THIS WEEK IN CAREGIVING



March 22, 2023



CAREGIVING IN THE NEWS

The Five Things I Wish I Knew Before Becoming a Family Caregiver

When my brother was diagnosed with schizophrenia in his 20s, his life wasn't the only one forever changed. In an instant, my parents and I became around the clock caregivers, scrambling to handle all of his complex medical, housing, and legal needs. We had no idea what lay ahead: the maze of insurance policies, the lack of good outcomes, and the ever-elusive dream of a "great" residential facility, which always seemed to be just out of reach. The chronic stress, fear, and stigma left us feeling isolated and alone. The list — believe it or not — goes on.

From: Forbes | Published: March 17, 2023

READ MORE

Senior Care is Crushingly Expensive. Boomers Aren't Ready.

Beth Roper had already sold her husband Doug's boat and his pickup truck. Her daughter sends \$500 a month or more. But it was nowhere near enough to pay the \$5,950-a-month bill at Doug's assisted-living facility. So last year, Roper, 65, abandoned her own plans to retire.

To the public school librarian from Poquoson, Va., it feels like a betrayal of a social contract. Doug Roper, a longtime high school history teacher and wrestling coach, has a pension and Social Security. The Ropers own a home; they have savings. Yet the expense of Doug's residential Alzheimer's care poses a grave threat to their middle-class nest

Why Are Falls so Serious in Older People?

Senate Minority Leader Mitch McConnell (R-Ky.) suffered a concussion and has been hospitalized after he tripped and fell at a hotel. The senator will stay in the hospital for observation and treatment, his spokesman said Thursday.

Every year, millions of Americans older than 65 experience falls, according to the Centers for Disease Control and Prevention. This translates to 1 in 4 older adults falling, resulting in more than 800,000 emergency department visits, with 1 in 5 of the falls resulting in serious injuries such as broken hips or other bone fractures, or head trauma, according to CDC. Falls are the leading cause of injury and death in this age group, the CDC says.

egg.

From: Washington Post | Published: March 18, 2023

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From: Washington Post | Published: March 9, 2023

READ MORE



NAC NEWS AND UPDATES



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



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.

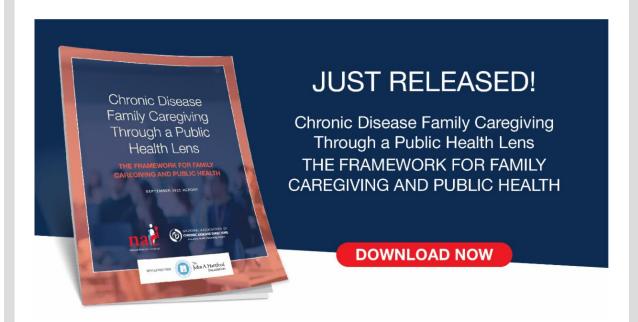
LEARN MORE



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. Assessing the Pain of Care Recipients: Tools Available to Family Caregivers utilizes a rapid literature review to identify and discuss the tools available to chronic pain caregivers to assess pain in their care recipient and how these caregivers can be better supported in their role.

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

VIEW THE REPORT



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



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 <u>ACL</u> 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.



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.



TBI WARRIOR®

FOUNDATION

Traumatic Brain Injury and Caregiving

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

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

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

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



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.

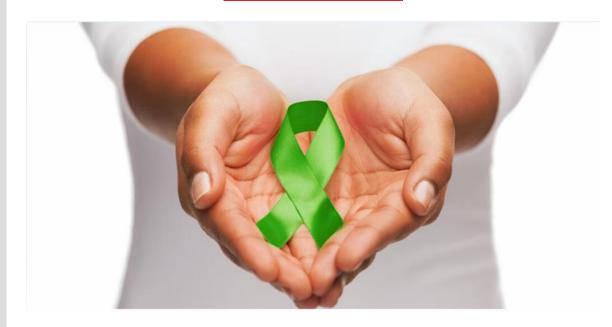
Many of us also experience the weight and pain of the loss of the person we are caring for before their death, yet never identify these feelings as anticipatory grief, or understand the impact this grief has on our well-being.

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.

REGISTER >



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.

REGISTER >



Anticipatory Grief: Grieving Before Death?

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

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

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

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

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

REGISTER

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.

The Dr. Is In: Difficult Dementia Behaviors

March 30, 2023 | 5:00 PM - 6:30 PM ET | Online

On March 30th, join Valley Caregiver Resource Center for a 90-minute class about coping with difficult dementia behaviors. The host will be Dr. Steven Grossman, a physician and hospice and palliative care specialist. There will be an opportunity to discuss and ask questions.

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

REGISTER

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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

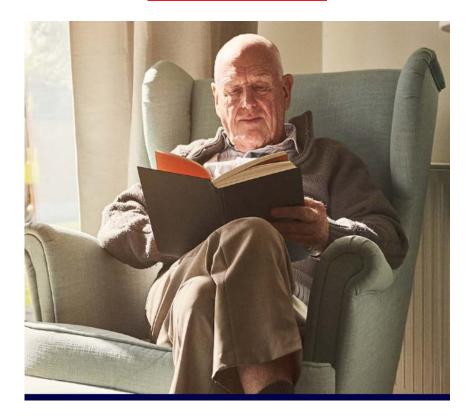
More than 50 million people live with dementia worldwide, with figures reaching to more than 75 million by 2030. Being a progressive condition, in its advanced stages, dementia reduces the opportunities of the person to receive proper care, and more specialist end-of-life care is needed to ensure that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



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.

REGISTER

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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.

REGISTER



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.

REGISTER

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Aging in Place: Know Your Housing Options

April 11 - 13, 2023 | 1:00 PM - 2:30 PM ET | Online

Beginning on April 11th, the Benjamin Rose Institute on Aging will host "Aging in Place: Know Your Housing Options," a three-day online course designed teach participants how to assess their homes for safety, accessibility, and affordability; explore ways to use home equity to stay in their homes; and discover housing options.

To register for this course, 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 guestions, you can reach out to Heather Tomko at caregiving@pitt.edu.

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 >



A New Model of Care: Dementia Connection Model

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

If you are a healthcare professional or family caregiver, who provides care for Alzheimer's and Dementia individuals, this webinar is for you.

In this dementia care webinar, you will learn about the first-ever cognitive-behavioral approach to care called the Dementia Connection Model©, created by Dr. Jennifer Stelter, clinical psychologist, dementia expert, and Johns Hopkins Press author of The Busy Caregiver's Guide to Advanced Alzheimer Disease . The model ties together three key concepts in understanding Alzheimer's disease and other forms of dementia and how to provide the best quality of care. You will better understand the "why?" of dementia to provide a quality of life for those you care for. Then, you will exercise your brain in learning "how" to best implement the "what" -- sensory-based, non-pharmacological approaches that positively influence the emotions and memories for those living with dementia, enabling positive, productive behavior expressions and a better connection.

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

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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

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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.

REGISTER >

Beyond Movement Changes: The Emotional Impact of Parkinson's Disease

April 26, 2023 | 1:30 PM - 2:30 PM ET | Online

It is well recognized that Parkinson's Disease affects body movement. Join Banner Sun Health Research Institute for a program that will focus on helping attendees better grasp the common emotional changes that occur in the person with PD. Learn how increasing empathy for both caregivers and their person can reduce frustration.

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.

REGISTER >

MAY



Caregiver Mental Health: How to

Reduce Anxiety for Better Living

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

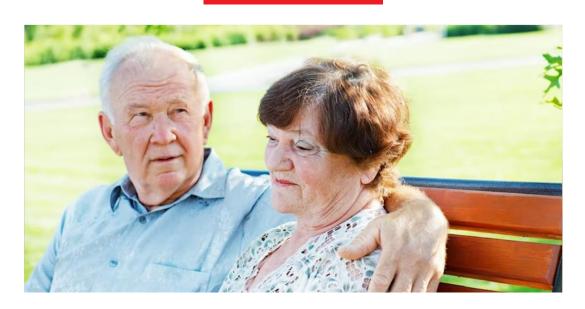
The caregiving role can bring forth many different feelings and emotions, and anxiety is one which can be problematic for those managing care. In observance of Mental Health Week this May, we welcome back Dr. Patrick McGrath to talk about:

- 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



As Dementia Progresses: Moderate to Advanced Stage

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

Join Banner Alzheimer's Institute on May 2nd for an online class that will discuss the moderate to advanced stages of Alzheimer's disease or related dementias. Attendees will learn about expected changes in memory, thinking, mood, behavior and function as the disease progresses. Practical strategies will be provided to assist caregivers to find success in their efforts.

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 >



Conversations and Events

Advance Care Planning: Advance Directives Deep Dive

May 19, 2023 | 1:00 PM - 2:00 PM ET | Online

Advance directives are tricky to complete if you don't understand the context or consequences of the medical decisions you are asked to make. What is a health care proxy, and what does the role entail? What does artificial nutrition actually entail? How about a ventilator? Putting yourself into a future state is hard enough, but much harder when you don't fully understand the implications of what you're signing up for.

Join BJ Miller, Mettle Health founder, palliative care and hospice physician and author, for an informal and interactive conversation on what's in an advance directive and how to complete them. Advance care planning IS confusing, and we hope to shed some light in this session.

All online discussions begins with a basic overview of the day's topic before opening up to the group for Q&A and conversation. This session should feel as supportive as it does educational, so bring your questions and comments, or feel free to just listen. Together,

we'll explore real life examples and address your questions on the topic.

Discussions are held online and once registered, you will receive a link via email to join on video or by phone.

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

REGISTER >



Comfort for Caregivers: Strategies for Dealing with Caregiver Stress

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

Caring for a loved one strains even the most resilient people. In this workshop, we will discuss strategies for dealing with caregiver stress and learn effective ways to preserve your own health and well-being. There will be time for Q&A following the presentation.

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.



JUNE

Aspects of Caregiving

June 2, 2023 | 1:00 PM - 2:00 PM ET | Online

Join BJ Miller, Mettle Health founder, palliative care and hospice physician and author, for an informal and interactive conversation on caregiving and what it entails to be a caregiver.

All online discussions begins with a basic overview of the day's topic before opening up to the group for Q&A and conversation. This session should feel as supportive as it does educational, so bring your questions and comments, or feel free to just listen. Together, we'll explore real life examples and address your questions on the topic.

Discussions are held online and once registered, you will receive a link via email to join on video or by phone.

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

REGISTER



Caring for Your Caregiver

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

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

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

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

REGISTER >

PATIENT AND CAREGIVER STUDIES



PAF Survey

Patient Advocate Foundation (PAF) has launched a national survey aimed at gaining patient and caregiver insights for crafting a common understanding of the services and supports patients and families need. The results of this endeavor will be used as the foundation for developing new public policy proposals that will help all of us access the care, services and support we need, including proposals that will go before Congress and the Administration.

Please contribute your insights by completing this research survey. It should take no more than 15 minutes to complete.

Please also help circulate this survey with other patients and caregivers using the advocate and partner toolkit, which includes tools to help you share this opportunity with your community so they can be heard, included and counted. The survey will close on March 31, 2023. For questions, please contact Melissa.Williams@npaf.org.

To complete the survey, click the red button below.

LEARN MORE
>

Dementia Caregiving Skills for Family Caregivers

Start: May 2021

End: February 28, 2025

Enrollment: 332

Who is sponsoring this study? University of California, Irvine

Where is this study located? California

What Is This Study About?

This study will evaluate a culturally and language-appropriate dementia caregiver program designed to reduce stress and improve caregiver skills in ethnic and underserved dementia family caregivers. Participants will be randomly assigned to receive either an inhome caregiver education program delivered by bilingual community health workers or information on Alzheimer's resources and services. The in-home program includes six home visits over three months. Based on group assignment, participants will wear a smartwatch during the day and a smart ring at night for three months to monitor caregiver stress and sleep. Community health workers will also administer surveys at the start of the study, after three months, and six months. Researchers will measure the effects of the program on caregiver burden, depression, health-related quality of life, confidence, dementia behavior problem-solving skills, stress, and sleep outcomes.

Do I Qualify To Participate in This Study?

Minimum Age: 18 Years Maximum Age: N/A

Must have:

- Family caregiver of community-dwelling person with dementia (e.g., Alzheimer's disease or related dementia, such as frontotemporal dementia)
- Provides primary care for the person with dementia
- Self-reporting ethnicity/race as Korean, Vietnamese, Latino/Hispanic, or non-Hispanic white
- Able to speak English, Spanish, Vietnamese, or Korean

Must NOT have:

- Cognitive impairment that would interfere with providing consent or completing study surveys
- · Chronic drug abuse
- Currently receiving treatment for cancer
- Need for hospice care
- Significant health problems that would interfere with wearing a smartwatch

and smart ring (e.g., pacemaker, epilepsy, or neurologic disorder)

For more information call Jung-Ah Lee at (949)824-2855 or email her by clicking the red button below.



Escitalopram for Agitation in Alzheimer's Disease

Start: January 3, 2018 End: August 2024 Enrollment: 392

Who is sponsoring this study? JHSPH Center for Clinical Trials

Where is this study located? Multiple states

What Is This Study About?

Escitalopram (Lexapro) is a drug approved by the U.S. Food and Drug Administration for the treatment of depression and generalized anxiety disorder. This study will evaluate its safety and efficacy to treat agitation in Alzheimer's disease. Participants will be randomly assigned to take up to 15 mg per day of the study drug or a placebo (one to three capsules per day) for 12 weeks. Before being assigned to the drug intervention, participants with clinically significant agitation and their caregiver(s) will receive a structured psychosocial intervention for three weeks. If participants do not show a response, then they will be randomly assigned to the study drug or placebo.

Do I Qualify To Participate in This Study?

Minimum Age: 18 Years Maximum Age: 109 Years

Must have:

- Alzheimer's dementia diagnosis
- Mini-Mental State Examination Telephone score of 3-20
- Meets criteria for agitation in cognitive disorders per the International Psychogeriatric Association
- Clinically significant agitation/aggression as assessed by the Neuropsychiatric Inventory
- Availability of a caregiver who spends at least several hours per week with the
 participant, supervises his or her care, and is willing to accompany the participant to
 study visits and participate in the study
- Use of antipsychotics for agitation or psychosis must be stable for at least seven days

Must NOT have:

- Major depression in the past 90 days
- Brain disease other than Alzheimer's that explains the dementia, such as extensive brain vascular disease, Parkinson's disease, dementia with Lewy bodies, traumatic brain injury, or multiple sclerosis
- Residence in a skilled nursing or long-term acute care facility
- Contraindication to escitalopram, such as use of monoamine oxidase inhibitors in past 30 days or sensitivity to escitalopram or citalopram (Celexa) or any inactive ingredients
- Prior failed treatment with citalopram or escitalopram for agitation
- Indication for psychiatric hospitalization or acute suicidality

- Changes in antipsychotics, anticonvulsants, or psychosis (delusions or hallucinations) within seven days requiring a change in antipsychotic treatment
- Abnormal corrected QT interval as determined on electrocardiogram (more than 450 ms for men and 470 ms for women)
- Severely reduced renal function in past 30 days as identified by a Glomerular filtration rate clearance of less than 30 ml per minute or reduced liver function
- Prohibited medications within seven days: antidepressants (other than 100 mg or less of trazodone per day at bedtime), benzodiazepines (other than lorazepam), or psychostimulants
- Changes in dextromethorphan/quinidine, prazosin, and pimavanserin within two weeks
- Use of medical marijuana within two weeks
- Current participation in a clinical trial or study that may add a significant burden or affect study outcomes
- Significant communicative impairments that would affect participation
- Any condition that makes it medically inappropriate or risky to enroll in the trial

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



Lucidity in Severe End-Stage Dementia

Start: December 1, 2021 End: August 31, 2025 Enrollment: 520

Who is sponsoring this study? NYU Langone Health

Where is this study located? New York

What Is This Study About?

This study aims to establish methods for measuring episodes of lucidity, or episodes of clarity, in people with severe, end-stage dementia. The study is divided into two phases. In Phase 1, a family member, friend, or caregiver will record symptoms of the person with dementia in a diary, and researchers will measure brain activity through video electroencephalogram monitoring (video brain recording). Researchers will analyze how frequently the symptom diary entries indicate potential moments of lucidity and note any participant experiences of distress or discomfort from using the diary and video brain recording device. Phase 2 of the study aims to expand the study population, improve study methods, and create a definition and measurement scale for lucidity to inform future research.

Do I Qualify To Participate in This Study?

Minimum Age: 18 Years Maximum Age: N/A

Must have:

- Study participants will include:
 - Adults with severe dementia based on neurological testing
 - Hospice workers, geriatric and palliative care physicians, and other health care providers
 - Family, friends, and caregivers of a person with severe dementia
- Participants with severe dementia will need to meet the following criteria:

- Currently admitted or accepted for hospice care
- No longer being provided with nutrition or fluids
- Dry or almost dry disposable underwear in any 24-hour period

Must NOT have:

- Mild, moderate, or moderately severe dementia, based on neurological testing
- Cognitive or functional impairment due to a diagnosis other than dementia

For more information call Sam Parnia at (646)501-6923 or email him by clicking on the red button below.



Retinal Imaging for Mild Cognitive Impairment and Alzheimer's Disease

Start: July 2017

End: December 31, 2025

Enrollment: 1000

Who is sponsoring this study? Duke University

Where is this study located? North Carolina

What Is This Study About?

Noninvasive retinal imaging may be able to identify biomarkers, or signs within the body, associated with mild cognitive impairment (MCI), Alzheimer's disease, and Parkinson's Disease (PD), or other neurodegenerative disease. In this study, researchers are investigating the optical coherence tomography angiography (OCTA) imaging technique as a potential screening tool. Participants will undergo noninvasive eye scans with OCTA. Researchers will use the scans to assess the structure and function of retinal blood vessels in people with these diseases compared to those without.

Do I Qualify To Participate in This Study?

Minimum Age: 18 Years Maximum Age: N/A

Must have:

• Diagnosis of MCI, Alzheimer's disease, Parkinson's disease, multiple sclerosis, and Huntington's disease.

Must NOT have:

- Diagnosis of a dementia other than Alzheimer's
- Diabetes
- Evidence of glaucoma, macular degeneration, or other neurologic or age-related eye or vision condition that could impact results
- Previous eye surgery, other than cataract surgery
- Inability to cooperate with or complete testing

Note: If two eyes satisfy the inclusion criteria, both eyes will be included in the study. If one eye satisfies the inclusion criteria, the eye that qualifies will be included in the study.

For more information call Dilraj Grewal at (919)684-4458 or email him by clicking on the

red button below.



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.

LEARN MORE >

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.

LEARN MORE >

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.



Longitudinal Early-Onset Alzheimer's 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:

- Psvchosis
- 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.



IN CASE YOU MISSED IT...

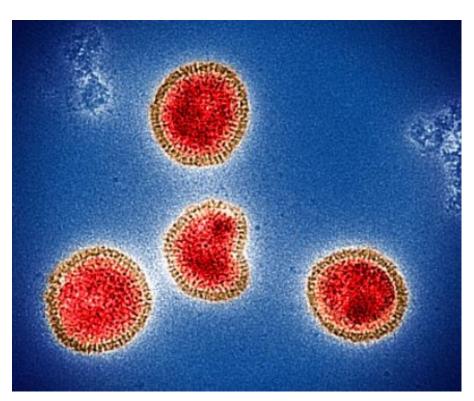
Part 1: Building a Treatment Team with Your Loved One



Part 1 of this series focuses on the treatment team, the network of providers and other professionals who support your loved one's care. Hear from mental health providers about how they're involved in your loved one's care, what you can do to help your loved one connect with them, and what you can expect your role to be.



RESEARCH & RESOURCES

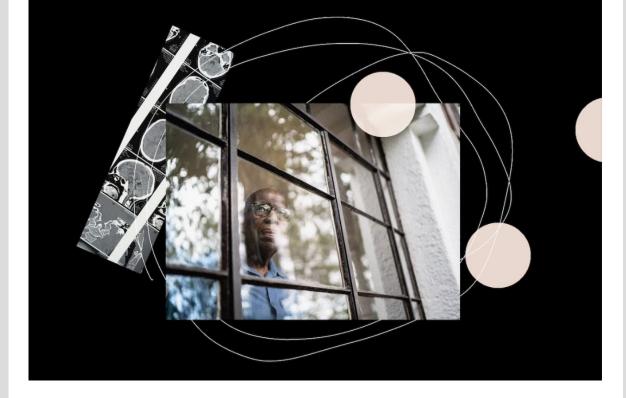


Links Found Between Viruses and Neurodegenerative Diseases

Neurodegenerative diseases can damage different parts of the nervous system, including the brain. This may lead to problems with thinking, memory, and/or movement. Examples include Alzheimer's disease (AD), multiple sclerosis (MS), and Parkinson's disease (PD). These diseases tend to happen late in life. There are few effective treatments.

Previous findings have suggested that viruses may play a role in certain neurodegenerative diseases. For example, a recent study found a link between Epstein-Barr virus infection and the risk of MS. There are also concerns about cognitive impacts from SARS-CoV-2, the virus that causes COVID-19.

To learn more, click the red button below.



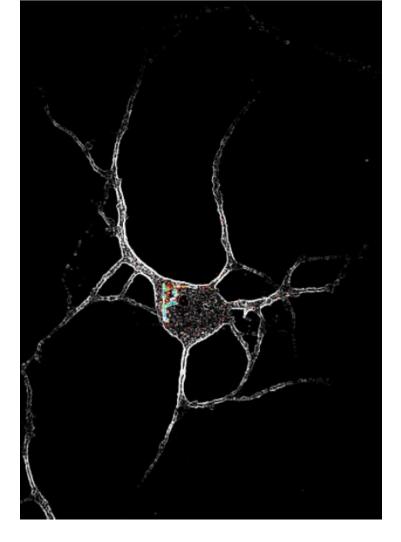
Ask a Doctor: Who Will the New Alzheimer's Drug Help?

Who will the experimental Alzheimer's drug lecanemab, which has been shown to moderately slow the effects of the disease, help? Is it safe? Is there reason to feel hopeful about the future of dementia/Alzheimer's therapy?

To learn more, click the red button below.

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How Psychedelic Drugs May Help with Depression

Some types of psychedelic drugs, such as psilocybin and MDMA (ecstasy), have shown promise as therapies for treatment-resistant depression and post-traumatic stress disorder. They appear to work by encouraging the growth of new connections between neurons in the brain. This ability of the brain to make new connections is called plasticity.

To learn more, click the red button below.



The Best Treatment for Depression? It Could be Exercise.

Exercise as a treatment for severe depression is at least as effective as standard drugs or psychotherapy and by some measures better, according to the largest study to date of exercise as "medicine" for depression.

The study pooled data from 41 studies involving 2,265 people with depression and showed that almost any type of exercise substantially reduces depression symptoms, although some forms of exercise seemed more beneficial than others.

To learn more, click the red button below.

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Understanding Genetic Testing for Cancer Risk

Genetic testing is the use of medical tests to look for certain mutations (changes) in a person's genes. Many types of genetic tests are used today, and more are being developed.

Predictive genetic testing is a type of testing used to look for inherited gene mutations that might put a person at higher risk of getting certain kinds of cancer.

To learn more, click the red button below.



Building Your Caregiver Toolkit

Caregiving for a loved one who lives with depression or bipolar disorder is a journey that can be both fulfilling and challenging. It requires patience, dedication, and a willingness to learn. While caregiving can be difficult at times, it can also be one of the most rewarding experiences of your life. It can enhance family relationships and unite families.

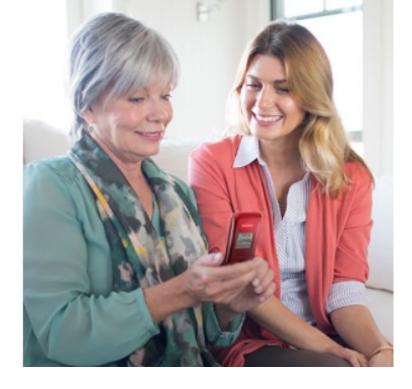
Families for Depression Awareness understands the challenges that come with caregiving. That's why we provide you with the tools and resources to navigate this journey successfully. With practical information and actionable advice for the many dimensions of caregiving, we've got you covered.

Our Building Your Family Caregiver Toolkit will help you create a robust and comprehensive caregiver toolkit.

To view the toolkit, click the red button below.

VIEW THE TOOLKIT

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5 Tips When Shopping for Caregiving Tech

The beauty of technology is that it's always accessible and constantly adapting to better meet our needs. But that's also its downfall: the lightning pace of updates and upgrades can be discouraging to less active users—especially when there are so many options. How do you know what app will work best? How do you know what product will be the easiest to use and give you the most value for the time and effort it takes to integrate it? And unless the services are free, how do you know they're worth the cost?

To learn more, click the red button below.

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Defining the Help You Need

In caregiving circles we hear a lot about the word "support". Family caregivers regularly seek supportive relationships with other caregivers, knowing they can provide the emotional sustenance needed during difficult times.

What support doesn't do however, is change the circumstances under which you are living. It doesn't relieve you of some of your responsibilities. It doesn't minimize the job at hand. That's the work of a different word - and that word is HELP.

To learn more, click the red button below.

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PREVIOUSLY APPEARED

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.

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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

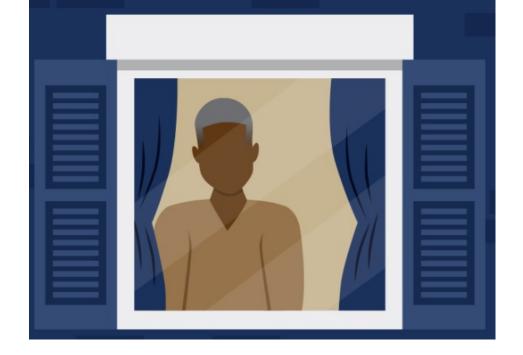
Parents often feel they need to "do it all" to be good parents. They sacrifice a lot of their time and energy to provide for their children. When a child faces a challenge—a diagnosis, a disability, or a mental health struggle—a parent gives even more.

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.

VIEW THE REPORT >



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.

To learn more, click the red button below.





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.

To learn more, click the red button below.

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

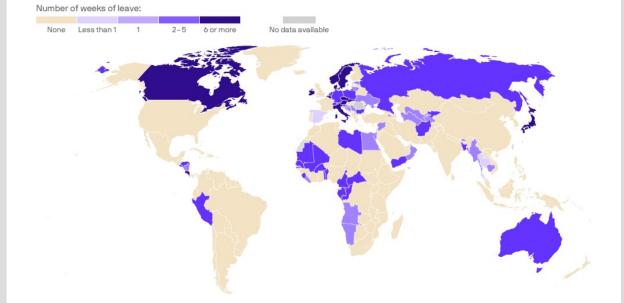
Tardive Dyskinesia Awareness Advocacy Week Toolkit

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

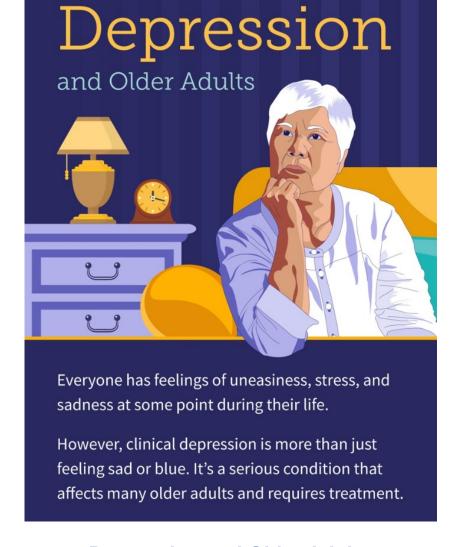
The lack of paid leave for new parents in the U.S. often grabs headlines, but there's a different kind of leave becoming an increasingly urgent issue: time off for workers to care for a sick parent.

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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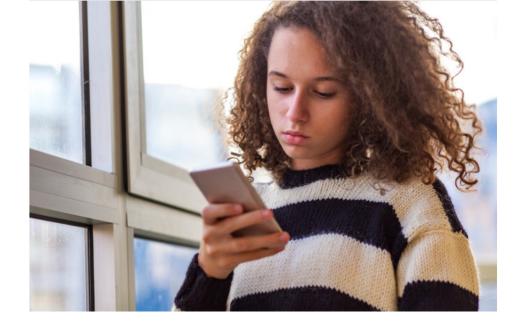


Depression and Older Adults

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.

To learn more, click the red button below.

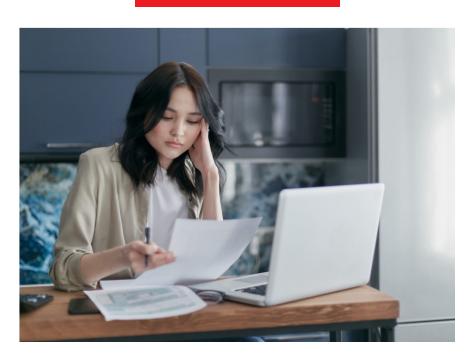


5 Free Mental Health Apps that Could Help Your Teen

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.



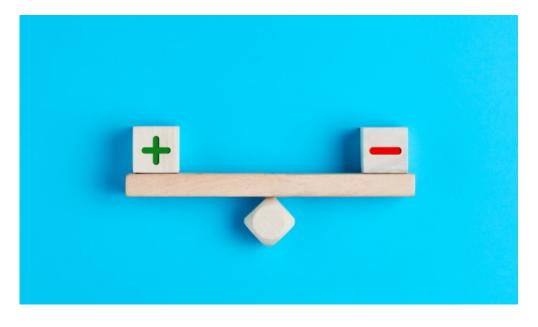
7 Myths About Caregiving You Shouldn't Believe

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.

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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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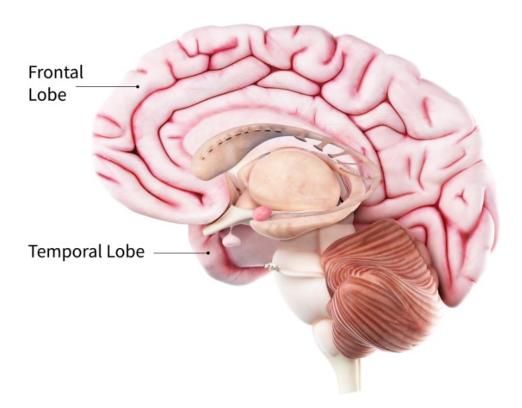
Learn more at autoimmune.org

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.

To learn more, click the red button below.



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.



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.

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Managing Personality and

Behavior Changes in Alzheimer's

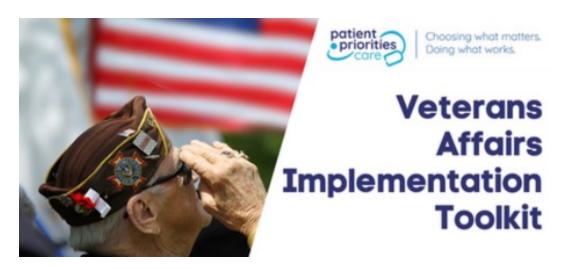
Alzheimer's disease causes brain cells to die, so the brain works less well over time. This changes how a person acts. Common personality and behavior changes you may see include:

- 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.

To learn more, click the red button below.



Legal Issues for LGBTQ+ Caregivers

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

To learn more, click the red button below.

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Rush Caring for Caregivers (C4C)

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

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

To learn more, click the red button below.



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.

To learn more, click the red button below.



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."

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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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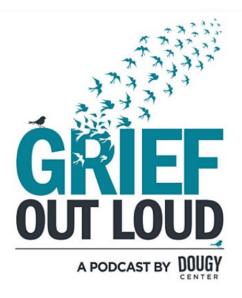
Taking Care of Yourself: Tips for Caregivers

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.

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Podcast: Caring for a Parent at the End of Life

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

This episode of the <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.

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Resources for Alzheimer's and Dementia Caregivers

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

To learn more, click the red button below.

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Family Caregiving HelpGuide

<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.

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

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

To learn more, click the red button below.

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Podcast: How to Take Better Care of Your Loved Ones

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

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

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

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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

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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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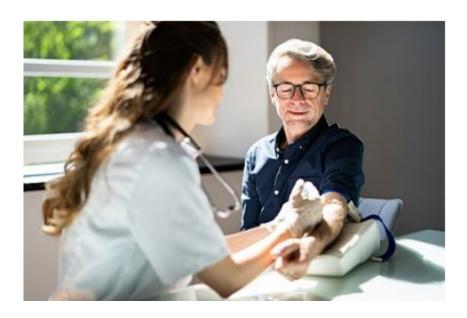
Understanding Chronic Sorrow

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 β). These oligomers can start to form more than a decade before symptoms appear and before other known disease markers form. The ability to detect these oligomers would permit early disease diagnosis. This would make strategies to intervene before irreparable brain damage occurs possible.

To learn more, click the red button below.

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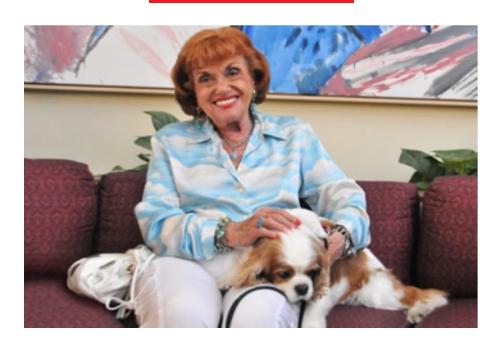
Your Body's Disease Defenses

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

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

To learn more, click the red button below.

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Adapting Activities for People With Alzheimer's Disease

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

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

To learn more, click the red button below.





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 >

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