

# THIS WEEK IN CAREGIVING



October 20, 2021



## CAREGIVING IN THE NEWS

*From: National Alliance for Caregiving | Published: October 2021*

### **New RAISE Report Outlines 5 Goals to Improve Lives of Family Caregivers**

The challenges of being a family caregiver have generally been viewed as a private, personal matter. But in a noteworthy shift, a new report to Congress lays the groundwork for a much-needed national strategy to assist the over 48 million Americans who care for a parent, spouse or other loved one.

Family caregivers provide an immense contribution, often at significant personal cost and with little guidance. Experts have estimated the value of their unpaid services at \$470 billion — almost half a trillion dollars. These folks provide in-home medical care and perform nursing tasks, on top of a wide range of duties that include personal care, household chores, coordinating appointments, transportation, meal preparation, shopping — you name it. And that's not all: 6 in 10 family caregivers also hold down jobs outside the home.

*From: AARP | Published: October 12, 2021*

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### **Biden's \$400B Plan to Overhaul Home Care is 'More of a Repair Effort Than a New Direction'**

If the scope of President Joe Biden's social spending plan is too large to grasp, then consider Nancy Slomba of Western New York state.

She spends 84 hours a week caring for her son Joe Slomba, who has cerebral palsy and needs assistance to bathe, get in and out of bed and leave the family's house.

### **Sleep Loss Puts Family Caregivers at Risk for Health Problems of Their Own**

Nicknamed the “sandwich generation,” many older adults over 50 care for both aging parents and children. Caregivers are typically female – some 75 percent. And 17 percent of all adults over 65 help someone, according to the American Association of Retired Persons (AARP).

And with 40 percent of caregivers juggling full-time work and families – stress is constant – leading to sleep deprivation.

The 59-year-old resident of a small Wyoming County town about 35 miles east of Buffalo gets paid \$12.50 an hour to care for Joe through a New York state-based program. She and Joe's twin brother, Ben, split the caregiving hours throughout the week.

*From: Democrat & Chronicle | Published: October 19, 2021*

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It is no wonder that most caregivers lack sleep. The Centers for Disease Control (CDC) says 37 percent of all caregivers report insufficient sleep. But caregiver sleep loss goes beyond missing a few hours to binge-watch a favorite show. It is a constant decline in sleep quantity and quality. And sleep deprivation causes serious health issues.

*From: 50 Plus Advocate | Published: October 13, 2021*

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## EVENTS & OPPORTUNITIES

### Innovations in Alzheimer's Caregiving Awards

#### The Deadline Has Been Extended to November 1

With support from The Rosalinde and Arthur Gilbert Foundation and Bader Philanthropies, Inc. we're happy to announce that the application process is now open for this year's Innovations in Alzheimer's Caregiving Awards.

One award of \$20,000 will be given in each of the following three categories:

- Creative Expression
- Diverse/Multicultural Communities
- Public Policy
- Background

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### Caregivers, This Free, Virtual Event is For You

#### Guilt, Grief, and Guideposts: A Conversation with Dr. Pauline Boss and Kathy Ritchie

Wed, October 27, 2021  
12:00 PM – 2:30 PM EDT

Sensations of guilt and grief are inevitable for caregivers. They often yearn for relief from their circumstances, while feeling tremendous love for, and attachment to, their loved one.

The ambiguous grief of losing a loved one as they were, as in the case of dementia, also accompanies caregivers throughout their journey. The relationship is changed forever.

That's why Duet: Partners In Health & Aging is hosting Guilt, Grief and Guideposts: A Conversation with Dr. Pauline Boss and Next Avenue's health and caregiving editor,

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## **WISER's Annual Women's Symposium**

### **A Virtual Event**

**25 Years of Improving Women's Financial Security**  
**Where We Stand: Possibilities & Progress !**

Friday, October 29, 2021  
11:30am - 3:00pm ET

Join the Women's Institute for a Secure Retirement (WISER) for a virtual symposium to celebrate WISER's 25 years of helping women, educators and policymakers address the important challenges women face when saving for retirement. This year's event will explore how financial services providers, lawmakers, public policy experts, and community leaders can work together to make the *next* 25 years more financially secure for all women.

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HERE](#)

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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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## AHEAD Study

Join a trial that aims to help prevent Alzheimer's disease, funded by the National Institutes of Health (NIH) and Eisai Inc., which is testing an investigational treatment aimed at delaying memory loss before noticeable signs of Alzheimer's disease begin.



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## LEAF: Life Enhancing Activities for Family Caregivers



Life Enhancing  
Activities for  
Family Caregivers  
**LEAF**

Researchers at UCSF and Northwestern University are testing a program for family caregivers of people with Alzheimer's Disease designed to increase levels of positive emotion, which in turn can help lower stress and support ways of coping with the stresses of caregiving.

Click the red link below to learn more and click [HERE](#) to take the pre-screening survey.

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## Veteran User Experience Research Study

Are you a Veteran? Active duty or Reserves? A caregiver? A family member? The Department of Veterans Affairs wants to make it easier for you to explore, apply for, manage, and track your VA benefits. Teams at the VA want to hear your feedback about improvements they are making to VA websites, mobile applications, and other digital tools

-- to ensure that these services are usable and relevant for you.

Click the red link below to learn more and click [HERE](#) to register.

[LEARN MORE](#)



## 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.**



### **How Emerging U.S. Children's Hospice Homes are Fulfilling an Unmet Need for Overnight Respite**

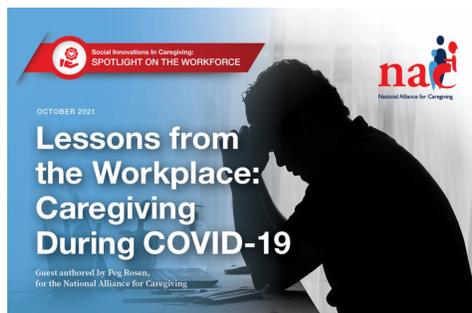
ARCH joined the BREAK Exchange to present this webinar with Jonathan Cottor, MBA, MPH, Father, Advocate, co-founder of Ryan House in Phoenix, Arizona. Ryan House was recognized by ARCH as an Innovative and Exemplary Respite Service in 2020.

The #1 wish that all families with a child on a life-limited journey wants is a cure, next is some sleep. The U.K. Children's Hospice Home model started almost 40 years ago with Helen House and has grown to over 54 homes today around the globe. This simple concept focuses on family and caregiver support by providing overnight respite, and pediatric palliative and end-of-life hospice care throughout a child's journey. Thankfully three communities have succeeded in opening this much needed care model in the U.S., and many more are in various stages of development.

**Click below to view the video.**



## RESEARCH & RESOURCES



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 pharmaceutical 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. “I 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

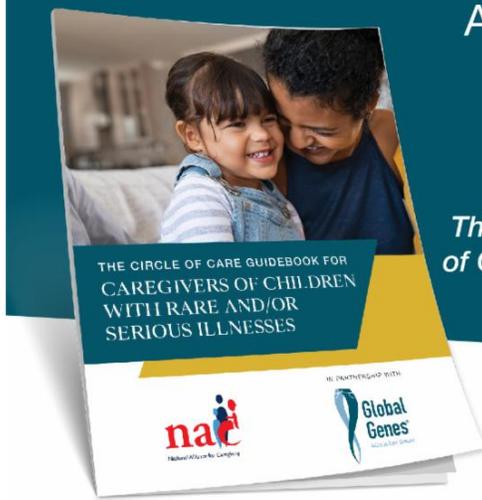
In the first **article** of its new Spotlight series, Social Innovations in Caregiving, the National Alliance for Caregiving details the hardships the COVID-19 crisis magnified for millions of working caregivers and explores the mismatch between what family caregivers need to meet the demands of working 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**



## 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*, a new 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**



## New 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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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 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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