

# THIS WEEK IN CAREGIVING



August 9, 2023



## CAREGIVING IN THE NEWS

### **Biden-Harris Administration Announces Medicare Dementia Care Model**

The Biden-Harris Administration is taking further action on its commitment to promote care and support for people with Medicare living with dementia and their unpaid caregivers. The U.S. Department of Health and Human Services (HHS), through the Centers for Medicare & Medicaid Services (CMS), announced its Guiding an Improved Dementia Experience (GUIDE) Model, which aims to improve the quality of life for people living with dementia, reduce strain on unpaid caregivers, and help people remain in their homes and communities through a package of care coordination and management, caregiver education and support, and respite services.

*From: U.S. Department of Health and Human Services | Published: July 31, 2023*

**READ MORE**



### **How Hybrid Work Has Given Family Caregivers a Lifeline**

Hybrid and remote models are not just influencing how we do our jobs but significantly transforming the approach towards elder care. These new work formats have empowered the way we care for our elderly loved ones while diminishing the previously unchallenged role of senior housing facilities.

*From: Entrepreneur | Published: August 1, 2023*

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### **How Caregivers Deal with Anticipatory Grief**

For both caregivers and care recipients, the losses—of relationships, control, companionship and intimacy, identity, freedom, and love—can be staggering. “Grief can begin at the time of diagnosis,” says Barbara Karnes, RN, a hospice nurse in Vancouver, WA, and author of *The Final Act of Living*. “And it’s typically much more intense for caregivers than non-caregivers because of the close bond they form with the people they are caring for.”

*From: Brain & Life | Published: August 3, 2023*

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## NAC NEWS AND UPDATES



### 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

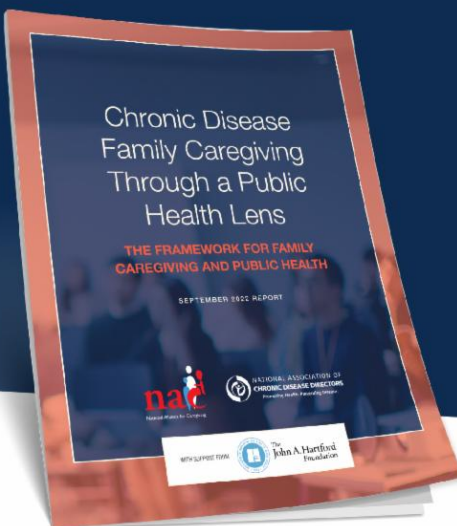




It's important to recognize those with chronic pain and the family caregivers that help care for them. This second installment in the Social Innovations Spotlight Series is written by Dr. Fawn Cothran, PhD, RN, GCNS-BC, FGSA, Hunt Research Director at the National Alliance for Caregiving, and explores 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**  
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The image shows the cover of a report. The title 'Chronic Disease Family Caregiving Through a Public Health Lens' is at the top. Below it, the subtitle 'THE FRAMEWORK FOR FAMILY CAREGIVING AND PUBLIC HEALTH' is written in red. The date 'SEPTEMBER 2022 REPORT' is at the bottom. The NAC logo is in the bottom left corner. A small white box at the bottom right of the cover mentions 'WITH SUPPORT FROM John A. Hartford Foundation'. The background of the cover is a dark blue image of people.

**JUST RELEASED!**

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

**DOWNLOAD NOW**

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

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

Included in this report:

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

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

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

**VIEW THE REPORT**



## EVENTS & OPPORTUNITIES

**AUGUST**



**THE MICHAEL J. FOX FOUNDATION  
FOR PARKINSON'S RESEARCH**

### **Your Legacy: Estate Planning, Philanthropy and Parkinson's**

**August 9, 2023 | 12:00 PM - 1:00 PM ET | Online**

Join The Michael J. Fox Foundation for a special webinar featuring Martin M. Shenkman, CPA, MBA, PFS, AEP, JD, an estate planning attorney and author of 42 books. Martin will share practical and often overlooked estate planning steps you should take if you or a loved one is living with Parkinson's disease and tips to increase your financial wellness and maximize the impact of your philanthropy.

Contact our Planned Giving Team if you have questions about this event or gift planning.

212-509-1524 or [plannedgiving@michaeljfox.org](mailto:plannedgiving@michaeljfox.org)

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



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## Care Connection Webinar: Preventing Neurocognitive Decline

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

Join the Alzheimer's Foundation of America on August 10th for an online presentation by Dr. Kieran Reid about recent studies that have shown that dedicated physical exercise programs in senior centers for older adults have been able to not only reduce the number of falls but improve cognitive function. He will also describe his efforts to develop senior center-based physical activity programs that can achieve these goals and improve the quality of life for at-risk older adults.

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

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## Understanding Alzheimer's and Dementia

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

Alzheimer's disease is not a normal part of aging. Join the Alzheimer's Association on August 10th to learn about the impact of Alzheimer's; the difference between Alzheimer's and dementia; stages and risk factors; and current research and treatments available for some symptoms.

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

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# Del Mar Caregiver Resource Center

A Program of Health Projects Center

## Legal Planning For Caregivers

**August 10, 2023 | 4:00 PM - 5:00 PM ET | Online**

What legal and financial matters are important for caregivers of adult family members living with a chronic illness? Tune in on August 10th for a webinar that will address this topic and provide information regarding powers of attorney, health care directives, wills, trusts, and conservatorships.

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

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## Virtual Family Caregiver Workshop

**August 11, 2023 | 9:00 AM - 12:00 PM ET | Online**

Communication is more than just talking and listening – it's also about sending and receiving messages through attitude, tone of voice, facial expressions and body language. As people with Alzheimer's disease and other dementias progress in their journey and the ability to use words is lost, families need new ways to connect.

Join the Alzheimer's Association on August 11th to explore how communication takes place when someone has Alzheimer's, learn to decode the verbal and behavioral messages delivered by someone with dementia, and identify strategies to help you connect and communicate at each stage of the disease. The Effective Communication Strategies program of the Alzheimer's Association was designed to provide practical information and resources to help dementia caregivers learn to decode verbal and behavioral messages from people with dementia.

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

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## Planning for Getting Paid for Caring for a Family Member

**August 11, 2023 | 2:00 PM - 3:00 PM ET | Online**

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

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

Before joining us:

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

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

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

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**caringkind**  
**connect 2 culture**

## Meaningful Engagement and Enjoyment for Families Impacted by Dementia

**August 14, 2023 | 6:00 PM - 8:00 PM ET | Online**

Learn about connect2culture®, CaringKind's program that connects families to cultural organizations that develop programs specifically created for people living with dementia and their care partners.

Meredith Wong, Director of connect2culture, will speak about some of connect2culture's partner programs.

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

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## Create a Plan for Recovery During Caregiving

**August 15, 2023 | 1:00 PM - 2:00 PM ET | Online**

After an intense period, like a hospitalization or decline, you and your caree deserve a Recovery Plan. The plan gives you a period of time after the crisis for your mind, body and spirit to recover. In addition, you can plan for how your caree will recover by considering a new routine and adding help.

Tune in on August 15th for a webinar featuring Denise Brown that will discuss how to come up with a Recovery Plan for carers and carees.

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

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## Useful Technology for Caregivers

**August 15, 2023 | 7:00 PM - 8:00 PM ET | Online**

As a caregiver, technology can make your life so much easier! There are so many useful gadgets and tools out there that can help you with everything from keeping track of



medication schedules to monitoring your loved one's safety. With the help of these tools, caregivers can better care for their loved ones while still maintaining their own well-being. So don't be afraid to try out some of these useful technologies and see how they can benefit you and your loved one!

Join Willing Hearts, Helpful Hands on August 15th for a discussion of the ways that technology can assist caregivers taking care of a loved one.

A Zoom meeting ID and password will be emailed to all participants 15 minutes prior to the start of the event.

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

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## **Rethinking Carer Empowerment and Resilience**

**August 15, 2023 | 8:30 PM - 10:30 PM ET | Online**

Tune in on August 15th for a free, two-hour interactive webinar that will feature emerging evidence and discussion on the terms empowerment and resilience as they relate to caregiving. This webinar will explore these contentious terms, with the aim of moving towards a more constructive framework for operating.

Designed for a wide audience, evidence presented will include research findings, evidence-based practice, and the lived experience of caring.

The webinar will be interactive and enable participants to share their own ideas and experiences on the topic of carer empowerment as it relates to their identity as a carer and their overall health and wellbeing.

### **About the Carer Knowledge Exchange**

The Carer Knowledge Exchange is a partnership project delivered by Carers NSW and the Institute for Public Policy and Governance (IPPG) at the University of Technology Sydney, proudly funded by the NSW Government.

The Exchange brings together carers, researchers, students, decision makers, professionals and service providers to share their knowledge about carers and learn from each other with the aim to improve outcomes for carers across Australia by connecting research to practice.

This interactive webinar is for anyone with an interest in connecting carer\* related research to practice, including carers and former carers; academic and not-for-profit researchers; research students; policy makers and practitioners; and people who receive care.

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

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## **Taking Care of Yourself**

**August 16, 2023 | 8:30 AM - 10:00 AM ET | Online**

If you care for someone with dementia, this is your chance to consider your own wellbeing and develop some tools and skills to help you.

“Resilience is the way we cope with stress and adversity in life. By learning new ways of thinking, behaving and interacting with others, we develop ways to cope even when life is tough.”

Put another way, resilience is building the ability to make choices when we are under under pressure.

Our instincts are designed to protect us and can take over and make decisions for us, but this isn't always helpful. Resilience gives us the awareness to notice this and the ability to choose how to act rather than a knee jerk reaction.

There are a number of ways we can build resilience that we will discuss in this session.

Join the UK's Dementia Carers Count on August 16th for a discussion about how caregivers can take care of themselves while caring for another. This session is for you if you would like to:

- Learn about how resilience can be built to support your well being
- Gain ideas and strategies to support your own wellbeing
- Spend time with experienced healthcare professionals who will answer your questions in a safe, supportive environment
- Meet other people who are taking care of a friend or family member with dementia in a similar situation

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

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## Does When I Eat Matter? -- Understanding Intermittent Fasting

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

Intermittent fasting/ time-restricted eating. There has been quite a bit of discussion surrounding the optimal times to consume meals and the benefits of resting our digestive systems. Does this have any merit? What does it mean for our longevity, brain health, and overall wellness?

**ABOUT OUR SPEAKER:** Brian Browne MS CSA

Brian Browne is the president of Dementia Care Education, founder of Neuro-Nutrition®, and a research consultant to the Cleveland Clinic. Brian is a cognitive scientist and neuro-nutritionist and possesses over 20 years of expertise in the fields of aging, dementia, clinical research, and nutrition. He is a noted public speaker and a frequent lecturer at meetings and conferences regionally and nationally. Brian has been featured by many media outlets and produces regular expert content for various publications. His research interests include examining the role of nutrition and gut health to promote cognitive performance, successful aging, and reduce the risks of cognitive decline and neurodegenerative diseases.

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

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## Caregiving: Where Do I Start?

**August 16, 2023 | 2:00 PM - 3:00 PM ET | Online**

Caring for a senior loved one can be challenging and even overwhelming at times. Don't go it alone. Join The Senior Source on August 16th for an online session that will help you identify some key components of caregiving such as assessing home safety, organizing important documents, identifying community resources, and mobilizing your care network.

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

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## Tips for Caregivers to Safely Assist with Mobility and Navigate Change



Does your care recipient need help getting up from a chair or transitioning from place to place? Is this task new and difficult for you? Is this something that you may be struggling with? Sometimes moving and providing physical support to your care recipient can be challenging. Caregivers may not realize that they can risk their own physical health while doing their best to negotiate these new tasks.

Join the Ontario Caregiver Organization on August 17th to learn more about:

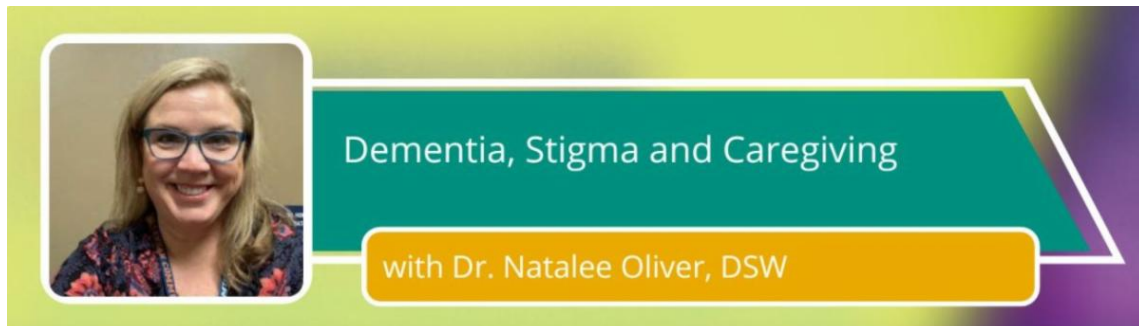
- Acknowledging the emotional challenges that accompany this part of the role
- Tips for moving your care recipient safely
- A discussion on in-home safety devices that could support you
- Lived caregivers' experiences

Who should attend this event? Caregivers who want to learn more about safe moving and handling of care recipients.

Our speaker: Taryn Bolt is a Community Education Program Lead and registered Occupational Therapist at the Mississauga Halton Regional Learning Centre. Taryn brings over a decade of educational and clinical experience in community healthcare to her current role.

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

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## **Dementia, Stigma and Caregiving**

August 17, 2023 | 1:00 PM - 2:00 PM ET | Online

Currently, there are over 6.2 million Americans living with Alzheimer's disease, yet many caregivers do not talk about it or even admit their loved one has it. Why is there so much stigma? How can we stop the stigma so that others will get the help they need as caregivers of someone living with dementia? Join Dr. Natalee Oliver, DSW, on August 17th as she discusses why it's important to share what you are going through as a caregiver and how you can talk to others about it.

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

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## Empowering Loved Ones

**August 17, 2023 | 1:00 PM - 2:00 PM ET | Online**

Providing effective support to friends and family members with a mental health disorder is an essential part of the recovery journey. Discuss the complications of mental illness, the four dimensions of recovery, and how to develop a recovery plan with a licensed therapist, Jaymi Dormaier.

Jaymi is a Licensed Master Social Worker with ten years of experience in the mental health field. In her career as a social worker and therapist she has worked with diverse populations focusing on anxiety, depression, grief, trauma, foster care, adoption, homelessness, and addiction. She is passionate about helping others live a life they love.

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

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# Dementia and Hospice

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

Join HopeHealth Hospice & Palliative Care on August 21st for an online program that will provide participants with a focused look at Medicare hospice guidelines when the terminal diagnosis is a form of dementia. This presentation will discuss the qualifying criteria as well as contributing factors that lead to eligibility for hospice care.

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

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## Relationships, Family, and Mental Health

**August 23, 2023 | 11:00 AM - 12:00 PM ET | Online**

The complicated nature of mental illnesses can make relationships challenging, and caregiver stress — the emotional and physical stress of caregiving — is common. Learn strategies to set boundaries, respond to difficult behavior, and manage your own stress in this one-hour webinar with a licensed therapist.

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

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

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

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## Effective Communication Strategies

**August 23, 2023 | 7:00 PM - 8:00 PM ET | Online**

Communication is more than just talking and listening – it's also about sending and receiving messages through attitude, tone of voice, facial expressions and body language. As people with Alzheimer's disease and other dementias progress in their journey and the ability to use words is lost, families need new ways to connect.

Join the Alzheimer's Association on August 23rd for a presentation that will explore how communication takes place when someone has Alzheimer's, learn to decode the verbal and behavioral messages delivered by someone with dementia, and identify strategies to help you connect and communicate at each stage of the disease. The Effective Communication Strategies program of the Alzheimer's Association was designed to provide practical information and resources to help dementia caregivers learn to decode verbal and behavioral messages from people with dementia.

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

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## **Coping with Emotions of Caregiving**

**August 23, 2023 | 9:00 PM - 10:00 PM ET | Online**

Caring for others is filled with many mixed and varied emotions such as feelings of love, loss, anger, affection, sadness, frustration, and guilt. It's not uncommon for family caregivers to feel lonely and isolated. It takes a lot of physical, mental, spiritual, and emotional energy to care for a loved one. Caregivers often experience a higher rate of stress, anxiety, and depression than those who aren't caregivers.

Join the Family Caregiver Alliance on August 23rd for a class that will explore these emotions and learn about ways to help cope and manage them.

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

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## **Understanding and Responding to Dementia-Related Behavior**

**August 24, 2023 | 1:00 PM - 2:00 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 Alzheimer's Association on August 24th to 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.

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## **CONFIDENCE Financial Education Program**

**Thursdays, August 24, - September 21, 2023 | 5:00 PM - 7:00 PM ET | Online**

Join the University of Southern California Family Caregiver Support Program for a virtual program designed to help Latino and Hispanic family caregivers to persons living with Alzheimer's disease or a related dementia lower the out-of-pocket costs of caregiving. Over 5 weeks, caregivers will meet virtually and gather in group sessions led by trained facilitators to discuss: how to navigate community resources, strategies for seeking help, how to balance employment and caregiving, and more!

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

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## Release a Worry with a Family Emergency Plan

**August 25, 2023 | 1:00 PM - 2:00 PM ET | Online**

When you care for a family member, making plans can feel impossible. Even worse, making back-up plans feels completely out of the question. Consider two stats:

- 49% of survey respondents say they receive no help from family members.
- 74% say they do not have a back-up or a trained back-up to provide care in their absence if they become ill, have an emergency or want to take a vacation.

With the direct care workforce shortage, planning becomes even more important.

Join The Caregiving Years Training Academy on August 25th for a 50-minute planning session to create the plans you need to connect with Denise M. Brown, who has been supporting those who care for 30 years and Certified Caregiving Consultants (CCC).

The agenda for this webinar includes:

- 15-minute overview with Denise Brown
- Small group discussions with a CCC
- Wrap-up

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

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## Creating an End-of-Life Plan

**August 29, 2023 | 11:30 AM - 1:00 PM ET | Online**

Thinking and talking about your final wishes can be tough. But doing the work of deciding, discussing, documenting and sharing those wishes with your loved ones can provide peace of mind for everyone. Getting the practical side of your affairs in order will unburden your loved ones from having to make difficult decisions as they grieve.

Join AARP on August 29th for a webinar that will show you how to:

- Plan and document your wishes in case of medical or other emergencies
- Track important medical and insurance information
- Store key information on property, vehicles and non-financial assets
- Document what you have and what you owe

- Make the "unseen" visible by creating a digital estate plan
- Express your final wishes for how you'd like to be remembered
- Provide grief support to your loved ones before and after your death
- Store and digitally access all your final wishes documents

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

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## **Virtual Ask the Expert: Estate Planning, Probate or Long Term Care Planning**

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

Do you have questions about estate planning, probate or long term care planning? Maybe you've wondered if estate planning is only for the very wealthy?

Join the Alzheimer's Association on August 29th to learn tips for managing someone else's finances, how to prepare for future care costs and the benefits of early planning. This event will feature Nick Maggard, an estate planning and elder law attorney.

*Please note that Nick cannot provide legal advice but informational guidance only. You can submit your questions when registering, but we can't guarantee that every one will be answered. A second program will be in November. This will not be recorded.*

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

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## **Memory Connections: Helping Families Navigate Their Dementia Journey with a Menu of Program Options**

**August 29, 2023 | 3:00 PM - 4:00 PM ET | Online**

The National Alzheimer's and Dementia Resource Center (NADRC) is holding a webinar on August 29th, "Memory Connections: Helping Families Navigate Their Dementia Journey with a Menu of Program Options." Participants will learn how Senior Services Inc. and their partners Novant Health, Atrium Health Sticht Center, Winston-Salem State University Occupational Therapy Department and the Maya Angelou Center for Health Equity are working together to create a unique continuum of dementia care. Presenters will highlight the Maya Angelou Center for Health Equity's Caregiver College, a week-long program that educates African Americans about Alzheimer's disease and related dementias. Caregiver College graduates apply their newly acquired knowledge by delivering presentations to their social groups, churches, family members, friends and business connections.

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

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**SEPTEMBER**



## Care Essentials for Care Partners Workshops

**Tuesdays, September 5 - September 26, 2023 | 6:30 PM - 8:30 PM ET | Online**

Join the Alzheimer Society of Durham Region (Canada) on September 5th for a four-part series that will provide family and friends of persons living with dementia an opportunity to explore approaches to care in an interactive and supportive atmosphere. Each session features a workbook and helpful resources.

### Week 1: Care Essentials: What to Expect (September 5th)

First in our four-part series, this session will provide an overview of the progression and symptoms of dementia and discuss how you can support remaining abilities for the person living with dementia.

### Week 2: Care Essentials: Communicating Effectively (September 12th)

Second in our four-part series, this session explores communication changes in dementia and strategies for effective communication.

### Week 3: Care Essentials: Responding to Behaviour (September 19th)

Third in our four-part series, this session will explore whole person care, behavior changes and how to use problem solving solutions in your caregiving journey.

### Week 4: Care Essentials: Supporting Daily Activities (September 26th)

Fourth in our four-part series, this session will help care partners explore meaningful activities, ways to support daily living and will discuss local resources available.

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.

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## Driving Safety for Older Adults

**September 6, 2023 | 1:00 PM - 2:00 PM ET | Online**

The topic of driving is often one that involves a lot of emotions. For many, driving equates to independence and the freedom to go when and where you want. As a person ages, it can be helpful to openly communicate about driving abilities and safety, rather than doing so due to a crisis such as a crash or a "close call." Families often turn to professionals for



guidance and insights on how to talk about driving and the best approach to taking away the keys.

Join the American Society on Aging on September 6th for a webinar to learn about the importance of developing a plan to help older adults move out of the driver's seat when necessary, while still remaining engaged with friends, family and community.

**Participants in this webinar will be able to:**

- Identify potential signs an older adult might be an unsafe driver
- Understand some common conditions and aging-related diseases that can affect driving
- Learn the best approaches to develop a plan to transition out of driving before a crisis occurs
- Discover tips to help reduce the potential for isolation and depression after an older adult stops driving

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

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## **Understanding and Responding to Dementia-Related Behavior**

**September 13, 2023 | 1:30 PM - 3:00 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 Alzheimer's Association on September 13th to 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.

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# TOOLS & TIPS FOR CAREGIVERS

## Tools and Tips for Caregivers

**September 13, 2023 | 7:00 PM - 8:00 PM ET | Online**

Between aging, the impacts of long COVID, accidents, and a myriad of other causes, the need for a caregiver can arise at any moment.

Join Westchester Community Foundation executive director Laura Rossi in conversation with Moira Laidlaw, Esq., of Hollis Laidlaw & Simon, P.C. and Michael Picon, author of *The Caregiver's Notebook*, to learn more about the ins-and-outs of caregiving for a loved one. You'll gain an understanding of the scope of caregiving and resources available, learn about healthcare and legal systems that caregivers navigate, and receive practical tools to decrease stress and get support.

This event is open to the general public and is ideal for family and chosen family members currently, or interested in, supporting others.

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

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## **Caring for a Patient with Dementia: Disease Progression and Care Tips**

**September 20, 2023 | 10:00 AM - 11:00 AM ET | Online**

Tune in on September 20th for a presentation by HopeHealth Hospice & Palliative Care that will identify characteristics of each stage of dementia, discuss common challenges in providing care and identify communication and care tips to improve our daily interactions with patients living with dementia.

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

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## **Surviving and Thriving: Pancreatic Cancer and Caregiver Workshop**

**September 22, 2023 | 10:30 AM - 5:00 PM ET | Online**

Join the Siteman Cancer Center and the Cancer Support Community of Greater St. Louis on September 22nd for a Pancreatic Cancer Patient and Caregiver Workshop. This free education and support workshop is open to pancreatic cancer patients, survivors, and their primary caregivers.

Participants will learn how to positively impact the survivorship experience after a pancreatic cancer diagnosis.

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

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# Planning Your Temporary Career Leave



## Planning Your Temporary Career Leave

**September 22, 2023 | 11:00 AM - 1:00 PM ET | Online**

We do our best to keep our career on track as we manage our caregiving responsibilities. Sometimes, though, we need to take a leave because of a crisis, our caree's decline, our caree's transition to a different care setting or our caree's end of life care needs.

Tune in on September 22nd for a presentation by The Caregiving Years Training Academy that will help you think through when you may want to use either a paid leave benefit or Family Medical Leave. Participants will also learn how to effectively manage their leave so they're ready to return to work.

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

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## Hearing and Balance Disorders in Older Adults

**September 28, 2023 | 1:00 PM - 2:00 PM ET | Online**

Hearing loss and balance disorders increase with age. But did you know hearing and balance degenerate independently? This means they should be evaluated separately.

Join the American Society on Aging on September 28th for an overview of hearing loss and balance disorders in older adults, including signs, symptoms and treatment options to help improve quality of life. The discussion covers tips to assess the conditions and effective communication strategies to integrate into your care setting.

**Participants in this webinar will be able to:**

- Identify common symptoms of hearing loss and cite treatment options.
- Demonstrate and explain strategies for improving communication with older adults.
- Identify signs/symptoms/effects of balance loss.
- List treatment options for balance loss.

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

**REGISTER**  
>

**OCTOBER**



## A Plan for You After Your Family Member's Diagnosis

**October 3, 2023 | 1:00 PM - 2:00 PM ET | Online**

It's not a holiday, Diagnosis Day, but it's a day that's so momentous for all the wrong reasons that it becomes etched in our memories. The world looks the same but a diagnosis changes how the world feels. It all feels so strange.

How do you manage after a family member's diagnosis?

Join Denise Brown on October 3rd for a discussion of how to proceed once a diagnosis has been made.

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

**REGISTER**



**Alzheimer's Program: Healthy Living  
for Your Brain & Body**

**October 10, 2023 | 4:00 PM - 5:30 PM ET | Online**

For centuries, we've known that the health of the brain and the body are connected. But now, science is able to provide insights into how to make lifestyle choices that may help you keep your brain and body healthy as you age. Join the Kedlac Neurological Resource Center on October 10th to learn about research in the areas of diet and nutrition, exercise, cognitive activity and social engagement, and use hands-on tools to help you incorporate these recommendations into a plan for healthy aging.

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

**REGISTER**



## **Smoking and Dementia**

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

Smoking can affect nearly every organ of the body, leading to diseases such as cancer, stroke, heart disease, and lung diseases. In fact, it is among the top risk factors for dementia. Join the American Society on Aging on October 18th for a course that will provide strategies and resources to address smoking and build cognitive resilience.

**Participants in this webinar will be able to:**

- List 6 or more modifiable risk factors for dementia.
- Summarize the link between smoking and dementia.
- Identify effective interventions and strategies to address smoking.
- Identify special considerations for high-risk populations.

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

**REGISTER**



## Planning Your Return to Work



### Planning Your Return to Work After a Caregiving Leave

**October 20, 2023 | 11:00 AM - 1:00 PM ET | Online**

When you take a leave or break from your career because of your caregiving responsibilities, you need support and encouragement to return. Join the Caregiving Years Training Academy on October 20th for a presentation that will offer ideas, plans and resources to help you return to your career.

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

**REGISTER**



### PATIENT AND CAREGIVER STUDIES

#### Psilocybin for Depression in People with Mild Cognitive Impairment or Early Alzheimer's

**Who is sponsoring this study?** Johns Hopkins University

**Where is this study located?** Maryland

Start: March 24, 2021

End: December 2024

Enrollment: 20

#### What is this study about?

Psilocybin is a hallucinogenic chemical found in certain mushrooms. This pilot study will evaluate whether psilocybin, provided in a supervised environment, reduces depression and improves the quality of life in people with mild cognitive impairment or early-stage



Alzheimer's disease. All participants will receive eight weeks of weekly psychological support and two doses of psilocybin in weeks four and six. Researchers will assess levels of depression and quality of life at the start of the study, two weeks after the second dose of psilocybin, and again after six months.

## Do I qualify to participate in this study?

Minimum Age: 18 Years

Maximum Age: 85 Years

### Must have:

- Mild cognitive impairment or Alzheimer's disease with mild severity
- Clinical Dementia Rating memory score at screening of > 0.5
- Mini-Mental State Examination score of 18 to 26
- Mild to moderate depression
- Availability of a close friend or family member willing and able to serve as an observer and assist with data collection

### Must NOT have:

- Currently taking antidepressants, antipsychotics, or monoamine oxidase inhibitors
- Use of sildenafil, tadalafil, or similar medications within 72 hours of psilocybin treatment
- Personal or family history of schizophrenia, bipolar I disorder, or psychotic disorder (unless substance-induced or due to a medical condition)
- Any significant or uncontrolled medical condition that could interfere with the study, including:
  - Cardiovascular condition (e.g., atrial fibrillation, bradycardia, artificial heart valves)
  - Transient ischemic attack (i.e., mini-stroke) in the past six months
  - Stroke Uncontrolled high blood pressure
  - Seizure disorder Insulin-dependent diabetes
  - Kidney disease

To learn more or participate in this study, click the red button below.

**LEARN MORE**  
>

## CORT108297 for People at Increased Risk for Alzheimer's

**Who is sponsoring this study?** Johns Hopkins University

**Where is this study located?** Maryland

Start: June 28, 2021

End: January 2027

Enrollment: 52

### What is this study about?

CORT108297 is an FDA-approved drug used to manage the neural and hormonal responses to stress. This study will test whether the drug can improve memory and thinking in people who have mild cognitive impairment (MCI) due to Alzheimer's or who are at risk for developing Alzheimer's due to family history, genetics, or memory problems. Participants will be randomly assigned to take three tablets of either the study drug or a placebo, every day for two weeks. Over 10 weeks, each group will alternate between

receiving the study drug or placebo, attend six study visits, and complete cognition and memory tests. After doing a brief, stressful activity, such as public speaking or mental arithmetic, participants will provide saliva samples to measure stress hormone response.

### **Do I qualify to participate in this study?**

Minimum Age: 55 Years

Maximum Age: N/A

#### **Must have:**

Inclusion Criteria for Participants with MCI:

- Meet NIA-Alzheimer's Association diagnostic criteria for MCI due to Alzheimer's disease

Inclusion Criteria for Participants at Risk for Developing Alzheimer's Disease:

- Normal cognition based on clinical and cognitive assessment
- Have at least one of the following risk factors for Alzheimer's disease:
  - Known to have at least one apolipoprotein E (APOE) epsilon 4 allele
  - T-score <40 on the Multifactorial Memory Questionnaire Satisfaction Scale
  - First-degree relative (mother, father, sister, or brother) with dementia

Inclusion Criteria for All Participants:

- Body mass index >17 and <30
- Post-menopausal, if female
- Nonsmoker
- Availability of a study partner who:
  - Has frequent contact with the participant (10+ hours/week in person and by telephone)
  - Can provide information about the participant's functioning
- Native English speaker
- Good general health

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

- Participation in another clinical trial during the study
- Irregular heart rate, or arrhythmia, based on an electrocardiogram
- Any significant neurologic disease other than Alzheimer's disease
- History of significant head trauma resulting in a physical dysfunction (e.g., speech or walking problems) or known structural brain abnormalities
- Major depression or bipolar disorder within the past year
- History of alcohol or drug dependence
- General surgery within the last three months
- Any significant illness or unstable medical condition
- Uncorrected vision or hearing problems significant enough to interfere with the study
- Prohibited medications:
  - Antidepressants, neuroleptics, sedative hypnotics, or glucocorticoids, within the last six months
  - Any medications processed by the enzymes CYP2C9 or CYP2C19, such as clopidogrel and proton pump inhibitors, within the last six months
  - CYP3A inhibitor medication or supplement, including grapefruit juice and St. John's Wort

To learn more or participate in this study, click the red button below.

**LEARN MORE**



**Genetic and Epigenetic Signatures of Translational Aging  
Laboratory Testing (GESTALT)**

**Who is sponsoring this study?** National Institute on Aging (NIA)

**Where is this study located?** Maryland

Start: March 15, 2015

End: December 2099

Enrollment: 900

### **What Is This Study About?**

This long-term study will help researchers learn more about biomarkers in human blood and tissues and their relationship to aging. People who are healthy, frail, or have a medical condition can participate. Participants will take part in a medical history, physical exam, blood and urine tests, and heart tests. There will be a two-day baseline visit, followed by visits every two years for up to 10 years, during which they will repeat screening procedures, including balance and walking tests, leg and grip strength tests, health and mental state questions, and memory and problem-solving tests. Participants will also undergo cytopheresis, a procedure that removes blood through a needle in the vein of one arm, runs it through a machine, then returns it through a needle in a vein of the other arm. Visits may include magnetic resonance imaging (MRI) scans, a diabetes test, and removal of a small amount of muscle tissue and/or skin.

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

Minimum Age: 20 Years

Maximum Age: 105 Years

#### **Must have:**

##### Healthy Participants

- 20 years of age or older
- Consent to genetic testing and storage at the screening visit and all subsequent visits
- Willingness to return every two years for study visit procedures
- Good vein access for blood sampling
- Eligible for apheresis, a technology in which one's blood is passed through an apparatus that separates one particular constituent and returns the rest to circulation
- Weight of 110 pounds or greater and a body mass index of less than 30
- Able to care for self without assistance
- Able to walk for at least 400 meters without assistance and to perform normal activities of daily living without shortness of breath or other severe symptoms
- Able to read and speak English
- Able to undergo MRI (e.g., not claustrophobic, and do not have metal implants, or hip or knee replacements)

##### Frail Participants and Non-Healthy Participants

- 20 years of age or older
- Consent to genetic testing and storage at the screening visit and all subsequent visits
- Willingness to return every two years for study visit procedures
- Good vein access for blood sampling
- Weight of 110 pounds or greater and a body mass index of less than 35
- Ability to read and speak English
- Ability to undergo MRI (e.g., not claustrophobic, and do not have metal implants, or hip or knee replacements)

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

##### Healthy Participants

- Participants who develop cognitive and motor problems from medical conditions can continue in the study but are excluded from tests in which the medical condition is excluded.
- Genetic disease such as sickle cell anemia, hemochromatosis (iron overload), cystic fibrosis, or Ehlers-Danlos syndrome (connective tissue disorder)

- Autoimmune diseases such as Hashimoto's thyroiditis, myasthenia gravis, or rheumatoid arthritis
- Cognitive impairment or dementia (Mini-Mental State Examination <26 or Blessed Mental >3)
- History of cardiovascular disease or cerebrovascular disease, including angina requiring treatment, myocardial infarction, congestive heart failure, uncontrolled hypertension, pacemaker, stroke, or transient ischemic attack
- History of diabetes requiring medical treatment other than diet and exercise, with fasting glucose level <126 mg/dL
- Cancer within the past 10 years, except for locally limited squamous and basal cell cancer
- Clinically significant hormonal dysfunction; mild hypothyroidism in participants over age 60 is allowed
- History of neurological disease or birth defect (other than minor anatomical abnormalities, which do not affect physical and/or cognitive function)
- History of kidney or liver disease; history of severe gastrointestinal disease requiring chronic treatment (GERD, Crohn's disease, ulcerative colitis); history of severe pulmonary disease (COPD or asthma requiring continuous medication use); muscle-skeletal conditions due to diseases or traumas that cause pathological weakness and/or chronic pain
- History of severe psychiatric conditions associated with behavioral problems or requiring chronic medical treatment
- Medical condition that requires continuous, long-term treatment with antibiotics, corticosteroids, immunosuppressors, H2 blockers and/or proton pump inhibitors, or pain medications, or that requires the use of chronic anticoagulant medication such as Coumadin, heparin, or antiplatelet agents other than low-dose aspirin
- Important sensory deficits that preclude participating in standard neuropsychological tests or providing informed consent
- Pregnant or nursing
- Current smoking or smoking within the past three months
- History of allergy to acid-citrate-dextrose (ACD) anticoagulant or active bleeding disorder such as hemophilia or Von Willebrand disease.
- History of seizures within the last three months
- History of Lyme disease, unless six weeks after treatment and no new symptoms
- HIV virus infection; hepatitis B or C; active syphilis, gonorrhea, or tuberculosis requiring treatment
- Laboratory results outside ranges determined by study leaders; positive urine drug screen (unless taking prescribed medication)

#### Frail Participants and Non-Healthy Participants

- Genetic disease such as sickle cell anemia, hemochromatosis (iron overload), cystic fibrosis, or Ehlers-Danlos syndrome (connective tissue disorder)
- Important sensory deficits that preclude participating in standard neuropsychological tests or providing informed consent
- Pregnant or nursing
- Current acute medical condition
- History of active bleeding disorder such as hemophilia or Von Willebrand disease.
- History of seizures within the last three months

To learn more or participate in this study, click the red button below.

**LEARN MORE**



## **BIIB080 for Mild Cognitive Impairment Due to Alzheimer's Disease or Mild Alzheimer's Dementia**

**Who is sponsoring this study?** Multiple states

**Where is this study located?** Biogen

Start: Aug. 24, 2022



## What is this study about?

This Phase 2 clinical trial will evaluate the effects and safety of different dosages of the study drug, BIIB080, on cognition and daily functioning in people with mild cognitive impairment (MCI) due to Alzheimer's disease or mild Alzheimer's dementia. BIIB080 is an experimental research drug designed to reduce the production of tau, a protein associated with Alzheimer's. Participants will be randomly assigned to receive either a low or high dosage of BIIB080 or a placebo by cerebrospinal fluid (CSF) injection, for either every 12 or 24 weeks for up to 72 weeks. At the start of the study and after 72 weeks, participants will complete questionnaires and other tests to measure cognitive and daily functioning. All participants will be monitored for adverse side effects up to two years.

## Do I qualify to participate in this study?

Minimum Age: 50 Years  
Maximum Age: 80 Years

### Must have:

- Meet all clinical requirements for MCI due to Alzheimer's or mild Alzheimer's dementia, including the following at the study screening visit:
  - Memory impairment, with Repeatable Battery for the Assessment of Neuropsychological Status Delayed Memory Index score of < 85
  - Clinical Dementia Rating global score of 0.5 or 1
  - Mini-Mental State Examination score of 22 to 30
- Positive for amyloid deposits, based on positive emission tomography brain scan or CSF test
- If taking a non-disease-modifying Alzheimer's medication, including but not limited to donepezil, rivastigmine, galantamine, tacrine, and memantine, the dosage must be stable for at least two months prior to the study screening

### Must NOT have:

- Known allergy to BIIB080 or a history of hypersensitivity to any of the inactive ingredients in the drug product
- Previous participation in this study or other studies with BIIB080
- Current enrollment, plan to enroll, or previous participation in a research study for:
- Any therapy designed to have a disease-modifying effect in Alzheimer's, including gene therapy and any immunotherapy targeting amyloid protein or tau protein, unless:
  - Study was for a passive immunotherapy targeting tau protein, then participation in this study may be possible if the last treatment occurred at least six months, or long enough for the therapy to clear the body, prior to the study screening
  - Documentation is available that the participant received a placebo, then participation in this study would still be possible
- Current or previous use of medications designed to have a disease-modifying effect on Alzheimer's, outside of a research study
- Any vaccination within 10 days before or after the first day of starting study treatment or any of the study clinic visits
- Any condition that could make having a brain MRI unsafe (e.g., MRI-incompatible pacemaker, MRI-incompatible aneurysm clips, artificial heart valves, or other metal foreign body, claustrophobia that cannot be medically managed)

To learn more or participate in this study, click the red button below.

**LEARN MORE**



# MIB-626 for Alzheimer's Disease

**Who is sponsoring this study?** Brigham and Women's Hospital

**Where is this study located?** Massachusetts

Start: Dec. 1, 2021

End: December 2024

Enrollment: 50

## What is this study about?

This Phase 1/2 clinical trial will test the safety and effectiveness of the experimental drug MIB-626 to improve cognitive and daily functioning in people with Alzheimer's disease. MIB-626 is designed to activate certain pathways involved in brain cell energy to reduce the breakdown of brain cells associated with Alzheimer's. Participants will be randomly assigned to take either MIB-626 or a placebo tablet twice a day for three months. At the start and end of the study, participants will provide cerebrospinal fluid and blood samples, undergo MRI imaging, complete cognitive tests, and answer questionnaires about daily functioning and mental health. Researchers will use this information to measure changes in cognitive and daily functioning, levels of the study drug in the blood and brain, and biological measures of aging and Alzheimer's.

## Do I qualify to participate in this study?

Minimum Age: 55 Years

Maximum Age: 85 Years

### Must have:

- Diagnosis of Alzheimer's disease, with:
  - Evidence of amyloid protein buildup in cerebrospinal fluid, based on spinal tap analysis
  - Clinical Dementia Rating global score of 0.5 or 1
  - Mini-Mental State Exam Score of 18 to 26
  - Geriatric Depression Scale score of < 6
  - Impaired memory, based on study screening evaluation
- If taking FDA-approved medications for Alzheimer's (e.g., cholinesterase inhibitors, memantine), dosage must be stable for at least two months before study screening
- Adequate vision and hearing to complete study tests
- Availability of a study partner who has regular contact with the participant, knows them well, and is able to attend study visits
- Fluent in English

### Must NOT have:

- Any systemic illness or unstable medical condition that could jeopardize safety or interfere with the study results, including:
- Neurological disease other than Alzheimer's that could cause cognitive impairment, including:
  - Parkinson's disease, vascular dementia, dementia with Lewy bodies, frontotemporal dementia, Huntington's disease
  - Normal pressure hydrocephalus
  - Corticobasal syndrome
  - Brain tumor, seizure disorder
  - Subdural hematoma within the last year
  - Multiple sclerosis
  - History of significant head trauma followed by persistent neurologic deficits
- Known brain structure abnormalities
- Abnormalities in the blood vessels supplying blood to the brain (e.g., stroke,

- hemorrhage), based on MRI brain scan
- Psychiatric disorder (e.g., major depressive disorder within the last year, bipolar disorder, schizophrenia) or current major psychiatric symptoms that could interfere with study procedures
- Serious back or spinal disease that would make a lumbar puncture difficult or unsafe
- History of alcohol or substance abuse or dependence within the past two years
- Currently taking any of the following medications:
  - Niacin or dietary supplements containing nicotinamide mononucleotide or nicotinamide riboside
  - Antipsychotic medications or antidepressant medications with anticholinergic side effects (prospective participants taking psychoactive medications must discontinue use at least two months before study screening)
  - Blood thinners
- Abnormal laboratory test results
- Participation in another study testing an experimental drug within the past three months or recent enough that the experimental drug is still in the body

To learn more or participate in this study, click the red button below.

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## Neflamapimod for Dementia With Lewy Bodies

**Who is sponsoring this study?** EIP Pharma Inc.

**Where is this study located?** Multiple states

Start: May 1, 2023

End: March 2025

Enrollment: 160

### What is this study about?

- This Phase 2 clinical trial will evaluate the effectiveness of neflamapimod to improve memory, learning, and problem-solving skills in people with dementia with Lewy bodies (DLB). Participants will be randomly assigned to receive either neflamapimod or placebo capsules three times a day for four months. At the start and end of the study, participants will complete cognitive and neuropsychological tests and undergo an electroencephalogram, or EEG, to measure brain activity. Researchers will measure changes in memory, cognitive function, mobility, dementia symptoms (e.g., sleep, hallucinations), and functional connections in the brain.

### Do I qualify to participate in this study?

Minimum Age: 55 Years

Maximum Age: N/A

### Must have:

- Probable DLB, based on diagnostic criteria, including:
  - Brain imaging (DaTscan) results consistent with DLB
  - If brain imaging results are negative, then must have a history of a REM sleep behavioral disorder, based on polysomnography testing
  - Clinical Dementia Rating Global Score of 0.5 or 1.0
- If currently receiving cholinesterase inhibitor therapy:
  - Therapy must be for longer than three months
  - Stable dosage for at least six weeks before starting the study
  - Dosage must not change during the study, except for dose reduction due to

- tolerance
- If not currently receiving cholinesterase inhibitor therapy, but received such therapy in the past:
  - Therapy must have been discontinued at least three months before starting this study
- Able to perform all aspects of the study's cognitive and function tests with:
  - Normal or corrected eyesight and hearing
  - No history of learning difficulties that could interfere with test completion
- Vaccinated for SARS-CoV-19, unless excluded for medical reasons
- Must have a reliable study partner
- If female, must be:
  - Postmenopausal for more than one year before starting the study, or
  - Surgically sterile (e.g., hysterectomy)

**Must NOT have:**

- Any central nervous system condition other than DLB (e.g., post-stroke dementia, vascular dementia, Alzheimer's disease, or Parkinson's disease)
- Blood levels of tau protein > 2.4 pg/mL, a protein associated with Alzheimer's
- Serious risk of suicide, based on study screening evaluation
- Ongoing major and active psychiatric disorder and/or other medical condition that could compromise study safety or completion
- Alcohol or drug abuse within the past two years
- Abnormal blood or urine test results that are clinically significant
- Known human immunodeficiency virus, hepatitis B, or active hepatitis C virus infection
- Past participation in a research drug trial less than six weeks before or long enough before to ensure that the other research drug has cleared the body before starting this study
- History of brain surgery within the past five years
- If male with female partner(s) of child-bearing potential, unwilling or unable to adhere to contraception requirements specified in the protocol
- Positive pregnancy test result during study screening and/or is unwilling or unable to adhere to the study's contraception requirements
- Body weight less than 132 pounds
- Poorly controlled medical illness that would interfere with study measurements, such as:
  - High blood pressure
  - Heart attack within past six months, uncompensated congestive heart failure, or other significant heart disease
  - Significant lung, kidney, liver, infectious disease, immune, metabolic, or hormonal disorders

To learn more or participate in this study, click the red button below.

**LEARN MORE**  
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## Online Insomnia Therapy for People with Mild Cognitive Impairment

**Who is sponsoring this study?** University of Virginia

**Where is this study located?** Virginia

Start: Feb. 27, 2023

End: January 2028

Enrollment: 144

**What is this study about?**



This Phase 2 study, named SHUTi MIND, will test whether online cognitive behavioral therapy for insomnia (CBTi) can improve sleep and cognition in older adults with mild cognitive impairment. Participants will be randomly assigned to complete a sleep health education program either with or without weekly CBTi sessions for up to nine weeks. All study activities are online and all participants will keep daily sleep diaries. At the start and end of the program, and at six-, 12-, 18-, and 24-month follow-up appointments, all participants will complete questionnaires related to their sleep, fatigue, cognition, mental health, and overall quality of life.

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

Minimum Age: 65 Years

Maximum Age: N/A

#### **Must have:**

- Able to speak and read English
- Living in the United States
- Access to any internet-enabled device (computer, tablet, smartphone) with email
- Current problems falling asleep and/or staying asleep, which have caused significant distress or impairment in social, work-related, or other areas of functioning over the past three months
- Cognitive impairment, based on testing at study screening
- If currently taking medications, dosage regimen must be stable

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

- Currently undergoing psychological treatment for insomnia
- Psychological or psychiatric treatment that started within the past three months
- Any of the following medical conditions, which may interfere with the study:
  - Huntington's or Parkinson's disease
  - Psychotic or bipolar disorder, or severe depression
  - Epilepsy without stable treatment for at least three months
  - Asthma or respiratory concerns with night treatment
  - Brain tumor, injury, or infection that has not yet healed
  - Any untreated sleep disorders other than insomnia (e.g., obstructive sleep apnea)
  - Chronic pain treated with opioids
- Currently being treated for hyperthyroidism
- Currently undergoing chemotherapy
- Irregular sleep schedule
- Currently taking any medication that is known to cause insomnia, including stimulating medications taken in the evening or taken for less than three months
- Moderate to high risk of suicide
- Alcohol or drug abuse within the past year

To learn more or participate in this study, click the red button below.

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**IN CASE YOU MISSED IT...**

**Expanding Inclusion for LGBTQ+ Older Adults**



This program examines some of the unique challenges and needs of aging LGBTQ+ people and explores suggestions and resources to help families and colleagues create inclusive environments for LGBTQ+ older adults and lays the groundwork for caregiver networks to realize their commitment to serving LGBTQ+ older adults.



## RESEARCH & RESOURCES



### **Study: Older Dementia Patients Go to ER Twice as Often as Other Seniors**

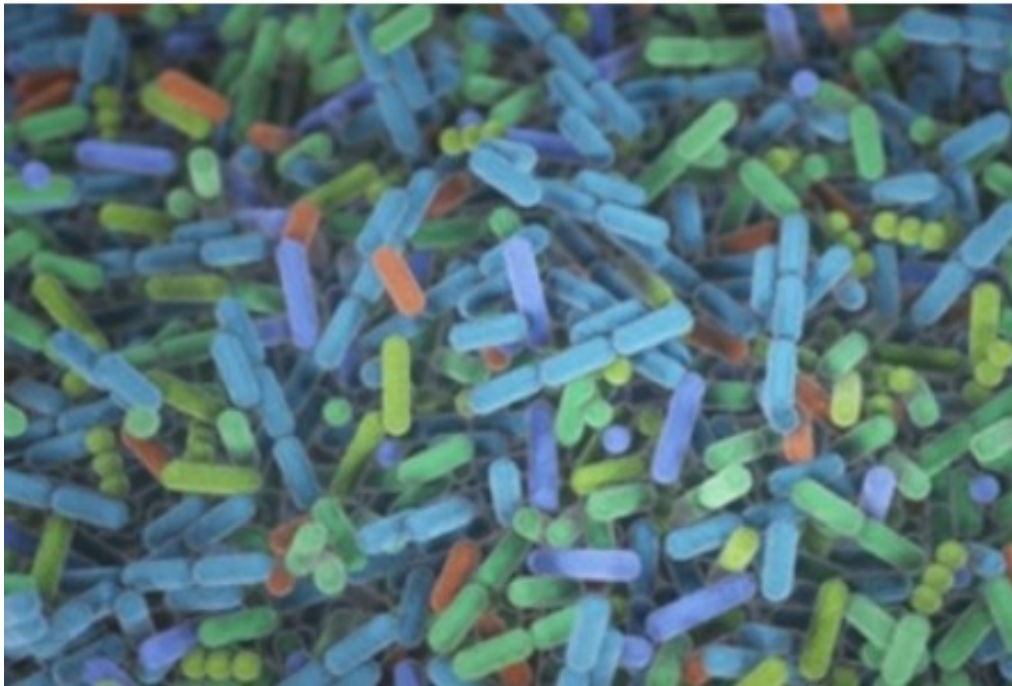
Older people with dementia seek care in the emergency room twice as often as their peers, a new analysis suggests — leading to what researchers call “potentially avoidable and harmful visits” for some patients.

The study, published July 24 in *JAMA Neurology*, examined data from the 2016-2019 National Hospital Ambulatory Medical Care Survey, which collects demographic and other information about a nationally representative sample of ER visits. About 1.4 million

of the annual 20.4 million ER visits among adults over 65 involved patients with Alzheimer's disease and related dementias, researchers found.

To learn more, click the red button below.

**LEARN MORE**



## **Changes in Human Microbiome Precede Alzheimer's Cognitive Declines**

In people with Alzheimer's disease, the underlying changes in the brain associated with dementia typically begin many years — or even decades — before a diagnosis. While pinpointing the exact causes of Alzheimer's remains a major research challenge, they likely involve a combination of genetic, environmental, and lifestyle factors. Now an NIH-funded study elucidates the role of another likely culprit that you may not have considered: the human gut microbiome, the trillions of diverse bacteria and other microbes that live primarily in our intestines.

To learn more, click the red button below.

**LEARN MORE**





## How the Aging Brain Affects Thinking

The brain controls many aspects of thinking — remembering, planning and organizing, making decisions, and much more. These cognitive abilities affect how well we do everyday tasks and whether we can live independently.

Some changes in thinking are common as people get older. For example, older adults may:

- Be slower to find words and recall names
- Have problems with multitasking
- Experience mild decreases in the ability to pay attention

To learn more, click the red button below.

**LEARN MORE**



## Advance Care Planning and Health Care Decisions: Tips for Caregivers and Families

Knowing what matters most to your loved one can help you honor their wishes and give you peace of mind if they become too sick to make decisions. Unfortunately, only one in three people in the United States has a plan for their future health care in place. There are steps you can take to help your friend or family member navigate future medical decisions — and to be prepared to make decisions for them, if needed. This is part of advance care planning, which involves preparing for decisions about future medical care and discussing those wishes with loved ones.

To learn more, click the red button below.

**LEARN MORE**







## Preparing a Living Will

If you're seriously ill and can't communicate your wishes about medical care, a living will can help ensure you get the care you want. A living will is an important part of advance care planning, which involves discussing and preparing for future health care decisions in the event you can't make them. These decisions are often put into legal documents called advance directives. A living will is one of the most common types of advance directives. The other common advance directive is called a durable power of attorney for health care, which names a person (called a health care proxy) who can make decisions on your behalf.

To learn more, click the red button below.

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## A Guide to Walk-In Showers for the Elderly

According to a 2021 Home and Community Preferences Survey by AARP, 75% of people over age 50 plan to live in their current homes or communities for the rest of their lives. Aside from their unwillingness to move, older adults prefer aging in place as it allows them to retain their independence and is exponentially more affordable. However, one of the main concerns of aging in place is safety.

Unfortunately, most longtime homes cannot meet the seniors' needs or present safety hazards. Since seniors often struggle with mobility and balance, they have a higher risk for falls. According to the Centers of Disease and Prevention(CDC), falls are the leading cause of death, and non-fatal injuries among adults 65 years of age or older. This highlights the importance of home modifications to lower the risk of falls and make aging in place safer for seniors.

To learn more, click the red button below.

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**PREVIOUSLY APPEARED**

# ROSALYNN **FOR** CARTER **CAREGIVERS** INSTITUTE

## **Prepared Caregivers: A Toolkit for Caregivers of Veterans for Disaster Preparedness**

The Rosalynn Carter Institute for Caregivers has released a brand new toolkit to help caregivers of Veterans prepare for disasters. The toolkit, titled Prepared Caregivers: A Toolkit for Caregivers of Veterans for Disaster Preparedness, is the result of countless conversations with caregivers and emergency response personnel who all said the same thing: caregivers need support in order to be better prepared in emergencies.

Prepared Caregivers is made up of plans, advice, insight and conversation prompts for caregivers of Veterans, with customizable checklists designed to create a plan suited to caregivers' unique needs. Resources include but are not limited to:

- Explanations of key terms used in the preparedness sector but that are not commonly known
- A military-caregiver-specific emergency plan
- Checklists for caring for people with special needs, pets and service animals in an emergency
- Insight into how the physical and mental wounds of war may cause Veterans to experience disasters differently from other care recipients
- Strategies to help Veterans process their emotions in precarious situations
- Tips for service animals
- Month-by-month guides for assembling disaster kits
- Procedures for navigating life after a disaster

This guide is fully customizable to meet the unique needs of each military caregiver and is designed to be self-paced.

To view the toolkit, click the red button below.

**VIEW THE TOOLKIT**  
>



## What Is Lewy Body Dementia?

Lewy body dementia (LBD) is a brain disorder that can lead to problems with thinking, movement, behavior, and mood. Visual hallucinations, or seeing things that are not there, are a common symptom, and tend to happen early on.

More than 1 million people in the United States are diagnosed with LBD, which is one of the most common forms of dementia. It is a progressive disease, meaning symptoms start slowly and worsen over time.

To learn more, click the red button below.

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## Work-Life Balance 'Crucial' for Head and Neck Cancer Caregivers

Caregivers carry important responsibilities, especially those caring for patients with head and neck cancer. However, it is necessary to bring awareness to the quality-of-life caregivers have when working with nonworking patients who have head and neck cancer.

“Caregivers of patients with (head and neck cancer) face psychological, emotional, social and financial stressors related to the caregiving. Many caregivers do this because they love and respect the person they're caring for, or they feel like it's their duty,” Dr. Leila Mady, co-author of the study and assistant professor of otolaryngology – head and neck surgery at John Hopkins University School of Medicine, told CURE®. “But taking care of someone can be hard on the caregivers physically and emotionally. Because of this, the caregiver might not take care of themselves as well. This is especially true for caregivers of patients who can't or don't work and describe a lower quality of life.”

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## **How to Stay Close While Caregiving from a Distance**

Raising a young family, working full time and caring for aging parents creates a constant juggling act. The juggling becomes much more complex when parents or loved ones don't live nearby. Liz O'Donnell and her family lived in the Boston suburbs, about an hour and a half from her parents on Cape Cod. O'Donnell would drive out to her parents at least twice a month to help them go food shopping, check their mail and pay their bills.

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## **New Study Shows Nearly Half of Americans with Parkinson's Don't See a Neurologist**

A new study identified critical gaps in care for people living with Parkinson's disease (PD) in the United States, including disparities affecting underrepresented communities, such as women, residents of rural areas, and those who identify as Asian, Black, Hispanic/Latino or Native American. The study, supported by The Michael J. Fox Foundation (MJFF), Parkinson's Foundation, NORC at the University of Chicago and Perelman School of Medicine at the University of Pennsylvania, recently published results in [npj Parkinson's Disease](#).

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## Digestible Tips: Your Gut and Parkinson's (podcast)

How's this for a dinnertime conversation starter... did you know that what happens in your gut can have an impact on your brain health? Some experts even call the gut "the second brain" because of its huge community of microbes and large nerve network that links the gut to brain disease, like Parkinson's.

This podcast episode features a panel of experts who cover the latest research on this link between gut and brain health. They discuss common symptoms of Parkinson's — constipation, nausea and bloating — and what you can do to manage and treat them.

To learn more, click the red button below.

**LISTEN TO THE PODCAST**  
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## Dementia: Is This Dementia and What Does It Mean?

What comes to mind when you hear someone has dementia?

For many people, the term carries with it frightening associations. In fact, dementia is a group of symptoms, personality changes, or unusual behavior. These can include:

- short-term memory loss
- confusion
- inability to problem-solve
- inability to complete multi-step activities (preparing a meal, or balancing a checkbook)

Saying that someone has dementia recognizes these changes in the person, but it says nothing about why they have these symptoms. It doesn't explain the cause.

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



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## Genetic Variant Specific to African Ancestry is Associated with Increased Alzheimer's Risk

Researchers have found that having a genetic variant observed often in people of African ancestry may increase a person's risk of developing Alzheimer's disease. The APOE ε3[R145C] variant, present in more than 4% of African Americans and very rare in people of European ancestry, is associated with an increased risk of Alzheimer's in adults of African ancestry who also carry a separate version of the APOE gene, called ε4. Findings from the NIA-funded study were published in JAMA.

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## Bipolar Depression: Understanding Your Loved One's Experience

In recent years, commercials for prescription medications for “bipolar depression” have run all day and night. You've probably heard the ads so often that you can name one or more of the medications that are on the market for bipolar depression. Bipolar depression is not a medical diagnosis; rather, it refers to depression that occurs within a bipolar disorder diagnosis.

Bipolar disorder can be difficult to live with and difficult to treat. But caregivers can provide essential support to their loved ones when they understand the different aspects of bipolar disorder. Although bipolar disorder is a chronic condition, people with bipolar disorder can have productive, fulfilling lives, especially with proper treatment and consistent self-care.

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## Detecting Alzheimer's Disease: Older Adults' Experiences with Cognitive Screening & Blood Biomarker Testing

Over six million Americans have Alzheimer's disease (AD), the most common type of dementia, yet many of these individuals have not been formally diagnosed with the condition. Early detection of AD and related dementias has become an increasingly important public health priority. Cognitive screening (e.g., memory testing) is currently available to facilitate early recognition of cognitive impairment, while blood biomarker tests are an emerging option for detecting the abnormal buildup of proteins in the brain that might be an early sign of AD.

In March 2023, the University of Michigan National Poll on Healthy Aging asked a national sample of adults age 65–80 about their use and awareness of cognitive screening and blood biomarker testing, as well as their perceptions of the tests' benefits, limitations, and risks.

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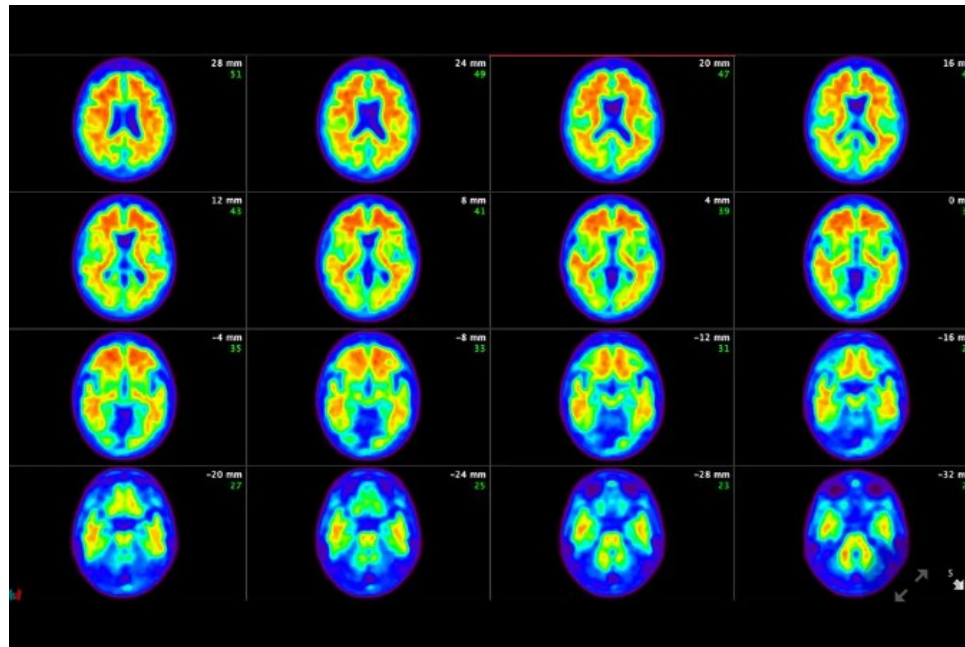
**'There Are So Many Caregivers and a Lot of Fragmented Resources.' These Free Videos May Help**

Caregiving can be an overwhelming job, especially for someone with little experience, background or education. Training videos, even just five minutes long, could be a step in the right direction for overcoming some of the challenges associated with the role.

Tualta, a caregiving training company, has teamed up with 32 states to offer hundreds of free videos to caregivers on a multitude of topics: managing prescriptions, adopting self-care rituals and spotting the signs of dementia, to name a few. The company recently rolled out the content in Spanish, in an attempt to help groups of caregivers that can be hard to reach, said Jonathan Davis, founder and chief executive officer of Tualta, which focuses primarily on family caregivers.

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## Treating Alzheimer's Very Early Offers Better Hope of Slowing Decline, Study Finds

Treating Alzheimer's patients as early as possible -- when symptoms and brain pathology are mildest -- provides a better chance of slowing cognitive decline, a large study of an experimental Alzheimer's drug presented Monday suggests.

The study of 1,736 patients reported that the drug, donanemab, made by Eli Lilly, can modestly slow the progression of memory and thinking problems in early stages of Alzheimer's, and that the slowing was greatest for early-state patients when they had less of a protein that creates tangles in the brain.

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## Hearing Aids May Cut Risk of Cognitive Decline by Nearly Half

Older adults at greater risk for dementia may be able to protect themselves against cognitive decline by using hearing aids, new research shows.

A study published Monday in the *Lancet* found that the use of hearing aids can reduce the risk of cognitive decline by about half — 48 percent — for adults with more risk factors for dementia, such as elevated blood pressure, higher rates of diabetes, lower education and income, and those living alone. The study was presented at the Alzheimer's Association International Conference in Amsterdam.

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## Duchenne Muscular Dystrophy: A Caregiver's Guide

People with Duchenne muscular dystrophy (DMD) require some level of caregiving throughout their whole lives, particularly as the disease progresses and patients become less mobile and more reliant on assistive devices. It can feel like a monumental task, but being knowledgeable about the disease and its treatment and management and knowing where to go for support and resources can go a long way in ensuring caregivers are able to give their loved ones the best possible care and help them maintain their quality of life. The following articles can help DMD caregivers educate themselves, figure out next steps, and learn how to take time for themselves.

To learn more, click the red button below.

**VIEW THE GUIDE**







## Heat Affects Older People More. Here's How to Stay Safe

We are experiencing the hottest days in history. Heat waves have blanketed the Northern Hemisphere this week, with temperatures reaching 100 degrees Fahrenheit on three continents.

Extreme heat can be deadly for anyone, but older adults are uniquely vulnerable. In the heat wave that suffocated Europe in the summer of 2022, people age 65 and older accounted for approximately 90 percent of heat-related deaths.

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## The Positive Aspects of Dementia Caregiving in Asian Communities

In the United States, Asian Americans represent more than 30 nationalities and ethnic groups, but they are typically categorized as Asian or AAPIs (Asian Americans and Pacific Islanders) for reporting.

Therefore, exploring the positive aspects of caregiving in the context of Asian communities is critical to developing a more robust understanding of dementia caregivers within this population.

According to research published in BMC Geriatrics, positive aspects of caregiving are significant coping resources for informal caregivers of people with dementia (PWD). The study revealed three major themes: positive aspects within the self, positive aspects between caregiver and PWD, and positive aspects between caregiver and others.

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## 7 Stages of Dementia

### The 7 Stages of Dementia: A Guide for Caregivers

Caring for someone with dementia can be a difficult, stressful process and a tough balance. On the one hand, you want to help them maintain as much independence as possible; on the other hand, you want to make sure they're safe and receive the care they require.

Alzheimer's disease and other types of dementia are often slow-progressing. It can take years before the symptoms of dementia fully develop and significantly impact the person's life. It can take even longer until they are no longer able to care for themselves and require full-time services. Fortunately, early detection of dementia symptoms followed by treatment may be able to help slow down the disease's progression and may help your loved one retain their memory and cognitive abilities longer.

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# Regenstrief Institute

## Understanding the Intersection of Alzheimer's Disease Caregiving and the LGBT Experience

A new study of caregivers of LGBT older adults living with Alzheimer's disease provides rare insight into the intersection of caregiving and the LGBT experience.

Researchers from Regenstrief Institute and the medical schools of Indiana University and University of Colorado report that many common caregiver experiences — such as feelings of social isolation and of being overwhelmed — are similar for caregivers, whether an individual with Alzheimer's disease is LGBT or not. However, because LGBT older adults often do not have adult children who can serve as caregivers or may be estranged from their families of origin, provision of the care they need, frequently provided by spouses or partners, is especially challenging.

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## Study of Indigenous South Americans Supports a Lifestyle 'Sweet Spot' for Aging Brain Health

Brain size typically declines with age, but the severity and prevalence of that decline may be related to lower activity levels, higher food consumption, and other evolutionary changes in lifestyle that are common in industrialized societies. An NIA-funded study of two indigenous South American groups, published in Proceedings of the National Academy of Sciences, supports the idea that there may be a lifestyle “sweet spot” for healthy aging.

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## The Apartment: A Guide to Creating a Dementia-Friendly Home

Dementia-related illnesses impact the mind and affect virtually every aspect of a person's life, including making many facets of daily living more difficult. Most residences are not built with the needs of an individual living with Alzheimer's disease or other dementia-related illnesses in mind. However, almost every part of a residence can impact quality of life for someone living with a dementia-related illness and their family care partners. Even seemingly-cosmetic choices, such as wall colors, furniture patterns, and dishware, make a difference.

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## Immune Resilience is Key to a Long and Healthy Life

Do you feel as if you or perhaps your family members are constantly coming down with illnesses that drag on longer than they should? Or, maybe you're one of those lucky people who rarely becomes ill and, if you do, recovers faster than others.

It's clear that some people generally are more susceptible to infectious illnesses, while others manage to stay healthier or bounce back more quickly, sometimes even into old age. Why is this? A new study from an NIH-supported team has an intriguing answer. The difference, they suggest, may be explained in part by a new measure of immunity they call immune resilience — the ability of the immune system

to rapidly launch attacks that defend effectively against infectious invaders and respond appropriately to other types of inflammatory stressors, including aging or other health conditions, and then quickly recover, while keeping potentially damaging inflammation under wraps.

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## NIA Statement on Report of Lecanemab Reducing Cognitive Decline in Alzheimer's Clinical Trial

The U.S. Food and Drug Administration (FDA) today granted [traditional approval for Legembi \(lecanemab-irmb\) for the treatment of Alzheimer's](#). This occasion — combined with ongoing scientific pursuits and advances in Alzheimer's and related dementias research — helps mark decades of scientific progress toward effectively treating and preventing these diseases. NIA remains eternally grateful to the research community as well as to the many clinical trial participants who have played significant roles in advancing knowledge, data, and discoveries.

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## Virtual Memory Screenings

The Alzheimer's Foundation of America offers free virtual memory screenings which allow individuals to receive one-on-one, confidential memory screenings from a qualified professional using their computer, smart phone or tablet. This service, which is part of AFA's National Memory Screening Program, began during the COVID-19 pandemic to ensure that people could still get screened from the safety and comfort of their homes.

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## Dementia Warning Signs

It's important to see your primary doctor if you or a loved one are experiencing changes in memory, mood, or behavior. Your physician can identify if you or your loved one is exhibiting any warning signs of dementia.

Having a memory problem does not necessarily mean someone has a dementia-related illness. Medical conditions such as stroke, B12 deficiency, hypothyroidism, depression and infections can cause dementia-like symptoms and are treatable if diagnosed. If the symptoms are caused by dementia, an early diagnosis can allow for the opportunity to connect with support, education, and medical treatments.

To learn more, click the red button below.

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## 5 Steps to Getting Started with Medicare Saving Programs

Medicare provides vital health care coverage for adults age 65 and older. But it doesn't

pay for everything, and there are out-of-pocket costs to consider. These include premiums, deductibles, copayments, and coinsurance.

If you have low income and are struggling to afford Medicare cost sharing, you could qualify for one of the Medicare Savings Programs (MSPs). These are special benefit programs offered by state Medicaid agencies. MSPs were created to relieve some out-of-pocket Medicare expenses for people who have limited income and assets.

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## **With Paid Leave, Older Adults Care for Parents Instead of Grandchildren**

In 2004, California passed a law requiring employers above a certain size to provide paid family leave to their employees.

Much of the research looking at this policy has examined its impact on the work, income and leave-taking of new parents and women of childbearing age—but less research has focused on how paid leave may impact older adults.

To learn more, click the red button below.

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## How Family Members Can Cope with Sudden Caregiving

Up until that moment when my father's brain cancer revealed itself, he seemed perfectly fine. A lawyer, devoted father and husband and a former college athlete, he spent his days arguing cases in court, playing baseball with me and my younger brother and swimming miles of laps in a YMCA pool. Then, one fall evening when I was 14, he turned to a neighbor visiting our home to make a comment about a TV show and out of his mouth came a string of gibberish — word fragments and random sounds that made no sense. Cancer cells had infiltrated the language center in his brain. In an instant, he had lost the ability for intelligible speech.

To learn more, click the red button below.

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## Caring for a Person with Depression

Depression sucks all the oxygen out of the room. Depression preoccupies a person to a point where they often lack sensitivity to the needs of others. The needs of caregivers are often overlooked. The relationship with the caregiver suffers.

The depressed person doesn't intend this to happen; it's the nature of the illness.

To learn more, click the red button below.

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## 7 Ways to Prevent Someone with Dementia from Getting Lost or Hurt

One of the most common safety concerns for people with dementia is that they will leave the house and get lost. In my 35 years of caregiving and work experience, no one I have encountered who is living with dementia just “wanders” aimlessly. In their minds, there’s a reason: They are looking for something or someone; they believe they should be somewhere (work, home, picking up a child after school, etc.); they want to do something (I once lost an adult day-care client because he wanted to go fishing); they have an unmet need (hungry, thirsty, tired, lonely, etc.); or they are scared. We may not understand what they are thinking or why they are confused — and they may not be able to communicate it.

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## Tips for Traveling With Dementia

Whether taking a short trip to see friends and family or traveling farther for vacation, it is important to consider the difficulties and benefits of travel for a person with dementia. In the early stages of dementia, a person may still enjoy traveling. As the disease progresses, travel may become too overwhelming. It is imperative to discuss any travel with the individual's physician to evaluate whether or not travel is recommended or safe.

To learn more, click the red button below.

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## 11 Tips for Getting the Most Out of a Family Meeting

Caring for someone with Alzheimer's disease or a related illness is a complicated task, and for families requires consensus and vigilance. Family meetings are important to ensure information is shared, formulate care plans, and arrange task divisions with family members. A family meeting is a specific time set aside to promote communication, decision-making, and problem-solving, and to encourage strong family relationships.

To learn more, click the red button below.

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### Eating and Dementia

A good diet is vital to a person's health and well-being, but eating with Alzheimer's or dementia can be difficult. Because the brain is involved in all aspects of eating, when parts of it are damaged by disease, a person can have trouble eating. Some may not want to eat and others may not be able to feed themselves. Some may even forget how to chew and swallow. When a person with dementia can't eat, they don't get the nutrition they need to stay healthy, comfortable and strong.

To learn more, click the red button below.

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### 9 End of Life Documents Everyone Needs

Many of us have thought about writing a will, but there are several other documents you need to cover all aspects of your end of life wishes. Without them, your family will have to make tough decisions on your behalf, not knowing what you would have wanted.

To learn more, click the red button below.



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