# THIS WEEK IN CAREGIVING



March 15, 2023



## CAREGIVING IN THE NEWS

## Companies Enhance Benefits to Help Employees Balance Their Work and Caregiving Demands

Sinem Buber is a labor economist at ZipRecruiter. She's reviewed the data on how lack of affordable care options is affecting the U.S. labor force. She's seen 1.2 million fewer women show up in the workforce data since the pandemic started, in part due to child-care issues.

And as the mother of two boys, now ages 4 and 6, she's also lived it firsthand, especially when her children, as well as those of her colleagues, were sick this winter.

"I had to work during the night, [which is] when my other colleague can work, after his son goes to sleep," said Buber. "So it was really a hard time for us to go through this winter."

From: CNBC | Published: March 9, 2023

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#### New AARP Report Finds Family Caregivers Provide \$600 Billion in Unpaid Care Across the U.S.

Just two hours per week is all the time that family caregiver Ayda Beltré devotes to herself.

That's on Sundays when she goes to church and must leave her 86-year-old dad, Eugenio, alone. Eugenio is bedridden with a few ailments and has been on oxygen since COVID-19 hit the family in February. Beltré can't afford the high costs of weekend caregiving help.

From: AARP | Published: March 8, 2023

#### Childhood Leukemia: Two Moms Share What They've Learned About Caregiving

Leukemia is the most common cancer diagnosed in young people under age 20, and makes up just over 25 percent of cancer cases in this age group, according to the Leukemia and Lymphoma Society. What's more, the American Cancer Society states that around 3 out of 4 cases of leukemia diagnosed in children are acute lymphocytic leukemia (ALL), which has a survival rate of about 90 percent.

Still no family expects to find themselves grappling with this situation.

From: Everyday Health | Published: March 13,

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## NAC NEWS AND UPDATES

2023



## 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** 

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

Sponsored by Travere 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** 



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. <a href="Assessing the Pain of Care Recipients: Tools Available to Family Caregivers">Assessing the Pain of Care Recipients: Tools Available to Family Caregivers</a> 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



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**



#### **How to Handle Uncertainty**

March 15, 2023 | 11:00 AM - 12:00 PM ET | Online

Caregivers often experience a series of common emotions in the process of providing care. When we don't address these emotions, they can impact upon our physical and mental health.

One thing for certain is that being a caregiver comes with a lot of uncertainty! It's hard to know what's around the corner and how to plan for the unknown.

Tune in on March 15th for an interactive session hosted by WellMed Charitable Foundation that will address ways to cope with the uncertainty that caregivers all feel at times. It will include a forum on how to make informed decisions as a caregiver.

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





## U.S. and U.K. Celebrate Caregiving Youth Action Day on March 15th

March 15, 2023 | 6:00 PM - 8:00 PM ET | Online

The American Association of Caregiving Youth (AACY), in collaboration with the Carers Trust in the U.K and U.S. partners, are jointly celebrating a day of recognition on March 15 for those in the U.S. known as Caregiving Youth.

A free Zoom event will be hosted by AACY from 6:00 PM to 8:00 PM (Eastern time) on March 15th, 2023.

One Zoom guest will be Daniela Castro-Martinez who is now a freshman at Stanford University. For several years she provided care for her mother who had ALS. Another featured guest is Andy McGowan of the UK where he heads policy for Young and Young Adult Carers there through its Carers Trust and founded the Young Carers Alliance, a network of over 150 organizations and 300 individuals. Kaylin Jean-Louis, a teen caregiver of Tallahassee will also participate – she is an award-winning Caregiving Youth who has her own website and podcast.

The Zoom will conclude with several exciting announcements for future participation.

Registration is required to attend this event. To register, send an email to Autumn Rogers at AACY by clicking on the red button below.

**REGISTER** 

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#### 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 16<sup>th</sup> (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.



#### 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 >



#### 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: <a href="www.nia.nih.gov/2023-dementia-care-summit">www.nia.nih.gov/2023-dementia-care-summit</a>

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



#### **Black Feathers Live**

March 21, 2023 | 3:00 PM to 4:30 PM ET | Online

In celebration of Developmental Disabilities Awareness Month, the Black Feathers Podcast will be putting on a live show in collaboration with the National Association of Councils on Developmental Disabilities (NACDD).

The <u>Black Feathers Podcast</u> is a product of the The State of the States in Intellectual and Developmental Disabilities Project of National Significance funded through ACL and produced in collaboration with the Kansas University Center on Developmental Disabilities (KUCDD). Podcast episodes are posted on the Black Feathers Podcast website. Special guests include Sarah Young Bear-Brown from the Sac and Fox Tribe of the Mississippi in Iowa, Cheryl and Kody Funmaker of the Ho-Chunk Nation in Wisconsin, and Darold H. Joseph of Paa-Is-wung-wa (Water Coyote Clan) from the Hopi Village of Lower Moenkopi.

Email <u>stateofthestates@ku.edu</u> with any questions about the event or accommodation needs.

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



## Supporting a Loved One with Schizophrenia: CAT for Families

March 21, 2023 | 6:30 PM to 8:30 PM ET | Online

Cognitive Adaptation Training (CAT) is a practical, evidence-based approach for families and caregivers of adults living with schizophrenia. In this interactive workshop you will gain strategies and tools to help your loved one build independence in taking care of themselves, their spaces, and participating in their communities.

#### Our presenter:

Erin AuCoin (she/her) is a Registered Occupational Therapist working in the Cognitive Adaptation Training (CAT) service at the Centre for Addiction and Mental Health. In her 5 years as an OT, Erin's work has focused on empowering individuals experiencing complex mental health issues to lead more independent and rewarding lives by enabling engagement with their daily activities and communities. Erin currently supports individuals in both inpatient and outpatient settings to work toward their recovery goals and building independence through CAT, and facilitates various education sessions to support its implementation throughout the hospital.

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



#### **Understanding Older Adult Abuse: For Caregivers**

March 22, 2023 | 10:00 AM - 11:00 AM ET | Online

Join Yellow Brick House on March 22nd for a workshop that will examine what abuse is, its types, and how to identify it. Attendees will be provided with information about ageism, self-care tips and support resources for caregivers. Intended audience: caregivers of older adults.

To register for this event, 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.

REGISTER >



#### **Tools for Better Transitions Between Hospital and Home**

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

Transitioning between hospital and home can be stressful for family caregivers and their care recipients. In partnership with Ontario Health, this webinar provides caregivers with information, resources, and tools to support patient transitions between hospital and home. We will hear lived experiences from two caregivers, and Dr. Karen Okrainec, a Clinician-Scientist and Assistant Professor at University Health Network and the University of Toronto. Dr. Okrainec will showcase the Patient Oriented Discharge Summary (PODS) tool, designed to alleviate stress for patients and their caregivers during transitions.

Webinar participants will learn how to:

- Understand the importance of seamless, fully coordinated transitions between hospital and home
- Use the quality standard and patient guide to support conversations with health care providers on a written transition plan, medications, home and community care, medical equipment and devices, follow-up appointments, and possible changes to your routine at home
- Identify tools and resources that can help support families and caregivers through the transition process

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



#### **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.



#### **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.

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#### **Geriatric Mental Health Among African Americans**

March 24, 2023 | 12:00 PM - 4:30 PM ET | Online

This course will present core concepts of geriatric mental health but will do so with an emphasis on older adults of African-American and Caribbean-American background. There will be some discussion of approaches to mental illness, particularly anxiety disorders, depression, and psychotic disorders. There will be some exploration of cognitive disorders and substance use disorders as well. Special attention will be paid to elder abuse and support for caregivers.

#### Measurable Learning Objectives:

- Describe five core concepts of psychopharmacology for elders.
- List five signs of cognitive impairment.
- Identify three assessment tools that can help clinicians assess mental health conditions.
- Describe four ways to address elder abuse.
- Identify four factors that can impact outcomes of depression in Black elders.

#### About the Presenter:

Karinn Glover, MD, MPH, Assistant Professor of Psychiatry and Behavioral Sciences at Albert Einstein College of Medicine and Attending, Adult Outpatient Psychiatry Division, Montefiore Hospital, Bronx NY. Currently Assistant Professor of Psychiatry at the Albert Einstein College of Medicine, Dr. Glover teaches psychopharmacology and aspects of psychotherapy to Psychiatry and Family Medicine residents. Her decade-plus experience as a psychiatrist and leader in the primary care division at Montefiore Health System has informed her approach to health equity, Diversity, Equity, Inclusion and Belonging (DEI+B), and the styles of leadership that produce organizational success.

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

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### Sarcoma Patient and Caregiver Education Program





#### 2023 Sarcoma Patient and Caregiver Education Program

March 25, 2023 | 12:30 PM - 4:00 PM ET | Online

Fred Hutchinson Cancer Center is hosting a free, virtual patient education event for sarcoma patients and caregivers, in partnership with the Northwest Sarcoma Foundation and Sarcoma Foundation of America. During the event, providers will talk about:

- · Introduction to sarcoma,
- · Updates to radiation for treating sarcoma,
- Genetic testing,
- · Supportive care for patients with sarcoma, and
- · Information on rehab medicine and survivorship.

This event is open to Fred Hutch and/or UW Medicine as well as external patients and their caregivers.

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

**REGISTER** 

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#### **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.

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#### **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.

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# Life Lessons from Two Accidental Caregivers

## Life Lessons from Two Accidental Caregivers: *A*Caregiver's Journey with Lizanne Ryan and Proud and Out Loud with Marie Moliner

March 29, 2023 | 1:30 PM - 4:30 PM ET | Online

Lizanne Ryan will read from her manuscript, A Caregiver's Journey. Marie Moliner will speak about the process of caregiving which she refers to as Proud and Out Loud.

Each of our guests will present their ideas and experiences and read from their writing. There will be an opportunity for questions, discussions, and reflections.

Lizanne Ryan's career was in the field of Adult Education working in both community and academic environments from 1970 to 1997. She retired to look after her husband who was struck with ALS. Her decision to care for him in the home led her to become completely absorbed in his care. It took her five years to recover from the experience. She had not known how to take care of herself. Twenty years later, she has written her memoir, *A Caregiver's Journey*, culled from her journal writings. In sharing her journey, she hopes to help caregivers gain an understanding of the value of self-care and how they can apply it to their situation.

Marie Moliner is a full-time caregiver for Kevin Whitaker, her true love who has Parkinson's and dementia. She is tackling this role out loud and proud. In her spare time, she is writing *Divine Dementia: Diaries of an Accidental Caregiver* and volunteers as assistant editor for The Townships Sun. Before she retired at 55 to look after Kevin, she was a lawyer, public servant, and volunteered widely including a decade as a police commissioner for the Toronto Police Services Board, and Chair of the Centre for Social Innovation (CSI). In her spare time she joyfully pounds clay into useless objects.

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

REGISTER

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#### **Young Onset Dementia**

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

Join the <u>Alzheimer Society of Durham Region</u> (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.



#### **Making 'Cents' of Caregiving Costs**

March 30, 2023 | 12:00 PM - 1:00 PM ET | Online

In this informative session, you'll be introduced to essential information caregivers need to know to more easily manage the costs and complexities of caregiving - on creating a health care plan, choosing a power of attorney and budgeting for housing and transportation costs, for example. AARP's Financial Workbook for Family Caregivers will be reviewed, we'll explore how to incorporate the financial tips into your caregiving, and additional resources will be provided.

By the end of the session, we hope you have the confidence to make your own plans, as well as understand how to best plan for your care recipient. The presentation, part of a multi-event Financial Resilience series from AARP Massachusetts, will be given by a trained AARP volunteer and will include time for Q&A.

#### **How to Join**

You will need to register separately for each class you are interested in attending. Please note that you must be signed in to your AARP.org account or create an account to register for events. AARP membership is not required to create an account. Please do not opt out of event-related email, as you will be emailed a link to join the presentation via Zoom prior to the event.

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

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#### **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.

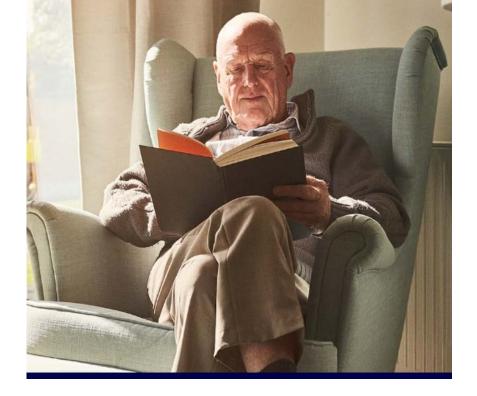
Whilst hospices are regarded as providers of gold-standard care for people requiring endof-life support, health care professionals working in these settings rarely receive dementia training and examples of evidence-based practices are currently lacking. More research is needed to investigate the experience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

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#### **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 ET) 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.

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## Home Care, Palliative Care, and Hospice: Making the Right Choice

April 10, 2023 | 10:00 AM - 11:00 AM ET | Online

When caring for a loved one requires more than we can do on our own, we need to know what services are out there to help us. In this workshop we will review the options available at all stages of illness, how they differ and how to know which one is the right choice for your loved one.

This workshop is part of a series 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.

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## Childhood Trauma: Secondary Traumatic Stress in Caregivers

April 10, 2023 | 1:00 PM - 2:00 PM ET | Online

Supporting children who have experienced trauma can affect our own mental health and

can lead to secondary traumatic stress. Learn how to safeguard yourself from emotional exhaustion & explore ways to manage stress reactions when helping children cope with their trauma. Sponsored by Polk County Iowa's Behavioral Health & Disability Services agency.

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

About the instructor: Susan Dannen is a Licensed Independent Social Worker with over 25 years of experience in the mental health field. Susan trained at Jane Addams College of Social Work, University of Illinois Chicago for her MSW and specializes in child and adult mental health, anxiety, depression, grief, trauma, play therapy, and foster care/adoption. She is passionate about educating and supporting others to find hope and healing.

Susan has held positions as an in-home therapist, day treatment therapist, school-based therapist, outpatient therapist, hospital/clinic therapist, program supervisor, and director. She has served as a trainer/writer for the Minnesota Child Welfare Training System, and as an Adjunct Professor at Adler Graduate School.

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





#### **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 <a href="mailto:caregiving@pitt.edu">caregiving@pitt.edu</a>.

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





#### **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 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



#### **Self-Care Course: Taking Care of Yourself**

April 18, 2023 | 1:00 PM - 2:00 PM ET | Online

Join the VA's Program of General Caregiver Support Services on April 18th for an online session about self-care for caregivers of Veterans.

Caregivers of Veterans who receive care from VA are eligible to attend. The course is presented to caregivers by virtual platforms or telephone access in their homes. The course is 2 hours in length and taught by a VA Caregiver Center Instructor. Everyone will receive a workbook to follow along during the presentation.

#### What You Will Learn:

- Healthy Eating and Recipes
- Protecting and Improving Your Physical Health
- Falling and Staying Asleep
- Protecting and Improving Your Emotional Health
- Caregiver Survival Tools
- How to Create a Personal Action Plan for Taking Care of You

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

REGISTER



## 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



#### **Helping Teens Heal from Trauma**

April 25, 2023 | 7:00 PM - 8:30 PM ET | Online

Trauma among teens is more common than you might believe. By the age of sixteen, approximately one-quarter (25%) of children and adolescents have experienced at least one traumatic event. As a caring adult, you have an important role to play in aiding them as they heal.

The effects of trauma can be debilitating, making it difficult for teens to cope with life's daily struggles. Adults can help by providing a safe, supportive environment and access to useful resources. With your help, teens can begin to heal from the trauma they have experienced and move forward in life.

Join Families for Depression Awareness on Tuesday, April 25, 2023, from 7:00 to 8:30 pm ET when Deborah Vinall, LMFT, Psy-D, defines trauma and discusses its impact on long-term wellness. She will also cover the signs of trauma in teens, effective treatment

approaches, and practical strategies that caring adults can use to encourage teen mental wellness.

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





#### 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. Tan 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.



MAY



## **Caregiver Mental Health: How to Reduce Anxiety for Better Living**

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

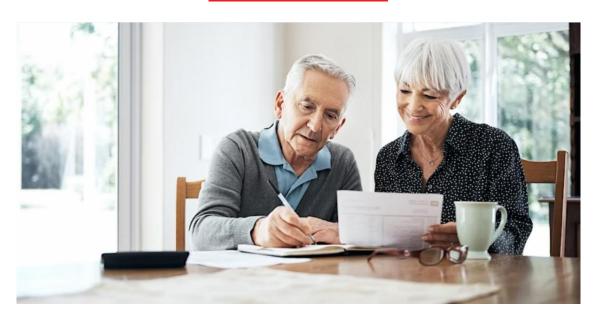
The caregiving role can bring forth many different feelings and emotions, and anxiety is one which can be problematic for those managing care. In observance of Mental Health Week this May, we welcome back Dr. Patrick McGrath to talk about:

- 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



**Advance Directives: What Families Should Know** 

#### May 8, 2023 | 10:00 AM - 11:00 AM ET | Online

Making medical decisions can be difficult when facing any illness. That is why an advance directive is so important to have. In this workshop we will discuss what advance directives are, who needs to have them and more.

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

REGISTER



#### **Dealing With Dementia**

May 23, 2023 | 5:00 PM - 9:00 PM ET | Online

Being a caregiver for a family member or friend with dementia comes with its own set of unique rewards and challenges. Hosted by the Rosalynn Carter Institute, the Dealing with Dementia workshop is here to provide insights and guidance on dementia and the caregiver journey. Participants will be mailed a free, comprehensive Dealing with Dementia guide designed specifically to help support caregivers.

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

REGISTER >

JUNE



**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 >

#### **PATIENT AND CAREGIVER STUDIES**

#### Pepinemab for Early-Stage Alzheimer's Disease

Start: July 22, 2021 End: February 28, 2024

Enrollment: 40

Who is sponsoring this study? Vaccinex Inc.

Where is this study located? Multiple states

#### What Is This Study About?

This Phase 1/2 study will assess the safety and effects of the experimental drug pepinemab, a monoclonal antibody treatment designed to improve memory, in older adults with early-stage Alzheimer's. Participants will be randomly assigned to receive either the

study drug or a placebo by IV infusion once a month for one year. Throughout the trial, participants will undergo PET and MRI brain imaging, complete memory tests, and provide blood and spinal fluid samples. Researchers will monitor all participants for safety and any side effects throughout the trial and one month after the last treatment.

#### Do I Qualify To Participate in This Study?

Minimum Age: 55 Years Maximum Age: 85 Years

#### Must have:

- Diagnosis of probable Alzheimer's with:
  - Global Clinical Dementia Rating of 0.5 or 1.0
  - Mini-Mental State Examination score of 17 to 26
- Must have either:
  - Positive amyloid PET scan before starting study
  - Positive amyloid cerebrospinal fluid test result before or at the study screening
- Availability of a study partner who has a close relationship with the participant and frequent in-person contact (> 3 times per week, for a minimum of 10 waking hours total per week)
- Female participants must be postmenopausal or surgically sterile
- Male participants must commit to a reliable method of birth control during the study and for six months after the last dose of the study drug
- Adequate vision, hearing, and physical function to complete study tests
- If taking medications for Alzheimer's, dosage must be stable for at least two months prior to the study screening visit
- If taking medication to manage heart rate or blood pressure, dosage must be stable for at least two months prior to the study screening visit
- Overall good physical health over the last six months, based on medical history and study screening evaluation

#### Must NOT have:

- Participation in another clinical trial for an experimental drug or medical device within one month prior to study screening; if experimental drug was an antibody therapeutic, must wait 180 days from the last treatment or long enough for the therapeutic to clear the body
- Known allergy to any ingredient in the study drug formulation
- Body weight greater than 275 pounds
- · Serious risk of suicide or suicide attempt in the past year
- History of substance abuse within one year prior to study screening
- Treatment with any FDA accelerated approval therapy for treatment of Alzheimer's
- Any unstable or uncontrolled medical illness or condition that could interfere with the study, including:
  - Serious infection, including a history of human immunodeficiency virus or acquired immunodeficiency syndrome, hepatitis B virus or hepatitis C virus infection at study screening
  - Serious blood, liver, heart, or kidney disease
  - Malignant cancer within two years of study screening (non-melanoma skin cancers, superficial bladder and prostate cancers are allowed)
- Diagnosis of a neurological condition causing cognitive impairment other than Alzheimer's, such as:
  - Non-Alzheimer's dementia (e.g., Lewy body dementia, frontotemporal dementia)
  - Psychiatric conditions that could cause cognitive impairment (e.g., schizophrenia)
  - · History of frequent concussions
- Any serious medical, laboratory, or behavioral abnormality at study screening, including:
  - Electrocardiogram abnormalities
  - MRI brain scan findings that indicate stroke, tumor, tangled blood vessels, swelling

- Any condition that could make undergoing an MRI or PET brain scan unsafe, including:
  - Claustrophobia or inability to lie on scanner bed for 45 minutes
  - Poor vein access
  - Metal shrapnel, pacemaker, presence of metal objects in eyes, skin, or heart
  - Body size and shape that prevents a comfortable fit in scanners
  - Prior radiation exposure that, when combined with study PET scan, would exceed radiation limits
- If undergoing a spinal tap, must not have:
  - Untreated bleeding or clotting disorders
  - Skin infections near spinal tap location
  - Increased brain pressure
  - Serious spinal injury
  - Allergies to numbing medications
  - Taking any of the following anticoagulant medications: coumarins and indandiones, Factor Xa inhibitors, heparins, or thrombin inhibitors

For more information about the study or to learn if it is being conducted in an area near you, click the red button below.



## Cannabidiol Oil for Agitation in People with Alzheimer's Disease

Start: February 26, 2021

End: March 2024 Enrollment: 40

Who is sponsoring this study? Eastern Virginia Medical School

Where is this study located? Virginia

#### What Is This Study About?

This Phase 2 study will evaluate the effectiveness of cannabidiol (CBD) oil to reduce agitation in people with Alzheimer's disease and lessen caregiver burden. Participants will be randomly assigned to take a capsule of CBD oil or placebo twice a day for six weeks and complete questionnaires during the 15-week study. Researchers will evaluate changes in agitation, aggression, and quality of life for the person with dementia, as well as caregiver burden. Researchers will also assess changes in other behavioral and psychological symptoms of dementia, cognitive function, and sleep quality.

#### Do I Qualify To Participate in This Study?

Minimum Age: 50 Years Maximum Age: 90 Years

#### Must have:

- Diagnosis of Alzheimer's disease or mixed dementia, in which Alzheimer's is combined with another type of dementia
- Mini-Mental State Exam score of 4-28
- Moderate to severe agitation/aggression with Neuropsychiatric Inventory test score for agitation/aggression > 3
- If taking cognition-enhancing medications (e.g., cholinesterase inhibitors and/or memantine), the dosage must be stable for at least one month prior to

- starting the study; or if discontinued, participation may begin after 15 days
- If taking antidepressants, the dosage must be stable within four weeks prior to group assignment and during the study
- If taking antipsychotics or benzodiazepines, the dosage must be stable for a week prior to group assignment and during the study
- Caregivers must either live with the participant or have a minimum of four hours of daily contact
- Fluent in English (reading, writing, and speaking)

#### **Must NOT have:**

- Any serious or unstable medical illness including heart, liver, kidney, respiratory, endocrine, neurologic, or blood disease
- Serious psychiatric disorders or neurological conditions (e.g., psychotic disorders, bipolar disorder, or schizophrenia)
- Current abuse of marijuana, alcohol, and/or other drugs
- Any seizure disorder
- Pregnant or breastfeeding
- Evidence of delirium
- Unable to swallow a soft gel pill
- Use of lithium, tricyclic antidepressants, fluoxetine, and/or carbamazepine
- History of hypersensitivity to any cannabinoid (e.g., marijuana)
- Frequent falling due to sudden low blood pressure when standing up from sitting or lying down
- · Living in a nursing home

For more information call David Elkins at (757)446-5675 or email him by clicking on the red button below.



## Tele-STELLA: Online Family Caregiver Program to Reduce Distressing Dementia Behaviors

Start: May 19, 2021 End: January 15, 2026

Enrollment: 300

Who is sponsoring this study? Oregon Health and Science University

Where is this study located? Oregon

#### What Is This Study About?

This study will test the effectiveness of Tele-STELLA, a videoconference-based caregiver education program, to help reduce upsetting behaviors related to dementia and improve caregiver well-being. Participants will participate in 16 weekly video conference classes, led by a professional guide, to learn how to manage challenging behaviors related to dementia. In the year following completion of the program, caregivers will complete online surveys about their emotions, coping skills, quality of life, and the behavior of their family member living with dementia.

#### Do I Qualify To Participate in This Study?

Minimum Age: 18 Years Maximum Age: N/A

#### Must have:

Person living with dementia:

- Diagnosis of moderate to late-stage Alzheimer's disease or a related dementia
- History of two or more behaviors listed on the Revised Memory and Behavior Problems Checklist that are upsetting to the caregiver and occur > three times per week

#### Caregiver:

- Relative, spouse, or close friend that is considered family, of a person living with dementia
- Provides care for at least four hours per week
- · Able to speak and understand English
- Owns a telephone (smartphone, cell phone, or landline)
- Has a mailing address to receive computer and study materials

#### **Must NOT have:**

Person living with dementia:

- Dementia not related to Alzheimer's or a related dementia disorder
- Unable to leave caregiver during the teleconference sessions
- Early-stage dementia

#### Caregiver:

- Unable to participate privately, without the care recipient, in the teleconference sessions
- Completed a similar telehealth program within the last year
- Serious hearing or vision problems that interfere with program participation

For more information call Allison Lindauer at (503)494-6976 or email her by clicking on the red button below



#### **Positive Emotion Skills Training for Family Caregivers**

Who is sponsoring this study? Northwestern University

Where is this study located? Illinois

Start: June 18, 2020 End: June 30, 2024 Enrollment: 500

#### What Is This Study About?

Practices that support positive emotions, such as joy and gratitude, can improve the ability to cope with stressful events and in turn improve well-being. In this study, dementia caregivers will participate in an online caregiver support program, called LEAF (Life Enhancing Activities for Family Caregivers), designed to teach caregivers positive emotion skills. The online program will be delivered to dementia caregivers in two ways, over five weeks. One group will be led by a trained facilitator and another group will complete the training activities independently. All participants will track and report their emotions daily. An evaluation of the two online program methods will be compared to emotions reported by participants placed on a waitlist for the study.

#### Do I Qualify To Participate in This Study?

Minimum Age: 18 Years Maximum Age: N/A

#### Must have:

- Primary caregiver of a family member with Alzheimer's Disease
- Speaks and reads English
- Access to high-speed internet connection at home or a another location which allows them to speak privately with a facilitator

For more information call Amanda Summers at (312)503-5247 or email her by clicking the red button below.



## Seeking Former Caregivers for the 'Learning From Former Dementia Care Partners' Study

When you cared for a person living with dementia, you gave so much. Some do okay after the death of a person with dementia they cared for and some need assistance after that experience. We're asking that you connect with us by phone to teach us the reasons why people have better or worse experiences after a death due to dementia. We will use this understanding to help improve the lives of those who may be struggling. Everything will occur over the phone with a member of our study team, and you will be paid \$50 for your time. If you are interested in participating or know someone who might be interested, please call (602)543-4492 or email Prof. Zachary Baker by clicking on the red button below.



## Are You a Caregiver for an Aging Parent or In-law? Seeking Romantic Couples for an Online Survey in Exchange for \$25 Amazon Gift Card

We are seeking couples for a study examining how people who provide care to their aging parents or in-laws feel about their caregiving experience. To qualify for the study, participants must:

- be part of a couple in which the female is a primary caregiver for an aging parent/inlaw and the male is not a primary caregiver
- be living with a romantic partner or spouse for at least 1 year
- not have a chronic condition in which you are dependent on your partner or a partner with a chronic condition in which they are dependent on you
- not have children with chronic physical, developmental, behavioral, or emotional conditions that require care beyond that required by other children generally
- both partners must also be 18 years of age or older, speak English as their first or primary language, and be willing to complete an online survey

If eligible, participation would involve you and your romantic partner completing a roughly 30-minute online survey.

You and your partner will receive \$25 in the form of an Amazon e-gift card as appreciation for completing the survey.

If you are interested in participating, please call the Principal Investigator, Kirby Magid, at (980)999-0655 to complete a quick screening questionnaire to confirm eligibility or email him by clicking the red button below.

## Cognitive-Motor Training to Improve Mobility in Healthy Older Adults

Start: March 3, 2022 End: Dec. 31, 2024 Enrollment: 30

Who is sponsoring this study? District of Columbia

Where is this study located? George Washington University

#### What Is This Study About?

This study will test whether a program that involves simultaneous physical and mental training can improve mobility and cognition in older adults. Participants will attend three training sessions a week for two months to complete different combinations of cognitive and motor tasks, such as counting items on a computer screen either while marching in place or standing still. During the training sessions, participants will wear wireless sensors on the skin of their legs to measure muscle activity. Participants will complete cognition, balance, and movement tests at the start of the study, after one month and at the end of the two-month study. Researchers will evaluate changes in mobility, cognition, and muscle activity.

#### Do I Qualify To Participate in This Study?

Minimum Age: 60 Years Maximum Age: 95 Years

#### Must have:

- Good overall health
- Adequate vision to complete study tasks (use of glasses or contact lenses okay)
- Able to stand on one foot for at least three seconds without losing balance

#### Must NOT have:

- Diagnosis of a neurological disorder that affects mobility or cognition
- Medical condition that affects muscle function
- History of heart attack or heart muscle disease
- Chronic kidney disease
- Severe obesity, with body mass index > 40
- Moderate to serious arthritis in legs or feet
- Pain in the legs or feet in the past 15 days
- Learning or attention deficit
- · Currently taking medication that affects attention, learning, or memory
- Color blindness

For more information call Keith Cole at (202)994-0423 or email him by clicking on the red button below.

**LEARN MORE** 

#### **Disease Study (LEADS)**

Start: April 30, 2018 End: August 31, 2023 Enrollment: 600

Who is sponsoring this study? Indiana University

Where is this study located? Multiple states

#### What Is This Study About?

The Longitudinal Early-Onset Alzheimer's Disease Study (LEADS) is a two-year observational study designed to look at disease progression in adults with early-onset Alzheimer's disease. Researchers are also recruiting cognitively normal volunteers for a one-year comparison. Participants will have clinical and cognitive assessments, computerized cognitive tests, biomarker and genetic tests, brain imaging scans (including positron emission tomography (PET) and MRI), and cerebral spinal fluid collection (optional). Researchers will compare data among participants and also to data from people with late-onset Alzheimer's disease to study different elements of disease progression.

#### Do I Qualify To Participate in This Study?

Minimum Age: 40 Years Maximum Age: 64 Years

#### Must have:

#### **Early-Onset Alzheimer's Participants**

- Meet criteria for mild cognitive impairment due to Alzheimer's disease or probable Alzheimer's disease dementia
- Global Clinical Dementia Rating score of 1 or less
- Capacity to provide informed consent or legally authorized representative or guardian who can provide consent

#### **Cognitively Normal Participants**

- Meet criteria for cognitively normal, based on an absence of significant impairment in cognitive functions or activities of daily living
- Have a global Clinical Dementia Rating score of 0
- Mini-Mental State Examination score of 26 to 30 (exceptions may be made for less than 8 years of education)

#### **All Participants**

- Study partner who spends at least 10 hours per week with the participant, is generally aware of the person's daily activities, and can provide information about cognitive and functional performance; if the participant does not have a study partner who spends 10 face-to-face hours per week, other arrangements may be considered
- Not pregnant or lactating; women must be two years post-menopausal, be surgically sterile, or have a negative pregnancy test prior to each PET scan
- Fluent in English

#### **Must NOT have:**

- Non-Alzheimer's disease dementia
- Two or more first-degree relatives with a history of early-onset dementia (unless known mutations in APP, PSEN1, PSEN2 have been excluded)
- Known mutation in APP, PSEN1, PSEN2, or other autosomal dominant genes

- associated with neurodegenerative disorders
- Inability to undergo MRI, including claustrophobia, pacemaker, select implants, and fragments or foreign objects in the eyes, skin or body
- Lifetime history of a brain disorder (except for headache)
- Evidence of infection or focal lesions, cortical strokes, or multiple lacunes on MRI
- Significant systemic illness or unstable medical condition that could interfere with study participation
- Medical radiation exposure higher than is safe, as deemed by investigators
- Investigational agents in past 30 days
- Previous enrollment in a therapeutic trial targeting amyloid or tau
- Participation in other clinical studies with neuropsychological measures, except the National Alzheimer's Coordinating Center Uniformed Data Set
- Lifetime history of schizophrenia spectrum disorders
- Diagnosis of mania or bipolar disorder in past year
- Moderate or severe substance abuse in past 6 months (nicotine or caffeine allowed)
- Suicidal behaviors in the past year or active suicidal ideations
- Reside in a 24-hour care skilled nursing facility
- History of torsades de pointes or taking medications known to prolong the QT interval
- Corrected QT interval greater than or equal to 458 milliseconds in males or 474 milliseconds in females
- For optional lumbar puncture procedure, exclusions include inability to undergo procedure; abnormal clinical laboratory values; suspected elevated intracranial pressure, malformation, or mass lesion; and anticoagulant medication use

For more information about the study or to learn if it is being conducted in an area near you, click the red button below.



### **Brain Training for Depression in Older Adults**

Start: November 18, 2020

End: July 31, 2024 Enrollment: 138

Who is sponsoring this study? UConn Health

Where is this study located? Connecticut

#### What Is This Study About?

Major depression in older adults is challenging to treat and can contribute to cognitive decline. This study will evaluate whether a computerized brain training program can improve cognitive fitness to reduce depression in older adults with or without mild cognitive impairment. Participants will be randomly assigned to either receive the computerized brain training program or a similar program. Researchers will measure cognition and depression severity at the start of the study and after six weeks.

#### Do I Qualify To Participate in This Study?

Minimum Age: 60 Years Maximum Age: N/A

#### Must have:

- Normal cognition or mild cognitive impairment
- Ability to read and write in English
- · Current major or mild depression despite ongoing treatment

Currently treated with an antidepressant for at least eight weeks

#### Must NOT have:

- Psychosis
- Other psychiatric disorders (except personality and generalized anxiety disorders)
- Substance use disorders in the prior year
- Clinical diagnosis of dementia
- Neurological disorders (e.g., stroke, epilepsy, brain injury with loss of consciousness > 30 minutes, brain tumors, multiple sclerosis)
- Impaired vision (<20/70) or color blindness

For more information call Jennifer Brindisi at (860)679-7581 or email her by clicking on the red button below.



# 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 <u>Hometimestudy@duke.edu</u>, call (919)668-4500, or click the red button below.

### 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, LBGTQ+, Youth, Rural Americans.

### **NORD and RDDC's Rare Disease Diversity Survey**

NORD and the <u>Rare Disease Diversity Coalition</u> (RDDC) 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: <a href="https://rarediseases.org/rdd-survey-social/">https://rarediseases.org/rdd-survey-social/</a>, 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.



## 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

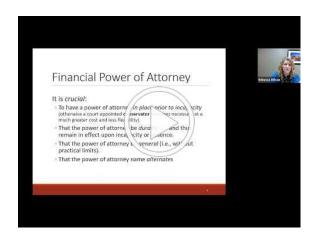
- Plan to move from the area within six months
- · Active treatment for a terminal illness or in hospice

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

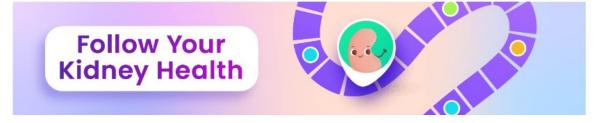
IN CASE YOU MISSED IT...

#### **Probate and Elder Law**



Join Rebecca L. Wilson (Attorney, Myers Billion LLP Law Firm) for a presentation that covers estate planning and elder law tools that can help you get your ducks in a row. She focuses on tools that enable caregivers to handle issues that arise, from paying bills to making medical decisions. Rebecca also discusses ways to create a plan that ensures an individual's wishes are carried out, both during any incapacity and on death.





#### **National Kidney Month 2023**

March is National Kidney Month! Did you know kidney disease is often referred to as a "silent disease," because there are usually no symptoms during its early stages? In fact, as many as 90% of Americans who have chronic kidney disease (CKD) don't know they have the disease until it is very advanced.

The good news is the earlier you find out you have kidney disease, the sooner you can take steps to protect your kidneys from further damage. Protecting your kidneys may allow you to continue to work, spend time with family and friends, stay physically active, and do other things you enjoy.

To learn more, click the red button below.



# Healthy Equity in IBD Report Underscores Need for Community-Centered Solutions to Inequity

In 2022, Aimed Alliance recognized that health disparities exist in the inflammatory bowel disease ("IBD") patient population. With rates of IBD continuing to increase over the last several years, there is a need to identify the root causes of outcome disparities for patients with IBD and develop solutions to redress these causes.

To identify sources of inequality within the IBD patient community, Aimed Alliance convened a panel of experts and others with a strong understanding of the IBD patient community, including pharmacists, patients with IBD, health care professionals, community leaders, health educators, and advocacy organizations. This group of participants was able to speak to the experiences of IBD patients and share knowledge related to IBD care, minority health, and community outreach. Ultimately, the panel's discussion identified grassroot access problems and best practices that should be used to engage impacted communities.

Aimed Alliance has summarized the concerns and practices raised during the roundtable meeting, and the report is now available **here**.

In conjunction with Aimed Alliance's "Health Equity in IBD" project, Aimed Alliance has developed new resources for patients with IBD. These new resources include (1) a brochure on the Americans with Disabilities Act and how some individuals with IBD may qualify for these protections; (2) a brochure on the Family Medical Leave Act which permits eligible employees with IBD to take protected time off for certain medical conditions; and (3) a brochure on how to appeal a health benefit denial.

To access these new resources, click the red button below.

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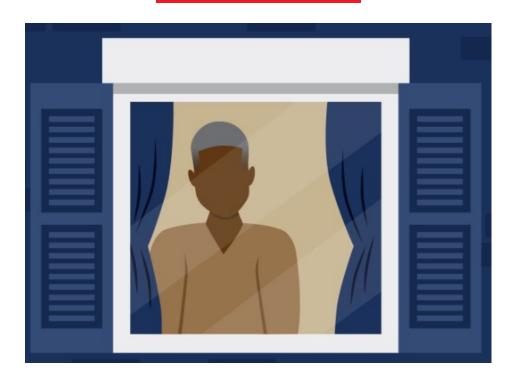
#### How to Identify, Prevent, and Fix Parent Burnout

Parents often feel they need to "do it all" to be good parents. They sacrifice a lot of their time and energy to provide for their children. When a child faces a challenge—a diagnosis, a disability, or a mental health struggle—a parent gives even more.

However, when a parent puts themselves last repeatedly, it is neither good for them nor the child. When parents are so spent, they don't have the energy left to attend to their needs. Who cares for the carer?

To learn more, click the red button below.

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**Trends in Loneliness Among Older Adults from 2018-2023** 

In January 2023, the University of Michigan National Poll on Healthy Aging (NPHA) asked a national sample of U.S. adults age 50–80 questions about loneliness (measured by their feelings of isolation and lack of companionship) and their social interactions. The NPHA asked the same questions to other similarly aged national samples of U.S. adults for reports in 2018 and 2020 and also included these questions in polls during 2021 and 2022.

The previous NPHA reports demonstrated that prior to the COVID-19 pandemic, a large portion of older adults experienced loneliness and infrequent social contact, and that those measures increased during the early months of the pandemic. This report presents findings from early 2023 with comparisons to prior surveys to describe trends in loneliness and social interactions among adults age 50–80 before and during the pandemic.

To view the poll's results, click the red button below.





#### **Top 17 Resources for Family Caregivers**

If you're a family caregiver, you may have questions about your care recipient's health condition, care planning or how to navigate daily care activities. The Family Caregiver Alliance has put together a one-sheet of top resources provides a wealth of answers and guidance to these questions and more.

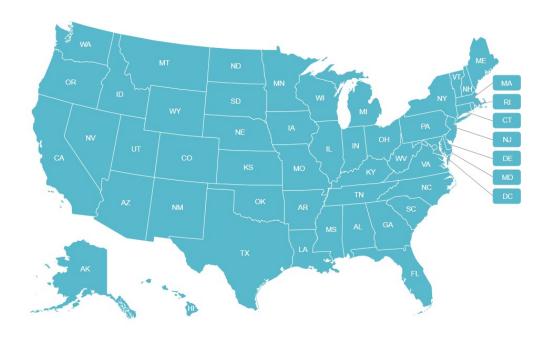
This list contains the most popular resources as rated by the family caregivers we've served for more than 40 years. We hope they help you too!

To view the list of caregiver resources, click the red button below.

VIEW THE RESOURCE SHEET >

### **Caregiving with Your Siblings**

Today's adult children and their parents are going through a new kind of family transition. Because parents are living longer—but with chronic illnesses—their adult children are now caring for them for up to a decade or more. Siblings—or in some cases step-siblings—might not have a model for how to work together to handle caregiving and the many practical, emotional, and financial issues that go with it. There is no clear path guiding who should do what, no roadmap for how siblings should interact as mature adults. While some families are able to work out differences, many others struggle.



### **Family Caregiver Services by State**

The Family Caregiver Alliance hosts an online tool intended to help family caregivers locate public, nonprofit, and private programs and services nearest their loved one—whether they are living at home or in a residential facility. Resources include government health and disability programs, legal resources, disease-specific organizations and more. Caregiving is challenging, but there are resources to help.

To view the list of caregiver resources, click the red button below.



#### **Personal Care Agreements**

Many families reach a point when they recognize that an ill or older relative needs help. There are usually warning signs: difficulty with daily activities; memory problems; trouble with banking and finances; multiple falls; problems with driving; forgetting medications. Sometimes an elderly or ill loved one needs more than occasional assistance — they need full-time care.

But who will provide that care? The answer is usually close to home: an adult child. One sibling might become the caregiver by default, or one is selected because he or she lives closer or has fewer family responsibilities of his/her own.

The person providing care for a loved one may make a significant sacrifice: giving up a job and employment benefits. A formal agreement among family members can provide a way to compensate a person providing care if he or she is no longer able to hold other employment. Even though most family members want to help and feel a sense of duty to care for a loved one, it is a job with heavy time commitments and responsibilities. One way of protecting the caregiver as well as the person receiving care is by putting the care relationship in writing.

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#### PREVIOUSLY APPEARED



May is Mental Health Awareness Month and May 1-7, 2023 is **Tardive Dyskinesia Awareness Week** 

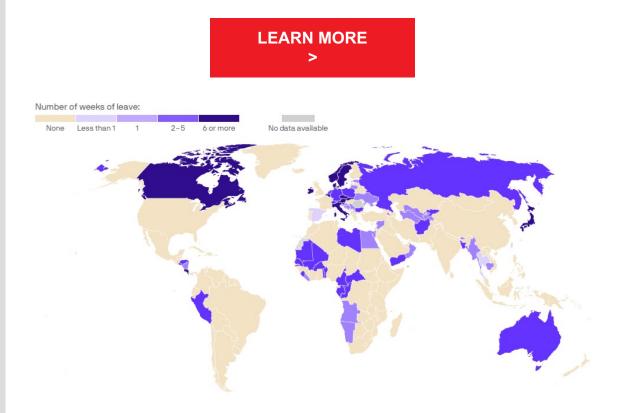
### **Tardive Dyskinesia Awareness Advocacy Week Toolkit**

Tardive dyskinesia (TD) is an involuntary movement disorder that is characterized by uncontrollable, abnormal, and repetitive movements of the face, torso, and/or other body parts. TD is associated with prolonged use of certain mental health medicines (antipsychotics) that can be used to treat bipolar disorder, depression, schizophrenia, and schizoaffective disorder. TD affects approximately 600,000 people in the U.S., and approximately 70%, or 7 out of 10 people living with TD, have not yet been diagnosed.

Now in its sixth year, TD Awareness Week (May 1st - 7th, 2023) encourages the mental health and broader communities to learn about TD, including how to recognize symptoms, understand the burden of the condition, and the importance of speaking with a healthcare provider if they or someone they know may be experiencing bothersome uncontrolled movements. As the reach for TD Awareness Week continues to grow each year, you'll be joining other advocates from across the country who are bringing awareness to TD.

Neurocrine Biosciences has put together a toolkit to assist individuals and advocacy groups who seek to promote greater awareness of TD.

To view the toolkit, click the red button below.



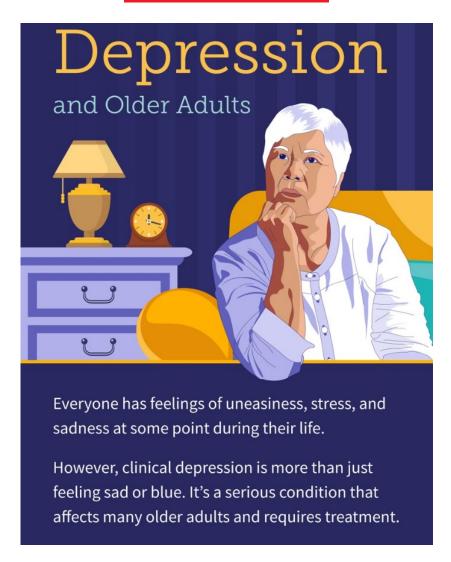
Map: Where Workers Get Paid Leave to Care for a Sick Parent

The lack of paid leave for new parents in the U.S. often grabs headlines, but there's a different kind of leave becoming an increasingly urgent issue: time off for workers to care for a sick parent.

The big picture: This kind of paid family health leave, typically structured as social insurance, is common in Europe. But globally, a majority of countries — including the U.S. — don't do it, according to a report from the World Policy Analysis Center

To learn more, click the red button below.

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#### **Depression and Older Adults**

Depression is a serious mood disorder. It can affect the way you feel, act, and think. Depression is a common problem among <u>older adults</u>, but clinical depression is not a normal part of aging. In fact, studies show that most older adults feel satisfied with their lives, despite having more illnesses or physical problems than younger people. However, if you've experienced depression as a younger person, you may be more likely to have depression as an older adult.

Depression is serious, and treatments are available to help. For most people, depression gets better with treatment. Counseling, medicine, or other forms of treatment can help. You do not need to suffer — help and treatment options are available.



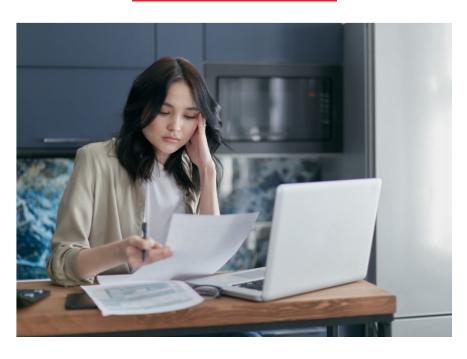
## 5 Free Mental Health Apps that Could Help Your Teen

The past several years have seen a dramatic increase in the number of mental health apps available for download. As a parent or caregiver of a teenager living with depression – or even dealing with stress, it can be confusing to determine which of these apps are effective ways to monitor and improve mental health. Which are evidence-based? Which are looking to hook your teen into making unnecessary in-app purchases? Here are a few apps that are both supported by mental health research and free for your teen to use.

To learn more, click the red button below.

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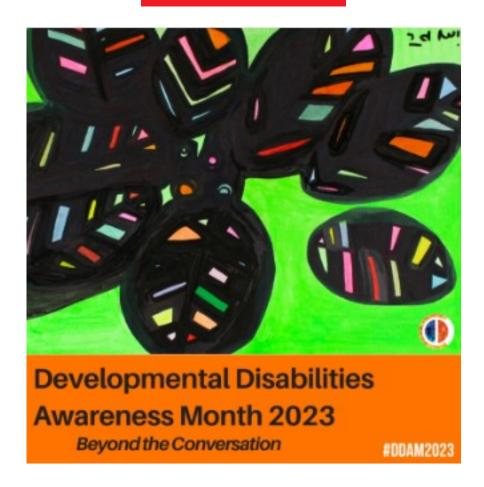
The Challenge of Paying for Mental Health Care

Nothing is more important than physical and mental well-being. However, it can be challenging and frustrating when you are the caregiver helping someone else get and pay for the mental health care they need.

Some mental health treatment options are covered by insurance, while some are not. Your loved one might need to see a specific provider who doesn't accept your insurance. The same mental health treatment or provider might be covered by one insurance plan but not another. As a result, many people receiving treatment pay out of pocket (with their own money because they are not paid for by insurance) for these expensive but vital services that help them live healthy lives.

To learn more, click the red button below.

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# Developmental Disabilities Awareness Month Resource Guide 2023

Every March, the National Association of Councils on Developmental Disabilities (NACDD) and its partners collaborate to lead **Developmental Disabilities Awareness**Month (DDAM). The campaign highlights how people with and without disabilities come together to form strong communities. DDAM raises awareness of the inclusion and contributions of people with developmental disabilities in all aspects of community life, and it's a time to explore the work we still need to do to remove barriers.

The 2023 theme, Beyond the Conversation, focuses on the question, "what next?" With this theme, NACDD plans to highlight change and innovation – what individuals and communities are doing to move past discussions and take action on education, employment, accessibility, and more.

The NACDD has put together a resource guide intended to help provide content for posting on social media during Developmental Disabilities Awareness Month.

To view the guide, click the red button below.

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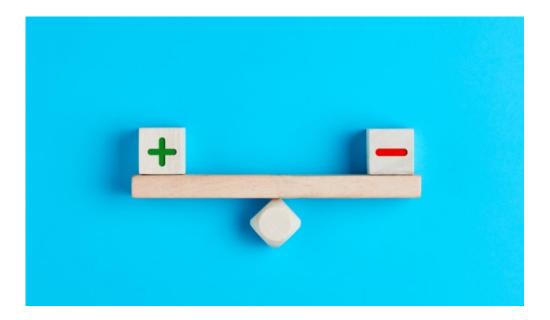


## 7 Myths About Caregiving You Shouldn't Believe

If you are the caregiver of a cancer patient, you may have found yourself thinking all of these things at some point. The only problem? None of them is true.

To address these and four other myths you may have heard, we spoke with senior social work counselor Paige Falcon. Here are seven caregiver falsehoods you shouldn't believe.

To learn more, click the red button below.



# Are Not-for-Profit Hospice Providers Better for the Family Caregiver Experience?

Family caregivers looking for a good hospice experience might want to consider a not-for-profit hospice provider over a for-profit provider, with new data from the RAND Corporation showing that not-for-profits get better ratings from family caregivers.

To learn more, click the red button below.

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## 5 Exercises to Keep an Aging Body Strong and Fit

When we're young, exercise can enable us to run a race after an all-nighter or snowboard on a diet of Doritos. But as we age, fitness has a much more far-reaching impact, boosting our energy levels, preventing injuries and keeping us mentally sharp.

Aging causes muscles to lose mass, bone density to thin and joints to stiffen -- affecting our balance, coordination and strength. At the same time, hormonal shifts and persistent low-level inflammation can set the stage for chronic diseases such as cancer, cardiovasular disease and diabetes.

To learn more, click the red button below.



## **Mealtime Made Easy: 6 Tips for Caregivers**

Among the many responsibilities of being a family caregiver is ensuring that your loved one's nutritional requirements are met and that food is provided in a safe manner that caters to their needs.

It's important to work with a primary care provider or dietitian because every health condition can greatly influence a person's nutritional needs.

When grocery shopping, consider food allergies or intolerances and other nutrition requirements such as low sodium, high protein, vitamins and minerals.

To learn more, click the red button below.

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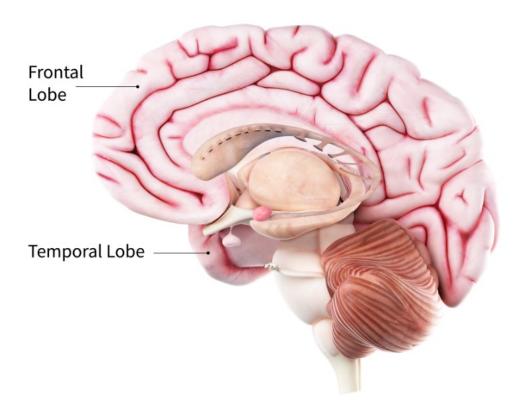
Learn more at autoimmune.org

#### **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.





# 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.



# 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.



## **Living with IDB**

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.

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### **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.

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#### 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.



## **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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# 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. <u>Medicines are</u> <u>available to treat these behaviors</u> 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.

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# 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.

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**Managing Personality and** 

### **Behavior Changes in Alzheimer's**

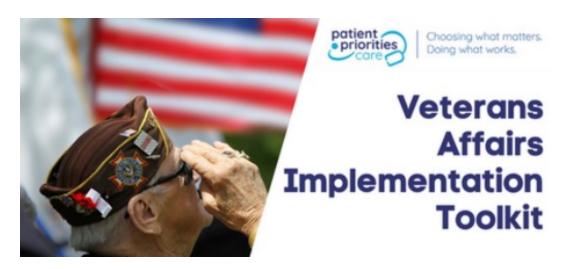
Alzheimer's disease causes brain cells to die, so the brain works less well over time. This changes how a person acts. Common personality and behavior changes you may see include:

- 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

<u>Patient Priorities Care</u> (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.



## 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.



## 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, <u>advance care directives</u>, <u>costs</u>, 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.



## **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.



#### 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.



## 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.



#### 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.



## **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.

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# 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 <u>respite to the primary</u> <u>caregiver</u> 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.

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#### **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.

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## **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 <u>long-term care</u> — 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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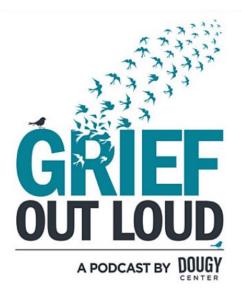


### **Taking Care of Yourself: Tips for Caregivers**

Taking care of yourself is one of the most important things you can do as a caregiver. Make sure you're <u>eating healthy</u>, <u>being active</u>, and <u>taking time for yourself</u>.

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.



### 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 <u>Dougy Center</u>'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.



## **Family Caregiving HelpGuide**

<u>HelpGuide.org</u> 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.



#### 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.



# 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

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## **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.





#### 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.





## **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.

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#### 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 <u>Sick Cells</u> 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.

VIEW THE MAP



## **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.





#### **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.





## 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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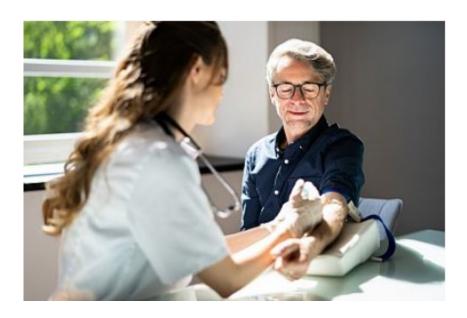
**Understanding Chronic Sorrow** 

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.

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## **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.

**LEARN MORE** 



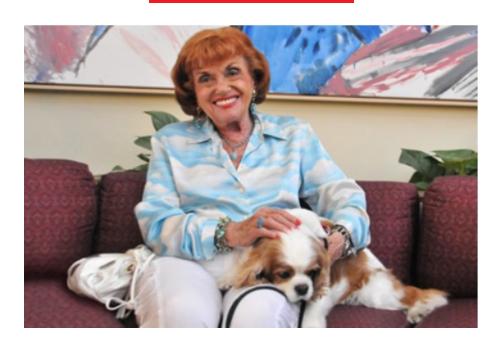
### **Your Body's Disease Defenses**

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.





## **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.

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### 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.

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## **Tips for People With Dementia**

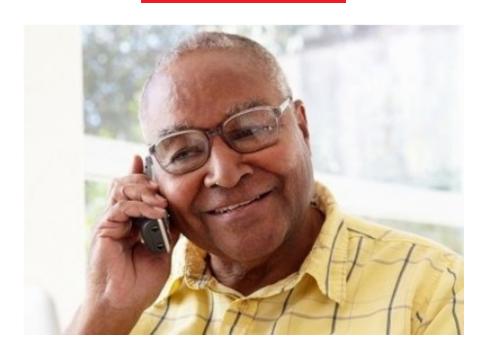
People with dementia experience a range of symptoms related to changes in thinking, remembering, reasoning, and behavior. Living with dementia presents unique challenges, but there are steps you can take to help now and in the future.

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.

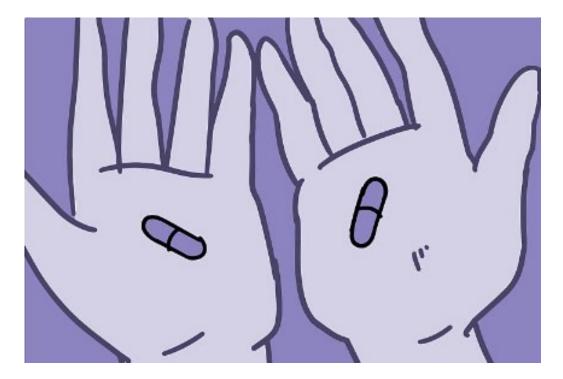
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#### Worry Less and Age Better with BenefitsCheckup

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.





#### 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.

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**Bathing, Dressing, and Grooming:** 

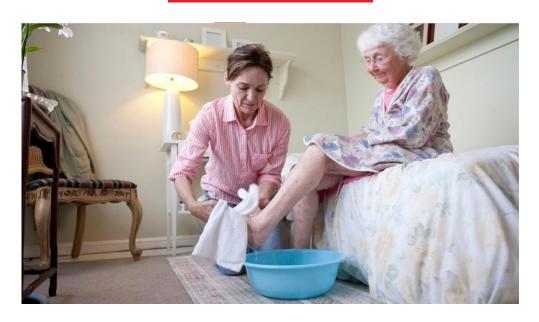
## **Alzheimer's Caregiving Tips**

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** 

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## 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.

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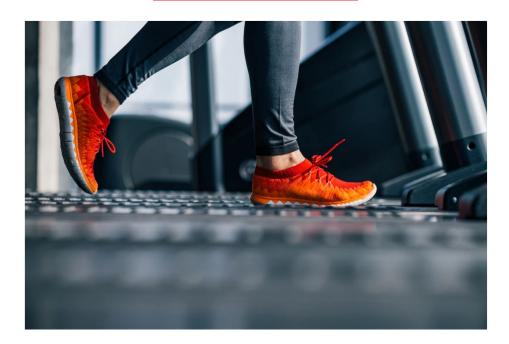
## **How Caregivers Can Counter Family Gaslighting**

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 badmouth 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 <u>new study</u> 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.

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## 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.

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### 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.

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#### 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.

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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.





#### **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.





#### **Finding Dementia Care and Local Services**

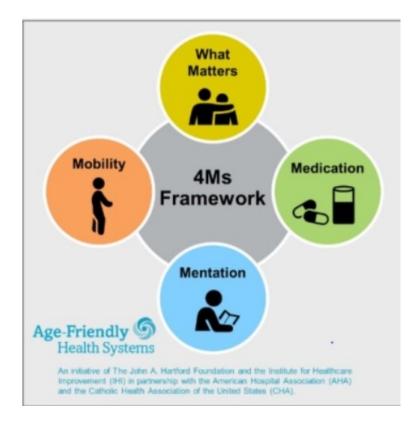
A person with dementia will need more care as symptoms worsen over time. Problems with memory, thinking, and behavior often present challenges for those with dementia as well as for their family members. Whether the disease is in early or late stages, there are support systems, resources, and services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





# 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 <u>right documents in place</u> or do we need to go to court for assistance? And who's going to <u>pay for everything</u>?

To learn more, click the red button below.

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