



Caregiver Pulse

MAY 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.

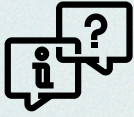
[Caregiver Pulse from Caregiver Action Network](#) serves as a vital bridge between caregivers and those who support them. The Caregiver Pulse initiative seeks and amplifies caregivers' voices, offering insights into their experiences, helping CAN and our partners develop more meaningful, targeted support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

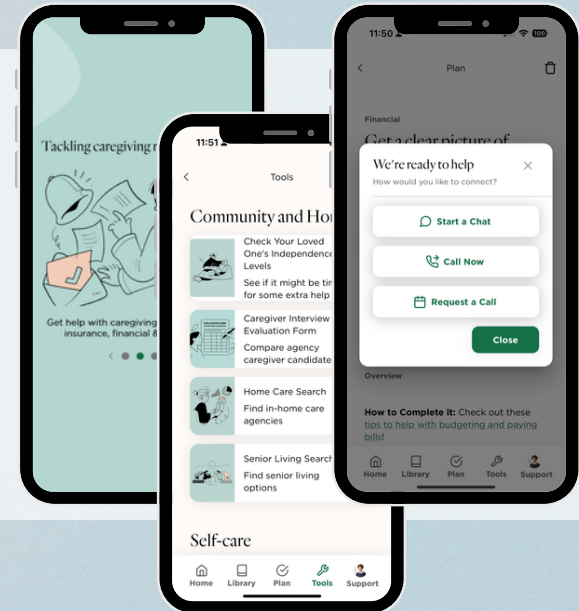


Community With Other Caregivers

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.

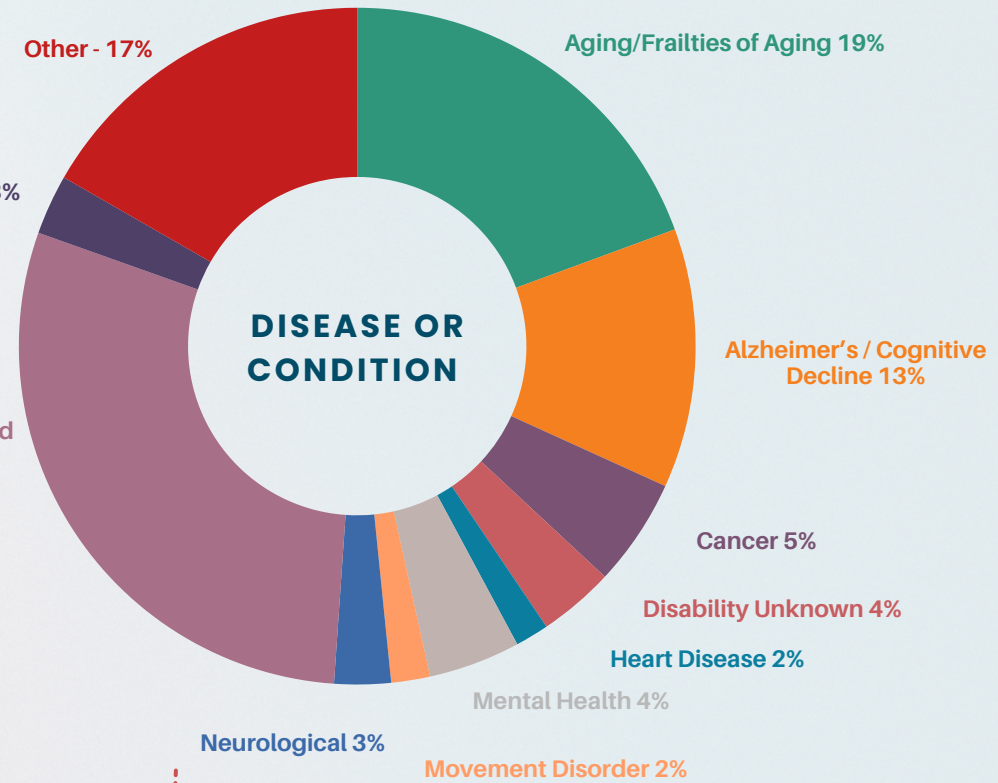
24/7 Access to Hundreds of Helpful Resources on the Help Desk App

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.

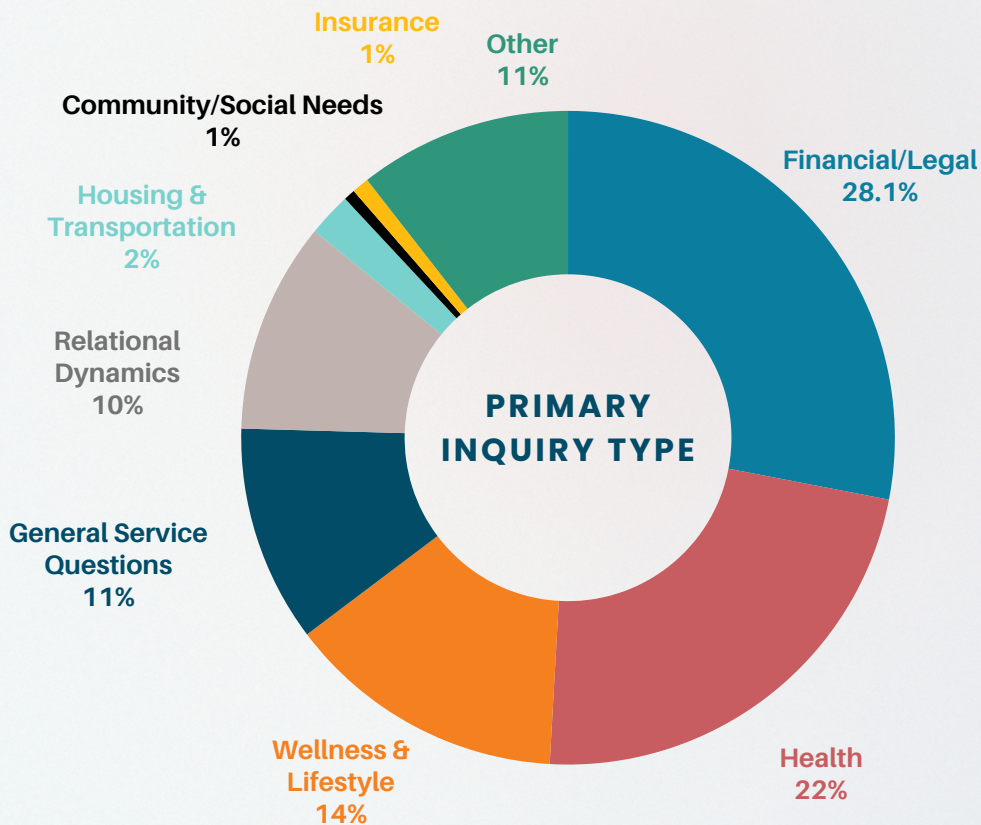


National Caregiver Help Desk

JANUARY - MARCH 2026



"Other" includes diseases or conditions such as arthritis, autoimmune disorders, COPD/lung disease, genetic disorders, infectious disease, substance abuse, terminal illness, traumatic brain injury, and urinary/kidney disease.



Caregiver Pulse Prompts

A SELECTION OF POSTS FROM
CAN'S FACEBOOK PAGE
JANUARY- APRIL 2026

What do you miss most about your life before you became a caregiver? What do you love about life right now?

Dyann Washburn
I miss my old life and freedom to cry when I want. What I love now is the chance to learn and make a difference in my parents' lives, handling everything from their medical appointments to daily care.
4d Like Reply 2 🍌🍌
Caregiver Action Network replied · 1 Reply

Top fan
Phoebe Priddy Hall
I miss the peace that my parents were self-sufficient. I love nurturing our relationship in healthy ways while taking care of myself, too. Learning to pour from full changes everything. 🍌
3d Like Reply Edited 1 🍌
Caregiver Action Network replied · 1 Reply

Shana Sierra
Am I bad for saying 🍌 freedom. And what I love is that it is my husband of 36 years of marriage and his had Parkinson for 27 years now. Not at all easy being a Caregiver Care partner.
4d Like Reply 2 🍌
Caregiver Action Network replied · 2 Replies

Melissa Baker
Freedom to travel and be sociable on my own schedule was a treasure I miss and look forward to some day. I will never regret the love and care I have had the freedom to offer my parents. May the universe allow us all the care we have given others.
4d Like Reply 3 🍌🍌
Caregiver Action Network replied · 1 Reply

Julene Rodriguez
I miss being able to take care of myself and I miss being social like before. I miss my old career but I love my new career. I love the family time and quiet peaceful moments. I actually love that we slowed down.
4d Like Reply 5 🍌🍌
Caregiver Action Network replied · 2 Replies

Karen Clark
I miss having someone to do the driving, decision making and just taking care of things he used to. Having ALL of the responsibility is stressful. I learned very quickly how much he spoiled me when he was healthy. 🍌
3d Like Reply 3 🍌
Caregiver Action Network replied · 1 Reply

What does "balance" look like for you as a caregiver?

Richard Tatum II
1. Acknowledge I (and my needs) matter.
2. Realize I cannot do everything.
3. Assess what I have to do versus what I don't have to do versus what can be delegated.
4. Prioritize what I have to do.
5. Ask for help with the things that don't have to be done by me.
6. Find time to relax.
4w Like Reply Edited 7 🍌🍌
Caregiver Action Network replied · 3 Replies

MIS Ab-Mayen-Ing Grace
A chocolate chip cookie 🍌 in one hand and an oatmeal cookie 🍌 in the other!
4w Like Reply 1 🍌
Caregiver Action Network replied · 1 Reply

CleaverlyChanging
Balance isn't something every caregiver has the luxury of experiencing—and I've made peace with that. I care for four loved ones living with chronic illnesses, while working full-time and running my own publishing business.
Instead of chasing balance, I've learned to honor reality. Some days will feel heavy, and on the days when I need to breathe, I give myself permission to ask for help.
4w Like Reply 3 🍌🍌

Jim Kally
For me . Basics first, and that's no ' Alzheimer's-ic' approach 🍌. Safety, physical care, and dignity are the foundation of great caregiving!
4w Like Reply 5 🍌🍌
Caregiver Action Network replied · 1 Reply

Leah Woodcomb
Setting healthy boundaries. In the past, I have allowed myself to be put in positions where my time has been spent mostly doing things for others. Now, I have "me" time every day. I also don't feel guilty when I want to treat myself with doing something that does not necessarily benefit anyone else.
4w Like Reply 1 🍌
Caregiver Action Network replied · 1 Reply

Who inspires you in your caregiving journey and why?

Chelle Jones
Other caregivers. There's just a strange bond immediately and you feel like you can be more vulnerable
10w Like Reply 7 🍌🍌

Karen Clark
I think about my uncle Charles. When I was a lil girl, we would go visit my mom's sister, Mabel. Mabel had a stroke and was bedridden. Her husband Charles did the majority of her caregiving. She was always clean and smelled nice. In addition to that, he did her hair and makeup just like she used to do. It didn't look like a man did it either. Mabel was that way for many years and so was Charles. 🍌
10w Like Reply 3 🍌🍌
Caregiver Action Network replied · 1 Reply

Epiphany Health Advocates
Our adult sons, called The TiTans (Titus and Tanner), are now lead caregivers in our firm. They show up as brilliant, problem solving gentlemen for my brother with MS and their grandparents. 🍌
10w Like Reply Edited 2 🍌🍌
Caregiver Action Network replied · 2 Replies

Julene Rodriguez
Other strong caregiver parents of medically fragile children and foster parents of special needs children. Especially those whom care for children in hospice like me.
10w Like Reply 1 🍌
Caregiver Action Network replied · 3 Replies

Caregiver Pulse Prompts

A SELECTION OF POSTS FROM
CAN'S FACEBOOK PAGE
JANUARY- APRIL 2026

If caregiving came with a theme song,
what would yours be?

Responses to our Caregiver Pulse Prompts show that caregiving is rarely simple or easy. It is a constant balance between exhaustion and love, loss and purpose. But within that complexity, many caregivers discover resilience, strength, and meaning in even the smallest acts of care.

Caregiving often brings a quiet, ongoing sense of grief for the life that came before. Many caregivers miss their independence, their careers, their social lives, and even the simple ability to care for themselves on their own terms. And yet, alongside that loss, there is also meaning. Many speak about the love they feel, the importance of being there for someone who needs them, and the deepening of relationships in ways they may not have expected. Some also find purpose in the act of caring—coordinating appointments, managing daily needs, and advocating for their loved one.

Rather than achieving perfect “balance,” most caregivers learn to adapt. They focus on what matters most—safety, dignity, and essential care—while letting go of unrealistic expectations. Setting boundaries and protecting their own well-being becomes essential, even if it takes time to feel comfortable doing so.

Practical tools and routines also play an important role in easing the day-to-day demands. This can help create structure, reduce stress, and even give loved ones a greater sense of independence. When caregivers find connection with one another, there is a unique understanding—a sense of not being alone, of being seen and supported by others walking a similar path.

For those balancing work and caregiving responsibilities, all of these experiences also shape caregivers into strong, capable employees. The same resilience, adaptability, and problem-solving they use at home often translate directly into the workplace. Caregivers are used to managing competing priorities, navigating complex systems, communicating under pressure, and staying organized in unpredictable situations. They develop patience, empathy, and a deep sense of responsibility—qualities that make them not only reliable team members, but thoughtful and effective contributors in any professional setting.



Caregiver-Ready Workplaces

A Growing Imperative for Employers



Caregiving is no longer just a personal responsibility—it's a critical workforce issue affecting employees and employers nationwide.

Millions of employees are balancing their jobs with caring for loved ones, often without the support they need. This growing reality can lead to significant strain for both workers and the organizations that employ them, including:

- Burnout and chronic stress among caregiving employees
- Increased absenteeism and reduced productivity
- Higher turnover rates and the loss of experienced talent
- Decreased engagement and overall workforce morale

Despite the widespread impact, **many organizations remain unprepared to address the needs of working caregivers.** Policies and benefits often lag behind the realities their employees face, leaving caregivers to navigate complex care responsibilities on their own. This gap not only affects employee well-being but also creates measurable costs for employers through lost talent and decreased engagement.

The **Caregiver-Ready Workplaces** initiative, by Caregiver Action Network, aims to bridge this gap. Designed by working caregivers themselves, the program brings real-world experience and practical solutions into the workplace—offering strategies that are both effective and empathetic.

Forward-thinking organizations are beginning to recognize that supporting caregivers isn't just the right thing to do—it's a smart business decision. **Creating a more caregiver-friendly workplace can include:**

Flexible scheduling and remote work options that allow employees to manage care responsibilities without sacrificing job performance

Caregiver leave policies that provide time when it's needed most

Access to resources and referrals that help employees navigate complex care situations

A workplace culture of openness, where employees feel safe discussing caregiving without fear of stigma or professional consequences

Caregiver-Ready Workplaces

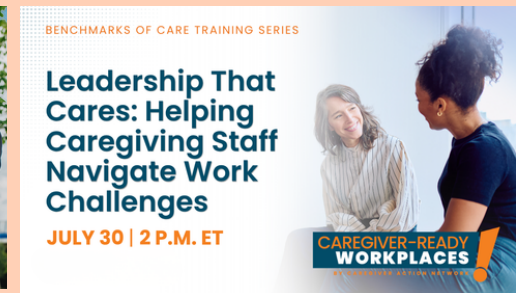
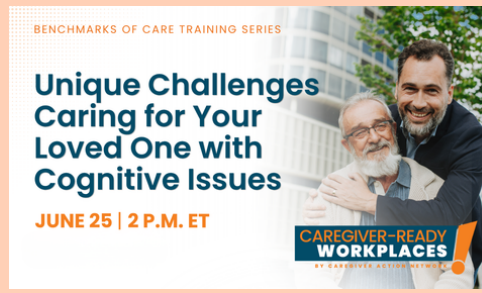
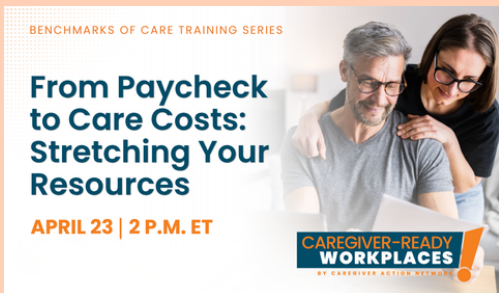
A Growing Imperative for Employers



As caregiving continues to touch more families and the population continues to age, workplace policies must evolve. Employers who act now will not only support their employees through one of life's most demanding roles—they'll also build stronger, more adaptable organizations for the future.

Initiatives like Caregiver-Ready Workplaces highlight a clear path forward: when employers support caregivers, everyone benefits.

Caregiver Action Network is hosting a monthly webinar series to educate employers on topics relevant to working caregivers.



Training details and session registration
caregiveraction.org/benchmarks-of-care/

What's New with the Caregiver Innovation Council

The Caregiver Innovation Council (CIC) held its first Annual Summit on May 14, 2026.

The Caregiver Innovation Annual Summit served as the capstone event for the first CIC cohort and the official launch of the second cohort. The 2-hour event showcased innovation, shared insights, and connected to the broader caregiving technology ecosystem.



Evolution of the CIC

In the first year, there were 19 founding members:



What's New with the Caregiver Innovation Council

Caregiver Innovation Council Membership

CIC membership allows you to be part of the CAN ecosystem. You'll get your brand in front of our audience of tens of thousands of caregivers nationwide, access our annual caregiver technology survey data, participate in caregiver roundtables, be invited to the annual CIC Summit, and receive early information on grants and opportunities we curate for the space. It's designed to be a meaningful but lower-lift engagement for all parties.

Membership Benefits:

- **Logo placement on CAN's CIC landing page** and inclusion in all CIC-branded communications
- **CIC digital badge** to display on members' website and marketing materials
- **Social media amplification** and CIC blog features
- The ability to **shape the annual Caregiver Tech Insight Survey** by suggesting questions and early exclusive access to the Survey data (this survey is drawing on CAN's network of 35,000+ caregivers, capturing data on technology adoption, barriers, AI usage, cost tolerance, and caregiver needs, providing CIC members with actionable insights that can inform product development, market strategy, and partnership opportunities)
- **Access to CAN's Caregiver Insights Panel** for user research and qualitative feedback (2- 4/year roundtables/convenings of caregiver- focus groups by theme)
- **Early access to CAN's Caregiver Pulse®** featuring current trends, disease-specific insights, and data-driven information from CAN's network
- **Invitation to the annual CIC Caregiver Innovation Summit** featuring forward-thinking leaders in caregiving innovation, offering members cutting-edge insights and inspiration
- **CAN-curated opportunity alerts** (grants, federal announcements, relevant industry news)
- Networking with fellow CIC members and ecosystem partners
- Participation in a future CAN-curated caregiver technology marketplace



What's New with the Caregiver Innovation Council

Caregiver Innovation Advisory Group (CIAG) - *by invitation only*

A curated group of 10-12 organizations, each representing a specific vertical within the caregiving technology ecosystem, serving as strategic advisors to CAN. Only one organization may hold each seat at a time, ensuring diverse representation and avoiding overlap between competing companies.

Select CIC members may be invited to join the Advisory Group. Advisory Group members receive all CIC Membership benefits, plus:

You advise CAN:

- Quarterly deep-dive advisory sessions with CAN leadership to brainstorm and strategize ways to scale impactful, collaborative solutions in caregiving
- Direct input into CAN's innovation strategy and program development

CAN delivers to you:

- **Highlighted logo placement on CAN's CIC landing page** and inclusion in all CIC-branded communications
- **Co-branded storytelling and thought leadership opportunities** (blog posts, webinars, white papers)
- **Priority consideration for grant co-submissions** and various co-creation opportunities with CAN (such as future caregiving tech moonshot/hackathon task groups)
- **Speaking and visibility opportunities at CAN events** (CLC meetings, NFC Month programming, annual CIC Caregiver Innovation Summit)
- **Early access to CAN's Caregiver Pulse®** featuring current trends, disease-specific insights, and data-driven information from CAN's network + the opportunity to be featured/acknowledged as partners in the quarterly publication
- **Collective caregiver-related policy advocacy opportunities** (sign-on letters, op-eds, thought leadership)

Caregiver Insights Panel in Action

CAN's Caregiver Insights Panel is now actively supporting CIC member product development. Carey (a family care concierge startup) is conducting one-on-one conversations with caregivers sourced from CAN's Insights Panel to validate product hypotheses and refine their offering—a direct example of the CIC's value in connecting innovators with real caregivers.

Caregiver Tech Insights Survey:

Caregivers Embrace Technology—But Barriers Remain

Family caregivers are increasingly **turning to technology to help manage the complex demands of caregiving**, according to findings from Caregiver Action Network's **2026 Caregiver Tech Insights Survey**. Drawing on **responses from 272 caregivers**, the report highlights a community that is digitally engaged, open to innovation, and actively seeking tools to ease the burden of care coordination. The goal of the survey was to find out **which technologies are working for caregivers, which are not, and what caregivers wish existed**. The information gathered will help shape the tools and resources that CAN develops for family caregivers.

Caregiving today involves significant logistical challenges.

More than 1/3

report spending 11 or more hours each week coordinating care.

It's time spent managing medications, scheduling appointments, and communicating with multiple providers. Despite these demands, most caregivers already use digital tools, with 90% relying on smartphone apps, patient portals, and telehealth services.

Interest in emerging technologies is also strong.

Nearly 60%

of caregivers have used or tried AI tools to better understand medical conditions, prepare for doctor visits, or organize information.

At the same time, caregivers express a clear desire for solutions that simplify their responsibilities—particularly tools that provide doctor visit summaries or concierge-style support for administrative tasks.

Adoption of technology is not without challenges.

Cost, Trust & Lack of Privacy Concerns

remain the most significant barriers. Many caregivers feel overwhelmed by the number of available tools and are unsure about which ones are reliable. Notably, nearly two-thirds believe that insurance programs like Medicare or Medicaid should cover caregiving technology, underscoring the financial strain many caregivers face.

Caregiver Tech Insights Survey: Caregivers Embrace Technology—But Barriers Remain

One of the survey's strongest findings is the demand for trusted guidance.

95%

of respondents said they would value a curated, nonprofit-backed platform to discover vetted caregiving tools and services.

This points to a critical opportunity to bridge the gap between innovation and accessibility.

Ultimately, the report paints a clear picture: caregivers are ready for better technology, but they need help navigating the landscape. With the right support, trusted recommendations, and more affordable options, technology has the potential to significantly reduce caregiver stress and improve care for millions of families.

What Caregivers had to say in their own words

Which tech is the most helpful?

"Medication reminder apps like Medisafe help track doses and avoid missed or duplicate medications, greatly reducing daily stress and safety risks."

"Shared calendars, like Google Calendar, help track appointments between multiple family members."

"MyChart and patient portals."

"Apps to monitor CPAP, hearing aids, and meds."

"ChatGPT for drafting message templates and helping with cognitive organizing. Visible App for Myalgic Encephalomyelitis tracking and reports and pacing."

"Online caregiver support groups."

What causes the most stress?

"Throughout the entire care experience, the most stressful aspect was providing 24/7 continuous care with no backup or rest periods, constantly worrying about the patient's safety and unexpected situations."

"The prolonged physical and mental exhaustion, emotional depletion, and lack of support and respite opportunities kept me in a state of high tension and anxiety for an extended period."

"The most stressful part of caregiving is trying to coordinate everything at once: appointments, medications, and daily care, while still managing my own responsibilities."

"Working outside the home and not knowing how my husband is doing when I am gone."

"Finding competent and reliable help."

What caregiving tool/service should exist, but doesn't?

"One simple app that automatically organizes medical records, appointments, medications, and doctor instructions in one place for caregivers and family."

"A single unified care dashboard."

"One single record-keeping system that a caregiver can access with all health history."

"Flexible, short-term home care replacement services."

"Professional caregivers who will come to your home for 1 hour, 2 hours, or half a day to take over your duties, allowing you to go shopping, visit the doctor, take a shower, and rest."

"There's no respite even for an hour when you need full-time or extended care support."

"A cheap, easy emergency alert that doesn't need complicated setup or monthly fees."

CARE 2030: Building a More Connected Future for Family Caregivers

The CARE 2030 initiative, led by Caregiver Action Network and its advisory group, outlines a strategic vision to better support family caregivers by addressing fragmentation across the caregiving ecosystem. Drawing together leaders from healthcare, policy, research, and advocacy, the group identified three interconnected roles for CAN: **Care Navigator**, **Ecosystem Orchestrator**, and **Incubator/Innovator**.

At its core, CAN aims to strengthen its role as a **Care Navigator**, helping caregivers more **easily access information and resources at critical moments**. This includes improving digital and human support systems, offering personalized care pathways, and ensuring caregivers receive coordinated, “closed-loop” referrals.

The **Ecosystem Orchestrator** role focuses on **coordinating a national caregiving agenda**, bridging gaps across organizations that often operate in silos. By bringing stakeholders together, fostering collaboration, and maintaining steady communication, CARE 2030 aims to create a **more unified and effective caregiving landscape**. A key near-term priority is amplifying existing caregiver resources across organizations, making it easier for families to find support regardless of where they enter the system.

The **Incubator/Innovator** role emphasizes the **need for forward-thinking solutions, particularly leveraging technologies such as artificial intelligence**, to meet the growing demands of caregiving. This includes exploring tools like AI-powered care navigation and developing new models for services, programs, and policies that can scale support for caregivers nationwide.

The group agreed on a phased approach: first building a strong internal foundation through small working groups and relationship-building, then expanding outward with broader messaging and impact. **Immediate next steps include identifying high-value caregiver resources for shared promotion, establishing quarterly meetings, and planning an annual CARE summit.**

Ultimately, CARE 2030 highlights a critical insight: before innovation and funding can reach their full potential, the caregiving field must first address its fragmentation. By aligning efforts, amplifying resources, and fostering collaboration, this initiative aims to create a more connected, accessible, and sustainable support system for caregivers.

By the Numbers

Between

63M & 106.5M

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

Sources: National Alliance for Caregiving and AARP. Caregiving in the U.S. 2025 and RAND, America's Military and Veteran Caregivers: Hidden Heroes Emerging from the Shadows. 2024

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

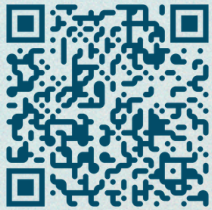
67%

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:

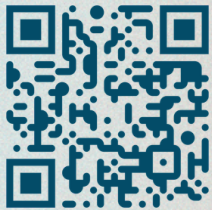


Partner with CAN to help expand our ability to support caregivers in our peer-to-peer network, provide education and training around Alzheimer's and cognitive impairment, and broaden our reach in educating people on long-term care financial planning and navigating finances as a caregiver.

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

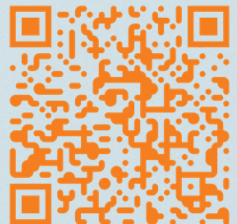


Engage with the Community – Connecting with other caregivers through CAN's communication channels fosters a sense of support and shared understanding.

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

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