Caregiver Pulse

MARCH 2025

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, CAN's newest publication 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, what concerns they have.
- **Social Meda Prompts.** Open-ended prompts posted on Meta and LinkedIn 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.
- **Caregiver Forum and Caregiver Story Project** which played an important role in collecting caregiver insights between 2014 and 2024 and helped form the Caregiver Action Network Community group on Meta.

Caregivers in Need of Help for Neurological Disorders Like Alzheimer’s and Cognitive Impairment

Caregivers help individuals with all kinds of daily and ongoing tasks resulting from a range of diseases and conditions. What we’ve seen over and over again is the deepening challenges for caregivers supporting loved ones with Alzheimer’s disease, cognitive impairment, and other neurological disorders.

INQUIRIES TO CAN

1 in 3

reach out about brain health related issues.

They are looking for support, education, and ways to know that they’re not alone.

> “It shocks me that there are childbirth classes and home-owner classes and marriage counseling etc, but nothing to prepare people for being a caregiver for a loved one with Alzheimer’s.”

Keri K., Milwaukee, WI

> “My dad has Alzheimer’s. He’s been getting agitated, so I thought it might help if I bought all the seasons of a show he likes. It worked, but now every night he wants to watch it. I don't like how it upsets me, how angry I get, and how annoyed and resentful of him I get every night. Can ANYONE identify?”

John C., New York, NY

> “I’m trying very hard to avoid getting angry at my dad for his verbal abuse and tell myself that it’s really the disease that he has that’s making me angry. However, it’s still very emotionally taxing.”

Lisa M., Kansas City, MO

Caregivers in Need of Help for Neurological Disorders Like Alzheimer's and Cognitive Impairment

WHAT CAN IS DOING

- **CAN's Alzheimer's-Embodied Labs** partnership has trained thousands of caregivers over the last year including CLC partner **First Quality**.

- CAN's newly developed and released **Guide for Supporting a Loved One with PTSD.**

- **CAN is working with Goodwin Living**, an aging services provider around their S**trongerMemory program** which focuses on cognitive impairment and helping people with mild cognitive impairment keep their brain strong.

- **CAN is working with a renowned cognitive impairment expert, Erin Bonitto** to develop accessible, replicable, and impactful training focused on developing communication skills.

- CAN's **Blueprint for BIPOC Caregivers of Children with Mental Health Issues**

Financial Support & Education

Nearly half of caregivers reaching out have questions around long-term care financial planning, how to get paid to be a caregiver, and how to navigate health insurance, Medicare, and Medicaid.

INQUIRIES TO CAN

Nearly Half

have questions about long-term care financial planning

> “It’s bad enough you get through the diagnosis and have to navigate through the medical and emotional rollercoaster, but you don’t think about the financial impact.”

Beverly B., Dallas, TX

> “You don’t think about the consequences of certain things, like choosing your health insurance. I have wonderful insurance, but it still didn’t cover a lot of things that I thought it would.”

James K. San Francisco, CA

> “I wish I had known about financial assistance programs such as government benefits, grants and financial aid for medical expenses. This assistance would have helped alleviate some of the financial stress that comes with caregiving.”

Tariq W., Brooklyn, NY

> "Caregiving often calls us to lean into love we didn't know possible, but the financial strain can be overwhelming, making the journey even more challenging."

Gregory P., Minneapolis, MN

Financial Support & Education

WHAT CAN IS DOING

Waterlily

CAN partnered with Waterlily to offer caregivers the tools and resources they need to make informed financial decisions and provide comprehensive care for their loved ones. Through this partnership, caregivers get practical solutions to help manage care for their loved ones and protect their financial security.

Webinar | Simplify Long-Term Care Planning for Your Family

November 20, 2024
Registrants: 141

Social Media Reach (**Nov. 2024**)
Organic: **2,215**
Paid: **32,176**

RubyWell

CAN partnered with RubyWell on content creation for CAN's Financial and Legal Toolbox. RubyWell is also creating financial resources for the CAN Help Desk.

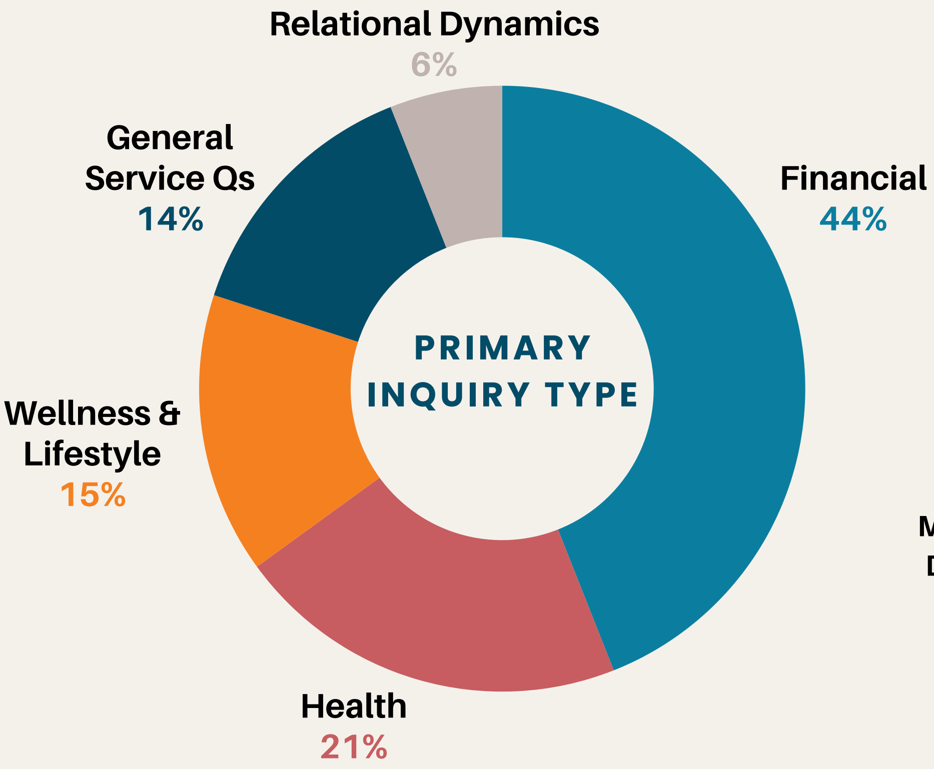
Webinar | Ongoing Home Healthcare: Eligibility & Availability

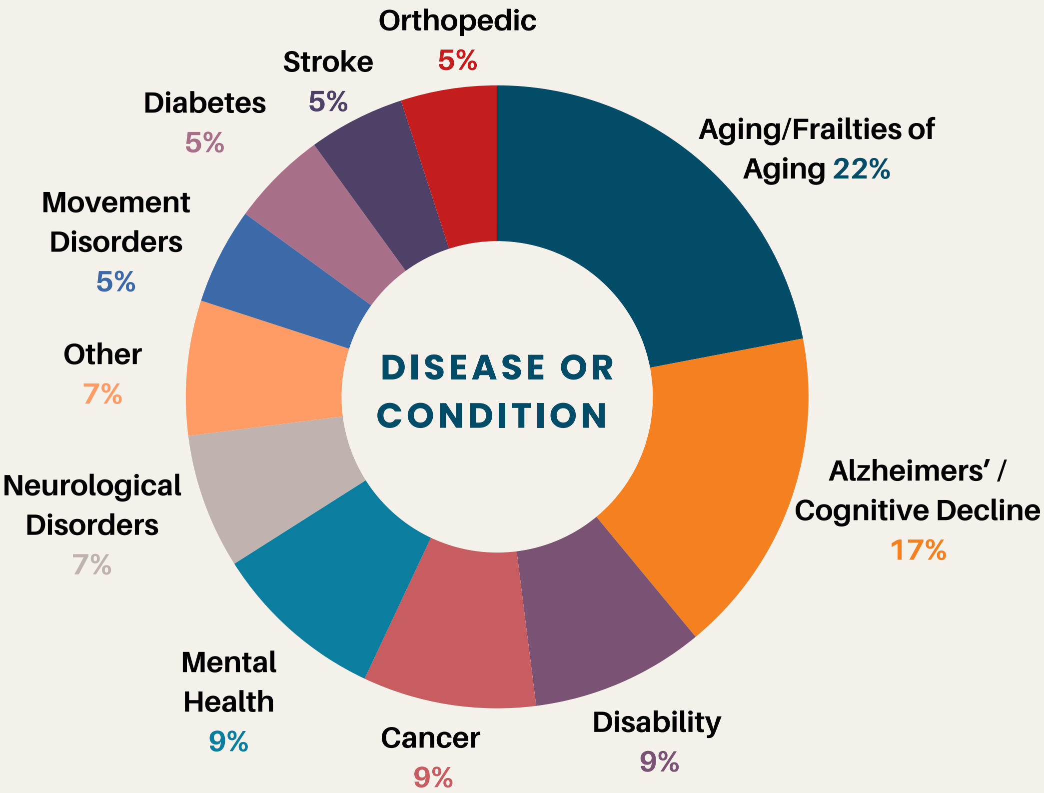
February 19, 2025
Registrants: 660

Social Media Reach (**Feb. 2025**)
Organic: **3,494**
Paid: **61,716**

Caregiver Help Desk

SEPTEMBER - DECEMBER 2024





Looking for Ways to Connect with Others

Inquiries to the Caregiver Help Desk and comments on the Caregiver Action Support Network Facebook group show that caregivers are looking for **support**, **education**, and **ways to know that they're not alone.**

"I wish I had known about online support groups for caregivers. It would have been comforting to hear from people who truly understand the unique challenges of caring for someone with the disease."

Joe M., St. Louis, MO

"Support groups would have been a big help. It would help to talk to other caregivers. Having someone to turn to is vital."

Maggie B., Syracuse, NY

"You need to build a support network. Let people know what you need and what you're going through."

Samuel B., Washington, DC

"I advise any new caregiver to find a support community as soon as possible AND you'll witness a love you didn't know was possible."

Kim M., Seattle, WA

"I'm in the 7th year of this caregiver journey. A few years ago, I took a part-time job at a health and fitness organization. Sometimes it's just a few hours a week, but it allows me to connect with coworkers and people who understand."

Eric P., Philadelphia, PA

Caregiver Roundtables

CONDUCTED
SEPTEMBER - DECEMBER 2024

WE ASKED CAREGIVERS...

What was one of the biggest challenges you faced?

"I was worried about my son dying. I lacked understanding of the disease, but information needs to be communicated in bite-sized chunks. You're already overwhelmed, then the flood of information overwhelms you even more."
-Joe M., son was diagnosed with AML leukemia at age 14

"It's hard trying to manage caregiving, kids, the household, my job, finances, etc. Everything suffers. The low times drag you down. It's been hard trying to help my kids understand when their daddy needs a break."
Maggie B., caring for her husband with PTSD

Is there information or a resource you wish you had known about earlier?

"I wish I was able to prepare for the changes in the family dynamic and communicate with others in the family so they would be aware of how things were going and details about the treatment plan. That way, all the responsibility wouldn't be on one person."
Victoria M., caring for a grandparent with leukemia

"It would be nice to be directed to resources through the medical care provider that are specific to families and how to support the individual with PTSD."
Lisa T., caring for her sister with PTSD

"I wish I had learned to prioritize self-care—to take a break, seek support from other people in my family, and join a support group."
Mercy B., caring for a grandparent with leukemia

KEY CHALLENGES AND NEEDS IDENTIFIED

- Time constraints and time management
- Desire to share stories and talk to other caregivers who understand what they're going through
- Sense of responsibility and isolation
- Emotional strain & depression
- Support system needed
- Lack of caregiver experience and training
- Lack of resources

Caregiver Pulse Prompts

A SELECTION OF POSTS FROM
SEPTEMBER – DECEMBER 2024

Corinne Sillapachai
Love and perseverance

Marita Choquette
Not to be insensitive to others who don't understand what you are going through.

Jaemee Witmer
Compassion

Colleen Ptak Baker
Sense of Humor

Lori-Ann Wells · Follow
My age, being able to relate to families and my clients.

Kitty Ogilvie Rak
Good listening

PL Patricia Pl
I was the only child that helped

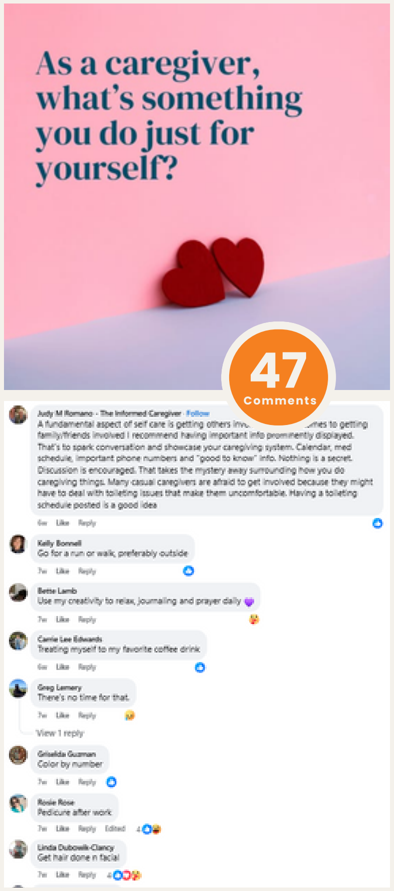
Tony Miano
Patient's.

Amy Fried
A deep empathy that comes from being an identical twin.

Roiann Smolinski
Love

Karen Lake, Caregiving Consultant and Care Navigator · Follow
I can be a fierce advocate; patient and professional, persistent and polite 😃

Tressimee Garner
Empathy



Judy M Romano - The Informed Caregiver · Follow
A fundamental aspect of self care is getting others inv mes to getting family/friends involved I recommend having important info prominently displayed. That's to spark conversation and showcase your caregiving system. Calendar, med schedule, important phone numbers and "good to know" info. Nothing is a secret. Discussion is encouraged. That takes the mystery away surrounding how you do caregiving things. Many casual caregivers are afraid to get involved because they might have to deal with toileting issues that make them uncomfortable. Having a toileting schedule posted is a good idea

Kelly Bonnell
Go for a run or walk, preferably outside

Bette Lamb
Use my creativity to relax, journaling and prayer daily 💜

Carrie Lee Edwards
Treating myself to my favorite coffee drink

Greg Lemery
There's no time for that.

View 1 reply

Griselda Guzman
Color by number

Rosie Rose
Pedicure after work

Linda Dubowik-Clancy
Get hair done n facial

Linda Green
The strength of my little family and spirit of my warrior.

Dana Peterson
That I was finally able to let go of the guilt that I was never doing enough for my medically complex child. Realizing I am just one person and doing the best that I possibly can.

Alison Kavchok
Being able to ask the hard questions and figure out the scary stuff in an effort to protect my loved one from it all so that they can remain positive 🥰

Rachel Renee Lacy
Being able to give my LO one on one care & her being surrounded by family 💜

Corinne Sillapachai
Always being there to care for and love my husband no matter how easy or difficult it may be.

Caring For Family Caregivers · Follow
I'm proud that I didn't put my life on hold during caregiving and my Mom's life continued to be full of love and life even after her stroke and loss of mobility and cognitive abilities.

Standards Care Ltd · Follow
It should always be a collective effort and shouldn't work the road alone in order to avoid any form of breakdown. Those little times and gestures you show will always be long long appreciated.

Whitney Stohr
Your job is to empower us, as a caregiving unit, to c
whatever that looks like.

Deborah L Powers
That this patient does not share the truth. He isn't ok.

View 1 reply

Kitty Ogilvie Rak
To talk directly to my non verbal adult daughter. They tend to speak to me. Just because she can't speak due to a stroke doesn't mean she doesn't understand everything perfectly!

View 1 reply

Angelina Vilchez
One pretending at taking thier meds....To when they are....Really enabling and giving them to the other that is an....Recovered/Relapsed Addict 💔....That the Dr took thiers away for that purpose 💔 Also that they are not following thier orders....Nor doing exactly to what they were recommended for them to do....Behind closed doors 💔

Tiffany Meyer
To please document that we caregivers are at the appointment and to document what we ask them to in their notes! The Caregiver program wants everything documented and some doctors aren't aware how much they actually need to include to make our criteria to be a caregiver validated!

Kristina Lynn
To listen to us. We spend 24/7 with them. We know their bodies as well as our own as far as what is normal and what isn't. Please listen when we tell you what's wrong.

View 1 reply

Top fan
Ryo Fujita
Treat us how you would treat your own family member with kindness respect and compassion.

Robin Baldwin Smith
To give me a few hours of freedom each and every weeke

Boyd N Lynn Hert
A day off to do something just for myself.

Senior Living Software - Tabula Pro · Follow
Access to resources! The more we know, the better we can care!

Newell Applegate
someone to take over my duties so that I can get the surgery that I need. and that someone isn't going to cost me an arm and a leg

Mary Lynn English
For them to work their way into our schedule, rather than waiting for us to "have time".

Deborah L Powers
Acknowledgment that Im still alive. No texts, no calls, no nothing...

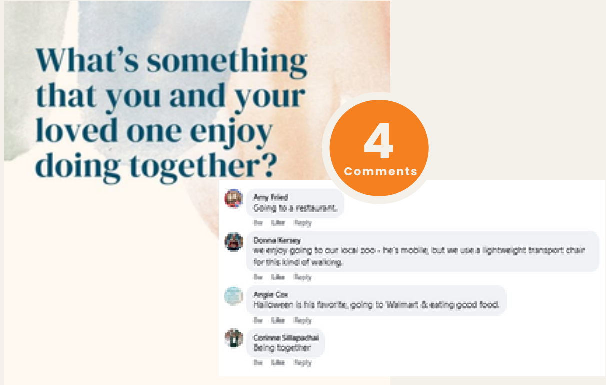
Jan Chronert
Caregivers need support ‼️ 🙏

Dana Parker
HELP!!!!!

Shannon Knower
Someone to actually help clean the house.

Jeannette Harris-Staebler
A day off or better yet a week I have worked 380 days straight

Teresa Britt Huston
Understanding.



Amy Fried
Going to a restaurant.

Donna Kersey
we enjoy going to our local zoo - he's mobile, but we use a lightweight transport chair for this kind of walking.

Angie Cox
Halloween is his favorite, going to Walmart & eating good food.

Corinne Sillapachai
Being together

Alison Kavchok
Anticipatory grief.

Dallas Britt
It was the lack of help that got to me.

Darci Morosko
The constant pressure to stay on top of his health my health and the entire family's appointments and upkeep. The constant knowledge that people think because I have no paying job that I have "free time". That's the worst of it—my family and close friends thinking that I have time to myself. I escape in meditation, zoning out a couple times of day. And twice a day I take a coffee break. I try to get my hair done twice a year. Every week I get the "me" time to go to the grocery store. Other than that I'm on duty 24/7/365.

View all 2 replies

Kitty Ogilvie Rak
The frustration of someone sitting behind a desk telling you what you need or don't need to care for a loved one.

View all 2 replies

Looking for Ways to Connect with Others

WHAT CAN IS DOING

- Caregivers have expressed a desire to connect with other caregivers who have a shared caregiving experience. **Kindly Human is a service through which caregivers can have 24/7 access to support from peers and resources within seconds.** This anonymous service connects caregivers with empathy and understanding as well as helpful pathways to navigate everyday life challenges.

- **CAN's partnership with Lundbeck and Otsuka** on our PTSD project uses **Kindly Human** to make these connections.

Kindly Human™ Lundbeck Otsuka

Psych Congress

OCT 29 - NOV 2, 2024
BOTON, MA

AUDIENCE OF 3,000+
HEALTHCARE PROFESSIONALS

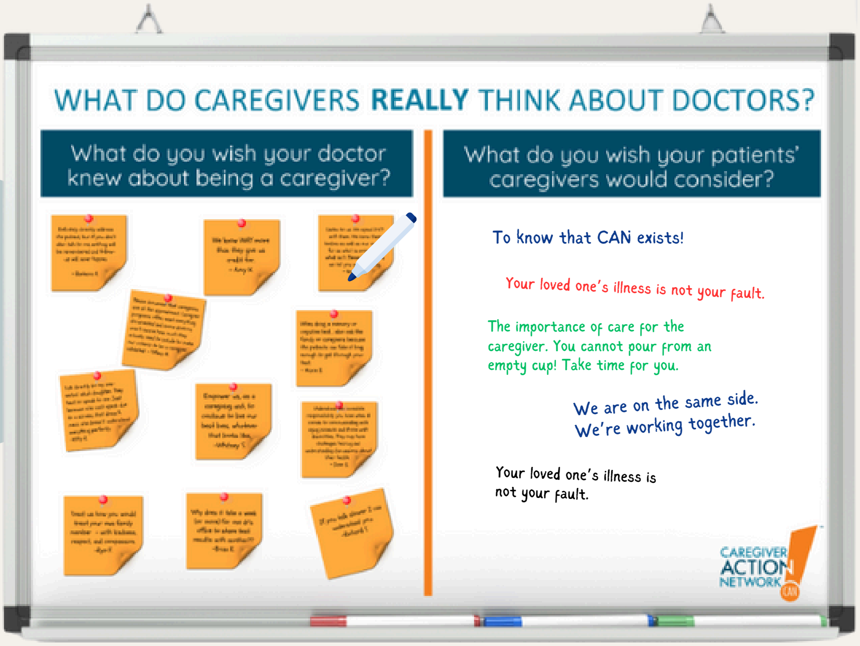
Psych Congress is the U.S.' largest independent mental health educational conference and a place to gather countless practical pearls to better personalize treatment strategies. Annually, Psych Congress attracts over 3,000 attendees which includes psychiatrists, psychologists, nurse practitioners, and other mental health professionals.

CAN exhibited at Psych Congress to bring awareness of the organization and engage with healthcare professionals.

An interactive display communicated messages from caregivers answering the question: *What do you wish your doctor knew about being a caregiver?*

The display included a whiteboard space for attendees to share a response to: *What do you wish your patients' caregivers would consider?*


CAN staff visiting with attendees at the CAN booth.


WHAT DO CAREGIVERS **REALLY** THINK ABOUT DOCTORS?

What do you wish your doctor knew about being a caregiver?

What do you wish your patients' caregivers would consider?

To know that CAN exists!

Your loved one's illness is not your fault.

The importance of care for the caregiver. You cannot pour from an empty cup! Take time for you.

We are on the same side. We're working together.

Your loved one's illness is not your fault.

Healthcare professionals shared...

We are on the same side. We're working together.

To know that CAN exists!

To consider if what your loved one is saying is true.

The importance of care for the caregiver. You cannot pour from an empty cup! Take time for you.

We are a team, be open.

If you don't tell us the truth or fully what's going on we won't have all the information we need to treat your loved one.

Come to appointments ready to talk about your love one's medications and changes you have noticed.

It's normal to be tired and resentful.

Seeing a new drug advertised on TV or online doesn't mean it's what your loved one should be taking.

Don't assume I know everything about your loved one's health at the start - other conditions, meds, etc.

Your loved one's illness is not your fault.

Let me know how to support your loved one daily.

A LOOK BACK

The Caregiver Story Project

We did a retrospective look back at our Caregiver Story Project that spanned from 2015 to 2024 and saw similar themes. Big topics of conversations were financial struggles, building social networks with friends and families, and finding resources to help them.

KEY THEMES

- **Emotional Toll and Burnout:** stress and mental health challenges, isolation, guilt over negative feelings toward their loved one, anger, and frustration
- **Sacrifices and Personal Impact:** declining physical and mental health, financial struggles, loss of identity
- **Lack of Support Systems:** lack of support from family and external systems
- **Love and Resilience:** profound love and dedication to their loved one despite challenges
- **Financial Struggles:** medical costs, need to cut back on hours or quit working, frustration from inadequate governmental or institutional support
- **Role Ambiguity and Identity Conflict:** balancing conflicting roles with caregiving duties

TRENDS

aging population, early onset disease or illness, systemic barriers to caregiver support, importance of community and support networks

TAKEAWAYS

- **Need for Education and Resources:** Information can empower caregivers to provide better care and manage expectations.
- **Importance of Self-Care:** Caregivers need to prioritize their health and well-being to sustain their ability to care for others.
- **Building Support Networks:** Support from family, friends, or community or professional services is essential to prevent burnout and distribute responsibilities.
- **Advocacy for Policy Changes:** Systemic obstacles that better policies, such as paid caregiver leave, financial assistance, and streamlined access to healthcare services could lessen.
- **Resilience and Adaptability:** Caregivers show remarkable resilience, often finding meaning and strength in their roles.

Why CAN Is Uniquely Equipped to Support Caregivers

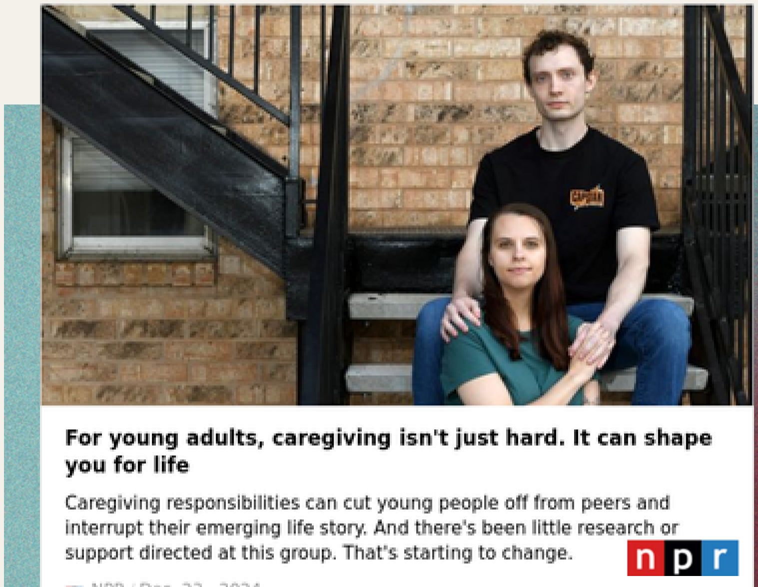
CAN is able to speak to and support caregivers because ***we are caregivers***. Here are just a few examples of the caregiving experience of CAN staff and others associated with CAN.

Dakota Heath, John Schall Policy and Program Fellow, Caregiver Action Network is caring for his partner, Jordyn.

He's one of the 25% of family caregivers between ages 18 and 36.

HEATH SAID

"There have been times when I have had breakdowns, because of everything piling up, accumulating," Heath says. "But on some level, I've always been a caregiver—it's part of me and I'm supposed to be here helping her do this."



For young adults, caregiving isn't just hard. It can shape you for life

Caregiving responsibilities can cut young people off from peers and interrupt their emerging life story. And there's been little research or support directed at this group. That's starting to change.

NPR / Dec. 23, 2024

Dakota and Jordyn are featured in an NPR article *"For young adults, caregiving isn't just hard. It can shape you for life,"* December 23, 2024.

Dawn Shedrick, President, JenTex Consulting; Lecturer, Columbia University School of Social Work; and Vice-Chair, CAN Board of Directors is caring for her mother with MS.

She’s seen how isolating and lonely caregiving can be. Now she’s determined to help other caregivers find support. Her consulting company, JenTex, provides training, professional development and continuing education for social workers and those in health and human services.

SHEDRICK SAYS
caregiving weighs on her, but, she says, she now knows who she is, who to lean on for support, and has a way to connect to others, by talking about her experience. “It gives me relief when I’m affirmed and validated, and that’s what I hear when I share my story,” she says. “If one person finds value in it, it’s worth it.” ‘

Dawn was featured in an NPR Shots Health News article, October 31, 2024.

Caregiving can be a tough, lonely mission. One daughter found ways to reconnect

Some 106 million people provide unpaid care for an adult in the U.S. Many feel invisible and profoundly lonely. But some are creating new ways to support each other.

NPR / Oct 31, 2024

CAN's Network Reach

Email Distribution Audience

35,230 Total Contacts // **28,593** Subscribers

Caregiveraction.org

Views: **462,000**
Active Users: **176,000**
Reporting period: Mar.1, 2024 - Feb. 28, 2025

Social Media

Reporting period: Mar.1, 2024 - Feb. 28, 2025

Facebook Caregiver Community Group

Members: **1,962**

Facebook Page

Followers: **17,756**
Published Posts: **717**
Post Impresssions (paid + organic): **12,361,905**

Instagram

Followers: **3,958**
Published Posts: **420**
Post Impresssions: **114,715**

LinkedIn

Followers: **8,077**
Published Posts: **654**
Post Impresssions: **168,841**

TikTok

Followers: **123**
Video Views: **8,473**

YouTube

Video Views: **1,476**

Campaigns

National Family Caregiver (NFC) Month: November 2024

Reporting period: Nov. 1, 2024 - Feb. 28, 2025

Published Social Media Posts: **38**
Post Impressions: **11,251,952**
Post Engagements: **3,011**
5 Campaign Emails: **99,761** recipients
Average Open Rate: **24.86%**

A Guide for Supporting a Loved One With PTSD

Reporting period: Nov. 1, 2024 - Feb. 28, 2025

Published Social Media Posts: **33**
Post Impressions: **5,681**
Post Engagements: **384**
Landing Page Views: **3,907**

Blueprint for BIPOC Caregivers of Children With Mental Health Issues

Reporting period: Nov. 1, 2024 - Feb. 28, 2025

Published Social Media Posts: **157**
Post Impressions: **804,618**
Post Engagements: **15,287**
Landing Page Views: **316**

Webinar Registrations

Simplify Long-Term Care Planning for Your Family

November 20, 2024
Registrants: **141**

StrongerMemory: Empowering Connections, Enhancing Independence

January 16, 2025
Registrants: **218**

Connecting Through Challenges: Masterful Communication for Cognitive Support

February 3, 2025
Registrants: **545**

Ongoing Home Healthcare: Eligibility & Availability

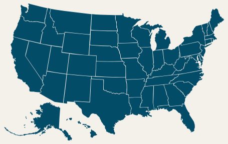
February 19, 2025
Registrants: **660**

Living With incontinence: Empowering Care and Practical Solutions

February 27, 2025
Registrants: **455**

By the Numbers

105.6 Million
Family Caregivers



40%
American adults

Only **22 Million** adults consider themselves caregivers.

Source: RAND study data

11.5 Million
Number of family members and other unpaid caregivers in the U.S. who provided care for individuals with Alzheimer's or other dementias.

=

18.4 Bllion
Hours of unpaid help.

Source: National Library of Medicine

7 Million Estimated number of Americans living with Alzheimer's dementia in 2024.

Source: Family Caregiver Alliance

250,000 People are diagnosed with Alzheimer's each year.

Source: Alzheimer's Association

1.2 Million People aged 18 years and older are diagnosed annually with adult onset brain disease/disorders in the United States.

Source: Family Caregiver Alliance

How You Can Help

You can help with the Caregiver Pulse initiative in several impactful ways:

1. **Become a partner** 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.
2. **Share Your Stories** – By participating in surveys or contributing personal experiences, you can help shape the conversation around caregiver needs and challenges.
3. **Engage with the Community** – Connecting with other caregivers through CAN's communication channels fosters a sense of support and shared understanding.
4. **Advocate for Resources** – Caregivers can help CAN and its partners develop more effective programs, policies, and services by voicing their struggles and suggestions.
5. **Spread Awareness** – Encouraging fellow caregivers to engage with Caregiver Pulse ensures that more voices are heard, leading to broader, more meaningful change.

CAREGIVER ACTION NETWORK

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