August 17, 2022

What I Learned When I Became My Parents' Caregiver

I didn’t volunteer to become a caregiver to my elderly parents. Instead, I was slowly initiated into the role. It started by doing little things to help. Even though they were in their mid-eighties, they insisted on staying in Pensacola, Fla., their home of 50 years. Since I lived in Virginia, I called twice a week to check on them and shopped for them online. With each visit, I tried to notice things that would tell me if they were doing all right.

From: Good Housekeeping | Published: July 26, 2022

READ MORE

How Sibling Criticism of Caregiving Can Hurt Parents with Alzheimer’s

Between 2015 and 2020, the number of unpaid caregivers in the United States increased from 43.5 million to 53 million, and one in five of those care for family members. According to a Pew Research Center study, the most significant percentage, 44%, provides care for aging parents. Of that percentage, there’s little information regarding siblings that share the responsibility of caring for parents.

From: Alzheimer's News Today | Published: August 8, 2022

READ MORE

Dance with Me? Study Uses Music to Soothe Dementia Patients and Caregivers

The room transformed as an older woman danced around the skilled nursing care unit to rock ‘n’ roll hits from her youth. Her husband later took her hands and joined her in a two-step tour of the space. First-year Penn State College of Medicine medical student John Bufalini watched in awe as the couple’s joy filled the room at the assisted living facility.

From: Penn State University | Published: August 2, 2022

READ MORE
World Carers Conversation 2022 Session Recordings

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

To view the slide deck used in the event, click here. To view the recordings, click below.

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.
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 Travere 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.
The Circle of Care Guidebook Series

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

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

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

VIEW THE GUIDEBOOKS >

EVENTS & OPPORTUNITIES

AUGUST

CONFIDENCE: Financial Education & Training for Latino Family Caregivers

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

CONFIDENCE is a free, 5-week virtual financial education program made for Latino family caregivers who help a loved one with dementia, including Alzheimer’s Disease, and/or memory problems.
As part of this course hosted by the University of Southern California's School of Gerontology, you will learn how to:

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

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

[EMAIL TO REGISTER]

Engaging Caregivers: A Program for Healthcare workers

August 17th, 2022

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

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

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

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

Registration links:

August 3rd at 11:00 am EST: [Defining Caregivers & Recognizing Their Experiences]
August 10th at 11:00 am EST: [Difficult Situations & Elder Abuse]
August 17th at 11:00 am at EST: [Diversity & Caregiving]

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

[VIEW THE FLYER]
Dementia 101: The Basics

August 17, 2022 | 6:00 PM - 7:00 PM EST | Online

If you’ve heard of dementia (or many of the other "memory loss" terms), but aren't sure what it is or you want to learn more, this webinar can help! Spend an hour learning the basics of all things "dementia". You're invited to bring your questions for an open Q+A!

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

REGISTER

AFPHS Training – Livable Communities and Social Determinants of Health

August 18, 2022 | 3:00 PM - 4:00 PM EST | Online

AARP defines a livable community as one “that is safe and secure. It offers choices in where to live and how to get around. And it equitably serves residents of all ages, ability levels, incomes, races, ethnicities, and other backgrounds.” Having safe, healthy, and livable communities where older adults can remain active and engaged is an important part of healthy aging.

This next installment of our 2022 training series will focus on how livable communities are addressing social determinants of health. Speakers will share national and local level innovative practices in livable communities and note valuable partnerships with departments of public health.

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

REGISTER
Spotlight Series: Let’s Talk About Driving

August 22, 2022 | 2:30 PM - 4:00 PM EST | Online

This educational event hosted by the Alzheimer Society of Durham Region (Canada) will discuss driving from the perspective of an older adult, people living with Mild Cognitive Impairment or people living with dementia and their families. Guest speakers from Alzheimer Society Southwest Partners and the Thames Valley Health Team will provide information on warning signs, retirement from driving, and the role of healthcare providers and the Canadian Ministry of Transportation. All populations are welcome to attend this presentation.

**Healthcare providers are welcome to attend, but this event will not provide training on how to assess fitness to drive.**

This session will be hosted on Zoom (with a phone in option)

Zoom session: Once you have registered for the session, you will receive a link with instructions on how to connect.

For Technological Support please contact the Community Education Team for education@alzheimerdurham.com

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

REGISTER

Emergency Preparedness Planning For Persons With Disabilities Webinar

August 24, 2022 | 2:30 PM - 4:00 PM EST | Online

During emergencies and natural disasters, health plans play a critical role in addressing and protecting their members’ health, safety, and independence. For persons with disabilities and their caregivers, it is crucial for health plans to consider individual circumstances and needs in order to effectively prepare for emergencies and disasters. This webinar will provide information on creating and strengthening emergency practices embedded in individualized care plans and health plan processes. Enhanced emergency practices will assist members and their caregivers in navigating emergencies and natural disasters.

By the end of this webinar, participants should be able to:
1. Understand populations and identify persons with access and functional needs (AFN) that may include individuals with disabilities, limited English proficiency, limited access to transportation and financial resources, older adults and others deemed at-risk.

2. Identify the role of care management and care coordination in including emergency preparedness planning in member care plans, including identifying members at high risk during emergencies.

3. Identify steps health plans can take to prepare members and their caregivers for emergencies and natural disasters.

4. Understand the benefits of emergency preparedness for dually eligible individuals.

**Intended Audience:**
This webinar is intended for providers, health plans, and health care organizations interested in creating or bolstering their emergency preparedness processes for individuals with disabilities.

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

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**Developing Successful Volunteer Opportunities in Dementia Programs**

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

Volunteers can provide valuable support for organizations serving people who are living with dementia and their caregivers by enabling organizations to expand their capacity and plan for long-term sustainability. This webinar will focus on how selected dementia programs recruit, train, and retain volunteers; by providing volunteers with meaningful work.

The key to this concept in the Respite for All program is building a dementia-friendly group where everyone has purpose, and no one is singled out for having memory issues. Volunteers are trained to create opportunity for those with dementia to be of service to their community.

The Durham Center for Senior Life (DSCS) engages volunteers in several activities and has leaned heavily on local students. Duke University undergraduate students have been trained to support the implementation of DCSL’s evidence-informed intervention. North Carolina Central University Master’s in Social Work students support dementia care management staff and have an opportunity to conduct social work activities with clients who are living with dementia and their families.
Participants in this webinar will:

- Be able to identify six factors in building a volunteer model that is sustainable.
- Be able to identify highly successful volunteer training concepts pertaining to mindset, communication and scheduling for those working with dementia.
- Learn how to create meaningful engagement opportunities for volunteers.
- Understand challenges and lessons learned when working with volunteers.

To learn more or to register for this event, click the red button below.

REGISTER >

The Grief Journey of the Dementia Caregiver

August 31, 2022 | 1:00 PM - 2:00 PM EST | Online

This program offers clinicians a breakdown of the types and stages of grief that affect caregivers of persons living with dementia. We will discuss how to identify the area of stress that is most burdensome to each particular caregiver and ways to lessen that burden in order to help that caregiver continue to provide optimal care.

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

REGISTER >

McCormick Dementia Services

Integrating Technology into Caregiving

August 31, 2022 | 7:00 PM - 9:00 PM EST | Online
Join us for a Zoom webinar where we learn how to integrate technology into caregiving for a person living with dementia.

Have you ever wondered if there is technology available that can assist you with caregiving and enhancing safety in the home?

Join us for a presentation with guest speakers Jennifer Watt, Occupational Therapist with the Behavioural Response Team in Geriatric Mental Health at LHSC and technology expert Ron Beleno, Consultant, Coach and Mentor from RB33. As a caregiver to his father who lived with Alzheimer's for 10+ years, Ron utilized technology and creative strategies to support his family's life to live well and as best as possible.

Together, Jenny and Ron will showcase a broad range of tools available to help you with caregiving and address everyday challenges that you might be facing, or potentially could face in the future. They will share information on what these tools can be used for taking into consideration the person living with dementia’s right to privacy, their cost, where to get them, and how to set them up.

Please come ready with your questions about caregiving and technology

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

[REGISTER]

SEPTEMBER

Communication in Dementia

September 7, 2022 | 11:00 AM - 12:00 PM EST | Online

A Person With Dementia is suffering from a terminal brain disease. Understanding how memory works, knowing the type of dementia your resident has, along with the stage of the disease, allows caregivers to target conversations to the memories that continue to function. Using this skill allows for interactions with old memory and can lead families and professional caregivers to new insights into their loved one’s younger life.

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

[REGISTER]
Webinar: Navigating a Dementia Diagnosis and Care Needs

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

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

Participants in this webinar will be able to:

- Review the 10 warning signs of Alzheimer’s disease and the importance of diagnosis
- Discuss what to expect after a diagnosis and what changes are likely to occur
- Learn communication strategies and care tips to best support the individual
- Discover resources for professionals and families for diagnosis, care and support

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

September 7, 2022 | 1:30 PM - 3:00 PM EST | Online

This event aims to explain how dementia can affect language and communication. There will be an opportunity to explore the emotional impact of a breakdown in communication / relationships for a carer and the person with dementia and to identify strategies to help establish effective and meaningful interactions.

This session is for you if:

- you would like to gain a better understanding of how communication can be affected for a person with dementia
- you would like to learn about different strategies to support a persons ability to communicate and understand
- you want to spend time with experienced healthcare professionals who will answer your questions in a safe, supportive environment
- you would like to meet other people who are taking care of a friend or family member with dementia in a similar situation

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

Common Family Reactions to Mental Illness

September 8, 2022 | 1:00 PM - 2:00 PM EST | Online

Understanding why people experience things differently can help to ease tension & increase acceptance. Discuss the caregiving experience, the stages of emotional response, and learn how to respond and cope in this one-hour seminar with a licensed therapist.

Fine print: Certificates of attendance are provided at no cost. CEUs are not provided. Everyone who registers will receive the webinar recording & resource info 24 hours after the live event.

About the instructor: Jaymi Dormaier is a Licensed Master Social Worker with ten years of experience in the mental health field. In Jaymi's career as a social worker and therapist she has worked with diverse populations focusing on anxiety, depression, grief, trauma, foster care, adoption, homelessness, and addiction. She is passionate about helping
Hopeful Alzheimer's & Caregivers' Symposium

September 10, 2022 | 11:00 AM - 3:00 PM EST | Online

The Hopeful Alzheimer's & Caregivers' Symposium provides education and information for caregivers of loved ones suffering from Alzheimer's disease. The 2022 program will include a video of persons suffering from various types of dementia. Additionally, some of these individuals will join us and answer questions. Dr. Monica Parker, Director of the Goizueta Alzheimer's Disease Research Center at Emory University will discuss the illness and the latest research findings. Mrs. Shondale Coleman of Amedicis Hospice will discuss how to access hospice services, once a person has an Alzheimer's diagnosis. Attorney Joseph Gilsoul will discuss how to apply for Social Security Disability benefits, once an Alzheimer's diagnosis is received.

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

REGISTER

Caregivers Count 12th Annual Conference

Saturdays, September 10 - October 1, 2022, 1:00 PM – 3:00 PM EDT | Online

The 12th Annual Caregivers Count Conference is tailored specifically for family or informal caregivers who are caring for older adults.

The conference will be held for four consecutive weeks, September 10, 17, 24, and October 1. Attendees will have the opportunity to hear from informative speakers as well as senior service agencies to learn about supportive services in Santa Clara County.

This year’s conference format will be streamed live via Zoom. In addition, for the opening session on September 10, there will be an optional in-person “watch party” held at a location in Santa Clara County (more info to come).

Sessions will also be recorded so that caregivers can refer back to them after the conference.

EVENT TOPICS:
September 10, 2022: Keynote: A Holistic Approach to Self-Care (Jenn Chan, Senior Shower Project)

September 17, 2022: Strategies for Dementia Caregiving (Tami Anastasia, Dementia Caregiver Educator & Trainer)

September 24, 2022: Introduction to Long-Term Care (Vanessa Souza, Alzheimer's Association)

October 1, 2022: Fall Prevention & Home Safety (Santa Clara County Fire Department; Jenn Schachner, Lecturer @ San Jose State University)

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

REGISTER >

**Building Partnerships to Scale Effective Dementia Care Supports: Indiana University and Indiana’s Area Agencies on Aging**

**September 12, 2022 | 1:00 PM - 2:00 PM EST | Online**

Indiana University (IU) was awarded grant funding in 2020 under the Administration for Community Living Alzheimer’s Dementia Programs Initiative to implement the Caregiver Stress Prevention Bundle (CSPB) for people living with dementia and their informal caregivers. The CSPB is delivered through five area agencies on aging (AAA) by trained care coaches who are community health workers employed by the AAAs and supported by IU dementia care experts. Presenters will share how the university partnered with AAAs to implement the dementia care program and results-to-date. Reasons why AAAs partnered with IU to launch a dementia care program and plans for sustainability will also be discussed.

**Participants in this webinar will:**
- Describe how IU partnered with five of Indiana’s AAAs to scale a dementia care program developed and tested at IU.
- List three key elements of the IU/AAA partnership leading to successful program implementation and process improvement.
- Identify three reasons why the AAAs partnered with IU to launch a dementia care program.
- Discuss plans for sustainability and statewide expansion of the IU/AAA dementia care program.

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

REGISTER >

2022 RARE Patient Advocacy Summit
Each year, Global Genes convenes one of the world’s largest gatherings of rare disease patients, caregivers, advocates, healthcare professionals, researchers, partners, and allies at the RARE Patient Advocacy Summit.

This year we’re celebrating being back together again, and have opportunities for you to join us in person or online for two days of connection opportunities, educational sessions, fun, and the RARE Champions of Hope Awards Ceremony and Dinner!

Summit sessions provide attendees with insights about the latest in rare disease innovations, best practices for advocating on an individual and organizational level, and actionable strategies to take home. This year, the Summit will be a hybrid event so all can attend – in person at the Town & Country Hotel in San Diego, California and live streamed online in our virtual event platform.

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

**Caregiver Educational Series - "Incontinence Products"**

**September 13, 2022 |12:45 PM - 2:30 15 EST | Online**

This webinar hosted by the Area Office on Aging of Northwestern Ohio will discuss incontinence products in the context of caregiving. It will be presented by Janet Firestone, National Account Executive Medicaid, Principle Business Enterprises/Tranquility Products.

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

To register for this event, click the red button below.
Join us for Reimagine Respite!, the 2022 National Lifespan Respite Conference to be held in Madison, WI on September 13-15, 2022. The ARCH National Respite Network and Resource Center and its cohost, the Respite Care Association of Wisconsin, are excited to provide this space to advance knowledge and understanding of respite by learning from and with national leaders and innovators in the field of respite.

You are invited to Reimagine Respite with us! Register today at arch.wildapricot.org/2022-Conference-Registration. The pandemic cast a harsh light on the lack of support for family caregivers, but it also presented opportunities to raise awareness and rethink traditional supports. Learn, grow, network, and imagine what we can do to expand respite options for all family caregivers by joining us in Wisconsin in September!

The full Conference Program can be found on the conference website.

To learn more about the conference, click the red button below.
Dementia Information Series

September 14, 2022 through November 2, 2022 | 7:00 PM - 9:00 PM EST | Online

The Dementia Information Series is a comprehensive 8-week series on Wednesday evenings is designed for families who are caring for a loved one with dementia or Alzheimer's disease. You can understand the disease, learn how it affects your relative, how to access support in the home and community, how to cope, and how to communicate.

Register as early as possible to reserve a spot for this popular education event.

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

REGISTER >

Request for Applications for NIA's Career Development Award Program

Deadline to apply: September 15, 2022

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

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

To learn more, click here or on the red button below.

LEARN MORE >
Virtual Event: Anchoring Race Equity and Advancing Health Justice

September 20th - 22nd, 2022

The Anchoring Race Equity and Advancing Health Justice convening seeks to create an inclusive space for Community Catalyst and local, tribal, state and national and community partners to engage in reflective learning and explore strategies and opportunities to build the power of a united health justice movement rooted in racial equity. Innovative ideas and perspectives will be unpacked through sessions, workshops and plenary discussions that move us towards coalition/movement building.

We encourage all community partner organizations to join for our three day virtual convening. Together, we’ll share, learn and participate in timely workshops on communications, policy, organizing and power building. We also look to forward networking, restorative opportunities and most importantly some radical truth telling as we vision forward.

To learn more about this event, click here. To register, click the red button below.
Virtual Duke Caregiver Community Event

September 20, 2022

Duke University is hosting a free, virtual event that will offer you the chance to learn about the latest disease research, understand advancements in caregiving, and discover ways to find support as you care for loved ones. After the event is held on September 20, 2022, its presentations and information sessions can be accessed online by those who register. Materials can be viewed at any time on your computer or mobile device through September 2023.

Conference materials will be available virtually in English and Spanish. Presentations will go live on Sept. 20 and cover these topics and more:

- African-American, Hispanic, Latino, and LGBTQ+ experiences in caregiving
- Challenges of long-distance caregivers
- Physical, occupational, and speech therapy options
- Adult guardianship benefits and misconceptions
- Finding help for mental health care
- Advancements in technology to understand health needs

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

REGISTER

Activities & Engagement in Dementia

September 21, 2022 | 6:00 PM - 7:00 PM EST | Online

Learn Montessori-style methods for engaging someone with dementia in daily care, activities, and how to balance high and low energy times of day.

To register, click the red button below.

REGISTER

OCTOBER

WHEN LIVING AT HOME IS NO LONGER AN OPTION

Alzheimer's Program: When Living at Home is No Longer an Option

October 11, 2022 | 4:00 PM - 5:30 PM EST | Online

Changes in thinking may reduce your ability to make appropriate decisions about self-care and your day-to-day needs as the disease progresses. You may be at increased risk for harm, falls, wandering and/or malnutrition. You also may have difficulty managing personal hygiene or household tasks, which can lead to unsafe living conditions. Plan ahead for how you will address your basic needs, including housing, meals and physical care.
If friends or family have expressed concern about your ability to perform certain roles or tasks, listen to their observations. Alzheimer's will eventually limit your own insights as to what you can safely do.

To register, click the red button below.

REGISTER

2022 National Caregivers Conference
October 16-17, 2022

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

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

Virtual Attendance
Family Caregiver
$100 Virtual Early Bird Family Caregiver
$125 Virtual Final Family Caregiver

Professional
$175 Virtual Early Bird Professional
$200 Virtual Final Professional

For more information about the conference, click here. To register, click the red button below.

REGISTER

2022 NHCGNE Leadership Conference
October 18th - 20th, 2022

The National Hartford Center of Gerontological Nursing Excellence (NHCGNE) will be
hosting its 2022 Leadership Conference from October 18-20, 2022.

The conference will feature plenary sessions, leadership workshops, discussant reports and panel discussions that explore the current state of knowledge about national and international aging, dementia and mental health science, curricular innovations, evidence-based clinical practice, and health policies.

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

**Forms and Stages of Dementia**

**October 19, 2022 | 6:00 PM - 7:00 PM EST | Online**

This webinar will provide attendees with a better understanding of what dementia is, the most common types, signs/symptoms, and its progression.

To register, click the red button below.

**AAHCM 2022 Annual Meeting**

**Home Based Medical Care: Growth Across the Field**

**October 27th - 29th, 2022**

The Home Care Medicine (HCM) landscape has evolved rapidly to become one of the fastest growing healthcare segments, expected to nearly double by 2028. Fueling this incredible growth is an aging population with both complex care requirements and an unprecedented desire to age in place with dignity and comfort. Collaboration across the HCM field is key to meeting the growing needs of this vulnerable population. From primary care to palliative care, social work to supportive care, hospital-at-home to home health agencies and beyond, we must work together to grow HCM and transform the industry for our patients.

Join colleagues, industry partners, and home care advocates to share insights and inspiration at the AAHCM 2022 Annual Meeting. For more than 25 years the Academy has represented the leaders of medical care in the home, and at this year’s meeting we will explore the incredible potential of home care medicine to improve the lives of patients and transform the healthcare industry.
Be a part of all the ways we can grow together — be at the 2022 Annual Meeting in Orlando!

We’ll dive into evidence-based clinical insights, decipher the evolving policy landscape, examine the latest in population health and health equity, share practice management innovations, and more.

For more information about the conference, click here. To register, click the red button below.

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**NOVEMBER**

**ALZHEIMER'S PROGRAM: Healthy Living for Your Brain & Body**

November 8, 2022 | 4:00 PM - 5:30 PM EST | Online

For centuries, we've known that the health of the brain and the body are connected. But now, science is able to provide insights into how to make lifestyle choices that may help you keep your brain and body healthy as you age. Join us to learn about research in the areas of diet and nutrition, exercise, cognitive activity and social engagement, and use hands-on tools to help you incorporate these recommendations into a plan for healthy aging.

To register, click the red button below.

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**PATIENT AND CAREGIVER STUDIES**

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NTG Family Support Committee Survey
The National Task Group on Intellectual Disabilities and Dementia (NTG) is a national advocacy and technical assistance organization chartered to aid and advocate around issues related to dementia among adults with intellectual disabilities and their caregivers.

The NTG is undertaking an initiative to expand the available information on dementia for families, agencies, and others and is reaching out to family and other caregivers to help us better understand where they get their information and what information might be of most use to them.

The NTG has developed a brief 15-item survey with questions tapping some key areas related to information and its access. It should not take more than 10 minutes to complete.

NTG does not ask for any identifiers and the information will be used only in aggregate form to help plan the organization's information initiative.

NTG is looking to get all responses as soon as possible and anyone who is a friend, advocate, mate, family member, or other care partner can participate.

If any questions about this survey arise please contact Family Support Committee familysupport@the-ntg.org. The NTG website can be accessed at www.the-ntg.org.

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

**TAKE THE SURVEY**

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**Generalized Myasthenia Gravis Survey**

Avalere Health is a Washington, DC-based healthcare consulting firm dedicated to improving healthcare. Avalere is supporting work focused on describing, and ultimately quantifying the total burden of disease for generalized myasthenia gravis (MG) in a holistic manner to include tangible and intangible impacts to patients and their caregivers. As a part of this work, Avalere would like to interview 15 adult (18+) patients with MG who are positive for antibodies against the Acetylcholine receptor (AChR) and 15 caregivers to patients with MG to better understand the severity, importance, and frequency of disease impacts to patients and caregivers. Participants will be invited to complete a guided survey after completing the interview.

Avalere would like to recruit a total of 15 patients and 15 caregivers* living in the US including the following:

*Partners diagnosed with MG less than 12 months ago
*Patients who are 1-5 years post-MG diagnosis
*Patients who are more than 5 years post-MG diagnosis
*Caregivers to patients with MG

Participants will be offered $125 for completing the interview. Patients will be offered an additional $35 for providing a doctor’s verification of their AChR antibody status. If participants elect to participate in the guided survey, they will be compensated an additional $125.

The interview will take place at a time that is convenient for you and will be approx. 60
The subsequent guided survey will be between 45 and 60-minutes long. Interviews and the guided survey will be conducted using Microsoft Teams. Participants will receive a calendar invitation containing dial-in information and a direct meeting link to the platform. Participants will have the option to join by dialing in via phone or by using the meeting link to join on the platform. A smart phone is not required to join the meeting. If participants prefer to join using the platform link, access to a web browser will be necessary.

To learn more, please email Anna Roberts by clicking on the red button below.

EMAIL ANNA ROBERTS

Families Coping Together with Alzheimer’s Disease Study (FACT-AD)

Does your mom or dad have memory loss?

If you are at least 18 years old, and you have a parent that is at least 55 years old and has early stage dementia, you and your parent may be eligible to participate in a free and confidential study to understand your experience coping with dementia together. Participation involves one 2-hour interview session and one 2-hour interactive session with you and your parent completing tasks together now and one year later. Interview and interaction sessions can be completed over the phone, by mail, or on the computer. Compensation up to $600 for completing all sessions.

To learn more or to see if you are eligible to participate, please contact Kathleen Williams at (203) 641-5373 or email her by clicking on the red button below.

EMAIL KATHLEEN WILLIAMS

Free Online Health and Wellness Education for Caregivers of People with Alzheimer’s

We are looking for adult caregivers who are taking care of a loved one who has Alzheimer’s. The purpose of this research is to help improve the health and wellness of caregivers.
Study participants who qualify will be asked to attend one 45-minute online session each week for four weeks. They will also be asked to complete questionnaires about the sessions and their health and wellbeing.

Participants must be at least 18 years old and a caregiver of a person with Alzheimer’s.

Each participant who completes the study will receive $30.

This study has been approved by the Northern Illinois University IRB protocol # HS21-0419.

If interested in participating or if you have questions, please contact Dr. Yujun Liu by clicking the red button below.

**CONTACT DR. LIU**

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Researchers at the University of Wisconsin-Madison Sandra Rosenbaum School of Social Work are seeking participants for a research study looking at the experiences of adult children who are currently caregiving for a parent who harmed them in childhood. The goal of the study is to gain an understanding of your needs and how healthcare professionals can best support you.

You may be eligible to participate if:

- You are 18+ years old
- You can speak and read in English
- You were harmed by a parent as a child and currently act as a caregiver for this parent
- Your parent has a serious illness or is near the end of life

Participation involves:

- A 1-hour virtual interview (phone or video call)
- Answering questions about your experiences as a caregiver and in childhood, motivations for caregiving, and interactions with healthcare professionals.
- You will receive a $25 electronic gift card upon completion of the interview.

For more information, please contact Jaime Goldberg, MSW, LCSW or Jooyoung Kong, MSW, PhD (faculty advisor) at 608-285-2188 or by clicking the red button below.
Social Engagement Study for Care Partners

The University of Illinois is seeking participants for a study about the importance of social engagement in the lives of those caring for loved ones with dementia. In order to be eligible, individuals must be over the age of 60, fluent in English, have access to a computer and internet connection, and be currently caring for a relative with dementia. In addition, participants must be able to attend two 45-minutes sessions each week for four weeks.

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

LEARN MORE

Lung Cancer Registry

The Lung Cancer Registry at the GO2 Foundation for Lung Cancer has initiated a new worldwide survey focused on the experiences of those caring for patients with lung cancer. The information collected will directly guide caregiver support programs and resource development.

To complete this survey, join the Lung Cancer Registry. Once you log in, you will be taken to the ‘Home’ page of the Lung Cancer Registry where you will find the Caregiver Survey. Every response is the start of a valued conversation.

Anyone with questions or concerns, please feel free to contact a registry coordinator at registry@go2foundation.org.

To participate in the study, click the red button below.
IN CASE YOU MISSED IT...

When Dementia Tips Don't Work

Dementia caregivers often don’t realize that they way they are responding to difficult dementia behaviors like sundowning, refusing to bathe, wandering, etc. is actually making things worse and adding to more stress. In this video I share a common dementia caregiving mistake that many caregivers make. It’s important to learn how to shift your caregiving approach so when someone with dementia starts to show a difficult behavior, you’ll know exactly the best dementia caregiving approach to take. We have to stop relying so much on the generic tips and tricks and open up our minds to thinking about what the best approach is for the individual person.

RESEARCH & RESOURCES

Early-Stage Partners in Care

Early-Stage Partners in Care, EPIC, is one of more than 40 dementia caregiving programs found in Best Practice Caregiving (bpc.caregiver.org), a free, online database that helps organizations identify, compare and adopt best-fit programs for their clients and community. EPIC is proven, vetted and ready to implement.

To learn more, click the red button below.
Mindfulness-Based Dementia Care

Mindfulness-Based Dementia Care is an evidence-based dementia caregiving program that offers eight in-person, group mindfulness practice sessions. 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 learn more, click the red button below.

LEARN MORE

Under the Hood: Best Practice Caregiving's Compare Feature

The Compare feature is one of the most deceptively simple (yet robust) functions of the Best Practice Caregiving site. In designing the database, the project developers — all experts in the caregiving and aging space — knew this feature was a must-have.

The Compare feature lets you compare up to three programs of like purpose or similar outcome. As you go through the database, searching for a perfect-fit program, you can check the ones (up to 3) that look promising. Then, compare them side by side, using the at-a-glance view that helps you narrow your choices, highlight differences and prioritize program characteristics.

To learn more, click the red button below.

LEARN MORE

PREVIOUSLY APPEARED

Loss of Smell Linked to Alzheimer’s Cognitive Impairment and Biomarkers
Decline in sense of smell is connected to faster buildup of Alzheimer’s disease-related pathology seen in brain scans, according to new research focused on older adults who live outside of nursing homes. The findings provide additional evidence that loss of smell (known as anosmia) is a key early sign of Alzheimer’s-related cognitive impairment and the accumulation of associated harmful proteins, such as amyloid-beta and tau. The research, led by NIA scientists, was published in the Journal of Alzheimer’s Disease.

Decline in sense of smell had previously been confirmed as an early warning sign for Alzheimer’s in both human and animal studies, but its connection to the uptick of dementia-related brain imaging biomarkers over time had not been as closely studied in larger populations of older adults. For this study, the team tracked 364 participants from the Baltimore Longitudinal Study of Aging (BLSA) over an average period of about 2.5 years. The NIA-led BLSA is the longest running study of healthy aging in America.

To learn more, click the red button below.

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“You’re Not Alone” Videos Shine a Light on Family Caregiving for ALS, MS, Parkinson’s, and Huntington’s Diseases

“If you’re looking for guidance on how to care for someone with a neurodegenerative disease, there’s not a lot out there,” says Leah Eskenazi, Operations Director at Family Caregiver Alliance of San Francisco. “Not only is there a shortage of information, there’s so much to learn—about treatment options, care planning, what’s covered by Medicare… the list goes on.”

Eskenazi wanted to address this need for caregivers, so she led a team at FCA to create “You’re Not Alone,” a four-part video series on caregiving for individuals diagnosed with a neurodegenerative disease.

“With ‘You’re Not Alone,’” says Eskenazi, “we packed need-to-know information about family caregiving for each disorder in one video.” There’s guidance for every stage of each disease, along with essential resources and recommended contacts you’ll need along the way.

In each “You’re Not Alone” video, caregivers learn what to expect, how to prepare for their role, essential legal and financial preparations, and much more. The videos are accompanied by fact sheets and essential resources guides.

To learn more or view the videos, click the red button below.
Research on Cancer Caregivers and Decision-Making

Caregivers are the unsung heroes in cancer care. They may be spouses, family members, or close friends. They are not paid and are usually not trained to provide cancer care, yet they often become the lifeline for a person with cancer.

Caregivers are faced with information needs as soon as their loved one is diagnosed, when they immediately become immersed in helping to make medical choices for which they are typically ill prepared. The weight of treatment decision-making involves significant logistical, physical, emotional, financial, and professional consequences. The challenges that cancer caregivers face are often exacerbated by a lack of information and knowledge sufficient to make sound medical and treatment decisions. In fact, recent studies, including ours, indicated that 30-40% need more information when they are in decision-making roles.

CancerCare has presented a white paper, Caregiver Treatment Decision-Making, that is based on a series of focus groups among CancerCare social workers and cancer caregivers. It explores the various ways caregivers participate in decision-making, their uncertainty and the lack of support they receive from clinicians.

Cancer Caregivers: National Research Report on Shared Treatment Decision-Making is a broad and deep exploration of shared decision-making dynamics, challenges and needs. It is based on the survey responses from a nationally representative sample of 2,700 unique cancer caregivers, and indicates that most need more information in order to more effectively share in making these very important decisions. It also shows that many of them are dissatisfied with the educational materials provided by the care team. The detailed data and analyses identify the scenarios that caregivers find particularly perplexing and why. We learn what exacerbates their distress and their opinions regarding resources and programs that could help them as they strive to provide the very best care. It provides enlightening findings regarding Hispanic vs. non-Hispanic caregivers, and identifies a psycho-social segmentation scheme that helps us understand the specific challenges and needs of each group.

To view the report, click the red button below.

READ THE REPORT

Finding Dementia Care and Local Services

A person with dementia will need more care as symptoms worsen over time. Problems
Policies and Resources Identified by Youth as Being Important to Prepare for Caregiving Responsibilities

The Journal of the American Board of Family Medicine's July edition features a new article examining ways to support young caregivers.

**Background:** Youth are increasingly upholding significant caregiving responsibilities. These caregiving responsibilities can have emotional, educational, and professional impacts on youth and young adults. And yet, policies and resources focus on adult caregivers and are limited in supporting young caregivers. The purpose of this study was to describe the different types of support that youth identify as being important to prepare to take care of an adult relative.

**Methods:** We conducted an open-ended, text-message based poll of youth ages 14 to 24 in August 2020. We conducted a content analysis to categorize and describe the different types of support respondents identified in their responses. We compared types of support identified by age-group, gender identity, and prior caregiving experience.

**Results:** Most respondents (42.2%) identified education (eg, skills training) as being an important resource. Other types of support reported included financial support (eg, assistive programs), workplace policies (eg, paid leave), mental health support, and professional support.

**Discussion:** Policy makers should extend existing policies (eg, Family and Medical Leave Act) to include and consider the circumstances of youth and young adults. Policies enabling young caregivers to actively participate in their adult relative's health care visits could be critical to preparing youth for the skills required and the physical and emotional demands associated with caregiving. Coordinated efforts between health and education systems could support youth in learning information about caregiving, medical decision making, and medical tasks.

To read the article, click the red button below.

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The Economic Effects of Family Caregiving on Women

Family caregivers—i.e., unpaid care providers, the majority of whom are women—provide an average of 23 hours of unpaid care per week, the equivalent of part-time employment. Persistent wage gaps for those who also do paid work and the lack of Federal policies to support caregivers intensify the negative economic effects of family caregiving on women.

The TIAA's [Women's Voices of Expertise and Experience](#) has produced a new report examining this topic written by NAC's Patrice Heinz and Fawn Cothran. To view the
The Impact of COVID-19 on Carers: An International Perspective

The International Alliance of Carer Organizations has produced a new report that explores international perspectives on caregiving during the COVID-19 pandemic. Building on IACO members' reports, statements, and surveys, this study provides an international view of caregivers' needs and the measures individual countries have taken to support carers during the COVID-19 pandemic and beyond.

To view the report, click the red button below.

Driving Safety and Alzheimer’s Disease

Good drivers are alert, think clearly, and make good decisions. When people with Alzheimer's disease are not able to do these things, they should stop driving. But some people may not want to stop driving or even think there is a problem.

As the caregiver, you must talk with the person about the need to stop driving. Do this in a caring way. Understand how unhappy the person may be to admit that he or she has reached this new stage.

To learn more about this topic, click the red button below.
What is Parkinson's Disease?

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

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

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

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

How To Evaluate Health Information on the Internet

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

To learn more about assessing health information online, click the red button below.
Know the Signs of Elder Abuse and How to Get Help

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

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

To learn more about the signs of elder abuse, click the red button below.
Our work life now includes our life’s work – caring for a family member with a chronic illness or disease or injury. How do we make room for both experiences in the workplace? How do we take time during our work day to manage our stress and worries? How do we console our colleagues who grieve?

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

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

To learn more, click here. To view or download the workbook, click the red button below.

VA and Rosalynn Carter Institute for Caregivers Launch Partnership

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

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

For more information about this partnership and the VA’s Caregiver Support Program, click the red button below.
Get the Support You Need

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

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

For more information about Operation Family Caregiver, click here. To enroll, click the red button below.

LEARN MORE >

Ignite Change as a Caregiver Advocate

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

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

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

CONTACT RCI >

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

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

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

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

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

How to Share Caregiving Responsibilities with Family Members

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

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

To learn more, click on the red button below.

FOLLOW US TO STAY CURRENT ON CAREGIVING!