

LIFE STAGE SERIES:

CAREGIVING



# The Journey of Caregiving: Honor, Responsibility and Financial Complexity

A Merrill Lynch study, conducted in partnership with Age Wave



**Merrill Lynch**  
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Unless otherwise noted, all information is current as of October 2017.

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Merrill Lynch and Age Wave are collaborating on a new research initiative to gain greater understanding of the experiences and challenges people face during different life stages. Through a series of studies over the coming years, we will investigate people as they journey through distinct life stages.

### WHAT IS A LIFE STAGE?

A life stage is a significant and distinct period of life that can last a long time. It is often sufficiently potent to transform an individual's identity—for example, transitioning into parenthood. A life stage also represents an individual's complex journey as they encounter and adapt to changes in emotional, practical and financial aspects of their life and the world around them. While the journey through a life stage is unique for each person, those navigating the same life stage often share experiences, milestones and challenges along the way. By examining some of the key life stages, we reveal opportunities to help those seeking advice, guidance and solutions tailored to their needs at significant junctures.

EARLY ADULTHOOD

PARENTING

CAREGIVING

RETIREMENT

WIDOWHOOD

END OF LIFE / LEGACY

### THE LIFE STAGE OF CAREGIVING

The following report highlights the preferences and priorities of those who traditionally have been referred to as “informal” caregivers—the tens of millions of Americans who provide a variety of services and supports for an adult family member or friend. This form of caregiving can occur in a variety of settings, including a care recipient's home or even when a caregiver visits their care recipient in a care facility.

While care professionals, such as home health aides, provide critical work in the care economy, **this report focuses on the attitudes and experiences of caregivers who perform these services outside of the professional caregiving and long-term care industry**—typically family members or friends of the care recipient.

*“I never expected to be a caregiver for my mother and help her through her illness and last years of life. It has changed my identity completely and I am grateful for the experience.”*

—Focus group participant



### CAREGIVING: AMERICA'S NEW NORMAL

According to this study, eight in ten Americans say that caregiving is the “new normal” in American families. Forty million Americans are currently caregivers—almost as many as the number of Americans holding student debt.<sup>1</sup> These caregivers are providing assistance to nearly 50 million adults receiving care.<sup>2</sup> Half became caregivers in the past year.<sup>3</sup>

### FROM AGE WAVE TO CAREGIVING CRUNCH

The massive generation of Boomers, 75 million strong today,<sup>4</sup> is creating both an age wave and a caregiving crunch as it moves into its seventh decade. In fewer than 10 years, the first Boomer will turn 80, when the likelihood of needing care increases even more. On the one hand, it's a tremendous accomplishment that lifespans have increased, growing steadily at roughly two months per year over the past several decades.<sup>5</sup> On the other hand, the advances in how long we can expect to live have not been matched with how long we can expect to stay healthy: our healthspans. For many health issues, the age of typical onset has not risen to keep pace with our longer lives. A few health conditions, notably diabetes and conditions related to obesity, have actually become more common and are diagnosed earlier in life.<sup>6</sup> The need for care is growing.

### FAMILY CAREGIVING: AMERICA'S OTHER SOCIAL SECURITY

Why is family caregiving so important? When care is needed, many turn to their first line of defense—family. More than two-thirds (68%) of Americans believe that they will be able to rely on their families to meet their long-term care needs when they require help.<sup>9</sup>

- ▶ Family members provide more than 95% of non-professional care for older adults who do not live in nursing homes.<sup>10</sup>
- ▶ In total, family caregivers provide 37 billion hours of care annually.<sup>11</sup>
- ▶ Caregivers looking after elderly family and friends log 3 times as many hours per year as professional caregivers.<sup>12</sup>
- ▶ The estimated economic value of family and friend caregiving is roughly \$500 billion per year—3 times greater than Medicaid's expenditures on professional long-term care.<sup>13</sup>

In addition to the emotional and familial ties that influence members of a family or community to care for each other, the cost of professional caregiving is staggering. Professional care, either inside or outside of a care facility, is often prohibitively expensive. While figures vary between states, care is costly. A full-time home health aide costs, on average, \$46,000 per year, and a nursing home costs \$82,000 per year for a semi-private room.<sup>14</sup> Given the steep expense, many families choose (or feel obliged) to step in to help a family member or friend.

### LITTLE PREPARATION

While the need for care is real, few are financially prepared. Only one-third of adults over 40 say they have money set aside to pay for their long-term care.<sup>15</sup> Only 11% of adults over 65 have long-term care insurance.<sup>16</sup> Forty-three percent of our respondents said that the biggest negative surprise of caregiving was how much care and care-related expenses cost. Many people are unaware of the high cost of paid care until care is needed.

### CAREGIVING IS AN UNDERESTIMATED NEED

# 7 in 10

Americans turning 65 today will need care for prolonged periods in their lives.<sup>7</sup>

# 4 in 10

Americans age 50+ believe they're likely to ever need care.<sup>8</sup>

### SUMMARY OF KEY FINDINGS

Our research, representing more than 2,000 caregivers, reveals:

#### **Caregiving is a Complex and Challenging**

**Life Stage:** Caregiving is a major and transformative life stage in which most of us will participate as caregivers, care recipients—or both. While the duration and particulars vary, most instances of caregiving involve significant shifts in the roles, responsibilities and relationship to a loved one.

#### **The Journey of Caregiving is Filled with Ups and Downs:**

Caregiving is a journey rife with emotions, with the ultimate goal of maintaining the dignity of the care recipient. It is a journey filled with honor, gratitude, and resilience, as well as stress, anxiety and fear. Six factors influence the journey:

1. the relationship between the caregiver and the recipient of care;
2. the presence (or absence) of others on a caregiving team;
3. the services and help needed;
4. the recipient's health condition and prognosis;
5. the duration and intensity of care; and
6. the financial resources available—both of the caregiver and the care recipient—to cover the costs of care.

#### **An Uncharted World of Financial**

**Caregiving:** Ninety-six percent of Americans agree that caregiving involves much more than hands-on care. However, while many aspects of caregiving have been previously studied, financial caregiving remains novel and largely uncharted. With 92% of caregivers also holding responsibilities as financial caregivers, in this report we explore—for the first time to date—the dynamics involved in being a financial contributor and/or financial coordinator in a caregiving relationship. Financial contributors pay for the costs of care for their care recipients, and financial coordinators oversee and organize other aspects of the care recipient's finances, such as paying bills, managing investments, preparing taxes, handling insurance and monitoring accounts. The financial contributor and coordinator roles are not mutually exclusive.

#### **Caregiving is a Burden and a Blessing:**

Caregiving is not without sacrifice. Many caregivers report significant costs in terms of their finances, their health, their time and leisure, their work and their other relationships. Yet despite the hefty cost, caregivers often feel fulfilled by caregiving. Ninety-one percent say they feel grateful for the opportunity to help someone they care about. Seventy-seven percent of caregivers say they would “gladly” do it again.

**The Coming Caregiving Crunch:** As we look to the future, we see four forces—longevity, demography, sociology and technology—converging to dramatically transform the caregiving landscape. We also offer recommendations for preparing for caregiving, both at a societal and individual level.







# Methodology



This research, fielded May 18 through June 9, 2017, was conducted by Merrill Lynch in partnership with Age Wave and executed by Kantar TNS utilizing the Kantar Lightspeed Panel, along with selected panel participants. The sample includes respondents who are age 18+, in the U.S., and who have been personally caregiving for an adult care recipient currently or at any point in the last three years. Those looking after adult children were excluded, as we will be conducting future research on this dynamic through a body of work on the life stage of parenting.

The survey included a total of more than 2,200 respondents, including 2,010 caregivers and 230 non-caregivers. Professional caregivers were excluded.

Some findings are drawn from an earlier survey fielded in December 2016 by Kantar TNS via an online data collection methodology. These findings represent roughly 2,000 caregivers aged 18+ who have been personally caregiving for someone currently or at any point in the last three years.

Two focus groups of caregivers were conducted in June 2016, where we gathered qualitative information about their emotions, preferences, experiences and needs as they navigate this complex life stage.

### ABOUT MERRILL LYNCH

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### ABOUT AGE WAVE

Age Wave is the nation's foremost thought leader on population aging and its profound business, social, financial, health care, workforce and cultural implications. Under the leadership of Founder/CEO Ken Dychtwald, Ph.D., Age Wave has developed a unique understanding of new generations of maturing consumers and workers and their expectations, attitudes, hopes and fears regarding their longer lives. Since its inception in 1986, the firm has provided breakthrough research, compelling presentations, award-winning communications, education and training systems and results-driven marketing and consulting initiatives to over half the Fortune 500. For more information, please visit [www.agewave.com](http://www.agewave.com). Age Wave is not affiliated with Bank of America Corporation.





# Complex and Challenging: The Caregiving Life Stage





## WHAT IS CAREGIVING?

We often think of caregiving as providing hands-on help with daily chores such as shopping, transportation, laundry, housework and meals, as well as personal care, such as help with dressing, toileting and bathing. However, caregiving also includes making choices and handling the daily responsibilities around health and finances. While caregiving can be provided through formal, paid care—by professional caregivers in a facility or those who support people living in their home—we focus in this report exclusively on those caring for an adult care recipient, usually a family member or friend. We included caregivers regardless of the setting where they provide care, including caregivers looking after someone who lives on their own (23%), together with their care recipient (37%), in a care facility (17%), or other living arrangement. Caregiving is a labor of love that is commonplace, complex and challenging.

## CAREGIVING IS PERVERSIVE

Today's 40 million family and friend caregivers make up roughly 16% of the adult population.<sup>17</sup> The number of Americans who have ever spent time as a caregiver is much higher, when considering those who cycle in and out of the life stage quickly, for example when looking after someone recovering from a short-term illness or injury. About 20 million people became caregivers last year, and others exited the life stage after their help was no longer needed.<sup>18</sup> As 75 million Boomers move through their seventies and into their eighties, when the likelihood of needing care jumps, caregiving will become even more common.

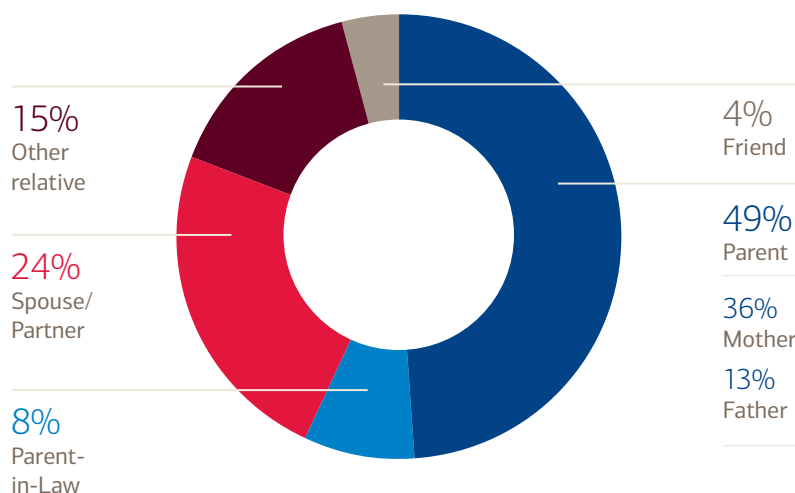
## ELDERCARE IS MOST COMMON

Eighty-six percent of caregivers are providing care to someone 50+.<sup>19</sup> Over half of the caregivers we surveyed are caregiving for a parent or in-law (Fig. 1). Caregivers are three times more likely to be caregiving for a mother than for a father, as well as for a mother-in-law versus a father-in-law.

*“There are only four kinds of people in this world: those who have been caregivers; those who currently are caregivers; those who will be caregivers; and those who will need caregivers.”*

—Rosalynn Carter, Former First Lady of the United States and Founder, Rosalynn Carter Institute for Caregiving

Fig. 1: CAREGIVERS ARE CARING FOR...



Base: Caregivers (select one)

About  
**20M**  
Americans became  
caregivers last year.<sup>18</sup>

### CARING UP THE LEARNING CURVE

At moments throughout the caregiving life stage, especially when first becoming a caregiver, there is a steep learning curve—often with minimal training or guidance.

Caregivers may face a barrage of new needs to address, new skills to learn, new routines, new systems to navigate and a new relationship with their loved one. All of this is complex and, in fact, is one of the greatest unifying features of the experience of caregiving.

### CAREGIVING'S COMPLEX EMOTIONS

Whether caregiving for a spouse, parent or other relative, caregivers are shouldering an enormous emotional burden. Caregiving brings a mix of positively and negatively charged emotions, sometimes in the same day. The majority of our caregivers said in the past month they often felt appreciated (76%), yet also worried (72%). Six in ten (64%) reported experiencing significant ups and downs from providing care.

Caregivers are balancing complex emotions as they try to achieve their top three goals in providing care:

1. preserving the dignity of the care recipient,
2. providing them the best care, and
3. keeping them out of institutions.

Many caregivers also believe part of their role is to make sure the recipient does not feel like a burden on them, even when they might be.

### THE CHALLENGE OF COMPETING CARE DEMANDS

Many of today's caregivers are part of the sandwich generation, which is balancing competing demands of providing care for both older and younger family members. As we see more and more women delaying childbearing until after 35 or later, the number of people facing these competing demands in terms of caring for both an older and younger generation is likely to rise.<sup>20</sup>

- ▶ 47% of adults aged 40-59 are simultaneously raising children and caregiving for aging parents.<sup>21</sup>
- ▶ Sandwiched caregivers are also often balancing work: among caregivers looking after a parent as well as children under age 18, 81% are employed, 64% full-time.<sup>22</sup>
- ▶ Sandwiched caregivers are often also trying hard to save for retirement, complicated by the fact that many are helping to provide financial support to their families.

# 83%

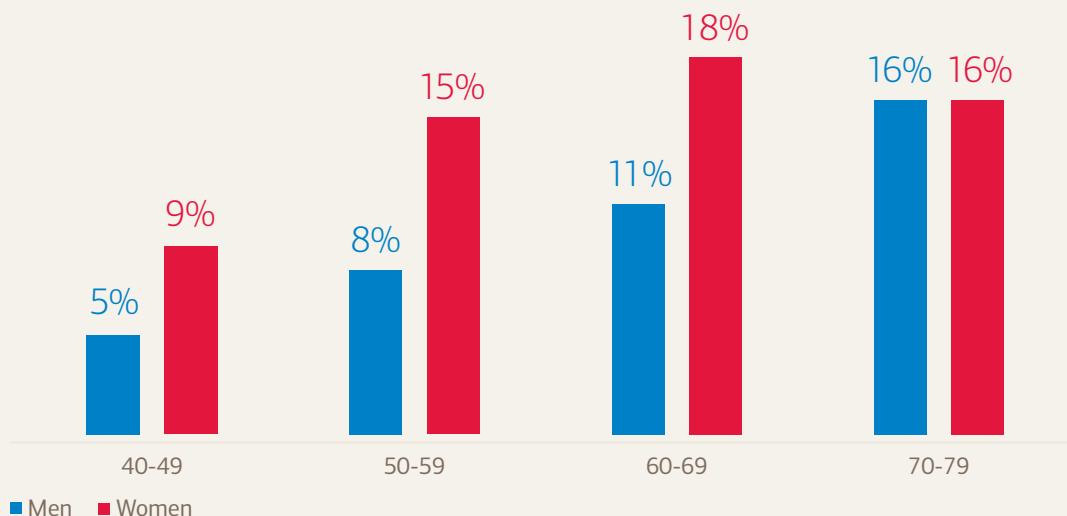
of sandwiched caregivers say they are struggling to find balance between caregiving and other responsibilities.



## Working Overtime: Women, Work and Care

Women have traditionally been the first responders when there's a caregiving need. Today, women act as 66% of all family caregivers<sup>23</sup> and are nearly twice as likely as men to be providing care from their 40s through their 60s (Fig. 2).

Fig. 2: CAREGIVING PREVALANCE BY GENDER AND AGE



Source: Annual Prevalence, National Academies Press, 2016. Families Caring for an Aging America: Proportion Caring for Older Adults 65+

Caregiving may be more nuanced today, but it remains gendered. Women caring for older adults (65+) tend to spend more years caregiving than men, 6 years vs. 4 years. That's roughly 10% of a woman's adult life.<sup>24</sup> Yet this trend may be changing as we see among millennial caregivers a much more equal split between men and women.<sup>25</sup>

### WIVES AND DAUGHTERS

A spouse is often the first person to step in and provide care. Decades of caregiver data show that wives tend to be the sole caregivers for husbands, irrespective of how much care their spouse needs. However, the more assistance a wife needs, the less likely her husband is to be her only caregiver.<sup>26</sup>

If there is no spouse, adult children are turned to for care, more often daughters than sons.<sup>27</sup> In total, daughters provide 31% of eldercare hours by family and friends versus 16% of all hours provided by sons.<sup>28</sup>

Caregiving falls more heavily on women today for both cultural and biological reasons:

- ▶ Women are generally 2-3 years younger than their spouses.<sup>29</sup>
- ▶ Women, on average, outlive men by 4 to 5 years.<sup>30</sup>
- ▶ Roughly half of all widowed Americans were previously caregivers for their spouse.<sup>31</sup>

Those caregiving for a spouse are less likely to have a caregiving team, and women are often the sole provider of all types of care, including hands-on physical care, care coordination and financial coordination. More women than men found it difficult to balance caregiving with other responsibilities (66% vs. 59%). Women caregivers were almost twice as likely to report feeling overwhelmed.



## Working Overtime: Women, Work and Care

### CAREGIVING'S GENDER GAP

Working female caregivers spend, on average, approximately 60% more time caregiving for aging loved ones, compared to their male counterparts.<sup>32</sup> And the cost is higher: for a woman caregiver who leaves the workforce, an average of \$324,000 is lost in wages and benefits, compared to \$284,000 for a man.<sup>33</sup> Employed women are likely to become caregivers regardless of salary level, while men who become caregivers tend to be lower wage earners.<sup>34</sup> Women are also three times more likely to retire earlier than expected to become a caregiver.<sup>35</sup>

Women caregivers are undervalued, as are all caregivers. The value of women's unpaid care is worth roughly \$273B per year.<sup>36</sup> Given the propensity for women to shoulder family caregiving needs and the lack of a national infrastructure to fully address the care needs of our aging citizens, it's no surprise that "daughter care" has been described as the most reliable form of care in America.<sup>37</sup>

*"I love being able to care for my mother-in-law, but it's hard to balance with my own kids and work. I'm always the one leaving work to take care of others."*

—Female focus group participant





# A Bumpy Journey: Navigating the Ups and Downs of Caregiving



Caregivers and care recipients are on a unique journey together that can have many different trajectories, from short-term care for someone recovering from an injury, to an indefinite period of time (sometimes a decade or more) caring for a parent or spouse whose physical or mental abilities are in gradual decline. The journey can be emotionally, physically and financially taxing, as the caregiver’s responsibilities may escalate. At the same time, however, caregivers report that the experience of caregiving gives them a sense of purpose and fulfillment.

FORCES SHAPING THE CAREGIVING JOURNEY

Caregiving is an emotional journey of ups and downs, with the ultimate goal to maintain the dignity of the person being cared for. While each caregiver’s journey is unique, six variables commonly shape the course:

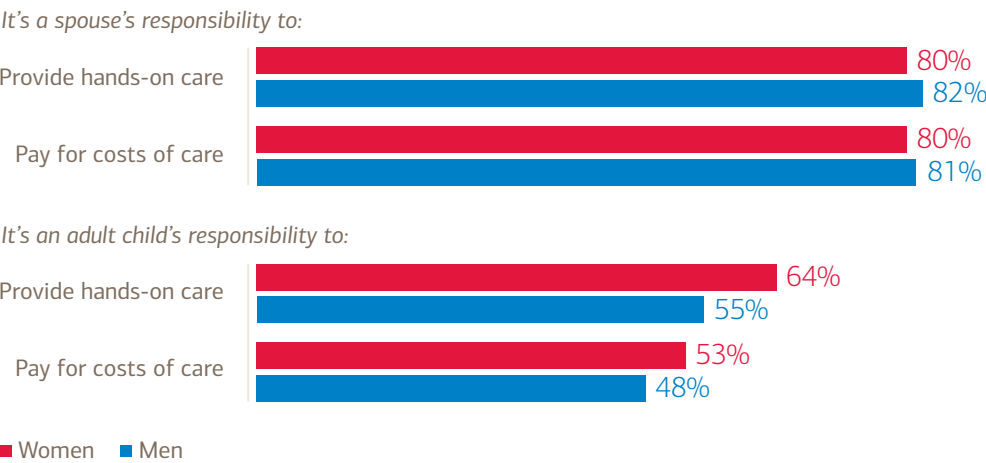
**1. The relationship to the recipient—**including the emotional closeness prior to caregiving as well as the type of relationship. Eight in ten non-caregivers say it is a spouse’s responsibility to provide hands-on care and to pay for it if their spouse should need caregiving (Fig. 3). Adult children are less likely to be held to the same standard. Women are more likely than men to say it’s an adult child’s responsibility to both provide hands-on care and pay for the costs of care for family.

**2. The recipient’s health condition—**dictates what services the caregiver provides and can certainly impact the emotional aspect of caregiving. Caregiving for someone with Alzheimer’s will have a different trajectory and pace than caregiving to someone recovering from surgery. Fifteen million Americans—22% of caregivers—provide unpaid care for someone with Alzheimer’s or dementia.<sup>38</sup> They spend 2.6 times more time caregiving than the average caregiver.<sup>39</sup>

22%  
of caregivers are looking after someone with Alzheimer’s or dementia.<sup>38</sup>

They spend  
2.6X  
more time caregiving than the average caregiver.<sup>39</sup>

Fig. 3: WHOSE RESPONSIBILITY IS IT TO PROVIDE CARE?



Base: Non-caregivers: general population age 18+ (percent agree)



### 3. The duration and intensity of care—

meaning how long the caregiver has been in the role and how many hours they provide care. In our survey, caregivers spent an average of 140 hours per month providing care. High intensity and long duration caregivers may get burned out without sufficient support from others. Some are caregivers for only a short time, while others devote years of their lives to caring for someone else (Fig. 4). Spousal caregivers are most likely to be long-term caregivers, often providing care for five or more years.

### 4. The services performed—

caregivers frequently reprioritize their lives in order to meet the changing suite of needs of the care recipients, such as scheduling around transportation needs or medication times. Roughly half are performing medical/nursing tasks for care recipients, many without receiving training to do so.<sup>40</sup> Financial responsibilities, often under-talked about, are extremely common.

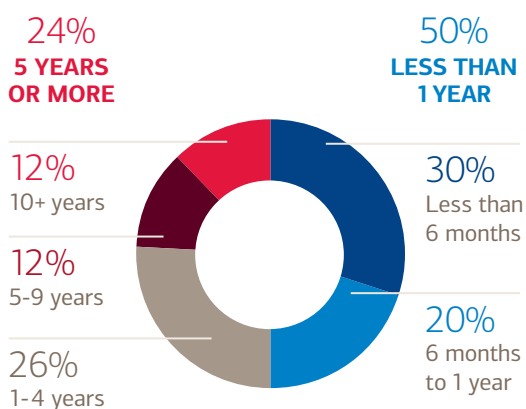
### 5. The caregiving team—

support from others, including family, friends and professionals. A team can help to share the load, facilitate respite and also provide expertise, yet not everyone has others to rely on. Those caregiving for a spouse are 2.5 times less likely to have a team than those providing care to an aging parent (64% vs. 18%) (Fig. 5). Caregivers looking after a parent are also two times more likely to have paid professional caregivers as part of their caregiving team (37% vs. 17%). The average caregiving team includes four members.

### 6. The financial resources available—

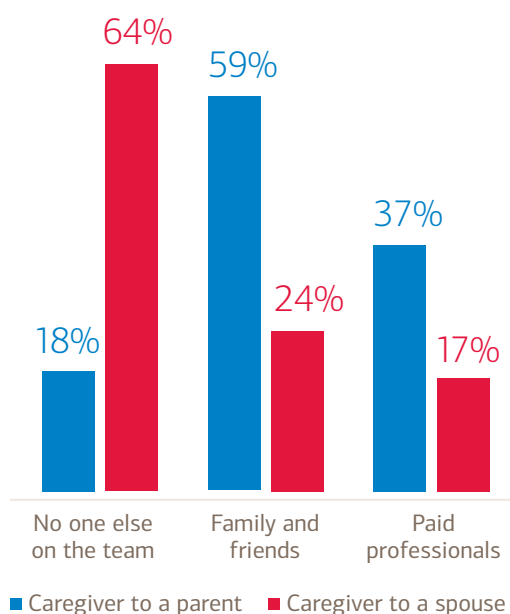
of both the caregiver and the care recipient. Professional care is expensive and having coverage or resources to spend on care-related costs, including out-of-pocket care expenses, can make the journey much smoother. This topic will be explored in greater detail in subsequent sections.

Fig. 4: HOW LONG CAREGIVERS HAVE BEEN CAREGIVING



Source: AARP/NAC, 2015. Caregiving in the U.S.

Fig. 5: MEMBERS OF THE CAREGIVING TEAM

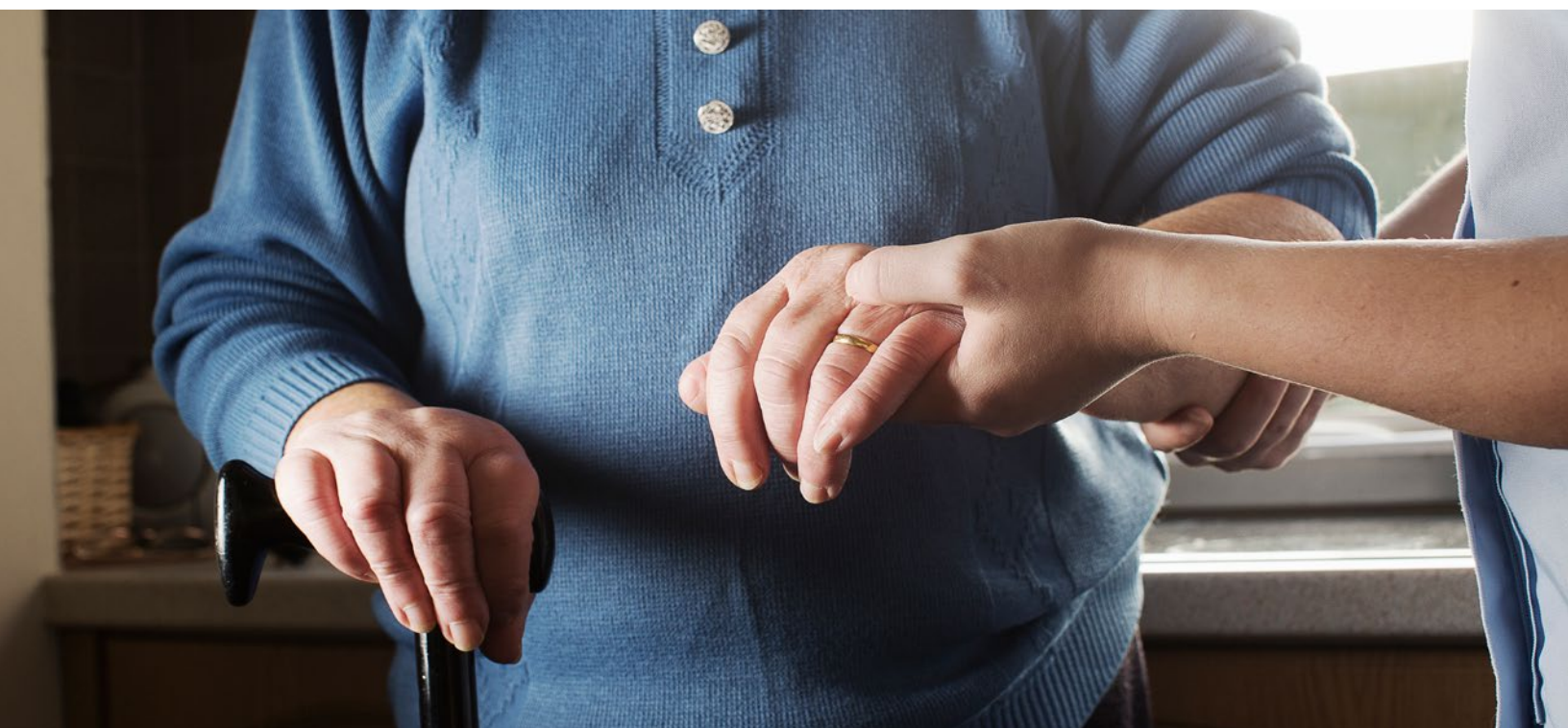
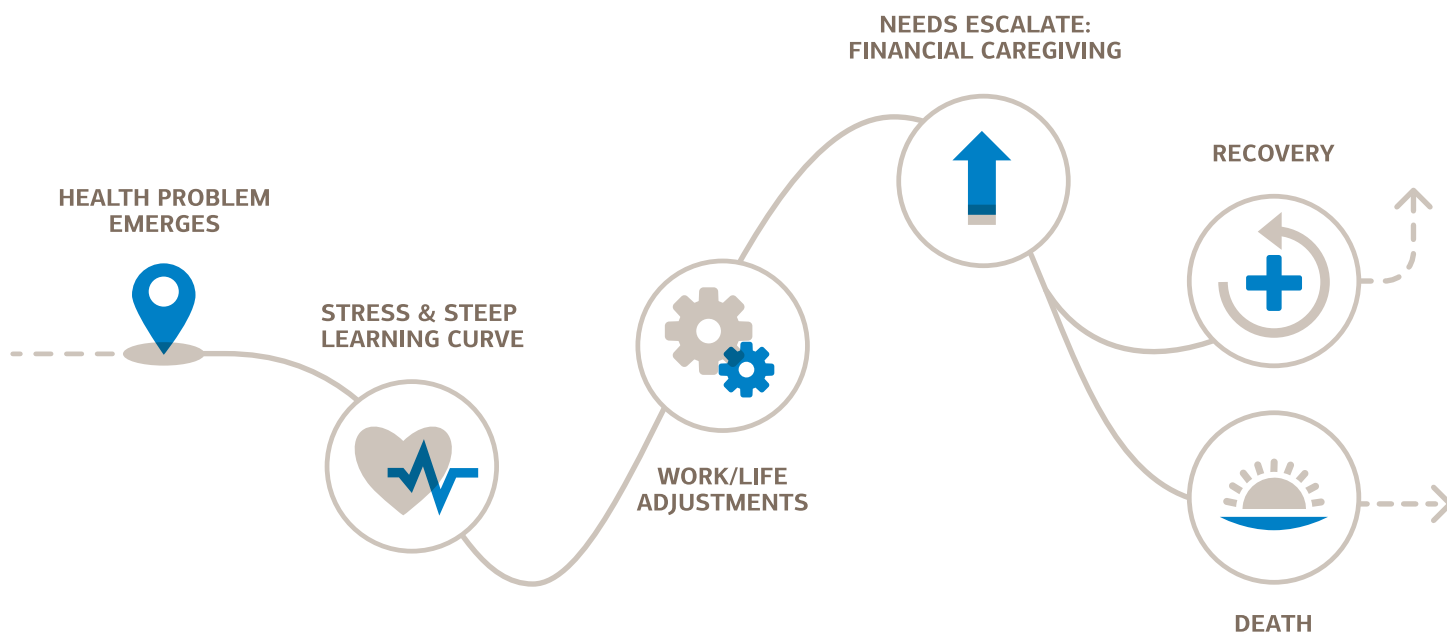


Base: Caregivers to a parent, caregivers to a spouse (select all that apply)

### HOW THE CAREGIVING JOURNEY UNFOLDS

A person's journey through caregiving can follow many different paths. Yet those navigating the journey often experience similar milestones, events and challenges along the way (Fig. 6).

Fig. 6: THE CAREGIVING JOURNEY



### THE START OF THE JOURNEY: A HEALTH PROBLEM EMERGES

Some people enter the caregiving role gradually by assisting a loved one occasionally, with the effort spent and roles performed growing over time. In the beginning, many may not even think of themselves as caregivers.

Many others enter the role suddenly and unexpectedly, the result of a crisis—an elderly mother falls and breaks a hip, a spouse is diagnosed with cancer. Although the need to provide care can often be anticipated, caregivers tend to say they feel unprepared. While more than half (59%) say they entered the life stage gradually as a loved one's needs grew, 41% say they entered the role of being a caregiver suddenly. In response to entering the life stage, a caregiver must quickly come up a learning curve, understand the needs of the recipient, establish the role as caregiver, line up others to help out and adjust other work and family responsibilities.



#### STRESS AT THE START AND THROUGHOUT

Stress may be high in the early period of the caregiving journey. Those who provide hands-on care are more likely to show symptoms of stress than those who are coordinating care.<sup>41</sup> We found that the amount of stress rises during the first year of caregiving, then generally declines. But after about five years of caregiving, stress around health, family and finances rises again.

One high stress area is addressing complex medical needs of the care recipient. Nearly half of caregivers perform medical tasks, and 40% of them feel stressed about making a mistake.<sup>42</sup>



#### WORK/LIFE ADJUSTMENTS

With time, the caregiver often finds a rhythm with the recipient and gains confidence in the role. Caregiving is then a steady routine punctuated by unpredictable events, such as hospitalizations, periods of extra effort toward recovery and readjustments in the balance between the caregiver's competing responsibilities, often related to work or other family. Two-thirds say they often feel overwhelmed with responsibilities.

41%

say they entered the role of being a caregiver suddenly.







NEEDS ESCALATE

Over the course of the journey, caregiving needs often transform into something much more serious as the physical and mental abilities of the care recipient decline. Responsibilities may build to include much more than hands-on/physical care: financial caregiving, care coordination, emotional and social support and more (Fig. 7). Fully 96% of respondents agree that caregiving means much more than hands-on care.

Institutionalization

Sometimes care needs escalate to a point where a caregiver reassesses what might be the most appropriate setting to suit the needs of their loved one. Seventeen percent of our respondents said the person they're caregiving for currently lives in a care facility. Even more have had a care recipient who has had a stay in a short term professional care facility.

For many, institutionalization is a major turning point—not an end—to the caregiving journey. Complexity of care is the top trigger to institutionalization. In fact, 76% of caregivers said they would consider moving their recipient to a care facility if their medical needs were too complex to handle on their own, while only 12% said they would move them due to burnout (Fig. 8).

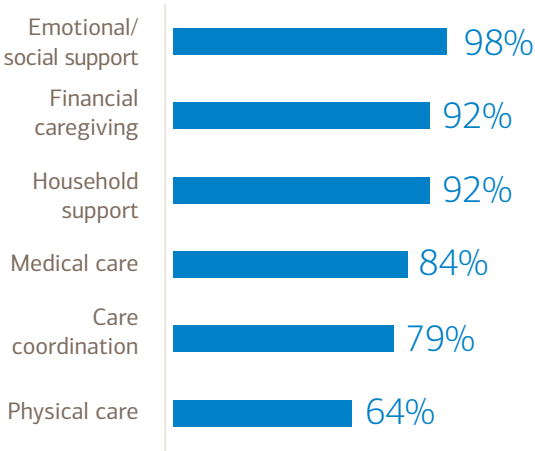
Caregivers are concerned about the negative stigma of sending their recipient to an institution. Sixty-one percent of those caring for a parent say they have considered moving their parent into a facility, compared to 46% of those caring for a spouse. Caregivers cite their top two concerns regarding long-term care facilities for caregivers as the quality of care (67%) and the chance the care recipient may feel uncomfortable in the institution (57%).

If a care recipient moves to a long-term care facility, a caregiver's role shifts to become less hands-on but is often more focused on coordinating care with facility staff and financial caregiving.

96%

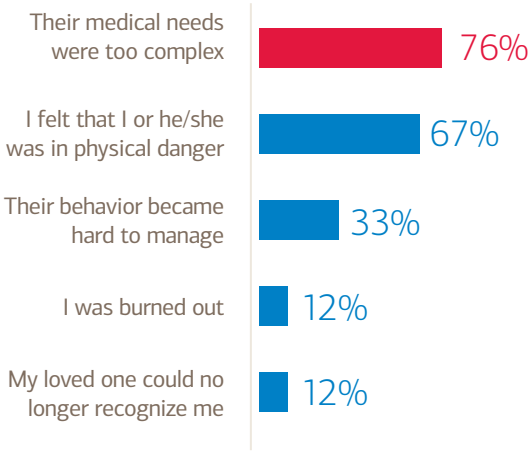
say caregiving involves much more than hands-on, physical care.

Fig. 7: CAREGIVER PROVIDES HELP WITH



Base: Caregivers (select all that apply)

Fig. 8: TRIGGERS FOR CONSIDERING A CARE FACILITY FOR A CARE RECIPIENT



Base: Caregivers who would consider moving recipient in to a care facility (select all that apply)

### Respite: Many Caregivers Say They Need a Break

Respite is essential in preventing burnout and keeping caregivers healthy. Respite is when a caregiver is temporarily relieved of their caregiving responsibilities and another person fills in on their behalf. Most caregivers get insufficient respite. Almost half of our respondents have never taken a break from their caregiving responsibilities. Only 26% of caregivers from our survey report having respite from caregiving. Another one in three caregivers do not currently have respite, but want it.

What prevents relief? Often the high cost of hiring professional caregivers and the unavailability of family and friends are the major barriers to receiving help. The emotional and/or psychological bonds between caregiver and recipient can come into play; nearly a third (30%) of caregivers say that the care recipient isn't comfortable getting help from others, and 27% say they don't feel others will provide as good a quality of care.

Of those who do get respite, 55% said other family members pitch in to give them a break, 38% said the person took care of themselves during that time and 28% relied on paid help. When we asked caregivers what they want during their downtime, they said they want to foster other family connections and engage in health-related activities.

Of those who wanted respite and weren't getting it, 66% said no one else was available to be a fill-in caregiver; 53% said they felt it was their responsibility to handle on their own; 42% said they could not afford to hire outside help; and 38% said they didn't want to ask others for help. Affluent caregivers, those with over \$1 million in investable assets, were 72% more likely to have professional caregivers step in to provide respite relief.



### THE AFTERMATH OF CAREGIVING: A FORKED PATH

Four in ten caregivers anticipate that the transition out of the life stage of caregiving will be difficult for them. For those helping a loved one for a foreseeably short period of time following a surgery or injury, it may be easier. But 61% of caregivers expect their role to end with the death of their loved one. Yet death itself does not signal the actual end to caregiving.

When caregiving is over, with either the recovery or death of the care recipient, the caregiver then readjusts their life, often while grieving and dealing with loss. Caregivers can spend months or even years settling the estate, paying bills, and collecting insurance on behalf of the deceased.

Caregiving changes the way those who give care think about their own future. Over a third (37%) say they think more about their own future care needs, and one in four (24%) has discussed those needs with spouse/partner or children. Three in ten (30%) report that they put their own plans and priorities on hold while looking after their loved one. In the aftermath of caregiving, caregivers have the challenge and opportunity of refocusing on their own priorities and plans.

# 1 in 3

caregivers do not  
get respite  
from caregiving  
responsibilities,  
but want it.

## Conclusion

The caregiving journey is varied, filled with ups and downs, including stress and a steep learning curve at the start. The most common experience as a caregiver, named by 64% of respondents, is simply “going through the ups and downs of providing ongoing care.” Caregivers make work/life adjustments, adapt to the needs of the care recipient and find time for respite if they can.

## Double Duty: High Toll of Caregiving for Those with Cognitive Decline

Today only about 10% of people age 65 and older have dementia,<sup>43</sup> but time spent caregiving for them totals to 40% of all care hours provided by family.<sup>44</sup> Caregivers looking after people with Alzheimer's or a related dementia shoulder more caregiving responsibilities than other caregivers, including helping with a wider variety of activities, providing more hours of care per week and supporting their care recipient over a longer duration of time. Caregivers to people with dementia are more likely to be performing medical responsibilities for their care recipient.<sup>45</sup> Caregivers to people with dementia are also two times more likely to report having difficulties performing medical caregiving tasks.

Dementia caregivers are struggling to balance work and home. Six in ten dementia caregivers were employed in the last year, working an average of 35 hours/week while caregiving.<sup>46</sup> More than half (57%) work full time and 70% say their supervisor is aware of their caregiving situation. Sixty-six percent of employed dementia caregivers struggle to balance work and caregiving and say their caregiving responsibilities affected their work in some way, versus 59% of non-dementia caregivers.<sup>47</sup> More than one in three dementia caregivers say their health has declined as a result of their caregiving responsibilities (35%) versus just one in five non-dementia caregivers.<sup>48</sup>

Caregiving for those with cognitive decline is costly, in terms of both time and money. The average person with dementia requires 171 hours of care per month—over 100 hours more than those caregiving for someone without dementia.<sup>49</sup> The average annual cost of caregiving for someone with dementia at home in the United States is estimated to be \$56,000.<sup>50</sup>

Caregiving for someone with cognitive decline is not only more physically taxing and expensive, but it is also an emotionally difficult labor of love to watch someone change so dramatically as their condition worsens. These caregivers may acquire a sense of resilience as they continue to care for a loved one who may not even recognize them.







## Charting the Uncharted: Uncovering the World of Financial Caregiving



Money may not be the first thing that comes to mind when we think about what caregivers do and who they are. But financial relationships are an integral and necessary part of caregiving, and they're part of almost every caregiving situation. Fully 92% of caregivers say they are also financial caregivers, performing at least one aspect of financial caregiving during their caregiving journey.

DEFINING FINANCIAL CAREGIVING

Financial caregiving describes when a caregiver serves as:

A Financial Contributor

A caregiver who pays for the costs of care for their care recipient, and/or

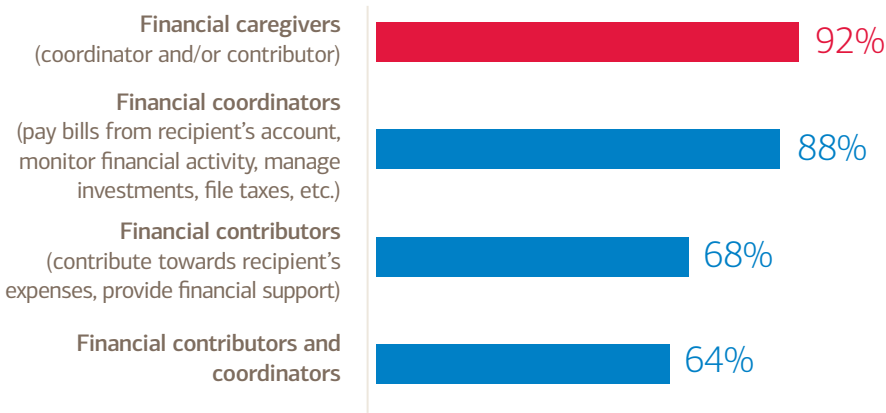
A Financial Coordinator

A caregiver who oversees and organizes other aspects of their care recipient's finances, such as paying bills, managing investments, preparing taxes, handling insurance and monitoring accounts.



Financial caregiving is far more complex and nuanced than simply contributing to the recipient's care. Interestingly, financial coordination, not direct financial contribution, is the most common form of financial caregiving. Eighty-eight percent of financial caregivers are financial coordinators and 68% are financial contributors (Fig. 9).

Fig. 9: PERCENTAGE OF CAREGIVERS WHO ARE...



Base: Caregivers (select all that apply)

FINANCIAL CONTRIBUTORS

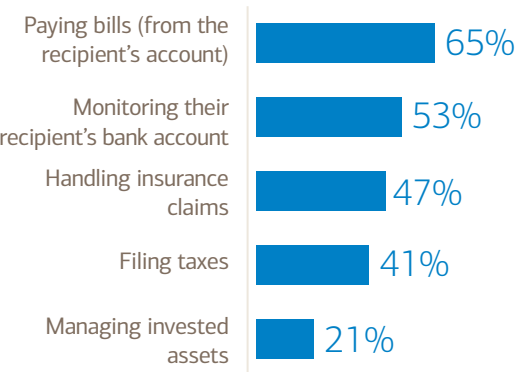
Sixty-eight percent of caregivers directly contribute financially to the care of their recipient. Paying for the costs of care may come from multiple stakeholders within a single family. For example, 17% of caregivers say a family member other than the caregiver or care recipient is contributing to care-related expenses. Discussions surrounding the costs of caregiving may be a tough topic for families. Seventy-six percent of caregivers think that if a sibling isn't providing hands-on care to a parent, they should pitch in by contributing financially to the cost of care.

On average, caregivers spend \$7,000 on caregiving per year, which goes toward paying for personal, medical and household needs.<sup>51</sup> Yet, many are contributing far more. Caregivers for people with Alzheimer's/dementia spend, on average, 54% more than the average caregiver.<sup>52</sup> Caregivers for a spouse spend 68% more than the average and those who are caregiving from a distance spend 71% more than the national average.<sup>53</sup>

FINANCIAL COORDINATORS

Financial coordinators are completing a variety of tasks that may include but are not exclusive to contributing. The most common coordination task is paying bills from the recipient's account (65%), followed by monitoring the recipient's bank accounts (53%) (Fig. 10). Coordinators are also handling insurance claims, filing taxes and managing investments.

Fig. 10: FINANCIAL COORDINATOR TASKS

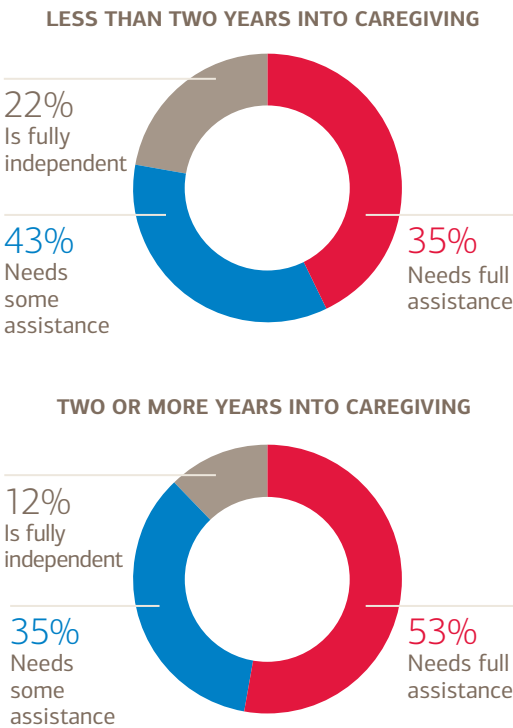


Base: Caregivers (select all that apply)

ESCALATING FINANCIAL NEEDS

Regardless of what financial caregiving tasks a caregiver is providing, it's likely that their involvement in the care recipient's finances will escalate. We found that, after two years of care, financial caregivers report that 53% of care recipients need full assistance with their finances (Fig. 11). After two years, only 12% of care recipients are independently managing their finances. With nearly 12 million people needing full assistance managing their finances,<sup>54</sup> one in four financial coordinators struggles to be granted permission from banks to access financial accounts, and 49% of financial caregivers do not have the legal authorization to perform their role.<sup>55</sup>

Fig. 11: PERCENT OF CARE RECIPIENTS NEEDING HELP MANAGING THEIR FINANCES OVER TIME



Base: Caregivers in their role for less than two years, greater than two years (select one)

In total, financial caregivers collectively spend an estimated

**\$190B**

per year on their care recipients for out-of-pocket, care-related expenses.



### STRESSED AND SILENT

Financial caregivers experience stress throughout the journey. Seventy-one percent of caregivers say their financial contributions cause them stress. In fact, many contribute even if that cost could put their own financial future in jeopardy. While some caregivers may feel compelled to contribute financially, not knowing how much they've spent makes it difficult to plan and can have ripple effects throughout their lives (see *Quantifying the Cost of Caregiving* for more).

Seventy-five percent of family caregivers have never discussed their financial role with their care recipient. It could be that talking about money is taboo, especially in the face of grave illness, or that the care recipient does not have the mental acuity to discuss finances. As we discussed earlier, caregivers do not want their loved one to feel that caring for them is a burden. But it can be a financial burden, one that families often haven't planned for or even discussed.

### UNTRACKED FINANCIAL CAREGIVING

Fifty-two percent of caregivers have no idea what they had spent to date on caregiving-related expenses in total, including home care, transportation, paying bills, everyday household expenses and even costly medical treatments. Forty-five percent were unable to estimate how much they spent in the last month.

The vast majority of caregivers (76%) are not being reimbursed at all for what they have paid for care. However, they may become an heir in the future.

### FINANCIAL CAREGIVERS NEED HELP

The message is clear: financial coordinators need help and 66% of caregivers feel they could benefit from financial advice. When asked about what might help them in their financial caregiving roles, 55% of financial caregivers would like banking alerts for unusual purchases from their recipient's account.<sup>56</sup> There is a lack of preparation among financial coordinators, in addition to a lack of training and support. Financial coordinators are in need of financial advice, support and resources in order to fulfill the responsibilities of their role.

66%

of caregivers feel they could benefit from financial advice.

### CAREGIVERS: A FIRST LINE OF DEFENSE AGAINST ELDER ABUSE

An estimated \$36 billion, which is likely underreported, is stolen through elder financial abuse each year.<sup>57</sup> Caregivers are a first line of defense against fraud, as financial caregivers are not only helping their care recipient pay bills, but also monitoring their accounts for suspicious activity. It's important to designate a trusted person to handle the responsibilities involved in financial caregiving, as well as to communicate clearly with them about their role.

## Conclusion

Financial caregiving is nearly uncharted territory, with little research identifying the flow and pace of transactions that individuals and their families experience as they navigate the caregiving journey. Similarly, little has been studied about the ways in which caregivers and care recipients need help financially. As Boomers age, the need for assistance in tracking, managing and paying for care-related expenses in complex relationships is destined to grow.

## Quantifying the Cost of Caregiving

Little research exists about the total costs of caregiving incurred by a care recipient and/or their family during the entire course of the caregiving life stage.

### CARE SCENARIOS

These case studies may represent two typical eldercare situations. Both caregivers are providing care to aging mothers. In the second case, the care recipient also has Alzheimer's, which adds significant costs and lengthens the period of time during which someone needs care. These two examples were constructed using national averages.<sup>58</sup> Direct costs include: professional caregivers, adult day care, long-term care facility, home maintenance, home modifications, grocery delivery, transportation and safety monitoring. Indirect costs include: lost hourly wages, reduced Social Security benefits and lost 401(k) contributions.

#### KAREN'S CAREGIVING JOURNEY:

Karen, 54 years old, took care of her mother, Tracy, for six years after her father passed away. At first Karen was only helping Tracy with light chores and transportation. Two years into caregiving, Tracy's needs escalated, and Karen decided to move her mother in with her and her two teenage daughters. A few years later, Tracy was sent to the hospital after having a stroke. The doctors told Karen it may be safer for Tracy to live in a care facility where she may have better access to medical attention. One year later, Tracy passed away at age 84. Let's see how Karen's caregiving role impacted Karen and her family's financial situation.

#### COSTS DURING KAREN'S CAREGIVING JOURNEY

THE SITUATION	DURATION	DIRECT COSTS*	INDIRECT COSTS*	TOTAL COSTS
Karen occasionally assists Tracy.	1 year	\$5,000	\$0	\$5,000
As Tracy's needs progress, Karen switches to part-time work and hires a part-time caregiver to care for Tracy in her own home.	2 years	\$40,000	\$31,000	\$142,000
Karen moves Tracy in with her. She works part time and hires a part-time caregiver to help Tracy when she is not there.	2 years	\$26,000	\$31,000	\$114,000
Tracy moves into a long-term care facility and lives there for the rest of her life.	1 year	\$92,000	\$31,000	\$123,000
<b>GRAND TOTAL</b>	<b>6 YEARS</b>	<b>\$229,000</b>	<b>\$155,000</b>	<b>\$384,000</b>

#### RODRIGO'S CAREGIVING JOURNEY:

Rodrigo, 57 years old, took care of his mother, Marie, for ten years. Halfway through, it was discovered she had some form of dementia. She was able to live in her home for four years before Rodrigo realized that it wasn't safe for Marie to be on her own. Rodrigo moved Marie in with him and his family for three years, until a relative encouraged him to move her into a care facility. Marie lived in the facility for three years until she passed away at age 89. Let's see how Rodrigo's caregiving role impacted his family's financial situation.

#### COSTS DURING RODRIGO'S CAREGIVING JOURNEY

THE SITUATION	DURATION	DIRECT COSTS*	INDIRECT COSTS*	TOTAL COSTS
Rodrigo helps Marie out occasionally.	2 years	\$5,000	\$0	\$10,000
As Marie's needs progress, Rodrigo switches to part-time work and hires a part-time caregiver to care for Marie in her own home.	2 years	\$51,000	\$31,000	\$164,000
Rodrigo moves Marie in with him. He works part time and hires a part-time caregiver to help Marie when he is not there.	3 years	\$49,000	\$31,000	\$240,000
Marie moves into a memory care facility and lives there for the rest of her life.	3 years	\$86,000	\$31,000	\$351,000
<b>GRAND TOTAL</b>	<b>10 YEARS</b>	<b>\$517,000</b>	<b>\$248,000</b>	<b>\$765,000</b>

\*Costs per year.



## A Burden and a Blessing: Costs and Compensations of Caregiving





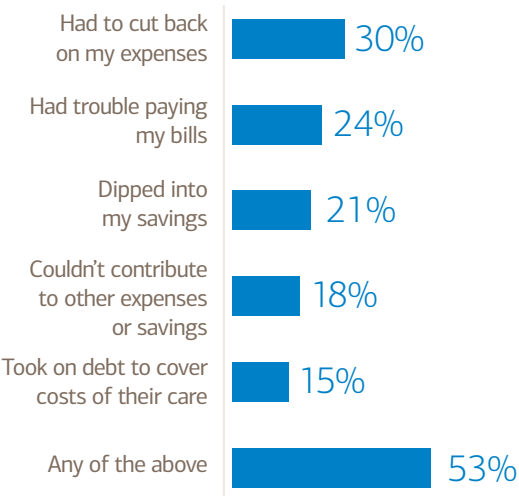
Many caregivers report significant costs in terms of their finances, their health, their time and leisure, their work and their other relationships. Yet despite the hefty cost, caregivers often feel fulfilled by caregiving and grateful for the opportunity to help someone they love in their time of need.

THE SACRIFICE OF CAREGIVING

Seventy-one percent of respondents say they are making sacrifices as a caregiver. These sacrifices can include time, respite, money and work, among other things. Most do it willingly and want to provide high quality care to their recipients, but willingness does not mean the sacrifices aren't keenly felt by the caregivers and other members of their household.

Financial contributors are making tradeoffs in order to pay for care. Half of financial contributors are making financial sacrifices, the most common being that about one-third are cutting back on their own expenses (Fig. 12). Nearly a quarter have trouble paying their bills and one in five have had to dip into their personal savings.

Fig. 12: CAREGIVERS ARE MAKING FINANCIAL SACRIFICES



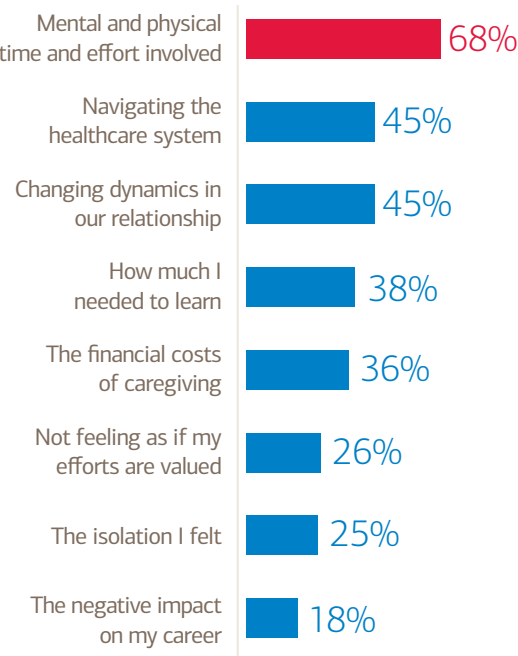
Base: Caregivers who contribute financially (percent who say they have done this; select all that apply)

TIME AND ENERGY

Caregivers say that the time and energy spent on caregiving is the hardest part of the role (68%) (Fig. 13). In addition, 45% face difficulties navigating the healthcare system, and 38% report that how much they needed to learn in their new role was a difficulty. One-quarter found the isolation extremely difficult.

71% of respondents say they are making a lot of sacrifices as caregiver.

Fig. 13: THE BIGGEST CHALLENGES OF CAREGIVING



Base: Caregivers (select top three)

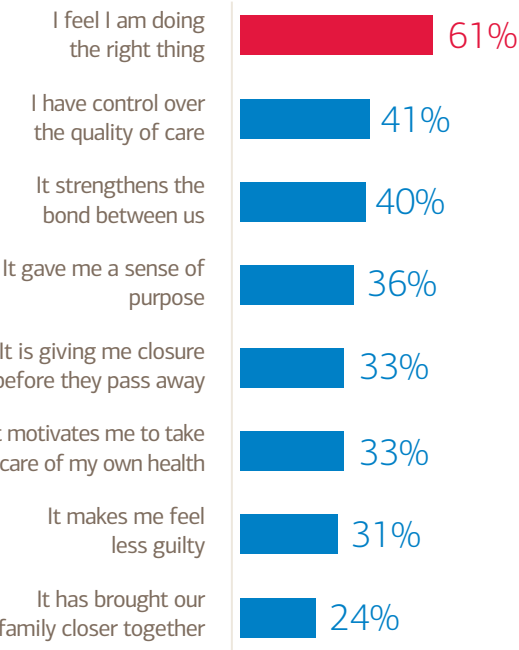
CAREGIVING GIVES BACK

Even though there are costs and sacrifices involved in providing care, caregivers are compensated by knowing that they are doing something good for someone they love. Sixty-one percent say that the biggest benefit of being a caregiver is doing the right thing (Fig. 14). In addition to doing something good, 41% say that having control over the quality of care the person receives is a benefit, and 40% report that the relationship between the caregiver and recipient strengthened due to caregiving.

COMPENSATED BY DOING SOMETHING GOOD

The vast majority of caregivers feel very positive about the experience. Overall, 91% of respondents feel grateful to provide care, and 77% would gladly do it again (Fig. 15).

Fig. 14: THE BIGGEST BENEFITS OF CAREGIVING

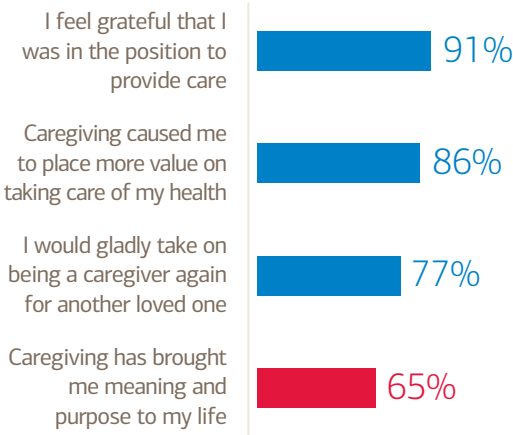


Base: Caregivers (select top three)

The emotional impact of caregiving is complex, and the flip side of doing all you can is feeling that you haven't done enough. More than half of our respondents say they feel guilty for not doing more for their loved one. In other studies, two-thirds of caregivers say the effort has brought them closer to the care recipient, and 86% say they gain satisfaction from knowing the recipient is well cared for.

Despite the sacrifices and challenges of caregiving, family caregivers are compensated by providing care to someone they love.

Fig. 15: CAREGIVING GIVES BACK TO CAREGIVERS



Base: Caregivers (percent agree)

65% say that caregiving has brought purpose and meaning to their life.

Conclusion

Caregiving is a life stage filled with costs and compensations, often simultaneously. Caregivers are making sacrifices in the workplace and at home, yet they are fulfilled by the meaning and purpose of doing the right thing for someone they care about. While many caregivers report making sacrifices in order to provide care, the vast majority are grateful for the opportunity to do so.

## Caregiving, Policy and the Workplace

Caregiving responsibilities do not adhere to a nine-to-five schedule. Yet three in five caregivers are also in the labor force.<sup>59</sup> Working caregivers must often leave work to take their care recipients to appointments, ask for time off if professional caregivers cancel, and devote time during the workday to managing appointments and care coordination. For many caregivers, taking a leave of absence from work is the only way to ensure their loved one gets the care they need, and this sense of immediacy is exacerbated by a rapidly deteriorating medical condition. For most working caregivers, achieving balance between working and caregiving is a constant struggle.

Leaving and re-entering the workforce is a significant challenge. The penalty of taking time off to care for a loved one often means foregoing upward mobility in the workplace. Re-entry can be marked by diminished opportunities, lack of knowledge of new technology and—coupled with grief or transitioning to post-caregiving life—presents a challenge to caregivers who go back to work after an extended absence.

In 1993, the federal government passed the Family Medical Leave Act (FMLA), guaranteeing 12 weeks of job protected, unpaid time off for family or medical reasons to workers at companies with 50 or more employees. Before FMLA, people routinely lost their jobs when they took time off to care for a child or sick family member. It is undeniably a good thing that FMLA exists; however, the reality for most is that they cannot go 12 weeks without pay.

Despite FMLA, only 56% of caregivers feel comfortable letting their employer know about their caregiving responsibilities.<sup>61</sup> About half (46%) of the caregivers we studied who had reduced wages due to caregiving did not realize that it could impact their Social Security or retirement savings.

Some companies offer a variety of programs to support caregivers. In 2017, AARP highlighted 14 companies that are providing services and benefits to their employees who are also caregivers.<sup>62</sup> One of them is Bank of America, which supports its employees who are caregivers through a variety of resources including access to emergency back-up care for adults and children, professional elder care assessments, elder care law services, and an internal Parents and Caregivers employee network.

Given the demographic reality of the coming caregiver crunch, it is in companies' best interest to support their employees who are concurrently working and caregiving. Policy, too, can help ameliorate the burden on caregivers in the future. In 2017, a bipartisan bill was proposed to Congress: the RAISE (Recognize, Assist, Include, Support, Engage) Family Caregivers Act, which would task the Department of Health and Human Services with developing a strategy to support family caregivers. If passed, the legislation could influence employer policies for working family caregivers across the country. Similarly, companies can continue to be leaders in employment benefits by expanding services offered to family caregivers as well as flexibility to those that need it most.

# 74%

of adults with eldercare responsibilities have worked at a paying job at some point during their caregiving experience.<sup>60</sup>





# The Future of Caregiving: The Coming Caregiving Crunch



Major innovations can have lasting impacts on the way we live our lives and age. Economic downturns, political upheaval and climate change can upend daily living. We do not know what the future holds, but we do know that the number of Americans needing long-term care is projected to grow from about 12 million today to 27 million by 2050.<sup>63</sup> Four major forces will continue to transform the caregiving landscape in the years ahead.

### THE FOUR FORCES:

#### 1. Longevity

The future of caregiving is a tenuous one, given the sheer number of people who will need care compared to those that are able to provide care. People age 80 and older are the most likely to need long-term care—and this is the fastest growing demographic in the decades ahead.<sup>64</sup> Between 2015 and 2050, life expectancy at birth is projected to increase from 79 to 84.<sup>65</sup>

The most important variable determining the future of caregiving may be the health of older Americans. As our longevity has grown steadily over several decades, our healthspan has not kept pace. Chronic conditions related to obesity are on the rise.<sup>66</sup> Health problems and mobility limitations associated with obesity could put an end to the increase in disability-free life expectancy.<sup>67</sup> The prevalence of Alzheimer's disease, in particular, affects healthspan and the need for caregiving: the number of people living with Alzheimer's disease is expected to grow from 5 million today to 14 million in 2050.<sup>68</sup>



*“With life expectancy rising and medical improvements, people live longer with illness. That means the caregiving journey is longer as well.”*

—A. Michael Bloom, President, Caregiving Without Regret and author of *The Accidental Caregiver's Survival Guide*

## 2. Demography

The future need for caregiving also depends upon our country's age structure, which affects the pool of potential people needing care as well as those who can potentially provide care. To date, researchers have defined the "caregiver support ratio" as the number of potential caregivers relative to the number of potential older adults needing care. However, these calculations are out-of-date, as they don't reflect caregivers who are ages other than 45-64—including the 25% of caregivers who are millennials.

In this report, we recalculate the caregiver support ratio to include potential caregivers from ages 18 through 64. The supply of caregivers will drop by nearly half in 2050 (Fig. 16). Meanwhile, the number of Americans 65 and older is projected to grow from just under 48 million in 2015 to 88 million in 2050.<sup>69</sup> The caregiver ratio is shrinking, and fast, from 4.8 caregivers per person in 2010, to 3.5 in 2020, to 2.8 in 2030.<sup>70</sup> With the coming age wave, we will face a caregiving crunch.

## 3. Sociology

Sociological forces, including the changing size, shape and distribution of families, will also impact the future of caregiving. Families are more likely to live further apart from each other.

Compared to previous generations:

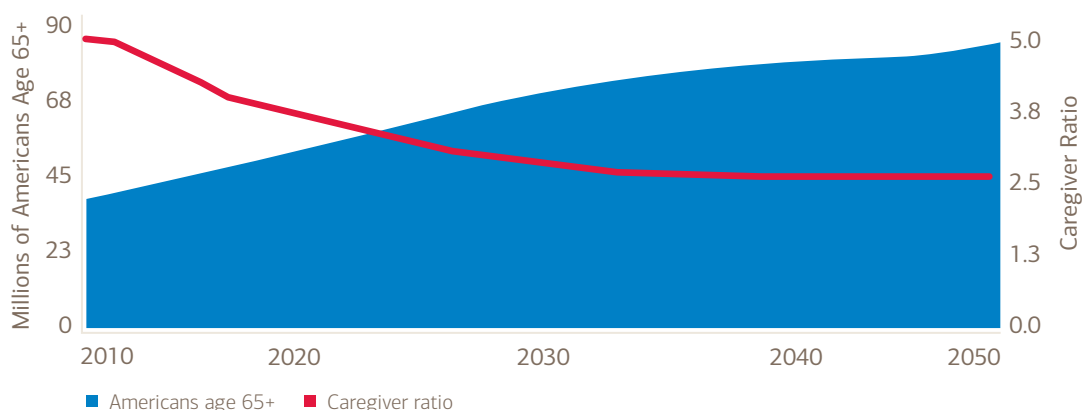
- ▶ Boomers are more likely to be alone in their later years, whether divorced, widowed, or never married. More divorced, single-parent, and blended families may lead to weaker family ties.
- ▶ Boomers are less likely to have children than previous generations, and those who do likely had fewer children. Childlessness among the older population is projected to increase to 21% in 2040, and another 49% will have only one or two children.<sup>71</sup>
- ▶ Being both less likely to have a spouse and to have adult children, one in four Boomers are at risk of becoming "elder orphans" without relationships to help shore up their family sources of care.<sup>72</sup> Relying heavily on fewer family caregivers could also add to caregiver costs—in the form of increased emotional and physical strain, competing demands of work and caregiving as well as financial hardships.

In total, the number of older adults without a living spouse is expected to more than double from roughly 875,000 to 1.8 million in 2030, and those without an adult child within 10 miles could increase by a multiple of six—from about 100,000 to more than 600,000.<sup>73</sup> Perhaps Boomers will increasingly rely on siblings as potential caregivers, especially since they are the first cohort to have entered midlife with so many sisters and brothers still alive. Other solutions might include communal or intergenerational living.

# 6X

increase in 75-year-olds without nearby children in 2030.<sup>73</sup>

Fig. 16: FROM AGE WAVE TO CAREGIVING CRUNCH



Caregiver ratio is the number of Americans ages 18-64 to the number of Americans ages 65+  
Source: U.S. Census Bureau, National Population Projections, 2014



### 4. Technology

Only 7% of caregivers are using any of the caregiving technology available on the market today, but as younger generations take on more caregiving tasks, technology adoption is predicted to soar.<sup>74</sup> And as technology companies become increasingly aware of caregiver needs, helpful products and services are likely to multiply.

While a variety of technologies exist that, in some way, target those on the journey of caregiving, few are truly addressing their needs.

As caregivers rely more on technology in the years ahead, the high touch element of caregiving cannot be neglected. Peer-to-peer tech-based learning holds potential to marry high tech and high touch, allowing caregivers to connect with one another to share experiences, resources and advice. Sixty-eight percent of caregivers say they already use or are likely to use social media or other technologies to connect with other caregivers to share and learn from personal experiences<sup>75</sup> and they are among the most likely groups to look online for

health information.<sup>76</sup>

Caregivers, more than anything, want technology that offers peace of mind, so they can check in on their care recipients from remote locations—seeing them, hearing them, monitoring their health status and talking to them.<sup>77</sup> To date, several innovations—medication and safety monitoring apps, telehealth and care coordination tools, smart home sensors and technologies, personal care and support robots, ride-sharing apps and autonomous vehicles, tech-based delivery services, as well as technologies to monitor and assist financial caregivers—have been purported to advance the state of caregiving. However, few have been a disruptive force that has reshaped how caregivers provide care.

*“Technology in caregiving is always a hot topic, but a majority of caregivers don’t know about it, don’t feel competent using it, so they don’t even try it.”*

—Amy Goyer, Family and Caregiving Expert, AARP



## THE TIME TO ACT IS NOW

The Congressional Budget Office projects Medicaid spending on Long Term Services and Supports will grow at an average of 5.5% per year, exceeding gross domestic product growth, to reach an estimated \$100 billion by 2023.<sup>78</sup>

Demand for care for Alzheimer's patients will be even more crunched in the future as the population of people with Alzheimer's is projected to grow. Between 2015 and 2050, the number of potential care recipients will grow 84% whereas the number of potential care recipients with Alzheimer's will grow much more (Fig. 17). In contrast, the number of potential caregivers will grow by 13%.

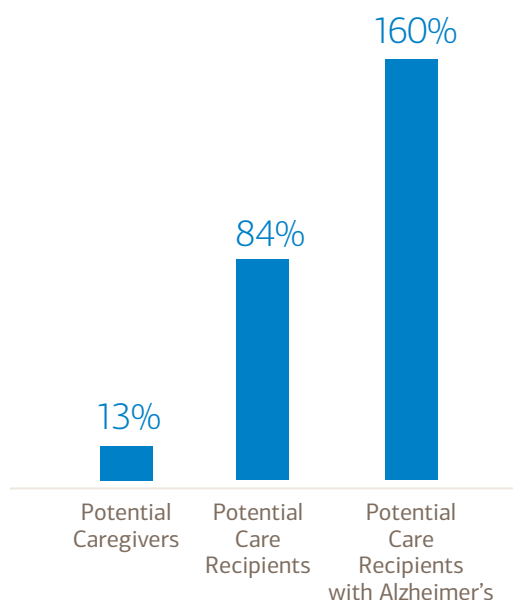
## BOLSTERING AMERICA'S CARE INFRASTRUCTURE

As more people need caregiving but don't have as many family and friends to provide care, we may need to rely more on professional caregiving. However, if caregivers continue to be undervalued, the supply will never meet the demand. Nine in ten Americans agree that professional caregivers, and the work they do, are undervalued.

## AGING BOOMERS DRIVE GROWTH IN CARE ECONOMY JOBS

Employment in the home care industry grew 83% in the last decade, compared to 6% overall job growth.<sup>79</sup> The demand for paid caregivers is projected to nearly double that of software developers by 2024, which means we'll need to attract more than half a million new caregivers to keep up with demand (Fig. 18).

Fig. 17: HOW CAREGIVING IS CHANGING: 2015-2050



Source: U.S. Census Bureau, National Population Projections, 2014; Alzheimer's Association, 2015 & 2017

Fig. 18: NEW JOB OPENINGS: 2014-2024



Source: U.S. Bureau of Labor Statistics, 2017

### MAKING AMERICA READY TO CARE

In the next decade, it is estimated that the demand for home health aides may exceed supply by more than three million.<sup>80</sup> The future of professional caregiving is also linked to the future of immigration policy in the United States. In 2015, 18% of certified nurse's assistants and 27% of home care aides were immigrants.<sup>81</sup> Among immigrant home aides, 24% each come from Central America and Asia, 23% come from the Caribbean and 10% are from Africa.<sup>82</sup> The highest percentages of home care aides who are immigrants are found in New York, New Jersey, California, Florida and Texas.<sup>83</sup>

There is also a severe lack of training among new doctors in the field of geriatric medicine. While older adults are the fastest growing segment of the population, only one physician is trained and certified as a geriatrician for every 13 pediatricians.<sup>84</sup> Only 14 of 159 medical schools surveyed in the U.S. have a full department of geriatrics<sup>85</sup> and 96% of U.S. medical students don't take a single course in geriatrics.<sup>86</sup>

**9 in 10**  
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### PRIORITIZING CARE

As a society, there are three major routes to support and strengthen our caregiving infrastructure:

- ▶ **Improve jobs for paid caregivers:** Supporting increased wages or benefits to professional, paid caregivers is one course. Encouraging more people to seek out caregiving as a profession is another. Many have proposed creating a new, federal caregiving employment program similar to AmeriCorps or Teach for America. This Caregiver Corps could create new job opportunities for high school and college graduates facing debt, those seeking meaningful work and retirees who are interested in giving back.<sup>87</sup>
- ▶ **Improve employee benefits for caregivers:** While 84% of employers say that caregiving will become an increasingly important issue to their company in the next five years, only 18% of employers strongly agree that their workplace currently is “caregiving friendly.”<sup>88</sup> Currently, employers shoulder an estimated \$50 billion per year productivity loss due to full-time employees struggling to balance their own health and caregiving responsibilities.<sup>89</sup> Leading organizations, including Bank of America, seek to support caregiving employees through benefits such as legal consultations and backup emergency care.

- ▶ **Increase government-backed research for Alzheimer’s and other diseases of aging:**

Alzheimer’s accounts for a disproportionate amount of caregiving hours, burden and cost. It’s also the sixth-leading growing cause of death, and kills more people than breast cancer and prostate cancer combined.<sup>90</sup> In fact, one in three older adults dies with Alzheimer’s disease or another dementia.<sup>91</sup> It is 100% fatal and 100% incurable. Despite these facts, research to find a cure is significantly underfunded. In 2016, the National Institutes of Health allocated \$5.6 billion toward cancer research. In contrast, less than one-fifth of that amount went to research on Alzheimer’s and dementia.<sup>92</sup> By 2050, it is projected to cost \$1.1 trillion per year,<sup>93</sup> which is 1,000 times greater than what we currently spend on research to cure the disease.<sup>94</sup>





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## Conclusion

We are at a critical moment as Boomers move up to and through their sixties and seventies and into their eighties. This unprecedented age wave will highlight the difference between our lifespans and our healthspans. Together with changes in our nation's demographic and family structures, along with costly professional long-term care, we can see a coming caregiving crunch. Now, more than ever, is the time to take steps to prepare for caregiving—both our own potential care needs as well as those of the people we love.





Action Needed



### PREPARING TO CARE

In today's world, when we're living longer than ever before, it's likely that either we will need care or we will become a caregiver to someone we love. In fact, it's estimated that 70% of Americans age 65 or older will need some form of long-term care in their lifetime.<sup>95</sup> What can we learn from today's caregivers that can help us think about our own and our family's future care needs?

### DESIGNATE SAVINGS FOR YOUR FAMILY'S HEALTH

Health care expenses are the number one financial worry in retirement<sup>96</sup> and 77% of people say they don't know how much they need to save for health and long-term care costs in retirement.<sup>97</sup> Neither Medicare nor Medicare supplemental coverage fully covers long-term care, yet 6 in 10 say they would use it to pay for their future care needs. Medicaid requires spending down financial assets before becoming eligible. Other options for financing care include:

- ▶ **Long-term care insurance:** While each policy is unique, long term care insurance covers a range of nursing, social and rehabilitative services for those needing on-going assistance. Long term care usually requires an annual payment years in advance of when you think you may need care.
- ▶ **Home equity credit line:** If you own a home, don't forget to include it in your assessment of financial resources for future care needs. A home equity credit line is a home loan that is secured using the equity in your home. It can offer access to cash, with generally lower interest rates than credit cards or personal loans. This may be a good option if you need a large sum of money quickly and believe you'll be able to pay it back. Home equity lines of credit feature variable interest rates that move up and down in tandem with the prime rate. The danger of variable interest rates is the possibility that rates will rise in the future. If the variable rate increases, you could find yourself paying significantly more in interest than if you had taken the fixed rate loan.
- ▶ **Tax credits:** Depending on the situation, care recipients can qualify as dependents of caregivers, thus giving the caregiver a tax break. There is also the dependent care tax credit for money spent by working caregivers on at-home aides or adult day care. States also may have their own tax credits, so it's good to do research or talk to a professional on what tax savings you can take advantage of.

- ▶ **Health Savings Account:** If your care recipient qualifies as a dependent, you may be able to use pre-tax incomes directed in to Health Savings Accounts (HSAs), Health Reimbursement Accounts (HRAs) and/or Flexible Spending Accounts (FSAs). Each account has different eligibility requirements, advantages and disadvantages. Talking to a professional can be helpful in navigating the complexities of these tax-advantaged accounts.

### TALK OPENLY WITH FAMILY

While care-related topics can be difficult to broach, being open and honest with each other early on can prevent headaches and heartaches down the road. Unfortunately, many are not currently having these conversations. While 86% of Americans want to live in their own home for the rest of their life, only 23% have shared this with their children.<sup>98</sup> When preparing to talk to your loved ones about your wishes for later life, consider:

- ▶ **Where do you want to live?** It's important to understand the practical and financial implications for someone who wants to remain at home or prefers to move into a facility. This can greatly impact the cost of care as well as the need for family and friends to provide care.
- ▶ **Whom do you want to handle different aspects of your care?** Would you prefer the same person to handle your finances and to provide hands-on care if you need it? By identifying who performs different tasks, you and your loved ones can have greater clarity as well as get assistance for legal authorization. Placing assets in a revocable trust now preserves flexibility and makes it easy for you to name an individual or financial institution to manage assets should you no longer be able to manage your financial affairs. The trust can be set up to receive income, pay bills and provide tax records.
- ▶ **What are your medical preferences and desires?** Four in ten caregivers from our survey were choosing medical care options on behalf of their recipients. It's important that you discuss what medications and treatments are acceptable—and not—in case there comes a time when you cannot advocate for yourself. A living will, also known as an advance directive, may be required.
- ▶ **Where are your important medical, legal and financial documents?** One in three respondents said a top challenge was locating passwords and account information. While this conversation should not take very long, it can save your family hours of searching. Include information about insurance, medical history and providers, bill arrangements and any legal documents.

### SEEK GUIDANCE AND SUPPORT

For many, caregiving is more a marathon than a sprint. Having people you can trust in times of need can make the journey easier. Here are some resources you may want to have as part of your extended care team:

- ▶ **Caregiver peers:** Our research revealed the power of peer learning. Caregivers readily shared tips, tools and services. New online platforms like AARP's Caregivers in the Community (CINC) app are facilitating peer learning and support. Many communities also offer caregiver support groups.
- ▶ **Care specialists:** Sometimes called geriatric care managers, they can help with issues such as home modifications, resolving conflicts between family members, and finding local resources. [AgingLifeCare.org](https://www.aginglifecare.org) allows you to find geriatric care managers in your area. Some employers, such as Bank of America, offer access to care specialists through employee benefits.
- ▶ **Financial & legal professionals:** Financial institutions and law firms employ specialists in areas related to caregiving, such as elder law specialists and financial gerontologists who can navigate the unique challenges caregivers and care recipients face in murky financial and legal territory. An estate planning attorney can help create a plan for dealing with common issues. The plan may use a power of attorney to grant legal authority to an individual to manage financial affairs in the event of incapacity. The plan could also create a trust to hold assets and designate an individual or institution to manage the assets, pay bills and carry out instructions regarding the future use and distribution of assets when the individual establishing the trust is no longer able to do so.

- ▶ **Friends and family:** Forty-four percent of caregivers from our survey said they often felt isolated. Family and friends can be the antidote. Make an effort to keep ties with family and friends, and to ask for help when needed.
- ▶ **Professional caregivers:** Not everyone has family members or friends who can provide respite. [Arch National Respite Network and Resource Center](https://www.arch.org) helps caregivers find respite resources, including free programs funded through state and federal government.

On the caregiving journey, help caregivers take care of themselves. Only half of today's caregivers report taking respite from their caregiving responsibilities. Caregivers who take respite are better able to keep their care recipients at home longer, delaying the high cost of nursing homes and other facilities.<sup>99</sup>



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