‘What if This is My Destiny?’ Children of Alzheimer’s Patients Sometimes Fear Future Diagnosis

At school pickup, Janet Perez always looks for the neon orange backpack that makes her 6-year-old son, Jayden, so easy to spot. But on a recent spring afternoon in Perris, Calif., she couldn’t find him. Her first response was primal: Someone had kidnapped him. Then she tried to remember what he had been wearing and realized she wasn’t sure if she had dropped him off that morning. A familiar dread washed over her: Was it happening? Was her forgetfulness an early sign that she had her mother’s illness, Alzheimer’s disease?

From: New York Times | Published: August 2, 2022

What It Feels Like to Live With Parkinson’s

Steven Heller, 70, has lived with Parkinson’s for more than 10 years. Véronique Vienne, 79, only recently learned that she had the disease. Both have had long careers as art directors, and the two have been friends for more than three decades. Back in March, the pair exchanged a flurry of emails over a 10-day period, where they explored the “before” and “after” of a Parkinson’s diagnosis. Here is an edited version of their conversation.

From: New York Times | Published: June 23, 2022

Your Job or Your Caregiving Responsibilities? This Company Doesn’t Want You to Have to Choose

Adrienne Schneider was at the pinnacle of her career. She held a leadership position for an airline company, and was in the midst of starting her own company. But in February 2020, her father’s health began to decline. As an only child whose mother had died over 20 years before, she had no other choice but to care for her father full-time. She left her job in June of that year.

From: Fortune | Published: August 5, 2022
World Carers Conversation 2022 Session Recordings

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

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

VIEW RECORDINGS

Global Voices of Caregiving: A PhotoVoice Project

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

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

Engaging Caregivers: A Program for Healthcare workers

**August 10th, and 17th, 2022**

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

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

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

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

Registration links:

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

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

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

To view the Caregiver Teleconnection flyer, click the red button below.
Healthy Aging: Creating Age-Friendly Health Systems

August 10, 2022 | 1:00 PM - 2:00 PM EST | Online

The nation’s adult population over age 65 is projected to reach 83.7 million by the year 2050, an increase from 21% of the population in 2012 to more than 39% in 2050. Age-Friendly health systems is an initiative of The John A. Hartford Foundation and the Institute for Healthcare Improvement in partnership with the American Hospital Association and the Catholic Health Association of the United States. The initiative is designed to meet the needs of older adults, looking beyond acute events, engaging the whole community, and achieving better health for older adults. By focusing on four key areas—what matters, medications, mobility and mentation—we aim to improve patient care, safety and outcomes; and reduce length of stay and readmissions. Join this webinar to learn about the importance and impact of the 4Ms Framework, hear bright spots in the field integrating value-based, Age-Friendly care and understand the benefits of joining the Action Community.

To learn more about this webinar, call the American Hospital Association at (312)422-2609.

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

Take a Breath! Tips from a Caregiver Coach

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

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

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

**Our Speaker**

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

**Information**

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

**REGISTER**

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**Balancing Caregiving and Work**

**August 11, 2022 | 6:30 PM - 7:30 PM EST | Online**

Join the Ontario Caregiver Association for a webinar about striking the right balance between caregiving and professional commitments. Learn more about caregiving experiences, explore the best strategies for balancing work and caregiving, and gain access to resources focused on their needs.

**REGISTER**
The Caregiver Circle

August 11, 2022 | 7:00 PM - 9:00 PM EST | Online

The Caregiver Connection brings family caregivers, expert guests, and those who may become caregivers together every month to talk about challenges, learn about specific areas of knowledge and to share. Our aim is to help you be more proactive, find the gifts and hear from knowledgeable people in the caregiving space.

REGISTER

10 Warning Signs of Alzheimer’s

August 16, 2022 | 4:00 PM - 5:30 PM EST | Online

Alzheimer’s and other dementias cause changes in memory, thinking and behavior that interfere with daily life. Join Kadlec Community Health to learn about 10 common warning signs and what to watch for in yourself and others.

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

REGISTER

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.
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.

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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 event.
**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.

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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.
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 (DCSL) 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.
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

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 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.

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 Amedicus 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.

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.

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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.
2022 National Lifespan Respite Conference

September 13th - 15th, 2022

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.

LEARN MORE >

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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.

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**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.

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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 15 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 >
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
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.
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.

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.
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.

PARTICIPATE IN THE STUDY
Study: Caregiver Perspectives on Alzheimer’s Disease and Related Dementias Clinical Trials

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

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

To participate in this study, the participant must be:

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

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

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

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

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

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

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

To learn more, click the red button below.
IN CASE YOU MISSED IT...

Legal and Financial Planning for Older Adults and Persons with Disabilities

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

RESEARCH & RESOURCES

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.

“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

PREVIOUSLY APPEARED
Finding Dementia Care and Local Services

A person with dementia will need more care as symptoms worsen over time. Problems with memory, thinking, and behavior often present challenges for those with dementia as well as for their family members. Whether the disease is in early or late stages, there are support systems, resources, and services that can help.

While it can be difficult for some to admit they need assistance with care or caregiving, it is okay to ask for help. In fact, when it comes to caregiving, taking care of yourself is one of the most important things you can do.

To find more information about dementia care and local services, click the red button below.

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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.

READ THE ARTICLE

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 report, click the red button below.

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**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.

**VIEW THE REPORT >**

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**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
What is Parkinson’s Disease?

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

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

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

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

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How To Evaluate Health Information on the Internet

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

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

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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.
A Workbook for Your Workplace Wellness

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

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

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

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

VIEW THE WORKBOOK >

VA and Rosalynn Carter Institute for Caregivers Launch Partnership

The VA is committed to caring for Veterans, caregivers, families and survivors. Strong partnerships within and outside of the VA are critical to ensuring caregivers receive the support they need. That’s why the VA is partnering with the Rosalynn Carter Institute for Caregivers (RCI) to further promote the health and well-being of those who care for our nation’s Veterans.
The VA and Rosalynn Carter Institute for Caregivers launched the new partnership to support caregivers of Veterans, caregivers who are Veterans, and caregivers who work for the VA. Both organizations will work collaboratively to increase awareness of the needs of caregivers of Veterans, increase caregiver access to programs, services and resources, and improve caregiver outcomes.

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

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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.

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

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

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

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

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

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

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

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

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

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

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

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

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