

THIS WEEK IN CAREGIVING



May 26, 2022



CAREGIVING IN THE NEWS

How to Deal with Alzheimer's Disease Caregiver Stress

May is mental health awareness month, and caregivers of Alzheimer's Disease need to take time to check on themselves, even when that can be hard.

Mark Applegate, from Bolivar, said his mother has Alzheimer's, and it was tough for him and his family to realize she had an issue. He said he hopes people out there don't make the same mistake and research quickly as they can, so you can spot the signs.

Applegate said his mother has been in residential care for five years and his grandmother passed away from Alzheimer's and other complications.

The Alzheimer's Association has tips for caregiver stress: physical activity, taking a needed break, speaking to others, and becoming educated.

From: KY3 | Published: May 21, 2022

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100 Caregiver Affirmations to Honor Yourself and the Amazing Work You're Doing

Caregiver affirmations can be a lifesaver for those whose lives are dedicated to meeting the needs of those unable to meet them themselves—it's an often thankless and unpaid (or sorely underpaid) job, and it's a necessary one to keep many of our loved ones healthy, safe and living with dignity.

Caregivers may experience compassion fatigue in addition to the stresses and tiredness that come with working in

California Caregiver Costs Amongst Highest in the Nation

California family caregivers are feeling the financial stress of taking care of their loved ones.

According to a recent study, 42 million Americans serve in this role. On average, 26% of their incomes go toward care. And in California, it can cost nearly \$40,000 to hire help outside of the home, which is among the highest rates in the nation.

Tricia Rosenbaum considers herself a care partner for her husband who was

general, and maintaining a sense of balance and wellbeing isn't always easy. Affirmations can help caregivers feel more centered, in control and at peace—but you have to choose your affirmations wisely.

“Affirmations are the positive words of hope and encouragement we need to hear from the most important person in our lives, the person that so often acts as our critic—ourselves,” Christina Furnival, mental health therapist and author of *Fear Not! How to Face Your Fear and Anxiety Head-On* tells Parade.

From: Parade | Published: May 4, 2022

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diagnosed with Parkinson's Disease.

"My husband is not at the point where he's not able to do anything," Rosenbaum said. "I think now, I do more of the cooking than I used to, so I think that's one of the tiny household things that we're already seeing because with dexterity and things like that, it's hard to actually do the things."

From: ABC10 | Published: May 5, 2022

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NAC NEWS AND UPDATES



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.

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

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JUST RELEASED!

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

DOWNLOAD NOW

NAC Releases New Report: 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](#)









JUST RELEASED!

Caregiving in a Diverse America:
Beginning to Understand
the Systemic Challenges
Facing Family Caregivers

[DOWNLOAD NOW](#)

MADE POSSIBLE THROUGH SPONSORSHIP BY



NAC Releases New Report: Caregiving in a Diverse America: Understanding the Systemic Challenges Facing Diverse Family Caregivers in the U.S.

The National Alliance for Caregiving is proud to present *Caregiving in a Diverse America: Understanding the Systemic Challenges Facing Family Caregivers in the U.S.*, a new report conducted with sponsorship by Amgen, Inc., with support from the Diverse Elders Coalition and in partnership with the National Minority Quality Forum. Based on a

secondary analysis of the survey results found in *Caregiving in the U.S. 2020*, the data presented includes multiple logistic regression analyses by Dartmouth College researchers. The report highlights significant disparities in support, caregiving intensity, health, and financial impacts among African American, Hispanic and Asian American and Pacific Islander caregivers, LGBTQ caregivers, as well as caregivers across different income brackets and geographical areas. While conducting the research for this report, it became clear that more inclusive methods of data collection are needed to inform research on the needs and possible supports and services that can be provided to diverse family caregivers.

The findings in this report highlight:

- African American, Hispanic, Asian American/Pacific Islander, LGBTQ, rural and socioeconomically diverse caregivers;
- Disparities in living situations, financial status, caregiving activities, self-reported health, and information and services used;
- Personal stories of diverse family caregivers that provide human context to the data;
- Next steps in ensuring data collection and research is inclusive of and equitable to all family caregivers;
- Future policies and improvements to supports, services and the health care system that can better the caregiver experience for diverse populations.

[LEARN MORE ABOUT THE NAC REPORT](#)



Addressing the Needs of Diverse Family Caregivers for Older Adults

This 20-page report is the product of a series of activities conducted by the Diverse Elders Coalition (DEC) and its members' organizations, and in partnership with the National Alliance for Caregiving, to better understand and highlight the lived experiences of diverse family caregivers for older adults. It highlights key findings from 300+ diverse caregivers for older adults from the DEC's constituent communities, including racially and ethnically diverse people; American Indians and Alaska Natives; and lesbian, gay, bisexual, transgender and queer/questioning (LGBTQ+) people as they provide care through the pandemic. The goal of the full length report is to offer research and recommendations to help ensure services and supports for caregivers intentionally address health disparities and systemic barriers that diverse family caregivers for older adults face.

[READ THE REPORT](#)



EVENTS & OPPORTUNITIES



Webinar: A Statewide Effort To Support People Living With Dementia, Their Family Caregivers And Their Communities

May 25, 2022 | 1:00 PM - 2:00 PM EST | Online

The Wisconsin Dementia Care Specialist program serves individuals, families and their communities as part of county-based aging and disability resource centers. Assisting the agency to become dementia capable, acting as a catalyst for dementia friendly communities, and supporting individuals living with dementia and their families to live at home in the community are the pillars of the program. How the program started and evolved to become statewide will be discussed.

Participants in this webinar will be able to:

- Describe community-based memory screening as a part of the program.
- Explain the three pillars of the DCS program.
- Propose planning and action items to state and local decision makers based upon the program's framework, in part or as a whole.

To register for the webinar, click the red button below.

REGISTER



**GRANTMAKERS
IN AGING**

**Conveying Empathy from a Distance:
Using E-empathy in Goals of Care
Conversations**

Conversations with GIA: Conveying Empathy from a Distance: Using E-empathy in Goals of Care Conversations

May 26, 2022 | 1:00 PM - 2:00 PM EST | Online

With the support of Cambia Health Foundation, the Coalition for Supportive Care of Kidney Patients recently developed an online training entitled E-empathy: How to Convey Empathy in Goals of Care Conversations Using Telehealth. This guide incorporates evidence-based practices and patient feedback to provide health care professionals with concrete skills and example scenarios to build empathetic, trusting relationships when communicating with seriously ill patients via telehealth.

The Rita and Alex Hillman Foundation is building upon this work through a grant to establish a culturally tailored approach to help clinicians more effectively communicate empathy when working with Black patients with kidney disease in a virtual/telehealth environment. Join Grantmakers In Aging for a conversation on this innovative work to build empathetic relationships with people through telehealth.

Panelists: Peggy Maguire, President, Cambia Health Foundation; Rachael Watman, Vice President, Programs, Rita and Alex Hillman Foundation; Adriana Glen, Assistant Professor, Nursing, RN-BSN Program Director & Academic Coach, The George Washington University, School of Nursing; Elizabeth Anderson, Assistant Professor of Social Work at Western Carolina University; and JoAnn Stevelos, Executive Director, Coalition for Supportive Care of Kidney Patients, School of Nursing, George Washington University.

To register for the webinar, click the red button below.

[REGISTER](#)
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Perspectives from Health Researchers in Advancing Health Equity in Diverse Communities' Part 1

May 26, 2022 | 1:00 PM - 2:00 PM EST | Online

The National Hispanic Council on Aging (NHCOA) and the Diverse Elders Coalition (DEC) will host a webinar to discuss the importance of collecting health research data from diverse populations and the benefits it will provide for researchers and health practitioners. We will discuss persisting health inequities and barriers that have prevented communities of color, LGBTQ+ communities, American Indian/Alaska Native communities, and others from participating in health research and how the All of Us Research Program resolves these inequities, making it easier for diverse communities to participate in health research.

Similarly, we will also be discussing the difficulties for health researchers in reaching diverse communities to participate in health research and how the All Of Us Research program may resolve these difficulties.

Invited Speakers: Fayron Epps, PhD, RN and Florencia Gonzalez, MPH will discuss persisting health inequities and barriers that have prevented communities of color, LGBTQ+ communities, American Indian/Alaska Native communities, and others from participating in health research and how the All of Us Research Program fights these inequities, making it easier for diverse communities to participate in health research.

For more information contact us at c.perez@nhcoa.org , ole@diverseelders.org or at 202-347-9733 (NHCOA office).

To register for the webinar, click the red button below.

REGISTER



Webinar: Choosing the Medicare Option That's Right For You When You Are Living With Paralysis

June 1, 2022 | 2:00 PM - 3:00 PM EST | Online

A webinar for the Christopher and Dana Reeve Foundation by the Center for Medicare Advocacy

The program will explore the pros and cons of getting Medicare through the traditional public program or a private managed-care Medicare Advantage program, whether you're:

- New to Medicare,
- Seeking to change your Medicare option during the annual election period, or
- Wondering if your changing life circumstances might present other opportunities for choosing how you get Medicare.

The presentation will also examine:

- Resources to optimize the decision on how you get Medicare,
- Strategies to avoid late enrollment penalties,
- Coordinating insurance when you have other types of health coverage, in addition to Medicare, and
- Programs that may assist in paying for the costs of Medicare.

Presented by Center for Medicare Advocacy Associate Director/ Attorney Kathy Holt, and Associate Director/Senior Policy Attorney David Lipschutz

To register for the webinar, click the red button below.

REGISTER





Education
Development
Center

National Collaboratory to Address Elder Mistreatment Mentorship Program

Deadline: June 3, 2022

As the nation's health system expands its focus on and commitment to improving care for the growing population of older adults, the National Collaboratory to Address Elder Mistreatment (NCAEM) is pleased to announce a request for applications for its new Mentorship Program. This one-year program is intended to identify and support clinicians, service providers, researchers, policymakers, and advocates from multiple disciplines who wish to focus on improving care for older adults experiencing or at risk of experiencing elder mistreatment. The first cohort for the program will be July 2022 to June 2023.

We recognize that improving elder mistreatment identification, intervention, and prevention requires supporting people with a broad range of interests and careers, and we plan to select a varied cohort to participate in this mentorship program. Applicants representing or working with underserved populations are encouraged to apply.

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

DOWNLOAD THE APPLICATION FORM



ASA RISE Applications Are Now Open!

Deadline: June 5, 2022

The American Society on Aging (ASA) is now accepting applications for the second cohort of its ASA RISE Fellowship, a leadership and social justice program for leaders of color in aging.

The field of aging needs more leaders of color—and a modern, sustainable leadership program to support them. Aging in the United States has never been an equitable experience across the barriers of economic and social justice. Exacerbating this issue is the fact that those who can best drive the change we need are often the people who were

raised, live and work in the communities most affected by these inequities. And so, much too often, the same inequities and lack of justice that require our response are those that prevent the most qualified people from having access to lead that response.

Simply put, ASA RISE is a launching pad for the next generation of aging leadership. Our vision for ASA RISE is that it will lead to improved well-being across an increasingly diverse aging population by creating a BIPOC leadership pool that improves policies and programs at the local, state and national levels.

Acceptance decisions will be shared and communicated by August 1, 2022

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



Apply to be a Care Fellow

Deadline: June 6, 2022

The Caring Across Generations Care Fellowship is a paid, six-month leadership development opportunity for current and former family caregivers, people with disabilities, and older adults who have given and/or received care.

Fellows will be expected to actively participate in the monthly Zoom meetings which will include training on organizing, advocacy, storytelling, media, and Get Out the Vote (GOTV) actions.

There will be ongoing opportunities to apply new skills acquired in trainings to advance the work of Caring Across Generations. Fellows will complete the fellowship with an understanding of how people power impacts policy-change at the state and federal level, learn how to use the power of their own lived experience to create structural change, and join a community of diverse individuals who are passionate about creating a care infrastructure that is affordable, accessible, and equitable for all.

The fellowship is primarily virtual with occasional, optional in-person activities. All in-person actions will have virtual options available for those unable to attend for any reason.

Stipend: \$250/month for 10 hours/month of work for a total of \$1,250.

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





Public Health Center on Excellence Webinar: Public Health and Faith

June 8, 2022 | 12:00 PM - 1:30 PM EST | Online

Faith-based organizations (FBOs) have always been very active in health promotion and disease prevention. Many of them provide dementia awareness and education programs, along with resources and support for community members with dementia, their families and caregivers. As trusted community institutions, faith-based organizations can be a key partner for public health agencies in their efforts to reach and support a larger number of people living with dementia and their caregivers. The first installment of this webinar series, will provide an overview of dementia-related work FBOs currently do, their role as public health agents in dementia caregiving, and share practical recommendations for public health agencies for effectively partnering with faith organizations.

To register for the webinar, click the red button below.

REGISTER



The Public Health Opportunities and Challenges of Dementia Caregiving

June 14th-15th, 2022

You are invited to the in-person BOLD Public Health Opportunities and Challenges of Dementia Caregiving Conference on June 14 & 15! Join the BOLD Public Health Center of Excellence in Dementia Caregiving in person @McNamara Alumni Center (MN), and hear from experts what states and communities are doing to elevate dementia caregiving as a public health issue.

To learn more or register for the conference, click the red button below.

REGISTER



NCCIH Request for Input on Whole Person Health -

Determinants

Deadline: June 17, 2022

The National Center for Complementary and Integrative Health (NCCIH) at the National Institutes of Health (NIH) is seeking your organizations input to delineate a set of common data elements that will guide research on whole person health. We have published a request for information (RFI), "**Identification of a Set of Determinants for Whole Person Health**," and invite you share it with your organization's members. Comments are due by June 17, 2022.

The purpose of this Request for Information (RFI) is to solicit public comment on defining a set of key determinants of health that addresses all the elements of the whole person health model, i.e., factors that can influence health either positively or negatively, and that encompass the full continuum of biological, behavioral, social, and environmental domains.

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

REGISTER



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.

APPLY



PATIENT AND CAREGIVER STUDIES

SilverBills: A Financial and Legal Tool for Dementia Caregivers

Start: June 1, 2022
End: May 31, 2023
Enrollment: 150

What Is This Study About?

This study will assess whether the SilverBills tool, which provides bill payment, budgeting, taxes, and secure legal document storage services, can decrease dementia caregiver stress, and increase quality of life. After an initial phone consultation, participants will be enrolled, free of charge, in the SilverBills service for approximately one year. Before and six months after using the service, researchers will measure caregiver burden including financial, physical, and emotional well-being. Participation in this study is fully remote and can be completed from home.

Do I Qualify To Participate in This Study?

Minimum Age: 18
Maximum Age: None

Must have:

- Provide care for a person with Alzheimer's disease or a related dementia

Must NOT have:

- Cognitive problems that could interfere with study participation or with providing study consent for self

If I Qualify, Who Do I Contact?

Contact study personnel listed either under the general study contact or the location nearest you.

Who Is the General Study Contact?

For more information and to enroll, please call 855-553-7330 or send an email to NIHStudy@silverbills.com



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 flier for this study, click the red button below.

VIEW THE FLIER



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



Study: In Caregiving, These Mindfulness Practices Could Help

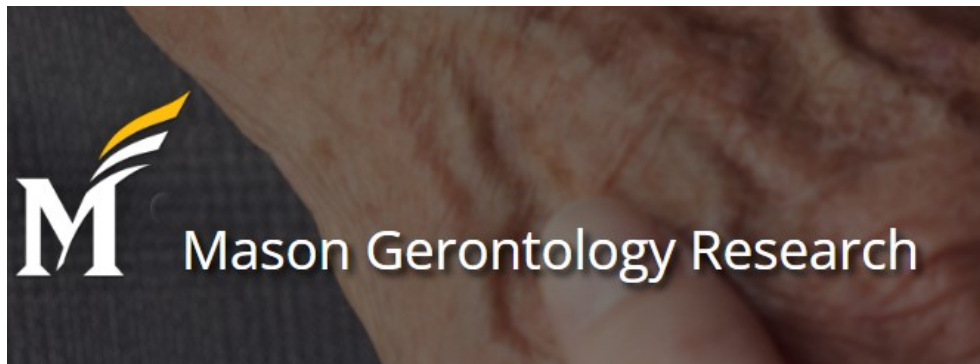
Family members who care for a loved one with dementia often experience chronic stress, anxiety and depression. Psychological research into mindfulness remains a fairly nascent field of study, but mindfulness practices have numerous benefits for care partners.

Research conducted by Felipe Jain, Director of Health Aging Studies at Mass General Hospital, has created and established the benefit of a mindfulness and guided imagery approach, Mentalizing Imagery Therapy (MIT), for family dementia caregivers.

The focus of Dr. Jain's research is now to identify strategies to deliver caregiver skills training and relaxation techniques remotely to improve caregiver well-being. The research has been funded by the National Institute on Aging and private foundations.

To learn more about how mindfulness can benefit caregivers, click [here](#). To sign up for an upcoming Mentalizing Imagery Therapy study, click the red button below.

SIGN UP
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Mason CARES

George Mason University Department of Social Work invites care partners caring for a loved one with dementia to participate in Mason CARES, a research study assessing the effect of an evidenced-based virtual education program on care partner stress-management. This program serves to reduce care partner stress/ burden and increase care partner well-being.

Family care partners provide more than 80% of the daily care of older adults in the U.S. In 2019, more than 16.1 million unpaid family care partners of people with dementia assumed caregiving tasks because of declining cognitive and physical functioning among older adults (Alzheimer's Association, n.d). Non-pharmacological, affordable interventions have evidence of effectiveness for families challenged with dementia in reducing care partner stress and increasing well-being.

Care partners in our research study will enroll in a virtual community of practice, receiving support from the George Mason University Mason CARES team through the 9-week evidence-based Stress-Busting Program (SBP) for Family Caregivers™, with a community of other care partners. We will collect information regarding stress and well-being before, during, and after the study ends. Upon completion of the SBP, the team will follow up with continued support for one month. Time commitment will be no more than 30 – 90 minutes per week depending on weekly activities.

To learn more about the Mason CARES study, click [here](#). To sign up, click the red button below.

SIGN UP



Alzheimers.gov Highlights

Information on living with dementia, dementia research, clinical trials, and resources

Volunteers Needed for Studies to Advance Dementia Research

Interested in volunteering for research on Alzheimer's disease, related dementias, and cognitive health? Learn about new and featured studies near you with the Alzheimers.gov Clinical Trials Finder by clicking on the red button below.

To learn more about other resources available at Alzheimers.gov, click [here](#).

FIND AN ALZHEIMER'S STUDY



Welcome to the WeCareAdvisor Research Study!

Are you a family caregiver for a person living with dementia? The WeCareAdvisor Study may be right for you!

The WeCareAdvisor is an innovative tool developed by researchers at Drexel University and University of California, Davis to help family caregivers manage common behavioral and psychological symptoms of dementia like anger, irritability, asking repeated questions, pacing, or refusing needed help. The WeCareAdvisor walks caregivers through a step-by-step approach to understand why behaviors may be occurring, and to provide strategies that are customized to the situation that caregivers can use to manage the behaviors.

Enrolled caregivers are randomly assigned to one of two groups, both of which have access to WeCareAdvisor. Caregivers also complete four phone interviews over six months, and receive a \$15 Amazon e-gift card for each completed interview.

The study is good fit for family caregivers who are 21 or older; able to read, speak, and understand English; the primary caregiver of a person diagnosed with dementia for at least the past 6 months; currently managing challenging dementia-related behaviors; have an internet-capable device, such as a computer, tablet, or smartphone; and have Internet access.

For more information, email WeCare@drexel.edu, call us at 267-359-1111, or visit <http://wecareadvisorstudy.com>.



Cancer Experience Registry

The Cancer Experience Registry (CER) is an IRB-approved research study that aims to understand the emotional, physical, practical, and financial impact of cancer and identify critical unmet needs among cancer patients, survivors, and caregivers. Our research is one of a kind because it captures the lived experiences of people impacted by cancer through longitudinal data collection, as well as patient and caregiver data that can be linked to understand how their experiences impact each other.

Who can take the survey? The CER is open to any adult who has been diagnosed with cancer at any point in their life or has been a family or informal caregiver to someone with cancer. Participants must live in the United States, a U.S. territory, or Canada and be able to read and understand English.

To learn more about the registry, click the red button below.

LEARN MORE



SHUT*i*CARE

Sleep Healthy Using the Internet - Caregiver Acceptability Research

SHUTi CARE Research Study

Many caregivers have sleep problems. Our team of researchers from researchers from the University of Virginia and the University of Pittsburgh developed and tested SHUTi, an interactive, web-based training program to improve the sleep of adults with insomnia. SHUTi provides a tailored educational program to individuals who are experiencing sleep difficulties, including those having difficulty falling asleep, waking in the middle of the night, or waking too early in the morning.

SHUTi has been tested and found successful in helping adults in the general population. The purpose of this study is to understand how caregivers who have sleep problems use

and benefit from SHUTi.

To learn more about the study, click [here](#). To participate, click the red button below.

SIGN UP
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Are You a Nurse and Family Caregiver?

What is this research study about?

We want to understand the issues that impact emotional and financial well-being for nurses who are also family caregivers.

What will I do?

If you qualify for this study you may:

- *Take a 30 minute survey
- *Participate in a 60 minute interview
- *Participate in a 90 minute focus group

You may qualify for this research study if:

- *You are 18 years of age or older
- *You care for someone with a chronic illness for 10 or more hours per week
- *You have worked as a nurse in the past two years

Participants will receive compensation for each phase of the study.

To learn more about this study, click the red button below.

LEARN MORE
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IN CASE YOU MISSED IT...

You're Not Alone Caregiver—Validating the Caregiver Experience



You're Not Alone—Validating the Caregiver Experience features Cancer Commons Director of Patient Services Deb Christensen, MSN, APRN, AOCNS, OCN, and interviews with experienced caregivers who have helped parents, children, spouses, friends, and other loved ones through a variety of challenges, including treatment and end-of-life care.

Discussions includes challenges, strategies, and resources for loved ones of cancer

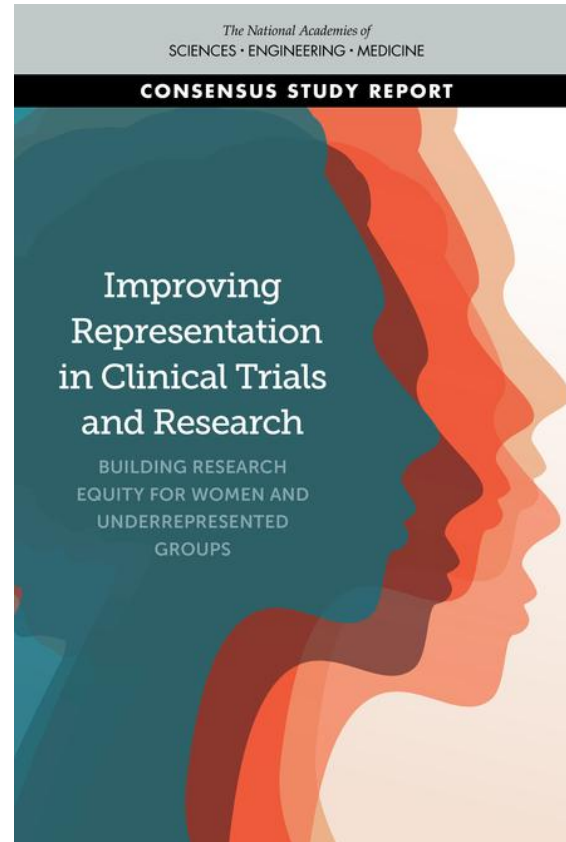
patients—particularly those affected by advanced or metastatic cancer.

This is the second event in Cancer Commons' Pat Looney Educational Series for Client Empowerment, a quarterly series focused on providing education and information to the cancer-impacted community.

The event was held virtually on May 18, 2022.



RESEARCH & RESOURCES



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.

[LEARN MORE](#)



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.

[READ THE SOCIAL SECURITY FACT SHEET](#)

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.

[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.

[LEARN MORE](#)




HCCI Learning Hub



Free Course on Diversity, Equity, and Inclusion for Home-Based Care

During National Minority Health Month, the Home Centered Care Institute (HCCI) has launched a new free course entitled, **“Diversity, Equity, and Inclusion for Home-Based Care.”**

This on-demand course, supported (in part) by the Josiah Macy Jr. Foundation, addresses the complex and multifaceted topic of health equity by discussing power and privilege, implicit and explicit bias, inferred cultural preferences, and more, which are especially relevant for providers working with patients and families in their home.

The course, designated for a maximum of 0.5 AMA PRA Category 1 Credit™, provides guidance in developing and implementing best practices for culturally sensitive care in the home environment and within the workplace. While the course targets home-based primary care (HBPC) providers and those interested in HBPC, non-clinical staff members can also benefit from understanding implicit bias as they support interactions with patients and caregivers (such as scheduling or billing), while those in leadership will learn how to better engage and retain high-performing, diverse teams.

To take the course, click the red button below.

[LEARN MORE](#)



CAREGIVER TLC - THRIVE, LEARN, CONNECT
SUPPORTING FAMILY CAREGIVERS



Caregiver TLC

What is Caregiver TLC?

The Caregiver TLC Research Program offers FREE ONLINE support to adults providing care to persons with memory loss, dementia, or chronic illness.

Caregivers will complete six weekly Zoom sessions led by trained facilitators. This workshop will teach coping skills to deal with stress, depression and burden, and strategies to improve quality of life.

Is Caregiver TLC For Me?

- Do you provide at least 4 hours of care a week to a person with a chronic illness or memory loss?

- Do you help your family member to:
 - Remember appointments?
 - Get bathed or dressed ?
 - Take their medications on time?
 - Could you attend six weekly 2-hour Zoom* sessions?
 - Would you like to connect with other caregivers near you?
 - Do you have a personal email address?

To register for Caregiver TLC, click [here](#). To learn more, click the red button below.

LEARN MORE



ASSOCIATION OF STATE AND TERRITORIAL HEALTH OFFICIALS

Older Adults and Healthy Aging (podcast)

Older-adult health has been increasingly on the radar of public health agencies over the course of the COVID-19 pandemic. For many, it prompted new or enhanced partnerships with their sibling agencies. As the population of older adults continues to grow, it is crucial for public health agencies to join partners in the aging network to create systems that support healthy aging.

In this podcast episode, Jewel Mullen (alumni-CT) offers perspectives on the value of cultivating partnerships between state public health agencies and state units on aging. In addition, Elizabeth Head (Deputy Director, Injury Prevention Section, Georgia Department of Public Health) and Aline Stone (Georgia Alzheimer's and Related Dementias Coordinator, Division of Aging Services, Georgia Department of Human Services) describe their collaboration to improve the health of older adults in Georgia. They share their experience participating in a pilot project with ASTHO and Trust for America's Health to cross reference their state health improvement and aging plans.

To listen to the podcast, click the red button below.

LISTEN TO THE PODCAST



Celebrate Older Americans Month 2022

Every May, the Administration for Community Living (ACL) leads the nation's observance of Older Americans Month (OAM). The theme for this year is "Age My Way."

In 2022, ACL will be focusing on aging in place – how older adults can plan to stay in their homes and live independently in their communities for as long as possible. The 2022 theme Age My Way is an opportunity for all of us to explore the many ways older adults can remain in and be involved with their communities.

ACL will be discussing how planning, participation, accessibility and making connections all play a role in aging in place – emphasizing that what each person needs and prefers is unique.

The 2022 logos, posters, templates, social media graphics and activity ideas are available to help you celebrate OAM in your community. Don't forget to share your

#OlderAmericansMonth plans, stories, & events on social media.

To learn more, click the red button below.

[LEARN MORE](#)



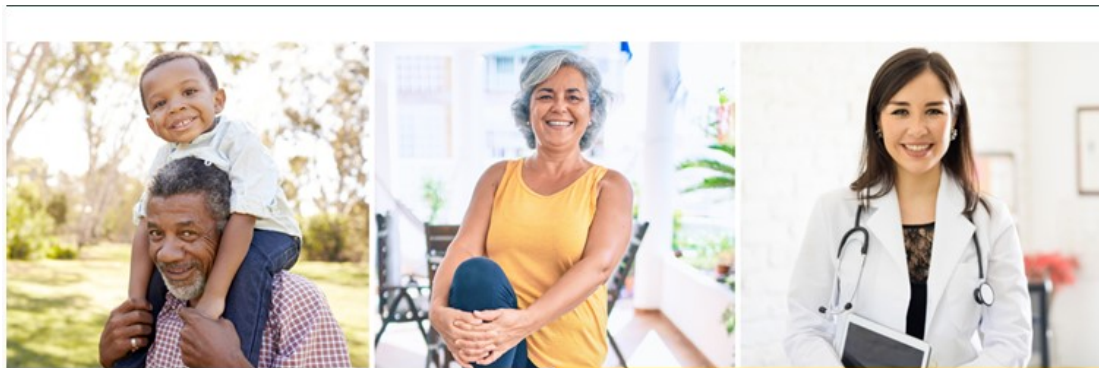
Frequently Asked Questions About Caregiving

Caregiving can be overwhelming for anyone. If you're new to caregiving, take a deep breath, then tackle one task at a time. Consider these tips when getting started:

- Assess your loved one's needs. Figure out what types of help the person you are caring for needs.
- Ask family members and friends to share caregiving tasks. Splitting up tasks among different people can help both the person needing care and the primary caregiver.
- Look for resources available in your community. Local resources may help you find in-home help, transportation, and home-modification services.
- Learn about different options for paying for care. The person needing care may qualify for certain financial options.

To learn more, click the red button below.

[LEARN MORE](#)



What Are the Signs of Mild Cognitive Impairment?

Mild cognitive impairment (MCI) is a condition where people have more memory or thinking problems compared to other people of the same age. The symptoms of MCI are not as severe as those of Alzheimer's disease or related dementias. People with MCI can usually take care of themselves and carry out their normal daily activities. A few signs of MCI may include:

- Losing things often
- Forgetting to attend important events or appointments
- Having more trouble coming up with words than other people of the same age

To learn more about the signs and symptoms of mild cognitive impairment on the Alzheimers.gov website, click the red button below.

[LEARN MORE](#)
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Eldercare Locator

The Eldercare Locator is a nationwide service that connects older Americans and their caregivers with trustworthy local support resources. Since 1991, the Eldercare Locator has been linking those who need assistance with state and local agencies on aging, as well as community-based organizations that serve older adults and their caregivers. Whether help is needed with services such as meals, home care or transportation, or a caregiver needs training and education or a well-deserved break from caregiving responsibilities, the Eldercare Locator is there to point that person in the right direction.

The Eldercare Locator is a public service of the Administration on Aging (AoA), an agency of the U.S. Administration for Community Living.

To learn more the Eldercare Locator, click the red button below.

[LEARN MORE](#)
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FOLLOW US TO STAY CURRENT ON CAREGIVING!

