

THIS WEEK IN CAREGIVING



March 1, 2023



CAREGIVING IN THE NEWS

Dementia Care Programs Help, if Caregivers Can Find Them

There's no cure, yet, for Alzheimer's disease. But dozens of programs developed in the past 20 years can improve the lives of both people living with dementia and their caregivers.

Unlike support groups, these programs teach caregivers concrete skills such as how to cope with stress, make home environments safe, communicate effectively with someone who's confused, or solve problems that arise as this devastating illness progresses.

Some of these programs, known as "comprehensive dementia care," also employ coaches or navigators who help assess patients' and caregivers' needs, develop individualized care plans, connect families to community resources, coordinate medical and social services, and offer ongoing practical and emotional support.

From: CBS News | Published: February 24, 2023

[READ MORE](#)



Bruce Willis Frontotemporal Dementia Diagnosis Reveals an Uncomfortable Truth

Last week Bruce Willis' family announced he had been diagnosed with frontotemporal dementia. The actor had been struggling with aphasia since at least last spring. Obviously, this was not the life — a loss of independence, and a sense of self — that any of us would wish for ourselves or our loved ones. But for the many family, friends and neighbors who step up as informal caregivers for older adults across the country, Willis' diagnosis is a reminder of a pervasive,

How Therapeutic Fibbing and Diversion Can Help Loved Ones with Dementia and Alzheimer's

It was hard, at first, for Jim Mangi to tell his wife what she wanted to hear.

Mangi's wife, Kathleen, was beginning to lose her memory as a consequence of what turned out to be Alzheimer's disease. Like other people in that situation, she sometimes slipped back into her past or became confused about her surroundings.

"At the beginning of the journey, I didn't

albeit often hidden burden shouldered by millions of Americans.

From: MNBC | Published: February 26, 2023

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>

know any better than to tell the truth all the time,” says Mangi, now 74, who lives in Saline, Michigan.

From: AARP | Published: February 24, 2023

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NAC NEWS AND UPDATES



The image shows the cover of a guidebook. The top half features a photograph of a diverse group of people, including men and women of various ethnicities, smiling. Below the photo, the text reads: "2023 GUIDEBOOK SUPPORTING DIVERSE FAMILY CAREGIVERS: A GUIDE FOR PATIENT ADVOCACY GROUPS". At the bottom of the cover, there are logos for "nac" (National Alliance for Caregiving) and "AstraZeneca".

JUST RELEASED!

Supporting Diverse Family Caregivers: A Guide for Patient Advocacy Groups

[DOWNLOAD NOW](#)

NEW RELEASE -- Supporting Diverse Family Caregivers: A Guide for Patient Advocacy Groups

The National Alliance for Caregiving (NAC) has released a new publication to assist patient advocacy groups in their efforts to support diverse family caregivers. Through research with professional patient advocacy group representatives and diverse family caregivers in the condition areas of lung cancer, heart disease, blood cancer and lupus, *Supporting Diverse Family Caregivers: A Guide for Patient Advocacy Groups* addresses the impact of culture and identity on the way that family caregivers provide care, and introduces ways in which patient advocacy groups can support their caregiving experience through culturally responsive resources and supports. The number of diverse family caregivers in the United States is growing yearly, and their aggregate number will soon surpass non-Hispanic white, non-LGBTQ+ caregivers. This guide was created with support from AstraZeneca.

To learn more, click the red button below.

[LEARN MORE](#)
>

Caregiving is
an emotional
experience.



CALL: 1.888.665.2190

to tell us about the challenges and joys
you experience as a family caregiver.

The National Alliance for Caregiving Opens Phone Line for Family Caregivers to Talk About Their Mental Well-Being

Sponsored by Traverre Therapeutics, the National Alliance for Caregiving is spearheading a project to advance the mental well-being of family caregivers in the United States. NAC wants to hear from family caregivers on the joys, challenges and struggles they've faced on their caregiving journey in order to better understand their needs and the supports and interventions that can be introduced to assist them.

If you're a family caregiver or have cared for someone in the past, call **1-888-665-2190** to share your caregiving story and the feelings associated with it.

If you would prefer to write out your response rather than leave an audio message, you may do so [here](#).

We want to know:

- What joys have you experienced as a caregiver?
- How are you feeling about being a caregiver?
- What are challenges you have faced as a caregiver?
- What are concerns you have about providing care?

The message you leave will inform policy and practice efforts to improve support for family caregivers like you! All messages left will be anonymous, with only the transcript being used to help us advocate for change.

To learn more, click the red button below.

LEARN MORE





Social Innovations In Caregiving:
SPOTLIGHT ON PAIN ASSESSMENT



AUGUST 2022

Assessing the Pain of Care Recipients: Tools Available to Family Caregivers

Fawn A. Cothran, PhD, RN, GCNS-BC, FGSA
Hunt Research Director

It's important to recognize those with chronic pain and the family caregivers that help care for them. This second installment in the Social Innovations Spotlight Series is written by Dr. Fawn Cothran, PhD, RN, GCNS-BC, FGSA, Hunt Research Director at the National Alliance for Caregiving, and explores those caring for someone with chronic pain and the tools that are available to assist them. [Assessing the Pain of Care Recipients: Tools Available to Family Caregivers](#) utilizes a rapid literature review to identify and discuss the tools available to chronic pain caregivers to assess pain in their care recipient and how these caregivers can be better supported in their role.

To read the report, click the red button below..

VIEW THE REPORT



JUST RELEASED!

Chronic Disease Family Caregiving Through a Public Health Lens
THE FRAMEWORK FOR FAMILY CAREGIVING AND PUBLIC HEALTH

SEPTEMBER 2022 REPORT

DOWNLOAD NOW

NAC Releases New Report: Chronic Disease Family Caregiving Through a Public Health Lens: The Framework for Family Caregiving and Public Health

The National Alliance for Caregiving is proud to present *Chronic Disease Family Caregiving Through a Public Health Lens: The Framework for Family Caregiving and Public Health*, a new report developed with support from The John A. Hartford Foundation and in partnership with the National Association of Chronic Disease Directors (NACDD). This framework outlines policy recommendations, implementation actions and messaging content to help the public health community address the complex needs of America's 53 million family caregivers.

Included in this report:

- A foundation of the framework and background into why it's needed;
- Strategies and recommendations for viewing family caregiving through a public health lens;
- A framework comprised of public health data gathering research, education, and awareness and service coordination and delivery across sectors and siloes;
- Actions for implementing an expanded family caregiver support infrastructure via a pilot program.

Guided by the expertise of state-based chronic disease directors, NAC's report and framework recognizes the importance of caregivers as a vital part of the health care team and that supporting these family caregivers is essential for improving public health outcomes for communities and the nation.

To read the report and access our findings, click the red button below.

[VIEW THE REPORT](#)



EVENTS & OPPORTUNITIES

MARCH



Understanding Compassion Fatigue and Burnout

March 7, 2023 | 1:00 PM - 2:00 PM ET | Online

Does compassion cause suffering? When does it go too far and how can caregivers protect their own wellbeing? Learn the warning signs, who is at risk, and how to restore

your emotional energy with a licensed therapist.

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.

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.

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



Taking Charge of My Life and My Health for Caregivers

Tuesdays, March 7 - April 11, 2023 | 1:00 PM - 2:30 PM ET | Online

This class introduces caregivers to the tenets and structure of Taking Charge of My Life and My Health. Through these sessions, you will examine your daily life by considering your Circle of Health, which includes everything from mindful awareness and personal relationships to exercise, diet, and sleep. What are you doing to stimulate your brain? How flexible is your body? How energetic do you feel? With what frequency are you waking up at night? How is your environment affecting you? What are your main causes of stress? Join us to learn how to take better care of your life and your health to experience reduced stress and greater peace.

The class runs weekly for 60 - 90 minutes over 6 weeks.

***Caregivers need to commit to all sessions.**

To register, click the red button below.



NASHP Webinar: Medicaid Structured Family Caregiving Enables Caregivers to Make Caregiving Their Primary Focus

March 8, 2023 | 3:00 PM - 4:00 PM ET | Online

Family caregivers play an important role in caring for Medicaid Home and Community Based (HCBS) waiver participants. Some states have moved to offer structured family caregiving (SFC) services within their Medicaid program to help HCBS waiver participants' primary caregivers fulfill that role. SFC services include payment, individualized training

based on the needs of the waiver participant, coaching, back-up or respite care, and other supports.

Join the National Academy for State Health Policy on March 8th for a webinar that will feature both a state official who oversees an SFC waiver program and a representative of the Alzheimer's Association who will offer his assessment of the approach from caregiver and Medicaid enrollees' viewpoints. Webinar participants will learn about state approaches to SFC, key policy considerations in program development, and program impact.

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

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Gerontological Society of America Call for Abstracts

Deadline to submit: March 9, 2023

The Gerontological Society of America (GSA) seeks compelling and discerning presenters/authors for the November [GSA 2023 Annual Scientific Meeting](#) who will address the most-pressing issues and challenges in our fields and generate actionable insights to share with meeting attendees from over 36 countries.

Multiple presentation options include papers, posters, and symposia. Enhance your career by presenting your research at the most prestigious gathering of experts in the field of aging. Inform your colleagues about the latest issues, trends and challenges. We look forward to seeing you in Tampa!

To learn more about submitting an abstract, click the red button below.

[LEARN MORE](#)



Supporting Your Adult Child Through Their Cancer Diagnosis and Treatment

March 9, 2023 | 2:00 PM - 3:00 PM ET | Online

This presentation will address the emotional and physical impacts on parents who have young adults with cancer. It will explore common stressors and concerns including the burnout that arises while caregiving for young adults with cancer. It will also identify coping strategies and interventions to help parents navigate through their adult child's cancer journey, including issues surrounding being a grandparent if the young adult has children.

This presentation is aimed at adult parents of young adults who have cancer but all are welcome to attend. There will be time to ask questions, as well as connect with other parents/grandparents.

Presenter Bio:

Sam Fortune is an oncology social worker, and the Women's Cancers Program Coordinator at CancerCare. She provides counseling and support to people coping with cancer, caregivers of cancer patients, and people who have experienced the loss of a loved one. Sam also develops and executes programmatic activities for the Women's Cancers Program, which cater to specific needs within the community. Furthermore, Sam participated in several national presentations on various Women's Cancers topics and has been a speaker in several CancerCare's Education Workshops as a leading expert in the field.

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



Planning for Getting Paid for Caring for a Family Member

March 10, 2023 | 2:00 PM - 3:00 PM ET | Online

The direct care workforce shortage means many families simply can't find a direct care worker to hire. More and more families may use the caregiving budget to reimburse a family member for providing care. With a new planning tool provided by The Caregiving Years Training Academy, families can create plans to hire a family member and be empowered to have effective conversations with a financial planner and elder law attorney to ensure that they created the right solution for their family.

Join Denise Brown for a 50-minute meeting to explore the possibility of paying a family member (including yourself) for providing care.

Before joining us:

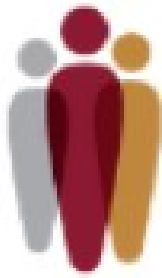
- Download our **Paying for Care Planning Tool** to use during our 50-minute session.

Denise began helping family caregivers in 1990 and launched one of the first online caregiving communities in 1996. She managed the community until its sale in March 2020 in order to focus on her training and development programs. Denise began helping her father in 2004 after his bladder cancer diagnosis. She also helped care for her mother for seven years until her death in August 2022.

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



REGISTER



PUBLIC HEALTH CENTER OF EXCELLENCE ON DEMENTIA CAREGIVING

Successful Public Health Approaches in Dementia Caregiving: Rhode Island (A Virtual Roundtable Series)

March 14, 2023 | 11:30 AM - 1:00 PM ET | Online

In each episode of this virtual roundtable series we will highlight the story of one state that has successfully implemented a state-wide, innovative, and integrative approach to advancing its dementia caregiving goals. The session will begin with an overview of the state's efforts in dementia caregiving, followed by a Q&A with attendees about key takeaways and ideas for action in their states and communities. This series offers a great opportunity for knowledge exchange, peer-learning and idea generation.

In this episode, we will present the story of Rhode Island.

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

REGISTER



Comfort for Caregivers: Strategies for Dealing with Caregiver Stress

March 14, 2023 | 1:00 PM - 2:00 PM ET | Online

Caring for a loved one strains even the most resilient people. Tune in on March 14th for a workshop presented by HopeHealth Hospice & Palliative Care that will discuss strategies for dealing with caregiver stress and show attendees effective ways to preserve your own

health and well-being.

This workshop is part of a series presented by HopeHealth Hospice & Palliative Care designed to provide education, support, and resources for those caring for loved ones with an illness. There will be time for Q&A following each presentation.

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

REGISTER



Hospice: Common Myths and Misconceptions

March 14, 2023 | 2:00 PM - 3:30 PM ET | Online

Vantage Aging invites you to join us for a virtual Caregiver Solutions Event on March 14th, 2023, that will discuss different aspects of hospice care. Common misconceptions surrounding hospice and palliative care can often present a tremendous roadblock in delivering the right level of care at the right time. If you care for an aging loved one, it's important to know about hospice care truths and options.

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

REGISTER



Caregiving: The Art of Effective Communication

March 16, 2023 | 12:00 PM - 1:00 PM ET | Online

The **National Alliance for Caregiving** reports that the number of caregivers in the United States increased by 9.5 million between 2015 and 2020, so that more than 1 in 5 Americans are now caregivers. It is critical that caregivers are equipped with the knowledge and skills to provide assistance with daily living activities, schedule doctor appointments and create a healthy living environment. However, a key skill that is often overlooked is the ability to communicate effectively.

On March 16th (12:00 PM ET), Shevel Mavins and Kaii Marie Robertson, cofounders of the Behavioral Health Mind Body Academy, will host an online session that will offer communication strategies to help caregivers get the best results. Attendees will learn how exhibiting a calm demeanor can defuse difficult caregiving situations, for example, and how empathy and patience can strengthen the caregiving relationship. As a result,

caregivers' own mental and emotional well-being can benefit.

Contact AARP North Carolina at ncaarp@aarp.org for more information.

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

REGISTER
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Preparing for an Outing with the Person You Care For

March 20, 2023 | 8:30 AM - 10:00 AM ET | Online

Tune in on March 20th for an online session hosted by Dementia Carers Count that will take a look at some of the challenges of going out in the community, both for the person with dementia and those who are caring for them.

This event will explore the importance of going out for both the person living with dementia and their carer. It will also look at ways to prepare and support someone with dementia before an outing and discuss about resources and support that may be helpful.

The session is for you if you would like to...

- gain some ideas for supporting the person and reduce your own fear or embarrassment of potential situations
- spend time with experienced health and care 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 who may be in a similar situation

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

REGISTER
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2023 NIA Dementia Care and Caregiving Research Summit

March 20th - 23rd, 2023 | 11:00 AM to 4:00 PM ET | Online

The 2023 National Research Summit on Care, Services, and Supports for Persons Living with Dementia and their Care Partners/Caregivers will build on progress of the previous Summits to review research progress, highlight innovative and promising research, and identify remaining unmet research needs with input from the research community, persons

living with dementia (PLWD) and their care partners.

The Summit will be held virtually from March 20-22, 2023 from 11 a.m. to 4 p.m. Eastern time each day. Submitting this registration form will enable you to join any or all three days of the Summit proceedings.

Please see the Summit webpage for more information: www.nia.nih.gov/2023-dementia-care-summit

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



NADRC Webinar on Dementia Screening in the Community

March 22, 2023 | 1:00 PM - 2:00 PM ET | Online

Community based organizations play a key role in conducting dementia screenings in the community. These screenings can lead to referrals for a comprehensive medical assessment to assist in diagnosing dementia.

Tune in on March 22nd for a webinar in which participants will learn about two [ACL](#) Alzheimer's Disease Programs Initiative grantees conducting dementia screenings in the community. The Chinese American Service League had success getting 596 of 800 people screened for dementia using the Mini-Cog. Some clients were linked to specialists for dementia diagnostic evaluation, and others were provided with case management and other services to meet their needs. OMID, through various outreach events and programs, has been successful in signing up community members for early memory screenings, using the Montreal Cognitive Assessment (MoCA) since August 2021. Once screening scores are calculated, case managers work with community members whose scores signal early memory loss to educate them about OMID's care coordination services and how they can assist them with securing additional testing and observation. These screenings are a pathway to dementia diagnosis. The benefits of these screenings cannot be underestimated even if the process to get a client to a medical assessment is lengthy.

Direct questions to NADRC-Webinars@rti.org.

Please note:

NADRC webinars are free and open to the public.

NADRC webinars are recorded and will be posted at <https://nadrc.acl.gov/>.

Closed captioning is available during the webinar and included in all recordings.

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





TBI WARRIOR[®]

FOUNDATION

Traumatic Brain Injury and Caregiving

March 23, 2023 | 12:00 PM - 1:00 PM ET | Online

In honor of Brain Injury Awareness Month, tune in on March 23rd for a conversation with Dr. Roxana Delgado, co-founder of TBI Warrior Foundation. The Foundation aims to improve the quality of life of veterans, civilians and children living with brain injury and their caregivers, through community integration, education, and advancement programs.

Dr. Delgado will describe the unique challenges of TBI in the military and how it affects caregiving. She will discuss the epidemiology of traumatic brain injury (TBI) in Veterans. She will provide tools and strategies to effectively care for a Veteran with TBI and poly trauma and share resources with the caregivers in the audience.

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

REGISTER



Anticipatory Grief Workshop for LGBTQ+ Caregivers

March 23, 2023 | 7:00 PM - 8:30 PM ET | Online

The feelings of grief tied to loss are an ongoing part of our role as caregivers when looking after family or friends suffering from chronic or terminal illnesses.

We grieve the gradual loss of those we care for due to their loss of cognition, mobility, or other aspects that defined them.

We grieve the loss of parts of who we are as we prioritize caregiving over personal activities that might have recharged us, brought us joy, or even offered us an escape from our day-to-day.

Many of us also experience the weight and pain of the loss of the person we are caring for before their death, yet never identify these feelings as anticipatory grief, or understand the impact this grief has on our well-being.

Join FCA for a 90-minute virtual workshop to better understand how anticipatory grief might be affecting you as a LGBTQ+ caregiver.

Subjects Covered During the Workshop: defining anticipatory grief, identifying ways in which anticipatory grief may be affecting you, discuss strategies to help process

anticipatory grief.

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



Driving and Dementia Roadmap

March 27, 2023 | 2:30 PM - 4:00 PM ET | Online

Making the decision to stop driving and the transition to non-driving is challenging and complex, especially for drivers living with dementia and their care partners. In this webinar, Drs. Gary Naglie and Mark Rapoport, who lead a team of researchers focused on dementia and driving, will describe the development and evaluation of the Driving and Dementia Roadmap (DDR - www.drivinganddementia.ca) - a recently launched online educational resource. They will also demonstrate how to use the DDR, whether you are a person living with dementia, a care partner/friend or a healthcare/service provider supporting others through this process.

****This event will not provide information or training on how to assess an individual's driving ability****

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



Anticipatory Grief: Grieving Before Death?

March 29, 2023 | 1:00 PM - 2:00 PM ET | Online

Please join the Breast Cancer Education Association (BCEA) on Wednesday, March 29th, for a discussion led by Allison Breininger, founder the non-profit [The Negative Space](#).

As a cancer caregiver, it can be hard to not think about the future and what it may or may not hold. In doing so, it is common for caregivers to experience anticipatory grief, in which we mourn the loss of our loved one while they are still here as well as grieve the future that is no longer available to us.

In this interactive session, Allison will discuss how being in the cancer community can both support and exacerbate these feelings and the tension many caregivers feel between enjoying the moment and anticipating the loss. The guilt that this may bring up in us will be acknowledged and permission will be granted to feel any and all emotions both in the session and beyond. During this conversation, Allison will explore anticipatory grief, discuss how and when these feelings emerge for us, and how we can cope when they do.

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

REGISTER



Young Onset Dementia

March 29, 2023 | 2:00 PM - 3:00 PM ET | Online

Join the [Alzheimer Society of Durham Region](#) (Canada) on March 29th for an online workshop that will distinguish Young Onset dementia from other types of dementia by identifying its core symptoms and by understanding the possible causes/risk factors that bring changes to brain structure and function. It will also discuss general ways of supporting people living with young onset dementia.

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

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

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

REGISTER



APRIL

The University of Manchester Institute for Collaborative Research on Ageing

Hospice Staff and Family Carers & End-of-Life Dementia Care

April 4, 2023 | 9:00 AM - 10:00 AM ET | Online

More than 50 million people live with dementia worldwide, with figures reaching to more than 75 million by 2030. Being a progressive condition, in its advanced stages, dementia reduces the opportunities of the person to receive proper care, and more specialist end-of-life care is needed to ensure that better quality of life is promoted during the last period of life.

Hospices offer an interdisciplinary care model for the person and their family supporters. This type of care can occur in different settings (e.g., in-ward hospital, nursing home, long-term facilities), it can be offered on a home-based service and or directly offered in the hospice through inpatient care.

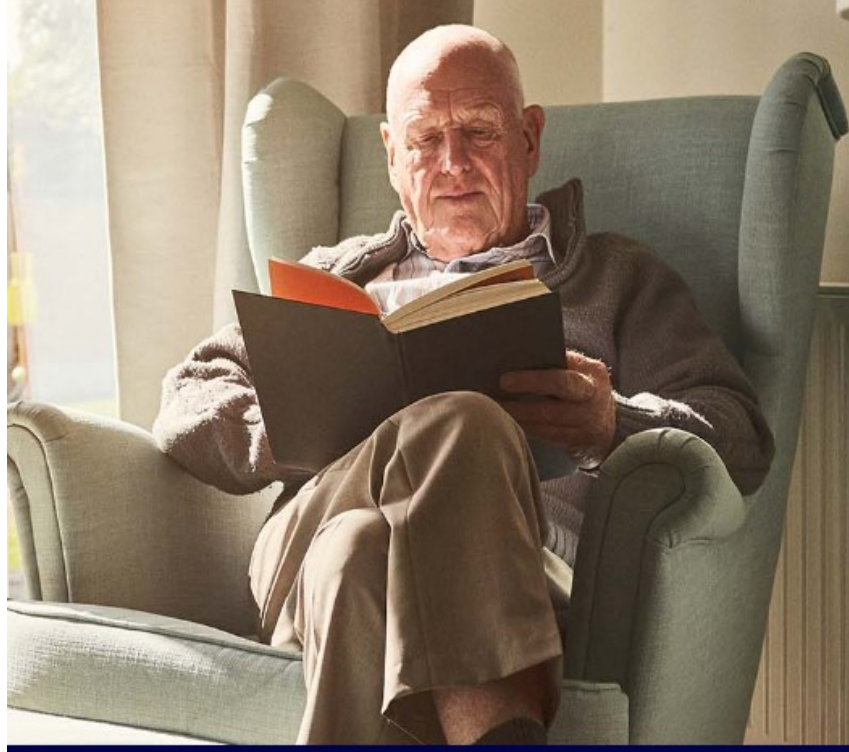
Whilst hospices are regarded as providers of gold-standard care for people requiring end-of-life support, health care professionals working in these settings rarely receive dementia training and examples of evidence-based practices are currently lacking. More research is needed to investigate the experience of care delivery in hospice staff and family carers of people with dementia.

Join the Manchester Institute for Collaborative Research on Ageing on April 4th for a seminar about a recent study on the experience of hospice clinical staff and family carers of end-of-life dementia care.

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

REGISTER





Caring for Burned-Out Caregivers

April 6, 2023 | 11:00 AM - 12:00 PM ET | Online

Caring for others can be a joyful and beautiful experience—or it can be detrimental to our well-being. Burnout in caretaker populations can go easily overlooked, as most attention may be given to the person being looked after. A caregiver with burnout often feels overwhelmed and may be physically, emotionally, and mentally exhausted from the stressors and weight of caring for loved ones.

So how can we encourage caregivers to look after themselves without feeling guilty about allocating time away from those they care for? What are ways to gain more satisfaction from caregiving? How do we know if we're burned out?

Join Marie Clouqueur, LICSW, on April 6th (11:00 AM) as she shares ways to identify burnout in caregiver populations, discusses how burnout can be prevented from happening, and answers questions about how caretakers can prioritize their own needs when it may feel difficult to do so.

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

[REGISTER](#)



NCFS Caregiver Advocacy Program

April 11, 2023 | 1:30 PM - 3:00 PM ET or 7:00 PM - 8:30 PM ET | Online

The University of Pittsburgh's National Center on Family Support (NCFS) is looking for caregivers who are interested in becoming involved in advocacy.

NCFS's newly-launched Caregiver Advocacy Program will consist of a series of virtual workshops that will empower unpaid family caregivers to learn about caregiving-related policies, and how to use their experiences to tell their story and advocate for change.

Caregivers don't need to be policy experts to take part – just interested in learning more about advocacy. By the end of our program, they'll have something tangible to share with legislators or advocacy groups.

The lives of caregivers are busy and free time is limited. The program's sessions will be virtual and offered both in daytime and evening sessions for scheduling flexibility. The first sessions will be held on April 11th.

If you have questions, you can reach out to Heather Tomko at caregiving@pitt.edu.

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

REGISTER



Caregiver Solutions

A VANTAGE AGING INITIATIVE

Heart Health for Family Caregivers

April 11, 2023 | 2:00 PM - 3:30 PM ET | Online

Often, family caregivers ignore their own health while caring for loved ones. Keeping your heart healthy by de-stressing and making small lifestyle changes can significantly reduce the impact of caregiving on your health.

Join the American Heart Association on April 11th for this edition of Vantage Agings' monthly event, Caregiver Solutions, intended to help caregivers find support and resources.

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

REGISTER



Understanding and Responding to Dementia-Related Behaviors

April 11, 2023 | 4:00 PM - 5:00 PM ET | Online

Behavior is a powerful form of communication and is one of the primary ways for people with dementia to communicate their needs and feelings as the ability to use language is lost. However, some behaviors can present real challenges for caregivers to manage. Join the Kadlec Neurological Resource Center on April 11th to how learn to decode behavioral messages, identify common behavior triggers, and learn strategies to help intervene with some of the most common behavioral challenges of Alzheimer's disease.

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

[REGISTER >](#)



HEALTH AND AGING
POLICY FELLOWS

Health and Aging Policy Fellowship 2023-2024 Call for Applications

Deadline to apply: April 17, 2023

With an aging population, one of the greatest challenges for the U.S. is ensuring that policies provide the best possible quality of life for all across all dimensions of society – from the communities where we live, the transportation we depend on, the food we eat, and the health care we receive. Success will require the translation of cutting-edge science and practical clinical experience into sound health policy. The goal of the Health and Aging Policy Fellows Program is to provide professionals in health and aging with the experience and skills necessary to help lead this effort, and in so doing, shape a healthy and productive future for older Americans.

The Health and Aging Policy Fellows Program offers two different tracks for individual placement: (1) a residential track that includes a 9-to-12-month placement in Washington, D.C. or at a state agency (as a legislative assistant in Congress, a professional staff member in an executive branch agency or in a policy organization); (2) a non-residential track that includes a health policy project and brief placement(s) throughout the year at

relevant sites. The project may be focused at a global, federal, state or community level.

In addition, through our partnership with the veterans health administration, VA employees can participate in the VA track as a non-residential fellow.

Core program components focused on career development and professional enrichment are provided for fellows in all tracks.

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

APPLY FOR THE FELLOWSHIP



Make Your Voice Heard: Tips for Effective Caregiver Communication

April 21, 2023 | 12:00 PM - 1:00 PM ET | Online

Caregivers navigate many relationships between the care recipient, healthcare professionals, family members, and others. When communicating in these environments, caregivers can often feel frustrated. Effective communication in relationships is essential for caregivers to best support their care recipients and alleviate stress and anxiety. Join Dr. Naomi Gryfe Saperia to learn practical communication skills to help advocate for those you care for – and yourself.

Dr. Saperia is a Clinical Health Psychologist in Ontario with over a decade of experience in hospitals and private practice. Her clinical practice currently specializes in helping clients cope with the emotional toll of having or caring for someone with an illness or disability.

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

REGISTER





Pain and Other Assessments in a Person with Dementia

April 27, 2023 | 11:00 AM - 12:00 PM ET | Online

Tune in on April 27th for an online session in which Dr. Tam Cummings will discuss Pain and Other Assessments in a Person With Dementia. Professionals use a variety of tools to determine decline and remaining function in Persons With Dementia. Specific tools help give physicians, nurses and caregiving staff a better picture of what is happening to the resident. Assessing for depression, anxiety, ADLs, IADLs, Pain, etc., keeps arguments out of the doctor's office and helps us to assist families in understanding the disease process.

Pain causes an estimated 50 percent of the behaviors in a Person With Dementia. Learn how to assess, plan and provide for pain treatment, including the use of narcotic medications.

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



Caregiver Mental Health: How to Reduce Anxiety for Better Living

May 2, 2023 | 12:00 PM - 1:00 PM ET | Online

The caregiving role can bring forth many different feelings and emotions, and anxiety is one which can be problematic for those managing care. In observance of Mental Health

Week this May, we welcome back Dr. Patrick McGrath to talk about:

- Anxiety in caregivers
- How to notice and address it
- Practical and unique tips to support your mental health

Dr. Patrick McGrath is a clinical psychologist and Emeritus Professor of Psychiatry at Dalhousie University and a scientist at the IWK Health Centre where his research is based. He is an Adjunct Professor of Psychiatry at the University of Ottawa and founder and president of 90Second Health Letters. He frequently treats caregivers with anxiety in his private practice.

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

REGISTER



Caring for Your Caregiver

June 8th, 2023 | 3:00 PM - 4:00 PM ET | Online

Your caregiver is your most valuable contact to help live a better life with Myasthenia Gravis. They need your understanding, patience, and care too. Join Toni Gities on June 8th for a webinar that will discuss the importance of caring for your caregiver.

Toni is the CEO of Caregiver Empowerment and the 2022 recipient of the Myasthenia Gravis Foundation's Emerging Leadership Award.

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

REGISTER



Are You a Spouse or Partner of Someone with Early - Stage Alzheimer's Disease or Dementia?

Duke University researchers are looking for persons living with Dementia and their spouses/partners to share their opinions on their recent experience in a healthcare setting. Your participation may help us figure out what people like yourselves may want out of a healthcare visit or experience.

Eligibility Requirements

*Persons must have mild Alzheimer's Disease or Dementia or be the spouse/partner of person living with mild Alzheimer's Disease or Dementia.

*Both Alzheimer's Disease or Dementia patient and their spouse/partner. Individuals must be age 18 or older.

*The Alzheimer's Disease or Dementia patient must have had a stay in a health care facility within the past 3 months (includes hospitalizations, day surgery, emergency department, etc.)

*Participants must be able to complete an audio recorded interview in English.

*Participants must live near Durham, NC (this is flexible).

About the Study

*Interviews will be conducted in-person with the person living with Alzheimer's Disease or Dementia.

*The interview with the spouse or partner may be conducted by phone or on the computer using a video call.

*Participants will be compensated for their time.

For more information email Hometimestudy@duke.edu, call (919)668-4500, or click the red button below.

LEARN MORE



RARE DISEASE DIVERSITY SURVEY

BE HEARD!

Share your stories and experiences in a national survey of underrepresented rare disease patients and caregivers. Help us in uncovering the gaps and barriers to accessing care you experience in managing your rare disease.



Take the survey today:
DiversityInRareDiseaseSurvey.org
or SCAN the QR code.

This survey is made possible through a grant provided by the Black Women's Health Imperative Rare Disease Diversity Coalition.



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Black, Latino, Indigenous, People of Color. People with Disabilities, Immigrant, Neurodivergent, Non-Binary, LBGQT+, Youth, Rural Americans.

NORD and RDDDC's Rare Disease Diversity Survey

NORD and the [Rare Disease Diversity Coalition](#) (RDDDC) have developed a first-ever national survey of underrepresented rare disease patients and caregivers to better understand their unique perspectives and experiences in accessing and affording health care. This massive, innovative endeavor is a joint venture between the two storied organizations and will help to identify and address gaps faced by rare disease patients, as well as help amplify.

This effort will be a true partnership with the entire rare disease community, which is why NORD has developed a social media toolkit to provide you with the tools to help share this opportunity with your community so they can be heard, included, and counted. The information gathered will help inform future efforts to bring stakeholders together to identify solutions, overcome barriers faced by rare disease patients and their families, and help amplify diverse and marginalized perspectives in rare disease advocacy and research.

If you click on this link: <https://rarediseases.org/rdd-survey-social/>, you'll see a social media toolkit to send out to your membership, including sample posts, images, etc. to bring awareness about the survey to your membership.

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

LEARN MORE



Dementia Education for Older Korean Americans with Probably Dementia and Their Caregivers

Start: April 20, 2021
End: March 31, 2024
Enrollment: 288

Who is sponsoring this study? Johns Hopkins University

Where is this study located? New York and Virginia

What Is This Study About?

This study will evaluate the effectiveness of a dementia education and care navigation support program, called PLAN, to help older Korean Americans with probable dementia and their caregivers access cognitive care. PLAN consists of two components: a one-hour dementia education session, and monthly counseling calls to assist participants in making an appointment with their doctor and identifying any challenges to getting care.

Participants will be randomly assigned to receive either the PLAN program or an educational brochure about dementia and a referral to their doctor. After six months, researchers will measure how many participants have received cognitive care. The researchers will also assess the caregiver's understanding of dementia, and evaluate self-efficacy, depression, quality of life, and other factors in the person with probable dementia, at the start of the study and after six months. All study materials will be available in Korean.

Do I Qualify To Participate in This Study?

Minimum Age: 18 Years

Maximum Age: N/A

Must have:

Participant With Memory Problems

- Age 65 years or older
- Self-identify as a first-generation Korean American
- Moderate memory loss with Clinical Dementia Rating score of at least 1
- Availability of caregiver to participate in the study

Caregiver

- Age 18 years or older
- Able to read and speak Korean
- Live in the same household with the person with memory problems or have weekly interactions together
- Allow the research team to review medical records for information related to dementia care

Must NOT have:

Participant With Memory Problems

- Previous diagnosis of dementia
- Any major psychiatric disease (e.g., schizophrenia)
- Neurological disorders other than Alzheimer's disease that might affect cognition (e.g., stroke)
- Use of psychotropic drugs (e.g., antidepressants, antipsychotics, benzodiazepines) or cognitive-enhancing agents (e.g., memantine and cholinesterase inhibitors)

Caregiver

- Plan to move from the area within six months
- Active treatment for a terminal illness or in hospice

To learn more about this study, call Hae-Ra Han at (410)614-2669 or email her by clicking on the red button below.

[LEARN MORE](#)



MEMORI Corps: Activity-Based Companion Care for People with Dementia

Start: October 1, 2021

End: September 29, 2024

Who is sponsoring this study? Johns Hopkins University

Where is this study located? Maryland

What Is This Study About?

MEMORI Corps is an individualized, activity-based companion care program for people with dementia living at home with their family caregivers. This study will evaluate the feasibility and effects of the MEMORI Corps program to reduce behavioral symptoms in people with dementia, improve caregiver well-being, and provide MEMORI Corps older adult volunteers with meaningful engagement through the programs peer support volunteer opportunities. Following a home-based assessment with the person with dementia and their caregiver, an individualized activity program plan is developed based on the interests and abilities of the person with dementia. In addition, MEMORI Corps older adult volunteers provide peer-to-peer companionship and supervise the in-home activity program with the person with dementia for eight hours each week for 12 weeks. Participants with dementia and their caregivers will be randomly assigned to either begin the program right away or to a waitlist group that will receive educational materials, check-in calls from the study's clinical team every other week, and complete the program at a later time. MEMORI Corps peer volunteers will also be randomly assigned to either begin the program right away to engage three families for one year, or to a waitlist group. Researchers will use questionnaires and interviews at the start of the study, after six months, and after one year to measure the programs effects on the quality of life of the person with dementia, as well as caregiver burden and depression. In addition, researchers will assess any changes in the physical function, cognition, and social and psychological engagement of the MEMORI Corps volunteers. The acceptability and feasibility of the MEMORI Corps program will also be evaluated from all participants perspectives.

Do I Qualify To Participate in This Study?

Minimum Age: 18 Years

Maximum Age: 115 Years

Must have:

Participants With Dementia:

- Diagnosis of dementia with a Clinical Dementia Rating Scale score of > 0.5
- Able to participate in at least two basic activities of daily living (e.g., bathing, dressing, getting in and out of bed or a chair, maintaining a safe environment)
- Living at home in Baltimore City or Baltimore County
- Speak English

Caregivers:

- Reliable, unpaid caregiver
- Live with the person with dementia
- Assist the person with dementia with some activities of daily living (e.g., bathing, dressing, getting in and out of bed or a chair, maintaining a safe environment)
- Speak English

MEMORI Corps Volunteer Facilitators:

- Able to read
- Able to pass a criminal background check, as well as drug and physical and mental health screening
- Reliable transportation and able to travel within 20 miles of home
- Mini-Mental State Examination score of 24 or above
- Good visual attention and ability to switch tasks easily, based on screening test results
- Able to participate in all study activities for up to one year (10 hours each week excluding travel time)
- Speak English
- 55 years of age or older

Must NOT have:

Participants with dementia:

- In a crisis or unsafe situation at the start of the study
- Planned move from home to a care facility in the next six months
- In the end stages of dementia (e.g., bed-bound, unable to communicate, hospice)
- Received formal respite care (e.g., in-home companion care, adult day center) within four weeks prior to study screening
- Urine or bowel incontinence
- Severe behavioral symptoms that could cause harm to self or others
- Currently enrolled in a dementia-related clinical trial

Caregivers:

- Plans to no longer live with the person with dementia in the next six months
- Current participation in another behavior- or education-based clinical trial

MEMORI Corps Volunteer Facilitators:

- Plans to move from the area in the next year

To learn more about this study, call (410)550-6744 or email Morgan Spliedt by clicking the red button below.

[LEARN MORE](#)



Memory Training to Improve Cognitive Function in Older Adults

Start: April 7, 2022

End: September 1, 2023

Enrollment: 30

Who is sponsoring this study? University of Michigan

Where is this study located? Michigan

What Is This Study About?

Working memory allows a person to remember and access information in the mind without losing track of what they are doing, such as a task. This study will test whether working memory training can improve learning and memory in people with mild cognitive impairment or normal cognition. Participants will receive online or in-person working memory training for 10 training sessions. At the start, end, and one month after the two-week training period, participants will take memory tests and undergo MRI brain imaging. Researchers will evaluate changes in task performance, memory, and cognition, and brain activity.

Do I Qualify To Participate in This Study?

Minimum Age: 60 Years

Maximum Age: N/A

Must have:

- Diagnosis of mild cognitive impairment
- Right-handed

Must NOT have:

- History of a neurological or medical condition known to affect cognitive functioning, other than mild cognitive impairment

- Serious mental illness
- Significant vision, hearing, or other impairment that limits the ability to participate
- History of alcohol or drug abuse
- Any condition that may make having an MRI brain scan unsafe (e.g., metal shrapnel, heart pacemaker, severe claustrophobia, epilepsy, body size and shape that prevents comfortable fit in scanners)

To learn more about this study, call Lauren Antonucci at (734)647-3704 or email her by clicking the red button below.

[LEARN MORE](#)



Online Training Program for Latino Dementia Caregivers

Start: November 2022

End: September 2024

Enrollment: 48

Who is sponsoring this study? University of Texas Health Science Center at San Antonio

Where is this study located? Texas

What Is this study about?

This study is evaluating the effectiveness of an online caregiver education program, named Learning Skills Together or Juntos, to improve confidence and overall well-being of Latino family caregivers of a person with dementia. Participants will be randomly assigned to participate in the program either immediately or as part of a waitlist group that will complete the program three months later. At the start and end of the six-week study, caregivers will answer questionnaires related to their confidence performing care tasks, resilience to challenging behaviors, and overall health.

Do I Qualify To Participate in This Study?

Minimum Age: 18 Years

Maximum Age: N/A

Must have:

- Family member to a person diagnosed with Alzheimer's disease or a related dementia
 - Person with dementia must have a Global Deterioration Score between 4 and 6
- Provide unpaid assistance with at least one major activity of daily living (e.g., bathing, eating, dressing)
- Able to read and speak English or Spanish

Must NOT have:

- Previous participation in the Learning Skills Together program
- Plans to place the care recipient in a skilled nursing facility within the next six months
- Severe depression, based on study screening evaluation

To learn more about this study, call Carole White at (210)380-5764 or email her by clicking on the red button below.

[LEARN MORE](#)



Firearm Safety in the Home of a Person with Dementia

Start: May 22, 2022

End: March 2024

Enrollment: 500

Who is sponsoring this study? Colorado School of Public Health.

Where is this study located? Colorado

What Is this study about?

This study will test the effectiveness of different online home safety tools to help family caregivers improve firearm safety in the home of person with dementia. Participants will be randomly assigned to use either an online firearm safety program or complete an online home safety checklist. All participants will complete questionnaires and other evaluations at the start of the study, after two weeks, and in follow-up after two and six months. Researchers will measure changes in caregiver confidence and burden, along with changes in the person with dementia's access to firearms, and any injuries or threatening situations involving the person with dementia and a firearm.

Do I Qualify To Participate in This Study?

Minimum Age: 18 Years

Maximum Age: N/A

Must have:

Caregivers:

- Informal caregiver (e.g., family member or friend) of a person with dementia who has access to a firearm
- Speak English or Spanish
- Access to the internet

Person with dementia:

- Cognitive decline with signs of dementia
- Access to a firearm
- Living at home or in a senior community

Must NOT have:

Person with dementia:

- In legal custody or institutionalized

To learn more about this study, call Marian Betz at (303)550-5669 or email her by clicking on the red button below.

LEARN MORE



Social Engagement Study for Care Partners of Persons with Dementia

There is a new contactless study at the University of Illinois to provide opportunities for care partners who want to:

- Connect with others outside the role of caregiving
- Attend to self-care needs
- Reminisce with others in a casual setting
- Engage with others on topics of shared interests

What is the study about?

We are evaluating the benefits of remote social engagement events for individuals 60 and over who care for a relative with dementia. In the events, participants see a short slideshow about various topics of interest (e.g, the 60s, cooking, movies). After the slideshow, participants enter a virtual breakout room to have a casual and engaging conversation with others about the topic. You will have the flexibility to pick the events which work best for your schedule.

How is this different than a support group?

While support groups offer opportunities to learn and share about caregiving, this program is focused on providing social engagement opportunities outside your role as a caregiver to support your social health from the comfort of your home using an online platform.

You may be eligible to participate if:

- Age 60 and above
- Comfortable speaking English
- Have a computer, tablet, or iPad with internet access
- Care for a relative with dementia
- Can participate in 30-minute discussions over four weeks

What do I need to participate?

You will need access to a computer, laptop, or tablet with a webcam/microphone and internet access.

What is the compensation?

Three assessments are completed throughout the study process. You are paid \$25 following each assessment.

If you have questions, please contact us by email at shs-caregiver-engage@illinois.edu or by phone at 217)333-5262.

If you want to participate in this study, click on the red button below.

LEARN MORE



CADASIL Registry

Start: June 3, 2022

End: October 2027

Enrollment: 2,500

Who is sponsoring this study? CADASIL Consortium

Where is this study located? Wisconsin

What is this study about?

CADASIL, or cerebral autosomal dominant arteriopathy with subcortical infarcts and leukoencephalopathy, is a rare genetic disorder affecting the small blood vessels in the brain. The CADASIL Registry is enrolling people who have or are at risk of developing CADASIL, or who have a family member or other loved one with CADASIL. After joining

the CADASIL Registry, volunteers will be invited to participate in studies on CADASIL.

Do I Qualify To Participate in This Study?

Minimum Age: 18 Years

Maximum Age: 90 Years

Must have:

- Person with CADASIL or at risk for CADASIL, or have a loved one or a family member with CADASIL

Must NOT have:

- None

To learn more or participate in this study, email the CADASIL Consortium by clicking on the red button below.

LEARN MORE



Nutrition in People With Dementia and Their Caregivers

Start: Oct. 25, 2022

End: Sept. 14, 2023

Enrollment: 120

Who is sponsoring this study? University of Kansas

Where is this study located? Kansas

What is this study about?

Informal caregivers perform many nutrition-related tasks as part of daily dementia care, including food shopping, preparation, and feeding. In this one-month observational study, a registered dietician will evaluate the nutritional health of people with dementia and their caregivers, as well as the caregivers' nutrition knowledge. Caregivers will complete questionnaires about their nutritional needs and knowledge. The results of the study will inform future research to reduce malnutrition in people with dementia and their caregivers, as well as reduce caregiver burden.

Do I Qualify To Participate in This Study?

Minimum Age: 18 Years

Maximum Age: N/A

Must have:

Participants with dementia:

- Diagnosed with Alzheimer's disease or other dementia
- Live at home with a family caregiver or a domestic partner
- Availability of past weight records with a minimum of two different timepoints

Caregiver participants:

- Primary caregiver who is responsible for food planning
- Normal cognition
- English speaking

Must NOT have:

Participants with dementia:

- Diagnosis of frontotemporal dementia, alcohol-related dementia, Huntington's disease, schizophrenia, or manic-depressive disorder

Caregiver participants:

- Vision problems that prevent completing questionnaires

All participants:

- Current participation in a nutrition treatment study

To learn more about this study, call Rebecca Mount at 913)945-8160 or email her by clicking on the red button below.

[LEARN MORE](#)



c a r e / c u i d a r

Racial/Ethnically Diverse Sexual and Gender Minority Caregivers of Individuals Living with Alzheimer's Disease and Related Dementias

To ensure that diverse sexual and gender minority (SGM) people are represented in Alzheimer's Disease and Related Dementias (ADRD) and caregiving research, the University of Nevada, Las Vegas is asking for insight on the lived experiences of racial/ethnically diverse SGM ADRD caregivers.

This research aims to provide valuable data necessary to design future caregiving interventions and services meant to improve the health and well-being of diverse ADRD caregivers.

Inclusion Criteria:

- Self-identify as lesbian, gay, bisexual, transgender, and queer (LGBTQ+) or a sexual and/or gender minority (SGM) and as a racial/ethnic minority.
- Provide care to an adult with Alzheimer's disease or related dementias (ADRD) at least eight hours a week on average.
- Able to complete an interview, up to 2 hours, in English or Spanish.

Exclusion Criteria:

- Severe substance use/abuse
- Psychiatric disorders
- Inability to provide verbal consent

Participation is voluntary. All information will be kept confidential.

Participants will receive a \$50 Visa E-gift card after completion of the phone interview.

To learn more about this study, email Dr. Krystal Kittle by clicking on the red button below.

LEARN MORE



Spirolactone for African Americans with Mild Cognitive Impairment or Early Alzheimer's Disease

Start: Sept. 6, 2022

End: September 2023

Enrollment: 30

Who is sponsoring this study? Emory University

Where is this study located? Georgia

What is this study about?

This Phase 4 study will evaluate the safety and effects of the FDA-approved blood pressure medication spironolactone in older African American adults with mild cognitive impairment or early Alzheimer's disease. Participants will be randomly assigned to take either spironolactone or a placebo pill once a day for one year. All participants will complete memory and thinking tests at the start, mid-point, and end of the study. Researchers will monitor participants for side effects throughout the study.

Do I Qualify To Participate in This Study?

Minimum Age: 50 Years

Maximum Age: N/A

Must have:

- Self-identify as African American
- Normal blood pressure or controlled high blood pressure (110-140/40-90 mmHg)
- Diagnosis of mild cognitive impairment or early-stage Alzheimer's disease:
 - Self-reported memory concerns
 - Montreal Cognitive Assessment score of 15-25
 - Functional Assessment Questionnaire score < 9
- Wechsler Memory Scale-Revised Logical Memory subscale score:
 - < 11 for 16 or more years of education
 - < 9 for 8-15 years of education
 - < 6 for less than seven years of education

Must NOT have:

- Stroke in the last three years
- Unable to complete study procedures due to communication problems or other factors
- Any medical issue that interferes with the study procedures (e.g., chest pain, shortness of breath, or abdominal pain)
- History of allergy or adverse reaction to an aldosterone antagonist
- Uncontrolled high blood pressure
- Currently taking RAAS modulating medications (i.e., angiotensin II receptor blocker, angiotensin converting enzyme inhibitor, renin inhibitor, or aldosterone antagonist such as eplerenone)
- Kidney disease, with baseline creatinine > 2.0 mg/dL
- High potassium, with blood potassium > 5.5 mEq/dL
- Diagnosis of a neurological or psychiatric condition other than mild cognitive impairment that could impact cognition (e.g., Parkinson's disease and related

- movement disorders, multiple sclerosis, epilepsy, schizophrenia, untreated major depressive disorder, or other psychotic disorders)
- Abnormal levels of thyroid stimulating hormone (> 10 milliunits (mU)/L) or vitamin B12 (<250 pg/mL) that impact cognitive function
- Any medical or psychiatric disease that could affect participant safety or study results, according to the study investigator
- Uncontrolled congestive heart failure, with poor exercise tolerance and shortness of breath
- Women must be postmenopausal

To learn more about this study, call Dr. Antoine Trammell at 404)712-6332 or email him by clicking on the red button below.

[LEARN MORE](#)



Interview about Family Relationships and Wellbeing in Dementia

If you are a caregiver to a family member with dementia, you're invited to participate in an interview about your caregiving experiences and wellbeing. The interview will last approximately 60-90 minutes and can be completed over the phone or via Zoom.

You will receive a \$10 Amazon gift card for participating. In order to participate you must:

- Be a caregiver to a FAMILY MEMBER living with dementia
- Be at least 18 years old
- Be able to read and speak English

To sign up for an interview, click the red button below.

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Participate in Patient and Care Partner Survey on Post-transplant Journey

PatientsLikeMe (PLM), a patient community and digital health management [platform](#), and Takeda, a global, values-based, R&D-driven biopharmaceutical leader, are conducting a research study to better understand the post-transplant journey of patients and care

partners to help determine any knowledge gaps and opportunities to better connect. The three-phase study seeks to better understand the transplant patient journey, particularly if they've experienced cytomegalovirus (CMV) infection, and identify changes in care journey experiences to help connect patients and their care providers.

PatientsLikeMe is a health tracking and learning platform embedded within an online social network. As of early 2020, the PLM community consists of ~860,000 members representing a wide range of conditions. The underlying PLM platform is designed, and continues to be optimized, to foster peer support and disseminate knowledge, including real-world insights. Members share personal stories about their health journey, engage with others who are (or were) in their situation, monitor symptoms, evaluate treatments, and track outcomes.

Participants will be compensated for their time and must:

1. Be 18 years of age or older
2. Be a patient or care partner of a patient who has had a solid organ transplant or hematopoietic stem cell transplant within the last three years.

If you fit the criteria below and want to share your experience via a written survey, click on the red button below.

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IN CASE YOU MISSED IT...

Promising Practices for Implementing Hybrid Programs



The January 20, 2023 webinar focused on hybrid programming. During the webinar, Older Adults Technology Services (OATS) from AARP and a Senior Planet trainer discussed Senior Planet's experiences piloting hybrid programs. Attendees also heard from the Baltimore County Department of Aging on its experiences with developing and implementing hybrid programming. All speakers shared tips, considerations and best practices for organizations interested in offering hybrid programs.



RESEARCH & RESOURCES

#AutoimmuneAwarenessMonth

March

AUTOIMMUNE
AWARENESS
MONTH



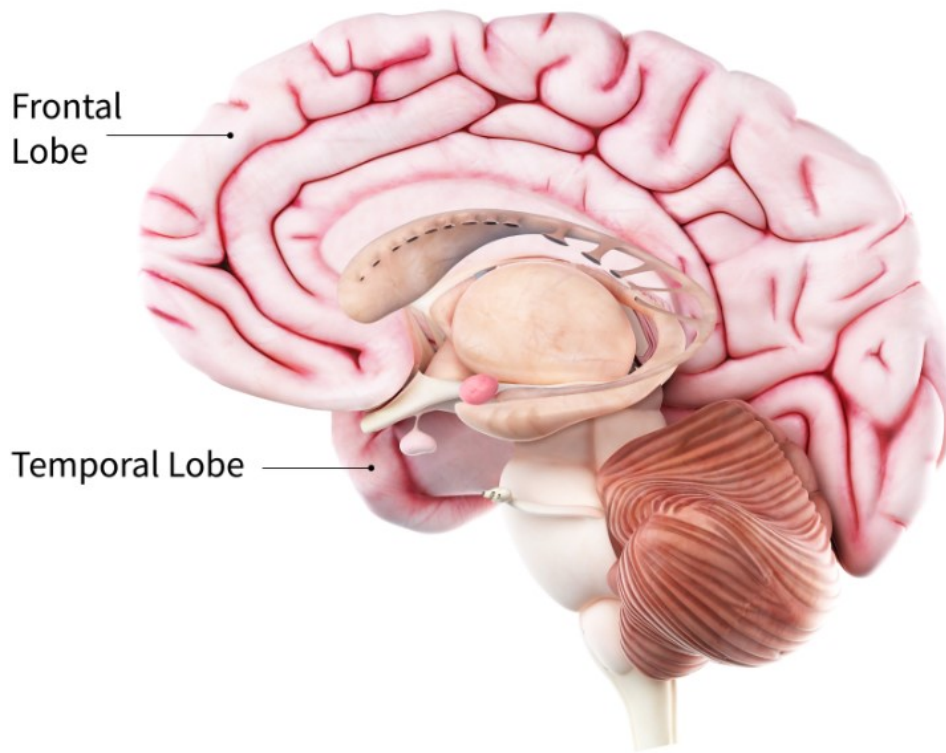
Learn more at autoimmune.org

Autoimmune Awareness Month Toolkit

March is Autoimmune Awareness Month. The Autoimmune Association has prepared a social media toolkit that contains resources organizations and individuals can use to help spread awareness about autoimmune disease, provide education, and communicate the urgent need for more research. Included are facts, sample social posts, graphics, and a sample video script.

To view the toolkit, click the red button below.

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What Are Frontotemporal Disorders? Causes, Symptoms, and Treatment

Frontotemporal disorders (FTD), sometimes called frontotemporal dementia, are the result of damage to neurons in the frontal and temporal lobes of the brain. Many possible symptoms can result, including unusual behaviors, emotional problems, trouble communicating, difficulty with work, or difficulty with walking. FTD is rare and tends to occur at a younger age than other forms of dementia. Roughly 60% of people with FTD are 45 to 64 years old.

To learn more, click the red button below.

[LEARN MORE](#)



Providing Care for a Person with a

Frontotemporal Disorder

People living with frontotemporal disorders, sometimes called frontotemporal dementia, can have a range of symptoms, including unusual behaviors, emotional problems, trouble communicating, and difficulty walking. Caring for someone with a frontotemporal disorder (FTD) can be hard, both physically and emotionally. Caregivers may face challenges with managing the medical and day-to-day care, as well as changing family and social relationships, loss of work, poor health, stress, decisions about long-term care, and end-of-life concerns.

To learn more, click the red button below.

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15 Things Every Caregiver Should Know about Navigating Eating Disorders

Knowing the right thing to do or say is not always easy, and there is no one-size-fits-all solution to navigating eating disorders. In fact, the “right thing” to say one day may be the “wrong thing” to say the next. It is a challenge both for the individual battling an eating disorder and their support system.

In honor of World Eating Disorders Action Day on June 2, 2023, the National Eating Disorders Association is focusing on the caregivers of those with eating disorders. There will be a number of ups and downs, advancements and backtracks during your loved one’s journey to recovery. To get you started, below is a list of 15 things those in the recovery community want all caregivers to know.

To learn more, click the red button below.

[LEARN MORE](#)





Living with IBD

We've all heard the phrase "trust your gut." For people with inflammatory bowel disease (IBD), trusting one's gut is not so simple. When the body sounds an alarm that something doesn't feel right, taking that internal voice seriously and actively speaking up is critical. For someone starting to feel the pain or flares associated with IBD, learning to trust your gut first means *listening* to your symptoms.

Takeda Pharmaceuticals America recently launched *Living With IBD*, a website to help support people living with Crohn's disease or ulcerative colitis (UC) navigate life with IBD. *Living With IBD* recognizes that the pain of IBD is real and these chronic diseases can be mentally and physically exhausting, and sometimes hard to talk about.

The information and resources included on LivingWithIBD.com aim to help people better understand IBD, equip patients with the information and tools needed to have productive and honest conversations with healthcare providers, and connect patients with community resources like the National Alliance for Caregiving.

To learn more, click the red button below.

[LEARN MORE](#)





Self-Care Tips for Caregivers: Your Health Matters, Too

What did you want to be when you grew up? An author, an astronaut, an architect, an actor? Whatever life you dreamed of for yourself, you probably never imagined the possibility of juggling your personal and professional life while also being a caregiver for someone who is living with medical challenges.

Whether you're moving an aging parent into your home, taking care of a partner who has cancer or managing any other scenario in which you're caring for a loved one with health needs, one thing remains true: Caregiving can be incredibly stressful.

To learn more, click the red button below.

[LEARN MORE](#)



Stroke: Signs, Causes, and Treatment

Having a stroke is just as serious as having a heart attack. So, it's important to know the signs of stroke and act quickly if you suspect you or someone you know is having one. Stroke is the fifth leading cause of death in the United States and is the number one cause of serious adult disability. Stroke risk increases with age, but strokes can — and do — occur at any age. The good news is that most strokes can be prevented, and there are steps you can take that may lower your chance of having a stroke.

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

[LEARN MORE](#)





Disability & Health Information for Family Caregivers

If you are a family member who cares for someone with a disability, whether a child or an adult, combining personal, caregiving, and everyday needs can be challenging. The CDC offers general caregiving tips intended to provide families with information on how to stay healthy and positive. These tips can be used to address many family issues. Information, support, advocacy, empowerment, care, and balance can be the foundation for a healthy family and are appropriate no matter what the challenge.

To learn more, click the red button below.

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PREVIOUSLY APPEARED



Coping with Agitation and Aggression in Alzheimer's Disease

People with Alzheimer's disease may become agitated or aggressive as the disease gets worse. Agitation means that a person is restless or worried. He or she doesn't seem to be able to settle down. Agitation may cause pacing, sleeplessness, or aggression, which is when a person lashes out verbally or tries to hit or hurt someone.

Most of the time, agitation and aggression happen for a reason. When they happen, try to find the cause. If you deal with the causes, the behavior may stop.

To learn more, click the red button below.

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Wandering and Alzheimer's Disease

Many people with Alzheimer's disease wander away from their home or caregiver. As the caregiver, you need to know how to limit wandering and prevent the person from becoming lost. This will help keep the person safe and give you greater peace of mind.

To learn more, click the red button below.

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Alzheimer's and Hallucinations, Delusions, and Paranoia

Due to complex changes occurring in the brain, people with Alzheimer's disease may see or hear things that have no basis in reality.

If a person with Alzheimer's has ongoing disturbing hallucinations or delusions, seek medical help. An illness or medication may cause these behaviors. [Medicines are available to treat these behaviors](#) but must be used with caution. The following tips may also help you cope with these behaviors.

To learn more, click the red button below.

[LEARN MORE](#)



When a Person with Alzheimer's Rummages and Hides Things

Someone with Alzheimer's disease may start rummaging or searching through cabinets, drawers, closets, the refrigerator, and other places where things are stored. He or she also may hide items around the house. This behavior can be annoying or even dangerous for the caregiver or family members. If you get angry, try to remember that this behavior is part of the disease.

To learn more, click the red button below.

[LEARN MORE](#)



Managing Personality and Behavior Changes in Alzheimer's

Alzheimer's disease causes brain cells to die, so the brain works less well over time. This changes how a person acts. Common personality and behavior changes you may see include:

- Getting upset, worried, and angry more easily
- Acting depressed or not interested in things
- Hiding things or believing other people are hiding things
- Imagining things that aren't there
- Wandering away from home
- Pacing a lot
- Showing unusual sexual behavior
- Hitting you or other people
- Misunderstanding what he or she sees or hears

You also may notice that the person stops caring about how he or she looks, stops bathing, and wants to wear the same clothes every day.

To learn more, click the red button below.

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Patient Priorities Care Veterans Affairs Implementation Toolkit

Patient Priorities Care (PPC) helps patients and clinicians focus all decision-making and healthcare on what matters most: patients' own health priorities. It was developed by clinicians, patients, caregivers, health system leaders, and payers.

PPC is particularly suited for older adults who must manage multiple conditions and navigate multiple clinicians. People with multiple conditions receive a lot of care that is often burdensome and may not address what matters most to them. Patient Priorities Care recognizes that, when faced with tradeoffs, older adults differ in their own health outcome goals (what they want to achieve from their healthcare) and in their care preferences (what they can do to achieve their goals).

PPC has released a new toolkit on guiding PPC implementation within Veterans Affairs (VA) clinical settings to help identify and make treatment decisions based on what matters to older veterans.

To access the toolkit, click on the red button below.

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A Caregiver's Guide to the Dying Process

Grief is not experienced only after death. As a caregiver, you may be susceptible to two types of grief: anticipatory grief during your loved one's illness, and then grief that occurs after the person dies.

Many caregivers experience "anticipatory grief" as they observe the physical, psychological, and cognitive declines occurring as the illness progresses. For many caregivers of people with dementia this may be especially painful, as their loved one becomes almost unrecognizable compared to the person "they used to be."

After the death of a loved one, it can be difficult to see how to ever go on. The grief journey may seem like a mountain that is too difficult to climb. The Hospice Foundation of America offers a booklet, *A Caregiver's Guide to the Dying Process*, that provides guidance to care providers facing these circumstances.

To view the booklet, click the red button below.

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Aging in Place: Growing Older at Home

Individuals intending to "age in place" in their own homes face a number of challenges. The good news is that with the right help you might be able to do just that.

Planning ahead is hard because you never know how your needs might change. The first step is to think about the kinds of help you might want in the near future. Maybe you live alone, so there is no one living in your home who is available to help you. Maybe you don't need help right now, but you live with a spouse or family member who does. Everyone has a different situation.

To learn more, click the red button below.

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Different Care Settings at the End of Life

The three most common places people at the end-of-life die are at home, in a hospital, or in a care facility. While not everyone has the chance to decide where they will die, people who know the end of life is approaching may be able to plan ahead. Several factors may help with this planning, including knowing the type of care you need and want, where you can receive this level of care, [advance care directives](#), [costs](#), and availability of family and friends to help.

To learn more, click the red button below.

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Providing Care and Comfort at the End of Life

Not all end-of-life experiences are alike. Death can come suddenly, or a person may linger in a near-death state for days. For some older adults at the end of life, the body weakens while the mind stays clear. Others remain physically strong while cognitive function declines. It's common to wonder what happens when someone is dying. You may want to know how to provide comfort, what to say, or what to do.

To learn more, click the red button below.

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Legal Issues for LGBTQ+ Caregivers

Lesbian, gay, bisexual and transgender people, in couples or not, face increasingly important legal and financial decisions as they age. These legal and financial decisions, the documents that enforce them, and the agents that you name in them will determine who has the legal authority to confer with your doctors and make medical decisions for you, and who has the legal authority to manage your financial resources if and when you become incapacitated, legally unable to act on your own behalf.

To learn more, click the red button below.

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Rush Caring for Caregivers (C4C)

The mission of Rush Caring for Caregivers is to support family members or friends who are caring for adults 60 and older by offering services that aim to reduce caregiver stress, prevent caregiver burnout, and assisting caregivers in finding a balance between the needs of their loved ones and their own needs.

The C4C program has been proven to have positive health-related outcomes for both adults age 60 and older as well as for their care partners. Funded by the RRF Foundation for Aging, it uses an evidence-based framework to improve care for older adults and caregivers through education, resources and support. C4C focuses on what matters to the caregiver by assisting in developing a plan for the caregiver's physical and emotional health and well-being while incorporating the care needs and preferences of the older adult. These services may be delivered in person, by telephone or via video conferencing. C4C does not charge for the initial meeting and other sessions are covered by most insurances.

To learn more, click the red button below.

[LEARN MORE](#)



Home Modification Toolkit: Lessons from the Field!

The University of Southern California Fall Prevention Center of Excellence and the Administration for Community Living have put together a toolkit designed to provide professionals with tools to enhance home modification availability and awareness for older

adults and persons with disabilities. The Toolkit has a specific emphasis on enhancing the Aging Network's ability to deliver and promote access to best practice home modification programs through targeted resource development, training, technical assistance, and information dissemination.

The Aging Network is an interconnected system of agencies funded under the Older Americans Act of 1965. The National Aging Network includes 56 State Units on Aging (SUAs), 622 Area Agencies on Aging (AAAs), and more than 260 Title VI Native American aging programs.

To learn more, click the red button below.

[LEARN MORE](#)



Caregiver's Guide to Medications and Aging

Modern medicines have contributed to longer life spans, improved health, and vastly improved our overall quality of life. Medications are the most common treatment for many diseases and conditions seen in older people and persons with disabilities. Medicines now not only treat and cure diseases that were untreatable just a few years ago, they aid in the early diagnosis of disease; prevent life-threatening illnesses; relieve pain and suffering; and allow people with terminal illnesses to live more comfortably during their last days.

However, for older adults and people with disabilities, medications—prescription, over-the-counter, social drugs such as alcohol, and herbal remedies/alternative medicines—can be a double-edged sword. When not used appropriately, effectively, and safely, medications can have devastating consequences.

To learn more, click the red button below.

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When It's Time to Leave Home

The decision about whether your parents should move is often tricky and emotional. Each family will have its own reasons for wanting (or not wanting) to take such a step.

One family may decide a move is right because the parents can no longer manage the

home. For another family, the need for hands-on care in a long-term care facility motivates a change.

To learn more, click the red button below.

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HIV-Associated Neurocognitive Disorder (HAND)

Since the start of the AIDS epidemic more than three decades ago, doctors, family and friend caregivers, and patients have observed that some people with the disease experience decline in brain function and movement skills, as well as shifts in behavior and mood. This disorder is called HIV-associated Neurocognitive Disorder, or “HAND.” Although advances in antiretroviral therapy from the past two decades have decreased the severity of HAND, symptoms still persist in 30–50% of people living with HIV. For many people, these symptoms continue to affect activities of daily living.

To learn more, click the red button below.

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Frequently Asked Questions about Caregiving

Caregiving can be overwhelming, especially when you’re starting out. Take a deep breath! Then tackle one task at a time.

First, assess your loved one’s needs. What types of help are needed? Ask family members and friends to share tasks. Look for resources in your community, such as home health care or adult day care centers. The [Eldercare Locator](#) can help you find in-home help; transportation; resources to install ramps, grab bars, or other home modifications; and other resources in your area. It can also help you learn about options for paying for care.

To learn more, click the red button below.

[LEARN MORE](#)



Paying for Mental Health Care: Your Questions Answered!

Paying for mental health care is no easy task. Even people with health insurance have trouble finding and paying for mental health care. The situation can feel dire.

A new fact sheet released by [Families for Depression Awareness](#) explains issues involved in paying for care and offers practical strategies that help you support your loved one in getting necessary mental health treatment.

To view the fact sheet, click the red button below.

[VIEW THE FACT SHEET](#)



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. First, try to define the caregiving responsibilities. You could start by setting up a family meeting and, if it makes sense, include the care recipient in the discussion.

To learn more, click the red button below.

[LEARN MORE](#)





Dementia-Related Pain: What Caregivers Need to Know

As dementia progresses, so does the likelihood that patients are experiencing pain. Between 50% and 80% of patients with moderate to severe dementia experience pain daily. Many patients receive inadequate treatment due lack of recognition. Alzheimer's disease causes the person to develop a mask-like facial expression. This minimizes typical facial expressions of pain, like a drawn mouth or furrowed brows. Also, patients may have lost the cognitive ability to tell caregivers about their pain with phrases such as "this hurts" or "I am in pain."

To learn more, click the red button below.

LEARN MORE



Paying for Long-Term Care

Many older adults and caregivers worry about the cost of medical care and other help they may need. These expenses can use up a significant part of monthly income, even for families who thought they had saved enough. How people pay for **long-term care** — whether delivered at home or in a hospital, assisted living facility, or nursing home — depends on their financial situation and the kinds of services they use.

To learn more, click the red button below.

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Taking Care of Yourself: Tips for Caregivers

Taking care of yourself is one of the most important things you can do as a caregiver. Make sure you're [eating healthy](#), [being active](#), and [taking time for yourself](#).

Caregiving, especially from a distance, is likely to bring out many different emotions, both positive and negative. Feeling frustrated and angry with everyone, from the care recipient to the doctors, is a common experience. Anger could be a sign that you are overwhelmed or that you are trying to do too much. If you can, give yourself a break: take a walk, talk with your friends, get some sleep — [try to do something for yourself](#).

To learn more, click the red button below.

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Podcast: Caring for a Parent at the End of Life

Mark Chesnut is a NYC-based journalist, editor, and public speaker. His book, *Prepare for Departure, Notes on a single mother, a misfit son, inevitable mortality, and the enduring allure of frequent flyer miles*, is about love and care and acceptance – not the infamous acceptance from the 5 stages of grief – but the acceptance that can happen between a mother and son when one of their lives is coming to an end.

This episode of the [Doug Center's](#) podcast "Grief Out Loud" travels to a lot of places, including: What Mark learned about grief from his mother after his father died. How those lessons shaped the way he approached caring for her and grieving her death. How Mark moved into a place of acceptance with his mother for the ways she responded when he came out to her as a young adult. The ways he dealt, and continues to deal with grief, even during the height of COVID, when he was unable to access his usual outlet, travel.

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

[LISTEN TO THE PODCAST](#)



Resources for Alzheimer's and Dementia Caregivers

The Alzheimer's Foundation of American (AFA) was founded by a family caregiver to be a resource for caregivers and a place they can turn to for help, guidance and support in their time of need. AFA provides a wide variety of resources for Alzheimer's and dementia caregivers. Whether you are just starting out on your journey with Alzheimer's or dementia, or have been on the journey for a while, we are here for you. No one is alone on their journey.

To learn more, click the red button below.

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Family Caregiving HelpGuide

[HelpGuide.org](https://www.helpguide.org) is an independent nonprofit that runs one of the world's leading mental health websites. Its team is a passionate group of people dedicated to providing you with balanced, responsible, helpful, and motivating mental health information, resources, and tools.

New family caregivers face many responsibilities. HelpGuide offers suggestions and resources that will assist you as you navigate your new role.

To learn more, click the red button below.

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Health Scams! Don't Take the Risk.

How to Spot a Scam... It's Called Health Fraud

- Lots of people are fooled into buying health products that sound great, but are really fakes.
- Some products may cause serious problems like pain, suffering, or even death.
- Some products may not mix well with your other medicines.
- You may also lose your money on scam products that don't work.

To learn more, click the red button below.

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Optimism Linked to Longevity and Well-being in Two Recent Studies

Optimism is linked to a longer lifespan in women from diverse racial and ethnic groups, and to better emotional health in older men, according to two NIA-funded studies. One study showed that the previously established link between optimism and longevity applies to racially and ethnically diverse populations of women and that the link is only partially due to changes in health behaviors. The other study showed that more optimistic men have fewer negative emotions, due in part to reduced exposure to stressful situations. These findings suggest that increasing optimism may be a way to extend lifespan and improve well-being in older adults.

To learn more, click the red button below.

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Podcast: How to Take Better Care of Your Loved Ones

Giving and receiving care—it's a natural part of life. But how do we offer the best possible support for our loved ones? Tune in for this podcast in which TED speakers share ideas on reimagining caregiving.

Guests include dementia care advocate Yvonne van Amerongen, attorney Diana Adams, inclusion advocate Sara Jones, and comedian Bill Bernat.

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

[LISTEN TO THE PODCAST](#)



Helping Children Understand Alzheimer's Disease

When a family member has Alzheimer's disease, it affects everyone in the family, including children and grandchildren. It's important to talk to them about what is happening. How much and what kind of information you share depends on the child's age and relationship to the person with Alzheimer's.

Talk with kids about their concerns and feelings. Some may not talk about their negative feelings, but you may see changes in how they act. Problems at school, with friends, or at home can be a sign that they are upset. A school counselor or social worker can help your child understand what is happening and learn how to cope.

To learn more, click the red button below.

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Managing Money Problems in Alzheimer's Disease

People with Alzheimer's disease often have problems managing their money. In fact, money problems may be one of the first noticeable signs of the disease.

Early on, a person with Alzheimer's may be able to perform basic tasks, such as paying bills, but he or she is likely to have problems with more complicated tasks, such as balancing a checkbook. As the disease gets worse, the person may try to hide financial problems to protect his or her independence. Or, the person may not realize that he or she is losing the ability to handle money matters.

To learn more, click the red button below.

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What Are the Signs of Alzheimer's Disease?

The symptoms of Alzheimer's can vary from one person to another. Memory problems are typically one of the first signs of the disease. Decline in non-memory aspects of cognition, such as finding the right word, trouble understanding visual images and spatial relationships, and impaired reasoning or judgment, may also signal the early stages of Alzheimer's. As the disease progresses, symptoms become more severe and include increased confusion and behavior changes.

To learn more, click the red button below.

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**GETTING YOUR
AFFAIRS IN ORDER:**
Advance Care Planning

Getting Your Affairs in Order

Long before she fell, Louise put all her important papers in one place and told her son where to find them. She gave him the name of her lawyer, as well as a list of people he could contact at her bank, doctor's office, insurance company, and investment firm. She

made sure he had copies of her Medicare and other health insurance cards. She made sure her son could access her checking account and safe deposit box at the bank. Louise made sure Medicare and her doctor had written permission to talk with her son about her health and insurance claims.

To learn more, click the red button below.

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Cancer Caregiver Resources Guide

The American Cancer Society Caregiver Resource Guide is a tool for people who are caring for someone with cancer. It can help you:

- Learn how to care for yourself as a caregiver.
- Better understand what your loved one is going through.
- Develop skills for coping and caring.
- Take steps to help protect your health and well-being.
- Find important resources for getting help and support.

To view the guide, click the red button below.

[VIEW THE GUIDE](#)





6 Valuable Support Resources for Caregivers of Veterans

If you regularly help an older veteran with tasks like dressing, bathing, grocery shopping, transportation, and preparing meals, you could be considered a caregiver.

More than 5.5 million people serve as informal caregivers for older and/or disabled veterans across America—many of them without any kind of compensation.

Caring for a veteran comes with special challenges, and burnout is a very real possibility. That's why it's important to take advantage of the caregiver support resources available to you.

To learn more, click the red button below.

[LEARN MORE](#)





The Journey Map of a Sickle Cell Disease Caregiver

The Journey Map of a sickle cell disease (SCD) is a blueprint of the encounters an individual can go through as a caregiver to a loved one with SCD. This diagram was created by [Sick Cells](#) and used during the May 2021 Roundtable on Resources for SCD Caregivers in an effort to visualize an individual's experience and align resources and support.

To view the SCD Journey Map, click the red button below.



Epilepsy Resources for Caregivers

Whether you've been a caregiver for years or if your duties as a caregiver are just beginning, it's comforting to know that there are epilepsy resources to help you navigate your loved ones' journey.

Many resources exist to connect you with others who are experiencing something similar. There are also support services that can help when you may be feeling a little lost. No matter your situation, there are people and places you can turn to when you need a helping hand.

To learn more, click the red button below.

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Informal Caregivers in Cancer

Being a caregiver means helping with the daily needs of another person. An informal caregiver is usually a relative or friend who may or may not live in the same house as the person they are caring for. A formal caregiver, such as a nurse, is paid and has training to care for a patient. Informal and formal caregivers help people with cancer during and after treatment in many ways.

The NIH's National Cancer Institute has put together a fact sheet about the roles, needs, and burdens of informal caregivers who are caring for a person with cancer. To view the fact sheet, click the red button below.

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What Parents and Caregivers Need to Know About the New Pediatric Obesity Guidance

For the first time in 15 years, the American Academy of Pediatrics (AAP) has updated its guidance on obesity in children, recommending a more proactive approach.

According to the Centers for Disease Control and Prevention, nearly 20% of children and adolescents in the United States are obese—meaning that their body mass index (BMI) is at or above the 95th percentile of the CDC growth chart. For children, BMI is an age- and sex-specific measurement using height and weight that helps assess body fat. Children who are obese are at higher risk for physical health issues, including heart disease and type 2 diabetes, as well as mental health issues, such as anxiety and depression.

To learn more, click the red button below.

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Understanding Chronic Sorrow

There is sneaky grief and loss that caregivers of children with mental illness experience. Chronic sorrow, as it has been called, is "ambiguous, one that rarely subsides over time, and is rarely acknowledged." As a caregiver of children who have struggled with mental illness, I have learned to celebrate the joy and stay in deep gratitude for healthy times, yet there is a constant dull ache that persists, and chronic sorrow gives this a name for me. In my professional role, I have listened as chronic sorrow creates an additional barrier for caregivers, complicating the stress and anxiety of caring for their children.

To learn more, click the red button below.

[LEARN MORE](#)



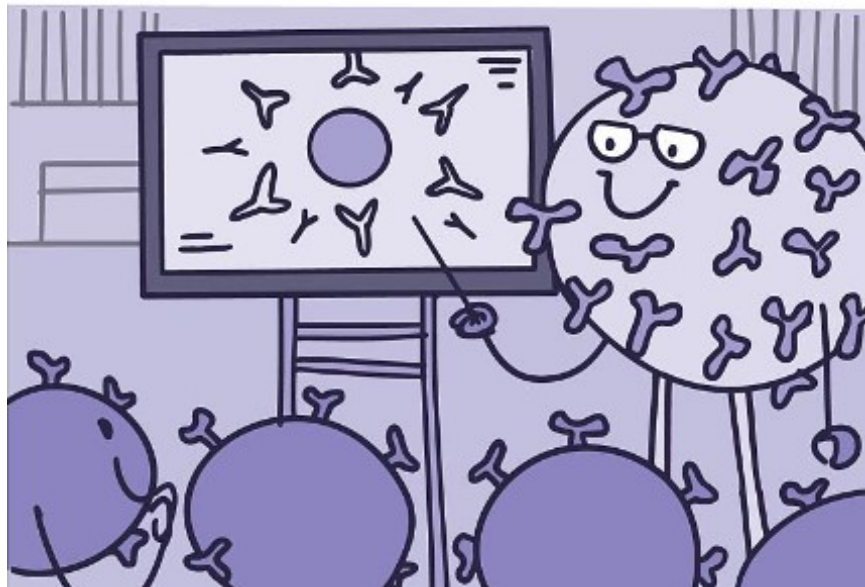
Blood Test for Early Alzheimer's Detection

One of the first stages of Alzheimer's disease involves formation of toxic aggregates, called oligomers, of the protein amyloid beta ($A\beta$). These oligomers can start to form more than a decade before symptoms appear and before other known disease markers form. The ability to detect these oligomers would permit early disease diagnosis. This would make strategies to intervene before irreparable brain damage occurs possible.

To learn more, click the red button below.

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Your Body's Disease Defenses

Every day while you eat, sleep, work, and play, battles are being fought throughout your body. You rarely feel it. But bacteria, viruses, and other microbes are constantly invading from the outside world.

Your body has a defense system for such invaders. It's called the immune system. Your immune system is made up of trillions of cells and proteins. These are found in your blood and every organ of your body. The immune system learns and changes over your lifetime—even before birth.

To learn more, click the red button below.

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Adapting Activities for People With Alzheimer's Disease

Doing things we enjoy gives us pleasure and adds meaning to our lives. People with Alzheimer's disease need to be active and do things they enjoy. However, it's not easy for them to plan their days and do different tasks.

People with Alzheimer's may have trouble deciding what to do each day, which could make them fearful and worried or quiet and withdrawn, or they may have trouble starting tasks. Remember, the person is not being lazy. He or she might need help organizing the day or doing an activity.

To learn more, click the red button below.

[LEARN MORE](#)



Long-Distance Caregiving: Twenty Questions and Answers

If you live an hour or more away from a person who needs care, you can think of yourself as a long-distance caregiver. This kind of care can take many forms—from helping with finances or money management to arranging for in-home care, from providing respite care for a primary caregiver to creating a plan in case of emergencies.

Many long-distance caregivers act as information coordinators, helping aging parents understand the confusing maze of new needs, including home health aides, insurance benefits and claims, and durable medical equipment.

The National Institute on Aging offers a booklet *Long-Distance Caregiving: Twenty Questions and Answers* intended to serve as a gateway to ideas and resources that can help make long-distance caregiving more manageable and satisfying.

To learn more, click the red button below.

[VIEW THE BOOKLET](#)





Healthy Eating and Alzheimer's Disease

Eating healthy foods helps everyone stay well. It's even more important for people with Alzheimer's disease.

When the person with Alzheimer's disease lives with you:

- Buy healthy foods such as vegetables, fruits, and whole-grain products. Be sure to buy foods that the person likes and can eat.
- Give the person choices about what to eat—for example, “Would you like green beans or salad?”
- Buy food that is easy to prepare, such as premade salads and single food portions.

To learn more, click the red button below.

[LEARN MORE](#)



Changes in Intimacy and Sexuality in Alzheimer's Disease

Alzheimer's disease can cause changes in intimacy and sexuality in both a person with the disease and the caregiver. The person with Alzheimer's may be stressed by the changes in his or her memory and behaviors. Fear, worry, depression, anger, and low self-esteem (how much the person likes himself or herself) are common. The person may become dependent and cling to you. He or she may not remember your life together and feelings toward one another. The person may even fall in love with someone else.

To learn more, click the red button below.

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End-of-Life Care for People With Dementia

People often live for years with dementia. While it can be difficult to think of these diseases as terminal, they do eventually lead to death. Caregivers often experience special challenges surrounding the end of life of someone with dementia in part because the disease progression is so unpredictable. Below are some considerations for end-of-life care for people with dementia.

To learn more, click the red button below.

LEARN MORE



Tips for People With Dementia

People with dementia experience a range of symptoms related to changes in thinking, remembering, reasoning, and behavior. Living with dementia presents unique challenges, but there are steps you can take to help now and in the future.

Alzheimer's disease and related dementias get worse over time. Even simple everyday

activities can become difficult to complete. To help cope with changes in memory and thinking, consider strategies that can make daily tasks easier. Try to adopt them early on so you will have more time to adjust.

To learn more, click the red button below.

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Getting Help with Alzheimer's Caregiving

Some caregivers need help when the person is in the early stages of Alzheimer's disease. Other caregivers look for help when the person is in the later stages of Alzheimer's. It's okay to seek help whenever you need it.

As the person moves through the stages of Alzheimer's, he or she will need more care. One reason is that medicines used to treat Alzheimer's disease can only control symptoms; they cannot cure the disease. Symptoms, such as memory loss and confusion, will get worse over time.

Because of this, you will need more help. You may feel that asking for help shows weakness or a lack of caring, but the opposite is true. Asking for help shows your strength. It means you know your limits and when to seek support.

To learn more, click the red button below.

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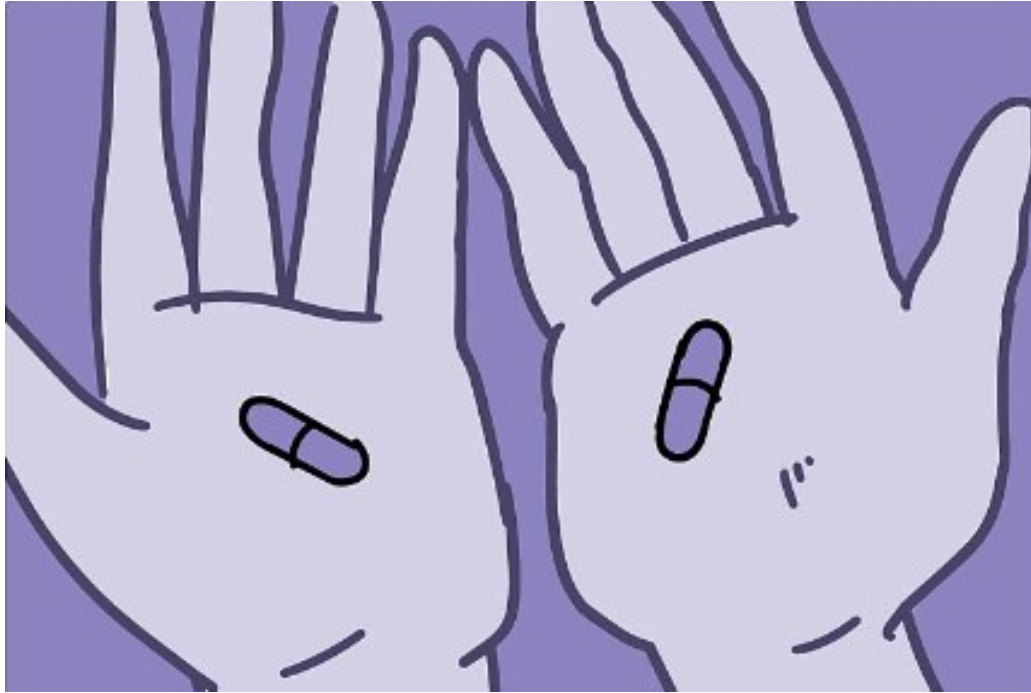


Worry Less and Age Better with BenefitsCheckup

BenefitsCheckUp is the nation's most comprehensive online tool to connect older adults and people with disabilities to benefits. This tool can make it easy to see if you may be eligible—and then help you find out where to apply online or how to get help from a benefits counselor. Answer questions anonymously to find out if you may be eligible for key benefits programs, including the Supplemental Nutrition Assistance Program (SNAP), Medicare Savings Programs, Medicaid, Medicare Part D Low Income Subsidy (LIS) - Extra Help, among others.

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

[LEARN MORE](#)



The Powerful Placebo

If you're feeling unwell, you may turn to medicine to find relief. But how do you know it was the drug that made you feel better? Sometimes, when you expect a treatment to work, it will. This phenomenon is called the placebo effect. Scientists are looking for ways to harness this effect for medical treatments.

To learn more about the placebo effect, click the red button below.

[LEARN MORE](#)



Bathing, Dressing, and Grooming:

Alzheimer's Caregiving Tips

At some point, people with Alzheimer's disease will need help bathing, combing their hair, brushing their teeth, and getting dressed. Because these are private activities, people may not want help. They may feel embarrassed about being naked in front of caregivers. They also may feel angry about not being able to care for themselves.

Click the red button below for suggestions for caregivers who help provide everyday care for individuals with Alzheimer's.

[LEARN MORE](#)



How Family Caregivers Can Help When Personal Hygiene Is a Problem

Pamela Toto's 102-year-old client had a problem: She was able to live alone, with help from her son, but getting in and out of her shower, where she had a chair and a handheld nozzle, was too difficult.

So, Toto, an occupational therapist, showed the son how to safely help his mother into her shower chair.

But, Toto says, "they didn't do it." She learned why in a talk with the son: "He said, 'I do everything for my mom, but I just don't want to see her naked.'" Toto helped the pair find a solution: a wrap-around towel robe the woman already had that she could wear on the way into and out of the shower.

It was a good illustration, Toto says, of the challenges, both practical and emotional, that caregivers and care recipients face when someone needs help with showering, using the toilet or other intimate hygiene tasks.

To learn more, click the red button below.

[LEARN MORE](#)





How Caregivers Can Counter Family Gaslighting

Intentionally misleading someone to believe something that isn't true is often called gaslighting, named for the Alfred Hitchcock–directed 1944 movie *Gaslight*, in which a devious husband uses trickery and deception to manipulate his gullible wife into thinking she's losing her mind. The term has become part of common parlance in our polarized age of decreased trust in institutions and one another.

People may feel gaslit by friends who are warm and supportive to their faces but bad-mouth them behind their backs; when caught, the gaslighter will say the person is crazy that they thought the comments were about them. An employee may complain of being gaslit by a boss who promises an increased bonus for working longer hours and then reneges, denying having made such a claim. And caregivers may feel gaslit by other family members who deliberately twist the truth about a care receiver's needs or the caregiver's responsibilities, to increase that caregiver's sense of duty and guilt.

To learn more, click the red button below.

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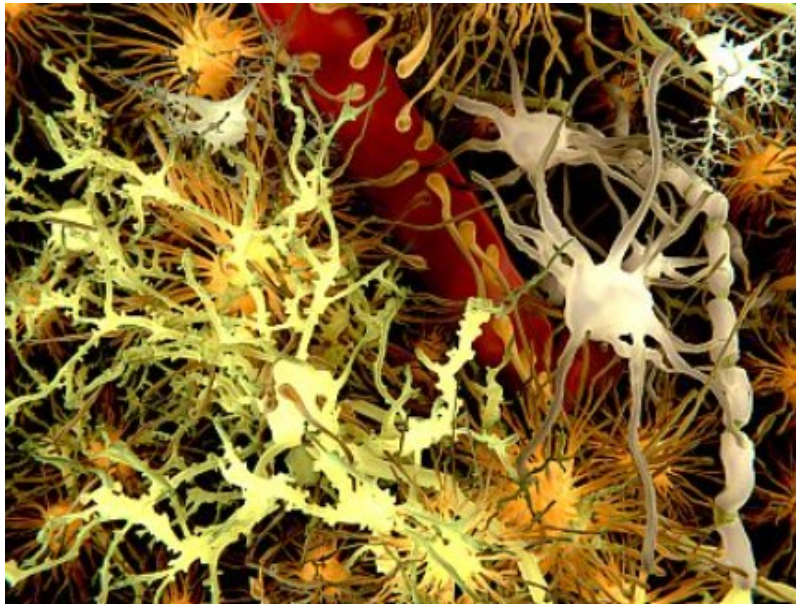


Does Exercise Really Help Aging Brains? New Study Raises Questions

Exercise and mindfulness training did not improve older people's brain health in a surprising [new study](#) published this week in JAMA. The experiment, which enrolled more than 580 older men and women, looked into whether starting a program of exercise, mindfulness — or both — enhanced older people's abilities to think and remember or altered the structure of their brains.

To learn more, click the red button below.

LEARN MORE



Alzheimer's Tied to Cholesterol, Abnormal Nerve Insulation

The protein apolipoprotein E (APOE) plays a key role throughout the body. It helps to transport cholesterol and other fatty molecules, or lipids. The gene that produces APOE comes in a few different varieties. The most common is called APOE3.

The most notorious is APOE4, which has long been linked to an increased risk of dementia in Alzheimer's disease. People who inherit one copy of the APOE4 gene have up to a fourfold greater risk of developing Alzheimer's disease dementia.

To learn more, click the red button below.

LEARN MORE



Vascular Dementia: Causes, Symptoms, and Treatments

Vascular dementia refers to changes to memory, thinking, and behavior resulting from conditions that affect the blood vessels in the brain. Cognition and brain function can be significantly affected by the size, location, and number of vascular changes.

People with vascular dementia almost always have abnormalities in the brain that can be seen on MRI scans. These abnormalities can include evidence of prior strokes, which are

often small and sometimes without noticeable symptoms. Major strokes can also increase the risk for dementia, but not everyone who has had a stroke will develop dementia.

To learn more, click the red button below.

[LEARN MORE](#)



What Are the Signs that an Aging Parent Needs Help?

When caring for an aging parent or relative from afar, it can be hard to know when your help is needed. Sometimes, your parent will ask for help. Or, the sudden start of a severe illness will make it clear that assistance is needed. But, when you live far away, some detective work might be necessary to uncover possible signs that support or help is needed.

To learn more, click the red button below.

[LEARN MORE](#)



Can a Hobby Keep Dementia at Bay? Experts Weigh In

To many, the word “hobby” signifies something lightweight or trivial. Yet taking on a new hobby as one ages might provide an important defense against dementia, some experts say.

About 5.8 million adults over 65 in the United States live with Alzheimer’s disease or other dementia disorders, according to the Centers for Disease Control and Prevention. One in 9 Americans over 65 has Alzheimer’s, according to the Alzheimer’s Association. And although the rate of dementia may be falling thanks to lifestyle changes, more of us are living longer, which means the societal burden of dementia is rising.

To learn more, click the red button below.

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Know Your Rights: Caregivers and Nursing Home Debt

Helping someone you love to move into a nursing home can be stressful enough. Nursing homes should not try to make you personally responsible for a loved one’s bill as a condition of admission.

To learn more, click the red button below.

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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. Alzheimers.gov has provided a set of tips and resources for finding

assistance in your local area.

To learn more, click the red button below.

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Caring for the Caregivers is Part of Optimal Age-Friendly Care

Recently, the Institute for Healthcare Improvement has deepened its commitment to supporting caregivers of older adults. The John A. Hartford Foundation has provided funding for Rush University Medical Center to partner with IHI on the Caregiver Intervention (4Ms-CGI) program, which has two goals: 1) transform how the staff of health systems think about and interact with family caregivers; and 2) provide programs and services for family caregivers to address their own needs and help them provide a reasonable amount of care for the older adult in their lives.

To learn more, click the red button below.

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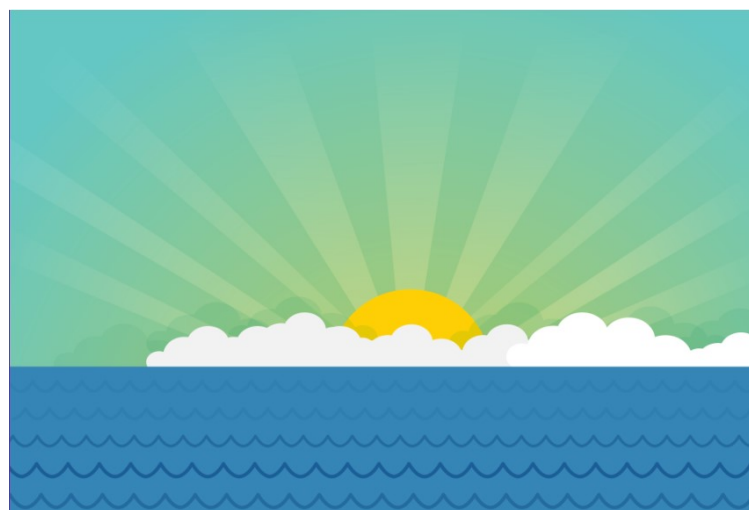


When Should Family Caregivers Apply for Medicaid for a Loved One?

Imagine your parent or spouse has had a fall or a stroke and is hospitalized. Usually, the following days and weeks are spent getting him or her stable, talking to family and doctors, and wrapping your mind around the incident that happened. It can be a shocking and overwhelming time. Often, these events are the beginning of a major life shift where the family has to come to terms with a loved one's changing needs and abilities. Where will he live? Who will take care of him? Do we have the [right documents in place](#) or do we need to go to court for assistance? And who's going to [pay for everything](#)?

To learn more, click the red button below.

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Religious and Spiritual Beliefs and Health Care

Religious and spiritual beliefs can offer support and meaning to those coping with health challenges. Because these beliefs may impact medical decision-making, health care providers are generally encouraged to ask patients about their faith background. In July 2022, the University of Michigan National Poll on Healthy Aging asked a national sample of adults age 50–80 about their religious and spiritual beliefs and how those beliefs may influence their health care decisions.

Most adults age 50–80 (84%) said that religious and/or spiritual beliefs are important to them, with 71% reporting their religious beliefs are important to them (45% very important,

26% somewhat important), and 80% stating their spiritual beliefs are important to them (50% very important, 30% somewhat important).

To learn more, click the red button below.

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Adapting Activities for People With Alzheimer's Disease

Doing things we enjoy gives us pleasure and adds meaning to our lives. People with Alzheimer's disease need to be active and do things they enjoy. However, it's not easy for them to plan their days and do different tasks.

People with Alzheimer's may have trouble deciding what to do each day, which could make them fearful and worried or quiet and withdrawn, or they may have trouble starting tasks. Remember, the person is not being lazy. He or she might need help organizing the day or doing an activity.

To learn more, click the red button below.

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Transcript: Across the Aisle with Seth Rogen and Laura Miller Rogen

Actor Seth Rogen and filmmaker Lauren Miller Rogen spoke with the Washington Post's Leigh Ann Caldwell on December 8th to discuss for a conversation with the couple about how their personal experiences as caregivers have informed their advocacy and the prospects for bipartisan cooperation on the issue in the new Congress.

To view the transcript of the chat, click the red button below.

[VIEW THE TRANSCRIPT](#)



New Resources in Search. Find. Help. for Older Adults and Caregivers during Emergencies

The purpose of Search. Find. Help. is to help leaders and staff of organizations serving community-dwelling older adults and their caregivers find resources they can use to support these populations during all types of public health emergencies, including disease outbreaks like COVID-19, natural disasters, and severe weather.

The site includes resources addressing social isolation, managing chronic conditions, elder abuse and neglect, caregiver support, delayed medical care, and emergency preparedness.

Search. Find. Help. has been updated with **over 60 new resources** to support older adults during other public health emergencies such as natural disasters and severe weather with a focus on disproportionately affected populations, including Tribal populations and people with disabilities.

NORC at the University of Chicago has provided an action plan to help organizations select, adapt, and implement programs to meet the needs of their communities. To view the action plan click the red button below.

[VIEW THE ACTION PLAN](#)



the Playbook

*Better Care for People
with Complex Needs*

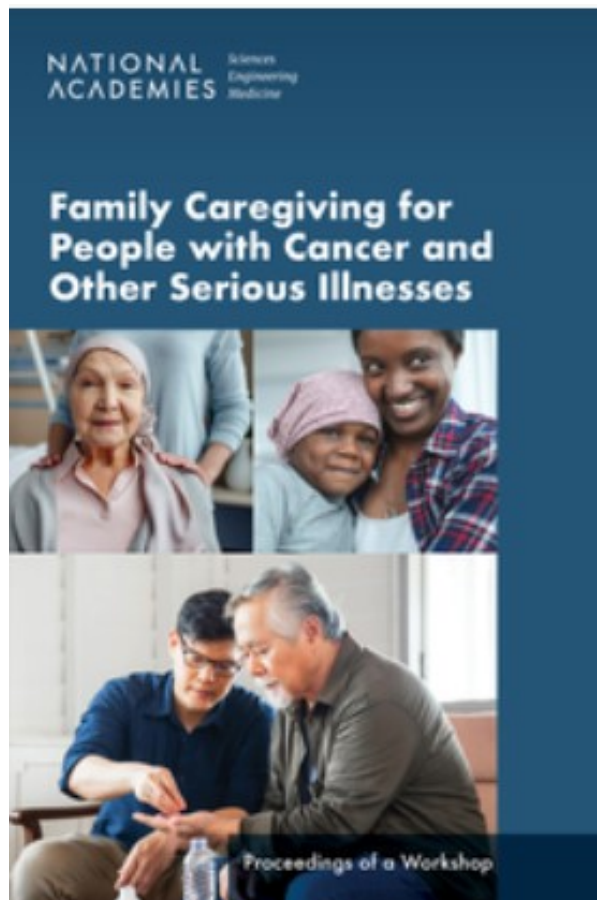
The Hurdles Facing Black Families Navigating Serious Illness -- Podcast

Serious illnesses like cancer and kidney failure are painful for patients and hard on their caregivers. Services like hospice and palliative care exist to support families and ensure their loved ones live easier lives and die more comfortable deaths. But data show Black individuals are less likely to have their pain treated and less likely to use hospice and palliative care.

In this Tradeoffs podcast episode from November 10, 2022 — the latest in a series made possible by the Better Care Playbook — a researcher details ways to make this care more equitable and a caregiver shares her family's journey navigating a serious illness.

To listen the podcast, click the red button below.

LISTEN TO THE PODCAST



Family Caregiving for People with Cancer and Other Serious Illnesses: A Workshop

On May 16 and 17, 2022 the Roundtable on Quality Care for People with Serious Illness, the National Cancer Policy Forum and the Forum on Aging, Disability and Independence will host a collaborative public workshop that will examine opportunities to better support family caregiving for people with cancer or other serious illnesses.

The proceedings summarize presentations and discussions from the May 2022 workshop, which was hosted by the Roundtable on Quality Care for People with Serious Illness, the National Cancer Policy Forum and the Forum on Aging, Disability, and Independence. To view the archived videos and presentations, please see the project [Webpage](#).

To view the workshop's proceedings, click the red button below.

[VIEW THE PROCEEDINGS](#)



Grandfamilies and Kinship Support Network: A National Technical Assistance Center

The Grandfamilies & Kinship Support Network is the first-ever national technical assistance center for those who serve grandfamilies and kinship families. The Network exists, free of charge, to offer a new way for government agencies and nonprofit organizations in states, tribes, and territories to collaborate and work across jurisdictional and systemic boundaries—all to improve supports and services for grandfamilies and kinship families. Our work is rooted in cultural competence and linguistically appropriate approaches and is fully accessible to people with disabilities.

The Grandfamilies & Kinship Support Network will create lasting change for families around the country by connecting and supporting:

- Policy and program leaders at government agencies in states, tribes, and territories within aging/elder/senior services, child welfare, disability, education, housing, nutrition, Medicaid and Medicare, and Temporary Assistance for Needy Families (TANF);
- Kinship navigators; and
- Leaders of nonprofit, community-based, and faith-based organizations focused on supporting grandfamilies and kinship families.

To learn more about the Grandfamilies & Kinship Support Network, click the red button below.

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What Do We Know About Healthy Aging?

Many factors influence healthy aging. Some of these, such as genetics, are not in our control. Others — like exercise, a healthy diet, going to the doctor regularly, and taking care of our mental health — are within our reach. Research supported by National Institute on Aging and others has identified actions you can take to help manage your health, live as independently as possible, and maintain your quality of life as you age. Read on to learn more about the research and the steps you can take to promote healthy aging.

To learn more, click the red button below.

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Caregiving After Cancer Treatment Ends

Many factors influence healthy aging. Some of these, such as genetics, are not in our control. Others — like exercise, a healthy diet, going to the doctor regularly, and taking care of our mental health — are within our reach. Research supported by National

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To learn more, click the red button below.

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Legal and Financial Planning for People with Dementia

Many people are unprepared to deal with the legal and financial consequences of a serious illness such as Alzheimer's disease or a related dementia. Legal and medical experts encourage people recently diagnosed with a serious illness — particularly one that is expected to cause declining mental and physical health — to examine and update their financial and health care arrangements as soon as possible. Basic legal and financial documents, such as a will, a living trust, and advance directives, are available to ensure that the person's late-stage or end-of-life health care and financial decisions are carried out.

To learn more, click the red button below.

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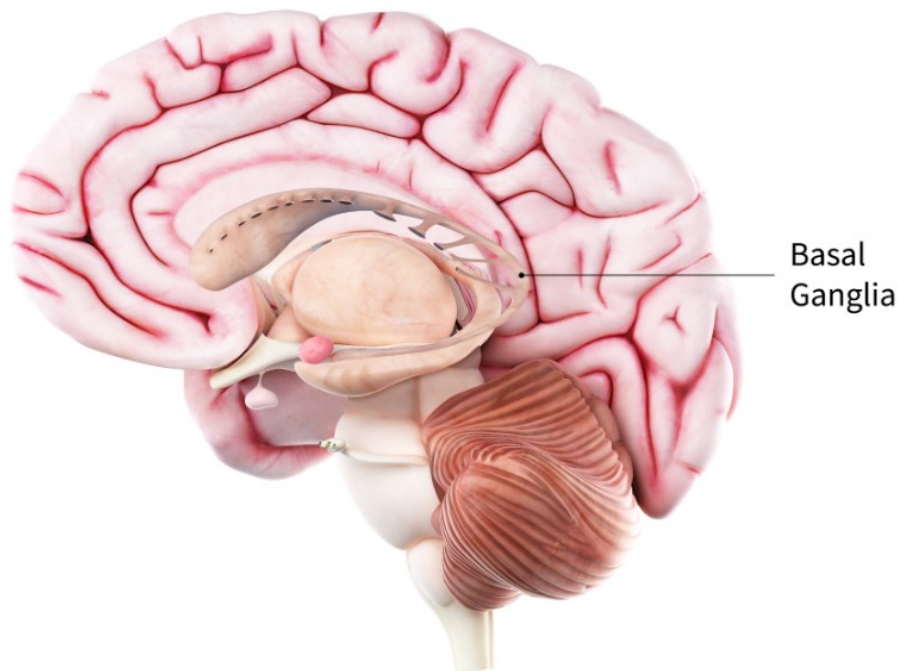


I Am Not Alone Care Alliance

ianacare, the market leader in family caregiver benefits, is now forming the “I Am Not Alone Care Alliance” to create a full infrastructure of support across all sectors. They have galvanized key leaders and influencers from Fortune 500 companies, digital health, public sectors, and HR & benefits communities to lead the conversation and shape the future of caregiving resources. Designed for action and launched during National Family Caregivers Month, the I Am Not Alone Care Alliance will change the way public and private sectors work together to amplify the voice of millions of family caregivers and to fill the gaps - so no caregiver does this alone.

To learn more, click the red button below.

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Parkinson's Disease: Causes, Symptoms, and Treatments

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. As the disease progresses, people may have difficulty walking and talking. They may also have mental and behavioral changes, sleep problems, depression, memory difficulties, and fatigue.

To learn more, click the red button below.

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Support for Families When a Child Has Cancer

When a child has cancer, every member of the family needs support. Parents often feel shocked and overwhelmed following their child's cancer diagnosis. Honest and calm conversations build trust as you talk with your child and his or her siblings. Taking care of yourself during this difficult time is important; it's not selfish. As you dig deep for strength, reach out to your child's treatment team and to people in your family and community for support.

To learn more about long-term care, click the red button below.

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