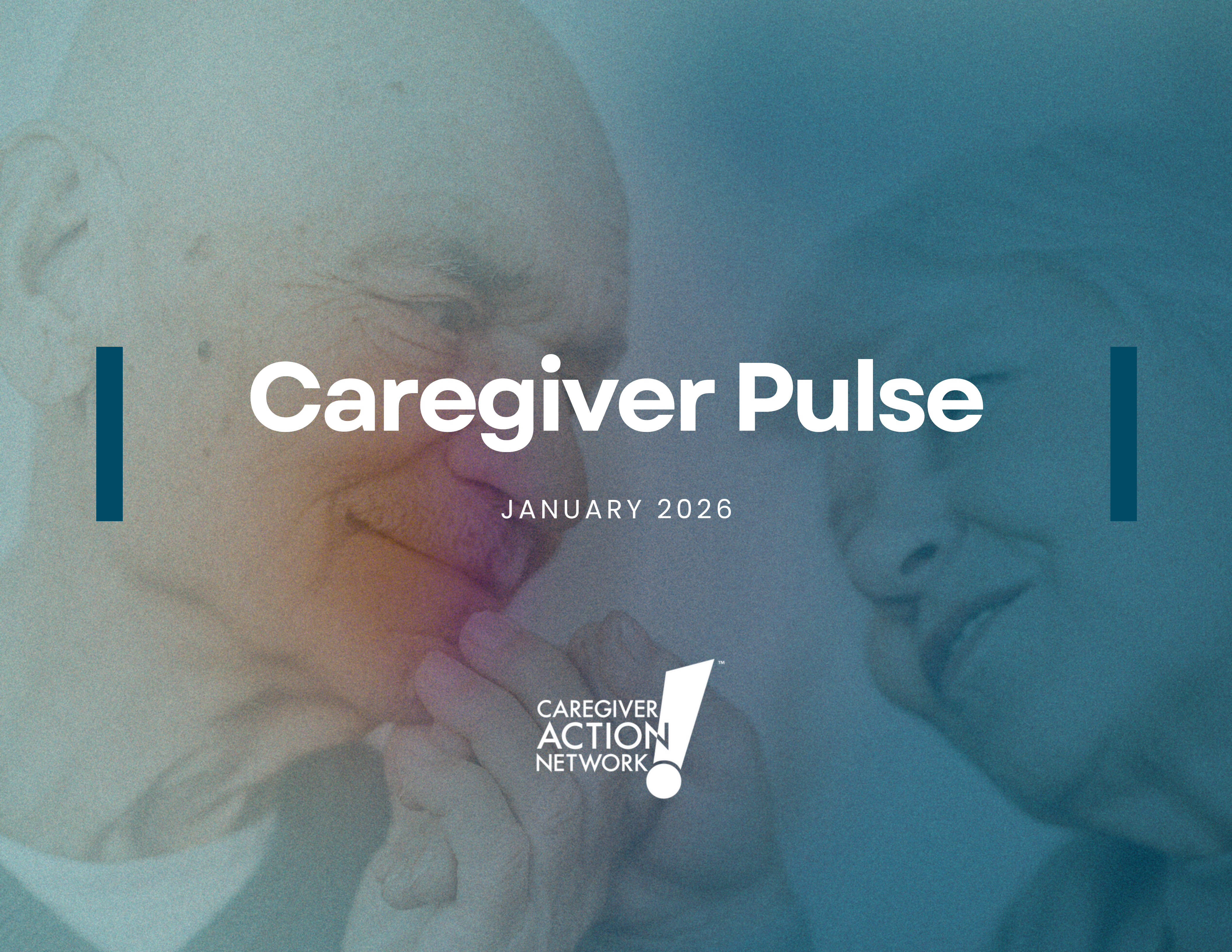


Caregiver Pulse

JANUARY 2026

CAREGIVER ACTION NETWORK

Caregiver Pulse

Imagine having a direct line to the hearts and minds of family caregivers nationwide. That's exactly what CAN has created through its communication channels, where caregivers can share their daily struggles, hopes, and needs.

Caregiver Pulse from Caregiver Action Network serves as a vital bridge between caregivers and those who support them. The Caregiver Pulse initiative seeks and amplifies caregivers' voices, offering insights into their experiences, helping CAN and our partners develop more meaningful, targeted support for these everyday heroes.

CAN's corporate partners will have exclusive early access to each issue of Caregiver Pulse before it is released to non-profit partners, Capitol Hill, and the general caregiver community.

Information for Caregiver Pulse comes from:

- Data from the Caregiver Help Desk. Why caregivers reach out, what disease or conditions are involved, and what concerns they have.
- Social Media Prompts. Open-ended prompts posted on Meta each week allow caregivers to share on the post topic.
- Caregiver Roundtables. Gatherings for caregivers of loved ones with a particular disease or condition.
- Input from the Caregiver Insights Panel. A group of 600+ caregiver grass tops, who have volunteered to share their stories, perspectives, and expertise with a range of audiences, including Congress, the media, and CAN directly as we launch new programming and tailor caregiver messaging.
- Topics requested by Employee Resource Groups that would be helpful to their staff, and the subsequent themes that come up in those conversations and presentations.
- Surveys sent to our caregiver network.

National Caregiver Help Desk

Personalized Guidance from Caregiving Experts

Available Monday-Friday, 8 am – 7 pm ET, Care Advocates are available for personalized support, guidance, and assistance via phone or online chat.

Expert-Led Virtual Fireside Chats

These 30-minute virtual fireside chats address the complex and often difficult topics encountered by caregivers.

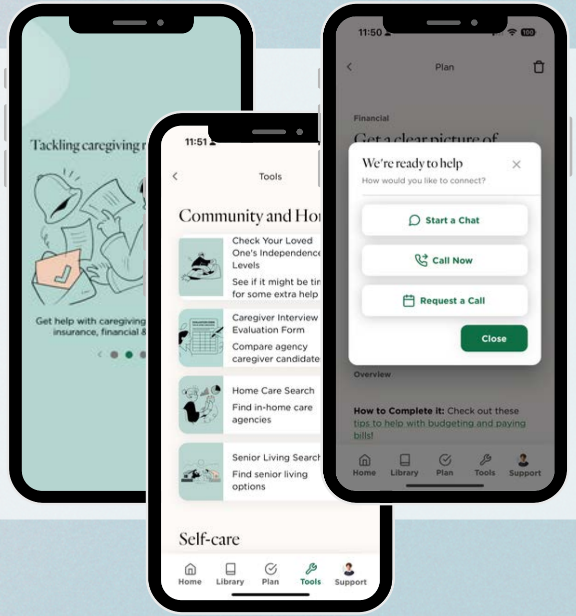
Community With Other Caregivers

Carallel's Support Groups give caregivers a place to ask questions, feel understood, and build confidence in their caregiving journey. Caregivers can sign up for a Support Group on the Help Desk online.

24/7 Access to Hundreds of Helpful Resources on the Help Desk App

The National Caregiver Help Desk App, powered by Carallel, is full of bite-sized resources crafted to help caregivers build skills, validate what they're feeling, and get stuff done.

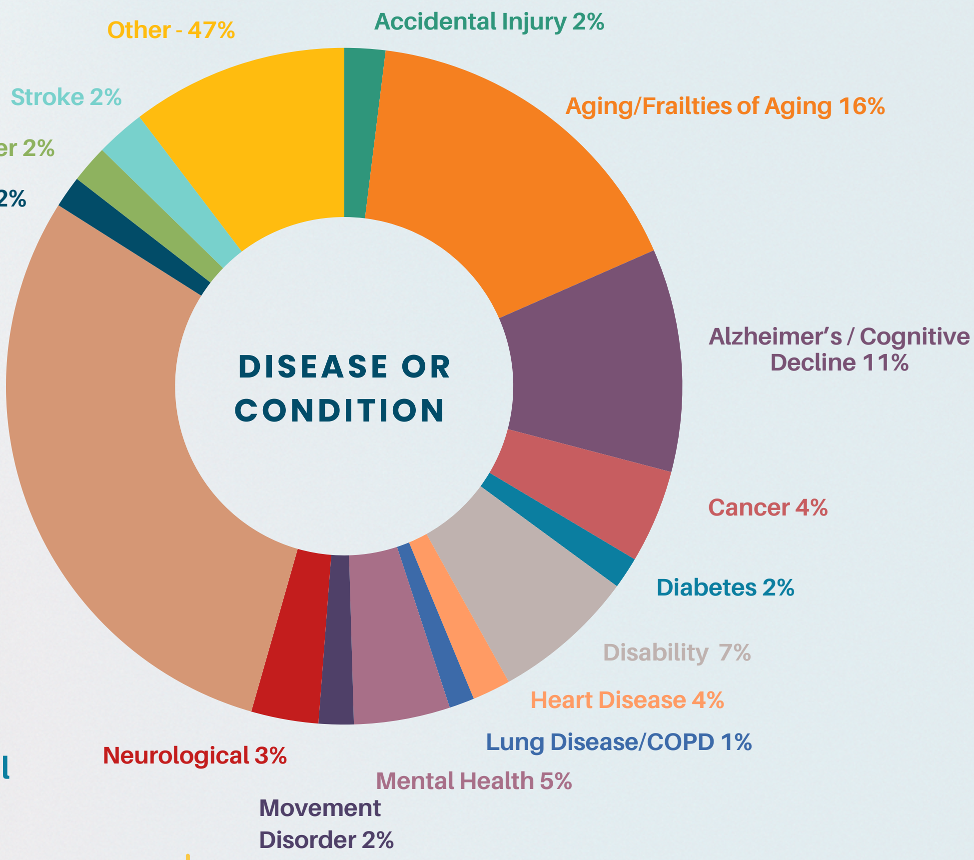
Carallel™
You care, we help.



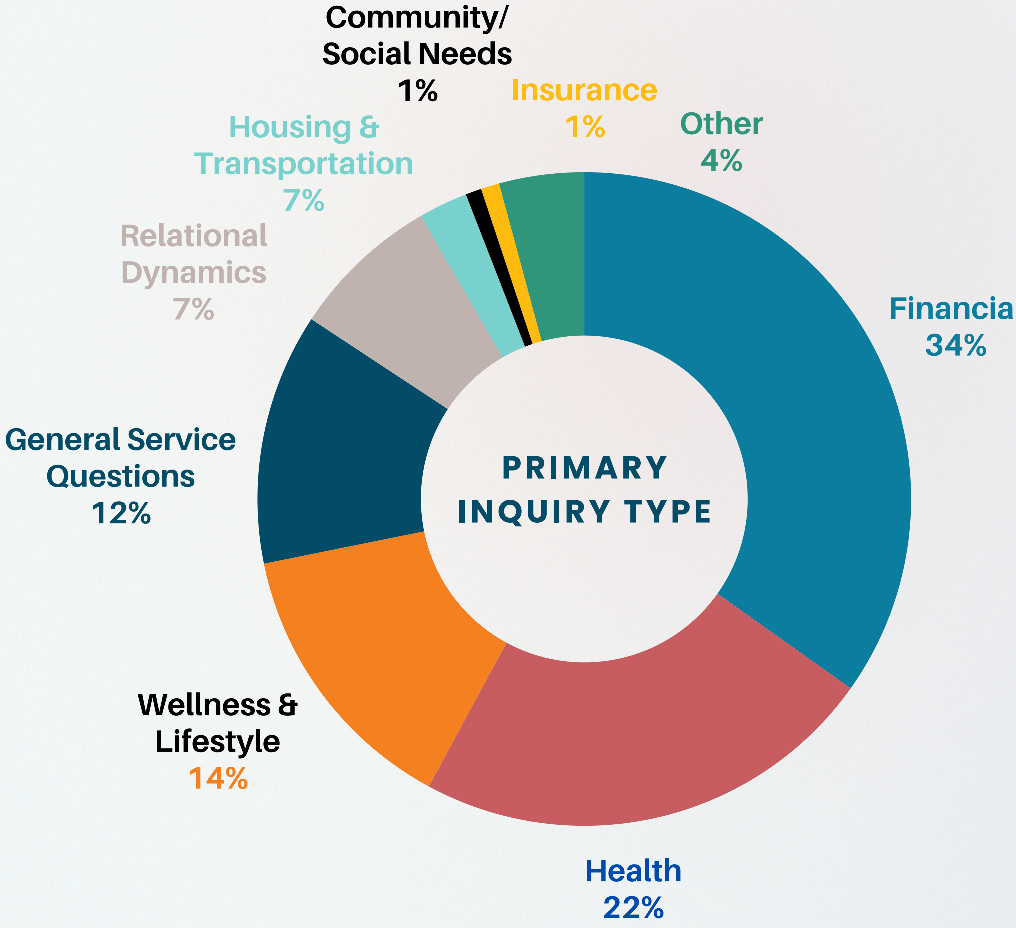
How to Complete it: Check out these tips to help with budgeting and paying bills!

National Caregiver Help Desk

JANUARY - OCTOBER 2025

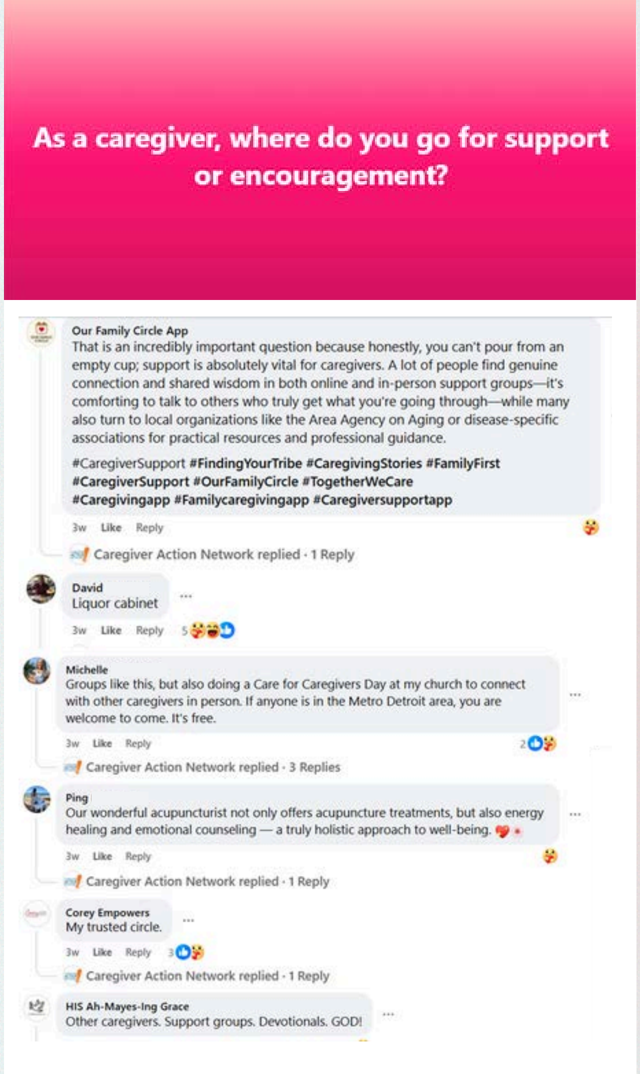


"**Other**" includes diseases or conditions such as: arthritis, autoimmune disorders, genetic disorders, infectious disease, sickle cell disease, terminal illness, and urinary/kidney disease.



Caregiver Pulse Prompts

A SELECTION OF POSTS FROM
CAN'S FACEBOOK PAGE
SEPTEMBER- OCTOBER 2025



As a caregiver, where do you go for support or encouragement?

Our Family Circle App
That is an incredibly important question because honestly, you can't pour from an empty cup; support is absolutely vital for caregivers. A lot of people find genuine connection and shared wisdom in both online and in-person support groups—it's comforting to talk to others who truly get what you're going through—while many also turn to local organizations like the Area Agency on Aging or disease-specific associations for practical resources and professional guidance.

#CaregiverSupport **#FindingYourTribe #CaregivingStories #FamilyFirst #CaregiverSupport #OurFamilyCircle #TogetherWeCare #Caregivingapp #Familycaregivingapp #Caregiversupportapp**

3w Like Reply

Caregiver Action Network replied · 1 Reply

David
Liquor cabinet

3w Like Reply 5

Michelle
Groups like this, but also doing a Care for Caregivers Day at my church to connect with other caregivers in person. If anyone is in the Metro Detroit area, you are welcome to come. It's free.

3w Like Reply 2

Caregiver Action Network replied · 3 Replies

Ping
Our wonderful acupuncturist not only offers acupuncture treatments, but also energy healing and emotional counseling — a truly holistic approach to well-being. ❤️

3w Like Reply

Caregiver Action Network replied · 1 Reply

Corey Empowers
My trusted circle.

3w Like Reply 3

Caregiver Action Network replied · 1 Reply

HIS Ah-Mayes-Ing Grace
Other caregivers. Support groups. Devotionals. GOD!

What's something caregiving has taught you about yourself?

Klaren
It is a "journey" (hate that term) of self-questioning. Did I do this right? Should I have done this? Is this person comfortable or just saying everything is alright? We should not have gone on that outing today. I need to keep down my anxiety so as to not make them anxious... For me it is the hardest thing in the world, but strangely, the most rewarding. Doing your very best to make someone's life a little better.

6w Like Reply 2

Caregiver Action Network replied · 1 Reply

Kristina
I have a hard time offering grace to people who refuse to understand. I don't care how "differently" you would do it. You aren't doing it; I am. Stop talking and get to walking.

6w Like Reply 4

Caregiver Action Network replied · 1 Reply

LaDonne
That i'm capable of caring for someone that once cared for me

6w Like Reply 3

Caregiver Action Network replied · 1 Reply

Dana
I can do hard things and learn tons from Youtube...

Danielle
That I need to give care to myself alongside providing care for others. ❤️

6w Like Reply 5

Caregiver Action Network replied · 1 Reply

Terry
I'm tougher than I thought I was. It took time, but by stepping away when I need to, I can offer the best of myself to the stranger who used to my mother.

6w Like Reply 2

Caregiver Action Network replied · 1 Reply

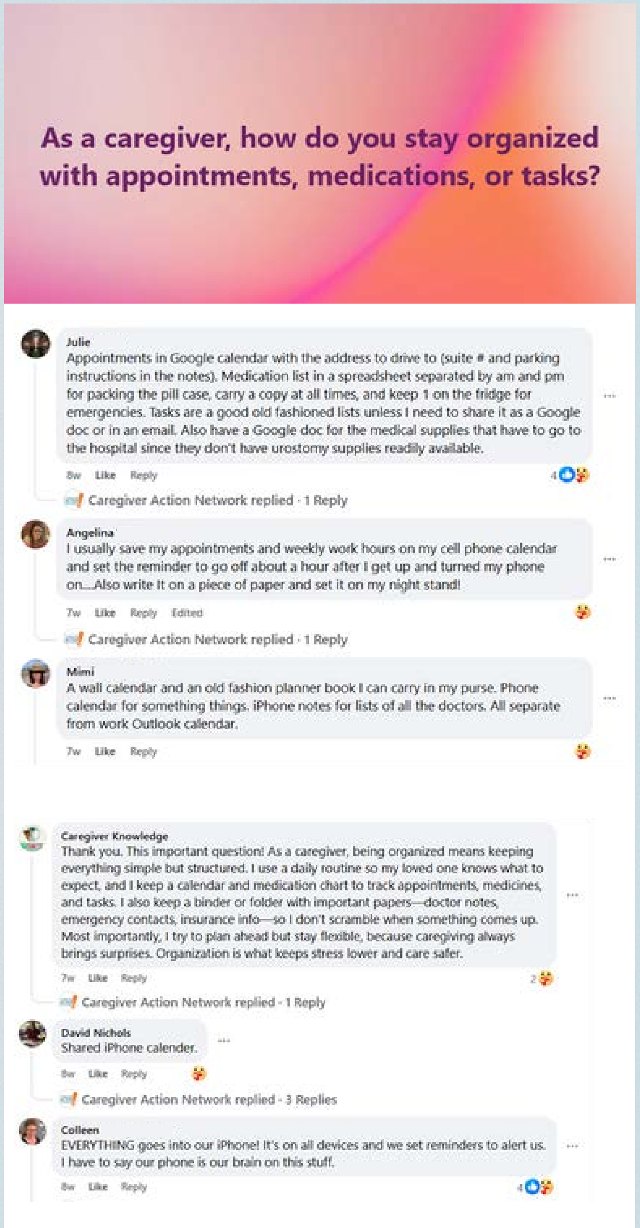
SMP Home Care, LLC · Follow
That all any of us need is love understanding and patience. Being a caregiver is like the serenity prayer. I've learned that patience and compassion are just as important as love - it's amazing how caregiving can teach us about ourselves and our capacity for kindness

4w Like Reply

Caregiver Action Network replied · 1 Reply

Navigating Alzheimer's
In the beginning, I didn't know what I didn't know. Caregiving taught me that I could do hard things, and it drove home the fact that God is faithful with "new mercies" every morning. ❤️🙏💪

6w Like Reply 2



As a caregiver, how do you stay organized with appointments, medications, or tasks?

Julie
Appointments in Google calendar with the address to drive to (suite # and parking instructions in the notes). Medication list in a spreadsheet separated by am and pm for packing the pill case, carry a copy at all times, and keep 1 on the fridge for emergencies. Tasks are a good old fashioned lists unless I need to share it as a Google doc or in an email. Also have a Google doc for the medical supplies that have to go to the hospital since they don't have urostomy supplies readily available.

8w Like Reply 4

Caregiver Action Network replied · 1 Reply

Angelina
I usually save my appointments and weekly work hours on my cell phone calendar and set the reminder to go off about a hour after I get up and turned my phone on....Also write It on a piece of paper and set it on my night stand!

7w Like Reply Edited

Caregiver Action Network replied · 1 Reply

Mimi
A wall calendar and an old fashion planner book I can carry in my purse. Phone calendar for something things. iPhone notes for lists of all the doctors. All separate from work Outlook calendar.

7w Like Reply

Caregiver Knowledge
Thank you. This important question! As a caregiver, being organized means keeping everything simple but structured. I use a daily routine so my loved one knows what to expect, and I keep a calendar and medication chart to track appointments, medicines, and tasks. I also keep a binder or folder with important papers—doctor notes, emergency contacts, insurance info—so I don't scramble when something comes up. Most importantly, I try to plan ahead but stay flexible, because caregiving always brings surprises. Organization is what keeps stress lower and care safer.

7w Like Reply 2

Caregiver Action Network replied · 1 Reply

David Nichols
Shared iPhone calender.

8w Like Reply

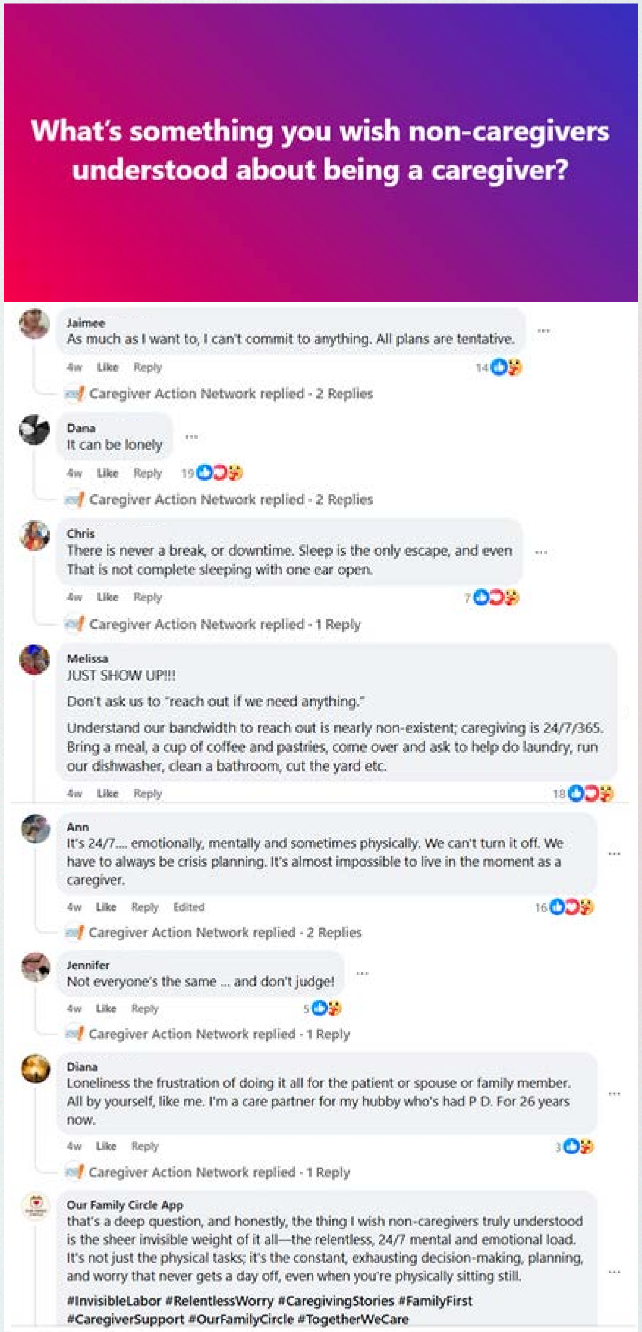
Caregiver Action Network replied · 3 Replies

Colleen
EVERYTHING goes into our iPhone! It's on all devices and we set reminders to alert us. I have to say our phone is our brain on this stuff.

8w Like Reply 4

Caregiver Pulse Prompts

A SELECTION OF POSTS FROM
CAN'S FACEBOOK PAGE
SEPTEMBER- OCTOBER 2025



What's something you wish non-caregivers understood about being a caregiver?

Jaimee
As much as I want to, I can't commit to anything. All plans are tentative.
4w Like Reply 14
Caregiver Action Network replied · 2 Replies

Dana
It can be lonely
4w Like Reply 19
Caregiver Action Network replied · 2 Replies

Chris
There is never a break, or downtime. Sleep is the only escape, and even That is not complete sleeping with one ear open.
4w Like Reply 7
Caregiver Action Network replied · 1 Reply

Melissa
JUST SHOW UP!!!

Don't ask us to "reach out if we need anything."

Understand our bandwidth to reach out is nearly non-existent; caregiving is 24/7/365. Bring a meal, a cup of coffee and pastries, come over and ask to help do laundry, run our dishwasher, clean a bathroom, cut the yard etc.
4w Like Reply 18

Ann
It's 24/7.... emotionally, mentally and sometimes physically. We can't turn it off. We have to always be crisis planning. It's almost impossible to live in the moment as a caregiver.
4w Like Reply Edited 16
Caregiver Action Network replied · 2 Replies

Jennifer
Not everyone's the same ... and don't judge!
4w Like Reply 5
Caregiver Action Network replied · 1 Reply

Diana
Loneliness the frustration of doing it all for the patient or spouse or family member. All by yourself, like me. I'm a care partner for my hubby who's had P D. For 26 years now.
4w Like Reply 3
Caregiver Action Network replied · 1 Reply

Our Family Circle App
that's a deep question, and honestly, the thing I wish non-caregivers truly understood is the sheer invisible weight of it all—the relentless, 24/7 mental and emotional load. It's not just the physical tasks; it's the constant, exhausting decision-making, planning, and worry that never gets a day off, even when you're physically sitting still.

#InvisibleLabor #RelentlessWorry #CaregivingStories #FamilyFirst #CaregiverSupport #OurFamilyCircle #TogetherWeCare

Responses to our Caregiver Pulse Prompts reveal caregiving as an **all-consuming role—emotionally, mentally, and logistically demanding.** Caregivers rely heavily on connection and organization to get through each day, seeking encouragement from those who understand while building systems to manage constant responsibilities and uncertainty.

Despite the isolation and exhaustion, many describe profound personal growth, resilience, and meaning—highlighting both the **high cost and quiet strength of caregiving.**

Family caregivers make exceptional employees, bringing adaptability, empathy, accountability, and real-world problem-solving skills that strengthen teams and organizations. Navigating constant change and high-stress situations builds resilience, while balancing work and caregiving **sharpens time management, prioritization, and critical thinking.**

Caregiving also deepens **emotional intelligence and communication**—qualities that enhance teamwork, leadership, customer relationships, and workplace culture. Purpose-driven and dependable, caregivers often show **strong loyalty and engagement when supported by flexible, understanding employers.**

CAN invites employers to become a **Caregiver-Ready Workplace** through a new national program offering scalable, expert-informed tools, training, and recognition. A Caregiver-Ready Workplace acknowledges, supports, and actively uplifts employees balancing professional responsibilities with caregiving at home.

Caregiver Community Event

This in-person event from Duke Health featured concurrent education sessions and a special track of educational sessions for professionals, designed to inform attendees about a variety of support options that can assist in the caregiving journey.

SEPTEMBER 9-10, 2025
DURHAM, NC

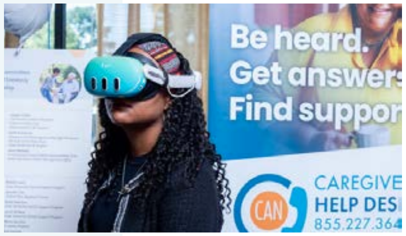
EVENT ATTENDEES:
1,000+ FAMILY CAREGIVERS
200 HEALTHCARE PROFESSIONALS

This year, CAN joined forces with Duke Health and Embodied Labs for this event that brought caregivers together. Through Embodied Labs' cutting-edge virtual reality platform, caregivers **stepped into their loved ones' shoes**—literally experiencing the world through their eyes. The event drew **more than 1,000 family caregivers and 200 healthcare professionals from 11 states,** including many from North Carolina's rural communities—significant, considering that after Texas, North Carolina has the highest percentage of rural residents in the nation.

In small towns and remote communities, **family caregivers aren't just helping out—they're holding up the entire healthcare system.** When the nearest specialist is hours away and broadband is limited, caregivers become the lifeline, managing complex medications, coordinating distant appointments, and filling gaps that geography creates. **Events like this one validate the essential, often invisible work that caregivers do every single day.**

Event Participation Takeaways

- **Caregivers are looking for resources/support that meet them where they are.** Local help that can get to them--with how time-consuming caregiving is sometimes, they need the help to come to them.
- **Caregivers are excited to see more organizations making time for them.** Many of them expressed that they feel alone/lost, so this event was a breath of fresh air for a lot of them. Participants hope that other organizations will hold community events like this that show caregivers that they are being heard.
- This event showed that **caregivers come from all walks of life**, from accountants to retail workers, caregivers are everywhere, and no matter their confidence level, sometimes everyone needs a little extra bit of help.



National Alzheimer's Caregiving Education Initiative

In 2025, Caregiver Action Network (CAN), supported by Lundbeck and Otsuka, launched a comprehensive national education and support effort to help family caregivers navigate neuropsychiatric symptoms (NPS) in Alzheimer's and cognitive decline—including agitation, paranoia, depression, and hallucinations.

By the Numbers

1,900+

caregivers engaged through online courses, webinars, and a summit

1,000+

participants joined live events

75%

of participants were from rural or underserved communities

Diverse Participation • Older adults • LGBTQ+ caregivers • Rural families • Caregivers of color

What Caregivers Told Us

80%	rely on trial and error to manage neuropsychiatric symptoms
41%	need in-home respite or backup care
19%	want mental health and emotional support for themselves

What works best in caregiving

- Music therapy
- Gentle touch
- Structured routines
- Peer learning and community connection

Most Valued Aspect

Hearing from other caregivers who truly understand the experience—repeatedly described as "life-changing".

Caregivers have expressed how invaluable peer connections are. CAN works with several partners to provide opportunities for those connections. Kindly Human provides 24/7 peer support with trained peer listeners who have been through similar caregiving situations.

CAN's National Caregiver Help Desk powered by Carallel offers personalized guidance from caregiving experts, online support groups, monthly virtual caregiver conversations on a variety to topics, and a new Caregiver Help Desk App offering 24/7 access to helpful resources.

National Alzheimer's Caregiving Education Initiative

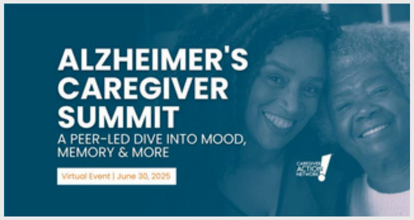
Educational Events & Resources

Navigating Alzheimer’s Course

Practical, non-medication approaches to calm and connect with loved ones

Connecting Through Challenges Webinar

Communication techniques to reduce frustration and strengthen relationships



Alzheimer's Caregiver Summit

Peer-led conversations where diverse caregivers shared real experiences

NPS Roundtable

Gathered qualitative insights on emotional strain and family challenges

From Isolation to Connection: Rural Alzheimer's Care Webinar

Addressed unique challenges facing rural caregivers

National Alzheimer's Caregiving Education Initiative

Key Insights on What Caregivers Need

Real-world strategies that work beyond trial and error

Backup care for breaks and mental health resources

Connection with others who understand the caregiving journey

One key takeaway was simple but powerful: **caregivers need care, too**. Many participants shared how they've started taking **small steps**, such as going for a walk, talking to a therapist, or joining a support group, to protect their own well-being. As one caregiver put it, "I can't pour from an empty cup. Taking care of myself is how I keep showing up for my mom."

Moving Forward Together

Caregiver Action Network will continue to expand education, support, and connection for family caregivers in every community. By listening to caregivers' voices and sharing real-life solutions, CAN aims to ensure that **no one faces the challenges of Alzheimer's care alone**. Because when we support one another—with compassion, understanding, and the right tools—we can transform even the most challenging moments into opportunities for support and connection.

> *"I am a yoga and spin instructor and use MEDS acronym to help me through stressful times. I also give myself grace and only allow myself one catastrophe a day! Humor is also a great release."*
>
> ***Debra A.***

> *"I encourage you all to join a local support group or find an online one. We keep giving out to our loved ones and need a sustainable support system to buffer against all external chaos and internal noise."*
>
> ***Terry B.***

Caring in Isolation: The Realities of Rural Caregiving

In rural America, family caregivers often shoulder heavy responsibilities in environments that lack the infrastructure and support found in urban areas. The population tends to be older, distances are greater, and access to care is limited. For those caring for a loved one with a chronic illness or disability, this isolation and scarcity of resources make caregiving even more demanding.

Limited Providers and Support. A major challenge for rural caregivers is the shortage of formal care providers, including home health aides, respite workers, specialists, and long-term care facilities. Large service areas and low population density make it difficult to build sustainable care networks.

Family caregivers often become the only support available. Appointments may take weeks to schedule, home health visits may be infrequent, and sometimes there are simply no local options. With few chances for respite, caregivers face higher levels of exhaustion, burnout, and stress.

Isolation compounds these burdens. Without nearby peers, support groups, or backup caregivers, many rural caregivers describe feeling "invisible"—doing it all alone, with little recognition or relief.

Webinar: From Isolation to Connection: Rural Alzheimer's Care & Behavioral Support" | Aug. 28, 2025

87.3% of participants reported **experiencing challenges accessing support.**

93.1% of participants reported having **inadequate access**.

CAREGIVER WEBINAR

From Isolation to Connection

Rural Alzheimer's Care & Behavioral Support

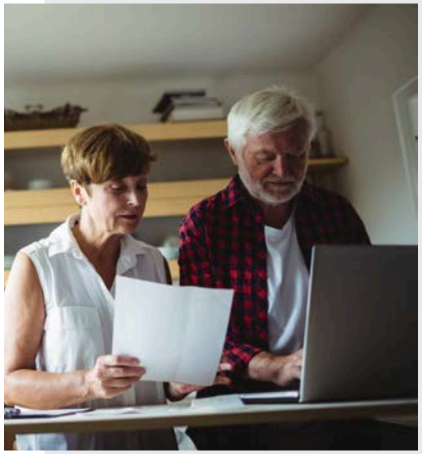
August 28 | 1:00 PM EST

Caring in Isolation: The Realities of Rural Caregiving

Distance and Transportation Burdens

Travel is a defining part of rural caregiving. Specialist appointments, therapy sessions, or even grocery runs often require hours of driving on rural roads, sometimes in challenging weather conditions, and without access to public transportation.

The time, fuel costs, and lost work hours add up. For caregivers, every trip means stress and planning; for loved ones, travel can be physically draining or risky. This constant travel further isolates caregivers, reducing opportunities to rest or connect with others.



Financial and Emotional Strain

Rural caregivers often face greater financial pressure due to out-of-pocket costs, travel expenses, and limited employment flexibility. Many also report higher emotional strain from being disconnected—few support groups, limited mental health resources, and little time for self-care.

The result is a cycle of isolation, with less access to help, fewer chances to recharge, and an ever-growing sense of being alone in their caregiving journey.

Caring in Isolation: The Realities of Rural Caregiving

Policy Threats: Cuts to Medicare and Medicaid

Caregivers in rural areas are navigating policy shifts that threaten to make the landscape even more challenging. Two of the major public “backbones” of health coverage and care support in rural America are Medicaid and Medicare.

Medicaid

Rural communities rely heavily on Medicaid for hospitals, clinics, long-term services, and supports. Cuts or reductions in Medicaid funding have a significant impact on rural hospitals and home- and community-based services.

Recent analysis by the American Hospital Association[1] found that proposed Medicaid cuts could lead to 1.8 million rural individuals losing coverage by 2034, and hundreds of rural providers and hospitals being forced to reduce services or shut down entirely.

For caregivers, these cuts could further the sense of isolation and vulnerability.

For a caregiver, this means that there are fewer local providers, less staff to assist with home care, fewer agencies willing to operate in some regions, and fewer “options” when help is needed.

Medicare

Cuts to Medicare payments are also affecting rural providers, which may result in them offering fewer services or even closing altogether. The underserved rural population is already at higher risk for chronic disease and worse outcomes. Payment reductions in Medicare threaten to widen these gaps. For caregivers, this could mean a loved one’s Medicare-covered services (home health, skilled nursing visits, therapies) may become harder to access locally, or they may face longer travel times or higher out-of-pocket burden.

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[1] *American Hospital Association, Rural Hospitals at Risk: Cuts to Medicaid Would Further Threaten Access (Fact Sheet, June 2025).*

Caring in Isolation: The Realities of Rural Caregiving

The Cumulative Effect
Many rural families live in true **healthcare and support "deserts,"** where providers are scarce, services are spread across long distances, and reliable help is hard to find. For caregivers, this isolation means fewer resources, fewer connections, and greater strain as they try to manage their loved one's needs with limited support.

Rural caregivers often have **multiple roles**: advocate, driver, nurse, scheduler, and emotional anchor. With limited access to services, they must manage care largely on their own. When a hospital closes or a provider leaves, there are few backup options.

This **lack of connection**—to healthcare systems and to peers—creates a form of social isolation that is both emotional and structural. It doesn't just affect morale; it affects health, safety, and the sustainability of care.

Finding Connection and Support

Despite these challenges, rural caregivers can take steps to reduce isolation and strengthen support.

- ✓ **Use telehealth** when possible to minimize travel.
- ✓ **Reach out to Area Agencies on Aging**, rural health clinics, and local faith communities—hidden resources sometimes exist close by.
- ✓ **Join virtual support groups** or online caregiver networks to connect with peers who understand.
- ✓ **Advocate for policy protections** for home- and community-based services in your state.
- ✓ **Make time for self-care**—even short breaks or online peer chats can make a difference.

Caring in Isolation: The Realities of Rural Caregiving

> *“ I’m caring for my mother in rural east Tennessee. Living in a rural community means doing everything myself—driving hours to appointments, juggling work and care, and worrying about what happens when help is too far away. The isolation can be overwhelming, but you keep going because there’s no other choice.”*
>
> ***JoAnn B.***

> *“Caring for my wife in North Dakota means wearing a lot of hats. Help is farther away, appointments take all day to reach, and there’s no backup when I’m exhausted—but I keep going because she’s counting on me.”*
>
> ***Douglas P.***

> *“Out here, getting care isn’t just about making an appointment—it’s about whether there’s a doctor at all, how far you have to drive, and whether I can get time off from work to drive dad to the appointment. The lack of healthcare resources here turns everyday caregiving into a constant balancing act. The information given in this webinar and the ability to talk to other caregivers are invaluable.”*
>
> ***Clara H.***

By the Numbers

63M+

U.S. adults care for a spouse, elderly parent or relative, or special-needs child.

Source: National Alliance for Caregiving and AARP. Caregiving in the U.S. 2025

24%

Roughly one in four American adults is a family caregiver.

Source: National Alliance for Caregiving and AARP. Caregiving in the U.S. 2025

Nearly 12M

Americans provide unpaid care for an individual with Alzheimer's or another form of cognitive decline.

Source: Alzheimer's Association.
Support for People Living with Dementia and Their Caregivers. 2025

19.2B

Hours of unpaid care provided by family caregivers to people with Alzheimer's and other cognitive decline.

Source: Alzheimer's Association. 2025 Alzheimer's Disease Facts and Figures. June 2025

7.2M

Americans age 65 and older living with Alzheimer's dementia in 2025. 74% are age 75 or older.

Source: Alzheimer's Association. 2025 Alzheimer's Disease Facts and Figures. June 2025

$7,200

Average out-of-pocket amount spent on caregiving expenses by a family caregiver, a significant drain on finances.

Source: Alzheimer's Association. 2025 Alzheimer's Disease Facts and Figures. June 2025

67%

Family caregivers who experience difficulty balancing their jobs and caregiving duties.

Source: AARP. AARP Research Insights on Caregiving. March 2025

How You Can Help

You can help Caregiver Action Network support caregivers nationwide in several impactful ways:

Partner with CAN to help expand our ability to support caregivers in our peer-to-peer network, provide education and training around Alzheimer's and cognitive impairment, and broaden our reach in educating people on long-term care financial planning and navigating finances as a caregiver.

www.caregiveraction.org/corporate-partners

Share Your Stories – By participating in surveys or contributing personal experiences, you can help shape the conversation around caregiver needs and challenges.

www.caregiveraction.org/caregiver-story

Engage with the Community– Connecting with other caregivers through CAN's communication channels fosters a sense of support and shared understanding.

www.caregiveraction.org

Advocate for Resources – Caregivers can help CAN and its partners develop more effective programs, policies, and services by voicing their struggles and suggestions.

www.caregiveraction.org/caregiver-advocacy

Spread Awareness – Encouraging fellow caregivers to engage with Caregiver Pulse ensures that more voices are heard, leading to broader, more meaningful change.

www.caregiveraction.org/caregiver-statistics

CAREGIVER ACTION NETWORK

1150 Connecticut Ave NW, Suite 501
Washington, DC 20036
202.454.3970
www.CaregiverAction.org
info@caregiveraction.org