

# THIS WEEK IN CAREGIVING



September 23, 2021



## CAREGIVING IN THE NEWS

### **RAISE Council Releases Report to Congress Intended to Better the Lives of Caregivers**

On September 22, 2021, the RAISE Family Caregiving Advisory Council released its initial report to Congress. This report outlines the challenges faced by family caregivers, federal programs currently available to support them, and provides 26 recommendations for better supporting family caregivers. The recommendations will form the foundation of the National Family Caregiving Strategy, which will include action steps to increase recognition and support for family caregivers.

The report includes an inventory of federally funded efforts to support caregivers as well as written narratives of interviews the National Alliance for Caregiving conducted with 26 caregivers representing a range of caregiving situations and needs. NAC has been engaged with the RAISE Council since its inception, supporting its work by offering its Advocacy Collaborative's policy recommendations for caregivers, providing the narratives and producing a series of video vignettes of the interviews.

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

[READ THE REPORT](#)



### **Paid Family and Medical Leave Is Essential for Older Adults, Too**

When people think of paid family and medical leave, they often think of parents taking time off to bond with their newborns. As important as that is, an often-overlooked group that also urgently needs a robust system of paid leave is older Americans — even those who are retired.

For older adults who are still in the workforce, paid leave is crucial to manage chronic, as well as acute, health conditions. Such medical concerns can affect workers of all ages, but they're felt disproportionately by older ones since health almost inevitably deteriorates with age.

*From: Next Avenue | Published: September 8, 2021*

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## Caregiving Shortage Worsens Throughout the Country as Population Ages

A program at Detroit's Hannan Center that provides day care for adults with dementia, offering a needed break for their caregivers, was one of the projects discussed by panelists at a public forum on issues facing caregivers and possible solutions for them.

Paula Duren, a Detroit-based psychologist, is one of an increasing number of caregivers of elderly adults who felt overwhelmed by the task of caring for aging parents, both of whom suffered from dementia.

"There were moments that felt like you didn't even know what to do," Duren said. "It brings about a helplessness."

Duren was a panelist at a virtual forum last week hosted by the New York & Michigan Solutions Journalism Collaborative, a group of news, community and academic organizations that cover chronic problems with a solutions-focused lens, and Strides for Seniors, an annual month-long event series focused on Detroit's senior centers.

*From: Detroit Free Press | Published: September 14, 2021*

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## Student Caregivers Face Challenging Dual Responsibilities

Caregivers pursuing bachelors or other degrees face increased emotional distraction and financial strain that educational institutions could ease by implementing some basic policies and support systems, a recent AARP study revealed.

The academic, economic, and emotional toll for students with added caregiving responsibilities is clear. Seven in 10 student caregivers reported that their caregiving duties impacted their ability to handle academic commitments, the study found, while six in 10 said that they have struggled to pay for school. Emotional distress (and the resulting distraction) was the most commonly cited impact, but about one-third struggled with late assignments, missed classes, and lack of test preparation because of their caregiving duties.

Still, many of these student caregivers keep the stress hidden from school officials who may be best positioned to lend help, including financial aid departments and student health centers.

*From: AARP | Published: September, 2021*

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## EVENTS & OPPORTUNITIES

### Health Literacy: A Three-Part Series to Support Better Communication

**Fall 2021 | Online**

Join the National Health Council (NHC) this Friday, Sept. 24, for the first session of our webinar series, Health Literacy: A Three-Part Series to Support Better Communication. Each week, we will explore how to ensure your advocacy and scientific communications are developed and delivered in a way your audience will understand.

- Introduction to Health Literacy: Your Clear Communication Toolkit - Sept. 24, 12:00

- 2:00 p.m. ET
- Health Literacy Strategies for Advocacy - Oct. 1, 12:00 - 2:00 p.m. ET
- Health Literacy for Science Communication: A Tool to Boost Understanding and Build Trust - Oct. 7, 12:00 - 2:00 p.m. ET

The first hour of these webinars will be open to the public. The second hour of the webinar will be an NHC-members and **Symposium** Registrant-only workshop. If you have any questions about registration for the webinar please contact Silke Schoch at [sschoch@nhcouncil.org](mailto:sschoch@nhcouncil.org).

To learn more click on the button below. Click [here](#) to register online.

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## Call for Nominations for the Caregiving Visionary Awards

**Deadline to Submit Nominations: October 1, 2021**

Show your appreciation for the family, professional, or volunteer caregiver in your life, and nominate them for our sixth annual Caregiving Visionary Awards.

The Caregiving Visionary Awards honor individuals and organizations that act as beacons of hope for family caregivers and former family caregivers.

To nominate an individual or organization you know or to nominate yourself, please complete [the nomination application](#). The deadline to submit a nomination is Friday, October 1. Winners will be revealed on November 23 at the inaugural Caregiving Visionary Award Show!

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## National Family Caregiving Strategies and Policy Recommendations from the RAISE Family Caregiving Advisory Council

**October 4, 2021 1:00 - 3:00 PM EST | Online**

The 15th annual Katz Policy Lecture will examine the RAISE Family Caregivers Act, which directs the U.S. Department of Health and Human Services to develop and maintain a national strategy to recognize and support family caregivers. [Get more info](#).

Keynote speaker, Alan B. Stevens, PhD, will discuss family caregiving strategies and policy recommendations from the RAISE Family Caregiving Advisory Council, and the impact these will have on our communities.

Following our keynote address, a reactor panel of industry experts will give their responses to the presentation, and discuss how the Act impacts different types of individuals and communities, as well as state level policy.

REGISTER



## PATIENT AND CAREGIVER STUDIES

### 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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### Survey: COVID-19 and Its Impact on Gastrointestinal (GI) Illnesses

With the help of patients, caregivers, and our Industry Council, IFFGD has created a survey to gain insight into the impact COVID-19 and the pandemic has had on the Gastrointestinal (GI) Illness population. We hope this will assist healthcare providers, law makers and industry partners on the future care of patients.

\*Approximate time to take this survey is 7 minutes

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### Caregivers: How Much Do You Know About Managing Money?

Help evaluate a free virtual program by the Alzheimer's Association about making financial decisions and planning for future care costs. Visit [alz.org/managingmoney](https://www.alz.org/managingmoney) to learn more.



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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.

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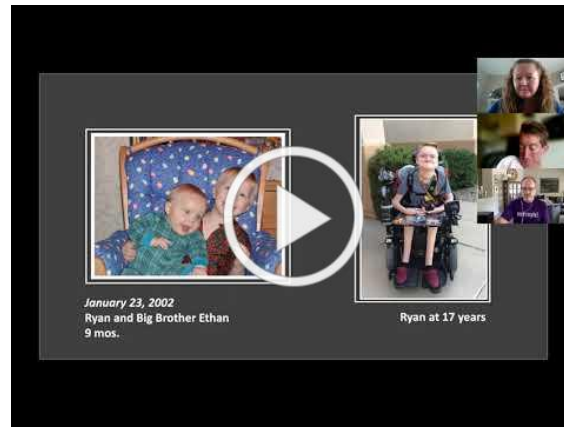
**IN CASE YOU MISSED IT...**

**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

**JUST RELEASED!**

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

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

**DOWNLOAD NOW**

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### NAC Presents The Circle of Care Guidebook for Caregivers of Children with Rare and/or Serious Illnesses

The National Alliance for Caregiving is proud to present *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 it's 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 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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