

Pathways

SERVING FAMILIES AND CAREGIVERS OF BRAIN IMPAIRED ADULTS AND THE FRAIL ELDERLY

Caregiver, Care Partner, Companion? Why Language Matters

To be the best caregiver possible, be as true to yourself as you are true to the person in your care.

By Carol Levine



WHEN I BECAME A CAREGIVER

for my late husband in 1990, I was labeled an “informal caregiver.”

“Just because I am not paid,” I thought, “what I do each day and night for a man who has quadriplegia caused by a traumatic brain injury is hardly “informal.”

As the AARP-led survey Home Alone Revisited explains, “The label informal reflected the understanding of what caregivers did—household chores and personal care activities, duties that most caregivers could readily perform.” This survey, published in 2019, and the one that preceded it, demonstrated that many caregivers also performed “medical/nursing tasks” for which they were poorly trained.

When possible, I chose to call myself Howard’s “family caregiver.” Some colleagues didn’t like that term because “not all caregivers are family members.” Yet, terminology has evolved to reflect reality. As Jean Accius II, senior vice president at AARP, said in an e-mail, “Human beings, at our deepest core, want to be seen. We want our experiences validated and to know that our voices matter.”

Now it is widely understood, although not always explicit, that family caregivers include both relatives by birth and marriage and chosen family, as well as friends, neighbors, and community members.

Changing Times, Changing Language

Families were always assumed to be caregivers for their older and ill rela-

Inside this issue:

Caregiver, Care Partner, Companion? (continued)	2-3
Caregiver’s Column	4
Staff Spotlight	5
Del Oro’s 35th Anniversary	5
Friendly Volunteers NEEDED	6
BIG DAY OF GIVING—COMING SOON!	6
Thank You to Our Generous Donors	7



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"Caregiver, Care Partner, Companion?" continued from page 1 . . .

tives. The modern discussion dates from 1966 when the Medicare and Medicaid programs were established. Then, paying for care for an aging and poor population became a government responsibility, at least partly, but now it has a new urgency. Over 50 million Americans have entered the ranks of caregiving because family members or friends have been diagnosed with cancer, heart disease, dementia, and other common diseases. Still, others have become caregivers in the twin pandemics of COVID-19 and its variants or opioid or substance abuse disorders.

Family caregivers include both relatives by birth and marriage and chosen family, as well as friends, neighbors, and community members.

Words matter and none are so fraught with meaning as those applied to us as individuals. Gender, sexuality, race and ethnicity, religion, and other characteristics are in flux—identity is often seen as a spectrum, not an either/or, and changeable almost at will. For example, pronouns used to be discussed only by grammarians; now, emails and other forms of identification include the writer's preference for pronouns such as she, hers, and they. And for many, the terminology is settled; caregiver is the preferred term.

Next Avenue uses the word caregiver, as do all the major caregiving organizations. Still, every advisory board I have been on begins its work with a discussion about terminology. Beyond the recognition that not all clients or potential clients embrace "caregiver," a practical reason is that services for people who provide care for an older, disabled, or ill person will find help, if it exists, under the rubric of "caregiver" resources or supports.

Indeed, what that person likes to be called and needs to know to access services may differ.

Is "Partner" a Viable Alternative to "Caregiver?"

Some organizations are beginning to discuss alternatives to "caregiver," for the most part, "partner." "Partner" en-

tered the caregiving language during the AIDS epidemic to denote same-sex couples; it is now used much more broadly, particularly among younger heterosexual couples, instead of "boyfriend" or "girlfriend."

"The term [caregiver] suggests that the recipient of care takes a passive role."

But the use of the term is still not fully incorporated in caregiving language. The Huntington's Outreach Project for Education website at Stanford (HOPES) asks, "What is the difference between a care partner and a caregiver?" The answer: "The difference between a one- versus a two-way street. The term [caregiver] suggests that the recipient of care takes a passive role."

The National Aphasia Association distinguishes the terms similarly to "connote the partnership between the person who needs care and the person who gives it." The Michael J. Fox Foundation uses "care partner" as well as "caregiver" but seems to prefer "partner" in its advocacy for people affected by Parkinson's disease.

The diseases addressed by these organizations are all long-term chronic conditions that affect mental and physical functioning. It is reasonable to consider the person needing assistance a partner for decision-making and other aspects of care. But does it work for advanced dementia or terminal cancer where the term may have an emotional resonance but not a functional one?

What Term Do Caregivers Prefer?

People who are caregivers by any definition may still say: Am I a caregiver, or am I a partner? Could I be both? Wouldn't it be simpler to call people like me "helpers," "supporters," or "companions"? The British call us "carers," why not use that term?

Caregivers from ethnic communities may say, "There's no word for the caregiver in my language," or "I am his daughter; isn't that enough?"

The National Aphasia Association conducted an informal survey of clients, caregivers, and professionals.



People who are caregivers by any definition may still say: Am I a caregiver, or am I a partner? Could I be both? Wouldn't it be simpler to call people like me "helpers," "supporters," or "companions?"

You can do a lot to be called by your preferred name. Ask the health care team for an opportunity to express your terminology preferences and discuss what the difference means to you.

Overall, care partner was slightly more preferred (45%) than caregiver (41.3%). A substantial number (12.5%) liked both terms, and a few (1.3%) did not like either term. However, respondents who were caregivers preferred that term (54.3%) over care partner (30.4%). More detailed results are available online. A scientific study involving caregivers (or partners) who care for people with different diseases would give us more insight into differences or similarities.

Men might be considered an underserved caregiver population. Jean C. Accius of AARP wrote in the e-mail cited earlier, "Caregiving can be a lonely experience. This is often the case for men because caregiving has traditionally been viewed as a woman's role. AARP Family Caregiving provides an easy way to join an online community and connect with others who understand caregiving challenges."

Similarly, Jack's Caregiver Coalition, an organization in Minnesota that provides social, practical, and emotional support to men who are caregivers, calls them "guy caregivers." Kyle Woody, co-founder, and executive director explained in a Zoom call, "This term makes it easier for men to

ask for help and gives them an identity in which they feel comfortable." The website adds: "Face it, guys, caregiving is a colossal challenge. It's not just hard. It's probably the hardest thing you'll ever do."

Sensitivity to language, however, is not the only need. Terry Davis, Chief of the Division of Healthcare Disparities at Louisiana State University Health Shreveport, and a health literacy expert, reminded me in a phone call, "In rural areas, there are not enough services, so caregivers don't worry about what they are called; they just want help."

What Can You Do as a Caregiver?

You can do a lot to be called by your preferred name. Ask the health care team for an opportunity to express your terminology preferences and discuss what the difference means to you. Kathleen Kelly, executive director of the Family Caregiver Alliance, said in a phone call, "This should be a respectful process in which the family defines their role and preferences."

Clarify what you are expected to do and what limits might be set. This discussion could be revisited later as your caregiving demands increase or diminish. In addition to talking to others, look up "caregiver resources" on websites and Google searches. Enlist a young family member to help with the online search. And talk to the person you care for about their preferences.

Depending on where you live, and your financial assets, the list of resources and services may be long or nonexistent. Don't give up! Think about what you used to or have always wanted to do. Then try to find something that fits into that category. The first step is the hardest. Ask friends and family for advice and help.

And remember being a caregiver does not define you. You are also a person with likes, dislikes, strengths, values, and anxieties. To be the best caregiver possible, be as true to yourself as you are true to the person in your care. ■

Carol Levine is a Senior Fellow at the United Hospital Fund in New York and a freelance writer. She was awarded a MacArthur Fellowship for her work in AIDS policy and ethics and named a 2016 Next Avenue Influencer in Aging. Reprinted with permission from Next Avenue, 2022, <https://www.nextavenue.org/>.

Men's Caregiver Support Group:

Caring for a Loved One in the Home

3rd Tuesday of the month

2:00 pm-3:00 pm

Online via Zoom

Are you tired of toughing it out alone?

Join this unique support group designed for male caregivers of a loved one with a cognitive impairment AND

- Connect with other male caregivers
- Discuss the issues and challenges you face
- Develop more effective coping strategies
- Identify resources to assist in your caregiving journey



in partnership with



To RSVP

Contact Facilitator **Mendi Bates**
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CAREGIVER'S COLUMN

MY WIFE

By Trey Mudge



I loved this woman most of my life,
I loved her so much—I made her
my wife.

The stars in the heavens,
The ocean below,
Couldn't hold all the love,
I felt for her so.

Together we traveled life's long
dusty road,
Together we stayed until we'd
grown old.

The laughter, the good times,
The sorrow, the tears:
Together we experienced them,
All of these years.

The children we raised grew fast
and grew strong,
They learned to live life, and tell
right things from wrong.
And our children had children—
An incredible thing,
When they sat on my knee,
It made my heart sing.

And, so, we walked life's long
winding trail;
We had great successes, though
sometimes we failed.
But no matter the bumps,
When we kept our sights clear,
Over life's many pitfalls,
We successfully steered.

Just after sunset, it came to an end.
I lost a lover, a helper, a wife and
a friend.

It came without fanfare,
Or warning or fuss:
In the cool of the evening,
You departed from us.

One thing I can say that I do not know,
Is how many years I still have to go.
I'll make those years full,
You'd want it that way,
But cannot deny,
I'll miss you each day.

Bodies expire, spirits do not,
Love does go on, all's not forgot.
All the future may hold,
Is not mine to say,
But I know that again,
I'll meet you one day.

Perhaps on a corner or on a side street,
I'll suddenly see you and together
we'll meet.

Will I know who you are?
I think that I will.
Will you know who I am?
I think you will, still.

And together we'll stand and think of
times past,
And knowing they can't, but wishing
they'd last.

What we'll do next,
We'll just have to see,
And that will be up,
To you and to me.

INVITATION TO CONTRIBUTE TO CAREGIVER'S COLUMN

We invite you to submit original work (poetry and prose) to be featured in upcoming newsletters. Send submissions directly to crc@deloro.org or complete the form on our website www.deloro.org. If you reference or borrow from specific sources, please be sure to cite them properly. **Submit no later than Friday, February 17, 2023 to be considered for our Spring 2023 issue.**



Friendly Volunteers NEEDED!

**Do you love people?
Do you love Del Oro Caregiver
Resource Center?**

We are looking to fill several volunteer positions at Del Oro and we need YOU! Whether you can spare a few hours a week, or make a more significant time commitment, please consider becoming a Del Oro volunteer.

We can use your help in the following areas:

- Office Help
- Fundraising
- Speaking Engagements
- Advocacy

If you are interested, please contact Amber Henning, Director of Finance and Administrative Services, at ahenning@deloro.org or **(916) 728-9333**.



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Call In Service – Confidential telephone discussions for people 60+ who may be lonely, isolated, grieving, depressed, anxious and/or thinking about death or suicide, their caregivers and/or younger disabled adults.

For additional information or to schedule a presentation by Founder and Director Patrick Arbore, Ed.D, please contact Natalie Schroeder at 415.750.4137 or nschroeder@ioaging.org



Staff Spotlight



Amber Henning
Director of Finance and Administration

Amber Henning has a B.S. in Business Administration and before joining the Del Oro team acted as an Office Manager at several small businesses. Now with over 17 years of administrative experience in the non-profit sector, Amber maintains the day-to-day operations and finances at Del Oro, ensuring that the organization can

continue to provide caregivers with essential services. Outside of work, she enjoys spending time with friends, wine tasting, and going to the ocean as often as possible. Amber lives with her husband Mark, their two adult children Avery and Breanna, and three cats Mickey, Majic, and Aria.



Matthew Dayrit
Family Consultant

Matthew Dayrit graduated from California State University, Sacramento with a bachelor's degree in Gerontology. He is currently in classes for a nursing program and eventually wants to become a family nurse practitioner (FNP). While in his undergrad, he worked various jobs in customer service. After college, he served as Del Oro's Program Assistant and now acts

as one of our newest Family Consultants! Outside of his work life, he loves to go on adventures with his two Corgis, Koda and Rorschach, spend time with friends, and watch movies. He recently got engaged, so he and his fiancé are now planning a wedding in 2023!



Del Oro is 35 Years Old!

In 1984, the **Comprehensive Act for Family Caregivers of Brain-Impaired Adults** became law, due in large part to avid advocacy of unpaid family caregivers in the San Francisco Bay Area. This legislation established the **California Caregiver Resource Center (CRC) system** that today represents roughly 5.5 million people. Since 1987, Del Oro Caregiver Resource Center has served as the greater Sacramento region's local CRC, carrying out our mission to improve the well-being of family caregivers through various services designed to support the physical and mental health of those caring for another vulnerable adult. As we celebrate this significant milestone, we want to highlight some of our achievements over the last 35 years: **Del Oro Caregiver Resource Center** has:

- Served a total of **14,770** clients served
- Provided hundreds of thousands of hours of direct services, including:
 - Respite: **570,605** hours = **\$15,447, 287.89** vouchered
 - Legal: **3,015.25** hours = **\$340,552.50** vouchered.
 - Counseling: **9,079.5** hours = **\$234,082.50** vouchered
- Raised **\$667,416** through our fundraising efforts (above and beyond state and federal dollars we receive) to expand services for family caregivers.

We are grateful, first and foremost, to our clients for the amazing service they provide as unpaid family caregivers but also to the many donors and sponsors who continue to support the work of our agency. **Cheers!**



BIG DAY OF GIVING is COMING!!



MARK YOUR CALENDARS!

On **Thursday, May 4, 2023**, join the Sacramento region for a celebration of philanthropy! Our community will come together for one **Big Day of Giving**, a 24-hour giving challenge that brings together the region's nonprofit community to help raise much needed unrestricted funds and shine a spotlight on the work nonprofits do to in our region. We hope your heart is with

Del Oro Caregiver Resource Center, serving family caregivers of adults with cognitive and neurodegenerative diseases and of seniors who need assistance with multiple activities of daily living (ADLs).

Visit us at <https://www.bigdayofgiving.org/deloro cares to donate!>

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