

THIS WEEK IN CAREGIVING



May 18, 2022



CAREGIVING IN THE NEWS

Caregiver Burnout: How to Combat the Emotional and Physical Toll

Lack of sleep, irritability, and increased anxiety can signal oncoming burnout for caregivers—those who provide critical support to a loved one with a chronic illness or disability. According to the **National Alliance for Caregiving**, 9.5 million Americans fit this category as of 2020. For some, caregiving has taken such an emotional and physical toll, that new or worsening symptoms don't trigger warnings about their own wellbeing.

But there are ways to combat these symptoms and to head off the effects of severe burnout if you know what to look for.

Caregivers are tasked with a seemingly endless to-do list: providing meals, administering medication, and offering mental stimulation and companionship. With a job description that broad and relentless, exhaustion seems inevitable.

From: Fortune | Published: May 11, 2022

READ MORE



How to Keep Resentment, Anger at Bay When Caregiving Is Difficult

There is one particular low moment as a caregiver that Stacey Dunn, 52, of Seattle, will never forget. Her daughter, Minnie, 26, had been born with autism and cerebral palsy, and in 2019, just before the COVID-19 pandemic shut down the world, she was diagnosed with bipolar disorder. Dunn is a caregiver for five people: her daughter and husband, her parents who live nearby in Seattle and herself (as a three-time cancer survivor).

When Caregiving Falls To Family And Friends

It's rare that I write about something personal, but I am making an exception here. I just spent the last five days as the sole caregiver for Jenny, a friend from childhood who lives in a very small town in the mountains of California. Jenny is 70 and has a rare form of cancer. Her condition is terminal and she knows it. At this point in time, she is mostly confined to a hospital bed in her living room. The cancer and the aftermath of some of the treatments have proved so painful that she is often unable to elevate herself to walk the 15 steps to the bathroom. Sitting

Minnie was discharged from a local hospital after Dunn was told she could “admit her after she attempts suicide.” That sent her on a desperate hunt to find a hospital that would take her daughter and set up a treatment plan around her dual diagnosis.

From: AARP | Published: May 10, 2022

READ MORE



is the most painful position for her and Jenny is a large woman, so the toilet isn't her friend.

From: Fortune | Published: May 9, 2022

READ MORE



NAC NEWS AND UPDATES



2022
WORLD CARERS
Conversation

A VIRTUAL GLOBAL SUMMIT HIGHLIGHTING INNOVATIONS
IN CAREGIVING RESEARCH, PRACTICE AND POLICY

nac
National Alliance for Caregiving

embracing
carers

SAVE THE DATE: 19 MAY 2022

World Carers Conversation 2022: Register Now

May 19, 2022 | 8:00 AM - 6:00 PM EST | Online

As the uncertainty around the future of the global COVID-19 pandemic continues, support for carers remains critical. NAC is convening global leaders, experts, influencers, researchers, policymakers, innovators, and other stakeholders in caregiving to share their unique research, case studies, programs, interventions, and perspectives on the future of caregiving as part of this event.

This free event will be made available to the public via Zoom and Facebook Live. The 2020 World Carers Conversation enjoyed participation of caregiving experts and stakeholders from six continents (Africa, Asia, Europe, Oceania, North America, South America) and fifteen countries (Australia, Canada, China, France, Ghana, India, Ireland, Israel, Mexico, New Zealand, South Korea, Taiwan, United Kingdom, United States) with more than 4,000 attendees.

The agenda for this event is now open. To see the agenda and learn more, click [here](#). To register for the event, click the red button below.

REGISTER





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



2022 National Voices of Medicare Summit & Senator Jay Rockefeller Lecture

CMA's 2022 National Voices of Medicare Summit & Senator Jay Rockefeller Lecture

May 18, 2022 | 12:30 PM - 4:30 PM EST | Online

The Center for Medicare Advocacy (CMA) will hold its 9th annual National Voices of Medicare Summit & Senator Jay Rockefeller Lecture via virtual presentation on May 18.

The Summit, titled "Medicare in Jeopardy - How Do We Save It?," will include how to best expand Medicare for all beneficiaries, the need for Medicare coverage for audiology and oral health care, and access to Medicare-covered home health care and rehabilitation services - looking at all through a health equity lens.

This year's Senator Jay Rockefeller Lecturer will be E.J. Dionne, Jr., an American journalist, political commentator, and columnist for the Washington Post.

To learn more about the event, click [here](#). To register for the webinar, click the red button below.

REGISTER



INSTITUTE FOR
HEALTHCARE POLICY & INNOVATION
UNIVERSITY OF MICHIGAN

Webinar: Optimizing Health and Well-Being as We Age

May 19, 2022 | 1:00 PM - 2:30 PM EST | Online

Join us for a webinar to celebrate the fifth anniversary of the University of Michigan National Poll on Healthy Aging, presented by the Institute for Healthcare Policy & Innovation and AARP. Distinguished national leaders will share the latest research and discuss opportunities to enhance health as we age.

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

REGISTER



Webinar: Technology as a Social Determinant of Health

May 19, 2022 | 3:00 PM - 4:00 PM EST | Online

Join Trust for America's Health for a webinar that will focus on ways that embracing technology as a social determinant of health helps to engage key stakeholders and policymakers. Older adults and their families with access to technology, including broadband internet, relevant devices and skill-building opportunities, have been able to seek out a wider array of information, services, and social connections more quickly, and organizations were able to reach them more effectively during the pandemic. Older adults without such access have been disproportionately impacted and will continue to be unless digital equity efforts and funding opportunities consider all of us.

Technology is a social determinant of health and the May session of the AFPHS Training Series will feature the Massachusetts Healthy Aging Collaborative (MHAC), a cross-sector and statewide network of stakeholders promoting and supporting inclusive age- and dementia friendly communities. James Fuccione, Senior Director of MHAC, will discuss strategies such as advocacy, partnerships and elevating promising practices to ensure older adults are included in digital equity work. Some of MHAC's partners advancing local and regional digital equity solutions will also share their work and experiences. Overall, participants will learn how embracing technology as a social determinant of health helps to engage key stakeholders and policymakers.

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

REGISTER
>

FCA Presents: A Conversation With the 2021 Innovations in Alzheimer's Caregiving Award Winners

May 24, 2022 | 11:00 AM - 12:00 PM EST | Online

Join the Family Caregiver Alliance (FCA) for a panel discussion with the most recent Innovations in Alzheimer's Caregiving Award recipients. The winners include the following programs:

Creative Expression

-Elderwise

Using the Spirit-Centered Care® philosophy at its core, Elderwise teaches, models, and promotes culture change among caregivers, family members, and healthcare professionals by recognizing the intrinsic value of each person and their capacity to live a rich and joyful life regardless of their cognitive or physical condition.

-“Art Is...In”

“Art Is...In” is a technology-free, professionally curated art-at-home program that aims to engage and encourage meaningful creative expression for caregivers and individuals living with dementia who cannot participate in virtual activities or those with limited access or ability to use a computer or internet.

Diverse/Multicultural Communities

-Care NYC

Sunnyside Community Services (SCS) based in Queens is a multifaceted organization

...serving one of the largest growing Spanish-speaking Latin American groups in the United States. In response to the growing linguistic and cultural needs, their program CARE NYC created a comprehensive targeted program to honor the differences in cultural, linguistic, family dynamics, and religious identities for caregivers of individuals with Alzheimer's disease or other dementias seeking and receiving services.

To register, click the red button below.

REGISTER



**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





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.



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.



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.



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

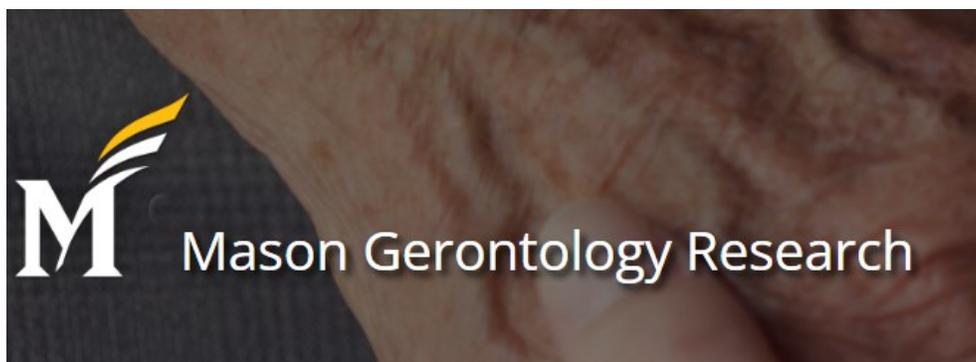
Family members who care for a loved one with dementia often experience chronic stress, anxiety and depression. Psychological research into mindfulness remains a fairly nascent field of study, but mindfulness practices have numerous benefits for care partners.

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



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](#)



SHUTi 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
>

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
>

IN CASE YOU MISSED IT...

**Hospice Care & Family Moments with Traci Lamb, CEO of
Smart Caregiving + willGather**



This week's guest is Traci Lamb, CEO of Smart Caregiving. Traci has spent the last 20 years in the healthcare industry with over 14 of those years working in hospice. She is the primary caregiver for both of her parents who are in their 80s - this led our conversation today as well as her personal experience working in hospice care.

Families have many questions- what is hospice care? How is it different than palliative care? What is comfort care? Why would we choose hospice? What are the benefits? How do we have these important conversations? We look at the value of grief support and how everyone experiences grief differently.

Traci has a passion for helping people, she leads with integrity and desires to support families through their care journeys. Traci's company was voted a Top 100 Healthcare Visionary by IFAH.



RESEARCH & RESOURCES



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



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](https://www.alzheimers.gov) website, click the red button below.

[LEARN MORE](#)



Eldercare Locator

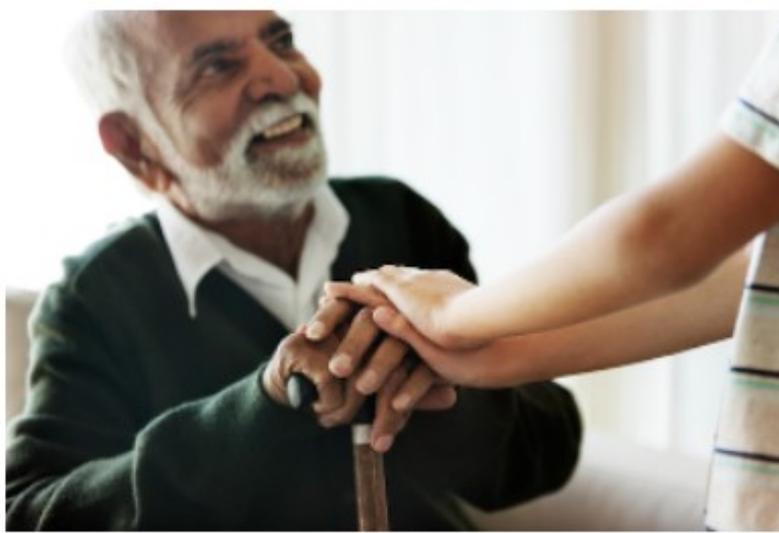
The Eldercare Locator is a nationwide service that connects older Americans and their caregivers with trustworthy local support resources. Since 1991, the Eldercare Locator has been linking those who need assistance with state and local agencies on aging, as well as community-based organizations that 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](#)





Dementia Resources for Caregivers and Families

The VA Geriatric Research, Education, and Clinical Centers (GRECCs) are VA geriatric centers of excellence focused on aging. GRECC-Connect's team of doctors, social workers, occupational therapists, and nurses reviewed over 100 online dementia resources and selected options available to assist and support people with dementia and their families.

The GRECC-Connect team took care in choosing the most informative and easy to use resources in varied formats (booklet, brochure, video etc.). The resources suggested are organized by topic and available for viewing online. Many resources can be printed directly from the pdf or the direct link shared via email or chat.

To learn more about these online resources, click the red button below.

[EXPLORE ONLINE DEMENTIA RESOURCES](#)



Hidden Helpers at the Frontlines of Caregiving: Supporting the Healthy Development of Children from Military and Veteran Caregiving Homes

A 2017 RAND Study commissioned by the Elizabeth Dole Foundation (EDF) found that there have been no published studies examining the impact of caregiving on military children. In response to these findings, over the last four years, EDF has been regularly convening leaders in the military and veteran space for dialogues around the needs of military children in caregiving households.

One outcome of these meetings has been EDF's launch of a first-of-its-kind, groundbreaking research study focused on military caregiver children and adolescents, *Hidden Helpers at the Frontlines of Caregiving: Supporting the Healthy Development of Children from Military and Veteran Caregiving Homes*. The findings will help us understand the impact caregiving has on the lives of these children and how we can most effectively support them. This research, funded by Wounded Warrior Project, will be our North Star as we work alongside our Coalition members to address the unmet needs and challenges of military caregiver kids and youth.

To read the study's findings, click the red button below.

[READ MORE](#)



Welcome to The Arc's Virtual Program Library

On this site, people with intellectual and developmental disabilities (IDD) and their caregivers can find and share on-demand activities that they can use whenever it is convenient for them in the comfort of their own homes. Service providers can also find and share resources that they can use to facilitate or deliver live, remote programming for people with IDD.

[EXPLORE THE ARC'S LIBRARY](#)



END OF LIFE

Helping with Comfort and Care

End of Life: Helping with Comfort and Care

At the end of life, each story is different. Death comes suddenly, or a person lingers, gradually fading. For some older people, the body weakens while the mind stays alert. Others remain physically strong, but cognitive losses take a huge toll. Although everyone dies, each loss is personally felt by those close to the one who has died.

End of Life: Helping with Comfort and Care is a guidebook intended to provide guidance and help in understanding the unfamiliar territory of death. This information is based on research, such as that supported by the National Institute on Aging (NIA), along with other parts of the National Institutes of Health. It also includes suggestions from healthcare

providers with expertise in helping individuals and families through this difficult time. Most of the stories included are examples of common experiences at the end of life.

To view the guidebook, click the red button below.

[READ MORE](#)



National Institute on Aging

Cataract Removal Linked to a Reduction in Dementia Risk

Undergoing cataract removal was associated with a lower risk of developing dementia among older adults, according to a new study, supported in part by NIA. Published in JAMA Internal Medicine on Dec. 6, 2021, the study suggests that the improvement in the quality of life for the affected individual and family is likely considerable given the substantial association and its lasting effect beyond 10 years.

To learn about the study's findings, click the red button below. .

[READ MORE](#)



Older Adults' Preparedness to Age in Place

“Aging in place” refers to living independently, safely, and comfortably in one’s home for as long as possible, and it’s an important goal for many older adults and their families. Without home modifications and additional support from others, however, unexpected medical events and declines in health can make it challenging to remain in one’s home. Over January and February 2022, the University of Michigan National Poll on Healthy Aging asked a national sample of adults age 50–80 about their perspectives on aging in place, their homes, and available social supports.

To learn about the poll's findings, click the red button below.

[READ MORE](#)



Planning for the Future After a Dementia Diagnosis

If you or a loved one has been diagnosed with Alzheimer's disease or a related dementia, it may be difficult to think beyond the day to day. However, taking steps now can help prepare for a smoother tomorrow.

Over time, the symptoms of Alzheimer's and related dementias will make it difficult to think clearly. Planning as early as possible enables you to make decisions and communicate those decisions to the right people.

Below are important legal documents to consider, and resources and tips that can help with planning ahead for health care, financial, long-term care, and end-of-life decisions.

To learn more, click the red button below.

LEARN MORE



White Paper on Why Older Adult Mental Health Matters

In anticipation of National Mental Health Awareness Month (MHAM) in May, the National Coalition on Mental Health and Aging (NCMHA) has developed a set of materials emphasizing the growing need to address older adult mental health issues, including a white paper on the importance of mental health in older adults.

To read the white paper, click the red button below. For additional NCMHA materials on this topic, click [here](#).

READ MORE



FOLLOW US TO STAY CURRENT ON CAREGIVING!

