

THIS WEEK IN CAREGIVING



January 12, 2022



CAREGIVING IN THE NEWS

Can wartime trauma cause dementia? This scholar has a personal reason to find out

Oanh Meyer was a postdoctoral fellow studying the experiences of caregivers for those with dementia in 2012 when her research took a very personal turn.

That year, her mother, a Vietnamese immigrant, began to show signs of dementia and paranoia that seemed to be linked to the trauma she had suffered during the long war in Vietnam, when bombing raids often drove her to hide underground and she lived in fear of Communist troops.

Growing up as a Vietnamese American, Meyer had noticed a reluctance to address mental health issues in her community, an issue she pursued in her studies. She conducted her doctoral research at the University of California-Davis on disparities in mental health care among Asian Americans.

Now an associate adjunct professor at the Alzheimer's Disease Center at UC Davis Health, Meyer, 45, is leading an investigation into the link between trauma and dementia in the Vietnamese community. With a \$7.2-million grant from the National Institute on Aging, the five-year study, which could begin recruiting as early as this month, will follow more than 500 Vietnamese elders in Northern California, measuring how early life adversity, trauma and other factors correlate with memory and cognition.

From: Los Angeles Times | December 10, 2021

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What My Mother-in-Law's Dementia Diagnosis Taught Me About Caregiving

IN THE WINTER OF 2016, we were walking in a long, deviating oval around Trout Lake, on the east side of Vancouver, and Kenny said, "I think

Caregiving Benefits Can Support Workers—and the Bottom Line

When it comes to providing caregiving benefits to employees, times have changed. Onsite child care, once the gold standard of caregiving benefits, may not be as necessary or compelling in a remote and hybrid working environment.

there's something wrong with Omma." He sped up.

"Wrong how?" I hurried to keep pace.

We'd been together for four years at that point. He chewed his lip and squinted down at our dog padding between us. It was a gorgeous day, and there were dogs everywhere, chasing, yawping.

"Did she say something?" I asked.

"No. But you know how she's been calling. A lot."

I did know. Sometimes we woke to a dozen missed calls from Kenny's 68-year-old mom. The week before, they'd made lunch plans, confirmed the location twice, and she still wound up waiting at the wrong restaurant. This lost quality of hers had been coming on so slowly, though, that it seemed halfway natural. Then again, my take didn't count for much because, to me, Kenny's mom was always a little obscured by a language barrier—her English was rudimentary and my Korean non-existent.

"Well, what are we talking about?" I asked Kenny as we turned off the path, onto the lakeshore. "Do you mean something mental? Like you think she's got dementia?"

From: Reader's Digest | Published: January 5, 2022

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With so much changing in the workplace, the need to make sure benefits are relevant and useful to employees has never been greater—especially during a time of high turnover and an extremely competitive market for talent.

Getting caregiving benefits right is also critical to an employer's bottom line: When employees have difficulty juggling caregiving responsibilities, their well-being and productivity can suffer. A 2021 survey of 1,309 people conducted by the Rosalynn Carter Institute for Caregivers found that among employees with caregiving responsibilities:

- 73 percent had to leave work early or unexpectedly.
- 70 percent had to call out from work for one day.
- 68 percent did not take on additional responsibilities or projects.
- 60 percent felt the quality or timeliness of their work suffered.
- 59 percent had to take two or more days off in a row from work.
- 52 percent lost income because they had to miss work.

For employers, these findings are being felt in the form of absenteeism, lost productivity and turnover. One way to counteract these trends is to help employees with their caregiving responsibilities.

From: SHRM | Published: January 7, 2022

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EVENTS & OPPORTUNITIES

The National Rehabilitation Research and Training Center on Family Support
at the University of Pittsburgh presents:

Building Bridges: Advancing Family Caregiving Research Across the Lifespan

Second Biennial Conference on Caregiving Research

March 3-4, 2022

Building Bridges: Advancing Family Caregiving Research Across the Lifespan

The National Center on Family Support (NCFS) is excited to host their second **biennial conference** on caregiving research in Pittsburgh, Pennsylvania.

This conference will bring together a multidisciplinary group of national leaders in caregiving research, policy, and practice across the lifespan. Sessions will showcase innovations in research and build bridges across disciplines and conditions to address the urgent community, clinical and policy needs of family caregivers.

Registration Information

Register before January 6, 2022 to take advantage of our early bird rates!

General Registration: \$250

Post-Doctoral and Clinical Trainees: \$100

Students: \$25

REGISTER NOW!

The National Rehabilitation Research and Training Center on Family Support at the University of Pittsburgh and the University of Pittsburgh School of Nursing are collaborating to provide nursing continuing professional development (NCPD) contact hours for the educational activity entitled: Building Bridges: Advancing Family Caregiving Research Across the Lifespan – Second Biennial Conference on Caregiving Research. Nurses completing the entire activity and evaluation tool may be awarded a maximum of 10.75 contact hours of NCPD. The University of Pittsburgh School of Nursing is accredited as a provider of nursing continuing professional development by the American Nurses Credentialing Center's Commission Accreditation.

[REGISTER FOR THE CONFERENCE](#)



[PATIENT AND CAREGIVER STUDIES](#)



Does your
parent
have any
memory
loss?

Yale Families Coping Together With Alzheimer's Disease Study

If you are at least 18 years old, and you have a parent at least 55 years old and has early stage dementia, you and your parent may be eligible to participate in a free and confidential study to understand your experience coping with dementia together. Participation involves one 2-hour interview session and a one 2-hour interactive session with you and your parent completing tasks together now and one year later. Interview and interaction sessions can be completed over the phone, by mail, or on the computer.

Compensation of up to \$600 for completing all sessions .

To learn more or to see if you are eligible to participate, please contact Kathleen Williams at **(203)641-5373** or email her at **kathleen.williams@yale.edu**.

Alzheimer's Disease and Related Diseases (ADRD) Partner/Spousal Caregiver Study

This study by Rush University's College of Nursing will explore how partner/spousal caregivers manage/deal with the challenges of caring for persons with Alzheimer's disease and related dementias (ADRD). Additionally, the study will explore the feasibility and acceptability of recruiting, interviewing, and consenting partner/spousal caregivers using technology.

To participate in this study, you are must:

- be at least 65 years old
- self-identify as a partner/spousal caregiver
- have a partner/spouse who has been diagnosed with Alzheimer's disease by a healthcare professional
- have a partner/spouse is at least 65 years old
- have a partner/spouse resides in the same household

If you volunteer to be in this study, your participation will consist of an online interview using Zoom. Your participation would involve one interview session, which will take approximately 60 minutes of your time.

- Participants will receive a \$25.00 Target gift card upon completion of the interview. Participation is completely voluntary, information collected is protected, and participants may terminate at any time.

For more information or to volunteer participation please contact:

Shandra Burton, MSN, RN, PhD Student

Black Male Dementia Caregiver Burden Study

GW School of Medicine and Health Sciences is actively recruiting Black men aged 30-85 who are either caregivers or non-caregivers of loved ones diagnosed with dementia. Participants will engage in a series of questionnaires, surveys, and a focus group, and can receive up to \$125 in compensation. Click the link below for additional information.

[LEARN MORE](#)



COVID-19 Study

The University of Tennessee College of Nursing is seeking adults who are currently providing care (at least 8 hours a week) to an older adult with a chronic condition.

Are you a caregiver for an older adult with a chronic condition? Please consider taking part in this important research study to understand caregiving during #COVID-19. The University of Tennessee College of Nursing is seeking adults who are currently providing care (at least 8 hours a week) to an older adult with a chronic condition for a research study. The purpose of the study is to understand the experiences of caregivers during COVID-19. The study involves responding to an online survey questionnaire with questions related to caregiving and one interview to talk about their experiences using online caregiving resources. The one-time interview takes approximately 30–45 minutes to complete. Participants will receive a \$25 Amazon gift card for completing the interview and a separate \$10 Amazon gift card for completing the survey.

[LEARN MORE](#)



Intuition Study

Biogen has officially opened enrollment for the virtual Intuition Study in the United States. Using everyday devices, this first-of-its-kind study aims to measure changes in thinking and memory in adults, as well as identify longer-term changes in brain health. For more information about who is eligible and how to enroll, click the link below.

[LEARN MORE](#)



IN CASE YOU MISSED IT...

Congressional Briefing on Family Caregiving in Diverse Communities

Diverse Elders Coalition and its members, in partnership with the National Alliance for

Caregiving, discuss findings from their recently released report, *Family Caregiving for Older Adults from Diverse Communities*. The report highlights impacts of the COVID-19 pandemic on family caregivers; related implications for older adults from diverse communities; and ways to strengthen recommendations from the recently released RAISE Family Caregivers Act Initial Report to Congress to better address the unmet needs of racially and ethnically diverse family caregivers.

Click below to view the video.



RESEARCH & RESOURCES

JUST RELEASED!

Caregiving in a Diverse America:
Beginning to Understand
the Systemic Challenges
Facing Family Caregivers

[DOWNLOAD NOW](#)

MADE POSSIBLE THROUGH SPONSORSHIP BY
AMGEN

NAC Releases New Report: Caregiving in a Diverse America: Understanding the Systemic Challenges Facing Diverse Family Caregivers in the U.S.

The National Alliance for Caregiving is proud to present *Caregiving in a Diverse America: Understanding the Systemic Challenges Facing Family Caregivers in the U.S.*, a new report conducted with sponsorship by Amgen, Inc., with support from the Diverse Elders Coalition and in partnership with the National Minority Quality Forum. Based on a secondary analysis of the survey results found in *Caregiving in the U.S. 2020*, the data presented includes multiple logistic regression analyses by Dartmouth College researchers. The report highlights significant disparities in support, caregiving intensity, health, and financial impacts among African American, Hispanic and Asian American and Pacific Islander caregivers, LGBTQ caregivers, as well as caregivers across different

income brackets and geographical areas. While conducting the research for this report, it became clear that more inclusive methods of data collection are needed to inform research on the needs and possible supports and services that can be provided to diverse family caregivers.

The findings in this report highlight:

- African American, Hispanic, Asian American/Pacific Islander, LGBTQ, rural and socioeconomically diverse caregivers;
- Disparities in living situations, financial status, caregiving activities, self-reported health, and information and services used;
- Personal stories of diverse family caregivers that provide human context to the data;
- Next steps in ensuring data collection and research is inclusive of and equitable to all family caregivers;
- Future policies and improvements to supports, services and the health care system that can better the caregiver experience for diverse populations.

[LEARN MORE ABOUT THE NAC REPORT](#)



REPORT: Addressing the Needs of Diverse Family Caregivers for Older Adults

This 20-page report is the product of a series of activities conducted by the Diverse Elders Coalition (DEC) and its members' organizations, and in partnership with the National Alliance for Caregiving, to better understand and highlight the lived experiences of diverse family caregivers for older adults. It highlights key findings from 300+ diverse caregivers for older adults from the DEC's constituent communities, including racially and ethnically diverse people; American Indians and Alaska Natives; and lesbian, gay, bisexual, transgender and queer/questioning (LGBTQ+) people as they provide care through the pandemic. The goal of the full length report is to offer research and recommendations to help ensure services and supports for caregivers intentionally address health disparities and systemic barriers that diverse family caregivers for older adults face.

[READ THE REPORT](#)



Welcome to The Arc's Virtual Program Library

The Arc's virtual program library is a free hub of on-demand activities that can be done from home by people with disabilities, their families, and service providers.

The library is expanding all the time and has activities in a wide variety of areas, such as arts, life skills, health and wellness, virtual clubs, and more.

Browse listings to find activities like:

- Participating in dance, yoga, and other movement activities
- Learning about internet safety
- Virtually touring places like Disney World and museums
- Making your own Jeopardy templates

- Finding self-advocacy support

GET STARTED

Planning for the Future Is Possible. The Arc is Here to Help.

Thinking about the future after a caregiver is no longer able to provide support to a loved one with disabilities is difficult. To make it less daunting, The Arc's Center for Future Planning has a wide range of tools and resources to support you through the process. Whether you're looking for information about financial planning, housing, supported decision-making, or more, we'll help you get started and stay organized!

Our newest resources include [an informative video series](#) on ways to save money and protect public benefits. The videos are also [available in Spanish](#). Not sure where to start? Email futureplanning@thearc.org if you have any questions.

GET STARTED



New Resources from Caring Men Global

Caring Men Global Inc. has published two new resources for male caregivers. In conjunction with the development of CMG's website, a new page has been added to help men adjust to their new caregiving roles. This feature provides caregivers with a guideline to help them know where to begin.

Because the importance of having caregivers maintain their physical and mental health as they take care of their loved ones is often lost -- and as a consequence, frequently results in caregiver burnout -- GMG has also created a new guide tailored to helping male caregivers avoid burnout and find ways to meet their needs.

To learn more about Caring Men Global Inc. and how to access their new guide, click the on the red button below.

**Learn more about Caring Men Global
Inc.**

NASHP RAISE Act State Policy Roadmap for Family Caregivers: Part 4 - Financial and Workplace Security for Family Caregivers

The National Academy for State Health Policy (NASHP) has released section 4 of a new RAISE Act State Policy Roadmap for Family Caregivers, "Financial and Workplace Security for Family Caregivers."

The purpose of the roadmap is to support states that are interested in developing and expanding supports for family caregivers of older adults by offering practical resources on identifying and implementing innovative and emerging policy strategies. The Financial and Workplace Security for Family Caregivers section highlights how states are supporting employed family caregivers and promoting financial security among caregivers.

Congress enacted the Recognize, Assist, Include, Support and Engage (RAISE) Family Caregivers Act in 2018, which created an Advisory Council to develop the country's first national Family Caregiver Strategy. NASHP created this roadmap with guidance from policymakers and leaders from across state government, using the RAISE Act goals and recommendations as a framework.

LEARN MORE



One Caregiver Resource Center

A centralized platform to support caregivers and adults to support caregivers and adults with intellectual and developmental disabilities who may be at risk of, or are living with, Alzheimer's disease or related dementia.

WE ARE HERE TO SUPPORT YOU!

onecaregiverresourcecenter.org

Click here!

Find resources on....

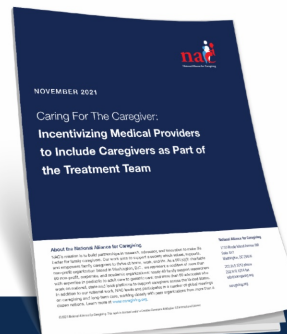
- Healthy Aging
- What is Dementia?
- Dementia in Adults with an Intellectual and Developmental Disability
- Effective Communication about Dementia
- Advanced Planning and End of Life Decisions
- Self-Care and Respite for Caregivers
- Research and Clinical Trials
- Upcoming Educational Opportunities
-and more!

This new site aims to serve as a platform to support caregivers and adults with intellectual and developmental disabilities (IDD) who may be at risk of, or are living with Alzheimer's Disease or related Dementia (ADRD). As an aging service provider who works closely with caregivers of all ages, demographics, and capacities, we are excited to provide a centralized tool that will provide direct access to webinars across the county, trainings, updated research, and resources.

VIEW WEBSITE

The National Alliance for Caregiving Releases a White Paper Analyzing Existing Incentives for Caregiver Services

Caregivers are not well integrated into U.S. healthcare systems. Across care settings, caregivers lack formal and consistent roles on the care receiver's care team and can struggle to manage their care recipient's needs with their own. Only 29 percent of caregivers report being asked by a healthcare professional about their caregiving needs; this rate drops to

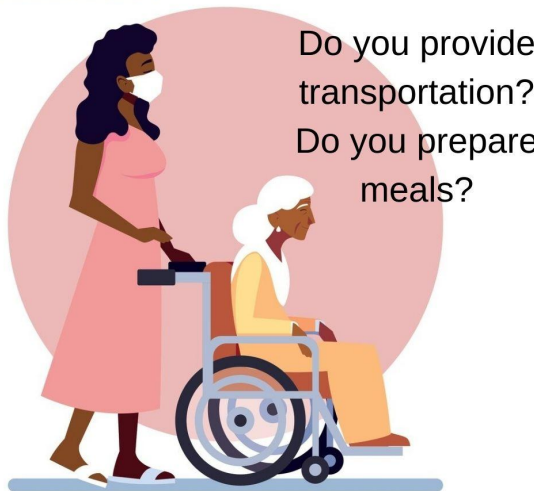


Caring For The Caregiver:
Incentivizing Medical Providers to Include Caregivers as Part of the Treatment Team

DOWNLOAD

13 percent when the question referred to what the caregiver needed to be able to care for themselves (**2020 Report of Caregiving in the U.S.; AARP and National Alliance for Caregiving**).

LEARN MORE



Do you provide transportation?
Do you prepare meals?

YOU MAY BE A CAREGIVER!

Livanta #MyRole Social Media Toolkit

To help improve public awareness of family caregivers and increase family caregivers' self-identification, Livanta has created #MyRoleCounts, a social media toolkit for partners and stakeholders. The social media toolkit consists of a variety of recommended graphic files, social media posts, and hashtags. Content is written using simple, plain language. Graphics are vibrant, use eye-catching colors, and cultural diversity to engage followers. Items from the toolkit can easily be downloaded below from Livanta's website or cross-posted on social media.

Click the link below to download and share the kit today!

**DOWNLOAD
HERE**



There are 23 million working caregivers in this country.

One in six working Americans provides unpaid care to a family member or friend with a chronic, serious, or disabling health condition. Cancer researcher Shivapriya Ramaswamy counts herself among the privileged minority in this significant, but historically marginalized, group.

Employed by a Fortune 500 pharma giant in the Boston Area, Ramaswamy has a steady salary and access to copious caregiver-friendly benefits, among them paid family medical leave, backup elder care, assistance referral services, and flexible work arrangements.

Yet, during the four years that Ramaswamy lived with and cared for both her aging parents, she made little use of what was on offer. "It took

time I didn't have to go over what was available... and going to HR for help felt too public and impersonal," she says. Though she desperately wanted a more flexible schedule, she never considered asking. "I had colleagues who worked some days from home.

“

I'd find myself staring at my computer screen, unable to think at work, partially because I was exhausted and partly because I was so worried about what was going on at home.

They were seen as less committed," she says. "I couldn't afford that stigma."

So Ramaswamy—like many of the 23 million working caregivers in this country—stretched herself until she nearly snapped. "I'd find myself staring at my computer screen, unable to think at work, partially because I was exhausted and partly because I was so worried about what was going on at home," she says. "I know that I brought some of this on myself. But the truth is I didn't feel comfortable discussing my caregiving issues at work and never thought of my employer as a solution to my problems."

Ramaswamy is, indeed, among the most privileged working caregivers in this country. Still, her story illustrates many of the issues that have generally stood between caregivers and the

Lessons from the Workplace: Caregiving During COVID-19

In the first article of its new Spotlight series, Social Innovations in Caregiving, the National Alliance for Caregiving details the hardships the COVID-19 crisis magnified for millions of working caregivers and explores the mismatch between what family caregivers need to meet the demands of working while caregiving and what benefits and supports employers offer. "The pandemic has exposed the reality that working Americans must too often choose between caring for loved ones and holding onto their jobs," says Grace Whiting, President, and CEO of NAC.

Offering potential solutions on how employers can address this mismatch, NAC advances recommendations for workplace policies and practices that employers can provide to caregivers. These recommendations include flextime, compressed workweeks, and public policy strategies to help reinforce workplace solutions such as redefined paid leave criteria.

[READ HERE](#)

Are you or someone you know caring for a child with a rare and/or serious illness?

Download our guidebook
The Circle of Care Guidebook for Caregivers of Children with Rare and/or Serious Illnesses

[DOWNLOAD NOW](#)

MADE POSSIBLE WITH SUPPORT BY:

Global Genes
Mallinckrodt Pharmaceuticals

NAC's Circle of Care Guidebook for Caregivers of Children with Rare and/or Serious Illnesses

The National Alliance for Caregiving recently produced *The Circle of Care Guidebook for Caregivers of Children with Rare and/or Serious Illnesses*, resource designed in partnership with Global Genes and with support by Mallinckrodt Pharmaceuticals to provide caregivers with the support, services and specialized information they need to care for a child with a rare and/or serious illness. This guidebook offers an extensive list of resources to help a caregiver in any situation throughout the entirety of their journey as a rare disease caregiver, compiled by those in the rare disease space and caregivers themselves. This list is supplemented by the specialized information needed in order to care for a child with a rare and/or serious illness. If you or someone you know cares for a child living with a rare and/or serious illness, make sure to check out the guidebook at the link below.

You'll learn about:

- The process of getting an accurate diagnosis for a rare and/or serious illness;
- Genetic testing, clinical trials and support groups that can help;
- Information on treatment and care coordination with specialized teams;
- Understanding the cost of care and treatment;
- Advocating for your child, their care and in their disease space;
- Empowering your child to manage their rare and/or serious illness through all aspects of their life, including when they become an adult; and
- Caring for yourself and your family.

There is also an appendix with a comprehensive list of online resources, supports and services for caregivers, the child living with the rare and/or serious illness, and his or her family that are referenced throughout the guidebook.

Click on the button below to access the Guidebook.

[VIEW THE GUIDEBOOK](#)



Dental Help for Adults With Disabilities

Special care dentistry (SCD) is a branch of dentistry that facilitates care for impaired patients with physical, intellectual, sensory, mental, emotional, medical, or social disabilities.

Special care dentistry is taught as a postgraduate course that equips dentists to offer dental services to patients with special care needs.

International organizations like the Special Care Dentistry Association (SCDA) are made up of oral dental professionals dedicated to promoting the oral health of persons with special needs.

Those qualified for special-care dentistry are people who need free comprehensive dental treatment. This includes:

- The elderly
- Disabled people
- Mentally and medically compromised persons

[SEE MORE](#)



Best Practice Caregiving: Infographic Series on Dementia Caregiving Program

The Family Caregiver Alliance (FCA) is publishing a series of blogs and one-page infographics as part of a series about specific dementia caregiving programs that are found in Best Practice Caregiving.

Best Practice Caregiving (bpc.caregiver.org) is a free online database that helps health care and social service organizations identify, compare and adopt best-fit programs for their clientele and community.

SEE MORE



Diverse Family Caregivers Toolkit

Download the Diverse Elders Coalition's **Resources for Providers: Meeting the Needs of Diverse Family Caregivers Toolkit**. This toolkit offers topline information on what providers need to know, and key pieces from our comprehensive training curriculum, **Caring For Those Who Care: Meeting the Needs of Diverse Family Caregivers**. Whether you've already attended one or more of our trainings, or this is your first time looking into what's available to help you support diverse family caregivers, we think you'll find these resources to be invaluable in building a more welcoming, supportive practice.

SEE MORE



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