

THIS WEEK IN CAREGIVING



July 20, 2022



CAREGIVING IN THE NEWS

The Underground Economy of Unpaid Care

In August 2021, when my 62-year-old mother said hello on FaceTime, she was holding the side of her jaw, grimacing. She was in anguish, but kept repeating, “I’m OK, I’m OK.”

At the time, my mom was living in Bellingham, Washington, two years into providing unpaid live-in care for her father-in-law (my step-grandfather, who I reluctantly call “Grandpa,” despite not having much of a relationship with him). He was suffering from debilitating cancer and heart disease. But providing home care to him came at a price to my mom’s health, safety, financial security, and family. The job was all-consuming: She quit painting and gardening, which she loved, and she grew isolated from her own children and grandkids during the COVID-19 pandemic.

From: Yes! Magazine | Published: July 12, 2022

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Op-Ed: At 29, I Wasn’t Prepared to Be a Caregiver. Life Had Other Plans

I was on the subway headed to a friend’s comedy show on the Lower East Side when I received a call that changed every plan I had for myself. I answered and stepped off the train, and from that moment on, everything moved like lightning. Within a couple of days, I was home, back in Los Angeles. My mother’s and grandmother’s need for my care was so sudden and so vast that I didn’t comprehend that the move would be permanent.

7 Things Everyone Should Know About Caregiving

The true definition of the word “caregiver” can be found in its root meaning, which can be defined as “being anxious or solicitous; grieve; feel concern or interest.” It is no wonder that taking care of a loved one can feel like a confluence of these tough emotions. Although I had a graduate degree in social work, absolutely nothing prepared me for taking care of my (now late) husband after he was diagnosed with advanced cancer.

From: Psychology Today | Published: July 18, 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

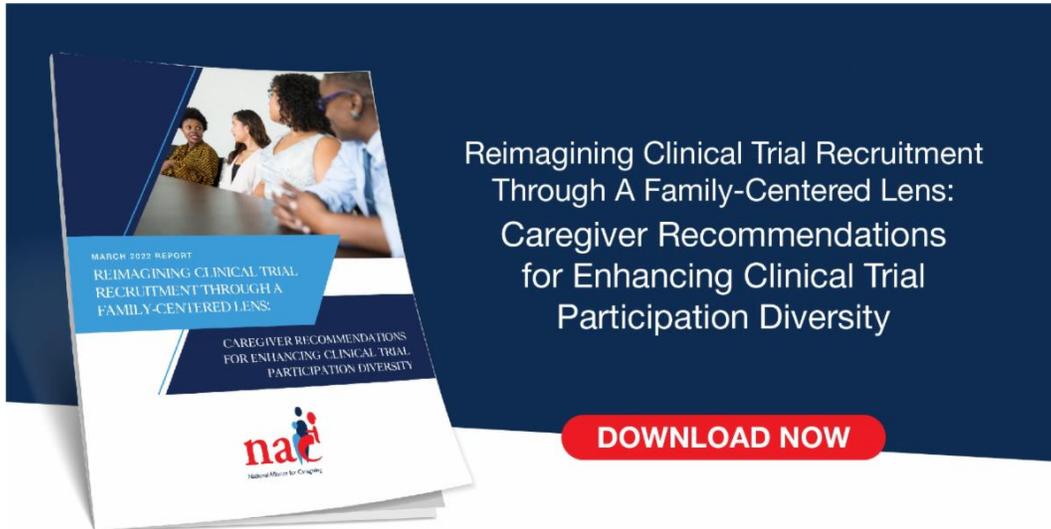
As part of the World Carers Conversation 2022, NAC worked with Chief Story Officer Anne Levy and caregivers from around the globe to help them tell their own story through a series of photos. These photos addressed simple questions about being a caregiver, such as what works, what doesn't work, and what 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

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](#)



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](#)



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



CONFIDENCE: Financial Education & Training for Latino Family Caregivers

Thursdays, July 21 - August 18, 2022, 4:00 PM – 7:00 PM EDT | Online

CONFIDENCE is a free, 5-week virtual financial education program made for Latino family caregivers who help a loved one with dementia, including Alzheimer's Disease, and/or memory problems.

As part of this course hosted by the University of Southern California's School of Gerontology, you will learn how to:

- Lower your out-of-pocket care expenses
- Find community resources
- Manage someone else's money
- Balance employment and caregiving
- ... and more!

To register for this class, email Alex Gonzalez by clicking on the red button below.

EMAIL TO REGISTER





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.

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)

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

REGISTER



**NEUROENDOCRINE TUMOR
RESEARCH FOUNDATION**

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



COMEDY THAT CARES

Improv for Caregivers

July 26, 2022 | 1:30 PM - 3:00 PM EST | Online

At Improv for Caregivers, we know you want an easygoing relationship with your loved one. Caregiving for someone with Alzheimer's or dementia is a heavy burden with daily responsibilities that can feel overwhelming, depleting, and unappreciated. You need support in navigating these difficult circumstances, but it's hard to find anything that really

makes a difference. That's why we started Improv for Caregivers, an ongoing support group that blends therapeutic techniques and improvisational comedy games to help caregivers cultivate ease, joy, and flexibility in their relationships and feel more hopeful. In our interactive workshops and support groups, you'll have fun developing a skill set that helps you communicate in new ways, understand your loved one's changing perspective, diffuse challenging behavior, and cope with the stress of it all. When you learn improv skills for caregiving, you'll worry less, laugh more, and find joy in the everyday with your loved ones.

This workshop is funded by AWARE and The Dallas Foundation for Dallas area family caregivers.

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



Live Virtual Roundtable: Family Reunions and Caregiving

July 28, 2022 | 2:00 PM - 3:00 PM EST | Online

Join Second Wind Dreams and AARP Georgia for an online roundtable discussion about how we manage the needs of individuals living with dementia and family expectations at social gatherings.

Facilitated by SWD CEO Gwenyth Johnson, discuss and learn about resources, new developments and best practices available to caregivers.

Thanks to generous support from our sponsor AARP Georgia, there is no cost to register. Click the Register button sign up.

Contact us at 678-624-0500 or info@secondwind.org with any questions.

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

REGISTER



**DFA-Mid County Presents a Virtual
Family Caregiver Conference**

July 30, 2022 | 10:00 AM - 1:00 PM EST | Online

Please join DFA Mid-County for a FREE virtual conference for individuals living with dementia and family caregivers to include break out sessions for Male Caregivers and Youth.

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

REGISTER
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AUGUST



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 or call 202-508-9490.

To apply, click the red button below.

APPLY
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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.



Engaging Caregivers: A Program for Healthcare workers

August 3rd, 10th, and 17th, 2022

WellMed's Caregiver Teleconnection sessions are one hour learning sessions for caregivers of older persons. Experts from around the country share information important to caregiving. Caregivers will have the opportunity to ask questions as well as hear from other caregivers.

Our sessions are geared for the family members taking care of a loved one over the age of 60. Professionals are also welcome to participate as well.

Learn about defining roles and responsibilities with patients and caregivers, the role of diversity and culture, and where to find resources to help with difficult situations and elder abuse.

Upcoming Caregiver Teleconnection sessions will be held on August 3rd, 10th, and 17th. Click on any of the three links below to learn more or register for each event. A certificate of attendance will be provided upon request.

Registration links:

August 3rd at 11:00 am EST: [Defining Caregivers & Recognizing Their Experiences](#)

August 10th at 11:00 am EST: [Difficult Situations & Elder Abuse](#)

August 17th at 11:00 am at EST: [Diversity & Caregiving](#)

To view the Caregiver Teleconnection flyer, click the red button below.

[VIEW THE FLYER](#)



Cultivating Positivity in Caregiving: Research-Based Ways to Promote Happiness and Well-being

August 4, 2022 | 12:30 PM - 1:30 PM EST | Online

Research shows that caregiving and navigating day-to-day life with memory and movement disorders can be positively impacted by planting seeds of happiness.

Join Banner Alzheimer's Institute & Banner Sun Health Research Institute as we share research-based ideas to cultivate happiness, well-being and success for caregivers and people living with memory and movement disorders. Research proves that happiness not only lifts spirits, it can also improve overall quality of life and well-being. Learn research-based tips to improve coping skills, emotional well-being and quality of life throughout the dementia journey.

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

[REGISTER](#)



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.

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

REGISTER



Take a Breath! Tips from a Caregiver Coach

August 11, 2022 | 12:00 PM - 1:00 PM EST | Online

Caregiving is complicated. Knowing where to turn and how to care for yourself can be overwhelming. Caregiver coaches get it – they have real-life experience, tips, and tools to help you! Join the Ontario Caregiver Organization's webinar with a Caregiver Coach to:

- Discover helpful OCO tools and resources
- Try some practical 5-minute self-help activities you can do TODAY
- Learn how to create a self-care plan with helpful tips

Our Speaker

Suzanne McKenna has been a caregiver for 15 years for her son with a severe traumatic brain injury due to an accident. With a certification in Motivational Interviewing/Counselling and ten years of work experience as a System Navigator, she has many skills in compassionate support. As a caregiver coach and mentor, Suzanne guides the caregiver in building confidence through their ups and downs, helps find resources and encourages them to find time for themselves without guilt.

Information

- Please note that this presentation is available in English only.
- For any difficulty with registration or any other questions, please contact us at info@ontariocaregiver.ca or call 1-888-877-1626 X 1011

REGISTER



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





NIA IMPACT
COLLABORATORY
TRANSFORMING DEMENTIA CARE

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



**NATIONAL
CAREGIVERS
CONFERENCE**

"Emerging Forward, Together"

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
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PATIENT AND CAREGIVER STUDIES



Brain Donation: A Gift for Future Generations

Brain donation helps researchers study brain disorders, such as Alzheimer's disease and related dementias, that affect millions of people. Learn about why people donate their brains, the process of brain donation, and how you can enroll to make this generous gift.

Our brains are amazing, intricate networks that help us think, love, and breathe. But sometimes things go awry and cause brain disorders, such as Alzheimer's disease and related dementias. By studying the brains of people who have died — both those who had a brain disorder and those who were healthy during life — researchers learn more about how types of dementia affect the brain and how we might better treat and prevent them. Brain donation provides an opportunity to help researchers better understand these disorders, which can lead to improved treatments for future generations.

While many people think that signing up to be an organ donor includes donating their brain, the purpose and the process of brain donation are different. Rather than helping to keep others alive, such as with kidney donation, brain donation helps advance scientific research. One donated brain can make a huge impact, potentially providing information for hundreds of studies. But many brains are needed from diverse populations and ages to help researchers investigate the causes of disease and to develop more effective therapies that can then be applied broadly.

Researchers use donated brain tissue to study brain diseases that affect millions of people. These diseases include Alzheimer's disease, Lewy body dementia, frontotemporal disorders, mixed dementia, Parkinson's, and Huntington's disease, as well as brain injuries such as trauma and stroke.

To learn more about brain donation, click the red button below.

LEARN MORE



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.

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, call: 540-231-9250 or email us at 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

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 or call (646)481-2858.

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

[VIEW THE FLYER](#)
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IN CASE YOU MISSED IT...

Medications in Older Adults



Learn more about how the aging process can affect how the medication is absorbed, used in the body, and exits the body. What alternative medications may need to be discussed with a health care provider. **Sponsored by the North Central Texas Caregiver Teleconnection program**



RESEARCH & RESOURCES



What is Parkinson's Disease?

Parkinson's disease is a brain disorder that causes unintended or uncontrollable movements, such as shaking, stiffness, and difficulty with balance and coordination. Symptoms usually begin gradually and worsen over time. Common symptoms include:

- Tremor in hands, arms, legs, jaw, or head
- Muscle stiffness, where muscle remains contracted for a long time
- Slowness of movement
- Impaired balance and coordination, sometimes leading to falls

While the exact cause of the disease remains unknown, many researchers believe that Parkinson's results from a combination of genetic and environmental factors. There is no cure for Parkinson's, but there are medicines, surgical treatments, and other therapies that can relieve some of the symptoms associated with the disease.

To learn more about Parkinson's disease, click the red button below.

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>



How To Evaluate Health Information on the Internet

The internet makes finding health information easy and fast. But, it can also lead you to a lot of false and misleading information. The National Institutes of Health offers tips on how to decide whether the health information you find on the internet is reliable.

To learn more about to assessing health information online, click the red button below.

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SPOTTING THE SIGNS OF ELDER ABUSE

About **1 in 10** adults over age 60 are abused, neglected, or financially exploited.



Know the Signs of Elder Abuse and How to Get Help

The mistreatment of older adults can be by family members, strangers, health care providers, caregivers, or friends. Abuse can happen to any older adult, but often affects those who depend on others for help with activities of everyday life. Learn how to recognize some of the signs of elder abuse so you can step in and help. For example, you may notice that the older adult:

- Seems depressed, confused, or withdrawn
- Appears dirty, underfed, or dehydrated
- Has unexplained bruises, burns, cuts, or scars
- Has unpaid bills or recent changes in banking or spending patterns

To learn more about the signs of elder abuse, click the red button below.

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PREVIOUSLY APPEARED

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



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



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.

LEARN MORE



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



engAGED

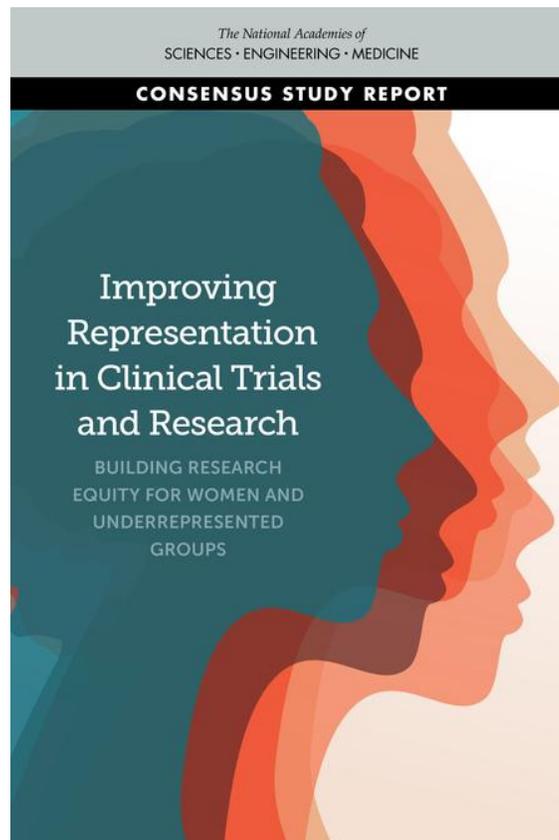
The National Resource Center for Engaging Older Adults

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.

[LEARN MORE](#)



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, or click the red button below.

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FOLLOW US TO STAY CURRENT ON CAREGIVING!

