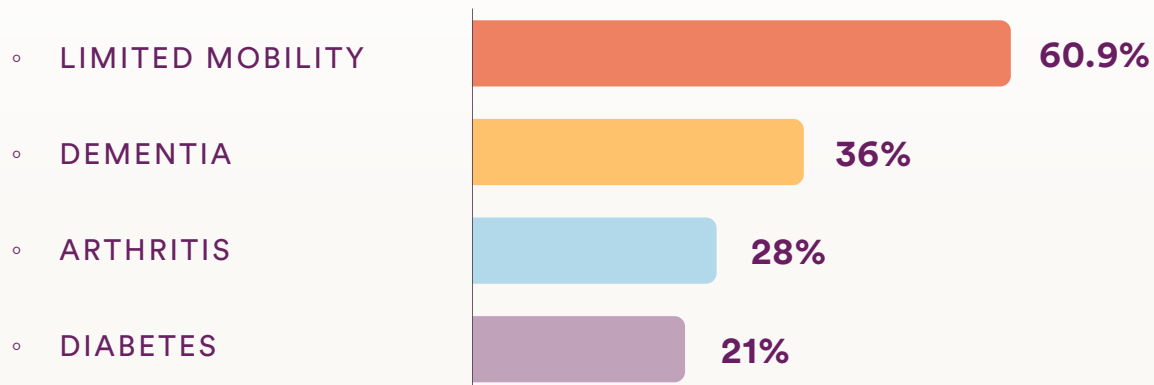


# Who Are Family Caregivers?

## CAREGIVING DEMOGRAPHICS

As of 2022, there are more than 53 million family caregivers in the U.S, a 21% increase from 43 million in 2015<sup>1</sup>. The vast majority have no formal medical training and are often suddenly thrust into the role of caregiver having to adapt to care for their loved one quickly. The average caregiver is a woman in her 60s caring for a spouse, parent, or in-law<sup>2</sup>. However, that's slowly changing as millennials and Gen Z are increasingly taking on caregiving roles<sup>1</sup>.

Caregiving looks different for everyone, but the leading causes are<sup>2</sup>:




Either way, caregivers provide a broad range of assistance depending on their care recipients' abilities. Tasks may range from helping with groceries and providing transportation to 24-hour care that requires assistance with daily living needs such as bathing, eating, and dressing.

## CAREGIVING AND CAREERS

A 2021 survey by Carewell found that more than 50% of caregivers provide over 40 hours of care to their care recipients a week while balancing a full-time job. Although many continue working outside the home while caring for a loved one, a large portion struggles to stay afloat financially, as 91% receive no additional financial assistance leading them to pay for their care recipients' needs out-of-pocket. Moreover, caregivers report spending around 26% of their income on the loved ones they care for.

MORE THAN  
**50%**



Is the percentage of  
caregivers who provide  
over **40 hours of care**  
pre week while  
maintaining  
a full-time job

## CAREGIVING AND HEALTH

In addition to the financial impact, caregiving affects caregivers' mental and physical health. Although caring for a loved one can be incredibly rewarding, it isn't without stress. Being responsible for a loved one's well-being and overall health can lead to anxiety, exhaustion, mood swings, and even depression<sup>3</sup>. It can also cause caregivers to neglect their own needs and health because they're laser-focused on their care recipient. This can lead to caregiver burnout, an extreme form of exhaustion, and adverse health outcomes. On average, four of every 10 caregivers report suffering from burnout<sup>1</sup>, and 11% say that their physical health is worse due to caregiving responsibilities<sup>4</sup>.

**4** IN **10**  
CAREGIVERS  
EXPERIENCE  
BURNOUT



## CAREGIVERS OVERALL

In summary, the average family caregiver is a woman in her 60s with no formal health training caring for a spouse or in-law. However, the number of younger caregivers is on the rise. Caregivers typically provide 40 hours of care to their care recipient while balancing a full-time job. They assist their care recipients with everything from managing finances to providing transportation, and some provide 24/7 care. Limited mobility and dementia are the leading reasons why people require care, and the responsibilities associated with caregiving can negatively impact caregivers' financial, mental, and physical health.

# The Needs of Caregivers

In September 2022, Carewell surveyed its customer base to understand family caregivers' needs. The survey was sent to the company's email subscribers and remained open for two weeks to gather answers. In total, it received more than 400 responses.

The survey questions focused on caregivers' satisfaction with the level of support they receive from their family, community, employers, and the government. The survey also explored the support caregivers would most appreciate to help them on their journey

## **Survey limitations:**

- Allowed open-ended “other” responses to gather additional data and insight
- No way to determine if a respondent completed the survey more than once
- Inability to confirm whether a respondent said they weren't a caregiver to complete survey

## **FAMILY AND FRIENDS**

Overall, respondents were satisfied with the support their friends and family provided. When asked about the type of support they find most helpful, 56% percent wanted more emotional support. Help with the care recipient and respite care came in second and third, respectively. At the same time, only 20% would find financial support most helpful. Family and friends play an essential role in supporting caregivers. From providing respite care to much-needed social interaction, caregivers benefit from the help of their loved ones.





**Rate emotional support  
as most helpful**

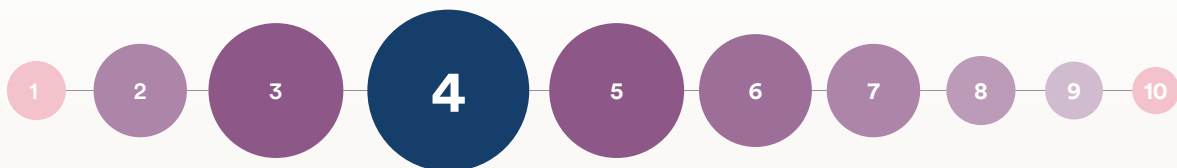


**Rate financial support  
as most helpful**

## GOVERNMENTAL SUPPORT

When asked about governmental assistance, the responses weren't as positive. On a scale of 0 to 10 – 0 being unsatisfied and 10 being satisfied – the average level of satisfaction with government assistance available for caregivers was a four (4). When we dove into the type of assistance that would be most beneficial to their situation, financial assistance and free respite programs were the most popular selections. Many respondents commented on the rising costs of products for their care recipients, specifically incontinence products.

### Satisfaction with government assistance available for caregivers



## COMMUNITY RESOURCES

In terms of community resources, 76% percent of respondents indicated having never used the caregiving resources available in their communities, such as support groups or respite programs. In addition, the average satisfaction level with the resources offered by the community was five (5).

**76%**

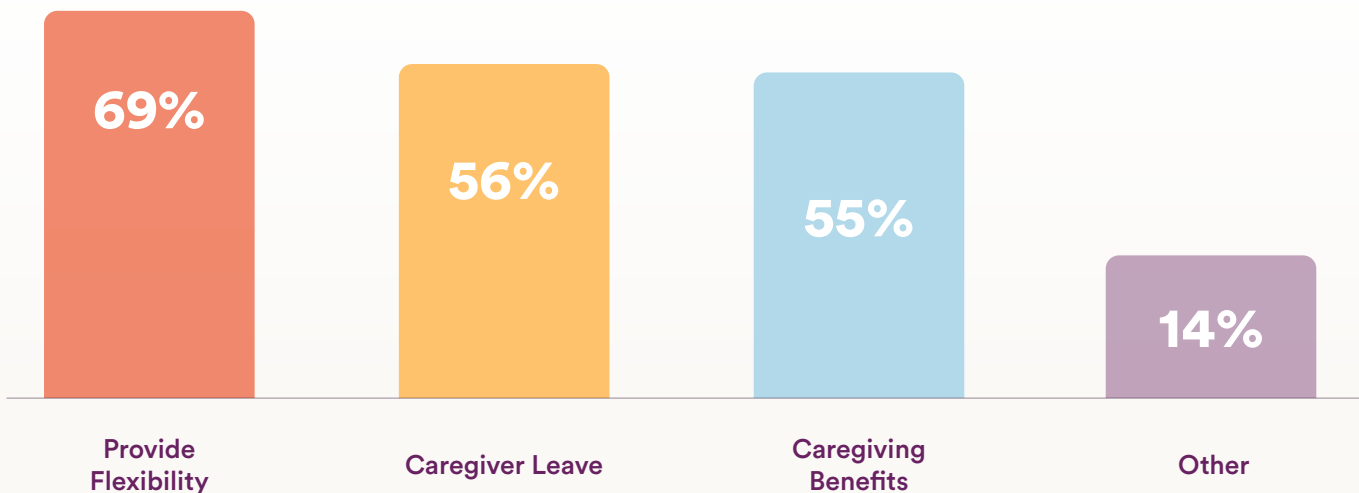
Have never used resources available in the community.



## EMPLOYER SUPPORT

The survey found that 69% of caregivers selected flexibility as the best way employers could support them. Options like remote work or flexible schedules allow working caregivers to balance their responsibilities and roles better. Most caregivers have full-time jobs outside their homes while providing a loved one with an average of 40 hours of care per week. Without adequate flexibility from employers, some caregivers must quit their jobs to be able to support their loved ones.

### What is the best way employers can support caregivers?



## **SOCIETY'S ROLE**

When asked how society can support caregivers, 53% of respondents asked for understanding and patience. Numerous respondents also mentioned acknowledging their role and efforts would go a long way. In contrast, others focused on the need for companionship as caregiving can be an isolating experience.

# How to Support Caregivers

## IT TAKES A VILLAGE

Providing family caregivers with the support they need to better perform their responsibilities without sacrificing their mental, physical, and financial health starts at home. It's easy to feel hopeless and in a constant state of stress as a caregiver. In addition, worrying about the needs and health of a loved one increases the risk of developing anxiety, depression, and other adverse health effects<sup>5</sup>.

Family and friends play a key role in helping caregivers process their emotions and feel connected with the world outside of their caregiving bubble. Providing emotional support by allowing the caregiver in your life to vent their frustrations without the fear of judgment can provide a cathartic experience that they desperately need.

Beyond just listening, reassure caregivers that they're doing their best and have compassion for their situation. This is not only a kind gesture, but emotional support can lower stress and increase individuals' well-being, according to the American Psychological Association<sup>6</sup>. You can also consider donating your time to care for their care recipient to allow for the caregiver time for themselves. Respite care, even if for only a few hours, can have a profound impact on caregivers.



## FEDERAL AND STATE-LEVEL SUPPORT

Considering that the majority of caregivers pay for their care recipient's needs out-of-pocket, it's easy to understand why respondents were most interested in financial assistance from government organizations. While most private health insurance plans and programs like Medicaid and Medicare may offer some relief by covering certain costs, caregivers still spend an average of \$7,242 each year<sup>7</sup>. A few governmental programs also allow family caregivers to earn money while they provide care. They are available through Medicaid and Veteran Affairs, but not all care recipients/caregivers qualify.

**\$7,242**

**Yearly average expense  
by caregivers**

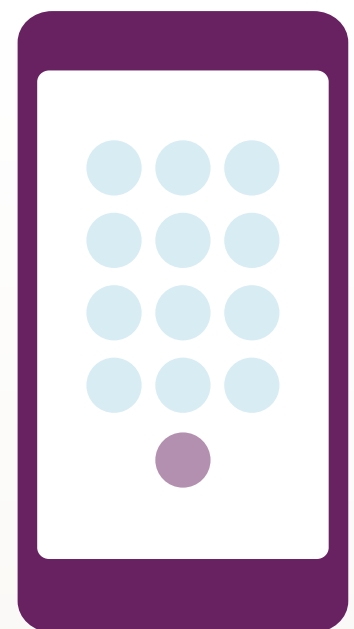
The survey also found that caregivers are interested in free respite programs. The average duration of a caregiver's role is four (4) years, and only 30% of caregivers provide care for less than one year<sup>8</sup>. It is a long-term commitment requiring breaks to endure the length of their responsibilities. Studies also indicate that for many caregivers, respite allows them to process the emotions they suppress while focusing on caregiving tasks.

In summation, respondents felt that financial assistance would alleviate some of the financial strain that is associated with meeting the needs of their loved ones. Although there are current programs in place that can assist, only some families qualify. Free respite care programs would also go a long way in providing caregivers the opportunity to rest and manage their emotions and provide better care.

## **BUILDING ONLINE COMMUNITIES**

Our communities provide us with a sense of belonging and purpose that can tremendously impact our well-being. The same is true for family caregivers. Sharing their experiences and emotions with others who can relate can be transformational. But unfortunately, while communities may have resources like support groups and respite services available for caregivers, the majority aren't learning about the opportunities available in their areas.

Family caregivers are increasingly turning to social media. A 2010 study by UnitedHealthcare and the National Alliance for Caregiving found that 70% of the caregiver respondents they surveyed used social media to find information or support related to caregiving<sup>9</sup>. As such, community programs should focus on reaching caregivers via social media. Partnering with local caregivers that are leading voices within the community can help bring awareness to the available resources. In addition, by building a social media presence, programs can reach family caregivers that aren't aware that help exists.



# **70%**

**of caregivers surveyed used social media to find information or support**

## RETAINING TALENT WITH CAREGIVING BENEFITS

Caring for a loved one is already stressful. Choosing between your job and providing care for a family member can induce anxiety, panic, and even depression. The February 2022 Federal Reserve's Monetary Policy Report showed that caregiving was the second leading reason keeping people out of the workforce<sup>10</sup>. As the demand for caregiving increases throughout the next decade, more people will look toward their employers to identify accommodations that will allow them to continue working while providing care.

More companies have begun to add caregiving flexibilities to their benefit packages. Options like family leave and employee resource groups are among the most popular options offered by employers. However, our survey found that remote work opportunities and customizable schedules would benefit caregivers the most, allowing them to better balance work and caregiving. A 2021 study by the Rosalynn Carter Institute for Caregivers found that employee caregivers who used company benefits such as remote work and flexible scheduling reported lower levels of emotional stress<sup>11</sup>.

Providing employees with these flexibilities doesn't just help caregivers. It also benefits companies. According to a study by The Caring Company, 32% of employees have left jobs to care for a loved one. In addition, more than three-quarters of employee caregivers admitted that their care responsibilities impacted their performance<sup>12</sup>. Allowing employees to work from home or change their schedules can help companies retain talented employees committed to their roles.

32%

have left jobs  
to care for a  
loved one

75+%

Had caregiving  
impact their work  
performance

## OFFER UNDERSTANDING AND EMPATHY

Being a caregiver affects every aspect of life. And although rewarding, it changes caregivers' hobbies, sleep schedules, finances, and social life. As a result, caregivers face an increased risk of depression. For example, between 40% to 70% of caregivers experience signs of depression caused by the demands of caregiving and the social isolation that comes with it<sup>13</sup>.

Caregivers ask that, as a society, we recognize their efforts and understand their essential role in our communities, families, and country. Extending empathy and understanding their needs can help relieve the immense pressure many feel and help combat the isolation they experience.



**40-70%**

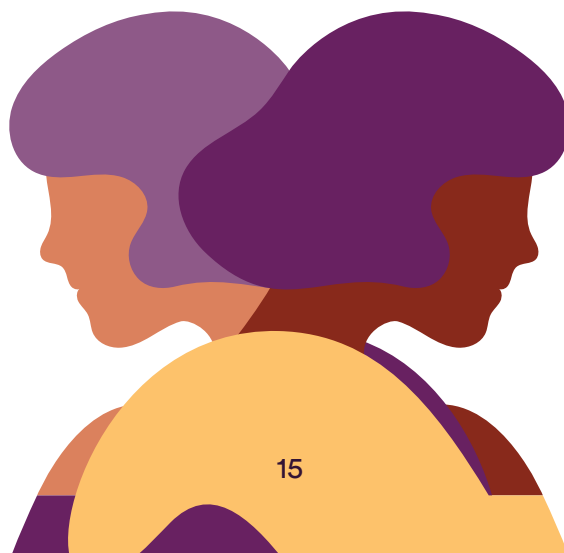
The percentage of caregivers  
**who experience depression**  
due to caregiving demands



# Conclusion

The need for family caregivers is going to grow exponentially within the next decade. By 2030, all Baby Boomers – 73 million people – will be over 65<sup>14</sup>. Moreover, the caregiver support ratio – the number of people available to care for a person during their high-risk years (80+) – is forecasted to decrease. The ratio will drop from seven people for every person who needs care to only four people per care recipient by 2030<sup>15</sup>. In addition, in the U.S., there is an unprecedented increase in the number of older people<sup>16</sup>. Sometimes referred to as the Silver Tsunami. These factors will exponentially increase the need for care and stir an awakening around the importance of caregivers.

The challenges caregivers face will continue, and as the demand for care increases, these obstacles go beyond caregivers. They will profoundly affect the labor force, companies, the long-term care industry, and the healthcare system. There are already 53 million family caregivers navigating the caregiving journey, many without experience or adequate support. By filling the gaps and implementing programs/benefits that meet the needs of caregivers, we can ensure that this “invisible workforce” has what it needs to care well. They will no longer have to continue providing care without sacrificing their mental, emotional, physical, and financial health.



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