



# Helping the Helpers:

A Look at Caregivers and How We Can Better Serve Them

Presented by: Leanne Benvignati



# The Importance of this Research

In 2020, 53 million Americans provided unpaid care to an adult over the age of 18 or a child with special needs.

(Source: My LifeSite, *The State of Unpaid Family Caregiving in the U.S*)

"23% say caregiving has made their own health worse."

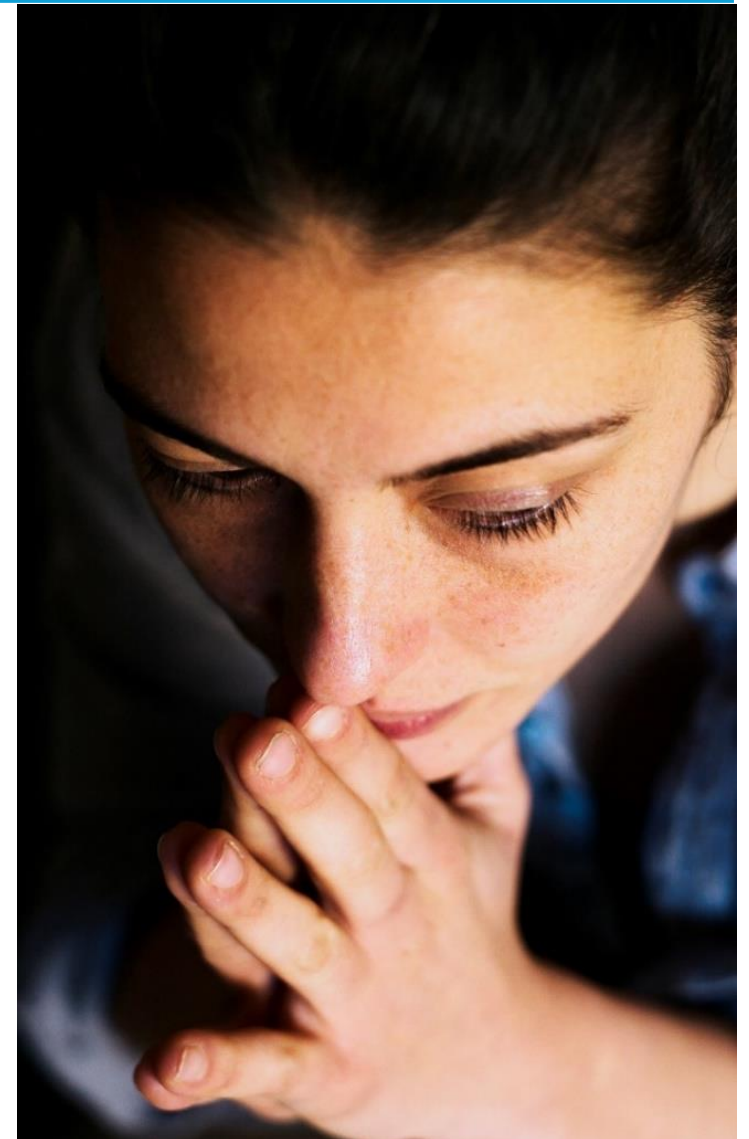
(Source: AARP, *Caregiving in the United States, 2020*)

"Nearly 1 in 5 [family caregivers] experience significant financial strain."

(Source: AARP, *Planning for Retirement? Don't Forget Caregiving Costs*)

"Three-quarters of adults caring for parents surveyed reported strains on their relationships because of caregiving, with 46% saying it damaged their romantic relationships and 25% saying it played a major role in their divorce."

(Source: Arbor Assisted Living, *Is Caregiving Ruining Your Relationships?*)



# About the Study

## Background

Given the number of unpaid caregivers in the United States, our study examines the impacts, challenges, and needs of these individuals.

In addition to identifying unmet needs, we explored ways insurance companies and employers may be able to bridge these gaps.



The findings in this presentation are from the quantitative phase of this research, with quotes and context from the qualitative phase.

## Methodology

**Phase 1: 12, 60-minute IDIs**

**Phase 2: 519 online surveys**

- Field period: July 28, 2023–August 7, 2023

### Screening criteria:

- All unpaid caregivers
- Care for an adult aged 18 or older who is unable to care for self, or care for a child with special needs
- Spends at least three hours per week caring for a loved one
- Long-term caregiver (three months or longer)
- Expect caregiving role to last six months or longer
- Loved one does not live in a long-term care facility

**Sample was procured from our valued partner:**



# A PROFILE OF CAREGIVERS



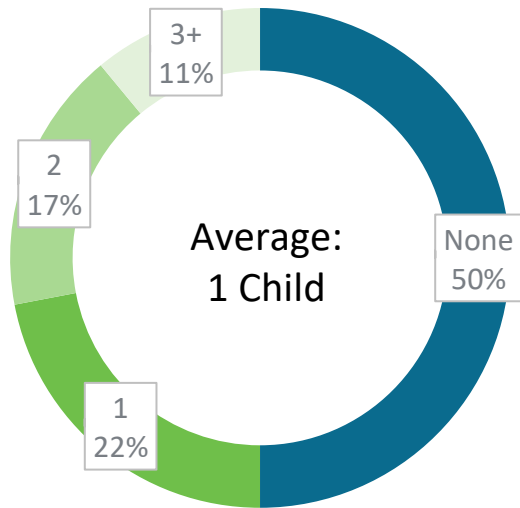
# About Our Caregivers

(Quantitative Findings)

**Average Age** 47

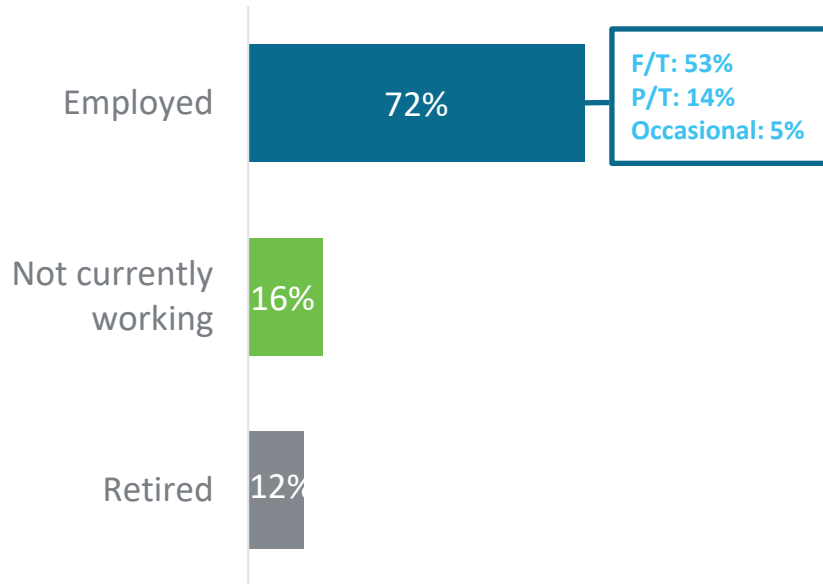
**Gender** 66% Female 34% Male

## Number of Children Under 18 in Household



46% of caregivers caring for a parent have at least one child in their household

## Employment Status



Caregivers with full-time jobs provide an average of 33 hours of care a week

## Caregiver Health Status

10% Excellent  
23% Very Good  
42% Good  
22% Fair  
3% Poor

## Caregiver Ethnicity

70% White/Caucasian  
21% Black/African American  
14% Hispanic  
4% Asian/Pacific Islander  
3% Other

## Household Income

28% Under \$50,000  
36% \$50,000 to less than \$100,000  
35% \$100,000 or more

# About Caregiving

## Individual Receiving Care



Parent: **44%**



Special needs child: **23%**

*Of those, 86% are caring for a child under 18 and 14% for a child 18 or older*



Someone else: **23%**

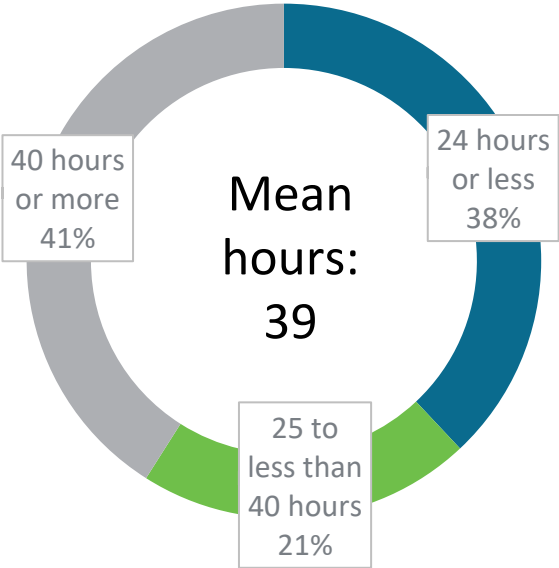
*Sibling: 5%  
Other family member: 14%  
Friend: 4%*




Spouse: **10%**

## Time Devoted to Caregiving

Average hours per week (minimum of 3 hours)

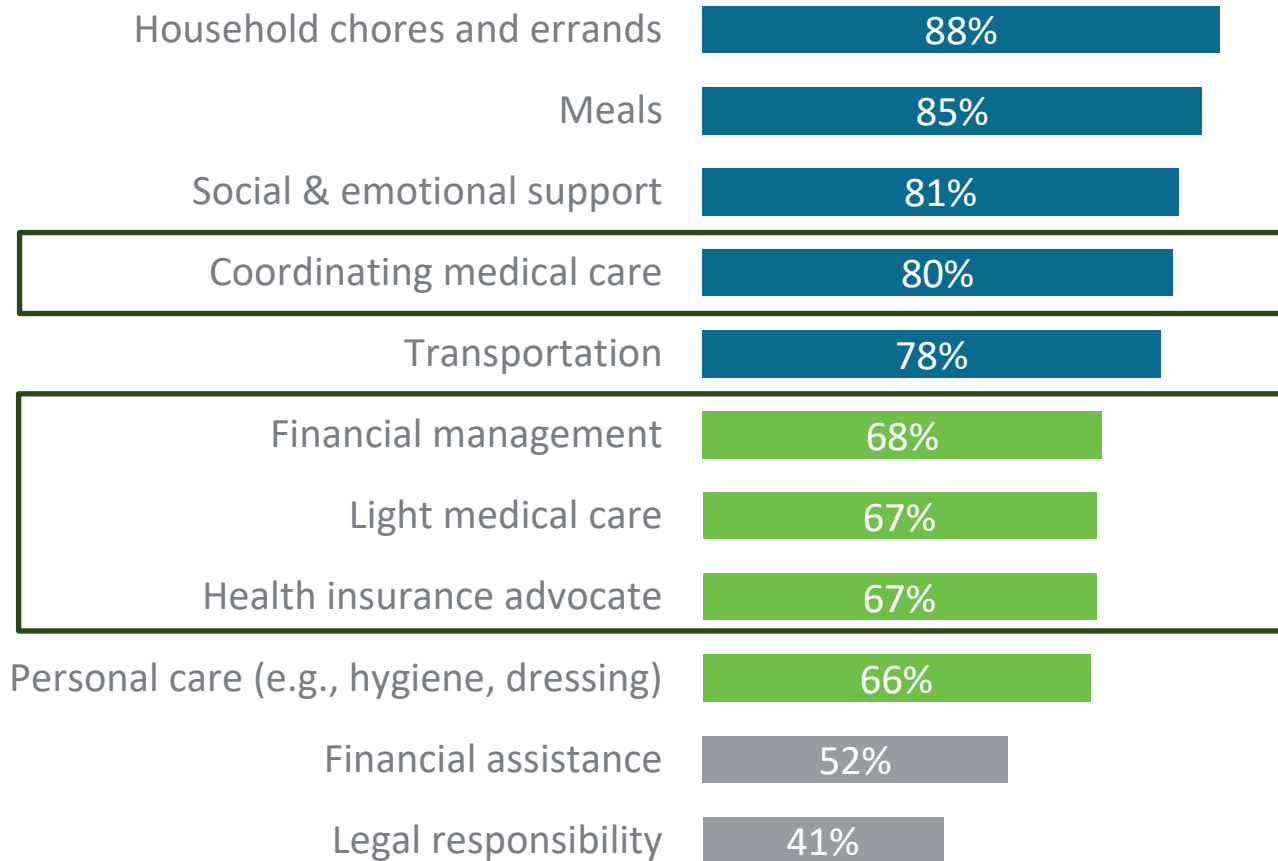


 73% of caregivers say they are the sole or primary caregiver

## Top Reasons Caregiving is Needed

- 20% Physical/mobility issues
- 15% Generally disabled
- 14% Alzheimer's/dementia
- 14% Cognitive disability
- 9% Mental disability
- 6% Old age
- 6% Stroke/seizure/epilepsy
- 6% Cancer

# Types of Support Caregivers Provide



## In Respondents' Own Words...

“ I'm her mental health support and advocate person. I provide emotional support and financial support. I'm also like a doctor, a veterinarian because she has a cat, house fixer-upper, and organizer of family stuff. I take care of almost everything. ”

(Caregiver for parent)



# Home Modifications



**75%** of caregivers have made **modifications to the home** to keep their loved one safe

## The Most Common Modifications:

- Grab bars in bathroom: 71%
- Shower chair: 66%
- Removed furniture or rugs: 57%
- Security cameras: 55%
- Safety locks: 44%
- Wheelchair ramps: 28%

## In Respondents' Own Words...

“ In every room of the house, there is something to help guide you along going down the hall, into the bedroom, in the bathroom, in the shower. There is something somewhere in every room. Everywhere you would be, there is something for guidance. ”

(Caregiver for a parent)



# IMPACTS OF CAREGIVING

# Feelings About Caregiving



## Percentage Who **DISAGREE** With Each Statement

- 40%** It is easy to find resources related to caring for my loved one
- 35%** I get the mental health care I need to take care of my own mental health
- 27%** I have a plan in place for if I am no longer able to provide care for my loved one
- 25%** I feel I have the support I need to care for my loved one

**68%** of caregivers feel it is **difficult to balance** caregiving with other aspects of life

“

*I wish I knew I could get help from outside, whether it's from the government or non-profits, because for both my mom and my daughter, you go for so many years and you find out, 'You could have had that? That would have helped.' People don't know [or] have enough knowledge of the resources that are out there.*

”

(Caregiver of adult child)

# Challenges of Caregiving

22% of caregivers say caregiving has had a **major negative impact** on their own physical health



## In Respondents' Own Words...

“Caregivers don't sleep, don't eat on a schedule, forget to take our meds, we run all day long [...] we have everybody else's doctor's appointments, and have to reschedule ours four times. We don't get the care we need most of the time because they come first.  
(Caregiver for a partner)

With the way things are here, I'm essentially—I hate to describe it this way, but this is how I often feel—I often feel like I'm a prisoner in my own house.  
(Caregiver for an adult child)

It's very stressful and I have really bad anxiety sometimes. I talk to my primary doctor, and he prescribes Xanax.  
(Caregiver for an adult child)

# Impacts of Caregiving on Relationship with Loved One



**24%** of caregivers say caregiving has had a **major negative impact** on their relationship with their loved one

## In Respondents' Own Words....

“ *It's frustrating at times. It's almost like she's a child. So, she's an adult, but she has childlike issues.*

(Caregiver for parent)

*I get frustrated, and I don't like when she sees me that way. I know her blood pressure goes up when I get a little edgy, like, 'Ooh, I don't know what to do.' You know? I'm trying to get her to eat her food instead of giving it to the dog, I'm trying to have her get dressed because we have to go to an appointment, instead she keeps taking it—like, I turn around and she's taken everything off, I'm like, 'No.' So, I get frustrated.*

(Caregiver for parent)

”



# If Caregivers Had Three Wishes to Make Life Easier...

(Top Mentions)

- 45% More support from family, friends, and others
- 43% Financial support
- 33% More free time for myself; better life balance
- 17% Improved health for loved one
- 16% Improved health for myself (the caregiver)
- 11% More training/preparation for caregiving

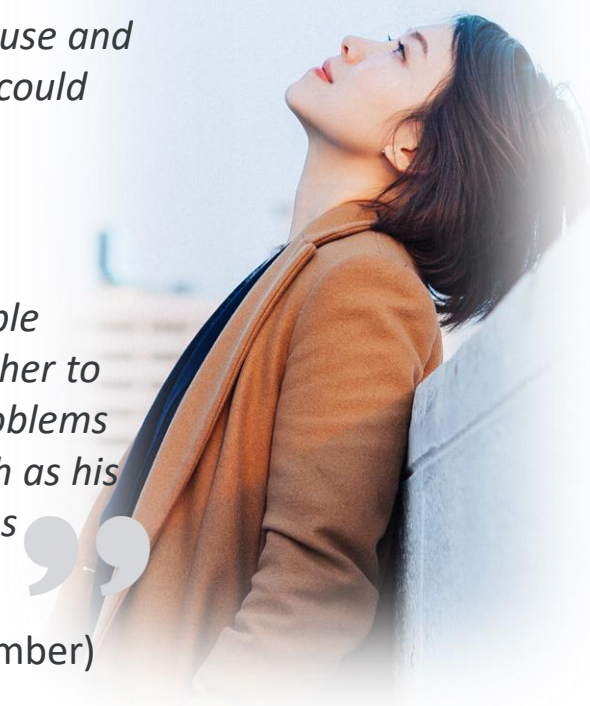
## In Respondents' Own Words...

““ *I wish another family member would come to the house and stay for three to four days so I could take a short vacation.*

(Caregiver for parent)

*I wish I was more knowledgeable about some tactics for my brother to help him when he is having problems dealing with his emotions (such as his anger), so his actions are not as destructive.*””

(Caregiver for other family member)



# CAREGIVER PREPAREDNESS & RESOURCE NEEDS

# Caregiver Preparedness



**52%** of caregivers wish they had a **better understanding** of what it means to be a caregiver before becoming one

## In Respondents' Own Words...

“ I wish I'd known about the stress and everything you had to go through when you did it.

(Caregiver for a parent)

I'm not equipped to care for her. My brother is not equipped to care for her.

(Caregiver for a parent)



# Offerings for Loved Ones

(Care Receivers)

	<b>Top Offerings Currently Receive</b>	<b>Currently Use</b> (Among those received)	<b>Would Find Valuable</b> (Among those not received)
Therapist/Counselor	39%	90%	81%
Home health aide/nurse	29%	88%	83%
Transportation services	25%	85%	78%
Food delivery service	24%	87%	82%
Care Manager	23%	79%	76%
Receive none of these	18%	N/A	N/A



# Offerings for Caregivers

All offerings are specifically related to caregiving

	Currently Receive	Currently Use (Among those received)	Would Find Valuable (Among those not received)
Unpaid time off from work*	30%	46%	56%
Educational materials	24%	<b>55%</b>	59%
Paid time off from work*	23%	<b>52%</b>	<b>83%</b>
A caregiver hotline	21%	45%	55%
Caregiver training	19%	<b>55%</b>	<b>65%</b>
Counselor or Care Manager	19%	47%	<b>69%</b>
Disease management info	16%	40%	55%
Employee Assistance Program*	16%	35%	<b>75%</b>
Respite care	12%	<b>52%</b>	<b>63%</b>

## Training Opportunities (From qualitative)

- Time management strategies
- “How-to” strategies to help manage caring for a loved one, other relationships, specific conditions, self-care
- Financial planning support
- Lists of resources available for caregivers and loved ones



38% of caregivers feel a health insurer is **best** suited to provide support to help them care for their loved ones (28% say their loved one’s insurer and 10% say their own insurer), followed by doctors (25%)

\*Based on employed caregivers



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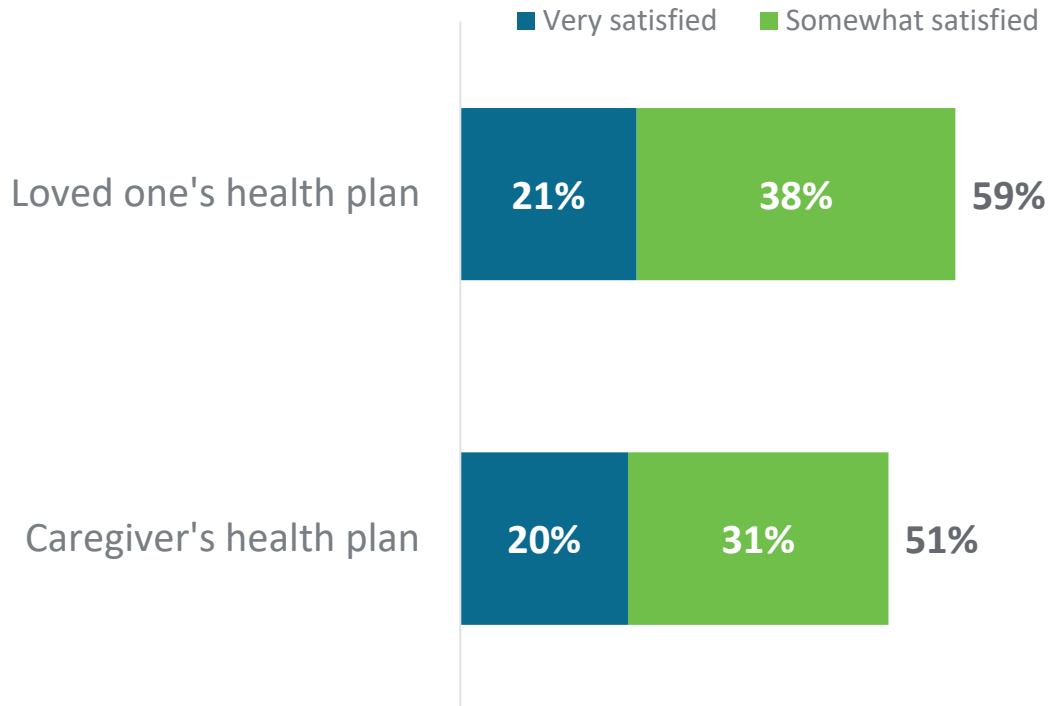
*I need coaching. I need a 15-minute, 30-minute coaching session. How do I approach this? Is it right to feel this way? Is this normal? I would ask a lot of questions...I need to know how to do it right the first time...In Noom, there's a nutritional coach, why not a caregiving coach?*

”

(Caregiver for parent)

# Caregiver Support from Health Insurers

## Caregivers' Satisfaction with Support Received From...



### Opportunities for Improvement (From qualitative)

- Information on specific diseases
- A caregiver portal/mobile app
- A caregiver hotline
- Respite care/home health aide
- Assisted living planning services
- Care Manager for caregiver
- Care facility support/placement help
- Access to mental health services

### In Respondents' Own Words...

“ I also love 5-, 10-, 15-minute videos. I would love it if a portal offered caregiver tips. ‘Here’s how to do this more efficiently.’ ‘Here’s how to destress.’ ‘Here’s how to take time for yourself.’ ‘Here’s how to get qualified for respite care.’ ‘Here’s the definition of respite care.’ I would love if it was all consolidated.”  
(Caregiver for parent)

“*We've tried to get palliative care for her. We've tried to get some home healthcare, and her doctor has been very good in trying to help us, but it's the insurance companies that are a pain in the neck that are, 'Ah, you don't need it,' like, 'Really?' The ridiculous thing is, if they provided that, she would have stayed out of both the ER and the hospital a lot of times.*”

(Caregiver for an adult child)

# The Need for Mental Health Resources



**32%** of caregivers say caregiving has had a major **negative impact** on their mental health

## Support Opportunities

(From qualitative)

- Access to more affordable mental wellness programs
- Access to therapists who specialize in caregiving, with a focus on stress management
- Choice of in-person and virtual options to accommodate already strained schedules

## In Respondents' Own Words...

“ My greatest worry is my own mental health...There's a lot of days where I think I'm either going to snap or I'm going to hurt her or I'm just going to pack my stuff up and leave the house and not even blink. Because it's that hard, and I just—I tell her long-term care caseworker this all the time, and I feel like it's falling on deaf ears, because the girl is 26 maybe, and I don't think she has any idea how hard this is. ”

(Caregiver for a child)

“*I don't want to burden my boyfriend talking about this. He can tell that there are times that I'm a little stressed out and I want to be very careful about pulling my brother or sister in, because I'm sure they have their own stresses surrounding this as well. I don't want to overload them.*”

**(Caregiver for parent)**

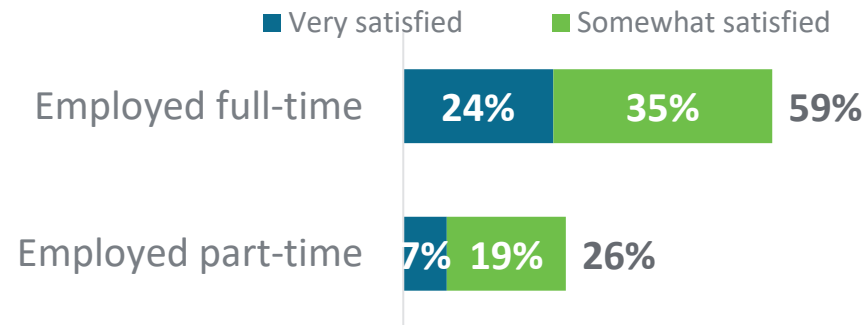


# Caregiver Support from Employers



**25%** of caregivers employed full-time say caregiving has had a **major negative impact** on their job/employment

## Caregivers' Satisfaction With Support From Employer



### Opportunities for Improvement (From qualitative)

- Access to mental health therapy
- Ability to set own schedule
- Paid/unpaid time off for caregiving
- Financial planning support; matching program

## In Respondents' Own Words...

“ There should be caregiver leave...my kids' school district will give teachers 10 days to just do whatever that they need to do. Because I've used everything: I've used short-term leave, I've used sabbaticals, I've called in everything in the book.

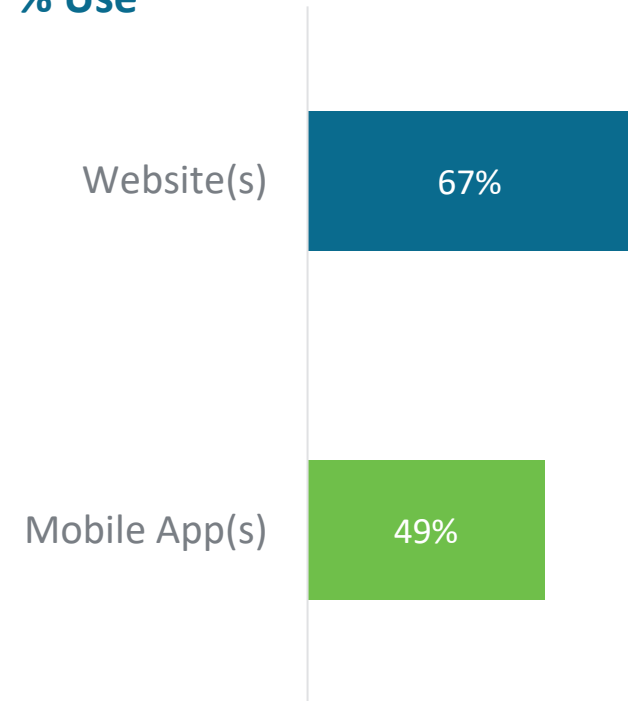
(Caregiver for parent)

I had to stop working outside and start doing stuff at home so I could stay there with him all the time.

(Caregiver for partner)

# Digital Tools for Caregivers

## Use of Digital Tools for Caregiving % Use

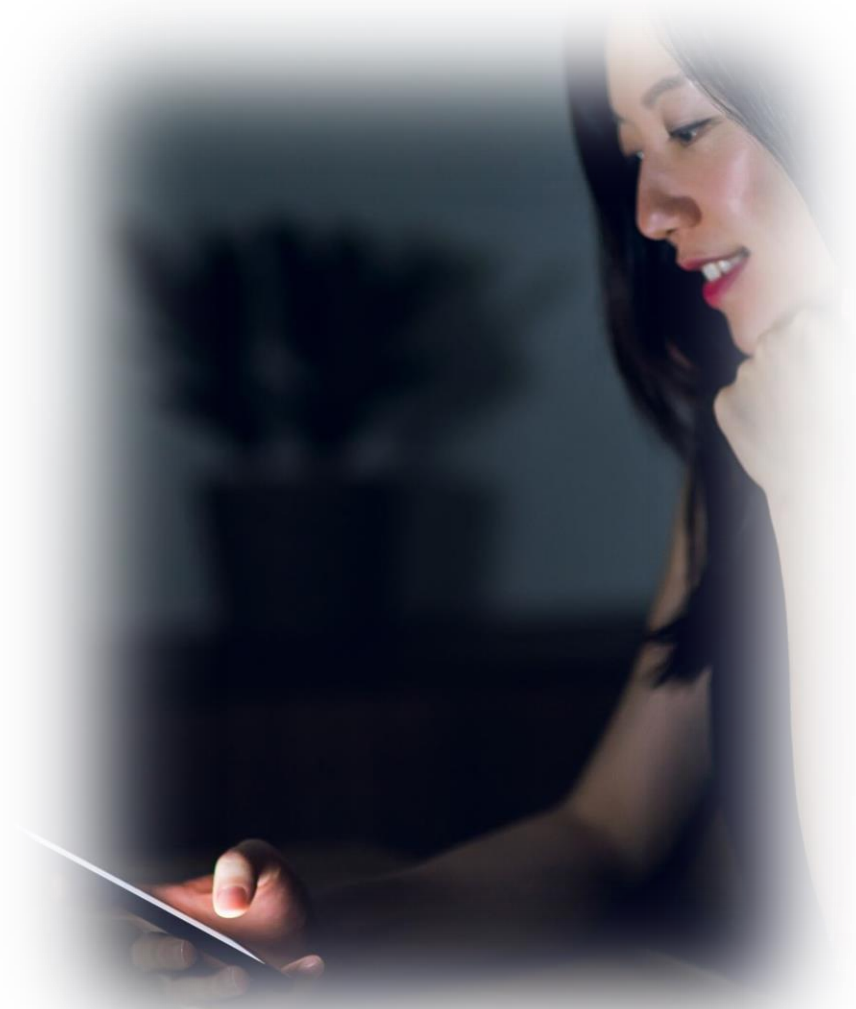


### Most Commonly Used Websites

- WebMD (26%)
- Google (19%)
- AARP (7%)
- Care.com (7%)
- YouTube (6%)

### Most Commonly Used Apps

- Google (13%)
- WebMD (12%)
- MyChart/patient portal (8%)
- AARP (6%)
- YouTube (6%)



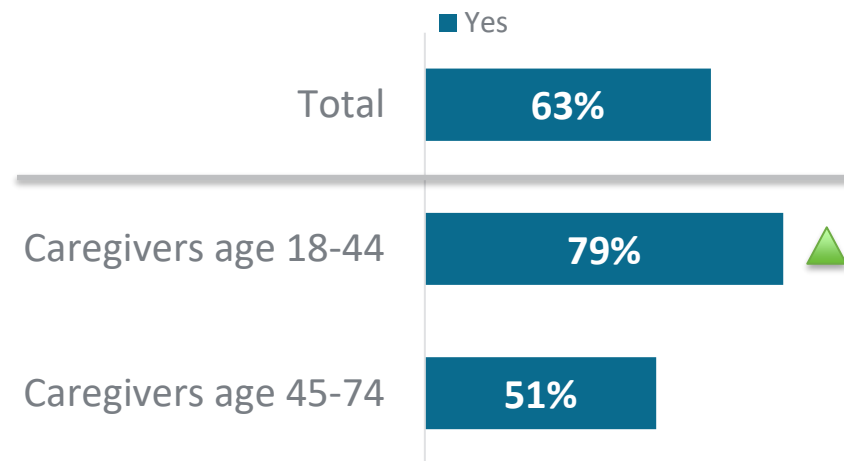
# Role of Financial Advisors



**26%** of caregivers work with a financial advisor

## Financial Advisor Helps with Planning Loved One's Future

Among those who work with an advisor



▲ Significant difference at 95% confidence level

## In Respondents' Own Words...

“ They didn't save enough, and although they had prepaid funeral plans and a little bit of life insurance...they didn't accumulate the savings they should have. I wish I had known then what I know now about how expensive it is to take care of someone. I know how expensive it is to take care of a child, but I plan. I planned from the minute these kiddos were born.

(Caregiver for parent)



# CAREGIVER PERSONAS

# Meet Renee



AGE	39
CARES FOR	18 y/o son with special needs
CAREGIVER ROLE	Sole caregiver   Lives with loved one   30+ hours of care per week
EMPLOYMENT	Self-employed   Full-time   Remote work   Flexible schedule
MARITAL/HOME STATUS	Divorced with 2 children, including her special needs son
OFFERINGS USED	Occupational therapy   Respite care   Online support group

## Renee's Story

Renee has a good understanding of what it means to be a caregiver to her son, but she struggles to balance her caregiving responsibilities with other aspects of her life. Caregiving has had a negative impact on her family life and her marriage. She chose to start her own business for flexibility and more balance. She is uncertain as to what the future holds for her son, but is making financial plans for his future when she is no longer around.

## Her Wishes

- Stipends or compensation benefits through health insurance
- Access to trustworthy caregivers
- More balance/breaks from her “around the clock” caregiving duties

“You're still trying to take care of them first. It's like the opposite of when you're in an airplane, and they say always put your oxygen on first. You're still going to do theirs first.”



# Meet Angela



AGE	53
CARES FOR	79 y/o mother with limited mobility and various health issues
CAREGIVER ROLE	Sole caregiver   Lives with loved one   30+ hours of care per week
EMPLOYMENT	Full-time   In-office   Flexible schedule
MARITAL/HOME STATUS	Married with three children
OFFERINGS USED	Home health aide/nurse

## Angela's Story

Angela often feels as if she has four full-time jobs. She wishes she could share her caregiver role with her siblings. She cannot afford to honor her mother's wishes to be placed in a senior assisted community. Instead, Angela moved her mother into her home to live with her family. Angela is transforming her home by installing rails and ramps to accommodate her mother's mobility issues.

*“She's no longer self-sufficient financially. She's your dependent. She doesn't qualify for any of this. In our culture, talking about money and talking about planning...oh, gosh, you never ask your parents that. You just didn't talk about that because it was understood that we would take care of them. That's how it is in our culture.”*

## Her Wishes

- More caregiving support from her siblings
- Stipends or compensation for caregiving expenses such as home modifications
- Financial advice to help with planning for her mother's future

# Meet David



*“It started after dad died...She had a pacemaker put in, she has fibromyalgia, it's not like that gets any better, so I check-in [on her] a couple times a week, making sure she has milk, or that there is food in the fridge.”*

AGE	59
CARES FOR	88 y/o recently widowed mother who lives on her own
CAREGIVER ROLE	Shared caregiver   visits loved one   15 hours of care per week
EMPLOYMENT	Full-time   Hybrid   Semi-flexible schedule
MARITAL/HOME STATUS	Lives with partner and two dogs
OFFERINGS USED	Meals on Wheels

## David's Story

David worries about his mother's future well-being. He wishes he was more prepared for his role as a caregiver. David's aging mother relies on him and his brother to take her to doctor visits or prepare her meals. David struggles to find time for himself and his partner. Instead of going on vacation, David is saving up his time off and money for caregiving expenses. He is eager to use caregiving services to make things easier but has limited knowledge of what is available or how to get them.

## His Wishes

- Access to caregiver training
- Additional paid time off from work to allow for caregiving
- Employee Assistance Program (EAP)

# KEY TAKEAWAYS

# Key Takeaways

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- Caregivers are a diverse group; however, the challenges they face when caring for their loved ones often unite them—the worry, physical exhaustion, emotional toll, stress, mental health issues, fear of unknown, and difficulty with time management top the list.
- Many caregivers are unprepared for their role and seek support to aid them in providing care to loved ones. A caregiving counselor or Care Manager and caregiver training top the list of most-valued services.
- Caregivers would also welcome additional support for their loved ones via home health aides, food delivery services, therapists, transportation, or Care Managers.
- Health insurers and employers are well-positioned to provide much-needed assistance. When considering caregiver training, services, and benefits, it may be helpful to use a “relationship lens” to ensure content is tailored appropriately for those caring for parents, children with special needs, and other family members.

# Thank you!

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For more information, please contact:

Leanne Benvignati, Vice President,  
Zeldis Research Associates  
**[Leanne@ZeldisResearch.com](mailto:Leanne@ZeldisResearch.com)**