I Am a Full-Time, Sandwich-Generation Dementia Caregiver. I Am Exhausted.

"Caregivers don't speak up because we’re depleted. We haven't slept. We don’t eat right. We drink too much (or too little). We are desperately trying to hold onto some semblance of our pre-caregiving lives while that version passes us by. For the people thinking, “Well it’s your mother, of course you’d take care of her.” That’s not the issue. I would do it all over again, but how about a little more support? We don’t know what we don’t know, and often we don’t know how—or have the time—to access what is available.

Until society recognizes family caregiving as a normal part of life, we’ll continue to look for validation that we matter and that what we’re doing is valued. So instead of asking your family caregiver friend “what’s new?”, ask them how they are doing. This question comes in many forms and can be as simple as: “Have you been able to get any rest?”; “Have you eaten?”; “Is there anything I can help you with?”; and “Do you need groceries?” When you’re not sure what to say, providing a compassionate ear goes a long way. We just need a safe place to share our fears, hopes, and all that is weighing on our hearts and minds.”

From: Caregiving.com | March 4, 2021

Six States to Participate in NASHP's Caregiving Institute

"The National Academy for State Health Policy (NASHP) has selected six states (CT, DE, IL, MD, NY, and UT) to participate in its State Medicaid Policy Institute on Family Caregiving. State teams will work with state leaders, NASHP staff, and experts to develop and strengthen policies and strategies that support family caregivers, with a particular focus on home- and community-based approaches for older

Cancer Caregivers Report More Stress During Pandemic

"Dr. Margaret Longacre, chair of the department of public health at Arcadia University, said her team found that more than 72% of caregivers said that the most pressing problem now is emotional stress, but there’s more.

'52% indicated that their level of physical strain was much higher or somewhat higher than pre-COVID-19 caregiving time,' she detailed.
The institute’s focus will include peer-to-peer state learning, technical assistance, promising practices, and an award of $40,000."

"Behind that though is also their indication of financial strain. So, 42% indicated that their level of financial stress was much higher or somewhat higher than pre-COVID-19 caregiving."

INTRODUCING A Unified Strategy to Support Family Caregivers Across the Nation

The National Alliance for Caregiving (NAC) has released From Momentum to Movement: Developing a Unified Strategy to Support Family Caregivers Across the Nation.

This report represents the first iteration of a living document and compilation of resources to help guide advocates in developing statewide caregiving strategies that address community-level needs. This report presents a strategic process to foster the development of actionable goals in new state plans. It also includes core policy recommendations in person-centered domains intended to coordinate alignment across key global, national, and state-level priorities and to strengthen movement toward a robust, unified caregiving strategy for caregivers across the lifespan.

COVID-19 Vaccine for Homebound Older Adults:
Challenges and Solutions

March 31, 2021 | 3:00-4:30 PM EST | Online

There are up to 15 million older adults and people with disabilities in America that are experiencing challenges accessing the COVID-19 vaccine due to issues that prevent them from traveling to a vaccine site. With support from The John A. Hartford Foundation and the Cambia Health Foundation, Trust for America’s Health is offering a webinar to explore the challenges and policy barriers to vaccine access and highlight innovative vaccine distribution practices. Participants will also learn about the complexities of vaccine distribution to homebound individuals, as well as the crucial partnerships among public health departments, aging services and other community stakeholders that are key to expanding vaccine access.

The webinar will include time for Q&A from the audience. Presenters:
- Amanda Cohn, MD, Chief Medical Officer, National Center for Immunization and Respiratory Diseases at Centers for Disease Control and Prevention
- Thomas Cornwell, MD, Senior Medical Director, Village Medical at Home
- Ingrid Ulrey, Public Policy Director, Public Health Seattle-King County

REGISTER

RARE on the Road: Global Genes Rare Disease Leadership Tour

March-May 2021

Since 2017, Global Genes and the EveryLife Foundation have partnered to host RARE on the Road events around the country, developing the next generation of advocacy leaders. With feedback from the community, RARE on the Road 2021 will consist of one interactive webinar, open to all who wish to attend, regardless of their geographic location, and three virtual, state-specific meetings focusing on issues and resources relevant to residents in Nevada, Florida, and Illinois. Click the red link below to learn more.

A Rare Disease Leadership Interactive Webinar will be hosted on March 23, 2021 from 11 AM - 1:30 PM EST. Click HERE to register now.

LEARN MORE

Health Equity Summit

April 28, 2021 | 11 AM - 2:30 PM EST | Online

Amgen’s 2020 Health Equity Summit illuminated the value of cross-sector/functional partnerships intended to disrupt systemic barriers to good health among vulnerable populations.

The 2021 Summit will highlight innovative collaborations that have emerged from this time of adversity and best practices for building strategic partnerships to help make American
CALL FOR APPLICATIONS

Apply to Be a Health and Aging Policy Fellow

Deadline: April 15, 2021

Candidates with a strong commitment to health and aging issues, leadership potential, and interest in aging-relevant policy work are invited to join the next class of Health and Aging Policy Fellows (2021-2022).

The Health and Aging Policy Fellows Program continues to make great strides in advancing policy with creative solutions in the context of COVID-19.

CALL FOR PUBLIC COMMENTS

Help the NIH End Structural Racism in Biomedical Research

Deadline: April 9, 2021

The NIH is requesting a moment of your time to respond to a Request for Information for input on practical and effective approaches to improve and strengthen racial equity, diversity, and inclusion across all facets of the biomedical research enterprise, both within NIH and the external community, and expand research to eliminate or lessen health disparities and inequities.

The NIH invites you to share your perspective and recommendations as we thoughtfully consider NIH’s proactive approach to address racial and health inequities in biomedical research.

Comments can be submitted through the submission website and must be received by April 9, 2021.

IN CASE YOU MISSED IT...
Caregiving During a Pandemic: A Year in Review

March 24, 2021

Home Instead gerontologist and caregiver advocate Dr. Lakelyn Hogan was joined by caregiving expert C. Grace Whiting from the National Alliance for Caregiving as they review how the pandemic has impacted caregivers and lessons learned for the future of caregiving.

Grace and Lakelyn discussed:
- The impact of the pandemic on family caregiving and older adults
- Silver linings that have emerged for aging adults and caregivers
- Tips for family caregivers as they continue to navigate COVID-19
- Ways the pandemic will impact caregiving going forward

Caregiving in America: A Chronic Disease Day Livestream Series

March 25, 2021 | 1 PM EST
Jessica Zitter, MD (Extremis, Extreme Measures) is an ICU and palliative care physician, author, speaker and documentarian. Her latest film, Caregiver: A Love Story, examines the rising public health crisis of family caregiver burden. Jessica joins How We Got Here to discuss her trajectory from medical school student to caregiver advocate. Jessica emphasizes the importance of advance care planning and talks about why it's so hard for us to talk about death. She also describes her grandmother— the first person in her life she realized was a caregiver. Jessica explains that the family caregiving experience was not the original topic she set out to explore with Caregiver: A Love Story and what compelled her to share that story instead. At the end of the episode, Jessica offers a special message of encouragement for family caregivers.

How We Got Here, a caregiver podcast from Caregiving.com and The Whole Care Network, is sponsored by Anthem.

Caregiving.com Caregiver Salary Calculator

Caregivers: You can be a part of social change for the caregiving community in a matter of minutes. We are proud to partner with Caregiving.com and invite you to use their caregiver salary calculator to compute the value of your unpaid care work! Fill out the questions and send an invoice to your senators.

Start by clicking the red link below!

Make sure to follow Caregiving.com on social media: @caregivingsupport on Facebook and @caregiving on Twitter.
State-by-State Resources for Family Caregivers

AARP created local caregiver resource guides to help family caregivers access key programs, services and agencies in their community. Just click the red link below and you’ll be able to click or tap on a state to find tools and support for everything from health, legal and financial assistance to respite care in your community.

SEE MORE >

Dementia: Best Practice Caregiving

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.

SEE MORE >

NEW RESEARCH

Meeting the Challenges of Caring for Persons Living with Dementia and their Care Partners

A new report from The National Academies of Sciences Engineering Medicine (NASEM) "assesses the quality of the existing evidence about care for people living with dementia and their caregivers and recommends interventions for broad dissemination and implementation. Meeting the Challenge of Caring for Persons Living with Dementia and Their Care Partners and Caregivers: A Way Forward also provides a blueprint to advance the field, and guide future research and actions toward better dementia care."

From: The National Academies of Sciences Engineering Medicine | February 24, 2021

LEARN MORE >
Family Caregiver Training Needs and Medicare Home Health Visit Utilization

New research finds that training family caregivers in certain activities, such as medication management, household chores, and self-care, may affect home health visit utilization. The research points to the importance of family caregiver training needs in improving the utilization of health care for older adults and their health outcomes. Family caregivers are an important part of the health care team and need support and training to deliver quality care at home.

LEARN MORE >

FOLLOW US TO STAY CURRENT ON CAREGIVING!