

THIS WEEK IN CAREGIVING



November 24, 2021



CAREGIVING IN THE NEWS

From: National Alliance for Caregiving | Published: November 2021

If you're feeling tired this holiday season, you're not alone. Taking care of others — and yourself — can be difficult work. Those who care for caregivers may wonder why the caregiver in their life doesn't always notice the good they do for their families, their friends, our communities, and our society at large.

This Thanksgiving, take a minute to express genuine thanks to the caregivers in your life. Research has demonstrated that expressing gratitude can offset compassion fatigue and restore positive feelings that are necessary for our resilience. Those who care are the foundation of our families, and our health care systems, our social care systems, and our economies. That gives us 53 million reasons to give thanks.

Resources, Gadgets and Tools to Care for an Older Adult at Home

According to AARP's "Home and Community Preferences" survey, 3 out of 4 adults age 50 or older say they want to stay in their homes and communities as they age. And many do: Nearly 9 in 10 care recipients live in their own home, in someone else's home or in their caregiver's home. Some homes are well-suited for aging and providing care, but many require modifications.

When my parents needed 24-hour care and moved in with me, we didn't have the budget to build an addition or completely revamp the house. But with some research and advice, I found easier, affordable ways to make the home safe and navigable. And I continued to adapt as their needs changed. Eventually, I was able to fully remodel a bathroom for Dad's

The Truth About Caregiving: Your Determination Isn't Enough

The text with the video attachment landed in the middle of an important work meeting on Zoom. I should have stayed focused on the discussion at hand, but instead I let my finger hover over the image on the screen and then let it tap "play."

My mother, 85 and her mind riddled by dementia, was dancing at a happy hour at the assisted-living center near me where she lives. There she was: her hair perfectly coifed, still jet black, the slight swivel of the hips, the intentional way she tapped her Mary Jane-clad feet in time to "When the Saints Go Marching In." My mother. The woman who had come to the United States from Ireland as a new bride

safety, as well as get entry threshold ramps.

The goal is to help loved ones be as independent as possible at home, for as long as possible. To tailor your or your loved ones' residence for care at home, you can start with a home assessment by an occupational therapist, physical therapist, geriatric care manager (aging life care specialist), certified aging-in-place specialist (CAPS) or qualified professional via the area agency on aging or Department of Veterans Affairs.

From: AARP | Published: November 3, 2021

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in 1957 — not the pale imitation of the woman I had last seen dance this way at her grandson's wedding in August 2019, the night before a stroke would set off the tumbling dominoes of dementia. The 15-second snippet would carry me — giddy — through the rest of the day's meetings. I eagerly looked forward to visiting her that night to hear her tell me about the afternoon that had clearly brought her so much joy.

From: Washington Post | October 26, 2021

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EVENTS & OPPORTUNITIES

Webinar: Congressional Briefing on Family Caregiving in Diverse Communities: Addressing the Needs of Diverse Family Caregivers for Older Adults

Date: December 8, 2021 at 1:00 PM (EST)

Join the Diverse Elders Coalition and its members, in partnership with the National Alliance for Caregiving, as they 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.

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AHHQI has an open RFP: 2022 Home Health Grant Request for Proposals

The Deadline is December 23, 2021

The Alliance for Home Health Quality and Innovation (AHHQI) seeks to sponsor a research project to help advance home health care and may seek to improve care delivery at home through quality and innovation. Funding will be awarded up to a total of \$75,000 maximum (including indirect costs). Multiple projects may be funded if they do not exceed the total funding allocated for all projects of \$75,000. Proposals are due by close of

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PATIENT AND CAREGIVER STUDIES

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.

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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.

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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.

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IN CASE YOU MISSED IT...

NAC Elevates The Voice of The Nation's Caregivers In a New Video Campaign

NAC has produced a series of vignettes designed to capture the voice of our nation's caregivers. Included in the RAISE Council's final recommendations to Congress, the vignettes offer a timely, added layer of social support and recognition for family and friends providing unpaid care.

To help support caregivers, NAC supports the implementation of policies that will reinforce those caring for a diverse range of people across different lifespans and experiencing different health conditions.

Click below to view the video.



RESEARCH & RESOURCES

The National Alliance for Caregiving Releases a New 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 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**).

As discussed in a new white paper published by NAC, no single solution that can address this complex area of need. Variations in payment models, insurance coverages, healthcare settings, and types of provider challenge innovators to generate flexible solutions. Emerging models of caregiver support show promise that integrating caregivers

A promotional graphic for a white paper. It features the white paper cover with the title "Caring For The Caregiver: Incentivizing Medical Providers to Include Caregivers as Part of the Treatment Team" and the NAC logo. A blue "DOWNLOAD" button is positioned at the bottom right of the graphic.

NOVEMBER 2021

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

DOWNLOAD

more fully not only benefits caregivers, but may improve patient outcomes.

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Is What Matters to You Today the Same as Two Years Ago?

Millions of people will travel to see friends and family in person over the upcoming holiday season, many for the first time in nearly two years. Our world and society have changed dramatically over the course of the COVID-19 pandemic and the upheaval has led many to reevaluate their own hopes and expectations for the future.

Now is a good time to talk about what matters to you with those who care about you, especially related to your health and care needs as you age. It's also an opportunity to have conversations with people whose care you may be responsible for.

Whether you are a clinician or other professional working with older adults, or you are considering what matters in your own personal life, here are resources to help begin or facilitate these sometimes difficult conversations.

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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!

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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."

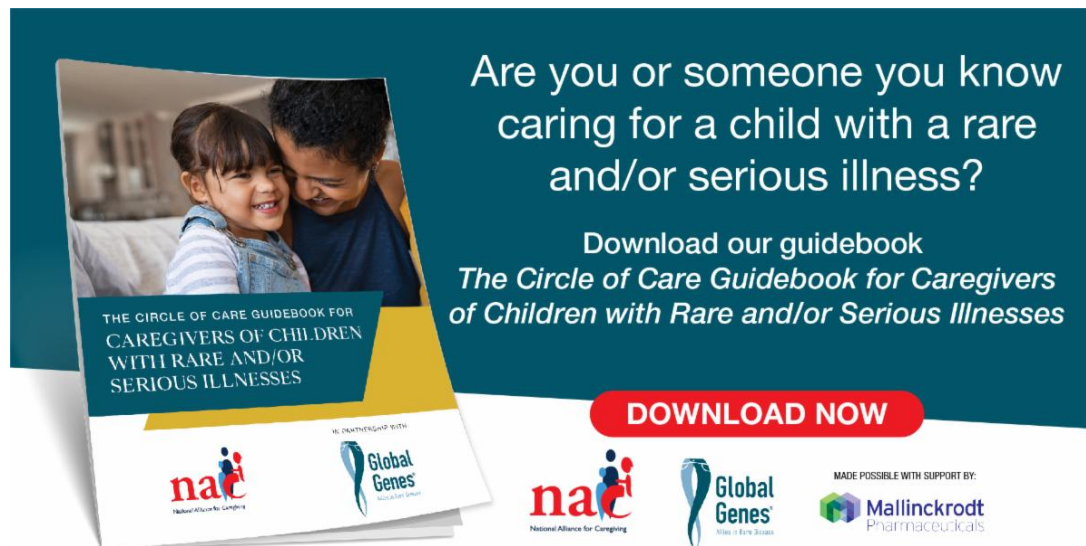
Ramaswamy is, indeed, among the most privileged working caregivers in this country. Still, her story illustrates many of the issues that have generally stood between caregivers and the

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.

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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

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IN PARTNERSHIP WITH

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
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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

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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.

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Plain Language Resource for Crime Victims With Disabilities

A new fact sheet, created by The Arc's National Center on Criminal Justice and Disability, is designed for people with disabilities to understand their rights if they are victimized. The document outlines different types of abuse, what people with disabilities -- or the caregivers who help them -- can do if they become a crime victim, and where to go for help. **Download it now** and share it in your community!

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What's Public Health Got To Do With... Family Caregiving?

Trust for America's Health (TFAH) has published a blog, "What's Public Health Got To Do With... Family Caregiving?," to launch its new monthly blog series on Age-Friendly Public Health Systems. This series is designed to stir up conversation, generate interest, and challenge healthy aging stakeholders to engage more deeply in age-friendly public health issues.

Author of this month's blog on "What's Public Health Got To Do With... Family Caregiving?," Megan Wolfe, TFAH's Senior Policy Development Manager, outlines five potential roles for public health departments to support caregivers, organized according to TFAH's AFPHS 5Cs Framework. The roles include collecting and disseminating data, coordinating existing supports and services, connecting and convening multiple sectors, communicating, and complementing existing supports.

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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.

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Dementia Care Providers Database

Best Practice Caregiving is a free online database of proven dementia programs for family caregivers. It offers a searchable, interactive, national database of vetted, effective programs that offer much-needed information and support. The database is an invaluable tool for healthcare and community-based organizations, as well as funders and policy makers to discover and share high quality programs for caregivers.

In the Best Practice database you will find detailed information about:

- focus of each program
- (e.g., reducing stress, understanding dementia, planning care, skill-building, health & wellness, etc.)
- program implementation
- research findings
- direct utilization experiences of delivery sites
- program developer information.

Click [here](#) to learn more about the database or click the button below to access it.

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Home Is Where the Care Is

What if you were one of the 2 million adults who are homebound in the United States? Wouldn't you want care to come to you? With the nation's older adult population increasing, home-based primary care is quickly becoming the future of health care for patients who are medically complex. New resources share needed information about delivering primary care in the home:

- The **Better Care Playbook's Home-Based Primary Care Collection** provides research, resources and tools for delivering care at home. The collection includes blogs from Rush@Home detailing its care model elements and implementation insights, and the Department of Veterans Affairs highlighting its successful program.
- A **Home Centered Care Institute (HCCI) House Calls 101 course** offers a simulated educational experience to help you get started with home-based primary care.

Click [here](#) to the online course. Click the button below to browse the collection.

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Report: The United States Should Recognize and Support Caregiving Youth

In the United States, more than 5.4 million children and adolescents under age 18 provide care for family members who are aging or have chronic illness, disability, or other health conditions that require assistance.

In this policy study published in the Society for Research in Child Development's *Social Policy Report*, the authors describe youth's care for the family and highlight the increasing prevalence, global challenges, and uneven successes of measurement and categorization. They briefly summarize research on how caregiving affects youth's academic, social, and emotional well-being. Next, they present novel, emerging evidence from the public school-based 2019 Youth Risk Behavior Survey for the State of Florida, which suggests that as many as 24 percent of middle school students and 16 percent of high school students provide at least some care to the family on a regular basis. Drawing on this evidence, the authors' discuss targeted social programs which have been shown to promote the well-being of caregiving youth outside of the United States, as well as a 13-year-old school-based intervention in The School District of Palm Beach County, Florida.

The report concludes with specific recommendations for a path toward recognizing and supporting caregiving youth via policy and practice in the United States. Its aim is to increase the awareness and feasibility of identifying and supporting caregiving youth and their families via government-organized data collection and targeted social policies.

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2021 Global State of Caring Report

The International Alliance of Carer Organization's 2021 Global State of Care report

provides an in-depth profile of the issues, approaches, policies, and innovations that are needed to support carers. It profiles the carer policies and practices in 18 countries. This interacting tool features carer initiatives addressing six universal carer priorities:

- Recognition: Legislation and awareness campaigns
- Financial support: Income support, pensions, and benefits
- Work and education: Carer-friendly workplaces and educational initiatives
- Health and well-being: Health and social supports
- Information and knowledge: Resources and education
- Evidence-informed practices: Innovative policies and practices

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The John A. Hartford Foundation's Dissemination Center

Funded and disseminated by **The John A. Hartford Foundation**, The American Association of Retired Persons (AARP) has released a new series of how-to videos and accompanying resource guides that walk family caregivers through what to expect before, during, and after a planned or emergency hospital stay.

The videos and resource guides, many of which are available in both English and Spanish, are free of charge and were developed by **Home Alone Alliance** members—the

The “How-To” videos and resource guides for family caregivers are on specific medical/nursing tasks – including preparing special diets, managing incontinence, wound care, mobility, and managing medications.

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Navigating the Pandemic: A Survey of U.S. Employers

Employers play a vital societal role by providing employment, work experience, employee benefits, and the ability for workers to save and invest for a secure retirement. This report examines the pandemic's impact on employers across the company, their response, and timely opportunities. A strong employee benefits package, including retirement benefits, health insurance, workplace wellness programs, and caregiver support, can create a win-win situation for employers and their employees. Especially now, as our nation is emerging from the pandemic, employers need support from policymakers to continue paving the way for their recovery and to make it as easy as possible to enhance their business practices and expand their benefits offerings.

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