

# THIS WEEK IN CAREGIVING



July 13, 2022



## CAREGIVING IN THE NEWS

### Jobs Aplenty, but a Shortage of Care Keeps Many Women From Benefiting

A dearth of child care and elder care choices is causing many women to reorganize their working lives and prompting some to forgo jobs altogether, hurting the economy at a moment when companies are desperate to hire, and forcing trade-offs that could impair careers.

*From: New York Times | Published: July 8, 2022*

[READ MORE](#)



### Chronic Stress Linked to Future Health Risk in Caregivers

A recent study from the University of Liverpool, U.K., in the journal *Brain Behavior, Immunity, and Health*, has revealed that the chronic stress of caring can have a damaging effect on the future health of caregivers. Caregivers, who were initially healthy at study entry, had a 33 percent greater risk of illness or disability just eight years later.

*From: Psychology Today | Published: July 8, 2022*

[READ MORE](#)



### How to find caregiver resources by state

At some point, even the most fiercely independent people must accept that they need help. This lesson becomes even more poignant among aging seniors – many of whom want nothing more than to maintain their independence as they age. As the activities of daily living get harder to accomplish, seniors and family caregivers may realize that it's time to search for assistance.

*From: Senior Matters | Published: July 7, 2022*

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# NAC NEWS AND UPDATES



## World Carers Conversation 2022 Session Recordings

World Carers Conversation returned May 19, 2022 as a global, virtual event with the support of EMD Serono and Embracing Carers. Innovators, researchers, policymakers and carer advocates from around the globe learned about advancements in the field, got inspired, and made connections that matter for the future of carers everywhere. These recordings cover the primary conversations and topics discussed.

To view the slide deck used in the event, click [here](#). To view the recordings, click below.

[VIEW RECORDINGS](#)



## Global Voices of Caregiving: A PhotoVoice Project

As part of the World Carers Conversation 2022, NAC worked with Chief Story Officer Anne Levy and caregivers from around the globe to help them tell their own story through a series of photos. These photos addressed simple questions about being a caregiver, such as what works, what doesn't work, and what a world that embraces and supports caregivers would look like. Each one of these stories is unique to the caregiver's own experience and tells a diverse story of what it's like to care for others, an act which connects us all.

“  
I am always learning from and sharing with my fellow carers how to care for myself while caring for my loved one.  
– Jean, Taiwan

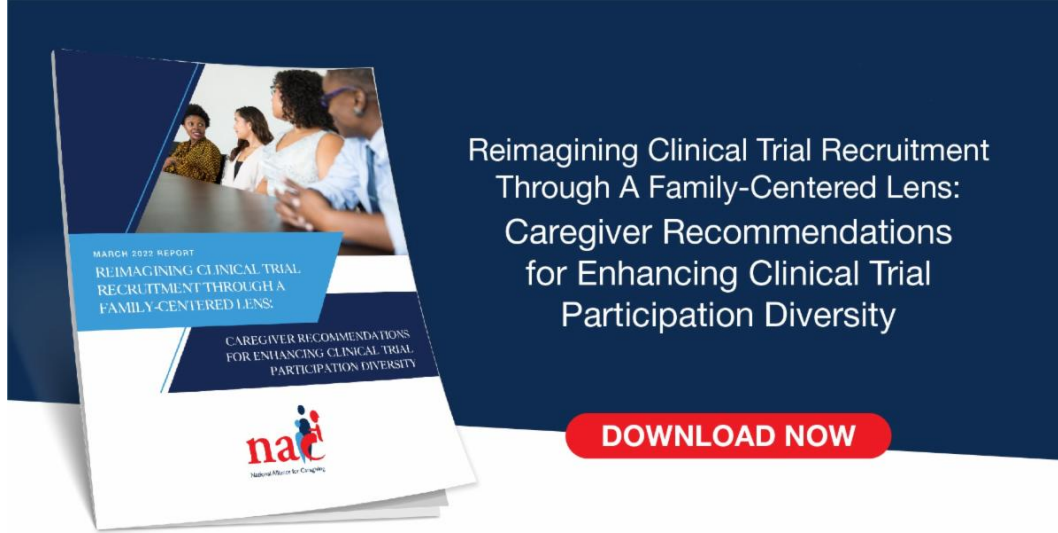
2022 WORLD CARERS Conversation  
A VIRTUAL GLOBAL SUMMIT HIGHLIGHTING INNOVATIONS IN CAREGIVING RESEARCH, PRACTICE AND POLICY

nac National Alliance for Caregiving  
embracing carers

To view and hear these stories, please click on the red button below.

[VIEW STORIES](#)





## Reimagining Clinical Trial Recruitment Through a Family-Centered Lens: Caregiver Recommendations for Enhancing Clinical Trial Participation Diversity

The National Alliance for Caregiving is proud to present *Reimagining Clinical Trial Recruitment Through a Family-Centered Lens: Caregiver Recommendations for Enhancing Clinical Trial Participation Diversity*, a new report developed with sponsorship from Traverre Therapeutics. Building on the priority area of clinical trials recruitment and retention identified in NAC's 2019 report *Paving the Path for Family-Centered Design: A National Report on Family Caregiver Roles in Medical Product Development*, this report synthesizes outputs from a series of three roundtables. In collaboration with Health Leads, NAC mobilized its network of researchers, policymakers, innovators, patients, families and caregivers to discuss and develop strategies for improving how researchers engage caregivers from populations most impacted by structural inequities in order to better understand how to increase representation of diverse patients in clinical trials.

Included in this report:

- Summary of caregiver expert convening including their key insights on caregivers' role in clinical trials and barriers to patient and caregiver participation;
- Summary of clinical trial roundtable including current strategies that improve caregiver engagement and support caregiver roles related to trials;
- Direct quotations from caregiver experts about their experiences with clinical trial participation;
- Outputs of a co-design session with both caregiver experts and clinical trial experts;
- Individual-level, community-level and systems-level focus areas for acting on these co-developed recommendations.

NAC's report underlines that engaging caregivers more effectively in the clinical trials process to promote better trial enrollment diversity requires investment and collaboration from not only industry partners and sponsors, but also from federal regulatory agencies, policymakers, healthcare leaders, community care providers and patients and caregivers themselves. Recognizing the value – the contributions, the expertise, the health impact – of what caregivers do, as partners in innovation, is a key part of creating a more equitable, person and family-centered health care system.

To read the report and access our findings, click on the red button below.

LEARN MORE





## The Circle of Care Guidebook Series

The National Alliance for Caregiving's *Circle of Care* library is a series of guidebooks dedicated to providing resources, support and information to caregivers caring for someone in a specific disease space. Part of an ongoing effort of NAC, these first three guidebooks were developed with the assistance of both patient-advocacy and consumer-facing partners:

- **Circle of Care: A Guidebook for Mental Health Caregivers**
- **Circle of Care: A Guidebook for Caregivers of Children and Adolescents Managing Crohn's Disease**
- **The Circle of Care Guidebook for Caregivers of Children with Rare and/or Serious Diseases**

NAC is proud to lend their expertise on caregiving through these guidebooks. To access the guidebooks for yourself and to share them with other caregivers in your life, please visit the link below.

[VIEW THE GUIDEBOOKS](#)



## EVENTS & OPPORTUNITIES

**JULY**



### Peer Support Mentoring Program – Spirituality Calls

The [VA Peer Support Mentoring \(PSM\) Program](#) and the [National Chaplain Office](#) will be hosting a 12-month series addressing spirituality and caregiving. These calls are open to caregivers of Veterans enrolled in both the [Program of General Caregiver Support Services \(PGCSS\)](#) and the [Program of Comprehensive Assistance for Family Caregivers \(PCAFC\)](#).

Calls will be held on the first Friday of each month from 12:00 p.m. to 12:30 p.m. ET (11:00 a.m. to 11:30 a.m. CT; 10:00 a.m. to 10:30 a.m. MT; 9:00 a.m. to 9:30 a.m. Pacific) and will be hosted on WebEx using the dial-in information below. There is NO registration required. Meeting Call in number: USA Toll-free Number 1-833-558-0712. Meeting number (access code): 2762 030 9378

#### Topics

- July 2022 - Spirituality and PTSD
- August 2022 - Spirituality and Grief
- September 2022 - Spirituality and Self Reflection

To learn more, click the red button below.

[LEARN MORE](#)



### Spotlight on Caring for the Caregiver

**July 13, 2022 | 6:00 PM - 7:30 PM EST | Online**

Please join Partners in Care Foundation and AARP for the last session of a 3-part virtual series, "Spotlight on Caring for the Caregiver," on Zoom.

#### Moderators:

- June Simmons, President & CEO, Partners in Care Foundation
- Adriana Mendoza, Associate State Director, AARP California

To register for this event, click the red button below.

[REGISTER](#)



**MICHIGAN STATE UNIVERSITY**

### RELAX: Alternatives to Anger for Parents and Caregivers

**July 14, 2022 | 1:00 PM - 2:30 PM EST | Online**

Hosted by Michigan State University, this interactive workshop for parents and those who

provide care for young children is designed to help adults increase their knowledge about anger and strong emotion in young children and the developmental stages of social emotional self-control. Parents and caregivers will learn what anger is and what triggers anger, explore ways to practice and reinforce positive communication skills, and learn methods of incorporating children's literature into the process of teaching problem solving skills.

Facilitator: Georgina Guzman, [perrygeo@msu.edu](mailto:perrygeo@msu.edu).

This workshop is free.

Attendees must register by July 13. Click the red button below to do so.

**REGISTER**



# Powerful Tools FOR Caregivers

## Powerful Tools for Caregivers – Virtual

**July 14, 2022 | 7:00 PM - 8:30 PM EST | Online**

In conjunction with Catholic Charities Southwestern Ohio, Powerful Tools for Caregivers presents this second meeting in 6-week self-care class for family caregivers where you will access valuable resources, connect with other caregivers, reduce stress, guilt, anger and depression, learn to communicate effectively with family members, doctors, or other help, and learn how to take care of yourself, relax, set goals and problem solve. Uses companion book "The Caregiver Helpbook", available at [www.powerfultoolsforcaregivers.org](http://www.powerfultoolsforcaregivers.org).

To register for this event, click the red button below. Attendees must register by July 7, 2022.

**REGISTER**



**New Learning Collaborative:  
Proxy Access for Older Adults**

**July 18, 2022 | 1:00 PM - 2:00 PM EST | Online**

**What:** OpenNotes is working on patient portal-based solutions to help older adults and their care partners get the information they need. We're excited to invite other collaborators to join us in this effort. To that end, we are convening a learning collaborative that will discuss best practices for increasing care partner adoption of the patient portal and other health information technology innovations aimed at increasing access to health information. We'll talk about health care organization-specific strategies and patient and care partner-centered needs.

**Who:** We welcome health care organizations and staff, professionals, patients, clinicians, vendors, and care partners to come together and learn from each other.

**When:** The collaborative will have quarterly, one-hour meetings beginning in July.

For more information about how to get involved with the learning collaborative, please contact Deb Wachenheim at [dwachenh@bidmc.harvard.edu](mailto:dwachenh@bidmc.harvard.edu).

**Join our first collaborative meeting:**

The first quarterly meeting of our new learning collaborative on patient portal use for older adults and care partners will take place on Monday, July 18, 1-2pm EST. We welcome anyone interested in working together to improve access to healthcare information for care partners of older adults.

To register for the July 18 event, click the red button below.

**REGISTER**



**Alzheimer's Disease: Symptoms,  
Stigma and Sexual Expression**

**July 19, 2022 | 1:00 PM - 2:00 PM EST | Online**

A diagnosis of Alzheimer's or dementia does not negate the need to express one's sexuality. Join Dr. Natalee Oliver, DSW to explore stigma and sexual expression for people living with dementia in the long-term care environment.

To register for this event, click the red button below.

**REGISTER**





## Webinar: Using a Positive Approach (in Dementia Care)

July 20, 2022 | 11:00 AM - 12:00 PM EST | Online

People with dementia experience the world around them differently than we do. Understanding their experience and allowing that to guide our approach can make all the difference when caring for a person with dementia. Guided by Teepa Snow's Positive Approach to Care, attendees of this webinar will walk away with tools to aid in their caregiving for their loved one with dementia.

To register for this event, click the red button below.

REGISTER  
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## Webinar: AFPHS Training – Using Data to Address Social Determinants of Health

July 21, 2022 | 3:00 PM - 4:00 PM EST | Online

Data systems that include information on the health of older adults are crucial to developing programs and services that meet their health and social needs. Organizations and agencies can use this information to target resources, identify community partners, support grant applications, and develop strategies to address health disparities and social needs in their communities.

The July training will focus on the importance of data in addressing social determinants of health among older adults. This session will also highlight how some states have developed and used data on older adults to advance healthy aging in their communities.

To register for this event, click the red button below.

REGISTER  
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# Sankofa

## SUMMER SCHOOL

### Care and Caregiving in the African American Youth Experience

July 22, 2022 | 7:00 PM | Online

The Sankofa Summer School is offering a course on July 22 about African-American youth caregiving. This one-day class, entitled "Sometimes I Feel Like a Motherless Child," will be taught by Dr. Feylyn Lewis.

Care and caregiving has always been a part of the African-American experience in the United States. Unpaid family caregiving continues to exist on the margins, especially when children uptake caregiving roles. There are an estimated 5.4 million youth caregivers in the US. Youth caregivers are children and teenagers who provide unpaid care, support, and assistance to disabled, ill, or injured family members, friends and romantic partners. Youth caregivers act as our country's safety net for broken communities, social, and health care systems. This is especially true for poor or Black youth caregivers---when systems and services fail the disabled or sick adults in their life, poor and Black children step in to cover the gap by becoming caregivers.

After this course, attendees will better understand the role of care and caregiving in the Black youth experience, drawing on both historical and present-day truths. This course takes a trauma-informed, liberation approach to caregiving and attendees will consider the complexity of Black generational trauma and self-care.

This class is \$25 per person. To learn more about the Sankofa Summer School, click [here](#). If you have additional questions, email the school at [info@SankofaSummerSchool.com](mailto:info@SankofaSummerSchool.com).

To register for this class, click the red button below.

REGISTER





## Online Care Circle for Family Caregivers

**July 23, 2022 (Saturday) | 11:00 AM - 12:00 PM EST | Online**

Join Bay Area Cancer Connections in this opportunity to connect with other caregivers in a small setting from the comfort of your own home!

Tell your story, share your experiences and gain support from others who understand what you're going through in this safe and welcoming environment.

These free virtual meetings are supported by coaches volunteering their time, allowing you to reduce stress while giving you hope. This session is facilitated by Christine Young, Communications Coach at CCYConsulting.com and hosted by Bay Area Cancer Connections ([www.bayareacancer.org](http://www.bayareacancer.org))

To register for this event, click the red button below.

**REGISTER**



## Virtual Conference for Neuroendocrine Tumor (NET) Patients and Caregivers

**July 24, 2022 | 10:30 AM - 4:30 PM EST | Online**

Join the Neuroendocrine Tumor Research Foundation (NETRF) UChicagoMedicine for KNOW YOUR NETs, our third annual virtual education conference for patients and caregivers. Our conference focuses on the topics you told us are most helpful to you. NET experts from around the country will discuss the latest treatments and research and provide practical information for living well with neuroendocrine cancer.

Presentations include:

- \*New Treatments and Clinical Trials: Targeted Therapies, Radioligand Therapy/PRRT, Interventional Therapy
- \*Treatment Sequencing and Guidelines
- \*Risks and Benefits of Surgery
- \*What you need to know now about somatostatin analogues
- \*How to read your radiology and pathology reports
- \*Patient perspectives on diagnosis and survivorship

To register for this event, click the red button below.

**REGISTER**



## What New Family Caregivers Need to Know

**July 26, 2022 | 12:00 PM - 1:00 PM EST | Online**

New and even experienced family caregivers can feel overwhelmed by the difficult challenges of caring for others while still caring for themselves. But nearly 50 years of family caregiving research can provide some answers about how caregivers can best cope. Please join Barry J. Jacobs, Psy.D., as he discusses applicable research findings on what helps and hurts family caregivers during the long caregiving years.

To register for this event, click the red button below.

**REGISTER**



## Webinar: "Mindfulness and Meditation"

**July 26, 2022 | 6:15 PM - 7:45 PM EST | Online**

This webinar hosted by the Area Office on Aging of Northwestern Ohio will discuss mindfulness and meditation in the context of caregiving. It will be presented by Deb Reis.

To RSVP and obtain access instructions, call Jennifer Forshey at (419) 725-6983, or email her by clicking on the red button below

To register for this event, click the red button below.

**REGISTER**





**BENJAMIN ROSE**  
**INSTITUTE ON AGING**  
SERVICE • RESEARCH • ADVOCACY

## **Legal and Financial Planning for Older Adults and Persons with Disabilities**

**July 26, 2022 | 12:00 PM - 1:00 PM EST | Online**

Join the Benjamin Rose Institute on Aging for an informative webinar discussing how older adults and people with disabilities can protect their assets against financial exploitation. Information will include how to properly draft powers of attorney, the use of trusts in legal planning, and the rules and guidelines of Medicaid. Lastly, you will learn about an evidence-based care-coaching program, BRI Care Consultation™, that is available for free in various counties in Ohio and West Virginia to support individuals with, or at risk of, dementia, including individuals with intellectual and developmental disabilities, and their caregivers.

To register for this event, click the red button below.

**REGISTER**



**AUGUST**

*Leading***Age**®

### **Larry Minnix Leadership Academy**

**Deadline: August 1, 2022**

The Larry Minnix Leadership Academy is designed to develop the leadership capacities and core competencies of aging services professionals by tapping into their natural talents and authentic leadership styles, irrespective of their professional experience, job title or type of position within an organization.

Unlike many leadership programs that focus on building a core skillset for new leaders or are geared toward nurturing a specific career path for “emerging” leaders, the Leadership Academy provides a leadership foundation rooted in reflective practice—developing a deep understanding of one’s self, uncovering one’s unique leadership attributes, and learning how to stretch and leverage those capacities to have the most impact as leaders.

The year-long curriculum draws on adult learning theory to delve into the core principles of reflective leadership through a variety of components. The program emphasizes self-exploration and relationship-building to enable participants to embrace diversity of thought, move beyond pre-conceived assumptions and view their own experiences and those of

others as learning opportunities.

To learn more about the Larry Minnix Leadership Academy, contact [BMoss@LeadingAge.org](mailto:BMoss@LeadingAge.org) or call 202-508-9490.

To apply, click the red button below.



## Apply to Be a Macy Faculty Scholar

**Deadline: August 1, 2022**

The Macy Faculty Scholars Program, now in its second decade, aims to identify and nurture promising early career educators in medicine and nursing. The Program will help develop the next generation of national leaders in medical and nursing education by identifying outstanding educators, physicians, nurses, and role models—individuals who represent the breadth of diversity seen in learners, patient populations, and health care settings around the country. By providing the Scholars with resources—especially protected time, mentorship, and a professional network of colleagues—the Program aims to accelerate Scholars' careers, to turn their teaching practice into scholarship, and to help them become impactful leaders locally, nationally, and beyond.

To learn more about the Macy Faculty Scholars Program, click [here](#). To apply, click the red button below.



## Why Do They Do That? Managing Common Challenging Dementia-Related Behaviors

**August 4, 2022 | 11:00 AM - 12:15 PM EST | Online**

[Conversations with Dr. Tam Cummings - A Monthly Education Series for the Dementia Caregiver](#)

Dr. Tam Cummings will discuss common behaviors witnessed by dementia family caregivers including:

Cursing  
Movement changes

Hunting and gathering  
Accusations of theft  
Taking away the car keys  
Sundowning  
Bathroom issues, including toileting and bathing  
Bedtime issues

We will also review the five senses which addresses changes leading to potentially dangerous or annoying behaviors. Stress relief tips will be shared, and handouts will include materials to self-measure caregiver stress and self-compassion.

Questions can be directed to [VirtualSeminars@arden-courts.org](mailto:VirtualSeminars@arden-courts.org).

To register for this event, click the red button below.



**SEPTEMBER**



## **Webinar: Navigating a Dementia Diagnosis and Care Needs**

**September 7, 2022 | 1:00 PM - 2:00 PM EST | Online**

Knowing the warning signs of Alzheimer's disease is important for early detection and diagnosis. Family members often are the first to notice the signs, but may struggle on how to approach their loved one about scheduling an appointment with their doctor. Once they do broach the subject, they may be met with resistance or denial. If a diagnosis is received, the individual and their family may be at a loss for what to do next and what to expect for their loved one's care needs. As professionals, it is important to help older adults and their families navigate life after a dementia diagnosis by providing them with useful information and support. Join this webinar during World Alzheimer's Month to learn more about what to do next after a dementia diagnosis, what changes to expect and how to best care for someone living with dementia.

**Participants in this webinar will be able to:**

- Review the 10 warning signs of Alzheimer's disease and the importance of

diagnosis

- Discuss what to expect after a diagnosis and what changes are likely to occur
- Learn communication strategies and care tips to best support the individual
- Discover resources for professionals and families for diagnosis, care and support

To register for this event, click the red button below.

**REGISTER**



## **Request for Applications for NIA's Career Development Award Program**

**Deadline to apply: September 15, 2022**

The National Institute for Aging's IMPACT Collaboratory seeks to build the nation's capacity to conduct pragmatic clinical trials of interventions embedded within health care systems for people living with dementia and their care partners.

IMPACT Collaboratory has issued a request for applications for its Career Development Award Program. The award is intended for scientists pursuing careers in embedded pragmatic clinical trials for people living with Alzheimer's disease and Alzheimer's disease-related dementias (AD/ADRD) and their care partners

To learn more, click [here](#) or on the red button below.

**LEARN MORE**



## **2022 National Caregivers Conference**

**October 16-17, 2022**

The Family Resource Network, a New Jersey-based organization, will re-convene many of the nation's industry leaders and family caregivers for the 2022 National Caregivers Conference.

The theme of NCC 2022 is “Emerging Forward, Together”. COVID-19 took a significant toll on the Nation becoming the most challenging times we’ve ever faced. Unpaid family caregivers were impacted by the pandemic in four categories: environmental, technological, societal, and economic. As the Nation is on the path of recovery, The Family Resource Network puts emphasis on the necessity to address the issues in conjunction with the others. The effectiveness of the recovery relies solely on how well policymakers, leaders, and professionals work together. The National Caregivers Conference is committed to creating a space to collaborate, learn and support.

Virtual Attendance

Family Caregiver

\$100 Virtual Early Bird Family Caregiver

\$125 Virtual Final Family Caregiver

Professional

\$175 Virtual Early Bird Professional

\$200 Virtual Final Professional

For more information about the conference, click [here](#). To register, click the red button below.

**REGISTER**



## **PATIENT AND CAREGIVER STUDIES**



**School of Social Work**  
**UNIVERSITY OF GEORGIA**

### **University of Georgia Survey on Access to Health Services (Georgia residents only)**

Elisa Childs, a doctoral student at the University of Georgia's School of Social Work, is conducting a study examining older Georgians' access to health care. Georgia has one of the fastest-growing populations of adults 65 and older yet has some of the worst access to health care in the country.

If you are a Georgian who is at least 65 in age, your participation in this 15-minute survey can help bring attention to this critical issue. Survey results will be used for Ms. Childs's doctoral dissertation and will potentially serve as the foundation for federal and state grant applications aimed to increase access, minimize disparities, and improve health outcomes in rural areas.

To learn more about this survey, click [here](#), or feel free to contact Ms. Childs at [emc04605@uga.edu](mailto:emc04605@uga.edu).

To participate in the study, click the red button below.

**PARTICIPATE IN THE STUDY**





## Study: Caregiver Perspectives on Alzheimer's Disease and Related Dementias Clinical Trials

Our team at the University of Illinois Urbana-Champaign is conducting a study to learn more about engaging family caregivers of racial/ethnic minority participants in clinical trials for Alzheimer's Disease and related dementias (ADRD).

We'd like to learn more about your experiences with helping your relative navigate participation in clinical trials for ADRD. We hope to learn about ways that we can better support family caregivers so they can better support their relative through these trials.

To participate in this study, the participant must be:

- Age 18 or older
- Speak and understand English
- A caregiver for someone with ADRD who has either a) received information about a clinical trial, b) been invited to participate in a clinical trial, or c) has participated in a clinical trial
- Identify as part of a racial or ethnic minority community

Participation includes a 25-30 minute virtual interview. Participant will receive a \$25 gift card upon completing the interview.

Please contact Dr. Minakshi Raj if you are interested in participating by clicking the link below.

[CONTACT](#)  
>

## Participants Needed for Study on Caregiving for Family Member with Memory Problems

Are you helping a family member with memory problems? The Virginia Tech Center for Gerontology is seeking grandchildren, siblings, nieces/nephews, and step family members (any relationship) living in Virginia to participate in a research study about caring for a relative with dementia living in the community (not in an assisted living or nursing home). This study involves one initial phone interview (approx. 70 minutes) and a brief phone interview for 8 days in a row (15-20 minutes each evening).

You will be asked questions about your experiences providing care, family involvement and use of paid services, and challenges you face caring for your relative.

Compensation is \$110 for full participation (VT IRB# 20-742). Interested? Visit the study website [careex.isce.vt.edu](http://careex.isce.vt.edu), call: 540-231-9250 or email us at [careex@vt.edu](mailto:careex@vt.edu).

To learn more, click the red button below.

[LEARN MORE](#)  
>

## VetCareMind Project

Do you provide unpaid care for a veteran or non-veteran with a neurocognitive disorder and/or Post Traumatic Stress Disorder (PTSD)? Are you 18 years old or older? Do you have a computer, tablet, or smartphone? If so, researchers developing an intervention want your help! Eligible caregivers will complete an online survey before participating in two focus group interviews with 4 to 5 participants. The online survey will take about 30 minutes and the focus groups will be between 90 to 120 minutes each.

Participants will receive a \$30 gift card after each focus group interview.

For any questions about the study, please contact the research team at the following email or phone number:

Email: [vetcaremind@illinois.edu](mailto:vetcaremind@illinois.edu)

Phone: 217-244-9363

Principal Investigator: Dr. Sandraluz Lara-Cinisomo

To determine if you are eligible to participate, complete a brief online screening by clicking on the red button below.

**COMPLETE THE SCREENING**



## Weill Cornell Medicine Geriatrics & Palliative Medicine

### Are You Caring for a Loved One With Dementia

Researchers at Weill Cornell Medicine are conducting a research study examining well-being and resource use in dementia caregivers. The aim of this study is to identify and examine the needs of caregivers and the types of resources and support services that would be most beneficial to promote well-being in caregivers.

If you are eligible and agree to participate, you will be asked to complete an online survey lasting 20-30 minutes. Then, you will be given the option to participate in a follow-up phone interview with a member of our research staff. You will be asked to answer some questions about your demographic characteristics, care responsibilities, challenges experienced, and ways you have coped with those challenges. Then, you'll be asked to answer some questions about your use of community resources, barriers to accessing and using resources, and suggestions for resources that you would be interested in using in the future based on your own personal needs.

You will receive a stipend of \$25 for your completed surveys. For those who choose to participate in the open-ended interview, you will be compensated with another \$40.

If you have any questions about this survey, please feel free to email Francesca Falzarano [fbf4001@med.cornell.edu](mailto:fbf4001@med.cornell.edu) or call (646)481-2858.

To view the flyer for this study, click the red button below.

**VIEW THE FLYER**



**Recruiting Participants for a Study on Accessibility**

# Information in Cities

Our research team at the University of Illinois at Chicago is inviting you to participate in a research study to improve the availability and use of data on sidewalk accessibility for people with disabilities. We would like your input to help understand new ways our tools and the data collected can be used to advocate for more accessible cities and be used by people with disabilities to better understand their community's accessibility.

Participation includes two 2.5 hours workshops on one these dates: May 5, 6, 9, 11, 19, 20. The workshop will be either at 10:00am to 12:30pm or 1:00pm to 3:30pm.

To maintain COVID-19 safety precautions the first workshop will be held virtually via Zoom. During these workshops our research team will lead group activities and discussions. We will focus on priorities, needs, and concerns related to accessible sidewalks, and hope to gain your valuable perspectives on the design and usability of a tool we developed. We are also interested in discussing the opportunities and needs around data on accessibility of cities.

Participants will receive \$50 per session for their participation.

To Participate in this workshop, participants must be:

- 18 years of age or older
- Speak and understand English
- Identify as a member of **one** of the following groups:

\*People with limitations in mobility OR

\*People who are Blind/low vision OR

\*A caregiver of a person with a disability

Have experience with or regularly leave home and travel in the community OR travel with someone with a disability

For more information or to schedule a time to participate in the study please contact:

Sierra Berquist

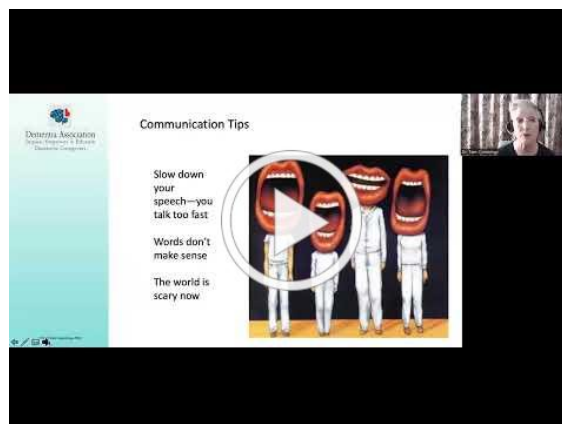
Research Assistant

Email: [sberqu2@uic.edu](mailto:sberqu2@uic.edu)

[CONTACT >](#)

## IN CASE YOU MISSED IT...

### The ABCs of Frontotemporal Dementias



*Conversations with Dr. Tam Cummings - A Monthly Education Series for the Dementia Caregiver*

In this webinar, the three domains and subsets of “young persons’ dementia” were reviewed, allowing family caregivers an opportunity to identify the form of Frontotemporal Dementia (FTD) their loved one has and what to expect for the future. Often challenging to recognize as a dementia due to the person’s age, the FTDs can cause especially high levels of stress for the family caregiver. This session with Dr. Tam Cummings addressed the stages, domains, unique behaviors and decline in persons living with FTD and the impact this disease has on the family caregiver.

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## RESEARCH & RESOURCES

# A WORKBOOK FOR YOUR WORKPLACE WELLNESS

**BY DENISE M. BROWN**

### **A Workbook for Your Workplace Wellness**

Our work life now includes our life’s work – caring for a family member with a chronic illness or disease or injury. How do we make room for both experiences in the workplace? How do we take time during our work day to manage our stress and worries? How do we console our colleagues who grieve?

**The Caregiving Years Training Academy** has come up with a free new tool to caregivers for managing caregiving, grieving and working. *A Workbook for Your Workplace Wellness* shares tools to help you manage your experiences as an employee, a co-worker and a family caregiver.

The workbook includes a Worksheets section which features tools to use daily and weekly to manage your stress, grief and wellness.

To learn more, click [here](#). To view or download the workbook, click the red button below.

**VIEW THE WORKBOOK**





U.S. Department  
of Veterans Affairs

## VA and Rosalynn Carter Institute for Caregivers Launch Partnership

The VA is committed to caring for Veterans, caregivers, families and survivors. Strong partnerships within and outside of the VA are critical to ensuring caregivers receive the support they need. That's why the VA is partnering with the Rosalynn Carter Institute for Caregivers (RCI) to further promote the health and well-being of those who care for our nation's Veterans.

The VA and Rosalynn Carter Institute for Caregivers launched the new partnership to support caregivers of Veterans, caregivers who are Veterans, and caregivers who work for the VA. Both organizations will work collaboratively to increase awareness of the needs of caregivers of Veterans, increase caregiver access to programs, services and resources, and improve caregiver outcomes.

For more information about this partnership and the VA's Caregiver Support Program, click the red button below.

LEARN MORE



ROSALYNN **FOR**  
CARTER **CAREGIVERS**  
INSTITUTE 

## Get the Support You Need

The Operation Family Caregiver (OFC) program at the Rosalynn Carter Institute for Caregivers helps create stronger, healthier, more resilient families by supporting the unsung heroes behind our heroes: the caregivers. These friends and family who take care of America's wounded warriors do so, in many cases, at the expense of their own health and well-being. The challenges that our veterans face can affect the entire family, but services and programs rarely focus on the caregiver.

OFC provides eight free and confidential one-on-one coaching to the families, friends and supporters of those who have served our nation and returned home with either visible or invisible injuries. OFC is tailored to each caregiver's unique needs and delivered virtually on their schedule.

For more information about Operation Family Caregiver, click [here](#). To enroll, click the red button below.

LEARN MORE



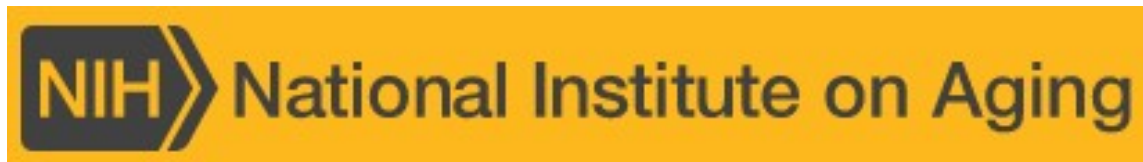
## Ignite Change as a Caregiver Advocate

This fall Rosalynn Carter Institute (RCI) for Caregivers is launching its first-ever grassroots advocacy network to fundamentally change the way caregivers are seen and supported. Will you join the movement?

Over the past two years, the essential role of our country's 53 million caregivers has been elevated to the national stage, emphasizing the fragmented, inaccessible, and oftentimes nonexistent systems in place to support this indispensable population. In the words of our founder, former First Lady Rosalynn Carter, we must "seize this moment" to affect meaningful, systemic change.

To learn more or become an advocate, contact the RCI by clicking the red button below.

[CONTACT RCI](#)



## Caring for a Person with Alzheimer's Disease: Your Easy-to-Use Guide

Get Alzheimer's caregiving information and advice in this comprehensive, easy-to-read guide produced by the National Institute on Aging. Learn caregiving tips, safety information, common medical problems, and how to care for yourself.

To view or download the guide, click the red button below.

[VIEW THE GUIDE](#)



**MAKE YOURSELF  
A PRIORITY, TOO**  
[ TIPS FOR CAREGIVERS ]

## Make Yourself a Priority, Too: Tips for Caregivers

Caregiving can be rewarding, but difficult. Learn how you can put yourself back on the priority list.

Share this infographic and help spread the word about caring for yourself while caring for others. Click on the social media icons above, or copy and paste the URL and post it to your account (Twitter, Facebook, etc.).

To download the infographic, click on the red button below.

[DOWNLOAD THE INFOGRAPHIC](#)





## How to Share Caregiving Responsibilities with Family Members

Caring for an older family member often requires teamwork. While one sibling might be local and take on most of the everyday caregiving responsibilities, a long-distance caregiver can also have an important role.

As a long-distance caregiver, you can provide important **respite to the primary caregiver** and support to the aging family member.

To learn more, click on the red button below.

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## PREVIOUSLY APPEARED



### Making the Invisible Visible: State Strategies for Identifying and Reaching Family Caregivers

Family caregivers — often relatives, friends, and neighbors — provide vital assistance to support the health and functional needs of older adults, but often face physical, emotional, and financial challenges related to their caregiving responsibilities.

Many states are seeking to better support this important workforce, particularly family caregivers in communities of color, but need an effective way to accurately identify the number, diversity, and unique needs of family caregivers in their state.

In identifying family caregivers, states should recognize cultural considerations, including distinct racial and ethnic perspectives associated with caregiving, that may have implications for identification.

This brief by the Center for Health Care Strategies presents key strategies to help states better identify and reach family caregivers.

To view this brief, click on the red button below.

VIEW THE STUDY



**AARP/National Geographic  
"Second Half of Life Study"**

Older Americans are not only the happiest adult Americans as a whole, but also consider themselves healthier and more financially secure than those in their 40s and 50s, reveals a new study published in *AARP Bulletin*. The "Second Half of Life Study," conducted with *National Geographic*, surveyed thousands of adults age 18 to 90 to explore how Americans perceive their current life, their expectations for the future and aging in general as we emerge from the COVID pandemic. About two-thirds of adults over 80 said that they were living their "best possible life" or close to it, compared with just 1 in 5 younger adults.

The study disproves many common misconceptions about aging and suggests that greater focus should be put on adults in their 40s and 50s, who reported higher levels of stress and worry and lower levels of life satisfaction and health than older Americans.

To view the study, click on the red button below.

[VIEW THE STUDY](#)



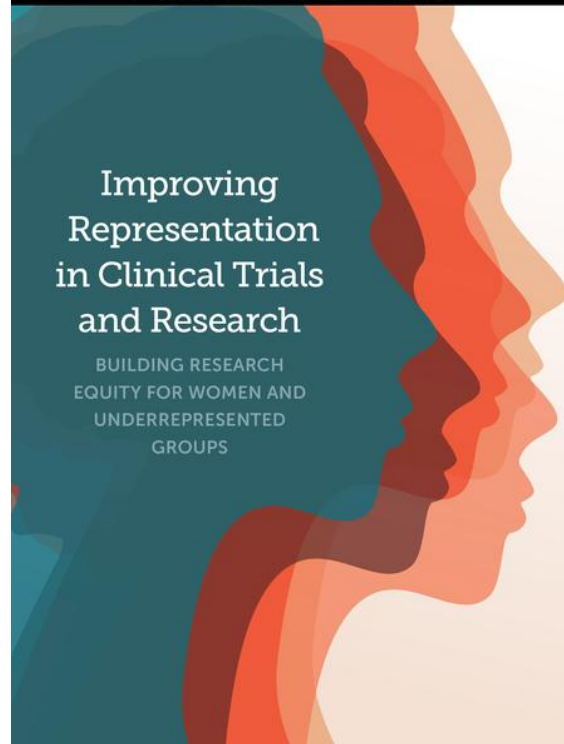
## **New Additions to the engAGED Innovations Hub**

The engAGED Social Engagement Innovations Hub houses best and emerging social engagement programs. Searchable by a variety of filters—including social engagement intervention type, geographic area served or partners involved—the Innovations Hub gives you access to replicable examples to inspire and inform your organization's social engagement efforts. Each program summary within the Innovations Hub contains all you need to know about that particular program, such as partners involved, outcomes demonstrated, lessons learned, resources needed and contact information to learn more.

To access the Hub, click the red button below.

[ACCESS THE HUB](#)





## Improving Representation in Clinical Trials and Research: Building Research Equity for Women and Underrepresented Groups

The United States has long made substantial investments in clinical research with the goal of improving the health and well-being of our nation. There is no doubt that these investments have contributed significantly to treating and preventing disease and extending human life. Nevertheless, clinical research faces a critical shortcoming. Currently, large swaths of the U.S. population, and those that often face the greatest health challenges, are less able to benefit from these discoveries because they are not adequately represented in clinical research studies. While progress has been made with representation of white women in clinical trials and clinical research, there has been little progress in the last three decades to increase participation of racial and ethnic minority population groups. This underrepresentation is compounding health disparities, with serious consequences for underrepresented groups and for the nation.

At the request of Congress, *Improving Representation in Clinical Trials and Research: Building Research Equity for Women and Underrepresented Groups*, identifies policies, procedures, programs, or projects aimed at increasing the inclusion of these groups in clinical research and the specific strategies used by those conducting clinical trials and clinical and translational research to improve diversity and inclusion. This report models the potential economic benefits of full inclusion of men, women, and racial and ethnic groups in clinical research and highlights new programs and interventions in medical centers and other clinical settings designed to increase participation.

To learn more or to access the report, click the red button below.

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Securing today  
and tomorrow

## How to Get Help from Social Security

Local Social Security offices are offering more in-person appointments and have resumed in-person service for people without an appointment.

As in-person service expands, the Social Security Administration expects its offices to become increasingly busy. The SSA strongly encourages beneficiaries seeking assistance to continue to go online, call for help, and schedule appointments in advance.

The Social Security Administration has provided a fact sheet for those seeking assistance. To read the fact sheet, click the red button below.

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## Home Safety Checklist for Alzheimer's Disease

Use the following room-by-room checklist provided by the National Institute on Aging to alert you to potential hazards and to record any changes you need to make to help keep a person with Alzheimer's disease safe. You can buy products or gadgets necessary for home safety at stores carrying hardware, electronics, medical supplies, and children's items.

To view the checklist, click the red button below.

VIEW THE CHECKLIST



## At a Glance: Reducing Disability in Alzheimer's Disease

Check out this 1-page infographic for a quick, top-level overview of Reducing Disability in Alzheimer's Disease (RDAD), a dementia caregiving program that offers 12 in-person (individual or group) exercise training and education sessions for caregivers and persons living with dementia. It's focused on gentle exercise for the person with dementia and caregiver training to manage behavioral symptoms and identify pleasant events.

Feel free to print it out, save for reference or send to a peer or colleague who may be interested learning more about the program. You can find full information, including program components and characteristics, research evidence, sustainability strategies and more at the program's full [\*\*profile page at Best Practice Caregiving\*\*](#).

To view the infographic, click the red button below.

[VIEW THE INFOGRAPHIC](#)



## A Caregiver Program that Creates Lasting Improvements

BRI Care Consultation™ is a proven care-coaching solution delivered by telephone and email to adults with health conditions and their family or friend caregivers, empowering both to more effectively manage short- and long-term needs.

BRI Care Consultation uses a combination of ongoing assessment, action planning and follow-up support to create real and lasting changes in the caregiving situation, resulting in a decrease in unmet needs, stress and strain, and symptoms of depression for both caregivers and the person receiving care.

BRI Care Consultation helps to change the cycle of ongoing care, uncovering alternatives to current care methods, identifying helpful new community resources, mobilizing family and friend assistance, and driving lasting changes in the care situation.

Through numerous research studies, BRI Care Consultation has been proven to provide positive outcomes, including:

- Improved satisfaction with care from doctors and other professionals
- Reduced symptoms of depression
- Less relationship strain between the caregiver and person receiving care
- Fewer costly emergency room visits and hospital re-admissions.

If you'd like more information, contact Michelle Palmer at [mpalmer@benrose.org](mailto:mpalmer@benrose.org), or click the red button below.

[LEARN MORE](#)



## New Blood Test Can Help Diagnose Alzheimer's Disease

Alzheimer's disease is characterized by the buildup of a protein called beta-amyloid, which forms sticky plaques on the brain and can cause brain cells to die. Testing for the presence of these amyloid plaques on the brain is an important part of Alzheimer's diagnosis and research.

A study, funded in part by NIA, found that a new blood test can accurately predict the presence of beta-amyloid in the brain. The blood test became even more accurate when the research team took into account the version of APOE (a gene linked to Alzheimer's risk) that each person had. Scientists note that the blood test performs comparably to

existing brain scan- or spinal tap-based tests. However, the blood samples used in the study were from majority white, affluent individuals, and may not be generalizable to other demographic groups.

Using blood samples will make it easier to screen healthy people for potential enrollment in Alzheimer's clinical trials and could help lower costs and expand the availability of diagnostic studies for Alzheimer's.

To learn more, click the red button below.

LEARN MORE



## Caregiving While Black Course

Caregiving While Black is a six week culturally appropriate caregiving training and education course. The overall goal of this project is to address the cultural reality of "Caregiving while Black" during a public health crisis. We are aiming to develop and prototype-test a highly accessible program designed to enhance the mastery of Black American caregivers to provide care to family members or friends living with a dementia illness in a time of crisis.

A \$40 gift card will be provided for participation in each baseline and post-intervention interview and each semi-structured interview.

If you'd like more information, click [here](#). If you'd like to participate, click the red button below.

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