



Helping the Helpers:

A look at caregivers and how we can better serve them

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The *Importance* of this Research



"In 2020, 48 million Americans provided unpaid care to an adult over the age of 18."

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

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

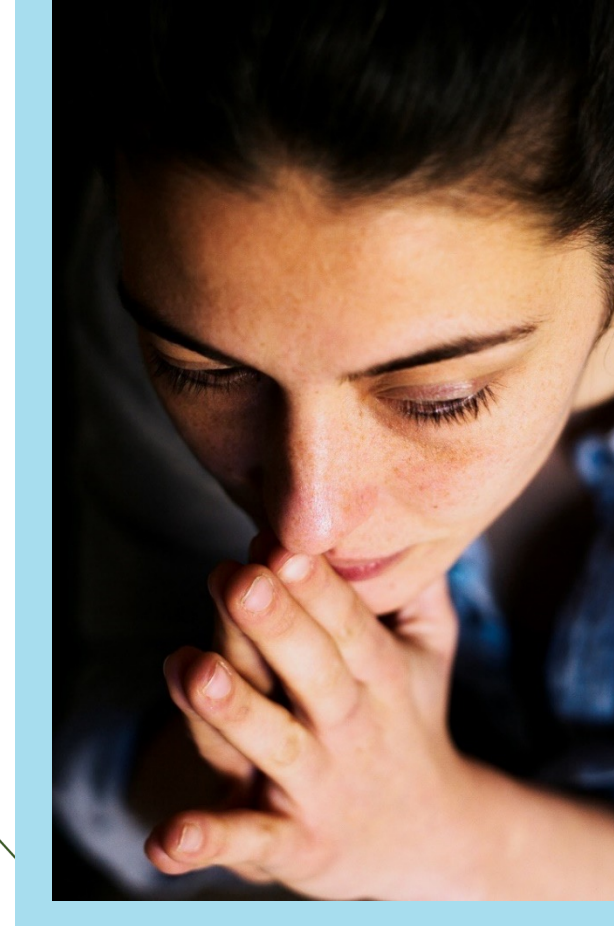
(Source: AARP: Caregiving in the United States 2020)

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

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

"40.7% of caregivers report having two or more chronic diseases."

(Source: CDC: Caregiving for Family and Friends – A Public Health Issue)



About *This Study*



Our study examines the impacts, challenges, and needs of caregivers. We seek to understand what kind of support caregivers need, as they care for their loved ones.



Background

There are about 50 million unpaid caregivers in the U.S. They are faced with daily challenges while trying to balance their lives with the demanding responsibility of caregiving.

This research tries to uncover:

- ✓ Caregiving impacts and challenges
- ✓ Support gaps suitable to be addressed by insurance companies and employers

Methodology & Timing

Twelve, 60-minute in-depth interviews were conducted with caregivers who provide care for a loved one (adult or child with special needs).

Criteria:

- ✓ Caregivers providing care for 3 months or more
- ✓ Loved one does not currently live in a long-term care facility.

Field Period

June 30th – July 7th

Qualitative Limitations

As with all qualitative research the following insights to be considered directional and interpreted with caution

Meet the *caregivers...*



Our 12
caregivers
include...



1

Full-time caregivers living with
a child with special-needs



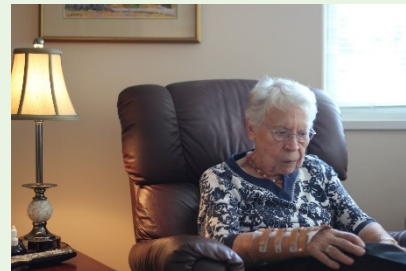
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Full-time caregivers living with
an adult (child, parent(s) or
significant other)



3

Part- and full- time caregivers
caring for an adult living in
their own home



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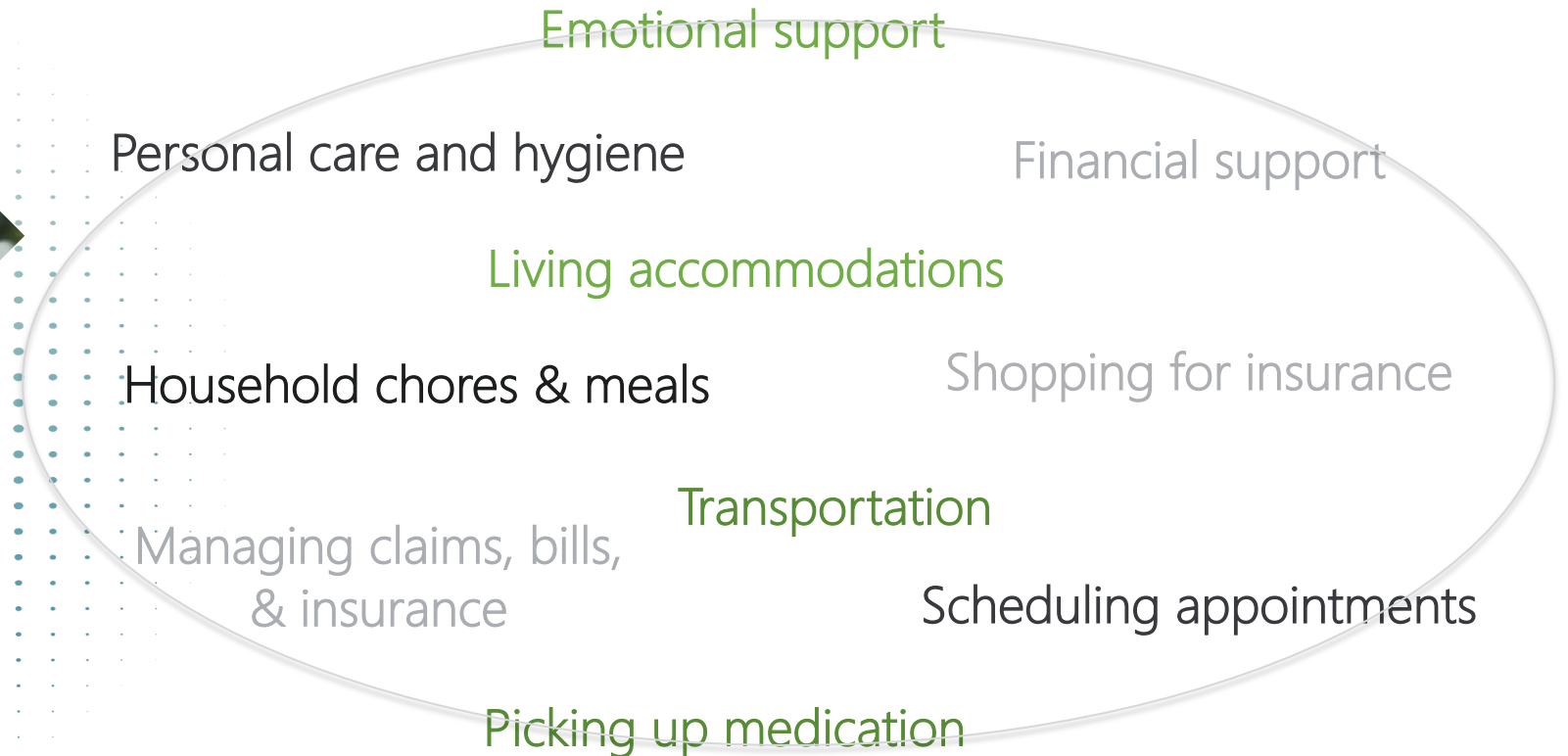
It's a full time job. So, I feel like it's like I work at [the university], but [caregiving] is like a 40-hour work week type thing. Like it never stops. It's always something else. So, it's like living a second life. (Full-time caregiver for parent)

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Caregivers provide all kinds of *support*....



...that impact all facets of daily living



“ 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.

Part-time caregiver for a parent

Caregivers often feel *unprepared for their role*



'What do I wish I knew before becoming a caregiver?'

The impact of caring for a loved one

I wish I'd known about *the stress and everything you had to go through* when you did it. – Full-time caregiver of parent

She's very, very stubborn. She does not want to go into any kind of assisted living. *I'm not equipped to take care of her*, my brother's not equipped to take care of her. – Full-time caregiver of parent

An understanding of parent's finances

I wish I had been more inquisitive about my parent's financial situation. 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. – Full-time caregiver of parent

Parents' medical and long-term care plans

I would have talked to my mom about what her health insurance was going to look like when she retired...A lot of her decisions were made by herself and she didn't share them with us. *"Do you have a plan for your own long-term care? What do you want to see for your own health? Who do you want to take care of you?"* Those questions were never asked and it fell on me. – Full-time caregiver of parent

Resources available to help

I wish I knew the ability to get help from outside, whether it's governmental or non-profits because both my mom and my daughter, you go for so many years and *you find out, "Oh, you could have had that? Gee, that would have helped."* I think that's the big thing is people don't know - have enough knowledge of the resources that are out there. – Full-time caregiver of adult child

Impacts of Caregiving



Impact of Caregiving on Relationships



The impact of caregiving on relationships can be stressful and destructive, and lead to isolation.



Relationship with *Loved One*

- Strained at times
- A sense of obligation
- Difficult to maintain patience
- Feelings of frustration can lead to guilt

Relationship with *Family Members*

- Marital relations are impacted
- Resentment towards siblings not providing care
- Worry about impact on children when grandparents live in-home

Relationship with *Friends*

- Critically important
- May be difficult to maintain
- Finding time can be a factor

“ I think we have a stronger relationship, but it's frustrating at times. It's almost like she's a child. So, she's an adult, but she has childlike issues. – Full-time caregiver of parent

I have an older sister that lives [far away], that does not take part in any of this decision making and any of the care because she lives [there]. So, everything is like I'm just telling her what happens or my mom is telling her. It would be very helpful if I had someone to share that responsibility with. – Full-time caregiver of parent

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“

Caregiving is stressful and involves a lot of trial-and-error to figure out what works. There is an emotional toll, financial toll, and it put a strain on my relationship with my husband which led us to divorce.

Full-time caregiver for an adult child

”

Impact of Caregiving on Caregiver Health



Caregiving can be physically and emotionally draining

Physical health

- Lack of sleep
- Brain fog
- Importance of self-care, but may be difficult to achieve

Emotional/mental health

- Stress
- Anxiety/worry
- Feel trapped
- May feel inadequate



“

[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. – Full-time caregiver of partner

It's very stressful and I have really bad anxiety sometimes. I talk to my primary doctor and he prescribes Xanax. – Full-time caregiver for an adult child

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. – Full-time caregiver for an adult child

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Impact of Caregiving on *Work and Finances*



“
I had to stop working outside and start doing stuff at home so I could stay there with him all the time. – Full-time caregiver for partner
”

Employment

The majority of the caregivers interviewed have a remote job, their own business, or an office job with considerable flexibility



Finances

Most feel their finances are strained, and caregiving needs take precedent over other needs

“
We like to go, do, see, that type of stuff and sometimes I have to make an economic choice – mom needs this, that means I don't have money to do this.
– Part-time caregiver for parent
”

Work-Life Balance

Caregivers try to balance the strenuous demands of caregiving with their jobs, and while they often have a system, it still poses challenges

“
I work from home and then when the kids get home from school they will stay with mom so I can go into the office. – Full-time caregiver for a parent
”

Financial Support

Some say they receive financial support from family members/ exes, or organizations that help pay for groceries, medical visits or prescriptions.

“
I use the child support for all of that. If I need extra, I will tell him...He doesn't fight me on that one, which is a blessing, but I also have to be very mindful. – Full-time caregiver for a child
”

Impacts of caregiving on *the home*



Caregivers take the necessary steps to keep their loved ones safe in their homes.

Installations

- Handrails
- Shower benches
- Special toilet seats
- Ramps
- Security cameras
- ‘Babyproofing’ the kitchen

Remodeling

- Furniture rearrangements
- Living room to bedroom conversions
- Door removals

“

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. – Full-time caregiver for a parent

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Additional caregiving challenges



Lack knowledge of loved ones' conditions and how to care for them

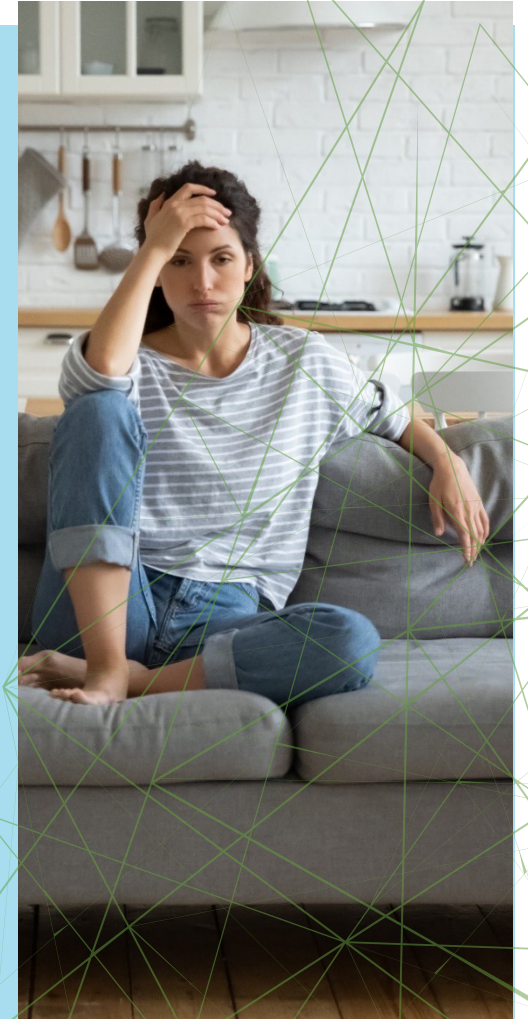
- Caring for loved ones with conditions they know nothing about
- Need to handle unforeseen symptoms by trial and error

“ I never heard about neuro-divergence, and I find it hard to explain to others what she has. – Full-time caregiver for an adult child ”

Securing outside help or long-term care

- Limited access to respite care
- Limited access to long-term care or memory care facilities
- No long-term care insurance
- High out-of-pocket costs for insurance

“ That other part of the driving decision of moving her into a facility is that 'Where are we going to get the money?' I mean, one of us is likely going to have to either dip heavily into our savings or take a loan against our retirement or something to kickstart that plan.– Part-time caregiver for a parent ”



Caregiver Resources and Support Needs



Caregiver *Training and Preparedness*



Current State

Caregivers use the Internet, caregiver forums on social media, and doctors to obtain information on caring for their loved ones, but there is a great deal more that would benefit them.

What caregivers need:

- A caregiver coach or care manager
- A caregiver hotline
- Time management strategies
- ‘How to’ strategies to help manage: time, other relationships, specific conditions, self-care
- Financial planning support
- Lists of resources available for caregivers and loved ones

“

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, and I would be very open because I need to know how to do it right the first time. That would be fantastic. In Noom, there's nutritional coach, why not a caregiving coach? - Full-time caregiver for a parent

I wish my dad had been a little bit better in terms of financially planning. Mom is pretty much living on her social security and dad's death benefits and any money that my dad had saved through the 401(k). He didn't have a pension for work and the 401(k) that he saved, is just about gone. - Full-time caregiver for a parent

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Mental health support



Current State

Whether it is personal (friends/family, social media groups) or professional (doctor, therapist), all caregivers seek out mental health support to cope and deal with stressors caused by caregiving.

What caregivers need:

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

“

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..— Full-time caregiver for a child

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“ 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 in 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. ”

Part-time caregiver for a parent

Community forum resources



Current State

Interest in support groups is mixed – some feel they are valuable while others think they are another ‘to-do’ in their already busy schedule.

What caregivers need:

- Virtual support groups
- Success stories
- To feel they are not alone
- Advice and tips for caregiving
- Access to professionals via support groups

“

The online forums offer 'solidarity' and people are generous with their stories and their time. – Full-time caregiver for a parent

.....
My fear is that I will sign on to some sort of forum and start reading doom and gloom stories and then I'll go someplace dark, I don't want to do that. So, I think that would not be a benefit to me. – Full-time caregiver for a parent

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Technology resources



Current State

Several caregivers use technology to help them in their role as a caregiver, but additional resources would be valuable.

What caregivers need:

- Mobile app related to caregiving
- Caregiver portal
- User-friendly shared calendars
- Emails or texts related to caregiving
- Social media support groups

“

Aside from every once in a while, being able to have a doctor's visit through Zoom.I'm not on any apps at the moment...Do you know of one?
- Full-time caregiver of adult

I think they should send more emails or text messages, anything on caregiving entities. A lot of information like help you, self-help, I think that would be wonderful if they could send that out for insurances because I had to look a lot of it up. Full-time caregiver for spouse

”



Support from *health insurers*



Current State

Caregivers expect more support from health insurers for themselves and their loved ones. Some say their loved ones have a care manager, but not all. Many pay-of-pocket for services their loved ones require.

What caregivers need:

- Information on specific diseases
- Simpler eligibility for necessary services
- A caregiver portal / mobile app
- A caregiver hotline
- Respite care
- Proactive assisted living planning services
- Care Manager for caregiver and loved one
- Care facility support/placement assistance
- Access to mental health professionals
- Notification of changes to loved one's health plan



I also love 5-, 10-minute, 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. - Full-time caregiver for a parent

Have a hotline for caregivers to disseminate information especially about a disease, to have an advocate who can help them and a care manager just for them because most of the time, it's the caregivers that are doing all the work for the patient. - Full-time caregiver for an adult child



“We've tried to get palliative care for her. We've tried to get some home health care, 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.

”

Part-time caregiver for a parent

Support from *employers*



Current State

Caregivers who are currently employed do not receive support from their employers beyond a flexible schedule or remote work options. While very few expect their employer to provide additional support, there are opportunities to help meet their needs.

What caregivers need:

- Benefits specific to caregivers
- Access to mental health therapy
- Caregiver contribution matching
- Ability to set own schedule
- Paid (or unpaid) time off for caregiving
- Financial planning support

“ It would be nice if I had some kind of fund or something to be able to dip into to help... Maybe it might be some kind of a matching thing. I put in \$500.00 a year and then my employer might match \$500.00 a year for care expenses for someone who I provide care for. – Part-time caregiver for a parent

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. – Full-time caregiver of parent





Thank you!

For more information, please contact:

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